

THE SOCIETY FOR THE STUDY
of
INBORN ERRORS OF METABOLISM

Annual General Meeting

Honorary Chair: Manuel Schiff

Minutes: Honorary Secretary: Helen Michelakakis

Held in Rosa Mota Pavilion, Porto, Portugal, at 13:00 local time on Wednesday 4th September 2024

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:** Christian Hendriksz, Laura Steinbusch, Bruce Barshop, Amal Alhashem and Johannes Haeberle.

The SSIEM would like to recognise all those members and individuals involved with IEM that have passed in 2023-2024 including Prof Claude Sansaricq, Prof Iswar Chander Verma and Dr Mark Sharrard.

- 2 Minutes of previous meeting (held, ICC, Jerusalem, Israel at 13:00 local time on Wednesday 30th August 2024)**

Minutes of the previous meeting held in Jerusalem on 30th August 2023 were received and signed by the Chair as a true record following the correction of Kner to Knerr, item 7. Proposer by Gajja Salomons and seconded by Stephanie Grünewald.

- 3 Matters arising from the previous meeting**

There were no matters arising from the previous meeting.

- 4 Society Accounts and Balance Sheet for 2023 (Honorary Treasurer – Philippa Mills)**

The Honorary Treasurer's Report for 2023 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 €122,668 to stand at €3,026,875 as of 31st December 2023.

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

The SSIEM continues to support ERNDIM/SSIEM collaboration and ETAC.

In 2023, the Society had given eight awards under the Parent/Carers Societies/Support Group Fund, thirty Symposium Travel Scholarships and seven Travel & Training Bursaries. Additionally, fourteen individuals received supported membership, and two Dietitian's courses were organised. There were no applications received for guideline development. The total investment in these initiatives in 2023 was €56,517, compared to 2022 of €71,386.

The 2023 accounts were submitted for approval - proposed by Shamima Rahman and seconded by Matthias Baumgartner

There was no increase in membership fees for 2024. As agreed at the AGM 2023 a three tier subscription has been implemented i.e. high and middle income and rest of the world which started in 2024. The cost for all categories for the Rest of the world is €10 per annum.

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.

5 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 authorise the SSIEM Directors to determine their remuneration for 2025 which was seconded by Matthias Baumgartner.

6 Future SSIEM Symposium (Honorary Secretary)

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

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

Two excellent bids were received in response to the call regarding the bid proposal for the organisation of SSIEM 2028 Symposium, one from Basel, Switzerland, by the Swiss Group for Inborn Errors of Metabolism (SGIEM), co-chaired by the three directors of the Swiss Reference Centers of Inborn Errors of Metabolism, and one from Florence Chaired by Giancarlo la Marca. Both bids have been circulated to the Advisory Council Members.

Due to the outstanding quality of both bids, the Council proposed that the SSIEM offers the above two bids the option of 2028 or 2030, with the winner picking the year, providing the Biding teams agree.

This proposal has been approved by both the Advisory Council Members and the Biding groups.

Following the results of the secret ballot held during the earlier Council and Advisory Council Members Meeting the 2028 SSIEM Symposium will be organised in Florence, Italy and the 2030 SSIEM Symposium will be organised in Basel, Switzerland.

7 JIMD report (Senior Editor in Chief - Shamima Rahman)

The JIMD Report for 2024 had been circulated in advance with the notice of the Annual General Meeting.

All articles in both JIMD and JIMD reports are peer reviewed. The JIMD maintained the leading impact factor in the field.

JIMD reports recently converted from ‘book series’ to open access journal. An Impact factor for JIMD reports is pending.

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

Print journals ceased at the end of 2023. Themed issues are in development and regular reviews are commissioned by Review Editors.

Currently moving to continuous publishing and a new simpler online submission system.

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

The Honorary Chair thanked the Senior Editor in Chief - Shamima Rahman and the Editorial Team.

8 Education, Training & Advisory Committee (ETAC) report (Elaine Murphy)

Two former observer members have become full ETAC members – Apolline Imbard (Scientist) and Sarah Grünert (Clinician). The rest of the Committee remains the same. Elaine Murphy is the designated Chair from the end of the Academy in 2025.

The 2024 Academy took place in Amsterdam on 22nd - 23rd April. It followed the usual format, with 80 delegates (plus a few local delegates) – 40 clinicians and 40 lab scientists. As usual there were many more applications, some 180, but only 25 entirely new delegates could be accepted. 55 of 80 places were given to those who had attended previous Academies in the cycle. It was accredited by EACCME as usual.

The 2025 ETAC Academy will take place in Prague.

ETAC proposed and SSIEM Council agreed to move the ETAC Academy from a 4-year curriculum to a 3-year and to extend the length of course from 1.5 days to 3 days.

Johannes Haberle, Elaine Murphy and Peter Hoyer will be doing a site accreditation visit in Dusseldorf in January

The Honorary Chair thanked Elaine Murphy and the ETAC Chair Johannes Haberle plus the ETAC members.

9 SSIEM – Special Interest Groups

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

A training course for adult metabolic medicine is planned for March 2025. In order to provide further training, discussions about including an adult section within the ETAC academy are ongoing. The Clinical Syllabus for Adult Metabolic Medicine is currently being looked at. SSIEM terms of reference for the AMPG to be finalised.

The election of new chair and secretary of the AMPG is due by the end of 2024, the new term starting in January 2025

The Honorary Chair thanked Fanny Mochel and the Adult Metabolic Physicians Group.

10 SSIEM – Special Interest Groups

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 695 members from 78 different countries. SSIEM terms of reference for the DG have been prepared.

The DG continued its educational training meetings which are aimed at improving the skills of less experienced colleagues. The 4th SSIEM DG Academy on Glutaric aciduria will take place in November 2024 and the 5th in January 2025.

During the 2024 SSIEM Symposium an in-person session, SSIEM DG Academy Review: Addressing dietetic challenges, was held for the first time.

During the DG Meeting Alice Dianin was nominated as the next Chair of the DG starting January 2025.

The Honorary Chair thanked Julio Rocha and the Dietitians Group.

11 Any Other Business

The Honorary Secretary noted that for 2025 a hybrid Annual General Meeting is planned. Details will be circulated.

The Chair called the AGM to a close at 14.00.

Signed:

Date:

Since this meeting the date of the SSIEM Symposium in Helsinki has had to be changed to Tuesday 25th August to Friday 28th August 2026.
Next Generation Metabolic Medicine to be held at Messukeskus Helsinki Exhibition and Convention Centre