

Friday programme*

Please note that from 10:30 on Friday the Programme will split into three separate programmes that will run concurrently for the rest of the day:
Scientific Programme | Patients' Programme | Delegates' Programme

The ESPKU Annual General Meeting
 The AGM will be held on Friday at 21:00

Common Programme

SPAZIO 3 & 4

08:45	WELCOME Anna Maria Marzenta , President COMETA ASMME Eric Lange , President, ESPKU Dr Luciano Flor , General Director of the Hospital of Padua Dr Domenica Taruscio , Director of the National Center for Rare Diseases of the Superior Institute of Sanità Prof F van Spronsen ESPKU Scientific Advisory Board
09:00	Chaired by Prof Maria Gizewska and Prof Alberto Burlina
09:05	Care for PKU in Italy: how does it work? Prof Alberto Burlina
09:20	Liver transplantation in MSUD and other metabolic diseases: can it be done for PKU? Dr René Santer
09:45	Discussion
10:15	COFFEE BREAK

Patients' Programme

SPAZIO 3 & 4

10:45	Moderator: Mrs Susan Mutter COMETA Board Member – all sessions
10:45	Italian Difficulties Of Living With PKU Giulia Zangrando, adult patient
11:15	How to grow up with PKU in Moldova – a non EU Country Dan-Cristian Usurelu
11:45	My path to the turning point Francesca Padoan, adult patient
12:15	Planning a new life with PKU Lisa Andreatta, adult patient
12:45	LUNCH
14:00	NSPKU Survey: The biggest ever survey in the world about PKU – completed by those living with PKU Suzanne Ford
14:30	PKU in school canteens: my experience between difficulties and achievements Eleonora Turco, parent
15:00	Growing up in Turkey with PKU Lal Atakay and Emine Kilinc
15:30	COFFEE BREAK – Exhibition area
16:00	PKU and research – story of a better life Giacomo Gaiga, adult patient
16:30	PKU & Me Nicolò Cardoselli (AMMeC Firenze) and Veronica Cassani (APMMC Milano)
17:00	The Vitaflò interactive cooking workshop with Chef Neil

Scientific Programme

SPAZIO 1 & 2 Professionals ONLY

10:30	Chaired by Prof Francjan van Spronsen and Prof Vincenzo Leuzzi
10:30	New diagnostic work-up for infants with a positive newborn screening for PKU Prof Nenad Blau
10:55	Phenylalanine measurement: can we do better? Prof Francjan J van Spronsen
11:20	Discussion
11:30	FREE ORALS
11:30	Living with Phenylketonuria in adulthood: the PKU-Attitude study Dr Alessandro Burlina
11:45	Prospective, longitudinal, controlled parallel study over 12 months comparing Glycomacropeptide and conventional amino acid protein substitutes in children: effect on blood phenylalanine, tyrosine, phenylalanine to tyrosine ratio and growth Anne Daly
12:00	LUNCH
13:00	Chaired by Kirsten Ahring and Prof Alberto Burlina
13:00	FREE ORALS
13:00	PKU adult women: what challenges do they encounter? Suzanne Ford
13:20	The extended tetrahydrobiopterin loading test (168 hours) in PKU patients, a Dutch pilot cohort-study Annemiek van Wegberg
13:35	Clinical characterization of tremor in patients with Phenylketonuria Dr Francesca Nardecchia
13:50	Is overweight an issue for PKU patients using long term BH4? Results from a 6-year follow up Prof Hülya Gökmen Özel
14:05	Getting off to the best start in PKU: time to stability in blood phenylalanine levels in the newborn Laura Guilder
14:20	Investigating psycho-social outcomes in adults with early-treated Phenylketonuria Lynne Aitkenhead
14:35	Arginine an anti-aggregation agent is a potential therapeutic for treatment Phenylketonuria associated with aggregated mutant PAH protein Michael Nafisinia
14:50	Correction of Phenylketonuria by Human Amnion Epithelial Stem Cell Therapy without Immunosuppression Dr Roberto Gramignoli
15:05	Food neophobia in patients with Phenylketonuria Dr Tássia Tonon
15:20	COFFEE BREAK – Exhibition area

Scientific Programme cont.

SPAZIO 1 & 2 Professionals ONLY

15:50	PKU patients and their brains chaired by Prof Anita MacDonald and Dr Alessandro Burlina
15:50	Adult PKU patients outcome: first results of study in France Francois Maillot
16:15	Different methods to test neuropsychological outcome in PKU patients Rianne Jahja
16:40	The elderly brain of PKU patients: what should be expected? Dr Andrea Pilotto
17:05	What is the real cause of PKU brain dysfunction? Danique van Vliet
17:30	Discussion
17:45	End of day

Delegates' Programme

ROOMS B & C Country Delegates ONLY

10:45	Welcome Eric Lange
10:50	What's been happening? Guideline implementation issues Tobias Hagedorn
11:15	Palestine Dr Akram Asfour
11:30	Transition – Swedish Model Malin Grande and Stephanie Juran, RD Sweden
12:15	Transition Workshop – White Paper discussion
12:45	LUNCH
14:00	Transition Workshop – White Paper discussion continued
14:45	Strategy for the future – including an EU All Party Parliamentary Group: Brainstorming
15:30	COFFEE BREAK – Exhibition area
16:00	Health Technology Assessment: Why payers are keen to use it. What is a disease model? What is discounting? Edmund Jessup, NHS, UK
17:00	Round up
21:00	AGM

SPAZIO 3 & 4

18:00	Informal – Patients meet professionals
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Saturday programme*

Common Programme

SPAZIO 3 & 4

08:45	Chaired by Prof Maria Gizewska and Prof Vincenzo Leuzzi
08:45	Parents' experiences of parenting an infant with PKU: Challenges and Solutions Dr Anja Wittkowski
09:10	Adult PKU patients Dr Alessandro Burlina
09:35	What is the neuropsychological outcome of our PKU adults? Christina Romani
10:00	The elderly brain of PKU patients: what should be expected? Dr Andrea Pilotto
10:30	COFFEE BREAK – Exhibition area
11:00	Chaired by Prof Francjan van Spronsen and Dr Alberto Burlina
11:00	PKU and sports Dr Julio Rocha
11:20	PKU: effects of GMP Anne Daly
11:40	Are there already changes by the Guidelines and are there topics the guidelines have not answered ? Annemiek van Wegberg and Tobias Hagedorn
12:10	Discussion
12:30	Sheila Jones award introduced by Prof Anne Green
12:45	Closing Ceremony and comments Eric Lange
13:00	BUFFET LUNCH
14:15	Coaches – Buses leave from the front of the Hotel
18:30	Return from Venice
20:00	Gala dinner