

REGISTERED COMPANY NUMBER: 10646129 (England and Wales)
REGISTERED CHARITY NUMBER: 1175311

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

(A COMPANY LIMITED BY GUARANTEE)

Report of the Trustees and

Financial Statements for the Year Ended 31 March 2021

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

Reference and Administrative Details for the Year Ended 31 March 2021

Trustees	J E Green T Hiwot Mrs T A Mathieson Dr A Dardis (appointed 12.10.20) M Vanier
Company secretary	Mrs T A Mathieson
Registered office	Suite 2 Vermont House Washington Tyne and Wear NE37 2SQ
Registered company number	10646129 (England and Wales)
Registered charity number	1175311
Independent examiner	James Anderson & Co Chartered Accountants Pentland Estate Straiton Edinburgh EH20 9QH

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

Aims and Objectives

The International Niemann-Pick Disease Registry (INPDR) is an independent, not-for-profit charitable company registered in the UK. Created by a collaboration of patients, health professionals and medical researchers, it offers a single, disease-specific global registry data resource that includes both clinical data and patient reported data for Acid Sphingomyelinase Deficiency (ASMD) Niemann-Pick disease, and Niemann-Pick disease type C.

Due to its rarity, registration for Niemann-Pick diseases is particularly important. Registration can provide sufficient data to understand its complex natural history, support accelerated recruitment to trials and facilitate the development and monitoring of care standards.

The mission of the INPDR is to document the Niemann-Pick patient experience; to improve diagnosis, treatment and care, to advance research and ultimately, to improve health outcomes for all those affected.

Our vision is the creation and ongoing development of a comprehensive, international data resource, specific to Niemann-Pick diseases which benefits patients by increasing understanding of these rare conditions, encourages efficient and timely diagnosis, enables progress in research and clinical trials, and facilitates the development of therapeutic interventions.

A key strength of the INPDR is the collaborative relationships developed from the outset and enabling the powerful combination of patient leadership and professional implementation. This ensures the legitimacy of the patient perspective and ensures that it is at the heart of our organisation and mission.

The INPDR will work to enhance and facilitate progress through the following aims and objectives:

Aims

- To build a high quality, complete International population-based Niemann-Pick Disease Registry
- Protect patient privacy and ensure compliance with data protection and the highest clinical standards
- To facilitate clinical research through data sharing and provision of analytical services
- Provide evidence to facilitate advocacy and inform public debate

Objectives

- To describe the epidemiology and natural history of ASMD Niemann-Pick disease and Niemann-Pick Type C
- To support development of standards of diagnosis, clinical management and quality of care
- To establish genotype-phenotype correlations
- To provide support for equal access to biochemical and genetic testing
- To facilitate accelerated recruitment to interventional studies
- To provide a regulatory compliant registry to satisfy post-marketing obligations
- To support regulatory interaction between national/supranational medicines agencies and pharmaceutical companies
- To accelerate progress in understanding NPD, by encouraging education of health professionals and researchers

The purpose of the registry

The INPDR was established in order to enhance and facilitate progress in Niemann-Pick diseases by providing a collaborative approach to the challenges faced by this rare disease community. The more patients who are enrolled, the more effective the Registry will become. The Registry purpose is:

- a) To establish the natural history of the 3 Niemann-Pick diseases (their characteristics, management and outcomes)
- b) To provide an inventory of patients for recruitment to potential clinical trials
- c) To establish genotype-phenotype correlations
- d) To provide support for equal access to biochemical and genetic testing, education of health professionals, and patient empowerment.

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

Report of the Trustees for the Year Ended 31 March 2021

The purpose of the registry (continued)

The Registry is a regulatory compliant, secure database of consenting patients, with appropriate security, management and controls. Data is collected via a secure web-based electronic data capture (EDC) platform for the systematic and uniform collection of clinical data of patients diagnosed with either ASMD or NPC. The active participation of clinicians and patients from around the world facilitate the collection of demographic information, diagnostic results, treatment and health outcomes data.

The INPDR is a long term initiative that will continue to grow data collection internationally and to create mechanisms to ensure that the data collected works hardest to serve patient needs.

Significant activities

During the year we have worked to accelerate the INPDR's global recruitment, to further develop and strengthen the governance of the INPDR and to enable the collected data to be appropriately and securely shared to facilitate research, with the aim of achieving better outcomes for patients.

Although the achievement of our objectives has been slowed somewhat by the challenges of the COVID-19 pandemic, we remain focussed on the achievement of a sustainable patient-led database of at least 1000 patients, that includes, comprehensive natural history data, leading to potential genotype/phenotype correlations; identifies patients eligible for clinical trials; supports post-marketing surveillance and therapy development; supports research; supports regulatory interaction between national/supranational agencies and industry and supports collaboration.

Quality of life questionnaires are also collected directly from patients through our Patient Reported Dataset (PRD). This PRD registry is a separate module from the Clinical Reported Database (CRD) and allows for patients across the world to consent to data collect and contribute without attending a medical facility. Patients are able to consent to the PRD without being enrolled into the CRD, although patients are able to enrol into both. Currently work is in progress to link patients enrolled into the PRD and CRD to allow for clinical and quality of life data to be matched.

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)'.

Achievement and performance

This year, the INPDR has recruited key leadership roles, which has enabled the provision of essential support to clinical centres, with on-boarding of the registry and ongoing data entry. This will increase the completeness and quality of patient data to meet regulatory standards in research, which will facilitate the generation of new knowledge, leading to optimized clinical management and new therapeutic insights.

Recruitment to the INPDR

- At the end of March 2021, the number of patients actively engaging with the INPDR through the Patient Reported Data (PRD) platform stood at 73, from 15 different countries. Translations are currently underway to more effectively support users and encourage greater engagement.
- Recruitment to the Clinical Reported Database (CRD) has continued at a slower pace than expected, due to the COVID-19 pandemic, numbers stand at 311 patients across 8 countries as of March 31st 2021.
- A USA based Clinical Research Associate was successfully recruited in October 2020, enabling further progress in recruiting 10 US clinical sites. A global development plan has been initiated and will operate a phased approach to enable expansion into new jurisdictions to increase the number of patients in the registry.

Governance

- A Strategic Business Plan detailing work and plans for the period 2020-2022 was launched in October 2020. This is available to view on our website www.inpdr.org
- Building on our already robust governance model, we have developed and implemented policies to manage data sharing, support research and engage with industry. Our risk management programme has been revised to include a routine audit cycle and records management system to promote a culture of continuous improvement.

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

Report of the Trustees for the Year Ended 31 March 2021

Achievement and performance (continued)

Governance (continued)

- Work has commenced to further develop our data quality management programme, including a comprehensive data review, to enable a broader range of data collection and enable the data to be used in support of clinical and epidemiological research, through the introduction of a data sharing model that will both protect sensitive patient data and also ensure that the data is accessible so it can be used effectively to improve understanding of Niemann-Pick disease.
- A key aspect of this will be working closely with regulatory authorities to ensure our data meets user and regulatory requirements. Therefore, we have continued to engage with regulators including the FDA and the European Medicines Agency (EMA), with whom the process to achieve a Qualification Opinion is underway.

Communication

- The implementation of a comprehensive communication plan has been implemented to stimulate use of the INPDR by patients and researchers within our existing global networks and to promote collaboration with the broader rare-disease community.
- An Abstract was successfully submitted for a platform presentation at the Virtual WORLD Symposium held in February 2021 "Niemann-Pick diseases and the International Niemann-Pick Disease Registry (INPDR)".
- The INPDR Registry Management Team also presented virtually at the following events in 2020:
 - Ara Parseghian Medical Research Foundation "2020 Michael, Marcia, and Christa Parseghian Scientific Conference for NPC Research - Virtual Symposiums" May 2020
 - National Niemann-Pick Disease Foundation Virtual Family Conference, August 2020
 - Niemann-Pick UK Virtual Interactive Workshop on Niemann-Pick Diseases, September 2020
 - Niemann-Pick UK Family Conference, September 2020
 - Findacure Virtual Rare Disease Showcase "A Technological Revolution", November 2020

Sustainability

A sustainability plan for the INPDR has been introduced, including a commercial subscription model and costing model for the non-commercial sectors, plus a trust and corporate grant strategy, with the aim of diversifying income and continuing to operate as a non-profit organisation.

Financial review

Donations and grants were received in the year of £390,375 (2020 £266,803).

The grants were received from Orphazyme, Sanofi Genzyme and Escape Bio. In addition, a restricted grant was received from the University of Notre Dame, through its Ara Parseghian Medical Research Fund and Michael, Marcia and Christa Parseghian Endowment for Excellence in Niemann Pick Type C Research. The funds received have enabled the continuing development and growth of the Registry, and alongside the high level of support and interaction from the patient and clinical communities, demonstrates the potential of the Registry to make a positive difference for the global Niemann-Pick patient community.

Reserves policy

The free reserves at 31 March 2021 amount to £217,868 (2020 £127,160). The board aim is to hold six months running costs in reserve. At 31 March 2021 there are sufficient reserves but as the registry activities grow a higher level of reserve will be required.

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

Report of the Trustees for the Year Ended 31 March 2021

Future Plans - priorities for the year ahead include

The INPDR's Strategic Plan 2020-2022 is a flexible working document and will be regularly updated with the information and plans needed to achieve the successful implementation of the INPDR's aims and objectives during this three-year period. It is underpinned by Annual Deliverables and Milestones that will reflect priorities and critical requirements plus an annual operational plan which will guide the day to day work of the INPDR. The next phase of development will see the INPDR realise its potential to improve the outcomes for those affected by Niemann-Pick diseases and will focus on three primary themes:

1. Strengthening Governance

Building on the robust governance model developed since 2013, the INPDR shall embed policies to manage data sharing, support research and engage with industry. We shall develop a risk management programme including routine audit cycle and records management system to promote a culture of continuous improvement.

2. Planning for Sustainability

The INPDR will implement a sustainability plan that will encourage stakeholder support and interaction, enable Registry development and help to accelerate progress for this global rare disease community. A subscription and charging policy will provide the opportunity for commercial organisations to invest in the INPDR enabling expansion and enhancing the range of services that can be offered. A wholly owned commercial subsidiary company - INPDR Gateway Ltd - has also been established to facilitate service delivery and further support expansion of the INPDR.

3. Extended data collection: promoting completeness and quality

The INPDR shall further develop our data quality management programme, including a comprehensive data review, to enable a broader range of data collection and seek to continue its expansion globally into new jurisdictions to increase the number of patients in the registry. A key aspect of this will be working closely with regulatory authorities to ensure our data meets user and regulatory requirements.

Promoting Research

For the Registry to realise its potential to improve patient outcomes, the collected data must be used for research to improve understanding of the disease and help support therapeutic and diagnostic development activity. The Registry is approaching a maturity that shall enable the data to be used in support of clinical and epidemiological research. Primarily the registry will achieve this through sharing data with experts in the Niemann-Pick research field, including clinicians, academics and industry. The Registry has implemented a data request process to support research and will actively encourage use of registry data with the aim of facilitating at least 15 research studies over the next two years.

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

Report of the Trustees for the Year Ended 31 March 2021

Structure, governance and management

Status and Governing Document

INPDR is a company limited by guarantee governed by its Memorandum and Articles of Association. The company has one member, the International Niemann-Pick Disease Alliance.

INPDR is also registered as a charity with the Charity Commission.

Recruitment and appointment of new trustees

Up to three trustees may be appointed by the Member. Each partner may nominate up to one Trustee for appointment by the Board.

Organisational Structure

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

The Trustees are directly responsible for the effective governance of the charity and for providing appropriate support and guidance and monitoring of all staff and activities. This is carried out in accordance with statutory guidance and legislation as provided by the Charity Commissioners. The Trustees meet on average every two years with at least four additional teleconferences 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.

Key management remuneration

All trustees give of their time freely and no trustee received remuneration in the period year. The board is 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 size of the organisation is also taken into account.

Wider network

The charity's member is the International Niemann-Pick Disease Alliance (INPDA) which 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.

Risk management

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.

The current Covid-19 pandemic has created a challenging context for all clinical research and it presents challenges for the INPDR to undertake on-site data collection and quality assurance that may create delays in data collection. In addition, the Trustees will also closely monitor the impact of the departure of the UK from the European Union as well as other geopolitical changes on its activities and regulatory requirements. While these events are outside of the control of the INPDR, a strong risk management structure will ensure that the impact of such events on registry activities are minimised.

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 22 December 2021 and signed on its behalf by:



James Green
Trustee

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

Independent examiner's report to the trustees of International Niemann-Pick Disease Registry ('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.

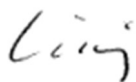
Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of ICAS which is one of the listed bodies.

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 T Spalding
ICAS
James Anderson & Co
Chartered Accountants
Pentland Estate
Straiton
Edinburgh
EH20 9QH

Date: 22 December 2021

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

		Unrestricted fund £	Restricted fund £	2021 Total funds £	2020 Total funds £
	Notes				
Income and endowments from					
Donations and legacies	2	331,098	59,277	390,375	266,803
Expenditure on					
Charitable activities	3				
Charitable activities		240,389	24,866	265,255	139,398
NET INCOME		90,709	34,411	125,120	127,405
Reconciliation of funds					
Total funds brought forward		127,159	-	127,159	(246)
Total funds carried forward		<u>217,868</u>	<u>34,411</u>	<u>252,279</u>	<u>127,159</u>

The notes form part of these financial statements

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

Balance Sheet 31 March 2021

	Notes	2021 £	2020 £
Current assets			
Debtors	8	1,917	-
Cash at bank		<u>262,905</u>	<u>135,042</u>
		264,822	135,042
Creditors			
Amounts falling due within one year	9	(12,543)	(7,883)
		<u>252,279</u>	<u>127,159</u>
Net current assets			
		252,279	127,159
Total assets less current liabilities			
		<u>252,279</u>	<u>127,159</u>
NET ASSETS			
		<u>252,279</u>	<u>127,159</u>
Funds	11		
Unrestricted funds		217,868	127,159
Restricted funds		<u>34,411</u>	<u>-</u>
Total funds		<u>252,279</u>	<u>127,159</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

- (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 22 December 2021 and were signed on its behalf by:



James Green
Trustee

The notes form part of these financial statements

1. 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.

International Niemann-Pick Disease Registry meets the definition of a public benefit entity under FRS 102.

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.

Cash in bank and in hand

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

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.

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

1. Accounting policies - continued

Pension Costs

The company operates a defined contribution scheme, 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.

2. Donations and legacies

	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
Donations	105	-	105	267
Grants	<u>330,993</u>	<u>59,277</u>	<u>390,270</u>	<u>266,536</u>
	<u>331,098</u>	<u>59,277</u>	<u>390,375</u>	<u>266,803</u>

Grants received, included in the above, are as follows:

	2021 £	2020 £
Together Strong Foundation	-	56,536
Orphazyme	76,000	60,000
Sanofi Genzyme	250,000	150,000
University of Notre Dame du Lac	59,277	-
Escape Bio	<u>4,993</u>	<u>-</u>
	<u>390,270</u>	<u>266,536</u>

3. Charitable activities costs

	Direct Costs (see note 4) £
Charitable activities	<u>265,255</u>

4. Direct costs of charitable activities

	2021 £	2020 £
Equipment costs	1,271	-
Wages & NIC	52,089	9,085
Registry hosting	28,647	45,971
Travel & meetings	459	6,349
Registry development and maintenance	84,790	-
Website costs	762	835
Other staff costs	440	3,558
Office expenses	3,660	922
Promotional expenses	439	215
Conferences and awareness raising	-	12,132
Fundraising	-	395
Executive meetings	583	3,053
Independent examiner's fee	<u>1,200</u>	<u>852</u>
Carried forward	174,340	83,367

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

4. Direct costs of charitable activities - continued

	2021 £	2020 £
Brought forward	174,340	83,367
Other professional fees	204	396
Consultancy	65,095	55,635
Legal fees	<u>25,616</u>	<u>-</u>
	<u>265,255</u>	<u>139,398</u>

5. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the period ended 31 March 2021 (2020 - nil)

Trustees' expenses

During the period no trustees were reimbursed for travel expenses. (2020 nil)

6. Staff costs

	2021 £	2020 £
Salaries and wages	50,336	9,085
Social security costs	817	-
Pension costs	<u>936</u>	<u>-</u>
	<u>52,089</u>	<u>9,085</u>

The average monthly number of employees during the year was as follows:

	2021	2020
Coordination and administration	<u>2</u>	<u>1</u>

No employees received emoluments in excess of £60,000.

7. Comparatives for the statement of financial activities

	Unrestricted fund £
Income and endowments from	
Donations and legacies	266,803
Expenditure on	
Charitable activities	
Charitable activities	<u>139,398</u>
NET INCOME	127,405
Reconciliation of funds	
Total funds brought forward	(246)

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

7. Comparatives for the statement of financial activities - continued

Unrestricted
fund
£

Total funds carried forward

127,159

8. Debtors: amounts falling due within one year

2021
£

2020
£

Prepayments

1,917

-

9. Creditors: amounts falling due within one year

2021
£

2020
£

Social security and other taxes

1,519

843

Accruals and deferred income

11,024

7,040

12,543

7,883

10. Analysis of net assets between funds

2021
Unrestricted
fund
£

2020
Total
funds
£

Current assets

230,411

135,042

Current liabilities

(12,543)

(7,883)

217,868

127,159

11. Movement in funds

At 1/4/20
£

Net
movement
in funds
£

At
31/3/21
£

Unrestricted funds

General fund

127,159

90,709

217,868

Restricted funds

APMRF

-

34,411

34,411

TOTAL FUNDS

127,159

125,120

252,279

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

11. 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	331,098	(240,389)	90,709
Restricted funds			
APMRF	59,277	(24,866)	34,411
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>390,375</u>	<u>(265,255)</u>	<u>125,120</u>

Comparatives for movement in funds

	At 1/4/19 £	Net movement in funds £	At 31/3/20 £
Unrestricted funds			
General fund	(246)	127,405	127,159
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>(246)</u>	<u>127,405</u>	<u>127,159</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	266,803	(139,398)	127,405
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>266,803</u>	<u>(139,398)</u>	<u>127,405</u>

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

The APMRF fund is to accelerate progress by facilitating registry recruitment in the USA.

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

12. Related party disclosures

The International Niemann-Pick Disease Alliance (INPDA) is the only member of the company. During the year costs were charged by INPDA to INPDR of £1,696 (2020 £4,477). At 31 March 2021 there was a balance due to INPDA of £22 (2020 £1,241).

Niemann-Pick UK (NPUK) is a member of the INPDA. During the year there were recharges for shared staff, travel and overheads by NPUK to INPDR of £7,799 (2020 £10,334). At 31 March 2021 there was a balance due to NPUK of £Nil (2020 £573).

INTERNATIONAL NIEMANN-PICK DISEASE REGISTRY

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

	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
Income and endowments				
Donations and legacies				
Donations	105	-	105	267
Grants	<u>330,993</u>	<u>59,277</u>	<u>390,270</u>	<u>266,536</u>
	<u>331,098</u>	<u>59,277</u>	<u>390,375</u>	<u>266,803</u>
Total incoming resources	331,098	59,277	390,375	266,803
Expenditure				
Charitable activities				
Equipment costs	583	688	1,271	-
Wages & NIC	52,089	-	52,089	9,085
Registry hosting	19,598	9,049	28,647	45,971
Travel & meetings	459	-	459	6,349
Registry development and maintenance	84,790	-	84,790	-
Website costs	762	-	762	835
Other staff costs	134	306	440	3,558
Office expenses	3,660	-	3,660	922
Promotional expenses	439	-	439	215
Conferences and awareness raising	-	-	-	12,132
Fundraising	-	-	-	395
Executive meetings	583	-	583	3,053
Independent examiner's fee	1,200	-	1,200	852
Other professional fees	204	-	204	396
Consultancy	50,272	14,823	65,095	55,635
Legal fees	<u>25,616</u>	<u>-</u>	<u>25,616</u>	<u>-</u>
	<u>240,389</u>	<u>24,866</u>	<u>265,255</u>	<u>139,398</u>
Total resources expended	<u>240,389</u>	<u>24,866</u>	<u>265,255</u>	<u>139,398</u>
Net income	<u>90,709</u>	<u>34,411</u>	<u>125,120</u>	<u>127,405</u>

This page does not form part of the statutory financial statements