

**THE SOCIETY FOR THE STUDY  
of  
INBORN ERRORS OF METABOLISM**

**NOTICE OF  
ANNUAL GENERAL MEETING – 2022**

to be held in

Freiburg, Germany

on

Wednesday 31st August 2022

at 13.30 local time

Prof M Schiff  
Honorary Secretary

# THE SOCIETY FOR THE STUDY of INBORN ERRORS OF METABOLISM

## ANNUAL GENERAL MEETING – 2022

### AGENDA (Chair: Prof G S Salomons)

1. Apologies (Honorary Chair)
2. To receive the minutes of the previous meeting held on Friday 10th September 2021 online (Honorary Chair)
3. Matters arising from the previous meeting (Honorary Chair)
4. Election of Honorary Officers and Directors/Trustees (Honorary Secretary)
5. Society Accounts & Balance Sheet for 2021 (Honorary Treasurer)
6. Council to tender for the Society's Auditors/Accountants (Honorary Treasurer)
7. JIMD report (Editor in Chief)
8. ETAC (Education, Training & Advisory Committee) report (Chair of ETAC)
9. Future SSIEM Symposium (Honorary Secretary)
10. SSIEM – Special Interest Groups
  - A Adult Metabolic Physicians Working Group report (Chair AWG)SSIEM – Special Interest Groups
  - B Dietitians Group report (Chair DG)
11. Any other business (Honorary Secretary)

# HONORARY SECRETARY'S REPORT

## 2021-2022

### MEMBERSHIP

The membership at the end of 2021 had slightly decreased by 5 members from 2020 to a total membership of 1405. 2021 was the fifth year of the new two-tier subscription rate being applicable to “high income countries” and the “rest of the world”. Membership subscription is applied to those countries in the high-income group as identified by the World Bank List of Economies to keep the SSIEM more accessible and affordable on a global scale. Membership came from over 75 different countries.

Council remains very aware of the burden that the subscription may have on individuals in different countries, associated with the different pay scales of many of its members. A standard rate applies for membership subscription to citizens from the high-income countries as identified by the World Bank List of Economies and a reduced rate to citizens from all other countries, making membership of the SSIEM more accessible and affordable on a global scale. A reduced fee was set for those who do not fit the category of the standard rate (i.e. fully qualified, tenured position applicable to physician, researcher, scientist, geneticist or equivalent). This scheme is deemed to be fair and equitable for most individuals in the differing specialties and countries. The membership support scheme will remain in place for those requiring subscription support and we would ask our existing members to please inform their colleagues of this scheme.

### COUNCIL

Council met virtually on four occasions during the year under the Chair of Prof G S Salomons. The Chair announced during the Annual General Meeting that Prof E Morava-Kozicz (Editor-in-Chief JIMD) would be stepping down as of 31st December 2021 to be replaced by Prof S Rahman.

Membership of Council for 2021 comprised of:

- Prof G S Salomons (Honorary Chair)
- Prof M Schiff (Honorary Secretary)
- Prof P B Mills (Honorary Treasurer)
- Prof Dr D M Cassiman
- Dr A Garcia-Cazorla
- Prof G la Marca
- Dr R J Lapatto
- Dr H Michelakakis
- Asst Prof F M J Mochel
- Dr M D S Quelhas
- Prof J C Rocha
- Prof E Morava-Kozicz (Editor-in-Chief JIMD, Ex-Officio),
- Prof Dr J D B Häberle (Chair ETAC, Ex-Officio).

The Council has updated the detailed risk assessment relating to the Society's activities and it is reviewed on a regular basis.

## **ADVISORY COUNCIL MEMBERS**

Council appreciated the support and comments from individual Advisory Council members during the year. Advisory Council members can play an important role in choosing the venue for the Annual Symposium and in providing nominations for Council. Advisory Council members for 2021 were:

Dr J M Fletcher (Australia), Prof Dr D Karall (Austria), Dr J Songailiene (Baltic Countries), Prof M-C Nassogne (Belgium), Prof G A Mitchell (Canada), Prof K Fumic (Croatia), Prof A M Lund (Denmark), Dr P I Nevalainen (Finland), Dr D Dobbelaere (France), Prof Dr R Santer (Germany), Dr M Moraitou (Greece). Dr C W Fung (Hong Kong), Dr S Bijarnia-Mahay (India), Prof T Z Zaman (Iran), Ms P Fitzsimons (Ireland), Prof Y Anikster (Israel), Dr A B Burlina (Italy), Prof K Nakamura (Japan), Prof L Chabraoui (Morocco), Dr B Woldseth (Norway), Dr A H Khan (Pakistan), Prof J Sykut-Cegielska (Poland/Hungary), Dr D C Gomes (Portugal), Prof L A Barrera (South America), Prof D González-Lamuño (Spain), Prof A Nordenstrom (Sweden), Prof M Baumgartner (Switzerland), Dr T G J Derks (The Netherlands), Prof A Ben Chehida (Tunisia), Prof Dr T Coskun (Turkey), Dr J E Davison (United Kingdom), Dr B A Barshop (United States of America).

## **2021 EVENTS**

The 14th International Congress of Inborn Errors of Metabolism was held in Sydney Australia after being postponed until November and made into a hybrid meeting. Due to this postponement the SSIEM held another virtual symposium in September which was well attended by over 600 members and non-members and supported by Industry. The SSIEM would like to thank Dr A Garcia-Cazorla, Prof F M J Mochel, Prof E Morava, Prof G S Salomons, and Mr R Kerschbaumer, SSIEM Corporate Liaison Officer, together with everybody associated with the excellent virtual symposium all must be congratulated on hosting another most successful scientific day.

The Archibald Garrod Award Lecture for 2021, Simplifying the clinical classification of polymerase gamma (POLG) disease based on age of onset; studies using a cohort of 155 cases by Prof Laurence A Bindoff, Bergen, Norway.

## **FUTURE SSIEM and ICIEM SYMPOSIA**

The following are the venues for future SSIEM Symposia:

- SSIEM Annual Symposium, Freiburg, Germany, 2022
- SSIEM Annual Symposium, Jerusalem, Israel 2023
- SSIEM Annual Symposium, Porto, Portugal 2024
- 15th International Congress, SSIEM together with Australasian Society for Inborn Errors of Metabolism-ASIEM, Japanese Society of Inherited Metabolic Diseases-JSIMD, Society for Inherited Metabolic Disorders-SIMD, USA Based and Sociedad Latinoamericana de Errores Innatos del Metabolismo y Pesquisa Neonatal-Latin American Society-SLEIMPN the ICIEM, Japan, 2025

## **ETAC TRAINING**

The 13th SSIEM Training Academy was to take place in Amsterdam, The Netherlands, in April 2020 but due to the COVID-19 pandemic it was cancelled and will now take place in 2022 and a Virtual Training Academy took place in 2021.

The SSIEM Academy administrative team is comprised of Dr Sara Gardner, Miss Jennifer Barrett and Ms Katie Sheils. Prof Dr Johannes Häberle is the Chair, with Prof Simon Heales as the Secretary.

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# Honorary Secretary's Report

## **SSIEM ADMINISTRATION OFFICE**

The Council acknowledges the support given by Mr Nic Law and Mrs Caroline Hankinson of the new SSIEM Administration office in providing Council and the membership with invaluable support throughout the year, updating the website and liaising with third part organisations.

## **JOURNAL OF INHERITED METABOLIC DISEASE (JIMD)**

A more detailed report on the Journal is covered elsewhere within this Annual Report. Council appreciates the significant contribution of the Editorial team, the communicating editors and the publishers. Council would also like to thank the 2021 Editor-in-Chief, Prof E Morava, whose 6 year tenure came to an end on 31st December 2021 and to welcome the new Editorial Team and Editors-in-Chief Prof S Rahman (Senior) and Prof M Baumgartner after a bidding process.

The Editors and Council thank all for supporting the JIMD and JIMD Reports and are grateful to the Wiley Editorial team for their support.

## **SSIEM SUBGROUPS**

Prof F M J Mochel is the Chair of the SSIEM-Adult Metabolic Physicians' Group and Dr M Langeveld is the Secretary. The adult group continues to support the membership and organise meetings and training courses.

The SSIEM-Dietitians' Group led by Prof J C Rocha, continues to make an important contribution to the organisation of the dietetic component of the Society including new training events.

*Prof M Schiff  
Honorary Secretary  
22nd July 2022*

# HONORARY TREASURER'S REPORT 2021

## INCOME

The SSIEM continues with the tiered membership fee structure reflecting the need to make the membership fee financially acceptable across members' professions and countries. The SSIEM is under negotiation with the new publishers of the JIMD, John Wiley & Sons Limited, to continue its relationship for an additional five years to provide the SSIEM with a royalty payment hopefully in excess of €360,000 per year.

A small income was also generated from the investments and the revaluation of the Society's ethical investment portfolio with the original small loss becoming a small surplus in the accounts. However, the increase in the ethical portfolio is unrealised as it stays within our ethical investment portfolio. It was the second year of a large reduction in income and expenditure which is normal when the ICIEM Congress takes place. The original budget for 2021 reflected a large deficit however restrictions on travel, meetings, the exceptional work from Wiley's for the JIMD royalty and by Rathbones on investments, has changed the deficit to a paper surplus. We anticipate that with a face to face symposium in 2022 the SSIEM's finances will again show a small surplus. The Society's own Administration Team have been employed for over a year and are helping the Society to grow and enter into a new phase of the SSIEM's development.

## EXPENDITURE

The overall expenditure for 2021 was similar to 2020 when excluding the cancellation cost for the 2020 symposium.

Again in 2021 due to the COVID-19 pandemic restriction on travel and face-to-face meetings kept expenditure lower. However, items of expenditure include:

- SSIEM Administration team
- Awards, Grants and Scholarships
- Governance Costs relating to the Society and Symposium
- Legal advice
- Journal Production
- Website development
- ERNDIM-SSIEM collaboration
  - o Funding support agreed at 2015 AGM and will be extended until 2022.

Future expenditure 2022:

- Travel support for educational activities
  - o Any healthcare professional seeking experience in centres of excellence
  - o ETAC-NAMA collaboration
- Symposium
- Awards, Grants and Bursaries
- Development of the SSIEM own administration team and PCO
- Additional training events.

## BALANCE SHEET

Total amount in accumulative fund increased in 2021, by €79,466 and stands at €2,813,947.

## **FINANCIAL POLICY**

Publishing and administration – our policy is to cover the majority of the journal and support administrative costs from member’s subscriptions and journal royalties. All direct costs attributable to the symposium will be funded by the symposium.

Lower risk ethical investments are in place to realise a better financial return on our accumulated funds.

A financial sub-committee of Council is in place to review the Society’s financial activities and investments. 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 ethical investments there is unlikely to be any delay or shortfall in realising the assets into cash if this becomes necessary.

## **RESERVES**

It is the policy of the Society to maintain unrestricted funds, which are the pre-reserves, at a level that is sufficient to cover management, and administration support costs, and allows the Society to be managed efficiently. It is the policy of Council to use some of the unrestricted funds to encourage the sharing of experience and training between Centers. The reserve is currently set at €1,000,000. Although the reserves appear substantial, Council has always considered that such reserves be maintained in order to cover the eventuality of a major disaster with an Annual Symposium and also running costs of the Society for 12 months as it is now an employer.

The reserves will also be used to develop:

- The SSIEM Academy
- Future-proof the SSIEM administrative functions
- Education and practical support for countries introducing investigation and treatment of inborn errors of metabolism
- Patient treatment guidelines
- Training and Educational events
- Supporting symposia in and outside of Europe
- Awards and Grants for individuals to attend educational meetings or attend educational or training facilities.

Those members who have colleagues who find it financially difficult to join the Society are encouraged to suggest that their colleagues apply directly to the Honorary Treasurer for a Membership Support Grant for 1 to 5 years, application available online via the SSIEM website.

## **SECRETARIAT**

The SSIEM is now developing its own administration team.

## **RISK MANAGEMENT**

A thorough risk assessment has been undertaken. The trustees have examined the major strategic, business and operational risks that the Society faces and have established systems so that the necessary steps can be taken to lessen these risks. The risk assessment is reviewed at each Council meeting.

## **COVID-19**

There is still a possibility that something could happen with the Freiburg Symposium for 2022 but this is constantly checked by the SSIEM.

## **AUDITORS**

The SSIEM Council looked at tendering for the Society's Auditors/Accountants and have concluded that the SSIEM should stay with Buzzacott LLP for the immediate future.

A copy of the full accounts is appended to this report and is also available on the SSIEM website.

*Prof P B Mills  
Honorary Treasurer  
22nd July 2022*

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# Honorary Treasurer's Report

# JOURNAL OF INHERITED METABOLIC DISEASE (JIMD) REPORT 2021-2022

After a competitive bidding process, Profs Shamima Rahman and Matthias Baumgartner began their tenure as Editors in Chief of JIMD and JIMD Reports in January 2022 and thank Prof Eva Morava for her service to the journals as Editor in Chief for the last 6 years.

In 2021, 114 articles were printed in “JIMD” (original articles, reviews and invited articles) and 80 articles were published in the open access journal “JIMD Reports”. Submissions came from 46 different countries. For JIMD, the majority of articles originated from the USA, China, Germany, Italy, the Netherlands and United Kingdom. For JIMD reports, the majority of articles came from the USA, Canada, UK and Australia. In 2020-2021 the JIMD Impact Factor increased to 4.982 (4.036 in 2019-2020) because of a change in the way that impact factors are calculated. **The latest impact factor for 2020-2021 is 4.75**, which overall shows a steady increase over a 2-year period if the artefactual elevation of 2019-2020 is discounted (the 5-year Impact Factor is 4.9). JIMD is currently ranked 52nd out of 146 titles in the category “Endocrinology & Metabolism”, 44th out of 175 in “Genetics & Heredity” and 63rd out of 139 in the category “Medicine, Research & Experimental”, meaning that JIMD is ranked in the top 30% of its peers.

All of our recent **Themed issues** have been a great success and have contributed above average to the development of the Impact Factor. We have recently compiled a special, free access, online collection of 17 articles on “Metabolic Cardiomyopathy” sourced from both JIMD and JIMD Reports.

**The Communicating Editor Awards 2022** for work in 2021 go to Drs Areeg El-Gharbawy and Roberto Giugliani as busiest Editors, and to Dr Carlos Ferreira as fastest Editor. We remain indebted to all Communicating Editors and reviewers who have added invaluable expertise and invested considerable effort, contributing to the continuing success of the Journal of Inherited Metabolic Disease and JIMD Reports. A special thanks to Prof Emeritus Lars Morkrid who supports us as a Statistical Editor and to our Social Media Editor Dr James Nurse. The visual abstracts and podcasts, created under the direction of Dr James Nurse, are very popular with our readers. At submission, please indicate whether you are interested in presenting your published data in a podcast version and/or would like support for a visual abstract. In 2022-2023 we will be pleased to welcome as Editorial Associates Drs Nicola Brunetti-Pierri, Patrick Forny, Kaustuv Bhattacharya, Karolina Stepien and Jirair Bedoyan, who will each spend a period of three months working with the Editorial Team.

We look forward to seeing you at the SSIEM Symposium in Freiburg when the Archibald Garrod Award 2022 will be presented by Friederike Hörster on Tuesday 30 August 2022. All publications in 2021 that provided a comprehensive, representative analysis of the clinical features, treatment and outcome of an inherited metabolic disease were considered for this prize.

If you have an idea for a themed issue, editorial or new conceptual ideas, please contact us! Follow us on Twitter @JIMD\_Editors

*On behalf of the Editorial Team  
Prof Shamima Rahman and Prof Matthias Baumgartner, Editors in Chief,  
Prof Eva Morava, Prof Marc C Patterson,  
Prof Dr Verena Peters, and Prof Johannes Zschocke*

# REFERENCE AND ADMINISTRATIVE DETAILS

## For the year ended 31 December 2021

### **Trustees**

Prof Dr D M Cassiman  
Dr A Garcia-Cazorla  
Prof Dr Med J D B Häberle  
Prof G la Marca  
Dr R J Lapatto  
Dr H Michelakakis  
Prof P B Mills, Treasurer  
Prof F M J Mochel  
Dr M D S Quelhas  
Prof S Rahman  
Prof J C Rocha  
Prof G S Salomons, Chair  
Prof M Schiff

### **Company Secretary**

Prof M Schiff

### **Company Registered Number**

02567711

### **Charity Registered Number**

1010639

### **Registered Office**

C/O Stone King LLP  
Boundary House  
91-93 Charterhouse Street  
London  
EC1M 6HR

### **Independent Auditor**

Buzzacott LLP  
130 Wood Street  
London  
EC2V 6DL

### **Bankers**

Barclays Bank PLC  
PO Box 43  
Sheffield  
S9 2LF

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# General Information

# TRUSTEES' REPORT

## **For the year ended 31 December 2021**

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 2021.

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

Prof Dr Med J D B Häberle

Prof G la Marca

Dr R J Lapatto

Dr H Michelakakis

Prof P B Mills, Treasurer

Prof F M J Mochel

Prof E Morava-Kozicz (resigned on 1 January 2022)

Dr M D S Quelhas

Prof J C Rocha

Prof G S Salomons, Chair

Prof M Schiff, Secretary

## **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).

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') comprises the current Honorary Treasurer, Honorary Chair, Honorary Secretary, Chair and Secretary Elect, previous Honorary Treasurer and an independent financial advisor plus invited members of staff and CLO.

## **ACHIEVEMENTS AND PERFORMANCE**

### ***Review of activities***

During the year ended 31 December 2021 the Society published Journals and continued development of its own administration. The SSIEM held a virtual symposium and AGM in 2021 as the ICIEM (International Congress of Inborn Errors of Metabolism) Congress was postponed until November 2021.

The membership subscription structure remained the same as 2020.

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 2021 was a virtual Academy. The SSIEM also held Dietitian and Adult training courses.

The SSIEM Journal of Inherited Metabolic Disease (JIMD) and JIMD Reports were 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.

The SSIEM offered modest financial support for non-profit organisations such as parent support groups or societies. In 2021 eight applications were received in the 1st round and twelve in the 2nd 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 was awarded to two individuals along with membership support.

The Society also supported the development of guidelines associated with inborn errors of metabolism which will be published in the JIMD.

The ICIEM which is a International Congress hosted by SSIEM and its sister societies, ASIEM, JSIMD, SIMD and SLEIMPN, on a rotation basis. Congress surplus goes to the hosting society which was held in Sydney, Australia as a hybrid meeting.

## **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 about the COVID-19 pandemic.

The Society is truly international with membership drawn from more than 75 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 2021, the annual subscriptions of 4 (2020: 4) members were paid by the Society.

### ***Results for the year***

Overall, the financial result for the year was a net increase in the reserves of €79,466 (2020: €34,476 net decrease in reserves) to a year-end figure of €2,813,947 (2020: €2,734,481).

### ***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 (2020: €1,000,000). This is considered to be enough to cover a year's worth of expenditure if no income were earned. The Council proposes that a proportion of the surplus funds are invested, currently €1,100,000 (2020: €900,000); 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. 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. Travel bursaries, symposium scholarships and also development of guidelines associated with inborn errors of metabolism are also supported. As at 31st December 2021 an unrestricted fund balance of €2,813,947 (2020: €2,734,481) was held.

During the year, the Council utilised some of the reserves to develop its administration with the employment of two staff members and purchase of operating systems. Support of non-profit organisations, such as parent support groups, was also promoted.

### ***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.
- Making the Symposia a hybrid 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 back-up routinely.
- Compliance with GDPR regulations. Specialist advice has been sought to ensure compliance.

### 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 persists and 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.

### 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:

- Develop the SSIEM own administration team & Professional Conference Organiser (PCO)
- Review and develop corporate governance.
- Continually assess and manage risk.
- Develop the new SSIEM website.
- Develop/update Symposium and SSIEM apps.
- Support parent support groups or Societies through the funding award scheme.
- Support healthcare professionals 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.
- Support for the CDB-IMB-database.

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 reschedule the symposium planned for September 2020 to 2022 in Freiburg and to continue as a face to face meeting has been investigated by the SSIEM and will be updated monthly to see if the meeting should be made Hybrid. The SSIEM must be cognitive that other pandemics or a COVID-19 recurrence are a real risk and plan accordingly.

The SSIEM did not realise any significant income in 2021 due to the ICIEM symposium in Sydney but the SSIEM did hold a virtual symposium which made a small surplus thanks to the excellent organising team. The success of this event has helped the SSIEM to hold other events to benefit the membership.

The SSIEM has been able to host its Council meetings using video conferencing technology. This has negated council costs. However at least one face to face meeting per year would be valuable.

### ***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.

#### ***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***  
***Treasurer***  
***22nd July 2022***

# INDEPENDENT AUDITORS’ REPORT

## *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 2021, 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 2021 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.

## *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 matter 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 14, 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.

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.

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# Independent Auditor's Report

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;
- we considered the impact of COVID-19 on the Society and its internal controls; 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 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; and
- tested journal entries to identify unusual transactions.

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

- 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  
22nd July 2022***

# STATEMENT OF FINANCIAL ACTIVITIES

## For the year ended 31 December 2021

		Unrestricted funds 2021	Unrestricted funds 2020
	Note	€	€
<b>Income and expenditure</b>			
<b>Income from:</b>			
Charitable activities – symposium and memberships	3	202,780	288,769
Charitable activities – journal royalties and courses	4	378,129	400,912
Investments	5	<u>17,647</u>	<u>15,447</u>
<b>Total income</b>		<b><u>598,556</u></b>	<b><u>705,128</u></b>
<b>Expenditure on:</b>			
Charitable activities	6	677,206	651,223
Exceptional expenditure	10	<u>–</u>	<u>144,336</u>
<b>Total expenditure</b>		<b><u>677,206</u></b>	<b><u>795,559</u></b>
<b>Net expenditure before investment gains and losses</b>		<b>(78,650)</b>	<b>(90,431)</b>
Unrealised gain on revaluation of fixed asset investment	11	41,661	105,624
Net gain on investments	11	16,855	11,847
Gain/(loss) on retranslation of fixed asset investments	11	<u>99,600</u>	<u>(61,516)</u>
<b>Net movement in funds</b>		<b>79,466</b>	<b>(34,476)</b>
<b>Reconciliation of funds:</b>			
Total funds at the beginning of the year	14	<u>2,734,481</u>	<u>2,768,957</u>
<b>Total funds at the end of the year</b>		<b><u>2,813,947</u></b>	<b><u>2,734,481</u></b>

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 23 to 28 form part of these financial statements.

# STATEMENT OF FINANCIAL POSITION

## As at 31 December 2021

	Note	€	2021 €	€	2020 €
<b>Fixed assets</b>					
Investments	11		<b>1,353,878</b>		1,215,138
<b>Current assets</b>					
Debtors	11	<b>288,094</b>		445,667	
Cash at bank and in hand		<b><u>1,433,921</u></b>		<u>1,323,431</u>	
		<b>1,722,015</b>		1,769,098	
<b>Creditors: amounts falling due within one year</b>					
	13	<b><u>(261,946)</u></b>		<u>(249,755)</u>	
<b>Net current assets</b>			<b><u>1,460,069</u></b>		<u>1,519,343</u>
<b>Net assets</b>			<b><u>2,813,947</u></b>		<u>2,734,481</u>
<b>Charity funds</b>					
Unrestricted funds:					
General fund	14	<b>2,750,468</b>		2,595,782	
Designated fund	14	<b><u>63,479</u></b>		<u>138,699</u>	
			<b><u>2,813,947</u></b>		<u>2,734,481</u>
<b>Total unrestricted funds</b>			<b><u>2,813,947</u></b>		<u>2,734,481</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 22nd July 2022 and signed on their behalf, by:

*Prof P B Mills*  
*Treasurer*

The notes on pages 23 to 28 form part of these financial statements.

# STATEMENT OF CASH FLOWS

## For the year ended 31 December 2021

	2021	2020
	€	€
<b>Cash flow from operating activities</b>		
Net cash generated from/(used in) operating activities	A <u>73,467</u>	<u>(295,892)</u>
<b>Cash flow from investing activities</b>		
Purchase of investments	(532,694)	(110,099)
Disposal of investments	552,070	46,089
Investment income	<u>17,647</u>	<u>15,447</u>
Net cash generated from/(used in) investing activities	37,023	(48,563)
<b>Change in cash and cash equivalents in the year</b>	<b>110,490</b>	<b>(344,455)</b>
<b>Cash and cash equivalents at beginning of year</b>	<b><u>1,323,431</u></b>	<b><u>1,667,886</u></b>
<b>Cash and cash equivalents at end of year</b>	B <b><u>1,433,921</u></b>	<b><u>1,323,431</u></b>
 <b>A Reconciliation of net income to net cash flow from operating activities</b>		
	2021	2020
	€	€
Net income/(loss) for the year (as per the Statement of financial activities)	79,466	(34,476)
<b>Adjustments for</b>		
Gain on revaluation of investments	(41,661)	(105,624)
Gain on disposal of investments	(16,855)	(11,847)
Gain/(loss) on retranslation of fixed asset investments	(99,600)	61,516
Investment income	(17,647)	(15,447)
Decrease in debtors	157,573	195,948
Increase/(decrease) in creditors	<u>12,191</u>	<u>(385,962)</u>
Net cash generated from/(used in) operating activities	<u><u>73,467</u></u>	<u><u>(295,892)</u></u>
 <b>B Analysis of cash and cash equivalents</b>		
	2021	2020
	€	€
Cash at bank and in hand	1,376,471	1,295,080
Cash held by investment managers	<u>57,450</u>	<u>28,351</u>
<b>Total cash and cash equivalents</b>	<b><u><u>1,433,921</u></u></b>	<b><u><u>1,323,431</u></u></b>

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# Statement of Cash Flows

# NOTES TO THE FINANCIAL STATEMENTS

## For the year ended 31 December 2021

### 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 11. 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 (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.

The Trustees have considered the impact of the current COVID-19 pandemic on the Society's ability to continue as a going concern. The Trustees do not consider this to be cause for material uncertainty in respect of the Society's abilities to continue as a going concern. The Society has adapted well, implementing contingency plans, and has continued to generate revenues despite the difficult circumstances. The Society has sufficient cash resources, including fixed asset investments, to continue for the foreseeable future, despite the current crisis. Therefore, the financial statements have 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.

### *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.

## 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

	<b>Unrestricted funds</b>	<b>Total funds</b>	Ttal funds
	<b>2021</b>	<b>2021</b>	<b>2020</b>
	€	€	€
Annual symposium	<b>74,871</b>	<b>74,871</b>	171,341
Subscriptions	<b>125,333</b>	<b>125,333</b>	117,428
Academy income	<b><u>2,576</u></b>	<b><u>2,576</u></b>	<u>–</u>
	<b><u>202,780</u></b>	<b><u>202,780</u></b>	<u>288,769</u>

## 4. INCOME FROM CHARITABLE ACTIVITIES – JOURNAL ROYALTIES AND COURSES

	<b>Unrestricted funds</b>	<b>Total funds</b>	Total funds
	<b>2021</b>	<b>2021</b>	<b>2020</b>
	€	€	€
Journal royalties	<b>362,208</b>	<b>362,208</b>	400,342
Courses	<b><u>15,921</u></b>	<b><u>15,921</u></b>	<u>570</u>
	<b><u>378,129</u></b>	<b><u>378,129</u></b>	<u>400,912</u>

## 5. INCOME FROM INVESTMENTS

	Unrestricted funds	Total funds	Total funds
	2021	2021	2020
	€	€	€
Income bonds	26	26	5,060
Interest income	5,908	5,908	2,620
Dividend income	<u>11,713</u>	<u>11,713</u>	<u>7,767</u>
	<u>17,647</u>	<u>17,647</u>	<u>15,447</u>

## 6. ANALYSIS OF CHARITABLE ACTIVITIES

	Unrestricted funds	Total funds	Total funds
	2021	2021	2020
	€	€	€
<b>Direct costs</b>			
Council symposium expenses	2,391	2,391	1,782
Publication of journal	106,921	106,921	174,833
JIMD Honorarium	21,000	21,000	20,500
Academy expenses	138,494	138,494	134,550
Symposium awards	–	–	2,500
Symposium expenses	81,140	81,140	89,960
Courses	<u>22,600</u>	<u>22,600</u>	<u>5,217</u>
<b>Total direct costs</b>	<b>372,546</b>	<b>372,546</b>	<b>429,342</b>
<b>Support costs</b>			
Salaries and wages	89,340	89,340	–
Council travel and subsistence	5,306	5,306	3,648
Printing, postage, stationery and carriage	13,987	13,987	576
Exchange rate variance	12,783	12,783	9,491
Website costs	21,256	21,256	13,068
Other administration expenses	55,457	55,457	54,071
Secretarial expenses	39,769	39,769	46,457
Telephone and fax	366	366	648
IT supplies	20,276	20,276	3,542
Bad debts	2,182	2,182	–
Irrecoverable VAT	<u>21,714</u>	<u>21,714</u>	<u>62,648</u>
<b>Total support costs</b>	<b>282,436</b>	<b>282,436</b>	<b>194,149</b>
<b>Governance costs</b>			
Audit & accountancy fees	22,194	22,194	25,668
Professional charges	<u>30</u>	<u>30</u>	<u>2,064</u>
<b>Total governance costs</b>	<b><u>22,224</u></b>	<b><u>22,224</u></b>	<b><u>27,732</u></b>
<b>Total expenditure on charitable activities</b>	<b><u>677,206</u></b>	<b><u>677,206</u></b>	<b><u>651,223</u></b>

Two delegates were supported with financial grants of €3,750 (2020: €Nil) during the year.

## 7. TRUSTEES' REMUNERATION

No Trustees received any remuneration or benefits in kind in respect of their services during the year (2020:€Nil). During the year, a Trustee received reimbursement of expenses of €33 (2020: €5,207, 7 Trustees).

## 8. AUDITOR'S REMUNERATION

Auditor's remuneration amounts to a current year audit fee of €14,293 (2020: €15,240) and fees charged for other non-audit services amounts to €5,777 (2020: €8,729).

9. STAFF COSTS	2021	2020
	€	€
Wages and salaries	75,922	–
Social security costs	7,875	–
Pension costs	5,543	–
	<u>89,340</u>	<u>–</u>

The average monthly number of employees during the year was 2 (2020: Nil).

During the year, no staff received emoluments exceeding €60,000 excluding employer pension contributions.

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 €89,340 (2020: €nil).

## 10. EXCEPTIONAL EXPENDITURE

	Unrestricted funds	Total funds	Total funds
	2021	2021	2020
	€	€	€
Cancellation costs	–	–	144,336
	<u>–</u>	<u>–</u>	<u>144,336</u>

During the year, cancellation costs totalling €Nil (2020: €144,336) were incurred by the Society with respect to the cancellation of the symposium.

## 11. FIXED ASSET INVESTMENTS

	Listed securities	Other investments	Total
	€	€	€
At 1 January 2021	773,014	442,124	1,215,138
Additions at cost	532,694	–	532,694
Disposals at book value (proceeds: €75,642, profit: €16,855)	(58,787)	(476,428)	(535,215)
Foreign exchange movement	65,296	34,304	99,600
Revaluations	41,661	–	41,661
At 31 December 2021	<u>1,353,878</u>	<u>–</u>	<u>1,353,878</u>
At 31 December 2020	<u>773,014</u>	<u>442,124</u>	<u>1,215,138</u>
<b>Investments at market value comprise of the following:</b>		<b>2021</b>	<b>2020</b>
		€	€
Listed investments		1,353,878	733,014
Other investments		–	442,124
		<u>1,353,878</u>	<u>1,215,138</u>

Other investments comprised of £400,000 National Savings Bank income bonds, disposed of during the year. Investments are held to provide an investment return.

All fixed asset investments are held in the UK.

## 12. DEBTORS

	2021	2020
	€	€
Symposium related debtors	5,000	93,908
Prepayments and accrued income	<u>283,094</u>	<u>351,759</u>
	<u>288,094</u>	<u>445,667</u>

## 13. CREDITORS:

### Amounts falling due within one year

	2021	2020
	€	€
Other creditors	62,361	33,584
Accruals and deferred income	<u>199,585</u>	<u>216,171</u>
	<u>261,946</u>	<u>249,755</u>

	2021	2020
	€	€
Deferred income at beginning of year	68,495	1,890
Resources deferred during the year	48,582	68,495
Amounts released from previous years	<u>(68,495)</u>	<u>(1,890)</u>
Deferred income at end of year	<u>48,582</u>	<u>68,495</u>

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

## 14. UNRESTRICTED FUNDS

	Balance at 1 January 2021	Income	Expenditure	Gains on investments	Transfers between funds	Balance at 31 Dec 2021
	€	€	€	€	€	€
General fund	2,595,782	598,556	(677,206)	158,116	75,220	2,750,468
Designated fund	<u>138,699</u>	—	—	—	<u>(75,220)</u>	<u>63,479</u>
	<u>2,734,481</u>	598,556	(677,206)	158,116	—	<u>2,813,947</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.

## 13. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year. During the last accounting year, the Society provided services totalling €42,704 to European Research Network for Evaluation and Improvement of screening, Diagnosis and Treatment of Inborn Errors of Metabolism (ERNDIM). Ms A Y Brown, a Trustee of ERNDIM, was also a Trustee of the Society in the last accounting year.

