

Become a Trustee

Information pack 2025

Uniting for a life *unlimited*



Hello!

Welcome from Richard Hunt CBE, Chair of Trustees

Cystic Fibrosis Trust is uniting for a life unlimited for everyone affected by cystic fibrosis. Our mission is to create a world where being born with CF no longer means a lifelong burden of care and an early death, and where everyone living with the condition can look forward to a long, healthy life.

The last few years have been ones of challenge and change across the cystic fibrosis community. Scientific and clinical breakthroughs now offer the promise of longer and healthier lives for many, however, we know that there is so much more to do to truly deliver our vision of a life unlimited.

At this critical time, due to normal rotational retirements, we are looking for more people with the right commitment, talent and skills to join our Trustee team.

As a Board member you will be instrumental in helping make change happen and ensuring we remain relevant to everyone affected by cystic fibrosis.

We have a number of vacancies and are particularly interested in those who can offer professional skills and experience in:

- finance and accountancy
- legal practice
- fundraising and income generation
- marketing and communications
- data and digital strategies
- basic science research

We welcome applications from all and are hoping to increase the representation of people with lived experience of cystic fibrosis or those in non-clinical support of people with CF .

Whatever experience you may offer we are looking, above all, for new trustee colleagues with a passion to make a difference for people with cystic fibrosis. If you are interested in this role, please do get in touch.

A word from David Ramsden, Chief Executive

Cystic Fibrosis Trust is at the heart of a community on an extraordinary journey to transform the lives and prospects of people with cystic fibrosis.

Advances in science and understanding have put us in an unprecedented position. People are living longer and healthier lives, and we are closer than ever to ensuring that this becomes a reality for everyone living with cystic fibrosis.

As a Trustee, you will ensure the Trust continues to be an energetic and forward-thinking organisation by overseeing our strategic direction and making sure we deliver results that put people with CF at the very centre of everything we do.



About CF and Cystic Fibrosis Trust

What is cystic fibrosis?

Cystic fibrosis is a life-limiting, genetic condition that slowly destroys the lungs and digestive system. It impacts physical and mental health and has no cure, and someone in the UK dies every week from the condition.

There are over 11,000 people living with CF in the UK. You are born with CF and cannot catch it later in life, and more than two million of us carry the gene that causes CF, usually without knowing.

Cystic fibrosis affects everyone differently, but for many it involves a rigorous daily treatment regime including physiotherapy, oral, nebulised and occasionally intravenous antibiotics, and taking enzyme tablets with food. Some people with CF will have a feeding tube overnight.

While babies born with the condition today are expected to live much longer than they were years ago, people with CF are still dying decades too soon.

Who is Cystic Fibrosis Trust?

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out and support each other as we race towards effective treatments for all. We invest in cutting-edge research, drive up standards of clinical care at specialist CF centres and clinics across the UK, provide trusted information, advice and support to those affected, and campaign hard on the issues that matter.

For more information about all our work, the challenges and progress we have made and our future direction, please visit our website: cysticfibrosis.org.uk



1 in 25

of us in the UK carries the faulty gene that causes cystic fibrosis

4 people are diagnosed with the condition each week in the UK



11,000

people are living with CF in the UK

The Trustee role

As part of the Board of Trustees, your role will be to oversee the overall governance and strategic direction of the charity, developing the organisation's aims, objectives and goals in accordance with the governing document and legal and regulatory guidelines.

Statutory duties

Trustees are required:

- to ensure that Cystic Fibrosis Trust complies with its governing document, charity law, company law and any other relevant legislation or regulations
- to ensure that the Trust pursues its objectives as defined in its governing document
- to contribute actively to the Board of Trustees' role of giving strategic direction to the organisation, setting overall policy, defining goals, setting targets and evaluating performance against agreed targets
- to ensure that the organisation uses its resources exclusively in pursuance of its objectives. The organisation must not spend money on activities that are not included within its own objectives, no matter how worthwhile or charitable those activities may be
- to safeguard the good name and values of the Trust and ensure it is inclusive in all its operations
- to ensure the effective and efficient administration of the organisation
- to ensure the Trust remains financially stable
- to follow the Governance Manual and current best practice on being a Trustee at all times

In addition to the above duties, Trustees should:

- be an ambassador and advocate for the Trust
- be willing and able to use any specific knowledge or experience they may have to help the Board of Trustees reach sound decisions. This will involve scrutinising board papers, leading discussions, focusing on key issues and providing advice and guidance requested by the board or the Chief Executive in areas where the Trustee might add value and insight to deliberations
- be an active member of the Trustee body in exercising its responsibilities and functions and attend meetings faithfully
- maintain good relations with the staff team

Time commitment

Up to one day a month on average, comprised of preparation for and attending:

- Four board meetings a year (either in person or remotely) and Away Days
- Sit on at least one sub committee and attend one quarterly sub committee meeting in person or remotely
- Attend Trust related events and activities
- Sit on appraisal, recruitment and disciplinary panels as required

Remuneration

This role is voluntary and unpaid. Travel expenses as well as other out of pocket expenses directly incurred as part of official trustee duties will be reimbursed.

"Being a Trustee is deeply rewarding. I have been able to add my unique perspective and experience to tackle important issues and make impactful decisions for the benefit of this dynamic and diverse community."

Maya Desai



"Being a Trustee allows me the opportunity to contribute to an important community with whom I share many experiences. It's also inspiring to work with such a dedicated team."

Michelle Shore



Person specification

The Trust is committed to making a difference for all people with CF, and for all Trustee positions we're looking for people who have:

- a genuine interest in the vision and purpose of the charity, with a commitment to people living with CF and an interest in extending their own knowledge of CF
- a willingness to devote time and effort
- strategic vision
- good, independent judgement
- a commitment to equality, diversity and inclusion
- an ability to champion the Trust and the needs of people living with CF to a range of external stakeholders, including influencing behaviour and gaining their support
- an understanding and acceptance of legal duties, responsibilities and liabilities of Trusteeship
- an ability to work effectively as a member of a team while contributing their own viewpoint
- a commitment to Nolan's seven principles of public life: selflessness, integrity, objectivity, accountability, openness, honesty and leadership

The cystic fibrosis community includes people from all backgrounds and ages, and we are keen ensure that diversity is reflected on our Board. We welcome and are particularly interested in hearing from those with lived experience of CF, disabled people, Black, Asian and minority ethnic and LGBTQI candidates. We would also encourage interested parties not to be put off from applying because of their age.

As stated in the foreword from our Chair, we would also like to hear from you if you have any experience of:

- finance and accountancy
- legal practice
- fundraising and income generation
- marketing and communications
- data and digital strategies
- basic science research
- non-clinical CF professions, such as psychology or social worker

As part of our long-term succession planning, we would also welcome interest from candidates who may be open to taking on additional Board leadership responsibilities in the future, such as Chair, treasurer, or committee roles.



How to apply

Please prepare:

- a **CV** outlining your career history, including responsibilities and achievements.
- a **cover letter** (max two A4 pages) explaining why you want to be a Trustee, what skills you can bring to the Board of Trustees and what you want to take away from this opportunity.

Then [submit your application on Hireful](#), our applicant tracking system.

Important dates

The closing date for completed applications is **Wednesday 20 August 2025**

First interviews are scheduled for week commencing **8 September 2025**

Second interviews are scheduled for week commencing **15 September 2025**

Further information

If you have any queries about the role or would like any further information, please email our Recruitment team at recruitment@cysticfibrosis.org.uk

To learn more about the work of the Trust and its involvement in the CF community, please visit our website and social media channels.

cysticfibrosis.org.uk

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