



Report of the Board of Trustees and Accounts – 1 April 2023 to 31 March 2024

Contents

OBJECTIVES AND AIMS.....	2
Charitable objects	2
Aims	3
PERFORMANCE AND ACHIEVEMENTS DURING 2023-24	3
Activities.....	3
2024-25 plans.....	5
FINANCIAL REVIEW	6
Performance	6
Reserves policy.....	6
STRUCTURE, GOVERNANCE AND MANAGEMENT	6
Constitution	6
Trustees.....	6
Public benefit	6
Management.....	6
Risk management.....	7
Membership.....	7
REFERENCE AND ADMINISTRATIVE INFORMATION.....	7
STATEMENT OF FINANCIAL ACTIVITIES.....	8

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 2024. 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, translational 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 2023-24

Activities



"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 attended regular online ERKNet meetings until her passing in March 2024 (see tribute below).



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.

We continued to update the Ciliopathy Alliance website.

CILIOPATHY ALLIANCE

Annual Report and Financial Statement for the year ended 31 March 2024



We represented the Ciliopathy Community at the Rare Disease Day event at the House of Commons on 29th February 2024, where Andrew Stephenson (Minister for Health and Secondary Care) launched the government's plan to continue supporting patients with Rare Diseases. The standout points were the piloting of Syndromes Without a Name clinics for people with rare undiagnosed conditions and the 'Generation Study' where newborn babies will be screened for rare diseases.

We continued to represent patients on the organising committee of Cilia24. The largest scientific meeting for cilia and flagella research which includes patients.



Many ciliopathies, many ciliopathy charities



We held our first webinar on 11th November 2023 via Zoom with the following presentations:-

- Cilia and the role they play in the human body from Amelia Shoemark
- Bendert De Graaf's personal story and about the BBS Group in the Netherlands and about Project Predict

- Plans for the Ciliopathy Alliance UK over the next few years by Fiona Copeland, Trustee of the Ciliopathy Alliance



On Thursday, 19th October 2023 we hosted a lunch for our Ciliopathy Patient Groups. It was the first time since the pandemic that we have all met face-to-face and it was a great opportunity to meet new people and build new relationships.

Representatives for Alstrom, BBS, PCD and Usher attended as well as Hannah Mitchison, Chair of CAUK and Elizabeth Forsythe, Trustee of CAUK.



We supported the UK Cilia Network to hold their meeting in Edinburgh in September 2023. The UK Cilia Network Autumn meeting was a great opportunity to reconnect with colleagues, discuss new findings and share results. The calibre of research on display was outstanding and exemplifies why the UK Cilia Network is so valuable; it facilitates the sharing of ideas and collaborations between groups that might otherwise not meet.

In March 24 we sadly lost one of the Ciliopathy Alliance's biggest allies, Tess Harris.

Tess was a tireless advocate for Polycystic Kidney Disease (PKD) for over 20 years, as a Trustee and later becoming the CEO of the PKD Charity.

She was one of the founder members of the Ciliopathy Alliance taking on many roles:-

- As the Secretariat since 2010
- Organising the Cilia Conference biennial series since its conception in 2012
- Playing an integral role in large research consortia both in Europe and nationally within the UK, representing the ciliopathy alliance patients (TheRaCil, CiliaREN, SCiLS)
- Generally raising awareness and advancing research into ciliopathies, further amplifying her impact within the rare disease community.



She will be remembered for her unwavering dedication to helping people with PKD and other ciliopathies, as well as her warmth and empathy.

2024-25 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, attending 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 2024, the charity's income was £1201 (2023: £398).

The charity incurred expenses of £2147(2023: £1950) resulting in a deficit of -£952 (2023: £1552).

Reserves policy

The trustees considered that the charity had sufficient reserves at the year-end to fund its activities during 2024-25.

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

Until March 2024, the trustees delegated administration and secretariat functions of the charity to Ms Tess Harris, a volunteer, who was the CEO of the PKD Charity (a member of the Ciliopathy Alliance) until her death. The charity's accounts were prepared by Temitope Oyefuga (Treasurer). This secretariat role has been filled by Mrs Fiona Copeland after the loss of Ms Harris. 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.

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:

Institute of Child Health

30 Guildford Street

London

WC1N 1EH

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 21 November 2024 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 2024

	Unrestricted funds	Restricted funds	2024 Total funds	2023 Last year
	£	£	£	£
Income				
Donations and Legacies		-		
Other Income	1,131	-	1,131	347
Bank Interest	70	-	70	51
Total	1,201	-	1,201	398
Expenditure				
Charitable Activities				
Conferences and Workshops	862	-	862	79
Bank Charges	60	-	60	78
Subscriptions	-	-	-	44
Postage and Travel	15	-	15	-
Website Costs	1,170	-	1,170	1,326
Governance Costs				
Trustee Costs	-	-	-	-
Companies House	-	-	-	333
Information Commissioners Office	-	-	-	50
Information Commissioners Office	40	-	40	40
Total Expenditure	2,147	-	2,147	1,950
NET INCOME	-	-	-	-
	946	-	946	1,552
Transfers	900	-	900	-
Cash funds last year end	35,151	-	35,151	36,703
Cash funds this year end	35,105	-	35,105	35,151
RECONCILIATION OF FUNDS				
Total funds brought forward				
TOTAL FUNDS CARRIED FORWARD	35,105	-	35,105	35,151

CILIOPATHY ALLIANCE
Annual Report and Financial Statement for the year ended 31 March 2024

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

BALANCE SHEET AT 31 MARCH 2024

	Unrestricted funds	Restricted funds	2024 Total funds	2023 Last year
	£	£	£	£
CURRENT ASSETS				
Cash at Bank	35,105	-	35,105	36,051
CREDITORS				
Amounts falling due within one year	-	-	-	900
NET CURRENT ASSETS	35,105	-	35,105	35,151
TOTAL ASSETS LESS CURRENT LIABILITIES	35,105	-	35,105	35,151
NET ASSETS	35,105	-	35,105	35,151
FUNDS				
Unrestricted funds			35,105	35,151
Restricted funds			-	-
TOTAL FUNDS			35,105	35,151

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2024 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.

CILIOPATHY ALLIANCE
Annual Report and Financial Statement for the year ended 31 March 2024

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.

The financial statements were approved by the Board of Trustees on 21 November 2024 and were signed on its behalf by:



Professor Hannah Mitchison - Trustee