10 October 2026

World Mental Health Day Statement from the PKU Cross-Party Alliance: Embedding Mental Well-Being into European Health Policy

On World Mental Health Day, the PKU Cross-Party Alliance reaffirms a shared conviction that mental well-being must be treated as a core pillar of European health policy.

Across Europe, people living with phenylketonuria (PKU) and other rare diseases face daily pressures that extend far beyond the clinical management of their condition.[2] Their experience demonstrates why mental health can no longer be considered an optional component of care.

> *"I feel that I am not able to realise my potential at work and in relationships with friends and family… I conform to the diet. I take my medication. I manoeuvre my whole life around it, I STILL SUFFER." – Adult living with PKU*[1]

PKU is a rare inherited metabolic disease where the body can't break down an essential amino acid called phenylalanine, which is found in protein (both plant and animal). Because it can't be processed properly, phenylalanine builds up and can cause severe brain damage and cognitive problems, as well as serious mental health issues. PKU affects people differently at every stage of life, but one reality is constant: from birth to the end of life, the disease dictates daily choices, limits freedoms, and places a relentless mental burden on patients, carers and their families.

> *"As a carer for a child of PKU […] It takes so much time and planning every day that at times it is hard to sustain. Difficult as a parent to be always saying no and having to be so controlling over what he eats, where he goes etc for fear of noncompliance. […] PKU rules our lives." – Parent of a child with PKU*[1]

Although PKU is widely regarded as a success story in rare disease care because Newborn Screening has made early diagnosis possible, the current standard of care, which has remained largely unchanged for 50 years, is extremely burdensome. Patients must adhere to a rigid low-protein diet combined with *specialised PKU protein substitutes* that can be difficult to access and costly. This is necessary to maintain well-balanced Phe levels, neither too high (causing neurological harm) nor too low (resulting in conditions such as anorexia, alopecia, listlessness, faltering growth and osteopenia).

The constant monitoring, the social limitations imposed by dietary restrictions, and the fear of long-term consequences create significant psychological strain for patients, families and caregivers. Many experience anxiety, stress, stigma and isolation. Yet mental health support for the PKU community remains uneven and insufficient across Europe.

> *"My daughter is never at peace with the world. [..] Anxiety about going to school, nervous about new situations, angry when gets answers wrong, struggling at school needs extra help " – Parent of a child with PKU*[1]

[1] Living with Phenylketonuria: Lessons from the PKU community
[2] Capturing the full picture: A joint Policy Paper on the unmet medical need in Phenylketonuria

This is illustrative of a wider challenge. While European institutions and national governments have made important commitments to improving mental health outcomes, implementation has not kept pace with need. Rare disease communities are particularly affected, often falling between specialist pathways and mainstream mental-health provision. As policymakers, we recognise that this gap undermines the principle of equitable care.

The PKU Cross-Party Alliance calls for a more integrated and consistent approach to mental health within European health systems. Mental health support must be embedded into chronic disease and rare disease care models, ensuring access to psychological services, peer support, and interventions tailored to the realities of lifelong conditions like PKU. This is not an add-on; it is essential to deliver high-quality care.

We also urge stronger coordination at the European level. The EU's evolving health agenda, including initiatives on non-communicable diseases, digital health infrastructure, and rare-disease collaboration, provides an opportunity to ensure mental health indicators and support structures are systematically included. National governments should align with this momentum by investing in mental health capacity, training healthcare professionals to recognise psychological strain in metabolic conditions and supporting research into the mental-health impacts of rare diseases.

"I have mood swings, extremely tired and want to sleep all the time and feels like this is a grey cloud hanging over my head, but not depression. I find it difficult to plan, be organised and find that I lack energy, enthusiasm and motivation. I have blank moments where I can't think or get my words out that I am trying to say. I experience anxiety and I get paranoid. All this impacts my work life as my job is very fast paced. I get "brain fog" tend to become irritable and uneasy in social settings." – Adult living with PKU[1]

On World Mental Health Day, we speak with one voice: **mental well-being must be recognised as integral to health policy across Europe**. For people living with PKU, and for all those managing chronic rare conditions, mental health deserves the same priority, investment, and attention as physical health. A stronger, fairer European health system is one that supports the whole person – their body and mind.

On behalf of the PKU Cross-Party Alliance:

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[1] Living with Phenylketonuria: Lessons from the PKU community
[2] Capturing the full picture: A joint Policy Paper on the unmet medical need in Phenylketonuria