



## EVENT REPORT



### **PID Forum: Breaking the Silence on Mental Health & PIDs**

*5 December 2023*

On 5 December 2023, the International Patient Organisation for Primary Immunodeficiencies (IPOPI) organised a PID Forum titled “Breaking the Silence on Mental Health & PIDs”. The event took place in the European Parliament in Brussels and was co-hosted by the Members of the European Parliament (MEPs) **Estrella Durá Ferrandis** (S&D, Spain), **Radka Maxová** (S&D, Czechia) and **Tomáš Zdechovský** (EPP, Czechia).

The moderator of the event, **Leire Solís**, Health Policy and Advocacy Senior Manager at IPOPI, opened the event by welcoming the European Commission’s acknowledgement that mental health is an integral part of a citizen’s wellbeing in their Communication for “A comprehensive approach to mental health”. She regretted that, despite the European Commission recognising that mental health challenges are conditioned by personal and external factors, their proposal failed to recognise that there are approximately 36 million individuals affected by a rare disease in Europe who have a significantly higher incidence of mental health difficulties, compared to the general population.

#### **Welcome Address**

**MEP Estrella Durá Ferrandis** (S&D, Spain) welcomed the audience to the event and drew upon her own experiences working as both a psychologist and a Member of the European Parliament. While she welcomed the European Commission’s Mental Health Communication, she also emphasised the need to invest more in mental health infrastructure to address existing disparities in care. To illustrate this point, she highlighted



that there are 11 psychiatrists per 100,000 inhabitants in Spain, while France, Sweden and Germany have more than twice as many. Ms Durá Ferrandis called for a European-level strategy on mental health, with a holistic, cross-cutting, multidisciplinary approach, integrated into the public health system that identifies practical solutions and ensures that mental health problems are better addressed for primary immunodeficiency (PID) patients.

In her opening remarks, **MEP Radka Maxová** (S&D, Czechia) noted that mental health problems have been a silent epidemic affecting around 84 million people in the EU over the past years. She expressed



regret that the European Commission's Mental Health Communication does not sufficiently acknowledge the mental health needs of those living with a rare disease. As such, Ms Maxová called on EU policymakers to ensure equitable access to mental health services across EU member states for vulnerable individuals such as PID patients. She also underscored the importance of a holistic approach to healthcare and her hopes for the cause of IPOPI and PID patients to be aligned with a wider call for the inclusion of vulnerable groups within the European Union's priorities when it comes to mental health.

## Setting The Scene

**Jose Drabwell**, Member of the Board of IPOPI, provided an overview of the organisation's work, PIDs and the range of mental health challenges patients have to overcome. She emphasised that the sheer fact of being diagnosed with a PID can have a deep psychological impact on both patients and their families, with patients often having to readjust their lifestyle in order to accommodate treatment. She highlighted that the very nature of PIDs, as rare and chronic disorders,



entail mental wellbeing challenges throughout the patient's lifetime as PID patients realise that they will be undergoing a lifelong therapy plan as well as potential threat to their health. Coupled with the side effects of the treatment, this can take both a physical and mental toll on patients.

Ms Drabwell also detailed the importance of employing a holistic care approach when it comes to treating those living with PID. She noted how important it is to facilitate access to qualitative psychological support, for both patients and carers, to ensure no one is left behind and to better manage the disease.

## Panel: Supporting The Mental Health of Rare Disease Patients

**Vida Ramšak Marčeta**, patient representative at the Slovenian Society for Immune Disorders, launched the panel discussion by sharing her own experience of living with Cartilage Hair-Hypoplasia, a rare form of PID. Ms **Ramšak** shared some insights into her personal journey and the extent to which her condition

has impacted her physical and psychological well-being. As a result, she has to deal with low self-esteem, anxiety and loneliness while living in another country. She stressed how important psychological support is for those with a PID, noting that it would help patients navigate these challenges. When asked about the situation in Slovenia, Ms **Ramšak** remarked that psychological support for patients is very limited and should be improved upon.



**Ellen Desmet**, board member at the Belgian Patient Organisation for Primary Immunodeficiencies (BePOPI), shared her experience of accessing adequate psychological care for her daughter

diagnosed with a PID, autism and Attention Deficit Hyperactivity Disorder (ADHD). She revealed that multidisciplinary approaches to care in Belgium are lacking and that hospitals do not provide the appropriate psychological support for PID patients. Ms Desmet also outlined the difficulties surrounding waiting lists and cost barriers faced by her family when trying to access adequate psychological support for her daughter. When the baby girl was able to gain psychological support, Ms Desmet underlined that her overall well-being improved significantly. She voiced her concerns about future psychological support and called for improvements in the Belgian healthcare system to ensure that PID patients receive the care they need.



**Dr Virgil Dalm**, physician and principal investigator at Erasmus University Medical Center (Rotterdam, the Netherlands), provided his perspective on the mental health challenges faced by PID patients in the Netherlands. According to Dr Dalm, PID patients are three to four times more likely to experience psychological distress when compared to the general population. However, a study that he previously conducted found that only 45% of PID patients had received some form of psychological support.

He stated that PIDs have a huge impact on the daily lives of those living with the condition, causing them to miss school or work. Providing better psychological services to those living with a PID can be effective in helping them overcome these challenges. With the increased availability of treatments that address the physical symptoms of PIDs, Dr Dalm called for more focus on the mental health challenges that accompany PIDs and that increasing the availability of such services would also lead to fewer hospitalisations. Finally, Dr Dalm emphasised the hurdles that physicians in the Netherlands face when trying to access adequate mental health services given the limited number of psychologists specialising in rare diseases and the financial barriers facing patients in need of support.

**Rosalind Fisher**, President of the International Nursing Group for Immunodeficiencies (INGID) and Specialist Nurse Practitioner at Oxford University Hospitals NHS Foundation Trust in the United Kingdom, gave an overview of the physical and psychological activities undertaken by her organisation to support

PID patients. Ms Fisher underlined the importance of nurses when it comes to the treatment of PID patients, emphasising that they have a unique relationship with patients and have the ability to advocate for them with other health professionals. As nursing specialists, they often have the most contact with PID patients and can play an important role in addressing their holistic needs.

Nurses who are specifically qualified to deal with PIDs often have to provide psychological support to patients, despite not being trained to do so. She called for the inclusion of psychologists in multidisciplinary treatment teams for PID patients, as it would provide patients with a better and more comprehensive treatment plan and lead to better overall care for PID patients. Ms Fisher also said that patients often find themselves in situations where their condition is not fully understood by family and friends, and their primary health practitioner is often the first person that they turn to. As such, the provision of adequate psychological care is imperative. Ms Fisher urged for these provisions to be made available throughout Europe, as nurses are currently struggling to fill the gap left by a lack of psychological services.



**Janne Houben**, clinical psychologist & behavioural therapist at University Hospital Leuven (Belgium), spoke about the importance of a holistic approach to PID treatments. She said that, while there has been little research on the correlation between PIDs and mental illness, it is widely known that chronic illness is a risk factor that can lead to depression and anxiety. Speaking about the correlation between mental and physical health, Ms Houben noted that mental and physical symptoms can often be indistinguishable from each other and possibly also have an impact on each other. She stated that early intervention is key when it comes to addressing mental health challenges. To tackle these challenges, she launched CARE4KIDS, a project which looked at the need for multidisciplinary care for children with PIDs. While the project did not receive state funding in Belgium, PID patients were given wide support from a variety of specialists, including psychologists, dietitians, and physiotherapists.

## Open Floor Discussion

The panel discussion was followed by an open floor discussion. Several patient representatives from across Europe took the floor to highlight some of their concerns and challenges.



**Kersti Urbala**, the president of the Estonian Patient Society for Primary Immunodeficiencies spoke of her own experience as both a mother of children with PIDs and a mental health nurse. **Janine Smith**,

board member of the Dutch PID patient organisation, Stichting voor Afweerstoornissen (SAS), spoke about the work that SAS is doing to support the mental health needs of PID patients. **David Jiménez Gonzalez**, board member of the Spanish PID patient organisation, Asociación Española de Déficit Inmunitarios Primarios (AEDIP), shared his own experience of living with a PID. He also spoke about AEDIP's work in providing psychological support for PID patients in Spain.

## Closing Statements



In a video statement, **Tomáš Zdechovský (EPP, Czechia)**, emphasised the need for a holistic EU approach to mental health. He also highlighted the importance of addressing mental health challenges faced by patients with PIDs and committed to amplifying the voice of patients and incorporating their contributions into the EU's mental health approach. Despite recent improvements, he emphasised the ongoing importance of prioritising mental health efforts, particularly for vulnerable groups like PID patients. MEP Zdechovský said that mental health will be a prominent topic in the upcoming decade and he expressed his support for IPOPI.

**MEP Estrella Durá Ferrandis** thanked participants for their contributions. She assured participants that she would do her utmost to ensure that patient voices are translated into tangible improvements for those living with a PID. She also reassured IPOPI of her future support and said she would be happy to review and promote the Call to Action that will follow the event.

In her closing statement, **MEP Radka Maxová** also thanked the panellists and representatives for providing their perspectives. She was grateful to the event's various speakers who deepened her understanding of the challenges faced by individuals dealing with PIDs and the urgency of addressing the mental health dimensions surrounding these conditions. She also reassured participants that the day's discussions would not be confined to the PID Forum, advising that she would use the event to shape the Parliament's upcoming mental health policies.

Closing the PID Forum, Ms Solís thanked attendees, panellists, patient representatives, sponsors and EU representatives for their participation. She emphasised the importance of collective efforts and stakeholder collaboration and expressed her intention to translate the concerns raised at the event into actionable recommendations thanks to the Call to Action.