

**Cystinosis Support Network Europe**  
**(A Company Limited by Guarantee and not having a Share Capital)**  
**Financial Statements**  
**For the Financial Year Ending 31 December 2020**

## Directors and Other Information

Directors: Anne Marie O’Dowd – Ireland (appointed 12 May 2020)  
Claudia Sproedt – Germany (appointed 12 May 2020)  
Marjolein Bos – Netherlands (appointed 12 May 2020)  
Niamh O’Brien – Ireland (appointed 26 June 2020)

Secretary: Denise Dunne – Ireland (appointed 12 May 2020)

Company Number: 670605

Registered Address: 1-2 Cavendish Row, Dublin 1

Email: [denise.dunne@cystinosis-europe.eu](mailto:denise.dunne@cystinosis-europe.eu)

Website: [www.cystinosis-europe.eu](http://www.cystinosis-europe.eu)

Bankers: AIB Bank  
Blackrock  
Co Dublin

## *Cystinosis Support Network Europe – Financial Statements 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:

Anne Marie O'Dowd

Niamh O'Brien

Claudia Sproedt

Marjolein Bos

Denise Dunne 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.

### Directors' Responsibilities Statement

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

Irish company law requires the directors to prepare Financial Statements for each financial year. Under 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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### Principal and Future Activities

Cystinosis Support Network Europe (trading as Cystinosis Network Europe – CNE) registered as a company in Dublin, Ireland in May 2020. It is in the process of applying for charitable status with the Charity Regulatory Authority (CRA) in Ireland. Unfortunately, due to significant delays in the processing of applications by the Regulator, this process is not yet complete. Following guidance from the CRA, we expect to be granted charitable status before the end of 2021.

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. CNE has two primary objectives: hosting the CNE International Cystinosis Conference every two years (next to be held in July 2022 in Leuven, Belgium) 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.

The directors are not expecting to make any significant changes in the nature of the company's principal activity in the near future.

### What is Cystinosis?

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.

### Principal Risks and Uncertainties

The principal risk and uncertainty facing the company is the delay in decision of the CRA in assessing the application for charitable status. While we are confident that the application will be successful, the risk must be acknowledged. Funding for CNE will be come from unrestricted grants from pharmaceutical and other healthcare related companies and not public fundraising.

As at the time of approving these financial statements, the company continues to be exposed to the effects of the Covid-19 pandemic. The global pandemic has had a severe impact worldwide, and a specific impact for people living with cystinosis, particularly those who are immunocompromised following organ transplant. The impact of Covid-19 cannot be fully quantified at the time of the directors approving these financial statements and the directors acknowledge this uncertainty.

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### Events after the end of the reporting period

The world continues to experience the global Covid-19 pandemic. While CNE will not be relying on public fundraising for income, the nature of the organisation relies on our community members working together and being able to communicate effectively across borders. The work of CNE is primarily virtual since the outbreak of the pandemic. While this in some ways limits us, it allows those without the means (either time or limited resources in their national organisation to support travel costs) to engage on a more regular basis. The organisation will continue to ensure the most access possible to events through both in person and online opportunities.

### Accounting Records

The directors have taken measures to ensure compliance with the requirements of sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records. The accounting records of the company are located at 1-2 Cavendish Row, Dublin 1.

### Relevant Audit Information

Cystinosis Support Network Europe is availing of the audit exemption as provided for in Chapter 15 of Part 6 of the Companies Act 2014.

## Transparency in Funding

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.

The initial funding for CNE has come through donations made by supporters, including CNE member organisations, which were initially intended to fund the 2020 CNE International Conference to be held in Dublin in July 2020, hosted by Cystinosis Ireland. As the pandemic broke across the world in March 2020, the decision was made by Cystinosis Ireland and CNE to move the event to a virtual, online conference on 25<sup>th</sup> April instead of a three day in-person event in July. It was a significant and ultimately very successful decision. In the space of six weeks, the organising committee transformed a planned in person event to an online day reaching more than 600 participants in 49 countries, across 20 time zones and in eight languages, achieving unexpected global connectedness. The value derived by attendees of the online conference has been an important lesson for us to remember those who, for many reasons, cannot travel to join events in person. The Virtual Conference marked the start of what we hope will be a more extensive online outreach to families everywhere.


Various funders had committed sponsorship to cover the costs of the in-person event. When this did not take place, Cystinosis Ireland and CNE worked with these donors to agree that the funds could be repurposed to provide seed funding for CNE to officially form as a company and seek charitable status in Ireland. While these negotiations were ongoing, Cystinosis Ireland held the funds in escrow, only transferring them to CNE when agreement was finalised. CNE thanks these sponsors for their commitment to the organisation and our collaborative work and thanks Cystinosis Ireland for facilitating the secure transfer of the funds.

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Anne Marie O'Dowd

Director

20 October 2021

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Niamh O'Brien

Director

20 October 2021

*Cystinosis Support Network Europe – Financial Statements 2020*

**Cystinosis Support Network Europe**  
**(A Company Limited by Guarantee and not having a Share Capital)**  
**Income and Expenditure Account**  
**For the Financial Year Ending 31 December 2020**

	<b>2020</b>
<b>Income</b>	€22,988.72
<b>Expenditure</b>	€0.00
	<hr/>
	<b>€22,988.72</b>
<b>Surplus for the financial year</b>	<b>€22,988.72</b>

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.

## Cystinosis Support Network Europe – Financial Statements 2020

**Cystinosis Support Network Europe**  
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**Balance Sheet As at 31 December 2021**

	2020
<b>Current Assets</b>	
Cash at Bank	€22,988.72
<b>Creditors:</b> Amounts falling due within one year	€0.00
<b>Net Current Assets:</b>	<b>€22,988.72</b>
 <b>Reserves:</b>	
Income and Expenditure account	<b>€22,988.72</b>

We, as directors of Cystinosis Support Network Europe state that:

- a) Cystinosis Support Network Europe is availing itself of the exemption provided for by Chapter 15 of Part 6 of the Companies Act 2014,
- b) the company is availing itself of the exemption on the grounds that the conditions specified in s.358 are satisfied,
- c) the shareholders of the company have not served a notice on the company under s.334(1) in accordance with s.334(2),
- d) we acknowledge the company's obligations under the Companies Act 2014, to keep adequate accounting records and prepare Financial Statements which give a true and fair view of the assets, liabilities and financial position of the company at the end of its financial year and of its profit or loss for such a year and to otherwise comply with the provisions of Companies Act 2014 relating to Financial Statements so far as they are applicable to the company,
- e) the company has relied on the specified exemption contained in s.352 Companies Act 2014; has done so on the grounds that the company is entitled to the benefit of that exemption as a small company and the abridged Financial Statements have been properly prepared in accordance with s.353 Companies Act 2014.

On behalf of the board:

DocuSigned by:  
  
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 Anne Marie O'Dowd  
 Director  
 20 October 2021

DocuSigned by:  
  
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 Niamh O'Brien  
 Director  
 20 October 2021