

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 2020

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

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CYSTINOSIS IRELAND
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DIRECTORS AND OTHER INFORMATION

Directors	Susan Maguire Michael Swift Niamh O'Brien Anne Marie O'Dowd (Appointed 15th July 2020) James Ennis (Appointed 26th November 2020) Liam McFadden (Appointed 26th November 2020) Rachael Power (Appointed 26th November 2020) Andrew Maguire (Appointed 26th November 2020) Thomas McDonald (Appointed 26th November 2020)
Secretary	Susan Maguire (Resigned 24th June 2021) Denise Dunne (Appointed 24th June 2021)
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: www.twitter.com/cystinosisIrl LinkedIn: www.linkedin.com/company/cystinosis-ireland
Auditor	Cronin and Company 1 Terenure Place Terenure Dublin 6W

CYSTINOSIS IRELAND
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DIRECTORS AND OTHER INFORMATION (CONTINUED)

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

Registered Charity Number CHY 15517

Charities Regulatory Authority Number 20053796

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

DIRECTORS REPORT
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

The directors present their annual report and the audited Financial Statements of the company for the financial year ended 31st December 2020.

Directors

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

Susan Maguire
Michael Swift
Niamh O'Brien
Anne Marie O'Dowd
James Ennis
Liam McFadden
Rachael Power
Andrew Maguire
Thomas McDonald

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

During the course of the year, the Company undertook a strategic review of all its operations, activities and structures, including a compliance review to ensure that Cystinosis Ireland was adhering to all applicable rules and regulations. As a result of this work, a key recommendation was that all existing members of the Executive committee, that were not already Directors be appointed as Directors of the Company, as outlined on page 1.

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 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. 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. We are also mindful of the reputational risk to the charity and partners through any wrong doing and therefore strive to manage the charity's affairs to the highest standards through adhering to all applicable regulations.

CYSTINOSIS IRELAND
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DIRECTORS REPORT (CONTINUED)
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

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.

As at the time of approving these financial statements, the company continues to be exposed to the effects of the Covid-19 pandemic, where the impact continues to significantly limit fundraising opportunities. Certain fundraising events for 2021 have already been cancelled, whilst others have been postponed and tentatively planned for later in the year. The directors continue to monitor events and plan as conditions allow.

Results

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

Events after the end of the reporting period

Throughout the first half of 2021, the Covid-19 pandemic has continued to have a profound and disruptive impact worldwide. In common with many countries, the Irish government has continued to issue guidance and restrictions as varying waves of Covid-19 have emerged.

Whilst the outbreak continues through new variants, optimism continues to grow that a successful vaccination rollout will allow for the reopening of economies and a gradual return to normal. However, uncertainty does exist around the timing of a full return to normal life.

Throughout this time, fundraising and fundraising opportunities have been significantly impacted. Given Cystinosis Ireland's strong financial position, research opportunities continue to be sought and funded. Currently the directors do not see any need to make changes to any ongoing operations; they don't foresee any change in their approach to funding research, supporting families and communities or in how to raise awareness of the Cystinosis community.

There have been no other significant events affecting the company 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 retention 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.

Auditors

In accordance with Section 383(2) of the Companies Act 2014, the auditors, Cronin and Company, Certified Public Accountants and Statutory Audit Firm, 1 Terenure Place, Terenure, Dublin 6W will continue in office.

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

DIRECTORS REPORT (CONTINUED)
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

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.

Since 2018, two members of staff have worked with Cystinosis Ireland, both continuing to work on a part time basis. The areas of work carried out centre on the overall management of all operational matters relating to the charity and secondly all matters specific to Cystinosis research, including all aspects of research sourcing, project support and administration.

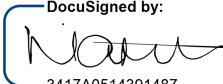
Whilst all staff related costs are paid by the charity and reflected in these financial statements, separate funding continues to be provided by a private donor, ensuring that there is no cost or financial impact on the charity. Otherwise, we do not have any overheads such as fundraising commissions, 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.

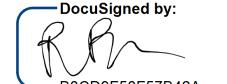
Over the years, we have been very successful in securing joint funding for research projects through the Health Research Charities Ireland (HRCI) (formerly the Medical Research Charities Group) Health Research Board / HRCI Joint Funding Scheme. Projects are selected for proposal to the HRB/HRCI Joint Funding Scheme following extensive independent peer review overseen by Cystinosis Ireland's Research Group and approved by Cystinosis Ireland Board. Other projects (outside of the HRB / HRCI scheme) are independently reviewed and processed through the Research Group and the Board.

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

Throughout 2019, Cystinosis Ireland was working to organise and host the 2020 International Cystinosis Conference, which was due to be held in July 2020. However, such was the impact of Covid-19 that the event had to be altered and re-modelled into a one-day virtual conference, which was held on 25th April 2020. This was a first for the global cystinosis community and included an all on-line presentation of 15 different talks, translated to 8 languages, with 950 registered attendees from 49 different countries.

Cystinosis Ireland, as a founder member of the Cystinosis Network Europe (CNE) continues to provide operational support and acts as the Secretariat to the Company. More details on their work can be seen at <https://cystinosis-europe.eu/>

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Director
Niamh O'Brien
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Director
Rachael Reilly
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CYSTINOSIS IRELAND
(A Company Limited by Guarantee and not having a Share Capital)

DIRECTORS RESPONSIBILITIES STATEMENT
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

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.

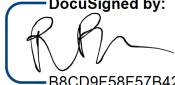
In preparing these Financial Statements, the directors are required to:

- 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.

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Niamh O'Brien
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Director DocuSigned by:

Rachael Reilly
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INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF CYSTINOSIS IRELAND (CONTINUED)

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 2020 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 2020 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.

We have nothing to report in this regard.

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

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.

**INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
CYSTINOSIS IRELAND (CONTINUED)**

Donal Cronin

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

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

INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

	2020 €	2019 €
Income	111,105	207,630
Expenditure		
Medical Research Projects	(14,706)	(84,505)
Administrative Expenses	(110,371)	(100,542)
	(125,077)	(185,047)
(Loss)/Surplus for the financial year	(13,972)	22,583

The notes on pages 12 to 14 form part of these Financial Statements.

CYSTINOSIS IRELAND
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BALANCE SHEET
AS AT 31ST DECEMBER 2020

	Note	2020 €	2019 €
Current Assets			
Debtors	6	1,726	2,202
Cash at Bank		341,460	352,363
		343,186	354,565
Creditors: Amounts falling due within one year	7	(5,755)	(3,162)
Net Current Assets		337,431	351,403
Total Assets less Current Liabilities		337,431	351,403
Net Assets		337,431	351,403
Reserves			
Income and Expenditure Account		337,431	351,403
Members Funds		337,431	351,403

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 on25 September 2021..... and signed on behalf of the board by:

Director DocuSigned by:

Niamh O'Brien
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Director DocuSigned by:

Rachael Reilly
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CYSTINOSIS IRELAND
(A Company Limited by Guarantee and not having a Share Capital)

NOTES TO THE FINANCIAL STATEMENTS
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

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

Like many companies, Cystinosis Ireland continues to be exposed to the effects of the Covid-19 pandemic. The company continues to operate as normal, though fundraising activity and opportunities have been limited. The Directors have prepared budgets and cash flows for a period of at least twelve months from the date of approval of the financial statements which demonstrate that there is no material uncertainty regarding the company's ability to meet its liabilities as they fall due, and to continue as a going concern.

On this basis, the Directors consider it appropriate to prepare the financial statements on a going concern basis. Accordingly, these financial statements do not include any adjustments to the carrying amounts and classification of assets and liabilities that may arise if the company was unable to continue as a going concern.

The financial statements have been prepared on a going concern basis.

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.

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

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

Defined contribution plans

Contributions to defined contribution plans are recognised as an expense in the period in which the related service is provided. Prepaid contributions are recognised as an asset to the extent that the prepayment will lead to a reduction in future payments or a cash refund.

When contributions are not expected to be settled wholly within 12 months of the end of the reporting date in which the employees render the related service, the liability is measured on a discounted present value basis. The unwinding of the discount is recognised in finance costs in profit or loss in the period in which it arises.

4. Limited by Guarantee

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

5. Staff Costs

The average number of persons employed by the company during the financial year, including the directors was 2 (2019: 2).

The aggregate payroll costs incurred during the financial year were:

	2020	2019
	€	€
Wages and Salaries	62,333	55,444
Social Insurance Costs	6,888	6,071
Retirement Benefits	344	-
	69,565	61,515

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

	2020	2019
	€	€
Other Debtors	-	476
Prepayments	1,726	1,726
	1,726	2,202

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

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

7. Creditors: Amounts falling due within one year

	2020	2019
	€	€
Tax and Social Insurance:		
PAYE and Social Welfare	5,288	2,048
Accruals	467	1,114
	5,755	3,162

8. Events after the end of the reporting period

Throughout the first half of 2021, the Covid-19 pandemic has continued to have a profound and disruptive impact worldwide. In common with many countries, the Irish government has continued to issue guidance and restrictions as varying waves of Covid-19 have emerged.

Whilst the outbreak continues through new variants, optimism continues to grow that a successful vaccination rollout will allow for the reopening of economies and a gradual return to normal. However, uncertainty does exist around the timing of a full return to normal life.

Throughout this time, fundraising and fundraising opportunities have been significantly impacted. Given Cystinosis Ireland's strong financial position, research opportunities continue to be sought and funded. Currently the directors do not see any need to make changes to any ongoing operations; they don't foresee any change in their approach to funding research, supporting families and communities or in how to raise awareness of the Cystinosis community.

There have been no other 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 .

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

CYSTINOSIS IRELAND
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DETAILED INCOME AND EXPENDITURE ACCOUNT
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

	2020 €	2019 €
Income		
Private Donor to fund staff costs	<u>40,000</u>	<u>65,000</u>
BBQ4Cystinosis	-	494
Louise's Fundraisers	-	280
Gary & Rob's CyclingForACure	-	12,240
100K Thames Path Challenge	-	1,997
Deposit Interest Received	324	11
Church Gate Collection - Leixlip	-	1,191
Leixlip Tennis Fundraiser	900	700
Cricket for Cystinosis Fundraiser	920	1,154
Belfast Skinworks Fundraiser	-	1,085
Corporate Donors and Friends	9,148	27,000
Conference Fundraising Activities	20,000	25,000
Golf Classic Days (Grange/Ashbourne/Kilcock)	12,735	51,663
Donations from Families	5,786	5,546
London Group	-	1,154
Christmas Donations	3,154	1,711
Monthly Donations	1,202	1,502
Dublin Mini Marathon	-	135
General Donations and Other Fundraising Events	<u>16,936</u>	<u>9,767</u>
	<u>71,105</u>	<u>142,630</u>
Total Income	<u><u>111,105</u></u>	<u><u>207,630</u></u>

CYSTINOSIS IRELAND
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DETAILED INCOME AND EXPENDITURE ACCOUNT (CONTINUED)
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

	2020 €	2019 €
Expenditure		
Medical Research Projects		
The University of California	-	25,213
Dublin Cystinosis Workshop	350	29,354
Seed Corn Funded Projects	14,356	29,938
	<hr/> 14,706	<hr/> 84,505
	<hr/> <hr/>	<hr/> <hr/>
Overheads		
Administrative Expenses	110,371	100,542
	<hr/> 110,371	<hr/> 100,542

CYSTINOSIS IRELAND
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DETAILED INCOME AND EXPENDITURE ACCOUNT (CONTINUED)
FINANCIAL YEAR ENDED 31ST DECEMBER 2020

	2020 €	2019 €
Overheads		
Administrative Expenses		
Wages and Salaries	62,333	55,444
Social Welfare Costs	6,888	6,071
Staff Pension Costs	344	-
Golf Classic Day Fees	6,630	8,559
Website and IT Development	412	1,408
Strategy Analysis and Development	16,520	-
Consultancy Fees	6,667	15,000
Bank Charges/Merchant Service Fees	563	648
Realex Fees	7	221
General Expenses	8,734	12,143
Subscriptions	1,273	1,048
	110,371	100,542