

ONLINE



IPOPI
LATIN AMERICAN
PID PATIENTS MEETING

OCTOBER 13-14, 2021

MEETING **REPORT**



an IPOPI event

INTRODUCTION

In mid-October it was finally time for IPOPI to welcome its Latin American National Member Organisations (NMOs) to this year's regional meeting, organised October 13-14, in parallel with the congress of the Latin American Society for Immunodeficiencies (LASID). The meeting was well attended, with over 35 participants from 10 countries in the region (Argentina, Bolivia, Chile, Ecuador, El Salvador, Mexico, Nicaragua, Paraguay, Puerto Rico, Venezuela), speaking mainly in Spanish. The combination of educational sessions as well as multiple interactive elements created a great mix and many good discussions, and IPOPI was thrilled to once again have the opportunity to bring together our regional patient leaders and strengthen the PID patient community in Latin America.



MEETING OBJECTIVES

- IMPROVE KNOWLEDGE ON DIAGNOSIS AND TREATMENT FOR PIDS
- PROVIDE AN UPDATE ON THE COVID-19 STATUS IN LATIN AMERICA
- IDENTIFY AND DESCRIBE PRIORITIES ON PID DIAGNOSIS
- PRACTICE REACTING TO TREATMENT SHORTAGES
- LEARN FROM NMO BEST PRACTICES
- STRENGTHEN REGIONAL COOPERATION

PARTICIPATION OVERVIEW

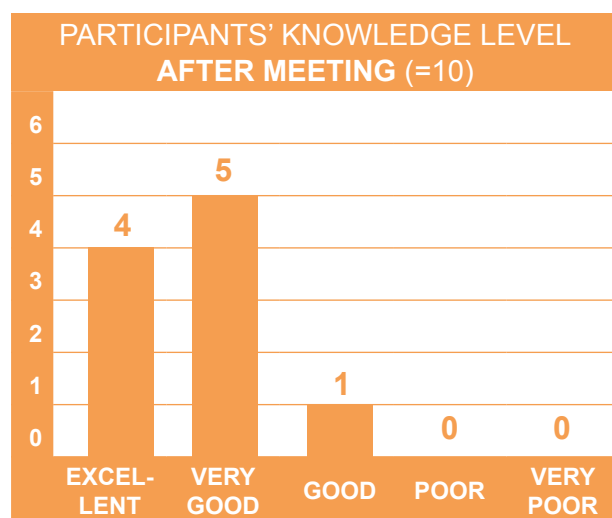
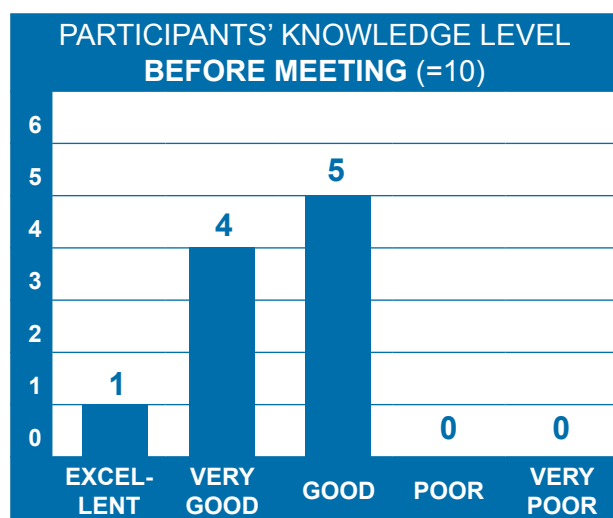
TOTAL PARTICIPANTS: 37

COUNTRIES REPRESENTED: Argentina, Bolivia, Chile, Ecuador, El Salvador, Mexico, Nicaragua, Paraguay, Puerto Rico, Venezuela.

PARTICIPATION FEEDBACK

“Despite the distance, a close space was created in which to share very valuable information. I consider the exchange with the rest of the countries of the region of great importance. The organization was impeccable, as always. Very grateful for the opportunity.”

– Meeting participant



SESSION 1: INTRODUCTION AND WELCOMING WORDS

MODERATED BY MS MARTINE PERGENT

- Introduction and welcome, Ms Martine Pergent, IPOPI President
- Catching up, Ms Roberta Anido de Pena, IPOPI Board member / President of Asociación de Ayuda al Paciente con Inmunodeficiencia Primaria, Argentina
- LASID welcome, Dr Liliana Bezrodnik, LASID President, Director of the Center for Clinical Immunology, Argentina
- Sponsor's welcome, Mr Marcelo Cases, Public Affairs Manager, Argentina & South Cone, Takeda
- Setting the scene in Latin America – A status update based on the PID Life Index, Ms Julia Nordin, IPOPI NMO Programmes 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 American members. She emphasized how much she had wished to be able to meet in Chile this year, but that this virtual setting also offers new, albeit different, possibilities. When setting the scene for the meeting, Martine highlighted issues with access to diagnosis and treatment, as well as a good quality of life for patients with PID on this vast continent. These challenges need to be addressed, which is why this kind of meeting is so important. By joining forces internationally and exchanging experiences and best practices, patient organisations in Latin America will become stronger and better at improving lives for the people living with PIDs in Latin American countries.

Following a brief catch up session led by Roberta Anido de Pena, IPOPI board member and AAPIDP president, the floor was given to Dr Liliana Bezrodnik, LASID president. On behalf of the LASID society, she welcomed the patient representatives to the meeting and wished them two fruitful meeting days, with good discussions and doctor-patient cooperation. After a brief sponsor's welcome by Mr Marcelo Cases from Takeda, the session was wrapped up with an intervention by Julia Nordin, IPOPI NMO Programmes Manager, presenting a status update of Latin America based on IPOPI's interactive tool the [PID Life Index](#).




¡Únase al PID Life Index!

Los datos en el índice provienen de:

1. Miembros de IPOPI, con el apoyo de su MAP
2. Expertos médicos en países donde IPOPI no tiene ninguno miembro

¡Todavía nos faltan países latinoamericanos!
¡Te animamos a que te unas al PID Life Index y lo uses para "advocate" en tu país!





SESSION 2: THE COVID-19 STATUS IN LATIN AMERICA

MODERATED BY MS ROBERTA ANIDO DE PENA

- COVID-19 treatment and vaccination, Dr Cecilia Poli, Director of the Program of Immunogenetics and Translational Immunology (PIGIT) at the Institute of Science and Innovation in Medicine, at Universidad del Desarrollo, Santiago, Chile
- Open floor - Questions about COVID-19
- Leading an NMO during the COVID-19 pandemic, Dr José-Angel Cova, IDP Venezuela, Ms Vivian Kohlberg, FIDEP Bolivia, Ms Blanca Imbert, APIP Puerto Rico

The second session focused on the important theme of COVID-19 and its status in the region. The topic was introduced by Dr Cecilia Poli from Chile, who provided a comprehensive overview of COVID-19 and its infection phases, as well as a presentation of clinical symptoms and signs and potential therapies. She also took the opportunity to discuss COVID-19 in children and elaborate further on the different available vaccines for SARS-CoV-2. This was an appreciated presentation, followed by an open floor discussion where participants were eager to ask their questions on themes such as vaccinations in PID patients, risks of developing severe COVID-19, and concerns about potential allergic reactions.

Following this, and to highlight the important work done by the national member organisations (NMOs) during the pandemic, IPOPI had invited three NMO representatives to present on the theme of "Leading an NMO during the COVID-19 pandemic". First out was Dr José-Angel Cova from Inmunodeficiencias Primarias Venezuela (IDP Venezuela), who gave a comprehensive overview of the work done since early 2020 with information sharing, production of material and the possibility for patients to ask questions to the medical advisors. This was followed by Ms Vivian Kohlberg from Fundación FIDEP Bolivia, who presented both FIDEP's informative videos, as well as highlighted their impressive work with a national law which will ensure a better life for patients with PID in Bolivia. The session ended with an overview by Ms Blanca Imbert from the Puerto Rico Alliance of PID patients (APIP), highlighting their work in for example supporting plasma donation campaigns, producing masks as well as devoting much time and effort to psychologically support their members during this period.



SESSION 3: KEYS TO DIAGNOSIS

MODERATED BY MS MARTINE PERGENT AND DR SILVIA SÁNCHEZ-RAMÓN

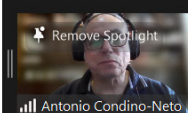
- Diagnosis overview, Dr Antonio Condino-Neto, Professor of Experimental Medicine at Institute of Biomedical Sciences, University of São Paulo, Brazil
- Introduction to workshop, Ms Roberta Anido de Pena, IPOPI Board member / AAPIDP President, Argentina
- Practical exercise: Building your skill set – Establishing priorities on diagnosis
- Closure of the day, Ms Roberta Anido de Pena, Dr Silvia Sánchez-Ramón, Associate Professor of Immunology, Complutense University of Madrid School of Medicine, Spain

IEI: DIAGNOSTIC OVERVIEW

ANTONIO CONDINO-NETO, MD, PhD, FAAAAI

Department of Immunology
Institute of Biomedical Sciences
University of São Paulo

The Jeffrey Modell Center São Paulo - Brazil



During the final session the attendees got the opportunity to dive deep into the topic of diagnosis. The session began with an overview by Dr Antonio Condino-Neto from Brazil, who, in his presentation, discussed problems with late diagnosis, misdiagnosis, or no diagnosis at all. He lingered on the issue on diagnosis delay and mentioned that 90% of all PID patients are still estimated to lack diagnosis. On a more positive note, he presented the Brazilian case of newborn screening for severe combined immunodeficiency, which has recently been introduced on a national level. This was an appreciated presentation that, despite many challenges, left the audience with some hope and inspiration from the steps that had been taken in Brazil.

WELCOME TO MORAXICA



After Dr Condino-Neto's presentation it was time for the participants to roll up their sleeves on the theme of diagnosis. Divided in two groups the participants were introduced to the fictional Latin American country "Moraxica", where challenges concerning diagnosis were many. In this scenario each participant was ascribed the role as a board member of the national patient organisation PID Moraxica and asked to discuss a set of challenges they were given (low diagnostic rates, lack of medical awareness, specialist care only available in two cities etcetera). After intense discussions a number of action points were agreed on, clearly demonstrating the active and goal-oriented mindset of the participants.


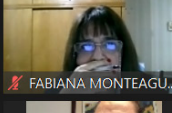




Bienvenido a Moraxica

Todos ustedes son ciudadanos del país ficticio Moraxica, ubicado en la región de America Latina, y miembros de la junta directiva de la organización nacional de pacientes con IDP, llamada Moraxica IDP.

Moraxica IDP está llevando a cabo una reunion de la junta directiva en la que se ha acordado centrarse en el diagnóstico y en dónde se dispondrán los recursos.

Su país está experimentando muchos desafíos para los pacientes con IDP en la región y a continuación se presenta un resumen de los más importantes.





SUMMARY OF ACTION POINTS (SHORT AND LONG TERM):

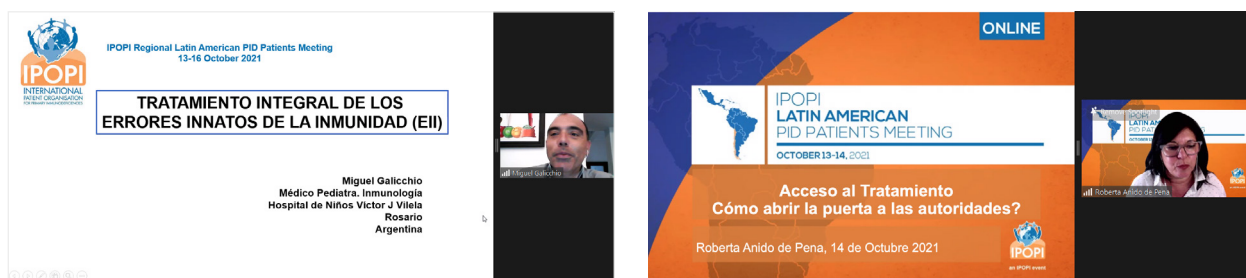
- Mentor and train recently graduated doctors and raise awareness on PIDs, in cooperation with medical societies and medical colleges
- Advocate to ensure access to diagnosis and treatment center in each city, not only in two cities
- Ensure that low-cost diagnostic tests are implemented
- Join forces with other rare disease organisations, as well as collaborate internationally with IPOPI
- Put primary immunodeficiencies on the public agenda
- Use communication as a tool! Launch information campaigns and call to action to highlight this problem and publicise the actions taken by the group
- Inform patients about their rights so they can more easily demand them and commit to making the problem visible
- Work to establish a patient registry

SESSION 1: OPEN THE DOOR TO TREATMENTS

MODERATED BY MS MARTINE PERGENT

- Welcome to the second day, Ms Martine Pergent, IPOPI President
- PID treatments overview, Dr Miguel Galicchio, Allergy and Immunology Service of the Victor J. Vilela de Rosario Children's Hospital, Argentina
- Access to treatment: How to open the door to authorities, Ms Roberta Anido de Pena, Argentina, IPOPI Board member / AAPIDP President, Argentina
- Practical exercise: Take action on treatment!

The participants were greeted back to the second day by Martine Pergent. The first theme of the day was treatment, and the participants enjoyed a generous overview by Dr Miguel Galicchio, touching upon everything from preventive measures (e.g. hygiene), to prophylaxis and treatments such as immunoglobulin. This presentation gave room for many questions from the audience, leading to discussions on bone marrow transplants, bad reactions to immunoglobulins as well as the difficulty to access both subcutaneous and intravenous immunoglobulin.



The second part of this session was devoted to activation. It began with a very interesting presentation from Roberta Anido de Pena, covering the topic of how to open the door to authorities and providing the attendees with many useful tips to consider. In the following practical exercise, the participants returned to the fictional country Moraxica to react to a scenario of reduced access to immunoglobulin, causing great stress and suffering for the PID patient population.

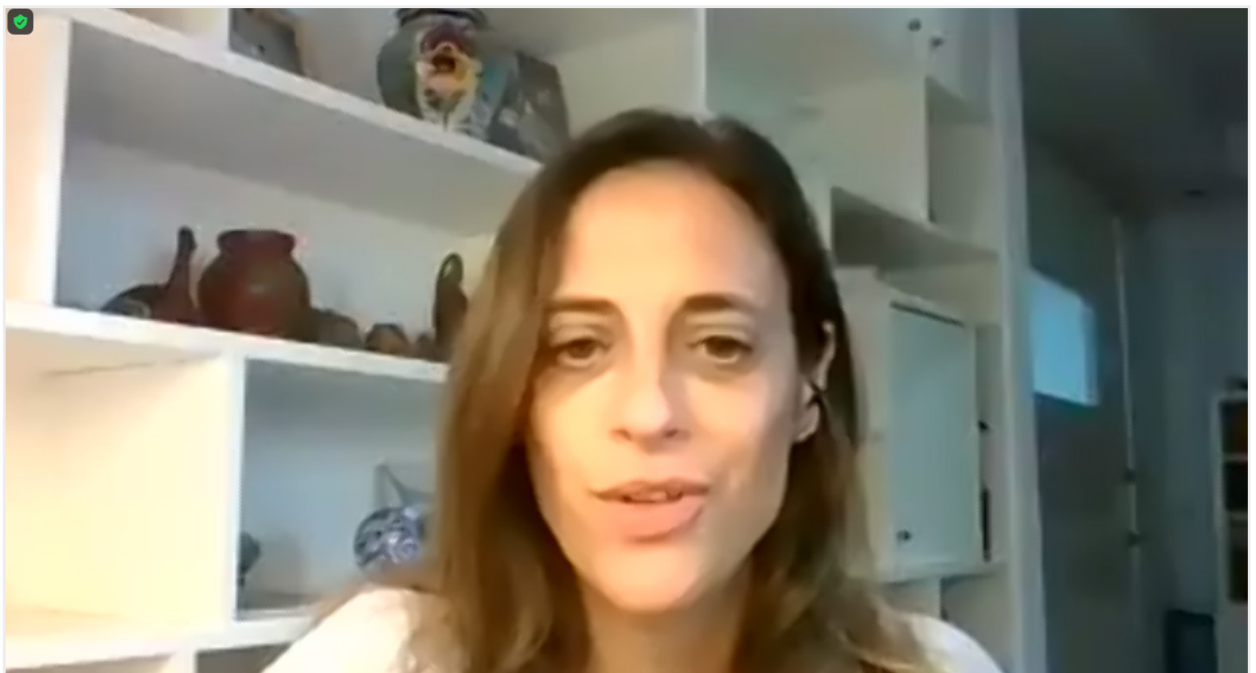
SUGGESTED ACTION POINTS (INCLUDING SHORT, MEDIUM AND LONG TERM)

- Gather data to prove the importance of patients using appropriate medicines
- Prepare a strategy and approach health authorities and express the seriousness of the problem, using data to compare quality of life of a well-treated patient versus one who is lacking treatment
- Prepare a press release to express concern about the current situation, backed by international regulations regarding fundamental rights, and supported by doctors and medical societies
- Demonstrate at the main medical centres in Moraxica
- Request a meeting with the Ministry of Health
- Request a meeting with representatives of the parliament, in cooperation with other rare disease associations in the country

SESSION 2: SHORT AND LONG TERM THINKING AND ACTING

MODERATED BY MS JULIA NORDIN

- Immunoglobulin use in Latin America today and tomorrow, Dr Lorena Regairaz, Chief of Immunology unit at Hospital Sor Maria Ludovica, La Plata, Buenos Aires, Argentina
- Towards a campaign: Defining your audience, identify key messages and tools, Magda Lourenço, IPOPI Communications Manager
- Practical exercise: How to build a communication campaign around plasma collection
- Highlights from LASID meeting, Dr Segundo Gesmar Rodriguez, LASID President-Elect, Professor of Pediatrics Department, Universidade Federal de Uberlandia, Brazil
- Concluding remarks, Martine Pergent, IPOPI President

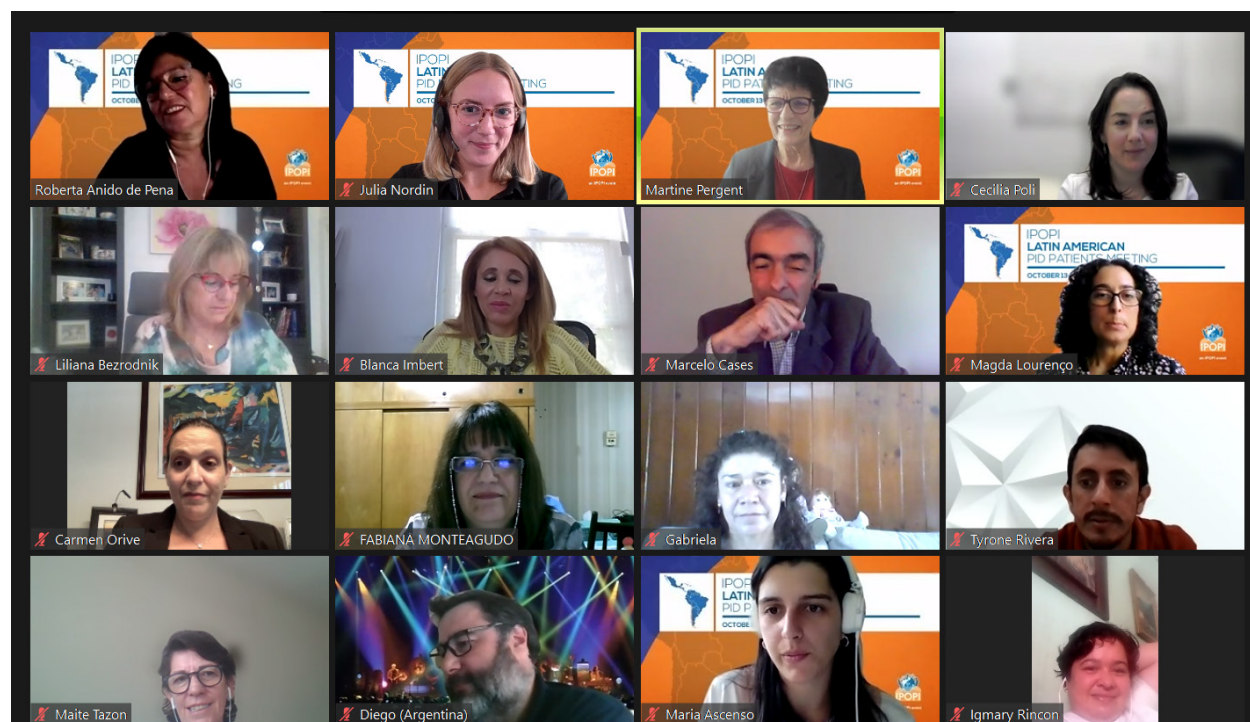


Lasid Meeting 2021

- Medical Meeting
 - New diseases
 - New diagnostic tools
 - New therapies



The final session was opened by Julia Nordin, IPOPI NMO Programmes Manager, who gave the floor to Dr Lorena Regairaz from Argentina for her to provide an overview of immunoglobulin use in Latin America. She did this in a splendid way, clearly demonstrating the need to improve access to immunoglobulins in this region, based on the increased diagnosis rate between 2013 and 2018 and thus the increased need for this treatment. After an introductory presentation by Magda Lourenço, IPOPI Communications Manager, on how to build a campaign, it was time for the participants to get active one last time. After dividing the participants in two groups where they got the opportunity to practice building a communications campaign to encourage plasma donation, the participants returned with a new set of skills, ready to campaign in their countries.



To wrap up this meeting IPOPI had invited Dr Segundo Gesmar Rodriguez, Incoming LASID President, to provide a few highlights from the LASID meeting. In his valuable presentation Dr Gesmar Rodriguez stressed the importance of patient-doctor collaboration, and cooperation across borders, to address the challenges ahead. This was followed by closing words from Martine Pergent, who thanked the participants on behalf of IPOPI and invited them to the follow up call in December to continue this cooperation.

CONCLUSION

IPOPI's Latin American PID Patients meeting was a well appreciated two-day meeting with participation from all over Latin America. The attendees got the opportunity to learn from PID experts on a wide range of important topics, strengthen ties between peers, and exchange experience and skills build for the future, in order to continue the work in their national patient organisations. As always it was a pleasure for IPOPI to meet with representatives from these NMOs, and we look forward to welcoming the participants back in December for the follow up meeting.



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



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