



NIEMANN-PICK UK

Company number 07775835

Charity registration numbers

1144406 (England & Wales)

SC045407 (Scotland)

REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 APRIL 2023

NPUK (Niemann-Pick UK) is a charitable organisation dedicated to making a positive difference to the lives of those affected by Niemann-Pick diseases their families and the health professionals caring for them. We raise much needed awareness, provide practical and emotional support, advice, information, and facilitate research into potential therapies.

We are the only UK patient group to provide specialist support to those affected by Niemann-Pick diseases and over 32 years, we have developed valuable insights into living with this condition and the challenges it presents.

- Through contact with our care and support team, those affected, and their families report improved emotional resilience and feel better able to cope with the day-to-day challenges of this rare disease.

- Through use of our services, they report better physical and mental wellbeing feeling less anxious and less isolated,

- We rely entirely on voluntary donations, charitable grants and fundraising to support our work with those affected by Niemann-Pick diseases.

At our Annual General Meeting in November 2022, Dr William Evans stood down as Chair. Remaining as a Trustee, we thank him for his leadership, guidance, and support during his six-year tenure. Helen Carter and Joella Melville were appointed as Co-Chairs with the unanimous support of the Board, who look forward to working with them to further our vision, mission, and objectives.

Reference & Administrative Details
For the Year ended 30 April 2023

| | |
|---|---|
| <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> | Helen Carter (Co-Chair) Joella Melville (Co-Chair) Dr William Evans (Resigned as Chair, November 2022) Dave Roberts Janice Brooks Bill Owen Dr David Holton Jacqueline Imrie Fiona Dunne Thomas Kirkegaard |
| <i>Chief Executive:</i> | Toni Mathieson |
| <i>Co-opted Members:</i> | Claire Fyvie Prof. Frances Platt Anthony Mead-Wynne |
| <i>Bankers:</i> | HSBC 33 Town Square, Basildon, Essex SS14 1BA |
| <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 2023.**

The trustees present their annual report and financial statements of the charity for the year ended 30 April 2023. 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,

NPUK is dedicated to making a positive difference to the lives of those affected by Niemann-Pick diseases and their families, from diagnosis to bereavement and beyond. Our vision is a world where the burden of these diseases is minimised, where those affected have access to effective therapies, can meaningfully participate in society, reach their full potential and achieve the best possible quality of life.

We offer clinical, advocacy and emotional support, connecting our community through virtual and in-person events which helps to reduce feelings of isolation and despair. Our strong digital presence, with educational and inspiring content encourages mutual support and improves understanding of these ultra-rare diseases. Our care, support and information services are also used by the health, social and education professionals involved in their care.

We have strong governance, strategic and operational leadership with the needs of the community and their voice at the heart of all we do. Our Trustees bring skills and experience including health care and scientific research, project management, company law and health communications. They have close connections to our community, with six Trustees having first-hand experience of the impact of diagnosis and living with the disease on daily basis.

Our office base located in Washington, Tyne and Wear, is the central hub for of our activities, including collaboration and partnership working. From here, we develop and share supportive information on all aspects of Niemann-Pick diseases, via our website, a 24-hour help line, educational resources, regular newsletters, e-bulletins and social networking platforms.

Our Communications Manager coordinates our online presence and community engagement by developing informative resources for patients, family members, and the broader public. This content includes but is not limited to; producing short films and videos, digital content, engaging our community through our website, social networking platforms and magazines/e-newsletters which provide current disease-specific information, plus practical advice for daily living and the latest developments in research. Special focus is given to including true community participation and representation in the development of our content and campaigns. This ensures we truly reflect their experience and that we fully understand and can meet their changing needs.

Our Clinical Nurse Specialist provides expert clinical care and practical advice, helping families to manage complex symptoms and disease progression and advocating on their behalf with health professionals, schools, and social services. Her experience and exceptional expertise in Niemann-Pick diseases enables her to recognise complex and changing individual support needs, pre-empting crisis points and providing appropriate advice and measures to improve quality of life and experiences for all. She helps families to navigate health services, including the transition from child to adult services, and supports them in making informed decisions about treatment and care.

Our Families Officer provides non-clinical advice, and emotional support, advocating for patients' needs and ensuring they receive appropriate support to fulfil their potential. Her individual advocacy service includes assistance and support at home, school or in clinic, help in exploring statutory rights and entitlements covering benefits, housing, education, and employment.

Our Counselling and Wellbeing Officer is dedicated to providing mental health and emotional support to our community, offering tailored and inclusive support to build resilience and empower patients and families. His experience and support help our community to cope with the emotional aspects of living with a rare disease, including the challenges of bereavement.

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

Our Objectives and Activities (Continued)

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 plans approved by the Board of Trustees. At a strategic level, our Chief Executive is a member the Clinical Reference Group for 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, using our voice to influence policies relating to specialised services and increase awareness that will bring lasting change for those affected by rare diseases. In addition, our Chief Executive plays a key role within the International Niemann-Pick Disease Alliance (INPDA), the International Niemann-Pick Disease Registry (INPDR) and the UK Lysosomal Disorder Patient Collaborative (LSD Collaborative).

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 continuing and long-term support at community events. Their support is pivotal to the success of our events and meetings, and we would not be able to effectively achieve our objectives without their valued contribution.

Return to normal activities.

Whilst throughout this year we saw the end of COVID restrictions, there remained an increased demand for the services we provide due to the slow return of NHS and Statutory services, and the reduction in local community-based support services.

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 team, therefore, has retained use of the most effective methods of virtual communication whilst gradually taking the opportunity to return to in-person meetings and activities with patients and their families. This ensured that we stayed connected with our community, that we maintained strong relationships and were able to reduce isolation, increase self-confidence and improve emotional resilience.

Achievements and Performance.**Care and Support.**

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

This year has seen a huge increase in the demand for our services as the NHS, social care and voluntary sector struggled to get back to pre-covid working. Increasingly, families and siblings are having to fill the gaps left by a shortage of social care, and social workers and newly diagnosed families and those experiencing the distress of disease progression are finding it more difficult to access necessary health services.

Our care and support team work together to offer a high quality and holistic support service to all those affected by Niemann-Pick diseases. Our return to normal service has enabled, face to face visits with families, health and social care professionals and the wider Niemann-Pick community. This has helped families to access support from local health and statutory services and to reduce anxiety and stress.

- Our Clinical Nurse Specialist has been vital in providing individualised patient-centred care and has provided urgent support and medication for newly diagnosed patients, affected children and adults. Bringing together and working with families, clinicians and healthcare providers has helped families access vital support for those most in need. This has helped to support and maintain patients' mobility, cognitive function, and physical and mental wellbeing. Working with schools and parents the Clinical Nurse Specialist has also provided information sessions for teaching staff and guidance on how to manage ongoing anxiety in children returning to school following COVID.

- The work of our Families Officer has a huge impact on the emotional wellbeing of patients and families. In an increasingly difficult economic environment, she has assisted patients and families in securing much-needed financial assistance, statutory benefits, and grant support. In so doing, she has helped to reduce anxiety and distress and has improved family relationships. Advocating for access to Special Educational Needs and Disabilities support, Education Health and Care Plans and home adaptations provided essential support to those finding it difficult to navigate these processes and ensured they achieved the desired outcome. Providing ongoing emotional support to newly diagnosed families and bereaved families also formed an essential part of her role.

Trustees Annual Report**For the Year ended 30 April 2023****Care and Support (Continued)**

- Our Counselling and Wellbeing Officer has helped to improve our engagement with BAME communities and to develop a support system for the male members of our community. A primary focus throughout this year has been the provision of counselling and therapeutic support for adults helping to improve resilience and mental wellbeing, through a person-centred, holistic approach which enables families to thrive by addressing a range of issues including personal, emotional and psychological problems as well as health and relationship problems. Although this service has brought many benefits for our community, in particular during the COVID pandemic, take up has declined throughout the year and following review, we have agreed that this service will be provided as a contractual part time consultancy role. We will monitor the benefits of this new arrangement and adjust the level of support as appropriate.

Friendship and mutual support.

'It's a great feeling to just be yourself amongst friends who know what you're going through and be able to share stories, benefit from each other's experiences and spend time away from the day to day worries and routines'

Creating the opportunity for families to socialise and share their stories helps enormously when trying to make sense of this devastating disease and also helps to reduce isolation and despair. With the lifting of COVID restrictions we were able to hold a Families' Day at Tatton Park and Farm in June. Children and adult patients, along with their parents, carers, and friends, were all able to share their feelings and experiences, support each other and make new connections. Most importantly, they were able to connect with the NPUK team, relax, have fun, and take a break from their daily routines. Two further, very successful regional meetings were held in Edinburgh, Scotland and Dublin, Ireland.

In October our Annual Family Conference saw 235 attendees meet face to face for the first time since the COVID pandemic. This created another opportunity for families to mix with each other and with researchers, scientists and health professionals who do not, very often, have a chance to meet the patients who benefit from the work that they do. Our programme included a variety of topics, with speakers from all over the world, ranging from research and clinical updates, progress in the development of new therapies, gene therapy and newborn screening through to developing emotional resilience, practical care and support and family voices. Feedback received from those attending this event ensures that the whole Niemann-Pick community has the opportunity to shape our future events. In addition, and adjacent to the main programme, we provided a varied and entertaining activity programme for children and young adults, helping to ensure parents and carers were able to benefit from the presentations and workshops, as well as enjoying social time together.

As usual and prior to the Family Conference, we were able to hold the very popular and successful Interactive Workshop on Niemann-Pick Diseases. This was attended by 78 scientists and healthcare professionals, from around the world, who were able to discuss the latest developments in basic research into Niemann-Pick diseases, the development of therapies and the sharing of information within industry standards.

To round off the Calendar year, 65 members of our community came together for our annual Christmas Party, which is always a highlight for our younger members, offering a chance for them to enjoy games and dancing, party food and, of course, to receive a present from Father Christmas.

These activities, with the help and support of our dedicated volunteers, helped to bring our community closer together, reduce stress and isolation and enabled families to enjoy much-needed time out.

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".

NPUK creates dynamic and engaging content, across all platforms with the aim of raising awareness and increasing the understanding of Niemann-Pick diseases. Our strong connections enable us to partner with our community to create content that they can identify with and that is relevant to them. This includes sharing their lived experience of Niemann-Pick and tips on how to deal with their day-to-day challenges, fundraising news and achievements and the latest research news plus practical help and resources, and interactive support opportunities.

As a result, our community connections are stronger and we see families connect with each other and form friendships that are long-lasting and offer understanding and mutual support.

Facebook continues to lead the way as our most active form of communication and is the most used social media platform by our community. Therefore, we tailor our content to build better engagement and interaction between our team, families, and the general public. This year we also began efforts to enhance our presence on other platforms such as Instagram, LinkedIn and TikTok in order to reach a wider audience. Introducing LinkedIn helps

Trustees Annual Report**For the Year ended 30 April 2023****Communications and Information (Continued)**

to ensure we engage with professionals in Niemann-Pick and wider rare disease field, with relevant clinical and scientific content, alongside expert views from our experienced staff and Board teams.

Our website, www.npuk.org, consistently tracks well on Google Analytics and as such is one of the first sites that those affected by Niemann-Pick find when searching for information. Although we consistently receive good feedback about the website, we realise that with so much content, the navigation and functionality need updating.

We have the intention to start this work during the financial year of 2023/2024 and plan to engage with our community and key stakeholders to ensure any updates suit their needs and offer better functionality and general experience.

Following the release of our multi-award-winning short film *Go Make Memories* in 2019, we have witnessed first-hand the benefits of developing experimental narrative pieces which engage and utilise the patient and community voice. In 2021, *This year, Invisible Manners*, combined illustration with the voices of our community members and well-known names like Billy Boyd, Isy Suttie and Weruche Opia to showcase the many emotions and challenges of living with an “invisible” condition. This short film went on to win Silver in the Charity Film Awards in March 2023. During 2022, we developed accompanying interviews in the form of a short documentary series, called *Invisible Interviews*, giving a true voice to four members of our community and a platform to share their lived experience. These interviews give patients and families the opportunity to tell their own story and we hope the films will encourage people not to make assumptions and consider that we never really know what someone is going through.

As a member of the Newborn Screening Collaborative, our Communications team are helping to coordinate a campaign that will raise awareness of this important with families, advocacy groups, key stakeholders, and the general public.

In order to contend with the increasing workload and the necessity for communications across all of our platforms, the NPUK Board of Trustees approved the employment of a part time Social Media Assistant. Transferring from the government sponsored “Kickstart” scheme, this post will create additional capacity and provide much needed support to the Communications Manager.

Collaboration

“We share similarities with other rare disease charities and are stronger by working together rather than apart”

In late 2022, our Chief Executive who also holds the position of Chair of the UK LSD Collaborative, helped this organisation to complete the process of registration with the Charity Commission for England and Wales. The formalisation of this successful network, which has been in operation for 18 years, will enable us to better utilise our combined resources and to strengthen our collaborative campaign for better healthcare outcomes for the LSD and wider rare disease community. Building on our strong relationship with the UK LSD Collaborative, we have taken part in many high-level meetings with national rare disease groups and representative bodies to influence national policy for the benefit of all those affected by Niemann-Pick diseases. With the UK LSD Collaborative now established as a charitable organisation, we will be able to work more closely with each other to raise funds, reduce costs, increase capacity, and sustain our services for patients and their support networks. Under this arrangement, each member charity retains their own unique voice and identity but benefits from being part of a larger organisation.

We continued to support the International Niemann-Pick Disease Alliance (INPDA) in all of its activities, and we continue to play a key role in supporting 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 look forward to strengthening our commitment by hosting a second NPUK Oxford NPC Research Forum This small, hybrid meeting enabled experts from around the world to discuss current and future research and therapeutic options for our disease area, in a confidential setting. The outcomes from this meeting influence the NPUK Research Strategy and create the context for our annual Interactive Workshop on Niemann-Pick Diseases, an event exclusively for clinicians, health professionals and scientists working in the field.

Trustees Annual Report**For the Year ended 30 April 2023****Research (Continued)**

Newborn Screening (NBS) creates the possibility of diagnosing Niemann-Pick diseases, as early as possible and before a baby shows signs and symptoms of the disease. As a committed member of the "UK Newborn Screening (NBS) Collaborative", which includes representation from 17 rare disease patient organisations plus Genetic Alliance UK, we have worked to influence the UK Rare Disease Framework commitment to Priority 1: 'helping patients get a final diagnosis faster', with specific regard to Newborn Screening. In addition, as it is felt that the NBS service is failing to keep pace with the rapid developments in science, technology, and Whole Genome Sequencing, we have campaigned for the introduction of three key policy changes to support the appropriate and efficient expansion of the UK NBS programme, asking the National Screening Committee (NSC) to bring about positive change in the way they evaluate new applications. As active members of Genetic Alliance and RDUK forums, we played a part in developing 'The UK Strategy for Rare Diseases' (Published November 2013) and as this latest campaign demonstrates, we continue to use our voice to influence policy through our collaboration with rare disease stakeholders,

We continue to work closely 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 our part-time Fundraising Officer has been working to support and nurture our fundraisers by providing advice, publicity, and fundraising resources. The Fundraising Officer also connects with our donors, as appropriate, keeping them up to date with the work we are doing and how they can help.

Fundraisers have undertaken the most amazing events and activities, running many miles, taking on physical challenges such as Tough Mudder or baking non-stop for coffee mornings. Instead of receiving gifts, they raise funds in lieu of birthdays, anniversaries and in memory of their loved ones. Rotary Clubs, local businesses and the Tesco Blue Token Scheme have given their support to family appeals and made space for collection boxes. In addition, our 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. We owe each and every one of our loyal and generous supporters a huge debt of gratitude for time, achievements, and ongoing support of our work...thank you.

Impact

Whilst all COVID restrictions were removed in February 2022, many in our community struggled with the challenges of returning to "normal" life and activities whilst having to cope with a reduction in the essential statutory services. The whole NPUK team worked hard to develop and maintain strong and positive relationships with our community and the health, social and education teams who work with them. Over the period May 2022 to April 2023, we collected information to show the impact of our work, with some of the key differences experienced by those we support summarised below:

- Community members tell us that continued access to our clinical, practical, emotional, and financial support, makes a significant difference to their lives, with some describing it as a lifeline
- Newly diagnosed patients and their families, coming to terms with diagnosis, felt less isolated, more informed about Niemann-Pick diseases and felt more confident about facing the future and the challenges of caring for their affected loved one.
- Patients, their families, and carers, who were not able to see a doctor or clinician in person due to COVID, felt less anxious and better able to cope after accessing urgent clinical support, medication advice and guidance from our Clinical Nurse Specialist.
- Families experiencing financial hardship reported feeling less anxious as a result of interventions and support from our Families Officer.
- Patients and family members accessing our counselling and wellbeing support service developed more confidence and reported improved emotional resilience and mental wellbeing.
- Families reported an improvement in their relationships and ability to communicate their feelings following interaction with our Care and Support team, virtual engagement programmes and mutual support via our social media platforms.

Trustees Annual Report.**For the Year ended 30 April 2023****Impact (Continued)**

- Loneliness and isolation were also reduced, through contact with our team and other community members attending virtual and in-person meetings.
- 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.
- Affected children and their siblings have benefitted from the support of our Clinical Nurse Specialist and have improved physical and mental wellbeing.
- Patients and their family members have reported improved physical and mental wellbeing through access to craft materials, educational and outdoor play / exercise equipment supplied by our Care and Support team
- Children and young adults affected by Niemann-Pick diseases have maintained fine motor and cognitive skills and participation in virtual social and community events through access to iPads supplied by NPUK.
- Parents, carers, siblings, and extended family members of affected children benefitted from one-to-one support and information helping to improve family wellbeing and quality of life
- Bereaved families and individuals felt supported and better able to cope with day-to-day life through contact with the NPUK Reflections programme and access to counselling.
- Professionals tell us that access to our services helps patients and families to cope with the day-to-day challenges of living with Niemann-Pick diseases, boosting physical and emotional resilience, increasing confidence, and reducing anxiety.

Governance.

Trustees and members of staff held a two-day strategic review in July 2022 to consider our future operational challenges and the outcomes from our annual risk assessment. This review was facilitated by Moore Kingston Smith (MKS), a Non-profit advisory team of experts providing key services for impact, fundraising, financial sustainability and strategic planning.

MKS established that Trustees and Staff had a well-developed level of understanding about our business objectives, strengths, weaknesses, opportunities, and threats and were aligned in our priorities and direction of travel. There was a strong desire to be impact led and to better publicise our outcomes and the wider impact of the services we provide. However, it was identified that we needed to action our succession planning strategy and better measure our impact in order to strengthen our opportunities of securing grants to improve our financial performance and sustain the services we provide.

An in-depth examination of our Business Model highlighted the need to focus more on the generation of income. The cost of fundraising at 4% of expenditure was considered too low to generate sufficient funds to sustain the long-term future of the charity. Further discussion concluded the need to broaden our audience and to recruit a professional fundraiser to focus on diversifying our income streams and increase income from Grant Giving Organisations. In addition, we would restructure third party fees for services provided by the NPUK staff team.

Succession Planning for the post of Chief Executive Officer has long been considered a risk to the future success of the organisation but with the risk assessment increasing from moderate to high, the Trustees agreed to the interim appointment of an Executive Assistant, to give high level support to the CEO, when funds permitted.

Action plans were developed in the key areas of; income generation, collaboration, impact measurement, full cost recovery, broadening our audience appeal, and succession planning. These plans were reviewed at each board meeting and whilst internal actions are generally on track there are concerns around the lack of success in the recruitment of a grant fundraising professional. This matter is now carried forward as a priority for the first quarter of the Financial Year 2023/2024.

Following on from the Strategic Review, an Impact Workshop was held in March 2023. This was facilitated by an experienced consultant who helps charities to grow and develop by understanding and increasing the social impact they create. The workshop explored the principles and process of Impact measurement, the differences we make as a charity and the data we collect as evidence of change. Based on our process for recording staff outputs and outcomes, and building on our impact measurement work already done, it was agreed that we should further develop our existing database to support recording of meaningful impact measures in line with our existing data collection processes.

Trustees Annual Report.**For the Year ended 30 April 2023****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.

Principal Risks.

The principal risks for the foreseeable future relate to:

- A forecast reduction in grant funding income combined with increased competition for a reducing number of long-term grant funding opportunities.
- The lack of capacity to increase the rate of grant applications and income generation.
- Further external economic and social pressures which will adversely affect voluntary income.
- A strong dependence on key members of staff and Trustees 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 perceived lack of a robust process for measuring the impact of the service we provide.

The actions we are taking to address these risks are to:

- Recruit an Executive Assistant to give high level support to the CEO, when funds permit.
- Recruit a Grant and Income Generator.
- Actively recruit two new Trustees and a Treasurer.
- Recover the cost of the services we provide to third party organisations.
- Improve the process for measuring the outcomes of the services we provide.
- Further develop the role of Fundraising Officer and Social Media Assistant to create additional voluntary income from the wider general public through awareness and social media campaigns and by promoting community fundraising events.

Plans for Future Periods.

- We will regularly evaluate progress towards the outcomes agreed at our Strategic Review meeting and complete the related action plans to create a robust, resilient, and financially sustainable charity.
- We will increase and diversify the number of grant applications by recruiting a Grants Income Generator in line with our Fundraising and Income Generation Strategy.
- We recognise that Succession Planning is a key priority, and we will recruit an Executive Assistant to support the CEO when funds become available and will ensure that key posts held by Trustees are covered by planned progression and recruitment.
- We will monitor our Care and Support service to ensure we meet the developing needs of affected children, young adults and adults who have learning, behavioural and mental health challenges.
- 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 produce printed and digital resources to create awareness of Niemann-Pick diseases and their symptoms and will continue to support development of Newborn Screening and other campaigns.
 - We will take notice of need to refresh our website and involve our community in the "need for change" programme.
 - We will keep up to date with the latest research into Niemann-Pick diseases and focus on supporting the UK Newborn Screening Collaborative,
 - We will collaborate with UK research and academic institutions and, if possible, providing small grants in support of relevant projects.
 - We will build on our strong relationship with the UK LSD Collaborative and collaborate with other relevant organisations to improve access to mental health services and influence national policy in those areas that impact the Niemann-Pick and wider LSD patient community.
 - We will collaborate with pharmaceutical companies and NICE to provide evidence in support of appraisal processes for new therapies arising from clinical trials; Working to identify appropriate clinical endpoints and gather evidence that helps to demonstrate the effectiveness of new drugs will become a key challenge for our community.

Trustees Annual Report.**For the Year ended 30 April 2023****Plans for Future Periods (Continued)**

- We will engage and work alongside other rare disease organisations to improve diagnosis and access to newborn screening for rare diseases and actively engage with worldwide experts and emerging biotech companies interested in developing new therapies for the treatment of Niemann-Pick diseases.
- 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.
- We will strive to continually improve and address any shortfalls in our performance that we become aware of.

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.

FINANCIAL REPORT**Context**

2022/2023 was characterised by a return to normal working, an increase in the demand for the services we provide and a return to our face-to-face Family Conference and Interactive Workshop. At the same time, grant funding for small charitable organisations became more competitive with fewer opportunities and a move, by some grant giving organisations, to favour grass root projects in local communities over more distanced nationwide communities.

These changes, when factored into the budget for 2022/2023 resulted in a deficit of £92,121 and Trustees approved a planned draw down in reserves to cover this funding gap. Actions we have taken to improve the Income from Charitable Activities will show significant improvements from the Financial Year 2024/2025 onwards but this means there will be a further need to draw down reserves in 2023/2024. (£105,360)

The following notes for income and expenditure describe the performance against budget and, where relevant, the performance against the previous financial year 2021/2022.

Income

Income for the period May 2022 to April 2023 was £306,594 against a budget of £366,564 (84%). This was £59,970 worse than budget and was a reduction of £109,809 by comparison to the previous year (£416,403).

In a little more detail;

- The ending of COVID related grants combined with fewer successful grant applications resulted in a total grant funding income of £75,215 against a budget of £90,352. (-£15,137) This shortfall was due to the lack of grant funding from the National Lottery Community Fund (-£18,750) and a shortfall in funding by the Hollie Foundation (-£8,000). However, these negative variances were partly offset by a Children in Need Continuation Grant of £31,743 which was £10,914 better than budget.
- Fundraising income (£108,370) remained in line with the previous year (£106,893) but, with the ending of COVID regulations, this fell short of the budget (£130,970). Nevertheless, this was an encouraging result in a difficult economic environment.
- Voluntary donations of £36,432 were in line with the budget (£36,053) but less than the previous year (£49,020). However, this result was helped by an increase in Gift Aid (£14,585) against a budget of £7,760 (+£7,640) and the previous year Gift Aid of £6,744.
- Other negative variances were caused by the lack of any additional pharmaceutical donations (-£15,000) and, unlike previous years, we did not receive any non-specified windfalls (-£50,000)
- Additional benefits against budget were the receipt of conference income and grants totalling £64,993 against a budget of £50,000 (+£14,993) and a slightly improved Investment income of £5,106 against a budget of £4,000 (+£1,106)

We are extremely grateful to our families and friends for their very generous donations and all those who worked so hard to raise funds through fundraising events, the grant giving organisations who make such a valuable contribution to the care and support of our affected patients and their families, to the pharmaceutical companies who made unrestricted educational grants of £44,989 which were used in support the Family Conference, the Charities Aid Foundation for grants totalling £41,472 which were used for the strategic review, collaboration and for strengthening the organisation, to Children in Need for a Continuation Grant (£31,743) which was used to

Trustees Annual Report.**Financial Report (Continued)**

support the wage costs of the Clinical Nurse Specialist and to the Hollie Foundation (£2,000) for a grant which was used to support the Children's Activities at the Family Conference.

Expenditure

Expenditure for the period May 2022 to April 2023 was £440,372 against a budget of £458,685 (-£18,313) and £337,827 for the previous year. The increase on the previous year reflected an increased need for our services and a return to face to face meetings and support.

All expenses were broadly in line with the budget but in more detail, the exceptions above a 5% variance were;

- Total conference costs were £71,562 against a budget of £63,000 (+£8,562). This was due to an overall increase in costs of the conference and interactive workshop (£6,130) and an increase in the cost of travel and expenses for overseas speakers (£2,432)
- Total governance costs were £26,195 against a budget of £18,445 (+£7,750) with the principal variances being an overspend on the strategic review meeting (+£5,274) and trustee, staff and governance meetings (+£1,756)
- Total I.T. costs were £977 against a budget of £600 and reflected an increase in support for the Central Office.
- Research non-project research activities were £8,611 against a budget of £2,000 (+£6,611) due to a non-forecast contribution of £8,611 towards an ASMD paediatric patients study and non-project collaboration costs were £7072 against a budget of £2,500 (+£4,571) arising from a non-forecast LSD mental health workshop (£5,750) which was supported by a CAF grant.

These increases in cost were offset by a reduction on research project costs which were £22,277 against a budget of £32,166 (-£9,899) due to an underspend on research projects.

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 commitments and to maintain 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 2022 to April 2023, 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 2023/2024.
- 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
- A forecast reduction in grant awards from grant giving organisations.

Level of Reserves.

The Trustees have reviewed the Reserves Policy and have taken into account the key objectives and commitments for 2023/2024. 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 2023/2024 are therefore;

- To fund an approved shortfall in forecast income over expenditure (£105,360).
- To hold sufficient funds (6 weeks) to manage salaries and cash flow for the day-to-day operation of the Charity. (£57,641).
- To hold sufficient funds to cover a three month period of notice for the Clinical Nurse Specialist in conformance with the agreed Salford Royal Foundation Trust contract (£16,346).

The total required reserves are therefore £179,347 which is equivalent to 4.31 months of planned expenditure.

Trustees Annual Report.**Financial Report (Continued)****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 2023/24 are;

- Three year PhD Studentship Agreement with Aston University; 12 months remaining (£12,166).

The total designated funds are therefore £12,166 which is equivalent to 0.29 months of planned expenditure.

The total unrestricted funds required for 2023/2024 are therefore £210,305 which is equivalent to 4.6 months of planned expenditure. The unrestricted fund at the end of April was £222,471

Endowment

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

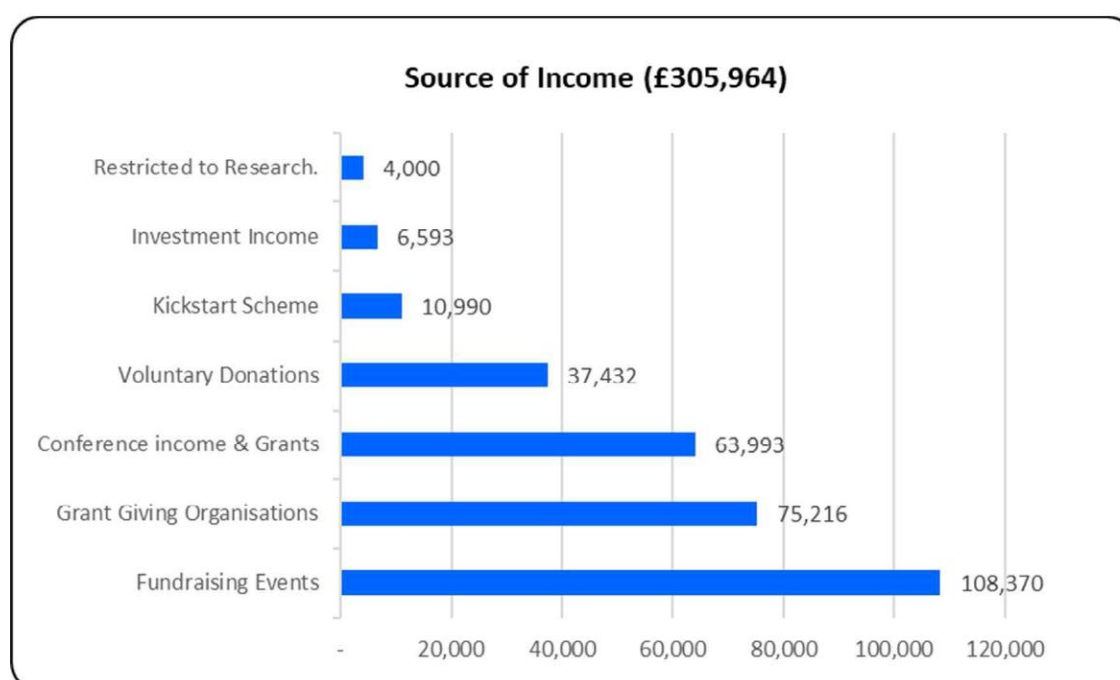
The value at 30 April 2023 stands at £201,993 which was a reduction in value of £16,340 by comparison to the previous year (£218,333). The income from investment for 2021/2022 was £5,106 (£4,428 for 2020/2021) and this represented a nominal of 2.5% return on investment.

The Trustees have reviewed the endowment and confirmed 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 therefore still considered appropriate and Investec Wealth & Investment was reconfirmed as the Fund Manager.

However, the loss of capital, as a result of worldwide financial turmoil, is a concern to the Trustees and whilst the return on investment was consistent with prevailing financial uncertainties, it is felt that other fixed rate investment opportunities may be more secure and would return a better dividend. The Trustees will therefore engage with Investec to explore other possibilities.

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

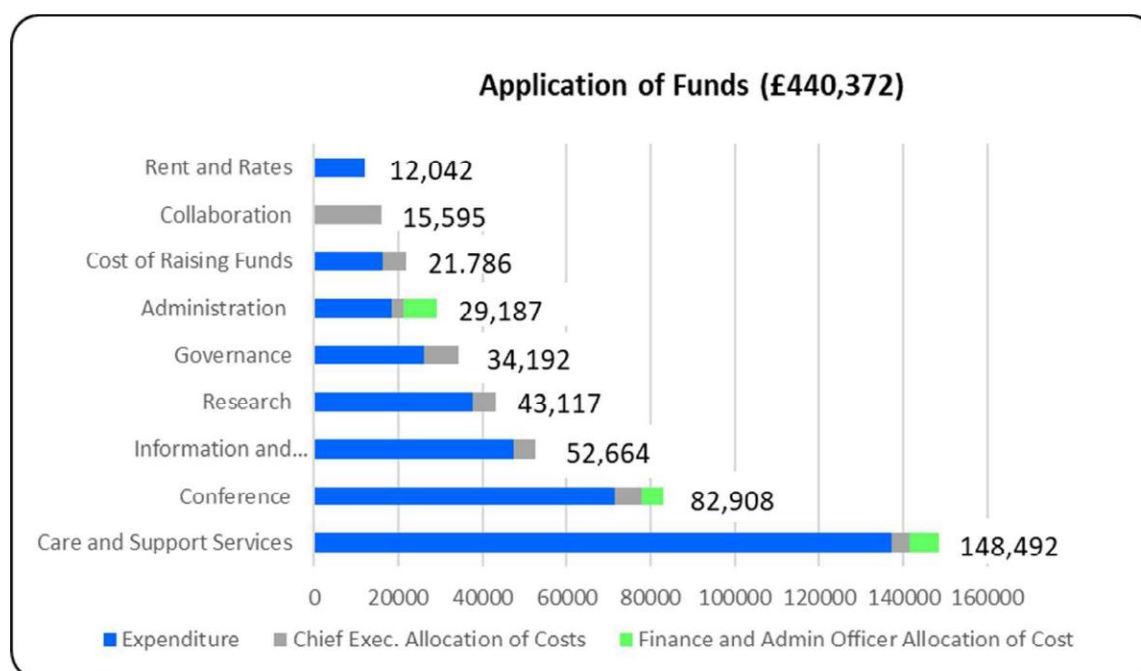
If, at any time, the Charity is forced to close, this Endowment will be used to fund alternative care and support arrangements for affected families during a period of transition to new providers. Any assets remaining will be transferred to another charitable institution in line with the Articles of Association. The endowment is monitored by the Trustees on an annual basis.

Source of Income

Trustees Annual Report.

Financial Report (Continued)

Application of Funds, including reserves

**Sources of Information for charts.**

- The Sources of Income were taken from the Statement of Accounts.
- The Expenditure was taken from the Statement of Accounts.
- The Allocation of costs for the Chief Executive and the Finance and Administration Officer were taken from the Management Accounts and allocated on the basis of "hours spent" on each category.

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.

**Trustees Annual Report
For the Year ended 30 April 2023***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.

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

Helen Carter

H. Carter
Trustee

Joella Melville

J. Melville
Trustee

28 September 2023

28 September 2023

I report on the accounts of the company for the year ended 30 April 2023 which are set out on pages 15 to 24.

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

28 September 2023

Statement of Financial Activities
(Incorporating Income and Expenditure Account)
For the year ended 30 April 2023

| | Notes | Unrestricted Funds £ | Restricted Fund £ | Endowment Fund £ | Total Funds £ | 2022 £ |
|--|-------|----------------------------|-------------------------|------------------------|---------------------|----------------|
| Income and endowments from: | | | | | | |
| Donations and legacies | 3 | 101,425 | 4,000 | - | 105,425 | 76,315 |
| Charitable activities | 4 | 10,991 | 75,215 | - | 86,206 | 228,718 |
| Other trading activities | 5 | 108,370 | - | - | 108,370 | 106,893 |
| Investments | 6 | 6,593 | - | - | 6,593 | 4,477 |
| Total income | | <u>227,379</u> | <u>79,215</u> | <u>-</u> | <u>306,594</u> | <u>416,403</u> |
| Expenditure on: | | | | | | |
| Raising funds | | 16,454 | - | - | 16,454 | 11,754 |
| Charitable activities | 7 | 254,146 | 169,772 | - | 423,918 | 326,073 |
| Total expenditure | | <u>270,600</u> | <u>169,772</u> | <u>-</u> | <u>440,372</u> | <u>337,827</u> |
| Net income / expenditure before losses on investments | | (43,221) | (90,557) | - | (133,778) | 78,576 |
| Net gains / (losses) on investments | | - | - | (16,400) | (16,400) | (9,157) |
| Net movement in funds | | (43,221) | (90,557) | (16,400) | (150,178) | 69,419 |
| Reconciliation of funds: | | | | | | |
| Total funds brought forward | | 265,692 | 92,557 | 218,333 | 576,582 | 507,163 |
| Total funds carried forward | 15 | <u>222,471</u> | <u>2,000</u> | <u>201,933</u> | <u>426,404</u> | <u>576,582</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 2023

| | Notes | 2023 £ | 2022 £ |
|-------------------------------------|-------|----------------|----------------|
| Fixed Assets | | | |
| Tangible fixed assets | 8 | - | - |
| Investments | 9 | 201,933 | 218,333 |
| | | <u>201,933</u> | <u>218,333</u> |
| Current Assets | | | |
| Debtors | 10 | 11,613 | 5,175 |
| Bank & cash | | 227,489 | 373,147 |
| | | <u>239,102</u> | <u>378,322</u> |
| Creditors | | | |
| Amounts falling due within one year | 11 | 14,631 | 20,073 |
| Net Current Assets | | <u>224,471</u> | <u>358,249</u> |
| Net Assets | | <u>426,404</u> | <u>576,582</u> |
| Funds | 15 | | |
| General fund | | 210,305 | 241,360 |
| Designated fund | | 12,166 | 24,332 |
| | | <u>222,471</u> | <u>265,692</u> |
| Unrestricted funds | | 222,471 | 265,692 |
| Endowment fund | | 201,993 | 218,333 |
| Restricted funds | | 2,000 | 92,557 |
| | | <u>426,404</u> | <u>576,582</u> |

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 April 2023.

The members have not required the charitable company to obtain audit of its financial statements for the year ended 30 April 2023 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 15 to 24 were approved by and signed on behalf of the board of directors on 28 September 2023.

Helen Carter

Joella McIvillie

H. Carter Trustee

J. McIvillie Trustee

**Notes to the Financial Statements
For the Year ended 30 April 2023****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 2023 (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.

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.

Note to the Financial Statements
For the Year ended 30 April 2023 (continued)

| | 2023 | 2022 |
|--|----------------|---------------|
| | £ | £ |
| 3. Income from donations & legacies | | |
| <i>General fund - unrestricted</i> | | |
| Conference income and grants | 64,993 | 23,295 |
| Voluntary donations | 36,432 | 49,020 |
| <i>Restricted fund</i> | | |
| Voluntary donations | 4,000 | 4,000 |
| | <u>105,425</u> | <u>76,315</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.

| | 2023 | 2022 |
|--|---------------|----------------|
| | £ | £ |
| 4. Income from charitable activities | | |
| <i>General fund - unrestricted</i> | | |
| Kickstart | 10,990 | 3,120 |
| <i>Restricted fund</i> | | |
| Charities Aid Foundation | 41,472 | 129,417 |
| National Lottery Community Fund | - | 9,827 |
| Big Lottery Fund | - | - |
| BBC Children in Need | 31,743 | 20,491 |
| Hollie Foundation | 2,000 | 11,063 |
| Pears Foundation | - | 9,800 |
| Orphazyme | - | 45,000 |
| | <u>86,205</u> | <u>228,718</u> |
| 5. Income from other trading activities | | |
| <i>General fund - unrestricted</i> | | |
| Fundraising events | 108,370 | 106,893 |
| 6. Investment income | | |
| <i>General fund - unrestricted</i> | | |
| Bank interest | 1,487 | 49 |
| Dividend income | 5,106 | 4,428 |
| | <u>6,593</u> | <u>4,477</u> |

Note to the Financial Statements
For the Year ended 30 April 2023 (continued)

| | 2023 | 2022 |
|--|------------------|----------------|
| | £ | £ |
| 7. Expenditure on charitable activities | | |
| Helpline / family support / travel | 137,287 | 129,640 |
| Information - social media & publications | 47,332 | 38,861 |
| Conference costs | 71,562 | 2,690 |
| Research costs | 37,785 | 53,931 |
| Central office wages | 73,113 | 70,358 |
| Upkeep computer | 977 | 594 |
| Rent & rates | 12,042 | 11,086 |
| Other administration costs | 14,503 | 12,420 |
| Insurance & subscription | 2,932 | 2,120 |
| Bank charges | 188 | 186 |
| Executive & management meetings | 5,135 | - |
| Strategic review meeting | 15,844 | 1,110 |
| Independent examiner's fee | 2,520 | 1,800 |
| Management & staff meetings | 2,696 | 1,277 |
| | <u>423,918</u> | <u>326,073</u> |
| Charged to - <i>General fund - unrestricted</i> | 254,146 | 182,212 |
| - <i>Restricted fund</i> | <u>169,772</u> | <u>143,861</u> |
| 8. Tangible assets | | |
| | Equipment | |
| | £ | |
| Cost | | |
| At 30 April 2022 and 2023 | <u>4,158</u> | |
| Depreciation | | |
| At 30 April 2022 and 2023 | <u>4,158</u> | |
| Net Book Value | | |
| At 30 April 2022 and 2023 | <u>-</u> | |
| 9. Fixed asset investments | 2023 | 2022 |
| | £ | £ |
| Balance brought forward | 218,333 | 227,490 |
| (Impairment) / Increase in value | <u>(16,400)</u> | <u>(9,157)</u> |
| Market value at 30 April 2023 | <u>201,933</u> | <u>218,333</u> |
| Historical cost of investments held at 30 April 2023 | <u>220,000</u> | <u>220,000</u> |
| Investments at fair value comprise: | | |
| | 2023 | |
| Fixed interest | 32.32% | |
| Securities | 34.75% | |
| Property | 8.69% | |
| Alternatives | 19.68% | |
| Cash | 4.57% | |

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 2023 (continued)

| | 2023 | 2022 |
|---|----------------|----------------|
| | £ | £ |
| 10. Debtors | | |
| Prepayments | 3,354 | 1,340 |
| Amounts due from INPDA (note 18) | 2,699 | 968 |
| Amounts due from INPDR (note 18) | 2,497 | 1,749 |
| Other debtors | 3,063 | 1,118 |
| | <u>11,613</u> | <u>5,175</u> |
| 11. Creditors: amounts falling due within one year | | |
| Amounts due to INPDR | - | 1,300 |
| Amounts due to INPDA | 243 | - |
| Other tax & social security | 2,296 | 2,898 |
| Accruals and deferred income | 12,092 | 15,875 |
| | <u>14,631</u> | <u>20,073</u> |
| 12. Employee information | No | No |
| The average monthly number of employees was: | <u>7</u> | <u>6</u> |
| | £ | £ |
| Staff Costs | | |
| Salaries | 160,007 | 143,367 |
| Social security costs | 16,210 | 14,713 |
| Pension costs | 3,273 | 3,085 |
| | <u>179,490</u> | <u>161,165</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 £82,678 (2022: £78,350).

13. Operating Leases

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

| | 2023 | 2022 |
|--|---------------|---------------|
| | £ | £ |
| <i>Expiry date</i> | | |
| Not later than one year | 10,800 | 10,800 |
| Later than one and not later than five years | 12,600 | 1,500 |
| | <u>23,400</u> | <u>12,300</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 £3,273 (2022: £3,085).

Note to the Financial Statements
For the Year ended 30 April 2023 (continued)

15. Statement of Funds

| 2022-2023 | Balance 30/4/2022 £ | Income £ | Expenditure £ | Transfer £ | Gains / (Losses) £ | Balance 30/4/2023 £ |
|---------------------------------|------------------------------------|---------------------|--------------------------|-----------------------|-----------------------------------|------------------------------------|
| General fund | 241,360 | 227,379 | 270,600 | 12,166 | - | 210,305 |
| Designated fund | 24,332 | - | - | (12,166) | - | 12,166 |
| Total unrestricted funds | 265,692 | 227,379 | 270,600 | - | - | 222,471 |
| Endowment fund | 218,333 | - | - | - | (16,400) | 201,933 |
| Restricted funds | | | | | | |
| BBC Children in Need | - | 31,743 | 31,743 | - | - | - |
| Charities Aid Foundation 1 | 65,490 | 36,472 | 101,962 | - | - | - |
| Charities Aid Foundation 2 | 8,975 | 5,000 | 13,975 | - | - | - |
| Stewardship Fund | - | 3,000 | 3,000 | - | - | - |
| Hollie Foundation | - | 2,000 | 2,000 | - | - | - |
| Lesley Carlton Jones | 2,000 | 1,000 | 1,000 | - | - | 2,000 |
| Orphazyme | 16,092 | - | 16,092 | - | - | - |
| Total restricted funds | 92,557 | 79,215 | 169,772 | - | - | 2,000 |
| Total funds | 576,582 | 306,594 | 440,372 | - | (16,400) | 426,404 |

| 2021-2022 | Balance 30/4/2021 £ | Income £ | Expenditure £ | Transfer £ | Gains / (Losses) £ | Balance 30/4/2022 £ |
|---------------------------------|------------------------------------|---------------------|--------------------------|-----------------------|-----------------------------------|------------------------------------|
| General fund | 199,677 | 186,805 | 193,966 | 48,884 | - | 241,360 |
| Designated fund | 73,176 | - | - | (48,844) | - | 24,332 |
| Total unrestricted funds | 272,853 | 186,805 | 193,966 | - | - | 265,692 |
| Endowment fund | 227,490 | - | - | - | (9,157) | 218,333 |
| Restricted funds | | | | | | |
| 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 |
| Total restricted funds | 6,820 | 229,598 | 143,861 | - | - | 92,557 |
| Total funds | 507,163 | 416,403 | 337,827 | - | (9,157) | 576,582 |

Note to the Financial Statements
For the Year ended 30 April 2023 (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 11.

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 |
| National Lottery Community Fund | Mental health & wellbeing |
| BBC Children in Need | Continuation funding towards the post of Clinical Nurse Specialist |
| Charities Aid Foundation 1 | Towards continuation and development of services |
| Charities Aid Foundation 2 | Towards strengthening organisation |
| Charities Aid Foundation 3 | Towards core salaries |
| Pears Foundation | Covid-19 funding for salary costs, overheads & family support |
| Stewardship fund | Research |
| Hollie Foundation | Funding of Family Officer |
| Lesley Carlton Jones | 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 £ |
|-----------------------------|----------------------------|--------------------------|-------------------------|---------------------|
| 2023 | | | | |
| Fixed asset investments | - | - | 201,933 | 201,933 |
| Current assets | 237,102 | 2,000 | - | 239,102 |
| Current liabilities | (14,631) | - | - | (14,631) |
| Net assets at 30 April 2023 | 222,471 | 2,000 | 201,933 | 426,404 |

| | Unrestricted Funds £ | Restricted Funds £ | Endowment Funds £ | Total Funds £ |
|-----------------------------|----------------------------|--------------------------|-------------------------|---------------------|
| 2022 | | | | |
| Fixed asset investments | - | - | 218,333 | 218,333 |
| Current assets | 285,766 | 92,557 | - | 378,323 |
| Current liabilities | (20,074) | - | - | (20,074) |
| Net assets at 30 April 2022 | 265,692 | 92,557 | 218,333 | 576,582 |

Note to the Financial Statements
For the Year ended 30 April 2023 (continued)

17. Trustees

No remuneration was paid to Trustees during the financial period. During the year 9 trustees (2022: 3) were reimbursed travel and administration expenses in pursuit of charitable objectives and this amounted to £4,947 (2022: £149). Of this amount, £3,520 was paid for accommodation for the two-day Strategic Review meeting.

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:

| | 2023 | 2022 |
|--|-------------|-------------|
| | £ | £ |
| With INPDA | | |
| Wages | 4,393 | 4,113 |
| Other costs | 7,162 | 1,263 |
| Reimbursement of research costs received | 8,611 | 7,170 |
| Sum due to NPUK (note 10) | 2,699 | 968 |
| With INPDR | | |
| Wages | 11,113 | 11,073 |
| Other costs | 3,365 | 3,622 |
| Sum due to NPUK | 2,497 | 449 |