

**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

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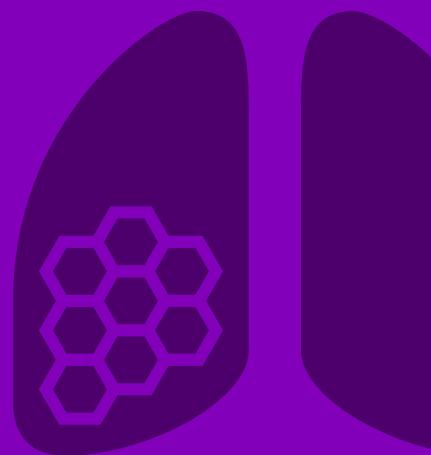
Follow us on socials:



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



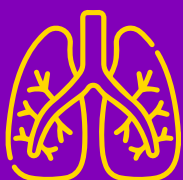
Demand for our services is rapidly out-stripping our capacity to support people. **Too many people say they wish they found APF sooner.**



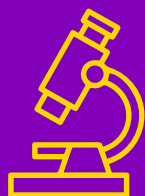
People living with PF can feel isolated and alone, and struggle to find **support and trusted and accurate information** about the disease.



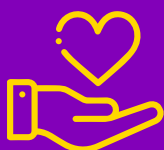
Many health care professionals have limited understanding of PF and how to correctly diagnose it. Symptoms can be confused with other respiratory conditions and with lengthy hospital waiting times it commonly takes **a year to get an accurate diagnosis.**



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

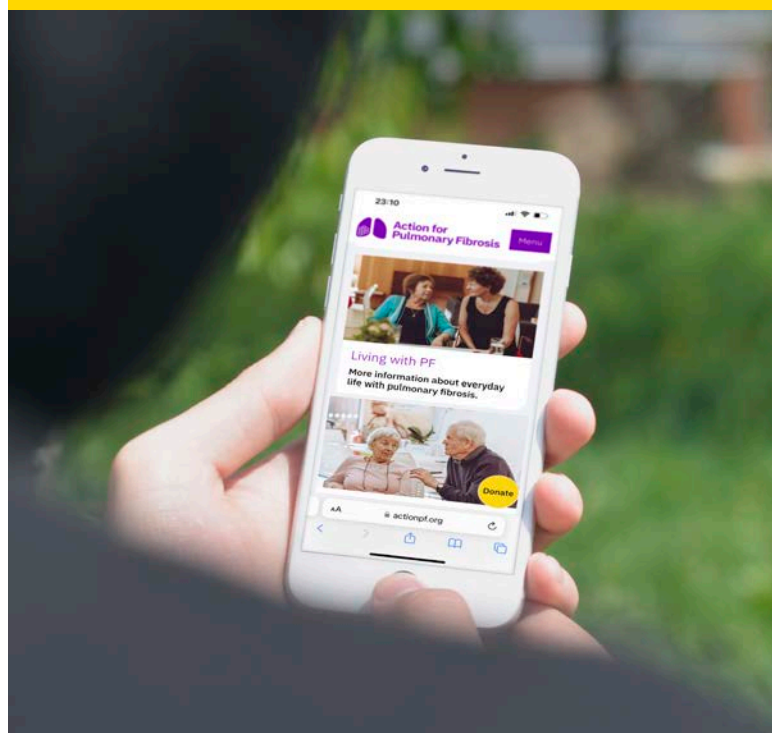
Principal Advisors:

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.

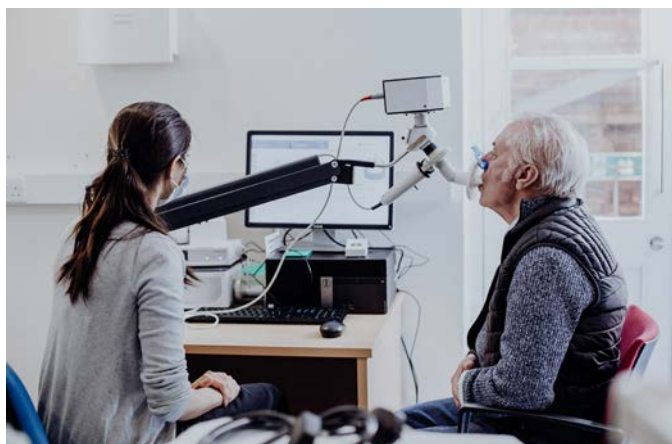
Demand for the support line continues to grow and we must ensure we can continue to grow the capacity of the service so we can meet people's needs in a timely way.

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, befriender

"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, befriender

"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, befriender

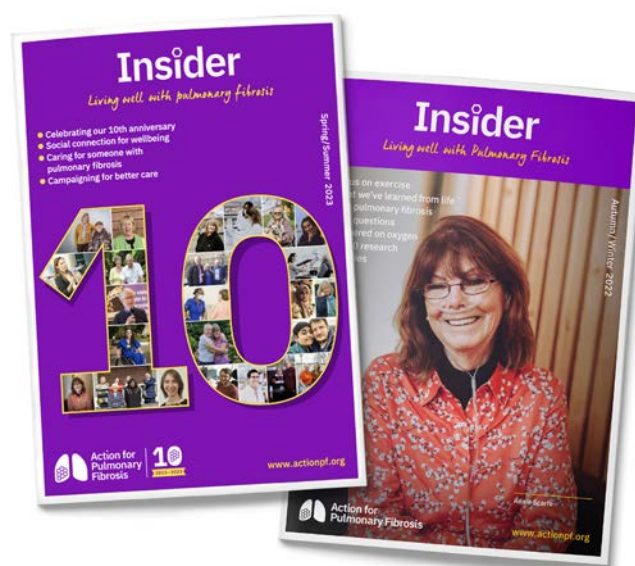
Tackling myths about pulmonary fibrosis with trusted information

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

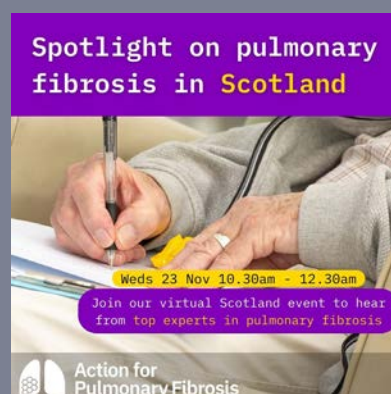
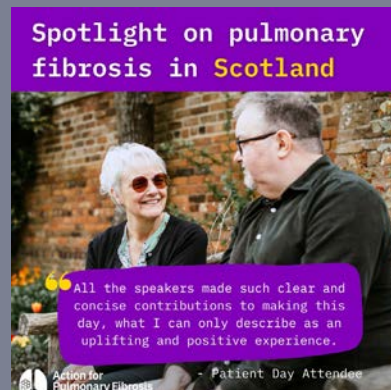
‘Spotlight Scotland’ was our first virtual patient information event specifically for Scotland bringing together clinicians, specialist nurses and patients to discuss health and lifestyle needs of PF.

- 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.”



Our vital services:

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



**“Together
we will STOP
pulmonary fibrosis.”**

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



2015



2017

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.

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.

ON THE UP

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



2018



2019

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.

HERE FOR ALL TYPES OF PF

APF broadens its 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.



2023



2022



2021



2020

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.

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.

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.

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.



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.

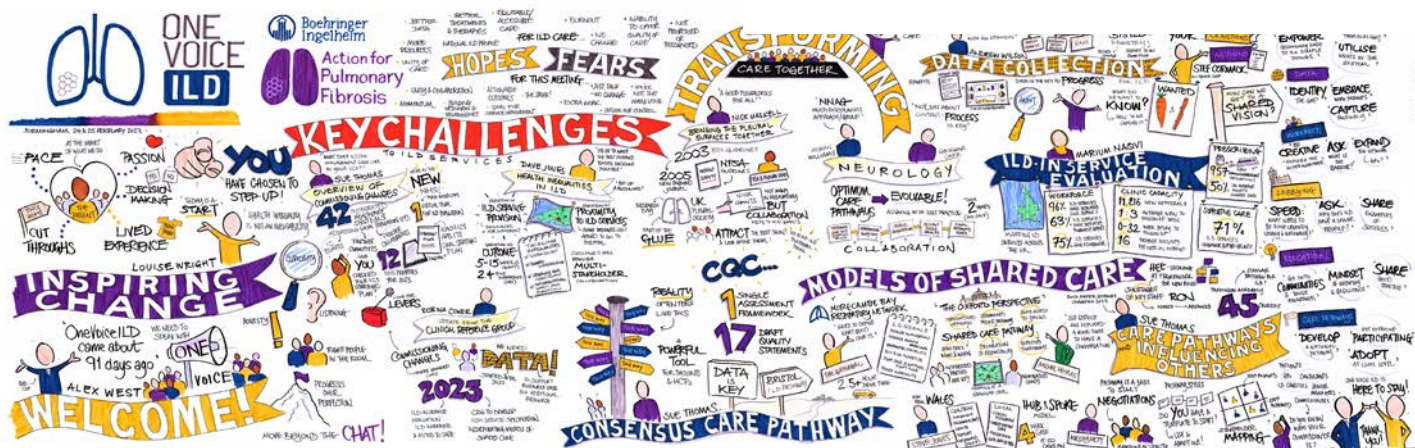
Dr Nazia Chaudhuri, IL Respiratory Consultant and Chair of the British Thoracic Society Specialist Advisory Group on IL, said the following words...

“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 Chaudhuri, 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 to 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.



£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

2022
2023

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

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 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		<u>278,094</u>	<u>1,168,806</u>	<u>1,446,900</u>	<u>974,578</u>
Expenditure on:					
Raising funds		-	248,560	248,560	168,909
Charitable activities		<u>298,822</u>	<u>656,773</u>	<u>955,595</u>	<u>626,329</u>
Total expenditure	7	<u>298,822</u>	<u>905,333</u>	<u>1,204,155</u>	<u>795,238</u>
Net income / (expenditure) and net movement in funds	10	(20,728)	263,473	242,745	179,340
Reconciliation of funds:					
Total funds brought forward		<u>64,748</u>	<u>1,205,001</u>	<u>1,269,749</u>	<u>1,090,409</u>
Total funds carried forward		<u><u>44,020</u></u>	<u><u>1,468,474</u></u>	<u><u>1,512,494</u></u>	<u><u>1,269,749</u></u>

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		<u>149,666</u>		<u>264,095</u>
		1,706,928		1,356,347
Liabilities				
Creditors: amounts falling due within 1 year	15	<u>(204,228)</u>		<u>(86,598)</u>
Net current assets			<u>1,502,700</u>	<u>1,269,749</u>
Net assets	16		<u><u>1,512,494</u></u>	<u><u>1,269,749</u></u>
Funds	17			
Restricted funds			44,020	64,748
Unrestricted funds				
Designated funds			1,286,601	1,023,128
General funds			<u>181,873</u>	<u>181,873</u>
Total charity funds			<u><u>1,512,494</u></u>	<u><u>1,269,749</u></u>

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

Steve Jones

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.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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			2022
	Restricted £	Unrestricted £	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.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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
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Allocation of support and governance costs	60,924	231,483	(292,407)	-
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Total expenditure	248,560	955,595	-	1,204,155
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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
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Allocation of support and governance costs	39,211	144,022	(183,233)	-
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Total expenditure	168,909	626,329	-	795,238
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Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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:		
<u>Support groups-</u>		
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
	<hr/>	<hr/>
Total grants payable to institutions	850	2,365
Grants payable to individuals	<hr/> 7,623	<hr/> -
Total grants committed during the period	<hr/> 8,473	<hr/> 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	<hr/> (8,473)	<hr/> (61,187)
Grant commitments carried forward	<hr/> 56,931	<hr/> 56,931

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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)	<u>5,500</u>	<u>4,350</u>

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	<u>159,262</u>	<u>86,829</u>
	<u>884,575</u>	<u>592,974</u>

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 No.	2022 No.
Average head count	<u>21</u>	<u>16</u>

12. Taxation

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

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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 Therapeutics	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					
<i>Designated funds</i>					
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 Therapeutics	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.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

17. Movements in funds (continued)

Purposes of restricted 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.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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 Therapeutics	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					
<i>Designated funds</i>					
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

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2023

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**

Follow us on socials:



General enquiries:

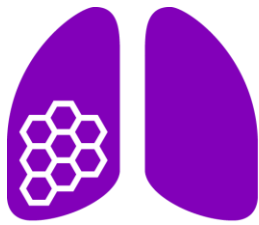
01733 839642
info@actionpf.org

www.actionpf.org

**Registered Office &
Operational Address:**

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

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.



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Follow us on [Twitter @actionpfcharity](https://twitter.com/actionpfcharity)

Registered charity 1152399 (England and Wales)
Registered address: Stuart House, St John's Street
Peterborough, PE1 5DD
Tel: 01733 475642
Web: www.actionpulmonaryfibrosis.org
Email: info@actionpulmonaryfibrosis.org

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 I 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

Steve Jones

Stephen Jones – Chair
For and on behalf of the trustees of Action for Pulmonary Fibrosis

Appendix I: Summary of Related Parties

Connected Organisation	Name	Nature of Connection
European Idiopathic Pulmonary Fibrosis & Related Disorders Federation	Stephen Jones	President