

REGISTERED COMPANY NUMBER: 07842342 (England and Wales)

REGISTERED CHARITY NUMBER: 1148034

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021
FOR**

**CILIOPATHY ALLIANCE
(A COMPANY LIMITED BY GUARANTEE)**

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**CILIOPATHY ALLIANCE
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Trustees

Professor Philip Beales (Professor of Medical Genetics) – resigned February 2022
Mrs Fiona Copeland – appointed February 2022
Dr Elizabeth Forsythe (Clinician)
Mrs Laura Dowswell – appointed May 2021, resigned February 2022
Dr Toby Hurd (Researcher) – resigned January 2022
Professor Hannah Mitchison (Researcher)

Scientific Advisory Board

Chaired by Professor Philip Beales (Chair)

Registered Office

91 Royal College Street
London
NW1 0SE

Telephone number: 020 7387 0543
Email address: info@ciliopathyalliance.org
Web address: www.ciliopathyalliance.org

Registered Company Number

07842342 (England and Wales) (Incorporated 10 November 2011)

Registered Charity Number

1148034 (registered 10 July 2012)

Bankers

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

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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 2021. 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).

INTRODUCTION

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:

- o Alström Syndrome: ultra-rare, 700 known families worldwide (50-60 in UK) causing childhood blindness, hearing loss, heart, kidney, and liver failure.
- o Bardet-Biedl Syndrome: rare, 1 in 100,000 prevalence, causing visual impairment, obesity, polydactyly, kidney abnormalities/renal failure, developmental delay, infertility.
- o Jeune Syndrome: very rare, 1 in 200,000 prevalence, causing skeletal malformations, lung/respiratory problems, renal cysts/renal failure.
- o 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.
- o 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.
- o Primary Ciliary Dyskinesia: 1 in 15,000 prevalence, causing upper and lower respiratory tract infection, lungs, sinuses, and ears.
- o Retinitis Pigmentosa: 1 in 4,000 prevalence, causing progressive sight loss.
- o Usher Syndrome: 1 in 6 - 7,000 prevalence, causing progressive hearing and sight loss, and balance problems.

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OBJECTIVES AND ACTIVITIES

Objectives and aims

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'.

To achieve these objects, the charity aims to:

- o Promote, support and stimulate the sharing of knowledge and understanding of ciliopathies, nationally and transnationally.
- o Encourage and facilitate communication between patients, health professionals, researchers and other organisations that support people with ciliopathies.
- o Promote awareness of ciliopathies and the respective patient organisations.
- o Promote, sponsor 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.
- o Invite and encourage patient involvement in research and clinical management of ciliopathies.
- o Provide information that will benefit people with ciliopathies, in particular to those patients who do not have a condition/disease-specific support group and those in hard-to-reach geographical/ethnic communities.
- o Provide information and educational materials for health professionals and similar with the aim of improving diagnosis, clinical management, and social care.
- o Communicate with/ lobby 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.
- o Organise conferences, symposia, workshop and similar, and support the publication and/or dissemination of information and best practice about ciliopathies.
- o Co-operate with other charities, alliances, voluntary organisations and statutory bodies to further the interests of people with ciliopathies.

ACTIVITIES DURING THE YEAR TO 31 MARCH 2021

COVID-19

COVID-19 continued to restrict the charity's work and the lives of its beneficiaries and trustees. No face-to-face meetings were held. At the time of preparing this report, there are still many restrictions which hinder the normal operation of the charity.

Information and awareness

Cilia2021 (rescheduled from 2020) was again cancelled. The steering committee has re-scheduled the event to October 2022.

The European Training Network for studying Ciliary Signalling in development and disease ('SCiLS'), funded

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by EU Horizon 2020 progressed. The Ciliopathy Alliance is the primary patient organisation and attended online progress meetings. [Find out more about SCiS.](#)

The Ciliopathy Alliance was represented at the European Reference Network for Rare Kidney Diseases (ERKNet). Ms Harris attends regular ERKNet meetings. Other Ciliopathy Alliance clinician/researcher Members participate in the European Reference Networks and relevant EU research applications.

The Ciliopathy Alliance website attracted 31,000 visitors during the year from a wide range of countries. The site contains information on the structure and function of cilia (the most popular pages on the site) and links to the patient support groups.

Miss Harris attended meetings on rare diseases organised by Genetic Alliance/RDUK, inter alia.

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FINANCIAL REVIEW

Performance

During the year ended 31 March 2021, the charity's income was £24,148 (2020: £13). The increase was due to a generous anonymous donation received during the year.

The charity incurred expenses of £357 (2020: £735) resulting in a surplus of £23,792 (2020: -£722).

Full details of the charity's performance are set out in page 8 of the statement of financial activities to the financial statements.

Reserves policy

The directors considered that the charity had sufficient reserves at the year-end to fund its routine activities during 2021-22.

FUTURE PLANS

The charity will review its strategy. The website will be maintained and kept up to date.

Cilia2022 will be held from 4-7 October in Cologne as a 'hybrid' event, including a 'Patient's Day', free of charge to ciliopathy patients, family members/carers and ciliopathy patient support groups. [Find out more about Cilia2022](#). The Ciliopathy Alliance is a member of the steering committee.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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.

Organisation structure and governance

The trustees of the charity, who are the directors of the limited company, are responsible for the governance of the charity. The charity has four 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.

The Trustees recognise their obligations to maintain a dynamic board of trustees and as part of reviewing and refining its management of trusteeships, the Ciliopathy Alliance is continuing a rolling programme of new trustee appointments in preparation for eventual retirement of longer-standing trustees.

Public benefit

All charitable activities are undertaken to further charitable purposes for public benefit. The trustees confirm

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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 the 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.

Approved by order of the board of trustees on 1 March 2022 and signed on its behalf by:



Professor Hannah Mitchison - Trustee

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STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 MARCH 2021

	Unrestricted fund £	Restricted fund £	2021 Total funds £	2020 Total funds £
INCOME AND ENDOWMENTS FROM				
Donations and legacies	<u>24,148</u>	<u>-</u>	<u>24,148</u>	<u>13</u>
Total	24,148	-	24,148	13
 EXPENDITURE ON				
Charitable activities				
Conferences and workshops	-	-	-	-
Subscriptions	23	-	23	22
Bank charges	75	-	75	60
Website costs	246	-	246	246
Governance costs				
Trustee expenses	-	-	-	394
Accountancy fees	-	-	-	-
Companies House	<u>13</u>	<u>-</u>	<u>13</u>	<u>13</u>
Total resources expended	357	-	357	-722
NET INCOME	23,792	-	23,792	-722
 RECONCILIATION OF FUNDS				
Total funds brought forward	7,179	-	7,179	7,901
TOTAL FUNDS CARRIED FORWARD	<u>30,971</u>	<u>-</u>	<u>30,971</u>	<u>7,179</u>

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

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**BALANCE SHEET
AT 31 MARCH 2021**

	Unrestricted fund £	Restricted fund £	2021 Total funds £	2020 Total funds £
CURRENT ASSETS				
Cash at bank	30,971	-	30,971	7,179
CREDITORS				
Amounts falling due within one year		-		-
	<u>30,971</u>	<u>-</u>	<u>30,971</u>	<u>7,179</u>
NET CURRENT ASSETS				
	30,971	-	30,971	7,179
TOTAL ASSETS LESS CURRENT LIABILITIES				
	<u>30,971</u>	<u>-</u>	<u>30,971</u>	<u>7,179</u>
NET ASSETS				
	<u>30,971</u>	<u>-</u>	<u>30,971</u>	<u>7,179</u>
FUNDS				
Unrestricted funds			30,971	7,179
Restricted funds			<u>-</u>	<u>-</u>
TOTAL FUNDS			<u>30,971</u>	<u>7,179</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2021 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.

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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 1 March 2022 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