

**Question for written answer E-002125/2019
to the Commission**

Rule 130

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Subject: Increasing awareness of Phenylketonuria (PKU) as a lifelong condition

In July 2018, a policy round table organised in cooperation with the European Society for Phenylketonuria and Allied Disorders (ESPKU) and hosted by the undersigned made it clear that there is a persistent and fundamental lack of awareness about, and appreciation of, the full neurocognitive impacts of poorly managed PKU and the impact and reality of living with this condition. Moreover, there is an ongoing misunderstanding that PKU is a paediatric condition, resulting in under-appreciation of the need to carry out follow-up checks and dietary and pharmacological treatment in adulthood. There is too little focus on the appropriate transition of patients from child to adult health services as well as on patients who do not regularly attend follow-up appointments and consequently fall between the cracks in healthcare systems.

Can the Commission say what can be done to increase awareness of the lifelong nature of PKU and the best ways to manage its unmet needs?