CYSTIC FIBROSIS TRUST

England & Wales · Charity number 1079049

Details

Status	Registered
Legal form	Charitable company
Company number	03880213
Registered	2000-01-21
Register	View on the Charity Commission register

Contact

Address	Cystic Fibrosis Trust 33 Creechurch Lane London EC3A 5EB
Phone	020 3795 1555
Email	enquiries@cysticfibrosis.org.uk
Website	www.cysticfibrosis.org.uk

Activities

Objects: 1) TO PROMOTE RESEARCH INTO THE CAUSES OF AND A CURE FOR CYSTIC FIBROSIS AND THE DISSEMINATION OF THE USEFUL RESULTS THEREOF FOR THE PUBLIC BENEFIT2) THE CARE, TREATMENT, EDUCATION AND ADVANCEMENT IN SUCH WAYS AS ARE CHARITABLE OF PERSONS SUFFERING FROM CYSTIC FIBROSIS IN ANY FORM AND3) THE EDUCATION OF THE GENERAL PUBLIC ABOUT THE CAUSES AND EFFECTS OF CYSTIC FIBROSIS

Activities: The Cystic Fibrosis Trust works to improve and transform the lives of people with cystic fibrosis by investing in research and its application to patients, driving up standards of clinical care in the NHS, providing information, advice and support for people with cystic fibrosis and their families, campaigning and influencing policy and raising awareness in the media and the general public.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Downloaded from opencharities.uk/ew/1079049

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£12,014,000	£13,832,000	£9,562,000	133
2024-03-31	£14,666,000	£15,094,000	£11,340,000	134
2023-03-31	£14,666,000	£12,772,000	£11,357,000	121
2022-03-31	£15,681,000	£15,968,000	£9,671,000	110
2021-03-31	£14,386,000	£13,905,000	£9,516,000	122

Trustees

Name	Role	Appointed
Richard Hunt CBE	Chair	2018-07-25
Anthony Hunter		2025-12-01
Daniel Beever		2025-12-01
Dr Maya Desai		2024-05-23
Jane Wainwright		2023-09-29
Joanna Barrett		2019-10-01
Martin Walshaw		2021-07-13
Michelle Shore		2019-09-24
Neil Priscott		2023-09-29
Sean Collins		2017-07-12
Sonya Trivedy		2021-07-13
Sophie Pierce		2021-07-13

Downloaded from opencharities.uk/ew/1079049

CYSTIC FIBROSIS TRUST

England & Wales - Charity number 1079049

Accounts

Cystic Fibrosis Trust

Annual Report and Financial Statements
for the year ended 31 March 2025



Unstoppable together

Uniting for a life unlimited

Contents

Thanks to you, in 2024/25...	4
Introduction from our Chair	6
Uniting for a life unlimited	8
Uniting in research	12
Putting people with CF first	18
Uniting for the CF Community	24
Diverse and together	32
Uniting in fundraising	42
Looking to the future	48
Financial review	54
Independent auditor's report to the Members and Trustees of Cystic Fibrosis Trust	64
Consolidated statement of financial activities	68
Consolidated and charity balance sheets	69
Consolidated statement of cash flows	71
Notes to the Financial Statements	72
Structure, governance and management	96
Open SRC/DA Awards	98
Open VIA Awards	99



We won't stop until CF does.



"Whenever I accomplish something, I think of my donor and hope they would be proud."

Zanib, who has CF and had a lung transplant in 2020

Thanks to you, in 2024/25...



We launched two new regional trial networks within our CTAP programme, meaning that even more people with CF will have the opportunity to take part in clinical trials.



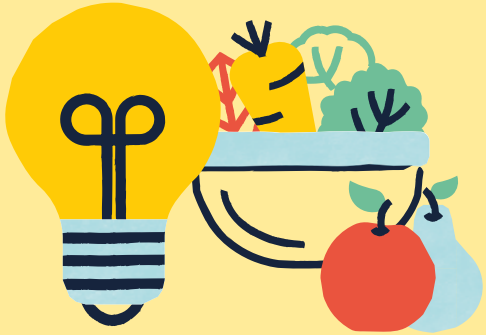
We awarded £1,379,000 across Strategic Research Centres (SRCs) and Development Awards (DAs) to support groundbreaking projects.



We helped people with CF access over £2.1million in benefits through our Welfare and Rights Advice Service.



We've handled over 4,500 enquiries to our busy Helpline across phone, email, WhatsApp, and social media.



We provided 550 Winter Support Fund grants, supporting low-income households with the basics needed to stay well over the difficult winter months.



We had an incredible combined reach of 4.7m across our social media channels and over 1,000 pieces of media coverage with a huge potential editorial reach of over 2 billion.

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2025. The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Charities Act 2011 and the Statement of Recommended Practice: Accounting and Reporting by Charities second edition effective 1 January 2019.

The requirements of 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013' are included within this Trustees' report. Pages 54 to 97 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 2024/25 Annual Report, which documents another year of impact, challenge and change.

I hope you will find it a comprehensive and impressive document and I would like to start by thanking everyone in the CF community for all they have done over the last 12 months to make the successes we report possible.

I am proud to be Chairman of the Trust and from that vantage point I can see how important all of our partners are as we strive together for a life unlimited.

The year saw us continue to mark the 60th anniversary of the Trust. Through supporter events and an awards ceremony, we were able to celebrate what has been achieved but also be very clear about all that remains to be done.

The anniversary gave us the opportunity to tell more stories, with podcasts, a special edition of CF Life and a digital timeline showing decades of progress, alongside the many challenges that still come with CF.

To address these we've funded more research, adding to our portfolio of Strategic Research Centres and funding a number of Development Awards.

In October, we announced our largest ever partnership, a £15 million Translational Innovation Hub Network co-funded with medical research charity LifeArc. The focus of this work over the next five years will be improving the diagnosis and treatment of CF lung infections and maintaining lung health.



Richard Hunt CBE



"The anniversary gave us the opportunity to tell more stories, with podcasts, a special edition of CF Life and a digital timeline showing decades of progress, alongside the many challenges that still come with CF."

We continue to work with new partners, funding a research study with Bowel Cancer Research UK to examine one potential aspect of growing older with CF.

Alongside our research activity, we have supported and developed our Clinical Trials Accelerator Platform, which has now enrolled over 6,000 people since its inception eight years ago.

We have ensured that the UK CF Registry provides comprehensive and timely information and analysis, supporting the best possible care and treatment for people with CF.

In fact, Registry analysis was at the heart of one of the most significant moments of the year, when, after a period of uncertainty, NICE gave formal approval for the long-term use of a portfolio of modulators on the NHS. Even as we marked that moment, our thoughts were already turning to the next drug in the pipeline, with Alyftrek being licensed for use by the MHRA in March.

This progress has been accompanied by concern about the supply of some medicines, most notably Creon, and we have been working throughout the year to do what we can to inform the CF community and minimise any long-term impact.

Promoting the highest quality care has remained a central priority and this year saw the publication of new **Standards of Care** for the treatment of CF. We also expanded our portfolio of events to include a conference focused on the future of CF care.

As we look to the future, we are also ensuring that we are able to support people's needs today.

Our Helpline has handled thousands of queries and over the winter months, we provided vital funds to 550 households. This is the highest ever.

Our Work Forwards programme has now held over a hundred advice sessions to help people in to employment and the Helen Barrett Bright Ideas Awards celebrated 10 years of backing so many aspiring entrepreneurs.

All of this is only possible due to the incredible support and involvement of the CF community. You fuel us with your fundraising and inspire us with your voice.

I would like to thank all colleagues whose work in the Trust has made this year so successful and to my colleagues on the Board, my personal thanks for your commitment and support.

We will not stop until CF does.

Thank you.

Richard Hunt CBE
Chairman of Trustees

Uniting for a life unlimited*

"Cystic fibrosis is a 365 day a year, 24 hour treatment regime... it doesn't stop. You never get a day off."

Jonathan, who has CF and featured in our **No day off** campaign



Objectives and activities

Our vision is to deliver a life unlimited for people with cystic fibrosis, and our objectives, as stated in our Articles of Association, are to promote:

- research into the causes of, and a cure for, cystic fibrosis and the dissemination of the useful results thereof for the public benefit
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from cystic fibrosis in any form
- the education of the general public about the causes and effects of cystic fibrosis.

About CF

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. You are born with CF and cannot catch it later in life. One in 25 of us carries the faulty gene that causes it, usually without knowing. More than 11,000 people in the UK live with the condition, enduring a brutal daily routine of physiotherapy and taking over 30 tablets a day just to stay healthy. Despite these treatments, some people with CF will go on to require a double lung transplant. The median age of death for someone with CF in 2023 was 46.

About us

Our mission

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all. We won't stop until we can all lead the lives we want. Until cystic fibrosis stops damaging and shortening lives.

Our vision

Our community is uniting towards the ultimate goal of effective treatment for all. We're at the forefront of innovation and progress. Boundaries will be broken by groundbreaking research and incredible discoveries that change lives for the better. To get there, we will inspire our community. We will campaign with passion. Use facts and information to empower us. And support each other – improving care and building better mental resilience and physical health.

It's thanks to our incredible supporters, clinicians, researchers, professionals, partners, and, most importantly, people with CF that over the last 60 years we've been able to make vital breakthroughs and discoveries in CF understanding and treatment.

We're uniting for a life *unlimited*

Our goals

Physically well

Together, we can live without the physical challenges of cystic fibrosis.



Mentally well

Together, we can manage the mental pressures of cystic fibrosis.



Fulfilment

Together, we can lead the life we want as part of a connected community.



Measuring success

We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact to the CF community. We hold impact workshops to assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track progress via internal monthly and quarterly monitoring mechanisms, including both data-driven and narrative analysis, backed up by SMART Key Performance Indicators.

Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.

To achieve these ambitious goals, we will work with our community and partners across the UK and internationally to support innovative, high-quality research, achieve access to the best treatments, drive up the quality of care, and provide and advocate for the support needs of people with cystic fibrosis.

We also know that to deliver on this vision we need to adapt and change as an organisation, including a greater focus on:

- **putting people with cystic fibrosis at the heart of everything we do**
- **building international and domestic partnerships**
- **optimising our working culture**
- **being great and innovative fundraisers**
- **making effective use of data and analytics, including implementing our new data strategy and a new quantitative impact framework**
- **working in ways that bring together our diverse community and staff, including our new equity, diversity and inclusion strategy.**

Uniting in research

We are continuing to drive and support innovative, world-leading research such as the Translational Innovation Hub Network on lung health and infection in CF in partnership with LifeArc. We are expanding clinical trial opportunities through establishing new regional networks within our Clinical Trials Accelerator Platform (CTAP), and strengthening partnerships across the life sciences sector, enabling faster access to new treatments and better outcomes for people with CF.

Developing effective treatments for all

CTAP remains one of the leading global CF clinical trials networks, screening over **9,000** participants and enrolling more than **6,000** since its launch eight years ago. This year, people with CF who are unable to benefit from modulators had the opportunity to take part in three new genetic therapy studies that could address the underlying cause of CF.

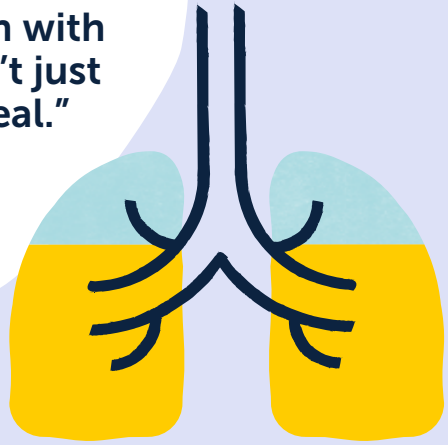
Two new regional trial networks have been launched within our CTAP programme, meaning that even more people with CF will have the opportunity to take part in clinical trials. One network covers the whole of Scotland and North East England, and a second spans across the South West of England.

> **"Not all CF centres are able to run clinical trials. Thanks to our regional network we're talking to each other and improving how we work together. It means that it's easier for people to take part in research going on at a CF trial centre within the network."**
>
> Dr Don Urquart, chair of the Scotland and Northeast Regional network



"Living with CF diabetes is like constantly being on a rollercoaster. It's juggling what I eat with how much insulin I'm giving myself. Mentally, it can cause a bit of an unhealthy obsession with what I'm eating – I can't just sit down and have a meal."

Annabelle, who has CF



Treating symptoms and complications of CF throughout the body

CF diabetes (CFD) is a difficult illness to manage alongside other CF symptoms.

The insights we gathered from those with lived experience of CFD through our involvement activities have informed many activities across the Trust, from a workshop at our MDT conference in March to a review of our information resources. They've also shaped the direction of a research project focused on creating an educational tool for those with CFD. Participation in involvement activities benefits members by empowering them to engage further.

To improve how CFD is treated and managed, we awarded **£300,000** over three years to Drs Ildem Ackerman and Vicky Salem to explore whether a Type 1 diabetes therapy could work for CF diabetes, potentially eliminating the need for insulin.

Improving the diagnosis and treatment of CF lung infections and maintaining lung health

In October, we announced a new £15 million Translational Innovation Hub Network, co-funded with medical research charity LifeArc.

Guided by insights and experiences of people with CF, the new CF Innovation Hubs will address new ways to detect, diagnose, treat, and manage lung infections and lung health, and help to overcome some of the barriers that can prevent scientists from turning their discoveries into real outcomes for patients.

"This condition affects everything about my life, every single day. I have to adjust my life around my symptoms, in everything from work to friendships.

"The dream, for me, is to have less of a treatment burden and more time feeling like a valuable member of society. These new Hubs give me hope because improving research into the cause of exacerbations and the development of potential new treatments takes away a lot of my fears around what my health is going to look like in the future."
– Sarah, who has CF

The new network aims to accelerate groundbreaking research, building on the success of the original CF Innovation Hub at the University of Cambridge, which made world-class advances in our knowledge of CF lung infections.



"This funding, along with the wraparound support provided by the CF AMR Syndicate, will help advance promising solutions to the urgent need for more effective treatments for CF lung infections. The aim is to accelerate the discovery of novel therapies that could significantly improve the lives of people with cystic fibrosis."

Dr Heather McKinnon, Head of Chronic Respiratory Infection at LifeArc

Uniting researchers to achieve a life unlimited for people with CF

This year we have held several events to build and strengthen the network of innovators, researchers and clinicians working in CF research.

In June over **60 delegates** attended our Industry Symposium immediately prior to European CF Society meeting in Glasgow. A third of the delegates were from organisations across the life sciences sector. We **presented a new animation** and invited speakers to highlight the **Trust's research support offer** to industry innovators. The event was kindly supported by **LifeArc**.

In October over **35** early career researchers attended our first Early Career Researchers conference in person or online to network, learn more about Cystic Fibrosis Trust, and empower them to continue to work in CF research in the future.

CF AMR Syndicate

The CF AMR Syndicate brings together academia, industry, patient organisations, R&D experts, clinical teams and, most importantly, people with CF. Your voice is key in helping innovators understand the unmet needs of people with cystic fibrosis.

In the last year, six biotech companies won support from the Syndicate's **Collaborative Discovery Programme** (CDP) to develop new anti-infective treatments guided by the Syndicate's patient-focused wishlists, known as Target Product Profiles. The companies are receiving hands-on expert support to develop their products.



Dr Lucy Allen

> **"We are delighted with the success of the CF Innovation Hub on lung health, which exemplifies what can be achieved with this level of investment and multidisciplinary collaboration."**
>
> Dr Lucy Allen, Director of Research and Healthcare Data

Enabling people to live longer, healthier lives

Improving the understanding of the physical and mental health challenges people with CF face as they grow older is an important area of CF research, and it starts with people with CF sharing their lived experience. Through our involvement activities, Laura Eccles shared her thoughts on growing older with CF with over **2,000 researchers** and clinicians at the opening session of the European CF Society.

As people with CF grow older, they face diseases, such as cancer, cardiovascular disease, and dementia, that may require earlier or adapted screening due to CF symptoms and complications. As guidelines are developed, it is vital that they are informed by the CF community.

One way we're supporting this is by funding a research study with Bowel Cancer Research UK, led by Professor Laura Ashley at the University of Leeds, to gather the views and experiences of people with CF and their CF teams on bowel cancer screening.

Accelerating research

Our CF Accelerating Research package supports life science industry partners to align their work with CF community needs. Through support from the UK CF Registry, our involvement work, and the support of our Clinical Trials Accelerator Platform, CTAP, the Trust has enabled companies to refine study designs, improve trial feasibility, and increase the speed at which clinical trials are set up and delivered.

Over the past year, we engaged **12** new commercial sponsors and maintained relationships with many more across a range of therapeutic areas, from pre-clinical studies to phase 3 trials testing the effectiveness of medicines.

This ongoing commitment to industry collaboration continues to drive progress in drug development, trial accessibility, and ultimately, improved treatment options for the CF community.

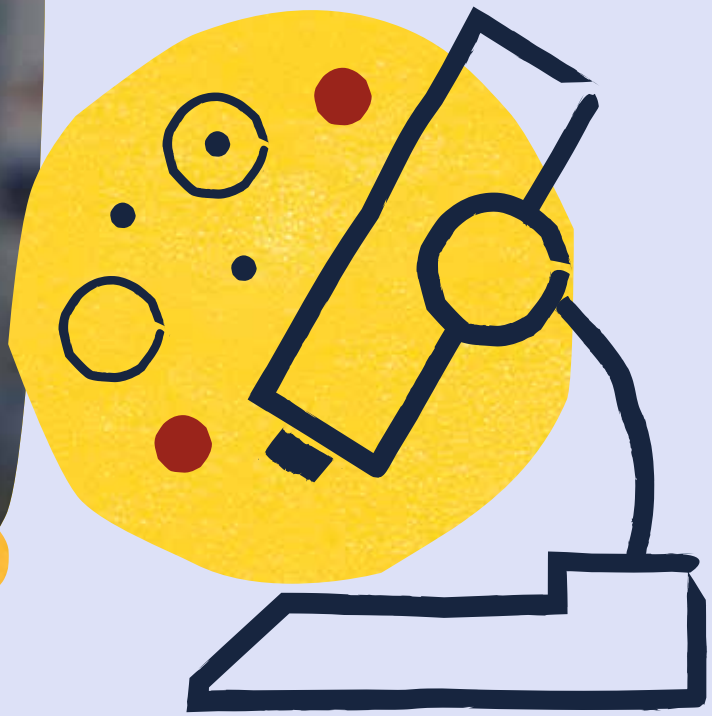




Funding world class research

We awarded **£1,379,000** across Strategic Research Centres (SRCs) and Development Awards (DAs) to support groundbreaking projects, exploring treatments for *Mycobacterium abscessus* lung infections and CF diabetes, and new ways to improve lung health.

Additional funding was allocated to early career researchers and novel CF studies through Venture Innovation Awards (VIAs), Fellowships, and Summer Studentships.



Putting people with CF first*

Collaborating with and supporting the clinical community to promote the highest quality of care

Our Clinical Advisory Group (CAG), made up of specialists in CF care, advises the Trust's information resources and clinical programmes. Its Chair oversees the longstanding Clinical Fellowship scheme, which helps launch careers in CF and has produced many leading clinicians.

The Trust sponsors and provides secretariat duties for the UK Cystic Fibrosis Medical Association, supporting doctors delivering CF clinical care nationwide. The Trust's clinical guidelines continue to promote best practice in CF care provision. In 2024/25 we published guidelines on:

- standards of care
- clinical psychology services
- nursing management of cystic fibrosis.

We also produced lay summaries of each guideline for people with CF and their families.

Updates are underway on several other key guidelines, including:

- antimicrobial treatment
- infection prevention and control
- physiotherapy management of cystic fibrosis.

Improving quality of care in CF

In October 2024, our patient experience survey of over 1,250 adults with CF showed that CF care is generally rated highly by those who receive it. However, some respondents struggle to access psychologists, social workers or pharmacy staff when needed. The survey also highlights a growing desire and need for person-centred care in the context of an ageing and diversifying CF population.

We continued to monitor staffing levels in CF services using our staffing tool, with a record **51 CF centres** contributing in October 2024. Participating CF centres received bespoke feedback in March 2025, and we published an updated report on UK CF service resourcing in early April.

We also worked with local CF teams on improvement projects and collaborated with CF professional interest groups to explore and address UK-wide challenges in CF care, such as gaps in psychology staffing.

Future of CF care conference

In March 2025, the Trust hosted its second dedicated conference for CF professionals, which featured presentations, panels, and workshops on ageing, CF diabetes, and gastrointestinal care. Over **150 CF professionals** attended, with many reflecting on how the event supported their professional development in CF. 100% of those who completed our evaluation survey said that the event met their expectations, describing it as excellent, informative and inspiring.



"I found the whole MDT event very helpful for me as I am new in post. I was very interested in how other teams in the country work. The workshops and panel discussions were highly informative."

Neil, who attended the MDT conference

Supporting the CF community through issues that affect them

Creon shortages

Creon shortages over the past year have caused stress and disruption for many people with CF. In response, we provided timely information and guidance to help people access medication. We engaged directly with the Department of Health and Social Care and the media to highlight the significant health impacts on people with CF, ensure that the voices of our community are heard, and push for solutions.



Households under financial pressure

Rising living costs coupled with the extra costs of living with CF continue to exert significant financial pressure on those in the CF community. Financial concerns are a key reason people contact our Helpline. We continue to hear regularly from people whose health is being directly impacted by poverty, as they struggle to afford the costs of food, travel, and keeping their home warm and dry, diverting time and energy from managing their CF.

This winter, over **550 households accessed our Winter Support Fund** – the highest levels ever – with 1 in 5 of grant recipients reporting missed CF clinic appointments in the past year, and 1 in 4 reporting weight loss due to food insecurity.

100% of Winter Support Fund recipients felt that the support had helped to maintain their or their loved one's CF health, and 70% of CF professionals surveyed felt it reduced winter hospital admissions.

This dramatic impact highlights both the troubling effect of living on a low income with CF, and the value of our welfare grants programme in supporting physical and mental health in vulnerable households.



Making sure our community is heard

Throughout 2024/25, we remained committed to amplifying the voices of the CF community and addressing the critical issues that affect them. The 2024 **Your Life and CF** survey captured invaluable insights from over 10% of the CF community into daily challenges like financial burdens, mental health concerns, and access to care.

These insights have directly informed our advocacy efforts, ensuring that our policy recommendations are rooted in the lived experiences of those with CF. For instance, the survey highlighted the continuing need for improved access to CF social workers and psychologists, leading us to advocate for appropriate support for these roles in the Darzi Review and subsequent consultation on the NHS 10-year plan.

Additional focus groups and engagement sessions with people with CF, their families, and healthcare professionals have provided a platform for the community to share their experiences and contribute to shaping our campaigns and policy positions.

In 2025, responding to community concerns about air quality and its impact on respiratory health, we began initiatives aimed at advocating for cleaner air policies and regulations.

Our campaign for free prescriptions in England has continued, targeting the outdated exemption list that excludes many with CF. Working with the Prescription Charges Coalition, we successfully lobbied for a freeze on prescription charges this year and continue to campaign for a comprehensive review of the exemption criteria.

Post-election, we're engaging newly elected MPs to ensure the voices of people with CF are heard, championing equitable access to treatments, financial support, and environmental health.

By centring the voices of those affected by CF in our work, we ensure that our advocacy is not only informed but also empowered by the community we serve as we race towards effective treatments for all. We won't stop until everyone can live without the limits of cystic fibrosis.

"Paying for my own prescription makes me feel unseen and invalidated as a student living with a life-changing illness. It's another cost on top of so many extra costs that CF brings to my life."

James, a Trust campaigner who has CF





James (left), James's dad, James's twin brother (who also has CF), and their mum

The UK CF Registry

The UK CF Registry is a world-class database that holds anonymised data on approximately 99% of people with CF in the UK who have consented to their data being submitted by their CF team.

Registry data is vital in helping people with CF and their families understand CF and make informed decisions, supporting research, improving services, monitoring the safety and efficacy of new treatments for CF, and helping commissioners provide funding to NHS CF centres.



In 2024/25 we have:

- supported three pharma research studies worth over £1.3million by providing analysis and reporting, and presented interim results at international conferences
- received up to £155,000 from NHS contracts for generating public reports and supporting the commissioning of CF services in England
- submitted anonymised 2023 data to the European CF Society Patient Registry (ECFSPR)
- received 60 data requests:
    - 43 requests were reviewed and approved by the Registry Research Committee.
    - 2 were declined and 2 are under review pending more information.
    - 8 requests from ECFS Patient Registry requesting UK data were approved.
    - 5 requests were withdrawn prior to review by Committee.

Data Validation Programme

23 centres had a Data Validation Visit (DVV) in 2024 which showed high data entry quality, with no variables below 97% for adults and paediatrics – an improvement since 2022. These visits confirm the Registry's suitability for use in research, pharmacovigilance studies, and NHS commissioning. Furthermore, undertaking these visits virtually have proven to be cost and time efficient. The UK CF Registry Data Validation Programme (DVP) has been adopted as a model of best practice by other CF Registries in Europe. For the 2023 data, a report has been sent to the ECFSPR to be added to their European Data Validation.

Registry development

The Registry platform was updated to enhance inclusivity and useability. We added new fields for gender identity; a new race-neutral lung function calculation; the new CFTR modulator therapy vanzacaftor (Alyftrek™); and reasons for pausing modulators. We also expanded the CF variant list in line with the CFTR2 database. A new dashboard enables users to monitor the annual review and encounter records across their patient cohort, and a new consent feature allows users to log and upload multiple consent forms. These changes reflect changes in CF care and the evolving needs of the CF community.

Annual Registry report

The 2023 UK CF Registry data report, published in November 2024, reported that there were **11,318 people with CF** registered within the UK CF Registry, of whom 93% had an annual review in 2023. It presented new data on modulator use, including demographic data on those not taking modulator therapies. **8,212 people with CF** were reported as being on a CFTR modulator by December 2023.

With colleagues across the Trust's Research and Healthcare Data Directorate, we launched an Accelerating Research support package for industry, showcasing how Cystic Fibrosis Trust can provide support across the clinical research pathway. The UK CF Registry has supported three pharma companies with pre-feasibility data identify suitable CF centres for trials.

"The UK CF Registry 2023 Annual Registry report shows that the median predicted survival for someone born with CF today has increased to 64 years in the UK but also shows that the survival gap between men and women with CF is closing. Differences in outcomes between genders is a hugely under-researched area in clinical medicine but we have the valuable resource of UK CF Registry data to begin to help identify and understand these differences as we strive to deliver personalised care to people living with CF." – Dr Jamie Duckers

Uniting for the CF community

Day-to-day support

Over the past year the CF community has faced significant challenges. We've been here to provide trusted information and emotional support to the CF community when it matters most.

We started this year in a place of uncertainty about the future of modulator treatments due to the NICE appraisal. We supported the community through this with key information updates and a safe space to share worries. We were delighted to then provide information on the positive conclusion to the appraisal as well as further updates on drug development and approvals as they happened.

More recently, we have been on hand to support the community with concerns about the impact of planned welfare reform, and we will continue to work with people affected by CF to advocate for their rights as this develops.

Alongside reactive support, we've continued to provide a range of services and resources to help people with CF manage daily challenges and the unpredictable impacts of the wider economic and political times we live in. Throughout all of this, we continue to provide individualised, holistic and flexible support that empowers people with CF to overcome barriers and live the lives they want.





Claire, Bob and their daughter Katy

"In the most challenging times, we received lots of advice and support from the online forums on Cystic Fibrosis Trust's website, especially when we were having treatment to conceive our daughter and wanted someone to speak to about our concerns. It was great to have a support network, information and all of the resources we needed."

Claire, whose husband Bob has CF

"When I heard of the Helen Barrett Bright Ideas Awards, I felt excited at the possibility of getting help to make my dreams into a reality."

Aiden, who has CF



Aiden



Grants

This year, we provided **1,465** welfare grants totalling over **£380,000**, our largest volume of grants ever. This included **550** Winter Support Fund grants, supporting low-income households with the basics needed to stay well over the difficult winter months. Alongside the grant, those supported by the Winter Support Fund received regular emails signposting to extra support, and were offered help from our welfare team to explore further financial aid.

Through the Joseph Levy Education Fund, we awarded **53** grants to support people with CF pursuing higher or further education. We also granted a total of **£20,000** to **10 people** with CF through our Helen Barrett Bright Ideas Awards to help them advance their own businesses. And thanks to support from the Joseph Levy Foundation, we supported over **60** adults and children facing a tough time with their CF to have a holiday or short break.

Over 90% of those who responded to our surveys told us the grant they received had positively impacted their physical and mental health.

"I was sleeping on the floor with handed-down sheets and pillows; it was uncomfortable, and I don't know how long I would've been in that position without the grant." – James, who has CF

Benefits advice

Our welfare benefits and income maximisation services continued to ensure people affected by CF were able to access the financial support they need – undertaking complex casework and providing support around benefit appeals and tribunals.

Government welfare reform proposals have caused deep concern in the CF community. Our specialist frontline knowledge in how CF interacts with the benefits system has put us in a strong position to support and advocate for people affected by CF.

This year, we helped over **300** people to secure benefits income of over **£2.1 million** – vital income to help them meet the extra costs of living with CF. We also helped **58** people access income maximisation services, identifying additional income for them of over **£4,000** per household.

Many of those affected by CF tell us that navigating the benefits system causes immense stress and worry, which affects their physical and mental health. Our specialist, dedicated service eases some of this worry, helping the CF community access the financial support they need to look after their health.

"CF and all the health and financial issues it comes with can be sometimes overwhelming. I feel there are people at the Trust who understand and genuinely want to help." – Cora*, who has CF (*name has been changed)

> **"All I could think about was the life expectancy of 41; I was 32 and I had an 8-year-old to think about. But the Trust were full of empathy and compassion and just listened to me, which is exactly what I needed."**
>
> Cheryl, who received a late diagnosis at 32



Helpline

Our Helpline service has provided practical support and information and a listening ear across phone, email, WhatsApp, and social media, handling over **4,550** enquiries this year. We improved our case recording to ensure a high-quality, consistent service and built capacity through volunteering. As the gateway to all our support services, the Helpline often deals with our most complex enquiries, ensuring people contacting us get the right support at the right time.

100% of those who responded to our feedback surveys said they would recommend our service to others.

Empowering the CF community through high-quality, accessible information

Last year we updated our extensive information offer with several new and updated resources, including:

- marathon training tips for people with CF
- testing for CF carriers in families
- clinical trials
- staying well over winter.

We updated our newborn diagnosis resource, providing families with sensitive, helpful information at the point of diagnosis, including a new series of e-newsletters to support families through their baby's first year.

We published two key clinical guidelines: our flagship Standards of Care guidelines, and, for the first time, new guidelines for clinical psychology services. Both guidelines were complemented by accessible lay summaries.

We also responded to ongoing and emerging issues with timely updates on topics such as the Creon shortages, collaborating with clinicians to publish accurate and timely information.

We retained our accreditation with the PIF TICK, a quality kitemark demonstrating our adherence to best practice in the production of health information.

Trusted Information Creator

Patient Information Forum



"Don't shy away from the diagnosis now. Encourage people to ask questions and not to Google. Family and friends have been amazing in asking and learning about it from us – as we learn too."

Sonja*, whose daughter Lily* has CF

*names have been changed

Dedicated support for children and young people

Our youth programme had a busy and fun-packed year. Building Brighter Futures, our programme for 6–14-year-olds with CF and their siblings, saw **116 children** attending **5 courses** and **28 one-off events**, including foam-clay classes, resilience workshops and science experiments explaining CF symptoms!

Our Youth Advisory Group (YAG) of 14–25-year-olds held **24 meetings**, creating a dictionary of CF terms for children and helping steer the Trust's work for young people.

Strong Beginnings supported parents of children with CF aged 0–6, with events such as peer support groups, Q&A sessions with CF physios, and baby massage classes. **59 parents** attended and shared positive testimonies of how the events helped them cope at the start of their CF journey.

"We had a conversation the other day about there being a cure for CF one day. He said he doesn't think he would get rid of it even if he could, because he only gets to do the Zoom workshops because he has CF!"

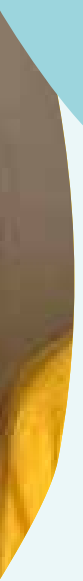
Nikolas*, whose son Hugo* is a member of Building Brighter Futures

"YAG is always looking for projects and campaigns that help to make our CF community better."

Tilly, YAG member



Tilly



"The connections we made have become an essential part of our lives. We now chat almost daily with the parents we met, and having this support system as our little girl grows up has been truly life changing. Thinking about it makes me quite emotional – we are no longer alone on this journey".

Yakov*, whose daughter Gabi* has CF

"It meant a lot to have someone acknowledge the challenges I've been facing and provide clear, practical guidance to help me move forward. The conversation felt like a safe space where I could be open about my frustrations, stress, and anxiety, which was incredibly valuable during such a difficult time."

Sanjana*, who has CF



(*names have been changed)

Work Forwards

Work Forwards employment programme

Thanks to funding from the National Lottery Community Fund, the Work Forwards programme continued to deliver employment, work, and careers support to people affected by cystic fibrosis. We supported **89** people through **107** advice sessions. We delivered **7** online sessions attended by **87** people, including a webinar on pensions – a first for the CF community, reflecting the changes in CF in recent years.

Many of our online sessions have been led by people with CF, including drama therapy sessions to build confidence in discussing CF with employers. We continue to share a broad range of stories of people with CF in a wide range of jobs and careers, reaching thousands of people.

We also delivered this year's Helen Barrett Bright Ideas Awards, which provide grants and support around self-employment, and have strengthened our support and guidance to applicants this year. This year marks 10 years of the Awards, and we're particularly delighted that previous Award winners have been actively involved in delivering sessions for our youth programme using their professional experience.

COMMUNITY FUND

Diverse and together*

This year, we've continued to find new ways to reach and engage people affected by CF – in the right way, at the right time. We have built new relationships with a diverse range of storytellers who generously share their time and stories with us to support our work, raise awareness and support our community.

We make sure the voice of the CF community is always heard and profiled through the stories we place in the media, on our website and through our fundraising materials. High-profile campaigns like our 60th anniversary and CF Week have been shaped and influenced by people with CF and their families via our active involvement groups.

"My wish is that the CF community continues to spread awareness by sharing stories. We can work together to continue fundraising and enlightening the world to the struggles that people with CF go through on a daily basis and show the impact donations make."

Sophie, who lost her dad to cystic fibrosis

CF in the media

We've had another incredible year for media, with over **1,000 pieces of media coverage**. We would like to thank all the journalists we've worked with, and all our spokespeople and storytellers for helping us to raise awareness of cystic fibrosis.

We raised awareness of the Creon shortages with the Sunday Times and the Express, and achieved national coverage with our awareness campaign. The Trust was also mentioned in hundreds of pieces of coverage when NICE approved permanent access to modulators.

Many regional and trade outlets picked up the launch of the CF Innovation Hubs and we also worked with First News on a child-led storyteller piece.

Our Trustee Sophie Pierce embarked on a row across the Atlantic, which gained great regional coverage, and news that the MHRA approved Alyftrek dominated national and regional health news.

We had 1,012 pieces of coverage over the last year with a huge potential editorial reach of over 2 billion.

60th anniversary

We continued to mark our 60th anniversary year, recognising that while there have been significant achievements over the last 60 years, there is still a lot more to do to ensure everyone with CF can live a life unlimited.

We held supporter events, a special awards ceremony, and shared content on the theme of **we won't stop**, including a podcast episode with our chief executive David Ramsden and a special edition of CF Life magazine.



"I attended Cystic Fibrosis Trust's 30th anniversary at St James's Palace in London all those years ago and as Harvey and I live and breathe, today and in the future, it is testament to the hard work and dedication of everyone at Cystic Fibrosis Trust."

Hazel, who has CF

Since 1964



Actress Elizabeth Green, who played the Character of Jade in Eastenders

Social media

Across Facebook, Instagram and TikTok we had an incredible combined **reach of 4.7m** and over **734,000** impressions across LinkedIn and X.

We've continued our social media initiatives, including Research Wednesday, Fundraiser Friday and a monthly CF media round-up, which aim to give space on a regular basis to share CF research news, celebrate the amazing achievements of our supporters, and keep the community updated on everything that is happening in the world of cystic fibrosis.

Our social channels allow us to respond to the CF community in a timely fashion on key themes such as the ongoing issues with Creon, the NICE appraisal of Kaftrio, and the Government's planned changes to disability benefits. Our ability to turn around video content, quickly enabled us to reassure our community during some challenging moments.

These are some of our top performing posts in 24/25:

- Our top-liked post on Facebook was our post confirming the King will continue as our Patron, with 665 likes and over 21,000 impressions.
- On Instagram, our highest-liked post was our video from CEO David Ramsden on the NICE Kaftrio approval, with 1,605 likes. This fell during CF Week and was a fantastic boost for the community amid ongoing worries around Creon supply.
- On TikTok, we were lucky enough to have Elizabeth Green, who played Jade (a character with CF) on Eastenders, in the office with us to film some Wear Yellow Day content. She answered questions about her experience and what she learned about CF preparing for the role, which accrued 458 likes.

Volunteering

Over the last year, we've been really grateful for the contribution of our volunteers, supporters and branches and groups, who provide invaluable support. All our volunteers come from a wide range of backgrounds and their individual experience and contribution enriches our work for people affected by CF. We've opened more volunteering activities from home, which has allowed more volunteers to support us and who otherwise would not have been able to volunteer. To recognise and acknowledge our volunteers, we celebrated National Volunteers Week in June 2024 and Trustee Week in November 2024.

Being an effective organisation

Our ability to achieve our vision depends on optimising our organisational effectiveness and working culture so that we can be a great workplace where our employees, volunteers, and other supporters are supported to do their best.

For our employees, we nurture this by building a rewarding working environment, and from our staff survey we know that our staff value many aspects of working for Cystic Fibrosis Trust, such as flexible working, a generous holiday entitlement, learning and development opportunities, and engaging communications, including regular briefings led by our CEO. During the last year we relocated to a smaller office with updated technologies and facilitating more effective use of office space, resulting in cost savings and an improved working environment.

As we move into 2025/26, we are in the process of developing our policies and practices to further improve our working culture, and help our people develop new skills and knowledge to continue to support the changing cystic fibrosis community.



Sharon receiving another fantastic donation to Cystic Fibrosis Trust

"I never thought I'd be able to make a difference to people who've got the condition right now; I thought it would just be the next generation. So it's an amazing feeling to know I've helped my cousin Donna and how grateful she is for the work I do with the Fakenham branch."

Sharon, from our Fakenham branch



Professor Jo Fothergill presenting at our ECR conference

> **"It was great to see an event just for ECRs – it was intimate, comfortable and not intimidating, and a nice way us to come together."**
>
> Ali*, who attended our Early Career Researcher conference

Events

This year we held a one-day symposium in London for early career researchers (ECRs). The event gave them the opportunity to come together in an informal session, meeting their peers and learning from more experienced CF researchers.

We held a hybrid CF Live community event in Glasgow, to coincide with the European Cystic Fibrosis Society conference which took place in the city in June 2024. We also held an online CF Live later in the year focusing on adult CF care.

The end of 2024 also saw two events to mark our 60th anniversary: a supporter event at the Royal College of Physicians, and an awards ceremony, hosted by Richard Madeley, to showcase and thank members of the CF community.

Our second conference for multidisciplinary teams (MDT) took place in Birmingham in March 2025. The one-day event saw over **150 individuals from MDTs across the UK** attend for a series of talks, workshops, and panel discussions.

We also held a hybrid CF Live event for the local CF community in Birmingham the night before the MDT conference, with presentations from Trust staff and local CF centre representatives.

And in early 2025, we launched the Coffee and Careers webinar series. We are joined by an experienced researcher at each webinar who has a conversation with our host about their career to date, focusing on how they got started, how they ended up where they are now, learning opportunities over the years, and advice for early career researchers.

Celebrities

Our celebrity supporters and ambassadors have continued to provide vital support, awareness and fundraising for the Trust.

A special thank you to our ambassadors:

- James Dunmore, who ran the London Marathon for us in less than three hours, raising vital funds
- Jenny Agutter, who authored our Gift in Wills campaign and officially welcomed guests at our 60th anniversary supporter event
- Richard Madeley, who hosted our 60th anniversary awards ceremony.

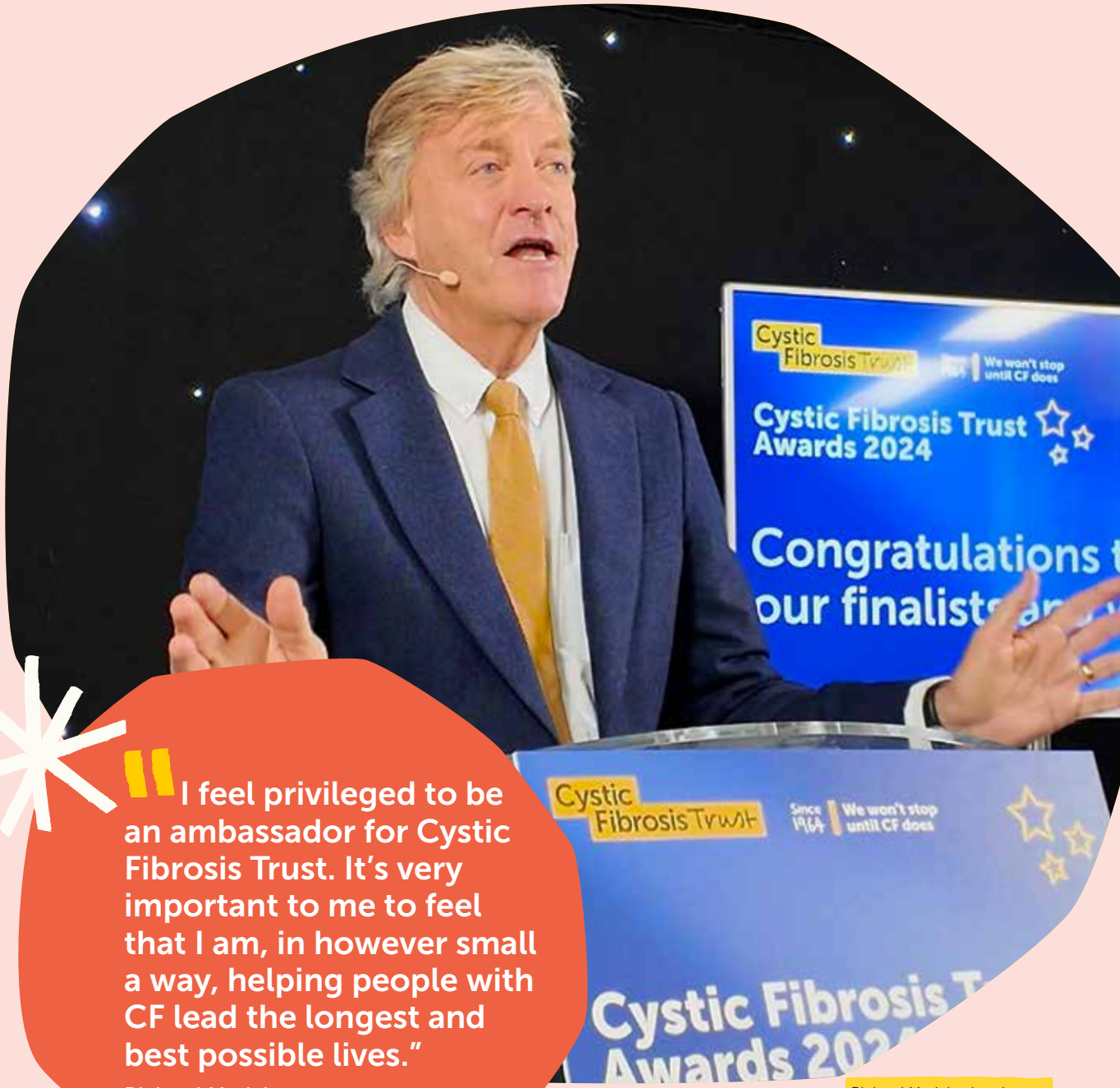
We're also incredibly grateful for support in 2024/25 from Ben Shephard, Vincent Franklin, Jack Kinsey, Annette Badland, Eleanor Matsuura, Roger Black, David Haig and Anna Maxwell Martin.

A huge thank you to all our celebrity ambassadors and influencers who continue to support our vital work!

Sharing stories from our community

We strive to share diverse stories from our community through our blogs and video content. This year we've developed multiform content which covers a range of topics, such as CF research, living with CF as a young person, mental health, taking part in clinical trials, neurodiversity, starting a business, bereavement, and more.

We listen to our community to share what's important and relevant to them, keeping them involved every step of the way to ensure we're telling their stories in their own authentic voices.



"I feel privileged to be an ambassador for Cystic Fibrosis Trust. It's very important to me to feel that I am, in however small a way, helping people with CF lead the longest and best possible lives."

Richard Madeley

Richard Madeley hosting our 60th awards ceremony



Our magazine

CF Life is our twice-yearly magazine, packed with the latest news, features, and real life stories from the CF community. It is mailed to over 20,000 of our supporters across the UK and can also be read online.

To mark our 60th anniversary, this year we published a special edition of CF Life magazine, featuring a fold-out timeline of key milestones from our history.

Our cover story was an interview with supporter and involvement group member Rob. Rob has CF and first featured on the cover of CF Life predecessor, CF News, as a 6-year-old boy to mark the Trust's 30th anniversary. 30 years later and he shared his story once again.

In 24/25, we also covered topics including:

- transplant and CF
- dealing with a new diagnosis
- research into CF lung infections.

A big thank you to everyone who has contributed to CF Life magazine this year!

"Being involved in the Trust's 60th anniversary has made me reflect on just how different the CF landscape is today than in 1994. I'm looking forward to the next 30 years and being involved in the 90th anniversary!"

Rob

CForYourself podcast

Our podcast launched in June 2022 with host Lucy having a cup of tea and a chat with others in the CF community, talking openly and honestly about a whole range of topics. For this year's series, we asked the community what they wanted us to talk about, and we've covered everything from pregnancy to exercise.

CForYourself is all about sharing honest insights into life with cystic fibrosis – the good, the bad and everything in between and has been a huge success with our community and beyond. While most of our listeners are in the UK, we've also reached the CF community across the world, from Australia to Argentina.

> "What an exciting episode! The discussion around CF and pregnancy is so important... this podcast is a fantastic resource for anyone navigating pregnancy with CF."
>
> Emma, podcast listener

Series 3 highlights

- 8 episodes
- 1,126 downloads
- Most popular episode: Pregnancy and CF



Lucy Baxter, host of the CForYourself podcast

"I wanted to be a guest editor for CF News because I am grateful to the Trust for so many things and I wanted to give back to this organisation. I am also an aspiring writer, so this is a great opportunity for me, and I'm happy to be given the chance to write something as personal as my CF."

Sarah, CF News guest editor



Whatever you do, do it in yellow

CF Week

CF Week is our annual awareness and fundraising week, ending with the brightest fundraising day of the year – Wear Yellow Day! CF Week 2024 focused on 60 years of Cystic Fibrosis Trust, the amazing progress we've made during that time, and the work that still needs to be done to ensure everyone with CF can live a life unlimited.

Highlights included:

- We shared a diverse range of stories from across the CF community, including Shanique and Thiago's, which had over **7,000** views across all platforms.
- Our e-newsletter CF News was guest edited by Sarah from the CF community, who shared her CF journey and being part of the LGBTQIA+ community.
- We aired a special podcast episode which went behind the scenes at Cystic Fibrosis Trust.
- We empowered the CF community to tell their story and share their #CFTruths through our social media platforms.
- Wear Yellow Day raised a fantastic **£125,000**.
- Celebrities including Ben Shephard, Vincent Franklin, Jenny Agutter and Elizabeth Green all got involved.
- June was a record month for website donations, with over 224 one-off donations.

Uniting in fundraising

We'd like to take this opportunity to thank all of our incredible supporters, donors, organisations, charitable trusts and foundations, and corporate partners who have supported our work this last year. It is because of you that we can be there for people with CF every step of the way.

In 2024/25, we raised an amazing £6.9m gross and £4.7m net. This was £1m less than last year, mainly due to a decrease in legacy income. We saw growth in several income streams – namely events, in-memory, and trusts. Overall, our income has not returned to pre-pandemic levels and remains impacted by the cost of living crisis and increasing competition for funds.

That said, we continue to innovate and develop our fundraising campaigns and appeals, building on learning from the year before. Our flagship Wear Yellow Day attracted one of the largest number of supporters to date.

It was a pleasure to have the opportunity to mark our 60th anniversary with our supporters and funders, and to reflect on the milestones the Trust and the CF community have experienced together. We also had the opportunity to honour some of the incredible fundraising achievements of our supporters at our 60th anniversary awards.

This year also saw the launch of our new Translational Innovation Hub Network, which builds on the successful model of the original Innovation Hub at the University of Cambridge. The new Network aims to drive a transformative shift in research to develop innovative diagnostic and treatment approaches that support the clinical management of lung health and infections, ultimately improving the quality of life for people living with CF. In partnership with LifeArc, over £3.5m has been committed across the four hubs in its launch year and we are delighted that the Robert Luff Foundation have continued their support for the new Hub Network.

Community and event fundraising

Thanks to all our incredible fundraisers, we have raised an incredible **£2,267,000** this year.

Our supporters took part in an array of challenge events, including London Marathon, Edinburgh Marathon, London Landmarks, Great North Run, London to Brighton Bike Ride, and skydives up and down the country. They also headed off around the world to take on overseas treks, marathons and other gruelling challenges. Together, these amazing individuals raised over **£1,171,000** for the Trust.

The CF community continue to get behind our Wear Yellow, Festive and FeBrewary campaigns, coming together at key points in the year to show their support. Alongside this, lots of people contributed their own way, just like our very own trustee, Sophie Pierce, who raised funds and awareness and even broke a world record by rowing the Atlantic in her crew of four, in 53 days.

Wear Yellow Day goes from strength to strength, raising **£125,000** last year. Over 212 individuals, 145 schools, and 250 parents of children with CF (who form the CF Mamas and Papas) came together to make it one of the biggest and brightest Wear Yellow Days to date.

We are also grateful to have the continued support and dedication from our branches and groups who resolutely raise awareness and funds to support the Trust's work. The year's total is **£98,000**, with activities ranging from carol concerts, fairs and garden parties, to running challenges and celebratory balls.



Sophie Pierce (second from right) and members of Team Cruising Free

"For me, this row isn't just a crazy personal adventure, it's also a chance to reimagine the future of cystic fibrosis and bring hope that one day, everyone with CF will be able to cruise free through life."

Sophie, our Trustee, who has CF



Pamela and her son Max, who has CF

"I started the CF Mamas fundraising group a few years ago after speaking to some special CF mummies. We wanted to do something as a big group and not only raise very important funding but also awareness."

Pamela, on setting up CF Mamas and Papas

Regular gifts

We're deeply grateful for our regular donors, whose ongoing support raised an incredible **£780,000** in 2024/25, including Gift Aid. Thanks to a telemarketing campaign, we gained an additional **£8,300** through upgraded and reactivated gifts. Giving this way is one of the most sustainable ways to support the Trust, allowing us to plan ahead and make a real difference in the lives of those affected by cystic fibrosis, funding life-changing research and vital care.

Gifts in Wills

Supporters leaving a gift in their Will to Cystic Fibrosis Trust continue to make an extraordinary and lasting difference, funding groundbreaking research and crucial support services for people with cystic fibrosis.

Thank you to everyone who has chosen to support us in this very special way, **with particular appreciation in 2024/25 for the 117 gifts received and 72 gifts pledged**. These considered acts of kindness bring us closer to a future where everyone can live a life unlimited by cystic fibrosis.

Giving through gifts in Wills remains a vital contribution to the current and future work of the Trust. This year our legacy appeal had a fantastic response rate of 14%, with more supporters making the choice to have a positive impact on our futures.

We continued to highlight the importance of having an up-to-date Will and promoted our free Will offers, helping supporters to be in control of their wishes and make a difference to causes that are close to their heart.

In memory

We are profoundly grateful to everyone who has donated in memory of someone special. In 2024/25, **over £250,000** was given in expression of love, remembrance, and a shared commitment to a future where everyone with CF can live free from the limits of the condition.

These gifts create real and lasting impact, and play a vital role in supporting our work.

Many families and friends chose to commemorate their loved ones through our Book of Remembrance, dedication wall, or personal tribute funds. These meaningful spaces provide comfort and connection, allowing memories to be celebrated and shared.

To those who have chosen to honour a life in this way – thank you. Your generosity keeps memories alive and offers support and hope to others affected by cystic fibrosis.



"As a family tradition, we choose not to send Christmas cards and instead donate this money to the Trust so it can be put to good use and help families similar to us. Cystic Fibrosis Trust has meant so much to me and my family since Dad passed because of their aim to spread awareness, find treatments and support people with CF alongside their families."

Sophie, who lost her dad Paul to CF

Sophie and family

Corporate partnerships

Building partnerships with existing and new corporate partners helps us raise both funds and awareness for the Trust. Crane CPE funded us for the sixth year running from their Crane Widows and Children Fund, and the skills and expertise of the Bip Group assisted us in ensuring that our Helen Barrett Bright Ideas Awards continue to support entrepreneurs with CF to launch or grow their businesses.

We were delighted to be named as charity of the year by Project Leaders, Atlantic Pumps, and Pyvital. Events such as the UK CF Clinical Trials Conference, UKCFC, and the Annual Registry Meeting are essential in showing the work we do. This would not be possible without the support of our sponsors, some of whom come back year after year. Our MDT conference, held in Birmingham in March 2025 with sponsorship from Recode Therapeutics, Enterprise Therapeutics, Essential Pharma and Nordice Pharma, was a standout event for us this year.

We would also like to thank our partners who have shared their expertise and resources with us this year, including Bird and Bird, and Cushman and Wakefield. We would like to thank Bauer Media Outdoor (formerly Clear Channel) for their gift-in-kind outdoor advertising to help support our vital awareness campaigns.

Philanthropy

We would like to thank the generous and committed support of trusts, foundations, and the National Lottery Community Fund, whose grants have been critical to our provision of services and new programmes for the CF community, alongside world-leading research.

We are especially thankful for our long-term partners, the Robert Luff Foundation, the Joseph Levy Foundation, and Garfield Weston Foundation.

Thanks to the generosity of these supporters, over the last year we have continued to ensure that people with CF can live a life unlimited. This has included progressing vital research, helping young people to build their futures and offering grants through our Winter Support Fund.

We are also deeply grateful for the committed support of our Sixty Five Roses Club members who are able to support us with a minimum donation of **£1,000** each year. The Club is thriving, with over **70 members** now helping to fund projects that support people with CF when they need us most.

Supporter experience

The Trust received 19 complaints in 2024/25. This is broadly in line with the 29 received in 2023/24, and 19 in 2022/23, with the main areas of improvement being more effective use of data (fewer mailing-related errors) and in dealing with sensitive subjects (like bereavement). Complaints are closely monitored and reviewed by senior management on an ongoing basis. In addition, we regularly review our complaints policy and processes to make it easier for people to give us feedback and to ensure that we listen and learn from what our supporters and community are telling us.

"Without the help of the Joseph Levy Education Fund grant, my university experience would have been completely different. The support that was there allowed me to pursue my degree knowing that I would be able to handle both university life and keep myself well."

Emily, who has CF



Looking to the future



> “I want to be able to inspire people. I’m 40 now, and I have friends with kids with CF. It’s important for me to be able to say I’m 40, I have a full time job, and I can do all these amazing things as well.”
>
> Rich, who has CF

Uniting in research for a life unlimited

We continue to work towards our research goals, guided by the priorities of the CF community. By funding innovative, world-class research and maximising our research partnerships, we're committed to improving the lives of a diverse CF community. We're excited about the potential of our partnership research programmes, such as CF AMR Syndicate and the Translational Innovation Hub Network, to improve the lung health for everyone with CF.

We're constantly seeking new partnerships and attracting companies to develop their products with the CF community in the UK. We offer combined research support to deliver trials that are easy to set up, efficient and meaningful, and could make a difference to people with CF and their families.

Early phase trials being supported by our CTAP programme will continue to assess medicines for people who can't benefit from modulators. Studies using UK CF Registry data will continue to monitor the long-term effects of modulators and help us better understand the changing nature of CF.

"It's a very exciting time in CF care. For 34 years of my life, there didn't seem to be any huge advancements, and now they are coming thick and fast. In all honesty, it's the most hopeful I've ever felt, and that's comforting as someone approaching 40 that didn't even think I'd be here, let alone experiencing these huge leaps forward in treatment."

Sarah, who has CF



Sarah



Nell

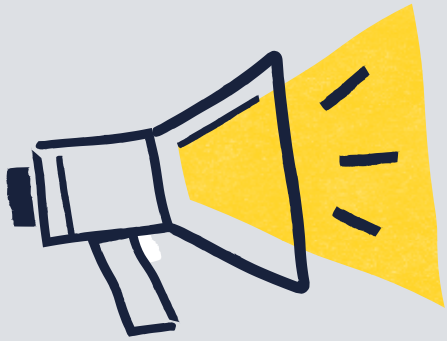
> “Cystic Fibrosis Trust have been amazing and the research and developments that have come about as a result of the charity’s efforts has been incredible to see. Kaftrio has made a huge difference for me and my brother, but I know it’s not a cure and some people can’t benefit from it, so I’m determined to run for everyone in the CF community.”
>
> Nell, who has CF

Being great fundraisers

Growing our income remains a key priority at the Trust so that we can build on the progress we have made, and make sure that in 2025 and beyond people with CF can live their lives without limits.

Next year we are embarking on a new fundraising strategy, with a renewed focus on building our supporter numbers and ensuring they have an excellent experience of supporting the Trust. Innovation will continue to run through our plans across all income areas, so we can offer a diverse portfolio of engaging and exciting ways for people to get involved – be that in their own time; participating in challenge events; or by taking part in one of our mass participation campaigns. We plan to develop more multi-year relationships with trusts and launch a new giving circle to help accelerate funding for our research programmes. Alongside this we will continue to fundraise to meet our £1.5million contribution towards the Translational Innovation Hub Network.

We want to get closer to our supporters, branches, CF centres, and corporate partners to work together to raise funds as one community with a shared purpose to improve the lives of people with CF and their loved ones.



Campaigning hard

Looking ahead, our advocacy will continue to focus on critical issues impacting the CF community. The impact of toxic air quality remains a significant concern, and later this year we will leverage findings from our commissioned research with the York Health Economics Consortium to advocate for stronger environmental policies.

The Government’s emphasis on science and innovation presents opportunities to advance CF research and treatment. We will advocate for policies that support research funding, innovation, and improved mobility for scientists, accelerating progress in CF care.

With a new legislative agenda unfolding, we remain vigilant, ready to respond to policy reviews and budget announcements as we have on the Government’s Pathways to Work social security reforms. Our commitment is unwavering: to seize every opportunity to advocate for improved care, support, and a future free from the limitations of cystic fibrosis.

Day-to-day support

We continue to develop our services and resources to meet changing needs, while maintaining our core provision.

This year, we've strengthened our peer support provision, recognising the importance of providing safe spaces for the CF community to come together and support each other. We have piloted new online events, continued to develop our online community, and provided updated training to our CF Connect volunteers, who provide parent-to-parent support over the phone. We have now shaped a clear forward strategy for peer support, highlighting the key role it plays in supporting emotional wellbeing and physical health. Over the year ahead, we will be developing this further with a view to seeking funding to expand our peer support provision.

We have been working with another national charity to explore ways to provide enhanced grief support to those bereaved by CF, and we will be taking this partnership forward in the year ahead.

Over the coming year, we will be developing information to support people with CF to manage their mental health and wellbeing, and starting work on updating our information around family planning, as well as continuing with updates to our guideline documents, including antimicrobial treatment, infection prevention and control, physiotherapy, and nutrition.

We will also be developing our work to support those in the CF community who are neurodivergent.



Jacob

"When Jacob was first diagnosed, the CF nurse at the hospital handed us a pamphlet from the Trust explaining what CF is. It helped us to have that information in one place and meant I didn't go searching on Google, which would have been the worst thing for me to do."

Morag, whose son Jacob has CF





> **"With the CF community evolving in size and age, new opportunities and challenges emerge, particularly for the NHS and CF teams dedicated to providing the best quality care to people with CF."**
>
> CEO David Ramsden

Quality improvement and clinical engagement

In 2025/26, we will report on findings from our first ever survey for CF professionals, which looks at how CF care and workload are evolving from the perspective of those working in the specialty. Data collection started in March 2025 and findings are anticipated in the early summer.

In October, new data will be collected on staffing levels in CF services as part of our annual CF staffing tool. And in November, we will open the third cycle of our patient experience survey in children's services.

We are continuing to roll out and expand our quality improvement support offer for CF centres, to support them to explore their data insights and plan targeted quality improvement activities.

The UK CF Registry

The UK CF Registry remains at the forefront of collaborative innovation, continuously expanding its portfolio to better serve people with CF. We are developing a new purpose-built CFSPID Registry. In parallel, we are partnering on new research initiatives, including projects focusing on pregnancy and cystic fibrosis.

The Registry continues to support collaborative studies monitoring the long-term health outcomes of Kaftrio, with publication of results expected in 25/26 alongside plans to present results at international conferences.

As the structure of the NHS evolves with the dissolution of NHS England, we are committed to maintaining strong partnerships with NHS organisations to ensure alignment with national priorities that will benefit people with CF.

Financial review

Results for the year

Over the last 12 months, like many charities, the Trust has faced challenges in maintaining income due to the wider economic climate. Therefore, the Trustees approved a business plan with a deficit budget for the financial year which assumed reduced income and reduced grant awards whilst maintaining services and support at a level similar to previous years.

The result for the year, excluding movements on investments, was a deficit of £1.8m (2024: deficit of £0.4 million) which is £0.4m better than budget, largely due to efficiencies and cost reductions made during the year.

Total income of £12.0m is £2.6m lower than in 2024, whilst total expenditure has decreased by 8% (£1.3m), which is principally due to a reduction in grant awards (and unclaimed grant commitments recredited to our accounts).

This deficit has been funded from unrestricted reserves. As explained below (see Reserves, page 58), despite the deficit in the year, the Trust continues to hold strong reserves. The Trustees have agreed a four-year financial plan to increase income whilst broadly maintaining activity at current levels. The aim is to deliver a balanced position by March 2029, while ensuring that the Trust maintains reserves within its reserves policy.

Income

The Trust's income from normal activities for the year to March 2025 was £12.0m (2024: £14.7m).

Voluntary income of £6.5m (2024: £8.0m) includes amounts from regular giving programmes and appeals, from branches, groups and communities, corporate partnerships and trusts. In common with many charities, the on-going cost of living crisis means that generating voluntary income remains challenging. Whist individual giving income is broadly similar to last year, income from trusts has reduced by £0.9m, primarily due to receiving a £1.2m donation in the prior year for a specific research project.

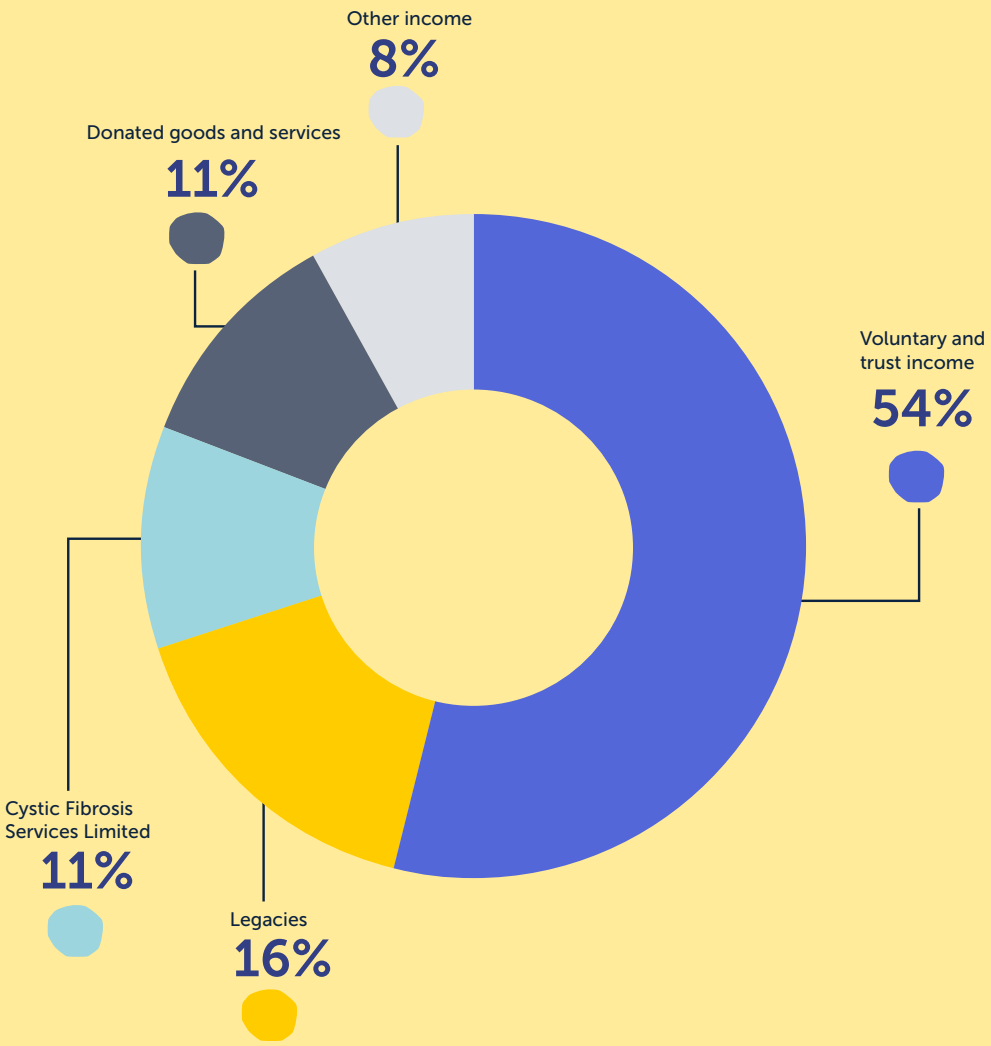
Legacy income of £2.0m is £0.6m less than in 2024, a year in which the Trust benefitted from several exceptional large gifts.

Income generated by Cystic Fibrosis Services Ltd ("CFSL"), the Trust's trading subsidiary, was £1.3m (2024: £1.3m). This income is mainly generated from contracts with pharmaceutical companies for our UK CF Registry to produce study reports for the regulators of medicinal products. The company expects to confirm contacts to support further studies within the next few months which will secure further income over the next three years.

We benefit from generous corporate donations in kind including outdoor advertising and advice supporting our campaigns. The value of these services was £1.3m (2024: £1.5m). The corresponding cost value of this donation is included in charitable expenditure as part of the information, advice and support costs.

Other income of £0.9m in the year (2024: £1.2m) includes investment income, contracts for services and recoverable VAT.

Income 2024/25



Expenditure

The Trust's total expenditure for the year was £13.8m, a £1.3m decrease compared to the previous year.

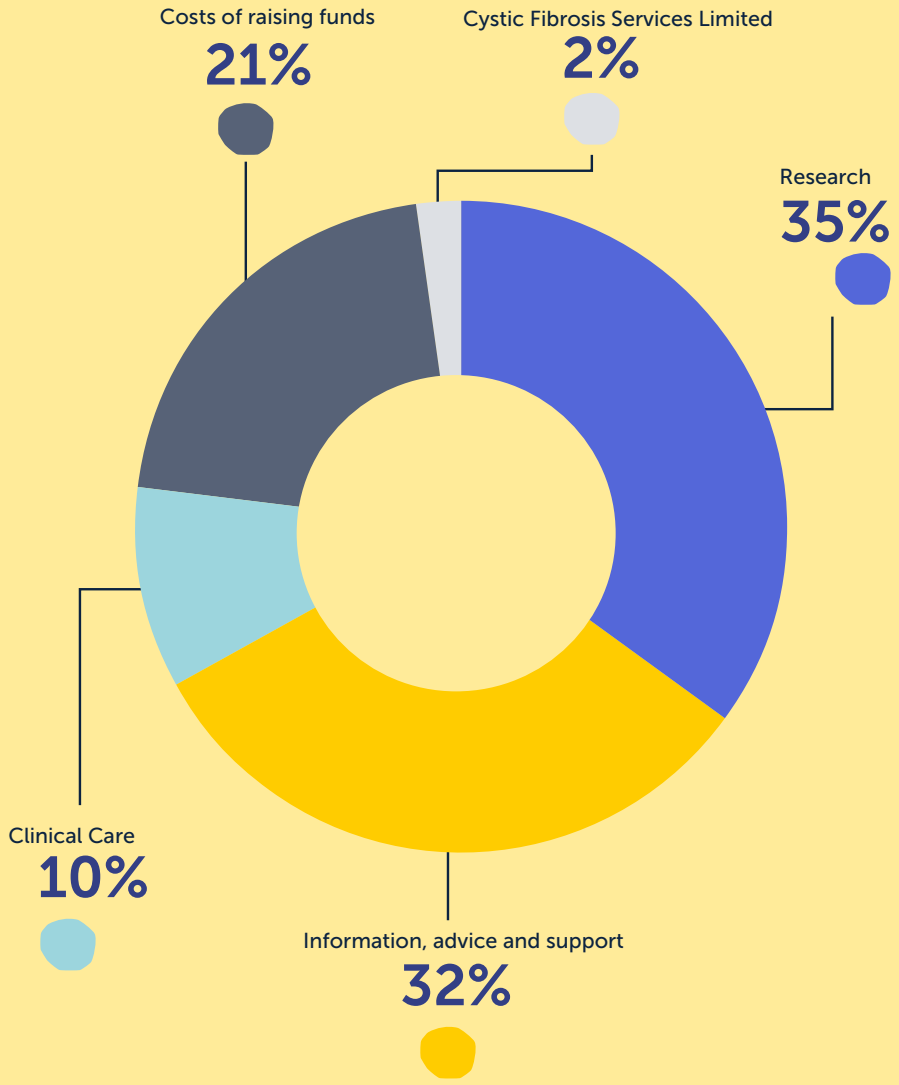
Expenditure on charitable activities in the year was £11.0m (2024: £12.3m). This includes funding research, providing information and advice and support and promoting the best clinical care. The reduction in costs is due to careful cost control during the year, which included a reduction in staff headcount and reduced research grant expenditure. Grants to support charitable activities included:

- £2.7m (2024: £3.9m) grants to a range of medical, academic and charitable institutions to support research. The Trust continues to seek funding and co-funding to enable it to increase funding for this vital research. The Trust also reviewed grants made in previous years where there has been no recent activity, and this resulted in £0.5m (2024: £0.3m) of grants made in previous years being recredited to our accounts
- £0.3m (2024: £0.4m) to fund the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme
- £0.3m (2024: £0.3m) grants to CF Centres to fund data collection for the Registry
- £0.3m (2023: £0.3m) to individuals through our Welfare Grant programme

(The total grants awarded are detailed in Note 5 to the financial statements.)

The cost of raising funds was £2.8m (2024: £2.7m).

Expenditure 2024/25



Investment policy

The Trust holds significant investments in cash and cash equivalents, and in a managed investment portfolio.

	2025 £'000	2024 £'000
Cash and cash equivalents	**11,558**	12,024
Managed investment portfolio	**5,835**	5,796
Total	**17,393**	17,820

The Finance and Audit Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to adopt a balance between generating sufficient income to support the on-going activities of the Trust, whilst maintaining the real capital value of the investments over the long-term.

The majority of the managed investment portfolio is kept in liquid funds although there is some exposure to less liquid assets such as property. Approximately 84% of the portfolio is now invested in the Responsible Multi-Asset Fund which aims to have a positive impact on people and the planet by avoiding harm through environmental, social, and governance integration and exclusions, benefiting stakeholders through responsible business activities and contributing to solutions through influence and investing for impact. The remaining funds are invested across various funds including the Charities Property Fund, Trojan Ethical Fund and the Columbia Threadneedle Responsible Equity Fund. The Trust does not permit direct investment in tobacco.

A number of small endowment funds are invested on a total return basis, enabling the Trust to utilise both income generated by the funds and increases in capital value, while protecting the original inflation-adjusted endowment values.

We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance and Audit Committee.

Review of investments in the year

The value of the investment portfolio (including endowment funds) was £5.8m as at 31 March 2025 (2024: £5.8m). Due to market conditions, there was no significant investment gain in the year. The Trusts targets a return of CPI plus 3%. Since the end of the financial year market conditions have been volatile, but despite losses in April, at the date of this report the value of the investment portfolio has increased to over £6.0m. No change was made to the allocation between amounts held as stocks and shares and that held as cash in the portfolio.

Income generated on investments totalled £0.7m (2024: £0.6m).

Reserves

The Trust has a reserves policy which is based on best practice as set out by the Charity Commission in CC19 **Charity reserves: building resilience**. The Trustees actively review the Trust's reserves to ensure that the Trust has sufficient funds to support future activities and meet all its commitments and obligations.

The Trust holds the following reserves:
Restricted funds which are to be used for specific uses specified by the donor. Expenditure which meets the donor's criteria is charged against the specific fund. At 31 March 2025 restricted funds totalled £0.5m (2024: £0.5m). Note 21 lists the individual restricted funds and their movement in the year.

Endowment funds where the donor requires the Trustees to hold the funds as capital investments. Income from the investment can be used by the Trust as specified in the terms of the endowment. The Trust is not entitled to spend the capital fund without permission from the donor. At 31 March 2025 the endowment funds totalled £1.0m (2024: £1.0m). See note 20 for information about the individual endowments.

Designated funds which are funds that the Trustees have set aside for specific projects or initiatives. There are three designated funds:

- Organisational reserve: £0.8m (2024: £1.0m) has been established for investment in process improvement and our digital/data strategy, including implementation of a new Customer Relationship Management (CRM) system.
- Fixed asset reserve of £0.06m (2024: £0.13m). The reserve is maintained as fixed assets cannot be readily realised as cash.
- Research fund reserve of £0.5m (2024: £nil). As explained in note 5 (page 80) various grants awarded in previous years totalling £465,000 were credited back to reserves in the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful. The Trustees consider that the funds have been committed to fund research and that this commitment remains. Therefore, they have created a designated fund for future research.

Retained Reserves which can be used to fulfil any part of the Trust's objectives.

The Trustees have adopted a reserves policy designed to ensure the Trust maintains sufficient funds to continue its activities, particularly in light of recent economic volatility.

The Trustees have set a minimum level of retained reserves and an upper target with the aim that unrestricted funds fall within this range. In setting this **core reserves range** the Trustees have considered:

- The level of reserves required to mitigate income risk. This includes the challenge of fundraising in the current economic environment and the risks associated with not securing further contract income for the UK CF Registry.
- The risk of not being able to contain costs in line with future saving targets.
- Risks of a significant fall in the value of the Trust's investment portfolio due to market volatility and the impact of falling interest rates.
- Maintaining sufficient working capital headroom.

Based on the 2025/26 budget and a review of the above risk factors, the target core reserves range is between £4.0m and £6.5m.

At 31 March 2025 the Trust's retained reserves were £6.7m (2024: £8.7m) which is slightly above this core reserves range. The Trustees approved a detailed business plan with a deficit budget for the next financial year which maintains services and grant awards at a level similar to last year and which will bring the Trust's retained reserves within this core range. (Retained reserves are forecast to be £5.3m at March 2026 and reduce further to £5.0m by March 2027.)



"Having CF doesn't stop you from doing the things you're passionate about, no matter what that may be."

Rosie

Principal risks and uncertainties

The Board of Trustees is responsible for ensuring effective risk management and internal controls to manage the major risks the Trust faces, including agreeing the Trust's 'risk appetite' (how much risk the Trust is willing to tolerate in key areas) and keeping oversight of the Trust's risk management framework. This framework, managed by the Senior Leadership Team, includes a Strategic Risk Register and provides a consistent approach to identifying, assessing and dealing with the risks facing the Trust. It is monitored at least quarterly to support informed decision-making and ensure appropriate mitigations and controls are in place to effectively manage any risks to our objectives.

The main strategic risks and uncertainties that management and Trustees have identified and the key actions to mitigate these risks are:

Strategic risk	Strategies/plans for managing risks
Relevance • Failure to be relevant and responsive to the needs and expectations of people with cystic fibrosis and our wider community could damage our reputation and ability to deliver our objectives. • Failure to get our message across in a way that conveys the impact of our work means we will not be seen as relevant and will not reach widest possible audience, and damage our reputation, losing support, credibility and income. • Failure to Influence key external stakeholders and decision makers will impede our ability to deliver on our strategy and erode our relevance in eyes of the community.	• Our strategies and work programmes reflect the views and priorities expressed by people with cystic fibrosis through consultation, involvement and co-design. • Our Equity Diversity and Inclusion Strategy reinforces our commitment to listening and representing the full range of stakeholders across our community. • We have detailed audience insight research analysis and are implementing the findings. • We continually develop strategies on emerging priorities, including Air Quality, Housing, Poverty, CF Care resourcing, and benefits and welfare reform. • Policies and processes in place to ensure quality control and the relevance of our messaging, including 'red flag' processes on potentially sensitive communications. • Our close links with the community, and ability to listen and closely monitor discussions and sentiment, gives us early warning on many emerging community priorities/issues.
Financial • Failure to operate a sustainable financial model could heavily compromise the Trust's operational viability and its ability to deliver for people with cystic fibrosis.	• The strategic financial framework for the next four years and budget for 2025/26 includes measures to closely track income and expenditure and is scrutinised by the Finance and Audit Committee. Our plans ensure that we will maintain unrestricted retained reserves within policy. • The new Fundraising strategy focusses on maximising sustainable net income, including exploring innovative new sources of income. • Our business planning has strong focus on prioritisation, and additional cost savings are actively explored.

Strategic risk	Strategies/plans for managing risks
Data • Failure to optimise our use of and adequately protect our data will limit our impact, reach, income and relevance, and harm our reputation if it falls into the wrong hands.	• We have a GDPR compliance framework, Data Protection Policies and Data Protection Officer. There is ongoing staff training. • We have implemented a data strategy with the focus on three strands: upgrading our CRM, ensuring data quality and ensuring we have a data-centric culture. • We continually review our data security including access controls (e.g. multifactor authentication) and utilise automated monitoring and reporting. • We have implemented a new AI policy and will continue to review this rapidly developing area.
People • Failure to deliver People Strategies that effectively support, protect, and develop our staff and volunteers will erode our ability to recruit and retain highly skilled and motivated staff and could have significant reputational impact.	• We have a comprehensive range of policies in place covering welfare, safeguarding, recruitment and retention, learning and development and employee benefits. These are reviewed and updated regularly with external professional support. Trustees have oversight of these through the People Committee. • There is a strong communications, feedback and learning processes in place (CEO briefings, staff survey, elected employee reps, exit interviews).
Autonomy • Failure to maintain autonomy in relationships with pharma, academic institutions and funding partners will compromise our relationships with the wider clinical community and may harm our reputation.	• Our governance processes include systematic declaration of interests, conflict of interest guidelines and robust research governance and awards processes. • Partnership working and ethical policies are in place defining criteria for establishing new partnerships to ensure risk is considered.

Processes in place regarding risk management and internal control include the following:

- A risk management framework that meets the Charity Commission's requirements. A top-down risk review by the Senior Leadership Team, and a bottom-up review by individual functions, is undertaken throughout the year and the risks identified through this process are documented in a risk register.
- The Finance and Audit Committee receives reports from the external auditors on the effectiveness of controls and, where appropriate, adopts the recommendations made in the external auditors' reports.
- The Board of Trustees receives a comprehensive risk management report each quarter to assist it in ensuring that an effective process is in place. This report provides an update on the risk reviews undertaken and provides the Board with the opportunity to engage in dialogue about, and to provide input into, the evaluation and management of key risks.
- Formal project delivery groups are established for major projects and programmes to ensure that these are carefully planned, managed and implemented.

Our work with the pharmaceutical industry

Our mission is to make sure everyone can live without the limits of cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

Partnerships between medical research charities and the life sciences industry can help us deliver that mission and bring huge benefits to patients including accelerating the development of new drugs and ensuring the safety and improvement of existing treatments.

We run the following flagship programmes involving pharmaceutical industry partners:

Clinical Trials Accelerator Platform

CTAP is a UK-wide initiative bringing together CF centres to increase participation and access to CF clinical trials. This initiative is building infrastructure and funding additional research capacity to support the life sciences industry with commercial clinical trial delivery.

As part of our collaboration with industry, CTAP offers a centralised feasibility service to support pharmaceutical companies with identification of suitable CF centres for clinical trial delivery.

Venture & Innovation Awards (VIAs)

VIAs support transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the life sciences industry.

The UK CF Registry

Long-term safety and efficacy studies of drugs available to people with CF across the UK are supported by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the regulators of medicinal products is covered by pharmaceutical companies holding the market authorisation for these medicines. You can read more about our work with industry to make medicines safer at **cysticfibrosis.org.uk/registry**.

In 2024/25 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £1.3m (2024: £1.3m) in fees for this service. This income was used to support and maintain the Registry, including staff costs, data collection through Centre grants and IT hosting and development.



Sponsorship and donations

The Trust seeks sponsorship and grants from pharmaceutical companies to ensure we have the funds to run the events that we know are so important for healthcare professionals and people affected by cystic fibrosis. These events enable us to keep these audiences informed on vital aspects of clinical care and research.

We would like to thank Vertex who provided Independent Medical Education Grants for the UK Clinical Trials Conference in March 2024, the Early Career Researchers conference in October 2024 and the Multi-disciplinary Team (MDT) Conference in March 2025. Recode Therapeutics were our headline sponsors at the MDT conference in March 2024 and sponsored our CTAP conference in March 2024 for which we were most grateful. Thanks also go to Enterprise Therapeutics, Essential Pharma and Nordic Pharma for their sponsorship support of the MDT conference.

Statement of Trustees' responsibilities

The Trustees, who are also directors of the Cystic Fibrosis Trust for the purposes of company law, are responsible for preparing the Trustees' report (including the Group Strategic Report) and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group, and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently,
- observe the methods and principles in the Charities SORP,
- make accounting estimates that are reasonable and prudent,
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustees investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware,
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustee's Report incorporating the Strategic Report was approved and authorised for issue by the Board of Trustees on 30 July 2025 and signed on its behalf by:



Richard Hunt, Chairman

Independent auditor's report to the members and trustees of Cystic Fibrosis Trust

Opinion

We have audited the financial statements of Cystic Fibrosis Trust (the 'charitable parent company') and its subsidiary (the 'group') for the year ended 31 March 2025 which comprise consolidated statement of financial activities (incorporating the income and expenditure account), the consolidated and charity balance sheets, the consolidated statement of cash flows, the principal accounting policies and the notes to the financial statements. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the charitable parent company's affairs as at 31 March 2025 and of the group's income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group and charitable parent company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report and financial statements, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report, which is also the directors' report for the purposes of company law and includes the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and

- the trustees' report, which is also the directors' report for the purposes of company law and includes the strategic report, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the charitable parent company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- proper and adequate accounting records have not been kept by the charitable parent company, or returns adequate for our audit have not been received from branches not visited by us; or

- the charitable parent company financial statements are not in agreement with the accounting records and returns; or

- certain disclosures of trustees' remuneration specified by law are not made; or

- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the charitable parent company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the charitable parent company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- The engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulation;
- We identified the laws and regulations applicable to the charitable parent company and group through discussions with key management;
- We focused on specific laws and regulations which we considered may have a direct material effect on the accounts or the activities of the charitable parent company and group; and
- We assessed the extent of compliance with the laws and regulations identified above through making enquiries of key management and review of minutes of trustees' meetings.

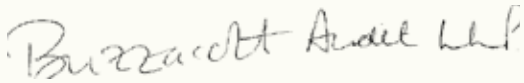
There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the trustees and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees as a body, in accordance with Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Shachi Blackmore (Partner)
For and on behalf of Buzzacott Audit LLP, Statutory Auditor
130 Wood Street,
London
EC2V 6DL

Date – 30 July 2025

Buzzacott Audit LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Cystic Fibrosis Trust

Consolidated statement of financial activities

For the year ending 31 March 2025

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2025 £'000**	Total Funds 2024 £'000
Income and endowments from:						
Donations and legacies	2	7,468	2,564	-	**10,032**	12,402
Charitable activities						
Other trading activities		1,257	-	-	**1,257**	1,304
Investments	3	655	-	-	**655**	628
Other income		70	-	-	**70**	332
Total income		**9,450**	**2,564**	**-**	**12,014**	14,666
Expenditure on:						
Raising funds	4	2,841	4	-	**2,845**	2,748
Charitable activities						
Research	4	3,584	1,526	2	**5,112**	6,409
Clinical care	4	672	749	-	**1,421**	1,477
Information, advice and support	4	4,192	262	-	**4,454**	4,460
Total charitable activities		**8,448**	**2,537**	**2**	**10,987**	12,346
Total resources expended	4	**11,289**	**2,451**	**2**	**13,832**	15,094
Net (expenditure)/income before investment gains/(losses)		**(1,839)**	**23**	**(2)**	**(1,818)**	(428)
Realised investment losses		-	-	-	**-**	(2)
Unrealised investment gains/(losses)	19	70	-	(30)	**40**	413
Net investment (losses)/gains		**70**	**-**	**(30)**	**40**	411
Net (expenditure)/income		**(1,769)**	**23**	**(32)**	**(1,778)**	**(17)**
Transfers between funds	19	35	(35)	-	**-**	-
Net movement in funds		**(1,734)**	**(12)**	**(32)**	**(1,778)**	(17)
Reconciliation of funds:						
Total funds brought forward		9,840	468	1,032	**11,340**	11,357
Total funds carried forward	19	**8,106**	**456**	**1,000**	**9,562**	11,340

All of the operations are continuing.

There were no recognised gains or losses other than those stated above.

A prior year comparative consolidated statement of financial activities has been included in the notes to the accounts (note 22).

The notes on pages 72 to 95 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated and charity balance sheets

For the year ending 31 March 2025

	Notes	Consolidated		Charity	
		Total 2025 £'000	Total 2024 £'000	**Total 2025 £'000**	Total 2024 £'000
Fixed assets					
Tangible assets	7	**64**	132	**64**	132
Investments	8	**5,835**	5,796	**5,835**	5,796
		5,899	5,928	**5,899**	5,928
Current assets					
Debtors	9	**2,996**	5,076	**2,934**	5,041
Cash held as short term investment		**11,558**	12,024	**11,558**	12,024
Cash at bank and in hand		**2,584**	4,046	**2,576**	4,036
		17,138	21,146	**17,068**	21,101
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	10	**(5,444)**	(6,235)	**(5,444)**	(6,235)
Creditors and accrued charges	11	**(2,714)**	(2,772)	**(3,494)**	(3,625)
		(8,158)	(9,007)	**(8,938)**	(9,860)
Net current assets		**8,980**	12,139	**8,130**	11,241
Creditors: amounts falling due after one year					
Grants payable	10	**(5,317)**	(6,727)	**(5,317)**	(6,727)
Total net assets		**9,562**	11,340	**8,712**	10,442

Continued on the next page

Cystic Fibrosis Trust

Consolidated and charity balance sheets (continued)

For the year ending 31 March 2025

	Notes	Consolidated		Charity	
		Total 2025 £'000	Total 2024 £'000	**Total 2025 £'000**	Total 2024 £'000
The funds of the charity:					
Endowment funds	20	**1,000**	1,032	**1,000**	1,032
Restricted income funds	21	**456**	468	**456**	468
Unrestricted funds					
Designated reserves					
Organisational reserves	19	**868**	1,000	**868**	1,000
Fixed asset reserve	19	**64**	132	**64**	132
Research fund reserve	19	**465**	-	**465**	-
Total designated funds		**1,397**	1,132	**1,397**	1,132
Retained reserves		**6,709**	8,708	**5,859**	7,810
Total unrestricted funds		**8,106**	9,840	**7,256**	8,942
Total charity funds	19	**9,562**	11,340	**8,712**	10,442

The notes on pages 72 to 95 form part of these financial statements.

Approved and authorised for issue by the Trustees on 30 July 2025 and signed on their behalf by:



Richard Hunt, Chairman
Company number 3880213

Cystic Fibrosis Trust

Consolidated Statement of cash flows

For the year ending 31 March 2025

	2025 £'000	2024 £'000
Net cash provided by/(used) operating activities (Note A)	**(2,584)**	565
Cash flows from investing activities:		
Dividends and interest	**655**	628
Purchase of property, plant and equipment	**-**	(41)
Purchase of investments	**-**	(255)
Movement in cash awaiting investment	**1**	(21)
Proceeds of sales of investments	**-**	279
	656	590
(Decrease)/increase in cash held as short term investments	**466**	(539)
(Decrease)/increase in cash (Note B)	**(1,462)**	616

No separate reconciliation has been prepared between the movements in net debt of the charity as there is no difference between the movements in cash and cash equivalents and the net cash (debt) of the charity.

Notes to cash flow statement

Note A – Reconciliation of net income to net cash flow from operating activities

	2025 £'000	2024 £'000
Net income for the reporting period (as per the statement of financial activities)	**(1,778)**	(17)
Adjustment for:		
Depreciation charges	**68**	64
Dividends and interest from investments	**(655)**	(628)
(Gains)/losses on investments	**(40)**	(411)
Decrease/(increase) in debtors	**2,080**	1,513
Increase/(decrease) in creditors	**(2,259)**	44
Net cash (used in)/provided by operating activities	**(2,584)**	565

Note B – Reconciliation of cash and cash equivalents in the reporting period

	2025 £'000	2024 £'000
Cash and cash equivalents at the beginning of the reporting period	**16,070**	14,915
Change in cash and cash equivalents in the reporting period	**(1,462)**	616
Increase in short-term investments	**(466)**	539
Cash and cash equivalents at the end of the reporting period (being cash at bank and in hand and cash held as short-term investments)	**14,142**	16,070

	2025 £'000	2024 £'000
Analysis of cash and cash equivalents:		
Notice deposits (less than 3 months)	**11,558**	12,024
Cash at bank and in hand	**2,584**	4,046
Total cash and cash equivalents	**14,142**	16,070

Cystic Fibrosis Trust
Notes to the Financial Statements
For the year ending 31 March 2025

1. Accounting policies

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

Basis of preparation
The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) (Charities SORP FRS 102), and the Companies Act 2006.

Cystic Fibrosis Trust meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Charity status
The Trust (charity registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 96. In the event of the company being wound up, each member is liable for a sum not exceeding £1.

Consolidation
The financial statements include the results and assets and liabilities of the Trust and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own statement of financial activities under section 408 of Companies Act 2006. The deficit of the parent charity was £2,629,000 (2024: deficit of £916,000).

Cystic Fibrosis Services Limited's results for the year ended 31 March 2025 are summarised in note 13. The net surplus for the year of £852,000 (2024: £899,000) will be donated in full to the parent charity after the year end.

Income
All income is recognised once the Trust has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably.

Donations and income from legacies are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable. Donations in kind are non-monetary donations received by the Trust. Income, and the corresponding cost of the donation, is recognised when the service is provided. The value of the income and expenditure is the estimated fair market value of the service provided.

Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

Interest on funds held on deposit is recognised in the statement of financial activities when receivable and the amount can be measured by the Trust. This is normally upon notification of the interest paid or payable by the bank.

Investment income is recognised on a receivable basis and the amounts can be measured reliably. Dividends are recognised once the dividend has been declared and notification has been received the dividends are due.

1. Accounting policies (continued)

Expenditure
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the Trust to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably.

Expenditure is recognised on an accruals basis as a liability is incurred and includes irrecoverable VAT where applicable.
Expenditure is classified under the following activity headings:

- Expenditure on raising funds comprises those costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs.

- Expenditure on charitable activities comprises those costs relating to activities where the primary aim is congruent with the objects of the Trust, along with an apportionment of support costs. This includes grants made to research institutions and individuals, the provision of information and support services to people with cystic fibrosis and their families, peer reviews of cystic fibrosis centres and the development of the CF Registry.

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the direct costs in each activity category.

Grants payable are included in the statement of financial activities when approved and the intended recipient has either received the funds or has been notified of the award and has satisfied any initial conditions. Grants approved but not paid at the end of the financial year are accrued.

Foreign currency transactions
Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the statement of financial activities.

Employee benefits
Employee benefits are accounted for as follows:

- Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.
- Termination payments are accounted for on an accrual basis and in line with FRS 102.
- Pension contributions: the Trust operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Trust pays fixed contributions into a separate entity. Once the contributions have been paid the Trust has no further payment obligations. The contributions are recognised as an expense in the statement of financial activities when they fall due.

Taxation
No charge to taxation arises on the result for the year because the Trust can take advantage of the tax exemptions available to charities.

Leases
The Trust recognises expenses under “operating leases” relating to capital equipment which it does not own. The annual rentals are charged to the statement of financial activities on a straight line basis over the lease term. The primary lease accounted for in the financial year is rent of office space.

1. Accounting policies (continued)

Fund accounting
Endowment Funds are funds where the donor requires the Trust to hold the funds as capital investments. Income from the investment can be used by the Trust as specified in the terms of the endowment. The Trust is not entitled to spend the capital fund without permission form the donor.

Restricted funds are to be used for specific uses laid down by the donor. Expenditure which meets the donor's criteria is charged against the specific fund.

Unrestricted funds are those which the Trust are free to use for any purpose in furtherance of the charitable objects. The Trustees may set aside some of the unrestricted reserves for specific purposes, for example to fund a future project. These funds are classified as designated funds.

Fixed assets and depreciation
All assets costing £500 or more and with an expected useful life exceeding one year are capitalised.

Tangible assets are stated in the balance sheet at cost less accumulated depreciation. Depreciation is provided at rates designed to write off the cost of the cost of the assets, less any residual value, by equal annual instalments over their estimated useful lives at the following rates:

Furniture and fittings	33%
Computer hardware	33%
Computer software	33%
Website development	33%
Platform development	50%

Website and platform development costs are capitalised on the basis that they lead to an asset that will generate funds for the Trust or where the primary aim is part of the objects of the Trust. The assets are depreciated once the asset is ready for use.

Investments
Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values of investments are shown as unrealised gains and losses in the statement of financial activities. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value.

Gains and losses on the sale of investments are shown as realised gains and losses in the statement of financial activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired during the financial year.

1. Accounting policies (continued)

Financial Instruments
The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value:

- Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

- Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

- Creditors and provisions are recognised where the Trust has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Critical accounting judgements and estimates
Preparation of the financial statements requires the Trust and management to make significant judgements and estimates. These judgements and estimates are continually evaluated and are based on historical experience and other factors, including expectations of future events.

The items in the financial statements where judgements and estimates have been made include:

- estimating entitlement to legacy income particularly in relation to complex estates
- estimating the useful economic life of tangible assets for the purposes of determining depreciation rates
- providing for bad debts
- allocation of support costs
- estimating future income and expenditure for assessing cash flows to assess whether the Trust is a going concern (see below).
- valuation of donations in kind received during the year.

The value of the contribution of the many thousands of hours donated by its unpaid volunteers as not been reflected in these financial statements. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

Going concern
The Trustees have reviewed the financial statements and supplementary financial information, including the budget for the year to March 2026 and forecasts and projections for the following three year, and conclude that the Trust will continue to operate within or above its reserves policy throughout that period and that the Trust is a going concern.

2. Income from donations and legacies

	Unrestricted Funds 2025 £'000	Restricted Funds 2025 £'000	Total 2025 £'000	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	Total 2024 £'000
Branches, Groups and Community	2,249	18	**2,267**	2,224	45	2,269
Legacies	2,093	143	**2,236**	2,745	196	2,941
Individual donations	309	37	**346**	309	40	349
Corporate	104	14	**118**	267	5	272
Regular giving and appeals	1,155	1	**1,156**	1,204	2	1,206
Trusts	31	2,351	**2,382**	187	3,093	3,280
Appeal for Innovation Hub	-	-	**-**	-	306	306
Donations in kind	1,338	-	**1,338**	1,543	-	1,543
NHS National Services England and Scotland	189	-	**189**	236	-	236
Total income from donations and legacies	**7,468**	**2,564**	**10,032**	8,715	3,687	12,402

Total income from donations and legacies includes gift aid of £463,000 (2024: £455,000).

Donations in kind refer to non-monetary donations received from partner organisations. They are recognised at the best estimate of their value as derived from the donor. In 2025 £1,338,000 (2024: £1,543,000) was recognised as income in respect of donated digital and cinema advertising space and professional fees. This was used to raise awareness of cystic fibrosis and the work of the Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, advice and support costs in note 4.

3. Investment Income

	Unrestricted Funds 2025 £'000	Restricted Funds 2025 £'000	**Total 2025 £'000**	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	Total 2024 £'000
Income from listed investments	615	-	**615**	607	-	607
Bank interest	40	-	**40**	21	-	21
Total investment income	**655**	**-**	**655**	628	-	628

4. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2025 £'000**	Total 2024 £'000
Raising funds	-	-	2,293	552	**2,845**	2,748
Charitable activities						
Research	1,413	1,111	1,655	933	**5,112**	6,409
Clinical care	286	75	784	276	**1,421**	1,477
Information, advice and support	118	283	3,186	867	**4,454**	4,460
Total charitable activities	**1,817**	**1,469**	**5,625**	**2,076**	**10,987**	12,346
Total resources expended	**1,817**	**1,469**	**7,918**	**2,628**	**13,832**	15,094

Support costs are apportioned based on the direct costs in each activity category.

4. Expenditure (continued)

Analysis of allocated Support Costs – current year	Governance £'000	Finance £'000	IT Support £'000	People and Organisational Development £'000	Office and Facilities £'000	**Total 2025 £'000**	Total 2024 £'000
Fundraising	122	78	162	66	124	**552**	438
Research	206	132	274	111	210	**933**	972
Clinical care	61	39	81	33	62	**276**	235
Information, advice and support	191	123	254	103	196	**867**	712
Total costs	**580**	**372**	**771**	**313**	**592**	**2,628**	**2,357**

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2024 £'000**
Raising funds	-	-	2,310	438	**2,748**
Charitable activities					
Research	1,976	1,962	1,499	972	**6,409**
Clinical care	454	77	711	235	**1,477**
Information, advice and support	149	167	3,432	712	**4,460**
Total charitable activities	**2,579**	**2,206**	**5,642**	**1,919**	**12,346**
Total resources expended	**2,579**	**2,206**	**7,952**	**2,357**	**15,094**

4. Expenditure (continued)

Analysis of allocated support costs – prior year

	Governance £'000	Finance £'000	IT Support £'000	People and Organisational Development £'000	HQ & Facilities £'000	**Total 2024 £'000**
Fundraising	108	42	128	59	101	**438**
Research	240	93	285	130	224	**972**
Clinical care	58	22	69	32	54	**235**
Information, advice and support	176	68	208	96	164	**712**
Total costs	**582**	**225**	**690**	**317**	**543**	**2,357**

Net income for the year is stated after charging

	2025 £'000	2024 £'000
Auditors remuneration excluding VAT	**28**	29
Depreciation	**67**	64
Operating leases – building	**282**	269
Operating leases – other	**3**	3
Trustees' travel expenses	**5**	1

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ending 31 March 2025

5. Grants

Grants were awarded during the year as follows:

	2025 £'000	2024 £'000
Grants to institutions	**2,885**	4,453
Grants to individuals	**401**	332
	3,286	4,785

Grants made to, and for, individuals affected by Cystic Fibrosis are for expenses such as respite care, building adaptations and equipment rental. These grants benefited a large number of individuals throughout the Trust's network of regions and branches.

During the year, grants were awarded to the following institutions:

	2025 £'000	2024 £'000
University of Cambridge	**964**	1,210
Imperial College London / Royal Brompton Hospital	**320**	1,116
University of Liverpool	**311**	182
University of Birmingham	**300**	-
Newcastle University	**275**	850
University of Manchester	**222**	-
Action Medical Research	**100**	105
Utrecht University, Netherlands	**75**	75
Medicines Discovery Catapult Limited	**42**	81
University of Northumbria	**55**	-
Innovation Hub Cambridge	**-**	100
Medical Research Council	**-**	100
Other Institutions (less than £20k)	**44**	132
	2,666	3,870

Other grants (see notes below)	**2025 £'000**	2024 £'000
Clinical fellowship grants		
Royal Brompton Hospital	**78**	-
Liverpool Heart and Chest Hospital	**-**	78
Trial coordinator grants to CTAP centres	**282**	436
Registry support grants to CF Centres	**324**	326
Release of grants made in previous years	**(465)**	(257)
Total grants made to institutions	**2,885**	4,453

Grants for medical research
Included in the above grants to institutions for medical research are grants to fund the Translational Innovation Hub Network which was launched in 2024 in partnership with LifeArc. The total grant programme will be £15.0m across five years. Grants made in the year to 31 March 2025 were:

	2025 £'000	2024 £'000
University of Manchester	**222**	-
Imperial College London	**302**	-
University of Cambridge	**96**	-
University of Liverpool	**307**	-
	927	-

Other grants
Trial coordinator payments: the Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme.

Registry support grants: the Trust provides grants to NHS Hospitals to support the collection of clinical data used by the Trust's Registry.

Release of grants made in previous years: Various grants totalling £465,000 (2024: £257,000) were released during the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful.

6. Staff costs

	2025 £'000	2024 £'000
Salaries	**5,287**	5,107
Social security costs	**565**	547
Other pension costs	**328**	318
	6,299	5,995

The average number of staff employed by the Trust:	2025 No.	2024 No.
Raising funds	**38**	38
Research	**24**	22
Clinical care	**10**	8
Information, advice and support	**38**	43
Support costs	**23**	23
Total average monthly headcount	**133**	134

The number of employees whose gross salary exceeded £60,000 in the year was:	2025 No.	2024 No.
£60,001 – £70,000	**7**	4
£70,001 – £80,000	**3**	3
£80,001 – £90,000	**1**	1
£130,001 – £140,000	**1**	1

Pension contributions to defined contribution pension schemes for employees noted above totalled £56,571 (2024: £44,083).

The total remuneration paid to key management personnel, including social security and employer pension contributions, was £669,676 which relates to 8 individuals who served on the Senior Leadership Team during the year (2024: £657,196 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. £4,987 of expenses were settled on behalf of 6 Trustees during the period (2024: £1,201 was paid to 5 Trustees). Trustee indemnity insurance is in place for the protection of the Trustees.

7. Tangible and intangible assets

Group and charity	Furniture and fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 1 April 2024	**630**	**970**	**286**	**462**	**183**	**2,531**
Additions	-	-	-	-	-	-
Disposals	(630)	(837)	(242)	(403)	(183)	(2,295)
At 31 March 2025	**-**	**133**	**44**	**59**	**-**	**236**
Depreciation						
At 1 April 2024	**630**	**904**	**254**	**428**	**183**	**2,399**
Charge for the year	-	33	15	20	-	68
Disposals	(630)	(837)	(242)	(403)	(183)	(2,295)
At 31 March 2025	**-**	**100**	**27**	**45**	**-**	**172**
Net book value At 31 March 2025	**-**	**33**	**17**	**14**	**-**	**64**
At 31 March 2024	-	66	32	34	-	132

At 31 March 2025 the Trust vacated its property at One Aldgate and moved to a new office. The disposals in the year represent fully depreciated assets that are no longer in use and were disposed of as part of the office closure.

8. Investments

Group and Charity	Total 2025 £'000	Total 2024 £'000
Opening market value	**5,796**	5,388
Additions at cost	**-**	255
Disposals at opening book value	**-**	(230)
Net gains/(losses) on investments	**40**	362
	5,836	5,775
Change in cash	**(1)**	21
Closing market value	**5,835**	5,796

Represented by:	Total 2025 £'000	Total 2024 £'000
Equities	**512**	587
Fixed Interest and multi-asset funds	**5,030**	4,909
Property	**184**	184
Cash	**109**	116
	5,835	5,796

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment.

The only asset that presents more than 5% of total investments in either financial year is the Responsible Multi-Asset Fund. The Trust's holding at 31 March 2025 was £4,924,000 (2024: £4,809,000).

The historical cost of investments held within the Trust portfolio at 31 March 2025 was £4,853,000 (2024: £4,853,000) and accumulated unrealised gains at 31 March 2025 were £1,252,000 (2024: (£1,213,000).

9. Debtors

	Group 2025 £'000	Group 2024 £'000	Charity 2025 £'000	Charity 2024 £'000
Trade debtors	**55**	35	**-**	-
Prepayments and accrued income	**2,903**	4,981	**2,896**	4,981
Other debtors	**38**	60	**38**	60
	2,996	5,076	**2,934**	5,041

10. Grants Payable

Group and charity	2025 £'000	2024 £'000
Opening grant creditor	**12,792**	13,263
Grants awarded during the year	**3,286**	4,785
Grants paid during the year	**(5,487)**	(5,256)
Closing grant creditor	**10,591**	12,792
Represented by		
Grants due within one year	**5,274**	6,065
Grants due after one year	**5,317**	6,727
	10,591	12,792

The Trust has considered the discounting of grant commitments due in more than one year but has not made any adjustments to the figures disclosed above as the impact of discounting is negligible.

11. Creditors

	Group 2025 £'000	Group 2024 £'000	Charity 2025 £'000	Charity 2024 £'000
Trade creditors	**576**	857	**572**	857
Other creditors	**43**	41	**42**	41
Other taxation and social security	**135**	147	**135**	147
Amounts owed to subsidiary undertaking	**-**	-	**790**	932
Accruals and deferred income	**1,960**	1,727	**1,955**	1,648
	2,714	2,772	**3,494**	3,625

12. Financial Instruments

	Group 2025 £'000	Group 2024 £'000	**Charity 2025 £'000**	Charity 2024 £'000
Financial assets measured at amortised cost	**14,201**	16,109	**14,224**	14,224
Financial assets measured at fair value	**5,835**	5,796	**5,835**	5,796
Financial liabilities measured at amortised cost	**(12,414)**	(15,063)	**(12,418)**	(15,142)
Net financial assets measured at amortised cost	**7,622**	6,842	**7,641**	4,878

The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Financial assets held at fair value include assets held as investments.

Financial liabilities measured at amortised cost include trade creditors, other creditors, accruals, grants payable, deferred income and amounts due to group undertakings.

13. Interest in subsidary undertaking

Cystic Fibrosis Services Limited is a company incorporated in England and Wales (company number 00900164) and is a wholly owned subsidiary of the Cystic Fibrosis Trust.

The subsidiary's activities include studies and report services to the pharmaceutical industry and sale of charity Christmas cards and other merchandise.

Summary profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March 2025:

	Total 2025 £'000	Total 2024 £'000
Sales and sundry income	**1,257**	1,304
Cost of sales and administration	**(338)**	(339)
Intercompany recharges	**(67)**	(66)
Net contribution to parent charity	**852**	899

13. Interest in subsidary undertaking (continued)

Summary balance sheet:	Total 2025 £'000	Total 2024 £'000
Current assets		
Debtors	**853**	968
Cash at bank	**8**	10
	861	978
Creditors: amounts falling due within one year	**(9)**	(79)
Net assets	**852**	899
Capital and reserves		
Called up share capital (£2)	**-**	-
Profit and loss account	**852**	899
Shareholder's funds	**852**	899

The Trust owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd which comprises 100 ordinary shares of £1 each. Two shares have been allotted, which are called up and fully paid.

The subsidiary's profit for the year will be donated in full to Cystic Fibrosis Trust after the year end.

14. Lease commitments

At 31 March, the Trust's future minimum operating leases payments relating to buildings were:

	Property		Equipment	
	2025 £'000	2024 £'000	**2025 £'000**	2024 £'000
Within one year	**205**	271	**2**	2
Between two and five years	**409**	-	**6**	6

Operating lease expenditure in the year is disclosed in note 4.

15. Contingent assets

As at 31 March 2025, the charity had been notified of a further 13 residual and pecuniary legacies which have not been recognised as income in the Statement of Financial Activities as they do not meet the criteria detailed in the accounting policies. These legacies have an estimated value of £275,000 which has not been accrued.

16. Related party transactions

The group has taken advantage of the exception which is conferred by FRS102 Section 33.1A **Related Party Disclosures** that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

Total donation income from the trustees in the period was £30,681 (2024: £16,701). In addition, six of the trustees (2024: seven trustees) were involved in fundraising activities carried out by regional fundraising branches.

Six trustees claimed expenses totalling £4,987 in the year (2024: four trustees totalling £1,201). These expenses related to travel and subsistence.

17. Post balance sheet events

There were no post balance sheet events or contingent liabilities when the accounts were signed and authorised for issue.

18. Analysis of net assets between funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	2025 £'000
Tangible fixed assets	64	-	-	**64**
Investments	4,835	1,000	-	**5,835**
Current assets	16,682	-	456	**17,138**
Current liabilities	(7,988)	-	-	**(7,988)**
Liabilities due in more than one year	(5,317)	-	-	**(5,317)**
Provisions due in more than one year	(170)	-	-	**(170)**
	8,106	**1,000**	**456**	**9,562**

Prior year funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	2024 £'000
Tangible fixed assets	132	-	-	**132**
Investments	4,764	1,032	-	**5,796**
Current assets	20,678	-	468	**21,146**
Internal obligations	(8,837)	-	-	**(8,837)**
Current liabilities	(6,727)	-	-	**(6,727)**
Liabilities due in more than one year	(170)	-	-	**(170)**
	9,840	**1,032**	**468**	**11,340**

19. Current year fund movements summary

	Balance 31 March 2024 £'000	Investment Gains/(Losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
The funds of the charity						
Endowment funds (Note 20)	1,032	(30)	-	(2)	-	**1,000**
Restricted funds (Note 21)	468	-	2,564	(2,541)	(35)	**456**
Unrestricted funds						
Designated reserves						
Organisational reserve	1,000	-	-	(132)	-	**868**
Fixed asset reserve	132	**-**	**-**	**(68)**	-	**64**
Research funds	-	**-**	**-**	**-**	465	**465**
Total designated funds	**1,132**	**-**	**-**	**(200)**	**465**	**1,397**
Retained reserves	8,708	70	9,450	(11,089)	(430)	**6,709**
Total unrestricted funds	**9,840**	**70**	**9,450**	**(11,289)**	**35**	**8,106**
Total charity funds	**11,340**	**40**	**12,014**	**(13,832)**	**-**	**9,562**

Movements in funds for prior periods are presented in note 23.

The designated funds are explained on page 58.

Retained reserves are funds which can be used to fulfil any part of the Trust's objectives. The Trustees have adopted a reserves policy designed to ensure the Trust maintains sufficient funds to continue its activities, particularly in light of recent economic volatility.

The Trustees have set a minimum level of retained reserves and an upper target with the aim that unrestricted funds fall within this range. Based on the 2025/26 budget and a review of the above risk factors, the target core reserves range is between £4.0m and £6.5m.

At 31 March 2025 the Trust's retained reserves were £6.7m (2024: £8.7m) which is slightly above this core reserves range. The Trustees approved a detailed business plan with a deficit budget for the next financial year which maintains services and grant awards at a level similar to last year and which will bring the Trust's retained reserves within this core range. (Retained reserves are forecast to be £5.3m at March 2026 and reduce further to £5.0m by March 2027.)

Transfers between funds

Transfers were made between retained reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been backfilled by restricted donations.

20. Endowment funds

	Balance 31 March 2024 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
Ena Bennie Endowment	523	(16)	-	(1)	-	**506**
EW Joseph Endowment	173	(5)	-	-	-	**168**
Joseph Levy Endowment	288	(9)	-	(1)	-	**278**
Sally Wrigley Memorial Fund	20	-	-	-	-	**20**
Other Endowment funds	28	-	-	-	-	**28**
Total endowment funds	**1,032**	**(30)**	**-**	**(2)**	**-**	**1,000**

Movements in funds for prior periods are presented in note 23.

The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.

- The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.
- The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home.
- The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ending 31 March 2025

21. Restricted funds

	Balance 31 March 2024 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
Restricted funds related to research						
Gene Therapy Research	-	-	2	(2)	-	**-**
General medical research	-	-	174	(174)	-	**-**
Sport England – Helping the active stay active	32	-	-	(32)	-	**-**
University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis	-	-	37	(37)	-	**-**
UCL Great Ormond Street Institute of children	-	-	5	(5)	-	**-**
The CFTR Folding and Function SRC	-	-	23	(23)	-	**-**
UK CF Infection Biorepository	106	-	-	(64)	-	**42**
Project Breathe	42	-	-	(42)	-	**-**
Maternal, Infant, Reproductive and Child Health in CF	-	-	75	(53)	-	**22**
Gut symptoms	66	-	10	(76)	-	**-**
Translational Innovation Hub Network	24	-	1,121	(986)	-	**159**
Quality Improvement Project	35	-	-	-	(35)	**-**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**309**	**-**	**1,447**	**(1,494)**	**(35)**	**227**

21. Restricted funds (continued)

	Balance 31 March 2024 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2025 £'000**
Restricted funds related to Information and Support						
Joseph Levy/Education grants	3	-	140	(66)	-	**77**
Building Brighter Futures	-	-	35	(19)	-	**16**
Support services (inc. welfare grants)	57	-	77	(98)	-	**36**
Work Forwards (England)	39	-	83	(72)	-	**50**
Work Forwards (Scotland)	4	-	-	(4)	-	**-**
Helpline	-	-	5	(5)	-	**-**
Total funds related to Information and Support	**103**	**-**	**340**	**(264)**	**-**	**179**
Other funds						
Clinical Trials Accelerator Platform (CTAP)	-	-	751	(751)	-	**-**
CTAP Clinical Trials Conference	5	-	-	(3)	-	**2**
Carols by Candlelight	5	-	-	(3)	-	**-**
Improving Transparency of Processes	10	-	-	-	-	**10**
Workforce survey (Vertex Circle of Care)	-	-	14	(14)	-	**-**
Vertex IME study	-	-	12	(12)	-	**-**
Other older funds	36	-	-	-	-	**36**
Total other funds	**56**	**-**	**777**	**(783)**	**-**	**50**
Total restricted funds	**468**	**-**	**2,564**	**(2,541)**	**(35)**	**456**

Movements in funds for prior periods are presented in note 23.

Restricted funds related to research are donations relating to grant commitments made by the Trust to research institutions.

Restricted funds related to information and support are donations to fund activities supporting people with cystic fibrosis and their families. These include:

- **Joseph Levy Education grants** – funding people with cystic fibrosis in their education and studies.
- **Building Brighter Futures** – funding a youth programme supporting young people with cystic fibrosis. This fund is supported by National Lottery Community Fund.
- **Support Services** – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
- **Work Forwards (England)** – funding to support people with cystic fibrosis so that they can take advantage of opportunities, build new futures and strengthen their long-term financial resilience. This is supported by the National Lottery Community Fund.

22. Prior year consolidated statement of financial activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2024 £'000
Income and endowments from:					
Donations and legacies	2	8,715	3,687	-	**12,402**
Charitable activities					
Other trading activities		1,304	-	-	**1,304**
Investments	3	628	-	-	**628**
Other income		332	-	-	**332**
Total income		**10,979**	**3,687**	**-**	**14,666**
Expenditure on:					
Raising funds	4	2,742	6	-	**2,748**
Charitable activities					
Research	4	4,401	2,008	-	**6,409**
Clinical care	4	655	822	-	**1,477**
Information, advice and support	4	4,082	378	-	**4,460**
Total charitable activities		**9,138**	**3,208**	**-**	**12,346**
Total resources expended	**4**	**11,880**	**3,214**	**-**	**15,094**
Net income/(expenditure) before investment gains/(losses)		**(901)**	**473**	**-**	**(428)**
Realised investment gains/(losses)		(2)	-	-	**(2)**
Unrealised investment gains/(losses)		353	-	60	**413**
Net investment gains/(losses)		**351**	**-**	**60**	**411**
Net (expenditure)/income		**(55)**	**473**	**60**	**(17)**
Transfers between funds	23	679	(679)	-	**-**
Net movement in funds		**129**	**(206)**	**60**	**(17)**
Reconciliation of funds:					
Total funds brought forward		9,711	674	972	**11,357**
Total funds carried forward	**23**	**9,840**	**468**	**1,032**	**11,340**

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ending 31 March 2025

23. Prior year movements in funds

Summary	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
The funds of the charity:						
Endowment funds (see below)	972	60	-	-	-	**1,032**
Restricted funds (see below)	674	-	3,687	(3,214)	(679)	**468**
Unrestricted funds:						
Designated reserves						
Organisational reserve	1,000	-	-	-	-	**1,000**
Fixed asset reserve	155	-	-	-	(23)	**132**
Appeal deficit	(1,285)	-	-	-	1,285	**-**
Total designated funds	**1,155**	**-**	**-**	**-**	**23**	**1,132**
Retained reserves	8,556	351	10,979	(11,880)	702	**8,708**
Total unrestricted funds	**9,711**	**351**	**10,979**	**(11,880)**	**679**	**9,840**
Total charity funds	**11,357**	**411**	**14,666**	**(15,094)**	**-**	**11,340**

The following transfers were made between funds in the year to 31 March 2024
- A transfer was made to the Fixed asset reserve to match the current balance on Fixed Assets
- Other transfers were made between Retained reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been backfilled by restricted donations.

Endowment funds	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Ena Bennie Endowment	491	32	-	-	-	**523**
EW Joseph Endowment	162	11	-	-	-	**173**
Joseph Levy Endowment	271	17	-	-	-	**288**
Sally Wrigley Memorial fund	20	-	-	-	-	**20**
Other endowment funds	28	-	-	-	-	**28**
Total endowment funds	**972**	**60**	**-**	**-**	**-**	**1,032**

24. Prior year movements in funds (continued)

Restricted funds

	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Restricted income funds						
Appeal: Innovation Hub at Cambridge	-	-	306	-	(306)	**-**
Restricted funds related to research:						
Genetic therapies	-	-	3	(3)	-	**-**
General medical research	-	-	260	(260)	-	**-**
Sport England – Helping the active stay active	32	-	-	-	-	**32**
University of Sheffield: Preventing Gastointestinal Cancer in CF	-	-	34	(34)	-	**-**
UCL/Great Ormond Street Institute of child health: Therapeutic gene editing	-	-	20	(20)	-	**-**
SRC Costed Extensions	-	-	379	(379)	-	**-**
University of Sheffield: Pulmonary magnetic resonance imaging for CF	366	-	7	-	(373)	**-**
UK CF Infection Biorepository	-	-	213	(107)	-	**106**
Project Breathe	-	-	1,188	(1,146)	-	**42**
Queen's university Belfast: Developing a novel gene therapy platform	-	-	15	(15)	-	**-**
Translational Innovation Hub Network	15	-	62	(38)	-	**64**
Quality Improvement Project	35	-	-	-	-	**35**
Gut Symptoms	39	-	27	-	-	**66**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**476**	**-**	**2,514**	**(2,002)**	**(679)**	**309**

24. Prior year movements in funds (continued)

	Balance 31 March 2023 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Restricted funds related to Information and Support						
Joseph Levy/Education Grants	11	-	41	(49)	-	**3**
Building Brighter Futures	16	-	-	(16)	-	**-**
Support services (inc. welfare grants)	93	-	212	(248)	-	**57**
Work Forwards (England)	13	-	83	(57)	-	**39**
Work Forwards (Scotland)	9	-	-	(5)	-	**4**
Helpline	-	-	5	(5)	-	**-**
Helen Barrett Bright Ideas Awards	-	-	3	(3)	-	**-**
Total funds related to Information and Support	**142**	**-**	**344**	**(383)**	**-**	**103**
Other funds						
CTAP (Clinical Trials Accelerator Platform)	-	-	804	(804)	-	**-**
CTAP Clinical Trials Conference	14	-	7	(16)	-	**5**
Carols by Candlelight	6	-	3	(4)	-	**5**
Improving Transparency of Processes	-	-	15	(5)	-	**10**
Other older funds	36	-	-	-	-	**36**
Total other funds	**56**	**-**	**829**	**(829)**	**-**	**56**
Total Restricted Reserves	**674**	**-**	**3,687**	**(3,214)**	**(679)**	**468**

Structure, governance and management

Royal Patron
- HRH King Charles III, KG, KT, GCB, OM

Honorary President
- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees
- Richard Hunt CBE **(Chair)**
- Sean Collins
- Anne Byrne
- Richard Hoey
- Michelle Shore
- Joanna Barrett
- Sophie Pierce
- Sonya Trivedy
- Professor Martin Walsh
- Jane Wainwright
- Neil Priscott
- Dr Maya Desai (appointed 23 May 2024)

Engagement Committee
- Richard Hoey **(Chair)**
- Sean Collins
- Joanna Barrett
- Sophie Pierce
- Neil Priscott

Finance and Audit Committee
- Sean Collins **(Chair)**
- Anne Byrne
- David Sawer (Independent member – resigned 29 April 2025)
- Michelle Shore
- Ed Rushton (Independent member, Investment Sub-Committee)
- Nick Wood (Independent member, Investment Sub-Committee)

People Committee
- Michelle Shore **(Chair)**
- Sonya Trivedy
- Joanna Barrett
- Dr Maya Desai (appointed to the People Committee 16 September 2024)

Senior Leadership Team
- David Ramsden – Chief Executive
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising (resigned October 2024)
- Vanessa Newton – Director of Fundraising (appointed October 2024)
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research and Healthcare Data
- Alex Fowles - Director of Finance and Resources
- Dr Sarah Clarke - Associate Director, Data and Quality Improvement

Company Secretary
- Alex Fowles

Principal and Registered Office

33 Creechurch Lane
London
EC3A 5EB

020 3795 1555
enquiries@cysticfibrosis.org.uk
cysticfibrosis.org.uk

Company limited by guarantee
Company registration number: 3880213
Charity registration number:
England & Wales — 1079049
Scotland — SC040196

Auditors

Buzzacott Audit LLP
130 Wood St
London
EC2V 6DL

Bankers

National Westminster Bank plc
15 Bishopsgate
London
EC2N 3NW

Investment Managers

Cazenove Capital Management
12 Moorgate
London
EC2R 6DA

Legal structure

Cystic Fibrosis Trust ('the Trust') is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1999 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

The Board of Trustees ('the Board') has full legal responsibility for corporate governance and all operations of the Trust, including determining its strategic direction.

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 12 Trustees with a range of skills. Several committees such as the Finance and Audit Committee, People Committee, Engagement Committee, Research Grant Review Committee and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Recruitment, induction and training of Trustees

Trustees consider the relevant skill set required to enable effective oversight and proper governance of the Trust. New Trustees are appointed after a rigorous recruitment process, which includes national advertising and can include recommendations.

Upon appointment to the Board, to help facilitate their understanding of the current issues concerning the Trust, each new Trustee is provided with information tailored to reflect any specific areas of responsibility. The new Trustee will meet with the Chair, Chief Executive Officer and staff working within their own specialist area.

Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Trust to the Chief Executive Officer, David Ramsden, and his Senior Leadership Team (SLT).

The Chief Executive Officer and the SLT report to the Board both formally at the Board meetings and informally (as appropriate) throughout the year, thereby ensuring a regular flow of information to aid decision making.

The remuneration of key management personnel is determined by a recognised job evaluation framework which takes into account the skills required and the complexity of individual roles. The remuneration of the Chief Executive Officer is approved by the Board. For all other staff the process, including the award of annual pay uplift, is approved by the People Committee.

Public benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. In reviewing our aims, objectives and planning future activities, the Trustees have taken into account the Charity Commission's general guidance on public benefit. The Trustees ensure that activities undertaken are always in line with the charitable objectives and aims of Cystic Fibrosis Trust.

Open Strategic Research Centres (SRC) and Development Awards (DA) Awards – April 2025

SRC/DA Award	Lead applicant and host institution	Research goal	Title	Cystic Fibrosis Trust commitment
SRC012*	Dr Daniel Peckham, St James' Hospital	Symptoms throughout the body	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC014*	Professor Jane Davies, Imperial College London	Diagnosis and treatment of lung infections	Personalised Approach to *Pseudomonas Aeruginosa* (PAPA)	£750,000
SRC015*	Dr Darius Armstrong-James, Imperial College London	Diagnosis and treatment of lung infections	TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis	£750,000
SRC016*	Professor Pietro Cicuta, University of Cambridge	Effective treatments for all	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC018	Professor Steven Renshaw, University of Sheffield	Living longer healthier lives	Preventing gastrointestinal cancer in cystic fibrosis	£749,214
SRC019	Professor James Shaw, University of Newcastle	Symptoms throughout the body	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes	£750,000
SRC020	Professor Stephen Hart, University College London	Effective treatments for all	Therapeutic gene editing of CFTR. Co-funded with CFF	£375,000 (Total award; £749,924)
SRC021	Professor David Sheppard, University of Bristol	Effective treatments for all	The CFTR Folding and Function SRC	£747,972
SRC022	Professor Jo Fothergill, University of Liverpool	Diagnosis and treatment of lung infections	An evidence-based preclinical framework for the development of antimicrobial therapeutics in cystic fibrosis (PIPE-CF). Co-funded with CFF	£374,689 (Total award: £749,373)
SRC023	Professor Alan Smyth, University of Nottingham / Queens University Belfast	Symptoms throughout the body	Gut Research Advancing a Mechanistic and Personalised Understanding of Symptoms in cystic fibrosis: A strategic research centre: The GRAMPUS-CF SRC	£749,592
SRC024	Dr Paola Vergani, University College London	Effective treatments for all	Restoring the fizz: Pharmacological repair of bicarbonate transport in cystic fibrosis. Co-funded with CFF	£374,987 (Total award: £749,973)
SRC025	Professor Jim Wild, University of Sheffield	Diagnosis and treatment of lung infections	Pulmonary magnetic resonance imaging for cystic fibrosis. Co-funded with CFF	£366,536 (Total award: £733,072)
SRC026	Dr Mike Gray, University of Newcastle	Effective treatments for all	PTSuppress – Novel lead compounds as potential suppressor drugs for CFTR PTC mutations	£799,808

*** Grant issued extension due to COVID-19 related delays**

Open Strategic Research Centres (SRC) and Development Awards (DA) Awards – April 2025

SRC/DA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment
SRC027	Dr Imogen Felton and Professor Jane Davies, Royal Brompton Hospital	Living longer healthier lives	MATRIARCH_CF – MATeRnal, InfAnt, Reproductive and Child Health in CF	£799,089
SRC028	Professor Andres Floto, University of Cambridge	Diagnosis and treatment of lung infections	Developing better treatments for *Mycobacterium abscessus*	£800,002
DA001	Professor Nicholas Simmonds, Royal Brompton Hospital	Effective treatments for all	ADVANCE-CFTR: Advanced Diagnostic Validation and Novel Clinical Evaluation across the CFTR spectrum	£299,536
DA002	Dr Freddy Frost, University of Liverpool	Living longer healthier lives	ITCH-CF: Investigating The Cardiovascular Health of people living with cystic fibrosis	£173,487
DA003	Dr Ildem Akerman University of Birmingham	Symptoms throughout the body	Developing autologous stem cell-derived therapies for cystic fibrosis diabetes	£300,000
DA004	Dr Mike Gray, Newcastle University	Effective treatments for all	Novel role for succinate chemosensing in the pathogenesis of CF airway disease	£275,265

Open Venture Innovation Awards (VIAs) – April 2025

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA036	Dr Fred Piehl, Imperial College London	Diagnosis and treatment of lung infections	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data	£42,500	£42,500 Imperial College London
VIA062	Prof Miguel Camara, University of Nottingham	Diagnosis and treatment of lung infections	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000	£50,000 University of Nottingham
VIA098	Dr Jonathan Cox, Aston University	Diagnosis and treatment of lung infections	Discovery of new and repurposed ß-lactamase inhibitors for improving *Mycobacterium abscessus* treatment	£25,000	£25,000 ANTRUK (Antibiotic Resistance UK)
VIA105	Professor Alan Smyth, University of Nottingham	Living longer healthier lives	Core Outcome Set Taskforce for Cystic Fibrosis (COST-CF): a patient-initiated core outcome set for CF	£93,089	£105,652 NIHR Biomedical Research Centre and Programme Development Grant
VIA107	Dr Rian Griffiths, University of Nottingham	Diagnosis and treatment of lung infections	Development of a rapid and highly sensitive analytical method for the detection of biomarkers of infection in samples from people with CF	£37,726	£886,437 BBSRC

Open Venture Innovation Awards (VIAs) – April 2025

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA115	Dr Freddy Frost, University of Liverpool	Diagnosis and treatment of lung infections	Postal Sputum Testing for Early Detection of *Pseudomonas aeruginosa* in CF: POSTED-CF	£17,215	£97,570 Asthma & Lung UK
VIA116	Professor Jane Davies, Imperial College London	Diagnosis and treatment of lung infections	Repurposing the multiple sclerosis drug, Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections	£99,999	£2,500,000 LifeArc Collaborative Discovery Programme call
VIA117	Professor Janis Shute, Ockham Biotech Ltd	Diagnosis and treatment of lung infections	Investigating anti-pseudomonal effects of roneparstat, a non-anticoagulant derivative of heparin with multiple anti-microbial, anti-inflammatory and mucolytic activities	£50,000	£2,500,000 LifeArc Collaborative Discovery Programme call
VIA118	Dr Paul McNally, Our Lady's Children's Hospital	Living longer healthier lives	ENHANCE – Establishing Natural History in an Advanced New CF Care Era	£96,424	£4,800,000 CFF
VIA119	Dr Mina King, University College London	Diagnosis and treatment of lung infections	Understanding Regional Lung Physiology in Cystic Fibrosis Using Advanced MRI	£49,994	£1,800,000 MRC Career Development Award
VIA121	Professor Ruth Keogh and Dr Emily Granger, London School of Hygiene and Tropical Medicine	Diagnosis and treatment of lung infections	Target trial emulation in cystic fibrosis: optimising methods for evaluating long term antibiotic treatment using registry data	£18,077	£150,000 – pending peer review NIHR Research for Patient Benefit
VIA123	Professor Ineke Braakman, Utrecht University, Netherlands	Effective treatments for all	Understanding hypo- and hyper-responding phenotypes of CFTR mutants for therapeutic use	£75,000	£64,000 Nederlandse Cystic Fibrosis Stichting (NCFS)
VIA124	Gerry McCauley, OmniSpirant Limited	Effective treatments for all	Cell engineering optimisation and electrophysiology assessment of OS001 CFTR Extracellular Vesicles (EVs)	£21,242	£22,360 OmniSpirant Limited
VIA126	Professor Laura Ashley, Leeds Beckett University	Living longer healthier lives	Cancer risk, screening, and surveillance for people with cystic fibrosis: a national co-designed survey of awareness, perceptions, and behaviours, and information and support needs	£20,920	£56,609.17 Leeds Beckett University
VIA127	Dr Malcolm Brodlie, Newcastle University	Diagnosis and treatment of lung infections	Tracking the mucosal immune response to viral respiratory tract infection in children with cystic fibrosis	£50,000	£160,000 Vertex Innovation Award

Open Venture Innovation Awards (VIAs) – April 2025

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA128	Professor Martin Welch, University of Cambridge	Diagnosis and treatment of lung infections	Investigating the impact of pathoadaptive mutations on the fitness of *Pseudomonas aeruginosa* in a polymicrobial airway environment.	£64,500	£90,000 BBSRC
VIA129	Professor Chris van der Gast	Symptoms throughout the body	Impact of respiratory infection antibiotics upon the gut microbiomes of children with CF	£55,226.00	£55,226.00 Northumbria University
VIA130	Dr Ewart Kuijk	Effective treatments for all	AIR max: 3D AIRway organoids to define and MAXimize the efficacy of CFTR gene therapy	£75,000	£150,000 Nederlandse Cystic Fibrosis Stichting (NCFS)
VIA131	CEO Lindsay Easton – Bowel research UK	Living longer healthier lives	Optimising bowel cancer screening and surveillance for people with cystic fibrosis: a qualitative study to identify and understand clinician and patient challenges and needs and ways to address these	£24,966.34	£49,932.68 Bowel Research UK
VIA132	Action Medical Research – Guy Moss	Effective treatments for all	New therapeutic approaches for treating cystic fibrosis	£99,999	£100,000 Action Medical Research
VIA133	Prof Camilla Godlee, University of Cambridge	Diagnosis and treatment of lung infections	Characterising the host-pathogen interactions required for intracellular *Pseudomonas aeruginosa* infection of people with cystic fibrosis	£59,000	£134,000 BBSRC

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2025. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 33 Creechruch Lane, London EC3A 5EB.

Uniting for a life unlimited

CYSTIC FIBROSIS TRUST

England & Wales - Charity number 1079049

Accounts

Cystic Fibrosis Trust

Unstoppable together



Annual Report and Financial Statements
for the year ended 31 March 2024

Uniting for a life unlimited

Contents

Thanks to you, in 2023/24...	4
Introduction from our Chair	6
Uniting for a life unlimited	8
Uniting in research	12
Putting people with CF first	20
Uniting for the CF Community	30
Diverse and together	38
Uniting in fundraising	42
Looking to the future	58
Financial review	64
Independent auditor's report to the Members and Trustees of Cystic Fibrosis Trust	74
Consolidated statement of financial activities	78
Consolidated and charity balance sheets	79
Consolidated statement of cash flows	81
Notes to the Financial Statements	82
Structure, governance and management	106
Open SRC Awards	108
Open Development Awards	109
Open VIA Awards	109



We won't stop until CF does.


Cystic Fibro
Trust
FINISHER
2024
tcs

Thanks to you, in 2023/24...



Over 2,000 people with CF enrolled on to a CTAP clinical trial, helping to develop new treatments for everyone with CF.



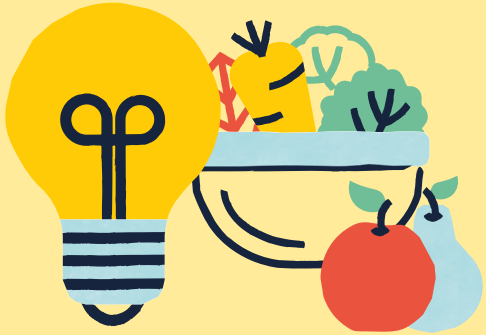
Two new Strategic Research Centres (SRCs) and two new grants in a newly created Development Award (DA) scheme launched to address top research priorities.



We helped people with CF to access over £1.9million in benefits through our Welfare and Rights Advice Service.



We've handled over 4,500 enquiries to our busy Helpline across phone, email, WhatsApp and social media.



We continued our time-limited cost of living fund, providing 324 grants over the winter period to support those on low incomes to afford food and essentials.



Our #CFTruths campaign continues to raise awareness with a reach of over 18 million through media and OOH advertising. We won bronze in the people's choice awards in the 2024 Smiley Charity Film Awards 2024!

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2024. The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Charities Act 2011 and the Statement of Recommended Practice: Accounting and Reporting by Charities second edition effective 1 January 2019.

The requirements of 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013' are included within this Trustees' report. Pages 66 to 107 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 2023/24 Annual Report and I would like to start by thanking everyone in the CF community for all they have done over the last 12 months to make our successes possible.

The report documents a year of intense activity, during which we were committed to uniting with all of our partners to achieve our vision of a life unlimited by cystic fibrosis.

As in recent years we have continued to fund innovative research. Two new Strategic Research Centres were established as well as our first two commitments under our new Development Award scheme, all informed by the research priorities set by the CF community.

A key focus over the year has been supporting the NICE appraisal process for the modular treatments now available and we were delighted to receive the news, shortly after the year end, that they had been formally approved for long-term use on the NHS. This was a very significant moment. However, we also never forget that these medicines are not a cure and are not a treatment available for everyone with CF.

Wider access to highly effective treatments has meant an increased focus on the opportunities as well as challenges of growing older with CF. For example it has been great to see our Work Forwards programme supporting people into employment develop significantly and it has now worked with 59 people in the CF community. We have also increased our focus on the wider health consequences of longer lives and the risks that may arise from other conditions.

"Our 'Your Life and CF' report has provided vital information about the reality of living with CF in 2024 and it informed our advocacy efforts to ensure that people with CF get as much of the help and support that they need."





Richard Hunt CBE

It is not just about the future, as we are also committed to helping with the challenges of the present. Our 'Your Life and CF' report has provided vital information about the reality of living with CF in 2024 and it informed our advocacy efforts to ensure that people with CF get as much of the help and support that they need.

The latter part of the year has also seen rising concern about the availability of the vital CF medicine, Creon. We have devoted considerable effort to providing information and advocacy to do all we can to address this important issue. This effort continues.

We have continued our efforts to raise wider public awareness of CF with press and wider media coverage. This is also the third year of our #CFTruths campaign as well as the second series of the CForYourself podcast.

The year has also seen the most in-person and hybrid events since before the pandemic. We held a very successful UKCF Conference in October, a Clinical Trials event in March and our first ever multi-disciplinary team share and learn day.

We have provided 1,242 welfare grants and helped to secure almost £2million in benefits income for c.300 people we supported.

Our Helpline remained a vital link and resource for the CF community responding to c.4,500 enquiries over the 12 months. In addition, our UKCF Registry is a world-leading source of health information and it passed a significant milestone, with its 500th data request in March.

It has been another year of progress and I would like to thank my fellow Trustees for their time and commitment and the whole Trust for all of the effort they have put in.

Finally, this year we mark 60 years since the formation of the Trust in February 1964. We know a great deal has been achieved, but we know there is also much more to do. We won't stop doing all we can to support people with CF and we know our inspirational community will be with us on every step of this challenge.

Thank you.

Richard Hunt CBE
Chairman of Trustees

Uniting for a life unlimited*



Objectives and activities

Our vision is to deliver a life unlimited for people with cystic fibrosis, and our objectives, as stated in the Articles of Association, are to promote:

- research into the causes of, and a cure for, cystic fibrosis and the dissemination of the useful results thereof for the public benefit
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from cystic fibrosis in any form
- the education of the general public about the causes and effects of cystic fibrosis.

About CF

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. You are born with CF and cannot catch it later in life. One in 25 of us carries the faulty gene that causes it, usually without knowing. Over 11,000 people in the UK live with the condition, having to undergo a brutal daily regimen of physiotherapy and take more than 30 tablets a day just to stay healthy. Despite these treatments, many people with CF will go on to require a double lung transplant. The median age of death for someone with CF in 2022 was 33.

About us

Our mission

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all. We won't stop until we can all lead the lives we want. Until cystic fibrosis stops damaging and shortening lives.

Our vision

Our community is uniting towards the ultimate goal of effective treatment for all. We're at the forefront of innovation and progress. Boundaries will be broken by groundbreaking research and incredible discoveries that change lives for the better. To get there, we will inspire our community. We will campaign with passion. Use facts and information to empower us. And support each other – improving care and building better mental resilience and physical health.

It's thanks for our incredible supporters, clinicians, researchers, professionals, partners and most importantly people with CF, that over the last 60 years we've been able to make vital breakthroughs and discoveries in CF understanding and treatment.

We're uniting for a life *unlimited*

Our goals

Physically well

Together, we can live without the physical challenges of cystic fibrosis.



Mentally well

Together, we can manage the mental pressures of cystic fibrosis.



Fulfilment

Together, we can lead the life we want as part of a connected community.



To achieve these ambitious goals, we will work with our community and partners across the UK and internationally to support innovative, high-quality research, achieve access to the best treatments, drive up the quality of care and provide and advocate for the support needs of people with cystic fibrosis.

We also know that to deliver on this vision we need to adapt and change as an organisation, including a greater focus on:

- **putting people with cystic fibrosis at the heart of everything we do**
- **building international and domestic partnerships**
- **optimising our working culture**
- **being great and innovative fundraisers**
- **making effective use of data and analytics, including implementing our new data strategy and a new quantitative impact framework**
- **working in ways that bring together our diverse community and staff, including our new equality, diversity and inclusion strategy.**

Measuring success

We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact to the CF community. We hold impact workshops to assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track progress via internal monthly and quarterly monitoring mechanisms, including both data-driven and narrative analysis, backed up by SMART Key Performance Indicators.

Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.



Uniting in research

Over the past year, our research has reflected the refreshed research priorities of the CF community. At the beginning of 2023, our research funding call highlighted the need to address these research priorities. Four new research awards as a result of this call were approved in March 2024, each addressing a top research priority. These included two new Strategic Research Centres (SRCs) and two new grants in a newly created Development Award (DA) scheme.

Addressing the CF community's top research priority

An SRC titled 'Novel lead compounds as potential suppressor drugs for CFTR Premature Termination Codon (PTC) mutations' will be led by Dr Mike Gray at the University of Newcastle – with an international collaboration of researchers based in Portugal, the Netherlands and Italy. The team will focus on designing compounds that could be CF medicines of the future for those with rare, 'Class 1' CFTR mutations who are not able to benefit from CFTR modulator medicines. This research addresses the CF community's top research priority.

The effects of modulators on areas of the body outside of the lungs

Another top 10 CF research priority was to understand more about the effects of modulators on areas of the body outside of the lungs. The second SRC awarded this year, 'MATeRnal, InfAnt, Reproductive & Child Health in CF (MATRIARCH)', will address one aspect of this.

The research programme will examine the impact of pregnancy, childbirth, and breastfeeding for those with CF. Access to modulators has increased the number of people with CF having children, but currently little is known about the impact of these medicines during pregnancy and breastfeeding.

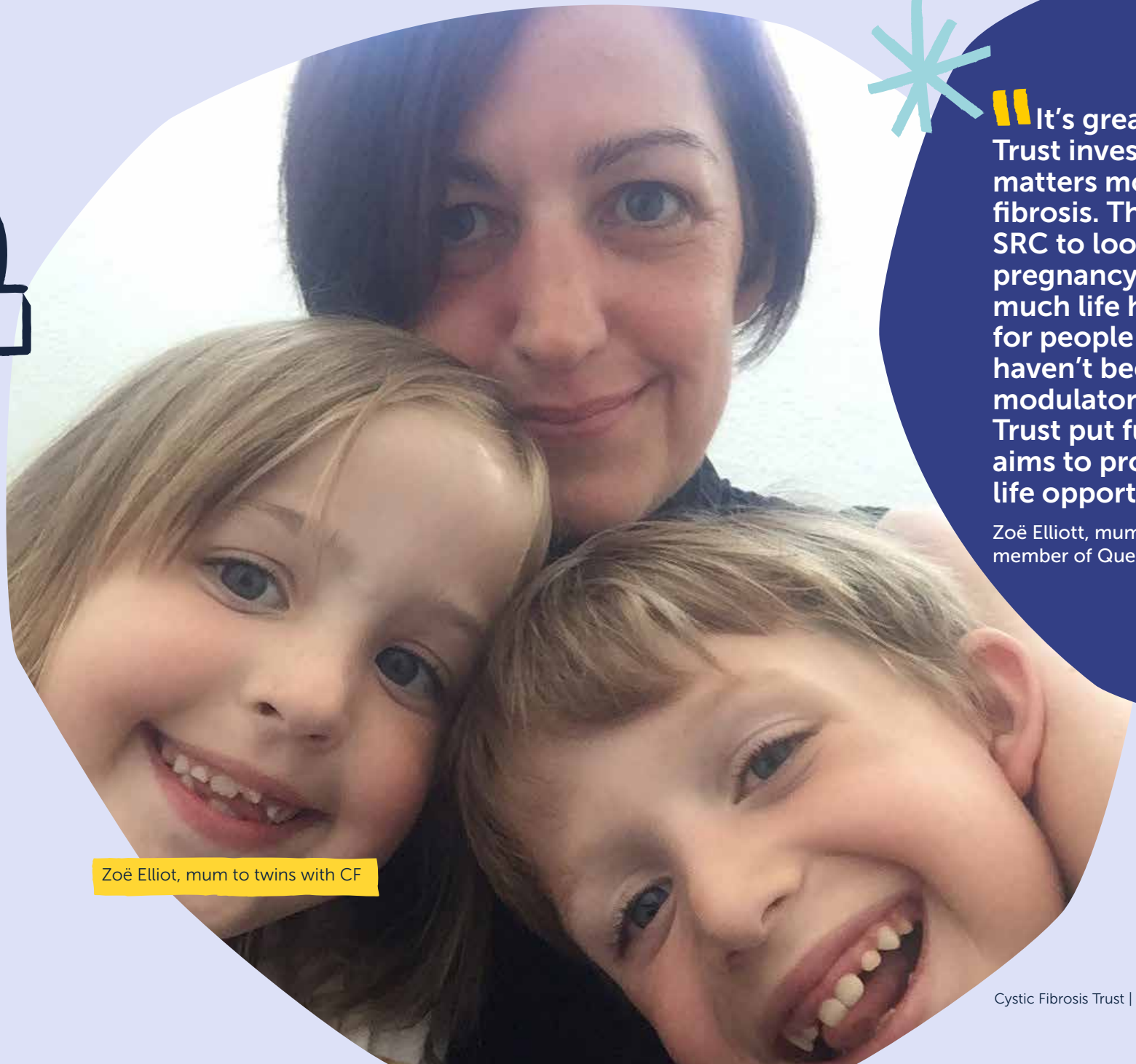
The SRC will also examine important reproductive health decision-making for women and girls with CF throughout their lives. This SRC will be led by Dr Imogen Felton and Professor Jane Davies of Royal Brompton Hospital, part of Guy's and St Thomas's NHS Foundation Trust, and Imperial College in London.



Our new Development Awards scheme

The aim of our new Development Awards (DA) scheme is to allow researchers to undertake preparatory work prior to developing future applications for further funding. The preparatory work might include generating preliminary data, strengthening collaborations and developing new partnerships.

The 'Advanced Diagnostic Validation and Novel Clinical Evaluation across the CFTR spectrum (ADVANCE-CFTR)' Development Award will investigate alternative ways of diagnosing people with cystic fibrosis who have rarer mutations. This research may also be able to predict whether modulator medicines could work for rare CF mutations. This DA will be led by Professor Nick Simmonds of Royal Brompton Hospital, and Imperial College London.



Zoë Elliot, mum to twins with CF

"It's great to see Cystic Fibrosis Trust investing in research that matters most to people with cystic fibrosis. The commencement of a SRC to look at the impact of pregnancy and beyond shows how much life has changed for the better for people with CF. And for those who haven't been able to benefit from modulators, it is fantastic to see the Trust put funding into research that aims to provide them with the same life opportunities."

Zoë Elliott, mum to twins with CF and a member of QuestionCF

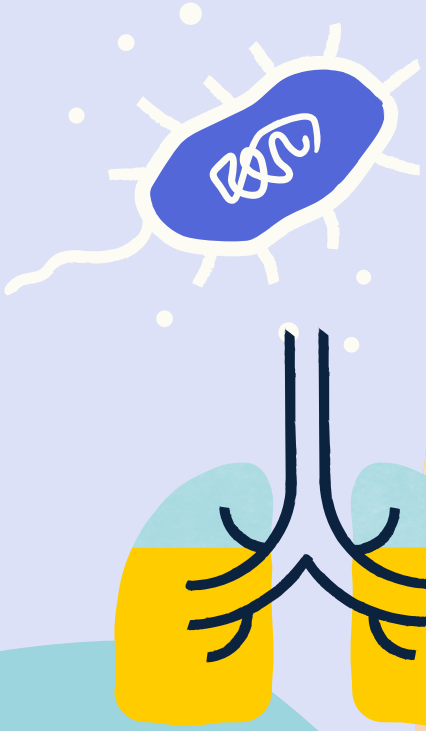
Growing older with CF

We know that there are few ongoing research studies addressing the research priority, 'How do we manage an ageing population with cystic fibrosis?' As a first step to address this, we held a one-day, in-person workshop in December 2023 with the aim of building networks in this area and to understand more about some of the topics and challenges involved. 51 people attended the workshop, including researchers, clinicians, healthcare professionals, representatives from the CF community and funder representatives. Our 'Growing older with CF' report explores the discussions at the workshop.

The 'Investigating the Cardiovascular Health of people living with cystic fibrosis (ITCH-CF)' DA will be led by Dr Freddy Frost from Liverpool Heart and Chest Hospital, and will focus on one of the topics discussed at the growing older with CF workshop. Focusing on understanding more about the risk of developing heart disease for people with CF, one study will look at whether full-body imaging scans could be used to assess future risk of heart disease. Another study within the project will examine existing health records for statistical information about heart disease risk.

What is the best way to diagnose lung infections when there is no sputum?

The second highest research priority for the CF community was 'What is the best way to diagnose lung infections when there is no sputum?'. It is a topic that the CF AMR Syndicate have recently been focusing on. The Syndicate is a partnership between Cystic Fibrosis Trust, Medicines Catapult and LifeArc which aims to accelerate the translation of CF antimicrobials and diagnostics to the clinic to bring new and effective treatment options to people with CF. This year saw the publication of the Syndicate's patient-centred Target Product Profiles (TPPs) on diagnostic tests for CF lung infections. This will be used to support and advance diagnostic research and development, focusing efforts where they are needed the most. Discussions are underway on how the Syndicate will use these TPPs to bring better diagnostics for CF infections to the clinic.





> "We hope the workshop and our report will generate new networks with ideas and opportunities for research proposals to address this priority."
>
> Dr Lucy Allen



> "Being invited to contribute to the development of the TPPs has provided much-needed reassurance that the demand for new or improved antibiotics for people with CF is still recognised as a critical requirement."
>
> Simon, who has CF



Dr Lucy Allen speaking at the 2023 UKCFC

> "It was inspiring to see the passion in the room, and the depth and breadth of ongoing research which will help improve the lives of people with CF."
>
> David Ramsden

UK CF Conference

At our UK CF Conference in October 2023, we were delighted that Professor Jane Davies agreed to give a plenary presentation on 'Re-learning CF', informed from members of the Trust's involvement group. The event was an opportunity to explore and showcase the Trust's research portfolio and was attended by 146 people in London, with a further 73 people joining online.

Included within the programme was a celebration of the CF Innovation Hub on lung health partnership at the University of Cambridge and our developing relationship with LifeArc, as well as the CF AMR Syndicate partnership. Trust-funded early career researchers gave fun and high energy elevator-pitch style presentations throughout the day. With support from CF community mentors, four early career researchers presented their research to the CF community in an online event a few weeks after the conference.

More people with CF taking part in research

The UK CF Clinical Trials Accelerator Platform (CTAP) is part of a highly successful global trials network. In the UK, we have established a robust clinical research infrastructure designed to support and deliver a diverse portfolio of CF studies with speed and efficiency. The majority of CF care centres in the UK are either an active member of CTAP or have pathways in place to refer patients to CTAP centres for study participation.

The CTAP network of 25 centres from across the UK is led by research-focused clinicians and trial coordinators with a range of experience, knowledge and skills in CF care and running clinical trials. **Collectively, the network covers ~90% of the UK CF community**.

Early phase clinical trial programme

The CTAP early phase trials programme funds six CTAP centres with a highly skilled early phase trial coordinator to oversee the set-up and delivery of early phase trials, which are often more resource intensive and time consuming than later phase trials. The early phase trial portfolio in the UK is steadily growing. The first early phase trial supported by funded early phase CTAP centres opened late in 2023, with two more opening later in 2024. This will create exciting opportunities for the UK and the CF community to support new and emerging CF therapies, such as genetic therapies, currently being developed and researched.

"I try to be a participant in as many trials as I can. The feeling of helping others with CF by putting myself forward for research makes me feel closer to our community, even if we cannot meet each other in person."

Sarah, who has CF



Since CTAP's official launch in September 2017...



- **over 4,000** babies, children and adults have enrolled on to a CTAP study



- **over 70** CF studies have been supported by CTAP so far
- study set-up times have **decreased by 73%** across the CTAP network



- more than three quarters of studies have exceeded **90% of their recruitment target**
- the average **retention rate** for CTAP studies is **98%**.



Sarah

> **"It's such a joy to speak with people with CF outside the normal clinical environment where there is actually the time to really get a handle on what research means to them and listen to their valuable lived experience."**
>
> Emma, Clinical researcher

Involving the CF community in shaping our research

Our community involvement group is made up of **almost 300 people with CF** and parents of children with CF. It gives people the chance to directly engage with sponsors to give meaningful feedback about trial design, from the conceptual stage onwards. This helps make future CF trials more patient-centred and less burdensome, with the aim of improved trial recruitment and retention rates.

Over the last year there have been a total of 24 research-related involvement activities, including 14 focus groups, covering everything from new diagnostics for lung infections to looking at the mental health effects of Kaftrio.

Delivering the UK CF Clinical Trials Conference

The sixth annual UK Cystic Fibrosis Clinical Trials Conference took place in Leeds in March 2024. It was an opportunity to bring together people working across CF research to talk about what's next in clinical trials. This year's event was titled 'Addressing research priorities through clinical research – the when and how'. With Cystic Fibrosis Trust celebrating its 60th anniversary this year, the conference was also an opportunity to look back on the past 60 years in clinical trials.

> **"When we meet next year, let's hope all of us have moved forward in this field and brought more answers to the CF community."**
>
> Dr Tim Lee



Dr Tim Lee

Putting people with CF first*



Collaborating with and supporting the clinical community to promote the highest quality of care

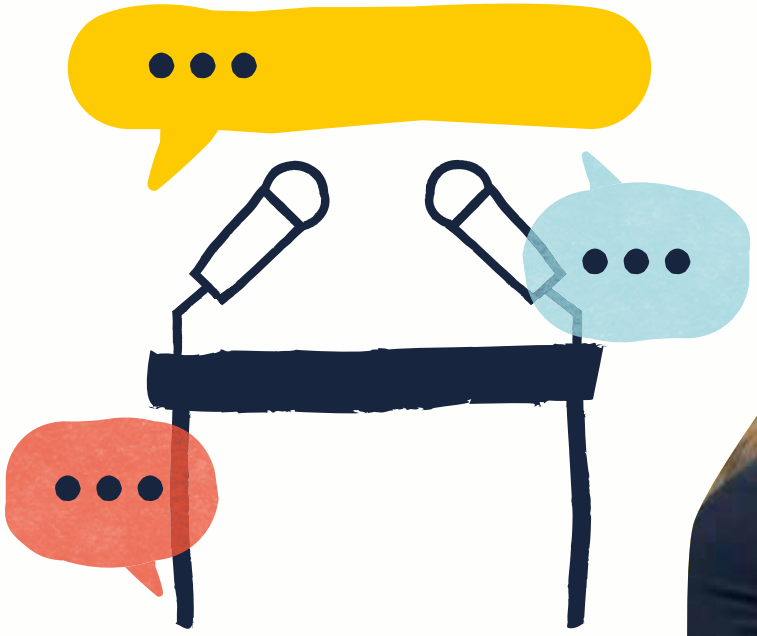
Our Clinical Advisory Group (CAG), made up of representatives from the specialist disciplines providing CF care and treatment, provides expert input into the Trust's information resources and clinical programmes. The Chair of CAG oversees the successful Clinical Fellowship scheme, which has run for a number of years. The scheme provides a unique opportunity for a fellow to start a career in CF, and has seen multiple candidates become prominent members of the CF clinical landscape.

The Trust sponsors and provides secretariat duties for the UK Cystic Fibrosis Medical Association, a group open to all doctors who deliver clinical care to people with cystic fibrosis in the UK.

The Trust's clinical guidelines continue to promote best practice in CF care provision. In 2023/24 work continued on several guidelines, including:

- the overarching standards of care
- psychological guidelines
- antibiotic treatment
- infection control.

We work directly with clinical teams to review and improve quality of care at a local level. We continue to influence NHS clinical policy; for example we provided providing input on the CF toolkit developed by NHS England.



Improving quality of care in CF

In September 2023, we published the latest findings from our patient experience survey in children's CF services. With over **800 responses from children with CF and their families**, the findings show that CF care is generally rated highly by those who receive it. However, the survey also reveals persistent gaps in access to specialist pharmacists, social workers and psychologists within paediatric CF teams. We are working to understand how this could be improved in future.

In November 2023, we initiated the second cycle of our patient experience survey in adult care, collecting new insights that will be reported later in 2024. We continue to monitor staffing levels in CF services using our staffing tool, creating bespoke staffing summaries for participating CF centres, and publishing an updated report on UK CF service resourcing in March 2024.

This year,we engaged over 150 CF professionals in our virtual, peer-led QI Share and Learn events, and ran bespoke quality improvement sessions with several paediatric CF teams to help them plan and deliver improvement projects.





Panel attendees at the new MDT Share and Learn conference

Collaborating for better care conference

In March 2024, the Trust hosted a new conference for CF professionals, covering hot topics in CF such as patient-centered care, the impact of neurodiversity in CF, and adherence to treatment. The event provided opportunities for clinicians to network and collaborate, with many reflecting on how the event supported them to improve their own practice. **100% of those who completed our post event evaluation told us that the event met their expectations**.



Supporting the CF community through issues that affect them

Creon

We've been monitoring issues with Creon supplies across the UK since late 2023 and have seen worrying fluctuations in the availability through early 2024. Many hospital and community pharmacies have struggled to maintain their usual supply, leading to increased demand for alternatives like Nutrizym and Pancrex. These supply issues prompted the Department of Health and Social Care to implement a Medicines Supply Notification specifying that access should be prioritised for those who need Creon the most, including people with CF.

The Trust and CF clinicians, dietitians and pharmacists have been working hard to ensure that the impact of shortages of Creon on the health and wellbeing of people with CF is minimised.

We're meeting regularly with Viatris and the NHS to ensure that all possible measures are being taken to resolve these issues. We've written to the Secretary of State for Health, calling for better communication to the community about what is happening, as well as long-term solutions, including research into alternative enzyme sources and new product development to reduce dependency on current raw materials.

We continue to keep our community informed through a dedicated hub on our website, blogs, videos, emails, social media, wider media and through our Helpline.

Our social media posts regarding the Creon shortages had a combined reach of 117,550 across Facebook and Instagram.



Carlie, who features in ***Rita's story***

"I would not be where I am today without the Trust. The grants that were offered to us during our crisis period and after moving to our new home has been lifesaving."

Rita*



Cost of living crisis

Although inflation has slowed in the UK, costs remain high, and the ever-present additional costs of living with cystic fibrosis means day-to-day living continues to present difficult financial choices. **84% of respondents from our 2024 'Your Life and CF' survey told us they were worried about the cost of living, with 1 in 5 going without food**.

In the past year, we've seen more people turning to us for assistance in bridging financial gaps caused by circumstances beyond their control. And we're seeing more complex issues, including family breakdown, domestic abuse, and concerns for the welfare of children, as the financial strain on households has continued to bite. These financial, social and emotional obstacles impact mental and physical health for people with cystic fibrosis and those who care for them, making it more difficult to maintain good health and manage the challenges that CF presents.

We continue to offer financial support through our grants, and information and support through a dedicated hub on our website, supporting content, and our Helpline, all aimed at helping those with CF safeguard their health.

In October 2023, we released ***Rita's story,*** told by Carlie who has CF, which demonstrates the complex and challenging situations people affected by CF can be put in, as highlighted in our ***Support in crisis: the unseen costs of cystic fibrosis report***.

NICE appraisal

In 2020, landmark interim deals for access to life-saving modulator treatments Orkambi, Symkevi and Kaftrio were reached between the NHS in England, Wales, Scotland and Northern Ireland and the pharmaceutical company Vertex. As part of these agreements, the UK Cystic Fibrosis Registry, in partnership with NHS England, NICE and Vertex collected real-world evidence, looking at the effectiveness of the therapies ahead of a formal appraisal from the National Institute of Clinical Excellence (NICE).

In 2022, the formal NICE appraisal began, with the Trust engaging proactively at all stages and keeping the CF community updated and supported through a variety of channels. In May 2023, **over 1,100 people from the CF community shared their views to inform our evidence submission to NICE**, ensuring the voices of the CF community were heard.

In November 2023, NICE's draft guidance said that while Orkambi, Symkevi and Kaftrio were clinically effective treatments, they were too expensive at the current price for them to be able to recommend them for use on the NHS. This was a distressing and challenging time for the community, with the Trust providing essential information and support.

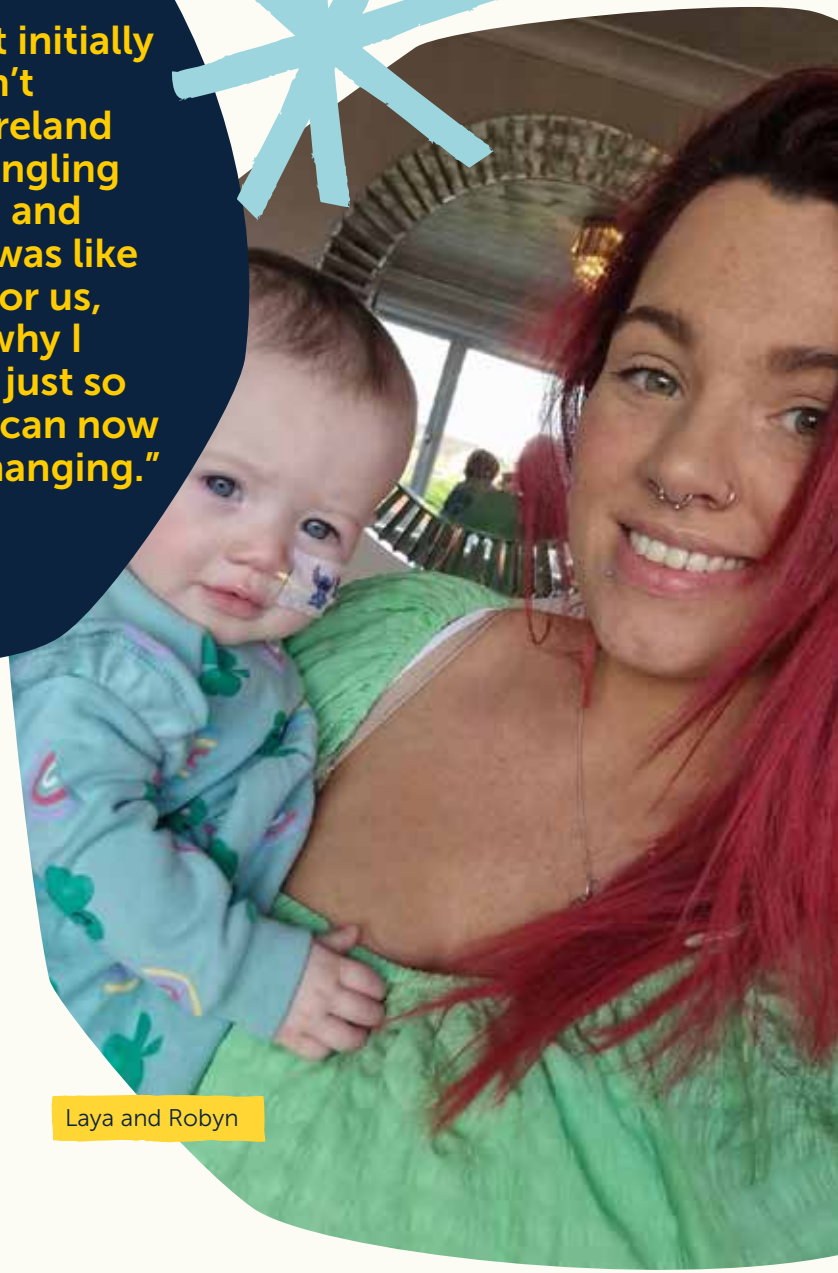
We were pleased that NICE, Vertex and the NHS confirmed unequivocally that access would be protected for those already on treatment, and that people could continue to start taking the medicines while the process was ongoing. In January 2024, NICE announced a pause to allow for commercial negotiations between Vertex and the NHS to take place.

Our social media posts regarding the NICE appriaisal had a combined reach of 327,440 across Facebook and Instagram.

> **"When we found out initially that these drugs weren't available in Northern Ireland it was like someone dangling a carrot in front of you and then taking it away. It was like a kick in the stomach for us, as parents, and that's why I campaigned for it. It is just so reassuring that Robyn can now access this – it's life changing."**
>
> Laya, mum to Robyn who has CF

Following sustained action from the whole CF community over months and years, we were delighted that in June 2024, NICE finally gave approval for modulator drugs to be made available on the NHS in England, following a deal between NHS England in Vertex. Similar deals have followed between NHS Wales, NHS Northern Ireland, and NHS Scotland.

We know that not everyone can benefit from Orkambi, Symkevi and Kaftrio, which is why we continue to invest in cutting-edge CF research for effective treatments for all. We won't stop until everyone with CF can live a life unlimited.



Laya and Robyn

"Those living with CF, or caring for those that do, know the condition better than anyone. Involvement provides an opportunity for people to use that experience to help shape the development, delivery and communication of research for the benefit of the wider CF community. Being part of the involvement group gives you a real insight as to the sorts of research projects taking place and provides lots of different ways to get involved. It's also really nice to be able to connect with other members of the community and share experiences."

Dan, who is part of our involvement group

From 1 April 2023 to 31 March 2024, cystic fibrosis was mentioned in parliaments across the UK 127 times.

Making sure our community is heard

Our community involvement group has grown to over **300 members**, consisting of people living with CF of all ages, parents of children with CF and other family members and loved ones, offering diversity of social profiling as well as CF profiling. On average, we induct 3 new registrations per month, ensuring perspectives are truly representative.

Due to the rapid changes being experienced in the clinical care and presentation of CF, recognition of the value and power of the patient voice has grown demand for activity as we prioritise the needs and requirements of the community we represent. The continuous engagement of the involvement group members enables us to meet this demand, reacting in timely manner to a diverse portfolio of activity.

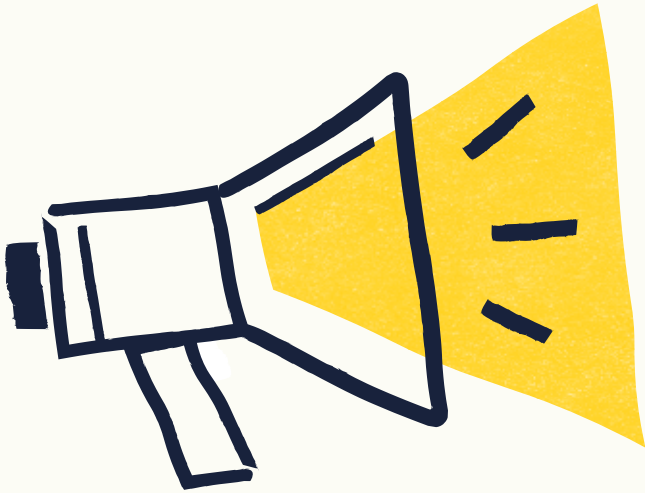
However, the true power and reach of collective community insights and themes lies in proactively encouraging investment in CF, both in financial and career terms, securing the both the future of CF research and clinical provision. Community involvement has ensured the success of applications to national funding streams, provided income generation opportunities and the power to leverage industry investment.

Campaigning hard

Prescription charges remains high on the agenda for people with cystic fibrosis in England, with the Trust working to influence parliamentarians through a number of debates and parliamentary questions. We have made sure the voices of people with cystic fibrosis are heard, with a leading role in the Prescription Charges Coalition. We have also written to key ministers and gained media traction for a review of the exemption list.

Underpinning the Trust's key campaign asks has been the annual ***Your Life and CF*** survey, now informed directly **by over 10% of the CF community**, which has included policy recommendations on the cost of living, Statutory Sick Pay (SSP), and air quality.

As we navigate the post-election landscape, our advocacy priorities remain firmly grounded in the needs of the CF community. The general election ushers in a period of significant change, presenting both opportunities and challenges. Building robust relationships with newly elected MPs is essential so that we are able to effectively champion the needs of the CF community, and make sure that our voices are heard in the new Parliament.

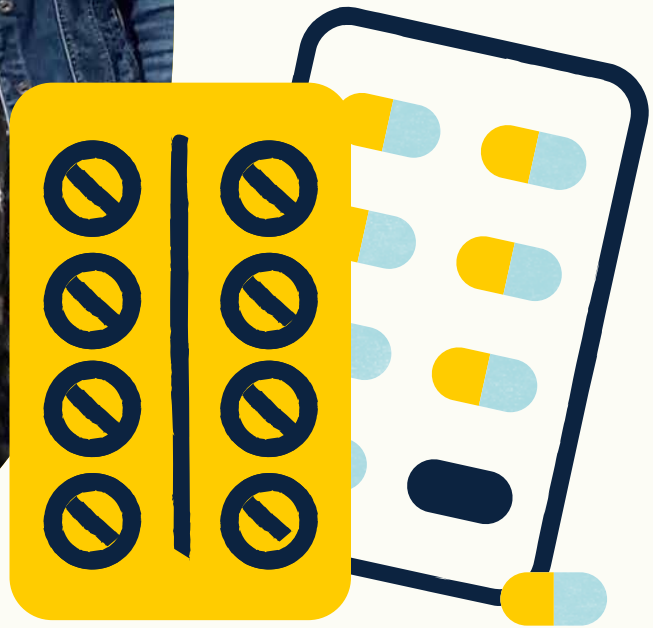




James (left), James's dad, James's twin brother (who also has CF), and their mum

"Paying for my own prescription makes me feel unseen and invalidated as a student living with a life changing illness. It's another cost on top of so many extra costs that CF brings to my life."

James, a Trust campaigner who has CF



The UK CF Registry

The UK CF Registry is a world-class database that includes data on **approximately 99% of people with CF in the UK** who have consented to their data being submitted by their CF team.

Anonymised Registry data is vital in helping people with CF and their families understand CF and make informed decisions, supporting research, service improvement, monitoring the safety and efficacy of new treatments for CF and helping commissioners provide funding to NHS CF centres.

In 2023/24 we have:

- concluded three drug safety studies, generating total income of over **£1.7 million**
- received up to **£160,000** from NHS contracts for generating public reports and supporting the commissioning of CF services in England
- submitted anonymised 2022 data to the European CF Society Patient Registry (ECFSPR)
- **received 51 data requests:**
  - **7** requests from ECFS Patient Registry requesting UK data
  - **7** requests withdrawn prior to review by Committee
  - **37** requests were submitted to the Registry Research Committee for review; **31** were approved and **6** were declined.

We're seeing a steady increase in the number and complexity of data requests received, reflective of the increasing richness of the Registry data. In March 2024, we received our 500th data request.

"The UK CF Registry is the envy of many disease conditions, and I believe it has been really important in helping to drive forward research and quality of care in the field of CF. We are grateful that over 99% of people with CF in the UK contribute to this powerful data resource which researchers from across the globe can apply to use in an anonymous or pseudonymous format."

Dr Jamie Duckers





Dr Jamie Duckers

Data Validation Programme

- From September to December 2023, CF centres with more than 55 patients participated in a virtual data validation visit to check the accuracy and validity of data submitted to the Registry.
- The Data Validation Programme (DVP) has confirmed a high level of data accuracy and completeness of UKCFR data; the process has provided further evidence that the Registry is fit for purpose for use in research, pharmacovigilance studies, and ongoing NHS commissioning requirements.
- The UK CF Registry DVP has been adopted as a model of best practice by other CF Registries in Europe. For the 2022 data, a report has been sent to the ECFSPR to be added to their European Data Validation Report.

Annual Registry report

The UK CF Registry report 2022 was published in October 2023. We reported that 7,950 people were taking a CFTR modulator by December 2022. As we continue to gather data on the use of CFTR modulators, a clearer picture of the health impact of the modulators will be formed.

An accessible highlights summary was also published, helping people with CF and their families to understand the data contained in the report. Both reports can be found on our website at **cysticfibrosis.org.uk/registry**

Annual Registry meeting

In October 2023, we held our Registry annual meeting in Birmingham. Around 60 Registry users from CF centres across the UK attended to hear from the team and clinical colleagues about the latest Registry updates, projects, and current research, as well as contributing to workshops looking to the future of the Registry.


BSA

Uniting for the CF community

Day-to-day support

We have continued to deliver support to the CF community when it matters most. This year has included some challenging times, including the draft NICE appraisal announcement in November and medicines shortages, particularly for Creon, We have provided vital information and support, helping the community to understand what's happening and listening and responding to questions.

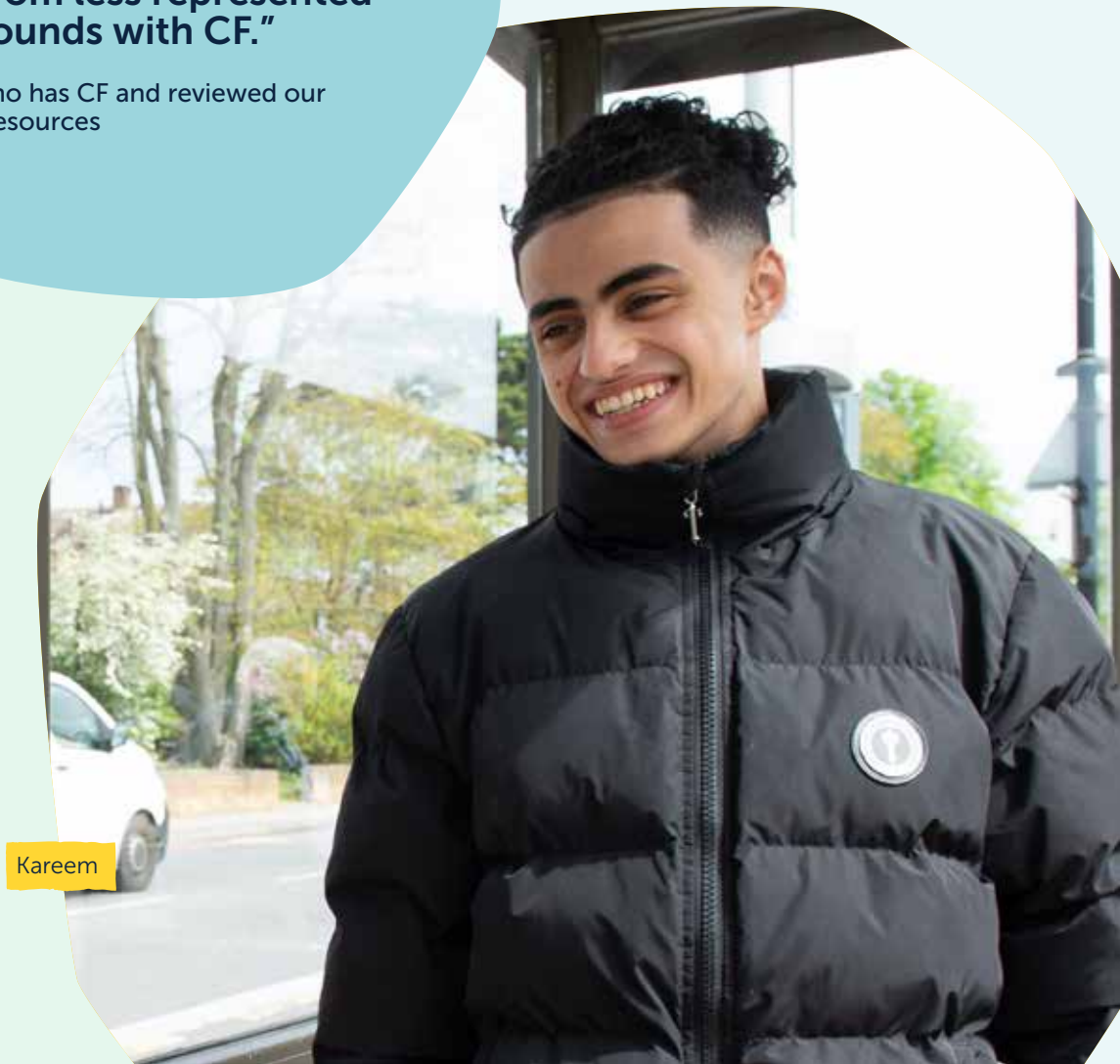
Alongside this reactive work, we've continued to provide a range of support services to help people with CF manage day to day life, with the ultimate aim of protecting CF health and helping people affected by CF to live the lives they want. This has included expanding our peer support offering by providing a safe space in our online community and training a new cohort of volunteers for CF Connect, our peer support service for parents with children with CF.

Many of those contacting us for support this year are experiencing complex emotional, social and financial issues, which impact on their physical and mental health. Through our individualised and holistic approach, we have been able to provide responsive, flexible support to help them move forward and support their long term health.

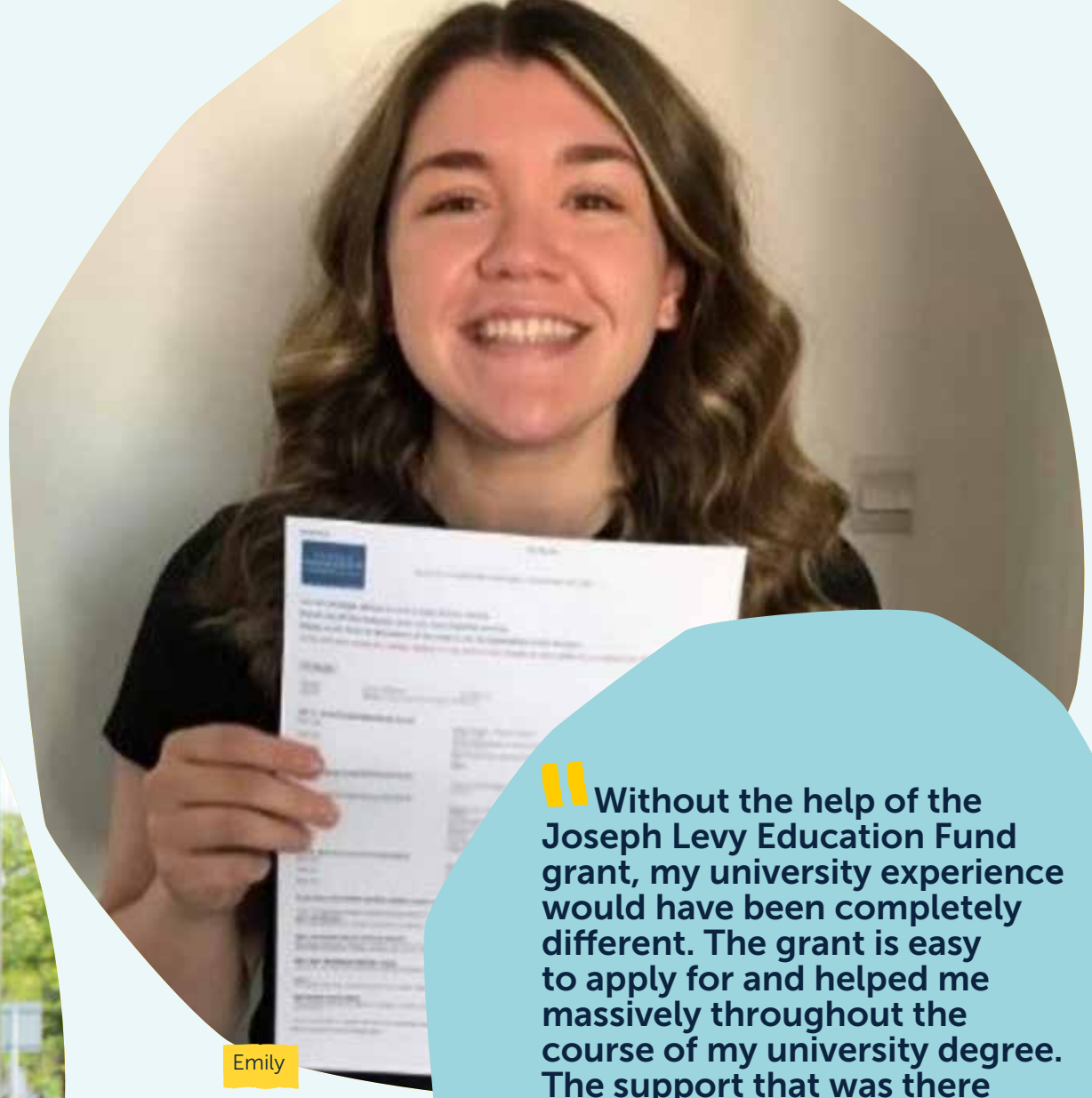


"Being involved in reviewing Cystic Fibrosis Trust's Ramadan resource was really rewarding for us. It felt good to provide our personal experience on something close to us and help those from less represented backgrounds with CF."

Kareem, who has CF and reviewed our Ramadan resources



Kareem



Emily



"Without the help of the Joseph Levy Education Fund grant, my university experience would have been completely different. The grant is easy to apply for and helped me massively throughout the course of my university degree. The support that was there allowed me to pursue my degree knowing that I would be able to handle both university life and keep myself well."

Emily, who has CF



Grants

This has been another busy year for our grants programme, and we've provided **1,242 welfare grants, totalling over £310,000**. This included **324 Cost of Living Fund grants**, supporting low income households with the basics needed to stay well over the difficult winter months.

We also provided **61 grants to support people with CF** in higher or further education through the Joseph Levy Education Fund. And through our Helen Barrett Bright Ideas Awards we've supported **9 people with CF with £20,000 of grants** to support them to take a step forward in running their own business.

Thanks to the support of the Joseph Levy Foundation, we've been able to open for applications for Rest & Relax holiday grants, enabling people who have been through a particularly challenging time to have a holiday.

We've also increased impact reporting across all our grant types this year. Over 90% of those who responded to our surveys told us the grant they received had a positive impact on their physical and mental health.

Benefits advice

We have continued to deliver expert benefits advice, income maximisation and student support to help secure financial stability for people affected by CF.

Our benefits advice service has been busy with detailed casework, particularly around Personal Independence Payments (PIP) this year, with more people needing support at tribunals. The impact of this support is evidenced by the staggering **£1.9 million in benefits income** we have secured for the 300 people supported through benefits advice.

We've helped a further **70 people with income maximisation and 23 students with CF** to identify all the financial and practical support available to them. Across both these services, we've been able to identify on average £5,000 per year of additional income, per household.

Helpline

Our Helpline service has continued to provide practical support and information and a listening ear. We've been able to meet people in the CF community where they are, by providing our service across a range of channels. We've handled over 4,500 enquiries across phone, email, WhatsApp and social media. The Helpline has acted as the gateway to all our support services, often dealing with our most complex enquiries and ensuring people contacting us get the right support, at the right time. 100% of those who responded to our feedback surveys said they would recommend our service to others.

"When I called the Helpline, the adviser at Cystic Fibrosis Trust went over and above his responsibilities and signposted me to ensure I had all the support and advice I needed but didn't know I could access. We are so grateful."

Rob, Helpline user





James, who has CF

"Cystic Fibrosis Trust are fantastic, and they have contributed to my life in different key moments. They offered me support when I was diagnosed, and I received a grant of £1,000 toward my first office space when I started my first business."

James, who has CF

Trusted Information Creator

Patient Information Forum

Empowering the CF community through high-quality, accessible information

We retained our accreditation with the PIF TICK, a quality kitemark demonstrating the Trust's strict adherence to best practice in the production of health information. Last year we added several new and updated resources to our extensive information offering, covering topics such as inhaled therapies, hearing loss, vaping, CFSPID (inconclusive CF diagnosis), CF diabetes and the sweat test. We also responded to ongoing and emerging topics such as the NICE appraisal and Creon shortages, publishing regular updates to ensure the community was kept up to date on these important issues. Looking ahead, a key focus for the coming year will be developing information to meet the needs of an ageing CF population.

"A new diagnosis is incredibly overwhelming and tough, which is part of the reason Cystic Fibrosis Trust is so important to us, because the first resource you're given is information written by the Trust specifically for parents of a child with new diagnosis."

Chris, whose son Ambrose has CF





Ambrose, who has CF

Dedicated support for children and young people

Our youth programme had a busy and fun-packed year. Building Brighter Futures, our programme for 6–14 year olds with CF and their siblings, saw **88 children attending 32 courses** and one-off events, including baking sessions, resilience workshops and exploding science experiments!

Our Youth Advisory Group (YAG) of 14–25 year olds with CF **held 17 meetings**, continuing work on a new dictionary of CF terms as well as helping steer the Trust's work for young people. We also piloted Strong Beginnings, a support programme for parents of children with CF aged 0–6, running peer support events, music sessions and parent and baby yoga. **Almost 40 parents** have attended these events so far, and shared positive testimonies of how the events helped them cope at the start of their CF journey.

"The best part of YAG is meeting people who also have CF. I think it's really important that we're able to connect online with the people we relate to most, as we can't meet in person due to cross-infection and this can get incredibly isolating. So, it's great that we can just have a chat and a catch up as well as working on upcoming projects."

Tilly, who's a member of YAG and has CF



Tilly

> **"I contacted the Work Forwards team to see how they could help and what advice they could offer. With the help of the team, I learned how to deal with my anxiety and not let my nerves control me – and after a few months, I was offered a job! I know this wouldn't have been possible without the help of Work Forwards. They have been imperative in offering advice and helping me prepare for interviews. Because of them, I feel more confident, and I am incredibly excited to start the next chapter of my life."**
>
> Jonathan, who has CF



Work Forwards

Work Forwards employment programme

Following its formal launch in early 2023, our Work Forwards employment programme has continued to support people affected by CF towards secure, fulfilling work. This year, we've provided detailed one to one support to 59 people and delivered a range of online group sessions on topics including transferable skills and rights and adjustments at work.

We've shared a range of stories from people with CF in different jobs and careers and we'll be building on this in the year ahead. The project has also included work with our Youth Advisory Group to look at how we can equip young people with knowledge of their rights and the delivery of this year's Helen Barrett Bright Ideas Awards, which provide grants and support around self-employment.

We're grateful to National Lottery Community Fund and Scope for their funding which has made this programme possible.

COMMUNITY FUND

Diverse and together*





This year, we've continued to find new ways to reach and engage people affected by CF in the right way at the right time. From growing our presence on TikTok and experimenting with social media advertising, to launching our third co-created awareness campaign and the second series of our CForYourself podcast.

We have built new relationships with a diverse range of storytellers who generously share their time and stories with us to support our work, raise awareness and support our community. We make sure the voice of the CF community is always heard and profiled through the stories we place in the media, on our website and through our fundraising materials. High-profile campaigns like our 60th anniversary, CF Week and #CFTruths have been shaped and influenced by people with CF and their families via our active involvement groups.

Learning more about our community through insights and market research

We conducted a crucial market research project with Humankind Research to understand the different needs of our community following the introduction of modulator treatments, and the challenges of the pandemic and the cost of living crisis.

We found that:

- we have incredibly high levels of positive brand sentiment, which to a large extent is driven by our excellent provision of information
- there are high levels of connection with research, and a desire to keep hearing updates in this area
- Kaftrio has bought new opportunities and a new sense of optimism for many, but this is, by no means, 'job done' and if anything the sense of anxiety and uncertainty has increased
- the fears and anxieties we might have seen before around mortality are still present
- and the uncertainty drives people to the extremes: either inward or outward facing
- especially for those who are more outward facing there is a frustration around low CF awareness.

This leads to a new set of needs and opportunities, particularly in finding ways to mitigate the uncertainty:

- helping our different stakeholders build a road map for a new future with CF, focusing on what growing older with CF looks like
- providing practical and emotional tools to help them along this journey
- providing reassurance (and research) around the future of Kaftrio
- providing platform(s) for the people who go 'outwards' – and tools to help them raise awareness and empathy
- providing support and understanding to those who go 'inwards'

To support this work, we have four key work streams to focus on what we can enhance, promote and develop around life stages, bereavement, awareness of CF and emotional support to ensure we remain relevant and continue to enhance and target our offer.



Our EDI strategy

At the Trust, we recognise that everyone's experience of CF is unique, with many people facing different barriers and challenges to being able to live a life unlimited. Over the last year, we've been consulting on and developing an Equity, Diversity and Inclusion (EDI) strategy, to ensure we put EDI at the heart of everything we do and recognise the full range of needs across the community.

Events

For our community

This year we ran four online and two hybrid CF Live events, which brings together the CF community, people involved in CF care, researchers and others with an interest in CF. The series spanned a range of topics including genetic therapies, a recap of our annual CF conference (UKCFC) and involvement and paediatric CF care.

We were also thrilled to be able to hold hybrid CF Live community events in Belfast and Glasgow, enabling us to engage with the wider community across the UK.

CF Live

For CF professionals

We supported the delivery of four key conferences and events for CF professionals. A one-day hybrid UKCFC event attended by over 150 individuals working in CF research, followed by another one-day event focusing on growing older with CF.

We hosted two further one-day conferences in Leeds: the Annual Clinical Trials Conference and the MDT Share and Learn Conference.

60th anniversary

In February 2024, landmarks across the UK lit up yellow to recognise 60 years of Cystic Fibrosis Trust. We launched new content and materials under the banner of 'we won't stop until CF does', recognising that while there have been significant achievements over the last 60 years, there is still a lot more to do to ensure everyone with CF can live a life unlimited. 10,000 posters were donated to us to raise awareness on bus shelters across the UK, totalling around £500,000 media value.

Since 1964

"I attended Cystic Fibrosis Trust's 30th anniversary at St James's Palace in London all those years ago and as Harvey and I live and breathe, today and in the future, it is testament to the hard work and dedication of everyone at Cystic Fibrosis Trust."

Hazel, who has CF



Hazel, 58, and Harvey, 60, who both have CF

CF Week

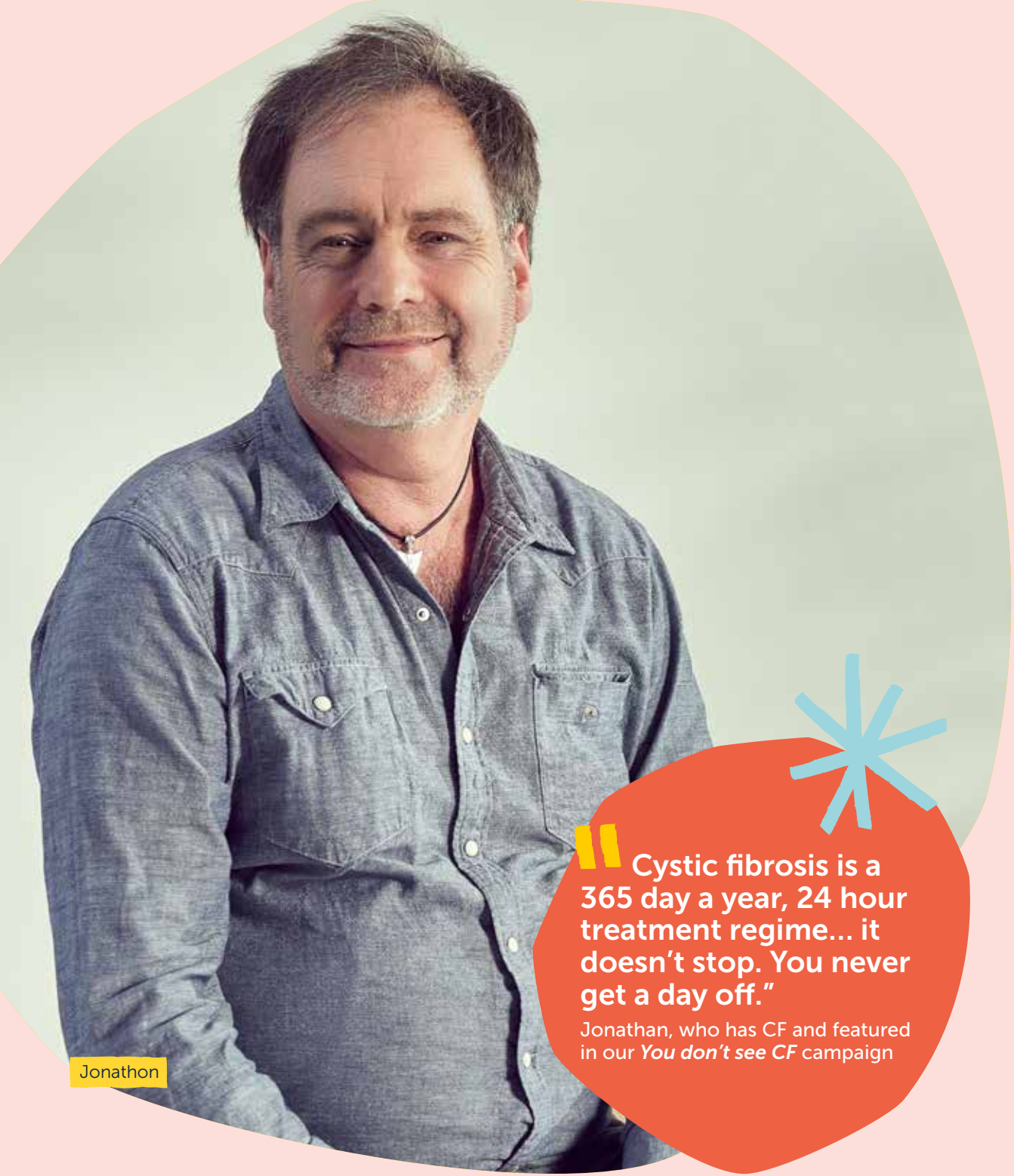
CF Week is our annual awareness and fundraising week, ending with our brightest fundraising day of the year – Wear Yellow Day. CF Week 2023 focused on some of the incredible progress we've already made in CF research, and looked forward to the breakthroughs we can make in the future. Together as one united community. We shared stories from across the CF community, went inside the lab with some CF researchers, and hosted a series of live events across our social media channels. This year:

- Wear Yellow Day raised a fantastic £78k
- media coverage during and after the week had a **potential audience of 1.7m**. Highlights included a James Dunmore interview in Fabulous magazine and an awareness piece in Take a Break magazine
- the ***Your Life and CF*** survey was continuously promoted via BBC Access All social media and syndicated to all BBC local radio station with **a combined reach of over 4.6m**
- we had a combined reach of over 450,000 across our social channels and over 1m impressions through our paid social media advertising
- we received 'out of home' (OOH) advertising coverage worth over **£115,000 with a reach of over 800,000 people**
- we visited two research centres, creating a range of video and blog content as well as adding to our growing suite of brand photography
- we empowered the CF community to tell their story and share their #CFTruths through our own platforms – including guest editing of CF News and Instagram stories takeovers
- eight celebrities got involved with CF Week including Nick Mohammed, Lyndall Grace, Jenny Agutter and Richard Madeley
- we engaged with politicians across the UK to share our resources and show their support, with:
    - **47 parliamentarians** wearing Trust pin badges
    - **22 CF parliamentary** mentions
    - Welsh First Minister, Mark Drakeford, publicly supporting CF Week.



Lyndall Grace





Jonathon

> **"Cystic fibrosis is a 365 day a year, 24 hour treatment regime... it doesn't stop. You never get a day off."**
>
> Jonathan, who has CF and featured in our ***You don't see CF*** campaign

#CFTruths

Our annual awareness campaign leaned into our 60th anniversary this year by recognising that improvements over the past 60 years have made life better for many, but as old problems diminish, they can bring new challenges and fears. And there is still no cure. No day off from CF.

The campaign is still live, but so far has achieved:

- over £450k donated for OOH advertising with a reach of over 7m
- over 479,000 impressions across paid social media
- over 4,000 clicks to the website through paid social media
- over 18,000 impressions and over 1,800 clicks to our website with over 700 conversions – including 10 purchases in our online shop, totalling almost £350 through a Google Performance Max campaign
- national coverage in the Mirror and syndicated across 11 regional outlets, with an editorial reach of over 11m.



Our ***You don't see CF*** campaign won bronze in the people's choice awards in the 2024 Smiley Charity Film Awards 2024.

Celebrity engagement

Our celebrity supporters and ambassadors have continued to provide vital support, awareness and fundraising for the Trust. Highlights include:

- Roger Black appearing on The Celebrity Chase and recording a video of support for participants of Great Strides
- James Dunmore and Married at First Sight Australia's Lyndall Grace featuring as guests on our podcast CForYourself
- Lyndall Grace taking part in an Instagram Live
- James Dunmore supporting us through media in Fabulous Magazine
- Jenny Agutter helping us to promote Carols by Candlelight on Loose Women. She also did a reading at Carols by Candlelight alongside James Dunmore, and actor David Haig
- Jenny Agutter and Vincent Franklin both taking part in an Instagram Reel to support our FeBREWary campaign
- a host of celebrities supporting Wear Yellow Day, including Richard Madeley, Jack Kinsey, and Nick Mohammed.

A huge thank you to all of our celebrity ambassadors and influencers who continue to support our work.

Sharing stories from our community

We strive to share diverse stories from our community through our blogs and video content. This year, we've developed multiform content which covers a range of topics such as CF research, poverty, mental health, travel, growing a family and the relentlessness of living with an invisible condition. We listen to our community to share what's important and relevant to them, keeping them involved every step of the way to ensure we're telling their stories in their own authentic voices.



"The amazing strides that have been made in treatments in the time since my sisters passed away is astounding and a true reflection of what is possible with increased awareness and funds."

James Dunmore

James Dunmore ran London Marathon for the Trust in 2024



Our magazine

CF Life is our twice-yearly magazine. Packed with the latest news, features, and real life stories from the CF community. It is mailed to over 20,000 of our supporters across the UK, and can also be read online.

In 23/24, CF Life covered topics including:

- transition from paediatric to adult care
- an interview with the founder of Vertex Save Us about the campaign for global access to Kaftrio
- diversity in clinical trials
- genetic therapies and CF.

Following the spring edition of CF Life magazine, we received a £5,000 donation in the post from a supporter. After reading Tilly's piece about what YAG means to her, the supporter wrote: **"Many things had me in tears... Say thank you to Tilly and tell her the donation is partly due to her!"**



CForYourself podcast

Our podcast launched in June 2022 with host Lucy having a cup of tea and a chat with others in the cystic fibrosis community, talking openly and honestly about a whole range of topics. In series 2 of the podcast, we covered everything from dating with CF to the menopause, and we also featured some well-known voices, including Made in Chelsea star James Dunmore and Lyndall Grace, star of Married at First Sight Australia.

CForYourself is all about sharing honest insights into life with cystic fibrosis, the good, the bad and everything in between and has been a huge success with our community – and beyond. Whilst most of our listeners are in the UK, we've also reached the CF community across the world, from Australia to Argentina.

Series 2 highlights

- 8 episodes
- 1,050 downloads
- Most popular episode: #CFTruths: Living with an invisible condition

"The episode was the first I have ever heard and it was great to listen. Keep going strong on the podcasts... not only are you helping those listening, you are helping your guests talking through their difficulties and triumphs."

Tim, Podcast listener



Lucy Baxter, host of the CForYourself podcast



Jade, played by actress Lizze Green, who appears in Eastenders

CF in the media

We've had an incredible year for media coverage and would like to thank all the journalists we've worked with, and all our spokespeople and storytellers for helping us to raise awareness of cystic fibrosis.

We saw amazing coverage of our London Marathon stories and reached national audiences through the BBC Access All podcast for the ***Your Life and CF*** survey. We also launched our cost-of-living campaign, raising awareness of the difficulties people with CF were facing, which received amazing coverage across the Express.

Once the NICE consultation began, and we had the news about Kaftrio being approved for 2-5 year olds, the Trust was in hundreds of national and regional outlets. Jenny Agutter, our celebrity ambassador, also appeared on Loose Women speaking about Carols by Candlelight. It was also incredible to see a CF storyline in EastEnders.

CF News

Our monthly newsletter is sent to over **10,000 opted in subscribers** sharing the latest CF research breakthroughs, stories from our community and wider news from the Trust. Over the past year, the newsletter

- averaged over **37% unique open rate**
- averaged over **1,000 click throughs** to our website
- covered popular articles such as CF Life magazine, our awareness campaign and topics important to our community such as the NICE appraisal.

We had 1,453 pieces of coverage over the last year with a huge potential editorial reach of 7.8 billion

Website

During 2023/24 we have delivered a number of projects to strengthen our website, led by the needs of the CF community and championing accessibility to ensure everyone can engage with the information they need.

These include:

- reducing the number of links in the main navigation menu
- introducing personalisation on the homepage to make it more engaging and relevant for repeat users
- redesigning the CF Trials Tracker
- implementing Google Analytics 4 to support our data collection and analysis.

Another highlight has been the growth of our online community forum, which has had over 500 new sign ups, over 400 posts and 34,000 page views.

"At the beginning, there were so many questions I had to ask. I went on Cystic Fibrosis Trust's online forum and absorbed so many different people's stories and different walks of CF life. It brings you so much hope and made me feel like, 'it's going to be okay'."

Shanique, CF parent



Shanique and Thiago, who has CF

Social media

From the beginning of 2023, we saw the continuation of our successful weekly social media initiatives: Research Wednesday, Thanking Thursday, and Fundraiser Friday, which aims to give space on a weekly basis to share CF research news and opportunities to get involved, as well as celebrate the amazing achievements of our supporters.

Our social channels allow us to respond to the CF community in a timely fashion on key themes such as the NICE process and ongoing Creon issues. Our ability to turn around video content quickly, direct from our Chief Executive, enabled us to reassure our community during some challenging moments.

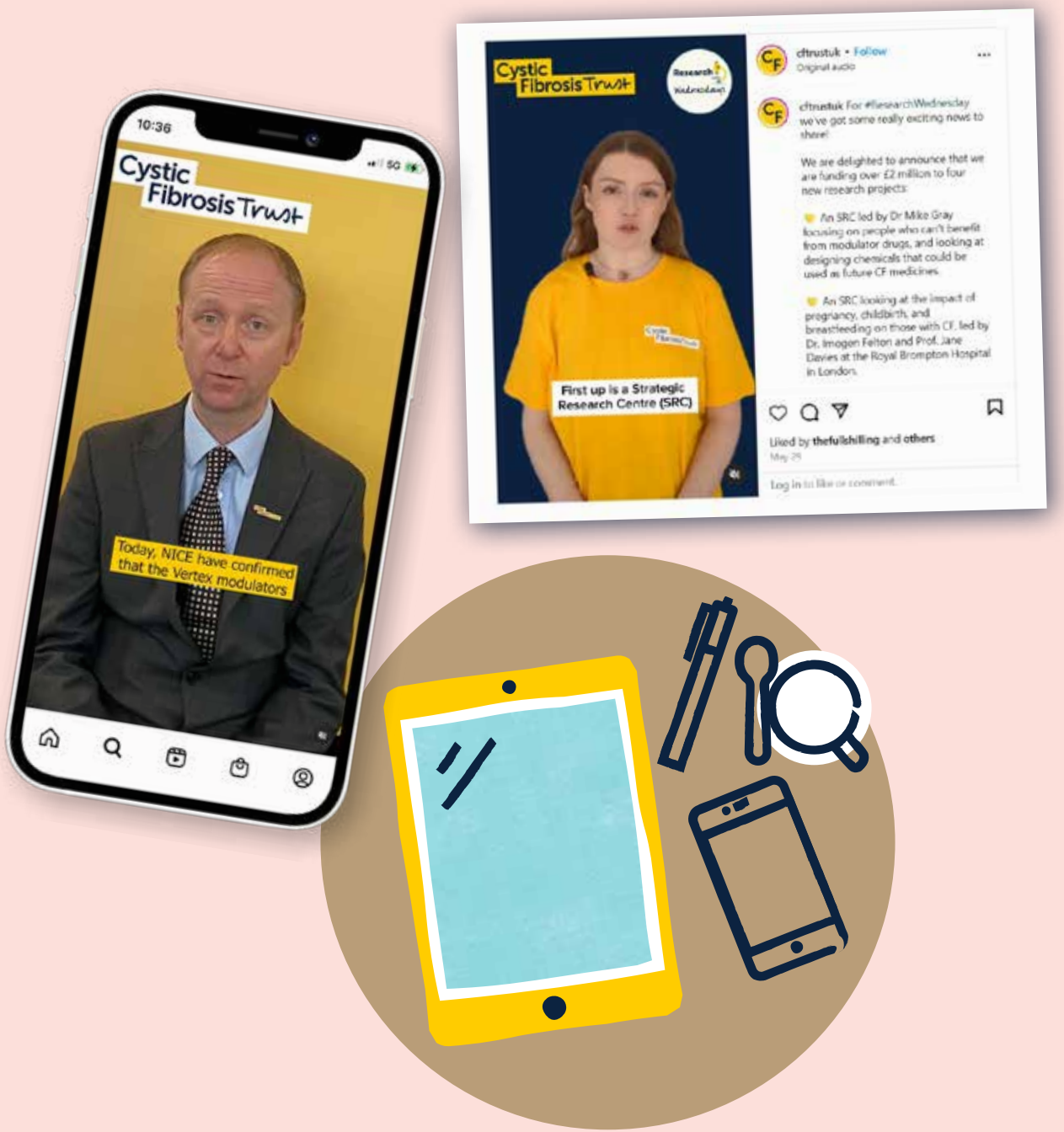
Across Facebook, Instagram and TikTok we had an incredible combined reach of **6.9m** and **1.9m** impressions across LinkedIn and X.

Our video content continues to perform incredibly well across all of our channels with over half a million views in the past year.

CF Connect

CF Connect is our peer support service for parents of children with CF, helping them connect with one another without the risk of cross-infection. We trained a new group of volunteers this year.

Recently we put Helena, who has a young baby with CF, in touch with one of our trained parent volunteers. Helena had been through a difficult time, figuring out her new routine and keeping her baby well, and she had questions about the future. Helena found solace in talking to one of our trained volunteers who had been there herself, and understood her worries. We provided a safe, nonjudgemental space for Helena to get things off her chest and talk her concerns through.




stic
Fibrosis the
eason I run

Uniting in* fundraising

We would like to thank all our amazing individual donors and supporters, organisations, charitable trusts, foundations and corporate partners who support our work to make sure everybody with CF can live a life unlimited. We really appreciate everything you do for the CF community, particularly when we know everyone is feeling the financial pressure. It makes your support so incredibly special to us.

We couldn't do what we do without you.

In 2023/24, total income of £7.9 million gross income was raised compared to £6.45 million in 2022/23 (+£1.4m) and £5.7 million net income. There were increases in many areas of fundraising including Community and Events income, In Memory income, Corporate Partnerships, Trusts and Foundations, and in particular income from gifts in wills of £2.6m which had an increase of £1.6m versus 2022/23. However, this still represents a 24% reduction in net income compared to pre-pandemic income in 2019-20 as our voluntary income at the Trust continues to be impacted by the cost of living crisis.

This year marks the final year of our groundbreaking CF Innovation Hub on lung health with the University of Cambridge, which started in 2018 under the leadership of Professor Andres Floto. We successfully raised £5 million for the Innovation Hub thanks to the incredible generosity of our supporters over these six years. Every pound raised was match-funded by the University of Cambridge.

We continue to innovate and adapt our fundraising plans. Examples of new innovations launched this year include a new gaming proposition #Game4CysticFibrosis, our winter wander and virtual event 60 for 60 for our 60th anniversary.

Our trustees agree and regularly review our fundraising strategy. We adhere to Data Protection Law and the Fundraising Preference Service. We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice and, as such, commit to their Fundraising Promise.

- We aim to exceed the standards included in our promise to our supporters:
- We will be transparent about our work
- We will be respectful
- We will listen and respond
- We are committed to high standards
- We are fair and responsible





Jamie

"The Trust has been a huge part of my journey for as long as I can remember. They have supported me, helped me find support in tough times and included me in their campaigns. I've been so glad to be able to raise money for them when competing in events such as London Marathon, as it's so important the Trust can continue their research."

Jamie, who has CF

Supporter experience

The Trust received 29 complaints in 2023/24. This is broadly in line with the 19 received in 2022/23, and 24 in 2021/22 and lower than our pre-pandemic average, with the main areas of improvement being more effective use of data (fewer mailing related errors) and in dealing with sensitive subjects (like bereavement). Complaints are closely monitored and reviewed by senior management on an ongoing basis. In addition, we regularly review our complaints policy and processes to make it easier for people to give us feedback and to ensure that we listen and learn from what our supporters and community are telling us.

Community and event fundraising

This year our aim has been to continue to grow income year on year and thanks to you, over **£2.27 million** has been raised.

Our unwavering fundraisers continue to take part in activities across our event portfolio including London Marathon, London Landmarks Half Marathon, Edinburgh Marathon Festival, London to Brighton Cycle Ride, skydives, and overseas treks. We have also seen an increase in fundraisers signing up to events that capture their imagination as a DIY activity. Together, our challenge event participants have raised over **£1 million**.

The CF community have been very busy fundraising through amazing events and activities such as Wear Yellow Day events, FeBrewary activities, balls, boxing matches, football matches, quiz nights, games nights, and the impressive list goes on. These fantastic endeavours **have raised over £1.08 million**. Our annual Wear Yellow Day **raised over £78,000**.

Our dedicated branches and groups located all over the United Kingdom **raised £100,000**.

.







Nell



"Cystic Fibrosis Trust have been amazing and the research and developments that have come about as a result of the charity's efforts has been incredible to see. Kaftrio has made a huge difference for me and my brother, but I know it's not a cure and some people can't benefit from it, so I'm determined to run for everyone in the CF community."

Nell, who has CF



Jacob

"When Jacob was first diagnosed, the CF nurse at the hospital handed us a pamphlet from the Trust explaining what CF is. It helped us to have that information in one place and meant I didn't go searching on Google, which would have been the worst thing for me to do.

Greater awareness of CF is essential to help raise money for future medications and research, and that's why Stuart and I do a lot of fundraising for Cystic Fibrosis Trust. My sister teaches hot yoga, so we have held classes on the beach to raise money for CF, and last year, we also put on a silent disco using headsets that the Trust kindly lent us. This year, we held a fundraising event at Jacob's nursery during CF Week, and everyone dressed up in yellow and raised a lot of money. We are hoping to do that again next year."

Morag, whose son Jacob has CF

Regular gifts

We'd like to express our gratitude to our loyal regular donors who provide invaluable ongoing support that enables us to plan effectively for the future. These supporters contributed **just over £800,000** in 2023/24, including Gift Aid. During this year, we carried out a direct mail appeal and a telemarketing campaign through Ethicall, our professional telephone fundraising agency. Ethicall have a respect and dignity policy that turns marketing calls into 'thank you' calls if they suspect the person that they are speaking to is vulnerable. These campaigns (a regular giving upgrade via both direct mail and telemarketing, and a direct debit recruitment campaign) resulted in an additional annual income of £18,000.

Gifts in Wills

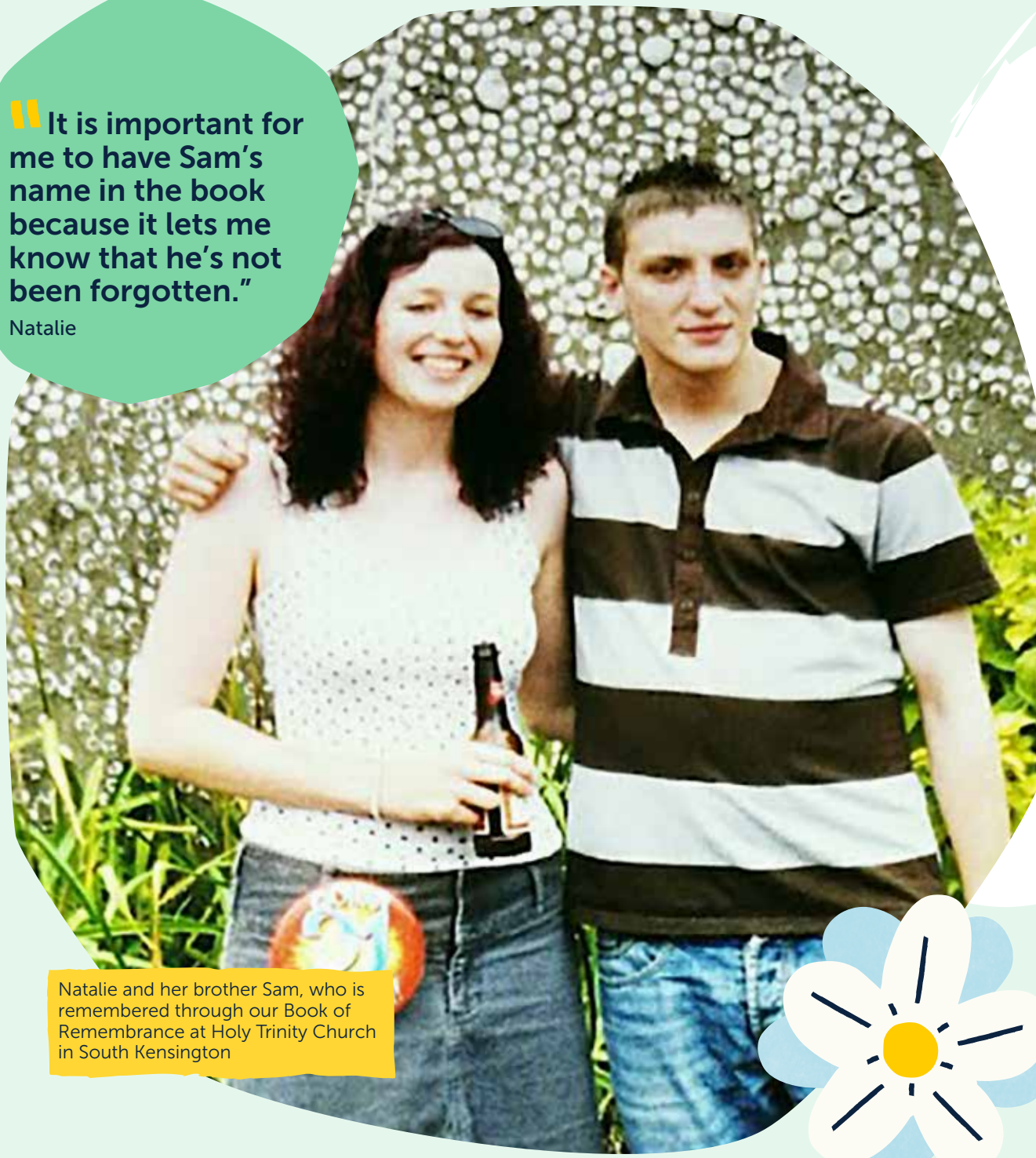
During 2023/24 we were privileged to receive **legacies from 88 supporters** who generously chose to include a gift in their Will to support the Trust. These special gifts will help us to continue our vital work for years to come. In 2023/24, 42 supporters informed us of their commitment to leaving a legacy gift. We remain committed to promoting legacy giving through various channels and providing a free Will service to our supporters all year round.

In memory

We continue to honour and remember all those with cystic fibrosis who have lost their lives and thank everyone who donates in their memory. In 2023/24, **more than £320,000 was donated in memory of loved ones** and they will always stay in our thoughts. Our Book of Remembrance, tribute funds and dedication wall remain special places where these individuals can be remembered.

"It is important for me to have Sam's name in the book because it lets me know that he's not been forgotten."

Natalie



Natalie and her brother Sam, who is remembered through our Book of Remembrance at Holy Trinity Church in South Kensington

Corporate partnerships

Building partnerships with existing and new corporate partners is vital to both raising funds and awareness for the Trust.

We would also like to highlight the continuing support we have had this year from longstanding partner AJN Steelstock for the Innovation Hub. Crane CPE provided the opportunity to apply and receive funding from their 'Crane Widows and Children Fund', and the skills and expertise of the Bip Group assisted us in ensuring that our Helen Barratt Bright Ideas Awards continues to go from strength to strength.

We were delighted to be named as charity of the year by C-Stem, Orlo, McLemore Konschnik LLP, and SHS Drinks, and the benefitting charity for the Britannia Stakes race at Ascot thanks to the Betting and Gaming Council and their members.

Events such as the UK CF Clinical Trials Conference, UKCFC and the Annual Registry Meeting are essential in showing the work we do within the cystic fibrosis sphere and we would like to thank our sponsors once again for the support they have given us, many of whom have supported the events in previous years.

We value all the support that our corporate partners have given us and the wonderful enthusiasm and dedication that comes with it.

Philanthropy

Philanthropic support from charitable trusts, foundations and individual supporters is key to the sustainability of our mission to improve the lives of those affected by cystic fibrosis.

We would like to thank the generous and committed support of trusts, foundations, the National Lottery Community Fund and BBC Children in Need who provide donations and multi-year grants. This is critical to the Trust's provision of services to our CF community and world-leading research. In this 60th anniversary year of the Trust, we are particularly grateful for our long-term partners, the Robert Luff Foundation and the Joseph Levy Foundation.

This year marks the final year of our groundbreaking CF Innovation Hub on lung health with the University of Cambridge, which was established in 2018 under the leadership of Professor Andres Floto. Thanks to the incredible generosity of our supporters, Cystic Fibrosis Trust successfully raised £5 million for the Innovation Hub, which was match-funded pound for pound by the University of Cambridge. As the programme draws to a close, we want to thank all our funders who supported us and enabled world class advances in our knowledge of CF lung infections.

We deeply appreciate the dedication of our Sixty Five Roses Club, a group of supporters **who commit to donating £1,000 a year** or more. Longstanding support from these members and other donors who pledge sustained giving is so important to our ability to deliver sustainable programmes. Members of the Sixty Five Roses Club have been on this journey every step of the way, **raising over £760,000 over the last decade** in support of our mission to ensure everybody with CF can live a life unlimited.

As the CF community faces post-pandemic adjustments and the cost of living crisis rolls on, philanthropic support has allowed us to extend our Cost of Living Support Package programme which launched in 2022. This year **we have supported 324 people with CF** in low-income households with grants for energy bills, food and basic essentials over winter.



Professor Andres Floto and his team working in the laboratory at the Cambridge LMB (Laboratory of Molecular Biology).

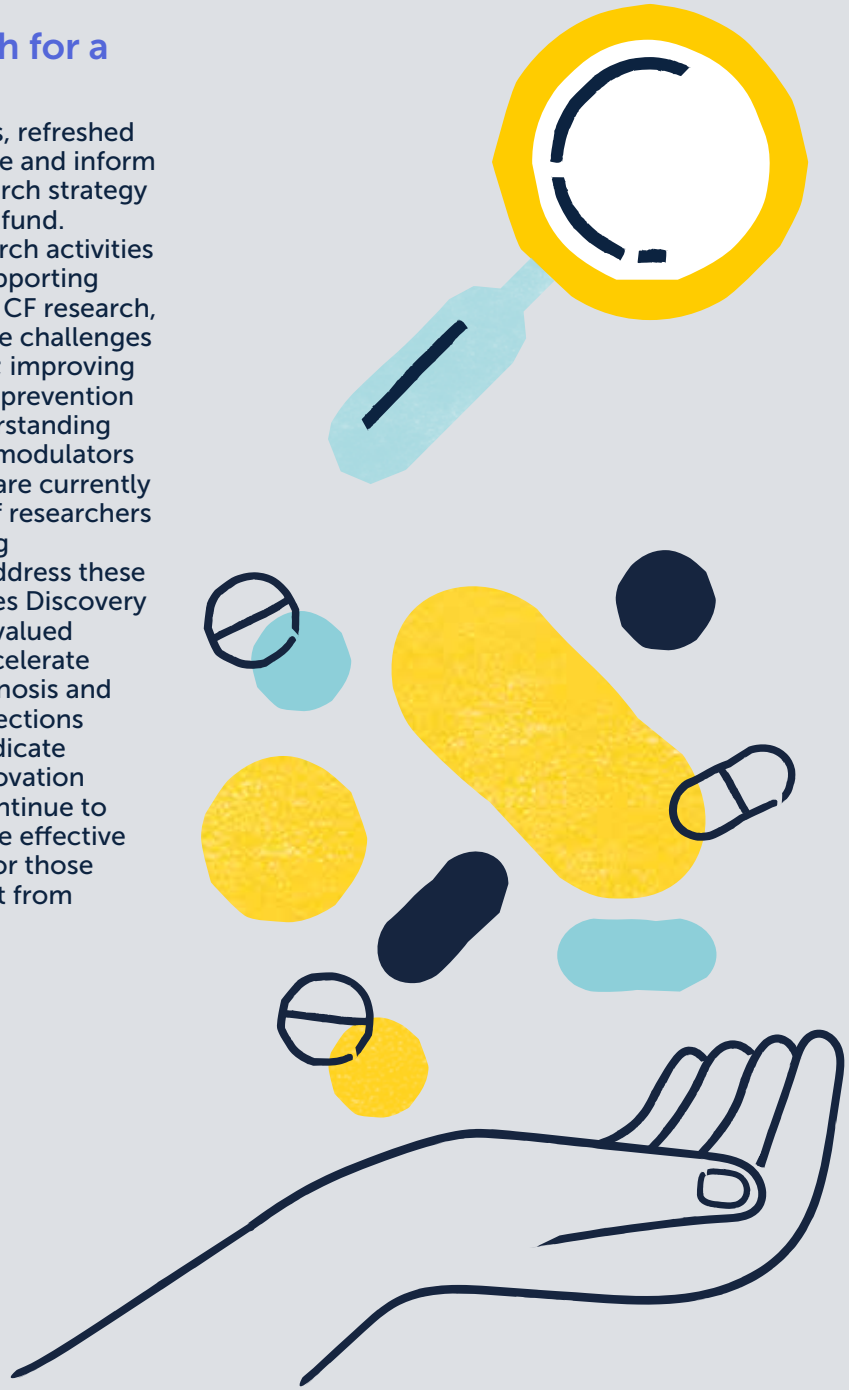


Looking to the future



Uniting in research for a life unlimited

The CF research priorities, refreshed in 2022, continue to guide and inform the direction of our research strategy and the research that we fund. Mapping of current research activities has led us to focus on supporting under resourced areas of CF research, such as understanding the challenges of growing older with CF; improving diagnosis, treatment and prevention of CF diabetes; and understanding the long-term effects of modulators outside of the lungs. We are currently building new networks of researchers and new research funding partnerships to help us address these new challenges. Medicines Discovery Catapult and LifeArc are valued partners in our aim to accelerate research to improve diagnosis and treatment for CF lung infections through the CF AMR Syndicate and the Translational Innovation Hub Network. We will continue to support research for more effective treatments, particularly for those who are unable to benefit from current modulators.





Sharon (right) receiving another fantastic fundraising donation to Cystic Fibrosis Trust



"I know my fundraising has contributed to CF research over the years and that's really important to me because I've seen firsthand what a difference Kaftrio has made."

Sharon

Whatever you do, do it in yellow

Being great fundraisers

Growing our income is vital to enabling us to expand our research programme and support everyone with CF to live a life unlimited. The continued support of our CF community is so incredibly special to us.

Throughout 2024, we look forward to celebrating our 60th anniversary and all that has been achieved with our incredible CF community. Some of the activities will include a special Wear Yellow Day in June, a campaign to promote leaving a gift in your will in September and our 60th Awards in November; shining a light on some of the incredible people who have made a difference to the CF community.

We will continue to work closely with our incredible supporters, branches and groups, and with our trusts, donors and corporate partners. In order to provide the very best experience when supporting the Trust, we will continually review and update our engagement and how we communicate with our supporters.

Innovation remains a key pillar of our fundraising strategy to develop new products and engage new supporters in order to diversify our income.

Building on the success of our first Innovation Hub with the University of Cambridge, we will launch our £15 million Translational Innovation Hub Network which is co-funded by the Trust and medical research charity LifeArc; to fast track new research and treatments to improve lung health and quality of life for people with CF over the next five years. We are delighted that the Robert Luff Foundation have continued their support for the new Hub Network.

Campaigning hard

Our advocacy will continue to emphasise critical issues such as air quality, which significantly impacts those with respiratory conditions like CF. The Government's focus on enhancing the UK's science and innovation sector provides unique opportunities for advancing CF research and treatment. We will advocate for policies that support research, innovation, and improved mobility for scientists, which can accelerate progress in CF treatment where needed.

With a new legislative agenda taking shape, we will remain flexible and proactive, diligently monitor announcements, ensuring we leverage every opportunity to advance our mission. Upcoming policy reviews and budget announcements will further shape our strategies as we advocate for sustained and increased investment in healthcare and research.

We will seize every opportunity to advocate for improved CF care and support. Our advocacy work puts the needs of people with CF, their families, and professionals working in CF care at the heart of everything we do.

Day-to-day support

We continue to develop our services and resources to meet changing needs, while maintaining our core vital provision.

This year, we formed a partnership with Home-Start UK, a national charity who support families with children under 5, to develop support for new parents who have CF. We have seen a significant increase in people with CF becoming parents in recent years, and we want to put support in place to enable them to make the most of early parenthood while also maintaining their own CF self-care.

We have piloted this project in Glasgow, training a cohort of Home-Start volunteers in cystic fibrosis, so that when new parents need support they can access this in the knowledge that the person supporting them understands the condition. This programme has shown how, as needs in the CF community change, we can work with other organisations to balance their experience and knowledge with our understanding of cystic fibrosis.

We have also been developing our work to support those in the CF community who are neurodivergent, and those bereaved by CF.





> "Accessing Kaftrio was a game changer for me and turned the clock back around 10 to 15 years in terms of my overall health. This was obviously great, but it did also bring some challenges. I had always preferred to live in the moment and never really thought much about saving for a pension, because as morbid as it sounds, I thought it was never going to be a problem I'd need to worry about."
>
> Jimmy, our Work Forwards Programme Manager who has CF



> "Thank goodness we're growing older with CF, but we need the security of knowing that the person behind the desk has heard of CF and how CF may interact with their specialism."
>
> Jane

Quality improvement and clinical engagement

In 2024/25, we will report on findings from the second cycle of our patient experience survey in adult services and will provide bespoke feedback to all adult CF centres that took part.

In the autumn, new data will be collected on staffing levels in CF services. We also plan to develop and launch a new survey for CF professionals, which will look at how CF care and workload is evolving from the perspective of those working in the specialty.

We are continuing to roll out and expand our holistic follow-up offer for CF centres, to support them to explore their data insights and plan targeted quality improvement activities. This offer will be extended to adult CF services in 2024.

The UK CF Registry

Registry data will continue to help NICE as they evaluate the impact of CF modulator therapies on the health and wellbeing of people with CF.

We plan to present at CF Live events in 2024/25, taking advantage of the opportunity to explain the meaning behind collection of data and answer questions from the community.

We will be reviewing and expanding the types of data we collect to further support our community as CF care and the needs of people with CF evolve.


Cystic Fibrosis Trust
Uniting for a life unlimited

Financial review

Results for the year

The final result for the year, excluding movements on investments, was a deficit of £0.4m (2023: surplus of £1.9 million).

Whilst total income of £14.7m is the same as in 2023, total expenditure has increased by 18% (£2.3m), which is principally due to an increase of £1.9m in grants to support innovative research projects that we hope will help us achieve our goal of a life unlimited for everyone living with cystic fibrosis. This increase in expenditure was funded by unrestricted reserves held by the Trust in March 2023.

Although, following the cost of living crisis, generating voluntary income remains challenging, the Trust still retains strong reserves and is committed to maintaining charitable expenditure in 2024/25 whilst continuing to take appropriate cost control measures.

In subsequent years we anticipate the need to make some reductions in expenditure and focus on income growth to ensure that unrestricted reserves are within the Trusts' reserves policy range.

Income

The Trust's income from normal activities for the year to March 2024 was £14.7m. This total income is unchanged from the previous year although the mix of income has changed significantly, with strong legacy income balancing lower income generated in other areas.

Voluntary and trust income of £7.7m (2023: £7.8m) includes amounts from regular giving programmes and appeals, from branches, groups and communities, corporate partnerships and trusts. In common with many charities, the on-going cost of living crisis means that generating voluntary income remains challenging.

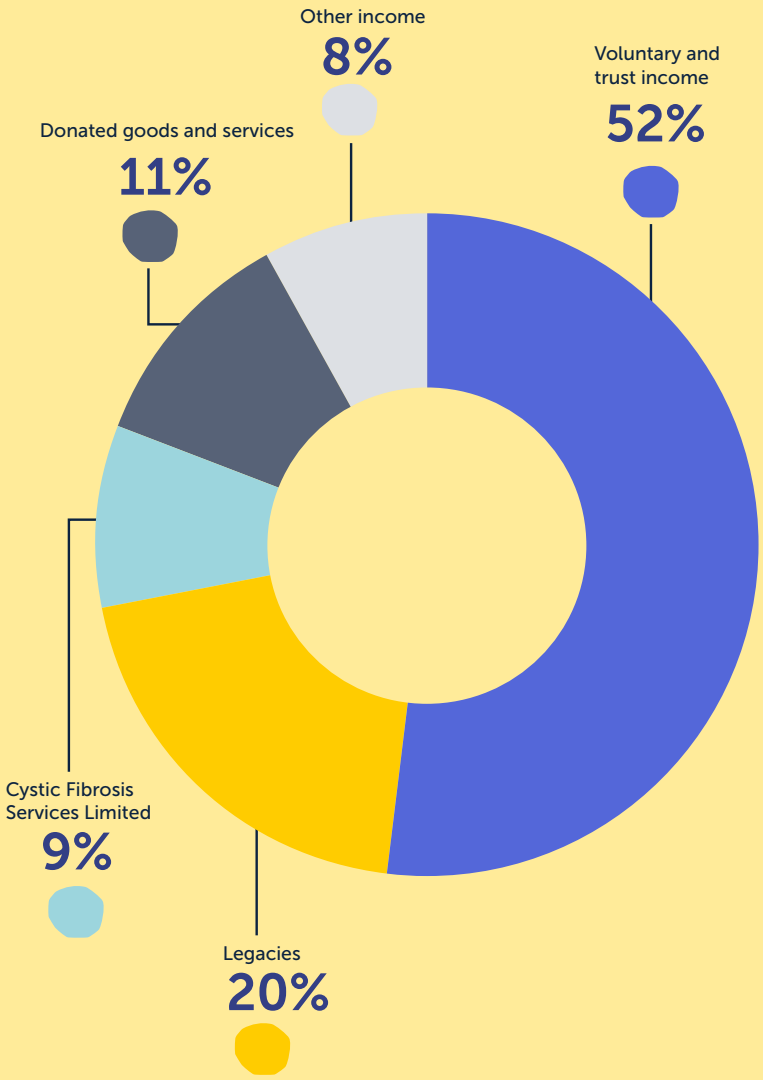
In addition, Legacy and In Memory income of £2.9m (2023: £1.2m) was raised which included several large gifts in wills. Income in the prior year was impacted by pressures in the housing market, meaning property left in estates was difficult to sell, and by processing delays at the Probate Office. The additional income in 2023/24 reflects some reduction in these pressures.

We benefit from generous corporate donations in kind including outdoor advertising and advice supporting our campaigns. The value of these services was £1.5m (2023: £1.2m). The corresponding cost value of this donation is shown included in charitable expenditure as part of the information, advice and support costs.

Income generated by Cystic Fibrosis Services Ltd ("CFSL"), the Trust's trading subsidiary, was £1.3m (2023: £2.9m). This income is mainly generated from contracts with pharmaceutical companies for our UK CF Registry to produce study reports for the regulators of medicinal products. Several contracts came to an end at the beginning of the financial year. Confirmation of the NICE approval of Kaftrio in 2024 and the pipeline of potential new treatments is likely to lead to new studies being commissioned and we expect revenues will increase over the next two years.

Other income of £0.3m in the year (2023: £1.1m) includes recoverable VAT. In the prior year the Trust received £1.0m income from a revenue share agreement with the Gene Therapy Consortium.

Income 2023/24



Expenditure

The Trust's total expenditure for the year was £15.1m, a £2.3m increase compared to the previous year.

Expenditure on charitable activities in the year was £12.0m (2023: £9.5m). This includes funding research, providing information and advice and support and supporting clinical care. The increase in expenditure is mainly grants to support research.

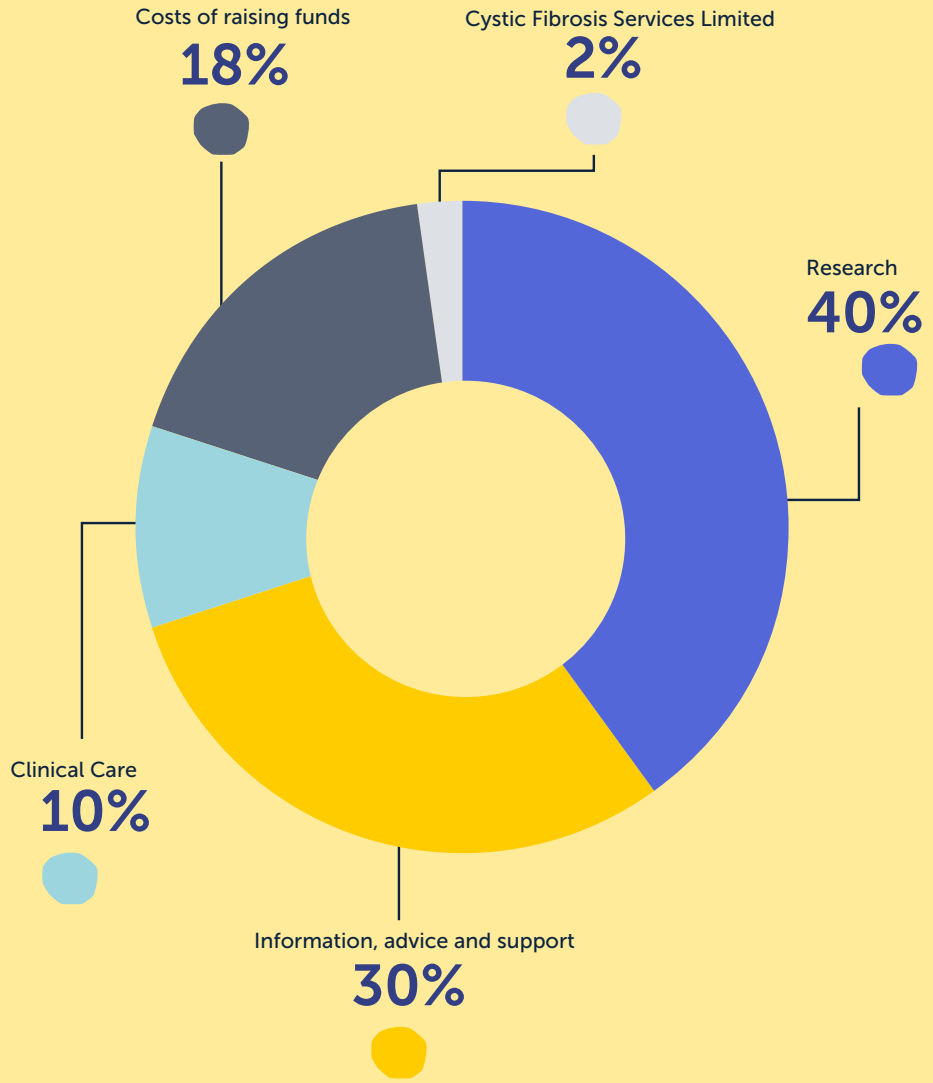
Grants to support charitable activities include:

- £3.9m (2023: £2.0m) grants to a range of medical, academic and charitable institutions to support research. The Trust continues to seek funding and co-funding to enable it to increase funding for this vital research. The Trust also reviewed grants made in previous years where there has been no recent activity, and this resulted releasing £0.3m (2023: £nil) made in previous years
- £0.4m (2023: £1.0m) to fund the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme
- £0.3m (2023: £0.6m) grants to CF Centres to fund data collection for the Registry
- £0.3m (2023: £0.3m) to individuals through our Welfare Grant programme

(The total grants awarded are detailed in Note 5 to the financial statements).

The cost of raising funds was £3.07m (2023: £3.32m) and includes direct fundraising costs of £2.73m (2023: £2.65m) and the costs of CFSL of £0.34m (2023: £0.67m). CFSL costs include UK CF Registry Support grants.

Expenditure 2023/24



Investment policy

The Finance Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to adopt a balance between generating a sufficient income to support the on-going activities of the Trust, whilst maintaining the real capital value of the investments over the long-term.

The majority of the general fund portfolio is kept in liquid Funds although there is some exposure to less liquid assets such as property. Approximately 83% of the portfolio is now invested in the Responsible Multi-Asset Fund which aims to have a positive impact on people and the planet by avoiding harm through environmental, social, and governance integration and exclusions, benefiting stakeholders through responsible business activities and contributing to solutions through influence and investing for impact. The Trust does not permit direct investment in tobacco.

A number of small endowment funds are invested on a total return basis, enabling the Trust to utilise both income generated by the funds and increases in capital value, while protecting the original inflation-adjusted endowment values.

We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance Committee.

Review of investments in the year

The value of the investment portfolio (including endowment funds) was £5.8m as at 31 March 2024 (2023: £5.4m). This increase of £0.4m is mainly due to investment gains in year.

No change was made to the allocation between amounts held as stocks and shares and that held as cash. Income generated on investments totalled £0.6m which is £0.3m more than in 2023 and reflects increased interest rates compared to prior year.

Reserves

The Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, at a level that mitigates the risks associated with fluctuations in fundraised income and cost pressures and ensure funds are available to maintain operational activity and invest in key strategic areas to support future impact and growth.

The Board believes an appropriate level of reserves is in the range of above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £4m and £6m.

At 31 March 2024, after adjusting for the designated reserves explained below, the Trusts' Unrestricted Reserves were £8.7m (2023: £8.6m). This level reflects the impact of a number of exceptional items in recent years which have acted to limit the impact of deficits from core activities.

The Trustees have approved a business plan and substantial deficit budget for the next financial year which maintains services and grant awards at a level similar to previous years despite the continued challenge of the wider economic climate and therefore Unrestricted reserves are forecast to fall to £7.5m at March 2025 and reduce further to £5.9m by March 2026 which will bring the Trust within the range detailed in its reserves policy.

The Trustees have opted to designate unrestricted reserves for the following purposes:

- Organisational reserve: £1.0m (2023: £1.0m) has been established for investment in process improvement and our digital/data strategy, including implementation of a new Customer Relationship Management (CRM) system and for the costs associated with moving to a new office in early 2025.
- Fixed asset reserve of £0.13m (2023: £0.16m). The reserve is maintained as fixed assets cannot be readily realised as cash.

The trust also holds Endowment and restricted funds:

- Endowment funds – The Trust maintains a number of endowment funds where the donor require the Trustees to hold the funds as capital investments. Income from the investment can be used by the Trust as specified in the terms of the endowment. The Trust is not entitled to spend the capital fund without permission from the donor. At 31 March 2024 the endowment funds totalled £1.0m (2023: £1.0m). See note 21 for information about the individual endowments.
- Restricted funds – Restricted funds are to be used for specific uses specified by the donor. Expenditure which meets the donor's criteria is charged against the specific fund. At 31 March 2024 restricted funds totalled £0.5m (2023: £0.7m). Note 22 lists the individual restricted funds and their movement in the year.

Total reserves at 31 March 2024 were £11.3m (2023: £11.4m).

The Trustees will continue to keep the Trusts' reserves policy under regular review to ensure it is set at the appropriate level to reflect changes in the business outlook as they materialise.

Principal risks and uncertainties

The Board of Trustees is responsible for ensuring effective risk management and internal controls to manage the major risks the Trust faces, including agreeing the Trust's 'risk appetite' (how much risk the Trust is willing to tolerate in key areas) and keeping oversight of the Trust's risk management framework. This framework, managed by the Senior Leadership Team, includes a Strategic Risk Register and provides a consistent approach to identifying, assessing and dealing with the risks facing the Trust. It is monitored at least quarterly to support informed decision-making and ensure appropriate mitigations and controls are in place to effectively manage any risks to our objectives.

The main strategic risks and uncertainties that management and Trustees have identified and the key actions to mitigate these risks are:

Strategic risk	Strategies/plans for managing risks
Relevance	
• Failure to be relevant and responsive to the needs and expectations of people with cystic fibrosis and our wider community, could damage our reputation and ability to deliver our objectives • Failure to get our message across means we might not be seen as relevant and will not reach widest possible audience • Failure to Influence key external stakeholders and decision makers could impede our ability to deliver on our strategy and erode our relevance in eyes of the community	• Our strategies and work programmes reflect the views and priorities expressed by people with cystic fibrosis through consultation, involvement and co-design • We are developing a new Equity Diversity and Inclusion Strategy to ensure relevance to all stakeholders across community • Audience insight research analysis was completed in 2024 and we are implementing the findings • We continually develop strategies on emerging priorities, including Air Quality, Housing, Poverty, CF Care resourcing, and benefits & welfare reform • Our close links with the community, and ability to listen and closely monitor discussions and sentiment, gives us early warning on many emerging community priorities/issues

Strategic risk	Strategies/plans for managing risks
Financial	
• Failure to operate a sustainable financial model could heavily compromise the Trust's operational viability and its ability to deliver for people with cystic fibrosis	• The strategic financial framework and budget for 2024/25 and beyond includes measures to closely track income and expenditure and is scrutinised by the Finance Committee • We have commissioned an external broad review of Fundraising and will implement changes based on this. • We continue to have a strong focus on business development and partnerships in research and other areas • Our business planning has strong focus on prioritisation, and additional cost savings are actively explored • Our plans ensure that we will maintain unrestricted retained reserves within policy

Strategic risk	Strategies/plans for managing risks
Data • Failure to optimise our use of and adequately protect our data will limit our impact, reach, income and relevance, and harm our reputation if it falls into the wrong hands	• We have a GDPR compliance framework, Data Protection Policies and DPO. There is ongoing staff training and oversight from Data Governance Group • We have implemented a data strategy with the focus on three strands: upgrading our CRM, ensuring data quality and ensuring we have a data-centric culture • In the last year we have made improvements to our data security including access controls (multifactor authentication) and further automated monitoring and reporting
People • Failure to deliver People Strategies that effectively support, protect, and develop our staff and volunteers will erode our ability to recruit and retain highly skilled and motivated staff and could have significant reputational impact.	• We have a comprehensive range of policies in place covering welfare, safeguarding, recruitment and retention, learning and development and employee benefits. These are reviewed and updated regularly with external professional support. • There is a strong communications, feedback and learning processes in place (CEO briefings, staff survey, elected employee reps, exit interviews).

Strategic risk	Strategies/plans for managing risks
Autonomy • Failure to maintain autonomy in relationships with pharmaceutical, academic institutions and funding partners may harm our reputation	• Our governance processes include systematic declaration of interests, conflict of interest guidelines and robust research governance and awards processes • Partnership working and ethical policies are in place defining criteria for establishing new partnerships to ensure risk is considered

Processes in place regarding risk management and internal control include the following:

- A risk management framework that meets the Charity Commission's requirements. A top-down risk review by the Senior Leadership Team, and a bottom-up review by individual functions, is undertaken throughout the year and the risks identified through this process are documented in a risk register.
- The Finance Committee receives reports from the external auditors on the effectiveness of controls and, where appropriate, adopts the recommendations made in the external auditors' reports.
- The Board of Trustees receives a comprehensive risk management report each quarter to assist it in ensuring that an effective process is in place. This report provides an update on the risk reviews undertaken and provides the Board with the opportunity to engage in dialogue about, and to provide input into, the evaluation and management of key risks.
- Formal project delivery groups are established for major projects and programmes to ensure that these are carefully planned, managed and implemented.

Our work with the pharmaceutical industry

Our mission is to make sure everyone can live without the limits of cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

Partnerships between medical research charities and the life sciences industry can help us deliver that mission and bring huge benefits to patients including accelerating the development of new drugs and ensuring the safety and improvement of existing treatments.

We run the following flagship programmes involving pharmaceutical industry partners:

Clinical Trials Accelerator Platform

Clinical Trials Accelerator Platform (CTAP) is a UK-wide initiative bringing together CF centres to increase participation and access to CF clinical trials. This initiative is building infrastructure and funding additional research capacity to support the life sciences industry with clinical trial delivery.

As part of our collaboration with industry, CTAP offers a centralised feasibility service to support pharmaceutical companies with identification of suitable CF centres for clinical trial delivery.

Venture & Innovation Awards (VIAs)

VIAs support transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the life sciences industry.

The UK Cystic Fibrosis Registry

Long-term safety and efficacy studies of drugs available to people with CF across the UK are supported by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the regulators of medicinal products is covered by pharmaceutical companies holding the market authorisation for these medicines. You can read more about our work with industry to make medicines safer at **cysticfibrosis.org.uk/registry**.

In 2023/24 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £1.3m (2023: £2.9m) in fees for this service. This income was used to support and maintain the Registry, including staff costs, data collection through Centre grants and IT hosting and development.



Sponsorship and donations

We seek sponsorship and grants from partners that include other charities and pharmaceutical companies to enable us to run events so important for both healthcare professionals and people affected by cystic fibrosis. These events enable us to keep these audiences informed on all aspects of clinical care and research.

We would like to thank LifeArc, Vertex, Nordic Pharma and Optic 11 Life sponsorship for the UK Cystic Fibrosis Conference (UKCFC) held in October 2023. We also received sponsorship from Vertex for the Annual Registry Meeting held in October 2023.

The Trust organised the UK CF Clinical Trials Conference in March 2024 at the Royal Armouries Museum in Leeds. We again received an Independent Medical Education (IME) grant from Vertex towards the cost of the event along with sponsorship support from Recode Therapeutics.



> "Enjoy your newborn and keep planning that big, bright future you want for them."
>
> Jade, mum to Penelope, age 7



Jade and Penelope, who has CF

Statement of Trustees' responsibilities

The Trustees, who are also directors of the Cystic Fibrosis Trust for the purposes of company law, are responsible for preparing the Trustees' report (including the Group Strategic Report) and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group, and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently,
- observe the methods and principles in the Charities SORP,
- make accounting estimates that are reasonable and prudent,
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustees investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware,
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustee's Report incorporating the Strategic Report was approved and authorised for issue by the Board of Trustees on **29 October 2024** and signed on its behalf by:



Richard Hunt, Chairman

Independent auditor's report to the members and trustees of Cystic Fibrosis Trust

Opinion

We have audited the financial statements of Cystic Fibrosis Trust (the 'charitable parent company') and its subsidiary (the 'group') for the year ended 31 March 2024 which the comprise the consolidated statement of financial activities, consolidated income and expenditure account, the consolidated and charitable parent company balance sheets and statement of cash flows, the principal accounting policies and the notes to the financial statements. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the charitable parent company's affairs as at 31 March 2024 and of the group's income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group and charitable parent company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report and financial statements, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the charitable parent company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the charitable parent company or to cease operations, or have no realistic alternative but to do so.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report, which is also the directors' report for the purposes of company law and includes the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements; and

- the trustees' report, which is also the directors' report for the purposes of company law and includes the strategic report, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the charitable parent company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept by the charitable parent company, or returns adequate for our audit have not been received from branches not visited by us; or

- the charitable parent company financial statements are not in agreement with the accounting records and returns; or

- certain disclosures of trustees' remuneration specified by law are not made; or

- we have not received all the information and explanations we require for our audit.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- The engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulation;
- We identified the laws and regulations applicable to the charitable parent company and group through discussions with key management;
- We focused on specific laws and regulations which we considered may have a direct material effect on the accounts or the activities of the charitable parent company and group; and
- We assessed the extent of compliance with the laws and regulations identified above through making enquiries of key management and review of minutes of trustees' meetings.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the trustees and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Shachi Blakemore (Partner)
For and on behalf of Buzzacott LLP, Statutory Auditor

130 Wood Street,
London
EC2V 6DL

Date: 30 October 2024

Cystic Fibrosis Trust

Consolidated statement of financial activities

For the year ending 31 March 2024

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2024 £'000**	Total Funds 2023 £'000
Income and endowments from:						
Donations and legacies	2	8,715	3,687	-	**12,402**	10,417
Charitable activities						
Other trading activities		1,304	-	-	**1,304**	2,873
Investments	3	628	-	-	**628**	279
Other income		332	-	-	**332**	1,097
Total income		10,979	3,687	-	**14,666**	14,666
Expenditure on:						
Raising funds	4	3,068	6	-	**3,074**	3,322
Charitable activities						
Research	4	4,075	2,008	-	**6,083**	3,766
Clinical care	4	655	822	-	**1,477**	1,947
Information, advice and support	4	4,082	378	-	**4,460**	3,737
Total charitable activities		8,812	3,208	-	**12,020**	9,450
Total resources expended	4	11,880	3,214	-	**15,094**	12,772
Net income/(expenditure) before investment gains/(losses)		**(901)**	**473**	**-**	**(428)**	1,894
Realised investment (losses)/gains		(2)	-	-	**(2)**	(32)
Unrealised investment (losses)/gains		353	-	60	**413**	(176)
Net investment (losses)/gains		**351**	**-**	**60**	**411**	(208)
Net income/(expenditure)		**(550)**	**473**	**60**	**(17)**	**1,686**
Transfers between funds	20	679	(679)	-	**-**	-
Net movement in funds		129	(206)	60	**(17)**	1,686
Reconciliation of funds:						
Total funds brought forward		9,711	674	972	**11,357**	9,671
Total funds carried forward	20	**9,840**	**468**	**1,032**	**11,340**	11,357

All of the operations are continuing.

There were no recognised gains or losses other than those stated above.

A prior year comparative consolidated statement of financial activities has been included in the notes to the accounts (note 23).

The notes on pages 82 to 105 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated and charity balance sheets

For the year ending 31 March 2024

	Notes	Consolidated		Charity	
		Total 2024 £'000	Total 2023 £'000	**Total 2024 £'000**	Total 2023 £'000
Fixed assets					
Tangible assets	7	**132**	155	**132**	155
Investments	8	**5,796**	5,388	**5,796**	5,388
		5,928	5,543	**5,928**	5,543
Current assets					
Debtors	9	**5,076**	6,589	**5,041**	5,396
Cash held as short term investment		**12,024**	11,485	**12,024**	11,485
Cash at bank and in hand		**4,046**	3,430	**4,036**	2,734
		21,146	21,504	**21,101**	19,615
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	10	**(6,065)**	(2,799)	**(6,065)**	(2,799)
Creditors and accrued charges	11	**(2,772)**	(2,257)	**(3,625)**	(2,500)
		(8,837)	(5,056)	**(9,690)**	(5,299)
Net current assets		**12,309**	16,448	**11,411**	14,315
Creditors: amounts falling due after one year					
Grants payable	10	**(6,727)**	(10,464)	**(6,727)**	(10,464)
Provisions: amounts falling due after one year	15	**(170)**	(170)	**(170)**	(170)
Total net assets		**11,340**	11,357	**10,442**	9,224

Continued on the next page

Cystic Fibrosis Trust

Consolidated and charity balance sheets (continued)

For the year ending 31 March 2024

	Notes	Consolidated		Charity	
		Total 2024 £'000	Total 2023 £'000	**Total 2024 £'000**	Total 2023 £'000
The funds of the charity:					
Endowment funds	21	**1,032**	972	**1,032**	972
Restricted income funds	22	**468**	674	**468**	674
Unrestricted funds					
Designated reserves					
Organisational reserves	20	**1,000**	1,000	1,000	1,000
Fixed asset reserve	20	**132**	155	132	155
Total designated funds		**1,132**	1,155	**1,132**	1,155
Retained reserves		**8,708**	8,556	**7,810**	6,423
Total unrestricted funds		**9,840**	9,711	**8,942**	7,578
Total charity funds	20	**11,340**	11,357	**10,442**	9,224

The notes on pages 82 to 105 form part of these financial statements.
As permitted by Section 408 of the Companies Act 2006, no separate Statement of Financial Activities or Income and Expenditure account has been presented for the charity alone.

Approved and authorised for issue by the Trustees on **29 October 2024** and signed on their behalf by:



Richard Hunt, Chairman
Company number 3880213

Cystic Fibrosis Trust

Consolidated Statement of cash flows

For the year ending 31 March 2024

	2024 £'000	2023 £'000
Net cash provided by/(used) operating activities (Note A)	**565**	(1,669)
Cash flows from investing activities:		
Dividends and interest	**628**	279
Purchase of property, plant and equipment	**(41)**	(161)
Purchase of investments	**(255)**	(417)
Movement in cash awaiting investment	**(21)**	(16)
Proceeds of sales of investments	**279**	437
	590	122
Increase in cash held as short term investments	**(539)**	(220)
Increase/(decrease) in cash (Note B)	**616**	(1,767)

No separate reconciliation has been prepared between the movements in net debt of the charity as there is no difference between the movements in cash and cash equivalents and the net cash (debt) of the charity.

Notes to cash flow statement

Note A – Reconciliation of net income to net cash flow from operating activities

	2024 £'000	2023 £'000
Net income for the reporting period (as per the statement of financial activities)	**(17)**	1,686
Adjustment for:		
Depreciation charges	**64**	25
Dividends and interest from investments	**(628)**	(279)
(Gains)/losses on investments	**(411)**	208
Decrease/(increase) in debtors	**1,513**	(2,641)
Increase/(decrease) in creditors	**44**	(838)
Increase in provisions	**-**	170
Net cash provided by/(used in) operating activities	**565**	(1,669)

Note B – Reconciliation of cash and cash equivalents in the reporting period

	2024 £'000	2023 £'000
Cash and cash equivalents at the beginning of the reporting period	**14,915**	16,462
Change in cash and cash equivalents in the reporting period	**616**	(1,767)
Increase in short-term investments	**539**	220
Cash and cash equivalents at the end of the reporting period (being cash at bank and in hand and cash held as short-term investments)	**16,070**	14,915

	2024 £'000	2023 £'000
Analysis of cash and cash equivalents:		
Notice deposits (less than 3 months)	**12,024**	11,485
Cash at bank and in hand	**4,046**	3,430
Total cash and cash equivalents	**16,070**	14,915

Cystic Fibrosis Trust
Notes to the Financial Statements
For the year ending 31 March 2024

1. Accounting policies

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

Basis of preparation
The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) (Charities SORP FRS 102), and the Companies Act 2006.

Cystic Fibrosis Trust meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Charity status
The Trust (charity registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 106. In the event of the company being wound up, each member is liable for a sum not exceeding £1.

Consolidation
The financial statements include the results and assets and liabilities of the Trust and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own statement of financial activities under section 408 of Companies Act 2006. The surplus of the parent charity was £853,000 (2023: £1,496,000).

Cystic Fibrosis Services Limited's results for the year ended 31 March 2024 are summarised in note 13. The net surplus for the year of £899,000 (2023; £2,134,000) will be donated in full to the parent charity after the year end.

Income
All income is recognised once the Trust has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably.

Donations and income from legacies are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable. Donations in kind are non-monetary donations received by the Trust. Income, and the corresponding cost of the donation, is recognised when the service is provided. The value of the income and expenditure is the estimated fair market value of the service provided.

Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

Interest on funds held on deposit is recognised in the statement of financial activities when receivable and the amount can be measured by the Trust. This is normally upon notification of the interest paid or payable by the bank.

Investment income is recognised on a receivable basis and the amounts can be measured reliably. Dividends are recognised once the dividend has been declared and notification has been received the dividends are due.

1. Accounting policies (continued)

Expenditure
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the Trust to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably.

Expenditure is recognised on an accruals basis as a liability is incurred and includes irrecoverable VAT where applicable.
Expenditure is classified under the following activity headings:

- Expenditure on raising funds comprises those costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs.

- Expenditure on charitable activities comprises those costs relating to activities where the primary aim is congruent with the objects of the Trust, along with an apportionment of support costs. This includes grants made to research institutions and individuals, the provision of information and support services to people with cystic fibrosis and their families, peer reviews of cystic fibrosis centres and the development of the CF Registry.

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the direct costs in each activity category.

Grants payable are included in the statement of financial activities when approved and the intended recipient has either received the funds or has been notified of the award and has satisfied any initial conditions. Grants approved but not paid at the end of the financial year are accrued.

Foreign currency transactions
Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the statement of financial activities.

Employee benefits
Employee benefits are accounted for as follows:

- Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.
- Termination payments are accounted for on an accrual basis and in line with FRS 102.
- Pension contributions: the Trust operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Trust pays fixed contributions into a separate entity. Once the contributions have been paid the Trust has no further payment obligations. The contributions are recognised as an expense in the statement of financial activities when they fall due.

Taxation
No charge to taxation arises on the result for the year because the Trust can take advantage of the tax exemptions available to charities.

Leases
The Trust recognises expenses under ‘operating leases’ relating to capital equipment which it does not own. The annual rentals are charged to the statement of financial activities on a straight line basis over the lease term.

1. Accounting policies

Fund accounting
Endowment Funds are funds where the donor requires the Trust to hold the funds as capital investments. Income from the investment can be used by the Trust as specified in the terms of the endowment. The Trust is not entitled to spend the capital fund without permission from the donor.

Restricted funds are to be used for specific uses laid down by the donor. Expenditure which meets the donor's criteria is charged against the specific fund.

Unrestricted funds are those which the Trust are free to use for any purpose in furtherance of the charitable objects. The Trustees may set aside some of the unrestricted reserves for specific purposes, for example to fund a future project. These funds are classified as designated funds.

Fixed assets and depreciation
All assets costing £500 or more and with an expected useful life exceeding one year are capitalised.

Tangible assets are stated in the balance sheet at cost less accumulated depreciation. Depreciation is provided at rates designed to write off the cost of the cost of the assets, less any residual value, by equal annual instalments over their estimated useful lives at the following rates:

Furniture & fittings	33%
Computer hardware	33%
Computer software	33%
Website development	33%
Platform development	50%

Website and platform development costs are capitalised on the basis that they lead to an asset that will generate funds for the Trust or where the primary aim is part of the objects of the Trust. The assets are depreciated once the asset is ready for use.

Investments
Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values of investments are shown as unrealised gains and losses in the statement of financial activities. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value.

Gains and losses on the sale of investments are shown as realised gains and losses in the statement of financial activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired during the financial year.

1. Accounting policies (continued)

Financial Instruments
The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value:

- Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

- Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

- Creditors and provisions are recognised where the Trust has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Critical accounting judgements and estimates
Preparation of the financial statements requires the Trust and management to make significant judgements and estimates. These judgements and estimates are continually evaluated and are based on historical experience and other factors, including expectations of future events.

The items in the financial statements where judgements and estimates have been made include:

- estimating entitlement to legacy income particularly in relation to complex estates
- estimating the useful economic life of tangible assets for the purposes of determining depreciation rates
- providing for bad debts
- allocation of support costs
- estimating future income and expenditure for assessing cash flows to assess whether the Trust is a going concern (see below).

The value of the contribution of the many thousands of hours donated by its unpaid volunteers as not been reflected in these financial statements. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

Going concern
The Trustees have reviewed the financial statements and supplementary financial information, including forecasts and projections to the year ending 31 March 2028, and conclude that the Trust will continue to operate within or above its reserves policy throughout that period and that the Trust is a going concern.

2. Income from donations and legacies

	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	Total 2024 £'000	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	Total 2023 £'000
Branches, Groups and Community	2,224	45	**2,269**	2,147	44	2,191
Legacies	2,745	196	**2,941**	1,240	3	1,243
Individual donations	309	40	**349**	383	74	457
Corporate	267	5	**272**	149	51	200
Regular giving and appeals	1,204	2	**1,206**	1,232	2	1,234
Trusts	187	3,093	**3,208**	13	3,056	3,069
Appeal for Innovation Hub	-	306	**306**	-	610	610
Donations in kind	1,543	-	**1,543**	1,234	-	1,234
NHS National Services England and Scotland	236	-	**236**	179	-	179
Total income from donations and legacies	8,715	3,687	**12,402**	6,577	3,840	10,417

Total income from donations and legacies includes gift aid of £455,000 (2023: £411,000).

Donations in kind refer to non-monetary donations received from partner organisations. In 2024 £1,543,000 (2023: £1,234,000) was donated in the form of digital and cinema advertising space and professional fees. This was used to raise awareness of cystic fibrosis and the work of the Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, advice and support costs in note 4 below.

3. Investment Income

	Unrestricted Funds 2024 £'000	Restricted Funds 2024 £'000	**Total 2024 £'000**	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	**Total 2023 £'000**
Income from listed investments	607	-	**607**	279	-	279
Bank interest	21	-	**21**	-	-	-
Total investment income	628	-	**628**	279	-	279

4. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2024 £'000**	**Total 2023 £'000**
Raising funds						
Fundraising	-	-	2,297	438	**2,735**	2,649
Trading and merchandising	-	326	13	-	**339**	673
Total raising funds	-	326	2,310	438	**3,074**	3,322
Charitable activities						
Research	1,976	1,636	1,499	972	**6,083**	3,766
Clinical care	454	77	711	235	**1,477**	1,947
Information, advice and support	149	167	3,432	712	**4,460**	3,737
Total charitable activities	2,579	1,880	5,642	1,919	**12,020**	9,450
Total resources expended	**2,579**	**2,206**	**7,952**	**2,357**	**15,094**	12,772

Support costs are apportioned based on the direct costs in each activity category.

4. Expenditure (continued)

Analysis of allocated Support Costs – current year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	Total 2024 £'000	Total 2023 £'000
Fundraising	108	42	128	59	101	**438**	**431**
Research	240	93	285	130	224	**972**	**638**
Clinical care	58	22	69	32	54	**235**	**318**
Information, advice and support	176	68	208	96	164	**712**	**609**
Total costs	**582**	**225**	**690**	**317**	**543**	**2,357**	**1,996**

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	Total 2023 £'000
Raising funds					
Fundraising	-	-	2,218	431	**2,649**
Trading and merchandising	-	609	64	-	**673**
Total raising funds	-	609	2,282	431	**3,322**
Charitable activities					
Research	601	1,345	1,182	638	**3,766**
Clinical care	999	58	572	318	**1,947**
Information, advice and support	164	103	2,861	609	**3,737**
Total charitable activities	1,764	1,506	4,615	1,565	**9,450**
Total resources expended	**1,764**	**2,115**	**6,897**	**1,996**	**12,772**

4. Expenditure (continued)

Analysis of allocated support costs – prior year

	Governance £'000	Finance £'000	IT Support £'000	People & Organisational Development £'000	HQ & Facilities £'000	**Total 2023 £'000**
Fundraising	41	59	140	60	131	**431**
Research	61	87	207	89	194	**638**
Clinical care	30	44	103	44	97	**318**
Information, advice and support	58	84	197	85	185	**609**
Total costs	190	274	647	278	607	**1,996**

Net income for the year is stated after charging

	2024 £'000	2023 £'000
Auditors remuneration excluding VAT	**29**	28
Depreciation	**64**	25
Operating leases – building	**269**	271
Operating leases – other	**3**	7
Trustees' travel expenses	**1**	2

5. Grants

Grants were awarded during the year as follows:

	2024 £'000	2023 £'000
Grants to institutions	**4,453**	3,565
Grants to individuals	**332**	414
	4,785	3,879

Grants made to, and for, individuals affected by Cystic Fibrosis are for expenses such as respite care, building adaptations and equipment rental. These grants benefited a large number of individuals throughout the Trust's network of regions and branches.

During the year, grants were awarded to the following institutions:

	2024 £'000	2023 £'000
University of Cambridge	1,210	121
Imperial College London / Royal Brompton Hospital	1,116	100
Newcastle University	850	20
University of Liverpool	182	17
Action Medical Research	105	-
Innovation Hub Cambridge	100	241
Medical Research Council	100	50
Utrecht University, Netherlands	75	-
UCL	50	-
Medicines Discovery Catapult Limited	42	81
OmniSpirant Limited	21	-
Leeds Beckett University	21	-
Queen's University Belfast	8	26
University of Nottingham	-	115
UCL Great Ormond Street	-	46
University of Sheffield	-	753
Cystic Fibrosis Canada (Fibrose Kystique)	-	116
Royal College of Surgeons in Ireland	-	96
MDC (CF AMR Syndicate)	-	20
Western General Hospital	-	78
Medusa Pharmaceuticals	-	50
Ockham Biotech Limited	-	50
Other Institutions (less than £20k)	68	28
	3,948	2,008
Trial Coordinator commitments made to CTAP centres (see note)	436	953
Registry support grants made to various CF centres	326	609
Release of grants made in previous years (see note below)	(257)	(5)
Total grants made to institutions	**4,453**	3,565

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme.

Various grants totalling £257,000 (2023: £5,000) were released during the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful.

6. Staff costs

	2024 £'000	2023 £'000
Salaries	**5,107**	4,481
Temporary Staff	**23**	80
Social security costs	**547**	493
Other pension costs	**318**	270
	5,995	5,324

The average number of staff employed by the Trust:

	2024 No.	2023 No.
Research	**22**	17
Clinical care	**8**	8
Information, advice and support	**43**	38
Fundraising	**38**	36
Management	**2**	2
Finance	**6**	6
IT and project management support	**8**	8
HR and organisation development	**6**	5
Facilities	**1**	1
Total average monthly headcount	**134**	121

The number of employees whose gross salary exceeded £60,000 in the year was:

	2024 No.	2023 No.
£60,001 – £70,000	**4**	1
£70,001 – £80,000	**3**	2
£80,001 – £90,000	**1**	2
£120,001 – £130,000	**-**	1
£130,001 – £140,000	**1**	-

Pension contributions to defined contribution pension schemes for employees noted above totalled £44,083 (2023: £33,525).

The total remuneration paid to key management personnel, including social security and employer pension contributions, was £657,196 which relates to 8 individuals who served on the Senior Leadership Team during the year (2023: £621,941 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. £1,201 of expenses were settled on behalf of 5 Trustees (2023: £4,684 was paid to 5 Trustees) as meetings were held equally in person and remotely during the period.

7. Tangible and intangible assets

Group and charity	Furniture and fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 1 April 2023	**630**	**929**	**286**	**462**	**183**	**2,490**
Additions	-	41	-	-	-	41
Disposals	-	-	-	-	-	-
At 31 March 2024	**630**	**970**	**286**	**462**	**183**	**2,531**
Depreciation						
At 1 April 2023	**630**	**871**	**243**	**408**	**183**	**2,335**
Disposals	-	-	-	-	-	-
Charge for the year	-	33	11	20	-	64
At 31 March 2024	**630**	**904**	**254**	**428**	**183**	**2,339**
Net book value At 31 March 2024	**-**	**66**	**32**	**34**	**-**	**132**
At 31 March 2023	-	58	43	54	-	155

8. Investments

Group and Charity	Total 2024 £'000	Total 2023 £'000
Opening market value	**5,388**	5,604
Adjustment to brought forward balance	**-**	12
Additions at cost	**255**	417
Disposals at opening book value	**(230)**	(469)
Net gains/(losses) on investments	**362**	(192)
	5,775	5,372
Change in cash	**21**	16
Closing market value	**5,796**	5,388

Represented by:	Total 2024 £'000	Total 2023 £'000
Equities	**587**	589
Fixed Interest and multi-asset funds	**4,909**	4,513
Property	**184**	162
Cash	**116**	124
	5,796	5,388

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment.

The only asset that presents more than 5% of total investments in either financial year is the Responsible Multi-Asset Fund. The Trust's holding at 31 March 2024 was £4,809,000 (2023: £4,417,000).

The historical cost of investments held within the Trust portfolio at 31 March 2024 was £4,853,000 (2023: £4,853,000).

9. Debtors

	Group 2024 £'000	Group 2023 £'000	Charity 2024 £'000	Charity 2023 £'000
Trade debtors	**35**	1,225	**-**	32
Prepayments and accrued income	**4,981**	5,293	**4,981**	5,293
Other debtors	**60**	71	**60**	71
	5,076	6,589	**5,041**	5,396

10. Grants Payable

Group and charity	2024 £'000	2023 £'000
Opening grant creditor	13,263	13,654
Grants paid during the year	**(4,924)**	(5,827)
Trial Coordinator commitments made to CTAP centres and payable within one year	**436**	953
Registry support grants made to various CF Centres and payable after one year	**326**	609
Release of grants made in previous years	**(257)**	(5)
Research grants approved and payable within one year	**1,380**	2,792
Research grants approved and payable after one year	**2,568**	1,087
Closing grant creditor	**12,792**	13,263
Represented by		
Grants committed and awaiting claim		
Grants due within one year	**6,065**	2,799
Grants due after one year	**6,727**	10,464
	12,792	13,263

The Trust has considered the discounting of grant commitments due in more than one year but has not made any adjustments to the figures disclosed above as the impact of discounting is negligible.

11. Creditors

	Group 2024 £'000	Group 2023 £'000	Charity 2024 £'000	Charity 2023 £'000
Trade creditors	**857**	610	**857**	600
Other creditors	**41**	36	**41**	36
Other taxation and social security	**147**	137	**147**	137
Amounts owed to subsidiary undertaking	**-**	-	**932**	257
Accruals and deferred income	**1,727**	1,474	**1,648**	1,470
	2,772	2,257	**3,625**	2,500

12. Financial Instruments

	Group 2024 £'000	Group 2023 £'000	**Charity 2024 £'000**	Charity 2023 £'000
Financial assets measured at amortised cost	**16,109**	16,145	**14,224**	14,224
Financial assets measured at fair value	**5,796**	5,388	**5,796**	5,388
Financial liabilities measured at amortised cost	**(15,063)**	(15,338)	**(15,142)**	(15,352)
Net financial assets measured at amortised cost	**6,842**	**6,195**	**4,878**	**4,287**

The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Financial assets held at fair value include assets held as investments.

Financial liabilities measured at amortised cost include trade creditors, other creditors, accruals, grants payable, deferred income and amounts due to group undertakings.

13. Interest in subsidary undertaking

Cystic Fibrosis Services Limited is a company incorporated in England and Wales (company number 00900164) and is a wholly owned subsidiary of the Cystic Fibrosis Trust.

The subsidiary's activities include medical services, information and data system support and the merchandising of marketing materials.

Summary profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March 2024:

	Total 2024 £'000	Total 2023 £'000
Sales and sundry income	**1,304**	2,873
Cost of sales and administration	**(339)**	(673)
Intercompany recharges	**(66)**	(66)
Net contribution to parent charity	**899**	2,134

13. Interest in subsidary undertaking (continued)

	Total 2024 £'000	Total 2023 £'000
Current assets		
Debtors	**968**	1,450
Cash at bank	**10**	696
	978	2,146
Creditors: amounts falling due within one year	**(79)**	(12)
Net assets	**899**	2,134
Capital and reserves		
Called up share capital (£2)	**-**	-
Profit and loss account	**899**	2,134
Shareholder's funds	**899**	2,134

The Trust owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd which comprises 100 ordinary shares of £1 each. Two shares have been allotted, which are called up and fully paid.

The subsidiary's profit for the year will be donated in full to the Cystic Fibrosis Trust after the year end.

14. Lease commitments

At 31 March, the Trust's future minimum operating leases payments relating to buildings were:

	Property		Equipment	
	2024 £'000	2023 £'000	**2024 £'000**	2023 £'000
Within one year	**271**	271	**2**	5
Between two and five years	**-**	271	**6**	18

Operating lease expenditure in the year is disclosed in note 4.

15. Provisions

The Trust's office at One Aldgate, London is under a lease that expires on 31 March 2025. Under the terms of the lease the Trust must restore the property to the condition prior to the Trust taking possession of the office. After seeking advice from surveyors, the Trust has maintained a provision of £170,000 (2023: £170,000) for this work.

16. Contingent assets

As at 31 March 2024, the charity had been notified of a further four residual and pecuniary legacies which have not been recognised as income in the Statement of Financial Activities as they do not meet the criteria detailed in the accounting policies. These legacies have an estimated value of £360,000 which has not been accrued.

17. Related party transactions

The group has taken advantage of the exception which is conferred by FRS102 Section 33.1A 'Related Party Disclosures' that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

Total donation income from the trustees in the period was £16,701 (2023: £11,911). In addition, 6 of the trustees (2023: 7 trustees) were involved in fundraising activities carried out by regional fundraising branches.

Five trustees claimed expenses totalling £1,201 in the year (2023: four trustees totalling £2,000). These expenses related to travel and subsistence.

18. Post balance sheet events

There were no post balance sheet events or contingent liabilities when the accounts were signed and authorised for issue.

19. Analysis of net assets between funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2024 £'000**
Tangible fixed assets	132	-	-	**132**
Investments	4,764	1,032	-	**5,796**
Current assets	20,678	-	468	**21,146**
Current liabilities	(8,837)	-	-	**(8,837)**
Liabilities due in more than one year	(6,727)	-	-	**(6,727)**
Provisions due in more than one year	(170)	-	-	**(170)**
	9,840	1,032	468	**11,340**

Prior year

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2023 £'000**
Tangible fixed assets	155	-		155
Investments	4,416	972	-	5,388
Current assets	20,830	-	674	21,504
Internal obligations	(5,056)	-	-	(5,056)
Current liabilities	(10,464)	-	-	(10,464)
Liabilities due in more than one year	(170)	-	-	(170)
	9,711	972	674	11,357

20. Current year fund movements summary

	Balance 31 March 2023 £'000	Investment Gains/(Losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
The funds of the charity						
Endowment funds (Note 21)	972	60	-	-	-	**1,032**
Restricted funds (Note 22)	674	-	3,687	(3,214)	(679)	**468**
Unrestricted funds						
Designated reserves						
Organisational reserve	1,000	-	-	-	-	**1,000**
Fixed asset reserve	155	-	-	-	(23)	**132**
Total designated funds	(1,155)	-	-	-	(23)	**1,132**
Retained reserves	8,556	351	10,979	(11,880)	702	**8,708**
Total unrestricted funds	**9,711**	**351**	**10,979**	**(11,880)**	**679**	**9,840**
Total charity funds	**11,357**	**411**	**14,666**	**(15,094)**	**-**	**11,340**

Movements in funds for prior periods are presented in note 24.

Designated Funds

- Organisational reserve: is designated for investment in process improvement and our digital/data strategy, including implementation of a new Customer relationship management (CRM) system and for the costs associated with moving to a new office in early 2025.
- The designated fixed assets reserve matches the net book value of the Trust's tangible fixed assets. These assets support the Trust's ongoing work and are not readily convertible to cash.

As explained on page 68, the Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, at a level that mitigates the risks associated with fluctuations in fundraised income and cost pressures and ensure funds are available to maintain operational activity and invest in key strategic areas to support future impact and growth.

The Board believes an appropriate level of reserves is in the range of above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £4m and £6m.

At 31 March 2024, after adjusting for the designated reserves explained below, the Trusts' Unrestricted Reserves were £8.7m (2023: £8.6m). This level reflects the impact of a number of exceptional items in recent years which have acted to limit the impact of deficits from core activities.

The Trustees have approved a business plan and substantial deficit budget for the next financial year which maintains services and grant awards at a level similar to previous years despite the continued challenge of the wider economic climate and therefore Unrestricted reserves are forecast to fall to £7.5m at March 2025 and reduce further to £5.9m by March 2026 which will bring the Trust within the range detailed in its reserves policy.

Transfers between funds

The following transfers were made between funds:

- A transfer was made to the Fixed asset reserve to match the current balance on Fixed Assets
- Other transfers were made between Retained reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been backfilled by restricted donations.

21. Endowment funds

	Balance 31 March 2023 £'000	Investment Gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Ena Bennie Endowment	491	32	-	-	-	**523**
EW Joseph Endowment	162	11	-	-	-	**173**
Joseph Levy Endowment	271	17	-	-	-	**288**
Sally Wrigley Memorial Fund	20	-	-	-	-	**20**
Other Endowment funds	28	-	-	-	-	**28**
Total endowment funds	**972**	**60**	**-**	**-**	**-**	**1,032**

Movements in funds for prior periods are presented in note 24.

The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.

- The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.
- The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home.
- The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education.

22. Restricted funds

	Balance 31 March 2023 £'000	Investment Gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Restricted Income Funds						
Appeal: Innovation hub at Cambridge	-	-	306	-	(306)	**-**
Restricted funds related to research						
Gene Therapy Research	-	-	3	(3)	-	**-**
General medical research	-	-	260	(260)	-	**-**
Sport England – Helping the active stay active	32	-	-	-	-	**32**
University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis	-	-	34	(34)	-	**-**
UCL Great Ormond Street Institute of children	-	-	20	(20)	-	**-**
SRC costed extensions	-	-	379	(379)	-	**-**
University of Sheffield: Pulmonary magnetic resonance imaging for CF	366	-	7	-	(373)	**-**
UK CF Infection Biorepository	-	-	213	(107)	-	**106**
Project Breathe	-	-	1,188	(1,146)	-	**42**
Queen's University Belfast: Developing a novel gene therapy platform	-	-	15	(15)	-	**-**
Life Arc	-	-	62	(38)	-	**24**
Quality Improvement Project	35	-	-	-	-	**35**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**437**	**-**	**2,181**	**(2,002)**	**(679)**	**243**

22. Restricted funds (continued)

	Balance 31 March 2023 £'000	Investment Gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2024 £'000**
Restricted funds related to Information and Support						
Joseph Levy/Education grants	11	-	41	(49)	-	**3**
Building Brighter Futures	16	-	-	(16)	-	**-**
Support services (inc. welfare grants)	93	-	212	(248)	-	**57**
Work Forwards (England)	13	-	83	(57)	-	**39**
Work Forwards (Scotland)	9	-	-	(5)	-	**4**
Helpline	-	-	5	(5)	-	**-**
Helen Barrett Bright Ideas Awards	-	-	3	(3)	-	**-**
Total funds related to Information and Support	**142**	**-**	**344**	**(383)**	**-**	**103**
Other funds						
Clinical Trials Accelerator Platform (CTAP)	-	-	804	(804)	-	**-**
CTAP Clinical Trials Conference	14	-	7	(16)	-	**5**
Gut symptoms	39	-	27	-	-	**66**
Carols by Candlelight	6	-	3	(4)	-	**5**
HDRUK2023-Improving Transparency of Processes	-	-	15	(5)	-	**10**
Other older funds	36	-	-	-	-	**36**
Total other funds	**95**	**-**	**856**	**(829)**	**-**	**122**
Total restricted funds	**674**	**-**	**3,687**	**(3,214)**	**(679)**	**468**

Movements in funds for prior periods are presented in note 24.

Restricted income funds are donations received during the year to support the Trust's commitment to contribute £3.5m to Cambridge University as part of the Innovation Hub flagship programme are recorded as restricted income funds. The funds are used to fund any additional commitments to the Innovation Hub made during the year.

Restricted funds related to research are donations relating to grant commitments made by the Trust to research institutions.

Restricted funds related to information and support are donations to fund activities supporting people with cystic fibrosis and their families. These include:

- **Joseph Levy Education grants** – funding people with cystic fibrosis in their education and studies.
- **Building Brighter Futures** – funding a youth programme supporting young people with cystic fibrosis. This fund is supported by BBC Children in Need.
- **Support Services** – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
- **Work Forwards (England)** – funding to support people with cystic fibrosis so that they can take advantage of opportunities, build new futures and strengthen their long-term financial resilience. This is supported by the National Lottery Community Fund.

23. Prior year consolidated statement of financial activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2023 £'000**
Income and endowments from:					
Donations and legacies	2	6,577	3,840	-	**10,417**
Charitable activities					
Other trading activities		2,873	-	-	**2,873**
Investments	3	279	-	-	**279**
Other income:		1,097	-	-	**1,097**
Total income		10,826	3,840	-	**14,666**
Expenditure on:					
Raising funds	4	3,301	21	-	**3,322**
Charitable activities					
Research	4	3,122	644	-	**3,766**
Clinical care	4	696	1,251	-	**1,947**
Information, advice and support	4	3,360	377	-	**3,737**
Total charitable activities		7,178	2,272	-	**9,450**
Total resources expended	4	10,479	2,293	-	**12,772**
Net income/(expenditure) before investment gains/(losses)		**347**	**1,547**	**-**	**1,894**
Realised investment gains/(losses)		(32)	(32)	-	**(32)**
Unrealised investment gains/(losses)		(102)	-	(74)	**(176)**
Net investment gains/(losses)		**(134)**	**(32)**	**(74)**	**(208)**
Net (expenditure)/income		**213**	**1,547**	**-**	**1,686**
Transfers between funds	23	1,144	(1,144)	-	**-**
Net movement in funds		1,357	403	(74)	**1,686**
Reconciliation of funds:					
Total funds brought forward		8,354	271	1,046	**9,671**
Total funds carried forward	**23**	**9,711**	**674**	**972**	**11,357**

24. Prior year movements in funds

Summary

	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
The funds of the charity:						
Endowment funds (note 21)	1,046	(74)	-	-	-	**972**
Restricted funds (note 22)	271	-	3,840	(2,293)	(1,144)	**674**
Unrestricted funds:						
Designated reserves						
Organisational reserve	-	-	-	-	1,000	**1,000**
Fixed asset reserve	19	-	-	-	136	**155**
Appeal deficit	(1,285)	-	-	-	1,285	**-**
Total designated funds	(1,266)	-	-	-	2,421	**1,155**
Operating reserves	3,411	-	-	-	(3,411)	**-**
Retained reserves	6,209	(134)	10,826	(10,479)	2,134	**8,556**
Total unrestricted funds	**8,354**	**(134)**	**10,826**	**(10,479)**	**1,144**	**9,711**
Total chairty funds	**9,671**	**(208)**	**14,666**	**(12,772)**	**-**	**11,357**

Endowment funds

	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2023 £'000
Ena Bennie Endowment	530	(39)	-	-	-	491
EW Joseph Endowment	175	(13)	-	-	-	162
Joseph Levy Endowment	293	(22)	-	-	-	271
Sally Wrigley Memorial fund	20	-	-	-	-	20
Other endowment funds	28	-	-	-	-	28
Total endowment funds	**1,046**	**(74)**	**-**	**-**	**-**	**972**

24. Prior year movements in funds (continued)

Restricted funds

	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
Restricted income funds						
Appeal: Innovation Hub at Cambridge	-	-	1,270	(241)	(1,029)	**-**
Restricted funds related to research:						
Genetic therapies	-	-	3	-	(3)	**-**
General medical research	-	-	34	(34)	-	**-**
Sport England – Helping the active stay active	7	-	25	-	-	**32**
Imperial SRC: *Pseudomonas aeruginosa*	-	-	10	-	(10)	**-**
SRC013-M GRAY Newcastle	-	-	1	-	(1)	**-**
Sheffield SRC: Gastrointestinal cancer	-	-	57	-	(57)	**-**
UCL/GOSH SRC: Therapeutic gene editing	-	-	16	-	(16)	**-**
SRC022 – Co Funded with CFF	-	-	-	-	-	**-**
SRC Costed Extensions	-	-	186	(186)	-	**-**
SRC025 – University of Sheffield (Co Funded with CFF)	-	-	366	-	23	**366**
UK CF Infection Biorepository	-	-	32	(32)	-	**-**
Carols by Candlelight 2022	-	-	12	(6)	-	**6**
CF Active Programme	-	-	5	(50)	45	**-**
Transition Information Resources	15	-	-	-	(15)	**-**
Quality Improvement Project	35	-	-	-	-	**35**
Aberdeen Unit	-	-	-	-	-	**-**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**61**	**-**	**2,107**	**(549)**	**(1,086)**	**443**

24. Prior year movements in funds (continued)

	Balance 31 March 2022 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
Restricted funds related to Information and Support						
E W Joseph/Homecare grants	3	-	-	(3)	-	**-**
Joseph Levy/Education Grants	4	-	53	(46)	-	**11**
Young Lives programme	29	-	26	(39)	-	**16**
Support services (inc. welfare grants)	112	-	240	(192)	(45)	**115**
Helpline	-	-	5	(5)	-	**-**
Forum	22	-	-	(9)	(13)	**-**
Young Entrepreneurs	3	-	16	(19)	-	**-**
Total funds related to Information and Support	**173**	**-**	**340**	**(313)**	**(58)**	**142**
Other funds						
Coombe Hill	8	-	5	(13)	-	**-**
Clinical Trials Accelerator Platform (CTAP)	-	-	1,262	(1,262)	-	**-**
Digital Health Programme	-	-	134	(134)	-	**-**
CTAP digital conference	(7)	-	43	(22)	-	**-**
Gut Symptoms	-	-	39	-	-	**39**
Other older funds	36	-	-	-	-	**36**
Total other funds	**37**	**-**	**1,483**	**(1,431)**	**-**	**89**
Total Restricted Reserves	**271**	**-**	**3,840**	**(2,293)**	**(1,144)**	**674**

Structure, governance and management

Royal Patron
- HRH King Charles III, KG, KT, GCB, OM

Honorary President
- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees
- Richard Hunt CBE **(Chair)**
- Professor Rosalind Smyth CBE FMedSci (resigned 30 November 2023)
- Sean Collins
- Anne Byrne
- Richard Hoey
- Michelle Shore
- Joanna Barrett
- Sophie Pierce
- Sonya Trivedy
- Professor Martin Walsh
- Jane Wainwright (appointed 29 September 2023)
- Neil Priscott (appointed 29 September 2023)
- Dr Maya Desai (appointed 23 May 2024)

Engagement Committee
(Previously Marketing, Communications & Income Generation Committee)
- Richard Hoey **(Chair)**
- Sean Collins
- Joanna Barrett
- Sophie Pierce
- Neil Priscott (appointed February 2024)

Finance Committee
- Sean Collins **(Chair)**
- Anne Byrne
- David Sawer (Independent member)
- Michelle Shore
- Ed Rushton (Independent member, Investment Sub-Committee)
- Nick Wood (Independent member, Investment Sub-Committee)

People Committee
- Michelle Shore **(Chair)**
- Sonya Trivedy
- Joanna Barrett
- Dr Maya Desai (appointed September 2024)

Senior Leadership Team
- David Ramsden – Chief Executive
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research and Healthcare Data
- Simon Hawkins – Director of Finance and Resources (resigned June 2023)
- Alex Fowles - Director of Finance and Resources (appointed June 2023)
- Dr Sarah Clarke - Associate Director, Data and Quality Improvement

Company Secretary
- Alex Fowles

Principal and Registered Office

One Aldgate
London
EC3N 1RE

020 3795 1555
enquiries@cysticfibrosis.org.uk
cysticfibrosis.org.uk

Company limited by guarantee
Company registration number: 3880213
Charity registration number:
England & Wales — 1079049
Scotland — SC040196

Auditors

Buzzacott LLP
130 Wood St
London
EC2V 6DL

Bankers

National Westminster Bank plc
15 Bishopsgate
London
EC2N 3NW

Investment Managers

Cazenove Capital Management
12 Moorgate
London
EC2R 6DA

Legal structure

Cystic Fibrosis Trust ('the Trust') is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1999 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

The Board of Trustees ('the Board') has full legal responsibility for corporate governance and all operations of the Trust, including determining its strategic direction.

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 12 Trustees with a range of skills. Several committees such as the Finance Committee, People Committee, Engagement Committee, Research Grant Review Committee and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Recruitment, induction and training of Trustees

Trustees consider the relevant skill set required to enable effective oversight and proper governance of the Trust. New Trustees are appointed after a rigorous recruitment process, which includes national advertising and can include recommendations.

Upon appointment to the Board, to help facilitate their understanding of the current issues concerning the Trust, each new Trustee is provided with information tailored to reflect any specific areas of responsibility. The new Trustee will meet with the Chair, Chief Executive Officer and staff working within their own specialist area.

Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Trust to the Chief Executive Officer, David Ramsden, and his Senior Leadership Team ('SLT').

The Chief Executive Officer and the SLT report to the Board both formally at the Board meetings and informally (as appropriate) throughout the year, thereby ensuring a regular flow of information to aid decision making.

The remuneration of key management personnel is determined by a recognised job evaluation framework which takes into account the skills required and the complexity of individual roles. The remuneration of the Chief Executive Officer is approved by the Board. For all other staff the process, including the award of annual pay uplift, is approved by the People Committee.

Public benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. In reviewing our aims, objectives and planning future activities, the Trustees have taken into account the Charity Commission's general guidance on public benefit. The Trustees ensure that activities undertaken are always in line with the charitable objectives and aims of Cystic Fibrosis Trust.

Open SRC Awards (April 2024)

SRC Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment
SRC012*	Dr Daniel Peckham, St James' Hospital	Managing GI Symptoms	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC014*	Professor Jane Davies, Imperial College London	Reducing negative affects of antibiotics	Personalised Approach to *Pseudomonas Aeruginosa* (PAPA)	£750,000
SRC015*	Dr Darius Armstrong-James, Imperial College London	Diagnosis of lung infections	TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis	£750,000
SRC016*	Professor Pietro Cicuta, University of Cambridge	Improving lung health, including tackling infection	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC018	Professor Steven Renshaw, University of Sheffield	Growing older with CF	Preventing gastrointestinal cancer in cystic fibrosis	£749,214
SRC019	Professor James Shaw, University of Newcastle	Preventing CF diabetes	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes	£750,000
SRC020	Professor Stephen Hart, University College London	Options for those not able to take modulators	Therapeutic gene editing of CFTR. Co-funded with CFF	£749,924
SRC021	Professor David Sheppard, University of Bristol	Options for those not able to take modulators	The CFTR Folding and Function SRC	£747,972
SRC022	Professor Jo Fothergill, University of Liverpool	Reducing negative affects of antibiotics	An evidence-based preclinical framework for the development of antimicrobial therapeutics in cystic fibrosis (PIPE-CF). Co-funded with CFF	£374,689 (Total award: £749,373)
SRC023	Professor Alan Smyth, University of Nottingham	Managing GI Symptoms	Gut Research Advancing a Mechanistic and Personalised Understanding of Symptoms in cystic fibrosis: A strategic research centre: The GRAMPUS-CF SRC	£749,592
SRC024	Dr Paola Vergani, University College London	Options for those not able to take modulators	Restoring the fizz: Pharmacological repair of bicarbonate transport in cystic fibrosis. Co-funded with CFF	£374,987 (Total award: £749,973)
SRC025	Professor Jim Wild, University of Sheffield	Improving lung health, including tackling infection	Pulmonary magnetic resonance imaging for cystic fibrosis. Co-funded with CFF	£366,536 (Total award: £733,072)
SCR026	Dr Mike Gray, University of Newcastle	Options for those not able to take modulators	PTSuppress – Novel lead compounds as potential suppressor drugs for CFTR PTC mutations	£799,808
SRC027	Dr Imogen Felton and Professor Jane Davies, Royal Brompton Hospital	Physical health	MATRIARCH_CF – MATeRnal, InfAnt, Reproductive and Child Health in CF	£799,089

*** Grant issued extension due to COVID-19 related delays**

Open Development Awards (April 2024)

Development Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment
DA001	Professor Nicholas Simmonds, Royal Brompton Hospital	Options for those not able to take modulators	ADVANCE-CFTR: Advanced Diagnostic Validation and Novel Clinical Evaluation across the CFTR spectrum	£299,536
DA002	Dr Freddy Frost, University of Liverpool	Growing older with CF	Investigating The Cardiovascular Health of people living with Cystic Fibrosis (ITCH-CF)	£173,846

Open VIA Awards (April 2024)

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA035	Dr Fred Piehl, Imperial College London	Improving lung health, including tackling infection	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data	£42,500	£42,500 Imperial College London
VIA036	Dr Fred Piehl, Imperial College London	Improving lung health, including tackling infection	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data	£42,500	£42,500 Imperial College London
VIA062	Prof Miguel Camara, University of Nottingham	Improving lung health, including tackling infection	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000	£50,000 University of Nottingham
VIA068	Professor Jane Davies, Imperial College London	Improving lung health, including tackling infection	The idealised LCI (i-LCI): tuning in on the 'silent years' of paediatric CF	£98,595	£550,000 EPSRC & Imperial College London
VIA070	Dr Laura Nolan, Imperial College London	Improving lung health, including tackling infection	Understanding interbacterial competition in the cystic fibrosis lung to identify opportunities for intervention	£30,000	£206,000 Imperial College London
VIA072	Dr Elizabeth Crone, Papworth Hospital	Diagnosis of lung infections	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis	£36,000	£108,000 Owlstone Medical & Papworth Hospital
VIA081	Dr Anand Shah, Imperial College London	Improving lung health, including tackling infection	FREAL – Fungal Resistance Evolution and Acquisition in chronic lung disease	£38,000	£247,350 MRC – Clinical Academic Research Partnership Award
VIA083	Dr Paul McNally, Our Lady's Children's Hospital	Long-term and non-lung effects of CF treatments	RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in people with CF)	£97,297	£3,000,000 CFF & CF Ireland

Open VIA Awards (April 2024)

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA092	Dr James Reihill, Queen's University Belfast	Options for those not able to take modulators	The ubiquitylation system as a therapeutic target in CF	£15,000	£101,127 Almac Discvoery, UKRI Innovation Scholars Secondment
VIA098	Dr Jonathan Cox, Aston University	Reducing negative effects of antibiotics	Discovery of new and repurposed ß-lactamase inhibitors for improving *Mycobacterium abscessus* treatment	£25,000	£25,000 ANTRUK (Antibiotic Resistance UK)
VIA104	Dr Beverley Isherwood, Medicines Discovery Catapult	Improving lung health, including tackling infection	Support for the UK CF Infection Biorepository	£95,000	£300,000 CFF
VIA105	Professor Alan Smyth, University of Nottingham	Long term and non-lung effects of CF treatment	Core Outcome Set Taskforce for Cystic Fibrosis (COST-CF): a patient-initiated core outcome set for CF	£93,089	£105,652 NIHR Biomedical Research Centre and Programme Development Grant
VIA107	Dr Rian Griffiths, University of Nottingham	Diagnosis of lung infections	Development of a rapid and highly sensitive analytical method for the detection of bio-markers of infection in samples from people with CF	£37,726	£886,437 BBSRC
VIA111	Professor Lorraine Martin, Queen's University Belfast	Options for those not able to take modulators	Developing a novel regenerative gene therapy platform technology for inhaled CF therapy	£26,000	£220,000 Emily's Entourage
VIA115	Dr Freddy Frost, University of Liverpool	Diagnosis of lung infections	Postal Sputum Testing for Early Detection of *Pseudomonas aeruginosa* in CF: POSTED-CF	£17,215	£97,570 Asthma & Lung UK
VIA116	Professor Jane Davies, Imperial College London	Reducing negative affects of antibiotics	Repurposing the multiple sclerosis drug, Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections	£99,999	£2,500,000 LifeArc Collaborative Discovery Programme call
VIA117	Professor Janis Shute, Ockham Biotech Ltd	Reducing negative affects of antibiotics	Investigating anti-pseudomonal effects of roneparstat, a non-anticoagulant derivative of heparin with multiple anti-microbial, anti-inflammatory and mucolytic activities	£50,000	£2,500,000 LifeArc Collaborative Discovery Programme call
VIA118	Dr Paul McNally, Our Lady's Children's Hospital	Long term and non-lung effects of CF treatment	ENHANCE – Establishing Natural History in an Advanced New CF Care Era	£96,424	£4,800,000 CFF
VIA119	Dr Mina King, University College London	Improving lung health, including tackling infection	Understanding Regional Lung Physiology in Cystic Fibrosis Using Advanced MRI	£49,994	£1,800,000 MRC Career Development Award

Open VIA Awards (April 2024)

VIA Award	Lead applicant and host institution	Research priority	Title	Cystic Fibrosis Trust commitment	Leveraged funding and funding source
VIA121	Professor Ruth Keogh and Dr Emily Granger, London School of Hygiene and Tropical Medicine	Reducing negative affects of antibiotics	Target trial emulation in cystic fibrosis: optimising methods for evaluating long term antibiotic treatment using registry data	£18,077	£150,000 – pending peer review NIHR Research for Patient Benefit
VIA123	Professor Ineke Braakman, Utrecht University, Netherlands	Options for those not able to take modulators	Understanding hypo- and hyper-responding phenotypes of CFTR mutants for therapeutic use	£75,000	£64,000 Nederlandse Cystic Fibrosis Stichting (NCFS)
VIA124	Gerry McCauley, OmniSpirant Limited	Options for those not able to take modulators	Cell engineering optimisation and electrophysiology assessment of OS001 CFTR Extracellular Vesicles (EVs)	£21,242	£22,360 OmniSpirant Limited
VIA125	Dr Claire Edmondson, MRC Clinical Academic Research Partnerships	Improving lung health, including tackling infection	The effects of sex hormones and menstruation on lung function and respiratory exacerbations in adolescents with cystic fibrosis	£99,990	£255,224 – pending peer review Wellbeing of Women
VIA126	Professor Laura Ashley, Leeds Beckett University	Growing older with CF	Cancer risk, screening, and surveillance for people with cystic fibrosis: a national co-designed survey of awareness, perceptions, and behaviours, and information and support needs	£20,920	£56,609 Leeds Beckett University

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2024. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 2nd Floor, One Aldgate, London EC3N 1RE.

Uniting for a life unlimited

CYSTIC FIBROSIS TRUST

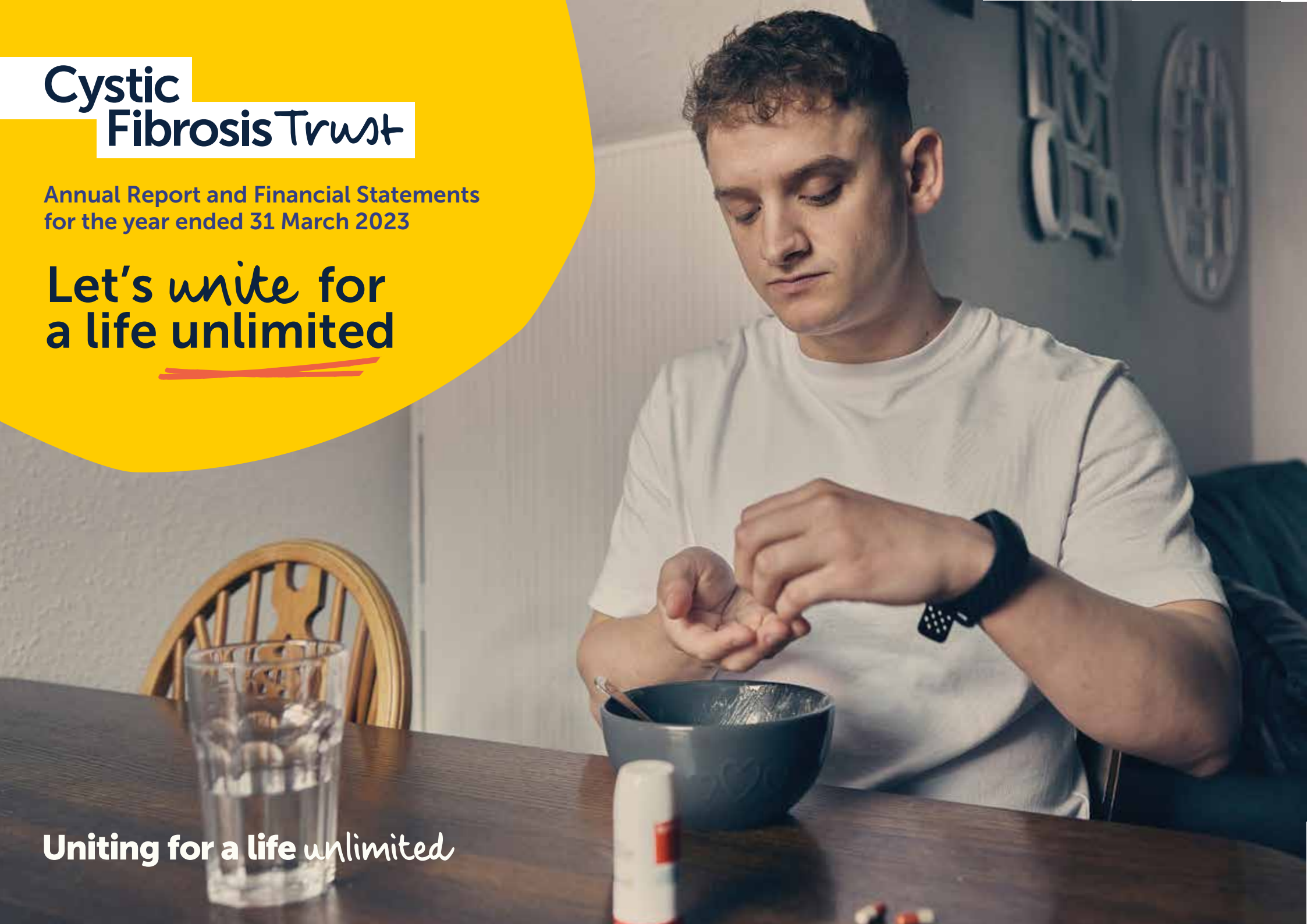
England & Wales - Charity number 1079049

Accounts

Cystic Fibrosis Trust

Annual Report and Financial Statements
for the year ended 31 March 2023

Let's unite for a life unlimited



Uniting for a life unlimited



Jamie Fox, who has CF and is a fundraiser for the Trust

Contents

Thanks to you, in 2022/23... 4
Introduction from our Chair 6

Uniting for a life unlimited
Objectives and activities 10
About CF 10
About us 10
Our goals 11
Measuring success 11

Uniting in research
Research into more detailed ways to monitor the lung health of people with CF 14
Restoring the Fizz: Pharmacological repair of bicarbonate transport in cystic fibrosis 15
Your bugs are helping researchers in the lab 16
More people with CF are taking part in research 16
CF genetic therapies 18
Involving the CF community in shaping our research 19

Putting people with cystic fibrosis at the heart of everything we do
Collaborating with and supporting the clinical community to promote the highest quality of care 22
The impact of the cost of living crisis on the CF community 22
Campaigning hard 23
Our cost of CF campaign 23
Making sure the voices of our community are heard 25
The UK CF Registry 26
Annual data report 27
Quality improvement (QI) 27

Coming together for the CF Community
Day-to-day support 31
Grants 31
Benefits advice 32
Helpline 33
Empowering the CF community through high-quality, accessible information 33
Dedicated support for children and young people 34

Being diverse and together as a community and an organisation
CF Live and social media 38
CF Week 38
#CFTruths 39
Celebrity engagement 41
Sharing stories from our community 42
CForYourself podcast 42
Website 43
Volunteering 43
Being an effective organisation 43



Uniting in fundraising
Supporter experience 47
Community and event fundraising 49
Gifts in Wills 50
In Memory 50
Regular gifts 50
Philanthropy 51
Corporate Partnerships 51

Looking to the future and building effective partnerships
Uniting in research for a life unlimited 54
Delivering our strategy 54
Being great fundraisers 55
Campaigning hard 55
Day-to-day support 56
UK CF Registry 57
Quality improvement 57

Financial review **58**

Independent auditor's report to the Members and Trustees of Cystic Fibrosis Trust **68**
Consolidated statement of financial activities **72**
Consolidated and charity balance sheets **74**
Consolidated statement of cash flows **76**
Notes to the Financial Statements **78**
Structure, governance and management **102**
Committed VIAs **104**
Currently active SRCs **107**
Summer Studentships **109**

Thanks to you, in 2022/23...



1,202 people with CF enrolled on to a CTAP clinical trial, helping to develop new medicines for everyone with CF. This is nearly four times greater than last year.



We co-funded a new Strategic Research Centre (SRC) to understand in detail what happens to bicarbonate transport in CF, with the hope that the lab-based studies could lead to ideas about new ways to treat CF in the future – tailored to individuals, based on the form of CF they have.



We helped people with CF to access over £900,000 in benefits through our Welfare and Benefits Advice service.



Our Helpline responded to 4,799 enquiries, making this the busiest year on record. We continued to provide support to our community through the cost of living crisis.



We launched a new time-limited cost of living fund, providing 342 grants over the winter period to support those on low incomes to afford food and essentials.



The second year of our #CFTruths campaign reached over 10 million through out of home advertising and had a reach of over 11 million via a combination of national and regional news.

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2023. The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Charities Act 2011 and the Statement of Recommended Practice: Accounting and Reporting by Charities second edition effective 1 January 2019.

The requirements of 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013' are included within this Trustees' report. Pages 60 to 103 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 2022/23 Annual Report.

As this report demonstrates, the past year has been one of wide-ranging activity and innovation as we continue to focus on achieving our vision of a 'Life Unlimited' by cystic fibrosis (CF).

The year started with optimism that we had left the worst challenges of the COVID-19 pandemic behind us. However, as we all know we were then faced with new concerns led by a war in Ukraine, a cost of living crisis and some domestic political turmoil.

Against this everchanging backdrop, throughout the year, we have continued to see the impact Kaftrio is having on the lives of many people with CF in our community. We have come to understand more about the scale and scope of the drug's positive impact as well as the various challenges that some people have experienced.

We recognise that the current available drugs are not a cure, and that too many people still have no therapies that work with their specific mutations. There is still much to do until everyone with CF can live a life unlimited.

These factors have helped to inform what has been a key area of focus for us this year, the James Lind Alliance Research Priority Refresh. This involved consulting the CF community on their priorities for research, which will now help direct research investments by the Trust and others in the years ahead.

"Our benefits and income maximization advice has continued to be vitally important and we have helped people to access around £900,000 in social support that they were eligible for during the year."



A further element of our research activity has been the continued development of the involvement of people with CF in clinical trials through the CTAP (Clinical Trials Accelerator Platform) programme. Over the year we have seen an exciting increase in the level of early phase trial activity, which includes a focus on new approaches to genetic therapies.



Richard Hunt CBE

We have continued to fund high quality research through our Strategic Research Centre programme covering areas such as Magnetic Research Imaging (MRI), and whether this could be used to track changes in lung health over time and how the flow of bicarbonate in different organs is affected by CF.

As the needs of people with CF change, so have the ways in which we offer information and support. Mindful of the particular financial challenges that some people within our community are facing, we have been advocating hard for their fair treatment. This includes the ending of all prescription charges in England for those living with CF. We also launched a specific Cost of Living Fund, which awarded 342 grants to people in our community who urgently need help.

Our benefits and income maximisation advice has continued to be vitally important and we have helped people to access around £900,000 in social support that they were eligible for during the year.

This year saw the launch of our brand-new podcast CForYourself. In each episode our host Lucy has a virtual 'cup of tea and a chat' with others in the CF community. They talk openly and honestly about a whole range of topics, from exercise regimes and employment to parenting and mental health.

We entered the second year of our awareness campaign, #CFTruths. This is a vital way we are telling the real story of life with CF to the widest possible public audience. We want to ensure that people with CF can live their lives to the fullest, in a world that understands them and understands that despite progress there is still no cure.

We must acknowledge that we can only do our work and everything mentioned within this report, due to the incredible commitment of our supporters and the CF community. Thank you. Your determination and passion motivates us every day and we won't stop until that vision of a life unlimited is a true reality for everyone with CF.

Finally, I must also express my thanks to the whole Trust team and my colleagues on the Board for their commitment and support over the last year. Sincere thanks to you all.

As I have said we won't stop until we have achieved our vision and I know our inspirational community will be with us every step of the way.

Richard Hunt CBE
Chairman of Trustees

Uniting for a life unlimited




Cystic Fibrosis Trust
LAURA

Objectives and activities

Our vision is to deliver a life unlimited for people with cystic fibrosis, and our objectives, as stated in the Articles of Association, are to promote:

- research into the causes of, and a cure for, cystic fibrosis and the dissemination of the useful results thereof for the public benefit
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from cystic fibrosis in any form
- the education of the general public about the causes and effects of cystic fibrosis.

About CF

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. You are born with CF and cannot catch it later in life. One in 25 of us carries the faulty gene that causes it, usually without knowing.

More than 10,900 people in the UK live with the condition, having to undergo a brutal daily regimen of physiotherapy and take up to 60 tablets a day just to stay healthy. Despite these treatments, many people with CF will go on to require a double lung transplant. The median age of death for someone with CF in 2022 was 33.

About us

Our mission

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all. We won't stop until we can all lead the lives we want. Until cystic fibrosis stops damaging and shortening lives.

Our vision

Our community is uniting towards the ultimate goal of effective treatment for all. We're at the forefront of innovation and progress. Boundaries will be broken by groundbreaking research and incredible discoveries that change lives for the better. To get there, we will inspire our community. We will campaign with passion. Use facts and information to empower us. And support each other – improving care and building better mental resilience and physical health.

We're uniting for a life unlimited.

Our goals

Physically well

Together, we can live without the physical challenges of cystic fibrosis.



Mentally well

Together, we can manage the mental pressures of cystic fibrosis.



Fulfilment

Together, we can lead the life we want as part of a connected community



Measuring success

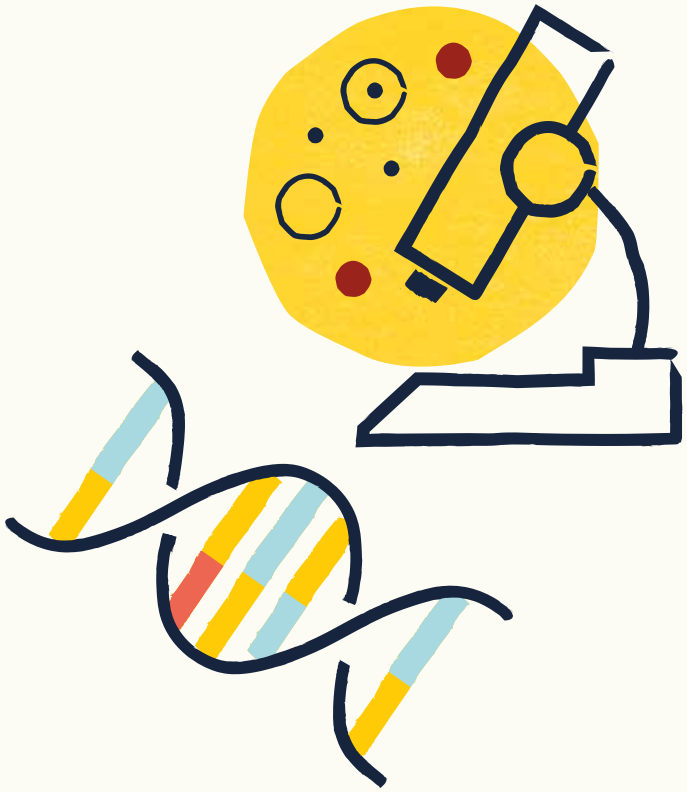
We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact to the CF community. We hold impact workshops to assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track progress via internal monthly and quarterly monitoring mechanisms, including both data-driven and narrative analysis, backed up by SMART Key Performance Indicators. Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.

Uniting in research





Over the past year, we've invested in innovative research projects across a wide range of areas to help us achieve our goal of a life unlimited for everyone living with cystic fibrosis.



Research into more detailed ways to monitor the lung health of people with CF

With the changing nature of cystic fibrosis, it is important that we continue to develop new ways to monitor people's health. This information could be used to manage their condition from day to day and also to find out the effectiveness of new treatments being tested in CF clinical trials.

People with CF on CFTR modulators medicines, such as Kaftrio, have fewer lung symptoms than before they had access to these medicines. This can make it much harder to spot any flare-ups of lung infection or changes in lung function.

New types of CF treatment, such as CF genetic therapies that have the potential to benefit everyone with CF, are starting to be tested in clinical trials. Doctors and researchers need to be able to see any changes in lung function due to these medicines as soon as possible.

A new Strategic Research Centre approved for funding by Cystic Fibrosis Trust this year will investigate whether Magnetic Resonance Imaging (MRI) could be used to track changes in lung health over time. New MRI methods have been developed by Professor Jim Wild, the Principal Investigator of this SRC, who is based at the University of Sheffield. The programme is co-funded by the Trust and the CF Foundation in the United States.

"I have taken part in over 20 trials throughout my life. Put it this way, if there is a trial, I'm going to agree to be part of it because it's my way of giving back and returning some of the help and support I've had over the years with my CF. I feel I have a responsibility to help the community as they have helped me"

Emma

Professor Wild will lead a collaborative, multidisciplinary programme of research to investigate how and whether these MRI methods can be incorporated into CF clinical practice, including developing easy-to-use software to process the MRI data and working out the best ways to support CF clinicians and the people with CF and families they care for, in understanding the significance of this new information for people's lung health.

If successfully adopted into CF care, these new MRI methods could give a much more detailed assessment of the lung health of people with CF and reduce their exposure to X-rays (as they may require fewer lung CT scans that require X-rays).

Restoring the Fizz: Pharmacological repair of bicarbonate transport in cystic fibrosis

Some people will be familiar with the chemical sodium bicarbonate, sometimes known as 'bicarbonate of soda'. It can be used to help make cakes rise and is also used for cleaning things around the house. If you add hot water to a teaspoon of sodium bicarbonate in a bowl or a mug, it will fizz, and it's the 'bicarbonate' part of the chemical that causes this.

Bicarbonate is an important chemical in the body, too. It can help keep fluids at the right acid-alkali balance and has a job in the production and movement of mucus. For bicarbonate to do its job in the body, it relies on being moved by the CF protein that is damaged or missing in CF.

The CF protein is found in different parts of the body, including in the lungs, intestines, pancreas and liver. It acts as a gate allowing the movement or transport of two chemicals - chloride and bicarbonate - out of cells. Researchers have conducted many studies to understand how chloride transport is affected in cystic fibrosis, but they know less about how bicarbonate transport defects lead to the symptoms of CF.

In October, a new Strategic Research Centre (SRC) led by Dr Paola Vergani, based at UCL in London, will begin a programme of research to understand in detail what happens to bicarbonate transport in CF. They will investigate it in different forms of CF (where people have rarer CF mutations) and in different tissues, particularly the liver. They hope that their lab-based studies could lead to ideas about new ways to treat CF in the future – tailored to individuals based on the form of CF they have – and could lead to drugs that treat CF in a different way than the current medicines. This research is co-funded by the Trust and the Cystic Fibrosis Foundation in the United States.

"Cystic Fibrosis Trust is a huge support when it comes to raising awareness and making medical and treatment miracles happen. Without the Trust, the CF community would not have seen the incredible, life-changing advancements in medicine, education and care that have been made possible."

Siobhan, who has CF



Siobhan

Your bugs are helping researchers in the lab

When people with CF develop lung infections, the bacteria that cause them adapt themselves to living within the thick sticky mucus in the CF lungs. In order to test whether new medicines to treat CF infections are likely to work, lab-based researchers need access to the adapted forms, or 'strains' of these bugs. However, getting access to CF strains of bugs can be very difficult for scientists, holding up their research. It is a problem that members of the CF Antimicrobial Resistance (AMR) Syndicate wanted to address.

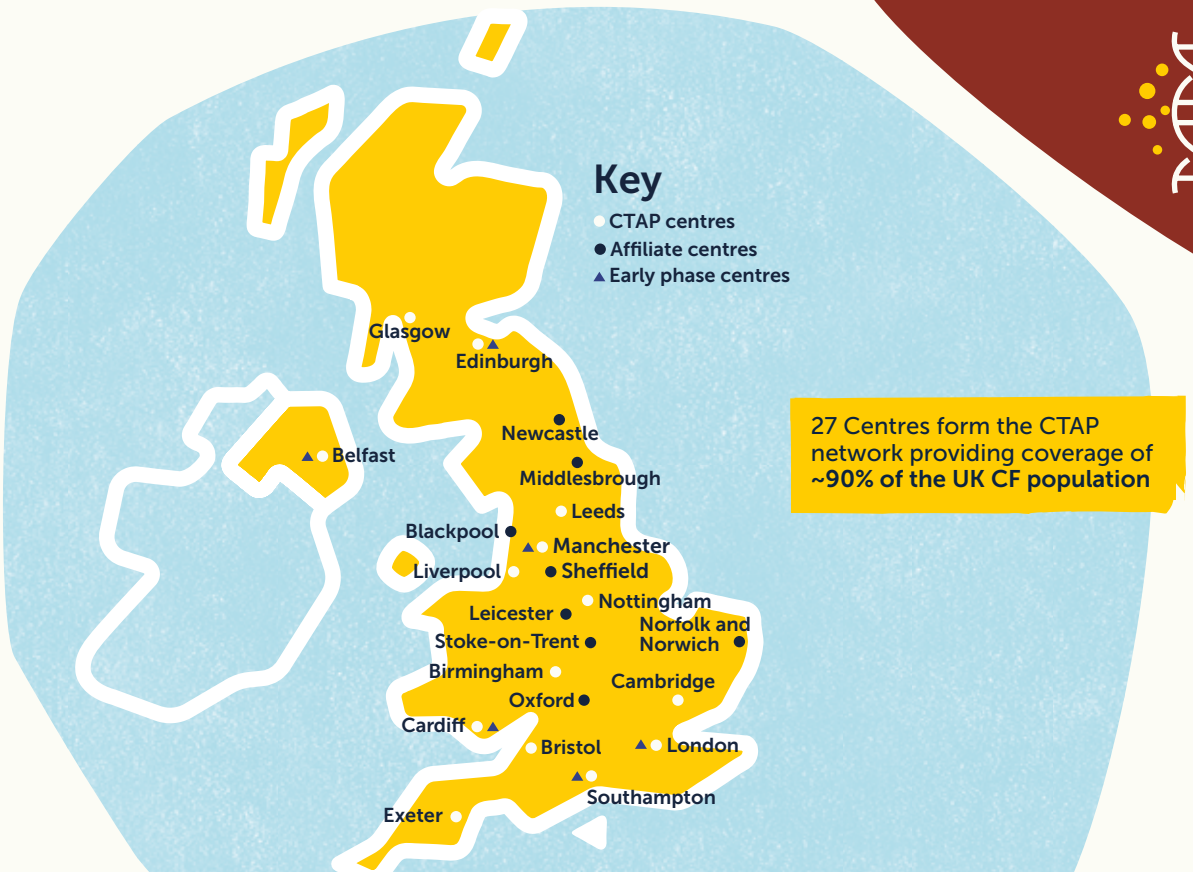
The CF AMR Syndicate is a partnership between Cystic Fibrosis Trust, Medicines Discovery Catapult (MDC) and LifeArc, a national medical research charity, to accelerate the development of new medicines to treat CF infections. It is a cross-sector initiative which enables the CF community to gain awareness of and timely access to these trials. People with CF are involved in all of the Syndicate's activities to ensure their needs and priorities are at its heart.

Following Venture and Innovation Awards (VIAs) from the Trust to pilot the scheme in the last few years, this year saw the launch of the Syndicate's UK CF Infection BioRepository, creating a central source of CF strains of infection-causing bugs. Coordinated by Medicines Discovery Catapult (MDC), the BioRepository brings together a network of eight centres in the UK who can work with researchers around the world, from universities, hospitals, and biotech and biopharmaceutical companies, to speed up CF research. The BioRepository is now supported by a grant from the CF Foundation in the United States.

More people with CF are taking part in research

Across the UK, the Trust has established a clinical trials network of 27 adult and paediatric CF centres. The Clinical Trials Accelerator Programme (CTAP), which is funded by the CF Foundation (CFF), provides invaluable support to sponsors (organisers of trials) with their delivery and a platform which enables the CF community to gain timely access to these trials. The Trust recently secured a further five years of funding, over $6m, from the CFF to maintain and further develop this network, which is a key part of the UK's CF research landscape.

The CTAP network of 27 centres from across the UK comprises a mix of research-focused clinicians and coordinators with a range of experience, knowledge and skills in CF care and running clinical trials. Collectively the network covers ~90% of the UK CF community.



Since CTAP's official launch in September 2017,

3,585 people with CF have been screened for a trial within the CTAP network (2,207 in the last 12 months)

2,270 enrolled on a trial (1,306 adults and 964 babies & children) - 1,202 were enrolled in the last 12 months which is nearly 4 times greater than the previous year

50 CF trials have been supported by CTAP, with 15 studies open to recruitment in the last 12 months



Rachel (right) and daughter Anna

"It's very exciting to hear about potential clinical trials for genetic therapies. I try to stay positive that something will come along for my daughter that could be a game changer, but there are times when I can't help but feel despondent. This gives me real hope that a 'wonder' drug could help her and give her more of a 'normal' life with no limitations.

Rachel, mum to Anna who has CF

"As a parent to a child with CF, it can feel like there are too many components that sit outside of your control. But being a part of QuestionCF has enabled us to feel like we're doing something proactive. It's refreshing to be part of a project that's actually giving those in the community a voice and a chance to share their own perspective. It's a really optimistic time to be part of the CF community, but there's a lot that needs to be done to make sure that the needs of everyone with CF are met. Those that have access to modulators, and those that don't."

Nicole and Martyn, parents to Arlo who has CF

CF genetic therapies

Over the next few years, we hope to run a number of early clinical trials on CF genetic therapies through the CTAP Early Phase Trials Network. These are therapies that would work in a completely different way to existing CF medicines, such as Kaftrio and other CFTR modulator medicines, and are particularly relevant and exciting for those people with CF who are unable to benefit from modulators. To support recruitment to these new trials, we have created some CF genetic therapy resources for our website: **cysticfibrosis.org.uk/genetictherapies**



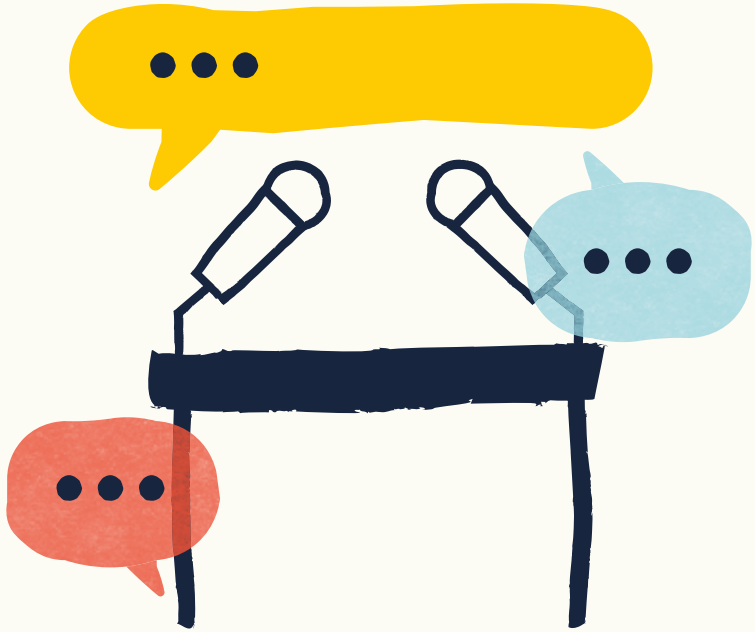
Nicole, Martyn and Arlo, who has CF

Involving the CF community in shaping our research

In 2016 the Trust was a partner in the QuestionCF project, identifying the research priorities of people with CF, as well as their families, carers, and CF teams. Other partners in the project included the CF community and researchers at the University of Nottingham. The priorities were identified in the Priority Setting Partnership (PSP), facilitated by the James Lind Alliance (JLA) team at the National Institute for Health and Care Research (NIHR). The research priorities were published in January 2017. Since then, these priorities have helped us decide what research we fund; much of this research is ongoing, and you can read about some examples of the exciting work underway in a **review article from December 2021**.

In 2022, in partnership with the University of Nottingham, the JLA and members of the CF community, we led a project to refresh the CF research priorities. The project started with a survey that opened in January 2022, asking the CF, research and clinical communities to identify those 2017 priorities they felt were still important to them, and gave respondents the opportunity to submit up to two new research questions or priorities.





We received over 1,600 responses to this first survey from across the world, including Europe, Canada, North America and Australia. The second survey, launched in the summer, asked participants to identify their top 10 priorities from a short-list of 71 questions, and the final list of priorities was completed in an online workshop in November. The refresh CF research priorities are:

1. What options are available for those not able to take current CFTR modulators (including rarer mutations, not eligible and unable to tolerate)?

2. What is the best way to diagnose lung infection when there is no sputum e.g. children and those on modulators?

3. How can we relieve gastrointestinal symptoms, such as stomach pain, bloating and nausea?*

4. How do we manage an ageing population with CF?

5. Is there a way of reducing the negative effects of antibiotics e.g. resistance risk and adverse symptoms in people with CF?*

6. What are the long-term effects of medications (including CFTR modulators) in CF?

7. What are the effects of modulators on systems outside the lungs, such as pancreatic function, liver disease, gastrointestinal, bone density etc?

8. What are the effective ways of simplifying the treatment burden of people with CF?*

9. Can genetic therapies (such as gene editing, stem cell and mRNA technology) be used as a treatment for CF?

10. Is there a way of preventing CF diabetes in people with CF*

*denotes priorities that were included in the top 10 priority list in 2017.

Work is now ongoing to bring the research community and other potential funders together to accelerate research to address these priorities.

Find out the latest updates on the refreshed research priorities: **cysticfibrosis.org.uk/researchpriorities**

Putting people with cystic fibrosis at the heart of everything we do





Collaborating with and supporting the clinical community to promote the highest quality of care

Through working with clinicians and other experts to develop high-quality clinical guidelines, we can improve the standards of care received by everyone with CF. Last year we updated three key guidelines, all of which are written and reviewed by CF expert clinicians, scientists, and community representatives:

- We updated our guidelines on CF diabetes, a condition which affects more than 30% of adults with CF and can have a significant detrimental impact on health.
- We updated guidance on the laboratory management of CF microbiology samples, a critical part of ensuring prompt diagnosis and treatment of CF pathogens.
- We published the third edition of our pharmacy's standards of care, which help ensure people with CF get the best possible outcomes from their medicines.

The impact of the cost of living crisis on the CF community

The impact of rising living costs was felt across the CF community, particularly over the winter months – with more people struggling to buy the basic essentials they needed to manage their health and stay well. Others in the community may have been just about managing but were unable to make ends meet when faced with the cost of a broken home appliance or the loss of income that comes with a hospital admission.

We provided responsive, wide-ranging support, helping people with CF and their families access the basics they needed through our grants offer. We then worked to identify all the financial support available to claimants, supporting them to understand their rights and, importantly, were there to listen and offer emotional support when times were tough.

In response to the cost of living crisis, we launched a new time-limited cost of living fund, providing 342 cost of living fund grants of £225 over the winter period to support those on low incomes to afford food and essentials.

85% of people who received a cost of living fund grant told us that without the grant, they would have struggled to buy enough food over the winter.

To support our community with the cost of living crisis, we also:

- developed a new cost of living hub on our website, providing the latest updated information and advice tailored to each of the four nations
- introduced spot-check appointments for benefit checks
- shared template letters for our community to send to energy companies, explaining the importance of a warm, dry home for staying well with CF
- introduced our new grant category, the Home Essentials Fund, to provide streamlined access to essential white goods, like washing machines and fridges, to store medication.

> **"I never thought I'd be this financially fragile in 2023, but here I am. Last week I had pasta and rice as my dinner for three nights until I could borrow money. I find myself losing weight I've spent years putting on. I want to stay as healthy as possible. I need the extra nutrition now more than ever. This grant helps me ensure I've got food in my fridge to do that."**
>
> Sam*, who has CF



* names changed for anonymity

Campaigning hard

We campaign hard to drive positive change for people with cystic fibrosis. We ensure policymakers have the evidence needed to pursue interventions which make a difference to those living with CF and their families.

"I think the Trust's Cost of CF campaign is really important as it will help people to understand that it's not just the condition that we live with, it's the actual cost of having the condition too."

Chantelle, who has CF

Our cost of CF campaign

In spring 2022, we surveyed the CF community as part of our Cost of CF campaign to truly understand the additional cost of living with cystic fibrosis. Our report revealed that 87% of people with CF were worried about the cost of living and that 1 in 3 had missed a hospital appointment due to the cost.

In January 2023, we published research in partnership with the University of Bristol, which found that a typical family with CF will lose £564 per month – or nearly £6,800 per year because of the condition. We used this evidence to call on governments across the UK to act.





"I would like not to have to worry about money. I am forever trying to think of ways to make money whilst juggling my child, part-time work, nursery costs, family life, dog... My health ends up as an afterthought. I'd like to be able to have time to myself, to work on my health and wellbeing."

Jamie*, who has CF



Carlie

> **"It's so important than every single one of us gets behind the campaigning work of the Trust because ten thousand of our voices are so much stronger, powerful, and louder than just one."**
>
> Carlie, who has CF

The Trust submitted evidence to a parliamentary inquiry on the cost of living, highlighting the need to address how the uprating of social security benefits did not keep pace with inflation, and that those who relied on this support were effectively worse off due to the challenges of living with a lifelong condition. Repeated lobbying of ministers and parliamentarians across the year prompted parliamentary questions and contributions to debates held by elected representatives across all four nations.

In early 2023, this culminated with a specific debate in the House of Commons on the financial cost of living with CF. We were pleased to see this advocacy work, and our partnership working through wider third-sector coalitions saw the Chancellor of the Exchequer confirm that uprating would occur in line with inflation rather than the proposed lower rate.

This debate on the cost of living with CF prompted further discussion in England around prescription charges. On behalf of the CF community, our CEO, David Ramsden, handed in a petition signed by 1,300 people to 10 Downing Street, calling for CF to be added to the list of conditions exempt from paying prescription charges.

Making sure the voices of our community are heard

In early 2023, the National Institute for Health and Care Excellence (NICE) launched the next stage of its assessment of modulator therapies. Over 1,000 people with CF shared their experiences of Kaftrio, Orkambi and Symkevi with us to inform our evidence submission to NICE for their appraisal of these medications.

Our community told us that living with CF can have a significant impact on their quality of life, and "there is no day off from CF" due to the high treatment burden and the challenging symptoms which can affect the whole body. They also highlighted how the introduction of modulator therapies, particularly Kaftrio, have transformed quality of life as well as hopes and aspirations for those who are able to benefit from them. The formal NICE committee hearing for this appraisal is due to take place later in 2023.

We continue to lobby hard on prescription charges and raised it with ministers ahead of the 2023 budget. We were part of the successful coalition working in partnership with financial advice expert Martin Lewis which campaigned to scrap the planned increase in the Energy Price Guarantee.

We will continue to raise awareness of the financial challenges people with CF are facing, campaign for greater support from the Government and strengthen the direct support that we provide to those in our community who need it most. Our community will always inform our advocacy work for the year ahead based on what they tell us in our annual 'Your life and CF' survey.



CEO David Ramsden and Cystic Fibrosis Trust staff members at 10 Downing Street



Dr Jamie Duckers

The UK CF Registry

The UK CF Registry is a world-class database that includes data on over 99% of people with CF in the UK who have consented to their data being submitted by their CF team. This Registry team supported the running of three drug safety studies, generating over £1.7 million in income. A significant proportion of these funds was used as grants to support centres in their data entry to the Registry. All three studies will be completed by the end of 2023.

In 2022, the Board of Trustees approved investment in a new Registry role, Senior Health Studies Development Manager, to build on existing partnerships and nurture new partnerships with industry and academia.

More information about how we use Registry data to keep medicines safe can be found at **cysticfibrosis.org.uk/registry**.

"The UK CF Registry is like gold dust; we're so lucky to have it. It guides how we help people with CF to manage their condition now, and we can conduct research to answer their questions about the future."

Dr Jamie Duckers



This year the Registry will receive up to £160,000 from NHS contracts for generating public reports and supporting the commissioning of CF services in England.

Anonymised Registry data supports research, service improvement, and information materials. Between April 2022 and March 2023, the Registry received 37 data requests, of which 34 were reviewed by the Registry Research Committee and 29 were approved. The Registry Research Committee ensures that all data requests adhere to the Registry protocol and are meaningful to people with CF and the wider community.

The UK CF Registry continued to play a pivotal role in evaluating the effect of Orkambi, Symkevi and Kaftrio following interim access agreements across the UK.



Throughout 2022 100% of CF centres committed to opting in to enter three 'encounters' (records of height, weight and lung function) throughout the year, supporting additional data collection to enable a more robust analysis of the rate of change in lung function due to these new medicines. This Data Collection Agreement also boosted the Trust's annual Registry Support Grant programme for a third year. The final report of the observational study of Orkambi and Symkevi was submitted at the end of 2022, with the final analysis of Kaftrio following in summer 2023. These two reports will form an important part of the NICE appraisal of these medicines in 2023.

Recruitment to the Registry-based clinical trial CF STORM, which was launched in Summer 2021, is ongoing. This trial is designed to find out whether people with cystic fibrosis can safely withdraw mucolytic therapy once they have started taking CFTR modulators.

In November 2022, the first face-to-face Registry Annual Meeting was held following pandemic restrictions. Around 90 Registry users from CF centres across all four nations in the UK attended the meeting in Birmingham to hear from the team and clinical colleagues about the latest Registry updates, projects, and current research and contributed to workshops looking to the future of the Registry.

Annual data report

The UK CF Registry annual data report on 2021 data was published in September 2022.

It was found that 7,384 people were reported as being on a CFTR modulator by December 2021. As we continue to gather data on the use of CFTR modulators, a clearer picture of the health impact of the modulators will be formed. An accessible at-a-glance summary of infographics highlighting the main trends for that period was also published, helping people with CF and their families to understand the data contained in the report. Both reports can be found on our website at **cysticfibrosis.org.uk/registry**.

We submitted anonymised 2021 data to the European CF Society Patient Registry, which published its reports online.

Quality improvement (QI)

In June 2022, we published a series of reports, sharing insights from patient experience surveys and the Trust's staffing tool. It was the first time that findings from our patient experience surveys were shared publicly, and social media posts about the launch were viewed over a thousand times in the month following publication.

In autumn 2022, the QI team initiated the second cycle of the Trust's patient experience survey in children's CF centres, collecting new insights that will be reported on next year. The team also continued to monitor staffing levels in CF services through the staffing tool, creating bespoke staffing data summaries for participating CF centres and publishing an updated report on CF service resourcing in March 2023.

Coming together for the CF community







“Our team introduced us to the Trust at diagnosis, and we have learnt so much. It has also given us a point to guide family and friends for information. It’s an amazing charity which is so supportive; they create huge awareness around CF, providing information and support to those living with CF and their friends and family. They are constantly striving to fund research for the CF community.”

Jason, dad to Luca, who has CF

Jason and his son Luca, who has CF

Day-to-day support

We've continued to see high levels of demand for support in all aspects of life with CF; many in our community have had worries about the cost of living. Through our grant programme, backed by our welfare and benefits advice services, we've been able to offer support in immediate financial crises to put food on the table. We also work to offer support for longer-term financial security. Our Helpline team provide a knowledgeable, non-judgmental listening ear, offering emotional support while also signposting to practical help and advice.

> **"All the leaflets and information that was given to us in the early days about CF were from the Trust and it made a big difference. The leaflet for family and friends was invaluable and made so much sense. We will still get strangers asking the wrong questions or saying the wrong comments, but at least we could equip our family and friends with the right things to say, making it a little easier when they did meet Rufus for the first time."**
>
> Ben, dad to Rufus who has CF

Grants

This year, we've provided 1,190 grants totalling over £310,000. This includes over 400 emergency grants, funding basic essentials like food. These are often needed when there has been a sudden, unexpected loss of income. This frequently happens when a hospital admission means someone with CF, or parents/carers of someone with CF, have to take time off work and lose income. This is in addition to coping with the costs of travel and food at hospital. The impact of this can be felt for many weeks or months, leaving people struggling to afford the basics, impacting their physical and mental health. A small emergency grant can help to ease some of this pressure.

Following feedback from the CF community, we have adapted our grant programme, ensuring we can meet the needs of those who need our support most. This included the launch of the Home Essentials Fund, supporting households on low incomes to quickly replace broken-down appliances which are needed to protect CF health. Between October and March, we funded 113 vital appliances, including fridges needed to store medication and washing machines needed to keep clothes and homes clean and hygienic.

Our Cost of Living Fund grants launched in October 2022 and provided vital support to protect the health of those who were most vulnerable to rising living costs.

Thanks to the generosity of the Joseph Levy Foundation, we have also been able to provide 57 Joseph Levy Education Fund grants, helping people with CF with the costs of higher or further education.

We also provided 10 Helen Barrett Bright Ideas Awards, supporting people with CF to take a step forward in self-employment, building confidence and giving an opportunity to shape a career that fits around their health.



Benefits advice

Our welfare team supported 377 people this year and secured benefits income of over £900,000 for people affected by cystic fibrosis. 300 people received detailed, personalised one-to-one benefits advice, and 50 people were supported by our Income Maximisation Service, which works to check for any financial support or savings available. 27 young people with CF accessed our Student Support Service, which provides one-to-one support to identify financial and practical support to help at university. As well as supporting people with CF and those who care for them, the team also provided support to cystic fibrosis specialist social workers, often working in partnership to get the best possible outcomes, particularly in complex benefits situations.

"The gentleman I spoke to was extremely helpful and gave me the accurate and precise information I was looking for. He followed it up by email, sending me the information and answering my further questions. He was patient, kind and generous with his time and knowledge, and I appreciate that enormously."

Dave*, who called our Helpline for advice



Sangeeta Enright, welfare and rights advisor

Helpline

With a total of 4,799 enquiries, this has been the busiest year on record for our Helpline. The Helpline acts as the gateway to all of our support services, providing emotional support with a detailed understanding of cystic fibrosis and signposting to our other services as well as external support.

100% of people who responded to our Helpline survey told us they felt heard and understood, and 98% said that they felt more confident dealing with the issue they contacted us about. The majority of enquiries come into the Helpline by email, but in February 2023, we launched a WhatsApp service, and the Helpline is available over the phone as well as via social media, making sure our support is as accessible as possible.



"Searching anything CF-related on the internet can be overwhelming. Most of the information can be just statistics and facts. But the information provided by the Trust is reliable and helpful for day-to-day life, from how to deal with everyday bellyache to diet and lifestyle information."

Margherita, whose partner Pierre has CF

Empowering the CF community through high-quality, accessible information

In 2022, Cystic Fibrosis Trust was awarded the PIF Tick, – a widely recognised quality kitemark awarded by the Patient Information Forum, which identifies Cystic Fibrosis Trust as a trusted information producer. Achieving the kitemark involved an intensive assessment, during which the Trust had to demonstrate it meets 12 criteria for developing high-quality patient information.

We published a significant new resource for younger audiences, featuring an animation voiced by children with CF and their siblings, as well as a fun activity pack. The animation quickly became one of the most-viewed videos on the Trust's YouTube channel.

For the first time, we published an Easy Read resource about cystic fibrosis, ensuring accessible, easily understood information about cystic fibrosis is available to those who need it.

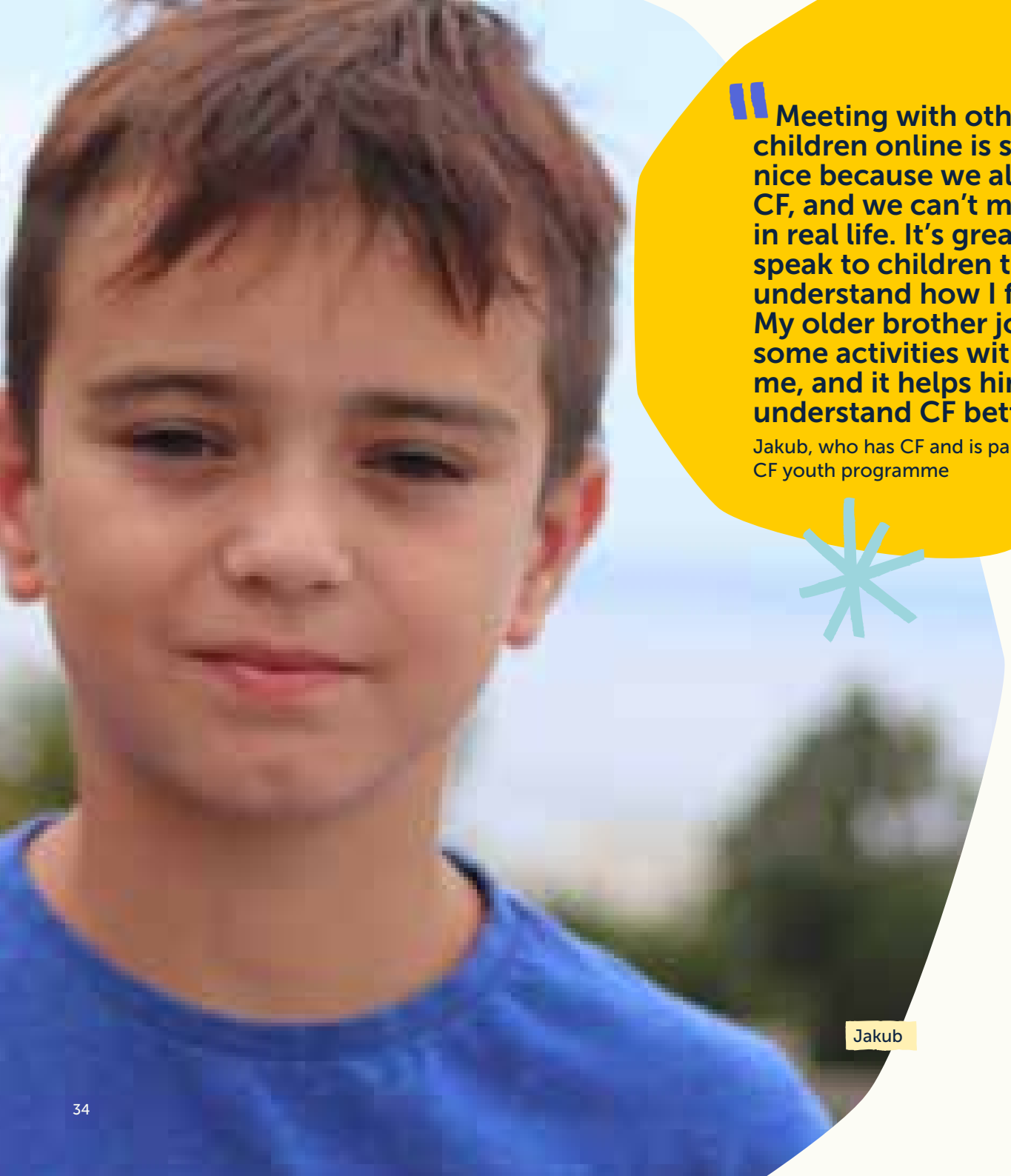
Trusted Information Creator

Patient Information Forum

We also developed and expanded our information in other key areas. We published new content on menopause in CF to coincide with Menopause Awareness Week 2022. Menopause is affecting increasing numbers of women with CF, and we provided information on treatment options and shared coping tips and personal stories. We also expanded our housing information in direct response to increasing challenges faced by some people with cystic fibrosis in their living situations, covering issues such as homelessness, housing discrimination and help with bills.



Layla (left) and Jason, two characters from our newest resources for young children



Jakub

> **"Meeting with other children online is super nice because we all have CF, and we can't meet in real life. It's great to speak to children that understand how I feel. My older brother joins some activities with me, and it helps him to understand CF better."**
>
> Jakub, who has CF and is part of our CF youth programme



Dedicated support for children and young people

Our thriving youth programme continued to attract both new and returning children with a diverse range of online events and workshops – including arts and crafts, singing and songwriting, coding, and our ever-popular games nights. For people with cystic fibrosis, cross-infection can be very harmful. This is why people with CF should not meet face to face, and it's also why we hold these events online.'

We held 28 one-off events and three six-week workshops, with 84 children taking part – over half of whom attended more than one event. Children with CF and their siblings aged 6–18 are welcome to join these free events, generously funded by BBC Children in Need, which receive wonderful feedback from children and parents alike. Regular surveys show children's confidence increases after taking part in the workshops. They also develop new skills and benefit from informal peer support through meeting others with CF in a safe online space.

Meanwhile, our Youth Advisory Group, comprising young people with CF and siblings aged 14-25, aimed at supporting other young people with CF. This included a careers-focused project, 'When I grow up', which shared positive stories about CF and employment to encourage young people with CF to develop their own career aspirations.

"I joined YAG to not only help other people with CF, but also to get to know other young people in the community and to have a support network that understood CF in its entirety. I loved the idea that it was a group of people with CF or a connection to CF making content and projects for those with the condition. It made so much sense!"

Cicely, member of Youth Advisory Group



Cicely

Being diverse and together as a community and an organisation





This year, we've continued to find new ways to engage with people affected by CF. From continuing to grow our presence on TikTok, to our youth programme and the launch of our new podcast, we have focused on reaching everyone affected by CF and connecting with people in the best way that works for them. We've also sourced a greater range of voices in the stories we tell on our website, the media stories we place, and in our fundraising packs. High-profile campaigns like CF Week and #CFTruths have been shaped and influenced by people with CF and their families via our active involvement groups.

CF Live and social media

CF Live, our series of online panel events with expert speakers, has continued to grow in popularity. Hundreds of attendees tuned in to our seven-part nutrition series, as well as our popular session on growing older with CF. As we increased our social media presence across all our platforms, we also jumped into CF-related conversations online to proactively offer help and support to people with CF who were struggling.

CF Week

CF Week is our annual awareness and fundraising week, with a focus on community engagement and sharing diverse stories from our community. The 2022 theme for CF Week was 'lifting the limits together', which we used as an opportunity to emphasise a message of togetherness and that we won't stop until everyone can live without the limits of CF.

This year:

- we raised over **£105,000**, with over **£53,000** being raised by CF Mamas' Wear Yellow Day Challenge through **74** incredible fundraisers
- had **290** signs ups with **66** identified school fundraisers
- media coverage during or just past the week had a potential audience of **1.7m**, including a feature in Women's Own which has a **76k** circulation
- received a donation of OOH coverage worth over **£50,000** with a reach of over **3 million**
- achieved over **20,000** views with our video content and over **387,000** impressions across our social platforms
- engaged with politicians across the UK to share our resources to show their support.



"A life unlimited to me means looking forward to a future with my husband and my son, and not worrying too much about how my health will decline or how it will impact me day to day."

Gillian, who has CF



#CFTruths

Following the success of our #CFTruths campaign last year, we worked with Kieron, who has CF, and the wider CF community to launch the next phase. You can't see CF, which focuses on the invisible burden of the condition, was co-created with members of the community and tested carefully with those new to CF too.

The campaign is still live, but so far has achieved:

- **£200,000** donated support for OOH advertising with a reach of **10 million**
- over **900,000** impressions across paid social media and display adverts
- over **700** clicks to the website through paid advertising
- over **115,000** impressions and over **41,000** views across social media
- over **11 million** via media with a combination of national and regional news.



"I always get told 'I didn't know you had CF'. I love this campaign so much; it means so much to me to know that people understand that life isn't 'normal' for people with CF as many would believe."

Ronnie*, commenting on social media

“You don’t see the hours coughing. Or the hours laughing. You don’t see the mountain of pills I’ve taken. The hours of physio. You don’t see me having to avoid meeting others with the same condition. The chance of catching an infection is simply too dangerous for us both. You’ll just see me. See me grow. See me cough sometimes. See me try to live a life unlimited.”

Kieron, who has CF and featured in our campaign posters and video



Celebrity engagement

Our celebrity ambassadors and supporters continued to help raise awareness and lend their support to key projects, including our big fundraising campaigns such as Wear Yellow Day and FeBrewary. Jenny Agutter, Richard Madeley and Vincent Franklin got behind our Cost of CF work by featuring in a video which told real-life stories from the CF community.

Jenny Agutter and Richard Madeley were interviewed for various publications across the year, including The Express, Candis Magazine and Fabulous Magazine. Olympian Roger Black and comedians Tim Key and Chris McCausland all appeared on celebrity editions of family favourite TV game shows, such as Mastermind and Pointless, to raise money for the Trust.

In March 2023, we were delighted to announce our newest official ambassador, James Dunmore.

A huge thank you to our celebrity ambassadors and supporters who help us to raise vital awareness.



CELEBRITY INTERVIEW

Back on track

Much-loved actor **Jenny Agutter** talks to Roz Lewis about her return to *The Railway Children* and the charity she espouses

From her home in London, Jenny Agutter is apologising for looking less than immaculate, while looking pretty much immaculate; wearing a soft grey polo neck, hair in a stylish bob.

This month sees the *Call the Midwife*, Hollywood and RSC actor back on the big screen in the film, *The Railway Children Return*. Based on the book by Edith Nesbit, the 1970 film *The Railway Children* tells the story of three children: Roberta (Bobbie), Phyllis and Peter, who move from London to a house near a railway in Yorkshire with their mother after their father unexpectedly goes away.

Reprising her famous role as Bobbie Waterbury – who she played in the BBC series and in the iconic Lionel Jeffries film – Jenny, now 69, was delighted to be given the chance to be in the sequel, the only actor from the original film to do so. "*The Railway Children* played an important part in my life," says Jenny. "I loved the idea of revisiting the role in a different time and liked the script, which pays tribute to Nesbit's story and Lionel Jeffries' film. This new film very much wanted to be in the same locations, so was filmed back in Haworth and at Oakworth station, which was a real trip down memory lane."

It is the fourth time Jenny has been involved in a *Railway Children* project, now part of the childhood of many generations. As well as the BBC television series in 1968, filmed when Jenny was just 14 and at ballet school,

Below Jenny Agutter and Sheridan Smith in *The Railway Children Return*

14 JULY 2022 | CANDIS.CO.UK



Chris McCausland appearing on Celebrity Mastermind

Sharing stories from our community

We strive to share diverse and new stories from our community through our blogs and video content, which continues to grow. This year, we've developed videos which cover a range of topics such as CF research, menopause, mental health, breastfeeding, and what it's really like living with an invisible condition. We listen to our community to share what's important and relevant to them, keeping them involved every step of the way to ensure we're telling their stories in their own authentic voices.

> **"I'm in high school with CF and sometimes feel a bit different. It is a hard time for anyone being a teenager, but sometimes I feel no one understands me. But then I listened to your podcast and I felt you and the Trust understood. I feel like I'm in the room with you and you're my friend."**
>
> Lizzie, podcast listener



Lucy Baxter, host of the CForYourself podcast

CForYourself podcast

Our podcast launched in June 2022 with host Lucy having a cup of tea and a chat with others in the cystic fibrosis community where they talk openly and honestly about a whole range of topics, from exercise and employment to parenting and mental health. Each episode features a CF expert, who shares their knowledge and advice for everyone affected by CF.

CForYourself is all about sharing honest insights into life with cystic fibrosis, the good, the bad and everything in between and has been a huge success with our community – and beyond. Whilst most of our listeners are in the UK, we've also reached the CF community across the world, from Australia to the United States, Africa and beyond.

6 episodes, 1182 downloads, most popular episode: CF and mental health, demographic: (according to Spotify): 28-34 (32%) and 63% female, reach: worldwide

> **"From the moment that I was asked to host this podcast, I knew that I wanted it to be really special and open and vulnerable so that people with CF or help with people with CF can understand and relate to something."**
>
> Lucy Baxter, CForYourself podcast host



Website

We launched our new website in March 2021 and have continued to improve the user experience based on analysis, polling, user testing, and internal feedback. In March 2022, the website was redesigned in line with the overall brand refresh, and in June 2022, we launched a new community forum which now has over 700 active contributors and has been very positively received by our supporters.

We are continuing to improve the website with a current focus on navigation and personalising content for our different audience groups. We're also carrying out a content audit to ensure our content is as relevant and accessible as it can be.

Volunteering

Over the last year, we've been really grateful that the hard work of our volunteers, supporters, branches and groups has continued despite the cost of living crisis. Our volunteers come from a wide range of backgrounds and are at different life stages, ranging from those who already have a connection to CF, to university students, people working directly for companies partnering with the Trust, or those who have more time to give in their careers and want to use the skills they have developed to help us do more for people with CF. Since the pandemic, we've opened up more volunteering activities from home, which has allowed some volunteers to continue to support us that otherwise couldn't.

Being an effective organisation

The Trust's ability to achieve our vision depends on our effectiveness as an organisation, which is supported by our employees' and volunteers' skills, passion and energy. For employees, we nurture this by providing a positive working environment and employee benefits that we know from their feedback that our staff value, such as flexible working; holiday and parental leave allowances which exceed statutory requirements; learning and development opportunities; and good communication, such as regular briefings led by our CEO.

The Executive Team shares information with the People Committee on key human resources measures, which show how we are doing in areas such as staff turnover, sickness absence and participation in learning and development activities and update the Trustees on projects designed to enhance the engagement of our people and to make the Trust a welcoming and inclusive place to work. The People Committee also reviews the outcomes reported from the annual staff survey, which again this year had a high response rate of 78% and saw improved scores for most areas. We are extremely grateful for the efforts of our staff and volunteers during a challenging year.

The pressures on people with CF have been magnified by the cost of living crisis over the last year, which has resulted in a high volume of work for all teams at the Trust. As we move into 2023/24, we are in the process of introducing a newly refreshed set of values; planning activities to make our workplace even more inclusive; implementing a more streamlined recruitment process; and further improving learning and development.

Uniting in fundraising




Uniting for
a life unlimited
Cystic
Fibrosis Trust
Uniting for
a life unlimited
SINCE 1987

We would like to thank all the fantastic individual donors and supporters, organisations, charitable trusts, foundations and corporate partners who support our work to make sure everybody with CF can live a life unlimited. We know everyone is feeling the financial pressure much more this year, and that makes your support so incredibly special to us. We greatly appreciate everything you do for the CF community – we couldn't do it without you.

We aim to exceed the standards included in our promise to our supporters:

We will be transparent about our work

We will be respectful

We will listen and respond

We are committed to high standards

We are fair and responsible

Voluntary income at the Trust has been significantly impacted by the cost of living crisis this year, which has been challenging as we continue to build back after the reduction in income due to COVID-19. In 2022/23, £6.45 million gross income was raised compared to £7.4 million in 2021/22 and £4.29 million net income. The difference was due to a decrease in income from community, events and individuals as a result of the cost of living crisis, alongside a significant reduction in gifts in wills income of over £680,000 due to house sales falling through and the delays at the probate office and HMRC. Overall, this represents a 42% reduction in net income compared to pre-pandemic income in 2019-20.

We continue to innovate and adapt our fundraising plans. Examples of new innovations include a new look for Wear Yellow Day, our continued focus on engaging schools with fundraising and a new gaming proposition which will be launched in autumn 2023. We are now able to use Whatsapp to improve communication with event participants.

Our trustees agree and regularly review our fundraising strategy. We adhere to Data Protection Law and the Fundraising Preference Service. We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice and, as such, commit to their Fundraising Promise.





Some of our fantastic Wear Yellow Day fundraisers

Supporter experience

The Trust received 19 complaints in 2022/23. This is broadly in line with the 24 received in 2021/22 and lower than our pre-pandemic average, with the main areas of improvement being in the more effective use of data (fewer mailing related errors) and in dealing with sensitive subjects (like bereavement). Complaints are closely monitored and reviewed by senior management on an ongoing basis. In addition, we regularly review our complaints policy and processes to make it easier for people to give us feedback and to ensure that we listen and learn from what our supporters and community are telling us.

We are continuously improving our website through custom iterative developments to improve the user experience so that our supporters can access the content they need as quickly and easily as possible. We continue to review the content across all of our platforms based on feedback we receive and the data we analyse so that our content is relevant, useful and accessible. This has included a full analytical content audit of our website, identifying what is most useful and any gaps in our content. We also take into account feedback from a number of different surveys across the year, including the Your Life and CF survey, feedback from our Helpline and social media as well as proactively requesting stories from the CF community to develop relevant and timely content on topics our community are telling us are important to them. Our key campaigns, including CF Week and our awareness campaign, went through various involvement testing with our community to ensure it reflected their experiences. This allowed for the co-creation of content and stories throughout, and both campaigns received positive feedback and engagement.



"I want to run for David, for every CF warrior and every person who's sadly lost their life to it. You are all so incredible and if running 26.2 miles is even a tiny show of admiration, I would do it a thousand times over."

Amelia, Team CF runner whose partner, David, has CF

Amelia and David

Community and event fundraising

This year our focus has been to continue to offer a portfolio of activity and campaigns to grow our income back to pre-pandemic levels. This growth has continued to be slowed by the impact of the cost-of-living crisis.

Our portfolio of activities aims to capture the imaginations of all our wonderful supporters who continue to support us, despite all the external challenges they face. We are extremely grateful to everyone who walks, runs, bakes, dresses in yellow and every other fundraising activity they undertake for us.

- Our Team CF runners took on an array of races across the country, including, Belfast City Marathon, Cardiff Half Marathon, Edinburgh Running Festival, London Landmarks, Royal Parks and London Marathon. The amazing runners who took part in these events raised a combined total of £480,000.
- Our loyal branches and groups across the country raised a fantastic £124,000.
- Our annual Wear Yellow Day continues to go from strength to strength and raised £110,000 with growing numbers of our incredible CF Mamas and schools.
- The 20th Anniversary of the Carols by Candlelight event raised £60,000.





"The Trust is such an amazing charity for the diverse work that they do to support people with CF and their families. Any amount of money raised for them will make a huge difference to the lives of thousands of people."

Robyn, Team CF runner who has CF

Robyn

Gifts in Wills

In 2022/23, we received 93 legacies from supporters who generously included a gift to the Trust in their Will, as well as 48 supporters who told us they have pledged a gift. We are incredibly grateful to those who have thought of us in this special way or are considering doing so, and we continue to raise people's awareness of legacy giving.

In Memory

We continue to remember with respect and affection those who have lost their lives because of cystic fibrosis, and we thank all our supporters who fundraise in memory of their loved ones. In 2022/23, more than £259,000 was donated in memory of those who are no longer with us, and many will continue to be remembered through our Book of Remembrance, tribute funds, and in the hearts of all who were close to them.

Regular gifts

We'd like to express our gratitude to our loyal regular donors who provide invaluable ongoing support that enables us to plan effectively for the future. These supporters contributed just over £834,000 in 2022/23, including Gift Aid. This year, we carried out a telemarketing campaign through Ethicall, our professional telephone fundraising agency. Ethicall have a respect and dignity policy that turns marketing calls into thank you calls if they suspect the person that they are speaking to is vulnerable. These campaigns (a regular giving upgrade and a direct debit recruitment campaign) resulted in an additional annual income of £15,000.



"Continuing to raise awareness of CF is really important to me. The amazing strides that have been made in treatments in the time since my sisters passed away is astounding and a true reflection of what is possible with increased awareness and funds."

James Dunmore



James Dunmore

Philanthropy

The support we receive from charitable trusts, foundations and individual supporters has been more important this year than ever.

Many in the CF community are feeling the pressure of the cost of living crisis. To respond to this need, we launched our Cost of Living Support Package in October 2022, which was made possible by the support of generous donors. Thanks to those who contributed to our Cost of Living appeal, we were able to provide grants to 341 of the most vulnerable households this winter.

We have been supported by generous individuals who are longstanding supporters of our work. We are so grateful for the continued support of our Sixty Five Roses Club, which celebrated its 10th anniversary in 2022. The past decade has seen incredible advancements in CF care and treatments, changing what it means to live with the condition today.

Members of our Sixty Five Roses Giving Club have been on this journey every step of the way; raising over £700,000 over the last decade in support of our mission to ensure everybody with CF can live a life unlimited.

We are able to continue our critical work and plan effectively thanks to the support of trusts and foundations who provide multi-year donations and grants, particularly committed partners such as the Joseph Levy Foundation, BBC Children in Need and Rosetrees Trust. We are grateful for our new partnership with the National Lottery Community Fund, enabling us to set up our employment programme, Work Forwards.

Support has grown for our Innovation Hub, which has raised £3.4m to date with income received and pledges. We are particularly grateful to AJN Steelstock, Robert Luff Foundation and Garfield Weston Foundation for their continued support, among many others.

Corporate Partnerships

Over the last year, the corporate partnerships team have continued to strengthen relationships with existing partners and build new partnerships to raise funds and awareness for Cystic Fibrosis Trust.

We were delighted to be chosen as LaingBuisson's Charity of the Year 2022 through a nomination from an employee who has cystic fibrosis. For Wear Yellow Day, a team from LaingBuisson walked 32 miles from their office in Berkhamsted to London. They completed it in 12 hours and walked 75,000 steps! In addition, the LaingBuisson Awards raised nearly £8,000 on the night from a silent auction and donations.

We value the ongoing support from our advertising partners, such as Clear Channel, promoting our awareness campaigns, through gift-in-kind outdoor advertising and campaign advice. We would also like to thank Bip, who we have been working with since 2019 (as Chaucer), and have donated advice as well as joining the assessment panel for the Helen Barrett Bright Ideas Awards and running workshops for our 60th Anniversary.

We are grateful for fundraising through AmazonSmile, which has raised over £45,000 for the Trust in the five years before its closure in February 2023.

Thank you again to our sponsors for UK CF Clinical Trials Conference, the CF Registry Annual Meeting, and UKCFC, who we look forward to working with again this year.

Looking to the future and building effective partnerships





Uniting in research for a life unlimited

While a long-term aim of the Trust is to tackle the underlying cause of CF, leading to the development of potentially novel and innovative future treatments and care, we also need to continue to pursue research that will improve the health and wellbeing of people living with CF today.

With the recent breakthrough in access to highly effective modulators for a significant proportion of the CF community comes new health and research challenges for all people with CF. The research we fund, support and prioritise through the Trust must continue to be informed by and address the changing needs and priorities in CF.

The results of the James Lind Alliance CF Research Priority Refresh project conducted as a partnership between the Trust, the James Lind Alliance, and the University of Nottingham will guide the direction of future research funding and support.



Delivering our strategy

Our response during the pandemic and cost of living crisis highlighted how important it is that we demonstrate our relevance to our community by stepping up and addressing emerging issues during periods of crisis and change. As such, we have invested additional time, effort and resources into addressing the new and emerging challenges facing the cystic fibrosis community across the three following goals:

- physical wellbeing: together, we can live without the physical challenges of cystic fibrosis.
- mental wellbeing: together, we can manage the mental pressures of cystic fibrosis.
- fulfilment: together, we can lead the life we want as part of a connected community.

To achieve these ambitious goals, we will work with our community and partners across the UK and internationally to support innovative, high-quality research, achieve access to the best treatments, drive up the quality of care and provide and advocate for the support needs of people with cystic fibrosis.

We also know that to deliver on this vision we need to adapt and change as an organisation, including a greater focus on:

- putting people with cystic fibrosis at the heart of everything we do
- building international and domestic partnerships
- optimising our working culture
- being great and innovative fundraisers
- making effective use of data and analytics, including implementing our new data strategy and a new quantitative impact framework
- working in ways that bring together our diverse community and staff, including developing a new equality, diversity and inclusion strategy.

Being great fundraisers

Raising funds and growing our income back from the impacts of COVID-19 and the cost of living crisis is vital to enable us to continue our work to support people with CF to live a life unlimited. We understand the financial pressures everyone is experiencing, and it makes the continued support of the CF community so incredibly special to us. We will continue to work closely with our incredible supporters, branches and groups at a local level and with our trusts, donors and corporate partners.

In order to provide the very best experience when supporting the Trust, we will continually review and update our engagement and processes. We also want to strengthen our insight and analysis to ensure we understand the needs of our supporters and we are making the best decisions.

Innovation remains a key pillar of our fundraising strategy to diversify our income and engage new supporters. We will ensure our portfolio of activity includes new products and fundraising activities to test and learn from. Maximising the potential of our key campaigns continues including Wear Yellow Day, engagement with schools and gifts in wills, in addition to our challenge events, community activities and ways to donate. We are looking forward to launching our updated gaming proposition, #Game4CysticFibrosis in the Autumn of 2023 and marking our 60th anniversary in 2024.



Campaigning hard

Through our Cost of CF campaign, we will continue to highlight the additional financial burdens faced by the cystic fibrosis community – and expect to publish new data on this in mid-2023. Alongside this campaign, our core mission of ensuring as many people as possible can benefit from access to innovative new treatments continues, with the NICE appraisal of modulator therapies hopefully concluding in the autumn of 2023, and coinciding with a renewed focus from the government on research investment, particularly around antimicrobial resistance.

Day-to-day support

We want to make sure our support reaches as many people affected by CF as possible. This year, a significant development was the launch of a WhatsApp service, providing a new route for people to access our Helpline support.

As the landscape of cystic fibrosis changes, we've continued to evolve our support to meet the needs of everyone with CF. We launched our new Work Forwards employment programme, supported by the National Lottery Community Fund, which provides dedicated employment and careers advice to people with CF and those who care for them. This personalised support involves one-to-one and group sessions, exploring everything from CV writing to reasonable adjustments at work. The programme will support people affected by CF move towards secure, fulfilling work – whatever that means for them – and a sustainable financial future.

The past few years have been challenging and continue to leave a legacy on the mental health of many in the CF community. We've continued to support people with the impact of new treatments, both for those who have seen dramatic improvements in health, and for those who haven't. We re-launched our online forum this year, providing a safe-space for people to come together and share their experiences. We've also worked with people affected by CF and CF professionals to update our grants programme, with a focus on supporting the overall health and wellbeing of those who most need support to live well with CF.



UK CF Registry

The UK CF Registry Annual Report 2022 will be published later in 2023, followed by the Annual Registry meeting in Autumn allowing colleagues across the UK to meet in person and share best practice. The Data Validation Visit programme relaunched earlier this year, with a new hybrid meeting format of in person and online.

The initial wave of the programme will conclude in 23/24, and our data validation report will be published. Following submission to NICE of the final analysis report of the CFTR modulators in 2023, the Registry team will work with our collaborators on a publication of the final results and continue to provide input into the ongoing appraisal process.

After the merger of the Data and QI Directorate with the Research Directorate, the team continue to find collaborative opportunities and projects across the health data and research landscape, supported by the Senior Health Studies Development Manager, a new role in the team.

Quality improvement

In 2023/24, the QI team will report on findings from the second cycle of our patient experience survey in children's services and will provide bespoke feedback to all CF centres that took part. The team is also developing a follow-up offer for CF centres to support them to explore their findings and plan targeted quality improvement activities once they have received their bespoke data summaries.

In the autumn, new data will be collected on staffing levels in CF services, and the team will launch the second cycle of our patient-reported experience survey in adult CF centres.



Financial review




#TeamCF

Results for the year

The final result for the year, including movements on investments, was a surplus of £1.7m (2022: surplus of £0.1 million). This increase in surplus is driven by a small number of one off items including £1.0m (2022; £nil) income from a revenue share agreement with the Gene Therapy Consortium/Boehringer Ingelheim and a further grant of £0.6m from the Medical Research Council as part of their UK Government Covid Medical Research Charity Support Fund.

Due to the cost of living crisis, the underlying financial trend is that generating voluntary income is challenging whilst costs are increasing.

Income

The Trust's income from normal activities for the year to March 2023 was £14.7m, a reduction of £1.0m (6%) compared to the previous year.

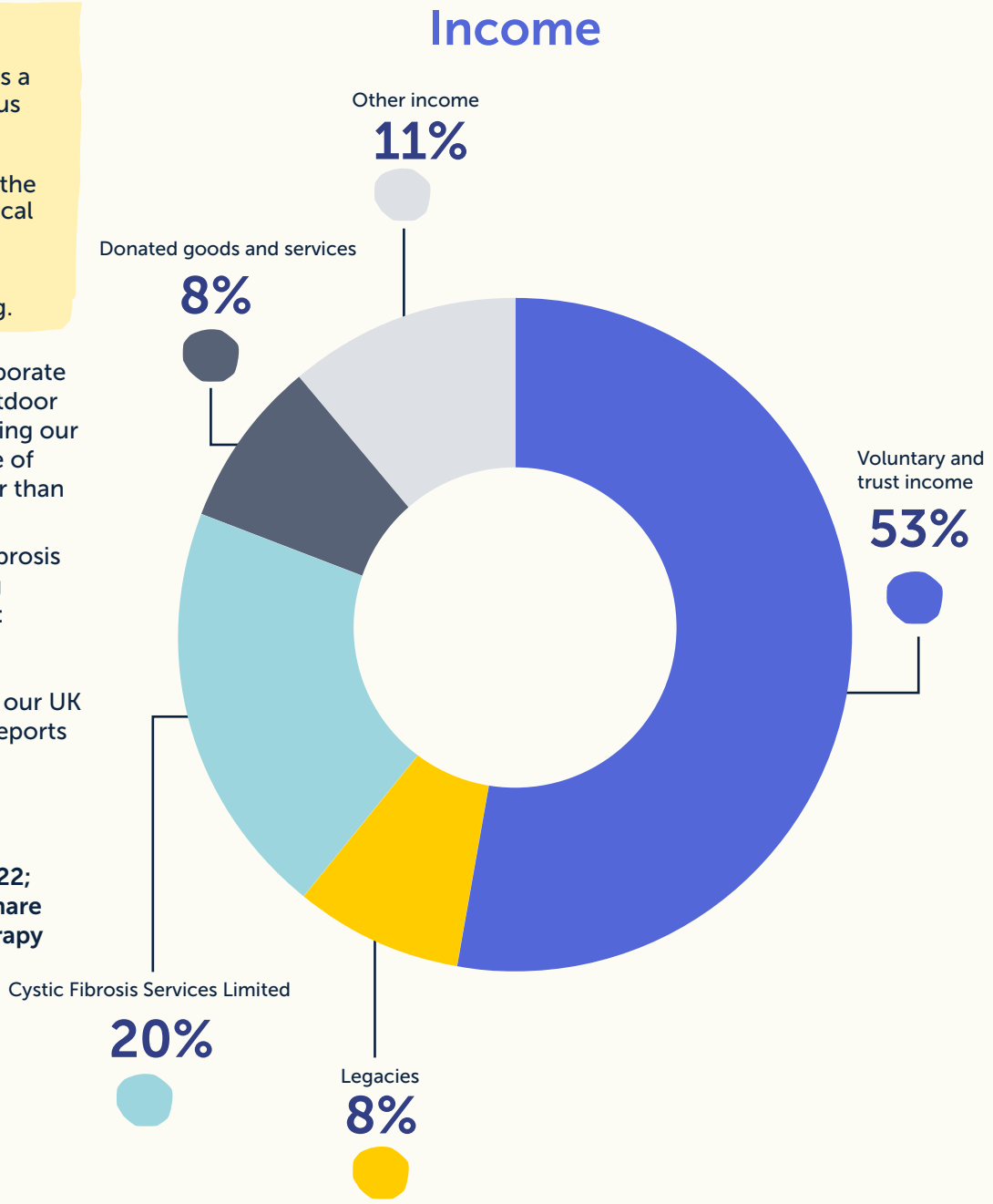
Voluntary and trust income of £7.8m (2022: £7.8m) includes regular giving programmes and appeals, from branches, groups and communities, corporate partnerships and trusts. In common with many charities, the on-going cost of living crisis means that generating income remains challenging. Income in 2023 is significantly below that generated in 2019 (£9.2m).

Legacy income of £1.2m (2022: £1.9m) has been impacted by pressures in the housing market meaning property left in estates can be difficult to sell or sells at lower values than in recent years. Processing delays at the probate office also contribute to the £0.7m reduction in legacy income compared to last year.

We benefit from generous corporate donations in kind including outdoor advertising and advice supporting our campaigns. However, the value of these services was £0.7m lower than in 2022.

Income generated by Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £2.9m (2022: £3.7m). This income is mainly generated from contracts with pharmaceutical companies for our UK CF Registry to produce study reports for the regulators of medicinal products.

Other income of £1.1m (2022: £0.1m) includes the £1.0m (2022; £nil) income from a revenue share agreement with the Gene Therapy Consortium.



Expenditure

The Trust's total expenditure for the year was £12.8m, a £3.2m (20%) reduction compared to the previous year.

Expenditure on charitable activities in the year was £9.4m (2022: £11.8m). This includes funding research, providing information and advice and support and supporting clinical care. The reduction in expenditure is mainly as a result of focusing on research projects most likely to address our priorities; £3.3m of grants were awarded in 2023, compared to £5.5m in the year to March 2022.

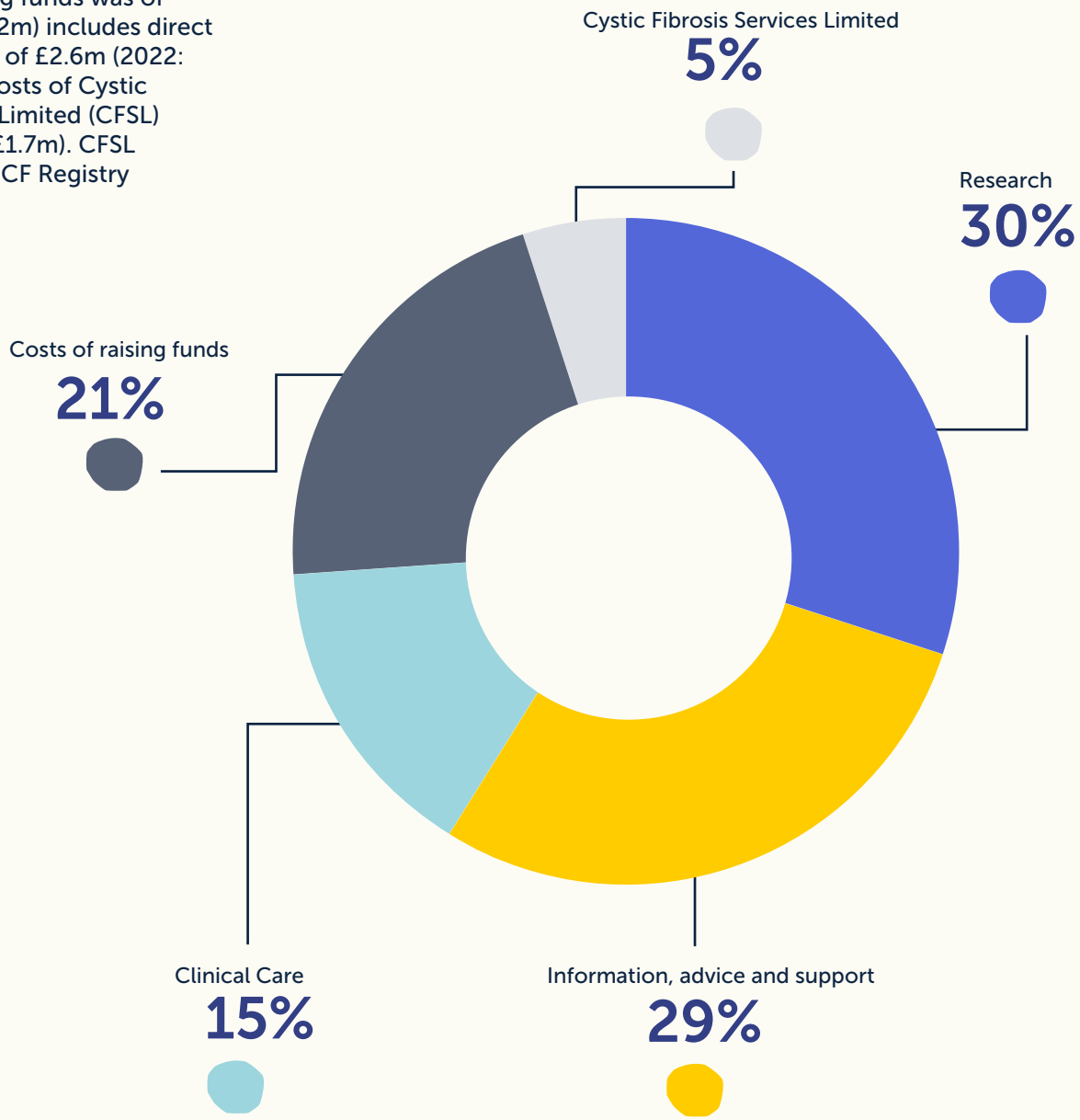
Grants to support charitable activities include:

- £2m (2022: £4.5m) grants to a range of medical and charitable institutions to support research. The Trust continues to seek funding and co-funding to enable it to increase funding for this vital research.
- £1m (2022: £0.7m) to fund the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme
- £0.3m (2022: £0.3m) to individuals through our Welfare Grant programme.

(The total grants awarded are detailed in Note 5 to the financial statements.)

The cost of raising funds was of £3.3m (2022: £4.2m) includes direct fundraising costs of £2.6m (2022: £2.5m) and the costs of Cystic Fibrosis Services Limited (CFSL) of £0.7m (2022: £1.7m). CFSL costs include UK CF Registry Support grants.

Expenditure



Investment policy

The Finance Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to adopt a balance between generating a sufficient income to support the on-going activities of the Charity, whilst maintaining the real capital value of the investments over the long-term.

The majority of the general fund portfolio is kept in liquid Funds although there is some exposure to less liquid assets such as property. Approximately 77% of the portfolio is now invested in the Responsible Multi-Asset Fund which aims to have a positive impact on people and the planet by avoiding harm through environmental, social, and governance integration and exclusions, benefiting stakeholders through responsible business activities and contributing to solutions through influence and investing for impact. The Trust does not permit direct investment in tobacco.

A number of small endowment funds are invested on a total return basis, enabling the Trust to utilise both income generated by the funds and increases in capital value, while protecting the original inflation-adjusted endowment values.

We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance Committee.

Review of investments in the year

The value of the investment portfolio (including endowment funds) was £5.4m at 31 March 2023 (2022: £5.6m). This is a reduction of £0.2m due to mainly unrealised investment losses due to the challenging year for both equities and bonds. No change was made tothe allocation between amounts held as stocks and shares and that held as cash. Income generated on investments totalled £0.3m which is £0.2m more than in 2022 and reflects increasing interest rates.

Reserves

The Trustees have a policy of maintaining Unrestricted Reserves, excluding designated reserves, in the range above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £3.6m and £5.8m.

At 31 March 2023, after adjusting for the designated reserves explained below, the Trusts' Unrestricted Reserves were £8.6m. This level of reserves has allowed the Trustees to approve a business plan and deficit budget for the next financial year which maintain services and grant awards at a level similar to previous years despite the continued challenge of returning income to pre Covid pandemic levels. Unrestricted reserves are forecast to be c£6.0m at March 2024 meaning that the Trust will be operating only marginally above its reserves policy.

The Trustees have opted to designate unrestricted reserves for the following purposes:

- Organisational reserve: £1m (2022: £nil) has been established for investment in process improvement and our digital/data strategy, including implementation of a new Customer Relationship Management (CRM) system.
- Fixed asset reserve of £0.16m (2022: £0.02m). The reserve is maintained as fixed assets cannot be readily realised as cash.

The trust also holds Endowment and restricted funds:

- Endowment funds – The Trust maintains a number of endowment funds where the donor require the Trustees to hold the funds as capital investments. Income from the investment can be used by the Trust as specified in the terms of the endowment. The Trust is not entitled to spend the capital fund without permission from the donor. At 31 March 2023 the endowment funds totalled £972,000 (2022: £1,046,000). See note 20 for information about the individual endowments.
- Restricted funds – Restricted funds are to be used for specific uses specified by the donor. Expenditure which meets the donor's criteria is charged against the specific fund. At 31 March 2023 restricted funds totalled £674,000 (2022: £271,000). Note 21 lists the individual restricted funds and their movement in the year.

Total reserves at 31 March 2023 were £11.4m (2022: £9.7m).

The Trustees will continue to keep the Trusts' reserves policy under regular review to ensure it is set at the appropriate level to reflect changes in the business outlook as they materialise.

Principal risks and uncertainties

The Board of Trustees is responsible for ensuring effective risk management and internal controls to manage the major risks the charity faces, including agreeing the Trust's 'risk appetite' (how much risk the Trust is willing to tolerate in key areas) and keeping oversight of the Trust's risk management framework. This framework, managed by the Senior Leadership Team, includes a strategic risk register and provides a consistent approach to identifying, assessing and dealing with the risks facing the Trust. It is monitored at least quarterly to support informed decision-making and ensure appropriate mitigations and controls are in place to effectively manage any risks to our objectives.

The main strategic risks and uncertainties that management and Trustees have identified and the key actions to mitigate these risks are:

Strategic risk	Strategies/plans for managing risks
Relevance	
• Failing to address the changing needs and expectations of people with cystic fibrosis • Failing to effectively get our message across to our community, key stakeholders and decision makers	• Our strategies and work programmes reflect the views and priorities expressed by people with CF through consultation, involvement and co-design. • We explore innovative new content and channels including podcasts, awareness campaigns and audience insight work. • We will build upon successes of access to medicines campaigns to pivot to new and emerging priorities including air quality, housing, poverty, CF care resourcing and benefits & welfare reform.

Strategic risk	Strategies/plans for managing risks
Financial	
• Failing to manage the impact of the cost of living crisis and other economic factors.	• Strategic financial framework and budget for 2023/24 includes measures to closely track income and expenditure including scrutiny from the Finance Committee. • Some cost savings already achieved, with further savings targets set over the next year. • Operating reserves will be maintained within policy.
Data	
• Failing to adequately protect the data we hold (especially the UKCF Registry)	• GDPR compliance framework; Data Protection Policies and DPO; ongoing staff training & oversight from Data Governance Group. • Regular penetration testing of website and Registry.

Strategic risk	Strategies/plans for managing risks
People • Failing to attract, retain and support a high quality and diverse group of staff. • Failing to safeguard young people & vulnerable adults.	• Comprehensive range of policies in place covering welfare, safeguarding, recruitment & retention, learning and development and employee benefits. • Development of EDI Strategy • Values refreshed and launched • Board safeguarding lead appointed
Reputation • Failing to proactively consider and prevent reputational issues in advance. • Failing to respond to damaging events in a timely and appropriate manner.	• Comms policies & processes in place to ensure quality control, including 'red flag' processes on potentially sensitive communications. •Clear and tested communications plans and processes in place to highlight and escalate contentious issues or complaints, agree public response and internally reflect on lessons learned.

Processes in place regarding risk management and internal control include the following:

- A risk management framework that meets the Charity Commission's requirements. A top-down risk review by the Senior Leadership Team, and a bottom-up review by individual functions, is undertaken throughout the year and the risks identified through this process are documented in a risk register.

- The Finance Committee receives reports from the external auditors on the effectiveness of controls and, where appropriate, adopts the recommendations made in the external auditors' reports.

- The Board of Trustees receives a comprehensive risk management report each quarter to assist it in ensuring that an effective process is in place. This report provides an update on the risk reviews undertaken and provides the Board with the opportunity to engage in dialogue about, and to provide input into, the evaluation and management of key risks.

- Formal project delivery groups are established for major projects and programmes to ensure that these are carefully planned, managed and implemented.





Our work with the pharmaceutical industry

Our mission is to make sure everyone can live without the limits of cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

Partnerships between medical research charities and the life sciences industry can help us deliver that mission and bring huge benefits to patients including accelerating the development of new drugs and ensuring the safety and improvement of existing treatments.

We run the following flagship programmes involving pharmaceutical industry partners:

Clinical Trials Accelerator Platform

CTAP is a UK-wide initiative bringing together CF Centres to increase participation and access to CF clinical trials. This initiative is building infrastructure and funding additional research capacity to support the life sciences industry with commercial clinical trial delivery.

As part of our collaboration with industry, CTAP offers a centralised feasibility service to support pharmaceutical companies with identification of suitable CF Centres for clinical trial delivery.

Venture & Innovation Awards (VIAs)

VIAs support transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the life sciences industry.

The UK Cystic Fibrosis Registry

Long-term safety and efficacy studies of drugs available to people with CF across the UK are supported by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the regulators of medicinal products is covered by pharmaceutical companies holding the market authorisation for these medicines. You can read more about our work with industry to make medicines safer at **cysticfibrosis.org.uk/registry**.

In 2022/23 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £2.9m (2022: £3.7m) in fees for this service. This income was used to support and maintain the Registry, including staff costs, data collection through Centre grants and IT hosting and development.



Sponsorship and donations

We seek sponsorship and grants from pharmaceutical companies to ensure we have the funds to run the events that we know are so important for healthcare professionals and people affected by cystic fibrosis. These events enable us to keep these audiences informed on all aspects of clinical care and research.

We would like to thank Gilead, Vertex and Chiesi who provided sponsorship for the UK Cystic Fibrosis Conference (UKCFC). We also received sponsorship from Vertex for the Annual Registry Meeting held in November 2022.

The Trust organised the UK CF Clinical Trials Conference in March 2023 at the ICC, South Wales. We again received an Independent Medical Education (IME) grant from Vertex towards the cost of the event and they were the sole sponsors.



"I'm proud of being part of the conversation and shaping how the Trust supports the CF community. With my social work background, I know how important it is to respond to the community's needs. I was involved in shaping the new advertising campaign, and I really appreciate getting to input on projects like that to ensure CF is represented honestly and fairly."

Sophie Pierce, Trustee


Sophie Pierce

Statement of Trustees' responsibilities

The Trustees, who are also directors of the Cystic Fibrosis Trust for the purposes of company law, are responsible for preparing the Trustees' report (including the Group Strategic Report) and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group, and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently,
- observe the methods and principles in the Charities SORP,
- make accounting estimates that are reasonable and prudent,
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustees investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware,
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustee's Report incorporating the Strategic Report was approved and authorised for issue by the Board of Trustees on **28 September 2023** and signed on its behalf by:



Richard Hunt, Chairman

Independent auditor's report to the members and trustees of Cystic Fibrosis Trust

Opinion

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2023 which comprise the Consolidated Statement of Financial Activities, Consolidated Income and Expenditure Account, the Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows, and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 March 2023 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Trustees' Annual Report and the Chairman's statement. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Annual Report (which includes the strategic report and the directors' report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements

- the strategic report and the directors' report included within the Trustees' Annual Report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the parent charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report (which incorporates the strategic report and the directors' report).

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charity Accounts (Scotland) Regulations (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept by the parent charitable company or returns adequate for our audit have not been received from branches not visited by us; or

- the parent charitable company financial statements are not in agreement with the accounting records and returns; or

- certain disclosures of trustees' remuneration specified by law are not made; or

- we have not received all the information and explanations we require for our audit; or

- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement (set out on page 67), the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the parent charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the parent charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion.

Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of noncompliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to fundraising regulations, charity and company law applicable in England, Wales and Scotland, and we considered the extent to which non-compliance might have a material effect on the financial statements.

We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Act 2011 and payroll taxes.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the completeness and cut-off of voluntary income, legacies, grant income and investment income. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud
- Evaluating management's controls designed to prevent and detect irregularities
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions
- Challenging assumptions and judgements made by management in their critical accounting estimates, in particular donation and legacy recognition, the recognition of grant income and the recognition of grant expenditure.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006.

Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Vikram Sandhu (Senior Statutory Auditor)
For and on behalf of Haysmacintyre LLP, Statutory Auditor

10 Queen Street Place,
London
EC4R 1AG

Date 10 October 2023

Cystic Fibrosis Trust

Consolidated statement of financial activities

For the year ended 31 March 2023

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2023 £'000**	Total Funds 2022 £'000
Income and endowments from:						
Donations and legacies	2	6,577	3,840	-	**10,417**	11,788
Charitable activities						
Other trading activities		2,873	-	-	**2,873**	3,703
Investments	3	279	-	-	**279**	78
Other income		1,097	-	-	**1,097**	112
Total income		10,826	3,840	-	**14,666**	15,681
Expenditure on:						
Raising funds	4	3,301	21	-	**3,322**	4,184
Charitable activities						
Research	4	3,122	644	-	**3,766**	6,457
Clinical care	4	696	1,251	-	**1,947**	1,345
Information, advice & support	4	3,360	377	-	**3,737**	3,982
Total charitable activities		7,178	2,272	-	**9,450**	11,784
Total resources expended	4	10,479	2,293	-	**12,772**	15,968
Net income/(expenditure) before investment gains/(losses)		**347**	**1,547**	**-**	**1,894**	(287)
Realised investment (losses)/gains		(32)	-	-	**(32)**	76
Unrealised investment (losses)/gains		(102)	-	(74)	**(176)**	366
Net investment (losses)/gains		**(134)**	**-**	**(74)**	**(208)**	442
Net income/(expenditure)		**213**	**1,547**	**(74)**	**1,686**	**155**
Transfers between funds	19	1,144	(1,144)	-	**-**	-
Net movement in funds		1,357	403	(74)	**1,686**	155
Reconciliation of funds:						
Total funds brought forward		8,354	271	1,046	**9,671**	9,516
Total funds carried forward	19	**9,711**	**674**	**972**	**11,357**	9,671

All of the operations are continuing.

There were no recognised gains or losses other than those stated.

A prior year comparative consolidated statement of financial activities has been included in the notes to the accounts (note 22).

The notes on pages 78 to 101 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated income and expenditure account

For the year ended 31 March 2023

	2023 £'000	2022 £'000
Income	**14,387**	15,603
Gains/(losses) on investments (excludes endowments)	**(134)**	379
Investment income	**279**	78
Gross income in the reporting period	**14,532**	16,060
Expenditure	**12,747**	15,950
Interest payable	**-**	-
Depreciation and charges for impairment of fixed assets	**25**	18
Total expenditure in the reporting period	**12,772**	15,968
Net income before tax for the reporting period	**1,760**	92
Tax payable	**-**	-
Net Income for the financial year	**1,760**	92

The consolidated summary income and expenditure account is derived from the statement of financial activities on page 72 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 78 to 101 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated and charity balance sheets

For the year ended 31 March 2023

	Notes	Consolidated		Charity	
		Total 2023 £'000	Total 2022 £'000	**Total 2023 £'000**	Total 2022 £'000
Fixed assets					
Tangible assets	7	**155**	19	**155**	19
Investments	8	**5,388**	5,604	**5,388**	5,604
		5,543	5,623	**5,543**	5,623
Current assets					
Debtors	9	**6,589**	3,948	**5,396**	2,824
Cash held as short term investment		**11,485**	11,265	**11,485**	11,265
Cash at bank and in hand		**3,430**	5,197	**2,734**	4,777
		21,504	20,410	**19,615**	18,866
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	10	**(2,799)**	(6,229)	(2,799)	(6,229)
Creditors and accrued charges	11	**(2,257)**	(2,708)	(2,500)	(3,107)
		(5,056)	(8,937)	**(5,299)**	(9,336)
Net current assets		**16,448**	11,473	**14,315**	9,350
Creditors: amounts falling due after one year					
Grants payable	10	**(10,464)**	(7,425)	(10,464)	(7,425)
Provisions: amounts falling due after one year	15	**(170)**	-	**(170)**	-
Total net assets		**11,357**	9,671	**9,224**	7,728

Continued on the next page

Cystic Fibrosis Trust

Consolidated and charity balance sheets (continued)

For the year ended 31 March 2023

	Notes	Consolidated		Charity	
		Total 2023 £'000	Total 2022 £'000	**Total 2023 £'000**	Total 2022 £'000
The funds of the charity:					
Endowment funds	20	**972**	1,046	**972**	1,046
Restricted income funds	21	**674**	271	**674**	271
Unrestricted funds	19				
Total designated funds		**1,155**	(1,266)	1,155	(1,266)
Operating reserves		**-**	3,411	-	3,411
Retained reserves		**8,566**	6,209	6,423	4,266
Total unrestricted funds		**9,711**	8,354	7,578	6,411
Total charity funds	19	**11,357**	9,671	**9,224**	7,728

The notes on pages 78 to 101 form part of these financial statements.

Approved and authorised for issue by the Trustees on 28 Septmber 2023 and signed on their behalf by:



Richard Hunt, Chairman
Company number 3880213

Cystic Fibrosis Trust

Consolidated Statement of cash flows

For the year ended 31 March 2023

	2023 £'000	2022 £'000
Net cash provided by operating activities (Note A)	**(1,669)**	1,728
Cash flows from investing activities:		
Dividends and interest	**279**	78
Purchase of property, plant and equipment	**(161)**	-
Purchase of investments	**(417)**	(1,082)
Movement in cash awaiting investment	**(16)**	8
Proceeds of sales of investments	**437**	1,108
	122	112
Increase in cash held as short term investments	**(220)**	(9)
Increase/(decrease) in cash (Note B)	**(1,767)**	1,831

Notes to cash flow statement

Note A – Reconciliation of net income to net cash flow from operating activities

	2023 £'000	2022 £'000
Net income for the reporting period (as per the statement of financial activities)	**1,686**	155
Adjustment for:		
Depreciation charges	**25**	18
Dividends and interest from investments	**(279)**	(78)
Losses/(gains) on investments	**208**	(442)
Increase in debtors	**(2,641)**	(647)
(Decrease)/increase in creditors	**(838)**	2,722
Increase in provisions	**170**	-
Net cash (used in)/provided by operating activities	**(1,669)**	1,728

Continued on the next page

Cystic Fibrosis Trust

Consolidated Statement of cash flows (continued)

For the year ended 31 March 2023

Note B – Reconciliation of cash and cash equivalents in the reporting period	2023 £'000	2022 £'000
Cash and cash equivalents at the beginning of the reporting period	**16,462**	14,622
Change in cash and cash equivalents in the reporting period	**(1,767)**	1,831
Increase in short-term investments	**220**	9
Cash and cash equivalents at the end of the reporting period (being cash at bank and in hand and cash held as short-term investments)	**14,915**	16,462

	2023 £'000	2022 £'000
Analysis of cash and cash equivalents:		
Notice deposits (less than 3 months)	**11,485**	11,265
Cash on hand	**3,430**	5,197
Total cash and cash equivalents	**14,915**	16,462

Cystic Fibrosis Trust
Notes to the Financial Statements
For the year ended 31 March 2023

1. Accounting policies

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

Basis of preparation
The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – (Charities SORP FRS 102), and the Companies Act 2006.

Cystic Fibrosis Trust meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Charity status
The charity (registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 102. In the event of the company being wound up, each member is liable for a sum not exceeding £1.

Consolidation
The financial statements include the results and assets and liabilities of the charity and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own statement of financial activities under section 408 of Companies Act 2006. The surplus of the parent charity was £1,496,000 (2022- deficit of £710,000).

Cystic Fibrosis Services Limited 's results for the year ended 31 March 2023 are summarised in note 13. The net surplus for the year of £2,134,000 (2022; £1,943,000) will be donated in full to the parent charity after the year end.

Income
All income is recognised once the charity has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably.

Donations and income from legacies are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable.

Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

Interest on funds held on deposit is recognised in the statement of financial activities when receivable and the amount can be measured by the Charity. This is normally upon notification of the interest paid or payable by the bank.

Investment income is recognised on a receivable basis and the amounts can be measured reliably. Dividends are recognised once the dividend has been declared and notification has been received the dividends are due.

Expenditure
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably.

Expenditure is recognised on an accruals basis as a liability is incurred and includes irrecoverable VAT where applicable.

Expenditure is classified under the following activity headings:

- Expenditure on raising funds comprises those costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs.

- Expenditure on charitable activities comprises those costs relating to activities where the primary aim is congruent with the objects of the charity, along with an apportionment of support costs. This includes grants made to research institutions and individuals, the provision of information and support services to people with cystic fibrosis and their families, peer reviews of cystic fibrosis centres and the development of the CF Registry.

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the direct costs in each activity category.

Grants payable are included in the statement of financial activities when approved and the intended recipient has either received the funds or has been notified of the award and has satisfied any initial conditions. Grants approved but not paid at the end of the financial year are accrued.

Foreign currency transactions
Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the statement of financial activities.

Employee benefits
Employee benefits are accounted for as follows:

- Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.

- Termination payments are accounted for on an accrual basis and in line with FRS 102.

- Pension contributions: the Charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Charity pays fixed contributions into a separate entity. Once the contributions have been paid the Charity has no further payment obligations. The contributions are recognised as an expense in the statement of financial activities when they fall due.

Taxation
No charge to taxation arises on the result for the year because the Charity can take advantage of the tax exemptions available to charities.

Leases
The trust recognises expenses under 'operating leases' relating to capital equipment which it does not own. The annual rentals are charged to the statement of financial activities on a straight line basis over the lease term.

Fund accounting
Endowment Funds are funds where the donor requires the Trustees to hold the funds as capital investments. Income from the investment can be used by the Charity as specified in the terms of the endowment. The Charity is not entitled to spend the capital fund without permission form the donor.

Restricted funds are to be used for specific uses laid down by the donor. Expenditure which meets the donor's criteria is charged against the specific fund.

Unrestricted funds are those which the Trustees are free to use for any purpose in furtherance of the charitable objects. The Trustees may set aside some of the unrestricted reserves for specific purposes, for example to fund a future project. These funds are classified as designated funds.

Fixed assets and depreciation
All assets costing £500 or more and with an expected useful life exceeding one year are capitalised.

Tangible assets are stated in the balance sheet at cost less accumulated depreciation. Depreciation is provided at rates designed to write off the cost of the cost of the assets, less any residual value, by equal annual instalments over their estimated useful lives at the following rates:

Furniture & fittings	33%
Computer hardware	33%
Computer software	33%
Website development	33%
Platform development	50%

Website and platform development costs are capitalised on the basis that they lead to an asset that will generate funds for the Trust or where the primary aim is part of the objects of the charity. The assets are depreciated once the asset is ready for use.

Investments
Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values of investments are shown as unrealised gains and losses in the statement of financial activities. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value.

Profits and losses on the sale of investments are shown as realised gains and losses in the statement of financial activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired during the financial year.

Financial Instruments
The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value:

- Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

- Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

- Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Critical accounting judgements and estimates
Preparation of the financial statements requires the Trustees and management to make significant judgements and estimates. These judgements and estimates are continually evaluated and are based on historical experience and other factors, including expectations of future events.

The items in the financial statements where judgements and estimates have been made include:

- estimating entitlement to legacy income particularly in relation to complex estates
- estimating the useful economic life of tangible assets for the purposes of determining depreciation rates
- providing for bad debts
- allocation of support costs
- estimating future income and expenditure for assessing cash flows to assess whether the Charity is a going concern (see below).

The value of the contribution of the many thousands of hours donated by its unpaid volunteers as not been reflected in these accounts. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

Going concern
The Trustees have reviewed the financial statements and supplementary financial information and conclude that the Trust is a valid going concern.

2. Income from donations and legacies

	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	Total 2023 £'000	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	Total 2022 £'000
Branches, Groups & Community	2,147	44	**2,191**	2,371	29	2,400
Legacies	1,240	3	**1,243**	1,593	321	1,914
Individual donations	383	74	**457**	364	93	457
Corporate	149	51	**200**	192	4	196
Regular giving and appeals	1,232	2	**1,234**	1,411	23	1,434
Trusts	13	3,056	**3,069**	94	2,521	2,615
Appeal for Innovation Hub	-	610	**610**	-	636	636
Donations in kind	1,234	-	**1,234**	1,892	-	1,892
Government grant income	-	-	**-**	129	-	129
NHS National Services England and Scotland	179	-	**179**	115	-	115
Total income from donations and legacies	6,577	3,840	**10,417**	8,161	3,627	11,788

Total income from donations and legacies includes gift aid of £411,000 (2022: £567,000).

Donations In Kind refer to non-monetary donations received from partner organisations. In 2023 £1,234,000 (2022: £1,892,000) was donated in the form of digital and cinema advertising space and professional fees. This was used to raise awareness of cystic fibrosis and the work of Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, Advice and Support.

Government grant income in 2022 related to the recovery of partial salary costs through the Job Retention Scheme during the COVID-19 pandemic.

3. Investment Income

	Unrestricted Funds 2023 £'000	Restricted Funds 2023 £'000	**Total 2023 £'000**	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	**Total 2022 £'000**
Income from listed investments	279	-	**279**	59	19	78
Bank interest	-	-	**-**	-	-	-
Total investment income	279	-	**279**	59	19	78

4. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2023 £'000**	**Total 2022 £'000**
Raising funds						
Fundraising	-	-	2,218	431	**2,649**	2,493
Trading and merchandising	-	609	64	-	**673**	1,691
Total raising funds	-	609	2,282	431	**3,322**	4,184
Charitable activities						
Research	601	1,345	1,182	638	**3,766**	6,457
Clinical care	999	58	572	318	**1,947**	1,345
Information, advice and support	164	103	2,861	609	**3,737**	3,982
Total charitable activities	1,764	1,506	4,615	1,565	**9,450**	11,784
Total resources expended	**1,764**	**2,115**	**6,897**	**1,996**	**12,772**	15,968

4. Expenditure (continued)

Support costs are apportioned based on the direct costs in each activity category

Analysis of allocated Support Costs – current year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2023 £'000**	**Total 2022 £'000**
Fundraising	41	59	140	60	131	**431**	**341**
Research	61	87	207	89	194	**638**	**886**
Clinical care	30	44	103	44	97	**318**	**184**
Information, advice and support	58	84	197	85	185	**609**	**546**
Governance	-	-	-	-	-	**-**	**-**
Total costs	**190**	**274**	**647**	**278**	**607**	**1,996**	**1,957**

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2022 £'000**
Raising funds					
Fundraising	-	-	2,152	341	**2,493**
Trading and merchandising	-	1,640	51	-	**1,691**
Total raising funds	-	1,640	2,203	341	**4,184**
Charitable activities					
Research	3,072	1,435	1,064	886	**6,457**
Clinical care	716	(61)	506	184	**1,345**
Information, advice and support	17	286	3,133	546	**3,982**
Total charitable activities	3,805	1,660	4,703	1,616	**11,784**
Total resources expended	**3,805**	**3,300**	**6,906**	**1,957**	**15,968**

4. Expenditure (continued)

Analysis of allocated support costs – prior year

	Governance £'000	Finance £'000	IT Support £'000	People & Organisational Development £'000	HQ & Facilities £'000	**Total 2022 £'000**
Fundraising	78	25	104	47	87	**341**
Research	203	67	269	121	226	**886**
Clinical care	42	14	56	25	47	**184**
Information, advice and support	125	40	166	75	140	**546**
Total costs	448	146	595	268	500	**1,957**

Net income for the year is stated after charging

	2023 £'000	2022 £'000
Auditors remuneration excluding VAT	**28**	20
Depreciation	**25**	18
Operating leases – building	**271**	272
Operating leases – other	**7**	5
Trustees' travel expenses	**2**	-

5. Grants

Grants were awarded during the year as follows:

	2023 £'000	2022 £'000
Grants to institutions	**3,565**	6,744
Grants to individuals	**314**	361
	3,879	7,105

Grants made to, and for, individuals affected by Cystic Fibrosis are for expenses such as respite care, building adaptations and equipment rental. These grants benefited a large number of individuals throughout the Charity's network of regions and branches.

During the year, grants were awarded to the following institutions:

	2023 £'000	2022 £'000
Innovation Hub Cambridge	241	1,500
University of Nottingham	115	880
University of Liverpool	17	-
UCL Great Ormond Street	46	750
University of Sheffield	753	-
University of Cambridge	121	365
Medical Research Council	50	267
Cystic Fibrosis Canada (Fibrose Kystique) CFC	116	141
RNID	-	105
Diabetes UK	-	105
Royal College of Surgeons in Ireland	96	-
MDC (CF AMR Syndicate)	20	95
Medicines Discovery Catapult Limited	81	-
Western General Hospital	78	-
University of Edinburgh	-	70
Imperial College London/Royal Brompton Hospital	100	70
Belfast City Hospital	-	50
Medusa Pharmaceuticals	50	-
Ockham Biotech Limited	50	-
University Hospital Llandough	-	45
Newcastle University	20	37
Aston University	-	25
The University of Manchester	-	23
Queen's University Belfast	26	-
Other Institutions (less than £20k)	28	39
	2,008	4,567
Trial Coordinator commitments made to CTAP centres (see note)	953	685
Registry support grants made to various CF centres	609	1,571
Release of grants made in previous years (see note below)	(5)	(79)
Total grants made to institutions	**3,565**	6,744

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform (CTAP) programme.

Various grants totalling £5,000 (2022: £79,000) were released during the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful.

6. Staff costs

	2023 £'000	2022 £'000
Salaries	**4,481**	3,898
Redundancy and other termination payments	**-**	34
Temporary Staff	**80**	16
Social security costs	**493**	412
Other pension costs	**270**	227
	5,324	4,587

No redundancy and other termination payments were paid in the financial year (2022: termination payment totalling £34,000 were paid to three members of staff).

Analysis of total average monthly headcount by category:

	2023 No.	2022 No.
Research	**17**	14
Clinical care	**8**	6
Information, advice and support	**38**	33
Fundraising	**36**	36
Management	**2**	2
Finance	**6**	5
IT and project management support	**8**	8
HR & OD	**5**	5
Facilities	**1**	1
Total average monthly headcount	**121**	110

(Remuneration includes employer National Insurance contributions and pension contributions.)

Pension contributions to defined contribution pension schemes for these employees totalled £66,370 (2022: £51,049).

The number of employees whose total remuneration exceeded £60,000 in the year was:

	2022 No.	2021 No.
£60,001 – £70,000	**9**	6
£70,001 – £80,000	**-**	2
£80,001 – £90,000	**2**	1
£90,001 – £100,000	**3**	2
£110,001 – £120,000	**-**	1
£140,001 – £150,000	**1**	-

The total remuneration paid to key management personnel, including pension and social security contributions, was £573,722 which relates to 7 individuals who served on the Senior Leadership Team during the year (2022: £584,529 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. £4,684 of expenses were settled on behalf of 5 Trustees (2021/22 – £154 was paid to 2 Trustees) as meetings were held equally in person and remotely during the period.

7. Fixed Assets

Group and charity	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 31 March 2022	**630**	**870**	**243**	**403**	**183**	**2,329**
Additions	-	59	43	59	-	161
Disposals	-	-	-	-	-	-
At 31 March 2023	**630**	**929**	**286**	**462**	**183**	**2,490**
Depreciation						
At 31 March 2022	**630**	**851**	**243**	**403**	**183**	**2,310**
Disposals	-	-	-	-	-	-
Charge for the year	-	20	-	5	-	25
At 31 March 2023	**630**	**871**	**243**	**408**	**183**	**2,335**
Net book value At 31 March 2023	**-**	**58**	**43**	**54**	**-**	**155**
At 31 March 2022	-	19	-	-	-	19

8. Investments

Group and Charity	Total 2023 £'000	Total 2022 £'000
Market value as at 31 March 2022	**5,604**	5,196
Adjustment to brought forward balance	**12**	(14)
Additions at cost	**417**	1,082
Disposals at opening book value	**(469)**	(1,018)
Net gains/(losses) on investments	**(192)**	366
	5,372	5,612
Change in cash	**16**	(8)
Market value as at 31 March 2023	**5,388**	5,604

Represented by:	Total 2023 £'000	Total 2022 £'000
Equities	**589**	343
Fixed Interest and multi-asset funds	**4,513**	4,767
Property	**162**	292
Cash	**124**	202
	5,388	5,604

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment. The only asset that presents more than 5% of total investments in either financial year is the Responsible Multi-Asset Fund. The Charity's holding at 31 March 2023 was £4,417,000 (2022: £4,566,000).

9. Debtors

	Group 2023 £'000	Group 2022 £'000	Charity 2023 £'000	Charity 2022 £'000
Trade debtors	**1,125**	1,124	**32**	-
Amount due from subsidiary undertaking	**-**	-	**-**	-
Prepayments and accrued income	**5,293**	2,784	**5,293**	2,784
Other debtors	**71**	40	**71**	40
	6,589	3,948	**5,396**	2,824

10. Grants Payable

Group and charity	2023 £'000	2022 £'000
Grant creditor at 31 March 2022	13,654	12,230
Prior year adjustment	-	(17)
Grants paid during the year	**(4,271)**	(4,019)
Grants approved before 31 March 2023 and payable within one year	**2,792**	3,379
Grants approved before 31 March 2023 and payable after one year	**1,088**	2,081
Grant creditor at 31 March 2023	**13,263**	13,654
Represented by		
Grants due within one year at 31 March 2023	**2,799**	6,229
Grants due after one year at 31 March 2023	**10,464**	7,425
	13,263	13,654

The Trust has considered the discounting of grant commitments due in more than one year but has not made any adjustments to the figures disclosed above as the impact of discounting is negligible.

11. Creditors

	Group 2023 £'000	Group 2022 £'000	Charity 2023 £'000	Charity 2022 £'000
Trade creditors	**610**	668	**600**	655
Other creditors	**36**	-	**36**	-
Other taxation and social security	**137**	108	**137**	108
Amounts owed to subsidiary undertaking	**-**	-	**257**	412
Accruals and deferred income	**1,474**	1,932	**1,470**	1,929
	2,257	2,708	**2,500**	3,104

12. Financial Instruments

	Group 2023 £'000	Group 2022 £'000	**Charity 2023 £'000**	Charity 2022 £'000
Financial assets measured at amortised cost	**16,145**	17,593	**14,224**	16,048
Financial assets measured at fair value	**5,388**	5,604	**5,388**	5,604
Financial liabilities measured at amortised cost	**(15,338)**	(16,255)	**(15,325)**	(16,238)
Net financial assets measured at amortised cost	**6,195**	**6,942**	**4,287**	**5,414**

The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Financial assets held at fair value include assets held as investments.

Financial liabilities measured at amortised cost include trade creditors, other creditors, accruals, grants payable, deferred income and amounts due to group undertakings.

13. Interest in subsidary undertaking

Cystic Fibrosis Services Limited is a company incorporated in England and Wales (company number 00900164) and is a wholly owned subsidiary of the Cystic Fibrosis Trust.

The subsidiary's activities include medical services, information and data system support and the merchandising of marketing materials.

Summary profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March 2023:	**Total 2023 £'000**	Total 2022 £'000
Sales and sundry income	**2,873**	3,703
Cost of sales and administration	**(673)**	(1,691)
Intercompany recharges	**(66)**	(69)
Net contribution to parent charity	**2,134**	1,943

13. Interest in subsidary undertaking (continued)

Summary balance sheet at 31 March 2023	Total 2023 £	Total 2022 £
Current assets		
Debtors	**1,450**	1,539
Cash at bank	**696**	420
	2,146	1,959
Creditors: amounts falling due within one year	**(12)**	(16)
Net assets	**2,134**	1,943
Capital and reserves		
Called up share capital (£2)	**-**	-
Profit and loss account	**2,134**	1,943
Shareholder's funds	**2,134**	1,943

The Charity owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd which comprises 100 ordinary shares of £1 each. Two shares have been allotted, which are called up and fully paid.

The subsidiary's profit for the year will be donated in full to the Cystic Fibrosis Trust after the year end.

14. Lease commitments

At 31 March, the Trust's future minimum operating leases payments relating to buildings were:

	Property		Equipment	
	2023 £'000	2022 £'000	**2023 £'000**	2022 £'000
Within one year	**271**	271	**5**	9
Between two and five years	**271**	543	**18**	14

Operating lease expenditure in the year is disclosed in note 4.

15. Provisions

The Charity's office at One Aldgate, London is under a lease that expires on 31 March 2025. Under the terms of the lease the Charity must restore the property to the condition prior to the Charity taking possession of the office. After seeking advice from surveyors, the Charity has made a provision of £170,000 (2022: £nil) for this work.

16. Related party transactions

The group has taken advantage of the exception which is conferred by FRS102 Section 33.1A 'Related Party Disclosures' that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

Total donation income from the Trustees in the period was £11,911 (2022: £14,428). In addition, 7 of the trustees (2022: 7) were involved in fundraising activities carried out by regional fundraising branches.

Four trustees claimed travel expenses totalling £2,000 in the year (2022: no trustees claimed expenses).

17. Post balance sheet events

There were no post balance sheet events or contingent liabilities when the accounts were signed and authorised for issue.

18. Analysis of net assets between funds

	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2023 £'000**
Tangible fixed assets	155	-	-	**155**
Investments	4,416	972	-	**5,388**
Current assets	20,830	-	674	**21,504**
Current liabilities	(5,056)	-	-	**(5,056)**
Liabilities due in more than one year	(10,464)	-	-	**(10,464)**
Provisions due in more than one year	(170)	-	-	**(170)**
	9,711	972	674	**11,357**

Prior year	Unrestricted £'000	Endowment funds £'000	Other restricted £'000	**2022 £'000**
Tangible fixed assets	19	-		19
Investments	4,558	1,046	-	5,604
Current assets	20,139	-	271	20,410
Current liabilities	(8,937)	-	-	(8,937)
Liabilities due in more than one year	(7,425	-	-	(7,425)
	8,354	1,046	271	9,671

19. Current year fund movements summary

	Balance 31 March 2022 £'000	Investment Gains/(Losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
The funds of the charity						
Endowment funds (Note 20)	1,046	(74)	-	-	-	**972**
Restricted funds (Note 21)	271	-	3,840	(2,293)	(1,144)	**674**
Unrestricted funds						
Designated reserves						
Organisational reserve	-	-	-	-	1,000	**1,000**
Fixed asset reserve	19	-	-	-	136	**155**
Appeal deficit	(1,285)	-	-	-	1,285	**-**
Total designated funds	(1,266)	-	-	-	2,421	**1,155**
Operating reserves	3,411	-	-	-	(3,411)	**-**
Retained reserves	6,209	(134)	10,826	(10,479)	2,134	**8,556**
Total unrestricted funds	**8,354**	**(134)**	**10,826**	**(10,479)**	**1,144**	**9,711**
Total charity funds	**9,671**	**(208)**	**14,666**	**(12,772)**	**-**	**11,357**

Movements in funds for prior periods are presented in note 23.

Designated Funds

- Organisational reserve: is designated for investment in process improvement and our digital/data strategy, including implementation of a new Customer relationship management (CRM) system.
- The designated fixed assets reserve matches the net book value of the charity's tangible fixed assets. These assets support the Trust's ongoing work and are not readily convertible to cash.
- Appeal Deficit. At the end of March 2022 the Trust had committed £3.8m in the form of a research grant to Cambridge University as part of the Innovation Hub flagship programme. At that date it had received £2.5m from donors in funding for this grant (shown in the separate restricted fund line, see note 21). The Trust has committed the to fund the commitment in full from new donations, and therefore there was a £1.3m funding deficit. Appeal income in the year to March 2023 of £1.3m means this deficit has been eliminated.

As explained on page **62**, retained reserves are held in the range above six months' core running costs and below six months' forecast unrestricted expenditure. We currently estimate this range to be between £3.6m and £5.8m. The Trustees have approved a business plan and deficit budget for the next financial year which maintain services and grant awards at a level similar to previous years despite the continued challenge of building income to pre Covid pandemic levels. Unrestricted reserves are forecast to be c£6.0m at March 2024 meaning that the Trust will be operating only marginally above its reserves policy.

Transfers between funds

The following transfers were made between funds:

- A transfer was made to establish the organisational reserve.
- A transfer was made to from the restricted income fund for the Innovation Hub at Cambridge to remove the appeal deficit fund as the deficit has now been eliminated.
- A transfer was made to the Fixed Asset Reserve to match the current balance on Fixed Assets
- Other transfers were made between Retained Reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been backfilled by restricted donations.

20. Endowment funds

	Balance 31 March 2022 £'000	Investment Gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
Ena Bennie Endowment	530	(39)	-	-	-	**491**
EW Joseph Endowment	175	(13)	-	-	-	**162**
Joseph Levy Endowment	293	(22)	-	-	-	**271**
Sally Wrigley Memorial Fund	20	-	-	-	-	**20**
Other Endowment funds	28	-	-	-	-	**28**
Total endowment funds	**1,046**	**(74)**	**-**	**-**	**-**	**972**

Movements in funds for prior periods are presented in note 23.

The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.

- The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.
- The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home.
- The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education.

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

21 Restricted funds

	Balance 31 March 2022 £'000	Investment Gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
Restricted Income Funds						
Appeal: Innovation hub at Cambridge	-	-	1,270	(241)	(1,029)	**-**
Restricted funds related to research						
Genetic therapies	-	-	3	-	(3)	**-**
General medical research	-	-	200	(200)	-	**-**
Sport England – Helping the active stay active	7	-	25	-	-	**32**
Imperial SRC: *Pseudomonas aeruginosa*	-	-	10	-	(10)	**-**
University of Sheffield: Preventing gastrointestinal cancer in cystic fibrosis	-	-	77	(20)	(57)	**-**
University College London: Therapeutic gene editing	-	-	16	-	(16)	**-**
University of Sheffield: Pulmonary magnetic resonance imaging for cystic fibrosis	-	-	366	-	-	**366**
UK CF infection biorepository	-	-	32	(32)	-	**-**
CF Active programme	-	-	5	(50)	45	**-**
Transition information resources	15	-	-	-	(15)	**-**
Quality Improvement project	35	-	-	-	-	**35**
Other research related restricted funds	4	-	-	-	-	**4**
Total funds related to research	**61**	**-**	**2,004**	**(543)**	**(1,085)**	**437**

21 Restricted funds (continued)

	Balance 31 March 2022 £'000	Investment Gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2023 £'000**
Restricted funds related to Information and Support						
EW Joseph/Homecare grants	3	-	-	(3)	-	**-**
Joseph Levy/Education grants	4	-	53	(46)	-	**11**
Building Brighter Futures	29	-	26	(39)	-	**16**
Support services (inc. welfare grants)	112	-	186	(160)	(45)	**93**
Work Forwards (England)	-	-	42	(29)	-	**13**
Work Forwards (Scotland)	-	-	12	(3)	-	**9**
Helpline	-	-	5	(5)	-	**-**
Forum	22	-	-	(9)	(13)	**-**
Helen Barrett Bright Ideas Awards	3	-	16	(19)	-	**-**
Total funds related to Information and Support	**173**	**-**	**340**	**(313)**	**(58)**	**142**
Other funds						
Coombe Hill	8	-	5	(13)	-	**-**
Clinical Trials Accelerator Platform (CTAP)	-	-	1,262	(1,262)	-	**-**
Digital Health programme	-	-	134	(134)	-	**-**
CTAP digital conference	(7)	-	43	(22)	-	**14**
Gut symptoms	-	-	39	-	-	**39**
Carols by Candlelight	-	-	12	(6)	-	**6**
Other older funds	36	-	1	-	(1)	**36**
Total other funds	**37**	**-**	**1,496**	**(1,437)**	**(1)**	**95**
Total restricted funds	**271**	**-**	**3,840**	**(2,293)**	**(1,144)**	**674**

Movements in funds for prior periods are presented in note 23.

Restricted income funds are donations received during the year to support the Trust's commitment to contribute £3.5m to Cambridge University as part of the Innovation Hub flagship programme are recorded as restricted income funds. The funds are used to fund any additional commitments to the Innovation Hub made during the year. Any surplus is the set against the designated appeal deficit fund (see note 19).

Restricted funds related to research are donations relating to grant commitments made by the Trust to research institutions.

Restricted funds related to information and support are donations to fund activities supporting people with cystic fibrosis and their families. These include:

- **EW Joseph home care fund** – grants to support adults and children with cystic fibrosis to be safe and comfortable at home through challenging times.
- **Joseph Levy Education grants** – funding people with cystic fibrosis in their education and studies.
- **Building Brighter Futures** – funding a youth programme supporting young people with cystic fibrosis. This fund is supported by BBC Children in Need.
- **Support Services** – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
- **Work Forwards (England)** – funding to support people with cystic fibrosis so that they can take advantage of opportunities, build new futures and strengthen their long-term financial resilience. This is supported by the National Lottery Community Fund (RC England Wide).

22. Prior year consolidated statement of financial activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	Total Funds 2022 £'000
Income and endowments from:					
Donations and legacies	2	8,161	3,627	-	**11,788**
Charitable activities					
Other trading activities		3,703	-	-	**3,703**
Investments	3	59	19	-	**78**
Other income:		112	-	-	**112**
Total		12,035	3,646	-	**15,681**
Expenditure on:					
Raising funds	4	4,183	-	1	**4,184**
Charitable activities					
Research	4	3,239	3,215	3	**6,457**
Clinical care	4	431	914	-	**1,345**
Information, advice and support	4	3,874	106	2	**3,982**
Total charitable activities		7,544	4,235	5	**11,784**
Total resources expended	4	11,727	4,235	6	**15,968**
Net income/(expenditure) before investment gains/(losses)		**308**	**(589)**	**(6)**	**(287)**
Realised investment gains/(losses)		5	-	71	**76**
Unrealised investment gains/(losses)		374	-	(8)	**366**
Net investment gains/(losses)		**379**	**-**	**63**	**442**
Net (expenditure)/income		**687**	**(589)**	**57**	**155**
Transfers between funds	23	(612)	612	-	**-**
Net movement in funds		75	23	57	**155**
Reconciliation of funds:					
Total funds brought forward		8,279	248	989	**9,516**
Total funds carried forward	**23**	**8,354**	**271**	**1,046**	**9,671**

Cystic Fibrosis Trust

Notes to the Financial Statements (continued)

For the year ended 31 March 2023

23 Prior year movements in funds Summary

	Balance 31 March 2021 £'000	Investment gains/(losses)	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
The funds of the charity:						
Endowment funds	989	63	-	(6)	-	1,046
Restricted funds	248	-	3,646	(4,235)	612	271
Unrestricted funds:						
Designated reserves						
Fixed asset reserve	37	-	-	-	(18)	19
Appeal deficit	(421)	-	-	-	(864)	(1,285)
Strategic reserve	200	-	-	-	(200)	-
Total designated funds	(184)	-	-	-	(1,082)	(1,266)
Operating reserves	3,448	-	-	-	(37)	3,411
Retained reserves	5,015	379	12,035	(11,727)	507	6,209
Total unrestricted funds	**8,279**	**379**	**12,035**	**(11,727)**	**(612)**	**8,354**
Total chairty funds	**9,516**	**442**	**15,681**	**(15,968)**	**-**	**9,671**

Endowment funds	Balance 31 March 2021 £'000	Investment gains/(losses) £0'00	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Ena Bennie Endowment	491	42	-	(3)	-	530
EW Joseph Endowment	165	11	-	(1)	-	175
Joseph Levy Endowment	285	10	-	(2)	-	293
Sally Wrigley Memorial fund	20	-	-	-	-	20
Other endowment funds	28	-	-	-	-	28
Total endowment funds	**989**	**63**	**-**	**(6)**	**-**	**1,046**

23 Prior year movements in funds Summary (continued)

	Balance 31 March 2021 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Restricted income funds						
Appeal: Innovation Hub at Cambridge	-	-	636	(1,500)	864	-
Restricted funds related to research:						
Genetic therapies	87	-	28	-	(115)	-
General medical research	-	-	438	(438)	-	-
Sport England - Helping the active stay active	7	-	-	-	-	7
Imperial SRC: *Pseudomonas aeruginosa*	-	-	15	-	(15)	-
Imperial SRC: Targeting immuno theraphy for fungal infections	-	-	4	-	(4)	-
Sheffield SRC: Gastrointestinal cancer	-	-	2	-	(2)	-
UCL/GOSH SRC: Therapeutic gene editing	4	-	41	-	(45)	-
Bristol SRC: CFTR folding and function	-	-	208	(208)	-	-
University College London: Pharmacological repair of bicarbonate transport in cystic fibrosis	-	-	375	(375)	-	-
Life expectancy project	(23)	-	-	-	23	-
Transition information resources	15	-	-	-	-	15
Quality Improvement project	-	-	35	-	-	35
Other research related restricted funds	(7)	-	5	-	6	4
Total funds related to research	**83**	**-**	**1,151**	**(1,021)**	**(152)**	**61**

23 Prior year movements in funds Summary (continued)

	Balance 31 March 2021 £'000	Investment gains/(losses) £'000	Income £'000	Expenditure £'000	Transfers £'000	Balance 31 March 2022 £'000
Restricted funds related to Information and Support						
E W Joseph/Homecare grants	18	-	7	(22)	-	3
Joseph Levy/Education Grants	(15)	-	37	(48)	30	4
Building Brighter Futures	28	-	50	(21)	(28)	29
Support services (inc. welfare grants)	80	-	148	(2)	(114)	112
Forum	-	-	-	-	22	22
CF Connect (youth and parents)	26	-	-	-	(26)	-
Helen Barrett Bright Ideas Awards	-	-	16	(13)	-	3
Total funds related to Information and Support	**137**	**-**	**258**	**(106)**	**(116)**	**173**
Other funds – various categories:						
Coombe Hill	8	-	-	-	-	8
SmartCare CF	(10)	-	-	-	10	-
Clinical Trials Accelerator Platform (CTAP)	(10)	-	914	(914)	10	-
Digital Health Research Programme (Project Breathe)	-	-	684	(684)	-	-
CTAP digital conference	-	-	3	(10)	-	(7)
CF Registry	(12)	-	-	-	12	-
Consensus documents	21	-	-	-	(21)	-
HDRUK grant award	(5)	-	-	-	5	-
Other older funds	36	-	-	-	-	36
Total other funds	**28**	**-**	**1,601**	**(1,608)**	**16**	**37**
Total Restricted Reserves	**248**	**-**	**3,646**	**(4,235)**	**612**	**271**

Structure, governance and management

Patron

- The former Prince of Wales, KG, KT, GCB, OM

Honorary President

- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees

Chair

- Richard Hunt CBE
- Professor Rosalind Smyth CBE FMedSci
- Sean Collins
- Anne Byrne
- Richard Hoey
- David Titmuss (resigned June 2022)
- Michelle Shore
- Joanna Barrett
- Sophie Pierce
- Sonya Trivedy
- Professor Martin Walshaw MD FRCP

Engagement Committee

(Previously Marketing, Communications & Income Generation Committee)

Chair

- Richard Hoey
- Sean Collins
- Joanna Barrett
- Sophie Pierce (appointed February 2023)
- David Titmuss (resigned June 2022)
- Joanne Hilditch – Independent member (resigned May 2022)

Finance Committee

Chair

- Sean Collins
- Anne Byrne
- David Sawer – Independent member
- Michelle Shore
- Ed Rushton – Independent member, Investments Committee
- Nick Wood – Independent member, Investments Committee

People Committee

Chair

- Michelle Shore
- Sonya Trivedy
- Joanna Barrett

Senior Leadership Team

- David Ramsden – Chief Executive
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising
- Rebecca Cosgriff – Director of Data and Quality Improvement (resigned June 2022)
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research and Healthcare data
- Simon Hawkins – Director of Finance and Resources (appointed February 2022, resigned June 2023)
- Alex Fowles - Director of Finance and Resources (appointed June 2023)
- Sarah Clarke - Associate Director, Data and Quality Improvement (appointed September 2022)

Company Secretary

- Alex Fowles

Principal and Registered Office

One Aldgate
London
EC3N 1RE

020 3795 1555
enquiries@cysticfibrosis.org.uk
cysticfibrosis.org.uk

Company Limited by Guarantee
Company registration number:
3880213
Charity registration number:
England & Wales —1079049
Scotland —SC040196

Auditors

Haysmacintyre LLP
10 Queen Street Place,
London EC4R 1AG

Bankers

Natwest Plc
15 Bishopsgate London EC2N 3NW

Investment Managers

Cazenove Capital Management
12 Moorgate London EC2R 6DA

Legal structure

Cystic Fibrosis Trust ('the Trust') is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1964 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

The Board of Trustees ('the Board') has full legal responsibility for corporate governance and all operations of the Trust, including determining its strategic direction.

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 10 Trustees with a range of skills. Several committees such as the Finance Committee, People Committee, Engagement Committee, Research Grant Review Committee and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Recruitment, induction and training of Trustees

Trustees consider the relevant skill set required to enable effective oversight and proper governance of the Trust. New Trustees are appointed after a rigorous recruitment process, which includes national advertising and can include recommendations.

Upon appointment to the Board, to help facilitate their understanding of the current issues concerning the Trust, each new Trustee is provided with information tailored to reflect any specific areas of responsibility. The new Trustee will meet with the Chair, Chief Executive Officer and staff working within their own specialist area.

Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Trust to the Chief Executive Officer, David Ramsden, and his Senior Leadership Team ('SLT').

The Chief Executive Officer and the SLT report to the Board both formally at the Board meetings and informally (as appropriate) throughout the year, thereby ensuring a regular flow of information to aid decision making.

The remuneration of key management personnel is determined by a recognised job evaluation framework which takes into account the skills required and the complexity of individual roles. The remuneration of the Chief Executive Officer is approved by the Board. For all other staff the process, including the award of annual pay uplift, is approved by the People Committee.

Public benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. In reviewing our aims, objectives and planning future activities, the Trustees have taken into account the Charity Commission's general guidance on public benefit. The Trustees ensure that activities undertaken are always in line with the charitable objectives and aims of Cystic Fibrosis Trust.

Committed VIAs 2022/23

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment	Source of External Funds	External Leveraged Funds
VIA108	Prof David Denning	University of Manchester	Developing polygenic scores for aspergillosis in CF	£22,986	MRC Partnership grant	N/A Application unsuccessful in MRC peer review
VIA109	Dr James Duboff	Medusa Pharma	Developing combination therapeutics that overcome antimicrobial resistance in *Pseudomonas aeruginosa* infections and reduce treatment-associated side effects	£50,000	Innovate UK Biomedical Catalyst feasibility grant	£50,000
VIA110	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro 'carbon copy' of lung disease	£80,000	EPSRC	N/A application unsuccessful in EPSRC peer review
VIA111	Professor Lorraine Martin	Queens University Belfast	Developing a novel regenerative gene therapy platform technology for inhaled CF therapy	£26,000	Emily's Entourage	£220,000
VIA112	Prof Martin Welch	University of Cambridge	Investigating the impact of pathoadaptive mutations on the fitness of *Pseudomonas aeruginosa* in a polymicrobial airway environment	£47,100	NC3Rs	£181,820
VIA113	Dr Chrissie Jones	University of Surrey	Mindfulness-based well-being intervention for parents who have a child with cystic fibrosis (CF)	£64,084	NIHR RfPB	N/A application unsuccessful in NIHR peer review
VIA114	Dr Guy Moss	University College London	Exploring the therapeutic potential of BK channels	£44,601	CFF	£217,229
VIA115	Dr Freddy Frost	Liverpool Heart and Chest Hospital	Postal Sputum Testing for Early Detection of *Pseudomonas aeruginosa* in CF: POSTED-CF	£17,214	Asthma and Lung UK	£97,570
VIA 116	Prof Jane Davies	Imperial College London	Repurposing the multiple sclerosis drug, Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections	£99,999	LifeArc CDP call	£2,500,000
VIA 117	Prof Janis Shute	Ockham Biotech	Investigating anti-pseudomonal effects of roneparstat, a non-anticoagulant derivative of heparin with multiple anti-microbial, anti-inflammatory and mucolytic activities.	£50,000	LifeArc CDP call	£2,500,000
VIA 118	Prof Paul McNally	Royal College of Surgeons in Ireland (RCSI)	ENHANCE – Establishing Natural History in an Advanced New CF care era	£96,424	CFF	£4,771,000 (6,100,000 USD)
			Total CF Trust Committed	£431,338 (excluding unsuccessful awards)	**Total Potential Leverage**	£10,537,619(excluding unsuccessful awards)

Summer Studentships 2022/23

Supervisor	Host Institution	Student & Project
Dr Guy Moss	UCL	Miss Saidi Li – Understanding the rheology of mucociliary clearance
Dr Bettina Schock	Queen's University Belfast	Mr Sean Sexton – Effect of corticosteroids on anti-inflammatory A20 expression and investigating the synergy of a combination therapy

Open SRC Awards (March 2023)

SRC Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
SRC 011*	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)	£749,694
SRC 012*	Dr Daniel Peckham	St James' University Hospital	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC 013*	Dr Mike Gray	Newcastle University	Personalised Therapies for all: Restoring airway function in CF using Alternative Chloride Channels	£750,000
SRC 014*	Prof Jane Davies	Imperial College London	Personalised Approach to *Pseudomonas aeruginosa* (PAPA)	£750,000
SRC 015*	Dr Darius Armstrong-James	Imperial College London	TrIFIC: Targeting Immunotherapy for Fungal Infections in Cystic Fibrosis	£750,000
SRC 016*	Prof Pietro Cicuta	University of Cambridge	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC 017*	Dr Martin Welch	University of Cambridge	Gas, food and lodging; understanding the physiological and metabolic requirements of *Pseudomonas aeruginosa* in the cystic fibrosis airways	£748,538
SRC 018	Professor Steven Renshaw	University of Sheffield	Preventing Gastrointestinal Cancer in cystic fibrosis	£749,214
SRC 019	Professor James Shaw	University of Newcastle	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes	£750,000
SRC 020	Prof Stephen Hart	University College London	Therapeutic gene editing of CFTR	£740,142
SRC 021	Prof David Sheppard	University of Bristol	The CFTR Folding and Function SRC	£747,972
SRC 022	Dr Jo Fothergill	University of Liverpool	An evidence-based preclinical framework for the development of antimicrobial therapeutics in cystic fibrosis (PIPE-CF) **Co-funded with CFF**	£749,373
SRC 023	Prof Alan Smyth	University of Nottingham	Gut Research Advancing a Mechanistic & Personalised Understanding of Symptoms in Cystic Fibrosis: A Strategic Research Centre: The GRAMPUS-CF SRC	£749,592
SRC 024	Dr Paola Vergani	University College London	Restoring the Fizz: Pharmacological Repair of Bicarbonate Transport in Cystic Fibrosis **Co-funded with CFF**	£749,973

***Grant issued extension due to COVID-19 related delays.**

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA035	Dr Fred Piehl	Imperial College London	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA036	Dr Fred Piehl	Imperial College London	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA039	Ms Laura Birch	Bristol University	Dietary manipulation to improve glycaemic control in young people with cystic fibrosis and altered glucose handling: a feasibility study	£25,000
VIA045	Professor Chris van der Gast	Manchester Metropolitan University	Detection of CF lung pathogens using engineered bacteriophages	£45,950.50
VIA051	Dr Tanmay Bharat	Action Medical Research	Elucidating the structural role of filamentous bacteriophage in *Pseudomonas aeruginosa* biofilms for disrupting infection in cystic fibrosis airways	£89,917.50
VIA052	Professor Jane Davies	Imperial College London	Exploring the utility of novel 'antimicrobial resistance breakers' on strains of *Pseudomonas aeruginosa* obtained from patients with cystic fibrosis	£50,000
VIA059	Dr Joseph Jacob	UCL	Quantifying bronchiectasis severity in cystic fibrosis	£50,000
VIA061	Prof Alan Smyth	University of Nottingham	Gut Imaging for Function and Transit in CF – The GIFT Study	£35,369
VIA062	Prof Miguel Camara	University of Nottingham	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000
VIA063	Prof Stephen Hart	University College London	Development of in vitro Transcribed mRNA Therapeutics for cystic fibrosis	£51,545
VIA064	Dr Andrew Jones	University of Manchester	Arthropathy in Adults with cystic fibrosis	£34,000

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 067	Dr Martin Welch	University of Cambridge	Tackling CF Lung Infection in vitro: Assessing the Global Impact of Antibiotics on the CF Airway Microflora in a Laboratory Bioreactor	£33,000
VIA 068	Professor Jane Davies	Imperial College London	The idealised LCI (i-LCI): tuning in on the 'silent years' of paediatric CF	£98,594.93
VIA 070	Dr Laura Nolan	Imperial College London	Understanding interbacterial competition in the Cystic Fibrosis lung to identify opportunities for intervention	£30,000
VIA 071	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA 072	Dr Charles Haworth	Papworth Hospital	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis	£36,000
VIA 073	Dr Viek Dua	University College London	Modelling and machine learning to aid the design of CF therapy	£50,000
VIA 076	Dr Luke Allsopp	Imperial College London	In the thick of it: Competitive Microbial Interactions in Biofilms	£20,000
VIA 077	Prof Chris van der Gast	Manchester Metropolitan University	Organisation and function of the gut microbiota in cystic fibrosis	£47,000
VIA 078	Prof Chris van der Gast	Manchester Metropolitan University	Non-tuberculosis mycobacteria infection and the wider lung microbiota in cystic fibrosis	£48,000
VIA 079	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)	£32,600
VIA 081	Dr Anand Shah	Imperial College London	FREAL – Fungal Resistance Evolution and Acquisition in chronic Lung disease	£38,000
VIA 082	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£21,304
VIA 083	Dr Paul McNally	Our Lady's Children's Hospital	RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in People with CF)	£97,297

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 085	Professor Jane Davies	Imperial College London	Exploring the utility of quorum sensing inhibitors and biofilm disruptors on growth and virulence behaviours of *Pseudomonas aeruginosa* obtained from patients with cystic fibrosis	£50,000
VIA 086	Dr Christabella Ng	Univeristy of Nottingham	Gut Imaging for Function & Transit in cystic fibrosis Study 3	£65,000
VIA 088	Prof Kevin Southern	University of Liverpool	A randomised registry-based open label study to assess change in respiratory function for people with cystic fibrosis (pwCF) with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of muco-active aerosolised therapies (the CF STORM study)	£18,931.70
VIA 090	Prof Michael Givskov	University of Copenhagen	Co-therapy of a novel Pseudomonas aeruginosa biofilm disruptor with standard of care antibiotics	£26,500
VIA 091	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA 092	Dr James Reihill	Queen's University Belfast	The ubiquitylation system as a therapeutic target in CF	£15,000
VIA 093	Dr Anand Shah	Imperial College London	Development and validation of the use of videogames and virtual reality to enable autonomous remote monitoring of ototoxicity in high-risk population groups	£15,000
VIA 094	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro carbon copy of lung disease	£40,000
VIA 095	Dr Beverley Isherwood	Medicines Discovery Catapult	CF AMR Biorepository	£49,500
VIA 096	Prof Jane Davies	Imperial College London	The Pseudomonas aeruginosa c-di-GMP signalling network: adaptation and impact in clinical strains	£47,692
VIA 097	Prof David Denning	University of Manchester	Developing polygenic scores for aspergillosis in CF	£22,510

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 098	Dr Jonathan Cox	Aston University	Discovery of new and repurposed ß-lactamase inhibitors for improving *Mycobacterium abscessus* treatment	£25,000
VIA 099	Professor Chris Ward	Newcastle University	An implementation study investigating the feasibility of using gastrointestinal patient related outcome measures in people with cystic fibrosis	£37,000
VIA 101	Gerry McCauley	OmniSpirant Limited	Electrophysiology assessment of OS001 CFTR exosomes	£4,200
VIA 102	Dr Michelle Willicombe	Kidney Research UK	Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people (MELODY Study)	£50,000
VIA 103	Mr Andy Short	Ockham Biotech Ltd	Development of a non-anticoagulant heparin derivative as a therapy in CF	£50,000
VIA 104	Dr Beverley Isherwood	Medicines Discovery Catapult	Support for the UK CF Infection Biorepository	£95,000
VIA 105	Professor Alan Smyth	University of Nottingham	Core Outcome Set Taskforce for Cystic Fibrosis (COST-CF): a patient-initiated core outcome set for CF	£93,089
VIA 106	Dr Robert Gray	University of Edinburgh	A live airway model that incorporates a network of optical sensors for drug discovery and regenerative therapy development	£70,000
VIA 107	Dr Rian Griffiths	University of Nottingham	Development of a rapid and highly sensitive analytical method for the detection of biomarkers of infection in samples from people with CF	£37,726
VIA 108	Prof David Denning	University of Manchester	Developing polygenic scores for aspergillosis in CF	£22,986
VIA 109	Dr James Duboff	Medusa Pharmaceuticals	Developing combination therapeutics that overcome antimicrobial resistance in *Pseudomonas aeruginosa* infections and reduce treatment-associated side effects	£350,000
VIA 110	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro 'carbon copy' of lung disease (Phase 2)	£80,000

Open VIA Awards (March 2023)

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA 111	Prof Lorraine Martin	Queen's University Belfast	Developing a novel regenerative gene therapy platform technology for inhaled CF therapy	£26,000
VIA 112	Dr Martin Welch	University of Cambridge	Investigating the impact of pathoadaptive mutationson the fitness of *Pseudomonas aeruginosa* in a polymicrobial airway environment	£47,100
VIA 113	Dr Christina Jones	University of Surrey	Mindfulness-based well-being intervention for parents who have a child with cystic fibrosis	£64,084
VIA 114	Dr Guy Moss	UCL	Exploring the therapeutic potential of BK channels	£44,601
VIA 115	Dr Freddy Frost	University of Liverpool	Postal Sputum Testing for Early Detection of *Pseudomonas aeruginosa* in CF: POSTED-CF	£17,215
VIA 116	Prof Jane Davies	Imperial College London	Repurposing the multiple sclerosis drug, Glatiramer acetate, to potentiate the action of conventional antibiotics for cystic fibrosis airway infections	£99,999
VIA 117	Prof Janis Shute	Ockham Biotech	Investigating anti-pseudomonal effects of roneparstat, a non-anticoagulant derivative of heparin with multiple anti-microbial, anti-inflammatory and mucolytic activities.	£50,000
VIA 118	Prof Paul McNally	Royal College of Surgeons in Ireland (RCSI)	ENHANCE – Establishing Natural History in an Advanced New CF care era	£96,424

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2023. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 2nd Floor, One Aldgate, London EC3N 1RE.

Uniting for a life unlimited

CYSTIC FIBROSIS TRUST

England & Wales - Charity number 1079049

Accounts

Cystic Fibrosis Trust

Let's unite for a life unlimited

Annual Report and Financial Statements
for the year ended 31 March 2022



Uniting for a life unlimited

Contents

Thanks to you, in 2021/22... 4
Introduction from our Chair 6

Uniting for life unlimited
Objectives and activities 10
About CF 10
About us 10
Our goals 11
Measuring success 11

Uniting in research
Understanding and treating lung infections 14
Tackling the underlying cause of CF 14
Understanding and treating the symptoms of CF 15
Digital health research 16
Refreshing the research priorities for CF 17

Uniting to ensure everybody with CF can access the care and support they need
Collaborating with and supporting the clinical community to promote the highest quality of care 20
The impact of Kaftrio on the CF community 22
The impact of COVID-19 on the CF community 23
Keeping the community informed 23
Campaigning hard 24
The UK CF Registry 26
Annual data report 27
Quality improvement 27

On the cover: Dom



Supporting access to medicines at every step from laboratory to medicine cabinet
Clinical Trials Accelerator Programme 30
Network of CTAP centres 30
Early phase coordinator pilot 30
CTAP's new five-year strategy 31
Community involvement 32
Aligning the UK's Clinical Research Programme 33
Delivering the UK CF Clinical Trials Conference 33
CF Clinical Trials Hub 33

Providing day-to-day support; and reaching people with cystic fibrosis when they need us most
Day-to-day support 36
Grants 36
Benefits advice 37
Helpline 37
Information 38
Youth programme 39



Reaching all people with CF
CF Week 2021 42
#CFTruths 43
CF Live 43
Our brand 43
Website 43
Volunteering 44
Being an effective organisation 44

Uniting in fundraising
Supporter experience 49
Regular gifts 49
Community fundraising 49
Corporate partnerships 50
Gifts in Wills 50
In memory 51
Philanthropy 51

Looking to the future
Uniting in research for a life unlimited 54
Delivering our strategy 54
Being great fundraisers 55
Campaigning hard 55
Day-to-day support 56
UK CF Registry 57
Quality improvement 57

Financial review 58

Independent auditor's report to the Members and Trustees of the Cystic Fibrosis Trust 68
Consolidated statement of financial activities 72
Consolidated and charity balance sheets 74
Consolidated statement of cash flows 76
Notes to the Financial Statements 78
Structure, governance and management 102
Committed VIAs 104
Currently active SRCs 107
Summer Studentships 109

Thanks to you, in 2021/22...



321 people with cystic fibrosis enrolled on to a CTAP clinical trial, helping to develop new medicines for everyone with CF.



We co-funded a new Strategic Research Centre (SRC) on CFTR folding and function, with the aim to design new and innovative medicines to act on the CFTR protein that will make a bigger difference for more people with cystic fibrosis.



We helped people with CF to access at least £1.025 million in benefits through our Welfare and Benefits Advice service.



Our Helpline responded to over 4,200 enquiries from people affected by CF and continued to provide support to the community through the COVID-19 pandemic.



Through our new Winter Hardship Support Fund, we supported 250 people on low incomes with a grant to fund household essentials such as food and energy, protecting their health through the coldest winter months.



We launched our public awareness campaign #CFTruths, resulting in a 120% increase in cystic fibrosis-related searches online.

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ending 31 March 2022. The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Charities Act 2011 and the Statement of Recommended Practice: Accounting and Reporting by Charities second edition effective 1 January 2019.

The requirements of 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013' are included within this Trustees' report. Pages 72 to 103 also form part of the Trustees' report.

Introduction from our Chair

I am delighted to present Cystic Fibrosis Trust's 21/22 Annual Report.

This past year was another influenced by the challenges of the COVID-19 pandemic. It certainly had its lows, but also some significant highs.

January saw Kaftrio being made available to 6–11-year-olds across the UK, which marked another critical step forward after the years of campaigning by the Trust and the CF community.

It has also been a year when we have continued to focus on the fact that Kaftrio is not a cure and alongside those who can't benefit from it, we know that many challenges remain. It is vital that we are fully committed to a diverse and innovative research portfolio to help us achieve our goal of a life unlimited for everyone with CF.

The changing CF landscape also led to new information and support needs. We've reflected this in the information resources we provide, updating our Kaftrio factsheet to recognise the complex and individual responses across the CF Community. We have also been working to understand and respond to emerging needs, developing programmes of support to ensure health improvements can translate into life opportunities.

The pandemic has also created new challenges for many, both socially and economically. In many ways it has highlighted, or perhaps accelerated, new challenges that we must face head on. As reflected in our current Strategy, we are increasingly aware of the need to support not just physical health but also mental health, and the additional pressures that can now arise in seeking to achieve a fulfilled life.



Richard Hunt CBE

When increases in the cost of living left many with CF worrying about how they would afford to heat and eat properly this winter, we immediately launched a Winter Hardship Support Fund. Through this Fund, we supported 250 people on low incomes with a grant to fund household essentials such as food and energy, protecting their health through the coldest winter months.

"When increases in the cost of living left many with CF worrying about how they would afford to heat and eat properly this winter, we immediately launched a Winter Hardship Support Fund."

Through our first ever Cost of CF survey, launched in the spring, we want to help highlight and address the economic challenges many in the community are facing and uncover the daily hidden costs of living with a life-limiting condition. We will use the insights from the survey to inform and guide our actions and the actions we call on others to make.

We believe it is important that as many people as possible understand what life with CF is like and in 21/22, we were thrilled to launch #CFTruths, our public awareness campaign. The campaign was devised by Caitlin, who has cystic fibrosis and was struck by how the COVID-19 pandemic made common many of the everyday experiences of the CF community. It's been wonderful to see the response to this campaign, and how the community are using it as an opportunity to increase understanding of CF and kickstart conversations about life with the condition.

Ensuring our community's voice is at the heart of our work is something we always strive for, and we were delighted to partner with QuestionCF in the James Lind Research Priority Refresh that launched back in January. Over 1,600 people shared their views in the first survey telling us what's on their CF research wishlist.

A second survey and online workshops will follow and the refreshed priorities will be published at the end of 2022. At a time of such profound change, we want to make sure we listen to our community and your priorities for the years ahead. This will enable us to make our vision, that every person with cystic fibrosis can live a long and full life, a reality.

I would like to finish by thanking all our wonderful supporters for their passion and determination to support the Trust. In these challenging times, what you do is especially important and we couldn't do what we do without you.

On behalf of the Board, I would also like to thank the Cystic Fibrosis Trust team for all they do to support our CF community. Thank you.

Finally, I would also like to thank my Board colleagues for their time, commitment and support for the Trust. For all of us, it is another unusual year and a busy year. And we know there is always much more to do to fulfil our objectives and ensure everybody with CF can live a life unlimited.

Richard Hunt CBE
Chairman of Trustees

Uniting for a
life unlimited

Objectives and activities

Our vision is to deliver a life unlimited for people with cystic fibrosis and our objectives, as stated in the Articles of Association, are to promote:

- research into the causes of, and a cure for, cystic fibrosis and the dissemination of the useful results thereof for the public benefit
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from cystic fibrosis in any form
- the education of the general public about the causes and effects of cystic fibrosis.

About CF

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. You are born with CF and cannot catch it later in life. One in 25 of us carries the faulty gene that causes it, usually without knowing. More than 10,800 people in the UK live with the condition, having to undergo a brutal daily regimen of physiotherapy and take up to 60 tablets a day just to stay healthy. Despite these treatments, many people with CF will go on to require a double lung transplant. The median age at which someone with CF dies is just 36 years old.

About us

Our mission

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all. We won't stop until we can all lead the lives we want. Until cystic fibrosis stops damaging and shortening lives.

Our vision

Our community is uniting towards the ultimate goal of effective treatment for all. We're at the forefront of innovation and progress. Boundaries will be broken by groundbreaking research and incredible discoveries that change lives for the better. To get there, we will inspire our community. We will campaign with passion. Use facts and information to empower us. And support each other – improving care and building better mental resilience and physical health.

We're uniting for a life unlimited.

Our goals

Physically well

Together, we can live without the physical challenges of cystic fibrosis.



Mentally well

Together, we can manage the mental pressures of cystic fibrosis.



Fulfilment

Together, we can lead the life we want as part of a connected community



Measuring success

We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact for the CF community. We have Delivery Review Groups that assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track the progress of projects using our Project Portfolio and internal monthly and quarterly monitoring mechanisms, including both data-driven and narrative analysis, backed up by SMART Key Performance Indicators. Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.

Uniting in research

"Thanks to research, the world is looking so much brighter for people with cystic fibrosis. There have been so many advances in the time since my children were diagnosed; however, now is not the time to rest on our laurels. We need to harness the energy across the community and really push forward with supporting future research. This way we can make life with CF the best it can be."

Zoë, mum to Alex and Isobel, who have CF

Over the past year, we've invested in innovative research projects across a wide range of areas to help us achieve our goal of a life unlimited for everyone living with cystic fibrosis.



Understanding and treating lung infections

People with CF are susceptible to developing infections, due to the thick sticky mucus in their lungs. The infections can be extremely difficult to treat, as many bugs are resistant to the antimicrobial medicines available. Left untreated, the infections may cause progressive lung damage and shorten people's lives.

We are funding research into some of the most common and dangerous CF infections through the UK Cystic Fibrosis Innovation Hub, including *Pseudomonas aeruginosa* and *Mycobacterium abscessus*, to develop better treatments and detect infections faster.

In 2021, Trust-funded researchers published two prestigious research reports highlighting new information on how infections caused by the *Mycobacterium abscessus* bacteria are passed on to people with CF, and how these bugs adapt and evolve to live in the unique environment within the sticky mucus in the lungs of people with CF. This information can be used to prevent and treat CF infections in the future.

Tackling the underlying cause of CF

This year, we were delighted to co-fund a new Strategic Research Centre (SRC) on CFTR folding and function. Led by Professor David Sheppard at the University of Bristol, the aim of this SRC is to design new and innovative medicines to act on the CFTR protein that will make a bigger difference for more people with cystic fibrosis.

"For a very long time we could study whether the CFTR protein was working or not, but we had to speculate about what its shape or its structure was," explained Professor David Sheppard, when talking about the impact this SRC could have. **"It is important to look at how the shape of the proteins made from faulty CFTR genes affects their function.**

"Now we have information on how the proteins are working and their structure, we can start to link the two together and understand more about what is causing CF. We are working with colleagues across Europe in this SRC and we're incredibly grateful to the Trust for the funding."

Understanding and treating the symptoms of CF

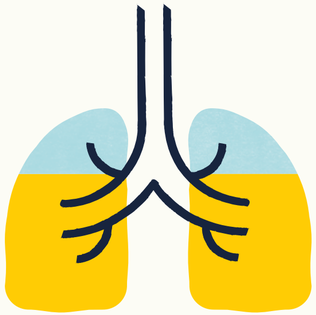
Last year we published a ***Research in Focus*** report highlighting progress in research studies to better understand and monitor gut symptoms with CF. In 2017, a list of the CF community's top 10 health priorities was published, and relief of GI symptoms was rated as the second highest, so we know that this is a key issue for people with CF.

The Trust is funding research to better understand how the biochemical and physiological changes within the gut of those with CF lead to these symptoms. This will hopefully mean the development of more effective, less invasive, and better tolerated treatments for conditions such as Distal Intestinal Obstructive Syndrome (DIOS), and ultimately a better quality of life for people with cystic fibrosis.

Professor Alan Smyth, Dr Christabella Ng and their colleagues at the University of Nottingham have been investigating the best method for studying these symptoms as they happen in people with CF in hospital-based studies. They've shown that Magnetic Resonance Imaging (MRI) methods can be used to study these symptoms, as opposed to the more invasive and radiation-based methods that are usually used.

Professor Soraya Shirazi-Beechey at the University of Liverpool is leading a lab-based SRC to develop better tolerated and more effective treatments for DIOS, which is when people with CF experience serve blockages in the intestine. The SRC team have shown that it is possible to enhance the intestinal fluidity using already-licenced drugs. The results provide a strong basis for the planning of future clinical trials to test the effect of these drugs in treating DIOS in people with cystic fibrosis.

"Digestive problems are a debilitating issue for people with CF and we're urgently looking for ways to treat and manage these symptoms. We hope the results of the research we're funding will set the direction for future treatments," said Dr Lucy Allen, our Director of Research.





Dr Lucy Allen

Digital health research

Since 2016, Trust-funded CF researchers have been exploring how digital ways of monitoring health could be applied to improving and personalising CF care. Digital health approaches to CF care could result in a longer, healthier life that is less limited by having cystic fibrosis.

One approach is through Project Breathe, a study to address the current standards of care which require all people with CF to attend their CF centre on a regular basis, regardless of their need or CF condition. The aim of this study is to understand whether home-based remote monitoring combined with machine learning could change how clinical care is delivered and move away from the typical 'one size fits all' approach.

As a first step, home-based remote monitoring is being developed to provide the evidence that a routine clinic outpatient appointment is not needed when the patient is well. Over 400 people have been recruited from four UK sites. A Canadian site is also ready to open and start recruiting.

The ambition of the project is to test a range of monitoring devices, such as cough monitors, which could be added to the devices supported by the platform. This could increase the wealth of predictive data being collected about an individual, in the least burdensome way. This work is in development.



Refreshing the research priorities for CF

Five years ago, the Trust was a partner in the James Lind Alliance Priority Setting Partnership in Cystic Fibrosis, with the aim to find out the top health priorities of people with CF, as well as their families, carers and CF teams. Over 600 people took part and we've acted on what the community told us. The top priorities have guided our decisions on what research to fund. They've also set the topics for research studies around the world.

We know a lot has changed for people with CF in the years since the first research project. Many now have access to CFTR modulators, and due to the pandemic, many people's care will have changed. So this year, we felt it was time to review the research priorities and find out what matters most to the community right now. A priority refresh project was set up – QuestionCF for short – and we are working with researchers at the University of Nottingham, people from the CF community, and the James Lind Alliance team at the National Institute for Health and Care Research (NIHR) to review these priorities and help shape the direction of future research.

Over 1,600 people shared their views in the first survey, with a second survey and online workshops to come. The refreshed priorities will be published in late 2022.



Nicole and son Arlo

"As a CF parent it can feel like you're a bit helpless and there's too many components that sit outside of your control. But being a part of QuestionCF has enabled us to feel like we're doing something proactive that we know will benefit so many people with CF. It's refreshing to be part of a project where it's not medical professionals or pharmaceutical companies telling the community what they think the priorities are, but it's actually giving those in the community a voice and a chance to share their own perspective."

Nicole, mum to Arlo, who has CF

Uniting to ensure everybody with CF can access the care and support they need

Collaborating with and supporting the clinical community to promote the highest quality of care

COVID-19 has changed how people with CF have experienced care and it is likely to have a long-term impact on how care is delivered in the UK. The Trust has played a vital role in ensuring that people with CF could access the care they needed, despite pandemic restrictions, and that policymakers understood and addressed the challenges facing the community.

In 2021/22, the Trust continued to work closely with the UK CF Medical Association (UKCFMA). The CFMA provides expert advice and opinion to Government bodies, the NHS, and other outside agencies. It represents the CF medical community in discussions with the NHS and Department of Health about provision of services for people with CF.



This year, for the first time ever, the Trust launched a new Exercise Practitioner fellowship, to develop training for exercise professionals and improve access to tailored exercise support for people with CF. The successful candidate is now in post.

We also continued to update our suite of clinical guidelines to support best practice in cystic fibrosis care and treatment, including the development of new guidelines on psychological and social.

The Trust worked with psychological and social care professionals in CF care to understand and begin to address workforce challenges in multidisciplinary teams, and we will continue to campaign on this issue in the future.

With input from our Clinical Trials Accelerator Platform governance board, we fed into the Medicines and Healthcare Products Regulatory Agency (MHRA) on their proposals for legislative changes for clinical trials. This ensured the experience and expertise of CF specialists was at the heart of our response.





The impact of Kaftrio on the CF community

2022 saw the approval of Kaftrio for 6–11-year-olds across the UK. This was a huge milestone in the Kaftrio journey following years of campaigning by people with cystic fibrosis and their families.

More than 1,500 children across the UK and Northern Ireland stand to benefit from this drug and limit the damage CF does in these critical early years.

For Stacey, mother of Katy, 8, who has CF, it was life-changing news:

"Having access to Kaftrio changes Katy's future. Kaftrio means that we can really dream of Katy becoming a mummy and having a family of her own. My hopes for the future are to watch Katy live a long and healthy life and not miss a single event in life, as that's what she deserves. I want her to be able to share memories with her brother and sister that don't involve lots of hospital stays, meds and physiotherapy."

For all in the CF community, whether they can benefit from modulator therapies or not, the roll-out of Kaftrio has brought a significant change in the CF landscape and led to new information and support needs.

We recently updated our Kaftrio factsheet to recognise the complex and individual responses across the CF community as more people with CF gain access.

We have also been working to understand and respond to emerging needs, developing programmes of support to ensure health improvements from Kaftrio translate into life opportunities. Some have experienced challenges in adapting to improved health and we have been on hand to provide information and to develop safe spaces for people to share their varied experiences.

Kaftrio is not a cure and we continue to deliver vital support services, ensuring everyone has the help they need to stay as well as possible while research continues into new treatments to benefit everyone with CF.

We won't stop until everyone with CF has access to the support and treatments they need.



Katy

The impact of COVID-19 on the CF community

This year COVID-19 continued to challenge our community, with new variants circulating and cases rising. We focused on encouraging our community to get the COVID-19 vaccines and boosters, as well as informing them about new treatments available for people who are part of the clinically vulnerable group.

Mindful of the particular needs of those in our community who are immunosuppressed, we responded to the changing government policies and the needs of the CF community by providing regular and rapid advice across our channels on the Helpline, website and social media. Our content was regularly updated and proactively shared to provide the latest advice and support.

Our broad Q&A content received over **12,400** views



Our Helpline team responded to enquiries related to COVID-19, providing a listening ear for those worried about infection risk as well as practical information and signposting. Working with the UK CF Medical Association, we shared important clinical guidance with the community as restrictions began to lift across the UK.

Since COVID-19 continued to be unpredictable, we saw varying levels of concern among our community. Our polls continued to show that our advice and support content was "useful" or "very useful", including our advice for people who are clinically extremely vulnerable.

Shielding guidance throughout the year changed, often with different nations offering different advice. We worked hard to ensure that we were able to respond to and support members of our community wherever they live across the UK.

Our Registry team has continued to record incidents of cases in our community, as well as working closely with our international colleagues to record global cases.

Keeping the community informed

We continued to source and share more personal stories from our community about their experience of life during lockdown. For example, Lucy Baxter shared her frustration at still having to shield while life returned to normal for those around her; and Dr Jamie Duckers, Consultant in CF and Respiratory Medicine at Cardiff and Vale University Health Board, wrote a blog on how health services have changed for people with CF.

Marking the two-year anniversary of COVID-19, Dr Rachel Massey-Chase, co-chair of the UK Psychosocial Professionals in CF group, wrote an open letter to the CF community which acknowledged the mixed feelings many felt as restrictions eased across the UK and provided tips on managing uncertainty and anxiety.

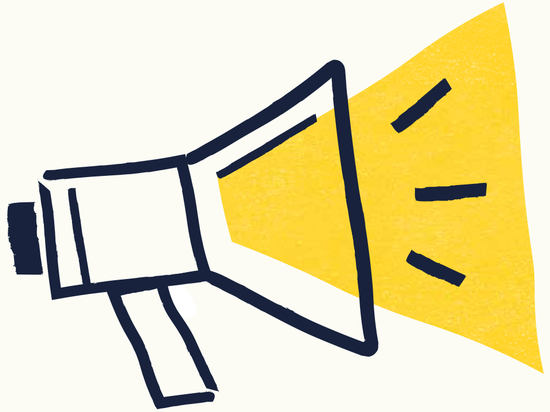
Campaigning hard

Cystic Fibrosis Trust campaigns hard to drive positive change for people with cystic fibrosis. We ensure policymakers have the evidence needed to pursue interventions which make a difference to those living with CF and their families.

In recent years the Trust's focus has been on the Access to Medicines campaign and on the response to the COVID-19 pandemic. The impact of both these issues is having a profound impact on the cost of living for some in the CF community.

Access to modulator therapies (specifically Kaftrio) has ushered in a period of change that could extend and transform the lives and prospects of many people with CF. With this change comes new opportunities and challenges for both those eligible for a modulator therapy and those who are not.





Similarly, because of factors like COVID-19 and the conflict in Ukraine, the cost of living has been rising and the Trust has experienced an increase in demand for advice and support from across the community.

In spring 2022 Cystic Fibrosis Trust launched its Experience of CF survey as part of our Cost of CF campaign. This poll, open to the entire community, asked questions on everything from the daily hidden costs of living with CF to the choices people make about education and work. We aim to repeat this survey every year to build up a regular picture of how the things going on around us are directly impacting those in the CF community. We will also be using the results of the 2022 survey to inform our campaigning work throughout the year ahead.





The UK CF Registry

The UK CF Registry is a world-class database that includes data on over 99% of people with CF in the UK who have consented to their data being submitted by their CF team. Anonymised Registry data is vital in supporting research, service improvement and information materials.

This year the Registry team supported the running of three drug safety studies and completed a fourth study. More information about how we use Registry data to keep medicines safe can be found at **cysticfibrosis.org.uk/registry**.

In 2021/22, the Registry also supported the NHS to generate public reports and help with the commissioning of CF services in England.

In 2021, the Registry approved 32 requests for data. In 2022, to date, the registry approved 12 requests for data, bringing the overall total up to 457.

Through working with the NHS and pharmaceutical companies, we were able to generate over £1.8million, this enabled us to provide grants to support centres in their data entry, and fund other key aspects of our work.

The UK CF Registry is playing a pivotal role in evaluating the effect of highly effective modulators following interim access agreements across the UK. The Registry continues to support an observational study of Orkambi, Symkevi and Kaftrio to satisfy the Vertex Data Collection Agreements with NHS England and NHS Improvement, with several interim and outcome reports submitted to NICE during 21/22.

This agreement has continued to boost the Trust's Registry Support Grant programme, with 100% of CF centres committing to opt in to enter three 'encounters' (records of height, weight and lung function) throughout the year. This enables a more robust analysis of the impact on rate of change in lung function due to these new medicines.





Through forging formal partnerships with Health Data Research UK, SAIL databank and its BREATHE innovation hub, we have taken the first steps towards linking UK CF Registry data to wider NHS data sources, and migrating data into a Safe Haven, also known as a Trusted Research Environment.

The Registry-based clinical trial CF STORM was launched in summer 2021, with the addition of electronic consent which helped enhance the capabilities of the Registry. This trial is designed to find out whether people with cystic fibrosis can safely withdraw mucolytic therapy aiming to reduce treatment burden for people with CF.

Annual data report

The UK CF Registry annual data report on 2020 data was published in December 2021, including data on COVID-19 infections and the impact of the pandemic. An accessible 'at-a-glance' summary of infographics highlighting the main trends for that period was also published, helping people with CF and their families to understand the data in the report.

We submitted anonymised 2020 data to the European CF Society Patient Registry, which published its reports at **www.ecfs.eu/projects/ecfs-patient- registry**.





Quality improvement

In 2021/22, the Quality Improvement (QI) team analysed over 1,500 responses to its patient-reported experience surveys. For the first time, the team then provided tailored feedback reports to all children's and adult CF centres that had taken part in the surveys. These centre-level reports help CF services to better understand local patients' experiences, to evidence existing best practice and to identify areas for quality improvement.

The QI team also captured further information about staffing levels in CF centres in 2021 and started to develop a QI Strategy together with our QI Working Group, which is made up of people with CF, family members and CF health professionals.

Supporting access to medicines at every step from laboratory to medicine cabinet

Clinical Trials Accelerator Platform

The Clinical Trials Accelerator Platform (CTAP) has continued to expand and develop over the last year. CF trial activity has increased significantly, despite an initial drop due to the COVID-19 pandemic. Relations with pharmaceutical companies have strengthened, and the pipeline of CF clinical trials (both early and late phase) looks strong for the coming years.

Network of CTAP centres

The CTAP network of 27 centres supported by 18 CTAP Trial Coordinators aims to support and accelerate the set-up and delivery of CF clinical trials ensuring the CF community can gain timely access to these trials. The network of centres covers around 89% of the UK CF community.

The CTAP network of centres work together to share expertise and best practice, and work collectively to address shared clinical research challenges, and discuss recruitment strategies.

Early phase coordinator pilot

Six CTAP centres within the network were competitively selected to lead in the delivery of early phase CF trials as part of a newly funded CTAP programme to support translational research in the UK. Each of these centres were awarded an additional early phase trial coordinator grant. Through this new infrastructure, we are well placed to ensure the UK continues to be a worldwide leader in early phase CF trial delivery.



Impact of CTAP

Since CTAP's official launch in September 2017, a total of:

1,339 people with cystic fibrosis have been screened for a clinical trial within the CTAP network (468 in the last 12 months)

1,047 people with cystic fibrosis (535 children, 512 adults) have enrolled on to a CTAP clinical trial (321 in the last 12 months)

42 CF clinical trials have been supported by CTAP (eight in the last 12 months).

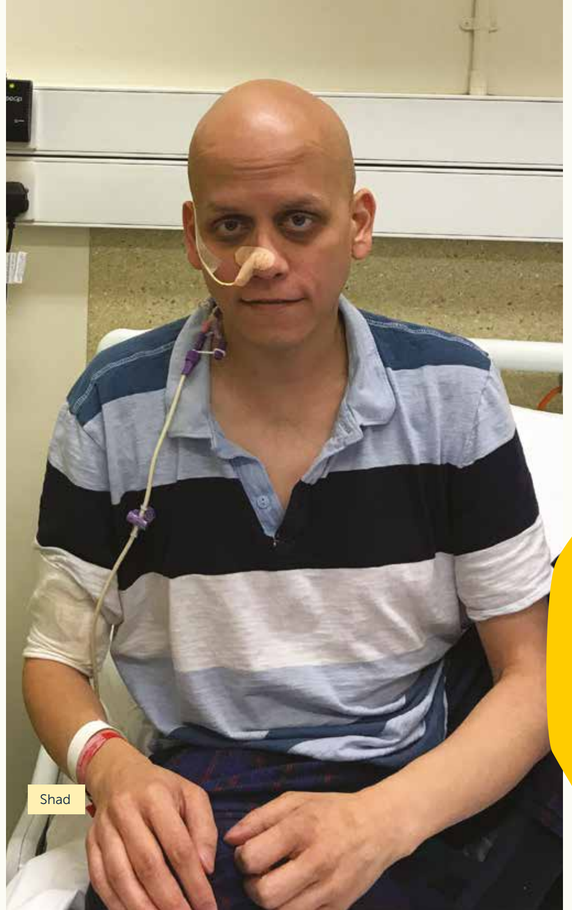


CTAP's new five-year strategy

Over the last year, we have seen significant changes in the clinical and research landscape due to access to new modulator therapies, and also changes in the delivery of clinical care in response to the pandemic. In response to these changes, a new five-year CTAP strategy was developed in collaboration with the CTAP governance board, CTAP centres and, most importantly, representatives from the CF patient community. CTAP's vision for the next five years is:

To sustain the UK's position as a world leader in delivering a broad and innovative portfolio of clinical research in cystic fibrosis, accelerating the development of new and improved treatments for cystic fibrosis whilst acting as an exemplar for condition-specific clinical trial networks.

A $6m funding proposal was successfully submitted to the Cystic Fibrosis Foundation (CFF) which will allow us to extend and expand the CTAP programme for a further five years, with a commitment to deliver the new CTAP five year vision.



Shad

Community involvement

Our CTAP community involvement work is key to ensuring that the clinical research studies being delivered and supported by the UK, whether they are being led by companies or clinical academic researchers, have been developed in partnership with the CF community. Active engagement of the CF community in research not only ensures that research studies include the insights and lived experience of people living with CF, but that these insights can also inform future research requirements and shape clinical trial designs.

The CTAP Youth Involvement Group is a group of young people, aged 12 to 25, who have attended workshops to develop their understanding of the research and clinical trials process, learning how and where their insights are valuable and informative. Through this supported group, they have reviewed project proposals and participant information sheets, developed guidance for sponsors, and information for the community on how best to involve and engage young people in research.

"Engaging with Cystic Fibrosis Trust has been a blessing. Through their support, I have had the courage to speak up and share my story. The Trust has been the missing advocate for me. It is also fantastic to be a part of their Involvement group, as it gives me the opportunity for my voice to be heard on a range of topics that will shape future support for people with CF, so that we'll all able to live a life unlimited."

Shad, who has CF

Aligning the UK's Clinical Research Infrastructure

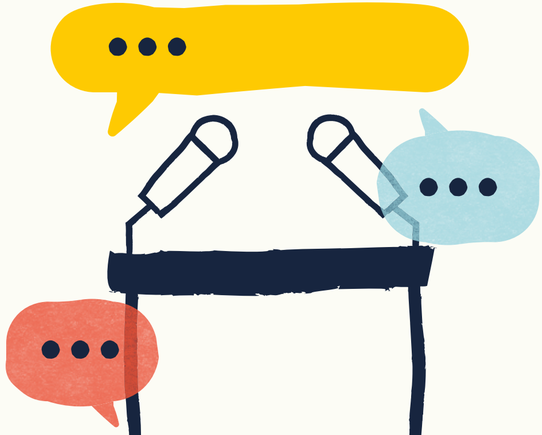
The infrastructure in the UK to support CF clinical research delivery is broad ranging, and often complex. In partnership with key stakeholders, such as the UK's National Institute for Health and Care Research (NIHR) and the European Cystic Fibrosis Society's Clinical Trials Network (ECFS-CTN), CTAP is working to align and streamline the various services and processes helping those wanting to set up research studies in the UK to do so more effectively and efficiently.

Delivering the UK CF Clinical Trials Conference

The first annual clinical trials conference took place in 2018 and it brought together CF teams, representatives from pharmaceutical companies, and Cystic Fibrosis Trust to share information and hold focused talks relating to the changing CF clinical trials landscape.

This year, with the conference now in it's fourth year, the Trust agreed to manage this important event for the clinical research community.

Members of the CTAP, Events, and Corporate Sponsorship teams successfully co-led the organisation of the March 2022 event, with 73 delegates attending in person and over 60 online.





CF Clinical Trials Hub

The CF Clinical Trials Hub provides a wealth of information about taking part in clinical trials and includes the CF Trials Tracker database.

Since launching in September 2017:

The Hub has been visited over **13,000** times, with over 2,100 visits in the past year

The Trials Tracker database has been visited **20,000** times, with over 2,500 visits in the last year.

Providing day-to-day support; and reaching people with cystic fibrosis when they need us most

Day-to-day support

Over the past year, we've continued to provide dedicated information and support to the cystic fibrosis (CF) community. Together, we have navigated the ongoing impact of the pandemic; the exciting new challenges and new support needs that have arisen as a result of Kaftrio; and the increased financial pressures as the cost of living has rapidly increased. We have continued to adapt our services and resources to meet these changing needs; and we've worked with the CF community to understand and develop responses to emerging issues.

Grants

Last year, we provided over **940** grants, totalling over **£292,000**. These grants helped to protect the health of people with CF by supporting those in urgent need to buy the basics needed to stay well, as well as providing access to goods and services to promote long-term health and wellbeing.

Our grants supported people with CF, such as Annie*, a toddler who has CF and requires a specific diet to keep her well. The family are on a low income with no money to spare each month, and through no fault of their own an error with their benefits had left them without enough money for food. Without a grant from us, they would have had to manage with empty shelves and only enough money for very basic food which wouldn't meet Annie's needs.

*names have been changed to protect identity



Fiona with daughter Zara

When rapid increases in the cost of living left many with CF worrying about how they would afford to eat properly this winter, we immediately launched a Winter Hardship Support Fund. Through this Fund, we supported 250 people on low incomes with a grant to fund household essentials such as food and energy, protecting their health through the coldest winter months. All those we supported through this Fund were offered additional support from our welfare advice team to support their longer-term financial stability.

We also provided over £21,000 in homecare grants to support people who are experiencing particularly poor health or a personal crisis, ensuring they can be safe and comfortable at home.

"For my husband and I, the Trust is a one-stop shop for all information about CF. It gives us hope for an improved future for Zara. We feel part of a community, knowing we don't have to deal with this alone. The Trust's vision that everyone with CF can live a life unlimited means everything to us. We want Zara to be able to experience life the same as everyone else, seizing as many opportunities as possible."

Fiona, whose daughter Zara has CF

Through the Joseph Levy Education Fund, we awarded 87 grants totalling just under £47,000 to support people with CF into higher education or vocational training, ensuring they have the support to pursue their education and career goals.

Benefits advice

Since 2016, our Welfare and Rights Advice service has provided expert dedicated benefits advice. This year, we supported 305 people to navigate the benefits system, ensuring they can access the long-term financial support they need to manage the extra costs of living with CF.

Our Income Maximisation Service has supported 93 people to increase their household finances by an average of £4,269 per household, further building their financial security.

Our student support service continues to help students with CF access the support they may need to get the most out of their studies and enjoy student life.

We also continue to offer a benefits advice service in Northern Ireland through a specialist partnership, providing expert advice on the benefits system.

In 2021/22, Cystic Fibrosis Trust helped people to access at least £1.025 million in benefits.



Helpline

This financial year, our Helpline responded to over 4,200 enquiries from people affected by CF and continued to provide support to the community through the COVID-19 pandemic, as well as on a broad range of other issues.

Many people who come to us need practical answers to their questions, but they also need our support and understanding. The Helpline has continued to provide helpful information and signposting, as well as a listening ear and a safe space for people with CF and those who care for them to talk through any worries and concerns. This year, following work to ensure the Helpline is as easy to access as possible, the number of Helpline enquiries received via social media increased significantly.



Kareem

> **"Being involved in reviewing Cystic Fibrosis Trust's Ramadan resource was really rewarding for us. It felt good to provide our personal experience on something close to us and help those from less represented backgrounds with CF."**
>
> Kareem, who has CF

Information

We continued to develop our extensive information library, developed in collaboration with people with CF and specialist CF clinicians. Resources including airway clearance, portacaths, and genetic screening were updated.

We published a new resource on fasting during Ramadan and CF, recognising the diverse information needs of the CF community, which was well-received by both people with CF and clinicians alike. As understanding of Kaftrio continued to grow, we updated our resource ***Kaftrio – Complex and Individual Experiences.***

Work on several consensus documents continued, including, for the first time, new psychological and social care and treatment guidelines.

We also continued to develop the COVID-19 hub to ensure people with CF could readily access the latest information about the pandemic.

We're grateful to the people with CF and their families, as well as the expert CF clinicians, who gave their time to help us develop and improve our information resources.

Youth programme

Building Brighter Futures is a programme of online events for children with CF and their siblings aged 6–18, funded by BBC Children in Need. The programme continued to attract both new and returning participants. Events on offer included six-week workshops on arts and crafts, drama, and enhanced coding skills, alongside our popular game nights, movie nights and new activities such as baking.

Demand for these events remains high and feedback from both parents and participants shows that children gain a great deal from the chance to come together safely online with others with CF, have fun and learn new skills.

Our Youth Advisory Group (YAG), comprising of young people affected by CF aged 14–25, continued to shape the direction of the Trust's youth work. This year, YAG led the alphabexercise project, a fun social media initiative to promote physical activity in young people.



Amy

> **"It has made me think about how I can help people who are younger than me to get the best out of life – can my experience help them in some way?"**
>
> Amy, young person with CF and member of YAG



Illustrations taken from the YAG AlphabExercises programme

Reaching all people with CF

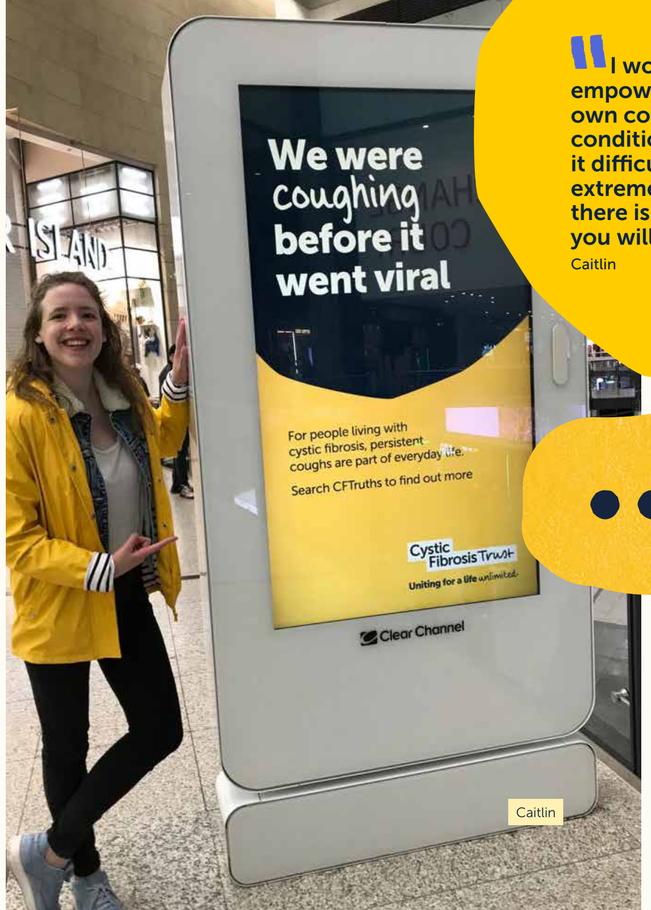
This year, we've continued to find more ways to engage with more people affected by CF. From our active youth programme to growing our presence on the social media platform TikTok, we've prioritised finding even more ways to engage with younger audiences. We've sourced a greater range of voices in the stories we tell on our website, the media stories we place and in our fundraising packs. To ensure that we continue to reflect the broad range of experiences and backgrounds of our community, all of our key external activities, like CF Week and #CFTruths, have been shaped and influenced by involvement groups.

CF Week 2021: a great success

CF Week is our annual awareness and fundraising week, with a focus on community engagement and sharing the CF community's stories. The 2021 theme for CF Week was 'we won't stop', which allowed us to introduce our evolved strategic goals: physically well, mentally well, and fulfilled.

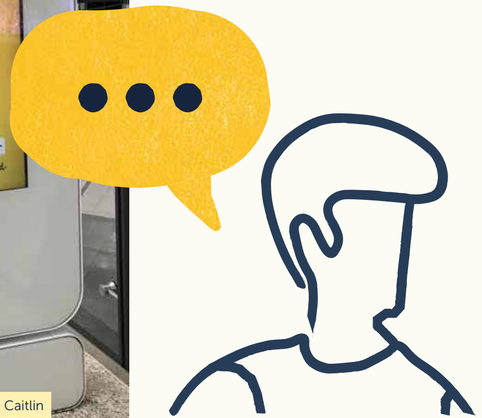
This year:

- over £135,000 was raised, which exceeded our target and continues the trend of year-on-year growth
- we had high-profile media coverage:
  - top 25 articles having a combined total reach of 176 million people
  - a feature article in *The Lady* with Jenny Agutter
  - an interview with Richard Madeley on ITV's *Lorraine*
  - BBC News feature on BBC Morning Live. The BBC programme has an average audience of 1.5million viewers
- we launched an out-of-home marketing campaign on 48 Clear Channel digital billboards in a diverse range of locations across the country
- we shared a range of stories from the community
- time spent on our relevant CF Week pages increased by 18.5% year on year
- we delivered an anxiety session for parents and promoted the Student Support Service.



Caitlin

> "I would love if #CFTruths empowered people with CF to own conversations around their condition. Some people find it difficult to talk about, as it is extremely personal and I think there is sometimes a fear that you will be treated differently."
>
> Caitlin



#CFTruths

In March 2022 we launched #CFTruths, a public awareness campaign devised by Caitlin, who has CF, and developed *pro bono* with Ogilvy Health. The campaign sought to raise awareness of CF amongst the general population, to provide a space for our community to tell their own CF Truth, and to enable easier conversations about life with CF, especially in education and in the workplace. The campaign is still live, but since its launch we've seen a 120% increase in cystic fibrosis-related keyword search terms leading to our website. The campaign has generated strong regional media coverage, with a potential reach of over 300,000 people, and has been visible on over 1,000 Clear Channel digital advertising billboards, with a media value of over £200,000. Our paid social advertising had a reach of almost 500,000 people on launch.

CF Live

CF Live, our online programme of speaker events uniting the CF community, has continued to be popular. Hundreds of attendees tuned in to hear from a range of experts talking about Kaftrio, financial support, and the UK CF Registry, among other topics.

Growing our social media presence across all our platforms, we also jumped into CF-related conversations online to proactively offer help and support to people with CF who were struggling.

Our brand

As we revised our vision, mission and goals, we evolved our brand story and messaging in order to communicate this in an engaging and motivating way. We want to make sure it's clear what the Trust is trying to achieve, and why people should get involved to give their time, money or voice.

We refreshed our brand positioning and expression (such as our visual identity and tone of voice) so that it's more accessible and relevant.

We shaped our brand around the changing context for people affected by CF, including:

- the need for research and new therapies post-Kaftrio, as not everyone can benefit from modulator drugs
- the uncertain economic environment and cost of living crisis
- increased focus on mental health due to external insights including our Kantar research
- increased focus on diversity and inclusion including content for key festivals, our photography and stories.

Website

We launched our new website in March 2021 and have continued to improve the user experience based on analysis, polling, user testing and internal feedback. Users now stay on the website longer and our bounce rate has reduced by over 10%. Site speeds have improved and, when polled, a majority of users have told us that the website is either excellent or good. We are continuing to improve the website with a current focus on the navigation. We're also carrying out a content audit to ensure our content is as relevant and accessible as it can be.

Volunteering

Over the last year, we've been really grateful that the hard work of our volunteers, supporters, and branches and groups has continued, despite the interruptions caused by the pandemic.

Our volunteers come from a wide range of backgrounds and different life stages, ranging from those who already have a connection to someone with cystic fibrosis (CF), to university students, people working directly for companies partnering with the Trust, or those who have more time to give in their careers and wanting to use the skills they have developed to help us do more for people with CF.

COVID-19 restrictions have caused challenges for volunteering. We've responded to that by opening up more volunteering activities from home, which has allowed some volunteers to continue to support us that otherwise couldn't.

Being an effective organisation

The Trust's ability to achieve our vision depends on our effectiveness as an organisation, which is supported by our employees' skills, passion and energy. We nurture this by providing benefits that our staff value, such as flexible working; holiday and parental leave allowances, which exceed statutory requirements; learning and development opportunities; and good communications, such as a two-weekly online and face-to-face briefing led by our CEO.

"I chose to volunteer for Cystic Fibrosis Trust initially to raise funds and awareness. I organised two large-scale events and aimed to do more. When the pandemic hit and large events weren't possible, I used my background in publishing to lend a hand to the comms and marketing team. I would thoroughly recommend volunteering with the Trust; not only are they an absolutely wonderful bunch of people, but you get to help out a great cause and it looks great on your CV! I've been lucky enough to work on some amazing campaigns and projects and can't wait to see what comes next!"

Lian



The Executive Team shares information with the People Committee on key human resources measures and projects to improve our inclusivity as an organisation and the engagement of our people. The People Committee also reviews the outcomes reported from the annual staff survey, which again this year had a high response rate of 81% and positive scores for most areas.

We are extremely grateful for the efforts of our staff and volunteers during a challenging year. The pressures on people with CF have been magnified yet again by the COVID-19 pandemic, which has resulted in a high volume of work for all teams at the Trust. Reduced fundraising activity due to COVID-19 resulted in a reduction of 25% net income. This meant we had to restructure and make several redundancies across fundraising.

As we move into 2022/23, we are in the process of introducing a new performance and development process; updating policies to make our workplace even more inclusive; and reviewing pay and benefits.

Uniting in fundraising

We would like to thank all the fantastic individual donors and supporters, organisations, charitable trusts, foundations and corporate partners who support our work to make sure everybody with CF can live a life unlimited. We simply couldn't do what we do without you!

The Trust continues to build back after the reduction in income due to COVID-19. In 2021/22, £7.4 million gross income was raised and £5.54 million net income, which is slightly higher than income raised in 2020/21 but lower than pre-pandemic net income by 25%. The difference is that although we were delighted that our community and events income was significantly higher than in 2020/21 with events and activities taking place, we saw a reduction in legacy, corporate partnerships and trusts income in 2021/22. This is in addition to the one-off COVID-19 emergency appeal in 2020/21 which raised £829,000 and was not repeated in 2021/22.

We continue to innovate and adapt our fundraising plans with both physical and virtual events continuing to take place. Examples of new innovations include our online shop, which was launched in November 2021; a focus on engaging schools with fundraising; a new Festive 5k, and promotion of gifts in Wills.

Our trustees agree and regularly review our fundraising strategy. We adhere to Data Protection Law and the Fundraising Preference Service. We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice and, as such, commit to their Fundraising Promise. We aim to exceed the standards included in our promise to our supporters:

We will be transparent about our work
We will be respectful
We will listen and respond
We are committed to high standards
We are fair and responsible



Beatriz and son Yoel

"The Trust have been there for me when I didn't know who to speak to. They have shown me that I'm not alone and provided the right information and support when I needed it most. The Trust give me an opportunity to believe."

Beatriz, mum to Yoel, who has CF

Supporter experience

The Trust is so grateful to our committed and passionate supporters, who regularly go the extra mile to raise vital funds for everyone affected by cystic fibrosis. Improving our supporter experience is a key focus for the Trust at every interaction. We continuously analyse and use feedback collected from supporters including face-to-face, online or offline. We are constantly reviewing our communications, ensuring that we provide the right materials for their fundraising and in particular, communicate how their hard work is making an impact to the lives of people living with cystic fibrosis.

The Trust received 24 complaints in 2021/22. This was broadly in line with the 28 received in 2020/21, and remains lower than pre-pandemic levels (46 in 2019/20) as a result of fewer in-person fundraising activities in early 2021. Complaints are closely monitored and reviewed by senior management on an ongoing basis. In addition, we regularly review our complaints policy and processes to make it easier for people to give us feedback, and to ensure that we listen and learn from what our supporters and the community are telling us.

Regular gifts

We'd like to express our gratitude to our loyal regular donors who provide invaluable ongoing support that enables us to plan effectively for the future. These supporters contributed just over £775,000 in 2021/22, including Gift Aid.

During this year, we carried out a telemarketing campaign through Ethicall, our professional telephone fundraising agency. Ethicall have a 'respect and dignity' policy that turns marketing calls into 'thank you' calls if they suspect the person that they are speaking to is vulnerable. These campaigns (a regular giving upgrade and a direct debit recruitment campaign) resulted in an additional annual income of £20,000.

Community and event fundraising

The COVID-19 pandemic has continued to impact on community and event fundraising, and our focus has been on building back our activities and income following the uncertainty of recent years.

We developed a hybrid portfolio of activity which was fully embraced by our amazing supporters, and despite the lockdown restrictions they faced, we were so grateful that so many people continued to fundraise for us in a variety of ways.

Our Team CF runners were finally able to take on the Great North Run and London Marathon, raising £60,000 and £419,000 respectively.

Our virtual Great Strides™ My Way challenge raised £63,000 and our Running Festival raised £26,000.

Our loyal branches and groups across the country raised a fantastic £93,000.

Our annual Wear Yellow Day continues to go from strength to strength and raised £135,000.

We'd hoped festive favourite Carols by Candlelight would be able to go ahead in person, but again due to COVID-19 was moved to online. We were joined by an array of celebrity speakers and raised £55,000. Our other festive fundraising activities, including the Festive 5K virtual run, raised an additional £50,000.

Corporate partnerships

The Trust continues to work in partnership with companies to raise funds and awareness of cystic fibrosis. We also work in partnership with companies to maximise the valuable benefits they can give through *pro bono* and gift-in-kind support. For example, this year we were delighted to have the support of Ogilvy, a leading marketing agency whose generous *pro bono* support enabled us to launch our brand-new campaign #CFTruths. This campaign shed light on the realities of living with CF and shared stories of some of the day-to-day challenges that having CF can bring.

We are incredibly grateful for the ongoing support from our advertising partners such as Clear Channel, Talon and Goodstuff, who provide gift-in-kind outdoor advertising and campaign advice, which is incredibly valuable in helping us promote our work.

We would also like to thank Chaucer, a strategy consultancy who supported us with *pro bono* advice across a range of projects, from fundraising campaigns to our own Helen Barrett Bright Ideas Awards.

We were delighted to be supported by employees and their companies such as XTX Markets, B&Q and Stark Software. We also continued to work on commercial partnerships with companies such as Prestige Flowers and Amazon Smile. Any commercial activities where the Trust benefits from the sale of products in exchange for use of our logo operates against a formal agreement and are monitored closely.

This year also saw sponsorship from the pharmaceutical industry for the UK CF Clinical Trials Conference, the CF Registry Annual Meeting, and UKCFC. We look forward to working with our sponsors again next year.

Gifts in wills

We received 92 legacies in 2021/22 from supporters who generously included a gift to the Trust in their Will, as well as 49 supporters who told us they have pledged a gift.

We are incredibly grateful to those who have thought of us in this special way or are considering doing so, and we continue to raise people's awareness of legacy giving.



In memory

We continue to remember with respect and affection those who have lost their lives because of cystic fibrosis and we thank all our supporters who fundraise in memory of their loved ones. In 2021/22, we received more than £249,000 in memory of those who are no longer with us, and many will continue to be remembered through our Book of Remembrance, tribute funds, and in the hearts of all who were close to them.

Philanthropy

The support we receive from charitable trusts, foundations and individual supporters continues to play a crucial role in funding the work we do.

This year we have been pleased to continue our partnerships with the Joseph Levy Foundation, which supports our Information and Support work; BBC Children in Need, which supports our CF Youth programme; Sport England; and the National Lottery Awards for All, which supports the development of our Helpline.

In addition, we have worked with generous individuals who are long-standing supporters of our work, and our loyal Sixty-Five Roses Club members have also continued their amazing support, despite another challenging year.



(Photo: Jake Sugden Photography)

Support for the UK Cystic Fibrosis Innovation Hub continues to grow, with cash and pledges from trusts, corporates and individuals – including our two cornerstone funders, AJN Steelstock and the Robert Luff Foundation – totalling over £3.1m to date.

We were delighted to welcome members of the CF community to a reception at St James's Palace with His Royal Highness The former Prince of Wales, KG, KT, GCB, OM, who became our Patron in 2014 in our 50th year. This was to mark the progress that has been made since the CFTR gene that causes CF was discovered over 30 years ago. The event highlighted the challenges still facing people affected by the life-limiting condition, and the importance of continued investment in research and treatments to help those with CF live a life unlimited.

Looking to the future

Uniting in research for a life unlimited

While a long-term aim of the Trust is to tackle the underlying cause of CF, leading to the development of potentially novel and innovative future treatments and care, we also need to continue to pursue research that will improve the health and wellbeing of people living with CF today.

With the recent breakthrough in access to highly effective modulators for a significant proportion of the CF community comes new health and research challenges for all people with CF. The research we fund, support and prioritise through the Trust must continue to be informed by and address the changing needs and priorities in CF.

The results of the James Lind Alliance CF Research Priority Refresh project conducted as a partnership between the Trust, the James Lind Alliance and the University of Nottingham will guide the direction of future research funding and support.



Delivering our strategy

Our response during the pandemic highlighted how important it is that we demonstrate our relevance to our community by stepping up and addressing emerging issues during periods of crisis and change. As such, we have invested additional time, effort and resources into addressing the new and emerging challenges facing the cystic fibrosis community, across the three following goals:

- **Being physically well:** together, we can live without the physical challenges of cystic fibrosis.
- **Being mentally well:** together, we can manage the mental pressures of cystic fibrosis.
- **Fulfilment:** together, we can lead the life we want as part of a connected community.

To achieve these ambitious goals, we will work with our community and partners across the UK and internationally to support innovative, high-quality research, achieve access to the best treatments, drive up the quality of care and provide and advocate for the support needs of people with cystic fibrosis.

We also know that in order to deliver on this vision we need to adapt and change as an organisation, including a greater focus on:

- putting people with cystic fibrosis at the heart of everything we do
- building international and domestic partnerships
- adopting a virtual first workstyle
- being great and innovative fundraisers
- making effective use of data and analytics, including a new data strategy and quantitative impact framework
- working in ways that brings together our diverse community and staff, such as improving diversity in clinical trials, reviewing internal policies and processes, and implementing a new performance development system.

Being great fundraisers

Raising funds is vital to enable us to continue our work to support people with CF to live a life unlimited. We will continue to work closely with our incredible supporters, branches and groups at a local level and with our trusts and corporate partners. We know the cost of living pressures everyone is experiencing right now, and it makes the support of the cystic fibrosis community so incredibly special to us.

In order to provide the very best experience when supporting the Trust, we will continually review and update our engagement and processes.

Innovation remains a key pillar of our strategy to diversify our income and engage new supporters. We will ensure our portfolio of activity provides a hybrid offering which is accessible to all, irrespective of age and ability, and we will continue to maximise the potential of our campaigns including Wear Yellow Day, Run for Research and Great Strides™. We are looking forward to the 20th year of Carols by Candlelight in December.



Campaigning hard

Our Cost of CF campaign has already begun to highlight the additional cost pressures facing the CF community, such as:

- paying for life-changing drugs when other conditions are exempt from prescription charges in England
- the challenge of rising domestic fuel prices over the winter of 2021/22 and the concern about further increases ahead of the next winter
- the need for specific reform of the way that social security assistance is paid to those with lifelong conditions – including reviewing whether it is necessary to place additional stresses on people's health by requiring them to undergo regular reassessments for financial support.

We will continue to campaign hard to make sure our community can live without the limits of cystic fibrosis.

Day-to-day support

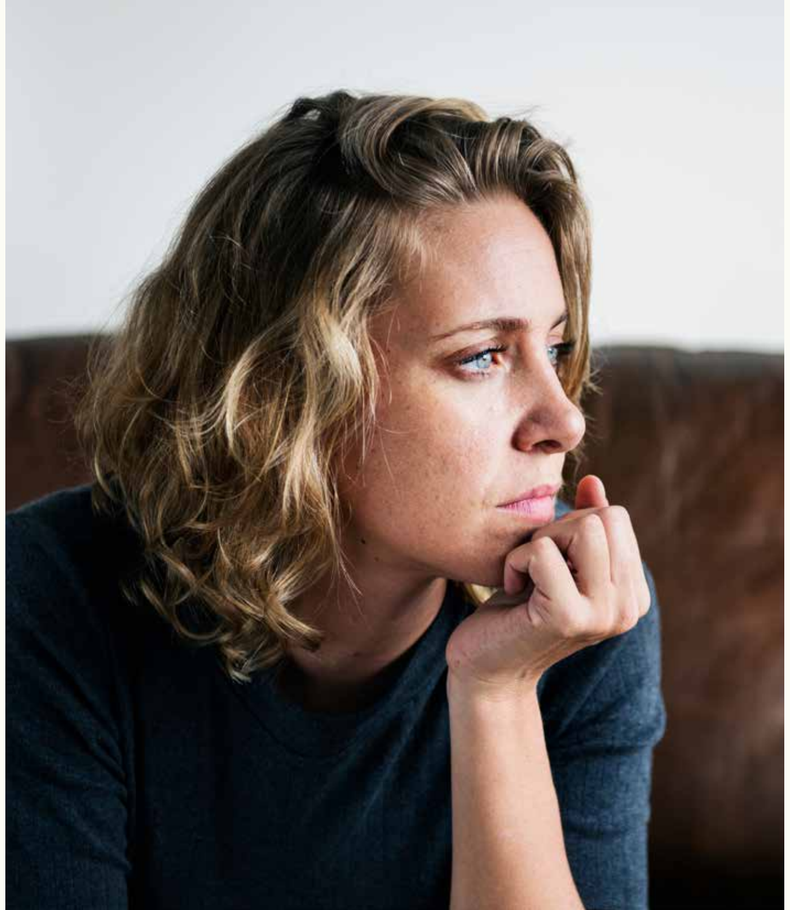
We will continue to respond to immediate needs as the community copes with the cost of living crisis, adjusts to the changing CF landscape, and recovers from the impact of the pandemic.

Our core services and resources will continue to provide expert, dedicated help with the day-to-day challenges CF brings. We'll also develop new programmes of work, including an ambitious programme of employment support, empowering people with CF to access secure, fulfilling work without compromising their health.

We will be developing our information library, updating key resources such as our new diagnosis pack, as well as new consensus guidelines which reflect the changing nature of CF care and treatment. We'll continue to run our successful youth programme, providing more opportunities for children and young people with CF to take part in fun social events and skill-building activities, while building confidence and making new friends.

We'll also continue our drive to ensure all our services and resources are accessible, relevant and representative of a diverse CF community, and we'll explore innovative new ways to deliver information and support.

We look forward to relaunching our forum, creating a safe space for anyone affected by CF to come together online and discuss issues that matter to them.



UK CF Registry

The UK CF Registry Annual Report 2021 will be published later in 2022. The Trust will report the final analysis of the efficacy of CFTR modulators to NICE as part of the Interim Access Oversight Committee in October 2022, with the final report submitted in June 2023.

The Annual Registry Meeting will return as an in-person meeting in Winter 2022, allowing colleagues across the country to come together once again for this important meeting. The team will continue to hold virtual workshops and coffee mornings for Registry users to provide support and guidance throughout the year.

Our validated data sets will become available within a Data Safe Haven, enhancing our abilities to link UK CF Registry data with other healthcare data sets as part of approved research projects.

2022 will also see the relaunch of the Data Validation Visits programme, with a new format enabling both virtual and in-person validation visits.

Quality improvement

We will publish UK-level reports, sharing the insights from all the QI team's data collections, in the summer of 2022. These reports will summarise current data on patient experiences in children's and adult CF services, as well as staffing levels, across the UK. We will also look to re-run the staffing tool as well as the patient experience survey for children's CF centres in the autumn of 2022. This will enable us to understand how experiences and staffing levels change over time.

The QI team will also continue to work with the QI Working Group to deliver our QI Strategy, and to improve our data collections and feedback offer for CF services.



Financial review

Income

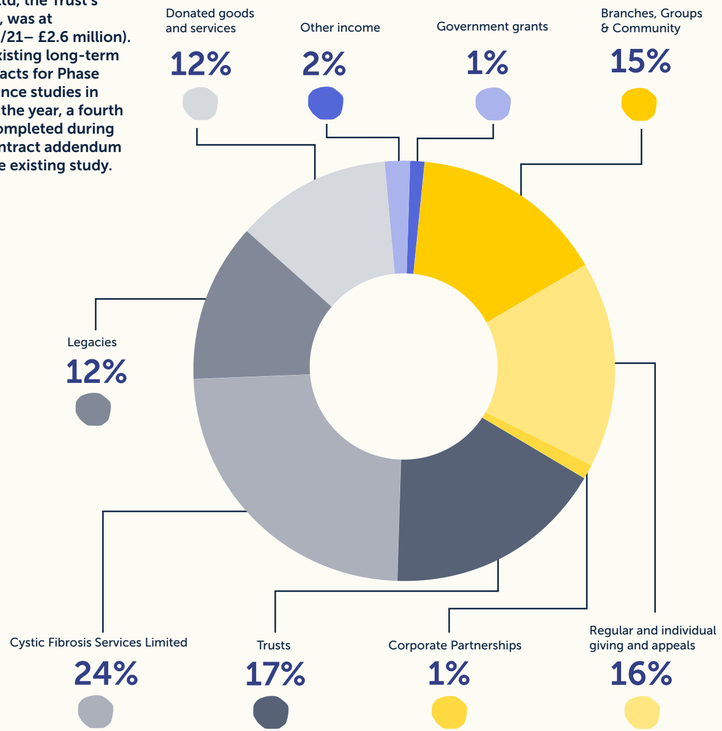
The Trust's income from normal activities for the year to March 2022 was £15.7 million, an increase of 9% over the previous year.

75% of the Trust's total income is made up of donations and legacies, totalling £11.2 million, (2020/21 – £11.7 million). This percentage is 6% lower than in the previous year, although our Community and Events income was significantly higher than in 2020/21, we saw a reduction in legacy, corporate partnerships and trusts income in 2021/22, in addition to the one off COVID-19 emergency appeal in 2020/21 which raised £829,000 and was not repeated in 2021/22.

We once again gratefully received donated unsold advertising space from Clear Channel as part of their 'Platform for Good' in the year, worth £1.8 million – this value was 15% higher due to the successful uptake of our two awareness campaigns. In the prior year, we had fewer advertising opportunities during the pandemic due to their focus and allocation of COVID-19 public health campaigns.

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, was at £3.7 million (2020/21– £2.6 million). As well as three existing long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, a fourth contracted was completed during the year, and a contract addendum was signed for one existing study.

2021/22 income by income stream



Expenditure

The Trust's total expenditure for the year was £16.0 million, a 15% increase compared to the previous year. The largest area of spend was on charitable activities at £11.8 million (2020/21 – 10.2 million), accounting for 74% of total spend. This comprises programmes of research, information, advice and support and clinical care.

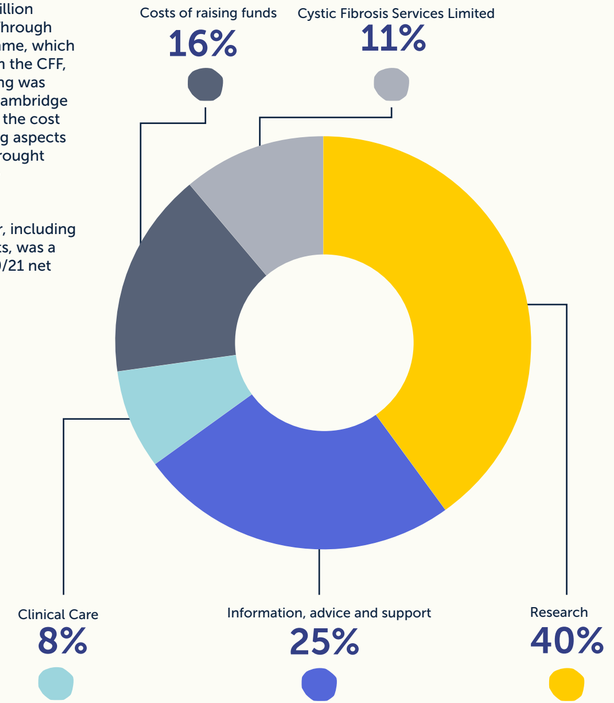
The remainder was spent on activities for generating funds, including £1.6 million paid to NHS cystic fibrosis clinical centres across the UK to support the resources necessary to add patient data to the CF Registry.

Total grant commitments in the year were £5.5 million (2020/21 – £3.8 million), of which £4.6 million (2020/21 – £3.5 million) were committed to a range of institutions, including £1.8 million committed for two Strategic Research Centres and some agreed cost extensions (2020/21 – £2.3 million for three centres). The remaining £0.3 million (2020/21 – £0.3 million) was awarded to individuals through our ongoing Welfare Grant progamme.

The Clinical Trial Accelerator Platform flagship programme continued to develop throughout the year, with total spend of £0.8 million (2020/21 – £0.8 million). Through the Digital Health Programme, which is funded by an award from the CFF, £0.7 million of grant funding was awarded to University of Cambridge and partner organisations; the cost of some remote monitoring aspects of this programme were brought forward in response to the COVID-19 pandemic.

The final result for the year, including movements on investments, was a net Surplus of £155k (2020/21 net surplus of £1.3 million).

2021/22 expenditure by cost type



Investment policy

The Finance Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to maintain real long-term capital value, looking to balance short-term volatility and protection against inflation with a moderate risk tolerance. The Trust does not permit direct investment in tobacco. General funds are invested in a balanced portfolio that includes some exposure to less liquid assets such as property, and utilises funds that do not invest in tobacco. A number of small endowment funds are invested on a Total Return basis, enabling the Trust to utilise both income generated by the funds and increases in capital value, while protecting the original inflation-adjusted endowment values. We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance Committee.

Review of investments in the year

The value of the investment portfolio (included endowment funds) has increased by £0.4 million this year (2020/21: decrease by £0.5 million). No change was made to the allocation between amounts held as stocks and shares and that held as cash. Income generated on investments totalled £0.1m, which realised and unrealised gains on the investment portfolio totalled £0.4m.

Reserves

The Trust's reserves, as of 31 March 2022, totalled £9,671,000 (2021 – £9,516,000). Reserves are held in order to ensure the continuity of service provision, as well as enabling the Trust to move forward with strategically important programmes of work as and when opportunities arise. The Trustees maintain the following reserves:

- Designated reserves – the Trustees have opted to set aside free reserves for the following purposes:
  - A fixed asset reserve, equal to the net book value of the Trust's fixed assets (£19,000) is held to ensure these are not considered to be realisable.
  - A deficit has been recognised being the difference between the £2million grant awarded to the Innovation Hub at Cambridge and the £3.75million of income committed so far for the corresponding project. This deficit has been under-written by Cystic Fibrosis Trust while we continue to attract supporters and partners.
- Operating reserve – held at a value (£3,411,000) sufficient, as a minimum, to cover six months' operating costs, major fluctuations in income from budget, contingencies for long-term commitments and any deficit on restricted reserves due to over commitment or payment on those projects.
- Retained Reserves (£6,209,000) to be deployed in financing our strategic ambitions in a way that maximises the impact for people with cystic fibrosis. Retained reserves are expected to be utilised through a managed spend programme over the next 36 months. The impact on income generation from the cost of living crisis, the continuing fall out from the COVID-19 pandemic and the war in Ukraine means that these reserves are likely to be utilised over a shorter period. It is the intention to use retained reserves while maintaining the Operating reserve as described above.
- Restricted income funds (£271,000) – relating to donations restricted to various specified activities.
- Endowment funds (£1,046,000) - The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.

More information about the reserves can be found in note 17a to the accounts.

The Trustees keep reserves policy under regular review to ensure it is set at the appropriate level to reflect changes in the business outlook as they materialise. The reserves as outlined above meet the Trust's reserves policy.

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.



Our approach to reserves

The Trustees have a policy, informed by Charity Commission guidance, of maintaining an Operating Reserves equivalent to six months' core running costs. We currently estimate that to be c.£3.4 million.

The Board is also committed to maintaining our impact for the benefit of people with cystic fibrosis at a point when we believe it will still take considerable time for fundraising income to recover to pre COVID-19 pandemic levels. The cost of living crisis is also impacting our community and is expected to continue to do so for some time to come. The Board have, therefore, approved a deficit budget for the year ended 31 March 2023 and we also anticipate that planned deficits are likely in the subsequent two financial years.

This will have the effect of substantially reducing our free reserves, to ensure that we can:

- Invest in research, programmes of work and resources to ensure that we remain responsive and relevant to the changing needs of the cystic fibrosis community
- Mitigate the risks associated with our fundraised income and enable us to support innovation to diversifying our income base
- Ensure that we can invest sufficient funding into the Trust's activities and infrastructure to ensure long term sustainability

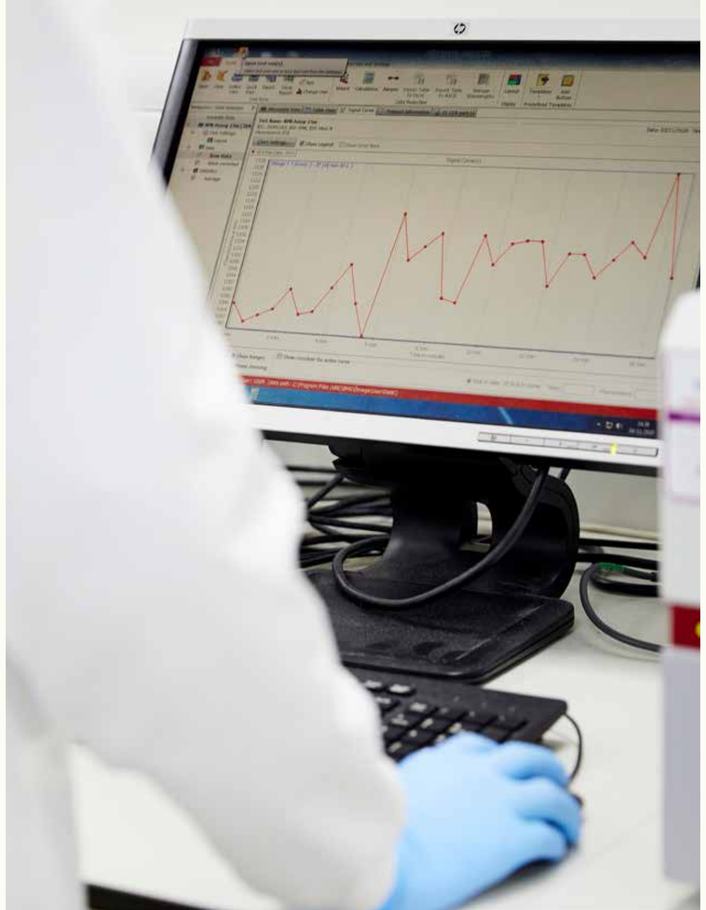
Principal risks and uncertainties

The Board of Trustees is responsible for ensuring effective risk management and internal controls to manage the major risks the charity faces, including agreeing the organisation's 'risk appetite' (how much risk the Trust is willing to tolerate in key areas) and keeping oversight of the Trust's risk management framework. This framework, managed by the Senior Leadership Team, includes a strategic risk register and provides a consistent approach to identifying, assessing and dealing with the risks facing the charity. It is regularly monitored (quarterly) to support informed decision-making and ensure appropriate mitigations and controls are in place to effectively manage any risks to our objectives.

The main strategic risks and uncertainties that management and Trustees have identified include: the risks of failing to remain relevant to the changing needs of our community; delivering a financially sustainable model in the midst of the cost of living crisis; keeping Trust/Registry data secure; getting our message across; influencing key stakeholders, maintaining business continuity; delivering effective people strategies; maintaining our autonomy; and managing our reputation.

Processes in place regarding risk management and internal control include the following:

- A risk management framework that meets the Charity Commission's requirements. A top-down risk review by the Senior Leadership Team, and a bottom-up review by individual functions, is undertaken throughout the year and the risks identified through this process are documented in a risk register.
- The Finance Committee receives reports from the external auditors on the effectiveness of controls and on progress against both its audit plan and the recommendations made in its reports.
- The Board of Trustees has received a comprehensive risk management report to assist it in ensuring that an effective process is in place. This report provided an update on the risk reviews undertaken, and provided the Board with the opportunity to engage in dialogue about, and to provide input into, the evaluation and management of key risks.
- Formal project delivery groups are established for major projects and programmes, such as the Life Unlimited programme, to ensure that these are properly planned, managed and implemented.



Our work with the pharmaceutical industry

Our mission is to make sure everyone can live without the limits of CF. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

Partnerships between medical research charities and the life sciences industry can help us deliver that mission and bring huge benefits to patients— from accelerating the development of new drugs to ensuring the safety and improvement of existing treatments.

We run the following flagship programmes involving industry partners:

Clinical Trials Accelerator Platform

CTAP is a UK-wide initiative bringing together CF centres to increase participation and access to CF clinical trials. This initiative is building infrastructure and funding additional research capacity to support the life sciences industry with commercial clinical trial delivery.

As part of our collaboration with industry, the Trials Accelerator offers a centralised feasibility service to support pharmaceutical companies with identification of suitable CF centres for clinical trial delivery.

Venture & Innovation Awards (VIAs)

Venture & Innovation Awards (VIAs) VIAs support transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the life sciences industry.

The UK Cystic Fibrosis Registry

Long-term safety and efficacy studies of drugs available to people with CF across the UK are conducted by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the regulators of medicinal products is covered by pharmaceutical companies holding the market authorisation for these medicines. You can read more about our work with industry to make medicines safer at **cysticfibrosis.org.uk/registry.**

In 2021/22 Cystic Fibrosis Services Ltd, the Trust's subsidiary, received £3.7m in fees for this service. As well as the three existing long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, a fourth contracted was completed during the year, and a contract addendum was signed for one existing study.

Sponsorship and donations

Sponsorship from pharmaceutical companies helps pay for our annual UK Cystic Fibrosis Conference, enabling us to stage a free event to keep healthcare professionals and people affected by CF informed on all aspects of clinical care and research. In 2021/22, we received sponsorship for the UK Cystic Fibrosis Conference and would like to thank the following companies: PARI Medical, Gilead, Vertex and Chiesi. In 2021/22 we also received sponsorship from TEVA for the online Annual Registry Meeting held in June 2021.

For the first time, the Trust was involved in organising the UK CF Clinical Trials Conference held in Nottingham in March 2022. We received an Independent Medical Education grant from Vertex towards the cost of the event. We also secured sponsorship from Vertex, Abbvie, Boehringer-Ingleheim, Chesi and KrystalBio. We would like to extend our thanks to PARI Medical, Gilead, Vertex and Chiesi, who sponsored the 2021 conference.



"Cystic Fibrosis Trust, to me, means hope. Without it we wouldn't have had the funding to conduct the research that has changed so many people's lives, not only for people with CF, but their loved ones too. The Trust always gave me hope that one day, through research, the lives of those with CF and especially my brother, would be changed for the better forever."

Alice Collins, early career researcher whose brother has CF

Statement of Trustees' responsibilities

The Trustees, who are also directors of the Cystic Fibrosis Trust for the purposes of company law, are responsible for preparing the Trustees' report (including the Group Strategic Report) and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group, and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP
- make and accounting estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustees investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustee's Report incorporating the Strategic Report was approved and authorised for issue by the Board of Trustees in **November 2022** and signed on its behalf by:



Richard Hunt, Chairman

Independent auditor's report to the members and trustees of Cystic Fibrosis Trust

Opinion

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2022 which comprise the Consolidated Statement of Financial Activities, Consolidated Income and Expenditure Account, the Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows, and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 March 2022 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Trustees' Annual Report and the Chairman's statement. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Annual Report (which includes the strategic report and the directors' report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements
- the strategic report and the directors' report included within the Trustees' Annual Report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the parent charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report (which incorporates the strategic report and the directors' report).

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charity Accounts (Scotland) Regulations (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept by the parent charitable company or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement (set out on page 67), the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the parent charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the parent charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to fundraising regulations, charity and company law applicable in England, Wales and Scotland, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Act 2011 and payroll taxes.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the completeness and cut-off of voluntary income, legacies, grant income and investment income. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud
- Evaluating management's controls designed to prevent and detect irregularities
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions
- Challenging assumptions and judgements made by management in their critical accounting estimates, in particular donation and legacy recognition, the recognition of grant income and the recognition of grant expenditure.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at **www.frc.org.uk/auditorsresponsibilities**. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Kathryn Burton (Senior Statutory Auditor)
For and on behalf of Haysmacintyre LLP, Statutory Auditor

10 Queen Street Place,
London
EC4R 1AG

Cystic Fibrosis Trust
Consolidated statement of financial activities
For the year ended 31 March 2022

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2022 £'000**	Total Funds 2021 £'000
Income and endowments from:						
Donations and legacies	2a	8,161	3,627	-	**11,788**	11,678
Charitable activities						
Other trading activities	12	3,703	-	-	**3,703**	2,580
Investments	2b	59	19	-	**78**	128
Other income		112	-	-	112	-
Total income		12,035	3,646	-	**15,681**	14,386
Expenditure on:						
Raising funds	3a	4,183	-	1	**4,184**	3,721
Charitable activities						
Research	3a	3,239	3,215	3	**6,457**	4,975
Clinical care	3a	431	914	-	**1,345**	1,132
Information, advice & support	3a	3,874	106	2	**3,982**	4,077
Total charitable activities		7,544	4,235	5	**11,784**	10,184
Total resources expended	3a	11,727	4,235	6	**15,968**	13,905
Net income/(expenditure) before investment gains/losses		**308**	**(589)**	**(6)**	**(287)**	481
Realised investment gains/(losses)		5	-	71	**76**	17
Unrealised investment gains/(losses)		374	-	(8)	**366**	793
Net investment gains/(losses)		**379**	**-**	**63**	**442**	810
Net (expenditure)/income		**687**	**(589)**	**57**	**155**	1,291
Transfers between funds	17a	(612)	612	-	**-**	-
Net movement in funds		75	23	57	**155**	1,291
Reconciliation of funds						
Total funds brought forward		8,279	248	989	**9,516**	8,225
Total funds carried forward	17a	**8,354**	**271**	**1,046**	**9,671**	9,516

All of the operations are continuing. There were no recognised gains or losses other than those stated above. A prior year comparative Consolidated Statement of Financial Activities has been included in the notes to the accounts (note 18)

The notes on pages 78 to 101 form part of these financial statements.

Cystic Fibrosis Trust
Consolidated income and expenditure account
For the year ended 31 March 2022

	All income funds 2022 £'000	All income funds 2021 £'000
Income	**15,603**	14,258
Gains/(losses) on investments	**379**	711
Investment income	**78**	128
Gross income in the reporting period	**16,060**	15,097
Expenditure	**15,950**	13,876
Interest payable	**-**	-
Depreciation and charges for impairment of fixed assets	**18**	23
Total expenditure in the reporting period	**15,968**	13,899
Net income before tax for the reporting period	**92**	1,198
Tax payable*	**-**	-
Net Income for the financial year	**92**	1,198

The Consolidated Summary Income and Expenditure Account is derived from the Statement of Financial Activities on page 72 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 78 to 101 form part of these financial statements.

Cystic Fibrosis Trust

Consolidated and charity balance sheets

For the year ended 31 March 2022

	Notes	Consolidated		Charity	
		Total 2022 £'000	Total 2021 £'000	**Total 2022 £'000**	Total 2021 £'000
Fixed assets					
Tangible assets	5	**19**	37	**19**	37
Investments	6	**5,604**	5,196	**5,604**	5,196
		5,623	5,233	**5,623**	5,233
Current assets					
Debtors	7	**3,948**	3,301	**2,824**	2,337
Cash held as short term investment		**11,265**	11,256	**11,265**	11,256
Cash at bank and in hand		**5,197**	3,366	**4,777**	3,246
		20,410	17,923	**18,866**	16,839
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	9	**(6,229)**	(7,407)	(6,229)	(7,407)
Creditors and accrued charges	10	**(2,708)**	(1,410)	(3,107)	(1,404)
		(8,937)	(8,817)	**(9,336)**	(8,811)
Net current assets		**11,473**	9,106	**9,530**	8,028
Creditors: amounts falling due after one year					
Grants payable	9	**(7,425)**	(4,823)	(7,425)	(4,823)
Total net assets		**9,671**	9,516	**7,728**	8,438

Continued on the next page

	Notes	Consolidated		Charity	
		Total 2022 £'000	Total 2021 £'000	**Total 2022 £'000**	Total 2021 £'000
The funds of the charity:					
Endowment funds	17a	**1,046**	989	**1,046**	989
Restricted income funds	17a	**271**	248	**271**	248
Unrestricted funds:					
Designated reserves	17a				
Fixed asset reserve		**19**	**37**	**19**	**37**
Appeal deficit		**(1,285)**	**(421)**	**(1,285)**	**(421)**
Strategic reserve		**-**	**200**	**-**	**200**
Total designated reserves		**(1,266)**	**(184)**	**(1,266)**	**(184)**
Operating reserves		**3,411**	**3,448**	**3,411**	**3,448**
Retained reserves		**6,209**	**5,015**	**4,266**	**3,937**
Total charity funds		**9,671**	9,516	**7,728**	8,438

The notes on pages 78 to 101 form part of these financial statements.

The net movement in funds for the Trust for the year ended 31 March 2022 was +£1,788,000 (2021: -£219,000). As permitted by Section 408 of the Companies Act 2006, no separate Statement of Financial Activities or Income and Expenditure account has been presented for the charity alone.

Approved and authorised for issue by the Trustees on 16 November 2022 and signed on their behalf by:



Richard Hunt, Chairman
Company number 3880213

Cystic Fibrosis Trust

Consolidated Statement of cash flows

For the year ended 31 March 2022

	2022 £'000	2021 £'000
Net cash provided by operating activities (Note A)	**1,728**	329
Cash flows from investing activities:		
Dividends and interest	**78**	128
Purchase of property, plant and equipment	**0**	(36)
Purchase of investments	**(1,082)**	(116)
Movement in cash awaiting investment	**8**	(4)
Proceeds of sales of investments	**1,108**	1,404
Total cash flows provided by investing activities	**112**	1,376
(Increase)/decrease in cash held as short term investments	**(9)**	(1,278)
Increase/(decrease) in cash (Note B)	**1,831**	427

Notes to Cash Flow Statement

A. Reconciliation of net income/(expenditure) to net cash flow from operating activities

	2022 £'000	2021 £'000
Net (expenditure)/income for the reporting period (as per the statement of financial activities)	**155**	1,291
Adjustment for:		
Depreciation charges	**18**	23
Dividends and interest from investments	**(78)**	(128)
(Gains)/losses on investments	**(442)**	(810)
Decrease/(increase) in debtors	**(647)**	(682)
Increase/(decrease) in creditors	**2,722**	635
Net cash provided by operating activities	**1,728**	329

Continued on the next page

B. Reconciliation of cash and cash equivalents in the reporting period

	2022 £'000	2021 £'000
Cash and cash equivalents at the beginning of the reporting period	**14,622**	12,917
Change in cash and cash equivalents in the reporting period	**1,831**	427
Increase in short-term investments	**9**	1,278
Cash and cash equivalents at the end of the reporting period	**16,462**	14,622
(being cash at bank and in hand and cash held as short-term investments)		

	2022	2021
Analysis of cash and cash equivalents:	**£'000**	£'000
Cash on hand	**5,197**	3,366
Notice deposits (less than 3 months)	**11,265**	11,256
Total cash and cash equivalents	**16,462**	14,622

Cystic Fibrosis Trust
Notes to the Financial Statements
For the year ended 31 March 2022

1. Accounting policies

The principle accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

a) Basis of preparation
The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – (Charities SORP FRS 102), and the Companies Act 2006.

Group financial statements have been prepared in respect of Cystic Fibrosis Trust and its wholly owned trading subsidiary, Cystic Fibrosis Services Limited. In accordance with the Companies Act 2006 and SORP 2015, no separate Statement of Financial Activities is presented for Cystic Fibrosis Trust.

Cystic Fibrosis Trust meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Charity status
The charity (registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 102. In the event of the company being wound up, the liability in respect of the guarantee is limited to £1 per member of the company.

c) Consolidation
The financial statements include the results and assets and liabilities of the charity and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own Statement of Financial Activities under section 408 of Companies Act 2006. The deficit for the parent charity was £1,788,000 (2020/21- surplus of £219,000).

The subsidiary's net surplus of £1,943,000 will be donated in full to the parent charity after the year end.

d) Income
All income is recognised once the charity has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably.

Donations and legacies income are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable.
Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

Investment income is recognised on a receivable basis and the amounts can be measured reliably. Dividends are recognised once the dividend has been declared and notification has been received the dividends are due.

e) Resources expended
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably.

Expenditure is recognised on an accruals basis as a liability is incurred, and includes irrecoverable VAT where applicable.

Expenditure is classified under the following activity headings:

- Expenditure on raising funds comprises those costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs.

- Expenditure on charitable activities comprises those costs relating to activities where the primary aim is congruent with the objects of the charity, along with an apportionment of support costs. This includes grants made to research institutions and individuals, the provision of information and support services to people with cystic fibrosis and their families, peer reviews of cystic fibrosis centres and the development of the CF Registry.

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the estimated amount of time spent by the support area on each activity category. The basis for allocation was reviewed in the year in order to give a more accurate view of the level of support provided within different business areas. The prior year allocations have been restated in order to be consistent with the revised allocation basis.

f) Grants
Grants committed and awarded during the year are expensed.

g) Foreign currency transactions
Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the Statement of Financial Activities.

h) Employee benefits
- Short term benefits - Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.

- Employee termination benefits - Termination benefits are accounted for on an accrual basis and in line with FRS 102.

- Pension scheme - The Charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Charity pays fixed contributions into a separate entity. Once the contributions have been paid the Charity has no further payment obligations. The contributions are recognised as an expense in the Statement of Financial Activities when they fall due.

i) Taxation
No charge to taxation arises on the result for the year because the company is able to take advantage of the tax exemptions available to charities.

j) Leases
The trust recognises expenses under "operating leases" relating to capital equipment which it does not own. The annual rentals are charged to the Statement of Financial Activities on a straight line basis over the lease term.

k) Funds
Unrestricted reserves are those which the Trustees are free to use for any purpose in furtherance of the charitable objects.

Designated reserves are set aside out of unrestricted reserves by the Trustees, for particular purposes.

Restricted reserves are monies, which have legal restrictions on their use where donors have specified the funds can only be spent on certain of the charity's activities.

Endowment Funds are funds where the Trustees are required to hold capital, as represented by the investments, and are not entitled to spend it. Income arising from these funds is either restricted income or unrestricted income depending upon the details included with the original gift.

l) Fixed assets and depreciation
Tangible fixed assets costing £500 or more are capitalised and are depreciated by equal annual instalments over their estimated useful lives. The current estimated rates of depreciation are:

Furniture & fittings	33.33%
Computer hardware	33.33%
Computer software	33.33%
Website development	33.33%
Platform development	50%

Website and Platform development costs are capitalised on the basis that they lead to an asset that will generate funds for the Trust or where the primary aim is part of the objects of the charity. The assets are depreciated once the asset is ready for use.

m) Investments
Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values of investments are shown as unrealised gains and losses in the Statement of Financial Activities.

Profits and losses on the realisation of investments are shown as realised gains and losses in the Statement of Financial Activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired subsequent to the first day of the financial year. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value. Realised and unrealised investment gains and losses are combined in the Statement of Financial Activities.

n) Financial Instruments
The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value

- Debtors – Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

- Cash at bank and in hand – Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

- Creditors and provisions – Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

o) Critical accounting judgements and estimates
In preparing these financial statements, management has made judgements, estimates and assumptions that affect the application of the Charity's accounting policies and the reported assets, liabilities, income and expenditure and the disclosures made in the financial statements. Estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. The key areas that are deemed to be material for these financial statements is as follows:

- Accruing for income derived from legacies where complicated issues surrounding the measurement of the group's entitlement to income existed at the year end.

- The value of the contribution of the many thousands of hours donated by its unpaid volunteers has not been reflected in these accounts. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

p) Going concern status
The Trustees have reviewed the financial statements and supplementary financial information and conclude that the Trust is a valid going concern.

2a. Income from donations and legacies

	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	**Total 2022 £'000**	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	**Total 2021 £'000**
Branches, Groups & Community	2,201	28	**2,229**	1,546	8	1,554
Legacies	1,574	321	**1,895**	2,082	185	2,267
Individual donations	291	93	**384**	394	32	426
Corporate	191	4	**195**	269	107	376
Regular giving and appeals	1,108	23	**1,131**	1,285	39	1,324
Trusts	94	2,521	**2,615**	97	2,551	2,648
Appeal for Innovation Hub	-	636	**636**	-	658	658
Donations in kind	1,892	-	**1,892**	1,648	-	1,648
Gift Aid	566	1	**567**	345	-	345
Government grant income	129	-	**129**	304	-	304
NHS National Services England and Scotland	115	-	**115**	128	-	128
Total income from donations and legacies	8,161	3,627	**11,788**	8,098	3,580	11,678

2b. Investment Income

	Unrestricted Funds 2022 £'000	Restricted Funds 2022 £'000	**Total 2022 £'000**	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	**Total 2021 £'000**
Income from listed investments	59	19	**78**	46	18	64
Bank interest	-	-	**-**	64	-	64
Total investment income	59	19	**78**	110	18	128

Donations In Kind refer to non-monetary donations received from partner organisations. In 2021/22 £1,892,000 was donated in the form of digital and cinema advertising space and professional fees (2020/21: £1,648,000). This was used to raise awareness of cystic fibrosis and the work of the Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, Advice and Support.

Government grant income relates to the recovery of partial salary costs through the Job Retention Scheme during the COVID-19 pandemic.

3a. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2022 £'000**
Raising funds					
Fundraising	-	-	2,152	341	**2,493**
Trading and merchandising	-	1,640	51	-	**1,691**
Charitable activities					
Research	3,072	1,435	1,064	886	**6,457**
Clinical care	716	(61)	506	184	**1,345**
Information, advice and support	17	286	3,133	546	**3,982**
	3,805	3,300	6,906	1,957	**15,968**

The net urestricted grants relating to Clinical Care are negative - this is due to the release of a commitment made in a prior year. See note 3b for more information.

Analysis of allocated Support Costs – current year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2022 £'000**
Fundraising	78	25	104	47	87	**341**
Research	203	67	269	121	226	**886**
Clinical care	42	14	56	25	47	**184**
Information, advice and support	125	40	166	75	140	**546**
Governance	-	-	-	-	-	**-**
Total costs	448	146	595	268	500	**1,957**

Costs are allocated based on identifiable activities undertaken by central teams to support the wider organisation.

3a. Expenditure continued

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2021 £'000**
Raising funds					
Fundraising	-	-	1,902	382	**2,284**
Trading and merchandising	-	1,376	61	-	**1,437**
Charitable activities					
Research	1,891	1,255	998	831	**4,975**
Clinical care	299	48	596	189	**1,132**
Information, advice and support	262	88	3,046	681	**4,077**
Governance	-	-	-	-	**-**
	2,452	2,767	6,603	2,083	**13,905**

Analysis of allocated Support Costs – prior year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2021 £'000**
Fundraising	62	52	105	50	113	**382**
Research	136	114	228	109	244	**831**
Clinical care	31	26	52	25	55	**189**
Information, advice and support	112	94	187	90	198	**681**
Governance	-	-	-	-	-	**-**
Total costs	341	286	572	274	610	**2,083**

3a. Expenditure continued

Net (expenditure)/income in the year:

	2022 £'000	2021 £'000
Auditors remuneration excluding VAT	**20**	22
Depreciation	**18**	23
Operating leases – building	**272**	244
Operating leases – other	**5**	6
Trustees' travel expenses	-	-

3b. Grants

Grants were awarded during the year as follows:

	2022 £'000	2021 £'000
Grants to institutions	**6,744**	4,870
Grants to individuals	**361**	350
	7,105	5,220

Grants made to, and for, individuals affected by Cystic Fibrosis are for expenses such as respite care, building adaptations and equipment rental and benefited a large number of individuals throughout the Trust's network of regions and branches.

	2022 £'000	2021 £'000
Balance at start of year	12,230	12,299
Adjustment to opening balance	-	-
Awarded in the year	7,105	5,220
Paid in year	(5,681)	(5,289)
Balance at end of year	**13,654**	**12,230**
Falling due within one year (note 9)	6,229	7,407
Falling due after more than one year (note 9)	7,425	4,823

3b. Grants continued

During the year, grants were awarded to the following institutions:

	2022 £'000	2021 £'000
Innovation Hub Cambridge	1,500	832
University of Nottingham	880	-
University of Liverpool	-	769
University of Bristol	-	749
UCL Great Ormond Street	750	750
University of Cambridge	365	-
Medical Research Council	267	17
Queen Elizabeth University Hospital	-	180
Cystic Fibrosis Canada (Fibrose Kystique) CFC	141	-
University Hospital Llandough	-	120
RNID	105	-
Diabetes UK	105	-
MDC (CF AMR Syndicate)	95	-
University of Edinburgh	70	2
Imperial College London / Royal Brompton Hospital	70	56
Belfast City Hospital	50	-
Medicines Discovery Catapult	-	50
University Hospital Llandough	45	-
Newcastle University	37	-
University of Copenhagen	-	27
Aston University	25	-
The University of Manchester	23	-
Queen's University Belfast	-	21
Other Insititutions (less than £20k)	39	9
	4,567	3,582

	2022 £'000	2021 £'000
Add: Trial Coordinator commitments made to CTAP centres (see note)	685	298
Add: Registry support grants made to various CF centres	1,571	1,376
Add: Other adjustments	-	15
Less: Release of grants made in previous years (see note)	(79)	(401)
Total grants made to institutions	**6,744**	4,870

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform programme. In most cases the trial coordinators are now in their fourth year of funding. In addition, a new cohort of Affiliate Centres were awarded funding in the year.

Various grants totalling £79,000 were released during the year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful.

The Trust has considered the discounting of grant commitments due in more than one year, but has not made any adjustments to the figures disclosed above as the impact of discounting is negligible.

4. Staff costs

Staff costs comprise the following:

	2022 £'000	2021 £'000
Salaries	**3,898**	4,220
Redundancy and other termination payments	**34**	34
Temporary Staff	**16**	75
Social security costs	**412**	432
Other pension costs	**227**	254
	4,587	5,015

£34,000 in redundancy and other termination payments were paid to three longstanding staff members (2020/21: paid to two staff members costing £34,000) following a review of the fundraising team structure due to the impact of COVID-19, which will result in a long-term recurring cost saving for the Trust.

Analysis of total average monthly headcount by category:

	2022 No.	2021 No.
Research	**14**	16
Clinical care	**6**	6
Information, advice and support	**33**	36
Fundraising	**36**	42
Management	**2**	2
Finance	**5**	7
IT and project management support	**8**	8
HR & OD	**5**	4
Facilities	**1**	1
Total average monthly headcount	**110**	122

The number of employees whose total remuneration exceeded £60,000 in the year was:

	2022 No.	2021 No.
£60,001 – £70,000	**6**	9
£70,001 – £80,000	**2**	2
£80,001 – £90,000	**1**	1
£90,001 – £100,000	**2**	-
£110,001 – £120,000	**1**	-
£140,001 – £150,000	**-**	1

Pension contributions to defined contribution pension schemes for these employees totalled £51,049 (2020/21: £53,168).

Remuneration of key management personnel: The total remuneration paid to key management personnel, including pension and social security contributions, was £584,529 which relates to 8 individuals who served on the Senior Leadership Team during the year (2020/21: £524,283 paid to 7 individuals).

5. Fixed Assets

	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 31 March 2021	**630**	**870**	**243**	**403**	**183**	**2,329**
Additions	-	-	-	-	-	-
Disposals	-	-	-	-	-	-
At 31 March 2022	**630**	**870**	**243**	**403**	**183**	**2,329**
Depreciation						
At 31 March 2021	**630**	**834**	**243**	**402**	**183**	**2,292**
Disposals	-	-	-	-	-	-
Charge for the year	-	17	-	1	-	18
At 31 March 2022	**630**	**851**	**243**	**403**	**183**	**2,310**
Net book value at 31 March 2022	**-**	**19**	**-**	**-**	**-**	**19**
Net book value at 31 March 2021	-	36	-	1	-	37

6. Investments

Group and Charity	**Total 2022 £'000**	Total 2021 £'000
Market value as at 31 March	**5,196**	5,670
Adjustment to brought forward balance	(14)	-
Additions at cost	**1,082**	116
Disposals at opening book value	(1,018)	(1,376)
Net gains/(losses) on investments	366	782
	5,612	5,192
Change in cash	(8)	4
Market value as at 31 March	**5,604**	5,196

6. Investments (continued)

Represented by:	**Total 2022 £'000**	Total 2021 £'000
Equities	**343**	3,921
Fixed Interest and multi-asset funds	**4,767**	495
Property	**292**	575
Cash	**202**	205
	5,604	5,196

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment.
The following asset was held at 31 March 2022. This is the only asset that is more than 5% of total investments:

	Total 2022 £'000
Responsible Multi Asset Fund	4,566

In 2014/15, the Trustees decided to exclude tobacco related stocks from investments. This change was implemented in 2015/16 and the investment portfolio is now fully ex-tobacco.

7. Debtors

	Group 2022 £'000	Group 2021 £'000	**Charity 2022 £'000**	Charity 2021 £'000
Trade debtors	**1,124**	1,085	**-**	-
Amount due from subsidiary undertaking	**-**	-	**-**	121
Prepayments and accrued income	**2,784**	2,151	**2,784**	2,151
Other debtors	**40**	65	**40**	65
	3,948	3,301	**2,824**	2,337

8. Cash held as short-term investment

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.

9. Grants Payable

	2022 £'000	2021 £'000
Grant creditor at 31 March	**12,230**	12,299
Prior year adjustment	**(17)**	-
Grants paid during the year	**(4,019)**	(3,914)
Grants approved before 31 March 2021 awarded but withdrawn	-	-
Grants approved in prior years and underprovided	-	-
Grants for Welfare approved and payable within the year	-	-
Grants approved before 31 March 2022 and payable within one year	**3,379**	2,347
Grants approved before 31 March 2022 and payable after one year	**2,081**	1,498
Grant creditor at 31 March	**13,654**	**12,230**
Represented by		
Grants committed and awaiting claim at 31 March	-	-
Grants due within one year at 31 March 2022	**6,229**	7,407
Grants due > 12 months	**7,425**	4,823
	13,654	**12,230**

10. Creditors

	Group 2022 £'000	Group 2021 £'000	Charity 2022 £'000	Charity 2021 £'000
Trade creditors	**668**	408	**655**	408
Other creditors	**108**	120	**523**	120
Accruals and deferred income	**1,932**	882	**1,929**	876
	2,708	1,410	**3,107**	1,404

11. Financial Instruments (Assets and Liabilities)

	Group 2022 £'000	Group 2021 £'000	Charity 2022 £'000	Charity 2021 £'000
Financial assets measured at amortised cost (Note A)	**17,593**	15,718	**16,048**	14,520
Financial assets measured at fair value (Note B)	**5,604**	5,196	**5,604**	5,196
Financial liabilities measured at amortised cost (Note C)	**(16,255)**	(13,529)	**(16,238)**	(13,521)
Net financial assets measured at amortised cost	**6,942**	**7,385**	**5,414**	**6,195**

(A) The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

(B) Financial assets held at fair value include assets held as investments.

(C) Financial liabilities measured at amortised cost include: trade creditors, other creditors, accruals, grants payable and deferred income and amounts due to group undertakings.

12. Interest in subsidary

Cystic Fibrosis Services Limited is incorporated in England (company number: 00900164) and is a wholly owned subsidiary of the Cystic Fibrosis Trust. The subsidiary's activities include medical services, information and data system support and the merchandising of marketing materials. The profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March can be summarised as:

	Total 2022 £'000	Total 2021 £'000
Sales and sundry income	**3,703**	2,580
Cost of sales and administration	**(1,691)**	(1,437)
Intercompany recharges	**(69)**	(71)
Net contribution to parent charity	**1,943**	1,072

The balance sheet of Cystic Fibrosis Services Limited at 31 March can be summarised as:

	Total 2022 £	Total 2021 £
Current assets		
Debtors	**1,538,869**	1,077,967
Cash at bank	**420,745**	120,205
	1,959,614	1,198,172
Creditors: amounts falling due within one year	**(16,226)**	(127,506)
Net current assets	**1,943,388**	1,070,666
Net assets	**1,943,388**	1,070,666
Capital and reserves		
Called up share capital	**2**	2
Profit and loss account	**1,943,386**	1,070,664
Shareholder's funds	**1,943,388**	1,070,666

The charity owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd, which comprises 100 ordinary shares of £1 each. 2 shares have been allotted, which are called up and fully paid.

The subsidiary's profit for the year will be donated in full to the Cystic Fibrosis Trust after the year end.

13. Leasing commitments

At 31 March, the Trust's future minimum operating leases payments relating to buildings were:

	2022 £'000	2021 £'000
Within one year	271	271
Between two and five years	543	814

A 10-year property lease with a five-year break clause was signed on 1 April 2015 for a new office in central London, with annual rent of £271,425. The break clause was not exercised and as such the remaining three years of the lease are now committed.

At 31 March, the Trust's future minimum operating leases payments relating to equipment were:

	2022 £'000	2021 £'000
Within one year	9	9
Between two and five years	14	20

The charge to the Statement of Financial Activities for all of these commitments is shown in note 3a.

14. Related party transactions

The group has taken advantage of the exception which is conferred by FRS102 Section 33.1A 'Related Party Disclosures' that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

Total donation income from the Trustees in the year was £14,428 (2020/21: £27,729). In addition 7 of the trustees (2020/21: 5) were involved in fundraising activities carried out by regional fundraising branches.

Any other transactions between the Trust and its trustees are disclosed in note 4.

15. Post balance sheet events

There were no post balance sheet events or contingent liabilities when the accounts were signed and authorised for issue.

16. Analysis of funds

	Unrestricted £'000	Endowment funds £'000	Gene Therapy restricted £'000	Other restricted £'000	2022 £'000
Tangible fixed assets	19	-	-	-	19
Investments	4,558	1,046	-	-	5,604
Current assets	20,139	-	-	271	20,410
Internal obligations	-	-	-	-	-
Current liabilities	(8,937)	-	-	-	(8,937)
Liabilities due in more than one year	(7,425)	-	-	-	(7,425)
	8,354	1,046	-	271	9,671

Prior year funds

	Unrestricted £'000	Endowment funds £'000	Gene Therapy restricted £'000	Other restricted £'000	2021 £'000
Tangible fixed assets	37	-	-		37
Investments	4,207	989	-	-	5,196
Current assets	17,660	-	-	263	17,923
Internal obligations	-	-	-	-	-
Current liabilities	(8,817)	-	-	-	(8,817)
Liabilities due in more than one year	(4,808)	-	-	(15)	(4,823)
	8,279	989	-	248	9,516

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2022

17a. Current year fund movements

	Balance 31 March 2021 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2022 £'000**
Fixed asset reserve	37	-	-	-	(18)	**19**
Appeal deficit: Innovation Hub at Cambridge	(421)	-	-	-	(864)	**(1,285)**
Strategic reserve	200	-	-	-	(200)	**-**
Total designated reserves	**(184)**	**-**	**-**	**-**	**(1,082)**	**(1,266)**
Operating reserve	3,448	-	-	-	(37)	**3,411**
Retained reserves	5,015	379	12,035	(11,727)	507	**6,209**
Total general reserves	**8,463**	**379**	**12,035**	**(11,727)**	**470**	**9,620**
Total unrestricted funds	**8,279**	**379**	**12,035**	**(11,727)**	**(612)**	**8,354**
Restricted income funds:						
Appeal: Innovation Hub at Cambridge	**-**	**-**	**636**	**(1,500)**	**864**	**-**
Restricted funds related to research:						
Genetic Therapies	87	-	28	-	(115)	**-**
General medical research	-	-	171	(171)	-	**-**
Sport England – Helping the active stay active	7	-	-	-	-	**7**
Imperial SRC: *Pseudomonas aeruginosa*	-	-	15	-	(15)	**-**
Imperial SRC: Targeting immuno therapy for fungal infections	-	-	4	-	(4)	**-**
Sheffield SRC: Gastrointestinal Cancer	-	-	2	-	(2)	**-**
UCL/Great Ormund St SRC – Therapeutic gene editing	4	-	41	-	(45)	**-**
Bristol SRC: CFTR Folding and Function	-	-	208	(208)	-	**-**
SRC costed extensions	-	-	267	(267)	-	**-**

Cystic Fibrosis Trust
Notes to the Financial Statements (continued)
For the year ended 31 March 2022

17a. Current year fund movements (continued)

	Balance 31 March 2021 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2022 £'000**
SRC024 University College London (UCL)	-	-	375	(375)	-	**-**
Life Expectancy Project	(23)	-	-	-	23	**-**
Transition Information Resources	15	-	-	-	-	**15**
Quality Improvement Project	-	-	35	-	-	**35**
Other research related restricted funds	(7)		5	-	6	**4**
Total funds related to research	**83**	**-**	**1,151**	**(1,021)**	**(152)**	**61**
Restricted funds related to Information and Support						
E W Joseph/Homecare grants	18	-	7	(22)	-	**3**
Joseph Levy/Education Grants	(15)	-	37	(48)	30	**4**
Young Lives programme	28	-	50	(21)	(28)	**29**
Support services (including welfare grants)	80	-	148	(2)	(114)	**112**
Forum	-	-	-	-	22	**22**
CF Connect (Youth and Parents)	26	-	-	-	(26)	**-**
Young entrepreneurs	-	-	16	(13)	-	**3**
Total funds related to Information and Support	**137**	**-**	**258**	**(106)**	**(116)**	**173**

17a. Current year fund movements (continued)

	Balance 31 March 2021 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2022 £'000**
Other funds – various categories:						
Coombe Hill	8	-	-	-	-	8
SmartCare CF	(10)	-	-	-	10	-
Clinical Trials Accelerator Programme (CTAP)	(10)	-	914	(914)	10	-
Digital Health Research Programme (Project Breathe)	-	-	684	(684)	-	-
CTAP Digital conference	-	-	3	(10)	-	(7)
CF Registry	(12)	-	-	-	12	-
Consensus documents	21	-	-	-	(21)	-
HDRUK grant award	(5)	-	-	-	5	-
Other older funds	36	-	-	-	-	36
Total other funds	**28**	**-**	**1,601**	**(1,608)**	**16**	**37**
Total restricted reserves	**248**	**-**	**3,646**	**(4,235)**	**612**	**271**
Endowment funds:						
Ena Bennie Endowment	491	42	-	(3)	-	530
EW Joseph Endowment	165	11	-	(1)	-	175
Joseph Levy Endowment	285	10	-	(2)	-	293
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other Endowment funds	28	-	-	-	-	28
Total endowment funds	**989**	**63**	**-**	**(6)**	**-**	**1,046**
Total funds	**9,516**	**442**	**15,681**	**(15,968)**	**-**	**9,671**

17a. Funds (continued)

Designated Funds: The designated fixed assets reserve matches the net book value of the charity's tangible fixed assets, the existence of which is fundamental to the charity being able to perform its charitable work and thereby achieve its charitable objectives. The value represented by such assets should not, therefore, be regarded as realisable.

Appeal Deficit: Innovation Hub at Cambridge – In 2017/18 we committed £2.0 million in the form of a research grant to the University of Cambridge as part of the Innovation Hub flagship programme. To date we have received £1.842m from donors in funding for this grant (shown in the separate restricted fund line, see below). The Trust has underwritten this grant, and we continue to work to secure additional pledges in order to fund the commitment in full and free up core funds to be made available where there is the greatest need.

General reserves: The operating reserve is held in order to provide, as a minimum, cover for six months operation costs, major fluctuations in income and contingencies for long term commitments, and any deficits arising on restricted funds.

Retained reserves are held for future initiatives.

Restricted income funds: Restricted income funds are held when donors specify a particular use for their donation. For the purposes of this report, the restricted income funds have been divided into the following categories:

- **Appeal for Innovation Hub at Cambridge:** We have received £1.842m to date in funding towards the £2.0m commitment made to the University of Cambridge. As further income is received it will be recognised within this restricted fund and matched against the commitment made in 2017/18 through a transfer to the designated fund (see above).

- **Restricted funds related to research:** Donations relating to grant commitments made by the Trust to research institutions. On occasion the donations were made in a different financial year to the original grant commitment; in such cases a transfer has been made to retained reserves to back-fill the original payments.

The following funds are held related to research:

Gene Therapy Research – funds available for gene therapy related activity.
General medical research – where the donor did not specify a particular research grant award.
- Matched against selected Strategic Research Centres.
- Matched against selected Venture Innovation Awards.
- Matched against selected Clinical Excellence and Innovation Awards.

Sport England funded work – A project at Exeter University: Helping the active stay active.

SRC costed extensions – Funding was secured from the Medical Research Council in 2022 to fund the extensions of SRC projects that had been delayed to the COVID-19 pandemic

Other research related restricted funds – including funding for grants to individuals for cystic fibrosis related summer student projects or travel to cystic fibrosis related conferences.

17a. Funds (continued)

- **Restricted funds related to information and support:** Donations relating various activities supporting people with cystic fibrosis and their families.

The following funds are held related to Information and Support:

- **EW Joseph/Homecare grants** – funding the promotion of increased care at home rather than in hospital for people with CF, and improvements in home care by education. See comments about the corresponding endowment fund below.
- **Joseph Levy/Education grants** – funding people with cystic fibrosis in their educational studies. See comments about the corresponding endowment fund below.
- **Young Lives Programme** – funding a youth porgramme supporting young people with cystic fibrosis. This fund is supported by Children In Need.
- **Support Services** – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
- **CF Connect Youth/Parents** – funding for projects to provide peer to peer telephone support service for young people with cystic fibrosis, and parents of children newly diagnosed with cystic fibrosis.

- **Other restricted funds:**
  Coombe Hill – funding education about cystic fibrosis.
  SmartcareCF – funding the development of the SmartcareCF platform, including both adult and paediatric study.
  Clinical Trials Accelerator Platform – funding this flagship programme.
  Digital Health Research Programme – funding this flagship programme, in collaboration with **Cambridge University and Papworth Hospital**, on digital health monitoring.

- **Endowment funds:** The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.

  The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.
  The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home (see EW Joseph/Homecare Grants above).
  The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education (see J Levy/Education Grants above).
  The Sally Wrigley Memorial Fund.

Transfers between funds – the following transfers were made between funds:

- A transfer was made between the Strategic Reserve and Retained Reserves to clear the balance within Designated Reserves
- A transfer was made between the Appeal Innovation Hub at Cambridge and the Appeal Deficit Innovation Hub at Cambridge.
- A transfer was made to the Fixed Asset Reserve to match against the current balance on Fixed Assets.
- Some transfers were made between Retained Reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been back-filled by restricted donations.

17b. Prior year fund movements

	Balance 31 March 2020 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2021 £'000**
Fixed asset reserve	24	-	-	-	13	**37**
Appeal deficit: Innovation Hub at Cambridge	(1,079)	-	-	-	658	**(421)**
Strategic reserve	-	-	-	-	200	**200**
Total designated reserves	**(1,055)**	**-**	**-**	**-**	**871**	**(184)**
Operating reserve	3,366	-	-	-	82	**3,448**
Retained reserves	4,778	712	10,788	(11,057)	(206)	**5,015**
Total general reserves	**8,144**	**712**	**10,788**	**(11,057)**	**(124)**	**8,463**
Total unrestricted funds	**7,089**	**712**	**10,788**	**(11,057)**	**747**	**8,279**
Restricted income funds						
Appeal for Innovation Hub at Cambridge	-	-	658	-	(658)	**-**
Restricted funds related to research:						
Gene therapy research	45	-	42	-	-	**87**
General medical research	-	-	179	(179)	-	**-**
Imperial College SRC: Pseudomonal infection	-	-	50	-	(50)	**-**
UCL SRC: Personalised Engineered Cell Therapies	-	-	3	-	(3)	**-**
Sport England -Helping the Active Stay Active	-	-	7	-	-	**7**
Imperial SRC: *Pseudomonas aeruginosa*	-	-	14	-	(14)	**-**
Targeting Immuno Theraphy for Fungal Infections-SRC15	-	-	2	-	(2)	**-**
RNA Interference of ENAC as Therapy for CF VIA 12	-	-	20	-	(20)	**-**
SRC020-Prof Stephen Hart-Therapeutic gene editing	-	-	379	(375)	-	**4**
SRC022-Co-funded with CFF			375	(375)	-	**-**
Life Expectancy Project	(20)	-	-	(3)	-	**(23)**
Transition Information Resources	15	-	-		-	**15**
Other research related restricted funds	1	-	5	(13)	-	**(7)**
Total funds related to research	41	-	1,076	(945)	(89)	**83**

17b. Prior year fund movements (continued)

	Balance 31 March 2020 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2021 £'000**
Restricted funds related to Information & Support:						
E W Joseph/Homecare grants	36	-	7	(25)	-	**18**
Joseph Levy/Education Grants	13	-	18	(46)	-	**(15)**
Young lives programme	6	-	61	(39)	-	**28**
Support services (inc. welfare grants)	81	-	224	(225)	-	**80**
CF Connect (youth and parents)	26	-	-	-	-	**26**
Total funds related to Information & Support	**162**	**-**	**310**	**(335)**	**-**	**137**
Other funds – various categories:						
Coombe Hill	8	-	-	-	-	8
SmartCareCF	(10)	-	-	-	-	(10)
CTAP – Clinical Trials Accelerator Platform	-	-	455	(465)	-	(10)
Digital Health Research Programme	-	-	1,024	(1,024)	-	-
CF Registry	(5)	-	-	(7)	-	(12)
Patient Reported Experience Measures	2	-	-	(2)	-	-
Consensus documents	23	-	-	(2)	-	21
HDRUK Grant Award	(14)	-	9	-	-	(5)
Other older funds	32	-	66	(62)	-	36
Total other funds	**36**	**-**	**1,554**	**(1,562)**	**-**	**28**
Total restricted reserves	**239**	**-**	**3,598**	**(2,842)**	**(747)**	**248**
Endowment funds:						
Ena Bennie Endowment	443	51	-	(3)	-	491
EW Joseph Endowment	150	16	-	(1)	-	165
Joseph Levy Endowment	257	30	-	(2)	-	285
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other endowment funds	27	1	-	-	-	28
Total endowment funds	**897**	**98**	**-**	**(6)**	**-**	**989**
Total funds	**8,225**	**810**	**14,386**	**(13,905)**	**-**	**9,516**

18. Prior year Consolidated Statement of Financial Activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2021 £'000**	**Total Funds 2020 £'000**
Income and endowments from:						
Donations and legacies	2	8,098	3,580	-	**11,678**	**15,196**
Charitable activities	-	-	-	-	-	-
Other trading activities	12	2,580	-	-	**2,580**	**1,078**
Investments	2b,6	110	18	-	**128**	**149**
Other income:						
Other income	2	-	-	-	-	**104**
Total		**10,788**	**3,598**	**-**	**14,386**	**16,527**
Expenditure on:						
Raising funds	3a	3,718	-	3	**3,721**	**3,563**
Charitable activities						
Research		3,008	1,966	1	**4,975**	**4,432**
Clinical care	3a	664	468	-	**1,132**	**2,132**
Information, advice and support	3a	3,667	408	2	**4,077**	**6,373**
Total charitable activities		**7,339**	**2,842**	**3**	**10,184**	**12,937**
Governance costs		**-**	**-**	**-**	-	-
Total resources expended	**3a**	**11,057**	**2,842**	**6**	**13,905**	**16,500**
Net income/(expenditure) before investment gains/losses		**(269)**	**756**	**(6)**	**481**	**27**
Realised investment gains/(losses)		17	-	-	**17**	**38**
Unrealised investment gains/(losses)		695	-	98	**793**	**(391)**
Net investment gains/(losses)		**712**	**-**	**98**	**810**	**(353)**
Net (expenditure)/income		**443**	**756**	**92**	**1,291**	**(326)**
Transfers between funds	17a	747	(747)	-	-	-
Net movement in funds		**1,190**	**9**	**92**	**1,291**	**(326)**
Reconciliation of funds:						
Total funds brought forward		7,089	239	897	**8,225**	**8,551**
Total funds carried forward	**17a**	**8,279**	**248**	**989**	**9,516**	**8,225**

Structure, governance and management

Patron

- The former Prince of Wales, KG, KT, GCB, OM

Honorary President

- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees

Chairman

- Richard Hunt CBE

- Professor Andrew Jones (term ended July 2021)
- Michael Winehouse (term ended July 2021)
- Louise King (term ended 2021)
- Ffyona Dawber (term ended March 2022)
- Professor Rosalind Smyth CBE FMedSci
- Sean Collins
- Anne Byrne
- Richard Hoey
- David Titmuss (resigned June 2022)
- Michelle Shore
- Joanna Barrett
- Sophie Pierce (appointed July 2021)
- Sonya Trivedy (appointed July 2021)
- Professor Martin Walshaw MD FRCP (appointed July 2021)

Marketing, Communications & Income Generation Committee

Chairman

- Richard Hoey

- Sean Collins
- Joanna Barrett
- David Titmuss (resigned June 2022)
- Joanne Hilditch (Independent member resigned May 2022)

Finance Committee

Chairman

- Sean Collins

- Anne Byrne
- David Sawer (Independent member)
- Michelle Shore
- Ed Rushton (Investments Committee)
- Nick Wood (Investments Committee)

People Committee

Chairperson

- Michelle Shore

- Sonya Trivedy
- Joanna Barrett

Charity Management

- David Ramsden – Chief Executive
- Louise Honeysett FCA —Director of Finance and Resources (resigned January 2022)
- Dr Keith Brownlee – Director of Medical Affairs
- Dr Anne Shinkwin – Director of Fundraising
- Rebecca Cosgriff – Director of Data and Quality Improvement (resigned June 2022)
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research
- Simon Hawkins – Director of Finance and Resources (appointed February 2022)

Company Secretary

- Simon Hawkins – Director of Finance and Resources

Principal and Registered Office

One Aldgate
London
EC3N 1RE

020 3795 1555
enquiries@cysticfibrosis.org.uk
cysticfibrosis.org.uk

Company Limited by Guarantee
Company registration number: 3880213
Charity registration number: England & Wales —1079049
Scotland —SC040196

Auditors

Haysmacintyre LLP
10 Queen Street Place,
London EC4R 1AG

Bankers

Natwest Plc
15 Bishopsgate London EC2N 3NW

Investment Managers

Cazenove Capital Management
12 Moorgate London EC2R 6DA

Recruitment, induction and training of Trustees

Trustees consider the relevant skill set required to enable effective oversight and proper governance of the organisation. New Trustees are appointed after a rigorous recruitment process, which includes advertising in the national press and on the basis of recommendation.

Upon appointment to the Board, in order to help facilitate their understanding of the current issues concerning the organisation, each new Trustee is provided with specific tailored information, and opportunities are also provided for the new Trustee to meet with the Chair and Chief Executive Officer, as well as meeting staff working within their own specialist area.

Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Charity to the Chief Executive Officer, David Ramsden, and his Senior Leadership Team (SLT).

The Chief Executive Officer and the SLT report to the Board both formally at the Board meetings and informally (as appropriate) throughout the year, thereby ensuring a regular flow of information to aid decision making.

The remuneration of key management personnel is determined by a recognised job evaluation framework taking into account the skills required and the complexity of individual roles. The process, including the award of annual pay uplift, is overseen by the Remuneration Panel made up of Trustees and chaired by the Chairman of the Trust.

Public benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. In reviewing our aims, objectives and planning future activities, the Trustees have taken into account the Charity Commission's general guidance on public benefit. The Trustees ensure that activities undertaken are always in line with the charitable objectives and aims of Cystic Fibrosis Trust.

Legal structure

Cystic Fibrosis Trust ('the Trust') is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1964 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

The Board of Trustees ('the Board') has full legal responsibility for corporate governance and all operations of the Trust, including determining its strategic direction.

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 10 Trustees with a range of skills. Several committees such as the Finance and Audit Committee, Nomination and Development Committee, Strategic Advisory Board, Strategic Implementation Board and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Committed VIAs

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA005	Dr Emma France	Stirling University	SCooP (Supporting Children's Physiotherapy for cystic fibrosis) Development of interventions to increase adherence to physiotherapy among young children with cystic fibrosis – Medical Research Council's complex intervention framework phase I study.	£20,000
VIA035	Dr Fred Piehl	Imperial College London	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA036	Dr Fred Piehl	Imperial College London	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data	£42,500
VIA039	Ms Laura Birch	Bristol University	Dietary manipulation to improve glycaemic control in young people with cystic fibrosis and altered glucose handling: a feasibility study	£25,000
VIA045	Professor Chris van der Gast	Manchester Metropolitan University	Detection of CF lung pathogens using engineered bacteriophages	£45,950.50
VIA051	Dr Tanmay Bharat	Action Medical Research	Elucidating the structural role of filamentous bacteriophage in *Pseudomonas aeruginosa* biofilms for disrupting infection in cystic fibrosis airways	£89,917.50
VIA052	Professor Jane Davies	Imperial College London	Exploring the utility of novel 'antimicrobial resistance breakers' on strains of *Pseudomonas aeruginosa* obtained from patients with cystic fibrosis	£50,000
VIA059	Dr Joseph Jacob	UCL	Quantifying bronchiectasis severity in cystic fibrosis	£50,000
VIA061	Prof Alan Smyth	University of Nottingham	Gut Imaging for Function and Transit in CF – The GIFT Study	£35,369
VIA062	Prof Miguel Camara	University of Notting-ham	Scholarship for the National Biofilms Innovation Centre (NBIC)	£50,000
VIA063	Prof Stephen Hart	University College London	Development of in vitro Transcribed mRNA Therapeutics for Cystic Fibrosis	£51,545
VIA064	Dr Andrew Jones	University of Manchester	Arthropathy in Adults with Cystic Fibrosis	£34,000
VIA067	Dr Martin Welch	University of Cambridge	Tackling CF Lung Infection in vitro: Assessing the Global Impact of Antibiotics on the CF Airway Microflora in a Laboratory Bioreactor	£33,000

Committed VIAs

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA068	Professor Jane Davies	Imperial College London	The idealised LCI (i-LCI): tuning in on the 'silent years' of paediatric CF	£98,594.93
VIA070	Dr Laura Nolan	Imperial College London	Understanding interbacterial competition in the Cystic Fibrosis lung to identify opportunities for intervention	£30,000
VIA071	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA072	Dr Charles Haworth	Papworth Hospital	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis	£36,000
VIA073	Dr Viek Dua	University College London	Modelling and machine learning to aid the design of CF therapy	£50,000
VIA076	Dr Luke Allsopp	Imperial College London	In the thick of it: Competitive Microbial Interactions in Biofilms	£20,000
VIA077	Prof Chris van der Gast	Manchester Metropolitan University	Organisation and function of the gut microbiota in cystic fibrosis	£47,000
VIA078	Prof Chris van der Gast	Manchester Metropolitan University	Non-tuberculosis mycobacteria infection and the wider lung microbiota in cystic fibrosis	£48,000
VIA079	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)	£32,600
VIA081	Dr Anand Shah	Imperial College London	FREAL – Fungal Resistance Evolution and Acquisition in chronic Lung disease	£38,000
VIA082	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£21,304
VIA083	Dr Paul McNally	Our Lady's Children's Hospital	RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in	£97,297
VIA085	Professor Jane Davies	Imperial College London	People with CF)	£50,000
VIA086	Dr Christabella Ng	Univeristy of Nottingham	Exploring the utility of quorum sensing inhibitors and biofilm disruptors on growth and virulence behaviours of *Pseudomonas aeruginosa* obtained from patients with cystic fibrosis	£65,000
VIA088	Prof Kevin Southern	University of Liverpool	Gut Imaging for Function & Transit in cystic fibrosis Study 3	£18,931.70

Committed VIAs

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
VIA090	Prof Michael Givskov	University of Copenhagen	Co-therapy of a novel *Pseudomonas aeruginosa* biofilm disruptor with standard of care antibiotics	£26,500
VIA091	Dr Elise Lammertyn	ECFS	Clinical Trials Network (ECFS-CTN)	£20,607
VIA092	Dr James Reihill	Queen's University Belfast	The ubiquitylation system as a therapeutic target in CF	£15,000
VIA093	Dr Anand Shah	Imperial College London	Development and validation of the use of videogames and virtual reality to enable autonomous remote monitoring of ototoxicity in high-risk population groups	£15,000
VIA094	Prof Pietro Cicuta	University of Cambridge	Technologies for an in-vitro carbon copy of lung disease	£40,000
VIA095	Dr Beverley Isherwood	Medicines Discovery Catapult	CF AMR Biorepository	£49,500
VIA098*	Dr Jonathan Cox	Aston University	Discovery of new and repurposed ß-lactamase inhibitors for improving *Mycobacterium abscessus* treatment	£25,000
VIA099*	Professor Chris Ward	Newcastle University	An implementation study investigating the feasibility of using gastrointestinal patient related outcome measures in people with cystic fibrosis	£37,000
VIA101*	Gerry McCauley	OmniSpirant Limited	Electrophysiology assessment of OS001 CFTR exosomes	£4,200
VIA102*	Kidney Research UK (KRUK)	MRC, KRUK, Bloodwise, Vasculitis UK	The MELODY Study	£50,000
VIA103*	Mr Andy Short	Ockham Biotech Ltd	Development of a non-anticoagulant heparin derivative as a therapy in CF	£50,000

***Awarded in the 2021/2022 financial year.**

Currently active SRCs

SRC Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
SRC004*	Dr Siobhan Carr	Royal Brompton Hospital	Cystic Fibrosis Epidemiological Network (CF-EpiNet) – Harnessing Data to Improve Lives	£747,259
SRC005*	Dr David Sheppard	University of Bristol	The F508del-CFTR SRC	£749,933
SRC006*	Prof Stephen Hart	University College London	Personalised Engineered Cell Therapies for cystic fibrosis	£718,602
SRC007*	Prof James Shaw	Newcastle University	The Cystic Fibrosis Related Diabetes Strategic Research Centre (CFRD-SRC)	£750,000
SRC008*	Prof Craig Williams	University of Exeter	Physical Activity, Exercise, Sport and Recreation Promotion for Adolescents with CF	£750,000
SRC009*	Prof Michael McDermott	St James' University Hospital	Targeting joint disease in cystic fibrosis: identifying therapeutic targets in CF arthropathy	£371,399
SRC010*	Professor Andres Floto	MRC Laboratory of Molecular Biology Cambridge Biomedical Campus	Novel Therapies for *Mycobacterium abscessus*	£749,941
SRC011**	Professor Soraya Shirazi-Beechey	University of Liverpool	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)	£749,694
SRC012**	Dr Daniel Peckham	St James' University Hospital	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis	£750,001
SRC013**	Dr Mike Gray	Newcastle University	Personalised Therapies for all: Restoring airway function in CF using Alternative Chloride Channels	£750,000
SRC014**	Prof Jane Davies	Imperial College London	Personalised Approach to *Pseudomonas aeruginosa* (PAPA)	£750,000
SRC015**	Dr Darius Armstrong-James	Imperial College London	TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis	£750,000

Currently active SRCs

SRC Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment
SRC016**	Prof Pietro Cicuta	University of Cambridge	Mucociliary clearance – from fundamentals to personalised treatment	£743,852
SRC017**	Dr Martin Welch	University of Cambridge	Gas, food and lodging; understanding the physiological and metabolic requirements of *Pseudomonas aeruginosa* in the cystic fibrosis airways	£748,538
SRC018	Professor Steven Renshaw	University of Sheffield	Preventing Gastrointestinal Cancer in cystic fibrosis	£749,214
SRC019	Professor James Shaw	University of Newcastle	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes	£750,000
SRC020	Prof Stephen Hart	University College London	Therapeutic gene editing of CFTR	£740,142
SRC021	Prof David Sheppard	University of Bristol	The CFTR Folding and Function SRC	£747,972
SRC022	Dr Jo Fothergill	University of Liverpool	An evidence-based preclinical framework for the development of antimicrobial therapeutics in cystic fibrosis (PIPE-CF)	£749,373

*** Grant in the process of closing – awaiting final invoicing and financial report**

**** Grant issued extension due to COVID-19 related delays**

Summer Studentships

Supervisor	Host Institution	Student & Project
Dr Malcolm Brodlie	Newcastle University	**Miss Simone Soars** – Clinical characteristics and outcomes for children with cystic fibrosis admitted to paediatric intensive care in the UK
Dr Siobhan Carr	Royal Brompton Hospital	**Mr Ciaran O'Toole** – Reliability of paediatric home spirometry in the clinical setting
Prof Deborah Gill	John Radcliffe Hospital	**Miss Ashwini Kurunatha** – Investigating the potential of a lentiviral vector to mediate long-term transgene expression in the airway
Dr Bettina Schock	Queen's University Belfast	**Ms Ariana Axia** – Self-supervised machine learning to decipher patient variability in the immune response to infection
Prof Stephen Todryk	Northumbria University	**Miss Hannah Munslow** – Immune responses against anaerobic (air-hating) bacteria in patients with cystic fibrosis
Prof Craig Williams	University of Exeter	**Miss Ieva Jakaityte** – The impact of physical activity on cystic fibrosis related diabetes: a mixed-methods feasibility study

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2022. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 2nd Floor, One Aldgate, London EC3N 1RE.

CYSTIC FIBROSIS TRUST

England & Wales - Charity number 1079049

Accounts

Cystic Fibrosis is why we're here

Cystic Fibrosis Trust
Annual Report and Financial Statements

For the year ended 31 March 2021

Company Registration No. 3880213
Charity No. 1079049 (England and Wales)
OSCR No. SC040196 (Scotland)

Fighting for a Life Unlimited

Contents

Introduction 4

Chairman's statement 4

Objectives and activities 5

About cystic fibrosis (CF) 5

About us 6

Our mission 6

Our vision 6

Measuring success 6

Success in research 6

Achievements and performance 6

- Strategic Research Centres (SRCs) 6
- Venture and Innovation Awards 9
- Summer Studentships 9
- CF Syndicate in AMR 9
- Innovation Hub 10
- Cellular Therapy 11
- Machine learning approaches to personalised medicine 11
- Digital health research programme 12

Collaborating and supporting the clinical community to promote the highest Quality of care 13

The impact of Kaftrio on the CF Community 14

Impact of COVID-19 15

- Shielding 15
- Emergency grants 15
- Coronavirus hub 15
- Registry 15

Campaigning hard 16

Clinical Fellowships 17

Data and quality improvement 17

- Registry Annual Meeting 17
- Annual data report 18
- Quality improvement 18

Supporting access to medicines at every step from labatory to medicine cabinet 18

Clinical Trials Accelerator Platform 18

- National collaborations 18
- Network of CTAP centres 18
- Membership renewal 19
- Early Phase Coordinator Pilot 19
- Impact of CTAP 20
- Lung Clearance index 20
- Engagement with Sponsors 20
- Community Involvement 20
- Clinical Trials Digital Hub 21
- Core outcome sets 21
- Youth Involvement Group 21
- Trial Results Reporting 21
- CTAP remit expansion 22

Providing day-to-day support; and seeking to reach all people with cystic fibrosis when they need us most 22

Day to day support 22

- Welfare grants 23
- Benefits advice 23
- Information 23
- Helpline 24
- Youth programme 24

Reaching all people 24

- Effectively engaging with our community and the public 24
- Events 25
- Social media 25
- CF Week 26

Communicating with supporters 26

- Volunteering 26

Being an effective organisation 27

- Supporter experience 28

Fundraising 28

- Fundraising events and activities 28
- Gifts in Wills 29
- Regular gifts 29
- Corporate partnerships 29

Philanthropy 29

Plans for the future 30
Research and UKCFC 30
Improving the quality of care 30
UK CF Registry 31
Improving trial outcomes 31
Campaigning hard and raising awareness 31
Day-to-day support 31
Being great fundraisers 32
Being an effective organisation 32

Financial review 33
Income 33
Expenditure 34
Investment policy 35
Review of investments in the year 35
Reserves 35

Principal risks and uncertainties 36

Our work with the pharmaceutical industry 37
Clinical Trials Accelerator Platform 37
The UK Cystic Fibrosis Registry 37
Venture & Innovation Awards (VIAs) 37

Sponsorship and donations 38

Statement of Trustees' responsibilities 39

Independent auditor's report 40
Opinion 40
Basis for opinion 40
Conclusions relatin to going concern 40
Other information 40
Opinions on other matters prescribed by the Companies Act 2006 40
Matters on which we are required to report by exception 41
Responsibilities of trustees for the financial statements 41
Auditors responsibilities for the audit of the financial statements 41
Use of our report 42

Consolidated statement of financial activities 43

Consolidated income and expenditure account 44

Consolidated and charity balance sheets 45

Consolidated statement of cash flows 46

Notes to the financial statements 47

Structure, governance and management 68
Recruitment, induction and training of Trustees 69
Senior Leadership Team 69
Public benefit 69
Legal structure 69

Currently active VIA Awards 70

Committed VIA Awards 2020/21 73

Summer studentships 74

The Trustees present their annual report and financial statements of the charity (company number 3880213) for the year ended 31 March 2021.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's memorandum and articles of association, the Charities Act 2011 and the Statement of Recommended Practice: Accounting and Reporting by Charities second edition effective 1 January 2019.

The requirements of 'The Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013' are included within this Trustees' report. Pages 43 to 67 also form part of the Trustees' report.

Chairman's statement

I am pleased to present the Cystic Fibrosis Trust's Annual Report for 2020/21.

This year represented the final year of our current three year 'Strategic Framework', however it was a twelve months unlike anything we or anyone else could have envisaged when we set out our initial course. Despite everything, it truly was a year not only of the many deep lows of the COVID-19 pandemic but also special highs!

Shortly before the start of the Financial Year, all people with cystic fibrosis were required to 'shield', which meant limiting their social interaction to the absolute minimum. Many faced new challenges such as, securing regular supplies of food, financial hardship, disruption to their usual care as well as the understandable anxiety about the virus itself.

The Trust responded rapidly by offering direct support where possible, as well as a wide range of specific information and guidance and continuously advocating for the needs of the Community at the highest level. At the same time, we moved to being a fully 'working from home' organisation requiring innovation in all areas of operation and in particular fundraising as many of our usual events and activities were unable to take place.

In this difficult period it was wonderful when at the end of June last year, it was announced that a deal had been agreed to fund Kaftrio. Initially in England, when as anticipated, it completed its regulatory steps over the summer months. This was quickly followed by similar agreements across all nations of the UK.

The breakthrough in access built on the 2019 announcements about Symkevi and Orkambi was the culmination of years of campaigning by the Cystic Fibrosis Community, which has been reflected in previous Annual Reports. As we now look back on these years we might comment that no group of people dealing with a life limiting condition should have to fight so hard to access life-saving drugs, nevertheless, everyone should feel really proud of what they have achieved. Kaftrio has already made a difference to so many lives but we are very mindful that there is still much more to do.

Over these last few months we have seen an incredibly rapid roll-out of Kaftrio and extensions to its license. This has been more great news, but we still remain focused on the fact that it is not a cure and it's not suitable for everyone with CF. That is why we are fully committed to a diverse and innovative research portfolio that includes projects from basic science, through to treatments.

During the year we have expanded our portfolio of Strategic Research Centres, funded the key Venture and Innovation Awards and promoted the next generation of CF Researchers through a Summer Student Scheme.



Richard Hunt CBE

In spite of some inevitable disruption, the Innovation Hub that we co-fund with the University of Cambridge, has continued to make significant progress. It has also been an important year of further development for our Clinical Trails Accelerator Platform, our work in Anti-Microbial Resistance and the use of digital health tools to deliver more effective care. Informing much of our work have been the insights gained from the continued excellence of the UK CF Registry.

The pandemic has meant that, like many organisations, we have needed to find new ways of working, communicating and engaging. What seemed like an initially daunting set of circumstances has actually driven innovation. Indeed, in the particular circumstances of CF and the usual risk of cross infection, many of the new approaches have enabled us to reach more people and to do so in a truly accessible way.

This has also been a period when we have reflected on ensuring that in all our activities we are working to support our whole community and recognising its diversity.

In summary, it is customary to thank people for all they have done over the last year to support the Trust in its efforts to change the lives of people with cystic fibrosis across the UK.

This year thank you seems insufficient to express the depth of gratitude I feel for so many people who have done so much during such a critical period. To my colleagues in the Trust and on behalf of the Board I simply say; thank you. You have worked wonderfully despite all the challenges and changes and with a tremendous spirit!

We therefore end this unprecedented year with energy and determination to deliver our vision of a 'life unlimited' for all those living with cystic fibrosis both now and in the years to come.

Thank you

Richard Hunt CBE
Chairman of Trustees

The last year has been a time of exceptional challenge, change and opportunity for the cystic fibrosis community with the impact of the COVID-19 pandemic and the licensing of Kaftrio. It was also the last year of our three-year corporate strategy, prompting us to reflect on what we have achieved and where we will focus as we look to the future.

Objectives and activities

Our vision is to deliver a Life Unlimited for people with cystic fibrosis and our objectives, as stated in the Articles of Association, are to promote:

- research into the causes of and a cure for, cystic fibrosis and the dissemination of the useful results thereof for the public benefit,
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from cystic fibrosis in any form, and
- the education of the general public about the causes and effects of cystic fibrosis.

About cystic fibrosis

Cystic fibrosis (CF) is a life-limiting genetic condition that destroys the lungs and digestive system. More than 10,600 people in the UK live with the condition and have to undergo a brutal daily regime of physiotherapy and take up to 60 tablets a day, just to stay healthy. Despite these treatments, many people with CF will go on to require a double-lung transplant.

According to the 2019 UK Cystic Fibrosis Registry Report, the median age of those who died in 2019 is just 31. The median predicted survival age of people born with CF in the UK today is 49.

About us

Our mission

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited for everyone affected by cystic fibrosis. Our mission is to create a world where being born with CF no longer means carrying a life-long burden; where everyone living with the condition will be able to look forward to a long, healthy life. In 2018 we launched a new three-year Strategic Framework.

We committed to:

- invest in a dynamic portfolio of research and innovation,
- collaborate with and support the clinical community to promote the highest quality of care,
- support access to medicines at every step from laboratory to medicine cabinet,
- provide day-to-day support; and
- seek to reach all people with cystic fibrosis when they need us most.

Our vision

We believe that through innovation, empowerment and accelerating the pace of change, we can beat CF for good. A Life Unlimited by cystic fibrosis continues to be our ambition.



Measuring success

We analyse our progress against criteria for success in order to ensure we are operating at our best and delivering the most impact for the CF community.

We have Delivery Review Groups that assess quarterly progress in achieving our objectives under each of the Trust's impact priorities. We also track the progress of projects using our Project Portfolio and internal monthly and quarterly monitoring mechanisms, including both data-driven and narrative analysis, backed up by 'SMART' Key Performance Indicators. Our performance is reviewed regularly by the Board of Trustees to ensure our accountability and continuous improvement.

Successes in research

By working together, we can be stronger and more effective and one of the main areas we achieve this is with our research.

Achievements and performance

>Strategic Research Centres (SRCs)

Strategic Research Centres (SRCs) are virtual centres of research excellence and are intended to create multidisciplinary teams to address questions of strategic relevance to people with cystic fibrosis. A maximum of £750k is available per SRC, with funding provided over three to four years.

Our SRCs aim to:

- create clusters of world-class researchers;
- bring experts from different disciplines together to tackle the complex problems caused by cystic fibrosis;
- widen awareness of CF research by attracting high-quality investigators from different research fields; and
- recruit the brightest and best young researchers into CF research.

Each SRC typically includes funding for five or six early-career researchers who work alongside experts, building a life-long interest in the field of CF research. The centres investigate the big issues affecting people with CF, such as CF-related diabetes, that are too big for smaller projects to tackle. The long-term nature of these centres allows an in-depth exploration of the issues and possible solutions.

Governance for funding for the SRCs at the Trust is overseen by the Strategy Implementation Board (SIB). Applications undergo a rigorous external peer-review process before being considered by the SIB, which recommends the highest-quality applications for funding. We maintain a balanced portfolio of high-quality research activity to address the varied issues associated with living with CF, from diagnosis to all stages of life.

This year, eight highly competitive preliminary applications were submitted at the Expressions of Interest stage in April 2020. Of these, three were progressed to the full application stage.

These applications underwent rigorous external specialist peer review in the autumn period, and the resulting scores and comments from the external peer reviewers and SIB members, as well as the rebuttal from the applicants, were deliberated in detail by the SIB. Following scrutiny of the applications based on the excellence of the science and the strategic relevance of CF, two applications were recommended by the SIB for funding.

The Board of Trustees agreed with these recommendations and agreed to fully fund the highest scoring SRC. In addition, the Board stated a commitment to exploring options for co-funding the second SRC with appropriate partners, which is currently ongoing.

> The CFTR Folding and Function SRC

Lead investigator: Prof David Sheppard, University of Bristol

Co-investigators: Prof Ineke Braakman (Utrecht University), Dr Cedric Govaerts (Université Libre de Bruxelles), Dr Isabelle Callebaut (Sorbonne Université)

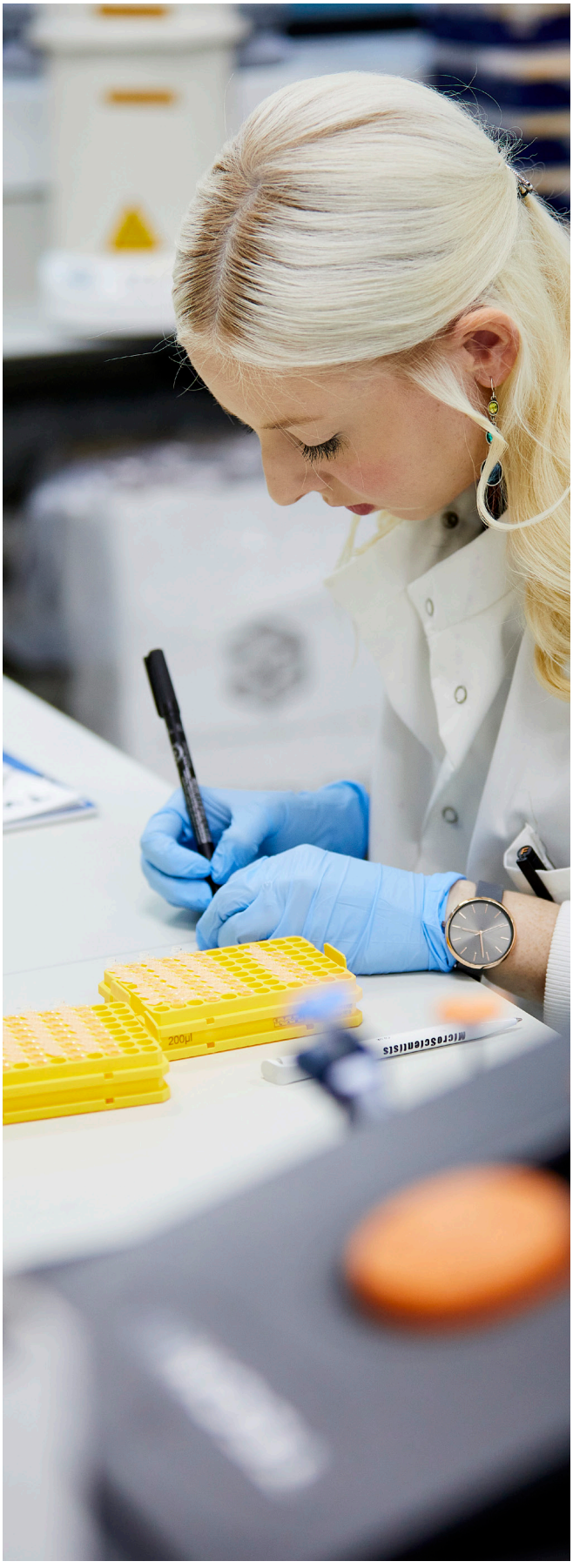
Excitingly, in this financial year, we have also been able to co-fund a third SRC from the 2019/20 SRC competition in partnership with the Cystic Fibrosis Foundation (CFF) in the United States of America.

> Therapeutic Gene Edition of CFTR

Lead investigator: Dr Stephen Hart, University College London

Co-investigators: Prof Deborah Baines (St George's University of London), Dr Paola Bonfanti (The Francis Crick Institute), Dr Patrick Harrison (University College Cork), Prof Isabelle Sermet-Gaudelus (Hôpital Necker Enfants Malades, Paris)

This new Strategic Research Centre aims to understand faulty CFTR to aid in the design and testing of novel therapies to rescue all forms of faulty CFTR, informing the development of innovative treatments for all people with CF including those for whom modulators are not yet available.



A list of currently active SRCs (as of March 2021) can be found below.

SRC	Principal investigator	Institution	Amount	Title
SRC004	Dr Siobhan Carr	Royal Brompton Hospital	747259	Cystic Fibrosis Epidemiological Network (CF-EpiNet) – Harnessing Data to Improve Lives
SRC005	Dr David Sheppard	University of Bristol	749933	The F508del-CFTR SRC
SRC 006	Prof Stephen Hart	University College London	718602	Personalised Engineered Cell Therapies for cystic fibrosis
SRC 007	Prof James Shaw	Newcastle University	750000	The Cystic Fibrosis Related Diabetes Strategic Research Centre (CFRD-SRC)
SRC 008	Prof Craig Williams	University of Exeter	750000	Physical Activity, Exercise, Sport and Recreation Promotion for Adolescents with CF
SRC 009	Prof Michael McDermott	St James' University Hospital	371399	Targeting joint disease in cystic fibrosis: identifying therapeutic targets in CF arthropathy
SRC 010	Professor Andres Floto	MRC Laboratory of Molecular Biology Cambridge Biomedical Campus	749941.02	Novel Therapies for *Mycobacterium abscessus*
SRC 011	Professor Soraya Shirazi-Beechey	University of Liverpool	749694	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)
SRC 012	Dr Daniel Peckham	St James' University Hospital	750000.61	The Impact of Gut Dysbiosis on Lung Inflammation in cystic fibrosis
SRC 013	Dr Mike Gray	Newcastle Univerity	750000	Personalised Therapies for all: Restoring airway function in CF using Alternative Chloride Channels
SRC 014	Prof Jane Davies	Imperial College London	750000	Personalised Approach to *Pseudomonas aeruginosa* (PAPA)
SRC 015	Dr Darius Armstrong-James	Imperial College London	750000	'TrIFIC: Targeting Immunotherapy for Fungal Infections in cystic fibrosis'
SRC 016	Prof Pietro Cicuta	University of Cambridge	743852	Mucociliary clearance – from fundamentals to personalised treatment
SRC 017	Dr Martin Welch	University of Cambridge	748538	Gas, food and lodging; understanding the physiological and metabolic requirements of *Pseudomonas aeruginosa* in the cystic fibrosis airways
SRC 018	Professor Steven Renshaw	University of Sheffield	749214	Preventing Gastrointestinal Cancer in cystic fibrosis
SRC 019	Professor James Shaw	University of Newcastle	750000	Mechanisms and measures of the pathways through which cystic fibrosis exocrine pancreatic disease leads to beta-cell dysfunction and diabetes
SRC 020	Prof Stephen Hart	University College London	740142	Therapeutic gene editing of CFTR

We would like to take this opportunity to thank the members of SIB for their commitment to the Trust and this review process.

>Venture and Innovation Awards (VIAs)

The Venture Innovation Award (VIA) scheme forms part of our five-year research strategy. By awarding grants to innovative new research projects that leverage funding from external sources, we can allow CF researchers to respond rapidly to new developments, gain additional funds for potentially transformational opportunities and to add value to our investment in research. VIA grants are awarded on a rolling basis by an internal committee that assesses the validity and value of individual projects against an agreed set of criteria.

The awards are contingent on projects undergoing the rigour of the peer review process of the partner organisation.

Due to the impact of the COVID-19 pandemic on the fundraising activities of the Trust, the difficult decision was taken to reduce the amount of budget available to support research projects through the VIA scheme. However, as shown in the table below, we have successfully supported the funding of research projects with a range of funding partners, including the NIHR, industry, research charities and other funders. The investment of £189k in research funding this year from the Trust through the VIA scheme has the potential to leverage an additional £2.48m in research funding for cystic fibrosis.

A list of currently active VIA awards (as of March 2021) can be found on pages 70 to 72



>Summer Studentships

Seven Summer Studentship grants of £1,500 each were awarded in 2020, with five being funded by the CF Trust and two being funded by the Asthma UK British Lung Foundation Partnership. These studentships provide living expenses for promising undergraduate students to carry out a research project over their summer academic break. In addition, the students are required to attend the UKCFC or a related conference and present their work in poster form.

Due to national COVID-19 lockdowns and labs being inaccessible over summer 2020, four of these studentships have been deferred until 2021, with the invitations left open for them to attend the next in-person research conference.

The Trust 2020/21 awarded studentships are detailed on page 74.

>CF Syndicate in AMR

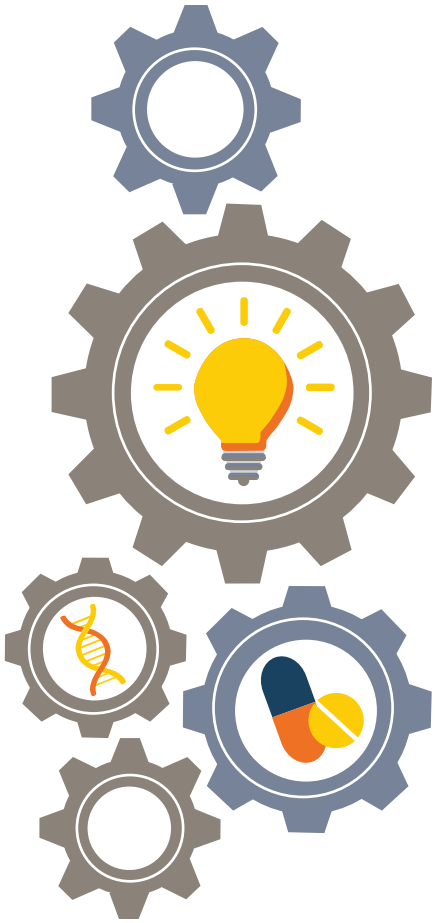
Antimicrobial resistance (AMR) is a growing concern, particularly for people with CF who frequently suffer from antibiotic failure. The NHS and the UK Government have highlighted AMR as an urgent priority. The Trust has partnered with the Medicines Discovery Catapult (MDC) to create the CF Syndicate in AMR, which was launched in September 2019.

The aim of the Syndicate is to accelerate the translation of novel antimicrobials to the clinic. To do this, the current aims of the Syndicate are to:

1. Streamline and enable access to clinically relevant samples for the preclinical screening and testing of CF antimicrobials.
2. Map and validate the preclinical screening and testing pathways to provide faster routes of bringing CF antimicrobials to the clinic.
3. Develop guidance for industry on the key characteristics and requirements that CF antimicrobials should meet in order to address the needs and priorities of people with CF, through the development of Target Product Profiles.

In the past year, the Syndicate has made significant progress and has successfully:

- engaged widely with the UK CF infection research community in academia and industry;
- established a Steering Committee of committed experts from academia, the clinic, industry and people with CF;
- developed a robust research agenda, aligned to the key challenges above identified in CF antimicrobial discovery;
- started to develop a 'toolkit' of enabling resources to address these challenges via collaborative research programmes, which includes developing a guidance document on strains to use for CF antimicrobial testing, a virtual biorepository of clinically relevant samples for CF AMR research and a set of patient-focused TPPs; and
- engaged with other potential funders to explore funding opportunities required to deliver these resources and support further development of the Syndicate.



>Innovation Hub

The UK Cystic Fibrosis Innovation Hub, based at Cambridge University, is a ground-breaking partnership between the Cystic Fibrosis Trust and the University of Cambridge. Launched in 2018, its aim is to harness multidisciplinary world-class research to accelerate progress towards preventing lung damage and the subsequent loss of lung function in people with CF. The Trust aims to raise £5 million over five years for the Innovation Hub, which the University of Cambridge has already committed to matching pound for pound.

The Innovation Hub was established in 2018 and significant progress has been made during the 1st phase of the Hub (Feb 2018 – March 2021) against three key challenges which are summarised below.

Antibiotic and anti-inflammatory drug discovery: This workstream aims to develop new antibiotics and anti-inflammatory drugs, as well as novel methods that could be used to accelerate drug discovery by industrial and academic researchers around the world.

- Novel antibiotic compounds have been developed that have activity against *M. abscessus* in vitro.
- New AI-based methods have been developed to rapidly develop antibiotics to potentially work against any bacteria, which could have a major impact on efforts to combat AMR globally.
- Key genes responsible for, and involved in, mycobacteria evolution and *M. abscessus* virulence have been identified, and the data published in the leading journal 'Science'.
- It has been shown that immune cells from people with CF behave differently, both as a direct result of CFTR dysfunction and because of genetic scarring due to chronic inflammation.

>Cellular therapy

This workstream aims to develop new stem cell therapies that could eventually be used to regenerate lungs damaged by CF with a person's own cells.

- Methods have been developed to create epithelial cells (the cells that line the airways in the lungs) and ionocytes (the cells with the most CFTR protein in them that seem to regulate the amount of liquid produced in the airways) from blood-derived stem cells.

- It has been shown that these cells can be introduced into a mouse, and can find areas of damaged lung and survive long term, paving the way for eventual cellular therapy in CF patients.

>Machine learning approaches to personalised medicine

Bringing together the rich data available from the home monitoring programmes (SmartcareCF, Project Breathe) and from National patient registries (in the UK, US and Canada), the aim of this workstream is to develop machine learning (ML) and artificial intelligence (AI) methods to predict when people with CF may become ill, and to help forecast their future health trajectories.

- Machine learning methods have been developed to predict the onset of clinical deterioration (pulmonary exacerbations) in adults with CF using home monitoring data.

- UK CF Registry data was successfully employed to develop new ML methods to predict the individual clinical trajectory of individuals with CF using interpretable deep-learning approaches.





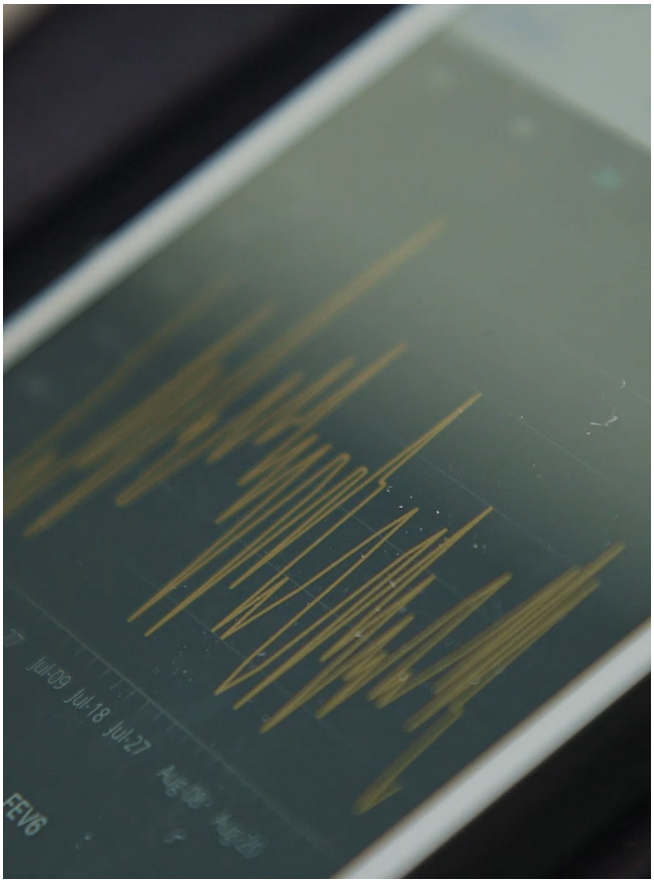
>Digital health research programme

The digital health research programme, 'Personalised Medicine: development of novel clinical decision-making tools', is a three-year programme of work funded by a £2.5 million grant from the Cystic Fibrosis Foundation (CFF) that started 1 October 2019. The programme seeks to explore the application of advanced data analytics to the understanding and management of people with CF, with the aim of gathering evidence to safely deliver Personalised Medicine. Two separate but complementary approaches are being pursued.

The first approach, Project Breathe, addresses the current standards of care which require all people with CF to attend their CF Centre on a regular basis, regardless of their need. The aim is to use home-based remote monitoring using Bluetooth devices combined with machine learning to redesign the clinical care packages and move away from the current 'one size fits all' approach to one where the clinic focusses on the needs of the individual at the optimal time for that individual's health. As a first step, home-based remote monitoring is being developed to provide the evidence that a routine clinic outpatient appointment is not necessarily needed.

The aim of the first year of Project Breathe was to build on the successful SmartCareCF study, which used frequent home-based measurements and supervised machine learning to identify pulmonary exacerbations, with the recruitment of patients to the project at one UK site, Royal Papworth Hospital. Interim analysis of the Papworth data at six months indicated that the home-based data resulted in a safe reduction of what would have been 'routine' outpatient visits by at least 50%; saving the individual time and cost of travel, lost time from work or education and avoidance of exposure to cross-infection risk. The feedback from users, (i.e. adults taking part in the study and specialist MDT using the data display dashboard) has enabled significant and ongoing improvements to be made to the app to improve its use.

Given the encouragingly positive results at this interim analysis stage, the project team sought permission from the CFF to accelerate the rollout of the research study to an additional three UK sites (Edinburgh, Glasgow and Cardiff). Set-up of this research study is also ongoing at sites in Canada.



The augmented intelligence approach to exploring in-depth analysis of CF registries is the second approach to Personalised Medicine. The team at the Alan Turing Institute, led by Professor Mihaela van der Schaar, have been analysing data focused on:

- predicting individual clinical trajectories using deep-learning and AI approaches to help predict future changes in health and response to medications, as well as potentially identifying subgroups of individuals who may be at greater risk of developing certain CF-related complications; and
- developing AI-based hypothesis testing methods to allow more accurate analysis of noisy or incomplete clinical metadata to better enable comparisons between and within groups of individuals. For example, this has allowed the team to start to accurately determine individual effect sizes for medications (such as ivacaftor) and understand determinants/predictors of response.

Collaborating with and supporting the clinical community to promote the highest quality of care

The global pandemic (COVID-19) has changed how people with CF have experienced care and it is likely to have a long-term impact on how care is delivered in the UK. The Trust has played a vital role in ensuring that people with CF could access the care they needed, despite pandemic restrictions and that policymakers understood and addressed the challenges facing the community.

The Trust coordinated international projects to understand the impact infection with Covid-19 would have on people with CF and together with the CFMA, provided regular updates to our community.

One area of focus was on remote monitoring where the Trust lobbied successfully for equipment to be provided which subsequently accelerated the next phase of our own digital health project to widen access.

The Trust, in partnership with the CFMA, ensured a rapid rollout of highly effective modulators for those who would benefit from them.

We are involved in the NHSE review of specialist CF care and will ensure people with CF are involved in the process, and that discussions are informed by accurate data and information.

The Trust has supported the formation and work of the UKCFMA throughout the year, supporting the establishment of a lung transplant working group, hosting their Annual General Meeting at the UK CF Conference, and organising meetings at European Cystic Fibrosis Society (ECFS), the North American CF Conference (NACFC), and their own annual event. We have also co-produced and collaborated with the UKCFMA on policy work and information about COVID-19. We have encouraged the collaboration of the UKCFMA with leads of the other allied health professional groups. Our Clinical Advisory Group (CAG) now consists of the chairs of all the clinician groups and four new representatives of people with CF and parents, including the chair of the UKCFMA.



The impact of Kaftrio on the CF Community

2020 saw a landmark deal for access to Kaftrio in England which was announced amidst the COVID-19 pandemic.

A collaboration between NHS England and Vertex resulted in a commercial agreement for access to Kaftrio, the first triple combination therapy for the treatment of cystic fibrosis (CF). This ground-breaking deal marked a significant and exciting moment for thousands of people living with CF. The deal subsequently led to further agreements for access to Kaftrio across the rest of the UK in Wales, Northern Ireland, Scotland, and the Crown Dependencies.

Kaftrio is a modulator therapy currently licensed for use in the UK for those age 12 and over with at least one copy of the F508del mutation. It has helped to transform the lives of many by treating the underlying cause of the condition. The deal meant that many more thousands of people with CF who had been unable to benefit from previous modulator therapies including Kalydeco, Orkambi and Symkevi could finally access these treatments for the very first time on the NHS.

The breakthrough followed years of relentless campaigning alongside the CF community, supporters, and parliamentarians to fight for access to new medicines, that included parliamentary debates, protests, and a health committee inquiry.

Clinical trial data show that many people taking Kaftrio will have improvements in gastrointestinal (GI) issues and overall quality of life. Further studies are underway to better understand the long-term effects Kaftrio will have on the overall health of people with CF, including infections, inflammation, mucus clearance, GI health, blood sugar, growth, and liver function.



For Lucy Baxter who has CF, having access to Kaftrio has been life changing. She reflects on the moment she found out she heard about the Kaftrio agreement and how this has positively impacted her life. She recalls:

"When I found out the Kaftrio deal was announced, I saw it on Facebook in my room and started crying. I rushed downstairs and told my mum and we both hugged and cried together. It was a life changing moment and it made me feel that my future was secured. One year on, I am still so thankful and don't take it for granted how lucky I am to be able to have this treatment. I feel so much better and healthier."

Whilst Kaftrio is not suitable for everyone, the Trust continues to commit to finding a treatment for those who are not able to take advantage of it. Chief Executive David Ramsden says:

"We re-commit to doing all we can to ensure that everyone who can benefit from Kaftrio gets rapid access to it and that we will continue to invest in research to find treatments for those who can't. We will not stop."

The Trust will continue to invest money into dedicated research with the goal of finding treatments for all to ensure that no one is left behind.

Impact of Covid-19

The impact of COVID-19 on the CF community cannot be overstated; from the initial guidance to commence shielding, the impact of the pandemic on routine clinical care, work/employment rights, the financial burden, through to the effectiveness of vaccines on those post-transplant, the Trust has worked tirelessly to provide timely information and support to those with CF and their families.

>Shielding

People with CF were identified as extremely vulnerable to COVID-19 by the Government and instructed to shield immediately. The shielding process was initially set for 12 weeks, but as the crisis unfolded, measures remained in place for over four months. As a result, people with CF struggled to access essentials such as food and exercise, which are crucial necessities to manage their condition and stay healthy.

The demand for our services rocketed at an unprecedented rate at a time when we ourselves were facing a substantial drop in our fundraising income due to cancellations of many of our key fundraising events. Whilst the advice to shield has been removed, there are, understandably, concerns around the increasing number of cases, emerging variants and further lifting of restrictions.

>Emergency grants

In response to increased applications for financial assistance, the Trust launched our emergency appeal in Spring 2020.. Our emergency exercise grants enabled people with CF to continue to exercise despite being advised not to leave the house . The increase in demand was driven by the economic hardship caused by the pandemic with most of our grants going to very low-income households: of those who provided data, over 50% of our grants between April and September 2020 (Q1-2) went to households with an income of less than £15,000 per annum.

Thanks to the emergency support of our donors, in our 20/21 financial year, we gave a total of 982 emergency grants, including our COVID emergency exercise grants, at a total cost of £165,723.44, more than double the value of emergency grants in the year before. A huge proportion of these grants—around 80%—were provided between April and September 2020 (Q1-2) when families were most impacted by the pandemic. In Q1 of 20/21 we gave over £100,000 more in emergency grants than in Q1 of 19/20 (up from £12,000 to £120,000). Our emergency grants provide a lifeline for families by supporting them through periods of financial stress and avoiding the spiral into longer-term financial difficulties.

>Coronavirus Hub

Over the past year, the Trust received a total of 822 Helpline enquiries relating to COVID-19 and provided regular updates through a dedicated 'Coronavirus Hub' on our website and via our social media accounts. This online information became a key information source with the Hub: our broad Q&A content received over 100,000 visits at its peak; our shielding advice pages received over 35,000 views; our Welfare FAQs received almost 20,000 views; and at the peak of the pandemic, our section on our collaboration with the UKCFMA received over 50,000 views.



>Registry

Although the Government identified people with CF as extremely clinically vulnerable to COVID-19, we entered the pandemic with very little clinical evidence into how COVID-19 would impact a person with cystic fibrosis. Our UK CF Registry team immediately began working closely with global clinical teams to monitor COVID-19 in people with CF across the UK, collecting unique data and updating the information every two weeks. To date, among the 331 people with CF have been reported as having COVID-19, none were receiving in-patient treatment as of the end of March 2021 Sadly, two adults with CF died of complications related to the virus. Whilst the numbers are too low to draw conclusions about the risk factors or outcomes associated with COVID-19, we remain at the forefront of monitoring the impact of COVID-19 in people with cystic fibrosis. We continue to collaborate globally to learn as much as possible and enable us to use the data to support the CF community and their clinical teams.

Campaigning hard

During 2020, the Trust successfully advocated for people with CF to be prioritised for the COVID-19 vaccine and for effective communications and rollout of the programme. We undertook this activity in parallel with a successful breakthrough in the access to medicines campaign to secure UK-wide access to the latest CF modulator therapy Kaftrio. We have continued to push for a timely and expansive roll out of the new drug to those eligible and continue to call for expanded and equitable access for all who will stand to benefit.

Since the start of the COVID-19 pandemic we have worked to ensure appropriate support for the shielding population across the four nations of the UK, with a particular focus on access to financial support, food and essential services, support for education and employment. As well as advocating for clear and timely communications from the government, particularly around shielding guidance, we also worked to interpret and share the latest guidance with the community. Close liaison with key bodies like the NHS, Department of Health and Social Care and the Deputy Chief Medical Officer ensured that we had the most up-to-date information and enabled us to raise the concerns of the CF community directly with policy makers.

We raised multiple COVID-19 campaign priorities with parliamentary champions in Westminster and the devolved assemblies, met with parliamentarians virtually, attended nine all party parliamentary groups (APPGs) and briefed parliamentarians ahead of debates.

We also drafted and tabled 47 parliamentary questions across the four nations in the UK via our parliamentary champions on issues such as kaftrio, prescriptions charges, shielding support and vaccine priority. The Trust wrote over 20 letters to the NHS, supermarkets, the JCVI and the Vaccines Minister. As a result, home spirometers were provided to over 4,000 people with CF to monitor their condition in the safety of their own home during the pandemic. We secured improved priority access to supermarket deliveries for those that were shielding, and the JCVI made a significant revision to move those who were most clinically extremely vulnerable higher up the Covid-19 vaccine priority list, resulting in faster access to the jab for adults with cystic fibrosis.



Clinical Fellowships

We have continued to support the recruitment and training of young doctors with our Clinical Fellowship Programme. This programme is more popular than ever, and we are confident that it will continue to enable future CF centre directors and consultants to gain valuable CF-specific training and experience.

Data and quality improvement

The UK CF Registry is a world-class database that includes data on over 99% of people with CF in the UK who have consented to their data being submitted by their CF team. This year saw two new drug safety studies opening, alongside a further two continuing to run, generating over £1.1 million in income. A significant proportion of these funds was used as grants to support centres in their data entry to the Registry.

More information about how we use Registry data to keep medicines safe can be found at cysticfibrosis.org.uk/registry.

The Registry received a further £160,000 from NHS contracts for generating public reports and supporting the commissioning of CF services in England.

Anonymised Registry data supports research, service improvement and information materials. In 2020/21, the Registry approved 41 requests for data, bringing the total up to 413.

The UK CF Registry is playing a pivotal role in evaluating the effect of Orkambi, Symkevi and Kaftrio following interim access agreements across the UK.

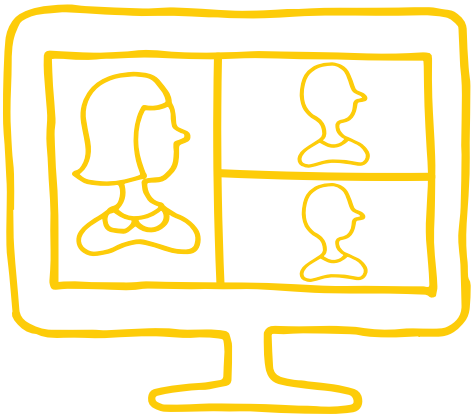
The Registry is supporting an observational study of Orkambi, Symkevi and Kaftrio to satisfy the Vertex Data Collection Agreements with NHS England and NHS Improvement. Data analysis will cover the whole of the UK and be made available to regulators in Scotland, Wales and Northern Ireland.

This includes sufficient funding to boost the Trust's Registry Support Grant programme and enable CF centres that choose to opt in to enter three 'encounters' (records of height, weight and lung function) throughout the year, enabling a more robust analysis of the impact on rate of change in lung function due to these new medicines. You can read more about the study here: cysticfibrosis.org.uk/news/the-latest-on-interim-access

The UK CF Registry team, having set up real-time reporting mechanisms for COVID-19 in March 2020, has continued to regularly report to people with CF and their families as well as the UKCFMA during 2020/21. Reporting on COVID-19 and vaccination is now fully embedded within the UK CF Registry system and we were the first Registry in the world to adapt data collection processes to gather important data on COVID-19. The UK CF Registry is at the forefront of international collaborative efforts to monitor COVID-19 within the CF community and ensure rapid publications to support future care.

>Registry Annual Meeting

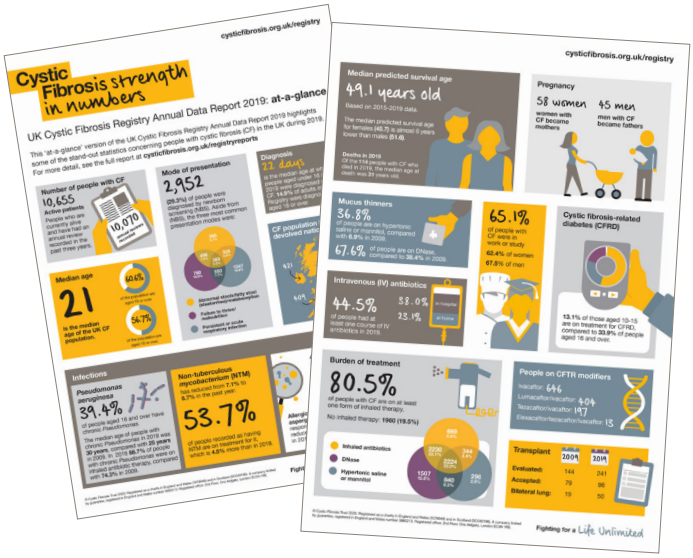
In response to COVID-19, the Registry Annual Meeting in 2020 was converted to a virtual event, with a series of videos released over the course of the summer providing updates about the Registry, data entry guidance and important information on the pandemic.



>Annual data report

The UK CF Registry annual data report on 2019 data was published in August 2020. An accessible 'at-a-glance' summary of infographics highlighting the main trends for that period was also published, helping people with CF and their families to understand the data contained in the report.

We submitted anonymised 2018 data to the European CF Society Patient Registry, which published its reports here: www.ecfs.eu/projects/ecfs-patient- registry



>Quality improvement

In 2020, the Quality Improvement (QI) Team published its first national report on Staffing levels in CF care across the whole of the UK. They also finished data collection for national surveys of Patient Reported Experience Measures (PREMs) in both adult and paediatric care, receiving over 1,500 responses. The reports will be published in 2021/22.

The team also set up the Quality Improvement Working Group, designed to guide development of our QI strategy and ensure maximum impact of the reports we generate. You can read more about the work of the QI team here: cysticfibrosis.org.uk/qualityimprovement

Supporting access to medicines at every step from laboratory to medicine cabinet

Clinical trials are the bedrock of translational research and are an essential element in ensuring new therapies are rapidly and safely translated to clinical use to transform the lives of people with cystic fibrosis. The aim of the Cystic Fibrosis Trust is to ensure that all people with cystic fibrosis can obtain access to new treatments as quickly as possible.

Clinical Trials Accelerator Platform

CTAP has continued to expand and develop over the last year, utilising the additional £2.1 million in funding provided by the CFF in 2019. The impact of COVID-19 has been significant, affecting trial activity at the centres as well as delaying some of the CTAP initiatives, but we have still seen substantial impact and progress in the four CTAP workstreams detailed below:

>National collaborations

This year we became formal partners of Health Data Research UK's 'Project Breathe' programme, designed to bring together 100 respiratory datasets for research use in a secure anonymised research environment. With this partnership we have secured funding to link UK CF Registry data to NHS health information, which will be made available to answer vital questions about CF towards the end of 2021.

>Network of CTAP centres

The current CTAP network consists of 27 centres, providing infrastructure to support sponsors with the delivery of CF clinical trials, and the platform to enable the CF community to gain timely access to these trials.

- 18 CTAP centres are funded with a CTAP Trial Coordinator.
- The remaining nine CTAP affiliate centres are formal members of the network and represented to sponsors as recruitment / referral centres, but they are not funded with a CTAP Trial Coordinator
- Collectively the network of centres cover up to ~89% of the UK CF community.
- Six CTAP centres have been awarded an additional early phase trial coordinator grant to support early phase CF trials.

The first site annual metrics reports was sent out to centres in the past year summarising site performance, and progress meetings were held with each centre to review these metrics and discuss future plans.



>Membership renewal

In January 2021, the network completed its first CTAP Centre Membership Renewal Scheme. The scheme aims to support the CTAP in recognising performance, commitment and contribution from the CTAP centres, identifying centres that may require additional support and ensuring only high-quality centres are retained in the network.

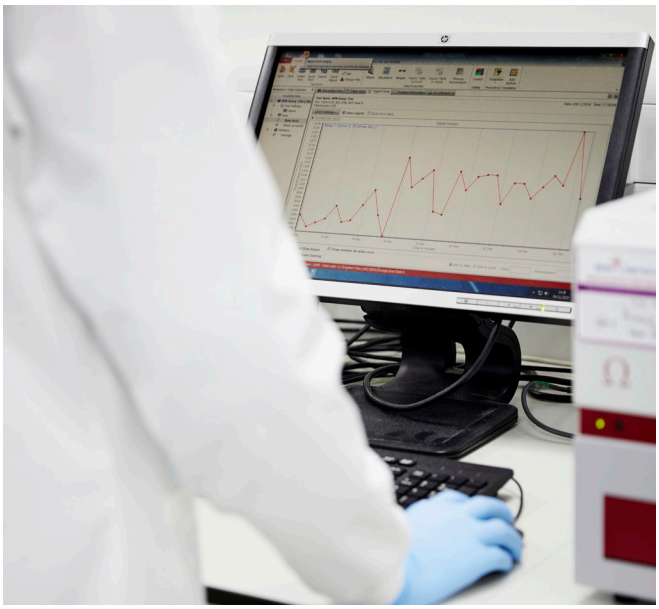
As part of the renewal process, sites were asked to summarise their experience of the CTAP programme, to which we received some very positive feedback:

"Our experience since joining the CTAP programme has been rewarding, successful on many levels and, most importantly, life changing for the patients who have been able to participate through their individual research journeys. The engagement and collaborations we have experienced through CTAP has enhanced our study capabilities and enabled us to prioritise the delivery of life transforming clinical trials within our institution. We have developed infrastructure and streamlined our approach to feasibility which has further improved our efficiency in trial set up".

"Our experience of being part of the CTAP programme has been overwhelmingly positive. We have recruited fully to all trials from phase I-III for both our adult and paediatric departments, which would not have been possible without a funded Trials Coordinator and the opportunities that CTAP provides. The peer support and collaboration throughout the programme has been fantastic and we have valued all opportunities, guidance and collaboration which have been made possible through CTAP. Prior to CTAP we were research active, but CTAP has given us resilience, sustainability and improved our capacity for trials metrics data and site intelligence."

>Early Phase Coordinator Pilot

The CTAP is currently rolling out a two-year Early Phase Trial Coordinator pilot. Six Early Phase Trial Coordinators will support delivery of phase 1 and 2 CF trials at six CTAP centres. The specialist team of coordinators will collaborate with each other and the wider team of CTAP coordinators to provide the CF community access to important clinical trial opportunities. Six CTAP centres experienced in delivering phase 1 trials were competitively selected to receive funding for an Early Phase Trial Coordinator and recruitment to these posts is now underway.



>Impact of CTAP

Since CTAP's official launch in September 2017, a total of:

- **871** people with cystic fibrosis have screened for a clinical trial within the CTAP network since CTAPs launch 3.5 years ago (246 of these screenings took place in the last 12 months);
- **726** people with cystic fibrosis (358 children, 368 adults) have enrolled on to CTAP clinical trial since CTAPs launch 3.5 years ago (224 of these enrolments took place in the last 12 months;
- **56%** of the 224 patients enrolled last year were for rollover studies i.e. patients were already on a study and moved over to an open label extension study. 26% of the enrolment was for a paediatric registry study that was able to continue as normal through the pandemic; and
- On average a CTAP centre has been involved in eight CF studies since CTAP started (range = 0 – 23).

>Lung Clearance Index

The CTAP Lung Clearance Index (LCI) training package provides opportunities for up to two members of staff from each CTAP centre / affiliate centre to become LCI qualified. The package also enabled CTAP to purchase six (reconditioned) LCI machines to support the initial certification of staff, and in the longer-term to be loaned free of charge to CTAP centres for clinical trial use.

Despite initial delays to the roll out of the CTAP LCI training package (due to the pandemic), progress of the training package is going well:

- The format of the training changed in response to the pandemic, with the two-day in-person workshop replaced with a series of e-modules and a webinar.
- 19 professionals from 13 CTAP centres have completed the e-modules, six professionals from one CTAP centre and three affiliate centres are in the process of completing the e-modules.
- 22 professionals have attended at least one of the webinars so far.
- We anticipate six professionals will be certified by June 2021, with a further six certified by September 2021. We anticipate the remaining staff will be fully certified by February 2022.

>Engagement with sponsors

The CTAP aims to support sponsors (pharmaceutical companies and academic institutes) with the design, feasibility, set-up and delivery of CF clinical trials.

Engagement with sponsors has significantly increased over the last year, reflecting not only the growing CF drug pipeline, but the increasing recognition of the clinical trial infrastructure and resource CTAP has embedded in the UK.

The CTAP Feasibility Service helps sponsors ensure the best-placed centres are selected for trial delivery and has been utilised for a total of 20 clinical trials, six of which were during this financial year. A total of 34 CF trials have been open for recruitment in the CTAP network, 7 over the course of the year.

>Community involvement

Over 50 CF Trial Ambassadors (people with CF and those that support people with CF, including parents, grandparents and partners) form our CTAP Community involvement group (previously known as Patient & Public Involvement (PPI) Group). It is through these groups that CTAP has created a platform for the CF community to directly engage with sponsors and give meaningful and robust feedback about trial design, from the conceptual stage onwards.

This workstream gives the CF community a voice to communicate with sponsors, making future clinical trials less burdensome on participants, resulting in better recruitment and retention rates. Awareness and recognition of the CTAP's PPI groups has grown over the last year, leading to increased activity. The PPI network of CF Ambassadors has supported a total of 48 different projects with sponsors, helping to shape the design of clinical trials and ensuring they meet the needs of the UK CF community.





12,000+ visits to the online clinical trials hub since launch in September 2017.

The clinical trials hub provides a wealth of information about clinical trials and what they entail, as well as stories from those that have taken part.

>Clinical Trials Digital Hub

We have created a Clinical Trials Digital Hub to engage and educate the CF community about clinical trials. See cysticfibrosis.org.uk/get-involved/ clinical-trials

Since launching in September 2017, the Hub has been visited over 12,000 times with >2,500 visits in the past year. The Trials Tracker database has been visited 17,000 times, with over 1,000 visits in the last year.

These statistics demonstrate the Trust has been successful in its ambition to establish the Hub as an important place of information for those wishing to find out more about taking part in CF trials.

The programme makes an important contribution to the Trust's campaign for access to life-saving drugs, providing the infrastructure and information to enable the UK CF community to gain the earliest possible access to the newest 'breakthrough' CF medicines being developed by pharmaceutical companies around the world.

>Core outcome sets

A core outcome set (COS) is an agreed standardised set of outcomes that should be measured and reported in all clinical trials within a specific disease area. Currently there is not an up-to-date, universally recognised COS for CF clinical trials. Development of a CF COS will allow for easy and robust comparison between studies. It will also be instrumental in ensuring CF clinical trials are as meaningful and patient-centred to the CF community as possible.

As well as the CF clinical and patient community, we anticipate both regulators and sponsors will be enthusiastic to adopt a COS for CF, especially one led by the patient community from the conception stage onwards.

The CTAP Involvement team will lead on the community involvement element of developing a CF patient-led COS. The CTAP Coordinating Team will support the project team in securing stakeholder buy-in from sponsors, in collaboration with ECFS-CTN. This project will be subject to funding (NIHR funding application is pending).

>Youth Involvement Group

Young people's involvement in research is often limited to their parents' feedback. The CTAP Involvement Team wish to provide a platform for young people with CF (12+ years old) to ensure their views and experiences are represented within the research community, and are therefore working to establish a CTAP Youth Involvement Group (YIG). The longer-term ambition of the YIG will be to create a channel to discuss, review and communicate to the research community what young people's research priorities are.

>Trial Results Reporting

The CTAP annual community survey highlighted that trial participants were not kept aware of trial results after the study had completed, and even if they were, the language would be difficult to understand. This is an area that the CTAP is focused on resolving. We are planning to update the trials tracker to capture all trial results in a lay-friendly language. We will be working with sponsors and the community to develop a robust and timely process so that participants can be well informed of trial outcomes.



20,000+
visits to the online Trials Tracker since launch in September 2017.

The Trials Tracker details all CF clinical trials that are open in the UK.

>CTAP remit expansion

Although the primary priority of CTAP is to support interventional clinical trials, the CTAP governance board has agreed to extend the remit of CTAP to include a wider breadth of CF studies (see below). This will ensure CTAP is adapting to the fast-changing clinical trials landscape, that there are enough trials in the CTAP portfolio to sustain the large number of network centres and ensure CTAP supports CF studies which are of national priority to the CF clinical, research and patient community.

Overview of CTAP's expanded trial remit:

- Interventional clinical trials (medication and non-medication interventions) – commercial and academic
- Real-World Evidence (RWE) studies
- Non-interventional academic studies which are multi-centred and competitively funded CF studies considered to be of national priority or urgency (assessed on a case-by-case basis)

Providing day-to-day support; and seeking to reach all people with cystic fibrosis when they need us most.

The last year has demonstrated the critical importance of the day to day support services that we provide to people affected by CF. We saw dramatic increases in people looking for information, advice and support and adapted our provision to meet that need.

The Trust has provided multiple evidence submissions to parliamentary and government inquiries and responded to 23 consultations, including government and NHS England inquiries, to ensure the voice of the cystic fibrosis community was heard clearly by policymakers.

Day to day support

- 47 CF related Parliamentary questions (PQs) UK wide.
- 30 PQs in England
- Six PQs in NI
- Six PQs in Wales
- Five PQs in Scotland
- 23 policy consultation responses submitted.
- Nine All Party Parliamentary Groups (APPGs)
- Our monthly campaigner newsletter was sent to over 1,500 campaigners.
- Our parliamentary newsletter was sent quarterly to over 240 parliamentarians.
- 20 letters sent to external stakeholders on a range of issues.
- Access to over 4,000 home spirometry monitoring devices



>Welfare Grants

Last year, we provided over 1,393 welfare grants, totalling £263,000, providing immediate financial support to those in urgent need, as well as providing access to goods and services to promote long-term health and quality of life. We rapidly altered our grant programme in response to COVID-19, pausing our holiday grants but introducing an exercise equipment grant to ensure people with CF could exercise safely at home whilst they adhered to shielding advice which advised against leaving home at all. Our emergency grant programme ensured we could provide immediate help for those struggling to afford food and basic essentials when they had suddenly lost income due to the pandemic, ensuring that their health was protected.



In addition, we were able to provide £26,000 in homecare grants to support people who are experiencing particularly poor health or a personal crisis so that they can be safe and comfortable at home.

We spent over £43,000 on education grants, awarded by the Joseph Levy Education Fund, to support young people with CF into higher education or vocational training, ultimately supporting them to pursue their career goals.

>Benefits advice

Our Welfare and Rights Advice service provides invaluable dedicated benefits advice. This year, our specialist adviser has supported 314 people in navigating the benefits service. In addition, our new Income Maximisation Service has supported 99 people, and those supported through this service have been able to increase their household income by over £3,800 on average, providing vital income to help with the additional costs of living with cystic fibrosis.

In 2020/21, the Cystic Fibrosis Trust helped people to access at least £1.6 million in benefits.

We also continue to offer a benefits advice service in Northern Ireland through a specialist partnership, providing expert advice on the benefits system.

>Information

We built on our extensive information library, publishing several new information resources. We added new factsheets on physiotherapy and nutrition, developed in collaboration with specialist CF clinicians. We launched a resource on the emotional impact of Kaftrio, working with psychologists to acknowledge the varying feelings across the CF community. We developed a significant suite of resources on transition to adult care, co-produced with young people with CF and their parents.

We also published new resources on clinical trials aimed at children and teenagers, including a 'Junior Agents' comic for younger audiences. We launched 'My CF Planner', an individual healthcare plan for secondary school students, and developed new information on bowel cancer in cystic fibrosis. Finally, we published detailed new guidelines setting out best practice in physiotherapy treatment for CF teams. We're grateful to the people with cystic fibrosis and their families, as well as the expert CF clinicians, who helped us develop these resources.



>Helpline

This financial year, our Helpline responded to over 4,400 enquiries from people affected by CF, making it our busiest year ever, providing information, support and a listening ear on a wide range of topics. Over 800 of these queries related to COVID-19, and the helpline team played a critical role in ensuring the CF community could access the information and support they needed at a particularly challenging time. Around 63% of enquiries were received by email, 31% came by phone and a further 5% came via social media. This year we expanded our helpline team, enabling us to explore new channels and promote the helpline more widely.



>Youth programme

Adolescence can be a period of vulnerability for those with CF, both in terms of physical health and emotional wellbeing. This year, young people also had the challenge of Covid-19 to contend with. We quickly adapted our youth programme, increasing the number of events on offer to create more opportunities for young people to come together, have fun and get active, therfore providing a distraction from the anxieties and isolation of the pandemic.

Our Youth Advisory Group (YAG), comprising of young people affected by CF aged 14-25, continued to shape the direction of the Trust's youth work. Two YAG-led projects were shared via the Trust's youth social media channels, providing a platform for young people with CF to share their achievements and talk about the issues that matter to them. We also secured a further three years of funding from BBC Children in Need for Building Brighter Futures, our programme of online events for children with CF and their siblings. We increased the number of events we ran to meet increased demand during the pandemic, offering fun new activities, such as juggling, as well as old favourites such as games and movie nights, and opportunities for children to get active. For the first time, we opened these events up to children under 10 to meet emerging demand. We also ran two new six-week workshops on stand-up comedy and creative writing which received very positive feedback.

Reaching all people

>Effectively engaging with our community and the public

Our work relies on the generosity of our supporters—those directly affected by cystic fibrosis as well as the general public. In a year dominated by COVID-19 and Kaftrio, it has been even important that we are relevant and responsive to the diverse needs of the CF community. Through our media work we raise awareness of cystic fibrosis as well as the Trust's aims, ambitions and key campaigns.

This year, we secured 275 pieces of news coverage, achieving a broadcast reach of 4.1m people and print media reach of 4.8m people. These figures include all areas of the Trust's work, ranging from our Christmas campaign, our new fundraising initiative – FeBREWary and our extensive media coverage in response to the coronavirus pandemic.

Highlights included our Christmas campaign, where we achieved our highest broadcast reach when our celebrity ambassador, Jenny Agutter, was interviewed on 'This Morning' and BBC Breakfast to promote our annual Christmas fundraiser, Carols by Candlelight.

Our responses to the news that the lifesaving drug Kaftrio, had been made available on the NHS achieved our widest-reaching print coverage in the Guardian and Daily Mail. In December, we also secured a celebratory piece on the benefits of Kaftrio in the Observer, featuring an interview with Dr Keith Brownlee on the success of this deal.

>Events

We held a series of regular online information events called ‘CF LIVE’. The events took place monthly and were themed to support issues and concerns facing the CF community, as well as to provide Trust updates and information. We ran nine events between July 2020 and February 2021, covering Kaftrio, returning to school, the importance of data, work and money, antimicrobial resistance research, clinical trials, physiotherapy and exercise, involvement, and a Christmas party for the community. Over 800 people attended these events live, with over 3,500 views on YouTube post-event. CF LIVE will return with another series of interactive events in 2021/22.

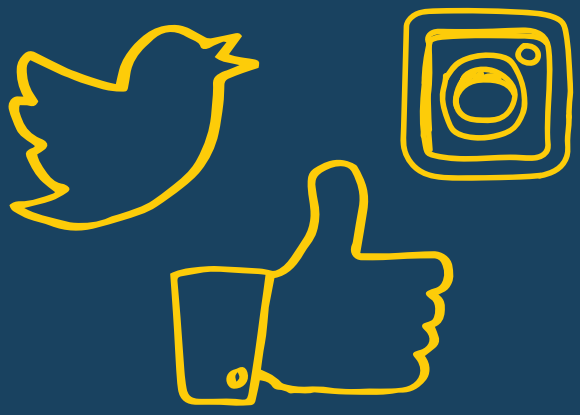
During CF week, we also ran the Big Yellow Party on Wear Yellow Day, which saw over 100 families joining in. The party finished off a fantastic CF Week and featured a range of performers, including those with cystic fibrosis.



>Social media

Our social media channels are a key way we engage with our community and showcase our work— from campaigning to fundraising. We also listen and respond to the needs of our community via social media, providing the information and support people need.

Since the start of the coronavirus pandemic, social media has increasingly become an avenue for people turning to us for help and information when they need it most; during this year we saw a 150% increase in incoming messages, with many choosing to direct message us, seeking urgent advice on a range of health and welfare issues. Over the last year we put out over 2.5K posts relating to coronavirus, which were seen over 14 million times.



Our social media presence is a key interaction point with the most engaged members of our community, and is a critical means to update and mobilise them. For many people eager to fundraise for us, it offers an important space for celebrating CF Week and bringing Wear Yellow Day to life.

When this year saw the access to medicines campaign result in a deal for Kaftrio across the UK, our breaking news posts alone reached over 681.5 thousand people

Along with our forum, our social media channels provide valuable insight into the types of things people with CF are talking about, ensuring we keep in sync with their needs and remain relevant.

During this year, we saw growth across all of our social media channels (Facebook 2%; Twitter 7%; LinkedIn 12%), particularly Instagram (29%), and an increase in engagement across all channels (325%) which is enabling us to reach an increasing diverse audience, including younger audiences and older people with cystic fibrosis.

>CF Week

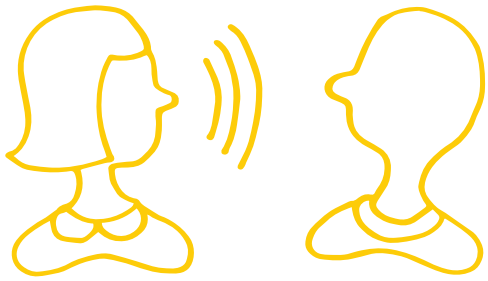
CF Week focused on the burden of care using the theme of 'balance.' We provided a platform for the CF community to share their stories and discuss issues and solutions, collaborating with the CF community at a challenging time.

We provided interactive ways to participate in the week including a series of online events. In addition to deeper engagement with the community and our content we were able to raise more funds than in 2019 with less money during a difficult climate for the Trust by maximising community stories across our platforms.



Communicating with supporters

Over the last year we moved to a new website platform to improve the user experience, save money in the longer term and futureproof longer-term digital requirements. Our new website is faster, has an improved search function and a streamlined navigation menu. We improved the donation journey making it quicker, easier and more flexible, including providing PayPal as a payment method. We also have a new home page to better present our key content and help users find the content they need more easily. When we launched our website 72% of those surveyed rated the new website as excellent on our online polls. We will continue to develop the website to provide the best possible service and experience.



>Volunteering

We have been grateful for the continuing contribution of our volunteers. With most in-person activities being on hold due to the continuing Covid-19 pandemic, the nature of that support has been different, but we remain dependent on the support of nearly 200 registered volunteers.

Volunteers come from a wide range of backgrounds and at different life stages, ranging from those who already have a connection to someone with cystic fibrosis, to university students, through to people working directly for companies partnering with the Trust or possibly winding down in their careers and wanting to use the skills they have developed to help us do more for people with cystic fibrosis.

2020/21 has been a particularly challenging year for our employees with, for legal and infection control reasons, all but a very few having to work at home for most of the year. For some, this was already the norm, but for others it was a new experience and we are grateful for the way people used the available technology helped to serve the needs of the cystic fibrosis community.

Being an effective organisation

Our performance is reviewed regularly by the Board of Trustees to ensure accountability and continuous improvement.

Our employees have helped us address the challenges presented by the reduction in our income by agreeing to be put on furlough, where eligible, enabling the Trust to claim money under the HMRC job retention scheme, and we were grateful to the 21 that voluntarily changed their terms and conditions to contribute to a reduction in staff costs. A further saving was made by restructuring the Senior Leadership Team, resulting in a saving of nearly £100,000 per annum going forward. In addition, we have not made a pay award this year. These initiatives and the actions and commitment of staff have enabled us to minimise redundancies, although as we enter 2021/22 we are consulting on some reductions to our community and events team where there has been a significant reduction in activity, which we do not expect to pick up quickly during the next year.



At the same time, other colleagues, particularly those providing information and support directly to people with cystic fibrosis, have experienced a significant increase in the demands placed on them. The Trust is grateful for the way these staff have responded to the change in circumstances with flexibility and good humour.

With many staff working at home there has been a focus on their support needs, both in terms of appropriate equipment to work safely, such as adjustable office chairs, second screens for computers and ergonomic wrist rests. We have also undertaken a lot of activity to support staff wellbeing, having appointed seven mental health first aiders and provided training to support people in managing their time effectively, practicing mindfulness and even sleeping effectively. The value of such initiatives was recognised by many of the staff who completed the annual staff attitude survey, which was again completed by around 80% of employees and showed improvements in the areas we have targeted.

Equality, diversity and inclusion remains a critical priority for us. We have continued to work with Breaking Down Barriers to strengthen our understanding and response to the diverse needs of our community. We have provided training in diversity in recruitment and changed our policy to require staff involved in recruitment to have completed that or similar training.



>Supporter experience

The Trust is grateful to our committed and passionate supporters, who regularly go the extra mile to raise vital funds for everyone affected by cystic fibrosis. Improving our supporter experience is a key focus for the Trust at every interaction. We continuously analyse and use feedback collected from supporters including face-to-face, online or offline. We are constantly reviewing our communications, ensuring that we provide the right materials for their fundraising and in particular, communicate how their hard work is making an impact to the lives of people living with cystic fibrosis.

The Trust received 28 complaints in 2020-21 which was a noticeable decrease from 46 in 2019-20. This was due to the decrease in fundraising activities as a result of the Covid-19 pandemic. Complaints are closely monitored and reviewed by senior management on an ongoing basis. In addition, we regularly review our complaints policy and processes to make it easier for people to give us feedback, and to ensure that we listen and learn from what our supporters and the community are telling us.



Fundraising

We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice.

We would like to thank all the fantastic individual donors, organisations, charitable trusts, foundations and corporate partners who support our work. The Cystic Fibrosis Trust receives no government funding.

Our Trustees agree and regularly review our fundraising strategy. We adhere to Data Protection Law and the Fundraising Preference Service. We are members of the Fundraising Regulator and abide by the Code of Fundraising Practice and, as such, commit to their Fundraising Promise. We aim to exceed the standards included in our promise to our supporters:

- **We will be transparent about our work**
- **We will be respectful**
- **We will listen and respond**
- **We are committed to high standards**
- **We are fair and responsible**

2020/21 was a very challenging year for fundraising with many external events and activities cancelled, and COVID-19 restrictions implemented. This impact was seen across the whole charity sector.

We worked quickly to adapt our fundraising plans, move events to virtual where possible and launch new activities. Thanks to the continued commitment of our incredible supporters, donors and partners, the Trust raised £5.6 million net income. This was a 25% reduction compared to 2019-20. The response to our Emergency COVID-19 Appeal was phenomenal and raised £829,000 to ensure our continued support for people with cystic fibrosis during this challenging time.

>Fundraising events and activities

Our supporters, including our branches and groups, have harnessed the changes and continued to raise funds for us. The total income from our virtual events is £260,000.

The 2.6 Challenge which was organised by a consortium of event companies raised £125,000, with over 150 people taking on a personal challenge, which included laps of their garden, walking up their stairs, bouncing on a space hopper or running. Other popular activities include the virtual Running Festival and Ride for Research.

Our annual Wear Yellow Day took place during the first national lockdown. Supporters held events online and we invited everyone to a virtual Big Yellow party to celebrate the resilience of the CF community. The support from celebrities and young people with cystic fibrosis ensured everyone had a great time and raised over £75,000.

Carols by Candlelight, which is organised by the Alice Martineau Committee, was held online for the first time. Hundreds of people from across the world watched the special event which was pre-recorded at Abbey Road Studios and St Luke's Church in Chelsea. The event raised £61,000.

New fundraising activities were launched this year including FeBREWary—which raised over £17,000 in its first year and engaged many new people—a new gaming product #CFNextLevel and CF face coverings, which flew off the shelf.

>Gifts in wills

This year we received 92 legacies from supporters who generously included a gift to the Trust in their Will, as well as 50 who told us they have included us in their Will. We are incredibly grateful to those who have thought of us in this special way or are considering doing so and continue to raise people's awareness of legacy giving.

>Regular gifts

We would like to express our thanks to our loyal regular monthly donors, who provide invaluable ongoing support that enables us to plan effectively for the future. Including Gift Aid, these supporters contributed more than £835,000 in 2020/21.

During this year, we carried out two telemarketing activities through Ethicall, who have a 'respect and dignity' policy that turns marketing calls into thank you calls if they suspect the person that they are speaking to is vulnerable. The activities (a regular giving upgrade and a Direct Debit conversion campaign) resulted in a new additional annual income of £18,000.

>Corporate partnerships

The Trust continues to work with corporate partners to raise funds and awareness for cystic fibrosis. In 2020-21, this support was more important than ever. The COVID-19 pandemic created challenges for businesses and their staff across the UK. We are incredibly grateful for the companies that supported us this year and helped us to provide vital support to people with cystic fibrosis throughout the pandemic.

Thanks particularly go to Barclays, who donated through their 100 X 100 Community Relief Fund Bridgepoint, Gilead Pharmaceuticals, and Talent84 who supported our COVID-19 Emergency Appeal. It is because of donations like these that we were able to provide emergency support, such as financial grants, to the CF community.

Thank you to companies such as Gaiger Bros, Lloyds, Whiskey Auctioneers Ltd, Sony, Talent84, Clarity Ltd and Stark who together with their staff donated, walked, ran, cycled, baked and barbecued their way through the virtual space to raise money for the Trust.

We're also incredibly grateful to our partners, Clear Channel and Goodstuff, who provide gift in kind outdoor advertising and campaign advice, which was invaluable in helping us promote our COVID-19 response and virtual fundraising throughout the year.

We continued to work with the pharmaceutical industry, who sponsored our Annual Registry Meeting, and we look forward to working with our sponsors on more activities next year.

Philanthropy

The Trust continues to work with charitable trusts, foundations and individual supporters to fund the work we do. This year we have been pleased to build on existing relationships with the Joseph Levy Foundation, which supports our Information and Support work; BBC Children in Need, which supports our work with young people; and Sport England. In addition, we have worked with generous individuals who are long-standing supporters of our work.

This year, in response to the pandemic, we have also been grateful to receive funding from the Coronavirus Community Support Fund, distributed by the National Lottery, to support core services such as our helpline and our welfare grants programme, to support the cystic fibrosis community through such a challenging and unprecedented time.

Plans for the future

Despite recent challenges, this is a truly exciting time for the CF community. We are in a period of profound change, that will both extend and transform the lives and prospects of many people with cystic fibrosis. As the only UK-wide organisation focusing on people with CF, the Trust has a vital role in driving forward positive change, and to this end, we have developed a new three-year strategy, updating our vision and objectives for a post-pandemic and post-Kaftrio world, informed by our research and the views and priorities of people with cystic fibrosis and their families.

We have a simple and ambitious vision: that every person with cystic fibrosis across the UK can live a long and full life.

To achieve this, we will work with our community and partners across the UK and internationally to support innovative, high-quality research, achieve access to the best treatments, drive up the quality of care and provide and advocate for the support needs of people with cystic fibrosis. We will focus our efforts toward achieving three key goals:

- Being physically well: that all people with CF are living lives free from the symptoms and physical health consequences of having CF.
- Being mentally well: people with CF and their families are supported to deal with the emotional and psychological consequences of living with a long-term, life-limiting condition.
- Reaching potential: that everyone with CF can reach their full potential, in a world that understands their needs and supports them in overcoming the challenges of living with cystic fibrosis.

We also know that in order to deliver on this vision we need to adapt and change as an organisation, including a greater focus on: adopting a virtual first workstyle; exploring innovative fundraising approaches; making effective use of data and analytics; building international and domestic partnerships; and working in ways that brings together our diverse community.

>Research and UKCFC

Our Research Strategy 2018–2023 will see the Trust continue to focus on securing access to medicines, ensuring the quality of clinical care, providing effective day-to-day support and reaching all people with cystic fibrosis. Our balanced portfolio of research programmes will continue to take advantage of funding from external sources and use novel approaches to tackle these issues.

Scoping and planning for the 2020/21 conference is ongoing, with the recommendation that the conference itself is held as a one-day research event with a focus on promoting scientific discussion and collaboration. It is also proposed that the next event be held in early 2021 to better align with the other key international respiratory conferences. It is likely that this will be a virtual event in light of current rules regarding mass gatherings.

>Improving the quality of care

It is essential that the quality of care people with CF experience continues to improve and change recognises the impact highly effective modulators have on their wellbeing and expectations.

We will work in partnership with the UKCFMA and health authorities to embed the learnings gained during the pandemic. We will continue to ensure standards are maintained by providing quality data and information and ensure continuous quality improvement and patient involvement are central to any change in how care is delivered.



>UK CF Registry

The coming months will see a publiction assessing risk to people with cystic fibrosis who are diagnosed with COVID-19, including over 1,400 cases from 22 countries around the world.

The UK CF Registry Annual Report 2020 will be published in summer 2021, including an analysis of the impact of the pandemic.

The Trust will continue to report early results of the efficacy of CFTR modulators to NICE as part of the Interim Access Oversight Committee. The UK CF Registry will also provide analysis to guide NHS England's review of CF Services, due to complete in November 2021.

Summer 2021 will see the launch of the new Registry-based clinical trial, CF STORM. This study is designed to find out whether people with cystic fibrosis can safely withdraw mucolytic therapy once they have started taking CFTR modulators. You can find out more about the study here: cysticfibrosis.org.uk/news/a-storm-is-coming

The Annual Registry Meeting will go ahead as a Virtual Video Series, allowing colleagues across the country to still benefit from this important meeting. Virtual content will be developed over the course of the year, providing sharing of best practice and important updates.

The new CFSPID (Cystic Fibrosis Screen Positive, Inconclusive Diagnosis) Registry will be launched during 2021/22.

>Improving trial outcomes

CTAP has innovative plans to continue to make the UK the pre-eminent place to deliver trials for CF therapies in Europe.

We will continue to build our reputation with pharmaceutical companies to establish the UK's position as a desirable place to invest in commercial CF trials, including early-phase trials: an increasingly important challenge given the UK's current political and healthcare climates. The early-phase pilot will be a big part of ensuring new early-phase trials are coming to the UK, and we will be working on a number of ideas from Key Opinion leaders to develop the early phase strategy.

>Campaigning hard and raising awareness

Campaigning hard and raising awareness across the UK, we continue to push for extended agreements to ensure modulator therapy research all who can benefit from them and ensure no one is left behind.

The Trust will continue to work with external stakeholders and parliamentarians across England, Scotland, Wales and Northern Ireland to identify key opportunities for parliamentary and community action to ensure that the issues that matter to those with cystic fibrosis, such as transplants, the future of CF care and welfare, are on the political agenda.

As the UK eases out of another lockdown, we will continue to push on all fronts to ensure that the clinically extremely vulnerable population is not left behind as the economy rebuilds, and that adequate back to work, education, financial and mental health support, is provided.

>Day-to-day support

We will continue our work to understand the current This year we will be continuing to support the CF community to recover from the impact of the pandemic, as well as looking forward to new and emerging support needs as modulator therapies change the landscape of cystic fibrosis. We will be developing two new advisory groups to make sure that people with CF can shape and develop our information and support, ensuring that we can meet the diverse needs of everyone affected by cystic fibrosis.

We'll continue to develop our youth programme, working with young people to ensure our work is relevant to them. We'll also pilot activities for adults with CF, creating opportunities for them to come together and gain informal peer support through participation in online activities.

We will continue to develop our information library, creating new resources on mental health and wellbeing as well as updated resources for young children and siblings, and new factsheets to meet emerging information needs.

We will also review and improve key resources, such as our new diagnosis pack, to ensure their relevance to diverse audiences, and continue work to improve accessibility of all of our information materials.

>Being great fundraisers

We will continue to work closely with our network of branches and groups, who are vital to our success at a local level, and develop new and innovative fundraising ideas. We will continue to offer an exceptional event portfolio, which will include virtual events that enable all supporters to take part, irrespective of age and ability. We will also continue to maximise the potential of our Great Strides™ and Wear Yellow Day campaigns. In addition, we will introduce additional processes and procedures to give fundraisers the very best experience when supporting the Trust.



We are also focusing on increasing engagement in our flagship activities such as CF Week, Great Strides™, Christmas and Resolutions (now known as Team CF Superheroes) while offering a diverse and exciting event portfolio.

We will continue to focus on developing multi-year partnerships with individuals, companies and Trusts, enabling us to invest in cutting-edge research, such as our exciting Innovation Hub partnership with the University of Cambridge, alongside providing vital support, information and advice services.

>Being an effective organisation

We will develop a series of impact indicators to help us track the long-term difference we are making in each area of our work for people with cystic fibrosis.

Increasing diversity will remain a key priority, as will supporting the mental health of all employees. Responding to changes in staffing needs resulting from the continuing COVID-19 pandemic, will also remain a challenge. We plan to maximise our use of government support while this is still available, and ensuring that our working practices are adapted to respond to changing needs will be critical.

To achieve this, we will work with our community and partners across the UK and internationally to support innovative, high-quality research, achieve access to the best treatments, drive up the quality of care and provide and advocate for the support needs of people with cystic fibrosis. We will focus our efforts toward achieving three key goals:

- Being physically well: that all people with CF are living lives free from the symptoms and physical health consequences of having CF.
- Being mentally well: people with CF and their families are supported to deal with the emotional and psychological consequences of living with a long-term, life-limiting condition.
- Reaching potential: that everyone with CF can reach their full potential, in a world that understands their needs and supports them in overcoming the challenges of living with cystic fibrosis.

We also know that in order to deliver on this vision we need to adapt and change as an organisation, including a greater focus on: adopting a virtual first workstyle; exploring innovative fundraising approaches; making effective use of Data & Analytics; building international and domestic partnerships; and working in ways that brings together our diverse community.



Financial review

>Income

The Trust's income from normal activities for the year to March 2021 was £14.4million, a decrease of 13% over the previous year.

80% of the Trust's total income is made up of donations and legacies, totalling £11.5million, (2019/20 – £15.2m). This percentage is 24% lower than in the previous year, with the decrease driven by a reduction in community and events income, resulting from events cancellations and restrictions imposed by the government in response to the COVID-19 pandemic. This unfortunately meant that our team of fundraisers, and our fundraising supporters, were unable to maintain their usual level of activity. The fall in income generation in this area was partially offset by a fantastic response to our emergency appeal which raised over £0.8m.

The appeal response included contributions from a number of corporate partners, major donors and trusts and foundations, and led to income from these income streams increasing compared to 2019/20.

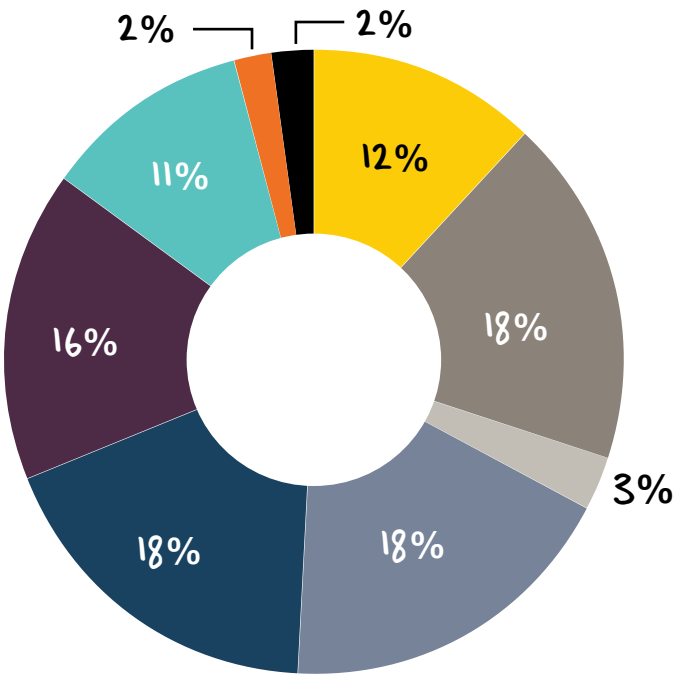
Further support for our Clinical Trials and Digital Health programmes from the Cystic Fibrosis Foundation in the US also drove increased Trust income.

Income from legacies was 22% lower than in 2019/20. We once again gratefully received free digital advertising space from Clear Channel in the year, worth £1.6m – this value was 57% lower than the prior year equivalent due to fewer advertising opportunities during the pandemic, and expansion of Clear Channel's charity advertising programme to benefit more organisations.

Income raised through Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, more than doubled in the year, totalling £2.6m (2019/20 – £1.1m). As well as 2 existing long-term commercial contracts for Phase IV pharmacovigilance studies in place throughout the year, a further four new contracts were signed during the year.

The Trust successfully applied for and received £0.3m through the government's Job Retention Scheme, having put a number of staff on furlough during the year in recognition of a drop in activity as a result of compliance with the government's Covid-19 restrictions.

>2020/21 income by income stream



- Branches, Groups & Community
- Regular and individual giving and appeals
- Corporate Partnerships
- Trusts
- Cystic Fibrosis Services Limited
- Legacies
- Donated goods and services
- Other income
- Government grants

Income from normal activities:	£'000
Branches, groups and community	1,672
Regular and individual giving and appeals	2,626
Corporate partnerships	377
Trust	2,647
Cystic Fibrosis Services Limited	2,580
Legacies	2,276
Donated goods and services	1,648
Government grants (Job retention scheme)	304
Other income	257
Total income from normal activities	**14,386**

>Expenditure

The Trust's total expenditure for the year was £13.9m, a 16% decrease compared to the previous year. The largest area of spend was on charitable activities at £10.2m (2019/20 – 12.9m), accounting for 73% of total spend. This comprises programmes of research, information, advice and support and clinical care.

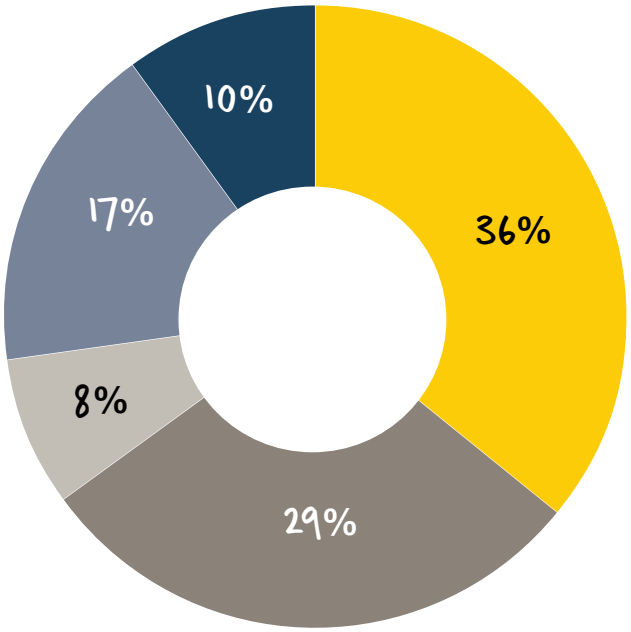
The remainder was spent on activities for generating funds, including £1.4m (2019/20 – £0.7m) paid to NHS cystic fibrosis clinical centres across the UK to support the resources necessary to add patient data to the CF Registry. The amount paid out to the clinical centres more than doubled compared to the prior year, reflecting an increase in the quantity and regularity of data being uploaded by the centres into the UK CF Registry.

Total grant commitments in the year were £3.8m (2019/20 – £4.8m), of which £3.5m (2019/20 – £4.4m) were committed to a range of institutions, including £2.3m committed for three Strategic Research Centres (2019/20 – £1.5m for one centre). The remaining £0.3m (2019/20 – £0.4m) was awarded to individuals through our ongoing Welfare Grant progamme.

The Clinical Trial Accelerator Platform flagship programme continued to develop throughout the year, with total spend of £0.8m (2019/20 – £0.7m). Through the new Digital Health Programme £0.7m of grant funding was awarded to Cambridge University and partner organisations; the cost of some remote monitoring aspects of this programme were brought forward in response to the Covid-19 pandemic.

The final result for the year, including movements on investments, was a net surplus of £1.3m (2019/20 net deficit of £0.3m).

>2020/21 expenditure by cost type



Expenditure	£'000
Research	4,975
Information, advice and support	4,077
Clinical care	1,133
Charitable activities total	**10,185**
Costs of raising funds	2,284
Cystic Fibrosis Services Limited	1,437
Total expenditure	**13,906**

>Investment policy

The Finance Committee has responsibility for setting investment policy and overseeing the investment portfolio. The overall investment objective is to maintain real long-term capital value, looking to balance short-term volatility and protection against inflation with a moderate risk tolerance. The Trust does not permit direct investment in tobacco. General funds are invested in a balanced portfolio that includes some exposure to less liquid assets such as property, and utilises funds that do not invest in tobacco. A number of small endowments funds are invested for income. We also hold cash reserves to maintain working liquidity and provide for current grant commitments in full. The performance of investments is monitored on a quarterly basis. The policy is reviewed annually by the Finance Committee.

>Review of investments in the year

The value of the investment portfolio (including endowment funds) has decreased by £0.5 million in the year (2019/20: decrease of £0.4 million); while the value of the investment holdings recovered in full from the market falling at the end of the prior year, a transfer of £1.3m was made out of the investments into cash deposits in accordance with the cash management policy. Income generated on investments totalled £0.1million, while realised and unrealised gains on the investment portfolio totalled £0.8 million.

>Reserves

The Trust's reserves as at 31 March 2021 totalled £9,514,000 (2020 – £8,225,000). Reserves are held in order to ensure the continuity of service provision, as well as enabling the Trust to move forward with strategically important programmes of work as and when opportunities arise. The Trustees maintain the following reserves:

- Designated reserves – the Trustees have opted to set aside free reserves for the following purposes:
  - A fixed asset reserve, equal to the net book value of the fixed assets (£37,000) is held to ensure these funds are not considered to be realisable

An Appeal Deficit has been recognised, being the difference between the £2.0 million grant awarded to the Innovation Hub at Cambridge and the £1.6 million income fundraised so far for the corresponding appeal. This deficit has been under-written by the Cystic Fibrosis Trust while we continue to appeal to donors for funds.

- Operating reserve – held at a value (£3,448,000) sufficient, as a minimum, to cover six months' operating costs, major fluctuations in income from budget, contingencies for long-term commitments and any deficit on restricted reserves due to over commitment or payment on those projects
- Retained reserves – (£5,013,000) to be deployed in financing the ambitions described in the Trust's Five-Year Business Delivery Plan in a way that maximises the impact for people with cystic fibrosis. Retained reserves had been expected to be utilised through a managed spend programme over the next 36 months. The impact on income generation due to the COVID-19 pandemic means that these reserves are likely to be utilised over a shorter period. It is the intention to use retained reserves while maintaining the Operating reserve as described above.
- Restricted income funds – (£248,000) relating to donations restricted to various specified activities.

More information about the reserves can be found in note **17a** to the accounts.

The Trustees keep reserves policy under regular review to ensure it is set at the appropriate level to reflect changes in the business outlook as they materialise. The reserves as outlined above meet the Trust's reserves policy.

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.

Principal risks and uncertainties

The Board of Trustees is responsible for ensuring effective risk management and internal controls to manage the major risks the charity faces, including agreeing the organisation's 'Risk Appetite' (how much risk the Trust is willing to tolerate in key areas) and keeping oversight of the Trust's risk management framework. This framework, managed by the Senior Leadership Team, includes a strategic risk register and provides a consistent approach to identifying, assessing and dealing with the risks facing the charity. It is regularly monitored (quarterly) to support informed decision-making and ensure appropriate mitigations and controls are in place to effectively manage any risks to our objectives.

The main strategic risks and uncertainties that management and Trustees have identified include: the risks of failing to remain relevant to the changing needs of our community; embedding a financially sustainable model post-COVID-19; keeping Trust/ Registry data secure; getting our message across; influencing key stakeholders, maintaining business continuity; delivering effective people strategies; maintaining our autonomy; and managing our reputation.



Processes in place regarding risk management and internal control include the following:

- A risk management framework that meets the Charity Commission's requirements. A top-down risk review by the Senior Leadership Team, and a bottom-up review by individual functions, is undertaken throughout the year and the risks identified through this process are documented in a risk register.
- The Finance Committee receives reports from the external auditors on the effectiveness of controls and on progress against both its audit plan and the recommendations made in its reports.
- The Board of Trustees has received a comprehensive risk management report to assist it in ensuring that an effective process is in place. This report provided an update on the risk reviews undertaken, and provided the Board with the opportunity to engage in dialogue about, and to provide input into, the evaluation and management of key risks.
- Formal project delivery groups are established for major projects and programmes, such as the Life Unlimited programme, to ensure that these are properly planned, managed and implemented.
- The Trust's projects and activities are assessed under a consistent risk assurance framework at inception to ascertain the appropriate level of management and oversight relative to financial, resource and risk exposure.
- Clear and easily accessible whistleblowing procedures are in place. In addition, there are processes in place to investigate and report on any serious incidents, including the implementation of required corrective actions.

Our work with the pharmaceutical industry

Our mission is to create a world where being born with CF no longer means a lifelong burden of care and an early death; when everyone living with the condition will be able to look forward to a long, healthy life.

Partnerships between medical research charities and the pharmaceutical industry can help us deliver that mission and bring huge benefits to patients—from accelerating the development of new drugs to ensuring the safety and improvement of existing treatments.

We run the following flagship programmes involving industry partners:

>Clinical Trials Accelerator Platform

CTAP is a UK- wide initiative bringing together CF centres to increase participation and access to CF clinical trials. This initiative is building the infrastructure and funding additional research capacity to support the pharmaceutical industry with commercial clinical trial delivery.

As part of our collaboration with industry, the Trials Accelerator offers a centralised feasibility service to support pharmaceutical companies with identification of suitable CF centres for clinical trial delivery. In 2020/21 the Trials Accelerator feasibility service was utilised for six clinical trials, generating an income of £1,819,000 for CTAP.

The Trials Accelerator also offers a protocol review service to support pharmaceutical companies with the design, feasibility and planning of clinical trials. In 2020/21 there was one submission from sponsors for protocol review and three additional reviews by the CTAP RSOB were performed on projects/ protocols submitted as part of the NIHR themed call workstreams.



>The UK Cystic Fibrosis Registry

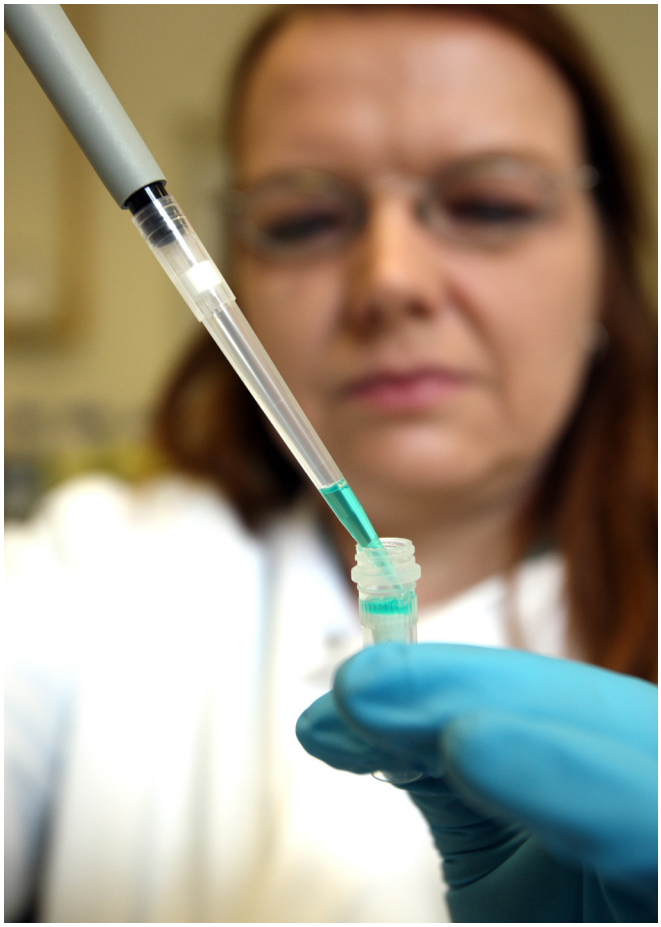
Long-term studies of drugs available to people with CF across the UK are conducted by the Trust's UK CF Registry. The cost of the Registry team producing study reports for the Regulator of medicinal products is covered by pharmaceutical companies holding the Market Authorisation for these medicines.

You can read more about our work with industry to make medicines safer at **cysticfibrosis.org.uk/registry**.

In 2020/21 Cystic Fibrosis Services Ltd, the Trust's trading subsidiary, received £2.5 million in fees for this service. There were four long-term commercial contracts for Phase IV pharmacovigilance studies and one contract for a Health Technology Appraisal study in place throughout the year.

>Venture & Innovation Awards (VIAs)

VIAs support transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the pharmaceutical industry.



Sponsorship and donations

The Cystic Fibrosis Trust takes funding from a range of sources including pharmaceutical companies to support our vital work fighting for a life unlimited for people with cystic fibrosis. We assess all funding relationships to ensure that they do not risk the interests of people affected by cystic fibrosis or the independence and reputation of the charity. All funding arrangements must meet the requirements of our Ethical Fundraising Policy, which is overseen by our trustees and we do not accept payment to promote or recommend specific treatments to individuals or influence prescribing practices for specific branded medicines

- The Clinical Trials Accelerator Platform – a UK-wide initiative to increase participation and access to CF clinical trials.
- The UK Cystic Fibrosis Registry – covering the cost of reporting to regulators on the safety and effectiveness of cystic fibrosis medicines, including providing data entry grants to CF care centres.
- Venture and Innovation Awards – supporting transformational and innovative research projects by providing financial support and bringing funding into the field of CF from external sources, including the pharmaceutical industry.
- The UK Cystic Fibrosis Conference – an event for healthcare professionals and people affected by CF informed on all aspects of clinical care and research.

In 2020/21, our UK Cystic Fibrosis Conference was postponed from February 2021 to May 2021, therefore we received no income for the event for this financial year.

In 2020/21, we received £5,000 in sponsorship from Chiesi for the Annual Registry Meeting.



Statement of Trustees' responsibilities

The Trustees, who are also directors of the Cystic Fibrosis Trust for the purposes of company law, are responsible for preparing the Trustees' report (including the Group Strategic Report) and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group, and of the incoming resources and application of resources, including the income and expenditure of the charitable group for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustees investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

So far as each of the Trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware, and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This Trustees report incorporating the Strategic report was approved and authorised for issue by the Board of Trustees on **13 July 2021** and signed on its behalf by:

Richard Hunt, Chairman

Independent auditor's report to the Members and Trustees of the Cystic Fibrosis Trust

>Opinion

We have audited the financial statements of Cystic Fibrosis Trust for the year ended 31 March 2021 which comprise the Consolidated Statement of Financial Activities, Consolidated Income and Expenditure Account The Consolidated and Charity Balance Sheets, the Consolidated Statement of Cash Flows, and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group and parent charitable company's affairs as at 31 March 2021 and of the group's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustees investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

>Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

>Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

>Other information

The trustees are responsible for the other information. The other information comprises the information included in the Trustees' Report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

>Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report (which includes the strategic report and the directors' report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the strategic report and the directors' report included within the Trustees' Report have been prepared in accordance with applicable legal requirements.

>Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report (which incorporates the strategic report and the directors' report).

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charity Accounts (Scotland) Regulations requires us to report to you if, in our opinion:

- adequate accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us]; or
- the charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit

>Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement set out on page 39, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

>Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the charitable company and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to the Companies Act 2006 and the Charity Accounts (Scotland) Regulations and the Charities Act 2011 and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered other factors such as income tax, payroll tax and sales tax.



We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and concluded that the risk was low. Audit procedures performed by the engagement team included:

- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions; and
- Challenging assumptions and judgements made by management in their critical accounting estimates

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

>Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Kathryn Burton (Senior Statutory Auditor)
for and on behalf of Haysmacintyre LLP, Statutory Auditor

10 Queen Street Place,
London
EC4R 1AG

Cystic Fibrosis Trust

> Consolidated statement of financial activities

For the year ended 31 March 2021

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2021 £'000**	**Total Funds 2020 £'000**
Income and endowments from:						
Donations and legacies	2	8,098	3,580	-	**11,678**	**15,196**
Other trading activities	12	2,580	-	-	**2,580**	**1,078**
Investments	2b,6	110	18	-	**128**	**149**
Other income						
Fixed aaset disposals gain	6	-	-	-	**-**	**-**
Other income	2	-	-	-	**-**	**105**
Total		10,788	3,598	-	**14,386**	**16,527**
Expenditure on:						
Raising funds	3	3,718	-	3	**3,721**	**3,563**
Charitable activities						
Research		3,008	1,966	1	**4,975**	**4,432**
Clinical care	3	664	468	-	**1,132**	**2,132**
Information, advice & support		3,668	407	2	**4,077**	**6,373**
Total charitable activities		7,340	2,841	3	**10,184**	**12,938**
Total resources expended	3	11,058	2,841	6	**13,905**	**16,501**
Net income/(expenditure) before investment gains/losses		**(270)**	**757**	**(6)**	**481**	**27**
Realised investment gains/(losses)		17	-	-	**17**	**38**
Unrealised investment gains/(losses)		694	-	99	**793**	**(391)**
Net investment gains/(losses)		**711**	**-**	**99**	**810**	**(353)**
Net (expenditure)/income		**441**	**757**	**93**	**1,291**	**(326)**
Transfers between funds	17a	747	(747)	-	**-**	**-**
Net movement in funds		1,188	10	93	**1,291**	**(326)**
Reconciliation of funds						
Total funds brought forward		7,089	239	897	**8,225**	**8,551**
Total funds carried forward	17a	**8,277**	**249**	**990**	**9,516**	**8,225**

All of the operations are continuing. There were no recognised gains or losses other than those stated above.
A prior year comparative Consolidated Statement of Financial Activities has been included in the notes to the accounts (note 16)

The notes on pages 47 to 67 form part of these financial statements.

Cystic Fibrosis Trust

> Consolidated income and expenditure account

For the year ended 31 March 2021

	All income funds 2021 £'000	All income funds 2020 £'000
Income	**14,258**	16,738
Gains/(losses) on investments	**711**	(219)
Investment income	**128**	149
Gross income in the reporting period	**15,097**	16,308
Expenditure	**13,876**	16,476
Interest payable	**-**	-
Depreciation and charges for impairment of fixed assets	**23**	18
Total expenditure in the reporting period	**13,899**	16,494
Net income before tax for the reporting period	**1,198**	(186)
Tax payable	**-**	-
Net Income for the financial year	**1,198**	(186)

The Consolidated Summary Income and Expenditure Account is derived from the Statement of Financial Activities on page 41 with movements on endowment funds removed to comply with Company law.

All income and expenditure is derived from continuing activities.

The notes on pages 47 to 67 form part of these financial statements.

Cystic Fibrosis Trust

> Consolidated and charity balance sheets

As at 31 March 2021

	Notes	Consolidated		Charity	
		Total 2021 £'000	Total 2020 £'000	**Total 2021 £'000**	Total 2020 £'000
Fixed assets					
Tangible assests	5	**37**	24	**37**	24
Investments	6	**5,196**	5,670	**5,196**	5,670
		5,233	5,694	**5,233**	5,694
Current assets					
Debtors	7	**3,301**	2,619	**2,337**	2,552
Cash held as short term investment		**11,256**	9,978	**11,256**	9,978
Cash at bank and in hand		**3,366**	2,939	**3,246**	2,672
		17,923	15,536	**16,839**	15,202
Liabilities					
Creditors: amounts falling due within one year					
Grants payable	9	**(7,407)**	(7,135)	(7,407)	(7,135)
Creditors and accrued charges	10	**(1,410)**	(705)	(1,404)	(699)
		(8,817)	(7,840)	**(8,811)**	(7,834)
Net current assets		**9,106**	7,698	**8,028**	7,367
Creditors: amounts falling due after one year					
Grants payable	9	**(4,823)**	(5,165)	(4,823)	(5,165)
Total net assets		**9,516**	8,225	**8,438**	7,897
The funds of the charity					
Endowment funds	17a	**989**	897	**989**	897
Restricted income funds	17a	**248**	239	**248**	241
Unrestricted funds					
Designated reserves	17a	(184)	(1,055)	(184)	(1,055)
Fixed asset reserve		37	24	37	24
Appeal deficit		(421)	(1,079)	(421)	(1,079)
Strategic reserve		200	-	200	-
Operating reserves		3,448	3,366	3,448	3,366
Retained reserves		5,015	4,778	3,937	4,449
Total charity funds		**9,516**	**8,225**	**8,438**	**7,897**

The notes on pages 47 to 67 form part of these financial statements.

The net movement in funds for the Trust for the year ended 31 March 2021 was – £219,000 (2020: 12 months +£655,000). As permitted by Section 408 of the Companies Act 2006, no separate Statement of Financial Activities or Income and Expenditure account has been presented for the charity alone.

Approved and authorised for issue by the Trustees on **13 July 2021** and signed on their behalf by:

Richard Hunt, Chairman

Company number 3880213

Cystic Fibrosis Trust

> Consolidated Statement of cash flows

As at 31 March 2021

	2021 £'000	2020 £'000
Net cash provided by (used in) operating activities (Note A)	**329**	(1,171)
Cash flows from investing activities:		
Dividends and interest	**128**	149
Purchase of property, plant and equipment	**(36)**	(2)
Purchase of investments	**(116)**	-
Movement in cash awaiting investment	**2**	9
Proceeds of sales of investments	**116**	-
	94	156
Increase/(decrease) in cash held as short term investments	(1,276)	1,436
Increase/(decrease) in cash (Note B)	**(853)**	421

Notes to Cash Flow Statement

A. Reconciliation of net income/(expenditure) to net cash flow from operating activities

	2021 £'000	2020 £'000
Net (expenditure)/income for the reporting period (as per the statement of financial activities)	**1,291**	(327)
Adjustment for:		
Depreciation charges	**23**	18
Dividends and interest from investments	**(128)**	(149)
(Gains)/losses on investments	**(810)**	352
Decrease/(increase) in debtors	**(682)**	(306)
Increase/(decrease) in creditors	**635**	759
	329	(1,171)

B. Reconciliation of cash and cash equivalents in the reporting period

	2021 £'000	2020 £'000
Cash and cash equivalents at the beginning of the reporting period	**12,919**	13,931
Change in cash and cash equivalents in the reporting period	**(853)**	424
Increase in short-term investments	**1,276**	(1,436)
Cash and cash equivalents at the end of the reporting period	**13,342**	12,919
(being cash at bank and in hand and cash held as short-term investments)		

Analysis of cash and cash equivalents:	**2021 £'000**	2020 £'000
Cash on hand	**3,366**	2,941
Notice deposits (less than 3 months)	**11,256**	9,978
Total cash and cash equivalents	**14,622**	12,919

> Notes to the Financial Statements

For the year ended 31 March 2021

1. Accounting policies

The principle accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

a) Basis of preparation
The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (second edition effective 1 January 2019) – (Charities SORP FRS 102), and the Companies Act 2006.

Group financial statements have been prepared in respect of Cystic Fibrosis Trust and its wholly owned trading subsidiary, Cystic Fibrosis Services Limited. In accordance with the Companies Act 2006 and SORP 2015, no separate Statement of Financial Activities is presented for Cystic Fibrosis Trust.

Cystic Fibrosis Trust meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Charity status
The charity (registration number 1079049) is a company limited by guarantee, with company number 03880213 and registered address One Aldgate, London EC3N 1RE. The members of the company include the Trustees named on page 3. In the event of the company being wound up, the liability in respect of the guarantee is limited to £1 per member of the company

c) Consolidation
The financial statements include the results and assets and liabilities of the charity and its wholly owned subsidiary Cystic Fibrosis Services Limited and are consolidated on a line by line basis. Both entities draw up their financial statements to 31 March each year. The parent charity has claimed exemption from presenting its own Statement of Financial Activities under section 408 of Companies Act 2006. The surplus for the parent charity was £401,000 (2019/20 – deficit of £655,000).

The subsidiary's net surplus of £1,071,000 will be donated in full to the parent charity after the year end.

d) Income
All income is recognised once the charity has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably.

Donations and legacies income are recognised where there is entitlement, probability of receipt and the amount of the gift is measurable.

Income from charitable activities is recognised as earned as the related services are provided. Income from other trading activities is recognised as earned as the related goods are provided.

Investment income is recognised on a receivable basis and the amounts can be measured reliably. Dividends are recognised once the dividend has been declared and notification has been received the dividends are due.

e) Resources expended
Liabilities are recognised as expenditure as soon as there is legal or constructive obligation committing the charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably.

Expenditure is recognised on an accruals basis as a liability is incurred, and includes irrecoverable VAT where applicable.

Expenditure is classified under the following activity headings:

- Expenditure on raising funds comprises those costs relating to activities where the primary aim is to raise funds, along with an apportionment of support costs

- Expenditure on charitable activities comprises those costs relating to activities where the primary aim is congruent with the objects of the charity, along with an apportionment of support costs. This includes grants made to research institutions and individuals, the provision of information and support services to people with cystic fibrosis and their families, peer reviews of cystic fibrosis centres and the development of the CF Registry.

Support costs, which include general management, payroll administration, budgeting and accounting, information technology, and human resources, are apportioned based on the estimated amount of time spent by the support area on each activity category. The basis for allocation was reviewed in the year in order to give a more accurate view of the level of support provided within different business areas. The prior year allocations have been restated in order to be consistent with the revised allocation basis.

f) Grants
Grants committed and awarded during the year are expensed.

g) Foreign currency transactions
Transactions in foreign currencies are recorded in sterling at the rate ruling at the date of the transaction. Monetary assets and liabilities are retranslated at the rate of exchange ruling at the balance sheet date. All exchange differences are taken to the Statement of Financial Activities.

h) Employee benefits
- **Short term benefits** – Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.

- **Employee termination benefits** – Termination benefits are accounted for on an accrual basis and in line with FRS 102.

- Pension scheme – The Charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Charity pays fixed contributions into a separate entity. Once the contributions have been paid the Charity has no further payment obligations. The contributions are recognised as an expense in the Statement of Financial Activities when they fall due.

i) Taxation
No charge to taxation arises on the result for the year because the company is able to take advantage of the tax exemptions available to charities.

j) Leases
The trust recognises expenses under 'operating leases' relating to capital equipment which it does not own. The annual rentals are charged to the statement of financial activities on a straight line basis over the lease term.

k) Funds
Unrestricted reserves are those which the Trustees are free to use for any purpose in furtherance of the charitable objects.

Designated reserves are set aside out of unrestricted reserves by the Trustees, for particular purposes.

Restricted reserves are monies, which have legal restrictions on their use where donors have specified the funds can only be spent on certain of the charity's activities.

Endowed Funds are funds where the Trustees are required to hold capital, as represented by the investments, and are not entitled to spend it. Income arising from these funds is either restricted income or unrestricted income depending upon the details included with the original gift.

l) Fixed assets and depreciation
Tangible fixed assets costing £500 or more are capitalised and are depreciated by equal annual instalments

Furniture & fittings	33.33%
Computer hardware	33.33%
Computer software	33.33%
Website development	33.33%
Platform development	50%

Website and Platform development costs are capitalised on the basis that they lead to an asset that will generate funds for the Trust or where the primary aim is part of the objects of the charity. The assets are depreciated once the asset is ready for use.

m) Investments
Investments are a form of basic financial instruments and are initially shown in the financial statements at fair value. Movements in the fair values values of investments are shown as unrealised gains and losses in the Statement of Financial Activities.

Profits and losses on the realisation of investments are shown as realised gains and losses in the Statement of Financial Activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired subsequent to the first day of the financial year. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value. Realised and unrealised investment gains and losses are combined in the Statement of Financial Activities.

n) Financial Instruments
The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value

- **Debtors** – Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

- **Cash at bank and in hand** – Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

- **Creditors and provisions** – Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

o) Critical accounting judgements and estimates
In preparing these financial statements, management has made judgements, estimates and assumptions that affect the application of the Charity's accounting policies and the reported assets, liabilities, income and expenditure and the disclosures made in the financial statements. Estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. The key areas that are deemed to be material for these financial statements is as follows:

- Accruing for income derived from legacies where complicated issues surrounding the measurement of the group's entitlement to income existed at the year end.

- The value of the contribution of the many thousands of hours donated by its unpaid volunteers has not been reflected in these accounts. The SORP does not permit the accounting for such contributions due to the inherent uncertainty in applying an accurate and reliable financial measurement in accordance with the SORP.

p) Going concern status
The Trustees have reviewed the financial statements and supplementary financial information and conclude that the Trust is a valid going concern.

q) Government grants
Government grants include Coronavirus Job Retention Scheme grants. These are recognised when the charity is entitled to the income, receipt is probable and the amount receivable can be reliably measured.

2a. Income from donations and legacies

	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	**Total 2021 £'000**	Unrestricted Funds 2020 £'000	Restricted Funds 2020 £'000	**Total 2020 £'000**
Branches, Groups & Community	1,546	8	**1,554**	3,599	15	**3,614**
Legacies	2,082	185	**2,267**	2,875	46	**2,921**
Individual donations	394	32	**426**	275	54	**330**
Corporate	269	107	**376**	222	-	**222**
Regular giving and appeals	1,285	39	**1,324**	1,167	42	**1,209**
Trusts	97	2,551	**2,648**	20	1,943	**1,963**
Appeal for Innovation Hub	-	658	**658**	-	438	**438**
Donations in kind	1,648	-	**1,648**	3,833	-	**3,833**
Gift Aid	345	-	**345**	538	-	**538**
Government grant income	304	-	**304**	-	-	**-**
NHS National Services England	81	-	**81**	81	-	**81**
NHS National Services Scotland	47	-	**47**	47	-	**47**
Total income from donations and legacies	8,098	3,580	**11,678**	12,657	2,539	**15,196**

Donations In Kind refer to non-monetary donations received from partner organisations. In 2020/21 £1,648,000 was donated in the form of digital and cinema advertising space and professional fees (2019/20: £3,833,000). This was used to raise awareness of cystic fibrosis and the work of the Cystic Fibrosis Trust. The corresponding cost value of this donation is shown within Information, Advice and Support.

Government grant income relates to the recovery of partial salary costs through the Job Retention Scheme during the COVID-19 pandemic.

2b. Investment Income

	Unrestricted Funds 2021 £'000	Restricted Funds 2021 £'000	**Total 2021 £'000**	Unrestricted Funds 2020 £'000	Restricted Funds 2020 £'000	**Total 2020 £'000**
Income from listed investments	46	18	**64**	64	7	71
Bank interest	64	-	**64**	78	-	78
Total investment income	110	18	**128**	142	7	149

3a. Expenditure

Total costs – current year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2021 £'000**
Raising funds					
Fundraising	-	-	1,902	382	**2,284**
Trading and merchandising	-	1,376	61	-	**1,437**
Charitable activities					
Research	1,891	1,255	998	831	**4,975**
Clinical care	299	48	596	189	**1,132**
Information, advice & support	262	88	3,046	681	**4,077**
	2,452	2,768	6,603	2,083	**13,905**

Analysis of allocated Support Costs – current year

	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2021 £'000**
Fundraising	62	52	105	50	113	**382**
Research	136	114	228	109	244	**831**
Clinical care	31	26	52	25	55	**189**
Information, advice & support	112	94	187	90	198	**681**
Total costs	341	286	573	273	609	**2,083**

Costs are allocated based on identifiable activities undertaken by central teams to support the wider organisation. The basis of allocation of support costs has been reviewed in the year. The prior year allocations have been restated in order to be consistent with the revised allocation basis.

Total costs – prior year	Grants Restricted £'000	Grants Unrestricted £'000	Direct costs £'000	Support costs £'000	**Total 2020 £'000**
Raising funds					
Fundraising	-	-	2,506	394	**2,900**
Trading and merchandising	-	602	61	-	**664**
Charitable activities					
Research	1,629	1,269	931	602	**4,432**
Clinical care	761	138	944	290	**2,133**
Information, advice & support	174	213	5,119	867	**6,373**
	2,564	2,223	9,561	2,154	**16,502**

The net restricted grants relating to Clinical Care are negative – this is due to the release of a commitment made in a prior year. See note 3b for more information.

Analysis of allocated Support Costs – prior year	Governance £'000	Finance £'000	IT Support £'000	People & OD £'000	HQ & Facilities £'000	**Total 2020 £'000**
Fundraising	78	52	101	56	108	**394**
Research	119	79	154	85	166	**601**
Clinical care	57	38	74	41	80	**291**
Information, advice & support	171	114	221	122	238	**866**
Governance	-	-	-	-	-	**-**
Total costs	424	283	551	302	591	**2,153**

3a. Expenditure (continued)

Net (expenditure)/income in the year:

	2021 £'000	2020 £'000
Auditors remuneration excluding VAT	**22**	21
Depreciation	**23**	18
Operating leases – building	**244**	244
Operating leases – other	**6**	6
Trustees' travel expenses	**-**	3

3b. Grants

Grants were awarded during the year as follows:

	2021 £'000	2020 £'000
Grants to institutions	**4,870**	4,402
Grants to individuals	**350**	385
	5,220	4,787

Grants made to, and for, individuals affected by Cystic Fibrosis are for expenses such as respite care, building adaptations and equipment rental, and benefited a large number of individuals throughout the Trust's network of regions and branches.

	2021 £'000	2020 £'000
Balance at start of year	12,299	12,502
Awarded in the year	5,220	4,765
Paid in year	(5,289)	(4,968)
Balance at end of year	12,230	12,299
Falling due within one year (note 9)	7,407	7,135
Falling due after more than one year (note 9)	4,823	5,165

During the year, grants were awarded to the following institutions:

3b. Grants (continued)

	2021 £'000	2020 £'000
University of Cambridge/Papworth Hospital	832	856
University of Liverpool	769	33
UCL Great Ormond Street	750	2
University of Bristol	749	2
Queen Elizabeth University Hospital	180	-
University Hospital Llandough	120	-
Imperial College London /Royal Brompton Hospital	56	163
Medicines Discovery Catapult	50	-
University of Copenhagen	27	-
CF Europe	21	21
Queen's University Belfast	17	3
MRC	3	-
Great North Children's Hospital	2	-
University of Birmingham	2	-
University of Edinburgh	2	-
University of Exeter	2	58
University of Newcastle/Newcastle Hospital	-	750
University of Sheffield	-	749
Kings College	-	157
Royal College of Surgeons in Ireland	-	97
Manchester University/Wythenshaw Hospital	-	95
Nottingham University	-	65
Royal Hospital for Children, Glasgow	-	50
Neem Biotech	-	30
ECFS	-	20
National heart and lung institute, London	-	20
Cardiff University		2
St George's University of London		2
Institute of Cancer Sciences, Glasgow		2
	3,579	**3,177**
Add: Trial Coordinator commitments made to CTAP centres (see note)	298	616
Add: Registry support grants made to various CF centres	1,376	602
Add: Other adjustments	19	7
Less: Release of grants made in previous years (see note)	(401)	-
Total grants made to institutions	**4,871**	**4,402**

The Trust has committed to funding the salaries of clinical trial coordinators as part of the Clinical Trials Accelerator Platform programme. In most cases the trial coordinators are now in their third year of funding. In addition, a new cohort of 'Affiliate Centres' were awarded funding in the year.

Various grants totalling £401,000 were released during the prior year. This was either due to the full grant value not being required by the grant recipient by the end of the project lifecycle, or an application for matched funding (upon which the Trust's funding was dependent) not being successful.

The Trust has considered the discounting of grant commitments due in more than one year, but has not made any adjustments to the figures disclosed above as the impact of discounting is negligible.

4. Staff costs

Staff costs comprise the following:

	2021 £'000	2020 £'000
Salaries	**4,220**	4,011
Redundancy and other termination payments	**34**	-
Temporary Staff	**75**	232
Social security costs	**432**	416
Other pension costs	**254**	235
	5,015	4,895

£34,000 in redundancy and other termination payments were paid to 2 (2019/20– £Nil) staff members in the year following a review of the senior leadership team structure, which will result in a long-term recurring cost saving for the Trust.

Pension commitments:
The Charity operates a defined contributions pension scheme. The assets of the scheme are held separately from those of the Charity in an independently administered fund. The pension cost charge represents contributions payable by the Charity to the fund and amounted to £254,000 (2019/20 – £235,000).

Analysis of total average monthly headcount by category:

	2021 No.	2020 No.
Research	**16**	13
Clinical care	**6**	5
Information, advice & support	**36**	34
Fundraising	**42**	38
Management	**2**	4
Finance	**7**	6
IT and project management support	**8**	6
HR & OD	**4**	7
Facilities	**1**	2
Total average monthly headcount	**122**	**115**

The number of employees whose total remuneration exceeded £60,000 in the year was:

	2021 No.	2020 No.
£60,001 – £70,000	9	2
£70,001 – £80,000	2	3
£80,001 – £90,000	1	-
£90,001 – £100,000	-	-
£110,001 – £120,000	1	1

Pension contributions to defined contribution pension schemes for these employees totalled £53,168 (2020/21 – £32,190).

Remuneration of key management personnel: The total remuneration paid to key management personnel, including pension and social security contributions, was £524,283 which relates to 7 individuals who served on the Senior Leadership Team during the year (2020/21– £652,905 paid to 8 individuals).

No remuneration was paid to the trustees, and no payments were made to third parties on behalf of the trustees. No expenses were settled on behalf of Trustees (2019/20 – £3,019 settled on behalf of 4) as all meetings were held remotely during the period.

5. Fixed assets

	Furniture & fittings £'000	Computer hardware £'000	Computer software £'000	Website development £'000	Platform development £'000	Total £'000
Cost						
At 31 March 2020	**630**	**834**	**243**	**403**	**183**	**2,293**
Additions	-	36	-	-	-	36
At 31 March 2021	**630**	**870**	**243**	**403**	**183**	**2,329**
Depreciation						
At 31 March 2020	**630**	**811**	**243**	**402**	**183**	**2,269**
Charge for the year	-	23	-	-	-	23
At 31 March 2021	**630**	**834**	**243**	**402**	**183**	**2,292**
Net book value at 31 March 2021	**-**	**36**	**-**	**1**	**-**	**37**
Net book value at 31 March 2020	-	23	-	1	-	24

6. Investments

Group and Charity	**Total 2021 £'000**	Total 2020 £'000
Market value as at 31 March 2020	**5,670**	6,031
Additions at cost	**116**	524
Disposals at opening book value	**(1,376)**	(524)
Net gains/(losses) on investments	**782**	(352)
	5,192	5,678
Change in cash	**4**	(9)
Market value as at 31 March 2021	**5,196**	5,670

6. Investments (continued)

Represented by:	**Total 2021 £'000**	Total 2020 £'000
Equities	**3,921**	2,952
Fixed Interest and multi-asset funds	**495**	468
Property	**575**	659
Cash	**205**	1,591
	5,196	**5,670**

Under the terms of the trust deed there are no restrictions on the trustees' powers of investment.

The following assets were held at 31 March 2021. These make up more than 5% of total investments:

	Total 2021 £'000
The equity income trust for charities	**670**
Charities property fund	**319**
Property income trust for charities	**256**
Schroders responsible multi asset fund	**2,398**

In 2014–15, the Trustees decided to exclude tobacco-related stocks from investments. This change was implemented in 2015–16 and the investment portfolio is now fully ex-tobacco.

7. Debtors

	Group 2021 £'000	Group 2020 £'000	**Charity 2021 £'000**	Charity 2020 £'000
Trade debtors	**1,085**	305	**-**	-
Amount due from subsidiary undertaking	**-**	-	**121**	238
Prepayments and accrued income	**2,151**	2,263	**2,151**	2,263
Other debtors	**65**	51	**65**	51
	3,301	2,619	**2,337**	2,552

8. Cash held as short-term investment

The charity recognises grant commitments in full when the constructive obligation is made. Included in cash held as short-term investments are balances held to meet grant commitments pending grantees drawing grants under the terms of their award.

9. Grants Payable

	2021 £'000	2020 £'000
Grant creditor at 31 March 2020	**12,299**	12,503
Grants paid during the year	**(3,914)**	(4,366)
Grants approved before 31 March 2021 and payable within one year	**2,347**	2,413
Grants approved before 31 March 2021 and payable after one year	**1,498**	1,749
Grant creditor at 31 March 2021	**12,230**	**12,299**
Represented by		
Grants due within one year at 31 March 2021	**7,407**	7,135
Grants due > 12 months	**4,823**	5,165
	12,230	12,300

10. Creditors

	Group 2021 £'000	Group 2020 £'000	Charity 2021 £'000	Charity 2020 £'000
Trade creditors	**408**	195	**408**	194
Other creditors	**120**	129	**120**	129
Accruals and deferred income	**882**	382	**876**	376
	1,410	**705**	**1,404**	**699**

11. Financial Instruments (Assets and Liabilities)

	Group 2021 £'000	Group 2020 £'000	Charity 2021 £'000	Charity 2020 £'000
Financial assets measured at amortised cost (note a)	**15,724**	13,241	**15,724**	13,241
Financial assets measured at fair value (note b)	**5,196**	5,309	**5,196**	5,309
Financial liabilities measured at amortised cost (note c)	**(13,529)**	(12,681)	**(13,529)**	(12,681)
Net financial assets measured at amortised cost	**7,391**	5,869	**7,391**	5,869

(a) The Trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

(b) Financial assets held at fair value include assets held as investments.

(c) Financial liabilities measured at amortised cost include: trade creditors, other creditors, accruals, grants payable and deferred income and amounts due to group undertakings.

12. Interest in subsidary

Cystic Fibrosis Services Limited is incorporated in England (company number: 00900164) and is a wholly owned subsidiary of the Cystic Fibrosis Trust. The subsidiary's activities include medical services, information and data system support and the merchandising of marketing materials. The profit and loss account of Cystic Fibrosis Services Limited for the year ended 31 March can be summarised as:

	Total 2021 £'000	Total 2020 £'000
Sales and sundry income	**2,580**	1,078
Cost of sales and administration	**(1,437)**	(664)
Intercompany recharges	**(71)**	(86)
Net contribution to parent charity	**1,072**	**328**

The balance sheet of Cystic Fibrosis Services Limited at 31 March can be summarised as:

	Total 2021 £	Total 2020 £
Current assets		
Debtors	**1,077,967**	305,005
Cash at bank	**120,205**	269,234
	1,198,172	**574,239**
Creditors: amounts falling due within one year	**(127,506)**	(245,834)
Net current assets	**1,070,666**	328,404
Net assets	**1,070,666**	328,404
Capital and reserves		
Called up share capital	**2**	2
Profit and loss account	**1,070,664**	328,402
Shareholder's funds	**1,070,666**	328,404

The charity owns the whole of the issued ordinary share capital of Cystic Fibrosis Services Ltd, which comprises 100 ordinary shares of £1 each. Two shares have been allotted, which are called up and fully paid.

The subsidiary's profit for the year will be donated in full to the Cystic Fibrosis Trust after the year end.

13. Leasing commitments

At 31 March, the Trust's future minimum operating leases payments relating to buildings were:

	2021 £'000	2020 £'000
Within one year	271	271
Between two and five years	813	1,084

A 10-year property lease with a five-year break clause was signed on 1 April 2015 for a new office in central London, with annual rent of £271,425. The break clause was not exercised and as such the remaining four years of the lease are now committed.

At 31 March, the Trust's future minimum operating leases payments relating to equipment were:

	2021 £'000	2020 £'000
Within one year	6	6
Between two and five years	24	24

The charge to the Statement of Financial Activities for all of these commitments is shown in note 3a.

14. Related party transactions

The group has taken advantage of the exception which is conferred by FRS102 Section 33.1A 'Related Party Disclosures' that allows it not to disclose transactions with group undertakings that are eliminated on consolidation.

Total donation income from the Trustees in the year was £27,729 (2019/20 – £10,285). In addition, 5 of the trustees (2019/20 – 5) were involved in fundraising activities carried out by regional fundraising branches.

Any other transactions between the Trust and its trustees are disclosed in note 4.

15. Post balance sheet events

There were no post balance sheet events or contingent liabilities when the accounts were signed and authorised for issue.

16. Analysis of funds

	Unrestricted	Endowment funds	Gene Therapy restricted	Other restricted	**2021**
	£'000	£'000	£'000	£'000	**£'000**
Tangible fixed assets	37	-	-	-	37
Investments	4,207	989	-	-	5,196
Current assets	17,660	-	-	263	17,923
Internal obligations	-	-	-	-	-
Current liabilities	(8,817)	-	-	-	(8,817)
Liabilities due in more than one year	(4,808)	-	-	(15)	(4,823)
	8,279	989	-	248	9,516

Prior year funds

	Unrestricted	Endowment funds	Gene Therapy restricted	Other restricted	**2020**
	£'000	£'000	£'000	£'000	**£'000**
Tangible fixed assets	7	-		-	7
Investments	4,772	898	-	-	5,670
Current assets	15,297	-	-	241	15,538
Internal obligations	-	-	-	-	-
Current liabilities	(7,840)	-	-	-	(7,840)
Liabilities due in more than one year	(5,178)	-	-	13	(5,165)
	7,058	898	-	254	8,210

17a. Current year fund movements

	Balance 31 March 2020 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2021 £'000**
Fixed asset reserve	24	-	-	-	13	37
Appeal deficit: Innovation Hub at Cambridge	(1,079)	-	-	-	658	(421)
Strategic reserve	-	-	-	-	200	200
Total designated reserves	**(1,055)**	**-**	**-**	**-**	**871**	**(184)**
Operating reserve	3,366	-	-	-	82	3,448
Retained reserves	4,778	711	10,788	(11,058)	(206)	5,013
Total general reserves	**8,144**	**711**	**10,788**	**(11,058)**	**(124)**	**8,461**
Total unrestricted funds	**7,089**	**711**	**10,788**	**(11,058)**	**747**	**8,277**
Restricted income funds:						
Appeal: Innovation Hub at Cambridge	-	-	658	-	(658)	-
Restricted funds related to research:						
Gene therapy research	45	-	43	-	-	87
General medical research	-	-	179	(179)	-	-
Imperial SRC: Pseudomonal infection	-	-	50	-	(50)	-
UCL SRC: Personalised engineered cell therapies	-	-	3	-	(3)	-
Sport England – Helping the active stay active	-	-	7	-	-	7
Imperial SRC: *Pseudomonas aeruginosa*	-	-	14	-	(14)	-
Targeting immuno theraphy for fungal infections–SRC15	-	-	2	-	(2)	-
RNA interference of ENAC as therapy for CF VIA 12	-	-	20	-	(20)	-
UCL/Great Ormund St SRC – Therapeutic gene editing	-	-	379	(375)	-	4
Liverpool SRC – Antimicrobeal therapeutics PIPE-CF	-	-	375	(375)	-	-
Life expectancy project	(20)	-	-	(3)	-	(23)
Transition information resources	15	-	-	-	-	15
Other research related restricted funds	1	-	4	(13)	-	(7)
Total funds related to research	**41**	**-**	**1,074**	**(944)**	**(89)**	**83**

Continued on next page

17a. Current year fund movements (continued)

Restricted funds related to Information and Support						
E W Joseph/Homecare grants	36	-	7	(25)	-	17
Joseph Levy/Education Grants	13	-	19	(46)	-	(15)
Young Lives programme	6	-	61	(39)	-	28
Support services (including welfare grants)	81	-	224	(225)	-	80
CF Connect (youth and parents)	26	-	-	-	-	26
Total funds related to Information and Support	**162**	**-**	**311**	**(335)**	**-**	**137**
Other funds – various categories:						
Coombe Hill	8	-	-	-	-	8
Kings fund	-	-	-	-	-	-
SmartCare CF	(10)	-	-	-	-	(10)
Clinical Trials Accelerator Programme (CTAP)	-	-	455	(465)	-	(10)
Digital Health Research Programme	-	-	1,024	(1,024)	-	-
CF Registry	(5)	-	-	(7)	-	(12)
Patient Reported Experience Measures	2	-	-	(2)	-	-
Consensus documents	23	-	-	(2)	-	22
HDRUK grant award	(14)	-	9	-	-	(5)
Other older funds	32	-	69	(62)	-	37
Total other funds	**36**	**-**	**1,557**	**(1,562)**	**-**	**28**
Total restricted reserves	**239**	**-**	**3,599**	**(2,841)**	**(747)**	**248**
Endowment funds:						
Ena Bennie Endowment	443	52	-	(3)	-	491
EW Joseph Endowment	150	17	-	(1)	-	165
Joseph Levy Endowment	257	30	-	(2)	-	285
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other Endowment funds	27	1	-	-	-	28
Total endowment funds	**897**	**99**	**-**	**(6)**	**-**	**989**
Total funds	**8,225**	**810**	**14,387**	**(13,906)**	**-**	**9,514**

17a. Funds (continued)

Designated Funds: The designated fixed assets reserve matches the net book value of the charity's tangible fixed assets, the existence of which is fundamental to the charity being able to perform its charitable work and thereby achieve its charitable objectives. The value represented by such assets should not, therefore, be regarded as realisable.

Appeal Deficit: Innovation Hub at Cambridge – In 2017/18 we committed £2.0 million in the form of a research grant to Cambridge University as part of the Innovation Hub flagship programme. To date we have received £1.58m from donors in funding for this grant (shown in the separate restricted fund line, see below). The Trust has underwritten this grant, and we continue to work to secure additional pledges in order to fund the commitment in full and free up core funds to be made available where there is the greatest need.

A new designated fund was set up in the year, to fund any cost grant extensions that are requested by research grant recipients as a direct result of delays due to COVID-19 restrictions.

General reserves: The operating reserve is held in order to provide, as a minimum, cover for six months operation costs, major fluctuations in income and contingencies for long term commitments, and any deficits arising on restricted funds.

Retained reserves are held for future initiatives.

Restricted income funds: Restricted income funds are held when donors specify a particular use for their donation. For the purposes of this report, the restricted income funds have been divided into the following categories:

- **Appeal for Innovation Hub at Cambridge:** We have received £1.58m to date in funding towards the £2.0m commitment made to Cambridge University. As further income is received it will be recognised within this restricted fund and matched against the commitment made in 2017/18 through a transfer to the designated fund (see above).

- **Restricted funds related to research:** Donations relating to grant commitments made by the Trust to research institutions. On occasion the donations were made in a different financial year to the original grant commitment; in such cases a transfer has been made to retained reserves to back-fill the original payments.

The following funds are held related to research:

Gene Therapy Research – funds available for gene therapy related activity.
General medical research – where the donor did not specify a particular research grant award.
- Matched against selected Strategic Research Centres.
- Matched against selected Venture Innovation Awards.
- Matched against selected Clinical Excellence and Innovation Awards.

Sport England funded work – A project at Exeter University: Helping the active stay active.
Other research related restricted funds – including funding for grants to individuals for cystic fibrosis related summer student projects or travel to cystic fibrosis related conferences

- **Restricted funds related to information and support:** Donations relating various activities supporting people with cystic fibrosis and their families.

The following funds are held related to Information and Support:

EW Joseph/Homecare grants – funding the promotion of increased care at home rather than in hospital for people with CF, and improvements in home care by education. See comments about the corresponding endowment fund below.
Joseph Levy/Education grants – funding people with cystic fibrosis in their educational studies. See comments about the corresponding endowment fund below.
Young Lives Programme – funding a youth porgramme supporting young people with cystic fibrosis. This fund is supported by Children In Need.
Support Services – various activities for supporting people with cystic fibrosis and their families, including the welfare grants programme.
CF Connect Youth/Parents – funding for projects to provide peer to peer telephone support service for young people with cystic fibrosis, and parents of children newly diagnosed with cystic fibrosis.

Continued on next page

17a. Funds (continued)

- **Other restricted funds:**

  Coombe Hill – funding education about cystic fibrosis.
  Kings College Hospital Award – funding the development of the cystic fibrosis centre at Kings College Hospital. The funds have now been accesed in full and work is in progress to refurbish the CF Adult Unit at the Kings College Hospital.
  Paediatrics – funding work in the paediatrics department at the Royal Brompton Hospital, including peer reviews.
  Vertex Everest Trip – funding an awareness-raising and fundraising trip to climb Mount Everest by a person with cystic fibrosis.
  SmartcareCF – funding the development of the SmartcareCF platform, including both adult and paediatric study.
  Clinical Trials Accelerator Platform – funding this flagship programme.
  Digital Health Research Programme – funding this flagship programme, in collaboration with Cambridge University and Papworth Hospital, on digital health monitoring.

- **Endowment funds:** The Trust maintains a number of endowment funds, where the capital is invested and the income arising from those investments is available to fund expenditure in the year.

  The Ena Bennie Memorial Fund was established in 1985. Income arising is unrestricted.
  The EW Joseph Fund was established in 1990. Income arising is restricted to the promotion of increased care at home (see EW Joseph/Homecare Grants above).
  The Joseph Levy Memorial Fund was established in 1999. Income arising is restricted to funding education (see J Levy/Education Grants above).
  The Sally Wrigley Memorial Fund.

Transfers between funds – the following transfers were made between funds:

- A transfer was made between the Appeal Innovation Hub at Cambridge and the Appeal Deficit Innovation Hub at Cambridge.
- A transfer was made to the Fixed Asset Reserve to match against the current balance on Fixed Assets.
- The balance of the Strategic Reserve was moved into Retained Reserves.
- Some transfers were made between Retained Reserves and various restricted funds to reflect commitments made in previous years that were originally funded from retained reserves but which have subsequently been back-filled by restricted donations.

17b. Prior year fund movements

	Balance 31 March 2019 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2020 £'000**
Fixed asset reserve	40	-	-	-	(16)	24
Appeal deficit: Innovation Hub at Cambridge	(1,306)	-	-	-	227	(1,079)
Strategic reserve	-	-	-	-	-	-
Total designated reserves	**(1,266)**	**-**	**-**	**-**	**211**	**(1,055)**
Operating reserve	3,393	-	-	-	(27)	3,366
Retained reserves	4,960	(219)	13,981	(14,058)	114	4,778
Total general reserves	**8,353**	**(219)**	**13,981**	**(14,058)**	**87**	**8,144**
Total unrestricted funds	**7,087**	**(219)**	**13,981**	**(14,058)**	**298**	**7,089**
Restricted income funds						
Appeal for Innovation Hub at Cambridge	-	-	477	(250)	(227)	-
Restricted funds related to research:						
Gene therapy research	-	-	45	-	-	45
General medical research	-	-	106	(105)	(1)	-
UCL SRC: Personalised engineered cell therapies	-	-	8	-	(8)	-
Sport England – Helping the active stay active	9	-	57	(57)	(9)	-
Imperial SRC: *Pseudomonas aeruginosa*	-	-	42	-	(42)	-
Targeting immuno therapy for fungal infections-SRC15	-	-	14	-	(14)	-
RNA interference of ENAC as therapy for CF VIA 12	-	-	15	-	(15)	-
Life expectancy project	5	-	-	(25)	-	(20)
Transition information resources	15	-	-	-	-	15
VIA general awards	-	-	-	-	-	-
Other research related restricted funds	9	-	-	(7)	(1)	1
Total funds related to research	**38**	**-**	**287**	**(194)**	**(90)**	**41**

Continued on next page

17b. Prior year fund movements (continued)

	Balance 31 March 2019 £'000	Investment Gains £'000	Income £'000	Expenditure £'000	Transfers £'000	**Balance 31 March 2020 £'000**
Restricted funds related to Information & Support:						
E W Joseph/Homecare grants	**62**	-	2	(28)	-	36
Joseph Levy/Education Grants	(12)	-	82	(69)	12	13
Young lives programme	49	-	48	(91)	-	6
Support services (inc. welfare grants)	70	-	117	(107)	1	81
CF Connect (youth and parents)	26	-	-	-	-	26
Total funds related to Information & Support	**195**	**-**	**249**	**(295)**	**13**	**162**
Other funds – various categories:						
Coombe Hill	40	-	-	(15)	(17)	8
Kings Fund	157	-	-	(157)	-	-
SmartCareCF	(10)	-	-	-	-	(10)
CTAP – Clinical Trials Accelerator Platform	-	-	856	(856)	-	-
Digital Health Research Programme	-	-	647	(647)	-	-
CF Registry	1	-	-	(6)	-	(5)
Patient Reported Experience Measures	-	-	3	(1)	-	2
Consensus documents	1	-	25	(2)	-	23
HDRUK Grant Award	-	-	-	(14)	-	(14)
Other older funds	(4)	-	2	2	31	31
Total other funds	**184**	**-**	**1,533**	**(1,696)**	**15**	**36**
Total restricted reserves	**417**	**-**	**2,546**	**(2,435)**	**(289)**	**239**
Endowment funds:						
Ena Bennie Endowment	522	(67)	-	(4)	(8)	443
EW Joseph Endowment	173	(22)	-	(1)	-	150
Joseph Levy Endowment	297	(38)	-	(2)	-	257
Sally Wrigley Memorial Fund	20	-	-	-	-	20
Other endowment funds	35	(7)	-	-	(1)	27
Total endowment funds	**1,047**	**(134)**	**-**	**(7)**	**(9)**	**897**
Total funds	**8,551**	**(353)**	**16,527**	**(16,500)**	**-**	**8,225**

18. Prior year Consolidated Statement of Financial Activities

	Note	Unrestricted Funds £'000	Restricted Funds £'000	Endowment Funds £'000	**Total Funds 2020 £'000**	**Total Funds 2019 £'000**
Income and endowments from:						
Donations and legacies	2	12,657	2,539	-	**15,196**	**16,054**
Other trading activities	12	1,078	-	-	**1,078**	**1,321**
Investments	2b,6	142	7	-	**149**	**273**
Other income:						
Other income	2	104	-	-	**104**	**121**
Total		13,981	2,546	-	**16,527**	**17,769**
Expenditure on:						
Raising funds	3	3,545	15	3	**3,563**	**3,517**
Charitable activities						
Research		3,346	1,085	1	**4,432**	**4,695**
Clinical care	3	1,085	1,047	-	**2,132**	**1,804**
Information, advice & support		6,082	288	3	**6,373**	**5,722**
Total charitable activities		10,513	2,420	4	**12,937**	**12,221**
Total resources expended	3	14,058	2,435	7	**16,500**	**15,738**
Net income/(expenditure) before investment gains/losses		**(77)**	**111**	**(7)**	**27**	**2,031**
Realised investment gains/(losses)		38	-	-	**38**	**4**
Unrealised investment gains/(losses)		(257)	-	(134)	**(391)**	**22**
Net investment gains/(losses)		**(219)**	**-**	**(134)**	**(353)**	**22**
Net (expenditure) income		**(296)**	**111**	**(141)**	**(326)**	**2,053**
Transfers between funds	17a	298	(289)	(9)	**-**	**-**
Net movement in funds		2	(178)	(150)	**(326)**	**2,053**
Reconciliation of funds:						
Total funds brought forward		7,087	417	1,047	**8,551**	**6,498**
Total funds carried forward	17a	**7,089**	**239**	**897**	**8,225**	**8,551**

Structure, governance and management

Patron
- HRH The Prince of Wales KG KT GCB OM

Honorary President
- Dr James Littlewood OBE MO FRCP FRCPE DCH

Trustees
Chairman
- Richard Hunt

- Professor Andrew Jones
- Michael Winehouse[1]
- Louise King[1]
- Ffyona Dawber
- Professor Rosalind Smyth
- Sean Collins
- Anne Byrne
- Richard Hoey
- David Titmuss
- Michelle Shore[1]
- Joanna Barret[1]

Finance Committee
Chairman
- Sean Collins

- Anne Byrne
- David Sawer (Independent member)
- Michelle Shore[1]
- David Titmuss
- Ed Rushton (Investments Committee)
- Nick Wood (Investments Committee)

People Committee
Chairperson
- Michelle Shore[1]

- Ffyona Dawber
- Louise King
- Michael Winehouse
- Joanna Barrett[1]

Charity Management
- David Ramsden – Chief Executive
- Louise Honeysett FCA —Director of Finance and Resources
- Dr Keith Brownlee – Director of Medical Affairs
- Anne Shinkwin – Director of Fundraising
- Rebecca Cosgriff – Director of Data & Quality Improvement
- Clare Corbett – Director of External Affairs
- Dr Lucy Allen – Director of Research

Company Secretary
- Louise Honeysett FCA —Director of Finance and Resources

Principal and Registered Office
One Aldgate
London
EC3N 1RE

T 020 3795 1555
E enquiries@cysticfibrosis.org.uk
W cysticfibrosis.org.uk

Company Limited by Guarantee
Company registration number: 3880213
Charity registration number:
England & Wales —1079049
Scotland —SC040196

Auditors
Haysmacintyre LLP
10 Queen Street Place, London EC4R 1AG

Bankers
Natwest Plc
15 Bishopsgate London EC2N 3NW

Investment Managers
Cazenove Capital Management
12 Moorgate London EC2R 6DA

[1] Indicates either person with cystic fibrosis, carer or close relative of someone with cystic fibrosis.

>Recruitment, induction and training of Trustees

Trustees consider the relevant skill set required to enable effective oversight and proper governance of the organisation. New Trustees are appointed after a rigorous recruitment process, which includes advertising in the national press and on the basis of recommendation.

Upon appointment to the Board, in order to help facilitate their understanding of the current issues concerning the organisation, each new Trustee is provided with specific tailored information, and opportunities are also provided for the new Trustee to meet with the Chair and Chief Executive, as well as meeting staff working within their own specialist area.

>Senior Leadership Team

The Trustees have delegated day-to-day responsibility for running the Charity to the Chief Executive, David Ramsden, and his Senior Leadership Team (SLT).

The Chief Executive and the SLT report to the Board both formally at the Board meetings and informally (as appropriate) throughout the year, thereby ensuring a regular flow of information to aid decision making.

The remuneration of key management personnel is determined by a recognised job evaluation framework taking into account the skills required and the complexity of individual roles. The process, including the award of annual pay uplift, is overseen by the Remuneration Panel made up of Trustees and chaired by the Chairman of the Trust.

>Public benefit

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. In reviewing our aims, objectives and planning future activities, the Trustees have taken into account the Charity Commission's general guidance on public benefit. The Trustees ensure that activities undertaken are always in line with the charitable objectives and aims of the Cystic Fibrosis Trust.

>Legal structure

Cystic Fibrosis Trust ('the Trust') is a registered charity in England and Wales (charity number 1079049) and in Scotland (charity number SC040196) and is also a company incorporated in 1964 and limited by guarantee (no 3880213). The overall objects and powers of the Trust are set out in the Memorandum and Articles of Association.

The Board of Trustees ('the Board') has full legal responsibility for corporate governance and all operations of the Trust, including determining its strategic direction.

For the purposes of the Companies Act 2006, members of the Board are directors of the company and the Board is comprised of 12 Trustees with a range of skills. Several committees such as the Finance and Audit Committee, Nomination and Development Committee, Strategic Advisory Board, Strategic Implementation Board and Registry Steering Group support the SLT and the Board in reviewing progress throughout the year and making recommendations to the Board for consideration.

Currently active VIA awards

VIA	Lead investigator	Institution	Amount	Title
VIA035	Dr Fred Piehl	Imperial College London	42500	PhD studentship 1 – Air pollution and environmental factors on infection – linking with Registry data
VIA036	Dr Fred Piehl	Imperial College London	42500	PhD studentship 2 – Air pollution and environmental factors on infection – linking with Registry data
VIA038	Dr Andres Floto	Cambridge University	45000	Post-Doctoral Research Associate Machine Learning
VIA039	Ms Laura Birch	Bristol University	25000	Dietary manipulation to improve glycaemic control in young people with cystic fibrosis and altered glucose handling: A feasibility study
VIA044	Professor Jane Davies	Imperial College London	90000	RAPID point-of-care infection detection and antibiotic-resistance TESTing enabled with laser-patterned microfluidic devices (RAPID-TEST)
VIA045	Professor Chris van der Gast	Manchester Metropolitan University	45950.5	Detection of CF lung pathogens using engineered bacteriophages
VIA047	Professor Jane Davies	Imperial College London/Cycle Pharma	30000	Preclinical testing to repurpose of Glatiramer Acetate (GA) for treatment of *Pseudomonas aeruginosa*
VIA051	Dr Tanmay Bharat	Action Medical Research	89917.5	Elucidating the structural role of filamentous bacteriophage in *Pseudomonas aeruginosa* biofilms for disrupting infection in cystic fibrosis airways
VIA052	Professor Jane Davies	Imperial College London	50000	Exploring the utility of novel 'antimicrobial resistance breakers' on strains of Pseudomonas aeruginosa obtained from patients with cystic fibrosis
VIA059	Dr Joseph Jacob	UCL	50000	Quantifying bronchiectasis severity in cystic fibrosis
VIA061	Prof Alan Smyth	University of Nottingham	35369	Gut Imaging for Function and Transit in CF – The GIFT Study
VIA062	Prof Miguel Camara	University of Nottingham	50000	Scholarship for the National Biofilms Innovation Centre (NBIC)
VIA063	Prof Stephen Hart	University College London	51545	Development of in vitro Transcribed mRNA Therapeutics for cystic fibrosis
VIA064	Dr Andrew Jones	University of Manchester	34000	Arthropathy in Adults with cystic fibrosis

Currently active VIA awards

VIA	Lead investigator	Institution	Amount	Title
VIA065	Prof Mark Baird	Diagnostig Ltd	20000	Development of a rapid diagnosis of infection with non-tuberculous mycobacteria in immune-compromised patients
VIA 067	Dr Martin Welch	University of Cambridge	33000	Tackling CF Lung Infection in vitro: Assessing the Global Impact of Antibiotics on the CF Airway Microflora in a Laboratory Bioreactor
VIA 068	Professor Jane Davies	Imperial College London	98594.93	The idealised LCI (i-LCI): Tuning in on the 'silent years' of paediatric CF
VIA 069	Dr Robert Gray	Edinburgh University	47000	Cystic fibrosis lung repair
VIA 070	Dr Laura Nolan	Imperial College London	30000	Understanding interbacterial competition in the cystic fibrosis lung to identify opportunities for intervention
VIA 071	Dr Elise Lammertyn	ECFS	20607	Clinical Trials Network (ECFS-CTN)
VIA 072	Dr Charles Haworth	Papworth Hospital	36000	The use of breath volatile organic compounds (VOCs) in early detection of acute pulmonary exacerbations in cystic fibrosis
VIA 073	Dr Viek Dua	University College London	50000	Modelling and machine learning to aid the design of CF therapy
VIA 076	Dr Luke Allsopp	Imperial College London	20000	In the thick of it: Competitive Microbial Interactions in Biofilms
VIA 077	Prof Chris van der Gast	Manchester Metropolitan University	47000	Organisation and function of the gut microbiota in cystic fibrosis
VIA 078	Prof Chris van der Gast	Manchester Metropolitan University	48000	Non-tuberculosis mycobacteria infection and the wider lung microbiota in cystic fibrosis
VIA 079	Professor Soraya Shirazi-Beechey	University of Liverpool	32600	Restoration of luminal fluidity and microbiota in the CF gut (CFGI-SRC)
VIA 081	Dr Anand Shah	Imperial College London	38000	FREAL – Fungal Resistance Evolution and Acquisition in chronic Lung disease
VIA 082	Dr Elise Lammertyn	ECFS	21304	Clinical Trials Network (ECFS-CTN)
VIA 083	Dr Paul McNally	Our Lady's Children's Hospital	97297	"RECOVER (Real World Clinical Outcomes with Novel Modulator Therapy Combinations in people with CF)"
VIA 084	Christine Dubois	ECFS	20000	ECFS & CFE Post-Doctoral Research Fellowship

Currently active VIA awards

VIA	Lead investigator	Institution	Amount	Title
VIA 085	Professor Jane Davies	Imperial College London	50000	Exploring the utility of quorum sensing inhibitors and biofilm disruptors on growth and virulence behaviours of Pseudomonas aeruginosa obtained from patients with cystic fibrosis
VIA 086	Dr Christabella Ng	University of Nottingham	65000	Gut Imaging for Function & Transit in cystic fibrosis Study 3
VIA 087	Prof Andres Floto	University of Cambridge	3000	Screening natural antibiotics against *Mycobacterium abscessus*
VIA 088	Prof Kevin Southern	University of Liverpool	18931.7	A randomised registry-based open label study to assess change in respiratory function for people with cystic fibrosis (pwCF) with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of muco-active aerosolised therapies (the CF STORM study)
VIA 090	Prof Michael Givskov	University of Copenhagen	26500	'Co-therapy of a novel *Pseudomonas aeruginosa* biofilm disruptor with standard of care antibiotics'
VIA 091	Dr Elise Lammertyn	ECFS	20607	Clinical Trials Network (ECFS-CTN)
VIA 092	Dr James Reihill	Queen's University Belfast	15000	The ubiquitylation system as a therapeutic target in CF
VIA 093	Dr Anand Shah	Imperial College London	15000	Development and validation of the use of videogames and virtual reality to enable autonomous remote monitoring of ototoxicity in high-risk population groups
VIA 094	Prof Pietro Cicuta	University of Cambridge	40000	Technologies for an in-vitro carbon copy of lung disease
VIA 095	Dr Beverly Isherwood	Medicines Discovery Catapult	49500	CF AMR Biorepository

Committed VIA Awards 2020/21

VIA Award Number	Lead Applicant(s)	Host Institution	Title	CF Trust Commitment	Source of External Funds	External Leveraged Funds
087	Prof Andres Floto	University of Cambridge	Screening natural antibiotics against *Mycobacterium abscessus*	£3,000	Demuris, University of Cambridge	£21,350
088	Prof Kevin Southern	University of Liverpool	CF STORM	£18,932	NIHR HTA	£1,492,268
089	Unsuccessful supporting bid – grant cancelled					
090	Prof Michael Givskov	University of Copenhagen	Co-therapy of a novel *Pseudomonas aeruginosa* biofilm disruptor with standard of care antibiotics	£26,500	Innovation Fund Denmark	£180,905
091	n/a	ECFS	Clinical Trials Network (ECFS-CTN)	£21,215	ECFS, CFE	£120,000
092 (pending successful review)	Dr James Reihill	Queen's University Belfast	The ubiquitylation system as a therapeutic target in CF	£15,000	Almac Discovery, UKRI Innovation Scholars Secondment	£300,000
093	Drs Anand Shah & Lorenzo Picinali	Imperial College London	Development and validation of the use of videogames and virtual reality to enable autonomous remote monitoring of ototoxicity in high-risk population groups	£14,374	RNID	£14,374
094 (pending successful review)	Dr Pietro Cicuta	University of Cambridge	Technologies for an in-vitro carbon copy of lung disease	£40,000	EPSRC	£300,000
095	Dr Beverly Isherwood	Medicines Discovery Catapult	Support for the CF Syndicate in AMR biorepository pilot	£49,500	Medicines Discovery Catapult	£49,500
			Total CF Trust Committed	£188,521	**Total Potential Leverage**	£2,478,397

Summer Studentships

Supervisor	Host Institution	Student & Project
Dr Bettina Schock	Queen's University Belfast	Miss Orla Fanthorpe – DREAM regulation of CF airways inflammation
Dr Helen Weavers	University of Bristol	Miss Isobel Davis – Developing a novel in vivo model of cystic fibrosis to explore cross-talk between airway damage, chronic inflammation and infection
Dr Robert Gray	University of Edinburgh	Miss Loren Hunt – Overexpression of CF antigen (Calprotectin) in the airways of people with CF
Prof Adilia Warris	University of Exeter	Mr Henry Phillips – Combatting CF-related Aspergillus infections with a combined treatment of antifungals and CFTR modulators
Dr Malcolm Brodlie	Newcastle University	Mr Robbie Bain – Characterisation of SARS-CoV-2 in people with cystic fibrosis

Cystic Fibrosis Trust

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2021. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 2nd Floor, One Aldgate, London EC3N 1RE.