

ACTION FOR PULMONARY FIBROSIS

Trustee Recruitment Pack 2021



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<https://www.actionpf.org/privacy> England and Wales Charity Registration Number: 1152399
Scotland Charity Registration Number: SC050992*

Our purpose.

Our vision: *to find a cure for pulmonary fibrosis and for everyone affected by the disease to have a better future.*

Our mission: *to 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.

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.

APF Trustee Recruitment Pack.

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Welcome from our Chair of Trustees.

Hello.

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

I'm Steve Jones, chair of trustees for APF. I was diagnosed with pulmonary fibrosis in 2008 and lived with the disease for eight years before receiving a single lung transplant in 2016.



APF 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 a 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; patients; 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 up to four 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
- from Black and/or Asian communities
- with professional healthcare experience (in any setting)
- with a background in (charity) finance and an ability to interpret accounts for long term decision making
- with experience of using health and care services to have a better quality of life
- of all ages over 18 to reflect the impact PF has on the whole family group

Becoming a volunteer charity trustee can be 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.

Steve Jones

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 find a cure for pulmonary fibrosis so that everyone affected by the disease has 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 6,000 people die from IPF every year in the UK. The disease has a devastating impact on everyday life and many patients and families feel marginalised and alone.

- We provide personalised support to patients and families through our telephone support line, volunteer befrienders and one-to-one contact with our staff support team
- We help to set up and give on-going support to PF support groups across the UK. There are currently 68 active groups and growing. Many now meet via Zoom
- We fund ground-breaking research to improve quality of life for people living with pulmonary fibrosis and, one day, to find a cure
- We give patients a voice by raising awareness of this little-known disease through campaigning & lobbying, fundraising and education

What we are looking for in new trustees.

We will be welcoming up to four new trustees to our board in February, 2022. 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 currently looking for new trustees who have skills or experience in one or more of the following areas:

- Achieving social change or overcoming personal challenges as we need ambassadors and mentors who can show our service users and supporters that this is possible
- Experience of supporting patients through the healthcare system
- Experience of campaigning or lobbying on an important issue to help us change the root causes of the problems our service users face
- Planning digital projects to help us improve access to our services digitally
- Setting up a start-up company or advising someone else who has done this because we want to explore creating a new trading arm to raise money for the charity.

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 a very 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.

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 on a Saturday morning (10.00-13.00) via Zoom. If we choose to meet in person in the future, meetings will be held at our offices in Peterborough
- 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 on a Saturday in May (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

APF Strategic Plan (continued)

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

COVID-19

The past 18 months have had a devastating impact on the lives of people living with pulmonary fibrosis. We are yet to fully understand the extent to which people will experience delays to timely and specialised healthcare, but we plan to find out more by working with others. We need to adapt or prioritise as the impact becomes clear.

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, November 29th, 2021**. 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 Steve (Chair) steve@actionpf.org or Louise (CEO) louise@actionpf.org

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 interviews will be contacted by telephone during the week beginning December 6th, 2021.

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