

Annual Accounts 2024



Trustees' Report and Accounts for the Year Ended 31 December 2024

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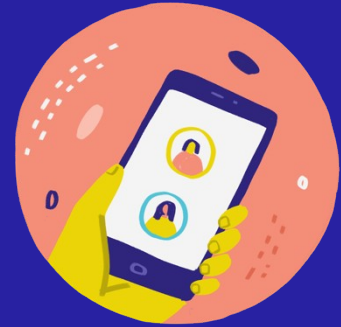
CHARITY INFORMATION

Charity name: Primary Ciliary Dyskinesia Support UK

Charity working name: PCD Support UK

Trustees:

Katie Dexter (Chair)
Abdullah Ihsan (Treasurer)
Myra Tipping
Michelle Forsythe
Katie Vance
Gerry Paul Rowe-Ham
Natasha Mary Bellwood



Principal Address:

PCD Support UK
3 Laggan Road,
Maidenhead,
Berkshire
SL6 7JY



Charity Number: 1207340

Bankers:

Barclays Bank PLC
93/95 Main Street
Garforth
Leeds



1. STRUCTURE, GOVERNANCE AND MANAGEMENT

Appointment of Trustees

Trustees are selected from members attending the annual general meeting or volunteering direct to the committee. They are appointed by the committee at management committee meetings.

Governing Document

PCD Support UK is constituted by a governing document dated March 1994 and revised 23 Jan 2021 and is a registered charity.

Objectives And Activities

The charity was formed to provide support to patients with PCD and families and carers of children known or suspected to have the condition. PCD Support UK's objectives are:

1. The relief of persons affected by primary ciliary dyskinesia and allied conditions.
2. To support medical research into the cause, cure, prevention or relief of such conditions provided that the useful results of the research shall be published.

The trustees have had regard to the Charity Commission's guidance of public benefit. The main activities undertaken to further the charity's purposes for the public benefit are:

1. Provide support to patients and their carers who have, or are suspected of having, PCD
2. Bring PCD to the attention of medics and provide an up-to-date information service for them and the general public.
3. To promote research to aid diagnosis and treatment of patients with PCD.
4. Support the NHS and other bodies to ensure patients have access to diagnostic services and on-going care.
5. Fundraise to support the above activities

2. ACHIEVEMENTS AND PERFORMANCE

Strategic Objective 1: Provide support to patients and their carers who have, or are suspected of having, PCD

- We continue to support people affected by PCD in the form of emails and contact through our website and social media channels, through arranging phone calls on a regular basis and ad hoc grants.
- We are active on Facebook (with 1.85 k followers, increasing from 1.8k in 2023), Instagram (with 1152 followers, increasing from 911 in 2023), Twitter (1100 followers, reducing from 1120 in 2023) and TikTok (with 100 followers and 200 likes, Increasing from 76 In 2023)
- PCD Connect is a private UK PCD community forum on Facebook and has 228 members (up from 215 in 2023). PCD Connect allows those with PCD in the UK to connect with one another in a safe and friendly setting.
- We revamped our LinkedIn, which now has 179 followers and we have 215 YouTube subscribers at the time of writing
- We held our AGM online again in 2024, which was well attended by families and people with PCD.
- We held another family day in October 2024. This was held at Chessington with over 100 people attended the event in-person.
- We rebranded our newsletter, changed our newsletter provider and revised our GDPR policy as part of our due diligence.
- We have supported several people with letters to their GP to advocate for better access to prescriptions and sputum testing.
- We have paid for 10 people with PCD to access support with applying for benefits such as Personal Independence Payment, by connecting them with a third-party provider and reimbursing their fee.
- We have purchased sensory toys for children with PCD who have additional needs, such as learning disabilities. We have also purchased exercise equipment, such as trampolines for children with PCD.

- We continue to run our monthly online public talks called 'PCD Live!', in which we invite specialists in PCD (from a variety of clinical and research domains) to give a talk, followed by a Q&A. This has been well attended, with around 20-60 households joining each talk. We record these talks and put them on our website and YouTube channel to promote further public reach.
- We have paid for the transport and overnight accommodation costs of families in remote locations such as Cornwall, rural Scotland and rural Wales attending appointments at specialist PCD centres.
- We held an online PCD Family Camp with an external provider called Over the Wall, which saw several young people and families with PCD meet each other for a day of games and interaction in a safe and virtual environment.



Strategic Objective 2: Bring PCD to the attention of medics who may come across PCD and continue to provide an up-to-date information service for them and the public

- We continue to develop our website in order to provide an up-to-date information service about PCD. We have re-written several sections of the website and are working on improving its accessibility. We have rebuilt the website and made changes to our online form, to make it easier for people to get in touch with us.
- Our Medical Board meeting was held in May. We had over 120 attendees from across the UK, including healthcare professionals from a wide range of disciplines. In addition to hosting a series of short talks and poster sessions specifically for healthcare professionals, we hired a graphic recording artist to capture the day's events, to provide an accessible summary of the discussions for the public.
- We are active on social media on a daily basis and share information that is relevant to both the public and to healthcare professionals.
- In October 2024, we took part in PCD awareness month, joining a global community of PCD-related patient advocacy groups to deliver a month of daily online content related to PCD, with the aim of accelerating awareness of PCD.
- We have spoken to Genomics and Genetics students at Cardiff University, Health Policy students at Oxford University, and have spoken at the BEAT-PCD Annual research meeting, which was also live-streamed Internationally.
- We continue to advocate for a PCD services in Scotland & Wales and have been in regular contact with the lead clinicians who are developing the NHS bids, to understand its progress.
- We maintain partnerships and memberships with Genomics England, Ciliopathy Alliance UK, Genetic Alliance UK, NCVO, Rare Disease UK, European Lung Foundation, either directly through our trustees or wider network of volunteers.
- We maintain patient and public involvement roles on several boards, including the BEAT-PCD Clinical Trial Network Protocol Review Committee, BEAT-PCD CRC, ERN Lung PCD Core Group, ELF Patient Advisory Committee, Cambridge Rare Disease Network and Genetic Alliance UK meetings.

Strategic Objective 3: To promote research to aid diagnosis and treatment of patients with PCD

- Our trustees continue to provide patient participation support on a number of studies, including covering topics from Airway Clearance Techniques (ACTs), fertility, PCD-Engage, transition (Paediatrics to Adult services) and psychological studies.
- We continue to review and give comments on research proposals that impact the UK PCD community and to provide input to researchers who want to know more about patient priorities in PCD. We write and review lay summaries for research applications, which has recently included international, as well as domestic ones.
- Our regular PCD-Live talks feature new PCD-related research, which is promoted to both healthcare professionals and the public.
- We are co-applicants on a number of bids for funding for PCD related research projects both in the UK and internationally.
- We work with our European counterparts to promote research within and from the BEAT-PCD ERS clinical research collaboration.
- We attended the European Respiratory Society Conference in Vienna, where we presented on 'Patient Involvement in Research'. We also attended the ELF patient organisation networking day, allowing us to learn from other patient organisations internationally, and attended networking events throughout the duration of the conference.
- We spoke at the BEAT-PCD Annual Research Meeting held In Vienna, speaking to over 100 people in-person and many more joining online.
- We have supported several researchers this year to recruit patient participants and have disseminated these studies through our social media and public talks.
- We funded a paper to be presented at the ERS In Vienna.
- We co-funded a PhD post at the University College London. We also provided a grant to digitalise the Quality of Life questionnaire, making it available across all four specialist centres in England.
- We gave a grant to support the running of cilia 2024

Strategic Objective 4: Support the NHS and other bodies to ensure patients have access to diagnostic services and on-going care

- We have been working closely with the NHS Specialised Services commissioners and the four PCD specialist centres to input into the development of the diagnostic and management services.
- We contributed to the development of a new standards of care document for the management of PCD, as well as the review of current standards of care in paediatric physiotherapy and nursing in PCD.
- We attended the annual cross centre meeting of PCD centres in England.
- We have provided feedback and protocol support regarding the establishment of a new patient registry across the four specialist centres in England. We attend the PCD registry steering committee on a regular basis.
- We have provided insights into patient experience of the PCD services to the service providers as part of an ongoing constructive dialogue with clinicians.
- We have mediated between families and clinical teams to ensure that patients and families understand their diagnosis letters.
- We have put primary and secondary care clinicians in touch with PCD specialists in order to facilitate better diagnostic and management pathways for people with (or suspected of having) PCD who are not currently on them.

Strategic Objective 5: Fundraise to support the above activities

- We have a small number of regular donors, as well as ad hoc donations.
- We supply prospective fundraisers with PCD Support UK merchandise and publicity via our communications channels to contribute to their fundraising efforts.
- We have had several donations in lieu of birthday gifts and instead of sending Christmas cards.
- We had an amazing fundraising of over 26k from Cumnor house who chose us as the charity of year and fundraised throughout 2024 to raise money.
- We have also purchased card machines this year to allow us to collect donations more easily at in-person events
- We encourage our community to donate to us through our JustGiving page, which has seen an increase in donations, for which we are immensely grateful.
- Our website has been designed to emphasise means of donating to PCD Support UK and we now encourage donations and fundraising at the end of our public talks.



Charity Number: 1207340

3. FINANCIAL REVIEW

In the financial year of 2024 there was no trading within this charity as the charity is going through a transition period to a CIO