

PCD Support UK

ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021



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

ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2021

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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

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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.

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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.

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- 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

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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.

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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 £3,000¹ from the NHS in relation 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 14th February 2022 and signed on their behalf.



Abdullah Ihsan - Treasurer and Trustee

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

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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

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Eagle House
28 Billing Road
Northampton
NN1 5AJ
Date: 14th March 2022

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	Unrestricted fund	Restricted funds	2021 Total	2020	2019
	£	£	£	£	£
RECEIPTS AND PAYMENTS ACCOUNT: GENERAL UNRESTRICITED FUND					
Income Receipts					
Grants and Donations	11,410	40,004 ²	51,409	25,686	9,404
Sponsored events and fundraising	555	-	555	-	4,078
NHS funding for website services	3,000	-	3,000 ³	7,500	4,500
Investment activities					
Interest receivable	3	-	3	23	59
Other Income	-	-	-	-	-
Total Receipts	14,963	40,004	54,967	33,209	18,041
Direct charitable expenditure					
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 ⁴	1,975	1,862
Conference costs	360	-	360	1,323	469
Research and treatment equipment grants	170	-	170	3,533	-
Total direct charitable expenditure	4,345	10,000	14,345	7,490	9,986
Support costs					
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
Total support costs	2,604	-	2,604	2,269	4,511
Total payments	6,949	10,000	16,949	9,759	14,497
Net increase/(decrease) in cash for the year	8,014	30,004	38,018	23,450	3,544
Cash balances at 31 December brought forward	53,624	10,000	63,624	40,174	36,630
Cash balances at 31 December carried forward	61,638	40,004	101,642	63,624	40,174

² Bequest from the estate of George H brown

³ Web hosting fees from the NHS to cover outstanding fees from 2020

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

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STATEMENT OF ASSETS AND LIABILITIES AS AT 31 DECEMBER 2021

	Unrestricted Funds	Restricted Funds⁵	2021 Total	2020	2019
	£	£	£	£	£
MONETARY ASSETS (all general fund)					
Cash at bank and in hand	61,638	40,004	101,642	63,624	40,174
Debtors					
Amounts due from NHS funding	6,000	-	6,000 ⁶	3,000	4,500
Creditors					
DNG Dove Naish LLP Independent Examiner's fees	750	-	750	600	300
2021 deposit for PCD medical board meeting	-	-	-	1,186	-

⁵ 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.

⁶ £6,000 still due for 2021 fees