

NIEMANN-PICK UK

Company number 07775835

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

**REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 APRIL 2021**

**Reference & Administrative Details
For the Year ended 30 April 2021**

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|---|---|
| <i>England & 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 |
| <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>Independent Examiners:</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 2021

The trustees present their annual report and financial statements of the charity for the year ended 30 April 2021. 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.

Throughout this year we have seen an increasing demand for our support services and our staff have worked hard to reduce the impact of the COVID-19 pandemic on our vulnerable community. We adapted our usual support services to our community by using virtual methods of staying connected so that we could maintain relationships, provide access to mental and physical well-being services, reduce isolation and help increase self-confidence and emotional resilience of the families we support.

Our Central Office, located in Washington, Tyne and Wear, saw a huge increase in demand for help and support via the 24-hour help line with similar increases in requests for support and information about COVID and how best to manage the impact of shielding. Educational literature, regular newsletters, e-bulletins and social networking platforms were all adapted to suit the needs of the community.

Our website provides information on all aspects of the Niemann-Pick diseases, practical advice for daily living and the latest developments in research. Extra sections were added to support families and help them navigate and cope with the challenges of the COVID 19 lockdown.

Our Clinical Nurse Specialist provides expert care and practical advice and during the lockdown contacted every patient and family to assess their needs and provide urgent support and medication as required. Liaising with and involving local services and healthcare professionals, on behalf of families, helped to offset the impact of shielding which, with some patients, resulted in a decline in mobility and cognitive ability.

Our Families Officer continued to provide non-clinical advice and emotional support. Organising regular interactive family events helped to reduce isolation and providing help in exploring COVID support, access to Emergency Funding and entitlements around benefits, housing education and employment helped to reduce anxiety and improve wellbeing.

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 helped us to establish contact with families who would not normally access our services and this enabled us to provide individual tailored COVID support to those families most in need. In addition, during the last year of the project, the Project Families Officer transitioned towards providing counselling and a person centred, holistic approach towards managing a range of issues, including personal, emotional and psychological issues, as well as health and relationship problems.

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 on the public benefit requirement (PB1) Public benefit: running a charity (PB2) and Public benefit: reporting (PB3). These matters are addressed throughout the body of the report.

Contribution made by volunteers

We are extremely grateful to the volunteers who have supported us throughout the COVID -19 pandemic. We would like to thank all those volunteers and families who were able to organise COVID safe fundraising activities and provide help and support at our virtual family conference and social events. Without this support, we would not be able to provide these much loved social activities.

Trustees Annual Report For the Year ended 30 April 2021

Our Objectives and Activities (continued)

Building on our strong relationship with the UK LSD Patient Collaborative we took part in many high-level virtual meetings with national rare disease groups to influence national policy for the benefit of all those affected by Niemann-Pick diseases. We value our relationship with clinicians and healthcare professionals and have been able to host joint webinars, throughout the lockdown, to address COVID-19 related questions raised by families.

We continued to support the International Niemann-Pick Disease Alliance (INPDA) in all of its activities and played a key role in further developing 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

Throughout the pandemic, our care, support and communications team have worked to maintain and develop strong and positive relationships with those affected, their families, carers and the healthcare teams who support them. This enabled us to directly engage with our beneficiaries, explain the services and support we offer and to make a difference to their daily lives during this challenging time.

Over the period May 2020 to April 2021, we 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;

- Families of newly diagnosed patients felt less isolated, more informed about Niemann-Pick disease and were better able to cope with the challenges it brings.
- In the absence of face to face clinic and GP appointments, the families were able to raise issues with our Clinical Nurse Specialist who provided urgent clinical support and medication plus emotional support.
- The mental wellbeing of families was supported and improved through regular access to interactive well-being support, counselling, expert information and mutual support through virtual social activities and community activities.
- Crisis situations have been averted through provision of our Coronavirus Emergency Response Fund which supported patients and families in meeting their basic and mental wellbeing needs
- Families and children have maintained their physical and mental wellbeing through access to craft materials, educational and outdoor play equipment.
- Families have become more emotionally resilient and feel better able to cope with the impact of the pandemic and the changing symptoms of disease progression.
- Family relationships have been improved through positive communication, mutual support and interaction with virtual engagement programmes.
- Children and young adults affected by the disease have an improved ability to cope with their physical symptoms, enabling participation in virtual social and community events.
- During the pandemic, we have increased our reach, as more community members have accessed our support and services and become integrated into the Niemann-Pick community through participation in virtual activities and events.
- Sadly, some families have suffered the heart-breaking loss of loved ones and NPUK has been able to provide counselling, emotional and practical support, plus counselling at these most difficult times.

Risk Management

The trustees 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 minimize or manage any potential impact on NPUK should those risks materialise.

Principal Risks

The principal risks for the foreseeable future relate to;

- A reduction in grant funding, from November 2020, following the completion of the National Lottery Community Fund project. (£80,000 per year)
- Increased competition for a reducing number of long-term grant funding opportunities.
- Continuing COVID restrictions which will impact on fund raising and voluntary income.

**Trustees Annual Report
For the Year ended 30 April 2021**

Principal Risks (continued)

- Late or non-commercialisation of new drugs which will impact on unrestricted educational grants from pharmaceutical companies.
- A reduction in overall income 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.
- Submitting applications for new COVID related grant funding opportunities.
- Researching Grant Giving Organisations and making appropriate applications for grant funding.
- Implementing an online database which will improve data collection and productivity.
- Recruitment of a part time Fundraising Officer to strengthen the links between Communication and Fundraising and to nurture new and existing fundraisers and donors.
- Creating additional voluntary income, from the wider general public, through new awareness and social media campaigns and by promoting digital fundraising events.
- Laying the foundations with other charities to explore potential collaborative working relationships to increase capacity and enable future sustainability through the provision of shared services in areas of common benefit – effective 2022/2023.
- Using reserves to offset the loss of grant income and fund the services we provide.
- Planning a Strategic Review to focus on the long-term financial and operational stability of the Charity - March 2022.

Financial Review

Income

Income for the period May 2020 to April 2021 was £350,918 against a like for like total of £347,835 for the previous year. However, this was only achieved by the additional income received from successful COVID support grants, (£85,601) and the generous support of pharmaceutical companies which amounted to £81,605. (an increase of £13,295 on the previous year) Without these additional funds, totalling £98,896, the total income would have been £252,022.

This underlying, very much reduced, income was due mainly to a reduction in fundraising income and donations amounting to £53,893 (£107,258 for 2019/2020). We are hugely grateful to our families, friends and supporters who continued with COVID safe fundraising events and all those who were able to continue making voluntary donations.

During COVID, we were extremely fortunate to provide COVID safe services to the families we support but could not have done so without the continuing support of our grant funding organisations; the National Lottery Community Fund 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. In addition, we were fortunate to receive COVID support funding from The National Lottery Community Fund, BBC Children in Need Covid-19 "Next Steps" programme and the Pears Foundation. We are hugely grateful to these organisations and thank them for their support during these difficult times.

Expenditure

Expenditure for the year was £331,592 against a budget of £386,148 and a total of £407,758 for the previous year.

In more detail, reflecting an increase in demand for our Family support services, expenditure on providing care and support, information and communications increased by £16,069 against a COVID adjusted budget. However, with "stay at home" advice severely restricting fundraising, face to face meetings and university projects, savings against budget of £30,360 were made in the cost of fundraising, governance, research, travel and the family conference. In addition, £5,820 was underspent on an end of project Big Lottery Independent Assessment and this is carried forward, as a restricted fund, to next year.

Net Assets

At 30 April 2021, the unrestricted funds amounted to £272,853 (2020: £257,939) the restricted fund was £6,820 (2020: £2,408) and the endowment fund was £227,490 (2020: £204,631).

**Trustees Annual Report
For the Year ended 30 April 2021**

Financial Review (continued)

Financial Strategy

Our Financial Strategy is based on levels of incoming funds 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, ensure the charity is able to meet its future demand for services and to achieve financial sustainability. We therefore hold a level of reserves to ensure the smooth running of the Charity during times of financial uncertainty.

Reserves Policy

Our Reserves Policy is to ensure that NPUK 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 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.

Our Reserves Policy conforms to the Charity Commissioners' guidance "Charity Reserves; Building Resilience" (CC19, published 29 January 2016) and, for the financial year, 2021 to 2022, takes into account;

- The risks associated with the charity's financial strategy and the potential impact on spending commitments and future liabilities.
- Three year financial forecasts and cash flow forecasts which take into account potential future risks to income.
- The need to address the risks of unplanned closure on the families, staff and beneficiaries who have come to rely on our support services.

Level of Reserves

The Trustees have reviewed the Reserves Policy and have taken into account the key objectives and commitments for 2021/2022, the risks associated with a forecast downward trend in voluntary income during this period and the outcomes from a three-year cash flow forecast.

The objectives of the reserves policy for the financial year 2021/2022 are therefore;

- To fund an approved shortfall in forecast income over expenditure (£122,311).
- To hold sufficient funds (6 weeks) to manage salaries and cash flow for the day to day operation of the Charity. (£44,389).
- To mitigate the risk of a shortfall in grants. (£15,000).

The total required reserves are therefore £181,700 which is equivalent to 5.7 months of planned expenditure.

Designated Funds

The Trustees have also identified designated funds that are set aside for a specific purpose or for future planned needs. These funds are therefore ring-fenced and no longer form part of our free reserves. 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 2021/2022 are;

- Three month charge for the Clinical Nurse Specialist to Salford Royal Foundation Trust in conformance with the SRFT agreed contract. (£14,342)
- Three year PhD Studentship Agreement with Aston University; (£36,500)
- To hold statutory funds in line with the Charity Commissioners' guidance "Charity Reserves; Building Resilience" (£22,334)

The total designated funds are therefore £73,176 which is equivalent to 2.3 months of planned expenditure.

Endowment

NPUK has an expendable endowment, arising from a legacy, which is managed by Investec Wealth Management Services to produce an expendable income.

The opening balance at 30 April 2019 was £220,000 and, following recovery from a worldwide financial uncertainty during 2020, the value at 30 April 2021 stands at £227,490.

The Endowment can be used to assist in financing of the family care and support service provided to families affected by Niemann-Pick diseases.

**Trustees Annual Report
For the Year ended 30 April 2021**

Endowment (continued)

Following a review of our three-year financial forecast and a risk assessment of our income streams, the Trustees are prepared to use their discretionary powers to transfer £50,000 of the endowment to income during 2022/2023 should it be necessary.

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.

Plans for Future Periods

- We will seek ways to create a robust and sustainable charity by creating additional capacity to enhance our fundraising capabilities in line with our Fundraising and Income Generation Strategy.
- We will continue to provide financial support to families through a new NPUK Support Fund. This will assist those experiencing hardship or unexpected expense which threatens to impact their physical or mental well-being as a result of the Coronavirus pandemic.
- We will find ways to safely provide a return to face to face services, in line with government advice, but will carry forward the benefits of remote and virtual meetings and consultations whenever practical. This will help to reduce costs and increase capacity.
- We will engage with schools to ensure the smooth return of children affected by Niemann-Pick disease and support those children who feel anxious and not able to return to the classroom.
- We will continue to provide a voice for all those affected by Niemann-Pick diseases. A key objective over the coming year is to gather patient/family experience data that can support health technology assessment, increase understanding and demonstrate disease impact. This will enable us to evidence the unmet need within our community and to advocate appropriately for the prompt approval of safe and effective therapies.
- We will continue to keep up to date with the latest research into Niemann-Pick diseases. Our focus in 2021/2022 will be to collaborate with UK research and academic institutions and, if possible, will provide small grants in support of relevant projects. We will engage with worldwide experts and emerging biotech companies who are interested in developing new therapies for the treatment of Niemann-Pick diseases.
- We will build on our strong relationship with the UK LSD Collaborative and other relevant organisations to share learning and best practice and to influence national policy for the benefit of all those affected by Niemann-Pick diseases. This will also include our participation in a New Born Screening initiative led by the Archangel Trust to collaborate with medical science and Members of Parliament to reform the way New Born Screening is approached in the UK.
- We will continue to support the International Niemann-Pick Disease Alliance (INPDA) in all of its activities and continue our key role in supporting the International Niemann-Pick Disease Registry (INPDR).
- We will remain involved in community driven campaigns to raise awareness and improve the care of those individuals affected by rare diseases. We value our relationship with the clinical teams at the NHS England Specialist Centres and will continue to work with them to further improve standards of care for those affected by these disorders.

Trustees Annual Report For the Year ended 30 April 2021

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, Communications and Campaigns Manager, Counselling and Well-being Officer and Families Officer. The Group also pays the full employment costs of a Clinical Nurse Specialist who is employed by the Salford Royal NHS Foundation Trust. The Trustees and all the other supporters of the Group are volunteers.

The Trustees are directly responsible for the effective governance of the charity and for providing appropriate support and guidance and monitoring of all staff and activities. This is carried out in accordance with statutory guidance and legislation as provided by the Charity Commissioners. The Trustees meet on average four occasions a year with at least four additional teleconferences to review reports and to carry out management and financial reviews.

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 NPUK Finance and Administration Officer and Communications and Campaigns Manager who are located at the Niemann-Pick UK Central Office.

**Trustees Annual Report
For the Year ended 30 April 2021**

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 trustees 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**

16 September
2021

I report on the accounts of the company for the year ended 30 April 2021 which are set out on pages 10 to 19.

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

21 September 2021

Statement of Financial Activities
(Incorporating Income and Expenditure Account)

For the year ended 30 April 2021

| | Notes | Unrestricted Funds £ | Restricted Fund £ | Endowment Fund £ | Total Funds £ | 2020 £ |
|--|-------|----------------------------|-------------------------|------------------------|---------------------|----------------|
| Income and endowments from: | | | | | | |
| Donations and legacies | 3 | 138,225 | 4,000 | - | 142,225 | 298,679 |
| Charitable activities | 4 | - | 185,974 | - | 185,974 | 135,260 |
| Other trading activities | 5 | 18,678 | - | - | 18,678 | 58,323 |
| Investments | 6 | 4,041 | - | - | 4,041 | 4,684 |
| Total income | | <u>160,944</u> | <u>189,974</u> | <u>-</u> | <u>350,918</u> | <u>496,946</u> |
| Expenditure on: | | | | | | |
| Raising funds | | 3,935 | - | - | 3,935 | 7,854 |
| Charitable activities | 7 | 142,095 | 185,562 | - | 327,657 | 399,904 |
| Total expenditure | | <u>146,030</u> | <u>185,562</u> | <u>-</u> | <u>331,592</u> | <u>407,758</u> |
| Net income / expenditure before losses on investments | | <u>14,914</u> | <u>4,412</u> | <u>-</u> | <u>19,326</u> | <u>89,188</u> |
| Net gains / (losses) on investments | | - | - | 22,859 | 22,859 | (15,369) |
| Net movement in funds | | <u>14,914</u> | <u>4,412</u> | <u>22,859</u> | <u>42,185</u> | <u>73,819</u> |
| Reconciliation of funds: | | | | | | |
| Total funds brought forward | | <u>257,939</u> | <u>2,408</u> | <u>204,631</u> | <u>464,978</u> | <u>391,159</u> |
| Total funds carried forward | 15 | <u>272,853</u> | <u>6,820</u> | <u>227,490</u> | <u>507,163</u> | <u>464,978</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 2021

| | Notes | 2021 £ | 2020 £ |
|-------------------------------------|-------|----------------|----------------|
| Fixed Assets | | | |
| Tangible fixed assets | 8 | - | - |
| Investments | 9 | 227,490 | 204,631 |
| | | <u>227,490</u> | <u>204,631</u> |
| Current Assets | | | |
| Debtors | 10 | 2,007 | 4,818 |
| Bank | | 287,176 | 292,432 |
| | | <u>289,183</u> | <u>297,250</u> |
| Creditors | | | |
| Amounts falling due within one year | 11 | 9,510 | 36,903 |
| Net Current Assets | | <u>279,673</u> | <u>260,346</u> |
| Net Assets | | <u>507,163</u> | <u>464,978</u> |
| Funds | 15 | | |
| General fund | | 199,677 | 150,939 |
| Designated fund | | 73,176 | 107,000 |
| | | <u>272,853</u> | <u>257,939</u> |
| Unrestricted funds | | 272,853 | 257,939 |
| Endowment fund | | 227,490 | 204,631 |
| Restricted funds | | 6,820 | 2,408 |
| | | <u>507,163</u> | <u>464,978</u> |

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 April 2021.

The members have not required the charitable company to obtain audit of its financial statements for the year ended 30 April 2021 in accordance with Section 476 of the Companies Act 2006.

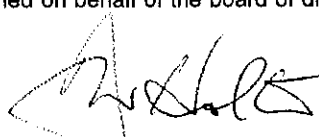
The trustees acknowledge their responsibilities for:

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) 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 10 to 19 were approved by and signed on behalf of the board of directors on 16 September 2021.


W Evans Trustee


D Holton Trustee

**Notes to the Financial Statements
For the Year ended 30 April 2021**

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 2021 (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 2021 (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.

| | 2021 £ | 2020 £ |
|--|----------------|----------------|
| 3. Income from donations & legacies | | |
| <i>General Fund - unrestricted</i> | | |
| Conference income and grants | 93,935 | 87,030 |
| Voluntary donations | 44,290 | 55,138 |
| Legacy donation | - | 149,111 |
| <i>Restricted fund</i> | | |
| Voluntary donations | 4,000 | 7,400 |
| | <u>142,225</u> | <u>298,679</u> |

Included above were unrestricted educational grants received from pharmaceutical companies:

Annual Conference and Interactive Workshop:

Cyclo Therapeutics - £15,000

Orphazyme - £15,000

Mallinckrodt - £11,350

Sanofi Genzyme - £15,000

Other restricted grants

Cyclo Therapeutics - £25,255

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.

| | 2021 £ | 2020 £ |
|--|----------------|----------------|
| 4. Income from charitable activities | | |
| <i>Restricted fund</i> | | |
| Big Lottery Fund | 124,859 | 98,867 |
| BBC Children in Need | 33,268 | 19,763 |
| Hollie Foundation | 13,313 | 16,630 |
| Pears Foundation | 14,534 | - |
| | <u>185,974</u> | <u>135,260</u> |
| 5. Income from other trading activities | | |
| <i>General fund – unrestricted</i> | | |
| Fundraising events | 18,678 | 58,323 |
| 6. Investment income | | |
| <i>General fund - unrestricted</i> | | |
| Bank interest | 105 | 444 |
| Dividend income | 3,936 | 4,240 |
| | <u>4,041</u> | <u>4,684</u> |

Note to the Financial Statements
For the Year ended 30 April 2021 (continued)

| | 2021 | 2020 |
|--|------------------|-----------------|
| | £ | £ |
| 7. Expenditure on charitable activities | | |
| Helpline / family support / travel | 140,703 | 154,914 |
| Information - social media & publications | 55,585 | 47,043 |
| Conference costs | 26,163 | 65,985 |
| Research project costs | 12,949 | 27,875 |
| Central office wages | 68,819 | 67,767 |
| Upkeep computer | 477 | 822 |
| Rent & rates | 11,760 | 12,442 |
| Other administration costs | 6,418 | 7,165 |
| Insurance & subscription | 2,101 | 1,742 |
| Bank charges | 213 | 296 |
| Strategic review meeting | - | 3,288 |
| Independent examiner's fee | 1,800 | 1,800 |
| Legal fees | 333 | - |
| Executive & management meetings | 336 | 8,765 |
| | <u>327,657</u> | <u>399,904</u> |
| Charged to - <i>General fund - unrestricted</i> | 142,095 | 243,200 |
| - <i>Restricted fund</i> | <u>185,562</u> | <u>156,704</u> |
| 8. Tangible assets | | |
| | Equipment | |
| | £ | |
| Cost | | |
| At 30 April 2020 and 2021 | <u>4,158</u> | |
| Depreciation | | |
| At 30 April 2020 and 2021 | <u>4,158</u> | |
| Net Book Value | | |
| At 30 April 2020 and 2021 | <u>-</u> | |
| 9. Fixed asset investments | 2021 | 2020 |
| | £ | £ |
| Balance brought forward | 204,631 | 220,000 |
| Increased / (Impairment) in value | <u>22,859</u> | <u>(15,369)</u> |
| Market value at 30 April 2021 | <u>227,490</u> | <u>204,631</u> |
| Historical cost of investments held at 30 April 2021 | <u>220,000</u> | <u>220,000</u> |
| Investments at fair value comprise: | | |
| | 2021 | |
| Fixed interest | 35.19% | |
| Securities | 38.95% | |
| Property | 8.84% | |
| Alternatives | 15.24% | |
| Cash | 1.78% | |

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 2021 (continued)

| | 2021 £ | 2020 £ |
|---|----------------|----------------|
| 10. Debtors | | |
| Amounts due from INPDA (note 18) | 450 | 2,109 |
| Amounts due from INPDR (note 18) | 651 | 1,359 |
| Other debtors | 906 | 1,350 |
| | <u>2,007</u> | <u>4,818</u> |
| 11. Creditors: amounts falling due within one year | | |
| Other tax & social security | 2,420 | 2,486 |
| Accruals and deferred income | 7,090 | 15,275 |
| Accruals for grants payable | - | 19,142 |
| | <u>9,510</u> | <u>36,903</u> |
| 12. Employee information | No | No |
| The average monthly number of employees was: | <u>5</u> | <u>6</u> |
| | £ | £ |
| Staff Costs | | |
| Salaries | 140,711 | 153,817 |
| Social security costs | 13,293 | 10,734 |
| Pension costs | 2,779 | 2,956 |
| | <u>156,783</u> | <u>167,507</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 and the finance and administration officer.

Their total employee benefits were £76,720. (2020 £74,640)

During the year, and after ten years of dedicated service, our Senior Families Advocate completed her phased retirement at the end of June 2020. A replacement Families Officer, recruited in October 2019, was adversely affected by the impact of the pandemic and left the charity at the end of December 2020. With the conclusion of our Big Lottery Project, and following due process, the Project Team leader re-joined the charity in January 2021 in the role of Families Officer. In addition, our Big Lottery Project Families Officer, having completed a formal training programme, transitioned to the role of Counselling and Well-being Officer at the beginning of February 2021.

Continuation of our support services was maintained throughout this period and additional capacity was provided by the ongoing specialist support of our retired Senior Family Advocate.

We extend our sincere thanks to our outgoing employees and wish them every success in their future careers.

13. Operating Leases

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

| | 2021 £ | 2020 £ |
|--------------------|--------------|--------------|
| <i>Expiry date</i> | | |
| Within one year | <u>3,240</u> | <u>3,240</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 £2,779 (2020: £2,956).

Note to the Financial Statements
For the Year ended 30 April 2021 (continued)

15. Statement of Funds

| | Balance 30/4/2020 £ | Income £ | Expenditure £ | Transfer £ | Gains / (Losses) £ | Balance 30/4/2021 £ |
|---------------------------------|---------------------------|----------------|------------------|---------------|--------------------------|---------------------------|
| 2020-2021 | | | | | | |
| General fund | 150,939 | 160,944 | 146,030 | 33,824 | - | 199,677 |
| Designated fund | 107,000 | - | - | (33,824) | - | 73,176 |
| Total unrestricted funds | 257,939 | 160,944 | 146,030 | - | - | 272,853 |
| Endowment fund | 204,631 | - | - | - | 22,859 | 227,490 |
| Restricted funds | | | | | | |
| Big Lottery Fund | 1,178 | 78,220 | 73,578 | - | - | 5,820 |
| Big Lottery Fund | - | 46,639 | 46,639 | - | - | - |
| BBC Children in Need | - | 18,840 | 18,840 | - | - | - |
| BBC Children in Need | - | 14,428 | 14,428 | - | - | - |
| Pears Foundation | - | 14,534 | 14,534 | - | - | - |
| Stewardship Fund | - | 3,000 | 3,000 | - | - | - |
| Hollie Foundation | - | 10,813 | 10,813 | - | - | - |
| Hollie Foundation | - | 2,500 | 2,500 | - | - | - |
| Hollie Foundation | 1,230 | - | 1,230 | - | - | - |
| Lesley Carlton Jones | - | 1,000 | - | - | - | 1,000 |
| Total restricted funds | 2,408 | 189,974 | 185,562 | - | - | 6,820 |
| Total funds | 464,978 | 350,918 | 331,592 | - | 22,859 | 507,163 |

| | Balance 30/4/2019 £ | Income £ | Expenditure £ | Transfer £ | Gains / (Losses) £ | Balance 30/4/2020 £ |
|---------------------------------|---------------------------|----------------|------------------|---------------|--------------------------|---------------------------|
| 2019-2020 | | | | | | |
| General fund | 37,507 | 354,286 | 251,054 | 10,200 | - | 150,939 |
| Designated fund | 117,200 | - | - | (10,200) | - | 107,000 |
| Total unrestricted funds | 154,707 | 354,286 | 251,054 | - | - | 257,939 |
| Endowment fund | 220,000 | - | - | - | (15,369) | 204,631 |
| Restricted funds | | | | | | |
| 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 | - | - | - |
| Total restricted funds | 16,452 | 142,660 | 156,704 | - | - | 2,408 |
| Total funds | 391,159 | 496,946 | 407,758 | - | (15,369) | 464,978 |

Note to the Financial Statements
For the Year ended 30 April 2021 (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 Trustees Annual Report on page 5.

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 |
| Big Lottery Fund | Covid-19 funding for salary costs, counselling & family support |
| BBC Children in Need | Funding towards the post of Clinical Nurse Specialist |
| BBC Children in Need | Covid-19 funding for care and support team salary costs |
| Pears Foundation | Covid-19 funding for salary costs, overheads & family support |
| Hope for Hollie | Research |
| 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 | NPUK Covid-19 Support Fund |
| 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 £ |
|------------------------------------|----------------------------|--------------------------|-------------------------|---------------------|
| 2021 | | | | |
| Fixed asset investments | - | - | 227,490 | 227,490 |
| Current assets | 282,363 | 6,820 | - | 289,183 |
| Current liabilities | (9,510) | - | - | (9,510) |
| Net assets at 30 April 2021 | 272,853 | 6,820 | 227,490 | 507,163 |
| | | | | |
| | Unrestricted Funds £ | Restricted Funds £ | Endowment Funds £ | Total Funds £ |
| 2020 | | | | |
| Fixed asset investments | - | - | 204,631 | 204,631 |
| Current assets | 294,842 | 2,408 | - | 297,250 |
| Current liabilities | (36,903) | - | - | (36,903) |
| Net assets at 30 April 2020 | 257,939 | 2,408 | 204,631 | 464,978 |

Note to the Financial Statements
For the Year ended 30 April 2021 (continued)

17. Trustees

No remuneration was paid to Trustees during the financial period. During the year no trustees (2020: six) were reimbursed travel and administration expenses in pursuit of charitable objectives and this amounted to £Nil (2020: £2,412).

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:

| | 2021 | 2020 |
|---------------------------|-------------|-------------|
| | £ | £ |
| With INPDA | | |
| Wages | 4,548 | 6,228 |
| Other costs | 132 | 8,831 |
| Sum due to NPUK (note 10) | 450 | 2,109 |
| With INPDR | | |
| Wages | 5,381 | 2,598 |
| Other costs | 168 | 6,128 |
| Sum due to NPUK (note 10) | 651 | 1,359 |