

Breaking the silence on Primary Immunodeficiencies (PIDs) and Mental Health:

A Call to Action for EU Policymakers

Primary immunodeficiencies (PIDs) are a large and growing group of [over 485 different genetic defects](#) caused when some components of the immune system do not work properly or at all. PIDs have an evident impact on the physical health of the person affected, but also on mental health, sometimes leading to emotional distress, anxiety, and depression among affected individuals and their families.

In recognising the intricate relationship between PIDs and mental health in the Comprehensive Approach to Mental Health, EU policymakers have a unique opportunity to pioneer a holistic understanding of the mental health needs of patients with chronic and rare diseases. By prioritising awareness, education, access to services, and systemic support, the European Union can champion a model that not only addresses the physical health challenges surrounding diseases such as PIDs but also fosters mental well-being. This call to action is a plea for European policymakers to commit to policies that ensure no one is left behind in the pursuit of better health outcomes.

In light of the above, we, the International Patient Organisation for Primary Immunodeficiencies (IPOPI) are calling for the following points to be taken into account:

Raise Awareness:

- Advocate for more consideration of vulnerable groups, such as persons with PIDs, in the Comprehensive Approach to Mental Health, to highlight the specific challenges they face.
- Promote the development of scientific guidelines by European Reference Networks (ERNs) that address the specific mental health needs of vulnerable groups, such as ERN-RITA (Primary Immunodeficiencies, Autoinflammatory disorders, Autoimmune Diseases and paediatric rheumatic diseases European Reference Network) when it comes to developing guidelines for patients with PIDs.
- Foster more understanding of the mental health needs of individuals with chronic and rare diseases, such as PID patients, at all levels to reduce stigma and enhance social support.

Integrated Healthcare Services:

- Encourage the development and implementation of multidisciplinary healthcare services that seamlessly integrate mental health support into PID care.
- Promote collaboration between immunologists, psychologists, nurses and other healthcare professionals to promote a holistic approach for patients with a chronic disorder such as PIDs.

- Explore innovative telemedicine solutions to overcome geographical barriers and provide remote mental health support for those in underserved regions.

Access to Mental Health Support:

- Encourage EU Member States to incorporate mental health services as a core component of their healthcare systems to overcome accessibility challenges such as financial costs and/or high demand of specialists / long waiting lists.
- Ensure equitable access to mental health services for individuals with PIDs across EU member states.
- Address growing shortages of professional psychologists in the EU and delayed access to mental health support by providing better working conditions and incentives for healthcare professionals.
- Nurture the development of patient support networks that can help patients with diseases, such as PIDs, to exchange and communicate with their peers.
- Strengthen support systems for patients and their families by establishing peer support groups, counselling services, and informational resources.