



**NIEMANN-PICK UK**  
**Company number 07775835**

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

**REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 APRIL 2022**

NPUK is a charitable organisation dedicated to making a positive difference to the lives of those affected by Niemann-Pick diseases. We raise much needed awareness, provide practical and emotional support, advice and information and facilitate research into potential therapies.

Families using our care and support services report feeling less anxious and isolated, better able to cope with the day to day challenges of caring for a loved one, improved emotional resilience and better physical and mental wellbeing.

We rely entirely on voluntary donations, charitable grants and fundraising to support our work with those affected by Niemann-Pick diseases, their families and the health professionals caring for them.

**Reference & Administrative Details  
For the Year ended 30 April 2022**

<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 (resigned 30 June 2022) Dr David Holton Jacqueline Imrie Joella Melville Fiona Dunne
<i>Chief Executive:</i>	Toni Mathieson
<i>Co-opted Members:</i>	Prof Frances Platt Claire Fyvie
<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 2022**

The trustees present their annual report and financial statements of the charity for the year ended 30 April 2022. 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 we provide clinical, non-clinical and emotional support as appropriate to meet the needs of those we support.

Our Central Office, located in Washington, Tyne and Wear, is the management hub for all NPUK activities including collaboration and partnership working. We provide support and information regarding all aspects of Niemann-Pick disease via our website, a 24-hour help line, educational literature, regular newsletters, e-bulletins and social networking platforms.

Our Communications and Campaigns Manager produces educational film material and maintains our social networking platforms and website which provide up to date information on all aspects of Niemann-Pick diseases, plus practical advice for daily living and the latest developments in research. Extra support sections were added to help families navigate and cope with the ever-changing COVID updates and requirements for shielding.

Our Clinical Nurse Specialist provides expert care and practical advice, liaises with healthcare professionals, schools and social services and provides information about the disease, develops healthcare plans, advocates on behalf of families and supports them with the transition from child to adult services.

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

Our Counselling and Wellbeing Officer provides a counselling service for all adults and develops programmes to improve mental health and wellbeing.

Our Fundraising Officer provides guidance, support and resources for all those who wish to raise funds on our behalf, nurtures relationships with donors and supporters and explores new income streams through corporate and community giving programmes.

Our Chief Executive provides leadership and is responsible for the day to day management of the Charity in line with the objectives and the strategic plan approved by the Board of Trustees. At a strategic level, our Chief Executive is a member the Clinical Reference Group for specialist inherited metabolic disorders and, as active members of the Specialised Healthcare Alliance and Rare Disease UK we continue to raise the profile of rare diseases across the UK, influence policies relating to specialised services and provide a voice to increase awareness and bring about lasting change for families and patients affected by rare diseases. In addition, the Chief Executive collaborates and plays a key role with the International Niemann-Pick Disease Alliance, (INPDA), the International Niemann-Pick Disease Registry (INPDR) and the Lysosomal Disorder Patient Collaborative. (LSD Collaborative)

## **Trustees Annual Report For the Year ended 30 April 2022**

### **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 our registered volunteers (15) for their support in getting us through COVID and for their continuing support at social events. Without this support, we would not have been able to return to our much loved face to face activities and social events.

### **Impact of COVID-19 and a return to normal activities.**

Whilst throughout this year we saw a gradual easing of COVID restrictions, there remained an increased demand for our support services due to the NHS and Statutory Services struggling to return to normal service.

COVID demonstrated the value and benefits of using digital technology to provide expert advice, health care and virtual support for our rare disease community. Our staff, therefore, retained the best of these virtual methods of communication whilst gradually taking the opportunity to meet face to face with patients and their families. This ensured that we stayed connected with families so that we could maintain relationships, reduce isolation and help increase the self-confidence and emotional resilience of the families we support.

### **Achievements and Performance.**

#### **Governance.**

Trustees and members of staff held strategic discussions to deal with the outputs from the risk assessment process and the challenges we face in the future. To progress the actions arising from these discussions, a Strategic Review Meeting has been planned and will be facilitated by Moore Kingston Smith, a Non-profit advisory team of experts providing key services for impact, fundraising, financial sustainability and strategic planning.

#### **Care and Support.**

*"Few people understand the heartbreak and heartache of being diagnosed with a rare condition. The NPUK team have made a huge difference to how we cope with this condition".*

NPUK care and support staff work together to offer a high quality and holistic service to all the families affected by Niemann-Pick diseases. Throughout the partial return to normal service we have kept the adapted COVID procedures and video conference calls and, alongside them, we have introduced a gradual return to face to face visits with families, health professionals and the wider Niemann-Pick community.

Our Clinical Nurse Specialist service has been vital in providing urgent support and medication for newly diagnosed patients, affected children and adults and working with families and healthcare providers has helped those in need to restore mobility and cognitive ability. She has worked with schools and parents to help children prepare for a return to school and has provided information sessions for teaching staff and explained how to alleviate any anxiety in children returning to school following COVID.

Our Families Officer continued to host our regular interactive family events and was able to organise four outdoor face to face family events where families could reunite with old friends and reconnect with the NPUK team, swapping stories, sharing news and rebuilding hope for the future. We were also able to organise a Christmas Party with a visit from Father Christmas weighed down with presents for the children. These activities, with the help and support of volunteers, helped to reduce stress and isolation and helped families to take part in a more normal way of life. She was able to provide help from the NPUK support fund to alleviate financial distress and helped to reduce anxiety and improve wellbeing by helping families secure statutory entitlements for social benefits, housing, education and employment.

Our newly transitioned Counselling and Wellbeing Officer engaged with ethnic minority organisations and disadvantaged families within the Niemann-Pick community helping to maintain contact and providing tailored support for families who would not normally access our services. In addition, this new service enabled individual counselling for those in need to improve their mental health and provided programmes to improve resilience and wellbeing. This person-centred, holistic approach enables families to thrive by addressing a range of issues including personal, emotional and psychological problems as well as health and relationship problems.

## Trustees Annual Report For the Year ended 30 April 2022

### Communications and Information.

*"NPUK is a massive community network which means I don't feel isolated and always get up to date information. To have this connectivity is something I feel really passionate about"*

Our website, online and social media platforms have seen an increase in activity and have enabled families to maintain contact and have reduced the feeling of isolation and boosted wellbeing during the gradual return to normal activities. The virtual support groups continue to provide much needed Zoom meetings and the opportunity to become more independent through discussion and the use of emotional resilience tools.

Our monthly newsletter keeps all of our members up to date with what's going on in the community and provides updates on our support services and fundraising.

We have initiated a number of family surveys to gain feedback and ensure that the services we provide are best suited to the needs of the community and, in addition, have commissioned a study to collect "Quality of Life" data in support of clinical trials and other related studies.

Our Communications and Campaigns Manager, in spite of lockdowns, was able to write and direct our latest short animated film "Invisible Manners." This raises awareness of both Niemann-Pick type B (ASMD NPB, Niemann-Pick type C (NPC) and other invisible diseases that are too often misunderstood by the outside world. With a limited budget the film was developed by a renowned animator and featured a narrative by renowned actors plus members and friends of the NPUK community.

NPUK joined a group of advocates aiming to highlight the unseen impact of the pandemic on people living with rare conditions. This group became known as Action for Rare Disease Empowerment (ARDEnt)

Planning for our 2021 Family Conference and Interactive workshop was influenced by the government guidance, uncertainty around vaccination rates, levels of immunity and rules covering the indoor hospitality industry. It was therefore decided to cancel the event for this year but with a renewed commitment to hold a full Family Conference and Interactive Workshop in October 2022. We look forward to welcoming our families and speakers from around the world and provide the opportunity to socialise and hear about the latest developments in clinical trials, research and therapeutic studies.

### Collaboration.

*"We share similarities with other rare disease charities and are stronger by working together than apart"*

Building on our strong relationship with the UK LSD Collaborative we have taken part in many high-level virtual meetings with national rare disease groups and national representative bodies to influence national policy for the benefit of all those affected by Niemann-Pick diseases. However, at a time of increasing financial burden on all patient organisations, the Trustees supported a proposal that the "Collaborative" should scope the possibility of becoming a charitable organisation. This would enable the member organisations to consider how they may collaborate even more closely, to raise funds, reduce costs, increase capacity and protect our patients and their support networks. It is stressed that each member charity would retain their own unique identity.

We continued to support the International Niemann-Pick Disease Alliance (INPDA) in all of its activities and we have 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. Both the INPDA and the INPDR are independent charitable companies with NPUK representatives appointed as Board Members.

### Research.

*"Research helps us to understand more about the disease and gives us hope for the future"*

Throughout the year we have continued to maintain a presence in the field of research and have hosted our first hybrid NPUK Oxford NPC Research Forum. This was held at the Department of Pharmacology, University of Oxford and the outcome was a set of agreed actions that will influence future research and the development of therapies for Niemann-Pick diseases. It will also inform the NPUK Research Strategy and create the context for the 2022 Interactive Workshop for clinicians, health professionals and scientists working in the field of Niemann-Pick diseases.

Newborn Screening (NBS) creates the possibility of diagnosing Niemann-Pick diseases, as early as possible and before the baby shows signs and symptoms of the disease. This year we have strengthened our commitment to

## Trustees Annual Report For the Year ended 30 April 2022

### Research (Continued)

NBS by becoming founding members of the "Newborn Screening Collaborative" which represents 13 principal rare disease patient organisations plus Genetic Alliance UK. This collaborative will work to bring positive change that enables the NBS service to keep pace with the rapid developments in science, technology and Whole Genome Sequencing.

We continue to collaborate with pharmaceutical companies and biotechnology companies involved in clinical trials and the development of therapies for Niemann-Pick diseases and continue to maintain an active role in the communication process, giving emotional and practical support to participating families, as appropriate.

### Fundraising

*"Fundraising is our lifeblood and ensures continuity of the services we provide"*

NPUK abides by the fundraising principles set out in the "Code of Fundraising Practice" and this year we have recruited a part time Fundraising Officer to nurture and support our fundraisers by providing advice, publicity and merchandise. The Fundraising Officer also connects with our donors, as appropriate, to keep them up to date with the work we are doing and how they can help.

Fundraisers have walked, ran, swam, biked, skydived, golfed, held disco's, school events and set up funding pages in lieu of birthdays, anniversaries and in memory of their loved ones. Rotary Clubs and local businesses have given their support to family appeals and made space for collection boxes. We owe each and every one of our amazing fundraisers a huge debt of gratitude for all they have achieved...thank you.

Regular donors have maintained their level of support and have provided a stable level of funding that has contributed to maintaining the services we provide. Again, we thank every one of them for their generosity.

### Impact

Throughout the pandemic, the whole NPUK team worked hard to maintain and develop strong and positive relationships with those affected, their families, carers and the healthcare teams who support them. This work has continued during the year with many families struggling with the challenges of returning to normal and a reduction in the essential statutory services. Over the period May 2021 to April 2022, 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, coming to terms with diagnosis, felt less isolated, more informed about Niemann-Pick disease and felt more confident about facing the future and the challenges of caring for their affected loved one.
- Families, who were not able to see a doctor or clinician, were able to discuss the need for urgent clinical support and medication with our Clinical Nurse Specialist and, felt less anxiety and better able to cope with day to day life.
- Families suffering financial hardship report feeling less anxious as a result of interventions and support from our Families Officer.
- Family members who accessed our counselling and wellbeing support service developed more confidence and reported improved emotional resilience and mental wellbeing.
- Families and children have improved their physical and mental wellbeing through access to craft materials, educational and outdoor play equipment.
- Family relationships have been improved through positive communication and support from our Care and Support team, virtual engagement programmes and mutual support via social media.
- 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 shown improved cognitive skills through access to iPads and participation in virtual social and community events
- Families who have lost a loved one have felt better able to cope with day-to-day life through counselling and contact with the NPUK Reflections programme.

## Trustees Annual Report For the Year ended 30 April 2022

### Risk Management.

The directors have a risk management strategy, which comprises:

- An annual risk assessment and 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 materialise.

### Principal Risks.

The principal risks for the foreseeable future relate to;

- Increased competition for a reducing number of long-term grant funding opportunities.
- An increasing tendency for new grants to be rooted in local communities.
- Further economic and social pressures which will adversely affect voluntary income.
- Lack of capacity to increase the rate of grant applications and income streams.
- A strong dependence on key members of staff with no spare capacity to provide cover and a Succession Planning strategy for staff and Trustees with no pool of resources to draw on.

### The actions we are taking to address these risks are;

- Having budgets and forecasts in place to give an early warning of action required.
- Seeking ways to reduce costs by sharing resources.
- Strengthening our Succession Planning Strategy to determine our emerging requirements over the next three to five years and putting plans in place to meet these needs
- Developing the role of Fundraising Officer to further 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 awareness and social media campaigns and by promoting digital fundraising events.
- Examining ways to fund the role of a Grants Officer who will research grant opportunities and to prepare and submit applications for grant funding.

### Financial Review.

*"We are hugely grateful to our families, friends and supporters who returned to fundraising and those who are able to continue making voluntary donations".*

### Income

Income for the period May 2021 to April 2022 was £416,403 against £350,918 for the previous year. This was an increase of £65,485 and was only made possible by additional income received from unplanned COVID grants (£119,417) and a windfall fundraising event in April 2022 (£53,000). Without these unplanned sources of income, our underlying annual income would have been £246,986 against a budget of £277,394.

In more detail, variations against budget were as follows;

- External factors affecting pharmaceutical companies resulted in an adverse variance of £55,000 in unrestricted educational grant funding and two unsuccessful grant applications resulted in a further adverse variance of £19,349.

However, these losses were made up by;

- Donations and fundraising events which were £88,049 better than budget and unplanned successful grant funding of £119,417.

During the year we were extremely fortunate to provide safe services to the families we support but could not have done so without the continuing support of our grant funding organisations; BBC Children in Need for the follow on grant funding towards the Clinical Nurse Specialist (£20,490) and the Hollie Foundation for their contributions towards our Families Officer and children's Christmas party (£11,062).

**Trustees Annual Report  
For the Year ended 30 April 2022**

***Income (Continued)***

In addition, we were extremely fortunate to receive a main grant from Charities Aid Foundation to support the services we provide (£109,417), a COVID resilience grant to develop a resilient and sustainable organisation (£10,000), and an additional grant to improve digital communications for our community (£10,000). We also received a grant from the National Lottery Community Fund (£9,827) to improve the mental health of children and families and a grant from the Department for Digital, Culture, Media and Sport and managed by the Pears Foundation, towards our Counselling and Wellbeing Officer (£9,800). Without these grants, we would not have been able to provide the required level of services to support our vulnerable and struggling community.

***Expenditure.***

Expenditure for the year was £337,827 against a budget of £393,394 and a total of £331,592 for the previous year. In more detail, variations from the budget were attributed to;

- The cost of fundraising activities (£11,754) represented 3.47% of total expenditure and was in line with the budget (£11,818). However, this was £3,903 more than the previous year due to the recruitment of a part time fundraising officer. This will increase further in 2022/2023 as we acknowledge the need for greater capacity to generate income.
- The cost of Information and Communication was £18,641 less than the budget of £57,499. This was achieved by small increases in budget being offset by sharing wage costs with third parties, (£3,330), reduced printing and circulation costs of the newsletters by publishing just one edition, (£7,335), a delay to completing a sequel to the short film, "Invisible Manners", (£6,482) and an underspend on equipment (£2,000).
- Lower than forecast costs of Regional events resulted a saving of £7,769 against budget (£15,000)
- Research project costs (£41,074) were £24,092 less than budget (£65,166). This was due to a delayed return to normal working by university laboratories (£15,000) and a project extension to gathering patient evidence in support of drug efficacy (£9,092). These reductions in expenditure were partly offset by non-forecast expenditure of £7,244 to fund the Oxford NPC Forum (£5,372) and attendance at the Ara Parseghian Medical Research conference (£1,872)
- The NPUK Support Fund (£10,000) was underspent by £8,110 and this gives NPUK the confidence to maintain the budget for 2022/2023 when demand is likely to increase.

***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 will 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).

The reserves policy for the financial year, May 2021 to April 2022, takes into account;

- The risks associated with the charity's financial strategy and a financial forecast which shows insufficient income to support our planned expenditure for 2022/2023.
- A three year financial forecast and cash flow forecast which takes into account the potential risks to income and the need to fund our succession planning strategy



**Trustees Annual Report  
For the Year ended 30 April 2022****Reserves Policy (Continued)**

- The need to address a reduction in pharmaceutical support and a forecast reduction in grant awards from Grant Giving Organizations.

**Level of Reserves.**

The Trustees have reviewed the Reserves Policy and have taken into account the key objectives and commitments for 2022/2023. They have considered the plans for future periods, the risks associated with a forecast downward trend in income generation and the outcomes from a three-year cash flow forecast.

The objectives of the reserves policy for the financial year 2022/2023 are therefore;

- To fund an approved shortfall in forecast income over expenditure (£92,121).
- To hold sufficient funds (6 weeks) to manage salaries and cash flow for the day to day operation of the Charity. (£52,925).
- To hold sufficient funds to recruit a part time Grant Applications Officer towards the second half of 2022/2023 (£18,000)
- To hold sufficient funds to cover a three month charge, for the Clinical Nurse Specialist, by the Salford Royal Foundation Trust in conformance with the SRFT agreed contract. (£19,347)
- To hold statutory funds in line with the Charity Commissioners' guidance "Charity Reserves; Building Resilience" £22,334)

The total required reserves are therefore £204,727 which is equivalent to 5 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 year PhD Studentship Agreement with Aston University; 2 years remaining (£24,332)

The total designated funds are therefore £24,332 which is equivalent to 0.64 months of planned expenditure.

The total unrestricted funds required for 2022/2023 are therefore £229,059. The unrestricted fund at the end of April was £265,692. The balance of unrestricted funds (£36,633) will be used in pursuit of our objectives and any surplus at the end of the financial year will go towards the budget for 2023/2024.

**Endowment**

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

The opening balance at 30 April 2021 was £227,490 and, following worldwide financial turmoil, the value at 30 April 2022 stands at £218,333. The Trustees have reviewed the endowment and reconfirmed the objective that we should aim to preserve the capital whilst generating a regular income. A diversified portfolio with low to medium risk investments was still considered appropriate and Investec Wealth & Investment was reconfirmed as the Fund Manager.

The income from investment for 2021/2022 was £4,477 (£4,041 for 2020/2021) and this represents a nominal of 2.05% return on investment. This is short of the target 2.5% minimum return but is consistent with prevailing financial uncertainties.

The Endowment can be used to assist in financing of the family care and support service provided to families affected by Niemann-Pick diseases and Trustees have the discretionary power to transfer funds should it become necessary to do so

If, at any time, the Charity is 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 is monitored by the Trustees on an annual basis.

**Trustees Annual Report  
For the Year ended 30 April 2022**

**Plans for Future Periods.**

- We will review outcomes from the Strategic Review meeting and develop action plans to create a resilient and more robust, financially sustainable charity.
- We will review our care and support service to ensure we meet the developing needs of families who have learning, behavioural and mental health issues related to lockdown, shielding and disease progression.
- We will increase and diversify the number of grant applications by recruiting a Grants Officer in line with our Fundraising and Income Generation Strategy.
- We will collaborate with pharmaceutical companies and NICE to gain a positive appraisal for any combination therapies or new drugs arising from clinical trials; Understanding clinical endpoints and completing the project to gather evidence to demonstrate the effectiveness of new drugs will become a key challenge for our community.
- We will formalise our strong relationship with the UK LSD Collaborative by supporting an application for its charitable status and collaborate with 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.
- We will keep up to date with the latest research into Niemann-Pick diseases and our focus over the coming year will be to collaborate with UK research and academic institutions and, if possible, provide small grants in support of relevant projects.
- We will engage with worldwide experts and emerging biotech companies interested in developing new therapies for the treatment of Niemann-Pick diseases, and work alongside other rare disease organisations to improve diagnosis and access to newborn screening.
- We will continue to support the INPDA in all of its activities and continue our key role in supporting the 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.
- At all times we will be aware of the changing needs of our community and will adapt and develop the charity and our services to meet their presenting needs.
- We will focus on addressing any shortfalls in our performance.

**The trustees have considered their financial obligations over the foreseeable future and have no concerns about the charity's ability to continue as a going concern.**

**Trustees Annual Report  
For the Year ended 30 April 2022****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.

Trustees are elected for a period of three years after which they are required to retire. A retiring Trustee may be reappointed for a further term of three years, offering themselves for retirement after each three year term.

*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 six employees, known as the Chief Executive, Finance and Administration Officer, Communications and Campaigns Manager, Counselling and Well-being Officer, Families Officer and Fundraising 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 the 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 Chief Executive, 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 2022**

**Statement of Trustees Responsibilities.**

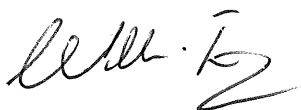
The charity's trustees are responsible for preparing a trustees annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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**

*10 November*  
**2022**

I report on the accounts of the company for the year ended 30 April 2022 which are set out on pages 13 to 22.

### **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.

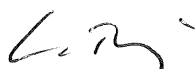
### **Independent examiner's statement**

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

10 November 2022

**Statement of Financial Activities**  
**(Incorporating Income and Expenditure Account)**  
**For the year ended 30 April 2022**

	Notes	Unrestricted Funds £	Restricted Fund £	Endowment Fund £	Total Funds £	2021 £
<b>Income and endowments from:</b>						
Donations and legacies	3	72,315	4,000	-	76,315	142,225
Charitable activities	4	3,120	225,598	-	228,718	185,974
Other trading activities	5	106,893	-	-	106,893	18,678
Investments	6	4,477	-	-	4,477	4,041
<b>Total income</b>		<u>186,805</u>	<u>229,598</u>	<u>-</u>	<u>416,403</u>	<u>350,918</u>
<b>Expenditure on:</b>						
Raising funds		11,754	-	-	11,754	3,935
Charitable activities	7	182,212	143,861	-	326,073	327,657
<b>Total expenditure</b>		<u>193,966</u>	<u>143,861</u>	<u>-</u>	<u>337,827</u>	<u>331,592</u>
<b>Net income / expenditure before losses on investments</b>		(7,161)	85,737	-	78,576	19,326
Net gains / (losses) on investments		-	-	(9,157)	(9,157)	22,859
<b>Net movement in funds</b>		<u>(7,161)</u>	<u>85,737</u>	<u>(9,157)</u>	<u>69,419</u>	<u>42,185</u>
<b>Reconciliation of funds:</b>						
Total funds brought forward		<u>272,853</u>	<u>6,820</u>	<u>227,490</u>	<u>507,163</u>	<u>464,978</u>
<b>Total funds carried forward</b>	15	<u>265,692</u>	<u>92,557</u>	<u>218,333</u>	<u>576,582</u>	<u>507,163</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 2022**

	Notes	2022 £	2021 £
<b>Fixed Assets</b>			
Tangible fixed assets	8	-	-
Investments	9	218,333	227,490
		<u>218,333</u>	<u>227,490</u>
<b>Current Assets</b>			
Debtors	10	5,175	2,007
Bank		373,147	287,176
		<u>378,322</u>	<u>289,183</u>
<b>Creditors</b>			
Amounts falling due within one year	11	20,073	9,510
<b>Net Current Assets</b>		<u>358,249</u>	<u>279,673</u>
<b>Net Assets</b>		<u>576,582</u>	<u>507,163</u>
<b>Funds</b>	15		
General fund		241,360	199,677
Designated fund		24,332	73,176
		<u>265,692</u>	<u>272,853</u>
Unrestricted funds			
Endowment fund		218,333	227,490
Restricted funds		92,557	6,820
		<u>576,582</u>	<u>507,163</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 April 2022.

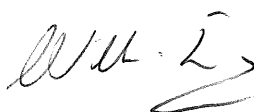
The members have not required the charitable company to obtain audit of its financial statements for the year ended 30 April 2022 in accordance with Section 476 of the Companies Act 2006.

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 13 to 22 were approved by and signed on behalf of the board of directors on 10 November 2022.



W Evans

Trustee



D Holton

Trustee

**Notes to the Financial Statements  
For the Year ended 30 April 2022****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) issued in October 2019 - (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 2022 (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 2022 (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.

	2022 £	2021 £
<b>3. Income from donations &amp; legacies</b>		
<i>General fund - unrestricted</i>		
Conference income and grants	23,295	93,935
Voluntary donations	49,020	44,290
<i>Restricted fund</i>		
Voluntary donations	4,000	4,000
	<u>76,315</u>	<u>142,225</u>

Included above were unrestricted educational grants received from pharmaceutical companies:

Orphazyme - £15,000 - Annual conference

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.

	2022 £	2021 £
<b>4. Income from charitable activities</b>		
<i>General fund - unrestricted</i>		
Kickstart	3,120	-
<i>Restricted fund</i>		
Charities Aid Foundation	129,417	-
National Lottery Community Fund	9,827	-
Big Lottery Fund	-	124,859
BBC Children in Need	20,491	33,268
Hollie Foundation	11,063	13,313
Pears Foundation	9,800	14,534
Orphazyme	45,000	-
	<u>228,718</u>	<u>185,974</u>
<b>5. Income from other trading activities</b>		
<i>General fund - unrestricted</i>		
Fundraising events	106,893	18,678
<b>6. Investment income</b>		
<i>General fund - unrestricted</i>		
Bank interest	49	105
Dividend income	4,428	3,936
	<u>4,477</u>	<u>4,041</u>

**Note to the Financial Statements**  
**For the Year ended 30 April 2022 (continued)**

	2022 £	2021 £
<b>7. Expenditure on charitable activities</b>		
Helpline / family support / travel	129,640	140,703
Information - social media & publications	38,861	55,585
Conference costs	2,690	26,163
Research costs	53,931	12,949
Central office wages	70,358	68,819
Upkeep computer	594	477
Rent & rates	11,086	11,760
Other administration costs	12,420	6,418
Insurance & subscription	2,120	2,101
Bank charges	186	213
Strategic review meeting	1,110	-
Independent examiner's fee	1,800	1,800
Legal fees	-	333
Executive & management meetings	1,277	336
	<u>326,073</u>	<u>327,657</u>
Charged to - <i>General fund - unrestricted</i>	182,212	142,095
- <i>Restricted fund</i>	<u>143,861</u>	<u>185,562</u>

**8. Tangible assets**

	Equipment £
<b>Cost</b>	
At 30 April 2021 and 2022	4,158
<b>Depreciation</b>	
At 30 April 2021 and 2022	4,158
<b>Net Book Value</b>	
At 30 April 2021 and 2022	-

	2022 £	2021 £
<b>9. Fixed asset investments</b>		
Balance brought forward	227,490	204,631
(Impairment) / Increase in value	(9,157)	22,859
	<u>218,333</u>	<u>227,490</u>
Market value at 30 April 2022	218,333	227,490
Historical cost of investments held at 30 April 2022	<u>220,000</u>	<u>220,000</u>
Investments at fair value comprise:	<b>2022</b>	
Fixed interest	33.55%	
Securities	40.15%	
Property	9.49%	
Alternatives	16.60%	
Cash	0.22%	

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 2022 (continued)**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
<b>10. Debtors</b>		
Prepayments	1,340	-
Amounts due from INPDA (note 18)	968	450
Amounts due from INPDR (note 18)	1,749	651
Other debtors	1,118	906
	<u>5,175</u>	<u>2,007</u>
<b>11. Creditors: amounts falling due within one year</b>		
Amounts due to INPDR	1,300	-
Other tax & social security	2,898	2,420
Accruals and deferred income	15,875	7,090
Accruals for grants payable	-	-
	<u>20,073</u>	<u>9,510</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	143,367	140,711
Social security costs	14,713	13,293
Pension costs	3,085	2,779
	<u>161,165</u>	<u>156,783</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 £78,350 (2021: £76,720).

**13. Operating Leases**

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

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
<i>Expiry date</i>		
Within one year	<u>12,300</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 £3,085 (2021: £2,779).

**Note to the Financial Statements**  
**For the Year ended 30 April 2022 (continued)**

**15. Statement of Funds**

	Balance 30/4/2021 £	Income £	Expenditure £	Transfer £	Gains / (Losses) £	Balance 30/4/2022 £
<b>2021-2022</b>						
General fund	199,677	186,805	193,966	48,884	-	241,360
Designated fund	73,176	-	-	(48,844)	-	24,332
<b>Total unrestricted funds</b>	<b>272,853</b>	<b>186,805</b>	<b>193,966</b>	<b>-</b>	<b>-</b>	<b>265,692</b>
<b>Endowment fund</b>	<b>227,490</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>(9,157)</b>	<b>218,333</b>
<b>Restricted funds</b>						
Big Lottery Fund	5,820	-	5,820	-	-	-
National Lottery Community Fund	-	9,827	9,827	-	-	-
BBC Children in Need	-	20,491	20,491	-	-	-
Charities Aid Foundation 1	-	109,417	43,927	-	-	65,490
Charities Aid Foundation 2	-	10,000	1,025	-	-	8,975
Charities Aid Foundation 3	-	10,000	10,000	-	-	-
Pears Foundation	-	9,800	9,800	-	-	-
Stewardship Fund	-	3,000	3,000	-	-	-
Hollie Foundation	-	11,063	11,063	-	-	-
Lesley Carlton Jones	1,000	1,000	-	-	-	2,000
Orphazyme	-	45,000	28,908	-	-	16,092
<b>Total restricted funds</b>	<b>6,820</b>	<b>229,598</b>	<b>143,861</b>	<b>-</b>	<b>-</b>	<b>92,557</b>
<b>Total funds</b>	<b>507,163</b>	<b>416,403</b>	<b>337,827</b>	<b>-</b>	<b>(9,157)</b>	<b>576,582</b>

	Balance 30/4/2020 £	Income £	Expenditure £	Transfer £	Gains / (Losses) £	Balance 30/4/2021 £
<b>2020-2021</b>						
General fund	150,939	160,944	146,030	33,824	-	199,677
Designated fund	107,000	-	-	(33,824)	-	73,176
<b>Total unrestricted funds</b>	<b>257,939</b>	<b>160,944</b>	<b>146,030</b>	<b>-</b>	<b>-</b>	<b>272,853</b>
<b>Endowment fund</b>	<b>204,631</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>22,859</b>	<b>227,490</b>
<b>Restricted funds</b>						
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
<b>Total restricted funds</b>	<b>2,408</b>	<b>189,974</b>	<b>185,562</b>	<b>-</b>	<b>-</b>	<b>6,820</b>
<b>Total funds</b>	<b>464,978</b>	<b>350,918</b>	<b>331,592</b>	<b>-</b>	<b>22,859</b>	<b>507,163</b>

**Note to the Financial Statements**  
**For the Year ended 30 April 2022 (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 8.

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
National Lottery Community Fund	Mental health and wellbeing
Charities Aid Foundation 1	Continuation and development of services
Charities Aid Foundation 2	Strengthening organisation
Charities Aid Foundation 3	Towards core salaries
Pears Foundation	Covid-19 funding for salary costs, overheads & family support
Hope for Hollie	Research
Stewardship fund	Research
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
Orphazyme	Towards the collection of patient evidence to support submissions to regulator in support of drug efficacy

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

	Unrestricted Funds £	Restricted Funds £	Endowment Funds £	Total Funds £
<b>2022</b>				
Fixed asset investments	-	-	218,333	218,333
Current assets	285,766	92,557	-	378,323
Current liabilities	(20,074)	-	-	(20,074)
<b>Net assets at 30 April 2022</b>	<b>265,692</b>	<b>92,557</b>	<b>218,333</b>	<b>576,582</b>
	Unrestricted Funds £	Restricted Funds £	Endowment Funds £	Total Funds £
<b>2021</b>				
Fixed asset investments	-	-	227,490	227,490
Current assets	282,363	6,820	-	289,183
Current liabilities	(9,510)	-	-	(9,510)
<b>Net assets at 30 April 2021</b>	<b>272,853</b>	<b>6,820</b>	<b>227,490</b>	<b>507,163</b>

**Note to the Financial Statements**  
**For the Year ended 30 April 2022 (continued)**

**17. Trustees**

No remuneration was paid to Trustees during the financial period. During the year 3 trustees (2021: None) were reimbursed travel and administration expenses in pursuit of charitable objectives and this amounted to £149 (2021: £Nil).

**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:

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
With INPDA		
Wages	4,113	4,548
Other costs	1,263	132
Reimbursement of research costs received	7,170	-
Sum due to NPUK (note 10)	968	450
With INPDR		
Wages	11,073	5,381
Other costs	3,622	168
Sum due to NPUK	449	651