

Charity no. 1152399



**Action for
Pulmonary
Fibrosis**

Action for Pulmonary Fibrosis Report and Financial Statements 30 June 2019



Action for Pulmonary Fibrosis

Reference and administrative details

For the year ended 30 June 2019

Charity number 1152399

**Registered office
and operational
address** Stuart House
East Wing
St John's Street
Peterborough
PE1 5DD

Trustees The trustees who served during the year were as follows:

Mr Stephen Jones*	Chair
Howard Almond*	
Elizabeth Bray**	
Dr Simon Hart	
Dr Gisli Jenkins	
Rebecca Lang**	(appointed 4 August 2018)
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 50% of trustees have been personally affected by pulmonary fibrosis either as a patient or family member. Our three trustees who are medical doctors, are also leading pulmonary fibrosis researchers.

Chief Executive Officer Louise Wright

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

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

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

What is pulmonary fibrosis?

Today, around 70,000 people in the UK live with pulmonary fibrosis (PF), a devastating lung disease. This little-known condition causes scarring or stiffening of the lungs, making it hard for oxygen to pass into the body. Over time, most people living with PF become increasingly breathless, find it difficult to walk more than a short distance and to do only the most basic tasks without supplementary oxygen. PF normally affects people over 50 and is often fatal.

The most common form of the disease is idiopathic pulmonary fibrosis (IPF), which affects around 32,500 people. There are limited treatments available, no cure and it has no known cause. Life expectancy is three to five years following diagnosis and around 6,000 people die from it every year in the UK.

Why we are needed

It can take over six months for people with PF to receive the correct diagnosis. Once a patient has been diagnosed, they find it difficult to find information about the disease, let alone explain it to others. Patients and their families often feel lonely and isolated. The debilitating nature of the disease means, as people become more and more breathless, their need for physical and emotional support increases. Yet there is very little dedicated support or understanding about the disease available.

This is why Action for Pulmonary Fibrosis was set up.

Our vision, mission and values

Our vision

APF's vision is to find a cure and 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 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** to improve the lives of people affected by PF and **bold** in the ways we do this.

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Introduction from Chair and Chief Executive

Since Action for Pulmonary Fibrosis was set up, in 2013, the charity has grown rapidly. Over the last six years, we have had many successes, but there is still so much to do in supporting people affected by the disease and to find a cure.

Although there are few treatments currently available for pulmonary fibrosis, there are new drugs under development, which give some hope. It is reassuring to see researchers collaborating widely and drawing on different areas of expertise to advance understanding and ultimately launch successful treatments for all types of pulmonary fibrosis. APF plays a key role in this process both by commissioning research and ensuring that patients' views are taken into account by pharmaceutical companies and others in developing new treatments.

During the year, we were delighted to appoint two Mike Bray Research Fellows: Dr Phil Molyneaux at Imperial College London and the Brompton Hospital, and Dr Richard Allen at the University of Leicester. Both scientists will carry out globally important research projects, which will increase our understanding of pulmonary fibrosis, and will hopefully lead to new treatments for patients.

This year, we also expanded our support to patients and their families – helping them to address their concerns here and now. Over the 12 months, with our help, the number of support groups in the UK increased from 59 to 73, helping more people affected by pulmonary fibrosis to find support near to them. We will continue to increase the number and range of groups still further, to ensure that no-one need feel abandoned or isolated when they receive a shattering diagnosis of pulmonary fibrosis.

This year, we also launched our telephone support line. We did this in response to patients and carers, who told us they cannot always get to a support group and need to speak to someone who understands their concerns and can give advice.

We are the only charity to harness the voice of patients across the length and breadth of the UK. Our 2018 Patient Survey was nationwide and the results were widely published in the national media.

We continue to be humbled and inspired by the families who fundraise for Action for Pulmonary Fibrosis. It's thanks to all our 'purple' runners, cyclists, sky divers, bakers, bucket shakers, card makers and others that we are able to continue our work.

In 2023, Action for Pulmonary Fibrosis will be ten years old and we have bold ambitions for the next three years as we approach this milestone. We are determined to make the biggest impact we can on the lives of patients and families with the funds raised. Together we are stronger.

Steve Jones (Chair)

Louise Wright (Chief Executive)

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Review of Support and Information

Support Groups

Reaching out to people living with or caring for someone who has pulmonary fibrosis and getting to know their individual needs is where our work begins. Our trustees and ambassadors have experience of living with pulmonary fibrosis and have spent many hours travelling across the UK helping to set up support groups and to aid their development.

This year APF helped set up 16 new groups around the UK, improving access to support for hundreds of patients and carers. We gave £1,500 in grants to four new support groups to help them get started.

We know that support groups are not for everyone, but they can provide information and offer a helping hand, mutual understanding and unrivalled comfort at times when all can seem lost:

"I suffer from idiopathic pulmonary fibrosis. Because the disease is relatively unknown within the community, it can be difficult having to explain to people what this disease is about. The support group is extremely helpful to me on two counts. Firstly, it is good to share experiences with fellow sufferers without the need to go through all the explanations. Secondly, the guest speakers at the meetings are interesting and informative. The support group and Action for Pulmonary Fibrosis offers invaluable support to those suffering from this little-known disease and gradually the public profile is being raised."

Colin, patient and support group attendee

In addition to their formal role, most trustees volunteered in other ways for the charity by visiting support groups, fundraising events and conferences, raising awareness of the charity. In addition to trustees, Wendy Dickinson is one of APF's most active volunteer ambassadors. She has talked about APF to support groups across the country and raised awareness of APF in the media, along with 30 other extremely active volunteers. Over the next few years, we plan to further develop APF ambassadors, with experience of living with the disease, to support the growth of the charity. We thank each and every one of you.

Support Line

Although over 4,000 patients and carers now attend a support group, there are many other people who would like to attend meetings, but cannot, either because of ill health, employment or transport issues. The Support Line was started in June 2018 to support these people and others needing advice.

Over the year, we supported over 200 people by phone, email and more recently social media. Most of these were calls answered by our interstitial lung disease (ILD) Specialist Nurse, with some patients receiving support from patient ambassadors.

"Speaking to Lucy improved my understanding of my condition and allowed a number of action points to be raised which, if I am able to follow through can assist me now and also improve my management of the condition in the future."

APF Support line caller

Information

Very few people have heard of pulmonary fibrosis before they are diagnosed. They then look to the internet for information and are often frightened by what they read about short life expectancy and the effects of the disease. This negativity prevents patients and families from taking action that can improve their everyday lives, such as treatments, tailored services and practical positive advice from peers.

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

In view of this, we have upgraded the information available on our website and social media. In the next year, we aim to improve this further so that we are more inclusive and also provide information for carers who tell us they can feel very isolated.

Targets 2018/19	Outcomes 2018/19	Targets 2019/20
Support 15 new groups to set up, totalling 72	Supported 16 new groups, totalling 73.	Support 10 new support groups, 100+ visits
3 newsletters per annum to share patient news	3 newsletters distributed to all groups with positive feedback	4 newsletters per annum
Set up a new Support Line service	Supported over 200 patients and carers	Support over 300 patients and carers
Increase our web traffic and social media engagement	Web traffic > 4,000 visitors per month Social media engagement to continue to grow	Web traffic > 8,000 visitors per month Social media engagement to continue to grow
		Develop the role of ambassadors with lived experienced of PF/IPF



Figure 1 Support Group Meeting

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Review of Research

“Research advances in the last 5 years mean that we now understand much more about the biology of pulmonary fibrosis, and the number of drug trials has increased hugely, raising real hope of finding better treatments for all people with pulmonary fibrosis. But there remains much more to understand, so it is fantastic to see that research in pulmonary fibrosis is gathering momentum with co-ordinated efforts of academia, industry and charities. The tremendous work of APF fundraisers will make a vital contribution to the ongoing future research effort.”

Dr Simon Hart is a Reader in Respiratory Medicine at Hull York Medical School, a consultant respiratory physician and an APF Trustee.

This year, APF is delighted to have committed £579,816 to two research fellowships and funded seven researchers to travel to conferences in Europe and North America to share their insights and learnings on IPF and PF.

The precise cause of IPF, the most common form of pulmonary fibrosis, is not known but it has been shown to be associated with almost 20 genetic variations in patients. Over the next three years, we expect to identify many more IPF-associated genetic variations as a result of research by Dr Richard Allen at the University of Leicester funded by APF (see box on page 7). This will hopefully lead to the identification of the different chemical and biological pathways involved in the process of fibrosis and to new treatments.

These new genetic insights into the disease are encouraging because they raise the future prospect of precision medicine making it possible to target treatments to patients with specific genetic or molecular abnormalities.

Another important avenue for research is the role played by bacteria in causing IPF and progress of the disease. This is being investigated by another major APF-funded research project being undertaken by Dr Phil Molyneaux of Brompton Hospital and Imperial College (see box on page 7). He is examining the role different bacteria play in disease progression and whether taking prophylactic antibiotics can slow down disease progression. If they do, this could open another possible new treatment for patients.

In addition to directly funding research, APF plays an important role in ensuring that patient views are included in the design and implementation of other major research projects, financed by the National Institute of Health Research (NIHR) and others.

We are involved in this way in two major NIHR studies. The first, at the University of Nottingham, seeks to identify biomarkers in the blood, which would make it possible to assess whether a person has rapidly or slowly progressing disease and to tailor their treatment accordingly. The second, coordinated by the University of East Anglia, is investigating the potential benefit for IPF patients of controlling gastric reflux. Both of these have the potential to transform treatments for patients.

In the UK, Europe and North America, increasing collaboration between doctors, scientists and patient advocacy groups is leading to real improvements in outcomes for patients with this devastating disease. As a charity run jointly by patients and leading clinicians, we are making an important contribution to these efforts. We are also founder member of the European IPF Federation (EU-IPFF) and maintain close contacts with its Scientific Advisory Group and developments across Europe.



Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

APF is now one of the main charities funding research on pulmonary fibrosis in Europe. With your help, we are determined to make the greatest contribution we can to national and global efforts to find a cure for this devastating disease.

APF Mike Bray Research Fellows

	<p>Dr Richard Allen, Research Fellow in Genetics at the University of Leicester.</p> <p><i>"I am so excited to be given the chance to extend my work on the genetics of IPF, which will help in the development of new treatments for this devastating disease."</i></p>
	<p>Dr Phil Molyneaux is a respiratory clinician at the Brompton Hospital and a Senior Lecturer at Imperial College.</p> <p><i>"It is fantastic to be funded by APF to undertake research into how bacteria interact with the cells in the lungs and what happens following antibiotics. Understanding this may help us to identify new treatments for IPF patients."</i></p>

APF will review its strategic priorities on research in 2019/2020 to maximise our impact in a fast-moving global environment. The aim is to launch our research strategy by December 2020. In the meantime, we will be highlighting the research progress of our Fellows, funding more travel awards, including those of patients and carers attending the first European IPF Patient Summit in April 2020 and collaborating with Nottingham University in an NIHR financed project to determine the research priorities of patients and their families.

Targets 2018/19	Outcomes 2018/19	Targets 2019/20
Fund one fellowship in to IPF/PF	Funded two fellowships	Develop a research strategy for APF
Fund up to 8 travel awards for international conferences	Funded 8 travel awards	Fund travel awards for up to 8 researchers and up to 20 patients and carers
		Support the first priority-setting partnership with Nottingham University

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Review of Education

The charity has continued to explore ways in which it can contribute to improving understanding of all forms of pulmonary fibrosis and to ensure that care for patients at least meets national guidelines (e.g. NICE Quality Standard 79 on IPF, 2015), wherever they live in the UK. This includes improving the understanding of the disease amongst non-specialist healthcare professionals (HCPs), especially those working in the community who are involved in the care of patients. Four study days, reaching around 80 HCPs were run in the year July 2018 to June 2019, completing a total of 21 study days over an 18-month period.

“All of it was really interesting. Your trainer is truly inspirational and considering I'm in district nursing with very minimal respiratory knowledge she kept my interest throughout.”

Study day participant

To educate a broad range of medical professionals and commissioners we used our 2018 Patient Survey 'Giving patients a voice' to lead a round table discussion attended by 30 patients, carers, charities, commissioners and medical professionals. This led to discussions with the Royal College of Physicians with the aim of co-developing a training module aimed at 100,000+ members of the RCGP on the diagnosis and treatment of IPF to be launched in 2020.

APF attended four UK conferences educating medical professionals on the needs of patients and carers and raising awareness of APF. We presented, distributed printed materials and made new connections resulting in the setting up of new support groups. A review of the conferences we attend indicates that they are most cost effective when there is a focus on respiratory medicine – this will inform our decisions on attendance at future conferences.

Looking forward, APF will launch an online training module co-developed with the Royal College of Physicians, continue to attend and support conferences aimed at medical professionals with an interest in respiratory medicine and continue to run targeted round table discussions to facilitate innovative new ways of working.

Targets 2018/19	Outcomes 2018/19	Targets 2019/20
Run 4 study days, completing a programme of 21 in total	4 study days run with positive feedback from participants	Review future of HCP training
Attend 4 UK conferences aimed at HCP's with an interest in respiratory	Attended 4 UK conferences	Attend 4 UK and other European conferences
		Run two round table discussions to highlight patient concerns and increase best practice

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Review of Campaigning and Awareness

Campaigning

Following the success of our 2015 Patient Survey, 'Working together; delivering a better future for patients with IPF', we launched the report of our 2018 survey 'Giving patients a voice' in February 2019. We were delighted that 776 patients from across the UK responded, more than double the number in 2015. Our analysis resulted in some remarkable findings: patient satisfaction with treatment has fallen; a third of patients still lack access to a specialist nurse; and only 63% of individuals feel 'well supported' in managing their IPF. The survey led to 5 recommendations that continue to drive the focus of our campaigning.

These are:

1. To improve the timely and accurate diagnosis of patients with PF;
2. Increase access to ILD specialist nurses;
3. Improve access to pulmonary rehabilitation that specifically meets their needs;
4. Increase the number of support groups available to patients and carers; and
5. Increase access to new technologies to speed up diagnosis and give early warning of acute exacerbations.

We used this survey to drive discussions within the National Health Service but also to raise awareness of PF and the key issues in the national media. Our patient survey was quoted in the national press, both on and offline reaching millions of readers across the UK.

"Thank you APF for raising awareness. It is a very debilitating condition. Awareness and education are crucial to ensure the support is there for those who have this condition and hopefully to find a cure one day."

APF Supporter

Raising Awareness

We also had articles on IPF published in The Guardian's health section, a mention on Channel Four News and stories in regional press and radio, many of the stories generated by support groups across the UK.

Lack of awareness adds to the anxiety and confusion patients and their family members feel at diagnosis and continues as the disease progresses. Raising awareness of the disease continues to be a high priority for patients, families and our fundraisers. We will continue to run campaigns in the media around the key issues raised in our Patient Survey and help patients highlight their stories so other families don't feel alone.

Targets 2018/19	Outcomes 2018/19	Targets 2019/20
Launch updated patient survey to highlight issues and recommendations	Launched patient survey in national media	Run two campaigns that address key issues
One APF story in national press	APF stories ran in several national newspapers (e.g. Daily Mail, Daily Express) and in Daily Mail Online	Several national papers (on and offline) picking up APF stories

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Review of Fundraising

"I think people are channelling their grief into fundraising to find comfort and hope. My husband was clearly a much-loved man, sadly missed by all who knew him but how fantastic that they are now united in a fundraising mission to help support others."

APF Supporter

Without the support of our amazing fundraisers, APF would not be able to fund research, or provide the support patients and families tell us makes a huge difference to their lives.

Many support groups make regular donations to APF's work. We thank each and every one. Family members of patients with pulmonary fibrosis, young and old across the UK donate regularly or run, cycle, bake, sky dive, dance and sing to raise vital funds to support our work. We couldn't do it without you!

We are enormously appreciative of the families who make generous funeral donations in memory of loved ones. We received legacies from five families supporting our work during the period, for which we are truly grateful.

APF does not receive any government funding.

Targets 2018/19	Outcomes 2018/19	Targets 2019/20
Increase our income to support our growing work	Income grew by 20%	Income to increase to support our growing work



Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

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.

All trustees have direct experience of IPF, either as patients, carers, family members or medical doctors.

The trustees meet formally four times a year to review the charity's progress, formulate general policy and strategy and ensure adherence to charity regulations. Reports are received on the charity's work during the quarter. An annual plan and budget for activities for the coming period are agreed. 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 further skills required. The Board seeks to appoint new members to strengthen the board and where necessary to replace a member who leaves the board. To date this has been done by personal contact and contacts made directly to the charity. It remains a requirement of all new trustees that they have a personal connection to pulmonary fibrosis.

New appointments are considered and agreed by all trustees at a meeting of the board or by electronic communication. A 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. This is reviewed by all trustees. Stage two is a meeting with the candidate and at least three trustees to discuss the application and provide information about the Board and its work. The result of this meeting is shared with all trustees. Provided there are no objections, the prospective trustee is then invited to attend a trustee meeting prior to confirmation of appointment. Once the appointment is agreed an induction process takes place which provides the new trustee with further background information on the charity, roles and responsibilities and current activities.

Organisational Structure

As reported last year, trustees agreed the charity had developed to a point where permanent staff were needed to ensure that activities are delivered in the most effective and cost-efficient way. A Chief Executive Officer was appointed in December 2018 following which a full strategic review took place. A staffing structure was proposed which has since been implemented. The Finance and Operations sub-group of trustees has continued meeting regularly to oversee the finances and to support the new CEO in her first year.

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. 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.

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Financial Review

The charity is in a strong financial position. Total income for the year was £631,646 and total expenditure was £924,151 details of which are set out in the attached accounts.

The source of funds continues to be mostly from individual fundraisers and memorial donations. The sustainability of this income depends on our active fundraising and communications programme, to inform our community of the charity's work and achievements. In a small number of cases, donations are made specifically for research and this is recognised in the accounts.

Reserves Policy

A Reserves Policy has been established which requires a minimum of 50% of projected annual core expenditure to be retained separately as Reserves. This is reviewed annually at the October 2019 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 £225,000 in November 2019.

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 requires the trustees are 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 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.

Action for Pulmonary Fibrosis

Report of the trustees

For the year ended 30 June 2019

Independent examiners

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

Approved by the trustees on 27 February 2020 and signed on their behalf by

A handwritten signature in black ink, appearing to read 'Stephen Jones', written in a cursive style.

Stephen Jones - Chair

Independent examiner's report

To the trustees of

Action for Pulmonary Fibrosis

I report to the trustees on my examination of the accounts of Action for Pulmonary Fibrosis (the CIO) for the year ended 30 June 2019, which are set out on pages 15 to 29.

Responsibilities and basis of report

As the charity trustees of the CIO you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the CIO's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

Since the CIO's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

Godfrey Wilson Limited also provides bookkeeping and payroll services to the charity. I confirm that as a member of the ICAEW I am subject to the FRC's Revised Ethical Standard 2016, which I have applied with respect to this engagement.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- (1) accounting records were not kept in respect of the CIO as required by section 130 of the Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Date: 26 MARCH 2020 .

Alison Godfrey FCA
Member of the ICAEW

For and on behalf of:
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 2019

	Note	Restricted £	Unrestricted £	2019 Total £	2018 Total £
Income from:					
Donations and legacies	3	9,466	617,360	626,826	521,959
Charitable activities	4	-	-	-	83,400
Investments		-	4,820	4,820	451
Total income		<u>9,466</u>	<u>622,180</u>	<u>631,646</u>	<u>605,810</u>
Expenditure on:					
Raising funds		-	91,117	91,117	78,771
Charitable activities		<u>39,817</u>	<u>793,217</u>	<u>833,034</u>	<u>180,617</u>
Total expenditure	6	<u>39,817</u>	<u>884,334</u>	<u>924,151</u>	<u>259,388</u>
Net income / (expenditure)		(30,351)	(262,154)	(292,505)	346,422
Transfers between funds		-	-	-	-
Net movement in funds	9	(30,351)	(262,154)	(292,505)	346,422
Reconciliation of funds:					
Total funds brought forward		<u>30,351</u>	<u>1,022,417</u>	<u>1,052,768</u>	<u>706,346</u>
Total funds carried forward		<u>-</u>	<u>760,263</u>	<u>760,263</u>	<u>1,052,768</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 2019

	Note	£	2019 £	2018 £
Current assets				
Debtors	12	34,932		23,011
Current asset investments	13	875,159		803,365
Cash at bank and in hand		<u>281,540</u>		<u>245,987</u>
		1,191,631		1,072,363
Liabilities				
Creditors: amounts falling due within 1 year	14	<u>287,512</u>		<u>19,595</u>
Net current assets			904,119	1,052,768
Creditors: amounts falling due after more than 1 year	15		<u>(143,856)</u>	<u>-</u>
Net assets	16		<u>760,263</u>	<u>1,052,768</u>
Funds				
Restricted funds	17		-	30,351
Unrestricted funds				
Designated funds			145,683	702,365
General funds			<u>614,580</u>	<u>320,052</u>
Total charity funds			<u>760,263</u>	<u>1,052,768</u>

Approved by the trustees on 27 February 2020 and signed on their behalf by



Stephen Jones - Chair

Action for Pulmonary Fibrosis

Statement of cash flows

As at 30 June 2019

	2019 £	2018 £
Cash provided by operating activities:		
Net movement in funds	(292,505)	346,422
Adjustments for:		
Investment income	(4,820)	(451)
Increase in debtors	(11,921)	(14,747)
Increase in creditors	<u>411,773</u>	<u>5,353</u>
Net cash provided by operating activities	<u>102,527</u>	<u>336,577</u>
Cash flows from investing activities:		
Investment income	<u>4,820</u>	<u>451</u>
Net cash provided by investing activities	<u>4,820</u>	<u>451</u>
Increase in cash and cash equivalents in the year	107,347	337,028
Cash and cash equivalents at the beginning of the year	<u>1,049,352</u>	<u>712,324</u>
Cash and cash equivalents at the end of the year	<u><u>1,156,699</u></u>	<u><u>1,049,352</u></u>
 Analysis of cash and cash equivalents		
Current asset investments	875,159	803,365
Cash at bank and in hand	<u>281,540</u>	<u>245,987</u>
Cash and cash equivalents at the end of the year	<u><u>1,156,699</u></u>	<u><u>1,049,352</u></u>

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

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 2015) - (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 2019

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 the time spent on each of these areas as follows:

	2019	2018
Raising funds	25%	25%
Charitable activities	75%	75%

i) Debtors

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

j) Current asset investments

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

k) Cash at bank and in hand

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

l) Creditors

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

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

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) Accounting estimates and key judgements

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

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

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

2. Prior period comparatives: statement of financial activities

	Restricted	Unrestricted	2018
	£	£	Total
			£
Income from:			
Donations and legacies	16,545	505,414	521,959
Charitable activities	80,400	3,000	83,400
Investments	-	451	451
	<u>96,945</u>	<u>508,865</u>	<u>605,810</u>
Total income			
Expenditure on:			
Raising funds	-	78,771	78,771
Charitable activities	70,531	110,086	180,617
	<u>70,531</u>	<u>188,857</u>	<u>259,388</u>
Total expenditure			
Net income and net movement in funds	<u>26,414</u>	<u>320,008</u>	<u>346,422</u>

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

3. Income from donations and legacies

	Restricted £	Unrestricted £	2019 Total £
Legacies	-	43,505	43,505
Donations from individuals and fundraising	<u>9,466</u>	<u>573,855</u>	583,321
Total income from donations and legacies	<u>9,466</u>	<u>617,360</u>	<u>626,826</u>

Prior year comparative:

	Restricted £	Unrestricted £	2018 Total £
Legacies	-	23,000	23,000
Donations from individuals and fundraising	<u>16,545</u>	<u>482,414</u>	498,959
Total income from donations and legacies	<u>16,545</u>	<u>505,414</u>	<u>521,959</u>

4. Income from charitable activities

	Restricted £	Unrestricted £	2019 Total £
Corporate grants	-	-	-
Trusts and foundations	<u>-</u>	<u>-</u>	<u>-</u>
Total income from charitable activities	<u>-</u>	<u>-</u>	<u>-</u>

Prior year comparative:

	Restricted £	Unrestricted £	2018 Total £
Corporate grants	77,400	-	77,400
Trusts and foundations	<u>3,000</u>	<u>3,000</u>	6,000
Total income from charitable activities	<u>80,400</u>	<u>3,000</u>	<u>83,400</u>

5. Government grants

The charitable incorporated organisation received no government grants during the year (2018: £nil).

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

6. Total expenditure

	Raising funds £	Charitable activities £	Support and governance costs £	2019 Total £
Staff costs (note 10)	-	10,590	32,315	42,905
Freelance costs (note 10)	15,566	51,126	24,193	90,885
Travel and subsistence	-	-	19,912	19,912
Grants payable (note 7)	-	588,566	-	588,566
Training costs	-	1,000	-	1,000
Patient surveys	-	25,057	-	25,057
Fundraising costs	24,435	-	-	24,435
Marketing and communications	4,823	39,996	-	44,819
Admin costs	7,393	-	50,718	58,111
Other staffing costs	-	-	12,054	12,054
Governance costs	-	-	16,407	16,407
Sub-total	52,217	716,335	155,599	924,151
Allocation of support and governance costs	<u>38,900</u>	<u>116,699</u>	<u>(155,599)</u>	<u>-</u>
Total expenditure	<u>91,117</u>	<u>833,034</u>	<u>-</u>	<u>924,151</u>

Prior year comparative:

	Raising funds £	Charitable activities £	Support and governance costs £	2018 Total £
Freelance costs (note 10)	21,682	66,142	32,673	120,497
Travel and subsistence	-	-	16,416	16,416
Grants payable (note 7)	-	9,100	-	9,100
Training costs	-	6,368	-	6,368
Patient surveys	-	8,186	-	8,186
Fundraising costs	21,422	-	-	21,422
Marketing and communications	7,089	20,221	-	27,310
Admin costs	5,044	-	32,290	37,334
Other staffing costs	-	-	275	275
Governance costs	-	-	12,480	12,480
Sub-total	55,237	110,017	94,134	259,388
Allocation of support and governance costs	<u>23,534</u>	<u>70,600</u>	<u>(94,134)</u>	<u>-</u>
Total expenditure	<u>78,771</u>	<u>180,617</u>	<u>-</u>	<u>259,388</u>

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

7. Grants payable

	Grants to institutions £	Grants to individuals £	2019 Total £
Travel grants (8 individuals)	-	7,250	7,250
Research:			
University of Leicester	280,171	-	280,171
Imperial College, London	299,645	-	299,645
Support groups:			
Boston and East Holland Support Group	300	-	300
Bolton Support Group	400	-	400
East Kent Support Group	300	-	300
Northamptonshire Support Group	500	-	500
	<u>581,316</u>	<u>7,250</u>	<u>588,566</u>

Prior year comparative

	Grants to institutions £	Grants to individuals £	2018 Total £
Travel grants (5 individuals)	-	4,500	4,500
Support groups:			
Frodsham Support Group	300	-	300
Bedford PF Support Group	300	-	300
Guys & St Thomas' PF Support Group	500	-	500
Sheffield PF Support Group	500	-	500
Worcester PF Support Group	400	-	400
Imperial IPF Support Network (St Mary's)	200	-	200
Fife & Tayside IPF Support Group	500	-	500
Mid Essex PF Support Group	500	-	500
Tameside PF Support Group	500	-	500
Gloucestershire Lung Fibrosis Support Group	300	-	300
Pulmonary Fibrosis East Surrey	600	-	600
	<u>4,600</u>	<u>4,500</u>	<u>9,100</u>

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

8. Grants commitments

	2019 £	2018 £
Grant commitments brought forward	-	-
Grants committed during the period (note 7)	588,566	9,100
Grants paid during the period	<u>(180,166)</u>	<u>(9,100)</u>
Grant commitments carried forward	<u>408,400</u>	<u>-</u>

9. Net movement in funds

This is stated after charging:

	2019 £	2018 £
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses (see note 19)	15,333	8,412
Independent examiner's remuneration:		
▪ Independent examination (including VAT)	2,580	2,520
▪ Other services (including VAT)	<u>5,166</u>	<u>5,040</u>

10. Staff costs and numbers

Staff costs were as follows:

	2019 £	2018 £
Salaries and wages	41,500	-
Pension costs	1,405	-
Freelance staff	<u>90,885</u>	<u>120,497</u>
	<u>133,790</u>	<u>120,497</u>

No employee or freelancer earned more than £60,000 during the year (2018: Nil).

The key management personnel of the charity comprise the trustees and Chief Executive (in post from December 2018). The total employee benefits of the key management personnel were £35,750 (2018: £Nil).

	2019 No.	2018 No.
Average head count	<u>1</u>	<u>-</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 2019

12. Debtors

	2019 £	2018 £
Accrued income	20,999	7,730
Prepayments	<u>13,933</u>	<u>15,281</u>
	<u><u>34,932</u></u>	<u><u>23,011</u></u>

13. Current asset investments

	2019 £	2018 £
Short term deposits	<u>875,159</u>	<u>803,365</u>

14. Creditors: amounts due within 1 year

	2019 £	2018 £
Trade creditors	18,037	12,050
Accruals	2,580	7,545
Tax and social security	1,849	-
Other creditors	502	-
Grant commitments (note 8)	<u>264,544</u>	<u>-</u>
	<u><u>287,512</u></u>	<u><u>19,595</u></u>

15. Creditors: amounts after 1 year

	2019 £	2018 £
Grant commitments (note 8)	<u>143,856</u>	<u>-</u>

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Current assets	-	554,083	637,548	1,191,631
Current liabilities	-	(264,544)	(22,968)	(287,512)
Long term liabilities	-	(143,856)	-	(143,856)
Net assets at 30 June 2019	-	145,683	614,580	760,263
Prior year comparative				
	£	£	£	£
Current assets	30,351	702,365	339,647	1,072,363
Current liabilities	-	-	(19,595)	(19,595)
Net assets at 30 June 2018	30,351	702,365	320,052	1,052,768

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

17. Movements in funds

	At 1 July 2018 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2019 £
Restricted funds					
Boehringer Ingelheim	16,064	-	(16,064)	-	-
Roche Products Limited	1,515	-	(1,515)	-	-
Research fund	12,772	9,466	(22,238)	-	-
Total restricted funds	30,351	9,466	(39,817)	-	-
Unrestricted funds					
<i>Designated funds</i>					
Research fund	557,314	-	(557,578)	717	453
Reserve fund	145,051	-	-	179	145,230
Total designated funds	702,365	-	(557,578)	896	145,683
General funds	320,052	622,180	(326,756)	(896)	614,580
Total unrestricted funds	1,022,417	622,180	(884,334)	-	760,263
Total funds	1,052,768	631,646	(924,151)	-	760,263

Purposes of restricted funds

Roche Products Limited

The funds were to provide short study sessions on IPF for hospital respiratory nurses, community nurses and other associated health care professionals, and to develop supporting educational materials.

Boehringer Ingelheim

The funds provided for the development and initial set up costs of 15 new patient support groups, from September 2017 to September 2018, together with costs for promoting groups, including newsletters and publicity materials.

Research fund

These are donations made to the charity specifically for the purpose of research.

The D'Oyly Carte Charitable Trust

These funds were provided in the prior year to provide support for the elderly.

The Crane Foundation

These funds were provided in the prior year for a patient event.

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

17. Movements in funds

Purposes of designated funds

Research fund

The trustees have established the Research Fund to award grants to research programmes that indicate clear objectives for the development of knowledge, leading to a better understanding of the causes of IPF and improved treatments. Two APF Mike Bray Fellowships were awarded by 30 June 2019 totalling £579,816, taken from the designated and restricted research funds.

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 2017 £	Income £	Expenditure £	Transfers between funds £	At 30 June 2018 £
Restricted funds					
Boehringer Ingelheim	-	65,000	(48,936)	-	16,064
Roche Products Limited	3,937	12,400	(14,822)	-	1,515
The D'Oyly Carte Charitable Trust	-	3,000	(3,000)	-	-
The Crane Foundation	-	3,773	(3,773)	-	-
Research fund	-	12,772	-	-	12,772
Total restricted funds	3,937	96,945	(70,531)	-	30,351
Unrestricted funds					
<i>Designated funds</i>					
Research fund	357,080	-	-	200,234	557,314
Reserve fund	70,087	-	-	74,964	145,051
Total designated funds	427,167	-	-	275,198	702,365
General funds	275,242	508,865	(188,857)	(275,198)	320,052
Total unrestricted funds	702,409	508,865	(188,857)	-	1,022,417
Total funds	706,346	605,810	(259,388)	-	1,052,768

Action for Pulmonary Fibrosis

Notes to the financial statements

For the year ended 30 June 2019

18. Financial instruments

	2019	2018
	£	£
Financial assets measured at amortised cost	1,177,698	1,057,082
Financial liabilities measured at amortised cost	<u>(429,519)</u>	<u>(19,595)</u>

Financial assets measured at amortised cost comprise cash and cash equivalents, current asset investments and accrued income.

Financial liabilities measured at amortised cost comprise trade creditors, accruals, grants payable and other creditors.

19. Related party transactions

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

	2019	2018
	£	£
Hotels	-	563
Subsistence	1,163	176
Travel expenses	13,075	7,545
Other expenses (gifts, stationery and postage)	<u>1,095</u>	<u>128</u>
	<u>15,333</u>	<u>8,412</u>

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

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