

Charity number: 1171274

NORRIE DISEASE FOUNDATION

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2022

NORRIE DISEASE FOUNDATION
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NORRIE DISEASE FOUNDATION
Report of the Trustees
For the year ended 31 December 2022

The Trustees have pleasure in presenting their report and the financial statements for the charity for the year ended 31 December 2022. 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 the Republic of Ireland (FRS 102) (effective 1 January 2015).

Structure, governance and management

The Norrie Disease Foundation was established as a Charitable Incorporated Organisation on 24 January 2017 and is managed by the Board of Trustees.

Risk assessment and management

The Trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. The Trustees regularly review the risks to which NDF is exposed, particularly activity, operational and financial risks and to ensure procures and reporting regimes to manage and reduce any identified risks are in place. The prime risk to which NDF is exposed is financial. The Trustees are satisfied that the current level of reserves is adequate to meet both unforeseen contingencies and the costs of planned activities for the future.

Objectives and charitable activities

Charitable objectives

To relieve the needs of those affected by Norrie disease by promoting greater understanding of the causes, symptoms, and treatment of Norrie disease in all its forms including:

- promoting research and sharing and disseminating of results of such research for the benefit of the general public; and
- raising public awareness of the symptoms, needs and related medical conditions of those living with Norrie disease.

Charitable activities:

The Trustees ensure that sufficient attention is paid to fundraising activities, monitoring grant funding opportunities and manage the charity's assets to ensure its sustainability and ability to carry out its charitable objectives. The charity relies heavily on its volunteers as it has no paid members of staff.

Public benefit

In exercising their duty, the Trustees confirm that they have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'. Our objectives are to offer support and information to families affected by Norrie disease. NDF liaises closely with researchers at UCL Great Ormond St Hospital (UCL GOSH) with regards to the ongoing pioneering research into hearing loss associated with Norrie disease. It also works constructively and in partnership with other agencies and organisations to continually improve support for families affected by Norrie disease - to change lives and make a difference to those living with the condition.

Summary of activities, achievement and performance

Key activities and achievements throughout the year include:

Peer Support

One of the main aims of the Foundation is to bring together families and the Norrie community to share experiences and provide peer support through the Norrie network. Due to the continuing Covid-19 pandemic, we were unfortunately unable to organise a Family Day but we continue to provide support via email and through the ND private Facebook group, where ND families have found comfort from hearing and sharing experiences.

Communications

- Communications with those within the Norrie community and the general public through the NDF website, and via social media
- On Facebook a public page for the general public is used as our primary form of outbound communication. We also have a closed support group for families affected by the condition.
- NDF also has active Twitter and Instagram pages.

Research

- The first research paper into the Norrie disease hearing loss 'The timing of auditory sensory deficits in Norrie disease has

NORRIE DISEASE FOUNDATION
Report of the Trustees Continued
For the year ended 31 December 2022

implications for therapeutic intervention', was dedicated to Professor Maria Bitner-Glindzicz, the driving force behind the creation of the NDF and the start of pioneering research into treating the hearing loss. <https://insight.jci.org/articles/view/148586>. This work was supported by Newlife the Charity for Disabled Children; SPARKS (Sport Aiding Medical Research for Kids); and Great Ormond Street Hospital Children's Charity, Royal National Institute for Deaf People (G86), and the National Institute for Health Research (NIHR) Great Ormond Street Hospital Biomedical Research Centre.

- The second published Norrie disease research paper 'Spectrum of Mutations in NDP Resulting in Ocular Disease; a Systematic Review' is another groundbreaking milestone in the journey of understanding Norrie disease <https://www.frontiersin.org/articles/10.3389/fgene.2022.884722/full>.

This work was supported by Great Ormond Street Hospital Children's Charity and the National Institute for Health Research (NIHR) Great Ormond Street Hospital Biomedical Research Centre.

- Dr Valda Pauzolyte received a PhD from University College London, funded by NewLife the Charity for Disabled Children in Hearing Loss in Norrie Disease and AAV-mediated Gene Therapy.

- NDF continues to support the Medical Advisory Board (MAB), which was formed to guide the trustees in scientific matters, including research efforts and direction, and consists of renowned experts in the field. The MAB continues to meet regularly to facilitate the expanding body of knowledge around Norrie disease so families can be better supported - the trustees are very grateful to the MAB members for their dedication and commitment to helping Norrie families. The MAB takes the lead in identifying research opportunities.

- The NDF are dedicated and committed to finding a treatment for the ND hearing loss. As part of this commitment, the NDF is funding a dedicated NDF PhD Studentship at UCL Great Ormond Street Institute of Child Health on gene therapy for ND investigating delivery of the NDP gene directly to the ear. NDF was part of the interview panel and the studentship commenced in March 2022.

Fundraising

- The Royal Parks Half took place in October 2022, and NDF had three official charity places in the event.

- The Trustees would like to thank all of NDF's incredibly generous supporters who donate regular and one-off donations.

- XiJaro and Pitch (the latter being Trustee and Ambassador Anthony Ryers) continue to support the NDF through online streaming events to raise funds and awareness of ND.

- Josh Horrobin wrote 'Losing my mind', a track which is available on Bandcamp to raise funds for NDF

- NDF would like to thank the Kelvedon Community Association and AKO Foundation for their generous donations.

Financial review and reserves policy

The charity Trustees continually monitor cash reserves to ensure its financial stability. The Trustees have examined the NDF's requirements for free reserves in light of predominant risks to the NDF. These are identified as a loss of income from donations and fundraising. The NDF is committed to building a reserves policy to ensure there is enough funding to cover one year's operating costs and the expenses for one family meet up per year which currently stand at £35,000. The charity has no outstanding financial obligations nor outstanding debts, with the exception of the future grant payments for the PhD as mentioned under research in the trustee's report and other creditors both short term and long term in the notes to the accounts. The total future liabilities amount to £50,000 split over 2 years and are dependent on annual reports being submitted by the PHD student

The charity's principal source of funds comes from the general public, either through donations or at one-off fundraising events.

NORRIE DISEASE FOUNDATION
Report of the Trustees Continued
For the year ended 31 December 2022

Chair's report**Statement of Trustees' responsibilities**

The Trustees are responsible for preparing the Trustees' report and the accounts in accordance with Charities Act 2011 and United Kingdom Generally Accepted Accounting Practice.

The Charities Act 2011 requires the Trustees to prepare accounts for each financial year which give a true and fair view of its financial activities during the year and of its financial position at the end of the year. In presenting those accounts, they are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP FRS 102;
- make judgements and estimates that are reasonable and prudent;
- follow applicable UK accounting standards and the Charities SORP FRS 102, disclosing and explaining any departures in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to do so.

The Trustees are responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the Charity and to enable them to ensure that the accounts comply with the Charities Act 2011 and with the requirements of the Statement of Recommended Practice Accounting and Reporting by Charities: statement of recommended practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) - Charities SORP FRS102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102). They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities besides the above responsibilities.

This report was approved by the trustees on 20th October 2023

OBJECTIVES AND ACTIVITIES**Objectives and aims**

The trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	NORRIE DISEASE FOUNDATION
Charity registration number	1171274
Principal address	PO BOX 12476 Colchester CO1 9RB

Trustees

The trustees and officers serving during the year and since the year end were as follows:

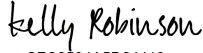
Theresa Peacock
 Kelly Louise Leggett
 Wendy Joan Horrobin
 Kelly Robinson
 Caroline Elizabeth Harding
 Anthony Reyers

Independent examiner

Beach Accountants Limited
 Chartered Certified Accountants
 10 Blue Sky Way
 Monkton Business Park South
 South Tyneside
 NE31 2EQ

NORRIE DISEASE FOUNDATION
Report of the Trustees Continued
For the year ended 31 December 2022

Approved by the Board of Trustees and signed on its behalf by

DocuSigned by:

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.....
Kelly Robinson

20 October 2023

NORRIE DISEASE FOUNDATION
Independent Examiners Report to the Trustees
For the year ended 31 December 2022

I report to the trustees on my examination of the accounts of the charity for the year ended 31 December 2022.

Responsibilities and basis of report

As the charity trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the 2011 Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiners 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 that in any material respect:

1. accounting records were not kept in respect of the Charity as required by section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.

DocuSigned by:

Gavin Spencer

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Beach Accountants Limited

Chartered Certified Accountants

10 Blue Sky Way

Monkton Business Park South

South Tyneside

NE31 2EQ

20 October 2023

NORRIE DISEASE FOUNDATION
Statement of Financial Activities
For the year ended 31 December 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 £	2021 £
Income and endowments from:					
Donations and legacies	2	47,571	-	47,571	71,304
Total		47,571	-	47,571	71,304
Expenditure on:					
Raising funds	4	(2,985)	-	(2,985)	(1,638)
Charitable activities	5	(25,450)	-	(25,450)	(184)
Total		(28,435)	-	(28,435)	(1,822)
Net income/expenditure		19,136	-	19,136	69,482
Reconciliation of funds					
Total funds brought forward		179,990	1,771	181,761	112,279
Total funds carried forward		199,126	1,771	200,897	181,761

NORRIE DISEASE FOUNDATION

Statement of Financial Position

As at 31 December 2022

	Notes	2022 £	2021 £
Current assets			
Debtors: amounts falling due within one year	10	25,000	-
Debtors: amounts falling due after more than one year	10	25,000	-
Cash at bank and in hand		201,653	182,349
		251,653	182,349
Creditors: amounts falling due within one year	11	(25,756)	(588)
Net current assets		225,897	181,761
Total assets less current liabilities		225,897	181,761
Creditors: amounts falling due after more than one year	12	(25,000)	-
Net assets		200,897	181,761
The funds of the charity			
Restricted income funds	13	1,771	1,771
Unrestricted income funds	13	199,126	179,990
Total funds		200,897	181,761

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:

DocuSigned by:

Kelly Robinson

CEC2504A5D64419

Kelly Robinson
Trustee

20 October 2023

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements
For the year ended 31 December 2022

1. Accounting Policies

Basis of accounting

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and 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 2015)', Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the Charities Act 2011.

NORRIE DISEASE FOUNDATION meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Going concern

The Trustees have assessed the financial viability of the Charity and have concluded that there is no reason why the Charity will not continue operating for at least 12 months following the year ending 31st December 2022. For this reason the financial accounts have been prepared on a going concern basis.

Funds

Unrestricted funds are incoming resources receivable or generated for the furtherance of the objectives of the Charity without a specified purpose and are available as general funds. Resources expended which meet these criteria are charged to the funds, together with a fair allocation of staff and support costs. Restricted funds are used for the specific purposes laid down by the donor or sponsor. Resources expended which meet these criteria are charged to the funds.

Incoming resources

Income is recognised in the period when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably and is not deferred.

Resources expended

Expenditure incurred is recognised in the period once there is a legal constructive obligation to make a payment to a third party. It is probable that settlement will be required and the amount of the obligation can be measured reliably.

Taxation

The Charity is exempt from taxation on its charitable activities, as it is a registered charity.

Debtors

Debtors are recognised at the settlement amount due after allowing for any discounts and as per the terms agreed. Prepayments are valued at the amounts prepaid for services and accrued income are valued at the amounts due per terms agreed and there is certainty of receipt.

Cash at bank and in hand

Cash at bank and cash in hand includes bank balance kept in current and deposit accounts.

Creditors and provisions:

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provision are normally recognised at their settlement amount after allowing for any discounts.

Critical accounting estimates and judgements:

There are no significant areas of judgement or key sources of estimation uncertainty arising from the preparation of accounts.

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2022

2. Income from donations and legacies

	2022	2021
	£	£
Unrestricted funds		
Donations received	47,571	68,804
Grants received	-	2,500
	<u>47,571</u>	<u>71,304</u>

*Sponsored Events***4. Expenditure on generating donations and legacies**

	2022	2021
	£	£
Unrestricted funds		
Support costs	2,985	1,638
	<u>2,985</u>	<u>1,638</u>

5. Costs of charitable activities by activity type

	Activities undertaken directly	Grant funding of activities	2022	2021
	£	£	£	£
Grant funding of activities				
Sponsored Events	450	25,000	25,450	184

6. Analysis of support costs

	2022	2021
	£	£
Governance costs		
Insurance	351	380
Website	96	133
Accountancy	756	588
Postage and stationary	410	437
Regulator costs	50	100
Commission and fees on receiving donations	1,322	-
	<u>2,985</u>	<u>1,638</u>

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2022

7. Particulars of employees

	2022	2021
	£	£
General	0	0
	<u>0</u>	<u>0</u>

8. Trustee remuneration and related party transactions

There are no disclosable trustee payments in 2022 financial year.

9. Comparative for the Statement of Financial Activities

The comparative year values on the Statement of Financial Activities are for unrestricted funds.

10. Debtors

	2022	2021
	£	£
Amounts due within one year:		
Prepayments and accrued income	25,000	-
	<u>25,000</u>	<u>-</u>
Amounts due after more than one year:		
Prepayments and accrued income	25,000	-
	<u>25,000</u>	<u>-</u>

Debtors relate to future costs of grant payments for funding of a PhD which will be paid over the next 2 years.

11. Creditors: amounts falling due within one year

	2022	2021
	£	£
Other creditors	25,000	-
Accruals and deferred income	756	588
	<u>25,756</u>	<u>588</u>

Short term other creditors relates to a grant payment for the funded PhD.

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2022

12. Creditors: amounts falling due after more than one year

	2022	2021
	£	£
Other creditors	25,000	-
	<u>25,000</u>	<u>-</u>

Long term other creditors relates to a grant payment for the funded PhD.

13. Movement in funds**Unrestricted Funds**

	Balance at 01/01/2022	Incoming resources	Outgoing resources	Balance at 31/12/2022
	£	£	£	£
<i>General</i>				
General	179,990	47,571	(28,435)	199,126
	<u>179,990</u>	<u>47,571</u>	<u>(28,435)</u>	<u>199,126</u>

Unrestricted Funds - Previous year

	Balance at 01/01/2021	Incoming resources	Outgoing resources	Balance at 31/12/2021
	£	£	£	£
<i>General</i>				
General	110,508	71,304	(1,822)	179,990
	<u>110,508</u>	<u>71,304</u>	<u>(1,822)</u>	<u>179,990</u>

Purpose of unrestricted Funds

General

To fund the general objectives of the charity.

Restricted Funds

	Balance at 01/01/2022	Balance at 31/12/2022
	£	£
Family fun day	1,771	1,771
	<u>1,771</u>	<u>1,771</u>

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2022

Restricted Funds - Previous year

	Balance at 01/01/2021	Balance at 31/12/2021
	£	£
Family fun day	1,771	1,771
	1,771	1,771

14. Analysis of net assets between funds

	Net current assets / (liabilities)	Creditors > one year	Net Assets
	£	£	£
Unrestricted funds			
<i>General</i>			
General	224,126	(25,000)	199,126
Restricted funds			
Family fun day	1,771	-	1,771
	225,897	(25,000)	200,897

Previous year

	Net current assets / (liabilities)	Creditors > one year	Net Assets
	£	£	£
Unrestricted funds			
<i>General</i>			
General	179,990	-	179,990
Restricted funds			
Family fun day	1,771	-	1,771
	181,761	-	181,761

NORRIE DISEASE FOUNDATION
Detailed Statement of Financial Activities
For the year ended 31 December 2022

	2022	2021
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	47,571	68,804
Grants receivable	-	2,500
	47,571	71,304
Total incoming resources	47,571	71,304
EXPENDITURE		
Charitable activities		
Cost of direct charitable activity	(450)	(184)
Cost of grant funded charitable activity	(25,000)	-
	(25,450)	(184)
SUPPORT COSTS		
Governance costs		
Governance costs	(2,985)	(1,638)
	(2,985)	(1,638)
Total resources expended	(28,435)	(1,822)
Net Income	19,136	69,482