

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 2014  
FOR

CILIOPATHY ALLIANCE  
(A COMPANY LIMITED BY GUARANTEE)

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

**CONTENTS OF THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2014**

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

**REFERENCE AND ADMINISTRATIVE DETAILS  
FOR THE YEAR ENDED 31 MARCH 2014**

**Trustees**

Professor Philip Beales (Professor of Medical Genetics) (appointed 10/7/2013)  
Mrs Suzanna Claire Glen (Researcher) (appointed 10/7/2014)  
Dr Thomas Kenny (Medical Adviser) (resigned 10/5/2013)  
Dr David Miller (Chair) (Research Scientist)  
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](mailto:info@ciliopathyalliance.org)  
Web address: [www.ciliopathyalliance.org](http://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 and Independent Examiner**

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

**CILIOPATHY ALLIANCE  
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**REPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 31 MARCH 2014**

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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 2014. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in March 2005.

#### **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 known 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 births, causing visual impairment, obesity, polydactyly, kidney abnormalities/renal failure, developmental delay, infertility.
- o Jeune Syndrome: very rare, 1 in 200,000, causing skeletal malformations, lung/respiratory problems, renal cysts/renal failure.
- o Joubert Syndrome: very rare, 1 in 100-250,000, 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 800 to 1,000 births, causing massive cystic kidneys and livers, kidney failure, brain aneurysms, cardiovascular disease; and the rare Autosomal Recessive PKD - 1 in 20-40,000 births, causing kidney failure and liver fibrosis, with stunted growth.
- o Primary Ciliary Dyskinesia: 1 in 15,000, causing upper and lower respiratory tract infection, lungs, sinuses and ears.
- o Retinitis Pigmentosa: 1 in 4,000, causing progressive sight loss.
- o Usher Syndrome: 1 in 6-7,000 incidence, causing progressive hearing and sight loss, and balance problems.

#### **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.

**CILIOPATHY ALLIANCE  
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**REPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 31 MARCH 2014**

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**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**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 now has five 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 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 and 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 and independently examined by Fryza Bannister Financials Limited, a firm of Chartered Certified Accountants.

**MEMBERSHIP**

Prior to becoming a registered charity, an alliance had been formed in 2010 of patient groups representing children and adults affected by ciliopathies, clinicians and scientists. These groups and individuals were the founding members of the charity.

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 to the directors, who approve new members. The directors have established classes of membership with different rights and obligations.

A membership register is maintained by the secretariat. A list of members can be found on the Ciliopathy Alliance website. At 31 March 2014, the members were:

**Patient Groups**

Alström Syndrome UK  
Jeune Syndrome UK  
Joubert Syndrome UK  
Laurence-Moon-Bardet-Biedl Society  
Polycystic Kidney Disease Charity  
Primary Ciliary Dyskinesia Family Support Group  
RP Fighting Blindness  
Sense

**Individuals**

Professor Phil Beales  
Ms Swadhin Chandra  
Dr Megan Davey  
Dr Claire Hogg  
Dr Takeshi Iwata  
Dr Dan Jagger  
Dr Tom Kenny  
Dr David Miller  
Dr Hannah Mitchison  
Dr Miriam Schmidts  
Mr Stephen Thacker  
Dr Timothy Vogel

**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.

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

**REPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 31 MARCH 2014**

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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 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.

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

**REPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 31 MARCH 2014**

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**OBJECTIVES AND ACTIVITIES**

**Significant activities**

**The first Ciliopathy Alliance Family Conference**

In 2012, the charity was awarded a £25,000 grant from Jeans for Genes (Genetic Disorders UK) to organise a family conference in spring 2013, with the aim to:

- o Update families and clinicians on latest research and best clinical practices.
- o Enable families to give feedback on patient experiences as input to support groups and specialised services commissioners.
- o Bring families/patients together with clinicians, researchers and commissioners.
- o Provide a forum to pool knowledge and expertise.
- o Develop shared strategies for improving patient care.
- o Provide help to patients without support groups to form a group.
- o Input into the charity's future strategy.

The Family Conference was held in May 2013 and attended by nearly 100 families, clinicians, researchers and allied health professionals. The proceedings of the Conference, including the plenary talks and a graphical record of the discussions, can be found on the Ciliopathy Alliance website:

<http://www.ciliopathyalliance.org/events/past-events/117-ciliopathy-alliance-family-conference-2013.html>

Although slightly less well attended than we had hoped, due mainly to logistical challenges faced by some families with visually impaired children, feedback from those who did attend was overwhelmingly positive. Patients and families in particular valued having informal access to clinicians and researchers in the field of ciliopathies.

It was an extremely lively conference with much participation and sharing of ideas on how the Ciliopathy Alliance can help to support ciliopathy patients and their families.

The outputs from the report are being used to develop a 3-year strategic workplan for the Alliance in the UK.

**Information and awareness**

The Ciliopathy Alliance website [www.ciliopathyalliance.org](http://www.ciliopathyalliance.org) attracted nearly 77,000 unique visitors in the period to 31 March 2014 (2013: 58,000 unique visitors). 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.

Members of the Ciliopathy Alliance attended Rare Disease Day in February 2014 at the House of Commons.

During the year, Tess Harris attended a number of meetings on rare diseases organised by Genetic Alliance/RDUK and on specialised services' commissioning organised by NHS England. She also attended the first IRDiRC (International Rare Diseases Research Consortium) Conference in Dublin, organised by the European Commission.

**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 the charity had sufficient reserves at the year-end to fund its proposed activities during 2014-15.

**Performance**

During the year ended 31 March 2014, the charity's income was £32,331 (2013: £83,982).

The charity incurred expenses of £32,483 (2013: £73,018) resulting in a deficit of £152 (2013: surplus £10,964).

The primary source of income in the year was from a grant from Jeans For Genes/Genetic Disorders UK.

Full details of the charity's performance may be taken from the statement of financial activities on page 8 to the financial statements.

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

**REPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 31 MARCH 2014**

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**FUTURE DEVELOPMENTS**

The long-term sustainability of the Ciliopathy Alliance remains a primary focus. A 3-year strategic workplan is being developed for the UK, funded by a Big Lottery Awards For All grant awarded in May 2014. Consultations with members and other key stakeholders will be reviewed and discussed at a Members' workshop.

The charity will also participate in CILIA 2014, the second international conference on cilia, held in Paris in November 2014. The conference will include a patient/family engagement event.

Approved by order of the board of trustees on 15 December 2014 and signed on its behalf by:



Dr D D Miller - Trustee



**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF  
CILIOPATHY ALLIANCE  
(A COMPANY LIMITED BY GUARANTEE)**

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I report on the accounts for the year ended 31 March 2014 set out on pages eight to fourteen.

**Respective responsibilities of trustees and examiner**

The charity's trustees (who are also the directors for the purposes of company law) are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under Section 144(2) of the Charities Act 2011 (the 2011 Act)) and that an independent examination is required.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under Section 145 of the 2011 Act
- to follow the procedures laid down in the General Directions given by the Charity Commission (under Section 145(5)(b) of the 2011 Act); and
- to state whether particular matters have come to my attention.

**Basis of the independent examiner's report**

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statements below.

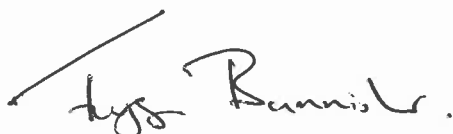
**Independent examiner's statement**

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that, in any material respect, the requirements
  - to keep accounting records in accordance with Section 386 and 387 of the Companies Act 2006; and
  - to prepare accounts which accord with the accounting records, comply with the accounting requirements of Sections 394 and 395 of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities

have not been met; or

- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Fryza Bannister Financials Limited  
Chartered Certified Accountants  
Commercial House  
High Street  
Hadlow  
Kent  
TN11 0EE

15 December 2014

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

**STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 31 MARCH 2014**

	Notes	Unrestricted fund £	Restricted fund £	YEAR ENDED 31/3/14 Total funds £	PERIOD 10/11/11 TO 31/3/13 Total funds £
<b>INCOMING RESOURCES</b>					
<b>Incoming resources from generated funds</b>					
Voluntary income	2	6,815	-	6,815	1,250
<b>Incoming resources from charitable activities</b>					
Conferences and workshops	3	-	25,000	25,000	82,699
Awareness, communication and stakeholder engagement		-	500	500	-
<b>Other incoming resources</b>	4	16	-	16	33
<b>Total incoming resources</b>		6,831	25,500	32,331	83,982
<b>RESOURCES EXPENDED</b>					
<b>Charitable activities</b>					
Conferences and workshops		2,790	19,380	22,170	66,151
Awareness, communication and stakeholder engagement		2,120	1,750	3,870	-
<b>Governance costs</b>	6	6,423	-	6,423	6,673
<b>Other resources expended</b>		20	-	20	194
<b>Total resources expended</b>		11,353	21,130	32,483	73,018
<b>NET INCOMING/(OUTGOING) RESOURCES</b>		(4,522)	4,370	(152)	10,964
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		10,964	-	10,964	-
<b>TOTAL FUNDS CARRIED FORWARD</b>		6,442	4,370	10,812	10,964

The notes form part of these financial statements

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

**BALANCE SHEET  
AT 31 MARCH 2014**

	Notes	Unrestricted fund £	Restricted fund £	2014 Total funds £	2013 Total funds £
<b>CURRENT ASSETS</b>					
Debtors	10	1,250	-	1,250	-
Cash at bank		7,042	4,870	11,912	35,964
		8,292	4,870	13,162	35,964
<b>CREDITORS</b>					
Amounts falling due within one year	11	(1,850)	(500)	(2,350)	(25,000)
		6,442	4,370	10,812	10,964
<b>NET CURRENT ASSETS</b>					
		6,442	4,370	10,812	10,964
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>					
		6,442	4,370	10,812	10,964
<b>NET ASSETS</b>					
		6,442	4,370	10,812	10,964
<b>FUNDS</b>					
Unrestricted funds	12			6,442	10,964
Restricted funds				4,370	-
				10,812	10,964
<b>TOTAL FUNDS</b>					
				10,812	10,964

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2014.

The members have not required the charitable company to obtain an audit of its financial statements for the year ended 31 March 2014 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 small charitable companies and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The financial statements were approved by the Board of Trustees on 15 December 2014 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 2014**

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**1. ACCOUNTING POLICIES**

**Accounting convention**

The financial statements have been prepared under the historical cost convention, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008), the Companies Act 2006 and the requirements of the Statement of Recommended Practice, Accounting and Reporting by Charities.

**Incoming resources**

All incoming resources are included on the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. The following policies are applied to particular categories of income:

Voluntary income is received by way of grants, donations and gifts. It is included in the full Statement of Financial Activities when receivable.

Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant.

Incoming resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance and are classified as incoming resources from charitable activities.

Investment income is included when it is earned.

Donated services and facilities are included at the value to the charity where this can be quantified.

**Resources expended**

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 includes Value Added Tax which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services to its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them (termed support costs).

To assist with the preparation of the financial statements all resources expended in connection with management and information technology have been classified as 'support costs'.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include costs linked to the strategic management of the charity and the accountant's fees.

**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:

Administration and secretariat fees - on a time basis  
Information technology - usage

**Taxation**

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

**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.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

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

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED  
FOR THE YEAR ENDED 31 MARCH 2014**

**2. VOLUNTARY INCOME**

	YEAR ENDED 31/3/14	PERIOD 10/11/11 TO 31/3/13
	£	£
Donations	6,265	1,250
Donated services and facilities	550	-
	<u>6,815</u>	<u>1,250</u>

**3. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES**

	Conferences and workshops £	Awareness, communication and stakeholder engagement £	YEAR ENDED 31/3/14 £	PERIOD 10/11/11 TO 31/3/13 £
Charitable activities	<u>25,000</u>	<u>500</u>	<u>25,500</u>	<u>82,699</u>
			<u>Total activities</u>	<u>Total activities</u>

The main purpose of the charity is to promote, support and stimulate the sharing of knowledge and understanding of ciliopathies, nationally and transnationally. To achieve this the charity organises conferences, workshops and where requested undertake project based activities.

Included within income for the year is £25,000 being a performance related grant received in the previous accounting period. The income was deferred as the grant was in relation to delivering the 2013 Spring family conference.

A performance related grant of £500 was received in the year in connection with an event to be held in the following accounting period. This income has been deferred to that accounting period.

**4. OTHER INCOMING RESOURCES**

	YEAR ENDED 31/3/14	PERIOD 10/11/11 TO 31/3/13
	£	£
Bank interest receivable	16	33
	<u>16</u>	<u>33</u>

**5. SUPPORT COSTS**

	Management £	Information technology £	Totals £
Governance costs	4,320	-	4,320
Conferences and workshops	2,700	90	2,790
Awareness, communication and stakeholder engagement	3,780	90	3,870
	<u>10,800</u>	<u>180</u>	<u>10,980</u>

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

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

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED  
FOR THE YEAR ENDED 31 MARCH 2014**

**5. SUPPORT COSTS - continued**

				YEAR ENDED 31/3/14	PERIOD 10/11/11 TO 31/3/13
	Governance costs £	Conferences and workshops £	Awareness, communication and stakeholder engagement £	Total activities £	Total activities £
Administration and secretariat fees	4,320	2,700	3,780	10,800	6,673
Website hosting fee	-	90	90	180	-
	<u>4,320</u>	<u>2,790</u>	<u>3,870</u>	<u>10,980</u>	<u>6,673</u>

**6. GOVERNANCE COSTS**

			YEAR ENDED 31/3/14	PERIOD 10/11/11 TO 31/3/13
			£	£
Trustees' expenses			440	-
Independent examiner's fee			550	-
Accountancy			950	-
Companies house fees			163	-
Support costs			4,320	6,673
			<u>6,423</u>	<u>6,673</u>

**7. NET INCOMING/(OUTGOING) RESOURCES**

Net resources are stated after charging/(crediting):

			YEAR ENDED 31/3/14	PERIOD 10/11/11 TO 31/3/13
			£	£
Independent examiner's fee			550	-
			<u>550</u>	<u>-</u>

The independent examiner's fee represents donated services.

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

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED  
FOR THE YEAR ENDED 31 MARCH 2014**

**8. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 March 2014 nor for the period ended 31 March 2013.

**Trustees' expenses**

	YEAR ENDED 31/3/14 £	PERIOD 10/11/11 TO 31/3/13 £
Trustees' expenses	440	-
	<u>440</u>	<u>-</u>

Trustee expenses relate to reimbursed travel expenses for attending meetings of the trustees.

**9. STAFF COSTS**

There were no staff costs for the year ended 31 March 2014 nor for the period ended 31 March 2013.

**10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2014 £	2013 £
Prepayments and accrued income	1,250	-
	<u>1,250</u>	<u>-</u>

**11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2014 £	2013 £
Accruals and deferred income	2,350	25,000
	<u>2,350</u>	<u>25,000</u>

Included in 'accruals and deferred income' is deferred income of £500 (2013: £25,000).

**12. MOVEMENT IN FUNDS**

	At 1/4/13 £	Net movement in funds £	At 31/3/14 £
<b>Unrestricted funds</b>			
General fund	10,964	(4,522)	6,442
<b>Restricted funds</b>			
Restricted fund	-	4,370	4,370
<b>TOTAL FUNDS</b>	<u>10,964</u>	<u>(152)</u>	<u>10,812</u>

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

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED  
FOR THE YEAR ENDED 31 MARCH 2014**

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**12. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	6,831	(11,353)	(4,522)
<b>Restricted funds</b>			
Restricted fund	25,500	(21,130)	4,370
<b>TOTAL FUNDS</b>	<u>32,331</u>	<u>(32,483)</u>	<u>(152)</u>

**13. PURPOSE OF RESTRICTED FUNDS**

The restricted fund arose from a performance related grant in connection with the provision of the 2013 spring family conference. A further grant has been received as sponsorship for a specific event. The grant in connection with the 2013 family event was in excess of related expenditure. The grant provider has agreed to the surplus being utilised by the charity for a particular ongoing project in connection with the charity's awareness, communication and stakeholder engagement activities. These monies remain restricted for this purpose.