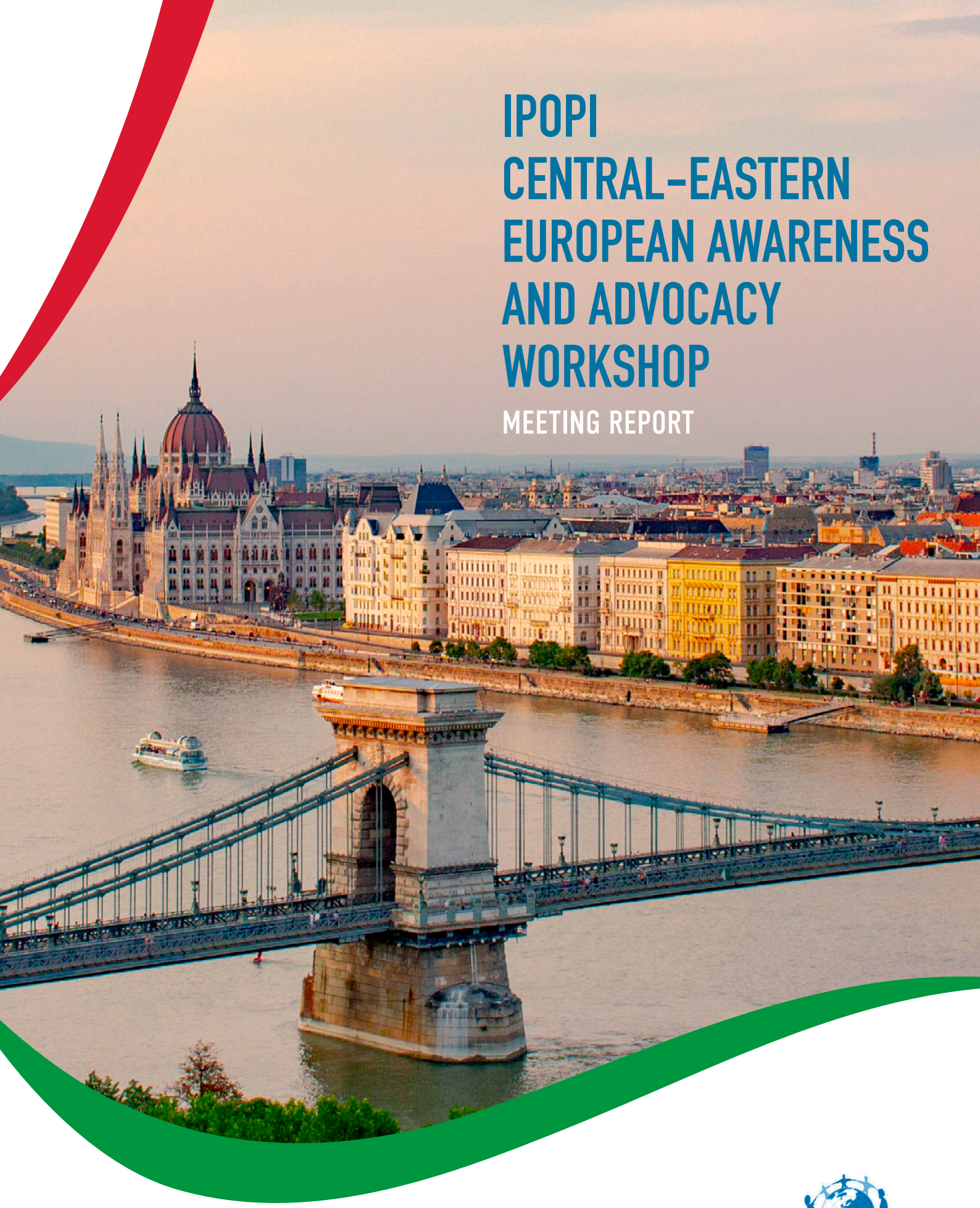
IPOPI CENTRAL-EASTERN EUROPEAN AWARENESS AND ADVOCACY WORKSHOP

MEETING REPORT



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On **27- 28 September 2025,** IPOPI had the pleasure of hosting the **Central-Eastern European Awareness and Advocacy Workshop** in **Budapest, Hungary**, bringing **together patient representatives and medical advisors from nine countries across the region.**

This **one-and-a-half-day workshop** was designed to **strengthen the capacity of National Member Organisations (NMOs)** by providing **practical tools, strategic guidance,** and **shared learning** to support the development of **effective, country-specific awareness and advocacy initiatives.** Beyond its educational value, the workshop created a **trusted space for dialogue and collaboration,** enabling patient representatives and medical advisors to exchange perspectives, build lasting connections, and explore opportunities for joint action to improve outcomes for people living with primary immunodeficiencies across Eastern Europe.

This report summarises the key discussions, insights, and ideas shared during the meeting. IPOPI warmly thanks all participants for their active engagement and valuable contributions, which were essential in making the meeting both productive and impactful.

Access the agenda, presentations, and pictures of the meeting.

Key Challenges and Achievements in Primary Immunodeficiency Care in Central-Eastern Europe

Common Reported Challenges:

1. **Limited or delayed access to diagnosis / genetic testing.**

2. **No or insufficient Hematopoietic Stem Cell Transplantation** (HSCT) availability.

3. **Limited awareness of PIDs** among General Practitioners (GPs) and other specialist doctors.

4. **Not implemented Severe Combined Immunodeficiency (SCID) newborn screening.**

5. **Administrative barriers,** including insurance procedures and bureaucratic obstacles.

Common Reported Achievements

1. **Improved immunoglobulin therapy access** (IVIG/SCIG/fSCIG) for children and adults.

2. **Progress on SCID newborn screening** (pilot or implementation)

3. **Expansion of genetic testing capacity,** even if uneven.

4. **Improved cooperation among doctors or reference centres,** enabling peer consultation and shared expertise.

5. **Patient group empowerment**

Country-Level Insights:

AUSTRIA	CHALLENGES	ACHIEVEMENTS
Patient perspective	Patients report not being taken seriously despite serious illness; increased insurance refusals for Ig therapy; long waiting times to see specialists.	Access to appropriate care and support; establishment of specialised PID centres.

BOSNIA AND HERZEGOVINA	CHALLENGES	ACHIEVEMENTS
Patient perspective	Diagnosis not covered; Lack of adult specialists to make transition possible.	IVIG included in the national essential medicines list and covered jointly by hospitals and health insurance for children and adults.
Doctor perspective	Delayed diagnosis due to limited laboratory capacity; insufficient funding for genetic testing; limited access to treatment for adults (IVIG is free for children, but it´s difficult for adults to access it).	PID warning signs included in healthcare professional (HCP) guidance; establishment of haematology and paediatric clinics; ongoing educational activities for HCPs and patients.

BULGARIA	CHALLENGES	ACHIEVEMENTS
Patient perspective	Limited PID awareness among paediatricians; legislation and authorities do not consider coverage.	Covered IVIG and subcutaneous Ig (SCIG) for children and adults; Excellent doctor–patient connection.
Doctor perspective	No access to HSCT; lack of coverage for biological treatments; JAK inhibitors not covered for patients above 18 years of age.	SCID newborn screening planned 2026; free IVIG and SCIG for all ages.

ESTONIA	CHALLENGES	ACHIEVEMENTS
Patient perspective	No national SCID newborn screening (pilot only); limited human and infrastructure resources.	Strong connection with IPOPI; having an experienced patient advocate to help other families.

HUNGARY	CHALLENGES	ACHIEVEMENTS
Patient perspective	Long diagnostic delays; low PID awareness among doctors; limited funding for genetic testing; lack of SCID newborn screening; no government coverage for subcutaneous equipment; and insufficient PID care units outside major centres.	Ig therapies (IVIg, SCIg, fSCIg) covered; restart of the national PID registry; active PID patient community; automated funding enabling rapid treatment initiation post-diagnosis; Restarted the PID registry by Délpesti Centrum Hospital, in Budapest, Hungary.
Doctor perspective	SCID newborn screening is not functional; regulatory barriers to genetic testing.	National network of over 100 doctors for peer case discussion; active PID patient community.

POLAND	CHALLENGES	ACHIEVEMENTS
Patient perspective	Low PID awareness among GPs; late diagnosis; weak collaboration between immunologists and other specialists.	Reimbursed and continuous Ig treatment; Committed medical teams.
Doctor perspective	Limited access to genetic testing (especially in adults); need to address broader patient needs (nutrition, education, work).	Simplified adult PID care protocols; practical recommendations for comorbidities; strong interdisciplinary collaboration; transition of care.

ROMANIA	CHALLENGES	ACHIEVEMENTS
Patient perspective	No SCID newborn screening.	Access to SCIG and facilitated SCIG; good patient–doctor collaboration.
Doctor perspective	Difficulty diagnosing late-onset PIDs; lack of curative treatments; limited access to antibiotics and antifungals; absence of plasma collection centres; no specialist in PIDs to perform HSCT.	Improved access to genetic testing, however it´s not covered; sufficient Ig supply with timely and adequate dosing.

SERBIA	CHALLENGES	ACHIEVEMENTS
Patient perspective	Poorly structured transition of care; heavy administrative burden for patients to access a diagnosis and treatment.	Access to genetic analysis; strong doctor–patient collaboration.
Doctor perspective	Inequalities in care around the country; limited PID awareness outside major centres; transition of care gaps.	Expanded genetic diagnostics; Excellent collaboration with geneticists; good approach to treatment.

UKRAINE	CHALLENGES	ACHIEVEMENTS
Patient perspective	Patient migration from the country and not having access to their treatment; need for a dedicated immunodeficiency centre.	SCID newborn screening; coverage of Ig therapy for children and adults.
Doctor perspective	Restricted access to diagnostics and advanced therapies.	SCID newborn screening introduced in 2022; access to bone marrow transplantation.

Cross-Border Initiatives to Improve PID Diagnosis

During the meeting, participants held discussions on cross-border initiatives to allow the improvement of PID diagnosis in the Central-Eastern European region, benefiting from the experience and resources of fellow countries in the region.

Ideas discussed:

• **School education programme** - Develop an educational outreach targeting schools and community organisations, particularly in rural areas. This would include information desks with IPOPI or local leaflets, and an interactive “learn PID from me” approach. Materials should be adaptable and translatable across countries.

• **Genetic testing access** - The discussion highlighted major disparities in access to genetic testing. To move forward, participants identified the need to involve patient organisations, legal experts, and key stakeholders. A proposed first step is to create a standardised legal and medical patient information form. This would support negotiations with governments and insurers, using examples such as Romania’s limited monthly voucher system.

• **Quarterly webinars for haematologists** - Organise online meetings across Eastern Europe to discuss cases and share experiences.

• **Regional doctor network** - Build a cross-border network to share PID cases, raise awareness among primary healthcare professionals, and provide updates on available diagnostic resources. Activities would include virtual case discussions, sessions for primary care physicians on recognising PIDs, and sharing country-specific information on diagnostic resources such as genetic testing.

Plasma Collection in the Region

A survey among participants from eight countries revealed significant differences in plasma collection practices, including supply gaps, regulatory and method variations, and information provided to the general public. Access to Plasma-Derived Medicinal Products (PDMPs) remains a concern, and plasma wastage is common.

• **Is plasma collected in your country for plasma-derived therapies?** - Only 3 countries reported sufficient plasma collection (Austria, Ukraine and Hungary), 4 reported insufficient collection (Poland, Bosnia and Herzegovina, Serbia and Bulgaria), and 1 country does not collect plasma at all (Romania).

• **How is plasma collected?** - Practices vary widely: 2 countries rely on plasmapheresis only (Ukraine and Hungary), 3 on whole blood collection only (Poland, Bosnia and Herzegovina and Serbia), 1 uses both methods (Austria), and 2 didn´t know (Romania[1] and Bulgaria).

• Most country representatives were aware of the difference in terms of plasma volumes collected in a whole blood donation and a plasma donation. This is an important point in **raising awareness about plasma collection and the different collection methods there are.**

• **Is plasma wasted?** - Wastage is common, occurring sometimes in 4 countries (Ukraine, Poland, Serbia, and Bulgaria), always in 1 (Romania), not at all in 2 (Austria and Hungary), and didn't know in 1 (Bosnia and Herzegovina).

1 Romania collects plasma via plasmapheresis, but it is used only as a whole plasma product in hospitals and is not processed into PDMPs.

• **Who collects plasma in your country?** - The public sector collects in 4 countries (Romania, Poland, Serbia and Bosnia and Herzegovina), private commercial in 1 (Ukraine), a combination of public and private non-profit in 1 (Bulgaria), and all sectors in 2 (Austria and Hungary).

• **Is plasma collection by the Private Sector-Commercial allowed in your country?** - Only 2 countries said that this allowed it (Ukraine and Hungary), 4 do not (Romania, Poland, Serbia and Bosnia and Herzegovina), and 2 didn´t know (Austria[2] and Bulgaria).

Proposed ideas to improve access to plasma collection:

• **Increasing plasma collection capacity** through public and private collaboration;

• **Engage with multiple stakeholders,** such as other patient organizations and medical experts like neurologists and hematologists, who also need access to PDMPs, to **work together in advocating for increased plasma collection.**

• Highlighting the **economic benefits** of healthy patients to policymakers;

• **Incentivising donors;**

• **Establishing new plasma collection centers;**

• Conducting **public engagement campaigns.**

Regulation Surrounding Access to Therapies

The session covered the **fundamentals of accessing therapies**, including key concepts such as **marketing authorisation, Health Technology Assessment (HTA), pricing, reimbursement,** and **availability**. Participants learned that access depends on multiple factors:

• Marketing authorisation ensures medicines are safe, effective, and of high quality;
• HTA provides guidance to decision-makers but is not binding; and
• Pricing and reimbursement are determined nationally or regionally.

Having a solid understanding of these fundamentals is essential for patient organisations to play a **valuable role in collaborating with stakeholders** and supporting **stable access to therapies.**

It was also emphasized that the **vital role of patient organisations,** working alongside **patient representatives and medical advisors,** in improving patient outcomes. Through **awareness, education, advocacy, and research,** organisations can drive earlier diagnosis, empower better disease management, improve access to treatment, and contribute to the development of future therapies.

2 IPOPI note: In Austria, it is allowed to collect plasma by the Private Sector-Commercial.

Transition of Care: From Teens to Adults

The session focused on the **importance of transition of care for patients with PIDs, highlighting the difference between transition and transfer:**

- **Transition** - a structured, planned, continuous, patient-centred process;
- **Transfer** - simply moving a file from one provider to another).

Examples from leading centres worldwide—including Val d'Hebron (Spain), Necker Hospital (France), GOSH (London), and Sainte-Justine Hospital (Canada)—illustrated how different structured transition practices can improve outcomes for patients moving from paediatric to adult care.

Key takeaways from the lecture emphasized that, thanks to progress in diagnosis and treatment, **transition of care is now essential. Successful transition requires: early planning,** a **structured process,** a **multidisciplinary approach, involvement of adult immunologists** with an interest in PIDs, **patient and family education**, and **individualised transition plans.**

A **role-play exercise** demonstrated **strategies to advocate** for improved transition at the national level, including:

- Preparing a **realistic and flexible plan.**

- **Understanding the audience and context.**

- **Communicating diplomatically** — explaining concepts carefully, even if they seem basic, and using phrases like "as you might know…" to allow the other person to confirm their understanding or listen comfortably.

- Remaining **professional and calm,** while **adopting a collaborative approach.**

- Providing **clear leave-behind documents** and **securing next steps.**

- Showing **appreciation for the time** and **input of decision-makers.**

The Power of Speaking Up

This session highlighted the powerful role patient organisations can play when they speak up with clarity, purpose, and confidence. A dedicated lecture emphasised that using **trustworthy international, national, and patient-driven sources** is essential to influence decision-makers and the wider public.

Using the **IPOPI Toolkit** as a practical foundation, participants translated theory into action. The proposed campaigns demonstrated creativity and strategic thinking—using social media, clear messaging, visual content, and calls to action to reach healthcare professionals, the general public, parents-to-be, and policymakers. Across all groups, a shared message emerged: **early diagnosis saves lives, reduces complications, and allows people with PID to live full, productive lives.**

The session concluded with a strong sense of empowerment, showing that informed, coordinated action enables patient organisations to speak up with confidence and drive meaningful improvements in diagnosis, treatment, and quality of life for PID patients.

Conclusion

The two-day workshop proved to be a **highly impactful and energising experience** for participants, combining **practical learning with meaningful human connection.** Attendees gained new perspectives on primary immunodeficiencies (PIDs), strengthened their knowledge, and developed concrete skills.

Beyond the learning outcomes, the workshop **fostered meaningful networking and collaboration between NMOs and medical advisors.** The relationships built during the meeting form a **strong foundation for future joint efforts** to improve diagnosis, treatment, and care for people living with primary immunodeficiencies across Central-Eastern Europe.

Participant Feedback

A feedback form was completed by 10 participants out of the 18 meeting participants, with all rating the workshop as **excellent** (10/10).

This meeting was made possible with the support of GRIFOLS

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