

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 2018
FOR**

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

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

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FOR THE YEAR ENDED 31 MARCH 2018**

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

**REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 31 MARCH 2018**

Trustees

Professor Philip Beales (Professor of Medical Genetics)
Mrs Claire Glen (University Administrator)
Dr Elizabeth Forsythe (Clinician)
Dr Toby Hurd (Researcher) (Appointed on 22 March 2018)
Dr David Miller (Chair) (Independent Consultant)
Mr Michael Parker (Retired Actuary)
Mr Stephen Thacker (Charity Volunteer)

Scientific Advisory Board

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

Accountants

Fryza Bannister Financials Limited
Chartered Certified Accountants
The Stables
Goblands Farm Business Centre
Cemetery Lane
Hadlow
Kent
TN11 0LT

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

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2018**

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 2018. 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 a number of 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.
- 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.
- 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, with stunted growth.
- Primary Ciliary Dyskinesia: 1 in 15,000 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.

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:

- Promote, support and stimulate the sharing of knowledge and understanding of ciliopathies, nationally and transnationally.
- Encourage and facilitate communication between patients, health professionals, researchers and other organisations that support people with ciliopathies.
- Promote awareness of ciliopathies and the respective patient organisations.
- 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.
- Invite and encourage patient involvement in research and clinical management of ciliopathies.
- 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.
- Provide information and educational materials for health professionals and similar with the aim of improving diagnosis, clinical management and social care.
- 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.
- Organise conferences, symposia, workshop and similar, and support the publication and/or dissemination of information and best practice about ciliopathies.
- Co-operate with other charities, alliances, voluntary organisations and statutory bodies to further the interests of people with ciliopathies.

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

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2018**

Significant activities

Information and awareness

The Ciliopathy Alliance was actively involved in the planning of Cilia 2018, the 4th of a series of conferences in whose origins the Ciliopathy Alliance played a pivotal role. Patient engagement continued to be championed by the Ciliopathy Alliance and feedback on this aspect from the Cilia 2016 conference was taken into account in preparing for Cilia 2018.

The Ciliopathy Alliance website www.ciliopathyalliance.org continues to attract over 80,000 visitors a year, with the majority being new to the site. 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.

During the year, Professor Beales continued to lead for the charity on liaison with NHS England on plans to commission a highly specialised service for ciliopathy patients. Although there have been slippages in the approval process timeline, it is hoped that the service will be commissioned by NHSE in 2019.

Trustees

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 has initiated a rolling programme of new trustee appointments in preparation for eventual retirement of longer-standing trustees.

General Data Protection Regulation (GDPR)

The impending introduction of the new GDPR necessitated a significant amount of administrative work for the Ciliopathy Alliance in order to ensure that the Charity was in a position to be adherent from its introduction in May 2018.

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.

FINANCIAL REVIEW

Reserves policy

The directors considered that, when combined with expected income, the charity had sufficient reserves at the year-end to fund its proposed activities during 2018-19. If, however, activities that require a more substantial funding base are to be undertaken, more substantial fund raising activities will need to be pursued.

Performance

During the year ended 31 March 2018, the charity's income was £3,141 (2017: £2,968).

The charity incurred expenses of £1,410 (2017: £1,151) resulting in a surplus of £1,731 (2017: £1,817).

Full details of the charity's performance are set out in page 6 of the statement of financial activities to the financial statements.

FUTURE PLANS

The charity aims to implement its 3-year strategic workplan including completing development of objectives to support this, and the focus will then be on fundraising to implement the plan and to sustain the charity.

The website will be updated during 2018.

The Ciliopathy Alliance will participate in the fourth international ciliopathies conference, CILIA 2018, which will take place in Copenhagen in the autumn of 2018.

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 seven trustees at 31 March 2018. 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.

**CILIOPATHY ALLIANCE
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**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2018**

STRUCTURE, GOVERNANCE AND MANAGEMENT (CONTINUED)

Organisation structure and governance (continued)

Trustees meet approximately quarterly and communicate by email in between meetings. Members' meetings are held regularly to allow sharing of knowledge and input into the charity's strategy.

Trustees are provided with copies of relevant Charity Commission guidance and publication, 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.

Volunteers

The administration and secretariat functions of the charity are undertaken by a volunteer, Miss Tess Harris, CEO of the PKD Charity (a member of the Ciliopathy Alliance).

Accountants

The charity's accounts were prepared by Fryza Bannister Financials Limited, a firm of Chartered Certified Accountants. 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. At 31 March 2018, the members were:

Patient Groups

Alström Syndrome (UK)
Bardet-Biedl Syndrome (UK)
Jeune Syndrome (UK)
Joubert Syndrome (UK)
Polycystic Kidney Disease Charity (UK)
Primary Ciliary Dyskinesia Family Support Group (UK)
RP Fighting Blindness (UK)
Sense (UK)
Dyskinesia (Belgium)
Sensenbrenner Syndrome patient group (Poland)
Usher Syndrome Coalition (international)

Individuals

Professor Philip Beales
Dr Sonia Christou-Savina
Dr Megan Davey
Dr Elizabeth Forsythe
Mrs Claire Glen
Dr Jay Gopalakrishnan
Dr Claire Hogg
Dr Toby Hurd
Dr Dan Jagger
Dr Swadhin Jana
Dr David Miller
Dr Hannah Mitchison
Dr Brian Piasecki

**CILIOPATHY ALLIANCE
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**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2018**

MEMBERSHIP (CONTINUED)

Individuals (continued)

Dr Ursula Rodgers
Dr Miriam Schmidts
Mr Stephen Thacker
Dr Joanna Walczak-Sltulpa

Organisations

Cincinnati Children's Hospital
National Institute of Sensory Organs
Poznan University of Medical Sciences

Approved by order of the board of trustees on 7 December 2018 and were signed on its behalf by:

Dr D D Miller - Trustee

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

**STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 MARCH 2018**

		2018 Unrestricted fund £	2017 Unrestricted fund £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	Notes 3	<u>3,141</u>	<u>2,968</u>
Total		3,141	2,968
EXPENDITURE ON			
Charitable activities	4		
Awareness, communication and stakeholder engagement		<u>1,410</u>	<u>1,151</u>
Total		1,410	1,151
NET INCOME		1,731	1,817
RECONCILIATION OF FUNDS			
Total funds brought forward		8,489	6,672
TOTAL FUNDS CARRIED FORWARD		<u>10,220</u>	<u>8,489</u>
CONTINUING OPERATIONS			
All income and expenditure has arisen from continuing activities.			

The notes form part of these financial statements

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

**BALANCE SHEET
AT 31 MARCH 2018**

	Notes	2018 Unrestricted fund £	2017 Unrestricted fund £
CURRENT ASSETS			
Cash at bank		11,060	9,329
CREDITORS			
Amounts falling due within one year	8	(840)	(840)
		<u> </u>	<u> </u>
NET CURRENT ASSETS		<u>10,220</u>	<u>8,489</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		10,220	8,489
		<u> </u>	<u> </u>
NET ASSETS		<u>10,220</u>	<u>8,489</u>
FUNDS	9		
Unrestricted fund		10,220	8,489
		<u> </u>	<u> </u>
TOTAL FUNDS		<u>10,220</u>	<u>8,489</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2018.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2018 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 7 December 2018 and were signed on its behalf by:

Dr D D Miller -Trustee

The notes form part of these financial statements

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

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2018**

1. GENERAL INFORMATION

Ciliopathy Alliance is a company limited by guarantee and has no share capital. It is incorporated in England and Wales and its registered office and principal address is 91 Royal College Street, London NW1 0SE.

The principal activity of the company is disclosed in the Report of the Trustees.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The trustees consider it appropriate to adopt the going concern basis of accounting in preparing the annual financial statements. Sufficient reserves and ongoing voluntary income are considered sufficient to meet the financial commitments for the foreseeable future.

The trustees also consider that there are no key assumptions or estimates that need separate disclosure.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donations and gifts are brought into account when received.

Grants received in relation to charitable activities, where entitlement is not conditional on the delivery of a specific performance, are recognised when the charity becomes unconditionally entitled to the grant. Where grants are related to performance and specific deliverables, these are accounted for as the charity earns the right to consideration.

Expenditure

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Expenditure on charitable activities comprise costs that can be allocated directly to such activities (termed direct costs) and those costs of an indirect nature necessary to support them (termed support costs).

Included under support costs are governance costs. Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include costs linked to the management of the charity and the accountancy fees.

Support costs (including governance costs) have been allocated to expenditure on charitable activities.

Allocation and apportionment of costs

All costs are allocated between expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned as follows:

Postage and stationary - usage
Administration and secretariat fees - on a time basis
Website hosting fee - pro rata based on deemed benefit

Governance costs are allocated in accordance with note 5.

Taxation

The charity is exempt from corporation tax on its charitable activities.

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

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 MARCH 2018**

2. ACCOUNTING POLICIES - continued

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can be used only for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes. the charity currently has no restricted funds.

Irrecoverable vat

Irrecoverable element of VAT is included with the item of expense to which it relates.

Debtors

Trade debtors are recognised at the amount due net of any trade discounts. Prepayments are valued at the amount prepaid, net of any trade discounts due.

Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

Financial instruments

The company has financial assets and financial liabilities only of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

3. DONATIONS AND LEGACIES

	2018	2017
	£	£
Donations	3,141	2,968
	<u>3,141</u>	<u>2,968</u>

4. CHARITABLE ACTIVITIES COSTS

	Support costs (See note 5)	Totals
	£	£
Awareness, communication and stakeholder engagement	<u>1,410</u>	<u>1,410</u>

5. SUPPORT COSTS

	Finance £	Information technology £	Governance costs £	Totals £
Awareness, communication and stakeholder engagement	<u>60</u>	<u>289</u>	<u>1,061</u>	<u>1,410</u>

Support costs, included in the above, are as follows:

**CILIOPATHY ALLIANCE
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**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 MARCH 2018**

5. SUPPORT COSTS - continued

Finance

	2018 Awareness, communication and stakeholder engagement	2017 Total activities
	£	£
Bank charges	<u>60</u>	<u>32</u>

Information technology

	2018 Awareness, communication and stakeholder engagement	2017 Total activities
	£	£
Website hosting fee	<u>289</u>	<u>219</u>

Governance costs

	2018 Awareness, communication and stakeholder engagement	2017 Total activities
	£	£
Trustees' expenses	289	47
Accountancy fees	840	840
Companies House fees	13	13
	<u>1,061</u>	<u>900</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2018 nor for the year ended 31 March 2017.

Trustees' expenses

	2018 £	2017 £
Trustees' expenses	<u>289</u>	<u>47</u>

Expenses were paid to one trustee, in reimbursement of travel expenses for attending trustees' meetings.

7. STAFF COSTS

There were no staff costs for the year ended 31 March 2018 nor for the year ended 31 March 2017.

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

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 MARCH 2018**

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2018 £	2017 £
Accruals and deferred income	<u>840</u>	<u>840</u>

9. MOVEMENT IN FUNDS

	At 1/4/17 £	Net movement in funds £	At 31/3/18 £
Unrestricted funds			
General fund	8,489	1,731	10,220
	<u>8,489</u>	<u>1,731</u>	<u>10,220</u>
TOTAL FUNDS	<u>8,489</u>	<u>1,731</u>	<u>10,220</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	3,141	(1,410)	1,731
	<u>3,141</u>	<u>(1,410)</u>	<u>1,731</u>
TOTAL FUNDS	<u>3,141</u>	<u>(1,410)</u>	<u>1,731</u>

Comparatives for movement in funds

	At 1/4/16 £	Net movement in funds £	At 31/3/17 £
Unrestricted Funds			
General fund	6,672	1,817	8,489
	<u>6,672</u>	<u>1,817</u>	<u>8,489</u>
TOTAL FUNDS	<u>6,672</u>	<u>1,817</u>	<u>8,489</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	2,968	(1,151)	1,817
	<u>2,968</u>	<u>(1,151)</u>	<u>1,817</u>
TOTAL FUNDS	<u>2,968</u>	<u>(1,151)</u>	<u>1,817</u>

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2018 and 31 March 2017.

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

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2018**

	2018 £	2017 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	3,141	2,968
	<u>3,141</u>	<u>2,968</u>
Total incoming resources	3,141	2,968
EXPENDITURE		
Finance		
Bank charges	60	32
Information technology		
Website hosting fee	289	219
Governance costs		
Trustees' expenses	208	47
Accountancy fees	840	840
Companies house fees	<u>13</u>	<u>13</u>
	<u>1,061</u>	<u>900</u>
Total resources expended	1,410	1,151
	<u>1,731</u>	<u>1,817</u>
Net income	<u>1,731</u>	<u>1,817</u>

This page does not form part of the statutory financial statements