

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

**Annual General Meeting**

Chairman: Gajja Salomons

Minutes: Manuel Schiff, Honorary Secretary

Held at the Megaron in Athens, Greece at 13:30 on Wednesday 5th September 2018

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

**1 Minutes of the Previous Meeting (Rio de Janeiro)**

Minutes of the previous meeting, held in Rio de Janeiro, Brazil on 6th September 2017 were received and signed by the Chairman as a true record.

**2 Matters arising from the previous meeting:** There were none.

**3 Honorary Treasurer's Report (Anny Brown)**

The Honorary Treasurer's Report for 2017 had been circulated in advance with the Notice of the Annual General Meeting and the Statement of the Financial Activities of the Society.

The Honorary Treasurer reported that the Society's accumulative reserve stood at €1,958,059 on the 31st December 2017. There was a net loss of income of €227,226, primarily due to no SSIEM Symposium income in 2017. The Symposium income is in the order of €2 million, the expenditure is slightly less. The intention is to generate only a modest surplus.

Governance costs are growing due to the increasing complexity of the SSIEM business.

At this stage it is difficult to assess any impact Brexit may have on the Society's finances or management.

Investments have been made ethically in Euro and Sterling, the aim is to future-proof the Society.

**Developments in progress to be funded from reserves:**

New initiatives:

- Education and practical support for countries introducing;
  - Treatment
  - Lab investigation

- E-learning modules
- Guideline development
- Supporting symposia in and outside of Europe
- SSIEM Council will explore innovative ways to educate and support countries and individuals.

- Encourage National meetings

Ongoing initiatives:

- Travel support for conferences, workshops or training.
  - Few takers
  - Advertise more
- ERNDIM development and support
- ETAC/NAMA
  - Cross support for candidates
  - Budget increased
- Parent/Carer Societies/Support Groups
  - Apply for financial support
  - Awarded twice a year (Mar/Sept)
- JIMD contract has been renegotiated.

### **2019 Budget:**

Assuming a cost neutral symposium it is anticipated there will be a €208,000 deficit.

The acceptance of the SSIEM Accounts was proposed by Peter Clayton and was seconded by Cornelis Jakobs and carried by a show of hands unanimously by the members.

The Treasurer concluded by mentioning the tremendous support of the Administrative Office led by Nic Law whose contribution is invaluable for the officers. The adoption of Honorary Treasurer's report by the attending members was proposed by Peter Clayton and was seconded by Cornelis Jakobs and carried by a show of hands unanimously by the members.

#### **4 Honorary Secretary's Report (Manuel Schiff)**

The Honorary Secretary's report had been circulated with the Notice of the Annual General Meeting. In addition, the Secretary highlighted the ongoing and future collaborative projects with the newly created metabERN lead by Maurizio Scarpa especially regarding education and training.

#### **5 JIMD Report (Eva Morava)**

The Journal's report was presented by Eva Morava, Editor-in-Chief, and had been circulated with the Notice of the Annual General Meeting. JIMD report:

- Impact factor is steady at 4.04.
- Wiley will be the new publishers replacing Springer as of January 1st 2019.
- JIMD report will be open access starting on January 1st 2019.
- Membership privileges: no charge for members who submit to JIMD report until January 1st 2019.
- General aim: to get an impact factor for JIMD reports.

#### **6 ETAC (Education, Training & Advisory Committee) Report (Andrew Morris)**

The ETAC Report was presented by Andrew Morris, Chairman of ETAC, and had been circulated with the Notice of the Annual General Meeting. Courses were again very well attended by both clinicians and biochemists. The 2018 course took place in London. The next SSIEM Academy will be in April 2019 near Zurich with a special focus on mitochondrial diseases. Continuing discussions with Nadia Belmatoug (metabERN) to promote joint education

initiatives between SSIEM and metabERN. A joint webinar on pediatric to adult transition in IEMs is scheduled for early 2019.

E-learning on UCDs and hyperNH<sub>3</sub> has been revisited and updated by Johannes Häberle and is now available from the SSIEM website. Jim Bonan is preparing an e-learning course on NBS.

Outside Europe courses endorsed by ETAC and SSIEM: on-going with a project of a course in Delhi in 2020

## **7 SSIEM – Special Interest Groups**

Lesley Robertson representing the SSIEM Dietitians Group stated that the group had 2 good meetings in Athens. Membership continues to grow: 343 members.

Anita McDonald will lecture at the yearly meetings from 2018 on.

Fanny Mochel representing the adult group reported that there was a very good meeting on the opening day of the SSIEM congress. Council has appointed Mirjam Janssen as secretary and Fanny Mochel as chair of the SSIEM adult group. They will be installed for two terms of 3 years each with an overlapping period. The adult group is currently preparing a course dedicated to adult physicians, to be launched in 2019.

## **8 Host Bids and Future Meetings**

The 2019 meeting will be in Rotterdam and the 2020 meeting in Freiburg.

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

The call for a bid for SSIEM 2022 was responded by Helsinki, Jerusalem and Porto.

The 3 cities respectively represented by Ritso Lapatto, Stanley Korman and Dulce Quelhas gave excellent presentations. These proposals were submitted to anonymous ballot at the Council and Advisory Council meeting held on September 5th 2018 at 12:30.

Results of the votes were collected and it was notified that as usual the outcome would be shared at the closure ceremony on Friday midday on September 7th 2018.

Future meetings: the possibility of a shared day between ESHG and SSIEM meetings will be discussed.

Postponing the SSIEM symposium to the second week of September will also be discussed.

## **9 IOC Report**

The ICIEM IOC is composed of 2 SSIEM members, 2 SIMD members, 2 Australasian Society members and subgroups. Discussion will have to occur regarding the possibility of an additional European meeting at the time of ICIEM meeting (every 4 year), but the general opinion was against this option. Cornelis Jakobs insisted that SSIEM should use its constitutional right to have the ICIEM organized more frequently in Europe. This was not further discussed.

## **10 New Initiative**

Details discussed in previous agenda items.

## **11 MetabERN Report**

Details discussed in previous agenda items.

## **12 Council Officers/Election of Council Members**

The Chairman announced that Heather Allen (Sheffield, UK) was therefore proposed as Council member representing the dietitians by Leslie Robertson and was seconded by Andrew Morris and carried by a show of hands unanimously by the members.

The Chairman announced that Anny Brown was proposed to stay for one more year as the Honorary Treasurer of the Society, by Ivo Baric and was seconded by Peter Clayton and carried by a show of hands unanimously by the members.

**13 Election of Auditors**

Anny Brown asked approval of the members to appoint Auditors Buzzacott LLP, which was proposed by Peter Clayton and seconded by Lesley Robertson and carried by a show of hands unanimously by the members.

**14 Any other business**

New initiatives: very open to be funded by the Society.

Questions from Ron Wevers: TV for SSIEM: initiative from a CDG patient: small company.  
To be discussed at the next SSIEM Council meeting in December 2018.

**The Chair called the AGM to a close at 13.50 h.**

Signed:

Date: