

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

**NOTICE OF  
ANNUAL GENERAL MEETING – 2020**

to be held Online

on

Thursday 3rd December 2020

at 19.00 GMT

Prof M Schiff  
Honorary Secretary

# THE SOCIETY FOR THE STUDY of INBORN ERRORS OF METABOLISM

## ANNUAL GENERAL MEETING – 2020

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

1. Apologies (Honorary Chair)
2. To receive the minutes of the previous meeting held on Wednesday 4th September 2019 in Rotterdam, The Netherlands (Honorary Chair)
3. Matters arising from the previous meeting (Honorary Chair)
4. Society Accounts & Balance Sheet for 2019 (Honorary Treasurer)
5. Election of Council Members (Honorary Secretary)
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)
11. SSIEM – Special Interest Groups  
B Dietitians Group report (Chair DG)
12. Any other business (Honorary Secretary)

# HONORARY SECRETARY'S REPORT

## 2019-2020

### MEMBERSHIP

The membership at the end of 2019 had increased by 0.01% or 3 members on 2018 but still an increase of 27% since the end of 2010 a total membership of 1447. This was the fourth year of the new two-tier subscription rate being applicable to “*high income countries*” and the “*rest of the world*” and the standard rate of 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 78 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 would ask our existing members to please inform their colleagues of this scheme.

### COUNCIL

Council met on four occasions during the year; three times in London and once in Rotterdam, under the Chair of Prof G S Salomons. The Chair announced during the Annual General Meeting that Prof Ivo Baric and Dr Andrew Morris were leaving the SSIEM Council and that Miss Heather Allen had stepped down from her position and that Prof Júlio Rocha was proposed by the SSIEM Dietitians Group to replace her. Ms Anny Brown is also stepping down but will stay in position until the new Treasurer is in place and will help with the handover. The following persons were elected Council members Prof Giancarlo la Marca, Prof Dr David Cassiman, Prof Júlio Rocha and Dr Philippa Mills as Honorary Treasurer position to commence in 2020.

Membership of Council for 2019-2020 comprised of:

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

Mr N Law Executive Administrator at the Society's Registered Office at 130-132 Tooley Street, London has provided Council and the membership with invaluable support throughout the year.

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# Honorary Secretary's Report

## **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 2019-2020 were:

Dr J M Fletcher (Australia), Prof Dr D Karall (Austria), Dr J Songailiene (Baltic Countries), Prof M-C Nassogne (Belgium), Dr G A Mitchell (Canada), Prof K Fumic (Croatia), Dr A M Lund (Denmark), Dr R J Lapatto (Finland), Dr D Dobbelaere (France), Prof Dr R Santer (Germany), Dr M Moraitou (Greece). Dr J Hui (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), Dr T Okuyama (Japan), Prof L Chabraoui (Morocco), Dr B Woldseth (Norway), Dr A H Khan (Pakistan), Prof J Sykut-Cegielska (Poland/Russia/Hungary), Dr M D S Quelhas (Portugal), Prof L A Barrera (South America), Dr A Garcia-Cazorla (Spain), Dr 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 R H Lachmann (United Kingdom), Dr B A Barshop (United States of America).

## **2019 ANNUAL SYMPOSIUM**

The 52nd SSIEM Symposium was held in Rotterdam, The Netherlands, organized on behalf of the Society by the LOC President Prof Dr Ans van der Ploeg together with the Organising Committee, the Dutch Society for the Study of Inborn Errors of Metabolism (ESN) and international Scientific Committee and the support of Mr Ralph Kerschbaumer, SSIEM Corporate Liaison Officer. Prof Dr Ans van der Ploeg and everybody associated with the excellent symposium must be congratulated on hosting a most successful scientific meeting and social programme. The Symposium was attended by more than 2850 attendees (49% Europeans, 11% Asian, 10% North American, 7.8% Middle Eastern, 6% other & 16% unknown) from 87 different countries. The meeting was supported by 40 corporate partners. The Komrower Memorial lecture was delivered by Dr C Vianey-Saban entitled “From fatty acid oxidation to riboflavin: make metabolism great again”. Prof Dr J D B Häberle was awarded the Archibald Garrod Medal for his paper “The impact of ammonia levels and dialysis on outcome in 202 patients with neonatal onset urea cycle disorders” which was published in our society journal (Journal of Inherited Metabolic Disease 2018; Volume 410 issue 4: 689-698).

## **FUTURE SSIEM and ICIEM SYMPOSIA**

The following are the venues for future SSIEM Symposia:

- ICIEM International Symposium, Sydney, Australia, 2021
- SSIEM Annual Symposium, Freiburg, Germany, 2022
- Annual Symposium, Jerusalem, Israel 2023
- SSIEM Annual Symposium, Porto, Portugal 2024

## **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 2021.

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

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# Honorary Secretary's Report

## **WEBSITE/Society and Conference App**

Council acknowledges the support of Mr M McConnell of Blackcat Websites in maintaining and developing the site as well as that of Mr N Law Executive Administrator. The SSIEM launched the new website designed by carpemedia GbR. The website is an important mechanism for communicating with the membership and Council would welcome material for inclusion on the site.

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

JIMD received its 2020 Impact Factor (IF), and it has unfortunately decreased: from 4.289 (2019 IF) to 4.036 (2020 IF) due mainly to the problems in transferring the journal to the new publishers. JIMD is currently ranked in the first 26% in endocrine and metabolism and genetics and heredity.

Jan 2018 JIMD Reports changed from a book series into an open access journal. So far no IF has been obtained but we are confident that JIMD Reports will get an IF within the next few years.

The editors and Council thank all for supporting 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. As of 1st January 2019, John Wiley & Sons Limited has become the new publisher for JIMD. The editors and Council are grateful to the JIMD Wiley Editorial team for their support in this transition.

## **SSIEM SUBGROUPS**

Asst 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 organise a successful session on adult metabolic disorders on the morning of the opening day of the Annual SSIEM Symposium.

The SSIEM-Dietitians' Group (SSIEM-DG) led by Ms L Robertson, continues to make an important contribution to the organisation of the dietetic component of the scientific programme of the Symposium.

## **METAB-ERN**

The EU, from 1 March 2017 on, officially launched the European Reference Network program (ERN). MetabERN is elected and funded by the European Commission as one of the 24 ERNs and is led by Prof M Scarpa. MetabERN involves 69 European HCPs specialized in IEMs. MetabERN has been intensively structured in 7 different subnetworks each of them working under the same operating frame. In 2019, SSIEM and MetabERN have launched the first joint training program as a successful webinar on transition from paediatrics to adulthood. A face-to-face meeting between SSIEM Council and MetabERN Board Member was scheduled in 2020 to better define areas of collaboration and interaction. Due to the COVID-19 pandemic, this meeting was cancelled and postponed.

*Prof M Schiff  
Honorary Secretary  
12th October 2020*

# HONORARY TREASURER'S REPORT 2019

## INCOME

A new membership fee structure was introduced for 2016 reflecting the need to make the membership fee financially acceptable across members' professions and countries. Under the contract with the new publishers of the JIMD, John Wiley & Sons Limited, the SSIEM will receive a greater percentage of royalties and in 2019 the Council was pleased to receive €261,721. A small income of €12,562 was also generated from modest investments. There was a net increase of income of €398,063 for 2019. The original budget for 2020 reflects a deficit of €470,000. This was a conservative estimate not including any income from the SSIEM Symposium to be held in Freiburg. This deficit also includes €260,000 over and above the established funding for charitable aims making the budgeted deficit similar to last years of €208,000. A surplus from the Freiburg Symposium is now not expected due to the postponement of our live annual symposium to 2022. 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. The early decision to postpone the symposium has reduced expenditure for 2020. 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. The Society continues to review the situation and will be holding virtual meetings for management and use all available IT facilities to engage with all those interested in inherited metabolic disorders through organizing virtual symposia and events.

## EXPENDITURE

The overall expenditure for 2019 has increased compared to 2018. This is due to the increase in charitable activities and administrative workload.

- Awards, Grants & Scholarships
- Governance Costs relating to the Society and Symposium
- Legal advice
- General & Council expenses
- Website development
- ERNDIM-SSIEM collaboration
  - Funding support agreed at 2015 AGM

Future expenditure 2020:

- Travel support for educational activities
  - Any healthcare professional seeking experience in centres of excellence
  - ETAC-NAMA collaboration
- Symposium and SSIEM app
- The budget has been increased for the support for parent support groups or societies
- Development of the SSIEM own administration team and PCO.

## BALANCE SHEET

Total amount in accumulative fund increased in 2019, by €348,865 and stands at €2,768,957.

## **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.

Low risk 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.

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.

## **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. The reserve is currently set at €800,000. In view of the SSIEM becoming an employer and developing its own PCO the reserve funds will be increased to €1,000,000 from 2021. It is the policy of Council to use some of the unrestricted funds to encourage the sharing of experience and training between centers. Part of the reserves includes the gift from Prof Komrower which was invested and the interest on that investment is used to fund expenses relating to the Komrower Lecture. 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.

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
- E-learning modules
- Guidelines
- Training & Educational Meetings
- Supporting symposia in and outside of Europe.

Those members who have colleagues who find difficulty in joining the Society and thereby receive the journal without financial support are encouraged to apply directly to the Honorary Treasurer for a Membership Support Grant for 3 to 5 years.

## **SECRETARIAT**

The SSIEM uses the administrative services of the Association for Clinical Biochemistry and Laboratory Medicine (ACB) in London, but is developing its own administration team for future years.

## **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.

## **COVID-19**

The decision to cancel the symposium planned for September 2020 in Freiburg was taken early (30th 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.

## **AUDITORS**

The SSIEM Council are tendering for the Society's Auditors/Accountants.

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

*Ms A Y Brown  
Honorary Treasurer  
12th October 2020*

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# Honorary Treasurer's Report

# JOURNAL OF INHERITED METABOLIC DISEASE (JIMD) REPORT 2019-2020

In 2019, 120 articles were printed in “JIMD” (original articles, reviews, letters and invited articles) and 71 articles were published in the open access journal “JIMD Reports”. Submissions came from 57 different countries. For JIMD, the majority of articles originated from the USA (17%), China (14%), the Netherlands (11%) and Italy, United Kingdom, Germany and France (each about 6-7%). For JIMD reports, the majority of articles came from the USA (25%), Canada (10%), UK (8%) and France (5%). The **JIMD Impact Factor** was 4.036 (4.287 in 2019). JIMD is currently ranked 38th out of 147 titles in the category “Endocrinology & Metabolism”, 47th out of 174 in “Genetics & Heredity” and 51st out of 136 in the category “Medicine, Research & Experimental”, meaning that JIMD is ranked in the top 30% of its peers.

The article “Clinical, radiological, and genetic characteristics of 16 patients with ACO2 gene defects: Delineation of an emerging neurometabolic syndrome” by Ronen Spiegel and colleagues, published in JIMD 2019, has been selected for the **Archibald Garrod Award 2020**. The **Communicating Editor Awards 2020** for work in 2019 go to Dr Olaf Bodamer, Prof Dr Jaak Jaeken and Prof Carla Hollak as busiest Editors, to Prof Dr Markus Ries as fastest Editor, and to Prof Dr Johannes Häberle/Prof Dr Beat Thöny as Guest Editors. 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. A special thanks to Prof Emeritus Lars Morkrid who supports us as a Statistical Editor. A special issue on “Mitochondrial Medicine”, prepared by Prof Shamima Rahman, will be published in 2020. The SSIEM Symposium issue, organized by Prof Dr Ans van der Ploeg, will be published in the first issue of 2021.

Together with Wiley we developed some new features for JIMD. In a joint collaboration between JIMD and the Journal Neuropathology and Applied Neurobiology (NAN), we have compiled a special, free access, online collection of 12 articles sourced from both journals, covering new disorders of neurotransmission, pathomechanisms and a neurometabolic disease review. Alongside our Social Media Editor Dr James Nurse, we have developed a new podcast section in JIMD (<https://onlinelibrary.wiley.com/page/journal/15732665/podcasts>). The podcasts are short interviews with article authors, allowing them to explain their work for a wider audience. We have also introduced Visual Abstracts that are distributed via our social media channels; these simple article summaries increase online engagement and encourage more people to access journal articles. Please indicate whether you are interested in presenting your published data in a podcast version and/or would like support for a visual abstract. Patient-oriented metabolic educational activities for JIMD and JIMD reports are planned together with Dr Terry Derks.

Since the SSIEM meeting in Freiburg had to be postponed to 2022, a one-day virtual SSIEM Symposium is in preparation for late 2020. The Garrod award lecture will be presented during this virtual symposium.

JIMD is particularly interested in publishing studies that provide a comprehensive, representative analysis of the clinical features, treatment and outcome of an inherited metabolic disease, and such papers also qualify for the annual Archibald Garrod Award. We obviously continue to welcome any articles that

provide important novel information about an inherited metabolic disease or relevant research findings, as well as Guidelines, Metabolic Dissertations, Letters to the Editors and Metabolic Images. We are also interested in receiving material for our Extras section. If you have an idea for a themed issue or new conceptual ideas, please contact us!

Follow us on Twitter @JIMD\_Editors

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

# REFERENCE AND ADMINISTRATIVE DETAILS

## For the year ended 31 December 2019

### **Trustees**

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

### **Company Secretary**

Prof M Schiff

### **Company Registered Number**

02567711

### **Charity Registered Number**

1010639

### **Registered Office**

130-132 Tooley Street  
London  
SE1 2TU

### **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 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.

### ***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 30th 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 January 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 1st round and sixteen 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 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.

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.

#### 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.

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.

### ***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.

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

***Ms A Y Brown***  
***Trustee***  
***27th October 2020***

# 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 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.

## *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 17, 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.

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  
Buzacott LLP  
Statutory Auditor  
130 Wood Street  
London  
EC2V 6DL  
27th October 2020***

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# Independent Auditor's Report

# STATEMENT OF FINANCIAL ACTIVITIES

## For the year ended 31 December 2019

		Unrestricted funds 2019	Unrestricted funds 2018
<b>Income and expenditure</b>	<b>Note</b>	<b>€</b>	<b>€</b>
<b>Income from:</b>			
Charitable activities	3	<b>2,306,813</b>	1,869,717
Investments	4	<b>12,562</b>	11,509
Other income	5	<b><u>269,492</u></b>	<u>309,578</u>
<b>Total income</b>		<b><u>2,588,867</u></b>	<u>2,190,804</u>
<b>Expenditure on:</b>			
Charitable activities	6	<b><u>2,349,126</u></b>	<u>1,695,583</u>
<b>Total expenditure</b>		<b><u>2,349,126</u></b>	<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 investment	9	<b>62,985</b>	(22,941)
Net gain on investments	9	<b>2,624</b>	1,910
Gain/(Loss) on retranslation of fixed asset investments		<b><u>43,515</u></b>	<u>(12,157)</u>
<b>Net movement in funds</b>		<b>348,865</b>	(462,033)
<b>Reconciliation of funds:</b>			
Total funds at 1 January 2019	12	<b><u>2,420,092</u></b>	<u>1,958,059</u>
<b>Total funds at 31 December 2019</b>		<b><u><u>2,768,957</u></u></b>	<u><u>2,420,092</u></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 23 to 28 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><u>1,673,786</u></b>		<b><u>1,642,872</u></b>
<b>Net assets</b>			<b><u>2,768,957</u></b>		<b><u>2,420,092</u></b>
<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>	
			<b><u>2,768,957</u></b>		<b><u>2,420,092</u></b>
<b>Total unrestricted funds</b>			<b><u>2,768,957</u></b>		<b><u>2,420,092</u></b>

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 27th October 2020 and signed on their behalf, by:

*Ms A Y Brown*  
*Trustee*

The notes on pages 23 to 28 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		<u>12,562</u>	<u>11,509</u>
Net cash (used in)/generated from investing activities		(196,266)	(628)
<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>		<b><u>1,188,944</u></b>	<b><u>1,233,241</u></b>
<b>Cash and cash equivalents at end of year</b>	B	<b><u>1,667,886</u></b>	<b><u>1,188,944</u></b>

### 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>		<b>348,865</b>	<b>462,033</b>
<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		<u>290,593</u>	<u>68,100</u>
<b>Net cash used in operating activities</b>		<b><u>675,208</u></b>	<b><u>(43,669)</u></b>

### 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		<u>94,507</u>	<u>7,339</u>
<b>Total cash and cash equivalents</b>		<b><u>1,667,886</u></b>	<b><u>1,188,944</u></b>

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

# 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 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 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.

### *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.

## 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	<u>7,938</u>	<u>7,938</u>	<u>7,038</u>
	<u><u>2,306,813</u></u>	<u><u>2,306,813</u></u>	<u><u>1,869,717</u></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	<u>5,355</u>	<u>5,355</u>	<u>4,910</u>
	<u><u>12,562</u></u>	<u><u>12,562</u></u>	<u><u>11,509</u></u>

## 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).

## 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

	Listed securities	Other investments	Total
Market value	€	€	€
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
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	<u>468,436</u>	<u>443,600</u>
	<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.

## 10. DEBTORS

	2019	2018
	€	€
Trade debtors	354,176	565,541
Prepayments and accrued income	<u>287,441</u>	<u>233,511</u>
	<u>641,617</u>	<u>799,052</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>635,717</u>	<u>345,124</u>

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

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

## 12. UNRESTRICTED FUNDS

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

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

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.

