

THE SOCIETY FOR THE STUDY
of
INBORN ERRORS OF METABOLISM

Annual General Meeting

Chairman: Peter Clayton

Held on Wednesday 3rd September 2014 at 12.30 at the SSIEM Symposium in Innsbruck, Austria

The SSIEM Council and seventy-five members attended.

1 Apologies for Absence

Apologies were received from one member.

2 Minutes of Previous Meeting (Barcelona)

Minutes of the previous meeting, held in Barcelona, Spain on Wednesday 4th September 2013 were received and signed by the Chairman as a true record.

3 Matters Arising from the Previous Meeting

There were no matters arising not covered on the Agenda.

4 Honorary Treasurer's Report

The Honorary Treasurer's Report for 2013-2014 had been circulated in advance with the Notice of the Annual General Meeting and the Statement of the Financial Activities of the Society. The Treasurer reported that membership had increased by 71 to 1348 compared to 1277 in 2012. The net income increased by €112,863, due primarily to a surplus from the ICIEM Meeting in Barcelona, an increase in the Royalties from the JIMD and a small increase in subscriptions; the accumulative reserve now stood at €985,762. Under the proposed amendments to the Articles of Association, she stated that a Finance Committee would be established to review the investments of the accumulated surplus and make recommendations to Council. For 2014-2015, the Treasurer proposed a deficit budget of €97K, based on a small surplus from the 2015 Symposium in Lyon and proposed no change to the annual subscriptions.

The Treasurer stated that Council had considered a number of alternative subscription categories, in order to facilitate members in emerging nations and younger members but no decision had yet been reached. These discussions would continue in 2015. The Treasurer also reported that a detailed risk assessment had been undertaken of all the Society's activities, as advised by the Auditors. This assessment will be reviewed by Council on a regular basis.

The Honorary Treasurer's Report was adopted by the members present.

5 Honorary Secretary's Report

The Honorary Secretary's Report had been circulated with the Notice of the Annual General Meeting. In addition, the Secretary stated that Council had taken the opportunity to review the Articles of Association and that a draft copy had been circulated to the members for consideration under Agenda Item No. 8 of the AGM. In addition, he stated that Council had reviewed the Governance of the Society and its subcommittee structure and had put in place a more robust structure, with written procedures covering most of the Society's activities, including the Symposium.

The Secretary concluded by acknowledging the support of all those who gave of their time to enable the Society to fulfil its aims and objectives, particularly those working in the SSIEM's registered Office in London and on the website.

The Honorary Secretary's Report was adopted by the members present.

6 JIMD Report

The Journals Report had been circulated with the Notice of the Annual General Meeting. Johannes Zschocke (JZ), Editor-in-Chief, reported that the Impact Factor for the JIMD for 2013 was now 4.14 and expected that the on-line journal JIMD Reports would be awarded an Impact Factor in 2015.

JZ stated that Garry Brown and Mike Gibson both decided to retire from the Editorial Board. He acknowledged their considerable contribution to the Journal over the years. He stated that Shamima Rahman and Matthias Baumgartner would be joining Eva Morava and Marc Patterson as editors along with Verena Peters (Managing Editor) and Johannes Zschocke (Editor-in-Chief)

JZ announced that the Archibold Garrod Award has been awarded to Dr Frederic Sedel for his paper, published in the JIMD entitled *Krabbe disease in adults: phenotypic and genotypic update from a series of 11 cases and a review*.

7 ETAC Report

The Education and Training Advisory Committee (ETAC) Report was presented by Vassili Valayannopoulos (chairman). Feedback from the 7th SSIEM Academy Meeting, held in Paris in April, was again very positive. The Course was over subscribed. Topics covered included Lysosomal storage and peroxisomal disorders, purine and pyrimidine disorders and related topics. The course is now accredited for CME by the EAP.

ETAC had received a request to assess training facilities for metabolic disorders from the unit in Hamburg and this inspection would be undertaken in the coming months.

8 Special Resolution – that the Memorandum and Articles of the Society be revised and amended

The Honorary Secretary introduced this Agenda Item at the invitation of the Chairman. The Secretary stated that when the Society attempted to register the amendments approved in 2012, it was noted that the amendments approved by the membership in 1990 had not been registered. Therefore, the opportunity was taken to review and update the Articles to reflect better the organisation and governance of the Society, taking into consideration the various subcommittees, while allowing Council to delegate responsibility to outside agencies under Service Level Agreements. The revisions which have been approved by Council were undertaken with the assistance of Ms Eva Abeles, Senior Solicitor, IBB Solicitors, Uxbridge, Middlesex, UK.

A significant number of the Articles, primarily those relating to the objectives of the Society, could not be changed without the agreement of the Charity Commission; these were not

amended. He stated that the revised Articles more clearly sets out the functions and duties of the Trustees (Directors and members of Council) and the mechanism for electing members to Council. It allows Council to review and amend the criteria for nomination. The mechanism, as outlined, is more transparent and was the process used to seek nominations this year. The Articles propose that Council would be limited to 14, three officers, the Chairman, Honorary Secretary and Honorary Treasurer, nine Council members and two ex-officio members, the Editor-in-Chief of the Journal and the Chairman of ETAC. The roles and responsibilities of each are more clearly defined as are the terms of office. It is proposed that the Corresponding Members would be formed into an Advisory Committee to Council and that a constituted Finance Committee be established.

There followed a lively discussion from the floor with members seeking clarification. The Chairman then commended the revision and amendments to the Memorandum and Articles of the Society to the membership. Following a show of voting cards, the Special Resolution was carried unanimously and the Resolution was adopted.

9 SSIEM – Special Interest Groups

SSIEM-Adult Metabolic Physicians Group. The chairman Robin Lachmann outlined the purpose of the Group, stating that in excess of 350 delegates had attended the Adult IEM session on the Tuesday of the Symposium. The Group was anxious to establish a discussion forum and would be prepared to contribute to the SSIEM Academy; Carla Hollack was the Group's nominated representative to Council when required.

SSIEM-Dietitian Group. Marjorie Dixon, on behalf of the Group stated that they had over 300 members, with more than 110 being dietitians. They contribute to the organisation of the Nutrition and Dietetic session in the Symposium and they too would like to contribute to the SSIEM Academy. Dr Reinhild Link had stepped down as Chair of the Group and a successor would be nominated shortly.

(Honorary Secretary Comment – membership of both Special Interest Groups is open to all members of the Society and interest can be indicated when paying annual subscription or by notifying the SSIEM's Registered Office).

10 Website Report

The Honorary Secretary acknowledged the support of the webmaster, Michael McConnell from Blackcat, in maintaining the website.

11 Future SSIEM Symposia

The Honorary Secretary reported that four expressions of interest had been received to host the SSIEM Symposium in 2018 and 2019. The bids had been reviewed and supported by Council and circulated to the Corresponding members for decision at the Council and Corresponding Members, meeting held on Tuesday 2nd September. Each sponsor made a 5 minute presentation followed by questions. Following a secret ballot, the 2018 Symposium was awarded to Dr Helen Michelakakis and Athens, Greece in September 4th to 7th and the 2019 Symposium to Prof. Ans van der Ploeg, and Rotterdam, the Netherlands in September 2nd to the 6th. The results of the ballot was extremely close and commiserations was offered to Prof. Ute Spiekerkötter and her team from Freiberg, Germany and to Prof. Anthony Luder from Jerusalem, Israel for two excellent but unsuccessful bids.

- SSIEM Annual Symposium, Lyon, France 2015
- SSIEM Annual Symposium, Rome, Italy 2016
- ICIEM International Symposium, Rio de Janeiro, Brazil 2017
- SSIEM Annual Symposium, Athens, Greece 2018
- SSIEM Annual Symposium, Rotterdam, The Netherlands 2019

12 International Organising Committee (IOC) Report

The Chairman stated that the IOC would be meeting the following day to receive a report on the plans for the next ICIEM meeting in Rio de Janeiro, Brazil 2017. He again stated that the SSIEM had yet to make a formal decision as to whether to host a SSIEM Symposium in 2021. The current thinking of Council was to host a smaller meeting that year for the benefit of the large number of European based SSIEM members who would be unable to travel to Rio de Janeiro. The meeting would not clash with the ICIEM meeting and it was probably the the meeting would have greater emphasis on teaching. Chairman stated that he would welcome comments from the membership.

13 Council Officers/Election of Council Members

There were three vacancies on Council, following the retirement of Philip Mayne (Honorary Secretary), Jaime Campistol Plana (Clinician) and Marjorie Dixon (Dietitian). The following nominations had been approved by Council – Katrin Õunap (Clinical Geneticist), Antonia Ribes (Biochemist/molecular geneticist) and Annemiek van Wegberg (Dietitian). Ute Spiekerkötter was nominated for a second term. Gajja Salomons had agreed to take on the role of Honorary Secretary. The nominations were approved by the membership. The Chairman thanked all the outgoing members for their contribution to Council over the past six years.

14 Corresponding Members

The Council and Corresponding Members meeting was held on the previous day. The main agenda items were the selection of venues for the SSIEM Symposium in 2018 and 2019 and the amendments to the Articles of the Society. The Corresponding Members had approved the formation of an Advisory Committee to Council as outlined at the meeting.

15 Election of Auditors

The Chairman proposed that Baker Tilly UK Audit LLP, Birmingham be re-elected as auditors to the SSIEM; this was seconded by Johannes Zschocke and carried unanimously by the members present.

16 Any other Business

There was no other business.

Signed:

Date: