

Our Ref: PA/CJ
Date: 6 February 2026
Code: PM1015

The Trustees
Northern Ireland Rare Disease Partnership
Guardian Chartered Accountants
2 William Street
Newtownards
BT23 4AH

Dear Fiona & Anne Marie

Please find attached PDF of the following document that requires your electronic signatures.

1. Accounts for the year ended 31 March 2025.

Yours sincerely

Paula Armstrong

[Paula Armstrong \(Feb 6, 2026 11:07:05 GMT\)](#)

Mrs Paula Armstrong
On behalf of MTS Chartered Accountants

Enc

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Registered to carry out audit work by the
Institute of Chartered Accountants in Ireland



Registered with The Chartered Institute of
Taxation as a firm of Chartered Tax Advisors

www.mtsaccountants.com – A full list of Directors of
McCreery Turkington Stockman Ltd is available at our website.

N.I. Registration No. NI626535.
MTS Chartered Accountants & MTS Prior McMahan
are trading names of McCreery Turkington Stockman Ltd.

Company registration number NI611153

**NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

| | |
|-----------------------------|---|
| Trustees | A O'Loan C McKenna Dr N Chaudhuri S Campbell (Appointed 1 January 2025) C Collins (Appointed 1 January 2025) A J McKnight (Appointed 1 January 2025) F McLaughlin (Appointed 1 January 2025) S Robinson (Appointed 1 January 2025) Eva Fox (Appointed 9 October 2025) |
| Charity number | 105261 |
| Company number | NI611153 |
| Registered office | Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH |
| Independent examiner | MTS Prior McMahon c/o Ards Business Hub Sketrick House Jubilee Road Newtownards Co Down BT23 4YH |

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2025

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

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of association, the Companies Act 2006 and "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).

Objectives and activities

There are 3 key objectives of the charity, as defined in the governing document, and they are:

1. To support and campaign on behalf of those persons in Northern Ireland ("the area of benefit") affected by or believed to be affected by a rare disease and their families, dependents, and carers.
2. To advance the education of the public and of relevant professionals and policy makers in all matters concerning rare diseases.
3. To advance any other exclusively charitable purpose as the trustees may, from time to time, decide in accordance with the law of charity.

NIRDP are committed to working constructively in partnership with others in the belief that we are stronger together and that we can make a real difference to the lives of people living with rare disease.

We **connect**: bringing together individuals, families, carers and professionals

We **advocate**: campaigning for better recognition and services

We **raise awareness**: educating the public, professionals and policy makers

We **innovate**: finding new ways to improve lives

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake. The Trustees believe that the charitable organisation provides a public benefit in a number of ways through the undertaking of a range of projects and by providing support to all persons affected by a rare disease including individuals, families, dependents and carers. The direct benefit that will flow from this benefit will be to improve the diagnosis, treatment, and support of individuals affected by rare diseases.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Achievements and performance

Significant activities and achievements against objectives

The trustees are delighted to share the progress and achievements of the charity below.

The Rare Support Hub – Strengthening Support Across Northern Ireland

The NIRDP Rare Support Hub has provided practical and emotional support to children, families, adults, and healthcare professionals across Northern Ireland. Key areas of assistance have included:

- Providing accurate, condition-specific information on rare diseases.
- Signposting to appropriate medical, psychological, and financial support services.
- Facilitating peer connections between people living with similar rare conditions.
- Supporting individuals to navigate diagnosis and treatment pathways.
- Addressing barriers to service access.

Through this work, many families have successfully secured appropriate benefits, approached Benefits Tribunals with greater confidence, and re-engaged with daily life after periods of significant loss of identity and wellbeing.

Over recent months, the Support Hub has expanded its remit, becoming a broader, more integrated service for people navigating the challenges of rare conditions, including the complexities of diagnostic odysseys and postcode variations in care provision. Advocacy remains a core element, with the Hub liaising between clinicians, consultants, and other healthcare professionals, as well as engaging MLAs through the Rare Disease All-Party Group, to ensure policy and service design reflect the needs of the rare disease community.

Core Functions of the Rare Support Hub

- Delivery of in-person and online peer support groups in local communities.
- Peer mentoring based on lived experience.
- One-to-one tailored casework.
- Advocacy for individuals and support for carers.
- Signposting to specialist organisations and local resources.
- Participation in multi-disciplinary teams to integrate health, social care, education, and community responses.

The Rare Support Hub prioritises a “listening first” approach, ensuring interventions are person-centred and responsive. This model not only improves individual wellbeing but also builds community capacity and informs systemic change for the estimated 1 in 17 people in Northern Ireland living with a rare disease.

Support Group Working

Foyle Region

Participants enjoyed an engaging and uplifting programme led by **Janice Tracey, nutritionist** and **Mandy Chism, Assistant Director, Facilitator, and Master Trainer at Resilio**. Both speakers brought a wealth of knowledge and practical advice, sharing strategies to support better mental health and overall well-being.

In collaboration with the Northwest-based charity **Resilio**, we hosted a *Resilience and Hope* session that resonated deeply with everyone in attendance. The feedback was overwhelmingly positive, with 100% of both patients and carers saying they left feeling inspired and motivated to incorporate the lessons and tips into their daily lives. The event not only provided valuable tools for coping and thriving but also strengthened the sense of connection and mutual support within our community.

Awards:

Celebrating Outstanding Care – Caring Award Recipient We are delighted to share the story of **Judith Hamilton**, who recently received the *Caring Award* in recognition of her exceptional dedication and compassion. Judith was nominated by her sister-in-law, Catherine, for the unwavering care she provides to her mother, Elsie, who is living with PSP.

The award was presented by **Sandra Campbell** trustee of the Northern Ireland Rare Disease Partnership, in a touching ceremony surrounded by Judith’s family. Catherine’s nomination highlighted Judith’s tireless commitment, kindness, and the difference she makes in her mother’s quality of life each day.

This celebration of Judith’s work serves as a reminder of the vital role carers play in supporting loved ones with rare conditions. We extend our heartfelt congratulations to Judith on this well-deserved recognition.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Online-Chat Rare

Summary of Online Chat Session – December 2024

One of our December chat sessions was held online with six participants, including individuals and families. During this session, we focused on self-care and discussed ways to strengthen ourselves by doing things we enjoy.

We emphasised the importance of being kind to ourselves and to others. Self-care is essential for everyone, but it is especially important for people living with rare diseases. Taking time for self-care can help manage a condition and improve quality of life.

We encouraged participants to try at least one self-care tip and highlighted that these practices can also benefit carers, helping them to relax and avoid feeling overwhelmed.

Understanding Rare project 2024

The "Understanding Rare" project was a mental health initiative run by the Northern Ireland Rare Disease Partnership (NIRDP) with funding from the Community Foundation's Mental Health Fund. Its purpose was to improve awareness, empathy, and professional skills in supporting people with rare diseases, a community of about 110,000 in Northern Ireland.

Core Activities and Impact Workshops brought together healthcare professionals, support workers, educators, and policymakers to deepen their understanding of rare diseases and the related mental health challenges.

The cascade effect—trained participants applied and shared their new knowledge in their own sectors—amplified the impact well beyond the original target audience.

Professionals became more adept at offering tailored mental health support, improving diagnosis pathways, and advocating effectively for patients and families.

The program directly benefited 60 people and indirectly improved the environment for the broader rare disease community with sectors such as housing, benefits, and social support. These sessions explored the unique mental health challenges that individuals with rare conditions may face at different stages of diagnosis and treatment. Real-life stories from the rare disease community added depth and emotional resonance, helping participants connect professional knowledge with lived experience.

Case Study 1: Healthcare Professional Gaining New Insights: A healthcare professional with over 15 years of experience attended the "Understanding Rare" workshop, initially seeking to broaden their knowledge of rare diseases. Although they had extensive experience in general healthcare, they admitted to having limited understanding of the unique challenges faced by rare disease patients. During the session, they were particularly struck by the stories shared by patients, especially the emotional and mental health struggles that often accompany these conditions. This new perspective profoundly influenced their approach to patient care. After the workshop, the participant said they would incorporate this newfound empathy into their practice, making more time to listen to patients' concerns and being more proactive in seeking out specialist resources for those with rare conditions. They reported that this shift would not only improve their patient interactions but also make them feel more fulfilled in their role, knowing they were offering more comprehensive and compassionate care.

Case Study 2: Parent Advocate Finding Empowerment: A parent of two children with a rare genetic condition attended the workshop, feeling isolated and overwhelmed by the daily challenges of managing their children's needs. The workshop provided them with not only critical information about rare diseases but also a sense of community and support. For the first time, the parent felt empowered to share their story with others who truly understood their struggles, especially after viewing our Rare Stories videos (available on our website www.nirdp.org.uk) and examples of advocate parents. This newfound session has been a lifeline, offering practical advice and emotional support. The parent reported feeling a renewed sense of strength and determination to advocate for their children's needs. They also expressed a desire to become more involved in raising awareness about rare diseases, hoping to help other families avoid the isolation they have felt.

Case Study 3: Newly Diagnosed Patient Finding Hope: A recently diagnosed rare disease patient attended the "Understanding Rare" workshop, seeking information and support. They had spent years experiencing unexplained symptoms and had only just received a correct diagnosis, leaving them feeling anxious and uncertain about the future. During the workshop, the patient was able to connect with others who had similar experiences (especially through our Rare Stories video content available on our website www.nirdp.org.uk), which was both reassuring and empowering. The patient shared their story for the first time in a safe and supportive environment, which helped them process the emotional impact of their diagnosis. After the workshop, they reported feeling less alone and more hopeful about managing their condition. They also expressed appreciation for the practical advice and resources provided, which gave them a clearer path forward. The patient now feels better equipped to navigate their healthcare journey and is motivated to continue learning and advocating for themselves and others in the rare disease community.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Strengthening Support in Schools: Working with the Education Authority

The Education Action Team, led by **Stephanie Duguez** (Senior Lecturer, School of Medicine, Ulster University) with volunteers **Sandra Campbell** and **Robbie Crouch**, recently met with the Special Educational Needs (SEN) lead at the Education Authority to explore ways of improving support for children and young people with rare conditions in Northern Ireland schools. As part of this work, Sandra and Stephanie conducted an anonymous education survey, gathering valuable feedback from parents and guardians about their experiences of the education system. The results and views shared by parents are documented in our *Rare Disease Education Toolkit*, which is freely available on our website www.nirdp.org.uk. These findings were also presented to the Education Authority and have helped shape ongoing collaboration, which includes delivering awareness sessions for school staff, providing practical tools through the Toolkit, hosting listening sessions with families, and offering signposting to supportive resources. NIRDp is now also listed as a useful resource for medical needs on the Education Authority's website, increasing visibility and access to our support services.

Rare Disease Day, Stormont, 26th February 2025

The Northern Ireland Rare Disease Partnership, Queen's University Belfast, Ulster University, Rare Diseases Ireland, and the Departments of Health in Northern Ireland and the Republic of Ireland convened a noteworthy event to celebrate Rare Disease Day as an all-Ireland group. The program included a welcome and an introduction by Fiona McLaughlin (Co-Chair NIRDp), setting the stage for discussions on advancements and strategic planning in the field of rare diseases. Videos from Mike Nesbitt, Minister of Health in Northern Ireland, and Minister for Health Jennifer Carroll MacNeill wished everyone a happy Rare Disease Day while supporting the group on this day. This was followed by in-depth presentations on the Northern Ireland Rare Disease Action Plan by Finola McGrady and the National Strategy for Rare Disease in the Republic of Ireland by Keith Lyons. The panel discussion, titled 'More than you can imagine: The power of connection and resilience,' was facilitated by Prof AJ McKnight and Dr Suja Somanadhan and featured Rosaline Callaghan, Dr Carleen Walsh, Dr Claire Hill, Melissa Kinch, and Dr Atif Awan, providing diverse perspectives and insights into the strengths and challenges within the rare disease community as parents, patients, carers, and researchers. Christine Collins MBE (Co-Chair NIRDp) provided closing remarks. The event underscored the importance of collaboration, strategic action, the resilience of individuals and families affected by rare diseases, and the spirit of unity in marking Rare Disease Day across the island.

Power of Connection Events, February to April, 2025

We successfully concluded our series of engagement events across Northern Ireland, (Bangor; Derry/Londonderry; Armagh; Belfast; Online) focused on shaping the NI Rare Disease Action Plan. These events, each focused on particular aspects of the Action Plan, facilitated vital conversations, shared powerful patient stories, and gathered crucial feedback from patients, carers, family members, academics/researchers/students, health professionals, policymakers (civil service/elected representatives), industry representatives, allied health professionals, and other community organisations in Northern Ireland working with people with rare diseases. A sincere thank you to the Department of Health, Queen's University Belfast, Ulster University, UCD Dublin, Rare Diseases Ireland, and all other organisations participating. The events were all well supported (even maxing out room capacity) highlighting the strong public support for improving rare disease services across Northern Ireland. Each event included a facilitated workshop using a Think-Pair-Share format to allow common themes and potential solutions to emerge. Emerging Findings are below.

We're preparing a report for the Health Minister to inform the next iteration of the Action Plan, alongside taking forward key findings, such as the importance of peer support and local community connections through intensifying our work at a local level. Some of the issues coming up and being shared at the events are detailed below.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Storytelling at Power of Connection events

Mr. A told of the journey to diagnosis for his son, which took 7 years from birth. During this time the family had no information and no support. They experienced isolation and bewilderment. This was his first rare disease event.

Ms. B talked about her experience during and after her husband's illness. He had been in hospital in Belfast, needing input from specialists in Edinburgh. He was able to go home only because Ms. B was a nurse and could manage his nasal feeding. Despite paid carers and district nurses visiting, Ms. B had to always be with him because of the risk of his involuntary movements pulling out the feeding tube. Despite his condition being progressive, the care package was reduced. There was no other support available.

Ms. C and her son **Mr. C** described their experiences of living with his rare condition, which has significant impact on his day-to-day life. Last year he took part in a clinical trial based in Belgium, resulting in a 3-month period where he could behave like his friends and experience a "normal" teenage life. The effect of the treatment wore off and his life is more limited again. As a UK resident he doesn't have access to that treatment any longer.

Ms. D spoke of the challenges of living remotely with an ill baby in tertiary care. She told of the impact of city rents and long travel, as well as being removed from family and local support networks.

Corporate Council

We continue to collaborate with our Corporate Council partners for a second year in a row. We are delighted and are incredibly grateful to have the support of industry and thank our Corporate Council members for their engagement and support.

All Party Group for Rare Disease

We have continued to hold the secretariat position for the All Party Group (APG) for Rare Disease at Stormont. There have been a number of meetings over the period with elected MLA's and input from patients, carers and stakeholders to raise awareness of rare disease and ask questions of our elected representatives. We want to thank the APG members for their time and membership, in particular, the Chair, Mark H Durkan, and look forward to continuing this into next year.

The trustees would like to thank the NIRDP team and volunteers for their continued support and efforts in upholding our key aim, which is to ensure that no one in Northern Ireland is disadvantaged due to the rarity of their health condition.

We also would like to thank our funders as follows;

ARN Foundation

The Community Foundation NI

The Department of Health

Our Corporate Council Partners

Our various private donators

Financial review

The financial results for the year are set out on pages 9- 17.

The charitable company generated a deficit for the year of £31,717 (2024: surplus £12,920), which included a deficit of unrestricted funds of £7,492 (2024: deficit £2,515) and a deficit of restricted funds of £24,225 (2024: surplus £15,435).

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Reserves policy

The charitable company's ongoing reserves policy is to maintain a minimum level of reserves which matches the needs of the organisation both at the current time and in the foreseeable future. The trustees will strive to maintain reserves in the future, sufficient to meet statutory obligations, committed expenditure, core salaries and running costs equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

Major risks

The trustees have a risk management strategy in place whereby major risks, to which the charity is exposed have been assessed, and Trustees are satisfied that systems are in place to mitigate exposure to the major risks. The risk management strategy comprises:

- an annual review of the risks the charity may face,
- the establishment of systems and procedures to mitigate those risks identified,
- financial risk is managed by the establishment of a reserves policy and its regular review by Trustees,
- attention is also focussed where necessary on the Protection of Children and Vulnerable Adults and Health & Safety in the workplace.

Structure, governance and management

The charity is a company limited by guarantee governed by its Memorandum and Articles of Association dated 22nd March 2021. The Northern Ireland Rare Disease Partnership (NIRDP) is a registered charity with the Charity Commission for Northern Ireland, Number 105261. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

| | |
|----------------|-----------------------------|
| C Donnelly | (Resigned 1 June 2024) |
| S Callaghan | (Resigned 20 December 2024) |
| A O'Loan | |
| J Wright | (Resigned 1 May 2024) |
| J McEvoy | (Resigned 31 August 2025) |
| C McKenna | |
| Dr N Chaudhuri | |
| S Campbell | (Appointed 1 January 2025) |
| C Collins | (Appointed 1 January 2025) |
| A J McKnight | (Appointed 1 January 2025) |
| F McLaughlin | (Appointed 1 January 2025) |
| S Robinson | (Appointed 1 January 2025) |
| Eva Fox | (Appointed 9 October 2025) |

Recruitment and appointment of trustees

The recruitment procedures for new Trustees are laid out in the NIRDP's Memorandum and Articles of Association. New trustees are recruited based on the relevance of their professional skills and their potential to be able to make a helpful contribution to the governance of NIRDP. As part of the recruitment process they are made aware of a Trustee's legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the charity's decision-making processes, the Strategic Plan and recent financial performance of the charity.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Organisational structure

NIRDP has a Board of 8 Trustees, who meet at least quarterly and are responsible for the strategic direction and running of the charity. There are 2 individuals engaged by the charity's trustees to assist in delivering the objectives of the charity and to assist in the management of day-to-day operations of the charity and they are supported by a number of volunteers who have been specifically trained to provide that support.

The trustees' report was approved by the Board of Trustees.

Anne Marie OLoan

[Anne Marie OLoan \(Feb 6, 2026 11:51:53 GMT\)](#)

A O'Loan
Director

6 February 2026

Fiona McLaughlin

[Fiona McLaughlin \(Feb 6, 2026 12:40:39 GMT\)](#)

F McLaughlin
Director

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report on the financial statements of the charity for the year ended 31 March 2025, which are set out on pages 9 to 17.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. 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 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the Companies Act 2006 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination; or
- 4 the financial statements 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 financial statements 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 financial statements to be reached.

Paula Armstrong

[Paula Armstrong \(Feb 6, 2026 12:42:06 GMT\)](#)

Paula Armstrong

For and on behalf of MTS Prior McMahon

Chartered Accountants
c/o Ards Business Hub
Sketrick House
Jubilee Road
Newtownards
Co Down
BT23 4YH

Dated: 6 February 2026

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2025

| | Notes | Unrestricted funds 2025 £ | Restricted funds 2025 £ | Total 2025 £ | Unrestricted funds 2024 £ | Restricted funds 2024 £ | Total 2024 £ |
|---|-------|------------------------------------|----------------------------------|--------------------|------------------------------------|----------------------------------|--------------------|
| Income from: | | | | | | | |
| Donations and membership fees | 2 | 19,649 | 10,000 | 29,649 | 9,700 | 52,000 | 61,700 |
| Total income | | 19,649 | 10,000 | 29,649 | 9,700 | 52,000 | 61,700 |
| Expenditure on: | | | | | | | |
| Charitable activities | 3 | 26,712 | 34,225 | 60,937 | 12,215 | 36,565 | 48,780 |
| Other expenditure | 7 | 429 | - | 429 | - | - | - |
| Total expenditure | | 27,141 | 34,225 | 61,366 | 12,215 | 36,565 | 48,780 |
| Net income/(expenditure) and movement in funds | | (7,492) | (24,225) | (31,717) | (2,515) | 15,435 | 12,920 |
| Reconciliation of funds: | | | | | | | |
| Fund balances at 1 April 2024 | | 16,757 | 28,163 | 44,920 | 19,272 | 12,728 | 32,000 |
| Fund balances at 31 March 2025 | | 9,265 | 3,938 | 13,203 | 16,757 | 28,163 | 44,920 |

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2025

| | Notes | 2025 | | 2024 | |
|---|-------|----------------|---------------|----------------|---------------|
| | | £ | £ | £ | £ |
| Fixed assets | | | | | |
| Tangible assets | 8 | | 1,085 | | 1,546 |
| Current assets | | | | | |
| Debtors | 9 | 9,093 | | 10,000 | |
| Cash at bank and in hand | | 6,892 | | 34,966 | |
| | | <u>15,985</u> | | <u>44,966</u> | |
| Creditors: amounts falling due within one year | 10 | <u>(3,867)</u> | | <u>(1,592)</u> | |
| Net current assets | | | 12,118 | | 43,374 |
| Total assets less current liabilities | | | <u>13,203</u> | | <u>44,920</u> |
| The funds of the charity | | | | | |
| Restricted income funds | 12 | | 3,938 | | 28,163 |
| Unrestricted funds | 13 | | 9,265 | | 16,757 |
| | | | <u>13,203</u> | | <u>44,920</u> |

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2025.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 6 February 2026

Anne Marie OLoan

[Anne Marie OLoan \(Feb 6, 2026 11:51:53 GMT\)](#)

A O'Loan

Director

Fiona McLaughlin

[Fiona McLaughlin \(Feb 6, 2026 12:40:39 GMT\)](#)

F McLaughlin

Director

Company registration number NI611153 (Northern Ireland)

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

Charity information

Northern Ireland Rare Disease Partnership is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "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)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

1.5 Resources expended

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent examination fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

| | |
|-----------------------|----------------------|
| Fixtures and fittings | 25% reducing balance |
|-----------------------|----------------------|

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

| | Unrestricted funds | Restricted funds | Total | Total |
|---|-----------------------|---------------------|---------------|---------------|
| | 2025 £ | 2025 £ | 2025 £ | 2024 £ |
| Donations and gifts | 2,149 | - | 2,149 | 2,186 |
| Grants | - | 10,000 | 10,000 | 56,014 |
| Membership fees | 17,500 | - | 17,500 | 3,500 |
| | <u>19,649</u> | <u>10,000</u> | <u>29,649</u> | <u>61,700</u> |
| For the year ended 31 March 2024 | <u>9,700</u> | <u>52,000</u> | | <u>61,700</u> |
| Donations and gifts | | | | |
| Other | 2,149 | - | 2,149 | 2,186 |
| | <u>2,149</u> | <u>-</u> | <u>2,149</u> | <u>2,186</u> |

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

3 Charitable activities

| | 2025 £ | 2024 £ |
|--|---------------|---------------|
| Staff costs | 32,044 | 35,809 |
| Staff and board training | 288 | - |
| Forum costs and room hire | 1,310 | - |
| Subscriptions | 648 | 115 |
| Insurance | 96 | 96 |
| Printing, postage and stationery | 498 | - |
| Telephone | 72 | 88 |
| Computer and internet costs | 1,773 | 2,188 |
| Motor and travel expenses | 2,574 | 659 |
| Consultancy | 14,020 | 7,501 |
| Event expenses | 5,223 | 41 |
| General expenses | 568 | 823 |
| | <u>59,114</u> | <u>47,320</u> |
| Share of governance costs (see note 4) | 1,823 | 1,460 |
| | <u>60,937</u> | <u>48,780</u> |
| Analysis by fund | | |
| Unrestricted funds | 26,712 | 12,215 |
| Restricted funds | 34,225 | 36,565 |
| | <u>60,937</u> | <u>48,780</u> |

4 Governance costs

| | Restricted £ | Unrestricted £ | 2025 £ | 2024 £ |
|-----------------------|-----------------|-------------------|--------------|--------------|
| Professional Services | - | 1,350 | 1,350 | 887 |
| Bank charges | - | 112 | 112 | 58 |
| Depreciation | - | 361 | 361 | 515 |
| | <u>-</u> | <u>1,823</u> | <u>1,823</u> | <u>1,460</u> |

5 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

6 Employees

The average monthly number of employees during the year was:

| | 2025 | 2024 |
|-------------------------|-------------------|-------------------|
| | Number | Number |
| | 2 | 3 |
| | <u> </u> | <u> </u> |
| Employment costs | 2025 | 2024 |
| | £ | £ |
| Wages and salaries | 30,654 | 35,211 |
| Other pension costs | 1,390 | 598 |
| | <u> </u> | <u> </u> |
| | <u>32,044</u> | <u>35,809</u> |
| | <u> </u> | <u> </u> |

There were no employees whose annual remuneration was more than £60,000.

7 Other

| | Unrestricted | Total |
|---|---------------------|-------------------|
| | funds | |
| | 2025 | 2024 |
| | | £ |
| Net loss on disposal of tangible fixed assets | 429 | - |
| | 429 | - |
| | <u> </u> | <u> </u> |
| | <u> </u> | <u> </u> |

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

8 Tangible fixed assets

| | Fixtures and fittings £ |
|------------------------------------|----------------------------|
| Cost | |
| At 1 April 2024 | 4,857 |
| Additions | 329 |
| Disposals | (1,680) |
| | <hr/> |
| At 31 March 2025 | 3,506 |
| | <hr/> |
| Depreciation and impairment | |
| At 1 April 2024 | 3,311 |
| Depreciation charged in the year | 361 |
| Eliminated in respect of disposals | (1,251) |
| | <hr/> |
| At 31 March 2025 | 2,421 |
| | <hr/> |
| Carrying amount | |
| At 31 March 2025 | 1,085 |
| | <hr/> <hr/> |
| At 31 March 2024 | 1,546 |
| | <hr/> <hr/> |

9 Debtors

| | 2025 £ | 2024 £ |
|---|-------------|-------------|
| Amounts falling due within one year: | | |
| Trade debtors | - | 10,000 |
| Other debtors | 3,693 | - |
| Prepayments and accrued income | 5,400 | - |
| | <hr/> | <hr/> |
| | 9,093 | 10,000 |
| | <hr/> <hr/> | <hr/> <hr/> |

10 Creditors: amounts falling due within one year

| | 2025 £ | 2024 £ |
|------------------------------------|-------------|-------------|
| Other taxation and social security | - | 387 |
| Accruals and deferred income | 3,867 | 1,205 |
| | <hr/> | <hr/> |
| | 3,867 | 1,592 |
| | <hr/> <hr/> | <hr/> <hr/> |

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

11 Retirement benefit schemes

| | 2025 | 2024 |
|---|--------------|------------|
| | £ | £ |
| Defined contribution schemes | | |
| Charge to profit or loss in respect of defined contribution schemes | 1,390 | 598 |
| | <u>1,390</u> | <u>598</u> |

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

12 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

| | At 1 April 2024 | Incoming resources | Resources expended | At 31 March 2025 |
|-----------------------|--------------------|-----------------------|-----------------------|---------------------|
| | £ | £ | £ | £ |
| | 28,163 | 10,000 | (34,225) | 3,938 |
| | <u>28,163</u> | <u>10,000</u> | <u>(34,225)</u> | <u>3,938</u> |
| Previous year: | | | | |
| | At 1 April 2023 | Incoming resources | Resources expended | At 31 March 2024 |
| | £ | £ | £ | £ |
| | 12,728 | 52,000 | (36,565) | 28,163 |
| | <u>12,728</u> | <u>52,000</u> | <u>(36,565)</u> | <u>28,163</u> |

13 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

| | At 1 April 2024 | Incoming resources | Resources expended | At 31 March 2025 |
|-----------------------|--------------------|-----------------------|-----------------------|---------------------|
| | £ | £ | £ | £ |
| General funds | 16,757 | 19,649 | (27,141) | 9,265 |
| | <u>16,757</u> | <u>19,649</u> | <u>(27,141)</u> | <u>9,265</u> |
| Previous year: | | | | |
| | At 1 April 2023 | Incoming resources | Resources expended | At 31 March 2024 |
| | £ | £ | £ | £ |
| General funds | 19,272 | 9,700 | (12,215) | 16,757 |
| | <u>19,272</u> | <u>9,700</u> | <u>(12,215)</u> | <u>16,757</u> |

14 Related party transactions

There were no disclosable related party transactions during the year (2024 - none).