ACTION FOR PULMONARY FIBROSIS

England & Wales · Charity number 1152399

Details

Other names	PULMONARY FIBROSIS UK
Status	Registered
Legal form	CIO
Registered	2013-06-12
Register	View on the Charity Commission register

Contact

Address	Action for Pulmonary Fibrosis Stuart House East Wing St John's Street Peterborough PE1 5DD
Phone	01733 475642
Email	info@actionpf.org
Website	www.actionpf.org

Activities

Objects: THE RELIEF OF SICKNESS AND THE PRESERVATION OF HEALTH IN PARTICULAR BY:A) ADVANCING EDUCATION AND RAISING AWARENESS OF PULMONARY FIBROSIS, THE SYMPTOMS ASSOCIATED WITH IT AND ENCOURAGING EARLIER DIAGNOSIS OF THE CONDITION.B) PROMOTING RESEARCH INTO THE UNDERSTANDING, DIAGNOSIS, CAUSES AND TREATMENTS OF PULMONARY FIBROSIS THROUGH DONATIONS AND GRANTS TO RELATED RESEARCH PROJECTS IN ORDER THAT THE USEFUL RESULTS OF RESEARCH ARE DISSEMINATED FOR PUBLIC BENEFIT.C) PROVIDING SUPPORT TO PATIENTS AND FAMILIES SUFFERING FROM PULMONARY FIBROSIS IN ANY OTHER WAY THE TRUSTEES SEE FIT.

Activities: APF raises awareness and understanding of pulmonary fibrosis with patients, families, the general public and the medical profession. We advocate for patients nationally to improve treatment and care. We support patients by assisting in setting up patient support groups, hold information events and by personal contact. We offer study sessions for health professionals and offer research grants.

Downloaded from opencharities.uk/ew/1152399

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-06-30	£1,991,368	£1,784,066	£1,012,998	34
2024-06-30	£1,485,083	£2,191,881	£805,696	32
2023-06-30	£1,446,900	£1,204,155	£1,512,494	21
2022-06-30	£974,578	£795,238	£1,269,749	16
2021-06-30	£651,809	£601,408	£1,090,409	11

Trustees

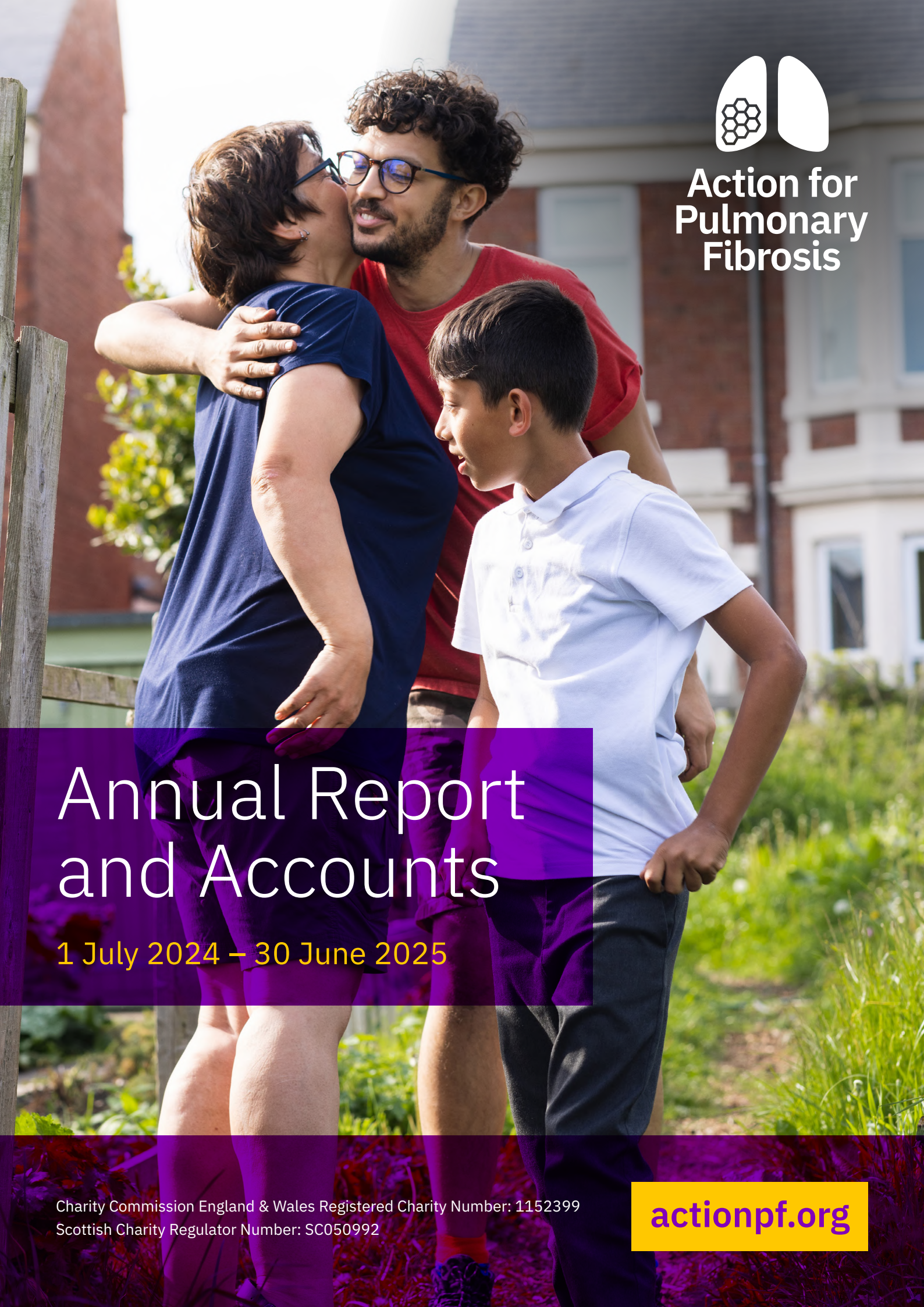
Name	Role	Appointed
Dr Michael James Stubbins	Chair	2022-05-07
Dr HELEN PARFREY BM,BCH,PHD		2013-04-09
Dr Simon Hart		2016-04-09
Emma Goodes		2024-11-09
Matthew Kemp		2024-02-03
Matthew Suddart		2022-05-07
Stephen Morgan-Hyland		2018-01-27
Wendy Anne Dickinson		2020-05-02

Downloaded from opencharities.uk/ew/1152399

ACTION FOR PULMONARY FIBROSIS

England & Wales - Charity number 1152399

Accounts



Action for Pulmonary Fibrosis

Annual Report and Accounts

1 July 2024 – 30 June 2025

Charity Commission England & Wales Registered Charity Number: 1152399
Scottish Charity Regulator Number: SC050992

actionpf.org

Contents

Our Impact in 24-25 3

Welcome 4

Who we are 5

Why APF is needed 6

Our purpose, vision and mission 8

The difference we make 9

Influencing and policy 16

Our fundraising achievements and supporters 21

Looking ahead – future priorities and strategy 24

Structure, governance and management 25

Financial review 24/25 26

Risk management 28

Statement of trustee responsibilities 31

Reference and administrative details 32

Independent auditor's report 33

Statement of financial activities 36

Balance sheet 37

Statement of cash flow 38

Notes to the financial statements 39

150,000+
people are currently living with pulmonary fibrosis

18,000
new cases of pulmonary fibrosis diagnosed each year

5,000+
people die from idiopathic pulmonary fibrosis (IPF) each year

Our Impact in 24-25

£2million
raised to support people and families with PF

Publications

4,587
About APF leaflet sent out to people

3,280
Understanding PF leaflet sent out to people

7,233
pirfenidone and nintedanib leaflets ordered

Digital

1,000+
people registered for our new education webinars

326,000
online views of our information resources

22,500+
website visitors per month

Support

3,000+
support line interactions

87
signposts to regional support groups across the UK

Research

£600,000
committed to advancing new research

19
studies added to our research study finder

160
people in our involvement network, now double the size

Welcome

Every day, people affected by pulmonary fibrosis turn to Action for Pulmonary Fibrosis for clarity, reassurance and support.

Over the past year, we responded to that need with greater reach, depth and consistency than ever before. More people contacted us for help, more families accessed trusted information, and more communities were supported to connect, share experience and feel less alone. At the same time, we strengthened the foundations needed to deliver high-quality support across the UK and to drive progress in research, now and in the years ahead.

Demand for support continued to grow as many people experienced delays in diagnosis, uneven access to specialist care and inconsistent information. In response, we expanded capacity across our services, strengthened professional expertise and widened access to reliable, accessible resources. From one-to-one conversations at moments of uncertainty, to education, peer support, research participation and national advocacy, our work focused on meeting people where they are and responding to what they need most.

Through the generosity of our supporters, APF received nearly £2 million in funding, the largest amount in our history. This enabled us to support people living with pulmonary fibrosis today, while also investing in high-quality research, systems change and partnerships that will improve understanding, treatment and care for future generations.

Above all, we thank the pulmonary fibrosis community. The experiences, insight and determination of people living with PF, and of those who care for them, shape every aspect of our work. Lived experience remains central to how we deliver services, influence policy and design and fund research, ensuring that progress is driven by real needs and real lives.

The sections that follow set out how this support and progress were delivered in practice over the year, from frontline services and peer support, to research, policy influence and national awareness. Together, they reflect both the impact achieved now and the foundations being laid so that no one affected by pulmonary fibrosis is left without information, support or a voice.

Daniel Saxton
Chief Executive Officer

Mike Stubbins
Chair

In memory of Clare Hodkinson

It is with great sadness that we remember **Clare Hodkinson**, a much-valued member of the Action for Pulmonary Fibrosis research team, who passed away during the year while in service.

Clare was living with pulmonary fibrosis and played a key role in establishing APF's grant-giving programme, helping to support researchers across the UK to advance understanding, care and treatment of pulmonary fibrosis. She brought to her work exceptional professionalism, insight and generosity of spirit, and her contribution continues to shape our research activity.

Clare is deeply missed by colleagues, partners and the pulmonary fibrosis community she cared so deeply about.

Who we are

Action for Pulmonary Fibrosis (APF) is the UK's leading charity dedicated to supporting people affected by pulmonary fibrosis (PF), driving research and shaping policy. We are rooted in the lived experiences of patients, families, carers and clinicians and united by a shared belief that **people with pulmonary fibrosis deserve better**.

Our work spans four interconnected areas:

Support	Awareness	Advocacy	Research
Providing trusted, compassionate support for people affected by pulmonary fibrosis.	Raising the profile of pulmonary fibrosis and tackling stigma and misinformation.	Campaigning for faster diagnosis, better care, and health equality.	Funding and influencing science that improves lives and brings hope.

Thanks to the generosity of our donors, funders, volunteers and partners, APF is able to reach more people impacted by pulmonary fibrosis every year, offering hope, support and a platform for raising awareness of this life-limiting condition.

Why APF is needed

Since our founding in 2013, Action for Pulmonary Fibrosis has grown from a grassroots initiative into the UK's leading charity for people affected by pulmonary fibrosis and a world-leading voice in pulmonary fibrosis patient advocacy. Born from the vision of patients and clinicians who knew that people deserved better, APF has become a driving force for support, awareness, research and policy change.

Support

We recognise the significant gap in both awareness and support for those affected by pulmonary fibrosis. Due to limited knowledge about the condition and the lengthy process of diagnosis, many individuals and families face uncertainty and isolation at a time when timely support is crucial. In healthcare settings, the support offered is often minimal, leaving patients and caregivers without the resources and guidance they need.

We offer a compassionate **support line** that offers personalised support for individuals and families navigating the challenges of the condition. Alongside this we offer a wide range of **information resources**, both digitally and in hard copy, to help people better understand the disease, its progression and available treatments. Through our **educational webinars**, we equip patients, caregivers and healthcare professionals with the latest knowledge to manage pulmonary fibrosis effectively. Additionally, we support a growing network of **local support groups**, fostering a sense of community and offer a **befriending service** that connects individuals with others who have lived experience, helping to reduce isolation and provide emotional support.

Awareness

Pulmonary fibrosis is a devastating disease and for far too long, it has been under-recognised, underfunded and misunderstood.

It causes progressive scarring of the lungs, making them stiff and reducing their ability to take in oxygen. This leads to breathlessness, a persistent cough and debilitating fatigue, making even simple tasks like getting dressed or walking short distances exhausting.

In the UK, it is estimated that **over 150,000 people are currently living with pulmonary fibrosis**, around **18,000 new cases are diagnosed**[1] **each year** in England alone and **more than 5,000 people die from the idiopathic pulmonary fibrosis (IPF) alone each year**.[2] Treatment options are limited, and there is no known cure.

Alarmingly, **one in three people in the UK have never heard of pulmonary fibrosis**. Without awareness of the symptoms, many individuals miss the chance to seek help early.

By raising awareness, we can ensure people get the support and medical care they need as soon as possible.

1 Extrapolation based on Gupta R, Morgan AD, George PM, et al Incidence, prevalence and mortality of idiopathic pulmonary fibrosis in England from 2008 to 2018: a cohort study Thorax 2024;79:624-631.

2 BTS ILD Registry Annual Report 2021, available at: https://www.brit-thoracic.org.uk/document-library/quality-improvement/ild-registry/uk-ipf-registry-2021-summary-for-the-general-public/

Why APF is needed

Advocacy

Although pulmonary fibrosis can progress rapidly, access to specialist care and accurate information is still inconsistent across the UK. These delays not only leave people feeling abandoned, but they can also allow the disease to advance, reducing the effectiveness of any future treatment.

Every year, more people turn to APF with advancing symptoms and increasingly complex healthcare needs. As the disease progresses, it places a growing physical, emotional and financial burden on both patients and their loved ones. This underlines the urgent need for earlier diagnosis, intervention and consistent, high-quality support.

Research

Despite its severe impact, pulmonary fibrosis remains drastically underfunded, with respiratory research receiving just 2% of the UK's total medical research funding. This lack of investment is a major barrier to finding new treatments and ultimately, a cure.

We believe no one should have to face pulmonary fibrosis alone. By expanding our support, partnering with healthcare professionals and driving forward research, we aim to end the fear, isolation and the loss of life caused by this disease.

Together, we can shine a light on this overlooked condition and offer real hope to those affected.

Our purpose, vision and mission

Our purpose

We bring people together to drive change so that everyone affected by pulmonary fibrosis can live well for longer.

Our mission

We work together to stop lives being lost to pulmonary fibrosis.

Our vision

A future where everyone with pulmonary fibrosis has access to effective, evidence-based care and ultimately, a cure.

We are a values-led organisation. In everything we do, we strive to be:

Compassionate

Listening to and acting on the voices of people affected by pulmonary fibrosis.

Bold

Challenging inequality and pushing for lasting change.

Expert

Combining lived experience with scientific and clinical evidence to inform everything we do.

Collaborative

Working across sectors and communities to achieve greater impact together.

The difference we make

Action for Pulmonary Fibrosis (APF) are committed to making a meaningful difference for everyone affected by pulmonary fibrosis (PF) by bringing hope and lasting support.

Through our dedicated Support Line, we provide a vital service, offering guidance, resources and emotional support to individuals and their families. In addition to our print and digital resources, we offer learning and empowerment through educational initiatives, including webinars and support groups.

We also advocate for critical research, policy changes and increased awareness to improve care and outcomes for those impacted by the condition. Our fundraising and communication efforts are essential in engaging the community, raising awareness and generating the support needed to drive these initiatives forward.

Over the last year we've reached more people than ever, deepened our impact and strengthened our community so no one has to face pulmonary fibrosis alone.

The difference we make

Support in action

Support Line

Our Support Line offers information, guidance and a listening ear to anyone affected by pulmonary fibrosis. Our trained team, managed by a specialist nurse, provide expert support and reassurance from practical information, emotional support or simply someone to talk to.

We answered over **2,000 calls** to our Support Line, a **31% increase** on the previous year.

Across the year, we saw the total number of contacts to our Support Line rise to **over 3,000**, a **38% increase** on the previous year.

> I am extremely grateful for the support, information and patience given to me. The Support Line offers hope at a time of great difficulty.
>
> **Patient living with pulmonary fibrosis**

> I can't begin to express how grateful my family and I are for the incredible support we've received from APF's specialist nurse on the Support Line. At a time when my father's pulmonary fibrosis diagnosis left us feeling overwhelmed and uncertain, they stepped in with not only vast medical knowledge but also with compassion and kindness. They have been a beacon of clarity and comfort. We are forever grateful.
>
> **Family member of person living with pulmonary fibrosis**

These personal stories emphasise the profound impact that timely support can have, particularly given the complex and fast-progressing nature of pulmonary fibrosis. Delays in receiving clinical care often lead people to contact us when their symptoms have advanced, making our support line an essential resource for many people, including their families and loved ones.

The difference we make

Support in action

Information and education

We understand that navigating a health condition can be overwhelming, which is why providing accessible, reliable and up-to-date information is at the heart of what we do. Through a combination of printed, digital resources and our expanding educational offerings, we strive to ensure that individuals and families have the support they need, when they need it.

We produced a new **Carers Booklet** of which 377 copies were downloaded, and 1,394 printed copies were ordered.

Our **About APF leaflet** was ordered and sent out 4,587 times and **Understanding PF**, 3,280 times.

Our **Recently Diagnosed pack** was sent out to 1,339 people whilst our **Benefits leaflet** was ordered 1,783 times.

Our most popular resources continue to be our leaflets on the antifibrotics treatments: **pirfenidone** and **nintedanib** which were ordered 7,233 inclusively.

Throughout the year our resources are reviewed and updated and we are progressing further information resources on worsening symptoms, difference between ILD and PF, eating well, end of life, grief and bereavement and oxygen.

We are also continuing to reflect our commitment to inclusivity by launching additional **translated resources**:

- The popular Recently Diagnosed pack is now available in Urdu and Welsh
- The treatment information resource Antifibrotics launched in Polish and Welsh

Our **online information resources**, accessible on the APF website, include symptom guides, treatment options and expert advice, have had over **326,000 views**. The most common page visit was 'cough' which had over **30,000 views**.

In October 2024, we launched a new programme of education webinars. Feedback following all the webinars highlighted an average rating of 4.5/5 with over 1,000 people registering to attend throughout the year.

> Very clear and well presented, without overloading the listener but providing a lot of information. I am so pleased I signed up to listen to it.
>
> **Anonymous website feedback form**

> The session was positive and helpful with clear information presented. Thank you.
>
> **Anonymous website feedback form**

The difference we make

Support in action

Support groups and professionals

We are proud to support healthcare professionals (HCPs), patients, carers and bereaved carers to set up and run independent support groups in their local communities. Alongside managing and facilitating our own groups, we work closely with the local support group leaders to help them create welcoming spaces where people can connect and share experiences. These groups form a vital focus of peer-to-peer support, reducing isolation and helping people affected by pulmonary fibrosis feel less alone.

> Thanks for supporting our first patient get together. It was a wonderful surprise to see so many people given the time of year and cold weather. Having Action for Pulmonary Fibrosis there to support was amazing and I hope they can support us at future events.
>
> **Jane Cowell, Respiratory Nurse, Gloucestershire Royal Hospital**

Local support groups

- Increased the number of support groups we signpost to through our website from 66 to 87 across the UK.
- Directly engaged with 2,142 support group members during 114 visits.
- Awarded 11 support group grants, to help new groups set up, with a total value of £4,875.

APF support groups

- These specialist groups were originally set up for support groups leaders, carers and anyone who has had, or is on, the transplant waiting list.
- This year we launched three new specialist groups for bereaved carers (life after caring), a Scottish rural network and a group for working age and younger people
- We facilitated 36 APF support group meetings during the year, attended by 597 people.

Healthcare professionals

- We network with HCPs to help establish new support groups in geographical areas where there are none.
- We have directly engaged with 1,312 HCPs at national conferences, regional respiratory and voluntary sector events.
- We have attended 55 clinic sessions in six UK hospitals, raising awareness of APF with nearly 1,000 people.

> Since I joined the group, I felt there was an understanding and friendship which wrapped me in a blanket of support.
>
> **Member of carers group**

The difference we make

Advancing research and participation

In the past year, our commitment to advancing research has continued to define our work. APF remains dedicated to being the catalyst for groundbreaking research into pulmonary fibrosis.

Direct Funding

In 2023–24, we committed **£600,000** to **advancing new research** through the funding of two, three-year fellowships. These continue to go from strength to strength, with notable progress from Dr Jenny Dickens, a Mike Bray Fellow at the University of Cambridge, who has recently been appointed Principal Investigator at the Cambridge Institute for Medical Research.

> We know that the only way to make a change in pulmonary fibrosis is via bold research. It's only through supporting innovative research like these projects that we can discover insights which will drive improvements for the lives of people with pulmonary fibrosis.
>
> **Bradley Price, Director of Policy, Research and Involvement**

The difference we make

Advancing research and participation

Small Research Grants

Our newly launched Small Research Grant Programme has allocated £20,000 to support UK-based researchers in advancing evidence to improve care and treatment. The programme has funded projects focused on analysing existing data to identify trends and inform policy, capturing patient and caregiver experiences through qualitative research and conducting scoping reviews to highlight knowledge gaps and shape future research priorities.

The two successful projects look at:

- Understanding the pathway to diagnosis and treatment of pulmonary fibrosis in the UK. It will look at the clinical experience of people with pulmonary fibrosis as they move through the healthcare system. This will help to identify where delays are occurring and who is more likely to experience such delays.
- The burden of sleep disordered breathing in progressive pulmonary fibrosis using retrospective data. This will help to identify health disparities across different groups and identify barriers and solutions.

> I feel privileged to be one of two recipients of APF's Small Research Grants. This grant will fund research into patient pathways – a detailed look at patients' journeys through the UK health-care system with a view to identifying barriers to earlier diagnosis. I am looking forward to beginning my research journey with support from APF and I hope that longer term, my work will help deliver diagnostic and treatment services for pulmonary fibrosis that are on a par with those for we currently have for cancer.
>
> **Dr Ann Morgan, Small Research Grant recipient**

The difference we make

Advancing research and participation

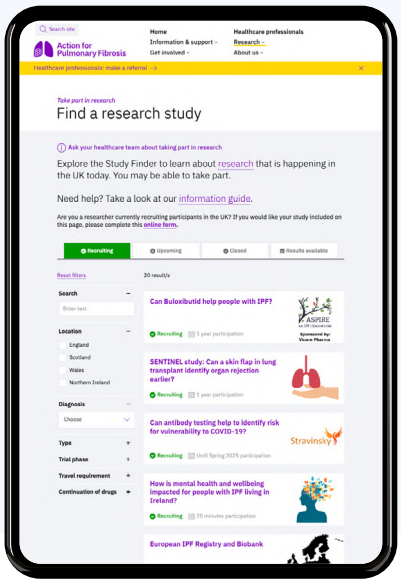
Early-career support

We funded Conference Awards to **seven early-career researchers**, enabling them to present cutting edge pulmonary fibrosis research at national and international conferences.

Alongside this we collaborated with the British Association of Lung Research (BALR) to fund a further two summer internships. Two students from University College London and the University of Birmingham will undertake an 8-week summer research project alongside senior interstitial lung disease researchers. One project looks at the behaviour of immune cells in idiopathic pulmonary fibrosis (IPF), whilst the other is using a 3D lung model to investigate the effects of a protein blocker on IPF.

Study Finder

After the successful launch of our **Study Finde**r in 2024, we have added a further 19 studies in accessible language, to help people who may want to take part in research, to understand what is currently happening and how they could take part. This tool had over 5,000 views, demonstrating the interest in taking part in research.



Involvement Network

The Involvement Network is a group of people who have lived experience of pulmonary fibrosis. We work closely with them to gain valuable insights and feedback on all aspects of our work and ensure that their challenges and perspectives are considered and integrated into what we do. This collaboration helps us create more compassionate and inclusive services, making sure that those directly impacted by pulmonary fibrosis are at the heart of what we do. We have:

- Doubled the number of people who are part of our involvement network to 160.
- Worked to recruit a diverse audience to ensure involvement activities accurately represent the breadth of the pulmonary fibrosis community.
- Provided Patient and Public Involvement (PPI) support to the CHORUS trial, a £2 million study funded by the National Institute for Health Research (NIHR) which looks at whether prednisolone helps slow down lung damage in people recently diagnosed with fibrotic hypersensitivity pneumonitis (a form of PF).
- Driven engagement with academia and industry to ensure patient views and preferences are represented across all types of research:
  - Supported PPI on 15 external projects
  - Ensured our Mike Bray Fellows have strong involvement from the patient community across their research.

Influencing and policy

Our Policy and Public Affairs team has continued to drive change that will transform the lives of people with pulmonary fibrosis. We have strengthened our advocacy program, influenced national policy discussions and ensured a wider awareness of pulmonary fibrosis in government and the NHS. Together, we are reshaping the future of pulmonary fibrosis care and creating lasting change.

OneVoiceILD and the National Integrated Care Pathway

In April 2024, APF spearheaded the launch of the OneVoiceILD national integrated care pathway, a blueprint to end the postcode lottery for pulmonary fibrosis diagnosis, care, treatment and support. This year has seen several pilot projects underway in England, looking to understand the different ways in which the pathway can be used and how they can overcome the challenges associated with implementation.

Devolved nations – developing pathways

- Agreed a consensus pathway for Northern Ireland, looking to standardise care and set a clear timed pathway for suspected ILD diagnosis and treatment.
- Worked with NHS Wales Performance and Improvement to design a new timed pathway for Wales.
- Worked with the Centre for Sustainable Delivery to design a new pathway for Scotland.

Supporting change

- Developed a business case tool kit: a practical guide to writing an impactful business case to boost local ILD services. This aims to address some of the challenges relating to waiting times and unequal access to services, in line with our goal of bringing ILD care closer to home.
- Delivered a presentation at the British Thoracic Society Winter Meeting, showcasing how the patient voice shapes clinical pathways and drives systems change.

Lived Experience

- The OneVoiceILD Lived Experience Panel, made up of patients and carers, offers invaluable firsthand insights to ensure our NHS transformation and pathway development align with real-world needs.

Influencing and policy

Parliamentary engagement

Through stronger engagement with parliamentarians, we're amplifying the voice of the pulmonary fibrosis community in key policy conversations. This growing momentum is vital to our mission of securing fair, compassionate and effective care for everyone affected by pulmonary fibrosis across the UK.

- We held an event focused on raising awareness of the links between social deprivation, distance from respiratory clinic and the outcomes in pulmonary fibrosis.
- Supporters were encouraged to email their MP and ask them to attend our parliamentary event.
- Over 1,100 emails were sent and over 40 MPs attended the event (almost 100% increase on the previous year).
- Arranged an Early Day Motion (EDM) in the House of Commons which was signed by 40 MPs. The EDM: "welcomes the ILD Care Pathway developed by OneVoiceILD, supported by Action for Pulmonary Fibrosis".

Co-hosted a Roundtable in the Scottish Parliament on Interstitial Lung Disease. Held to both raise awareness of the impact of the various conditions that sit under the umbrella of Interstitial Lung Disease (ILD) and to share the experiences and hopes of patients and clinicians for better ILD diagnosis and care in Scotland.

Understanding the reality of pulmonary fibrosis

Following on from the success of the 'I Wish It Was Cancer' report, this year saw the development of the 'State of the Nation' survey. The survey is aiming to create a quantitative dataset from people affected by pulmonary fibrosis which can be used to shape APF's work and provide robust information to help influence healthcare systems. We specifically want to understand the issues faced as a result of existing pathways and where the key areas of improvement are.

To help inform the questions of the survey and understand what is causing issues for people living with pulmonary fibrosis, we held 6 sessions, with each concentrating on a different group, such as people with different types of pulmonary fibrosis and carers.

Driving the policy conversation

This year we responded to national consultations on the NHS 10 Year Plan and the Darzi Review, highlighting key priorities for change. We also represented the views of people with pulmonary fibrosis in the NICE appraisal of a treatment for pulmonary hypertension associated with ILD (PH-ILD).

Shining a light on pulmonary fibrosis

Raising awareness of pulmonary fibrosis is at the heart of our mission. Despite its profound impact, many people have never heard of the condition, making education, visibility and public engagement essential. Through media coverage, powerful campaigns and clear, accessible resources, we strive to educate the public, spark important conversations and ultimately encourage earlier diagnoses and improved outcomes. By sharing personal stories and showcasing the latest research, we work to ensure that pulmonary fibrosis is no longer an unseen condition.

Growing reach

- **22,500+** average **website visitors** per month, with the majority of users coming organically from a search engine, strongly followed by a direct search of APF.
- **6,800+ e-newsletter subscribers** showing a 32% increase on last year and with an average open rate of over 47%.
- **23,500+ social media followers** with an increase of 12%, an additional 2,555 followers in the year.

We continue to see the number of subscribers to our **Insider magazine** grow. The publication is distributed twice a year in print and digital format:

- Spring/Summer 2024 ..... 4,319 subscribers
- Autumn/Winter 2024 ..... 4,671 subscribers
- Spring/Summer 2025 ..... 5,462 subscribers

When asked the following question:
'How likely are you to recommend Insider to other people with pulmonary fibrosis', feedback from 17 reviews were submitted

- 15/17 'very likely'
- 1/17 'unsure'
- 1/17 'very unlikely'.

Influencing and policy

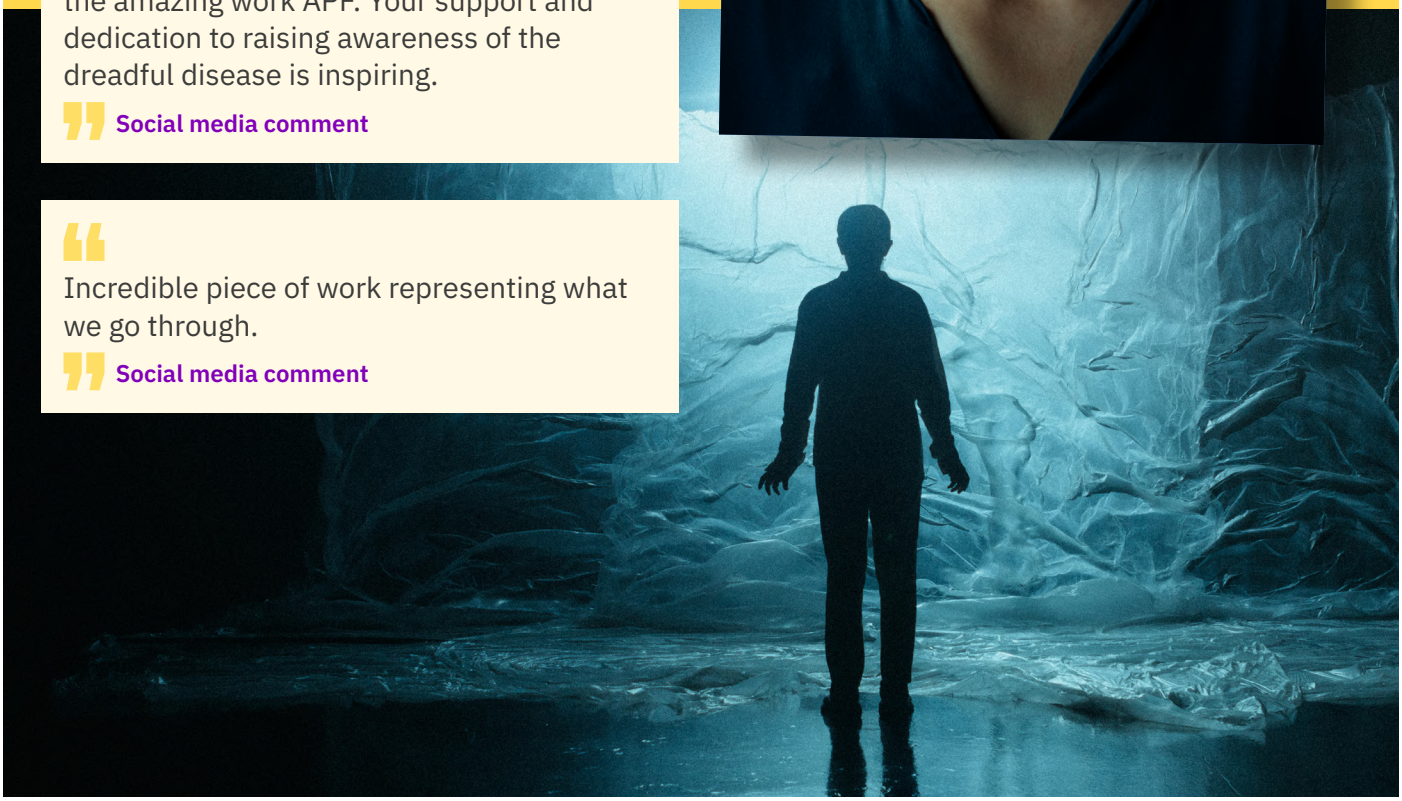
PF Awareness Month

Every September APF launches a campaign to coincide with Pulmonary Fibrosis Awareness Month, a global opportunity to increase visibility, educate, inspire action and drive positive change. Awareness month brings people together to unite around a common goal, offers a platform to get involved with fundraising and ultimately, raise awareness of the severity, symptoms and impact of living with pulmonary fibrosis.

- PF Month 2024 delivered a hard-hitting video, 'Breathe', designed to highlight the symptom of breathlessness to the wider audience, which was met with an overwhelmingly positive response.
- A mix of organic and paid-for social media posts reached over 103,000 people with hundreds of comments of support.
- 101 media articles mentioned APF with an estimated reach of 196 million. This was boosted by an APF presence across multiple BBC outlets, feeding into local media.

> "Really impactful campaign – keep up the amazing work APF. Your support and dedication to raising awareness of the dreadful disease is inspiring."
>
> **Social media comment**

> "Incredible piece of work representing what we go through."
>
> **Social media comment**



Influencing and policy

Case study

Fiona was diagnosed with pulmonary fibrosis at 37. Since then, she's become a mum to her son, Harry and shared her story as part of our Pulmonary Fibrosis Month 2024 campaign with an exclusive piece with the Press Association. Her story reached a national and regional audience in December 2024, resulting in a total reach of approximately 1.6 billion. Significant coverage appeared in publications such as The Mirror, Surrey Live and Manchester Evening News.

In June, Fiona was a guest on The Apple & The Tree podcast with her dad, Steven, where they talked openly about the impact of pulmonary fibrosis on their family. Fiona also reflected on how much our Support Line helped her during a difficult time

This high-profile case study highlights the power of personal stories in raising awareness and driving media engagement.

Our fundraising achievements and supporters

2024-2025 has been an exceptional year for APF, and we owe this success to the **unwavering support of our incredible community** and the **dedicated fundraisers** who have gone above and beyond in their efforts. Thanks to their hard work and generosity, we have raised nearly **£2 million**, an astonishing achievement.

These efforts allow us to continue providing vital services and care, while also driving forward research that holds the potential for ground-breaking advancements in treatment. With every donation, every event and every individual who gets involved, we are one step closer to a world where no one has to face pulmonary fibrosis alone.

Legacies and in memory giving

We are always so touched by anyone who chooses to support us through donations following funerals or as a way of remembering loved ones. 100's of dedication pages were set up over the year and over £385,000 was raised.

Alongside this we have received nearly £450,000 from gifts in Wills, including a significant gift of over £250,000 from one legator. We are forever grateful that people choose to remember APF in this way. A legacy gift is an incredibly meaningful contribution that has a lasting impact and provides us with the ability to plan for the future with confidence.

> I hope the funds raised go wherever they're needed most to support patients and carers. The APF community has been a lifeline for me.
>
> **Graham Daubney, community fundraiser**

Challenge and community events

Challenge and community events continued to be very popular throughout the year with some exceptional fundraisers going above and beyond. So many people got involved in so many activities, from the Three Peaks to the Great Manchester Run, from the Glasgow Kiltwalk to the London Marathon.

We also saw incredible fundraising in peoples communities, from golf days to music concerts, from rugby tours to support groups activities. There are always too many supporters to mention, but we thank each and every one that helped to raise over £480,000, an incredible contribution.

> It has been a labour of love for my dad, and a huge comfort to know that Action for Pulmonary Fibrosis is making such a powerful difference to sufferers and their families. It's been an honour to collaborate with Andy.
>
> **Sarah Rolph, community fundraiser and professional singer who organised a concert called 'Breathe'**

Our fundraising achievements and supporters

Case study

Sian and her dad, Colin, organised a Yorkshire Three Peaks trek in memory of their mother and wife, Emma and raised an incredible £16,000 for APF. Sian shares her story:

"After my mum passed away, I decided to take on The Three Peak Challenge, a goal I discussed with her when she was with us. Since we shared our plans, many have generously offered to participate in raising both funds and awareness for Action for Pulmonary Fibrosis.

Mum was diagnosed with Pulmonary Fibrosis in 2022 and by July of that year, she was placed on the double lung transplant list.

She fought valiantly during her battle with this illness, never losing her sense of humour, love for others, and appreciation for life.

Unfortunately, she wasn't strong enough to continue and passed away on 21 March 2025.

Those fortunate enough to know Mum recognise that she was the most special lady in the world; words can hardly convey the profound impact she had on so many of us. APF holds immense significance for us, and we wish to express our gratitude for the support we received throughout Mum's journey."

Our fundraising achievements and supporters

Transformative grant funding

We extend our deepest gratitude to all our grant funders, whose unwavering support has been instrumental in helping us grow. Their generous contributions have provided the essential resources needed to expand our reach, enhance our services and continue making a meaningful difference to the people we support. Special thanks to: Christos Lazari Foundation, Miss Hansons Charitable Trust, The Hospital Saturday Fund, The National Lottery Community Fund and The Noble Charitable Trust.

Partnerships in action

Through strategic collaborations with corporate partners and the pharmaceutical industry, we have significantly boosted our fundraising efforts this year. These partnerships have not only provided essential financial support but also our ability to deliver on key projects and initiatives. By aligning our mission with the goals of these partners, it strengthens our capacity to make a meaningful impact. Together, we've made great strides in advancing our cause, and we are deeply grateful for the continued commitment and generosity. Our sincere thanks go to: AIS, Avalyn, Boehringer Ingelheim, Bristol Myers Squibb, Ciconi, Endeavor, Equilaw, Irwin Mitchell, Kennett Leasing and Trevi Therapeutics.

Ambitious plans for the future

We have set bold and ambitious goals for the next five years, aiming to significantly increase our income to expand both our support services and research portfolio. Our vision is clear: A future where everyone with pulmonary fibrosis has access to effective, evidence-based care and ultimately, a cure. This expansion will allow us to provide more comprehensive support to patients and their families, fund groundbreaking research, and advance innovative treatments.

However, achieving these aspirations, relies on the continued generosity and commitment of our donors, fundraisers, corporate partners and trusts and foundations. Every contribution, no matter how big or small, plays a vital role in helping us achieve our mission and brings us one step closer to a world where no one has to navigate pulmonary fibrosis alone.

Your support not only transforms lives today but also creates a brighter future for all people affected by pulmonary fibrosis. We are deeply grateful for your unwavering commitment to our cause. Thank you for standing with us every step of the way, together we are stronger.

Looking ahead

The next five years represent a pivotal window for progress on pulmonary fibrosis care and research. Despite its severity, pulmonary fibrosis remains under-recognised and underfunded. The number of people affected is growing, NHS services are overstretched and research breakthroughs are urgently needed.

Our new 2025–2030 strategy is built around three bold priorities, each designed to drive meaningful change for people affected by pulmonary fibrosis.

These priorities respond to the opportunities we see and the urgent challenges we must confront. Each strategic priority sets out a major focus area where APF will concentrate energy, investment and leadership over the next five years.

Our three strategic priorities

For Every Breath

Expanding trusted support, information and services so that no one faces pulmonary fibrosis alone.

For Every Journey

Championing faster diagnosis, fairer care and a world-leading model of pulmonary fibrosis healthcare.

For Every Future

Investing in bold, inclusive research and discovery that improves lives now and brings us closer to a cure.

These priorities reflect who we are, a charity rooted in compassion, driven by lived experience and determined to create lasting change.

Every project and partnership we pursue through this strategy is aligned to these priorities.

Together, they form the engine of progress that will define the next chapter for Action for Pulmonary Fibrosis and, most importantly, for the thousands of families we serve.

Structure, governance and management

Governance overview

Action for Pulmonary Fibrosis (APF) was established as a Charitable Incorporated Organisation (CIO) in June 2013, registered with the Charity Commission for England and Wales. Its governing document, the Constitution, was approved by the trustees on 28 May 2013. On 25 May 2021, Action for Pulmonary Fibrosis also achieved registration with the Office of the Scottish Charity Regulator (OSCR).

Almost all trustees bring direct experience of pulmonary fibrosis, whether through personal or family connections or as medical professionals, ensuring the charity's work is informed by lived experiences and healthcare expertise.

Board of Trustees

The Board of Trustees meets quarterly to oversee the charity's progress, establish policy and strategy and ensure compliance with charity regulations. At the start of each financial year, the trustees approve an annual plan and budget. During each meeting, progress reports are reviewed, significant risks are assessed and the effectiveness of internal controls is monitored.

The Board also engages professional advisers as needed to provide legal and financial guidance.

Recruitment and appointment of trustees

To respond to evolving challenges and ensure a broad mix of expertise, the Board regularly reviews its structure and actively recruits new trustees when needed. Many of our trustees have a personal connection to pulmonary fibrosis and bring valuable skills and experience to help the charity thrive.

Trustee vacancies are publicly advertised and candidates take part in a structured selection process. This includes submitting a formal application and attending an interview with current trustees. Shortlisted applicants are then invited to observe a Board meeting before a final decision is made by the trustees.

Once appointed, new trustees complete an induction programme to help them understand the charity's mission, operations and their governance responsibilities as part of the Board.

Organisational structure

The Chief Executive Officer (CEO) works in close partnership with the senior leadership team to steer the charity, ensuring its work remains aligned with its strategic objectives. Together, they provide strong, effective leadership and foster a culture of collaboration, innovation and shared purpose across the organisation.

The foundation of APF's governance is the Finance and Risk Committee, which plays a crucial role in overseeing the charity's financial health and operational integrity. The committee ensures that budgets are well-managed, risks are effectively mitigated and policies are regularly reviewed to maintain high standards. It is also responsible for overseeing staff remuneration, ensuring fairness and alignment with the charity's values.

The committee comprises the CEO, Director of Finance and Operations, Director of Fundraising and Communications, Treasurer, and at least two trustees. It meets quarterly, ahead of Board meetings, to support informed, transparent and accountable decision-making.

In addition to this, the Board establishes sub-committees as needed to focus on specific initiatives or areas of work. These flexible working groups allow APF to respond swiftly and effectively to emerging priorities, helping the organisation remain agile and forward-thinking.

The Board of Trustees has approved a new staff pay framework policy as of December 2025. The framework adopts the NCVO job-level framework for role evaluation and pay benchmarking, with slight amendments to fit the needs of APF. The framework embeds compliance with the living wage foundation to ensure equality and transparency standards and supports recruitment, retention and motivation of staff through equitable and sustainable remuneration.

APF is proud to be registered with the Fundraising Regulator, demonstrating its commitment to ethical and transparent fundraising. This accreditation reinforces the charity's dedication to building trust with supporters and delivering meaningful, high-quality support to those affected by pulmonary fibrosis. APF did not receive any fundraising complaints during 2024-2025.

Related Party Transactions

Stephen Jones and Helen Parfrey, trustees of Action for Pulmonary Fibrosis (APF) and also board members of the European Idiopathic Pulmonary Fibrosis and related disorders Federation (EU-IPFF). During the year, APF received income of £3,989 from EU-IPFF for speaker fees (2023/24: £2,628 for speaker fees). No amounts were outstanding to APF at the year end.

APF received an aggregate value of £400 from one Trustee, with no conditions attached.

The trustees are not aware of any other related party transactions during the period.

Public benefit statement

The charity trustees have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission, in exercising their powers or duties. Charity activities and the support provided are available to all those affected by pulmonary fibrosis.

Financial review 24/25

We are pleased to report that Action for Pulmonary Fibrosis (APF) has increased its financial position, with a surplus of **£207,302** at the end of the financial year (2023/24: Deficit £706,798). Income for the year was **£1,991,368** (2023/24: £1,485,083). This increase was driven by an inspiring rise in legacy income, highlighted by an incredibly generous gift from a legator. We also saw strong growth across community and challenge events, as well as significant income raised through in-memory and individual giving, reflecting the wonderful commitment and support of our donors.

A restricted funds balance of **£114,008** reflects where donors have formally specified that their gifts are used for a particular purpose. This value includes grants for specific projects and appeals or campaign income where a project has been pre-defined.

The total value of unrestricted funds amounts to: **£898,990** which are funds that have been gifted to APF with no formal restriction, of which:

£359,430 have been designated out of the unrestricted funds by the Board of Trustees for specific purposes. These funds will be used in accordance with the fund descriptions and in line with donor wishes.

A free reserve balance of **£539,560** of unrestricted, undesignated funds that are not currently committed to a project and can be utilised as the Board of Trustees sees fit.

Our total expenditure for the year was **£1,784,066** (2023/24: £2,191,881). The previous year's figure included the award of £599,671 for two new three-year research fellowships.

Further details are provided in the attached accounts, but our overall financial health remains favourable. We look forward to building on this strong foundation in the coming year as we work toward our mission of supporting everyone affected by pulmonary fibrosis (PF).

Financial review 24/25

Statement on reserves

A new reserve policy was approved by the Board of Trustees in February 2025, which defines the charity's approach to holding reserves.

The Board of Trustees considers it prudent to maintain a level of free reserves that provides the charity with sufficient working capital to support its core fundraising, support and governance activities for a period of 3 months (£350,000), plus an additional £150,000 to meet any unexpected call on funds or opportunities that may present themselves at short notice.

Having carefully considered the best interests of the charity and its beneficiaries, the Board of Trustees believes it appropriate to aim to hold a total of £500,000 free reserves. This approach enables the charity to respond effectively to both new opportunities and unforeseen challenges, allowing time for a measured response and the creation of appropriate plans, rather than relying on emergency measures.

If free reserves drop below this threshold, the Board of Trustees will determine whether the shortfall is due to temporary circumstances, or if immediate corrective action is required.

As of 31 June 2025, the charity held free reserves totalling **£539,560** (2023/24: £328,257), exceeding the set reserve policy position.

APF is committed to advancing research and provides conference awards, small research grants and fellowship funding (every three years) through its grant giving function. In order to ensure that there is not a shortfall in the funds available as the grant giving needs arise, APF has designated some of its income to a total balance at year end of £359,430 towards research projects to provide financial stability for the future commitments.

APF may designate its income for the projects and programs that have been outlined in the new five-year strategy and as part of the financial planning for the future to deliver its objectives.

Risk management

The Board of Trustees have overall responsibility for ensuring there are effective risk management and internal control systems in place to manage the operational and strategic risks which APF may face. APF maintains a comprehensive risk register with regular review by the Senior Leadership Team, Finance and Risk Committee and the Board of Trustees that aims to reduce risks to their lowest possible level. Each risk has an assigned risk 'owner' from the Senior Leadership Team who is responsible for managing local risks alongside a 'handler' to work proactively to reduce the risk in between reviews. Emerging risks are assessed and added to the risk register as the occur and if necessary, a task and finish group assembled to proactively monitor and respond to an incident as required.

These risks have been grouped into principal categories for the purpose of the annual report:

1. Financial Resilience
2. Governance, Reporting & Board Decision-Making
3. Achieving Objectives
4. Regulatory Compliance
5. People
6. Data, Security, Systems & Internal Controls
7. Stakeholder Influence & Partnerships

These principal risk areas are not an indication of likelihood or specific concern but highlight the areas that the board have chosen to monitor to ensure that the charity is managed effectively.

The table on the following three pages highlights those principal risk areas and a summary of the mitigations in place:

Risk management

Principal risk area
Financial Resilience
Summary of risks
Economic uncertainty, high inflation, and a competitive fundraising environment may affect APF's income and financial stability. Dependence on specific income streams, as well as changes in government policy, tax regimes or funder priorities, could reduce funding and limit the charity's ability to deliver its strategy. Competition from other pulmonary fibrosis charities may also reduce profile and income, thereby impacting services for beneficiaries.
Mitigation
Financial performance is closely monitored by SLT and reviewed by the Finance & Risk Committee. Budgeting, forecasting and reporting have been strengthened, improving visibility of restricted income, dependencies and financial risk. Reserves are monitored against policy targets, and business cases are required for all new projects. APF continues to diversify income across individual giving, corporate partners, trusts and pharma to reduce dependency. A structured supporter journey, stewardship of major donors, and planned engagement with pharma partners support long-term growth and resilience.

Principal risk area
Governance, Reporting & Board Decision-Making
Summary of risks
Gaps in trustee skills, commitment, representation or diversity could weaken governance, strategic oversight and decision-making. Unmanaged conflicts of interest or insufficient strategic planning may undermine independence, credibility and organisational direction. Key strategic documents falling out of date or not being updated in line with legislation.
Mitigation
Mitigations include regular trustee skills analysis to inform recruitment and development. A skills audit for the Trustees will take place in 25/26 and as Trustee positions become available the charity will proactively recruit those that represent our community. Conflicts of interest are managed through declarations, registers, standing agenda items, and due diligence. This policy will be strengthened in 25/26. A document control system will be implemented to track all policies. All approved policies will be uploaded to the system for monitoring and compliance purposes. Accountability is demonstrated through the document owner who is responsible for updating necessary documents when there are legislative or other relevant changes.

Risk management

Principal risk area
Achieving Objectives
Summary of risks
Without clear strategic prioritisation and decision-making processes, the charity may struggle to deliver its objectives effectively.
Mitigation
Strategic delivery is supported through the approved strategy, SLT operational plans. In 2025/6 the charity will introduce clearer objectives and policies to support consistent decision making.

Principal risk area
Regulatory Compliance
Summary of risks
Failure to comply with fundraising regulations, donor restrictions, or statutory reporting requirements could lead to regulatory action, reputational damage and loss of funding.
Mitigation
APF adheres to the Fundraising Regulator Code, maintains ethical fundraising exclusions, and conducts enhanced due diligence for partners. The charity is preparing for the change in code (Nov 2025) Donor restrictions are supported by an improved income-coding structure, strengthened gift processing and month-end checks.

Principal risk area
People
Summary of risks
APF's ability to deliver its strategy relies on attracting, developing and retaining skilled and motivated staff and volunteers. Poor retention, lack of support or the emotional impact of the work could reduce capacity, impact wellbeing and disrupt service continuity. The nature of our work can take an emotional and physical toll, risks include our ability to effectively protect and support our staff and volunteers.
Mitigation
The Staff Handbook and HR processes have been updated, including structured reviews, flexible working, safeguarding guidance and learning & development pathways. Vero supports compliant recruitment, DBS checks, performance management and HR advice. Staff morale is monitored through an annual staff survey and regular communication updates help keep staff, volunteers informed. Retention is supported through training, supervision, pay review, exit interviews and quarterly reporting to the FRC. Health & Safety, safeguarding and lone-working risks are managed through policies, risk assessments, mandatory training, check-ins and safe travel arrangements.

Risk management

Principal risk area
Data, Security, Systems & Internal Controls
Summary of risks
Failure to protect and effectively use data could reduce APF's reach and impact, limit income generation and cause significant reputational harm should data be lost or misused. Weak internal controls and segregation of duties could lead to error and fraud risks.
Mitigation
Information governance has been strengthened through controlled SharePoint access, retention planning, and Multi Factor Authentication. Regulatory and data compliance is supported through updated Data Protection Policies, nominated Data Protection Officer, mandatory training and cyber insurance. External audits, policy updates and keeping abreast of regulatory and legislative updates help to protect the integrity and security of our data. Fraud and error risks are mitigated through approval hierarchies, restricted banking access, supplier verification and strengthened banking arrangements.

Principal risk area
Stakeholder Influence & Partnerships
Summary of risks
Adverse events or misaligned partnerships may damage APF's reputation and affect income or our ability to achieve our charitable objectives Risks include deterioration in relationships with major funders, leading to reduced funding, reduced support, and fewer resources available to deliver charitable activities and services. Research funding decisions that are not aligned with AMRC best practice and APF strategy.
Mitigation
External risks are managed through comprehensive risk management reporting. Reputation is protected through pro-active communications and stakeholder engagement, brand guidelines, ABPI awareness, and transparency around pharma relationships and lobbying. Research funding is controlled through budgeting, peer review and panel processes aligned to AMRC guidance and APF priorities.

Statement of trustee responsibilities

For the year ended 30 June 2025

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with 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).

The law applicable to charities in England and Wales, and in Scotland, requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and the incoming resources and application of resources, including the net income or expenditure, of the charity for the year.

In preparing those financial statements the trustees are required to:

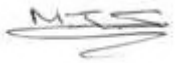
- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and accounting estimates that are reasonable and prudent
- state whether applicable accounting standards and statements of recommended practice have been 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 charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts(Scotland) Regulations 2006 (as amended) and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and the integrity of the corporate and financial information included in the charity's website. Legislation in the United Kingdom governing the preparation of the financial statements may differ from legislation in other jurisdictions. The trustees are members of the charity, but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Approved by the trustees on 9 April 2026 and signed on their behalf by

Mike Stubbins – Chair



Reference and administrative details

2024-25 Trustees	Notes
Dr. Mike Stubbins	Chair of the Board of Trustees
Wendy Dickinson	
Dr. Rebecca Lang	Stepped down on 13th September 2025
Stephen Morgan-Hyland	
Stephen Jones	Stepped down on 13th September 2025
Dr. Simon Hart	
Dr. Helen Parfrey	
Matt Suddart	
Matthew Kemp	
Emma Goodes	Joined APF on 9th November 2024

We extend our warmest thanks to all our Trustees for their service and dedication to Action for Pulmonary Fibrosis (APF). For those that have stepped down, we wish them every success for the future and remain deeply grateful for their contribution and guidance.

The Trustees volunteer their skills, experience and time to provide the leadership and guidance to further APF's mission. Their unwavering commitment and contributions have helped shape APF's work and will continue to improve the lives of people affected by pulmonary fibrosis (PF).

In keeping with the charity's ethos of being patient led, at least 70% of our trustees have been personally affected by pulmonary fibrosis either as a patient or family member. Our trustees also include medical professionals who are leaders in pulmonary fibrosis care and research.

Chief Executive Officer:
Daniel Saxton

Registered Charity Number:
1152399 (England & Wales)
SC050992 (Scotland)

Registered Office:
Stuart House, East Wing, St John's Street,
Peterborough, PE1 5DD

Bankers:
CAF Bank Limited, 25 Kings Hill Avenue,
Kings Hill, West Malling, Kent, ME19 4JQ

Auditors:
Godfrey Wilson Limited
(Chartered accountants and statutory auditors)
5th Floor Mariner House, 62 Prince Street,
Bristol, BS1 4QD

Lawyers:
Bevan Brittan
45 Church Street, Birmingham, B3 2RT

Independent auditor's report

To the trustees of Action for Pulmonary Fibrosis

Opinion

We have audited the financial statements of Action for Pulmonary Fibrosis (the 'charity') for the year ended 30 June 2025 which comprise the statement of financial activities, balance sheet, statement of cash flows and the related 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 charity's affairs as at 30 June 2025 and of its incoming resources and application of resources, 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 Charities Act 2011 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 charity 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 the provisions available for small entities, in the circumstances set out in note 10 to the financial statements, 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 charity'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 other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and 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.

Independent auditor's report

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- the information given in the trustees' report is inconsistent in any material respect with the financial statements; or
- sufficient and proper accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees 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 they 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 charity'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 charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

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 procedures we carried out and the extent to which they are capable of detecting irregularities, including fraud, are detailed below:

(1) We obtained an understanding of the legal and regulatory framework that the charity operates in, and assessed the risk of non-compliance with applicable laws and regulations. Throughout the audit, we remained alert to possible indications of non-compliance.

(2) We reviewed the charity's policies and procedures in relation to:
   - Identifying, evaluating and complying with laws and regulations, and whether they were aware of any instances of non-compliance;
   - Detecting and responding to the risk of fraud, and whether they were aware of any actual, suspected or alleged fraud; and
   - Designing and implementing internal controls to mitigate the risk of non-compliance with laws and regulations, including fraud.

(3) We inspected the minutes of trustee meetings.

Independent auditor's report

(4) We enquired about any non-routine communication with regulators and reviewed any reports made to them.

(5) We reviewed the financial statement disclosures and assessed their compliance with applicable laws and regulations.

(6) We performed analytical procedures to identify any unusual or unexpected transactions or balances that may indicate a risk of material fraud or error.

(7) We assessed the risk of fraud through management override of controls and carried out procedures to address this risk. Our procedures included:

- Testing the appropriateness of journal entries;
- Assessing judgements and accounting estimates for potential bias;
- Reviewing related party transactions; and
- Testing transactions that are unusual or outside the normal course of business.

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. Irregularities that arise due to fraud can be even 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 charity ' s trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008 and Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charity ' s trustees 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 charity and the charity ' s trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Godfrey Wilson Limited

Date: 13 April 2026

GODFREY WILSON LIMITED
Chartered accountants and statutory auditors
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD

Godfrey Wilson Limited is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

Statement of financial activities

For the year ended 30 June 2025

	Note	Restricted £	Unrestricted £	**2025 Total £**	2024 Total £
Income from:					
Donations and legacies	3	25,419	1,602,916	**1,628,335**	1,077,952
Charitable activities	4	262,703	83,080	**345,783**	381,138
Investments		-	17,130	**17,130**	25,043
Other trading income	5	-	120	**120**	950
Total income		288,122	1,703,246	**1,991,368**	1,485,083
Expenditure on:					
Raising funds		-	431,621	**431,621**	388,202
Charitable activities		292,123	1,060,322	**1,352,445**	1,803,679
Total expenditure	7	292,123	1,491,943	**1,784,066**	2,191,881
Net (expenditure) / income		(4,001)	211,303	**207,302**	(706,798)
Transfers between funds	19	(8,500)	8,500	**-**	-
Net movement in funds	10	(12,501)	219,803	**207,302**	(706,798)
Reconciliation of funds:					
Total funds brought forward		126,509	679,187	**805,696**	1,512,494
Total funds carried forward		114,008	898,990	**1,012,998**	805,696

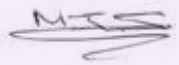
All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 19 to the accounts.

Balance sheet

As at 30 June 2025

	Note	£	2025 £	2024 £
Fixed assets				
Tangible assets	13		**7,984**	10,448
Current assets				
Debtors	14	**105,459**		97,741
Current asset investments		**928,420**		1,251,369
Cash at bank and in hand		**615,387**		122,075
		1,649,266		1,471,185
Liabilities				
Creditors: amounts falling due within 1 year	15	**(288,795)**		(260,139)
Net current assets			**1,360,471**	1,211,046
Total assets less current liabilities			**1,368,455**	1,221,494
Creditors: amounts falling due after more than 1 year	16		**(355,457)**	(415,798)
Net assets	18		**1,012,998**	805,696
Funds	19			
Restricted funds			**114,008**	126,509
Unrestricted funds				
Designated funds			**359,430**	350,930
General funds			**539,560**	328,257
Total charity funds			**1,012,998**	805,696

Approved by the trustees on 9 April 2026 and signed on their behalf by



Michael Stubbins - Chair

Statement of cash flow

For the year ended 30 June 2025

	2025 £	2024 £
Cash provided by operating activities:		
Net movement in funds	**207,302**	(706,798)
Adjustments for:		
Investment income	**(17,130)**	(25,043)
Increase in debtors	**(7,718)**	(35,440)
(Decrease) / increase in creditors	**(31,685)**	471,709
Depreciation	**7,037**	4,457
Loss on disposal of fixed assets	**1,756**	-
Net cash provided by / (used in) operating activities	**159,562**	(291,115)
Cash flows from investing activities:		
Investment income	**17,130**	25,043
Purchase of tangible fixed assets	**(6,329)**	(5,111)
Net cash provided by investing activities	**10,801**	19,932
Increase / (decrease) in cash and cash equivalents in the year	**170,363**	(271,183)
Cash and cash equivalents at the beginning of the year	**1,373,444**	1,644,627
Cash and cash equivalents at the end of the year	**1,543,807**	1,373,444

Analysis of cash and cash equivalents

Current asset investments	**928,420**	1,251,369
Cash at bank and in hand	**615,387**	122,075
Cash and cash equivalents at the end of the year	**1,543,807**	1,373,444

The charity has not provided an analysis of changes in net debt as it does not have any long term financing arrangements.

Notes to the financial statements

For the year ended 30 June 2025

1. Accounting policies

a) General information and basis of preparation

Action for Pulmonary Fibrosis is a charitable incorporated organisation registered in Scotland, England and Wales. The registered office address is Stuart House, East Wing, St John's Street, Peterborough, PE1 5DD.

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Action for Pulmonary Fibrosis 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 notes.

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern, which the trustees consider appropriate having regard to the current level of unrestricted reserves. There are no material uncertainties about the charity's ability to continue as a going concern.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the items of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from the government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

d) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

Notes to the financial statements

For the year ended 30 June 2025

1. Accounting policies (continued)

e) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

f) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

g) Grants payable

Grants payable are charged in the year in which the offer is conveyed to the recipient except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attached have been fulfilled. Grants offered subject to conditions at the year end are noted as commitment but are not accrued as expenditure.

h) Allocation of support and governance costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities on the basis of staff time spent on each of these area. The percentages used were as follows:

	2025	2024
Raising funds	**21%**	23%
Charitable activities	**79%**	77%

i) Tangible fixed assets

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment	3 years

Items of equipment are capitalised where the purchase price exceeds £1,000.

j) 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.

Notes to the financial statements

For the year ended 30 June 2025

1. Accounting policies (continued)

k) Current asset investments

Current asset investments consists of short term cash deposits with a maturity date of less than one year from the balance sheet date held for investment purposes rather than to meet short term cash commitments as they fall due.

l) 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.

m) Creditors

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.

n) Financial instruments

The charity 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 with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

o) Pension costs

The charity operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

p) Operating leases

Operating lease payments are recognised as an expense on a straight-line basis over the lease term.

q) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

There are no key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements.

Notes to the financial statements

For the year ended 30 June 2025

2. Prior period comparatives: statement of financial activities

	Restricted £	Unrestricted £	2024 Total £
Income from:			
Donations and legacies	17,147	1,060,805	1,077,952
Charitable activities	306,617	74,521	381,138
Investments	-	25,043	25,043
Other trading activities	-	950	950
Total income	323,764	1,161,319	1,485,083
Expenditure on:			
Raising funds	-	388,202	388,202
Charitable activities	241,275	1,562,404	1,803,679
Total expenditure	241,275	1,950,606	2,191,881
Net income / expenditure	82,489	(789,287)	(706,798)
Transfers between funds	-	-	-
Net movement in funds	82,489	(789,287)	(706,798)

3. Income from donations and legacies

	Restricted £	Unrestricted £	**2025 Total £**
Legacies	-	447,984	**447,984**
Donations from individuals and fundraising	25,419	1,154,932	**1,180,351**
Total income from donations and legacies	25,419	1,602,916	**1,628,335**

Prior period comparative

	Restricted £	Unrestricted £	2024 Total £
Legacies	-	25,687	25,687
Donations from individuals and fundraising	17,147	1,035,118	1,052,265
Total income from donations and legacies	17,147	1,060,805	1,077,952

Notes to the financial statements

For the year ended 30 June 2025

4. Income from charitable activities

	Restricted £	Unrestricted £	**2025 Total £**
Corporate grants	32,000	15,520	**47,520**
Trusts and foundations	230,703	36,257	**266,960**
Speaker and consultancy fees	-	31,303	**31,303**
Total income from charitable activities	262,703	83,080	**345,783**

Prior period comparative

	Restricted £	Unrestricted £	2024 Total £
Corporate grants	98,500	17,767	116,267
Trusts and foundations	208,117	54,126	262,243
Speaker and consultancy fees	-	2,628	2,628
Total income from charitable activities	306,617	74,521	381,138

5. Income from other trading activities

	2025 £	2024 £
Merchandise sales	**120**	950
Total income from other trading activities	**120**	950

All income from other trading activities was unrestricted in the current and prior years.

6. Government grants

The charity received a government grant, defined as funding from the National Lottery Community Fund, to fund support services. The total value of such grants for the year ending 30 June 2025 was £167,000 (2024: £168,118). There were no unfulfilled conditions or contingencies attached to these grants in 2024/25.

For the year ended 30 June 2025

7. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	**2025 Total £**
Staff costs (note 11)	228,739	874,088	120,918	**1,223,745**
Freelance costs (note 11)	62,604	54,825	33,120	**150,549**
Travel and subsistence	-	-	38,044	**38,044**
Grants payable (note 8)	-	37,780	-	**37,780**
Patient surveys	-	2,660	1,716	**4,376**
Fundraising costs	59,296	-	-	**59,296**
Marketing and communications	299	74,779	-	**75,078**
Premises costs	-	-	49,270	**49,270**
Admin costs	-	-	87,847	**87,847**
Other staffing costs	-	-	26,908	**26,908**
Governance costs	-	-	24,136	**24,136**
Depreciation	-	-	7,037	**7,037**
Sub-total	350,938	1,044,132	388,996	**1,784,066**
Allocation of support and governance costs	80,683	308,313	(388,996)	-
Total expenditure	**431,621**	**1,352,445**	**-**	**1,784,066**

Prior year comparative:

	Raising funds £	Charitable activities £	Support and governance costs £	2024 Total £
Staff costs (note 11)	231,311	763,210	90,254	1,084,775
Freelance costs (note 11)	8,225	43,860	62,330	114,415
Travel and subsistence	-	-	41,252	41,252
Grants payable (note 8)	-	614,625	-	614,625
Training costs	-	-	396	396
Patient surveys	-	192	-	192
Fundraising costs	55,200	-	-	55,200
Marketing and communications	658	75,569	300	76,527
Premises costs	-	-	49,606	49,606
Admin costs	-	-	105,515	105,515
Other staffing costs	-	-	34,271	34,271
Governance costs	-	-	10,650	10,650
Depreciation	-	-	4,457	4,457
Sub-total	295,394	1,497,456	399,031	2,191,881
Allocation of support and governance costs	92,808	306,223	(399,031)	-
Total expenditure	388,202	1,803,679	-	2,191,881

For the year ended 30 June 2025

8. Grants payable

During the year, 15 (2024: 8) new grants were awarded to 15 institutions (2024: 7) to fund research fellowships and support sessions and 10 to individuals (2024: 9) for travel to research events. Total grants committed to during the year were as follows:

	2025	2024
	£	£
Grants payable to institutions:		
Fellowships		
University of Cambridge	**-**	299,998
Imperial College London	**-**	299,673
Research awards		
British Association of Lung Research	**4,500**	4,500
University of Birmingham	**9,876**	-
Imperial College London	**9,829**	2,500
Support groups		
Portsmouth Support Group	**500**	-
Newcastle Support Group	**500**	-
Rhondda Cynon Taf Support Group	**500**	-
Worthing Support Group	**500**	-
Bradford Support Group	**500**	-
Isle of Wight Support Group	**135**	-
Epsom and St Helier Support Group	**500**	-
West Wiltshire Support Group	**500**	-
West Cornwall Support Group	**500**	-
Leicester South Asian Support Group	**500**	-
Crawley Support Group	**240**	-
Blackpool Support Group	**500**	-
Huddersfield Support Group	**-**	600
Tunbridge Wells and Maidstone Support Group	**-**	350
Torquay Support Group	**-**	500
Ayrshire Support Group	**-**	500
Total grants payable to institutions	**29,580**	608,621
Grants payable to individuals	**8,200**	6,004
Total grants committed during the period	**37,780**	614,625

Notes to the financial statements

For the year ended 30 June 2024

9. Grants commitments

	2025 £	2024 £
Grant commitments brought forward	**579,636**	56,931
Grants committed during the period (note 8)	**37,780**	614,625
Grants paid during the period	**(85,822)**	(91,920)
Grant commitments carried forward	**531,594**	579,636

10. Net movement in funds

This is stated after charging:

	2025 £	2024 £
Depreciation	**7,037**	4,457
Operating lease payments	**29,595**	20,079
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses	**Nil**	337
Auditors' remuneration:		
▪ Statutory audit (excluding VAT)	**7,000**	5,775

During the year, no trustees received reimbursed expenses (2024: 2 trustees were reimbursed £337 for travel expenses). All expenses incurred were in the course of the organisation's charitable activities.

In common with other charities of our size and nature we use our auditors to assist with the preparation of the financial statements.

11. Staff costs and numbers

Staff costs were as follows:

	2025 £	2024 £
Salaries and wages	**1,097,240**	958,898
Social security costs	**103,949**	88,882
Pension costs	**22,556**	36,995
Freelance staff	**150,549**	114,415
	1,374,294	1,199,190

One employee earned between £70,000 and £80,000 during the year (2024: one employee earned between £70,000 and £80,000).

The key management personnel of the charity comprise the trustees and senior leadership team (2023: the trustees and the Chief Executive). The total employee benefits of the key management personnel were £349,446 (2024: £344,633).

For the year ended 30 June 2025

11. Staff costs and numbers (continued)

Included in salaries and wages are redundancy and termination costs totalling £18,648 (2024: £2,000). Redundancy and termination costs have been funded from unrestricted general funds (note 19).

	2025 No.	2024 No.
Average head count	**34**	32

12. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

13. Tangible fixed assets

	Computer equipment	**Total £**
Cost		
At 1 July 2024	16,538	**16,538**
Additions in year	6,329	**6,329**
Disposals	(1,756)	**(1,756)**
At 30 June 2025	21,111	**21,111**
Depreciation		
At 1 July 2024	6,090	**6,090**
Charge for the year	7,037	**7,037**
At 30 June 2025	13,127	**13,127**
Net book value		
At 30 June 2025	**7,984**	**7,984**
At 30 June 2024	10,448	10,448

14. Debtors

	2025 £	2024 £
Trade debtors	**16,205**	55,806
Accrued income	**76,092**	30,037
Prepayments	**13,162**	11,898
	105,459	97,741

Notes to the financial statements

For the year ended 30 June 2025

15. Creditors: amounts due within 1 year

	2025 £	2024 £
Trade creditors	**48,404**	70,913
Accruals	**38,759**	6,930
Grant commitments (note 9)	**176,137**	163,838
Social security	**19,720**	18,458
Other creditors	**5,775**	-
	288,795	260,139

16. Creditors: amounts due after 1 year

	2025 £	2024 £
Grant commitments (note 9)	**355,457**	415,798

17. Contingent assets

Action for Pulmonary Fibrosis were notified of a number of legacies during the year ended 30 June 2025, for which the amount receivable cannot be reliably estimated. These financial statements do not include any estimated future amounts receivable. Indications are that the value of these potential legacies is in the region of £60,000 - £70,000 (2024: £72,000).

18. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	**Total funds £**
Fixed assets	-	-	7,984	**7,984**
Current assets	114,008	891,024	644,234	**1,649,266**
Current liabilities	-	(176,137)	(112,658)	**(288,795)**
Non-current liabilities	-	(355,457)	-	**(355,457)**
Net assets at 30 June 2025	**114,008**	**359,430**	**539,560**	**1,012,998**

Prior period comparative	Restricted funds £	Designated funds £	General funds £	Total funds £
Fixed assets	-	-	10,448	10,448
Current assets	126,604	330,895	1,013,686	1,471,185
Current liabilities	-	(163,838)	(96,301)	(260,139)
Non-current liabilities	-	(415,798)	-	(415,798)
Net assets at 30 June 2024	126,509	350,930	328,257	805,696

Notes to the financial statements

For the year ended 30 June 2025

19. Movements in funds

	At 1 July 2024 £	Income £	Expenditure £	Transfers between funds £	**At 30 June 2025 £**
Restricted funds					
National Lottery Community Fund	-	167,000	(97,417)	-	**69,583**
Onevoice ILD	70,460	30,000	(56,035)	-	**44,425**
Research donations	-	42,394	(42,394)	-	**-**
Support donations	-	23,808	(23,808)	-	**-**
Location specific support services	-	14,420	(14,420)	-	**-**
Research Fellowships	-	8,500	-	(8,500)	**-**
Trevi Therapeutics	13,209	2,000	(15,209)	-	**-**
Garfield Weston	39,442	-	(39,442)	-	**-**
Northern Ireland donations	1,213	-	(1,213)	-	**-**
Wales donations	855	-	(855)	-	**-**
Hospital Saturday Fund	630	-	(630)	-	**-**
Scotland donations	528	-	(528)	-	**-**
D'Oyly Carte Charitable Trust	172	-	(172)	-	**-**
Total restricted funds	126,509	288,122	(292,123)	(8,500)	**114,008**
Unrestricted funds					
Designated funds					
Research fund	350,930	-	-	8,500	**359,430**
Total designated funds	350,930	-	-	8,500	**359,430**
General funds	328,257	1,703,246	(1,491,943)	-	**539,560**
Total unrestricted funds	679,187	1,703,246	(1,491,943)	8,500	**898,990**
Total funds	805,696	1,991,368	(1,784,066)	-	**1,012,998**

Purposes of restricted funds

National Lottery Community Fund	Funding for APF's support services.
Onevoice ILD	Funding for APF to act as a central voice to advocate for patients with a range of Intersitial Lung Diseases.
Research donations	These are donations received specifically for research.
Support donations	These are donations received specifically for support services.
Location specifc support donations	Funding for support services within specific regions have been aggregated for the statutory accounts.

For the year ended 30 June 2025

19. Movements in funds (continued)

Purposes of restricted funds (continued)

Research Fellowships	Funding to contribute to APF's ongoing research fellowships.
Trevi Therapeutics	This fund is for support services in Scotland (including Support Group coordinator salary).
Garfield Weston	This fund is for support services growing volunteering, and is to be used towards volunteering salary costs, services admin and volunteer recruitment, training, expenses and marketing.
Northern Ireland donations	These donations for support services in Northern Ireland were received in the prior year.
Wales donations	These donations for support services in Wales were received in the prior year.
Hospital Saturday Fund	This fund is for support services.
Scotland donations	These donations for support services in Scotland were received in the prior year.
D'Oyly Carte Charitable Trust	This fund is to enable new and existing APF volunteers to receive training in order to better support patients and carers.

Purposes of designated funds

Research fund	A principal objective of Action for Pulmonary Fibrosis is to support and fund Research into the disease. Trustees have previously agreed to designate £951k for research to fund further research fellowships, with agreements totalling £599,671 awarded in the prior year. The balance carried forward is intended to be spent on future research fellowships.

Transfers between funds

Transfers between funds represent the contribution of restricted funds towards the research fellowship committed to in the prior year.

For the year ended 30 June 2025

19. Movements in funds (continued)

Prior period comparative

	At 1 July 2023 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2024 £
Restricted funds					
Onevoice ILD	-	90,000	(19,540)	-	70,460
Trevi Therapeutics	13,207	8,500	(8,498)	-	13,209
Hospital Saturday Fund	630	-	-	-	630
National Lottery Community Fund	10,919	168,118	(179,037)	-	-
D'Oyly Carte Charitable Trust	172	-	-	-	172
Garfield Weston	16,401	35,000	(11,959)	-	39,442
Northern Ireland donations	1,213	-	-	-	1,213
Research donations	-	17,146	(17,146)	-	-
Support donations	-	5,000	(5,000)	-	-
Scotland donations	623	-	(95)	-	528
Wales donations	855	-	-	-	855
Total restricted funds	44,020	323,764	(241,275)	-	126,509
Unrestricted funds					
Designated funds					
Research fund	950,601	-	(599,671)	-	350,930
Reserve fund	336,000	-	-	(336,000)	-
Total designated funds	1,286,601	-	(599,671)	(336,000)	350,930
General funds	181,873	1,161,319	(1,350,935)	336,000	328,257
Total unrestricted funds	1,468,474	1,161,319	(1,950,606)	-	679,187
Total funds	1,512,494	1,485,083	(2,191,881)	-	805,696

20. Operating leases

The charity had operating leases at the year end with total future minimum lease payments as follows:

	2025 £	2024 £
Amount falling due:		
Within 1 year	**5,361**	26,482
Within 1-5 years	**-**	1,306
	5,361	27,788

Notes to the financial statements

For the year ended 30 June 2025

21. Related party transactions

Stephen Jones and Helen Parfrey, trustees of Action for Pulmonary Fibrosis (APF), are also board members of European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF). During the year APF received income of £3,989 from EU-IPFF for speaker fees (2024: £2,628 for speaker fees). No amounts were outstanding to APF at the year end. Additionally, APF were invoied £254 for membership fees (2024: £nil), £254 was outstanding to EU-IPFF at the year end. In the year, the charity received £400 of unrestricted donations from trustees.

The trustees are not aware of any other related party transactions during the period.

Action for Pulmonary Fibrosis

General enquiries

01733 839642

info@actionpf.org

Contact our support team

supportline@actionpf.org

Support line: 01223 785725

Registered Office & Operational Address

Stuart House, East Wing, St John's Street, Peterborough PE1 5DD

actionpf.org

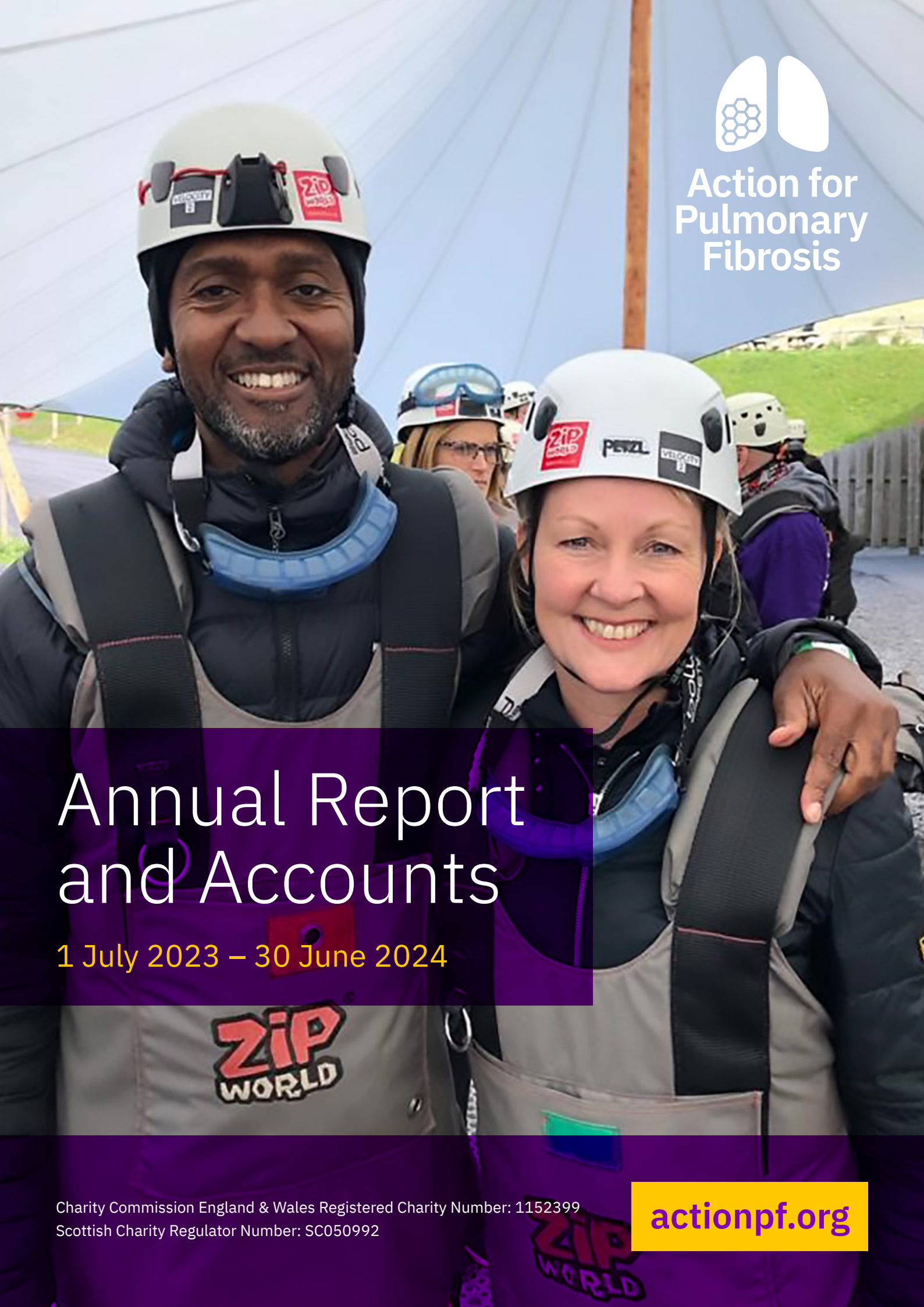
Charity Commission England & Wales Registered Charity Number: 1152399

Scottish Charity Regulator Number: SC050992

ACTION FOR PULMONARY FIBROSIS

England & Wales - Charity number 1152399

Accounts



Action for Pulmonary Fibrosis

Annual Report and Accounts

1 July 2023 – 30 June 2024

Charity Commission England & Wales Registered Charity Number: 1152399
Scottish Charity Regulator Number: SC050992

actionpf.org

Contents

Welcome 3

Who we are 4

Why APF is needed 5

Our purpose, vision and mission 6

The difference we make 7

Influencing and policy 12

Our supporters and fundraising achievements 17

Looking ahead – future priorities and strategy 19

Structure, governance and management 20

Financial review 23/24 22

Statement of trustee responsibilities 23

Reference and administrative details 24

Independent auditor's report 25

Statement of financial activities 28

Balance sheet 29

Statement of cash flow 30

Notes to the financial statements 31

Welcome

As we reflect on the past year at Action for Pulmonary Fibrosis (APF), we are incredibly proud of everything we have achieved. From developing vital information and education resources to investing in pioneering research fellowships that influence pulmonary fibrosis (PF) research on a global scale, we have worked tirelessly to improve the lives of those affected by this devastating disease.

Together, we reached over a million people through our PF Awareness Month campaign, raised more than £1.47 million to fund new research and expand our support, and surveyed over 1,000 people living with PF, using their voices to shape a new national integrated care pathway.

While these milestones are significant, our findings also highlight just how much work remains. Public awareness of PF is still low, care varies considerably depending on where people live, and many individuals and families continue to face profound injustices. These realities inspire us to continue growing our impact driving forward policy changes, collaborating with healthcare decision-makers, and expanding our support network so that no one faces PF alone.

We owe our deepest gratitude to all those who contribute to our mission, our volunteers, donors, partners, funders, and supporters - for their unwavering belief in a better future for those affected by PF. In particular, we want to thank the PF community members themselves, whose resilience and generosity, even amid daily struggles, continue to uplift and motivate us.

During this year, we also bid farewell to four valued trustees. We were deeply saddened by the loss of Sarah Weir, who passed away in service; Shama Malik, who stepped down for health reasons; and Howard Almond and Elizabeth Bray, who both completed many years of dedicated service. Their commitment has shaped APF's work and will be greatly missed. We also acknowledge the transitions in our leadership team: Louise Wright and Steve Jones stepped down as Chief Executive and Chair of Trustees respectively after guiding the charity with passion and expertise. It is our privilege to now carry forward their vision, and we look ahead with hope and determination.

Thank you for taking this journey with us. In the pages that follow, we invite you to explore our progress, celebrate our community's achievements, and look toward the future we are all working to create: a future where no one faces PF alone and where, together, we will drive research forward until we find a cure.

Daniel Saxton
Chief Executive Officer

Mike Stubbins
Chair

Who we are

Action for Pulmonary Fibrosis (APF) is the UK's leading charity dedicated to improving the health and wellbeing of everyone affected by pulmonary fibrosis (PF). We are committed to ensuring that no one faces this devastating condition alone.

Through our work, we provide:

Vital Support	Research	Advocacy and Awareness
Our helpline, online resources, and local support groups ensure that patients, carers, and families receive trusted, evidence-based information.	We invest in innovative research aimed at finding new treatments and, ultimately, a cure.	We raise the profile of PF and influence national policy, striving for better healthcare outcomes and accelerating access to treatments.

Thanks to the generosity of our donors, funders, volunteers, and partners, APF is able to reach more people impacted by PF every year, offering hope, support, and a platform for raising awareness of this life-limiting condition.

Why APF is needed

Limited public awareness

Pulmonary fibrosis (PF) is characterised by scarring (fibrosis) of the lungs, which become stiffer and smaller, leading to reduced oxygen intake. This causes symptoms such as breathlessness, persistent coughing, and overwhelming fatigue - often making everyday tasks like dressing or walking across a room exhausting. It is estimated that over 70,000 people in the UK are living with PF, and at least 8,000 people lose their lives to this disease each year. Treatment options are limited, and there is currently no known cure.

Far too many people in the UK (one in three) have never heard of PF. Without knowing the signs and symptoms, individuals struggle to get help in time. By raising awareness, we help those living with PF to seek the medical support they need sooner.

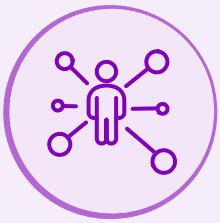
Mental health

A recent Action for Pulmonary Fibrosis (APF) led survey revealed that more than 30% of people with PF felt their mental health would have benefitted significantly from additional support at the point of diagnosis. For these families, learning about PF can be terrifying and isolating. Too often, they face this devastating diagnosis without immediate emotional or psychological care.

Delays in care

PF can progress quickly, yet access to prompt specialist care and information remains inconsistent. These delays not only leave individuals feeling alone but can also allow the disease to advance, making eventual treatments less effective.

Growing and complex needs



Each year, we see more people turning to APF with advanced symptoms and increasingly complex health issues. Their declining health and the heavy burden on caregivers illustrates the urgent need for earlier intervention and consistent, high-quality support.

Chronic underfunding of PF research

Despite its life-altering impact, respiratory research receives just 2% of the UK's medical research investment. This lack of funding stands between families and breakthroughs that could change or even save the lives of those living with PF.

We believe no one should have to fight PF alone. By extending our reach, partnering with medical experts, and fuelling vital research, we strive to end the fear, isolation, and ultimately, the loss of life associated with PF.

Together, we can bring light to this little-known disease, providing real hope for those who need it most.

Our purpose, vision and mission

Our purpose

We bring people together to drive change so more people affected by PF can live well for longer.

Our vision

We are determined everyone living with PF in the UK will have access to effective, evidence-based treatment.

Our mission

Together, we will stop lives being lost to pulmonary fibrosis.

We deliver our vision by living our values:

Compassionate
keeping people affected by PF at the heart of all we do

Bold
campaigning for justice and equality for people affected

Expert
bringing real-life experience together with scientific expertise

Collaborative
working with others to drive vital change

The difference we make

At Action for Pulmonary Fibrosis (APF), we are committed to making a substantial and lasting difference for everyone affected by this devastating disease. Over the past year, we've significantly expanded our reach and deepened our impact, ensuring no one has to face pulmonary fibrosis (PF) alone.

Support in action

Growing demand for our helpline

- We answered over **1,500 calls** to our support line – a **45% increase** on the previous year.
- Our trained team offers emotional and practical guidance, ensuring that callers receive reliable information, reassurance, and referrals to the most suitable services.

Our community said:

> I cannot thank her enough because she helped me last year. I was on the phone for half an hour to Pauline to calm me down enough to go and see my husband. And it was probably the worst day of my life. Pauline has been superb. She's amazing.
>
> **Sally, affected by PF**

> Spurred on by your suggestion of involving Citizens Advice, I have had a meeting with them and am now in the process of taking the case to the tribunal.
>
> **John, affected by PF**

> I was feeling very negative after being told the diagnosis in a dry way by the consultant. I feel so much better and more positive after speaking with you.
>
> **Claire, living with PF**

These personal accounts highlight how life-changing timely support can be, especially given the complex and rapidly progressing nature of PF. Delays in clinical care often mean people reach out to us with more advanced symptoms, making our helpline a true lifeline for many.

*names anonymised for confidentiality

The difference we make

Expanding our offer

Accessible welcome pathways

We've implemented tailored welcome pathways, ensuring that people who don't use email or the internet receive vital information and a personal invitation to our wide range of support options by letter.

Online information reach

Over 60,000 – 65,000 people per quarter accessed our web-based information resources, including symptom guides, treatment options, and expert advice.

Growing range of resources

- We produced a **'recently diagnosed'** pack to guide individuals at the earliest stages of their PF journey.
- We launched our **first translated resources** in Urdu for PF drug treatments, reflecting our commitment to inclusivity.

Befriending service

Originally set up during the pandemic for people isolated at home, our befriending service continued to grow and was redesigned to handle increased demand.

- **42 volunteer befrienders** dedicated their time to support over 80 individuals.
- **86% of those receiving support** said they would recommend the service to others.

The difference we make

Spotlight on ‘Talking PF’

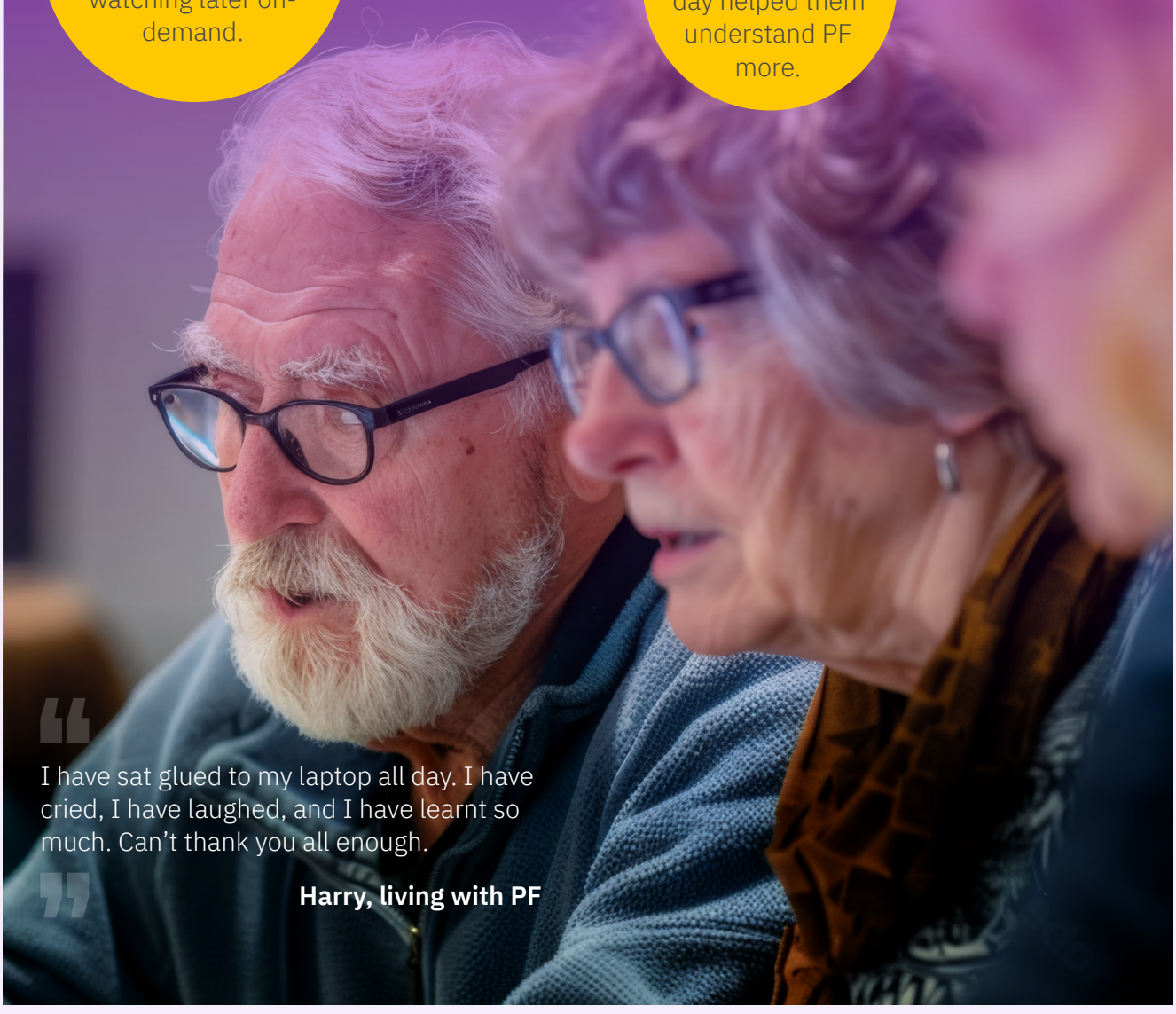
We ran a ‘Talking PF’ online education day in collaboration with the Royal Devon and Exeter and the Royal Brompton and Harefield hospitals.

Over **1,000 people** signed up, with about half joining live and others watching later on-demand.

Two in-person groups hosted watch parties in Devon.

Over **90%** of viewers felt the day helped them understand PF more.

Over **90%** said the event helped them live better with PF.



“I have sat glued to my laptop all day. I have cried, I have laughed, and I have learnt so much. Can’t thank you all enough.”

Harry, living with PF

The difference we make

Building trusted partnerships with support groups and professionals

Local support groups

We ended the year with **66 support groups** across the UK – vital hubs of peer support and information.

Healthcare referrals

Referrals from healthcare professionals rose by **197%**, enabling us to reach people earlier in their PF journey.

APF clinic pilot

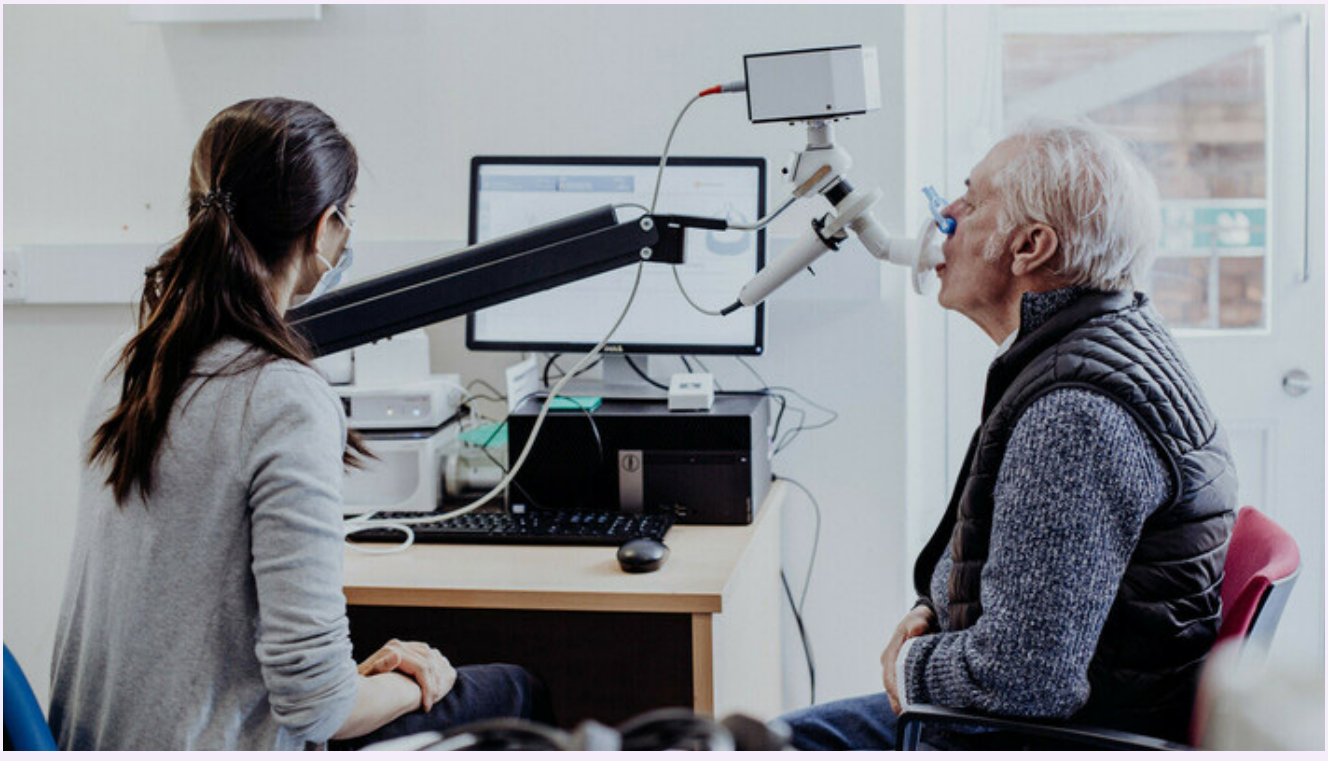
We launched our APF clinic pilot at Guy's and St Thomas' Hospital, offering regular outreach.

Empowering volunteers

Recruiting and retaining volunteers who are living with or caring for someone with a progressive, terminal condition can be challenging. We're developing **flexible, bite-sized opportunities** for people to shape and deliver our work via our Befriending Service and Involvement Network.

Expanding education

We piloted concise, targeted education modules – laying the groundwork for a comprehensive education programme for people affected by PF and healthcare professionals in 2024–25.



The difference we make

Advancing research and innovation

Despite PF receiving only a fraction of the UK's respiratory research funding, APF is determined to drive forward groundbreaking research that brings hope for new treatments and, one day, a cure.

Significant research investment

In 2023–24, we committed **£600,000+** to new research, including:

- Two three-year fellowships at the University of Cambridge and Imperial College London.
- Two research awards to the British Association of Lung Research and Imperial College London.

Fellowship programme

Our fellowship scheme, recognised globally, has so far contributed to **over 40 peer-reviewed publications** and paved the way for millions of pounds in further research funding worldwide.

"The APF Fellowships, recognised for supporting pioneering research in this field, offer me a unique opportunity to try to uncover new treatment targets and improve outcomes for patients."

Dr Bin (Kevin) Liu,
National Heart and Lung Institute, Imperial College London

Early-career support and engagement

We funded **eight early-career researchers** to present at international conferences and collaborated with the British Association of Lung Research (BALR) to fund summer internships. We also sponsored the Margaret Turner Warwick Centre for Fibrosing Lung Diseases lecture series.

Study Finder and Involvement Network

- We launched our **Study Finder**, co-created with our community, to raise awareness of ongoing trials and share results once available.
- Over **80 people** affected by PF joined our **Involvement Network**, shaping APF's initiatives and external research projects.

Influencing and policy

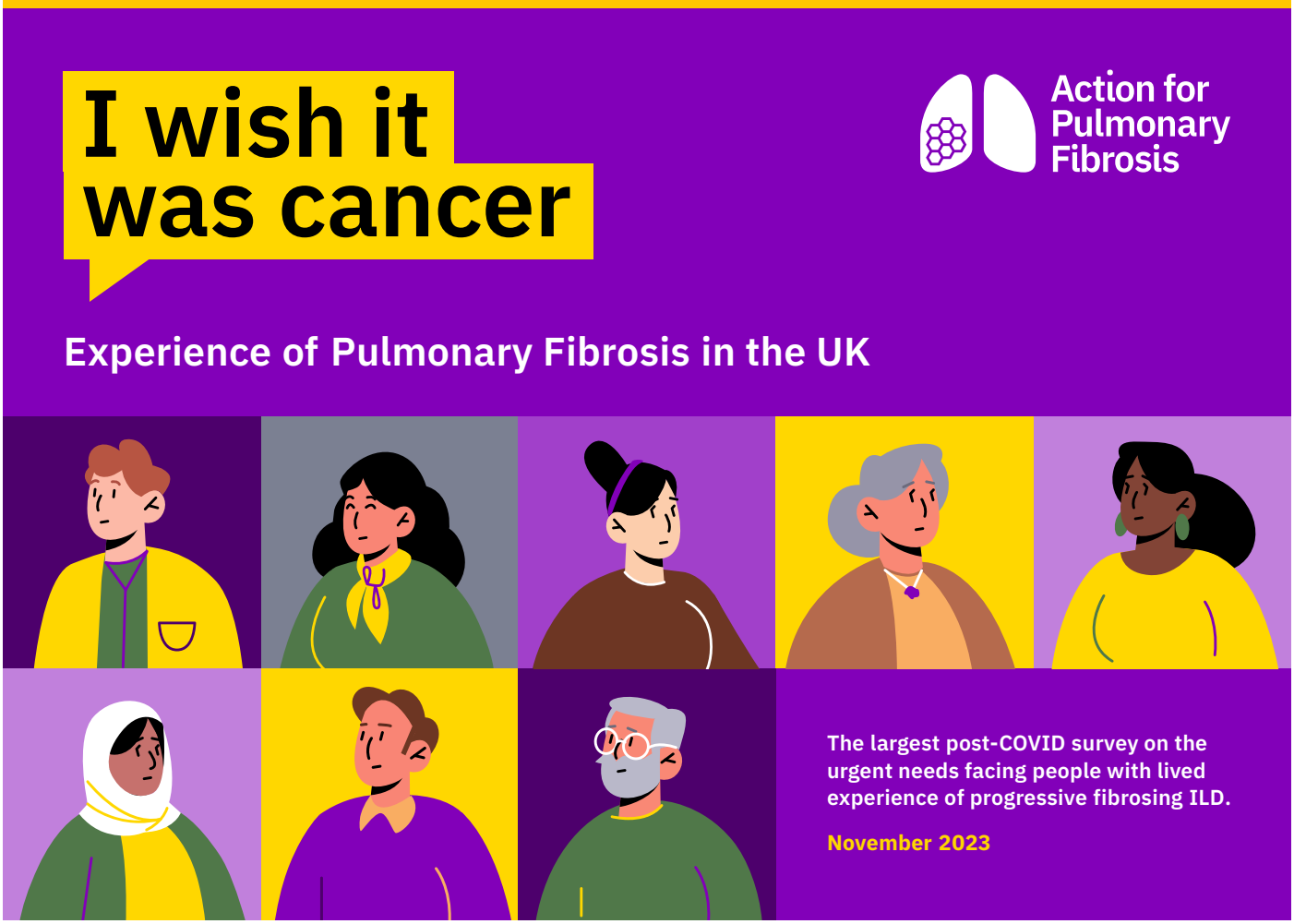
We know that to truly transform the lives of people with PF, we must influence the healthcare system and public policy at every level.

By amplifying the voices of those affected, collaborating with policymakers, and working closely with clinical experts, we strive to ensure consistent, equitable access to timely diagnosis, treatment, and ongoing support.

Together, we are reshaping the future of PF care and creating lasting change.

We published the 'I wish it was cancer' report

- This report spotlighted the devastating impact of PF on people's lives. We surveyed the PF community via workshops, interviews, and an anonymous survey—online and by post—to capture the real challenges they face.
- Insights from this report informed the fundamentals of the national integrated care pathway, and we also developed an animation to demonstrate how well-organised, well-resourced care can make all the difference.



Influencing and policy

OneVoiceILD and the National Integrated Care Pathway

- **Transforming PF care**
  In April 2024, APF spearheaded the launch of OneVoiceILD – a pioneering blueprint for reorganising PF care in England. Designed for NHS healthcare professionals and commissioners, this vision aims to end the postcode lottery by ensuring no one faces delays to diagnosis or struggles to access treatment and support.
- **What is a 'care pathway'?**
  A care pathway outlines a patient's journey through the healthcare system – from the first suspicion of PF to diagnosis, treatment, and the possibility of lung transplantation. By standardising care delivery, we ensure patients' needs are met equally across the country.
- **Nationwide implementation**
  Several pilot projects are underway in England, and we've established working groups in Wales and Northern Ireland, with further engagement planned in Scotland. This collaborative, UK-wide approach is essential to driving real, measurable progress for people with PF.

Influencing and policy

Parliamentary engagement

- **Giving PF a voice in Parliament**
  In October, we hosted our first-ever parliamentary drop-in event, welcoming 34 MPs from across the UK. Over 1,300 people with PF contacted their MPs, resulting in 75% of MPs hearing directly from constituents about the urgent needs surrounding PF care.
- **Securing commitments**
  Each attending MP pledged to raise public awareness of PF and to write to their local health body advocating for APF's gold standard pathway. We're also encouraging them to meet local support groups to gain deeper insight into the realities of living with PF.
- **Driving change for the future**
  By forging stronger relationships with parliamentarians, we're ensuring that the PF community's voice resonates in policy discussions. This momentum is crucial for achieving our goal of equitable, compassionate, and effective PF care across the country.

"We need this condition recognised. When people say cancer, people know what you're talking about. When you say, 'I have IPF', nobody knows what you mean."

Geoff, living with idiopathic pulmonary fibrosis (IPF)

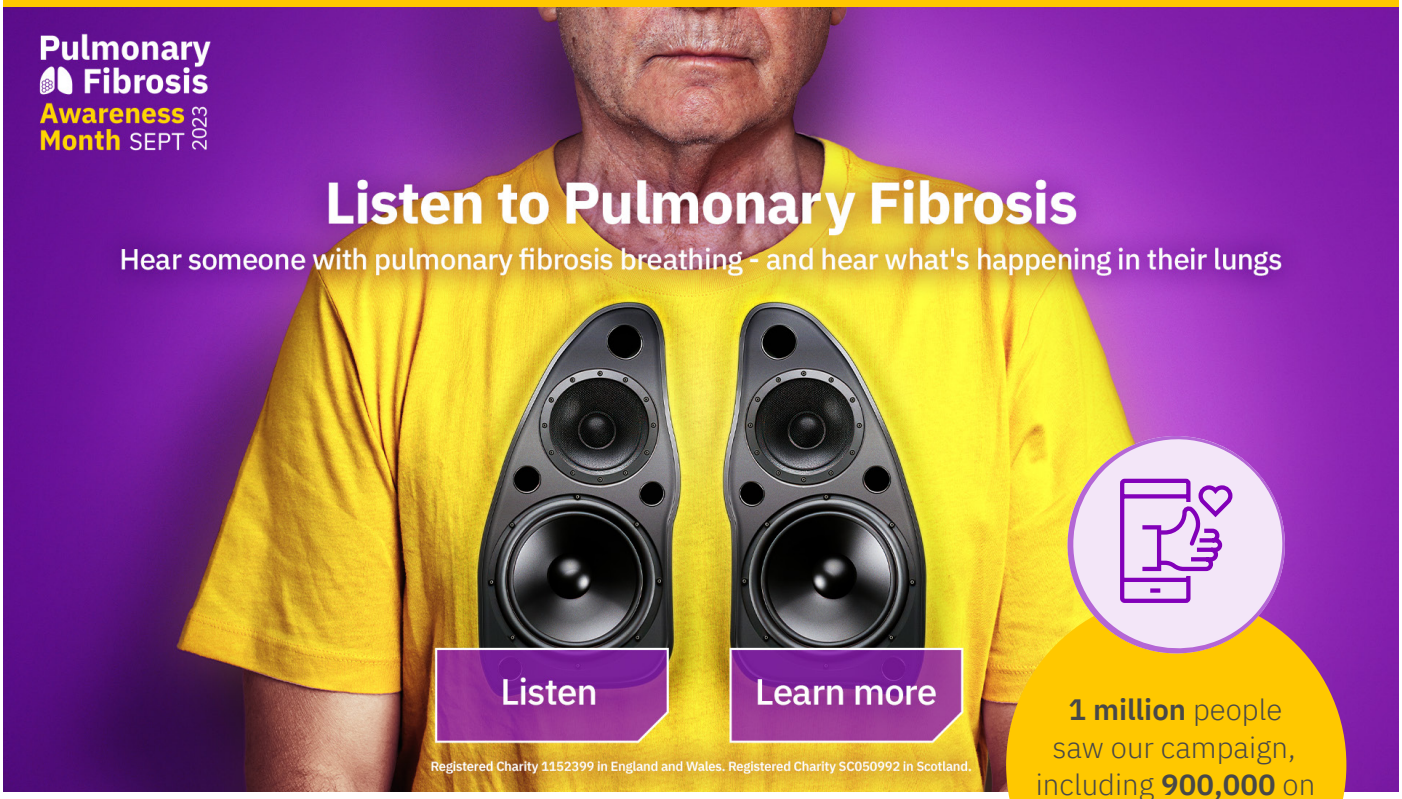
"I know what it's like to live with pulmonary fibrosis - it's a horrible disease that robs you of your breath and life. We need to grab people's attention, so more people know what pulmonary fibrosis is."

Amy, who lived with PF before receiving a lung transplant

Influencing and policy

‘Hear My Lungs’ campaign

During Pulmonary Fibrosis Awareness Month, we shared the crackling lung sounds typical of PF to raise awareness among the 1 in 3 people in the UK who have never heard of this disease.



1 million people saw our campaign, including **900,000** on social media.

Free billboard advertising in 30+ locations helpd us reach millions more.

We earned **national press coverage** in The Sun and MailOnline.

Influencing and policy

Shining a light on PF in public and media

Raising awareness of PF is a cornerstone of our mission. Despite the significant impact of this disease, many people in the UK have never heard of PF – making education, visibility, and public engagement absolutely critical. Through sustained media coverage, impactful campaigns, and clear, accessible resources, we aim to inform the public, prompt vital conversations, and ultimately drive earlier diagnoses and better outcomes. By sharing real-life experiences and highlighting the latest research, we ensure that PF no longer remains an invisible illness.

Growing reach

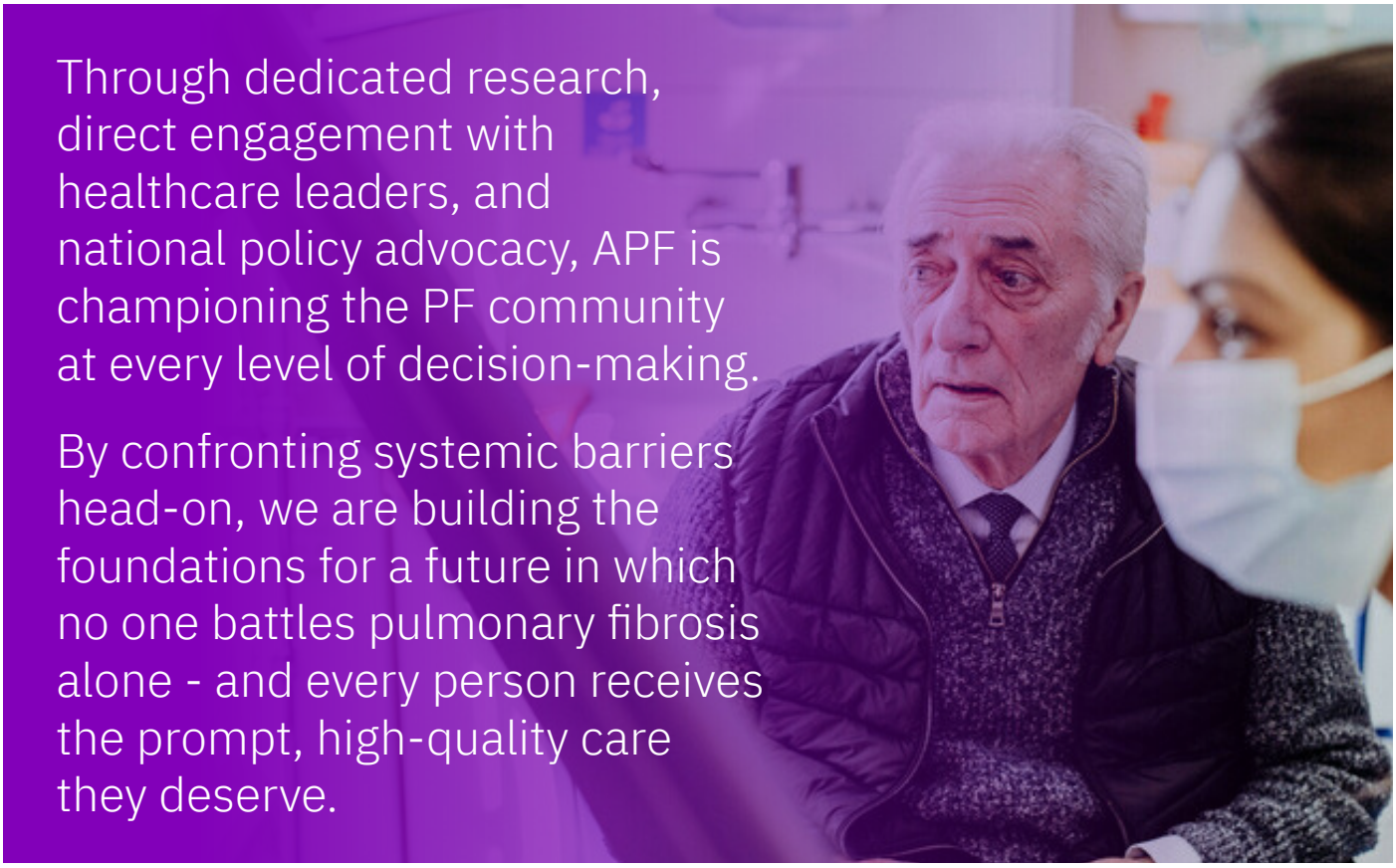
60,000+
website visitors per quarter

5,000+
e-newsletter subscribers

7,000+
copies of Insider magazine distributed

2,500+
new social media followers—an increase of 13.7%

750+
APF mentions in national and local media



Through dedicated research, direct engagement with healthcare leaders, and national policy advocacy, APF is championing the PF community at every level of decision-making.

By confronting systemic barriers head-on, we are building the foundations for a future in which no one battles pulmonary fibrosis alone - and every person receives the prompt, high-quality care they deserve.

Our supporters and fundraising achievements

In **2023-24**, our dedicated community of supporters came together to raise over **£1.47 million** for APF. This incredible achievement enables us to drive forward crucial support services and research.

Going the extra mile

- More than **550 supporters** ran, walked, climbed, and baked to raise funds, while over **1,000 individuals** made direct donations to support us.
- Our community rallied around **Go the Distance** in September for PF Awareness Month and again in April to **Walk for Hope**, channelling their passion into fundraising that will fuel new research and help us reach more people living with PF.

Transformative grant funding

We extend our deepest gratitude to all our grant funders, whose support has been instrumental in helping us grow. We'd particularly like to thank Garfield Weston and Miss Hanson's Charitable Trust for their support.

A special thanks goes to the **National Lottery Community Fund**, who awarded us our largest grant to date making it possible for APF to sustain its vital frontline services and reach even more people affected by PF.

"We are raising money for APF after losing our dad and auntie to pulmonary fibrosis. We wanted to make a difference and raise awareness with the hope that people won't have to go through what we did. APF have hugely supported our family, and we want to be able to contribute so they can continue offering support to other families."

Dan and Emma, affected by PF

Our supporters and fundraising achievements

Ambitious plans for the future

We have bold goals to increase our income over the next five years, expanding both our support services and our research portfolio so that no one faces PF alone.

Achieving these aspirations depends on the continued generosity of donors, fundraisers, corporate partners, and trusts and foundations. Every contribution, no matter how small, makes a real difference in transforming lives.

With the unwavering support of our community, we are driving meaningful progress to ensure that everyone living with pulmonary fibrosis has the help, hope, and advocacy they need. Thank you for standing with us every step of the way.

> Walking a mile is a relatively ordinary thing to do, but for a patient living with PF it takes an extraordinary effort—and we did it! I'm proud to have taken part in the Great West Run in our continued fight against pulmonary fibrosis.
>
> **George, living with PF**

> I will continue to raise funds in the hope we eventually find a cure to get rid of IPF for good.
>
> **Michelle, affected by PF**

Corporate Support

We have been delighted to see a huge increase in the number of companies fundraising for APF as well as match funding their employees' fundraising efforts. It's been great seeing how many companies have been supporting their teams whatever their fundraising events may be – golfing, hiking, running, dressing up, dressing down... we've seen it all this year!

We'd particularly like to thank Barclays Bank Procurement, Crane, GAP, Visa.com, Fox Williams, Linklaters and Aviva UK.

Looking ahead – future priorities and strategy

In 2023/24, we created a bold strategic overview centred on three dynamic pillars: providing accessible information and support for everyone, uniting key stakeholders to drive meaningful change, and raising widespread awareness of the signs of pulmonary fibrosis (PF). Building on these foundations, we will launch an ambitious five-year strategy in 2025 that harnesses the lessons we have learned to date and channels them into transformational initiatives. The first year will look to strengthen our governance and infrastructure to create a solid platform for accelerated growth.

In subsequent years, we aim to significantly expand our reach, deepening our engagement with our supporters, elevating research efforts, and offering impactful, real-time assistance to those currently affected by PF. Through close collaboration with healthcare professionals, notably via the OneVoice ILD project, we will strive to break new ground in care standards and advocacy. Our ultimate goal over the next 5-years is to implement a transformative shift in how PF is understood, managed, and supported, making a lasting difference to the lives of everyone touched by this condition.

We want to stop lives being devastated by pulmonary fibrosis (PF). Our five-year strategy, launched in 2024 sets out our ambitious plans to achieve this.

Our 3 strategic pillars

Information and support for all

More people affected by PF will be able to find support how and when they need it, to manage their health and wellbeing.

We are united to drive change

We will grow and unite our communities to take action on our shared goals of improving research and care.

More awareness of the signs of PF

More people at risk of PF will know the signs and symptoms so they can get help sooner.

Structure, governance and management

Governance overview

Action for Pulmonary Fibrosis (APF) was established as a Charitable Incorporated Organisation (CIO) in June 2013, registered with the Charity Commission for England and Wales. Its governing document, the Constitution, was approved by the trustees on 28 May 2013. On 25 May 2021, APF also achieved registration with the Office of the Scottish Charity Regulator (OSCR).

Almost all trustees bring direct experience with pulmonary fibrosis (PF), whether through personal or family connections or as medical professionals, ensuring the charity's work is informed by lived experiences and healthcare expertise.

Board of Trustees

The Board of Trustees meets quarterly to oversee the charity's progress, establish policy and strategy, and ensure compliance with charity regulations. At the start of each financial year, the trustees approve an annual plan and budget. During each meeting, progress reports are reviewed, significant risks are assessed, and the effectiveness of internal controls is monitored.

The Board also engages professional advisers as needed to provide legal and financial guidance.

Recruitment and appointment of trustees

To address emerging challenges and ensure a diverse range of skills, the Board periodically evaluates its composition and openly recruits new members when necessary. Most trustees have a personal connection to PF and bring the skills and competencies to support the charity to succeed.

Vacancies are advertised, and applicants undergo a structured selection process, including submitting a formal application and attending an interview with trustees. Shortlisted candidates are invited to attend a Board meeting before final approval by the trustees.

Once appointed, new trustees participate in an induction program to familiarise themselves with the charity's mission, operations, and their governance responsibilities.

Organisational structure

The Chief Executive Officer (CEO) works closely with the senior leadership team to guide the charity, driving its mission and ensuring that its activities align with its strategic goals. Together, they provide strong and effective leadership, fostering a culture of collaboration and innovation throughout the organisation.

A key aspect of APF's governance is the Finance and Risk Committee, which plays a vital role in overseeing the charity's finances and operations. This committee ensures that budgets are carefully managed, risks are effectively mitigated, and policies are regularly reviewed to uphold the charity's high standards. It also oversees staff remuneration, ensuring fairness and consistency with the charity's values. The committee, which includes the CEO, the Director of Finance and Operations, at least two trustees and a new Treasurer post as of November 2024, meets quarterly ahead of Board meetings to support informed and transparent decision-making.

In addition to the Finance and Risk Committee, the Board establishes sub-committees as required to focus on specific projects or tasks. These sub-committees enable APF to respond flexibly and efficiently to emerging needs, ensuring that its operations remain dynamic and forward-thinking.

APF is proud to be registered with the Fundraising Register, reflecting its commitment to ethical and transparent fundraising practices. This registration highlights the charity's dedication to building trust with its supporters and delivering meaningful support to those affected by PF.

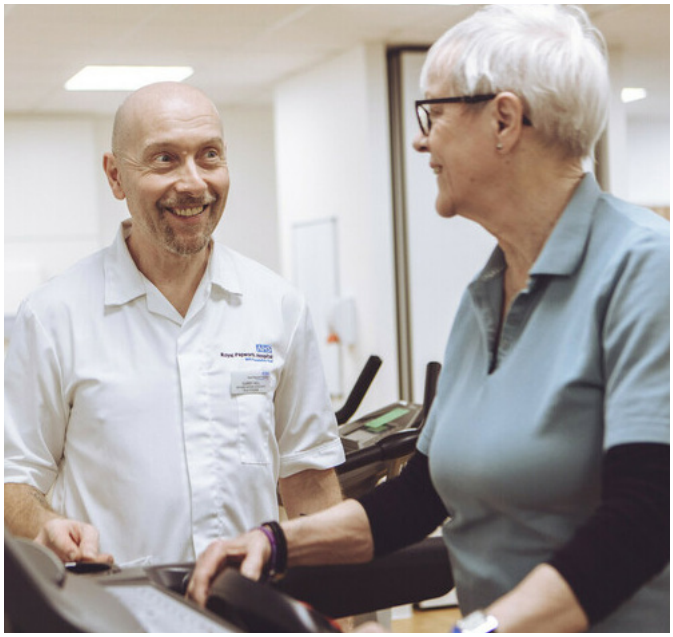
Structure, governance and management

Risk management

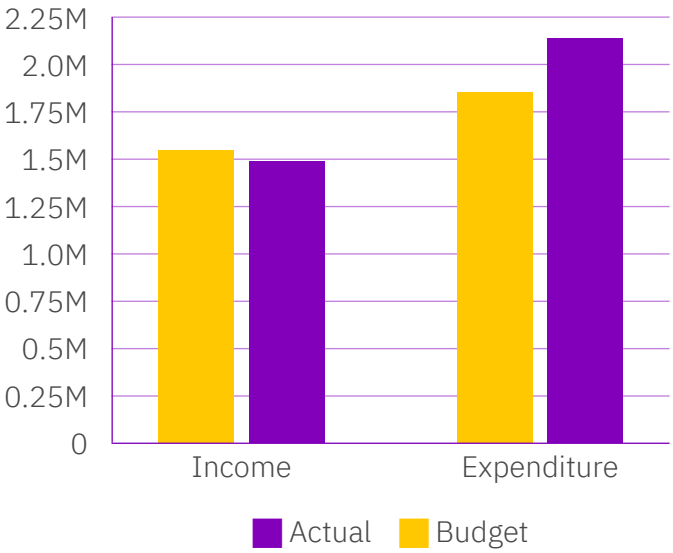
The trustees have overall responsibility for managing risk within the charity. A comprehensive risk register has been established and is regularly reviewed by the Finance and Risk Committee. Any identified risks are addressed with appropriate controls to mitigate or manage them effectively, ensuring the charity's operations remain secure and resilient.

Public benefit statement

The charity trustees have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission, in exercising their powers or duties. Charity activities and support provided are available to all those affected by PF.



Financial review 23/24



We are pleased to report that Action for Pulmonary Fibrosis (APF) remains in a positive financial position. Our total income for the year reached **£1,485,083**, compared with a budgeted **£1,539,400**. This shortfall was primarily due to lower-than-expected Legacy income and slower activity among trusts and corporations. However, community, challenge, and in-memory fundraising performed above expectations, helping to balance the overall income figure.

Our total expenditure for the year was **£2,191,881**, exceeding the budgeted **£1,825,107**. This variance largely reflects the award of 2 new research fellowships, whereby **£599,671** in costs were included within this year's accounts rather than being deferred.

Further details are provided in the attached accounts, but our overall financial health remains favourable. We look forward to building on this strong foundation in the coming year as we work toward our mission of supporting everyone affected by pulmonary fibrosis (PF).

The trustees consider that the charity will continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved. The trustees therefore consider it appropriate to adopt the going concern basis for the preparation of the accounts, as detailed in the auditor's report.

Statement on reserves

A new reserve policy was agreed by the Board of Trustees in February 2025. They believe it is prudent to hold a level of free reserves to have sufficient working capital to allow the fundraising, support and governance operations of the Charity to continue for 3-months (£350k) plus any associated dissolution expenses. This will allow the Charity to respond in a considered way to an adverse change in circumstances, giving sufficient time to enable emerging circumstances to be assessed and appropriate plans developed and implemented, without requiring a crisis response. In addition, the Trustees have agreed to hold £150k to meet an unexpected call on funds or opportunities that may present themselves at short notice. Having carefully considered the best interests of the Charity and its beneficiaries the Board of Trustees believes it appropriate to aim to hold a total of £500k free reserves. As of 30th June 2024, the charity's free reserves totalled £328,257, set against a target of £589,113. During the audit process, the charity reviewed it's reserves policy and on 22nd February 2025 approved a new policy and reserves statement with a target of £500k (against £352,015 in reserves). Whilst the charity remains below its reserves target, the Trustees are confident that reserves will increase in future years as fundraising increases and tighter cost control measures are brought in.

Fundraising Statement

APF is registered with the Fundraising Regulator, which shows we are committed to following the Code of Fundraising Practice and the Fundraising Promise outlined by the regulator. We use our own Ethical Partnerships and Donations Policy to reflect our commitment to transparent fundraising practices. The fundraising approach taken by APF involves raising funds from individuals, corporates, trusts and foundations, as well as community groups, stewarded by our dedicated team of professional fundraiser – which included a fundraising consultant in 2023/4. We have not logged any complaints in 2023/2024 regarding our fundraising activity. We use a fundraising database, Raiser's Edge, to monitor the activities of those fundraising for us.

Statement of trustee responsibilities

For the year ended 30 June 2024

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with 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).

The law applicable to charities in England and Wales, and in Scotland, requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and the incoming resources and application of resources, including the net income or expenditure, of the charity for the year.

In preparing those 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 judgements and accounting estimates that are reasonable and prudent;
- state whether applicable accounting standards and statements of recommended practice 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 charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts(Scotland) Regulations 2006 (as amended) and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

The trustees are members of the charity, but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Approved by the trustees on 14 March 2025 and signed on their behalf by
Mike Stubbins – Chair

Reference and administrative details

2023-24 Trustees	Notes
Sarah Weir OBE	Passed away in service on 19 December 2023
Howard Almond	Stepped down 4 November 2023 Board meeting
Elizabeth Bray	Stepped down 4 November 2023 Board meeting
Shama Malik	Resigned due to ill health. Formally noted at the Board meeting of 3 February 2024
Dr. Mike Stubbins	
Wendy Dickinson	
Dr. Rebecca Lang	
Stephen Morgan-Hyland	
Stephen Jones	
Dr. Simon Hart	
Dr. Helen Parfrey	
Matt Suddart	
Matthew Kemp	Appointed: 3 February 2024
Emma Goodes	Appointed: 9 November 2024

We extend our heartfelt thanks to our Trustees for their service and dedication to Action for Pulmonary Fibrosis (APF). For those that have stepped down, we wish them every success for the future, and we pay special tribute to Sarah Weir OBE, who sadly passed away in service in December 2023.

We are immensely grateful for their leadership, guidance, and unwavering commitment to our mission. Their contributions have helped shape APF's work to improve the lives of people affected by pulmonary fibrosis (PF).

In keeping with the charity's ethos of being patient led, we aim to recruit 70% of our trustees who have been personally affected by PF either as a patient or family member. Our trustees also include medical professionals who are leaders in PF care and research.

Two new trustees have joined the charity, Matthew Kemp and Emma Goodes.

Matt has personal experience with PF and Emma brings a strong charity finance skill set into the new role of treasurer.

Chief Executive Officer:
Louise Wright (to 5 May 2024)
Stef Cormack (interim CEO 5 May – 1 Sep 2024)
Daniel Saxton (appointed 1 Sep 2024)

Charity Number:
1152399 (England & Wales)
SC050992 (Scotland)

Registered Office:
Stuart House, East Wing, St John's Street,
Peterborough, PE1 5DD

Bankers:
CAF Bank Limited, 25 Kings Hill Avenue,
Kings Hill, West Malling, Kent, ME19 4JQ

Auditors:
Godfrey Wilson Limited
(Chartered accountants and statutory auditors)
5th Floor Mariner House, 62 Prince Street,
Bristol, BS1 4Q

Independent auditor's report

To the trustees of Action for Pulmonary Fibrosis

Opinion

We have audited the financial statements of Action for Pulmonary Fibrosis (the 'charity') for the year ended 30 June 2024 which comprise the statement of financial activities, balance sheet, statement of cash flows and the related 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 charity's affairs as at 30 June 2024 and of its incoming resources and application of resources, 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 Charities Act 2011 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 charity 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 the provisions available for small entities, in the circumstances set out in note 10 to the financial statements, 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 charity'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 other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and 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.

Independent auditor's report

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- the information given in the trustees' report is inconsistent in any material respect with the financial statements; or
- sufficient and proper accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees 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 they 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 charity'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 charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

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 procedures we carried out and the extent to which they are capable of detecting irregularities, including fraud, are detailed below:

(1) We obtained an understanding of the legal and regulatory framework that the charity operates in, and assessed the risk of non-compliance with applicable laws and regulations. Throughout the audit, we remained alert to possible indications of non-compliance.

(2) We reviewed the charity's policies and procedures in relation to:

- Identifying, evaluating and complying with laws and regulations, and whether they were aware of any instances of non-compliance;
- Detecting and responding to the risk of fraud, and whether they were aware of any actual, suspected or alleged fraud; and
- Designing and implementing internal controls to mitigate the risk of non-compliance with laws and regulations, including fraud.

(3) We inspected the minutes of trustee meetings.

Independent auditor's report

(4) We enquired about any non-routine communication with regulators and reviewed any reports made to them.

(5) We reviewed the financial statement disclosures and assessed their compliance with applicable laws and regulations.

(6) We performed analytical procedures to identify any unusual or unexpected transactions or balances that may indicate a risk of material fraud or error.

(7) We assessed the risk of fraud through management override of controls and carried out procedures to address this risk. Our procedures included:

- Testing the appropriateness of journal entries;
- Assessing judgements and accounting estimates for potential bias;
- Reviewing related party transactions; and
- Testing transactions that are unusual or outside the normal course of business.

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. Irregularities that arise due to fraud can be even 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 charity ' s trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008 and Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charity ' s trustees 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 charity and the charity ' s trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Date: 14 March 2025

GODFREY WILSON LIMITED
Chartered accountants and statutory auditors
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD

Godfrey Wilson Limited is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

Statement of financial activities

For the year ended 30 June 2024

	Note	Restricted £	Unrestricted £	**2024 Total £**	2023 Total £
Income from:					
Donations and legacies	3	17,147	1,060,805	**1,077,952**	1,131,442
Charitable activities	4	306,617	74,521	**381,138**	300,910
Investments		-	25,043	**25,043**	12,049
Other trading income	5	-	950	**950**	2,499
Total income		323,764	1,161,319	**1,485,083**	1,446,900
Expenditure on:					
Raising funds		-	388,202	**388,202**	248,560
Charitable activities		241,275	1,562,404	**1,803,679**	955,595
Total expenditure	7	241,275	1,950,606	**2,191,881**	1,204,155
Net income / (expenditure) and net movement in funds	10	82,489	(789,287)	**(706,798)**	242,745
Reconciliation of funds:					
Total funds brought forward		44,020	1,468,474	**1,512,494**	1,269,749
Total funds carried forward		126,509	679,187	**805,696**	1,512,494

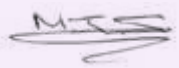
All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 19 to the accounts.

Balance sheet

For the year ended 30 June 2024

	Note	£	2024 £	2023 £
Fixed assets				
Tangible assets	13		**10,448**	9,794
Current assets				
Debtors	14	**97,741**		62,301
Current asset investments		**1,251,369**		1,494,961
Cash at bank and in hand		**122,075**		149,666
		1,471,185		1,706,928
Liabilities				
Creditors: amounts falling due within 1 year	15	**(260,139)**		(204,228)
Net current assets			**1,211,046**	1,502,700
Total assets less current liabilities			**1,221,494**	1,512,494
Creditors: amounts falling due after more than 1 year	16		**(415,798)**	-
Net assets	18		**805,696**	1,512,494
Funds	19			
Restricted funds			**126,509**	44,020
Unrestricted funds				
Designated funds			**350,930**	1,286,601
General funds			**328,257**	181,873
Total charity funds			**805,696**	1,512,494

Approved by the trustees on 14 March 2025 and signed on their behalf by



Michael Stubbins - Chair

Statement of cash flow

For the year ended 30 June 2024

	2024 £	2023 £
Cash provided by operating activities:		
Net movement in funds	**(706,798)**	242,745
Adjustments for:		
Investment income	**(25,043)**	(12,049)
Increase in debtors	**(35,440)**	(39,900)
Increase in creditors	**471,709**	117,630
Depreciation	**4,457**	1,633
Net cash (used in) / provided by operating activities	**(291,115)**	310,059
Cash flows from investing activities:		
Investment income	**25,043**	12,049
Purchase of tangible fixed assets	**(5,111)**	(11,427)
Net cash provided by investing activities	**19,932**	622
(Decrease) / increase in cash and cash equivalents in the year	**(271,183)**	310,681
Cash and cash equivalents at the beginning of the year	**1,644,627**	1,333,946
Cash and cash equivalents at the end of the year	**1,373,444**	1,644,627

Analysis of cash and cash equivalents

Current asset investments	**1,251,369**	1,494,961
Cash at bank and in hand	**122,075**	149,666
Cash and cash equivalents at the end of the year	**1,373,444**	1,644,627

The charity has not provided an analysis of changes in net debt as it does not have any long term financing arrangements.

Notes to the financial statements

For the year ended 30 June 2024

1. Accounting policies

a) General information and basis of preparation

Action for Pulmonary Fibrosis is a charitable incorporated organisation registered in Scotland, England and Wales. The registered office address is Stuart House, East Wing, St John's Street, Peterborough, PE1 5DD.

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Action for Pulmonary Fibrosis 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 notes.

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern, which the trustees consider appropriate having regard to the current level of unrestricted reserves. There are no material uncertainties about the charity's ability to continue as a going concern.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the items of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from the government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

d) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

Notes to the financial statements

For the year ended 30 June 2024

1. Accounting policies (continued)

e) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

f) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

g) Grants payable

Grants payable are charged in the year in which the offer is conveyed to the recipient except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attached have been fulfilled. Grants offered subject to conditions at the year end are noted as commitment but are not accrued as expenditure.

h) Allocation of support and governance costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities on the basis of staff time spent on each of these area. The percentages used were as follows:

	2024	2023
Raising funds	**23%**	21%
Charitable activities	**77%**	79%

i) Tangible fixed assets

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment	3 years

Items of equipment are capitalised where the purchase price exceeds £1,000.

j) 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.

Notes to the financial statements

For the year ended 30 June 2024

1. Accounting policies (continued)

k) Current asset investments

Current asset investments consists of short term cash deposits with a maturity date of less than one year from the balance sheet date held for investment purposes rather than to meet short term cash commitments as they fall due.

l) 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.

m) Creditors

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.

n) Financial instruments

The charity 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 with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

o) Pension costs

The charity operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

p) Operating leases

Operating lease payments are recognised as an expense on a straight-line basis over the lease term.

q) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

There are no key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements.

Notes to the financial statements

For the year ended 30 June 2024

2. Prior period comparatives: statement of financial activities

	Restricted £	Unrestricted £	2023 Total £
Income from:			
Donations and legacies	29,203	1,102,239	1,131,442
Charitable activities	248,891	52,019	300,910
Investments	-	12,049	12,049
Other trading activities	-	2,499	2,499
Total income	278,094	1,168,806	1,446,900
Expenditure on:			
Raising funds	-	248,560	248,560
Charitable activities	298,822	656,773	955,595
Total expenditure	298,822	905,333	1,204,155
Net (expenditure) / income	(20,728)	263,473	242,745
Transfers between funds	-	-	-
Net movement in funds	(20,728)	263,473	242,745

3. Income from donations and legacies

	Restricted £	Unrestricted £	**2024 Total £**
Legacies	-	25,687	**25,687**
Donations from individuals and fundraising	17,147	1,035,118	**1,052,265**
Total income from donations and legacies	17,147	1,060,805	**1,077,952**

Prior period comparative

	Restricted £	Unrestricted £	2023 Total £
Legacies	-	221,778	221,778
Donations from individuals and fundraising	29,203	880,461	909,664
Total income from donations and legacies	29,203	1,102,239	1,131,442

Notes to the financial statements

For the year ended 30 June 2024

4. Income from charitable activities

	Restricted £	Unrestricted £	**2024 Total £**
Corporate grants	98,500	17,767	**116,267**
Trusts and foundations	208,117	54,126	**262,243**
Speaker fees	-	2,628	**2,628**
Total income from charitable activities	306,617	74,521	**381,138**

Prior period comparative

	Restricted £	Unrestricted £	2023 Total £
Corporate grants	65,773	15,171	80,944
Trusts and foundations	183,118	33,828	216,946
Speaker fees	-	3,020	3,020
Total income from charitable activities	248,891	52,019	300,910

5. Income from other trading activities

	2024 £	2023 £
Merchandise sales	**950**	2,499
Total income from other trading activities	**950**	2,499

All income from other trading activities was unrestricted in the current and prior years.

6. Government grants

The charity received a government grant, defined as funding from the National Lottery Community Fund, to fund support services. The total value of such grants for the year ending 30 June 2024 was £168,118 (2023: £168,118). There were no unfulfilled conditions or contingencies attached to these grants in 2023/24.

For the year ended 30 June 2024

7. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	**2024 Total £**
Staff costs (note 11)	231,311	763,210	90,254	**1,084,775**
Freelance costs (note 11)	8,225	43,860	62,330	**114,415**
Travel and subsistence	-	-	41,252	**41,252**
Grants payable (note 8)	-	614,625	-	**614,625**
Training costs	-	-	396	**396**
Patient surveys	-	192	-	**192**
Fundraising costs	55,200	-	-	**55,200**
Marketing and communications	658	75,569	300	**76,527**
Premises costs	-	-	49,606	**49,606**
Admin costs	-	-	105,515	**105,515**
Other staffing costs	-	-	34,271	**34,271**
Governance costs	-	-	10,650	**10,650**
Depreciation	-	-	4,457	**4,457**
Sub-total	295,394	1,497,456	399,031	**2,191,881**
Allocation of support and governance costs	92,808	306,223	(399,031)	-
Total expenditure	**388,202**	**1,803,679**	**-**	**2,191,881**

Prior year comparative:

	Raising funds £	Charitable activities £	Support and governance costs £	2023 Total £
Staff costs (note 11)	139,242	529,057	57,014	725,313
Freelance costs (note 11)	5,350	74,700	79,212	159,262
Travel and subsistence	-	-	25,428	25,428
Grants payable (note 8)	-	8,473	-	8,473
Training costs	-	5,326	265	5,591
Patient surveys	-	5,434	-	5,434
Fundraising costs	40,917	-	-	40,917
Marketing and communications	2,127	101,122	523	103,772
Premises costs	-	-	33,564	33,564
Admin costs	-	-	54,209	54,209
Other staffing costs	-	-	30,779	30,779
Governance costs	-	-	9,780	9,780
Depreciation	-	-	1,633	1,633
Sub-total	187,636	724,112	292,407	1,204,155
Allocation of support and governance costs	60,924	231,483	(292,407)	-
Total expenditure	248,560	955,595	-	1,204,155

Notes to the financial statements

For the year ended 30 June 2024

8. Grants payable

During the year, 8 (2023: 3) new grants were awarded to 7 institutions (2023: 3) to fund research fellowships and support sessions and 9 to individuals (2023: 8) for travel to research events. Total grants committed to during the year were as follows:

	2024	2023
	£	£
Grants payable to institutions:		
Fellowships		
University of Cambridge	**299,998**	-
Imperial College London	**299,673**	-
Research awards		
British Association of Lung Research	**4,500**	-
Imperial College London	**2,500**	-
Support groups		
Huddersfield Support Group	**600**	-
Tunbridge Wells and Maidstone Support Group	**350**	-
Torquay Support Group	**500**	-
Ayrshire Support Group	**500**	-
Lanarkshire Support Group	**-**	500
Preston and Chorley Support Group	**-**	100
East Kent Support Group	**-**	250
Total grants payable to institutions	**608,621**	850
Grants payable to individuals	**6,004**	7,623
Total grants committed during the period	**614,625**	8,473

9. Grants commitments

	2024	2023
	£	£
Grant commitments brought forward	**56,931**	56,931
Grants committed during the period (note 8)	**614,625**	8,473
Grants paid during the period	**(91,920)**	(8,473)
Grant commitments carried forward	**579,636**	56,931

Notes to the financial statements

For the year ended 30 June 2024

10. Net movement in funds

This is stated after charging:

	2024 £	2023 £
Depreciation	**4,457**	1,633
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses	**337**	476
Auditors' remuneration:		
▪ Statutory audit (excluding VAT)	**5,775**	5,500

During the year, 2 trustees were reimbursed £337 for travel expenses (2023: 3 trustees were reimbursed £476 for training and related travel expenses). All expenses incurred were in the course of the organisation's charitable activities.

In common with other charities of our size and nature we use our auditors to assist with the preparation of the financial statements.

11. Staff costs and numbers

Staff costs were as follows:

	2024 £	2023 £
Salaries and wages	**958,898**	649,137
Social security costs	**88,882**	52,561
Pension costs	**36,995**	23,615
Freelance staff	**114,415**	159,262
	1,199,190	884,575

One employee earned between £70,000 and £80,000 during the year (2023: one employee earned between £60,000 and £70,000).

The key management personnel of the charity comprise the trustees and senior leadership team (2023: the trustees and the Chief Executive). The total employee benefits of the key management personnel were £344,633 (2023: £84,262).

Included in salaries and wages are redundancy and termination costs totalling £2,000. Redundancy and termination costs have been funded from unrestricted general funds (note 19).

	2024 No.	2023 No.
Average head count	**32**	21

12. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

Notes to the financial statements

For the year ended 30 June 2024

13. Tangible fixed assets

	Computer equipment	**Total £**
Cost		
At 1 July 2023	11,427	**11,427**
Additions in year	5,111	**5,111**
At 30 June 2024	16,538	**16,538**
Depreciation		
At 1 July 2023	1,633	**1,633**
Charge for the year	4,457	**4,457**
At 30 June 2024	6,090	**6,090**
Net book value		
At 30 June 2024	**10,448**	**10,448**
At 30 June 2023	9,794	9,794

14. Debtors

	2024 £	2023 £
Trade debtors	**55,806**	17,732
Accrued income	**30,037**	22,743
Prepayments	**11,898**	21,826
	97,741	62,301

15. Creditors: amounts due within 1 year

	2024 £	2023 £
Trade creditors	**70,913**	113,872
Accruals	**6,930**	10,104
Grant commitments (note 9)	**163,838**	56,931
Social security	**18,458**	23,321
	260,139	204,228

16. Creditors: amounts due after 1 year

	2024 £	2023 £
Grant commitments (note 9)	**415,798**	-

For the year ended 30 June 2024

17. Contingent assets

Action for Pulmonary Fibrosis were notified of a number of legacies during the year ended 30 June 2024, for which the amount receivable cannot be reliably estimated. These financial statements do not include any estimated future amounts receivable. Indications are that the estimated value of these potential legacies is in the region of £72,000.

18. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	**Total funds £**
Fixed assets	-	-	10,448	**10,448**
Current assets	126,509	930,566	414,110	**1,471,185**
Current liabilities	-	(163,838)	(96,301)	**(260,139)**
Non-current liabilities	-	(415,798)	-	**(415,798)**
Net assets at 30 June 2024	**126,509**	**350,930**	**328,257**	**805,696**

Prior period comparative	Restricted funds £	Designated funds £	General funds £	Total funds £
Fixed assets	-	-	9,794	9,794
Current assets	44,020	1,343,532	319,376	1,706,928
Current liabilities	-	(56,931)	(147,297)	(204,228)
Net assets at 30 June 2023	44,020	1,286,601	181,873	1,512,494

Notes to the financial statements

For the year ended 30 June 2024

19. Movements in funds

	At 1 July 2023 £	Income £	Expenditure £	Transfers between funds £	**At 30 June 2024 £**
Restricted funds					
Onevoice ILD	-	90,000	(19,540)	-	**70,460**
Trevi Theraupeutics	13,207	8,500	(8,498)	-	**13,209**
Hospital Saturday Fund	630	-	-	-	**630**
National Lottery Community Fund	10,919	168,118	(179,037)	-	**-**
D'Oyly Carte Charitable Trust	172	-	-	-	**172**
Garfield Weston	16,401	35,000	(11,959)	-	**39,442**
Northern Ireland donations	1,213	-	-	-	**1,213**
Research donations	-	17,146	(17,146)	-	**-**
Support donations	-	5,000	(5,000)	-	**-**
Scotland donations	623	-	(95)	-	**528**
Wales donations	855	-	-	-	**855**
Total restricted funds	44,020	323,764	(241,275)	-	**126,509**
Unrestricted funds					
Designated funds					
Research fund	950,601	-	(599,671)	-	**350,930**
Reserve fund	336,000	-	-	(336,000)	**-**
Total designated funds	1,286,601	-	(599,671)	(336,000)	**350,930**
General funds	181,873	1,161,319	(1,350,935)	336,000	**328,257**
Total unrestricted funds	1,468,474	1,161,319	(1,950,606)	-	**679,187**
Total funds	1,512,494	1,485,083	(2,191,881)	-	**805,696**

Purposes of restricted funds

Onevoice ILD	Funding for APF to act as a central voice to advocate for patients with a range of Intersitial Lung Diseases.
Trevi Theraupeutics	This fund is for support services in Scotland (including SG coordinator salary) which launched in 22/23.
Hospital Saturday Fund	This fund is for support services.
National Lottery Community Fund	This fund is for support services.
D'Oyly Carte Charitable Trust	This fund is to enable new and existing APF volunteers to receive training in order to better support patients and carers.

For the year ended 30 June 2024

19. Movements in funds (continued)
Purposes of resticted funds (continued)

Garfield Weston	This fund is for support services growing volunteering, and is to be used towards volunteering salary costs, services admin and volunteer recruitment, training, expenses and marketing.
Northern Ireland donations	These are donations received specifically for Northern Ireland.
Research donations	These are donations received specifically for research.
Support donations	These are donations received specifically for support services.
Scotland donations	These are donations received specifically for Scotland.
Wales donations	These are donations received specifically for Wales.

Purposes of designated funds

Research fund	A principal objective of Action for Pulmonary Fibrosis is to support and fund Research into the disease. Trustees have previously agreed to designate £951k for research to fund further research fellowships, with agreements totalling £599,671 awarded in the current year.
Reserve fund	The Reserve Fund had been established, in line with the charity's previous reserves policy, to retain a minimum of 50% of projected annual core expenditure separately as reserves. Reserve funds are now held in general funds, to more accurately reflect the reserves available to the charity.

Transfers between funds
Transfers represent the incorporation of reserve funds within unrestricted general funds.

For the year ended 30 June 2024

19. Movements in funds (continued)

Prior period comparative

	At 1 July 2022 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2023 £
Restricted funds					
Boehringer Ingelheim	-	45,000	(45,000)	-	-
Trevi Theraupeutics	24,988	20,773	(32,554)	-	13,207
Hospital Saturday Fund	1,160	-	(530)	-	630
National Lottery Community Fund	10,920	168,118	(168,119)	-	10,919
D'Oyly Carte Charitable Trust	172	-	-	-	172
Garfield Weston	24,892	-	(8,491)	-	16,401
Northern Ireland donations	2,616	-	(1,403)	-	1,213
Research donations	-	28,348	(28,348)	-	-
Support donations	-	11,000	(11,000)	-	-
Scotland donations	-	4,000	(3,377)	-	623
Wales donations	-	855	-	-	855
Total restricted funds	64,748	278,094	(298,822)	-	44,020
Unrestricted funds					
Designated funds					
Research fund	687,128	-	(8,473)	271,946	950,601
Reserve fund	336,000	-	-	-	336,000
Total designated funds	1,023,128	-	(8,473)	271,946	1,286,601
General funds	181,873	1,168,806	(896,860)	(271,946)	181,873
Total unrestricted funds	1,205,001	1,168,806	(905,333)	-	1,468,474
Total funds	1,269,749	1,446,900	(1,204,155)	-	1,512,494

20. Operating leases

The charity had operating leases at the year end with total future minimum lease payments as follows:

	2024 £	2023 £
Amount falling due:		
Within 1 year	**26,482**	8,179
Within 1-5 years	**1,306**	
	27,788	8,179

Notes to the financial statements

For the year ended 30 June 2024

21. Related party transactions

Stephen Jones, trustee of Action for Pulmonary Fibrosis (APF), is also the chair of European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF). During the year APF received income of £2,628 from EU-IPFF for speaker fees (2023: £600 for speaker fees). No amounts were outstanding at year end.

The trustees are not aware of any other related party transactions during the period.

Action for Pulmonary Fibrosis

General enquiries

01733 839642

info@actionpf.org

Contact our support team

supportline@actionpf.org

Support line: 01223 785725

Registered Office & Operational Address

Stuart House, East Wing, St John's Street, Peterborough PE1 5DD

actionpf.org

Charity Commission England & Wales Registered Charity Number: 1152399

Scottish Charity Regulator Number: SC050992

ACTION FOR PULMONARY FIBROSIS

England & Wales - Charity number 1152399

Accounts

2022
2023

Action for Pulmonary Fibrosis

Annual Report & Audited Financial Statements

For the year ending 30 June 2023

Charity Commission England & Wales Registered Charity Number: 1152399 • Scottish Charity Regulator Number: SC050992

Contents

2022
2023

Introduction from our Chair and Chief Executive	3
Who we are and why we are needed	4
Our vision, mission and values	6
Reference and administrative details	7
Our vital services	8
Research: Contributing to global research and the search for new innovative treatments	18
Celebrating our ten-year anniversary	21
Influencing others to change lives	23
Fundraising: together we are stronger	29
Looking ahead – future plans and priorities	32
Structure, governance and management	33
Financial Review 2022/23	36
Statement of trustee responsibilities	37
Independent Auditor's Report	38

General enquiries:
01733 839642
info@actionpf.org

Email our support team:
support@actionpf.org

Follow us on socials:

Support line:
01223 785725

www.actionpf.org

Introduction from our Chair and Chief Executive

Looking back over the year, which marked APF's 10 year anniversary, fills us both with such pride. Over the last year, thousands of people used our support line, we reached over 4 million people on social media and hundreds of thousands visited our website for trusted information and advice.

This is a world away from the support available to people living with pulmonary fibrosis (PF) in 2013, when APF was set up.

But this doesn't mean we feel complacent – there is so much still to do.

Sadly, as you read throughout this report, many challenges remain; people are diagnosed late, wait too long for treatment and have to fight for the care and support that is their right.

Now, through our One Voice ILD* initiative we are working with people living with PF, healthcare professionals, NHS commissioners, MP's and other stakeholders to bring about the long-term systematic changes in treatment and care for people affected by PF across the UK. This is a bold and ambitious project, with people living with PF at the heart of change.

Although we are still a small charity, we punch well above our weight. We are significantly influencing research in the UK and globally. We ensure the voice and experience of people living with PF inspires, shapes and improves research, and fund fantastic researchers pushing the boundaries of understanding of PF, bringing us closer to our goal of stopping PF.

We are especially proud and humbled by the work our volunteers, supporters and partners do to support APF and ensure more people get better access to the support they desperately need.

Living with and being affected by PF is an enormous burden. Running a support group, organising a fundraiser, being a befriender or research champion and contributing to our work, on top of the daily challenges the disease brings, is a miracle. We are in awe and humbled by the support of our volunteers and supporters past and present. Thank you.

We will not rest until PF is stopped in its tracks. We hope you'll continue to be part of APF's journey over the next 10 years.

Steve Jones
(Chair of Trustees)

Louise Wright
(Chief Executive)

*Pulmonary Fibrosis is a type of 'Interstitial Lung Disease'.

Who we are and why we are needed

Reaching out to people to live well and live better with pulmonary fibrosis

APF is the UK's leading charity dedicated to improving the health and wellbeing of people affected by PF (or lung scarring).

PF describes a range of progressive lung diseases that scar the lungs making them stiffer and smaller, leading to low oxygen levels and reduced lung capacity. As breathlessness increases, ordinary daily tasks – washing, dressing, walking – can become exhausting, which impacts increasingly on the whole family and especially carers.

Progressive pulmonary fibrosis affects over 70,000 people a year. It is a life-limiting disease. While trends in life expectancy are improving, no one can tell an individual exactly how long they will live. Research that suggests an average life expectancy of between 3–5 years, was carried out before treatments that can slow down the rate of lung scarring were widely available. There are many factors that will affect life expectancy such as the cause of pulmonary fibrosis, a person's age and any underlying health conditions.

To support people living with PF, we offer trusted, evidenced-based information and advice, and share knowledge and expertise. Our thriving and growing community network for people with lived experience, means that everyone affected by lung scarring can find support, help and friendship. We aim for people to live well for longer and find hope for the future.

We contribute to finding better treatments for PF by funding UK based research and amplifying the patient voice within the global research community.

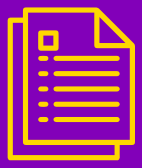
Through awareness campaigns we tackle misconceptions and raise awareness of the signs and symptoms of PF among the public, so people better understand the impact of living with PF.

Alongside this vital work we support healthcare professionals so they can deliver the best care. Working with the NHS and a wide range of partners we challenge health inequalities to make PF a priority for respiratory services.

We remain deeply indebted to our partners, supporters, donors and volunteers who are integral to our work.

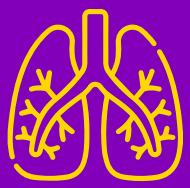
Why we are needed

Demand for our services is rapidly out-stripping our capacity to support people. Too many people say they wish they found APF sooner.

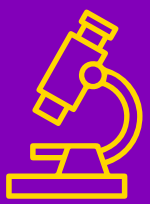


People living with PF can feel isolated and alone, and struggle to find support and trusted and accurate information about the disease.

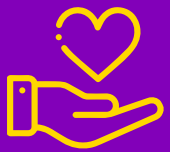
Many health care professionals have limited understanding of PF and how to correctly diagnose it. Symptoms can be confused with other respiratory conditions and with lengthy hospital waiting times it commonly takes a year to get an accurate diagnosis.



There is no national NHS pathway of care, creating postcode lotteries for treatment – with those close to specialist hospitals often getting better treatment and care.



Research into PF is seriously under resourced. Despite over 30% of deaths being attributed to respiratory illness, respiratory research funding accounts for a mere 2% of UK investment.



We are determined to reach out to every person affected by PF. By to live well and live better with the disease and stop PF.

Our vision, mission and values

APF's vision is to find a cure for pulmonary fibrosis so everyone affected by the disease has a better future.

We provide support to families, raise awareness, campaign and educate to improve access to the highest standard of care. We are committed to finding a cure through funding research.

Our values drive everything we do:

Patient-led: We empower patients, who are at the heart of everything we do.

Caring and compassionate: We respect and understand the needs of patients and carers, and help them to get the support they need.

Striving for excellence: We work with integrity and professionalism in all that we do.

Open and approachable: We ensure people affected by PF feel able to turn to us for advice and support in their time of need.

Ambitious: We will improve the lives of people affected by PF and be bold in the ways we do this.

Reference and administrative details

Charity Number:

1152399 (England & Wales)
SC050992 (Scotland)

Registered Office & Operational Address:

Stuart House, East Wing
St John's Street
Peterborough
PE1 5DD

Charity Trustees:

Steve Jones* (Chair)
Howard Almond*
Elizabeth Bray**
Wendy Dickinson**
Dr Simon Hart
Dr Rebecca Lang**
Shama Malik* (appointed 22 April, 2023)
Stephen Morgan-Hyland**
Dr Helen Parfrey
Dr Michael Stubbins**
Matthew Suddart**
Sarah Weir OBE* (appointed 22 April, 2023)

* Living with PF
** Family member of someone with PF

In keeping with the charity's ethos of being patient led, over 75% of trustees have been personally affected by pulmonary fibrosis either as a patient or family member. Our trustees also include medical professionals who are leaders in pulmonary fibrosis care and research.

Chief Executive Officer:

Louise Wright

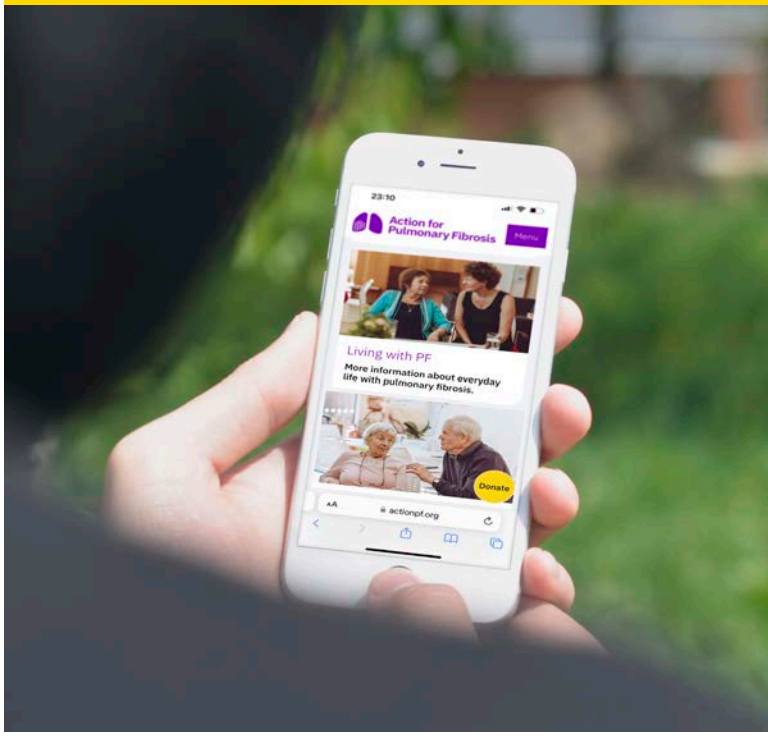
Principal Advisors:

Bankers:

CAF Bank Limited
25 Kings Hill Avenue
Kings Hill
West Malling Kent
ME19 4JQ

Auditors:

Godfrey Wilson Limited
(Chartered accountants and statutory auditors)
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD



Our vital services

More than ever, far too many people face a diagnosis of PF feeling confused, frightened and devastated. We believe no one should have to face PF alone. Demands for our services continue to rise exponentially.

Unprecedented NHS backlogs, an NHS postcode lottery, late diagnosis due to the Covid-19 pandemic, and people being eligible for treatment after changes to prescribing contribute to this challenging situation. Alongside this, PF's profile continued to grow as we extended our reach to help more people.

In response we have increased different areas of our work in Support Services. We are committed to reaching more people with the right information at the right time in their PF diagnosis and supporting the healthcare professionals who care for them.

Supporting people's changing needs

Our support line is an essential service. After a devastating diagnosis, many feel lost and alone and need somewhere accessible to reach out to where they feel understood and get expert specialist information and support.

Additional funding this year allowed us to transform the support line into a more convenient and responsive service. We recruited additional clinical nurse support, ending the need for people to pre-book appointments to speak to a specialist advisor. Our team also now supports people reaching out to APF on social media.

As a result, demand has rocketed to 1062 calls this year (251 in 2021-22) and 2102 people in total supported through calls in and out, email, web forms and social media (363 last year).

The nature of enquiries varies significantly. Medical queries about the condition, advice on preparing for clinical appointments alongside uncertainties around travel, finances and disability are just some of the common calls we receive. Sadly, another common theme is dealing with distress caused by NHS waiting times and inequality in accessing treatment.

Alongside clinical information about the condition, we offer practical advice and signpost or refer to other charities and organisations, provide resources, and emotional and wellbeing support. We also receive calls from carers and people who are bereaved. Call backs are offered to people needing longer-term support for more complex enquiries.

Becoming members of the Helplines Partnership this year ensures we stay at the forefront of best practice and the right assurances are in place.

Alongside significant growth, our impact and quality measures have improved:

- 94% of support line callers were likely or extremely likely to recommend the service
- 83% of callers felt more empowered to make decisions

We stayed in touch with and offered direct support to over a thousand new patients and carers after they were referred to us by their health care professional.

> *"Thank you to the lovely lady who answered, she made me feel a lot calmer about what my dad is going through at the moment."*
>
> **Lucy, caller from Cambridge**

> *"I've had more information from APF than anyone. I've moved forward; the ball is rolling now."*
>
> **Harry – newly diagnosed with pulmonary fibrosis**

The support line offers a vital lifeline to many, and it also helps us understand the changing unmet needs of people with PF and their families so that we can develop our information, education and support as well as campaign for change.

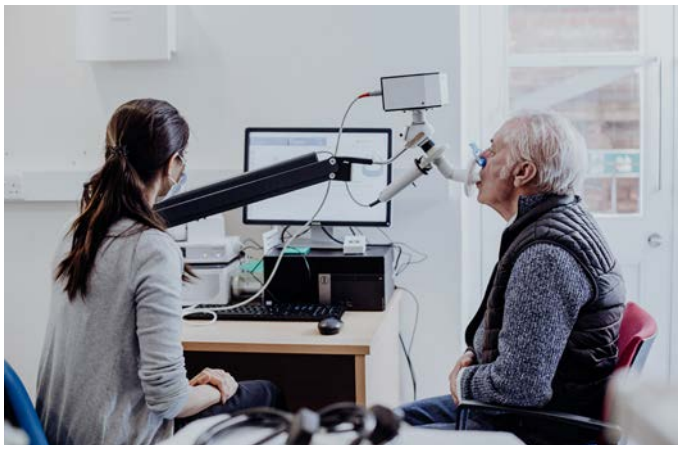
Demand for the support line continues to grow and we must ensure we can continue to grow the capacity of the service so we can meet people's needs in a timely way.

New initiatives to support healthcare professionals

Building relationships with healthcare professionals is a critical way to find people earlier in their diagnosis. It means that patients and families are referred to APF as soon as they are part of a respiratory service – not when they are in crisis.

A new online referral form for healthcare professionals launched this year, alongside the facility to take referrals from busy NHS clinical teams by email and phone. We are delighted to see that referrals from health professionals have increased to around 20 per month through the year.

Nevertheless, far too many people who need our support still don't get to us soon enough.



Befriending – friendship and compassion from the heart

There is no substitute for speaking to someone who really understands you because they've been there themselves – a principle that lies at the heart of our befriending service.

The scheme works by matching people and family members living with or affected by PF to our amazing team of trained volunteers. Our befrienders come from a variety of backgrounds and lived experiences. They build a nurturing relationship around people's unique needs and circumstances, and an empathetic approach as they are often negotiating their own PF journey.

Befriendees primarily want to connect with someone who understands what they are going through. Sadly, the vast majority (80%) of people who ask to be matched with an APF Befriender tell us they received mediocre, poor or no wellbeing support after their PF diagnosis and are coming to us for further support.

This year we grew our befriending service slightly to support 50 people (47 last year).

- All respondents said they would be 'extremely likely to recommend the service.'
- All felt either very or extremely well connected to someone who understands them.
- All felt very or extremely well supported by their befriender.

We grew our befriending team by almost 20% last year to 25 incredible volunteers by the end of the year. We pay tribute and give heartfelt thanks to all our befrienders. Their compassion and time to listen provides invaluable support at a time when people need them most.

> *"My befriender has given me the confidence to ask questions in healthcare appointments."*
>
> **Izzy, befriendee**

> *"I've only been a befriender for a few months but already it is helping me to feel connected to my sister. It feels good to know that I am passing on bits of information that helped and comforted her, sometimes sadly too late. My sister would have benefitted so much from something like APF's befriender service. She didn't always want to talk to her family about what she was going through for fear of upsetting them – she was selfless like that – but she might have opened up to a befriender who was more removed. I want to make sure others can access this service and I know she would too."*
>
> **Sophie, befriender**

"I spoke to Elaine for three years. To begin with, we spoke every week but, over time the time between calls naturally elongated. I really can't thank her enough for her support during that time. I still deal with grief every day, it never goes away, but speaking to Elaine helped."

Linda, befriendee

"The befriending service is invaluable to me. Knowing there are people who are coping and can help you get through a difficult period of your life and how best to adapt is tremendously useful. Thank you."

Michael, befriendee

Tackling myths about pulmonary fibrosis with trusted information

APF are proud to be a source of trusted and evidence-based information. Many people with PF have stories of myths and misinformation they encounter when trying to find out more about the disease. This negatively impacts their wellbeing and understanding on how to live well with PF.

Our information and support webpages were sought out by people over 727,000 times this year. People searched for general information on living well with PF as well as lifestyle advice on things like holiday travel with the disease. To support our information provision, we also recruited a new clinical Information Coordinator.

We produce a wide range of printed resources about living well with PF. These are sent directly by us and distributed by specialist healthcare professionals to their patients.

Our bi-annual magazine 'Insider' continues to share stories of living well with PF as well as sharing news and information to help people feel connected and informed.

"After my diagnosis, support from my GP was non-existent. I was at a loss, not understanding what had been thrust on me or what to expect. My consultant suggested I look into your charity and having done so it has been the one big support I have. The information provided has answered so many questions. I just wanted to thank you for all the support I have found and reassurance as to what to expect. Keep up the fight!"

Roger, living with PF

Our vital services:

Welcoming our new patient information panel

Everything we do is driven by the needs of people living with PF. To ensure our information content meets the different needs of living with PF a team of sixteen volunteers, all of whom are affected by PF, have become newly formed Patient Panel. They offer advice and guidance on what our priorities should be and give feedback on resources (like leaflets and packs).

We are so grateful for all the insight and guidance our volunteers provide and look forward to developing this further next year.

Education

Through hosting live events, our education offer is an interactive way of bringing experts and people with lived experience together. People benefit from seeing specialists in action and being in a live learning environment with other people with the disease.

This year we held two major education events to help educate, empower and support.

Spotlight on Scotland

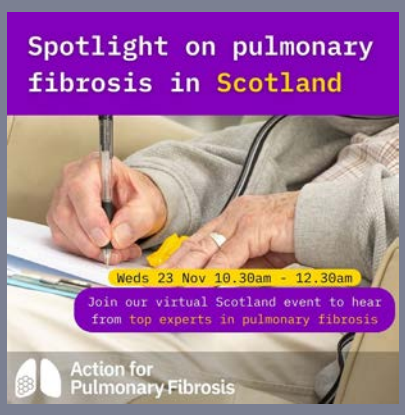
‘Spotlight Scotland’ was our first virtual patient information event specifically for Scotland bringing together clinicians, specialist nurses and patients to discuss health and lifestyle needs of PF.

- 222 people registered to watch the event.
- Over 95% agreed or strongly agreed that they understood more about PF after the event.
- Over 90% felt more able to manage, or more able to support others to manage life with PF.
- Over 90% improved their sense of hope for the future.

After the event we were delighted to be able to bring people together to launch support groups and see a greater awareness across Scotland of the support available.

> *“This meeting has left me feeling better as regards not only my own future but also the future of others who may later suffer from this disease... the positivity as regards the research to slow down and eventually control this disease is very good news indeed.”*

> *“Excellent, informative webinar with great speakers. Great to have patients speaking and participating.”*



National APF online information day

In partnership with the Royal Brompton and Harefield hospitals, part of Guy's and St Thomas's NHS Foundation Trust, and Liverpool University Hospitals NHS Trust we held our second national live-streamed information day. There was also the option for people with limited digital access to attend in person at Aintree Hospital.

We were delighted to work alongside leading clinicians in the UK in the field of respiratory care. Attendees could put their questions to a range of experts including:

– **Professor Sujal Desai**
Consultant Radiologist

– **Dr Peter George**
Consultant Lung Specialist

– **Dr Lisa Spencer MBE**
Consultant Lung Specialist

– **Professor Athol Wells**
Consultant in Respiratory Medicine

Subjects covered a wide range of topics including; 'Bloods, biopsies and scans', 'How do ILD doctors make a diagnosis?' and 'The ins and outs of oxygen'.

- Over 1000 registered to watch this event which had 22 speakers and 239 questions were asked.
- Over 90% agreed or strongly agreed the day helped them understand more about PF.
- Over 90% agreed or strongly agreed the day provided them with a sense of hope for the future.

> *"There is no other way for me to get the kind of information you shared. It will help me discuss my own condition better with my friends and family. The speakers were fantastic."*
>
> **Heba, attendee**

> *"The most positive day I've had since being diagnosed with PF."*
>
> **Daniel, attendee**

Support Networks: together we are stronger

Support groups offer a welcoming and understanding space where people come together in their local area. They are an absolute lifeline for many people who can feel frightened and alone after a diagnosis of PF and want to connect with others.

This year, NHS teams felt more exhausted and overwhelmed. They are seeing existing backlogs increasing as hugely inflated case-loads aren't matched with resource. Support for people with PF and our NHS colleagues is needed more than ever.

This is where we truly see the value of Support Groups. They are led by a mix of incredible people some who are living with PF, others who are specialist healthcare professionals.

Our dedicated regional co-ordinators work in partnership with them, providing expert guidance, financial support and networking opportunities. We also host a national Support Group Leaders' forum and lead national online support groups for people on a transplant journey, carers, and those in Wales.

We proudly supported between 60 and 70 groups who were starting up, relaunching, wrestling with challenges or seeking to grow and develop groups.

Many people living with PF were still shielding from Covid-19 so in-person support group meetings remained difficult. Despite challenging circumstances the tenacious network of local partner groups offered incredible support to many and still managed to hold some stand-out events including a special event at Windsor Support Group with Dr Nazia Chaudhuri.

> *"APF helped our group get started."*
>
> **Support Group leader, southern region**

> *"It's really helpful getting the updates. You've got your finger on the pulse so I don't have to."*
>
> **Support Group leader, northern region**

> *"Our partnership with APF works well. I couldn't come close to providing the quality of support I do without APF."*
>
> **Senior nurse specialist**

Research:

Contributing to global research and the search for new innovative treatments

With no imminent cure for the disease and just two antifibrotic drugs to slow the progression of PF, delivering better diagnosis, treatment and care is urgently needed.

Research helps us to answer questions and solve problems but is critically underfunded. Every penny we invest in research has the potential to make a big difference.

APF plays a vital role in the research landscape of the UK and internationally.

This year we funded research through grants and opportunities to support the careers of the next generation of researchers. Working closely with the research community we helped embed the lived experience of people with PF to improve the quality and impact of research.

> *"APF supported Tony through his journey (with PF), and we really hope our donations play a big part in finding a treatment for this terrible disease."*
>
> **Lisa, APF Fundraiser**

Funding vital research and putting patients at the heart of research

This year we launched two new research fellowships that will lead to a significant investment in research from 2024 onwards, helping to find treatments that could slow, stop or reverse fibrosis.

Other research we have funded looks at how changes in cells in the body contribute to the disease.

Our team of research volunteers have worked hard to encourage greater participation in research studies by people living with the condition. They have also networked with clinicians and researchers to improve patient inclusion in research. Working alongside drug developers, universities and healthcare professionals our APF community have provided expert insight about living with PF to over thirty research projects. These included projects to develop new treatments, digital technology and enhanced remote care.

We funded 8 awards so researchers could attend international conferences. By collaborating with the British Association of Lung Research, we were able to create a unique opportunity for a budding researcher to be mentored by experts through a summer internship.

> *"This summer internship has given me real-world experience. It allowed me to develop my skills in a range of areas such as raw data handling and also exposed me to common problems faced in research that cannot be simulated in a classroom environment."*
>
> **Researcher, Francesca Thornton-Wood**

REMAP-ILD: A bold project for 2023

This year we continued to collaborate on a bold and ambitious international project called REMAP-ILD. We want to revolutionise the way clinical trials are carried out, meaning more people can take part and we can find treatments faster. Our research volunteers co-developed a suite of webinars attended by people from over 25 countries. These have already been viewed over 2000 times.

APF funded genetic research: understanding more about DNA and pulmonary fibrosis

This year marked the conclusion of Dr Richard Allen’s four-year APF funded research programme.

Dr Allen helped us understand more about why some people get PF by discovering new genes that are associated with the disease. This will help us to identify effective treatments more quickly. Dr Allen is now a lecturer at University of Leicester and continuing his research into PF.

Dr Richard Allen and Chair Steve Jones at the end of his research fellowship.

"Dr Allen's contributions to the genetic understanding of PF are significant. The work funded by APF is influencing scientists around the world and shaping what we know about PF."

Wendy Adams, Director of Research APF

Celebrating our ten-year anniversary

10

2013 – 2023

This year, we're celebrating 10 years of Action for Pulmonary Fibrosis.

What we have achieved over the past decade from starting the first support groups, to influencing NICE guidelines on access to treatment, and funding research into pulmonary fibrosis and growing our support line would not be possible without the passion and dedication of our APF community. Thank you.

It is a privilege to be part of the PF journey of the people in our community. As we have been over the last ten years, we are determined to be there every step of the way for every person who needs us for the next ten years and beyond.

> *"I still remember the meeting where we considered the first possibility of forming a charity. It didn't seem possible that Action for Pulmonary Fibrosis would grow into something this amazing 10 years later."*
>
> **Professor Gisli Jenkins,**
> **APF President and founding member**

Gisli Jenkins

Ten years. One goal. #StopPF

Our journey

10 groundbreaking years!

2013

FOUNDED AND OUR FIRST DONATIONS

Action for Pulmonary Fibrosis (APF) is founded. Donations flood in from supporters affected by PF. Income in Year 1 exceeds expectations at £50K.

FIRST SUPPORT GROUPS

Founding Chair Mike Bray and other trustees criss-cross the country meeting health care practitioners and encouraging new support groups. Over 25 support groups formed in first three years, with sponsorship from pharmaceutical companies.

APF INFLUENCES NICE

APF influences NICE on quality standards for IPF treatment and on new antifibrotic drugs.

2015

APF INTERNATIONAL

APF is a founder member of the European Pulmonary Fibrosis Federation and establishes links with PF organisations in North America.

FUTURE PROOFING CARE FOR IPF PATIENTS

APF's report on its first survey used to campaign in parliament for better care.

2017

ON THE UP

Our yearly income was £360k, reaching new levels.

2018

A GROWING TEAM

Board of trustees decides to appoint full-time staff to drive development of the charity. Steve Jones becomes Chair of Trustees.

CAMPAIGN ON ACCESS TO ANTIFIBROTICS

APF launches campaign to persuade NICE and the Scottish Medicines Consortium to make antifibrotics more widely available for people with PF.

NEW WAYS TO HELP

Support Line launches, reaching 200 people in its first year.

2019

HERE FOR ALL TYPES OF PF

APF broadens it's aims so it serves everyone affected by PF, not just IPF.

RESEARCH PROJECTS LAUNCHED

Our first two research fellowships, costing £600K, are funded helping to make life-changing progress possible.

2020

ONLINE ONLY

We help 30 support groups meet online throughout the pandemic and implement a buddying system for people feeling isolated.

COVID HUB HITS

13,000 people visit our new online Covid Hub in one month.

2021

FUNDING WIN

We're awarded a £489k grant from the National Lottery Community Fund to extend our services for people living with PF now.

FIRST VIRTUAL EDUCATION DAY

During the pandemic, our first virtual education day sees more than 800 people registering to join.

ANTIFIBROTIC CAMPAIGN SUCCESS

Following APF's campaign, NICE and the SMC authorises the antifibrotic drug nintedanib for use by almost all PF patients in UK.

2022

PRIORITISING RESEARCH

1400 people help to produce our top 10 research priorities for pulmonary fibrosis in the UK.

CELEBRITY SUPPORT

Our first celebrity appeal goes live, with Julie Hesmondhalgh as the face of the campaign.

2023

CAMPAIGNING FOR CHANGE

The launch of #OneVoiceILD with health care professionals across the UK to improve treatment and care for people with PF.

ON THE UP

APF is on track to raise over £1m in 2023 which will help us reach more people than ever and fund vital new research.

Influencing others to change lives

We understand people affected by PF often have to fight to get the support they need. That's why we use our collective voice to spearhead changes on the issues that matter most to people with PF.

One significant area of new activity this year, and one where APF played a pivotal role, was bringing people, groups and communities together and mobilising them to influence government, statutory bodies and the NHS.

Securing the approval and support from the PF and the healthcare community to help us tackle the complex challenges associated with this condition is critical.

We are proud to be leading this fledgling movement.

APF and our community secures historic win to secure patient access to life saving drugs

It is essential that those with PF get access to treatment as quickly as possible.

Previously, someone with idiopathic PF could only access antifibrotic medicine if they had a predicted forced vital capacity (or lung capacity) of between 80%-50%. This excluded many people with PF who would benefit from the few treatments available.

Today, after continual and persistent campaigning from APF, anyone diagnosed with PF can have access to treatments at the point of diagnosis. This is a significant milestone and achievement.

Sending our collective message to government

Joining forces with our PF community, we launched our first government petition during our Pulmonary Fibrosis Awareness month in September 2022.

Over 13,000 people signed our petition calling for increased NHS funding for interstitial lung disease. This is an immense achievement as it helps improve the visibility of PF among decision-makers in government.

The government returned with a standard response, as we expected, given that it was the first petition on a little-known disease. But this is the start, not the end.

To make a sustained impact in influencing government and the NHS a new dedicated Policy and Public Affairs team was created this year to put PF on the national health agenda. We look forward to seeing this work drive change in the next few years.

OneVoiceILD – our APF community working together to improve NHS care

This year we took a pivotal role in launching an ambitious new initiative: One Voice ILD

A new and rapidly growing movement, OneVoice ILD strives to improve treatment, care and support for people affected by PF. Led by APF, this group is committed to greater collaboration. It brings together the entire PF community of people affected by the disease, healthcare professionals, policy makers, charities, pharmaceuticals and corporate partners to make change happen.

In February 2023 we established three main priorities for the coming year:

1. Raise awareness of PF with parliamentarians who can support our mission;
2. Gather data to build an accurate picture of the care received by people living with PF and the impact on their quality of life; and
3. Develop the gold standard in care that will help clinicians and people living with PF.

Dr Nazia Chaudhuri, ILD Respiratory Consultant and Chair of the British Thoracic Society Specialist Advisory Group on ILD, said the following words...

> *"As one voice working together with patients and carers we can continue to raise awareness of pulmonary fibrosis and ensure our policy makers are aware of the need to invest in services so we can continue to provide equitable and safe care for our patients."*
>
> **Dr Nazia Chaudhury, Consultant in Respiratory medicine**

Important work has already begun on creating a new national care pathway for PF. To help us reveal the challenging experience of life with interstitial lung disease we are planning the largest post-Covid patient survey on the urgent needs facing people with PF.

We look forward to sharing insights from this vital piece of work in the next financial year.

Reaching out to people through social and traditional media

Raising awareness of a misunderstood disease among the public and reaching out to more people with PF is an integral part of our communications activity. Over the year we increased our reach on social media to over 4.4 million users.

Through our social media and traditional media work, including our annual Pulmonary Awareness Month in September, we increased our social media followers to 17,713, an increase of 23%.

Impactful storytelling through the eyes of people affected by PF bring the issues to life and engage the public at large. Key events including International Nurses Day and British Science Week helped us to reach new audiences.

Facebook still remains our most popular channel for engagement, with Twitter (now known as X) the preference of more professional audiences with Linked In a growing platform for interaction.

We secured 232 news stories with links to APF. Over the year we achieved national and regional media coverage which equates to traditional media advertising costs of circa £250,000.

> *"Breathing has always been so mundane. I think this activity puts the difficulty that those with the disease have into perspective"*
>
> **Comment from a participant in our first Great Exhibition Road Festival 'Creative Science Lates' "take your breath away".**

Annual awareness month

Every year we launch a new groundbreaking campaign to raise awareness of PF. This year our focus was to explain to people what life with the most common symptoms of PF feels like.

Developed by our APF team, symptoms were transformed into impactful and thought-provoking campaign key messages.

‘Scars your lungs, takes your breath, steals your life.’

‘You don’t think about breathing until you can’t.’

‘Imagine trying to breathe through cling film.’

‘Is it Asthma, is it Cancer, pulmonary fibrosis what’s that?’

Pulmonary Fibrosis Awareness Month SEPT 2022

Alongside our social media campaign, digital posters ran in ten different NHS hospitals. We also secured free outside advertising with 48 sheet posters on 15 billboard sites across England thanks some wonderful corporate support from 75 Media.

This hugely popular campaign was well supported and applauded by our PF community. We doubled the number of website visits over the month and achieved over 45,000 impressions on X (previously Twitter).

“These need to be posted everywhere. Not enough is out there about this horrible disease. I had never heard of it until my dad’s diagnosis.”

Helen D on Facebook

“My dear husband passed away. The timing of this publicity campaign couldn’t be better.”

Laura B on Facebook

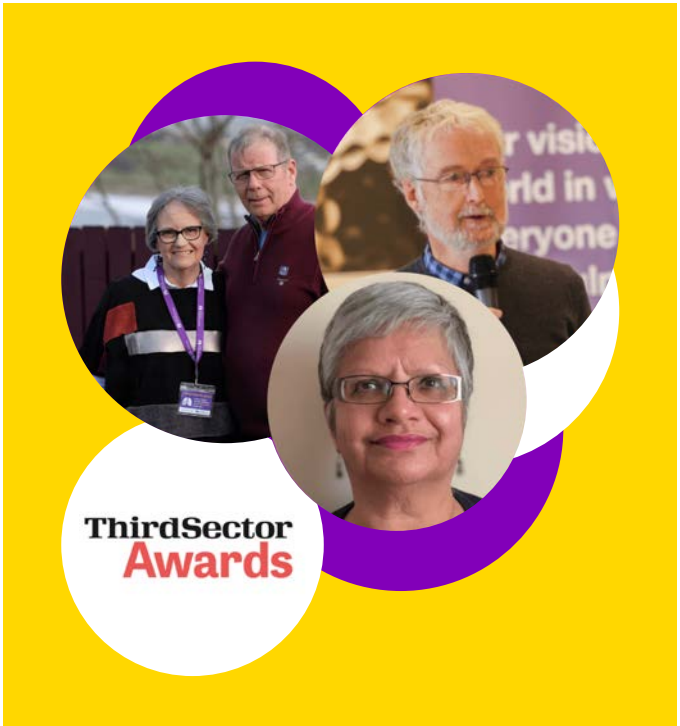
Celebrating our inspirational people

APF volunteer Elaine Kirby was recognised by Their Majesties The King and The Queen Consort as part of the Coronation celebrations in the summer.

Almost 5,000 entries were submitted for the prestigious award that recognised exceptional volunteers.

Speaking on her award Elaine said:

> *"I feel so honoured. Everything I do is for and with a great team of people. This year marks 50 years of my voluntary work so it's a wonderful way to mark that."*



Third Sector Award nominations

We were thrilled when three outstanding members of our community were nominated for the Third Sector Awards in August.

Charity Chair of the Year Award Nominee:
Steve Jones

Unsung Hero of the Year Nominee:
Dee Bryan

Volunteer of the Year Nominee:
Tom McMillan

We are proud to work with inspirational people who are dedicated to making life with PF better for all.

Fundraising: together we are stronger

The challenges of the last few years of the pandemic continue to impact fundraising. We have moved out of the Covid-19 pandemic crisis and into a cost-of-living crisis.

Both domestically and globally we are in an uncertain political and economic climate. All of this impacts on the ability of individuals and organizations to donate, fund and mobilise to raise money.

We raised £1.4m throughout the year, a 48% increase on 2021-22.

This wouldn't have been possible without our amazing community supporters.

We are humbled by the extraordinary kindness and generosity of everyone that has run, walked, baked, donated and raised funds in memory of loved ones. We would like to thank our grant givers and funders including the National Lottery Community Fund who significantly contribute to our Support Services.

Every pound raised has helped us be there for people affected by PF. As a result, we have been able to grow our services and move closer to our mission to stop PF and improve people's quality of life with the disease.

We have worked hard to diversify our income streams to make us more resilient. The unwavering support of everyone in our community has meant we ended the year in a financially stable position.

Raising the profile of PF on national TV

We were delighted when we were accepted to take part in BBC's TV Lifeline Appeal – a unique opportunity for charities to reach out to new audiences and raise money on the world's leading broadcaster.

Meteorologist Sarah Keith-Lucas, who has a personal connection to PF, kindly hosted the appeal and alongside raising much needed awareness we raised over £20,000. Sarah also generously selected APF to benefit from funds raised during her appearance on BBC's Celebrity Mastermind, raising a further £3,000 to support our work.

Actor Julie Hesmondhalgh supported the promotion of our annual 'Walk for Hope' to raise vital funds towards life changing research. Gaining almost 20,000 views on social media, the appeal raised over £6,000.

We're so thankful to have received support from Sarah and Julie throughout 2022-23.

Sarah Keith-Lucas

Julie Hesmondhalgh

We'd like to extend our special thanks to:

- The late Valerie Phelps for leaving a generous gift of £113k in her will to help us continue our vital work. Our gratitude to Valerie's partner, John Payne, for his generous support in Valerie's memory.
- The late David Coulson for leaving a generous legacy gift of £50k;
- The National Lottery Community Fund for their continued investment in of our support services that has allowed them to grow and reach more people affected by PF; and
- Our wonderful London Marathon runners who collectively raised over £20k.

We need to do so much more to improve people's access to information, treatment and care and tackle the huge inequity in care and support across the UK for PF.

COMMUNITY FUND

£1.4m

Raised throughout 2022/23

APF is needed now more than ever, but we can't do it alone.

We rely on the continued support of our community, grant funders and corporates to support more people affected by PF when they need us most.

"Fundraising for APF has been incredibly healing [...] it doesn't have to be a marathon, but having this focus has given me the space and platform to reflect and remember my Dad, and the wonderful time we spent together."

Laura, APF fundraiser

"Fundraising is a way of saying thank you to the amazing team at APF, and helping to ensure they can continue to important work they're doing to support patients and their families."

Andreas, APF fundraiser

"We lost our Nana Barbara to pulmonary fibrosis... I hope to keep raising money to help other families and people who are living with pulmonary fibrosis."

Caitlin, APF fundraiser

Together we are stronger

Looking ahead – future plans and priorities

Continued political and economic turmoil, the cost-of-living crisis and global conflicts mean we anticipate the needs of people living with and affected by PF to be higher than ever.

We remain resolute in our drive to meet the increasing daily challenges of people affected by PF.

Building on the progress we've made over the past ten years, we will develop our capability and focus our efforts on what makes the most significant difference to the lives of people living with and affected by PF over the coming years.

The launch of a new strategy taking APF to 2030 strives to meet the growing and changing needs of a diverse population affected by PF.

Structure, governance and management

Action for Pulmonary Fibrosis was registered with the Charity Commission in England and Wales as a Charitable Incorporated Organisation (CIO) in June 2013. The governing document is the Constitution, which was approved by the trustees on 28 May 2013.

On 25 May 2021 Action for Pulmonary Fibrosis was granted registration with the Office of the Scottish Charity Regulator (OSCR).

All trustees have direct experience of PF, either as lived experience or as family members or medical doctors, helping us to maintain our lived experience and healthcare led approach.

The Board of Trustees meets formally four times a year to review the charity's progress, formulate general policy and strategy and ensure adherence to charity regulations. An annual plan and budget for activities for the coming period are approved at the beginning of the financial year. At each meeting reports are received on the charity's work during the quarter. Attention is paid to any significant risks that may arise from time to time and the effectiveness of the system of internal controls is monitored. The quarterly meetings are supported by regular telephone and online communication.

The Board contracts with professional advisers as necessary, for advice and guidance on legal and financial issues.

Appointment of new trustees

The Board of Trustees regularly reviews the skills and experience of its members and considers if changes are needed to face new and emerging challenges. The Board openly recruits new members to strengthen the Board and where necessary to replace a member who leaves. It remains an important requirement that all new trustees have a personal connection to PF.

Vacancies are advertised and an application process is in place which includes receipt of a formal application providing personal details and outlining the skills and experience which the applicant can bring to APF. Candidates are then invited to meet with at least two trustees to discuss the application and to receive information about the Board, its work and the responsibilities of a trustee. Prospective trustees are invited to attend a trustee meeting for approval of all trustees prior to confirmation of appointment.

An induction process follows providing the new trustee with comprehensive information on the charity and their responsibilities as a trustee.

In April 2023 two new trustees were appointed, Sarah Weir OBE and Shama Malik, both of whom have been personally affected by the disease.

Organisational structure

The Chief Executive Officer (CEO) leads the charity together with the senior leadership team.

The Finance and Risk Committee is a standing committee which oversees and monitors the finances and budgets of the charity, risks, policies, and remuneration of staff.

The Committee, which includes a minimum of three trustees and the CEO, meets quarterly prior to the Board meeting. Other sub-committees of the Board of Trustees are established to deal with specific tasks from time to time.

Action for Pulmonary Fibrosis is registered with the Fundraising Register.

Risk management

Responsibility for risk management lies with trustees and a risk register has been established which is reviewed regularly by the Finance and Risk Committee. Any risks identified have controls in place to mitigate or manage them.

Public benefit statement

The charity trustees have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission, in exercising their powers or duties. Charity activities and support provided are available to all those affected by PF.

Here to help...

Email our support team:
support@actionpf.org

Support line:
01223 785725

Financial review and independent auditor's report

Financial Review 2022/23

The charity is in a strong financial position. Total income for the year was £1,446,900 and total expenditure was £1,204,155. Details are set out in the attached accounts.

Our income for the year was higher than budgeted due to an increase in legacies, in-memoriam and individual giving. We had budgeted cautiously in these areas due to the cost-of-living crisis but they surpassed expectation.

The Fundraising team have stayed abreast of trends and trialled new ways of fundraising and stewardship including:

- A national appeal as part of BBC Lifeline; and
- Continuing our paid-for advertising on social media.

Diversifying income has been key, monitoring our return on investment across the different income streams. Continued support from National Lottery Community Fund has been crucial to our sustainability, funding around 60% of support services costs.

We are pleased with end of year income, and the year has provided us with learning that we are carrying forward to 2023/24, as we continue to follow world events and sector trends.

Expenditure was also lower than budgeted due to some planned activities being cancelled, or continuing to be completed virtually.

Going concern

The trustees consider that the charity will continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved. The trustees therefore consider it appropriate to adopt the going concern basis for the preparation of the accounts, as detailed in note 1(b) to the financial statements.

Reserves policy

Trustees have agreed a reserves policy of holding an amount equivalent to six months of expenditure on charitable activities (c. £478k), as designated reserves.

Charitable expenditure includes staff and running costs, fundraising costs, planned activities and the provision of patient and family support activities. This is to ensure that the charity can continue offering services to its patient community during times of reduced income. It is reviewed annually at the July trustee meeting.

The reserves account balance remains at £336,000 as per 2021/22. Reserves as at 30 June 2023 also include £181,873 of unrestricted general funds. Together these two fund balances meet the reserves policy.

Statement of trustee responsibilities

For the year ended 30 June 2023

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with 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).

The law applicable to charities in England and Wales, and in Scotland, requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and the incoming resources and application of resources, including the net income or expenditure, of the charity for the year.

In preparing those 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 judgements and accounting estimates that are reasonable and prudent;
- state whether applicable accounting standards and statements of recommended practice 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 charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts(Scotland) Regulations 2006 (as amended) and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

The trustees are members of the charity, but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditors

Godfrey Wilson Limited were re-appointed as auditors to the charity during the year and have expressed their willingness to continue in their capacity.

Approved by the trustees on 3rd February 2024 and signed on their behalf by

steveJOnes

Stephen Jones – Chair

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

Opinion

We have audited the financial statements of Action for Pulmonary Fibrosis (the 'charity') for the year ended 30 June 2023 which comprise the statement of financial position, balance sheet and statement of cash flows, and the related 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 charity's affairs as at 30 June 2023 and of its incoming resources and application of resources, including its 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 Charities and Trustees Investment (Scotland) Act 2005, regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011.

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 charity 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 charity'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 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.

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

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.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report. We have nothing to report in respect of the following matters in relation to which the Charities Act 2011 requires us to report to you if, in our opinion:

- sufficient accounting records have not been kept;
- the financial statements are not in agreement with the accounting records and returns; or
- we have not obtained all the information and explanations necessary for the purposes of our audit.

Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees 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 they 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 charity'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 charity or to cease operations, or have no realistic alternative but to do so.

Our 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 procedures we carried out and the extent to which they are capable of detecting irregularities, including fraud, are detailed below:

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

(1) We obtained an understanding of the legal and regulatory framework that the charity operates in, and assessed the risk of non-compliance with applicable laws and regulations. Throughout the audit, we remained alert to possible indications of non-compliance.

(2) We reviewed the charity's policies and procedures in relation to:

- Identifying, evaluating and complying with laws and regulations, and whether they were aware of any instances of non-compliance;
- Detecting and responding to the risk of fraud, and whether they were aware of any actual, suspected or alleged fraud; and
- Designing and implementing internal controls to mitigate the risk of non-compliance with laws and regulations, including fraud.

(3) We inspected the minutes of trustee meetings.

(4) We enquired about any non-routine communication with regulators and reviewed any reports made to them.

(5) We reviewed the financial statement disclosures and assessed their compliance with applicable laws and regulations.

(6) We performed analytical procedures to identify any unusual or unexpected transactions or balances that may indicate a risk of material fraud or error.

(7) We assessed the risk of fraud through management override of controls and carried out procedures to address this risk. Our procedures included:

- Testing the appropriateness of journal entries;
- Assessing judgements and accounting estimates for potential bias;
- Reviewing related party transactions; and
- Testing transactions that are unusual or outside the normal course of business.

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. Irregularities that arise due to fraud can be even 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.

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charity's trustees 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 charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Godfrey Wilson Limited

Date: 3 February 2023
GODFREY WILSON LIMITED
Chartered accountants and statutory auditors
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD

Action for Pulmonary Fibrosis

Statement of financial activities

For the year ended 30 June 2023

	Note	Restricted £	Unrestricted £	**2023 Total £**	2022 Total £
Income from:					
Donations and legacies	3	29,203	1,102,239	**1,131,442**	733,751
Charitable activities	4	248,891	52,019	**300,910**	222,402
Investments		-	12,049	**12,049**	6,313
Other trading income	5	-	2,499	**2,499**	12,112
Total income		278,094	1,168,806	**1,446,900**	974,578
Expenditure on:					
Raising funds		-	248,560	**248,560**	168,909
Charitable activities		298,822	656,773	**955,595**	626,329
Total expenditure	7	298,822	905,333	**1,204,155**	795,238
Net income / (expenditure) and net movement in funds	10	(20,728)	263,473	**242,745**	179,340
Reconciliation of funds:					
Total funds brought forward		64,748	1,205,001	**1,269,749**	1,090,409
Total funds carried forward		44,020	1,468,474	**1,512,494**	1,269,749

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 17 to the accounts.

Action for Pulmonary Fibrosis

Balance sheet

As at 30 June 2023

	Note	£	2023 £	2022 £
Fixed assets				
Tangible assets	13		**9,794**	-
Current assets				
Debtors	14	**62,301**		22,401
Current asset investments		**1,494,961**		1,069,851
Cash at bank and in hand		**149,666**		264,095
		1,706,928		1,356,347
Liabilities				
Creditors: amounts falling due within 1 year	15	**(204,228)**		(86,598)
Net current assets			**1,502,700**	1,269,749
Net assets	16		**1,512,494**	1,269,749
Funds	17			
Restricted funds			**44,020**	64,748
Unrestricted funds				
Designated funds			**1,286,601**	1,023,128
General funds			**181,873**	181,873
Total charity funds			**1,512,494**	1,269,749

Approved by the trustees on 3 February 2024 and signed on their behalf by

steveJones

Stephen Jones - Chair

Action for Pulmonary Fibrosis

Statement of cash flows

As at 30 June 2023

	2023 £	2022 £
Cash provided by operating activities:		
Net movement in funds	**242,745**	179,340
Adjustments for:		
Investment income	**(12,049)**	(6,313)
Decrease / (increase) in debtors	**(39,900)**	(2,899)
Increase / (decrease) in creditors	**117,630**	(70,407)
Depreciation	**1,633**	-
Net cash provided by operating activities	**310,059**	99,721
Cash flows from investing activities:		
Investment income	**12,049**	6,313
Fixed asset additions	**(11,427)**	-
Net cash provided by investing activities	**622**	6,313
Increase in cash and cash equivalents in the year	**310,681**	106,034
Cash and cash equivalents at the beginning of the year	**1,333,946**	1,227,912
Cash and cash equivalents at the end of the year	**1,644,627**	1,333,946

Analysis of cash and cash equivalents

Current asset investments	**1,494,961**	1,069,851
Cash at bank and in hand	**149,666**	264,095
Cash and cash equivalents at the end of the year	**1,644,627**	1,333,946

The charity has not provided an analysis of changes in net debt as it does not have any long term financing arrangements.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

1. Accounting policies

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 in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Action for Pulmonary Fibrosis 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 notes.

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern, which the trustees consider appropriate having regard to the current level of unrestricted reserves. There are no material uncertainties about the charity's ability to continue as a going concern.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the items of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from the government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

d) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

e) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

f) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

g) Grants payable

Grants payable are charged in the year in which the offer is conveyed to the recipient except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attached have been fulfilled. Grants offered subject to conditions at the year end are noted as commitment but are not accrued as expenditure.

h) Allocation of support and governance costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities on the basis of staff time spent on each of these area. The percentages used were as follows:

	2023	2022
Raising funds	**21%**	21%
Charitable activities	**79%**	79%

i) Tangible fixed assets

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment	3 years

Items of equipment are capitalised where the purchase price exceeds £1,000.

j) 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.

k) Current asset investments

Current asset investments consists of short term cash deposits with a maturity date of less than one year from the balance sheet date held for investment purposes rather than to meet short term cash commitments as they fall due.

l) 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.

m) Creditors

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.

n) Financial instruments

The charity 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 with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

o) Pension costs

The charity operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

p) Operating leases

Operating lease payments are recognised as an expense on a straight-line basis over the lease term.

q) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

There are no key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements.

2. Prior period comparatives: statement of financial activities

	Restricted £	Unrestricted £	2022 Total £
Income from:			
Donations and legacies	22,764	710,987	733,751
Charitable activities	200,692	21,710	222,402
Other trading activities	-	12,112	12,112
Investments	-	6,313	6,313
Total income	223,456	751,122	974,578
Expenditure on:			
Raising funds	-	168,909	168,909
Charitable activities	225,860	400,469	626,329
Total expenditure	225,860	569,378	795,238
Net income / (expenditure)	(2,404)	181,744	179,340
Transfers between funds	1,952	(1,952)	-
Net movement in funds	(452)	179,792	179,340

3. Income from donations and legacies

	Restricted £	Unrestricted £	**2023 Total £**
Legacies	-	221,778	**221,778**
Donations from individuals and fundraising	29,203	880,461	**909,664**
Total income from donations and legacies	29,203	1,102,239	**1,131,442**

	Restricted £	Unrestricted £	2022 Total £
Legacies	-	36,200	36,200
Donations from individuals and fundraising	22,764	674,787	697,551
Total income from donations and legacies	22,764	710,987	733,751

4. Income from charitable activities

	Restricted £	Unrestricted £	**2023 Total £**
Corporate grants	65,773	15,171	**80,944**
Trusts and foundations	183,118	33,828	**216,946**
Speaker fees	-	3,020	**3,020**
Total income from charitable activities	248,891	52,019	**300,910**

Prior period comparative

	Restricted £	Unrestricted £	2022 Total £
Corporate grants	3,200	-	3,200
Trusts and foundations	197,492	2,675	200,167
Consultancy fees	-	17,039	17,039
Speaker fees	-	1,996	1,996
Total income from charitable activities	200,692	21,710	222,402

5. Income from other trading activities

	2023 £	2022 £
Conference sponsorship	**-**	7,988
Merchandise sales	**2,499**	4,124
Total income from other trading activities	**2,499**	12,112

All income from other trading activities was unrestricted in the current and prior years.

6. Government grants

The charity received a government grant, defined as funding from the National Lottery Community Fund, to fund support services. The total value of such grants for the year ending 30 June 2023 was £168,118 (2022: £153,492). There were no unfulfilled conditions or contingencies attached to these grants in 2022/23.

7. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	**2023 Total £**
Staff costs (note 11)	139,242	529,057	57,014	**725,313**
Freelance costs (note 11)	5,350	74,700	79,212	**159,262**
Travel and subsistence	-	-	25,428	**25,428**
Grants payable (note 8)	-	8,473	-	**8,473**
Training costs	-	5,326	265	**5,591**
Patient surveys	-	5,434	-	**5,434**
Fundraising costs	40,917	-	-	**40,917**
Marketing and communications	2,127	101,122	523	**103,772**
Premises costs	-	-	33,564	**33,564**
Admin costs	-	-	54,209	**54,209**
Other staffing costs	-	-	30,779	**30,779**
Governance costs	-	-	9,780	**9,780**
Depreciation	-	-	1,633	**1,633**
Sub-total	187,636	724,112	292,407	**1,204,155**
Allocation of support and governance costs	60,924	231,483	(292,407)	-
Total expenditure	**248,560**	**955,595**	**-**	**1,204,155**

Prior year comparative:

	Raising funds £	Charitable activities £	Support and governance costs £	**2022 Total £**
Staff costs (note 11)	98,646	362,320	45,179	506,145
Freelance costs (note 11)	-	69,915	16,914	86,829
Travel and subsistence	-	-	4,696	4,696
Grants payable (note 8)	-	2,365	-	2,365
Training costs	-	1,725	-	1,725
Patient surveys	-	3,212	-	3,212
Fundraising costs	22,371	-	-	22,371
Marketing and communications	8,681	42,770	-	51,451
Premises costs	-	-	33,384	33,384
Admin costs	-	-	58,355	58,355
Other staffing costs	-	-	18,682	18,682
Governance costs	-	-	6,023	6,023
Sub-total	129,698	482,307	183,233	**795,238**
Allocation of support and governance costs	39,211	144,022	(183,233)	-
Total expenditure	**168,909**	**626,329**	**-**	**795,238**

7. Total expenditure (continued)

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. They are distinct from costs incurred to support those affected by Pulmonary Fibrosis, which are included under charitable activities.

8. Grants payable

During the year, 3 (2022: 3) new grants were awarded to 3 institutions (2022: 3) to fund support sessions and 8 to individuals (2022: nil) for travel to research events. Total grants committed to during the year were as follows:

	2023	2022
	£	£
Grants payable to institutions:		
Support groups-		
Lanarkshire Support Group	**500**	-
Preston and Chorley Support Group	**100**	-
East Kent Support Group	**250**	-
North Cumbria Support Group	**-**	508
Northern Trust Support Group	**-**	1,713
Brighton Support Group	**-**	144
Total grants payable to institutions	**850**	2,365
Grants payable to individuals	**7,623**	-
Total grants committed during the period	**8,473**	2,365

9. Grants commitments

	2023	2022
	£	£
Grant commitments brought forward	**56,931**	115,753
Grants committed during the period (note 8)	**8,473**	2,365
Grants paid during the period	**(8,473)**	(61,187)
Grant commitments carried forward	**56,931**	56,931

10. Net movement in funds

This is stated after charging:

	2023	2022
	£	£
Depreciation	**1,633**	-
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses	**476**	67
Auditors' remuneration:		
▪ Statutory audit (excluding VAT)	**5,500**	4,350

During the year, 3 trustees were reimbursed £476 for training and related travel expenses (2022: 1 trustee were reimbursed £67 for training and related travel expenses). All expenses incurred were in the course of the organisation's charitable activities.

11. Staff costs and numbers

Staff costs were as follows:

	2023	2022
	£	£
Salaries and wages	**649,137**	453,321
Social security costs	**52,561**	40,536
Pension costs	**23,615**	12,288
Freelance staff	**159,262**	86,829
	884,575	592,974

One employee earned between £60,000 and £70,000 during the year (2022: one).

The key management personnel of the charity comprise the trustees and Chief Executive. The total employee benefits of the key management personnel were £84,262 (2022: £78,028).

	2023	2022
	No.	No.
Average head count	**21**	16

12. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

13. Tangible fixed assets

	Computer Equipment	**Total**
		£
Cost		
At 1 July 2022	-	**-**
Additions in year	11,427	**11,427**
At 30 June 2023	11,427	**11,427**
Depreciation		
At 1 July 2022	-	**-**
Charge for the year	1,633	**1,633**
At 30 June 2023	1,633	**1,633**
Net book value		
At 30 June 2023	**9,794**	**9,794**
At 30 June 2022	-	-

14. Debtors

	2023	2022
	£	£
Trade debtors	**17,732**	4,984
Accrued income	**22,743**	12,339
Prepayments	**21,826**	5,078
	62,301	22,401

15. Creditors: amounts due within 1 year

	2023	2022
	£	£
Trade creditors	**113,872**	8,894
Accruals	**10,104**	20,773
Grant commitments (note 9)	**56,931**	56,931
Social security	**23,321**	-
	204,228	86,598

16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	**Total funds £**
Fixed assets	-	-	9,794	**9,794**
Current assets	44,020	1,343,532	319,376	**1,706,928**
Current liabilities	-	(56,931)	(147,297)	**(204,228)**
Net assets at 30 June 2023	**44,020**	**1,286,601**	**181,873**	**1,512,494**

Prior year comparative	Restricted funds £	Designated funds £	General funds £	Total funds £
Current assets	64,748	1,080,059	211,540	1,356,347
Current liabilities	-	(56,931)	(29,667)	(86,598)
Net assets at 30 June 2022	64,748	1,023,128	181,873	1,269,749

17. Movements in funds

	At 1 July 2022 £	Income £	Expenditure £	Transfers between funds £	**At 30 June 2023 £**
Restricted funds					
Boehringer Ingelheim	-	45,000	(45,000)	-	**-**
Trevi Theraupeutics	24,988	20,773	(32,554)	-	**13,207**
Hospital Saturday Fund	1,160	-	(530)	-	**630**
National Lottery Community Fund	10,920	168,118	(168,119)	-	**10,919**
D'Oyly Carte Charitable Trust	172	-	-	-	**172**
Garfield Weston	24,892	-	(8,491)	-	**16,401**
Northern Ireland donations	2,616	-	(1,403)	-	**1,213**
Research donations	-	28,348	(28,348)	-	**-**
Support donations	-	11,000	(11,000)	-	**-**
Scotland donations	-	4,000	(3,377)	-	**623**
Wales donations	-	855	-	-	**855**
Total restricted funds	64,748	278,094	(298,822)	-	**44,020**
Unrestricted funds					
Designated funds					
Research fund	687,128	-	(8,473)	271,946	**950,601**
Reserve fund	336,000	-	-	-	**336,000**
Total designated funds	1,023,128	-	(8,473)	271,946	**1,286,601**
General funds	181,873	1,168,806	(896,860)	(271,946)	**181,873**
Total unrestricted funds	1,205,001	1,168,806	(905,333)	-	**1,468,474**
Total funds	1,269,749	1,446,900	(1,204,155)	-	**1,512,494**

Purposes of restricted funds

Boehringer Ingelheim	This fund is for support line ambassadors and the newsletter.
Trevi Theraupeutics	This fund is for support services in Scotland (including SG coordinator salary) which launched in 22/23.
Hospital Saturday Fund	This fund is for support services.
National Lottery Community Fund	This fund is for support services.
D'Oyly Carte Charitable Trust	This fund is to enable new and existing APF volunteers to receive training in order to better support patients and carers.

17. Movements in funds (continued)
Purposes of resticted funds

Garfield Weston	This fund is for support services growing volunteering, and is to be used towards volunteering salary costs, services admin and volunteer recruitment, training, expenses and marketing.
Northern Ireland donations	These are donations received specifically for Northern Ireland.
Research donations	These are donations received specifically for research.
Support donations	These are donations received specifically for support services.
Scotland donations	These are donations received specifically for Scotland.
Wales donations	These are donations received specifically for Wales.

Purposes of designated funds

Research fund	A principal objective of Action for Pulmonary Fibrosis is to support and fund Research into the disease. Trustees have agreed to designate £951k for research to fund further research fellowships, with agreements totalling £600k approved since the year end.
Reserve fund	The Reserve Fund has been established, in line with the charity's reserves policy, to retain a minimum of 50% of projected annual core expenditure separately as reserves.

Transfers between funds
Transfers from general funds to designated funds represent additional designated funds, as agreed by the board.

17. Movements in funds (continued).
Prior year comparative

	At 1 July 2021 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2022 £
Restricted funds					
Boehringer Ingelheim	9,545	1,200	(10,759)	14	-
Roche	18,750	-	(18,772)	22	-
Trevi Theraupeutics	24,988	-	-	-	24,988
Independent Age	10,000	-	(10,528)	528	-
Shanly Foundation	750	-	(1,230)	480	-
Hospital Saturday Fund	1,167	10,000	(10,007)	-	1,160
National Lottery Community Fund	-	153,492	(142,572)	-	10,920
NeRRe Therapeutics	-	2,000	(2,872)	872	-
D'Oyly Carte Charitable Trust	-	3,500	(3,328)	-	172
Edwards Cadbury Charitable Trust	-	5,000	(5,036)	36	-
Garfield Weston	-	25,000	(108)	-	24,892
Ian Askew Charitable Trust	-	500	(500)	-	-
Northern Ireland donations	-	4,329	(1,713)	-	2,616
Research donations	-	18,435	(18,435)	-	-
Total restricted funds	65,200	223,456	(225,860)	1,952	64,748
Unrestricted funds					
Designated funds					
Research fund	683,767	-	(30,518)	33,879	687,128
Reserve fund	278,725	-	-	57,275	336,000
Total designated funds	962,492	-	(30,518)	91,154	1,023,128
General funds	62,717	751,122	(538,860)	(93,106)	181,873
Total unrestricted funds	1,025,209	751,122	(569,378)	(1,952)	1,205,001
Total funds	1,090,409	974,578	(795,238)	-	1,269,749

18. Operating leases
The charity had operating leases at the year end with total future minimum lease payments as

	2023 £	2022 £
Amount falling due:		
Within 1 year	**8,179**	9,360
Within 2 - 5 years	**-**	-
	8,179	9,360

19. Related party transactions

Steve Jones, the chair of Action for Pulmonary Fibrosis (APF), is also the chair of European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF). During the year APF received income of £600 from EU-IPFF for speaker fees (2022: £415 for speaker fees). No amounts were outstanding at year end.

The trustees are not aware of any other related party transactions during the period.

Action for Pulmonary Fibrosis is a patient-driven charity. Our vision is to stop pulmonary fibrosis so that everyone affected has a better future.

Action for Pulmonary Fibrosis

General enquiries:
01733 839642
info@actionpf.org

www.actionpf.org

Registered Office & Operational Address:
Stuart House, East Wing
St John's Street
Peterborough PE1 5DD

Follow us on socials:

Registered Charity 1152399 in England and Wales. Registered Charity SC050992 in Scotland.

Action for Pulmonary Fibrosis

Alison Godfrey FCA
Godfrey Wilson Limited
Chartered Accountants & Statutory Auditors
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD

3 February 2024

Dear Alison

Letter of Representations on the Financial Statements for the Year Ended 30 June 2023

This representation letter is provided in connection with your audit of the financial statements of the charity for the year ended 30 June 2023.

We confirm that the following representations are made on the basis of enquiries of the trustees, management and staff with relevant knowledge and experience (and, where appropriate, of inspection of supporting documentation) sufficient to satisfy ourselves that we can properly make each of the following representations to you:

1. We have fulfilled our responsibilities as trustees, as set out in the terms of your engagement letter dated 23 June 2020, under the Charities Act 2011 for preparing financial statements, in accordance with 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).

2. We confirm that in our opinion the financial statements give a true and fair view and in particular that where any additional information must be disclosed in order to give a true and fair view that information has in fact been disclosed. We confirm that the selection and application of the accounting policies used in the preparation of the financial statements are appropriate, and we approve these accounts for the year ended 30 June 2023.

3. We confirm that all accounting records have been made available to you for the purpose of your audit, in accordance with your terms of engagement, and that all the transactions undertaken by the charity have been properly reflected and recorded in the accounting records. All other records and related information, including minutes of all management, trustees' and members' meetings, have been made available to you. We have given you unrestricted access to persons within the charity in order to obtain audit evidence and have provided any additional information that you have requested for the purposes of your audit.

4. We confirm the charity has satisfactory title to all assets and there are no liens or encumbrances on the assets, except for those disclosed in the financial statements.

5. We confirm that significant assumptions used by us in making accounting estimates, including those measured at fair value, are reasonable. We confirm that we have no plans or intentions that may materially alter the carrying value and where relevant the fair value measurements or classification of assets and liabilities reflected in the financial statements.

6. We confirm that the charity has no liabilities or contingent liabilities other than those disclosed in the financial statements.

7. We confirm that all known actual or possible litigation and claims whose effects should be considered when preparing the financial statements have been disclosed to you and accounted for and disclosed in accordance with the applicable financial reporting framework.

8. We confirm that there have been no events since the balance sheet date which require disclosing or which would materially affect the amounts in the financial statements, other than those already disclosed or included in the financial statements.

9. We confirm that we are aware that a related party of the charity is a person or organisation which either (directly or indirectly) controls, has joint control of, or significantly influences the charity or vice versa and as a result will include: trustees, other key management, close family and other business interests of the previous. We confirm that the related party relationships and transactions set out in appendix 1 are a complete list of such relationships and transactions and that we are not aware of any further related parties or transactions.

10. We confirm that the charity neither had, at any time during the year, any arrangement, transaction or agreement to provide credit facilities (including advances and credits granted by the charity) for trustees, nor provided guarantees of any kind on behalf of the trustees except as disclosed in the financial statements.

11. We confirm that the charity has not contracted for any capital expenditure other than as disclosed in the financial statements.

12. We confirm that the charity has complied with all aspects of contractual agreements that could have a material effect on the financial statements in the event of non-compliance.

13. We confirm that we are not aware of any possible or actual instance of non-compliance with those laws and regulations which provide a legal framework within which the charity conducts its activities and which are central to the charity's ability to conduct its activities, except as explained to you and as disclosed in the financial statements.

14. We acknowledge our responsibility for the design, implementation and maintenance of internal controls to prevent and detect fraud. We confirm that we have disclosed to you the results of our risk assessment of the risk of fraud in the organisation. There have been no deficiencies in internal control of which we are aware.

15. We confirm that there have been no actual or suspected instances of fraud involving trustees, management or employees who have a significant role in internal control or that could have a material effect on the financial statements. We also confirm that we are not aware of any allegations of fraud by trustees, former trustees, employees, former employees, regulators or others.

16. We confirm that, in our opinion, the charity's financial statements should be prepared on the going concern basis on the grounds that current and future sources of funding or support will be more than adequate for the charity's needs. In reaching this conclusion, we have taken into account all relevant matters of which we are aware, and have considered a period of at least one year from the date on which the financial statements will be approved.

17. We confirm that in our opinion the effects of uncorrected misstatements are immaterial, both individually and in aggregate, to the financial statements as a whole. A list of the uncorrected misstatements is set out in the management letter.

18. We confirm that we are not aware of any matters of material significance that should be reported to regulators. We confirm that all correspondence with the Charity Commission has been made available to you.

19. We confirm that all grants, donations and other income, including those subject to special terms or conditions or received for restricted purposes, have been notified to you. There have been no breaches of terms or conditions during the period regarding the application of such income.

20. We acknowledge our legal responsibilities regarding disclosure of information to you as auditors and confirm that: (a) so far as each trustee is aware, there is no relevant audit information of which you as auditors are unaware; and (b) each trustee has taken all the steps that they ought to have taken as a trustee to make themselves aware of any relevant audit information and to establish that you are aware of that information.

Yours sincerely

Stephen Jones – Chair
For and on behalf of the trustees of Action for Pulmonary Fibrosis

Appendix 1: Summary of Related Parties

Connected Organisation	Name	Nature of Connection
European Idiopathic Pulmonary Fibrosis & Related Disorders Federation	Stephen Jones	President

ACTION FOR PULMONARY FIBROSIS

England & Wales - Charity number 1152399

Accounts

Trustees' Annual Report & Audited Accounts

For the year ending 30 June 2022

Action for Pulmonary Fibrosis

Charity Commission England & Wales Registered Charity Number: 1152399
Scottish Charity Regulator Number: SC050992

2021
2022

Contents

What is pulmonary fibrosis?	3
Why we are needed	4
Our vision, mission, and values	6
Trustees, staff, and advisors	7
Introduction from Chair and Chief Executive	8
Report of the Board of Trustees:	
– Support and information	9
– Education	14
– Research	15
– Influencing and raising awareness	18
– Fundraising	22
– Plans for the future	24
– Structure, governance, and management	25
– Financial review	27
Independent Auditor's Report	29
Statement of Financial Activities	34
Balance Sheet	35
Statement of Cash Flows	36
Notes to Financial Statements	37

Action for Pulmonary Fibrosis

Support line
01223 785725

General enquiries:
01733 475642
info@actionpf.org

www.actionpf.org

Registered Charity 1152399 in England and Wales. Registered Charity SC050992 in Scotland.

What is pulmonary fibrosis?

Pulmonary fibrosis is an umbrella term for a range of progressive lung diseases, which cause stiffening and scarring of the lungs.

The lung scarring eventually prevents the transfer of oxygen into the bloodstream. It affects around 70,000 people in the UK. Idiopathic pulmonary fibrosis (IPF) is the most aggressive and common form and affects around 30,000 people in the UK.

Key symptoms of pulmonary fibrosis include breathlessness and chronic cough. On physical examination, Velcro-like crackles are likely to be heard and sometimes the ends of fingers or toes may appear enlarged or 'clubbed'. Key symptoms can be confused with other respiratory disorders, such as chronic obstructive pulmonary disorder (COPD), asthma and bronchiectasis.

Other forms of pulmonary fibrosis include: familial pulmonary fibrosis; those associated with autoimmune diseases (such as rheumatoid arthritis and systemic sclerosis); toxicity caused by some medications; exposure to inorganic substances (such as asbestos and coal dust); hypersensitivity pneumonitis caused by exposure to organic dusts and fibres (such as bird feathers and mould found on hay, straw and grain), and sarcoidosis.

Why we are needed

Tens of thousands of people are affected by pulmonary fibrosis, yet it remains a mystery to many people.

The debilitating nature of the disease means as people become increasingly breathless, their need for physical and emotional support become greater. Patients and their families can experience a profound sense of loss as the disease progresses. Pulmonary fibrosis affects every area of family life, yet there is very little dedicated support available to patients and their families.

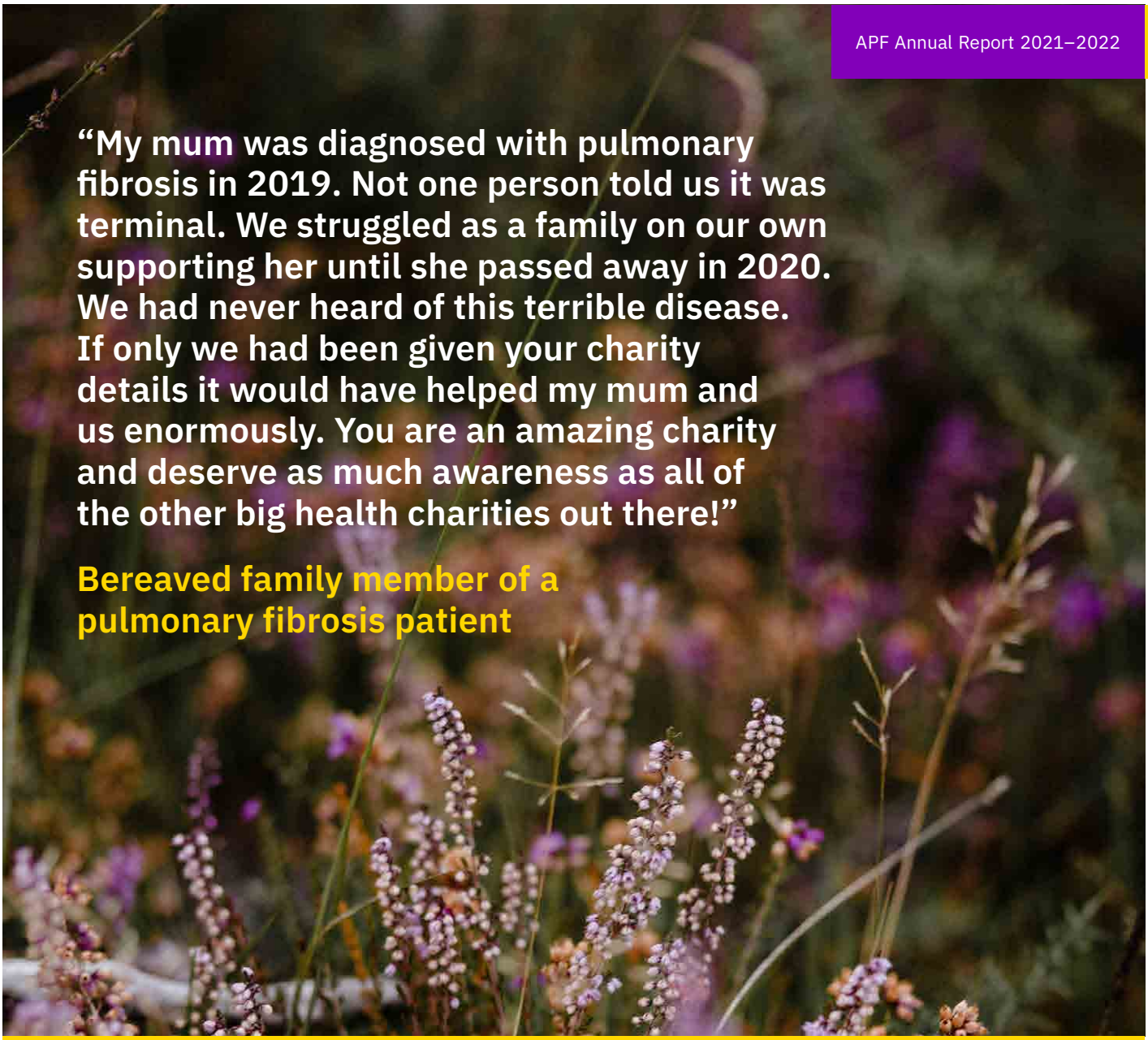
As breathlessness increases, ordinary daily tasks – washing, dressing, walking - can become exhausting, which impacts increasingly on the whole family and especially carers. As an unfamiliar condition, many patients can struggle to find information and support and find themselves repeatedly explaining the diagnosis to healthcare professionals, family and friends, which causes distress. We want everyone affected by the disease to be understood and to have access to the information and support they need when they need it. Our support community, peer groups, befrienders, and information are vital in helping patients and carers feel more connected, supported and reassured.

Pulmonary fibrosis can be very difficult to detect, with patients frequently waiting over a year for an accurate diagnosis. We need to speed up the process of diagnosis so that patients can start treatment sooner.

Our understanding of the disease has progressed rapidly over the last 10 years but there are too few treatments that slow the progression of the disease.

We need to go further than this. We want to stop the disease in its tracks. That's why we're committed to funding research to find new treatments and a cure.

Together we can make this happen.



“My mum was diagnosed with pulmonary fibrosis in 2019. Not one person told us it was terminal. We struggled as a family on our own supporting her until she passed away in 2020. We had never heard of this terrible disease. If only we had been given your charity details it would have helped my mum and us enormously. You are an amazing charity and deserve as much awareness as all of the other big health charities out there!”

Bereaved family member of a pulmonary fibrosis patient

Our vision, mission, and values

Our vision

Action for Pulmonary Fibrosis is a patient-driven charity. Our vision is to find a cure for pulmonary fibrosis so everyone affected has a better future.

Our mission

We provide support to families, raise awareness of the disease, campaign and educate to improve access to the highest standard of care for people living with all forms of pulmonary fibrosis. We are committed to funding research to improve the quality of life for people living with pulmonary fibrosis today and tomorrow.

Our values drive everything we do:

Patient led:
We empower and are led by patients who are at the heart of everything we do.

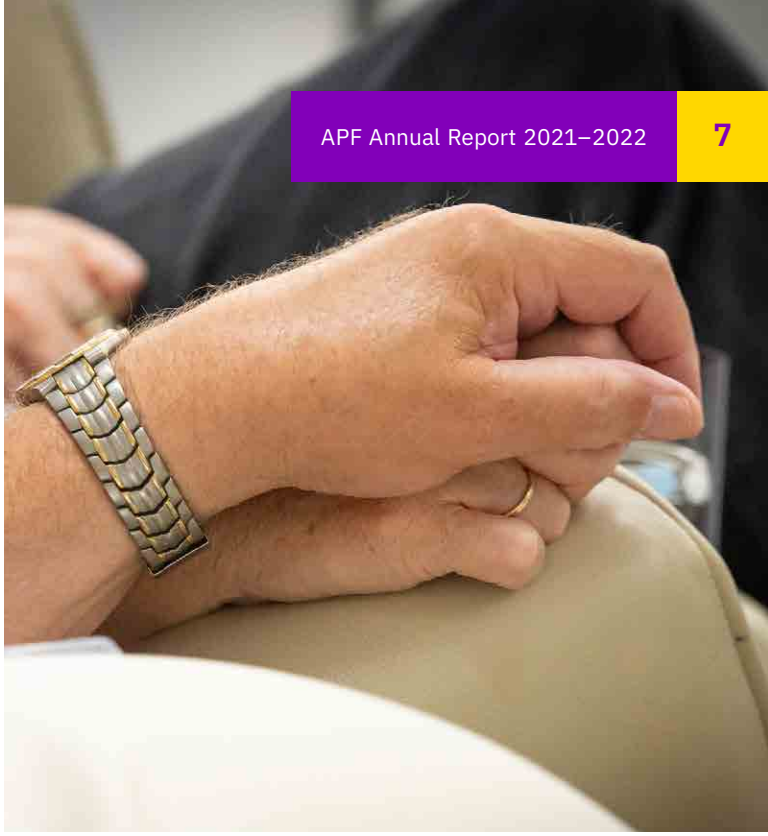
Caring and compassionate:
We respect and understand the needs of patients and carers and help them to get the support they need.

Striving for excellence:
We work with integrity and professionalism in all that we do.

Open and approachable:
We ensure people affected by pulmonary fibrosis feel able to turn to us for advice and support in their time of need.

Ambitious and bold:
We improve the lives of people affected by pulmonary fibrosis and are bold in the ways we do this.

Trustees, staff, and advisors



Charity President:
Prof Gisli Jenkins

Charity Trustees:
Mr Stephen Jones* (Chair)
Mr Howard Almond*
Mrs Elizabeth Bray**
Mrs Wendy Dickinson**
Dr Simon Hart
Dr Rebecca Lang**
Mr Stephen Morgan-Hyland**
Dr Helen Parfrey
Dr Michael Stubbins** (*Appointed 7 May 2022*)
Mr Matthew Suddart** (*Appointed 7 May 2022*)
Prof Gisli Jenkins (*Resigned 7 May 2022*)

* living with PF
** family member of someone with PF

In keeping with the charity's ethos of being patient led, over 60% of trustees have been personally affected by pulmonary fibrosis either as a patient or family member. Our trustees also include medical professionals, who are leaders in pulmonary fibrosis care and research.

Chief Executive:
Louise Wright

Registered Office and Principal Address:
Stuart House, East Wing
St John's Street
Peterborough
PE1 5DD

Charity Commission Registered Number:
1152399

Scottish Charity Regulator Number:
SC050992

Principal Advisors:

Bankers:
CAF Bank Limited
25 Kings Hill Avenue
Kings Hill
West Malling
Kent ME19 4JQ

Auditors:
Godfrey Wilson Limited
(Chartered Accountants and statutory auditors)
5th Floor Mariner House
62 Prince Street
Bristol BS1 4QD

Introduction from Chair and Chief Executive

July 2021 – June 2022

At Action for Pulmonary Fibrosis, we believe people affected by pulmonary fibrosis (PF) are worse off than before Covid-19. Even greater delays to diagnosis occur, due to difficulties accessing GPs and diagnostic tests. People with pulmonary fibrosis have told us that having fewer opportunities to meet specialist teams face to face, and get timely access to supportive care, is having a detrimental effect on their physical and mental health. With no cure, getting support to stay active and well for longer or preparing for your own or a loved one's end of life is vitally important. Interstitial lung disease (ILD) clinicians and healthcare professionals lack the support and investment they desperately need to meet the growing demands.

We recognise that progress is not where we want it to be if you have a diagnosis of pulmonary fibrosis, yet there have been many successes over the past twelve months that give us a real sense of optimism.

Our campaign to ensure people get timely access to anti-fibrotic treatments has, in part, been successful. Around 15,000 more people with progressive pulmonary fibrosis from a known cause now have access to the treatments right from diagnosis. We continue to push for people with idiopathic pulmonary fibrosis to get the same access to treatment, and won't stop until this changes.

Over the past year, our work to raise awareness has led to more people finding us than ever before. This has meant that more people have accessed expert information and support which just a few years ago didn't exist.

Curing pulmonary fibrosis is fast becoming a reality for future generations. We've helped more people living with pulmonary fibrosis contribute to a greater number of research projects, ensuring the quality of the work and that it is a success right from the start.

Over 800 people registered for our first virtual patient day, and over 90% of those of you who watched told us you felt more able to manage your pulmonary fibrosis after the event. The power of peer support continues as we increase opportunities for people and families affected by pulmonary fibrosis to access support online, face to face and by phone.

To ensure we are a diverse and inclusive force for change, we have increased the team and welcomed two new trustees to the board as part of our growth.

We have been overwhelmed by the continued support of people living with and affected by pulmonary fibrosis. Every walker, runner, cake baker, donor and volunteer has meant more people than ever before have had better access to information and support, improving wellbeing and hope for a better future.

Together we are stronger.

Steve Jones
(Chair of Trustees)

Louise Wright
(Chief Executive)

Support and information

This year, the world we live in still felt very vulnerable. NHS teams felt exhausted and overwhelmed with workload and worry, as they responded to Covid surges, backlogs, commissioning changes – and, for respiratory teams, fears around greater workloads, as access to antifibrotic medication increases for non IPF patients. Many patients and carers continued to shield, with prolonged periods of isolation threatening their wellbeing. While some connected digitally, including via support groups, many did not or could not, risking further exclusion. Lack of consistency in access to care across the country remained real, affecting patient health and quality of life.

"I'm overwhelmed with the support I've received from APF and things are starting to move in the right direction."

Stephen – PF Patient

Direct national services

Our befriending service, launched in June 2020, provided vital friendship, support and understanding to 89 patients and carers across the UK. Our incredible volunteer befrienders gave their time, energy, compassion and listening ears when they were needed more than ever. We can't thank them enough.

"I felt so low and alone I just seemed to be slipping more and more into depression... I so look forward to calls from my befriender - they provide everything I need really - we laugh about our pets' antics and just chat."

"I'm four years on with pulmonary fibrosis but past few months have started to struggle... this is an amazing service with very special people."

"It's wonderful to have someone to talk to that really understands the condition."

PF Patients

Our support line gave information, advice and emotional support to 343 people, a slight increase on last year. We saw demand growing through the year and expect this to increase next year. We are very proud of the vital work of our support line but we felt the support line was under-resourced this year. We would have liked to have been able to offer a quicker, more accessible service over a greater number of hours, as well as promote it more to reach more people in need.

"You've cheered me up and given me some hope, my wife will have to put up with me for a long time yet."

"You have a kind voice and have given me positivity back and questions to ask the medical team, thank you."

PF Patients

COMMUNITY FUND

We worked hard to develop and update our information this year on a wide range of topics, including the launch of a brand new guide for carers. Over 150,000 people accessed our website for vital information.

The power of peer support: working in partnership with support groups

Pulmonary fibrosis support groups across the UK faced ongoing challenges this year with continuing uncertainty around Covid, many members still shielding, and continuing massive pressures in the NHS. We supported groups who were starting up, relaunching, wrestling with whether to restart face to face meetings, struggling with bereavements or lack of volunteers, or seeking to grow and develop their work. We provided training, information, advice, practical support and small grants. We supported between 60 and 70 support groups right across the UK, and whilst the number of groups didn't change significantly, some groups combined across regions for online meetings so coverage was improved (though still very patchy since Covid).

"I feel quite emotional hearing people for the first time in a similar situation to me with similar feelings."

"Sometimes, you really think it's just you and no one really understands. But when you meet family or patients, you feel a little bit happy that someone understands what you're going through. Great work @ actionpulmonaryfibrosis - keep going."

PF Patients

"I would like to express my thanks to the organisers of the (Support Group Leaders') course for the high standard of content and delivery. I found it to be a very detailed and informative training session and has greatly enhanced my understanding of the subject. Many thanks for giving me the opportunity to take part."

We want to extend our heartfelt thanks and appreciation to all our support group leads for their tireless efforts through trying times and for the tremendous support they offer people with pulmonary fibrosis (PF) and their families.

Thanks to funding from the National Lottery Community Fund, we were thrilled to grow our team of regional coordinators this year, to offer more help to support groups and be better connected to local and regional issues for people affected by PF.

"It's sometimes hard to think of the upsides of life with PF but one of them has been meeting amazing people, and the friends we have made. We try to remain as positive as we can, even though some days can be very difficult. On those days we cry together, we hug, but most importantly, we talk."

Person living with PF

Together we are stronger.

“If you are not able to talk to a loved one for whatever reason, then find a support group or reach out to Action for Pulmonary Fibrosis. It is a place where people are going through what you are going through, a place where people understand. You don’t have to explain anything, because they already know, and they know how to support and help you.”

Clive, living with PF, and his wife Sue

Education

Print resources

After running a series of focus groups with health care professionals and ILD clinicians, we listened and made changes to our resources and website. We designed and distributed print resources to be given out at diagnosis and ensured that the extensive health information across our website was ‘print friendly’, enabling health care professionals to print and share tailored information easily, dependent on the stage of the disease.

Virtual Patient Day 2021

A new collaboration with Brompton and Harefield Hospital resulted in a first for the organisation, a fantastic online learning event for people affected by PF. Over 800 registered and 90% of people told us they felt more able to manage their PF after the event.

Participants from our online learning event told us:

“Suddenly someone has turned a light on. After years of no knowledge and fear or Googling I have knowledge and hope”.

“The combination of sessions was well judged and I found each and every one useful. I think it is a must to do again. The empathy and professionalism touched my soul. Thank you for that.”

Research

This year Action for Pulmonary Fibrosis and our community have worked harder than ever before with scientists from around the world. Together, we are changing the future for everyone affected by pulmonary fibrosis.

"Together we will find a cure for pulmonary fibrosis."

We have:

- Directly funded research to better understand the causes of pulmonary fibrosis. We now know more about the genetics of the disease and this will help scientists to identify new treatments. We understand more about how different forms of pulmonary fibrosis progress over time, and this vital research has helped us to campaign for antifibrotic medication to be made available to more patients.
- Helped budding scientists to share their findings at global conferences, meaning more people have learnt about the latest research more quickly.
- Worked with over 25 universities, hospitals and drug developers to shape their future research, making sure it is what patients want and need.

Prioritising research for the future

Everyone affected by pulmonary fibrosis knows the urgency of being able to better understand and treat this devastating disease. With so much to do, determining what should be done next is a really tough decision. So we asked patients, carers, clinicians and everyone affected by pulmonary fibrosis what was important to them.

Action for Pulmonary Fibrosis partnered with Imperial College London and the James Lind Alliance to carry out a priority setting partnership with our community. We asked our community what were their priorities for research. Over 1400 people completed two rounds of surveys. We held an event where clinicians and patients, carers and people affected by PF shared why their priorities were important to them and together they decided on a Top 10.

The Top 10 priorities for research can be grouped into three core themes:

- Early and accurate diagnosis.
- Effective treatments that stop, slow or reverse fibrosis and extend patients' lives.
- Interventions that help improve patients' quality of life.

The work we do today, will change tomorrow

We urgently need new treatments, tests and interventions to be developed to improve the lives of people affected by PF. Taking part in research is one way to help to make this happen, but many patients do not know how to, or feel wary about taking part. This year, patients and family members have been working with researchers to help improve the design of their research so more people will want to take part. We have also helped more patients know what is available to them by sharing opportunities to take part in research through our website and social media channels. Our dedicated team of Research Champion volunteers have been working within their communities and forming vital links with their hospitals to raise awareness and opportunities for everyone.

Our Research Fellows

Dr Molyneaux and Dr Allen have continued to be fantastic ambassadors for the APF community, sharing their research in scientific articles, presenting their work at international conferences and adding to the global understanding of pulmonary fibrosis. Their work is advancing what we know about pulmonary fibrosis and expanding opportunities to identify new treatments.

"The support APF has given me over the past three years has been genuinely amazing. The fellowships are a great opportunity to accelerate PF research and develop a career."

Dr Richard Allen

Dr Phil Molyneaux (Imperial College London) is investigating the role of bacteria, microbes and metabolites in pulmonary fibrosis and the impact of antibiotic treatment on disease progression. He is pioneering techniques for investigating the airways, lungs and guts of patients affected by pulmonary fibrosis. His research is improving our understanding of the fundamental mechanisms of the disease which will lead to more effective treatments being available to patients.

Dr Richard Allen (University of Leicester) is researching the genetics of disease. His ground-breaking research has identified new genes associated with idiopathic pulmonary fibrosis and the progression of the disease. Improving our understanding of genetics will help to identify new drug targets and support the development of personalised medicine, meaning each patient gets the right treatment.

Influencing and raising awareness

Reducing health inequalities in pulmonary fibrosis is a vital part of our work.

Being diagnosed with pulmonary fibrosis is frightening. People tell us they have never heard of the disease before they or a loved one were diagnosed. Many people have difficulty understanding the complex language used to describe the disease and its impact on both physical and mental health. A lack of general awareness means that people affected must explain the disease to others and are left feeling exhausted.

That's why it's vital we ensure more people know and understand what pulmonary fibrosis is and its impact on families.

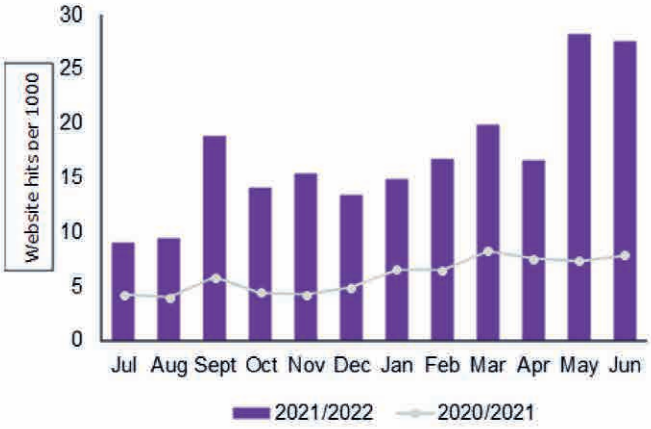
"When I tell people I have pulmonary fibrosis, they say at least I don't have cancer, or comment on how well I look. I've given up telling friends that it's terminal. No one understands. It makes me so angry and alone."

Person living with IPF

Awareness raising

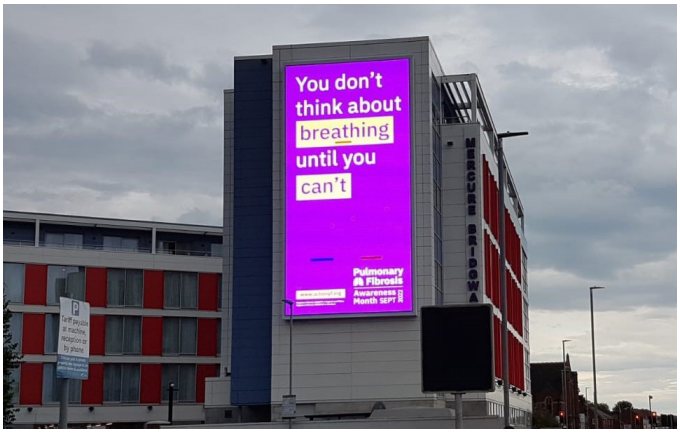
We are now reaching more people than ever before. Month on month we are finding new people with pulmonary fibrosis who desperately need information and to hear from others affected by the disease. Raising awareness of pulmonary fibrosis remains vitally important to our community, so more people can spot the symptoms and get support sooner.

We have worked hard to ensure we are seen by a more diverse audience and to increase the range of people engaging with the brand online and through our services and, crucially, finding us earlier at diagnosis of the disease.



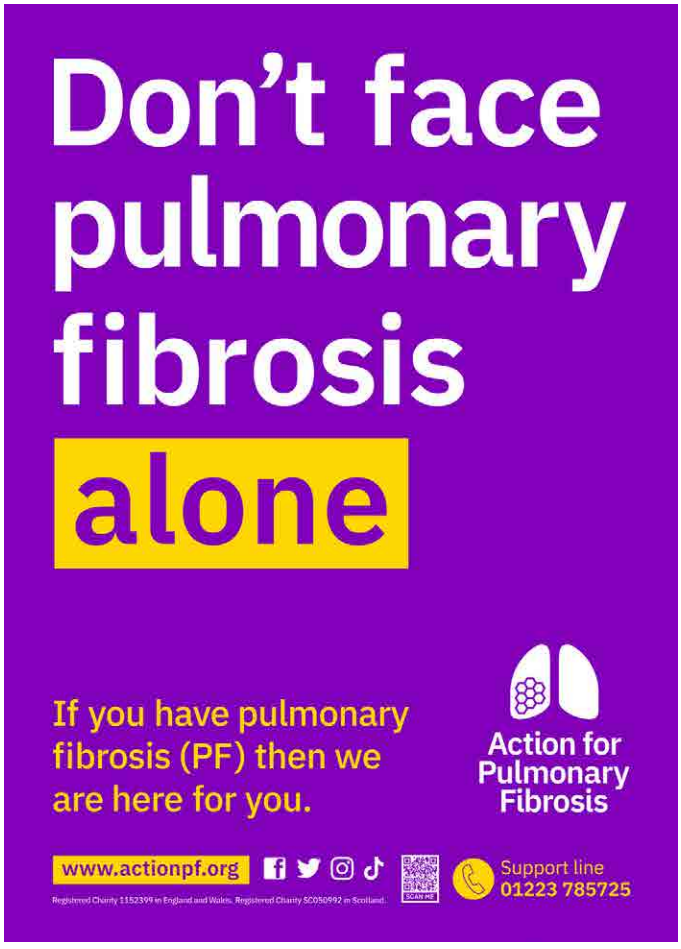
Every September marks global pulmonary fibrosis awareness month. Many continued to shield during September 2021. When surveyed, over 70% of people living with and affected by the disease told us that they worried about being judged for their cough.

We dedicated the month to lifting the stigma and providing support. More people found support and understood the issues through our work on social media, in the press and through our partnerships. We ran social media advertising for the first time during the month which significantly contributed to the number of people finding us.



"When my husband was diagnosed in 2019, I remember saying to a friend if he had a diagnosis of cancer or dementia I would have known the direction of travel, what language would be used and what lay ahead. But I didn't have a clue, because I'd never heard of the disease before, or known anyone with it."

Carer of someone with PF



In May 2022 we developed posters and leaflets and advertised in key locations in five ILD specialist centres, raising awareness for pulmonary fibrosis patients in waiting rooms and hospital corridors that there is no need to 'face it alone' and that we are here as a charity to help.

Influencing others to improve services

Following our successful efforts, in June 2021 the Scottish Medicines Consortium increased access to Nintedanib, a treatment that slows the progress of fibrosis, to people with non-IPF. In October 2021 this was rolled out to England. Yet, we have unfinished business. People with IPF still have to wait until their lung function drops before they can access the life-prolonging treatments. We continue to fight this.

In December 2021 we started a series of virtual workshops engaging a broad spectrum of stakeholders, to better understand the issues and opportunities facing people living with and caring for people with pulmonary fibrosis.

Working with stakeholders including people living with PF and decision makers, we are building the case for better care for people with pulmonary fibrosis, who are at high risk of being worse off than before Covid-19.

This work will continue into 2022/23 as we look to better understand the issues, particularly around the costs of care and how smarter investment could improve health outcomes.

“In the beginning it was just like a typical winter cough but it just wouldn’t go away. In fact it got worse. Eventually, I began suffering bouts of coughing that would lead to retching and choking to the extent I was desperately fighting to catch a breath. I pride myself in being a strong character but on more than one occasion I would be on the verge of tears as a result. I now understand my limitations and avoid the known triggers. There is medication out there that can help, along with self learning.”

Robert, living with PF

Fundraising

2021/22 was a financially challenging year across the charity sector, with the ongoing threat of Covid and economic uncertainty impacting all areas of fundraising. However, thanks to the generosity and continued determination of our supporters, we were able to grow our income by 50% compared to the previous year.

Growth in income has been vital to increasing activity across all areas of our work. A generous three year grant from the National Lottery Community Fund, as well as support from other grant making trusts and pharmaceutical companies, enabled us to grow services and increase our reach within the community by 40%. Our supporters donated and fundraised towards our Hope for All Research Appeal, helping us raise £810k towards vital new research. And our fundraisers skydived, ran, walked and cycled to help ensure APF can continue to be here for everyone affected by pulmonary fibrosis.

While we ended the year in a financially stable position, there is still so much more we need to do – and we anticipate another challenging year ahead. With investment in digital fundraising, individual and in-memory giving, and our ongoing Hope for All Research Appeal, we are determined to raise the funds we need to ensure nobody has to face this cruel disease alone.

We are so incredibly thankful to everyone who has supported APF throughout 2021/22. Together we are stronger.

"If you're going to do it, do it with enthusiasm."

Clive, person living with PF

"I'm running a half marathon to raise money for APF and support their vision to find a cure for pulmonary fibrosis."

Kit, APF fundraiser

"Since Dad's passing, I have found raising money for APF comforting. It keeps a part of Dad alive and means he didn't lose his fight – he just passed the baton on."

Ashleigh, APF fundraiser

£900,000+

Raised throughout 2021/22

Plans for the future

Continued political and economic turmoil, the cost of living crisis and global conflicts mean we anticipate the needs of people living with and affected by pulmonary fibrosis to be higher than ever.

Yet we remain resolute in our drive to meet the increasing daily challenges of people affected by pulmonary fibrosis. Next year will be Action for Pulmonary Fibrosis' 10 year anniversary. We shall be celebrating the advances made over the 10 years and looking ahead to what more needs to be achieved. We shall launch a new five year strategy taking APF to 2028 as we strive to meet the needs of more people affected by pulmonary fibrosis.

We hope you'll join us in the fight against pulmonary fibrosis.

Structure, governance, and management

Action for Pulmonary Fibrosis was registered with the Charity Commission in England and Wales as a Charitable Incorporated Organisation (CIO) in June 2013. The governing document is the Constitution, which was approved by the trustees on 28 May 2013.

On 25 May 2021 Action for Pulmonary Fibrosis was granted registration with the Office of the Scottish Charity Regulator (OSCR).

All trustees have direct experience of PF, either as lived experience or as family members or medical doctors, helping us to maintain our lived experience and healthcare led approach.

The Board of Trustees meets formally four times a year to review the charity's progress, formulate general policy and strategy and ensure adherence to charity regulations. An annual plan and budget for activities for the coming period are approved at the beginning of the financial year. At each meeting reports are received on the charity's work during the quarter. Attention is paid to any significant risks that may arise from time to time and the effectiveness of the system of internal controls is monitored. The quarterly meetings are supported by regular telephone and online communication.

The Board contracts with professional advisers as necessary, for advice and guidance on legal and financial issues.

Appointment of New Trustees

The Board of Trustees regularly reviews the skills and experience of its members and considers if changes are needed to face new and emerging challenges. The Board appoints new members to strengthen the Board and where necessary to replace a member who leaves. It remains an important requirement that all new trustees have a personal connection to pulmonary fibrosis.

An appointment process is in place which includes receipt of a formal application providing personal details and outlining the skills and experience which the applicant can bring to APF. Candidates are then invited to meet with at least three trustees to discuss the application and to receive information about the Board, its work and the responsibilities of a trustee. Prospective trustees are invited to attend a trustee meeting for approval of all trustees prior to confirmation of appointment.

An induction process follows providing the new trustee with comprehensive information on the charity and their responsibilities as a trustee.

To date this has been done by personal contact and through contacts made directly to the charity. In order to ensure diversity and make opportunities more widely available, the process for appointment was reviewed at the year end and it was agreed that trustee vacancies would be advertised.

In May 2022 two new trustees were appointed, Michael Stubbins and Matthew Suddart, both of whom have been personally affected by the disease. Prof Gisli Jenkins resigned as a trustee to become the new Charity President.

Organisational Structure

The Chief Executive Officer leads the charity together with the senior leadership team.

The Finance and Risk Committee is a standing committee which oversees and monitors the finances and budgets of the charity, risks, policies, and remuneration of staff.

The Committee, which includes three trustees and the CEO, meets quarterly prior to the Board meeting. Other sub-committees of the Board of Trustees are established to deal with specific tasks from time to time.

Action for Pulmonary Fibrosis is registered with the Fundraising Register.

Risk Management

Responsibility for risk management lies with trustees and a risk register has been established which is reviewed regularly by the Finance and Risk Committee. The risks identified are minimal and controls are in place to manage them.

Public Benefit Statement

The charity trustees have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission, in exercising their powers or duties. Charity activities and support provided are available to all those affected by pulmonary fibrosis.

Financial review

The charity is in a strong financial position. Total income for the year was £974,578 and total expenditure was £795,238. Details are set out in the attached accounts.

Our income for the year was higher than budgeted due to an increase in community and individual giving. We had budgeted cautiously in these areas due to Covid but they surpassed expectation.

The Fundraising Team have stayed abreast of trends and trialled new ways of fundraising and stewardship including:

- **Our first fundraising video**
- **In Memory virtual event**
- **Paid-for advertising on social media or community activities.**

Diversifying income has been key, with investment in individual and in-memory giving meaning this area is now our biggest income line. Investment in trusts and grants has also been key, with over 60 applications being submitted during Quarters 3 and 4. This has secured income in the current financial year and will result in further income in 2022/23. Receiving our first National Lottery Community Fund grant has been crucial to sustainability, funding around 60% of support services costs.

We are pleased with end of year income, and the year has provided us with learning that we are carrying forward to 2022/23, as we continue to follow world events and sector trends.

Expenditure was also lower than budgeted due to some planned activities being cancelled, or continuing to be completed virtually, due to the pandemic.

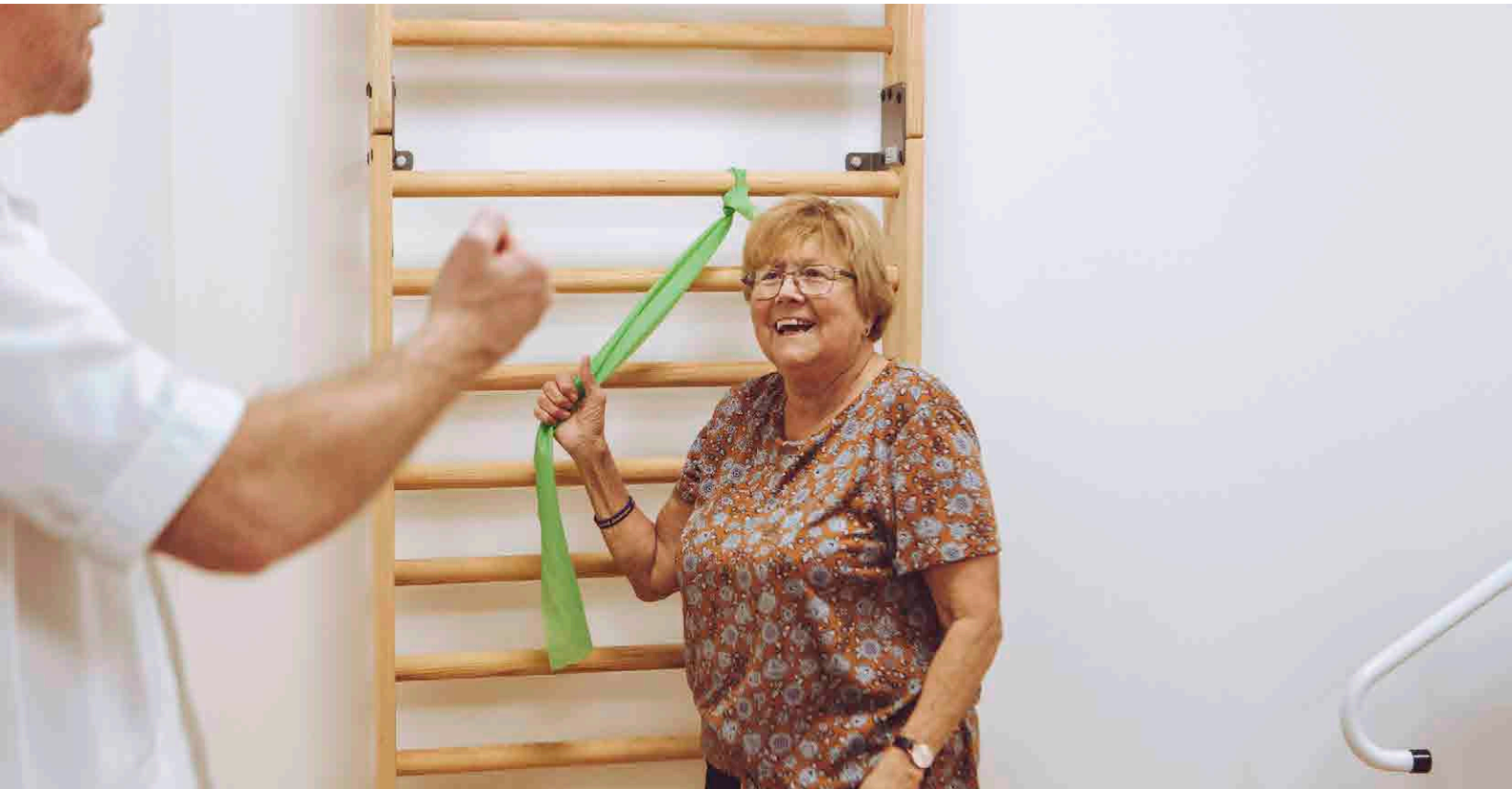
The 2021/22 budget was set with our Senior Leadership Team being optimistic that Covid would not continue to greatly affect our activities and plans for the financial year. This has clearly not been the case with the impact of Covid still being felt nearly two years on.

Going Concern

The trustees consider that the charity will continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved. The trustees therefore consider it appropriate to adopt the going concern basis for the preparation of the accounts, as detailed in note 1(b) to the financial statements.

Reserves Policy

Trustees have agreed a reserves policy of holding an amount equivalent to six months of charitable expenditure, as designated reserves. Charitable expenditure includes staff and running costs, fundraising costs, planned activities and the provision of patient and family support activities. This is to ensure that the charity can continue offering services to its patient community during times of reduced income. It is reviewed annually at the July trustee meeting. The projection of increased operational costs for the coming year resulted in agreement to increase the balance on the reserves account to meet the requirements of the policy. This was carried out and the reserves account balance has been increased to £336,000 (£278,725 in 2021/22).



Independent Auditor's Report

Report of the trustees
For the year ended 30 June 2022

Statement of responsibilities of the trustees

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with 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).

The law applicable to charities in England and Wales, and in Scotland, requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and the incoming resources and application of resources, including the net income or expenditure, of the charity for the year. In preparing those 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 judgements and accounting estimates that are reasonable and prudent;
- state whether applicable accounting standards and statements of recommended practice 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 charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts(Scotland) Regulations 2006 (as amended) and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditors

Godfrey Wilson Limited were re-appointed as auditors to the charity during the year and have expressed their willingness to continue in their capacity.

Approved by the trustees on 4th February 2023 and signed on their behalf by

Stephen Jones

Stephen Jones - Chair

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

Opinion

We have audited the financial statements of Action for Pulmonary Fibrosis (the 'charity') for the year ended 30 June 2022 which comprise the statement of financial position, balance sheet and statement of cash flows, and the related 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 charity's affairs as at 30 June 2022 and of its incoming resources and application of resources, including its 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 Charities and Trustees Investment (Scotland) Act 2005, regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011.

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 charity 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 charity'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 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.

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

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.

Matters on which we are required to report by exception
In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report. We have nothing to report in respect of the following matters in relation to which the Charities Act 2011 requires us to report to you if, in our opinion:

- sufficient accounting records have not been kept;
- the financial statements are not in agreement with the accounting records and returns; or
- we have not obtained all the information and explanations necessary for the purposes of our audit.

Responsibilities of the trustees
As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees 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 they 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 charity'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 charity or to cease operations, or have no realistic alternative but to do so.

Our 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 procedures we carried out and the extent to which they are capable of detecting irregularities, including fraud, are detailed below:

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

(1) We obtained an understanding of the legal and regulatory framework that the charity operates in, and assessed the risk of non-compliance with applicable laws and regulations. Throughout the audit, we remained alert to possible indications of non-compliance.

(2) We reviewed the charity's policies and procedures in relation to:

- Identifying, evaluating and complying with laws and regulations, and whether they were aware of any instances of non-compliance;
- Detecting and responding to the risk of fraud, and whether they were aware of any actual, suspected or alleged fraud; and
- Designing and implementing internal controls to mitigate the risk of non-compliance with laws and regulations, including fraud.

(3) We inspected the minutes of trustee meetings.

(4) We enquired about any non-routine communication with regulators and reviewed any reports made to them.

(5) We reviewed the financial statement disclosures and assessed their compliance with applicable laws and regulations.

(6) We performed analytical procedures to identify any unusual or unexpected transactions or balances that may indicate a risk of material fraud or error.

(7) We assessed the risk of fraud through management override of controls and carried out procedures to address this risk. Our procedures included:

- Testing the appropriateness of journal entries;
- Assessing judgements and accounting estimates for potential bias;
- Reviewing related party transactions; and
- Testing transactions that are unusual or outside the normal course of business.

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. Irregularities that arise due to fraud can be even 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.

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charity's trustees 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 charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Date: 2 February 2023

GODFREY WILSON LIMITED
Chartered accountants and statutory auditors
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD

Action for Pulmonary Fibrosis

Statement of financial activities

For the year ended 30 June 2022

	Note	Restricted £	Unrestricted £	**2022 Total £**	2021 Total £
Income from:					
Donations and legacies	3	22,764	710,987	**733,751**	518,882
Charitable activities	4	200,692	21,710	**222,402**	127,832
Investments		-	6,313	**6,313**	5,095
Other trading income	5	-	12,112	**12,112**	-
Total income		223,456	751,122	**974,578**	651,809
Expenditure on:					
Raising funds		-	168,909	**168,909**	109,856
Charitable activities		225,860	400,469	**626,329**	491,552
Total expenditure	7	225,860	569,378	**795,238**	601,408
Net income / (expenditure)		(2,404)	181,744	**179,340**	50,401
Transfers between funds		1,952	(1,952)	**-**	-
Net movement in funds	10	(452)	179,792	**179,340**	50,401
Reconciliation of funds:					
Total funds brought forward		65,200	1,025,209	**1,090,409**	1,040,008
Total funds carried forward		64,748	1,205,001	**1,269,749**	1,090,409

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 17 to the accounts.

Action for Pulmonary Fibrosis

Balance sheet

As at 30 June 2022

	Note	£	**2022** **£**	2021 £
Current assets				
Debtors	13	**22,401**		19,502
Current asset investments		**1,069,851**		1,071,858
Cash at bank and in hand		**264,095**		156,054
		1,356,347		1,247,414
Liabilities				
Creditors: amounts falling due within 1 year	14	**(86,598)**		(127,040)
Net current assets			**1,269,749**	1,120,374
Creditors: amounts falling due after more than 1 year	15		**-**	(29,965)
Net assets	16		**1,269,749**	1,090,409
Funds	17			
Restricted funds			**64,748**	65,200
Unrestricted funds				
Designated funds			**1,023,128**	962,492
General funds			**181,873**	62,717
Total charity funds			**1,269,749**	1,090,409

Approved by the trustees on 1 February 2023 and signed on their behalf by

Stephen Jones - Chair

Action for Pulmonary Fibrosis

Statement of cash flows

As at 30 June 2022

	2022 £	2021 £
Cash provided by operating activities:		
Net movement in funds	**179,340**	50,401
Adjustments for:		
Investment income	**(6,313)**	(5,095)
Decrease / (increase) in debtors	**(2,899)**	(5,577)
Increase / (decrease) in creditors	**(70,407)**	(93,233)
Net cash provided by operating activities	**99,721**	(53,504)
Cash flows from investing activities:		
Investment income	**6,313**	5,095
Net cash provided by investing activities	**6,313**	5,095
Increase in cash and cash equivalents in the year	**106,034**	(48,409)
Cash and cash equivalents at the beginning of the year	**1,227,912**	1,276,321
Cash and cash equivalents at the end of the year	**1,333,946**	1,227,912

Analysis of cash and cash equivalents

Current asset investments	**1,069,851**	1,071,858
Cash at bank and in hand	**264,095**	156,054
Cash and cash equivalents at the end of the year	**1,333,946**	1,227,912

The charity has not provided an analysis of changes in net debt as it does not have any long term financing arrangements.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

1. Accounting policies

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 in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Action for Pulmonary Fibrosis 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 notes.

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern. The charity holds unrestricted, general reserves of £181,873, designated reserves that can be drawn down if necessary of £1,023,128 and a cash balance of £264,095. The combined value of cash and current asset investments at 30 June 2022 was £1.33m. The trustees consider that the charity has sufficient cash reserves to continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the items of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from the government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

d) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

e) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

f) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

g) Grants payable

Grants payable are charged in the year in which the offer is conveyed to the recipient except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attached have been fulfilled. Grants offered subject to conditions at the year end are noted as commitment but are not accrued as expenditure.

h) Allocation of support and governance costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities on the basis of staff time spent on each of these areas. In the prior period an estimate was used, but in the current period a more thorough analysis of staff time by role was possible as there was a more significant number of employees. The percentages used were as follows:

	2022	**2021**
Raising funds	21%	17%
Charitable activities	79%	83%

i) 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.

j) Current asset investments

Current asset investments consists of short term cash deposits with a maturity date of less than one year from the balance sheet date held for investment purposes rather than to meet short term cash commitments as they fall due.

k) 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.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

l) Creditors

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.

m) Financial instruments

The charity 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 with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

n) Pension costs

The charity operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

o) Operating leases

Operating lease payments are recognised as an expense on a straight-line basis over the lease term.

p) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

There are no key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

2. Prior period comparatives: statement of financial activities

	Restricted £	Unrestricted £	2021 Total £
Income from:			
Donations and legacies	-	518,882	518,882
Charitable activities	99,238	28,594	127,832
Investments	-	5,095	5,095
Total income	99,238	552,571	651,809
Expenditure on:			
Raising funds	-	109,856	109,856
Charitable activities	59,545	432,007	491,552
Total expenditure	59,545	541,863	601,408
Net income and net movement in funds	39,693	10,708	50,401

3. Income from donations and legacies

	Restricted £	Unrestricted £	**2022 Total £**	2021 Total £
Legacies	-	36,200	**36,200**	5,000
Donations from individuals and fundraising	22,764	674,787	**697,551**	513,882
Total income from donations and legacies	22,764	710,987	**733,751**	518,882

All income from donations and legacies in the prior year was unrestricted.

4. Income from charitable activities

	Restricted £	Unrestricted £	**2022 Total £**
Corporate grants	3,200	-	**3,200**
Trusts and foundations	197,492	2,675	**200,167**
Consultancy fees	-	17,039	**17,039**
Speaker fees	-	1,996	**1,996**
Total income from charitable activities	200,692	21,710	**222,402**

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

4. Income from charitable activities (continued)

Prior period comparative

	Restricted £	Unrestricted £	2021 Total £
Trusts and foundations	99,238	28,594	127,832
Total income from charitable activities	99,238	28,594	127,832

5. Income from other trading activities

	2022 £	2021 £
Conference sponsorship	**7,988**	-
Merchandise sales	**4,124**	-
Total income from other trading activities	**12,112**	-

6. Government grants

The charity received a government grant, defined as funding from the National Lottery Community Fund, to fund support services. The total value of such grants for the year ending 30 June 2022 was £153,492 (2021: £nil). There were no unfulfilled conditions or contingencies attached to these grants in 2021/22.

7. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	2022 Total £
Staff costs (note 11)	98,646	362,320	45,179	**506,145**
Freelance costs (note 11)	-	69,915	16,914	**86,829**
Travel and subsistence	-	-	4,696	**4,696**
Grants payable (note 8)	-	2,365	-	**2,365**
Training costs	-	1,725	-	**1,725**
Patient surveys	-	3,212	-	**3,212**
Fundraising costs	22,371	-	-	**22,371**
Marketing and communications	8,681	42,770	-	**51,451**
Premises costs	-	-	33,384	**33,384**
Admin costs	-	-	58,355	**58,355**
Other staffing costs	-	-	18,682	**18,682**
Governance costs	-	-	6,023	**6,023**
Sub-total	129,698	482,307	183,233	**795,238**
Allocation of support and governance costs	39,211	144,022	(183,233)	-
Total expenditure	**168,909**	**626,329**	**-**	**795,238**

Prior year comparative:

	Raising funds £	Charitable activities £	Support and governance costs £	2021 Total £
Staff costs (note 11)	53,902	256,691	59,827	**370,420**
Freelance costs (note 11)	11,023	57,445	-	**68,468**
Travel and subsistence	-	-	359	**359**
Grants payable (note 8)	-	1,350	-	**1,350**
Training costs	-	3,610	-	**3,610**
Patient surveys	-	2,903	-	**2,903**
Fundraising costs	16,280	-	-	**16,280**
Marketing and communications	3,716	50,807	-	**54,523**
Premises costs	-	-	20,327	**20,327**
Admin costs	-	-	37,302	**37,302**
Other staffing costs	-	-	17,046	**17,046**
Governance costs	-	-	8,820	**8,820**
Sub-total	84,921	372,806	143,681	**601,408**
Allocation of support and governance costs	24,935	118,746	(143,681)	-
Total expenditure	**109,856**	**491,552**	**-**	**601,408**

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. They are distinct from costs incurred to support those affected by Pulmonary Fibrosis, which are included under charitable activities.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

8. Grants payable

	2022	2021
	£	£
Support groups:		
North Cumbria Support Group	**508**	-
Northern Trust Support Group	**1,713**	-
Brighton Support Group	**144**	-
Nottingam Support Group	**-**	850
Windsor Support Group	**-**	500
	2,365	1,350

9. Grants commitments

	2022	2021
	£	£
Grant commitments brought forward	**115,753**	242,318
Grants committed during the period (note 8)	**2,365**	1,350
Grants paid during the period	**54,566**	114,403
Grant commitments carried forward	**56,931**	115,753

10. Net movement in funds

This is stated after charging:

	2022	2021
	£	£
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses	**67**	2,275
Auditors' remuneration:		
▪ Statutory audit (including VAT)	**5,220**	4,680
▪ Other services (including VAT)	**Nil**	Nil

During the year, 1 trustee was reimbursed £67 for travel expenses (2021: 9 trustees were reimbursed £2,275 for training and related travel expenses). All expenses incurred were in the course of the organisation's charitable activities.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

11. Staff costs and numbers

Staff costs were as follows:

	2022	2021
	£	£
Salaries and wages	**453,321**	331,691
Social security costs	**40,536**	29,731
Pension costs	**12,288**	8,998
Freelance staff	**86,829**	68,468
	592,974	438,888

One employee earned between £60,000 and £70,000 during the year (2021: one).

The key management personnel of the charity comprise the trustees and Chief Executive. The total employee benefits of the key management personnel were £78,028 (2021: £71,475).

	2022	2021
	No.	No.
Average head count	**16**	11

12. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

13. Debtors

	2022	2021
	£	£
Trade debtors	**4,984**	4,822
Accrued income	**12,339**	11,440
Prepayments	**5,078**	3,240
	22,401	19,502

14. Creditors: amounts due within 1 year

	2022	2021
	£	£
Trade creditors	**8,894**	33,863
Accruals	**20,773**	5,480
Other creditors	**-**	1,909
Grant commitments (note 9)	**56,931**	85,788
	86,598	127,040

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

15. Creditors: amounts due after 1 year

	2022	2021
	£	£
Grant commitments (note 9)	**-**	29,965

16. Analysis of net assets between funds

	Restricted funds	Designated funds	General funds	**Total funds**
	£	£	£	**£**
Current assets	64,748	1,080,059	211,540	**1,356,347**
Current liabilities	-	(56,931)	(29,667)	**(86,598)**
Net assets at 30 June 2022	**64,748**	**1,023,128**	**181,873**	**1,269,749**

Prior year comparative	Restricted funds	Designated funds	General funds	Total funds
	£	£	£	£
Current assets	65,200	1,078,245	103,969	1,247,414
Current liabilities	-	(85,788)	(41,252)	(127,040)
Long term liabilities	-	(29,965)	-	(29,965)
Net assets at 30 June 2021	65,200	962,492	62,717	1,090,409

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

17. Movements in funds

	At 1 July 2021 £	Income £	Expenditure £	Transfers between funds £	**At 30 June 2022 £**
Restricted funds					
Boehringer Ingelheim	9,545	1,200	(10,759)	14	**-**
Roche	18,750	-	(18,772)	22	**-**
Trevi Theraupeutics	24,988	-	-	-	**24,988**
Independent Age	10,000	-	(10,528)	528	**-**
Shanly Foundation	750	-	(1,230)	480	**-**
Hospital Saturday Fund	1,167	10,000	(10,007)	-	**1,160**
National Lottery Community Fund	-	153,492	(142,572)	-	**10,920**
NeRRe Therapeutics	-	2,000	(2,872)	872	**-**
D'Oyly Carte Charitable Trust	-	3,500	(3,328)	-	**172**
Edwards Cadbury Charitable Trust	-	5,000	(5,036)	36	**-**
Garfield Weston	-	25,000	(108)	-	**24,892**
Ian Askew Charitable Trust	-	500	(500)	-	**-**
Northern Ireland donations	-	4,329	(1,713)	-	**2,616**
Research donations	-	18,435	(18,435)	-	**-**
Total restricted funds	65,200	223,456	(225,860)	1,952	**64,748**
Unrestricted funds					
Designated funds					
Research fund	683,767	-	(30,518)	33,879	**687,128**
Reserve fund	278,725	-	-	57,275	**336,000**
Total designated funds	962,492	-	(30,518)	91,154	**1,023,128**
General funds	62,717	751,122	(538,860)	(93,106)	**181,873**
Total unrestricted funds	1,025,209	751,122	(569,378)	(1,952)	**1,205,001**
Total funds	1,090,409	974,578	(795,238)	-	**1,269,749**

Purposes of restricted funds

Boehringer Ingelheim	This fund is for support line ambassadors and the newsletter.
Roche	This fund is for general support services to December 2021.
Trevi Theraupeutics	This fund is for support services in Scotland (including SG coordinator salary) which is launching in 22/23.
Independent Age	This fund is for resuming face to face services (support groups).
Shanly Foundation	This fund is for support services in the South.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

Purposes of restricted funds (continued)

Hospital Saturday	This fund is for support services.
National Lottery Community Fund	This fund is for support services.
NeRRe Therapeutics	This fund is to support PF awareness month.
D'Oyly Carte Charitable Trust	This fund is to enable new and existing APF volunteers to receive training in order to better support patients and carers.
Edwards Cadbury Charitable Trust	The fund is for the continuation and growth of the support services to help provide information for patients and families to enable them to make informed choices about health and wellbeing, as well as raising awareness and understanding of PF.
Garfield Weston	This fund is for support services growing volunteering, and is to be used towards volunteering salary costs, services admin and volunteer recruitment, training, expenses and marketing.
Ian Askew Charitable Trust	This fund is for support services.
Northern Ireland donations	These are donations received specifically for Northern Ireland.
Research donations	These are donations received specifically for research.

Purposes of designated funds

Research fund	A principal objective of Action for Pulmonary Fibrosis is to support and fund Research into the disease. Trustees have agreed to designate £687K for research to fund further research fellowships, expected in 2023-24.
Reserve fund	The Reserve Fund has been established, in line with the charity's reserves policy, to retain a minimum of 50% of projected annual core expenditure separately as reserves. This is reviewed annually.

Transfers between funds

A transfer has been made from general funds to various restricted funds to cover overspends.

Transfers from general funds to designated funds represent additional designated funds, as agreed by the board.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2022

17. Movements in funds

Prior year comparative

	At 1 July 2020 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2021 £
Restricted funds					
Boehringer Ingelheim	25,507	35,000	(50,962)	-	9,545
Roche	-	25,000	(6,250)	-	18,750
Trevi Theraupeutics	-	24,988	-	-	24,988
Independent Age	-	10,000	-	-	10,000
Shanly Foundation	-	2,250	(1,500)	-	750
Hospital Saturday Fund	-	2,000	(833)	-	1,167
Total restricted funds	25,507	99,238	(59,545)	-	65,200
Unrestricted funds					
Designated funds					
Research fund	568,172	-	-	115,595	683,767
Reserve fund	225,023	-	-	53,702	278,725
Total designated funds	793,195	-	-	169,297	962,492
General funds	221,306	552,571	(541,863)	(169,297)	62,717
Total unrestricted funds	1,014,501	552,571	(541,863)	-	1,025,209
Total funds	1,040,008	651,809	(601,408)	-	1,090,409

18. Operating leases

The charity had operating leases at the year end with total future minimum lease payments as follows:

	2022 £	2021 £
Amount falling due:		
Within 1 year	**9,360**	5,517
Within 2 - 5 years	**-**	-
	9,360	5,517

19. Related party transactions

Steve Jones, the chair of Action for Pulmonary Fibrosis (APF), is also the chair of European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF). During the year APF received income of £415 from EU-IPFF for speaker fees (2021: £4,084 for services relating to the Global Patient Partnership Summit). No amounts were outstanding at year end.

The trustees are not aware of any other related party transactions during the period.

Action for Pulmonary Fibrosis is a patient-driven charity. Our vision is to find a cure for pulmonary fibrosis so everyone affected has a better future.

Action for Pulmonary Fibrosis

Charity Commission England & Wales Registered Charity Number: 1152399
Scottish Charity Regulator Number: SC050992

ACTION FOR PULMONARY FIBROSIS

England & Wales - Charity number 1152399

Accounts

Trustees' Annual Report & Accounts

For the year ending 30 June 2021

Action for Pulmonary Fibrosis

Charity Commission England & Wales Registered Charity Number: 1152399
Scottish Charity Regulator Number: SC050992

2020
2021

Contents

What is pulmonary fibrosis?	3
Why we are needed	4
Supporting through Covid	5
Our vision, mission, and values	6
Trustees, staff, and advisors	7
Introduction from Chair and Chief Executive	8
Report of the Board of Trustees:	
– Support and Information	10
– Research	14
– Education	16
– Campaigning and Awareness	18
– Fundraising	20
– Plans for the future	22
– Structure, governance, and management	23
– Financial Review	25
Independent Auditor's Report	27
Statement of Financial Activities	31
Balance Sheet	32
Statement of cash flows	33
Notes to Financial Statements	34

Action for Pulmonary Fibrosis

Support line
01223 785725

General enquiries:
01733 475642
info@actionpf.org

www.actionpf.org

Registered Charity 1152399 in England and Wales. Registered Charity SC050992 in Scotland.

What is pulmonary fibrosis?

Pulmonary fibrosis is an umbrella term for a range of progressive lung diseases, which cause stiffening and scarring of the lungs.

The lung scarring eventually prevents the transfer of oxygen into the bloodstream. It affects around 70,000 people in the UK. Idiopathic pulmonary fibrosis is the most aggressive and common form and affects around 30,000 people in the UK.

Key symptoms of pulmonary fibrosis include breathlessness and chronic cough. On physical examination, Velcro-like crackles are likely to be heard and sometimes the ends of fingers or toes may appear enlarged or 'clubbed'. Key symptoms can be confused with other respiratory disorders, such as chronic obstructive pulmonary disorder (COPD), asthma and bronchiectasis.

Other forms of pulmonary fibrosis include: familial pulmonary fibrosis; those associated with autoimmune diseases (such as rheumatoid arthritis and systemic sclerosis); toxicity caused by some medications; exposure to inorganic substances (such as asbestos and coal dust); hypersensitivity pneumonitis caused by exposure to organic dusts and fibres (such as bird feathers and mould found on hay, straw and grain), and sarcoidosis.

Why we are needed

Tens of thousands of people are affected by pulmonary fibrosis, yet it remains a mystery to many people.

The debilitating nature of the disease means as people become increasingly breathless, their need for physical and emotional support become greater. Patients and their families can experience a profound sense of loss as the disease progresses. Pulmonary fibrosis affects every area of family life, yet there is very little dedicated support available to patients and families affected.

As breathlessness increases, ordinary daily tasks – washing, dressing, walking can become exhausting, which impacts increasingly on the whole family and especially carers. As an unfamiliar condition, many patients can struggle to find information and support and find themselves repeatedly explaining the diagnosis to healthcare professionals, family and friends, which causes distress. We want everyone affected by the disease to be understood and to have access to the information and support they need when they need it. Our support community, peer groups, befrienders, and information are vital in helping patients and carers feel more connected, supported and reassured.

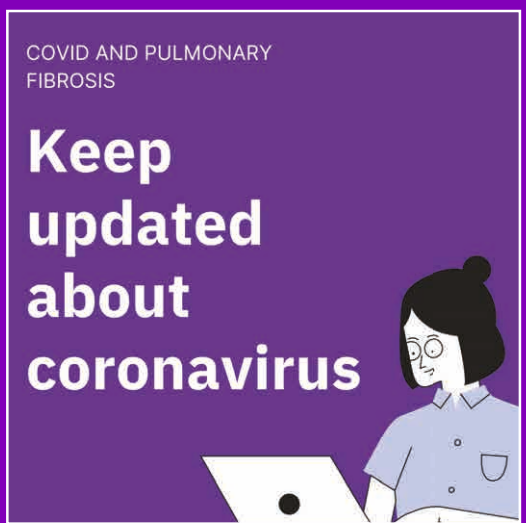
Pulmonary fibrosis can be very difficult to detect, with patients frequently waiting over a year for an accurate diagnosis. We need to speed up the process of diagnosis so that patients can start treatment sooner.

Our understanding of the disease has progressed rapidly over the last 10 years leading to treatments becoming available that slow the progression of the disease.

But we need to go further than this. We want to stop the disease in its tracks. That's why we're committed to funding research to find new treatments and a cure.

Together we can make this happen.

Supporting through Covid



The Covid pandemic has had a profound impact across the world, but it is particularly tough for those with a respiratory condition like pulmonary fibrosis.

Research by APF trustee Professor Gisli Jenkins shows that if pulmonary fibrosis patients are hospitalised, they are more likely to get severe Covid and more likely to die. Patients, understanding the very real risk, have been forced to shield and most continue to do so. Many of those who have managed to protect themselves from Covid have felt the severe impact on their mental health as a result.

Interstitial Lung Disease (ILD) services have been under immense pressure – as has the health service as a whole, and the individual staff within it.

In turn, this means the demands on APF – a charity driven by patients, carers and healthcare professionals – have been great. In person support group meetings were put on hold, as we adapted to online and telephone support. Fundraising became more of a challenge as events from coffee mornings to marathons were no longer an option.

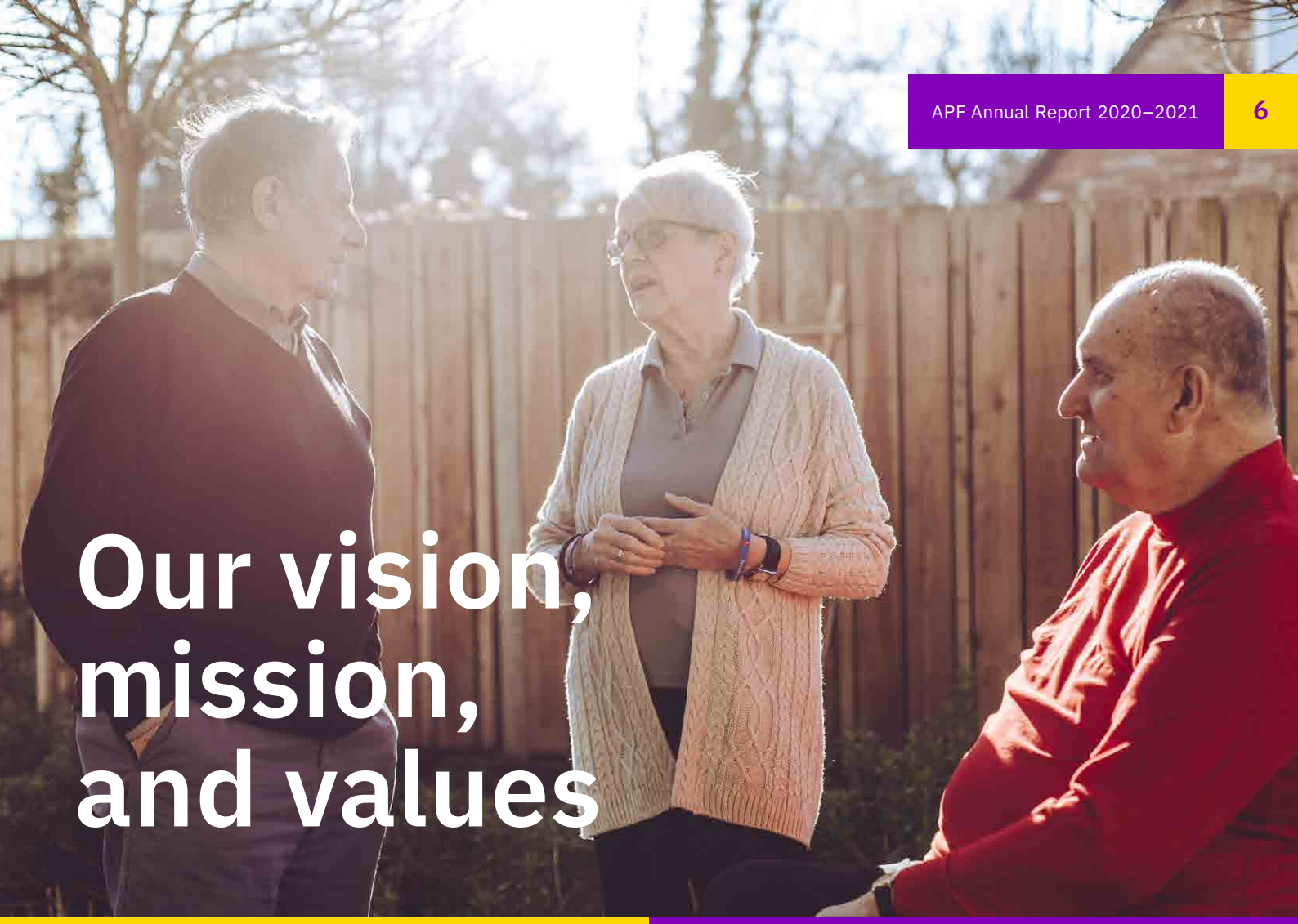
At the same time, campaigning has been even more critical - initially, pulmonary fibrosis was not included on the list of conditions that put people at high risk from Covid. Lobbying by APF led to its inclusion on the list under category 4, opening up more support for PF patients such as priority shopping. We also campaigned successfully for IPF patients to have priority access to lung function tests so that they could be started on antifibrotics when eligible.

The APF trustees have also considered the impact that the Covid pandemic will have on the charity's current and future financial position. These are likely to include falls in:

- Average donations from patients and their families as we enter a global recession; and
- Community fundraising income, in particular, as fundraisers are restricted from taking part in group events and activities such as the London Marathon.

The charity is taking the following steps to mitigate the potential threats of Covid to the organisation:

- We are planning on the assumption that there will not be any growth in income for the foreseeable future;
- We will review our financial progress monthly and make changes, as required; and
- We have increased our capacity to bring in income from trusts and foundations.



Our vision, mission, and values

Our vision

APF's vision is to find a cure for everyone affected by pulmonary fibrosis to have a better future.

Our mission

We provide support to families, raise awareness of the disease, campaign and educate to improve access to the highest standard of care for people living with all forms of pulmonary fibrosis. We are committed to funding research to improve the quality of life for people living with pulmonary fibrosis today and tomorrow.

Our values drive everything we do:

Patient led:
We empower and are led by patients who are at the heart of everything we do.

Caring and compassionate:
We respect and understand the needs of patients and carers and help them to get the support they need.

Striving for excellence:
We work with integrity and professionalism in all that we do.

Open and approachable:
We ensure people affected by PF feel able to turn to us for advice and support in their time of need.

Ambitious and bold:
We improve the lives of people affected by PF and are bold in the ways we do this.

Trustees, staff, and advisors

Charity Trustees:
Mr Stephen Jones* (Chair)
Mr Howard Almond*
Mrs Elizabeth Bray**
Mrs Wendy Dickinson**
Dr Simon Hart
Prof Gisli Jenkins
Dr Rebecca Lang**
Mr Stephen Morgan-Hyland**
Dr Helen Parfrey

* living with PF
** family member of someone with PF

In keeping with the charity's ethos of being patient led, over 60% of trustees have been personally affected by pulmonary fibrosis either as a patient or family member. Our trustees also include medical professionals, who are leaders in pulmonary fibrosis care and research.

Chief Executive:
Louise Wright

Registered Office and Principal Address:
Stuart House, East Wing
St John's Street
Peterborough
PE1 5DD

Charity Commission Registered Number:
1152399

Scottish Charity Regulator Number:
SC050992

Principal Advisors:

Bankers:
CAF Bank Limited
25 Kings Hill Avenue
Kings Hill, West Malling
Kent ME19 4JQ

Auditors:
Godfrey Wilson Limited
Chartered Accountants and statutory auditors
5th Floor Mariner House, 62 Prince Street
Bristol BS1 4QD

Introduction from Chair and Chief Executive

July 2020 – June 2021

Writing this year's annual report has given us reason to pause and reflect on what has been the toughest year in APF's short history. As news headlines told of the devastating impact of Covid on people and the economy we saw our face-to-face services pause temporarily and our income grind to a near halt. We could see APF was needed more than ever but we knew our income would be badly affected.

Rising cases of anxiety, depression and lack of access to healthcare professionals and timely care saw an increase in demand for our services. But, with lockdowns expected throughout the year, opportunities to fundraise were severely diminished. Many of our small team juggled caring for family and work, and we all had to adapt quickly to new ways of working. Meanwhile we faced the greatest volume of requests for support we had ever seen.

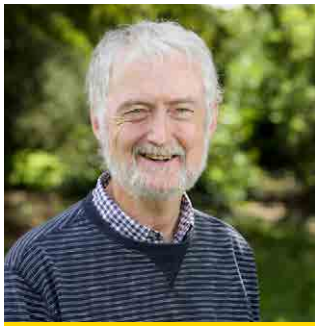
Fortunately, APF was able to respond with rapid digitisation of support services, an enhanced website offering and alternative fundraising suggestions and opportunities. A key achievement was The Covid Hub on our website, providing instant accessible support and information tailored for PF patients, which received over 13,000 hits. Research continued, as our research fellows adjusted their schedules and place of work throughout the pandemic. We sought to work with others as much as possible during this challenging time. This included charities, government and respiratory bodies such as the EUIPFF and the British Thoracic Society. We strongly believe in the value of partnerships to achieve our vision for the future.

While we looked for savings through delivery of services online, we also invested in postal and telephone-based support to ensure those not online were still able to receive the personal quality-based support for which APF is known. This included our first ever telephone befriending service.

We continue to be a driver for change, to deliver and inspire life-changing work. It is such a privilege to lead APF and our brilliant team at this historic moment. For eight years the organisation has empowered patients and positively contributed to the transformation of care and support that exists for everyone affected by pulmonary fibrosis. But we need you like never before.

Despite progress, tens of thousands of people across the UK are living with the daily burden of pulmonary fibrosis. Covid has increased feelings of isolation and despair. The challenges we face are complex, but can be diminished by our combined talent, focus and ambition – and of course your continuing support.

Together we can keep making progress in serving pulmonary fibrosis patients and their families.



Steve Jones
(Chair of Trustees)

Louise Wright
(Chief Executive)

Together we are stronger.

"At 86 I feel I am missing out on all the pleasures of my remaining years. I am avoiding catching and dying of Covid just to die of IPF."

APF COVID Survey recipient

Report of the Board of Trustees

Support and Information

Being diagnosed with pulmonary fibrosis can be a lonely, terrifying experience, which is made even harder by the pandemic. Over this year, access to local health services has been limited and many patients have been shielding at home. We have worked to make life that bit easier by developing services which enable people to look forward to a positive future. We have increased access to information and emotional support to manage the changes that life with PF brings.

The power of peer support

We know that creating opportunities for people to share their experiences improves overall wellbeing. Support groups enable people to share practical and emotional impacts of what they are going through, and find mutual support. Being together during tough times like this builds resilience, friendship and the sharing of helpful information.

We support a network of more than 60 support groups with grants, training and guidance. But the pandemic hit groups hard, particularly where respiratory teams were under huge pressure or where members felt less digitally confident. Our first online survey of groups showed that active membership fell to half pre-Covid levels, with 54% struggling to gain referrals and recruit new members.

However, there were positive signs of growth later in the year. New support groups began in Forth Valley, while new groups such as the Pulmonary Fibrosis Transplant Patients Support Group (PFTx) and Carers continued to offer peer support on shared issues. We helped more than 30 groups to set up online meetings and created the leaders' network for mutual support. We listened to specific needs throughout the pandemic and piloted confidence-building training around 'supporting people through challenging times', and leadership, group facilitation and mental wellbeing as a response.

Overwhelmingly, leaders felt that groups help members to manage their PF, have hope for the future and feel more supported. More than 90% of members felt their support group helps them feel informed about PF, manage symptoms more effectively, and feel more connected and able to access other support. However, a challenge remains to recruit new members from all parts of the community, so that everyone who wants to can access good peer support.

"I found the 'supporting' training so helpful and insightful and still use the information today."

Maureen, Fife and Tayside Support Group leader and APF telephone befriender

"I take comfort in our shared experience and much food for thought about how I navigate my path through all the physical, emotional and practical challenges that we face."

Lynne, member of Sheffield Support Group

Telephone befrienders

Among the many challenges that life with pulmonary fibrosis brings, isolation is one of the hardest, especially during a pandemic. In view of this, we developed the telephone support service. Our team of trained, DBS-checked volunteer befrienders have personal experience of PF as patients, carers, family or friends, and provide a friendly listening ear.

The telephone support calls are an opportunity to keep in touch and connect with someone who really understands. Befrienders also signpost to local services, support groups and APF's own resources and support line.

Over the year, 19 volunteers were trained as befrienders and reached out to 47 patients and carers with regular calls, to feel empowered, more connected and supported.

"Lockdown literally shut down my life. You don't meet many younger people like myself with PF and it's rare to find someone who understands what you're experiencing. My volunteer inspires me so much... and totally understands the specific challenges of living with PF. The impact she's had on me is tremendous - I would say it's a lifeline. I so look forward to our weekly calls."

Dawn, member of the Sheffield Support Group who has a telephone befriender

Reaching those who need us

Patients and families living with PF need to be able to access information and support regularly. This reduces anxiety and stress at a time of isolation and enables more choice about one's future care.

The Covid Hub section of our website was viewed over 13,000 times throughout the year and new information on topics from diagnosis to supportive care, breathing and exercise, helped bring reassurance and guidance when the world around seemed ever-changing and access to local health services very limited. An additional 23,000 people found our website compared to the previous year.

APF's support line gave reassurance and guidance for 338 patients and carers, many grappling with complex issues around pulmonary fibrosis, often compounded with other health or social issues. Many have gone on to be supported through an APF befriender or local PF support group, and to receive our refreshed Insider magazine bringing health news and shared experiences.

New information developed with patients, carers and local health teams included a PF leaflet giving handy advice from diagnosis, a television advert for clinic waiting rooms to ensure patients know about their local PF support groups, and more than 1,500 'please give me space' lanyards to bring reassurance and confidence when vulnerable patients and carers have to go out in public.

Together we are stronger.

"Thank you for the lanyard, it saved me a huge embarrassment the other day. Was in a gift shop near Cromer. (I had a mask on.) I had a little cough and the shop lady told me to leave the shop... My friend who I was with was shocked at the lady. I was just so pleased to have the lanyard round my neck, as a cough can just occur. So very grateful."

Linda, member of Northamptonshire SG

Research

Our vision is to find a cure for pulmonary fibrosis and ensure that everyone affected by the disease has a better future. Research makes this vision possible.

£120,000+

Invested over the last 12 months

We play a critical role in the research landscape by:

- Directly funding life-changing research through our fellowship funding programme;
- Helping shape the future of pulmonary fibrosis research and supporting its development and delivery through amplifying the patient voice; and
- Enabling more people to get involved in research studies and clinical trials.

Over the last 12 months we have invested over £120,000 in research. This will help us to better understand the causes of pulmonary fibrosis and has the potential to lead to the development of new treatments.

Dr Phil Molyneaux (Imperial College London) is investigating the role of bacteria, microbes and metabolites in pulmonary fibrosis and the impact of antibiotic treatment on disease progression. He is pioneering techniques for investigating the airways, lungs and guts of patients affected by pulmonary fibrosis and has rapidly adapted his research in response to the Covid pandemic. His research is advancing our understanding of the fundamental mechanisms of disease which will lead to more effective treatments being available to patients.

Our Research Fellows

Despite the challenges posed by the coronavirus pandemic, our research fellows have continued their dedicated work into pulmonary fibrosis.

Our research fellows have published their work in multiple scientific journals and at international conferences around the world, adding to the global knowledge and understanding of the disease.

Dr Richard Allen (University of Leicester) is researching the genetics of disease. His ground-breaking research has identified new genes associated with idiopathic pulmonary fibrosis and the progression of the disease. Improving our understanding of genetics will help to identify new drug targets and support the development of personalised medicine, meaning each patient gets the right treatment.

Supporting the next generation of outstanding scientists

We are passionate about supporting students and early career scientists to develop their careers and shape the future of pulmonary fibrosis research. Our Travel and Attendance Award Scheme enables scientists to share their research at conferences around the world, by giving talks, presenting posters and through networking opportunities. Attendance at conferences provides a valuable opportunity for career development and raises the profile of pulmonary fibrosis research.

With support from APF, exciting and far-reaching new knowledge has been shared about the relationship between exercise and breathlessness, the role of cells lining the airways in pulmonary fibrosis, and the role of bacteria, viruses and other microbes in the development of progressive pulmonary fibrosis. This is a key achievement for APF, enabled by the support from our many fundraisers.

“Where there is research, there is hope.”

Howard, IPF patient and APF Trustee

Patients as partners in research

Action for Pulmonary Fibrosis is dedicated to supporting research throughout the research cycle. In 2020/21 we collaborated with researchers in the UK and abroad to support the design, development and delivery of research. We have provided expert insight and a national perspective of the unmet needs of patients and families affected by pulmonary fibrosis. Members of the APF community have shared their lived experiences with researchers to help them better understand the impact of the disease and ensure that studies reflect the needs and priorities of patients.

Shaping the future of pulmonary fibrosis research

Progressive pulmonary fibrosis treatment and care is an under-researched area and requires greater attention. Our partnership with James Lind Alliance and patients will directly set the top 10 future priorities for researchers in the UK and across the world and we are excited to be driving this work forward. In 2020 we received over 600 survey responses from patients, carers, family members and healthcare professionals, generating over 1,400 questions. This fantastic project is continuing into 2021/22, when the pulmonary fibrosis community will be deciding their top 10 research priorities.

Education

We understand that diagnosis takes too long for patients. Before Covid the average time of diagnosis after the initial doctor's appointment is over seven months. This will now be even longer.

Levels of care often do not meet national guidelines (e.g., NICE Quality Standard 79 on IPF, 2015). We are committed to raising healthcare professionals' awareness of the disease through APF attendance at conferences and delivering training.

With respiratory healthcare professionals being moved to work on the Covid frontline, and many conferences postponed, we took the difficult decision to pause much of our planned work to improve the awareness and education of healthcare professionals on the signs and symptoms of pulmonary fibrosis.

"It's good to know awareness has been raised although we still have a lot to do I think. GPs should tell their patients when diagnosed about APF. I came out of the doctors realising it was a serious diagnosis but knowing nothing. She just said you've got PF and referred me to my consultant."

Sylvia, patient with PF

Healthcare Professional Focussed Education and Awareness

The British Thoracic Society and its 4,000 members share our vision of a future without the burden of lung disease. We attended their winter meeting in February aimed at specialist respiratory physicians in order to raise awareness of our work, future funding opportunities and to stay up to date with the very latest thinking in lung health.

We continue to raise awareness of our GP module, developed in partnership with the Royal College of GPs, through online marketing and print publicity. Over 300 GPs have so far completed the training.

Sharing knowledge and empowering patients and family members

We turned our attention to the education and support of patients and some health care professionals, who through our Covid Survey, 78% told us they were very concerned about their lung disease.

We contributed to the European Lung Foundation Networking Day in Sept 2020.

We attended and delivered talks at the Boehringer Ingelheim Global Patient Partnership Summit, February 2021 and the European Pulmonary Fibrosis Federation (EU-IPFF) Patient Summit in April 2021, enabling us to share our experiences as well as learn from experts around the world. Steve Jones, our Chair of Trustees, is currently President of EU-IPFF.

In collaboration with Boehringer Ingelheim and 11London we co-developed a series of five webinars based on key topics as identified by patients and carers. These hour-long webinars ran every two weeks from May to June 2021. Topics ranged from mental health, oxygen, caring for others and pulmonary rehabilitation, and were designed to be accessible, informative sessions. We had overwhelmingly positive feedback, with many people saying they understood their diagnosis fully for the first time.

Talking PF

"I'm absolutely delighted about this 'Talking PF' webinar initiative by APF. I have shared with our support group members and will certainly be taking part myself."

Tom McMillan, Carer and Support Group Leader

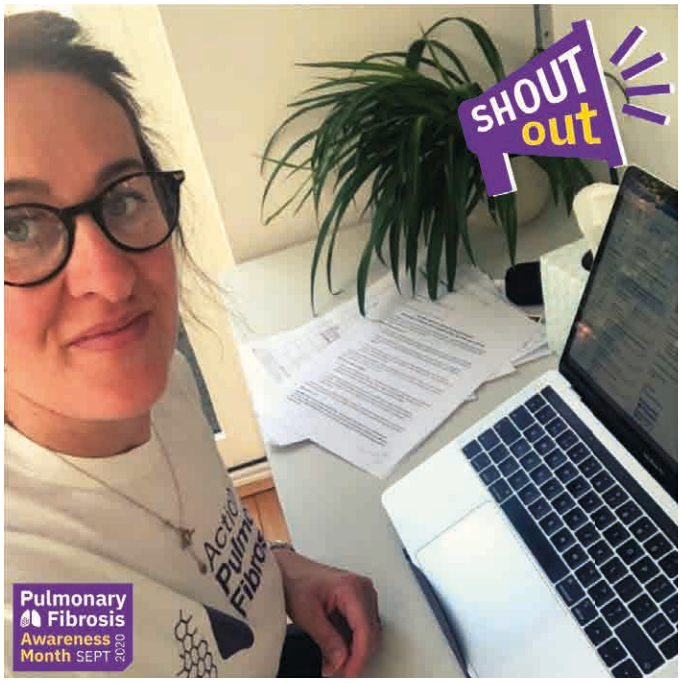
Talking PF meetings are a collaboration between Action for Pulmonary Fibrosis and Boehringer Ingelheim Limited. Boehringer Ingelheim Limited provided funding and support, with organising and project management in line with the ABPI Code of Practice.

Campaigning and Awareness

Reducing health inequalities in pulmonary fibrosis is a vital part of our work.

There are multiple injustices facing someone diagnosed with pulmonary fibrosis. These include, but are not limited to:

- Being recognised as clinically extremely vulnerable to COVID, enabling access to a higher level of support or faster access to vaccinations;
- Slow or late diagnosis due to lack of awareness with GPs;
- Waiting until your lung function declines before you can access anti-fibrotic treatments to slow your lung fibrosis;
- No access to anti-fibrotic treatments if you have one of the other types of pulmonary fibrosis other than idiopathic pulmonary fibrosis;
- Long waiting times for every test, consultation or referral to supportive care due to long term under investment into ILD services;
- Lack of timely support for carers and family members; and
- Inequality of access to clinical trials; only patients who live near one of five of the 23 specialist centres in the UK get regular access to cutting edge research.



At APF, we work across all these areas of need both locally and nationally.

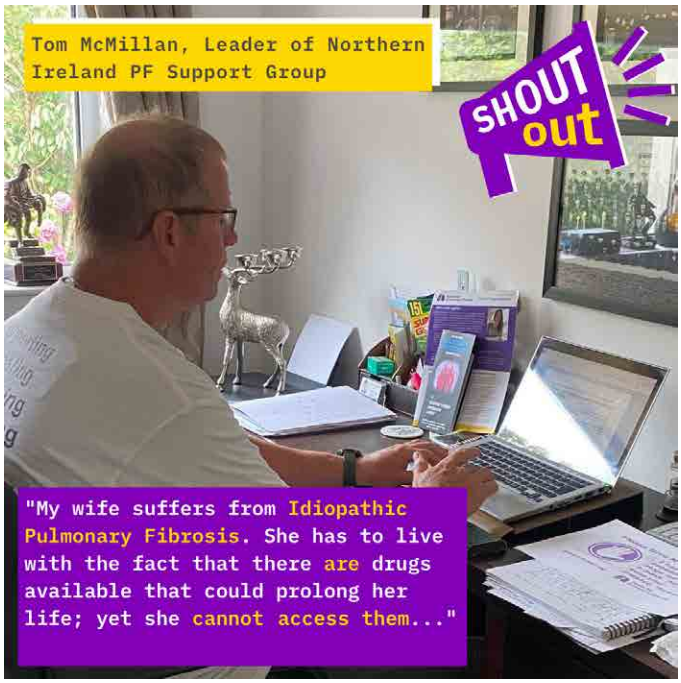
We work with vibrant and active support groups who engage with their MPs, NHS Trusts and local health networks improving timely access to care and support in their local area.

As part of APF's #ShoutOut Campaign, in September 2020 patients wrote to over 50 MPs around the country calling for England's National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium to review access to the only treatment that slows lung fibrosis making it available to people with all forms of pulmonary fibrosis. This campaign, spearheaded by APF was successful, with the roll out of the treatments to be made available across the UK from January 2022.

But the fight is far from over.

APF continues to campaign across many injustices. A huge thank you to our many supporters who use their voice and platform to help us raise awareness. Our special thanks go to Amy and Katie Price and James Martin and the late Janice Long, who all brought pulmonary fibrosis to the attention of the media. We thank patients and their families, past and present who bravely share their stories.

In 2021/22 we plan to increase our efforts, influencing the NHS to further invest in ILD services and support carers right from diagnosis.



Fundraising

Over £500,000 was raised by our fundraisers and donors throughout 2020/21.

As a charity that receives no government funding, we are entirely reliant on charitable income, with every penny raised and donated by our generous supporters helping to fund our vital work. As well as the obvious devastating effects on our health and wellbeing, the Covid pandemic continued to impact our income throughout 2020/21 with mass events and other community activities postponed or cancelled. However, thanks to the determination of our dedicated fundraisers and donors, we have been able to fund the growth of our services and launch our Hope for All Research Appeal.

We know there may be challenges in the year ahead, but we are confident that with the support of the pulmonary fibrosis community and our generous donors, we can continue to raise the crucial funding we need. We are determined to ensure nobody need face this devastating illness alone, and to give hope of a better future to the thousands of people affected by pulmonary fibrosis.

#GoTheDistanceForAPF

"Sadly, their memories of my lovely mum will be limited given their ages, but raising money for APF gives us a positive focus and helps them remember her."

Catherine, APF donor

"I wish that we had known about APF whilst Dad was alive. I hope my contribution may help in the fight against pulmonary fibrosis."

Bob, APF fundraiser

£500,000+

Raised throughout 2020/21

Plans for the future

We anticipate significant disruption to the care, support and daily lives of people affected by pulmonary fibrosis largely due to Covid over the coming year.

As such, we remain committed to the continued development of APF's strategic aims to help find a cure for pulmonary fibrosis and for more people affected by the disease to have a better future. New challenges require fresh thinking, and we have adopted a balanced scorecard methodology to underpin a new collaborative and creative approach to big challenges. Over the coming year we will continue to grow our income, so that we can support and empower more families affected by this devastating disease.

We hope you'll join us in the fight against pulmonary fibrosis.

Structure, governance, and management

Action for Pulmonary Fibrosis was registered with the Charity Commission in England and Wales as a Charitable Incorporated Organisation (CIO) in June 2013. The governing document is the Constitution, which was approved by the trustees on 28 May 2013.

In 2021 the charity applied for, and on 25 May 2021 was granted, registration with the Office of the Scottish Charity Regulator (OSCR).

All trustees have direct experience of IPF, either as patients, carers, family members or medical doctors, helping us to maintain our patient and healthcare led approach.

The Board of Trustees meets formally four times a year to review the charity's progress, formulate general policy and strategy and ensure adherence to charity regulations. An annual plan and budget for activities for the coming period are approved at the beginning of the financial year. At each meeting reports are received on the charity's work during the quarter. Attention is paid to any significant risks that may arise from time to time and the effectiveness of the system of internal controls is monitored. The quarterly meetings are supported by regular telephone and online communication.

The Board contracts with professional advisers as necessary, for advice and guidance on legal and financial issues.

Appointment of New Trustees

The Board of Trustees regularly reviews the skills and experience of its members and considers if changes are needed to face new and emerging challenges. The Board appoints new members to strengthen the board and where necessary to replace a member who leaves. It remains an important requirement that all new trustees have a personal connection to pulmonary fibrosis.

An appointment process is in place which includes receipt of a formal application providing personal details and outlining the skills and experience which the applicant can bring to APF. Candidates are then invited to meet with at least three trustees to discuss the application and to receive information about the Board, its work and the responsibilities of a trustee. Prospective trustees are invited to attend a trustee meeting for approval of all trustees prior to confirmation of appointment. An induction process follows providing the new trustee with comprehensive information on the charity and their responsibilities as a trustee.

To date this has been done by personal contact and through contacts made directly to the charity. In order to ensure diversity and make opportunities more widely available, the process for appointment was reviewed at the year end and agreed that trustee vacancies would be advertised.

Organisational Structure

The Chief Executive Officer leads the charity together with the management team.

The Finance and Risk Committee is a standing committee which oversees and monitors the finances and budgets of the charity, risks, policies, and remuneration of staff. The committee, which includes three trustees and the CEO, meets quarterly prior to the Board meeting. Other sub-committees of the Board of Trustees are established to deal with specific tasks from time to time.

Action for Pulmonary Fibrosis is registered with the Fundraising Register.

Risk Management

Responsibility for risk management lies with trustees and a risk register has been established which is reviewed regularly by the Finance and Risk Committee. The risks identified are minimal and controls are in place to manage them.

Public Benefit Statement

The charity trustees have complied with their duty, to have due regard to the guidance on public benefit published by the Charity Commission, in exercising their powers or duties. Charity activities and support provided are available to all those affected by pulmonary fibrosis.

Financial Review

The charity is in a strong financial position. Total income for the year was £651,809 and total expenditure was £601,408. Details are set out in the attached accounts.

Our income for the year was lower than budgeted as there was a delay in receipt of grant funding and reduced community events due to Covid.

Expenditure was also lower than budgeted due to some underspend and planned activities being cancelled, or completed virtually, due to the pandemic.

The 2020/21 budget was set during the initial stages of the Covid pandemic. Our Senior Leadership Team were optimistic that Covid would only affect our activities and plans for the first six months of the financial year, but this has clearly not been the case with the impact of Covid still being felt 18 months later with ongoing social restrictions.

Going Concern

The trustees consider that the charity will continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved. The trustees therefore consider it appropriate to adopt the going concern basis for the preparation of the accounts, as detailed in note 1(b) to the financial statements.

Reserves Policy

Trustees have agreed a reserves policy of holding an amount equivalent to six months of charitable expenditure, as Designated Reserves. Charitable expenditure includes staff and running costs, fundraising costs, planned activities and the provision of patient and family support activities. This is to ensure that the charity can continue offering services to its patient community during times of reduced income. It is reviewed annually at the July trustee meeting. The projection of increased operational costs for the coming year resulted in agreement to increase the balance on the Reserves account to meet the requirements of the Policy. This was carried out and the Reserves Account balance has been increased to £336,000 (£278,725 in 2020/21).

"Without APF I don't know where any of us would be."

Dee, carer to her husband Roger with pulmonary fibrosis

Statement of responsibilities of the trustees

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with 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).

The law applicable to charities in England and Wales, and in Scotland, requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and the incoming resources and application of resources, including the net income or expenditure, of the charity for the year. In preparing those 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 judgements and accounting estimates that are reasonable and prudent;
- state whether applicable accounting standards and statements of recommended practice 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 charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity 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 charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditors

Godfrey Wilson Limited were re-appointed as auditors to the charity during the year and have expressed their willingness to continue in that capacity.

Approved by the trustees on 5 February 2022 and signed on their behalf by

steve jones

Stephen Jones - Chair

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

Opinion

We have audited the financial statements of Action for Pulmonary Fibrosis (the 'charity') for the year ended 30 June 2021 which comprise the statement of financial position, balance sheet and statement of cash flows, and the related 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 charity's affairs as at 30 June 2021 and of its incoming resources and application of resources, including its 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 Charities and Trustees Investment (Scotland) Act 2005, regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011.

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 charity 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 charity'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.

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

Other information
The trustees are responsible for the other information. The other information comprises the information included in the annual report 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.

Matters on which we are required to report by exception
In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report. We have nothing to report in respect of the following matters in relation to which the Charities Act 2011 requires us to report to you if, in our opinion:

- sufficient accounting records have not been kept;
- the financial statements are not in agreement with the accounting records and returns; or
- we have not obtained all the information and explanations necessary for the purposes of our audit.

Responsibilities of the trustees
As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees 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 they 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 charity'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 charity or to cease operations, or have no realistic alternative but to do so.

Our 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 procedures we carried out and the extent to which they are capable of detecting irregularities, including fraud, are detailed below:

(1) We obtained an understanding of the legal and regulatory framework that the charity operates in, and assessed the risk of non-compliance with applicable laws and regulations. Throughout the audit, we remained alert to possible indications of non-compliance.

(2) We reviewed the charity's policies and procedures in relation to:

- Identifying, evaluating and complying with laws and regulations, and whether they were aware of any instances of non-compliance;
- Detecting and responding to the risk of fraud, and whether they were aware of any actual, suspected or alleged fraud; and
- Designing and implementing internal controls to mitigate the risk of non-compliance with laws and regulations, including fraud.

(3) We inspected the minutes of trustee meetings.

(4) We enquired about any non-routine communication with regulators and reviewed any reports made to them.

(5) We reviewed the financial statement disclosures and assessed their compliance with applicable laws and regulations.

(6) We performed analytical procedures to identify any unusual or unexpected transactions or balances that may indicate a risk of material fraud or error.

(7) We assessed the risk of fraud through management override of controls and carried out procedures to address this risk. Our procedures included:

- Testing the appropriateness of journal entries;
- Assessing judgements and accounting estimates for potential bias;
- Reviewing related party transactions; and
- Testing transactions that are unusual or outside the normal course of business.

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. Irregularities that arise due to fraud can be even 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.

Independent auditors' report

To the members of

Action for Pulmonary Fibrosis

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charity's trustees 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 charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Godfrey Wilson Limited

Date: 8 February 2022

GODFREY WILSON LIMITED
Chartered accountants and statutory auditors
5th Floor Mariner House
62 Prince Street
Bristol
BS1 4QD

Action for Pulmonary Fibrosis

Statement of financial activities

For the year ended 30 June 2021

	Note	Restricted £	Unrestricted £	**2021 Total £**	2020 Total £
Income from:					
Donations and legacies	3	-	518,882	**518,882**	673,638
Charitable activities	4	99,238	28,594	**127,832**	104,800
Investments		-	5,095	**5,095**	6,609
Total income		99,238	552,571	**651,809**	785,047
Expenditure on:					
Raising funds		-	109,856	**109,856**	94,977
Charitable activities		59,545	432,007	**491,552**	410,325
Total expenditure	6	59,545	541,863	**601,408**	505,302
Net income / (expenditure) and net movement in funds	9	39,693	10,708	**50,401**	279,745
Reconciliation of funds:					
Total funds brought forward		25,507	1,014,501	**1,040,008**	760,263
Total funds carried forward		65,200	1,025,209	**1,090,409**	1,040,008

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 17 to the accounts.

Action for Pulmonary Fibrosis

Balance sheet

As at 30 June 2021

	Note	£	**2021** **£**	2020 £
Current assets				
Debtors	12	**19,502**		13,925
Current asset investments	13	**1,071,858**		1,113,208
Cash at bank and in hand		**156,054**		163,113
		1,247,414		1,290,246
Liabilities				
Creditors: amounts falling due within 1 year	14	**(127,040)**		250,238
Net current assets			**1,120,374**	1,040,008
Creditors: amounts falling due after more than 1 year	15		**(29,965)**	-
Net assets	16		**1,090,409**	1,040,008
Funds	17			
Restricted funds			**65,200**	25,507
Unrestricted funds				
Designated funds			**962,492**	793,195
General funds			**62,717**	221,306
Total charity funds			**1,090,409**	1,040,008

Approved by the trustees on 5 February 2022 and signed on their behalf by

steve jones

Stephen Jones - Chair

Action for Pulmonary Fibrosis

Statement of cash flows

As at 30 June 2021

	2021	2020
	£	£
Cash provided by operating activities:		
Net movement in funds	**50,401**	279,745
Adjustments for:		
Investment income	**(5,095)**	(6,609)
Decrease / (increase) in debtors	**(5,577)**	21,007
Increase / (decrease) in creditors	**(93,233)**	(181,130)
Net cash provided by operating activities	**(53,504)**	113,013
Cash flows from investing activities:		
Investment income	**5,095**	6,609
Net cash provided by investing activities	**5,095**	6,609
Increase in cash and cash equivalents in the year	**(48,409)**	119,622
Cash and cash equivalents at the beginning of the year	**1,276,321**	1,156,699
Cash and cash equivalents at the end of the year	**1,227,912**	1,276,321

Analysis of cash and cash equivalents

Current asset investments	**1,071,858**	1,113,208
Cash at bank and in hand	**156,054**	163,113
Cash and cash equivalents at the end of the year	**1,227,912**	1,276,321

The charity has not provided an analysis of changes in net debt as it does not have any long term financing arrangements.

1. Accounting policies

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 in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Action for Pulmonary Fibrosis 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 notes.

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern. However, the COVID-19 pandemic has had a profound impact on the global economy,but only minimal impact on the the charity. The trustees have considered the impact of this issue on the charity's current and future financial position. The charity holds unrestricted, general reserves of £62,717, designated reserves that can be drawn down if necessary of £962,492 and a cash balance of £156,054. The combined value of cash and current asset investments at 30 June 2021 was £1.23m. The trustees consider that the charity has sufficient cash reserves to continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the items of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from the government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

d) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

e) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

f) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

g) Grants payable

Grants payable are charged in the year in which the offer is conveyed to the recipient except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attached have been fulfilled. Grants offered subject to conditions at the year end are noted as commitment but are not accrued as expenditure.

h) Allocation of support and governance costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities on the basis of staff time spent on each of these areas. In the prior period an estimate was used, but in the current period a more thorough analysis of staff time by role was possible as there was a more significant number of employees. The percentages used were as follows:

	2021	**2020**
Raising funds	17%	16%
Charitable activities	83%	84%

i) 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.

j) Current asset investments

Current asset investments consists of short term cash deposits with a maturity date of less than one year from the balance sheet date held for investment purposes rather than to meet short term cash commitments as they fall due.

k) 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.

l) Creditors

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.

m) Financial instruments

The charity 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 with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

n) Pension costs

The charity operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

o) Operating leases

Operating lease payments are recognised as an expense on a straight-line basis over the lease term.

p) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

There are no key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements.

2. Prior period comparatives: statement of financial activities

	Restricted £	Unrestricted £	**2020 Total £**
Income from:			
Donations and legacies	-	673,638	**673,638**
Charitable activities	104,800	-	**104,800**
Investments	-	6,609	**6,609**
Total income	104,800	680,247	**785,047**
Expenditure on:			
Raising funds	-	94,977	**94,977**
Charitable activities	79,293	331,032	**410,325**
Total expenditure	79,293	426,009	**505,302**
Net income and net movement in funds	25,507	254,238	**279,745**

3. Income from donations and legacies

	Restricted £	Unrestricted £	**2021 Total £**	2020 Total £
Legacies	-	5,000	**5,000**	25,000
Donations from individuals and fundraising	-	513,882	**513,882**	648,638
Total income from donations and legacies	-	518,882	**518,882**	673,638

All income from donations and legacies in the prior year was unrestricted.

4. Income from charitable activities

	Restricted £	Unrestricted £	**2021 Total £**	2020 Total £
Corporate grants	-	-	**-**	82,500
Trusts and foundations	99,238	28,594	**127,832**	22,300
Total income from charitable activities	99,238	28,594	**127,832**	104,800

All income from charitable activities in the prior year was restricted.

5. Government grants

The charitable incorporated organisation received no government grants during the year (2020: £nil).

6. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	**2021 Total £**
Staff costs (note 10)	53,902	256,691	59,827	**370,420**
Freelance costs (note 10)	11,023	57,445	-	**68,468**
Travel and subsistence	-	-	359	**359**
Grants payable (note 7)	-	1,350	-	**1,350**
Training costs	-	3,610	-	**3,610**
Patient surveys	-	2,903	-	**2,903**
Fundraising costs	16,280	-	-	**16,280**
Marketing and communications	3,716	50,807	-	**54,523**
Premises costs	-	-	20,327	**20,327**
Admin costs	-	-	37,302	**37,302**
Other staffing costs	-	-	17,046	**17,046**
Governance costs	-	-	8,820	**8,820**
Sub-total	84,921	372,806	143,681	**601,408**
Allocation of support and governance costs	24,935	118,746	(143,681)	-
Total expenditure	**109,856**	**491,552**	**-**	**601,408**

Prior year comparative:

	Raising funds £	Charitable activities £	Support and governance costs £	**2020 Total £**
Staff costs (note 10)	20,191	105,937	76,088	**202,216**
Freelance costs (note 10)	20,328	33,377	16,968	**70,673**
Travel and subsistence	-	-	16,313	**16,313**
Grants payable (note 7)	-	2,800	-	**2,800**
Training costs	-	33,094	-	**33,094**
Patient surveys	-	4,588	-	**4,588**
Fundraising costs	17,420	-	-	**17,420**
Marketing and communications	3,778	56,027	-	**59,805**
Premises costs	-	-	26,852	**26,852**
Admin costs	-	-	53,338	**53,338**
Other staffing costs	-	-	7,260	**7,260**
Governance costs	-	-	10,943	**10,943**
Sub-total	61,717	235,823	207,762	**505,302**
Allocation of support and governance costs	33,260	174,502	(207,762)	-
Total expenditure	**94,977**	**410,325**	**-**	**505,302**

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. They are distinct from costs incurred to support those affected by Pulmonary Fibrosis, which are included under charitable activities.

7. Grants payable

	Grants to institutions £	**2021 Total £**
Support groups:		
Nottingam Support Group	850	**850**
Windsor Support Group	500	**500**
	1,350	**1,350**

Prior year comparative

	Grants to institutions £	Grants to individuals £	**2020 Total £**
Travel grants (2 individuals)	-	1,500	**1,500**
Support groups:			
Worthing Support Group	500	-	**500**
Luton and Dunstable University Hospital	500	-	**500**
Harlow Support Group	300	-	**300**
	1,300	1,500	**2,800**

8. Grants commitments

	2021	2020
	£	£
Grant commitments brought forward	**242,318**	408,400
Grants committed during the period (note 7)	**1,350**	2,800
Grants paid during the period	**114,403**	239,518
Grant commitments carried forward	**115,753**	242,318

9. Net movement in funds

This is stated after charging:

	2021	2020
	£	£
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses (see note 19)	**2,275**	9,715
Auditors' remuneration:		
▪ Statutory audit (including VAT)	**4,680**	4,500
▪ Other services (including VAT)	**Nil**	3,702

10. Staff costs and numbers

Staff costs were as follows:

	2021	2020
	£	£
Salaries and wages	**331,691**	179,101
Social security costs	**29,731**	17,774
Pension costs	**8,998**	5,341
Freelance staff	**68,468**	70,673
	438,888	272,889

One employee earned between £60,000 and £70,000 during the year (2020: one employee earned more than £60,000).

The key management personnel of the charity comprise the trustees and Chief Executive. The total employee benefits of the key management personnel were £71,475 (2020: £69,854).

	2021	2020
	No.	No.
Average head count	**11**	5

11. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

12. Debtors

	2021	2020
	£	£
Trade debtors	**4,822**	-
Accrued income	**11,440**	10,165
Prepayments	**3,240**	3,760
	19,502	13,925

13. Current asset investments

	2021	2020
	£	£
Short term deposits	**1,071,858**	1,113,208

14. Creditors: amounts due within 1 year

	2021	2020
	£	£
Trade creditors	**33,863**	1,264
Accruals	**5,480**	4,500
Other creditors	**1,909**	2,156
Grant commitments (note 8)	**85,788**	242,318
	127,040	250,238

15. Creditors: amounts due after 1 year

	2021	2020
	£	£
Grant commitments (note 8)	**29,965**	-

16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	**Total funds £**
Current assets	65,200	1,078,245	(150,111)	**1,247,414**
Current liabilities	-	(85,788)	212,828	**127,040**
Long term liabilities	-	(29,965)	-	**(29,965)**
Net assets at 30 June 2021	**65,200**	**962,492**	**62,717**	**1,344,489**

Prior year comparative	Restricted funds £	Designated funds £	General funds £	Total funds **£**
Current assets	25,507	1,035,513	229,226	1,290,246
Current liabilities	-	(242,318)	(7,920)	(250,238)
Net assets at 30 June 2020	25,507	793,195	221,306	1,040,008

17. Movements in funds

	At 1 July 2020 £	Income £	Expenditure £	Transfers between funds £	**At 30 June 2021 £**
Restricted funds					
Boehringer Ingelheim	25,507	35,000	(50,962)	-	**9,545**
Roche	-	25,000	(6,250)	-	**18,750**
Trevi Theraupeutics	-	24,988	-	-	**24,988**
Independent Age	-	10,000	-	-	**10,000**
Shanly Foundation	-	2,250	(1,500)	-	**750**
Hospital Saturday Fund	-	2,000	(833)	-	**1,167**
Total restricted funds	25,507	99,238	(59,545)	-	**65,200**
Unrestricted funds					
Designated funds					
Research fund	568,172	-	-	115,595	**683,767**
Reserve fund	225,023	-	-	53,702	**278,725**
Total designated funds	793,195	-	-	169,297	**962,492**
General funds	221,306	552,571	(541,863)	(169,297)	**62,717**
Total unrestricted funds	1,014,501	552,571	(541,863)	-	**1,025,209**
Total funds	1,040,008	651,809	(601,408)	-	**1,090,409**

Purposes of restricted funds

Boehringer Ingelheim	This fund is for support line ambassadors and newsletter.
Roche	This fund is for general support services to December 2021.
Trevi Theraupeutics	This fund is for support services in Scotland (including SG coordinator salary).
Independent Age	This fund is for resuming face to face services (support groups).
Shanly Foundation	This fund is for Support Services General – South.
Hospital Saturday	This fund is for Support Services General.

17. Movements in funds

Purposes of designated funds

Research fund — A principal objective of Action for Pulmonary Fibrosis is to support and fund Research into the disease. Trustees have agreed to designate £684K for research to fund further research projects, following the successful launch of our Mike Bray Fellowships in 2018/19.

Reserve fund — The Reserve Fund has been established, in line with the charity's reserves policy, to retain a minimum of 50% of projected annual core expenditure separately as reserves. This is reviewed annually.

Prior year comparative

	At 1 July 2019 £	Income £	Expenditure £	Transfers between funds £	**At 30 June 2020 £**
Restricted funds					
Boehringer Ingelheim	-	52,000	(26,493)	-	**25,507**
COVID-19	-	18,800	(18,800)	-	**-**
D'Oyly Carte	-	3,500	(3,500)	-	**-**
Galapagos	-	30,500	(30,500)	-	**-**
Total restricted funds	-	104,800	(79,293)	-	**25,507**
Unrestricted funds					
Designated funds					
Research fund	453	-	-	567,719	**568,172**
Reserve fund	145,230	-	-	79,793	**225,023**
Total designated funds	145,683	-	-	647,512	**793,195**
General funds	614,580	680,247	(426,009)	(647,512)	**221,306**
Total unrestricted funds	760,263	680,247	(426,009)	-	**1,014,501**
Total funds	760,263	785,047	(505,302)	-	**1,040,008**

18. Operating leases

The charity had operating leases at the year end with total future minimum lease payments as follows:

	2021	2020
	£	£
Amount falling due:		
Within 1 year	**5,517**	18,391
Within 2 - 5 years	**-**	27,586
	5,517	45,977

19. Related party transactions

Trustees' reimbursed expenses comprised the following payments during the year:

	2021	2020
	£	£
Subsistence	**-**	547
Trustee training	**2,216**	-
Travel expenses	**59**	8,751
Other expenses (gifts, stationery and postage)	**-**	417
	2,275	9,715

Trustee training for 9 trustees was held in the year. Travel expenses relate to reimbursed travel costs for one trustee.

All expenses were incurred in the course of the organisation's charitable activities.

Steve Jones, the chair of Action for Pulmonary Fibrosis (APF), is also the chair of European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF). During the year APF received income of £4,084 from EU-IPFF for services related to the Global Patient Partnership Summit (2020: £nil). At 30 June 2021 there was £2,915 owed to APF (2020: £nil).

Wendy Dickinson, a trustee of APF, is also a member of the Nottingham Pulmonary Fibrosis Support Group. During the year, APF provided a grant to Nottingham Pulmonary Fibrosis Support Group of £850 (2020: £nil). There were no amounts outstanding at the year end.

The trustees are not aware of any other related party transactions during the period.

godfreywilson

consultants | chartered accountants | statutory auditors

Action for Pulmonary Fibrosis

Year Ended 30 June 2021

Management Letter

Contents

1 Introduction 1

2 Scope of the Audit 1

3 Audit Method & Materiality 2

4 Independence & Objectivity 2

5 Audit Opinion 3

6 Significant Aspects of the Entity's Accounting Practices 3

7 Significant Matters Discussed During the Audit 4

8 Significant Difficulties Encountered During the Audit 4

9 Recommendations for Improvements 5

10 Acknowledgements 5

11 Contact Us 5

12 Appendix 1: Recommendations 6

13 Appendix 2: Audit Adjustments & Unadjusted Errors 7

1 Introduction

This is our management letter to you following the audit of the financial statements for the year ended 30 June 2021. The management letter is designed to communicate to the trustees the audit approach, the key audit risks, any significant audit issues, the audit adjustments and unadjusted errors (if any), and our recommendations for improvements to systems, controls, and governance processes. We would appreciate it if this report is circulated to the trustees and discussed at a trustees' meeting.

The contents of this report and appendices are for the attention and information of the trustees only. You may only disclose the contents of this letter and appendices to third parties (such as funders) with our permission and we cannot be held liable for any reliance placed on the contents by third parties.

2 Scope of the Audit

The scope of the audit and our responsibilities are set out in our engagement letter dated 23 June 2020.

The objective of the audit work is to enable us to give an opinion as to whether the financial statements show a true and fair view of the results for the year and the state of affairs at the year end. As part of our work we also review whether the financial statements comply with relevant accounting standards. We design audit tests to provide assurance that the charity's financial statements are free from material error and so that we have a reasonable expectation of detecting material misstatement in the financial statements or accounting records resulting from irregularities and fraud.

Although it is not explicitly stated, an unqualified audit report means that we did gather adequate audit evidence to support the assertions in the financial statements, that we are satisfied that the books and records are in agreement with the financial statements and that

we received all the information and explanations we considered necessary for the audit. We are also satisfied with the disclosures in the notes to the financial statements. We do not audit the trustees' annual report, but we do check that this is consistent with the financial statements.

The audit procedures are designed to give us reasonable assurance that the financial statements, taken as a whole, are free of material misstatement. However, it is the responsibility of the trustees to ensure, as far as possible, that accurate and reliable accounting records are maintained and to operate appropriate controls.

3 Audit Method & Materiality

We used "substantive testing" – meaning that we verified particular transactions or balances by looking at a sample of invoices and receipts or by tracing from source documents to the final financial statements.

The audit work seeks evidence that the financial statements are materially correct. Small amounts do not affect a reader's understanding of the financial position. For this audit, the level of materiality we used was £38,000 for the balance sheet and £9,800 for the SoFA. These figures were used only as a guide and were subject to judgemental change depending on the findings during the audit. Materiality is not applied to certain transactions which are always material even when the amount involved is small, such as transactions with trustees.

4 Independence & Objectivity

We operate checks to ensure that we continue to act independently. We have enquired whether our staff have a connection to the charity, its staff, or trustees. We are not aware of any connections which would impact on our independence and objectivity as auditors.

We also provide non-audit services to you in the form of accounts preparation and bookkeeping support. We are therefore required to put safeguards in place to ensure we remain objective and independent as auditors. Under the Ethical Standards: Provisions Available to Smaller Entities ("ES PASE") we are required to identify persons deemed to be "informed management" within your organisation. Any judgements or decisions we make in the course of our work must be clearly explained to those persons. We have identified Claire Baker, Finance and Operations Manager, as informed management and have already discussed all adjustments and matters of judgement with them.

5 Audit Opinion

The audit proceeded as planned. We can confirm that the audit opinion will be unqualified.

Our audit adjustments and unadjusted errors are shown in appendix 2. Trustees should ensure they are satisfied with these.

6 Significant Aspects of the Entity's Accounting Practices

Action for Pulmonary Fibrosis complies with all the accounting policies listed in the notes to their financial statements, the Financial Reporting Standard applicable in the UK and Republic of Ireland FRS 102 and the Charities Statement of Recommended Practice (FRS 102) (effective 1 January 2019). All accounting estimates made by the charity are reasonable. The financial statements contain all the disclosures expected.

7 Significant Matters Discussed During the Audit

Opening balances

Our review of the opening balances in Quickbooks found that these did not agree to the prior year signed accounts, even though last year's audit journals had been posted. The differences arose from changes made to a handful of bank transactions and invoices since our work was started in the prior year. As a result, we have posted an audit adjustment this year to correct the issue, which has added £12.4k to the existing surplus.

If the bank has been reconciled correctly, there should not be a need to change bank transactions once they have been reconciled. There should not usually be a need to post journals to the bank. We would recommend the following to make sure that opening balances, and bank balances, are correct in the future:

- Bank transactions should be reconciled by ticking off against a statement. Please note that bank feeds into Quickbooks / Xero are not 100% reliable, and can occasionally duplicate or miss transactions;
- Where a bank receipt or payment does not exactly match the invoice posted in Quickbooks / Xero, this should be fixed by posting an adjustment to the customer / supplier account, rather than by deleting the original invoice; and
- Once audit adjustments have been posted, a trial balance should be run and balances checked against the signed accounts. Once agreed, the period should be locked, so no edits can be made.

8 Significant Difficulties Encountered During the Audit

No significant difficulties were encountered during the audit.

9 Recommendations for Improvements

As part of our audit work we review the internal systems and controls and the governance processes in operation. In this letter, we report any weaknesses that we identified during the course of our work, and suggest recommendations. Please note this does not constitute a comprehensive review of your systems, it is simply a summary of our observations. Our observations, in addition to those set out in section 7, are included in appendix 1. We hope you find the feedback useful and the recommendations practical.

10 Acknowledgements

We would like to express our thanks to Claire Baker and all the other staff for all their help with the audit.

11 Contact Us

The partner in charge of your audit is Alison Godfrey. If you have any questions or feedback about the audit, please do not hesitate to contact us.

Godfrey Wilson Limited
5th Floor, Mariner House
62 Prince Street
Bristol
BS1 4QD

Tel: 0117 971 3445

Email: alison@godfreywilson.co.uk

12 Appendix 1: Recommendations

Issue	Implication	Recommendation
Tracking categories in Xero The charity currently does not use tracking categories to track their restricted funds.	The charity may miss restricted income and expenditure which would result in misstatement of restricted fund balances. Even if restrictions are identified at year end it would take more time to compile this information without using this functionality.	We recommend using these tracking categories with your move to Xero. This functionality enables restricted fund balances to be tracked more easily for management account purposes. Additionally, tracking categories can be used to run reports to funders so they can review how their money is being spent.

13 Appendix 2: Audit Adjustments & Unadjusted Errors

Audit Adjustments

Nominal Account	Debit	Credit
3001 General Funds	12,430.66	
4013 Fundraising:Community income:Community General		(4,419.49)
4020 Individual donations		(1.055.79)
4021 Individual donations:Individual Giving		(3.60)
4026 Individual donations:Memorial donations		(4,419.49)
5032 Marketing & communications:General marketing & communications		(97.81)
6021 Freelance costs:Freelancers & consultants		(2,200.00)
6253 Travel & subsistence:Travel		(376.70)
6402 IT costs:IT software	142.22	
Opening balance adjustments.		
1006 Nationwide	511.21	
1005 Shawbrook Research	2,868.16	
4051 Investment income:Bank Interest		(3,379.37)
To recognise investment income received in the year.		
1101 Prepayments	520.63	
5056 Governance costs:Insurance		(520.63)
To release the prior year prepayment.		

Nominal Account	Debit	Credit
1103 Accrued Income		(6,155.67)
4020 Individual donations	6,115.67	
To release the prior year accrued income.		
1103 Accrued Income	11,439.81	
4041 Fundraising:Community income:Corporate donations		(11,439.81)
To post gift aid in accrued income.		
2109 Accruals		(180.00)
5055 Governance costs:Audit & accountancy	180.00	
To adjust the audit fee accrual.		

Unadjusted Errors

Nominal Account	Debit	Credit
Debtors	2,803.62	
Donation income		(2,803.62)
To recognise June 2021 MuchLoved donations.		
Debtors	3,733.00	
Donation income		(3,733.00)
To recognise June 2021 Benevity donations.		
Accruals		(8,416.88)
Gross wages	8,416.88	
To recognise holiday pay owed at year end.		
Grants payable creditors	707.78	
Grant commitments (expense)		(707.78)
To recognise the time value of money on the long term grant payable.		