

**Charity registered number: 1010639**

**The Society for the Study  
of Inborn Errors of Metabolism**

**(A company limited by guarantee)**

**Annual report and financial statements**

For the year ended 31 December 2022

Company registered number: 02567711

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## Reference and administrative details

For the year ended 31 December 2022

|                                  |   |
|----------------------------------|---|
| <b>Trustees</b>                  | Prof Dr D M Cassiman<br>Dr A Garcia-Cazorla<br>Dr S Grünewald<br>Prof Dr Med J D B Häberle<br>Prof Dr Med I Knerr<br>Prof G la Marca<br>Dr R J Lapatto<br>Dr H Michelakakis<br>Prof P B Mills<br>Dr M D S Quelhas<br>Prof S Rahman<br>Prof J C Rocha<br>Prof M Schiff |
| <b>Company secretary</b>         | Dr H Michelakakis   |
| <b>Company registered number</b> | 02567711  |
| <b>Charity registered number</b> | 1010639   |
| <b>Registered office</b>         | C/O Stone King LLP<br>Boundary House<br>91-93 Charterhouse Street<br>London<br>EC1M 6HR   |
| <b>Independent auditor</b>       | Buzzacott LLP<br>130 Wood Street<br>London<br>EC2V 6DL  |
| <b>Bankers</b>                   | Barclays Bank PLC<br>PO Box 43<br>Sheffield<br>S9 2LF   |

### Trustees' report

For the year ended 31 December 2022

The Trustees present their annual report together with the financial statements of The Society for the Study of Inborn Errors of Metabolism ('SSIEM') ('the Society') for the year ended 31 December 2022.

Since the Society qualifies as small under section 383 of the Companies Act 2006, the Strategic report required of medium and large companies under The Companies Act 2006 (Strategic report and Directors' report) Regulations 2013 is not required.

#### STRUCTURE, GOVERNANCE AND MANAGEMENT

##### Constitution

The Society is constituted under a Memorandum of Association dated 12 December 1990 and amended by Resolutions dated 13 September 1991, 6 September 2007, 31 August 2011 and 3 September 2014. It is a registered charity with its charity number being 1010639.

The Society is limited by guarantee and does not have share capital. All trustees are members of the Society and guarantee to contribute £1 in the event of winding up.

##### Trustees

The Trustees who served during the year were:

Prof Dr D M Cassiman  
Dr A Garcia-Cazorla  
Dr S Grünewald (appointed 31<sup>st</sup> August 2022)  
Prof Dr Med J D B Häberle  
Prof Dr Med I Knerr (appointed 31<sup>st</sup> August 2022)  
Prof G la Marca  
Dr R J Lapatto  
Dr H Michelakakis  
Prof P B. Mills  
Asst Prof F M J Mochel (resigned 31<sup>st</sup> August 2022)  
Dr M D S Quelhas  
Prof S Rahman (appointed 1<sup>st</sup> January 2022)  
Prof J C Rocha  
Prof G S Salomons (resigned 31<sup>st</sup> August 2022)  
Prof M Schiff

#### OBJECTIVES AND ACTIVITIES

##### Policies and objectives

The principal objective of the Society is to foster the study of inherited metabolic disorders and related topics.

In order to further these objectives, membership of the Society promotes the exchange of ideas between professional workers in different disciplines who are interested in inherited metabolic disorders. The aim is pursued in scientific meetings, training courses and publications. The Society supports an annual symposium concentrating on different topics relating to inborn errors of metabolism each year and publishes its journals (Journal of Inherited Metabolic Disease (JIMD) and JIMD reports).

## **Trustees' report (continued)**

For the year ended 31 December 2022

Membership of the Society is open to all and especially to those who are professionally involved in metabolic disorders or related topics.

### **Public benefit**

In supporting an annual symposium and publishing its journal, the Society aims to advance health by sharing ideas on different topics relating to Inborn Errors of Metabolism. In doing so, the Society has considered the Charity Commission's guidance on public benefit.

### **Organisational structure and decision-making**

A General Council made up of Honorary Officers of the Society and additional members manage the organisation. The Honorary Officers are a Chair, a Secretary and a Treasurer. Council Members are elected at the Annual General Meeting. Honorary Officers are appointed by the General Council. Honorary Officers of the Society may hold office for three years and are eligible for re-appointment to the same office for a further three years. Members of the General Council other than Honorary Officers may hold office for three years; they may be re-elected for a further three years.

All Honorary Officers of the Society and Members of the General Council are considered to be key management of SSIEM although all are non-paid volunteers.

The Finance Sub-Committee ('FSC') to help run the financial side of the Society was announced at the 2014 AGM and installed in 2015. The FSC comprises the current Honorary Treasurer, a Council member (currently the SSIEM Chair), the previous SSIEM Honorary Treasurer or Ex-Officio member of Council and an independent financial advisor.

### **Trustees' responsibilities statement**

The Trustees (who are also directors of The Society for the Study of Inborn Errors of Metabolism for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the Society and of the incoming resources and application of resources, including the income and expenditure, of the Society for that period.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with 'the Financial Reporting Standard applicable to the UK and Republic of Ireland' ('FRS 102');
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable United Kingdom Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Society will continue in operation.

## **Trustees' report (continued)**

For the year ended 31 December 2022

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Society's transactions and disclose with reasonable accuracy at any time the financial position of the Society and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the Society and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the Society's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

### **ACHIEVEMENTS AND PERFORMANCE**

#### **Review of activities**

The membership subscription structure remained the same as 2020 & 2021.

During the year ended 31 December 2022 the Society published Journals and continued development of its own administration. The SSIEM held a symposium in Freiburg, Germany 2022 which was attended by 2442 delegates. The Society supported 30 travel scholarships to attend the symposium which covered the registration fees, accommodation and travel expenses of the awardees.

The SSIEM Journal of Inherited Metabolic Disease (JIMD) was again run from the JIMD Editorial Office in Heidelberg. A new agreement was made with the JIMD Editorial Office with continued support from the Publisher Wiley. Negotiations to extend the current Wiley's contract for an additional 5 years was started and a draft contract to start from 1<sup>st</sup> January 2023 for six years is under review.

SSIEM Education and Training Advisory Committee (ETAC) exercised its responsibilities for the training syllabi and the recognition of training centres for paediatric metabolic medicine. ETAC also organised the annual SSIEM Academy course which for 2022 was held in Amsterdam, The Netherlands.

The SSIEM organised three Dietitian's meetings.

The SSIEM offered modest financial support for non-profit organisations such as parent support groups or societies. In 2022 seven applications were received in the 1<sup>st</sup> round and five in the 2<sup>nd</sup> round. These applications were independently judged by a panel from the SSIEM Advisory Council. A total of six awards were made.

Five Travel & Training Bursaries for educational activities for healthcare professionals seeking experience in centres of excellence or to attend conferences or meetings were awarded. The SSIEM continued to help seven individuals in the Ukraine within the IEM community with supported membership together with six others from different countries.

The SSIEM awarded a group with support for guideline development and publishing.

A total of €71,386 was given in awards, grants and bursaries for 2022.

#### **FINANCIAL REVIEW**

##### **Principal funding**

The overall income excluding any surplus from the symposium is used to pay the administrative and running costs of the Society including ETAC and to allow for publication of educational journals devoted to the study of the inborn errors of metabolism and organise training & educational events. Surplus funds are invested. Interest from investments is used in pursuance of the educational objectives of the Society.

## **Trustees' report (continued)**

For the year ended 31 December 2022

The Council is cognisant of the current global financial crisis and has taken steps to protect investment and secure the financial position of the Society so that it can continue to meet its objectives.

The Society is truly international with membership drawn from more than 82 countries. The Society exists to promote the exchange of ideas between all who are professionally interested in Inherited Metabolic Disease. It is the wish of the Council that this exchange should occur between members in as many countries as possible. The Council has agreed to set aside an amount of money from any surplus generated from normal activities to make membership more widely available to those who would otherwise be unable to participate without support from the Society. In 2022, the annual subscriptions of 13 (2021: 4) members were waived by the Society.

### **Results for the year**

Overall the financial result for the year was a net increase in the reserves of €188,496 (to a year-end figure of €3,002,443).

### **Reserves policy**

It is the policy of the Society to maintain unrestricted funds, which are the free reserves, at a level that is sufficient to cover future management and administration, symposium and support costs for a limited period which would allow the Society to be managed efficiently if there were a significant downturn. This reserve is set at €1,000,000 (2021: €1,000,000). The Council proposes that a proportion of the surplus funds are invested, currently €979,000 (2021: €1,100,000); the purpose of the investment is to provide the SSIEM with a modest income from its surplus.

The remaining surplus is used in pursuance of the educational and charitable objectives of the Society. These include Adult & Dietitian meetings, ETAC Academy and the annual symposium, plus a limited number of awards, grants and bursaries. The latter includes: the Travel & Training Bursaries to finance individual members to visit, or work for short periods of time in, other centres of expertise; support of non-profit organisations, such as parent support groups holding events or parent/carer projects; Symposium scholarships for travel, accommodation and registration at the SSIEM Symposium and development of Guidelines. As at 31 December 2022 an unrestricted fund balance of €3,002,443 (2021: €2,813,947) was held.

### **Investment policy and performance**

All investments have been acquired in accordance with powers available to the Council. The assets are sufficient to guarantee normal running of the Society for a period of not less than one year and to support the SSIEM Symposium if there were financial difficulties. The Council considers that this is the best way of ensuring the independence of the Society and that its educational objectives can be fulfilled. Since the majority of assets are financial investments there is unlikely to be any delay or shortfall in realising the assets into cash if this becomes necessary.

### **Risk management**

The trustees have assessed the major risks to which the Society is exposed, in particular those related to the operations and finances of the Society, and are satisfied that systems and procedures are in place to mitigate our exposure to the major risks.

## Trustees' report (continued)

For the year ended 31 December 2022

The main risks and the methods by which the risks are mitigated are:

### Symposia risk

- Insurance against bodily or material harm including third parties.
- Insurance against cancellation was considered unacceptably expensive and therefore inappropriate use of funds. However, this can be reviewed with each symposium.
- Agreement re a force majeure event.
- Making the Symposia a hybrid or virtual meeting if required

It is expected that the above insurance policies and agreements are included in any contract with any Professional Conference Organiser (PCO) providing services for the annual Symposium.

### Data risk

- The IT and data facilities are virtual and backed-up routinely.
- Compliance with new GDPR regulations. Specialist advice has been sought to ensure compliance.

### Financial risk

- The major risk to the SSIEM is the potential lack of success of the annual symposium which is covered above. The financial surplus of the Society is conservatively managed and is considered to be low risk as funds are held in Sterling and Euro.

## PLANS FOR FUTURE PERIODS

### Future developments

The Council will continue to:

- Develop our administration team.
- Review and develop corporate governance.
- Review and develop structures of committees, succession planning and terms of reference
- Continually assess and manage risk.
- Develop communications links with the members.
- Develop/update our Symposium and meetings.
- Support parent support groups or societies through the funding award scheme.
- Support healthcare professional seeking experience in centres of excellence.
- Support for Guideline Developments.
- Support and/or invite Societies to provide educational meetings or training courses.
- Encourage ERNDIM-SSIEM Collaboration.
- Encourage MetabERN SSIEM joint training.

ETAC will continue to:

- Canvas the views of SSIEM members on training issues.
- Undertake accreditation visits when requested.
- Update the training syllabus on a regular basis.
- Consider whether courses in inborn errors of metabolism are suitable for training needs.
- Organise further specific training programmes as part of the SSIEM academy.
- Encourage ETAC-NAMA Collaboration.

The SSIEM's Journal of Inherited Metabolic Disease will:

- Continue and will further develop the JIMD with a revised contract with the Publishers Wiley's.
- Develop special issues.
- Make the JIMD environmentally friendly by going paperless.

## **Trustees' report (continued)**

For the year ended 31 December 2022

The Society actively encourages the formation of National Societies which can communicate with each other through the SSIEM to raise awareness of metabolic diseases so that standards of care and research are improved.

### **Going concern**

After making appropriate enquiries, the Trustees have a reasonable expectation that the Society has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements.

### **Trustees' responsibilities statement**

The Trustees (who are also directors of The Society for the Study of Inborn Errors of Metabolism for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the Society and of the incoming resources and application of resources, including the income and expenditure, of the Society for that period.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with 'the Financial Reporting Standard applicable to the UK and Republic of Ireland' ('FRS 102');
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable United Kingdom Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Society will continue in operation.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Society's transactions and disclose with reasonable accuracy at any time the financial position of the Society and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the Society and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the Society's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

### **Disclosure of information to auditor**

Each of the persons who are Trustees at the time when this Trustees' report is approved has confirmed that:

- So far as that Trustee is aware, there is no relevant audit information of which the Society's auditor is unaware, and
- The Trustee has taken all the steps that ought to have been taken as a trustee in order to be aware of any relevant audit information and to establish that the Society's auditor is aware of that information.

## Trustees' report (continued)

For the year ended 31 December 2022

### Small companies exemption

In preparing this report, the Trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

This report was approved by the Trustees and signed on their behalf by:



.....  
**Prof P B Mills**

Trustee

Date: 28 July 2023

## **Independent auditor's report to the Trustees of The Society for the Study of Inborn Errors of Metabolism**

For the year ended 31 December 2022

### **Opinion**

We have audited the financial statements of The Society for the Study of Inborn Errors of the Metabolism ('the Society') for the year ended 31 December 2022, which comprise the Statement of financial activities, the Statement of financial position, the Statement of cash flows and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the Society's affairs as at 31 December 2022 and of its result for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### **Basis for opinion**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) 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 Society in accordance with the ethical requirements that are relevant to our audit of the financial statements in the United Kingdom, including the Financial Reporting Council's Ethical Standard, 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**

In auditing the financial statements, we have concluded that the Trustees' 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 Society's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

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

## **Independent auditor's report to the Trustees of The Society for the Study of Inborn Errors of Metabolism (continued)**

For the year ended 31 December 2022

### **Other information**

The Trustees 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.

### **Opinion on other matters prescribed by the Companies Act 2006**

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' report, which is also the directors' report for the purpose of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' report, which is also the directors' report for the purpose of company law, has been prepared in accordance with applicable legal requirements.

### **Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the Society and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' report. We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemptions in preparing the Trustees' report and from the requirement to prepare a Strategic report.

### **Responsibilities of Trustees**

As explained more fully in the Trustees' responsibilities statement on page 7, the Trustees (who are also the directors of the charitable company for the purpose of company law) 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 Trustees 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 Trustees of The Society for the Study of Inborn Errors of Metabolism (continued)**

For the year ended 31 December 2022

In preparing the financial statements, the Trustees are responsible for assessing the Society'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 Trustees either intend to liquidate the Society or to cease operations, or have no realistic alternative but to do so.

### **Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) 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.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

Our approach to identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, was as follows:

- the engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulations; and
- the audit team held a discussion to identify any particular areas that were considered to be susceptible to misstatement, including with respect to fraud and non-compliance with laws and regulations; and
- we obtained an understanding of the legal and regulatory frameworks that are applicable to the Society and determined that the most significant frameworks which are directly relevant to specific assertions in the financial statements are those that relate to the reporting framework (Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011), the Companies Act 2006 and those that relate to data protection (General Data Protection Regulation).

We assessed the susceptibility of the Society's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud and their knowledge of actual, suspected and alleged fraud; and
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations.

To address the risk of fraud through management bias and override of controls, we:

- performed analytical procedures to identify any unusual or unexpected relationships;
- assessed whether judgements and assumptions made in determining the accounting estimates set out in the accounting policies were indicative of potential bias; and
- tested journal entries to identify unusual transactions.

## Independent auditor's report to the Trustees of The Society for the Study of Inborn Errors of Metabolism (continued)

For the year ended 31 December 2022

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation;
- reading the minutes of meetings of those charged with governance; and
- enquiring of management as to actual and potential litigation and claims.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the Trustees and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our Auditor's report.

### Use of our report

This report is made solely to the Society's Trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the Society'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 Society and the Society's members, as a body, for our audit work, for this report, or for the opinions we have formed.



Mark Worsey (Senior statutory auditor)  
for and on behalf of  
**Buzzacott LLP**  
Statutory Auditor  
130 Wood Street  
London  
EC2V 6DL

Date:

28 July 2023

## Statement of financial activities

For the year ended 31 December 2022

| Income and expenditure  | Note | Unrestricted<br>funds<br>2022<br>€ | Unrestricted<br>funds<br>2021<br>€ |
|---|------|------------------------------------|------------------------------------|
| <b>Income from:</b>   |      |                                    |                                    |
| Charitable activities – symposium and memberships                   | 3    | 2,341,281                          | 202,780                            |
| Charitable activities – journal royalties and courses               | 4    | 452,374                            | 378,129                            |
| Investments   | 5    | 24,153                             | 17,647                             |
| <b>Total income</b>   |      | <b>2,817,808</b>                   | <b>598,556</b>                     |
| <b>Expenditure on:</b>  |      |                                    |                                    |
| Charitable activities   | 6    | 2,312,844                          | 677,206                            |
| <b>Total expenditure</b>  |      | <b>2,312,844</b>                   | <b>677,206</b>                     |
| <b>Net expenditure before investment<br/>gains and losses</b>       |      | <b>504,964</b>                     | <b>(78,650)</b>                    |
| Unrealised (loss)/gain on revaluation of fixed asset<br>investments | 10   | (265,111)                          | 41,661                             |
| Net gain on investments   | 10   | 18,834                             | 16,855                             |
| (Loss)/gain on retranslation of fixed asset investments             | 10   | (70,191)                           | 99,600                             |
| <b>Net movement in funds</b>  |      | <b>188,496</b>                     | <b>79,466</b>                      |
| <b>Reconciliation of funds:</b>                                     |      |                                    |                                    |
| Total funds at the beginning of the year                            | 13   | 2,813,947                          | 2,734,481                          |
| <b>Total funds at the end of the year</b>                           |      | <b>3,002,443</b>                   | <b>2,813,947</b>                   |

The Statement of financial activities includes all gains and losses recognised in the year.

All of the Society's activities derived from continuing operations during the above two financial years.

The notes on pages 16 to 22 form part of these financial statements.

## Statement of financial position

As at 31 December 2022

|   | Note | €                | 2022<br>€               | €                | 2021<br>€        |
|---|------|------------------|-------------------------|------------------|------------------|
| <b>Fixed assets</b>                                   |      |                  |                         |                  |                  |
| Investments   | 10   |                  | <b>1,042,152</b>        |                  | 1,353,878        |
| <b>Current assets</b>                                 |      |                  |                         |                  |                  |
| Debtors   | 11   | <b>686,305</b>   |                         | 288,094          |                  |
| Cash at bank and in hand                              |      | <b>1,646,165</b> |                         | <u>1,433,921</u> |                  |
|   |      | <b>2,332,470</b> |                         | <u>1,722,015</u> |                  |
| <b>Creditors: amounts falling due within one year</b> | 12   | <b>(372,179)</b> |                         | <u>(261,946)</u> |                  |
| <b>Net current assets</b>                             |      |                  | <b>1,960,291</b>        |                  | 1,460,069        |
| <b>Net assets</b>                                     |      |                  | <b><u>3,002,443</u></b> |                  | <u>2,813,947</u> |
| <b>Charity funds</b>                                  |      |                  |                         |                  |                  |
| Unrestricted funds:                                   |      |                  |                         |                  |                  |
| General fund  | 13   | <b>3,002,443</b> |                         | 2,750,468        |                  |
| Designated fund                                       | 13   | <u>-</u>         |                         | <u>63,479</u>    |                  |
|   |      |                  | <b>3,002,443</b>        |                  | 2,813,947        |
| Total unrestricted funds                              |      |                  | <b><u>3,002,443</u></b> |                  | <u>2,813,947</u> |

The Trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime and in accordance with the provisions of FRS102 Section 1A – small entities.

The financial statements were approved by the Trustees on 28 July 2023 and signed on their behalf by:



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**Prof P B Mills**

Treasurer

The notes on pages 16 to 22 form part of these financial statements.

## Statement of cash flows

For the year ended 31 December 2022

|  | 2022               | 2021             |
|--|--------------------|------------------|
|  | €                  | €                |
| <b>Cash flow from operating activities:</b>            |                    |                  |
| Net cash generated from operating activities           | A <u>192,833</u>   | <u>73,467</u>    |
| <b>Cash flow from investing activities</b>             |                    |                  |
| Purchase of investments                                | (272,862)          | (532,694)        |
| Disposal of investments                                | 268,120            | 552,070          |
| Investment income                                      | <u>24,153</u>      | <u>17,647</u>    |
| <b>Net cash generated from investing activities</b>    | <u>19,411</u>      | <u>37,023</u>    |
| <b>Change in cash and cash equivalents in the year</b> | <u>212,244</u>     | <u>110,490</u>   |
| <b>Cash and cash equivalents at beginning of year</b>  | <u>1,433,921</u>   | <u>1,323,431</u> |
| <b>Cash and cash equivalents at end of year</b>        | B <u>1,646,165</u> | <u>1,433,921</u> |

### A Reconciliation of net income to net cash flow from operating activities

|   | 2022           | 2021          |
|---|----------------|---------------|
|   | €              | €             |
| <b>Net income for the year (as per the Statement of financial activities)</b> | 188,496        | 79,466        |
| <b>Adjustments for:</b>   |                |               |
| Loss/(gain) on revaluation of investments                                     | 265,111        | (41,661)      |
| Gain on disposal of investments   | (18,834)       | (16,855)      |
| Loss/(gain) on retranslation of fixed asset investments                       | 70,191         | (99,600)      |
| Investment income   | (24,153)       | (17,647)      |
| (Decrease)/increase in debtors  | (398,211)      | 157,573       |
| Increase in creditors   | <u>110,233</u> | <u>12,191</u> |
| <b>Net cash generated from operating activities</b>                           | <u>192,833</u> | <u>73,467</u> |

### B Analysis of cash and cash equivalents

|  | 2022             | 2021             |
|--|------------------|------------------|
|  | €                | €                |
| Cash at bank and in hand               | 1,583,280        | 1,376,471        |
| Cash held by investment managers       | <u>62,885</u>    | <u>57,450</u>    |
| <b>Total cash and cash equivalents</b> | <u>1,646,165</u> | <u>1,433,921</u> |

## Notes to the financial statements

For the year ended 31 December 2022

### 1. General information

The Society for the Study of Inborn Errors of Metabolism ('the Society') is a company limited by guarantee. The members of the Society are the Trustees named on page 1. In the event of the Society being wound up, the liability in respect of the guarantee is limited to £1 per member of the Society. The Society is incorporated in England and Wales. Its registered office and principal place of business is C/O Stone King LLP, Boundary House, 91-93 Charterhouse Street, London, EC1M 6HR. The company registration number is 02567711 and the charity registration number is 1010639.

### 2. Accounting policies

#### 2.1 Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention, with the exception of investments, which are included on a market value basis. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP FRS 102), Section 1A of Financial Reporting Standard 102, 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' ('FRS 102'), the Charities Act 2011 and the Companies Act 2006.

The charity constitutes a public benefit entity as defined by FRS 102.

The financial statements are presented in Euros (€).

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

#### 2.2 Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the Society has adequate resources to continue in operational existence for the foreseeable future. For this reason, the Society will continue to adopt the going concern basis in preparing the financial statements.

#### 2.3 Fund accounting

The general fund is an unrestricted fund which is available for use at the discretion of the Trustees in furtherance of the general objectives of the Society and which has not been designated for other purposes.

#### 2.4 Income

All income is recognised in the Statement of financial activities when the Society has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

##### *Annual symposium*

Symposium income is the gross revenue generated by the symposium organiser on behalf of SSIEM and includes the registration fees and sponsorship fees at the event.

## Notes to the financial statements

For the year ended 31 December 2022

### 2. Accounting policies (continued)

#### *Subscriptions income*

Income from subscriptions are recognised in the period the membership relates to.

#### *Journal royalties*

Journal royalties are recognised on an accruals basis.

#### *Investment income*

This comprises interest on bank deposits and National Savings Bank income bonds and dividend income. Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Society. This is normally upon notification of the interest paid or payable by the bank. Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

### 2.5 Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the Society to make a payment to a third party or it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. All expenditure is stated inclusive of irrecoverable VAT.

All expenditure is accounted for on an accruals basis. Expenditure comprises direct costs and support costs. All expenses, including support costs, relate to the charitable activities of the Society.

Expenditure on charitable activities includes all costs associated with furthering the charitable purposes of the Society through the provision of its charitable activities. Such costs have been apportioned as follows:

- Direct costs – These are the costs associated directly to meeting the charitable objects of the Society and include annual symposium expenditure, grants payable and costs incurred in respect of producing journals.
- Support costs – These are the costs incurred directly in support of expenditure on the objects of the Society and include project management carried out at Headquarters.
- Governance costs – These are the costs directly attributable to the meetings and audit process such as staff costs, printing, meetings and travel costs.

#### *Annual symposium*

Symposium expenditure is the gross expenses incurred by the symposium organiser on behalf of the Society.

#### *Grants payable*

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, with such grants being recognised as expenditure when the conditions attached are completed by the Society. Grants offered subject to conditions which have not been met at the year-end are noted as a commitment, but not accrued as expenditure.

### 2.6 Fixed asset investments

Investments are stated at market value at the reporting date. The Statement of financial activities includes the net gains and losses arising on revaluations and disposals throughout the year.

### 2.7 Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered and net of any provision. Prepayments are valued at the net amount prepaid.

## Notes to the financial statements

For the year ended 31 December 2022

### 2. Accounting policies (continued)

#### 2.8 Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

#### 2.9 Liabilities and provisions

Liabilities are recognised when there is an obligation at the reporting date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably. Liabilities are recognised at the amount that the Society anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

#### 2.10 Financial instruments

The Society only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

#### 2.11 Foreign currencies

Monetary assets and liabilities denominated in foreign currencies are translated into Euros at rates of exchange ruling at the balance sheet date.

Transactions in foreign currencies are translated into Euros at the rate ruling on the date of the transaction.

Exchange gains and losses are recognised in the Statement of financial activities incorporating income and expenditure account.

### 3. Income from charitable activities – symposium and memberships

|                  | Unrestricted<br>funds<br>2022<br>€ | Total<br>funds<br>2022<br>€ | Total<br>funds<br>2021<br>€ |
|------------------|------------------------------------|-----------------------------|-----------------------------|
| Annual symposium | 2,190,406                          | 2,190,406                   | 74,871                      |
| Subscriptions    | 141,795                            | 141,795                     | 125,333                     |
| Academy income   | 9,080                              | 9,080                       | 2,576                       |
|                  | <u>2,341,281</u>                   | <u>2,341,281</u>            | <u>202,780</u>              |

### 4. Income from charitable activities – journal royalties and courses

|                   | Unrestricted<br>funds<br>2022<br>€ | Total<br>funds<br>2022<br>€ | Total<br>funds<br>2021<br>€ |
|-------------------|------------------------------------|-----------------------------|-----------------------------|
| Journal royalties | 440,984                            | 440,984                     | 362,208                     |
| Courses           | 11,390                             | 11,390                      | 15,921                      |
|                   | <u>452,374</u>                     | <u>452,374</u>              | <u>378,129</u>              |

## Notes to the financial statements

For the year ended 31 December 2022

### 5. Income from investments

|                 | Unrestricted<br>funds<br>2022<br>€ | Total<br>funds<br>2022<br>€ | Total<br>funds<br>2021<br>€ |
|-----------------|------------------------------------|-----------------------------|-----------------------------|
| Income bonds    | -                                  | -                           | 26                          |
| Interest income | 11,463                             | 11,463                      | 5,908                       |
| Dividend income | 12,690                             | 12,690                      | 11,713                      |
|                 | <b>24,153</b>                      | <b>24,153</b>               | <b>17,647</b>               |

### 6. Analysis of charitable activities

|   | Unrestricted<br>funds<br>2022<br>€ | Total<br>funds<br>2022<br>€ | Total<br>funds<br>2021<br>€ |
|---|------------------------------------|-----------------------------|-----------------------------|
| <b>Direct costs</b>                               |                                    |                             |                             |
| Council symposium expenses                        | 11,882                             | 11,882                      | 2,391                       |
| Publication of journal                            | 111,789                            | 111,789                     | 106,921                     |
| JIMD Honorarium                                   | 21,000                             | 21,000                      | 21,000                      |
| JIMD Illustrations                                | 698                                | 698                         | -                           |
| Academy expenses                                  | 145,604                            | 145,604                     | 138,494                     |
| Symposium expenses                                | 1,555,540                          | 1,555,540                   | 81,140                      |
| Courses   | 31,171                             | 31,171                      | 22,600                      |
| Awards/bursaries and grants                       | 71,386                             | 71,386                      | -                           |
| <b>Total direct costs</b>                         | <b>1,949,070</b>                   | <b>1,949,070</b>            | <b>372,546</b>              |
| <b>Support costs</b>                              |                                    |                             |                             |
| Salaries and wages                                | 109,479                            | 109,479                     | 89,340                      |
| Council travel and subsistence                    | 13,002                             | 13,002                      | 5,306                       |
| Printing, postage, stationery and carriage        | 15,150                             | 15,150                      | 13,987                      |
| Exchange rate variance                            | (7,582)                            | (7,582)                     | 12,783                      |
| Website costs                                     | 3,652                              | 3,652                       | 21,256                      |
| Other administration expenses                     | 24,938                             | 24,938                      | 55,457                      |
| Secretarial expenses                              | 170                                | 170                         | 39,769                      |
| Telephone and fax                                 | 973                                | 973                         | 366                         |
| IT supplies                                       | 6,844                              | 6,844                       | 20,276                      |
| Bad debts   | -                                  | -                           | 2,182                       |
| Irrecoverable VAT                                 | 169,322                            | 169,322                     | 21,714                      |
| <b>Total support costs</b>                        | <b>335,948</b>                     | <b>335,948</b>              | <b>282,436</b>              |
| <b>Governance costs</b>                           |                                    |                             |                             |
| Audit & accountancy fees                          | 27,192                             | 27,192                      | 22,194                      |
| Professional charges                              | 634                                | 634                         | 30                          |
| <b>Total governance costs</b>                     | <b>27,826</b>                      | <b>27,826</b>               | <b>22,224</b>               |
| <b>Total expenditure on charitable activities</b> | <b>2,312,844</b>                   | <b>2,312,844</b>            | <b>677,206</b>              |

5 delegates were supported with financial grants of €6,392 (2021: €3,750) during the year.

## Notes to the financial statements

For the year ended 31 December 2022

### 7. Trustees' remuneration

No Trustees received any remuneration or benefits in kind in respect of their services during the year (2021: €Nil). During the year, 12 Trustees received reimbursement of expenses of €9,724 (2021: €33, 7 Trustees).

### 8. Auditor's remuneration

Auditor's remuneration amounts to a current year audit fee of €16,940 (2021: €14,293) and fees charged for other non-audit services amounts to €6,928 (2021: €5,777).

### 9. Staff costs

|                       | 2022           | 2021          |
|-----------------------|----------------|---------------|
|                       | €              | €             |
| Wages and salaries    | 103,150        | 75,922        |
| Social security costs | 9,648          | 7,875         |
| Pension costs         | 6,937          | 5,543         |
|                       | <u>119,735</u> | <u>89,340</u> |

The average monthly number of employees during the year was 2 (2021: Nil).

The number of higher paid employees was:

|                   | 2022     | 2021     |
|-------------------|----------|----------|
|                   | €        | €        |
| €80,001 – €90,000 | 1        | -        |
|                   | <u>1</u> | <u>-</u> |

Within Symposium costs are amounts totalling €10,256 (2021: Nil) payable to an employee.

The Society considers the Board of Trustees, the administrator and executive administrator as their key management personnel. The total employment benefits (including employer's national insurance contributions and employer's pension contributions) of key management personnel was €119,735 (2021: €89,340).

## Notes to the financial statements

For the year ended 31 December 2022

### 10. Fixed asset investments

| Market value   | Listed securities<br>€ | Total<br>€       |
|--|------------------------|------------------|
| At 1 January 2022  | 1,353,878              | <b>1,353,878</b> |
| Additions at cost  | 272,862                | <b>272,862</b>   |
| Disposals at book value (proceeds: €268,120 profit: €18,834) | (249,286)              | <b>(249,286)</b> |
| Foreign exchange movement                                    | (70,191)               | <b>(70,191)</b>  |
| Revaluations   | (265,111)              | <b>(265,111)</b> |
|  | <hr/>                  | <hr/>            |
| At 31 December 2022  | 1,042,152              | <b>1,042,152</b> |
|  | <hr/>                  | <hr/>            |
| At 31 December 2021  | 1,353,878              | <b>1,353,878</b> |

|   | 2022<br>€        | 2021<br>€        |
|---|------------------|------------------|
| <b>Investments at market value comprise of the following:</b> |                  |                  |
| Listed investments  | <u>1,042,152</u> | <u>1,353,878</u> |
|   | <b>1,042,152</b> | <b>1,353,878</b> |

Investments are held to provide an investment return.

All fixed asset investments are held in the UK.

### 11. Debtors

|                                | 2022<br>€      | 2021<br>€      |
|--------------------------------|----------------|----------------|
| Trade debtors                  | 21,249         | -              |
| Symposium related debtors      | 269,129        | 5,000          |
| Prepayments and accrued income | 395,927        | 283,094        |
|                                | <hr/>          | <hr/>          |
|                                | <b>686,305</b> | <b>288,094</b> |

## Notes to the financial statements

For the year ended 31 December 2022

### 12. Creditors: Amounts falling due within one year

|                                      |                 |          |
|--------------------------------------|-----------------|----------|
|                                      | <b>2022</b>     | 2021     |
|                                      | €               | €        |
| Other creditors                      | <b>217,621</b>  | 62,361   |
| Accruals and deferred income         | <b>154,558</b>  | 199,585  |
|                                      | <b>372,179</b>  | 261,946  |
|                                      |                 |          |
|                                      | <b>2022</b>     | 2021     |
|                                      | €               | €        |
| Deferred income at beginning of year | <b>48,582</b>   | 68,495   |
| Resources deferred during the year   | <b>36,306</b>   | 48,582   |
| Amounts released from previous years | <b>(48,582)</b> | (68,495) |
| Deferred income at end of year       | <b>36,306</b>   | 48,582   |

Deferred income relates to the deferral of subscription income over the period to which it relates.

### 13. Unrestricted funds

|                 | <b>Balance at<br/>1 January<br/>2022</b> | Income    | Expenditure | Losses from<br>investments | Transfers<br>between<br>funds | <b>Balance at 31<br/>December<br/>2022</b> |
|-----------------|--|-----------|-------------|----------------------------|-------------------------------|--|
|                 | €  | €         | €           | €                          | €                             | €  |
| General fund    | <b>2,750,468</b>                         | 2,817,808 | (2,312,844) | (316,468)                  | 63,479                        | <b>3,002,443</b>                           |
| Designated fund | <b>63,479</b>                            | -         | -           | -                          | (63,479)                      | -  |
|                 | <b>2,813,947</b>                         | 2,817,808 | (2,312,844) | (316,468)                  | -                             | <b>3,002,443</b>                           |

The general fund represents the 'free reserves'.

The designated fund represented ring-fenced funding in respect of providing funding for a Scientific Deputy in the ERNDIM office. It was decided during the year that this was no longer required and the balance was transferred to the general fund.

### 14. Related party transactions

There were no related party transactions during the year (2021: none).