

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

**NOTICE OF  
ANNUAL GENERAL MEETING - 2015**

to be held in

Lyon

on

Wednesday 2nd September 2015

at 1.00 p.m.

Prof Gajja S Salomons  
Hon Secretary

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

## **ANNUAL GENERAL MEETING - 2015**

### **AGENDA (Chair: Prof P T Clayton)**

1. Apologies for absence
2. To receive the minutes of the previous meeting held on Wednesday 3rd September 2014 in Innsbruck, Austria
3. Matters arising from the previous meeting
4. Honorary Treasurer's report, including new membership structure & subscription proposal
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
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. New Honorary members
14. Any other business



# HONORARY SECRETARY'S REPORT 2014-2015

## MEMBERSHIP

The membership at the end of 2014 had grown by just over 4.1% over the previous year and by more than 23% since the end of 2010; the proportion of those less than 35 years of age category has grown by over 101% and the retired category has grown by over 138% since 2010, representing just over 17% of the total membership. Members come for 77 different countries, 44 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 Council has proposed a standard rate 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. Furthermore Council proposes a reduced fee 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 scheme to be proposed, at the AGM in Lyon, 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 Innsbruck, under the chairmanship of Prof P T Clayton. On September 3rd 2014 Prof P D Mayne, Honorary Secretary de-mitted from Council and was replaced by Prof G S Salomons, Prof J Campistol and Ms M A Dixon also de-mitted from Council. New appointees to Council were Prof K Ounap, Dr A Ribes, Ms A M J van Wegberg and Dr V Valayannopoulos as Chairman ETAC (Ex-Officio). Membership of Council for 2014-2015 comprised of:

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

The Societies Articles and Memorandum of Association were amended and approved at the 2014 AGM and have been implemented. The Council has updated the detailed risk assessment relating to the Society's activities and it is reviewed on a regular basis.

Nic 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.

## 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 2013-2014 were:

Janice Fletcher (Australia/New Zealand), Daniela Karall (Austria), Katrin Ounap (Baltic Countries), Marie-Cecile Nassogne (Belgium), Grant Mitchell (Canada), Ksenija Fumic (Croatia), Pavel Martasek (Czech Republic/Slovakia), Allan Lund (Denmark),

Risto Lapatto (Finland), Dries Dobbelaere (France), Rene Santer (Germany), Helen Michelakakis (Greece), Joannie Hui (Hong Kong), Sunita Bijarnia Mahay (India), Talieh Zaman (Iran), Yair Anikster (Israel), Ubaldo Caruso (Italy), Hiroyuki Ida (Japan), Layachi Chabraoui (Morocco), Berit Woldseth (Norway), Jolanta Sykut-Cegielska (Poland/Russia/Hungary), Luisa Diogo (Portugal), Luis Barrera (South America), Domingo Gonzalez-Lamuno (Spain), Anna Nordenstrom (Sweden), Matthias Baumgartner (Switzerland), Jer-Yurran Wu (Taiwan), Nanda Verhoeven Duif (The Netherlands), Turgay Coskun (Turkey), Robin Lachmann (UK), Bruce Barshop (USA).

## **2014 ANNUAL SYMPOSIUM**

The 48th SSIEM Symposium was held in Innsbruck, Austria, organised on behalf of the Society by the Co-Presidents Daniela Karall, Sabine Scholl-Burgi and Johannes Zschocke together with the Organising Committee and PCO Tyrol Congress/CMI. They and their PCO partners are to be congratulated for hosting a most successful scientific meeting and social programme. The Symposium was attended by more than 2150 delegates from 73 Countries, including 521 non members. The meeting was supported by 30 corporate partners, nine of whom sponsored meet the expert sessions. The Komrower Memorial lecture was delivered by Prof Gary Brown entitled “A wide circle around lactic acid”. Dr Frederic Sedel was awarded the Archibald Garrod Medal for his paper “Krabbe disease in adults: phenotypic and genotypic update from a series of 11 cases and a review” which was published in the September issue of our society journal (*Journal of Inherited Metabolic Disease* 2013; **36**: 859-868).

## **FUTURE SSIEM and ICIEM SYMPOSIA**

The following are the venues for future SSIEM Symposia:

- SSIEM Annual Symposium, Lyon, France, 2015
- 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

## **TRAVEL SCHOLARSHIPS**

From a budget of €29,500 twenty-two Travel Scholarships of up to €2,250 were approved for members and non-members to attend the SSIEM Symposium in Lyon. 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 €1300. Thirty applications were received and were judged by Prof B Plecko, Prof I Baric and Prof G S Salomons.

## **TRAINING**

The 8th SSIEM Training Academy took place in London in April 2015, covering Mitochondrial Disorders, Glycogen Storage Disorders, Congenital Glycosylation Disorders and Neurotransmitter defects and related topics. This was the fourth training meeting in the second of a four year cycle programme. The number of applications was similar to the previous year with one hundred and twelve applications received for the 80 places but this year with more applications of clinicians (66) than scientists (46). Again the majority of those who attended came from greater Europe, but others came from South America (Brazil, Columbia), North America (USA, Canada), Asia (Iran, India, Malaysia, Hong Kong), North Africa (Tunisia) and Australia. The Course included a number of combined clinical and

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# Honorary Secretary's Report

scientific 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, Vassili Valayannopoulos (Chairman), Andrew Morris (Honorary Secretary) and Sara 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 9th SSIEM Training Academy in Freiburg in April 2016. The ETAC officers together with council are developing a new governance plan for ETAC which is in line with the Society's Memoranda and Articles of Association: 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.

## **WEBSITE**

Council acknowledges the support of Michael McConnell of Blackcat Websites in maintaining and developing the site. The website is an important mechanism for communicating with the membership and Council would welcome material for inclusion of the site. Michael McConnell also has a valuable role in the Symposium abstract submission, selection and processing and his contribution is much appreciated.

## **JIMD**

A more detailed report on the Journal is covered elsewhere within this Annual General Meeting (AGM) bulletin. Shamima Rahman and Matthias Baumgartner joined the editorial team of Johannes Zschocke (Editor-in-Chief), Verena Peters (Managing Editor), Eva Morava and Marc Patterson (editors). Mike Gibson (Editor-in-Chief) and Garry Brown stepped down at the end of 2014. Johannes Zschocke will step down at the end of 2014 as Editor-in-Chief having served 10 years as an editor. The expertise, knowledge and contribution of all three demitting editors to the success of the Journal has been much appreciated by Council. 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 reduced from 4.138 to 3.365 and an IF for JIMD Reports is expected by 2016.

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.

Council has been seeking bids for a new Editor-in-Chief and team. Council has improved the governance plan for JIMD which is in line with the Society's Memoranda and Articles of Association. Both the Editor-in-Chief as well as the editorial board members will serve for an initial 3 year term, which will be extended for another 3 year term by mutual agreement. If the new Editor-in-Chief has already served on the editorial board another 3+3 years in this new role is possible. The Editor-in-Chief will be an ex-officio council member of SSIEM Council.

## **SSIEM SUBGROUPS**

The SSIEM-Adult Metabolic Physicians' Group, led by Robin Lachman (Chairman) and Carla Hollak (Secretary) continues to organise a successful session on adult metabolic disorders on the morning of the openings day of the annual SSIEM Symposium.

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

*Prof G S Salomons  
Honorary Secretary  
July 2015*

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# Honorary Secretary's Report

# HONORARY TREASURER'S REPORT 2014

The Accounts for 2014 are again shown in Euro (€) as agreed at the 2009 AGM.

## INCOME

Receipt of subscriptions for 2014 increased compared with 2013, a surplus was also realised from the 2014 SSIEM Symposium in Innsbruck.

Membership increased by 56 during 2014, as at 31 December 2014 there were 1404 members names on the database compared with 1348 as at 31 December 2012.

Under the contract with the publishers of the JIMD we receive a share of the Royalties; in 2014 Council was pleased to receive €139,663 for 2014, together with editorial expenses of €44,153.

The net income for 2014 had increased substantially over the net income of 2013. This is primarily due to the continual success of the SSIEM symposium and the JIMD.

The budget for 2016 reflects a deficit of €120k, this is a conservative estimate excluding any surplus from the 2016 symposium and includes a minimum of €50k set aside for development costs. A review of membership subscription fees will be presented at the AGM, should the current membership fee structure remain Council proposes that the annual subscription should not be increased from Ordinary Members €130, 35 years and under €80 and Retired €15.

There will again be no additional charge for accepting Card payments. 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.

## EXPENDITURE

The overall expenditure, excluding the symposium, for 2014 has not increased significantly compared to 2013. The administrative workload and subsequent costs to the Society however will increase due to:

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

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 Hon. Treasurer for a Membership Support Grant for 3 to 5 years.

## BALANCE SHEET

Total amount in accumulative fund increased in 2014, by €852,847 and stands at €1,838,609.

## 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.
- 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 2015*

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# Honorary Treasurer's Report

# JIMD REPORT 2014-2015

The number of submissions to JIMD and JIMD Reports increased from 440 manuscripts in 2013 to 521 manuscripts in 2014. Submissions came from 49 different countries, with the majority from USA (15%), Italy (7%), United Kingdom (7%), Germany (7%), the Netherlands (7%), China (5%), Turkey (4%), Australia (4%), Spain (4%), and Brazil (4%). 101 articles were printed in JIMD and 120 articles in the online journal “JIMD Reports”. The JIMD Impact Factor is now 3.36. 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 2015** will be awarded to Yannis Trakadis, Montreal, Canada for the article “Update on transcobalamin deficiency: clinical presentation, treatment and outcome”, published in the JIMD in 2014.

**The Communicating Editor Awards 2015** for work in 2014 will be presented to Bridget Wilcken, Mike Gibson and Ertan Mayatepek as busiest Editors, to Gregory Enns as fastest Editor, and to Antonia Ribes and Jeame Campistol as Guest Editors. We remain indebted to all Communicating Editors and reviewers who have added invaluable expertise and invested considerable effort that has contributed to the Journal of Inherited Metabolic Disease.

In 2015, we published themed issues on “Complex Lipids”, coordinated by Guest Editors Jean-Marie Saudubray, Ronald Wanders and Matthias Baumgartner, on “Glycogen Storage Disease”, collated by Georg Hoffmann, Peter Smit and Benedikt Schoser, and on “Next generation mitochondrial disease”, organized by Eva Morava and Garry Brown. 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 on an inherited metabolic disease or relevant research findings, as well as Guidelines, Metabolic Dissertations, Letters to the Editors or Metabolic Images. We also continue to welcome material for the Extras section; in particular, think of writing an obituary for JIMD if you learn of the death of an SSIEM member or other person related to inherited metabolic diseases

*The Editorial Team*  
*Matthias Baumgartner, Eva Morava, Marc Patterson,*  
*Verena Peters, Shamima Rahman and Johannes Zschocke*

# REFERENCE AND ADMINISTRATIVE DETAILS

## For the year ended 31 December 2014

### Trustees/Directors

Prof P T Clayton, Honorary Chair	
Prof P D Mayne, Honorary Secretary	(resigned 3 September 2014)
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) (appointed 3 September 2014)
Prof I Baric	
Prof J Campistol	(resigned 3 September 2014)
Dr C Dionisi Vici	
Ms M A Dixon	(resigned 3 September 2014)
Prof K Ounap	(appointed 3 September 2014)
Prof B Plecko	
Dr A Ribes	(appointed 3 September 2014)
Prof U Spiekerkoetter	
Dr C Saban	
Ms A M J van Wegberg	(appointed 3 September 2014)

### 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

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# General Information

# TRUSTEES' REPORT

## **For the year ended 31 December 2014**

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 2014. The Trustees confirm that the Annual report and financial statements of the charitable company comply with the current statutory requirements, the requirements of the charitable company's governing document and the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issued in March 2005.

## **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 proposal to set-up a Finance Sub-Committee (FSC) to help run the financial side of the Society was announced at the 2014 AGM. 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 and for attendance at the annual symposium (SSIEM Travel Support Scholarship).

SSIEM Membership Support 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 SSIEM Travel Support 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 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 2014 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 Lyon 2015 and 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 (ASIEM), Sociedad Latinoamericana de Errores Innatos del Metabolismo y Pesquisa Neonatal (SLEIMPN), on the preparation of the International Congress of Inborn Errors of Metabolism (ICIEM) in Rio De Janeiro, Brazil for 2017. It was also agreed at the 2014 AGM that the SSIEM symposiums for 2018 and 2019 would be held in Athens and Rotterdam respectively.

Membership has continued to increase. 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 Morris

Administrator: S Gardner

Senior Advisor: Prof J H Walter

#### **Clinical**

Dr A Morris

Dr V Valayannopoulos

Prof U Spiekerkoetter

Prof S Rahman

#### **Laboratory**

Prof B Fowler

Dr M Henderson

Dr C 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 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 2014 this consisted of a two day concurrent course held in Paris 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.

Although the net payment to the publishers of the JIMD is higher under the new contract, the Society will receive a share of the Royalties.

### ***Symposium***

In 2014 the Society for the Study of Inborn Errors of Metabolism held its annual Symposium in Innsbruck, which was attended by over 2,150 people. Plans are well advanced with the organisation of the annual symposiums to be held in Lyon in 2015 and Rome in 2016.

## **FINANCIAL REVIEW**

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

The net incoming resources for the year amounted to €852,847 (2013: €112,863), which was the amount attributable to general reserves, which at the year end stood at €1,838,609 (2013: €985,762).

There have been no important events since the balance sheet date.

### ***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. Council proposes to use some of the unrestricted funds to encourage the sharing of experience and training between centres. 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.

During 2014, the Council was pleased to give financial assistance to 18 individuals enabling them to attend the SSIEM Symposium in Innsbruck. 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 2014 the Annual Subscriptions of 9 members were paid by the Society; in addition members and non members were given financial assistance to attend the SSIEM Symposium in Innsbruck.

### ***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.
- manage risk.

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.

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.

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

This report was approved by the Trustees on 26th June 2015 and signed on their behalf by

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

# 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 2014 set out on pages 18 to 24. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (effective April 2008) (United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities).

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](http://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 2014 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 applicable to Smaller Entities; 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 Trustees' report 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 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

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# Independent Auditor's Report

- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemption from the requirement to prepare a strategic report or in preparing the Trustees' report.

*William Devitt (Senior statutory auditor)  
for and on behalf of  
Grant Thornton UK LLP  
Statutory Auditor  
Chartered Accountants  
Northampton  
17th July 2015*

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# Independent Auditor's Report

**STATEMENT OF FINANCIAL ACTIVITIES**  
**(Incorporating Income and Expenditure Account)**  
**For the year ended 31 December 2014**

		Unrestricted funds 2014 €	Total funds 2014 €	Total funds 2013 €
	Note			
<b>Incoming resources</b>				
Incoming resources from generated funds:				
Investment income	2	6,031	6,031	7,841
Incoming resources from charitable activities	3	1,796,507	1,796,507	1,703,171
Other incoming resources	4	<u>183,816</u>	<u>183,816</u>	<u>223,237</u>
<b>Total incoming resources</b>		<u>1,986,354</u>	<u>1,986,354</u>	<u>1,934,249</u>
<b>Resources expended</b>				
Charitable activities	5, 6, 7	1,145,707	1,145,707	1,779,765
Governance costs	8	<u>19,280</u>	<u>19,280</u>	<u>28,941</u>
<b>Total resources expended</b>		<u>1,164,987</u>	<u>1,164,987</u>	<u>1,808,706</u>
<b>Net incoming resources before revaluations</b>		821,367	821,367	125,543
Gains and losses on revaluations of investment assets		<u>31,480</u>	<u>31,480</u>	<u>(12,680)</u>
<b>Net movement in funds for the year</b>		852,847	852,847	112,863
Total funds at 1 January 2014		<u>985,762</u>	<u>985,762</u>	<u>872,899</u>
<b>Total funds at 31 December 2014</b>		<u>1,838,609</u>	<u>1,838,609</u>	<u>985,762</u>

The notes on pages 19 to 24 form part of these financial statements.

# BALANCE SHEET AS AT 31ST DECEMBER 2014

	Note	€	2014 €	€	2013 €
<b>Fixed assets</b>					
Investments	10		511,080		479,600
<b>Current assets</b>					
Debtors	11	195,759		402,848	
Cash at bank		<u>1,396,474</u>		<u>332,272</u>	
		<u>1,592,233</u>		<u>735,120</u>	
<b>Creditors:</b>					
amounts falling due within one year	12	<u>(264,704)</u>		<u>(228,958)</u>	
<b>Net current assets</b>			<u>1,327,529</u>		<u>506,162</u>
<b>Net assets</b>			<u>1,838,609</u>		<u>985,762</u>
<b>Charity funds</b>					
Unrestricted funds	13		<u>1,838,609</u>		<u>985,762</u>
<b>Total funds</b>			<u>1,838,609</u>		<u>985,762</u>

The financial statements have been prepared in accordance with the provisions applicable to small companies within Part 15 of the Companies Act 2006 and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The financial statements were approved by the Trustees on 26th June 2015 and signed on their behalf, by

*Ms A Y Brown*  
*Honorary Treasurer*

The notes on pages 19 to 24 form part of these financial statements.

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## Balance Sheet

# NOTES TO THE FINANCIAL STATEMENTS

## For the year ended 31 December 2014

### 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 at market value, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008). The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP), 'Accounting and Reporting by Charities' published in March 2005, applicable accounting standards and the Companies Act 2006.

#### 1.2 Company status

The charitable company is a company limited by guarantee. The members of the company are the Trustees named on page 9. 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 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 designate for other purposes.

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

#### 1.5 Incoming resources

All incoming resources are included in the Statement of Financial Activities when the charitable company has entitlement to the funds, certainty of receipt and the amount can be measured with sufficient reliability.

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

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

#### 1.6 Resources expended

Expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs for allocation to activities. Where costs cannot be directly attributed to particular activities they have been allocated on a basis consistent with the use of the resources.

Charitable activities include expenditure associated with the publication of the journal, expenditure associated with the annual symposium and expenditure associated with ETAC. These include both the direct costs and support costs relating to those activities.

Support costs are those costs incurred directly in support of expenditure on the objects of the charitable company and include project management carried out at Headquarters.

Governance costs are those incurred in connection with administration of the charitable company and compliance with constitutional and statutory requirements.

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 attaching 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.

### 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.

## 2. INCOMING RESOURCES FROM GENERATED FUNDS

	<b>Unrestricted funds 2014 €</b>	<b>Total funds 2014 €</b>	<b>Total funds 2013 €</b>
Investment income	<u>6,031</u>	<u>6,031</u>	<u>7,841</u>

## 3. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES

	<b>Unrestricted funds 2014 €</b>	<b>Total funds 2014 €</b>	<b>Total funds 2013 €</b>
Annual Symposium	1,650,935	1,650,935	1,564,500
Subscriptions	140,902	140,902	138,671
Academy income	<u>4,670</u>	<u>4,670</u>	-
	<u>1,796,507</u>	<u>1,796,507</u>	<u>1,703,171</u>

#### 4. OTHER INCOMING RESOURCES

	<b>Unrestricted funds 2014 €</b>	<b>Total funds 2014 €</b>	<b>Total funds 2013 €</b>
Journal royalties	139,663	139,663	180,161
Editorial expenses contribution	<u>44,153</u>	<u>44,153</u>	<u>43,076</u>
	<u>183,816</u>	<u>183,816</u>	<u>223,237</u>

#### 5. GRANTS PAYABLE IN FURTHERANCE OF CHARITABLE ACTIVITIES

	<b>Number</b>	<b>Total 2014 €</b>	<b>Number</b>	<b>Total 2013 €</b>
Support for delegates to attend symposium	<u>18</u>	<u>24,173</u>	<u>19</u>	<u>22,345</u>

#### 6. DIRECT COSTS

	<b>Unrestricted funds €</b>	<b>Total 2014 €</b>	<b>Total 2013 €</b>
Council symposium expenses	8,233	8,233	8,082
Publication of journal	49,191	49,191	226,839
SSIEM Academy (ETAC)	39,020	39,020	29,309
Symposium awards	3,500	3,500	2,938
Symposium expenses	<u>913,340</u>	<u>913,340</u>	<u>1,371,960</u>
	<u>1,013,284</u>	<u>1,013,284</u>	<u>1,639,128</u>

#### 7. SUPPORT COSTS

	<b>Unrestricted funds €</b>	<b>Total 2014 €</b>	<b>Total 2013 €</b>
Council travel and subsistence	20,681	20,681	19,726
Printing, stationery and postage	(1,779)	(1,779)	18,119
Exchange rate variance	4,602	4,602	6,811
Website costs	1,688	1,688	1,391
Irrecoverable VAT	20,786	20,786	8,751
Other administration	7,604	7,604	23,319
Secretarial expenses	<u>54,668</u>	<u>54,668</u>	<u>40,175</u>
	<u>108,250</u>	<u>108,250</u>	<u>118,292</u>

## 8. GOVERNANCE COSTS

	Unrestricted funds €	Total 2014 €	Total 2013 €
Auditors' remuneration	11,629	11,629	10,200
Professional charges	6,711	6,711	17,665
Other administration	<u>940</u>	<u>940</u>	<u>1,076</u>
	<u>19,280</u>	<u>19,280</u>	<u>28,941</u>

## 9. NET INCOMING RESOURCES

This is stated after charging:

	2014 €	2013 €
Auditors' remuneration	<u>11,629</u>	<u>10,200</u>

During the year, no Trustees received any remuneration (2013 - €NIL).

During the year, no Trustees received any benefits in kind (2013 - €NIL).

15 Trustees received reimbursement of expenses amounting to €18,951 in the current year, (2013 - 12 Trustees - €21,458).

## 10. FIXED ASSET INVESTMENTS

	Other investments €
<b>Market value</b>	
At 1 January 2014	479,600
Foreign exchange movement	<u>31,480</u>
At 31 December 2014	<u>511,080</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

	2014 €	2013 €
Trade debtors	-	190,104
Other debtors	33,976	12,871
Prepayments and accrued income	<u>161,783</u>	<u>199,873</u>
	<u>195,759</u>	<u>402,848</u>

## 12. CREDITORS:

Amounts falling due within one year	2014	2013
	€	€
Accruals and deferred income	<u>264,704</u>	<u>228,958</u>
<b>Deferred income</b>		
Deferred income at 1 January 2014		49,750
Resources deferred during the year		50,986
Amounts released from previous years		<u>(49,750)</u>
Deferred income at 31 December 2014		<u>50,986</u>

## 13. STATEMENT OF FUNDS

	Brought forward	Incoming resources	Resources expended	Gains/ (Losses)	Carried forward
	€	€	€	€	€
<b>Unrestricted funds</b>					
General Funds	<u>985,762</u>	<u>1,986,354</u>	<u>(1,164,987)</u>	<u>31,480</u>	<u>1,838,609</u>

## 14. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds	Total funds	Total funds
	2014	2014	2013
	€	€	€
Fixed asset investments	511,080	511,080	479,600
Current assets	1,592,233	1,592,233	735,120
Creditors due within one year	<u>(264,704)</u>	<u>(264,704)</u>	<u>(228,958)</u>
	<u>1,838,609</u>	<u>1,838,609</u>	<u>985,762</u>

## 15. 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 2014 (2013: 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 €14,765 (2013: €10,274) to ERNDIM for Education and Training Society (ETAC) administrative functions. There were no balances outstanding as at 31 December 2014 (2013: nil).

