

NORRIE DISEASE FOUNDATION

For the year ended 31 December 2020

Report of the Trustees and Unaudited Financial Statements

NORRIE DISEASE FOUNDATION
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NORRIE DISEASE FOUNDATION
Independent Examiners Report to the Trustees
For the year ended 31 December 2020

I report to the trustees on my examination of the accounts of the charity for the year ended 31 December 2020.

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:

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

27 August 2021

NORRIE DISEASE FOUNDATION
Reference and Administrative Information
For the year ended 31 December 2020

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
Louise Elaine Atkins (Resigned: 10 September 2020)
Caroline Elizabeth Harding

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
For the year ended 31 December 2020

The Trustees have pleasure in presenting their report and the financial statements for the charity for the year ended 31 December 2020. 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 procedures 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. In 2019, one additional trustee was recruited. In addition, three Ambassadors from the Norrie community were added to our team to raise awareness of the condition.

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. In February 2020, the third official Family Day took place at the RNIB Pears Centre for Specialist Learning with 20 families attending. Funded through a previous grant from Genetic Disorders UK, the day enabled families to get to know each other and share their experiences of living with Norrie disease, and what has and hasn't worked for them. Prof Jane Sowden attended to provide an update to families on the research activities into the progressive hearing loss taking place at UCL GOSH.
- NDF have continued to provide a range of information booklets offering guidance and support for ND families including Information for educational settings ND information for families.

NORRIE DISEASE FOUNDATION
Report of the Trustees
For the year ended 31 December 2020

Covid-19

ND families have found comfort from hearing and sharing experiences via the ND private Facebook group. NDF have continued to provide a range of information booklets offering guidance and support for ND families including

Medical Advisory Board (MAB)

The MAB 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.

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 took part in pilot dual sensory clinics at the new Sight and Sound Hospital at GOSH and 20 families got seen in a dual sensory clinic.
- The 3 year laboratory study at UCL GOSH, sponsored by Sparks and Newlife, investigating the hearing loss in Norrie to better understand if this can be treated through gene therapy concluded in 2020. The results are due to be published shortly.
- The NDF continue to work with UCL GOSH to set up a Norrie patient registry with view to collaborating globally.
- In 2019, NDF formally entered into a research partnership with Great Ormond Street Hospital Children's Charity (GOSHCC) & Sparks for its national funding call 2019, which aims to tackle the understanding and treatment of rare diseases in children. The successful application was announced in January 2020 and was awarded to Prof Jane Sowden to investigate whether replacing the faulty gene that causes deafness in Norrie Disease could save the hearing of boys with the condition, who are born blind. This is a continuation of the pioneering work done by Professor Maria Bitner-Glindzicz, who sadly passed away in 2018. As part of the partnership, NDF provided 25% (£62,500) of the project costs.

Raising Awareness

- The September 2020 edition of British Association of Teachers of the Deaf magazine featured two articles about Norrie Disease. Trustee Theresa Peacock put together one article, and a second article was written by two multi-sensory-impairment (MSI) practitioners for Sense Specialist Services. We would also like to thank parent Carla Golledge for also sharing her experience to contribute to the article.
- Costello Medical developed, on a pro-bono basis, an educational leaflet 'Guidance for Schools and Educational Settings to Support Children and Young People with Norrie Disease' which aims to provide general information about Norrie Disease (ND), its management and how to support the education of children and young people in schools and educational settings.
- NDF Ambassador Anthony Pitch Reyers was nominated for a 2020 RARE Champion of Hope Global Genes Award in recognition of his phenomenal contribution to the Norrie community.

Fundraising

- Much of the planned fundraising for 2020 (including Royal Parks Half Marathon and Ride London) were cancelled due to the Covid-19 pandemic. The NDF would like to say a huge thank you to John Ball School's virtual Heath for Health race 2020 raising funds for local charities and including NDF as a beneficiary. The Trustees would like to thank all of NDF's incredibly generous supporters who donate regular and one-off donations.
- Ambassador Anthony Ryers co-hosted a 24 hours XiJaro & Pitch live streaming fundraising marathon on Twitch. Some of the biggest players in the trance music community came together to collaborate whilst raising over £30,000 for NDF.
- NDF is grateful to Genetic Disorders UK for its support and providing grants to enable the NDF family day to take place. We would also like to thank the AKO Foundation for its donation as part of its employee 'Give Back' scheme.

NORRIE DISEASE FOUNDATION
Report of the Trustees
For the year ended 31 December 2020

Financial review and reserves policy

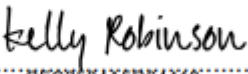
The charity Trustees continually monitor cash reserves to ensure its financial stability.

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 principle source of funds comes from the general public, either through donations or at one-off fundraising events.

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

DocuSigned by:

CFC2504X5D64419...

Kelly Robinson

27 August 2021

NORRIE DISEASE FOUNDATION
Statement of Financial Activities
For the year ended 31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	2020 £	2019 £
Income and endowments from:					
Donations and legacies	2	57,768	-	57,768	55,675
Charitable activities	3	5,029	-	5,029	45,106
Total		62,797	-	62,797	100,781
Expenditure on:					
Raising funds	4	(63,956)	-	(63,956)	(2,126)
Charitable activities	5	(1,313)	(1,349)	(2,662)	(5,004)
Total		(65,269)	(1,349)	(66,618)	(7,130)
Net income/expenditure		(2,472)	(1,349)	(3,821)	93,651
Reconciliation of funds					
Total funds brought forward		114,329	1,771	116,100	22,449
Total funds carried forward		111,857	422	112,279	116,100

NORRIE DISEASE FOUNDATION
Statement of Financial Activities
As at 31 December 2020

	Notes	2020 £	2019 £
Current assets			
Cash at bank and in hand		112,819	116,640
		112,819	116,640
Creditors: amounts falling due within one year	10	(540)	(540)
Net current assets		112,279	116,100
Total assets less current liabilities		112,279	116,100
Net assets		112,279	116,100
The funds of the charity			
Restricted income funds	11	422	1,771
Unrestricted income funds	11	111,857	114,329
Total funds		112,279	116,100

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

DocuSigned by:

Kelly Robinson

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Kelly Robinson
Trustee

27 August 2021

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements
As at 31 December 2020

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 2020 . For this reason the financial accounts have been prepared on a going concern basis.

2. Income from donations and legacies

	2020	2019
	£	£
Unrestricted funds		
Donations received	57,768	50,675
Grants received	-	5,000
	<u>57,768</u>	<u>55,675</u>

3. Income from charitable activities

	2020	2019
	£	£
Unrestricted funds		
<i>Sponsored Events</i>		
Sponsored Events	5,029	45,106

4. Expenditure on generating donations and legacies

	2020	2019
	£	£
Unrestricted funds		
Donations	62,500	-
Support costs	1,456	2,126
	<u>63,956</u>	<u>2,126</u>

NORRIE DISEASE FOUNDATION

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5. Costs of charitable activities by activity type

	2020	2019
	£	£
Activities undertaken directly		
Sponsored Events	2,662	5,004

6. Analysis of support costs

	2020	2019
	£	£
Governance costs	1,456	2,126

7. Particulars of employees

	2020	2019
General	0	0
	<u>0</u>	<u>0</u>
	<u>0</u>	<u>0</u>

8. Trustee remuneration and related party transactions

The only related party transaction in the year was that of a reimbursement of fundraising costs to Trustee (K Robinson) £292.80

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2020

9. Comparative for the Statement of Financial Activities

	Unrestricted funds £	Restricted funds £	2019 £
Income and endowments from:			
Donations and legacies	50,675	5,000	55,675
Charitable activities	45,106	-	45,106
Total	95,781	5,000	100,781
Expenditure on:			
Charitable activities	(1,775)	(3,229)	(5,004)
Total	(1,775)	(3,229)	(5,004)
Net income	94,006	1,771	95,777
Reconciliation of funds			
Total fund brought forward	22,449	-	22,449
Total funds carried forward	116,455	1,771	118,226

10. Creditors: amounts falling due within one year

	2020 £	2019 £
Accruals and deferred income	540	540
	540	540

11. Movement in funds

Unrestricted Funds

	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

Unrestricted Funds – Previous year

	Balance at 01/01/2019 £	Incoming Resources £	Outgoing Resources £	Balance at 31/12/2019 £
<i>General</i>				
General	22,449	95,781	(3,901)	114,329
	22,449	95,781	(3,901)	114,329

NORRIE DISEASE FOUNDATION
Notes to the Financial Statements Continued
For the year ended 31 December 2020

Purpose of unrestricted Funds

General

To fund the general objectives of the charity

Restricted Funds

	Balance at 01/01/2020 £	Incoming Resources £	Outgoing Resources £	Balance at 31/12/2020 £
Family fun day	1,771	-	(1,349)	422
	1,771	-	(1,349)	422

Restricted Funds – Previous year

	Balance at 01/01/2019 £	Incoming Resources £	Outgoing Resources £	Balance at 31/12/2019 £
Family fun day	-	5,000	(3,229)	1,771
	-	5,000	(3,229)	1,771

12. Analysis of net assets between funds

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

Previous year

	Net current assets / (liabilities) £	Net Assets £
Unrestricted funds		
General		
General	114,329	114,329
Restricted funds		
Family fun day	1,771	1,771
	116,100	116,100

NORRIE DISEASE FOUNDATION
Detailed Statement of Financial Activities
For the year ended 31 December 2020

	2020	2019
	£	£
INCOME AND ENDOWMENT		
Donations and legacies		
Donations	57,768	50,675
Grants receivable	-	5,000
	<u>57,768</u>	<u>55,675</u>
Charitable activities		
Income from charitable activities	5,029	45,106
	<u>5,029</u>	<u>45,106</u>
Total incoming resources	<u>62,797</u>	<u>100,781</u>
EXPENDITURE		
Raising donations and legacies		
Donations	(62,500)	-
	<u>(62,500)</u>	<u>-</u>
Charitable activities		
Cost of direct charitable activities	(2,662)	(5,004)
	<u>(2,662)</u>	<u>(5,004)</u>
SUPPORT COSTS		
Governance costs		
Governance costs	(1,456)	(2,126)
	<u>(1,456)</u>	<u>(2,126)</u>
Total resources expended	<u>(66,618)</u>	<u>(7,130)</u>
Net Expenditure	<u>(3,821)</u>	<u>(93,651)</u>