

**NIEMANN-PICK UK**

**Company number 07775835**

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

**REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 APRIL 2020**

**Reference & Administrative Details  
For the Year ended 30 April 2020**

<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

## **Trustees Annual Report For the Year ended 30 April 2020**

The trustees present their annual report and financial statements of the charity for the year ended 30 April 2020. The directors of the charitable company are its trustees for the purposes of charity law.

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 have developed a strong family support network, helping to reduce feelings of isolation and despair and provide clinical, non-clinical and emotional support as appropriate to the needs of the families we support.

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 and Families Officer provide 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 engage with ethnic minority organisations and disadvantaged families within the Niemann-Pick community. These actions have helped us to establish contact with families that would not normally access our services and has enabled us to provide individual tailored support.

#### *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 take part in 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.

## Trustees Annual Report For the Year ended 30 April 2020

### Achievements and Performance

NPUK staff, volunteers and trustees continue to provide the high quality service and support that our beneficiaries have come to expect.

Following our family meeting in Ireland, we held a very successful regional meeting for those families in Scotland who found it difficult to travel to our Annual Family Conference at Wyboston Lakes. We will now formalise bi-annual meetings for families in all of Ireland and Scotland as a regular calendar event.

Our Care and Support Team play a vital role in supporting an increasing number of the families coping with disease progression and continuing changes in welfare reform. In addition, they have provided much needed emotional support to strengthen positive mental wellbeing and resilience.

This work intensified as the UK government's coronavirus action plan, published on 3 March, set out measures to respond to the COVID-19. Families of affected children and adults were classed as clinically vulnerable and this meant staying at home as much as possible and keeping interactions outside to a minimum. This caused social isolation from friends, family and school, limited contact with health care teams and feelings of anxiety and issues with sleeping and mental health.

Our staff team worked tirelessly to adapt procedures, in line with government guidance, and introduced video conference calls to replace face to face visits with families and clinicians.

Staff had to quickly develop new skills to engage effectively with families by Zoom and other video platforms and became alert to any signs of safeguarding issues. Working as a team, our Families Officers were able to provide necessary support to reduce the causes anxiety and deal with the non-clinical challenges faced by families in lockdown. In addition, our Clinical Nurse Specialist was able to play a leading role in helping to manage communications with clinicians and healthcare professionals regarding medications and the clinical needs of our patients during a time of reduced NHS services due to the pandemic.

To further support families, the Board of Trustees approved additional care and support capacity and created an Emergency Response Fund to enable the payment of essential bills and the purchase of essential items which included food, play and educational equipment for children.

Our Communications Officer continues to maintain and develop our website and 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. To support families during COVID-19 restrictions, the staff team provided additional online content, activities and daily updates, plus a structured ten-week schedule to support, inform, and entertain the NPUK Community, referred to as our "Social Not Distant" campaign.

Our new short film, "Go make Memories" was developed with help from our community to raise awareness of Niemann-Pick disease. By using a mixture of live action and animation the film explores the shock of being diagnosed with Niemann-Pick Type C and the impact of disease progression on the family and the emotional turmoil that comes hand in hand with such a diagnosis.

Since its premier at the Family Conference in September, it has gone on to win a number of awards at film festivals throughout the world and we hope its impact will continue to raise awareness.

The Big Lottery grant has enabled us to strengthen our family support process and over the year we have met our indicators of change in all four desired outcomes. We continue to make a positive contribution to Breaking Down Barriers, a network of 30 organisations working together to improve the lives of people from BAME backgrounds, and we use lessons learned to focus on effective engagement with our own minority and disadvantaged families. To help develop confidence and improve overall wellbeing, we have introduced health challenges, accompanied members to community events and have been able to get a number of our male members into volunteer programmes.

The Youth Council has been strengthened by additional support from the Families Officer and by parents writing blogs and actively supporting some of the younger members of our community. A new blog page provides new content each week on a wide range of topics providing information and guidance, plus Question and Answer sessions throughout the year.

## Trustees Annual Report For the Year ended 30 April 2020

### Achievements and Performance Continued

We 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 2020/2021 will be to collaborate and provide small grants to UK laboratories for basic research, engage with emerging biotech companies who are interested in developing new therapies for the treatment of Niemann-Pick type C and to collaborate with other rare disease organisations to progress research into disease prevention and New Born Screening.

At a strategic level, our Chief Executive has been reappointed as a member the Clinical Reference Group for specialist inherited metabolic disorders and as active members of the Specialised Healthcare Alliance we continue to raise the profile of rare diseases across the UK, influence policies relating to specialised services and seek to bring about lasting change for families and patients affected by rare diseases.

We continue to provide a voice for all those affected by Niemann-Pick diseases and a key objective over the coming years will be to collaborate with pharmaceutical companies and NICE to gain a positive appraisal for any new drugs arising from clinical trials. Understanding and gathering evidence from families to demonstrate the effectiveness of new drugs will become a key challenge for our community.

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 remain involved in community driven campaigns to raise awareness, advance the understanding and improve the care of those individuals affected by rare diseases. We value our relationship with clinicians at specialist centres and collaborate to improve the clinical standards of care for those affected by these disorders.

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 (INPDR). This is a collaboration between clinicians, scientists, researchers and patient associations across the world to collect clinical, genetic, diagnostic and outcome data from patients with Niemann-Pick diseases. The INPDR is now registered as an independent charitable company with NPUK representatives appointed as board members.

### 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 our beneficiaries, 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 2019 to April 2020 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. Some of the key differences 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 are able to stop situations developing into a crisis.
- 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.

**Trustees Annual Report  
For the Year ended 30 April 2020**

**Financial Review**

**Income**

Income for the period May 2019 to April 2020 was £496,946 against a budget of £364,930. However, this was only achieved by an extremely generous legacy of £149,111. The underlying income was therefore £347,835.

A like for like comparison of underlying income with previous years shows £347,835 for 2019/2020, £345,760 for 2018/2019 and £347,665 for 2017/2018

In more detail, the Management Accounts showed funding gaps against budget, of;

- £12,657 shortfall in donations from pharmaceutical companies (£64,343 against a budget of £77,000)
- £14,006 shortfall in general donations (£16,549 against a budget of £30,555)
- £9,601 shortfall in just giving activities (£17,199 against a budget of £26,800)

These shortfalls were made up by slightly better than budget income in other categories and the legacy. Facebook donations continue to grow (£10,427 against a budget of £10,000) and this underlines the importance of developing the link between our Communication and Fundraising strategies.

We are hugely grateful for the legacy donation and to 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. In addition, we thank our grant funding organisations; the Big Lottery for fully funding our "Shaping our Future Together" project, BBC Children in Need for follow on grant funding towards the Clinical Nurse Specialist and the Hollie Foundation for their contributions towards the Families Officer, children's programmes and literature. Thank you.

At 30 April 2020, the unrestricted funds amounted to £257,939 (2019: £154,707), the restricted fund was £2,408 (2019: £16,452) and the endowment fund was £204,631 (2019: £220,000).

**Expenditure**

Expenditure for the year was £407,758 against a budget of £416,545. However, within the detail, there were some planned increases in some key budgets by comparison to the previous year.

These increases, against the previous year, (above £5k) were distributed across the services we provide as follows;

£10,703 family care and support; succession planning.

£11,476 Information and Communication; final development and production of the animated film.

£10,021 Family Conference and children's programme.

These planned increases were approved by the Trustees and were to provide continuing support for our families and to create awareness of the impact of Niemann-Pick diagnosis and disease progression.

**Reserves Policy**

NPUK Financial Strategy is based on levels of incoming resources matching the expenditure required to deliver our objectives and the services we provide to families and beneficiaries. Whilst income will be spent within a reasonable period of receipt to fund the operation of the Charity, we have a responsibility to manage risk and to ensure the charity is able to meet its future commitments.

Our Reserves Policy is; "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".

This 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 forecasts and cash flow forecasts which take into account the ending of a Big Lottery Grant in January 2021. (Last grant payment is November 2020)
- 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 Annual Report  
For the Year ended 30 April 2020  
Financial Review (continued)**

**Level of Reserves**

The Trustees have reviewed the Reserves Policy and have taken into account, the key objectives and commitments for 2020/2021, the risks associated with a forecast downward trend in voluntary income and a three year cash flow forecast.

The objectives of the reserves policy for the financial year 2020/2021 are therefore;

- To fund an approved shortfall in forecast income over expenditure. (£74,967)
- To hold sufficient funds (6 weeks) to manage salaries and cash flow for the day to day operation of the Charity. (£44,603)
- Accrual to pay Salford Royal Foundation Trust a 3 month charge for the Clinical Nurse Specialist in conformance with the SRFT agreed contract. (£13,958)
- To hold statutory funds in line with the Charity Commissioners' guidance "Charity Reserves; Building Resilience" (£17,525)

The total required reserves are therefore £151,053 which is equivalent to 4.7 months of planned expenditure. The level of free reserves at 30 April 2020 was £150,939.

The required level of reserves will be maintained by a contribution from unrestricted funds 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.

**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 2020/2021 are;

- 3 year grant to the University of Oxford for a nominated a PhD student, Final year 3 (£10,000)
- Funding towards a 3 year joint project (University of Oxford and Action Medical Research) to investigate a new potential therapy, for Niemann-Pick disease type C, commencing May 2019, Year 3 (£8,333)
- Part funding towards a bridging grant for a postdoctoral researcher to trial NPC genome editing at the University of Oxford (£8,667)
- Funding towards the Care and Support service for 1 year following the final quarterly grant payment from the Big Lottery Grant (November 2020) in order to create the lead time necessary to seek alternative grant funding (£80,000)

The total designated funds are therefore £107,000 which is equivalent to 3.3 months of planned expenditure.

**Endowment**

NPUK has an expendable endowment, arising from a legacy, which is managed by Investec to produce an expendable income. The opening balance at 30 April 2019 was £220,000 and, following worldwide financial uncertainty, the value at 30 April 2020 had reduced to £204,631

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 another charitable institution in line with the Articles of Association.

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

**Trustees Annual Report  
For the Year ended 30 April 2020**

**Risk Management**

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.
- The implementation of actions and procedures designed to minimise or manage any potential impact on NPUK should those risks materialize.

**Principal Risks**

The principal risks for the foreseeable future relate to;

- a reduction in grant funding, from November 2020, following the completion of the Big Lottery project. (£80,000)
- increased competition for a reducing number of long-term grant funding opportunities.
- economic and social pressures which will adversely affect voluntary income.
- the possibility of reduced capacity, following the completion of the Big lottery project at a time of increasing demand for our services.

**These risks have been mitigated to varying degrees by:**

- Having budgets in place to ensure expenditure levels are appropriate.
- Proposal to implement an online database which will improve data collection and productivity,
- 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 and by promoting digital fundraising events.
- Maintaining reserves at a level to offset the loss of Big Lottery funding in year1 and enabling time to gain additional grant funding.
- Creating the opportunity to converting any year on year capital growth in the endowment fund to unrestricted 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 current financial year. However, our future financial management will depend on our ability to attract grant funding to replace the Big Lottery grant and a continuation of unrestricted funding from pharmaceutical companies towards our Annual Family Conference.

We will continue to support the needs of our families and through the Big Lottery grant, we continue to offer support to siblings, newly diagnosed adults and hard to reach groups including ethnic minority communities, lads and dads. We will continue this work and implement a management system that will facilitate a more efficient way to collect data about the services we provide.



**Trustees Annual Report  
For the Year ended 30 April 2020**

**Plans for Future Periods (continued)**

In addition, we will consolidate programmes that prepare young patients and their families for the transition to adult services by helping patients, their families and adult healthcare teams to build strong relationships based on knowledge and mutual trust.

We recognise the specific needs of families affected by ASMD Type B Niemann-Pick disease and will develop an awareness campaign to raise public awareness and improve diagnosis.

We are driven by the needs of our community and will continue to adapt our services in response to the spread of COVID-19. We will implement Personal Protective Equipment requirements, safeguarding and other guidance to protect our employees as well as those we support. We will continue to engage with families and children, plus their education and healthcare teams to ensure our advice and services are relevant and helpful and we will be proactive in identifying emerging gaps. In addition, we will review policies and procedures as required, continue to develop the use of video conferencing and review arrangements for our Family Conference.

We will continue to build on our strong relationship with the International Niemann-Pick Disease Alliance, the LSD Collaborative and other national organisations to provide a voice for our community and create awareness of the challenges we face. We will engage with the Specialised Healthcare Alliance and Rare Disease UK to raise the profile of rare disease across the UK and the need to fully implement the UK Strategy for Rare Diseases.

We 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.

**Strategic Review**

NPUK Trustees and staff representatives held a Strategic Review in March 2020, before Covid-19 measures were introduced, and agreed the following high level aims over the next three year period. Strategies have been developed to deliver these aims with actions and key performance indicators now being developed to support of the strategies.

Over the three year period from March 2020 to 2023 we aim to;

- To optimise our extraordinary service;
- To develop our people and manage succession;
- To be proactive in seeking opportunities to improve the lives of those within our community and to respond with agility to evolving research, treatment, social care needs and preventative interventions;
- To be effective in our communications, reflecting our community and the range of our activity and influence;
- To ensure a robust and sustainable organisation.

**Trustees Annual Report  
For the Year ended 30 April 2020**

**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.

*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.

**Trustees Annual Report  
For the Year ended 30 April 2020**

**Statement of Trustees Responsibilities**

The charity's trustees are responsible for preparing a trustees 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 trustees 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 trustees 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.

**By Order of the Board**



**W Evans  
Trustee**

15<sup>th</sup> September 2020

I report on the accounts of the company for the year ended 30 April 2020, which are set out on pages 12 to 21.

**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.

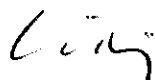
**Independent examiner's statement**

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

22 September 2020

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

For the year ended 30 April 2020

	Notes	Unrestricted Funds £	Restricted Fund £	Endowment Fund £	Total Funds £	2019 £
<b>Income and endowments from:</b>						
Donations and legacies	3	291,279	7,400	-	298,679	311,498
Charitable activities	4	-	135,260	-	135,260	118,734
Other trading activities	5	58,323	-	-	58,323	73,820
Investments	6	4,684	-	-	4,684	709
<b>Total income</b>		<u>354,286</u>	<u>142,660</u>	<u>-</u>	<u>496,946</u>	<u>504,761</u>
<b>Expenditure on:</b>						
Raising funds		7,854	-	-	7,854	9,235
Charitable activities	7	243,200	156,704	-	399,904	409,085
<b>Total expenditure</b>		<u>251,054</u>	<u>156,704</u>	<u>-</u>	<u>407,758</u>	<u>418,320</u>
<b>Net income / expenditure before losses on investments</b>		103,232	(14,044)	-	89,188	86,441
Net losses on investments		-	-	(15,369)	(15,369)	-
<b>Net movement in funds</b>		103,232	(14,044)	(15,369)	73,819	86,441
<b>Reconciliation of funds:</b>						
Total funds brought forward		154,707	16,452	220,000	391,159	304,718
<b>Total funds carried forward</b>	15	<u>257,939</u>	<u>2,408</u>	<u>204,631</u>	<u>464,978</u>	<u>391,159</u>

All income and expenditure derives from continuing activities.

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

**Balance Sheet**  
**As at 30 April 2020**

	Notes	2020 £	2019 £
<b>Fixed Assets</b>			
Tangible fixed assets	8	-	-
Investments	9	204,631	220,000
		<u>204,631</u>	<u>220,000</u>
<b>Current Assets</b>			
Debtors	10	4,818	16,409
Bank		292,432	222,877
		<u>297,250</u>	<u>239,286</u>
<b>Creditors</b>			
Amounts falling due within one year	11	36,903	68,127
<b>Net Current Assets</b>		<u>260,346</u>	<u>171,159</u>
<b>Net Assets</b>		<u>464,978</u>	<u>391,159</u>
<b>Funds</b>	15		
General fund		150,939	37,507
Designated fund		107,000	117,200
		<u>257,939</u>	<u>154,707</u>
Unrestricted funds			
Endowment fund		204,631	220,000
Restricted funds		2,408	16,452
		<u>464,978</u>	<u>391,159</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 April 2020.

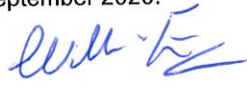
The members have not required the charitable company to obtain audit of its financial statements for the year ended 30 April 2020 in accordance with Section 476 of the Companies Act 2006.

The trustees 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 12 to 21 were approved by and signed on behalf of the Board of Directors on 15 September 2020.

  
W Evans      Trustee  
15/9/20

  
D Holton      Trustee

**Notes to the Financial Statements  
For the Year ended 30 April 2020**

**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 2020 (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 2020 (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.

	2020 £	2019 £
<b>3. Income from donations &amp; legacies</b>		
<i>General Fund – unrestricted</i>		
Conference income and grants	87,030	90,664
Voluntary donations	55,138	212,168
Legacy donation	149,111	-
<i>Restricted fund</i>		
Voluntary donations	7,400	8,666
	<u>298,679</u>	<u>311,498</u>

Included above were unrestricted grants received from pharmaceutical companies:

CTD Holdings - £12,000  
 Orphazyme - £10,000  
 Mallinckrodt- £11,310  
 Sanofi Genzyme - £35,000

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 £25,000 from the Institute of Demolition Engineers.

	2020 £	2019 £
<b>4. Income from charitable activities</b>		
<i>Restricted fund</i>		
Big Lottery Fund	98,867	84,614
BBC Children in Need	19,763	17,818
Hollie Foundation	16,630	16,302
	<u>135,260</u>	<u>118,734</u>
<b>5. Income from other trading activities</b>		
<i>General fund – unrestricted</i>		
Fundraising events	58,323	73,820
	<u>58,323</u>	<u>73,820</u>
<b>6. Investment income</b>		
<i>General fund - unrestricted</i>		
Bank interest	444	709
Dividend income	4,240	-
	<u>4,684</u>	<u>709</u>

**Note to the Financial Statements**  
**For the Year ended 30 April 2020 (continued)**

	2020 £	2019 £
<b>7. Expenditure on charitable activities</b>		
Helpline / family support / travel	154,914	124,783
Information - social media & publications	47,043	35,571
Conference costs	65,985	55,963
Research project costs	27,875	94,657
Central office wages	67,767	64,776
Upkeep computer	822	1,320
Rent & rates	12,442	11,152
Other administration costs	7,165	5,991
Insurance & subscription	1,742	1,755
Bank charges	296	425
Strategic review meeting	3,288	-
Independent examiner's fee	1,800	120
Auditors remuneration	-	4,800
Executive & management meetings	8,765	7,772
	<u>399,904</u>	<u>409,085</u>
Charged to - <i>General fund - unrestricted</i>	243,200	269,822
- <i>Restricted fund</i>	<u>156,704</u>	<u>139,263</u>

**8. Tangible assets**

	Equipment £
<b>Cost</b>	
At 30 April 2019 and 2020	<u>4,158</u>
<b>Depreciation</b>	
At 30 April 2019 and 2020	<u>4,158</u>
<b>Net Book Value</b>	
At 30 April 2019 and 2020	<u>-</u>

**9. Fixed asset investments**

	2020 £	2019 £
Balance brought forward	220,000	-
Additions	-	220,000
Impairment in value	<u>(15,369)</u>	<u>-</u>
Market value at 30 April 2020	<u>204,631</u>	<u>220,000</u>
Historical cost of investments held at 30 April 2020	<u>220,000</u>	<u>220,000</u>
Investments at fair value comprise:		
	2020	
Fixed interest	34.42%	
Securities	28.96%	
Property	5.9%	
Alternatives	13.02%	
Cash	17.69%	

The fair value of investments is determined by reference to the quoted price for identical assets in an active market at the balance sheet date.

**Note to the Financial Statements**  
**For the Year ended 30 April 2020 (continued)**

	2020 £	2019 £
<b>10. Debtors</b>		
Amounts due from INPDA (note 18)	2,109	11,466
Amounts due from INPDR (note 18)	1,359	4,943
Other debtors	1,350	-
	<u>4,818</u>	<u>16,409</u>
<b>11. Creditors: amounts falling due within one year</b>		
Other tax & social security	2,486	2,544
Accruals and deferred income	15,275	28,368
Accruals for grants payable	19,142	37,215
	<u>36,903</u>	<u>68,127</u>
<b>12. Employee information</b>	<b>No</b>	<b>No</b>
The average monthly number of employees was:	<u>6</u>	<u>5</u>
	<b>£</b>	<b>£</b>
<b>Staff Costs</b>		
Salaries	153,817	131,572
Social security costs	10,734	9,787
Pension costs	2,956	1,875
	<u>167,507</u>	<u>143,234</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 families' officer and the social media communications officer. Their total employee benefits were £104,220 (2019: £105,782)

**13. 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	<u>3,240</u>	<u>-</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 £2,956 (2019: £1,875).

**Note to the Financial Statements**  
**For the Year ended 30 April 2020 (continued)**

**15. Statement of Funds**

	Balance 30/4/2019 £	Income £	Expenditure £	Transfer £	Gains / (Losses) £	Balance 30/4/2020 £
<b>2019-2020</b>						
General fund	37,507	354,286	251,054	10,200	-	150,939
Designated fund	117,200	-	-	(10,200)	-	107,000
<b>Total unrestricted funds</b>	<b>154,707</b>	<b>354,286</b>	<b>251,054</b>	<b>-</b>	<b>-</b>	<b>257,939</b>
<b>Endowment fund</b>	<b>220,000</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>(15,369)</b>	<b>204,631</b>
<b>Restricted funds</b>						
Big Lottery Fund	13,687	98,867	111,376	-	-	1,178
BBC Children in Need	-	19,763	19,763	-	-	-
Hope for Hollie	2,765	-	2,765	-	-	-
Stewardship fund	-	3,000	3,000	-	-	-
Norwegian Families	-	3,400	3,400	-	-	-
Hollie Foundation	-	10,400	10,400	-	-	-
Hollie Foundation	-	5,000	5,000	-	-	-
Hollie Foundation	-	1,230	-	-	-	1,230
Lesley Carlton Jones	-	1,000	1,000	-	-	-
<b>Total restricted funds</b>	<b>16,452</b>	<b>142,660</b>	<b>156,704</b>	<b>-</b>	<b>-</b>	<b>2,408</b>
<b>Total funds</b>	<b>391,159</b>	<b>496,946</b>	<b>407,758</b>	<b>-</b>	<b>(15,369)</b>	<b>464,798</b>
<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>

**Note to the Financial Statements**  
**For the Year ended 30 April 2020 (continued)**

**15. Statement of Funds 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
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

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

	Unrestricted Funds £	Restricted Funds £	Endowment Funds £	Total Funds £
<b>2020</b>				
Fixed asset investments	-	-	204,631	204,631
Current assets	294,842	2,408	-	297,250
Current liabilities	(36,903)	-	-	(36,903)
	<u>257,939</u>	<u>2,408</u>	<u>204,631</u>	<u>464,978</u>
Net assets at 30 April 2020				
	<u>257,939</u>	<u>2,408</u>	<u>204,631</u>	<u>464,978</u>
<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)
	<u>154,707</u>	<u>16,452</u>	<u>220,000</u>	<u>391,159</u>
Net assets at 30 April 2019				
	<u>154,707</u>	<u>16,452</u>	<u>220,000</u>	<u>391,159</u>

**17. Trustees**

No remuneration was paid to Trustees during the financial period. During the year six trustees (2019: five) were reimbursed travel and administration expenses in pursuit of charitable objectives and this amounted to £2,412 (2019 £3,215).

**Note to the Financial Statements**  
**For the Year ended 30 April 2020 (continued)**

**18. 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:

	2020 £	2019 £
With INPDA		
Wages	6,228	10,937
Other costs	8,831	8,985
Sum due to NPUK (note 11)	2,109	11,465
With INPDR		
Wages	2,598	1,968
Other costs	6,128	7,115
Sum due to NPUK (note 11)	1,359	4,943