



Event report

Age group specific seminar package for parents and affected children below 9 years and for adolescent and adult patients above 15 years of age

As part of their patient- and family-centered work, and aiming to improve patients empowerment and health literacy, DIG PKU has organised two age-specific seminars that took place simultaneously and at the very same venue near Frankfurt between November 17th and 19th, 2022.

The Seminar for families with PKU children below 9 years of age

95 individuals, representing approximately 35 affected families took part in this fully booked seminar. Some of them have just recently been confronted with the traumatising diagnosis of PKU as an unknown rare disease, others have already settled with the disease and the therapies for their child.

From an experienced metabolic physician, participants learned about the key factors they can focus on to simplify the therapy implementation in their daily lives as a family. In another workshop with a food technologist who is a PKU patient herself, they learned about the composition and mechanism of amino acid supplements, and about their importance for the nutritional therapy as a whole. In a psychologically facilitated workshop, unaffected siblings reflected their self-awareness, discussed their roles within the families and learned how to articulate their individual needs. Another workshop provided an opportunity to ask questions to adolescent and adult patients and to develop a sense of future perspectives of a life with PKU.

The Seminar for adolescents and adults above 15 years of age

60 individuals, representing approximately 30 patients and their spouses and partners, took part in this also 'sold-out' seminar. Some are challenged by the onset of independence and autonomy, others have already started their own families and feel uncertain about their future health and care as first early diagnosed patient generation.

In a workshop with a professional personal coach, participants practiced being confident and quick-witted when talking to their acquaintances and to strangers. With the DIG PKU board and director, they discussed their unmet or inadequately met needs as adult patients with an invisible and publically unknown disease in a complex and challenging healthcare system. From an experienced metabolic physician, they gathered information about latest research and development of cutting edge therapies, discussed the aspects of active participation in clinical trials and their expectations on access to future innovative orphan drugs.

Beyond the lectures and workshops and with their children being professionally cared for, the participants of both seminars had the opportunity to freely share their fears and concerns but also empowering experiences with each other and with the seminar facilitators.

A PKU experienced chef supported the kitchen crew of the event hostel to provide appropriate low protein meals and thus helped the participants to fully focus on their seminars without worrying about their food.

DIG PKU organisers and participants are grateful for the financial support of the seminar package from the German Association of Mandatory Health Insurance Providers (VDEK) and with a grant from the Society for the Study of Inborn Errors of Metabolism (SSIEM).