



## Report of the Board of Trustees and Accounts – 1 April 2021 to 31 March 2022

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The trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

## OBJECTIVES AND AIMS

The Ciliopathy Alliance is a global alliance of patient support groups, researchers, doctors, and allied health professionals representing patients and families living with and affected by diseases caused by defects in the function or structure of cilia.

Malfunctioning cilia are known to underlie several often chronically disabling and sometimes life-threatening genetic conditions. They affect multiple systems, causing blindness, deafness, chronic respiratory infections, kidney disease, heart disease, infertility, obesity, and diabetes.

Individual disorders caused by malfunctioning cilia are rare, but more than 100 diseases have been identified - known collectively as 'ciliopathies' - and they affect as many as one in 500 - 1,000 people.

The ciliopathies currently represented by the Ciliopathy Alliance are:

- Alström Syndrome: ultra-rare, 700 known families worldwide (50-60 in UK) causing childhood blindness, hearing loss, heart, kidney, and liver failure.
- Bardet-Biedl Syndrome: rare, 1 in 100,000 prevalence, causing visual impairment, obesity, polydactyly, kidney abnormalities/renal failure, developmental delay, infertility.
- Jeune Syndrome: very rare, 1 in 200,000 prevalence, causing skeletal malformations, lung/respiratory problems, renal cysts/renal failure, visual impairment.
- Joubert Syndrome: very rare, 1 in 100 - 250,000 prevalence, causing ataxia (lack of muscle control), abnormal breathing pattern, sleep apnoea, abnormal eye and tongue movements, visual impairment.
- Polycystic Kidney Diseases (PKD): Autosomal Dominant PKD - 1 in 1 - 4,000 prevalence, causing massive cystic kidneys and livers, kidney failure, brain aneurysms, cardiovascular disease; and the rare Autosomal Recessive PKD - 1 in 20 - 40,000 prevalence, causing kidney failure and liver fibrosis.
- Primary Ciliary Dyskinesia: 1 in 7,500 prevalence, causing upper and lower respiratory tract infection, lungs, sinuses, and ears.
- Retinitis Pigmentosa: 1 in 4,000 prevalence, causing progressive sight loss.
- Usher Syndrome: 1 in 6 - 7,000 prevalence, causing progressive hearing and sight loss, and balance problems.

### Charitable objects

The objects of the Ciliopathy Alliance are governed by the memorandum and articles of association and are as follows:

'To relieve sickness and promote and protect good health of children and adults living with ciliopathies, with a view to improving their conditions of life'.

### Aims

The charity aims to:

- Promote, support and stimulate the sharing of knowledge and understanding of ciliopathies, nationally and transnationally.
- Encourage and facilitate communication between patients, health professionals, researchers and other organisations that support people with ciliopathies.
- Promote awareness of ciliopathies and the respective patient organisations.

- Promote, sponsor and/or participate in national and transnational laboratory, translational and clinical research into ciliopathies and related syndromes, with the aim of developing effective therapies and management of patients with ciliopathies.
- Invite and encourage patient involvement in research and clinical management of ciliopathies.
- Provide information that will benefit people with ciliopathies, in particular to those patients who do not have a condition/disease-specific support group and those in hard-to-reach geographical/ethnic communities.
- Provide information and educational materials for health professionals and similar with the aim of improving diagnosis, clinical management, and social care.
- Communicate with/ lobby national and international governments and other relevant organisations to promote the interests of people with ciliopathies and encourage an integrated approach to their health and social care.
- Organise conferences, symposia, workshop and similar, and support the publication and/or dissemination of information and best practice about ciliopathies.
- Co-operate with other charities, alliances, voluntary organisations and statutory bodies to further the interests of people with ciliopathies.

## PERFORMANCE AND ACHIEVEMENTS DURING 2021-22

COVID-19 continued to restrict the charity's work. No face-to-face meetings or events were held.



The charity participated in the planning of Cilia2022 to be held from 4-7 October in Cologne. A key part of the conference is the 'Patient's Day', an opportunity for ciliopathy patients, family members/carers and ciliopathy patient support groups to engage with up to 400 scientists and clinicians.



*"SCiIS echoes the EU message of solidarity with the Ukrainian people, and supports over 7,000 Russian researchers who spoke out against the military action in Ukraine"*



The charity continued to participate in the European Training Network for studying Ciliary Signalling in development and disease ('SCiIS'), funded by EU Horizon 2020, as the primary patient partner. Owing to COVID-19, all progress meetings were held online.



The charity was represented at the European Reference Network for Rare Kidney Diseases (ERKNet) by Ms Harris who attends regular online ERKNet meetings.

The charity supported the first stage of a European ciliopathies research application (outcome awaited).

During the year, three trustees resigned. The charity would like to express their gratitude for their service. Two new trustees were appointed and the board began a strategy review.

## 2022-23 plans

1. We will finalise the strategy review.
2. We will participate in-person at Cilia2022 in Cologne and manage the Patients' Day.

## FINANCIAL REVIEW

### Performance

During the year ended 31 March 2022, the charity's income was £6,134 (2021: £24,148).

The charity incurred expenses of £401 (2021: £357) resulting in a surplus of £5,733 (2021: £23,792).

### Reserves policy

The trustees considered that the charity had sufficient reserves at the year-end to fund its activities during 2022-23.

## STRUCTURE, GOVERNANCE AND MANAGEMENT

### Constitution

The Ciliopathy Alliance was established as a company limited by guarantee in 2011 and registered with the Charity Commission in 2012. The charity is governed by its Memorandum and Articles of Association.

### Trustees

The trustees of the charity, who are the directors of the limited company, are responsible for the governance of the charity. The charity has five trustees. Trustees are appointed by the charity based on their skills and expertise. A minimum of two trustees must be present at each meeting for decisions to be made.

Trustees meet approximately quarterly and communicate by email in between meetings. A members' meeting is held at the annual AGM to allow sharing of knowledge and input into the charity's strategy.

Trustees are provided with copies of relevant Charity Commission guidance and publications, including 'The Essential Trustee', 'Charities and Public Benefit' and 'It's your decision: charity trustees and decision making'.

All trustees are required to declare interests and may be required to withdraw from relevant proceedings during a board meeting. The trustees give their time freely but may claim reasonable out of pocket expenses.

### Public benefit

All charitable activities are undertaken to further charitable purposes for public benefit. The trustees confirm they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives, and in carrying out and planning current and future activities respectively.

### Management

The trustees delegate the administration and secretariat functions of the charity to Ms Tess Harris, a volunteer, who is the CEO of the PKD Charity (a member of the Ciliopathy Alliance). The charity's

accounts were prepared by Ms Susan Hartley (volunteer bookkeeper). The charity was exempt from the requirement to have an Independent Examination.

### Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

### Membership

Membership is open to any organisation or individual worldwide who shares the vision of the charity to 'improve the quality of life for people living with ciliopathies'.

Individuals and the nominated representatives of organisations can apply for membership, which is subject to the directors' approval. The directors have established classes of membership with different rights and obligations.

A membership register is maintained by the secretariat.

## REFERENCE AND ADMINISTRATIVE INFORMATION

### **Ciliopathy Alliance:**

Registered charity in England and Wales

Number 1148034

A company limited by guarantee

Registered company in England and Wales (Incorporated 10 November 2011)

Number 07842342

### **Registered Office:**

91 Royal College Street

London

NW1 0SE

Telephone number: 020 7387 0543

Email address: [info@ciliopathyalliance.org](mailto:info@ciliopathyalliance.org)

### **Directors and Trustees who served during the year and to the date of this report:**

Professor Philip Beales (resigned February 2022)

Mrs Fiona Copeland (appointed February 2022)

Dr Elizabeth Forsythe

Mrs Laura Dowswell (resigned February 2022)

Mrs Tonia Hymers (appointed 3 March 2022)

Dr Toby Hurd (resigned January 2022)

Dr Roly Megaw (appointed 31 May 2022)

Professor Hannah Mitchison

### **Scientific Advisory Board:**

Chaired by Professor Philip Beales

### **Bankers:**

CAF Bank Limited

25 Kings Hill Avenue

CILIOPATHY ALLIANCE  
Annual Report and Financial Statement for the year ended 31 March 2022

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West Malling  
ME14 4JQ

Approved by order of the board of trustees on 6 November 2022 and signed on its behalf by:



Professor Hannah Mitchison - Trustee

**STATEMENT OF FINANCIAL ACTIVITIES**  
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)  
FOR THE YEAR ENDED 31 MARCH 2022

			2022	2021
	Unrestricted funds	Restricted funds	Total funds	Total funds
	£	£	£	£
<b>INCOME</b>				
Donations and legacies	6,134	-	6,134	24,148
<b>Total</b>	<b>6,134</b>	<b>-</b>	<b>6,134</b>	<b>24,148</b>
<b>EXPENDITURE</b>				
<b>Charitable activities</b>				
Conferences and workshops	-	-	-	-
Subscriptions	-	-	-	23
Bank charges	102	-	102	75
Website costs	286	-	286	246
<b>Governance costs</b>				
Trustee expenses	-	-	-	-
Accountancy fees	-	-	-	-
Companies House	13	-	13	13
<b>Total expenditure</b>	<b>401</b>	<b>-</b>	<b>401</b>	<b>357</b>
<b>NET INCOME</b>	<b>5,733</b>	<b>-</b>	<b>5,733</b>	<b>23,791</b>
<b>RECONCILIATION OF FUNDS</b>				
<b>Total funds brought forward</b>	<b>30,970</b>	<b>-</b>	<b>30,970</b>	<b>7,179</b>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<b>36,703</b>	<b>-</b>	<b>36,703</b>	<b>30,970</b>

**CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

## BALANCE SHEET

AT 31 MARCH 2022

			2022	2021
	Unrestricted funds	Restricted funds	Total funds	Total funds
	£	£	£	£
<b>CURRENT ASSETS</b>				
Cash at bank	36,703	-	36,703	30,970
<b>CREDITORS</b>				
Amounts falling due within one year	-	-	-	-
	-	-	-	-
<b>NET CURRENT ASSETS</b>	36,703	-	36,703	30,970
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>	36,703	-	36,703	30,970
<b>NET ASSETS</b>	36,703	-	36,703	30,970
<b>FUNDS</b>				
Unrestricted funds			36,703	30,970
Restricted funds			-	-
<b>TOTAL FUNDS</b>			36,703	30,970

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2022.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2022 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to charitable small companies.



CILIOPATHY ALLIANCE  
Annual Report and Financial Statement for the year ended 31 March 2022

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The financial statements were approved by the Board of Trustees on 6 November 2022 and were signed on its behalf by:



Professor Hannah Mitchison - Trustee