

Meeting report

The IPOPI Latin American Patients Meeting

5-6 October 2017, São Paulo, Brazil



The Latin American Patients Meeting was organised back to back with the LASID Congress on 5-6 October 2017. The two-day intensive meeting included educational lectures and brainstorming workshops for the patient representatives. The 70 participants to the meeting included patient leaders from IPOPI Latin American national member organisations (NMOs), but also patients and parents from other countries, other PID and Rare Disease organisations, nurses and physicians from all over Latin America. To our knowledge, 12 countries were represented in the patients meeting: Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, El Salvador, Mexico, Paraguay, Peru, Venezuela and Puerto Rico.

The first day of the meeting, 5th of October, was opened with welcoming remarks from **Prof Antonio Condino-Neto**, President of Latin American Society of Immunodeficiencies (LASID), **Ms Jose Drabwell**, President of IPOPI and **Ms Marta Reis**, the President of the National Patient Organisation for PIDs in Brazil (ANPIC).

Dr Fransisco Espinosa from Mexico gave the first lecture of the day with the topic of “*Novel ways of looking at PID warning signs*”, based on a research paper he co-authored and that was published in 2013. He stated that there are 3 main problems in the PID field: 1) GPs usually think that PIDs are extremely rare and therefore nothing to worry about; 2) diagnostics are not easily available with only a few labs with specialized tests; and 3) treatment is expensive and not available for everybody. He went over different warning signs for suspecting PIDs and went a step further, giving an overview of warning signs for different specialities such as pulmonologists, gastroenterologists, dermatologists, haematologists, rheumatologists, pneumologists and others (based on an article “Attending to Warning Signs of Primary Immunodeficiency – Diseases Across the Range of Clinical Practice, by Beatriz Carvalho et al.). He concluded that going into this depth with the warning signs will likely improve the chances of diagnosis for PID patients.

Ms Roberta Anido de Pena, IPOPI Board member and President of Argentinean Patient Organisation for PIDs (AAPIDP), gave the second lecture of the morning with an overview on *what is at stake in the Latin America region*. She went over the development of the number of NMOs in the region across the last decade and data from LASID registry including the number of registered PID patients, number of centres and the treatment options available in each country according to the registry. She concluded her presentation by stating the most important areas that need to be addressed by the patient organisations in the region in terms of PID diagnosis and treatment.

After lunch, the second session of the day took place with presentations from the NMOs of IPOPI. Everyone had 15 minutes to present the current PID trends and the situation in their country as well as introduce the others to the activities taking place in their organisations in the past and in the near future. IPOPI gave the floor to another external PID patient organisation in Brazil (Eu Luto pela Imuno) to introduce their activities to IPOPI and its regional membership. After the presentations there was a discussion about why working together with one unified PID voice is important and what the organisations can do to reach this objective nationally.

The second day of the patient meeting, 6th of October, was opened by Ms Jose Drabwell and Ms Roberta Anido de Pena. Their opening words were followed by the first educational lecture of the session, by **Dr Jose Luis Franco** from Colombia. His talk was about *Access to subcutaneous immunoglobulin and prophylaxis treatment*. He gave an overview of the most common treatment types for the most common PIDs and explained briefly the function of immunoglobulins in the human body, where does it come from and can it be used and administered as a treatment. He explained the reasons behind why it is important to give patients the freedom of choice between SCIG and IVIG and what are the main variables to be considered before making the decision. He also compared the two IG administration types, giving an overview of pros and cons of both. Finally, Dr Franco stated that careful, holistic and individual consideration is key to a successful PID care.

Dr Lucia Sposito from Argentina gave the second educational lecture of the day. Her topic was “*Access to treatment: bone marrow transplantation (BMT)*”. In her presentation, she explained that there are different levels of severity of PIDs. The prognosis of the patient depends on the level of severity of the PID but also the characteristics of the patient (age, comorbidities) and the possibilities of the patient to access treatment options and care centres. She also explained that the planning for BMT treatment is always a multidisciplinary task. Dr Sposito went through the curative treatments for PID (HSCT, Gene therapy and BMT). She then moved on to talk about donor requirements and the most common donor-recipient considerations. She concluded her presentation stating that, being a donor of HSCT is very important and stressed that working in multidisciplinary teams in well-equipped treatment centres, existing national regulatory bodies and familial support are crucial for the patient’s diagnosis, further treatment measures and holistic wellbeing.

The second session had the focus on collaboration and the importance of working together, and was highlighted by **Ms Jose Drabwell** with her presentation on *IPOPI examples of working together*. She gave examples of fruitful ways of national collaboration, regional collaboration and international stakeholder collaboration. She concluded her presentation with the goals of collaboration on its many levels: to make sure the PID community’s voice is heard and patient priorities are acted upon, to act as examples for each other, to ensure that key messages and actions are delivered consistently, to share data for research through registries and importantly, to make sure PID patients are diagnosed early and have access to appropriate treatments.

The next presentation was a physician testimony and was given by **Dr Carolina Fernandez** from Paraguay on the topic of “*why a patient organisation is important to me*” and was followed by two patient organisation testimonials from Ms Roberta Anido de Pena from the Argentinean patient organisation and Blanca Imbert (from distance) from Puerto Rico patient organisation, on their views on why working

together is important giving examples of successful outcomes from collaborative actions. After the testimonials there was a short discussion among the participants.

The third and last session of the second day was dedicated to a brainstorming workshop on *NMO skills building and future strategies*. The workshop was opened by **Dr Carmela Glinder** the State Secretary of Health and the coordinator of neonatal screening programme and rare disease plan of São Paulo, with a presentation on the topic of *Challenges in advocating for treatment options in Brazil*. In her presentation, she gave an overview of rare diseases in Brazil, stating that there is a unified health system and that there are up to 24,000 new detections every year in the state of São Paulo. She went over the greatest challenges for the state in terms of rare diseases, such as health-related migration, ageing population and detection of diseases resemble very prevalent chronic diseases. She highlighted the fact that patients who are well cared for, are a large saving for the government. Even though São Paulo is quite advanced in terms of rare diseases, Brazil still faces a lot of regional disparities in the coverage of the health system. Brazil has currently 2 PID taskforces.

After the introductory lecture, the NMO workshop began. The workshop was based on a **Latin American Call to Action** that was launched in collaboration with IPOPI, LASID and INGID, during the opening session of the congress. During the workshop the NMO leaders had the chance to brainstorm on strategies on the five key issues stated on the Call to Action: 1) early detection and diagnosis 2) adequate and sustained treatment, 3) education of healthcare professionals 4) promotion of research and data gathering and 5) PID awareness.

Results of the NMO Advocacy workshop:

1) Early detection and diagnosis:

- Information to GPs, other specialities
- IPOPI leaflets to hospitals and clinics (speciality specific)
- Translating existing tools, creating new ones e.g. infographics
- Awareness in schools, among medical students

2) Adequate and sustained treatment:

- Finding contacts in the Ministry
- Identify the programmes and the people in them
- Identify the relevant laws – find “loop wholes”
- Where could we fit PIDs?
- Learn from haemophilia organisations
- Pharmacovigilance

3) Education of healthcare professionals:

- Training medical students
- Hospital inspectors
- Mobile app to suspect PID
- Infographics
- Training nurses: to treat and to suspect
- Lawyers specialised in medical cases
- Contact with lawyer professional societies
- Sharing information – leaflets, flyers

4) Research and data gathering:

- National disease specific registry
- Regional registry
- Clinical trials
- Patients must be experts of their own condition

5) PID awareness:

- Latin American campaign video, by professionals – fundraising plan
- Social Media and other online channels (youtube)
- From national to regional level
- Join international campaigns
- WPIW, Rare disease day
- IPOPI NMO Toolkit on www.ipopi.org
- Ask media contacts from pharma companies and others
- Magazines: maternal health, babies, women
- Education of new parents
- Creation of a LATAM PID mascot

Ms Jose Drabwell closed the meeting concluding that even though the patient organisations are all in different stages of maturity, they all have the same interest and therefore should work together. She highlighted the importance of having one unified PID voice nationally in order to have that voice better heard among the decision makers. The NMOs were reminded about the existing and relevant documents such as the WHO list of essential medicines and the PID Principles of Care that they can use in their advocacy efforts. Finally, she stated that while it is important for the NMOs to be the experts in PIDs, they should reach out for help to other stakeholders such as other rare diseases organisations, medical experts, lawyers, public prosecutors and of course IPOPI, when necessary.

The Latin American Call to Action:

IPOPI, INGID and LASID launched a [Call to Action](#) on equal access to lifesaving treatment in Latin America, with already 1600 signatures and several endorsing societies and organisations in the PID and rare diseases field. The Call to Action will help IPOPI's NMOs in their national advocacy efforts. The NMOs in Latin America will address this Call to Action to their national governments urging them to develop supportive health policies for the care of PID patients across the region.



The graphic features the IPOPI and LASID logos at the top. Below them, the text reads: 'Petitioning Health Ministries of Latin American countries and 2 others', followed by the bold title 'Primary Immunodeficiencies (PIDs) in Latin America: Equal access to lifesaving treatment'. It also includes the text 'ENGLISH - ESPAÑOL - PORTUGUES Primary Immunodeficiencies (PIDs) are hereditary, chronic and genetic defects in the immune...' and a red 'Read more' button next to the 'change.org' logo.