



IPOPI LATIN AMERICAN PID PATIENTS' MEETING

OCTOBER 19-20, 2023
MEXICO CITY, MEXICO

an **IPOPI** event

MEETING REPORT

COLLABORATION



SUPPORTED BY



Introduction

The vibrant city of **Mexico City** served as the host to the **IPOPI Latin American PID Patients Meeting on October 19-20, 2023**, held in parallel with the **Latin American Society for Primary Immunodeficiencies (LASID) meeting**. The two-day program was thoughtfully tailored to address the pressing challenges and opportunities faced by the region.

A key focus was a session dedicated to **navigating the regulatory processes**, on immunoglobulin approval, countering counter-fake medicines, and pharmaceutical co-vigilance. This session provided valuable insights into ensuring the safety and authenticity of medical treatments. Participants sharpened their **advocacy skills**, for enhanced treatment access and plasma collection. Topics included strategies for **future endemics, PID diagnosis, treatment, care**, participation in an interactive transition care panel, and engaging in a workshop.

A highlight of the meeting was the opportunity to **hear from various national member organisations (NMOs)** about **their latest impactful projects in their respective countries**. This exchange allowed participants to learn from each other's successes and innovations, **fostering inspiration and collaboration**.

This meeting was provided in English and Spanish, with the use of an AI translation service, to allow the participation of all our delegates.

Meeting objectives

- Improve knowledge on diagnosis and treatment for PIDs
- Practice how to raise awareness and advocate on a subject
- Identify and address the challenges of living with a PID
- Learn from NMO's best practices
- Strengthen regional cooperation

Participation overview

Total of participants: 35

Countries represented: Argentina, Bolivia, Brazil, Chile, Costa Rica, Ecuador, El Salvador, Mexico, Paraguay, Peru, Puerto Rico, and Uruguay.



MEXICO

PUERTO RICO

EL SALVADOR

BRAZIL

COSTA RICA

ECUADOR

PERU

BOLIVIA

CHILE

ARGENTINA

PARAGUAY

URUGUAY

Participation feedback (12)



Excellent **92%**



Very good **8%**



I really liked the workshops we held by country because we always learn something new and it gives us ideas to carry out in our countries. But what I liked the most were the presentations of the doctors. Very clear and very interesting; in a certain way some of the talks give us more expectations of treatments and improvements in PIDs.



Meeting programme

The full meeting programme is available [here](#).

Presentations available

Authorised presentations provided at this meeting are available on the [NMO support webpage](#) for educational purposes.

Pictures available

Check out selected pictures from this meeting [here](#).

Report

This report captures key lessons and action points from this two-day meeting, aimed at empowering patient organisations and stakeholders to enhance PID patient care in Latin America. Rather than summarising all presentations, it focuses on actionable insights.

We encourage patient representatives and stakeholders to prioritise these points and collaborate effectively to improve PID patients' lives in their countries.

Programme

Click on topics you're interested in to learn more.

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Day 1 | 19 October

01 Session

Introduction and welcoming words

Moderated by **Ms Martine Pergent**

- Welcome remarks - Ms Martine Pergent, IPOPI President.
- Welcome remarks to Mexico from AMPIP - Ms Gabriela Sušrez Martinez, AMPIP President (Mexico).
- Welcome remarks from sponsors - Grifols and Takeda.
- Icebreaker, Ms Roberta Anido de Pena (IPOPI Regional Board Member) and Ms Leire Solis (IPOPI Health Policy and Advocacy Senior Manager).

Martine Pergent, IPOPI President, opened the meeting and welcomed the participants to the first out of two exciting meeting days for IPOPI's Latin America meeting. **Ms Gabriela Martinez** (AMPIP) and **Ms Maite Tazon** (Takeda), joined Ms Pergent in welcoming all participants to Mexico.

The **icebreaker segment** provided the participants an opportunity to **meet each other and identify common challenges and focus points** such as: improving medical awareness, treatment access, and organisational strength. The session set the stage for deeper discussions on addressing shared challenges.



Patient leaders from 12 countries introducing themselves

02 Session

PIDs: Latin America Today

Moderated by *Ms Roberta Anido Pena*

- Addressing the Challenges and Opportunities for PIDs in Latin America
 - Physician perspective - Prof Gesmar Segundo (LASID President, Brazil).
 - Patient representative perspective - Ms Roberta Anido de Pena.
- Identify & Resolve: Tackling challenges together (group activity).

The meeting continued with a valuable session dedicated to **identifying challenges and opportunities**, followed by a workshop to generate ideas on how to address them. This session's outcomes highlighted the following points:

- **Improve medical education:** Collaborate with medical schools to include content on rare diseases and PIDs; develop local programs for immunologists, nurses and physicians; motivate medical trainees to specialise in immunology.
- **Public awareness campaigns:** Use social media and influencers to raise awareness about PIDs.
- **Plasma collection:** Educate on plasma collection, differentiating it from blood donation; advocate for the need to increase plasma collection in Latin America.
- **Enhance diagnostic and screening access:** Improve access to basic and genetic testing; advocate for newborn screening programs for SCID.
- **Develop national patient registries:** Create or improve existing registries to gather valuable data for advocacy and research.
- **Empower Patient Associations:** Empower these groups to advocate for better access to treatments and work closely with medical professionals; Utilise the [PID Life Index](#) data for targeted actions.
- **Specialised Centers:** Promote the establishment of multidisciplinary centers for PIDs.



Prof Gesmar Segundo presenting: Leading advocate for awareness and educational empowerment.

Other related resources:

- [IPOPI educational leaflets for healthcare professionals and patients](#)
- [IPOPI video series “What is a PID?”](#)
- [World Blood/Plasma Donor Day](#), on June 14
- [WHO Essential Diagnostics List](#)
- [International Neonatal Screening Day](#), on June 28.
- [Article on registries: So You Want to Build Your Disease's First Online Patient Registry: An Educational Guide for Patient Organizations Based on US and European Experience | The Patient - Patient-Centered Outcomes Research \(springer.com\)](#)
- [Article on registries: Registries are shaping how we think about primary immunodeficiency diseases - Journal of Allergy and Clinical Immunology \(jacionline.org\)](#)



Group discussions aimed at addressing regional challenges effectively.

03 Session

Navigating through the regulatory process

Moderated by Ms Miriam Ferreira

- What is needed for an Immunoglobulin to be approved?, Ms Leire Solis
- What is a counter-fake medicine?, Prof Antonio Condino Neto (Brazil)
- Pharma co-vigilance scheme, Dr Priscila R. Sánchez Buenfil (Mexico)

The three presentations in this session provided valuable insights, emphasising key lessons and actionable proposals on the topic **regulatory process**:

- **Understand the approval process:** Immunoglobulin approval involves plasma collection, fractionation, and marketing authorisation from the regulatory agency.
 - ▶ Action: Familiarise yourself with your country's regulatory agency and its approval process.
- **Recognise access challenges:** Regulatory approval doesn't guarantee patient access; coverage decisions are often political.
 - ▶ Action: Prepare to advocate for immunoglobulin coverage with policymakers and insurers.
- **Leverage patient power:** Patient organisations play a crucial role in influencing coverage decisions.
 - ▶ Action: Organise and collaborate with other patients to create awareness campaigns and lobby for better access, availability and coverage.
- **Utilise international support:** International organizations can provide backing for your arguments.
 - ▶ Action: Reference [WHO's Essential Medicines List](#) and other global health initiatives in your advocacy efforts.
- **Monitor drug quality and safety:** Pharmacovigilance is crucial for ensuring ongoing safety and effectiveness.
 - ▶ Action: Encourage patients and doctors to report adverse effects to improve drug monitoring; provide educational materials to healthcare professionals to raise awareness of counterfeit medicines and educate patients.

By focusing on these actionable items, PID patient organisations and partners can work towards improving access to safe, effective immunoglobulin treatments and contribute to a more robust regulatory environment.

Other related resources:

- IPOPI's new statement on "Patients with PIDs should have access to safe, efficacious and high-quality immunoglobulin therapies"
- IPOPI's statement on "Patients with PIDs need sustained & continued access to their Ig therapies!"
- IPOPI's statement on "Managing demand for immunoglobulins: PIDs are a priority indication at all times"



Dr Priscila R. Sánchez Buenfil introducing pharmacovigilance

04 Session

How to advocate for access to treatment?

Moderated by Ms Leire Solis

PART 1

- IPOPI PID Life Index: analysis of the treatments available, Ms Martine Pergent
- Workshop: Exploring the landscape of access to treatment: availability, coverage and personalisation.

PART 2

- Process of plasma collection to fractionation, Ms Roberta Anido de Pena
- Present case studies from NMOs on plasma collection: Argentina and Brazil, Ms Roberta Anido de Pena and Ms Juçaira Giusti
- Workshop: Turning challenges on plasma collection into opportunities

The presentations and workshops highlighted the **complex challenges but also opportunities for improving access to treatment and plasma availability in Latin America**. A multi-faceted approach was discussed, highlighting that **patient organisations can play a key role** in advocacy and education efforts.

Part 1 - Access to Plasma-Derived Therapies

- Shortages of **immunoglobulins and other plasma-derived products (PDMPs)** in many regions
 - ▶ Action: Focus advocacy efforts on ensuring stable supply and accessibility of treatments.
- Inequitable **access to treatments** across different countries
 - ▶ Action: Collaborate with other patient organisations, such as rare diseases, to strengthen advocacy efforts to improve treatment availability and coverage.
- Limited **variety of products available** to meet diverse patient needs (e.g., different concentrations, and infusion methods)
 - ▶ Action: Advocate for availability of various medicines with different types of infusion and product concentrations to meet diverse patient needs.

Part 2 - Plasma collection availability

- Many countries have laws prohibiting the commercialization of blood/plasma or lack clear **legislation on plasma collection**
 - ▶ Action: Advocate for legislative changes to facilitate plasma collection, potentially leveraging existing rare disease laws
- Lack of **infrastructure and capacity for efficient plasma collection and processing**
 - ▶ Action: Advocate for the development of national/regional strategies for plasma self-sufficiency, focusing on both collection and processing capabilities, considering public-private partnerships as the **Plasma4life experience**.
- Low **public awareness about the importance of plasma donation**
 - ▶ Action: Launch education campaigns to raise awareness about plasma donation and its critical role in life-saving treatments for PID patients.



Patient leaders working hard to improve access to PDMPs

Other related resources:

- IPOPI leaflets: [Plasma-derived therapies](#)
- [International Plasma Awareness Week](#), first week of October
- [IPOPI call for increased plasma collection to ensure patients with PIDs have access to their therapies, on IPAW 2020](#)



Patient leaders working hard to improve access to PDMPs

05 Session

How to address future endemics?

Moderated by *Ms Martine Pergent*

- Vaccination for PID patients, Dr Tamara Staines Boone (Mexico)
- Endemic infectious diseases in the region, Prof Gesmar Segundo (LASID President, Brazil)
- Antimicrobial resistance
 - ▶ Physician perspective: what is the problem?, Dr Silvia Sánchez-Ramón (Spain)
 - ▶ Patient organisation: How can NMOs get involved in the topic?, Ms Leire Solis

The following session aimed at discussing how to be **better prepared to navigate future endemics**, reducing risks and ensuring the specialised care of PID patients.

- **Educate patients and families** about which vaccines are safe and beneficial for specific types of PIDs;
- Emphasize the **importance of family members getting vaccinated** to protect immunocompromised patients.
- Advocate for **implementation of newborn screening programs** for severe combined immunodeficiencies (SCID) before BCG vaccination.
- Emphasize the **importance of basic sanitation** in preventing many endemic diseases, especially in remote areas.
- Advocate for **more data collection and research on how endemic diseases specifically affect patients with primary immunodeficiencies**, including them on vaccine efficacy studies.

The session followed with other key presentations on the topic of **antimicrobial resistance (AMR)**. It was explained that AMR is a growing threat, posing a serious threat in particular to PID patients who rely heavily on antibiotics for infection prevention and control. It was highlighted that:

- **Collaboration with medical societies** to develop evidence-based guidelines on the use of prophylactic antibiotics in PID patients.
- Launch of **awareness campaigns to educate patients, doctors, policymakers and the general population** about responsible antibiotic use (**World Antimicrobial Awareness Week, on November 18-24**).

Other related resources:

- IPOPI leaflet on **“Vaccines and primary immunodeficiencies”**



Dr. Tamara Staines Boone presenting on vaccination

06 Session

PID diagnosis, treatments and care

Moderated by *Ms Roberta Anido de Pena*

- Diagnostics: from basics to genetics, Dr Carolina Prando (Brazil)
- Advancements in curative and targeted treatments, Dr Pere Soler-Palacín (Spain)
- Transition care from paediatric to adult clinics: Interactive panel discussion with a children and an adult physician, Dr. Miguel Galicchio (children) (Argentina) and Dr Leila Ferreyra Mufarregue (adult) (Argentina)
- Sharing Success: NMOs' impactful actions in diagnosis, treatment, and care, IPOPI NMOs (National Member Organisations), and Ms Miriam Ferreira (IPOPI NMO Programmes Officer)

This session allowed our participants to learn more about the advances in PID diagnosis, treatment, and holistic care.

“From basics to genetics in diagnostics”. Here are some key lessons learned:

- Basic lab tests like blood cell counts and advanced genetic testing significantly improves treatment outcomes and patient survival rates.
- Next-generation sequencing, including whole-genome and exome sequencing, is vital for identifying genetic causes of immunodeficiencies, aiding precise treatment strategies.

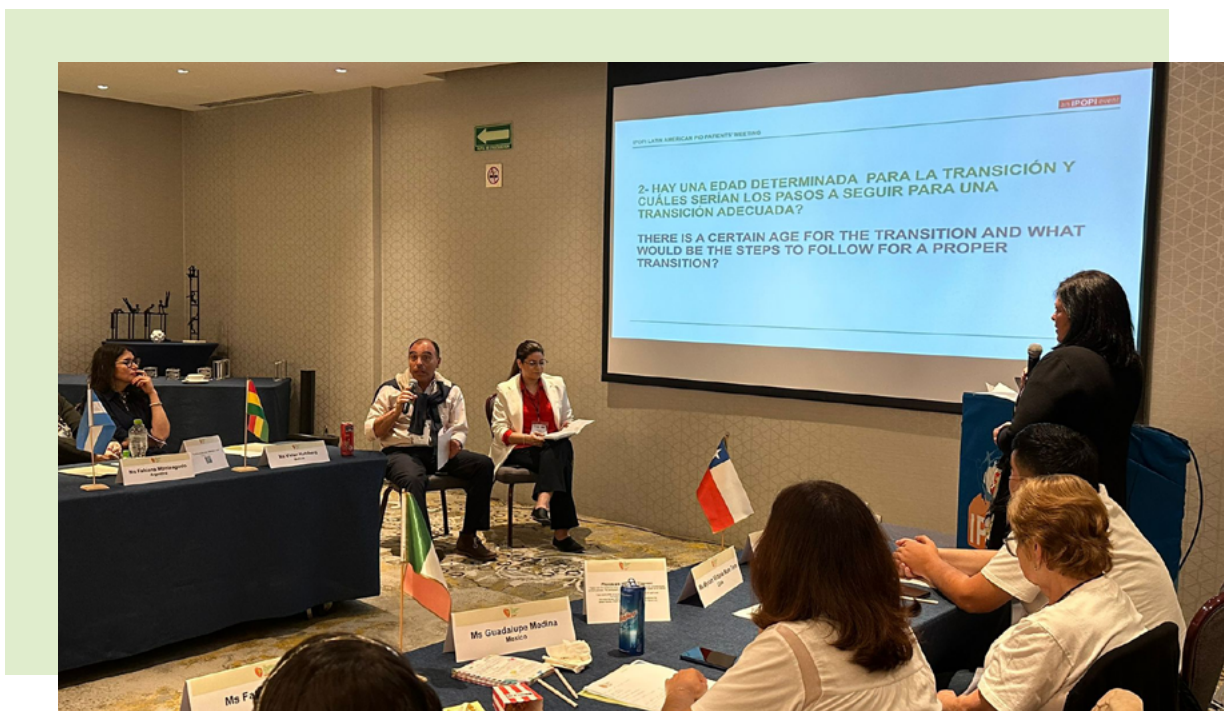
“Advancements in curative and targeted treatments”. Key learnings included:

- The importance of aligning treatment options with the resources available in each country to manage patient expectations effectively;
- The significance of genetic testing and targeted treatments, which can significantly improve patient outcomes but also require careful consideration of long-term effects and accessibility.

The session followed with an interactive discussion emphasising the **crucial transition from paediatric to adult care**, particularly in managing chronic diseases like PIDs. Key points included:

- Transition should occur within a flexible age range, tailored to individual patient needs, rather than a fixed date.
- Steps involve patient preparation, collaborative planning with families and healthcare providers, and integrating care into adult settings.
- Stakeholders include patients, families, paediatricians, adult doctors, plus support from psychologists, educators, and peers.
- Goals: patient autonomy, understanding their condition, and ensuring continuity of quality care.
- Patient organisations play a crucial role in educating families, providing information, and supporting the transition process.

To conclude the session, **IPOPI members shared successful initiatives addressing national challenges**. Examples include Argentina’s healthcare app, El Salvador’s advocacy campaign on access to genetic diagnosis, and Puerto Rico’s campaign to get PID patients early access to COVID vaccine. Get inspired by checking the full presentations [here](#).



Dr. Miguel Galicchio and Dr. Leila Ferreyra Mufarregue discussing the crucial transition from paediatric to adult care

Other related resources:

- IPOPI leaflet “Essentials of PID Diagnosis”, “Genetic Diagnosis of PIDs”, and “Targeted Therapies for PIDs”



Mr Hector Amaya presenting on El Salvador successful action

07 Session

Addressing transition care

Moderated by Ms Roberta Anido de Pena and Ms Leire Solis

- Transition Challenges in Adult PID Care: Perspectives from an NMO, Mr Hector Amaya (El Salvador)
- Implementation of Transition Care: Insights from an NMO Expérience, Ms Gabriela Suárez Martínez (Mexico)
- Workshop: Advocating for transition care, Ms Leire Solis

During this session, we explored **transition care from various perspectives**. The key takeaways are:

- **Need for integrated transition policies:** collaborating with medical societies to create standardised protocols and advocating for pilot projects; promoting interdisciplinary teams.
- **Lack of adult immunologists:** collaborate with medical societies to advocate for increased specialised training in rare immunological disorders; and integrating immunology education into the medical curriculum.
- **Continuos patient support:** advocate for phycological support services during the transition process; orgasing workshops for patients approaching adolescence; creating interactive guides for adult healthcare facilities.

Other related resources:

- IPOPI leaflet on “Moving from child to adult care”.



Patient leaders working on actions to advocate for transition care

08 Session

Joint session with LASID

Moderated by Dr Lorena Regairaz

- Physician Forum: what did you speak of during your meeting?
- Closing remarks, Ms Martine Pergent

The final session provided a deeper conversation on the **PID landscape and its future**, having the panel highlight the key points:

- Importance of **patient-centered** care and networking across Latin America for shared solutions in primary immunodeficiencies (PIDs).
- Introduction of **subcutaneous immunoglobulin therapies** highlighted, promoting patient choice and accessibility regionally.
- Advocacy emphasized **broader availability and affordability of advanced treatments**, ensuring all patients can access optimal care options globally.



Participants asking questions to the panel of clinical immunologists

Conclusion

IPOPI's Latin American PID patients meeting was a vibrant and engaging gathering, with the active participation of our patient representatives. Over two days, discussions centered on advocacy, regional challenges in PIDs, particularly focusing on regulatory processes, advocacy for treatment accessibility, and sharing impactful projects from our NMOs. The meeting aimed to foster collaboration and commitment to improving healthcare access in the region, welcoming prospective members from Peru and Costa Rica to strengthen our collective efforts.



The meeting aimed to foster collaboration and commitment to improving healthcare access in the region.

IPOPI would like to thank Grifols and Takeda for their generous support towards this meeting.



GRIFOLS

The logo for Grifols, featuring the word "GRIFOLS" in a bold, blue, sans-serif font, centered within a white rectangular box.

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