

IPOPI REGIONAL LATIN AMERICAN PID PATIENTS MEETING



10-11 OCTOBER 2019
Cancún, Mexico



IPOPI Regional Latin American PID patients meetings report

In parallel to the biennial Latin American Society for Immunodeficiencies (LASID) congress, IPOPI organised its Regional Latin American PID Patients Meeting on 10-11 October 2019, in Cancún, Mexico. The meeting started with IPOPI president **Mrs Martine Pergent** receiving a kind invitation to speak at the LASID grand opening session, followed by two meeting days with patient representatives from a majority of IPOPI's Latin American National Member Organisations (NMOs). This year the participants represented Argentina, Bolivia, Brasil, Ecuador, El Salvador, Mexico, Nicaragua, Paraguay, Puerto Rico and Venezuela. The successful meeting offered educational lectures, various workshops and a networking dinner for the participants, giving them an opportunity to learn, to share and to be challenged by new scenarios in the workshops. All presentations from the meeting are available at www.ipopi.org

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Educational sessions

- Welcoming remarks, **Dr Francisco Espinosa**, LASID President
- Welcoming remarks, **Mrs Martine Pergent**, IPOPI President
- Setting the scene, **Mrs Roberta Anido de Pena**, AAPIDP President & IPOPI Board member
- The ABC of PIDs and Autoimmunity, **Dr Liliana Bezrodnik**, LASID Vice President
- Vaccination and PIDs, **Dr Jose Franco**, Colombia
- IPOPI overview of recent key international policy developments, **Ms Leire Solis**, Health Policy and Advocacy Senior Manager, IPOPI

Workshop - What's up in Latin America?

The first workshop of the day was focused on the current situation for PID patients in Latin America and connected to key international policy developments relevant for the region to further provide a global overview. The session was introduced by **Ms Leire Solis**, IPOPI Health Policy and Advocacy Senior Manager, who gave the participants an overview of IPOPI's projects in terms of international policy.

This was followed by individual **SWOT analyses** (Strengths, Weaknesses, Opportunities and Threats) by each patient representative, providing a brief and operational insight on the current situation in their respective countries. The main challenges differentiate from country to country, but in general terms the most pressing issues are poor access to diagnosis and availability of adequate treatment.



Mr Hector Amaya, President Fundación Escudo de Amor para las IDP El Salvador, presenting his SWOT analysis

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Workshop - How to interact with health authorities

The second and final workshop of this first meeting day was aimed at improving the skills of the participants when preparing for a meeting with the authorities. The workshop was led by **Mrs Roberta Anido de Pena**, IPOPI Board Member and **Ms Leire Solis** who divided the participants in two groups with the task to prepare for a simulated meeting with the Ministry of Health (including the Minister of Health herself!). In this roleplay the Minister of Health was played by **Ms Leire Solis** and the clerk and civil servant by **Mrs Roberta Anido de Pena** and **Mr Hector Amaya** from IPOPI's NMO in El Salvador. The objective of this workshop was to expose the participants to a semi-real situation and evaluate their performance to see improvement for possible future meetings with authorities.

What was good?

- Participants were excellent in introducing the patient's perspective in the meeting, to support what had first been explained by a patient representative and/or a medical doctor.
- Participants kept calm and cool when facing a difficult interlocutor, which is very important in meetings with authorities or policy makers.
- Attempts were made to get a follow-up meeting, something of high interest when trying to build a stable and working relationship with policy makers and authorities.

Tips for future meetings

- Mention your objective and what your NMO is trying to reach at the beginning of a meeting.
- Know how to explain PIDs in one minute.
- Keep in mind relevant arguments that could help convince your counterpart (quotes from national policy makers favorable to the patient's cause etc).
- Bring informative material! It also works as a leave behind to be remembered.
- Have in mind some key data or some key definitions/descriptions on PIDs.
- If you have a registry: remember to mention it and to bring the data to the meeting in order to clarify your demands.
- Lack of info in some aspects is perfectly normal! Inform that you do not have the information but that you will return with it via email.
- Manners are important and key to make a good impression. Always thank people for their time and availability: both at the meeting and via an email afterwards.



Workshop - Simulated meeting with the Ministry of Health

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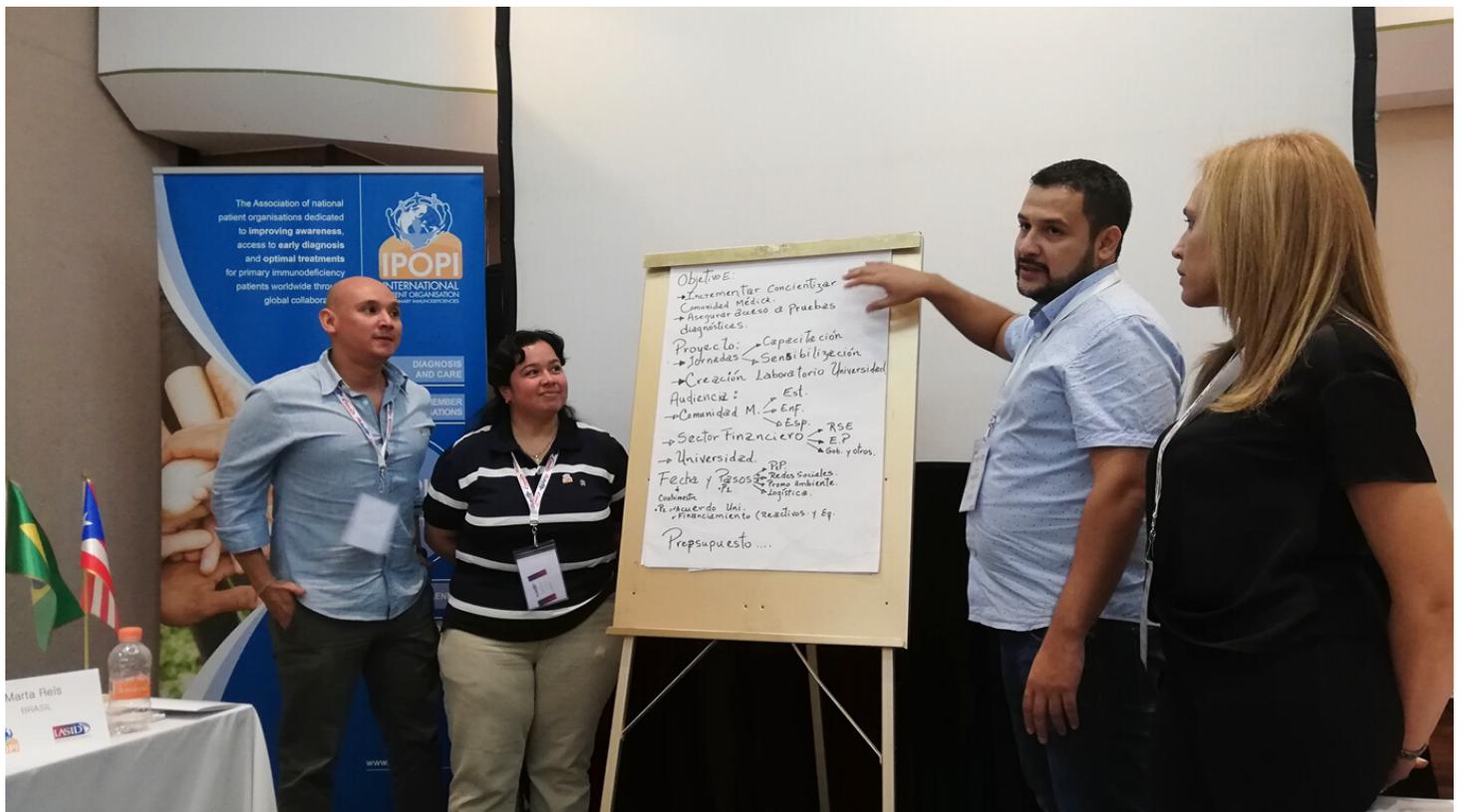
Educational sessions

- Plasma: what it is and how it is collected, **Dr René Büchel**, Takeda
- Immunoglobulin replacement therapies: what are they, **Dr Leila Ferreyra Mufarregue**
- An overview of the immunoglobulin market in Latin America, **Mr Patrick Robert**, President Marketing Research Bureau
- Preparing a strategic plan and a fundraising proposal, **Mrs Martine Pergent**, IPOPI
- Examples of successful media and awareness campaigns, **Ms Julia Nordin**, NMO Programmes Officer IPOPI

Workshop - How to plan and fundraise

The objective of this workshop was to provide the participants with the right mind and skill set to put together an example of a strategic plan, something which will support them both in their internal work and when fundraising. It will also give them with a more professional approach and raise their confidence among PID stakeholders. Working towards predefined strategic objectives gives the NMOs a framework to focus their activities towards, something which will facilitate their future work. With this workshop we wanted to convey the message that a strategic plan is not complicated, but necessary, and that they are all capable of producing one.

The two groups were asked to choose the one IPOPI member country to prepare a strategic plan for, while the other participants acted as strategic plan consultants ready to give their advice. The workshop ended with the two groups presenting their strategic plans, leading to fruitful discussions and valuable new insights for our NMOs.



Workshop. From the left: Mr Salvador Bendaña Martinez (Nicaragua), Mrs Igmery Rincon (Venezuela), Mr Hector Amaya (El Salvador), Mrs Blanca Imbert (Puerto Rico)

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Workshop - Media, Advocacy and Awareness



Workshop. From the left: Mrs Igmery Rincon (Venezuela), Mr Fabian Japa (Ecuador), Mrs Vivian Kohlberg (Bolivia)

During the final session of the day the two groups were given two workshop assignments. One group was asked to hold a press conference to follow their previous simulated meeting with the Ministry of Health, and the second group were to hold a press conference in the context of World PI Week. The excellent journalist acting was performed by **Mrs Blanca Imbert**, from IPOPI's NMO in Puerto Rico as well as by our returning actors **Mrs Roberta Anido de Pena**, **Ms Leire Solis** and **Mr Hector Amaya**. Despite receiving difficult questions both from political reporters and from tabloids searching for juicy scoops, both groups did a great job in keeping their focus in the press conference and conveying their message.

What was good?

- Participants learnt quickly from their first role play and made very good first introduction to the meeting and their objectives.
- Even with difficult questions they brought back the discussion to what was important to them.
- Participants kept calm and didactic with difficult questions from media... and even with questions that were off topic!
- Participants were very diligent in preparing a press dossier, with relevant information regarding the topic approached.

Tips for future meetings

- Always be positive and remain calm even with difficult people or questions.
- Prepare some simple examples, PIDs are a complex topic and not easy to grasp in a first attempt.
- Try to keep focused on the objective of the meeting and on its topic - you may only get one chance!
- Be conscious of the opinions you express: try not to be too critical, instead be constructive. Expressing only negative and critical opinions may discourage your audience from helping you!

PID patients need more plasma donors!

The meeting was organised at same time as International Plasma Awareness Week (IPAW), an annual campaign aimed at raising global awareness on the need for plasma. To support this important message IPOPI launched the flash campaign PID patients need more plasma donors! This campaign was dedicated to the worldwide need for more plasma donors and more plasma, the starting material for immunoglobulin therapies and other life-saving plasma derived medicinal products. The campaign shared facts and figures about PIDs, immunoglobulins and plasma, appealed to current plasma donors and to prospective ones as well as encouraged our NMOs to take part!

"One single PID patient requires 130 donations of plasma a year to stay alive"

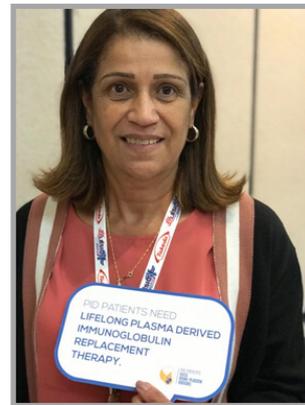
"PID patients need lifelong plasma derived immunoglobulin replacement therapy"



Fabiana Monteagudo
AAPIDP, Argentina



Vivian Kohlberg
FIDEP, Bolivia



Marta Reis
ANPIC, Brasil



Carmen Orive de la Rosa
APIP, Puerto Rico



Conclusion

This year's edition of IPOPI's Regional Latin American PID Patients Meeting was a successful event focusing on the importance of local, regional and global cooperation for all PID stakeholders. It brought together patient representatives from all parts of the region and invited them to share their work as well as learn from their counterparts in the other participating countries. We trust that we will have a continued great cooperation with our Latin American NMOs and look forward to future meetings in Latin America.

Thank you!



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IPOPI, Rocky Bottom, Trierieve, Derry, PL11 3LY, United Kingdom
www.ipopi.org