

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

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## 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 phones 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 member are also members of 2 Scottish Government Cross Party Groups, CPG for Rare Diseases and CPG for Lung Health.

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**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



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## ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2020

	Unrestricted fund	Restricted funds	2020 Total	2019	2018
	£	£	£	£	£
<b>RECEIPTS AND PAYMENTS ACCOUNT:</b>					
<b>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>
<b>Total payments</b>	<b>9,759</b>	<b>-</b>	<b>9,759</b>	<b>14,497</b>	<b>18,300</b>
<b>Net increase/(decrease) in cash for the year</b>	<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

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## 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