

**NIEMANN-PICK UK**

**Company number 07775835**

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

**REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 APRIL 2018**

**Reference & Administrative Details  
For the Year ended 30 April 2018**

<i>England &amp; Wales Charity registration number:</i>	1144406
<i>Scotland Charity registration number:</i>	SC045407
<i>Company registration number:</i>	07775835
<i>Trustees:</i>	Dr William Evans (Chair) Dave Roberts Janice Brooks Helen Carter Bill Owen Richard Rogerson Dr David Holton Jacqueline Imrie Joella Melville
<i>Chief Executive:</i>	Toni Mathieson
<i>Co-opted Members:</i>	Prof Frances Platt
<i>Bankers:</i>	HSBC 53 High Street Grays Essex RM17 6NH
<i>Independent Examiner:</i>	Christopher Spalding C.A. James Anderson & Co Chartered Accountants Pentland Estate Straiton Edinburgh EH20 9QH
<i>Registered address:</i>	Suite 2 Vermont House Concord Washington Tyne & Wear NE37 2SQ
<i>Governing document:</i>	Memorandum & Articles of Association

**Report of the Directors  
For the Year ended 30 April 2018**

The trustees who are also the directors present their annual report and financial statements of the charity for the year ended 30 April 2018.

The financial statements comply 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 applicable in the UK and Republic of Ireland (FRS 102).

**Our Objectives and Activities***Objectives*

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 UK (NPUK) 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, e-bulletins and social networking platforms.

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.

In addition, our Senior Families Advocate provides non-clinical advice, and an individual advocacy service which includes assistance and support at meetings, the provision of information to help families make informed decisions and help in exploring statutory rights and entitlements around benefits, housing education and employment.

Our Big Lottery Project Team Leader and Project Families Officer continue to develop links with organisations and families within the Niemann-Pick community and these actions have helped us to establish contact with "hard to reach groups" and give additional support to the male members of our community

*Public benefit statement*

In shaping our objectives for the year and planning our activities, the Trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

*Contribution made by volunteers*

We are extremely grateful to the volunteers who get involved with fundraising activities and who provide help and support at the Annual Family Conference, the Christmas party and other social events. Without this support, we would not be able to provide these much loved social events.

**Report of the Directors  
For the Year ended 30 April 2018****Achievements and Performance**

We have continued to provide a high quality service from our Clinical Nurse Specialist, Senior Families Advocate, Project Families Officer and Central Office staff.

With an increasing number of new cases reported over the year and continuing changes in welfare reform, these posts play a vital role by providing much-needed advice, care and support to patients, families and the wider Niemann-Pick community. In addition our Social Media and Communications Officer continues to create awareness through the production of high quality reports and leaflets and has strengthened our social media presence across all platforms, including the introduction of Instagram and the further development of our own YouTube channel.

Our Central Office team has also been heavily involved in the update and implementation of policies and procedures to ensure that we comply with the General Data Protection Regulation (GDPR), which came into effect in May 2018.

We continue to maintain a strong presence in the field of research and with four clinical trials in progress we continue to maintain our involvement in the communication process and to give emotional and practical support to participating families, as appropriate.

The Big Lottery grant has enabled us to strengthen our family support process and over the year we have become a leading member of the "Breaking Down Barriers" project, a network of charities working to support black and minority ethnic (BME) communities affected by rare and genetic diseases, which focuses on effective engagement with minority and 'hard to reach' families. In addition, we have launched a Lads, Dads and Carers group. This is to provide an open forum for the male members of our community and it has been very successful in reducing isolation and helping to improve overall wellbeing.

At a strategic level, we continue to provide a voice for all those affected by Niemann-Pick diseases and joined the "Dementia Strikes Children Too" campaign, which as well as raising awareness aims to achieve real change by lobbying for better clinical education, earlier diagnosis and access to care and treatment for those affected.

We continue to support the International Niemann-Pick Disease Alliance (INPDA) in all of its activities and building on our strong relationship with the LSD Patient Collaborative we have taken part in many high-level meetings with national Rare Disease groups to influence national policy for the benefit of all those affected by Niemann-Pick diseases. In addition, we continue our involvement with the Expert Advisory Group for Lysosomal Storage Disorders, which works to improve the clinical standards of care for those affected by these disorders.

**Financial Review**

Income for the year at £347,665 was higher than the previous year (2017: £244,025). Expenditure for the year totalled £337,638 (2017: £358,400).

At the year end, the unrestricted fund was £56,403 (2017: £36,522), the restricted fund was £28,315 (2017: £26,742) and the endowment fund was £220,000 (2017: £233,877).

In more detail, the principal funding sources were: conference income and unrestricted grants 80,078 (2017: £71,495); funding of charitable activities £120,371 (2017: £79,224), fundraising income £85,500 (2017: £44,395) and voluntary donations of £55,448 (2017: £33,748).

All sources of income were higher than budget and the level of voluntary income and unrestricted donations was helped by the awareness and publicity created by our amazing families who were featured in the Children in Need programmes and the very generous donations and fundraising by our newly diagnosed families.

Funding of charitable activities (grants from grant giving organisations) was in line with budget but better than the previous year due to the timing of payment schedules.

**Report of the Directors  
For the Year ended 30 April 2018**

**Financial Review (continued)**

Expenditure at £337,638 was in line with the budget of £340,175 and some four minor overspends of less than £4,000 were offset by savings in other areas. The reported spend on a Strategic Review meeting in the 2018 accounts was due to a late invoice for the actual meeting in March 2017.

The support of our families, friends and grant providers is essential to maintaining the work we do and the services we provide. We are extremely grateful for their support, generosity and the difference they make.

**Reserves Policy**

NPUK 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 the year and have taken into account the objectives for the financial year, the risks associated with periods of reduced income and the Charity Commission's guidance "Charity Reserves; Building Resilience" (CC19, Published 29 January 2016).

For 2018/2019, the Trustees have set the required level of reserves at £86,000 to ensure that identified risks to income, cash flow and other contingencies do not impact on the services we provide. The free reserves held at 30 April 2018 were £56,403.

Our free reserves at £56,403 (2017: £36,522) are in line with the actions taken by Trustees to reach our objective of £86,000 and this trend will significantly improve over the period 2018/2019. However, we will need to further increase our level of reserves in 2019/2020 to offset the reduction in funding from the Big Lottery.

Following a review of our investments, The Trustees, with advice from an Independent Financial Adviser, are in the process of switching the endowment fund to a more diversified investment portfolio. For this reason, £220,000 is held on deposit pending allocation to a more suitable investment fund.

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.

**Principal risks**

The directors have a risk management strategy, which comprises:

- An annual review of the principal risks and uncertainties that NPUK faces.
- The establishment of policies, procedures and systems to mitigate those risks identified in the annual review.
- The implementation of procedures designed to minimise or manage any potential impact on NPUK should those risks materialise.

The principal risks relate to the completion of the Big Lottery project in November 2020, increased competition for a reducing number of long-term grant funding opportunities and a continuing reliance on voluntary donations and fundraising. These risks have been mitigated to varying degrees by:

- Having budgets in place to ensure expenditure levels are appropriate.
- Continuing to build up reserves over a number of years.
- Creating additional voluntary income, from the wider general public, through awareness and social media campaigns and the impact of our rebranding programme.
- Transferring any year on year capital gains in the endowment fund to income.
- Researching Grant Giving Organisations and making appropriate applications for grant funding

**Report of the Directors  
For the Year ended 30 April 2018****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. In addition, we will develop programmes that will prepare the young person and the family for the transition to adult services and to help patients, their families and healthcare teams to build strong relationships of trust and knowledge. 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 continue to 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 specialised 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 additional opportunities for clinical trials in the UK.

**Reference and Administrative Details**

The information relating to Niemann-Pick UK is on page 1. The organisation changed its name on 12 April 2017 from Niemann-Pick Disease Group (UK) to Niemann-Pick UK.

**Structure Governance and Management***Status*

The organisation is a charitable company limited by guarantee and the liability of each member is limited to £1. The organisation was registered as a charity in England and Wales on 24 October 2011 and in Scotland on 9 February 2015.

*Governing Document*

The charity is governed by its Memorandum and 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.

*Organisational 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 Chief Executive, 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.

**Report of the Directors (Continued)**  
**For the Year ended 30 April 2018**

*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*

Niemann-Pick 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 UK Central Office.

**Statement of Directors Responsibilities**

The charity's directors are responsible for preparing a directors' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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;
- observe the methods and principles in the applicable Charities SORP;
- 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 Act 2011, 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.

**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**



**W Evans**  
Trustee

**20 September 2018**

I report on the accounts of the company for the year ended 30 April 2018, which are set out on pages 8 to 17.

**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.

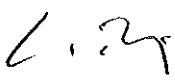
**Basis of independent examiner's report**

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

20 September 2018



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

For the year ended 30 April 2018

	Notes	Unrestricted Funds £	Restricted Funds £	Endowment Fund £	Total Funds £	2017 £
<b>Income and endowments from:</b>						
Donations and legacies	3	129,557	5,969	-	135,526	105,243
Charitable activities	4	-	120,371	-	120,371	79,224
Other trading activities	5	90,015	-	-	90,015	52,574
Investments	6	1,753	-	-	1,753	6,984
<b>Total income</b>		<u>221,325</u>	<u>126,340</u>	<u>-</u>	<u>347,665</u>	<u>244,025</u>
<b>Expenditure on:</b>						
Charitable activities	7	200,807	124,767	-	325,574	337,445
Raising funds		12,064	-	-	12,064	20,955
<b>Total expenditure</b>		<u>212,871</u>	<u>124,767</u>	<u>-</u>	<u>337,638</u>	<u>358,400</u>
<b>Income less expenditure</b>		8,454	1,573	-	10,027	(114,375)
Gains / (losses) on investments		-	-	(2,450)	(2,450)	13,835
<b>Net (expenditure) / income</b>		8,454	1,573	(2,450)	7,577	(100,540)
Transfers between funds		11,427	-	(11,427)	-	-
<b>Net movement in funds</b>		19,881	1,573	(13,877)	7,577	(100,540)
<b>Reconciliation of funds:</b>						
Total funds brought forward		<u>36,522</u>	<u>26,742</u>	<u>233,877</u>	<u>297,141</u>	<u>397,681</u>
<b>Total funds carried forward</b>	15	<u>56,403</u>	<u>28,315</u>	<u>220,000</u>	<u>304,718</u>	<u>297,141</u>

All income and expenditure derive from continuing activities.

The statement of financial activities includes all gains and losses recognised during the year.

**Balance Sheet**  
As at 30 April 2018

	Notes	2018 £	2017 £
<b>Fixed Assets</b>			
Investments – endowment fund	9	-	233,877
<b>Current Assets</b>			
Investments	10	220,000	-
Sundry debtors		1,966	500
Bank		91,168	80,365
		<u>313,134</u>	<u>80,865</u>
<b>Creditors</b>			
Amounts falling due within one year	11	8,416	17,601
<b>Net Assets</b>			
		<u>304,718</u>	<u>297,141</u>
<b>Funds</b>			
Unrestricted fund	15	56,403	36,522
Endowment fund		220,000	233,877
Restricted funds		28,315	26,742
		<u>304,718</u>	<u>297,141</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 April 2018.

The members have not required the charitable company to obtain audit of its financial statements for the year ended 30 April 2018 in accordance with Section 476 of the Companies Act 2006.

The directors acknowledge their responsibilities for:

- ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- 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 Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

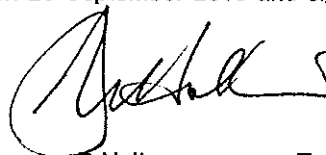
These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

The financial statements on pages 8 to 17 were approved on 20 September 2018 and signed on its behalf.



W Evans

Trustee



D Holton

Trustee

**Notes to the Financial Statements  
For the Year ended 30 April 2018**

**1. Statutory information**

Niemann-Pick UK is a private company, limited by guarantee and incorporated in England. It is registered as a charity in England and Scotland. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The company's registration number and registered office address can be found at page 1 on the Reference and Administrative Details page.

The presentation currency of the financial statements is the Pound Sterling (£).

**2. Accounting policies**

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

**a) Basis of preparation**

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) – (Charities SORP (FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Niemann-Pick UK meets the definition of a public benefit entity under FRS 102.

The financial statements are prepared on a going concern basis under the historical cost convention, modified to include certain items at fair value.

**b) Funds**

Unrestricted income funds comprise those funds which the trustees are free to use for any purpose in furtherance of the charitable objects. Unrestricted funds include designated funds where the trustees, at their discretion, have created a fund for a specific purpose.

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.

Endowment funds represent those assets which are held permanently by the charity. Income arising on the endowment funds can be used in accordance with the objects of the charity and is included as unrestricted income. Any capital gains or losses arising on the investments form part of the fund. The trustees have the power to convert the fund to an income fund.

**c) Income**

All income is recognised once the charity has entitlement to the income, there is sufficient certainty of receipt and so it is probable that the income will be received, and the amount of income receivable can be measured reliably.

Donations and grants are recognised when they have been communicated in writing with notification of both the amount and settlement date. In the event that a donation or grant is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

Interest on funds held on deposit and is included upon notification of the interest paid or payable by the Bank. Dividends received are included upon notification of the distribution being paid.

No amount is included in the financial statements for volunteer time in line with the SORP (FRS 102). Further detail is given in the Trustees' Annual Report.

**Note to the Financial Statements  
For the Year ended 30 April 2018 (continued)**

**d) Expenditure**

Expenditure is recognised 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.

All expenditure is accounted for on an accruals basis. All expenses, including support costs and governance costs, are allocated or apportioned to the applicable expenditure headings in the statement of financial activities.

Expenditure on charitable activities includes any VAT which cannot be recovered and is reported as part of the expenditure to which it relates and comprises those costs incurred by the charity in the delivery of its activities and services for 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.

**e) Tangible fixed assets & depreciation**

Tangible fixed assets are stated at cost or valuation less accumulated depreciation and impairment losses. Cost includes costs directly attributable to making the asset capable of operating as intended.

Depreciation is provided on all tangible fixed assets, at rates calculated to write off the cost, less estimated residual value, of each asset on a systematic basis over its expected useful life as follows:

Computer equipment – 3 years straight line.

**f) Investments**

Investments are recognised initially at fair value which is normally the transaction price excluding transaction costs. Subsequently, they are measured at fair value with changes recognised in 'net gains / (losses) on investments' in the SoFA if the shares are publicly traded or their fair value can otherwise be measured reliably.

**g) Impairment**

Assets not measured at fair value are reviewed for any indication that the asset may be impaired at each balance sheet date. If such indication exists, the recoverable amount of the asset, or the asset's cash generating unit, is estimated and compared to the carrying amount. Where the carrying amount exceeds its recoverable amount, an impairment loss is recognised in profit or loss unless the asset is carried at a revalued amount where the impairment loss is a revaluation decrease.

**h) Debtors and creditors receivable / payable within one year**

Debtors and creditors with no stated interest rate and receivable or payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in expenditure.

**i) Cash in bank and in hand**

Cash at bank and cash in hand includes cash and short term highly liquid investments.

**j) Pension costs**

The company operates defined contribution schemes, the assets of which are held separately from those of the charity. The pension cost charge represents contributions payable by the charity to the scheme.

**Note to the Financial Statements  
For the Year ended 30 April 2018 (continued)**

**k) Taxation**

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

**l) Operating leases**

Rentals payable under operating leases are charged to the Income and Expenditure Account on a straight line basis over the period of the lease.

**m) Going concern**

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist. The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern.

	2018 £	2017 £
<b>3. Income from donations &amp; legacies</b>		
Conference income and unrestricted grants	80,078	71,495
Voluntary donations	55,448	33,748
	<u>135,526</u>	<u>105,243</u>

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

Actelion Pharmaceuticals UK Ltd – Interactive workshop £10,000  
 Actelion Pharmaceuticals UK Ltd - towards Family Conference £10,000  
 CTD Holdings - towards Annual Family Conference £7,425  
 Orphazyme - towards Family Conference £9,994  
 Sucampo- towards Family Conference £10,000  
 Sanofi Genzyme - towards Family Conference and Regional Events £18,000

NPUK remains transparent, independent and impartial in all of its dealings with pharmaceutical companies. Unrestricted donations used for the Interactive Workshop and Family Conference are provided without any control or influence over the content of the programme or the selection of speakers.

**4. Income from charitable activities**

Big Lottery Fund	75,930	53,889
BBC Children in Need	16,430	9,365
Awards for All	9,329	-
Hollie Foundation	18,548	15,970
European Union (EAHC)	134	-
	<u>120,371</u>	<u>79,224</u>

**5. Income from other trading activities**

Fundraising events	85,500	44,395
Sale of promotional items etc	26	80
INPDA costs recharged	4,489	8,099
	<u>90,015</u>	<u>52,574</u>

**Note to the Financial Statements**  
**For the Year ended 30 April 2018 (continued)**

	2018	2017
	£	£
<b>6. Investment income</b>		
Bank interest	28	84
Income trust distribution	1,725	6,900
	<u>1,753</u>	<u>6,984</u>
<b>7. Expenditure on charitable activities</b>		
Helpline/family support/travel	129,827	132,038
Information – social media & publications	18,433	12,894
Conference costs	50,390	49,654
Research project costs	31,356	49,673
Central office wages	59,861	58,280
Upkeep computer	4,092	212
Rent	12,960	12,960
Other administration costs	5,270	6,514
Insurance & subscription	1,522	1,138
Bank charges	355	484
INPDR project	-	3,205
Strategic review meeting	2,040	2,313
Independent examiner's fee	1,560	1,799
Executive & management meetings	7,908	6,281
	<u>325,574</u>	<u>337,445</u>
<b>8. Tangible assets</b>		
	<b>Equipment</b>	
	<b>£</b>	
<b>Cost</b>		
At 30 April 2017 & 2018	4,158	
<b>Depreciation</b>		
At 30 April 2017	4,158	
Charge for the year	-	
	<u>4,158</u>	
At 30 April 2018	-	
<b>Net Book Value</b>		
At 30 April 2018	-	
At 30 April 2017	-	
	<u>-</u>	
<b>9. Fixed Asset Investments</b>		
	2018	2017
	£	£
Balance brought forward	233,877	220,042
(Decrease) / increase in value of investment	( 2,450)	13,835
Disposal	( 231,427)	-
	<u>-</u>	<u>-</u>
Market value at 30 April 2018	-	233,877
	<u>-</u>	<u>-</u>
Historical cost of investments held at 30 April 2018	-	202,000
	<u>-</u>	<u>-</u>

**Note to the Financial Statements  
For the Year ended 30 April 2018 (continued)**

	2018 £	2017 £
<b>10. Current Asset Investments</b>		
Short term deposits	220,000	-
<b>11. Creditors: amounts falling due within one year</b>		
Other tax & social security	2,190	1,630
Other creditors & accruals	6,226	15,971
	<u>8,416</u>	<u>17,601</u>
<b>12. Employee information</b>	<b>No</b>	<b>No</b>
The average monthly number of employees was:	5	5
	<u>£</u>	<u>£</u>
<b>Staff Costs</b>		
Salaries	105,084	99,027
Social security costs	7,222	6,130
Pension costs	936	63
	<u>113,242</u>	<u>105,220</u>

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

The key management personnel of the charity comprise the chief executive, the finance and administration officer, the families' officer and the social media communications officer. Their total employee benefits were £98,813 (2017: £93,035)

**13. Operating Leases**

The total minimum future lease payments under non-cancellable operating leases are as follows:

	2018 £	2017 £
<i>Expiry date</i>		
Within one year	2,700	2,700
	<u>2,700</u>	<u>2,700</u>

**14. Pension Costs**

The company operates a money purchase (defined contributions) pension scheme. The assets of the scheme are held separately from those of the company in independently administered funds. The pension cost represents contributions payable by the company to the funds and amounted to £936 (2017: £63).

**Note to the Financial Statements**  
**For the Year ended 30 April 2018 (continued)**

**15. Fund reconciliation**

2017-2018	Balance 30/4/2017 £	Income £	Expenditure £	Transfer £	Gains / (Losses) £	Balance 30/4/2018 £
<b>Unrestricted fund</b>	36,522	221,325	212,871	11,427	-	56,403
<b>Endowment fund</b>	233,877	-	-	(11,427)	(2,450)	220,000
<b>Restricted funds</b>						
Big Lottery Fund	11,770	75,929	76,384	-	-	11,315
BBC Children in Need	-	16,430	16,430	-	-	-
Awards for All	-	9,329	-	-	-	9,329
Hope for Hollie	3,765	-	1,000	-	-	2,765
Kate Elliot fund	5,077	312	483	-	-	4,906
Stewardship fund	-	3,000	3,000	-	-	-
Siri & Audun Blegan	-	1,695	1,695	-	-	-
Dr Heti Davies	5,000	-	5,000	-	-	-
Hollie Foundation	-	13,098	13,098	-	-	-
Hollie Foundation	-	5,250	5,250	-	-	-
Hollie Foundation	1,130	-	1,130	-	-	-
Lesley Carlton Jones	-	1,000	1,000	-	-	-
Campbell Burns Trust	-	297	297	-	-	-
<b>Total Restricted funds</b>	<b>26,742</b>	<b>126,340</b>	<b>124,767</b>	<b>-</b>	<b>-</b>	<b>28,315</b>
<b>Total funds</b>	<b>297,141</b>	<b>347,665</b>	<b>337,638</b>	<b>-</b>	<b>(2,450)</b>	<b>304,718</b>
<b>2016-2017</b>	<b>Balance 30/4/2016 £</b>	<b>Income £</b>	<b>Expenditure £</b>	<b>Transfer £</b>	<b>Gains / Losses £</b>	<b>Balance 30/4/2017 £</b>
<b>Unrestricted fund</b>	113,856	152,567	229,901	-	-	36,522
<b>Endowment fund</b>	220,042	-	-	13,835	-	233,877
<b>Restricted funds</b>						
Big Lottery Fund	38,420	53,889	80,539	-	-	11,770
BBC Children in Need	-	9,365	9,365	-	-	-
Hope for Hollie	3,815	-	50	-	-	3,765
Kate Elliot fund	5,418	1,295	1,636	-	-	5,077
Hope for Hannah	-	398	398	-	-	-
Stewardship fund	-	3,000	3,000	-	-	-
Siri & Audun Blegan	-	1,168	1,168	-	-	-
Dr Heti Davies	5,000	-	-	-	-	5,000
Grace's Wish	10,000	-	10,000	-	-	-
Hollie Foundation	-	2,000	2,000	-	-	-
Hollie Foundation	-	12,766	12,766	-	-	-
Hollie Foundation	-	5,254	5,254	-	-	-
Hollie Foundation	1,130	-	-	-	-	1,130
Lesley Carlton Jones	-	1,000	1,000	-	-	-
Daytrippers	-	246	246	-	-	-
Campbell Burns Trust	-	300	300	-	-	-
CTD Holdings	-	777	777	-	-	-
<b>Total Restricted funds</b>	<b>63,783</b>	<b>91,458</b>	<b>128,499</b>	<b>-</b>	<b>-</b>	<b>26,742</b>
<b>Total funds</b>	<b>397,681</b>	<b>244,025</b>	<b>358,400</b>	<b>13,835</b>	<b>-</b>	<b>297,141</b>



**Note to the Financial Statements**  
**For the Year ended 30 April 2018 (continued)**

**Fund descriptions**

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
Awards for All	Support through transition
Hope for Hollie	Travel fund
Kate Elliot fund	Adult NPC Patient Support
Hope for Hannah	Research
Stewardship fund	Research
Siri & Audun Blegan	Research
Dr Heti Davies	Funding towards the Children's Programme; Family Conference
Grace's Wish	Research
Hollie Foundation	Travel Fund
Hollie Foundation	Funding of Family Officer & children's programmes
Hollie Foundation	Funding of Children's programmes
Hollie Foundation	Literature re; Families Officer & Clinical Support Nurse
Lesley Carlton Jones	Research; Peter Carlton Jones award
Campbell Burns Trust	NPUK summer outing

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

	Unrestricted Funds £	Restricted Funds £	Endowment Funds £	Total Funds £
<b>2018</b>				
Current assets	60,854	32,280	220,000	313,134
Current liabilities	(4,451)	(3,965)	-	(8,416)
	<hr/>	<hr/>	<hr/>	<hr/>
Net assets at 30 April 2018	56,403	28,315	220,000	304,718
	<hr/>	<hr/>	<hr/>	<hr/>
<b>2017</b>				
Investments	-	-	233,877	233,877
Current assets	42,523	38,342	-	80,865
Current liabilities	( 6,001)	(11,600)	-	( 17,601)
	<hr/>	<hr/>	<hr/>	<hr/>
Net assets at 30 April 2017	36,522	26,742	233,877	297,141
	<hr/>	<hr/>	<hr/>	<hr/>

**17. Trustees**

No remuneration was paid to Trustees during the financial period. During the year five trustees were reimbursed travel and administration expenses in pursuit of charitable objectives and this amounted to £1,523 (2017 £7,350).

**Note to the Financial Statements**  
**For the Year ended 30 April 2018 (continued)**

**18. Related Party Transactions**

Niemann-Pick UK is a member of the International Niemann-Pick Disease Alliance (INPDA). The Finance and Administration Officer and the Social Media & Communications Officer work for both parties. In the year £11,919 (2017 £13,327) was paid to the INPDA as a contribution towards The Finance and Administration Officer. £9,698 (2017: £8,231) was recharged to INPDA in respect of the Social Media & Communications Officer. Other transactions with INPDA are shown at Notes 5 and 7.