ACTION FOR PULMONARY FIBROSIS

Treasurer Trustee Recruitment Pack 2024
Our purpose.

Our vision, mission and values guide us in everything we do.

Our ultimate goal is to STOP Lung Fibrosis.

We will do this by focusing on: supporting research to find better treatments and a cure; give a voice, support and hope to everyone affected by pulmonary fibrosis and campaign to improve equality of care.

We will work in ways which are;

- **Compassionate** – We are patient-led and ensure that all those affected by pulmonary fibrosis are at the heart of everything we do.
- **Expert** – We bring together real-life experience with scientific expertise from across the world.
- **Bold** – We work with all those affected by pulmonary fibrosis to campaign against the injustices and inequalities they face.
APF Trustee Recruitment Pack.

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Welcome from our Chair of Trustees.

Hello.

Thank you for your interest in becoming a trustee of Action for Pulmonary Fibrosis.

I’m Mike Stubbins, chair of trustees for APF. My mother was diagnosed with idiopathic pulmonary fibrosis in 2007 and lived with the disease for almost ten years before she passed away in 2017.

APF is patient-led charity and is committed to maintaining a trustee board in which all members – just like me - have either a personal or professional connection to the disease. We believe it gives us unique insight into the experiences of patients and families and a genuine credibility with all our stakeholders.

Other trustees include health professionals working in PF treatment and research; people living with PF; carers and family members. We each bring our own professional and life skills to the board, as well as our lived experience of the disease.

We are currently looking for new trustees and are committed to increasing the diversity of the team, without losing that special quality of connection.

We particularly welcome applications from people:

- with types of pulmonary fibrosis connected to other diseases (such as autoimmune disease) or workplace exposure
- who are Black or Asian or other racialised communities
- with a background in (charity) finance and an ability to interpret accounts for long term decision making

Becoming a volunteer charity trustee is an immensely rewarding experience. It is not just about the impact you will have on the lives of people affected by pulmonary fibrosis but also what you will gain. Volunteering is a two-way street and the personal development, ‘job’ satisfaction, knowledge and experience you will take from it could be life-changing.

If you believe you could be one of our new trustees, we look forward to receiving your application.

Mike Stubbins
Who we are.

Action for Pulmonary Fibrosis was formed in 2013 by a small and ambitious group of patients and carers, two leading Interstitial Lung Disease doctors and a registered nurse. This was at a time when few people, apart from health specialists, knew about the disease. There was little research and limited treatments. Patients and families were crying out for support and to be given a voice.

Today APF is the leading charity supporting PF patients in Europe and is a vibrant, effective and growing community of patients, families, researchers and healthcare professionals. We are all striving to stop pulmonary fibrosis in its track and support everyone affected by the disease for a better future.

What we do.

There are more than 70,000 people living with PF in the UK. Around half of those have Idiopathic Pulmonary Fibrosis (IPF), which has no known cause. Others have PF connected to other conditions, such as rheumatoid arthritis or sarcoidosis. Pulmonary fibrosis is usually terminal and causes scarring and stiffening of the lungs, making it hard for oxygen to pass into the body. There are limited treatments available and life expectancy for people with IPF, is three to five years following diagnosis. Around 1% of people die from PF every year in the UK. The disease has a devastating impact on everyday life and many people living with PF and their families feel marginalised and alone.

- We support a nationwide network of care; face to face, by phone, email and online led by people living with PF so no one faces PF alone

- We fund ground-breaking research to improve quality of life for people living with pulmonary fibrosis and improve the quality of research around the world through our patient and public involvement programme

- We give people living with PF a voice by raising awareness of this little-known disease through influencing the NHS for better access to care, raising awareness of the disease through national awareness campaigns and fundraise so more people have access to the support and care they deserve
What we are looking for in new trustees.

We will be welcoming up to two new trustees to our board in April 2024. We are committed to having a more diverse board, reflective of the communities we serve and knowledgeable about the lives lived by people from all parts of society. We are keen to hear from people who might not have previously considered joining a board of trustees. Although PF is predominantly a disease affecting older people, we want to encourage applicants from all ages. We will support anyone who needs it to acquire new skills. Just because you haven’t yet doesn’t mean you shouldn’t or can’t!

According to current law you cannot be a trustee if:
- if you are under 18
- have been convicted of offences relating to fraud, terrorism, deception, sexual offences
- currently declared bankrupt or subject to bankruptcy restrictions or an interim order
- subject to a debt relief order, a debt relief restrictions order or interim order
- disqualified from being a company director.

We are also looking for a treasurer with the following skills:
- Significant budgetary and financial experience (may be a qualified accountant) with demonstrable commercial awareness and knowledge or an experienced charity treasurer who has provided strategic financial leadership to a board of trustees (>£3M+ t/o)
- Knowledge of charity SORP and impending changes
- Proven ability to communicate and explain complex financial information to a non-financial audience
- Demonstrable knowledge and experience of charity fundraising and finance practices, including developing financial policies, risk management and investment strategies
Your responsibilities as a trustee.

Being a charity trustee is an important leadership role that has specific responsibilities and legal duties. Our trustees have overall responsibility for the charity but they do not run it on a day-to-day basis - this is done by our staff and volunteers. The board of trustees collectively make decisions about the approach and direction the charity will take and makes sure the charity complies with all legal obligations.

The Charity Commission describes the role as follows:

"Trustees have overall control of a charity and are responsible for making sure it is doing what it was set up to do. They may be known by other titles, such as: directors; board members; governors; committee members. Whatever they are called, trustees are the people who lead the charity and decide how it is run."

A trustee must:

- Be committed to the charity's mission and to achieving the purpose that we were set up for
- Give the time and commitment needed to carry out their role well
- Act with integrity and honesty; be an ambassador for the charity
- Think carefully about where APF is going as a charity and how we can deliver our purposes effectively in the short and long term
- Think for themselves, probe facts and challenge assumptions and contribute to decisions that trustees as a group can show are good for the charity
- Be willing to be creative and to think beyond how we do things today
- Be willing to speak their mind in a way that is polite and respects others that have different ideas and opinions
- Work well as a team with the rest of the trustees and our staff team, including when we have different views on how to do things
- Understand that as a trustee you can be liable for a loss to the charity if you don’t act properly or abuse the role you have within the charity.
Your commitment as a trustee.

- Attend trustee meetings every quarter normally on a Saturday morning (10.00-14.00) in person (Peterborough) or via Zoom.
- Prepare for and attend quarterly finance and risk committee meetings (via online video calls)
- Read the meeting agendas and papers, which are typically emailed to each trustee a week before, and prepare thoroughly for the meetings
- Once a year attend a trustee awayday where we think about our future plans and take part in training. This is usually mid week in the Spring (but this is flexible).

Our commitment to you.

- If you haven’t been a trustee before we can provide extra training and/or ask another trustee to be a ‘buddy’ to talk through trustee papers, answers questions you have and provide support
- Our experienced staff team is always on hand to offer support and information
- Being a trustee is a voluntary role but the charity will pay for out-of-pocket expenses, for example for travel to trustee meetings or childcare costs so you can attend meetings
- We can offer you other volunteering opportunities with the charity in-between trustee meetings, although this is not a requirement. For example, you can attend support group meetings (most are currently virtual); share ideas for fundraising and help to organise events as part of our fundraising committee or help keep our finances up to date by assisting our finance and risk committee.
Action for Pulmonary Fibrosis
Five-year Strategic Plan (summary)

What will make the biggest difference to people’s lives?

1. Better treatments and a cure – faster
Families tell us that it’s too late for them now, but they want better treatments and a cure so that families in the future don’t have to go through what they have.

By 2024, APF will progress its support of research in the following areas:
✓ More researchers will collaborate and share their breakthroughs
✓ More people with PF will have the opportunity to participate in research than ever before
✓ Increased funding of research on IPF making APF the leading funder in Europe
✓ New technologies improving the diagnosis and treatment of PF

2. Faster and more accurate diagnosis and care
A third of patients told us it took six months or more to get a diagnosis. Patients and their families really value the help of nurses, physiotherapists and other healthcare professionals but getting access to help is sometimes hard and they don’t always understand PF or IPF.

By 2024, APF will progress the education of healthcare professionals in the following areas:
✓ Greater awareness and training to help accurate and timely diagnosis amongst healthcare professionals (especially GP’s and Nurses)
✓ Greater access to tailored pulmonary rehabilitation
✓ Improve timely access to palliative care services

3. Families who are better informed and supported to live well with pulmonary fibrosis
Being diagnosed with pulmonary fibrosis is frightening and confusing. Families need information that is easy to access, understand and tailored to them at every stage in their journey. Support from others going through the same thing at the same time is invaluable and helps practically and emotionally.

By 2024, APF will progress providing support and information so that there is:
✓ More tailored information from APF online, via email and phone
✓ Easier access to help and support; locally and remotely
✓ More support for carers and family members
4. Quality public services and a nation more aware of pulmonary fibrosis
Some changes to public services will take longer than the five years of this strategy to achieve. APF is committed to ensuring patients’ views and experiences influence the nature and quality of public services that are needed to live well. Families tell us how low awareness of the disease affects not just their diagnosis, but also how they are treated. Talking to their own friends and families can be hard. Raising awareness of PF can bring about positive changes, locally and nationally.

By 2024, APF will progress campaigning and raising awareness so that:
✓ More people will be aware of PF, the symptoms and how to better support someone with the disease
✓ There is greater access to a wider variety of treatments
✓ There is greater equality of healthcare
✓ PF will be recognised as a disease equal in seriousness to many cancers

5. APF - Here for as long as it takes; sustainable and well run
As the numbers of people living with PF are expected to grow and families tell us about their long road to diagnosis, their battle for care and their hope that one day there will be a cure, APF must invest for the future.

By 2024, APF will continue to develop and invest so that:
✓ We continue to focus on efficiency and effectiveness; investing in systems and processes to improve our capacity
✓ We have a greater knowledge of our impact and the difference we make to people’s lives everyday
✓ We look after our fundraisers so that we can make a greater difference to more people
✓ We grow our dedicated staff and volunteer team who are focussed on impact and rooted in APF’s values
How to apply to become an APF trustee.

We are an equal opportunities employer and all applicants will be considered without consideration of ethnicity or heritage, age, gender, sex, gender identity, sexual orientation or disability.

The closing date for applications is midnight on Monday 11th March 2024. Applications received after that date will not be considered.

Send your completed application or video to recruitment@actionpf.org with TRUSTEE in the subject line.

You can apply in writing or by submitting a short video. Both formats require answering the following questions:

1. Brief biography, including your connection to pulmonary fibrosis.
2. Why would you like to join APF as a trustee?
3. What do you hope to bring to APF as a board member (please relate to the criteria set out on page 5)?
4. What would you like to get from being a trustee at APF?
5. Do you have any questions for us?

Include your contact details, including full name, home address, contact number and email address (for the video, please send contact details by email).

You are welcome to explore more about the role by having a confidential chat with Mike (Chair) or Louise (CEO). Email recruitment@actionpf.org to set this up.

Applications will only be considered if they meet the requirements below:

- Written applications must be no longer than 2 sides of A4, font size 12.
- Videos must be no more than 5 minutes in length.

We will acknowledge receipt of your application and those candidates who are shortlisted and offered Zoom/Teams interviews will be contacted by telephone during the week beginning 18th March 2024.

We will also contact non-shortlisted candidates by email.

To help with your application you may want to look at the following links.

- [www.actionpf.org](http://www.actionpf.org)
- [www.actionpf.org/about/people](http://www.actionpf.org/about/people)
- [www.actionpf.org/about/annual-reports](http://www.actionpf.org/about/annual-reports)
- [The essential trustee: what you need to know, what you need to do (CC3) - GOV.UK (www.gov.uk)](http://www.gov.uk)
- [https://www.gov.uk/guidance/charity-trustee-disqualification](https://www.gov.uk/guidance/charity-trustee-disqualification)