

THE SOCIETY FOR THE STUDY
of
INBORN ERRORS OF METABOLISM

Annual General Meeting

Chairman: Peter Clayton

Held at the Conference building, at 1pm in Lyon, France
on Wednesday 2nd September 2015

The list of SSIEM members, including SSIEM Council members who attended is present at the Registered Office.

1 Apologies for Absence

Apologies were received from four members.

This year unfortunately Council was notified that the following SSIEM members / individuals working in the field of inborn errors passed away. Prof Elisabeth Holme, Prof Sven Lindstedt, Prof Akemi Tanaka, Dr Birgitte Wuyts, Prof Dr Frits Hommes, Prof Dr Christian Korner, Prof Dr Frans van Sprang.

2 Minutes of the Previous Meeting (Innsbruck)

Minutes of the previous meeting, held in Innsbruck, Austria on 1st September 2014 were received and signed by the Chairman as a true record.

3 Honorary Treasurer's Report (Anny Brown)

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 56 to 1404. The net income increased by €852,847, due primarily to a surplus from the SSIEM Meetings and especially from the Innsbruck Symposium, as well as from JIMD publications, revaluation of investment assets and a small increase in subscriptions; the accumulative reserve stood at €1,838,609 on the 31st of December 2014.

A Finance Committee (former and current Honorary Treasurer, Jim Bonham, Anny Brown, the Honorary Secretary, Gajja Salomons and Chris Wiggins an independent financial adviser) was established to review the investments of the accumulated surplus and an ethical investment fund manager has been selected – Rathbone Greenbank for which the paperwork is almost done. For 2015-2016, the Treasurer proposed a deficit budget of €17K, based on a budget neutral symposium in Rome, and proposed a change to the annual subscriptions. The Treasurer stated

that a reserve of 2 years of running costs is essential, but that SSIEM is also at a point that development funds can be afforded. However, caution needs to be taken into account as in 2017 there will be an international meeting (and as we do not host the meeting no extra surplus will be generated) as well as the fact that there are discussions on possible VAT liability.

Developments in progress to be funded from reserves:

- Expenses support for attending conferences, workshops or training. This is already in place for ERNDIM. Policy to be determined.
- ERNDIM development: Support for website reporting, Purchase of compounds (pilot).
- Vademecum metabolicum app and JIMD app.
- Increased number of SSIEM travel scholarships (in 2015 22 awards were given) for age 35 and under. It was requested by the members that this age range be upgraded to age 40 and under, which will be confirmed in next Council meeting.
- Cost to be incurred to investigate VAT liability. The auditors have advised the SSIEM officers and our liaison officer to seek advice on liability for VAT, as our income is above the threshold for VAT registration. It was discussed that SSIEM might be at risk of getting a fine retrospectively and we have been advised to be careful, as this cannot be ruled out.
- Banded subscription Fees: The Treasurer presented a proposal for a banded subscription fee in order to allow access to the SSIEM fair and equitable for all its members in the differing specialties and countries. A standard rate to be applied for membership subscription to citizens from the high income countries as identified by the World Bank List of Economies and a reduced rate to citizens from all other countries. A reduced fee was set for those who do not fit the category of the standard rate (i.e. fully qualified, tenured position applicable to physician, researcher, scientist, geneticist or equivalent). Almost unanimously the membership voted for this proposal for scaled membership fees and the proposal was accepted.

The Treasurer announced that those who really cannot afford membership or traveling can apply to the Treasurer / Admin Team for financial support. The members suggested including an option on the website to allow voluntary donation.

The Treasurer concluded by mentioning the tremendous support of the Admin Team led by Nic Law whose contribution is invaluable for the Officers. The Honorary Treasurer's Report was adopted by the members present.

4 Election of Auditors

Grant Thornton UK LLP has audited the annual financial statement as Baker Tilly UK Audit LLP was no longer able to do it. The Chairman asked the member for approval to Council to appoint Grant Thornton UK LLP and to determine the numeration of the auditors for the coming year. Philip Mayne and Jim Bonham were proposer and seconder, respectively, and this was agreed by a show of hands.

5 Honorary Secretary Report (Gajja Salomons)

The Honorary Secretary's Report had been circulated with the Notice of the Annual General Meeting. In addition, the Secretary highlighted the following items:

- 1 An invitation to bid to form the new editorial team was sent to all our members. The winning bid came from the current editorial team lead by Eva Morava. The Chairman congratulated Eva and her team and as of 1st of January 2016 Dr Morava will be the new Editor-in-Chief.
- 2 Similar to JIMD, Council is also discussing bringing governance for ETAC in line with the recommendations for the Council itself (in terms of tenure of officers etc.).

3 Each year travel awards are available but only a few students apply. The aim is to make attendance available to the new generation.

6 JIMD Editorial Report (Johannes Zschocke)

The Journals Report was presented by Johannes Zschocke (JZ), Editor-in-Chief (EiC), which had been circulated with the Notice of the Annual General Meeting. The Impact Factor for the JIMD for dropped, due to lack of strong special issue, from 4.3 to 3.6, but it maintains its leading position in IEM field. It is expected that the online journal JIMD Reports will be awarded an Impact Factor in 2016. JZ is retiring as EiC after having served two terms of 5 years and will remain editor for one year. Eva Morava will be the new EiC in January 2016. Furthermore JZ highlighted that the major contribution to the success of the journal from the reviewers, the communicating editors (CE) and the editors. Reviewers that do their job well are often invited to become a CE or editor. Furthermore the development of an app that would allow easy reading of the journal on a tablet or phone, in addition to the existing digital version of the journal, is currently being discussed.

The Archibold Garrod Award, with a price of €1500 for the best clinical series paper of the JIMD in the last year. The 2014 prize has been awarded to Dr Trakadis for the paper “*Update on transcobalamin deficiency: clinical presentation, treatment and outcome*”.

7 ETAC Report (Vassili Valayannopoulos)

The Education and Training Advisory Committee (ETAC) Report was presented by Vassili Valayannopoulos (Chairman of ETAC) and had been circulated with the Notice of the Annual General Meeting. Courses were again well attended by both clinicians and biochemists. The ETAC faculty in its current composition has now been together for eight years. The Chairman stated that new members are welcome, usually by first being invited to participate in the training. Simon Heales will replace Mick Henderson. Next meeting will be in Freiburg 18-19th April 2016 hosted by Ute Spiekerkoetter. In early October this will be advertised.

8 Council Officers

The Chairman stated that two years ago he announced to Council that he will be stepping down in 2106 and that subsequently Gajja Salomons, our current Honorary Secretary said that she was willing to take this position. The Chairman proposed that Gajja Salomons should take over as Chairman in September 2016, this was seconded by Andrew Morris and carried by a show of hands unanimously by the members. If no Council member can take up the position of Honorary Secretary, Council will have to co-opt a candidate from outside the current Council. One nomination for this position has been received for an SSIEM member from France. The Chairman asked the members to consider who they would they like to have to represent them in the future and nominate individuals (before the 1st of November) for co-opting as a future Honorary Secretary as well as for membership of Council.

9 Honorary Members

Four members were this year elected as Honorary members and received a certificate for their service to Council:

Philip Mayne (for service as Honorary Secretary)

Mick Henderson (for service on Council and for ERNDIM and ETAC)

Johannes Zschocke (for service as Editor-in-Chief of JIMD)

Mike Gibson (for service as Editor-in-Chief of JIMD).

10 Special Interest Groups

The *Dietitians Group* (Lesly Robertson) stated that the group had a good meeting at this symposium as well as several papers that were already being published.

The Adult Metabolic Physicians Group (Carla Hollak) reported that there was a very good meeting on the opening day of this symposium, including a business meeting. There were many items that the adult group would like to discuss but due to lack of time the Chairman invited Carla Hollak or Robin Lachmann to join next SSIEM Council meeting.

11 Host Bids

The Chairman pre-announced the next call to submit a bid for the 2020 meeting. This call will be announced early 2016.

The ICIEM in 2021 will be hosted by the Australian Society in Sydney.

Signed:

Date: