

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

Annual General Meeting

Honorary Chair: Manuel Schiff

Minutes: Honorary Secretary: Helen Michelakakis

Held virtually on Tuesday 26th August 2025, 16.30-17.40 UK time

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

- 1 **Apologies for absence had been received from:** Matthias Baumgartner, Elaine Murphy, Stephanie Grunewald, Verena Peters, Mirjam Langeveld, Timothy Fazio, Thomas Opladen, Kaustuv Bhattacharya, Eresha Jasinge, Marina Moraitou, Margarita Jimenez, Anastasia Skouma, Nataliia Suslova.

The SSIEM would like to recognise all those members and individuals involved with IEM that have passed including Prof Stephen Kahler and Mr Hari Patel.
- 2 **To receive the minutes of the previous meeting held on Wednesday 4th September 2024 (Honorary Chair – Manuel Schiff)**
Minutes of the previous meeting held in Porto on Wednesday 4th September 2024 were received and signed by the Chair as a true record. Proposed by Philippa Mills and seconded by Julien Park. It was also pointed out that the 2026 SSIEM Symposium in Helsinki, Finland will now take place from 25th – 28th August 2026.
- 3 **Matters arising from the previous meeting (Honorary Chair – Manuel Schiff)**
There were no matters arising from the previous meeting.
- 4 **Election of Directors/Trustees (Honorary Secretary – Helen Michelakakis)**
David Cassiman, Giancarlo la Marca and Júlio César Rocha have stepped down from Council at the end of their six-year terms. The Honorary Secretary and Honorary Chair thanked them for their hard work and dedication. The Honorary Secretary expressed appreciation for the number of high calibre nominations put forward for the three vacant positions on Council. Following due consideration, Council proposed the appointment of Ms Alice Dianin – Chair of the Dietitians Group (Verona, Italy), Dr Mirjam Langeveld – Chair of the Adult Metabolic Physicians Group (Amsterdam, The Netherlands) and Professor Tomas Honzik (Prague, Czech Republic) as new members of Council.

Proposed by Pasi Nevalainen and seconded by Giancarlo la Marca.

5 Election of Honorary Members (Honorary Chair – Manuel Schiff)

It was explained that Honorary Membership of SSIEM is awarded in recognition of a long and distinguished service to the Society. He reported that Council had approved the following members for election to Honorary Membership with effect from 2026:

- Dr Carlo Dionisi-Vici
- Prof Dr Bwee Tien Poll-The
- Dr Antonia Ribes
- Prof Maria Isabel Tavares de Almeida
- Prof Dr Ron Wanders
- Prof Dr Ron Wevers

Proposed by Sunita Bijarnia-Mahay and seconded by Helen Michelakakis.

6 Society Accounts and Balance Sheet for 2024 (Honorary Treasurer – Philippa Mills)

The Honorary Treasurer's Report for 2024 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 €575,445 to stand at to stand at €3,602,320 as of 31st December 2024.

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 Society had given eight awards under the Parent/Carers Societies/Support Group Fund, thirty-two Symposium Travel Scholarships, four Travel and Training Bursaries were awarded to SSIEM members and twenty-one individuals received supported membership. There were no applications for Guideline Development. The total invested for these initiatives in 2024 was €78,585, compared to 2023 in €56,517.

Support was also provided for the ETAC Academy, the Dietician Group Academy and the Dietician Group Research Meeting: an additional investment of €70,220.

There was no increase in membership fees for 2025. As agreed at the AGM 2023, a three-tier subscription rate has been implemented (i.e. High Income, Middle Income and Rest of World) which started in 2024. The cost for all rest of the world subscriptions is €10 per annum.

The 2024 accounts were submitted for approval – proposed by Ann Hallett and seconded by Diana Balhausen.

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.

7 2026 Membership Subscription Rates (Honorary Treasurer – Philippa Mills)

The Honorary Treasurer reported a Membership Committee has undertaken a review of the membership fee structure and associated categories. The existing income bands of High Income, Middle Income and Rest of World had proved effective in supporting membership from lower income countries and will remain in place for 2026.

On the recommendation of the Membership Committee, Council have approved that the membership categories be rationalised as follows:

- Trainee and Subsidised members will be combined into a single "Subsidised" category.
- Retired and Student members will be combined into a single "Concessions" category.

	Honorary	Retired/Student (Concessions)	Standard	Subsidised/Trainee (Subsidised)	Supported
High Income	€0	€25	€140	€90	€0
Middle Income	€0	€15	€80	€40	€0
Rest of World	€0	€10	€10	€10	€0

- 8 On the proposal of Council to re-appoint Buzzacott LLP to be Auditors of the Society and to authorise Council to determine the remuneration (Honorary Treasurer – Philippa Mills)**
On behalf of Council, the Honorary Treasurer proposed the motion that SSIEM use Buzzacott LLP as auditors and authorise the SSIEM Directors to determine their remuneration for 2026.
Proposed by Ann Hallett and seconded by Tobias Hagedorn.

- 9 Future SSIEM Symposia (Honorary Secretary – Helen Michelakakis)**
The 2026 SSIEM Symposium will take place in Helsinki, Finland 25th-28th August, Chaired by Risto Lapatto.
The 2027 SSIEM Symposium will take place in Dublin, Ireland 31st August – 3rd September, Chaired by Ina Kner.
The 2028 SSIEM Symposium will take place in Florence, Italy, organised by Giancarlo la Marca (29th August to 1st September 2028).
In 2029 there will be no SSIEM symposium, but an ICIEM Symposium in Toronto, Canada.
The 2030 SSIEM Symposium will take place in Basel, Switzerland, organised 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 (27th-30th August 2030).
SSIEM Council approved revised early bird registration fees for SSIEM Symposia, to take effect from the forthcoming meeting in Helsinki. The fees for SSIEM Members will be as follows:
- Standard Member early bird fee: reduced from €350 to €250.
 - Student, Trainee, Dietitian, Nurse and Patient Group Member early bird fee: reduced from €200 to €100.
- To qualify for the reduced member rate, SSIEM members must have paid both the current year's and the preceding year's membership fees.

- 10 JIMD Report (on behalf of Senior Editor in Chief – Sean Froese)**
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 Impact Factor of the JIMD fell slightly to 3.8, but this is in line with other journals in the field. JIMD Reports has been accepted for indexing in Web of Science and has been given an impact factor for 2024 of 1.8.
The submission system has now changed from Editorial Manager to the REX submission system, which should improve the process for authors. There have been some initial teething problems which are being addressed by the Editors and the publisher, Wiley.
All JIMD articles are published online only and have moved to continuous publishing.
Four themed issues were published in 2024 and five are ongoing for 2025.
James Nurse, the JIMD social media editor, continues to actively promote the JIMD and JIMD Reports and produces the excellent JIMD Podcasts.
The Honorary Chair thanked Sean Froese and the Editorial Team.

11 Education, Training and Advisory Committee (ETAC) report (Secretary of ETAC – Dr Apolline Imbard)

Elaine Murphy took over the ETAC Chair from Johannes Häberle at the end of the Academy in Prague in April. Apolline Imbard became the Secretary at the same time, with Frederic Vaz stepping down. Both Johannes Häberle and Frederic Vaz will remain as members of ETAC to ease the transition. Christine Vianey-Saban stepped down from her role as Senior Advisor and has been replaced by Jörn Oliver Sass. The rest of the Committee remains the same.

The 2025 Academy took place in Prague on 27th-29th April. It followed the usual format, with 83 delegates and received very positive feedback. It was accredited by EACCME as usual.

The new course format, approved last year, moving to a three-year curriculum and extending the length of each Academy to three days, will be implemented in 2026. To successfully respond to the increased work demands arising from this change, the Committee will be increased by four members (two clinicians, two laboratory scientists).

The Honorary Chair thanked Apolline Imbard and the ETAC Chair Elaine Murphy plus the ETAC members.

**12 SSIEM – Special Interest Groups
A – Dietitians Group Report (Chair DG – Alice Dianin)**

The SSIEM DG committee is comprised of nine members and tasks are divided between them accordingly.

Currently the DG has 683 members from 80 different countries. To improve communication a survey was launched in November 2024, followed by two virtual meetings.

The DG Terms of Reference have been approved by SSIEM Council and will be implemented.

The DG continued its educational meetings which are aimed at improving the skills of less experienced colleagues.

In collaboration with the Japanese organising Committee, GMDI, ASIEM and the immense contribution of the SSIEM-DG Country Representatives network, a pre-congress Metabolic dietitians Group Meeting will take place during the 2025 ICIEM Symposium in Kyoto.

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

The 5th SSIEM DG Academy on Glutaric Aciduria took place in November 2024 and the 6th on Glycogen Storage Diseases types Ia -Ib -III-IX took place in January 2025. In May 2025 the 3rd SSIEM-DG Research Meeting was organised.

The Honorary Chair thanked Alice Dianin and the Dietitians Group.

**13 SSIEM – Special Interest Groups
B – Adult Metabolic Physicians Group (AMPG) Report**

No report was given since neither the Chair nor the Secretary of the group could be present.

14 Any Other Business

None confirmed to the Administration Office in advance or raised

The Chair called the AGM to a close at 17.40.

Signed:

Date: