

**IPOPI**  
**Indonesian PID Clinical Care Meeting and National PID Patients Meeting**  
**Jakarta, Indonesia**  
**6<sup>th</sup> and 7<sup>th</sup> of May 2017**



## Report

### Introduction

The National Indonesian PID Clinical Care Meeting took place on the 7<sup>th</sup> of May in IMERI aula, Faculty of Medicine, University of Indonesia in Jakarta. The meeting was hosted by the University of Indonesia Faculty of Medicine (FKUI) and brought together more than 170 participants including physicians and medical students from 4 different islands of Indonesia to learn about Primary Immunodeficiencies (PIDs). The meeting aimed to share knowledge about PID diagnosis and care and to raise awareness among health care professionals in the country. There are currently 6 referral centres in Indonesia with only one centre where immunoglobulin is available located in the capital.

Back to back with the clinical care meeting which was directed at doctors and medical students, IPOPI organised its 2<sup>nd</sup> national patients meeting and at the DoubleTree Hotel Cikini, Jakarta on 6<sup>th</sup> of May. This brought together families of 10 PID patients in Indonesia. The meeting was also attended by nurses and Immunologists and aimed at starting a discussion among participants to identify next steps for the organisation. The key objective was to start engaging more patients in the activities of the organisation.

### Indonesian PID Patients Meeting

The Indonesian PID patients meeting was the second of its kind organised by IPOPI and brought together 30 participants consisting of patients and their families from different regions of Indonesia (Java and Borneo), nurses, physicians, patient leaders from neighbouring countries as well as IPOPI representatives.

The meeting featured presentations by IPOPI President **Ms Jose Drabwell**, MyPOPI President and IPOPI Board member **Mr Bruce Lim** and IPIPS Founder and a PID specialist from Cipto Mangunkusumo Hospital **Dr Dina Muktiarti**. Ms Drabwell gave an overview of IPOPI's activities and highlighted the importance of national PID groups and why patient involvement is key in running the organisations. Mr Lim then provided examples from the Malaysian patient group MyPOPI and the experiences and positive outcomes they have reached in their work. He went over practical examples on how MyPOPI has managed to advocate for better treatment levels and increased awareness in the country by effective collaboration and innovative means. Dr Muktiarti then presented an overview on the activities of the Indonesian NMO IPIPS, in which doctors have been mostly involved and is looking to engage patients and family members.

After the presentations, a discussion took place among the participants. The patients and parents raised questions to the international patient leaders and medical advisers as well as exchanged experiences with each other. After the discussions, Ms Drabwell invited participants to raise their hands if they were willing to get involved in the activities of IPIPS. This resulted in several family members volunteering to play a role. The IPIPS patient committee members were selected and the direction of the patient group together with the next steps discussed. The agreed next steps were: 1) register the organisation officially, 2) begin campaigning actively on social media and 3) develop a website for the organisation.

#### **The selected interim patient committee members:**

*Dimas Adhi Sugiharto, Chair*  
*Bonarsius Sipayung, treasurer*  
*Dewi Nurlita, secretary*  
*Nurul Hidayanti, member*  
*Yenny Cornelia Harahap, member*  
*Hendy Wijaya Budijanto, member*  
*Yohana Rini Mulyani, member*



#### **The PID Clinical Care Meeting**

The Clinical Care meeting took place at the Faculty of Medicine of University of Indonesia (FKUI) in Jakarta on Sunday 7<sup>th</sup> of May. The meeting aimed to educate and share knowledge about PIDs among general practitioners, paediatricians and other specialists in Indonesia and to extend the knowledge beyond the capital region. The meeting consisted of four sessions; an introductory session 1 with opening remarks from the organising committee, IPOPI and the sponsors, session 2 concentrating on Diagnosis and Management, session 3 on Case Studies and session 4 on Regional Updates. The international panel of speakers consisted of PID experts from the Netherlands, South Africa, Australia, Singapore, Thailand and Indonesia.

#### ***Diagnosis and Management Session***

The session was hosted by **Dr Zakiudin Munasir** from Jakarta and began with a presentation about the Historical Evolution of PID Treatment by **Dr Monika Esser** from Cape Town, South Africa. She gave an

overview of the most important names in the history of primary immunodeficiencies, the developments reached in the treatments and gene discovery since the 1920s to this day. Dr Esser described the historical breakthroughs affecting PID research. She concluded her presentation by describing the field of immunology today with cutting edge technologies, therapies and diagnostics of PIDs. The partnership between clinical and diagnostic immunology has reached new heights in genetic testing leading to even more rapid pace of discovery in the field.

The next speaker in this session was **Prof Martin Van Hagen** from Rotterdam, the Netherlands. His presentation touched on novel insights of PID and new genetic defects. He focused in particular on immunophenotyping of PIDs, classical drug therapies for PIDs, immunogenetics and its role in diagnosis and therapy of PIDs. Specific concrete examples were reviewed to illustrate new genetic defects such as gain of function mutations, as well as an overview of lessons learnt with the use of whole genome or exome sequencing.

**Dr Joanne Smart** from Melbourne, Australia spoke about how to suspect and diagnose PIDs. She stressed the importance of awareness of PIDs to be able to suspect a PID in a patient. Her interactive presentation went through real life examples of patients from the Royal Children's Hospital Melbourne and the symptoms that should make one suspect a PID. She made the case that patient history is vital in suspecting PIDs and that there is no such thing as "bad luck" of patients with recurrent infections. She summarised that it is critical for physicians to have an index of suspicion and that with early diagnosis the patients will have reduced morbidity and better chance of survival.

**Dr Monika Esser** followed with her second presentation on how to manage PIDs in a less resourced region. She provided an overview about PIDs in African countries and the challenges faced in this huge continent. These included challenges in diagnostics: access, affordability and accuracy as well as challenges in treatment: availability, distribution, trained staff, patient education and home care. She stressed the importance of data and registries to define differences in needs and outcomes for patients, collaboration with regional immunology societies as well as other rare diseases. She went through some available tests that can be used in basic laboratories and finally introduced steps to identify PIDs in Indonesia and the SEA region.

### **Case Studies Session**

The session was opened with a foreword from **Dr Nia Kurniati** followed by a presentation about the Melbourne Royal Children's Hospital experience on PID diagnosis and therapy: case study examples by **Dr Joanne Smart**. Dr Smart went through some PID cases from her hospital, the reasons that led to further investigations and eventually to PID diagnosis. She highlighted the warning signs found in each case but also brought up some more atypical cases of SCID that were more difficult to diagnose. In the presentation, she also touched upon the subject of SCID and other PIDs management and introduced the audience to some useful collaboration projects such as TAPID (Transplantation and PID) that aims to facilitate dialogue between specialists in Australia and New Zealand and can help in reaching the right diagnosis and solutions for PID patients.

**Prof Martin Van Hagen** was the second presenter of the session with a presentation about the immune system and auto-inflammation. He went through some auto-inflammatory and autoimmune syndromes which are caused by dysregulations of the immune system. He introduced both hereditary and acquired autoinflammatory syndrome cases, the path that led to diagnosis and the treatment provided. He concluded that most inflammatory diseases are combined autoimmune-autoinflammatory diseases and usually closely related to PIDs.

The session was closed with a presentation by **Dr Liew Woei-Kang** about managing Indonesian PID cases in Singapore. Since patients in Indonesia struggle to receive accurate diagnosis and treatment which are not available in the country, many have had to travel to Singapore to get the care they need. Dr Woei-Kang went over some cases that had been referred to him from the University Hospital in Jakarta. He discussed the pathway that led to diagnosis, the outcomes of treatment and lessons learnt.

He highlighted the fact that hematopoietic stem cell transplantation is not available in Indonesia and that funding has been found to be difficult for patients needing it. He made the case that there is an urgent need to develop transplantation nationally and that solutions for funding have to be explored.

### **Regional Updates Session**

**Dr Narissara Suratannon** from Bangkok, Thailand started the session with her presentation on management of PIDs in South East Asia. She introduced the audience to SEAPID and the collaboration on the South East Asian regional level. The SEAPID Network aims at educating doctors in the region about PIDs, sharing knowledge and implementing a patient registry in the future. Looking forward, the SEAPID Network hopes to grow with inviting new countries to join them. Dr Suratannon also went through some PID statistics and cases gathered from the region and the projects implemented through this cooperation. Her presentation gave the audience an opportunity to take part in the discussion.

The next presentation was an overview of managing PID cases in Indonesia by **Dr Dina Muktiarti** from Jakarta, Indonesia. She stated that the prevalence is very high in Indonesia compared to other SEA countries and yet the reported cases are less than one per cent of the prevalence. She reflected the situation in Indonesia with the PID Principles of Care and stated that underdiagnosis due to lack of awareness is a huge challenge for PIDs in the country together with lack of laboratory facilities, PID specialists, availability of treatment and access to financial support. In Indonesia, there are only 6 referring hospitals located in two islands in a country with a population of 260 million scattered in 17,000 islands. IVIG treatment is only available and covered by the national health insurance in the Magunkusumo Hospital in Jakarta and stem cell transplantation is not available in the country. Dr Muktiarti concluded that it is critical to continue to raise awareness, build networking, identify facilities for improving diagnosis capability and open discussion with policy makers.

The final presentation of the day was given by **Dr Nia Kurniati** from Jakarta, Indonesia. In her presentation, she went over PID cases that have been diagnosed in Mangunkusumo Hospital, Jakarta. She described five PID cases showing their patient history and gave examples how, after diagnosis and starting the treatment, the health of these patients had improved. She stated that raising awareness of PIDs should be a part of the hospital's clinical practice and that a specialised team is needed to help with managing PIDs in Indonesia.



## **Conclusion**

The Indonesian Patients meeting was successful in motivating patients and parents to get involved in the patient organisation IPIPS that until now had been run by doctors. It was agreed that the doctors will still have a role as advisers of the organisation and will assist in the transition phase from the doctors to the patient committee. The next steps for the organisation were identified to help the new patient committee to move forward.

The National Clinical Care meeting was the first of its kind in Indonesia and gathered over 170 health care professionals from different regions of Indonesia as well as from many different specialities such as paediatricians, allergists, immunologists, nutritionists, infectiologists, parasitologists, dermatologists, pathologists, stem cell specialists and general practitioners together with medical students and nurses. The meeting was CME accredited and well received by the audience. Having brought together so many physicians was a great achievement and IPOPI is convinced that the meeting has succeeded in raising awareness and interest in PIDs among the medical community in the country.

During the meeting IPOPI announced, with the collaboration of Erasmus University Hospital in Rotterdam, that to further improve the diagnosis levels in Indonesia a health care professional or a laboratory technician from Magunkusumo Hospital will have a chance to travel and to learn from colleagues in Erasmus University Hospital in the Netherlands. During the visit this person will learn about PID diagnostics and later share this knowledge with other centres in Indonesia. Furthermore, discussions during the meetings with representatives from neighbouring countries Singapore and the Philippines led to identifying challenges and progresses taking place in these countries and facilitated future collaboration projects.

IPOPI wishes to thank for the support of this event

