

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

**Company number 07775835**

**Charity registration numbers  
1144406 (England & Wales)  
SC045407 (Scotland)**

**REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 APRIL 2015**

<b>Board of Trustees:</b>	Dave Roberts (Chair) Jim Green Janice Brooks Helen Carter William Evans Bill Owen Richard Rogerson David Holton Jacqueline Imrie
<b>Secretary:</b>	Toni Mathieson
<b>Co-opted Members:</b>	Prof Frances Platt
<b>Bankers:</b>	HSBC 53 High Street, Grays, Essex RM17 6NH
<b>Independent Examiner:</b>	Christopher Spalding C.A. James Anderson & Co, Chartered Accountants, Pentland Estate, Straiton, Edinburgh EH20 9QH
<b>Registered Address:</b>	Suite 2 Vermont House, Concord, Washington, Tyne & Wear NE37 2SQ
<b>Company Registration No:</b>	07775835
<b>England &amp; Wales Charity No:</b>	1144406
<b>Scotland Charity No:</b>	SC045407
<b>Governing Document:</b>	Memorandum & Articles of Association

**Report of the Directors (Trustees)  
For the Year ended 30 April 2015**

The Trustees present their report and financial statements for the year ended 30 April 2015.

**Structure Governance and Management***Status*

The organisation is a charitable company limited by guarantee, incorporated on 15 September 2011 and registered as a charity in England and Wales on 24 October 2011. On 9 February 2015, the charity was registered with the Scottish Charity Regulator (OSCR).

*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.

**Report of the Directors (Trustees) (Continued)**  
**For the Year ended 30 April 2015**

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, the Charities and Trustee Investment Scotland Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended). 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.

**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. The Niemann-Pick Disease Group UK conforms to the Charities and Trustee Investment (Scotland) Act 2005 and provides care, support and information to those affected by Niemann-Pick Diseases, their families and associated professionals.

**Financial Review**

The free reserves at 30 April 2015 amounted to £248,814. 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 16 September 2015 and signed on its behalf.



**D Roberts**  
Trustee

I report on the accounts of the company for the year ended 30 April 2015, 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) or under Regulation 10 (1)(a) to (c) of The Charities Accounts (Scotland) Regulations 2006 (the 2006 Accounts Regulations) and that an independent examination is needed. The charity is required by company law to prepare accrued accounts and I am qualified to undertake the examination by being a qualified member of ICAS.

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 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 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
- 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 and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulation 2006. 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 next statement.

**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 section 44(1)(a) of the 2005 Act and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations and
- which are consistent 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

17 September 2015

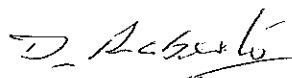
**Statement of Financial Activities**  
**For the year ended 30 April 2015**

	Notes	Unrestricted Fund £	Restricted Funds £	Endowment Fund £	Total Funds £	2014 £
<b>Incoming Resources</b>						
Voluntary income		60,999	17,961	-	78,960	66,593
Activities for generating Funds		98,915	-	-	98,915	117,377
Investment income		7,180	-	-	7,180	5,292
Income resources from charitable activities		-	61,864	-	61,864	52,331
<b>Total Incoming Resources</b>	<b>2</b>	<u>167,094</u>	<u>79,825</u>	<u>-</u>	<u>246,919</u>	<u>241,593</u>
<b>Resources Expended</b>						
Cost of generating voluntary income		16,759	-	-	16,759	7,919
Costs of charitable activities		159,543	70,477	-	230,020	242,702
Governance costs		7,805	-	-	7,805	10,618
<b>Total Resources Expended</b>	<b>3</b>	<u>184,107</u>	<u>70,477</u>	<u>-</u>	<u>254,584</u>	<u>261,239</u>
<b>Net Outgoing Resources before transfers</b>		( 17,013)	9,348	-	( 7,665)	( 19,646)
Gain / (Deficit) on revaluation of investment		-	-	20,557	20,557	( 11,948)
<b>Net movement in funds</b>		( 17,013)	9,348	20,557	12,892	( 31,594)
<b>Balance brought forward 30 April 2014</b>		<u>39,471</u>	<u>9,685</u>	<u>205,799</u>	<u>254,955</u>	<u>286,549</u>
<b>Balance carried forward 30 April 2015</b>	<b>7</b>	<u>22,458</u>	<u>19,033</u>	<u>226,356</u>	<u>267,847</u>	<u>254,955</u>

**Balance Sheet**  
**As at 30 April 2015**

	Notes	2015 £	2014 £
<b>Fixed Assets</b>			
Tangible assets	5	-	1,386
Investments – endowment fund	4	226,356	205,799
		<u>226,356</u>	<u>207,185</u>
<b>Current Assets</b>			
Prepayments		1,000	1,000
Bank		48,817	52,674
		<u>49,817</u>	<u>53,674</u>
<b>Creditors</b>			
Amounts falling due within one year	6	8,326	5,904
<b>Net Assets</b>		<u>267,847</u>	<u>254,955</u>
<b>Funds</b>			
Unrestricted fund		22,458	39,471
Restricted funds		19,033	9,685
Endowment fund		226,356	205,799
	7	<u>267,847</u>	<u>254,955</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 16 September 2015 and signed on its behalf.



D Roberts      Trustee



D Holton      Trustee

**Notes to the Financial Statements**  
**For the Year ended 30 April 2015**

**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

<b>2. Incoming Resources</b>	<b>2015 £</b>	<b>2014 £</b>
<i>Voluntary income</i>		
Donations received	78,960	66,593
<i>Activities for generating funds</i>		
Fundraising income	98,915	117,377
<i>Investment income</i>		
Bank interest	12	23
Fixed interest fund distribution	7,168	5,269
	7,180	5,292
<i>Incoming resources from charitable activities</i>		
BBC Children in Need	16,370	15,552
Roald Dahl MCC	6,000	-
Awards for All	9,268	-
Hope for Hollie Foundation	12,900	-
European Union (EAHC)	17,326	27,131
Sanofi – Aventis US	-	4,594
Genetic Disorders UK	-	4,935
Other	-	119
	61,864	52,331
<b>Total Incoming Resources</b>	<b>246,919</b>	<b>241,593</b>



**Note to the Financial Statements**  
**For the Year ended 30 April 2015 (Continued)**

**2. Incoming Resources (Continued)**

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

Actelion Pharmaceuticals Ltd; Research Day £10,000 and Family Conference £13,000;  
 Genzyme, a Sanofi Company; Family Conference £8,000, Grants £5,100 and Conference fees & travel £2,100.

	2015 £	2014 £
<b>3. Resources Expended</b>		
<i>Cost of generating voluntary income</i>		
Fundraising costs	16,759	7,919
<i>Cost of charitable activities</i>		
Helpline/family support/travel	81,545	78,924
Conference costs	30,647	27,478
Research project costs	24,683	41,909
Central office wages	62,217	66,647
Upkeep computer	394	1,024
Rent	12,960	13,140
Other administration costs	5,795	10,124
Insurance & subscription	1,097	1,088
Bank charges	589	426
Teleconferences	-	556
INPDA Grant	7,500	-
INPDA	1,207	-
Depreciation	1,386	1,386
	230,020	242,702
<i>Governance costs</i>		
Independent examiner's fee	1,248	1,250
Executive & management meetings	6,557	5,186
Strategic review meetings	-	4,182
	7,805	10,618
<b>Total Resources Expended</b>	254,584	261,239
<b>4. Investments – Endowment Fund</b>		
Balance brought forward	205,799	217,747
Increase / (Decrease) in value of investment	20,557	( 11,948)
Market value at 30 April 2015	226,356	205,799
Historical cost of investments held at 30 April 2015	202,000	202,000

The investment is 345,002 units in Schroders the Income Trust for Charities A Income Units and is held in the U.K.

**Note to the Financial Statements**  
**For the Year ended 30 April 2015 (Continued)**

**5. Tangible Assets**

	Equipment £	
<b>Cost</b>		
At 30 April 2014 & 2015	4,158	
<b>Depreciation</b>		
At 30 April 2014	2,772	
Charge for the year	1,386	
At 30 April 2015	4,158	
<b>Net Book Value</b>		
At 30 April 2015	-	
At 30 April 2014	1,386	
	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>

**6. Creditors**

Amounts falling due within one year		
Other tax & social security	1,285	195
Accruals	7,041	5,709
	<u>8,326</u>	<u>5,904</u>

**7. Movement in Funds**

	Balance 30/4/2014 £	Incoming Resources £	Outgoing Resources £	Revaluation of Investments £	Balance 30/4/2015 £
<b>Endowment fund</b>	205,799	-	-	20,557	226,356
<b>Unrestricted fund</b>	39,471	167,094	184,107	-	22,458
<b>Restricted funds</b>					
BBC Children in Need	-	16,370	16,370	-	-
Hope for Hollie	3,765	-	-	-	3,765
Kate Elliot fund	2,920	2,348	-	-	5,268
Stewardship fund	-	800	800	-	-
Pride in Leyton	3,000	-	3,000	-	-
Siri & Audun Blegan	-	2,313	2,313	-	-
European Union (EAHC)	-	17,326	17,326	-	-
Dr Heti Davies	-	2,000	2,000	-	-
Grace's Wish	-	10,000	-	-	10,000
Roald Dahl MCC	-	6,000	6,000	-	-
Hope for Hollie Foundation	-	12,900	12,900	-	-
Awards for All	-	9,268	9,268	-	-
Campbell Burns Met Trust	-	500	500	-	-
	<u>9,685</u>	<u>79,825</u>	<u>70,477</u>	<u>-</u>	<u>19,033</u>
<b>Total funds</b>	<u>254,955</u>	<u>246,919</u>	<u>254,584</u>	<u>20,557</u>	<u>267,847</u>

**Note to the Financial Statements**  
**For the Year ended 30 April 2015 (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
Stewardship fund	Research
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
Grace's Wish	Research
Roald Dahl MCC	Support for parents and siblings
Hope for Hollie Foundation	Funding of Family Officer & children's Christmas party
Awards for All	Meeting the needs of siblings
Campbell Burns Met Trust	Fund accommodation for Legoland

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

	Unrestricted Funds £	Restricted Funds £	Endowment Funds £	Total Funds £
Investments	-	-	226,356	226,356
Current assets	30,784	19,033	-	49,817
Current liabilities	( 8,326)	-	-	( 8,326)
Net assets at 30 April 2015	22,458	19,033	226,356	267,847

	2015 £	2014 £
<b>9. Employee Information</b>		
Average number of persons employed during the year was:	4	4
Costs		
Salaries	80,894	83,033
Social security costs	6,284	7,650
	87,178	90,683

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 £3,164 (2014 £2,004)

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**Note to the Financial Statements**  
**For the Year ended 30 April 2015 (Continued)**

**11. Related Party Transactions**

The Niemann-Pick Disease Group (UK) is a member of the International Niemann-Pick Disease Alliance (INPDA). The administrator works for both parties and in the year £8,670 was paid to the INPDA as a contribution towards this cost.