



# Trustees' Annual Report & Accounts

For the year ending  
30 June 2021



Action for  
Pulmonary Fibrosis

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

2020  
2021

# Contents

What is pulmonary fibrosis?	3
Why we are needed	4
Supporting through Covid	5
Our vision, mission, and values	6
Trustees, staff, and advisors	7
Introduction from Chair and Chief Executive	8
Report of the Board of Trustees:	
– Support and Information	10
– Research	14
– Education	16
– Campaigning and Awareness	18
– Fundraising	20
– Plans for the future	22
– Structure, governance, and management	23
– Financial Review	25
Independent Auditor's Report	27
Statement of Financial Activities	31
Balance Sheet	32
Statement of cash flows	33
Notes to Financial Statements	34



**Action for  
Pulmonary Fibrosis**

**General enquiries:**

01733 475642  
info@actionpf.org



**Support line  
01223 785725**

[www.actionpf.org](http://www.actionpf.org)



# What is pulmonary fibrosis?

**Pulmonary fibrosis is an umbrella term for a range of progressive lung diseases, which cause stiffening and scarring of the lungs.**

The lung scarring eventually prevents the transfer of oxygen into the bloodstream. It affects around 70,000 people in the UK. Idiopathic pulmonary fibrosis is the most aggressive and common form and affects around 30,000 people in the UK.

Key symptoms of pulmonary fibrosis include breathlessness and chronic cough. On physical examination, Velcro-like crackles are likely to be heard and sometimes the ends of fingers or toes may appear enlarged or 'clubbed'. Key symptoms can be confused with other respiratory disorders, such as chronic obstructive pulmonary disorder (COPD), asthma and bronchiectasis.

Other forms of pulmonary fibrosis include: familial pulmonary fibrosis; those associated with autoimmune diseases (such as rheumatoid arthritis and systemic sclerosis); toxicity caused by some medications; exposure to inorganic substances (such as asbestos and coal dust); hypersensitivity pneumonitis caused by exposure to organic dusts and fibres (such as bird feathers and mould found on hay, straw and grain), and sarcoidosis.



# Why we are needed

**Tens of thousands of people are affected by pulmonary fibrosis, yet it remains a mystery to many people.**

The debilitating nature of the disease means as people become increasingly breathless, their need for physical and emotional support become greater. Patients and their families can experience a profound sense of loss as the disease progresses. Pulmonary fibrosis affects every area of family life, yet there is very little dedicated support available to patients and families affected.

As breathlessness increases, ordinary daily tasks – washing, dressing, walking can become exhausting, which impacts increasingly on the whole family and especially carers. As an unfamiliar condition, many patients can struggle to find information and support and find themselves repeatedly explaining the diagnosis to healthcare professionals, family and friends, which causes distress. We want everyone affected by the disease to

be understood and to have access to the information and support they need when they need it. Our support community, peer groups, befrienders, and information are vital in helping patients and carers feel more connected, supported and reassured.

Pulmonary fibrosis can be very difficult to detect, with patients frequently waiting over a year for an accurate diagnosis. We need to speed up the process of diagnosis so that patients can start treatment sooner.

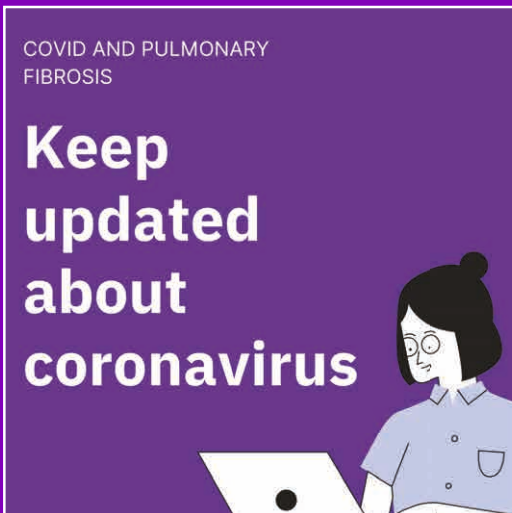
Our understanding of the disease has progressed rapidly over the last 10 years leading to treatments becoming available that slow the progression of the disease.

But we need to go further than this. We want to stop the disease in its tracks. That's why we're committed to funding research to find new treatments and a cure.

**Together we can make this happen.**



# Supporting through Covid



The Covid pandemic has had a profound impact across the world, but it is particularly tough for those with a respiratory condition like pulmonary fibrosis.

Research by APF trustee Professor Gisli Jenkins shows that if pulmonary fibrosis patients are hospitalised, they are more likely to get severe Covid and more likely to die. Patients, understanding the very real risk, have been forced to shield and most continue to do so. Many of those who have managed to protect themselves from Covid have felt the severe impact on their mental health as a result.

Interstitial Lung Disease (ILD) services have been under immense pressure – as has the health service as a whole, and the individual staff within it.

In turn, this means the demands on APF – a charity driven by patients, carers and healthcare professionals – have been great. In person support group meetings were put on hold, as we adapted to online and telephone support. Fundraising became more of a challenge as events from coffee mornings to marathons were no longer an option.

At the same time, campaigning has been even more critical - initially, pulmonary fibrosis was not included on the list of conditions that put people at high risk from Covid. Lobbying by APF led to its inclusion on the list under category 4, opening up more support for PF patients such as priority shopping. We also campaigned successfully for IPF patients to have priority access to lung function tests so that they could be started on antifibrotics when eligible.

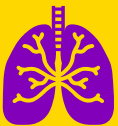
**The APF trustees have also considered the impact that the Covid pandemic will have on the charity's current and future financial position. These are likely to include falls in:**

- Average donations from patients and their families as we enter a global recession; and
- Community fundraising income, in particular, as fundraisers are restricted from taking part in group events and activities such as the London Marathon.

**The charity is taking the following steps to mitigate the potential threats of Covid to the organisation:**

- We are planning on the assumption that there will not be any growth in income for the foreseeable future;
- We will review our financial progress monthly and make changes, as required; and
- We have increased our capacity to bring in income from trusts and foundations.

# Our vision, mission, and values



## Our vision

APF's vision is to find a cure for everyone affected by pulmonary fibrosis to have a better future.



## Our mission

We provide support to families, raise awareness of the disease, campaign and educate to improve access to the highest standard of care for people living with all forms of pulmonary fibrosis. We are committed to funding research to improve the quality of life for people living with pulmonary fibrosis today and tomorrow.



## Our values drive everything we do:

### Patient led:

We empower and are led by patients who are at the heart of everything we do.

### Caring and compassionate:

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

### Striving for excellence:

We work with integrity and professionalism in all that we do.

### Open and approachable:

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

### Ambitious and bold:

We improve the lives of people affected by PF and are bold in the ways we do this.

# Trustees, staff, and advisors

## Charity Trustees:

Mr Stephen Jones\* (Chair)  
 Mr Howard Almond\*  
 Mrs Elizabeth Bray\*\*  
 Mrs Wendy Dickinson\*\*  
 Dr Simon Hart  
 Prof Gisli Jenkins  
 Dr Rebecca Lang\*\*  
 Mr Stephen Morgan-Hyland\*\*  
 Dr Helen Parfrey

\* living with PF

\*\* family member of someone with PF

In keeping with the charity's ethos of being patient led, over 60% of trustees have been personally affected by pulmonary fibrosis either as a patient or family member. Our trustees also include medical professionals, who are leaders in pulmonary fibrosis care and research.

## Chief Executive:

Louise Wright

## Registered Office and Principal Address:

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

## Charity Commission Registered Number:

1152399

## Scottish Charity Regulator Number:

SC050992



## Principal Advisors:

### Bankers:

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

### Auditors:

Godfrey Wilson Limited  
 Chartered Accountants and statutory auditors  
 5th Floor Mariner House, 62 Prince Street  
 Bristol BS1 4QD

# Introduction from Chair and Chief Executive

## July 2020 – June 2021

Writing this year's annual report has given us reason to pause and reflect on what has been the toughest year in APF's short history. As news headlines told of the devastating impact of Covid on people and the economy we saw our face-to-face services pause temporarily and our income grind to a near halt. We could see APF was needed more than ever but we knew our income would be badly affected.

Rising cases of anxiety, depression and lack of access to healthcare professionals and timely care saw an increase in demand for our services. But, with lockdowns expected throughout the year, opportunities to fundraise were severely diminished. Many of our small team juggled caring for family and work, and we all had to adapt quickly to new ways of working. Meanwhile we faced the greatest volume of requests for support we had ever seen.

Fortunately, APF was able to respond with rapid digitisation of support services, an enhanced website offering and alternative fundraising suggestions and opportunities. A key achievement was The Covid Hub on our website, providing instant accessible support and information tailored for PF patients, which received over 13,000 hits. Research continued, as our research fellows adjusted their schedules and place of work throughout the pandemic. We sought to work with others as much as possible during this challenging time. This included charities, government and respiratory bodies such as the EUIPFF and the British Thoracic Society. We strongly believe in the value of partnerships to achieve our vision for the future.

While we looked for savings through delivery of services online, we also invested in postal and telephone-based support to ensure those not online were still able to receive the personal quality-based support for which APF is known. This included our first ever telephone befriending service.

We continue to be a driver for change, to deliver and inspire life-changing work. It is such a privilege to lead APF and our brilliant team at this historic moment. For eight years the organisation has empowered patients and positively contributed to the transformation of care and support that exists for everyone affected by pulmonary fibrosis. But we need you like never before.

Despite progress, tens of thousands of people across the UK are living with the daily burden of pulmonary fibrosis. Covid has increased feelings of isolation and despair. The challenges we face are complex, but can be diminished by our combined talent, focus and ambition – and of course your continuing support.

Together we can keep making progress in serving pulmonary fibrosis patients and their families.



**Steve Jones**  
(Chair of Trustees)



**Louise Wright**  
(Chief Executive)



Together  
we are  
**stronger.**

*“At 86 I feel I am missing out on all the pleasures of my remaining years. I am avoiding catching and dying of Covid just to die of IPF.”*

APF COVID Survey recipient



# Report of the Board of Trustees

---

## Support and Information

Being diagnosed with pulmonary fibrosis can be a lonely, terrifying experience, which is made even harder by the pandemic. Over this year, access to local health services has been limited and many patients have been shielding at home. We have worked to make life that bit easier by developing services which enable people to look forward to a positive future. We have increased access to information and emotional support to manage the changes that life with PF brings.



## The power of peer support

We know that creating opportunities for people to share their experiences improves overall wellbeing. Support groups enable people to share practical and emotional impacts of what they are going through, and find mutual support. Being together during tough times like this builds resilience, friendship and the sharing of helpful information.

We support a network of more than 60 support groups with grants, training and guidance. But the pandemic hit groups hard, particularly where respiratory teams were under huge pressure or where members felt less digitally confident. Our first online survey of groups showed that active membership fell to half pre-Covid levels, with 54% struggling to gain referrals and recruit new members.

However, there were positive signs of growth later in the year. New support groups began in Forth Valley, while new groups such as the Pulmonary Fibrosis Transplant Patients Support Group (PFTx) and Carers continued to

offer peer support on shared issues. We helped more than 30 groups to set up online meetings and created the leaders' network for mutual support. We listened to specific needs throughout the pandemic and piloted confidence-building training around 'supporting people through challenging times', and leadership, group facilitation and mental wellbeing as a response.

Overwhelmingly, leaders felt that groups help members to manage their PF, have hope for the future and feel more supported. More than 90% of members felt their support group helps them feel informed about PF, manage symptoms more effectively, and feel more connected and able to access other support. However, a challenge remains to recruit new members from all parts of the community, so that everyone who wants to can access good peer support.



*"I found the 'supporting' training so helpful and insightful and still use the information today."*

**Maureen, Fife and Tayside Support Group leader and APF telephone befriender**

*"I take comfort in our shared experience and much food for thought about how I navigate my path through all the physical, emotional and practical challenges that we face."*

**Lynne, member of Sheffield Support Group**

## Telephone befrienders

Among the many challenges that life with pulmonary fibrosis brings, isolation is one of the hardest, especially during a pandemic. In view of this, we developed the telephone support service. Our team of trained, DBS-checked volunteer befrienders have personal experience of PF as patients, carers, family or friends, and provide a friendly listening ear.

The telephone support calls are an opportunity to keep in touch and connect with someone who really understands. Befrienders also signpost to local services, support groups and APF's own resources and support line.

Over the year, 19 volunteers were trained as befrienders and reached out to 47 patients and carers with regular calls, to feel empowered, more connected and supported.

## Reaching those who need us

Patients and families living with PF need to be able to access information and support regularly. This reduces anxiety and stress at a time of isolation and enables more choice about one's future care.

The Covid Hub section of our website was viewed over 13,000 times throughout the year and new information on topics from diagnosis to supportive care, breathing and exercise, helped bring reassurance and guidance when the world around seemed ever-changing and access to local health services very limited. An additional 23,000 people found our website compared to the previous year.

APF's support line gave reassurance and guidance for 338 patients and carers, many grappling with complex issues around pulmonary fibrosis, often compounded with other health or social issues. Many have gone on to be supported through an APF befriender or local PF support group, and to receive our refreshed Insider magazine bringing health news and shared experiences.

New information developed with patients, carers and local health teams included a PF leaflet giving handy advice from diagnosis, a television advert for clinic waiting rooms to ensure patients know about their local PF support groups, and more than 1,500 'please give me space' lanyards to bring reassurance and confidence when vulnerable patients and carers have to go out in public.

*“Lockdown literally shut down my life. You don't meet many younger people like myself with PF and it's rare to find someone who understands what you're experiencing. My volunteer inspires me so much... and totally understands the specific challenges of living with PF. The impact she's had on me is tremendous - I would say it's a lifeline. I so look forward to our weekly calls.”*

**Dawn, member of the Sheffield Support Group who has a telephone befriender**



# Together we are stronger.



*“Thank you for the lanyard, it saved me a huge embarrassment the other day. Was in a gift shop near Cromer. (I had a mask on.) I had a little cough and the shop lady told me to leave the shop... My friend who I was with was shocked at the lady. I was just so pleased to have the lanyard round my neck, as a cough can just occur. So very grateful.”*

Linda, member of Northamptonshire SG



# Research

**Our vision is to find a cure for pulmonary fibrosis and ensure that everyone affected by the disease has a better future. Research makes this vision possible.**

# £120,000+

**Invested over the last 12 months**

## **We play a critical role in the research landscape by:**

- Directly funding life-changing research through our fellowship funding programme;
- Helping shape the future of pulmonary fibrosis research and supporting its development and delivery through amplifying the patient voice; and
- Enabling more people to get involved in research studies and clinical trials.

Over the last 12 months we have invested over £120,000 in research. This will help us to better understand the causes of pulmonary fibrosis and has the potential to lead to the development of new treatments.



### **Dr Phil Molyneaux (Imperial College London)**

is investigating the role of bacteria, microbes and metabolites in pulmonary fibrosis and the impact of antibiotic treatment on disease progression. He is pioneering techniques for investigating the airways, lungs and guts of patients affected by pulmonary fibrosis and has rapidly adapted his research in response to the Covid pandemic. His research is advancing our understanding of the fundamental mechanisms of disease which will lead to more effective treatments being available to patients.



### **Dr Richard Allen (University of Leicester)**

is researching the genetics of disease. His ground-breaking research has identified new genes associated with idiopathic pulmonary fibrosis and the progression of the disease. Improving our understanding of genetics will help to identify new drug targets and support the development of personalised medicine, meaning each patient gets the right treatment.

## **Our Research Fellows**

Despite the challenges posed by the coronavirus pandemic, our research fellows have continued their dedicated work into pulmonary fibrosis.

Our research fellows have published their work in multiple scientific journals and at international conferences around the world, adding to the global knowledge and understanding of the disease.



## Supporting the next generation of outstanding scientists

We are passionate about supporting students and early career scientists to develop their careers and shape the future of pulmonary fibrosis research. Our Travel and Attendance Award Scheme enables scientists to share their research at conferences around the world, by giving talks, presenting posters and through networking opportunities. Attendance at conferences provides a valuable opportunity for career development and raises the profile of pulmonary fibrosis research.

With support from APF, exciting and far-reaching new knowledge has been shared about the relationship between exercise and breathlessness, the role of cells lining the airways in pulmonary fibrosis, and the role of bacteria, viruses and other microbes in the development of progressive pulmonary fibrosis. This is a key achievement for APF, enabled by the support from our many fundraisers.

## Patients as partners in research

Action for Pulmonary Fibrosis is dedicated to supporting research throughout the research cycle. In 2020/21 we collaborated with researchers in the UK and abroad to support the design, development and delivery of research. We have provided expert insight and a national perspective of the unmet needs of patients and families affected by pulmonary fibrosis. Members of the APF community have shared their lived experiences with researchers to help them better understand the impact of the disease and ensure that studies reflect the needs and priorities of patients.

## Shaping the future of pulmonary fibrosis research

Progressive pulmonary fibrosis treatment and care is an under-researched area and requires greater attention. Our partnership with James Lind Alliance and patients will directly set the top 10 future priorities for researchers in the UK and across the world and we are excited to be driving this work forward. In 2020 we received over 600 survey responses from patients, carers, family members and healthcare professionals, generating over 1,400 questions. This fantastic project is continuing into 2021/22, when the pulmonary fibrosis community will be deciding their top 10 research priorities.

“Where there  
is **research**,  
there is hope.”

Howard, IPF patient and APF Trustee

# Education

We understand that diagnosis takes too long for patients. Before Covid the average time of diagnosis after the initial doctor's appointment is over seven months. This will now be even longer.

Levels of care often do not meet national guidelines (e.g., NICE Quality Standard 79 on IPF, 2015). We are committed to raising healthcare professionals' awareness of the disease through APF attendance at conferences and delivering training.

With respiratory healthcare professionals being moved to work on the Covid frontline, and many conferences postponed, we took the difficult decision to pause much of our planned work to improve the awareness and education of healthcare professionals on the signs and symptoms of pulmonary fibrosis.

## Healthcare Professional Focussed Education and Awareness

The British Thoracic Society and its 4,000 members share our vision of a future without the burden of lung disease. We attended their winter meeting in February aimed at specialist respiratory physicians in order to raise awareness of our work, future funding opportunities and to stay up to date with the very latest thinking in lung health.

We continue to raise awareness of our GP module, developed in partnership with the Royal College of GPs, through online marketing and print publicity. Over 300 GPs have so far completed the training.

*"It's good to know awareness has been raised although we still have a lot to do I think. GPs should tell their patients when diagnosed about APF. I came out of the doctors realising it was a serious diagnosis but knowing nothing. She just said you've got PF and referred me to my consultant."*

**Sylvia, patient with PF**



## Sharing knowledge and empowering patients and family members

We turned our attention to the education and support of patients and some health care professionals, who through our Covid Survey, 78% told us they were very concerned about their lung disease.

We contributed to the European Lung Foundation Networking Day in Sept 2020.

We attended and delivered talks at the Boehringer Ingelheim Global Patient Partnership Summit, February 2021 and the European Pulmonary Fibrosis Federation (EU-IPFF) Patient Summit in April 2021, enabling us to share our experiences as well as learn from experts around the world. Steve Jones, our Chair of Trustees, is currently President of EU-IPFF.

In collaboration with Boehringer Ingelheim and 11London we co-developed a series of five webinars based on key topics as identified by patients and carers. These hour-long webinars ran every two weeks from May to June 2021. Topics ranged from mental health, oxygen, caring for others and pulmonary rehabilitation, and were designed to be accessible, informative sessions. We had overwhelmingly positive feedback, with many people saying they understood their diagnosis fully for the first time.



*“I’m absolutely delighted about this ‘Talking PF’ webinar initiative by APF. I have shared with our support group members and will certainly be taking part myself.”*

**Tom McMillan, Carer and Support Group Leader**



Mini talks and live Q&As about **lungs, life and keeping strong**



Talking PF meetings are a collaboration between Action for Pulmonary Fibrosis and Boehringer Ingelheim Limited. Boehringer Ingelheim Limited provided funding and support, with organising and project management in line with the ABPI Code of Practice.

# Campaigning and Awareness

Reducing health inequalities in pulmonary fibrosis is a vital part of our work.

**There are multiple injustices facing someone diagnosed with pulmonary fibrosis. These include, but are not limited to:**

- Being recognised as clinically extremely vulnerable to COVID, enabling access to a higher level of support or faster access to vaccinations;
- Slow or late diagnosis due to lack of awareness with GPs;
- Waiting until your lung function declines before you can access anti-fibrotic treatments to slow your lung fibrosis;
- No access to anti-fibrotic treatments if you have one of the other types of pulmonary fibrosis other than idiopathic pulmonary fibrosis;
- Long waiting times for every test, consultation or referral to supportive care due to long term under investment into ILD services;
- Lack of timely support for carers and family members; and
- Inequality of access to clinical trials; only patients who live near one of five of the 23 specialist centres in the UK get regular access to cutting edge research.



## At APF, we work across all these areas of need both locally and nationally.

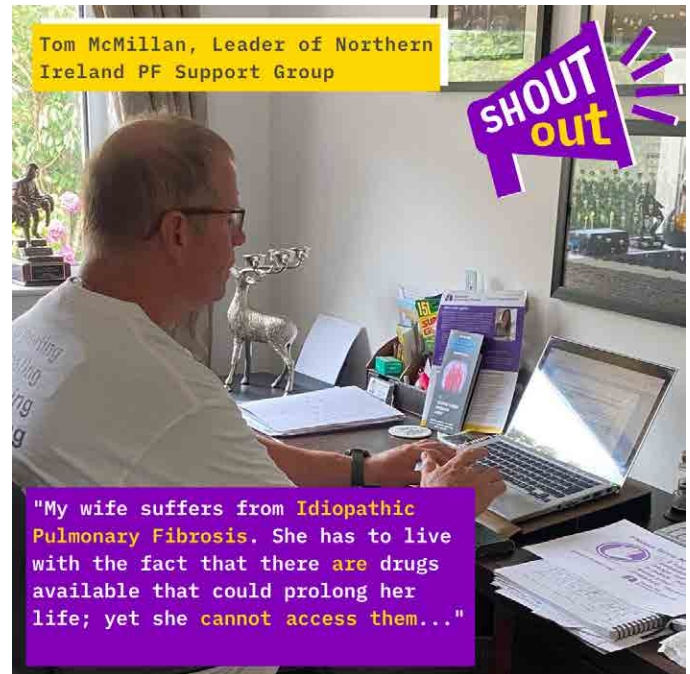
We work with vibrant and active support groups who engage with their MPs, NHS Trusts and local health networks improving timely access to care and support in their local area.

As part of APF's #ShoutOut Campaign, in September 2020 patients wrote to over 50 MPs around the country calling for England's National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium to review access to the only treatment that slows lung fibrosis making it available to people with all forms of pulmonary fibrosis. This campaign, spearheaded by APF was successful, with the roll out of the treatments to be made available across the UK from January 2022.

### But the fight is far from over.

APF continues to campaign across many injustices. A huge thank you to our many supporters who use their voice and platform to help us raise awareness. Our special thanks go to Amy and Katie Price and James Martin and the late Janice Long, who all brought pulmonary fibrosis to the attention of the media. We thank patients and their families, past and present who bravely share their stories.

In 2021/22 we plan to increase our efforts, influencing the NHS to further invest in ILD services and support carers right from diagnosis.



# Fundraising

**Over £500,000 was raised by our fundraisers and donors throughout 2020/21.**

As a charity that receives no government funding, we are entirely reliant on charitable income, with every penny raised and donated by our generous supporters helping to fund our vital work. As well as the obvious devastating effects on our health and wellbeing, the Covid pandemic continued to impact our income throughout 2020/21 with mass events and other community activities postponed or cancelled. However, thanks to the determination of our dedicated fundraisers and donors, we have been able to fund the growth of our services and launch our Hope for All Research Appeal.

We know there may be challenges in the year ahead, but we are confident that with the support of the pulmonary fibrosis community and our generous donors, we can continue to raise the crucial funding we need. We are determined to ensure nobody need face this devastating illness alone, and to give hope of a better future to the thousands of people affected by pulmonary fibrosis.



**#GoTheDistanceForAPF**

*“Sadly, their memories of my lovely mum will be limited given their ages, but raising money for APF gives us a positive focus and helps them remember her.”*

Catherine, APF donor

*“I wish that we had known about APF whilst Dad was alive. I hope my contribution may help in the fight against pulmonary fibrosis.”*

Bob, APF fundraiser

# £500,000+

Raised throughout 2020/21



# Plans for the future

**We anticipate significant disruption to the care, support and daily lives of people affected by pulmonary fibrosis largely due to Covid over the coming year.**

As such, we remain committed to the continued development of APF's strategic aims to help find a cure for pulmonary fibrosis and for more people affected by the disease to have a better future. New challenges require fresh thinking, and we have adopted a balanced scorecard methodology to underpin a new collaborative and creative approach to big challenges. Over the coming year we will continue to grow our income, so that we can support and empower more families affected by this devastating disease.



**We hope you'll join us in the fight against pulmonary fibrosis.**

# Structure, governance, and management

---

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

In 2021 the charity applied for, and on 25 May 2021 was granted, registration with the Office of the Scottish Charity Regulator (OSCR).

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

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

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



## Appointment of New Trustees

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

An appointment process is in place which includes receipt of a formal application providing personal details and outlining the skills and experience which the applicant can bring to APF. Candidates are then invited to meet with at least three trustees to discuss the application and to receive information about the Board, its work and the responsibilities of a trustee. Prospective trustees are invited to attend a trustee meeting for approval of all trustees prior to confirmation of appointment. An induction process follows providing the new trustee with comprehensive information on the charity and their responsibilities as a trustee.

To date this has been done by personal contact and through contacts made directly to the charity. In order to ensure diversity and make opportunities more widely available, the process for appointment was reviewed at the year end and agreed that trustee vacancies would be advertised.

## Organisational Structure

**The Chief Executive Officer leads the charity together with the management team.**

The Finance and Risk Committee is a standing committee which oversees and monitors the finances and budgets of the charity, risks, policies, and remuneration of staff. The committee, which includes three trustees and the CEO, meets quarterly prior to the Board meeting. Other sub-committees of the Board of Trustees are established to deal with specific tasks from time to time.

Action for Pulmonary Fibrosis is registered with the Fundraising Register.

## Risk Management

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

## Public Benefit Statement

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



# Financial Review

**The charity is in a strong financial position. Total income for the year was £651,809 and total expenditure was £601,408. Details are set out in the attached accounts.**

Our income for the year was lower than budgeted as there was a delay in receipt of grant funding and reduced community events due to Covid.

Expenditure was also lower than budgeted due to some underspend and planned activities being cancelled, or completed virtually, due to the pandemic.

The 2020/21 budget was set during the initial stages of the Covid pandemic. Our Senior Leadership Team were optimistic that Covid would only affect our activities and plans for the first six months of the financial year, but this has clearly not been the case with the impact of Covid still being felt 18 months later with ongoing social restrictions.

## Going Concern

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

## Reserves Policy

Trustees have agreed a reserves policy of holding an amount equivalent to six months of charitable expenditure, as Designated Reserves. Charitable expenditure includes staff and running costs, fundraising costs, planned activities and the provision of patient and family support activities. This is to ensure that the charity can continue offering services to its patient community during times of reduced income. It is reviewed annually at the July trustee meeting. The projection of increased operational costs for the coming year resulted in agreement to increase the balance on the Reserves account to meet the requirements of the Policy. This was carried out and the Reserves Account balance has been increased to £336,000 (£278,725 in 2020/21).



***“Without APF I don’t know where any of us would be.”***

**Dee, carer to her husband Roger with pulmonary fibrosis**

## Action for Pulmonary Fibrosis

### Report of the trustees

#### For the year ended 30 June 2021

---

##### Statement of responsibilities of the trustees

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

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

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

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

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

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

##### Auditors

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

Approved by the trustees on 5 February 2022 and signed on their behalf by

*steve jones*

Stephen Jones - Chair

## **Independent auditors' report**

### **To the members of**

#### **Action for Pulmonary Fibrosis**

---

##### **Opinion**

We have audited the financial statements of Action for Pulmonary Fibrosis (the 'charity') for the year ended 30 June 2021 which comprise the statement of financial position, balance sheet and statement of cash flows, and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 30 June 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities and Trustees Investment (Scotland) Act 2005, regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011.

##### **Basis for opinion**

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

##### **Conclusions relating to going concern**

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

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

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

## **Independent auditors' report**

### **To the members of**

#### **Action for Pulmonary Fibrosis**

---

##### **Other information**

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

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

We have nothing to report in this regard.

##### **Matters on which we are required to report by exception**

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

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

##### **Responsibilities of the trustees**

As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

##### **Our responsibilities for the audit of the financial statements**

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

## **Independent auditors' report**

### **To the members of**

#### **Action for Pulmonary Fibrosis**

---

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

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

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

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

(3) We inspected the minutes of trustee meetings.

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

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

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

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

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

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. Irregularities that arise due to fraud can be even harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

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

## **Independent auditors' report**

### **To the members of**

#### **Action for Pulmonary Fibrosis**

---

#### **Use of our report**

This report is made solely to the charity's trustees, as a body, in accordance with section 144 of the Charities Act 2011 and the regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

*Godfrey Wilson Limited*

Date: 8 February 2022

#### **GODFREY WILSON LIMITED**

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

## Action for Pulmonary Fibrosis

### Statement of financial activities

For the year ended 30 June 2021

	Note	Restricted £	Unrestricted £	2021 Total £	2020 Total £
<b>Income from:</b>					
Donations and legacies	3	-	518,882	<b>518,882</b>	673,638
Charitable activities	4	99,238	28,594	<b>127,832</b>	104,800
Investments		-	5,095	<b>5,095</b>	6,609
<b>Total income</b>		<u>99,238</u>	<u>552,571</u>	<u><b>651,809</b></u>	<u>785,047</u>
<b>Expenditure on:</b>					
Raising funds		-	109,856	<b>109,856</b>	94,977
Charitable activities		<u>59,545</u>	<u>432,007</u>	<u><b>491,552</b></u>	<u>410,325</u>
<b>Total expenditure</b>	6	<u>59,545</u>	<u>541,863</u>	<u><b>601,408</b></u>	<u>505,302</u>
<b>Net income / (expenditure) and net movement in funds</b>	9	39,693	10,708	<b>50,401</b>	279,745
<b>Reconciliation of funds:</b>					
Total funds brought forward		<u>25,507</u>	<u>1,014,501</u>	<u><b>1,040,008</b></u>	<u>760,263</u>
<b>Total funds carried forward</b>		<u><u>65,200</u></u>	<u><u>1,025,209</u></u>	<u><u><b>1,090,409</b></u></u>	<u><u>1,040,008</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 2021

	Note	£	2021 £	2020 £
<b>Current assets</b>				
Debtors	12	19,502		13,925
Current asset investments	13	1,071,858		1,113,208
Cash at bank and in hand		<u>156,054</u>		<u>163,113</u>
		<b>1,247,414</b>		1,290,246
<b>Liabilities</b>				
Creditors: amounts falling due within 1 year	14	<u>(127,040)</u>		<u>250,238</u>
<b>Net current assets</b>			<b>1,120,374</b>	1,040,008
Creditors: amounts falling due after more than 1 year	15		<u>(29,965)</u>	<u>-</u>
<b>Net assets</b>	16		<u><b>1,090,409</b></u>	<u>1,040,008</u>
<b>Funds</b>	17			
Restricted funds			<b>65,200</b>	25,507
Unrestricted funds				
Designated funds			<b>962,492</b>	793,195
General funds			<u><b>62,717</b></u>	<u>221,306</u>
<b>Total charity funds</b>			<u><b>1,090,409</b></u>	<u>1,040,008</u>

Approved by the trustees on 5 February 2022 and signed on their behalf by

*Steve Jones*

Stephen Jones - Chair

## Action for Pulmonary Fibrosis

### Statement of cash flows

As at 30 June 2021

	2021 £	2020 £
<b>Cash provided by operating activities:</b>		
Net movement in funds	50,401	279,745
Adjustments for:		
Investment income	(5,095)	(6,609)
Decrease / (increase) in debtors	(5,577)	21,007
Increase / (decrease) in creditors	(93,233)	(181,130)
<b>Net cash provided by operating activities</b>	<b>(53,504)</b>	<b>113,013</b>
<b>Cash flows from investing activities:</b>		
Investment income	5,095	6,609
<b>Net cash provided by investing activities</b>	<b>5,095</b>	<b>6,609</b>
<b>Increase in cash and cash equivalents in the year</b>	<b>(48,409)</b>	<b>119,622</b>
Cash and cash equivalents at the beginning of the year	1,276,321	1,156,699
<b>Cash and cash equivalents at the end of the year</b>	<b>1,227,912</b>	<b>1,276,321</b>
 <b>Analysis of cash and cash equivalents</b>		
Current asset investments	1,071,858	1,113,208
Cash at bank and in hand	156,054	163,113
<b>Cash and cash equivalents at the end of the year</b>	<b>1,227,912</b>	<b>1,276,321</b>

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 2021

---

#### 1. Accounting policies

##### a) Basis of preparation

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

Action for Pulmonary Fibrosis meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

##### b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern. However, the COVID-19 pandemic has had a profound impact on the global economy, but only minimal impact on the charity. The trustees have considered the impact of this issue on the charity's current and future financial position. The charity holds unrestricted, general reserves of £62,717, designated reserves that can be drawn down if necessary of £962,492 and a cash balance of £156,054. The combined value of cash and current asset investments at 30 June 2021 was £1.23m. The trustees consider that the charity has sufficient cash reserves to continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved.

##### c) Income

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

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

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

##### d) Interest receivable

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

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

---

**e) Funds accounting**

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

**f) Expenditure and irrecoverable VAT**

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

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

**g) Grants payable**

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

**h) Allocation of support and governance costs**

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Governance costs are the costs associated with the governance arrangements of the charity, including the costs of complying with constitutional and statutory requirements and any costs associated with the strategic management of the charity's activities. These costs have been allocated between cost of raising funds and expenditure on charitable activities on the basis of staff time spent on each of these areas. In the prior period an estimate was used, but in the current period a more thorough analysis of staff time by role was possible as there was a more significant number of employees. The percentages used were as follows:

	2021	2020
Raising funds	17%	16%
Charitable activities	83%	84%

**i) Debtors**

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

**j) Current asset investments**

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

**k) Cash at bank and in hand**

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

## **Action for Pulmonary Fibrosis**

### **Notes to the financial statements**

**For the year ended 30 June 2021**

---

**l) Creditors**

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

**m) Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently recognised at amortised cost using the effective interest method.

**n) Pension costs**

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

**o) Operating leases**

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

**p) Accounting estimates and key judgements**

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

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

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

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

#### 2. Prior period comparatives: statement of financial activities

	Restricted £	Unrestricted £	2020 Total £
<b>Income from:</b>			
Donations and legacies	-	673,638	<b>673,638</b>
Charitable activities	104,800	-	<b>104,800</b>
Investments	-	6,609	<b>6,609</b>
<b>Total income</b>	<b>104,800</b>	<b>680,247</b>	<b>785,047</b>
<b>Expenditure on:</b>			
Raising funds	-	94,977	<b>94,977</b>
Charitable activities	79,293	331,032	<b>410,325</b>
<b>Total expenditure</b>	<b>79,293</b>	<b>426,009</b>	<b>505,302</b>
<b>Net income and net movement in funds</b>	<b>25,507</b>	<b>254,238</b>	<b>279,745</b>

#### 3. Income from donations and legacies

	Restricted £	Unrestricted £	2021 Total £	2020 Total £
Legacies	-	5,000	<b>5,000</b>	25,000
Donations from individuals and fundraising	-	513,882	<b>513,882</b>	648,638
<b>Total income from donations and legacies</b>	<b>-</b>	<b>518,882</b>	<b>518,882</b>	<b>673,638</b>

All income from donations and legacies in the prior year was unrestricted.

#### 4. Income from charitable activities

	Restricted £	Unrestricted £	2021 Total £	2020 Total £
Corporate grants	-	-	-	82,500
Trusts and foundations	99,238	28,594	<b>127,832</b>	22,300
<b>Total income from charitable activities</b>	<b>99,238</b>	<b>28,594</b>	<b>127,832</b>	<b>104,800</b>

All income from charitable activities in the prior year was restricted.

#### 5. Government grants

The charitable incorporated organisation received no government grants during the year (2020: £nil).

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

#### 6. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	2021 Total £
Staff costs (note 10)	53,902	256,691	59,827	370,420
Freelance costs (note 10)	11,023	57,445	-	68,468
Travel and subsistence	-	-	359	359
Grants payable (note 7)	-	1,350	-	1,350
Training costs	-	3,610	-	3,610
Patient surveys	-	2,903	-	2,903
Fundraising costs	16,280	-	-	16,280
Marketing and communications	3,716	50,807	-	54,523
Premises costs	-	-	20,327	20,327
Admin costs	-	-	37,302	37,302
Other staffing costs	-	-	17,046	17,046
Governance costs	-	-	8,820	8,820
<b>Sub-total</b>	<b>84,921</b>	<b>372,806</b>	<b>143,681</b>	<b>601,408</b>
Allocation of support and governance costs	24,935	118,746	(143,681)	-
<b>Total expenditure</b>	<b>109,856</b>	<b>491,552</b>	<b>-</b>	<b>601,408</b>
<b>Prior year comparative:</b>				
	Raising funds £	Charitable activities £	Support and governance costs £	2020 Total £
Staff costs (note 10)	20,191	105,937	76,088	202,216
Freelance costs (note 10)	20,328	33,377	16,968	70,673
Travel and subsistence	-	-	16,313	16,313
Grants payable (note 7)	-	2,800	-	2,800
Training costs	-	33,094	-	33,094
Patient surveys	-	4,588	-	4,588
Fundraising costs	17,420	-	-	17,420
Marketing and communications	3,778	56,027	-	59,805
Premises costs	-	-	26,852	26,852
Admin costs	-	-	53,338	53,338
Other staffing costs	-	-	7,260	7,260
Governance costs	-	-	10,943	10,943
<b>Sub-total</b>	<b>61,717</b>	<b>235,823</b>	<b>207,762</b>	<b>505,302</b>
Allocation of support and governance costs	33,260	174,502	(207,762)	-
<b>Total expenditure</b>	<b>94,977</b>	<b>410,325</b>	<b>-</b>	<b>505,302</b>

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

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

#### 7. Grants payable

	Grants to institutions £	2021 Total £
<b>Support groups:</b>		
Nottingham Support Group	850	<b>850</b>
Windsor Support Group	500	<b>500</b>
	<u>1,350</u>	<u><b>1,350</b></u>

#### Prior year comparative

	Grants to institutions £	Grants to individuals £	2020 Total £
<b>Travel grants (2 individuals)</b>	-	1,500	<b>1,500</b>
<b>Support groups:</b>			
Worthing Support Group	500	-	<b>500</b>
Luton and Dunstable University Hospital	500	-	<b>500</b>
Harlow Support Group	300	-	<b>300</b>
	<u>1,300</u>	<u>1,500</u>	<u><b>2,800</b></u>

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

#### 8. Grants commitments

	2021 £	2020 £
Grant commitments brought forward	242,318	408,400
Grants committed during the period (note 7)	1,350	2,800
Grants paid during the period	<u>114,403</u>	<u>239,518</u>
Grant commitments carried forward	<u>115,753</u>	<u>242,318</u>

#### 9. Net movement in funds

This is stated after charging:

	2021 £	2020 £
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses (see note 19)	2,275	9,715
Auditors' remuneration:		
▪ Statutory audit (including VAT)	4,680	4,500
▪ Other services (including VAT)	<u>Nil</u>	<u>3,702</u>

#### 10. Staff costs and numbers

Staff costs were as follows:

	2021 £	2020 £
Salaries and wages	331,691	179,101
Social security costs	29,731	17,774
Pension costs	8,998	5,341
Freelance staff	<u>68,468</u>	<u>70,673</u>
	<u>438,888</u>	<u>272,889</u>

One employee earned between £60,000 and £70,000 during the year (2020: one employee earned more than £60,000).

The key management personnel of the charity comprise the trustees and Chief Executive. The total employee benefits of the key management personnel were £71,475 (2020: £69,854).

	2021 No.	2020 No.
Average head count	<u>11</u>	<u>5</u>

#### 11. 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 2021

#### 12. Debtors

	2021 £	2020 £
Trade debtors	4,822	-
Accrued income	11,440	10,165
Prepayments	3,240	3,760
	<u>19,502</u>	<u>13,925</u>

#### 13. Current asset investments

	2021 £	2020 £
Short term deposits	<u>1,071,858</u>	<u>1,113,208</u>

#### 14. Creditors: amounts due within 1 year

	2021 £	2020 £
Trade creditors	33,863	1,264
Accruals	5,480	4,500
Other creditors	1,909	2,156
Grant commitments (note 8)	85,788	242,318
	<u>127,040</u>	<u>250,238</u>

#### 15. Creditors: amounts due after 1 year

	2021 £	2020 £
Grant commitments (note 8)	<u>29,965</u>	<u>-</u>

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

#### 16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Current assets	65,200	1,078,245	(150,111)	<b>1,247,414</b>
Current liabilities	-	(85,788)	212,828	<b>127,040</b>
Long term liabilities	-	(29,965)	-	<b>(29,965)</b>
<b>Net assets at 30 June 2021</b>	<b>65,200</b>	<b>962,492</b>	<b>62,717</b>	<b>1,344,489</b>
<b>Prior year comparative</b>				
	Restricted funds £	Designated funds £	General funds £	Total funds £
Current assets	25,507	1,035,513	229,226	1,290,246
Current liabilities	-	(242,318)	(7,920)	(250,238)
<b>Net assets at 30 June 2020</b>	<b>25,507</b>	<b>793,195</b>	<b>221,306</b>	<b>1,040,008</b>

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

#### 17. Movements in funds

	At 1 July 2020 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2021 £
<b>Restricted funds</b>					
Boehringer Ingelheim	25,507	35,000	(50,962)	-	<b>9,545</b>
Roche	-	25,000	(6,250)	-	<b>18,750</b>
Trevi Therapeutics	-	24,988	-	-	<b>24,988</b>
Independent Age	-	10,000	-	-	<b>10,000</b>
Shanly Foundation	-	2,250	(1,500)	-	<b>750</b>
Hospital Saturday Fund	-	2,000	(833)	-	<b>1,167</b>
<b>Total restricted funds</b>	<b>25,507</b>	<b>99,238</b>	<b>(59,545)</b>	<b>-</b>	<b>65,200</b>
<b>Unrestricted funds</b>					
<i>Designated funds</i>					
Research fund	568,172	-	-	115,595	<b>683,767</b>
Reserve fund	225,023	-	-	53,702	<b>278,725</b>
<b>Total designated funds</b>	<b>793,195</b>	<b>-</b>	<b>-</b>	<b>169,297</b>	<b>962,492</b>
General funds	221,306	552,571	(541,863)	(169,297)	<b>62,717</b>
<b>Total unrestricted funds</b>	<b>1,014,501</b>	<b>552,571</b>	<b>(541,863)</b>	<b>-</b>	<b>1,025,209</b>
<b>Total funds</b>	<b>1,040,008</b>	<b>651,809</b>	<b>(601,408)</b>	<b>-</b>	<b>1,090,409</b>

#### Purposes of restricted funds

Boehringer Ingelheim	This fund is for support line ambassadors and newsletter.
Roche	This fund is for general support services to December 2021.
Trevi Therapeutics	This fund is for support services in Scotland (including SG coordinator salary).
Independent Age	This fund is for resuming face to face services (support groups).
Shanly Foundation	This fund is for Support Services General – South.
Hospital Saturday	This fund is for Support Services General.

## Action for Pulmonary Fibrosis

### Notes to the financial statements

For the year ended 30 June 2021

#### 17. Movements in funds

##### Purposes of designated funds

Research fund

A principal objective of Action for Pulmonary Fibrosis is to support and fund Research into the disease. Trustees have agreed to designate £684K for research to fund further research projects, following the successful launch of our Mike Bray Fellowships in 2018/19.

Reserve fund

The Reserve Fund has been established, in line with the charity's reserves policy, to retain a minimum of 50% of projected annual core expenditure separately as reserves. This is reviewed annually.

##### Prior year comparative

	At 1 July 2019 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2020 £
<b>Restricted funds</b>					
Boehringer Ingelheim	-	52,000	(26,493)	-	<b>25,507</b>
COVID-19	-	18,800	(18,800)	-	-
D'Oyly Carte	-	3,500	(3,500)	-	-
Galapagos	-	30,500	(30,500)	-	-
<b>Total restricted funds</b>	-	104,800	(79,293)	-	<b>25,507</b>
<b>Unrestricted funds</b>					
<i>Designated funds</i>					
Research fund	453	-	-	567,719	<b>568,172</b>
Reserve fund	145,230	-	-	79,793	<b>225,023</b>
<b>Total designated funds</b>	145,683	-	-	647,512	<b>793,195</b>
General funds	614,580	680,247	(426,009)	(647,512)	<b>221,306</b>
<b>Total unrestricted funds</b>	760,263	680,247	(426,009)	-	<b>1,014,501</b>
<b>Total funds</b>	<u>760,263</u>	<u>785,047</u>	<u>(505,302)</u>	<u>-</u>	<u><b>1,040,008</b></u>

## Action for Pulmonary Fibrosis

### Notes to the financial statements

#### For the year ended 30 June 2021

---

#### 18. Operating leases

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

	2021 £	2020 £
Amount falling due:		
Within 1 year	5,517	18,391
Within 2 - 5 years	-	27,586
	<u>5,517</u>	<u>45,977</u>

#### 19. Related party transactions

Trustees' reimbursed expenses comprised the following payments during the year:

	2021 £	2020 £
Subsistence	-	547
Trustee training	2,216	-
Travel expenses	59	8,751
Other expenses (gifts, stationery and postage)	-	417
	<u>2,275</u>	<u>9,715</u>

Trustee training for 9 trustees was held in the year. Travel expenses relate to reimbursed travel costs for one trustee.

All expenses were incurred in the course of the organisation's charitable activities.

Steve Jones, the chair of Action for Pulmonary Fibrosis (APF), is also the chair of European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF). During the year APF received income of £4,084 from EU-IPFF for services related to the Global Patient Partnership Summit (2020: £nil). At 30 June 2021 there was £2,915 owed to APF (2020: £nil).

Wendy Dickinson, a trustee of APF, is also a member of the Nottingham Pulmonary Fibrosis Support Group. During the year, APF provided a grant to Nottingham Pulmonary Fibrosis Support Group of £850 (2020: £nil). There were no amounts outstanding at the year end.

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



consultants | chartered accountants | statutory auditors

Action for Pulmonary Fibrosis

Year Ended 30 June 2021

Management Letter

# Contents

I	Introduction .....	I
2	Scope of the Audit.....	I
3	Audit Method & Materiality.....	2
4	Independence & Objectivity.....	2
5	Audit Opinion.....	3
6	Significant Aspects of the Entity's Accounting Practices.....	3
7	Significant Matters Discussed During the Audit .....	4
8	Significant Difficulties Encountered During the Audit.....	4
9	Recommendations for Improvements .....	5
10	Acknowledgements .....	5
11	Contact Us.....	5
12	Appendix 1: Recommendations .....	6
13	Appendix 2: Audit Adjustments & Unadjusted Errors.....	7

# 1 Introduction

This is our management letter to you following the audit of the financial statements for the year ended 30 June 2021. The management letter is designed to communicate to the trustees the audit approach, the key audit risks, any significant audit issues, the audit adjustments and unadjusted errors (if any), and our recommendations for improvements to systems, controls, and governance processes. We would appreciate it if this report is circulated to the trustees and discussed at a trustees' meeting.

The contents of this report and appendices are for the attention and information of the trustees only. You may only disclose the contents of this letter and appendices to third parties (such as funders) with our permission and we cannot be held liable for any reliance placed on the contents by third parties.

## 2 Scope of the Audit

The scope of the audit and our responsibilities are set out in our engagement letter dated 23 June 2020.

The objective of the audit work is to enable us to give an opinion as to whether the financial statements show a true and fair view of the results for the year and the state of affairs at the year end. As part of our work we also review whether the financial statements comply with relevant accounting standards. We design audit tests to provide assurance that the charity's financial statements are free from material error and so that we have a reasonable expectation of detecting material misstatement in the financial statements or accounting records resulting from irregularities and fraud.

Although it is not explicitly stated, an unqualified audit report means that we did gather adequate audit evidence to support the assertions in the financial statements, that we are satisfied that the books and records are in agreement with the financial statements and that

we received all the information and explanations we considered necessary for the audit. We are also satisfied with the disclosures in the notes to the financial statements. We do not audit the trustees' annual report, but we do check that this is consistent with the financial statements.

The audit procedures are designed to give us reasonable assurance that the financial statements, taken as a whole, are free of material misstatement. However, it is the responsibility of the trustees to ensure, as far as possible, that accurate and reliable accounting records are maintained and to operate appropriate controls.

### 3 Audit Method & Materiality

We used “substantive testing” – meaning that we verified particular transactions or balances by looking at a sample of invoices and receipts or by tracing from source documents to the final financial statements.

The audit work seeks evidence that the financial statements are materially correct. Small amounts do not affect a reader's understanding of the financial position. For this audit, the level of materiality we used was £38,000 for the balance sheet and £9,800 for the SoFA. These figures were used only as a guide and were subject to judgemental change depending on the findings during the audit. Materiality is not applied to certain transactions which are always material even when the amount involved is small, such as transactions with trustees.

### 4 Independence & Objectivity

We operate checks to ensure that we continue to act independently. We have enquired whether our staff have a connection to the charity, its staff, or trustees. We are not aware of any connections which would impact on our independence and objectivity as auditors.

We also provide non-audit services to you in the form of accounts preparation and bookkeeping support. We are therefore required to put safeguards in place to ensure we remain objective and independent as auditors. Under the Ethical Standards: Provisions Available to Smaller Entities (“ES PASE”) we are required to identify persons deemed to be “informed management” within your organisation. Any judgements or decisions we make in the course of our work must be clearly explained to those persons. We have identified Claire Baker, Finance and Operations Manager, as informed management and have already discussed all adjustments and matters of judgement with them.

## 5 Audit Opinion

The audit proceeded as planned. We can confirm that the audit opinion will be unqualified.

Our audit adjustments and unadjusted errors are shown in appendix 2. Trustees should ensure they are satisfied with these.

## 6 Significant Aspects of the Entity’s Accounting Practices

Action for Pulmonary Fibrosis complies with all the accounting policies listed in the notes to their financial statements, the Financial Reporting Standard applicable in the UK and Republic of Ireland FRS 102 and the Charities Statement of Recommended Practice (FRS 102) (effective 1 January 2019). All accounting estimates made by the charity are reasonable. The financial statements contain all the disclosures expected.

## 7 Significant Matters Discussed During the Audit

### Opening balances

Our review of the opening balances in Quickbooks found that these did not agree to the prior year signed accounts, even though last year's audit journals had been posted. The differences arose from changes made to a handful of bank transactions and invoices since our work was started in the prior year. As a result, we have posted an audit adjustment this year to correct the issue, which has added £12.4k to the existing surplus.

If the bank has been reconciled correctly, there should not be a need to change bank transactions once they have been reconciled. There should not usually be a need to post journals to the bank. We would recommend the following to make sure that opening balances, and bank balances, are correct in the future:

- Bank transactions should be reconciled by ticking off against a statement. Please note that bank feeds into Quickbooks / Xero are not 100% reliable, and can occasionally duplicate or miss transactions;
- Where a bank receipt or payment does not exactly match the invoice posted in Quickbooks / Xero, this should be fixed by posting an adjustment to the customer / supplier account, rather than by deleting the original invoice; and
- Once audit adjustments have been posted, a trial balance should be run and balances checked against the signed accounts. Once agreed, the period should be locked, so no edits can be made.

## 8 Significant Difficulties Encountered During the Audit

No significant difficulties were encountered during the audit.

## 9 Recommendations for Improvements

As part of our audit work we review the internal systems and controls and the governance processes in operation. In this letter, we report any weaknesses that we identified during the course of our work, and suggest recommendations. Please note this does not constitute a comprehensive review of your systems, it is simply a summary of our observations. Our observations, in addition to those set out in section 7, are included in appendix I. We hope you find the feedback useful and the recommendations practical.

## 10 Acknowledgements

We would like to express our thanks to Claire Baker and all the other staff for all their help with the audit.

## 11 Contact Us

The partner in charge of your audit is Alison Godfrey. If you have any questions or feedback about the audit, please do not hesitate to contact us.

Godfrey Wilson Limited  
5<sup>th</sup> Floor, Mariner House  
62 Prince Street  
Bristol  
BS1 4QD

Tel: 0117 971 3445

Email: [alison@godfreywilson.co.uk](mailto:alison@godfreywilson.co.uk)

## 12 Appendix 1: Recommendations

Issue	Implication	Recommendation
<b>Tracking categories in Xero</b>  The charity currently does not use tracking categories to track their restricted funds.	The charity may miss restricted income and expenditure which would result in misstatement of restricted fund balances. Even if restrictions are identified at year end it would take more time to compile this information without using this functionality.	We recommend using these tracking categories with your move to Xero. This functionality enables restricted fund balances to be tracked more easily for management account purposes. Additionally, tracking categories can be used to run reports to funders so they can review how their money is being spent.

## 13 Appendix 2: Audit Adjustments & Unadjusted Errors

### Audit Adjustments

Nominal Account	Debit	Credit
3001 General Funds	12,430.66	
4013 Fundraising:Community income:Community General		(4,419.49)
4020 Individual donations		(1,055.79)
4021 Individual donations:Individual Giving		(3.60)
4026 Individual donations:Memorial donations		(4,419.49)
5032 Marketing & communications:General marketing & communications		(97.81)
6021 Freelance costs:Freelancers & consultants		(2,200.00)
6253 Travel & subsistence:Travel		(376.70)
6402 IT costs:IT software	142.22	
<i>Opening balance adjustments.</i>		
1006 Nationwide	511.21	
1005 Shawbrook Research	2,868.16	
4051 Investment income:Bank Interest		(3,379.37)
<i>To recognise investment income received in the year.</i>		
1101 Prepayments	520.63	
5056 Governance costs:Insurance		(520.63)
<i>To release the prior year prepayment.</i>		

Nominal Account	Debit	Credit
1103 Accrued Income 4020 Individual donations <i>To release the prior year accrued income.</i>	6,115.67	(6,155.67)
1103 Accrued Income 4041 Fundraising:Community income:Corporate donations <i>To post gift aid in accrued income.</i>	11,439.81	(11,439.81)
2109 Accruals 5055 Governance costs:Audit & accountancy <i>To adjust the audit fee accrual.</i>	180.00	(180.00)

## Unadjusted Errors

Nominal Account	Debit	Credit
Debtors Donation income <i>To recognise June 2021 MuchLoved donations.</i>	2,803.62	(2,803.62)
Debtors Donation income <i>To recognise June 2021 Benevity donations.</i>	3,733.00	(3,733.00)
Accruals Gross wages <i>To recognise holiday pay owed at year end.</i>	8,416.88	(8,416.88)
Grants payable creditors Grant commitments (expense) <i>To recognise the time value of money on the long term grant payable.</i>	707.78	(707.78)