

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 2018

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	Avril Daly Patricia Towey Barbara Flynn (Resigned 5 April 2018) David Barton Eileen Treacy (Resigned 12 January 2018) Avril Kennan (Resigned 12 January 2018) Kevin Whelan (Appointed 31 January 2019) Lorraine Dempsey (Resigned 17 August 2018) Clair Kelly (Resigned 17 August 2018) Anne Lawlor Paula Guerin Mary Kearney
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 2018.

Directors

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

Avril Daly
Patricia Towey
Barbara Flynn (Resigned 5 April 2018)
David Barton
Eileen Treacy (Resigned 12 January 2018)
Avril Kennan (Resigned 12 January 2018)
Lorraine Dempsey (Resigned 17 August 2018)
Clair Kelly (Resigned 17 August 2018)
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.

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Directors report (continued)

Development and performance

Rare Diseases Ireland (formerly GRDO - the Genetic and Rare Disorders Organisation) 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. RDI's name change was approved at the 2017 AGM (October 24th) and the organisation officially relaunched on Rare Disease Day 2018 (February 28th) with an updated website www.rdi.ie.

Throughout 2018 RDI has liaised with national and international stakeholders to raise awareness of rare diseases and highlight issues of concern to the RD community in Ireland.

RDI held a seminar on European Reference Networks (ERNs) following our AGM on October 23rd, 2018. Matt Bolz-Johnson, EURORDIS patient advocate provided an overview on ERN's and his work in developing European Patient Advocacy Groups for each ERN. A panel discussion followed, on the potential benefit of ERN's to the delivery of care for rare disease patients in Ireland.

A Rare Diseases Technology Review Committee (RDTRC) was established in October 2018 (as recommended in the National Rare Disease Plan 2014-2018) to facilitate the patient and clinician's perspective in the drugs reimbursement process. Membership of the Committee includes Consultant Physicians, pharmacists and two patient representatives elected by membership of the Rare Disease Task Force to represent the patient perspective. The RDTRG does not have the authority to approve drugs but will make recommendations based on the impact of disease, real world evidence and scientific data to the HSE's Drugs Committee with whom the final decision lies. The RDTRG has no remit to discuss price.

RDI detailed the challenges facing rare disease patients around access to innovative treatments at an Oireachtas Joint Health Committee meeting to discuss access to orphan medicines in November 2018. RDI made 3 requests of policy makers: 1) implement a reimbursement system that meets the needs of all patients; 2) introduce genetic services in Ireland that are fit-for-purpose; 3) include patients as decision makers at relevant points along the reimbursement pathway.

RDI is represented on the Clinical Care Programme and liaises closely with Professor Eileen Treacy, Clinical lead for Rare Diseases in Ireland and the team at the National Rare Disease Office (Mater Hospital Dublin). RDI have worked with this group on developing a Model of Care for Rare Diseases in Ireland.

RDI presented on the burden of living with rare disease at the European Conference of Rare Disease in Vienna in May 2018. 20 representatives from the RD community in Ireland were in attendance.

RDI Round Table of Companies (RDRTC) in 2018. This is a platform for industry partners to engage with patient groups in order to build consensus on issues of common concern regarding access to medicines for rare disease patients in Ireland.

In late 2018 RDI took on an Interim CEO to assist the board in advancing the work of RDI.

Assets and liabilities and financial position

The company had a deficit in the year of -€1,990 (2017: -€654). At the end of the year the company had assets of €6,959 (2017: €7,453) and liabilities of €2,377 (2017: €881). The net assets of the company reduced to €4,582 (2017: €6,572).

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.

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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 22 October 2019 and signed on behalf of the board by:

Avril Daly
Director

Patricia Towey
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 2018 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 5, 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 12 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 2018 and of its loss 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

22 October 2019

Rare Diseases Ireland
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Profit and loss account
Financial year ended 31 December 2018

	Note	2018	2017
		€	€
Turnover	5	4,972	2,147
Gross surplus		<u>4,972</u>	<u>2,147</u>
Administrative expenses		(6,962)	(2,801)
Operating loss		<u>(1,990)</u>	<u>(654)</u>
Deficit before taxation		<u>(1,990)</u>	<u>(654)</u>
Tax on deficit		-	-
Deficit for the financial year		<u><u>(1,990)</u></u>	<u><u>(654)</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 12 to 15 form part of these financial statements.

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Statement of income and retained earnings
Financial year ended 31 December 2018

	2018	2017
	€	€
Deficit for the financial year	(1,990)	(654)
Retained earnings at the start of the financial year	<u>6,572</u>	<u>7,226</u>
Retained earnings at the end of the financial year	<u><u>4,582</u></u>	<u><u>6,572</u></u>

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Balance sheet
As at 31 December 2018

	Note	2018 €	€	2017 €	€
Current assets					
Debtors	8	518		481	
Cash at bank and in hand		6,441		6,972	
		6,959		7,453	
Creditors: amounts falling due within one year					
	9	(2,377)		(881)	
Net current assets					
			4,582		6,572
Total assets less current liabilities					
			4,582		6,572
Net assets					
			4,582		6,572
Capital and reserves					
Profit and loss account	11		4,582		6,572
Members funds					
			4,582		6,572

These financial statements were approved by the board of directors on 22 October 2019 and signed on behalf of the board by:

Avril Daly
Director

Patricia Towey
Director

The notes on pages 12 to 15 form part of these financial statements.

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Statement of cash flows
Financial year ended 31 December 2018

	2018	2017
	€	€
Cash flows from operating activities		
Deficit for the financial year	(1,990)	(654)
<i>Adjustments for:</i>		
Accrued expenses/(income)	1,496	(369)
<i>Changes in:</i>		
Trade and other debtors	(37)	(36)
Cash generated from operations	<u>(531)</u>	<u>(1,059)</u>
Net cash used in operating activities	<u>(531)</u>	<u>(1,059)</u>
Net increase/(decrease) in cash and cash equivalents	(531)	(1,059)
Cash and cash equivalents at beginning of financial year	6,972	8,031
Cash and cash equivalents at end of financial year	<u>6,441</u>	<u>6,972</u>

Rare Diseases Ireland
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Notes to the financial statements
Financial year ended 31 December 2018

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 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

Grants received from government agencies towards revenue expenditure and other sources are released to the profit and loss account as the related expenditure is incurred..

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 2018

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:

	2018	2017
	€	€
Event income	1,795	-
Memberships	2,850	-
Donations	-	2,147
	4,645	2,147
	4,645	2,147

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

6. Appropriations of profit and loss account

	2018	2017
	€	€
At the start of the financial year	6,572	7,226
Deficit for the financial year	(1,990)	(654)
At the end of the financial year	4,582	6,572
	4,582	6,572

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Notes to the financial statements (continued)
Financial year ended 31 December 2018

7. Tangible assets	Fixtures, fittings and equipment €	Total €
Cost		
At 1 January 2018 and 31 December 2018	1,286	1,286
Depreciation		
At 1 January 2018 and 31 December 2018	1,286	1,286
Carrying amount		
At 31 December 2018	-	-
At 31 December 2017	-	-
8. Debtors	2018 €	2017 €
Prepayments	518	481
9. Creditors: amounts falling due within one year	2018 €	2017 €
Accruals	2,377	881
10. Financial instruments		
The carrying amount for each category of financial instruments is as follows:		
	2018 €	2017 €
Financial assets that are debt instruments measured at amortised cost		
Other debtors	518	481
Cash at bank and in hand	6,114	6,972
Financial liabilities measured at amortised cost		
Other creditors	2,377	881
11. Reserves		
The income and expenditure account represents cumulative surpluses and deficits.		

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Notes to the financial statements (continued)
Financial year ended 31 December 2018

12. 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.

13. Approval of financial statements

The board of directors approved these financial statements for issue on 22 October 2019.

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

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Detailed profit and loss account
Financial year ended 31 December 2018

	2018	2017
	€	€
Turnover		
Event income	1,795	-
Memberships	2,850	-
Donations	327	2,147
	<u>4,972</u>	<u>2,147</u>
Gross surplus	<u>4,972</u>	<u>2,147</u>
Gross surplus percentage	100.0%	100.0%
Overheads		
Administrative expenses		
Programme expenses	(4,496)	(545)
Insurance	(604)	(605)
Printing, postage and stationery	(508)	(180)
Telephone	(446)	(420)
Auditors remuneration	(861)	(861)
Bank charges	(27)	(24)
General expenses	(20)	(166)
	<u>(6,962)</u>	<u>(2,801)</u>
Operating loss	(1,990)	(654)
Operating loss percentage	40.0%	30.5%
Deficit before taxation	<u>(1,990)</u>	<u>(654)</u>