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Copenhagen – 2026
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– Copenhagen –

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This program is subject to change. Please find the latest version of the program and Bios for the speakers online at:
https://bit.ly/ESPKU2026

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Children's disclaimer

The children's participation in the program of the ESPKU conference is at their parents' risk and responsibility. The European Society for Phenylketonuria and allied disorders treated as Phenylketonuria (ESPKU) is in no way responsible or liable for any direct or indirect damages of any kind (including any physical or mental injury) incurred in relation to the participation or organization of activities and child care during the conference.

The parents and the guardians of the children and any other persons related to the organization or the child care of the event, hereby irrevocably and unconditionally waive any claims against the ESPKU to the extent permissible by applicable law. Representatives of ESPKU acting as guardians, custodians or in any other function for children who are involved in the program of the ESPKU conference are not responsible or liable for any kind of damages which incur during the event and no claims may be raised against any of these persons.

In addition, the parents of the attending children are required to confirm that they are not aware of any health problem or medical condition of their child which could make their participation risky or questionable. In case of a child's necessity of medical assistance, the parents are obligated to provide this assistance and to inform the guardians about the respective health problem or medical disorder, so that the safety of the child can be granted at each point in time during the conference.

In accordance to provide their children's participation in the ESPKU conference, the parents must sign an exclusion of liability and accept the conditions of participation when allowing their children to take part in the creche and childcare programme. Please contact the people at the registration desk.

Foreword by the ESPKU President

It is with great pleasure that I welcome you to the 40th Annual ESPKU Conference here in Copenhagen, Denmark at the Hangar Conference Centre, Copenhagen Airport.

This year we celebrate the 40th Anniversary of the ESPKU and hope to bring you some snap shots of prior conferences. Here are some important topics discussed from the very first Conference in Aalter Belgium:

1. The ideal blood levels of phenylalanine for adequate control
2. The most desirable age limits for strict dieting
3. The issue of whether children should ever be taken off diet
4. The role of breast feeding in feeding infants with PKU
5. The long-term problem of maternal PKU

Topics which are still discussed today. We would like to think we are closer to resolving them. Also note the first resolution passed by the ESPKU was to challenge the EU (EEC as it was then) about aspartame – hazardous to the treatment of PKU. This is why you see warnings signs on Chewing Gum and sugar free drinks today.

The last time we were in Copenhagen -2010 - I recall the Little Mermaid was on loan to the Chinese for an exhibition in Shanghai. However, I am glad to say she is back and you may wish to take a selfie/photo of her during your stay. There is much to see in Copenhagen – such as the Tivoli Gardens and the iconic waterfront.

Conference is a wonderful opportunity to highlight PKU throughout Denmark bring together the PKU Community to work in unison to help PKU patients have a stronger voice and better life outcomes. It is also a great occasion for the ESPKU to bring together its Member Organisations, Industry, Professionals and Patients under one roof and discuss all things PKU.

This year we have nearly 30 posters approved by our Scientific Advisory Board. I urge you all to take time to read them. There is plenty for everyone – Professionals, Patients, and Industry.

The ESPKU acknowledge the continued support from our Sponsors and supporters; PKU Denmark and help from the Hotel in putting the Conference together.

We all know the challenge of living with PKU, and the challenges ahead are many – but not unsurmountable. How we deal with these is dependent upon you. Together we can make a difference.

Eric Lange

President, European Society for Phenylketonuria & Allied disorders

"Ask not what PKU can do for you—ask what you can do for PKU!"

Jean Marie Criem

Foreword from the Chair of the Scientific Advisory Committee

It is a great pleasure to welcome you all to Copenhagen for the 40th Annual ESPKU Conference.

This year marks an important milestone: 40 years of ESPKU bringing together people with PKU and their families, healthcare professionals, researchers, patient organisations and industry partners from across the globe.

As Chair of the Scientific Advisory Committee, I am particularly delighted by the strength and breadth of this year's scientific programme. PKU care is entering an exciting period of change. New treatments, technologies and research are transforming what may be possible for people with PKU, while our understanding of the lifelong impact of the condition continues to develop.

Our programme reflects this evolution, with presentations spanning maternal PKU, neurocognitive and psychological health, menopause, ageing, gut microbiome, point-of-care testing, new treatments and the wider impact of living with PKU. I am especially pleased to see so many healthcare professionals attending and contributing to the meeting. Sharing experience across disciplines and countries is essential if we are to continue improving standards of care.

Scientific progress is most valuable when it translates into meaningful improvements in the lives of people with PKU. This requires researchers and healthcare professionals to work closely with people with PKU, their families and patient organisations, ensuring that our research continues to address the issues that matter most.

I would like to thank all our speakers and presenters, and everyone who has contributed to developing such an exciting programme. I also extend our thanks to PKU Denmark for welcoming us to Copenhagen and to all those who have worked so hard to make this conference possible.

I hope the meeting stimulates lively discussion, new collaborations and new ideas that will help shape the future of PKU research and care.

Welcome to Copenhagen, and I hope you have an inspiring and enjoyable conference.

Professor Francjan van Spronsen

On behalf of the Scientific Advisory Committee:

Professor Maria Giżewska. Dr Kirsten Ahring and Professor Anita MacDonald

Foreword by the Chair of PKU Denmark

As Chair of the PKU Association for Denmark, it is my great pleasure to welcome you to Copenhagen for the 40th anniversary of ESPKU. Hosting this milestone event and the largest ESPKU conference ever, is something our small Danish board is incredibly proud of.

This year, we have had the honour of shaping the family and patient programme and setting the overall theme: PKU in the family. PKU is a lifelong condition, and it follows us through every stage of life.

Throughout the weekend, you will find sessions reflecting this journey, from childhood and adolescence to adulthood and the +50 generation. Our hope is that the programme feels relevant, familiar and true to the everyday realities of living with PKU.

A heartfelt thank-you goes to our many volunteers. They will welcome you at registration, pack programmes, support your children, appear in film recordings, and contribute in countless ways behind the scenes. Their commitment and kindness are at the heart of this conference.

We also hope you will enjoy Copenhagen on Saturday afternoon before returning for the networking dinner at 19:00. A three-course meal will be served for all participants, and we look forward to an evening of shared experiences, conversation and entertainment.

On a personal note, I joined the Danish PKU Association in 2024 with the simple intention of helping organise cooking days and family activities. I never expected to become Chair, or to help host ESPKU 2026 just two years later. It has been overwhelming, exciting and deeply meaningful, and I am grateful to share this anniversary year with all of you.

Thank you for being here. We wish you an inspiring and memorable conference.

Louise Rømer

Chair, PKU Association of Denmark

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Programme – Friday

Common programme

The common programme will take place at the Hanger 4 and 5 at Comfort Hotel.

08:30	**Welcome:** PKU Denmark, Eric Lange, Prof. Dr Francjan J. Van Spronson	
09:00	**Common Programme, Chairs:** Prof. Dr Maria Gizewska, Prof. Dr Allan Lund	
09:00	**40 Years of ESPKU** Mr Jean Marie Criem, Frau Dr Ursula Wachtel, Tricia Rutherford	Eric Lange
09:30	**Experience with patients with maternal PKU**	Susan Waisbren
09:50	**Experience with PKU in Denmark**	Kirsten Ahring
10:10	**Gut microbiome and Brain**	Cathrine Rodriquez
10:30	**Maternal PKU and Child outcome: Can the Copenhagen team close the knowledge gap?**	Mette Ørngreen
10:50	**Discussion**	
11:00	**Coffee break**	

Patient and family - Purple

The patient and family programme will take place at the Hanger 4 and 5 at Comfort Hotel.

11:30	**The Unique Child** - **How PKU Affects the nervous system** - **Creating Calm and Structure in Everyday Life with a Child with PKU**
12:15	**Q&A**
12:30	**Life with PKU as a Child – Short Film** Amanda 8-year-old PKU'er, Magnus 12-year-old PKU'er
12:40	**Being a Parent to a Child with PKU** **Experiences, Challenges and Everyday Life** Sanne Hildebrandt Karlsen, Louise Rømer, The Unique Child
13:00	**Lunch**
14:00	**PKU and Adult Life: Finding Balance in Everyday Life** Signe Tomgren, Rasmus Odder
14:30	**Case Study: About Wrong Diagnosis** Signe Tomgren, Mette Ødegaard Nielsen
15:00	**Coffee Break**
15:30	**Bridging the Gap: Transitioning from Paediatric to Adult PKU care** Anna Wieland
15:50	**A Lifetime with PKU: Growing Older and Living Well - Short Film** Lis Lund, Kirsten Ahring
16:10	**Pushing Limits: Living, Training and Competing with PKU – Short Film** Marcus Sonne

16:30	**Panel:** Anna Wieland, Mette Ødegaard Nielsen, The Unique Child	
17:05	**Collaboration Between the Patient Organisations in Scandinavia** Louise Rømer	
17:20	**Making Life Easier with PKU – Short Film** Easy PKU App	
17:35	**Diet for Life** PKU Norway	
18:00	**Families Meet the Professionals**	
19:00	**Dinner**	

Delegates - Red

The delegates programme will take place in the Merlin room at Comfort Hotel.

11:30	**Registration**	
11:35	**Welcome, Meet & Greet**	
11:40	**Infographics – What's Next?**	
11:45	**Setting the Scene: Key Concepts and Meeting Objectives**	
12:00	**Workshops**	
12:45	**Presentation of Points from Group Discussions**	
13:00	**Lunch**	
14:00	**Discussion: Categorisation of Points into Care and Policy Categories; Prioritisation of Points Raised**	
15:30	**Coffee Break**	
16:00	**Discussion: Next Steps**	
16:45	**Brief Recess**	
17:00	**Industry Meets Delegates**	

Professionals - Blue

The professional programme will take place at Ellehammer 1 and 2 at Clarion Hotel.

11:30	**Chairs:** Prof. Dr Francian J. van Spronson	
11:30	**Case Series of Late-Treated Patients from Other Countries – The Story Repeats. Discussion of Ethical Issue**	Charlotte Lubout
11:50	**Verbal Discourse in PKU Patients – How Can It Help Us Understand Brain Dysfunction and Develop New Drugs for Patients?**	Susan Waisbren
12:10	**Cognitive Health: New Aspects in >40-Year-Olds**	Cristina Romani
12:30	**The Neurocognitive, Neuropsychological, Neurological and Psychiatric Outcome in French Adults**	Francois Maillot
12:50	**Discussion**	
13:00	**Lunch**	
14:00	**Invited Lectures and Free Orals:** Prof. Dr Anita MacDonald, Dr Mette Ørngreen	
14:00	**How to Test for Responsivity for Sepiapterin: What Have We Learned from the Sapropterin Studies?**	Francjan J. van Spronsen
14:35	**Lost After Transition: Dietary Disengagement, Metabolic Control and Neuropsychiatric Morbidity in Adults with Phenylketonuria**	Samreen Safdar

14:42	**Improved Efficacy with Sepiapterin in Participants with Phenylketonuria Receiving Sapropterin at Study Screening in AMPLIPHY**	Maria Gizewska
14:49	**Eating Disorders and Disordered Eating in PKU: A Systematic Review**	Sharon Evans
14:56	**High Prevalence of Caregiver-Reported Neurodivergent Traits in Children with Phenylketonuria**	Ann Daly
15:13	**Toward Personalized Treatment in Phenylketonuria: Intra-Individual Variation of In Vivo Phenylalanine Oxidation Using the 13C-Phenylalanine Breath Test**	Sietske Haitjema
15:20	**A Next Step for Personalised Treatment in Phenylketonuria: Intra-Individual Variation of In Vivo Phenylalanine Oxidation in Children Using the 13C-Phenylalanine Breath Test**	Ellis van Steenis
15:27	**Discussion**	
15:30	**Coffee Break**	
16:00	**Chairs:** Dr. Kirsten Ahring	
16:00	**Newborn Genetic Screening for PKU**	Asbjørg Stray-Pedersen
16:14	**Visualizing the Effect of Lifetime Phenylalanine on Neurocognition in Adult Phenylketonuria Patients**	Ellis van Steenis
16:28	**Gastrointestinal Symptoms Are Common in PKU but Under-Recognised in Routine Care**	Alex Pinto
16:42	**Adults with Phenylketonuria Experience Greater Cognitive and Executive Functioning Difficulties Than Healthy Adults Despite High Levels of Independence**	Alex Pinto
16:56	**Metabolomic Profiles in Adult Patients as Insight into Pathophysiological Pathways in Phenylketonuria**	Yannick Moutapam-Ngamby-Adriaasen
17:10	**The Invisible Burden of Phenylketonuria: A Qualitative Exploration of the Experienced Impact of Phenylketonuria Across Borders**	Sidra Jendo
17:24	**Beyond Phenylalanine: Phenylacetic Acid Improves Prediction of Multitasking Performance in Phenylketonuria Patients: An FDPD+ Databank Study**	Ellis van Steenis
17:28	**Sepiapterin Enables Liberalisation of Natural Protein Intake While Improving Metabolic Control in Adolescents with Phenylketonuria**	Anita MacDonald
17:42	**Discussion**	
18:00	**Patients Meet Professionals**	

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Programme – Saturday

Common program

The common programme will take place at Hanger 4 and 5 at Comfort Hotel.

09:00	**Chairs:** Prof. Dr Francjan J. van Spronson, Dr Mette Ørngreen	
09:00	**The Importance of Psychological Wellbeing in PKU**	Susan Waisbren
09:20	**Menopause and PKU:** **Overlapping Symptoms and Paths to Effective Care**	Jerzy Giżewski
09:40	**Comorbidities in PKU**	Péter Reismann
10:00	**Ageing in PKU: A Future Perspective**	John Bassatt
10:20	**Point-of-Care Testing for Phenylalanine:** **Are We There?**	Alex Pinto
10:40	**Coffee Break**	
11:10	**Chairs:** Prof. Dr Maria Gizewska , Prof. Dr Allan Lund	
11:10	**New Treatments: The Landscape**	Amaya Belanger
11:30	**Decide on Adult Targets: What Do We Need?**	Roman Trepp, Francjan J. van Spronsen
12:10	**Discussion**	
12:30	**Sheila Jones Awards and Closing Ceremony** Eric Lange	
13:00	**Lunch and End of ESPKU 2026**	
19:00	**Networking dinner – Sponsor by Nutricia**	

Hotel and food

The 2026 ESPKU conference is being held in collaboration with two hotels: Comfort Hotel and Clarion Hotel. Be aware, that the program includes areas of both hotels.

Breakfast will be served Friday through Sunday at your hotel's restaurant at their regular times. All other meals will be served at the Hanger at Comfort hotel.

Networking dinner

If you have purchased a ticket to the networking dinner, then be aware that there will be served a 3-course meal. It is therefore important to be at the Hanger at 19:00 Saturday, in your best party outfit.

Children's activities

To facilitate the best possible experience for both parents and children, young and old there will be a children's area in in the hanger behind the registration desk. There will be supervision and activities between 10:00 and 12:00, 14:00 and 16:00, and 18:00 and 19:00 Friday, as well as 09:00 and 13:00 Saturday.

While there aren't facilitated any activities at other times, children and parents are still welcome.

The hotel also has an area with a foosball table and table tennis available.

Youth breakout group

Friday between 14:30 and 15:00, there will be a youth breakout group, facilitated by The Unique Child and PKU Denmark. This breakout session will be more relevant to teens and young adults with PKU and better relate to their life situation. This breakout group is for 15- to 25-year-olds. Location t.b.a.

Posters

During ESPKU 2026 there will be posters with the most up to date research in the field of PKU. These posters can be found in the corridor between the Comfort and Clarion Hotels.

PKU Dictionary

First time at ESPKU? The conference explores the newest and most cutting edge in the world of PKU. Part of that journey is based on certain terms and words, that may be new to some. Below, you can find a brief overview of some of these terms.

BH4 (Tetrahydrobiopterin): A cofactor the PAH enzyme needs to function. Some patients are "BH4-responsive," meaning BH4 medication improves their remaining enzyme activity

Comorbidities: Health issues seen at higher rates in PKU populations, often in long-term outcome studies.

Dried Blood Spot: Traditional home Phe sampling: a drop of blood on filter paper, mailed to a lab.

Dietary treatment / low-protein diet: The cornerstone of PKU management

European PKU guidelines: Consensus treatment recommendations standardizing care across countries.

Gene therapy: Experimental approach to correct/replace the faulty PAH gene.

Hyperphenylalaninemia (HPA): The broader medical term for elevated blood phenylalanine; PKU is the most severe form.

LNAA (Large Neutral Amino Acids): Supplement strategy competing with Phe for brain uptake; mainly used in some adults alongside diet.

Maternal PKU: Risk to a developing fetus from high maternal Phe during pregnancy; strict control before/during pregnancy is critical.

Newborn screening: The heel-prick test given to newborns that detects PKU shortly after birth.

PAH (Phenylalanine Hydroxylase): The liver enzyme that normally converts phenylalanine into tyrosine.

Pegvaliase: Injectable enzyme substitution therapy for adults; allows a freer diet but needs careful dose escalation due to allergic-reaction risk.

Phe (Phenylalanine): An amino acid found in all natural protein (meat, dairy, eggs, grains). People with PKU must limit intake because their bodies can't process it normally.

Sapropterin: BH4-based medication (BioMarin) that boosts PAH activity in BH4-responsive patients.

Sepiapterin: Newer oral BH4-precursor drug, effective in a broader patient group than Sapropterin.

Tyrosine: The amino acid Phe would normally be converted into. Often given as a supplement.

Welcome to Denmark

The Danish culture can seem peculiar and complex, as we are generally open minded but also reserved, we are tolerant and friendly but also can come across selfish and rude to people unaccustomed to our nature. Here's a quick guide to navigating our habitat smoothly:

Sarcasm: Probably about 90% of our verbal expressions. Danes master targeted sarcasm and self-irony at Olympic athlete level. Especially millennials. This can be confusing but keep up and we're ready to crack a joke about that, too.

Personal space: Danes can be quite reserved and particular about their personal space, especially in public transportation or other public areas. If other seats are available, do not sit closely next to a stranger. It's not stranger danger; it is just respectful.

Safety: Denmark is overall a very safe country. Mind you there are pickpockets especially in the big cities (Danish scale), but we are unafraid to leave our babies and dogs outside stores and cafes, and this is considered normal, not negligent.

Icebreakers: If you feel comfortable starting a conversation with a stranger (this is not always advised in public, read *Personal Space), the weather is a safe choice. Danes love to talk about the weather, and we can always find something to complain about (not just regarding weather, this is another Danish talent) - it is probably too wet or too dry, too dark or too bright, too cold or too hot, too windy or too still. Please bear with us.

Coffee: Don't mess with our coffee.

We hope this does not scare you off, when you get to know us, we are quite lovely and hugging people.

Daylight saving time

Be aware that on Sunday the October 25th, parts of Europe and Denmark changes time due to daylight savings. Therefore, you must turn your clocks back one hour between Saturday and Sunday.

Danish dictionary

Good morning: Godmorgen

Hello: Goddag

Good evening: Godaften

Thank you: Tak

One/two coffee, please: En/to kaffe, tak

With/without milk: Med/uden mælk, tak

Which way?: Hvilken vej?

Excuse me: Undskyld mig

Protein: Protein

Nutritional contents: Næringsindhold

Contains phenylalanine: Indeholder phenylalaninkilde

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Transport

Transportation: We Danes prefer to walk or cycle anywhere, so there are bikes everywhere!

Around the Copenhagen airport there is plenty of public transport.

There are several different modes of transport in Denmark:

- Buses
- Regional / intercity train
- S-train
- Metro
- Light rail

When traveling to and around the airport where the ESPKU conference is being held, it is recommended that you either take a regional train or use the Metro, as these go directly to the airport.

If you want to explore the rest of Copenhagen, then taking the S-train or the Metro is recommended. The metro is typically best for city-centre traveling, while the S-train is better for traveling across the city, or to the outskirts of Copenhagen. Buses are also a good option for certain routes.

To find out which mode of transport best suits your route, you can use the local app ***Rejseplanen***, which specifically shows public transport routes. Otherwise, you can use Google Maps, which generally works well in Denmark for public transport.

Tickets

Please note, that there is a large ticket for traveling without a valid ticket.

For an easier public transport experience, it is recommended to use the app ***Rejsebillet***.

You can find tickets for public transport here:

Public Transport Tickets

https://bit.ly/PublicTransportTickets

Day-pass tickets

https://bit.ly/CityDayPass

Rejsebillet

https://bit.ly/Rejsebillet

Your notes

This section is dedicated to your learnings and experiences at this year's ESPKU conference.

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