

THE SOCIETY FOR THE STUDY
of
INBORN ERRORS OF METABOLISM

Annual General Meeting

Honorary Chair: Manuel Schiff

Minutes: Honorary Secretary: Helen Michelakakis

Held in ICC, Jerusalem, Israel at 13:00 local time on Wednesday 30 August 2023

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

- 1 Apologies for absence had been received from:** Dr Dianne Webster, Prof Dr Med Ina Knerr, Dr Kaustuv Bhattacharya, Prof Allan Lund, Dr Pasi Nevalainen, Dr Cheuk Wing Fung, Dr Sunita Bijarnia-Mahay, Ms Patricia Fitzsimons, Dr Daniel Gomes, Dr Amal Alhashem and Dr Bruce Barshop.

The SSIEM would like to recognise all those members and individuals involved with IEM that had passed including Prof Charles Scriver, Dr Ben Poorthuis and Mr Malcolm Heron.

- 2 Minutes of previous meeting (held, Messe Freiburg, Freiburg, Germany, 31 August 2022)**
Minutes of the previous meeting held in Freiburg on 31 August 2022 were received and signed by the Chair as a true record. Proposer by Stephanie Grünwald and seconded by Daniela Karall.

- 3 Matters arising from the previous meeting**
The Chair stresses the fact that the SSIEM is an inclusive Society, eager to promote new areas of interest and ideas. To that end special sessions and new categories in the themes of the SSIEM Annual Symposia will be incorporated. The need to act as the focal point for training experts from different areas, essential in the field of IEMs, is also recognised by the Society.

- 4 Election of Honorary Officers and Directors/Trustees (Honorary Secretary)**
Dulce Quelhas, having completed six years as a Council member, is stepping down at the meeting. She will remain on Council as a Co-opted Council Member (Non-Voting) for one more year as the President of the 2024 Annual Symposium.

Four excellent nominations were received. One of whom has been selected, based on experience and diversity within the Council. The nominee to become the new Director/Trustee of the Society is Dr Andrea Elena Dardis (Udine) which was proposed by Helen Michelakakis and seconded by Dulce Quelhas. Approved.

5 Honorary Treasurer's Report (Honorary Treasurer – Philippa Mills)

The Honorary Treasurer's Report for 2022 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 the unrestricted fund increased by €188,496 to stand at €3,002,443 as at 31 December 2022.

The Financial sub-committee of Council oversees the Society's investments and the long-term strategy to future proof the Society and provide fund to support and develop the aims of the Charity.

The SSIEM continues to support ERNDIM and ETAC.

The Society had given six awards under the Parent/Carers Societies/Support Group Fund, thirty Symposium Travel Scholarships, five Travel and Training Bursaries, eleven individuals received supported membership, an award for Guideline development together with organising three Dietitians courses. The total invested for these initiatives in 2022 was €71,386, compared to 2021 of €66,670.

The 2022 accounts were submitted for approval – proposed by Stephanie Grunewald and seconded by Shamima Rahman.

There will be no increase in membership fees for 2024, however as previously agreed as of January 2024 the JIMD will be online only. A new level of membership will be introduced for the low income and lower middle income countries as agreed by the World Bank List of Economies of ten Euros. The SSIEM will therefore have three levels of membership by countries of High Income/Middle Income and Rest of the World (RoW). This was agreed by all those present and proposed by the Honorary Treasurer and seconded by Andrew Morris.

The Treasurer paid a very big thank you to Nic Law and Caroline Hankinson, the SSIEM Administration Team, Ralph and Tobias at Studio12 and the ETAC Administrators.

6 Council to tender for the Society's Auditors/Accountants

On behalf of Council, the Honorary Treasurer proposed that SSIEM use Buzzacott LLP as auditors and authorize the SSIEM Directors to determine their remuneration for 2024 which was seconded by Matthias Baumgartner.

7 Future SSIEM Symposium (Honorary Secretary)

The 2024 Symposium will take place in Porto, Portugal 3-6 September. President of the Symposium is Dulce Quelhas. The programme is well advanced.

In 2025 it is the joint society ICIEM Symposium in Kyoto, Japan 3-6 September. Chaired by Prof Nakamura.

The 2026 and 2027 SSIEM Symposia will take place in Helsinki, Finland 1-4 September, Chaired by Risto Lapato and Dublin, Ireland 31 August – 3 September. Chaired by Ina Knerr, respectively.

In January 2024 bids for the 2028 SSIEM Symposium will be asked from the advisory council members. The SSIEM Council is looking forward to receiving your proposals.

8 SSIEM – Special Interest Groups

A - Adult Metabolic Physicians Working Group Report (The Chair – Fanny Mochel).

In 2023 the training course for adult metabolic medicine took place in Berlin with 35 participants from 22 countries. In order to provide further training, discussions about including an adult section within the ETAC academy have been initiated. The Clinical Syllabus for Adult Metabolic Medicine is currently being looked at.

The Honorary Chair thanked Fanny Mochel and the Adult Group.

B – Dietitians Group (DG) report (The Chair – Julio Rocha)

SSIEM DG committee is comprised of nine members and tasks are divided between members accordingly. DG regulations have been approved by SSIEM Council. Membership of the group has increased to 618 members from 75 different countries.

The DG continued its educational training meetings which are aimed at improving the skills of less experienced colleagues. In November 2022 the 3rd SSIEMDG Academy, a two-day virtual course on methylmalonic acidemia was held with 32 attendees from 22 countries. The second DG Research Meeting, a half-day virtual meeting, took place on 23 March with 85 attendees from Europe, America, Asia and Africa. The 2023 DG Academy took place virtually in June on urea cycle disorders, and included workshops, lectures and parental testimony for the first time. These events were all remarkably successful.

The Honorary Chair thanked Julio Rocha and the DG Group.

9 Education, Training and Advisory Committee (ETAC) report (The Chair – Johannes Haberle)

ETAC has three new members Oliver Saas, Rebecca Heiner-Fokkema and Ann Bowron, replacing members that have stepped down. Two new observers Sarah Grünert and Apolline Imbard will join next year's Academy. NAMA has representatives in the ETAC Academy. The 2023 ETAC Academy, organised by Andrew Morris, took place in Manchester, 24-25 April with 80 delegates (40 from 86 clinical applicants and 40 from 66 laboratory applicants) participating. The overall feedback was positive.

The 2024 ETAC Academy will take place in Amsterdam.

The Clinical syllabus is awaiting endorsement by UEMS. It will be used for developing the SSIEM adult and laboratory syllabi.

Not many applications for ETAC accreditation as a training center are received but there is one currently in the process of being accredited.

The Honorary Chair thanked Johannes Haberle and the ETAC members.

10 JIMD report (Senior Editor in Chief – Shamima Rahman)

The JIMD Report for 2023 had been circulated in advance with the notice of the Annual General Meeting. Eva Morava has stepped down from the editorial team and Sean Froese has joined to replace her.

All articles in both JIMD and JIMD reports are peer reviewed and the JIMD has the highest IF of any metabolic journal.

Article processing fee for JIMD reports is paid by the SSIEM for members – however please check if your Institutions have an agreement with Wileys before using this route and only use when an agreement doesn't exist with your institution.

James Nurse, the JIMD social media editor, continues to actively promote the JIMD and JIMD reports and produces the excellent JIMD Podcasts.

11 Any Other Business

There was no other business.

The Chair called the AGM to a close at 14.00.

Signed:

Date: