

Vacancy: CHIEF EXECUTIVE

PCD Support UK – Specialist Clinical, Scientific and Patient Advocacy Role

Job Title

Chief Executive Officer (CEO)

Reports to

Board of Trustees, with line management by the Chair

Location

Remote, with national and international travel

Salary

£ competitive

Hours

0.6 FTE, with occasional weekend and evenings required, and several conferences per year which may require travel and/or overnight stays

Contract length

Initial one-year contract, with strong expectation of renewal as the organization continues to develop and secure funding streams

Start date

As soon as possible

How to apply

Please submit a CV to the Chair of the Board of Trustees before 5pm on 4 May 2026:

chair@pcdsupport.org.uk

This is a rare opportunity to become the first Chief Executive of a respected, specialist charity at a pivotal moment in its development. With new governance arrangements in place and a clear ambition to grow its impact, PCD Support UK is seeking a leader who can translate clinical insight and patient need into sustainable, high-quality support and advocacy.

The successful applicant will be passionate about the charity's work and will bring with them a strong track record of leadership in a relevant setting. They must be an outstanding communicator, very adaptable and able to enthuse patients, families, medical professionals and funders about the values and goals of PCD Support UK. We are looking for someone with a clear

vision as to how the charity can level up in the future and with the commitment and drive to carry this out.

The charity aims to be a progressive, supportive employer and to create a healthy, balanced working environment for its first Chief Executive. This includes offering family-friendly flexible working arrangements, encouraging remote or hybrid working where practical, and supporting reasonable adjustments to help the postholder thrive. The organization is committed to fair pay, transparent decision-making, and ensuring the Chief Executive has access to appropriate professional development, supervision, and wellbeing support. As a small, values-driven charity, we will work with the postholder to shape an open, respectful, and compassionate workplace culture.

About PCD Support UK

We are here for those affected by PCD. We talk about PCD as widely as possible and we champion research to improve its diagnosis, management and treatment.

We do this by:

- Providing a source of information about PCD, its research and its treatments through our website and social media
- Connecting our UK based PCD community via online forums, social media and live events
- Helping people in the UK access specialist PCD services
- Working alongside researchers, doctors and other organisations to encourage the future direction of PCD research and treatments
- Putting people affected by PCD in touch with other organisations who might be of help
- Providing small grants for specific needs (such as equipment) to individuals and families affected by PCD
- Raising awareness of PCD in the medical community, so that more healthcare professionals are aware of this condition

1. Role Purpose

The Chief Executive Officer is responsible for the operational leadership, sustainability, and delivery of the PCD Support UK's mission. The CEO serves as the charity's senior (and, for now, only) employee and principal operational leader, implementing trustee-approved strategy while maintaining a clear separation between governance (trustees) and management (CEO).

This role requires the postholder to have or develop highly specialised knowledge of Primary Ciliary Dyskinesia, and they must be able to translate complex scientific and medical knowledge into accessible information for the patient community. This role provides a pivotal function between the clinical and patient community, ensuring that the charity's mission to improve outcomes relating to PCD is achieved. The CEO will take a lead in developing the charity's strategy with trustees, motivating and inspiring volunteers and any paid staff, to maintain and develop PCD Support UK's reputation and performance. They will be the primary lead, working closely with trustees and volunteers, for ensuring the charity delivers high-quality patient support, engages effectively with medical and scientific stakeholders, and secures funding and charitable donations ensuring the charity's continued sustainability.

2. Governance and Accountability

The CEO is accountable to the Board of Trustees, which retains ultimate legal responsibility for governance, strategy, and regulatory compliance.

The CEO has delegated authority to manage the charity's day-to-day operations within trustee-approved strategic and financial parameters.

The CEO is not a trustee and does not exercise trustee governance functions.

3. Key Responsibilities

A. Strategic Implementation and Organisational Leadership

- Implement the strategic direction set by trustees
- Develop operational plans aligned with trustee-approved strategy
- Advise trustees on emerging risks, opportunities, and developments
- Support trustees in fulfilling their legal and governance responsibilities

B. Specialist Clinical and Scientific Engagement

- Engage with clinicians, researchers, and the scientific community
- Maintain expert knowledge of developments relating to the condition
- Review and contribute to relevant research activity where appropriate
- Translate complex scientific and medical information into accessible formats for patients and families
- Represent the charity within clinical and scientific networks both nationally and internationally

C. Patient Advocacy and Support

- Provide specialist support and advocacy to patients and families
- Assist patients in accessing services, including support with disability benefit applications where appropriate
- Advocate on behalf of patients with healthcare providers, schools, and statutory services where necessary
- Ensure patient support services reflect best practice and clinical understanding

D. Income Generation and Financial Sustainability

- Identify and pursue funding opportunities, including grant applications
- Develop relationships with funders, donors, and partners
- Support trustees in ensuring financial sustainability
- Operate within trustee-approved budgets and financial controls

E. Communications and Stakeholder Engagement

- Act as principal operational representative of the charity
- Manage charity communications, including website, social media, publications, and outreach
- Organise and oversee charity events
- Maintain relationships with the patient community and key stakeholders

F. Operational Management

- Manage day-to-day operations of the charity
- Ensure effective administrative systems
- Ensure compliance with policies approved by trustees
- Manage staff and volunteers (if applicable)

G. Risk and Compliance Support

- Identify operational risks and bring these to trustee attention
- Support trustees in maintaining regulatory compliance
- Ensure operational compliance with safeguarding and data protection

4. Governance Boundaries (Reserved Matters)

Unless otherwise stated by the Charity's constitution or given authority via appropriate governance mechanisms, the CEO does not have authority to do the following (as these responsibilities remain exclusively with Trustees):

- Amend the charity constitution
- Appoint or remove trustees
- Approve strategy independently
- Approve budgets independently
- Override trustee decisions
- Act as a trustee

Our commitment

PCD Support UK is committed to supporting people affected by PCD and expects all staff and volunteers to share this commitment. PCD Support UK is committed to equal opportunities and to treating all of our candidates and jobseekers fairly. We welcome and encourage applications from everyone.

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pay, transparent decision-making, and ensuring the Chief Executive has access to appropriate professional development, supervision, and wellbeing support. As a small, values-driven charity, we will work with the postholder to shape an open, respectful, and compassionate workplace culture.

For more details on our policies including data protection and how we store and use your data, please don't hesitate to be in touch.

5. Person Specification

Essential

- Significant knowledge of Primary Ciliary Dyskinesia or similar complex medical condition
- Ability to interpret scientific and medical research for patient benefit
- Ability to communicate complex medical information clearly
- Experience engaging with healthcare professionals and developing lasting relationships
- Strong organisational and leadership skills
- Experience working in health charity, health research or related sector
- Excellent written and verbal communication skills
- Experience supporting patients with benefits or advocacy

Desirable

- Experience in grant writing and fundraising
- Experience working in rare disease or specialist healthcare settings
- Experience with website and social media management
- Experience working with underserved communities
- Social research experience and experience of survey design