



# IPOPI African Regional Patients Meeting Kestrel Meeting Room Sun City Congress Centre, South Africa 7 June 2013

## Report

### I. Introduction

On Friday 7 June 2013, a regional patients meeting was organised by IPOPI (International Patient Organisation for Primary Immunodeficiencies) at the Sun City congress centre in parallel to the 3<sup>rd</sup> Congress of the African Society for Immunodeficiencies (ASID) jointly organised with the Allergy Society of South Africa (ALLSA) and the Thoracic Society of South Africa (SATS).

The meeting brought together around 30 participants including patient representatives, doctors, nurses and stakeholders from South Africa, Morocco, Uganda, Senegal and Zambia. The meeting was formally opened by Mrs Jose Drabwell who highlighted the tremendous progress made since the very first ASID-IPOPI joint meeting in Casablanca in 2009 and invited participants to introduce themselves.

The purpose of the meeting was to strengthen stakeholder collaboration in the region, share experiences between countries, identify key regional priorities and promote PID patient organizations development in Africa.

The meeting's programme featured several presentations covering the following subjects and was followed by an interactive and productive discussion:

- Overview of IPOPI key regional developments and latest IPOPI survey outcomes
- Overview of patient access to care and diagnosis challenges and opportunities in South Africa and Morocco
- Physician perspective on the regional challenges and opportunities facing the PID community
- Educational lecture on IG Treatment options and subcutaneous IG therapies
- Overview of IPOPI's available support programmes and tools to strengthen existing and promote new patient organisations in the region

### II. Presentations

1. Overview of IPOPI achievements including IPOPI survey outcomes – Johan Prévot
2. PID in South Africa: challenges & opportunities: Patient perspective – Janet Grab

3. PID in Morocco: challenges & opportunities: Patient perspective – Mohammed Fdhil
4. PID in Africa: challenges & opportunities: Physician perspective – Dr Monika Esser
5. IG treatment options in PID with focus on the SCIG infusion therapy – Prof. Ann Gardulf
6. What help is available from IPOPI – Jose Drabwell

## 1. Presentation of IPOPI Achievements and Survey Outcomes

Johan Prévot provided an overview of IPOPI's activities specifically pointing out the successes from IPOPI's regional outreach programmes. The presentation provided a brief historical overview of IPOPI's development, structure and key strategic objectives. Several IPOPI regional campaigns were reviewed to provide an example of regional cooperation such as the IPOPI EU newborn screening campaign, the IPOPI Latin American regional campaigns in collaboration with LASID as well as the work of IPOPI with key regional stakeholders such as PLUS. IPOPI's communications tools available to NMOs to increase awareness of primary immunodeficiencies were also explored. Lastly the presentation provided a summary of the key outcomes of IPOPI's latest patient survey which looked at Patient Needs and Outlooks. Professor Gardulf invited all participants to use the excellent data and information from the survey in their respective campaigns.



## 2. Presentation of PID Patients Perspective in South Africa

Mrs Janet Grab went over PiNSA's (IPOPI's National Member Organisation in South Africa) history, key achievements and strategic objectives moving forward. She highlighted the key challenges facing patients in South Africa including the need for local guidelines for diagnosis and treatment of primary Immunodeficiencies, the need for PID to be placed on the Chronic Disease List (CDL) so that it will be a defined prescribed Minimum Benefit (PMB) condition, the need to have immunoglobulin therapy added to the Essential Drugs list (EDL) in South Africa and the need to improve access to SCIG in the country which is currently limited. Mrs Grab also highlighted key aspects of the public and private healthcare sectors which both have their set of

specific challenges ranging from poor administration, treatment delays, lack of coverage, limited available treatments and poor infrastructures. Mrs Grab described the opportunities to improve patient access to diagnosis and care in the region including the growth and influence of PID advocates, stakeholder collaborative opportunities (ie IPOPI-ASID) and the opportunities brought about by organisations such as the International Alliance for Patient Organisations (IAPO) and the Patient Health Alliance of Non-Governmental Organisations (PHANGO).

### 3. Presentation of PID Patients Perspective in Morocco



Mohammed Fdhil provided an update on the activities and achievements of Hajar, IPOPI's NMO in Morocco. In his presentation Mr Fdhil summarized the historical development of Hajar and its main successes to date. Hajar was launched in 2000 and named after a little girl who tragically passed away as her parents could not afford BMT treatment. Whilst Hajar's first ten years of existence were focused on providing support to patients and their families, the association now has expanded its activities to

also focus on lobbying and advocacy/awareness and fundraising to finance projects on research, training, education and financial support to patients. Among the key objectives of the association the creation of a BMT centre in Morocco and universal access to care for all patients in Morocco were specifically highlighted as currently still 55% of treatments for patients are covered directly by Hajar. *(Picture above: Hajar's 'Awareness Caravan' campaign)*

### 4. PID in Africa Challenges & Opportunities – The Physician's Perspective

Dr Monika Esser then presented the physician perspective of the challenges and opportunities for the PID community in Africa outlining the challenges presented by conditions such as Malaria, TB and HIV in the region. She quoted the recently published article by Professor Bousfiha et al on primary immunodeficiency diseases worldwide which estimates the number of PID patients in Africa to be over 900,000. She described the mis-allocation of resources, the lack of accountability, the lack of training and the need for greater awareness as the main challenges facing the PID community rather than the lack of resources. She also outlined the many opportunities lying ahead and born out of the great efforts made by the African Society for Immunodeficiencies (ASID) working hand in hand with other stakeholders. She thanked IPOPI for organising this important stakeholders meeting.



### 5. IG treatment options in PID with focus on the SCIG infusion therapy

Professor Ann Gardulf then followed with an interactive presentation outlining IG treatment options for PID patients and sharing her experience with subcutaneous immunoglobulin (SCIG)

therapy. Professor Gardulf described use of SCIG from a historical perspective drawing from her experience at the Karolinska Institute Sweden which was received with much interest by participants at the meeting as subcutaneous immunoglobulin therapies are largely unavailable in African countries. Professor Gardulf highlighted the importance of having different IG therapies and modes of administration.

## 6. Presentation: What help is available from IPOPI?

In her presentation Mrs Drabwell summarized the numerous IPOPI support programmes and tools available to patient organisations.



The presentation went over the details of the IPOPI Awareness and Advocacy Patient Toolkits, the Awareness Campaign National Workshop Programme, the Advocacy and Media Training Regional Workshop programme as well as other IPOPI NMO support programmes such as the World Primary Immunodeficiencies Week (WPIW) support programme. The presentation described the successes of implementing patient campaigns through these programmes and toolkits in other regions and countries. Mrs Drabwell also highlighted the many benefits in terms of raising awareness which a global campaign such as WPIW can bring to PID stakeholders and reviewed the recent outcomes of this year's campaign.

Stakeholder collaboration and the work of IPOPI and other international patient organisations through platform such as PLUS was also described as a key component to successful awareness and advocacy campaigns.

## III. Discussion and Key Regional Priorities

The presentations were then followed by an interactive discussion during which the following key priorities and recommendations were identified for the African region:

- the need for clinical and diagnosis guidelines in the region
- the importance of increasing medical awareness
- the benefits of working with other active regional patient and advocacy groups
- the need for more patients support
- the need for more data on prevalence and epidemiology,
- the need for more research and data on impact of misdiagnosis vs diagnosis for PID patients
- the importance of having an integrated approach to screening and diagnosis
- the need for awareness campaigns targeting both primary care and tertiary care levels in hospitals
- the importance of tackling the lack of diagnosis capacity in many African countries such as Uganda.
- the importance of creating PID networks for doctors and patients

- the need for advocacy campaigns targeting the health authorities for better coverage of PID treatment

### III. Conclusions

The meeting provided an excellent platform for African patient groups and their stakeholders to meet and discuss the current status of PID diagnosis and treatment environment in Africa. Helpful priorities were identified on which the PID community should focus their activities and collaborate in the future. Several new contacts were also made with stakeholders in African countries which will provide an excellent basis for developing more IPOPI NMOs in the region. IPOPI is committed in continuing to provide regional and national development of patient organisations and to report on achievements in the African region during the next ASID-IPOPI meeting which will be held in 2015 in Algiers

The meeting was held with the endorsement of the International Alliance of Patients' Organisations (IAPO) of which IPOPI is a member and official partner of the first Patients Solidarity Day in Africa later this year on 30 October.

*The meeting was organised with the invaluable support of IPOPI's core sponsors:*

*Baxter (Platinum), Octapharma (Platinum)*

*CSL Behring (Gold)*

*Grifols (Silver)*



## List of participants

Jose Drabwell	IPOPI
Johan Prevot	IPOPI
Nizar Mahlaoui	CEREDIH
Aziz Bousfiha	HAJAR
Mohammed Fdhil	HAJAR
Leila Jeddane	HAJAR
Ann Gardulf	KAROLINSKA INSTITUTE
Allyson Ben-Israel	PiNSA
Sue Gordon	PiNSA
Janet Grab	PiNSA
Danielle Guignet	PiNSA
Karin Ludwig	PiNSA
Katharine McKenzie	PiNSA
Nishendra Moodley	PiNSA
Annie Pienaar	PiNSA
Chantelle Richards	PiNSA
Joy Rosario	PiNSA
Mariana du Toit	PiNSA
Hellen Aanyu Tukamuhebwa	MULAGO HOSPITAL UGANDA
James Chipeta	UNIVERSITY OF ZAMBIA
Tandakha Dieye	CHEIKH ANTA DIOP DAKAR UNIVERSITY SENEGAL
Winnie Namara	UGANDA
Sugania Moodley	NBI
Andrea Muller	NBI
Gunnar Philipp	CSL BEHRING