

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 2016**

Board of Trustees: Dave Roberts (Chair)
Jim Green
Janice Brooks
Helen Carter
William Evans
Bill Owen
Richard Rogerson
David Holton
Jacqueline Imrie
Joella Melville (appointed 12 March 2016)

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

England & Wales Charity No: 1144406

Scotland Charity No: SC045407

Governing Document: Memorandum & Articles of Association

**Report of the Directors (Trustees)
For the Year ended 30 April 2016**

The trustees who are also the directors present their annual report and financial statements of the charity for the year ended 30 April 2016.

The financial statements comply with the with the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended), the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities.

Objects of the Charity

To relieve sickness amongst families afflicted by Niemann-Pick Disease and any distress which may arise there from. 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

Niemann-Pick Disease Group (UK) is a charitable organisation offering care, support and information to families affected by Niemann-Pick disease and the professionals involved in their care. We give emotional, as well as practical support and have developed a strong family support network, helping to reduce feelings of isolation and despair.

From our Central Office, located in Washington, Tyne and Wear, we provide support and information regarding all aspects of Niemann-Pick Disease, via a 24-hour help line, educational literature, regular newsletters and e-bulletins.

Our website provides information on all aspects of the Niemann-Pick diseases, plus practical advice for daily living.

Our Clinical Nurse Specialist provides expert care and practical advice, plus home visits whenever necessary. Genetic counselling and advocacy services are also provided.

Our Families Officer provides non-clinical advice and information, offering an individual advocacy service which includes home visits and assistance at clinic appointments.

In addition we promote relevant research, raise awareness and offer education and information to carers, associated professionals and the general public.

We hold an Annual Family Conference, comprising of adult and children's programmes, and the Conference also highlights the most recent advances in research, and provides an ideal opportunity to strengthen our family support network.

Achievements & Performance

Our Clinical Nurse Specialist, Families Officer and dedicated Central Office team continue to provide a high quality service that responds to the needs of the families we support. Awareness Indicators provide an overview of our services and during the financial year we have recorded average monthly totals of 21 home visits, 10 clinic attendances and ongoing tailored support for 28 families. In addition, there have been 90 calls to the help line and 87 requests for information each month.

We have been successful in achieving a grant of £447,108 over 5 years from the Big Lottery Fund towards a project "Shaping our Future Together" This project strengthens our existing work and builds capacity to support an increasing number of newly diagnosed adults and provide services for those families who are harder to reach.

We have continued to build a strong relationship with our stakeholders and have strengthened our on-line presence and communications.

In addition we have supported research into therapies for Niemann-Pick disease and have facilitated the possibility of bringing about clinical trials in the UK.

**Report of the Directors (Trustees)
For the Year ended 30 April 2016****Financial Review**

Income for the year was £405,370 (2015: £246,919). Expenditure for the year totalled £269,222 (2015: £254,584). The large increase in income was due to a very generous legacy and this had the effect of increasing the unrestricted fund to £113,856 (2015: £22,458).

Reserves Policy

NP-UK should have sufficient assets to consistently fund the services it provides to families affected by Niemann-Pick diseases and hold sufficient funds to address risks and contingencies identified by the Trustees.

The Board of Trustees have reviewed the reserves policy for 2016/2017 and have taken into account the objectives for the financial year 2016/2017, the risks associated with periods of reduced income and the Charity Commissioners' guidance "Charity Reserves; Building Resilience" (CC19, Published 29 January 2016),

The unrestricted fund at 30 April 2016 was £113,856 and for 2016/2017, the Trustees have set the level of reserves at £86,000. This is to ensure that identified risks to income, cash flow and other contingencies do not impact on the services we provide.

In addition, £27,000 of unrestricted funds has been designated to finance projects and commitments in support of our aims and objectives for 2016/2017

We remain committed to holding the endowment fund which is for use, when required, to assist in financing the family care and support service provided to families affected by Niemann-Pick Diseases. However, should the Charity be forced to close, this endowment will be used to fund alternative care and support arrangements during a period of transition to new providers.

The level of reserves is equivalent to 3 months expenditure and any excess funds will be spent in furtherance of the objectives. The total free reserves at the end of April 2017, including the endowment, are expected to be in the order of 11 months of forecast expenditure.

Plans for Future Periods

Whilst continuing to meet the needs of our community through our current care and support service, we will further develop the support we offer to siblings, provide support for the increasing number of newly diagnosed adults and work to deliver meaningful services for hard to reach families. At all times we will be aware of the changing needs of our community and will adapt and develop the charity and our services to meet their presenting needs.

We will build on our strong relationship with the INPDA and LSD Collaborative and will remain active in providing an expert patient voice and perspective to NHS England in respect of highly specialized services for LSDs, access to treatment and therapies and the approvals process for new therapies.

We will further develop our website and create a stronger and more compelling identity that more effectively targets our audience and engages with the wider population.

We will fully support the continuing development of the International Niemann-Pick Disease Registry, promote Niemann-Pick disease research and facilitate clinical trials in the UK.

Reference and Administrative Details

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

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).

**Report of the Directors (Trustees)
For the Year ended 30 April 2016**

Governing Document

Memorandum & Articles of Association.

Appointment & Recruitment of new Trustees

New Trustees shall be appointed by the Trustees following a nomination received from the Nominations Committee pursuant to article 61 and in line with the Terms and Reference of the Nominations Committee. All Trustees are volunteers and have the skills and experience to take on responsibilities within the Group to co-ordinate/support an aspect of the Group requirements.

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. At the end of the Financial Year, the Group had five employees, known as the Executive Director, Finance and Administration Officer, Families Officer and two part time employees, known as the Project Team Leader and Families Officer, working 20 hours per week. 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.

Pay Policy for Senior Staff

All trustees give of their time freely and no trustee received remuneration in the year. The Board of Trustees is responsible for setting employee salary levels. These are based on local government pay scales which are extensively used to benchmark roles in the voluntary sector. As a small charity, we take into account our levels of income and do not guarantee annual wage increases.

Related Parties

The Niemann-Pick Disease Group (UK) is a member of the International Niemann-Pick Disease Alliance (INPDA) and shares the services of the Finance and Administration Officer who is located at the Niemann-Pick Disease Group (UK) Central Office.

Risk Management

The Board of Trustees have considered and reviewed the possible risks to which the Group may be exposed, and have established procedures to manage these risks.

**Report of the Directors (Trustees) (Continued)
For the Year ended 30 April 2016****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, 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.

Legal and Administrative Details

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

Trustees

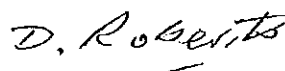
The Trustees who served during the period are shown on page 1.

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.

By Order of the Board

**D Roberts
Trustee**

14 September 2016

I report on the accounts of the company for the year ended 30 April 2016, which are set out on pages 7 to 13.

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

14 September 2016

**Statement of Financial Activities
(Incorporating Income and Expenditure Account)**

For the year ended 30 April 2016

	Notes	Unrestricted Funds £	Restricted Funds £	Endowment Fund £	Total Funds £	2015 £
Income and endowments from:						
Donations and legacies	4	214,055	53,224	-	267,279	127,653
Charitable activities	5	36,301	61,159	-	97,460	61,864
Other trading activities	6	33,687	-	-	33,687	50,222
Investments	7	6,945	-	-	6,945	7,180
Total income		<u>290,987</u>	<u>114,383</u>	<u>-</u>	<u>405,370</u>	<u>246,919</u>
Expenditure on:						
Charitable activities	8	189,481	69,633	-	259,114	237,826
Raising funds		10,108	-	-	10,108	16,759
Total expenditure		<u>199,589</u>	<u>69,633</u>	<u>-</u>	<u>269,222</u>	<u>254,584</u>
Net income / (expenditure)		91,398	44,750	-	136,148	(7,665)
(Losses)/gains on investment assets		-	-	(6,314)	(6,314)	20,557
Net movement in funds		91,398	44,750	(6,314)	129,834	20,557
Reconciliation of funds:						
Total funds brought forward		<u>22,458</u>	<u>19,033</u>	<u>226,356</u>	<u>267,847</u>	<u>254,955</u>
Total funds carried forward	12	<u>113,856</u>	<u>63,783</u>	<u>220,042</u>	<u>397,681</u>	<u>267,847</u>

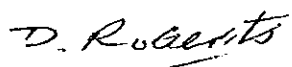
Balance Sheet
As at 30 April 2016

	Notes	2016 £	2015 £
Fixed Assets			
Tangible assets	10	-	-
Investments – endowment fund	9	220,042	226,356
		<u>220,042</u>	<u>226,356</u>
Current Assets			
Prepayments		-	1,000
Bank		184,544	48,817
		<u>184,544</u>	<u>49,817</u>
Creditors			
Amounts falling due within one year	11	6,905	8,326
Net Assets			
		<u>397,681</u>	<u>267,847</u>
Funds			
Unrestricted fund	12	113,856	22,458
Endowment fund		220,042	226,356
Restricted funds		63,783	19,033
		<u>397,681</u>	<u>267,847</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.

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 January 2015).

The financial statements on pages 7 to 13 were approved on 14 September 2016 and signed on its behalf.



D Roberts Trustee



D Holton Trustee

**Notes to the Financial Statements
For the Year ended 30 April 2016**

1. Accounting Policies

a) Basis of preparing the financial statements

The financial statements of the charitable company have been prepared in accordance with the Charities SORP (FRSSE) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (the FRSSE) (effective 1 January 2015)', the Financial Reporting Standard for Smaller Entities (effective January 2015) and the Companies Act 2006. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) 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.

c) Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. 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.

d) 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.

e) Investments

Investments are stated at their market value.

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

g) 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.

2. Legal Status

The company is limited by guarantee and therefore has no share capital. Every member of the company undertakes to contribute such sum as may be required (not exceeding £1) to the company's assets if it should be wound up while he/she is a member or within one year after he/she ceases to be a member.

Note to the Financial Statements
For the Year ended 30 April 2016 (Continued)

	2016	2015
3. Employee Information		
The average monthly number of full time employees was:	4	4
	£	£
Staff Costs		
Salaries	85,078	80,894
Social security costs	4,852	6,284
	<u>89,930</u>	<u>87,178</u>

The Information Officer (12 hours) left the Charity at the end of March 2016.

A part time Families Officer (20 hours) and a part time Project Team Leader (20 hours) joined the Charity at the beginning of March 2016. Both of these posts were fully paid for by a grant from the Big Lottery.

No staff member is remunerated at a level in excess of £60,000 per annum.

4. Income from Donations & Legacies

Gifts	79,276	95,166
Conference income	33,443	32,487
Legacies	154,560	-
	<u>267,279</u>	<u>127,653</u>

Included in gifts were unrestricted grants received from pharmaceutical companies and these were used for the purposes shown;

Actelion Pharmaceuticals Ltd; towards the Research Professional's Day £10,000 and Family Conference £10,000;
 Genzyme, a Sanofi Company; towards Family Support £6,000.
 CTD Holdings; £3,154 towards Family Support

5. Income from Charitable Activities

Big Lottery Fund	55,589	-
BBC Children in Need	8,185	16,370
Roald Dahl MCC	3,334	6,000
Awards for All	-	9,268
Hope for Hollie Foundation	15,157	12,900
European Union (EAHC)	15,195	17,326
	<u>97,460</u>	<u>61,864</u>

6. Income from other activities

Fundraising events	33,687	50,222
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7. Investment income

Bank interest	45	12
Fixed interest fund distribution	6,900	7,168
	<u>6,945</u>	<u>7,180</u>

Note to the Financial Statements
For the Year ended 30 April 2016 (Continued)

	2016 £	2015 £
8. Expenditure on charitable activities		
Helpline/family support/travel	103,037	81,545
Conference costs	43,912	30,647
Research project costs	20,089	24,683
Central office wages	65,019	62,217
Upkeep computer	394	394
Rent	12,960	12,960
Other administration costs	3,648	5,795
Insurance & subscription	1,133	1,097
Bank charges	417	589
INPDA Grant	-	7,500
INPDA	930	1,207
Depreciation	-	1,386
Independent examiner's fee	1,373	1,248
Executive & management meetings	6,202	6,557
	<u>259,114</u>	<u>230,020</u>
9. Investments – Endowment Fund		
Balance brought forward	226,356	205,799
(Decrease) / increase in value of investment	(6,314)	20,557
	<u>220,042</u>	<u>226,356</u>
Market value at 30 April 2016	220,042	226,356
	<u>220,042</u>	<u>226,356</u>
Historical cost of investments held at 30 April 2016	202,000	202,000
	<u>202,000</u>	<u>202,000</u>
<p>The investment is 345,002 units in Schrodgers the Income Trust for Charities A Income Units and is held in the U.K.</p>		
10. Tangible Assets		
	Equipment	
	£	
Cost		
At 30 April 2015 & 2016	4,158	
Depreciation		
At 30 April 2015	4,158	
Charge for the year	-	
	<u>4,158</u>	
At 30 April 2016	4,158	
	<u>4,158</u>	
Net Book Value		
At 30 April 2016	-	
At 30 April 2015	-	
	<u>-</u>	
	<u>2016</u>	<u>2015</u>
	<u>£</u>	<u>£</u>
11. Creditors: amounts falling due within one year		
Other tax & social security	1,296	1,285
Accruals	5,609	7,041
	<u>6,905</u>	<u>8,326</u>

Note to the Financial Statements
For the Year ended 30 April 2016 (Continued)

12. Movement in Funds

	Balance 30/4/2015 £	Incoming Resources £	Outgoing Resources £	Revaluation of investments £	Balance 30/4/2016 £
Unrestricted fund	22,458	290,987	199,589	-	113,856
Endowment fund	226,356	-	-	(6,314)	220,042
Restricted funds					
Big Lottery Fund	-	55,589	17,169	-	38,420
BBC Children in Need	-	8,185	8,185	-	-
Hope for Hollie	3,765	50	-	-	3,815
Kate Elliot fund	5,268	150	-	-	5,418
Stewardship fund	-	3,000	3,000	-	-
Siri & Audun Blegan	-	2,249	2,249	-	-
European Union (EAHC)	-	15,195	15,195	-	-
Dr Heti Davies	-	5,000	-	-	5,000
Grace's Wish	10,000	-	-	-	10,000
Roald Dahl MCC	-	2,834	2,834	-	-
Hope for Hollie Foundation	-	17,776	17,776	-	-
Hope for Hollie Foundation	-	1,130	-	-	1,130
Lesley Carlton Jones	-	3,000	3,000	-	-
Daytrippers	-	225	225	-	-
Total Restricted funds	19,033	114,383	69,633	-	63,783
Total funds	267,847	405,370	269,222	(6,314)	397,681

The **unrestricted fund** is free to use in accordance with the objects of the Charity.

The **endowment 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. Should the Charity be forced to close, this endowment will be used to fund alternative care and support arrangements during a period of transition to new providers

The **restricted funds** are for use in terms of the grants awarded by the donors as follows:

Big Lottery Fund	Shaping our future together
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
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 programmes
Hope for Hollie Foundation	Literature re; Families Officer & Clinical Support Nurse
Lesley Carlton Jones	Research; Peter Carlton Jones award
Daytrippers	NPUK summer outing

Note to the Financial Statements
For the Year ended 30 April 2016 (Continued)

13. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Endowment Funds £	Total Funds £
Investments	-	-	220,042	220,042
Current assets	120,761	63,783	-	184,544
Current liabilities	(6,905)	-	-	(6,905)
Net assets at 30 April 2016	<u>113,856</u>	<u>63,783</u>	<u>220,042</u>	<u>397,681</u>

14. 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 £1,533 (2015 £3,164).

15. Related Party Transactions

The Niemann-Pick Disease Group (UK) is a member of the International Niemann-Pick Disease Alliance (INPDA). The Finance and Administration Officer works for both parties and in the year £10,073 was paid to the INPDA as a contribution towards this cost.