Company registration number: 140743

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

Financial statements

for the financial year ended 31 December 2025

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

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Rare Diseases Ireland
Company limited by guarantee

Directors and other information

Directors	Mairéad Hennessy Anne Micks Laura Egan Avril Daly Susanne O'Reilly Fergal Griffin Darran Brennan Eamonn O'Neill (Appointed 7 September 2026) Michael Blighe (Resigned 20 October 2025) Susan O'Connell (Resigned 26 January 2026) John McCormack (Resigned 15 June 2026)
Secretary	Anne Micks
Company number	140743
Registered office	Carmichael House North Brunswick Street Dublin 7
Business address	Carmichael House North Brunswick Street Dublin 7
Auditor	McCloskey & Co Workhub 51 Bracken Road Sandyford Business Park Dublin D18 CV48
Bankers	AIB 9 Terenure Road Rathgar Dublin 6
Registered Charity Number	20044633
CHY (Revenue) Number	CHY 13930

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

Directors report

The directors present their annual report and the audited financial statements of the company for the financial year ended 31 December 2025.

Directors and secretary
The names of the persons who at any time during the financial year were directors of the company are as follows:

Directors
Mairéad Hennessy
Anne Micks
Laura Egan
Avril Daly
Susanne O'Reilly
Fergal Griffin
Darran Brennan
Michael Blighe (Resigned 20 October 2025)
Susan O'Connell (Resigned 26 January 2026)
John McCormack (Resigned 15 June 2026)

Secretary
Michael Blighe (Resigned 17 November 2025)
Anne Micks (Appointed 17 November 2025)

Principal activities
The main object for which the Company is established is to act as a national alliance for voluntary groups representing the views and concerns of people affected by or at risk of developing genetic or other rare diseases.

Subsidiary Object(s)
In furtherance exclusively of the main object, the Company will have the following subsidiary objects and any income generated from the subsidiary objects is to be applied to the main object only

a. To voice and promote views of the member organisations on issues of common concern.
b. To be a strong and united voice that will increase public awareness of genetic and other rare diseases.
c. To promote further development of genetic services in Ireland.
d. To advocate for the availability of adequate care services in Ireland for people living with genetic and rare diseases.
e. To facilitate the exchange of information between member organisations that represents people living with genetic and rare diseases.
f. To establish a liaison with geneticists and other relevant specialists nationally and internationally to help Rare Diseases Ireland achieve its aims and objectives.
g. To collaborate with national and international stakeholders on policy and regulation issues in the area of genetic and rare diseases.

Development and performance

Rare Diseases Ireland (RDI) is the national alliance for rare disease patient organisations in Ireland, working across all rare diseases to improve the lives of the estimated 300,000 people living with rare diseases in Ireland. We advocate for, empower and engage organisations and advocates, as well as people living with rare diseases, their caregivers and their families, to mobilise together with a strong voice to shape policies and solutions driven by the needs of all people living with rare diseases.

Our vision is a country where all people living with rare diseases live longer and better lives, reaching their full potential, and are included in a society that leaves no one behind. This means we want equity for people living with rare diseases in Ireland - equitable access to diagnosis, treatment, health and social care and opportunity.

RDI works with patient organisations and people living with rare diseases, their caregivers and their families, with healthcare providers treating people living with rare diseases, with the National Rare Diseases Office (NRDO), the National Genetics & Genomics Office (NGGO), with industry and researchers with an interest in rare diseases, and with policy makers, including leadership across government, the Oireachtas, the Department of Health and the HSE to advance our mission to improve the lives of all people living with rare diseases and their caregivers and families.

We exist to give voice to the 300,000 people in Ireland living with rare diseases. Across 2025 and into 2026 we continued to pursue that mission through a combination of awareness building, policy engagement, stakeholder partnership and direct advocacy on issues that affect diagnosis, care and access. The period covered by this statement was a pivotal one for our community. It saw the publication of the National Rare Disease Strategy 2025-2030, which RDI helped to shape, and the beginning of the far harder work of turning that strategy into real change on the ground. It also saw access to orphan medicines become one of the most prominent health issues in national public debate.

We worked with EURORDIS-Rare Diseases Europe and rare disease national alliances across Europe to promote development of EU wide and international strategies, policies and programmes which influence policy in Ireland. As a small organisation and a small country, we must work closely with our EU and international counterparts to supplement capacity in Ireland. Our National Strategy calls for such collaboration across policy and healthcare delivery. Structures such as the European Reference Networks are a case in point, allowing expertise to be shared across the EU. Ireland’s Presidency of the Council of the European Union (July-December 2026) also presents a particular opportunity in this regard, allowing us the highlight rare diseases on the international stage.

Awareness of rare diseases is the foundation upon which solutions are built. If there is no awareness and understanding of rare diseases, there will be no impetus to drive change. Awareness and public engagement thus remain central to our work.

Rare Disease Day 2025 was marked with an Oireachtas event on 26 February, ensuring the rare disease patient voice was visible at the heart of discussions in the new Dáil and Seanad as work on the new national strategy neared completion. Media coverage around the day highlighted a real shift in political commitment, with rare disease funding growing from nothing in 2024 to €6.5m in 2025 and €8m in 2026.

Development and performance (continued)

For Rare Disease Day 2026 Rare Disease Ireland published the results of a new national survey of 177 people living with rare diseases and family carers, conducted six months after publication of the new strategy. The findings were stark: 39% rated their access to health services as bad or very bad, compared with 30.5% who rated it as good or very good, and 60% were probably/definitely pessimistic about whether the strategy would make a real difference to their lives, with only 8% probably/definitely optimistic. Respondents described their care as “disjointed” and “overwhelming” and told us that “the constant fight for everything is overwhelming and mentally draining”. Our message was clear - no one living with a rare disease in Ireland should feel invisible within our health system, and people need visible, time-bound implementation, not just policy frameworks.

We continued to support the international ‘Light Up for Rare’ campaign, with landmark buildings and sites across the country lit up in the Rare Disease Day colours in 2025 and 2026. There is enormous and growing interest in Rare Disease Day across Ireland, as evidenced by interest from national and local TV, radio and newsprint, and activity on social media.

The I Am Number 17 campaign, which we launched in 2024 with Rare Ireland and Takeda, continued to grow over the period. On 11 September 2025 we launched the I Am Number 17 book at Dublin’s Mansion House - a richly illustrated volume featuring the portraits of the campaign’s 17 “Changemakers”, photographed by Julien Behal, together with their stories, and a foreword by Irish rugby star James Lowe, who spoke publicly about his own experience of living with Juvenile Idiopathic Arthritis. The launch attracted widespread national and regional coverage, and the “Meet the 1 in 17” stories continue to be shared through iamnumber17.ie and our own channels. The campaign has changed the conversation about rare diseases by putting real people and real experiences at its centre, and reminding the public and policymakers that rare conditions are more common than many think.

Our political engagement over the period built on that public awareness. In early 2025 RDI re-launched the All-Party Group on Rare Diseases to brief newly elected Oireachtas members on the need for a new national rare disease strategy and the lived-experience evidence underpinning it. Further meetings throughout 2025 and 2026 have been held on topics such as access to medicines and the EU Presidency.

On 15 October 2025 RDI’s CEO appeared before the Oireachtas Joint Committee on Health on access to orphan medicines. RDI’s evidence showed that only 19 of the 68 orphan medicines authorised in Europe between 2019 and 2023 (28%) had been reimbursed in Ireland, that the average time to reimbursement was 1,024 days - almost two years and nine months - after European authorisation, and that one application had been in the system for six years. We called for all orphan medicines to be available within 12 months of European authorisation, for a cross-sectoral working group to be established by the first quarter of 2026, and for early access schemes and a reimbursement system that is fit for purpose for rare diseases.

Development and performance (continued)
Access to medicines remained a major focus through 2026. In January 2026 RDI joined IPPOSI and UCAN Ireland in a joint statement welcoming the conclusion of two new Framework Agreements on the pricing and supply of medicines. When the Minister for Health announced an end-to-end review of the medicines approval system in June 2026, RDI made clear in the national media that patients with rare diseases cannot wait for yet another review and called for a streamlined system to be designed within six months, together with emergency compassionate access arrangements. RDI does not ordinarily advocate for individual medicines, but in August 2026 the CEO and Board of RDI wrote to the HSE Senior Leadership Team in support of reimbursement of Skyclarys (omaveloxolone) for people living with Friedreich's ataxia, who had waited more than 30 months since European authorisation. We asked the HSE to fund the medicine through a managed access arrangement, with specialist prescribing, structured outcomes data collection and a commitment to formal reassessment. The HSE subsequently agreed to reimburse the medicine. In welcoming that decision, we highlighted that patients and families should not have to protest and litigate to access treatment, and that what is needed is a predictable pathway that does not require patients to fight this hard.

Advocacy activity was transparently recorded. RDI submitted more than a dozen lobbying returns over the period describing activity around the Programme for Government 2025 – Securing Ireland's Future, the All-Party Group on Rare Diseases, the National Rare Disease Strategy, screening, access to orphan medicines, and engaging on the European stage in addition to communications with designated public officials at the Department of Health and HSE leadership. These activities continue to drive greater visibility of rare disease priorities among elected representatives, policy makers and HSE leadership.

Our advocacy helped secure commitments in the Programme for Government 2025, Securing Ireland's Future. These most notably include a commitment to publish and fund a new National Rare Disease Plan and improving access to orphan drugs. The Strategy was published in August 2025, with dedicated funding of €6.5m in 2025 and €8m in 2026. The second remains a work in progress that should be progressed through implementation of the National Strategy, including new methods for earlier reimbursement and early access schemes for rare diseases. It further commits to increase the number of clinical trials, and to work towards a more coordinated approach to reimbursement and pricing negotiation at European level.

Policy engagement and formal representation were sustained and deepened through the development and publication of the National Rare Disease Strategy 2025-2030. RDI's CEO served on the National Rare Disease Steering Group charged with developing the strategy, alongside patient representatives, and co-chaired the Rare Disease Patient Forum which captured lived experience and fed that evidence directly into the strategy. The strategy was published by the Minister for Health, Jennifer Carroll MacNeill, on 27 August 2025, together with an Easy Read version and the Patient Forum Workshop Report. Its commitments include a Rare Disease Partnership Advisory Group to ensure a continuous patient voice, establishment of appropriate governance, leadership and accountability structures, expanded newborn screening, integrated and coordinated care, a rare disease patient registry, access to orphan medicines and development of an implementation plan against which progress can be measured. In January 2026 the Department of Health sought expressions of interest from people with lived experience to join the Implementation Oversight Group, which RDI promoted across our community, and the Group held its first meeting in February 2026.

This group has since come under the purview of the HSE, and Rare Diseases Ireland is now an active member of the Group.

RDI worked closely with the NRDO and the office of the Chief Clinical Officer to design and develop a strategic implementation plan. This plan has recently been endorsed by HSE leadership, and we are pushing for its publication. More recently HSE has sought expressions of interest from people with lived experience to join the implementation working groups. We promoted this opportunity across our community.

Development and performance (continued)
We also continued our membership and advisory roles on implementation of the National Genetic & Genomic Medicines Strategy, including membership of the PPI working group of the National Genetics & Genomics Office, and membership of the Model of Care working group. Our role is to ensure patient needs inform implementation of this important strategy.

RDI's CEO served on the Department of Health's National Clinical Trials Oversight Group, whose report, published in November 2025, set out recommendations to transform Ireland's clinical trials landscape, including a Clinical Trials Advisory Council with patient representation to bridge to a National Clinical Trials Body by 2027. These reforms are particularly important for people living with rare diseases, for whom a clinical trial is often the only route to treatment. We also contributed to other cross-agency forums, including HIQA's Health Technology Assessment Expert Advisory Group, and continued our engagement at European level through the governing board of the European Rare Disease Research Alliance (ERDERA).

Research and evidence continue to underpin our advocacy. We continue to lead on research as a member of the HRB funded RD Catalyst research grant. Through this grant we have partnered with EURORDIS-Rare Diseases Europe and the UCD School of Nursing, Midwifery and Health Systems on the development of RD-PREM, a patient-reported experience measure designed specifically for rare disease care, capturing long diagnostic journeys, the shortage of specialist expertise, the complexity of navigating care across multiple providers and the emotional toll of living with a rare disease. The questionnaire is being tested with people living with rare diseases and their care givers in 2026 so that it can in time be used to improve rare disease care in Ireland and internationally. We have also conducted research on the role of patient centred outcome measures in reimbursement decision making and established the Irish Patient Advocacy Group (IPAG). These research partnerships extend our influence, supplement our capacity and ensure Ireland's rare disease community benefits from national and international collaboration and research expertise.

The period also saw progress on a long-standing RDI priority. After years of advocacy, including our Get Rare Aware campaign, the national newborn bloodspot screening programme was expanded on 13 April 2026 to include Severe Combined Immunodeficiency (SCID) and Spinal Muscular Atrophy (SMA), bringing to ten the number of conditions for which every baby born in Ireland is screened. This is a life-changing development for the families who will benefit, and RDI will continue to press for further expansion of newborn screening in line with best practice in Europe.

Service development and care pathways remain front and centre. RDI continued to work closely with the National Rare Diseases Office on the development of rare disease care pathways, most notably through the EU's Joint Action on Rare Disease Integration (JARDIN) collaboration where RDI had an active role in development of a generic rare disease care pathway framework. RDI attended NRDO symposia held in Galway and Cork in 2026. These were well attended and great opportunities to build networks and relationships across the country. We also welcomed the development by the NRDO of a Rare Diseases Education Programme for healthcare professionals and the masterclass on rare disease research hosted by RCPI. Throughout the period we continued to press for appropriate resourcing and integration of European Reference Networks (ERNs) within Irish healthcare services so that people living with rare diseases and their healthcare professionals can access specialist expertise without unnecessary delay. A number of care coordinators and data managers have now been recruited at the ERNs. We continue to press for transition coordinators and allied health professionals in the regions to ease the day-to-day burden of living with a rare disease in Ireland.

Development and performance (continued)
Media engagement and communications underpinned all of RDI's work. Our campaigns, evidence and events were supported by a steady stream of coverage across national outlets, including the Irish Times, the Irish Examiner, RTÉ, Newstalk and the Irish Medical Times, as well as regional press and radio, and by active use of our social channels to amplify patient voices and evidence. This combined approach helped lift issues such as access to orphan medicines, implementation of the national strategy, diagnostic delay and newborn screening into mainstream public debate throughout 2025 and 2026.

Governance and organisational resilience were also priorities for RDI. We continued to strengthen Board membership, skills and oversight, and the Board worked closely with the executive on RDI's advocacy, as reflected in its direct engagement with HSE leadership on access to medicines. We pursued diversified funding, including grant and research partnerships, to build capacity, and maintained our focus on good governance in line with the Charities Regulator's Charities Governance Code. In line with good corporate governance we have refreshed our Board with new members and planned for transition of key board roles (Chair and Treasurer) as retirements approached. These steps are necessary to sustain RDI's increasing policy workload and to ensure we can represent people living with rare diseases effectively at national and EU levels.

Looking ahead, RDI's work in 2025-2026 has positioned the organisation to play a central role in the implementation of the National Rare Disease Strategy 2025-2030. We will continue to press for publication of the strategic implementation plan and for meaningful lived-experience representation in its oversight and implementation. We will revisit our own strategy and update it to meet the needs of the evolving political and healthcare landscape. We will sustain parliamentary engagement through the All-Party Group and other channels. We will also use Ireland's EU Presidency to keep rare diseases on the European agenda and host a major event during the presidency 'Research as Care: Why Rare Diseases Matter for Europe's Future; Embedding Research and Innovation as Standard of Care in Rare Diseases'. The event will highlight rare diseases as both a major health priority and a strategic opportunity for Europe to strengthen its research, innovation and life sciences ecosystem while improving outcomes for the 30 million people living with a rare disease across Europe. Across three sessions - covering the Biotech Act, research and innovation as standard of care, and the call for a European Action Plan on Rare Diseases - the day will build one argument: in rare diseases, the human case and the competitiveness case are aligned - a Europe that embraces innovation will drive both health and economic benefits for its citizens.

While progress is incremental and many challenges remain, the combination of public awareness, evidence-based advocacy and cross-sector partnership gives us a firm foundation to continue pushing for equitable access to diagnosis, treatment and care for everyone living with a rare disease in Ireland.

Financial results, assets and liabilities and financial position
The company had a deficit in the year of -€10,879 (2024: €41,928) and this was transferred from reserves at the year end. At the end of the year the company had assets of €108,180 (2024: €118,297) and liabilities of €9,096 (2024: €8,334). The net assets at the year end were €99,084 (2024: €109,963).

Directors report (continued)

Principal risks and uncertainties

The Directors have identified that the key risks and uncertainties the company faces relate to the risk of reduced government funding, memberships and fundraising in the future and of the potential increase in compliance requirements in accordance with company, health and safety, taxation and other legislation.

The company mitigates these risks continually monitoring the level of activity and by monitoring emerging changes to regulations and legislation on an ongoing basis.

Internal control risks are minimised by the implementation of procedures for authorisation of all transactions.

Likely future developments

The company plans to continue the activities outlined above in the forthcoming years subject to satisfactory funding arrangements.

Events after the end of the reporting period

There have been no significant events affecting the company since the year end.

Accounting records

The measures taken by the directors to secure compliance with the requirements of sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records are the implementation of necessary policies and procedures for recording transactions, the employment of competent accounting personnel with appropriate expertise and the provision of adequate resources to the financial function. The accounting records of the company are located at the registered office.

Relevant audit information

In the case of each of the persons who are directors at the time this report is approved in accordance with section 332 of Companies Act 2014:

• so far as each director is aware, there is no relevant audit information of which the company's statutory auditors are unaware, and

• each director has taken all the steps that he or she ought to have taken as a director in order to make himself or herself aware of any relevant audit information and to establish that the company's statutory auditors are aware of that information.

Auditors

The auditors, McCloskey & Co, have indicated their willingness to continue in office in accordance with the provisions of Section 383(2) of the Companies Act 2014.

This report was approved by the board of directors on …… and signed on behalf of the board by:

Director Director

Directors responsibilities statement

The directors are responsible for preparing the directors report and the financial statements in accordance with applicable Irish law and regulations.

Irish company law requires the directors to prepare financial statements for each financial year. Under the law, the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council. Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the company as at the financial year end date and of the surplus or deficit of the company for the financial year and otherwise comply with the Companies Act 2014.

In preparing these financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets, liabilities, financial position and surplus or deficit of the company to be determined with reasonable accuracy, enable them to ensure that the financial statements and directors report comply with the Companies Act 2014 and enable the financial statements to be audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Independent auditor's report to the members of Rare Diseases Ireland

Report on the audit of the financial statements

Opinion

We have audited the financial statements of Rare Diseases Ireland (the 'company') for the financial year ended 31 December 2025 which comprise the income and expenditure account, statement of income and retained earnings, balance sheet, statement of cash flows and notes to the financial statements, including a summary of significant accounting policies set out in note 3. The financial reporting framework that has been applied in their preparation is Irish law and FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland.

In our opinion, the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2025 and of its loss for the financial year then ended;
- have been properly prepared in accordance with FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland; and
- have been prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are further described in the auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of the financial statements in Ireland, including the Ethical Standard issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and the provisions available for small entities, in the circumstances set out below, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

As a small entity under the provisions of the IAASA Ethical Standard we engage our auditor to assist with the presentation of the financial statements.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Company's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other Information

The directors are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2014

Based solely on the work undertaken in the course of the audit, we report that:

- in our opinion, the information given in the directors' report is consistent with the financial statements; and
- in our opinion, the directors' report has been prepared in accordance with applicable legal requirements.

We have obtained all the information and explanations which we consider necessary for the purposes of our audit.

In our opinion the accounting records of the company were sufficient to permit the financial statements to be readily and properly audited, and financial statements are in agreement with the accounting records.

Matters on which we are required to report by exception

Based on the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report.

The Companies Act 2014 requires us to report to you if, in our opinion, the disclosures of directors' remuneration and transactions required by sections 305 to 312 of the Act are not made. We have nothing to report in this regard.

Respective responsibilities

Responsibilities of directors for the financial statements

As explained more fully in the directors' responsibilities statement, the directors are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the directors determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the directors are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the management either intends to liquidate the company or to cease operations, or has no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As part of an audit in accordance with ISAs (Ireland), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

The purpose of our audit work and to whom we owe our responsibilities

Our report is made solely to the company's members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members, as a body, for our audit work, for this report, or for the opinions we have formed.

Thomas McCloskey (Senior Statutory Auditor)

For and on behalf of
McCloskey & Co
Chartered Accountants & Statutory Auditor
Workhub
51 Bracken Road
Sandyford Business Park
Dublin
D18 CV48

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

Income and expenditure account
Financial year ended 31 December 2025

	Note	2025 €	2024 €
Income	**5**	110,381	175,028
Gross surplus		110,381	175,028
Expenditure		(121,260)	(133,100)
Operating (deficit)/surplus		(10,879)	41,928
(Deficit)/surplus before taxation		(10,879)	41,928
Tax on (deficit)/surplus		-	-
(Deficit)/surplus for the financial year		(10,879)	41,928

All the activities of the company are from continuing operations.

The company has no other recognised items of income and expenses other than the results for the financial year as set out above.

The notes on pages 18 to 21 form part of these financial statements.

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

Statement of income and retained earnings
Financial year ended 31 December 2025

	2025	2024
	€	€
(Deficit)/surplus for the financial year	(10,879)	41,928
Retained earnings at the start of the financial year	109,963	68,035
Retained earnings at the end of the financial year	99,084	109,963

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

Balance sheet
As at 31 December 2025

	Note	2025		2024	
		€	€	€	€
Fixed assets					
Tangible assets	**8**	120		240	
			120		240
Current assets					
Debtors	**9**	20,444		5,720	
Cash at bank and in hand		87,616		112,337	
		108,060		118,057	
Creditors: amounts falling due within one year	**11**	(9,096)		(8,334)	
Net current assets			98,964		109,723
Total assets less current liabilities			99,084		109,963
Net assets			99,084		109,963
Capital and reserves					
General funds			99,084		109,963
Members funds			99,084		109,963

These financial statements were approved by the board of directors on ..... and signed on behalf of the board by:

Director Director

The notes on pages 18 to 21 form part of these financial statements.

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

Statement of cash flows
Financial year ended 31 December 2025

	Note	2025 €	2024 €
Cash flows from operating activities			
(Deficit)/surplus for the financial year		(10,879)	41,928
Adjustments for:			
Depreciation of tangible assets		120	120
Accrued expenses/(income)		492	-
Changes in:			
Trade and other debtors		(14,724)	(5,000)
Trade and other creditors		366	1,792
Cash generated from operations		(24,625)	38,840
Net cash (used in)/from operating activities		(24,625)	38,840
Net increase/(decrease) in cash and cash equivalents		(24,625)	38,840
Cash and cash equivalents at beginning of financial year	**10**	112,045	73,205
Cash and cash equivalents at end of financial year	**10**	87,420	112,045

1. General information

The company is a private company limited by guarantee, registered in Ireland. The address of the registered office is Carmichael House, North Brunswick Street, Dublin 7.

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

3. Accounting policies and measurement bases

Basis of preparation

The financial statements have been prepared on the going concern basis, under the historical cost basis and comply with the financial reporting standards of the Financial Reporting Council and promulgated by CHartered Accountants Ireland and the Companies Act 2014.

The financial statements are prepared in Euro, which is the functional currency of the entity.

Turnover

Grant income from Public Sector Bodies/Government Agencies and other sources are credited when received or when the ultimate amount receivable can be assessed with reasonable certainty.

Expenditure

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.

Taxation

No charge to current or deferred taxation arises as the charity has been granted charitable status under Sections 207 and 208 of the Taxes Consolidation Act 1997, Charity No CHY 13930.

Tangible assets

Tangible assets are initially recorded at cost, and are subsequently stated at cost less any accumulated depreciation and impairment losses.

Depreciation

Depreciation is calculated so as to write off the cost or valuation of an asset, less its residual value, over the useful economic life of that asset as follows:

Fittings fixtures and equipment	-	20%

If there is an indication that there has been a significant change in depreciation rate, useful life or residual value of tangible assets, the depreciation is revised prospectively to reflect the new estimates.

Impairment

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

Departure from Companies Act 2014 presentation
The directors have elected to present an Income and Expenditure account instead of a Profit and Loss account in these financial statements as this compnay is a not for profit entity.

4. Limited by guarantee

The company is one limited by guarantee not having a share capital and consequently the liability of members is limited, subject to an undertaking by each member to contribute to the net assets or liabilities of the company on winding up such amounts as may be required not exceeding €1.27.

5. Income

Income arises from:

	2025	2024
	€	€
Memberships	-	50
Donations	888	15,623
RDI - Round Table of Companies	90,000	61,500
Research grant - UCD	15,444	47,640
Project income	-	50,000
Other income	4,049	215
	110,381	175,028

The whole of the turnover is attributable to the principal activity of the company which is wholly undertaken in Ireland.

6. Staff costs

The average number of persons employed by the company during the financial year was as follows:

	2025	2024
	Number	Number
Administrative	2	2

The aggregate payroll costs incurred during the financial year were:

	2025	2024
	€	€
Wages and salaries	90,988	66,345
Social insurance costs	10,168	7,353
	101,156	73,698

Increase in payroll costs reflects increased working time over period.

7. Appropriations of income and expenditure account

	2025	2024
	€	€
At the start of the financial year	109,963	68,035
(Deficit)/surplus for the financial year	(10,879)	41,928
At the end of the financial year	99,084	109,963

8. Tangible assets

	Fixtures, fittings and equipment	**Total**
	€	**€**
Cost		
At 1 January 2025 and 31 December 2025	1,886	1,886
Depreciation		
At 1 January 2025	1,646	1,646
Charge for the financial year	120	120
At 31 December 2025	1,766	1,766
Carrying amount		
At 31 December 2025	120	120
At 31 December 2024	240	240

9. Debtors

	2025	2024
	€	€
Trade debtors	5,000	5,000
Other debtors	15,444	-
Prepayments	-	720
	20,444	5,720

10. Cash and cash equivalents

	2025	2024
	€	€
Cash at bank and in hand	87,616	112,337
Bank overdrafts	(196)	(292)
	87,420	112,045

11. Creditors: amounts falling due within one year

	2025	2024
	€	€
Amounts owed to credit institutions	196	292
Trade creditors	277	-
Tax and social insurance:		
PAYE and social welfare	6,881	6,792
Accruals	1,742	1,250
	9,096	8,334

12. Analysis of changes in net debt

	At 1 January 2025	Cash flows	At 31 December 2025
	€	**€**	**€**
Cash and cash equivalents	112,337	(24,721)	87,616
Bank overdrafts	(292)	96	(196)
	112,045	(24,625)	87,420

13. Events after the end of the reporting period

There have been no significant events affecting the charity since the year end.

14. Ethical standards

As a small entity under the provisions of the IAASA Ethical Standard we engage our auditor to assist with the presentation of the financial statements.

15. Approval of financial statements

The board of directors approved these financial statements for issue on .

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

The following pages do not form part of the statutory accounts.

Rare Diseases Ireland
(A Company Limited by Guarantee and not having Share Capital)

Detailed income and expenditure account
Financial year ended 31 December 2025

	2025	2024
	€	€
Income		
Memberships	-	50
Donations	888	15,623
RDI - Round Table of Companies	90,000	61,500
Other income	4,049	215
Research grant - UCD	15,444	47,640
Project income	-	50,000
	110,381	175,028
Gross surplus	110,381	175,028
Gross surplus percentage	100.0%	100.0%
Overheads		
Administrative expenses		
Wages and salaries	(90,988)	(66,345)
Employer's PRSI contributions	(10,168)	(7,353)
Programme expenses	(6,739)	(52,056)
Insurance	(1,608)	(864)
Printing, postage and stationery	(107)	(14)
Advertising	20	-
Telephone	(374)	(343)
Computer costs	-	(925)
Legal and professional	(5,069)	-
Accountancy fees	-	(711)
Auditors remuneration	(1,722)	(1,230)
Bank charges	(317)	(293)
General expenses	(112)	(259)
Subscriptions	(3,956)	(2,587)
Depreciation of tangible assets	(120)	(120)
	(121,260)	(133,100)
Operating (deficit)/surplus	(10,879)	41,928
Operating (deficit)/surplus percentage	9.9%	24.0%
(Deficit)/surplus before taxation	(10,879)	41,928