

Rare Diseases Ireland
Carmichael House
North Brunswick Street
Dublin 7

DATE:

McCloskey & Co
Chartered Accountants
Apex Business Centre
Blackthorn Road
Sandyford
Dublin 18

**RE: Rare Diseases Ireland
Audit year ended 31 December 2021**

Dear Sirs,

This representation letter is provided in connection with your audit of the financial statements of Rare Diseases Ireland for the year ended 31 December 2021 for the purpose of expressing an opinion as to whether the financial statements give a true and fair view of the state of affairs of the company as at 31 December 2021 and of its results for the period then ended in accordance with the Companies Act 2014 and with accounting standards generally accepted in Ireland, including FRS 102 the Financial Reporting Standard Applicable in the UK and Ireland.

We acknowledge as Directors/Trustees our responsibilities under the Companies Act 2014 for maintaining proper accounting records and preparing financial statements which give a true and fair view and making accurate representations to you.

We confirm, to the best of our knowledge and belief and having made appropriate enquiries of other Directors/Trustees and officials of the company, the following representations:

- **Accounting records and information**

We confirm our responsibility:

- a. For the preparation and fair presentation of the financial statements in accordance with Companies Act 2014 and accounting standards issued by the Financial Reporting Council including FRS 102, The Financial Reporting Standard applicable in the UK and Ireland (Generally Accepted Accounting Practice in Ireland);
- b. For such internal controls as is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error; and
- c. To provide the auditor with:
 - i. Access to all information of which we are aware that is relevant to the preparation of the financial statements such as records, documentation and

- other matters;
- ii. Additional information that you have requested from us for the purpose of the audit; and
 - iii. Unrestricted access to persons within the entity from whom you determined it necessary to obtain audit evidence.

We confirm that we have secured compliance with the charity's/company's obligation to maintain proper accounting records by the use of appropriate systems and procedures and by the employment of competent persons and that the company has kept proper books of account throughout the year.

In this regard, we confirm that we have fulfilled our responsibility for the preparation of the financial statements in accordance with the applicable financial reporting framework, including where relevant their fair presentation, as set out in the terms of the audit engagement.

All transactions have been recorded in the accounting records and are reflected in the financial statements.

All the accounting records have been made available to you for the purpose of your audit and all other records and related information which might affect the truth and fairness of, or necessary disclosure in, the financial statements, including details of all bank accounts, minutes of directors'/trustees, shareholders' and relevant management meetings, have been made available to you and no such information has been withheld. All information which we consider important and relevant to the financial statements and your audit of them has been brought to your attention.

- **Accounting policies**

We confirm that we have reviewed the company's accounting policies and estimation techniques and, having regard to the possible alternative policies and techniques, the accounting policies and estimation techniques selected for use in the preparation of the financial statements are the most appropriate to give a true and fair view of the company's particular circumstances, as required by FRS 102.

- **Accounting estimates**

We confirm that the significant judgements and key sources of estimation uncertainty and the assumptions used by us in making accounting estimates, including those measured at fair value, are reasonable.

- **Revenue recognition**

We confirm that the recognition of revenue from sales of goods and services and other sources, reflects the substance of all relevant contracts and arrangements with customers and other parties. Accordingly, revenue has been recognised only to the extent that all significant risks and rewards of ownership have been transferred to third parties.

All unrestricted income and donations are included in the financial statements on the basis of amounts received during the year.

Donations in kind are included at their estimated value to the foundation in both revenue and expenditure in the year of receipt.

Grants received to fund capital expenditure are deferred and amortised to income over the estimated useful lives of the related fixed assets. Grants and assistance to fund non-capital expenditure are credited to income and expenditure in the period in which the related expenditure is incurred.

- **Related Party Transactions**

There were no other related party transactions during the year ended 31 December 2021.

They are not aware of any other matters which require to be disclosed under S.33 of FRS 102 or other requirements including Companies Act 2014.

- **Transactions with Directors/Trustees (Or persons connected with them)/Directors/Trustees remuneration**

The Directors/Trustees confirm that no transactions, arrangements or agreements were made or entered into by the company for persons who at any time during the period were Directors/Trustees or officers of the charity/company, or persons connected with them.

We also confirm Directors/Trustees' remuneration as disclosed is nil.

- **Compliance with law and regulation**

We confirm that, we are not aware of any actual or potential material non-compliance with those laws and regulations which provide a legal framework within which the charitable company conducts its business and which are central to the charity's/company's ability to conduct its business and hence to the results and financial position to be disclosed in the financial statements for the year ended 31 December 2015, together with the actual or contingent consequences which may arise therefrom.

We are not aware of any instances of actual or potential breaches of, or non-compliance with laws and regulations, including the Companies Acts and the Taxes Acts, that are central to the company's ability to conduct its business or that could have a material effect on the financial statements.

- **Assets**

The charitable company has satisfactory title to all assets and there are no liens or encumbrances on the charity's assets, except for those that are disclosed in the notes to the financial statements

We are satisfied that the current assets in the balance sheet are expected to realise, in the ordinary course of business, no less than the net book amounts at which they are stated.

- **Contractual Arrangements**

All contractual arrangements entered into by the charity/company with third parties have been properly reflected in the accounting records or, where material (or potentially material) to the financial statements, have been disclosed to you.

The charity/company has complied with its obligations under contractual agreements where non-compliance could have a material effect on the financial statements.

There are no other agreements not in the ordinary course of business.

- **Liabilities**

Full provision has been made for all liabilities at the balance sheet date including guarantees, commitments and contingencies where the items are expected to result in significant loss. Contingent liabilities, where in our opinion provision is not required, have been appropriately disclosed in the financial statements.

We are not aware of any pending or threatened litigation, proceedings, hearing or claims negotiation, which may result in significant loss to the company

All guarantees and commitments given to third parties, including oral guarantees and commitments made on behalf of an affiliate, director, officer or any other third party have been disclosed where appropriate in the financial statements.

- **Retirement benefits (where applicable)**

All retirement benefits that the charity/company is committed to providing, including any arrangements that are statutory, contractual or implicit in the charity's/company's actions, wherever they arise, whether funded or unfunded, approved or unapproved, have been identified and properly accounted for and/or disclosed.

- **Grants and donations**

All grants, donations and other income, the receipt of which is subject to specific terms or conditions, have been notified to you. There have been no breaches or conditions in the application of such income.

- **Unusual transactions**

No transactions which had the primary objective of altering the appearance of the accounts have been entered into during the period.

- **Depreciation and impairment (where applicable)**

We are satisfied that the useful lives by reference to which depreciation has been calculated are appropriate. We confirm that an impairment review has been carried out and that there has been no impairment of fixed assets above the amount depreciated in the current period.

- **Going concern**

The financial statements have been prepared on the going concern basis. Having considered the company's trading performance since the year end, its profit and cash flow budgets / forecasts and its future business plans, we confirm that we have a reasonable expectation that the company has adequate resources to continue in operational existence for the foreseeable future.

- **Fraud and error**

We acknowledge our responsibility for the implementation and operations of accounting and internal control systems that are also designed to prevent and detect fraud and error. We have disclosed to you all significant facts relating to any frauds or suspected frauds known to management that may have affected the entity. We have disclosed to you the results of our assessment of the risk that the accounts may be materially misstated as a result of fraud.

We are not aware of any irregularities, or allegations of irregularities, including fraud, involving management or employees who have a significant role in the accounting and internal control systems, or that could have a material effect on the financial statements.

- **Unadjusted audit differences**

We confirm that the financial statements have no unadjusted misstatements that are considered to be, both individually and in aggregate, material to the truth and fairness of the financial statements either taken as a whole or in connection with the ability to assess the performance and the financial position of the charity/company.

- **Events after the balance sheet date**

The arrival of the COVID-19 coronavirus pandemic in the early months of 2021 has had a significant effect on the activities of Rare Diseases Ireland in terms of strategy and planning events. It is hoped that as the restrictions are eased the activities will gradually return to pre COVID-19 levels.

- **Statement of Relevant Information**

We confirm our compliance with the requirements of Section 330 of the Companies Act 2014. We acknowledge that Section 330 requires that we as the directors of the company make a statement in the directors report that each of the persons who are directors of the company at the time of the report, that in so far as they are aware there is no relevant audit information of which the company's statutory auditors are unaware and the directors have taken all steps that he or she out 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.

- **Non-Exchange Transactions**

We confirm that any donated cash, services, goods or legacies received through a non-exchange transaction, have been measured using fair value as the basis for cost on the date of acquisition in accordance with the requirements of S.13.5A of FRS 102 and Section 34 PBE of FRS 102. Where it has not been practicable to estimate the value of the resource with sufficient reliability the income relating to non-exchange transactions has been recognised when the resource was sold.

This letter was tabled at the meeting of the Board of Directors/Trustees on

Yours faithfully,

Director/Trustee

Director/Trustee

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 2021

DRAFT FOR APPROVAL

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	Patricia Towey John McCormack Anne Micks David Barton Paula Guerin Mairéad Hennessy Kevin Whelan Michael Blighe Laura Egan Ann Lawlor
Secretary	Michael Blighe
Company number	140743
Registered office	Carmichael House North Brunswick Street Dublin 7
Business address	Carmichael House North Brunswick Street Dublin 7
Auditor	McCloskey & Co Apex Business Centre Blackthorn Road Sandyford Dublin 18
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 2021.

Directors

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

Patricia Towey
John McCormack (Appointed 29 June 2021)
Anne Micks (Appointed 19 October 2021)
David Barton
Paula Guerin
Mairéad Hennessy
Kevin Whelan
Michael Blighe
Anne Lawlor

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

Throughout 2021 RDI liaised with all stakeholders to raise awareness of rare diseases, highlight issues of particular concern to the rare disease community in Ireland, engage with development of rare disease health services 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, and with policy makers, including leadership across the government, the Oireachtas, the Department of Health and the HSE to advance our mission:

RDI also worked with EURORDIS-Rare Diseases Europe to develop 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 influence rare disease policy across the EU and nationally.

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

Directors report (continued)

Development and performance (cont'd)

2021 opened in the grips of the global COVID-19 pandemic. Notwithstanding, there was reason to be optimistic as vaccines were being rolled out across Ireland. RDI worked with colleagues across patient organisations to ensure that those living with rare conditions and at highest risk from COVID-19 would have early access to vaccines. RDI also worked with the HSE's National Rare Diseases Office to ensure that recommendations and learnings from colleagues across Europe, through the European Reference Networks, were captured in Ireland's vaccine rollout plans. By the end of 2021 vaccines were widely available and Irish society reopened. While COVID is now endemic in Ireland, and those in the rare community remain vigilant, life for many is returning to normal, and new treatments and vaccines will provide further reassurance into the future.

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 launched for the first time our new family friendly 'Raise A Toastie' campaign to mark RDD 2021. 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. The campaign was widely promoted through national and local tv, radio and newsprint, and through our social media channels. The day itself saw us trending on social media and was considered to be a huge success for our first inclusive family friendly event.

RDI also marked RDD with several on-line meetings. Most notable and well attended were the launch of EURORDIS' Rare 2030 Outcomes report and a webinar entitled The Hopes and Challenges for those living with a rare disease in Ireland. Finally, we 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 rare disease day across Ireland.

For the very first time, RDI collaborated with Science Foundation Ireland (SFI) to bring rare disease awareness into the classroom during Science Week. This is the first time we have had an opportunity to link into the classroom. Awareness in this age group is important both in terms of understanding the challenges that some of their classmates may be facing but also in terms of their future career opportunities and the positive impact that they can have by being rare aware.

Throughout the year RDI maintained communications with elected representatives and leadership at the Department of Health and the HSE, in particular seeking delivery of commitments made in the Program for Government: Our Shared Future. RDI met with the Minister for Health and with the Health Committee. RDI also made a submission for changes to the Health (Pricing and Supply of Medical Goods) Act 2013.

RDI sought support from the government for a UN Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families." Our successful campaign led Ireland to be one of the first countries globally to co-sponsor the Resolution which was adopted in December.

The ground-breaking Resolution is the first UN document to recognise the specific challenges of those living with rare conditions and their families. The Resolution goes beyond health. It affirms that addressing the needs of the rare community is essential to advancing the UN's 2030 Agenda for Sustainable Development, which includes access to education and decent work, reducing poverty, tackling gender inequality, and supporting the inclusion of those living with rare conditions in society.

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

Directors report (continued)

Development and performance (cont'd)

RDI worked with the National Rare Diseases Office (NRDO) to continue development of care pathways across a range of rare conditions. RDI engaged with patient organisations and individuals in the rare community to ensure that the patient voice was captured in the development of the care pathways. 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 conditions with a particular need for psychological support and counselling across their life course and for family members.

At the end of the year we also welcomed the EU's announcement that applications from Irish centres for membership of 16 European Reference Networks (ERNs) had been approved. Ireland now has membership of 19 of the 24 designated ERNs giving those living with rare conditions access to expertise across Europe and ensuring that healthcare providers have additional opportunities for rare disease training and research. We very much welcome this development and are working with the NRDO towards integration into the Irish healthcare system.

RDI ran its first comprehensive survey of the health care experiences of the rare community during 2021. The results of this research was published in early 2022 and 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 over the coming years. We anticipate that development of care pathways and integration of ERNs will result in practical progress and improvements in the care of those living with rare conditions.

The pandemic required a change to work practices for RDI, with much activity moved on-line. This change in work practice has enabled more people to get involved and contribute to our work. While we look forward to meeting in-person again we will continue with on-line meeting and events to enable more people to get involved on an on-going basis.

RDI continued expansion of its Board in 2022, 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 also committed to achieving compliance with the Charities Regulator's Governance Code. RDI continues to grow its funding seeking to diversify sources and secure funding for projects. RDI also enabled on-line donations to be made.

Assets and liabilities and financial position

The company had a surplus in the year of €51,613 (2020: €5,342). At the end of the year the company had assets of €87,491 (2020: €39,132) and liabilities of €1,250 (2020: €1,004). The net assets at the year end were €86,241 (2020: €34,628).

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.

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

Directors report (continued)

Likely future developments

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

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

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

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 2021 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 2021 and of its profit 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

We have nothing to report in respect of the following matters in relation to which ISAs (Ireland) require us to report to you where:

- the directors' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the directors have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

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
Apex Business Centre
Blackthorn Road
Sandyford
Dublin 18

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

Income and expenditure account
Financial year ended 31 December 2021

	Note	2021	2020
		€	€
Income	5	115,845	59,969
Gross surplus		<u>115,845</u>	<u>59,969</u>
Expenditure		(64,232)	(54,627)
Operating surplus		<u>51,613</u>	<u>5,342</u>
Surplus before taxation		<u>51,613</u>	<u>5,342</u>
Tax on surplus		-	-
Surplus for the financial year		<u><u>51,613</u></u>	<u><u>5,342</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 15 to 18 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 2021

	2021	2020
	€	€
Surplus for the financial year	51,613	5,342
Retained earnings at the start of the financial year	34,628	29,286
Retained earnings at the end of the financial year	<u>86,241</u>	<u>34,628</u>

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

Balance sheet
As at 31 December 2021

	Note	2021 €	€	2020 €	€
Current assets					
Debtors	9	675		1,335	
Cash at bank and in hand		86,816		37,797	
		<u>87,491</u>		<u>39,132</u>	
Creditors: amounts falling due within one year	10	<u>(1,250)</u>		<u>(4,504)</u>	
Net current assets			86,241		34,628
Total assets less current liabilities			<u>86,241</u>		<u>34,628</u>
Net assets			<u><u>86,241</u></u>		<u><u>34,628</u></u>
Capital and reserves					
General funds			86,241		34,628
Members funds			<u><u>86,241</u></u>		<u><u>34,628</u></u>

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 15 to 18 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 2021

	2021	2020
	€	€
Cash flows from operating activities		
Surplus for the financial year	51,613	5,342
<i>Adjustments for:</i>		
Accrued expenses/(income)	246	-
<i>Changes in:</i>		
Trade and other debtors	660	(647)
Trade and other creditors	(3,500)	3,500
Cash generated from operations	49,019	8,195
Net cash from operating activities	49,019	8,195
Net increase/(decrease) in cash and cash equivalents	49,019	8,195
Cash and cash equivalents at beginning of financial year	37,797	29,602
Cash and cash equivalents at end of financial year	86,816	37,797

DRAFT FOR APPROVAL

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

Notes to the financial statements
Financial year ended 31 December 2021

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

Notes to the financial statements (continued)
Financial year ended 31 December 2021

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:

	2021	2020
	€	€
Memberships*	213	1,850
Donations	18,086	18,190
RDI - Round Table of Companies	49,000	38,500
Project income**	48,546	1,429
	<u>115,845</u>	<u>59,969</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
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Notes to the financial statements (continued)
Financial year ended 31 December 2021

6. Staff costs

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

	2021	2020
	Number	Number
Administrative	1	1

The aggregate payroll costs incurred during the financial year were:

	2021	2020
	€	€
Wages and salaries	42,000	35,705
Social insurance costs	4,641	3,502
	<u>46,641</u>	<u>39,207</u>

Increase in payroll costs reflects increased working time over period.

7. Appropriations of income and expenditure account

	2021	2020
	€	€
At the start of the financial year	34,628	29,286
Surplus for the financial year	51,613	5,342
At the end of the financial year	<u>86,241</u>	<u>34,628</u>

8. Tangible assets

	Fixtures, fittings and equipment	Total
	€	€
Cost		
At 1 January 2021 and 31 December 2021	<u>1,286</u>	<u>1,286</u>
Depreciation		
At 1 January 2021 and 31 December 2021	<u>1,286</u>	<u>1,286</u>
Carrying amount		
At 31 December 2021	<u>-</u>	<u>-</u>
At 31 December 2020	<u>-</u>	<u>-</u>

Rare Diseases Ireland
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Notes to the financial statements (continued)
Financial year ended 31 December 2021

9. Debtors

	2021	2020
	€	€
Other debtors	-	654
Prepayments	675	681
	675	1,335
	675	1,335

10. Creditors: amounts falling due within one year

	2021	2020
	€	€
Accruals	1,250	1,004
Deferred income	-	3,500
	1,250	4,504
	1,250	4,504

11. Financial instruments

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

	2021	2020
	€	€
Financial assets that are debt instruments measured at amortised cost		
Other debtors	675	1,335
Cash at bank and in hand	86,816	37,797
	86,816	37,797
	86,816	37,797
Financial liabilities measured at amortised cost		
Other creditors	1,250	1,004
	1,250	1,004
	1,250	1,004

12. Analysis of changes in net debt

	At 1 January 2021	Cash flows	At 31 December 2021
	€	€	€
Cash and cash equivalents	37,797	49,019	86,816
	37,797	49,019	86,816
	37,797	49,019	86,816

13. 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.

DRAFT FOR APPROVAL

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

Detailed income and expenditure account
Financial year ended 31 December 2021

	2021	2020
	€	€
Income		
Memberships	213	1,850
Donations	18,086	18,190
RDI - Round Table of Companies	49,000	38,500
Project income	48,546	1,429
	<u>115,845</u>	<u>59,969</u>
Gross surplus	<u>115,845</u>	<u>59,969</u>
Gross surplus percentage	100.0%	100.0%
Overheads		
Administrative expenses		
Wages and salaries	(42,000)	(35,705)
Employer's PRSI contributions	(4,641)	(3,502)
Programme expenses	(10,020)	(9,762)
Insurance	(901)	(892)
Printing, postage and stationery	(2,142)	-
Telephone	(373)	(373)
Motor expenses	(560)	-
Consultancy fees	-	(1,705)
Accountancy fees	(766)	(1,042)
Auditors remuneration	(1,230)	(984)
Bank charges	(288)	(341)
General expenses	(1,031)	(141)
Subscriptions	(280)	(180)
	<u>(64,232)</u>	<u>(54,627)</u>
Operating surplus	51,613	5,342
Operating surplus percentage	44.6%	8.9%
Surplus before taxation	<u>51,613</u>	<u>5,342</u>