

Charity number: 1171274

NORRIE DISEASE FOUNDATION

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 December 2021

NORRIE DISEASE FOUNDATION
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NORRIE DISEASE FOUNDATION
Report of the Trustees
For the year ended 31 December 2021

The Trustees have pleasure in presenting their report and the financial statements for the charity for the year ended 31 December 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 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. During 2020-20221 the Foundation signposted Norrie families to the GOSH dual sensory clinics for state of the art dual sensory testing using cutting edge equipment. This was part of the groundbreaking dual sensory clinics at the new GOSH Sight and Sound hospital.

NORRIE DISEASE FOUNDATION
Report of the Trustees Continued
For the year ended 31 December 2021

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

- 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.

- NDF published its Research Strategy committing the charity to supporting laboratory and clinical research focused on:

(i) understanding the genetics of ND and the causes of hearing loss including how and when it occurs, in order to identify the right time for intervention with a potential therapy, and

(ii) NDP gene therapy or other approaches to correct the damaging effect of the faulty gene in order to prevent the disease.

- The NDF are dedicated and committed to finding a treatment for the ND hearing loss.

- 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, commencing March 2022.

Fundraising

- Much of the planned fundraising was cancelled due to the Covid-19 pandemic. The Royal Parks Half was postponed to October 2021, and NDF had six official charity places in the event. NDF also received a charity place at the London Marathon, and had runners fundraising for NDF at several other iconic races across the country, including the Great North Run.

- 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.

- NDF is grateful to Genetic Disorders UK for its support in providing grants and we would also like to thank the AKO Foundation for its donation as part of its employee 'Give Back' scheme.

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.

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

NORRIE DISEASE FOUNDATION
Report of the Trustees Continued
For the year ended 31 December 2021

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
(Appointed: 27 January 2021)

Independent examiner

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

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

DocuSigned by:

Kelly Robinson

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30 September 2022

Kelly Robinson

NORRIE DISEASE FOUNDATION
Independent Examiners Report to the Trustees
For the year ended 31 December 2021

I report to the trustees on my examination of the accounts of the charity for the year ended 31 December 2021.

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

30 September 2022

NORRIE DISEASE FOUNDATION
Statement of Financial Activities
For the year ended 31 December 2021

	Notes	Unrestricted funds	Restricted funds	2021	2020
		£	£	£	£
Income and endowments from:					
Donations and legacies	2	71,304	-	71,304	57,768
Charitable activities	3	-	-	-	5,029
Total		71,304	-	71,304	62,797
Expenditure on:					
Raising funds	4	(1,638)	-	(1,638)	(63,956)
Charitable activities	5	(184)	-	(184)	(2,662)
Total		(1,822)	-	(1,822)	(66,618)
Net income/expenditure		69,482	-	69,482	(3,821)
Reconciliation of funds					
Total funds brought forward		110,508	1,771	112,279	116,100
Total funds carried forward		179,990	1,771	181,761	112,279

NORRIE DISEASE FOUNDATION
Statement of Financial Position
As at 31 December 2021

	Notes	2021 £	2020 £
Current assets			
Cash at bank and in hand		182,349	112,819
		182,349	112,819
Creditors: amounts falling due within one year	10	(588)	(540)
Net current assets		181,761	112,279
Total assets less current liabilities		181,761	112,279
Net assets		181,761	112,279
The funds of the charity			
Restricted income funds	11	1,771	422
Unrestricted income funds	11	179,990	111,857
Total funds		181,761	112,279

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

DocuSigned by:

Kelly Robinson

CFC2504A5D64419

 Kelly Robinson
 Trustee

30 September 2022

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements
For the year ended 31 December 2021

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 2021 . For this reason the financial accounts have been prepared on a going concern basis.

2. Income from donations and legacies

	2021	2020
	£	£
Unrestricted funds		
Donations received	68,804	57,768
Grants received	2,500	-
	<u>71,304</u>	<u>57,768</u>

3. Income from charitable activities

	2021	2020
	£	£
<i>Sponsored Events</i>		
Income from charitable activities	-	5,029

4. Expenditure on generating donations and legacies

	2021	2020
	£	£
Unrestricted funds		
Donations	-	62,500
Support costs	1,638	1,456
	<u>1,638</u>	<u>63,956</u>

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2021

5. Costs of charitable activities by activity type

	2021	2020
	£	£
Activities undertaken directly		
Sponsored Events	184	2,662

6. Analysis of support costs

	2021	2020
	£	£
Governance costs	1,638	1,456

7. Particulars of employees

	2021	2020
General	0	0
	<u>0</u>	<u>0</u>
	<u>0</u>	<u>0</u>

8. Trustee remuneration and related party transactions

There are no reportable transactions in the year with Trustees that need to be declared.

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2021

9. Comparative for the Statement of Financial Activities

	Unrestricted funds £	Restricted funds £	2020 £
Income and endowments from:			
Donations and legacies	57,768	-	57,768
Charitable activities	5,029	-	5,029
Total	62,797	-	62,797
Expenditure on:			
Raising funds	(62,500)	-	(62,500)
Charitable activities	(1,313)	(1,349)	(2,662)
Total	(63,813)	(1,349)	(65,162)
Net expenditure	(1,016)	(1,349)	(2,365)
Reconciliation of funds			
Total funds brought forward	114,329	1,771	116,100
Total funds carried forward	113,313	422	113,735

10. Creditors: amounts falling due within one year

	2021 £	2020 £
Accruals and deferred income	588	540
	588	540

11. Movement in funds**Unrestricted Funds**

	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
	110,508	71,304	(1,822)	179,990

Unrestricted Funds - Previous year

	Balance at 01/01/2020 £	Incoming resources £	Outgoing resources £	Balance at 31/12/2020 £
<i>General</i>				
General	114,329	62,797	(65,269)	111,857
	114,329	62,797	(65,269)	111,857

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2021

Purpose of unrestricted Funds

General

To fund the general objectives of the charity.

Restricted Funds

	Balance at 01/01/2021	Outgoing resources	Balance at 31/12/2021
	£	£	£
Family fun day	1,771	-	1,771
	<u>1,771</u>	<u>-</u>	<u>1,771</u>

Restricted Funds - Previous year

	Balance at 01/01/2020	Outgoing resources	Balance at 31/12/2020
	£	£	£
Family fun day	1,771	(1,349)	422
	<u>1,771</u>	<u>(1,349)</u>	<u>422</u>

12. Analysis of net assets between funds

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

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2021

Previous year

	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
<i>General</i>		
General	111,857	111,857
Restricted funds		
Family fun day	422	422
	112,279	112,279

NORRIE DISEASE FOUNDATION
Detailed Statement of Financial Activities
For the year ended 31 December 2021

	2021	2020
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	68,804	57,768
Grants receivable	2,500	-
	71,304	57,768
Charitable activities		
Income from charitable activities	-	5,029
	-	5,029
Total incoming resources	71,304	62,797
EXPENDITURE		
Raising donations and legacies		
Donations	-	(62,500)
	-	(62,500)
Charitable activities		
Cost of direct charitable activity	(184)	(2,662)
	(184)	(2,662)
SUPPORT COSTS		
Governance costs		
Governance costs	(1,638)	(1,456)
	(1,638)	(1,456)
Total resources expended	(1,822)	(66,618)
Net Income	69,482	(3,821)