

# PRIMARY CILIARY DYSKINESIA SUPPORT UK

England & Wales · Charity number 1049931

## Details

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Other names	PCD FAMILY SUPPORT GROUP, PRIMARY CILIARY DYSKINESIA (PCD) FAMILY SUPPORT GROUP, PCD SUPPORT UK
Status	Registered
Legal form	Other
Registered	1995-10-17
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Address	3 Laggan Road Maidenhead Berkshire SL6 7JY
Phone	000000000000
Email	<a href="mailto:chair@pcdsupport.org.uk">chair@pcdsupport.org.uk</a>
Website	<a href="http://www.pcdsupport.org.uk">www.pcdsupport.org.uk</a>

## Activities

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**Objects:** 1) THE RELIEF OF PERSONS AFFECTED BY PRIMARY CILIARY DYSKINESIA AND ALLIED CONDITIONS. 2) TO ADVANCE MEDICAL RESEARCH INTO THE CAUSE, CURE, PREVENTION OR RELIEF OF SUCH CONDITIONS PROVIDED THAT THE USEFUL RESULTS OF THE RESEARCH SHALL BE PUBLISHED.

**Activities:** 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.

## Classification

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- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

## Geography

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- Scotland
- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2024-12-31	£66,445	£41,020	-	-
2023-12-31	£20,511	£51,272	-	-
2022-12-31	£36,913	£25,308	-	-
2021-12-31	£54,967	£16,949	-	-
2020-12-31	£33,209	£9,759	-	-

## Trustees

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Name	Role	Appointed
<b>Katie Dexter</b>	Chair	2021-01-01
Abdullah Ihsan		2020-06-27
Gary Tipping		
Myra Tipping		

**PRIMARY CILIARY DYSKINESIA SUPPORT UK**

England & Wales - Charity number 1049931

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# Accounts

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# 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:**

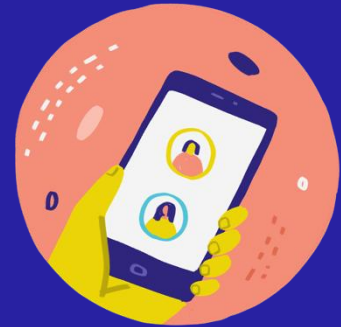
Katie Dexter (Chair)

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

Leeds

**Independent Examiner:**

Shaw Gibbs Limited

Eagle House

28 Billing Road

Northampton

Northants NN1 5AJ



# 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.*

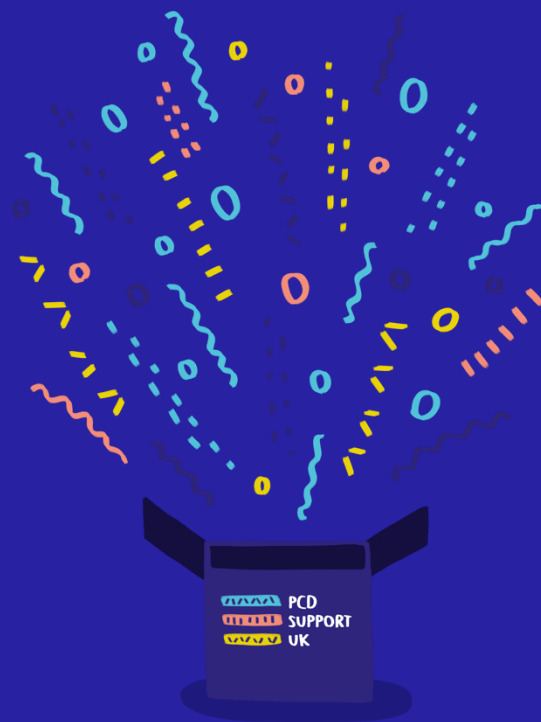
*PCD Support UK have previously bought my daughter a new trampoline so she can be encouraged to do her physio after her old one took off in the wind, I have had lengthy chats with Lucy multiple times on the phone when I have been at my wits end needing someone to talk to, and recently I was awarded a 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

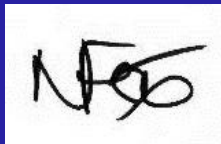
I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

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	£	£
<b>Income Receipts</b>		
Grants and Donations	65,994	14,228
Other Income	-	-
NHS funding for website services	-	6,000
<b>Investment activities</b>		
Interest receivable	451	283
Other Income	-	-
<b>Total Receipts</b>	<b>66,445</b>	<b>20,511</b>
<b>Direct charitable expenditure</b>		
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
<b>Total direct charitable expenditure</b>	<b>33,663</b>	<b>43,030</b>
<b>Support costs</b>		
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	-
<b>Total support costs</b>	<b>7,357</b>	<b>8,242</b>
<b>Total payments</b>	<b>41,020</b>	<b>51,272</b>
Net increase/(decrease) in cash for the year	<b>25,425</b>	<b>-30,762</b>
Cash balances at 31 December brought forward	82,486	113,247
Cash balances at 31 December carried forward	<b>107,912</b>	<b>82,486</b>

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

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

**PRIMARY CILIARY DYSKINESIA SUPPORT UK**

England & Wales - Charity number 1049931

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# Accounts

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**PCD Support UK**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**



**TRUSTEES' REPORT AND ACCOUNTS  
FOR THE YEAR ENDED 31 DECEMBER 2021**

**PCD Support UK**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**

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**PCD Support UK**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**

**CHARITY INFORMATION**

**CHARITY NAME:** Primary Ciliary Dyskinesia Support UK

**OTHER NAME CHARITY IS KNOWN AS (Working Name):** PCD Support UK

**TRUSTEES:** Lucy Dixon (Chair)  
Abdullah Ihsan (Treasurer)  
Myra Tipping  
Gary Tipping  
Susanne Shanks  
Poonam Jagdish Sodha - appointed 01/01/21  
Katie Dexter - appointed 01/01/21  
Nhu Tran - resigned 01/12/2021  
Edel Clough - resigned 01/12/2021

**PRINCIPAL ADDRESS:** PCD Support UK  
PO Box: 2233  
Buckingham  
MK18 9DX

**CHARITY NUMBER:** 1049931

**BANKERS:** Barclays Bank PLC  
93/95 Main Street  
Garforth  
Leeds

**INDEPENDENT EXAMINER:** DNG Dove Naish LLP  
Chartered Accountants  
Eagle House  
28 Billing Road  
Northampton  
Northants NN1 5AJ

## **TRUSTEES' REPORT: 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 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 advance 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

## TRUSTEES' REPORT: ACHIEVEMENTS AND PERFORMANCE

During 2021, PCD Support UK has:

### **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, as well as arranging phone calls on a regular basis. We have an active Facebook page (with 1.6k followers, increasing from 1.2k in 2020), an Instagram page (with 552 followers, increasing from 379 in 2020), a Twitter page (923 followers, increasing from 785 in 2020) and a 'Health-Unlocked' online discussion board (with 565 users, up from 429 in 2020).
- In 2021, we supported patients to set up a private community forum called PCD Connect on Facebook, which has 196 members and allows those with PCD in the UK to connect with one another in a safe and friendly setting.
- For the second year running, we were unable to hold our annual PCD Day in person (due to Covid-19). Instead, we held our PCD day and AGM online. The event was better attended than most in-person events we have run in the past and gave patients and families the opportunity to participate in a Q&A led by the PCD clinical specialists. We envisage switching to the online model in future years, particularly as infection control and prevention guidelines discourage in-person mixing of people with PCD, due to risk of cross infection.
- We revealed our new rebrand and new charity name that brings PCD Support UK in line with our wish to be as inclusive and accessible to the patient community as possible. We also have undertaken a process of streamlining our online presence, by removing duplicate social media accounts (such as the Scotland sub-committee's Facebook page) and renaming our Scotland sub-committee 'PCD Support UK - Scotland Team'.
- We regularly provide newsletters with information about latest research developments and charity news. We have commissioned a review of our newsletter

## PCD Support UK

### ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021

process for 2022, including plans to change the provider we use to send our newsletter.

- We continue to support the PCD community through the Covid-19 pandemic and have sent several letters of support to patients and their GPs when patients have struggled to obtain Covid-19 vaccines or adequate healthcare during the pandemic.
- 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 continue to work collaboratively on a project with a medical technology company (who are offering their service pro bono), in order to explore a digital solution to monitoring and managing PCD. This research is participatory and is being co-produced by the PCD community. We have set up a patient involvement group to provide regular feedback and a clinical trial is planned for 2022.
- The Scotland Team (committee subgroup) continue to work towards setting up a Scottish service for PCD and although Covid-19 stalled much of this progress, the group continued to meet regularly via videoconference and to support Scottish patients to access appropriate health services during the pandemic.
- We have helped ensure that the Adult PCD service has been set up smoothly and have raised awareness of this among the patient community to ensure that as many as possible access this new, bespoke service for adults with PCD.
- We have supported families and individuals with small grants including for trampolines, help with travel costs, cost of application for welfare benefits advice, purchasing of portable nebulisers and other ad hoc requests.
- We have worked with an organisation called Over the Wall to arrange an online family camp for 2022, to help more young people with PCD meet others with the condition. This began recruiting in 2021 and this will be held 6 March 2022. Families will join online and will receive a box of activities to do on the day.
- We worked jointly with the University of Southampton and provided a grant to assist with the production of four patient information videos that will be used to inform those accessing diagnostic PCD services about what to expect during diagnostic testing.
- We have a new volunteer who is helping to translate research articles about PCD into lay summaries to make this knowledge more accessible to the patient community.

ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021

**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 general public**

- We have an active website page and regularly use social media sites such as Facebook, Instagram and Twitter to reach our members, as well as email newsletter publications.
- We continued to educate the wider community about PCD by speaking to Medical Students at Cardiff University and Genetic Counselling students at the University of Southampton for a second year running.
- We gave a talk to the Cross-Party Group for Medical Research at the Welsh Assembly (remotely) on PCD and the importance of Medical Research.
- Our committee members and volunteers have continued to engage the wider medical community giving talks to MSc Genetics students at Imperial College London, participating in the Real-World Evidence Live Virtual Series and delivering a talk to Genomics England Research Seminar.
- We have commissioned a new website and are working with the PCD medical community to continue to update and improve the information service available.
- We have taken part in numerous Patient and Public Involvement and Engagement opportunities, including committee members representing us on several committees and boards of the BEAT-PCD CRC, ERN Lung PCD Core Group and Genetic Alliance UK meetings.
- We have spoken at the Journal of Cell Science BSCB Genetics Society Symposia to an audience of cilia experts. We have also spoken at the ERN LUNG PCD core meeting “Adapting to Digital Communications during the COVID-19 pandemic” in June and presented a poster at the ELF Patient Organisation Networking Day in September.
- 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.
- Due to Covid-19 we had to postpone our biennial PCD Medical Board meeting for another year and have rescheduled this to 2022, however the costs of this were rolled over from 2020.
- We contacted respiratory experts in Wales and have begun talks for bidding for a bespoke PCD service for Wales-based patients.
- We resumed our conference attendance this year and held an online stand at the British Thoracic Society conference in November 2021. We also took part in the virtual Scottish Thoracic Society conference in June 2021.

## PCD Support UK

### ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021

- Our Scottish Team members represented us at two Scottish Government Cross Party Groups: CPG for Rare, Genetic and Undiagnosed Conditions and CPG for Lung Health. They have also taken part in developing the Rare Disease Scottish framework.
- One of our committee members participated in a global focus group with the Chan-Zuckerberg Initiative, which raised considerable awareness of PCD via a two-day international workshop on Advancing Diagnosis for Rare Diseases.

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

- We continue to work as part of the Ciliopathy Alliance and with the British Lung Foundation.
- We continue to work with the adult bronchiectasis physicians as patient representatives for the BronchUK group.
- We are co-applicants on a number of bids for funding for PCD related research projects in conjunction with the PCD Centres.
- We work with our European counterparts to promote research within and from the BEAT-PCD ERS clinical research collaboration.
- We have promoted several research projects this year and continue to sponsor the Covid-19 and PCD study in order to ensure its continuation.
- We have supported many researchers this year to recruit patient participants and have disseminated these studies through our social media and public talks.
- Our Chair completed a Master's thesis on how PCD impacts the patient community beyond the traditional clinical domains. This was shared with the patient and clinical community and has contributed to generating further research possibilities, previously not considered.
- Since May 2021, two of our committee members and three volunteer families have regularly participated in a Public Participation and Involvement group as part of a physiotherapy study.

### **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

## PCD Support UK

### ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021

and management services. We are active participants in their regular review meetings.

- We have collated and provided patient feedback to the NHS Specialised Services commissioners about the implementation of the 'NHS@Home' spirometry rollout.
- We have offered to financially support one of the specialist centres with additional costs of a patient receiving a second opinion for a transplant at a centre outside of the UK (this continues to be finalised).
- We have provided feedback and protocol support regarding the establishment of a new patient registry across the four specialist centres in England.
- We have also been working closely with the adult PCD physicians and NHS Specialised Services in the implementation plans for the adult service. We are pleased that the adult service is beginning to come into effect, with most specialist centres now operating the service via teleconference or in person. We have regularly been in contact with some of the adult PCD centres where there have been delays to the service being established, to ensure that patients are not missing out and to facilitate NHS access to patients who have not previously been under a specialist service.
- We have also been working with the NHS regarding the reallocation of services from the Royal Brompton Hospital. We continue to participate in the public consultation group for the new building at the Evelina London Children's Hospital at St Thomas', which is where the paediatric PCD service at the Royal Brompton will eventually relocate to in several years' time.
- We have had conversations with Cystic Fibrosis consultants in Wales about the possibility of establishing a PCD service in Wales. These discussions are ongoing.

### Strategic Objective 5: Fundraise to support the above activities

- We have had several donations in lieu of birthday gifts and instead of sending Christmas cards. We have also had an increase in fundraising from our members, who have fundraised for us through many innovative means this year, despite cancelled sporting events.
- The sale of PCD jewellery by our "PCD Angel" Debbie Richards continued to contribute funds to our cause. We have a small number of regular donators and will be looking to continue to increase this source of income.
- We encourage our community to donate to us through AmazonSmile and our JustGiving page has seen a substantial increase in donations, for which we are immensely grateful.
- Our new website has been designed to emphasise means of donating to PCD Support UK.

**PCD Support UK**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**  
**TRUSTEES' REPORT: 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 reserves at the end of 2021 stood at £101,642 (2020: £63,624). The committee and members continued their fundraising efforts through several events this year (even with the restrictions of Covid-19) and as a result we have a substantial increase in the total funds donated. Another reason for an increase is due to the £40k bequest from the estate of George H Brown. The income for the year totalled £54,967 (2020: £33,209), including grants, donations and fundraising received totalling £51,409 (2020: £25,686) and contributions of £3,000<sup>1</sup> from the NHS in relation to the ongoing costs of the PCD website. We are still waiting on an outstanding £6,000 from NHS support funds, whilst £1,500 of fees from some NHS trusts were settled in early 2022. Investment income generated from interest totalled £2.96, a decrease of 87% when compared to investment income generated in 2020.

We have a commitment to fund support of the website on top of the normal expenditure incurred which includes attending conferences, producing leaflets, newsletters and delivering ongoing events and educational talks. We have increased our presence regionally 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 £61,638.

In line with trustees' agreement, the charity changed its registered name with the Charity Commission to Primary Ciliary Dyskinesia Support UK, with a working name of PCD Support UK in January 2021. We updated and modernised our governing document in accordance with these changes.

The trustees would like to express thanks to all of the fundraisers who have contributed their efforts to the charity or donated funds during 2021. Special thanks go to: The Brown family, the Brooks family, Nhu Tran and Kylie, James Nancarrow, Georgia Dixon, Ruby Spooner, John Burton, Nina Peters and family.

This report was approved by the trustees on Monday 14<sup>th</sup> February 2022 and signed on their behalf.



Abdullah Ihsan - Treasurer and Trustee

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<sup>1</sup> £3,000 received from NHS centres in 2021 to cover outstanding fees for 2020 web hosting.

**PCD Support UK**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**  
**INDEPENDENT EXAMINERS STATEMENT**

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE PRIMARY CILIARY DYSKINESIA FAMILY SUPPORT GROUP**

I report on the accounts of the Primary Ciliary Dyskinesia Family Support Group (Charity number: 1049931) year ended 31 December 2021 which are set out on pages 12 and 13.

**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 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 Trust 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 confirm that there are no other matters to which your attention should be drawn 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  
DNG Dove Naish LLP  
Chartered Accountants

**PCD Support UK**

**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**

Eagle House  
28 Billing Road  
Northampton  
NN1 5AJ  
Date: 14<sup>th</sup> March 2022

PCD Support UK

ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021  
**ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021**

	Unrestricted fund	Restricted funds	2021 Total	2020	2019
	£	£	£	£	£
<b>RECEIPTS AND PAYMENTS ACCOUNT: GENERAL UNRESTRCITED FUND</b>					
<b>Income Receipts</b>					
Grants and Donations	11,410	40,004 <sup>2</sup>	51,409	25,686	9,404
Sponsored events and fundraising	555	-	555	-	4,078
NHS funding for website services	3,000	-	3,000 <sup>3</sup>	7,500	4,500
<b>Investment activities</b>					
Interest receivable	3	-	3	23	59
Other Income	-	-	-	-	-
<b>Total Receipts</b>	<b>14,963</b>	<b>40,004</b>	<b>54,967</b>	<b>33,209</b>	<b>18,041</b>
<b>Direct charitable expenditure</b>					
AGM & Family Day	282	-	282	616	2,785
Regional Events	275	-	275	-	1,348
Marketing (leaflets, newsletter, and merchandise)	835	-	835	43	3,522
Website costs incl. maintenance of multi-media resource	2,423	10,000	12,423 <sup>4</sup>	1,975	1,862
Conference costs	360	-	360	1,323	469
Research and treatment equipment grants	170	-	170	3,533	-
<b>Total direct charitable expenditure</b>	<b>4,345</b>	<b>10,000</b>	<b>14,345</b>	<b>7,490</b>	<b>9,986</b>
<b>Support costs</b>					
Printing, telephones, postage, and stationery	518	-	518	146	348
Travel Expenses of trustees	266	-	266	848	2,713
Subscriptions	803	-	803	717	1,032
Sustenance	201	-	201	73	202
Independent Examination fee	600	-	600	300	-
Fundraising services	216	-	216	185	216
<b>Total support costs</b>	<b>2,604</b>	<b>-</b>	<b>2,604</b>	<b>2,269</b>	<b>4,511</b>
<b>Total payments</b>	<b>6,949</b>	<b>10,000</b>	<b>16,949</b>	<b>9,759</b>	<b>14,497</b>
Net increase/(decrease) in cash for the year	<b>8,014</b>	<b>30,004</b>	<b>38,018</b>	<b>23,450</b>	<b>3,544</b>
Cash balances at 31 December brought forward	53,624	10,000	63,624	40,174	36,630
Cash balances at 31 December carried forward	<b>61,638</b>	<b>40,004</b>	<b>101,642</b>	<b>63,624</b>	<b>40,174</b>

<sup>2</sup> Bequest from the estate of George H brown

<sup>3</sup> Web hosting fees from the NHS to cover outstanding fees from 2020

<sup>4</sup> 10,000 of this was spent from the grant received by the UK Government Covid-19 fund, distributed via the Lottery Community Grants

PCD Support UK

ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021  
**STATEMENT OF ASSETS AND LIABILITIES AS AT 31 DECEMBER 2021**

	Unrestricted Funds	Restricted Funds <sup>5</sup>	2021 Total	2020	2019
	£	£	£	£	£
<b>MONETARY ASSETS</b> (all general fund)					
Cash at bank and in hand	61,638	40,004	101,642	63,624	40,174
<b>Debtors</b>					
Amounts due from NHS funding	6,000	-	6,000 <sup>6</sup>	3,000	4,500
<b>Creditors</b>					
DNG Dove Naish LLP Independent Examiner's fees	750	-	750	600	300
2021 deposit for PCD medical board meeting	-	-	-	1,186	-

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<sup>5</sup> Restricted funds are to be used for purely for Research and Development as requested by the family of George W Brown. The family have also mentioned this can be used in other areas if required. We will request the permission of the family before being used in other areas of our charity.

<sup>6</sup> £6,000 still due for 2021 fees

**PRIMARY CILIARY DYSKINESIA SUPPORT UK**

England & Wales - Charity number 1049931

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# Accounts

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THE PRIMARY CILIARY DYSKINESIA FAMILY SUPPORT GROUP  
ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2020



**TRUSTEES' REPORT AND ACCOUNTS  
FOR THE YEAR ENDED 31 DECEMBER 2020**

THE PRIMARY CILIARY DYSKINESIA FAMILY SUPPORT GROUP  
ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2020

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THE PRIMARY CILIARY DYSKINESIA FAMILY SUPPORT GROUP  
ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2020

## CHARITY INFORMATION

**OTHER NAME CHARITY IS KNOWN AS:** PCD Family Support Group

**TRUSTEES:** Lucy Dixon (Chair) – Appointed 27<sup>th</sup> June 2020  
Abdullah Ihsan (Treasurer)-appointed 27<sup>th</sup> June 2020  
Edel Clough  
Myra Tipping  
Gary Tipping  
Nhu Tran  
Susanne Shanks  
Fiona Copeland – resigned 27<sup>th</sup> June 2020  
Beatrice Redfern – resigned 27<sup>th</sup> June 2020  
Terry Irwin – resigned 27<sup>th</sup> June 2020

**PRINCIPAL ADDRESS:** PO Box: 2233  
Buckingham  
MK18 9DX

**CHARITY NUMBER:** 1049931

**BANKERS:** Barclays Bank PLC  
93/95 Main Street  
Garforth  
Leeds

**INDEPENDENT EXAMINER:** DNG Dove Naish LLP  
Chartered Accountants  
Eagle House  
28 Billing Road  
Northampton  
Northants NN1 5AJ

## TRUSTEES' REPORT: 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

The Primary Ciliary Dyskinesia (PCD) Family Support Group is constituted by a governing document dated March 1994 and is a registered charity.

### OBJECTIVES AND ACTIVITIES

The charity was formed to provide support to patients with PCD and parents of children known to have the condition. 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 who may come across PCD and continue to 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. Work with the NHS and other bodies to ensure patients have access to diagnostic services and on-going care
5. Fundraise to support the above activities

## TRUSTEES' REPORT: ACHIEVEMENTS AND PERFORMANCE

During the year the Primary Ciliary Dyskinesia Family Support Group has: -

### **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 answering phone calls, emails and contact through our website and social media channels. We have an active Facebook page (with 1.2k followers), an Instagram page (with 379 followers), a twitter page (785 followers) and a 'Health-Unlocked' online discussion board (with 429 users).
- Due to the Covid-19 pandemic, we were unable to hold our annual PCD Day in person, nor our Scottish PCD day. Instead, we held our PCD day and AGM online. The event was better attended than most in-person events we have run in the past and gave patients and families the opportunity to participate in a Q&A led by the PCD clinical specialists. We also said goodbye to our longstanding chair of 17 years, Fiona Copeland BEM (who received a New Year's Honour for her contribution to supporting the PCD community this year)
- We regularly provide newsletters with information about latest research developments.
- The outbreak of Covid-19 across the UK meant that all people with PCD were considered 'Clinically Extremely Vulnerable' and advised to shield by the UK government. We therefore offered small grants to individuals and families to purchase exercise equipment in order to maintain their fitness levels during this period of confinement. We provided 9 grants of £80 each in total.
- We have started a monthly, online public talk called 'PCD Live!', in which we invite a specialist in PCD (from a variety of clinical domains) to give a talk, followed by a Q&A. This has been well attended, with about 20-30 households joining each talk. We record these talks and put them on our website to promote further public reach.
- We are collaboratively working on a project with a MedTech company (who are offering their service pro bono), in order to explore a digital solution to monitoring and managing PCD. This research is participatory and is being co-produced by the PCD community, who are supporting its evolution via responding to surveys and voting on their research priorities.
- The subgroup for Scottish PCD patients is doing well in raising awareness of the condition and improving patient care in Scotland. They are currently working towards setting up a Scottish service.

### **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 general public.**

- We have an active website page and regularly use social media sites such as Facebook and Twitter to reach our members, as well as email newsletter publications.
- We continued to educate the wider community about PCD by speaking to Medical Students at Cardiff University and Genetic Counselling students University of Southampton. We have also given talks to the Genomics Wales Youth Café, which had nearly 100 attendees. Some committee members also spoke at other events like Genetic Alliance UK, NHS Research Scotland, Glasgow Caledonian university (presenting to 60 physiotherapy student)
- Most conferences this year were cancelled due to the pandemic. However, a lot were held online and attended by many committee members (like ERS congress and Beat-PCD).
- Additionally, we have been working with a collaborative pan-European network on a longitudinal research study that monitors the impact of Covid-19 on the PCD community.
- Our Scottish sub group members are also members of 2 Scottish Government Cross Party Groups, CPG for Rare Diseases and CPG for Lung Health.

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

- Supported the Biomedical Research Unit at the Royal Brompton Hospital with Patient and Public representation on the Chronic Suppurative Lung Disease Consortium – in particular helping them identify and to prioritise research into PCD.
- We continued to work as part of the Ciliopathy Alliance and with the British Lung Foundation.
- We continue to work with the adult bronchiectasis physicians as patient representatives for the BronchUK group.
- We are co-applicants on a number of bids for funding for PCD related research projects in conjunction with the PCD Centres.
- We have promoted a number of research projects this year and have sponsored the Covid-19 and PCD study in order to ensure its continuation.

**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 Specialist Commissioners and the four PCD specialist centres to input into the development of the diagnostic and management services. We are active participants in their regular review meetings.
- We have also been working closely with the adult PCD physicians and NHS Specialised Commissioning in the implementation plans for the adult service. We are pleased that the adult service is beginning to come into effect, with most specialist centres now operating the service via teleconference.
- We have also been working with the NHS regarding the reallocation of services from the Royal Brompton Hospital. We continue to participate in the public consultation group for the new building at the Evelina London Children's Hospital at St Thomas', which is where the paediatric PCD service at the Royal Brompton will eventually relocate to in several years' time.

**Strategic Objective 5: Fundraise to support the above activities**

- We have had a number of donations in lieu of birthday gifts and instead of sending Christmas cards. We have also had an increase in fundraising from our members, who have fundraised for us through many active and innovative means this year, despite the many cancelled sporting events.
- The sale of PCD jewellery by our "PCD Angel" Debbie Richards continued to contribute funds to our cause. We have a small number of regular donators and will be looking to continue to increase this source of income.
- We successfully obtained a Lottery Grant as part of the Covid-19 response fund, which is specifically to support a rebrand and a new website. With all activity and engagement set to take place online in the future, we think this is an urgent priority for continuing to meet our strategic objectives in the medium term

## TRUSTEES' REPORT: 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 reserves at the end of 2020 stood at £63,624 (2019: £40,174). The committee and members continued their fundraising efforts through several events this year (even with the restrictions of Covid-19) and as a result we have a substantial increase in the total funds donated. Another reason for an increase is due to the £10k Covid-19 Response Fund grant that has been awarded to us via a lottery grant. The income for the year totalled £33,209 (2019: £18,041), including grants, donations and fundraising received totalling £25,686 (2019: £13,482) and contributions of £7,500<sup>1</sup> from the NHS in relation to supporting the ongoing costs of the PCD website. We are still waiting on an outstanding £1,500 from NHS support funds, whilst £1,500 of fees from some trusts were settled in early 2021. Investment income generated from interest totalled £23, a decrease of 61% when compared to investment income generated in 2019.

We have a commitment to fund support of the website on top of the normal expenditure incurred which includes attending conferences, producing leaflets, newsletters and delivering ongoing events and educational talks. We have increased our presence regionally 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 to hold 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 £29,679.

The Trustees agreed in early 2021 that the charity will be changing its registered name with the Charity Commission to PCD Support UK.

The trustees would like to express thanks to the many fundraisers who have contributed their efforts to the charity or donated funds during 2020. Special thanks go to – Paula Jarzabkowski, ShieldUs, CIC, George Rodrigues & Bartlett Mitchell foundation, Lucy Phipson, Rebecca Surender, Steven Fries, Becky Smith, the Copeland family and Dan Fisher.

This report was approved by the trustees on 23/03/2021 and signed on their behalf.



Abdullah Ihsan - Treasurer and Trustee

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<sup>1</sup> £4,500 received from NHS centres in 2020 to cover outstanding fees for 2019 web hosting. £3,000 was for fees incurred in 2020 and £3,000 remains outstanding.

## INDEPENDENT EXAMINERS STATEMENT

### INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE PRIMARY CILIARY DYSKINESIA FAMILY SUPPORT GROUP

I report on the accounts of the Primary Ciliary Dyskinesia Family Support Group (Charity number: 1049931) year ended 31 December 2020 which are set out on pages 9 and 10.

#### 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 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 Trust 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 confirm that there are no other matters to which your attention should be drawn 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  
DNG Dove Naish LLP  
Chartered Accountants  
Eagle House  
28 Billing Road  
Northampton  
NN1 5AJ

Date: 25 March 2021

THE PRIMARY CILIARY DYSKINESIA FAMILY SUPPORT GROUP  
ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2020

## ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2020

	Unrestricted fund	Restricted funds	2020 Total	2019	2018
	£	£	£	£	£
<b>RECEIPTS AND PAYMENTS ACCOUNT: GENERAL UNRESTRICITED FUND</b>					
<b>Income Receipts</b>					
Grants and Donations	15,686	10,000	25,686	9,404	6,546
Sponsored events and fundraising	-	-	-	4,078	7,723
NHS funding for website services	7,500	-	7,500 <sup>2</sup>	4,500	4,500
 <b>Investment activities</b>					
Interest receivable	23	-	23	59	58
Other Income	-	-	-	-	-
<b>Total Receipts</b>	<b>23,209</b>	<b>10,000</b>	<b>33,209</b>	<b>18,041</b>	<b>18,827</b>
 <b>Direct charitable expenditure</b>					
AGM & Family Day	616	-	616 <sup>3</sup>	2,785	3,321
Regional Events	-	-	- <sup>4</sup>	1,348	2,704
Marketing (leaflets, newsletter and merchandise)	43	-	43 <sup>5</sup>	3,522	882
Website costs incl. maintenance of multi-media resource	1,975	-	1,975	1,862	1,964
Conference costs	1,323	-	1,323 <sup>6</sup>	469	2,107
Research and treatment equipment grants	3,533	-	3,533 <sup>7</sup>	-	1,509
<b>Total direct charitable expenditure</b>	<b>7,490</b>	<b>-</b>	<b>7,490</b>	<b>9,986</b>	<b>12,487</b>
 <b>Support costs</b>					
Printing, telephones, postage and stationery	146	-	146	348	362
Travel Expenses of trustees	848	-	848	2,713	4,087
Subscriptions	717	-	717	1,032	657
Sustenance	373	-	373	202	293
Fundraising services	185	-	185	216	414
<b>Total support costs</b>	<b>2,269</b>	<b>-</b>	<b>2,269</b>	<b>4,511</b>	<b>5,813</b>
 Total payments	 <b>9,759</b>	 <b>-</b>	 <b>9,759</b>	 <b>14,497</b>	 <b>18,300</b>
 Net increase/(decrease) in cash for the year	 <b>13,450</b>	 <b>10,000</b>	 <b>23,450</b>	 <b>3,544</b>	 <b>527</b>
Cash balances at 31 December brought forward	40,174	-	40,174	36,630	36,103
Cash balances at 31 December carried forward	<b>53,624</b>	<b>10,000</b>	<b>63,624</b>	<b>40,174</b>	<b>36,630</b>

<sup>2</sup> £4,500 of this was for 2019 fees.

<sup>3</sup> Due to Covid-19 the AGM was held online so the cost of deposit for AGM was returned

<sup>4</sup> Due to Covid-19 there were no regional events held

<sup>5</sup> Due to Covid-19 there was minimal spend on Marketing

<sup>6</sup> Conference cost increased as a deposit was paid for our Medical board meeting which has now been moved to 2021

<sup>7</sup> We offered grants for exercise equipment to support the PCD community and £2,500 was given for research

THE PRIMARY CILIARY DYSKINESIA FAMILY SUPPORT GROUP  
ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2020

## STATEMENT OF ASSETS AND LIABILITIES AS AT 31 DECEMBER 2020

	Unrestricted Funds	Restricted <sup>8</sup> Funds	2020 Total	2019	2018
	£	£	£	£	£
<b>MONETARY ASSETS</b> (all general fund)					
Cash at bank and in hand	53,624	10,000	63,624	40,174	36,630
<b>Debtors</b>					
Amounts due from NHS funding	3,000	-	3,000 <sup>9</sup>	4,500	3,000
<b>Creditors</b>					
DNG Dove Naish LLP Independent Examiner's fees	600	-	600	300	-
2021 deposit for conference	1,186	-	1,186	-	-

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<sup>8</sup> Restricted Funds are to be used for the website project as per agreement with lottery grant. This was spent through the 1st quarter of 2021. This was split by £3,000 for rebrand, £5,500 for Website and £1,500 for illustrations.

<sup>9</sup> £3,000 still due for 2020 fees