



cystinosis
ireland

Company Registration Number: 371955

CYSTINOSIS IRELAND LIMITED

(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

DIRECTOR'S REPORT AND FINANCIAL STATEMENTS

FOR THE FINANCIAL YEAR ENDED 31st DECEMBER 2017

Research - Awareness - Support



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DIRECTORS AND OTHER INFORMATION

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



DIRECTORS AND OTHER INFORMATION

Registered Charity Number	CHY 15517
Charities Regulatory Number	20053796



DIRECTORS REPORT

The directors present their annual report and the audited Financial Statements of the company for the financial year ended 31st December 2017.

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.

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.



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 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.

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 2016, Cystinosis Ireland was in the position of being able to employ a full time member of staff to work on new projects and additional areas that wasn't previously possible.

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, 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.



DIRECTORS REPORT(continued)

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. 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.

In 2017, we launched our Seed Corn funding programme to accommodate and facilitate investment in smaller more innovative research projects and ideas around Cystinosis research. This programme will allow us more flexibility to take on more early stage research projects, typically with a timeframe of 6-12 months and capped at a value of €10,000.

Anne Marie O'Dowd

Anne Marie O'Dowd
Director

Michael Swift

Michael Swift
Director

7th June 2018



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.

Anne Marie O'Dowd

Anne Marie O'Dowd

Director

Michael Swift

Michael Swift

Director



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 2017 which comprise the Income and Expenditure Account, Balance Sheet, statement of changes in equity 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 2017 and of its loss 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 our opinion.

Conclusions relating to Going Concern

We have nothing to report in respect of the following matters in relation to which ISAs (Ireland) require us to report to you where:

- the 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 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
(continued)

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 report is consistent with the Financial Statements; and
- in our opinion, the 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 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 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 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.



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

As part of an audit in accordance with ISAs (Ireland), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the Financial Statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the Financial Statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the Financial Statements, including the disclosures, and whether the Financial Statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

The purpose of our audit work and to whom we owe our responsibilities

Our report is made solely to the company's members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members, as a body, for our audit work, for this report, or for the opinions we have formed.

Donal Cronin

Cronin and Company
Certified Public Accountants and Statutory Audit Firm
1 Terenure Place
Terenure
Dublin 6W

7th June 2018



INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

	Note	2017	2016
		€	€
Income	5	181,085	232,509
Expenditure			
Medical Research Projects		(217,583)	(134,297)
Administrative Expenses		(58,549)	(31,803)
		<u>(276,132)</u>	<u>(166,100)</u>
(Deficit) / Surplus for the financial year		<u><u>(95,047)</u></u>	<u><u>66,409</u></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 15 form part of these Financial Statements



BALANCE SHEET
AS AT 31ST DECEMBER 2017

		2017		2016	
	Note	€	€	€	€
Current Assets					
Debtors	7	6,465		-	
Cash at Bank		309,348		430,859	
		<u>315,813</u>		<u>430,859</u>	
Creditors: Amounts falling due within one year	8	<u>(959)</u>		<u>(20,958)</u>	
Net Current Assets			314,854		409,901
Total Assets less Current Liabilities			<u>314,854</u>		<u>409,901</u>
Net Assets			<u>314,854</u>		<u>409,901</u>
Reserves					
Income and Expenditure Account			314,854		409,901
Members Funds			<u>314,854</u>		<u>409,901</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 7th June 2018 and signed on behalf of the board by:

Anne Marie O'Dowd

Anne Marie O'Dowd
Director

Michael Swift

Michael Swift
Director

The Notes on pages 12 to 15 form part of these Financial Statements



NOTES TO THE FINANCIAL STATEMENTS
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

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.

The significant accounting policies adopted by the company and applied consistently in the preparation of these financial statements are as follows:

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 government funding, 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.

Revenue from the sale of goods is recognized when the significant risks and rewards of ownership have transferred to the buyer, usually on dispatch of the goods; the amount of revenue can be measured reliably; it is probable that the associated economic benefits will flow to the entity and the costs incurred or to be incurred in respect of the transactions can be measured reliably.

Revenue from the rendering of services is measured by reference to the stage of completion of the service transaction at the end of the reporting period provided that the outcome can be reliably estimated. When the outcome cannot be reliably estimated, revenue is recognized only to the extent that expenses recognized are recoverable.



NOTES TO THE FINANCIAL STATEMENTS (continued)
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

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.

Financial Instruments

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

Basic financial instruments are initially recognized at the transaction price, unless the arrangement constitutes a financing transaction, where it is recognized 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 amortized cost.

Where investments in non-convertible preference shares and non-puttable ordinary shares or preference shares are publicly traded or their fair value can otherwise be measured reliably, the investment is subsequently measured at fair value with changes in fair value recognized in profit or loss. All other such investments are subsequently measured at cost less impairment.

Other financial instruments, including derivatives, are initially recognized at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Other financial instruments are subsequently measured at fair value, with any changes recognized in profit or loss, with the exception of hedging instruments in a designated hedging relationship.

Financial assets that are measured at cost or amortized cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognized in profit or loss immediately.

For all equity instruments regardless of significance, and other financial assets that are individually significant, these are assessed individually for impairment. Other financial assets are either assessed individually or grouped on the basis of similar credit risk characteristics.

Any reversals of impairment are recognized in profit or loss immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds what the carrying amount would have been had the impairment not previously been recognized.

4. Limited by Guarantee

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



NOTES TO THE FINANCIAL STATEMENTS (continued)
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

5. Income

Income arises from:

	2017	2016
	€	€
Health Research Board - Joint Funding Receipt	-	102,936
Voluntary Donations/Fundraisers	181,085	129,573
	<u>181,085</u>	<u>232,509</u>

Where Cystinosis Ireland has received joint funding support from the HRB to fund a research project; the HRB's part of the funding is transferred to Cystinosis Ireland for onward payment to the research institution. Cystinosis Ireland did not receive any funding in 2017 (2016: €102,936).

6. Staff Costs

The average number of persons employed by the company during the financial year, including the directors was 1 (2016: 1).

The aggregate payroll costs incurred during the financial year were:

	2017	2016
	€	€
Wages and Salaries	31,634	12,753
Social Insurance Costs	3,403	1,273
	<u>35,037</u>	<u>14,026</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.

7. Debtors

	2017	2016
	€	€
Prepayments	6,465	-
	<u>6,465</u>	<u>-</u>



NOTES TO THE FINANCIAL STATEMENTS (continued)
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

8. Creditors: Amounts falling due within one year

	2017	2016
	€	€
Donations Received	-	20,000
Tax and Social Insurance	893	880
Accruals	66	78
	<u>959</u>	<u>20,958</u>

9. Events after the end of the reporting period

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

10. Approval of Financial Statements

The board of directors approved these Financial Statements for issue on 7th June 2018.



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



DETAILED INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

Income

Health Research Board - Joint Funding Receipt	-	102,936
Private Donor to fund staff costs	42,000	14,000
The Gap Disco - Moate	6,555	-
BBQ4Cystinosis	6,083	-
Louise Harkness' Tea Party	2,325	-
Belfast Marathon	2,247	-
Hell and Back	-	60
HRB Support 2017 Dublin Cystinosis Workshop	1,000	-
Deposit Interest Received	808	1,376
Church Gate Collection - Leixlip	1,510	1,765
Leixlip Tennis Fundraiser	750	720
Zumbathon	-	916
Corporate Donors and Friends	40,000	20,000
The Cube Fundraising Night	-	560
Donations from New Families	-	5,526
Golf Classic Days (Grange/Ashbourne/Kilcock)	60,226	60,601
Donations from Families	2,000	8,000
Ring of Kerry Cycle Race	-	1,000
London Group	2,405	2,913
Quiz Fundraiser	-	1,180
TV3 Fundraising	-	123
Christmas Donations	2,265	890
Dublin Mini Marathon	2,635	4,609
General Donations and Other Fundraising Events	8,276	5,334
	<u>139,085</u>	<u>115,573</u>
Total Income	<u>181,085</u>	<u>232,509</u>



DETAILED INCOME AND EXPENDITURE ACCOUNT (continued)
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

Expenditure

Medical Research Projects

The University of Auckland	101,045	93,052
The University of Florida	-	36,245
The University College Dublin	16,000	5,000
The University of Leuven	25,064	-
The University of California	24,185	-
2017 Dublin Cystinosis Workshop	19,040	-
2016 HRB/MRCG Joint Funding Scheme	18,750	-
2014 HRB/MRCG Joint Funding Scheme	13,499	-
	<u>217,583</u>	<u>134,297</u>

Overheads

Administrative Expenses	58,549	31,803
	<u>58,549</u>	<u>31,803</u>



DETAILED INCOME AND EXPENDITURE ACCOUNT (continued)
FINANCIAL YEAR ENDED 31ST DECEMBER 2017

Overheads

Administrative Expenses

Wages and Salaries	31,634	12,753
Social Welfare Costs	3,403	1,273
Golf Classic Day Fees	10,200	11,070
Cystinosis Family Support	-	3,000
Dublin Research and Family Conference	7,029	1,597
Survey Monkey	-	350
Website and IT Development	4,269	-
Bank Charges	196	140
Merchant Services / Realex Fees	948	933
General Expenses	420	312
Subscriptions	450	375
	<u>58,549</u>	<u>31,803</u>