

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 2019

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 Mary Kearney (Appointed 31 January 2019) David Barton (Appointed 31 January 2019) Paula Guerin (Appointed 31 January 2019) Mairéad Hennessy (Appointed 25 March 2020) Kevin Whelan (Appointed 31 January 2019) Michael Blighe (Appointed 25 March 2020) Anne Lawlor
Secretary	Anne Lawlor
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

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Directors report

The directors present their annual report and the audited financial statements of the company for the financial year ended 31 December 2019.

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 (Appointed 31 January 2019)
David Barton (Appointed 31 January 2019)
Paula Guerin (Appointed 31 January 2019)
Kevin Whelan (Appointed 31 January 2019)
Anne Lawlor
Avril Daly (Resigned 1 January 2020)

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.

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Directors report (continued)

Development and performance

Rare Diseases Ireland 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 2019 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.

Rare Disease Day, on the last day of February, is the international day designated to raising awareness for the rare disease community worldwide. RDI ran a PR campaign in the run up to Rare Disease Day to help promote awareness across Ireland of the challenges of living with a rare condition. The PR campaign included 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, particularly those relating to genetic diagnosis and subsequent genetic counselling and support.

RDI also hosted a seminar to mark Rare Disease Day on February 28th, 2019, with over 250 individuals registered and in attendance, including patients, patient organisations, healthcare providers, researchers, industry and policy makers. The theme of the event was Bridging Health and Social Care, and included a range of speakers from across Ireland and an interactive Q- session.

RDI was a member of Rare Disease Research Partnership (RAinDRoP) to identify top research priorities for rare diseases, which focused on a life-course perspective of living with a rare condition. RAinDRoP brought together diverse voices from the rare disease community including patients, carers, healthcare providers and researchers, via both on-line questionnaires and surveys and an in-person workshop held during April, in UCD, Dublin. The output was published in 2020.

RDI held a seminar entitled "Burden of Rare Diseases in Ireland" following our AGM on October 22nd. The seminar presented recent research on the prevalence of rare diseases in Europe and Ireland, the incidence of rare diseases in the Irish paediatric population and the burden of living with a rare vision impairment in Ireland. The seminar highlighted to value of robust research for our advocacy work.

RDI was represented on the HSE's National Clinical Programme for Rare Diseases. RDI liaises closely with Professor Eileen Treacy, Clinical Lead for the Programme, Grace O'Sullivan Programme Manager and the team at the National Rare Disease Office (Mater Hospital, Dublin). RDI worked with this group on developing a Model of Care for Rare Diseases in Ireland, published in July. RDI advocated for and supported the Programme to process membership applications for Europe's 24 European Reference Networks (ERNs), providing every rare disease patient with direct access to the expertise of specialist health care providers across Europe. 17 such applications were made to the EU in 2019.

In 2019 there was a European election to elect Ireland's MEPs for the 5 years 2019-2024. RDI launched an e-mail and on-line campaign '#Pledge4RD' asking all candidates running for 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 role of Europe in the development and provision of care for people living with rare conditions is increasingly important with legislation governing Orphan Medicinal Products and Cross-Border Healthcare and the 24 ERNs.

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Directors report (continued)

Throughout the year RDI has worked closely with stakeholders across the rare disease community to ensure the voice of the rare disease community is heard and integrated into all areas of policy and service development. RDI had multiple meetings and communications across the year with the Minister for Health, various politicians, the Department of Health and the HSE advocating for full implementation of the National Rare Disease Plan, genetic services and development of a genetics/genomics strategy for the country, expanded new born screening, access to innovative medicines, transition to community care via Slaintecare, integrated health information systems and patient registries, and support for the on-line rare disease information portal, orpha.net.

RDI officially launched it's Round Table of Companies (RDI-RTC) in 2019, building on the exploratory meeting held in 2018. This is a 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. RDI also engaged with industry partners via participation in Advisory Boards and delivery of seminars and education modules.

RDI attended a number of EURORDIS-Rare Diseases Europe meetings and contributed to the development of strategy, policy and programmes in areas such as Rare Disease Day, Rare Foresight Study (Rare 2030) and data sharing across Europe. RDI also presented on Holistic and Integrated care at the EURORDIS Membership Meeting 2019 in Bucharest, Romania, in May 2019.

RDI brought on a number of new Board members in 2019, bringing more skills, experience and depth to the Board of RDI to assist the development and advancement of the work of RDI.

Finally co- founder of Rare Diseases Ireland, Michael Griffith, was presented with a Lifetime Achievement Award by EURORDIS- Rare Diseases Europe, at their 2019 Black Pearl Awards. He was recognised for his exceptional work and vast achievements, including his role in founding and growing a number of patient organisations - Fighting Blindness, Debra Ireland, Health Research Charities Ireland and IPPOSI. Michael spent many years working with these organisations and has been a central figure in making a true and lasting difference for people living with a rare disease through his collegiate approach to advancing and funding medical research and providing platforms that represent the patient voice and improve patient

Assets and liabilities and financial position

The company had a surplus in the year of €24,704 (2018: -€1,990). At the end of the year the company had assets of €30,290 (2018: €6,959) and liabilities of €1,004 (2018: €2,377). The net assets of the company increased to €29,286 (2018: €4,582).

Principal risks and uncertainties

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

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

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

Likely future developments

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

Events after the end of the reporting period

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.

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Directors report (continued)

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 1 October 2020 and signed on behalf of the board by:

Patricia Toweey
Director

Anne Lawlor
Director

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Directors responsibilities statement

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

Irish company law requires the directors to prepare financial statements for each financial year. Under the law, the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council, and promulgated by the Institute of Chartered Accountants in Ireland. 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

We have audited the financial statements of Rare Diseases Ireland for the year ended 31 December 2019 which comprise the profit and loss account, statement of income and retained earnings, balance sheet, statement of cash flows and related notes. The relevant financial reporting framework that has been applied in their preparation is 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 and promulgated by the Institute of Chartered Accountants in Ireland.

This 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 auditors 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.

Respective responsibilities of directors and auditor

As explained more fully in the directors responsibilities statement set out on page 6, the directors are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view and otherwise comply with the Companies Act 2014. Our responsibility is to audit and express an opinion on the financial statements in accordance with Irish law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's (APB's) Ethical Standards for Auditors, including "APB Ethical Standard - Provisions Available for Small Entities (Revised)", in the circumstances set out in Note 13 to the financial statements.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the directors; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the directors report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

Opinion on financial statements

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 2019 and of its profit for the year then ended; and
- have been properly prepared in accordance with the relevant reporting framework and, in particular the requirements of the Companies Act 2014.

Matters on which we are required to report by the Companies Act 2014

- 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.
- The financial statements are in agreement with the accounting records.
- In our opinion the information given in the directors report is consistent with the financial statements.

Matters on which we are required to report by exception

We have nothing to report in respect of our obligation under the Companies Act 2014 to report to you if, in our opinion, the disclosures of directors remuneration and transactions specified by sections 305 to 312 of the Act are not made.

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

Thomas McCloskey

For and on behalf of
McCloskey & Co
Chartered Accountants & Registered Auditor
Apex Business Centre
Blackthorn Road
Sandyford
Dublin 18

1 October 2020

Rare Diseases Ireland
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Profit and loss account
Financial year ended 31 December 2019

	Note	2019	2018
		€	€
Turnover	5	56,024	4,972
Gross surplus		<u>56,024</u>	<u>4,972</u>
Administrative expenses		(31,320)	(6,962)
Operating surplus/(deficit)		<u>24,704</u>	<u>(1,990)</u>
Surplus/(deficit) before taxation		<u>24,704</u>	<u>(1,990)</u>
Tax on surplus/(deficit)		-	-
Surplus/(deficit) for the financial year		<u><u>24,704</u></u>	<u><u>(1,990)</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 13 to 16 form part of these financial statements.

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Statement of income and retained earnings
Financial year ended 31 December 2019

	2019	2018
	€	€
Surplus/(deficit) for the financial year	24,704	(1,990)
Retained earnings at the start of the financial year	<u>4,582</u>	<u>6,572</u>
Retained earnings at the end of the financial year	<u><u>29,286</u></u>	<u><u>4,582</u></u>

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Balance sheet
As at 31 December 2019

	Note	2019 €	€	2018 €	€
Current assets					
Debtors	9	688		518	
Cash at bank and in hand		29,602		6,441	
		<u>30,290</u>		<u>6,959</u>	
Creditors: amounts falling due within one year					
	10	<u>(1,004)</u>		<u>(2,377)</u>	
Net current assets			<u>29,286</u>		<u>4,582</u>
Total assets less current liabilities			<u>29,286</u>		<u>4,582</u>
Net assets			<u><u>29,286</u></u>		<u><u>4,582</u></u>
Capital and reserves					
Profit and loss account	12		<u>29,286</u>		<u>4,582</u>
Members funds			<u><u>29,286</u></u>		<u><u>4,582</u></u>

These financial statements were approved by the board of directors on 1 October 2020 and signed on behalf of the board by:

Patricia Towey
Director

Anne Lawlor
Director

The notes on pages 13 to 16 form part of these financial statements.

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Statement of cash flows
Financial year ended 31 December 2019

	2019	2018
	€	€
Cash flows from operating activities		
Surplus/(deficit) for the financial year	24,704	(1,990)
<i>Adjustments for:</i>		
Accrued expenses/(income)	(1,373)	1,496
<i>Changes in:</i>		
Trade and other debtors	(170)	(37)
Cash generated from operations	<u>23,161</u>	<u>(531)</u>
Net cash from/(used in) operating activities	<u>23,161</u>	<u>(531)</u>
Net increase/(decrease) in cash and cash equivalents	23,161	(531)
Cash and cash equivalents at beginning of financial year	<u>6,441</u>	<u>6,972</u>
Cash and cash equivalents at end of financial year	<u>29,602</u>	<u>6,441</u>

Rare Diseases Ireland
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Notes to the financial statements
Financial year ended 31 December 2019

1. General information

The company is a charitable 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 historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through profit or loss.

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.

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.

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Notes to the financial statements (continued)
Financial year ended 31 December 2019

Financial instruments

A financial asset or a financial liability is recognised only when the company becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the transaction price, unless the arrangement constitutes a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Debt instruments are subsequently measured at amortised cost.

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:

	2019	2018
	€	€
Event income	3,924	1,795
Memberships	1,300	2,850
Donations	2,500	327
RDI - Round Table of Cocompanies	47,800	-
Other income	500	-
	<u>56,024</u>	<u>4,972</u>

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

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Notes to the financial statements (continued)
Financial year ended 31 December 2019

6. Staff costs

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

	2019	2018
	Number	Number
Administrative	1	-

The aggregate payroll costs incurred during the financial year were:

	2019	2018
	€	€
Wages and salaries	14,000	-
Social insurance costs	1,533	-
	<u>15,533</u>	<u>-</u>

7. Appropriations of profit and loss account

	2019	2018
	€	€
At the start of the financial year	4,582	6,572
Surplus/(deficit) for the financial year	24,704	(1,990)
At the end of the financial year	<u>29,286</u>	<u>4,582</u>

8. Tangible assets

	Fixtures, fittings and equipment	Total
	€	€
Cost		
At 1 January 2019 and 31 December 2019	1,286	1,286
Depreciation		
At 1 January 2019 and 31 December 2019	1,286	1,286
Carrying amount		
At 31 December 2019	-	-
At 31 December 2018	-	-

9. Debtors

	2019	2018
	€	€
Prepayments	688	518

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Notes to the financial statements (continued)
Financial year ended 31 December 2019

10. Creditors: amounts falling due within one year

	2019	2018
	€	€
Accruals	1,004	2,377

11. Financial instruments

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

	2019	2018
	€	€
Financial assets that are debt instruments measured at amortised cost		
Other debtors	688	518
Cash at bank and in hand	29,602	6,114
Financial liabilities measured at amortised cost		
Other creditors	1,004	2,377

12. Reserves

The income and expenditure account represents cumulative surpluses and deficits.

13. Ethical standards

In common with many other businesses of our size and nature we use our auditors to assist with the preparation of the financial statements.

14. Approval of financial statements

The board of directors approved these financial statements for issue on 1 October 2020.

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

Rare Diseases Ireland
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Detailed profit and loss account
Financial year ended 31 December 2019

	2019	2018
	€	€
Turnover		
Event income	3,924	1,795
Memberships	1,300	2,850
Donations	2,500	327
RDI - Round Table of Cocompanies	47,800	-
Other income	500	-
	<u>56,024</u>	<u>4,972</u>
Gross surplus	56,024	4,972
Gross surplus percentage	100.0%	100.0%
Overheads		
Administrative expenses		
Wages and salaries	(14,000)	-
Employer's PRSI contributions	(1,533)	-
Programme expenses	(13,539)	(4,496)
Insurance	(656)	(604)
Printing, postage and stationery	-	(508)
Telephone	(373)	(446)
Auditors remuneration	(984)	(861)
Bank charges	(35)	(27)
General expenses	(20)	(20)
Subscriptions	(180)	-
	<u>(31,320)</u>	<u>(6,962)</u>
Operating surplus/(deficit)	24,704	(1,990)
Operating surplus/(deficit) percentage	44.1%	40.0%
Surplus/(deficit) before taxation	<u>24,704</u>	<u>(1,990)</u>