



REVIEW OF ACTIVITIES AND ACHIEVEMENTS

2024

IPOPI.ORG





an IPOPI event

IPIC2025

**INTERNATIONAL
PRIMARY
IMMUNODEFICIENCIES
CONGRESS**

**DIAGNOSIS
AND CLINICAL CARE**

**PRAGUE, CZECH REPUBLIC
5-7 NOVEMBER 2025**

ipic2025.com



A MESSAGE FROM IPOPI'S PRESIDENT AND EXECUTIVE DIRECTOR



MARTINE PERGENT
President



JOHAN PRÉVOT
Executive Director

As IPOPI continues to grow and strengthen its global community, we remain committed to uniting patient voices and advancing care for people living with primary immunodeficiencies (PIDs) and associated conditions. Our network of 75 member countries embodies the spirit of collaboration and shared purpose.

A key 2024 highlight was the XVIII Global Patients' Meeting (GPM) in Marseille, France, which brought together nearly 100 participants from almost 50 countries — marking a record number of National Member Organisations (NMOs). This inspiring event also marked a transition with our newly elected Board of Directors taking on the important mission of advancing advocacy and ensuring

our work reflects the needs of the global PID community, whilst saying goodbye to longstanding members leaving the Board, who played an integral role in shaping IPOPI's remarkable journey.

The year also brought new projects and activities as IPOPI embraced the fast-paced evolution of the healthcare environment. This included exploring the promises of what artificial intelligence can deliver to improve rare diseases management and the rapidly expanding understanding of our field with now over 559 forms of primary immunodeficiency reported in the 2024 IUIS classification, not to mention the increasingly better characterised crossovers with other conditions including secondary immunodeficiencies. Ensuring we do not only keep up with advances in the field but play an active role in anticipating what comes next remained an objective for us, as exemplified by the organisation of a very successful IPOPI global stakeholders' summit which led to the publication of the well-received article "Navigating disruption in the PID landscape: embracing opportunities and anticipating threats in the next ten years".

IPOPI also delved into important regulatory and policy topics throughout the year ensuring the voice of our patients' community was heard in advocating for enhanced access to care and accurate diagnosis. This included, among others, our work with multi-stakeholder platforms such as AGORA or TRANSFORM focusing on ATMPs and our collaboration within Screen4rare to ensure equitable access to newborn screening. Our advocacy work also focused on access to immunoglobulins and the importance of increasing plasma collection, including with the release of our educational mini documentaries on this very topic. We also provided support, advice and specifically tailored actions to assist several of our national member organisations with their priorities. This included the organisation of our 5th Regional Asian Meeting which was also IPOPI's first-ever meeting held in Japan.

Alongside that, IPOPI provides valuable educational resources to support the global PID community. This year, we published five new informational leaflets, each addressing key aspects of primary immunodeficiencies (PID). These resources offer clear and accessible guidance on a range of topics, empowering both healthcare professionals and patients.

Whilst we take stock of the insights emanating from these various activities to shape our future work, we will be forever guided by the vision of our dear friend and cherished colleague, Jose Drabwell—a world where no PID patient is left behind. We were deeply saddened by Jose's passing in January 2025, just three months after she stepped down from our Board of Directors in Marseille.

As we step into the new year, we carry forward Jose's vision, positive energy and our shared commitment to building a better future for PID patients everywhere. Thank you to our NMOs, partners, and supporters for being part of this journey.

We warmly invite you to explore our Annual Review to learn more about the initiatives, events, and impact of the past year.

Martine Pergent
IPOPI President

Johan Prévot
IPOPI Executive Director

EXECUTIVE COMMITTEE, OFFICERS AND STAFF 2024

EXECUTIVE COMMITTEE	MEDICAL ADVISORY PANEL	
<p>Martine Pergent, Chair Bruce Lim, Vice - Chair Whitney Ayoub Goulstone Jose Drabwell (until October 2024) Cynthia Olotch Roberta Anido John Seymour (until October 2024) Tracy Shaw (from October 2024) Dimas Sugiharto (from October 2024) Otilia Stanga (Treasurer)</p>	<p>Dr Nizar Mahlaoui, Chair – France Prof Martin van Hagen, Vice Chair – Netherlands</p> <p>PANEL MEMBERS Dr Adli Ali – Malaysia Prof Tadej Avcin – Slovenia Prof Aziz Bousfiha – Morocco Prof Antonio Condino-Neto – Brazil Prof Charlotte Cunningham-Rundles – USA Dr Virgil Dalm – The Netherlands Prof Tandakha Dieye – Senegal Dr Nahla Hashim Hassan Erwa – Sudan Prof Alain Fischer – France Dr Elie Haddad – Canada Prof Steven Holland – USA Dr Pamela Lee – Hong Kong Prof Isabelle Meyts – Belgium</p>	<p>Dr Olaf Neth – Spain Dr Cecilia Poli – Chile Dr Elizabeth Rivers – UK Dr Silvia Sánchez-Ramón – Spain Prof Surjit Singh – India Prof Stuart Tangye – Australia Prof Klaus Warnatz – Germany</p> <p>HONORARY CHAIRPERSON Prof Helen Chapel – UK</p> <p>HONORARY VICE-CHAIR Dr Teresa Español – Spain</p>
STAFF		
<p>Johan Prevot: Executive Director Alicia Bartos: Events and Logistics Assistant Patricia Boldescu: Communications Assistant Samya van Collie: Medical Affairs Project Manager (until August 2024) Marc Desmet: Accounting and Administration Manager Miriam Ferreira: NMO Programmes Officer</p>	<p>Clare Glynn: Financial Advisor Rafael Graça: Communications Manager Lúcia Mamede: Medical Affairs Project Manager (from September 2024) Carla Morgado: Office Manager Mercedes Muraca: Events and Logistics Coordinator Leire Solis: Health Policy and Advocacy Senior Manager</p>	

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

- 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

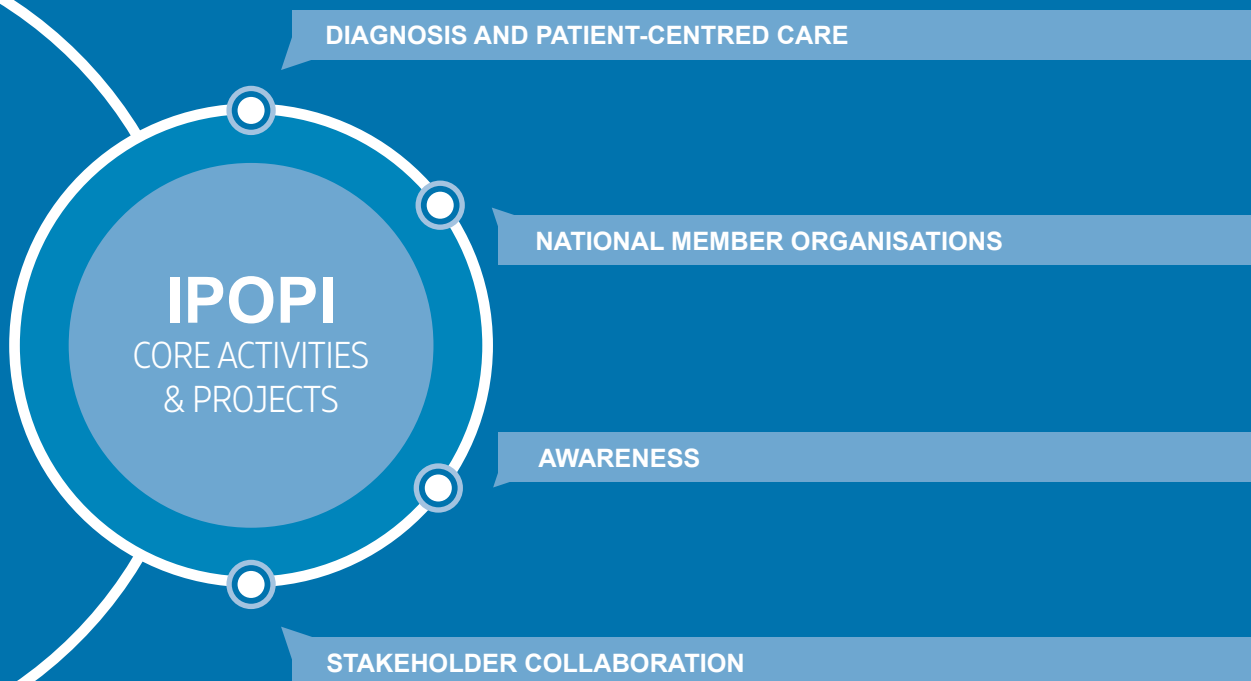
MISSION AND OBJECTIVES

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*



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. In addition the crossovers between PID and associated conditions such as autoimmunity, autoinflammation, lymphoproliferation, malignancies, allergies and secondary immunodeficiencies are increasingly better understood.

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. SCIg 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 add to 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, 2024

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 – EMPOWERING THE PID COMMUNITY THROUGH RARE DISEASE POLICIES

On March 21, IPOPI held the EU PID Forum Empowering the PID Community through Rare Disease Policies 2024-2029” at the European Parliament in Brussels (Belgium). The Forum was chaired by Member of the European Parliament (MEP) Radka Maxová (S&D, Czechia).

The Forum, moderated by Leire Solis, IPOPI’s health policy and advocacy senior manager, reviewed the 2019-2024 parliamentary term from the perspective of patients with primary immunodeficiencies (PIDs) and healthcare experts. It also explored the remaining unmet needs and key priorities for the new term following the European elections in June. As an outcome of the Forum, a political manifesto 2024-2029 was launched so that EU national member organisations (NMOs) could, if they wished to, engage with politicians during the political campaign or after their election.

Speakers in the Forum were: Anne-Sophie Henry Eude, representative of the French patient organisation IRIS, Patricia Luck, Vice-President of the International Nursing Group of Immunodeficiencies (INGID) and an advanced practice nurse in immunology at University Children’s Hospital Zurich (Switzerland), Prof Isabelle Meyts, PID physician paediatrician at University Hospital Leuven (Belgium), Dr Eva Varga, Vice President of the Hungarian Organisation for Patients with Immunodeficiencies (HOPI) and Wim De Geest, Chairman of the Belgian Patient Organisation for Primary Immunodeficiencies (BePOPI).

The discussions were supported by interventions from different patient representatives in the room during the Forum.



EU PID FORUM – NAVIGATING THE COMPLEXITIES OF THE PHARMACEUTICAL LEGISLATION

On November 5, IPOPI held the EU PID Forum on “Exploring the Impact of Medicine Shortages on PID Patients” at the European Parliament in Brussels (Belgium). The Forum was co-chaired by Member of the European Parliament (MEP) Vystenis Andriukaitis (S&D, Lithuania) and MEP Tomislav Sokol (EPP, Croatia).

The Forum, moderated by Johan Prévot, IPOPI’s Executive Director, explored the current challenges faced by PID patients in accessing their therapies. It also addressed the impact on healthcare professionals, including treating doctors and nurses, and highlighted the new mandate given to the European Medicines Agency (EMA) to support Member States in addressing this issue. The discussions highlighted the need for EU-level action and participants and speakers welcomed initiatives such as the proposed Critical Medicines’ Act (CMA), the European Rare Disease Action Plan and the formation of the Critical Medicines’ Alliance.

The speakers of this Forum were: Leire Solis, IPOPI health policy and advocacy senior manager, Klaus Kruttwig, EMA medicines and medical devices shortages specialist, Otilia Stanga, president of the Romanian Association for Patients with PIDs (ARPID) and IPOPI treasurer and Lúcia Mamede, Medical Affairs Project Manager at IPOPI, on behalf of Dr Nizar Mahlaoui, (Necker-Enfants Malades University Hospital) and Chairman of IPOPI's Medical Advisory Panel.

The Forum attracted the attention of many patient representatives from the different national patient organisations as well as other stakeholders working in the field.



PIDETECT PROGRAMME: INTENSIVE PID DIAGNOSTICS TRAINING

The IPOPI PIDetect Programme provides intensive training to selected doctors from LMIC to improve their skills in recognising and diagnosing PIDs. The programme is hosted in a PID reference centre working in partnership with IPOPI and is aimed both at clinicians and laboratory scientists with an interest in PIDs. It comprises intensive clinical and/or laboratory training tailored to the individual needs and background of each attendee, followed by a local implementation activity whereby the acquired expertise is shared more widely with doctors in the target country.

The IPOPI PIDetect programme aims to enhance PID diagnosis in low- and middle-income countries by providing intensive training to selected doctors. In 2024, one doctor and one nurse from Cambodia received training at the Hospital Pakar Kanak-Kanak UKM (UKM Specialist Children's Hospital) in Kuala Lumpur, Malaysia, under the guidance of Dr Adli Ali. Both health care professionals have since been committed to implementing PID diagnostic protocols in their host institution and to fostering close relationships with international experts.

Additionally, two clinicians from Mali received training at the Children's Hospital, Ibn Rochd University Hospital in Casablanca, Morocco, led by Prof Aziz Bousfiha. Following this, a webinar targeting Malian paediatricians helped to disseminate the acquired knowledge on PID at a nationwide level. Moreover, medical educational workshops targeting multiple speciality doctors were organised in Segou and Bamako with the aim to raise awareness and ultimately improve PID diagnosis rates in the country.



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:

SECONDARY IMMUNODEFICIENCIES: HAEMATOLOGICAL AND IMMUNOLOGICAL INSIGHTS

The first Hard Talk webinar took place on May 17 and explored secondary immunodeficiencies (SIDs) from both haematological and immunological perspectives, with 60 participants from 46 countries registered for the event.

Dr Nizar Mahlaoui, and Dr Elena Cabezudo, delved into this subject, exploring the aetiology, clinical manifestations, management strategies and future perspectives of SIDs.



DIAGNOSIS AND MANAGEMENT OF PAEDIATRIC CONGENITAL ATHYMIA

The following webinar took place on June 7 and brought together 95 participants from 39 countries. In this engaging dialogue, Prof Andrew Gennery and Dr Keith Sacco addressed contemporary diagnostic approaches and management options, while also considering regional differences in treatment accessibility.



ADVANCES IN THE MANAGEMENT AND TREATMENT OF X-LINKED AGAMMAGLOBULINEMIA

On July 11, the webinar gathered 131 participants from 40 countries for an in-depth discussion on current and emerging approaches to treating X-linked Agammaglobulinemia. Prof Isabelle Meyts and Dr Pamela Lee examined evolving standards of care and innovative options such as HSCT, with a special focus on adult patients' needs.

The banner features a central blue circle with a white question mark icon. Text inside the circle reads: "IPOPI HARD TALKS EXPLORING THE COMPLEXITY OF OUR FIELD" and "ADVANCES IN MANAGEMENT AND TREATMENT OF X-LINKED AGAMMAGLOBULINEMIA". Below this, it says "THURSDAY 11 JULY, 15.00 CEST". On the left, a circular portrait of Prof Isabelle Meyts is shown with her name and "BELGIUM" below it. On the right, a circular portrait of Dr Pamela Lee is shown with her name and "HONG KONG" below it. The IPOPI logo is in the bottom left, and the CSL Behring logo is in the bottom right. A small orange box in the top right corner says "an IPOPI Webinar".

THE IMPACT AND BURDEN OF VIRAL RESPIRATORY INFECTIONS IN ANTIBODY DEFICIENCY

On September 19, IPOPI organised another session of its Hard Talks series, where 148 participants from 41 countries came together to focus on the impact and burden of viral respiratory infections in patients with antibody deficiency.

Dr Virgil Dalm shared insights from his experience managing COVID-19 and other respiratory infections in antibody-deficient patients, discussing their impact and complexities. This was followed by an engaging debate led by Dr David Lowe on vaccination and other challenges.

The banner features a central blue circle with a white question mark icon. Text inside the circle reads: "IPOPI HARD TALKS EXPLORING THE COMPLEXITY OF OUR FIELD" and "INSIGHTS ON THE IMPACT AND BURDEN OF VIRAL RESPIRATORY INFECTIONS IN ANTIBODY DEFICIENCY". Below this, it says "THURSDAY 19 SEPTEMBER, 15.00 CEST". On the left, a circular portrait of Dr David Lowe is shown with his name and "UK" below it. On the right, a circular portrait of Dr Virgil Dalm is shown with his name and "THE NETHERLANDS" below it. The IPOPI logo is in the bottom left, and the Moderna logo is in the bottom right. A small orange box in the top right corner says "an IPOPI Webinar".

MANAGEMENT AND TREATMENT OF AUTOIMMUNE PULMONARY ALVEOLAR PROTEINOSIS (APAP)


On October 10, 109 participants from 26 countries joined to explore the advances in the management and treatment of autoimmune pulmonary alveolar proteinosis (aPAP).



FLOW CYTOMETRY SCREENING FOR EARLIER PID DIAGNOSIS

The final session on November 19, explored the role of flow cytometry in early PID diagnosis, gathering 195 viewers from 52 countries.

The session, led by Martine Pergent (IPOPI President) and Dr Nizar Mahlaoui (Chair of IPOPI MAP), featured Dr Rita Carsetti, who emphasised the versatility of flow cytometry as a tool for reducing diagnostic delays. Dr Antonio Condino Neto expanded the conversation by addressing age-related challenges in diagnosis and identifying key markers for specific PIDs.



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 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 two policy events in 2024.

The first event was held online on May 23. The webinar highlighted the key role of European Reference Networks (ERNs) in advancing the newborn screening agenda, with contributions from representatives of three ERNs: Prof Maurizio Scarpa, from MetabERN (metabolic disorders), Prof Teresinha Evangelista, from EuroNMD (neuromuscular disorders) and Prof Michael Albert, from ERN RITA (immunological disorders).

Additional speakers included: Ms Hana Horka, from the European Commission, Prof Jim Bonham, President of the International Neonatal Screening Society (ISNS), Prof Peter Schielen, Secretary of ISNS, Johan Prevot, IPOPI's Executive Director, and Leire Solis, Health Policy and Advocacy Senior Manager at IPOPI.

The event also featured a video statement from MEP Stelios Kypourououlos (EPP, Greece) and a written statement from MEP Brando Benifei (S&D, Italy).

The event highlighted four key Screen4Rare principles:

1. The importance of working collaboratively to provide unbiased evidence.
2. The recognition that while newborn screening programmes offer significant benefits, they can also cause harm if poorly implemented.
3. Respect for Member States' autonomy, while promoting awareness of the need to update national plans;
4. The value of clear case definitions supported by real-world data.

Building on Screen4Rare's previous meeting with EU Health Commissioner Stella Kyriakides to stress equity in healthcare for all EU citizens, including those with rare diseases detectable through NBS, Screen4Rare was invited to present its goals at the ERN Board of Member States on October 22—an important step in strengthening dialogue with policymakers.

In addition, Screen4Rare held a meeting at the European Parliament (Brussels, Belgium) on November 6, to discuss how to prioritise newborn screening for treatable rare diseases with greater support from the EU in the next EU political mandate (2024-2029) as well as the benefits of the collaboration between Screen4Rare and the European Reference Networks (ERNs).

The event, hosted by S4R champion MEP Billy Kelleher (Renew, Ireland) and supported by the participation of MEP András Kulja (EPP, Hungary) representing the S4R MEPs Alliance, facilitated dialogue between EU institutions and S4R leaders Johan Prevot (IPOPI), Prof James Bonham and Peter Schielen (ISNS). Insights from Dr Andrea Bordugo and Prof Maurizio Scarpa (MetabERN) and Dr Alessandra Magnani (ERN RITA) further highlighted ERNs' contributions.

Challenges persist in ensuring equitable and sustainable NBS (Newborn Screening) across Member States. While more screening does not necessarily mean better screening, there are significant and unwarranted differences in the number of conditions screened across Member States. New advances in genomic sequencing present a crucial opportunity, but sustained EU political support and coordination over the next five years will be essential to ensure equitable and effective NBS across the EU.





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 of diseases 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 MEP Brando Benifei. At the national level, countries worldwide joined the effort, uniting around the call to ensure that 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 2024, 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 SPEAKS AT UNITAR ROUNDTABLE ON ACCESS TO PLASMA-DERIVED MEDICINES

Roberta Anido, IPOPI Board Member and President of the Argentinian PID Patient Organisation, and Leire Solis, IPOPI's Health Policy and Advocacy Senior Manager, were speakers at a breakfast roundtable hosted by the United Nations Institute for Training and Research (UNITAR) on "Plasma4Life: Bridging the gap in access to plasma and plasma-derived medicinal products" on May 29, in Geneva, Switzerland.

Prof Adli Ali, Head of immunology and rheumatology services, Hospital Pakar Kanak-Kanak UKM (Malaysia) and member of the IPOPI's Medical Advisory Panel was also a speaker at the event.

The roundtable discussion aimed to present the progresses made by the project in which patients, medical experts, governments, the private sector and other stakeholders have teamed up to explore potential solutions to increase access to plasma for the development of immunoglobulin replacement therapies and other plasma-derived medicines.

Plasma4Life is a neutral platform facilitated by UNITAR that aims at increasing awareness, building partnerships and facilitating access to the latest scientific knowledge and best practices about plasma and plasma-derived medicinal products. The project also seeks to support countries in their identification of the best national solution to improve the plasma ecosystems and increase patient access to care.

WORLD BLOOD DONOR DAY

On June 14, IPOPI joined the global community in celebrating World Blood Donor Day under the slogan: “20 Years of Celebrating Giving: Thank You, Blood Donors!” The global celebration was used to raise awareness of the need for safe blood and blood products, including immunoglobulin replacement therapies, and to thank donors for their life-saving gifts.

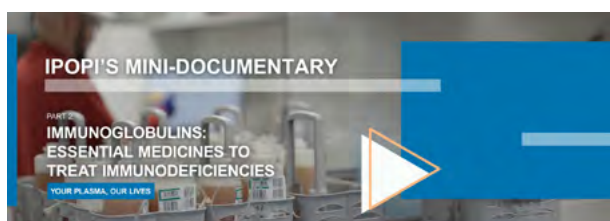
To mark the campaign, IPOPI released a special video showcasing the impact of blood and plasma donations. These life-saving contributions help patients with PIDs and countless others in need. **Watch the video here.**



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 October 7-11. IPOPI actively supports this global campaign, advocating for increased and more regionally balanced plasma collection.

In celebration of IPAW 2024, IPOPI released **two mini documentaries** showcasing the critical importance of plasma in producing essential medicines as immunoglobulin (Ig) replacement therapies. The mini documentaries also shed light on the challenges linked to plasma collection and treatment access for patients with primary immunodeficiencies (PIDs). Both mini documentaries can be accessed on **IPOPI's YouTube channel.**



IPOPI WELCOMES NEW EU SOHO REGULATION

In 2024, the European Union adopted the Regulation on Substances of Human Origin (SoHO), aiming to strengthen EU plasma collection and reduce reliance on third-country imports. IPOPI welcomed this important development, as immunoglobulin therapies—derived from human plasma—are essential, lifelong treatments for many people with primary immunodeficiencies (PIDs).

With plasma shortages affecting 14 countries in 2024, IPOPI strongly supports the Regulation's recognition of the unique nature of plasma for fractionation, the importance of prioritising plasmapheresis, and the role of public-private collaboration.

Looking ahead, an adequate implementation with set objectives to ensure ambitious collection targets and solid national plans needs to be developed by EU countries. Alignment between the SoHO Regulation (looking at plasma as starting material) and the forthcoming EU pharmaceutical legislation (looking at medicines, such as immunoglobulin therapies) will be key to ensuring stable and equitable access to immunoglobulin replacement therapies.



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. 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 is revising pharmacovigilance guidelines to enhance the safety monitoring of medicines.

Other important topics under discussion include the integration of artificial intelligence, utilisation of patient experience data, and the advancement of innovative therapies. These initiatives aim to improve access to safe, effective, and innovative treatments for patients across the European Union.

IPOPI actively engaged in these discussions through the participation of IPOPI's Board Member Jose Drabwell and Health Policy and Advocacy Manager 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 GLOBAL PID EVENTS

IPOPI'S XVIII GLOBAL PATIENTS' MEETING (GPM)

From October 16-19, IPOPI brought together 100 participants from nearly 50 countries, in Marseille, marking a record number of National Member Organisations (NMOs). Held alongside the European Society for Immunodeficiencies (ESID) and the International Nursing Group for Immunodeficiencies' (INGID) congresses, this flagship biennial event highlighted collaboration across the primary immunodeficiency (PID) community.

This meeting featured insightful sessions on mental health, innovative therapies, artificial intelligence and much more. IPOPI introduced two key tools: the "Level Up" Board Game, and a new Toolkit with 25+ practical resources. The programme was well-balanced, combining educational sessions with skill-building workshops to empower attendees with practical tools and strategies to strengthen their organisations.

On October 17, the IPOPI community also came together to honour outstanding contributions to the primary immunodeficiency field through the PID Champion Awards.







IPOPI WELCOMES NEW BOARD OF DIRECTORS

During the Annual General Assembly held during the Global Patients' Meeting on 18 October in Marseille, IPOPI's National Member Organisations elected a new Board of Directors.

IPOPI congratulates Cynthia Olotch (Kenya), Roberta Anido (Argentina), Tracy Shaw (USA), and Dimas Adhi Sugiharto (Indonesia) on their election for the 2024–2028 term. Bruce Lim (Malaysia) was co-opted for the 2024–2026 term.

Following the meeting, the Board re-elected Martine Pergent as Chair, Bruce Lim as Vice-Chair, and Otilia Stan-ga as Treasurer.

Together, the Board will continue to guide IPOPI's advocacy and global collaboration efforts to support PID pa-tients worldwide.

IPOPI REGIONAL PID EVENTS

IPOPI 5TH ASIAN PID PATIENTS AND DOCTORS MEETING

IPOPI was proud to host the 5th Regional Asian PID Patients and Doctors Meeting on March 24-25, in parallel with the 5th Asia-Pacific Society for Immunodeficiency (APSID) Congress and the 7th Annual Scientific Meeting of the Japanese Society for Immunodeficiency and Autoinflammatory Diseases (JSIAD) in Tokyo, Japan.

An impressive number of 50 participants from 13 different countries across Asia were in attendance including from Bangladesh, Cambodia, China, India, Indonesia, Japan, Malaysia, Nepal, Philippines, Singapore, South Korea, Thailand, and Vietnam. The two-day meeting featured insightful discussions on key aspects of effective primary immunodeficiency (PID) patient care, diagnosis' challenges, and the rapidly evolving landscape of PIDs. The latest regional initiatives from both patient representatives and physicians were explored, sparking interest-ing and fruitful discussions.

On March 22, IPOPI also held a fruitful strategic meeting with Tsubasa-no-Kai members, medical advisors, and stakeholders, addressing our organisation's specific challenges.



WORLD PI WEEK 2024: ADVOCATING FOR ACCESS TO CARE FOR ALL PID PATIENTS

IPOPI supports the yearly World Primary Immunodeficiencies Week (WPIW). The 2024 campaign spotlighted a crucial theme: “Access to care for all patients with primary immunodeficiency (PID), everywhere”. The message was clear: let’s make early diagnosis and timely access to quality treatment a reality worldwide. Stakeholders from across the globe rallied under this important cause, uniting their efforts to highlight the challenges and advancements in PID care.

IPOPI celebrated WPIW 2024 by supporting 37 IPOPI National Member Organisations (NMOs) innovative initiatives to raise awareness about PIDs. These activities included artist gatherings, PID conferences, family days, social media campaigns, educational videos, and so much more.

Additionally, IPOPI launched a video campaign featuring testimonies from NMOs worldwide. These shared experiences and challenges in accessing PID care emphasised the importance of timely and quality treatment, early diagnosis, specialised centres for PID treatment, and reimbursement.



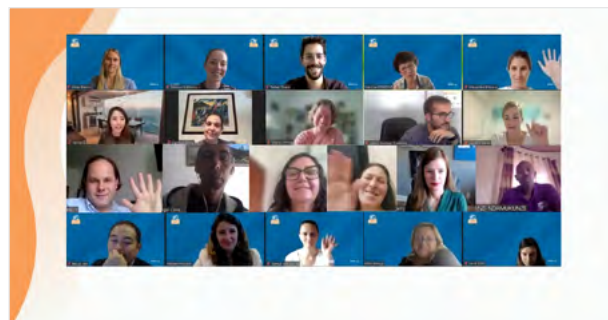
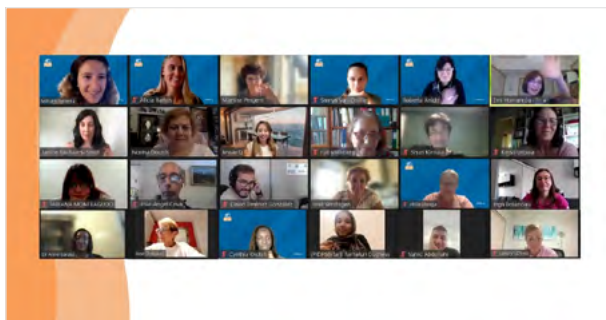
IPOPI NMO SUPPORT PROGRAMME 2024

Throughout 2024, IPOPI was pleased to be able to fund several NMO projects and campaigns through its NMO Support Programme among which:

- China - Exploring PID through Art: A Touring Exhibition on PIDs
- Israel - Annual patients’ conference
- Netherlands - PID Experts programme
- United Kingdom - Dissemination of printed IPOPI booklets to immunology centers

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 2024, four webchats were held on subjects such as access to PID care, IPOPI’s strategic plan, adult PID patients’ needs and mental health.



IPOPI NMO NEWS BITES

The IPOPI NMO News Bites is a member-focused newsletter released 4 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

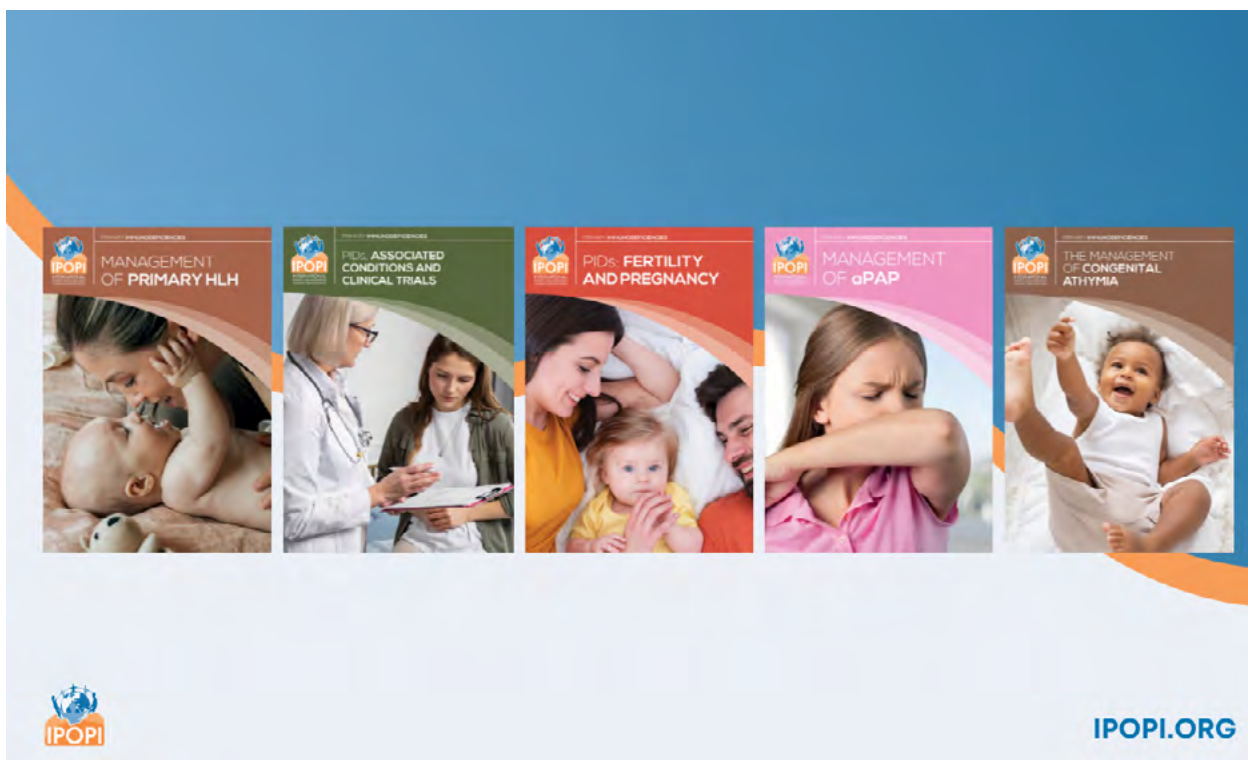
IPOPI uses communication tools and strategies to spread awareness of PID, share information, for medical education and promote the collection of key PID data.

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 2024 five new IPOPI information leaflets were published, covering the following topics:

- Management of Autoimmune Pulmonary Alveolar Proteinosis (aPAP)
- Management of Primary Haemophagocytic Lymphohistiocytosis (HLH)
- Management of Congenital Athymia
- PIDs: Associated Conditions & Clinical Trials
- PIDs: Fertility and Pregnancy

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'S RESEARCH GRANT PROGRAMME

IPOPI launched its Research Grant Programme* a new initiative aimed at promoting scientific and clinical research in the field of primary immunodeficiencies.

An impressive number of over 30 grant applications were received. IPOPI awarded two-year funding to four research projects addressing critical areas all over the globe, including newborn screening, plasma access, mental health, and diagnostic improvements. 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.

* 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, the programme reflects her unwavering commitment to patient-centred research and innovation.

NEW TWO-PART DOCUMENTARY SERIES: "YOUR PLASMA, OUR LIVES"

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).

TURNING PLASMA INTO LIFE-SAVING TREATMENTS

The first documentary named Turning plasma into lifesaving treatments explores plasma's journey from collection to production focusing on its role in immunoglobulin (Ig) replacement therapies. It highlights the critical need to expand global plasma collection to address the growing demand for plasma-derived medicinal products (PDMPs).

The mini documentary features insights from both patients and donors, showing the importance of plasma in their lives. It also highlights the crucial role of national regulatory agencies in ensuring that PDMPs meet the necessary safety, efficacy, and quality standards before making them available to patients.



IMMUNOGLOBULINS: ESSENTIAL MEDICINES TO TREAT IMMUNODEFICIENCIES

The second mini documentary highlights immunoglobulins (Ig) as essential medicines for patients with primary immunodeficiencies (PIDs). It features interviews and testimonies from doctors, the mother of a PID patient, and regulatory experts, all emphasising the importance of Ig therapies for the well-being of patients.

These documentaries serve as an invaluable resource for patients, member organisations, policymakers, and healthcare professionals. **Watch them here.**

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

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.

RECOMB'S ANNUAL MEETING

Recomb is a European research consortium dedicated to developing gene therapy for recombination activating gene-1 (RAG-1) deficient SCID, of which IPOPI is a leading partner. This project came to an end on December 31, after a generous 24-month extension by the EU Horizon 2020 programme.

In 2024, multiple efforts were made to increase the number of recruited patients. The recruitment flyer, originally published in English was translated into Dutch, German, Polish, Turkish, Italian and Spanish. This flyer is designed to reach and connect with patients across Europe and help them learn more about the trial and the inclusion criteria. Finally, 3 more patients were included and infused in 2024. So far, the trial has recruited five patients, all of whom have successfully been treated with their genetically modified cells and are showing encouraging immune recovery.

Additionally, results on the project's study on 'ethical' and social acceptability of the proposed gene therapy trial and the economic evaluation of this treatment option were shared in a webinar on December 2.

Despite the end of the project, the consortium remains resolute in continuing the follow-up and recruitment of new patients whilst aiming for market approval. As a partner and work package leader of the RECOMB project, IPOPI is determined to continue collaborating on the next phase of this immensely valuable initiative for our patients' community.

www.recomb.eu

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



3D-GATA2 PROJECT

Launched in 2024, the 3D-GATA2 project is a collaborative EU-funded initiative focused on improving research and care for patients with GATA2 deficiency, a rare immune disorder. IPOPI is proud to be part of this important effort, which will continue to develop over the coming years.



ACCESS TO GENE THERAPIES FOR RARE DISEASES (AGORA)

Johan Prevot, Executive Director of IPOPI, is a founding board member of the AGORA initiative (Access to Gene therapies for RARE 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

IPOPI's collaboration with the European Reference Network RITA has continued, 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, IPOPI has actively participated in the Coalition's Partners' exchange of views on the revision of the pharmaceutical legislation held in April as well as in several other relevant committee and plenary meetings.



RARE
DISEASES
INTERNATIONAL

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.

PLUS – PLATFORM OF PLASMA PROTEIN USERS

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

PLUS
PLATFORM OF PLASMA
PROTEIN USERS



Over the course of the two-day conference, participants engaged in key discussions on ongoing issues, including the latest developments in the revision of the European legislation for the collection of blood and plasma (SoHO regulation), the EU pharmaceutical legislation and the World Health Organisation's controversial decision to include cryoprecipitate on the List of Essential Medicines. Several elements emerged as shared priorities during the discussions and participants agreed to continue their collaboration based on these common goals.

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, throughout the year
- ERN-RITA Communications WP, throughout the year
- ERN RITA transition working group 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
- RIPAG meetings, throughout the year
- UNITAR liaison meetings, throughout the year
- World PI Week steering committee meetings, throughout the year

- PLUS stakeholders meeting, January 2024
- AGORA regulatory workshop, January 2024
- VACCELERATE workshop, January 2024
- IPFA/EBA Symposium on Plasma Collection and Supply, February 2024
- RITA webinar Which patients with IEI should be referred for HSCT? February 2024
- EU Health Coalition plenary meeting, February 2024
- IPOPI NMO webchat, February 2024
- Joint HMA/EMA multi-stakeholder workshop on Patient Registries, February 2024
- ENVI committee SoHo Meeting, February 2024
- AfSBT Educational Webinar: Quality Management again and again, February 2024
- SUPPLY Project Stakeholders Meeting, February 2024
- Joint EMA PCWP-HCPWP Meeting, February 2024
- EMA/EORTC workshop: How can Patient Reported Outcomes (PROs) and Health Related Quality of Life (HRQoL) data inform regulatory decisions? February 2024
- Rare Diseases in the EU: Joint Action shaping the future of ERNs Meeting, March 2024
- Workshop “Navigating Diagnostics Through the Lens of the Pharmaceutical Package”, March 2024
- EMA multi-stakeholder workshop on data quality framework for ADR reporting, March 2024
- IPPC, Athens, April 2024
- IPFA/PEI Workshop, Denmark, April 2024
- EFPIA meeting, April 2024
- EMA Webinar on a pilot of a novel methodology to identify and validate Patient Experience Data, April 2024
- Inaugural Meeting of the Forum of the Critical Medicines Alliance, April 2024
- World Health Assembly, May 2024
- RDI Webinar on WHO Essential List of Medicines, May 2024
- UNITAR high level meeting, Geneva, May 2024
- EURORDIS Healthcare Webinar on Approaches to Evaluate Evidence on Rare Disease Guidelines, May 2024
- TRANSFORM alliance strategy workshop, May 2024
- EMA Clinical Trials Information System Forum, May 2024
- DGA EU elections countdown webinar, May 2024
- EPF workshop on critical medicines, May 2024
- INTENT research project webinar, May 2024
- Consultation Conference - EU guidance on public procurement of medicines, May 2024
- Workshop “Countdown to the EU HTA: how can we seize this opportunity to improve patient access to medicines?”
- Kick-off meeting of the European Network for Infection Prevention and Antimicrobial Resistance, June 2024
- Conference on the new Regulation on Substances of Human Origin, Brussels, June 2024
- European Hematology Congress, June 2024
- Joint EMA PCWP-HCPWP Meeting, July 2024
- EU Health Coalition plenary meeting, September 2024
- TRANSFORM workshop, September 2024
- Ljubljana 2024 Genomics in Newborn Screening International Workshop, September 2024
- World Allergy Congress, September 2024
- Global Network for Rare Diseases Updates - RDI Members Webinar, September 2024
- 2024 Asia-Pacific Plasma Leaders’ Network (APPLN) Dialogue Forum, September 2024
- EMA Scientific Symposium on Advanced Therapy Medicinal Products - Contribution, evolution, revolution, October 2024
- International Plasma Awareness Week social media activities, October 2024
- Kick off meeting of the International Newborn Screening Development Coordination Group, October 2024
- ERN-RITA General Assembly Meeting, October 2024
- ERN Board of Member States Meeting, October 2024
- ESGCT conference Rome, October 2024
- ERDERA Kick Off Meeting, October 2024
- EMA Scientific Symposium on Advanced Therapy Medicinal Products - Contribution, evolution, revolution
- EURORDIS webinar EHDS and Primary Data, October 2024
- EU Health Coalition Plenary Meeting, November 2024

- Eurordis webinar EHDS & Primary data Webinar, November 2024
- Webinar WHO resolution on social participation, November 2024
- TRANSFORM Round Table EU Parliament, November 2024
- WHO 5th SAGE IVD meeting Open Session webinar, November 2024
- ECDC Webinar on European Antibiotic Awareness Day, November 2024
- Eurordis webinar EHDS & Secondary data Webinar, November 2024
- EMA CHESSMEN workshop on shortages, November 2024
- RECOMB Meeting, Leiden, The Netherlands, November 2024
- EMA/HMA Big Data Stakeholder Forum, November 2024
- WHO webinar on “WHO report to estimate the impact of vaccines on antimicrobial resistance and use”, November 2024
- EUROCAM One Health Webinar, November 2024
- ESID Grand Rounds webinar: Monogenic atopic disorders, November 2024
- RECOMB Consortium Final Meeting, Leiden, The Netherlands, November 2024
- ERN-RITA Webinar How I treat Wiskott Aldrich Syndrome, November 2024
- EU Critical Medicines Alliance webinar, December 2024
- Plasma4Life Knowledge Partners webinar, December 2024
- ERICA ERN Research Conference, December 2024
- ERDERA Joint Transnational Call 2025 Information Webinar, December 2024
- Access to care / patient empowerment meetings and/or calls with doctors and patients in Australia, Belgium, Botswana, Brazil, Cambodia, Chile, China, Costa Rica, Estonia, France, Hungary, Laos, Lebanon, Malta, Mali, Moldova, Namibia, Netherlands, Nigeria, Panama, Peru, Portugal, Romania, Rwanda, Singapore, Spain, Suriname, Sweden, Taiwan, Tanzania, USA, Zambia, Zimbabwe, among others.

IPOPI IN 2025 AND BEYOND

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

Exciting initiatives are underway, including the RareFind AI project, which will use AI to reduce diagnostic delays for patients, the production of two mini-documentaries on living with PIDs and autoimmune PAP in PIDs, the organisation of regional meetings in Africa and Latin America, forums at the European Parliament, national advocacy campaigns, and much more.

Through new initiatives, workshops, and regional meetings, IPOPI is expanding its efforts to empower National Member Organisations and reinforce PID care and advocacy worldwide.

We look forward to welcoming the global community to IPIC in **Prague, Czech Republic, on November 5-7, 2025.**



The banner features a photograph of the Charles Bridge in Prague, Czech Republic, with the Vltava River in the foreground. To the right of the image is a blue information box with white text and a logo. The logo consists of a globe with hands holding it, symbolizing global unity and care. The text in the box reads: **IPIC2025**, INTERNATIONAL PRIMARY IMMUNODEFICIENCIES CONGRESS, DIAGNOSIS AND CLINICAL CARE, PRAGUE, CZECH REPUBLIC, 5-7 NOVEMBER 2025, an IPOPI event, and ipic2025.com. At the bottom left of the banner is the IPOPI.org logo, and at the bottom right is the IPOPI logo.

**REVIEW
OF ACTIVITIES
AND ACHIEVEMENTS**

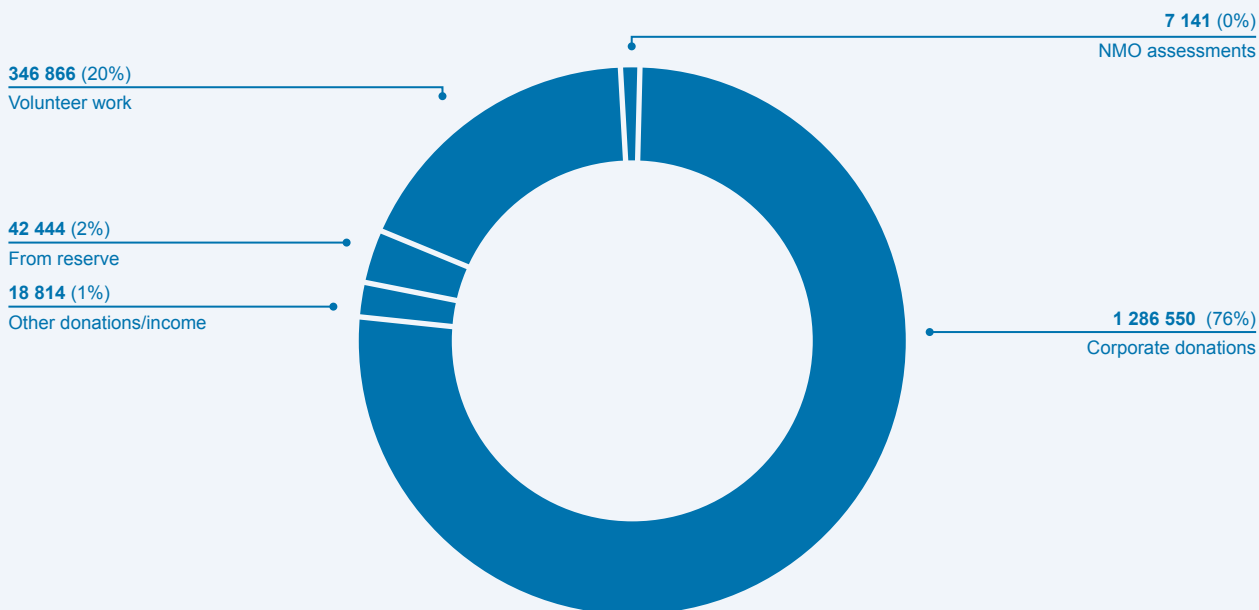
**FINANCIAL
REPORT**

2024

FINANCIAL REPORT 2024

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 2024. 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 2024 (EURO)



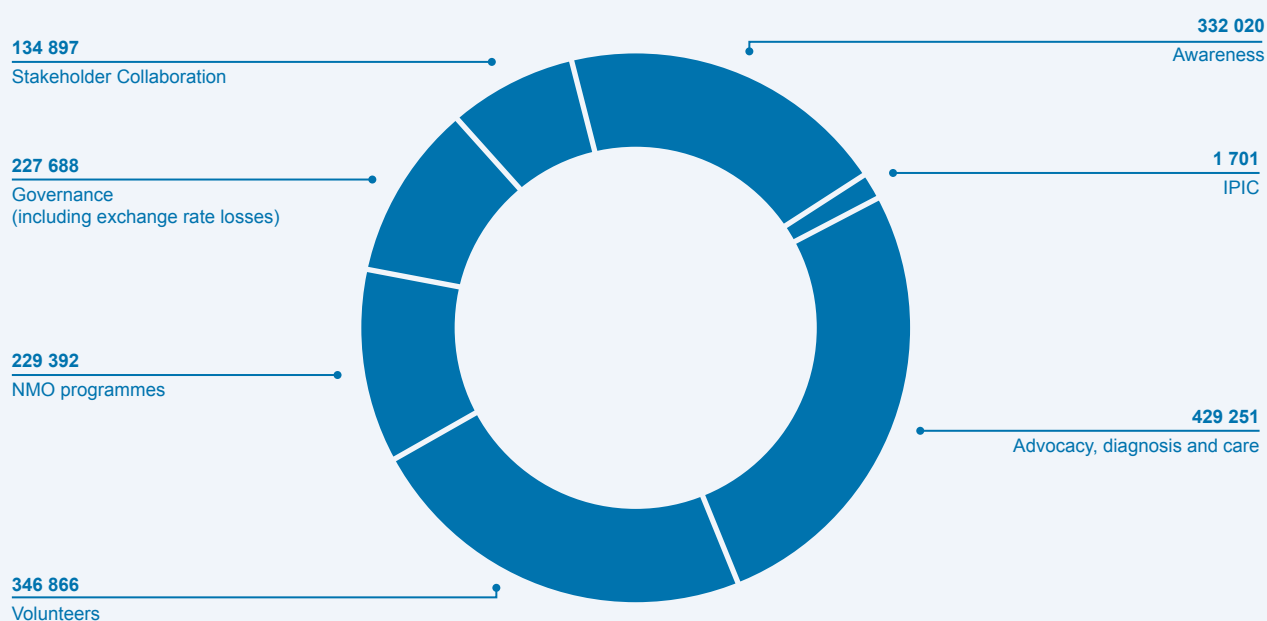
INCOME 2024

€ EURO

%

	€ EURO	%
NMO assessments	7 141	0
Corporate donations	1 286 550	76
Other donations/income	18 814	1
Volunteer work	346 866	20
From reserve	42 444	2
TOTAL	1 701 815	100

RESOURCES EXPENDED 2024 (EURO)



EXPENDITURE 2024

€ EURO

IPIC	1 701
Advocacy Diagnosis and Care	429 251
NMO programmes	229 392
Awareness	332 020
Stakeholder Collaboration	134 897
Governance (including exchange rate losses)	227 688
Volunteers	346 866
TOTAL EXPENDITURE	1 701 815

No contribution received from a single company reached the majority of the total income. The highest single contribution by a company represented 17% of the total income, including volunteer time contributions and 21% 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 75 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



GOLD



SUPPORTERS



PROJECT SPONSORS

In 2024, 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
- Chiesi
- CSL Behring
- Grifols
- ImmunoIVD
- Kedrion
- LFB
- Moderna
- Novartis Gene Therapies
- Octapharma
- Orchard Therapeutics
- Pfizer
- Pharming
- Revvity
- 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 2024, including but not limited to:

Active Citizenship Network, ACT4EU research consortium on ATMPs, AGORA gene therapies consortium, AIPI Meeting Faculty and Stakeholders Group, Asia Pacific Plasma Leaders Network (APPLN), Asia Pacific Economic Cooperation (APEC) Rare Diseases committee, BASICS Delphi Study project on SID, Council of Europe, Care-for-Rare Foundation, EU-PAD microbiome research consortium, European Centre for Disease Prevention and Control (ECDC), European Medicines Agency's Patient and Consumer Working Party (PCWP), European Medicines Agency's Medicines Shortages Single Point of Contact (SPOC) Working Party, EuropaBio Patients Bio-Forum, European Commission SoHo Unit, European Foundation for the Care of Newborn Infants (EFCNI), European Health Parliament Think Tank, European Network For Paediatric Research (Enpr-EMA), European Patients Forum (EPF), European Rare Disease Organisation (EURORDIS), European Reference Network on Immunological Diseases (ERN-RITA), European Reference Network Expert Platform on NBS, ESID Registry steering committee, ESID Clinical Working Party, EU Health Coalition Steering Committee, Friends of Europe think tank, 3D GATA2 research consortium (EJP funded Project), Health First Europe (HFE), IEI-Haem Research Consortium (EJP funded project), Integrate ATMP Research Consortium, International Society Blood Transfusion (ISBT), International Society for Neonatal Screening (ISNS), JAKI Consensus Consortium (under ESID & EBMT), NAUTILUS research consortium (currently at proposal stage), NGO Committee for Rare Diseases, Platform of Plasma Protein Users membership consulting to the European Commission (PLUS), PLUS Stakeholders Consensus Conference, PPTA Stakeholders Group, Rare Diseases International (RDI) advocacy committee, RECOMB consortium (EU funded project), SPRING research consortium on newborn screening, TRANSFORM, TREAT JAK-STAT research consortium (currently at proposal stage), United Nations Institute for Training and Research (UNITAR), UK Plasma Action Group, World Allergy Organization, World Health Organisation expert committees, World PI Week Steering Committee, World PI Week steering committee, WHIM International Consortium, Key Medical regional and international societies including: ESID, LASID, APSID, ASID, SEAPID, ICHS, IUIS, other national PID doctors societies and INGID.

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

IPOPI.ORG



INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES
IPOPI aisbl is an international non-profit association registered in Belgium (BE 0761.784.055)

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