

**NIEMANN-PICK DISEASE GROUP (UK)**

**Company number 07775835**

**Charity registration number 1144406**

**REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 APRIL 2014**

**Board of Trustees:** Dave Roberts (Chair)  
Jim Green  
Janice Brooks  
Helen Carter  
William Evans  
Bill Owen  
Richard Rogerson  
David Holton  
Jacqueline Imrie

**Secretary:** Toni Mathieson

**Co-opted Members:** Prof Frances Platt

**Bankers:** HSBC  
53 High Street, Grays, Essex RM17 6NH

**Independent Examiner:** Christopher Spalding C.A.  
James Anderson & Co, Chartered Accountants, Pentland Estate,  
Straiton, Edinburgh EH20 9QH

**Registered Address:** Suite 2 Vermont House, Concord, Washington, Tyne & Wear NE37 2SQ

**Company Registration No:** 07775835

**Charity Registration No:** 1144406

**Governing Document:** Memorandum & Articles of Association

**Report of the Directors (Trustees)  
For the Year ended 30 April 2014**

The Trustees present their report and financial statements for the year ended 30 April 2014.

**Structure Governance and Management***Governing Document*

Memorandum & articles of association.

*Appointment & Recruitment of new Trustees*

Future Trustees shall be appointed by the Trustees from time to time following a nomination received from the Nominations Committee. They are volunteers and each takes on responsibilities within the Group to co-ordinate/support an aspect of the Group functions.

*Induction and Training of Trustees*

New Trustees are briefed on their legal obligations, the contents of the memorandum & articles of association, the board and decision making processes, the business plan and the recent financial performance of the charity. During the induction they will meet the other Trustees and key members of staff.

*Structure*

The structure of the charity is governed by its objects and Articles of Association. The Group currently has four employees, known as the Executive Director, Information Officer, Finance and Administration Officer and Families Officer. The Group also pays the full employment costs of a Clinical Nurse Specialist who is employed by the Salford Royal NHS Foundation Trust.

The Trustees and all the other supporters of the Group are volunteers.

The Trustees are directly responsible for the effective governance of the charity and for providing appropriate support and guidance and monitoring of all staff and activities. This is carried out in accordance with statutory guidance and legislation as provided by the Charity Commissioners. The Trustees meet on average four occasions a year with at least four additional teleconferences to review reports and to carry out management and financial reviews.

*Risk Management*

The Trustees are satisfied that the major risks to which the charity is exposed have been reviewed and procedures have been established to manage these risks.

**Statement of Directors Responsibilities**

Company law requires the directors to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the company and of the profit or loss of the company for that period. In preparing those financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for keeping adequate accounting records which disclose with reasonable accuracy at any time the financial position of the company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

**Report of the Directors (Trustees) (Continued)**  
**For the Year ended 30 April 2014**

**Objects of the Charity**

To relieve sickness amongst families afflicted by Niemann-Pick Disease and any distress which may arise therefrom. To advance the education of such families, interested parties and the general public in all matters concerning the disease as the committee may determine.

**Review of Activities**

What the charity does and what has been achieved in the year is laid out in the charity's annual report of which these accounts form part.

**Financial Review**

The free reserves at 30 April 2014 amounted to £ 40,337. The Board consider that the aim should be for free reserves to be at a level of expenditure for a year. The income from the endowment fund is available to be used, when required, to assist in financing the family care and support service provided to families affected by Niemann-Pick Diseases.

**Legal and Administrative Details**

The information relating to Niemann-Pick Disease Group (UK) is contained on page 1.

**Trustees**

The Trustees who served during the period are shown on page 1.

**Share Capital**

The company is limited by guarantee and has no share capital.

**Independent Examiner**

Christopher Spalding C.A. has indicated his willingness to continue in office as independent examiner and a resolution proposing his re-appointment will be put to the Annual General Meeting.

**Small Company Rules**

This report has been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006. It was approved by the board on 5 September 2014 and signed on its behalf.



**D Roberts**  
**Trustee**

I report on the accounts of the company for the year ended 30 April 2014, which are set out on pages 5 to 11.

**Respective responsibilities of trustees and examiner**

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The 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 needed.

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 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 statement below.

**Independent examiner's statement**

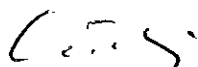
In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 386 of the Companies Act 2006; and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements of section 396 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.



Christopher Spalding C.A. (ICAS)  
James Anderson & Co  
Chartered Accountants  
Pentland Estate  
STRAITON  
Edinburgh  
EH20 9QH

5 September 2014

**Statement of Financial Activities**  
**For the year ended 30 April 2014**

	Notes	Unrestricted Fund £	Restricted Funds £	Endowment Fund £	Total Funds £	2013 £
<b>Incoming Resources</b>						
Voluntary income		54,205	12,388	-	66,593	120,344
Activities for generating Funds		117,377	-	-	117,377	24,581
Investment income		5,292	-	-	5,292	6,006
Income resources from charitable activities		9,648	42,683	-	52,331	60,453
<b>Total Incoming Resources</b>	<b>2</b>	<u>186,522</u>	<u>55,071</u>	<u>-</u>	<u>241,593</u>	<u>211,384</u>
<b>Resources Expended</b>						
Cost of generating voluntary income		7,919	-	-	7,919	4,308
Costs of charitable activities		186,037	56,665	-	242,702	242,842
Governance costs		10,618	-	-	10,618	5,951
<b>Total Resources Expended</b>	<b>3</b>	<u>204,574</u>	<u>56,665</u>	<u>-</u>	<u>261,239</u>	<u>253,101</u>
<b>Net Outgoing Resources before transfers</b>		( 18,052)	( 1,594)	-	( 19,646)	( 41,717)
(Deficit) / Gain on revaluation of investment		-	-	( 11,948)	( 11,948)	7,312
<b>Net movement in funds</b>		( 18,052)	( 1,594)	( 11,948)	( 31,594)	( 34,405)
<b>Balance brought forward 30 April 2013</b>		<u>57,523</u>	<u>11,279</u>	<u>217,747</u>	<u>286,549</u>	<u>320,954</u>
<b>Balance carried forward 30 April 2014</b>	<b>7</b>	<u>39,471</u>	<u>9,685</u>	<u>205,799</u>	<u>254,955</u>	<u>286,549</u>

**Balance Sheet**  
**As at 30 April 2014**

	Notes	2014 £	2013 £
<b>Fixed Assets</b>			
Tangible assets	5	1,386	2,772
Investments – endowment fund	4	205,799	217,747
		<u>207,185</u>	<u>220,519</u>
<b>Current Assets</b>			
Debtor - INPDA		-	4,189
Prepayments		1,000	7,827
Bank		52,674	58,301
		<u>53,674</u>	<u>70,317</u>
<b>Creditors</b>			
Amounts falling due within one year	6	5,904	4,287
<b>Net Assets</b>		<u>254,955</u>	<u>286,549</u>
<b>Funds</b>			
Unrestricted fund		39,471	57,523
Restricted funds		9,685	11,279
Endowment fund		205,799	217,747
	7	<u>254,955</u>	<u>286,549</u>

These annual accounts have not been audited because the company is entitled to the exemption provided by S477 of the Companies Act 2006 and members have not required the company to obtain an audit of its accounts for the period in accordance with S476 of the Companies Act 2006. The directors acknowledge their responsibilities for ensuring that the company keeps accounting records that comply with S386 of the Companies Act 2006. The directors also acknowledge their responsibilities for preparing accounts which give a true and fair view of the state of affairs of the company as at the end of the financial year in accordance with S396 Companies Act 2006, and which otherwise comply with the requirements of that Act relating to accounts, so far as applicable to the company. The financial statements on pages 5 to 11 were approved on 5 September 2014 and signed on its behalf.

*D. Roberts*

D Roberts Trustee

*D. Holton*

D Holton Trustee

**Notes to the Financial Statements**  
**For the Year ended 30 April 2014**

**1. Accounting Policies**

**a) Basis of Accounting**

The financial statements are prepared under the historical cost convention and in accordance with the Statement of Recommended Practice - Accounting and Reporting of Charities (SORP 2005) and in accordance with the Companies Act 2006.

**b) Incoming Resources**

Income is accounted for as received by the charity.

**c) Investments**

Investments are stated at their market value.

**d) Expenditure**

All expenditure is included on an accruals basis and has been directly attributed to one of the financial categories of resources expended in the Statement of Financial Activities. The Charity is not registered for Vat and accordingly expenditure is shown gross of irrecoverable Vat.

**e) Taxation**

No provision for corporation tax is necessary as the company has charitable status. The company is not registered for VAT and suffers input tax on some of its expenditure.

**f) Tangible Fixed Assets & Depreciation**

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment – 3 years straight line

**2. Incoming Resources**

	2014 £	2013 £
<i>Voluntary income</i>		
Donations received	66,593	120,344
<i>Activities for generating funds</i>		
Fundraising income	117,377	24,581
<i>Investment income</i>		
Bank interest	23	53
Fixed interest fund distribution	5,269	5,953
	5,292	6,006
<i>Incoming resources from charitable activities</i>		
BBC Children in Need	15,552	13,180
Big Lottery Fund	-	47,273
European Union (EAHC)	27,131	-
Sanofi – Aventis US	4,594	-
Genetic Disorders UK	4,935	-
Other	119	-
	52,331	60,453
<b>Total Incoming Resources</b>	<b>241,593</b>	<b>211,384</b>



**Note to the Financial Statements**  
**For the Year ended 30 April 2014 (Continued)**

**2. Incoming Resources (Continued)**

Unrestricted grants were received from pharmaceutical companies and used for the purposes shown;

Actelion Pharmaceuticals Ltd; Family conference £10,000; Interactive Workshop £10,000.  
 Genzyme, a Sanofi Company; Family conference £8,000; Publications £3,000.

	2014 £	2013 £
<b>3. Resources Expended</b>		
<i>Cost of generating voluntary income</i>		
Fundraising costs	7,919	4,308
<i>Cost of charitable activities</i>		
Helpline/family support/travel	78,924	70,494
Conference costs	27,478	34,728
Research project costs	41,909	46,198
Central office wages	66,647	53,729
Upkeep computer	1,024	3,078
Rent	13,140	10,800
Other administration costs	10,124	13,253
Insurance & subscription	1,088	1,281
Bank charges	426	886
Teleconferences	556	1,316
INPDA	-	5,693
Depreciation	1,386	1,386
	242,702	242,842
<i>Governance costs</i>		
Legal fees	-	204
Independent examiner's fee	1,250	1,200
Executive & management meetings	5,186	4,547
Strategic review meetings	4,182	-
	10,618	5,951
<b>Total Resources Expended</b>	261,239	253,101
<b>4. Investments – Endowment Fund</b>		
Balance brought forward	217,747	210,435
(Decrease) / Increase in value of investment	( 11,948)	7,312
Market value at 30 April 2014	205,799	217,747
Historical cost of investments held at 30 April 2014	202,000	202,000

The investment is 178,335 units in Schroders Charity Fixed Interest Fund and is held in the U.K.

**Note to the Financial Statements**  
**For the Year ended 30 April 2014 (Continued)**

**5. Tangible Assets**

	<b>Equipment £</b>	
<b>Cost</b>		
At 30 April 2013 & 2014	4,158	
<b>Depreciation</b>		
At 30 April 2013	1,386	
Charge for the year	1,386	
At 30 April 2014	2,772	
<b>Net Book Value</b>		
At 30 April 2014	1,386	
At 30 April 2013	2,772	
	<b>2014 £</b>	<b>2013 £</b>
<b>6. Creditors</b>		
Amounts falling due within one year		
Accruals	5,904	4,287

**7. Movement in Funds**

	Balance 30/4/2013 £	Incoming Resources £	Outgoing Resources £	Revaluation of investments £	Balance 30/4/2014 £
<b>Endowment fund</b>	217,747	-	-	( 11,948)	205,799
<b>Unrestricted fund</b>	57,523	186,522	204,574	-	39,471
<b>Restricted funds</b>					
BBC Children in Need	-	15,552	15,552	-	-
Hope for Hollie	3,765	-	-	-	3,765
Kate Elliot fund	2,920	-	-	-	2,920
Sanofi – Aventis US	4,594	-	4,594	-	-
Stewardship fund	-	303	303	-	-
Genetic Disorders UK	-	4,935	4,935	-	-
Pride in Leyton	-	3,000	-	-	3,000
Siri & Audun Blegan	-	2,150	2,150	-	-
European Union (EAHC)	-	27,131	27,131	-	-
Dr Heti Davies	-	2,000	2,000	-	-
	11,279	55,071	56,665	-	9,685
<b>Total funds</b>	286,549	241,593	261,239	( 11,948)	254,955

**Note to the Financial Statements**  
**For the Year ended 30 April 2014 (Continued)**

**7. Movement in Funds (Continued)...**

**Purpose of endowment fund**

The fund is expendable and is available to be used, when required, to assist in financing the family care and support service provided to families affected by Niemann-Pick Diseases.

**Purpose of restricted fund**

BBC Children in Need	Funding towards the post of Clinical Nurse Specialist
Hope for Hollie	Travel fund
Kate Elliot fund	Adult NPC Patient Support
Sanofi – Aventis US	Teenagers & young adults with NPD: Facing the future together
Stewardship fund	Research
Genetic Disorders UK	Interactive family support project
Pride in Leyton	Create awareness & publicity
Siri & Audun Blegan	Research
European Union (EAHC)	Contribution to setting up a rare disease registry for Niemann-Pick Disease Type A, B & C
Dr Heti Davies	Funding towards the Children's Programme; Family Conference

**8. Analysis of net assets between funds**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Endowment Funds £</b>	<b>Total Funds £</b>
Tangible assets	1,386	-	-	1,386
Investments	-	-	205,799	205,799
Current assets	43,989	9,685	-	53,674
Current liabilities	( 5,904)	-	-	( 5,904)
Net assets at 30 April 2014	<u>39,471</u>	<u>9,685</u>	<u>205,799</u>	<u>254,955</u>

**9. Employee Information**

Average number of persons employed during the year was:

Costs

Salaries	83,033	65,023
Social security costs	7,650	5,833
	<u>90,683</u>	<u>70,856</u>

The increase in persons employed during the year is due to the recruitment of a part time Finance and Administration Officer. This post is fully funded by a grant from the European Union (EHRC) No staff member is remunerated at a level in excess of £60,000 per annum.

**10. Trustees**

No remuneration was paid to Trustees during the financial period. Trustees are reimbursed travel and administration expenses in pursuit of charitable objectives and this amounted to £2,044. (2013 £1,645)

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**Note to the Financial Statements**  
**For the Year ended 30 April 2014 (Continued)**

**11. Related Parties**

The Niemann-Pick Disease Group (UK) is a member of the International Niemann-Pick Disease Alliance (INPDA). During the year costs of £13,019 were incurred on behalf of the INPDA and reimbursed by INPDA.