

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

**NOTICE OF
ANNUAL GENERAL MEETING - 2014**

to be held in

Innsbruck

on

Wednesday 3rd September 2014

at 12.00 p.m.

Philip D Mayne
Hon Secretary

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

ANNUAL GENERAL MEETING - 2014

AGENDA

1. Apologies for absence
2. To receive the minutes of the previous meeting held on Wednesday 5th September 2013 in Barcelona, Spain
3. Matters arising from the previous meeting
4. Honorary Treasurer's report
5. Honorary Secretary's report
6. JIMD report
7. ETAC (Education, Training & Advisory Committee) report
8. Special Resolution– that the Memorandum and Articles of the Society be revised and amended
9. SSIEM – Special Interest Groups
10. Website report
11. Future SSIEM Symposia
12. IOC Report
13. Council Officers/ Election of Council Members
14. Corresponding members report
15. On the proposal of Council to re-appoint Baker Tilly UK to be Auditors of the Society and to authorise Council to determine the remuneration
16. Any other business

HONORARY SECRETARY'S REPORT 2013-2014

MEMBERSHIP

The membership at the end of 2013 had grown by just over 5.5% over the previous year and by more than 18% since the end of 2010; the proportion of those less than 35 years of age has remained steady over the past couple of years, representing just under 14% of the total membership. Members come from 73 different countries, 37 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 yet to devise a subscription scheme that is deemed to be fair and equitable for all its members in the differing specialties. The membership support scheme remains in place for those requiring subscription support.

COUNCIL

Council met on four occasions during the year; three times in London and once in Barcelona, under the chairmanship of Prof Peter Clayton, Prof Viktor Kozich de-mitted from Council following two terms and was replaced by Prof Ivo Baric; Prof Kozich has kindly agreed to remain as the SSIEM's representative on the European Society of Human Genetics (ESHG) Genetic Services Quality Committee. Membership of Council for 2013-2014 comprised of:

Prof P. Clayton (Chairman), Prof P. Mayne (Hon Secretary), Ms A. Brown (Hon Treasurer), Prof I. Baric, Prof J. Campistol, Dr C. Dionisi-Vici, Ms M. Dixon, Prof B. Plecko, Dr G. Salomons, Prof U. Spiekerkoetter, Dr C. Vianey-Saban, Prof J. Zschocke (Editor-in-Chief, JIMD).

During the year it was identified that the amendments to the Articles of Association which had been approved by the membership in 1990 had not been registered. As a consequence the opportunity was taken to review and update the Articles to reflect better the organisation and governance of the Society. In addition, Council reviewed the Governance of the Society and its subcommittee structure and the Treasurer carried out a detailed risk assessment relating to the Society's activities. The risk assessment will now be reviewed on an annual 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.

CORRESPONDING MEMBERS

Council appreciated the support and comments from individual corresponding members during the year. Corresponding members play an important role in choosing the venue for the Annual Symposium and in providing nominations for Council. Under the recommended revised Articles, if approved, the Corresponding members will form an Advisory Committee to Council. Corresponding members for 2012-2013 were:

Janice Fletcher (Australia/New Zealand), Daniela Karall (Austria), Katrin Ounap (Baltic Countries), Marie-Cécile Nassogne (Belgium), Grant Mitchell (Canada), Ksenija Fumic (Croatia), Pavel Martasek (Czech Republic/Slovakia), Allan Lund (Denmark/Norway), Risto Lapatto (Finland), Dries Dobbelaere (France), Robert Steinfeld (Germany), Helen Michelakakis (Greece), Joannie Hui (Hong Kong), Ishwar Verna (India), Talieh Zaman (Iran), Anthony S. Luder (Israel), Ubaldo Caruso (Italy), Hiroyuki Ida (Japan),

Berit Woldseth (Norway), Jolanta Sykut-Cegielska (Poland/Russia/Hungary), Luisa Diogo (Portugal), Luis Barrera (South America), Domingo González-Lamuño (Spain), Anna Nordenstrom (Sweden), Matthias Baumgartner (Switzerland), Jer-Yurran Wu (Taiwan), Gajja Salomons (The Netherlands), Turgay Coskun (Turkey), Robin Lachmann (UK), Bruce Barshop (USA).

2013 ANNUAL SYMPOSIUM

The 12th ICIEM meeting was held in Barcelona, organised by the SSIEM on behalf of the International Organising Committee. The local organising committee was headed up by Prof Jaime Campistol Plana and Dr Antonia Ribes. 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 2400 delegates; 538 were SSIEM members, representing approximately 45% of the membership. The meeting was supported by 28 corporate partners, seven of whom sponsored satellite meetings. 880 abstracts were accepted for either oral or poster presentations. The Komrower Memorial lecture was delivered by Dr Carlo Dionisi-Vici entitled “The daily challenge of understanding and treating metabolic diseases in children”. Dr Susan Waisbren was awarded the Archibald Garrod Medal for her paper on The Adult Galactosemic Phenotype which was published in the March 2012 issue of the Journal (*J Inherit Metab Dis.* 2012; **35**: 279).

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

Expression of interest have been received to host the 2018 and 2019 Annual Symposia and these will be put to the Council and Corresponding Members meeting during the Symposium.

TRAVEL SCHOLARSHIPS

From a budget of €22,000, nineteen Travel Scholarships of up to €2,100 were approved for members and non-members to attend the SSIEM Symposium in Innsbruck. Eleven Travel Scholarships were awarded on the basis of financial need and seven on the scholarship of the submitted abstract. For those travelling from within greater Europe the scholarship was restricted to €1200. Forty applications were received and were judged by Prof G. Salomons, Prof B. Plecko, and Prof P. Mayne.

TRAINING

The 7th SSIEM Training Academy took place in Paris in April 2014, covering lysosomal storage and peroxisomal disorders, purine and pyrimidine disorders and related topics. This was the third 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 eight applications received for the 80 places, divided equally between clinicians and scientists. Again the majority of those who attended came from greater Europe, but others came from India, Australia, the USA and Argentina. The Course included a number of combined clinical and 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). ETAC proposes to hold the 8th SSIEM Training Academy in London in April 2015.

Honorary Secretary's Report

In September 2013, Professor Brian Fowler, on behalf of ETAC and the SSIEM, participated in a workshop on Laboratory Diagnostic techniques in Inborn Errors of Metabolism in South India. The workshop was organised by Dr Pragna Rao, Professor of Biochemistry at Kasturba Medical College (KMC), Manipal, South India. The practical workshop was attended by 20 scientists and the associated lectures by more than 100 scientists and paediatricians from the various local biochemistry and paediatric departments in South India. The workshop was well received by all those who attended.

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 AGM bulletin. Eva Morava and Marc Patterson joined the editorial team of Johannes Zschocke and Mike Gibson (Editors-in-Chief), Garry Brown (Editor) and Verena Peters (Managing Editor). However, both Mike Gibson and Garry Brown will be stepping down at the end of 2014. Their expertise, knowledge and contribution to the success of the Journal is 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 stands at 4.07 and an IF for JIMD Reports is expected by 2015.

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

Following the resignation of Frédéric Sedel as Chair of the SSIEM-Adult Metabolic Physicians' Group, Robin Lachman was nominated Chairman and Carla Hollak its representative to Council. Council would like to acknowledge Frédéric Sedel's contribution in establishing this important special interest group. The SSIEM-Dietitians' Group (SSIEM-DG) led by Dr Reinhild Link, continues to make an important contribution to the organisation of the dietetic component of the scientific programme of the Symposium.

*Prof Philip Mayne
Honorary Secretary
July 2014*

Honorary Secretary's Report

HONORARY TREASURER'S REPORT 2013-2014

The Accounts for 2013 are again shown in Euro (€) as agreed at the 2009 AGM.

INCOME

Receipt of subscriptions for 2013 increased compared with 2012, a surplus was also realised from the 2013 ICIEM Symposium in Barcelona.

Membership increased by 71 during 2013, as at 31st December 2013 there were 1348 members names on the database compared with 1277 as at 31st December 2012.

Under the contract with the publishers of the JIMD we receive a share of the Royalties; in 2013 Council was pleased to receive €180,161 for 2013, together with editorial expenses of €43,076.

The net income 2013 had increased substantially over the net income of 2012. This is primarily due to the success of the ICIEM symposium and the JIMD.

The budget for 2015 reflects a deficit of €97k, this is a conservative estimate assuming a small surplus from the 2015 symposium and includes €30k 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 €130 for 2015 for members over 35 years and €80 for those 35 years and under.

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 2013 shows a small increase of approximately 10% compared to 2012. There are a number of reasons for this:

- An increase in Governance Costs relating to the Society and Symposium.
- Travel scholarship support continues to increase.
- 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 2013, by €112,863 and stands at €985,762.

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 will be created to review the Society's financial activities.

JOURNALS

It is our policy to mail journals only to those members for whom a full subscription has been received.

Honorary Treasurer's Report

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 Professor 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 present auditor Baker Tilley UK Audit LLP be reappointed.

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

*A Y Brown
Honorary Treasurer
July 2014*

Honorary Treasurer's Report

JIMD REPORT 2013-2014

In 2013, 444 articles were submitted to JIMD and JIMD Reports, coming from 49 different countries. The majority of articles came from the USA (14%), Italy (8%), Germany (8%), the Netherlands (7%), Brazil (5%), United Kingdom (4%), Turkey (4%), Japan (3%), Spain (3%), India (3%), France (2%) and China (2%). 109 articles were printed in JIMD and 100 articles in the online journal “JIMD Reports”. This journal includes important scientific and case reports. JIMD Reports is now fully and correctly indexed and crosslinked in PubMed/PubMed Central. Articles in “JIMD Reports” are professionally typeset in a comparable fashion to “JIMD” articles.

The Archibald Garrod Award 2014 will be awarded to Frédéric Sedel, Paris, for the study entitled “Krabbe disease in adults: phenotypic and genotypic update from a series of 11 cases and a review”.

The Communicating Editor Awards 2014 for work in 2013 will be presented to Frits Wijburg, John Christodoulou, Nicole Wolf as busiest Editors, to John Walter as fastest Editor, and to Chris Hendriksz as Guest Editor. A Special Award goes to Henk Blom, Brian Fowler and Viktor Kozich for the highly cited themed issue on “Homocystein and B-vitamin metabolism” (13.3 citations per article on average). We remain indebted to all Communicating Editors and reviewers who have added invaluable expertise and invested considerable effort that have contributed to our significantly improved impact factor!

We are currently preparing a themed issue on “Complex Lipids” with articles arising from the Workshop “Diagnosis approach, and classification of IEM affecting the synthesis and catabolism of complex lipids” in Paris, France (2013). Guest Editors are Jean-Marie Saudubray, Ron Wanders and Matthias Baumgartner. Further, articles coming from the Glycogen Storage Disease Conference in Heidelberg, Germany (2013) are collected by Georg Hoffmann, Peter Smit and Benedikt Schoser, and a themed issue on “Next generation mitochondrial disease”, organized by Eva Morava and Garry Brown is in preparation. If you have an idea for a themed issue, please contact us!

Last but not least we will have a major change in the Editorial Team. After 20 and 14 years on the JIMD Editorial Team, respectively, Garry Brown and Mike Gibson have decided to retire from their duties as JIMD Editors. We are extremely grateful for their longstanding intensive work for the journal and will miss them very much. Marc Patterson has already joined the Editorial Team in March 2014, and Shamima Rahman and Matthias Baumgartner will start as new team members in September. We trust that we will be able to keep the high editorial quality in the future.

*The Editorial Team
(Garry Brown, Mike Gibson, Eva Morava,
Marc Patterson, Verena Peters and Johannes Zschocke)*

GENERAL INFORMATION

DIRECTORS AND TRUSTEES

I Baric (appointed 4 September 2013)
A Y Brown
J Campistol
P T Clayton
C Dionisi Vici
M A Dixon
V Kozich (resigned 4 September 2013)
P D Mayne
B Plecko
C Vianey-Saban
G S Salomons
U Spiekerkötter
J Zschocke

CHAIRMAN

P T Clayton

HONORARY SECRETARY

P D Mayne

HONORARY TREASURER

A Y Brown

REGISTERED OFFICE

Third Floor
130-132 Tooley Street
London SE1 2TU

BANKERS

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

AUDITORS

Baker Tilly UK Audit LLP
Registered Auditors
St Philips Point
Temple Row
Birmingham B2 5AF

Company Registration Number (England & Wales) 2567711

Charity Registration Number 1010639

General Information

TRUSTEES' REPORT

The Trustees present their report together with financial statements for the year ended 31 December 2013. The Trustees confirm that the financial statements comply with current statutory requirements and with those of the company's Memorandum and Articles of Association.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

The company which is governed by its Memorandum and Articles of Association dated 12 December 1990, is constituted as a company limited by guarantee and has been given the registered company number 2567711.

The company is also a registered charity and has been given the registered charity number 1010639.

Trustees

The Directors, who are also the Trustees of the charity, are listed below:

I Baric (appointed 4 September 2013)
A Y Brown
J Campistol
P T Clayton
C Dionisi Vici
M A Dixon
V Kozich (resigned 4 September 2013)
P D Mayne
B Plecko
C Vianey-Saban
G S Salomons
U Spiekerkötter
J Zschocke

Being a company limited by guarantee, there is no share capital.

Organisation

A General Council made up of officers of the Society and additional members manage the organisation. The officers are a Chairman, an Honorary Secretary, and an Honorary Treasurer. Officers and Council members are elected at the Annual General Meeting. Another SSIEM member must nominate members standing for election. Officers of the Society may hold office for 3 years and are eligible for re-election to the same office for a further 3 years. Members of the General Council other than officers may hold office for 3 years; they may be re-elected for a further 3 years. All officers of the Society and members of the General Council are paid expenses to attend Council meetings.

It should be noted that the current SSIEM Treasurer is also on the ERNDIM Board of Trustees and that the SSIEM pays ERNDIM for ETAC administrative functions.

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' Report

Risk Management

The Trustees have examined the major strategic, business and operational risks that the Society faces and have established systems so that the necessary steps can be taken to lessen these risks.

The 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

The objects of The Society for the Study of Inborn Errors of Metabolism (“SSIEM”) are to foster the study of inherited metabolic disorders and related topics.

In order to further these objects, 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, the *Journal of Inherited Metabolic Disease* (JIMD) and *JIMD Reports*.

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

ACHIEVEMENTS AND PERFORMANCE

During the year ended 31 December 2013 the Society published its Journals and continued development of its own internet website. In addition, arrangements progressed 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 and hosting of the International Congress of Inborn Errors of Metabolism (ICIEM) in Barcelona. A new constitution has been formulated to reflect the current governance and activities of the Society and these will be put to the membership. Its membership has continued to increase. The General Council has met on a number of occasions to pursue the objectives of the Society.

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 Vassili Valayannopoulos
Secretary: Dr Andrew Morris
Administrator: Sara Gardner
Senior Advisor: Prof John Walters

Clinical

Andrew Morris
Vassili Valayannopoulos
Ute Spiekerkötter
Shamima Rahman

Laboratory

Brian Fowler
Mick Henderson
Christine Vianey-Saban
Jorgen 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 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

ETAC now organises an SSIEM Academy course for training in areas of inherited metabolic disease. In 2013 this consisted of a two day concurrent course for both paediatricians 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, run by two Editors in Chief together with an Editorial manager. 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 2013 the Society for the Study of Inborn Errors of Metabolism along with the Local Organising Team chaired by Prof Jaime Campistol Plana and Dr Antonia Ribes organised the 12th ICIEM meeting in Barcelona on behalf of the International Organisation Committee. Plans are well advanced with the organisation of the SSIEM Symposium to be held in Lyon in 2015.

FUNDING

Approximately 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 educational journals devoted to the study of the Inborn Errors of Metabolism.

Surplus funds are invested. Interest from investments is used in pursuance of the educational objectives of the Society, 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 75 countries. The Society exists to promote the exchange of ideas between all who are professionally interested in Inherited Metabolic Disease. It is the wish of the Council that this exchange should occur between members in as many countries as possible. The Council has agreed to set aside an amount of money from any surplus generated from normal activities to make membership more widely available to those who would otherwise be unable to participate without support from the Society. In 2013 the Annual Subscription of 5 members were paid by the Society; in addition members were given financial assistance to attend the 13th ICIEM symposium in Barcelona, Spain.

FINANCIAL REVIEW

The net incoming resources for the year amounted to €112,863 (2012: €54,186), which was the amount attributable to general reserves, which at the year end stood at €985,762 (2012: €872,899).

From 1 January 2010 the Council took the decision to report in the Euro currency as the majority of transactions were undertaken in this currency and the charity services the wider European community.

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

Investment powers and 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.

The Society has made no commitments or guarantees other than those covered in this report.

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. This will take the form of a limited number of grants to finance individual members to visit, or work for short periods of time in, other centres of expertise.

During 2013, the Council was pleased to give financial assistance to 19 individuals to attend the 13th ICIEM meeting in Barcelona, Spain. Council has also agreed to utilise some of the reserves to develop the SSIEM Academy and to make training more readily available.

Future work

Council will continue to:

- adopt and amend the Memorandum of Articles of Association as agreed at the AGM;
- review and develop corporate governance;
- manage risk.

ETAC will continue to:

- undertake accreditation visits when requested;
- update the training syllabus on a regular basis based on training need;
- participate in further specific training programmes as part of the SSIEM academy if or when required.

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.

Trustees' responsibilities for the financial 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 which 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 estimates that are reasonable and prudent;
- state whether applicable UK 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 business.

The trustees are responsible for keeping proper accounting records that 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.

In so far as the Trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware; and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from the legislation in other jurisdictions.

Small company exemptions

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies' exemption.

***By order of the Board
P D Mayne
Hon Secretary
27th June 2014***

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 2013 on pages 17 to 23. 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).

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 the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of Trustees and auditors

As explained more fully in the Statement of Trustees' responsibilities set out on pages 14, the trustees (who are also the directors of the 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 (APB'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 Financial Reporting Council's website at [http://www.frc.org.uk/Our-Work/Codes-Standards/Audit-and-assurance/Standards-and-guidance/Standards-and-guidance-for-auditors/Scope-of-audit/UK-Private-Sector-Entity-\(issued-1-December-2010\).aspx](http://www.frc.org.uk/Our-Work/Codes-Standards/Audit-and-assurance/Standards-and-guidance/Standards-and-guidance-for-auditors/Scope-of-audit/UK-Private-Sector-Entity-(issued-1-December-2010).aspx)

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 2013 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 Companies Act 2006.

Opinion on other requirement of 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:

- the charitable company has not kept adequate accounting records, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or

- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees' were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption from the requirement to prepare a strategic report or in preparing the Trustees' Report.

Paul Oxtoby (Senior Statutory Auditor)
For and on behalf of Baker Tilly UK Audit LLP, Statutory Auditor
Chartered Accountants
St Philips Point
Temple Row
Birmingham
B2 5AF
10th July 2014

Independent Auditor's Report

STATEMENT OF FINANCIAL ACTIVITIES AND INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2013

		Unrestricted and total funds 2013	Unrestricted and total funds 2012
	Note	€	€
Incoming resources			
<i>Incoming resources from generating funds:</i>			
Investment Income		7,841	8,394
<i>Incoming Resources from Charitable Activities</i>	2	328,775	1,412,820
Other incoming resources	2	<u>223,237</u>	<u>245,873</u>
Total incoming resources		<u>559,853</u>	<u>1,667,087</u>
Resources expended			
<i>Charitable Activities</i>			
Symposium	3	83,559	1,309,969
Publication of Journal	3	280,266	250,286
ETAC	3	<u>32,906</u>	<u>33,398</u>
		396,731	1,593,653
Governance Costs	6	<u>37,579</u>	<u>31,368</u>
Total resources expended		<u>434,310</u>	<u>1,625,021</u>
Net income for the year		125,543	42,066
Unrealised exchange (losses)/gains		<u>(12,680)</u>	<u>12,120</u>
Net movement in funds		112,863	54,186
Fund balances brought forward at 1 January 2013		<u>872,899</u>	<u>818,713</u>
Fund balances carried forward at 31 December 2013	10	<u><u>985,762</u></u>	<u><u>872,899</u></u>

There are no recognised gains or losses other than those included in the statement of financial activities for the two financial years.

The above results are derived from continuing operations.

Statement of Financial Activities

BALANCE SHEET AS AT 31ST DECEMBER 2013

	Note	€	2013 €	€	2012 €
Fixed assets					
Investments	7		479,600		492,280
Current assets					
Debtors	8	402,848		146,231	
Cash at bank and in hand		<u>332,272</u>		<u>555,023</u>	
		735,120		701,254	
Creditors:					
amounts falling due within one year	9	<u>(228,958)</u>		<u>(320,635)</u>	
Net current assets			<u>506,162</u>		<u>380,619</u>
Total net assets			<u>985,762</u>		<u>872,899</u>
Funds					
Unrestricted funds	10		<u>985,762</u>		<u>872,899</u>

The financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

The financial statements on pages 17 to 23 were approved by the board of directors and authorised for issue on 27th June 2014 and are signed on their behalf by:

A Y Brown
Hon Treasurer and Director

NOTES TO THE ACCOUNTS

YEAR ENDED 31 DECEMBER 2013

1 ACCOUNTING POLICIES

Basis of accounting

The accounts have been prepared in accordance with applicable accounting standards under the historical cost convention and in accordance with the recommendations of the Statement of Recommended Practice: "Accounting and Reporting by Charities" (SORP 2005) issued in March 2005, applicable UK accounting standards, the Companies Act 2006.

Going Concern

The financial position on page 18 demonstrates that the charity is operating within its available cash funds and has net current assets at the year end. The charity has maintained income from journal publications and royalties and expects similar levels of this income in the future. The Trustees believe the charity is well placed to manage its business risk despite the difficult economic climate.

The Trustees have a reasonable expectation that the charity 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.

Incoming resources

Income from charitable activities includes subscriptions income which is accounted for in the accounting period in which it is receivable and symposium income which is accounted for on a receivable basis.

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

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

Resources expended

Expenditure is recognised when a liability is incurred. Liabilities are recognised as resources expended as soon as there is a legal or constructive obligation committing the charity to the expenditure. Expenditure is directly attributable to specific activities and has been included in those cost categories. Resources expended include attributable VAT which cannot be recovered.

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.

Governance costs include those incurred in the governance of the charity and its assets and are primarily associated with constitutional and statutory requirements.

Support costs include central functions and have been allocated to activity cost categories on an income generated basis.

Grants payable are charged to the Statement of Financial Activities when they have been approved by the Board of Trustees.

Cash flow statement

The company has taken advantage of the exemption from preparing a cash flow statement conferred by Financial Reporting Standard No.1 on the grounds that it is entitled to the exemptions available for small companies.

Fund accounting

The charity's accumulated funds consist of funds which the company may use at the discretion of its Trustees.

Unrestricted funds are those available at the discretion of the Council in furtherance of the general activities of the Society which have not been designated for other purposes.

Foreign currencies

Transactions are expressed in Euro being the functional and presentational currency of the charity. Transactions in other currencies are translated into Euro and recorded at rates of exchange approximating to those ruling at the date of the transaction. Monetary assets and liabilities in other currencies are translated at rates ruling at the balance sheet date. All differences are taken to the statement of financial activities. The exchange rate used for conversion at the balance sheet date was €1.19.

Investments

Long term investments are valued at the lower of cost and market value. Gains/losses on retranslation of investments at the year end are included in the Statement of Financial Activities as unrealised gains/(losses).

2 INCOMING RESOURCES FROM CHARITABLE ACTIVITIES

	2013	2012
	€	€
Annual Symposium	190,104	1,281,039
Subscriptions	<u>138,671</u>	<u>131,781</u>
	<u>328,775</u>	<u>1,412,820</u>

Other Incoming Resources

	2013	2012
	€	€
Journal Royalties	180,161	206,923
Editorial expenses contribution	<u>43,076</u>	<u>38,950</u>
	<u>223,237</u>	<u>245,873</u>

3 ANALYSIS OF CHARITABLE EXPENDITURE

	Symposium €	Journal €	ETAC €	2013 €	2012 €
Direct Costs					
Publication of Journal	-	226,839	-	226,839	190,529
Council symposium expenses	8,082	-	-	8,082	6,965
Support for delegates to attend symposium (Note 5)	22,345	-	-	22,345	17,729
SSIEM Academy (ETAC)	-	-	29,309	29,309	30,950
Awards	2,938	-	-	2,938	750
Komrower Lecture	-	-	-	-	1,500
Symposium expenses	<u>(2,436)</u>	<u>-</u>	<u>-</u>	<u>(2,436)</u>	<u>1,149,465</u>
	30,929	226,839	29,309	287,077	1,397,999
Support Costs (Note 4)	<u>52,630</u>	<u>53,427</u>	<u>3,597</u>	<u>101,384</u>	<u>195,765</u>
	<u>83,559</u>	<u>280,266</u>	<u>32,906</u>	<u>396,731</u>	<u>1,593,653</u>

During the year 12 (2012: 10) trustees were paid expenses of €21,458 (2012: €36,133)

4 ALLOCATION OF SUPPORT COSTS

Support costs include central functions and have been allocated to activity costs categories on an income generated basis.

	Symposium €	Journal €	ETAC €	2013 €	2012 €
Council travel and subsistence	15,781	2,959	986	19,726	21,205
Secretarial expenses	10,511	21,026	-	31,537	40,407
Printing and stationery	8,860	8,860	-	17,720	17,220
Postage	100	300	-	400	1,537
Website	278	835	278	1,392	1,463
Consultancy	-	-	-	-	660
Other administration	6,995	13,990	2,333	23,318	10,954
Exchange losses	5,449	1,362	-	6,811	21,910
Irrecoverable VAT	<u>4,656</u>	<u>4,095</u>	<u>-</u>	<u>8,751</u>	<u>80,409</u>
	<u>52,630</u>	<u>53,427</u>	<u>3,597</u>	<u>109,654</u>	<u>195,765</u>

The Trustees receive no remuneration but are reimbursed for expenses incurred.

5 GRANTS PAYABLE IN FURTHERANCE OF CHARITABLE ACTIVITIES

	2013 €	2012 €
Support for delegates to attend symposium	<u>22,345</u>	<u>17,729</u>

All grants have been paid to individuals.

6 GOVERNANCE COSTS

	2013	2012
	€	€
Audit remuneration in respect of audit services	10,200	8,500
Professional charges	17,665	4,187
Secretarial expenses	8,638	11,067
Council expenditure	-	5,808
Other administration	<u>1,076</u>	<u>1,806</u>
	<u>37,579</u>	<u>31,368</u>

7 INVESTMENTS

	2013	2012
	€	€
Unlisted investments:		
Cost		
At 1 January	492,280	480,160
Retranslation (loss)/gain	<u>(12,680)</u>	<u>12,120</u>
	<u>479,600</u>	<u>492,280</u>

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

8 DEBTORS

	2013	2012
	€	€
Other debtors	333,136	111,309
Prepayments	<u>69,712</u>	<u>34,922</u>
	<u>402,848</u>	<u>146,231</u>

9 CREDITORS: amounts due within one year

	2013	2012
	€	€
Deferred income	49,750	67,520
Accruals	<u>179,208</u>	<u>253,115</u>
	<u>228,958</u>	<u>320,635</u>

The movement in deferred income is as follows:

	2013	2012
Opening balance	67,520	145,567
Released to the Statement of Financial Activities	(67,520)	(145,567)
Amounts deferred during the year	<u>49,750</u>	<u>67,520</u>
	<u>49,750</u>	<u>67,520</u>

Notes to the Accounts

10 STATEMENT OF FUNDS

Unrestricted accumulated fund

	2013	2012
	€	€
At 1 January	872,899	818,713
Net incoming resources for the year	<u>112,863</u>	<u>54,186</u>
At 31 December	<u>985,762</u>	<u>872,899</u>

11 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 2013.

