

REGISTERED COMPANY NUMBER: 08287609 (England and Wales)
REGISTERED CHARITY NUMBER: 1150256

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE
(A COMPANY LIMITED BY GUARANTEE)**

Report of the Trustees and

Financial Statements for the Year Ended 31 March 2024

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

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for the Year Ended 31 March 2024**

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**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Reference and Administrative Details
for the Year Ended 31 March 2024**

Trustees	Ms S Cowie President Ms J A Crowe Vice-President (resigned 10.11.24) Mrs T A Mathieson Ms I Hontanilla (resigned 12.11.23) Ms L Chavez (resigned 10.11.23) J E Green Miss S Jannetta (appointed 18.11.23)
Company secretary	Mrs T A Mathieson
Registered office	Suite 2 Vermont House Washington Tyne and Wear NE37 2SQ
Registered company number	08287609 (England and Wales)
Registered charity number	1150256
Independent examiner	James Anderson & Co Chartered Accountants Pentland Estate Straiton Edinburgh EH20 9QH

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2024

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2024. The trustees have adopted the provisions of 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) (effective 1 January 2019).

Objectives and activities

Our objectives and aims

The objects for which the company is established are to relieve sickness amongst families affected by Niemann-Pick diseases, any distress which may arise therefrom and to advance the education of such families, interested professionals and the general public in all matters concerning such diseases as the governing council may in its discretion determine.

The following aims were agreed at the first meeting:

- To enhance progress and maximise the use of resources through international collaboration.
- To share available information.
- To facilitate strong networks of Foundations, Researchers, Clinicians and Industry representatives.
- To identify shared goals and address common challenges.
- To co-ordinate access to clinical trials and therapies.
- To be able to act as an international advocate for those affected these diseases.
- To act as an advocate, speaking with one voice re. health policy.

Review of activities

The INPDA provides a collaborative forum for the sharing of information and experience regarding all aspects of Niemann-Pick disease, including care and support, the provision and distribution of information and the furtherance of research. Our global network of non-profit organisations working in the field of Niemann-Pick disease (NPD) now extends to 27 members in 20 countries, with members united by a single aim - to improve outcomes for all those affected by Niemann-Pick diseases:

Argentina, Australia, Belgium, Brazil (2), Canada, China, France (2), Germany, India, Italy, The Netherlands, Norway, Pakistan, Poland, Spain (3), Switzerland, Taiwan, Tunisia, United Kingdom, USA (4).

All our activities are undertaken in line with our aim of facilitating progress in the field of Niemann-Pick diseases. By providing a forum for mutual support, the INPDA aims to establish working links between all non-profit Niemann-Pick support groups and to raise awareness of the nature and operations of these, sometimes very different, organisations.

Our Executive Committee oversees the day-to-day management of the INPDA and reports regularly to the Full Member Council via quarterly teleconferences. This year, we have continued to facilitate progress by:

- Supporting and developing patient advocacy leadership and offering practical advice and support to newly established patient groups.
- Using our shared experience to highlight and promote best practice in patient care and treatment
- Accelerating research through the creation of networks and sharing of information
- Encouraging a cross-sector collaborative approach
- Undertaking global advocacy activities in support of therapy development
- Engaging in advocacy with regulators and payers as new therapies are evaluated and approved
- Supporting global interaction and communication
- Fostering the effective use of resources and minimising duplication
- Evidence generation including collection of patient experience data and real-world evidence to support drug development, treatment strategies, plus discussions with regulatory bodies and health technology assessment authorities.

Objectives and activities

Significant activities

A key element of our work is raising awareness of our collective challenges and the high level of unmet need that exists within the global Niemann-Pick community. Never has the need for awareness of Niemann-Pick diseases been more apparent, and in order to achieve our aim to accelerate progress, there are multiple targets for our awareness efforts, including:

- regulators and the pharmaceutical industry - to assist understanding of the unmet needs of our community and to accelerate progress towards approved therapies
- clinicians - to improve the diagnostic odyssey faced by patients and families
- researchers and scientists - to accelerate research in NPD
- funders - to underline the need for our efforts in advocacy and research to continue- newborn screening and its potential benefits

Representatives of the INPDA have attended and presented at key conferences around the world, including patient group events and wider rare disease events.

We have also maintained and further developed our relationships with clinical and research institutions, drug developers and other key stakeholders. The high-level work provides the opportunity for us to advocate for improvements to care and services, access to clinical standards of care, and access to treatments and therapies where they exist.

Representatives have also met with statutory bodies, health authorities and regulators around the world. These essential efforts support research and progress in clinical care, and address issues such as the current regulatory environment, working with the pharmaceutical industry and HTA bodies, including;

- Continuing to work with our members to provide information and evidence to support access to approved therapies, or early access to promising therapies
- Advocating on behalf of our global community directly with regulators
- Appropriate involvement in regulatory meetings
- Collection of evidence through surveys, information gathering
- The need to provide expert patient advocates who can speak on behalf of the whole patient community in activities to support disease understanding and therapy development, including regulator or industry led advisory boards
- Continuing to work with clinicians and researchers to develop patient reported outcome measures that effectively record disease progression and quality of life
- Working with the global Niemann-Pick and wider Lysosomal disease community to identify biomarkers and clinical endpoints
- Working with global health professional and patient representatives to identify digital health technologies that could support research and further understanding

We have continued to undertake our own community research studies, aiming to collect and develop evidence of impact and unmet need, and to provide information that will increase disease understanding, and support research and therapy development.

Our Biennial Face-to-Face meeting was held in Tarragona Spain in November 2023. The meeting was very well attended and provided a dynamic and impactful opportunity for our patient advocacy leadership representatives plus key figures in the clinical, research and scientific field of Niemann-Pick diseases to come together, share updates and build networks that will support the ongoing growth of the community. The program at the Face-to-Face meeting enabled the sharing of knowledge and experience and included presentations on the latest clinical and research updates. This meeting helps to ensure patient advocacy leaders are aware of current research, providing information that supports their ability to inform their communities and advocate on their behalf. This event was attended by approximately 80 delegates including senior representatives of patient associations, clinicians, researchers, and pharmaceutical industry representatives helping to strengthen relationships, encourage collaboration and enable the formation of mutual support networks. In addition, this meeting also enabled the INPDA to agree its strategic priorities, supporting the future direction of the organisation.

To assist capacity building, we have in place four voluntary Executive Liaison Roles to support progress in the INPDA's key priority areas. These roles were recruited internally (from INPDA Member Groups) and externally (individuals / organisations with the necessary experience/interest) and in line with the requirements of our Governing document:

- Research Liaison Officer, ASMD
- Research Liaison Officer, NPC
- Membership Liaison Officer
- Newborn Screening Liaison Officer

In support of wider collaboration, and to ensure our voice is heard at all levels, the INPDA is a member of EURORDIS and Rare Disease International.

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2024

Objectives and activities Key Projects

The INPDA is currently engaged in a number of key projects. Each project aims to make a difference in the areas of scientific, clinical and therapeutic research, patient care, access to treatments and time to diagnosis.

The International Niemann-Pick Disease Registry (INPDR), which is an independently governed non-profit organisation, has the power to increase knowledge and understanding of NPD through the collection of much needed patient data a global scale. The INPDA was intrinsic in the realisation of this important resource and continues to support its development, by acting as an ambassador, sharing information and supporting the collection of data.

The Think Again. Think NP-C Campaign first launched in 2015, has done much to improve diagnosis of NPC by targeting specialist health care professionals who are currently unfamiliar with the condition and giving them the tools they need to recognise and act upon the symptoms of NPC. We are also currently exploring an opportunity to revitalize this campaign and redevelop a suspicion index tool to support earlier diagnosis for NPC.

The INPDA Information Portal was developed with the support of a Genzyme PAL grant. This open access Portal, which is hosted on the INPDA website, brings together a wide range of helpful information for patients, families, and professionals working in the NPD field, in a range of different languages and formats. The Portal reflects the collaborative spirit of the INPDA and continues to grow along with our respective member groups, who provide articles and documents, and translations where necessary, further boosting the ongoing global effort.

INPDA Biennial Face-to-Face meeting was held in Tarragona Spain with more than 80 delegates present.

Support and planning for the Reuss Valley NPC Scientific Meeting to be held in Switzerland in October 2024. This is a biennial scientific meeting focused on NPC research that supports our goal of building networks and facilitating research in NPC.

Public benefit

In shaping our objectives for the year, agreeing our priorities and planning our activities, the trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

As a network for non-profit organisations associated with the group of rare diseases known as Niemann-Pick diseases, we aim to facilitate progress through the provision of an international collaborative forum for the sharing of information and experience regarding all aspects of Niemann-Pick disease, including care and support, the provision and distribution of information and the furtherance of research. We meet virtually every three months and bi-annually face to face, with ad hoc meetings as required.

Benefits of the INPDA

The INPDA has a global reach; therefore, it is ideally placed to effectively communicate information to the Niemann-Pick community, offering equity of access and ensuring consistency and accuracy of the information provided.

- By sharing information and maximising communication, we can help each organisation to develop their leadership and to use their time and resources efficiently and effectively.
- We aim to ensure that all member organisations are informed of, and if appropriate, able to act upon, the most recent scientific and therapeutic developments.
- Wherever possible, we will help to encourage research by supporting the formation of networks, providing seed funding and working in partnership to secure grant funding.
- By working together, members have a stronger voice with which to influence change and bring improvements for Niemann-Pick patients everywhere.

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2024

Achievement and performance

Charitable activities

Following upon our learnings during the COVID 19 Pandemic we have maximised use of virtual technology to keep each other informed and to stay connected. This connection provides member groups the opportunity to share their experiences, stay informed and continue to raise our voice on behalf of those affected by Niemann-Pick diseases.

We have continued to maintain a strong presence in the field of research and have collaborated with other rare disease organisations, research and academic institutions on a global basis to progress research, facilitate clinical development of promising therapies and influence Newborn Screening.

We continue to sustain appropriate relationships with the pharmaceutical companies engaged in clinical programmes and activities in the field of Niemann-Pick diseases and to provide high level support and information to the patient advocacy leaders supporting our community.

We continue to support the International Niemann-Pick Disease Registry (INPDR) in its objectives to collect clinical, genetic, diagnostic and outcome data from patients with Niemann-Pick diseases. The INPDR is an independent charitable company with INPDA representatives appointed as Board and Scientific Advisory Committee Members.

Financial review

Income

Grant funding in the form of unrestricted grants enabled the charity to carry out its activities. Further funding came from the Roy & Murray Green Together Fund. Incoming funds were higher in this year at £214,845 as compared to £72,316 in the previous year.

Expenditure

Expenditure for the year was £89,725 as a result of the Face-to-Face Conference in comparison to £57,617 in the previous year.

Financial Strategy

Our Financial Strategy is based on levels of incoming funds matching the expenditure required to deliver our objectives and activities. Whilst income will be spent within a reasonable period of receipt to fund the operation of the Charity, we have a responsibility to manage risk, and to ensure the charity is financially sustainable. We will therefore hold a level of reserves to ensure the smooth running of the Charity during times of financial uncertainty.

Reserves policy

The free reserves at 31 March 2024 amounted to £169,059 (2023 £49,543). The Board aim to hold six months running costs in reserve and therefore this figure is considered higher than usual, due to the late receipt of grant funding, resulting in delays to activities which will now extend into the next fiscal year.

Future plans

At Face-to-Face meeting in November 2023, we agreed on a series of priorities for 2023-2025. Our priorities were agreed as follows:

- To safeguard sustainability by ensuring we have the resources we need (financial resources, personnel, member engagement, skills and capacity) to undertake our planned activities
- To establish support mechanisms for new and developing groups, encourage further support for ASMD, introduce new associate members.
- To strengthen our internal and external communication with regular meetings, use of our web portal, social media, and newsletter
- Continue to raise awareness through ongoing activities and influencing/educating regulators and health policy makers
- Continue to support and facilitate International Niemann Pick Disease Awareness Day on October 19
- To further enable research by providing opportunities to collaborate on research projects, minimize duplication and accelerate progress, explore opportunities for evidence generation such and facilitate development of consensus papers
- To continue our support for the International Niemann-Pick Disease Registry (INPDR) to facilitate the enrolment of patients around the globe into this disease-specific patient registry
- To continue our support for the Reus Valley NPC Research meeting scheduled for October 2024
- Plan for the next INPDA Face-to-Face meeting for September 2025 to be held in Argentina.

Structure, governance and management

Governing document

The charity is governed by its memorandum and articles of association and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2024

Structure, governance and management

Recruitment and appointment of new trustees

Future Trustees shall be appointed by the Trustees from time to time following a nomination received from the Nominations Committee (Governing Council). They are volunteers and each takes on responsibilities within the Alliance to co-ordinate/support an aspect of the Alliance functions.

Organisational structure

The Trustees and all other supporters of the INPDA are volunteers. The Trustees are directly responsible for the effective governance of the charity and for providing appropriate support and guidance and monitoring of all activities. This is carried out in accordance with statutory guidance and legislation as provided by the Charity Commission. Members are asked to follow a code of conduct, which provides clear guidelines as to the standards of behaviour, responsibilities, and best practice expected of those involved with the INPDA. An Executive Committee oversees the day-to-day management of the INPDA and reports regularly to the Full Member Council via quarterly virtual meetings. The Trustees and members meet face-to-face every two years with at least four additional virtual meetings each year in order to review reports and to carry out management and financial reviews.

Induction and training of new 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.

Pay policy for staff

Currently, the INPDA has no paid staff members. The Trustees are responsible for the day-to-day management of the Charity, with the support of an Executive Committee. All trustees give of their time freely and no trustee received remuneration in the year, outside of travel and subsistence expenses. In the event of employment, the Trustees are responsible for setting employee salary levels. All salaries are benchmarked with similar roles in the voluntary sector, not with the public or private sectors. The small size of the organisation is also taken into account.

Wider network

The International Niemann-Pick Disease Alliance (INPDA) is an alliance of non-profit support organisations who are associated with the rare group of genetic diseases known collectively as Niemann-Pick Disease. The Alliance was formed with a view to providing a forum where, through the exchange of information, experience and knowledge, progress could be accelerated.

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2024

Structure, governance and management

Related parties

None of our trustees receive remuneration or other benefit from their work with the charity. At present there are 27 separate foundations in the Alliance.

Member Groups:

Argentina - Asociaion Niemann Pick de Argentina
Australia - Australian NPC Disease Foundation
Brazil - Associação Niemann Pick Brasil - ANPB
Canada - Niemann-Pick Canada
China - China Niemann-Pick Disease Association
France - Vaincre Les Maladies Lysosomales
Germany - Niemann-Pick Selbsthilfegruppe
Italy - Associazione Italiana Niemann Pick
Netherlands - Volwassenen, Kinderen en Stofwisselingsziekten
Norway - NP Foreningen I Norge
Spain - Fundacion Niemann-Pick de Espana
Switzerland - Niemann-Pick Suisse
UK - Niemann-Pick UK
USA - National Niemann-Pick Disease Foundation

Associate Members:

Belgium - Belgische Organisatie voor Kinderen en volwassenen met een Stofwisselingsziekte BOKS
Brazil - Niemann-Pick B R-S
India - Niemann-Pick India Charitable Trust
France - Niemann-Pick Francais
Pakistan - LSD Society Pakistan
Poland- Stowarzyszenie Chorych na Chorobe Niemann Picka i Choroby Rzadkie (Niemann-Pick and Rare Diseases Assoc. Poland)
Spain - Asociacón Niemann Pick de Fuenlabrada
Spain - ASMD Espana
Taiwan - Niemann-Pick Taiwan
Tunisia - Association Tunisienne des Maladies Lysosomales
USA - The Wylder Nation Foundation
USA - Ara Parseghian Medical Research Foundation APMRF
USA - Firefly Fund

Related party disclosures are shown at note 11.

Principal risks

The principal risks for the foreseeable future relate to;

- Increased competition for a reducing number of grant funding opportunities and a limited number of funders
- Further economic and political pressures which will adversely affect voluntary income.
- Lack of capacity to increase the rate of grant applications and income streams.
- A strong dependence on volunteers with no spare capacity to provide cover / plan for succession

Statement of trustees' responsibilities

The trustees (who are also the directors of International Niemann-Pick Disease Alliance for the purposes of company law) are responsible for preparing the Report of the Trustees and the 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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable 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 Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Report of the Trustees
for the Year Ended 31 March 2024**

Statement of trustees' responsibilities - continued

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the board of trustees on 24 December 2024 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Sandra Cowie', written in a cursive style.

Ms S Cowie - Trustee

Independent examiner's report to the trustees of International Niemann-Pick Disease Alliance ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2024.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

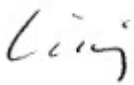
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Christopher Spalding

James Anderson & Co
Chartered Accountants
Pentland Estate
Straiton
EH20 9QH

24 December 2024

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Statement of Financial Activities
(Incorporating an Income and Expenditure Account)
for the Year Ended 31 March 2024**

		Unrestricted fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
Income and endowments from	Notes				
Donations and legacies		<u>198,363</u>	<u>16,482</u>	<u>214,845</u>	<u>72,316</u>
Expenditure on					
Charitable activities	3				
Meetings		62,047	10,878	72,925	45,484
Charitable activities		<u>16,800</u>	<u>-</u>	<u>16,800</u>	<u>12,133</u>
Total		<u>78,847</u>	<u>10,878</u>	<u>89,725</u>	<u>57,617</u>
NET INCOME		119,516	5,604	125,120	14,699
Reconciliation of funds					
Total funds brought forward		<u>49,543</u>	<u>17,500</u>	<u>67,043</u>	<u>52,344</u>
Total funds carried forward		<u>169,059</u>	<u>23,104</u>	<u>192,163</u>	<u>67,043</u>

The notes form part of these financial statements

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Balance Sheet
31 March 2024**

	Notes	2024 £	2023 £
Current assets			
Debtors	7	-	25,822
Cash at bank		<u>195,246</u>	<u>43,498</u>
		195,246	69,320
Creditors			
Amounts falling due within one year	8	(3,083)	(2,277)
		<u> </u>	<u> </u>
Net current assets		<u>192,163</u>	<u>67,043</u>
Total assets less current liabilities		<u>192,163</u>	<u>67,043</u>
NET ASSETS		<u>192,163</u>	<u>67,043</u>
Funds	10		
Unrestricted funds		169,059	49,543
Restricted funds		<u>23,104</u>	<u>17,500</u>
Total funds		<u>192,163</u>	<u>67,043</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2024 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 the 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 provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 24 December 2024 and were signed on its behalf by:



S Cowie - Trustee

The notes form part of these financial statements

1. Statutory information

International Niemann-Pick Disease Alliance is a private company, limited by guarantee with charitable status and registered in England and Wales. 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 on the Reference and Administrative Details page.

The presentation currency of the financial statements is the Pound Sterling (£).

2. Accounting policies

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

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.

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.

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.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

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.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

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.

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2024**

2. Accounting policies - continued

**Debtors and creditors receivable / payable within one year
Cash in bank and in hand**

Cash at bank and cash in hand includes cash and short term highly liquid investments.

3. Charitable activities costs

	Direct Costs (see note 4) £
Meetings	72,925
Charitable activities	<u>16,800</u>
	<u><u>89,725</u></u>

4. Direct costs of charitable activities

	2024 £	2023 £
Finance & admin costs	7,314	1,653
IT costs	470	195
Meetings, conferences, travel and accommodation	72,925	45,484
Project costs - research	4,302	4,535
Think again: Think NPC	216	269
Social media & communications	-	2,719
Other overheads	3,304	1,694
Independent examiner's fee	<u>1,194</u>	<u>1,068</u>
	<u><u>89,725</u></u>	<u><u>57,617</u></u>

5. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

Trustees' expenses

During the period there one trustees was reimbursed expenses of £921 (2023 £567) for travel.

6. Comparatives for the statement of financial activities

	Unrestricted fund £	Restricted funds £	Total funds £
Income and endowments from			
Donations and legacies	<u>66,266</u>	<u>6,050</u>	<u>72,316</u>
Expenditure on			
Charitable activities			
Meetings	45,484	-	45,484
Charitable activities	<u>12,133</u>	<u>-</u>	<u>12,133</u>
Total	<u><u>57,617</u></u>	<u><u>-</u></u>	<u><u>57,617</u></u>
NET INCOME	8,649	6,050	14,699
Reconciliation of funds			
Total funds brought forward	40,894	11,450	52,344

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2024**

6. Comparatives for the statement of financial activities - continued

	Unrestricted fund £	Restricted funds £	Total funds £
Total funds carried forward	<u>49,543</u>	<u>17,500</u>	<u>67,043</u>

7. Debtors: amounts falling due within one year

	2024 £	2023 £
Trade debtors	<u>-</u>	<u>25,822</u>

8. Creditors: amounts falling due within one year

	2024 £	2023 £
Other creditors	1,943	1,209
Accruals and deferred income	<u>1,140</u>	<u>1,068</u>
	<u>3,083</u>	<u>2,277</u>

9. Analysis of net assets between funds

	Unrestricted fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
Current assets	172,142	23,104	195,246	69,320
Current liabilities	<u>(3,083)</u>	<u>-</u>	<u>(3,083)</u>	<u>(2,277)</u>
	<u>169,059</u>	<u>23,104</u>	<u>192,163</u>	<u>67,043</u>

10. Movement in funds

	At 1/4/23 £	Net movement in funds £	At 31/3/24 £
Unrestricted funds			
General fund	49,543	119,516	169,059
Restricted funds			
Roy & Murray Green Together Fund	17,500	3,547	21,047
Brazilian Patient Organisations Travel Fund	<u>-</u>	<u>2,057</u>	<u>2,057</u>
	<u>17,500</u>	<u>5,604</u>	<u>23,104</u>
TOTAL FUNDS	<u>67,043</u>	<u>125,120</u>	<u>192,163</u>

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2024**

10. Movement in funds - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	198,363	(78,847)	119,516
Restricted funds			
Roy & Murray Green Together Fund	6,882	(3,335)	3,547
Brazilian Patient Organisations Travel Fund	<u>9,600</u>	<u>(7,543)</u>	<u>2,057</u>
	<u>16,482</u>	<u>(10,878)</u>	<u>5,604</u>
TOTAL FUNDS	<u><u>214,845</u></u>	<u><u>(89,725)</u></u>	<u><u>125,120</u></u>

Comparatives for movement in funds

	At 1/4/22 £	Net movement in funds £	At 31/3/23 £
Unrestricted funds			
General fund	40,894	8,649	49,543
Restricted funds			
Roy & Murray Green Together Fund	<u>11,450</u>	<u>6,050</u>	<u>17,500</u>
TOTAL FUNDS	<u><u>52,344</u></u>	<u><u>14,699</u></u>	<u><u>67,043</u></u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	66,266	(57,617)	8,649
Restricted funds			
Roy & Murray Green Together Fund	<u>6,050</u>	<u>-</u>	<u>6,050</u>
TOTAL FUNDS	<u><u>72,316</u></u>	<u><u>(57,617)</u></u>	<u><u>14,699</u></u>

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

The Roy & Murray Green Together Fund is to enhance the development and integration of the INPDA including the support of travel and staffing for the organization.

Brazilian Patient Organisations Travel Fund - to support travel costs of Niemann-Pick B-RS and ANPB patient groups in Brazil to attend INPDA Face 2 Face meetings.

**INTERNATIONAL NIEMANN-PICK DISEASE
ALLIANCE**

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2024**

11. Related party disclosures

During the year salary, admin and travel costs etc were recharged by a member of the alliance, Niemann-Pick UK(NPUK) of £15,455 (2023 £8,750). Costs of £127 (2023 £243) were incurred on behalf of NPUK. There was a balance owed to NPUK of £1,945 at 31 March 2024 (2023 £965).

The International Niemann-Pick Disease Alliance (INPDA) is a member of the International Niemann-Pick Disease Registry (INPDR). During the year costs were incurred on behalf of the INPDR and reimbursed of £4,422 (2023 £578). Costs were incurred by INPDR on behalf of the INPDA and reimbursed of £3,014 (2023 - £2,920). At 31 March 2024 there was a balance owed by INPDR of £nil (2022 £578).

During the year costs were recharged by a member of the alliance, National Niemann-Pick Disease Foundation of £2,175 (2023 £39,543). There was no balance outstanding at the year end.

**INTERNATIONAL NIEMANN-PICK DISEASE
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**Detailed Statement of Financial Activities
for the Year Ended 31 March 2024**

	2024 £	2023 £
Income and endowments		
Donations and legacies		
Donations	204,628	72,316
INPDA Biennial Meetings	<u>10,217</u>	<u>-</u>
	<u>214,845</u>	<u>72,316</u>
Total incoming resources	214,845	72,316
Expenditure		
Charitable activities		
Finance & admin costs	7,314	1,653
IT costs	470	195
Meetings, conferences, travel and accommodation	72,925	45,484
Project costs - research	4,302	4,535
Think again: Think NPC	216	269
Social media & communications	-	2,719
Other overheads	3,304	1,694
Independent examiner's fee	<u>1,194</u>	<u>1,068</u>
	<u>89,725</u>	<u>57,617</u>
Total resources expended	<u>89,725</u>	<u>57,617</u>
Net income	<u><u>125,120</u></u>	<u><u>14,699</u></u>