REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 APRIL 2013
Board of Trustees:  
Dave Roberts (Chair)  
Jim Green  
Janice Brooks  
Richard Brooks (resigned 24 November 2012)  
Helen Carter  
William Evans  
Bill Owen  
Richard Rogerson  
David Holton (appointed 13 April 2013)  
Jacqueline Imrie (appointed 13 April 2013)

Secretary:  
Toni Mathieson

Co-opted Members:  
Prof Frances Platt

Bankers:  
H S B C  
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 2013

The Trustees present their report and financial statements for the year ended 30 April 2013.

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 three employees, known as the Executive Director, Information 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.
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 2013 amounted to £57,523. 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.

By Order of the Board of Trustees

D Roberts
Trustee

25 September 2013
I report on the accounts of the company for the year ended 30 April 2013, which are set out on pages 5 to 10.

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) 25 September 2013
James Anderson & Co
Chartered Accountants
Pentland Estate
STRAITON
Edinburgh
EH20 9QH
**Statement of Financial Activities**
For the year ended 30 April 2013

<table>
<thead>
<tr>
<th>Notes</th>
<th>Unrestricted Estates Fund</th>
<th>Restricted Estates Funds</th>
<th>Endowment Funds</th>
<th>Total Funds</th>
<th>Period 15/09/11-30/04/12</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td><strong>Incoming Resources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary income</td>
<td>109,659</td>
<td>10,685</td>
<td>-</td>
<td>120,344</td>
<td>19,893</td>
</tr>
<tr>
<td>Activities for generating Funds</td>
<td>24,581</td>
<td>-</td>
<td>-</td>
<td>24,581</td>
<td>6,420</td>
</tr>
<tr>
<td>Investment income</td>
<td>6,006</td>
<td>-</td>
<td>-</td>
<td>6,006</td>
<td>1,716</td>
</tr>
<tr>
<td>Income resources from charitable activities</td>
<td>-</td>
<td>60,453</td>
<td>-</td>
<td>60,453</td>
<td>36,791</td>
</tr>
<tr>
<td><strong>Total Incoming Resources</strong></td>
<td>140,246</td>
<td>71,138</td>
<td>-</td>
<td>211,384</td>
<td>64,820</td>
</tr>
</tbody>
</table>

| **Resources Expended** | | | | | |
| Cost of generating voluntary income | 4,308 | - | - | 4,308 | 839 |
| Costs of charitable activities | 176,233 | 66,609 | - | 242,842 | 53,478 |
| Governance costs | 5,951 | - | - | 5,951 | 4,095 |
| **Total Resources Expended** | 186,492 | 66,609 | - | 253,101 | 58,412 |

| **Net Outgoing Resources before transfers** | | | | | |
| (46,246) | 4,529 | - | (41,717) | 6,408 |
| Transfers | 2,488 | (2,488) | - | - | - |
| Gain on revaluation of investment | - | - | 7,312 | 7,312 | (5,172) |
| **Net movement in funds** | | | | | |
| (43,758) | 2,041 | 7,312 | (34,405) | 1,236 |
| Balance brought forward 30 April 2012 | 101,281 | 9,238 | 210,435 | 320,954 | 319,718 |
| Balance carried forward 30 April 2013 | 57,523 | 11,279 | 217,747 | 286,549 | 320,954 |
Balance Sheet  
As at 30 April 2013

<table>
<thead>
<tr>
<th></th>
<th>Notes</th>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fixed Assets</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>5</td>
<td>2,772</td>
<td>-</td>
</tr>
<tr>
<td>Investments – endowment fund</td>
<td>4</td>
<td>217,747</td>
<td>210,435</td>
</tr>
<tr>
<td></td>
<td></td>
<td>220,519</td>
<td>210,435</td>
</tr>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtor - INPDA</td>
<td></td>
<td>4,189</td>
<td>-</td>
</tr>
<tr>
<td>Prepayments</td>
<td></td>
<td>7,827</td>
<td>-</td>
</tr>
<tr>
<td>Bank</td>
<td></td>
<td>58,301</td>
<td>111,911</td>
</tr>
<tr>
<td></td>
<td></td>
<td>70,317</td>
<td>111,911</td>
</tr>
<tr>
<td><strong>Creditors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amounts falling due within one year</td>
<td>6</td>
<td>4,287</td>
<td>1,392</td>
</tr>
<tr>
<td><strong>Net Assets</strong></td>
<td></td>
<td>286,549</td>
<td>320,954</td>
</tr>
<tr>
<td><strong>Funds</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endowment fund</td>
<td></td>
<td>217,747</td>
<td>210,435</td>
</tr>
<tr>
<td>Unrestricted fund</td>
<td></td>
<td>57,523</td>
<td>101,281</td>
</tr>
<tr>
<td>Restricted funds</td>
<td></td>
<td>11,279</td>
<td>9,238</td>
</tr>
<tr>
<td></td>
<td></td>
<td>286,549</td>
<td>320,954</td>
</tr>
</tbody>
</table>

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 10 were approved on 25 September 2013 and signed on its behalf.

D Roberts            Trustee
Notes to the Financial Statements
For the Year ended 30 April 2013

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
      Furniture, fixtures & equipment – 15% reducing balance

2. Incoming Resources

   Period 15/09/11-30/04/12
   Year 2013
   £    £

   Voluntary income
   Donations received 120,344 19,893

   Activities for generating funds
   Fundraising income 24,581 6,420

   Investment income
   Bank interest 53 114
   Fixed interest fund distribution 5,953 1,602

   6,006 1,716

   Incoming resources from charitable activities
   BBC Children in Need 13,180 4,176
   Big Lottery fund 47,273 32,615

   60,453 36,791

   Total Incoming Resources 211,384 64,820
Note to the Financial Statements  
For the Year ended 30 April 2013 (Continued)

<table>
<thead>
<tr>
<th>Period</th>
<th>Year 2013 £</th>
<th>Period 15/09/11-30/04/12 £</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Resources Expended</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost of generating voluntary income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fundraising costs</td>
<td>4,308</td>
<td>839</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost of charitable activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helpline/family support/travel</td>
<td>65,981</td>
<td>16,514</td>
</tr>
<tr>
<td>Hollie travel fund</td>
<td>-</td>
<td>981</td>
</tr>
<tr>
<td>Website costs</td>
<td>-</td>
<td>12,000</td>
</tr>
<tr>
<td>Conference costs</td>
<td>34,728</td>
<td>531</td>
</tr>
<tr>
<td>Central office wages</td>
<td>53,729</td>
<td>13,164</td>
</tr>
<tr>
<td>Upkeep computer</td>
<td>3,078</td>
<td>2,887</td>
</tr>
<tr>
<td>Other administration costs</td>
<td>24,053</td>
<td>6,216</td>
</tr>
<tr>
<td>Insurance &amp; subscription</td>
<td>1,281</td>
<td>815</td>
</tr>
<tr>
<td>Bank charges</td>
<td>886</td>
<td>370</td>
</tr>
<tr>
<td>Teleconferences</td>
<td>1,316</td>
<td>-</td>
</tr>
<tr>
<td>Newsletter</td>
<td>4,513</td>
<td>-</td>
</tr>
<tr>
<td>INPDA</td>
<td>5,693</td>
<td>-</td>
</tr>
<tr>
<td>Research</td>
<td>34,491</td>
<td>-</td>
</tr>
<tr>
<td>Collaboration</td>
<td>11,707</td>
<td>-</td>
</tr>
<tr>
<td>Depreciation</td>
<td>1,386</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>242,842</td>
<td>53,478</td>
</tr>
<tr>
<td>Governance costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal fees</td>
<td>204</td>
<td>1,243</td>
</tr>
<tr>
<td>Independent examiner’s fee</td>
<td>1,200</td>
<td>672</td>
</tr>
<tr>
<td>Executive &amp; management meetings</td>
<td>4,547</td>
<td>2,180</td>
</tr>
<tr>
<td></td>
<td>5,951</td>
<td>4,095</td>
</tr>
<tr>
<td>Total Resources Expended</td>
<td>253,101</td>
<td>58,412</td>
</tr>
</tbody>
</table>

4. Investments – Endowment Fund

<table>
<thead>
<tr>
<th></th>
<th>Year 2013</th>
<th>Period 15/09/11-30/04/12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance brought forward</td>
<td>210,435</td>
<td>215,607</td>
</tr>
<tr>
<td>Increase in value of investment</td>
<td>7,312</td>
<td>(5,172)</td>
</tr>
<tr>
<td>Market value at 30 April 2013</td>
<td>217,747</td>
<td>210,435</td>
</tr>
</tbody>
</table>

Historical cost of investments held at 30 April 2013 | 202,000 | 202,000 |

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

<table>
<thead>
<tr>
<th></th>
<th>Equipment £</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cost</strong></td>
<td></td>
</tr>
<tr>
<td>Additions</td>
<td>4,158</td>
</tr>
<tr>
<td>30 April 2013</td>
<td>4,158</td>
</tr>
<tr>
<td><strong>Depreciation</strong></td>
<td></td>
</tr>
<tr>
<td>Charge for the year</td>
<td>1,386</td>
</tr>
<tr>
<td>30 April 2013</td>
<td>1,386</td>
</tr>
<tr>
<td><strong>Net Book Value</strong></td>
<td></td>
</tr>
<tr>
<td>30 April 2013</td>
<td>2,772</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>6. Creditors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amounts falling due within one year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accruals</td>
<td>1,200</td>
<td>1,392</td>
</tr>
</tbody>
</table>

7. Movement in Funds

<table>
<thead>
<tr>
<th></th>
<th>Balance 30/4/2012 £</th>
<th>Incoming Resources £</th>
<th>Outgoing Resources £</th>
<th>Transfers £</th>
<th>Change on revaluation of investments £</th>
<th>Balance 30/4/2013 £</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Endowment fund</strong></td>
<td>210,435</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>7,312</td>
<td>217,747</td>
</tr>
<tr>
<td><strong>Unrestricted fund</strong></td>
<td>101,281</td>
<td>140,246</td>
<td>(186,492)</td>
<td>2,488</td>
<td>-</td>
<td>57,523</td>
</tr>
</tbody>
</table>

**Restricted funds**

<table>
<thead>
<tr>
<th>Fund</th>
<th>Balance 30/4/2012 £</th>
<th>Incoming Resources £</th>
<th>Outgoing Resources £</th>
<th>Transfers £</th>
<th>Change on revaluation of investments £</th>
<th>Balance 30/4/2013 £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Big Lottery fund</td>
<td>2,820</td>
<td>47,273</td>
<td>(47,605)</td>
<td>(2,488)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>BBC Children in Need</td>
<td>-</td>
<td>13,180</td>
<td>(13,180)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Hope for Hollie</td>
<td>3,765</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>4,594</td>
<td>2,376</td>
</tr>
<tr>
<td>Kate Elliot fund</td>
<td>2,653</td>
<td>267</td>
<td>-</td>
<td>-</td>
<td>2,920</td>
<td>2,733</td>
</tr>
<tr>
<td>Sanofi – Aventis US</td>
<td>-</td>
<td>9,145</td>
<td>(4,551)</td>
<td>-</td>
<td>-</td>
<td>4,594</td>
</tr>
<tr>
<td>Stewardship fund</td>
<td>-</td>
<td>1,273</td>
<td>(1,273)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total restricted funds</td>
<td>9,238</td>
<td>71,138</td>
<td>(66,609)</td>
<td>(2,488)</td>
<td>-</td>
<td>11,279</td>
</tr>
</tbody>
</table>

**Total funds**

|                        | 320,954              | 211,384               | (253,101)            | -           | 7,312                                  | 286,549             |
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

<table>
<thead>
<tr>
<th>Fund</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>BBC Children in Need</td>
<td>Funding of support nurse</td>
</tr>
<tr>
<td>Big Lottery fund</td>
<td>Family care and interactive support service</td>
</tr>
<tr>
<td>Hope for Hollie</td>
<td>Travel fund</td>
</tr>
<tr>
<td>Kate Elliot fund</td>
<td>Specialised family support</td>
</tr>
<tr>
<td>Sanofi – Aventis US</td>
<td>Teenagers &amp; young adults with NPD: Facing the future together</td>
</tr>
<tr>
<td>Stewardship fund</td>
<td>Research</td>
</tr>
</tbody>
</table>

The transfer in the year represents a correction to a Big Lottery capital underspend misallocated to funding in the previous period.

8. Analysis of net assets between funds

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Endowment Funds</th>
<th>Total Funds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Tangible assets</td>
<td>2,772</td>
<td>-</td>
<td>-</td>
<td>2,772</td>
</tr>
<tr>
<td>Investments</td>
<td>-</td>
<td>-</td>
<td>217,747</td>
<td>217,747</td>
</tr>
<tr>
<td>Current assets</td>
<td>59,038</td>
<td>11,279</td>
<td>-</td>
<td>70,317</td>
</tr>
<tr>
<td>Current liabilities</td>
<td>( 4,287)</td>
<td>-</td>
<td>-</td>
<td>( 4,287)</td>
</tr>
<tr>
<td>Net assets at 30 April 2013</td>
<td>57,523</td>
<td>11,279</td>
<td>217,747</td>
<td>286,549</td>
</tr>
</tbody>
</table>

9. Employee Information

Average number of persons employed during the year was: 3

Costs

<table>
<thead>
<tr>
<th></th>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salaries</td>
<td>65,023</td>
<td>19,286</td>
</tr>
<tr>
<td>Social security costs</td>
<td>5,833</td>
<td>1,713</td>
</tr>
<tr>
<td></td>
<td>70,856</td>
<td>20,999</td>
</tr>
</tbody>
</table>

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 and this amounted to £1,645.