PCD RESEARCH

England & Wales · Charity number 1197528

Details

Status	Registered
Legal form	CIO
Registered	2022-01-17
Register	View on the Charity Commission register

Contact

Address	31A Berrymede Road London W4 5JE
Phone	07920572992
Email	info@pcdresearch.org
Website	www.PCDresearch.org

Activities

Objects: THE OBJECT OF THE CIO IS TO ADVANCE THE HEALTH OF CHILDREN AND ADULTS WITH PRIMARY CILIARY DYSKINESIA (PCD), INVOLVING INHERITED MOTILE OR NON-MOTILE CILIARY DYSFUNCTION. THE CIO WILL CARRY OUT THIS OBJECT FOR THE PUBLIC BENEFIT BY VARIOUS MEANS, INCLUDING: • FUNDING AND SUPPORTING PURE SCIENTIFIC AND APPLIED/TRANSLATIONAL RESEARCH TO UNDERSTAND INHERITED CILIARY DYSFUNCTION; • ADVOCATING FOR AN EFFECTIVE CARE REGIME AND THERAPIES FOR PCD; • PROVIDING PATIENT VOICE TO ENSURE THAT RESEARCH AND THERAPEUTICS REFLECT LIVED EXPERIENCES OF PEOPLE WITH PCD; AND • RAISING AWARENESS ABOUT INHERITED CILIOPATHIES. NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CIO FOR THE PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH SECTION 7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) ACT 2005 AND SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008

Activities: To advance the health of children and adults with Primary Ciliary Dyskinesia (PCD) by supporting research intoA) Understanding PCDB) Novel therapeutic targets and therapies for PCDC) Advocating for improved standard of care for people with PCD

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Defined Groups, The General Public/mankind

Geography

- Australia
- Denmark
- France
- Germany
- Greece
- Israel
- Italy
- Japan
- Norway
- Portugal
- Spain
- Switzerland
- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-01-01	£238,634	£19,254	-	-
2024-01-01	£40,802	£11,691	-	-
2023-01-01	£153,776	£2,468	-	-

Trustees

Name	Role	Appointed
Dr Harriet Holme	Chair	2022-01-01
Dr Gurhan Erturan		2022-01-01
Florence Barkats		2024-11-04
Monica Dawes		2023-11-24
Natalie Gehl		2022-01-01

PCD RESEARCH

England & Wales - Charity number 1197528

Accounts

PCD Research
PCDresearch.org

(A Charitable Incorporated Organisation
Regulated by the Charity Commission for England and Wales)

Registered Number
1197528

Annual Report and Accounts
Period ending
1st January 2025

Registered Address:
31A Berrymede Road, London, W4 5JE
info@PCDResearch.org

1. Overview

This document provides the annual report and accounts of PCD Research CIO ("PCD Research", or the "charity"). The trustees present their report and accounts for its second financial year, the period from 2nd January 2024 to the 1st January 2025.

1.1. Objectives and Principal Activities

The charity is registered and regulated by the Charity Commission for England and Wales. Its reference is 1197528.

The objectives of the charity are to advance the health of children and adults with Primary Ciliary Dyskinesia (PCD), involving inherited motile or non-motile ciliary dysfunction.

The charity will carry out this object for the public benefit by various means, including:

- funding and supporting pure scientific and applied/translational research to understand inherited ciliary dysfunction;
- advocating for an effective care regime and therapies for PCD;
- providing patient voice to ensure that research and therapeutics reflect lived experiences of people with PCD; and
- raising awareness about inherited ciliopathies.

1.2. Trustees and Governance

PCD Research does not have any staff at the moment. Instead, it is governed by its board of trustees, who are dedicating their time and efforts on a pro bono basis. PCD Research was set up as a Charitable Incorporated Organisation. Its constitutional document includes provisions relating to the appointment of trustees.

The following persons served as trustees during the period ending on 1st January 2025:

Dr Harriet Holme - Chair of the Trustees - Appointed on 17th January 2022
Dr Gurhan Erturan - Trustee - Appointed on 17th January 2022
Natalie Gehl – Trustee - Appointed on 17th January 2022
Michelle Levene - Trustee - Appointed on 24th April 2023
Harriet Nowell-Smith - Trustee - Appointed on 24th April 2023 resigned on 7th March 2024
Oliver Burgel - Trustee - Appointed on 24th April 2023 resigned 2nd December 2024
Monica Dawes – Trustee – Appointed 24th November 2023
Florence Barkats – Trustee – Appointed 4th November 2024

The trustees were approached and appointed with the aim of establishing a board with diverse professional experience at senior level, as well as direct patient experience and impact of PCD on family life. At present, the range of professional expertise covers clinical medicine, research (scientific, translational and medical), drug development strategy and development in advanced therapeutics, rare diseases and law. Two of the trustees are parents of a child with PCD.

The charity's key policy documents, such as Conflict of Interest Policy, Funding Policy, Animal Research Policy, Expense Policy and Research Strategy are available on request by contacting info@PCDResearch.org

2. Annual Report of the Trustees

PCD Research is a medical charity that was incorporated and registered with the Charity Commission for England and Wales on 17th January 2022. The aims of PCD Research are to advance the health of children and adults with Primary Ciliary Dyskinesia (PCD).

2.1. What is Primary Ciliary Dyskinesia

Primary ciliary dyskinesia is a genetic condition that affects approximately 1 in 7,500 people. Mutations in more than 50 genes have been found to cause PCD. This leads to a range of severity. PCD leads to permanent damage of the lungs and for people with the most severe disease, the damage happens decades earlier than those with milder disease. One in 20 people are carriers, with one affected copy of a gene that causes PCD.

Motile cilia are like microscopic hairs that beat in the airways and sinuses to clear out secretions and infections. In PCD, the cilia are abnormal and unable to move in the usual way, such that secretions and infections affect the lungs, sinuses, ears and nose. Cilia are also important for the propulsion of sperm and likely also both the fallopian tubes and endometrium leading to impaired transport of the oocyte and early embryo, so fertility is commonly affected as well. It is likely that PCD affects other pathways in the body in ways that are not yet understood.

2.2. Treatment and Outcome

PCD is a life altering and life shortening condition. Children with PCD have been found to have worse lung function than those with cystic fibrosis (CF)[1] but are unable to access the same standard of care in the UK. In the case of CF, there has been an active program of research that has led to breakthrough drugs (CFTR modulators) that are widely recognised to be very effective for CF. Sadly these drugs are not suitable for people with PCD.

There are no dedicated treatments for PCD. Instead, current treatments for PCD have been borrowed from experience with people with CF. People with PCD and their family members face a significant burden and daily challenges from living with the disease. Daily treatment includes several hours of chest physiotherapy to try to clear mucus from the lungs, using methods borrowed from a mechanistically distinct disease (CF) without evidence of efficacy in PCD. In addition, patients are subject to frequent courses of antibiotics to treat frequent episodes of pneumonia. Some people with PCD will still progress to end stage respiratory failure and need a lung transplant. People with loss of function of the genes *CCDC39* and *CCDC40* are now widely acknowledged to have a significantly poorer outcome[2]. The average length of survival post lung transplantation in people with PCD is 5.9 years[3].

While children and adults with PCD may appear healthy, PCD is a progressive disease, where lung function declines over time. At present there are no treatments that can stop or reduce this decline, nor restore cilia function. There are no NICE guidelines.

2.3. Achievements of PCD Research during 2024

The key achievements of the charity during its third year are:

[1]Rubbo, B. *et al.* Clinical features and management of children with primary ciliary dyskinesia in England. *Arch Dis Child* **105**, 724–729 (2020).

[2] Kinghorn B, McNamara S, Genatossio A, Sullivan E, Siegel M, Bauer I, et al. Comparison of Longitudinal Outcomes in Children with Primary Ciliary Dyskinesia and Cystic Fibrosis. Ann Am Thorac Soc. 2024 Oct 9.

[3] Marro M, *et al.* Lung Transplantation for Primary Ciliary Dyskinesia and Kartagener Syndrome: A Multicenter Study. Transpl Int. 2023 Feb 14;36:10819.

- First PCD Research (PCDR) funded research project commenced.
- Industry Accelerator Event: Getting Cilia Moving 1st October 2024.
- Co-hosted first global PCD patient advocacy event.
- PCDR is key partner of the new £10 million LifeArc Rare Respiratory Centre, with PCD as one of the three disease exemplars.
- PCDR Awareness Event
- Consolidated governance and recruited pro bono legal support.
- Fundraising activities.
- Raised awareness in the UK Parliament and continued engagement with relevent All Party Parliamentary Groups (APPG).
- Patient Survey
- Continued outreach

2.3.1. First PCDR Funded Research

In 2023, the inaugural meeting of the SAP was held virtually to peer-review the grant applications from the first PCD Research grant call. This was to fund a two-year post-doctorate in collaboration with the Nucleic Acid Therapeutic Accelerator (NATA). Professor Hart's project was chosen by the SAP, out of a total of three high quality applicants. The grant contracts between PCD Research and (1) NATA and (2) Univerity College London were signed in 2024. Pro bono support with regards contracting from Pinsent Masons made this possible. The pro bono team at Pinsent Masons were shortlisted for a prize for this work.

Figure 1 Prof Nick Lench (CEO NATA) and Dr Harriet Holme announcing the funding agreement

Figure 2 shows one of the long-term goals for PCDR - assist development of disease modifying treatments for people with PCD. This research project will prioritise steps 1-3.

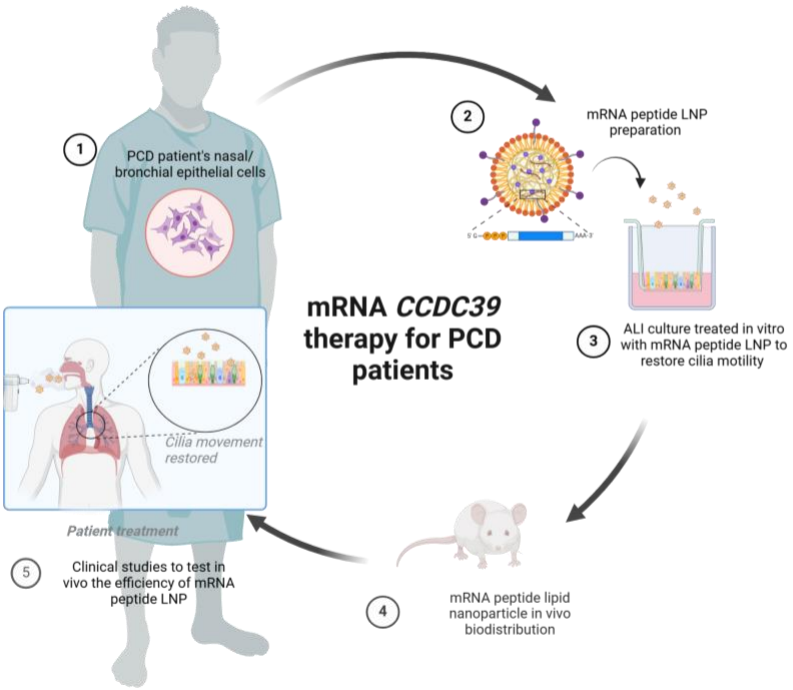

Figure 2 Aims of the PCD Research–funded research, illustrating prioritisation of Steps 1–3 as foundational components of the long-term goals.

The project will look to optimise lipid nanoparticle (LNP) technology encoding mRNA targeting loss of function of *CCDC39*, first in cellular models (air liquid interface culture - ALI culture). Successful LNP constructs will be taken forward to optimise nebulised delivery in healthy mice. The third phase will be to see if the LNP construct can functionally restore cilia function in a mouse model of loss of function of Ccdc39. Figure 3 shows the step-by-step process of growing nasal cells from patients with primary ciliary dyskinesia (PCD) in the lab, and testing whether a new mRNA treatment can restore normal function. Cells are collected from patients and cultured, then genetically modified so they can grow continuously. These cells are then grown in a special system that mimics the airway, called an air-liquid interface. The new treatment, mRNA for the faulty *CCDC39* gene, is delivered to the cells. Scientists can then check if this restores normal cilia movement, which is essential for lung health. These are the first steps towards ultimately developing an mRNA treatment for people with faulty CCDC39.

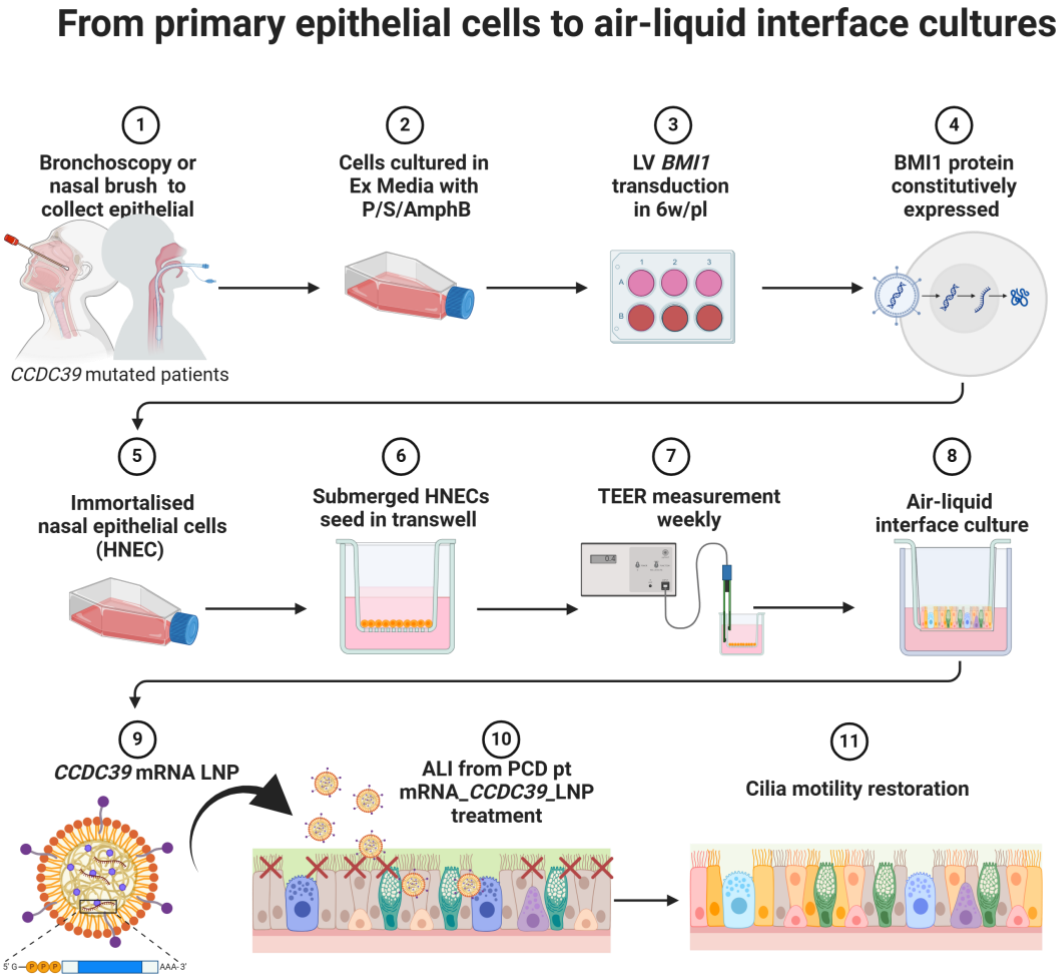

Figure 3 Steps to create a patient derived cellular model to develop and test mRNA encoding CCDC39 as the foundation for developing a potential future treatment.

2.3.2. Industry engagement

At the start of primary ciliary dyskinesia awareness month, PCD Research, sponsored by LifeArc, Recode Therapeutics, Axon, MRC National Mouse Genetics Network, Congenital Anomalies Cluster and Weatherden, hosted an industry day on 1st October 2024 entitled “Getting Cilia Moving” at the Francis Crick Institute, London. This event aimed to accelerate development of disease modifying agents for PCD, by leveraging academic advancements and progress made in other respiratory diseases. By involving industry and funders, PCD Research aimed to provide a runway to the clinic, by demonstrating the unmet need of PCD, the progress made towards de-risking the landscape and the value proposition, with wider applicability to the respiratory disease landscape. The event was designed to be novel and disruptive, with the aim of breaking down silos, sharing knowledge and showcasing a cohesive strategy that harnessed the strengths of each sector within the ecosystem and aligned them to a shared goal. The charity had a strategy of selling individual tickets and raising sponsorship to fund the event. Twenty-four (24) prominent speakers, coming from industry and academia, offered to present at the event, with the majority of them agreeing to speak without fees. An audience of 121 people across the therapeutic lifecycle (42% biopharma industry; 31% clinician scientists; 10% investors; 6% Policy (DHSC, NICE); 6% patients; 5% legal) attended. 94% of attendees reported the event as excellent/very good; 87% reported it was extremely/very valuable; 94%

reported the event was extremely / very well organised; and 94% reported they would be very likely to attend another PCD Research event. We are grateful for the pro bono support of Axon Communication who provided graphical design for all conference material. Volunteer in chief, Florence Barkats led our small and mighty team of volunteers and pro bono supporters with special thanks to Monica Dawes, Dan Glatman and Evangelo Panagi, Samantha Robinson, Nat Turner, Caroline McHugh and Amy Dréan.

More information about the event can be found on our website at https://pcdresearch.org/gettingciliamoving/

Figure 4 Getting Cilia Moving photograph of panel including Prof Pleasantine Mill, Prof Emma Rawlins and Dr Sara Wells MBE, chaired by Dr Harriet Holme

Figure 5 Graphical design of brochure kindly produced pro bono by Axon

Figure 6 Trustees Florence Barkats and Dr Harriet Holme at the event

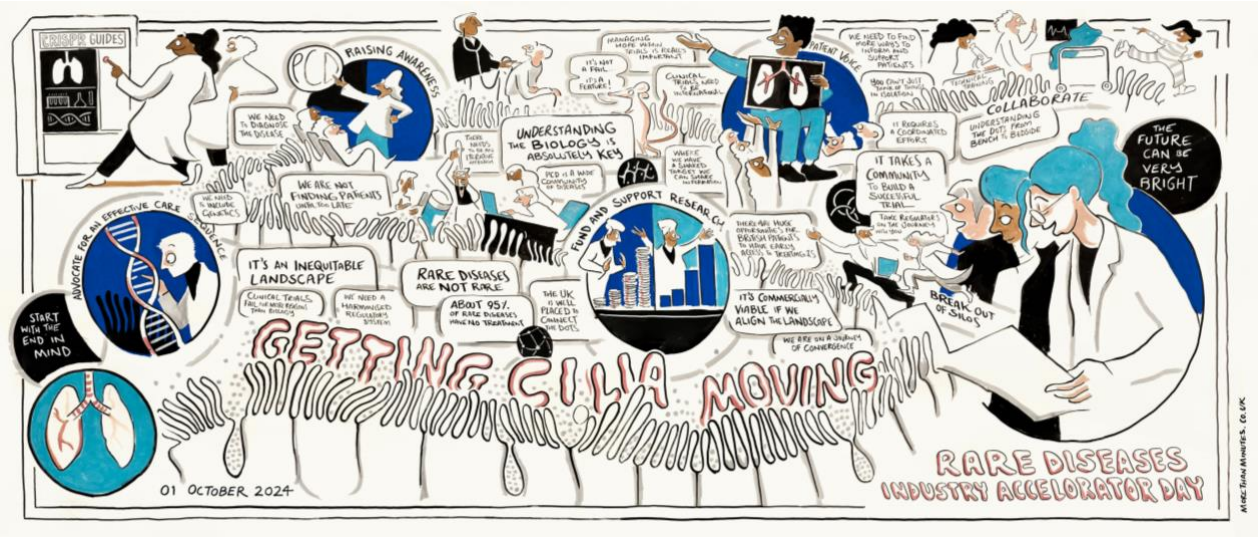

Figure 7 Graphical representation of the day Live Scribed by Jonny Glover at More Than Minutes

2.3.3. Co-hosted First Global PCD Patient / Carer Advocacy Event

PCDR together with the PCD Foundation co-hosted a globaly advocacy event 2nd October 2025 to bring together the different voices to discuss challenges and goals (see Figure 8). We are grateful to Pinsent Masons who kindly hosted this event pro bono. Recode Therapuetics kindly provided travel grants for representatives from international patient groups to travel and the LifeArc Centre for Rare Respiratory Diseases sponsored the event.

It brought together representatives from Primary Ciliary Dyskinesia patient organizations in person and online from 9 countries: PCD Australia, Brazil, France, Georgia, Germany, Israel, Spain, US PCD Foundation and UK (PCD Support UK, PCD Research).

The event looked to reframe the narrative of PCD as a mild disorder, to advocate for more investment in PCD research and accelerate access to clinical trials necessary for much-needed treatments. Also highlighting the need to develop shared resources and strategies and research-savvy partners in driving the translational agenda.

We are grateful to James Chalmers (Dundee), Claire Hogg (Royal Brompton), Magee Lee (UNC) and Adam Shapiro (McGill) for sharing their clinical perspectives in the afternoon. Thank you also to Dr John Matthews and Dr Jessica Couch ReCode Therapeutics and Dr Carsten Rudolph, Ethris for sharing their candid thoughts on industry perspectives on the PCD pre-and clinical trial landscapes, and how patient involvement is key.

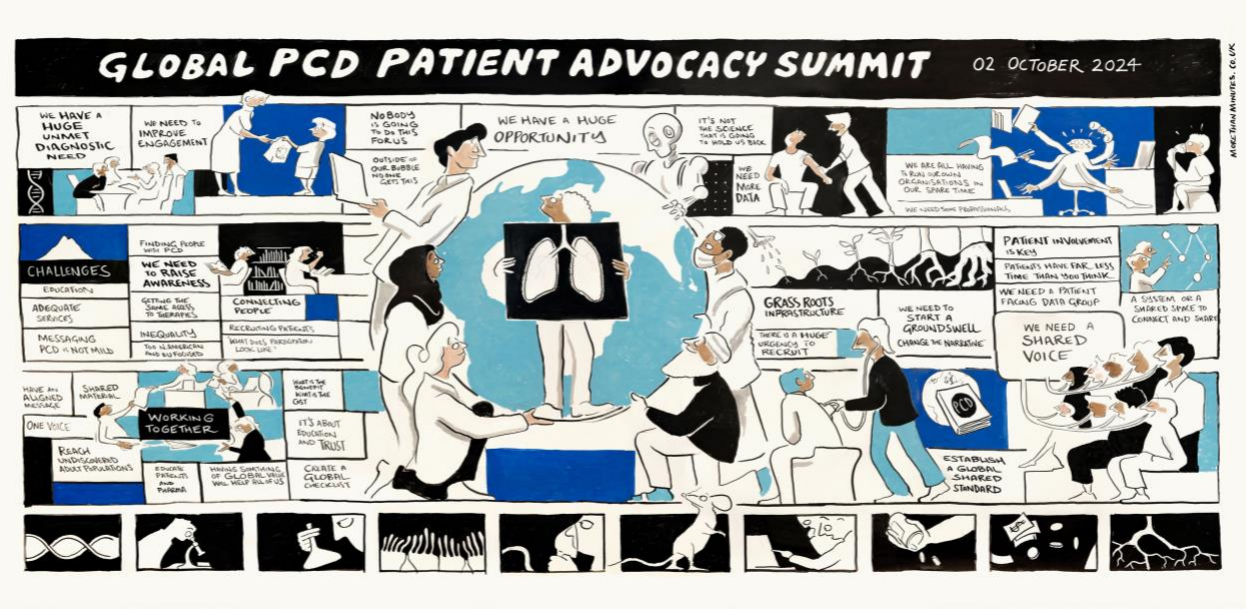

Figure 8 Graphical representation of themes discussed Live Scribed by Jonny Glover at More Thank Minutes

2.3.4. LifeArc Rare Respiratory Centre

PCD Research supported a successful bid to the LifeArc Rare Disease Translational Challenge. The new LifeArc Rare Respiratory Centre, with PCD as one of the three disease exemplars, has the potential to transform the landscape of PCD by providing the first significant investment in the field. The LifeArc Centre for Rare Respiratory Diseases will unite children, adults and families affected by relevant conditions with clinical experts, researchers, investors and industry leaders. The centre's experts will work in collaboration, aiming to overcome some of the barriers that can prevent new tests and treatments reaching patients with rare diseases.

The new centre will focus on rare lung diseases to accelerate diagnosis and development of much-needed therapies. The centre is a partnership between Universities and NHS Trusts, co-led by Edinburgh with partners in Nottingham, Dundee, Cambridge, Southampton and at University College London. It is supported by six other clinical partners in Belfast, Cardiff, Leeds, Leicester, Manchester and at Royal Brompton. The collaboration will create a UK-wide bank of anonymised tissue samples and models of disease, allowing researchers to advance pioneering therapies.

It will work to lower the risk of investment in rare respiratory disease research, building the partnerships and innovative infrastructure needed for clinical trials in patients with rare conditions. The centre team also aims to boost public awareness of the realities of living with rare respiratory diseases and raise patient awareness of resources that can improve their quality of life.

Dr Harriet Holme will represent PCDR as a lead for Patient and Public Involvement and Engagement (PPIE) and also industry engagement.

2.3.5. PCDR Awareness Event

In May 2024, we held our first awareness event, a first for for PCD Research, part fundraiser, part rallying call for influence. It was designed not only to raise vital funds, but also to inspire people to act within their own spheres of influence.

Broadcast leader and Channel 4 CEO, Dr Alex Mahon generously supported the event as a speaker, interviewed by Hattie Brett, Editor in Chief, Grazia. Alex's reflections on raising children in today's digital world provided a moving backdrop to the more personal story I shared, about my own family's journey with PCD. While I usually keep such experiences private, I felt compelled to speak openly to help fill the "imagination gap" that often exists around rare diseases. Some friends in the audience who have known me for years said they, in all honesty, had no idea about the daily burden of disease and treatment. Sharing the reality was hard.

We are enormously grateful to Dr Alex Mahon and Hattie Brett for hosting the evening, to Dr Justine Kluk and TK International for their generous contributions, to Caroline McHugh and Emma Tinsley, along with everyone who kindly donated to the auction. Special thanks also to Alexandra Roche for beautifully capturing the evening in photographs. This event raised over £6,000.

Figure 9 Dr Alex Mahon, Hattie Brett and Dr Harriet Holme

Figure 10 Dr Alex Mahon in conversation with Hattie Brett

Figure 11 Dr Alex Mahon in conversatino with Hattie Brett

2.3.6. Consolidated governance and recruited pro bono legal support.

PCD Research has refined its objectives to better reflect the scope and direction of its ongoing work.

PCD Research has established contracts for pro bono advice from Pinsent Masons to draw up PCD Research's standard grant terms and terms for the contracts between NATA, UCL and PCD Research.

PCD Research also received pro bono support from Hogan Lovells with regards communication with NHSE to advocate for an improved PCD service.

2.3.7. Fundraising

PCD Research received £71,634.15 between 02/01/2024 to 01/01/2025 from a range of fundraising activities, including community based initiatives, a PCDR awareness event and unrestricted grants.

2.3.8. Raising Awareness in the Houses of Parliament

Liz Twist MP, Chair of the All Party Parliamentary Group on Rare, Genetic and Undiagnosed Diseases, in a parliamentary debate on respiratory health, highlighted that "PCD is not a mild condition. In fact, children with PCD, have a worse lung function than children with cystic fibrosis. It is vital that we do what we can to raise awareness of these conditions, including the rare condition of PCD, and their impact, whether they are primarily genetic in nature or driven by preventable causes."

Watch the debate via the link and hear Liz at 14.09.
https://parliamentlive.tv/event/index/2b92a086-290a-45bc-8a1d-a0d0d32c3f8d?in=14:07:56

Read the transcript here https://hansard.parliament.uk/Commons/2024-11-14/debates/454A1DF1-3B97-44ED-BFDA-C66E06E96217/RespiratoryHealth?highlight=pcd#

2.3.9. Patient Survey

For PCD Awareness Month 2024, we invited people living with PCD, as well as parents and carers of children with PCD, to share what matters most to them. Their reflections offer a powerful insight into the lived reality of this rare condition, highlighting the daily challenges, unmet needs, and hopes for the future. From the emotional toll of delayed diagnosis, to the burden of intensive treatment routines, to the desire for better information, coordinated care, and more research into therapies, these perspectives underscore why our work is so urgent.

Figure 12 to Figure 16 provide a summary of the key themes and individual voices captured through this awareness initiative, giving a platform to those most affected and helping inform the direction of our advocacy and research.

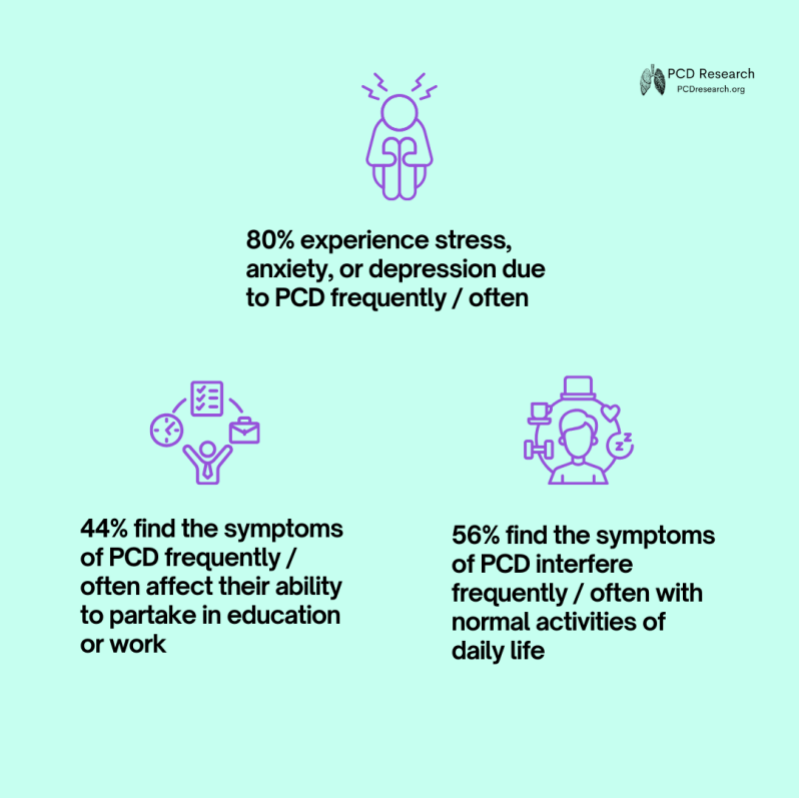

Figure 12 Summary of views captured by PCD Research Patient survey

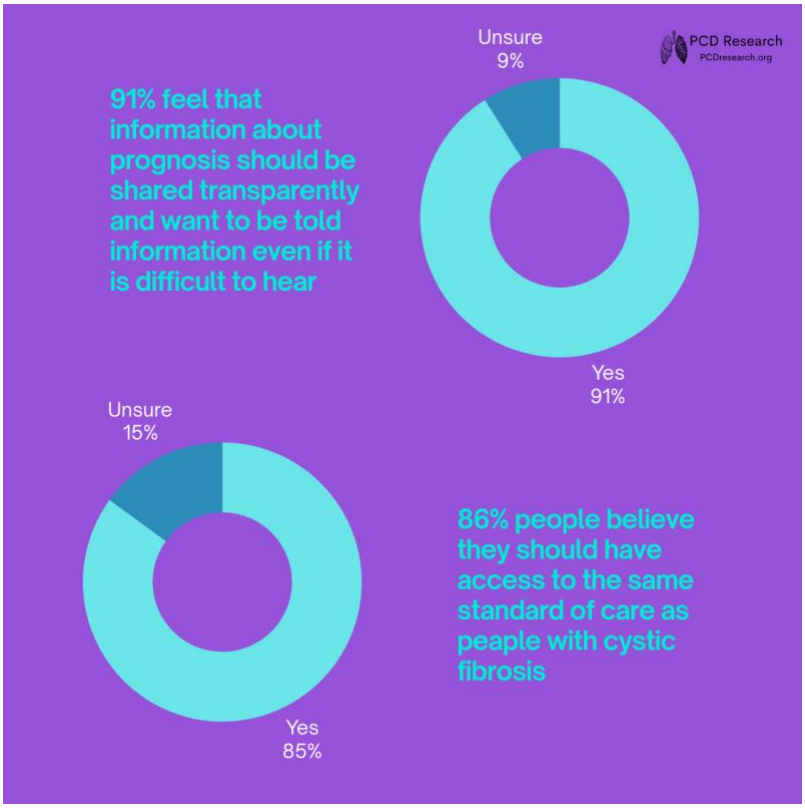

Figure 13 Summary of views captured by PCD Research Patient survey

Figure 14 Summary of views captured by PCD Research Patient survey

Figure 15 Summary of views captured by PCD Research Patient survey

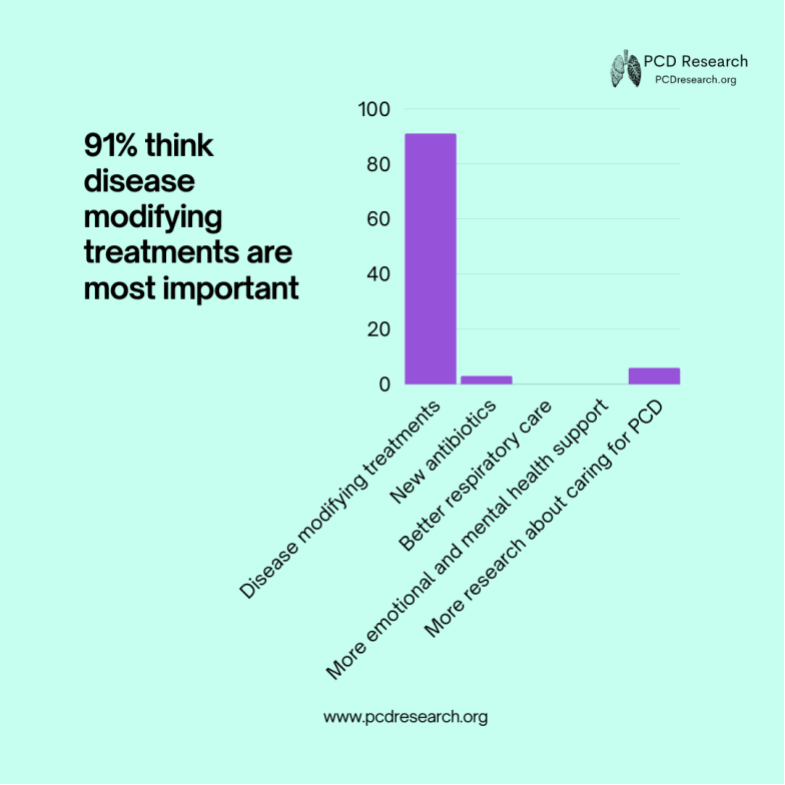

Figure 16 Summary of views captured by PCD Research Patient survey

2.3.10. Outreach

Interested members of the public are able to subscribe and receive updates by email from the charity.

@PCD_research on Instagram enables communication of our mission, goals and progress with more than 1000 followers. PCD Research is also active on LinkedIn.
https://www.linkedin.com/company/pcd-research/?viewAsMember=true

PCD Research continues to have links across multiple patient advocacy groups.

PCD Research was represented at the following meetings in 2024:

- Dr Harriet Holme:
    - January On the Move Conference, PCD Foundation in Puerto Rico
    - February Genetic Alliance Rare Disease Day Parliamentary Event
    - March Advanced Therapies, London
    - April 21st Orphan Drugs and Rare Diseases Global Congress, London (invited panelist)
    - May Pre-clinical Modelling of Human Genetic Disease and Therapy, Edinburgh (invited speaker)
    - July Genomics England Summit, London
    - July BioAssociation Summer Event, London
    - November N=1 Collaborative webinar – invited speaker
    - December Sano Genetics Webinar – invited speaker

2.3.11. Scientific Advisory Panel

To ensure that the most promising research is funded, PCD Research has dedicated time to engaging with leading academics in the fields of PCD, CF, bronchiectasis, gene augmentation and gene editing.

This has enabled PCD Research to form a Scientific Advisory Panel (SAP) with a range of experience, who are international and independent, to focus on development of novel therapies for PCD. The SAP were appointed to act as an advisory board to robustly scrutinise grant applications, so that only the most promising research is funded. Ian Brooks remains the parent representative and Heidi Bjornson-Pennell the Chair.

2.4. Outlook

The charity committed to substantial expenses in 2023 when it awarded its first research grant. Disburssion of this award commenced in 2024, after the successful negotiation of contractual terms between NATA, UCL and PCD Research.

The charity's other main expenses are reimbursing reasonable costs for attending meetings and conferences. It maintains appropriate reserves and has adequate funding to meet expected expenses in 2025.

This report was approved by the trustees on 23rd October 2025 and signed on their behalf.

Dr Harriet Holme
Chair

3. Statement of Trustees' Responsibilities

The Trustees are responsible for preparing the annual report and the financial statements in accordance with applicable laws and regulations.

UK Charity law (Charities Act 2011 and subsequent amendments) requires the Trustees to prepare accounts for each financial year. The accounts have been prepared on a receipts and payments basis as provided for under section 133 of the Charities Act 2011. PCD Research is a smaller charity for the purpose of reporting.

Under charity law the Trustees must not approve the accounts unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the profit or loss of the charity for that period. When preparing these accounts, the Trustees:

- selected suitable accounting policies and applied them consistently;
- made judgements and estimates that are reasonable and prudent;
- prepared the financial statements on the going concern basis.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with applicable regulations. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

This report was approved by the trustees on 23rd October 2025 and signed on their behalf.

Dr Harriet Holme
Chair

4. Financial Review

4.1. Receipts and Payments for the period from 2nd January 2024 to 1st January 2025

	Notes	Unrestricted	Restricted	Endowment	Total 2025
		£	£	£	£
Receipts					
- Donations		43,611.04	167,000	-	210,611.04
- Charitable activities		20,726.39	-	-	20,726.39
- Investments		7,296.72	-	-	7,296.72
- Other		-	-	-	-
Total Receipts		**71,634.15**	**167,000**	**-**	**238,634.15**
Payments					
- Raising funds		-633.70	-	-	-633.70
- Charitable Activities		-18,620.25	-	-	-18,620.25
- Other		-	-	-	-
Total Payments		**-19,253.95**	**-**	**-**	**-19,253.95**
Net Income		**52,380.20**	**167,000**	**-**	**219,380.20**
Transfer of Funds		-	-	-	-
Revaluation of Fixed Assets		-	-	-	-
Other Gains / Losses		-	-	-	-
Net Movement in Funds		**52,380.20**	**167,000**	**-**	**219,380.20**
Balances Carried Forward at 1st Jan 2024		**180,419.41**	-	-	**180,419.41**
Balances Carried Forward at 1st January 2025		**232,799.21**	**167,000**	**-**	**399,799.21**

During the period ending 1st January 2025 the charity recorded receipts of £238,634.15. The largest receipt was a grant awarded by NATA amounting to £167,000. The remainder of the other receipts were from donations, conference sponsorship, ticket sales and auction proceeds.

The payments made during the financial year amounted to £19,235.95. These consisted of mainly of travel expenses, conference admission fees, fees for outside counsel, IT expenses for website and email programmes, membership fees, with the remainder representing minor administrative expenses for items such a stationary and merchandising.

4.2. Statement of Assets and Liabilities as at 1st January 2025

	Jan 2025	Jan 2024
	£	£
Fixed Assets		
Intangible Assets	-	-
Tangible Assets	-	-
Heritage Assets	-	-
Investments	-	-
Total Fixed Assets	-	-
Current Assets		
Stocks	-	-
Debtors	-	-
Investments	-	-
Cash at Bank	399,799.21	180,419.41
Total Current Assets	**399,799.21**	**180,419.41**
Liabilities		
Creditors: Amounts Falling Due Within One Year	-	
Net Current Assets	**399,799.21**	**180,419.41**
Total Assets Less Current Liabilities	**399,799.21**	**180,419.41**
Creditors: Amounts Falling Due Within More Than One Year	-	-
Provision for Liabilities		
Net Assets	**399,799.21**	**180,419.41**
Capital and Reserves		
Unrestricted Funds	399,799.21	180,419.41
Restricted Funds	-	-
Endowment Funds	-	-
Total Charity Funds	**399,799.21**	**180,419.41**

As of 1st January 2025, the only asset owned by the charity consisted of cash held on its two bank accounts. The charity has no financial or other liabilities.

As a result of the fundraising activities by the charity exceeding the expenses incurred, the charity's own funds at 1st January 2025 amounted to £399,799.21.

Dr Harriet Holme
Chair
Approved by the trustees on 23rd October 2025

4.3. Cash-Flow Statement as at 1st January 2025

	Period ending 1st January 2025
Opening Cash as of 2nd January 2024	**180,419.41**
Cash receipts during the year	238,634.15
Payments made during the year	-19,253.95
Net Movement of Funds	219,380.20
Closing Cash as of 1st January 2025	**399,799.21**

5. Notes to the Financial Statements for the period from 2nd January 2024 to 1st January 2025

5.1. Accounting Policies

Basis of preparation
The accounts have been prepared on a receipts and payments basis as provided for under section 133 of the Charities Act 2011. PCD Research is a smaller charity for the purpose of reporting.

The charity is a Charitable Incorporated Organisation and does not have any subsidiaries or branches.

Recognition of Income
All forms of income are recognised on a cash basis at the point when the charity receives funds into its bank account.

Recognition of Expenses
All expenditures are accounted for on a payment basis and are recognised at the point where funds leave the charity's bank account.

5.2. Statement of Funds

	1st January 2024	Receipts	Payments	1st Janaury 2025
	£	£	£	£
General Unrestricted Funds	180,419.41	71,634.15	-19,253.95	232,799.21
Designated Unrestricted Funds	-	-	-	-
Total Unrestricted Funds	**180,419.41**	**71,634.15**	**-19,253.95**	**232,799.21**
Total Restricted Funds	**-**	**167,000**	**-**	**167,000**
Total Endowment Funds	**-**	**-**	**-**	**-**
Total	**180,419.41**	**238,634.15**	**-19,253.95**	**399,799.21**

As of 1st January 2025, the charity held restricted funds of £167,000 relating to a research project grant received from NATA. All other funds are represented as General Unrestricted Funds and these were not earmarked for a specific purpose. The charity held no endowment funds. There were no transfers between any classes of funds during the year.

5.3. Independent Examination

As the 2024 annual receipts of the charity exceeded £25,000 an independent examiner was appointed to provide independent assurance that the charity's money has been appropriately accounted for.

5.4. Trustees Remuneration and Expenses

During the period ending on 1st January 2025, none of the trustees received any remuneration or benefits from an employment with the charity.

5.5. Reserves Policy

It is the charity's aim to hold reserves so that it can be confident of its financial position and can meet its financial obligations at any point. The charity's current financial obligations are of a discretionary nature.

The charity's reserves policy takes into account that it may commit to fund research expenditures over the medium term whilst recognising that there may be a level of volatility in its income due to the inherent uncertainty of fundraising activities. The trustees have therefore decided that PCD Research will not enter into financial commitments with third parties unless it has secured prior funding. The charity will hold sufficient funds in reserves to ensure that it can meet any contractual commitment to funding future research and clinical projects.

Notwithstanding the above, given the lack of data points on fundraising and a normalised level of expenses, the trustees have also decided to keep a minimum reserve of £10,000 at all times earmarked for any contingencies.

5.6. Guarantees and Secured Debts

As of 1st January 2025, no guarantees were given by PCD Research. No debts are outstanding as of the date of statement of assets and liabilities.

CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees	PCD Research		
On accounts for the year ended	Period ended 31 Dec 2024	**Charity no (if any)**	1197528
Set out on pages	18 - 22 (remember to include the page numbers of additional sheets)		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 Dec 2024.

Responsibilities and basis of report

As the charity's trustees, 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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the 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 which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records

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.

Signed:		**Date:**	23/10/2025
Name:	Michael Rowe		
Relevant professional qualification(s) or body (if any):	CPFA		
Address:	Piccadilly Business Centre, Unit C Aldow Enterprise Park, Blackett Street, Manchester M12 6AE		

PCD RESEARCH

England & Wales - Charity number 1197528

Accounts

PCD Research
PCDresearch.org

A Charitable Incorporated Organisation
Regulated by the Charity Commission for England and Wales

Registered Number
1197528

Annual Report and Accounts
Period ending
31st December 2023

Registered Address:
87 Belsize Lane
London NW3 5AU
info@PCDResearch.org

1. Overview

This document provides the annual report and accounts of PCD Research CIO ("PCD Research", or the "charity"). The trustees present their report and accounts for its second financial year, the period from 1st January 2023 to the 31st December 2023.

1.1. Objectives and Principal Activities

The charity is registered and regulated by the Charity Commission for England and Wales. Its reference is 1197528.

The objectives of the charity are to advance the health of children and adults with primary ciliary dyskinesia (PCD) by supporting research into A) understanding PCD and B) novel therapeutic targets and therapies for PCD. The charity will carry out these objectives by funding pure scientific and applied/translational research for the public benefit of improving the health and outcome of people with PCD.

1.2. Trustees and Governance

PCD Research does not have any staff at the moment. Instead, it is governed by its board of trustees, who are dedicating their time and efforts on a pro bono basis. PCD Research was set up as a Charitable Incorporated Organisation. Its constitutional document includes provisions relating to the appointment of trustees. Each trustee is appointed for an initial term of three years, whereupon they can be reappointed.

The following persons served as trustees during the period ending on 31st December 2023:

Dr Harriet Holme - Chair of the Trustees - Appointed on 17th January 2022
Dr Gurhan Erturan - Trustee - Appointed on 17th January 2022
Natalie Gehl – Trustee - Appointed on 17th January 2022
Lucy Dixon – Trustee - Appointed on 17th January 2022, resigned on 24th April 2023
Michelle Levene - Trustee - Appointed on 24th April 2023
Harriet Nowell-Smith - Trustee - Appointed on 24th April 2023
Oliver Burgel - Trustee - Appointed on 24th April 2023
Monica Dawes – Trustee – Appointed 24th November 2023

The trustees were approached and appointed with the aim of establishing a board with diverse professional experience at senior level, as well as direct patient experience and impact of PCD on family life. At present, the range of professional expertise covers clinical medicine, research (scientific, translational and medical), drug development strategy and development in advanced therapeutics, rare diseases, public and international law and finance. Two of the trustees are parents of a child with PCD.

The charity's key policy documents, such as Conflict of Interest Policy, Funding Policy, Animal Research Policy, Expense Policy and Research Strategy are available on request by contacting info@PCDResearch.org

2. Annual Report of the Trustees

PCD Research is a medical research charity that was incorporated and registered with the Charity Commission for England and Wales on 17th January 2022. The aims of PCD Research include improved treatment options for people with PCD by funding research and improving the standard of care.

2.1. What is Primary Ciliary Dyskinesia

Primary ciliary dyskinesia is a genetic condition that affects approximately 1 in 7,500 people. Mutations in more than 50 genes have been found to cause PCD. This leads to a range of severity. PCD leads to permanent damage of the lungs and for people with the most severe disease, the damage happens decades earlier than those with milder disease. One in 20 people are carriers, with one affected copy of a gene that causes PCD. Leaders in the field think that carriers might have a separate set of symptoms that overlap with difficult to treat asthma.

Motile cilia are like microscopic hairs that beat in the airways and sinuses to clear out secretions and infections. In PCD, the cilia are abnormal and unable to move in the usual way, such that secretions and infections affect the lungs, sinuses, ears and nose. Cilia are also important for the propulsion of sperm and likely also both the fallopian tubes and endometrium leading to impaired transport of the oocyte and early embryo, so fertility is commonly affected as well. It is likely that PCD affects other pathways in the body in ways that are not yet understood.

2.2. Treatment and Outcome

PCD is a life altering and life shortening condition. Children with PCD have been found to have worse lung function than those with cystic fibrosis (CF)[1] but are unable to access the same standard of care in the UK. In the case of CF, there has been an active program of research that has led to breakthrough drugs (CFTR modulators) that are widely recognised to be very effective for CF. Sadly these drugs are not suitable for people with PCD.

There are no dedicated treatments for PCD. Instead, current treatments for PCD have been borrowed from experience with people with CF. People with PCD and their family members face a significant burden and daily challenges from living with the disease. Daily treatment includes several hours of chest physiotherapy to try to clear mucus from the lungs, using methods borrowed from a mechanistically distinct disease (CF) without evidence of efficacy in PCD. In addition, patients are subject to frequent courses of antibiotics to treat frequent episodes of pneumonia. Some people with PCD will still progress to end stage respiratory failure and need a lung transplant. People with loss of function of the genes *CCDC39* and *CCDC40* are now widely acknowledged to have a significantly poorer outcome. The average length of survival post lung transplantation in people with PCD is 5.9 years[2].

While children and adults with PCD may appear healthy, PCD is a progressive disease, where lung function declines over time. At present there are no treatments that can stop or reduce this decline, nor restore cilia function. There are no NICE guidelines.

2.3. Achievements of PCD Research during 2023

The key achievements of the charity during its second year are:

[1]Rubbo, B. *et al.* Clinical features and management of children with primary ciliary dyskinesia in England. *Arch Dis Child* **105**, 724–729 (2020).

[2] Marro M, *et al*. Lung Transplantation for Primary Ciliary Dyskinesia and Kartagener Syndrome: A Multicenter Study. Transpl Int. 2023 Feb 14;36:10819. doi: 10.3389/ti.2023.10819. PMID: 36865666; PMCID: PMC9970992.

- Inaugural meeting of the Scientific Advisory Panel to complete the first peer-review process.
- Becoming a Full Member of the Association of Medical Research Charities (AMRC) and joining other professional organisations.
- Supported an application for the £10 million LifeArc Rare Disease Translational Challenge bid for a national Rare Respiratory Centre, with PCD as one of the three disease exemplars.
- Consolidated governance and recruited pro bono legal support.
- Fundraising.
- Raised awareness in the UK Parliament and three relevant All Party Parliamentary Groups (APPG).

2.3.1. Inaugural Meeting of the Scientific Advisory Panel (SAP)

In March, the inaugural meeting of the SAP was held virtually to peer-review the grant applications from the first PCD Research grant call. This was to fund a two-year post-doctorate in collaboration with the Nucleic Acid Therapeutic Accelerator (NATA). Professor Hart's project was chosen by the SAP, out of a total of three high quality applicants.

The project will look to optimise lipid nanoparticle (LNP) technology encoding mRNA targeting loss of function of *CCDC39*, first in cellular models (air liquid interface culture – ALI culture). Successful LNP constructs will be taken forward to optimise nebulised delivery in healthy mice. The third phase will be to see if the LNP construct can functionally restore cilia function in a mouse model of loss of function of *CCDC39*.

The grant contracts between PCD Research and (1) NATA and (2) University College London are expected to be signed in 2024.

2.3.2. Joined Relevant Professional Organisations

The Association of Medical Research Charities (AMRC) is a membership organisation dedicated to supporting medical research charities in saving and improving lives through research and innovation. The AMRC ensures its members fund the best research by developing guides, providing training, and carrying out an audit of their funding processes. They unite and champion the sector, helping to drive positive change in the research and health landscape. In 2022, AMRC members invested almost £2 billion in UK research, equivalent to that funded by the NIHR and MRC combined.

In 2023, PCD Research became a member of the AMRC. AMRC membership is established as the hallmark for quality research funding. By granting membership, AMRC is recognising the processes put in place to ensure PCD Research funds research of the highest standards.

The clarity and independence of PCD Research's funding process was recognised by the AMRC, who congratulated the charity on having accomplished this from the outset. PCD Research will continue to expand and establish further academic links with the research community in the UK and overseas.

PCD Research seeks to form and strengthen links with other organisations supporting rare disease and therapeutic development and joined Genetic Alliance and the UK Bioindustry Association.

2.3.3. Supported an Application to the LifeArc Rare Disease Translational Challenge

The LifeArc Rare Disease Translational Challenge has the potential to transform the landscape of PCD by providing the first significant investment in the field. Dr Harriet Holme was invited by LifeArc to give the Keynote presentation at the launch event about her experience of the translational challenges in

rare disease. Dr Holme provided patient and public involvement and engagement (PPIE) and support for a £9.4 million National Rare Respiratory centre bid with PCD as one of the three disease exemplars.

2.3.4. Pro bono Legal Support

PCD Research has established contracts for pro bono advice from Pinsent Masons to (1) draw up PCD Research's standard grant terms and terms for the contracts between NATA, UCL and PCD Research and (2) provide advice for advertising campaigns to raise awareness about PCD.

2.3.5. Fundraising

PCD Research received over £40,000 in 2023 from a range of fundraising activities, including sponsorship from 16 runners who gave up their time to run in the London Landmarks Half Marathon generating over £6,000 of donations.

2.3.6. Raising Awareness to Improve the Standard of Care

Tulip Siddiq MP asked a Parliamentary question about PCD on the 1st September 2023, on behalf of PCD Research: "to ask the Secretary of State for Health and Social Care, what steps his Department is taking to ensure children with primary ciliary dyskinesia receive similar care to those with cystic fibrosis."

The following response was provided by Will Quince MP on the 11th September 2023[3]: "The Government is committed to improving the lives of those living with rare diseases such as primary ciliary dyskinesia. In 2021, the Government published the UK Rare Diseases Framework, providing a national vision for how to improve the lives of those living with rare diseases. The framework lists four priorities collaboratively developed with the rare disease community: helping patients get a final diagnosis faster; increasing awareness of rare diseases among healthcare professionals; better coordination of care; and improving access to specialist care, treatments and drugs. The framework committed to nation-specific action plans and England published its second Rare Diseases Action Plan in February this year. The framework and action plans are not disease specific, but aim to improve the lives of all people living with rare diseases."

Dr Holme worked with colleagues in Scotland and Wales to raise awareness in other parts of the UK.

2.3.7. Built relationships with relevant All Party Parliamentary Groups (APPG)

On the 7th September 2023, Dr Harriet Holme, Harriet Nowell-Smith and Oliver Burgel met Liz Twist MP, the chair of the APPG for Rare, Genetic and Undiagnosed Diseases. This meeting was to raise awareness about PCD, the lack of research funding and inequity of clinical care. Dr Harriet Holme was also invited to attend the APPG meeting on the 11th December 2023 and to give a short presentation on the challenges of research in rare disease. Dr Harriet Holme also consulted with Hugh McKinney, Policy adviser to the APPG for Respiratory Health and the secretariat for the APPG on Medical Research.

2.4. Industry engagement

The charity engaged with representatives of biotech and pharma to raise awareness about PCD, to demonstrate the ways PCD Research is involved in clearing translational roadblocks and to share information from a patient perspective.

[3] https://questions-statements.parliament.uk/written-questions/detail/2023-09-01/197023

PCD Research, together with LifeArc and Weatherden, will host an industry day on 1st October 2024 entitled "Getting Cilia Moving." This event aims to accelerate development of disease modifying agents for PCD, by leveraging scientific advancements and progress made in other respiratory diseases. The charity aims to demonstrate to industry and funders the unmet need caused by PCD and progress made towards de-risking this space to change the value proposition, with applicability to the wider respiratory disease landscape.

2.5. Outreach

The website that was built for PCD Research was re-designed and updated during 2023. Interested members of the public are able to subscribe and receive updates by email from the charity.

@PCD_research on Instagram enables communication of our mission, goals and progress with more than 1000 followers. PCD Research is also active on LinkedIn.

PCD Research continues to have links with the PCD Foundation in the USA, PCD Support UK, the Ciliopathy Alliance, PCD Australia, and BEAT-PCD (based in the UK and Europe).

PCD Research was represented at the following meetings in 2023:

- Dr Harriet Holme:
    - Decentralising Science, Crick Institute (January).
    - GRC Physiological and Pathological Mechanisms of the Mucociliary System, Italy (February).
    - NATA symposium, Birmingham (May).
    - ARMC Festival of Partnerships, Wellcome Trust (October).
    - Westminster Health Forum policy conference, virtual (October).
    - 2nd World Orphan Drug Congress 2023, Barcelona (November).
    - Beacon – The London Rare Disease Showcase (November).
    - ABPI - Rare Disease event, London (December).

- Harriet Nowell-Smith and Michelle Levene:
    - BEAT-PCD meeting, Milan (September).

- Dr Harriet Holme, Gurhan Erturan, Harriet Nowell-Smith and Oliver Burgel
    - LifeArc Rare Disease Translational Challenge Launch (June).

2.6. Scientific Advisory Panel

To ensure that the most promising research is funded, PCD Research has dedicated time to engaging with leading academics in the fields of PCD, CF, bronchiectasis, gene augmentation and gene editing. This has enabled PCD Research to form a Scientific Advisory Panel (SAP) with a range of experience, who are international and independent, to focus on development of novel therapies for PCD. The SAP were appointed to act as an advisory board to robustly scrutinise grant applications, so that only the most promising research is funded.

Katie Dexter, SAP patient representative stepped down on the 30th August 2023 to take the position of Chair of PCD Support UK. Ian Brooks was appointed on the 31st August 2023 as parent representative on the SAP. There are now 29 people on the SAP, including Ian Brooks and Heidi Bjornson-Pennell (chair).

2.7. Outlook

The charity committed to substantial expenses in 2023 when it awarded its first research grant. The grant is expected to be disbursed through the charity beginning in 2024, pending the successful negotiation of contractual terms between NATA, UCL and PCD Research.

The charity's other main expenses are reimbursing reasonable costs for attending meetings and conferences. It maintains appropriate reserves and has adequate funding to meet expected expenses during 2024.

This report was approved by the trustees on 24 May 2024 and signed on their behalf.

Dr Harriet Holme
Chair

3. Statement of Trustees' Responsibilities

The Trustees are responsible for preparing the annual report and the financial statements in accordance with applicable laws and regulations.

UK Charity law (Charities Act 2011 and subsequent amendments) requires the Trustees to prepare accounts for each financial year. The accounts have been prepared on a receipts and payments basis as provided for under section 133 of the Charities Act 2011. PCD Research is a smaller charity for the purpose of reporting.

Under charity law the Trustees must not approve the accounts unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the profit or loss of the charity for that period. When preparing these accounts, the Trustees:

- selected suitable accounting policies and applied them consistently;
- made judgements and estimates that are reasonable and prudent;
- prepared the financial statements on the going concern basis.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with applicable regulations. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

This report was approved by the trustees on 24 May 2024 and signed on their behalf.

Dr Harriet Holme
Chair

4. Financial Review

4.1. Receipts and Payments for the period from 1st January 2023 to 31st December 2023

	Notes	Unrestricted	Restricted	Endowment	Total 2023
		£	£	£	£
Receipts					
- Donations		40,676.38	-	-	40,676.38
- Charitable activities		-	-	-	-
- Investments		125.67	-	-	-
- Other		-	-	-	-
Total Receipts		**40,802.05**	**-**	**-**	**40,802.05**
Payments					
- Raising funds		-231.00	-	-	-231.00
- Charitable Activities		-11,459.73	-	-	-11,459.73
- Other					
Total Payments		**-11,690.73**	**-**	**-**	**-11,690.73**
Net Income		**29,111.32**	**-**	**-**	**29,111.32**
Transfer of Funds		-	-	-	-
Revaluation of Fixed Assets		-	-	-	-
Other Gains / Losses		-	-	-	-
Net Movement in Funds		**29,111.32**	**-**	**-**	**29,111.32**
Balances Carried Forward at 1st Jan 2023		**151,308.09**	-	-	**151,308.09**
Balances Carried Forward at 31st December 2023		**180,419.41**	**-**	**-**	**180,419.41**

During the period ending December 2022 the charity recorded receipts of £40,802.05. The largest donation was made by a donor for the amount of £7,000. The remaining funds were raised from c. 300 small donations.

As mentioned in the annual report, the charity began to negotiate the legal terms of a contract to fund research at University College, London (UCL) in collaboration with Nucleic Acid Therapy Accelerator (NATA). The funding need for this grant is expected to be about £83,000. As the negotiations had not been completed by December 2023, no grant payments were made during the financial year 2023.

The payments made during the financial year amounted to £11,690.73. These consisted of mainly of travel expenses (c. 66%), conference admission fees (c. 12%), fees for outside counsel (c. 8%), IT expenses for website and email programmes (c. 5%), membership fees (c. 5%), with the remainder representing minor administrative expenses for items such a stationary and merchandising.

4.2. Statement of Assets and Liabilities as at 31st December 2023

	Dec 2022	Dec 2023
	£	£
Fixed Assets		
Intangible Assets	-	-
Tangible Assets	-	-
Heritage Assets	-	-
Investments	-	-
Total Fixed Assets	-	-
Current Assets		
Stocks	-	-
Debtors	-	-
Investments	-	-
Cash at Bank	151,308.09	180,419.41
Total Current Assets	**151,308.09**	**180,419.41**
Liabilities		
Creditors: Amounts Falling Due Within One Year	-	
Net Current Assets	**151,308.09**	**180,419.41**
Total Assets Less Current Liabilities	**151,308.09**	**180,419.41**
Creditors: Amounts Falling Due Within More Than One Year	-	-
Provision for Liabilities		
Net Assets	**151,308.09**	**180,419.41**
Capital and Reserves		
Unrestricted Funds	151,308.09	180,419.41
Restricted Funds	-	-
Endowment Funds	-	-
Total Charity Funds	**151,308.09**	**180,419.41**

As of 31st December 2023, the only asset owned by the charity consisted of cash held on its two bank accounts. The charity has no financial or other liabilities.

As a result of the fundraising activities by the charity exceeding the expenses incurred, the charity's own funds at 31st December 2023 amounted to £180,419.41.

Harriet Holme,
Chair
Approved by the trustees on 24 May 2024

4.3. Cash-Flow Statement as at 31st December 2023

	Period ending 31st December 2022
Opening Cash as of 1st January 2023	**151,308.09**
Cash receipts during the year	40,802.05
Payments made during the year	-11,690.73
Net Movement of Funds	29,111.32
Closing Cash as of 31st December 2023	**180,419.41**

The charity's cash position evolved as a result of the inflow from donations exceeding the payments made during the financial year. As a result, the year-end cash position in its two bank accounts amounted to £180,419.41. This situation is expected to change during 2024 as the charity will begin to fund its first research project.

5. Notes to the Financial Statements for the period from 1st January 2023 to 31st December 2023

5.1. Accounting Policies

Basis of preparation
The accounts have been prepared on a receipts and payments basis as provided for under section 133 of the Charities Act 2011. PCD Research is a smaller charity for the purpose of reporting.

The charity is a Charitable Incorporated Organisation and does not have any subsidiaries or branches.

Recognition of Income
All forms of income are recognised on a cash basis at the point when the charity receives funds into its bank account.

Recognition of Expenses
All expenditures are accounted for on a payment basis and are recognised at the point where funds leave the charity's bank account.

5.2. Statement of Funds

	1st January 2023	Receipts	Payments	31st December 2023
	£	£	£	£
General Unrestricted Funds	151,308.09	40,802.05	-11,690.73	180,419.41
Designated Unrestricted Funds	0	0	0	0
Total Unrestricted Funds	**151,308.09**	**40,802.05**	**-11,690.73**	**180,419.41**
Total Restricted Funds	**0**	**0**	**0**	**0**
Total Endowment Funds	**0**	**0**	**0**	**0**
Total	**151,308.09**	**40,802.05**	**-11,690.73**	**180,419.41**

As of 31st December 2023, all funds represented as General Unrestricted Funds. These were not earmarked for a specific purpose. During the financial year 2022, the charity held neither restricted funds nor endowment funds. There were no transfers between any classes of funds during the year.

5.3. Independent Examination

As the 2023 annual receipts of the charity exceeded £25,000 an independent examiner was appointed to provide independent assurance that the charity's money has been appropriately accounted for. The independent examiner has waived any fees for his services.

5.4. Trustees Remuneration and Expenses

During the period ending on 31st December 2023 none of the trustees received any remuneration or benefits from an employment with the charity.

5.5. Related Party Transactions

In the period ending on 31st December 2023 the charity refunded one trustee expenses of £415.65. These were incurred in connection with IT expenses and travel to a conference. During the process of preparing these accounts it became apparent that within this total, £116 had been refunded in error and the trustee subsequently repaid the charity in January 2024.

5.6. Reserves Policy

It is the charity's aim to hold reserves so that it can be confident of its financial position and can meet its financial obligations at any point. The charity's current financial obligations are of a discretionary nature.

The charity's reserves policy takes into account that it may commit to fund research expenditures over the medium term whilst recognising that there may be a level of volatility in its income due to the inherent uncertainty of fundraising activities. The trustees have therefore decided that PCD Research will not enter into financial commitments with third parties unless it has secured prior funding. The charity will hold sufficient funds in reserves to ensure that it can meet any contractual commitment to funding future research and clinical projects.

Notwithstanding the above, given the lack of data points on fundraising and a normalised level of expenses, the trustees have also decided to keep a minimum reserve of £10,000 at all times earmarked for any contingencies.

5.7. Guarantees and Secured Debts

As of 31st December 2023, no guarantees were given by PCD Research. No debts are outstanding as of the date of statement of assets and liabilities.

5.8. Subsequent Events

In December 2022 PCD Research was notified that its application for a £250,000 research grant in collaboration with the Medical Research Council (MRC) funded Nucleic Acid Therapy Accelerator (NATA) was successful. PCD Research and NATA will jointly fund a two-year post-doctoral position, with PCD Research contributing one third (£83,000) towards the project. The grant will be administered by PCD Research. In March 2023 the Scientific Advisory Panel decided to award the funds to a project team lead by Prof. Hart from University College, London (UCL). As of December 2023 the charity was continuing to negotiate the terms of the contract with UCL.

The grant contract between PCD Research and NATA was signed on 21 February 2024 and on 24 March 2024 the charity received the portion of the funding to be contributed by NATA (£167,000) into its accounts. PCD Research expects that the grant will be disbursed to UCL during the financial years 2024 and 2025.

CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of	PCD Research		
On accounts for the year ended	Period ended 31 Dec 2023	**Charity no (if any)**	1197528
Set out on pages	9-13 of the Annual Report and Accounts (remember to include the page numbers of additional sheets)		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 Dec 2023.

Responsibilities and basis of report

As the charity trustees of the Trust, 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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the 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 which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

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

Signed:		**Date:**	9 Jun 2024
Name:	Benjamin Greene		
Relevant professional qualification(s) or body (if any):	Fellow of Institute of Chartered Accountants in England and Wales		
Address:	21 Greville Park Road, Ashtead, KT21 2QU		

PCD RESEARCH

England & Wales - Charity number 1197528

Accounts

PCD Research
PCDresearch.org

(A Charitable Incorporated Organisation Regulated by the UK Charities Commission)

Registered Number
1197528

Annual Report and Accounts
Period ending
31st December 2022

Registered Address:
87 Belsize Lane
London NW3 5AU
info@PCDResearch.org

1. Overview

This document provides the annual report and accounts of PCD Research CIO ("PCD Research", or the "charity"). The trustees present their report and accounts for its initial financial year, the period from its date of incorporation on 17th January 2022 to 31st December 2022.

1.1. Objectives and Principal Activities

The charity is registered and regulated by the UK Charity Commission. Its reference is 1197528.

The objectives of the charity are to advance the health of children and adults with primary ciliary dyskinesia (PCD) by supporting research into A) understanding PCD and B) novel therapeutic targets and therapies for PCD. The charity will carry out these objectives by funding pure scientific and applied/translational research for the public benefit of improving the health and outcome of people with PCD.

1.2. Trustees and Governance

PCD Research does not have any staff at the moment. Instead, it is governed by its board of trustees, who are dedicating their time and efforts on a pro bono basis. PCD Research was set up as a Charitable Incorporated Organisation. Its constitutional document includes provisions relating to the appointment of trustees. Each trustee is appointed for an initial term of three years, whereupon they can be reappointed.

The following persons served as trustees during the period ending on 31st December 2022:

Dr Harriet Holme - Chair of the Trustees - Appointed on 17th January 2022
Dr Gurhan Erturan - Trustee - Appointed on 17th January 2022
Natalie Gehl – Trustee - Appointed on 17th January 2022
Lucy Dixon – Trustee - Appointed on 17th January 2022, resigned on 24th April 2023

Subsequently, the following additional trustees were appointed:
Michelle Levene - Trustee - Appointed on 24th April 2023
Harriet Nowell-Smith - Trustee - Appointed on 24th April 2023
Oliver Burgel - Trustee - Appointed on 24th April 2023

The trustees were approached and appointed with the aim of establishing a board with diverse professional experience at senior level as well as direct patient experience and impact of PCD on family life. At present, the range of professional expertise covers clinical medicine, research (scientific, translational and medical), drug development strategy and development in advanced therapeutics, rare diseases, public and international law, fundraising and finance. Two of the trustees are parents of a children with PCD.

The charity's key policy documents, such as Conflict of Interest Policy, Funding Policy, Animal Research Policy Expense Policy and Research Strategy are available on request by contacting info@PCDResearch.org.

The charity's address is 87 Belsize Lane, London NW3 5AU.

2. Trustees' Report

PCD Research is a medical research charity that was incorporated and registered with the UK Charity's Commission on 17th January 2022. The aims of PCD Research include improved treatment options for people with PCD by funding research and improving the standard of care. It is the only charity worldwide funding research towards finding a cure for PCD. PCD Research also uses conceptual models from the field of oncology to advance research into better treatments.

2.1. What is Primary Ciliary Dyskinesia

Primary ciliary dyskinesia is a genetic condition that affects approximately one in 7,500 people. Mutations in approximately 50 genes have been found to cause PCD. This leads to a range of severity. PCD leads to permanent damage of the lungs, and for people with the most severe disease, this happens decades earlier than those with milder disease. One in 20 people are carriers with one affected copy of a gene that causes PCD. Leaders in the field think that carriers might have a separate set of symptoms that overlap with difficult to treat asthma.

Motile cilia are like microscopic hairs that beat throughout the body, including in the airways and sinuses, clearing out secretions and infections. In PCD, the cilia are abnormal and unable to move in the usual way, such that secretions and infections affect the lungs, sinuses, ears and nose. Cilia are also important for the propulsion of sperm, so fertility is commonly affected as well. It is likely that PCD affects other pathways in the body in ways that are not yet understood.

2.2. Treatment and Outcome

PCD is a life altering and life shortening condition. Children with PCD have been found to have worse lung function than those with cystic fibrosis (CF) but are unable to access the same standard of care in the UK. In the case of CF, there has been an active program of research that has led to breakthrough drugs that almost cure CF. Sadly these drugs are not suitable for people with PCD.

At present the respiratory aspect of PCD is managed by a brutal regimen of chest physiotherapy to try to prevent and slow lung function decline. There are no dedicated treatments for PCD, instead current treatments have been borrowed from experience with people with CF. Physiotherapy is supplemented with frequent courses of antibiotics to treat and reduce episodes of pneumonia. This is a significant burden on people with PCD and their families.

People with PCD face dramatic challenges from living with the disease. Treatment causes an enormous burden in terms of the hours of daily chest physiotherapy needed to clear the lungs of mucus, using methods borrowed from a mechanistically distinct disease (cystic fibrosis) without evidence of efficacy in PCD. In addition, patients are subject to frequent courses of antibiotics in an attempt to reduce the rate of lung function decline. Some people with PCD will still need a lung transplant.

While children and adults with PCD may look healthy, PCD is a progressive disease, where lung function declines over time. At present there are no medications that can stop this decline or restore cilia function. There are no NICE guidelines. The Commissioned Service Providers are currently developing a Standard of Care.

2.3. Formation of the Charity and Research Objectives

PCD Research was set up to advance the health of children and adults with primary ciliary dyskinesia (PCD) by supporting research into A) understanding PCD and B) novel therapeutic targets and

therapies for PCD. The charity will carry out these objectives by funding pure scientific and applied/translational research for the public benefit of improving the health and outcome of people with PCD.

2.4. Achievements of PCD Research during 2022

The key achievements of the charity during its first year after foundation can be summarised as follows:

- Establishment of the charity,
- Appointment of a world-class Scientific Advisory Panel (SAP),
- Development of a research strategy, and
- Establishment of successful fundraising and grant application process.

2.4.1. Appointment of a Scientific Advisory Panel

To ensure that the most promising research is funded, PCD Research is engaging with leading academics in the fields of PCD, CF, bronchiectasis, gene augmentation and gene editing. This has enabled PCD Research to form a Scientific Advisory Panel (SAP) with a range of experience, who are international and independent, to focus on development of novel therapies for PCD. The members of the SAP were appointed to robustly scrutinise grant applications, so that only the most promising research is funded. The SAP currently comprises 25 academics from top tier universities and teaching hospitals in the UK, US, Germany, Canada, Israel, France and Belgium.

Academics in the PCD Research community have been delighted to offer up their time to do this, and were excited at the possible future research opportunities PCD Research will facilitate. Heidi Bjornson-Purnell was appointed as the Chair of the SAP. Heidi currently works as a project manager at the Chan Zuckerberg Initiative (CZI) Rare As One, is a former barrister and the parent of two children with PCD.

2.4.2. Development of a Research Strategy

PCD Research's primary goal is to advance the health of children and adults with Primary Ciliary Dyskinesia (PCD). To meet this mission, our research strategy focuses on targeting the most severe disease phenotypes (inner dynein arm defects with microtubular disorganisation caused by loss of function in genes *CCDC39* and *CCDC40*) because these have the greatest chance of demonstrating efficacy and therefore attaining regulatory approval. This patient population is relatively easy to identify and their form of PCD is so severe that they are likely to be willing to participate in time-consuming and invasive medical trials. We envisage this as a proof of concept stage, such that any novel therapy could then simply be readily adapted for other genes and variants that cause PCD.

PCD Research was founded to support the development of disease modifying or curative therapies for PCD. We support the strategy of prioritising the development of therapies that:

- will have the greatest impact for all patients with PCD within in the shortest period of time;
- are likely to have the greatest success through the regulatory process;
  are likely to justify the use of public money for research by having the potential to deliver the greatest savings for publicly funded health care systems (not just in England) by postponing or removing the need for lung transplants.

Development of novel therapies in the most severe disease phenotype would help those people who experience the most severe disease and are most at risk of dying prematurely.

2.4.3. Establishment of Successful Fundraising and Grant Application Process

During its first year of operation, PCD Research established a fundraising routine and was successful in securing two scientific collaborations.

In 2022 PCD Research raised £153,776.27 through donations. This was raised from a small number of substantial individual donations and various community fundraising efforts. As Chair of PCD Research I would like to personally thank the Brooks family for their substantial fundraising efforts as "100G for PCD", together with donations from Matt Holme, and the Mather Family Charitable Trust.

The scientific collaborations are described below:

- **National Facility for Mouse Genetics Network "Patient-led functional genomics" Cluster, Mary Lyon Centre, Harwell**
  In collaboration with Professor Mill, co-lead of the UKRI MRC National Mouse Genetics Network cluster 'Congenital anomalies: patient-led functional genomics, the Medical Research Council (MRC) funded National Facility for Mouse Genetics Network (NMGN) "Patient-led functional genomics" cluster at the Mary Lyon Centre, Harwell, has agreed to fund an inducible model of PCD caused by loss of function of gene *CCDC39*. PCD Research was instrumental in negotiating and advocating for this patient-derived PCD mouse model. We believe this will be valuable for the research community and will provide the opportunity for future *in vivo* validation of novel therapeutics, together with understanding delivery challenges and safety studies.

- **Nucleic Acid Therapeutic Accelerator (NATA) Collaboration**
  PCD Research will collaborate with the Medical Research Council (MRC) funded Nucleic Acid Therapy Accelerator (NATA) to jointly fund a two-year post-doctoral position. PCD Research will contribute one third (£83,333) of the total cost (£250,000) of this project.

  The scope of this project will be based on the optimisation and delivery of nucleic acid therapies in PCD. Development and optimisation of mRNA therapy that has the potential to restore ciliary function in air-liquid interface cell culture (ALI), which allow scientists to generate stable and functional in vitro 3D human airway cell models that closely mimic respiratory tract epithelia. A grant call for applicants to determine the exact nature of the project and supervisors occurred in the first quarter of 2023.

  The additional benefit to this project is the added significant potential for the researchers to see if the therapy works in a mouse model of PCD that will go into production in Q3 2023 at the MRC funded National Mouse Genetics Network Congenital Anomalies Cluster (loss of function of the CCDC39 gene). This research will provide vital proof of concept for future research targeting different genes causing PCD.

2.4.4. Other Outreach

A website for PCD Research was built in January 2022 that details the mission, shares information about the charity, about the epidemiology of PCD, the SAP and provides information for researchers. @PCD_research and @PCDresearch have been set up on Instagram/Facebook and Twitter respectively, to enable communication of our mission, goals and progress with the patient population, academics and future commercial partners.

PCD Research has also founded links with other organisations representing patients with PCD, both PCD Support UK and internationally the PCD Foundation, USA. Dr Harriet Holme was invited to

highlight the work of PCD Research at PCD Support UK's annual medical board meeting with both an oral presentation and poster.

Dr Harriet Holme represented PCD Research at the EMBO Cilia2022 conference held in Cologne in October 2022. This was a valuable meeting to talk with academics from around the world about the latest research in PCD, roadblocks and how to successfully navigate round these.

2.4.5. Outlook

While the charity had early successes in fund raising and grant application processes, it did not incur substantial expenses during the year of its foundation. This is expected to change during 2023 as the NATA grant will be disbursed through the charity from the beginning of the 2023/24 academic year.

The SAP held its inaugural meeting in March 2023 to peer-review the applications for project and supervision of the research collaboration with NATA. We anticipate that the process of advertising/appointing a post-doctorate position at UCL to start in Q3/4 2023.

PCD Research applied, and was granted membership in February 2023, to the Association of Medical Research Charities (AMRC). AMRC membership is the hallmark of quality research funding for medical research charities. Attaining membership recognises the processes we have put in place to ensure PCD Research only funds research of the highest standards through the SAP peer-review process. We will continue to expand and establish further academic links with the research community and commercial links with interested parties.

PCD Research will continue to build community links with schools for ground roots awareness raising and fundraising and consider our wider strategy for fundraising, while continuing to engage with potential cooperate donors. PCD Research will also seek to form and strengthen links with other charities supporting rare disease such as Genetic Alliance (which PCD Research joined in June 2023) and RareBeacon.

This report was approved by the trustees on 15 August 2023 and signed on their behalf.

Dr Harriet Holme
Chair

3. Statement of Trustees' Responsibilities

The Trustees are responsible for preparing the annual report and the financial statements in accordance with applicable laws and regulations.

UK Charity law (Charities Act 2011 and subsequent amendments) requires the Trustees to prepare accounts for each financial year. The accounts have been prepared on a receipts and payments basis as provided for under section 133 of the Charities Act 2011. PCD Research is a smaller charity for the purpose of reporting.

Under charity law the Trustees must not approve the accounts unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the profit or loss of the charity for that period. When preparing these accounts, the Trustees:

- selected suitable accounting policies and applied them consistently;
- made judgements and estimates that are reasonable and prudent;
- prepared the financial statements on the going concern basis.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with applicable regulations. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

This report was approved by the trustees on 15 August 2023 and signed on their behalf.

Dr Harriet Holme
Chair

4. Financial Review

4.1. Receipts and Payments for the period from 17th January 2022 to 31st December 2022

	Notes	Unrestricted	Restricted	Endowment	Total 2022
		£	£	£	£
Receipts					
- Donations		153,776.27	-	-	153,776.27
- Charitable activities		-	-	-	-
- Investments		-	-	-	-
- Other		-	-	-	-
Total Receipts		**153,776.27**	**-**	**-**	**153,776.27**
Payments					
- Raising funds		-2,240.00	-	-	-2,240.00
- Charitable Activities		-228.18	-	-	-228.18
- Other					
Total Payments		**-2,468.18**	**-**	**-**	**-2,468.18**
Net Income		**151,308.09**	**-**	**-**	**151,308.09**
Transfer of Funds		-	-	-	-
Revaluation of Fixed Assets		-	-	-	-
Other Gains / Losses		-	-	-	-
Net Movement in Funds		**151,308.09**	**-**	**-**	**151,308.09**
Balances Carried Forward at 17st Jan 2022		-	-	-	-
Balances Carried Forward at 31st December 2022		**151,308.09**	**-**	**-**	**151,308.09**

During the period ending December 2022 the charity recorded receipts of £153,776.27. The largest donation was made by an individual donor for the amount of £100,000. The remaining funds of £53,776.27 were raised from about 60 individual donations.

As the charity was in the process of commencing its activities, no grants were made during the financial year 2022. The payments made during the financial year were £2,468.18. These consisted of minor administrative expenses of £228.18 incurred in conjunction with operating the charity and £2,240 incurred for securing places for the 2023 London Charities Half Marathon that raised approximately £6,000.

4.2. Statement of Assets and Liabilities as at 31st December 2022

	Jan 2022	Dec 2022
	£	£
Fixed Assets		
Intangible Assets	-	-
Tangible Assets	-	-
Heritage Assets	-	-
Investments	-	-
Total Fixed Assets	-	-
Current Assets		
Stocks	-	-
Debtors	-	-
Investments	-	-
Cash at Bank	-	151,308.09
Total Current Assets	-	**151,308.09**
Liabilities		
Creditors: Amounts Falling Due Within One Year	-	
Net Current Assets	**-**	**151,308.09**
Total Assets Less Current Liabilities		**151,308.09**
Creditors: Amounts Falling Due Within More Than One Year	-	-
Provision for Liabilities		
Net Assets	**-**	**151,308.09**
Capital and Reserves		
Unrestricted Funds	-	151,308.09
Restricted Funds	-	-
Endowment Funds	-	-
Total Charity Funds	**-**	**151,308.09**

As of 31st December 2022, the only asset owned by the charity consisted of cash held on its bank account. The charity has no financial or other liabilities.

As a result of the fundraising activities by the charity exceeding the expenses incurred, the charity's own funds at 31st December 2022 amounted to £151,308.09.

Harriet Holme
Chair
Approved by the trustees on 15 August 2023.

4.3. Cash-Flow Statement as at 31st December 2022

	Period ending 31st December 2022
Opening Cash as of 17th January 2022	0
Cash receipts during the year	153,776.27
Payments made during the year	-2,468.18
Net Movement of Funds	**151,308.09**
Closing Cash as of 31st December 2022	**151,308.09**

The charity's cash position evolved strongly as a result of the strong inflow from donations exceeding the administrative expenses incurred during the financial year. As a result, the year-end cash position in its bank account amounted to £151,308.09. This situation is expected to change during 2023 as the charity will begin to move towards funding its first research projects.

5. Notes to the Financial Statements for the period from 17th January 2022 to 31st December 2022

5.1. Accounting Policies

Basis of preparation
The accounts have been prepared on a receipts and payments basis as provided for under section 133 of the Charities Act 2011. PCD Research is a smaller charity for the purpose of reporting.

The charity is a Charitable Incorporated Organisation and does not have any subsidiaries or branches.

Recognition of Income
All forms of income are recognised on a cash basis at the point when the charity receives funds into its bank account.

Recognition of Expenses
All expenditures are accounted for on a payment basis and are recognised at the point where funds leave the charity's bank account.

5.2. Statement of Funds

	17st January 2022	Receipts	Payments	31st December 2022
	£	£	£	£
General Unrestricted Funds		153,776.27	-2,468.18	151,308.09
Designated Unrestricted Funds	0	0	0	0
Total Unrestricted Funds	**0**	**153,776.27**	**-2,468.18**	**151,308.09**
Total Restricted Funds	**0**	**0**	**0**	**0**
Total Endowment Funds	**0**	**0**	**0**	**0**
Total Funds	**0**	**153,776.27**	**-2,468.18**	**151,308.09**

As of 31st December 2022, all funds represented as General Unrestricted Funds. These were not earmarked for a specific purpose. During the financial year 2022, the charity held neither restricted funds nor endowment funds. There were no transfers between any classes of funds during the year.

5.3. Independent Examination

As the 2022 annual receipts of the charity exceeded £25,000 an independent examiner was appointed to provide independent assurance that the charity's money has been appropriately accounted for. The independent examiner has waived any fees for his services.

5.4. Trustees Remuneration and Expenses

During the period ending on 31st December 2022 none of the trustees received any remuneration or benefits from an employment with the charity. In addition, no trustee expenses were incurred.

5.5. Related Party Transactions

During the period ending on 31st December 2022 the charity received a £25 donation from a trustee as part of the account opening process with the charity's account bank.

5.6. Reserves Policy

It is the charity's aim to hold reserves so that it can be confident of its financial position and can meet its financial obligations at any point. The charity's current financial obligations are of a discretionary nature.

The charity's reserves policy takes into account that it may commit to fund research expenditures over the medium term whilst recognising that there may be a level of volatility in its income due to the inherent uncertainty of fundraising activities. The trustees have therefore decided that PCD Research will not enter into financial commitments with third parties unless it has secured prior funding. The charity will hold sufficient funds in reserves to ensure that it can meet any contractual commitment to funding future research and clinical projects.

Notwithstanding the above, given the lack of data points on fundraising and a normalised level of expenses, the trustees have also decided to keep a minimum reserve of £10,000 at all times earmarked for any contingencies.

5.7. Guarantees and Secured Debts

As of 31st December 2022, no guarantees were given by PCD Research. No debts are outstanding as of the date of statement of assets and liabilities.

5.8. Subsequent Events

In December 2022 PCD Research was notified that its application for a £250,000 research grant in collaboration with the Medical Research Council (MRC) funded Nucleic Acid Therapy Accelerator (NATA) was successful. PCD Research and NATA will jointly fund a two-year post-doctoral position. PCD Research will contribute one third (£83,333) towards the budget, which is well within its available resources. The grant will be administered by PCD Research and the Scientific Advisory Panel subsequently decided to award the funds to a project team lead by Prof. Hart from University College, London. At the time of publication of this report, the charity was engaged in negotiating the terms of the contract with UCL.

CHARITY COMMISSION FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of	PCD Research		
On accounts for the year ended	Period ended 31 Dec 2022 (Charity registered 17 Jan 2022)	**Charity no (if any)**	1197528
Set out on pages	6-12 of the Annual Report and Accounts (remember to include the page numbers of additional sheets)		

Responsibilities and basis of report

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period from registration on 17 Jan 2022 to 31 Dec 2022.

As the charity trustees of the Trust, 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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the 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 which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

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

Signed:	BC Greene	**Date:**	10 Oct 2023
Name:	Benjamin Greene		
Relevant professional qualification(s) or body (if any):	Fellow of Institute of Chartered Accountants in England and Wales		
Address:	21 Greville Park Road, Ashtead, KT21 2QU		