

REVIEW OF ACTIVITIES AND ACHIEVEMENTS

2025



UPCOMING



XIX IPOPI GLOBAL PATIENTS' MEETING

an **IPOPI** event

#GPM2026

14-16 OCTOBER 2026

MAASTRICHT, THE NETHERLANDS



A MESSAGE FROM IPOPI'S PRESIDENT AND EXECUTIVE DIRECTOR

Guided by our commitment to improving the lives of people living with primary immunodeficiencies (PIDs) and associated conditions, 2025 has been another year of continued progress, collaboration and growth for IPOPI. Together with our **79 National Member Organisations (NMOs)**, healthcare professionals, researchers and a wide network of other partners, we have continued to strengthen the voice of the PID community whilst advancing our strategic priorities through patient-centred advocacy, education, research and international collaboration.

Our National Member Organisations are at the heart of everything we do. Throughout the year, we strengthened our global network notably through regional meetings in Kenya and Argentina, bringing together NMO leaders to exchange experiences, share best practices and identify common priorities across regions. We also organised our first national advocacy workshop in China, continued to deliver our NMO Support Programmes, educational webinars, and expanded opportunities for new collaborations. As part of World PI Week, we also supported a range of awareness and advocacy activities led by our NMOs, helping to strengthen their national campaigns. These initiatives further strengthened our global network and demonstrated the value of collaboration and shared learning.

79 NATIONAL

MEMBER ORGANISATIONS

One of the defining moments of the year was the success of IPIC 2025 in Prague. Bringing together more than 900 participants from around the world, the congress once again demonstrated the strength, expertise and commitment of the global PID community. By fostering scientific exchange, multidisciplinary collaboration and meaningful engagement between patients, clinicians and researchers, IPIC continues to play a vital role in advancing knowledge and improving patient care worldwide.

Innovation continued to shape IPOPI's work throughout 2025, particularly in the rapidly evolving field of artificial intelligence. Recognising the transformative potential of AI to improve the diagnosis and management of rare immune disorders, we worked to ensure that the patient perspective remained central to discussions on its development and implementation. AI, quantum computing and digital health were indeed one of the key topics discussed at the IPOPI Global Stakeholder Summit which continued to provide a forward-thinking forum designed to provoke a prospective and multidimensional discussion to tackle the future priorities of the PID community.

Advocacy remained at the heart of IPOPI's mission throughout 2025. From supporting patient leaders through global advocacy initiatives and promoting equitable newborn screening worldwide to engaging with policymakers, regulators and international organisations, we worked to ensure that the voices of people living with PIDs continued to influence decisions affecting their lives. Whether advocating for improved access to diagnosis and immunoglobulin therapies, strengthening patient involvement in research, addressing the opportunities and challenges of artificial intelligence in healthcare, or contributing to discussions on sustainable plasma collection and secondary immunodeficiencies, our objective remained the same: to advance policies that improve outcomes for patients wherever they live.

Education, communication and research remained essential pillars of our work. We continued to strengthen knowledge-sharing across the global PID community by providing reliable educational resources, expanding opportunities for learning and dialogue, and raising awareness through innovative communication initiatives, including the *Immunity Pulse* podcast, the *IPOPI Hard Talks* webinar series and two new mini-documentaries. Alongside these efforts, we were proud to launch our new renamed IPOPI José Drabwell Research Grant Programme, reaffirming our commitment to supporting innovative patient-centred research and advancing innovations that will improve the diagnosis, treatment and quality of life of people living with PIDs and associated conditions.

Collaboration remains one of IPOPI's greatest strengths and remains a fundamental objective to achieve lasting change. Throughout the year, we worked alongside clinicians, researchers, policymakers, regulators, industry partners and international organisations on initiatives including the World Primary Immunodeficiency Week, the Plasma4Life project, the International Neonatal Screening Day, Screen4Rare, AGORA, TRANSFORM, and collaborative research programmes. We also continued our work with the European

Medicines Agency on numerous fronts. These partnerships continue to strengthen research, improve healthcare systems and ensure that patient voices remain at the centre of innovation and decision-making.

As we look ahead, preparations are well underway for the **Global Patients Meeting in Maastricht, from 14–16 October 2026**. This gathering will provide another important opportunity to strengthen our international community, exchange knowledge and shape the future of PID advocacy together.

We thank everyone who contributed to this remarkable year and invite you to explore this Annual Review to discover the many initiatives, collaborations and successes that made 2025 another important year of progress for the global PID community.



A stylized white signature of Martine Pergent on a blue background.

Martine Pergent
IPOPI President



A stylized white signature of Johan Prévot on a blue background.

Johan Prévot
IPOPI Executive Director

EXECUTIVE COMMITTEE, OFFICERS AND STAFF 2025

EXECUTIVE COMMITTEE

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Bruce Lim, Vice, Chair
Otilia Stanga, Treasurer
Whitney Ayoub
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Roberta Anido
Tracy Shaw
Dimas Sugiharto

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VICE CHAIR
Prof Silvia Sánchez Ramón
(from November 2025)

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Dr Elizabeth Rivers - UK
Dr Silvia Sánchez-Ramón - Spain
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Prof Klaus Warnatz - Germany

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Prof Tadej Avcin - Slovenia
Prof Aziz Bousfiha - Morocco
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Miriam Ferreira: NMO Programmes Manager

Clare Glynn: Financial Advisor

Lúcia Mamede: Medical Affairs Project Manager

Carla Morgado: Office Manager

Mercedes Muraca: Events and Logistics Coordinator

Rafael Graça: Communications Manager

Leire Solis: Health Policy and Advocacy Senior Manager

NETWORK OF EXPERTS

The IPOPI Network of Experts (IPOPI NEX) serves as a valuable consultative network within IPOPI's framework. While not formally integrated into IPOPI's governance structure, IPOPI NEX was established to offer voluntary expert advice and information to the IPOPI Board of Directors. Distinguished by their diverse fields of expertise, IPOPI NEX consultants provide a crucial supplement to the clinical and scientific proficiency of the IPOPI Medical Advisory Panel (MAP).

IPOPI NEX MEMBERS 2025

Dr Manuela Mura (Regulator)

Dr Peter Jawroski (Ethicist)

Nurse Mary Louise Daly (Nursing)

Prof Albert Farrugia (Plasma industry/access specialist)

Prof Bobby Gaspar (Advanced therapies industry specialist)

Prof James Taylor (Ethicist)

Prof Dr Frank Staal (Academic ATMP specialist)

Prof Dr Cornelis Boersma (Health economist)

Mr Matthew Hotchko, PhD (Plasma Industry market data specialist)

IPOPI STRATEGIC PLAN

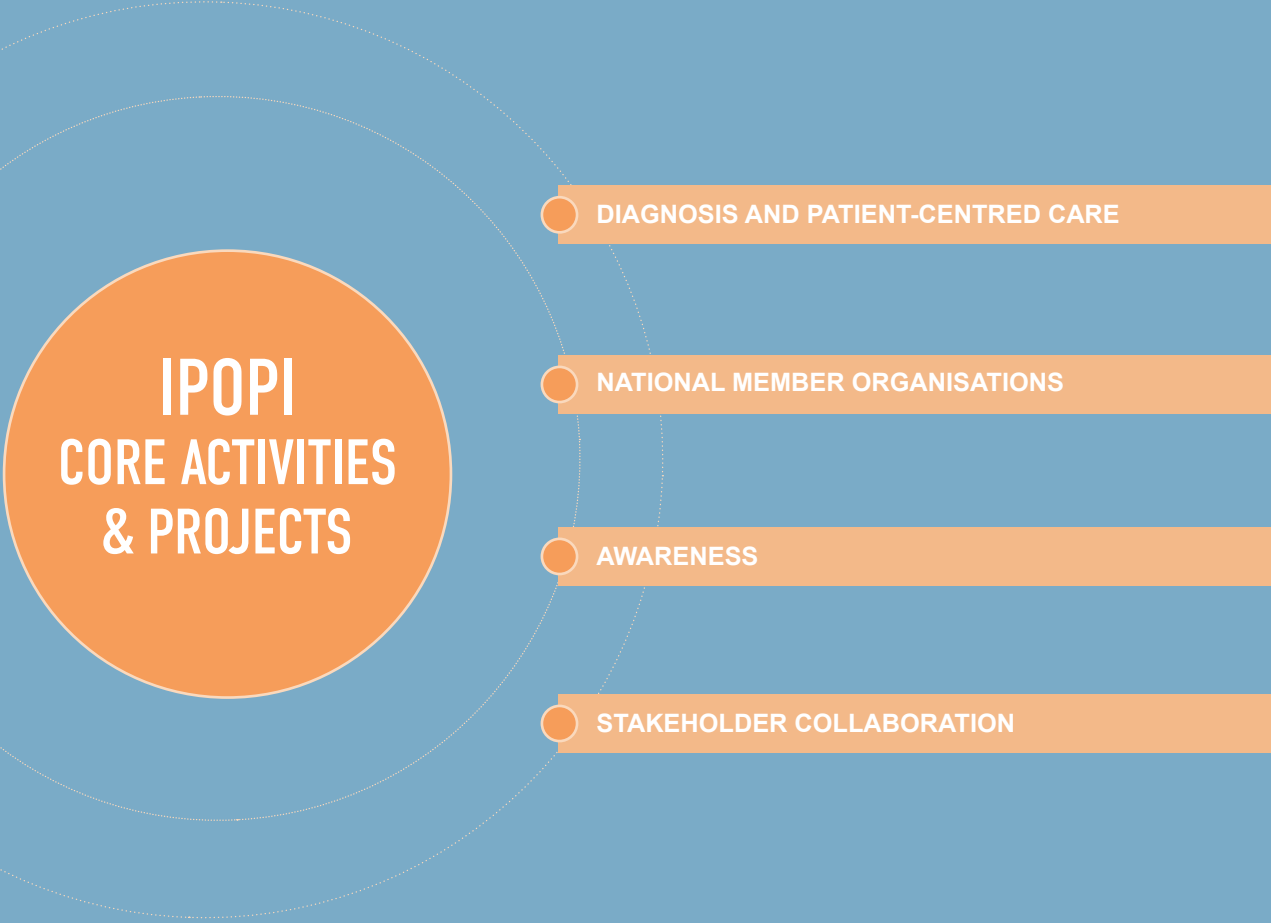
MISSION AND OBJECTIVES

IPOPI is a non-profit international organisation and the leading advocate for patients living with primary immunodeficiencies (PID) and associated conditions worldwide, working in collaboration with patients, doctors, politicians, regulators, the pharmaceutical industry and other relevant stakeholders.

IPOPI is the Association of National PID patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for primary immunodeficiency patients worldwide through global collaboration.

IPOPI STRATEGIC OBJECTIVES 2021-2025

1. Improve access to early diagnosis and patient-centred care *through advocacy and awareness.*
2. Build capacity and support IPOPI's national member organisations *to improve living conditions for people living with PID*
3. Educate, promote knowledge and data sharing *to increase understanding of PID, improve clinical care and advance research*
4. Strengthen multi-stakeholder cooperation to optimise *all programmes and activities*



IPOPI CORE ACTIVITIES & PROJECTS

DIAGNOSIS AND PATIENT-CENTRED CARE

NATIONAL MEMBER ORGANISATIONS

AWARENESS

STAKEHOLDER COLLABORATION

WHAT ARE PIDs?

Primary immunodeficiencies (PIDs, also referred to as 'Inborn errors of Immunity' — IEI) are a large and growing group of over 559 different genetic defects that cause some components of the immune system (mainly cells and proteins) to be lacking or not work properly.

Whilst PIDs are generally recognised as rare disorders, some are more common than others and, taken as a whole, they affect an important group of people whose lives are profoundly impacted by their condition.

The majority of PIDs are caused by genetic defects of the immune system, which are mostly hereditary. The immune system normally helps the body fight off infections caused by germs (or 'micro-organisms') such as bacteria, viruses, fungi and protozoa. It also helps to prevent inflammation, autoimmunity, severe allergies and malignancies, which are frequent manifestations in PID patients.

When PIDs are left underdiagnosed or are misdiagnosed, the immune system remains defective, often leading to illness, disability, permanent organ damage or even death.

DIAGNOSIS

Whilst it is estimated that around 60% of PIDs can be easily diagnosed with simple and inexpensive blood tests, many PIDs remain underdiagnosed on a global scale. Hopefully, as the technical ability to identify gene defects improves, more and more genetic causes of PID are being identified.

Medicine and Science are advancing very rapidly, and novel therapies that target the specific cause of the disease are becoming available. These may have significant advantages for PID patients, so it is important that patients throughout the world have access to these treatment possibilities.

Screening for some of the most severe forms of immunodeficiency, such as Severe Combined Immunodeficiencies (SCID), will also diagnose more individuals at an earlier stage, thus improving treatment outcomes.

TREATMENT

With appropriate access to different and very effective therapies, which can only happen if an early and correct diagnosis is made, many sequelae will be avoided, and the lives of patients will be saved.

People with PIDs are normally treated by doctors who specialise in diseases of the immune system. How a patient is treated depends on which PID they have and on many other factors. Mainstay or curative treatments for PIDs include immunoglobulin (Ig) replacement therapies (IgRT), Hematopoietic Stem Cell Transplantation (HSCT, also known as 'bone marrow transplantation'), gene therapy, cytokines such as Granulocyte-Colony Stimulating Factor (G-CSF), recombinant gamma interferon, enzyme replacement therapy such as recombinant adenosine deaminase for patients with ADA1 deficiency, anti-infectious prophylaxis (with antibiotics, antifungals and/or antivirals), monoclonal antibodies, among others.

IMMUNOGLOBULIN REPLACEMENT THERAPY

In the case of Ig replacement therapies, it is important to know that different Ig products are not interchangeable or mixable. Ig can be administered intravenously or subcutaneously. They are considered essential medicines for PIDs by the World Health Organisation. Intravenous immunoglobulin (IVIG) infusion usually takes 2-4 hours, allowing high doses to be given and only needs to be given every 3-4 weeks, which may suit some patients better.

Subcutaneous immunoglobulin (SCIg) can only be given in small doses. It only takes 1-2 hours and can often be administered at home by patients themselves, parents or carers. This option may therefore be more convenient for some patients. SC infusion preceded by an SC infusion of recombinant human hyaluronidase, which is known as 'facilitated' subcutaneous immunoglobulin (fSCIG), allows patients to have SC 3-4 hours long infusions every 3-4 weeks. IgRT should be discussed on a shared-decision basis for each individualised case, according to patient needs and preferences.

CLASSIFICATION

PIDs are currently classified by the IUIS PID/IEI expert committee into 10 groups: predominantly antibody deficiencies; combined immunodeficiencies; combined immunodeficiencies with associated or syndromic features; diseases of immune regulation; congenital defects of phagocyte number or function, or both; defects of innate immunity; auto-inflammatory disorders; complement deficiencies, based on the main immunological defects; phenocopies of Primary Immunodeficiencies and inherited bone marrow failures. IPOPI is committed to continuing to disseminate information to patients, their relatives and doctors and work towards better access to early diagnosis and treatment for all patients living with a PID.

For more information about PIDs and how they are treated and diagnosed, as well as advice on how to stay healthy, please refer to the IPOPI information leaflets.



IPOPI'S KEY ACHIEVEMENTS AND ACTIVITIES, 2025

STRATEGIC OBJECTIVE 1

IMPROVE ACCESS TO EARLY DIAGNOSIS AND PATIENT-CENTRED CARE

IPOPI remains dedicated to fostering long-term improvements in PID diagnosis and ensuring that all PID patients have access to appropriate, patient-centred care. Through various advocacy, awareness-raising, and educational campaigns and programmes, IPOPI works diligently to make a difference. By continuing these efforts, IPOPI aims to create a better future where the diagnosis of PID is improved, and all patients receive the quality care they deserve.

EU PID FORUM – UNDERSTANDING AI'S ABILITY TO TRANSFORM PID HEALTHCARE

On January 27, IPOPI PID Forum brought together a vibrant group of patient advocates, experts, and policy-makers to explore how artificial intelligence (AI) can transform healthcare for people with Primary Immunodeficiencies (PIDs) in the European Union. The EU PID Forum on “Understanding AI's Ability to Transform PID healthcare” was chaired by the Member of the European Parliament (MEP) András Kulja (EPP, Hungary) and was held at the European Parliament in Brussels (Belgium).

The Forum, moderated by Leire Solis, IPOPI's Health Policy and Advocacy Director, explored the challenges and opportunities to ensure a patient-centered use of AI, from improving diagnostics to enhancing care and treatment.

The speakers of this Forum were: Martine Pergent, IPOPI President, Dr Jacques Riviere, paediatric immunologist from Vall d'Hebron University Hospital (Spain), Dr Helen Leavis, from UMC Utrecht (the Netherlands), Johan Prevot, IPOPI Executive Director, Martin Ulbrich, AI expert from the AI Office of the EU Commission, Ms Nooshin Amirifar, from CEN-CENELEC.

There was a full room at the Forum, with representation of several NMOs: Otilia Stanga (President of the Romanian Association for Patients with PIDs, ARPID, and IPOPI treasurer), David Jimenez (Board member of the Spanish PID patient organisation, AEDIP), Dr Eva Varga (Board member of the Hungarian PID patient organisation) and Marie-Sophie Enry-Aude (Board member of the French PID patient organisation, IRIS).



EU PID FORUM – SHAPING THE FUTURE OF RESEARCH: PATIENTS AS EQUAL PARTNERS

On 14 May, the International Patient Organisation for Primary Immunodeficiencies (IPOPI) organised a PID Forum titled 'Shaping the Future of Research: Patients as Equal Partners'. The event took place in Brussels (Belgium) in the European Parliament. It was co-hosted by Member of the European Parliament (MEP) Romana Jerković (S&D, Croatia) and Nicolás González Casares (S&D, Spain).

Martine Pergent, President of IPOPI, moderated the Forum, which aimed at discussing how EU research could benefit from the inclusion and recognition of patient organisations as equal partners.

The speakers of the Forum were the following: Johan Prevot, IPOPI Executive Director, Dr Daria Julkowska, Coordinator at the European Rare Diseases Research Alliance (ERDERA), Prof Frank Staal, Recombination Coordinator working at Leiden University Medical Center (the Netherlands), Dr Filomeen Haerynck, Paediatric Immunologist at UZ Gent (Belgium), Christina Kyriakopoulou, Scientific Policy Officer at DG RTD.D.2 of the European Commission,

The Forum drew a large audience, including delegates from various NMOs: Janine Bastiaans (Board member of the Dutch PID patient organisations), David Jimenez (Board member of the Spanish PID patient organisation, AEDIP) and Anne-Sophie Henry-Aude (Board member of the French PID patient organisation, IRIS).



EU PID FORUM – SECURING ACCESS FOR PID PATIENTS THROUGH THE CRITICAL MEDICINES ACT

On November 12, IPOPI organised a PID Forum to discuss how access could be secured for persons living with primary immunodeficiencies (PIDs) in the EU. The PID Forum specifically looked at a legislative initiative under discussion at the EU level called the Critical Medicines Act and focused on immunoglobulin replacement therapies and gene therapies. The Forum, held online, welcomed the interventions of the Members of the European Parliament Tomislav Sokol (EPP; Croatia), Peter Agius (EPP, Malta) and Ondrej Dostal (NI, Czechia).

Moderating the event, Johan Prévot, Executive Director of IPOPI, emphasised the importance of the CMA for PID patients and the opportunity it presents to strengthen Europe's capacity to ensure equitable access to essential medicines, reinforce supply resilience and improve crisis preparedness.

Speakers in this Forum were: Martine Pergent, IPOPI President, Daniela Ene, a person living with a SCID, Prof Fabio Candotti, President of the European Society for Immunodeficiency (ESID), Otilia Stanga, President of the Romanian patient organisation (ARPID) and IPOPI Board member, Rafal Ramotowski, Associate Director and Lead for EU Public Affairs and Communications at the Plasma Protein Therapeutics Association (PPTA), Dr Leni von Bonsdorff, Executive Director of the International Plasma and Fractionation Association (IPFA).

The online format of this Forum increased the number of participants, reaching an audience of around 100 participants.



EU PID FORUM – WHEN RARE MEETS THE NOT-SO-RARE: THE CASE OF PIDS AND SIDS

On December 9, the IPOPI PID Forum convened policymakers, clinicians, patient advocates, and experts at the European Parliament in Brussels for an in-depth exploration of the growing intersection between Primary Immunodeficiencies (PIDs) and Secondary Immunodeficiencies (SIDs).

The Forum, titled “When rare meets the not-so-rare: The case of PIDs and SIDs,” highlighted the increasing need for integrated European policies that ensure timely diagnosis, access to care, and adequate protection for all individuals living with immune-related conditions. The event was chaired by MEP Michalis Hadjipantela (EPP, Cyprus) and MEP Tomislav Sokol (EPP, Croatia). It was moderated by Leire Solis, IPOPI’s Health Policy and Advocacy Director.

The Forum opened with a video from a patient, Vicente Rodrigo, who had overcome two lymphomas to be then diagnosed with a PID, providing a very personal but powerful example of the path followed by many individuals. It was followed by Martine Pergent, IPOPI President, who set the scene by introducing key concepts and the context for addressing PIDs and SIDs together, their similarities, differences and common challenges.

A central part of the event was a panel featuring Prof Silvia Sanchez-Ramón (IPOPI Medical Advisory Panel Vice-Chair), from Hospital Clínico San Carlos (Spain); Andrew Symes, from the Royal Free London NHS Foundation Trust (UK) and the International Nursing Group for Immunodeficiencies (INGID) and Martine Pergent (IPOPI President). The panellists discussed the links between primary and secondary immunodeficiencies, the need for a multidisciplinary approach, as well as for cross-fertilisation when approaching individualised care for patients with a primary or a secondary immunodeficiency. The participants had plenty of opportunities to interact with panellists and important aspects were touched upon: key aspects of genetic studies, of getting a diagnosis that helps establish an adequate treatment, but also care for the patient, the essential role of nurses in supporting the patient not just with the treatment, but with coping with the diagnosis and the subsequent care required. Savvas Savva, representing the Cypriot PID patient group, explained the importance of an accurate diagnosis and how it was challenging to obtain in certain Member States.



IPIC2025 IN PRAGUE, CZECH REPUBLIC

The International Primary Immunodeficiencies Congress (IPIC) 2025 took place in Prague, Czech Republic in November 2025. IPIC2025 surpassed expectations, achieving remarkable success with increased attendance and enhanced content quality whilst fostering a more collaborative atmosphere than ever before. With **OVER 900** participants, IPIC solidified its reputation as the global conference for those dedicated to advancing their understanding of PID diagnosis and clinical care. Moreover, the congress showcased 258 approved posters, with a significant contribution from passionate young physicians propelling PID research and clinical practices forward.



PIDETECT PROGRAMME: INTENSIVE PID DIAGNOSTICS TRAINING

The IPOPI PIDetect Programme provides intensive training to selected healthcare professionals from LMIC to improve their skills in recognising and diagnosing PIDs. The programme is hosted at a PID reference centre working in partnership with IPOPI and aims to improve the diagnosis of PIDs in the target country while simultaneously building a local network. It comprises intensive clinical and/or laboratory training tailored to the individual needs and backgrounds of each attendee, followed by a local implementation activity in which the acquired expertise is shared more widely with doctors and other healthcare professionals in the target country.

Building on the PIDetect training programme implemented in previous years, IPOPI continued to support capacity building for the diagnosis of primary immunodeficiencies (PIDs) in Cambodia.

In 2025, to share the knowledge and expertise gained through PIDetect, Dr Chin Soey led the country's first pilot newborn screening activity for PIDs at the National Pediatric Hospital in Phnom Penh. The pilot focused on introducing dried blood spot (DBS) screening for severe and life-threatening PIDs, particularly Severe Combined Immunodeficiency (SCID) and X-linked Agammaglobulinaemia (XLA). The initiative aimed to assess the feasibility of newborn PID screening in Cambodia, strengthen local capacity for early diagnosis, and generate evidence to support future policy development.



In Africa, following the PIDetect training programme in Mali, the knowledge acquired was disseminated nationwide through a series of activities in 2025. These included a webinar for Malian paediatricians and medical education workshops for doctors across multiple specialties, organised in Segou and Bamako to raise awareness of PIDs and improve diagnosis rates across the country.

In 2025, the PIDetect Programme had a new edition, this time in South America. Dr Jenniffer Martínez, a paediatric immunologist from San Lorenzo de los Mina Maternity and Children's Hospital in the Dominican Republic, completed a one-month intensive training in October 2025 at Hospital Garrahan in Buenos Aires, Argentina, under the supervision of Dr Matías Oleastro, Head of the Immunology Service, and his experienced team. In 2026, the programme will move into its second phase, centred on a national implementation plan to share the knowledge acquired with healthcare professionals, strengthen diagnostic pathways, and ultimately ensure that more patients in the Dominican Republic receive timely diagnosis and appropriate care.

IPOPI PID HARD TALKS WEBINARS

IPOPI organised several digital events as part of its successful series of “IPOPI Hard Talks” launched in 2023. This engaging series is intended for all relevant stakeholders with an interest in primary immunodeficiency (PID) diagnosis and clinical management, including clinicians, nurses and patient group leaders. Featuring interactive discussions and a lively debate between expert speakers, “IPOPI Hard Talks” aims to address the more challenging topics in a stimulating fashion. The series also seeks to maximise outreach to key opinion leaders across different regions and increase expertise around key clinical care issues. This year the series consisted of the following episodes:

ADA-SCID MANAGEMENT – FROM DIAGNOSIS TO TREATMENT

The first Hard Talk webinar took place on 6 June and focused on the management of ADA-SCID, covering the patient journey from diagnosis to treatment.

Dr Reem Elfeky opened the session by tracing the timeline of major discoveries in ADA-SCID, outlining how diagnostic tools and treatment options have evolved. She also addressed recent advances, including gene therapy, and discussed current challenges in ensuring access to care.

Prof Fabio Candotti then explored what is known about the long-term effects of ADA-SCID treatments. His talk highlighted the importance of ongoing monitoring and multidisciplinary support to improve patient outcomes and quality of life.



CLINICAL APPLICATION OF CALCULATED GLOBULIN SCREENING

The following webinar took place on the 28th of October and brought together Prof Stephen Jolles, Dr Cecilia Poli, and Dr Nizar Mahlaoui to explore the implementation of calculated globulin screening for the diagnosis of patients with antibody deficiencies. The speakers discussed both the opportunities and challenges associated with this diagnostic approach, highlighting its potential to improve early diagnosis and patient outcomes. The session concluded with an engaging discussion, fostering valuable exchanges of knowledge and experience.



All IPOPI Hard Talks webinars can be viewed on the [IPOPI YouTube channel](#).

NEWBORN SCREENING

SCREEN4RARE

IPOPI continued its newborn screening work at EU level notably through Screen4Rare, a multi-stakeholder initiative launched by IPOPI, the International Society for Neonatal Screening (ISNS), and the European Society for Immunodeficiencies (ESID), with the aim to exchange knowledge and best practises on NBS for rare diseases. To advance this objective, Screen4Rare, together with the MEP Alliance on Newborn Screening, organised one policy event in 2025.



Screen4rare and the MEP Alliance for Rare Disease Newborn Screening organised a high-level meeting at the European Parliament on 23 September 2025 to discuss the future of newborn screening (NBS) for rare diseases. IPOPI, as a co-founder of screen4rare in collaboration with the European Society for Immunodeficiencies (ESID) and the International Neonatal Screening Society (ISNS), was amongst the speakers.

Hosted by MEP Tomislav Sokol (EPP, Croatia), the event gathered multiple Members of the European Parliament, including Sirpa Pietikäinen (EPP, Finland) and Billy Kelleher (Renew, Ireland). MEPs in attendance called for a renewed EU Rare Disease Action Plan that integrates newborn screening as a cornerstone of health innovation and equity across Member States. They highlighted the need for EU-level guidelines, benchmarking, and support to accelerate progress, underlining that “newborns cannot wait.”

From the patient and expert community, Johan Prevot (IPOPI) and Peter Schielen (ISNS) emphasised the urgency of addressing disparities in NBS implementation across Member States.

Prof Maurizio Scarpa (ERN MetabERN) showcased the European Reference Networks (ERNs) as a flagship EU achievement, and Prof Jim Bonham (ISNS) presented the newly proposed ERN advice and best practice contact point, recently welcomed by the ERN Board of Member States, which can ensure evidence-based guidance for all Member States.

Highlighting the future of screening, Prof Lennart Hammarström (Karolinska Institutet) outlined the potential of genomic newborn screening to transform early diagnosis and treatment of rare diseases—provided it is implemented responsibly, with appropriate governance and safeguards.

The discussions converged on a clear consensus: Europe has both the means and the moral imperative to act. Embedding newborn screening within the EU Life Sciences Strategy and Biotech Act, adopting a new Rare Disease Action Plan, and supporting genomic innovation will be key to ensuring every child in Europe has equal access to life-saving early detection, diagnosis and benefits from timely care.

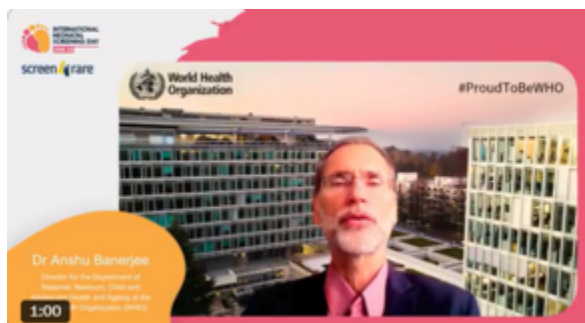


International Neonatal Screening Day

Every June 28, for the past four years, the world commemorates the International Neonatal Screening Day (INSD). INSD is a Screen4Rare initiative to highlight the value and immense impact of neonatal screening for treatable rare diseases in facilitating early detection and diagnosis, and timely access to treatment and care.



INSD offers a unique global platform to raise awareness about the vital role of newborn screening in accelerating diagnosis and treatment. Led by Screen4Rare, the campaign brings together Screen4Rare partners, including IPOPI's National Member Organisations, as well as a wide range of stakeholders in the newborn screening field. This year's campaign featured video statements from the World Health Organization (WHO) and screening experts from different countries, while also receiving support from organisations including UNITAR, UNICEF, the NHS and the European Reference Networks (ERNs). Countries around the world joined the campaign, reinforcing the call to ensure every newborn with SCID has the best possible start in life—regardless of where they are born.



EFFORTS TO SECURE A STABLE IMMUNOGLOBULIN SUPPLY

IPOPI firmly believes that increasing plasma collection is essential to ensuring a stable and sufficient supply of immunoglobulin, so that patients can rely on uninterrupted access to their therapies. In all policy discussions, the focus must remain on patients, safeguarding their access to life-saving treatments. Efforts must be made to strengthen plasma collection in all regions of the world and establish appropriate fractionation programmes. In 2025, IPOPI spearheaded several collaboratives, patient-centred initiatives to advocate for global sufficiency in plasma-derived medicinal products (PDMPs) by promoting a more balanced distribution of plasma collection across different regions.

IPOPI PARTICIPATES AT THE COUNCIL OF EUROPE MEETING ON PLASMA SUPPLY CONTINUITY

Leire Solis, IPOPI Health Policy and Advocacy Director, spoke at a stakeholder meeting on plasma supply continuity organised by the European Directorate for the Quality of Medicines and Healthcare (EDQM) on 26 and 27 March 2025 in Strasbourg (France). Leire brought the patient perspective into plasma collection and the urgent need for countries to step up and increase their plasma collection so that more plasma is available for the manufacturing of immunoglobulin therapies.

The event aimed at providing an update on the latest developments in plasma supply in Europe and provide a forum to exchange on strategies to improve and increase the safe collection and adequate supply of plasma and plasma-derived medicines, such as immunoglobulins, addressing current challenges, key needs and actions.

The EDQM, part of the Council of Europe, is the body contributing to ensuring the availability of and access to good quality and safe medicines in 39 European countries and is responsible, amongst others, for the Guide to the preparation, use and quality assurance of blood components (also known as the Blood Guide). This Guide is a compendium of harmonised European standards that provide safety, efficacy and quality requirements for the preparation, use and quality control of blood components (amongst which plasma) in Europe and beyond.



IPOPI ATTENDS THE 13TH CONGRESS OF THE INTERNATIONAL SOCIETY FOR NEONATAL SCREENING

Leire Solis, IPOPI advocacy and health policy director, took part at the 13th Congress of the International Society for Neonatal Screening (ISNS), on March 26, 2025, in Luxembourg. The session in which Leire took part discussed the activities developed by ISNS, IPOPI and ESID under the umbrella of Screen4Rare. Leire provided the patient perspective on the future of newborn screening. Other speakers of the session touched upon:

- Screen4Rare activities, covered by Prof Jim Bonham, ISNS President
- Identification of good and best screening practices on newborn screening, by Dr Peter Schielen, ISNS Secretary
- The importance of case definitions in newborn screening, so as to understand who the patient is, by Dr Annet Bosch, UMC Amsterdam (the Netherlands)
- Data-driven guidance of a screening strategy for rare diseases, by Prof Ulrike Mütze, Heidelberg University Hospital (Germany)
- The EU advisory committee on newborn screening under the umbrella of the ERNs, Prof Andrea Bordugo, University of Verona (Italy).

The discussions held after the presentations showed the need for continuing advancing on the promotion of equitable newborn screening for treatable rare diseases in the EU and the importance of having a committee that would support decision makers in having the most updated and unbiased information to take the best decisions for their national context.

The discussions held after the presentations showed the need for continuing advancing on the promotion of equitable newborn screening for treatable rare diseases in the EU and the importance of having a committee that would support decision makers in having the most updated and unbiased information to take the best decisions for their national context.



WORLD BLOOD AND PLASMA DONOR DAY

On June 14, IPOPI joined the global community in celebrating World Blood and Plasma Donor Day under the slogan: **“Give blood, give hope: together we save lives”**. The global campaign aimed to raise awareness of the need for safe blood and blood products, including immunoglobulin replacement therapies, and to thank donors for their life-saving treatment.

To mark the campaign, IPOPI published a social media post highlighting the importance of blood and plasma donation. The post explained how plasma donations help produce life-saving treatments for people with primary immunodeficiencies (PID) and encouraged more people to become donors.



INTERNATIONAL PLASMA AWARENESS WEEK

Each October, the primary immunodeficiency (PID) community unites to highlight the importance of plasma collection during International Plasma Awareness Week (IPAW) which took place this year on the 7-11th of October. IPOPI actively supports this global campaign, advocating for increased and more regionally balanced plasma collection.

In celebration of IPAW 2025, IPOPI posted an educational quiz on social media to raise awareness about plasma and promote public understanding of its importance.



3D-GATA2 PROJECT



Launched in 2024, the 3D-GATA2 project is a collaborative research project funded by the European Joint Programme, now under the ERDERA umbrella, titled “How GATA2 Deficiency affects development and disease”. Focusing on patients with GATA2 deficiency, a rare genetic immune disorder, the aim is to characterise the natural disease course. By generating a European centralised registry tied to multi-OMICs approaches

and in vitro and in vivo modelling, and combining the data with patient perspectives, the ultimate aim is to personalise therapy and care for patients with GATA2 deficiency.

IPOPI is the patient-representative voice in this consortium, leading work package 3, “Patients’ perspectives and expectations regarding follow-up and Quality of Life”. During 2025, multiple activities were carried out in this context, notably the development of the project website (<https://gata2project.eu>) and panel interviews with patients, carriers, caregivers, and family members to gather information on their experiences with the condition. Additionally, IPOPI supported the dissemination of consortium efforts, such as publications and symposium presentations, through its channels. IPOPI is proud to be part of this important effort, which will continue to develop over the coming years.

The 3D-GATA2 project has received funding from the European Joint Programme on Rare Diseases under the grant ANR-23-RAR4-0001, now falling under the ERDERA umbrella.

IPOPI'S ROLE IN EMA'S KEY INITIATIVES

IPOPI has been actively engaged with the European Medicines Agency (EMA) to ensure that the needs of patients with primary immunodeficiencies are prioritised. In 2025, IPOPI renewed its membership of the Patients' and Consumers' Working Party for the mandate 2025-2028.



EMA has focused on several key areas, including addressing medicine shortages and expanding the Union list of critical medicines to incorporate essential therapies such as immunoglobulin replacement. In addition, EMA reviewed its guidelines on clinical investigation of subcutaneous and intramuscular immunoglobulin therapies and organised a specific workshop on the challenges in drug development, regulation and clinical practice in immunoglobulins. Other important topics under discussion include the Patient experience with the use of patient experience data, the integration of artificial intelligence, and the advancement of innovative therapies. These initiatives aim to improve access to safe, effective, and innovative treatments for patients across the European Union.

In 2025, IPOPI actively engaged in these discussions through the participation of IPOPI's Board Member Otilia Stanga and Health Policy and Advocacy Director Leire Solis, who have both played vital roles in advocating for patient-centred policies at EMA.

STRATEGIC OBJECTIVE 2

BUILD CAPACITY AND SUPPORT IPOPI'S NATIONAL MEMBER ORGANISATIONS

IPOPI assists the establishment of new national member organisations and supports the development of existing National Member Organisations.

IPOPI REGIONAL PID EVENTS

IPOPI 9TH AFRICAN PID PATIENTS MEETING

On June 26-27, IPOPI welcomed 30 participants from 10 African countries — Algeria, Egypt, Ghana, Kenya, Morocco, Senegal, South Africa, Sudan, Tunisia, and Uganda — for a regional meeting in the lively city of Nairobi, Kenya.

The two-day event focused on key topics including the PID landscape in Africa, diagnosis and genetics, vaccination, plasma collection, treatments, and mental health. It provided a valuable platform for sharing experiences and strengthening efforts to improve PID care across the region.



IPOPI CENTRAL-EASTERN EUROPEAN AWARENESS AND ADVOCACY WORKSHOP

On September 27-28, IPOPI brought together patient representatives and medical advisors from nine countries in the region — Austria, Bosnia and Herzegovina, Bulgaria, Estonia, Hungary, Poland, Romania, Serbia, and Ukraine. The one-and-a-half-day workshop strengthened the capacity of Eastern European NMOs by providing tools for effective awareness and advocacy campaigns. Well received by participants, it offered a platform for collaboration between patient representatives and medical advisors and a network for sharing ideas. Key topics included diagnosis and genetic testing, plasma collection, access to therapies, transition of care, and speaking up for patients' rights.



IPOPI LATIN AMERICAN PID PATIENTS MEETING

On October 16–17, IPOPI welcomed in Buenos Aires, Argentina, patient leaders and healthcare professionals from 13 Latin American countries — Argentina, Bolivia, Brazil, Chile, Dominican Republic, Ecuador, El Salvador, Guatemala, Mexico, Peru, Puerto Rico, Uruguay, and Venezuela. Over two days, they participated in lectures, panels, and workshops, sharing experiences and building skills. Key discussions focused on PID care across the lifespan, diagnosis and innovation (including AI and newborn screening), plasma access and Ig therapies, as well as advocacy, treatment access, and fundraising strategies.



IPOPI REGIONAL PID EVENTS

IPOPI NATIONAL ADVOCACY AND AWARENESS WORKSHOP IN CHINA

On April 12–13, IPOPI, in collaboration with PID Care China, hosted the first-ever national PID Chinese workshop, bringing together patients, families, and healthcare professionals from over 11 provinces across China. The event featured expert sessions on the latest PID treatments and the vital role of plasma therapy, providing attendees with up-to-date medical insights. The second day focused on setting advocacy priorities and addressing key challenges in improving care and access for PID patients nationwide.



WORLD PI WEEK 2025: SEE THE UNSEEN



As a founding member, IPOPI actively supports the yearly World Primary Immunodeficiencies Week (WPIW). From April 22–29, World PI Week 2025 delivered a powerful call to action: “See the unseen: unite to uncover the true stories behind primary immunodeficiencies.” The campaign highlighted real people, real stories, and real progress, urging the world to look beyond what is visible and recognise the daily realities faced by those living with Primary Immunodeficiencies (PIDs). Across the globe, 40 National Member Organisations (NMOs) launched innovative awareness initiatives — from educational conferences for healthcare professionals and patients to awareness podcasts, patient experience surveys, short video testimonies, and even a walk in the dark. These diverse efforts helped bring visibility to the often-overlooked challenges of living with a PID.

Additionally, on April 22 at 1 PM CET, IPOPI and its members united for a Global Social Media Flash Mob, inviting the world to answer: What needs to be seen? Participants around the world shared powerful words, messages, and reflections to spotlight the unseen aspects of PIDs.

In a symbolic video, the IPOPI Board and Staff invited everyone to remove their blindfolds — both literally and figuratively — to truly see the daily realities faced by the community behind these rare conditions.

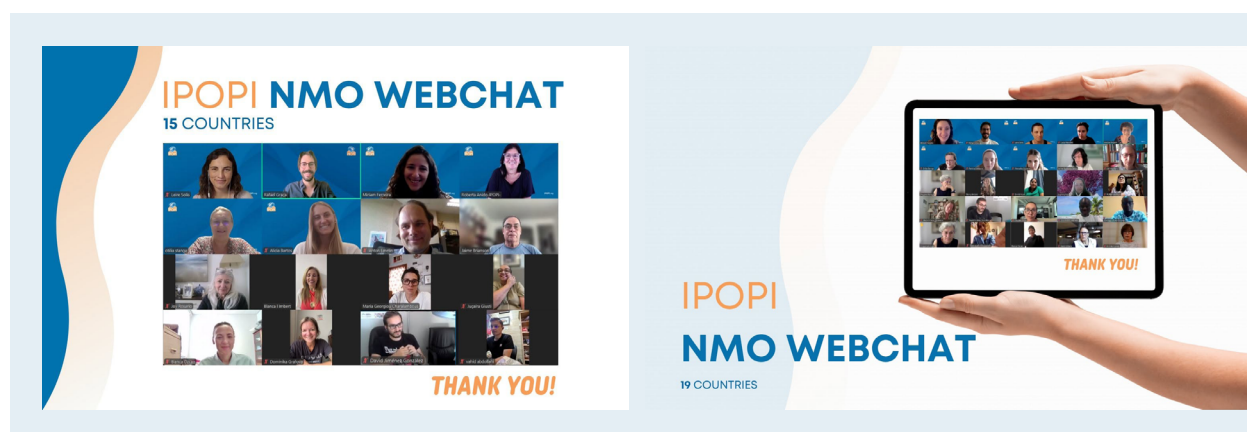
IPOPI NMO SUPPORT PROGRAMME 2025

Throughout 2025, IPOPI was pleased to be able to fund several NMO projects and campaigns through its NMO Support Programme among which:

- **ARGENTINA** - Relaunched of the campaign “We are looking for you”
- **AUSTRALIA** - IDFA’s 20-Year Celebration
- **BRAZIL** - Advocacy project “The strategic importance of self-sufficiency in immunoglobulin production in Brazil”
- **CANADA** - Canada-specific pediatric activity book on SCIG therapy
- **CHINA** - Reproducing, translating, and distributing IPOPI educational leaflets
- **ISRAEL** - Annual patients’ conference
- **MALAYSIA (Singapore)** - Singapore PID Awareness 2025 - A Cross-Border Collaboration with Singapore PID Organizing Committee
- **THE NETHERLANDS** - 2nd PID Event
- **SOUTH AFRICA, KENYA, SENEGAL AND TUNISIA** - ASID Registry
- **UNITED KINGDOM** - Online workshops on Mental Health

IPOPI NMO WEBCHATS

The IPOPI NMO Webchats are organised exclusively for IPOPI national patient organisations (NMOs), on a variety of topics identified as beneficial for our PID community. These online meetings provide both an educational lecture as well as an open forum for NMOs from around the world to discuss and ask questions. In 2025, five webchats were held on subjects such as empowerment of PID advocates through knowledge on the condition, genetics, daily disease management across age groups, health technology assessment (HTA), and a kick start on the World PI Week 2026 campaign.



IPOPI NMO NEWS BITES

The IPOPI NMO News Bites is a member-focused newsletter released 2-3 times a year. It features key sections like “Global Events”, “Medical Affairs News”, “Health Policy and Advocacy News”, providing essential information on important events, international campaigns, and internal deadlines for our members.

STRATEGIC OBJECTIVE 3

EDUCATE, PROMOTE KNOWLEDGE AND DATA SHARING

IPOPI uses communication tools and strategies to spread awareness of PID, share information, for medical education and promote the collection of key PID data.

IPOPI PID INFORMATION LEAFLETS

For a number of years, IPOPI has been producing information leaflets on a range of topics related to primary immunodeficiencies (PID). In 2025, IPOPI published one new information leaflet:

- Secondary Immunodeficiencies (SIDs)

Unlike Primary Immunodeficiency (PID), which is usually genetic, SIDs are acquired conditions caused by factors such as infections, certain diseases, medications, or malnutrition. People with SIDs may experience frequent or severe infections due to a weakened immune system.

The leaflet explains the causes, symptoms, diagnosis and treatment of SIDs, while highlighting the importance of early detection, infection prevention and appropriate care. It aims to raise awareness and support patients, caregivers and healthcare professionals in better understanding these conditions.

IPOPI is pleased to make these leaflets available in English and expects newly translated versions to be made available with the invaluable help of its national member organisations.



IPOPI JOSE DRABWELL RESEARCH GRANT PROGRAMME



In 2024, IPOPI launched its Research Grant Programme, a new initiative to promote scientific and clinical research on primary immunodeficiencies and associated conditions. The programme was renamed **IPOPI Jose Drabwell Research Grant Programme** in 2025, in honour of Jose Drabwell, a passionate advocate and long-time supporter of the PID community with an unwavering commitment to patient-centred research and innovation.

In 2025, the number of applications more than doubled since the programme's inception, demonstrating increased global interest in this funding mechanism.

IPOPI awarded two-year funding to four research projects addressing critical areas worldwide: cost-effective PID screening tools in Vietnam; metformin repurposing for STAT1 gain-of-function in Prague; diagnostic tools for CVID-associated enteropathy in The Netherlands; and a multi-approach study to improve access to quality care for patients with PID in Uganda. Each grant plays a vital role in improving outcomes and care for people living with PIDs.

This programme marked a significant step forward in IPOPI's mission to promote impactful, patient-focused research worldwide.

TWO NEW MINI DOCUMENTARIES

IPOPI expanded its educational resources by releasing two insightful mini documentaries. These highlight the importance of plasma for the development of essential medicines as immunoglobulin (Ig) replacement therapies and the challenges in plasma collection and access for patients with primary immunodeficiencies (PIDs).

PULMONARY ALVEOLAR PROTEINOSIS IN PIDS – A HIDDEN CHALLENGE

This mini documentary sheds light on Pulmonary Alveolar Proteinosis (PAP), an ultra-rare lung disease that can occur as a complication of Primary Immunodeficiencies (PIDs), and on autoimmune PAP (aPAP), the most common form of the condition.

Through patient testimonies and expert insights, the film explores the impact of living with a disease that is often misdiagnosed, while explaining how PAP develops, why it is so rare, and how it affects people with PIDs and aPAP.

Through this project, IPOPI aims to raise awareness of PAP, amplify the experiences of those affected, and promote earlier recognition and diagnosis among patients, families and healthcare professionals.



THE LIFE JOURNEY WITH PRIMARY IMMUNODEFICIENCIES

This mini documentary explores the journey of people living with Primary Immunodeficiencies (PIDs), highlighting the challenges of delayed diagnosis, access to treatment, and everyday life with a chronic condition. Through patient stories, expert insights and global perspectives, the film illustrates how PIDs affect individuals and families at every stage of life, while emphasising the need for greater awareness, timely diagnosis and equitable access to care.



These documentaries serve as an invaluable resource for patients, member organisations, policymakers, and healthcare professionals. [Watch them here.](#)

IMMUNITY PULSE PODCAST

IPOPI launched a new podcast series Immunity Pulse now available on Spotify. Through conversations with patients, caregivers, physicians and experts, the podcast explores primary immunodeficiencies (PIDs) and associated conditions, combining scientific insights with personal experiences to inform, inspire and raise awareness. Five episodes were released during the year:



- **Episode 1**
SID patients with an underlying PID



- **Episode 2**
Whole Lung Lavage Explained



- **Episode 3**
aPAP Clinical Trial Journey



- **Episode 4**
SID: The Hidden Diagnosis



- **Episode 5**
SIDs: Paediatric Cancer, Infections as warning

All episodes are available now on [Spotify](#).

IPOPI E-NEWS

One of our flagship publications, IPOPI e-News, is sent directly to thousands of readers and is also shared on social media. Published every quarter, e-News highlights the most significant achievements of IPOPI and its members in the previous months. The editorial in our newsletter, signed by IPOPI's President, is always one of the most read articles, as are the interviews with prominent PID community members.

e-news.ipopi.org



STRATEGIC OBJECTIVE 4

STRENGTHEN MULTI-STAKEHOLDER COOPERATION

IPOPI values the benefits of working together with partners and stakeholders and 2024 was a shining example of new partnerships being built.

TRANSFORM ALLIANCE



**European Alliance
for Transformative
Therapies**

Martine Pergent, President of IPOPI, continued representing the voice of patients with PIDs as the patient representative in the Board of the European Alliance for Transformative Therapies (TRANSFORM). This Alliance is a multi-stakeholder initiative representing patient groups, medical experts and associations, scientist and researchers and industry interested in the area of cell and gene therapies. TRANSFORM aims to foster dialogue between the initiative and European decision-makers so that evidence-based policy recommendations can be issued with the objective of enabling safe and timely patient access to cell and gene therapies, while ensuring the sustainability of healthcare systems.

CONCLUSION OF EUROPEAN RESEARCH CONSORTIUM RECOMB

Recomb was a European research consortium dedicated to developing gene therapy for patients with recombination activating gene-1 (RAG-1)- deficient SCID, with IPOPI as one of the leading partners. This project ended on December 31, 2024, following a generous 24-month extension from the EU Horizon 2020 programme.

On March 10, 2025, the RECOMB project—funded by Horizon 2020 and concluded on Dec 31, 2024—successfully had its final review meeting. By this point, the clinical trial included 17 patient consultations and 5 patients. Encouragingly, all treated patients have shown signs of recovery, and the first two patients are far enough after treatment to show antibody responses to vaccines, restored immune function, and no longer require immunoglobulin replacement therapy. These promising results highlight the potential of gene therapy to cure fatal immune disorders and further strengthen Europe's expertise in this field.

IPOPI, in coordination with the consortium partners, published the RECOMB 2025 Final Report, which summarises the project outcomes and outlines future perspectives for gene therapy in RAG1-SCID, offering new hope to affected families worldwide. The [report](#) was shared on the project's website (www.recomb.eu) and through dissemination channels.

Although the RECOMB project has officially ended, the consortium remains dedicated to ongoing patient follow-ups and recruiting new patients as the therapy moves through the complex process of market approval.

RECOMB has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement no. 755170 (RECOMB).



ACCESS TO GENE THERAPIES FOR RARE DISEASES (AGORA)

Johan Prevot, Executive Director of IPOPI, is a founding board member of the AGORA initiative (**A**ccess to **G**ene therapies **f**or **R**are diseases). AGORA's mission is to facilitate access to effective gene therapies for patients with ultra-rare diseases in Europe. Specifically, AGORA aims to establish a sustainable framework that increases access to pre-marketing authorisation phase treatments for ultra-rare diseases, with a focus on curative, one-shot treatments for single-gene disorders. As gene therapy holds immense potential for PID treatment, IPOPI is delighted that its patient community can be represented in this consortium.



EUROPEAN REFERENCE NETWORK FOR PIDS



Primary Immunodeficiencies / Autoinflammatory Disorders
Autoimmune Diseases / Paediatric Rheumatic Diseases

IPOPI's collaboration with the European Reference Network RITA has continued, including in the Transition Care working group, ensuring that the voices of PID patients are heard in the network's activities and decisions.

RITA stands for Rare Immunodeficiency, Autoinflammatory, and Autoimmune. It brings together specialised centres in Europe that focus on primary immunodeficiencies as well as other autoinflammatory and autoimmune disorders.

EU HEALTH COALITION



IPOPI continued its collaboration with the multistakeholder EU Health Coalition in a joint effort to look at mapping the future of healthcare in Europe. As a member of the EU Health Coalition, participated in the Coalition's Partners exchange of views on the revision of legislation and policy such as shortages, life sciences in different committee and plenary meetings.

RARE DISEASE INTERNATIONAL (RDI)

IPOPI continued participating in the activities organised by Rare Disease International, the global alliance of persons living with a rare disease. As such, IPOPI was involved in meetings discussing the World Health Assembly Resolution on Persons Living with a Rare Disease with the objective of making rare diseases a topic of relevance for health systems worldwide.



RARE
DISEASES
INTERNATIONAL

PLUS – PLATFORM OF PLASMA PROTEIN USERS

The Platform of Plasma Users (PLUS) organised its Stakeholder Consensus Conference on January 23-24, 2025, in Estoril (Portugal). The meeting gathered representatives from the following stakeholder organisations: *Alpha-1 Belgium, the American Platform of Plasma Users (A-PLUS), the European Blood Alliance (EBA), the European Haemophilia Consortium (EHC), the European Plasma Alliance (EPA), the GBS-CIDP Foundation International, the International Patient Organisation for Primary Immunodeficiencies (IPOPI), the International Plasma and Fractionation Association (IPFA), European Blood Alliance (EBA), Plasma Protein Therapeutics Association (PPTA), World Federation of Haemophilia (WFH), Marketing Research Bureau (MRB) and Thomas Kluszczynski (ACESO Healthcare Consulting).*

During the two-day conference, participants discussed current priority topics, including:

- An overview of the latest worldwide plasma and plasma-derived medicinal products supply situation;
- The role of the Critical Medicines Alliance in Europe and the procurement and supply of PDMPs;
- Stockpiling in the EU and how this could be applied for PDMPs;
- The ongoing implementation of the regulation on substances of human origin (SoHO) and the current discussions around the pharma legislation;
- The importance of ensuring the safety and efficacy of plasma-derived medicines worldwide.

Several elements were identified as shared interests during the discussions, and participants agreed to continue collaborating on that basis. As a result, some organisations agreed to a [joint statement on the safety of PDMPs](#) and to further discussions on the developments of the Critical Medicines Alliance from a plasma-derived medicines perspective.



OTHER KEY MEETINGS

IPOPI attended and participated in the following events among others:

- EU Health Coalition steering committee meetings throughout the year
- EU Health Coalition: Digital Transformation Working Group, throughout the year
- EU Health Coalition Health Systems Integration policy group, throughout the year
- ERN-RITA Board Meetings, Patients Committee, Communications WP, throughout the year
- ERN RITA transition working group meetings, throughout the year
- ERN-RITA Clinical Guidelines working group
- ERN-RITA Patient Groups meetings, throughout the year
- EMA PCWP/HCPWP meetings, throughout the year
- EMA SPOC meetings throughout the year
- European Alliance for Transformative Therapies (TRANSFORM) meetings, throughout the year
- RDI advocacy committee webinars throughout the year
- UNITAR liaison meetings, throughout the year
- World PI Week steering committee meetings, throughout the year
- PLUS, stakeholders meeting, January 2025
- EU Health Summit, January 2025
- IPOPI-UNITAR Liaison Meeting, January 2025
- EMA Clinical Trials Information System Forum, January 2025
- NAVIGATE consortium meeting, January 2025
- Immune AI consortium calls, January 2025
- ERN-RITA Board meeting, February 2025
- Plasma4Life Knowledge Partners Meeting, February 2025
- Critical Medicines Alliance Meeting, February 2025
- HTA Stakeholder Network webinar on emerging health technologies, February 2025
- Joint Clinical Assessments for ATMPs webinar, February 2025
- AGORA Academia Briefing Meeting with European Medicines Agency, February 2025
- Health Emergency Preparedness and Response Authority (HERA) Meeting, February 2025
- Barcelona PID Foundation Meeting, February 2025
- Rare Diseases Day 2025 meetings, February 2025
- EMA workshop on the challenges in drug development, regulation and clinical practice for immunoglobulins, March 2025
- AMR Dialogues | Connecting the dots: Substandard and falsified medical products & Antimicrobial Resistance Meeting, March 2025
- EDQM Stakeholders meeting on plasma supply, March 2025
- RDI International Federations Meeting, March 2025
- RECOMB Final Review Meeting, March 2025
- ERN-RITA Board meeting, March 2025
- ISNS International Development Coordination Group Call, March 2025
- TRANSFORM Alliance meeting, March 2025

- ISNS Newborn Screening International Conference Luxembourg, March 2025
- Council of Europe EDQM stakeholder event Strasbourg, March 2025
- AI-PI Meeting New York, March 2025
- 3D GATA2 Meeting, March 2025
- EU webinar Unlocking Europe's Future: Prioritising Health under the next Multiannual Financial Framework, March 2025
- EMA PCWP & HCPWP joint meeting, April 2025
- European Parliament Debate on Rare Diseases, April 2025
- Updates in Primary Immunodeficiency CME symposium, April 2025
- SEAPID anniversary meeting Bangkok, Thailand, April 2025
- Join4ATMP webinar, April 2025
- APSID conference Beijing, China, April 2025
- ERN-RITA Board meeting, April 2025
- 13th Plasma Product Biotechnology Meeting, Croatia, April 2025
- EMA Clinical Trials Information System Stakeholders Forum, April 2025
- Decoding Inborn Errors of Immunity" Meeting, Serbia, April 2025
- EU High Level Meeting "Building a Research & Innovation Eco-system for Rare Diseases", April 2025
- 4th ARAPID Congress, Casablanca, Morocco, April 2025
- IUIS 2025 Day of Immunology - Brain and Immunity: Immunological Insights into Neurological Disorders, May 2025
- AGORA Board meeting, May 2025
- EPF HTA Stakeholders Network Patient Organisation Meeting, May 2025
- EPF - Understanding patients' rights in the European Health Data Space, May 2025
- Webinar on ATMP development pathway (CAR-T cells), May 2025
- ERDERA webinar on EU research programmes eligibility, May 2025
- EuropaBio Patient BioForum 2025 "From Discovery to Access: Towards a Patient-Centric Health European Ecosystem "
- IPFA/PEI 31st Workshop in Heidelberg, Germany, May 2025
- EU Commission webinar "The EU HTA Regulation: Webinar for patients and clinical experts", May 2025
- 17th International Congress in Pediatric Laboratory Medicine (ICPLM), Brussels, May 2025
- EuromedLab & IFCC congress, Brussels, May 2025
- PPTA Stakeholders Meeting, Warsaw, Poland, May 2025
- International Plasma Protein Congress (IPPC), Poland, May 2025
- EU HTA Stakeholder Network Meeting, May 2025
- UNITAR Liaison Meeting, May 2025
- Meeting with Telethon Foundation, May 2025
- High Level Meeting on Rare Diseases Steering Committee Meeting, May 2025
- LifeScience4EU Conference, Krakow, Poland, May 2025
- TRANSFORM Alliance Meeting June 2025
- WHO webinar Prioritizing Blood Health: Empowering Patients and Healthcare Advocates, June 2025

- EPF Member's Circle on AMR Webinar, June 2025
- Immune AI consortium meeting, June 2025
- EMA-HMA Webinar "Strengthening evidence generation in the EU", June 2025
- Webinar "Experience of the universal neonatal screening programs SCID in Spain & Portugal", June 2025
- Annual meeting of EMA PCWP and FDA's Patient Engagement Collaborative (PEC), June 2025
- RDI General Assembly Meeting, June 2025
- ERN-RITA Board meeting, June 2025
- EMA Anniversary Stakeholders Meeting, Amsterdam, The Netherlands, June 2025
- European Parliament SANTE Committee meeting, June 2025
- European Hematology Congress, Milan, Italy June 2025
- 3D GATA2 Consortium Meeting, Milan, Italy, June 2025
- Spanish Chamber of Commerce meeting "Strengthening Financial Management in EU Projects: Supporting Associations for Sustainable Impact", Brussels, Belgium, June 2025
- IPOPI Meeting with Myeloma Patients Europe and CLL Advocates Network, Milan, June 2025
- HTAi meeting, Argentina, June 2025
- INSD celebratory meeting CHU Liège, Belgium, June 2025
- EU HTA Stakeholders Network, Brussels, Belgium, July 2025
- European Commission Conference on HTA, July 2025
- EC Meeting on "EU health technology assessment: Advent of a new era of collaboration", Brussels, Belgium, July 2025
- TRANSFORM Alliance Roundtable | ATMPs: Gateway to European Global Leadership, July 2025
- EMA Clinical Trials Information System Stakeholders Forum, July 2025
- HLM RARE - Steering Committee Call, July 2025
- 19th International IUIS Congress of Immunology, Austria, August 2025

IPOPI IN 2025 AND BEYOND

IPOPI continues to advance its mission of assisting the PID community through international awareness, advocacy, and medical education.

Our diverse programme of work will continue through initiatives such as the Immunity Pulse Podcast, the José Drabwell Research Grant, the development of a WHIM syndrome leaflet, regional meetings in Asia and the Middle East, a national workshop in Turkey, forums at the European Parliament, national advocacy campaigns, and much more.

Together, these initiatives will strengthen National Member Organisations, foster collaboration, and enhance PID care and advocacy around the world.

We look forward to welcoming the global PID community to the **Global Patients Meeting in Maastricht**, the Netherlands, on October **14-16, 2026**.

FINANCIAL REPORT 2025

Every year, IPOPI is required to have its accounts audited in Belgium by qualified accountants/auditors and submitted for approval. The following charts provide a summary of key aspects of our financial accounts in 2025. Our audited accounts are available on the Belgian National Bank register, and on request. IPOPI has included and independently reviewed economic valorisation of the work of its volunteers in the following charts.

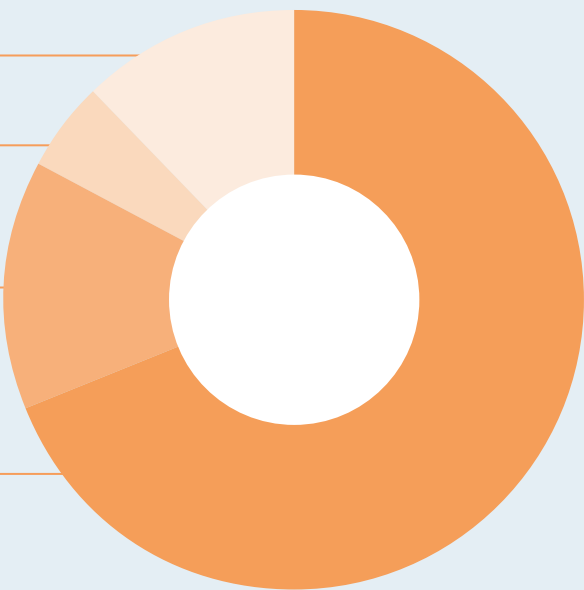
Income 2025 (EURO)

12% Volunteer work

5% Other donations/income

14% IPIC Registrations

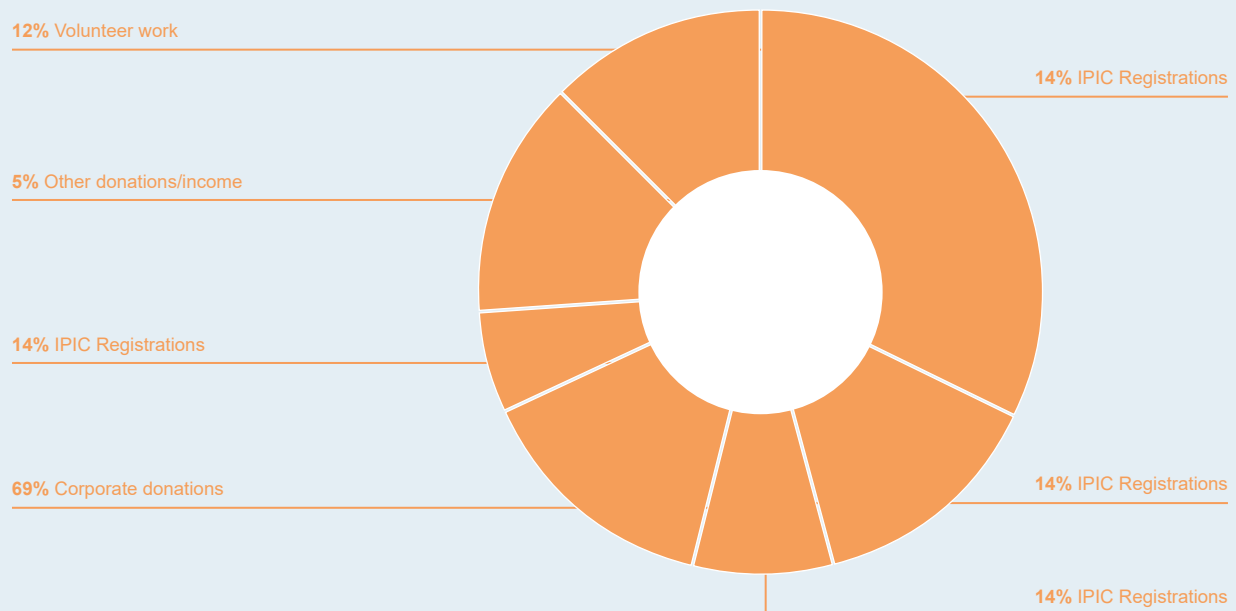
69% Corporate donations



Summary of Income

NMO assessments	8 300
Corporate donations	1 628 816
Other donations/income	122 775
Volunteer work	322 348
From reserve	289 002
TOTAL	2 381 241

Expenditure 2025 (EURO)



Expenditure 2025	
IPIC	755 812
Advocacy Diagnosis and Care	323 249
NMO programmes	184 433
Awareness	333 882
Stakeholder Collaboration	139 388
Governance (including exchange rate losses)	316 429
Volunteers	289 002
TOTAL EXPENDITURE	2 342 195

No contribution received from a single company reached the majority of the total income. The highest single contribution by a company represented 15.7% of the total income including volunteer time contributions and 17.8% excluding volunteer time contributions.

IPOPI would like to recognise the large number of people and stakeholder organisations who support our work through personal effort, shared objectives, alliances or financial support. These collaborations help IPOPI achieve more year after year for people living with primary immunodeficiency worldwide.

We also express our gratitude to our 79 National Member Organisations whose important activities and efforts in their respective countries are vital to improving the conditions for people living with a PID. Our NMOs are key stakeholders who contribute towards the global mission of IPOPI.

CORPORATE PARTNERS

IPOPI would like to extend its sincere thanks to the following corporate partners whose contributions helped us implement our mission through raising awareness, advocacy/ policy efforts, representation in key events, communications activities, organisation of international and regional meetings as well as support to national patient programmes and campaigns.

DIAMOND

The logo for Grifols, featuring the word "GRIFOLS" in a bold, blue, sans-serif font.

GOLD

The logo for CSL Behring, featuring the words "CSL Behring" in a red, sans-serif font.

SUPPORTERS



PROJECT SPONSORS

In 2025, the following corporate sponsors provided unrestricted grants towards various IPOPI ad-hoc projects that enhance our awareness, advocacy, communications, events and representational activities.

- BD
- Biotest
- Binding Site
- Cane Spa
- Chiesi
- CSL Behring
- Grifols
- ImmunoIVD
- Kedrion
- Koru
- LaCar
- LFB
- Octapharma
- Orchard Therapeutics
- Pfizer
- Pharming
- Savara
- Sumitomo Pharma
- Takeda
- X4 Pharmaceuticals

IPOPI's corporate relations with the above-mentioned sponsors are subject to IPOPI's corporate relations guiding principles available on IPOPI's website.

KEY STAKEHOLDERS

IPOPI has strategically been growing its stakeholder cooperation, and we would like to express our most sincere thanks to a number of stakeholder organisations for their partnership and collaboration in 2025, including but not limited to:

3D GATA2 Research Consortium (EJP-funded project), ACT4EU Research Consortium on ATMPs, Active Citizenship Network, AGORA Gene Therapies Consortium, AI-PI Consortium, Asia Pacific Economic Cooperation (APEC) Rare Diseases Committee, Asia Pacific Plasma Leaders Network (APPLN), Care-for-Rare Foundation, Council of Europe, E-FabRic Consortium, ESID Clinical Working Party, ESID Registry Steering Committee, EU Critical Medicines Alliance, EU Health Coalition Steering Committee, EU Health Emergency Preparedness and Response Authority (HERA), EuropaBio Patients Bio-Forum, European Centre for Disease Prevention and Control (ECDC), European Commission SoHO Unit, European Foundation for the Care of Newborn Infants (EFCNI), European Health Parliament Think Tank, European Medicines Agency's Medicines Shortages Single Point of Contact (SPOC) Working Party, European Medicines Agency's Patient and Consumer Working Party (PCWP), European Network for Paediatric Research (Enpr-EMA), European Network Infection Prevention & AMR (ENIPAR), European Patients' Forum (EPF), European Rare Disease Research Alliance (ERDERA), European Reference Network Expert Platform on Newborn Screening, European Reference Network on Immunological Diseases (ERN-RITA), EURORDIS (Rare Diseases Europe), Friends of Europe Think Tank, GE-NAM Gene Editing Research Consortium (proposal stage), Health First Europe (HFE), HIDDEN-IEI Research Consortium (proposal stage), IEI-Haem Research Consortium (EJP-funded project), ImmuneAI Research Consortium (proposal stage), Integrate ATMP Research, Consortium, International Society for Blood Transfusion (ISBT), International Society for Neonatal Screening (ISNS), JAKI Consensus Consortium (under ESID & EBMT), Key medical regional and international societies, including ESID, LASID, APSID, ASID, SEAPID, ICHS, IUIS, INGID and other national PID medical societies, NGO Committee for Rare Diseases, Platform of Plasma Protein Users (PLUS) – membership consulting to the European Commission, PLUS Stakeholders Consensus Conference, PPTA Stakeholders Group, Rare Diseases International (RDI) Advocacy Committee, RECOMB Consortium (EU-funded project), ReMAP Research Consortium (proposal stage), REPAIRE Research Consortium (proposal stage), TRANSFORM, UK Plasma Action Group, United Nations Institute for Training and Research (UNITAR), WHIM International Consortium, World Allergy Organization, World Health Organization Expert Committees, World PI Week Steering Committee.

IPOPI aisbl is an international non-profit association registered in Belgium (BE 0761.784.055)

IPOPI.org

