

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

**NOTICE OF
ANNUAL GENERAL MEETING – 2026**

to be held in

Helsinki Expo and Convention Centre,
Messukeskus, Helsinki, Finland

on

Wednesday 26 August 2026

at 13.00

Dr H Michelakakis
Honorary Secretary

THE SOCIETY FOR THE STUDY of INBORN ERRORS OF METABOLISM

ANNUAL GENERAL MEETING – 2026

AGENDA (Chair: Prof M Schiff)

1. Apologies (Honorary Chair)
2. To receive the minutes of the previous meeting held on Tuesday 26 August 2025 (Honorary Chair)
3. Matters arising from the previous meeting (Honorary Chair)
4. Special Resolution – Accept the revisions to the Society’s Memorandum and Articles of Association by adopting the new Articles circulated with the notice of the AGM
5. Election of Directors/Trustees (Honorary Secretary)
6. Society Accounts & Balance Sheet for 2025 (Honorary Treasurer)
7. 2027 Membership Subscription Rates (Honorary Treasurer)
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
9. Future SSIEM Symposia (Honorary Secretary)
10. JIMD report (Senior Editor in Chief)
11. Education, Training and Advisory Committee (ETAC) report (Chair of ETAC)
12. SSIEM – Special Interest Groups
A – Dietitians Group report (Chair DG)
13. SSIEM – Special Interest Groups
B – Adult Metabolic Physicians Group report (Chair AMPG)
14. Any other business (Honorary Secretary)

HONORARY SECRETARY'S REPORT 2025

MEMBERSHIP

The membership at the end of 2025 had slightly decreased from 2024 to a total membership of 1622. Council remains very aware of the burden that the subscription may have on individuals in different countries, associated with the different pay scales of many of its members. As agreed at the 2024 Annual General Meeting the 2025 SSIEM membership fee remained unchanged. SSIEM Memberships for 2025 came from 86 different countries.

With the different categories of membership from Standard, Subsidised, Standard and Subsidised Trainee, Student and Retired for the High & Middle income countries with fees ranging from €140.00 to €10.00 and the Rest of World countries paying a nominal fee of €10.00. This new scheme is deemed to be fair and equitable for most individuals in the differing specialties and countries. The membership support scheme will remain in place for those requiring subscription support and we would ask our existing members to please inform their colleagues of this scheme. The SSIEM continued to help those members from the Ukraine with supported membership.

COUNCIL

Council met on three occasions during the year under the Chair of Prof M Schiff.

Membership of Council for 2025 comprised of:

(Honorary Chair) Prof M Schiff
(Honorary Secretary) Dr H Michelakakis
(Honorary Treasurer) Prof P B Mills
(Members) Dr A E Dardis, Dr A Garcia-Cazorla, Dr S Grünewald, Prof Dr Med I Knerr, Dr R J Lapatto (appointed 26 August 2025) A Dianin RD, Prof T Honzik and Prof Dr M Langeveld (resigned 26 August 2025) Prof Dr D M Cassiman, Prof G la Marca, Prof J C Rocha (Ex-Officio Members) Prof M R Baumgartner (Senior Editor-in-Chief JIMD and JIMD Reports) and Prof Dr J D B Häberle (resigned 30 April 2025) Dr E M Murphy (appointed 30 April 2025) (Chair ETAC).

The Council has updated the detailed risk assessment relating to the Society's activities and it is reviewed on a regular basis.

ADVISORY COUNCIL MEMBERS

Council appreciated the support and comments from individual Advisory Council members during the year. Advisory Council members can play an important role in choosing the venue for the SSIEM Symposia and in providing nominations for Council. Advisory Council members for 2025 were:

Dr K Bhattacharya (Australia), Prof Dr D Karall (Austria), Dr J Songailiene (Baltic Countries), Prof M-C Nassogne (Belgium), Prof G A Mitchell (Canada), Prof K Fumić (Croatia), Prof A M Lund (Denmark), Dr P I Nevalainen (Finland), Dr D Dobbelaere (France), Dr T Gachechiladze (Georgia), Prof T Oplden (Germany), Dr A S Skouma (Greece), Dr C W Fung (Hong Kong), Dr S Bijarnia-Mahay (India), Prof T Z Zaman (Iran), Ms P Fitzsimons (Ireland), Prof Y Anikster (Israel), Dr A B Burlina (Italy), Prof K Nakamura (Japan), Prof S-C Jung (Korea, Republic of), Prof L Chabraoui (Morocco), Dr B Woldseth (Norway), Dr A H Khan (Pakistan), Prof J Sykut-Cegielska

(Poland/Hungary), Dr D C Gomes (Portugal), Dr A Alhashem (Saudi Arabia), Dr H Amartino (South America), Prof D González-Lamuño (Spain), Prof S Lajic (Sweden), PD Dr D Ballhausen (Switzerland), Dr T G J Derks (The Netherlands), Prof A Ben Chehida (Tunisia), Prof Dr T Coskun (Turkey), Dr B Schwahn (United Kingdom), Dr B A Barshop (United States of America).

2025 SYMPOSIUM

The SSIEM did not hold a Symposium as it was the 15th International Congress of Inborn Errors of Metabolism (ICIEM) held in Kyoto, Japan 2025, run by the JSIMD together with ASIEM, SIMD, SLEIMPN and the SSIEM.

The Archibald Garrod Award Lecture titled, The incidence of movement disorder increases with age and contrasts with subtle and limited neuroimaging abnormalities in argininosuccinic aciduria, by Dr Julien Baruteau, London, United Kingdom was held at the ICIEM 2025 Japan.

FUTURE SSIEM SYMPOSIA and ICIEM CONFERENCES

The following are the venues for future Symposia:

- SSIEM Symposium Helsinki, Finland 2026
- SSIEM Symposium, Dublin, Ireland 2027
- SSIEM Symposium, Florence, Italy 2028
- ICIEM Conference Toronto, Canada 2029
- SSIEM Symposium Basel, Switzerland 2030

SSIEM ADMINISTRATION OFFICE

The Council acknowledges the support given by Mr Nic Law and Mrs Caroline Hankinson of the SSIEM Administration office in providing Council and SSIEM Groups, Committees and the membership with invaluable support throughout the year. The SSIEM appointed a new member to the team on 10th November 2025 Katarzyna (Kasia) Straznikiewicz who has been a very welcomed addition to support the SSIEM aims.

JOURNAL OF INHERITED METABOLIC DISEASE (JIMD)

A more detailed report on the Journal is covered elsewhere within this Annual Report. Council appreciates the significant contribution of the Senior Editor-in-Chief Prof S Rahman and Editor-in-Chief Prof M Baumgartner and the Editorial team, the communicating editors, reviewers and the publishers in producing the JIMD and JIMD reports. The SSIEM Council would also like to thank all the individuals that have submitted papers and articles to the JIMD in 2024 and for supporting the JIMD and JIMD Reports.

The SSIEM's contract with Wiley's means that SSIEM went paperless from 1 January 2024, becoming environmentally friendly.

SSIEM SUBGROUPS

The SSIEM-Dietitians' Group led by the new Chair, continues to make an important contribution to the organisation of the dietetic component of the Society including a training event in 2025.

Honorary Secretary's Report

The new Chair of the SSIEM-Adult Metabolic Physicians' Group which continues to support the membership and organise meetings and training events.

The SSIEM wishes to thank the outgoing Chair of the Dietitians Group Prof J C Rocha and the outgoing Chair of the Adult Metabolic Physicians' Group Prof F M J Mochel for their excellent contributions to managing these Groups.

Detailed reports from both Groups are included in this Annual Report.

Dr H Michelakakis
Honorary Secretary

Honorary Secretary's Report

HONORARY TREASURER'S REPORT 2025

INCOME

In 2025, SSIEM continued to operate its three-tier membership fee structure, based on World Bank economic classifications of high-income, middle-income and Rest of the World (RoW) countries. Royalty income from JIMD and JIMD Reports remained a significant component of the Society's revenue, helping to support the Society's activities for members and the wider inherited metabolic disorders community. The SSIEM Council and members are grateful to all those whose contributions continue to support the success of these journals.

Overall, the Society's income and expenditure decreased significantly in 2025, primarily because no Symposium was held during the year. Royalty income from JIMD and JIMD Reports increased, while other income streams, including membership subscriptions and investment income, remained stable. Total income for 2025 amounted to €589,053. This income continued to support the Society's core priorities on behalf of members, including education, training and professional collaboration.

EXPENDITURE

Total expenditure for 2025 amounted to €660,892 which, after adjustment for the Society's investments, resulted in a loss of €51,002. This expenditure reflects the Society's continued investment in services, education and opportunities that benefit members and support the wider community.

Over the past four years, the Society's Administration Team has developed significantly and continues to play an important role in supporting members, delivering the Society's activities and enabling its next phase of development, including the addition of a further full-time team member in late 2025.

Expenditure during the year included:

- SSIEM Administration Team
- Journal production
- Awards, grants and scholarships, including travel support for educational activities, support for healthcare professionals seeking experience in centres of excellence, and the new Non-SSIEM International Scientific Meeting support of €50,000.00 per annum, helping members and colleagues access learning and development opportunities.
- ETAC Academy
- Governance costs relating to the Society
- Additional training events.
- Council Expenses
- Irrecoverable VAT
- Exchange rate variance

BALANCE SHEET

The total amount held in the accumulated fund decreased in 2025 to €3,551,298.

FINANCIAL POLICY

It is the Society's policy to fund the majority of journal publication and administrative support costs and governance costs from members' subscriptions and journal royalties.

SSIEM holds lower-risk ethical investments in order to achieve an improved financial return on its accumulated funds. The Council considers this approach to be the most appropriate way of preserving the Society's independence while ensuring that its educational objectives can continue to be met. As the majority

of assets are held in ethical financial investments, any delay or shortfall in realising these assets into cash, should this become necessary, is considered unlikely.

A financial sub-committee of the Council is in place to review the Society's financial activities and investments.

RESERVES

It is the policy of the Society to maintain unrestricted funds, being which are the pre-reserves, at a level sufficient to cover management and administrative support costs and to enable the Society to operate efficiently. It is also the policy of the Council to use part of the unrestricted funds to encourage the sharing of experience and training between centres for the benefit of members and the wider community. The reserve is currently set at €1,000,000. Although the reserves may appear substantial, the Council has consistently considered it prudent to maintain them in order to safeguard against the potential financial impact of a major disruption to an Annual Symposium and to ensure that the Society can continue to meet its running costs for 12 months, particularly in light of its responsibilities as an employer.

The reserves will also be used to support:

- The SSIEM Academy
- Long-term administrative sustainability
- Education and practical support for countries introducing investigation and treatment of inborn errors of metabolism
- Development of treatment guidelines
- Training and educational events
- Awards and grants for individuals to attend educational meetings or attend educational or training facilities.

Members who are aware of colleagues who may face financial barriers to joining the Society are encouraged to direct them to apply for an SSIEM Membership Support Grant. Through this support, eligible individuals may be helped to engage with the Society for up to five years. Details of how to apply are available on the SSIEM website.

RISK MANAGEMENT

A thorough risk assessment has been undertaken. The trustees have reviewed the principal strategic, business and operational risks facing the Society and have established systems and processes to ensure that appropriate action can be taken to mitigate those risks. The risk assessment is reviewed at each Council meeting.

AUDITORS

The SSIEM Council recommends continuing the appointment of the Society's auditors and accountants, Buzzacott LLP, for the immediate future.

A copy of the full accounts is appended to this report and is also available on the SSIEM website for members and other interested readers.

Prof P B Mills
Honorary Treasurer

Honorary Treasurer's Report

JOURNAL OF INHERITED METABOLIC DISEASE (JIMD) and JIMD REPORT 2025

In 2025, 123 articles were printed in “JIMD” (original articles, reviews and invited articles) and 61 articles were published in the open access journal “JIMD Reports”. The total number of submissions has increased by approximately 30% for both journals. For JIMD, the majority of submitted articles originated from China, USA, France, The Netherlands, Italy, Turkey and Germany. For JIMD Reports, the majority of articles came from the USA, Canada, UK, Australia, Italy and Japan. The latest impact factor for 2024 is 3.8 for JIMD and 1.8 for JIMD reports. JIMD is currently ranked by Journal Citation Indicator 40th out of 193 titles in the category “Endocrinology & Metabolism”, 42th out of 192 in “Genetics & Heredity” and 46th out of 195 in the category “Medicine, Research and Experimental”, meaning that JIMD is ranked in the top 30% of its peers.

To mark the 60th anniversary of the SSIEM, Manuel Schiff and Peter Clayton curated a series of invited reviews for the “SSIEM 60th Anniversary” issue, highlighting progress in treatment of inborn errors of metabolism over the past six decades. Further, we compiled **themed issues** on “Cell trafficking disorders and complex lipids: an interconnected network” edited by Angeles García-Cazorla, Carlo Dionisi-Vici, Jean-Marie Saudubray, on “Lysosomal Disorders” edited by Roberto Giugliani and on “Challenges in drug development for rare diseases” edited by Sandra Sirrs and Robin Lachmann. We also have started a “Hot Topic Review” Series, featuring outstanding reviews from the field of basic research, edited by Sander Houten, Clara van Karnebeek, Ron Wanders, Sean Froese and Nicola Brunetti-Pierri. We thank all Guest Editors for their contributions.

In line with evolving publishing practices, themed issues are assembled virtually and can be updated on an ongoing basis. Further, to address the rapid developments in Artificial Intelligences (AI) tools, we have evaluated the opportunities and risks of artificial intelligence again and revised our standards for authors and reviewers accordingly.

The **Communicating Editor Awards 2026** for work in 2025 go to Peter Witters as busiest Communicating Editor, Johan van Hove for providing the best comments and to Angeles García-Cazorla, Carlo Dionisi-Vici and Jean-Marie Saudubray for their themed issue on “Cell trafficking disorders and complex lipids: an interconnected network” as best Guest Editors. We remain indebted to all editors and reviewers who have added invaluable expertise and invested considerable effort, contributing to the continuing success of the Journal of Inherited Metabolic Disease and JIMD Reports. A special thanks to Prof Emeritus Lars Mørkrid who supports us as a Statistical Editor and to our Social Media Editor Dr James Nurse. The visual abstracts, podcasts and videocasts, created under the direction of Dr James Nurse, are very popular with our readers and the social media activities steadily increase. At submission, please indicate whether you are interested in presenting your published data in a podcast episode and/or would like support for a visual abstract.

We look forward to seeing you at the SSIEM Symposium in Helsinki when the **Archibald Garrod Award 2026** will be presented by Andrew Morris for the study “Cystathionine β -synthase deficiency in the E-HOD registry”. All publications in 2025 that provided a comprehensive, representative analysis of the clinical features, treatment and outcome of an inherited metabolic disease were considered for this prize.

If you have an idea for a themed issue, editorial or new conceptual ideas, please contact us!

On behalf of the Editorial Team

*Prof Matthias Baumgartner Senior Editor in Chief and Prof Shamima Rahman Editor in Chief,
Prof Dr Verena Peters, Prof Sean Froese, Prof Nicola Brunetti and Prof Johannes Zschocke*

ADULT METABOLIC PHYSICIANS GROUP (AMPG)

REPORT 2025

OFFICIALS

Committee Chair: Mirjam Langeveld, Amsterdam, the Netherlands Committee Secretary: Timothy Fazio, Melbourne, Australia and Committee Education Leader: Michel Hochuli, Bern, Switzerland (all three appointed in their current positions January 2025, period ends 2030)

- Scientific subcommittee (involved in organising the yearly pre-conference meeting): Dr Sandra Sirrs, Vancouver Canada, Dr Robin Lachmann, Cambridge UK, Dr Yusof Rahman, Sydney, Australia, Dr Margreet Wagenmakers, Rotterdam the Netherlands, Dr Francois Maillot, Tours, France.

ACTIVITIES

- SSIEM adult metabolic course: 4th SSIEM adult course, 20-22 March 2025 San Joan de Deu Hospital, Barcelona, Spain. 38 participants, 13 members of teaching staff, evaluation positive.
- AMPG pre-conference meeting ICIEM Kyoto 2025: 2 September, from 8:30 to 12:00. Topic: 'Challenges in adult metabolic care', well attended despite limited advertisement.
- UEMS syllabus for adult IEM is planned (via ETAC, chair Elaine Murphy, London, UK), will be initiated once the paediatric syllabus is completed.
- Recognition of adult IEM as a subspecialty: ongoing activities (publications, outline of competences etc) led by Sandra Sirrs, Vancouver Canada and Analisa Sechi, Udine, Italy.

WORKING GROUPS

- Adult physicians involvement in newborn screening programs: opinion article published July 2025 (led by Fanny Mochel, Paris, France and Mirjam Langeveld, Amsterdam, The Netherlands).
- Obesity and it's treatment in patients with inborn errors of metabolism: data collection ongoing, large number of international centres involved (led by Timothy Fazio, Melbourne, Australia and Kasper ter Horst, Amsterdam, The Netherlands).

BUSINESS MEETING

- Conducted online October 2025, minutes have been distributed among members of the AMPG.

DIETICIAN'S GROUP REPORT 2025

The SSIEM-Dietitians Group (SSIEM-DG) is an international network of dietitians, nutritionists, and healthcare professionals dedicated to the field of Inherited Metabolic Diseases. Originating from a 1996 collaborative meeting in Cardiff, it was established as an SSIEM Special Interest Subgroup in 2010. The main aims of this group are:

1. Facilitating communication and networking among metabolic dietitians globally;
2. Providing high-quality education and training for professionals caring for patients with IMD;
3. Promoting research and collaboration to advance evidence-based nutritional treatment.

KEY ACTIVITIES AND ACHIEVEMENTS

In August 2025, the SSIEM-DG Regulations were updated with structured election procedures to ensure the executive committee reflects geographical diversity, clinical expertise, research and professional advocacy. In September 2025, Prof Júlio César Rocha stepped down as Chair of the SSIEM-DG, and we sincerely thank him for his fundamental guidance. Alice Dianin was elected as the new Chair and officially nominated as a General Council Member on 26 August, 2025. The Committee also welcomed two new members: María Jesús Leal Witt and Alexander Höller.

ACTIVITIES OF THE SSIEM-DG

SSIEM-DG Educational Virtual Events:

- **DG Academy Courses:** On February 12-13, 2025, we conducted our 6th Academy Course focusing on Glycogen Storage Disease types Ia-Ib-III-IX, training 42 attendees from 24 countries. We deeply thank our multidisciplinary faculty for underpinning this success.
- **3rd SSIEM-DG Research Meeting:** The aim of this meeting is to encourage young researchers to showcase their work. Held virtually on 8 May 2025, it featured 24 abstracts, 7 oral presentations and 70 attendees. We were honored to host Prof Melanie Gillingham as the keynote speaker.

15th International Congress of Inborn Errors of Metabolism (ICIM) in Kyoto:

In September 2025, the SSIEM-DG co-organized the highly successful pre-congress “Metabolic Dietitians Group Meeting”. Chaired by Alice Dianin and Mika Ishige, it drew over 500 participants. The Committee thanks our colleagues from key societies (SSIEM, JSIMD, GMDI, and ASIEM) for their collaborative efforts.

Global Network:

By the end of 2025, the SSIEM-DG counted more than 600 members across 80 different countries. Our network of SSIEM DG Country Representatives includes 18 countries, serving as a bridge to local metabolic dietetic communities. Feedback gathered during two April virtual meetings directly inspired the launch of the Metabolic Dietetics Global Project working group in October 2025.

Future Horizons:

Looking forward to the next years, through our ongoing Metabolic Dietetics Global Project we are piloting education, training, and workforce surveys. We will be holding our annual educational events DG-Academy and Research meeting and collaborating on the nutrition and dietetics session programmes of the SSIEM Symposia.

Executive Committee (2025):

Chair: Alice Dianin, IT

Business secretary: Charlotte Ellerton, UK

Training and Education Group: Bénédicte Samba, FR, Marjorie Dixon, UK, and Anne Daly, UK

Website managers: Helle Skandorff Vestergaard, DK, and Soraia Poloni, BR

SSIEM Council Representative: Alice Dianin, IT

Ordinary members: Alexander Höller, AT, María Jesús Leal Witt, CL

Former Chair and Council Representative until September 2025: Júlio César Rocha, PT

There is currently one vacancy on the Committee.

ETAC REPORT 2025

TRAINING ACADEMY

The 17th SSIEM ETAC training academy took place in Prague, Czechia in April 2025.

There were 185 applications (127 clinicians and 58 laboratory scientists). Four local delegates were accepted and initially places were offered to a further 40 laboratory scientists and 40 clinicians. Ultimately, 83 participants attended.

Ninety-seven point five percent of the participants who returned evaluation forms agreed or strongly agreed that “The topics are extremely relevant to my daily practice” and that “The meeting fulfilled my educational goals and expected learning outcomes”.

The previous four-year training cycle has now been replaced by a three-year, three-day cycle – which alongside lectures and workshops, now includes two new forms of teaching – round tables and interpret this!

The 18th SSIEM ETAC training academy will take place in Amsterdam, The Netherlands in November 2026. One hundred and fifteen applications have been received from clinicians and 70 from laboratory scientists (total of 185 applications, from 50 countries).

RELATIONSHIP WITH NAMA (NORTH AMERICAN METABOLIC ACADEMY)

Rebecca Heiner-Fokkema attended NAMA in Georgia, USA in 2025 as an external observer representing ETAC. Diana Ballhausen will attend in 2026. Eva Morava will attend the ETAC academy in 2026, representing NAMA.

COMMITTEE

Johannes Häberle has completed his term as chair and Frédéric Vaz has completed his term as secretary. Elaine Murphy (UK) and Apolline Imbard (France) have taken over as chair and secretary respectively.

SSIEM Council agreed that the committee size could be increased to 16 members to reflect the increasing workload. New committee members were sought by open advertisement. The current committee membership is as below:

Surname	First names	City, Country of work	Job role	ETAC Position
Murphy	Elaine	London, UK	Physician - adult	Chair (2025-)
Imbard	Apolline	Paris, France	Laboratory scientist	Secretary (2025-)
Haeberle	Johannes	Zurich, Switzerland	Physician - paediatric	Member
Morris	Andrew	Manchester, UK	Physician - paediatric	Senior advisor (medical)
Sass	Oliver	Rheinbach, Germany	Laboratory scientist	Senior advisor (laboratory)
Davison	James	London, UK	Physician - paediatric	Member
Ballhausen	Diana	Lausanne, Switzerland	Physician - paediatric	Member
Heiner-Fokkema	Rebecca	Groningen, The Netherlands	Laboratory scientist	Member

Bowron	Ann	Newcastle, UK	Laboratory scientist	Member
Gruenert	Sarah	Freiburg, Germany	Physician - paediatric	Member
Vaz	Fred	Amsterdam, The Netherlands	Laboratory scientist	Member
Rymen	Daisy	Leuven, Belgium	Physician - paediatric	Member
Opladen	Thomas	Heidelberg, Germany	Physician - paediatric	Member
Lam	Amanda	London, UK	Laboratory scientist	Member
Vermeersch	Pieter	Leuven, Belgium	Laboratory scientist	Member
O'Byrne	James	Dublin, Ireland	Physician - adult	Member (elect)

APPLICATIONS FOR CLINICAL TRAINING SITE ACCREDITATION

No applications are currently under review. A query has been raised from a Swiss centre – regarding the possibility of applying for accreditation together with another French speaking centre (in Switzerland) and a Germany speaking centre (in Germany).

ETAC AND THE SSIEM SYMPOSIUM

The ETAC academy have been invited to present a 1.5 hour session at the Symposium in Helsinki, Finland. This session will be titled: From presentation to diagnosis: a case-based education session with the SSIEM Educational and Training (ETAC) Academy.

REFERENCE AND ADMINISTRATIVE DETAILS

For the year ended 31 December 2025

Trustees

Prof M R Baumgartner (appointed 1 January 2025)

A Dianin RD (appointed 26 August 2025)

Dr A E Dardis

Dr A Garcia-Cazorla

Dr S Grünewald

Prof T Honzik (appointed 26 August 2025)

Prof Dr Med I M Knerr

Prof Dr M Langeveld (appointed 26 August 2025)

Dr R J Lapatto

Dr H Michelakakis

Prof P B Mills

Dr E M Murphy (appointed 30 April 2025)

Prof M Schiff

Company Secretary

Dr H Michelakakis

Company Registered Number

02567711

Charity Registered Number

1010639

Registered Office

C/O Stone King LLP

Boundary House

91-93 Charterhouse Street

London

EC1M 6HR

Independent Auditor

Buzzacott LLP

130 Wood Street

London

EC2V 6DL

Bankers

Barclays Bank PLC

PO Box 43

Sheffield

S9 2LF

General Information

TRUSTEES' REPORT

For the year ended 31 December 2025

The Trustees present their annual report together with the financial statements of The Society for the Study of Inborn Errors of Metabolism ('SSIEM') ('the Society') for the year ended 31 December 2025.

Since the Society qualifies as small under section 383 of the Companies Act 2006, the Strategic report required of medium and large companies under The Companies Act 2006 (Strategic report and Directors' report) Regulations 2013 is not required.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution

The Society is constituted under a Memorandum of Association dated 12 December 1990 and amended by Resolutions dated 13 September 1991, 6 September 2007, 31 August 2011 and 3 September 2014. It is a registered charity with its charity number being 1010639.

The Society is limited by guarantee and does not have share capital. All Trustees are members of the Society and guarantee to contribute £1 in the event of winding up.

Trustees

The Trustees who served during the year were:

Prof Dr Med M R Baumgartner (appointed 1 January 2025)

Prof Dr D M Cassiman (resigned 26 August 2025)

Dr A E Dardis

Ms A Dianin (appointed 26 August 2025)

Dr A Garcia-Cazorla

Dr S Grünewald

Prof Dr Med J D B Häberle (resigned 30 April 2025)

Dr T Honzik (appointed 26 August 2025)

Prof Dr Med I M Knerr

Prof G la Marca (resigned 26 August 2025)

Prof Dr M Langeveld (appointed 26 August 2025)

Dr R J Lapatto

Dr H Michelakakis

Prof P B. Mills

Dr E M Murphy (appointed 30 April 2025)

Prof S Rahman (resigned 1 January 2025)

Prof J C Rocha (resigned 26 August 2025)

Prof M Schiff

OBJECTIVES AND ACTIVITIES

Policies and objectives

The principal objective of the Society is to foster the study of inherited metabolic disorders and related topics.

In order to further these objectives, membership of the Society promotes the exchange of ideas between professionals in different disciplines who are interested in inherited metabolic disorders. The aim is pursued through scientific meetings, training courses and publications. The Society supports a symposium 3 out of 4 years concentrating on different topics relating to inborn errors of metabolism and publishes its journals (Journal of Inherited Metabolic Disease (JIMD) and JIMD reports).

Membership of the Society is open to all and especially to those who are professionally involved in metabolic disorders or related topics.

Public benefit

By supporting symposia, educational events and publishing its journals, the Society aims to advance health by sharing knowledge and ideas on different topics relating to inborn errors of metabolism. In doing so, the Society has considered the Charity Commission's guidance on public benefit.

Organisational structure and decision-making

A General Council made up of Honorary Officers of the Society, Ex-Officio members and additional members who are elected at the Annual General Meeting manage the organisation. The Honorary Officers are the Chair, Secretary and a Treasurer. Ex-Officio members are the chair of ETAC and Senior Editor-in-Chief of JIMD. The General Council appoints the Honorary Officers. Honorary Officers of the Society may hold office for three years and are eligible for re-appointment to the same office for a further three years. Ex-Officio members may hold office for three years; they may be re-elected for a further three years.

All Directors/Trustees of the Society are considered to be key management personnel of the SSIEM although all are non-paid volunteers. Other key management personnel include the SSIEM Administration team with whom the Directors/Trustees work closely.

The Finance Sub-Committee ('FSC') comprises the current Honorary Treasurer, Honorary Chair and Honorary Secretary along with Chair Elect, Secretary Elect and Treasurer Elect if applicable, the previous Honorary Treasurer, an independent financial advisor and invited members of the SSIEM Administrative team.

Trustees' responsibilities statement

The Trustees (who are also Directors of The Society for the Study of Inborn Errors of Metabolism for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the Society and of the incoming resources and application of resources, including the income and expenditure, of the Society for that period.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with 'the Financial Reporting Standard applicable to the UK and Republic of Ireland' ('FRS 102');
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable United Kingdom Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Society will continue in operation.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Society's transactions and disclose with reasonable accuracy at any time the financial position of the

Society and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the Society and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the Society's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

ACHIEVEMENTS AND PERFORMANCE

Review of activities

The three-tier membership subscription structure, based on the World Bank List of Economies, categorising countries into "high income countries" "middle income countries" and the "rest of the world" was again used in 2025. All categories within the "rest of the world" paid a nominal fee of €10.00 per annum.

During the year ended 31 December 2025 the Society published its Journals and continued development of its own administration team increasing to a team of three.

The SSIEM did not hold a symposium in 2025 as it was the joint ICIEM conference which was organised by the JSIMD in Kyoto, Japan.

The SSIEM Journal of Inherited Metabolic Disease (JIMD) continued to be run by the JIMD Editorial Office in Heidelberg.

The SSIEM Education and Training Advisory Committee (ETAC) exercised its responsibilities for the training syllabi and the recognition of training centres for paediatric metabolic medicine. ETAC also organised the annual SSIEM Academy course which for 2025 was held in Prague, Czech Republic.

The SSIEM organised two virtual dietitian's meetings and the SSIEM Adult course in Barcelona, Spain.

The SSIEM offered modest financial support for non-profit organisations such as parent support groups or societies. In 2025, sixteen applications were received for the first award call and twelve for the second. These applications were independently judged by a panel from the SSIEM Advisory Council. A total of seven awards were made.

Three Travel and Training Bursaries were awarded to healthcare professionals to support educational activities, either to gain experience in centres of excellence or to attend conferences or meetings. The SSIEM continued to help fifteen individuals in Ukraine within the IEM community with supported membership, along with six others from different countries.

There was one award for the SSIEM support for guideline development and their publication in the JIMD for 2025.

A new initiative to support non SSIEM international scientific meetings was created and nine applications were received and evaluated by a panel for an award of up to €50,000.00. The winning application was the 3rd International Conference on Ureagenesis Defects and Allied Conditions, to be held in April 2026.

A total of €88,884, was given in awards, grants and bursaries for 2025.

FINANCIAL REVIEW

Principal funding

The overall income is used to pay the administrative and operational costs of the Society, including ETAC, and to allow for publication of educational journals devoted to the study of the inborn errors of

metabolism and the organisation of training and educational events. Surplus funds are invested. Interest from investments is used in pursuance of the educational objectives of the Society.

The Council is cognisant of the current global financial crisis and has taken steps to protect investments and secure the financial position of the Society, ensuring that it can continue to meet its objectives. The Honorary Officers and Council have also reviewed the current global situation with regard to political unrest and ongoing conflicts.

The Society is truly international, with membership from 86 countries. It exists to promote the exchange of ideas between all who are professionally interested in Inherited Metabolic Disease. It is the wish of the Council that this exchange should occur between members in as many countries as possible. The Council has agreed to set aside an amount of money from any surplus generated from normal activities to make membership more widely available to those who would otherwise be unable to participate without support from the Society.

Results for the year

Overall, the financial result for the year was a net decrease in the reserves of €51,022 to a year-end figure of €3,551,298.

Reserves policy

It is the policy of the Society to maintain unrestricted funds, known as free reserves, at a level that is sufficient to cover management, administration and support costs to allow the Society to be managed efficiently. This reserve is set at €1,000,000 (2024: €1,000,000). In addition, the Council proposes that a proportion of the surplus funds are invested, currently €1,027,000 (2024: €1,027,000); the purpose of the investment is to provide the SSIEM with a modest income from its surplus. The remaining surplus is used in pursuance of the educational and charitable objectives of the Society. These include Adult and Dietitian meetings, the ETAC Academy and the SSIEM symposia, plus a limited number of awards, grants and bursaries. The latter includes: the Travel and Training Bursaries – to finance individual members to visit, or work for short periods of time in, other centres of expertise; support of non-profit organisations, such as parent support groups holding events or parent/carer projects; Symposium scholarships for travel, accommodation and registration at the SSIEM Symposium and development of Guidelines. As of 31 December 2025, an unrestricted fund balance of €3,551,298 (2024: €3,602,320) was held. The Council regularly reviews the balance and is constantly looking into charitable ways to use the funds.

Investment policy and performance

All investments have been acquired in accordance with powers available to the Council. The assets are sufficient to guarantee normal running of the Society for a period of not less than one year and to support the SSIEM Symposium if there were financial difficulties. The Council considers that this is the best way of ensuring the independence of the Society and that its educational objectives can be fulfilled. Since the majority of assets are financial investments there is unlikely to be any delay or shortfall in realising the assets into cash if this becomes necessary.

Risk management

The Trustees have assessed the major risks to which the Society is exposed, in particular those related to the operations and finances of the Society, and are satisfied that systems and procedures are in place to mitigate our exposure to the major risks.

The main risks and the methods by which the risks are mitigated are:

Symposia risk

- Insurance against bodily or material harm including third parties.
- Insurance against cancellation was considered unacceptably expensive and therefore inappropriate use of funds. However, this can be reviewed with each symposium.

- Agreement regarding a force majeure event.
- Making the Symposia a hybrid or virtual meeting if required.

It is expected that the above insurance policies and agreements are included in any contract with any Professional Conference Organiser (PCO) providing services for the annual Symposium.

Data risk

- The IT and data facilities are virtual and backed-up routinely.
- Compliance with GDPR regulations. Specialist advice has been sought to ensure compliance with GDPR in our contracts with third parties.

Financial risk

- The major risk to the SSIEM is the potential lack of success of the symposium which is covered under Symposia risk.
- The financial surplus of the Society is conservatively managed and is considered to be low risk as funds are held in Sterling and Euro.

Political unrest and ongoing conflicts

- The Society monitors reputable media sources to identify potential risks and plan accordingly.

PLANS FOR FUTURE PERIODS

Future developments

The Council will continue to:

- Develop our administration team.
- Review and develop corporate governance.
- Review and enhance structures of committees, succession planning and terms of reference.
- Continually assess and manage risks.
- Develop communication links with the members.
- Develop/update our Symposium and meetings, including reducing member registration fees which will be done for the 2026 SSIEM Symposium.
- Support parent support groups or societies through the funding award scheme.
- Support healthcare professionals seeking experience at centres of excellence.
- Provide support for Guideline Development.
- Continue to provide support for non-SSIEM international Scientific meetings.
- Encourage ERNDIM-SSIEM collaboration.
- Encourage joint training initiatives between MetabERN and SSIEM.
- Explore new initiatives to support the Society's aims.
- Continue to provide awards for supporting non-SSIEM meetings.

ETAC will continue to:

- Canvas the views of SSIEM members on training issues.
- Undertake accreditation visits when requested.
- Update the training syllabus on a regular basis.
- Consider whether courses in inborn errors of metabolism are suitable for training needs.
- Organise further specific training programmes as part of the SSIEM Academy.
- Encourage ETAC-NAMA collaboration.

The SSIEM's Journal of Inherited Metabolic Disease (JIMD) will:

- Continue and further develop the JIMD.
- Publish special issues.
- Develop a strategy for open access.

The Society actively encourages the formation of National Societies which can communicate with each other through the SSIEM to raise awareness of metabolic diseases so that standards of care and research are improved.

Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the Society has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements.

Disclosure of information to auditor

Each of the persons who are Trustees at the time when this Trustees' report is approved has confirmed that:

- So far as that Trustee is aware, there is no relevant audit information of which the Society's auditor is unaware, and
- The Trustee has taken all the steps required to ensure they are aware of any relevant audit information and to establish that the Society's auditor is aware of that information.

Small companies exemption

In preparing this report, the Trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

This report was approved by the Trustees and signed on their behalf by:

Prof P B Mills
Trustee
28 July 2026

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM

Opinion

We have audited the financial statements of The Society for the Study of Inborn Errors of Metabolism ('the charitable company') for the year ended 31 December 2025, which comprise the Statement of financial activities, the Statement of financial position, the Statement of cash flows and the related notes, including a summary of the principal accounting policies and the notes to the financial statements. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2025 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the United Kingdom, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of the report.

Other information

The Trustees are responsible for the other information contained within the annual report and financial statements. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude themselves that there is a material misstatement of this other information, we are required to report that fact.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' report, which is also the directors' report for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' report, which is also the directors' report for the purposes of company law, has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' report. We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemptions in preparing the Trustees' report and from the requirement to prepare a Strategic report.

Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement on page 15-16, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Society or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could

reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

Our approach to identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, was as follows:

- the engagement partner ensured that the engagement team collectively had the appropriate competence, capabilities and skills to identify or recognise non-compliance with applicable laws and regulations; and
- the audit team held a discussion to identify any particular areas that were considered to be susceptible to misstatement, including with respect to fraud and non-compliance with laws and regulations; and
- we obtained an understanding of the legal and regulatory frameworks that are applicable to the Society and determined that the most significant frameworks which are directly relevant to specific assertions in the financial statements are those that relate to the reporting framework (Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011), the Companies Act 2006 and those that relate to data protection (General Data Protection Regulation).

We assessed the susceptibility of the charitable company's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud and their knowledge of actual, suspected and alleged fraud; and
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations.

To address the risk of fraud through management bias and override of controls, we:

- performed analytical procedures to identify any unusual or unexpected relationships;
- assessed whether judgements and assumptions made in determining the accounting estimates set out in the accounting policies were indicative of potential bias; and
- tested journal entries to identify unusual transactions.

In response to the risk of irregularities and non-compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation;
- reading the minutes of meetings of those charged with governance; and
- enquiring of management as to actual and potential litigation and claims.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the Trustees and other management and the inspection of regulatory and legal correspondence, if any.

Independent Auditor's Report

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our Auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members, as a body, for our audit work, for this report, or for the opinions we have formed.

***Alison Pyle (Senior Statutory Auditor)
for and on behalf of
Buzacott LLP
Statutory Auditor
130 Wood Street
London
EC2V 6DL
29 July 2026***

Independent Auditor's Report

STATEMENT OF FINANCIAL ACTIVITIES

For the year ended 31 December 2025

		Unrestricted funds 2025	Unrestricted funds 2024
Income and expenditure	Note	€	€
Income from:			
Charitable activities – symposium and memberships	3	130,185	2,505,204
Charitable activities – journal royalties and courses	4	429,667	383,291
Investments	5	<u>29,201</u>	<u>28,469</u>
Total income		<u>589,053</u>	<u>2,916,964</u>
Expenditure on:			
Charitable activities	6	<u>660,892</u>	<u>2,363,786</u>
Total expenditure		<u>660,892</u>	<u>2,363,786</u>
Net (expenditure)/income before investment gains and losses		(71,839)	553,178
Unrealised gain/(loss) on revaluation of fixed asset investment	10	100,966	(13,486)
Net realised loss on investments	10	(22,755)	(17,461)
Gain on retranslation of fixed asset investments	10	<u>(57,394)</u>	<u>53,214</u>
Net movement in funds		(51,022)	575,445
Reconciliation of funds:			
Total funds at the beginning of the year	14	<u>3,602,320</u>	<u>3,026,875</u>
Total funds at the end of the year		<u>3,551,298</u>	<u>3,602,320</u>

The Statement of financial activities includes all gains and losses recognised in the year.

All of the Society's activities derived from continuing operations during the above two financial years.

The notes on pages 27 to 33 form part of these financial statements.

STATEMENT OF FINANCIAL POSITION

As at 31 December 2025

	Note	2025 €	2025 €	2024 €	2024 €
Fixed assets					
Investments	10		1,230,612		1,164,539
Current assets					
Debtors: amounts falling due after more than one year	11	11,537		11,537	
Debtors: amounts falling due within one year	12	373,691		479,418	
Cash at bank and in hand		<u>2,123,038</u>		<u>2,260,098</u>	
		2,508,266		2,751,053	
Creditors: amounts falling due within one year	13	(187,580)		(313,272)	
Net current assets			<u>2,320,686</u>		<u>2,437,781</u>
Net assets			<u>3,551,298</u>		<u>3,602,320</u>
Charity funds					
Unrestricted funds:					
General fund	14	<u>3,551,298</u>		<u>3,602,320</u>	
			<u>3,551,298</u>		<u>3,602,320</u>
Total unrestricted funds			<u>3,551,298</u>		<u>3,602,320</u>

The Trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime and in accordance with the provisions of FRS102 Section 1A – small entities.

The financial statements were approved by the Trustees on 28 July 2026 and signed on their behalf, by:

Prof P B Mills
Honorary Treasurer

The notes on pages 27 to 33 form part of these financial statements.

Statement of Financial Position

STATEMENT OF CASH FLOWS

For the year ended 31 December 2025

	2025 €	2024 €
Cash flow from operating activities		
Net cash (used in)/generated from operating activities	A <u>(120,085)</u>	<u>499,630</u>
Cash flow from investing activities		
Purchase of investments	(380,400)	(192,864)
Disposal of investments	335,144	197,859
Investment income	<u>28,281</u>	<u>28,469</u>
Net cash (used in)/generated from investing activities	(16,975)	33,464
Change in cash and cash equivalents in the year	(137,060)	533,094
Cash and cash equivalents at beginning of year	<u>2,260,098</u>	<u>1,727,004</u>
Cash and cash equivalents at end of year	B <u>2,123,038</u>	<u>2,260,098</u>

A Reconciliation of net income to net cash flow from operating activities

	2025 €	2024 €
Net (expenditure)/income for the year (as per the Statement of financial activities)	(51,022)	575,445
Adjustments for		
(Gain)/loss on revaluation of investments	(100,966)	13,486
Loss on disposal of investments	22,755	17,461
Loss/(gain) on retranslation of fixed asset investments	57,394	(53,214)
Investment income	(29,201)	(28,469)
Decrease/(increase) in debtors	106,647	(138,982)
(Decrease)/increase in creditors	<u>(125,692)</u>	<u>113,903</u>
Net cash (used in)/generated from operating activities	<u><u>(120,085)</u></u>	<u><u>499,630</u></u>

B Analysis of cash and cash equivalents

	2025 €	2024 €
Cash at bank and in hand	2,088,258	2,196,737
Cash held by investment managers	<u>34,780</u>	<u>63,361</u>
Total cash and cash equivalents	<u><u>2,123,038</u></u>	<u><u>2,260,098</u></u>

Statement of Cash Flows

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 December 2025

1. GENERAL INFORMATION

The Society for the Study of Inborn Errors of Metabolism ('the Society') is a company limited by guarantee. The members of the Society are the Trustees named on page 13. In the event of the Society being wound up, the liability in respect of the guarantee is limited to £1 per member of the Society. The Society is incorporated in England and Wales. Its registered office and principal place of business is C/O Stone King LLP, Boundary House, 91-93 Charterhouse Street, London, EC1M 6HR. The company registration number is 02567711 and the charity registration number is 1010639.

2. ACCOUNTING POLICIES

2.1 Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention, with the exception of investments, which are included on a market value basis. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP FRS 102), Section 1A of Financial Reporting Standard 102, 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' ('FRS 102'), the Charities Act 2011 and the Companies Act 2006.

The society constitutes a public benefit entity as defined by FRS 102.

The financial statements are presented in Euro (€) and rounded to the nearest Euro (€). This is the functional currency of the charity.

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

2.2 Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the Society has adequate resources to continue in operational existence for the foreseeable future and have identified no material uncertainties in this regard. For this reason, the Society will continue to adopt the going concern basis in preparing the financial statements.

2.3 Fund accounting

The general fund is an unrestricted fund which is available for use at the discretion of the Trustees in furtherance of the general objectives of the Society and which has not been designated for other purposes.

2.4 Income

All income is recognised in the Statement of financial activities when the Society has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

Annual Symposium

Symposium income is the gross or the net proceeds from revenue generated by the symposium organiser on behalf of SSIEM depending on whether the symposium organiser is acting as the agent or the principal. This revenue includes the registration fees and sponsorship fees at the event.

Subscriptions income

Income from subscriptions are recognised in the period the membership relates to.

Journal royalties

Journal royalties are recognised on an accruals basis.

Investment income

This comprises interest on bank deposits and National Savings Bank income bonds and dividend income. Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Society. This is normally upon notification of the interest paid or payable by the bank. Dividends are recognised once the dividend has been declared, and notification has been received of the dividend due.

2.5 Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the Society to make a payment to a third party or it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. All expenditure is stated inclusive of irrecoverable VAT.

All expenditure is accounted for on an accruals basis. Expenditure comprises direct costs and support costs. All expenses, including support costs, relate to the charitable activities of the Society.

Expenditure on charitable activities includes all costs associated with furthering the charitable purposes of the Society through the provision of its charitable activities. Such costs have been apportioned as follows:

- Direct costs – These are the costs associated directly to meeting the charitable objects of the Society and include annual symposium expenditure, grants payable and costs incurred in respect of producing journals.
- Support costs – These are the costs incurred directly in support of expenditure on the objects of the Society and include project management carried out at Headquarters.
- Governance costs – These are the costs directly attributable to the meetings and audit process such as staff costs, printing, meetings and travel costs.

Annual Symposium

Symposium expenditure is the gross expenses incurred, when the symposium organiser is acting as agent for the Society.

Grants payable

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, with such grants being recognised as expenditure when the conditions attached are completed by the Society. Grants offered subject to conditions which have not been met at the year-end are noted as a commitment but not accrued as expenditure.

2.6 Fixed asset investments

Investments are stated at market value at the reporting date. The Statement of financial activities includes the net gains and losses arising on revaluations and disposals throughout the year.

2.7 Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered and net of any provision. Prepayments are valued at the net amount prepaid.

2.8 Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

2.9 Liabilities and provisions

Liabilities are recognised when there is an obligation at the reporting date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably. Liabilities are recognised at the amount that the Society anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

2.10 Financial instruments

The Society has only financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

2.11 Foreign currencies

Monetary assets and liabilities denominated in foreign currencies are translated into Euros at rates of exchange ruling at the balance sheet date.

Transactions in foreign currencies are translated into Euros at the rate ruling on the date of the transaction.

Exchange gains and losses are recognised in the Statement of financial activities incorporating income and expenditure account.

3. INCOME FROM CHARITABLE ACTIVITIES – SYMPOSIUM AND MEMBERSHIPS

	Total funds	Total funds
	2025	2024
	€	€
Annual Symposium	–	2,375,574
Subscriptions	<u>130,185</u>	<u>129,630</u>
	<u>130,185</u>	<u>2,505,204</u>

4. INCOME FROM CHARITABLE ACTIVITIES – JOURNAL ROYALTIES AND COURSES

	Total funds	Total funds
	2025	2024
	€	€
Journal royalties	417,242	374,653
Courses	4,675	1,170
Academy income	<u>7,750</u>	<u>7,468</u>
	<u>429,667</u>	<u>383,291</u>

5. INCOME FROM INVESTMENTS

	Total funds 2025 €	Total funds 2024 €
Interest income	16,086	15,998
Dividend income	<u>13,115</u>	<u>12,471</u>
	<u>29,201</u>	<u>28,469</u>

6. ANALYSIS OF CHARITABLE ACTIVITIES

	Total funds 2025 €	Total funds 2024 €
Direct costs		
Council symposium expenses	18,804	12,123
Publication of the JIMD	94,259	130,244
JIMD Honorarium	21,000	21,000
JIMD Illustrations	174	1,222
Academy expenses	82,435	68,888
Symposium expenses	29,202	1,645,257
Courses	41,845	9,970
Awards/bursaries and grants	<u>88,884</u>	<u>78,585</u>
Total direct costs	376,603	1,967,289
Support costs		
Salaries and wages (note 9)	155,402	123,702
Council travel and subsistence	15,356	6,318
Printing, postage, stationery and carriage	991	1,076
Loss on exchange rate variance	16,105	58
Website costs	1,816	6,773
Other administration expenses	20,028	22,122
Secretarial expenses	204	198
Telephone and fax	1,193	1,134
IT supplies	12,237	8,178
Irrecoverable VAT	<u>28,731</u>	<u>195,560</u>
Total support costs	252,063	365,119
Governance costs		
Audit and accountancy fees	31,226	30,395
Professional charges	<u>1,000</u>	<u>983</u>
Total governance costs	32,226	31,378
Total expenditure on charitable activities	<u>660,892</u>	<u>2,363,786</u>

4 individuals were supported with financial grants of €7,158 (2024: €32,785 (38 individuals)) during the year.

7. TRUSTEES' REMUNERATION

No Trustees received any remuneration or benefits in kind in respect of their services during the year (2024: €Nil). During the year, 14 Trustees received reimbursement of expenses of €36,961 (2024: €15,660, 13 Trustees).

8. AUDITOR'S REMUNERATION

Auditor's remuneration amounts to a current year audit fee of €22,731 (2024: €21,809) and fees charged for other non-audit services amounts to €8,495 (2024: €8,586).

9. STAFF COSTS	2025	2024
	€	€
Wages and salaries	125,793	99,599
Social security costs	16,366	10,784
Pension costs	<u>13,243</u>	<u>13,319</u>
	<u>155,402</u>	<u>123,702</u>

The average monthly number of employees during the year was 2 (2024: 2).

The number of higher paid employees was:

	2025	2024
€60,001 – €70,000	–	1
€70,001 – €80,000	<u>1</u>	<u>–</u>
	<u>1</u>	<u>1</u>

Within Symposium costs are amounts totalling €nil (2024: €16,376) payable to employees.

The Society considers the Board of Trustees, the administrator and executive administrator as their key management personnel. The total employment benefits (including employer's national insurance contributions and employer's pension contributions) of key management personnel was €14,846 (2024: €123,702).

10. FIXED ASSET INVESTMENTS

	2025	2024
	€	€
At 1 January 2025	1,164,539	1,147,267
Additions at cost	380,400	192,864
Disposals at book value (proceeds: €335,144 loss: €22,755)	(357,899)	(215,320)
Unrealised gain/(loss) on revaluation of fixed asset investments	100,966	(13,486)
(Loss)/gain on retranslation of fixed asset investments	(57,394)	53,214
At 31 December 2025	<u>1,230,612</u>	<u>1,164,539</u>
Historic cost at 31 December 2025	<u>1,147,267</u>	<u>1,139,684</u>

Analysis of investments	2025	2024
	€	€
Investments at market value comprise of the following:		
Fixed income	390,291	556,584
Equities	807,925	567,879
Alternatives	<u>32,396</u>	<u>40,076</u>
	<u>1,230,612</u>	<u>1,164,539</u>

Investments are held to provide an investment return.

All fixed asset investments are held in the UK.

Notes to the Financial Statements

11. DEBTORS:		
Amounts falling due within one year	2025	2024
	€	€
Deposits	<u>11,537</u>	<u>11,537</u>
	<u>11,537</u>	<u>11,537</u>
12. DEBTORS:		
Amounts falling due within one year	2025	2024
	€	€
Trade debtors	51,490	390
Deposits	34,610	34,610
Other debtors	–	78,846
Payments and accrued income	<u>287,591</u>	<u>365,572</u>
	<u>373,691</u>	<u>479,418</u>
13. CREDITORS:		
Amounts falling due within one year	2025	2024
	€	€
Trade creditors	3,021	126,454
Other creditors	2,315	2,100
Other taxation	18,222	74,394
Grant creditors	50,000	–
Accruals and deferred income	<u>114,022</u>	<u>110,324</u>
	<u>187,580</u>	<u>313,272</u>
	2025	2024
	€	€
Deferred income at beginning of year	32,371	32,433
Resources deferred during the year	78,482	32,371
Amounts released from previous years	<u>(32,371)</u>	<u>(32,433)</u>
Deferred income at end of year	<u>78,482</u>	<u>32,371</u>

Deferred income relates to the deferral of subscription income over the period to which it relates.

14. UNRESTRICTED FUNDS

	Balance at 1 January 2025 €	Income €	Expenditure €	Gains from investments €	Transfers between funds €	Balance at 31 December 2025 €
General fund	<u>3,602,320</u>	<u>589,053</u>	<u>(660,892)</u>	<u>20,817</u>	–	<u>3,551,298</u>
	<u>3,602,320</u>	<u>589,053</u>	<u>(660,892)</u>	<u>20,817</u>	–	<u>3,551,298</u>
	Balance at 1 January 2024 €	Income €	Expenditure €	Gains from investments €	Transfers between funds €	Balance at 31 December 2024 €
General fund	<u>3,026,875</u>	<u>2,916,964</u>	<u>(2,363,786)</u>	<u>22,267</u>	–	<u>3,602,320</u>
	<u>3,026,875</u>	<u>2,916,964</u>	<u>(2,363,786)</u>	<u>22,267</u>	–	<u>3,602,320</u>

The general fund represents the ‘free reserves’.

Notes to the Financial Statements

15. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year (2024: none).

