EVENT REPORT

PID Forum: Rare and not-so-rare: Shaping EU policy for primary and secondary immunodeficiencies

23 June 2026, 15:30 - 17:30
European Parliament, Brussels (Belgium)

On 23 June 2026, **Member of the European Parliament (MEP) Dr Romana Jerković** (S&D, Croatia) hosted a PID Forum titled *"Rare and Not-So-Rare: Shaping EU Policy for Primary and Secondary Immunodeficiencies"* organised by the International Patient Organisation for Primary Immunodeficiencies (IPOPI).

The Forum brought together policymakers, healthcare professionals and patient representatives to discuss how EU health policy can better address the needs of people living with primary immunodeficiencies (PIDs) and secondary immunodeficiencies (SIDs).

Building on IPOPI's policy paper titled *"When Rare Meets the Not-so-Rare: Strengthening EU Policy for Primary and Secondary Immunodeficiencies",* developed in collaboration with rare disease and cancer patient organisations, the Forum focused on recognising the need to strengthen diagnosis, care pathways and multidisciplinary care for patients living with PIDs and SIDs, while also better integrating these priorities into EU healthcare policy.

Welcome addresses

Opening the Forum, **Dr Romana Jerković** said she was delighted to have the opportunity to bring together healthcare professionals and patient representatives to discuss the growing importance of immunodeficiencies within EU healthcare policy. She noted that advances in oncology, rare diseases and other medical fields have increased the number of people living with SIDs, making immunodeficiencies a challenge that requires stronger recognition within wider healthcare policy discussions. During her address, Dr Jerković emphasised her willingness to support EU policies leading to earlier diagnoses, stronger referral pathways, greater awareness among healthcare professionals and more equitable access to specialist expertise across the EU.

Setting the scene

Martine Pergent, **President of IPOPI,** outlined the rationale for bringing together the primary and secondary immunodeficiency communities, noting that patients often face similar challenges, including delayed diagnosis, fragmented care, unequal access to treatment and limited awareness outside specialist settings. Ms Pergent highlighted five policy priorities for improving the lives of PID and SID patients: earlier diagnosis, equitable access to treatment, stronger links between rare disease and cancer policy, greater recognition of the psychological impact of immunodeficiencies, and investment in multidisciplinary care and EU-level cooperation.

Panel discussion - Ensuring access, protection and innovation for secondary immunodeficiencies

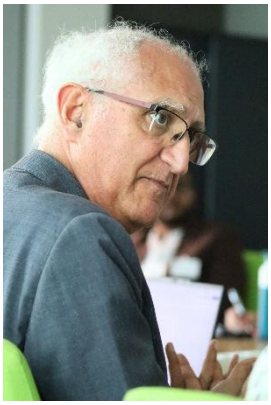
The panel discussion, moderated by **Leire Solís**, **IPOPI's Health policy and advocacy director**, explored how healthcare systems and EU policy can better respond to the needs of people living with PIDs and SIDs.

Anne-Sophie Henry-Eude, patient advocate, reflected on her own experience of being diagnosed with a PID at the age of 38, after developing autoimmune disease and cancer. She described diagnosis as the beginning rather than the end of her journey, arguing that patients frequently navigate multiple medical specialties throughout their lives. She called for healthcare systems to focus on coordinated care pathways rather than individual disease areas and highlighted the psychological burden associated with living with an invisible condition, particularly for children and young people who often experience stigma and social isolation.

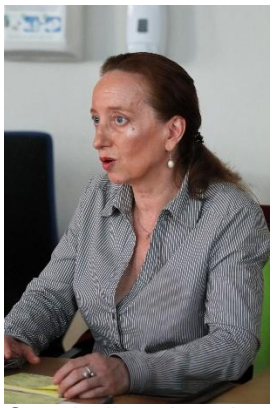
Prof Filomeen Haerynck, paediatric immunologist, UZ Ghent (Belgium), focused on the growing complexity of diagnosing PIDs. She argued that the traditional warning signs for PIDs should be updated and that improving diagnosis requires greater awareness among clinicians across multiple specialties, not only immunologists. During her contribution, Prof Haerynck also highlighted persistent differences in access to biologic therapies across Europe, the continuing shortage of immunoglobulins and the importance of sustained funding for European Reference Networks (ERNs).

Dr Elena Cabezudo Perez, haematology specialist, Catalan Institute of Oncology- Hospital Moisès Broggi, Barcelona (Spain), argued that immunodeficiency management should become an integral part of oncology and haematology practice. She called for enhanced clinician education, greater integration of patient perspectives into professional training, and improved referral pathways between hospitals to facilitate access to specialist expertise. Dr Cabezudo Perez also advocated for the development and broad dissemination of European consensus guidelines on the diagnosis, treatment, monitoring and identification of PIDs and SIDs. Lastly, Dr Cabezudo Perez proposed integrating immunodeficiency expertise management into the responsibilities of Comprehensive Cancer Centres (CCC) and their networks, giving it the same strategic importance as areas such as next-generation sequencing.

Dr Tadej Avčin, Department of Allergology, Rheumatology and Clinical Immunology, University Children's Hospital Ljubljana (Slovenia), argued that organising care for patients with immunodeficiencies is often a greater challenge than access to medicines themselves. Given the complexity of the immune system, he also stressed that multidisciplinary collaboration is essential. Implementation, he said, is the next major challenge for PIDs, as existing recommendations on multidisciplinary care and care transitions are not consistently applied in practice.



Felice Bombaci, member of Steering Committee (Italy), CLL Advocates Network, focused on the growing relevance of SIDs within cancer care. He argued that future revisions of the Europe's Beating Cancer Plan—should recognise SIDs as an important long-term comorbidity of cancer. Mr Bombaci also called for increased use of programmes such as Horizon Europe to promote cross-disciplinary education and training. Lastly, Mr Bombaci highlighted persistent disparities in access to immunoglobulin replacement therapy as another key concern.



Sarita Workman, senior clinical specialist nurse, East Kent Hospitals University NHS Foundation Trust (United Kingdom), INGID Board Member, focused on the evolving role of specialist nurses in the long-term management of immunodeficiencies. She explained that nurses increasingly coordinate care, provide education to patients and families, support research and contribute to clinical decision-making. She argued that this continuity of care places nurses in a unique position to ensure healthcare remains patient centred. Concluding her intervention, Ms Workman stressed that healthcare policy should be developed together with patients and healthcare professionals, noting that "good policy is designed not for people, but with people."

Bridging EU policy gaps for secondary immunodeficiencies

Following the panel discussion, the Forum turned to the broader EU rare disease policy landscape, with a presentation on the European Parliamentary Research Service's (EPRS) European Added Value Assessment on a European Action Plan on Rare Diseases.

Claudia Koreimann-Özkan, national expert at the EPRS, explained that the Added Value Assessment was intended to generate new insights into rare diseases, provide robust evidence to support legislators, and demonstrate the added value of EU action in this area. She argued that stronger European cooperation on rare diseases can improve patient outcomes by fostering collaboration and promoting more consistent approaches across Member States.

Building on Ms Koreimann-Özkan's contribution, **Mariana Dates**, **Principal consultant at Tetra Tech**, presented the findings of the Added Value Assessment, which identified measures to address persistent challenges across the rare disease patient pathway. Ms Dates noted that many of the study's conclusions closely aligned with the policy recommendations put forward by IPOPI for patients with PIDs and SIDs. She observed that, while nearly three decades of EU action and an extensive legislative framework have driven significant progress, the assessment found that rare disease policy remains fragmented and would benefit from a more coherent strategic framework.

The study therefore recommended strengthening EU coordination, funding and capacity-building across areas including diagnosis and screening, access to therapies, research and innovation, data sharing and family support. It also highlighted the need to better integrate and sustainably fund the European Reference Networks (ERNs), describing them as a key but underutilised source of EU added value.

Open floor discussion

Participants reinforced many of the themes discussed throughout the Forum during the open floor discussion.

Ewa Kapuscinska from the Polish Association for Patients with Primary Immunodeficiencies (Immunoprotect) highlighted the importance of recognising the need for multidisciplinary care for PID patients. **Tina Volcjak** from the Slovenian Society for Immune Disorders made a touching intervention on her son's PID diagnosis and treatment journey, illustrating how multidisciplinary collaboration enabled an accurate diagnosis after a prolonged diagnostic process.

Anna Mirabile, Policy lead at European Association of Hospital Pharmacists (EAHP), pointed to the key role of hospital pharmacists in the PID care pathway, as well as in improving and ensuring patient safety. Finally, **Sujan Sivasubramaniyam,** Head of global patient advocacy and policy at CSL Behring, emphasised that earlier PID diagnosis and coordinated care should be recognised as cost-effective investments into national health systems that reduce the prevalence of complications and hospitalisations.

Representing the Netherlands Foundation for Immunodeficiencies (Stichting voor Afweerstoornissen), **Soraja Ebbeling** reiterated the need for equitable access to specialist services, psychological support and measures to reduce stigma in order to improve quality of life of PID patients.

Strengthening EU action on primary and secondary immunodeficiencies

Closing the open floor discussion, **Martine Pergent** reflected on the broad consensus that had emerged throughout the Forum. She summarised the key points shared by the event's contributors and highlighted how they had consistently identified earlier diagnosis, equitable access to treatment, multidisciplinary care and stronger patient support as the key priorities for improving patient outcomes.

Ms Pergent emphasised that achieving these objectives requires better coordination across specialties, greater attention to the psychological impact of immunodeficiencies, improved transition between paediatric and adult care, as well as sustained investment in specialist expertise, multidisciplinary care and EU-level cooperation.

Closing statements

Closing the event, **Dr Romana Jerković** thanked IPOPI, the speakers and participants for bringing together diverse expertise to discuss the future of immunodeficiency care. She observed that rare diseases, cancer care and patient-centred healthcare remain too often addressed through separate policy frameworks despite being closely interconnected. Dr Jerković also stressed that improving outcomes will require sustained political commitment – which she is happy to provide –, stronger healthcare systems and continued investment in specialist expertise, professional training and equitable access to care.

Leire Solís concluded the event by welcoming the strong consensus reached during the Forum and reaffirming IPOPI's commitment to ensuring that the policy recommendations emerging from the discussions are reflected in future EU health initiatives.