

**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 2022**

**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**

<b>Directors</b>	Patricia Towey John McCormack Anne Micks David Barton (Resigned 31 August 2022) Paula Guerin Mairéad Hennessy Kevin Whelan (Resigned 21 April 2022) Michael Blighe Laura Egan Anne Lawlor
<b>Secretary</b>	Michael Blighe
<b>Company number</b>	140743
<b>Registered office</b>	Carmichael House North Brunswick Street Dublin 7
<b>Business address</b>	Carmichael House North Brunswick Street Dublin 7
<b>Auditor</b>	McCloskey & Co The Glasshouses Unit 16 The Cubes Offices Beacon South Quarter Sandyford Dublin D18 XD36
<b>Bankers</b>	AIB 9 Terenure Road Rathgar Dublin 6
<b>Registered Charity Number</b>	20044633
<b>CHY (Revenue) Number</b>	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 2022.

**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**

Patricia Towey  
John McCormack  
Anne Micks  
David Barton (Resigned 31 August 2022)  
Paula Guerin  
Mairéad Hennessy  
Kevin Whelan (Resigned 21 April 2022)  
Michael Blighe  
Laura Egan (Appointed 5 March 2022)  
Ann Lawlor

**Secretary**

Michael Blighe

**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 carers 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.

**Rare Diseases Ireland**  
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**Directors report (continued)**

**Development and performance (cont'd)**

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.

As in previous years and throughout 2022 RDI continued to work with all stakeholders to raise awareness of rare diseases, highlight issues nationally and internationally of particular concern to the rare disease community in Ireland, engage with development of policies and services to meet the needs of people living with rare diseases and advance our research priorities to support our advocacy efforts.

RDI worked with patient organisations and people living with rare diseases their carers and their families, with healthcare providers treating people living with rare diseases, with the national rare diseases office (NRDO), with industry with an interest in rare diseases and the landscape in Ireland, 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 carers and families.

RDI also worked with EURORDIS-Rare Diseases Europe and rare disease national alliances across Europe to promote development of EU wide strategies, policies and programmes which will influence policy in Ireland. As a small organisation and a small country, we must work closely with our EU counterparts to supplement capacity in Ireland. Therefore, EU rare disease policy is of critical importance for the community in Ireland.

Rare Disease Day (RDD), on the last day of February, is the international day designated to raising awareness for the rare disease community worldwide. RDI hosted our second family friendly 'Raise A Toastie' campaign to mark RDD 2022. The campaign is an inclusive opportunity for everyone to recognise the rare community and raise awareness for those living with rare conditions. People were invited to make a toastie in the comfort of their own homes and to post a photo of their creations on-line. We also joined the international 'Light Up' campaign, with many landmark buildings across the country lit-up in the RDD colours. There is enormous and growing interest in RDD across Ireland, as evidenced by interest from national and local tv, radio and newsprint, and activity on social media.

2022 also saw the launch of the new Rare Disease Forum. The RD Forum was established as a collaboration between RDI, Northern Ireland Rare Disease Partnership (NIRDP), Health Research Charities Ireland (HRCI) and Irish Platform for Patient Organisations, Science and Industry (IPPOSI), with Cystic Fibrosis Ireland as founding chair of the group. The RD Forum is a Public and Patient Involvement (PPI) Initiative for Ireland, North and South. The rationale for the RD Forum recognises that much more needs to be done to address the health and allied social care needs of those living with rare diseases. This is best done by listening to the voices of stakeholders across the spectrum and is achieved by hosting themed on-line symposia (approx. three each year). Through information sharing, discussion and consensus building with stakeholders, we can collectively and individually play a role in helping to shape rare disease related policy, services, and research to help alleviate the burden of living with a rare disease.

The first symposium of the RD Forum was jointly hosted by RDI and NIRDP around Rare Disease Day. The theme of the event was 'Rare Disease Programs, Plans and Policies' and served as the official launch of the RD Forum. The symposium was an opportunity to position rare disease care across Ireland and demonstrate how collaboration across Ireland can enhance care for people living with rare diseases. Subsequent symposia were themed around research 'What's new in rare disease research in Ireland?' and collaboration 'Partnering to advance the rare disease agenda'.

**Rare Diseases Ireland**  
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**Directors report (continued)**

**Development and performance (cont'd)**

Throughout the year RDI attended and spoke at events helping to raise the profile of rare diseases. These included in-person and on-line events on themes such as newborn screening, genetics, and access to medicines. RDI was also a member of the oversight panel of the Citizens Jury on the future use of genomics in Ireland.

Finally, RDI engaged with national and local media and our own social media channels throughout the year bringing stories, news and events to the public's attention.

RDI continues to work closely with the NRDO on initiatives to improve access to care for people living with rare diseases. Most notably we worked with the NRDO to further development of care pathways across a range of rare diseases and integration of European Reference Networks (ERNs) into the Irish health care system.

RDI engaged with patient organisations and individuals in the rare community to recruit them to add their voices and lived experience into work on the development of relevant care pathways. As pathway development transitioned into community support services RDI also attended and spoke at meetings with allied healthcare professionals bringing the voice of the rare disease community to these discussions. The contributions from those with lived experience have been very informative and highlighted the need for an integrated approach to hospital and community care for those living with rare diseases with a particular need for psychological support and counselling across their life course and for their family members.

ERNs are an initiative of the EU under the Cross Border Directive to ensure that people living with rare disease have access to best practice care, thus ensuring that no one is left behind. We are working with the NRDO to ensure that all ERNs are properly resourced and supported to enable affiliated health care providers to provide the highest standard of care to people living with rare diseases in Ireland and share information and best practice with colleagues across Europe.

During the year the HSE announced plans to develop a National Strategy for Genetics and Genomics in Ireland. Following an invitation from the HSE RDI took a seat on the Clinical Practice and Innovation Working Group for this strategy. RDI's role was to highlight the needs of patients, and in particular people living with rare diseases, in development of this ambitious strategy. This work coincided with on-going research in collaboration with the Department of Clinical Genetics at CHI, Crumlin into the experiences of people living with rare diseases when accessing genetics services in Ireland. The strategy was published late in the year, and RDI continues to contribute to the implementation group for this important development.

We anticipate that development of care pathways, integration of ERNs into the Irish health care system and implementation of the National Genetics and Genomics Strategy for Ireland will result in practical progress and improvements in the care of those living with rare diseases in Ireland. While progress remains slow, we are moving in the right direction.

Early in 2022 we launched our first Rare Reality research report examining the health care experiences of people living with rare diseases in Ireland. The research reveals the need for a focus on early diagnosis and integrated care. The complex nature of rare diseases means individuals are attending multiple specialists and clinics on both their diagnostic journey and for routine care following diagnosis. We now have an overview of the healthcare experiences of the rare community and where changes and improvements are needed in the future. We can measure progress with initiatives such as pathways and ERNs against this baseline over the coming years.

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**Directors report (continued)**

**Development and performance (cont'd)**

RDI commissioned and published nationally representative research on the public's views of newborn screening (the 'heel prick test'). Unsurprisingly there is wide support for expansion of the screening panel to include a larger number of rare diseases. The National Screening Advisory Council makes recommendations to the Minister for Health on diseases to be included in the panel with the HSE being responsible for implementation of such recommendations. The NSAC have a list of 35 rare diseases requested by health care providers and the public for inclusion in the panel. RDI is advocating for a streamlined and expedited process to speed up the work of NSAC and subsequent implementation at the HSE.

Research on the experiences of people accessing genetic services was undertaken in collaboration with researchers at UCD under the guidance of Prof Sally Ann Lynch, Clinical Geneticist at CHI, Crumlin. This research has been published in academic journals and meetings and has been used to inform the advocacy work of RDI. A full report detailing people's lived experience will be published over the coming period.

Following our successful 2021 campaign to secure Ireland's support for the UN Resolution on 'Addressing the Challenges of Persons Living with a Rare Disease and their Families' we further campaigned to secure support from the Minister for Health on a Czech led call on the European Commission to adopt a European Action Plan on Rare Diseases to support and complement on-going and future efforts at both the EU and Member State level to reduce unmet needs. This aligns with commitments in the Programme for Government and with the evolving landscape for rare disease policy across Europe and Ireland's role in policy formation.

RDI's work has continued into 2023. The Minister for Health released a statement on Rare Disease Day 2023 committing to development of a new national rare disease plan. We are working with the Department of Health and the NRDO to put a working group in place to develop and implement a new plan. RDI has also taken on secretariat of a new cross-party parliamentary group on rare diseases. This group has already met four times. There is growing interest across the political spectrum in rare diseases and the needs of the community. We have also launched our first major campaign targeting awareness across all elected representatives – Get Rare Aware! Finally, our collaboration with the NRDO and health care providers across the HSE continues to expand with collaborative research in the area of psychological supports for people with rare diseases and advocacy around support for integration of ERNs into the health care system.

As the pandemic fades into the background work practices are evolving. There has been a gradual return to in-person events over the course of the year. As a national organisation with membership right across the country we will continue to host many events on-line as this enables more people to get involved and contribute their voices to our work on an on-going basis.

RDI continues expansion of its Board, bringing more skills, experience and depth to the Board to assist the development and advancement of the organisation and the work it performs. RDI's board remains committed to achieving compliance with the Charities Regulator's Governance Code and we continue to grow core funding seeking to diversify sources and secure funding for specific projects.

**Financial results, assets and liabilities and financial position**

The company had a deficit in the year of -€26,902 (2021: surplus €51,613). At the end of the year the company had assets of €64,089 (2021: €87,491) and liabilities of €4,750 (2021: €1,250). The net assets at the year end were €59,339 (2021: €86,241).

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**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 continuing 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 charity 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 9 October 2023 and signed on behalf of the board by:

Mairéad Hennessy  
Director

Michael Blighe  
Director



**Rare Diseases Ireland**  
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**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 profit or loss 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 profit or loss 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 2022 which comprise the profit and loss 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 2022 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 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.

#### ***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.

**Independent auditor's report to the members of  
Rare Diseases Ireland (continued)**

***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.

**Independent auditor's report to the members of  
Rare Diseases Ireland (continued)**

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.

**Independent auditor's report to the members of  
Rare Diseases Ireland (continued)**

Thomas McCloskey (Senior Statutory Auditor)

For and on behalf of  
McCloskey & Co  
Chartered Accountants & Statutory Auditor  
The Glasshouses  
Unit 16 The Cubes Offices  
Beacon South Quarter  
Sandyford  
Dublin D18 XD36

9 October 2023

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

**Income and expenditure account**  
**Financial year ended 31 December 2022**

	<b>Note</b>	<b>2022</b> €	2021 €
<b>Income</b>	<b>5</b>	72,170	115,845
<b>Gross surplus</b>		<u>72,170</u>	<u>115,845</u>
Expenditure		(99,072)	(64,232)
<b>Operating (deficit)/surplus</b>		<u>(26,902)</u>	<u>51,613</u>
<b>(Deficit)/surplus before taxation</b>		<u>(26,902)</u>	<u>51,613</u>
Tax on (deficit)/surplus		-	-
<b>(Deficit)/surplus for the financial year</b>		<u><u>(26,902)</u></u>	<u><u>51,613</u></u>

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 16 to 20 form part of these financial statements.**

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**Statement of income and retained earnings**  
**Financial year ended 31 December 2022**

	<b>2022</b>	2021
	€	€
(Deficit)/surplus for the financial year	(26,902)	51,613
<b>Retained earnings at the start of the financial year</b>	<u>86,241</u>	<u>34,628</u>
<b>Retained earnings at the end of the financial year</b>	<u><u>59,339</u></u>	<u><u>86,241</u></u>

**Rare Diseases Ireland**  
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**Balance sheet**  
**As at 31 December 2022**

	Note	2022 €	€	2021 €	€
<b>Fixed assets</b>					
Tangible assets	8	480		-	
			480		-
<b>Current assets</b>					
Debtors	9	16,220		675	
Cash at bank and in hand		47,389		86,816	
		63,609		87,491	
<b>Creditors: amounts falling due within one year</b>	10	(4,750)		(1,250)	
<b>Net current assets</b>			58,859		86,241
<b>Total assets less current liabilities</b>			59,339		86,241
<b>Net assets</b>			59,339		86,241
<b>Capital and reserves</b>					
General funds			59,339		86,241
<b>Members funds</b>			59,339		86,241

These financial statements were approved by the board of directors on 9 October 2023 and signed on behalf of the board by:

Mairéad Hennessy  
 Director

Michael Blighe  
 Director

**The notes on pages 16 to 20 form part of these financial statements.**



**Rare Diseases Ireland**  
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**Statement of cash flows**  
**Financial year ended 31 December 2022**

	<b>2022</b>	2021
	€	€
<b>Cash flows from operating activities</b>		
(Deficit)/surplus for the financial year	(26,902)	51,613
<i>Adjustments for:</i>		
Depreciation of tangible assets	120	-
Accrued expenses/(income)	-	246
<i>Changes in:</i>		
Trade and other debtors	(15,545)	660
Trade and other creditors	3,500	(3,500)
Cash generated from operations	<u>(38,827)</u>	<u>49,019</u>
Net cash (used in)/from operating activities	<u>(38,827)</u>	<u>49,019</u>
<b>Cash flows from investing activities</b>		
Purchase of tangible assets	(600)	-
Net cash (used in)/from investing activities	<u>(600)</u>	<u>-</u>
<b>Net increase/(decrease) in cash and cash equivalents</b>	(39,427)	49,019
<b>Cash and cash equivalents at beginning of financial year</b>	86,816	37,797
<b>Cash and cash equivalents at end of financial year</b>	<u>47,389</u>	<u>86,816</u>

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

**Notes to the financial statements**  
**Financial year ended 31 December 2022**

**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.

**Rare Diseases Ireland**  
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**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2022**

**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 company 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:

	<b>2022</b>	2021
	<b>€</b>	€
Memberships*	3,675	213
Donations	14,225	18,086
RDI - Round Table of Companies	49,000	49,000
Project income**	5,000	48,546
Other income	270	-
	<u>72,170</u>	<u>115,845</u>

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

\*Partial membership fees collected in 2021. Membership renewals adjusted to coincide with calendar year from January 2022

\*\*Project income includes €24,265 relating to projects initiated in 2021 and invoiced in 2022.

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

**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2022**

**6. Staff costs**

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

	<b>2022</b>	2021
	<b>Number</b>	Number
Administrative	1	1

The aggregate payroll costs incurred during the financial year were:

	<b>2022</b>	2021
	€	€
Wages and salaries	56,000	42,000
Social insurance costs	6,188	4,641
	<u>62,188</u>	<u>46,641</u>

Increase in payroll costs reflects increased working time over period.

**7. Appropriations of income and expenditure account**

	<b>2022</b>	2021
	€	€
At the start of the financial year	86,241	34,628
(Deficit)/surplus for the financial year	(26,902)	51,613
<b>At the end of the financial year</b>	<u>59,339</u>	<u>86,241</u>

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

**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2022**

<b>8. Tangible assets</b>	<b>Fixtures, fittings and equipment</b>	<b>Total</b>
	€	€
<b>Cost</b>		
At 1 January 2022	1,286	1,286
Additions	600	600
	<u>1,886</u>	<u>1,886</u>
<b>At 31 December 2022</b>	<u>1,886</u>	<u>1,886</u>
<b>Depreciation</b>		
At 1 January 2022	1,286	1,286
Charge for the financial year	120	120
	<u>1,406</u>	<u>1,406</u>
<b>At 31 December 2022</b>	<u>1,406</u>	<u>1,406</u>
<b>Carrying amount</b>		
<b>At 31 December 2022</b>	<u>480</u>	<u>480</u>
At 31 December 2021	<u>-</u>	<u>-</u>
	<u>-</u>	<u>-</u>
<b>9. Debtors</b>	<b>2022</b>	<b>2021</b>
	€	€
Other debtors	15,500	-
Prepayments	720	675
	<u>16,220</u>	<u>675</u>
	<u>16,220</u>	<u>675</u>
<b>10. Creditors: amounts falling due within one year</b>	<b>2022</b>	<b>2021</b>
	€	€
Payments received on account	3,500	-
Accruals	1,250	1,250
	<u>4,750</u>	<u>1,250</u>
	<u>4,750</u>	<u>1,250</u>

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

**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2022**

**11. Financial instruments**

The carrying amount for each category of financial instruments is as follows:

	<b>2022</b>	<b>2021</b>
	€	€
<b>Financial assets that are debt instruments measured at amortised cost</b>		
Other debtors	16,220	675
Cash at bank and in hand	<u>47,389</u>	<u>86,816</u>
<b>Financial liabilities measured at amortised cost</b>		
Other creditors	<u>4,750</u>	<u>1,250</u>

**12. Analysis of changes in net debt**

	At 1 January 2022	Cash flows	At 31 December 2022
	€	€	€
Cash and cash equivalents	<u>86,816</u>	<u>(39,427)</u>	<u>47,389</u>

**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 provide basic bookkeeping and accounts preparation.

**15. Approval of financial statements**

The board of directors approved these financial statements for issue on 9 October 2023.

**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 2022**

	<b>2022</b>	2021
	€	€
<b>Income</b>		
Memberships	3,675	213
Donations	14,225	18,086
RDI - Round Table of Companies	49,000	49,000
Other income	270	-
Project income	5,000	48,546
	<u>72,170</u>	<u>115,845</u>
<b>Gross surplus</b>	<u>72,170</u>	<u>115,845</u>
<b>Gross surplus percentage</b>	100.0%	100.0%
<b>Overheads</b>		
<b>Administrative expenses</b>		
Wages and salaries	(56,000)	(42,000)
Employer's PRSI contributions	(6,188)	(4,641)
Programme expenses	(31,446)	(10,020)
Insurance	(819)	(901)
Printing, postage and stationery	(492)	(2,142)
Telephone	(405)	(373)
Computer costs	(864)	-
Motor expenses	-	(560)
Accountancy fees	(707)	(766)
Auditors remuneration	(1,230)	(1,230)
Bank charges	(353)	(288)
General expenses	(168)	(1,031)
Subscriptions	(280)	(280)
Depreciation of tangible assets	(120)	-
	<u>(99,072)</u>	<u>(64,232)</u>
<b>Operating (deficit)/surplus</b>	(26,902)	51,613
<b>Operating (deficit)/surplus percentage</b>	37.3%	44.6%
<b>(Deficit)/surplus before taxation</b>	<u>(26,902)</u>	<u>51,613</u>