Charity registration number: 1171274
Company number: CE008898

NORRIE DISEASE FOUNDATION
TRUSTEES' REPORT AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

Beach Accountants Limited
Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
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South Tyneside
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NORRIE DISEASE FOUNDATION
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NORRIE DISEASE FOUNDATION
Trustees' Report For The Year Ended 31 December 2025

The trustees present their report and the financial statements for the year ended 31 December 2025.

Objectives and Activities

Aims and Objectives

The Trustees have pleasure in presenting their report and the financial statements for the charity for the year ended 31 December 2025. 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

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

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Public Benefit - continued

- 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

- NDF and Prof Jane Sowden's research team was one of nine research projects selected as part of the 2024-2025 GOSHCC national funding call with a grant worth £250,000. The application is to test a gene therapy to prevent hearing loss in patients with Norrie disease.
- Shared information about the GOSH natural history study to encourage participation.
- Attended the RNID Hearing Therapeutics Summit 2025 in London. Mum and NDF supporter Carla talked about the devastating impact Norrie disease has had on her son. Prof Jane Sowden also spoke about the importance of the Norrie disease hearing loss research.
- Held the first Norrie Disease Virtual Meeting, a great opportunity for families around the world to meet each other and receive an update from the research team at UCL GOSH.
- 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

- Trustee Corne Kros took on a 10km run
- Mum and NDF supporter Jackie spent 5 hours climbing up to the summit of Monserrat mountain in Barcelona
- Cooper's Golf Day and auction
- The Trustees would like to thank all of NDF's incredibly generous supporters who donate regular and one-off donations, and undertake fundraising activities for the NDF.

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.

The trustees confirm that they have complied with the requirements of Section 17 of the Charities Act 2011 to have due regard to the Charity Commission's guidance on public benefit.

Reference and Administrative Details

Trustees

Ms Wendy Horrobin - Chair
Ms Prof Corné Kros
Mr Anthony Reyers
Ms Kelly Robinson
Ms Kelly Legget
Ms Theresa Peacock

Charity Number

1171274

Principal Address

PO BOX 12476
Colchester
CO1 9RB

Independent Examiner

Beach Accountants Limited Chartered Certified Accountants
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Chartered Certified Accountants
10 Blue Sky Way
Monkton Business Park South
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Statement of Trustees' Responsibilities

The trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing the financial statements the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgments and accounting estimates that are reasonable and prudent; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping adequate accounting records which disclose with reasonable accuracy at anytime the financial position of the charity and to enable them to ensure that the accounts comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. 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.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

The trustees' report was approved by the board of trustees and signed on its behalf by:

Kelly Robinson

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Ms Kelly Robinson

Trustee
16/10/2026

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.

Responsibilities and Basis of Report

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

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

Independent Examiner's 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.

Gavin Spencer
33130000-C814-4E3F-5D27-08DF291D0CA9

Beach Accountants Limited Chartered Certified Accountants

16/10/2026
10 Blue Sky Way
Monkton Business Park South
Hebburn
South Tyneside
NE31 2EQ

NORRIE DISEASE FOUNDATION
Statement of Financial Activities
For The Year Ended 31 December 2025

	Notes	2025 Unrestricted funds £	2024 Unrestricted funds £
INCOME AND ENDOWMENTS FROM:			
Donations and legacies	**3**	20,771	18,429
EXPENDITURE ON:			
Raising funds	**4**	(2,512)	(2,627)
Other		(45,778)	(87,465)
		(48,290)	(90,092)
NET EXPENDITURE		(27,519)	(71,663)
NET MOVEMENT IN FUNDS		(27,519)	(71,663)
RECONCILIATION OF FUNDS:			
Total funds brought forward		154,159	225,822
TOTAL FUNDS CARRIED FORWARD	**10**	126,640	154,159

The notes on pages 8 to 11 form part of these financial statements.

NORRIE DISEASE FOUNDATION
Balance Sheet
As At 31 December 2025

	Notes	2025 Unrestricted funds £	2024 Total funds £
CURRENT ASSETS			
Debtors	**7**	41,579	25,022
Cash at bank and in hand		127,541	154,995
		169,120	180,017
Creditors: Amounts Falling Due Within One Year	**8**	(21,702)	(25,858)
NET CURRENT ASSETS (LIABILITIES)		147,418	154,159
TOTAL ASSETS LESS CURRENT LIABILITIES		147,418	154,159
Creditors: Amounts Falling Due After More Than One Year	**9**	(20,778)	-
NET ASSETS		126,640	154,159
FUNDS OF THE CHARITY			
Unrestricted Funds		126,640	154,159
TOTAL FUNDS	**10**	126,640	154,159

On behalf of the board

Kelly Robinson

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Ms Kelly Robinson

Trustee
16/10/2026

The notes on pages 8 to 11 form part of these financial statements.

1. General Information

NORRIE DISEASE FOUNDATION is a charitable incorporated organisation registered with the Charity Commission, registered charity number 1171274. The principal address is PO BOX 12476, Colchester, CO1 9RB.

2. Accounting Policies

2.1. Basis of Preparation of Financial Statements

The financial statements 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 Charities Act 2011.

The charity is a Public Benefit Entity as defined by FRS 102.

2.2. Going Concern Disclosure

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 2025. For this reason the financial accounts have been prepared on a going concern basis.

2.3. Fund Accounting

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.

2.4. 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.

2.5. 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.

2.6. Cash and Cash Equivalents

Cash and cash equivalents are basic financial assets and include cash in hand and deposits held at call with banks, other short-term highly liquid investments that mature in no more than three months from the date of acquisition and are readily convertible to a known amount of cash with insignificant risk of change in value, and bank overdrafts.

2.7. Taxation

The charity is exempt from tax as all its income is charitable and applied for charitable purposes.

2.8. Additional policies

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.

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.

3. **Income from Donations and Legacies**

	2025 Unrestricted funds £	2024 Unrestricted funds £
Donations and gifts	20,771	18,429

4. **Analysis of Expenditure**

	Activities undertaken directly £	Support costs (see note 5) £	2025 Total £
Raising funds	51	2,461	2,512

	Activities undertaken directly £	Support costs (see note 5) £	2024 Total £
Raising funds	488	2,139	2,627

5. **Support Costs**

	2025 Raising funds £
Employee costs:	
Travel expenses	227
General administration:	
Insurance	655
Postage	516
Website costs	68
Accountancy fees	888
Subscriptions	47
Regulator charge	60
	2,461

	2024 Raising funds £
General administration:	
Insurance	610
Postage	445
Website costs	80

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Accountancy fees	858
Subscriptions	86
Regulator charge	60
	2,139

6. **Average Number of Employees**

Average number of employees during the year was: NIL (2024: NIL)

7. **Debtors**

	2025	2024
	£	£
Due within one year		
Prepayments and accrued income	41,555	25,000
Other debtors	24	22
	41,579	25,022

Prepayment includes payments to Great Ormond Street Hospital Children's Charity.

8. **Creditors: Amounts Falling Due Within One Year**

	2025	2024
	£	£
Other creditors	20,778	25,000
Accruals and deferred income	924	858
	21,702	25,858

9. **Creditors: Amounts Falling Due After More Than One Year**

	2025	2024
	£	£
Other creditors	20,778	-

10. **Movement in Funds**

	As at 1 January 2025	Income	Expenditure	As at 31 December 2025
	£	£	£	£
Unrestricted funds				
General:				
General unrestricted fund	154,159	20,771	(48,290)	126,640
Total funds	154,159	20,771	(48,290)	126,640

	As at 1 January 2024	Income	Expenditure	As at 31 December 2024
	£	£	£	£
Unrestricted funds				
General:				
General unrestricted fund	225,822	18,429	(90,092)	154,159
Total funds	225,822	18,429	(90,092)	154,159

The purpose of the unrestricted fund is to fund the general objectives of the charity.

11. **Transactions with Trustees**

None of the trustees received any remuneration or any other benefits from an employment with the charity or a related entity during the current or previous year.

No trustee expenses have been incurred.

12. **Related Party Disclosures**

There were no disclosable related party transactions in the financial year.

NORRIE DISEASE FOUNDATION
Detailed Statement of Financial Activities
For The Year Ended 31 December 2025

	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM:		
Donations and legacies		
Donations and gifts	20,771	18,429
	20,771	18,429
	20,771	18,429
EXPENDITURE ON:		
Raising funds		
Staging fundraising events	(51)	(488)
Travel expenses	(227)	-
Insurance	(655)	(610)
Postage	(516)	(445)
Website costs	(68)	(80)
Accountancy fees	(888)	(858)
Subscriptions	(47)	(86)
Regulator charge	(60)	(60)
	(2,512)	(2,627)
Other		
Cost of grant funded charitable activity	(45,778)	(87,465)
	(45,778)	(87,465)
	(48,290)	(90,092)
NET EXPENDITURE	(27,519)	(71,663)

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