

NIEMANN-PICK UK

Company number 07775835

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

REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 APRIL 2019

**Reference & Administrative Details  
For the Year ended 30 April 2019**

<i>England &amp; Wales Charity registration number:</i>	1144406
<i>Scotland Charity registration number:</i>	SC045407
<i>Company registration number:</i>	07775835
<i>Trustees (Directors):</i>	Dr William Evans (Chair) Dave Roberts Janice Brooks Helen Carter Bill Owen Richard Rogerson Dr David Holton Jacqueline Imrie Joella Melville Fiona Dunne (appointed 23 November 2019)
<i>Chief Executive:</i>	Toni Mathieson
<i>Co-opted Members:</i>	Prof Frances Platt Stefanie Rymza
<i>Bankers:</i>	HSBC 53 High Street Grays Essex RM17 6NH
<i>Investment Managers:</i>	Investec Wealth & Investment Limited 5 George Square Glasgow G2 1DY
<i>Auditors:</i>	James Anderson & Co 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 2019**

The trustees who are also the directors present their annual report and financial statements of the charity for the year ended 30 April 2019.

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 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*

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 an administration service plus 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 a broad range of information and advice for those affected by Niemann-Pick diseases plus practical advice for daily living. The information we develop covers a broad range of topics as well as information and resources specifically for health, education and social care professionals

Our dedicated Clinical Nurse Specialist provides expert care, practical advice and an expert advocacy service to all those affected by Niemann-Pick diseases. The Clinical Nurse Specialist also supports families in the home, at schools and at national specialist clinics, liaising with healthcare professionals as appropriate.

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 provides 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 integrate families into the Niemann-Pick community and strengthen links with a network of organisations which focus on the effective engagement with minority and "hard to reach" groups.

#### *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 fund the services we provide or these much loved social events and activities.

## **Report of the Directors For the Year ended 30 April 2019**

### **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. We held a very successful regional family meeting for all Ireland families, and friends, who find it difficult to attend the Annual Family Conference in England. We plan to hold a similar meeting in Scotland in 2019.

With an increasing demand for the services we provide, an increasing number of families coping with disease progression and continuing changes in welfare reform, our Care and Support Team play a vital role in the lives of families affected by Niemann-Pick diseases. They have worked, tirelessly, to provide much-needed emotional support, clinical and non-clinical advice and support and support to our patient's families and the wider Niemann-Pick community.

Our Central Office team has fully implemented the requirements of the General Data Protection Regulation (GDPR), which came into effect in May 2018 and has updated policies and procedures to ensure that the personal information and privacy of individuals is fully protected.

Our Communications Officer continues to create awareness of Niemann-Pick diseases through the production of high quality reports, publications and leaflets plus the development of family led stories and videos across social media platforms. Also in the pipeline is a NPUK produced short film "Go make Memories" which will be premiered at the Annual Family Conference in September 2019.

The Big Lottery grant has enabled us to strengthen our family support process and over the year we have played a major role in the "Breaking Down Barriers" project, which focuses on effective engagement with minority and 'hard to reach' families. The success of a Lads, Dads and Carers group has been followed by the launch of a Youth Council and this provides a voice for our adolescents and young adults so that we can better understand their needs and shape the services we provide for them. In addition, we have provided advice and support to help families develop coping strategies and make small changes that may improve their lives, wellbeing and relationships.

We continue to maintain a strong presence in the field of research and with four clinical trials at different stages of progress, we continue to maintain our involvement in the communication process and to give emotional and practical support to participating families, as appropriate. We continue to keep up to date with research into Niemann-Pick diseases and our focus for the 2019/2020 will continue to collaborate and provide small grants to laboratories for basic research and to collaborate with other rare disease organisations to gain support for preventative research into New Born Screening and a suitable test for Niemann-Pick Type C

At a strategic level, we continue to provide a voice for all those affected by Niemann-Pick diseases and 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. A key objective over the coming years will be to collaborate with pharmaceutical companies and NICE to improve the access to new drugs for rare diseases; understanding and gathering evidence from families to demonstrate the effectiveness of new drugs will become a key challenge for our community.

We continue to support the International Niemann-Pick Disease Alliance (INPDA) in all of its activities and we have played a key role establishing the International Niemann-Pick Disease Registry which is now owned and managed by the INPDA with support from professional partners involved in the care of patients affected by all types of Niemann-Pick diseases.

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 and we remain involved in community driven campaigns which aim to raise awareness, advance understanding and improve the care of those individuals affected by rare diseases and we continue to fully support the "Dementia Strikes Children Too" campaign.

## **Report of the Directors For the Year ended 30 April 2019**

### **Impact**

We provide a unique care, support and advocacy service for families affected by Niemann-Pick disease and the professionals caring for them. Our care, support and communications team have developed strong and positive relationships with those affected, their families, carers and the healthcare teams who support them. This enables us to directly engage with these groups, to explain the services we offer and to deliver an individualised clinical, non-clinical and advocacy support service tailored to their specific needs.

Over the year May 2018 to April 2019 we have collected information to show the impact of our work and have used outcomes and change indicators to track the differences we have made to the wellbeing of those we support.

These are summarised below:

- The families of newly diagnosed patients feel less isolated, more informed about Niemann-Pick disease and are better able to cope with the challenges it brings.
- The mental wellbeing of families has improved through access to information, individual support and a community who understands their needs and how they feel.
- Families have become more emotionally resilient, feel better able to cope with changing symptoms of disease progression and they are able to stop crisis situations developing.
- Family relationships have been improved through positive communication, mutual support and interaction.
- Families and patients have developed a greater understanding of the disease and its symptoms and they feel more confident in communicating their needs to healthcare professionals and statutory services.
- Harder to reach groups have become more integrated into the Niemann-Pick community, feel more comfortable in accessing support services and are participating in community events.
- Children and young adults affected by the disease have an improved ability to cope with their physical symptoms, enabling access education and participation in social and community events.

### **Financial Review**

#### **Income**

Income for the period May 2018 to April 2019 was a record £504,761 against a budget of £454,760.

However, we should acknowledge extraordinary unrestricted donations of £159,000 from Erith Construction and the Institute of Demolition Engineers. This was equivalent to 31.5% of total income. These donations contributed to the operating costs for 2018/2019 (£27,357), will provide a budget contribution to the Financial Year 2019/2020 (£53,127) and go towards designated funds for 2020/2021 (£78,516).

A like for like comparison with previous years shows a more realistic total income of £345,761 for 2018/2019 against a total of £347,665 for 2017/2018.

At the year end, the unrestricted funds were £154,707 (2018: £56,403), the restricted funds were £16,452 (2018: £28,315) and the endowment fund was £220,000 (2018: £220,000). The Free Reserves were £117,507.

All sources of income were better than budget and in addition we received non forecast Facebook donations of £8,042. The Facebook donations underline the important link between our Communication and Fundraising strategies and these will be further strengthened in 2019/2020.

We are hugely grateful to the Erith Group, the Institute of Demolition Engineers and all our families, friends and supporters who have done so much to raise funds on our behalf. We could not continue the services we provide without their help and support.

**Report of the Directors  
For the Year ended 30 April 2019**

**Financial Review (continued)**

**Expenditure**

Expenditure for the year (excluding commitments for future grant payments of £37,215) was £381,105 was broadly in line with the budget of £369,290 (£11,815 over budget). However, underspent budgets helped to offset two significant areas of overspend. In more detail, these were;

- Information and Communications expenditure included an overspend on the publication and circulation of newsletters (£2,209) and an approved non budgeted expenditure on the planning and development of an NP-C animated awareness film (£5,104).
- Research expenditure was £6,285 over budget due to late payment requests for a place at the Gordon Research Conference and a grant to Cardiff University both of which were approved last year.

**Reserves**

Our Reserves Policy conforms to the Charity Commissioners' guidance "Charity Reserves; Building Resilience" (CC19, Published 29 January 2016) and takes into account;

- The risks associated with the charity's financial strategy and the potential impact on spending commitments and future liabilities
- Financial and cash flow forecasts which take into account the ending of a Big Lottery Grant in January 2021.
- The need to address the risks of unplanned closure on the families, staff and beneficiaries who have come to rely on our support services.

Trustees will monitor the level of reserves at board meetings and will conduct an annual review of the Reserves Policy as part of the financial management process.

**Reserves Policy**

Our Financial Strategy is based on levels of incoming resources matching the expenditure required to deliver our objectives and the services that we provide to families and beneficiaries. Income will therefore be spent within a reasonable period of receipt to fund the operation of the Charity.

Our Reserves Policy is therefore; "To ensure that NP-UK has sufficient assets to consistently fund the services it provides to families affected by Niemann-Pick diseases and to hold sufficient funds to address the risks and contingencies identified by the Trustees".

The Trustees have reviewed the Reserves Policy and have taken into account the key objectives for this financial year, our existing commitments and the risks associated with forecast voluntary income and cash flow during forecast periods of reduced income.

The objectives of the reserves policy for the financial year 2019/2020 are therefore;

- To fund an approved shortfall in forecast income over expenditure to recruit an additional Families' Officer in line with Succession Planning (£25,546), to strengthen our Fundraising and Communications services (£20,286) and to support miscellaneous expenditure (£7,295),
- To hold sufficient funds (5 weeks) to manage cash flow for the day to day operation of the Charity. (£40,000)
- Contingency funding for UK laboratories, to cover requests for bridge funding in between grant cycles, seed funding to develop novel ideas that will go on to form the basis for larger grant applications and consumable items. (£15,000)
- Accrual to pay Salford Royal Foundation Trust a 3 month charge for the Clinical Nurse Specialist in conformance with the SRFT agreed contract. (£12,000)

To hold funds in line with the Charity Commissioners' guidance "Charity Reserves; Building Resilience" (£17,200)

**Report of the Directors  
For the Year ended 30 April 2019**

**Financial Review (continued)**

**Reserves Policy (continued)**

The total required reserves are therefore £137,327 which is equivalent to 4 months of planned expenditure.

The required level of reserves will be maintained by a contribution from unrestricted funds in the form of donations, expendable investment income and reserves when available and will be reviewed by the Board of Trustees on a quarterly basis. The Reserves Policy will be reviewed by the Board of Trustees on an annual basis. The total assets held in bank accounts at the 30 April 2019 was £222,877 and the level of "Free Reserves" was £117,507.

The level of reserves will be maintained by a contribution from unrestricted funds, when available, and will be reviewed by the Finance Subcommittee on a monthly basis and the Board of Trustees on a quarterly basis. The Reserves Policy will be reviewed by the Board of Trustees on an annual basis.

**Designated Funds**

The Trustees have also identified designated funds that are set aside to for a specific purpose or for future planned needs. These funds are therefore ring-fenced and no longer form part of our unrestricted funds. They can be reviewed by Trustees at any time and transferred, whole or in part, to the unrestricted fund.

The designated funds for the financial year 2019/2020 are;

- 3 year grant to the University of Oxford for a nominated a PhD student, Years 2 and 3 (£20,000)
- Funding towards a 3 year project (Oxford University) to investigate a new potential therapy, for Niemann-Pick disease type C, commencing May 2019, Years 1,2 and 3 (£17,200)
- Accrual to fund the Care and Support service for 1 year following the completion of the Big Lottery Grant (2020/2021) in order to create the lead time necessary to seek alternative grant funding (£80,000)

The total designated funds are therefore £117,200 which is equivalent to 3.4 months of planned expenditure.

## **Report of the Directors For the Year ended 30 April 2019**

### **Endowment**

NPUK has an expendable endowment (legacy) of £220,000. This is invested to produce an expendable income which will go towards reserves (Average £7,000 per annum). However, this fund is now being managed by Investec, an independent provider of Charity investment management service, and greater returns on investment are anticipated.

If required, the Endowment can be used to assist in financing of 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 for affected families during a period of transition to new providers. Any assets remaining will be transferred to some other charitable institution in line with the Articles of Association.

The endowment will be monitored by the Trustees on an annual basis.

### **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 the risks identified in the annual review.
- The implementation of actions and procedures designed to minimise or manage any potential impact on NPUK should those risks materialise.

The principal risks for the foreseeable future relate to the completion of the Big Lottery project in 2020, increased competition for a reducing number of long-term grant funding opportunities and a continuing reliance on voluntary donations and fundraising to help fund the services we provide.

These risks have been mitigated to varying degrees by:

- Having budgets in place to ensure expenditure levels are appropriate.
- Strengthening the links between Communication and Fundraising to nurture new and existing fundraisers and donors.
- Creating additional voluntary income, from the wider general public, through awareness and social media campaigns, including short films and maintaining the impact of our rebranding programme.
- Building up reserves to offset the loss of Big Lottery funding in year1.
- Converting any year on year capital gains in the endowment fund to income.
- Researching Grant Giving Organisations and making appropriate applications for grant funding.

Our Succession Planning Strategy runs alongside the Risk Management process to ensure we always have in place Trustees and Staff, with the appropriate skill sets to ensure we are able to meet the needs of the Charity and our Community. 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.

### **Plans for Future Periods**

We are in the fortunate position of having reserves and designated funds to enable the Charity to continue with the services we provide for the foreseeable future. However, this is dependent on successful grant funding applications to replace the Big Lottery grant, maintaining the Children in Need grant beyond 2020 and maintaining the continuing support of pharmaceutical grants for the Annual Family conference. There are no other foreseen risks or spending plans that cannot be met from anticipated future income streams.



**Report of the Directors (Continued)  
For the Year ended 30 April 2019**

**Plans for Future Periods (continued)**

We will continue to support the needs of our families and our services have now been extended to include the offer of support to siblings, the increasing number of newly diagnosed adults and hard to reach groups including ethnic minority communities, lads and dads. In addition, we will consolidate programmes that prepare the young patients and their families for the transition to adult services and to help patients, their families and healthcare teams to build strong relationships of trust and knowledge.

We will continue to build on our strong relationship with the International Niemann-Pick Disease Alliance, the LSD Collaborative and other national organisations and will remain active in providing an expert patient voice and perspective to NHS England in respect of highly specialised services for Lysosomal Storage Diseases and equal access to treatments and therapies. We will engage with the National Institute for Health and Care Excellence (NICE) and collaborate with pharmaceutical companies to understand and gather evidence from families to demonstrate the effectiveness of new drugs as part of the submission to fund new drugs for Niemann-Pick patients

We will fully support the continuing development of the International Niemann-Pick Disease Registry and the NHS Specialist Centres who support Niemann-Pick patients. We will facilitate additional opportunities for clinical trials in the UK and cooperate with NHS University Hospital Trusts who perform clinical trials and provide specialised diagnostic services.

We will promote research into Niemann-Pick diseases and collaborate with UK Universities, other research groups and international family groups in all matters relating to research into Niemann-Pick diseases. In addition, we will promote a Niemann-Pick Disease Prevention Strategy and form collaborative partnerships to develop research into New Born Screening for Niemann-Pick diseases.

**Reference and Administrative Details**

The information relating to Niemann-Pick UK is on page 1.

**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 2019***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 and the Niemann-Pick Communications Officer who are 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.

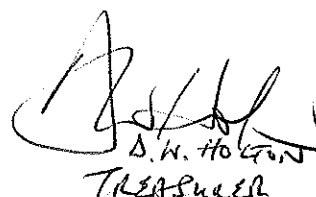
**Statement of Disclosure of Information to Auditors**

In the case of each of the persons who are trustees at the time when the directors report is approved:

- so far as the trustee is aware, there is no relevant audit information (information needed by the company's auditors in connection with preparing their report) of which the company's auditors are unaware, and
- each trustee has taken all the steps that he ought to have taken as a trustee in order to make himself aware of any relevant audit information and to establish that the company's auditors are aware of that information.

By Order of the Board

W Evans  
Trustee

  
D. W. Horton  
TREASURER

14 January 2020

### Opinion

We have audited the financial statements of Niemann-Pick UK (the 'charitable company') for the year ended 30 April 2019 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 30 April 2019, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

### Other information

The trustees are responsible for the other information. The other information comprises the information included in the Report of the Directors, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

#### **Opinions on other matters prescribed by the Companies Act 2006**

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Directors for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Directors has been prepared in accordance with applicable legal requirements.

#### **Matters on which we are required to report by exception**

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Directors.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of directors' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemption from the requirement to prepare a strategic report.

#### **Responsibilities of trustees**

As explained more fully in the Statement of Directors' Responsibilities set out on page 6, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

#### **Auditor's responsibilities for the audit of the financial statements**

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

**Use of our report**

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charitable company's trustees, as a body, in accordance with regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company, the charitable company's members as a body and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

*James Anderson & Co*

Mark Ferguson (Senior Statutory Auditor)  
for and behalf of James Anderson & Co, Statutory Auditors, Pentland Estate, Straiton, EH20 9QH

James Anderson & Co is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

28 January 2020

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

For the year ended 30 April 2019

	Notes	Unrestricted Funds £	Restricted Funds £	Endowment Fund £	Total Funds £	2018 £
<b>Income and endowments from:</b>						
Donations and legacies	3	302,832	8,666	-	311,498	135,526
Charitable activities	4	-	118,734	-	118,734	120,371
Other trading activities	5	73,820	-	-	73,820	90,015
Investments	6	709	-	-	709	1,753
<b>Total income</b>		<b>377,361</b>	<b>127,400</b>	<b>-</b>	<b>504,761</b>	<b>347,665</b>
<b>Expenditure on:</b>						
Raising funds		9,235	-	-	9,235	12,064
Charitable activities	7	269,822	139,263	-	409,085	325,574
<b>Total expenditure</b>		<b>279,057</b>	<b>139,263</b>	<b>-</b>	<b>418,320</b>	<b>337,638</b>
<b>Income less expenditure</b>		<b>98,304</b>	<b>(11,863)</b>	<b>-</b>	<b>86,441</b>	<b>10,027</b>
Transfers between funds		-	-	-	-	(2,450)
<b>Net movement in funds</b>		<b>98,304</b>	<b>(11,863)</b>	<b>-</b>	<b>86,441</b>	<b>7,577</b>
<b>Reconciliation of funds:</b>						
Total funds brought forward		56,403	28,315	220,000	304,718	297,141
<b>Total funds carried forward</b>	<b>16</b>	<b>154,707</b>	<b>16,452</b>	<b>220,000</b>	<b>391,159</b>	<b>304,718</b>

All income and expenditure derive from continuing activities.

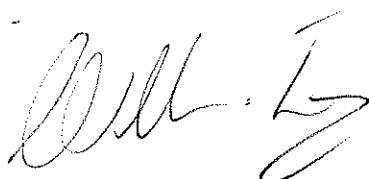
The statement of financial activities includes all gains and losses recognised during the year.

**Balance Sheet**  
**As at 30 April 2019**

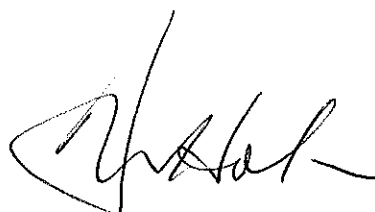
	Notes	2019 £	2018 £
<b>Fixed Assets</b>			
Tangible fixed assets	8	-	-
Investments	9	220,000	-
		<u>220,000</u>	<u>-</u>
<b>Current Assets</b>			
Investments	10	-	220,000
Debtors	11	16,409	1,966
Bank		222,877	91,168
		<u>239,286</u>	<u>313,134</u>
<b>Creditors</b>			
Amounts falling due within one year	12	68,127	8,416
<b>Net Current Assets</b>		<u>171,159</u>	<u>304,718</u>
<b>Net Assets</b>		<u>391,159</u>	<u>304,718</u>
<b>Funds</b>	16		
General fund		37,507	56,403
Designated fund		117,200	-
		<u>154,707</u>	<u>56,403</u>
Unrestricted funds		154,707	56,403
Endowment fund		220,000	220,000
Restricted funds		16,452	28,315
		<u>391,159</u>	<u>304,718</u>

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 13 to 23 were approved by and signed on behalf of the Board of Directors on 14 January 2020.



W Evans      Trustee



D Holton      Trustee

**Statement of Cash Flows**  
**For the Year ended 30 April 2019**

	Note	2019 £	2018 £
<b>Cash flows from operating activities</b>			
Cash generated from operations	1	131,000	(2,377)
Net cash provided by operating activities		131,000	(2,377)
<b>Cash flows from investing activities</b>			
Investment income		709	1,753
Transfer from endowment fund		-	11,427
Net cash used for investing activities		709	13,180
<b>Net increase in cash and cash equivalents</b>		131,709	10,803
Cash and cash equivalents at 30 April 2018		91,168	80,365
Cash and cash equivalents at 30 April 2019		222,877	91,168

**Note to Cash Flow Statement**

**1. Reconciliation of net income to net cash flow from operating activities**

Net income	86,441	10,027
Investment income	(709)	(1,753)
	85,732	8,274
(Increase) in debtors	(14,443)	(1,466)
Increase / (decrease) in creditors	59,711	(9,185)
Net cash provided by operating activities	131,000	(2,377)



**Notes to the Financial Statements  
For the Year ended 30 April 2019****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 Wales 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 and capital gains 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 2019 (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.

**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.

**Note to the Financial Statements**  
**For the Year ended 30 April 2019 (continued)**

**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.

	2019 £	2018 £
<b>3. Income from donations &amp; legacies</b>		
Conference income and unrestricted grants	90,664	80,078
Voluntary donations	220,834	55,448
	<u>311,498</u>	<u>135,526</u>

Included above were unrestricted grants received from pharmaceutical companies:

Actelion Pharmaceuticals UK Ltd – £20,000  
 CTD Holdings - £10,000  
 Orphazyme - £10,000  
 Mallinckrodt- £9,904  
 Sanofi Genzyme - £25,000

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

Voluntary donations include unrestricted donations of £159,000 from Erith Construction and the Institute of Demolition Engineers.

	2019 £	2018 £
<b>4. Income from charitable activities</b>		
Big Lottery Fund	84,614	75,930
BBC Children in Need	17,818	16,430
Awards for All	-	9,329
Hollie Foundation	16,302	18,548
European Union (EAHC)	-	134
	<u>118,734</u>	<u>120,371</u>
<b>5. Income from other trading activities</b>		
Fundraising events	73,820	85,500
Sale of promotional items etc	-	26
INPDA costs recharged	-	4,489
	<u>73,820</u>	<u>90,015</u>

**Note to the Financial Statements**  
**For the Year ended 30 April 2019 (continued)**

	2019 £	2018 £
<b>6. Investment income</b>		
Bank interest	709	28
Income trust distribution	-	1,725
	<u>709</u>	<u>1,753</u>
<b>7. Expenditure on charitable activities</b>		
Helpline / family support / travel	124,783	129,827
Information - social media & publications	35,571	18,433
Conference costs	55,963	50,390
Research project costs	94,657	31,356
Central office wages	64,776	59,861
Upkeep computer	1,320	4,092
Rent	11,152	12,960
Other administration costs	5,991	5,270
Insurance & subscription	1,755	1,522
Bank charges	425	355
Strategic review meeting	-	2,040
Independent examiner's fee	120	1,560
Auditors remuneration	4,800	-
Executive & management meetings	7,772	7,908
	<u>409,085</u>	<u>325,574</u>
Charged to - Unrestricted funds	269,822	200,807
- Restricted funds	<u>139,263</u>	<u>124,767</u>
<b>8. Tangible assets</b>		
	<b>Equipment</b>	
	<b>£</b>	
<b>Cost</b>		
At 30 April 2018 & 2019	<u>4,158</u>	
<b>Depreciation</b>		
At 30 April 2018	4,158	
Charge for the year	<u>-</u>	
At 30 April 2019	<u>4,158</u>	
<b>Net Book Value</b>		
At 30 April 2019	-	
At 30 April 2018	<u>-</u>	
<b>9. Fixed asset investments</b>		
	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Balance brought forward	-	233,877
Additions	220,000	-
(Decrease) / increase in value of investment	-	(2,450)
Disposal	<u>-</u>	<u>(231,427)</u>
Market value at 30 April 2019	<u>220,000</u>	<u>-</u>
Historical cost of investments held at 30 April 2019	<u>220,000</u>	<u>-</u>

**Note to the Financial Statements**  
**For the Year ended 30 April 2019 (continued)**

	2019 £	2018 £
<b>10. Current asset investments</b>		
Short term deposits	-	220,000
	<hr/>	<hr/>
<b>11. Debtors</b>		
Amounts due from INPDA (note 19)	11,466	1,687
Amounts due from INPDR (note 19)	4,943	279
	<hr/>	<hr/>
	16,409	1,966
	<hr/>	<hr/>
<b>12. Creditors: amounts falling due within one year</b>		
Other tax & social security	2,544	2,190
Accruals and deferred income	28,368	6,226
Accruals for grants payable	37,215	-
	<hr/>	<hr/>
	68,127	8,416
	<hr/>	<hr/>
<b>13. Employee information</b>	<b>No</b>	<b>No</b>
The average monthly number of employees was:	5	5
	<hr/>	<hr/>
	<b>£</b>	<b>£</b>
<b>Staff Costs</b>		
Salaries	131,572	105,084
Social security costs	9,787	7,222
Pension costs	1,875	936
	<hr/>	<hr/>
	143,234	113,242
	<hr/>	<hr/>

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 families' officer and the social media communications officer. Their total employee benefits were £105,782 (2018: £98,813)

**14. Operating Leases**

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

	2019 £	2018 £
<i>Expiry date</i>		
Within one year	-	2,700
	<hr/>	<hr/>

**15. 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 £1,875 (2018: £936).

Note to the Financial Statements  
For the Year ended 30 April 2019 (continued)

16. Statement of Funds

	Balance 30/4/2018 £	Income £	Expenditure £	Transfer £	Gains / (Losses) £	Balance 30/4/2019 £
<b>2018-2019</b>						
General fund	56,403	377,361	279,057	(117,200)	-	37,507
Designated fund	-	-	-	117,200	-	117,200
<b>Total unrestricted funds</b>	<b>56,403</b>	<b>377,361</b>	<b>279,057</b>	<b>-</b>	<b>-</b>	<b>154,707</b>
<b>Endowment fund</b>	<b>220,000</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>220,000</b>
<b>Restricted funds</b>						
Big Lottery Fund	11,315	84,613	82,241	-	-	13,687
BBC Children in Need	-	17,819	17,819	-	-	-
Awards for All	9,329	-	9,329	-	-	-
Hope for Hollie	2,765	-	-	-	-	2,765
Kate Elliot fund	4,906	-	4,906	-	-	-
Stewardship fund	-	3,000	3,000	-	-	-
Norwegian Families	-	4,116	4,116	-	-	-
Dr Heti Davies	-	550	550	-	-	-
Hollie Foundation	-	1,228	1,228	-	-	-
Hollie Foundation	-	9,824	9,824	-	-	-
Hollie Foundation	-	5,250	5,250	-	-	-
Lesley Carlton Jones	-	1,000	1,000	-	-	-
<b>Total restricted funds</b>	<b>28,315</b>	<b>127,400</b>	<b>139,263</b>	<b>-</b>	<b>-</b>	<b>16,452</b>
<b>Total funds</b>	<b>304,718</b>	<b>504,761</b>	<b>418,320</b>	<b>-</b>	<b>-</b>	<b>391,159</b>
<b>2017-2018</b>						
<b>Unrestricted fund</b>	<b>36,522</b>	<b>221,325</b>	<b>212,871</b>	<b>11,427</b>	<b>-</b>	<b>56,403</b>
<b>Endowment fund</b>	<b>233,877</b>	<b>-</b>	<b>-</b>	<b>(11,427)</b>	<b>(2,450)</b>	<b>220,000</b>
<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>

**Note to the Financial Statements**  
**For the Year ended 30 April 2019 (continued)**

**Fund descriptions**

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

The **designated funds** are funds set aside to for the specific purposes outlined in the Report of the Directors on page 6.

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	Research
Kate Elliot fund	Adult NPC Patient Support
Stewardship fund	Research
Norwegian Families	Research
Siri & Audun Blegan	Research
Dr Heti Davies	Funding towards the Children's Programme; Family Conference
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

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

	Unrestricted Funds £	Restricted Funds £	Endowment Funds £	Total Funds £
<b>2019</b>				
Fixed asset investments	-	-	220,000	220,000
Current assets	213,828	25,458	-	239,286
Current liabilities	(59,121)	(9,006)	-	(68,127)
Net assets at 30 April 2019	154,707	16,452	220,000	391,159
<b>2018</b>				
Current assets	60,854	32,280	220,000	313,134
Current liabilities	(4,451)	(3,965)	-	(8,416)
Net assets at 30 April 2018	56,403	28,315	220,000	304,718

**18. Trustees**

No remuneration was paid to Trustees during the financial period. During the year five trustees (2018: five) were reimbursed travel and administration expenses in pursuit of charitable objectives and this amounted to £3,215 (2018 £1,523).

**Note to the Financial Statements**  
**For the Year ended 30 April 2019 (continued)**

**19. Related Party Transactions**

Niemann-Pick UK is a member of the International Niemann-Pick Disease Alliance (INPDA). It also works closely with the International Niemann-Pick Disease Registry (INPDR). Various costs were incurred in the year by Niemann-Pick UK on behalf of these organisations and recharged.

The transactions in the year and the year end balances are as follows:

	2019 £	2018 £
With INPDA		
Wages	10,937	21,339
Other costs	8,985	3,604
Sum due to NPUK (note 11)	11,465	1,687
With INPDR		
Wages	1,968	279
Other costs	7,115	729
Sum due to NPUK (note 11)	4,943	279