



2026 ANNUAL SYMPOSIUM • HELSINKI FINLAND

SSIEM 2026 ANNUAL SYMPOSIUM:

PRELIMINARY PROGRAMME

25 - 28 AUGUST 2026 • HELSINKI FINLAND



SSIEM Symposium 2027

Society for the Study of Inborn Errors of Metabolism

31 AUG - 3 SEP 2027, DUBLIN, IRELAND

complexity | diversity | inclusion

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your interest



See you in Dublin!

- Vibrant European capital city
- Strong clinical, research, academic and patient communities
- Dublin 'buzz' - endlessly exciting
- Easy international access
- Rich culture, history and hospitality



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Dear Friends,

The 2026 SSIEM Symposium in Helsinki (25–28 August 2026) is rapidly approaching! We are excited to welcome you all soon. A warm thank you to everyone who has already registered. If you haven't yet, there is still time to do so.



We are incredibly grateful for the large number of high-quality abstracts submitted, and we owe a big thank you to the scientists who dedicated their time to evaluating them. Thanks to your contributions, this year's program will be more dynamic than ever. We will have a record number of parallel sessions and oral presentations.

New Presentation Formats: In addition to traditional oral presentations, we are introducing short, fast-paced “rapid-fire” presentations. This allows more researchers a chance to share their valuable work.

Posters & Parallel Sessions: Because we have many parallel sessions, we highly encourage oral presenters to also share their work in a poster format. This ensures your research reaches the widest possible audience.

Some Program Highlights to Look Forward To:

- **Lab Talks:** A brand new feature this year! Experienced scientists Philippa Mills and Sean Froese will share personal stories and insights to inspire career paths in the field of IEM.
- **Specialist Discussion Meetings:** We will host dedicated sessions on **Newborn Screening, Ensuring Patient Access to Innovation in Rare Diseases**, and the **Training of Healthcare Professionals in IEM**. We extend our sincere thanks to the many individuals and organizations helping us bring these sessions to life.

The Patient Advocacy group session on Wednesday will focus on sustainability, while the Local Organizing Committee will host an introductory session on Tuesday morning for newcomers to the IEM field. The SSIEM Dietitians' group and the Adult Metabolic Physicians' group will also host their traditional excellent pre-symposium sessions on Tuesday morning.

All of the sessions mentioned above are open to all attendees. We are also grateful to our numerous corporate sponsors for supporting the symposium and organizing engaging **satellite meetings**.

Stay Tuned for Updates

We will update our official webpage (www.ssiem2026.org) regularly throughout the summer. Please check the site for further details on e.g. schedules and registration for mentoring sessions.

We truly look forward to welcoming you to Helsinki for what promises to be an inspiring, productive, and memorable Symposium.

Warm regards,

Risto Lapatto

Symposium President

ORGANISATION & COMMITTEES

Organisation

With the support of City of Helsinki



Helsinki

Symposium President

- **Risto Lapatto** (Helsinki, Finland)

Committees

Local Organising Committee

- **Minna Harsunen** (Helsinki, Finland)
- **Mervi Hyvönen** (Helsinki, Finland)
- **Risto Lapatto** (Helsinki, Finland)
- **Päivi Miettinen** (Helsinki, Finland)
- **Irina Nagy** (Oulu, Finland)
- **Pasi Nevalainen** (Tampere, Finland)
- **Harri Niinikoski** (Turku, Finland)
- **Katrin Strengell** (Helsinki, Finland)
- **Jetta Tuokkola** (Helsinki, Finland)
- **Henna Tyynismaa** (Helsinki, Finland)

International Scientific Committee

- **Yair Anikster** (Ramat Gan, Israel)
- **Kaustuv Bhattacharya** (Dublin, Ireland)
- **Andrea Dardis** (Udine, Italy)
- **Alice Dianin** (Verona, Italy)
- **Angeles Garcia Cazorla** (Barcelona, Spain)
- **Anita Inwood** (Brisbane, Australia)
- **Ina Knerr** (Dublin, Ireland)
- **Helen Michelakakis** (Athens, Greece)
- **Philippa Mills** (London, United Kingdom)
- **Elaine Murphy** (London, United Kingdom)
- **Shamima Rahman** (London, United Kingdom)
- **Manuel Schiff** (Paris, France)
- **Trine Tangeraas** (Oslo, Norway)
- **Jerry Vockley** (Pittsburgh, United States)



SSIEM 2026

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SCIENTIFIC PROGRAMME

DAILY OVERVIEW



DAILY OVERVIEW

SUNDAY, AUGUST 23, 2026

15:00-21:30 INFORM Meeting Part I (registration at INFORM – limited places, venue Hilton Helsinki Kalastajatorppa, NOT Messukeskus)

MONDAY, AUGUST 24, 2026

8:00-17:30 INFORM Meeting Part II (registration at INFORM – limited places, venue Hilton Helsinki Kalastajatorppa, NOT Messukeskus)

	101ab	101c	101d	102	203a	208	209	210	211	212	213	214	215	216
8:00								8:00-18:00						
8:30								UCD						
9:00								Guideline						
9:30								group						
10:00								meeting (*)		10:00-12:00				
10:30										eHOD (*)				
11:00														
11:30														
12:00				12:00-14:00										
12:30				Recon4IMD										
13:00				(*)										
13:30	13:00-16:00		13:00-15:00											
14:00	SSiEM		eHOD (*)											
14:30	Dietitians'	14:00-16:00												
15:00	Group	MetabERN												
15:30	Academy	plenary												
16:00	Review	meeting (*)												
16:30					16:00-18:00	16:00-18:00			16:00-18:00		16:00-18:00	16:00-18:00	16:00-18:00	16:00-18:00
16:30					MetabERN/	MetabERN/			MetabERN/		MetabERN/	MetabERN/	SSiEM	MetabERN/
17:00					C-FAO (*)	LSD SNW (*)	16:30-20:30		PD SNW (*)		PM-MD (*)	NOMS (*)	Council	AOA SNW (*)
17:30							Board						meeting (*)	
18:00							meeting (*)							
18:30														
19:00														
19:30														
20:00														
20:30														

(*) = by invitation only



TUESDAY, AUGUST 25, 2026

	HALL 1	HALL 5A	HALL 5B	HALL 5C	101ab	101c	101d	102	208	209	210	214	
8:00			8:15-9:15 Introductory session by the local organizing committee								8:00-12:00 UCD Guideline group meeting (*)		
8:30	8:30-10:35 SSIEM Dietitians' Group (DG): Nutrition and Dietetics session	8:30-10:35 SSIEM Adult Metabolic Physicians' Group: Tailoring and discontinuation of therapy in adulthood				9:00-10:30 ERNDIM Workshop (*)	9:00-10:30 ERNDIM Workshop (*)	9:00-10:30 ERNDIM Workshop (*)	9:00-10:30 ERNDIM Workshop (*)	9:00-10:30 ERNDIM Workshop (*)			9:00-13:00 JIMD Editorial Board Meeting (*)
9:00													
9:30													
10:00													
10:30				10:30-11:00 COFFEE									
11:00	11:00-12:00 SSIEM DG & AMPG: Relaxation of PKU treatment in adulthood					11:00-12:45 ERNDIM Open meeting							
11:30													
12:00													
12:30			12:30-14:00 LUNCH				12:35-13:45 SSIEM Adult Metabolic Physicians' Group business meeting	12:30-14:00 LUNCH					
13:00		12:45-13:45 Satellite meetings by the sponsors											
13:30													
14:00	14:00-14:10 Opening of the Symposium												
14:30	14:10-14:40 Opening Lecture												
15:00	14:40-15:40 Plenary I The Foeto-Maternal Unit and Inborn Errors of Metabolism (IEM)												
15:30				15:40-16:15 COFFEE									
16:00	16:15-17:45 Parallel session A1: Dietetics and nutrition	16:15 - 17:45 Parallel session A4: Gene and innovative therapies	16:15-17:45 Parallel session A3: Mitochondrial disorders	16:15-17:45 Parallel session A2: Protein modification disorders including CDG		16:00-17:45 SSIEM, MetabERN and ISNS session on Newborn screening (**)							
16:30													
17:00													
17:30													
18:00	17:50-18:30 Garrod Lecture												
18:30													
19:00													
19:30		19:30-20:30 YSSIEM Inaugural Meeting			18:30-20:30 Welcome Reception, Posters								
20:00													
20:30													
21:00													

(*) = by invitation only

- = Plenary Session
- = Side & Administrative Meetings
- = Parallel Session
- = New Formats
- = Posters
- = Satellite Symposia by sponsors
- = Networking

WEDNESDAY, AUGUST 26, 2026

	HALL 1	HALL 5A	HALL 5B	HALL 5C	10lab	10lc	10ld	102	104	203b	208	
7:30						7:30-8:30 Speed Mentoring						
8:00		7:30-8:30 Satellite meetings by the sponsors 2									8:00-8:30 Lab Talk	
8:30												
9:00	8:45-10:15 "From presentation to diagnosis: a case- based education session with the SSIEM Educational and Training (ETAC) Academy"	8:45-10:15 Parallel session B1: Fatty acid oxidation and related disorders	8:45-10:15 Parallel session B2: Clinical studies and real world data	8:45-10:15 Parallel session B3: Newborn screening								
9:30												
10:00				10:00-10:40 COFFEE + COFFEE WITH JIMD EDITORS								
10:30							10:30-14:00 Patient advocacy group (PAG) session: Making PAG work sustainable					
11:00	10:40-12:15 Plenary 2 - New Diseases and Mechanisms											
11:30												
12:00				12:20-12:50 SSIEM Advisory Council & Coun- cil meeting (*)						12:00-14:00 Drug Repurposing consortium meeting		
12:30					12:15-14:15 LUNCH							
13:00				13:00-14:00 SSIEM Annual General Meeting (AGM) (SSIEM members only)								
13:30												
14:00	14:15-15:45 Parallel session C2: New methods	14:15-15:45 Parallel session C1: Disorders of vitamins and cofactors	14:00-16:00 Ensuring Patient Access to Inno- vation in Rare Diseases (details to follow)	14:00-16:00 SSIEM Dietitians' Group internal meeting								
14:30												
15:00					15:00-16:00 COFFEE							
15:30												
16:00	16:00-17:30 Plenary 3 - Physics and Mathematics Enter the World of IEM											
16:30												
17:00												
17:30			17:30-18:30 Poster Walk									
18:00												
18:30		18:30-19:30 Satellite meetings by the sponsors 3	18:30-19:30 Satellite meetings by the sponsors 4	18:30-19:30 Satellite meetings by the sponsors 5						18:00-20:00 GalNet meeting		
19:00												
19:30												
20:00												
20:30												

(*) = by invitation only

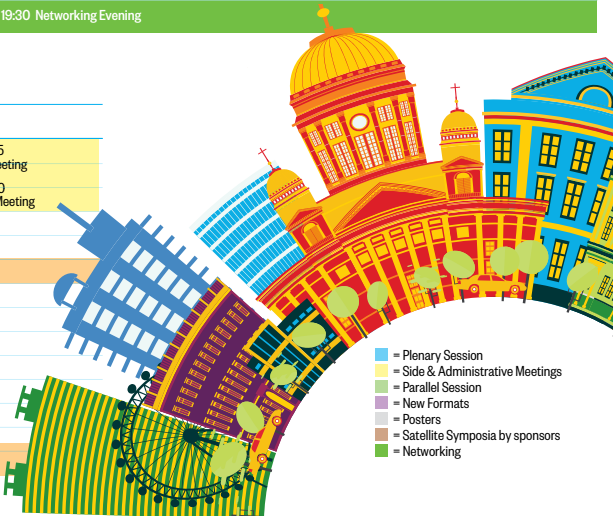
- = Plenary Session
- = Side & Administrative Meetings
- = Parallel Session
- = New Formats
- = Posters
- = Satellite Symposia by sponsors
- = Networking

THURSDAY, AUGUST 27, 2026

	HALL 1	HALL 5A	HALL 5B	HALL 5C	101ab	101c	101d	102	104	203B	208	210
7:00									7:00-8:00 eHOD CBS guidelines group (*)			
7:30		7:30-8:30 Satellite meetings by the sponsors	7:30-8:30 Satellite meetings by the sponsors	7:30-8:30 Satellite meetings by the sponsors	7:30-8:30 Satellite meetings by the sponsors	7:30-8:30 Speed Mentoring 2						
8:00											8:30-9:00 LAB Talk	
8:30												
9:00	9:00-10:30 Plenary 4 - OMICS data help us understand pathology in metabolic pathways											
9:30												
10:00												
10:30						10:30-11:00 COFFEE						
11:00	11:00-12:30 Parallel session D1: Lysosomal disorders	11:00-12:30 Parallel session D4: Organic acidurias	11:00-12:30 Parallel session D3: Neurometa- bolic disorders	11:00-12:30 Parallel session D2: Nurses' and allied healthcare professionals' meeting					11:15-12:15 JIMD Editors meeting (*)			
11:30												
12:00												
12:30						12:30-13:30 LUNCH						
13:00												
13:30	13:30-15:00 Plenary 5 - Mitochondria Now and Forever											
14:00												
14:30												
15:00						15:00-15:30 COFFEE						
15:30	15:30-17:00 Parallel session E1: Phenylke- tonuria	15:30-17:00 Parallel session E3: Carbohydrate disorders	15:30-17:00 Parallel session E2: Urea cycle disorders	15:30-17:00 Training in IEM: A roundtable discussion (paed/adult clin, clin lab, diet, nursing)								
16:00												
16:30												
17:00		17:00-18:00 Poster viewing										
17:30												
18:00												
18:30												
19:00												
19:30	19:30 Networking Evening											

FRIDAY, AUGUST 28, 2026

	HALL 1	104
7:30		7:30-8:15 ICIEM IOC Meeting
8:00		8:15-9:00 ICIEM SciOrg Meeting
8:30		
9:00	9:00-10:00 Late-Breaking News: 4 talks	
9:30		
10:00	10:00-10:30 COFFEE	
10:30	10:30-12:00 Plenary 6 - Looking Forward	
11:00	12:00-12:45 Komrower lecture	
11:30	12:45-13:00	
12:00	Awards Ceremony (LBN, posters)	
12:30	13:00-13:45 Closing remarks	
13:00		
13:30		
14:00	13:45-14:15 LUNCH	



- Plenary Session
- Side & Administrative Meetings
- Parallel Session
- New Formats
- Posters
- Satellite Symposia by sponsors
- Networking

SCIENTIFIC PROGRAMME

SUNDAY 23 AUGUST

- 15:00 - 21:30** **INFORM Meeting Part I**
(registration at INFORM – limited places, venue Hilton Helsinki Kalastajatorppa, NOT Messukeskus)

MONDAY 24 AUGUST

- 08:00 - 17:30** **INFORM Meeting Part II**
(registration at INFORM – limited places, venue Hilton Helsinki Kalastajatorppa, NOT Messukeskus)
- 08:00 - 18:00** **UCD Guideline group meeting**
(by invitation only)
- 10:00 - 12:00** **eHOD**
(by invitation only)
- 12:00 - 14:00** **Recon4IMD**
(by invitation only)
- 13:00 - 15:00** **eHOD**
(by invitation only)
- 13:00 - 16:00** **SSIEM Dietitians' Group Academy Review: addressing dietetic challenges**
(open to all)
- 14:00 - 16:00** **MetabERN plenary meeting**
(by invitation only)
- 16:00 - 18:00** **SSIEM Council meeting**
(by invitation only)
- 16:00 - 18:00** **MetabERN meetings**
(by invitation only)
- MetabERN LSD SNW
 - MetabERN AOA SNW
 - MetabERN NOMS
 - MetabERN PM-MD
 - MetabERN PD SNW
 - MetabERN C-FAO SNW
- 16:30 - 20:30** **ERNDIM Board meeting**
(by invitation only)

TUESDAY 25 AUGUST

- 08:00 - 12:00** **UCD Guideline group meeting**
(by invitation only)

- 08:15 - 09:15** **Introductory session by the local organizing committee:**
Brief talks on clinic, lab and diet for those who are new to the field and to the SSIEM (open to all)
- 08:30 - 10:35** **SSIEM Dietitians' Group (DG): Nutrition and Dietetics session**
(open to all)
- 08:30 - 10:35** **SSIEM Adult Metabolic Physicians' Group (AMPG):**
Tailoring and discontinuation of therapy in adulthood
(open to all)
- 09:00 - 10:30** **ERNDIM Workshops**
(by invitation only)
- 09:00 - 13:00** **JIMD Editorial Board Meeting**
(by invitation only)
- 11:00 - 12:00** **SSIEM DG & AMPG:**
Relaxation of PKU treatment in adulthood
- 11:00 - 12:45** **ERNDIM Open meeting**
- 12:15 - 13:45** **SSIEM Adult Metabolic Physicians' Group business meeting**
(SSIEM AMPG members only)
- 12:45 - 13:45** **Satellite meetings by the sponsors**
- 14:00 - 14:10** **Opening of the Symposium**
- 14:10 - 14:40** **Opening Plenary Lecture: From the zygote to a person: genes, epigenetics, environment, and chance**
Juha Kere (Sweden)
- 14:40 - 15:40** **Plenary 1 - The Foeto-Maternal Unit and Inborn Errors of Metabolism (IEM)**
- Prenatal Therapies for IEM
Tippi McKenzie (United States)
 - Managing Pregnancy in Inherited Metabolic Disorders: A Dietary Approach
Charlotte Ellerton (United Kingdom)
- 16:00 - 17:45** **SSIEM, MetabERN and ISNS session on Newborn screening**
(open to all)
- 16:15 - 17:45** **Parallel sessions A**
- A1: Dietetics and nutrition
 - A2: Protein modification disorders including CDG
 - A3: Mitochondrial disorders
 - A4: Gene and innovative therapies
- 17:50 - 18:30** **Garrod Award Lecture**
Andrew Morris (United Kingdom)
- 18:30 - 21:00** **Welcome Reception, Posters**
- 19:30 - 20:30** **YSSIEM (Young SSIEM) Inaugural Meeting**
(open to all)

WEDNESDAY 26 AUGUST

07:30 - 08:30 **Speed Mentoring**
(details to follow)

07:30 - 08:30 **Satellite meetings by the sponsors**

08:00 - 08:30 **Lab Talk by Philippa Mills** (United Kingdom)

08:45 - 10:15 **From presentation to diagnosis: a case-based education session with the SSIEM Educational and Training (ETAC) Academy**

08:45 - 10:15 **Parallel sessions B**

- B1: Fatty acid oxidation and related disorders
- B2: Clinical studies and real world data
- B3: Newborn screening

10:30 - 14:00 **Patient advocacy group (PAG) session: Making PAG work sustainable**

10:40 - 12:15 **Plenary 2 - New Diseases and Mechanisms**

- What have we learned from the undiagnosed disease program?
William Gahl (United States)
- Niemann-Pick Disease Type C: From Molecular Pathways to Therapeutic Impact
Frances Platt (United Kingdom)
- From Curiosity to Mechanism: Discovering a Ribosomopathy in Cobalamin Deficiency
Annita Achilleos (Cyprus)

12:00 - 14:00 **Drug Repurposing consortium meeting**

12:20 - 13:00 **ICIEM Organising Committee**

12:20 - 12:50 **SSIEM Advisory Council & Council meeting**
(by invitation only)

13:00 - 14:00 **SSIEM Annual General Meeting (AGM)**
(SSIEM members only)

14:00 - 16:00 **SSIEM Dietitians' Group internal meeting**
(SSIEM DG members only)

14:00 - 16:00 **Ensuring Patient Access to Innovation in Rare Diseases**
(details to follow)

14:15 - 15:45 **Parallel abstract sessions C**

- C1: Disorders of vitamins and cofactors
- C2: New methods

16:00 - 17:30 **Plenary 3 - Physics and Mathematics Enter the World of IEM**

- Metabolism Through the Lens of Physics: Transduction Gears, Regulation, and Metabolic Resilience
Massimiliano Esposito (Luxembourg)
- Membrane biology, chemistry and physics (title tbc)
Andre Nadler (Germany)
- Digital Metabolic Twins and Inherited Metabolic Diseases
Ines Thiele (Ireland)

17:30 - 18:30 **Poster Walk**

- 18:00 - 20:00 GalNet meeting**
(by invitation only)
- 18:30 - 19:30 Satellite meetings by the sponsors**

THURSDAY 27 AUGUST

- 07:00 - 8:00 EHOD – CBS guidelines group**
(by invitation only)
- 07:30 - 08:30 Speed Mentoring**
(details to follow)
- 07:30 - 08:30 Satellite meetings by the sponsors**
- 08:30 - 09:00 LAB Talk by Sean Froese (Switzerland)**
- 09:00 - 10:30 Plenary 4 - OMICS data help us understand pathology in metabolic pathways**
- Metabolomics and glycoproteomics to understand sugar metabolism
Dirk Lefeber (Netherlands)
 - Bileomics – Uncovering New Pathways in Health and Disease
William Griffiths (United Kingdom)
 - Global metabolomics and lipidomics implemented in routine diagnostics - examples of added value for unsolved cases
Katja Elgstoen (Norway)
- 11:00 - 12:30 Parallel abstract sessions D**
- D1: Lysosomal disorders
 - D2: Nurses' and allied healthcare professionals' meeting
 - D3: Neurometabolic disorders
 - D4: Organic acidurias
- 11:15 - 12:15 JIMD Editors meeting**
(by invitation only)
- 13:30 - 15:00 Plenary 5 - Mitochondria Now and Forever**
- Integrating Multi-Omics to Define Mitochondrial Homeostasis
Patrick Forny (United States)
 - Mitochondrial Insights into Fatty Acid Oxidation Disorders
Rikke Olsen (Denmark)
 - Metabolic keys to unlock mechanisms in mitochondrial diseases
Anu Suomalainen (Finland)
- 15:30 - 17:00 Training in IEM: A roundtable discussion**
(details to follow)
(paed/adult clin, clin lab, diet, nursing)
- 15:30 - 17:00 Parallel abstract sessions E**
- E1: Phenylketonuria
 - E2: Urea cycle disorders
 - E3: Carbohydrate disorders
- 17:00 - 18:00 Poster viewing**



FRIDAY 28 AUGUST

07:30-08:15 ICIEM IOC Meeting

08:15-09:00 ICIEM SciOrg Meeting

09:00 - 10:00 Late-Breaking News: 4 talks

10:30 - 12:00 **Plenary 6 - Looking Forward**

- Metabolic gene regulation - from molecular mechanism to physiological outcomes
Ville Hietakangas (Finland)
- Through the looking-glass; Congenital Disorders of Glycosylation
Eva Morava (United States)
- Nutrition for Precision Health (title tbc)
Holly Nicastro (United States)

12:00 - 12:45 **Komrower Lecture**

- Protein, Pathways and Personalised Nutrition
Marjorie Dixon (United Kingdom)

12:45 - 13:00 Awards Ceremony (LBN, posters)

13:00 Closing remarks



PLENARY SPEAKERS

Annita Achilleos, Nicosia, Cyprus

Marjorie Dixon, London, United Kingdom

Charlotte Ellerton, London, United Kingdom

Massimiliano Esposito, Luxembourg

Patrick Forny, St Louis, United States

William Gahl, Bethesda, United States

William Griffiths, Swansea, United Kingdom

Ville Hietakangas, Helsinki, Finland

Juha Kere, Stockholm, Sweden

Dirk Lefeber, Nijmegen, Netherlands

Tippi MacKenzie, San Francisco, United States

Eva Morava, New York, United States

Andrew Morris, Manchester, United Kingdom

Andre Nadler, Dresden, Germany

Holly Nicastro, Bethesda, United States

Rikke Olsen, Aarhus, Denmark

Frances Platt, Oxford, United Kingdom

Katja Prestø Elgstøen, Oslo, Norway

Anu Suomalainen, Helsinki, Finland

Ines Thiele, Galway, Ireland



INFORMATION ON SESSIONS

SPEED MENTORING

Speed Mentoring Sessions provide young professionals in IEM a unique chance to have one-on-one discussions with experienced researchers, clinicians and nutritionists from various specialties. In these 7-minute individual interviews with different mentors, participants can gain valuable advice on career planning, navigating career transitions and promotions, handling challenging work situations, and more. This event offers a supportive professional environment for attendees to interact with mentors who have diverse scientific backgrounds.

Key Facts

Where	Messukeskus
When	Wednesday, August 26, 2026 , from 7:30 AM to 8:30 AM Thursday, August 27, 2026, from 7:30 AM to 8:30 AM
How	Rolling system with different mentors
Who	Clinicians, scientists and laboratory specialists in training
Registration	Online

COFFEE WITH THE EDITORS

In Finland we say: "Let's go for a coffee!" which means Let's talk! This is your possibility to interact directly with the JIMD Editorial team. This will be an informal coffee moment, designed to foster a more personal and collaborative atmosphere, encouraging open dialogue and the exchange of ideas. And you get your coffee as well.

Key Facts

Where	Messukeskus
When	Wednesday, August 26, 2026 from 10:00 AM to 10:40 AM
Who	All participants

SPECIAL DISCUSSION MEETINGS

SSIEM, MetabERN and ISNS organize a joint meeting on newborn screening. The agenda is currently being finalized and will appear on the net soon.

The second special discussion meeting deals with patient access to new advanced and innovative medical therapies. We have a fantastic group of researchers, administrators, patient representatives and clinicians discussing how to make changes that will help more patients with an IEM to benefit from these advances.

The third meeting deals with training in IEM. We hear views from different countries and different HCPs (e.g., nurses, dietitians, lab scientists, clinicians).

And last but very importantly, we are hosting the inaugural meeting of the Young SSIEM (YSSIEM). Remembering our theme, we hope that the younger members of the SSIEM will form a group that will grow to become extremely useful and helpful to our society like the Dietitians' and the Adult Metabolic Physicians' groups have done. You do not have to be a member of the SSIEM to join this event, and we encourage all of you at some stage of training to attend. More details will appear later!

NETWORKING PROGRAMME

WELCOME RECEPTION

Tuesday, 25 August

18:30 - 21:00

The Welcome Reception offers a unique opportunity to connect with fellow attendees, speakers, and sponsors. This opening gathering serves as a catalyst for meaningful conversations, fostering new relationships and paving the way for potential collaborations. The exchange of ideas during this time can enrich your event experience and create lasting connections that continue well beyond the event itself.

We are delighted to invite you to join us for a welcome cocktail, a gift from the City of Helsinki, designed to set a warm and inviting tone for the days ahead. This special evening promises an atmosphere of camaraderie and inspiration, marking the perfect start to an engaging event.

POSTER WALK

Wednesday, 26 August

17:30 - 18:30

Posters will be available for viewing throughout the Symposium. We are asking the presenters to be near their poster during the Poster Walk to answer your questions. This offers an unrivalled platform for the exchange of cutting-edge research and ideas. By interacting with the diverse range of posters, you will have the opportunity to explore emerging trends, new methodologies and ground-breaking discoveries, broadening your intellectual horizons.

The Poster Walk provides a unique opportunity to engage with innovative research and fresh perspectives. As you interact with the poster presenters, you will discover emerging trends, explore advanced methodologies, and gain insight into significant new discoveries. This experience is designed to expand your knowledge and inspire meaningful intellectual growth.

NETWORKING PROGRAMME

YOUNG INVESTIGATORS EVENING (YSSIEM)

Wednesday, 26 August

20:00 - 22:00

Continuing from Tuesday's meeting this networking event gives you a chance to meet your peers in a relaxed atmosphere. Young scientists and professionals from every discipline within SSIEM, as well as those who appreciate engaging with emerging members, are warmly invited to attend the Young Investigator Evening. This special event is designed to encourage meaningful connections and promote the exchange of innovative ideas among participants. While there is no age restriction and all are welcome, the central purpose of this unique networking opportunity is to empower and support the next generation of SSIEM members, fostering their growth within the community.

NETWORKING EVENING

Thursday, 27 August

19:30 - 23:00

EUR 45,00 for delegates

EUR 90,00 for industry participants and accompanying persons

As the event draws to a close, we warmly invite you to join us for a memorable closing dinner. This special occasion is designed to celebrate the accomplishments, partnerships, and meaningful discoveries that have emerged throughout our time together. Your participation enhances the sense of collective pride and unity, making this evening a fitting tribute to all that we have achieved as a community.

The event takes place in the famous Finlandia Hall that has been recently renovated. In addition to networking, enjoying Finnish food and dancing the night away, you can also visit the special exhibition on Finnish culture, nature and design at any time you like during the evening.



GENERAL INFORMATION

SYMPOSIUM DATES

24 – 28 August 2026

WEBSITE

www.ssiem2026.org

SYMPOSIUM VENUE

Messukeskus

Messuaukio 1 (Main Entrance)

00520 Helsinki, Finland

SYMPOSIUM PRESIDENT

Dr. Risto Lapatto

Helsinki University Hospital – HUS

PROFESSIONAL CONGRESS ORGANISER

Confedent International Ltd

+358 50 4644757

ssiem2026@confedent.fi

www.confedent.fi

EXHIBITION MANAGEMENT AND SPONSORING

Society for the Study of Inborn Errors of Metabolism (SSIEM)

Ralph Kerschbaumer – Corporate Liaison Officer

PO Box 3375, South Croydon, CR2 1PN

United Kingdom

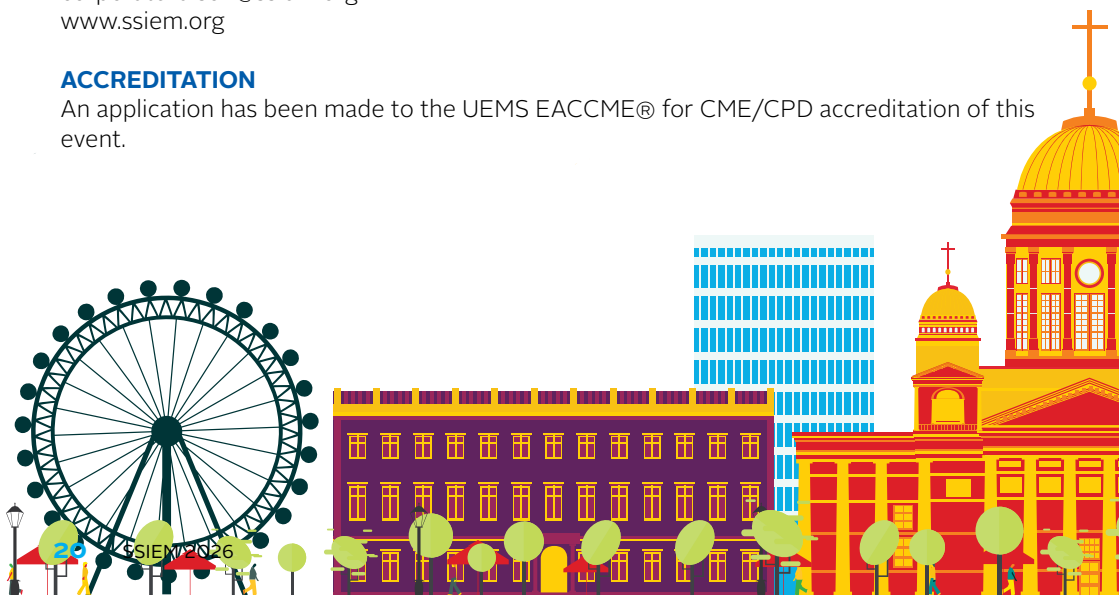
phone +43 512 890438

corporateliasion@ssiem.org

www.ssiem.org

ACCREDITATION

An application has been made to the UEMS EACCME® for CME/CPD accreditation of this event.



GENERAL INFORMATION

ARRIVAL

Arrive early to the Symposium venue to pick up your badge and Symposium material. Our registration desk will open on Monday 24 August.

BADGE

All participants must collect a name badge from the registration desk at the Symposium venue's main entrance.

To ensure security, wearing the badge is mandatory throughout the event, including at Networking events.

CLOAKROOM

There is a cloakroom available during the Symposium.

WIFI

WiFi service will be available during the Symposium.

REGISTRATION DESK OPENING HOURS

Monday	12:00 - 19:00
Tuesday	08:00 - 19:00
Wednesday	08:00 - 19:00
Thursday	08:00 - 16:00
Friday	08:00 - 14:00

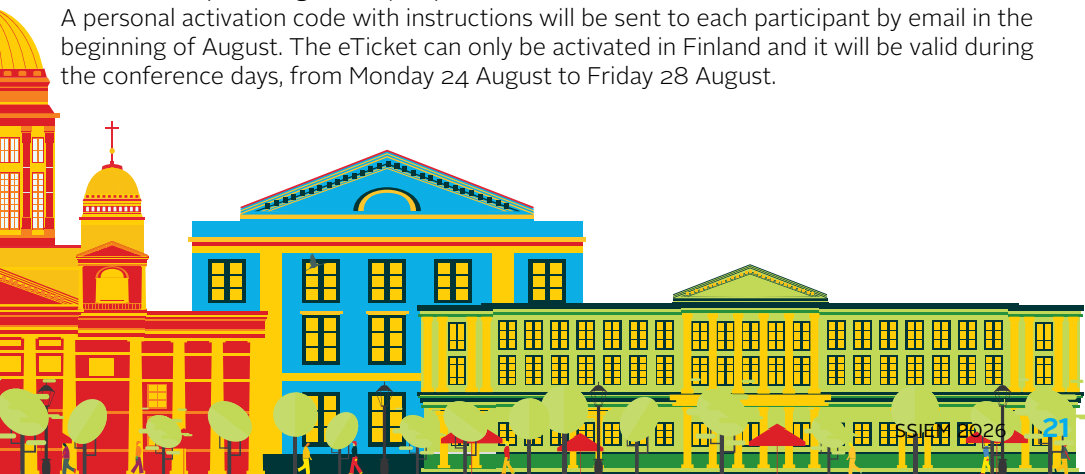
EXHIBITION HOURS

Tuesday	12:00 - 18:00
Wednesday	08:30 - 17:30
Thursday	08:30 - 15:30
Friday	09:00 - 13:00

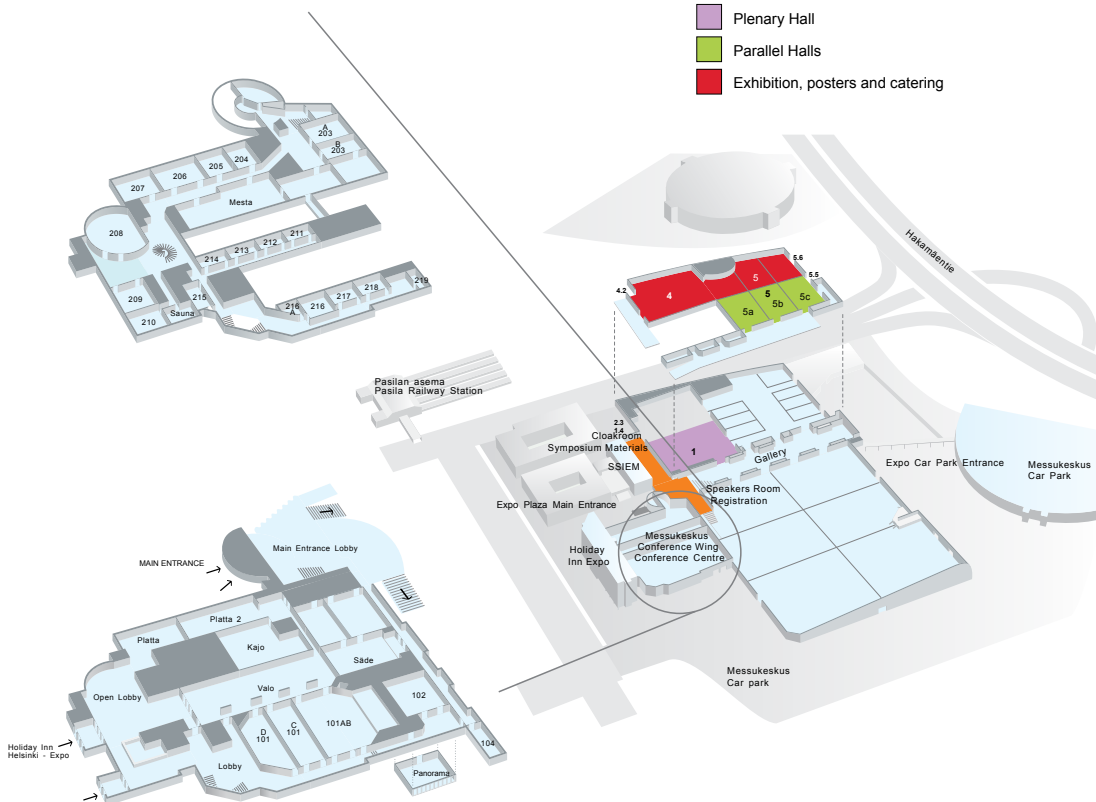
TRAVEL

All registered delegates will get a free 5-day eTicket for all public transportation in the Helsinki area (including the Airport).

A personal activation code with instructions will be sent to each participant by email in the beginning of August. The eTicket can only be activated in Finland and it will be valid during the conference days, from Monday 24 August to Friday 28 August.



- Entrance & Registration
- Plenary Hall
- Parallel Halls
- Exhibition, posters and catering



SYMPOSIUM REGISTRATION FEES

Registration Category	Early Bird until 23 June	Full Price from 24 June
SSIEM Member	250 €	400 €
Non-Member	650 €	800 €
SSIEM Member Student/Trainee**	100 €	250 €
Non-Member Student/Trainee**	350 €	500 €
SSIEM Member Dietitian/Nurse/Patient Group (Charities Employee)	100 €	250 €
Non-Member Dietitian/Nurse/Patient Group (Charities Employee)	350 €	500 €
SSIEM Member Single Day Ticket	75 €	155 €
Non-Members Single Day Ticket	200 €	300 €
Exhibitor registration only	250 €	250 €
Group registration fee (per person)	550 €	700 €

All registration fees are in Euro and include VAT 25,5%.

**Proof of being a Student or Trainee will be requested. Please note that working doctors with an MD are not eligible and research scientists with a PhD are not eligible for this category.

WHAT'S INCLUDED?

Full Delegate* fees

- Admission to all oral and poster sessions and exhibition area
- Scientific Programme and Symposium bag
- Access to the online abstract book
- Coffee, tea and 4 lunches during Symposium breaks
- Welcome Reception
- 5 day free travel pass for all public transportation (local trains, buses, trams and ferry to Suomenlinna Fortress Island) in Helsinki metropolitan area including the Helsinki-Vantaa Airport
- Official Attendance certificate.

*SSIEM Members, SSIEM Member Dietitians/Nurses/Patient Group (Charities Employee), SSIEM Member Students/Trainees, Non-Members, Non-Member Dietitians/Nurses/Patient Group (Charities Employee and Non-Member Students/Trainees, Group registrations.

Single-day Tickets

- Admission to all oral and poster sessions and exhibition area on the day of the ticket
- Scientific programme on the chosen day and Symposium bag
- Access to the online abstract book
- Coffee, tea and lunch during Symposium breaks of the day of the ticket.

Single day tickets do not allow access to social events. No more than two consecutive single day tickets can be purchased by one delegate.

NOTE! Students/Trainees will need to upload a letter from the Head of Department or a senior authority of their institution (on an official letter-headed paper) confirming their Student/Trainee status.

Exhibitor Registration Only

- Admission to the exhibition area
- Admission to industry symposia
- Coffee, tea and lunch during Symposium breaks
- Welcome Reception

Networking Evening and Social Programme are to be paid for additionally.

Participation in Networking Events

Activity	Participant	Accompanying person	Industry
Welcome Reception	Complimentary	Complimentary	Complimentary
Networking Evening	45 €	90 €	90 €

Travel

All registered delegates will get a free 5-day eTicket for all public transportation in the Helsinki area (including the Airport).
A personal activation code with instructions will be sent to each participant by email in the beginning of August. The eTicket can only be activated in Finland and it will be valid during the conference days, from Monday 24 August to Friday 28 August.



GET THE SSIEM 2026 MOBILE APP!

During the Symposium days, you can access features like:

- Scientific programme
- Networking events
- Satellite symposia
- Faculty list
- Abstract texts
- Create your own daily schedule
- Explore partner and exhibitor profiles
- Stay updated with the latest news
- Chat with other attendees

Instructions on how to upload the App will be sent to all registered participants in the beginning of August.

SPONSOR SECTION

SPONSORS LIST

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Bronze Sponsors



SATELLITE SYMPOSIA

SSIEM 2026 gratefully acknowledges the following companies for hosting symposia during the meeting.

TUESDAY, AUGUST 25TH, 2026

12.45-13.45



Ultragenyx

Hall 5A



Orchard Therapeutics

Hall 5B



BioMarin Pharmaceutical

Hall 5C



Takeda

101ab

WEDNESDAY, AUGUST 26TH, 2026

07.30-08.30



Chiesi Farmaceutici spa

Hall 5A



Mirum Pharmaceuticals

Hall 5B



Otsuka Pharmaceutical

Hall 5C



Sanofi

101ab

Wednesday, 26 August 2026

18:30–19:30 EEST

Floor 0, Hall 5C, Messukeskus Conference Centre, Helsinki, Finland

Reflecting on the Fabry journey to write the future of care



The Fabry story continues to evolve from advances that make headlines to the unmet needs still buried in the small print. Join our panel of expert faculty for an insightful symposium reflecting on the Fabry journey and exploring future chapters for people living with Fabry disease. **We look forward to seeing you.**

This session will explore:

- 1 Fabry in review:** progress to date and the unmet needs that remain
Professor Caroline Kistorp
- 2 Fabry today:** turning insights into action
Susanne Walls
- 3 Fabry today:** from diagnosis to treatment with clinical data and RWE
Dr Peter Nordbeck
- 4 Fabry futures:** shaping the next chapter in Fabry disease care together
All speakers

Meet our expert faculty:



**Professor
Caroline Kistorp**
Endocrinologist
Denmark



**Susanne
Walls**
Head Nurse
Finland



**Dr Peter
Nordbeck**
Cardiologist
Germany

RWE, real-world evidence

This satellite symposium has been funded and initiated by Amicus Therapeutics and is intended for healthcare professionals only. This is a promotional symposium, and product information will be discussed. A light meal will be available.

www.amicusrx.com

Com-NN-IN-26-00028-1 | June 2026

WEDNESDAY, AUGUST 26TH, 2026
18.30-19.30



PTC Therapeutics Hall 5A



Denali Therapeutics Hall 5B



Amicus Therapeutics Hall 5C

THURSDAY, AUGUST 27TH, 2026
07.30-08.30



Immedica Pharma AB Hall 5A



Chiesi Farmaceutici spa Hall 5B



Traverse Therapeutics Hall 5C



Takeda 101ab



Join our symposium to discover why **early intervention** and **normal Phe** (30-120 $\mu\text{mol/L}$) matter in adolescents with PKU

Tuesday, 25 August 2026

12:45-13:45 hrs | Hall 5-C (floor 0)

Complimentary lunch boxes
will be provided by SSIEM

The expert panel will provide insights into:

-  **Why adolescents are at critical window of intervention**
-  **How to optimise treatment outcomes for adolescents with PKU**
-  **Transforming care for adolescents: Real-world strategies**

Concluding with a fireside chat, leaning into lived experience of PKU

Faculty



**Ania C.
Muntau, MD**
Hamburg, Germany



**Erika
Vucko, APP**
Chicago, IL, USA



**Julia B.
Hennermann, MD**
Mainz, Germany



**Iris
Scala, MD**
Naples, Italy



**An individual
with PKU**

This symposium is intended for Healthcare Professionals only and will include information on BioMarin medicines. This symposium is organised and funded by

BOMARIN

90+ years of Chiesi

From handcrafted
beginnings to global
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and *quality* have always
been at our core.

Visit us at Booth *P03*

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ALL STAMPS FOR A
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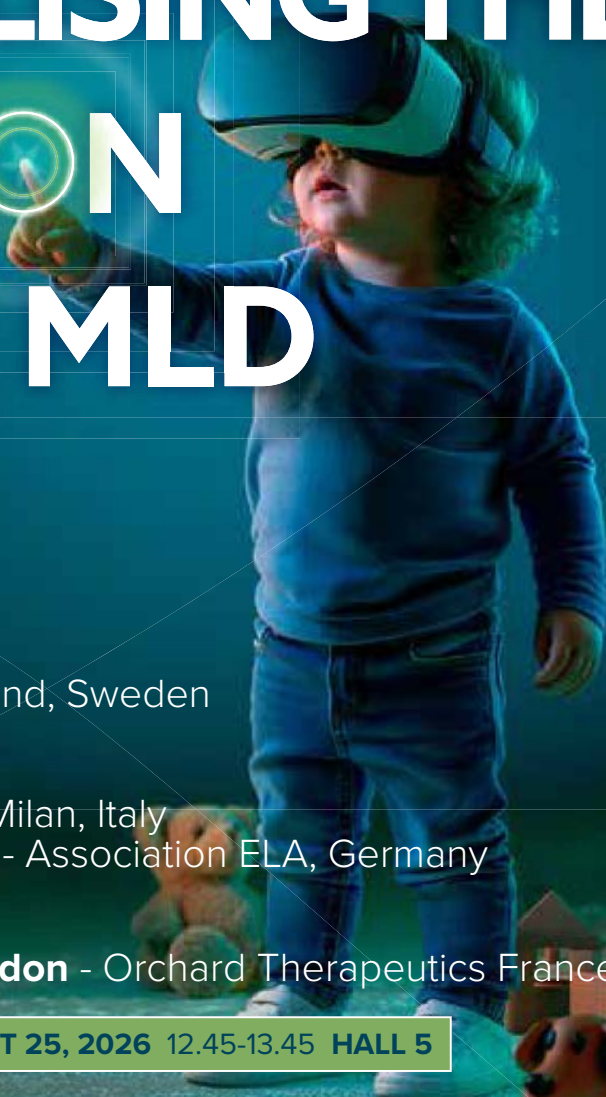
VISIT OUR
STAND
G03



Orchard Therapeutics

S A T E L L I T E S Y M P O S I U M

REALISING THE VISION FOR MLD



CHAIR & SPEAKER

Erik **Eklund** - Lund, Sweden

FEATURED SPEAKERS

Valeria **Calbi** - Milan, Italy

Michael **Scholz** - Association ELA, Germany

MODERATOR

Pascale **Vincendon** - Orchard Therapeutics France

THURSDAY, AUGUST 25, 2026 12.45-13.45 HALL 5

BOOTH: NUMBER G02

MESSUKESKUS HELSINKI,

EXPO AND CONVENTION CENTER

EM-NoP-2600024 - date of preparation June 2026

 AUTOLOGOUS
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 **Orchard**
therapeutics
A Kyowa Kirin Company

Sephience is indicated for the treatment of hyperphenylalaninaemia (HPA) in adult and paediatric patients with phenylketonuria (PKU).

This symposium is not intended for Finnish dietitians and nurses.

Sephience™: Evolving the Standard of Care for PKU¹

Lower Phe levels. Better outcomes. It's time to rethink what's possible in PKU care.^{1,2*}

Attend the Sephience symposium to hear leading PKU experts discuss the impact of Sephience in their clinical practice. Through real-world case studies and the latest data, the symposium will explore how achieving lower Phe levels may help support meaningful improvements in overall quality of life.²



Wednesday, 26 August 2026
18:30–19:30 EET
Hall 5A



DISCOVER MORE.

Visit our booth to discover what's possible for PKU patients in your clinic.¹

*In Part 2 of the AMPLIFY study, blood Phe reduction from baseline to Weeks 3–4 was significantly greater with sepiapterin than with sapropterin in the primary analysis set (LS mean difference, -180.4 µmol/L), corresponding to a 70% greater reduction.

LS=least squares; Phe=phenylalanine; PKU=phenylketonuria.

REFERENCES: 1. Gizewska M, Inwood A, Tyčová R, et al. Efficacy and safety of sepiapterin versus sapropterin in patients with phenylketonuria: results from the phase 3, randomized, crossover, open-label, active-controlled AMPLIFY trial. *Metabolism*. 2026;178:166513. 2. van Spronsen FJ, Peters H, Margvelashvili L, et al. Effect of long-term sepiapterin treatment on dietary phenylalanine tolerance in patients with phenylketonuria: interim results from the phase 3 APHENITY Extension Study. *Genet Med*. 2026;28(4):101683.



Actor portrayals.

Abbreviated Prescribing Information

Sephience 250 mg and 1000 mg oral powder in sachet. INDICATION: Sephience™ (active ingredient: sepiapterin) is indicated for the treatment of hyperphenylalaninaemia (HPA) in adult and paediatric patients with phenylketonuria (PKU). **POSLOGY AND ADMINISTRATION:** Treatment with Sephience must be initiated and supervised by a physician experienced in the treatment of PKU. Sephience should be administered orally once daily. The maximum recommended dose is 60 mg/kg/day. The recommended dose for patients aged 0 to < 6 months is 7.5 mg/kg/day, 6 to < 12 months is 15 mg/kg/day, 12 months to < 2 years is 30 mg/kg/day, and ≥ 2 years is 60 mg/kg/day. Sephience should be administered once daily with a meal, using mg/kg dosing. Sachets should be mixed in water, apple juice, or a small amount of soft food such as apple sauce and jams. Once mixed, the dose should be administered immediately. If not administered immediately, the liquid and soft food mixtures can be administered within 6 hours or 24 hours, when stored at room temperature (below 25 °C) or in a refrigerator (2 °C - 8 °C), respectively. Sephience oral powder may be administered via an enteral feeding tube 6 Fr or 8 Fr after mixing with water. For more details see full prescribing information. **CONTRAINDICATIONS:** Hypersensitivity to the active substance or to any of the excipients. **SPECIAL WARNINGS AND PRECAUTIONS FOR USE:** Patients treated with Sephience should undergo regular clinical assessments to align with their health care provider on appropriate dietary Phe intake (such as monitoring of blood Phe and tyrosine levels and nutritional intake). Co-administration of sepiapterin with DHFR inhibitors (e.g. trimethoprim, methotrexate, pemetrexed, pralatrexate, and trimetrexate) may require more frequent monitoring of blood Phe levels. Sephience 250 mg and Sephience 1000 mg oral powder, each sachet contains 400 mg and 1600 mg of isomalt, respectively. Patients with rare hereditary problems of fructose intolerance should not take this medicinal product. **INTERACTIONS:** Caution and more frequent monitoring of blood Phe are recommended when Sephience is co-administered with SR inhibitors, such as sulphasalazine or sulphamethoxazole. Inhibition of DHFR could potentially result in lower BH₄ concentration. Caution and more frequent monitoring of blood Phe are required in patients when sepiapterin is co-administered with a DHFR

inhibitor, such as trimethoprim, methotrexate, pemetrexed, pralatrexate, and trimetrexate. Caution is recommended during concomitant use of Sephience with medicinal products that cause vasodilation by affecting nitric oxide (NO) metabolism or action, including classical NO donors (e.g. glyceryl trinitrate [GTN], isosorbide dinitrate [ISDN], sodium nitroprusside [SNP], and molsidomin), phosphodiesterase type 5 (PDE 5) inhibitors (e.g. sildenafil, vardenafil, or tadalafil), and minoxidil. Caution should be exercised when prescribing Sephience to patients receiving treatment with levodopa to monitor neurological disorders such as exacerbation of convulsion, increased excitability and irritability, seizures, and exacerbation of seizures. **FERTILITY, PREGNANCY AND LACTATION:** No clinical studies on the effect on human fertility have been conducted for sepiapterin. As the data on pregnant women is limited, it is preferable to avoid the use of Sephience during pregnancy. It is unknown whether sepiapterin/metabolites are excreted in human milk. A risk to the newborns/infants cannot be excluded. A decision must be made whether to discontinue breast-feeding or to discontinue/abstain from Sephience therapy taking into account the benefit of breast-feeding for the child and the benefit of therapy for the woman. **EFFECTS ON ABILITY TO DRIVE AND USE MACHINES:** No or negligible influence on the ability to drive and use machines. **ADVERSE REACTIONS:** The frequency of adverse reactions was calculated based on pooled data from 2 pivotal clinical studies in patients with PKU (n=222): Very common (≥1/10): upper respiratory tract infection (19.8%), headache (15.3%), diarrhoea (14.9%), and abdominal pain (12.2%). Common (≥1/100 to <1/10): faeces discoloured (4.5%), and hypophenylalaninaemia (2.7%). Long-term safety data are limited. **MARKETING AUTHORISATION HOLDER:** PTC Therapeutics International Limited. **PACKAGES AND PRICING:** Not available in Finland: **CLASSIFICATION FOR SALE OR SUPPLY:** Prescription-only medicine. Please, always consult the SmPC before prescribing. **DATE OF PREPARATION:** June 2026.

▼ This medicine is subject to additional monitoring. Adverse events should be reported to PTC at pharmacovigilance@ptcbio.com.

Click here for the EU Summary of Product Characteristics for Sephience.



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June 2026, GL-SEP-0268

We invite you to a satellite symposium at SSIEM 2026

NOT ALL EVIDENCE IS EQUAL: INFORMING FABRY TREATMENT CHOICES



August 27, 2026
07:30–08:30 am
EEST



Room 101
Conference Centre (Kokoussiipi)
Helsinki, Finland



Prof. Sandro Feriozzi, MD
Nephrology Unit
University Campus Bio-Medico
Rome, Italy



Prof. Patrício Aguiar, MD, PhD
School of Medicine, University of
Lisbon, Reference Center for
Inherited Metabolic Disorders, ULS
Santa Maria, Portugal



Dr. Guillem Pintos Morell, MD, PhD
Vall d'Hebron Institute of Research
(VHIR), Vall d'Hebron Barcelona
Hospital Campus, Spain

JOIN US at this symposium where our experts will explore how real-world evidence and long-term registry data can inform Fabry disease management, including

- **long-term outcomes with agalsidase alfa**
- **key considerations in therapy selection**
- **meaningful endpoints**



**PROTECT EACH STEP,
FOR THE LONG-TERM**

This meeting is initiated, organized and funded by Takeda.
It is intended for an international HCP audience and might include promotional information.
Code: C-APROM/FI/REP/0040 | Date of preparation: June 2026.
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Join Us
at
SSIEM



SATELLITE SYMPOSIUM

Tuesday, 25th August / 12:45 - 13:45

Challenges and Opportunities in LC-FAOD and GSDIa Management

Symposium will use a case series to illustrate and highlight the challenges and opportunities in managing LC-FAOD and GSDIa



Ute Spiekerkötter, MD

Universitätsklinikum Freiburg, Germany



Sara Guillén Lopez, MS, RD, CSP

Instituto Nacional de Pediatría, Mexico City, Mexico



Malaya Mount, MS, RD, CND

Connecticut Children's Hospital, USA



Terry Derks, MD, PhD

UMC Groningen, Netherlands

Visit Our Booth

Learn about our programs
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We look forward to showcasing our latest clinical research and product innovation across our VitaFlo and Comidamed portfolios.

See you in Helsinki



Elämien parantaminen yhdessä

Enhancing Lives Together

Voices That Matter

Lived Experiences With CTX

26 August 2026

7:30 AM – 8:30 AM

Hall 5B

Learn About CTX

P. Barton Duell, MD

Oregon Health and Science University

Fireside Chat

Hear first-hand perspectives from
a patient and from a parent of two
children living with the condition

CTX, cerebrotendinous xanthomatosis.

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FI-NON-2600001; June 2026.





WeAre Making a *Rare* Difference

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