REPORT OF THE TRUSTEES AND UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2017 FOR

CILIOPATHY ALLIANCE (A COMPANY LIMITED BY GUARANTEE)

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REFERENCE AND ADMINISTRATIVE DETAILS FOR THE YEAR ENDED 31 MARCH 2017

Trustees

Professor Philip Beales (Professor of Medical Genetics)
Mrs Suzanna Claire Glen (Researcher)
Dr Elizabeth Forsythe (Clinician)(appointed 28 February 2017)
Dr David Miller (Chair) (Independent Consultant)
Mr Michael Parker (Retired Actuary)
Mr Stephen Thacker (Charity Volunteer)

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

Accountants

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

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2017

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 2017. 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.
- 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.
- 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.
- o 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.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2017

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.

o 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.

- 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.
- 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.
- 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.

Significant activities

Strategic workplan

The Ciliopathy Alliance was awarded a Big Lottery Awards For All grant to develop a 3-year strategic workplan for the charity in the UK. During 2015-16, the balance of the grant was expended on the finalisation of the workplan. During 2016-17, the workplan was used as a foundation for the development of a set of Objectives that will support the implementation of the workplan. Major headings for the objectives include: Membership Engagement, Research Prioritisation, Registries, Fundraising and Spending, Operational/governance Matters.

Information and awareness

During 2015-16 and 2016-17, the Ciliopathy Alliance was a member of the steering committee of CILIA 2016, the third biennial international conference on ciliopathies which was held in Amsterdam in November 2016. Several Trustees (Beales, Parker and Miller) and Miss Harris attended the conference, either in full, or for the patient engagement activities. The conference was an acknowledged success and planning for the next in the series, Cilia 2018, is underway.

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, Miss Harris and Professor Beales led for the charity on liaison with NHS England on plans to commission a highly specialised service for ciliopathy patients. It is hoped that the service will be commissioned by NHSE in early 2018. Miss Harris also attended meetings on rare diseases organised by Genetic Alliance/RDUK, inter alia.

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 2017-18.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2017

FINANCIAL REVIEW

Performance

During the year ended 31 March 2017, the charity's income was £2,968 (2016: £6,400).

The charity incurred expenses of £1,151 (2016: £4,287) resulting in a surplus of £1,817 (2016: £2,113).

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 2017.

The Ciliopathy Alliance is a member of the steering committee of 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 six 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. 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 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.

Management

The trustees delegate the administration and secretariat functions of the charity to Tess Harris, an independent contractor, who is the CEO of the PKD Charity (a member of the Ciliopathy Alliance). 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 2017, 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)

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2017

MEMBERSHIP (continued)

Dyskinesia (Belgium) Sensenbrenner Syndrome patient group (Poland) Usher Syndrome Coallition (international)

Individuals

Professor Phil 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

Dr Ursula Rodgers

Dr Miriam Schmidts

Mr Stephen Thacker

Dr Joanna Walczak-Situlpa

Organisations

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

Approved by order of the board of trustees on 13 September 2017 and signed on its behalf by:

Dr D D Miller - Trustee

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 MARCH 2017

	Notes	Unrestricted fund £	Restricted fund £	2017 Total funds £	2016 Total funds £
INCOME AND ENDOWMENTS FROM Donations and legacies	3	2,968		2,968	6,400
Total		2,968		2,968	6,400
EXPENDITURE ON Charitable activities Conferences and workshops Awareness, communication and stakeholder engagement Total	4	1,151 1,151		1,151 1,151	1,188 3,099 4,287
NET INCOME		1,817		1,817	2,113
RECONCILIATION OF FUNDS					
Total funds brought forward		6,672		6,672	4,559
TOTAL FUNDS CARRIED FORWARD		8,489	-	8,489	6,672

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

BALANCE SHEET AT 31 MARCH 2017

	Notes	Unrestricted fund £	Restricted fund £	2017 Total funds £	2016 Total funds £
CURRENT ASSETS Cash at bank		9,329	-	9,329	7,622
CREDITORS Amounts falling due within one year	9	(840)		(840)	(950)
NET CURRENT ASSETS		8,489	-	8,489	6,672
TOTAL ASSETS LESS CURRENT LIABILITIES		8,489		8,489	6,672
NET ASSETS		8,489	-	8,489	6,672
FUNDS Unrestricted funds Restricted funds	10			8,489	6,672
TOTAL FUNDS				8,489	6,672

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2017.

The members have not required the charitable company to obtain an audit of its financial statements for the year ended 31 March 2017 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

Sand & Mills

- (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 small charitable companies.

The financial statements were approved by the Board of Trustees on 13 September 2017 and were signed on its behalf by:

Dr D D Miller - Trustee

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2017

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.

The presentational currency for the financial statements is £ sterling.

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 accountants 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.

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 MARCH 2017

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 only be used 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.

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

	2017	2016
	£	£
Donations	2,968	4,000
Grants	•	2,400
	2,968	6,400
Grants received, included in the above, are as follows:		
	2017	2016
	£	£
Capacity building grant		2,400

4. CHARITABLE ACTIVITIES COSTS

	Support costs (See note 5)	Totals
	£	£
Awareness, communication and stakeholder engagement	1,151	1,151

5. SUPPORT COSTS

		~
219	900	1,151
	2 219	2 219 900

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

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 MARCH 2017

SUPPORT COSTS - continued		
Management		
	2017	2016
	Total activities	Total activities
	£	£
Postage and stationery		64
		_
Finance		
	2017	2016
	Awareness,	
	communication	
	and	
	stakeholder	
	engagement	Total activities
	£	£
Bank charges	32	
Information technology		
	2017	2016
	Awareness,	
	communication	
	and	
	stakeholder	
	engagement	Total activities
	£	£
Website hosting fee	219	180
Governance costs		
Governance costs	2017	2046
	Awareness,	2016
	communication	
	and	
	stakeholder	
	engagement	Total activities
	£	£
Trustees' expenses	47	190
Accountancy fees	840	950
Companies house fees	13	13
Strategic planning fees	10	2,400
and the second s		
	900	3,553
TRUSTEES' REMUNERATION AND BENEFITS		
There were no trustees' remuneration or other benefits for the year ende 31 March 2016:	ed 31 March 2017 nor fo	or the year ende
Trustees' expenses		

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

Trustees' expenses

2017

47

£

2016

190

£

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 MARCH 2017

7. STAFF COSTS

There were no staff costs for the year ended 31 March 2017 nor for the year ended 31 March 2016.

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

		Unrestricted fund	Restricted fund	Total funds
	INCOME AND ENDOWMENTS FROM	£	£	£
	Donations and legacies	4,000	2,400	6,400
	Total	4,000	2,400	6,400
	EXPENDITURE ON			
	Charitable activities	4 400		4 400
	Conferences and workshops Awareness, communication and stakeholder engagement	1,188 699	2,400	1,188 3,099
	Total	1,887	2,400	4,287
	NET INCOME	2,113		2,113
	RECONCILIATION OF FUNDS			
	Total funds brought forward			
	As previously reported	1,359		1,359
	Prior year adjustment	3,200		3,200
	As Restated	4,559		4,559
	TOTAL FUNDS CARRIED FORWARD	6,672		6,672
9.	CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR			
			2017	2016
	Accorde and deferred income		£	£
	Accruals and deferred income		<u>840</u>	950
10.	MOVEMENT IN FUNDS			
		N	let movement	
		At 1/4/16	in funds	At 31/3/17
	Unrestricted funds	£	£	£
	General fund	6,672	1,817	8,489
		-		-
	TOTAL FUNDS	6,672	1,817	8,489

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED FOR THE YEAR ENDED 31 MARCH 2017

10. MOVEMENT IN FUNDS - continued

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
TOTAL FUNDS	2,968	(1,151)	1,817

11. RELATED PARTY DISCLOSURES

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

12. PURPOSE OF RESTRICTED FUNDS

The restricted fund was fully expended in the previous accounting period and related to a grant awarded to develop a 3 year work plan.

DETAILED STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2017

	2017	2016
	£	£
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations Grants	2,968	4,000 2,400
Giants		2,400
	2,968	6,400
Total incoming resources	2,968	6,400
EXPENDITURE		
Charitable activities		
Conferences and workshops		490
Support costs		
Management Protection and stationary		64
Postage and stationery Finance		04
Bank charges	32	
Information technology		
Website hosting fee	219	180
Governance costs	4-7	400
Trustees' expenses	47 840	190 950
Accountancy fees Companies house fees	13	13
Strategic planning fees	-	2,400
	900	3,553
Total resources expended	1,151	4,287
Net income	1,817	2,113