



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 2015

Research - Awareness - Support



CONTENTS

	Page
Director's and Other Information	1
Director's Report	2 - 3
Director's Responsibilities Statement	4
Independent Auditor's Report to the Members	5 - 6
Income and Expenditure Account	7
Balance Sheet	8
Statement of Cash Flows	9
Notes to the Financial Statements	10 - 13
Supplementary Information	14 - 16



DIRECTORS AND OTHER INFORMATION

Directors	Patrick G Hoey Sue Maguire Ann Kelsey 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
Auditor	Cronin and Company 1 Terenure Place Terenure Dublin 6W
Bankers	Allied Irish Bank 9 Terenure Road East Rathgar Dublin 6
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 2015.

Companies Act 2014

Companies Act 2014 became effective on 1st June 2015. As noted in the transitional provisions of the Companies Act 2014, guarantee companies which were incorporated under previous Companies Acts, can continue to use limited in their name until 30th November 2016. The directors will make a formal decision on the company structure within the transition period as allowed by the Companies Act 2014.

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
Ann Kelsey
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. It is an all-volunteer, non-profit organization dedicated to supporting those affected by Cystinosis, while also investing in research into new therapies and ultimately to find a cure. 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 to remove it from the cells. This in turn leads to an early cell death and Cystinosis therefore slowly destroys all organs of the body including kidneys, liver, eyes, muscles, pancreas, thyroid and the brain.

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



DIRECTORS REPORT (CONTINUED)

Results

The results for the year are dealt with on page 7.

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, by ensuring that adequate resources are assigned to this task with appropriate expertise to the financial function and liaising with the company's auditors. The accounting records of the company are located at 1-2 Cavendish Row, Dublin 1.

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

Cystinosis Ireland does not employ or remunerate any staff and is wholly run by volunteers. We do not have any overheads such as staff costs, fundraising commissions, rental of premises, office furniture or equipment except minimal 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 peer 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

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 organization, we are committed to maintaining the highest ethical and transparency standards.

Patrick Hoey

Patrick G Hoey
Director

Michael Swift

Michael Swift
Director



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 Certified Public 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.

Patrick Hoey

Patrick G Hoey
Director

Michael Swift

Michael Swift
Director



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

We have audited the financial statements of Cystinosis Ireland Limited for the year ended 31st December 2015 which comprise the Income and Expenditure Account, Balance Sheet, statement of changes in equity, 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 Certified Public 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 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.

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 Ethical Standards for Auditors.

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 31st December 2015 and of its profit for the year then ended; and
- have been properly prepared in accordance with the relevant reporting framework and, in particular the requirements of the Companies Act 2014.

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

- We have obtained all the information and explanations which we consider necessary for the purposes of our audit.
- In our opinion the accounting records of the company were sufficient to permit the financial statements to be readily and properly audited.
- The financial statements are in agreement with the accounting records.
- In our opinion the information given in the director's report is consistent with the financial statements.



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

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.

Cronin and Company

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

1st July 2016



INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

	Note	2015	2014
		€	€
Income	4	184,007	182,997
Medical Research Projects		(134,482)	-
Administrative Expenses		(22,029)	(10,617)
Operating Surplus		<u>27,496</u>	<u>172,380</u>
Surplus on ordinary activities before taxation		<u>27,496</u>	<u>172,380</u>
Tax on surplus on ordinary activities	6	-	-
Surplus for the financial year		<u><u>27,496</u></u>	<u><u>172,380</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 10 to 13 form part of these Financial Statements



BALANCE SHEET
AS AT 31ST DECEMBER 2015

		2015		2014	
	Note	€	€	€	€
Current Assets					
Debtors	7	15		436	
Cash at Bank		383,477		375,560	
		<u>383,492</u>		<u>375,996</u>	
Creditors: Amounts falling due within one year	8	<u>(40,000)</u>		<u>(60,000)</u>	
Net Current Assets			343,492		315,996
Total Assets less Current Liabilities			<u>343,492</u>		<u>315,996</u>
Net Assets			<u>343,492</u>		<u>315,996</u>
Capital and Reserves					
Income and Expenditure Account			343,492		315,996
Members Funds			<u>343,492</u>		<u>315,996</u>

These financial statements were approved by the board of directors on 1st July 2016 and signed on behalf of the board by:

Patrick Hoey

Patrick G Hoey
Director

Michael Swift

Michael Swift
Director

The Notes on pages 10 to 13 form part of these Financial Statements



STATEMENT OF CASHFLOWS
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

	2015	2014
	€	€
Cash flows from Operating Activities		
Surplus for the financial year	27,496	172,380
<i>Changes in:</i>		
Trade and other debtors	421	(205)
Cash generated from operations	<u>27,917</u>	<u>172,175</u>
Net cash from operating activities	<u>27,917</u>	<u>172,175</u>
Cash flows from Financing Activities		
Income received in advance	(20,000)	(20,000)
Net cash used in financing activities	<u>(20,000)</u>	<u>(20,000)</u>
Net increase/ (decrease) in cash and cash equivalents	7,917	152,175
Cash and cash equivalents at beginning of financial year	375,560	223,385
Cash and cash equivalents at end of financial year	<u>383,477</u>	<u>375,560</u>

The Notes on pages 10 to 13 form part of these Financial Statements



NOTES TO THE FINANCIAL STATEMENTS
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

1. 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' and the Companies Act 2014.

2. Accounting Policies

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

Basis of Preparation

The financial statements have been prepared on the going concern basis, under the historical cost convention, as modified by the revaluation of certain financial assets and liabilities and comply with the financial reporting standards of the Financial Reporting Council and promulgated by the Institute of Certified Public Accountants in Ireland and the Companies Act 2014.

The financial statements are prepared in Euro, which is the functional currency of the entity.

Transition to FRS 102

The entity transitioned from previous Irish GAAP to FRS 102 as at 1st January 2014. Details of how FRS 102 has affected the reported financial position and financial performance is given in note 11.

Income

Income generally represents amounts received and receivable. Donations received either in cash, cheque or on-line are only credited as income when they are lodged to the company's bank account.



NOTES TO THE FINANCIAL STATEMENTS
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

Financial Instruments

Financial Assets

Basic financial assets, including trade and other receivables, cash and bank balances are initially recognized at transaction price, unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest.

Such assets are subsequently carried at amortized cost using the effective interest method.

At the end of each reporting period financial assets measured at amortized cost are assessed for objective evidence of impairment. If an asset is impaired the impairment loss is the difference between the carrying amount and the present value of the estimated cash flows discounted at the asset's original effective interest rate. The impairment loss is recognized in profit or loss.

Financial assets are derecognized when the contractual rights to the cash flows from the asset expire or are settled; or substantially all the risks and rewards of the ownership of the asset are transferred to another party; or control of the asset has been transferred to another party who has the practical ability to unilaterally sell the asset to an unrelated third party without imposing additional restrictions on transfer.

Financial Liabilities

Basic financial liabilities, including trade and other payables, bank loans, overdrafts and amount owed to related parties are initially recognized at transaction price, unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future receipts discounted at a market rate of interest.

Debt instruments are subsequently carried at amortized cost, using the effective interest rate method. Fees paid on the establishment of loan facilities are recognized as transaction costs of the loan to the extent that it is probable that some or all of the facility will be drawn down. In this case, the fee is deferred until the draw-down occurs. To the extent there is no evidence that it is probable that some or all of the facility will be drawn down, the fee is capitalized as a pre-payment for liquidity services and amortized over the period of the facility to which it relates.

Trade payables are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade payables are recognized initially at transaction price and subsequently measured at amortized cost using the effective



NOTES TO THE FINANCIAL STATEMENTS
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

interest method.

Financial liabilities are derecognized when the liability is extinguished, that is when the contractual obligation is discharged, cancelled or expires.

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.

Offsetting

Financial assets and liabilities are offset and the net amounts presented in the financial statements when there is an enforceable right to set off the recognized amounts and there is an intention to settle on a net basis or to realize the asset and settle to liability simultaneously.

3. Limited by Guarantee

The company is limited by guarantee and does not have a share capital.

4. Income

Income arises from funding projects, donations and fund raising events.

	2015	2014
	€	€
Income	114,233	85,724
HRB Joint-funding receipts for Medical Research Projects	69,774	97,273
	-----	-----
	184,007	182,997
	-----	-----

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.

5. Staff Costs

There was no staff employed during the financial year. All directors carry out their duties on a voluntary basis and do not receive any remuneration for services provided.

6. Taxation

The company has been granted charitable status by the Revenue Commissioners under terms of Section 846A Taxes Consolidation Act, 1997 and therefore no provision is made for corporation tax.



NOTES TO THE FINANCIAL STATEMENTS
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

7. Debtors

	2015	2014
	€	€
Prepayments	15	436
	-----	-----

8. Creditors: Amounts falling due within one year

	2015	2014
	€	€
Donations Received	40,000	60,000
	-----	-----

9. Financial Instruments

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

	2015	2014
	€	€
Financial Assets that are debt instruments measured at amortized cost Cash at Bank	383,477	375,560
	-----	-----

10. Events after the end of the reporting period

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

11. Transition to FRS 102

These are the first financial statements that comply with FRS 102. The company transitioned to FRS 102 on 1st January 2014.

Reconciliation of Members Funds

No transitional adjustments were required.

Reconciliation of Surplus for the financial year

No transitional adjustments were required.

12. Approval of Financial Statements

The board of directors approved these financial statements for issue on 1st July 2016.



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



DETAILED INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

	2015 €	2014 €
Income		
Health Research Board - Joint Funding Receipt	69,774	97,273
Hell and Back	-	1,580
Irish Stock Exchange	-	2,000
General donations and one-off events	8,771	4,278
Deposit Interest Received	940	1,968
Bag Packing in Dunnes Stores	-	1,590
UK Kidney Group - Retirement Gift	-	1,264
Corporate Donors and Friends	20,000	28,025
Swim for a Mile	810	-
The Cube Fundraising Night	9,117	-
Donations from new families	7,476	-
Golf Classic Days (Grange and Ashbourne)	45,535	25,115
Donations from Families	7,705	6,500
Ring of Kerry Cycle Race	3,150	-
Individual Donation	2,500	-
London Day and Group	741	3,079
Run a Muck	-	4,908
Wellie Race	410	400
TV3 Fundraising	1,215	-
Omagh Half Marathon	695	-
Dublin Marathon	1,452	2,103
Limerick Marathon	-	1,000
Dublin Mini Marathon	2,361	1,256
The Nuts Challenge for Cystinosis	1,355	-
Cystinosis Foundation Ireland Christmas Cards	-	30
Coffee Morning	-	628
	<u>184,007</u>	<u>182,997</u>



DETAILED INCOME AND EXPENDITURE ACCOUNT (CONTINUED)
FINANCIAL YEAR ENDED 31ST DECEMBER 2015

	2015 €	2014 €
Overheads		
Medical Research Projects		
The University of Auckland Project	93,902	-
The University of Florida Project	35,834	-
The University College Dublin Project	4,746	-
	<u>134,482</u>	<u>-</u>
Administrative Expenses		
Research and Family Workshop Expenses	716	-
Salzburg Cystinosis Conference	1,478	-
Golf Classic Day Fees	6,228	4,368
Family Sponsorships - 8th Int' Conference In UK	-	1,800
Conference Sponsorship - Chicago	1,440	-
Donation - The Australian Cystinosis Support Group	-	2,000
Cystinosis T Shirts	-	1,175
Cystinosis Family Support	615	-
The Cube	6,500	-
Assistive Technology Expense	3,298	-
Survey Monkey	350	-
Insurance - RSA	79	-
Bank Charges	158	33
Merchant Service / Realex Fees	792	766
Subscriptions	375	475
	<u>22,029</u>	<u>10,617</u>