



Report of the Board of Trustees and Accounts – 1 April 2022 to 31 March 2023

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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 2023. 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
- Promote, sponsor, invite, and encourage patients, and/or participate in national and transnational laboratory, transitional and clinical research into ciliopathies and related syndromes, with the aim of developing effective therapies and management of patients with ciliopathies
- Provide information that will benefit people with ciliopathies, their support network (health professionals, schools etc) in particular to those patients who do not have a condition/disease-specific support group and those in hard-to-reach geographical/ethnic communities
- Communicate with 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
- Manage day to day activities of CA to ensure that they meet limited company rules, within the rules of the law and without political bias
- Fundraise to support the above activities

PERFORMANCE AND ACHIEVEMENTS DURING 2022-23

Strategy Review

We undertook a strategy review in 2022 where we agreed our aims and what activities we would undertake to achieve our goals.

Activities



The charity participated in Cilia2022 held from 4-7 October in Cologne. Cilia2022 continued the series of biennial European Cilia Conferences, which has been gaining momentum throughout Europe (London, Paris, Amsterdam, Copenhagen) since 2012 (the first initiated by the Ciliopathy Alliance UK). This meeting has now become the largest cilia meeting worldwide.

The meeting was attended by over 600 delegates from 35 countries around the world. It was a great opportunity for collaboration and networking between early students/PHD Applicants (30% of attendees), Industry (5%), patients (6%) and clinicians/scientists (59%) from around the world (35 different countries).

A key part of the conference was the 'Patient's Day'. Patients and families affected by ciliopathies got together to share their experiences with the attendees and learn more about cilia and research. All the patients reiterated how important it is for patients and researchers to work together to help prioritise research. It was felt that research into ciliopathies is continuing to grow, and it remains crucial that we keep the momentum up. [Read more on the Ciliopathy Alliance website.](#)



"SCiS 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 ('SCiS'), funded by EU Horizon 2020, as the primary patient partner.



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



TheRaCiL
Therapeutics for Renal
Ciliopathies

The charity supported an EU HORIZON renal ciliopathies research application, called TheRaCiL. Following the year end, the EU announced that the application was successful, and research would start in July 2023. The charity is the patient partner in TheRaCiL with the responsibility of ensuring meaningful patient involvement and engagement throughout the 4 years of the project.

The Ciliopathy Alliance website underwent an update.

During the year, one new trustee was appointed.

2023-24 plans

1. We will strengthen our network – with patient groups and scientific advisors ensuring we have all ciliopathies represented.
2. We will improve our website to ensure it is providing the information our users require.
3. Encourage networking within ciliopathy groups – holding annual lunches
4. We will promote cilia research by holding regular webinars, help with the planning of Cilia 24 in Dublin and participating as patient partners in TheRaCiL.
5. We will develop a digital and fundraising strategy.
6. We will appoint a Treasurer.

FINANCIAL REVIEW

Performance

During the year ended 31 March 2023, the charity's income was £398 (2022: £6,134).

The charity incurred expenses of £1,950 (2022: £401) resulting in a deficit of -£1,552 (2022: £7,733).

Reserves policy

The trustees considered that the charity had sufficient reserves at the year-end to fund its activities during 2023-24.

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 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

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

Mrs Fiona Copeland
Dr Elizabeth Forsythe
Mrs Tonia Hymers
Mrs Kerry Leeson-Beevers (appointed June 2023)
Dr Roly Megaw
Professor Hannah Mitchison

Scientific Advisory Board:

Chaired by Professor Philip Beales

Bankers:

CAF Bank Limited
25 Kings Hill Avenue
West Malling
ME14 4JQ

Approved by order of the board of trustees on 10 November 2023 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 2023

			2023	2022
	Unrestricted funds	Restricted funds	Total funds	Total funds
	£	£	£	£
INCOME				
Donations and legacies	147		147	6,134
Other income	200		200	-
Bank interest	51		51	-
Total	398		398	6,134
EXPENDITURE				
Charitable activities				
Conferences and workshops	79	-	79	-
Subscriptions	44	-	44	-
Bank charges	78		78	102
Website costs	1,326		1,326	286
Governance costs				
Trustee expenses	333	-	333	-
Accountancy fees	-	-	-	-
Companies House	50		50	13
ICO	40		40	
Total expenditure	1,950		1,950	401
NET INCOME	- 1,552	- -	1,552	5,733
RECONCILIATION OF FUNDS				
Total funds brought forward	36,703		36,703	30,970
TOTAL FUNDS CARRIED FORWARD	35,151	-	35,151	36,703

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

BALANCE SHEET

AT 31 MARCH 2023

			2023	2022
	Unrestricted funds	Restricted funds	Total funds	Total funds
	£	£	£	£
CURRENT ASSETS				
Cash at bank	36,051	-	36,051	36,703
CREDITORS				
Amounts falling due within one year	900	-	900	-
	-	-	-	-
NET CURRENT ASSETS	35,151	-	35,151	36,703
TOTAL ASSETS LESS CURRENT LIABILITIES	35,151	-	35,151	36,703
NET ASSETS	35,151	-	35,151	36,703
FUNDS				
Unrestricted funds			35,151	36,703
Restricted funds			-	-
TOTAL FUNDS			35,151	36,703

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2023 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 2023

The financial statements were approved by the Board of Trustees on 10 November 2023 and were signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Hannah Mitchison', with a long horizontal flourish extending to the right.

Professor Hannah Mitchison - Trustee