

Company registration number: 670605

**Cystinosis Support Network Europe
(A Company Limited by Guarantee and not having Share Capital)**

Financial statements

for the financial period ended 30 April 2022

Cystinosis Support Network Europe
(A Company Limited by Guarantee and not having Share Capital)

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**Cystinosis Support Network Europe
Company limited by guarantee**

Directors and other information

Directors	Anne Marie O'Dowd Claudia Sproedt Marjolein Bos Niamh O'Brien Eibhlis Shanahan
Secretary	Denise Dunne
Company number	670605
Registered office	1-2 Cavendish Row Dublin 1 D01 K883
Business address	1-2 Cavendish Row Dublin 1 D01 K883
Auditor	McCloskey & Co Apex Business Centre Blackthorn Road Sandyford Dublin 18
Bankers	AIB Blackrock Co Dublin
Registered Charity Number	20206325
CHY (Revenue) number	CHY 2296

Cystinosis Support Network Europe
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Directors report

The directors present their annual report and the audited financial statements of the company for the financial year ended 30 April 2022.

Directors

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

Anne Marie O'Dowd
Claudia Sproedt
Marjolein Bos
Niamh O'Brien

Principal activities

The Company is dedicated to supporting people with cystinosis, by bringing together the international network of national patient organisations across Europe, US, Australia, South Africa, Mexico, Turkey and Russia. Cystinosis Support Network Europe (CNE) has two primary objectives: hosting the CNE International Cystinosis Conference every two years and working with researchers at all stages of the development of their research processes through the Community Advisory Board (CAB). The aim of the CAB is to promote research relevant to the patient community and to support research that will deliver real therapeutic impact for people living with this condition.

Cystinosis is a rare, genetic disease, which is mostly diagnosed early in childhood, usually before the age of two. It is autosomal recessive, which means that it is inherited when a child receives two copies of an abnormal gene, one copy from each parent. Because the parents each have only one abnormal gene, they are not affected. It is estimated that cystinosis occurs in somewhere between 1 in 100,000 to 1 in 200,000 live births. There are 10 to 15 new cases of cystinosis diagnosed each year in Europe.

Cystinosis causes an increase of an amino acid called cystine in all of the cells of the body. This build up causes cystine crystals to form. These crystals form firstly in the kidneys and the eyes and later complications can occur in muscles, pancreas, thyroid gland and in other parts of the body. There is a specific treatment for Cystinosis, but there is no cure. Children with cystinosis are experiencing much better outcomes and many young adults are living happy and active lives but patient organisations are working towards a time when better treatments and possibly a cure are available.

Cystinosis Support Network Europe exists to support people with the condition and their families and to improve the ways in which national organisations work together to achieve these aims. We do this by networking with national organisations around the world to build capacity, share learning and provide peer support through the International Cystinosis Conference every two years; and to improve the research being done at all levels through the engagement of the Community Advisory Board. As an organisation, we are committed to maintaining the highest ethical and transparency standards.

Cystinosis Support Network Europe does not have any paid staff and all board members and national representatives are volunteers. It is hosted by the generosity of Cystinosis Ireland which provides in kind support through the work of their Operations Manager and registered address.

Cystinosis Support Network Europe would like to sincerely thank Cystinosis Ireland for the ongoing support it provides both in time and expertise shared.

**Cystinosis Support Network Europe
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Directors report (continued)

Development and performance

In 2021 the world continued to move in and out of restrictions and lock downs. Communities such as those living with cystinosis were particularly conscious of the possible implications of the pandemic, so CNE work continued online rather than in person. Throughout the year, the Community Advisory Board (CAB) met monthly. In 2021, following two years of mentorship from the EuroCAB team in EURORDIS (the European Rare Disorders Organisation), the Worldwide Cystinosis CAB took the decision to operate autonomously. This means that while we have the option to seek support from EURORDIS in the future, the CAB project is fully driven by CNE.

The CAB continued to meet monthly to undertake training and educational opportunities; discuss relevant areas in research developments; and meet with two key pharmaceutical companies who are working in the area of cystinosis treatment. The meeting between the CAB and AVROBIO took place in April and the meeting with Chiesi Farmaceutici S.p.A. took place in May but required significant preparations in reviewing documents and discussions among the group in advance. These meetings were of direct relevance to our worldwide community and were followed up through the year to determine where our representations can have real impact.

The membership of the CNE continued to grow in 2021 with more organisations from outside Europe becoming Associate members. Our membership at the end of the year includes as full members:

- Ireland (Chair, board members & secretariat)
- Germany (Board member)
- Netherlands & Belgium (Board member)
- France
- Italy
- Spain
- UK

And as Associate members:

- USA
- Australia
- South Africa
- Turkey
- Russia
- Mexico

The substantial work of CNE in 2021 was to establish the organisation as a registered charity in Ireland, where the organisation is registered as a company. This work involved ensuring our governance and planning were well developed and that the work of the organisation will meet the stringent requirements of charitable status in Ireland.

Funding for CNE has come in 2021 from three pharmaceutical companies through unrestricted grants and grants for participation in the CAB meetings. The companies who provided funding to CNE in 2021 were AVROBIO, Chiesi Farmaceutici S.p.A. and Recordati Rare Diseases. CNE is open to engaging with healthcare companies working in the field of cystinosis to represent the needs and priorities of the community to improve quality of life and ultimately secure better treatments and therapies for this condition.

**Cystinosis Support Network Europe
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Directors report (continued)

Principal risks and uncertainties

The Directors have identified that the key risks and uncertainties the company faces relate to the risk of reduced funding in the future and of the potential increase in compliance requirements in accordance with company, health and safety, taxation and other legislation;

The company mitigates these risks as follows: i) The company continually monitors the level of activity, prepares and monitors its budgets targets and projections. ii) The company closely monitors emerging changes to regulations and legislation on an ongoing basis.

Internal control risks are minimised by the implementation of procedures for authorisation of all transactions and projects.

Likely future developments

The company plans continuing the activities outlined above in the forthcoming years subject to satisfactory funding arrangements.

Accounting records

The measures taken by the directors to secure compliance with the requirements of sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records are the implementation of necessary policies and procedures for recording transactions, the employment of competent accounting personnel with appropriate expertise and the provision of adequate resources to the financial function. The accounting records of the company are located at the registered office.

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

The auditors, McCloskey & Co, were appointed as auditors to the charity in October 2022. In accordance with Section 383 (2) of the Companies Act 2014, McCloskey & Co. have indicated their willingness to continue in office.

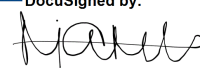
25 November 2022

This report was approved by the board of directors on and signed on behalf of the board by:

DocuSigned by:

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Anne Marie O'Dowd

Director

DocuSigned by:

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Niamh O'Brien

Director

**Cystinosis Support Network Europe
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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 period. 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. 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 period end date and of the profit or loss of the company for the financial period 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 Support Network Europe

Report on the audit of the financial statements

Opinion

We have audited the financial statements of Cystinosis Support Network Europe (the 'company') for the financial period ended 30 April 2022 which comprise the profit and loss account, statement of income and retained earnings, 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 30 April 2022 and of its profit for the financial period then ended;
- have been properly prepared in accordance with FRS 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 auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of the financial statements in Ireland, including the Ethical Standard issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

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

- the directors' 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 and, except to the extent otherwise explicitly stated in our report, 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 Support Network Europe (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 has no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Independent auditor's report to the members of Cystinosis Support Network Europe (continued)

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

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

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

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

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

**Independent auditor's report to the members of
Cystinosis Support Network Europe (continued)**

Thomas McCloskey (Senior Statutory Auditor)

For and on behalf of
McCloskey & Co
Chartered Accountants & Statutory Auditors
Apex Business Centre
Blackthorn Road
Sandyford
Dublin 18

Cystinosis Support Network Europe
(A Company Limited by Guarantee and not having Share Capital)

Income and expenditure account
Financial period ended 30 April 2022

	Note	Year ended 30/04/22 €	Period ended 30/04/20 €
Turnover		32,000	22,989
Gross surplus		<u>32,000</u>	<u>22,989</u>
Administrative expenses		(2,646)	-
Operating surplus		<u>29,354</u>	<u>22,989</u>
Surplus before taxation		<u>29,354</u>	<u>22,989</u>
Tax on surplus		-	-
Surplus for the financial period		<u><u>29,354</u></u>	<u><u>22,989</u></u>

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

The notes on pages 13 to 14 form part of these financial statements.

Cystinosis Support Network Europe
(A Company Limited by Guarantee and not having Share Capital)

Statement of income and retained earnings
Financial period ended 30 April 2022

	Year ended 30/04/22 €	Period ended 30/04/20 €
Surplus for the financial period	29,354	22,989
Retained earnings at the start of the financial period	<u>22,989</u>	<u>-</u>
Retained earnings at the end of the financial period	<u><u>52,343</u></u>	<u><u>22,989</u></u>

Cystinosis Support Network Europe
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Balance sheet
As at 30 April 2022

	Note	30/04/22 €	€	30/04/20 €	€
Current assets					
Cash at bank and in hand		53,593		22,989	
		<u>53,593</u>		<u>22,989</u>	
Creditors: amounts falling due within one year					
	6	(1,250)		-	
				<u>-</u>	
Net current assets		52,343		22,989	
Total assets less current liabilities		<u>52,343</u>		<u>22,989</u>	
Net assets		<u>52,343</u>		<u>22,989</u>	
Capital and reserves					
Income and expenditure account		52,343		22,989	
Members funds		<u>52,343</u>		<u>22,989</u>	

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime and in accordance with Section 1A of FRS 102 Financial Reporting Standard applicable in the UK and Republic of Ireland'.

25 November 2022

These financial statements were approved by the board of directors on and signed on behalf of the board by:

DocuSigned by:

 4A8C1DCD1FE44B0...
 Anne Marie O'Dowd
 Director

DocuSigned by:

 3417A0514391487...
 Niamh O'Brien
 Director

The notes on pages 13 to 14 form part of these financial statements.

Cystinosis Support Network Europe
(A Company Limited by Guarantee and not having Share Capital)

Notes to the financial statements
Financial period ended 30 April 2022

1. General information

The company is a private company limited by guarantee, registered in Ireland. The address of the registered office is 1-2 Cavendish Row, Dublin 1, D01 K883.

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 have been prepared on the going concern basis, under the historical cost convention, and comply with the financial reporting standards of the Financial Reporting Council and promulgated by Chartered Accountants Ireland and the Companies Act 2014.

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

Turnover

All incoming resources are included when the charity is entitled to the income and the amount can be quantified with reasonable accuracy.

4. Limited by guarantee

The liability of the members is limited. Every member of the company undertakes to contribute to the assets of the company in the event of its being wound up while they are members, or within one year thereafter, for the payment of the debts and liabilities of the company contracted before they ceased to be members, and of the costs, charges and expenses of winding up, and for the adjustment of the rights of the contributors among themselves, such amount as may be required, not exceeding €1.00 (One Euro).

5. Appropriations of income and expenditure account

	30/04/22	30/04/20
	€	€
At the start of the financial period	22,989	-
Surplus for the financial period	29,354	22,989
At the end of the financial period	<u>52,343</u>	<u>22,989</u>

6. Creditors: amounts falling due within one year

	30/04/22	30/04/20
	€	€
Accruals	<u>1,250</u>	<u>-</u>

Cystinosis Support Network Europe
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Notes to the financial statements (continued)
Financial period ended 30 April 2022

7. Approval of financial statements

The board of directors approved these financial statements for issue on 25 November 2022

Cystinosis Support Network Europe
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The following pages do not form part of the statutory accounts.

Cystinosis Support Network Europe
(A Company Limited by Guarantee and not having Share Capital)

Detailed income and expenditure account
Financial period ended 30 April 2022

	Year ended 30/04/22 €	Period ended 30/04/20 €
Turnover		
Donations	32,000	22,989
	<u>32,000</u>	<u>22,989</u>
Gross surplus	<u>32,000</u>	<u>22,989</u>
Gross surplus percentage	100.0%	100.0%
Overheads		
Administrative expenses		
Programme expenses	(1,251)	-
Auditors remuneration	(1,230)	-
Bank charges	(145)	-
General expenses	(20)	-
	<u>(2,646)</u>	<u>-</u>
Operating surplus	29,354	22,989
Operating surplus percentage	91.7%	100.0%
Surplus before taxation	<u>29,354</u>	<u>22,989</u>