Ciliopathy Alliance
Promoting care and improved quality of life for those with ciliary diseases

# Report of the Board of Trustees and Accounts – 1 April 2024 to 31 March 2025

## Contents



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 2025. 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

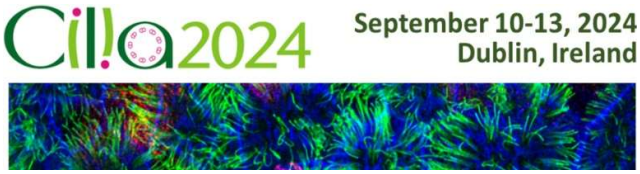
# PERFORMANCE AND ACHIEVEMENTS DURING 2024-25

## Activities

The charity is the patient partner in TheRaCiL with the responsibility of ensuring meaningful patient involvement and engagement throughout the 4 years (until 2027) of the project. Kerry Leeson-Beevers has taken on the role from Tess Harris.

The Charity is the patient partner for CiliaRen with the responsibility of patient engagement. Audrey Hughes has taken on the role from Tess Harris.
We continued to update the Ciliopathy Alliance website, Facebook page, Twitter and LinkedIn.

We represented the Ciliopathy Community at the Rare Disease Day event at the House of Commons on 28th February 2025. Minister Ashley Dalton, Parliamentary Under Secretary of State for Health and Social Care, spoke to attendees, providing a preview of the 2025 England Rare Diseases Action Plan. The standout points were NHS England has created a model to incentivise clinics for rare conditions to involve multiple healthcare professions together in the same session, improvements in facilitating rare disease clinical trials and a framework is being developed to deliver personalised therapies for rare disease patients.




We attended Cilia24, Fiona was on the organizing committee. Hannah and Roly attended the patient day with Kerry and Tonia. We had over 70 patients attended the patient day. With three families sharing their stories in the Main meeting. We followed this up with a Q&A session with clinicians and researchers.

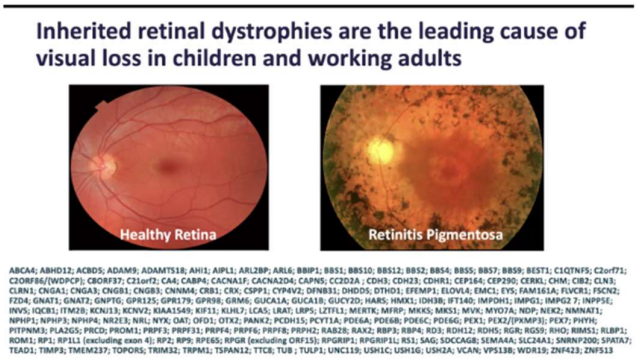
The key themes were:-


- Patients want better access to preimplantation, antenatal and newborn screening programmes
- We need a single source of info - either via support groups or via rare disease networks for clinicians/patients which has been verified by a consensus of experts.
- How do we get round the privacy concerns of rare disease registries?
- There is disparity dependent on where you live on what care you receive.
- The day allowed us to build relationships with people from

other countries to share 'best practice' models.

- We also had long discussions on how to set up new support groups.
- We need patient advocates to get involved in research – right through from concept to market. They also need training. Need to be treated as peers to avoid patient engagement tick boxing.
- Lots of discussions on how we can continue to get funding for research.

- There is a funding gap for patient advocacy. We need to make sure that we have passionate empowered patient advocates who are reimbursed for their expenses and time to attend meetings. Patient engagement is currently reliant on good will. Many of the charities are run entirely by volunteers who don't get reimbursement for their time. We should try and get PPI funding included in all grant applications. This probably needs to be addressed before we can ask any more of our existing patient cohort.




We held our 2nd webinar on Monday, 3rd June 2024 and had two really interesting speakers, learning about the latest research into RP from Dr. Roly Megaw, University of Edinburgh and about the patient's perspective into sight loss research for Usher patients from Steve White, Cure Usher.

The webinar demonstrated that there is much to be hopeful for in respect of sight loss research.

We undertook a strategy review with the help of Cranfield Trust in February 2025, thank you to everyone who participated and to Temi for her help in organising this. We now have a plan focusing on five key areas: digital transformation & communications; research facilitation & partnerships; advocacy & stakeholder engagement; governance & capacity building; and fundraising & financial sustainability. We want to unite and empower patients, families, healthcare professionals, researchers, and partner organisations to advance understanding, research, treatment, and advocacy for ciliopathies.

We appointed Temitope as our Treasurer in October and she has been instrumental in helping us review our strategy. We also had Audrey join our committee to represent the CiliaRen project and we are delighted she is now going to join us as a Trustee.

We unfortunately still had to spend some time picking up the reins from Tess … we are very grateful to PKD UK who helped us with this. Fiona has taken on the admin work, Kerry the TheRACILS project and Audrey joined us to represent the PKD community and CiliaREN. We are delighted that Audrey now has decided to become a Trustee to keep doing this great work.

## 2025-26 plans

We will continue to work on our new strategy paying particular attention to our communication plan, funding, advocacy and stakeholder engagement whilst maintaining strong governance.

We will in particular:-

1. Strengthen our network – with patient groups and scientific advisors ensuring we have all ciliopathies represented.
2. Improve our website to ensure it is providing the information our users require.
3. Encourage networking within ciliopathy groups – holding annual lunches
4. Promote cilia research by holding regular webinars, helping with the organisation of Cilia27, sponsoring UK Cilia and Centrosome Network Meetings and participating as patient partners in the UKRI-funded CiliaRen and EU-funded TheRaCiL and AI-Consortium.
5. Develop a digital and fundraising strategy.
6. Develop a resource plan (with volunteers, interns and paid resources)

## FINANCIAL REVIEW

### Performance

During the year ended 31 March 2025, the charity's income was £1689 (2024: £1201).

The charity incurred expenses of £ 10352 (2024: £2147) resulting in a deficit of -£8663 (2024: -£952). This increase in expenditure was primarily due to sponsorship and attendance of Cilia24 (£2.5K) which will incur every 2 years, hosting the Strategy Day (£3k) which was a one-off and general expenses.

### Reserves policy

The trustees considered that the charity had sufficient reserves at the year-end to fund its activities during 2025-26.

## 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 Secretariat role is fulfilled by Mrs Fiona Copeland. The Chair is Professor Hannah Mitchsion. The charity's accounts were prepared by Temitope Oyefuga (Treasurer). 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
Dr Roly Megaw
Professor Hannah Mitchison
Ms Temi Oyefuga

**Scientific Advisory Board:**
Chaired by Professor Philip Beales

**Bankers:**
CAF Bank

Approved by order of the board of trustees on 21 October 2025 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 2025

| | Unrestricted Funds £ | Restricted Funds £ | 2024/25 Total Funds £ |
|---|---|---|---|
| **Income from charitable activities** | | | |
| Donations and Legacies | | 1,477 | 1,477 |
| Other Trading Activities | | | |
| **Income from investments** | | | |
| Bank Interest received | 212 | | 212 |
| **Total Income** | 212 | 1,477 | 1,689 |
| **Expenditure:** | | | |
| Raising Funds | - | - | - |
| Charitable Activities -General | 7,141 | - | 7,141 |
| Other Trading Activities | 3,211 | - | 3,211 |
| **Total Expenditure** | 10,352 | - | 10,352 |
| **Resources retained for further use** | (10,140) | 1,477 | (8,663) |
| **Transfer between Funds** | - | 0 | - |
| **Net Movement in Funds** | **(10,140)** | **1,477** | **(8,663)** |
| **Reconciliations of Funds** | | | |
| **Brought forward 01/04/2024** | 35,105 | - | 35,105 |

| | | | | |
|---|---|---|---|---|
| **Carried forward 31/03/2025** | | **24,965** | **1,477** | **26,442** |

**CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

**BALANCE SHEET AT 31 MARCH 2025**

| | 2024/25 £ | 2023/24 £ |
|---|---|---|
| Fixed Assets | - | - |
| Current Assets | | |
| Prepayments and accrued income | | |
| Debtors | - | |
| Cash at Bank and in hand | 28,644 | 35,105 |
| Creditors | | |
| Amount due within One Year | (2,202) | 0 |
| Net Assets/Liabilities | **26,442** | **35,105** |
| **Reserves** | | |
| General Funds | 24,965 | 35,105 |
| Restricted Funds: | 1,477 | - |
| | **26,442** | **35,105** |

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2025.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2025 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.

The financial statements were approved by the Board of Trustees on 21 October 2025 and were signed on its behalf by:

Professor Hannah Mitchison - Trustee