

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

**NOTICE OF
ANNUAL GENERAL MEETING - 2013**

to be held in

Catalonia Palace of Congresses
(Room H1/H2)

Barcelona

on

Wednesday 4th September 2013

at 14.00 p.m.

Philip D Mayne
Hon Secretary

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

ANNUAL GENERAL MEETING - 2013

AGENDA

1. Apologies for absence
2. To receive the minutes of the previous meeting held on Wednesday 5th September 2012 in Birmingham, UK
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
9. SSIEM – Special Interest Groups
10. Website report
11. Future meetings
12. IOC Report
13. Council Officers/ Election of Council Member
14. Corresponding members
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 2012-2013

MEMBERSHIP

The membership continues to show a small but steady increase, with members coming from more than 75 countries worldwide. Council is acutely aware that the membership fee can be a significant financial outlay and attempts to maintain the subscription as low as possible to cover the Society's expenses. From time to time, Council has considered whether it is justifiable to have different subscription rates for different groups; this issue is complex due to the vastly different salaries from across the 75 plus different countries. At present Council has agreed not to change the current structure. However, the Society does support those with financial constraints from developing nations through the Membership Grants Scheme. While the Society has, over the years built up significant reserves, Council has considered it prudent to maintain a proportion of these in the event of an unforeseen financial failure of a symposium. Some of the reserve is used to maintain the subscription and some to fulfil the aims of the Society by promoting the study of inborn errors of metabolism, through education and travel support and in supporting those working in the speciality in less developed countries.

COUNCIL

Council met on three occasions in London, under the chairmanship of Peter Clayton. Prof Jim Bonham stepped down as Honorary Treasurer, following his second term. Council is grateful for his support in guiding the Society through the transition period, following the retirement of Malcolm Heron and the transfer of the organisational activities to be administered by the Association for Clinical Biochemistry and Laboratory Medicine (ACB). Ms Anny Brown took over as Honorary Treasurer having 'shadowed' Jim for the past year. Membership of Council for 2012-2013 comprised of:

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

With a Symposium budget in excess of one million euro and an ever increasing number of delegates, the organisation of the Symposium consumed a considerable amount of Council time, reviewing and agreeing the scientific programme and the associated events. However, a range of other issues, involving the management of the Society were discussed, including the Society's charitable status. Officers of the Society also dealt with an increasing number of requests for information from members and non-members.

Nic Law and his team in 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 appreciates the support and comments from individual corresponding members during the year. This helps to form opinion and to keep the Society relevant to a very disparate membership. Corresponding members for 2012-2013 are shown below; some minor changes took place in 2013:

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), A. M. Lund (Denmark/Norway),

Risto Lapatto (Finland), Dries Dobbelaere (France), Robert Steinfeld (Germany), Helen Michelakakis (Greece), Joannie Hui (Hong Kong), I. C. Verma (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), Yuann-Tsong Chen (Taiwan), Gajja Salomons (The Netherlands), Turgay Coskun (Turkey), Anupam Chakrapani (UK), Bruce Barshop (USA).

2012 ANNUAL SYMPOSIUM

The 47th SSIEM Symposium was held in Birmingham, UK, organised on behalf of the Society by the British Inherited Metabolic Disease Group (BIMDG), under its president Chris Hendriksz. The Symposium was attended by just over 1500 delegates, of which approximately 700 were SSIEM members. The Symposium was preceded by a joint meeting with the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and attended by over 200 delegates. In addition to the normal format of the Symposium, there were 5 sponsored meetings, organised by Pharma and related scientific companies. These satellite meetings were well attended. The Symposium was supported by a well organized and enjoyable, social programme.

The Komrower Memorial lecture was given by Professor Ron Wanders, entitled “Inborn Errors of Metabolism including Peroxisomal diseases in a changing world of omics and systems biology”. Dr Pérez-Poyato was awarded the Archibald Garrod Award for her paper on Juvenile neuronal ceroid lipofuscinosis and published in the October 2011 issue of the Journal.

FUTURE SSIEM and ICIEM SYMPOSIA

The membership endorsed the selection of Rome, submitted by Carlo Dionisi-Vici, to host the 2016 SSIEM Annual Symposium, at the AGM held in Birmingham. The unsuccessful bid was submitted by Ans van der Ploeg on behalf of Rotterdam.

The following are the venues for future SSIEM Symposia:

- ICIEM International Symposium, Barcelona, Spain, 2013
- SSIEM Annual Symposium, Innsbruck, Austria, 2014
- SSIEM Annual Symposium, Lyon, France, 2015
- SSIEM Annual Symposium, Rome, Italy, 2016
- ICIEM International Symposium, Rio de Janeiro, Brazil, 2017

The SSIEM Council, when under the chairmanship of Cornelis Jakobs, had agreed with the IOC, not to host an SSIEM Symposium during a year of an ICIEM meeting, up to 2017. Council revisited this decision on a number of occasions during the year. The merits of a larger meeting, covering a greater breath of metabolic disorders by more international speakers had to be offset by the cost to those attending such a meeting outside Europe by a majority of the SSIEM membership. Various alternative suggestions were proposed but Council did not come to a definitive conclusion to put to the membership.

TRAVEL SCHOLARSHIPS

From an approved budget of €22,000, nineteen Travel Scholarships of up to €1700 were approved for members and non-members to attend the ICIEM meeting in Barcelona. Thirty-four applications were

Honorary Secretary's Report

received. Twelve Travel Scholarships were awarded on the basis of financial need and seven on the scholarship of the submitted abstract.

TRAINING

The 6th SSIEM Training Academy took place in Lyon in April 2013, covering organic acidurias and related topics. One hundred and eleven applications were received for the 80 places, divided equally between clinicians and scientists. The majority of those who attended came from greater Europe, but others came from India, Australia, New Zealand and Brazil. The Course included a number of combined clinical and scientific sessions; these were well received by those attending. This was the second course of the second four year cycle. A nominal charge of €50, payable upon registration, was introduced in order to encourage all those registered for the Course to actually attend. 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 propose to hold the 7th SSIEM Training Academy in Paris in April 2014.

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 in the site.

JIMD

The Journal summary is covered elsewhere within this AGM bulletin. JIMD Reports have been accepted by PubMed Central for citation; this is cross-linked in PubMed. The increasing number of articles, both original and review, submitted to the JIMD and the JIMD-Reports continues to increase and this fully justified the request for, and approval of, additional clerical support. The hard work of the Editorial team in attracting articles of significant scientific merit has been rewarded with a further increase in the Impact Factor which now stands at 4.07. Approximately 4800 institutions worldwide purchase the Journal and this, along with requests for reprints, provides significant revenue to the Society.

Council appreciates the significant contribution of the Editors-in Chief, Johannes Zschocke and Mike Gibson, the Managing Editor Verena Peters and their team of editors, communicating editors and reviewers in continuing to enhance the two journals.

SSIEM SUBGROUPS

Council was recently informed by Frédéric Sedel that he will be standing down as chair of the SSIEM Adult Metabolic Physicians Group. Council acknowledges his significant contribution in establishing this important Group, which is evidenced by the large number of delegates that have attended the first two meetings held during the Symposium. The SSIEM-Dietitians' Group led by Dr Reinhild Link, is now well established and makes an important contribution to the organisation of the dietetic component of the scientific programme of the Symposium and to encourage dietitians to join the Society.

*Prof Philip Mayne
Honorary Secretary
July 2013*

Honorary Secretary's Report

HONORARY TREASURER'S REPORT 2012-2013

The Accounts for 2012 are again shown in Euro (€) as agreed at the 2009 AGM.

INCOME

Receipt of subscriptions for 2012 increased compared with 2011 and there was a surplus from the 2012 Annual Symposium in Birmingham.

There was a slight increase in the membership during 2012, as at 31st December 2012 there were 1277 names on the database, (1224 as at 31st December 2011).

Under the contract with the publishers of the JIMD we receive a share of the Royalties; in 2012 Council was pleased to receive €137,770 compared with €144,152 received in 2011. Also included in the 2012 accounts were contributions from the publishers for the JIMD Office of €69,000 for the previous two years.

The budget for 2014 is likely to show a deficit; however, Council proposes that the annual subscription should not be increased from €130 for 2014 for members over 35 years and €80 for those 35 years and under. Assuming a cost neutral symposium in 2014 the resulting budget shows a €110k deficit, including €45k development costs, however this remains prudent given the reserves.

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 2012 shows an increase of 19.5% compared to 2012. There are a number of reasons for this:

- 2010 and 2011 invoice being presented to the Society for work undertaken on the JIMD.
- An increase in the cost of the SSIEM Administration Office for the additional support for the Birmingham SSIEM Symposium.
- An increase in Governance Costs relating to the Symposium.
- Travel scholarship support continues to increase.
- Journal production also has increased to €12 per member to accommodate an increase in the annual page budget.

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

BALANCE SHEET

Total amount in accumulative fund increased in 2012, by €54,186 and stands at €872,899.

FINANCIAL POLICY

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

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.

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

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. These can be found on page 11 of the Trustees' Report.

AUDITORS

It is proposed that the present auditor Baker Tilly 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 2013

Honorary Treasurer's Report

JIMD REPORT 2012-2013

The Impact Factor increased from 1.57 in 2006 to 4.07 in 2012 and the total number of submissions has increased from 218 in 2006 to 449 in 2012. Submitted articles in 2012 came from 56 different countries, with the majority of articles coming from the USA (15%), United Kingdom (10%), Italy (8%), the Netherlands (7%), Germany (6%), Brazil (5%) and China (4%).

In 2013, we published many themed issues focused on different topics related to inborn errors of metabolism. The second issue in 2013 included 21 articles on Mucopolysaccharidoses with Chris Hendriksz as Guest Editor. Together with Maurizio Scarpa and David Begley we published articles that were presented at the Brains4Brain Meeting (Frankfurt, Germany) and with Gajja Salomons articles from the Farewell Symposium of Prof. Jakobs (Amsterdam, The Netherlands). Issue 4 included articles from the meeting of the German Pediatric Metabolic Society, APS (Fulda, Germany), organized by Julia B. Hennermann, and articles arising from the SSIEM Annual Meeting in Birmingham 2012 (Guest Editor Chris Hendriksz). The 2012 Archibald Garrod Award was awarded to María del Socorro Pérez Poyato for the study entitled “Juvenile neuronal ceroid lipofuscinosis: clinical course and genetic studies in Spanish patients” and the 2012 Communicating Editor Awards were presented to Jean-Marie Saudubray, Robin Lachmann, Ivo Baric, Jerry Vockley and Gerry Berry. We remain indebted to Communicating Editors and reviewers who have added invaluable expertise and invested considerable effort that have contributed to our significantly improved impact factor!

Since October 2010 we have accepted more than 200 articles for “JIMD Reports” (<http://www.springerlink.com/content/p21k17/>) which is now fully and correctly indexed and crosslinked in PubMed / PubMed Central. The establishment of JIMD Reports allows publication of a much larger number of articles than previously possible. Submissions to JIMD and JIMD Reports are submitted through the same Editorial Manager System and are handled by the same Editorial Team. Articles in JIMD Reports and JIMD are typeset in the same fashion and are available online free of charge to SSIEM members and subscribers. Abstracts of JIMD Reports appear as Extras in the print JIMD, and there is free access to full texts one year after online publication.

We continue to welcome interesting material for the “Extras” section. Any comments, announcements or metabolic news can be published in this 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 inborn errors of metabolism. Our former colleagues deserve to be remembered in print.

Last but not least we would like to acknowledge the ongoing support of our publisher, Springer, who worked with us to successfully launch JIMD Reports and continues to be a strong partner in the success of both sister Journals.

The Editorial Team

GENERAL INFORMATION

DIRECTORS AND TRUSTEES

J R Bonham (resigned 5 September 2012)
A Y Brown (appointed 5 September 2012)
J Campistol
P T Clayton
C Dionisi Vici
M A Dixon
V Kozich
P D Mayne
B Plecko
C Vianey-Saban
G S Salomons
U Spiekerkoetter
J Zschocke

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
Chartered Accountants and Registered Auditors
St Philips Point
Temple Row
Birmingham
B2 5AF

Registered Company Number (England & Wales) 2567711
Registered Charity Number 1010639

General Information

TRUSTEES' REPORT

The Trustees present their report together with financial statements for the year ended 31 December 2012. 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:

J R Bonham	(resigned 5 September 2012)
A Y Brown	(appointed 5 September 2012)
J Campistol	
P T Clayton	
C Dionisi Vici	
M A Dixon	
V Kozich	
P D Mayne	
B Plecko	
C Vianey-Saban	
G S Salomons	
U Spiekerkoetter	
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 non-paid volunteers.

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.

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 2012 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 of the International Congress of Inborn Errors of Metabolism (ICIEM). A new constitution has been formulated and agreed.

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 Jean-Marie Saudubray

Clinical

Andrew Morris
Vassili Valayannopoulos
Ute Spiekerkoetter
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 2012 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 2012 the Society for the Study of Inborn Errors of Metabolism organised a Symposium in Birmingham, UK, which was for the first time run through the SSIEM own accounts to great success. Plans are well advanced with the organisation of the 12th International Congress of Inborn Errors of Metabolism (ICIEM) to be held in Barcelona in 2013.

FUNDING

Approximately a third 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 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 2012 the Annual Subscription of 6 members were paid by the Society; in addition members were given financial assistance to attend the Symposium in Birmingham, UK

FINANCIAL REVIEW

The net incoming resources for the year amounted to €54,186 (2011: €170,046), which was the amount attributable to general reserves, which at the year end stood at €872,899 (2011: €818,713).

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 2012, the Council was pleased to give financial assistance to 16 members to attend the Symposium in Birmingham, UK. Council has also agreed to utilise some of the reserves to develop the SSIEM Academy and to make training more readily available.

Plans for the future

Future work - 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.

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
21 June 2013***

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 2012 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 APB's website at www.frc.org.uk/apb/scope/private.cfm

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 2012 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 charity 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
- Trustees' were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption 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
2013

Independent Auditor's Report

STATEMENT OF FINANCIAL ACTIVITIES AND INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2012

		Unrestricted and total funds 2012	Unrestricted and total funds 2011
	Note	€	€
Incoming resources			
<i>Incoming resources from generating funds:</i>			
Investment Income		8,394	8,135
<i>Incoming Resources from Charitable Activities</i>	2	1,412,820	268,054
Other incoming resources	2	<u>245,873</u>	<u>148,244</u>
Total incoming resources		<u>1,667,087</u>	<u>424,433</u>
Resources expended			
<i>Charitable Activities</i>			
Symposium	3	1,309,969	64,281
Publication of Journal	3	250,286	144,104
ETAC	3	<u>33,398</u>	<u>29,398</u>
		1,593,653	237,783
Governance Costs	6	<u>31,368</u>	<u>25,764</u>
Total resources expended		<u>1,625,021</u>	<u>263,547</u>
Net income for the year		42,066	160,886
Unrealised exchange gains		<u>12,120</u>	<u>9,160</u>
Net movement in funds		54,186	170,046
Fund balances brought forward at 1 January 2012		<u>818,713</u>	<u>648,667</u>
Fund balances carried forward at 31 December 2012	10	<u><u>872,899</u></u>	<u><u>818,713</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 2012

	Note	€	2012 €	€	2011 €
Fixed assets					
Investments	7		492,280		480,160
Current assets					
Debtors	8	146,231		222,674	
Cash at bank and in hand		<u>555,023</u>		<u>351,346</u>	
		701,254		574,020	
Creditors:					
amounts falling due within one year	9	<u>(320,635)</u>		<u>(235,467)</u>	
Net current assets			<u>380,619</u>		<u>338,553</u>
Total net assets			<u>872,899</u>		<u>818,713</u>
Funds					
Unrestricted funds	10		<u>872,899</u>		<u>818,713</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 21st June 2013 and are signed on their behalf by:

A Y Brown
Hon Treasurer and Director

NOTES TO THE ACCOUNTS

YEAR ENDED 31 DECEMBER 2012

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. Additional income has also been generated from organising an annual symposium in 2012. 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 €1.2307.

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

	2012	2011
	€	€
Annual Symposium	1,281,039	143,610
Publication of journal/subscriptions	<u>131,781</u>	<u>124,444</u>
	<u>1,412,820</u>	<u>268,054</u>

Other Incoming Resources

	2012	2011
	€	€
Journal Royalties	206,923	110,244
Editorial expenses contribution	<u>38,950</u>	<u>38,000</u>
	<u>245,873</u>	<u>148,244</u>

3 ANALYSIS OF CHARITABLE EXPENDITURE

	Symposium €	Journal €	ETAC €	2012 €	2011 €
Direct Costs					
Publication of Journal	-	190,529	-	190,529	112,530
Direct Mailing - second announcement	-	-	-	-	1,698
Council symposium expenses	6,965	-	-	6,965	15,652
Support for delegates to attend symposium (Note 5)	17,729	-	-	17,729	18,482
SSIEM Academy (ETAC)	-	-	30,950	30,950	27,789
Awards	750	-	-	750	1,500
Komrower Lecture	1,500	-	-	1,500	1,500
Symposium expenses	<u>1,149,465</u>	<u>-</u>	<u>-</u>	<u>1,149,465</u>	<u>-</u>
	1,176,409	190,529	30,950	1,397,888	179,151
Support Costs (Note 4)	<u>133,560</u>	<u>59,757</u>	<u>2,448</u>	<u>195,7652</u>	<u>58,632</u>
	<u>1,309,969</u>	<u>250,286</u>	<u>33,398</u>	<u>1,593,653</u>	<u>237,783</u>

During the year, 10 Trustees were paid expenses of £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 €	2012 €	2011 €
Council travel and subsistence	16,964	3,181	1,060	21,205	11,522
Secretarial expenses	13,468	26,939	-	40,407	29,080
Printing and stationery	8,610	8,610	-	17,220	7,235
Postage	384	1,153	-	1,537	2,166
Website	293	877	293	1,463	2,278
Consultancy	660	-	-	660	-
Other administration	3,285	6,574	1,095	10,954	5,774
Exchange (losses)/gains	17,528	4,382	-	21,910	577
Irrecoverable VAT	<u>72,368</u>	<u>8,041</u>	<u>-</u>	<u>80,409</u>	<u>-</u>
	<u>133,560</u>	<u>59,757</u>	<u>2,448</u>	<u>195,765</u>	<u>58,632</u>

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

5 GRANTS PAYABLE IN FURTHERANCE OF CHARITABLE ACTIVITIES

	2012 €	2011 €
Support for delegates to attend symposium	<u>17,729</u>	<u>18,482</u>

All grants have been paid to individuals.

6 GOVERNANCE COSTS

	2012	2011
	€	€
Audit remuneration in respect of audit services	5,996	7,012
In respect of non-audit services	6,691	-
Secretarial Expenses	11,067	7,965
Council Expenditure	5,808	3,156
Other Administration	1,806	1,820
Retirement gifts	-	5,811
	<u>31,368</u>	<u>25,764</u>

7 INVESTMENTS

	2012	2011
	€	€
Unlisted investments:		
Cost		
At 1 January	480,160	471,000
Retranslation gain	<u>12,120</u>	<u>9,160</u>
	<u>492,280</u>	<u>480,160</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

	2012	2011
	€	€
Other debtors	111,309	188,570
Prepayments	<u>34,922</u>	<u>34,104</u>
	<u>146,231</u>	<u>222,674</u>

9 CREDITORS: amounts due within one year

	2012	2011
	€	€
Deferred income	67,520	145,567
Accruals	<u>253,115</u>	<u>89,900</u>
	<u>320,635</u>	<u>235,467</u>

The movement in deferred income is as follows:

	2012	2011
Opening balance	145,567	53,082
Released to the Statement of Financial Activities	(145,567)	(53,082)
Amounts deferred during the year	<u>67,520</u>	<u>145,567</u>
	<u>67,520</u>	<u>145,567</u>

Notes to the Accounts

10 STATEMENT OF FUNDS

Unrestricted accumulated fund

	2012	2011
	€	€
At 1 January	818,713	648,667
Net incoming resources for the year	<u>54,186</u>	<u>170,046</u>
At 31 December	<u>872,899</u>	<u>818,713</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 2012.

