

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:

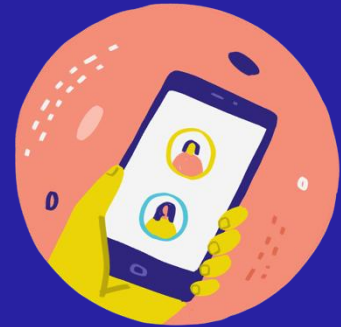
Katie Dexter (Chair)

Lucy Dixon (Vice-Chair) - Resigned 01/06/2024

Abdullah Ihsan (Treasurer)

Myra Tipping

Gary Tipping



Principal Address:

PCD Support UK

PO Box: 2233

Buckingham

MK18 9DX



Charity Number: 1049931

Bankers:

Barclays Bank PLC

93/95 Main Street

Garforth

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Independent Examiner:

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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

Case Study: A letter from one of our members



In the early years of my daughter's diagnosis, I was signposted towards PCD Support UK via The Royal Brompton Hospital. PCD Support UK are a fantastic charity and have been incredibly supportive towards myself, and my daughter and I will forever be grateful to them.

My daughter was diagnosed with PCD at 1.5 years old, however, during her diagnosis, I became a single parent and needed to go back to work. I struggled with holding down a job whilst caring for my daughter. Two previous employers had made me redundant for needing two weeks off work for my daughter's hospital admission, and I also needed time off myself due to struggling with my own mental health. Eventually, I decided to be my daughters full time carer, whilst studying for a degree at university.

PCD Support UK have previously bought my daughter a new trampoline so she can be encouraged to do her physio after her old one took off in the wind, I have had lengthy chats with Lucy multiple times on the phone when I have been at my wits end needing someone to talk to, and recently I was awarded a help with costs of living grant of £100 to help with costs of my gas and electric: this was honestly a weight off my shoulders. I have attended several online events which have been very helpful to be with other parents who understand what you are going through. Without this support and the funding available, I would be left struggling financially and I would be struggling emotionally.

PCD is still and will always be a huge part of myself and my daughter's life. Every day is a battle; however, I know that PCD Support UK are always one email away and will do anything they can to help support or provide for us as a family. I know first-hand when your child is diagnosed with PCD, it can feel very daunting, you feel alone, and lost, with so many questions going around your head, I remember it like it was yesterday, but always know that PCD Support UK will do their absolute best to help and support you.

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.



3. FINANCIAL REVIEW

The charity's reserves are retained for the purpose of funding future activities and projects as they arise. The trustees' general investment policy is to invest short-term surplus funds in assessable interest-bearing accounts, in order to maximise returns without risk.

Cash at bank at the end of **2024** stood at **£107,912** (2023: £82,486). The committee and members continued their fundraising efforts via several events this year. The income for the year totalled **£66,445** (2023: £20,511), including grants, donations and fundraising received totalling £65,994 (2023: £14,228). Investment income generated from interest totalled £451, an increase of 59% when compared to investment income generated in 2023. The increase in interest incomes reflects the increase in the interest rate offered on the account.

We have a commitment to fund our website on top of the normal expenditure incurred, which includes attending conferences, championing research, supporting patients and families, and delivering ongoing events and educational talks. We have increased our presence regionally and internationally and have had success in reaching out to PCD communities across the UK.

We are assured we have sufficient funds to continue the charity as a going concern for the foreseeable future. Our reserves policy is holding a minimum amount in reserve to fund one year's expenditure, which equates to approximately £15,000-£20,000 in a normal year. At the year-end these free reserves stood at £107,912

The trustees would like to express their thanks to all of the fundraisers who have contributed their efforts to the charity or donated funds during 2024. Special thanks go to: Cumnor House, Recode Therapeutics (John Matthews), CharterHouse School, Kate Rowe-Ham, Lucy Phipson, Sam Lee, Anna McEwan, Brian Clough, Jade Urch, NWI Ltd and many more.

This report was signed off by the committee on 31st October 2025



Abdullah Ihsan - Treasurer and Trustee

4. INDEPENDENT EXAMINERS STATEMENT

Independent examiner's report to the trustees of Primary Ciliary Dyskinesia Support UK

I report to the charity trustees on my examination of the accounts of Primary Ciliary Dyskinesia Support UK (the Charity) for the year ended 31 December 2024.

Responsibilities and basis of report

As the charity trustees of the Charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Charity's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

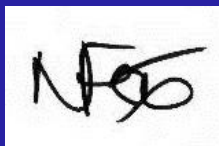
I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our independent examination work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our independent examination work, for this report, or for the opinions we have formed.



Nicola Fox FCA
Shaw Gibbs Limited
Eagle House
28 Billing Road
Northampton
Northamptonshire
NN1 5AJ

Date: 31/10/2025

5. ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2024

	2024	2023
Receipts And Payments Account: General Unrestricted Fund	£	£
Income Receipts		
Grants and Donations	65,994	14,228
Other Income	-	-
NHS funding for website services	-	6,000
Investment activities		
Interest receivable	451	283
Other Income	-	-
Total Receipts	66,445	20,511
Direct charitable expenditure		
AGM & Family Day	12,058	5,663
Regional Events	12,526	522
Marketing	2,372	4,392
Website costs	870	714
Conference costs	2,574	3,119
Research	727	22,231
Patient Grants	2,536	6,389
Total direct charitable expenditure	33,663	43,030
Support costs		
Printing, postage, and stationery	505	946
Travel expenses	3,864	3,859
Subscriptions	2,119	1,640
Sustenance	378	493
Independent examination fee	-	858
Fundraising services	216	446
Other	275	-
Total support costs	7,357	8,242
Total payments	41,020	51,272
Net increase/(decrease) in cash for the year	25,425	-30,762
Cash balances at 31 December brought forward	82,486	113,247
Cash balances at 31 December carried forward	107,912	82,486

6. STATEMENT OF ASSETS AND LIABILITIES AS AT 31 DECEMBER 2024

	2024	2023
	£	£
Monetary Assets (All General Fund)		
Cash at bank and in hand	107,912	82,486
Debtors		
Amounts due from NHS funding	6,000	-
Creditors		
Shaw Gibbs Limited IE fee	1,140	-