

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 2021

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

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INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Reference and Administrative Details for the Year Ended 31 March 2021

Trustees	Ms S Cowie President Ms J A Crowe Vice-President (appointed 4.10.20) Mrs T A Mathieson Ms I Hontanilla Ms L Chavez (appointed 4.10.20) J E Green
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	Christopher Spalding 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 2021

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 2021. 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.

Significant activities

At our Face to Face Meeting in Lyon 2019, the Governing Council agreed the following priorities. for the period June 2019-July 2021. Although progress towards achieving our priorities has been significantly slowed during this financial year, due to the COVID-19 pandemic, we have been able to move forward positively in the areas of communication, enabling research and raising awareness:

Sustainability – We need to ensure we have the personnel and financial resources, skills and capacity to undertake our planned activities, therefore we will:

- Further develop and strengthen our Board and Staff Team
- Increase fundraising and grant applications

Membership – As we grow, we will:

- Establish support mechanisms for new and developing groups
- Encourage participation in our networks, the sharing of information through the INPDA Information Portal
- Increase opportunities to learn from each other, share experience and mentor newly formed groups
- Expand support to the ASMD community in countries where this is not currently available

Communication – We will continue to work to strengthen both our internal and external communication, by:

- Maximising use of technology to support communication
- Hosting regular and interactive meetings
- Establishing a newsletter
- Maintaining appropriate relationships with industry and researchers
- Encouraging attendance at member group and external meetings
- Sharing information regarding scientific symposia
- Participating in Eurordis and RDI activities
- Maintaining the INPDA Information Portal, website and social media channels

Raising awareness - Through ongoing awareness activities, we will work to influence positive change and improvement to care, treatment and services for our global community, including:

- Supporting and further developing an annual Niemann-Pick awareness day on October 19
- Establishing an Expert Patient Board
- Raising our voice through social media and on-line activities
- Maintaining the Think Again. Think NPC Campaign
- Developing an ASMD awareness Campaign

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2021

Enabling Research - By sharing information, providing networking opportunities and supporting key initiatives, including:

- Supporting the ongoing development and implementation of the International Niemann-Pick Disease Registry (INPDR)
- Encouraging collaboration on research projects, to minimize duplication and accelerate progress
- Supporting Newborn Screening initiatives
- Interacting with regulators and health policy makers
- Developing global networks
- Supporting the Gene Therapy Activation and Loire Valley meetings
- Actively seeking and sharing relevant information with our membership
- Attend relevant conferences and symposia

Key Projects

The INPDA currently undertakes a number of key activities aiming 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 on a global scale. The INPDA was intrinsic in the realisation of this important resource and aims to support its continued development.

The Think Again. Think NPC Campaign aims 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.

The INPDA Information Portal is an open access and hosted on the INPDA website, it brings together a wide range of helpful information for patients, families, and professionals working in the Niemann-Pick 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.

Public benefit

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

We are a network for non-profit organisations associated with the group of rare diseases known as Niemann-Pick Disease. 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 an Executive Committee overseeing the day-to-day management of the organisation.

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2021

Achievement and performance Charitable activities

Various grants were received from funders in the year including Mallinckrodt ARD to enable the charity to carry out its activities.

Throughout this year our Board and membership have worked hard to help our vulnerable community to cope with the impact of the COVID-19 pandemic. We have maximised use of virtual technology to keep each other informed and to stay connected. In this way we have been able to maintain our activities but not without effects on our ability to network and to raise funds.

Staying connected has provided member groups the opportunity to share their experiences during this difficult time and has demonstrated the resilience of our community spirit as we 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 continued 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 Reserves policy

The free reserves at 31 March 2021 amounted to £36,988 (2020 £6,821). This reserve is considered a sufficient reserve against variations in funding which can arise from time to time. The board aim is to hold six months running costs in reserve. The 2020 figure of £15,364 is considered a more realistic benchmark as 2021 costs were much reduced due to Covid.

Future plans

Future Plans - priorities for the year ahead include

Sustainability - Organisational strengthening and development, to ensure we have the resources we need (financial resources, personnel, member engagement, skills and capacity) to undertake our planned activities

Membership - To further establish support mechanisms for new and developing groups, encourage and develop support for ASMD communities and introduce new associate members.

Communication - Continue to work to strengthen both our internal and external communication with regular meetings, use of our website, Information Portal and social media (INPDA.org, @INPDA), and newsletter

Raising awareness- Through ongoing awareness activities and interactions with regulators and health policy makers, plus support for the Think Again. Think NPC Campaign, and the development of specific ASMD awareness activities and support for the International Niemann Pick Disease Awareness Day on October 19

Enable Research - Support and facilitate global research and therapeutic development, by providing opportunities to collaborate on research projects, minimize duplication and accelerate progress

International Niemann Pick Disease Registry - Work with the INPDR to facilitate the enrolment of patients around the globe into this new built for purpose patient registry

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.

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.

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Report of the Trustees for the Year Ended 31 March 2021

Organisational structure

The Trustees and all the other supporters of the Organisation are volunteers.

The Trustees are directly responsible for the effective governance of the charity and for providing appropriate support and guidance and monitoring of all staff and activities. This is carried out in accordance with statutory guidance and legislation as provided by the Charity Commissioners. The Trustees meet face to face on average 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.

In order to achieve our identified priorities, a committee structure has been introduced to support the work involved. Committees will meet virtually at least once between each council meeting. The committee structure is intended to encourage the involvement of INPDA member organizations. Initially, four committees will be established and will report progress regularly to the Governing Council:

- Finance
- Communication
- Organization and membership
- Research

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

The trustees are the key management. All trustees give of their time freely and no trustee received remuneration in the year. 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 2021

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 23 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:

Brazil - Niemann-Pick B R-S
France - Niemann Pick Francais
Pakistan - LSD Society Pakistan
Spain - Asociacion Niemann Pick de Fuenlabrada
Spain - ASMD Espana
Taiwan - Niemann-Pick Taiwan
Tunisia - Association Tunisienne des Maladies Lysosomales
UK - The Hollie Foundation
USA - The Wylder Nation Foundation

Related party disclosures are shown at note 10.

Risk management

The trustees have identified and addressed the main risk which is the financial risk arising from our low level of funding and our limited number of funders.

The trustees risk management process comprises an annual review of the principal risks and uncertainties that the charity faces, the establishment of policies, systems and procedures to mitigate those risks. The trustees are satisfied that the major risks to which the charity is exposed have been reviewed and procedures have been established to manage these risks.

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 13 December 2021 and signed on its behalf by:



Mrs T A Mathieson – Trustee

**Independent Examiner's Report to the Trustees of
International Niemann-Pick Disease Alliance**

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 2021.

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').

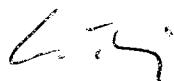
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). 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 (ICAS)
James Anderson & Co
Chartered Accountants
Pentland Estate
Straiton
EH20 9QH

Date: 13 December 2021

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the Year Ended 31 March 2021

	Notes	Unrestricted fund £	Restricted funds £	2021 Total funds £	2020 Total funds £
Income and endowments from					
Donations and legacies		37,040	3,367	40,407	34,178
Other trading activities	3	<u>1,179</u>	<u>-</u>	<u>1,179</u>	<u>1,250</u>
Total		38,219	3,367	41,586	35,428
 Expenditure on					
Raising funds		20	-	20	396
 Charitable activities					
Charitable activities		<u>8,032</u>	<u>-</u>	<u>8,032</u>	<u>33,418</u>
Total		<u>8,052</u>	<u>-</u>	<u>8,052</u>	<u>33,814</u>
 NET INCOME		30,167	3,367	33,534	1,614
 Reconciliation of funds					
Total funds brought forward		<u>6,821</u>	<u>2,270</u>	<u>9,091</u>	<u>7,477</u>
 Total funds carried forward		<u><u>36,988</u></u>	<u><u>5,637</u></u>	<u><u>42,625</u></u>	<u><u>9,091</u></u>

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Balance Sheet 31 March 2021

	Notes	2021 £	2020 £
Current assets			
Debtors	6	22	1,241
Cash at bank		<u>43,764</u>	<u>11,671</u>
		43,786	12,912
Creditors			
Amounts falling due within one year	7	(1,161)	(3,821)
		<u> </u>	<u> </u>
Net current assets		<u>42,625</u>	<u>9,091</u>
Total assets less current liabilities		<u>42,625</u>	<u>9,091</u>
NET ASSETS		<u>42,625</u>	<u>9,091</u>
Funds	9		
Unrestricted funds		36,988	6,821
Restricted funds		<u>5,637</u>	<u>2,270</u>
Total funds		<u>42,625</u>	<u>9,091</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2021.


The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of 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 13 December 2021 and were signed on its behalf by:


T. A. Mathieson – Trustee

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Notes to the Financial Statements for the Year Ended 31 March 2021

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.

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Notes to the Financial Statements - continued for the Year Ended 31 March 2021

2. Accounting policies - continued

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.

Cash in bank and in hand

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

3. Other trading activities

	2021 £	2020 £
Fundraised income	<u>1,179</u>	<u>1,250</u>

4. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

Trustees' expenses

During the period the Trustees were reimbursed £nil (2020 £1,082) for travel and accommodation expenses.

5. Comparatives for the statement of financial activities

	Unrestricted fund £	Restricted funds £	Total funds £
Income and endowments from			
Donations and legacies	20,000	14,178	34,178
Other trading activities	<u>1,250</u>	<u>-</u>	<u>1,250</u>
Total	21,250	14,178	35,428
Expenditure on			
Raising funds	396	-	396
Charitable activities			
Charitable activities	<u>18,425</u>	<u>14,993</u>	<u>33,418</u>
Total	<u>18,821</u>	<u>14,993</u>	<u>33,814</u>
NET INCOME/(EXPENDITURE)	2,429	(815)	1,614
Reconciliation of funds			
Total funds brought forward	<u>4,392</u>	<u>3,085</u>	<u>7,477</u>
Total funds carried forward	<u><u>6,821</u></u>	<u><u>2,270</u></u>	<u><u>9,091</u></u>

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Notes to the Financial Statements - continued for the Year Ended 31 March 2021

6. Debtors: amounts falling due within one year

	2021	2020
	£	£
Trade debtors	<u>22</u>	<u>1,241</u>

7. Creditors: amounts falling due within one year

	2021	2020
	£	£
Other creditors	93	1,253
Accruals and deferred income	<u>1,068</u>	<u>2,568</u>
	<u>1,161</u>	<u>3,821</u>

8. Analysis of net assets between funds

	Unrestricted fund	Restricted funds	2021 Total funds	2020 Total funds
	£	£	£	£
Current assets	38,149	5,637	43,786	12,912
Current liabilities	<u>(1,161)</u>	<u>-</u>	<u>(1,161)</u>	<u>(3,821)</u>
	<u>36,988</u>	<u>5,637</u>	<u>42,625</u>	<u>9,091</u>

9. Movement in funds

	At 1/4/20	Net movement in funds	At 31/3/21
	£	£	£
Unrestricted funds			
General fund	6,821	30,167	36,988
Restricted funds			
Roy & Murray Green Together Fund	2,270	3,367	5,637
TOTAL FUNDS	<u>9,091</u>	<u>33,534</u>	<u>42,625</u>

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	38,219	(8,052)	30,167
Restricted funds			
Roy & Murray Green Together Fund	3,367	-	3,367
TOTAL FUNDS	<u>41,586</u>	<u>(8,052)</u>	<u>33,534</u>

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

Notes to the Financial Statements - continued for the Year Ended 31 March 2021

9. Movement in funds - continued

Comparatives for movement in funds

	At 1/4/19 £	Net movement in funds £	At 31/3/20 £
Unrestricted funds			
General fund	4,392	2,429	6,821
Restricted funds			
New Member Travel	3,085	(3,085)	-
Roy & Murray Green Together Fund	-	2,270	2,270
	<u>3,085</u>	<u>(815)</u>	<u>2,270</u>
TOTAL FUNDS	<u>7,477</u>	<u>1,614</u>	<u>9,091</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	21,250	(18,821)	2,429
Restricted funds			
New Member Travel	-	(3,085)	(3,085)
Loire Valley Meetings	11,908	(11,908)	-
Roy & Murray Green Together Fund	2,270	-	2,270
	<u>14,178</u>	<u>(14,993)</u>	<u>(815)</u>
TOTAL FUNDS	<u>35,428</u>	<u>(33,814)</u>	<u>1,614</u>

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

The Roy & Murray Green Together Fund is to support travel by representatives of INDPA member organisations in order to stimulate understanding, collaboration and friendship.

The New Member travel fund is towards new member travel to allow face to face meetings.

The Loire Valley meeting fund is towards the Loire Valley meeting.

10. Related party disclosures

During the year costs were recharged by a member of the alliance, Niemann-Pick UK, for administration, social media, office and travel costs etc of £5,361 (2020 £10,798). There was a balance owed to Niemann-Pick UK of £Nil at 31 March 2021 (2020 £1,253).

The International Niemann-Pick Disease Alliance 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 £1,696 (2020 £4,477). At 31 March 2021 there was a balance owed by INPDR of £22 (2020 £1,241).

INTERNATIONAL NIEMANN-PICK DISEASE ALLIANCE

**Detailed Statement of Financial Activities
for the Year Ended 31 March 2021**

	2021 £	2020 £
Income and endowments		
Donations and legacies		
Donations	40,407	34,178
Other trading activities		
Fundraised income	<u>1,179</u>	<u>1,250</u>
Total incoming resources	41,586	35,428
Expenditure		
Raising donations and legacies		
Fundraising costs	20	396
Charitable activities		
Finance & admin costs	2,335	2,270
IT costs	79	-
Face to face meetings - all INPDA members	-	23,267
Meetings, conferences, travel and accommodation	204	2,951
Think again: Think NPC	330	610
Social media & communications	2,639	2,027
Other overheads	1,044	1,225
Independent examiner's fee	1,068	1,068
Legal fees	<u>333</u>	<u>-</u>
	<u>8,032</u>	<u>33,418</u>
Total resources expended	<u>8,052</u>	<u>33,814</u>
Net income	<u><u>33,534</u></u>	<u><u>1,614</u></u>