

IPOPI Regional African Patients Meeting

6th ASID-IPOPI Biennial Congress

IRESSEF Institute for Health Research, Dakar, Senegal

11th to 12th of April 2019



Meeting report

1 Introduction

The 6th ASID-IPOPI Biennial Congress took place in IRESSEF Institute for Health Research in Dakar, Senegal, from the 11th to 13th of April 2019. This year's edition brought together experts in immunology from the continent and overseas to strengthen the community of African physicians, biologists, scientists and PID patients committed to facilitating the implementation of solutions for managing PID patients. The theme of 2019 was “*Think primary immunodeficiency in Africa and save lives*” which aimed at highlighting the need to improve PID diagnostic rates in Africa. This functioned as the basis of discussions of recent developments about diagnosis, treatment, management and advocacy for PIDs.

IPOPI organised a Regional African Patients Meeting back to back with the ASID Congress on the 11th and 12th of April 2019, bringing together PID patient representatives from seven African countries (Kenya, Uganda, South Africa, Morocco, Nigeria, Tunisia, Senegal). Several Senegalese nurses also took part in the IPOPI meeting, giving their perspective in a very pragmatic way. This meeting offered a unique opportunity for patients and patient representatives in the region to interact with each other and to exchange experiences, with the aim to strengthen their national campaigning towards better care for PID patients in their countries. Interactive workshops were organised to do so but the meeting also included educational lectures to increase the understanding of the conditions of PID patients. In addition to this some parts of the ASID main programme was shared with IPOPI, allowing patients to take part in interesting lectures and sit with the physicians. The whole meeting was held in both French and English.

2 IPOPI Regional African Patients Meeting

The IPOPI Regional African Patients Meeting featured six sessions attended by patient representatives from seven African countries as well as physicians, nurses, other PID and other rare diseases organisations (HAE and Haemophilia) and company representatives from Africa and other parts of the world.

Session 1 was dedicated to introducing the joint ASID-IPOPI meeting and was opened by IPOPI President **Mrs Martine Pergent**. On the behalf of IPOPI she welcomed participants and gave them a brief introduction to IPOPI's focus areas and annual activities. Beyond this, she emphasized the immediate need for cooperation and organisation regarding PIDs in Africa and encouraged participants to establish and further strengthen already established NMOs in their respective countries.

The next opening remark was given by ASID President **Prof Tandakha Dieye** during which he positively expressed the unusual character of this meeting, gathering patients, nurses and physicians to discuss PID Management in Africa. He highlighted 5 areas that needs to be prioritized to access therapies in Africa: 1) improved PID diagnosis rates 2) increased availability of health insurance 3) advocacy to Ministries of Health to establish PID centres 4) secure immunoglobulins for all patients and 5) provision of allograft. He emphasized that Senegal still has a long way to go but that progress is being made, this meeting being an important part of that. This was followed by **Dr Ridha Barbouche (Tunisia)**, who discussed PID diagnostics in Africa and its status and future possibilities, arguing that one of the main challenges revolves around lack of data. Progress is visible in the North and Southern parts of Africa where national registries have been initiated, despite this he highlighted that there is still much to be done in this area to secure proper PID epidemiology for the African continent.

The first session of the meeting ended with **Dr Nizar Mahlaoui, Head of CEREDIH and IPOPI's MAP Chairman**, discussing PID treatment possibilities in developing countries. He highlighted that a common problem is that doctors in the African region often miss out on PIDs, as it is hidden amongst other more visible conditions such as malnutrition and infections in the shape of malaria, pneumonia, TB and HIV. In order to improve this situation early recognition, accurate evaluation and quick referral to appropriate specialists should be prioritized.

Session 2 came in the shape of a joint ASID-IPOPI welcome session where ASID president **Prof Tandakha Dieye** welcomed all congress participants to the 6th edition of ASID. This was followed by welcoming speeches by **Mrs Martine Pergent** (IPOPI), **Mrs Dorothea Grosse-Kreul** (INGID), and **Prof Yu Lung Lau** (APSID) and **Prof Aziz Bousfiha** presenting 10 years of ASID history. The session ended with an award ceremony where IPOPI President **Mrs Martine Pergent** was one of the recipients, in great company of the Senegalese Minister of Health representative, among others.





Session 3 was moderated by **Mrs Annie Pienaar**, IPOPI Board member and President of Primary Immunodeficiency South Africa (PINSA), who introduced **Dr Monika Esser (South Africa)**, member of IPOPI's Medical Advisor Panel. **Dr Esser's** presentation touched upon the topic of patient awareness regarding how to prepare for a meeting with a doctor, what questions to ask and which issues to prioritize. This was followed by a fruitful Frequently Asked Questions section where the patient representatives were given the chance to ask her various questions on PIDs.

Session 4 was dedicated to the role of patient groups and aimed at creating the

opportunity for knowledge exchange amongst participants originating from different countries. The session was opened by **Mrs Martine Pergent** who introduced many examples of successful advocacy campaigns from various NMOs. This was followed by **Prof Saliou Diop (Senegal)** from the World Federation of Haemophilia, who gave a complementary perspective of the Haemophilia experience in Africa, the challenges these patients face and how their community organise themselves in the shape of national member organisations. This functioned as a good example of how another rare disease patient group in Africa organises and advocates, even if access to treatment is not to be compared as patients with haemophilia can benefit from pharmaceutical companies' donation of clotting factors which is far not the case when it comes to IG, due to the global and increasing tension of this medicine.

The next two presentations highlighted two different patient representative perspectives, one given by **Mrs Cynthia Olotch** from PID Kenya and one by **Mrs Annie Pienaar** from PINSA South Africa. **Mrs Olotch** shared the story of how she successfully founded PID Kenya in 2018 and all the great work the organisation has done since then. **Mrs Pienaar** instead focused on sharing her experience of working with other Rare Disease Groups in South Africa and the benefits coming from such cooperation.

After the patient perspectives, **Dr Nahla Erwa (Sudan)**, incoming ASID president, presented her views on why it is important from a doctor's perspective to have an active patient group for PIDs and the positive outcomes that stem from working together. One of her conclusions was that the joint effort of patient groups will help advocacy and awareness and hence diagnostic and treatment facilities.

Session 5 was dedicated to a patient workshop with the purpose of exchanging experiences and to brain storm regarding possible future activities for the NMOs, especially from the perspective of World PI Week (WPIW) which was around the corner. In the light of this the session was introduced with a presentation by **Ms Julia Nordin**, IPOPI NMO Programmes Officer, offering the NMOs an overview of WPIW, including various tools available for them to use during WPIW 22 to 29 of April. After this the patient representatives were divided into two groups to discuss their own activities and present suggestions for new ones. The result was a mix of exciting ideas for future advocacy and awareness raising efforts in their countries.



Summary of suggested actions for PID patients in the African region

- Raise awareness among authorities (Minister of Health), emphasizing early diagnosis and access to treatment for all
- Work with the foundation “Servir le Sénégal” for support
- Manage schooling for children with teachers at home / in hospitals
- Special measures during the school test to give PID patients more time
- Train healthcare professionals + parents
- “Mass” screening + evaluation
- Organize event with warning signs
- Social media awareness campaign about warning signs
- Share what IPOPI publishes
- Organize meetings with medical professionals
- Print t-shirts and arrange awareness walks
- Participation in TV-programs and news papers
- Team up with Rare Diseases groups
- Share ideas and replicate (example: create Whatsapp groups)
- Reach out to immunologists through LinkedIn
- Make short snap/video and share for #WorldPIWeek
- Raise awareness within medical schools. Doctors need to know that PIDs exists
- Create news letters

Proposed immediate actions after this meeting

- Nigeria: Establish a patient organisation. Contact other patients, ask physician for contacts
- Senegal: Share their experiences through FB and Whatsapp
- Tunisia: Family meeting
- General: Plan next steps together with their NMOs

Table: Patient workshop suggestions.

3 Further opportunities in Dakar



Beyond the organisation of this meeting IPOPI was also eager to seize other opportunities to learn about the situation for PID patients in Senegal and the surrounding region. One example of this was a scheduled meeting with the **WHO representative based in Senegal, Dr Lucile Imboua**, on the 15th of April, attended by **IPOPI President Mrs Martine Pergent**. The meeting brought great insights into WHO’s work in Senegal and Sub-Saharan Africa and was a good opportunity for IPOPI to gain further knowledge on which area’s need prioritization.

Beyond this IPOPI had the honour to take part in two hospital visits, one to **the Centre Hospitalier National d’Enfants** (National Children’s Hospital), where **Dr Indou Deme Ly** coordinates the unit for children and adolescents with sickle cell anaemia and PIDs, and one to the **Centre National de Transfusion Sanguine** (National Blood Transfusion Center) led by **Prof Tandakha Ndiaye Dieye**. These hospital visits gave IPOPI a unique understanding of the current situation in Dakar which is of great importance for our future advocacy efforts in the region. IPOPI is very grateful to **Prof Tandakha Ndiaye Dieye** and **Dr Indou Deme Ly** for giving us the opportunity to visit these hospitals.

4 Conclusion

This year's edition of IPOPI's regional African patient's meeting was a successful event bringing together patient representatives from seven countries spread throughout the African continent. Prior to the meeting a **Call to Action, Improving the lives of patients with Primary Immunodeficiencies in Africa by providing sustained access to safe immunoglobulin replacement therapies**, was developed. This aims at encouraging African governments to ensure sustained access to safe immunoglobulin replacement therapies for African patients with primary immunodeficiencies. In light of the meeting with the WHO representative and the visits to the hospitals, IPOPI is more convinced than ever that this Call to Action will be very useful for future joint action amongst stakeholders.

IPOPI was impressed to see the work of our African NMOs and we are hopeful that the result of this meeting will be many new IPOPI NMOs established in the near future. The meeting demonstrated how valuable it is to bring people together. One thing that kept on being repeated during these two days was that meeting each other made the patient representatives feel less isolated, because they now know that there are people all over Africa experiencing the same difficulties as they do (not to mention that PIDs were long considered as Western conditions). In the light of this, IPOPI is confident that with dedication and cooperation, much can be improved in terms of PID awareness, diagnosis, treatments and registries in Africa. IPOPI is committed to keep collaborating with ASID and aims to organise more regional patient events back to back with ASID Congresses in the future.

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