



cystinosis
ireland

Company Registration Number: 371955

CYSTINOSIS IRELAND

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

FINANCIAL STATEMENTS

FOR THE FINANCIAL YEAR ENDED 31ST DECEMBER 2018

Research - Awareness - Support



CONTENTS

	Page
Director's and Other Information	1 - 2
Director's Report	3 - 5
Director's Responsibilities Statement	6
Independent Auditor's Report to the Members	7 - 9
Income and Expenditure Account	10
Balance Sheet	11
Notes to the Financial Statements	12 - 13
Supplementary Information	14 - 17



DIRECTORS AND OTHER INFORMATION

Directors	Patrick G Hoey (resigned 26 th July 2018) Sue Maguire Anne Marie O'Dowd Francis Noel Groome (resigned 7 th June 2018) Michael Swift
Secretary	Sue Maguire
Company Number	371955
Registered Office	1-2 Cavendish Row Dublin 1
Business Address	1-2 Cavendish Row Dublin 1 Email: mail@cystinosis.ie Facebook: www.facebook.com/cystinosisIrl Twitter: #cystinosisirl LinkedIn: www.linkedin.com/company-beta/10971136
Auditor	Cronin and Company 1 Terenure Place Terenure Dublin 6W
Bankers	Allied Irish Bank 9 Terenure Road East Rathgar Dublin 6 Permanent TSB Main Street Dundrum Dublin 14 KBC Bank Ireland Sandwith Street Dublin 2



DIRECTORS AND OTHER INFORMATION (continued)

Registered Charity Number CHY 15517

Charities Regulatory Number 20053796



DIRECTOR'S REPORT

The directors present their annual report and the audited Financial Statements of the company for the financial year ended 31st December 2018.

Directors

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

Patrick G Hoey
Sue Maguire
Anne Marie O'Dowd
Francis Noel Groome
Michael Swift

Sue Maguire held the position of company secretary for the duration of the financial year.

The directors and secretary have no beneficial interest in the company. The company is limited by guarantee and without a share capital.

Principal Activities

Cystinosis Ireland is an Irish registered charity which was founded in 2003. The Company is a non-profit organisation dedicated to supporting people with cystinosis, whilst investing in medical research with the aim of finding new treatments and ultimately one day finding a cure for the disease. Cystinosis is a rare metabolic disease in which the amino acid, cysteine, accumulates abnormally in all cells of the body due to a defective transport mechanism which fails to remove it from the cells. This in turn leads to early cell death and cystinosis can slowly destroy all organs of the body including kidneys, liver, eyes, muscles, pancreas, thyroid and the brain.

The principal activities of Cystinosis Ireland are to raise awareness of cystinosis in Ireland, participate in fundraising events to raise money to invest in research with the aim of ultimately finding a cure for cystinosis as well as improving existing treatments, and providing support to those living with cystinosis.

Principal Risks and Uncertainties

The principal risk and uncertainty facing the charity come from the risks associated with a fall in fundraising income. We are committed to a policy of complete transparency around all aspects of our fundraising. We recognise and value the implicit trust of all our funders and manage the business of our charity in accordance with current best practice.



DIRECTOR'S REPORT (continued)

Likely Future Developments

The directors are not expecting to make any significant changes in the nature of the company's principal activity in the near future.

Results

The results for the year are dealt with on page 10.

Events after the end of the reporting period

There have been no significant events affecting the charity since the year end.

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 1-2 Cavendish Row, Dublin 1.

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.

Statement on Ethical and Transparent use of Funds Raised by Cystinosis Ireland

We are committed to a policy of complete transparency around all aspects of our fundraising. We recognise and value the implicit trust of all our funders and manage the business of our charity in accordance with current best practice.

Cystinosis Ireland exists solely to support people with the condition and their families. We do this by funding research with the aim of better understanding the condition, improving existing treatments and hopefully one day discovering a cure.

DIRECTORS REPORT (continued)

We also support families affected by cystinosis through running information and support workshops and supporting families to attend cystinosis family conferences. We cover the cost of this work as far as possible through separate sponsorship outside of our core fundraising activities.

In 2018, a second member of staff joined Cystinosis Ireland, both now working on a part time basis. Our second member of staff joined to work specifically on research matters, including all aspects of research sourcing, project support and administration.

Whilst all staff related costs are paid by the Company and reflected in these financial statements, separate funding has been secured from a private donor to ensure there is no overall cost or financial impact on the Company. Otherwise, we do not have any overheads such as fundraising commissions, rental of premises, office furniture or equipment except overheads associated occasionally with fundraising costs, for example, the cost of providing meals for the fundraising dinner at our golf days. This ensures that all funds raised go into cystinosis research.

We have been successful in securing joint funding for research projects over time through the Health Research Board / MRCG Joint Funding Scheme. Projects are selected following extensive independent peer review by Cystinosis Ireland's Research Group and also by the HRB / MRCG Joint Funding Scheme. Other projects (outside of the HRB / MRCG scheme) are independently reviewed and processed through the Research Group and the Executive Board.

A detailed listing of all funds raised and used is presented in our Audited Financial Statements, available in the "Who are we" section of our website. For further details, please contact us directly at mail@cystinosis.ie.

In 2018, Cystinosis Ireland joined a collaborative effort with our friends from a number of European sister organizations to agree the setting up of a new cystinosis company, namely Cystinosis Network Europe. For the initial setting up period of the new company, Cystinosis Ireland will provide the Secretariat and the company will be domiciled in Ireland. This new company will have a strong research purpose and will look to manage the formation and operating of a cystinosis based Community Advisory Board (CAB).

In late 2018, Cystinosis Ireland was able to announce that Dublin will be the host city of the next International Cystinosis Conference, to be held in July 2020. This will mark Dublin's second staging of the event we last hosted in 2008, bringing together families, researchers, clinicians, supporters and many more from all over the cystinosis world.

We would like to take this opportunity to thank all of our supporters and encourage you to continue to assist us in achieving our goals. As an organisation, we are committed to maintaining the highest ethical and transparency standards.

Sue Maguire

Sue Maguire
Director

Michael Swift

Michael Swift
Director

27th April 2019



DIRECTOR'S 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 Irish law 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.

Sue Maguire

Sue Maguire
Director

Michael Swift

Michael Swift
Director

27th April 2019

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF CYSTINOSIS IRELAND LIMITED

Report on the audit of the Financial Statements

Opinion

We have audited the Financial Statements of Cystinosis Ireland for the financial year ended 31st December 2018 which comprise the Income and Expenditure Account, Balance Sheet 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 31st December 2018 and of its gain for the financial year then ended;
- have been properly prepared in accordance with Financial Reporting Standard 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 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 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 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; 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.

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF CYSTINOSIS IRELAND LIMITED

We have nothing to report in this regard.

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 have 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.

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.



cystinosis
ireland

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF CYSTINOSIS IRELAND LIMITED

Donal Cronin

Donal Cronin

For and on behalf of
Cronin and Company
Certified Public Accountants and Statutory Audit Firm
1 Terenure Place
Terenure
Dublin 6W

27th April 2019



INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2018

Note	2018	2017
	€	€
Income	183,926	181,085
Expenditure		
Medical Research Projects	(95,857)	(217,583)
Administrative Expenses	(74,103)	(58,549)
	<u>(169,960)</u>	<u>(276,132)</u>
Surplus/(Deficit) for the financial year	<u>13,966</u>	<u>(95,047)</u>

The Income and Expenditure Account has been prepared on the basis that all operations are continuing operations.

The company has no other recognized items of income and expenses other than the results for the financial year as set out above.

The Notes on pages 12 to 13 form part of these Financial Statements



BALANCE SHEET
AS AT 31ST DECEMBER 2018

	Note	2018 €	€	2017 €	€
Current Assets					
Debtors	6	7,105		6,465	
Cash at Bank		336,459		309,348	
		<u>343,564</u>		<u>315,813</u>	
Creditors: Amounts falling due within within one year	7	<u>(14,744)</u>		<u>(959)</u>	
Net Current Assets		328,820		314,854	
Total Assets less Current Liabilities		<u>328,820</u>		<u>314,854</u>	
Net Assets		<u>328,820</u>		<u>314,854</u>	
Reserves					
Income and Expenditure Account		328,820		314,854	
Members Funds		<u>328,820</u>		<u>314,854</u>	

These Financial Statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime and in accordance with FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

These Financial Statements were approved by the board of directors on 27th April 2019 and signed on behalf of the board by:

Sue Maguire
Sue Maguire
Director

Michael Swift
Michael Swift
Director

The Notes on pages 12 to 13 form part of these Financial Statements

NOTES TO THE FINANCIAL STATEMENTS

1. General Information

Cystinosis Ireland is a company domiciled and incorporated in Republic of Ireland. The address of the registered office is 1-2 Cavendish Row, Dublin 1.

2. Statement of Compliance

These Financial Statements have been prepared in compliance with FRS 102 Section 1A, 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

3. Accounting Policies and Measurement Bases

Basis of Preparation

The Financial Statements are prepared in Euro, which is the functional currency of the entity.

The Financial Statements have been prepared on the historical cost convention. The principal accounting policies adopted are set out below.

Going Concern

At the time of approving the financial statements, the directors have a reasonable expectation that the company has adequate resources to continue in operational existence for the foreseeable future. Thus the directors continue to adopt the going concern basis of accounting in preparing the financial statements.

Income and Expenditure

Income consists of donations and other funds generated by voluntary activities. Income and expenses are included in the financial statements as they become receivable or due.

Expenses include VAT where applicable as the company cannot reclaim it.

Taxation

No charge to current or deferred taxation arises as the company has been granted charitable status under Sections 207 and 208 of the Taxes Consolidation Act 1997, Charity Number CHY 15517.

4. Limited by Guarantee

The company is limited by guarantee not having a share capital.

NOTES TO THE FINANCIAL STATEMENTS (continued)

5. Staff Costs

The average number of persons employed by the company during the financial year, including the directors was 2 (2017: 1).

The aggregate payroll costs incurred during the financial year were:

	2018	2017
	€	€
Wages and Salaries	45,489	31,634
Social Insurance Costs	4,935	3,403
	<u>50,424</u>	<u>35,037</u>

Whilst all staff related costs are paid by the Company and reflected in these financial statements, separate funding has been secured by a private donor to ensure there is no overall cost or financial impact on the Company.

6. Debtors

	2018	2017
	€	€
Prepayments	7,105	6,465
	<u>7,105</u>	<u>6,465</u>

7. Creditors: Amounts falling due within one year

	2018	2017
	€	€
Other Creditors	10,000	-
Tax and Social Insurance	4,559	893
Accruals	185	66
	<u>14,744</u>	<u>959</u>

As mentioned in the Director's report, Cystinosis Ireland will be providing the Secretariat for the new Cystinosis Network Europe (CNE) group. As part of this role and considering that the CNE is still being set up as a Company, in Ireland, Cystinosis Ireland offered to hold in escrow a donation of €10,000 made to the new Company. These funds will be held and only dispersed upon formal instruction to Cystinosis Ireland, and the balance of funds will be forwarded to the bank account of CNE once that has been opened".

8. Events after the end of the reporting period

There have been no significant events affecting the company since the year end.

9. Approval of Financial Statements

The board of directors approved these Financial Statements for issue on 27th April 2019.



cystinosis
ireland

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



DETAILED INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2018

Income	2018	2017
Private Donor to fund staff costs	70,000	42,000
The Gap Disco - Moate	-	6,555
BBQ4Cystinosis	650	6,083
Louise Harkness	2,265	2,325
Belfast Marathon	-	2,247
HRB Support Dublin Cystinosis Workshop	9,000	1,000
General donations and other fundraising events	4,000	-
Deposit Interest Received	246	808
Church Gate Collection - Leixlip	1,735	1,510
Leixlip Tennis Fundraiser	-	750
Naas Tennis Fundraiser	4,000	-
Corporate Donors and Friends	20,000	40,000
Golf Classic Days (Grange/Ashbourne/Kilcock)	48,899	60,226
Donations from Families	7,528	2,000
London Group	230	2,405
Wicklow Mountains Half Marathon	1,315	-
Christmas Donations	2,411	2,265
"A to B for C"	6,600	-
Dublin Mini Marathon	1,348	2,635
General Donations and Other Fundraising Events	3,699	8,276
	<u>113,926</u>	<u>139,085</u>
Total Income	<u>183,926</u>	<u>181,085</u>



DETAILED INCOME AND EXPENDITURE ACCOUNT (continued)
FINANCIAL YEAR ENDED 31ST DECEMBER 2018

Expenditure

Medical Research Projects	2018	2017
The University of Auckland	-	101,045
The University College Dublin	-	16,000
The University of Leuven	24,936	25,064
The University of California	25,662	24,185
2018/2017 Dublin Cystinosis Workshop	16,659	19,040
2016 HRB/MRCG Joint Funding Scheme	-	18,750
2014 HRB/MRCG Joint Funding Scheme	-	13,499
2018 European Cystinosis Conference	10,000	-
Seed Corn Funded Projects	18,600	-
	<u>95,857</u>	<u>217,583</u>
Overheads		
Administrative Expenses	74,103	58,549
	<u>74,103</u>	<u>58,549</u>



DETAILED INCOME AND EXPENDITURE ACCOUNT (continued)
FINANCIAL YEAR ENDED 31ST DECEMBER 2018

Overheads

	2018	2017
Administrative Expenses		
Wages and Salaries	45,489	31,634
Social Welfare Costs	4,935	3,403
Golf Classic Day Fees	8,195	10,200
Dublin Research and Family Conference	10,884	7,029
Website and IT Development	1,570	4,269
Bank Charges/Merchant Service Fees	645	923
Realex Fees	221	221
General Expenses	1,491	420
Subscriptions	673	450
	<u>74,103</u>	<u>58,549</u>