

THE SOCIETY FOR THE STUDY
of
INBORN ERRORS OF METABOLISM

Annual General Meeting

Chairman: Peter Clayton

Held at the Palazzo dei Congressi, Auditorium Ground Floor, at 1pm in Rome, Italy
on Wednesday 7th September 2016

Chairman: Peter Clayton

The list of SSIEM members, including SSIEM Council members who attended is available at the Administrative Office.

1 Apologies for Absence: None received.

2 Minutes of previous meeting (Lyon)

Minutes of the previous meeting, held in Lyon, France on 2nd September 2015 were received and signed by the Chairman as a true record.

3 Matters arising from the previous meeting: There were none.

4 Honorary Treasurer's Report (Anny Brown)

The Honorary Treasurer's Report for 2014-2015 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 37 to 1441. The net income increased by €384,710, due primarily to a surplus from the SSIEM meetings and especially from the Lyon Symposium, as well as from JIMD publications, revaluation of investment assets and a small increase in subscriptions; the accumulative reserve stood at €2,223,319 on the 31st of December 2015. There will be no change to the membership subscription fees for 2017.

The 2015 investments realized only 1.2%. For 2016, UK government bonds will be maintained; their return is very low but safe (0.25%). It is proposed to redirect a proportion to the ethical investment fund.

Developments in progress to be funded from reserves:

- Expenses support for attending conferences, workshops or training: this is available and applicants are welcome. It was reported that this year, 2016, support was offered to a doctor from Greece for short-period training in Manchester

- ERNDIM development (website reporting) and support: Salary support for ERNDIM administration (€350,000 over 3.5 years)
- ETAC and North American Metabolic Academy (NAMA) cross support for candidates. Budget increased. Collaboration and exchanges of trainees
- Support for Vademecum app
- SSIEM app
- Discussion regarding parent/carer support to attend meetings (in process for CDGs family meetings: discussion with Eva Morava)
- MetabERN support from SSIEM for year 1: €30,000
- Renegotiate JIMD contract by the end of 2017
- 2017 budget might realise a small loss as the SSIEM will not be hosting a symposium. In 2017 the ICIEM will be held in Rio de Janeiro hosted by Prof Roberto Giuliani.

The Treasurer concluded by mentioning the tremendous support of the Administrative Office led by Nic Law whose contribution is invaluable for the officers. The Honorary Treasurer's report was adopted by the attending members.

5 Honorary Secretary's 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 item: new SSIEM app has been contracted for a 4-year period starting in 2016.

6 JIMD Editorial Report (Eva Morava)

The Journals report was presented by Eva Morava (EM), Editor-in-Chief, and had been circulated with the Notice of the Annual General Meeting. This year the JIMD Impact Factor has increased from 3.36 to 3.54. The annual number of submissions is steady about 480/year. The discussion regarding the impact factor for the online journal JIMD Reports lies in the hands of the publisher Springer and Thomson Reuters. The application is now in the evaluation process and we expect an answer by end of 2017. EM highlighted the major contribution to the success of the journal from the reviewers, the communicating editors (CE) and the editors but also insisted on the fact that the turnaround time should be improved. New categories of articles for 2017: Guidelines, The Garrodian, and Ambassadors (S Houten and P Witters: reader digests of key papers in other journals).

Social media interactions for JIMD readers will be encouraged.

The Archibald Garrod Award, with a prize of €1,500 for the best clinical series paper of the JIMD in the last year. The 2016 prize has been awarded to Prof Shamima Rahman for the paper "Paediatric single mitochondrial DNA deletion disorders: an overlapping spectrum of disease".

7 ETAC (Education, Training & Advisory Committee) Report (Andrew Morris)

The ETAC Report was presented by Andrew Morris (new Chairman of ETAC after the retirement of Vassili Valayannopoulos) and had been circulated with the Notice of the Annual General Meeting. Courses were again very well attended by both clinicians and biochemists. The 2016 course took place in Freiburg: beginning of the third 4-year cycle (all the iEMs are depicted in one cycle). Candidates are selected on the basis of their experience and equitable distribution among countries. Very low registration fee: 75€ (including 2 nights hotels and meals). Costs to the SSIEM 47,000€. The feedback was extremely positive.

SSIEM Academy 2017: Lyon 24-25 April: OAs, FAODs and metabolic courses on cardiomyopathies lectures and workshops joint for biochemists and clinicians.

Application opened from October 2016 and advertised on the website. There is an increased collaboration with NAMA: NAMA being more suitable for slightly more junior candidates. Two junior applicants for SSIEM academy have been redirected to NAMA and this was subsidized by SIMD and SSIEM travel grants.

ETAC faculties are changing: planned over several years:

Leaving: Vassili Valayannopoulos and Ute Spiekerkotter

Joining: Johannes Häberle and Rachel Carling

Several other people have expressed interests.

Accreditation of metabolic training centers through the EAP is still pending: Hamburg plans to apply and arrange a visit date.

8 SSIEM – Special Interest Groups

The Dietitians Group (Lesley Robertson), representing 59 different countries stated that the group had a good meeting at SSIEM.

The Adult Group (Robin Lachmann) reported that there was a very good meeting on the opening day of the SSIEM, including a business meeting. Robin Lachmann announced that he was stepping down and would be replaced by Prof Carla Hollak as chair. He also noted that the book on IEM in adults is now available.

9/10 Future SSIEM Symposia / International Organising Committee Reports

The Chairman announced the endorsement of the bid for the 2020 meeting in Freiburg.

The ICIEM in 2021 will be hosted by the Australian Society in Sydney: proposal to change slightly and move to an over the weekend symposium: from Friday to Tuesday. This was largely accepted by the audience.

Regarding the 2017 ICIEM in Rio, instead of the Komrower lecture there will be a Nestor Chamoles lecture.

11 Council Officers

The Chairman stated that he was stepping down and as decided at the 2015 AGM Gajja Salomons was becoming the new Chairman. The Chairman announced that Manuel Schiff had been coopted as Honorary Secretary elect in March 2016 to become Honorary Secretary in September 2016, this was seconded by Cornelis Jakobs and carried by a show of hands unanimously by the members. The Chairman announced that also Carlo Dionisi Vici (CDV), Barbara Plecko (BP) and Christine Vianey Saban (CVS) resigned in September 2016. The changes in the composition of Council members were proposed by the Chairman to be as followed: Vassili Valayannopoulos, Chairman ETAC (Ex-officio) resigned in September 2016 and would be replaced by Andrew Morris, Chairman ETAC (Ex-officio). CDV, BP and CVS would be replaced by Johannes Häberle, Fanny Mochel and Helen Michelakakis. This was proposed and seconded by Ron Wevers and Christine Vianey Saban respectively and carried by a show of hands unanimously by the members.

12 Election of Auditors

The Chairman asked approval of the members to reappoint Grant Thornton UK LLP and to determine the numeration of the auditors for the coming year, which was carried by a show of hands.

13 MetabERN

The Chairman recalled that there had been an EU invitation for proposals to form European Reference Networks (ERNs) for a wide range of rare diseases including IEMs. In early 2016, a questionnaire was sent to SSIEM members asking whether they wanted to support the bid by

Maurizio Scarpa. A substantial proportion of the members expressed some concerns and suggested SSIEM should keep a degree of control and be clearly identified as part of the MetabERN. SSIEM endorsed the application of Maurizio Scarpa, which was deemed satisfactory. Sixty-nine health care providers in 18 countries are included in the MetabERN application coordinated by Maurizio Scarpa.

14. Any other business. There was none

The Chair called the AGM to a close at 14.01h.

A handwritten signature in blue ink, appearing to read 'M. Schiff', written over a horizontal line.

Signed:

Date: 2nd December, 2016

Manuel Schiff
Honorary Secretary SSIEM