



29th ESPKU Annual Conference

Berlin, Germany, October 22nd – 25th, 2015

Preliminary Programme



Common Programme for all attendees

Welcome and introduction (E. Lange, T. Hagedorn, F.J. van Spronsen); **The local situation** (S. Beblo,)

The European Guidelines

Presentation of the European Guidelines (A. van Wegberg, F.J. van Spronsen); **Differences between European and USA guidelines** (S. Kearney);
USA commentary on the European PKU guidelines (H. Levy and R. Singh); **Discussion on European Guidelines**

Where do we go?

From understanding pathogenesis towards new treatment strategies (F.J. van Spronsen);
Where will we be in 10 years time? (H. Levy); **What needs to be solved in PKU?** (Discussion)

Programme for professionals

New treatment strategies

LNAA treatment in PKU mice (van Vliet)
GMP treatment in PKU mice (K. Ahring)
Experimental Gene Therapy for PKU (B. Thöny)
Nutritional compound in PKU mice (Bruinenberg)

The European Guidelines explained

How should we classify PAH deficiency?
(F.J. van Spronsen)
The questions who to treat (J. Campistol)
The nutritional part -protein and amino acids (A. McDonald)
The nutritional part - the micronutrients (F. Feillet)
The neurocognitive follow-up (Leuzzi)
Adults and PKU (F. Maillot)
Maternal PKU (F. Trefz)
Late treated and untreated PKU (M. Gizewska)
BH4 (A. Muntau)
The quality of life: how often and how? (G. van Rijn)
The guidelines practised by a metabolic paediatrician (A. Burlina)
What are the real reasons to consult the psychologist? (S. Kearney)

Programme for patients and families

Newborn screening

My father's journey to screening (P. Guthrie)
PKU screening and management in south-eastern Europe (M. Tansek)
Presentation of a documentary film about late diagnosed PKU (T. Hagedorn, E. Lange)

The opportunities of life

How my grandfather discovered PKU (G. Følling)
Meeting PKU's across the world (K. Alexander)
My travel experiences (M. Meyer)
My student exchange with USA (S. Drangmeister)

The global perspectives

PKU in Canada (J. Adams)
PKU in Israel (Y. Landau)
PKU in Gaza Strip (n.N.)

Another perspective

My life with MSUD (G. Schmieder)

From medical nutrition to tasteful diet

How my father changed paediatric medicine (M. Liberra)
The birthday cake bake off (Nutricia vs. Dr. Schaer)

Programme for delegates

Newborn screening

My father's journey to screening (P. Guthrie)
PKU screening and management in south-eastern Europe (M. Tansek)
Presentation of a documentary film about late diagnosed PKU (T. Hagedorn, E. Lange)

EU Politics

Development and difficulties in the implementation of Newborn Screening (K. Hall)
Current status of the review of EU legislation on dietary food (n.N.)

ESPKU Guidelines implementation

Workshop: Development of a concerted campaign for implementation of the ESPKU guidelines

ESPKU member's activities

General Meeting of ESPKU

This programme represents the status of September 22nd, 2015 and is subject to change.

