

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

9 December 2025

PID FORUM

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

AN IPOPI EVENT

MEP Michalis Hadjipantela (EPP, Cyprus)
MEP Tomislav Sokol (EPP, Croatia)

09 Dec 2025
17.00 - 18.30
EUROPEAN PARLIAMENT
SPINELLI A3F383

The poster features a blue background with a white road intersection. A man in a light blue shirt and dark trousers stands at the intersection, looking up at a signpost. The signpost has two signs: 'PIDs' and 'SIDs'. To the left of the signpost are the logos for 'epp' (European People's Party) and 'IPOPI' (Interdisciplinary Platform on Orphan and Rare Diseases). The overall design is clean and professional, with a focus on the intersection of PIDs and SIDs.



EVENT PROGRAMME

- 17:00** *Welcome Address*
- 17:15** *Living at the Intersection of SIDs and PIDs*
- 17:20** *Setting the Scene*
- 17:30** *Access, Protection and Innovation for SIDs*
- 18:00** *Open Floor Discussion*
- 18:15** *Key Takeaways & Policy Recommendations*
- 18:20** *Closing Statements*



WiFi: *(to be inserted)*

Follow us on social media: *@ipopi_info*



Welcome Address

MEP Michalis Hadjipantela (EPP, Cyprus)

MEP Tomislav Sokol (EPP, Croatia)



VICENTE RODRIGO

Patient from Spain with
Hodgkin and Burkitt lymphoma and
underlying PID



Setting the Scene

Martine Pergent, President, IPOPI

Primary and Secondary Immunodeficiencies (PIDs & SIDs): Bridging rare and common immune challenges



Martine Pergent
President, IPOPI

Introduction to IPOPI

What is IPOPI?

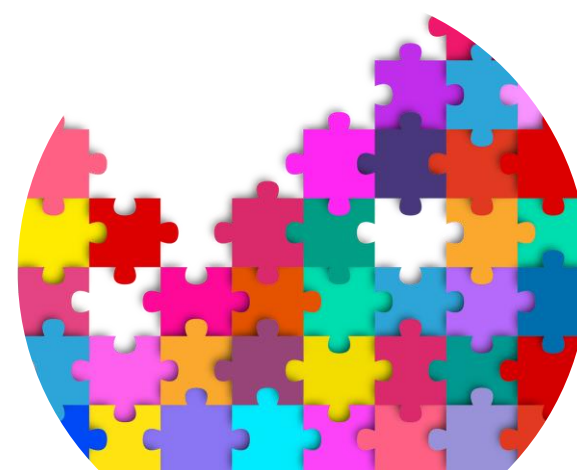
A **non-profit international** organisation

- The **leading advocate** for primary immunodeficiency (PID) patients worldwide
- Working in **collaboration** with patients, doctors, politicians, regulators, pharmaceutical industry and other relevant stakeholders.



Our mission

To improve awareness, access to early diagnosis and optimal treatments for primary immunodeficiency patients **worldwide** through global **collaboration**.



Why does this Forum matter?

- **Primary Immunodeficiencies (PIDs)**
600+ rare conditions affecting 90,000 people in the EU.
Most are underdiagnosed, with relevant health and social load.
- **Secondary Immunodeficiencies (SIDs)**
(e.g. cancer, autoimmune diseases, post-treatment)
affect millions of people in the EU.

Early diagnosis saves lives and reduces costs

- **Primary Immunodeficiencies (PIDs):**
 - Genetic disorders impairing immune function (e.g: SCID, CVID)
 - Often diagnosed late, lifelong management required
- **Secondary Immunodeficiencies (SIDs):** acquired immune dysfunction due to:
 - Cancer /chemotherapy (e.g: chronic lymphocytic leukemia (CLL), lymphoma, multiple myeloma)
 - Autoimmune diseases (e.g: rheumatoid arthritis)
 - The treatment used in certain diseases

Treating PIDs & SIDs – Anti-infectious prophylaxis

PID patients (ESID 2023):	SID patients
Antibiotics: <ul style="list-style-type: none"> • Continuous prophylaxis (e.g. cotrimazole for CVID) • rotating regimens to prevent resistance. 	Cancer-related SIDs: <ul style="list-style-type: none"> • guidelines exist for neutropenia or CMV reactivation
Vaccines: <ul style="list-style-type: none"> • Live vaccines contraindicated in severe PIDs (e.g. SCID). • Annual flu, pneumococcal, and COVID-19 boosters recommended. 	Autoimmune SIDs: <ul style="list-style-type: none"> • some prophylaxis established for certain SIDs
Antivirals/fungals: <ul style="list-style-type: none"> • Available guidelines, well established 	Post-COVID SIDs: <ul style="list-style-type: none"> • no standardised guidelines,
<p style="text-align: center;">Common challenges:</p> <ul style="list-style-type: none"> - antibiotic resistance: overuse in prophylaxis - vaccine hesitancy: low uptake in PID / SID patients - guideline fragmentation: EU vs US differences 	

Treating PIDs & SIDs - Immunoglobulins

- Immunoglobulin (Ig) therapy : a lifeline for patients with PIDs & SIDs
 - Why Ig therapy matters: **Prevention**
 - Replaces missing antibodies in PIDs
 - Prevents or reduces severity of infections in SIDs (e.g. post-chemotherapy, CLL)
 - **Challenges:**
 - Supply: shortages or tensions of Ig therapies
 - Access disparities: reimbursement varies across EU countries, not all routes continuously available
 - **Policy solutions:**
 - Increasing plasma supply > incentivise EU plasma collection
- Tackling shortages and addressing bottlenecks in availability of Igs
Continue ensuring the highest regulatory scrutiny to ensure safety, efficacy and quality of medicines

Treating PIDs & SIDs - Immunoglobulins

Ig use: guidelines and evidence

- Anti-infectious use (prophylaxis / treatment):
 - ESID/ASID Guidelines (2023): PID patients: 0.4–0.8 g/kg IgG every 3–4 weeks (IV/SC).
- Prophylaxis outside PID field: lack of guidelines
 - European expert consensus on treating secondary antibody deficiencies in haematological malignancies
 - Cancer patients: Ig reduces sepsis risk by 40% (NEJM 2022).
 - Post-transplant: Routine in some centers (e.g., HSCT).
 - Autoimmune SIDs: Emerging use in rheumatoid arthritis (off-label).
- Research gaps:
 - Start / no treatment with Ig?; when to start it?
 - Optimal dosing for SIDs / for which SIDs?
 - When to pause / stop Ig therapy?
 - Long-term outcomes in autoimmune-related SIDs
 - Cost-effectiveness studies for EU health systems

The hidden link: undiagnosed PIDs in SID patients

- Key issue:
 - An unknown proportion of SID patients have an undiagnosed PID
- Red flags to suspect (no consensus guidelines):
 - Infections with unusual pathogens, unusually severe, persistent.
 - Family history of PID / early deaths due to infections.
 - Immune dysregulation
 - Autoimmunity + immunodeficiency
- Potential policy actions:
 - Start / no treatment with Ig?; when to start it?
 - Optimal dosing for SIDs / for which SIDs?
 - Long-term outcomes in autoimmune-related SIDs
 - Cost-effectiveness studies for EU health systems

Next steps

- Listen, learn, exchange on:
 - The commonalities and divergences of PIDs & SIDs.
 - Policies supporting patient-centred care on PIDs & SIDs
- **This is not a one-off meeting:** This is the kick-off meeting for a continued exchange
- **Objective:** Hold a PID Forum in 2026 where to present policy recommendations and the way forward at EU level.

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Thank you for your attention

PID FORUM



Perspectives in Patient Involvement in EU Research

- ***Prof. Dr. Silvia Sánchez Ramón, Hospital Clínico San Carlos***
- ***Andrew Symes, The Royal Free London NHS Foundation Trust, International Nursing Group for Immunodeficiencies (INGID)***
- ***Martine Pergent, President, IPOPI***



Open Floor Discussion



Key Takeaways & Policy Recommendations



Closing Statements

MEP Michalis Hadjipantela (EPP, Cyprus)

**THANK YOU FOR
ATTENDING THE
PID FORUM!**

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