



Action for  
Pulmonary  
Fibrosis

# Trustee

(Lived Experience of Pulmonary Fibrosis)

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

[actionpf.org](https://actionpf.org)

## Job description

<b>Job title:</b>	<b>Trustee (Lived Experience of Pulmonary Fibrosis)</b>
<b>Location:</b>	<b>Hybrid</b> – Board meetings are held four times a year – two in person (normally at APF offices in Peterborough or a similar central venue) and two remotely (video conference). Board meetings are held on a Saturday from 10am – 3pm.
<b>Hours:</b>	<ul style="list-style-type: none"><li>• Four scheduled Board meetings per year</li><li>• Preparation time to read papers in advance</li><li>• Occasional participation in sub-committees or short advisory discussions</li><li>• Total time commitment is generally a few hours per month, with slightly more around meeting periods.</li></ul>
<b>Reports to:</b>	<b>Chair of the Board of Trustees</b>
<b>Term of Appointment:</b>	Three years, renewable for a further three-year term.
<b>Remuneration and Expenses:</b>	This is a voluntary, unpaid role. APF will reimburse reasonable out-of-pocket expenses (such as travel or caring costs) needed to fulfil trustee duties.

## Purpose of Role

Trustees provide strategic leadership and governance for Action for Pulmonary Fibrosis (APF). As a Trustee with lived experience of pulmonary fibrosis, whether as a patient, carer, family member or someone closely affected, you will help ensure that the PF community remains at the centre of APF's decision-making, priorities and culture.

Alongside other Trustees, you will share collective responsibility for:

- Setting APF's long-term direction
- Overseeing its performance and impact
- Ensuring financial stability and responsible use of charitable funds
- Upholding APF's values, independence and reputation
- Ensuring legal and regulatory compliance

You will bring insight grounded in lived experience to ensure APF's services, strategy, information, research priorities and campaigning remain authentic and relevant.



## About Action for Pulmonary Fibrosis

APF is the UK's leading patient charity for people affected by pulmonary fibrosis. We fund research, campaign for improved care, and provide crucial support and information. Our ambition is bold, our focus is clear, and our work is driven by people living with the condition.

## Key responsibilities

### Core Trustee Duties

- Ensuring APF pursues its charitable objects
- Helping develop and approve APF's long-term strategy
- Ensuring compliance with the constitution, charity law and relevant regulation
- Ensuring APF's resources are used solely to further its charitable purposes
- Protecting APF's assets and ensuring sound financial management
- Safeguarding APF's good name, values and reputation
- Ensuring effective governance, policies and risk management
- Overseeing the appointment, support and appraisal of the Chief Executive
- Reviewing Board papers, contributing to debate and applying specialist insight

### Lived Experience Contribution

In addition, the Lived Experience Trustee will:

- Provide insight grounded in PF lived experience to shape strategic decisions
- Highlight unmet needs, barriers to access and priorities for the PF community
- Support APF to embed patient and carer voice across programmes and governance
- Advise on accessibility, equity, inclusion and support for under-represented groups
- Offer perspective to ensure services, campaigns and communications are relevant and person-centred
- Act as an ambassador within the PF community where appropriate

### Desired Additional Skills

Where possible the Board of Trustees is also looking for individuals with experience of:

- HR and volunteer management and organisational culture and leadership
- Fundraising and supporter engagement, contributing insight to the Board's understanding of charitable income development



## Person Specification

### Essential experience and knowledge

- Personal lived experience of pulmonary fibrosis (as a patient, carer, family member or close supporter)
- Commitment to APF's mission and values
- Willingness to devote time and attention to Board work
- Good, independent judgement
- Ability to contribute thoughtfully to strategic discussions
- Confidence to ask questions and challenge constructively
- Ability to work collaboratively and respectfully within a group
- Willingness to learn about trusteeship (training provided)

### Desirable

- Experience in HR, volunteer management or people leadership
- Experience in fundraising, supporter engagement or community development
- Experience in advisory panels, boards or lived experience groups
- Awareness of health inequalities and accessibility issues

### Equality, Diversity and Inclusion

At Action for Pulmonary Fibrosis, we are committed to promoting equity and inclusion. Pulmonary fibrosis does not discriminate, and neither do we. We believe that our team should reflect the diverse communities we serve. We warmly welcome applications from all candidates, irrespective of age, disability, race, sex, pregnancy or maternity, gender reassignment, sexual orientation, religion or belief, or marital or civil partnership status.

### Nolan Principles

Trustees must uphold the principles of:

Selflessness, Integrity, Objectivity, Accountability, Openness, Honesty, Leadership

Registered office:

Action for Pulmonary Fibrosis, Stuart House,  
East Wing, St John's Street, Peterborough PE1 5DD

### Eligibility and Fit and Proper Person Requirement

Trustees must:

- Be at least 16 years old
- Not be disqualified from acting as a trustee
- Not have unspent convictions relating to dishonesty or financial misconduct
- Not be bankrupt or subject to insolvency restrictions
- Be willing to sign APF's Fit and Proper Person Declaration, confirming they:
  - Have not been removed from a charity or position of authority
  - Have not engaged in tax fraud or misuse of charitable funds
- Will ensure APF's funds are used only for charitable purposes
- Will uphold the standards expected of charity trustees

### Support, Training and Expenses

- Full induction on APF's governance, work and finances
- Ongoing training (e.g. charity law, safeguarding, financial oversight)
- All reasonable expenses reimbursed

