

**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 2017**

**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>	Avril Daly Patricia Towey Barbara Flynn (Resigned 5 April 2018) David Barton (Resigned 12 January 2018) Eileen Treacy (Resigned 12 January 2018) Avril Kennan (Resigned 12 January 2018) Lorraine Dempsey Clair Kelly Anne Lawlor (Appointed 24 October 2017)
<b>Secretary</b>	Anne Lawlor
<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

**Rare Diseases Ireland**  
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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 2017.

**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 (Resigned 12 January 2018)  
Eileen Treacy (Resigned 12 January 2018)  
Avril Kennan (Resigned 12 January 2018)  
Lorraine Dempsey  
Clair Kelly  
Anne Lawlor (Appointed 24 October 2017)

**Principal activities**

The principal activity of the company is acting 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 disorders. The main objects for which the company is established are:

- To promote an umbrella organisation for voluntary organisations in the state involved with genetic and inherited disorders.
- To promote the common needs of its members.
- To collect, disseminate and exchange information of common interest to its members.
- To promote the provision of adequate genetic services in the state.
- To collaborate with medical, research and statutory bodies in the field of genetics.

Subsidiary objects: In furtherance exclusively of the foregoing main objects the company shall have the following subsidiary objects:

- To increase public awareness of genetic and inherited disorders.
- To promote equality of educational and employment opportunities for its members.

**Development and performance**

There was minimal activity in the company in the year under review.

**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 18 September 2018 and signed on behalf of the board by:

Avril Daly  
Director

Patricia Towey  
Director

**Rare Diseases Ireland**  
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**Directors responsibilities statement**

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

Irish company law requires the directors to prepare financial statements for each financial year. Under the law, the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council, 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 2017 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 4, 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 below:

In common with many other businesses of our size and nature we use our auditors to assist with the preparation of 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 2017 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.

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

**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.

Thomas McCloskey

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

18 September 2018



**Rare Diseases Ireland**  
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**Profit and loss account**  
**Financial year ended 31 December 2017**

	<b>Note</b>	<b>2017</b>	<b>2016</b>
		<b>€</b>	<b>€</b>
<b>Turnover</b>	<b>5</b>	2,147	13,849
<b>Gross surplus</b>		<u>2,147</u>	<u>13,849</u>
Administrative expenses		(2,801)	(11,896)
<b>Operating (deficit)/surplus</b>	<b>6</b>	<u>(654)</u>	<u>1,953</u>
<b>(Deficit)/surplus before taxation</b>		<u>(654)</u>	<u>1,953</u>
Tax on (deficit)/surplus		-	-
<b>(Deficit)/surplus for the financial year</b>		<u><u>(654)</u></u>	<u><u>1,953</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 11 to 14 form part of these financial statements.

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**Statement of income and retained earnings**  
**Financial year ended 31 December 2017**

	<b>2017</b>	2016
	<b>€</b>	<b>€</b>
(Deficit)/surplus for the financial year	(654)	1,953
<b>Retained earnings at the start of the financial year</b>	<u>7,226</u>	<u>5,273</u>
<b>Retained earnings at the end of the financial year</b>	<u><u>6,572</u></u>	<u><u>7,226</u></u>

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**Balance sheet**  
**As at 31 December 2017**

	Note	2017 €	€	2016 €	€
<b>Current assets</b>					
Debtors	10	481		445	
Cash at bank and in hand		6,972		8,031	
		7,453		8,476	
<b>Creditors: amounts falling due within one year</b>					
	11	(881)		(1,250)	
<b>Net current assets</b>			6,572		7,226
<b>Total assets less current liabilities</b>			6,572		7,226
<b>Net assets</b>			6,572		7,226
<b>Capital and reserves</b>					
Profit and loss account	13		6,572		7,226
<b>Members funds</b>			6,572		7,226

These financial statements were approved by the board of directors on 18 September 2018 and signed on behalf of the board by:

Avril Daly  
Director

Patricia Towe  
Director

The notes on pages 11 to 14 form part of these financial statements.

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**Statement of cash flows**  
**Financial year ended 31 December 2017**

	<b>2017</b>	2016
	€	€
<b>Cash flows from operating activities</b>		
(Deficit)/surplus for the financial year	(654)	1,953
<i>Adjustments for:</i>		
Depreciation of tangible assets	-	225
Accrued expenses/(income)	(369)	(381)
<i>Changes in:</i>		
Trade and other debtors	(36)	(187)
Trade and other creditors	-	(389)
Cash generated from operations	<u>(1,059)</u>	<u>1,221</u>
Net cash (used in)/from operating activities	<u>(1,059)</u>	<u>1,221</u>
<b>Net increase/(decrease) in cash and cash equivalents</b>	(1,059)	1,221
<b>Cash and cash equivalents at beginning of financial year</b>	<u>8,031</u>	<u>6,810</u>
<b>Cash and cash equivalents at end of financial year</b>	<u><u>6,972</u></u>	<u><u>8,031</u></u>

**Rare Diseases Ireland**  
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**Notes to the financial statements**  
**Financial year ended 31 December 2017**

**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 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.

**Rare Diseases Ireland**  
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**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2017**

**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:

	<b>2017</b>	2016
	€	€
Funding received	2,147	13,849

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

**6. Operating (deficit)/surplus**

Operating (deficit)/surplus is stated after charging/(crediting):

	<b>2017</b>	2016
	€	€
Depreciation of tangible assets	-	225

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**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2017**

**7. Staff costs**

	<b>2017</b>	2016
	<b>Number</b>	Number
Administrative	-	1
	<u>          </u>	<u>          </u>

The aggregate payroll costs incurred during the financial year were:

	<b>2017</b>	2016
	<b>€</b>	€
Wages and salaries	-	6,093
Social insurance costs	-	424
	<u>          </u>	<u>          </u>
	<u>          </u>	<u>          </u>
	-	6,517
	<u>          </u>	<u>          </u>

**8. Appropriations of profit and loss account**

	<b>2017</b>	2016
	<b>€</b>	€
At the start of the financial year	7,226	5,273
(Deficit)/surplus for the financial year	(654)	1,953
	<u>          </u>	<u>          </u>
<b>At the end of the financial year</b>	<b>6,572</b>	<b>7,226</b>
	<u>          </u>	<u>          </u>

**9. Tangible assets**

	Fixtures, fittings and equipment	<b>Total</b>
	<b>€</b>	<b>€</b>
<b>Cost</b>		
<b>At 1 January 2017 and 31 December 2017</b>	1,286	1,286
	<u>          </u>	<u>          </u>
<b>Depreciation</b>		
<b>At 1 January 2017 and 31 December 2017</b>	1,286	1,286
	<u>          </u>	<u>          </u>
<b>Carrying amount</b>		
<b>At 31 December 2017</b>	-	-
	<u>          </u>	<u>          </u>
At 31 December 2016	-	-
	<u>          </u>	<u>          </u>

**10. Debtors**

	<b>2017</b>	2016
	<b>€</b>	€
Prepayments	481	445
	<u>          </u>	<u>          </u>

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**Notes to the financial statements (continued)**  
**Financial year ended 31 December 2017**

**11. Creditors: amounts falling due within one year**

	<b>2017</b>	<b>2016</b>
	<b>€</b>	<b>€</b>
Accruals	881	1,250
	<u>881</u>	<u>1,250</u>

**12. Financial instruments**

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

	<b>2017</b>	<b>2016</b>
	<b>€</b>	<b>€</b>
<b>Financial assets that are debt instruments measured at amortised cost</b>		
Other debtors	481	445
Cash at bank and in hand	6,972	8,031
	<u>6,972</u>	<u>8,031</u>
<b>Financial liabilities measured at amortised cost</b>		
Other creditors	881	1,250
	<u>881</u>	<u>1,250</u>

**13. Reserves**

The income and expenditure account represents cumulative surpluses and deficits.

**14. Approval of financial statements**

The board of directors approved these financial statements for issue on 18 September 2018.



**Rare Diseases Ireland**  
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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 2017**

	<b>2017</b>	2016
	€	€
<b>Turnover</b>		
Funding received	2,147	13,849
	<u>2,147</u>	<u>13,849</u>
<b>Gross surplus</b>	<u>2,147</u>	<u>13,849</u>
<b>Gross surplus percentage</b>	100.0%	100.0%
<b>Overheads</b>		
<b>Administrative expenses</b>		
Wages and salaries	-	(6,093)
Employer's PRSI contributions	-	(424)
Programme expenses	(545)	(1,723)
Rent payable	-	750
Insurance	(605)	(360)
Printing, postage and stationery	(180)	(536)
Telephone	(420)	(470)
Computer costs	-	(123)
Motor and travel	-	(834)
Legal and professional	-	(300)
Auditors remuneration	(861)	(1,230)
Bank charges	(24)	(81)
General expenses	(166)	(21)
Subscriptions	-	(226)
Depreciation of tangible assets	-	(225)
	<u>(2,801)</u>	<u>(11,896)</u>
<b>Operating (deficit)/surplus</b>	(654)	1,953
<b>Operating (deficit)/surplus percentage</b>	30.5%	14.1%
<b>(Deficit)/surplus before taxation</b>	<u>(654)</u>	<u>1,953</u>