

**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 31 December 2022**

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

**Contents**

|   | <b>Page</b>    |
|---|----------------|
| Directors and other information             | <b>1</b>       |
| Directors report                            | <b>2 - 4</b>   |
| Directors responsibilities statement        | <b>5</b>       |
| Independent auditor's report to the members | <b>6 - 9</b>   |
| Income and expenditure account              | <b>10</b>      |
| Statement of income and retained earnings   | <b>11</b>      |
| Balance sheet                               | <b>12</b>      |
| Notes to the financial statements           | <b>13 - 14</b> |

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

**Directors and other information**

|                                  |  |
|----------------------------------|--|
| <b>Directors</b>                 | Anne Marie O'Dowd<br>Claudia Sproedt<br>Marjolein Bos<br>Niamh O'Brien (Resigned 20 March 2023)<br>Eibhlis Shanahan (Appointed 27 September 2022)<br>Karen McCullagh |
| <b>Secretary</b>                 | Denise Dunne   |
| <b>Company number</b>            | 670605   |
| <b>Registered office</b>         | 1-2 Cavendish Row<br>Dublin 1<br>D01 K883  |
| <b>Business address</b>          | 1-2 Cavendish Row<br>Dublin 1<br>D01 K883  |
| <b>Auditor</b>                   | McCloskey & Co<br>The Glasshouses<br>Unit 16 The Cubes Offices<br>Beacon South Quarter<br>Sandyford<br>Dublin D18 XD36   |
| <b>Bankers</b>                   | AIB<br>Blackrock<br>Co Dublin  |
| <b>Registered Charity Number</b> | 20206325   |

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

**Directors report**

The directors present their annual report and the audited financial statements of the company for the financial period ended 31 December 2022.

**Directors and Secretary**

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

**Directors**

Anne Marie O'Dowd

Claudia Sproedt

Marjolein Bos

Niamh O'Brien (Resigned 20 March 2023)

Eibhlis Shanahan (Appointed 27 September 2022)

**Secretary**

Denise Dunne

**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 2022 the world began to emerge from covid restrictions and open up again. People living with cystinosis continued to be cautious but returned to their more normal lives. The work of CNE continued to support our national organisation members, organisations and individuals which are not members, and the wider community.

In July, the Dutch-Flemish cystinosis organisation hosted the 3rd International CNE Conference in Leuven, Belgium. The conference was a scientific and family meeting with more than 140 people attending in person. Due to lingering concerns about covid, the attendee numbers were smaller than hoped, but nonetheless the meeting was a huge success with strong engagement from all sectors of the community.

The Community Advisory Board continued to meet on a regular basis online, with an in person meeting co-ordinated with the conference in Leuven. We took the opportunity of meeting in person to plan for our year ahead and to meet with AVROBIO, a gene therapy company working to develop a clinical trial from the initial research of Dr Stephanie Cherqui in UC San Diego, California. The CAB also had meetings with Recordati Rare Diseases and Chiesi Farmaceutici S.p.A. during the year with ongoing contact between meetings.

In 2022 a number of issues around therapy access emerged in various countries, most notably Turkey following the natural disaster. CNE worked with local patient, clinical and healthcare company representatives in an effort to ease these roadblocks. While this was effective in some territories, it was less successful in others and the work is ongoing to identify and endeavour to remove the obstacles. Following our establishment of CNE as a company and securing our charitable status, the board worked hard in 2022 on our governance, policies and processes to ensure we are working to the highest standards in all we do. This work is on-going to ensure we will meet the stringent requirements of charitable status in Ireland.

Funding for CNE has come in 2022 from three pharmaceutical companies through unrestricted grants and grants for participation in the CAB meetings. The companies who provided funding to CNE in 2022 were AVROBIO, Chiesi Farmaceutici S.p.A. and Recordati Rare Diseases. Some of this funding was specific to the International Conference in Leuven.

The membership of CNE is: Ireland (Chair, board members & secretariat); Germany (board member); Netherlands & Belgium (board member); France; Italy; Spain; with Associate members: USA; Australia; South Africa; Turkey; Russia and Mexico.

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.

**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.

**Cystinosis Support Network Europe**  
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**Directors report (continued)**

**Likely future developments**

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

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

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

**Accounting records**

The measures taken by the directors to secure compliance with the requirements of sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records are the implementation of necessary policies and procedures for recording transactions, 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.

This report was approved by the board of directors on 18 September 2023 and signed on behalf of the board by:

Anne Marie O'Dowd

Director

Marjolein Bos

Director

**Cystinosis Support Network Europe**  
**(A Company Limited by Guarantee and not having 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 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.

The directors are responsible for the maintenance and integrity of the corporate and financial information included on the company's website. Legislation in the Republic of Ireland governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

**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 31 December 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 2023 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 the provisions available for small entities, in the circumstances set out below, 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.

As a small entity under the provisions of the IAASA Ethical Standard we engage our auditor to provide basic bookkeeping and accounts preparation.

***Conclusions relating to going concern***

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Company's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.



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

### ***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.

### ***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.

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

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.

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  
The Glasshouses  
Unit 16 The Cubes Offices  
Beacon South Quarter  
Sandyford  
Dublin D18 XD36

18 September 2023

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

**Income and expenditure account**  
**Financial period ended 31 December 2022**

|   | Note | Period<br>ended<br>31/12/22<br>€ | Period<br>ended<br>30/04/22<br>€ |
|---|------|----------------------------------|----------------------------------|
| Turnover                                |      | 90,500                           | 32,000                           |
| <b>Gross surplus</b>                    |      | <u>90,500</u>                    | <u>32,000</u>                    |
| Expenditure                             |      | (62,895)                         | (2,646)                          |
| <b>Operating surplus</b>                |      | <u>27,605</u>                    | <u>29,354</u>                    |
| <b>Surplus before taxation</b>          |      | <u>27,605</u>                    | <u>29,354</u>                    |
| Tax on surplus                          |      | -                                | -                                |
| <b>Surplus for the financial period</b> |      | <u><u>27,605</u></u>             | <u><u>29,354</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 31 December 2022**

|   | <b>Period<br/>ended<br/>31/12/22<br/>€</b> | <b>Period<br/>ended<br/>30/04/22<br/>€</b> |
|---|--|--|
| Surplus for the financial period                              | 27,605                                     | 29,354                                     |
| <b>Retained earnings at the start of the financial period</b> | <u>52,343</u>                              | <u>22,989</u>                              |
| <b>Retained earnings at the end of the financial period</b>   | <u><u>79,948</u></u>                       | <u><u>52,343</u></u>                       |

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

**Balance sheet**  
**As at 31 December 2022**

|   | Note | 31/12/22      | € | 30/04/22      | € |
|---|------|---------------|---|---------------|---|
| <b>Current assets</b>                                 |      |               |   |               |   |
| Cash at bank and in hand                              |      | 81,198        |   | 53,593        |   |
|   |      | <u>81,198</u> |   | <u>53,593</u> |   |
| <b>Creditors: amounts falling due within one year</b> | 6    | (1,250)       |   | (1,250)       |   |
| <b>Net current assets</b>                             |      | 79,948        |   | 52,343        |   |
| <b>Total assets less current liabilities</b>          |      | <u>79,948</u> |   | <u>52,343</u> |   |
| <b>Net assets</b>                                     |      | <u>79,948</u> |   | <u>52,343</u> |   |
| <b>Capital and reserves</b>                           |      |               |   |               |   |
| General funds   |      | 79,948        |   | 52,343        |   |
| <b>Members funds</b>                                  |      | <u>79,948</u> |   | <u>52,343</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'.

These financial statements were approved by the board of directors on 18 September 2023 and signed on behalf of the board by:

Anne Marie O'Dowd  
 Director

Marjolein Bos  
 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 31 December 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.

**Expenditure**

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates.

**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**

|   | <b>31/12/22</b> | 30/04/22      |
|---|-----------------|---------------|
|   | €               | €             |
| At the start of the financial period      | 52,343          | 22,989        |
| Surplus for the financial period          | 27,605          | 29,354        |
| <b>At the end of the financial period</b> | <u>79,948</u>   | <u>52,343</u> |

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

**Notes to the financial statements (continued)**  
**Financial period ended 31 December 2022**

**6. Creditors: amounts falling due within one year**

|          | <b>31/12/22</b>   | <b>30/04/22</b>   |
|----------|-------------------|-------------------|
|          | €                 | €                 |
| Accruals | 1,250             | 1,250             |
|          | <u>          </u> | <u>          </u> |

**7. Ethical standards**

As a small entity under the provisions of the IAASA Ethical Standard we engage our auditor to provide basic bookkeeping and accounts preparation.

**8. Approval of financial statements**

The board of directors approved these financial statements for issue on 18 September 2023.



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

**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 31 December 2022**

|                                     | <b>Period<br/>ended<br/>31/12/22<br/>€</b> | Period<br>ended<br>30/04/22<br>€ |
|-------------------------------------|--|----------------------------------|
| <b>Turnover</b>                     |  |                                  |
| Donations/sponsorship               | 62,500                                     | 32,000                           |
| Grants received (unrestricted)      | 20,000                                     | -                                |
| Other income                        | 8,000                                      | -                                |
|                                     | <u>90,500</u>                              | <u>32,000</u>                    |
| <b>Gross surplus</b>                | <u>90,500</u>                              | <u>32,000</u>                    |
| <b>Gross surplus percentage</b>     | 100.0%                                     | 100.0%                           |
| <b>Overheads</b>                    |  |                                  |
| <b>Administrative expenses</b>      |  |                                  |
| Programme expenses                  | (61,373)                                   | (1,251)                          |
| Auditors remuneration               | (1,230)                                    | (1,230)                          |
| Bank charges                        | (272)                                      | (145)                            |
| General expenses                    | (20)                                       | (20)                             |
|                                     | <u>(62,895)</u>                            | <u>(2,646)</u>                   |
| <b>Operating surplus</b>            | 27,605                                     | 29,354                           |
| <b>Operating surplus percentage</b> | 30.5%                                      | 91.7%                            |
| <b>Surplus before taxation</b>      | <u>27,605</u>                              | <u>29,354</u>                    |