

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

**NOTICE OF
ANNUAL GENERAL MEETING – 2016**

to be held in

Rome

on

Wednesday 7th September 2016

at 12.45 p.m.

Prof Gajja S Salomons
Honorary Secretary

THE SOCIETY FOR THE STUDY of INBORN ERRORS OF METABOLISM

ANNUAL GENERAL MEETING – 2016

AGENDA (Chair: Prof P T Clayton)

1. Apologies for absence
2. To receive the minutes of the previous meeting held on Wednesday 2nd September 2015 in Lyon, France
3. Matters arising from the previous meeting
4. Honorary Treasurer's Report, including evaluation new membership structure
5. Honorary Secretary's Report
6. JIMD Report
7. ETAC (Education, Training & Advisory Committee) Report
8. SSIEM – Special Interest Groups
9. Future SSIEM Symposia
10. IOC Report
11. Council Officers/ Election of Council Members
12. On the proposal of Council to re-appoint Grant Thornton UK LLP to be Auditors of the Society and to authorise Council to determine the remuneration
13. MetabERN
14. Any other business

HONORARY SECRETARY'S REPORT 2015-2016

MEMBERSHIP

The membership at the end of 2015 had grown by just over 2.6% over the previous year and by more than 26% since the end of 2010; the proportion of those less than 35 years of age category has grown by over 107% and the retired category has grown by over 173% since the end of 2010, representing just over 17.9% of the total membership. Members come from 74 different countries, of which are outside greater Europe.

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. Following much discussion the proposal to enable a fair subscription scheme of the Honorary Treasurer and Council was accepted by the membership at the annual general meeting. 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 all its members in the differing specialties and countries. The membership support scheme will remain in place for those requiring subscription support.

COUNCIL

Council met on four occasions during the year; three times in London and once in Lyon, under the Chairmanship of Prof P T Clayton. On September 2nd 2015 during the annual general meeting Prof P T Clayton announced his retirement as chairman and proposed that Prof G S Salomons, the current Honorary Secretary should take over as chairman in September 2016, this was seconded by Dr A A M Morris and carried by a show of hands unanimously by the members. Dr M Schiff was co-opted to shadow the Honorary Secretary as of the 4th of March 2016. In addition to Prof P T Clayton, Prof B Plecko, Prof C Vianey-Saban and Prof C Dionici-Vici will be retiring from Council all having completed two terms. Membership of Council for 2015-2016 comprised of:

Prof P T Clayton (Chairman), Prof G S Salomons (Honorary Secretary),
Ms A Y Brown (Honorary Treasurer), Prof I Baric, Dr C Dionisi-Vici, Prof K Ounap,
Prof B Plecko, Dr A Ribes, Prof U Spiekerkoetter, Dr C Vianey-Saban,
Ms A M J van Wegberg, Prof J Zschocke (until 31 December 2015: Editor-in-Chief JIMD,
Ex-Officio), Prof E Morava (as of 1st of January 2016: Editor-in-Chief JIMD, Ex-Officio),
Dr V Valayannopoulos (Chairman ETAC, Ex-Officio).

Four members were this year elected as honorary members and received a certificate for their service to Council: Prof P D Mayne (for service as Honorary Secretary), Prof M Henderson (for service on Council and for ERNDIM and ETAC), Prof J Zschocke (for service as Editor-in-Chief of JIMD), Prof K M Gibson (for service as Editor-in-Chief of JIMD). 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 and his team at the Society's Registered Office at 130-132 Tooley Street, London have provided Council and the membership with invaluable support throughout the year.

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. Under the revised Articles the Corresponding members form an Advisory Committee to Council. Corresponding members for 2015-2016 were:

Dr J M Fletcher (Australasia), Prof Dr D Karall (Austria), Dr J Songailiene (Baltic Countries), Dr M-C Nassogne (Belgium), Dr G A Mitchell (Canada), Prof K Fumic (Croatia), Dr P Martasek (Czech Republic/Slovakia), Dr A M Lund (Denmark), Dr R J Lapatto (Finland), Dr D Dobbelaere (France), Prof Dr R Santer (Germany), Dr H Michelakakis (Greece), Dr J Hui (Hong Kong), Dr S Bijarnia Mahay (India), Dr T Z Zaman (Iran), Ms P Fitzsimons (Ireland), Prof Y Anikster (Israel), Dr A B Burlina (Italy), Prof H Ida (Japan), Prof L Chabraoui (Morocco), Dr B Woldseth (Norway), Prof J Sykut-Cegielska (Poland/Russia/Hungary), Dr L Diogo Matos (Portugal), Prof L A Barrera (South America), Dr A García-Cazorla (Spain), Dr A Nordenstrom (Sweden), Dr M Baumgartner (Switzerland), Dr J-Y Wu (Taiwan), Prof N M Verhoeven Duif (The Netherlands), Prof Dr T Coskun (Turkey), Dr R Lachmann (United Kingdom), Dr B A Barshop (United States of America).

2015 ANNUAL SYMPOSIUM

The 49th SSIEM Symposium was held in Lyon, France, organised on behalf of the Society by the LOC President Prof C Vianey-Saban together with the Organising Committee, the PCO Cité Centre de Congres, Lyon and SSIEM Corporate Liaison Officer Mr R Kerschbaumer. Prof C Vianey-Saban and the partners are to be congratulated for hosting a most successful scientific meeting and social programme. The Symposium was attended by more than 2649 participants (67% Europeans) from in total 73 different countries, The meeting was supported by 30 corporate partners, nine of whom sponsored meet the expert sessions. The Komrower Memorial lecture was delivered by Prof Prof B T Poll-The entitled 'Peroxisomal disorders and more...: Why I have not stopped examining patients'. Dr Y Trakadis was awarded the Archibald Garrod Medal for his paper "Update on transcobalamin deficiency: clinical presentation, treatment and outcome" which was published in the September issue of our society journal (*Journal of Inherited Metabolic Disease* 2014; **37(3)**: 461-73).

FUTURE SSIEM and ICIEM SYMPOSIA

The following are the venues for future SSIEM Symposia:

- SSIEM Annual Symposium, Rome, Italy, 2016
- ICIEM International Symposium, Rio de Janeiro, Brazil, 2017
- SSIEM Annual Symposium, Athens, Greece, 2018
- SSIEM Annual Symposium, Rotterdam, The Netherlands, 2019
- SSIEM Annual Symposium, BID: Council announced at the SSEIM Lyon meeting in 2015 that expressions of interest from SSIEM members to host the 2020 Annual Symposium would be welcome. A notification letter and document with guidelines was send to all Council and Advisory Council members. Just one expression of interest was received and this will be put to the Council and Advisory Council Members meeting during the Symposium in Rome.
- ICIEM International Symposium, Sydney, Australia, 2021

TRAVEL SCHOLARSHIPS

From a budget of €35,000 twenty-seven Travel Scholarships of up to €2,250 were approved for members and non-members to attend the SSIEM Symposium in Rome. Two thirds of the Travel Scholarships were awarded on the basis of mainly the financial need and one-third mainly on the scholarship of the submitted abstract. For those travelling from within greater Europe the scholarship was restricted to €1,300. Forty-nine applications were received and were judged by Prof B Plecko, Prof I Baric, Dr M Schiff and Prof G S Salomons.

TRAINING

The 9th SSIEM Training Academy took place in Freiburg, Germany in April 2016, covering aminoacidopathies, urea cycle defects, and inherited metabolic disease affecting the liver. This was the first training meeting in the third of a four year cycle programme. The number of applications was higher than the previous year with 132 applications received for the 80 places with slightly more applications from clinicians (69) than scientists (63). Again the majority of those who attended came from greater Europe, but others came from South America (Argentina, Brazil), North America (Canada), Asia (Hong Kong, Malaysia, Pakistan), North Africa (Morocco) and Australia. The Course included a number of combined clinical and laboratory sessions; these were well received by those attending. Council acknowledges the contribution of all those who give of their time to teach on the Course and to the officers of ETAC, Dr V Valayannopoulos (Chairman), Dr A A M Morris (Honorary Secretary) and Dr S Gardner (Administrator). For help with the administration of ETAC Council has agreed to open a vacancy for a 0,5 fte position for administrative support. ETAC proposes to hold the 10th SSIEM Training Academy in 2017 in Lyon. The ETAC officers together with Council have developed a new governance plan for ETAC which is in line with the Society's Memoranda and Articles of Association, restricting the duration of membership to maximum two consecutive terms of each 4-years: The courses follow a 4 year cycle. The officers will be appointed for a period of maximum 4 plus 4 years. The chair will be an Ex-Officio Council member of SSIEM that will have its representation in Council for maximum 6 years, the Secretary will take over this position for the last two years. The current ETAC member (and the year of retirement) is as follows: Prof Dr U Spiekerkoetter 2016, Dr C Vianey-Saban (2016), Prof S Rahman (2017), Prof B Fowler (2017), Dr A A M Morris, Secretary (2018) Prof S J R Heales (start in 2015), Dr V Valayannopoulos, Chair (2019).

WEBSITE

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 from the Admin Team. The website is an important mechanism for communicating with the membership and Council would welcome material for inclusion of the site. Mr M McConnell also has a valuable role in the Symposium abstract submission, selection and processing and his contribution is very much appreciated.

JIMD

A more detailed report on the Journal is covered elsewhere within this Annual General Meeting (AGM) bulletin. On 31st of December 2015 Prof J Zschocke resigned as Editor-in-Chief having served 10 years. Prof E Morava took over the position of (Editor-in-Chief) as of the 1st of January 2016. The editorial team consisted of Prof S Rahman, Prof M Baumgartner, Prof J Zschocke, Prof M C Patterson and Dr V Peters (Managing Editor). The number of articles, both original and review, submitted to the JIMD and the JIMD-Reports continues to rise. The Impact Factor (IF) for the JIMD increased from 3.365 to 3.541 and an IF for JIMD Reports is expected by 2017.

Honorary Secretary's Report

Council appreciates the significant contribution of the Editorial team, the communicating editors and the publishers, Springer, for their commitment in maintaining the continuing success of the Journals.

SSIEM SUBGROUPS

The SSIEM-Adult Metabolic Physicians' Group, led by Dr R Lachmann (Chairman) and Prof C E M Hollak (Secretary) 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

In December 2015 the SSIEM Council has reached out to the members of the Society asking via a monkey survey the members opinion of the role of SSIEM on the call from the European Commission for the establishment of European Reference Networks (ERNs) which launch was expected in early 2016 <http://ec.europa.eu/health/ern>. This initiative arose out of the wish of the European Parliament and Council to facilitate cross border health care; if a healthcare provider in one member state cannot provide the highest standard of investigation and management of a rare disease, the patient should have access via the Reference Network to "centres of expertise". As it is envisaged that there should be just one ERN covering inherited metabolic diseases, Council needed to know about 1) possible initiatives to set up an metabolic ERN, 2) the wish of members to endorse / support the potential application from Prof M Scarpa (Wiesbaden, Germany and Padova, Italy) who was preparing an application for a metabolic ERN and had asked the SSIEM to endorse his application. The proposal of Prof M Scarpa was sent to the members, together with dr Scarpa's request contacting him in case the members had interest in participating this application. 3) since the role of industry is not well established yet an article on this subject lead by Carla Hollak, Amsterdam, The Netherlands has been circulated among the SSIEM members.

The SSIEM survey outcome (238 responses): the SSIEM membership revealed that 61% supported SSIEM endorsement of MetabERN lead by Prof M Scarpa, but 85% supported the proposal that the SSIEM should initiate a committee to guide the development of a metabolic ERN and advise on whether an ERN should be given, and continue to receive, SSIEM endorsement.

*Prof G S Salomons
Honorary Secretary
July 2016*

Honorary Secretary's Report

HONORARY TREASURER'S REPORT 2015

The Accounts for 2015 are again shown in Euro (€) as agreed at the 2009 AGM.

INCOME

Receipt of subscriptions for 2015 increased compared with 2014, a surplus was also realised from the 2015 SSIEM Symposium in Lyon, France.

Membership increased by 37 during 2015, as at 31 December 2015 there were 1441 members names on the database compared with 1404 as at 31 December 2014.

Under the contract with the publishers of the JIMD we receive a share of the Royalties; in 2015 Council was pleased to receive €120,388 for 2015, together with editorial expenses of €45,310.

The net income for 2015 had increased substantially over the net income of 2014. This is primarily due to the continual success of the SSIEM symposium and the JIMD.

The budget for 2017 reflects a deficit of €147k, this is a conservative estimate. As the ICIEM will be held in Rio de Janeiro in 2017 there will be no symposium surplus. A minimum of €50k set aside for development costs.

A review of membership subscription fees was presented at the AGM in Lyon. The membership fee structure proposed by Council (see below) reflected the need to make the membership fee financially acceptable across members professions and countries. The proposal was accepted and introduced for the 2016 membership fees.

| | High Income listed countries | | Rest of the World | |
|-----------------------|------------------------------|---------------|-------------------|---------------|
| | € | Print Journal | € | Print Journal |
| Standard* | 130 | Yes | 80 | Yes |
| Standard trainee** | 80 | Yes | 40 | Yes |
| Subsidised ^ | 80 | Yes | 40 | Yes |
| Subsidised trainee ^^ | 60 | Yes | 30 | Yes |
| Student \$ | 40 | No | 20 | No |
| Retired # | 15 | No | 10 | No |

Description of membership rates

- * Standard rate: Fully qualified, permanent contracted position (full or part-time) applicable to physician, researcher, scientist, geneticist or equivalent. In addition this rate is applicable for all individuals whose membership is paid for by commercial companies.
- ** Standard trainee rate: Applicable to physician, researcher, scientist, geneticist or equivalent in trainee positions.
- ^ Subsidised rate: All other professions and grades. This includes those employed by registered charities.
- ^^ Subsidised trainee rate: All other professions, individuals in trainee positions not yet registered with their professional body.
- \$ Student rate: In full-time education, not employed. A printed journal will not be posted.
- # Retired Rate: Retired members - must have been an SSIEM member for 10 years. Should retired members wish to receive a printed JIMD then they should select a subsidised members rate.

There will again be no additional charge for accepting card payments, but the SSIEM does not accept America Express. However, the cost of Bank transfers must be met by the transferee and full funds should be remitted to the SSIEM account and for those paying by cheque an additional €20 must be added to the membership payment.

Honorary Treasurer's Report

EXPENDITURE

The overall expenditure, excluding the symposium, for 2015 has increased significantly compared to 2014. This is due to the increase in charitable activities and administrative workload:

- Travel scholarship support.
- Support for the Vademecum Metabolicum app.
- An increase in Governance Costs relating to the Society and Symposium.
- Increase in legal advice.
- Increase in membership.
- Website maintenance.
- General expenses.

Those members who have colleagues working in the inborn error of metabolism field who are financially unable to join the society are encouraged to apply directly to the Honorary Treasurer for a Membership Support Scholarship for 3 to 5 years.

Future expenditure 2016:

- Travel support for educational activities
 - Any healthcare professional seeking experience in centres of excellence.
 - ETAC-NAMA collaboration
- Update and development of Admin IT
- ERNDIM-SSIEM collaboration
 - Funding support agreed at 2015 AGM
- Symposium and SSIEM app
- MetabERN

BALANCE SHEET

Total amount in accumulative fund increased in 2015, by €31,564 and stands at €2,223,319.

FINANCIAL POLICY

Publishing and administration – our policy is to cover the majority of the journal and administrative costs from subscriptions paid by members.

Low risk investments are being considered to realise a better financial return on our accumulated funds. A financial sub-committee of Council has been created to review the Society's financial activities.

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 Centres. Part of the reserves includes the gift from Prof Komrower which was been 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.

Honorary Treasurer's Report

- Future-proof the SSIEM administrative functions.
- Education and practical support for countries introducing investigation and treatment of inborn errors of metabolism.

SECRETARIAT

The SSIEM uses the administrative services of the Association for Clinical Biochemistry and Laboratory Medicine (ACB) in London and has established systems to help the Society in 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.

AUDITORS

It is proposed that the new auditor Grant Thornton UK LLP be reappointed.

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

*Ms A Y Brown
Honorary Treasurer
July 2016*

Honorary Secretary's Report

JIMD REPORT 2015-2106

The number of submissions to JIMD and JIMD Reports was similar to 2014 (498 in 2015 vs 521 in 2014). Submissions came from 54 different countries, with the majority from USA (14%), Germany (8%), Italy (7%), the Netherlands (6%) and United Kingdom (5%). 127 articles were printed in JIMD and 107 articles in the online journal “JIMD Reports”. This year the JIMD Impact Factor has increased from 3.36 to 3.54. JIMD Reports will hopefully receive an Impact Factor next year; pre-calculations indicate that the impact factor of JIMD Reports should be at or above 1. There are no publication fees for either journal, and all SSIEM members can download all articles published in JIMD or JIMD Reports for free via the homepage. JIMD Reports articles are available for everybody free of charge one year after publication.

The Archibald Garrod Award 2016 will be awarded to Shamima Rahman, London, United Kingdom for the article “Paediatric single mitochondrial DNA deletion disorders: an overlapping spectrum of disease”, published in the JIMD in 2015.

The Communicating Editor Awards 2016 for work in 2015 will be presented to Jaak Jaeken, Robin Lachmann and Oliver Sass as busiest Editors, to Mike Benett as fastest Editor, and to Jean-Marie Saudubray, Matthias Baumgartner and Ronald Wanders as Guest Editors for the excellent collection of articles on complex lipids.

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. Claude Bachmann, Doug Brooks, Gregory Enns, Jutta Gärtner and Rodney Pollitt decided to step down from the Editorial Board at the end of 2015. A special thanks to them for their great support of the journal during their time as CEs.

In 2015, we published themed issues on “Complex lipids”, coordinated by Guest Editors Jean-Marie Saudubray, Matthias Baumgartner and Ron Wanders, on “Next generation mitochondrial disease”, organized by Eva Morava and Garry Brown, on “Glycogen Storage disease” by Georg F. Hoffmann, Peter Smit and Bernhard Schoser and on “Alkaptonuria”, organized by Ranaganath Lakshminarayan, Oliver Timmis and James Gallagher. If you have an idea for a themed issue, please contact us! 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 other 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 interested in receiving material for our Extras section; in particular, think of writing for the new “Garrodian” section or an obituary for JIMD about any recently deceased colleague whose work has had an impact on our metabolic community.

Follow us on twitter @JIMD_Editors

The Editorial Team
Prof M Baumgartner, Prof E Morava, Prof M C Patterson,
Dr V Peters, Prof S Rahman and Prof J Zschocke

REFERENCE AND ADMINISTRATIVE DETAILS

For the year ended 31 December 2015

Trustees/Directors

Prof P T Clayton, Honorary Chair
Prof G S Salomons, Honorary Secretary
Ms A Y Brown, Honorary Treasurer
Prof J Zschocke, Editor-in-Chief JIMD (Ex-Officio)
Dr V Valayannopoulos, Chairman ETAC (Ex-Officio)
Prof I Baric
Dr C Dionisi-Vici
Prof K Ounap
Prof Dr B Plecko
Dr A Ribes
Prof Dr U Spiekerkoetter
Dr C Vianey-Saban
Ms A M J van Wegberg

Company Registered Number

02567711

Charity Registered Number

1010639

Registered Office

130-132 Tooley Street
London SE1 2TU

Company Secretary

Prof G S Salomons

Independent Auditor

Grant Thornton UK LLP
Chartered Accountants
300 Pavilion Drive
Northampton Business Park
Northampton
NN4 7YE

Bankers

Barclays Bank plc
Sheffield Arena Square Branch
PO Box 43
Sheffield S9 2LF

General Information

TRUSTEES' REPORT

For the year ended 31 December 2015

The Trustees (who are also directors of the charity for the purposes of the Companies Act) present their annual report together with the audited financial statements of The Society for the Study of Inborn Errors of Metabolism (SSIEM) (the charitable company) for the year ended 31 December 2015. The financial statements comply with current statutory requirements and have been prepared in accordance with the Accounting and Reporting by Charities: Statement of Recommended Practice applicable to Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK (FRS 102) (the Charities SORP (FRS102)).

STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution

The Society for the Study of Inborn Errors of Metabolism (SSIEM) 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, number 1010639.

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

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 Chairman, 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-election to the same officer for a further three years. Members of the General Council other than Honorary Officers may hold office for 3 years; they may be re-elected for a further three years. All Honorary Officers of the Society and Members of the General Council 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 comprise the current Honorary Treasurer, a Council member (currently the SSIEM Secretary), a previous SSIEM Honorary Treasurer or Ex-Officio member of Council and an independent financial advisor.

Risk Management

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

The main risks are:

Symposia risk:

- Insurance against bodily or material harm including third parties.
- Insurance against cancellation for major risks.
- Agreement re a force majeure event.

It is expected that the above insurance policies and agreements are included in any contract with any 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.

Financial risk:

- The major risk to the SSIEM is the annual symposium which is covered above.
- The financial surplus of the Society is conservatively managed and is considered to be low risk.

OBJECTIVES AND ACTIVITIES

Policies and objectives

The principal objective of the charitable company 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.

Grant making policies

The SSIEM provides grants for SSIEM Membership (Membership support scholarships) and for attendance at the annual symposium (Symposium Travel Scholarship).

SSIEM Membership Support Scholarship may be applied for via the SSIEM website by submitting a statement of why financial support is needed, a career summary and a letter of support from their Head of Department. Applications will be reviewed by the Honorary Officers and a decision will be made.

To apply for the Symposium Travel Scholarship individuals would need to fulfill the criteria mentioned on the website and follow the online application process via the SSIEM website submitting before the stated deadline.

Part of the Symposium Travel Scholarships will be awarded to those in financial need in combination with the scholarship of the application and the remaining on the basis of the scholarship of the application. Submissions will be ranked by three independent senior SSIEM members. In the event of a tie the award will be given to the SSIEM member.

The SSIEM Education & Training Advisory Committee (ETAC) holds an annual Academy for clinicians and laboratory scientists. Applications are required from those who wish to attend the Academy. These applications are reviewed and ranked by two members of ETAC (for clinicians) and two from ERNDIM (for laboratory scientists). Individuals are subsequently offered a place to attend the Academy which is secured by the payment of a small fee to the SSIEM. This is to guarantee attendance, all other costs, except travel are met by the Society.

ACHIEVEMENTS AND PERFORMANCE

Going concern

After making appropriate enquiries, the trustees have a reasonable expectation that the charitable company 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. Further details regarding the adoption of the going concern basis can be found in the Accounting Policies.

Review of activities

During the year ended 31 December 2015 the Society published Journals and continued development of its own internet website. In addition, arrangements progressed with the LOC & PCO for the SSIEM symposium in Rome 2016 plus arrangements with the Society for Inherited Metabolic Diseases (SIMD), the Japanese Society for Inherited Metabolism Diseases (JSIMD), the Australian Society for Inborn Errors of Metabolism (ASIMEM), Sociedad Latinoamericana de Errores Innatos del Metabolismo y Pesquisa Neonatal (SLEIMPAN), on the preparation of the International Congress of Inborn Errors of Metabolism (ICIEM) in Rio De Janeiro, Brazil for 2017. The first contacts with the LOC & PCOs of Athens (2018) and Rotterdam (2019) are being made.

Membership has continued to increase. At the AGM a proposed banded membership fee was accepted for the year 2016. This scheme is deemed to be fair and equitable for all its members in the differing specialties and countries. 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).

The General Council has met on a number of occasions to pursue the objectives of the Society. At the annual symposium it also has a joint meeting with the General Council and Advisory Council.

SSIEM Education and Training Advisory Committee (ETAC)

Purpose

Paediatric Metabolic Medicine (PMM) is a recognised subsection of the European Academy of Paediatrics (EAP), which is a section of the Union of European Medical Specialists (UEMS). Although the SSIEM has no formal role within the EU in the assessment of training for laboratory scientists, the SSIEM recognises a responsibility in this area. Consequently ETAC is now comprised of both clinicians and laboratory scientists.

The current membership of the committee is as follows:

Chairman: Dr V Valayannopoulos

Secretary: Dr A A M Morris

Administrator: Dr S Gardner

Senior Advisor: Prof J H Walter

Clinical

Dr A A M Morris

Dr V Valayannopoulos

Prof U Spiekerkoetter

Prof S Rahman

Laboratory

Prof B Fowler

Dr M Henderson

Dr C Vianey-Saban

Dr J Bierau

The responsibilities of ETAC are currently as follows:

Syllabus

Syllabi are published on the SSIEM website for both clinical and laboratory training.

Formal assessment of clinical training centres and training programmes

National societies can apply for centres within their country to be approved for training in Paediatric Metabolic Medicine (PMM). This process requires a formal written application followed by a site visit by two members of ETAC. ETAC will then submit their recommendation to EAP. As a part of the process for training centre approval the committee will require information about local training programmes and trainee assessment. Training programmes should aim to ensure the syllabus is covered. This may be a problem in small countries as experience may be limited. The authorities have to recognise any limitation and be prepared to fund training elsewhere. If there is insufficient experience in one country the importance of obtaining experience abroad will need to be emphasised. Such work needs to be properly funded and the experience in another country recognised for training. At the present time ETAC will not be responsible for the assessment of individual trainees but may be in a position to provide career guidance.

SSIEM Academy

Since 2008, ETAC has organised a yearly SSIEM Academy course for both clinicians & laboratory scientists who already have some experience in inherited metabolic disease. In 2015 this consisted of a two day concurrent course held in London for both clinical and laboratory scientists. It is planned that there will be a continued expansion in training courses as part of the role of the Academy.

JIMD

The JIMD Editorial Office is now well established in Heidelberg, Germany, currently run by one Editor-in-Chief together with an Editorial manager and Editorial team. The aim of the office is to facilitate the flow of articles for the journal.

Symposium

In 2015 the Society for the Study of Inborn Errors of Metabolism held its annual Symposium in Lyon, which was attended by over 2,600 people. Plans are well advanced with the organisation of the annual symposium to be held in Rome in 2016.

FINANCIAL REVIEW

Results for the year

The net incoming resources for the year amounted to €384.710 (2014: €852,847), which was the amount attributable to general reserves, which at the year-end stood at €2,223,319 (2014: €1,838,609).

Since the balance sheet dated 31st December 2015 the United Kingdom voted on the 23rd June 2016 to leave the EU. The SSIEM have UK and globally based investments and our bank reserves are in Euros. All future planned Symposia (excluding ICIEM meetings) are being hosted in the Eurozone. At time of going to print the Society has received financial advice on its investments and the SSIEM Council is reviewing events as they unfold.

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 contingency reserve is set at €700,000. Council proposes that a proportion of the surplus funds are invested, currently £650,000 (€881,790), this is to provide some financial security for the Society in years when the Society's income may be reduced and in the long term to enable the Society to further

develop its educational and charitable objectives. 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. As at 31st December 2015 an unrestricted fund balance of €2,223,319 was held.

During 2015, the Council was pleased to give financial assistance to 22 individuals enabling them to attend the SSIEM Symposium in Lyon. Council has also agreed to utilise some of the reserves to develop the SSIEM Academy and to make training more readily available.

Principal funding

Normally a quarter of the income of the Society is raised from subscriptions paid by individual members. This income is used to pay the administrative and running costs of the Society including ETAC and to allow for publication of an educational journal 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, to subsidise the journal to make it more widely available and to meet the expenses of an invited speaker at the annual symposia (Komrower Lecture).

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

The Society is truly international with membership drawn from more than 74 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 2015 the Annual Subscriptions of 6 members were paid by the Society; in addition members and non members were given financial assistance to attend the SSIEM Symposium in Lyon.

Investments policy

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. 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 became necessary.

PLANS FOR THE FUTURE

Future developments

Council will continue to:

- Review and develop corporate governance.
- Continually assess and manage risk
- Update and development of Admin IT
- Symposium and SSIEM app
- MetabERN

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
- To consider whether courses in inborn errors of metabolism are suitable for training needs

- Organise further specific training programmes as part of the SSIEM academy
- ETAC-NAMA collaboration
- ERNDIM-SSIEM 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.

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.

Trustees' responsibilities statements

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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company 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 the charities SORP;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company 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 charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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 charitable company's auditor is unaware, and
- that 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 charitable company's auditor is aware of that information.

This report was approved by the Trustees on 26th July 2016 and signed on their behalf by

***Prof G S Salomons,
Honorary Secretary***

Trustees' Report

INDEPENDENT AUDITORS' REPORT

We have audited the financial statements of The Society for the Study of Inborn Errors of Metabolism for the year ended 31 December 2015 set out on pages 20 to 28, which comprise the Statement of Financial Activities incorporating an income and expenditure account, the Balance Sheet the Cash Flow statement, and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland.

This report is made solely to the charitable company's members, 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 charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and its members, as a body, for our audit work, for this report, or for the opinion we have formed.

Respective responsibilities of Trustees and auditor

As explained more fully in the Trustees' responsibilities statement, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of the audit of the financial statements

A description of the scope of an audit of financial statements is provided on the Auditing Practices Board's website at www.frc.org.uk/auditscopeukprivate

Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2015 and of its incoming resources and application of resources including, its income and expenditure 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.

Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the Report of the Trustees' (including the directors and strategic reports) for the financial year for which the financial statements are prepared is consistent with the financial statements.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept; or

Independent Auditor's Report

- 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
- we have not received all the information and explanations we require for our audit.

William Devitt (Statutory Auditor, Chartered Accountants)
for and on behalf of
Grant Thornton UK LLP
Milton Keynes
17th July 2015

Grant Thornton UK LLP is eligible to act as an auditor
in terms of section 1212 of the Companies Act 2006

Independent Auditor's Report

STATEMENT OF FINANCIAL ACTIVITIES
(Incorporating Income and Expenditure Account)
For the year ended 31 December 2015

| | Note | Unrestricted funds 2015 € | Total funds 2015 € | Total funds 2014 € |
|---|------|------------------------------------|-----------------------------|-----------------------------|
| Income: | | | | |
| Income from charitable activities | 2 | 1,967,742 | 1,967,742 | 1,796,507 |
| Investment income | 3 | 6,840 | 6,840 | 6,031 |
| Other income | 4 | <u>165,698</u> | <u>165,698</u> | <u>183,816</u> |
| Total income | | <u>2,140,280</u> | <u>2,140,280</u> | <u>1,986,354</u> |
| Expenditure: | | | | |
| Expenditure on charitable activities | 5 | <u>1,787,134</u> | <u>1,787,134</u> | <u>1,164,987</u> |
| Total resources expended | | <u>1,787,134</u> | <u>1,787,134</u> | <u>1,164,987</u> |
| Net income/(expenditure) and net movement in funds before gains and losses on investment | | 353,146 | 353,146 | 821,367 |
| Other recognised gains/(losses): | | | | |
| Gain/(loss) on revaluation of investment assets | | <u>31,564</u> | <u>31,654</u> | <u>31,480</u> |
| Net movement in funds | | 384,710 | 384,710 | 852,847 |
| Reconciliation in funds: | | | | |
| Total funds at 1 January 2015 | | <u>1,838,609</u> | <u>1,838,609</u> | <u>985,762</u> |
| Total funds at 31 December 2015 | | <u>2,223,319</u> | <u>2,223,319</u> | <u>1,838,609</u> |

The financial activities above represent the incoming and outgoing resources relating to the charitable company.

All operations are ongoing.

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

BALANCE SHEET

As at 31 December 2015

| | | | 2015 | | 2014 |
|--|------|------------------|------------------|------------------|------------------|
| | Note | € | € | € | € |
| Fixed assets | | | | | |
| Investments | 10 | | 542,644 | | 511,080 |
| Current assets | | | | | |
| Debtors | 11 | 595,226 | | 195,759 | |
| Cash at bank | 12 | <u>1,193,985</u> | | <u>1,396,474</u> | |
| | | 1,789,211 | | 1,592,233 | |
| Creditors due within one year | 13 | <u>(108,536)</u> | | <u>(264,704)</u> | |
| Net current assets | | | <u>1,680,675</u> | | <u>1,327,529</u> |
| Total assets less current liabilities | | | <u>2,223,319</u> | | <u>1,838,609</u> |
| Charity funds | | | | | |
| Unrestricted funds | 14 | | <u>2,223,319</u> | | <u>1,838,609</u> |
| Total charity funds | | | <u>2,223,319</u> | | <u>1,838,609</u> |

The financial statements were approved by the Trustees on 26th July 2016 and signed on their behalf, by

Ms A Y Brown
Honorary Treasurer

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

STATEMENT OF CASH FLOWS

For the year ended 31 December 2015

| | 2015 | 2014 |
|---|--------------------------------|--------------------------------|
| | € | € |
| Net movement in funds | 384,710 | 852,847 |
| Gain on revaluation of investment | (31,564) | (31,480) |
| (Increase)/decrease in debtors | (399,467) | 207,089 |
| (Decrease)/increase in creditors | <u>(156,168)</u> | <u>35,746</u> |
| Net cash (used in)/generated from operating activities | <u>(202,489)</u> | <u>1,064,202</u> |
| | | |
| (Decrease)/increase in cash and cash equivalents in the year | <u>(202,489)</u> | <u>1,064,202</u> |
| | | |
| Cash and cash equivalents at the beginning of the reporting period | <u>1,396,474</u> | <u>332,272</u> |
| | | |
| Cash and cash equivalents at the end of the reporting period | <u><u>1,193,985</u></u> | <u><u>1,396,474</u></u> |

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

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 December 2015

1. ACCOUNTING POLICIES

1.1 Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention, with the exception of investments, which are included on a market value basis. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) (Charities SORP FRS 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.

In preparing the accounts, the Trustees have considered whether in applying the accounting policies required by FRS 102 and the Charities SORP FRS 102 the restatement of comparative items was required. Details of the restatement of comparative figures are set out in Note 17.

The charity is 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:

1.2 Company status

The charitable company is a company limited by guarantee. The members of the company are the Trustees named on page 11. In the event of the charitable company being wound up, the liability in respect of the guarantee is limited to £1 per member of the charitable company.

1.3 Going concern

The charitable company is operating within its available cash funds and has net current assets at the year end. The charitable company has maintained income from its Annual Symposium, journal publications and royalties and expects similar levels of this income in the future. The Trustees believe the charitable company is well placed to manage its business risk despite the difficult economic climate.

The Trustees have a reasonable expectation that the charitable company has adequate resources to continue in operational existence for the foreseeable future and thus the Trustees have concluded that it is appropriate to prepare the accounts on a going concern basis.

1.4 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charitable company and which have not been designated for other purposes.

Investment income, gains and losses are allocated to the appropriate fund.

1.5 Income

All income is recognised in the Statement of Financial Activities when the charitable company has entitlement to the income, it is probable that income will be received and the amount of the income receivable can be measured reliably.

Annual Symposium

Symposium income is the gross revenue generated by the annual symposium payable to the Society, net of expenditure, by the symposium organiser.

Investment income

Investment income comprises interest on bank deposits and National Savings bank income bonds and is recognised on a receivable basis.

Other income

Other income includes journal royalties which are accounted for on a receivable basis.

1.6 Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the Charity to the expenditure, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Charitable activities expenditure represents the overhead and staff costs incurred for furtherance of the charitable company's objectives as stated in the Trustees' Report. Charitable activities expenditure includes governance costs which represent the costs directly attributable to the Trustees' meetings and audit processes such as staff costs, printing, meetings and travel costs.

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, 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.

Expenditure is shown gross, inclusive of unrecoverable VAT and is charged on an accruals basis. Costs are allocated to the particular activity that directly relates to it.

Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with use of the resources. Overheads have been allocated on the basis of time spent by each staff member on a particular activity.

1.7 Investments

Investments are stated at market value at the Balance Sheet date. The Statement of Financial Activities includes the net gains and losses arising on revaluations and disposals throughout the year.

1.8 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.

1.9 Debtors

Trade and other debtors are recognised at the settlement amount due. Prepayments are valued at the amount prepaid net of any trade discounts.

1.10 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.

1.11 Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

Creditors are recognised at their settlement amount after allowing for any trade discounts due.

2. INCOME FROM CHARITABLE ACTIVITIES

| | Unrestricted funds 2015 € | Total funds 2015 € | Total funds 2014 € |
|------------------|--|---------------------------------------|---------------------------------------|
| Annual Symposium | 1,822,644 | 1,822,644 | 1,650,935 |
| Subscriptions | 138,136 | 138,136 | 140,902 |
| Academy income | 6,962 | 6,962 | 4,670 |
| | <u>1,967,742</u> | <u>1,967,742</u> | <u>1,796,507</u> |

3. INVESTMENT INCOME

| | Unrestricted funds 2015 € | Total funds 2015 € | Total funds 2014 € |
|--------------|--|---------------------------------------|---------------------------------------|
| Income bonds | 6,840 | 6,840 | 6,031 |

4. OTHER INCOME

| | Unrestricted funds 2015 € | Total funds 2015 € | Total funds 2014 € |
|---------------------------------|--|---------------------------------------|---------------------------------------|
| Journal royalties | 120,388 | 120,388 | 139,663 |
| Editorial expenses contribution | <u>45,310</u> | <u>45,310</u> | <u>44,153</u> |
| | <u>165,698</u> | <u>165,698</u> | <u>183,816</u> |

5. ANALYSIS OF TOTAL EXPENDITURE

| | Unrestricted funds 2015 € | Total funds 2015 € | Total funds 2014 € |
|-------------------------------|--|---------------------------------------|---------------------------------------|
| Charitable activities: | | | |
| Council symposium expenses | 6,531 | 6,531 | 8,233 |
| Publication of journal | 137,895 | 137,895 | 49,191 |
| SSIEM Academy (ETAC) | 61,209 | 61,209 | 39,020 |
| Symposium awards | 9,116 | 9,116 | 3,500 |
| Symposium expenses | 1,397,077 | 1,397,077 | 913,340 |
| Grants payable | 6 30,119 | 30,119 | 24,173 |
| Support costs | 7 127,841 | 127,841 | 108,250 |
| Governance costs | 8 <u>17,346</u> | <u>17,346</u> | <u>19,280</u> |
| | <u>1,787,134</u> | <u>1,787,134</u> | <u>1,164,987</u> |

6. GRANTS PAYABLE IN FURTHERANCE OF CHARITABLE ACTIVITIES

| | Number | Total 2015 € | Number | Total 2014 € |
|---|---------------|-----------------------------|---------------|-----------------------------|
| Support for delegates to attend symposium | 22 | 30,199 | 18 | 24,173 |

7. SUPPORT COSTS

| | Unrestricted funds € | Total 2015 € | Total 2014 € |
|----------------------------------|-------------------------------------|-----------------------------|-----------------------------|
| Council travel and subsistence | 19,569 | 19,569 | 20,681 |
| Printing, stationery and postage | 13,607 | 13,607 | (1,779) |
| Exchange rate variance | 12,007 | 12,007 | 4,602 |
| Website costs | 4,043 | 4,043 | 1,688 |
| Irrecoverable VAT | - | - | 20,786 |
| Other administration | 17,816 | 17,816 | 7,604 |
| Secretarial expenses | <u>60,799</u> | <u>60,799</u> | <u>54,668</u> |
| | <u>127,841</u> | <u>127,841</u> | <u>108,250</u> |

8. GOVERNANCE COSTS

| | Unrestricted funds 2015 € | Total funds 2015 € | Total funds 2014 € |
|------------------------|--|---------------------------------------|---------------------------------------|
| Auditors' remuneration | 12,752 | 12,752 | 11,629 |
| Professional charges | 3,303 | 3,303 | 6,711 |
| Other administration | <u>1,290</u> | <u>1,290</u> | <u>940</u> |
| | <u>17,346</u> | <u>17,346</u> | <u>19,280</u> |

9. NET INCOMING RESOURCES

This is stated after charging:

| | 2015 € | 2014 € |
|------------------------|-------------------|-------------------|
| Auditors' remuneration | <u>12,752</u> | <u>11,629</u> |

During the year, no Trustees received any remuneration (2014 - €NIL).

During the year, no Trustees received any benefits in kind (2014 - €NIL).

During the year, Trustees received reimbursement of expenses totalling €25,047 (2014 - €18,951).

10. FIXED ASSET INVESTMENTS

Other investments
€

Market value

| | |
|---------------------------|-----------------------|
| At 1 January 2015 | 511,080 |
| Foreign exchange movement | <u>31,564</u> |
| At 31 December 2015 | <u><u>542,644</u></u> |

Other investments comprise £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 charitable company. Investments are held to provide an investment return.

11. DEBTORS

| | 2015 | 2014 |
|--------------------------------|-------------------------|-----------------------|
| | € | € |
| Trade debtors | 1,869,032 | - |
| Other debtors | 32,658 | 33,976 |
| Prepayments and accrued income | <u>90,613</u> | <u>161,783</u> |
| | <u><u>1,992,303</u></u> | <u><u>195,759</u></u> |

12. CASH AND CASH EQUIVALENTS

| | 2015 | 2014 |
|--------------|------------------|------------------|
| | € | € |
| Cash at bank | <u>1,193,985</u> | <u>1,396,474</u> |

13. CREDITORS:

Amounts falling due within one year

| | 2015 | 2014 |
|------------------------------|-------------------------|-----------------------|
| | € | € |
| Accruals and deferred income | <u>108,536</u> | <u>264,704</u> |
| | <u><u>1,505,613</u></u> | <u><u>264,704</u></u> |

Deferred income

| | |
|--------------------------------------|----------------------|
| Deferred income at 1 January 2015 | 50,986 |
| Resources deferred during the year | 26,293 |
| Amounts released from previous years | <u>(50,986)</u> |
| Deferred income at 31 December 2015 | <u><u>26,293</u></u> |

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

13. STATEMENT OF FUNDS

| | Balance at 1 January 2015 | Income | Expenditure | Gains/ (Losses) | Balance at 31 Dec 2015 |
|---------------------------|------------------------------|------------------|--------------------|--------------------|---------------------------|
| | € | € | € | € | € |
| Unrestricted funds | | | | | |
| General Funds | <u>1,838,609</u> | <u>2,140,280</u> | <u>(1,787,134)</u> | <u>31,564</u> | <u><u>2,223,319</u></u> |

The general fund represents the 'free reserves'.

Notes to the Financial Statements

15. ANALYSIS OF NET ASSETS BETWEEN FUNDS

| | Unrestricted funds 2015 € | Total funds 2015 € | Total funds 2014 € |
|-------------------------------|--|---------------------------------------|---------------------------------------|
| Fixed asset investments | 542,644 | 542,644 | 511,080 |
| Current assets | 3,186,288 | 3,186,288 | 1,592,233 |
| Creditors due within one year | <u>(1,505,613)</u> | <u>(1,505,613)</u> | <u>(264,704)</u> |
| | <u>2,223,319</u> | <u>2,223,319</u> | <u>1,838,609</u> |

16. RELATED PARTY TRANSACTIONS

Certain trustees are also members of the Society. During the year they have paid membership fees on an arm's length basis and no balances are outstanding as at 31 December 2015 (2014: nil).

Ms A Y Brown, Honorary Treasurer, 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, SSIEM paid €19,472 (2014: €14,765) to ERNDIM for Education and Training Society (ETAC) administrative functions. There were no balances outstanding as at 31 December 2015 (2014: nil).

17. RECONCILIATION WITH PREVIOUS GENERALLY ACCEPTED ACCOUNTING PRACTICE

In preparing the financial statements, the Trustees have considered whether in applying the accounting policies required by FRS 102 and the Charities SORP FRS 102 the restatement of comparative items was required.

The policies applied under the entity's previous accounting framework are not materially different to FRS 102 and have not impacted on equity or profit or loss in the current or the prior year.

