

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 2020**

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 2020 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 2020 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 2020.

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 2020 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 19 Oct 2021

Yours faithfully,

  
Maíreada Hennessy  
Director/Trustee

  
Pólán Lacey  
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 2020**

**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 Toweey Mary Kearney (Resigned 1 October 2020) David Barton Paula Guerin Mairéad Hennessy Kevin Whelan Michael Blighe 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 Apex Business Centre Blackthorn Road Sandyford Dublin 18
<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 2020.

**Directors**

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

Patricia Towey  
Mary Kearney (Resigned 1 October 2020)  
David Barton  
Paula Guerin  
Mairéad Hennessy (Appointed 25 March 2020)  
Kevin Whelan  
Michael Blighe (Appointed 25 March 2020)  
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**

Rare Diseases Ireland (RDI) acts 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. Throughout 2020 RDI has liaised with all stakeholders to raise awareness of rare diseases and highlight issues of particular concern to the rare disease community in Ireland. 2020 was a particularly difficult year for everyone; the COVID-19 pandemic brought unimaginable challenges into every life, every home and every workplace.

Rare Disease Day on the last day of February, the international day designated to raising awareness for the rare disease community worldwide, was marked by the publication of The EasyGuide to Rare Diseases in Ireland. This handbook of rare diseases in Ireland details stories of people living with rare diseases and the needs of the community in terms of policy and service provision. The EasyGuide, produced by a number of patient organisations, was launched by Minister for Health Simon Harris on February 24th at the Mansion House, Dublin. The launch was attended by people living with rare conditions, patient organisations and media. RDI ran a PR campaign to accompany the launch of the EasyGuide across TV, radio and print media, in addition to social media, with individuals living with rare conditions telling their stories and spokespeople providing expert opinion on some of the challenges facing the community.

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

**Directors report (continued)**

**Development and performance (continued)**

On Rare Disease Day, February 29th, President Michael D. Higgins hosted a family party, inviting children living with rare conditions and their families to a special event at Áras an Uachtaráin. This was the highlight of the year for many of those lucky enough to attend on the day and was followed quickly by nationwide lockdowns as coronavirus arrived on our shores.

In February 2020 there was a general election in Ireland. RDI ran a campaign '#Pledge4RD' asking all candidates running in the election to demonstrate their support for the rare disease community in Ireland. By pledging support they committed to:

- accurate diagnosis and appropriate care within one year of coming to medical attention.
- holistic care and social systems that are inclusive of people living with rare diseases
- seizing opportunities in science and innovation for people living with rare diseases and their carers.

The needs of the rare disease community were recognised in the subsequent Programme for Government: Our Shared Future, published in July 2020. Commitments were made to implement changes in areas such as genetics and genomics, research and clinical trials and a rare disease plan.

Coronavirus arrived in Ireland in March 2020 and resulted in severe curtailment of all services for people living with rare conditions. RDI conducted a research survey to understand the impact of the pandemic on the lives of those living with rare conditions. The research, published in May, revealed a profound impact on the rare community, with many cocooning out of choice, and all services, including healthcare, respite and education severely curtailed. Towards the end of the year coronavirus vaccines were approved in Europe and RDI together with a broad spectrum of patient organisations lobbied to ensure early access to vaccination for those in the rare community living with high-risk conditions.

The pandemic required a change to work practices for RDI. Face-to-face events were no longer possible and much activity moved on-line. RDI hosted group conversations with people living with rare conditions to identify challenges and opportunities. RDI also met with healthcare providers across the spectrum of diseases to provide background on the roles and work of RDI and identify opportunities of improved collaboration into the future. RDI's Round Table of Companies continued in 2020. The platform, for industry partners to engage with patient groups in order to build consensus on issues of common concern for rare disease patients in Ireland, continues to grow year-on-year.

RDI worked with the National Rare Disease Office to begin the process of engaging people living with rare conditions in development of care pathways for individual rare conditions. This work is on-going and is important to ensure the needs and concerns of those living with rare conditions are captured as care pathways are developed and implemented. RDI also liaised with the Rare Disease Technology Review Committee to identify and support people living with rare conditions who could speak to the Committee about the challenges of living with conditions that can be treated by novel therapies and how these therapies may impact on their lives and experiences.

Throughout the year RDI worked closely with stakeholders across the rare disease community to ensure the voice of the rare disease community was heard and integrated into all areas of policy and service development. RDI communicated across the year with the Minister for Health, various politicians, the Department of Health and the HSE advocating on topics of concern for people living with rare conditions. RDI also attended a number of EURORDIS-Rare Diseases Europe Council of National Alliances meetings and contributed to the development of strategy, policy and programmes in areas such as COVID-19 & emerging from the lock-down and Newborn Screening.

RDI continued expansion of its Board in 2020, bringing more skills, experience and depth to the Board of RDI to assist the development and advancement of the organisation and the work it performs. RDI also continues to grow its funding seeking to diversify sources and secure funding for projects into the future.

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

**Directors report (continued)**

**Assets and liabilities and financial position**

The company had a surplus in the year of €5,342 (2019: €24,704). At the end of the year the company had assets of €39,132 (2019: €30,290) and liabilities of €4,504 (2019: €1,004). The net assets at the year end were €34,628 (2019: €29,286).

**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.

**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 **19 Oct 2021** ..... and signed on behalf of the board by:

*Mairéad Hennessy*  
Director

Director *Colmín Smyg*

**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 2020 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 2020 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)**

**Profit and loss account**  
**Income and expenditure account**  
**Financial year ended 31 December 2020**

	Note	2020 €	2019 €
<b>Turnover</b>	<b>5</b>	59,969	56,024
<b>Gross surplus</b>		59,969	56,024
Administrative expenses		(54,627)	(31,320)
<b>Operating surplus</b>		5,342	24,704
<b>Surplus before taxation</b>		5,342	24,704
Tax on surplus		-	-
<b>Surplus for the financial year</b>		5,342	24,704

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 14 to 17 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 2020**

	<b>2020</b>	2019
	€	€
Surplus for the financial year	5,342	24,704
<b>Retained earnings at the start of the financial year</b>	29,286	4,582
<b>Retained earnings at the end of the financial year</b>	<u>34,628</u>	<u>29,286</u>

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

**Balance sheet**  
**As at 31 December 2020**

	Note	2020 €	€	2019 €	€
<b>Current assets</b>					
Debtors	9	1,335		688	
Cash at bank and in hand		37,797		29,602	
		39,132		30, 90	
<b>Creditors: amounts falling due within one year</b>					
	10	(4,504)		(1,004)	
<b>Net current assets</b>			34,628		29,286
<b>Total assets less current liabilities</b>			34,628		29,286
<b>Net assets</b>			34,628		29,286
<b>Capital and reserves</b>					
General funds			34,628		29,286
<b>Members funds</b>			34,628		29,286

These financial statements were approved by the board of directors on 19 Oct 2021 and signed on behalf of the board by:

*Mairéad Hennessy*  
 Director

Director *William Long*

The notes on pages 14 to 17 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 2020**

	<b>2020</b>	2019
	€	€
<b>Cash flows from operating activities</b>		
Surplus for the financial year	5,342	24,704
<i>Adjustments for:</i>		
Accrued expenses/(income)	-	(1,373)
<i>Changes in:</i>		
Trade and other debtors	(647)	(170)
Trade and other creditors	3,500	-
Cash generated from operations	<u>8,195</u>	<u>23,161</u>
Net cash from operating activities	<u>8,195</u>	<u>23,161</u>
<b>Net increase/(decrease) in cash and cash equivalents</b>	8,195	23,161
<b>Cash and cash equivalents at beginning of financial year</b>	<u>29,602</u>	<u>6,441</u>
<b>Cash and cash equivalents at end of financial year</b>	<u><u>37,797</u></u>	<u><u>29,602</u></u>

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

**Notes to the financial statements**  
**Financial year ended 31 December 2020**

**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'. The Triennial review 2017 amendments to the standard have been early adopted.

**3. Accounting policies and measurement bases**

**Basis of preparation**

The Financial Statements are prepared on the going concern basis, under the historical cost convention, - 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 sundry 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.

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

**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2020**

**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.

**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. Turnover**

Turnover arises from:

	<b>2020</b>	2019
	€	€
Event income	-	3,924
Memberships	1,850	1,300
Donations	18,190	2,500
RDI - Round Table of Coampanies	38,500	47,800
Other income	1,429	500
	<u>59,969</u>	<u>56,024</u>

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, including the directors, was as follows:

	<b>2020</b>	2019
	Number	Number
Administrative	<u>1</u>	<u>1</u>

The aggregate payroll costs incurred during the financial year were:

	<b>2020</b>	2019
	€	€
Wages and salaries	35,705	14,000
Social insurance costs	3,502	1,533
	<u>39,207</u>	<u>15,533</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 2020**

<b>7. Appropriations of income and expenditure account</b>	<b>2020</b>	2019
	<b>€</b>	<b>€</b>
At the start of the financial year	29,286	4,582
Surplus for the financial year	5,342	24,704
<b>At the end of the financial year</b>	<u>34,628</u>	<u>29,286</u>
<b>8. Tangible assets</b>	Fixtures, fittings and equipment	<b>Total</b>
	<b>€</b>	<b>€</b>
<b>Cost</b>		
<b>At 1 January 2020 and 31 December 2020</b>	<u>1,286</u>	<u>1,286</u>
<b>Depreciation</b>		
<b>At 1 January 2020 and 31 December 2020</b>	<u>1,286</u>	<u>1,286</u>
<b>Carrying amount</b>		
<b>At 31 December 2020</b>	<u>-</u>	<u>-</u>
At 31 December 2019	<u>-</u>	<u>-</u>
<b>9. Debtors</b>	<b>2020</b>	2019
	<b>€</b>	<b>€</b>
Other debtors	654	-
Prepayments	681	688
	<u>1,335</u>	<u>688</u>
<b>10. Creditors: amounts falling due within one year</b>	<b>2020</b>	2019
	<b>€</b>	<b>€</b>
Accruals	1,004	1,004
Deferred income	3,500	-
	<u>4,504</u>	<u>1,004</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 2020**

**11. Financial instruments**

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

	<b>2020</b>	<b>2019</b>
	€	€
<b>Financial assets that are debt instruments measured at amortised cost</b>		
Other debtors	1,335	688
Cash at bank and in hand	<u>37,797</u>	<u>29,602</u>
<b>Financial liabilities measured at amortised cost</b>		
Other creditors	<u>1,004</u>	<u>1,004</u>

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

	At 1 January 2020	Cash flows	At 31 December 2020
	€	€	€
Cash and cash equivalents	<u>29,602</u>	<u>8,195</u>	<u>37,797</u>

**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.**

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

**Detailed profit and loss account**  
**Financial year ended 31 December 2020**

	<b>2020</b>	2019
	€	€
<b>Turnover</b>		
Event income	-	3,924
Memberships	1,850	1,300
Donations	18,190	2,500
RDI - Round Table of Companies	38,500	47,800
Other income	1,429	500
	<u>59,969</u>	<u>56,024</u>
<b>Gross surplus</b>	59,969	56,024
<b>Gross surplus percentage</b>	100.0%	100.0%
<b>Overheads</b>		
<b>Administrative expenses</b>		
Wages and salaries	(35,705)	(14,000)
Employer's PRSI contributions	(3,502)	(1,533)
Programme expenses	(9,762)	(13,539)
Insurance	(892)	(656)
Telephone	(373)	(373)
Consultancy fees	(1,705)	-
Accountancy fees	(1,042)	-
Auditors remuneration	(984)	(984)
Bank charges	(341)	(35)
General expenses	(141)	(20)
Subscriptions	(180)	(180)
	<u>(54,627)</u>	<u>(31,320)</u>
<b>Operating surplus</b>	5,342	24,704
<b>Operating surplus percentage</b>	8.9%	44.1%
<b>Surplus before taxation</b>	<u>5,342</u>	<u>24,704</u>