



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 31<sup>st</sup> DECEMBER 2016**

*Research - Awareness - Support*



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**DIRECTORS AND OTHER INFORMATION**

<b>Directors</b>	Patrick G Hoey Sue Maguire Ann Kelsey (resigned 27 <sup>th</sup> September 2016) Anne Marie O'Dowd Francis Noel Groome Michael Swift
<b>Secretary</b>	Sue Maguire
<b>Company Number</b>	371955
<b>Registered Office</b>	1-2 Cavendish Row Dublin 1
<b>Business Address</b>	1-2 Cavendish Row Dublin 1  Email: <a href="mailto:mail@cystinosis.ie">mail@cystinosis.ie</a> Facebook: <a href="http://www.facebook.com/cystinosisIrl">www.facebook.com/cystinosisIrl</a> Twitter: <a href="https://twitter.com/cystinosisirl">#cystinosisirl</a> LinkedIn: <a href="http://www.linkedin.com/company-beta/10971136">www.linkedin.com/company-beta/10971136</a>
<b>Auditor</b>	Cronin and Company 1 Terenure Place Terenure Dublin 6W
<b>Bankers</b>	Allied Irish Bank 9 Terenure Road East Rathgar Dublin 6  Permanent TSB Main Street Dundrum Dublin 14



**DIRECTORS AND OTHER INFORMATION**

<b>Registered Charity Number</b>	CHY 15517
<b>Charities Regulatory Number</b>	20053796



## **DIRECTORS REPORT**

The directors present their annual report and the audited financial statements of the company for the financial year ended 31st December 2016.

### **Companies Act 2014**

On the 30th November 2016, the company converted under the Companies Act 2014 to a Company Limited By Guarantee (CGL) (limited by guarantee not having a share capital).

### **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 (resigned 27<sup>th</sup> September 2016)

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. We are a non-profit organisation dedicated to supporting those with cystinosis, whilst investing in medical research with the aim of finding new treatments and ultimately one day finding a cure for cystinosis. 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 in order to 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 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 8.



## **DIRECTOR'S REPORT (CONTINUED)**

### **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.

### **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 the 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. All staff costs associated with our new employee is being separately funded by a private donor, who also provides office and related facilities. Otherwise, we do not have any overheads such as 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](mailto: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.

*Patrick Hoey*  
\_\_\_\_\_  
Patrick G Hoey

Director

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*Anne Marie O'Dowd*  
\_\_\_\_\_  
Anne Marie O'Dowd

Director

*Research - Awareness - Support*



## **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 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.



## **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 31<sup>st</sup> December 2016 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 5, the directors are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view and otherwise comply with the Companies Act 2014. Our responsibility is to audit and express an opinion on the financial statements in accordance with Irish law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's 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 31<sup>st</sup> December
- 2016 and of its gain 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  
(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.

*Cronin and Company*

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

31<sup>st</sup> May 2017



**INCOME AND EXPENDITURE ACCOUNT**  
**FINANCIAL YEAR ENDED 31<sup>ST</sup> DECEMBER 2016**

	Note	2016	2015
		€	€
<b>Income</b>	<b>4</b>	218,509	184,007
Medical Research Projects		(134,297)	(134,482)
Administrative Expenses		(17,803)	(22,029)
<b>Operating Surplus</b>		<u>66,409</u>	<u>27,496</u>
<b>Surplus on ordinary activities before taxation</b>		<u>66,409</u>	<u>27,496</u>
Tax on surplus on ordinary activities	<b>6</b>	-	-
<b>Surplus for the financial year</b>		<u><u>66,409</u></u>	<u><u>27,496</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 11 to 13 form part of these Financial Statements



**BALANCE SHEET**  
**AS AT 31<sup>ST</sup> DECEMBER 2016**

		2016		2015	
	Note	€	€	€	€
<b>Current Assets</b>					
Debtors	7	-		15	
Cash at Bank		430,859		383,477	
		<u>430,859</u>		<u>383,492</u>	
<b>Creditors: Amounts falling due within one year</b>	8	<u>(20,958)</u>		<u>(40,000)</u>	
<b>Net Current Assets</b>			409,901		343,492
<b>Total Assets less Current Liabilities</b>			<u>409,901</u>		<u>343,492</u>
<b>Net Assets</b>			<u>409,901</u>		<u>343,492</u>
<b>Capital and Reserves</b>					
Income and Expenditure Account			409,901		343,492
<b>Members Funds</b>			<u>409,901</u>		<u>343,492</u>

These financial statements were approved by the board of directors on 31<sup>st</sup> May 2017 and signed on behalf of the board by:

Patrick Hoey  
Patrick G Hoey  
Director

Anne Marie O'Dowd  
Anne Marie O'Dowd  
Director

The Notes on pages 11 to 13 form part of these Financial Statements



**STATEMENT OF CASHFLOWS**  
**FINANCIAL YEAR ENDED 31<sup>ST</sup> DECEMBER 2016**

	2016	2015
	€	€
<b>Cash flows from Operating Activities</b>		
Surplus for the financial year	66,409	27,496
<i>Adjustments for:</i>		
Accrued expenses/(income)	78	-
<i>Changes in:</i>		
Trade and other debtors	15	421
Trade and other creditors	880	-
Cash generated from operations	<u>67,382</u>	<u>27,917</u>
Net cash from operating activities	<u>67,382</u>	<u>27,917</u>
<b>Cash flows from Financing Activities</b>		
Income received in advance	(20,000)	(20,000)
Net cash used in financing activities	<u>(20,000)</u>	<u>(20,000)</u>
<b>Net increase/ (decrease) in cash and cash equivalents</b>	47,382	7,917
<b>Cash and cash equivalents at beginning of financial year</b>	383,477	375,560
<b>Cash and cash equivalents at end of financial year</b>	<u>430,859</u>	<u>383,477</u>



**NOTES TO THE FINANCIAL STATEMENTS**  
**FINANCIAL YEAR ENDED 31<sup>ST</sup> DECEMBER 2016**

**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 company.

**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.

**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.

*Financial Assets*

Basic financial assets, including trade and other receivables, cash and bank balances are initially recognised 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.

*Financial Liabilities*

Basic financial liabilities, including trade and other payables, bank loans, overdrafts and amount owed to related parties are initially recognised 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.

**3. Limited by Guarantee**

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

**4. Income**

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. In 2016 this amounted to €102,936 (2015: €69,774).



**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FINANCIAL YEAR ENDED 31ST DECEMBER 2016**

**5. Staff Costs**

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. All staff costs associated with our new employee is being separately funded by a private donor, who also provides office and related facilities. Otherwise, we do not have any overheads such as 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.

**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.

**7. Debtors**

	2016 €	2015 €
Prepayments	-	15
	<hr/>	<hr/>

**8. Creditors: Amounts falling due within one year**

	2016 €	2015 €
Donations Received	20,000	40,000
Tax and Social Insurance: PAYE and Social Insurance	880	-
Accruals	78	-
	<hr/>	<hr/>
	20,958	40,000

**9. Financial Instruments**

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

	2016 €	2015 €
Financial Assets that are debt instruments measured at amortized cost		
Cash at Bank	383,477	375,560
	<hr/>	<hr/>

**10. Events after the end of the reporting period**

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



**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FINANCIAL YEAR ENDED 31ST DECEMBER 2016**

**11. Approval of Financial Statements**

The board of directors approved these financial statements for issue on 31<sup>st</sup> May 2017.



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





**DETAILED INCOME AND EXPENDITURE ACCOUNT**  
**FINANCIAL YEAR ENDED 31<sup>st</sup> DECEMBER 2016**

	2016 €	2015 €
<b>Income</b>		
Health Research Board - Joint Funding Receipt	<u>102,936</u>	<u>69,774</u>
Hell and Back	60	-
General donations and one-off events	5,334	8,121
Deposit Interest Received	1,376	940
Tennis fundraiser	720	-
Zumbathon	916	-
Corporate Donors and Friends	20,000	20,000
Swim for a Mile	-	810
The Cube Fundraising Night	560	9,117
Donations from new families	5,526	7,476
Golf Classic Days (Grange / Ashbourne / Kilcock)	60,601	45,535
Donations from Families	8,000	7,705
Ring of Kerry Cycle Race	1,000	3,150
Individual Donation	-	2,500
London Day and Group	2,913	2,096
Quiz fundraiser	1,180	-
Wellie Race	-	410
TV3 Fundraising	123	1,215
Omagh Half Marathon	-	695
Dublin Marathon	-	1,452
Christmas donations	890	650
Dublin Mini Marathon	4,609	2,361
Church Gate collection – Leixlip	1,765	-
	<u>218,509</u>	<u>184,007</u>



**DETAILED INCOME AND EXPENDITURE ACCOUNT (CONTINUED)**  
**FINANCIAL YEAR ENDED 31<sup>ST</sup> DECEMBER 2016**

	2016 €	2015 €
<b>Overheads</b>		
<b>Medical Research Projects</b>		
The University of Auckland Project	93,052	93,902
The University of Florida Project	36,245	35,834
The University College Dublin Project	5,000	4,746
	<u>134,297</u>	<u>134,482</u>
<b>Administrative Expenses</b>		
Research and Family Workshop Expenses	-	716
Salzburg Cystinosis Conference	-	1,478
Golf Classic Day Fees	11,070	6,228
Conference Sponsorship - Chicago	-	1,440
Dublin family & research conference	1,597	-
Cystinosis Family Support	3,000	615
The Cube	-	6,500
Assistive Technology Expense	-	3,298
Survey Monkey	350	350
Insurance - RSA	-	79
Bank Charges	140	158
Merchant Service / Realex Fees	933	792
General expenses	338	-
Subscriptions	375	375
	<u>17,803</u>	<u>22,029</u>