

**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 2019

Registered number: 02567711

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## Reference and administrative details

For the year ended 31 December 2019

<b>Trustees</b>	Ms A Y Brown, Treasurer Prof Dr D M Cassiman Prof Dr J D B Häberle Prof G la Marca Dr H Michelakakis Asst Prof F M J Mochel Prof E Morava-Kozicz Prof K Ounap Dr M D S Quelhas Dr A Ribes Prof J C Rocha Prof G S Salomons, Chair Prof M Schiff
<b>Company secretary</b>	Prof M Schiff
<b>Company registered number</b>	02567711
<b>Charity registered number</b>	1010639
<b>Registered office</b>	130-132 Tooley Street London SE1 2TU
<b>Independent auditor</b>	Buzzacott LLP 130 Wood Street London EC2V 6DL
<b>Bankers</b>	Barclays Bank PLC PO Box 43 Sheffield S9 2LF

## **Trustees' report**

For the year ended 31 December 2019

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 2019.

### **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:

Ms A Y Brown  
Prof Dr D M Cassiman (appointed on 4 September 2019)  
Prof Dr J D B Häberle  
Prof G la Marca (appointed on 4 September 2019)  
Dr H Michelakakis  
Asst Prof F M J Mochel  
Prof E Morava-Kozicz  
Prof K Ounap  
Dr M D S Quelhas  
Dr A Ribes  
Prof J C Rocha (appointed on 4 September 2019)  
Prof G S Salomons, Chair  
Prof M Schiff  
Miss H C Allen (resigned on 18 April 2019)  
Dr A A M Morris (resigned on 30 April 2019)  
Prof I Baric (resigned on 4 September 2019)

### **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 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).

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

## Trustees' report (continued)

For the year ended 31 December 2019

### 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.

It should be noted that the current SSIEM Treasurer is also on the European Research Network for Evaluation and Improvement of Screening, Diagnosis and Treatment of Inborn Errors of Metabolism ('ERNDIM') Board of Trustees and that the SSIEM pays ERNDIM for Education and Training Society ('ETAC') administrative functions. 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), a previous SSIEM Honorary Treasurer or Ex-Officio member of Council and an independent financial advisor.

## ACHIEVEMENTS AND PERFORMANCE

### Review of activities

During the year ended 31 December 2019 the Society published Journals and continued development of its own website and app. In accordance with recent practice, a symposium was held in Rotterdam in 2019. In addition, arrangements progressed with the Local Organising Committee (LOC) and Professional Conference Organizer (PCO) for the SSIEM symposium Freiburg (2020). However, on 30<sup>th</sup> March 2020 the difficult decision was taken to postpone the annual meeting in Freiburg to 2022 due to the evolving SARS-CoV-2 (COVID-19) pandemic. This meeting was postponed to 2022 to avoid competition with the ICIEM\* symposium to be held in Sydney in 2021.

The membership subscription structure remained the same as that of 2018.

Travel Scholarships to the SSIEM symposium in Rotterdam were awarded to 23 healthcare professionals after an application and review process. 16 countries were represented.

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 was held in April 2019 in Zurich, Switzerland. Two additional training courses were held in 2019 the NGS course in Barcelona, Spain in March and the IMD adult Course in October in Paris, France.

The SSIEM Journal of Inherited Metabolic Disease (JIMD) was again run from the JIMD Editorial Office in Heidelberg. New agreements with the JIMD Editorial Office and a new contract with new publisher Wiley's were signed to start 1<sup>st</sup> January 2019.

## Trustees' report (continued)

For the year ended 31 December 2019

The SSIEM offered modest financial support for non-profit organisations such as parent support groups or Societies. In 2019, twenty two applications were received in the 1<sup>st</sup> round and sixteen in the 2<sup>nd</sup> round. These applications were independently judged by a panel from the SSIEM Advisory Council. A total of nine awards were made for a total of €20,000.

Travel support for educational activities for healthcare professionals seeking experience in centres of excellence is also available and three awards were made in 2019.

\*ICIEM (International Congress of Inborn Errors of Metabolism); global symposium hosted by SSIEM and its sister Societies on a rotation basis. Symposium surplus goes to the hosting Society and the 2021 congress will be held in Sydney, Australia.

### 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. Surplus funds are invested. Interest from investments is used in pursuance of the educational objectives of the Society.

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 Honorary Office and Council have also reviewed the current position with regard to the COVID-19 pandemic.

The Society is truly international with membership drawn from more than 78 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 2019, the annual subscription of 2 (2018: 1) members was paid by the Society.

#### Results for the year

Overall the financial result for the year was a net increase in the reserves of €348,865 to a year-end figure of €2,768,957.

#### 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 management and administration and support costs and allows the Society to be managed efficiently. This reserve is set at €1,000,000 (2018: €800,000). The Council proposes that a proportion of the surplus funds are invested, in 2019 this was increased by €250,000 now standing at €900,000 (2018: €650,000); the investments are split between Government Bonds (€400,000) and an ethically managed fund (€500,000). The purpose of the investment is to provide the SSIEM with a modest income from its surplus and to future proof the Society. The funds can be easily accessed if required. The remaining surplus is used in pursuance of the educational objectives of the Society. A limited number of grants will become available 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, is being further developed, together with travel bursaries, symposium scholarships and also development of Guidelines. As at 31 December 2019 an unrestricted fund balance of €2,768,957 (2018: €2,420,092) was held.

## Trustees' report (continued)

For the year ended 31 December 2019

During the year, the Council utilised some of the reserves to develop the SSIEM Academy and to make training more readily available. Two additional courses were funded and supported, Next Generation Sequencing (Barcelona) and management of Adult Inborn Errors of Metabolism (Paris). Further events are planned for 2020.

### 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.

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 in regards to a force majeure event.

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 run under contract with the Association for Clinical Biochemistry and Laboratory Medicine Office. A back-up of data is routinely scheduled and held off-site.
- Compliance with new GDPR regulations. Specialist advice has been sought to ensure compliance. A policy is being drawn up.

#### Financial risk

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

#### Brexit risk

- The uncertainty surrounding Brexit may pose risks to the Society in general. The Society continues to follow reputable media sources in order to better identify these risks and plan for them.

## Trustees' report (continued)

For the year ended 31 December 2019

### COVID-19

- The uncertainty surrounding the COVID-19 pandemic worldwide; the Society continues to review the situation and look into holding virtual meetings and use all available IT facilities to engage with all those interested in inherited metabolic disorders.

### PLANS FOR FUTURE PERIODS

#### Future developments

The Council will continue to:

- Review and develop corporate governance.
- Develop the SSIEM own administration team.
- Continually assess and manage risk.
- Develop the new SSIEM website hosted by Carpemedia.
- Develop/update Symposium and SSIEM apps.
- Support the Vademecum Metabolicum app if requested.
- Support parent support groups or Societies through the funding award scheme.
- Support healthcare professionals seeking experience in centres of excellence.
- Encourage ERNDIM-SSIEM Collaboration.
- Support and/or invite Societies to provide educational meetings or training courses.

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 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.

### COVID-19

The decision to cancel the symposium planned for September 2020 in Freiburg was taken early (30 March 2020) to prevent further unnecessary expense for the SSIEM, speakers, delegates and industry. Should travel restriction be lifted a significant disinclination to travel is anticipated and indeed many countries may still be under lockdown. This would have considerable impact on availability of speakers, delegate numbers and industry which in turn would affect the quality of the SSIEM experience and scientific standing.

In respect of SSIEM conferences, SSIEM has been able to mitigate cancellation costs for the symposium in Freiburg by negotiation with the venue and local conference organisers. Cancellation cost is approximately €144,336 equating to 10% of the expense budget. A small proportion of this expense reflects design and planning which can be transferred to the 2022 symposium.

The SSIEM will not realise any significant income in 2020 nor 2021 due to the ICIEM symposium in Sydney. It is fortunate that recent symposia have contributed to the SSIEM surplus providing a financial cushion at least for the next two years. However the SSIEM must be cognitive that other pandemics or a COVID-19 recurrence are a real risk and plan accordingly.

## Trustees' report (continued)

For the year ended 31 December 2019

The SSIEM has been able to host its Council meetings using video conferencing technology. This will reduce travel and accommodation costs. However if possible at least one face to face meeting per year would be valuable. The SSIEM is also investigating the possibility of a virtual conference to fill the gap in the 2020/2021 calendar. If successful this could be utilised for mini conferences and training events which could have a global reach without travel. This may also generate some income for the SSIEM.

### 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.

## Trustees' report (continued)

For the year ended 31 December 2019

### 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.

### 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:

  
A Y Brown (Oct 27, 2020 11:39 GMT)

**Ms A Y Brown**  
Trustee

Date: 27-Oct-2020

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

For the year ended 31 December 2019

### **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 2019, 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 2019 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**

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

- the Trustees who are also the directors of the Society for the purposes of company law use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the Society's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

## **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 2019

### **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 2019

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.

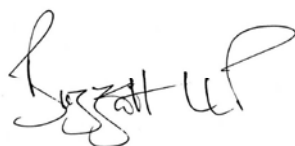
### **Auditor's responsibilities for the audit of the financial statements**

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.

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: 27 October 2020

## Statement of financial activities

For the year ended 31 December 2019

Income and expenditure	Note	Unrestricted funds 2019 €	Unrestricted funds 2018 €
<b>Income from:</b>			
Charitable activities	3	2,306,813	1,869,717
Investments	4	12,562	11,509
Other income	5	269,492	309,578
<b>Total income</b>		<u>2,588,867</u>	<u>2,190,804</u>
<b>Expenditure on:</b>			
Charitable activities	6	2,349,126	1,695,583
<b>Total expenditure</b>		<u>2,349,126</u>	<u>1,695,583</u>
<b>Net income before investment gains and losses</b>		<b>239,741</b>	495,221
Unrealised gain/(loss) on revaluation of fixed asset investments	9	62,985	(22,941)
Net gain on investments	9	2,624	1,910
Gain/(Loss) on retranslation of fixed asset investments		43,515	(12,157)
<b>Net movement in funds</b>		<b>348,865</b>	462,033
<b>Reconciliation of funds:</b>			
Total funds at 1 January 2019	12	2,420,092	1,958,059
<b>Total funds at 31 December 2019</b>		<u><b>2,768,957</b></u>	<u>2,420,092</u>

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

All of the charity's activities derived from continuing operations during the above two financial periods.

The notes on pages 15 to 21 form part of these financial statements.

## Statement of financial position

As at 31 December 2019

	Note	€	2019 €	€	2018 €
<b>Fixed assets</b>					
Investments	9		1,095,171		777,220
<b>Current assets</b>					
Debtors	10	641,617		799,052	
Cash at bank and in hand		<u>1,667,886</u>		<u>1,188,944</u>	
		<b>2,309,503</b>		<b>1,987,996</b>	
<b>Creditors: amounts falling due within one year</b>	11	<u>(635,717)</u>		<u>(345,124)</u>	
<b>Net current assets</b>			<b>1,673,786</b>		<b>1,642,872</b>
<b>Net assets</b>			<u><b>2,768,957</b></u>		<u><b>2,420,092</b></u>
<b>Charity funds</b>					
Unrestricted funds:					
General fund	12	2,558,440		2,143,600	
Designated fund	12	<u>210,517</u>		<u>276,492</u>	
			<u><b>2,768,957</b></u>		<u><b>2,420,092</b></u>
<b>Total unrestricted funds</b>			<u><b>2,768,957</b></u>		<u><b>2,420,092</b></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 27-Oct-2020 and signed on their behalf by:

A.Y. Brown  
A.Y. Brown (Oct 27, 2020 11:39 GMT)  
**Ms A Y Brown**  
 Trustee

The notes on pages 15 to 21 form part of these financial statements.

## Statement of cash flows

For the year ended 31 December 2019

	2019	2018
	€	€
<b>Cash flow from operating activities:</b>		
Net cash generated from/(used in) operating activities	A <u>675,208</u>	<u>(43,669)</u>
<b>Cash flow from investing activities</b>		
Purchase of investments	(223,264)	(20,608)
Disposal of investments	14,436	8,471
Investment income	12,562	11,509
<b>Net cash (used in)/generated from investing activities</b>	<u>(196,266)</u>	<u>(628)</u>
<b>Change in cash and cash equivalents in the year</b>	<b>478,942</b>	<b>(44,297)</b>
<b>Cash and cash equivalents at beginning of year</b>	<u>1,188,944</u>	<u>1,233,241</u>
<b>Cash and cash equivalents at end of year</b>	B <u>1,667,886</u>	<u>1,188,944</u>

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

	2019	2018
	€	€
<b>Net income for the year (as per the Statement of financial activities)</b>	348,865	462,033
<b>Adjustments for:</b>		
(Gain)/loss on revaluation of investments	(62,985)	22,941
Gain on disposal of investments	(2,624)	(1,910)
(Gain)/loss on retranslation of fixed asset investments	(43,515)	12,157
Investment income	(12,562)	(11,509)
Decrease/(increase) in debtors	157,436	(595,481)
Increase in creditors	290,593	68,100
<b>Net cash used in operating activities</b>	<u>675,208</u>	<u>(43,669)</u>

### B Analysis of cash and cash equivalents

	2019	2018
	€	€
Cash at bank and in hand	1,573,379	1,181,605
Cash held by investment managers	94,507	7,339
<b>Total cash and cash equivalents</b>	<u>1,667,886</u>	<u>1,188,944</u>

## Notes to the financial statements

For the year ended 31 December 2019

### 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 130-132 Tooley Street, London, SE1 2TU. The company registration number is 02567711 and the charity 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 (effective 1 January 2015) (Charities SORP FRS 102), Section 1A of Financial Reporting Standard 102, 'The Financial Reporting Standard applicable in the United Kingdom 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.

However, the coronavirus pandemic provides an inherent uncertainty regarding the Society's ability to continue as a going concern because it is not possible to predict the outcome of this unprecedented event. The Trustees are implementing contingency plans to mitigate any negative effects and therefore do not believe that the effect of the coronavirus will be significant. The financial statements have therefore been prepared on the going concern basis.

#### 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 2019

### 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 charity 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 fulfilled. 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 2019

### 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

	Unrestricted funds 2019 €	Total funds 2019 €	Total funds 2018 €
Annual symposium	2,164,044	2,164,044	1,744,419
Subscriptions	134,831	134,831	118,260
Academy income	7,938	7,938	7,038
	<u>2,306,813</u>	<u>2,306,813</u>	<u>1,869,717</u>

### 4. Income from investments

	Unrestricted funds 2019 €	Total funds 2019 €	Total funds 2018 €
Income bonds	4,988	4,988	4,645
Interest income	2,219	2,219	1,954
Dividend income	5,355	5,355	4,910
	<u>12,562</u>	<u>12,562</u>	<u>11,509</u>

## Notes to the financial statements

For the year ended 31 December 2019

### 5. Other Income

	Unrestricted funds 2019 €	Total funds 2019 €	Total funds 2018 €
Journal royalties	261,721	261,721	260,842
Editorial expenses contribution	-	-	48,736
Courses	7,771	7,771	-
	<u>269,492</u>	<u>269,492</u>	<u>309,578</u>

### 6. Analysis of charitable activities

	Unrestricted funds 2019 €	Total funds 2019 €	Total funds 2018 €
<b>Direct costs</b>			
Council symposium expenses	29,428	29,428	20,454
Publication of journal	173,479	173,479	110,956
JIMD Honorarium	19,000	19,000	52,000
Academy expenses	107,968	107,968	149,715
Symposium awards	1,236	1,236	1,500
Symposium expenses	1,511,284	1,511,284	782,410
Symposium scholarships	29,286	29,286	41,245
Courses	100,114	100,114	-
<b>Total direct costs</b>	<u>1,971,795</u>	<u>1,971,795</u>	<u>1,158,280</u>
<b>Support costs</b>			
Council travel and subsistence	67,069	67,069	49,030
Printing, postage, stationery and carriage	23,493	23,493	3,609
Exchange rate variance	(18,253)	(18,253)	1,154
Website costs	29,405	29,405	1,670
Other administration expenses	44,641	44,641	279,974
Secretarial expenses	82,922	82,922	87,574
Telephone and fax	646	646	965
IT supplies	5,044	5,044	(172)
Penalties & fines	4,239	4,239	4,107
Irrecoverable VAT	98,776	98,776	80,259
<b>Total support costs</b>	<u>337,982</u>	<u>337,982</u>	<u>508,170</u>
<b>Governance costs</b>			
Audit & accountancy fees	39,349	39,349	19,464
Professional charges	-	-	9,669
<b>Total governance costs</b>	<u>39,349</u>	<u>39,349</u>	<u>29,133</u>
<b>Total expenditure on charitable activities</b>	<u>2,349,126</u>	<u>2,349,126</u>	<u>1,695,583</u>

During the year, 28 (2018: 28) delegates were supported with financial grants totalling €29,286 (2018: €35,858).

## Notes to the financial statements

For the year ended 31 December 2019

### 7. Trustees' remuneration

No Trustees received any remuneration or benefits in kind in respect of their services during the year (2018: €Nil). During the year, 14 Trustees (2018: 12) received reimbursement of expenses totalling €13,738 (2018: €23,875).

### 8. Auditor's remuneration

Auditor's remuneration amounts to a current year audit fee of €20,599 (2018: €11,090) and fees charged for other non-audit services amounts to €18,750 (2018: €8,374).

### 9. Fixed asset investments

Market value	Listed securities €	Other investments €	Total €
At 1 January 2019	333,620	443,600	777,220
Additions at cost	223,264	-	223,264
Disposals at book value (proceeds: €9,190 Loss: €2,623)	(11,813)	-	(11,813)
Foreign exchange movement	18,679	24,836	43,515
Revaluations	62,985	-	62,985
	<u>626,735</u>	<u>468,436</u>	<u>1,095,171</u>
At 31 December 2019	<u>626,735</u>	<u>468,436</u>	<u>1,095,171</u>
Historical cost	<u>333,620</u>	<u>443,600</u>	<u>777,220</u>

Investments at market value comprise of the following:	2019 €	2018 €
Listed investments	626,735	333,620
Other investments	468,436	443,600
	<u>1,095,171</u>	<u>777,220</u>

Other investments comprise of £400,000 National Savings Bank income bonds, which have been retranslated into Euros at the year-end rate. Accordingly, they are included at cost, which represents the capital value of the bonds to the Society. Investments are held to provide an investment return.

All fixed asset investments are held in the UK.

## Notes to the financial statements

For the year ended 31 December 2019

### 10. Debtors

	2019 €	2018 €
Trade debtors	354,176	565,541
Prepayments and accrued income	<u>287,441</u>	<u>233,511</u>
	<u><b>641,617</b></u>	<u><b>799,052</b></u>

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

	2019 €	2018 €
Trade creditors	300,563	86,565
Other creditors	78,238	102,314
Accruals and deferred income	<u>256,916</u>	<u>156,245</u>
	<u><b>635,717</b></u>	<u><b>345,124</b></u>

	2019 €	2018 €
Deferred income at beginning of year	58,988	65,526
Resources deferred during the year	1,890	58,988
Amounts released from previous years	<u>(58,988)</u>	<u>(65,526)</u>
Deferred income at end of year	<u><b>1,890</b></u>	<u><b>58,988</b></u>

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

### 12. Unrestricted funds

	Balance at 1 January 2019 €	Income €	Expenditure €	Gain on investments €	Transfers between funds €	Balance at 31 December 2019 €
General fund	2,143,600	2,588,867	(2,283,151)	109,124	-	2,558,440
Designated fund	276,492	-	(65,975)	-	-	210,517
	<u><b>2,420,092</b></u>	<u><b>2,588,867</b></u>	<u><b>(2,349,126)</b></u>	<u><b>109,124</b></u>	<u><b>-</b></u>	<u><b>2,768,957</b></u>

The general fund represents the 'free reserves' and the designated fund represents ring-fenced funding in respect of providing three and a half years of funding for a Scientific Deputy in the ERNDIM office.

## Notes to the financial statements

For the year ended 31 December 2019

### 13. Related party transactions

Ms A Y Brown, a Trustee of the Society, is also a Trustee of the European Research Network for Evaluation and Improvement of screening, Diagnosis and Treatment of Inborn Errors of Metabolism (ERNDIM). During the year, ERNDIM provided services totalling €66,715 (2018: €73,539) for Education and Training Advisory Committee (ETAC) administrative functions. There was an amount payable to ERNDIM as at 31 December 2019 of €2,208 (2018: €nil).

### 14. Post balance sheet events

Since the year-end the value of the Society's investments has markedly decreased as a result of the economic implications of the COVID-19 pandemic. The loss on investments is consistent with all organisations that currently hold investments given that financial markets have decreased globally. The Society plans to hold its investments over the long-term and therefore all unrealised losses on investments arising from the economic impact of COVID-19 are expected to be temporary and over the long-term the valuation of its investments will reflect robust fundamentals. On this basis the directors are of the opinion that no adjustments are necessary within these financial statements.