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

MINUTES OF CILIOPATHY ALLIANCE ANNUAL GENERAL MEETING

The 14th Annual General Meeting of the Ciliopathy Alliance was held on 21 October 2025, at 12:30 to 13:15 on Microsoft Teams

Present:Rhoda Akilapa, Guys and St Thomas's Geneticist
Fiona Copeland, Trustee and PCD Representative
Audrey Hughes, PKD Representative
Tonia Hymers, Trustee and BBS Representative
Kerry Leeson-Beevers, Trustee and Alstrom Representative
Catherine Lewis, ASUK
Karen Liu , King's College London
Roly Megaw, Trustee University of Edinburgh
Hannah Mitchison, Interim Chair and Jeune representative
Chris Rowe, Cure Usher
Dagmar Watchen, University of Bonn

Apologies:

Chloe Joyner, Drina Parker, Michael Parker, Sharon O'Cansey, Charlie Softley Brown

MINUTES

Fiona Copeland (FC) opened the meeting and thanked everyone for attending. Apologies were noted.

Ordinary Business

1. Fiona Copeland (FC) reviewed the Minutes of the 13th Annual General Meeting held on 9 December 2024. Approval was proposed by FC and approved by the members.

2. Members received the accounts for the period 1st April 2024 to 31st March 2025. Approval was proposed by FC and approved by all members. Thanks to Michael Parker for providing comments and to Temitope Oyefuga for compiling the accounts.

   Net Position
   Net Deficit: £8663 (increased from a £946 deficit last year).

   The increase is attributed to the costs of Cilia24, the strategy day and TheRacil project.

   Cash Reserves
   Year-End Cash Balance: £26442 (down from £35105 last year).
   £25k invested in an interest savings account.
   Long term financial strategy has been kicked off and grant applications made.

   Overall Analysis and Recommendations

   Income Diversification: The charity's heavy reliance on "other income" is risky. Efforts are now being focused on securing grants, and reviving donations and legacies to secure long-term sustainability.

Expense Prioritization: Cilia24 and the strategy day dominate spending. While these are aligned with charitable objectives, the board should evaluate their return on investment to ensure maximum impact.
Reserves Policy: The cash reserves remain strong, (£26k) covering 24 months of average monthly expenses (based on an average year's spending). This provides a buffer for future uncertainties.
Conclusion: The charity is on a positive trajectory, with plans to secure funding from other sources and expenditure is currently low.

3. FC presented a summary of the year 2024-25:-

TheRaCil Therapeutics for Renal Ciliopathies

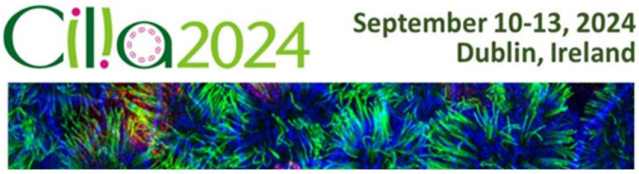
The charity is the patient partner in TheRaCiL with the responsibility of ensuring meaningful patient involvement and engagement throughout the 4 years (until 2027) of the project. Kerry Leeson-Beevers has taken on the role from Tess Harris.

CILIAREN Renal Ciliopathies National Network

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 that 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.

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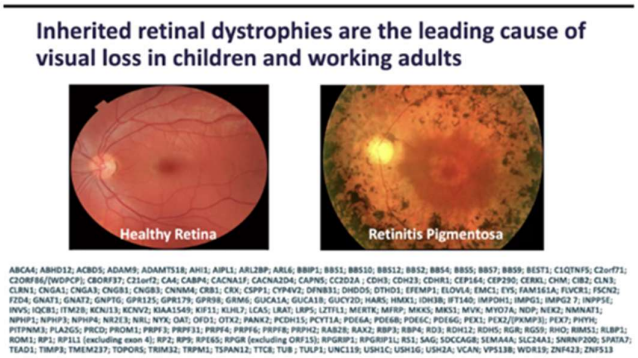
The key themes were:-

- 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.

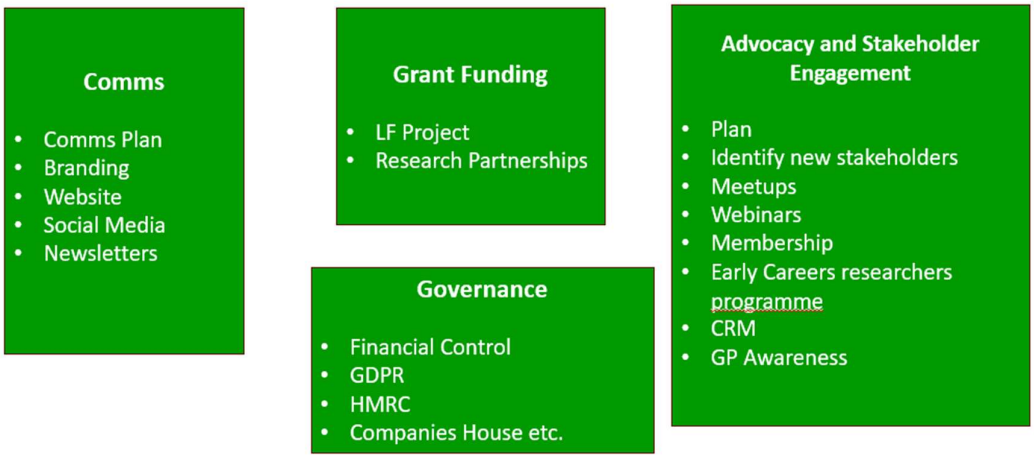
We appointed Temitope as our Treasurer in October 2024, and she has been instrumental in helping us review our strategy. We also had Audrey join our committee to represent the CiliaRen project and we are delighted she is now going to join us as a Trustee.

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

4. FC also updated the members of what activities had been undertaken so far in 25/26

- Administrative issues resolved e.g. bank accounts, Xero, MS365, Operational handbook
- Newsletter recommissioned
- Regular updates – LinkedIn, Facebook and Twitter
- Another webinar held on Skeletal Ciliopathies, Genetic Diagnosis and Support Groups, with speakers Rhoda Akilapa, Consultant in Clinical Genetics at Guys and St Thomas' and Matthew Carr from Retina UK in September 2025
- Supported TheRACILS and CiliaRen
- Patient Representatives on the Cilia27 Organising Committee
- Presented and sponsored Cilia and Centrosome Network Meeting
- Identified some free resource (volunteer programme and interns)
- Become Patient Partners for Cilia-AI Consortium
- Kicked off a grant funding project with the help of Louise Fish

The Future



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.

5. We formally appointed Rhoda Akilpa and Audrey Hughes as trustees from October 2025. Proposed by Fiona Copeland and seconded by Roly Megaw. We acknowledged Temitope Oyefuga's resignation and thanked her for her help this year.
   All remaining trustees are happy to remain on the Board for another year.

6. We approved membership for:-

   Katerina Apolinova and Heterotaxy Foundation
   Proposed by FC and approved by all members.

AOB

- Kerry Leeson-Beevers asked members to identify any families with Nephronophthisis - Audrey Hughes and Rhoda able to provide contacts.
- Suggested that we have a webinar about research – asking researchers to give presentations on how they got funding and involved patient advocates. Audrey Hughes also has a contact who is a radiologist who may be able to talk about patient advocacy.
- Roly asked whether there was any support for patients who did not qualify for patient trials. It was suggested that he refers patients to Deaf Blind UK who run the National Usher Service. FC to add to our project as a future stakeholder group.
- Tonia Hymers thanked Fiona for preparing the AGM.
- Hannah Mitchison congratulated Fiona on her honorary doctorate from the Open University in recognition of her patient advocacy work.

The AGM was closed.