

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 2019



<u>CYSTINOSIS IRELAND</u> (A Company Limited by Guarantee and not having a Share Capital)

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DIRECTORS AND OTHER INFORMATION

Directors Susan Maguire

Michael Swift

Niamh O'Brien (Appointed 24th May 2019) Anne Marie O'Dowd (Resigned 24th May 2019)

Secretary Susan 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: www.twitter.com/cystinosisIrl

LinkedIn: www.linkedin.com/company/cystinosis-ireland

Auditor Cronin and Company

1 Terenure Place

Terenure Dublin 6W

Bankers

Allied Irish Bank PermanentTSB KBC Bank Ireland
9 Terenure Road East Main Street Sandwith Street
Rathgar Dundrum Dublin 2

Rathgar Dundrum Dublin 6 Dublin 14

Registered Charity Number CHY 15517

Charities Regulatory Authority Number 20053796



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

DIRECTORS REPORT

The directors present their annual report and the audited Financial Statements of the company for the financial year ended 31st December 2019.

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

Susan 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 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.

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.

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 2020 have already been cancelled, whilst others have been postponed and tentatively



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DIRECTORS REPORT (CONTINUED)

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 2020, the Covid-19 virus has continued to spread worldwide. In common with many other countries, the Irish government has issued guidance and restrictions on the movement of people, designed to slow the spread of this virus. In early March 2020, many businesses closed voluntarily, followed by the imposition of more restrictions on people and businesses. On 28 March 2020, all "non-essential" businesses were ordered to close temporarily.

The recent and rapid development of the Covid-19 outbreak has required many companies to limit and even suspend business operations. The measures and policies introduced have significantly disrupted the activities of many entities. As the outbreak continues to progress and evolve, it is challenging at this juncture to predict the full extent and duration of its business and economic impact. The charity together with its directors are continuously monitoring the developments of Covid-19 and taking action as needed.

Whilst 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 any 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.



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DIRECTORS REPORT (CONTINUED)

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.

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 Executive Board. Other projects (outside of the HRB / HRCI scheme) are independently reviewed and processed through the Research Group and the Executive Board.

A detailed listing of all funds raised and used is presented in our Audited Financial Statements 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



<u>CYSTINOSIS IRELAND</u> (A Company Limited by Guarantee and not having a Share Capital)

DIRECTORS REPORT (CONTINUED)

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) provides operational support and acts as the Secretariat for this new group. Cystinosis Ireland would like to take this opportunity to once again sincerely thank all of our supporters and encourage you to continue to assist us in achieving our goals. As an organisation, we are committed to maintaining the highest ethical and transparency standards.

Sue Maguire
Sue Maguire
Director

Michael Swift
Michael Swift
Director

21st September 2020



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<u>DIRECTORS RESPONSIBILITIES STATEMENT</u> FINANCIAL YEAR ENDED 31ST DECEMBER 2019

The directors are responsible for preparing the directors report and the Financial Statements in accordance with applicable Irish law and regulations.

Irish company law requires the directors to prepare Financial Statements for each financial year. Under the law, the directors have elected to prepare the Financial Statements in accordance with Irish law and FRS 102, the Financial Reporting Standard applicable in the UK and Republic of Ireland issued by the Financial Reporting Council. Under company law, the directors must not approve the Financial Statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the company as at the financial year end date and of the profit or loss of the company for the financial year and otherwise comply with the Companies Act 2014.

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

- · select suitable accounting policies and then apply them consistently;
- · make judgments and accounting estimates that are reasonable and prudent;
- state whether the Financial Statements have been prepared in accordance with applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the Financial Statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets, liabilities, financial position and profit or loss of the company to be determined with reasonable accuracy, enable them to ensure that the Financial Statements and directors report comply with the Companies Act 2014 and enable the Financial Statements to be audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Sue Maguire
Sue Maguire

Director

21st September 2020

Michael Swift
Michael Swift
Director



INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF CYSTINOSIS IRELAND

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 2019 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 2019 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.



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

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.

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.



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

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.

Donal Cronin

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

21st September 2020



<u>CYSTINOSIS IRELAND</u> (A Company Limited by Guarantee and not having a Share Capital)

INCOME AND EXPENDITURE ACCOUNT FINANCIAL YEAR ENDED 31ST DECEMBER 2019

	2019 €	2018 €
Income	207,630	183,926
Expenditure Medical Research Projects	(84,505)	(95,857)
Administrative Expenses	$\frac{(100,542)}{(185,047)}$	(74,103) (169,960)
		·
Surplus for the financial year	22,583	13,966

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

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

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



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BALANCE SHEET AS AT 31ST DECEMBER 2019

	Note	€	2019 €	€	2018 €
Current Assets Debtors Cash at Bank	6	2,202 352,363 354,565		7,105 336,459 343,564	
Creditors: Amounts falling due within one year	7	(3,162)		(14,744)	
Net Current Assets			351,403		328,820
Total Assets less Current Liabilities			351,403		328,820
Net Assets			351,403		328,820
Reserves					
Income and Expenditure Account			351,403		328,820
Members Funds			351,403		328,820

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'.

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

These Financial Statements were approved by the board of directors on 21st September 2020 and signed on behalf of the board by:

Sue Maguire
Sue Maguire
Director

Michael Swift
Michael Swift
Director

21st September 2020



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

NOTES TO THE FINANCIAL STATEMENTS FINANCIAL YEAR ENDED 31ST DECEMBER 2019

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

During the first quarter of 2020, The Covid-19 pandemic has worldwide. The initial economic effect of this has been a worldwide slowdown in economic activity and the loss of jobs across many businesses. In Ireland there are restrictions placed on "non-essential" businesses which has resulted in many businesses temporarily closing in measures designed to restrict the movement of people and to slow down the spread of the virus.

Like many companies, Cystinosis Ireland is exposed to the effects of the Covid-19 pandemic. The company continues to operate during this period, where possible. 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.



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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FINANCIAL YEAR ENDED 31ST DECEMBER 2019

3. Accounting Policies and Measurement Bases (continued)

Income and Expenditure

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

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

Taxation

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

4. <u>Limited by Guarantee</u>

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 (2018: 2).

The aggregate payroll costs incurred during the financial year were:

	2019	2018
	€	€
Wages and Salaries	55,444	45,489
Social Insurance Costs	6,071	4,935
	61,515	50,424

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

	2019	2010
	€	€
Other Debtors	476	-
Prepayments	1,726	7,105
	2,202	7,105



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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FINANCIAL YEAR ENDED 31ST DECEMBER 2019

6. <u>Debtors (continued)</u>

As mentioned in the Director's report, Cystinosis Ireland is providing the Secretariat for the new Cystinosis Network Europe (CNE) group. As part of this role, Cystinosis Ireland has held in escrow the monies of CNE and made payments on their behalf. At 31st December 2019, a sum of €476 was due to Cystinosis Ireland.

In July 2020 and with the formalization of CNE's standing, a final balancing payment will be made between the parties.

7. Creditors: Amounts falling due within one year

	2019	2018
	€	€
Other Creditors	-	10,000
Tax and Social Insurance:		
PAYE and Social Welfare	2,048	4,559
Accruals	1,114	185
	3,162	14,744

8. Events after the end of the reporting period

Throughout the first half of 2020, the Covid-19 virus has continued to spread worldwide. In common with many other countries, the Irish government has issued guidance and restrictions on the movement of people, designed to slow the spread of this virus. In early March 2020, many businesses closed voluntarily, followed by the imposition of more restrictions on people and businesses. On 28th March 2020, all "non-essential" businesses were ordered to close temporarily.

The recent and rapid development of the Covid-19 outbreak has required many companies to limit and even suspend business operations. The measures and policies introduced have significantly disrupted the activities of many entities. As the outbreak continues to progress and evolve, it is challenging at this juncture to predict the full extent and duration of its business and economic impact. The charity together with its directors are continuously monitoring the developments of Covid-19 and taking action as needed.

Whilst 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 any 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.



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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FINANCIAL YEAR ENDED 31ST DECEMBER 2019

9. Approval of Financial Statements

The board of directors approved these Financial Statements for issue on 21st September 2020.



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



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DETAILED INCOME AND EXPENDITURE ACCOUNT (CONTINUED) FINANCIAL YEAR ENDED 31ST DECEMBER 2019

	2019	2018
	€	€
Income		
Private Donor to fund staff costs	90,000	70,000
BBQ4Cystinosis	494	650
Louise's Fundraisers	280	2,265
Gary & Rob's CyclingForACure	12,240	-
HRB Support Dublin Cystinosis Workshop	-	9,000
100K Thames Path Challenge	1,997	-
Deposit Interest Received	11	246
Church Gate Collection - Leixlip	1,191	1,735
Leixlip Tennis Fundraiser	700	-
Naas Tennis Fundraiser	-	4,000
Cricket for Cystinosis Fundraiser	1,154	-
Belfast Skinworks Fundraiser	1,085	-
Corporate Donors and Friends	27,000	20,000
Golf Classic Days (Grange/Ashbourne/Kilcock)	51,663	48,899
Donations from Families	5,546	7,528
London Group	1,154	230
Wicklow Mountains Half Marathon	-	1,315
Christmas Donations	1,711	2,411
"A to B for C"	-	6,600
Monthly Donations	1,502	1,452
Dublin Mini Marathon	135	1,348
General Donations and Other Fundraising Events	9,767	6,247
	117,630	113,926
Total Income	207,630	183,926



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DETAILED INCOME AND EXPENDITURE ACCOUNT (CONTINUED) FINANCIAL YEAR ENDED 31ST DECEMBER 2019

	2019 €	2018 €
Expenditure		
Medical Research Projects		
The University of Leuven	-	24,936
The University of California	25,213	25,662
Dublin Cystinosis Workshop	29,354	16,659
2018 European Cystinosis Conference	-	10,000
Seed Corn Funded Projects	29,938	18,600
	84,505	95,857
Overheads		
Administrative Expenses	100,542	74,103
	100,542	74,103



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<u>DETAILED INCOME AND EXPENDITURE ACCOUNT (CONTINUED)</u> <u>FINANCIAL YEAR ENDED 31ST DECEMBER 2019</u>

	2019	2018
	€	€
Overheads		
Administrative Expenses		
Wages and Salaries	55,444	45,489
Social Welfare Costs	6,071	4,935
Golf Classic Day Fees	8,559	8,195
Website and IT Development	1,408	1,570
Consultancy Fees	15,000	-
Bank Charges/Merchant Service Fees	648	645
Realex Fees	221	221
General Expenses	12,143	12,375
Subscriptions	1,048	673
	100,542	74,103