



Ciliopathy Alliance

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

MINUTES OF CILIOPATHY ALLIANCE ANNUAL GENERAL MEETING

The 13th Annual General Meeting of the Ciliopathy Alliance was held on 9 December 2024, at 10.00 a.m.-11:15 on Microsoft Teams

Present:

Fiona Copeland, Trustee and PCD Representative
Bendert de Graaf, BBS Netherlands
Elizabeth Forsythe, Trustee
Audrey Hughes, PKD Representative
Tonia Hymers, Trustee and BBS Representative
Kerry Leeson-Beevers, Trustee and Alstrom Representative
Helen May-Simera
Roly Megaw, Trustee
Hannah Mitchison, Interim Chair and Jeune representative
Sharon O'Cansey
Temitope Oyefuga, Treasurer
Michael Parker
Charlie Softley

Apologies:

Colin Bingle, Dagmar Wachten, Chloe Joyner, Drina Parker

Proxy Votes from: Girish Mali

MINUTES

Prof Hannah Mitchison (HM) opened the meeting and thanked everyone for attending. Apologies were noted.

Ordinary Business

1. Fiona Copeland (FC) reviewed the Minutes of the 12th Annual General Meeting held on 7 December 2023. Approval was proposed by FC and approved by the members.
2. Members received the accounts for the period 1st April 2023 to 31st March 2024. Approval was proposed by FC and approved by all members.

Temitope Oyefuga (OF) gave a summary of the finances:-

Income Analysis

Total Income: £1,201 (up 202% from £398 last year).

Other Income: £1,131 (up 226% from £347 last year). This represents 94% of total income this year, indicating a significant reliance on other income sources rather than donations or legacies.

Bank Interest: £70 (up 37% from £51 last year), contributing 6% of total income.

Key Observations:



Ciliopathy Alliance

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

The increase in other income is encouraging but highlights the absence of diversified revenue sources like donations and legacies, which contributed nothing this year compared to prior years. Bank interest has grown due to higher interest rates or larger average cash balances.

Expense Analysis

Total Expenses: £2,147 (up 10% from £1,950 last year).

Conferences and Workshops: £862 (up 992% from £79 last year), accounting for 40% of total expenses. This reflects a strategic focus on charitable activities but demands careful cost management.

Website Costs: £1,170 (down 12% from £1,326 last year), making up 54% of total expenses. Although reduced, it remains the largest expense item.

Bank Charges: £60 (down 23% from £78 last year), representing 3% of total expenses. This decline indicates improved cost efficiency.

Minor Costs:

Postage and Travel: £15 (newly reported; negligible at less than 1% of total expenses).; Information Commissioner's Fee: £40 (unchanged YoY; <2% of total expenses).

Key Observations:

Workshops and website costs together account for 94% of total expenses, emphasizing their centrality to the charity's activities.

Net Position

Net Deficit: £946 (improved 39% from a £1,552 deficit last year).

This reduction is attributable to a significant income boost from the TheR acil project and modest expense growth.

Cash Reserves

Year-End Cash Balance: £35,105 (down marginally by 0.1% from £35,151 last year).

The stability in cash reserves indicates effective cash flow management despite a deficit. £20,000 invested in an interest savings account.

Overall Analysis and Recommendations

Income Diversification:

The charity's heavy reliance on "other income" (94% of total) is risky. Efforts should focus on securing grants, and reviving donations and legacies to secure long-term sustainability.

Expense Prioritization:

Workshops and website costs dominate spending. While these are aligned with charitable objectives, the board should evaluate their return on investment to ensure maximum impact.

Deficit Management:

The 39% reduction in the deficit is commendable, but further measures are needed to reach a break-even or surplus position, especially by controlling costs or enhancing income streams.

Reserves Policy:

The cash reserves remain strong, covering 16 months of average monthly expenses (based on this year's spending). This provides a buffer for future uncertainties.

Conclusion: The charity is on a positive trajectory, with income growth outpacing expense increases and improved financial efficiency. Formal approval of the accounts is recommended, alongside a focus on income diversification and cost-effectiveness in workshops and website spending.



Ciliopathy Alliance

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

3. FC presented a summary of the year 2023-24:-

- We participated in the European Training Network for studying Ciliary Signalling in development and disease ('SCiLS'), funded by EU Horizon 2020, as the primary patient partner.
- We represented ciliopathy patients at the European Reference Network for Rare Kidney Diseases (ERKNet)
- We are the patient partner for a new project 'TheRaCiL' and CiliaREN.
- The Ciliopathy Alliance website underwent an update.
- We represented the patients on the Cilia24 organising committee.
- We supported the UK Cilia Network to hold their meeting in Edinburgh in September 2023.

We sadly lost Tess Harris in March 2024. Tess had a major role in the Ciliopathy Alliance:-

- As the Secretariat since 2010
- Organising the Cilia Conference biennial series since it's 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.

4. FC also update the members of what activities had been undertaken so far in 24/25

- We have appointed a Treasurer
- We have transferred Tess' work to Fiona, Kerry and Audrey
- Held our 2nd Webinar on Sight Loss Research
- Helped patients in the Netherlands kick start their own Ciliopathy Alliance
- Attended Cilia24
- Kicked off a new project looking at our Strategy with Cranfield Trust – FC to send Michael Parker invite to join the strategy workshop. **ACTION FC**

Kerry Leeson-Beevers gave an update on the TheRACIL project

- TheRacil is funded through the European Union's Horizon Europe Research and Innovation Programme
- It is a 4 year project and started in July 2023
- The Ciliopathy Alliance is a partner in the project
- The aim of the project is to develop therapeutics for renal ciliopathies (TheRacil)
- There are 7 work packages (WP) in total:
 - WP1 – Data integration and clustering for predictive signatures
 - WP2 – Molecular signatures for classification and therapy
 - WP3 – Patient eligibility to treatment: prognostic tools and biomarkers
 - WP4 – Drug screening and proof of concept studies
 - **WP5 – Patient involvement and reported outcome measures**



Ciliopathy Alliance

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

- WP6 – Coordination and management
- WP7 – Dissemination and exploitation
- The Ciliopathy Alliance are mainly involved in WP5 and are responsible for establishing the Patient and Public Involvement and Engagement (PPIE) advisory group, also known as the PELSI Board (Patient Ethical, Legal, Societal Issues).
- The project is mainly focussing on 3 ciliopathies – Autosomal Recessive Polycystic Kidney Diseases, Nephronophthisis and Bardet Biedl Syndrome. We have representatives from all 3 conditions on the PELSI Board.

Audrey Hughes gave an update on the CILIAREN project. CILIAREN is connecting stakeholders across the UK to improve the identification, diagnosis and management of patients with renal ciliopathies. The long-term mission is for the development of efficient molecular genetic diagnostics and novel therapies.

A PPIE working group has been formed and action points going forward are to embed patients and patient advocates in all aspects of research, expand RaDaR and other renal registries as much as possible for all renal ciliopathies and to identify and engage with regulators about the challenges for trial design for rare and ultra rare ciliopathies.

CiliaRen were present at Cilia2024 in Dublin and hosted a successful working lunch, welcoming 50 people including patients, patient organisation leads, researchers and clinicians from all over Europe.

5. FC presented our future plans:-
 - We will strengthen our network – with patient groups and scientific advisors ensuring we have all ciliopathies represented.
 - Encourage networking within ciliopathy groups – holding another annual lunch
 - We will promote cilia research by holding regular webinars, help with the planning of Cilia 27 in Milan and participating as patient partners in TheRaCiL and CiliaREN
 - We will develop a longer term strategy for the Ciliopathy Alliance
6. We formally appointed Temitope Oyefuga as a trustee from October 2024. We reappointed Fiona Copeland, Tonia Hymers, Roly Megaw and Hannah Mitchison for another 3 years. The members voted unanimously.
7. We approved membership for:-
Charlie Softley.
Proposed by FC and approved by all members.

Strategy

We asked for general input to the Ciliopathy Alliance strategy.

We had a discussion about the Patient Day at the Cilia24 conference and some of areas of concerns the patients had. Charlie Softley suggested that we try to get published the results of the day to give researchers



Ciliopathy Alliance

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

a better understanding of what patients are worried about and what their concerns are. FC to enlist Helen May-Simera's help with this. **ACTION FC**

The group agreed that webinars should continue and it would be helpful to have a mix of science and policy. We should get more scientists involved to do more talks.

The group are still keen to have some sort of patient day in between the Cilia biannual meeting, so long as this does not clash with any similar events by others. It is a great opportunity for researchers to meet patients and build those relationships. Could be arranged through the science research focused UK Cilia Network Meeting to ensure numbers and PPIE (next one June in London). Should consider them to be more UK Focused and topic led.

We should encourage all researchers writing grant applications to include costs for PPI and for core funding for Ciliopathy Alliance administration costs.

We had a discussion about how we can inform people about research opportunities. To include:

- Patient participation experiences
- Benefits of taking part
- What are the barriers and concerns
- Understanding the concerns and fears
- What are the risks, understanding of drug development and clinical trial processes.

The AGM was closed.