

EVENT REPORT



PID Forum: When Rare Meets the Not-So-Rare The Case of PIDs & SIDs

9 December 2025, 17:00 - 18:30

On 9 December 2025, **MEP Michalis Hadjipantela** (EPP, Cyprus) and **MEP Tomislav Sokol** (EPP, Croatia) hosted a PID Forum organised by the International Patient Organisation for Primary Immunodeficiencies (IPOPI) at the European Parliament.

Titled '**When Rare Meets the Not-So-Rare: The Case of PIDs & SIDs**', the event was moderated by Leire Solis, Health policy and advocacy director of IPOPI. She emphasised how expertise in primary immunodeficiencies (PIDs) can be applied to improving understanding, management and outcomes of certain secondary immunodeficiencies (SIDs).

She also noted that although PIDs are rare, the scientific, diagnostic and clinical knowledge surrounding them provides a rich model of immune dysfunction – one that is increasingly relevant given the dual relationship between cancer therapies and immunodeficiencies, which may reveal an underlying, undiagnosed PID.

Welcome addresses

Ms Solis invited both MEP hosts to take the floor to welcome participants to the event.



First, **MEP Michalis Hadjipantela** (EPP, Cyprus) shared his vision for stronger European cooperation on rare diseases. Drawing on his experience as Cyprus's former Minister of Health, he highlighted the distress faced by patients who wait more than 15 years for a diagnosis. He referred to the staggering findings of the European Parliament's Consultation on rare diseases, which showed

that nearly half of respondents reported having no treatment available.

MEP Hadjipantela emphasised that identifying undiagnosed immunodeficiencies is a crucial pillar in the fight against cancer, stressing the urgent need to improve diagnosis across Europe. He shared that, in Cyprus, only 8 out of an estimated 80 people living with PIDs are currently identified. He called on the EU to fully harness the potential of the European Reference Networks (ERNs) and the European Health Data Space (EHDS) to better support patients, particularly in smaller Member States.

MEP Tomislav Sokol (EPP, Croatia) then provided a comprehensive overview of how the EU can act in the field of health, despite health being a national competence. He argued that the EU must intervene where individual Member States – especially smaller ones – cannot address challenges alone, particularly in relation to research and funding for rare diseases.



He highlighted the pharmaceutical legislation and the Critical Medicines Act as key opportunities for rare disease patients, notably through extending joint procurement to orphan drugs, which would help small countries, such as Croatia and Cyprus, secure more equitable access to medicines. Looking ahead, MEP Sokol called for the EU to prioritise a long-term solution for rare diseases by leveraging programmes such as Horizon Europe and the European Social Fund to support specialised training. He also advocated for health to be allocated a dedicated budget line in the next Multiannual Financial Framework (MFF).

Living at the intersection of SIDs and PIDs

The Forum featured a video testimony from **Vicente Rodrigo**, a Spanish patient who survived two lymphomas before being diagnosed with a PID. He described the fear of a recurring, aggressive lymphoma and the subsequent realisation that his immune system was permanently fragile. Vicente spoke about the psychological challenge of shifting from a "curative" cancer mindset to accepting the status of a "chronic patient" requiring lifelong protection. His testimony highlighted the importance of strong support networks and the relief that comes with finally receiving a clear diagnosis and a structured treatment plan.



Bridging rare and common immune challenges

Martine Pergent, President of IPOPI, outlined both the similarities and differences between Primary (PIDs) and Secondary (SIDs) Immunodeficiencies. While PIDs are rare, inherited disorders, SIDs affect millions of people, often as a consequence of cancer or autoimmune treatments.



Despite these differences, she explained that both conditions frequently require similar management approaches, including immunoglobulin replacement therapies. She identified challenges both share, such as antibiotic resistance, vaccine hesitancy, and shortages of essential plasma-derived medicines. A clear sign of how expertise in PIDs can help manage certain SIDs.

Martine concluded with the concept of the "hidden link," explaining that an unknown proportion of patients diagnosed with SIDs may, in fact, have an underlying and previously undiagnosed PID. This underlines the need for greater "red flag" awareness among oncologists and haematologists.

Access, protection and innovation for SIDs



Prof Silvia Sánchez Ramón, Head of Immunology Department, Hospital Clínico San Carlos (Spain), explained that the clinical presentation of PIDs and SIDs is often indistinguishable, creating major diagnostic challenges.

Genetic analyses from her research covering a large cohort of patients with haematological malignancies – including lymphoma, chronic lymphocytic leukaemia, and multiple myeloma – revealed that almost 70% of patients initially classified as having a secondary immunodeficiency carried variants associated with a PID. These findings suggest that many cases treated as secondary conditions may be underlying PIDs unmasked by cancer, leaving patients more vulnerable to severe infections, secondary cancers, and inflammatory complications.

Prof Sánchez Ramón urged policymakers to expand access to genetic testing as, despite personalised therapies becoming increasingly available, genetic testing remains uneven across Europe. She also called for stronger infrastructure to enable the secure sharing of anonymised genetic data across borders, noting that current regulatory barriers continue to limit progress.

Andrew Symes, Senior Immunology Clinical Nurse Specialist at the Royal Free Hospital in London (United Kingdom) and a representative of the International Nursing Group for Immunodeficiencies (INGID), described the shock many patients experience when – after surviving cancer – they are told they now face a chronic condition requiring lifelong immunological care. He highlighted a notable shift in clinical practice. In 2025, his clinic received more referrals for SIDs than for PIDs for the first time.



Mr Symes emphasised that a key part of the nursing role is supporting patients through this transition by helping them process the diagnosis, normalise their condition, and reassure them that a good quality of life remains achievable. He also described how important it is to discuss immunoglobulin treatment options available to help patients decide the most suitable method for their particular circumstances. Finally, he also

welcomed the significant progress made in his centre, which now benefits from a full-time psychologist dedicated to supporting patients with the mental and emotional burden of immunodeficiency.

Returning to the discussion, **Martine Pergent** urged policymakers to identify stronger links between cancer programmes and rare disease strategies. She noted that many SID patients see infections merely as a “side effect” of cancer treatment rather than as a condition that can and should be treated. Education, awareness, and supportive policy frameworks are therefore essential to shift this mindset and improve patient outcomes.



Open floor discussion

A number of attendees made additional statements during the open floor discussion.

Françoise Rossi, Director of Scientific and Regulatory Affairs at the International Plasma and Fractionation Association (IPFA), asked whether it is possible to medically differentiate secondary and primary immunodeficiencies. **Prof Sánchez Ramón** confirmed that this remains a major challenge, as clinical presentations often overlap. She advised clinicians to look beyond the cancer diagnosis and consider medical and family history, including childhood infections and autoimmune diseases, to identify possible underlying PIDs.



Savvas Savva, Secretary of the Cyprus Primary Immunodeficiencies and Friends Association, called for patients, clinicians and nurses to take a leading role in shaping policy, as politicians often lack technical and medical expertise. He also urged policymakers to ensure health funding is given the importance it needs.

Irene de Cara Torres, Head of International Policy, Advocacy and Government Affairs at CSL Behring asked about the impact of the European Health Data Space on day-to-day research. Prof. Sánchez Ramón responded that although genetic technologies are advancing rapidly, data sharing remains a major bottleneck. She noted that even regional data exchange is difficult due to regulatory and consent barriers and stressed

that enabling EU-level sharing of anonymised data is essential to save time, resources and lives.

Finally, **Deborah Hibbett**, Senior Vice President, Head of Global Corporate Affairs and Sustainability, Plasma-Derived Therapies at Takeda, asked about the key drivers of collaboration between haematologists and immunologists. **Mr Symes** suggested growing clinical experience and deliberate efforts to align protocols across specialities had ensured significant progress in this area. **Ms Pergent** added that patient organisations play a crucial role in fostering cross-disciplinary collaboration, helping prevent patients from falling through the gaps created by siloed healthcare systems.

Closing statement



Leire Solis thanked all participants for their valuable contributions and highlighted the clear consensus that had emerged during the event. She noted that the interplay between PIDs and SIDs remains an underdeveloped research area, yet one of growing importance for advancing understanding and improving outcomes for both PIDs and SIDs. She also underlined the urgent need for

multidisciplinary approaches that bridge oncology, haematology, and immunology, and stressed that patients must remain at the heart of these policy developments to ensure systems reflect their daily realities.

Ms Solis concluded by announcing that the discussions held during the event would form the foundation of an upcoming **IPOPI White Paper on PIDs and SIDs** that would be discussed during a 2026 PID Forum in the European Parliament.