

**HYBRID**



# IPOPI AFRICAN PID PATIENTS MEETING

OCTOBER 1-2, 2021

## MEETING **REPORT**



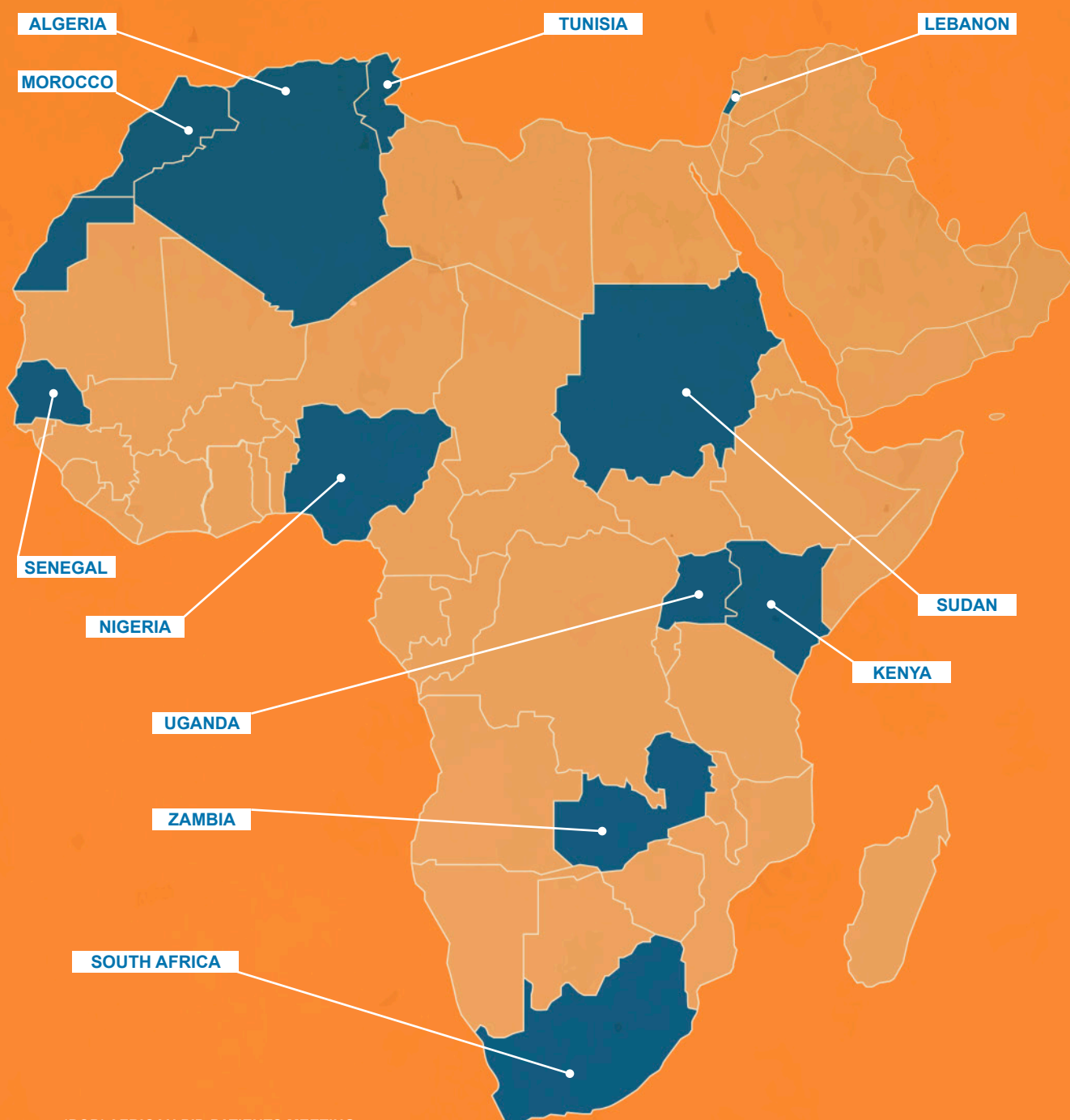
an IPOPI event

# INTRODUCTION

IPOPI started the month of October by welcoming patient representatives from 11 countries from the continent to this year's African PID Patients Meeting, organised 1-2 October 2021 alongside the 7<sup>th</sup> Congress of the African Society for Immunodeficiencies (ASID). The theme of this year's ASID congress was "*PID-IEI in Africa: Where and how to find them?*", bringing together both health care professionals and patient representatives from Africa as well as from nearby regions to discuss this important and relevant theme.

The IPOPI meeting was for the very first time organised in a hybrid format, with Sudanese patient representatives attending the meeting in person in the city of Khartoum, and the other participants joining the session online. This was a successful format, allowing for participants to speak in English, French or Arabic as well as facilitating co-operation across national borders. IPOPI was thrilled to once again have the opportunity to connect with African patient representatives and join forces to build skills around diagnosis and care for patients with PID in the region.

IPOPI would like to thank ASID and IPOPI's Sudanese member organisation SOPPI (Sudanese Organisation for Patients with Primary Immunodeficiency) for good collaboration and support towards this meeting.



## MEETING OBJECTIVES

- IMPROVE KNOWLEDGE ON PID DIAGNOSIS AND TREATMENTS
- FACILITATE DISCUSSIONS ON DAILY LIFE FOR PATIENTS WITH PID
- IDENTIFY NATIONAL AND REGIONAL CHALLENGES AND DISCUSS HOW TO ADDRESS THEM
- EXCHANGE OF EXPERIENCES AND BEST PRACTICES
- STRENGTHEN REGIONAL COOPERATION

## PARTICIPATION OVERVIEW

**TOTAL PARTICIPANTS:** 57

**COUNTRIES REPRESENTED:** Algeria, Kenya, Morocco, Nigeria, Senegal, South Africa, Sudan, Tunisia, Uganda, Zambia, Lebanon.

## PARTICIPATION FEEDBACK

“Very interesting, thank you very much. We have learned a lot. Looking forward to attending the workshop on implementing actions to move forward.”

“Ways to improve the mental well-being of patients can be a topic of discussion as well. I loved how broad the topic of hygiene was covered.”



# SESSION 1: OPENING CEREMONY (JOINT SESSION ASID – IPOPI – INGID)

- Opening message from the ASID president: Where do we find PID and how to deal with them in Africa? Dr Nahla Erwa, ASID President and Clinical Immunology consultant, Soba University Hospital, Khartoum, Sudan
- Welcoming words, Ms Patricia Luck, INGID representative, Switzerland
- Opening remarks, Ms Martine Pergent, IPOPI President
- Schematic approach to a child with suspected PID, Prof Shereen M Reda, Faculty of Medicine, Ain Shams University, Cairo, Egypt

**7th ASID Congress**  
Khartoum, SUDAN  
October 1<sup>st</sup> - 2<sup>nd</sup>, 2021

**IEI-PID IN AFRICA:**  
Inborn Errors of Immunity - Primary Immunodeficiencies  
**WHERE AND HOW TO FIND THEM?**

**October 1<sup>st</sup> - Opening message from ASID President**

**Reasons behind low diagnosis**

- Complexity of the diseases.
- Heterogeneity and varied presentations.
- Distractions by more "urgent" healthcare problems (HIV, malaria, TB, Leishmaniasis...); **BUT ARE THERE PIDs HIDDEN AMONGST THESE?**
- Reduced awareness at all levels.

**Nahla Erwa (Sudan)**  
Clinical Immunology Consultant,  
Assistant Professor  
Soba University Hospital & Faculty of  
Medicine, University of Khartoum

**Topic:**  
Where do we find PID  
and how to deal with  
them in Africa?

**Platinum Sponsors:**  
**Takeda**  
NATIONAL BIOPRODUCTS INSTITUTE NPC

The first meeting day began with a joint session with IPOPI, ASID and INGID. In her opening address, ASID President Dr Nahla Erwa, highlighted the importance of diagnosing patients with PIDs and how to manage them once diagnosed. She stressed the need to investigate endemic diseases and consider if they are "hiding" any patients with PID. Dr Erwa finished by sending a warm thank you to IPOPI, SOPPI and INGID, among others, for making this meeting possible. Following INGID's welcome address by Ms Patricia Luck, Martine Pergent, IPOPI President, took the floor and welcomed

participants to the joint session and highlighted how vital this congress is for PID awareness in Africa. She also mentioned the importance of the congress theme "PID-IEI in Africa: Where and how to find them?", and stressed that in a continent with 1.3 billion inhabitants there should be close to a million patients, *so where are they?* Many countries in Africa are making great strides in diagnosing and treating these patients, but much remains to be done. She closed her welcome address by giving support towards a continued IPOPI-ASID partnership, joining forces to raise awareness, and advocating for these diseases.

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**WHERE AND HOW TO FIND THEM?**

**October 1<sup>st</sup> - Opening Ceremony**

**ONLINE**

**IPOPI AFRICAN PID PATIENTS MEETING**

**Platinum Sponsors:**  
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**Logos:** ASID, IPOPI, INGID, iapids, HAEI, Soba University Hospital, Ain Shams University

# SESSION 2: PID PATIENTS IN AFRICA: WHERE DO WE STAND?

*MODERATED BY MS MARTINE PERGENT AND MS CYNTHIA OLOTCH*

- Welcoming words and introduction to IPOPI, Ms Martine Pergent, IPOPI President
- Sponsor's welcome, Dr Sugania Moodley, Export Manager, National Bioproducts Institute, South Africa
- Round table – status update from the African region, moderated by Ms Cynthia Olotch, IPOPI Board member / Chair of PIDs Kenya

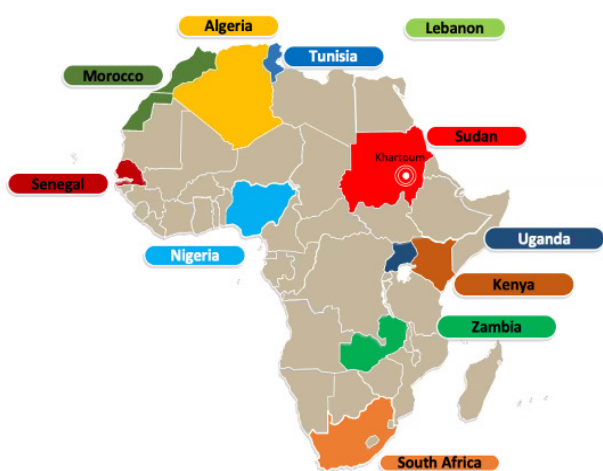


Following the joint session, IPOPI's separate programme began with a session addressing the current PID environment in Africa. Ms Martine Pergent opened the session and welcomed the participants to two educational and interactive meeting days with the African IPOPI family. She stressed the need for more and stronger patient organisations in Africa, as it remains the continent with the lowest number of established PID organisations so far, in comparison with the number of countries (54). Following this Martine took a moment to thank the SOPPI team in Sudan for their great job in ensuring that patient representatives in Sudan could take part in the meeting in person, and then gave

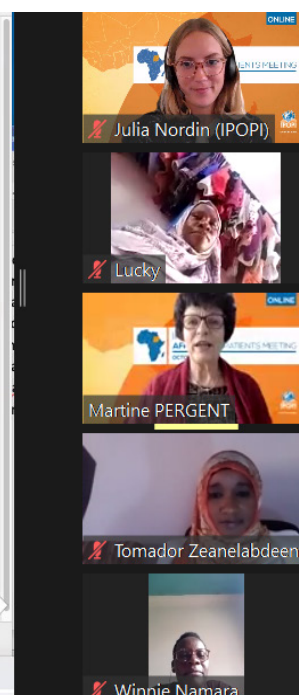
the floor to Dr Sugania Moodley to give welcoming words on behalf of the meeting sponsor, the National Bioproducts Institute. To begin the more interactive part of the meeting Ms Cynthia Olotch, IPOPI board member, opened the floor to warm up the participants and understand their expectations on the meeting. When asked about why this meeting was important to them and why they were attending, the participants mentioned “for experience sharing”, “to understand how to raise awareness”, and “to try to meet the needs of their members”, among other reasons. Already in this first interaction the participants showed their motivation to take active part in the meeting and to share their experience from their home countries.

## IPOPI African family ...

So far ...



Bienvenue

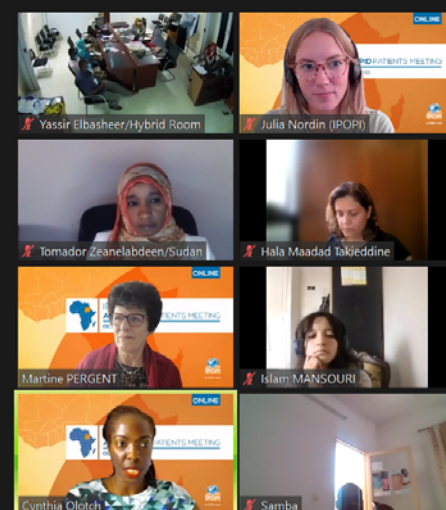


# CHALLENGES IN AFRICA

During the second part of the first day the participants were asked to roll up their sleeves in a workshop addressing “Challenges in Africa”. With co-moderation by Martine Pergent, Cynthia Olotch and Dr Salma Ali Elmahdi from SOPPI Sudan, the participants were asked to identify challenges in the region and prioritise among them. What was noticeable in this exercise was that even though the participants were divided in groups based on their home countries and spoken languages (English, French, Arabic), many of the challenges were repeated in the different groups. Low awareness of PIDs, poor diagnosis rates and access to treatment were indicated regardless of the participants’ domiciles. Many participants also flagged that they lack support in the education system for their children, as well as the lack of psychological support. Another recurrently indicated challenge was problems with insurance companies and the lack of coverage for diagnosis and treatments in many countries, making it impossible for patients and their family to afford their life saving treatments. Although it was obvious that many struggle greatly in their countries, the participants were in good spirits and all willing to engage and share their experiences.

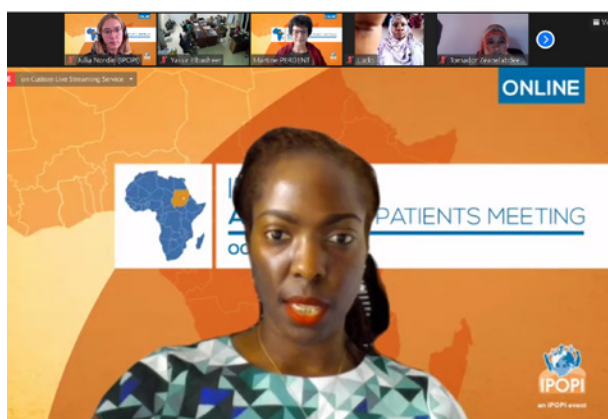
## Challenges in Africa – Template

CHALLENGE	AFFECTED COUNTRY	PRIORITY (high/low)
Two- tiered health care system (private/public)	South Africa	
Lack of a national association for PIDs	Lebanon	
Lack of awareness of PIDs	Uganda	
Lack of access to immunoglobulins	Uganda	
Lack of psychological support to caregivers	Kenya, Lebanon	
Affordability of treatment (requirement for co-payment can be prohibitive)	South Africa	
Lack of diagnosis	Uganda	
Cooperation amongst patients/within the patient group		
Financial support to patients		

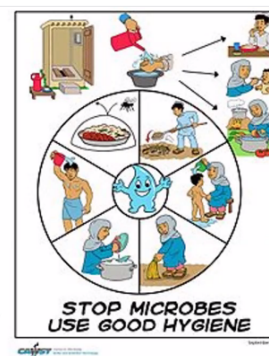


# SESSION 1: LIVING WITH A PRIMARY IMMUNODEFICIENCY IN AFRICA

- Welcoming words and icebreaker, Ms Cynthia Olotch, IPOPI / PIDs Kenya
- Daily life with a PID (treatment, hygiene, nutrition), Dr Nahla Erwa, ASID President and Clinical Immunology Consultant, Soba University Hospital, Khartoum, Sudan
- Addressing a stigma - can we speak about our condition? Prof Tandakha Dieye, Université Cheikh Anta Diop -Dakar, IRESSEF Institut de Recherche en Santé, de Surveillance Epidémiologique et de Formation, Senegal
- The importance of patient-doctor cooperation, Dr Nizar Mahlaoui, Necker-Enfants Malades Hospital, Paris, France
- Closing words, Ms Martine Pergent, Ms Cynthia Olotch, Ms Julia Nordin



- Cleanliness reduces exposure to germs.
- Home especially toilets and kitchens:
  - Regular surface and floor cleaning.
  - Using nets to rid of harmful insects.
  - Proper waste disposal.
  - Medicines and first aid storage.



Cynthia Olotch welcomed the participants back to the second day and introduced them to the first speaker, Dr Nahla Erwa, who presented on daily life with a PID. Dr Erwa presented both in Arabic to the participants in Sudan as well as in English to the online participants, and covered treatment, hygiene, and nutrition. This was a very well appreciated presentation addressing key issues for patients with PID. She mentioned that doctors sometimes take these themes for granted, but that it is very important to talk about it with patients like it was done in this IPOPI meeting. She lingered on the area of hygiene, highlighting that it is key to avoid spreading diseases and maintaining as healthy as possible. This was a very well appreciated presentation by all the participants based on the comments shared at the end of her talk.



The second presentation of the day addressed the complex theme of stigma. In many parts of the world patients with PID and their family still face stigma, something which may be difficult to speak about. IPOPI wanted to provide an opportunity to do so at this meeting and had therefore invited Professor Tandakha Dieye, to present and moderate a session on this topic. Professor Dieye presented cases of stigma that he had encountered in his career, with children facing issues both in school and with family members. This opened for a discussion, with many participants sharing stories from their countries. IPOPI was grateful for the confidence and trust from the participants, and hope they felt comforted in the fact that there are other patients and families out there who understand their situations and have means to address the issue with.

## IPOPI's African PID Patients Meeting

**Prof Tandakha Ndiaye DIEYE**



*OCTOBRE, 2<sup>nd</sup> 2021*

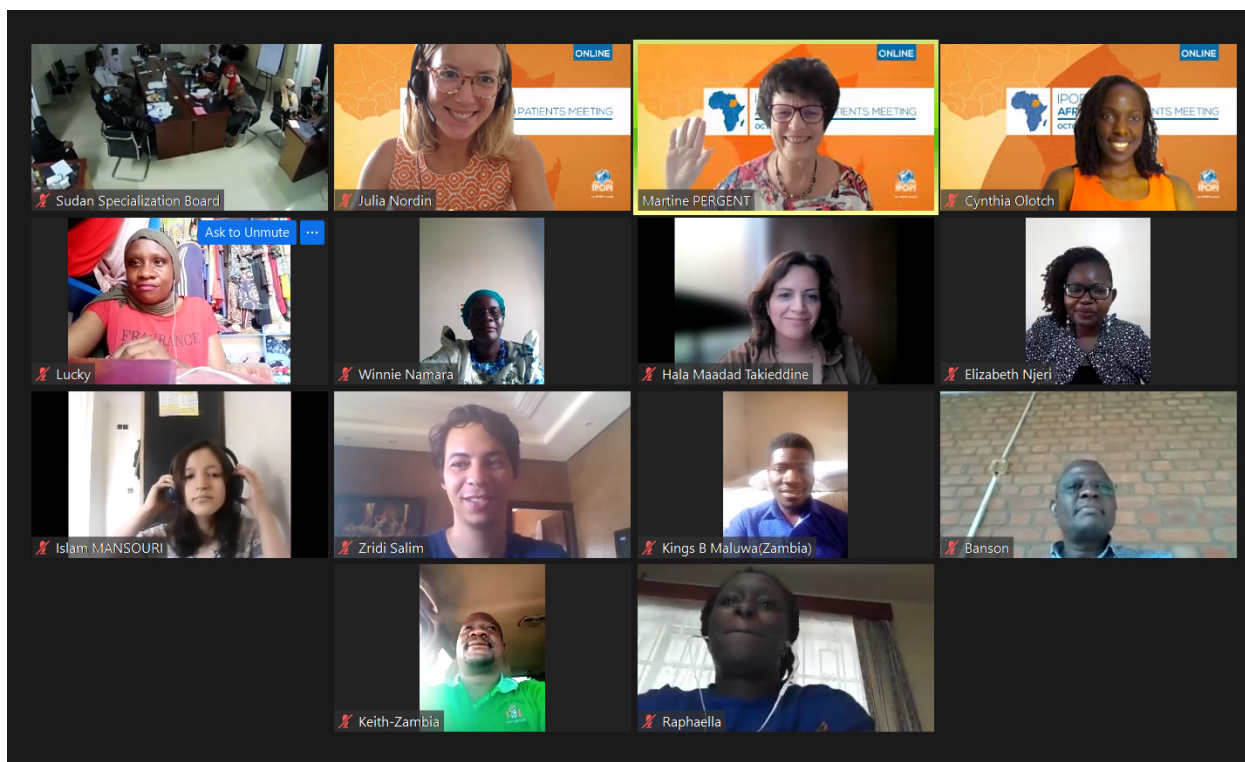


The second and final part of this meeting hosted an extended Question and Answer session with Prof Tandakha Dieye and Dr Nizar Mahlaoui to allow for participants to raise their important questions to the physicians. The attendees were ready with a high number of questions, touching upon topics such as “why does my son get sick after he gets his immunoglobulin treatment?”, “should patients with PID get vaccinated?” and “can patients get speech and hearing loss?”. Among others, these questions were thoroughly addressed by the physicians in all three languages, to ensure that the patient representatives got answers to their questions.

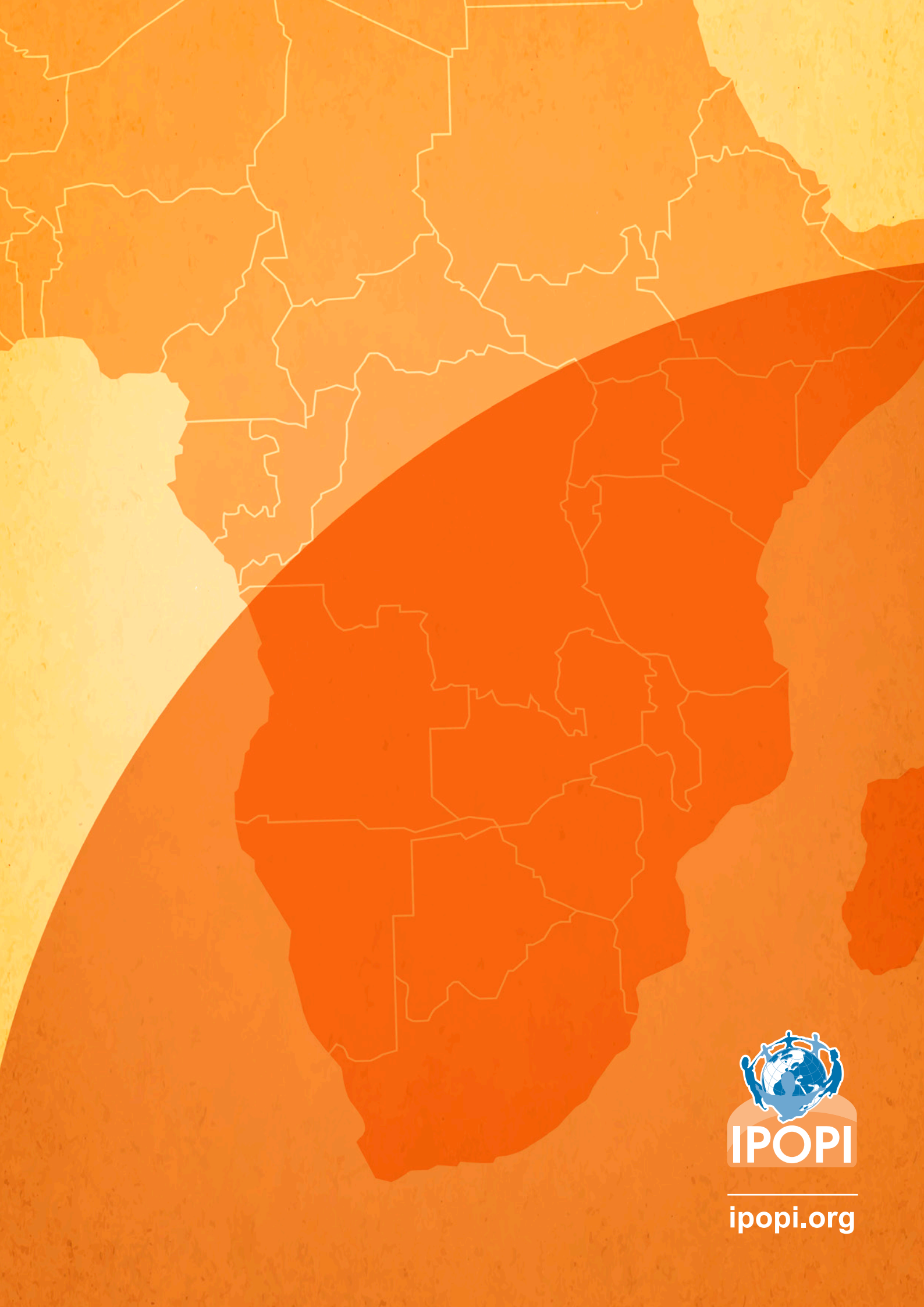


# CONCLUSION

IPOPI's hybrid African PID Patients meeting was a well-attended and interactive meeting, and the first one of its kind for IPOPI in the continent. The objectives of the meeting were met, with an increased awareness of PID diagnosis and treatment as a result, and a strengthened African PID community. To continue the dialog with the African patient representatives, a follow-up meeting will be organised in November to keep up to speed with the activities of the NMOs in the region. It was a pleasure to organise this meeting and IPOPI board and staff are already looking forward to the next one.



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



**IPOPI**

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