



IPOPI 8TH AFRICAN PID PATIENTS' MEETING

14-15 JUNE 2023

CASABLANCA, MOROCCO

an IPOPI event

MEETING REPORT



COLLABORATION



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INTRODUCTION

In mid-June it was time for IPOPI to welcome its African National Member Organisations (NMOs) to the 8th Regional African PID Patients Meeting, organised in **June 14-15, 2023**, in parallel with the congress of the African Society for Immunodeficiencies (ASID). The meeting was very well attended, with **over 50 participants** from **10 countries** in the region (Algeria, Kenya, Morocco, Namibia, Rwanda, Senegal, South Africa, Sudan, Tunisia and Uganda).

The two-day patients' meeting provided a valuable platform for attendees to share insights on the **current state of primary immunodeficiencies (PIDs) in the region**. The discussions focused on the **latest advancements in the treatment and care of PIDs in Africa**, the **role of technology in healthcare**, and various other relevant topics. In addition, the participants actively engaged in a **workshop** focused on raising awareness about the importance of national financial coverage for PID treatments.

This meeting was provided in English, French, and Arabic to allow the participation of all our delegates.

MEETING OBJECTIVES

- Improve knowledge on diagnosis and treatment for PIDs
- Practice on how to raise awareness 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: 53

Countries represented: Algeria, Kenya, Morocco, Namibia, Rwanda, Senegal, South Africa, Sudan, Tunisia and Uganda

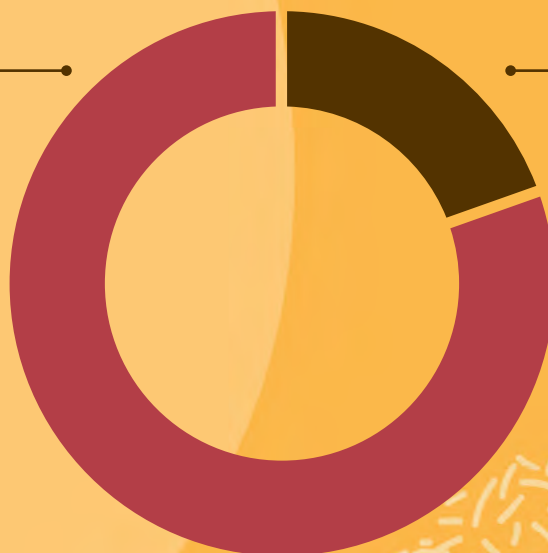
PARTICIPATION FEEDBACK (10)

EXCELLENT

8

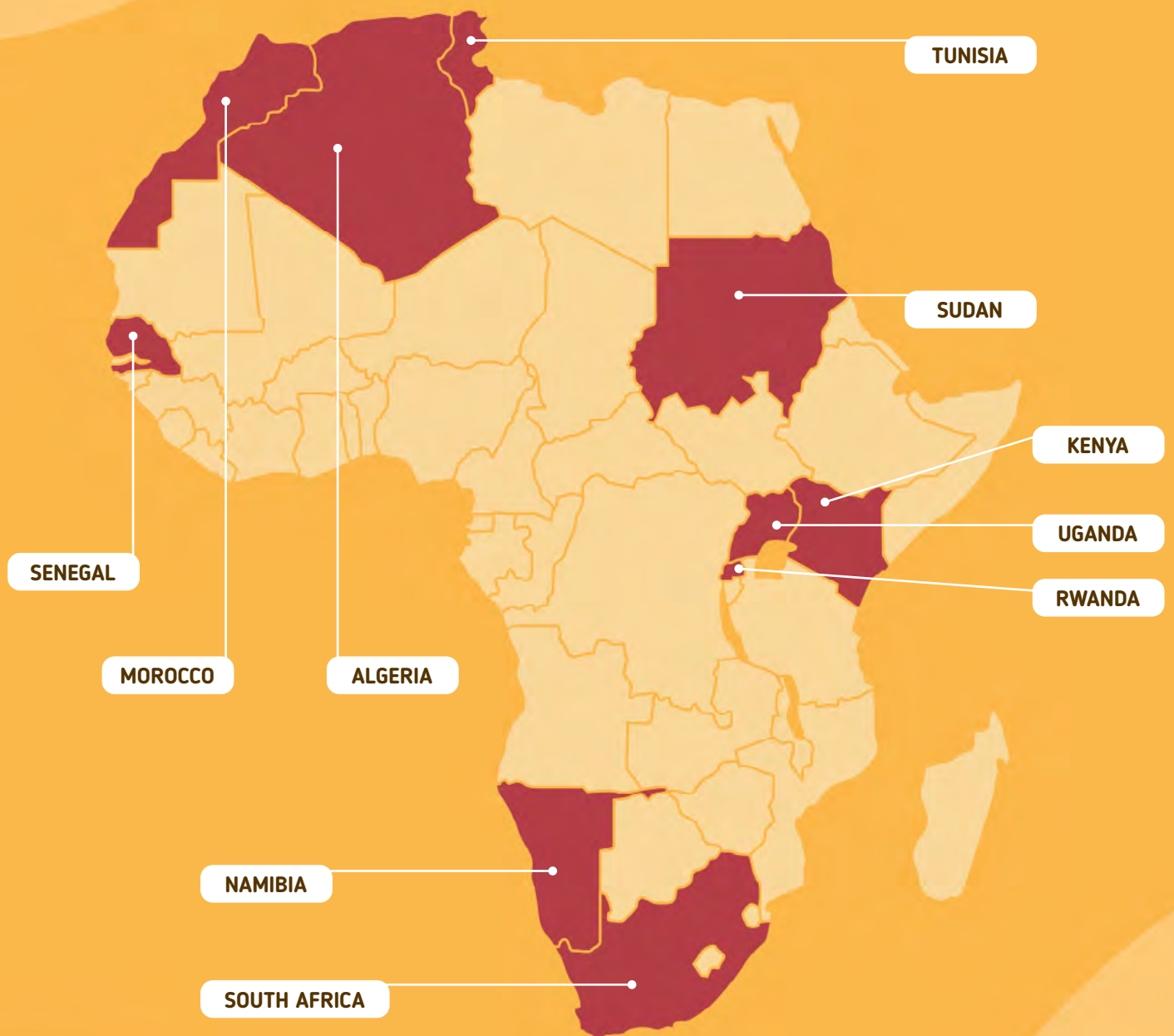
VERY GOOD

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PRESENTATIONS AVAILABLE

Authorised presentations provided at this meeting are available on the **NMO support webpage** for educational purposes.



"Thank you very much, it was very instructive. I was also pleased to meet other African patients. The exchange with Dr. Nizar and Dr. Nahla also added a lot of value to the meeting, bringing patients closer to the scientific medical committee."

– Meeting participant

INTRODUCTION AND WELCOMING WORDS

Moderated by Ms Martine Pergent

- Opening remarks, **Ms Martine Pergent**, IPOPI President (France).
- Introduction from HAJAR, **Ms Bouchra Benhayoun**, HAJAR general secretary (Morocco).
- Icebreaker, **Ms Martine Pergent**

Martine Pergent, IPOPI President, opened the meeting and welcomed the participants to the first out of two exciting meeting days for IPOPI's African meeting. Martine introduced IPOPI and emphasised the importance for each patient organisation to have a strategic project to develop different objectives in their country.

Ms Bouchra Benhayoun welcomed all participants to Morocco and outlined the path taken by HAJAR, which started over 20 years ago, to aid children with Immunodeficiency, inspired by a girl named Hajar who passed away due to lack of treatment. Currently, HAJAR welcomes the development made in diagnosis and access to treatment for patients with PID, and the fact that more specialised doctors are committed to PIDs and is proud of the unity achieved among their members.



Ms. Martine Pergent



Ms Bouchra Benhayoun



Participants introductions

SESSION 1 – PIDS: WHERE ARE WE IN AFRICA?

Moderated by Ms. Martine Pergent

- Growing up with a PID in Africa - current status and possibilities, **Dr Leïla Jeddane**, ASID President (Morocco).
- Status update from the African region: patients' perspective, All
- 3 IPOPI National Member Organisations' (NMOs) presentations from the African region on 1 successful action, **Mr Anton van der Zandt** (PiNSA, South Africa), **Mr Moses Muchege** (PIDs Kenya, Kenya) and **Ms Mariam Fourati** (ATunDip, Tunisia).



Ms. Martine Pergent



Dr Leïla Jeddane



Mr Anton van der Zandt



Mr Moses Muchege



Ms Mariam Fourati

The second session focused on the current status of PIDs in the continent, commencing with a presentation by **Dr Leïla Jeddane**. By drawing upon patient cases, she spotlighted the current diagnostic and treatment challenges. Dr Jeddane then stressed three key areas of improvement: PID awareness, drug and therapies availability advocacy, and an ASID registry establishment, as a crucial tool to empower the advocacy for treatment access, research and epidemiology. She concluded with an inspirational note of “hope”.

Following this, we had the opportunity to hear the status of PIDs in the continent from the participants, as well as hear from the latest activities developed by some of our NMOs, from South to North of Africa.

Mr Anton van der Zandt's presentation highlighted PiNSA's efforts in South Africa, addressing challenges such as distance, language, and unequal healthcare access. He shared that PiNSA has focused on awareness, support, and advocacy, using social media and a dedicated member's portal. Their motto is: “I am not alone.”, highlighting the valued collaboration with IPOPI.

Mr Moses Muchege shared his journey as a PID Kenya member, highlighting awareness efforts through video interviews with patients and physicians, along with psychological support for members. Their endeavors center around educating communities and medical professionals for early diagnosis and treatment, especially in rural areas, as well as expanding their membership and collaboration with doctors.

In her presentation, **Ms Mariam Fourati** discussed ATunDip's recent advances. She emphasised their work on raising awareness through family meetings and educational flyers. She also presented their 2023 focus, that shall include supporting members' psychological well-being and facilitating treatment access.



Hearing from the PID status in the continent



Mr Moses Muchege (Kenya) presenting

SESSION 2 – THE ROLE OF DIGITAL TECHNOLOGY IN HEALTH

Moderated by Ms Cynthia Olotch

- How can digital technology benefit patients, **Ms Miriam Ferreira** (IPOPI NMO Programmes Officer).
- Summary remarks, **Ms Cynthia Olotch** (IPOPI Board Member, Kenya) and **Ms Miriam Ferreira** (IPOPI NMO Programmes Officer).



Ms Cynthia Olotch



Ms Miriam Ferreira

This session explored the potential of digital technology in healthcare. **Ms Miriam Ferreira** emphasised its impact on global information access, communication enhancement (especially in remote areas), access to specialised care, and empowerment of patient self-management. Concrete tools were highlighted such as IPOPI's digital resources – like **leaflets**, **educational webinars**, and **minidocumentaries** –, telemedicine, online medical libraries, and health apps – such as the **IPOPI 4-ID app** and the **ASID PID classification mobile app**. The importance of consulting physicians for accurate diagnosis and treatment was underlined.



Participants



Ms Miriam Ferreira (IPOPI) presenting

SESSION 3 – ASID/IPOPI/INGID JOINT SESSION

- Opening remarks – **Ms Martine Pergent** (IPOPI President, France) and **Prof Aziz Bousfiha** (Morocco)
- Opening lectures – **Dr Azis Diakité** (Mali), **M. Moudatir** (Morocco), **S. Manyundo** (Burundi), **Mr Johan Prévot** (IPOPI Executive Director), **Prof Aziz Bousfiha** (Morocco) and **F. Adnane** (Morocco)
- Transition from Paediatrics to Adults, **Dr Nizar Mahlaoui** (IPOPI MAP Chairperson, France)
- Transition: The Moroccan experience, **Dr Ibtihal Benhsaien** (Morocco)
- New PIDs on the IUIS 2022 Classification, **Dr Leïla Jeddane** (ASID President, Morocco)



ASID/IPOPI/INGID Joint session

The ASID meeting commenced with short addresses from representatives from regional and international organisations, comprising doctors, patients, and nurses, underscoring the vital significance of comprehensive collaboration between all stakeholders for improved care of PID patients.

Opening lectures were moderated by Dr Azis Diakité (Mali), M. Moudatir (Morocco), S. Manyundo (Burundi), Mr Johan Prevot (Belgium), Prof Aziz Bousfiha (Morocco), and F. Adnane (Morocco).

The first lecture was presented by **Dr Nizar Mahlaoui**, who discussed the critical transition process for patients moving from pediatric to adult care, emphasising the importance of tailored support and comprehensive medical management during this crucial phase. **Dr Ibtihal Benhsaien** followed with a presentation on Morocco's strategy and experience in patient transition care. Lastly, **Dr Leïla Jeddane** presented the latest additions to the International Union of Immunological Societies (IUIS) 2022 Classification for Primary Immunodeficiencies (PIDs).

The meeting's first day wrapped up with a fantastic traditional Moroccan musical performance, adding a lively touch to a successful meeting.

SESSION 4 – TREATMENT AND CARE OF PIDS IN AFRICA

Moderated by Mr Johan Prévot

- Welcome to the second day, **Ms Martine Pergent**, IPOPI President
- Vaccination for PID patients, **Prof Aziz Bousfiha** (Morocco) and **F. Adnane** (Morocco)
- How to fight off infections (Anti-infectious, daily life measures), **Dr Anne Barasa** (Kenya)
- Immunoglobulin therapy: The journey from plasma to medicine, **Mr Johan Prévot** (IPOPI Executive Director, Belgium).
- How are immunoglobulin therapies administrated? **Nurse Houda Chadil** (Morocco)
- Curative therapies: Transplant and gene therapy, **Prof Monia Ouederni** (Tunisia)



Ms Martine Pergent



Mr Johan Prevot



Prof Aziz Bousfiha



Dr Anne Barasa



Ms Houda Chadi



Prof Monia Ouederni

The participants were greeted back on the second day by Martine Pergent. **Prof Aziz Bousfiha** started this session with a vibrant presentation on the vital importance of immunisation of PID patients. He stressed that vaccination extends beyond the individual to safeguard the family and community. Lastly, the presentation underscored the necessity of a comprehensive vaccine culture and urged active advocacy for widespread immunisation.

Dr Anne Barasa followed with an insightful presentation of strategies to combat infections. She outlined individualised anti-infective measures, antimicrobial prophylaxis, vaccination, tailored medication choices, immunoglobulin therapies, and personal hygiene practices. Lastly, she highlighted the importance of teamwork between healthcare professionals, patients, and their families.

Next, **Mr Johan Prévot** provided a presentation on Plasma's composition, collection methods, and fractionation. He highlighted the global disparities in collection and emphasised the importance of increasing plasma availability to ensure regional sustainability, and shared relevant public-private partnership initiatives in Africa, to increase plasma access.

Subsequently, **Nurse Houda Chadi** delivered an informative presentation focused on intravenous immunoglobulin administration, discussing indications, contraindications, proper preparation, infusion protocol, side effects management, and premedication. In this presentation, she highlighted the need for careful patient monitoring and adequate hydration. Lastly, **Prof Monia Ouederni** presented on curative therapies for PIDs. She highlighted bone marrow transplantation's effectiveness, challenges, and patient eligibility. Additionally, she presented the potential of gene therapy and emphasised the importance of international collaboration for improved PID management in Africa.



Prof Aziz Bousfiha (Morocco) presenting



Dr Prof Monia Ouederni (Tunisia) presenting

SESSION 5 – PID AWARENESS WORKSHOP

Moderated by Ms Miriam Ferreira

- Introduction to workshop.
- Practical exercise: How to take advantage of momentum?
- NMO examples of successful awareness campaigns in Latin America and Asia, **Ms Miriam Ferreira** (IPOPI NMO Programmes Officer).
- Summary, **Ms Miriam Ferreira**



Ms Miriam Ferreira

The following session was focused on an interactive workshop moderated by **Ms Miriam Ferreira**, where the participants learned to leverage a momentum for raising awareness on PIDs in Africa. Using **Universal Health Coverage Day** as an example, our patient leaders developed very captivating campaign messages and posters, for one of two meetings: one with their membership to recruit volunteers; and another with a potential sponsor for funding. Participants were divided into language-specific sub-groups (English, French and Arabic), to ensure the active participation of all, and even the children helped in the crafting collages of the poster. In the second part of the workshop, each group showcased their campaign, followed by an interactive role-playing session. In this session, each group engaged in challenging scenarios with industry sponsors and uninvolved volunteers (played by IPOPI members). Their goal was to effectively persuade these entities to support their respective campaigns.

LESSONS LEARNED:

1. **Be Clear about Needs:** It's important to say exactly what you want, the amount required, and the timeline to secure the support you need.
2. **Plan Ahead:** Planning ahead helps you to communicate effectively and be prepared for questions.
3. **Include Everyone:** Involving different perspectives improves campaigns and engagement.
4. **Explain Benefits:** Clearly explaining what supporters get makes interaction more effective.



Working group



Working group



Working group



Campaigns presentation and interactive role-playing



Campaigns presentation and interactive role-playing



Campaigns presentation and interactive role-playing

SESSION 6 – GROWING UP WITH PIDS IN AFRICA: HOW CAN PATIENT ORGANISATIONS MAKE THE DIFFERENCE?

Moderated by Ms Martine Pergent

- What are the challenges of living with a PID/RD?, **Mr Manzi Ndamukunze** (Rwanda).
- PID as a disability, IPOPI Statement endorsed by ASID, **Ms Cynthia Olotch** (IPOPI Board Member, Kenya).
- Practical exercise: PID as a disability.
- The importance of patient-doctor cooperation, **Dr Nahla Erwa** (Sudan).
- Physician forum: what did you speak of during your meeting? **Dr Nizar Mahlaoui** (France) and **Dr Nahla Erwa** (Sudan)



Ms Martine Pergent



Mr Manzi Ndamukunze



Ms Cynthia Olotch



Dr Nahla Erwa



Dr Nizar Mahlaoui

After the lunch break, our final session delved into the experience of living with a Primary Immunodeficiency (PID) in Africa, encompassing the challenges of stigma and the potential opportunities.

Mr Manzi Ndamukunze commenced by sharing his journey in overcoming the challenges of the stigma associated with a rare disease. He emphasised the significance of uniting as a community, educating the society and the development of patient organisations as pivotal actions to support patients and families.

Ms Cynthia Olotch followed, discussed PID as a disability, exploring its concept, classification, social and legal implications, as well as associated protection and benefits. **IPOPI's statement** and participants' experiences shed light on the complex subject, discussing the challenges and potential benefits in each country.

Dr Nahla Erwa highlighted the significance of patient-doctor cooperation. She explained how this relationship is rooted in effective communication and trust, enabling the patients' personalised treatment. She also emphasised the importance of the active participation of patient organisations, in collaboration with medical societies, to share knowledge, promote research, and advocate for improved PID care.

This session was concluded with a physician forum led by IPOPI Medical Advisory Panel members, **Dr Nizar Mahlaoui** and **Dr Nahla Erwa**, discussing the ASID program topics for patients. Patient representatives engaged in interesting questions about genetics and genetic counseling, infection prevention, treatment access, and multidisciplinary support.



Participants



Mr Manzi Ndamukunze (Rwanda) presenting

CONCLUSION

IPOPI's 8th African PID patients meeting marked a heart-warming in-person reunion, post the COVID-19 pandemic, drawing in our regional community. 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 building, laying the groundwork for future initiatives. IPOPI was delighted to connect once again with representatives from its NMOs, as well as with its network of physicians from this continent, and to welcome representatives from Namibia and Rwanda for the first time.



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

GRIFOLS



