

Charity number: 1171274

Company number: CE008898

(England and Wales)

NORRIE DISEASE FOUNDATION

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2023

NORRIE DISEASE FOUNDATION
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For the year ended 31 December 2023

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NORRIE DISEASE FOUNDATION
Report of the Trustees
For the year ended 31 December 2023

The Trustees have pleasure in presenting their report and the financial statements for the charity for the year ended 31 December 2023. 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:

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

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. 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/X and Instagram pages.

Research Conference:

- On 2 December 2023, the first NDF conference brought together families and medical professionals at Great Ormond Street Institute of Child Health to share experiences and learn about the pioneering research into treating the hearing loss.
- 80 in-person attendees, and many more joining online, heard personal accounts from parents and young people alongside presentations from researchers, clinicians and other stakeholders.

NORRIE DISEASE FOUNDATION
Report of the Trustees Continued
For the year ended 31 December 2023

- As part of NDF's commitment to include parents, carers, children and young people affected by Norrie Disease, we were pleased to be able to cover travel and accommodation expenses for families so that as many could attend in person as possible. We also provided activities for younger attendees, including interactive touch tours of the current research into treating the hearing loss using model cochlear and other specially adapted resources. Younger members enjoyed sensory musical activities in a sensory room. Teenagers were able to meet other teens affected by Norrie disease for the first time.

- Since the conference NDF has connected with new families in the UK and globally interested in supporting the research.

Research:

- 'Systemic gene therapy paper rescues retinal dysfunction and hearing loss in a model of Norrie disease'. This paper shares the findings of an international team led by researchers at GOSH, UCL and the National Institute of Health and Care Research Great Ormond Street Hospital Biomedical Research Centre (NIHR GOSH BRC) led by Professor Jane Sowden funded in partnership by GOSHCC & Sparks and the Norrie Disease Foundation. <https://www.embopress.org/doi/full/10.15252/emmm.202317393>

- James Arwyn-Jones was awarded a fellowship through the Lewis Spitz Surgeon Scientist PhD programme at UCL Great Ormond Street Institute of Child Health (GOS ICH) and will work under the supervision of Professor Jane Sowden and Mr Robert Nash to use a mouse genetic model of Norrie disease to evaluate potential gene therapies. The aim is to perform a pre-clinical gene therapy trial in the mouse model, delivering the NDP gene sequence which is faulty in Norrie disease by intracochlear injection and measuring the outcomes of prevention of hair cell death and hearing loss. James started his three-year PhD project in October 2023.

- 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 and is due to be completed in 2025.

Fundraising:

- The Royal Parks Half took place in October 2023, and NDF had three official charity places in the event. NDF also had fundraisers running the Bath Half and taking part in the 3 Peaks Challenge, and an incredible challenge of climbing Ben Nevis and cycling 500 miles home. Thank you to all who take part in these incredible activities for NDF!

- 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.

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. The charity has no outstanding financial obligations nor outstanding debts. 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 2023

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 30th August 2024

OBJECTIVES AND ACTIVITIES

Objectives and aims

The trustees have considered the Charity Commision'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
Company registration number	CE008898
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 2023

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

DocuSigned by:

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31 August 2024

Kelly Robinson

NORRIE DISEASE FOUNDATION
Independent Examiners Report to the Trustees
For the year ended 31 December 2023

I report to the trustees on my examination of the accounts of the charitable company for the year ended 31 December 2023.

Responsibilities and basis of report

As the charity Trustees, who are also directors for the purposes of company law, 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 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 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 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 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.

DocuSigned by:

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

31 August 2024

NORRIE DISEASE FOUNDATION
Statement of Financial Activities (including Income and Expenditure Account)
For the year ended 31 December 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 £	2022 £
Income and endowments from:					
Donations and legacies	2	30,562	-	30,562	47,571
Total		30,562	-	30,562	47,571
Expenditure on:					
Raising funds	4	(1,783)	-	(1,783)	(2,985)
Charitable activities	5	(3,854)	-	(3,854)	(25,450)
Total		(5,637)	-	(5,637)	(28,435)
Net income/expenditure		24,925	-	24,925	19,136
Reconciliation of funds					
Total funds brought forward		199,126	1,771	200,897	181,761
Total funds carried forward		224,051	1,771	225,822	200,897

NORRIE DISEASE FOUNDATION
Statement of Financial Position
As at 31 December 2023

	Notes	2023 £	2022 £
Current assets			
Debtors: amounts falling due within one year	10	50,022	25,000
Debtors: amounts falling due after more than one year	10	-	25,000
Cash at bank and in hand		226,556	201,653
		276,578	251,653
Creditors: amounts falling due within one year	11	(50,756)	(25,756)
Net current assets		225,822	225,897
Total assets less current liabilities		225,822	225,897
Creditors: amounts falling due after more than one year	12	-	(25,000)
Net assets		225,822	200,897
The funds of the charity			
Restricted income funds	13	-	1,771
Unrestricted income funds	13	225,822	199,126
Total funds		225,822	200,897

For the year ended 31 December 2023 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

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

DocuSigned by:

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Kelly Robinson
Trustee

31 August 2024

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements
For the year ended 31 December 2023

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 Companies Act 2006.

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 2023

2. Income from donations and legacies

	2023	2022
	£	£
Unrestricted funds		
Donations received	30,562	47,571
	30,562	47,571

Sponsored Events

4. Expenditure on generating donations and legacies

	2023	2022
	£	£
Unrestricted funds		
Support costs	1,783	2,985
	1,783	2,985

5. Costs of charitable activities by activity type

	2023	2022
	£	£
Activities undertaken directly		
Sponsored Events	3,854	25,450

6. Analysis of support costs

	2023	2022
	£	£
Governance costs		
Insurance	401	351
Website	113	96
Accountancy	756	756
Postage and stationary	463	410
Regulator costs	50	50
Commission and fees on receiving donations	-	1,322
	1,783	2,985

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2023

7. Particulars of employees

	2023	2022
General	0	0
	<u>0</u>	<u>0</u>

8. Trustee remuneration and related party transactions

There are no disclosable trustee payments in the 2023 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

	2023	2022
	£	£
Amounts due within one year:		
Prepayments and accrued income	50,000	25,000
Other debtors	22	-
	<u>50,022</u>	<u>25,000</u>
Amounts due after more than one year:		
Prepayments and accrued income	-	25,000
	<u>-</u>	<u>25,000</u>

Prepayments includes uninvoiced fees for phd funding which are payable upon completion of work, the remaining funding is now expected to be completed and invoiced in 2024. This is why all prepayments are now shown as short term.

11. Creditors: amounts falling due within one year

	2023	2022
	£	£
Other creditors	50,000	25,000
Accruals and deferred income	756	756
	<u>50,756</u>	<u>25,756</u>

Other creditors includes uninvoiced fees for phd funding which are payable upon completion of work, the remaining funding is now expected to be completed and invoiced in 2024. This is why all other creditors are now shown as short term.

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2023

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

	2023	2022
	£	£
Other creditors	-	25,000
	<u>-</u>	<u>25,000</u>

13. Movement in funds**Unrestricted Funds**

	Balance at 01/01/2023	Incoming resources	Outgoing resources	Transfers	Balance at 31/12/2023
	£	£	£	£	£
<i>General</i>					
General	199,126	30,562	(5,637)	1,771	225,822
	<u>199,126</u>	<u>30,562</u>	<u>(5,637)</u>	<u>1,771</u>	<u>225,822</u>

Unrestricted Funds - Previous year

	Balance at 01/01/2022	Incoming resources	Outgoing resources	Transfers	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>-</u>	<u>199,126</u>

Purpose of unrestricted Funds

General

To fund the general objectives of the charity.

Restricted Funds

	Balance at 01/01/2023	Transfers	Balance at 31/12/2023
	£	£	£
Family fun day	1,771	(1,771)	-
	<u>1,771</u>	<u>(1,771)</u>	<u>-</u>

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2023

Restricted Funds - Previous year

	Balance at 01/01/2022	Transfers	Balance at 31/12/2022
	£	£	£
Family fun day	1,771	-	1,771
	1,771	-	1,771

All restricted funds in the year have been transferred to unrestricted funds to cover part of the costs of the conference. This is in line with the 'terms of the use' of the restricted funds and the terms of the funds received by donors.

Purpose of restricted funds

Family fun day

To fund family fun days and conferences as stipulated by the terms of funds received.

14. Analysis of net assets between funds

	Net current assets / (liabilities)	Creditors > one year	Net Assets
	£	£	£
Unrestricted funds			
<i>General</i>			
General	225,822	-	225,822
Restricted funds			
	225,822	-	225,822

Previous year

	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

NORRIE DISEASE FOUNDATION
Detailed Statement of Financial Activities
For the year ended 31 December 2023

	2023	2022
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	30,562	47,571
	30,562	47,571
Total incoming resources	30,562	47,571
EXPENDITURE		
Charitable activities		
Cost of direct charitable activity	(3,854)	(450)
Cost of grant funded charitable activity	-	(25,000)
	(3,854)	(25,450)
SUPPORT COSTS		
Governance costs		
Governance costs	(1,783)	(2,985)
	(1,783)	(2,985)
Total resources expended	(5,637)	(28,435)
Net Income	24,925	19,136