

ONLINE

REPORT

IPOPI INDONESIAN PID CONFERENCE **JUNE 2021**



an IPOPI event

INTRODUCTION

IPOPI's engagement and support in the Asian region continues! Recently, IPOPI organised a virtual Indonesian PID Conference, held on June 19-20 and 26, 2021. The meeting was divided in two parts hosting both a **Clinical Care Meeting** and a **PID Patients' Meeting**, both well attended and appreciated by the audiences. The participation in the meeting exceeded expectations, demonstrating the demand and continuous need for educational sessions on primary immunodeficiencies in Indonesia. This meeting was IPOPI's third Indonesian meeting, taking place four years after the previous ones in 2017 and 2015. Since the last meeting the PID community has continued to grow and IPOPI was delighted to connect with the patients and doctors once again in this country.

The conference was co-organised with Cipto Mangunkusumo Hospital, Universitas Indonesia, and the Indonesian Primary Immunodeficiency Patient Society.



CLINICAL CARE MEETING

The clinical care meeting for Indonesian doctors, co-organised with Cipto Mangunkusumo Hospital, Universitas Indonesia, took place over two days and four sessions. Both national and international speakers contributed with their expertise, covering talks on diagnosis advances and recognising PIDs in adults, as well as presentations on HSCT, gene therapy and immunoglobulin replacement therapy. The audience also learnt about COVID-19 in patients with PID and enjoyed an interesting discussion on complex cases with a panel of experts.

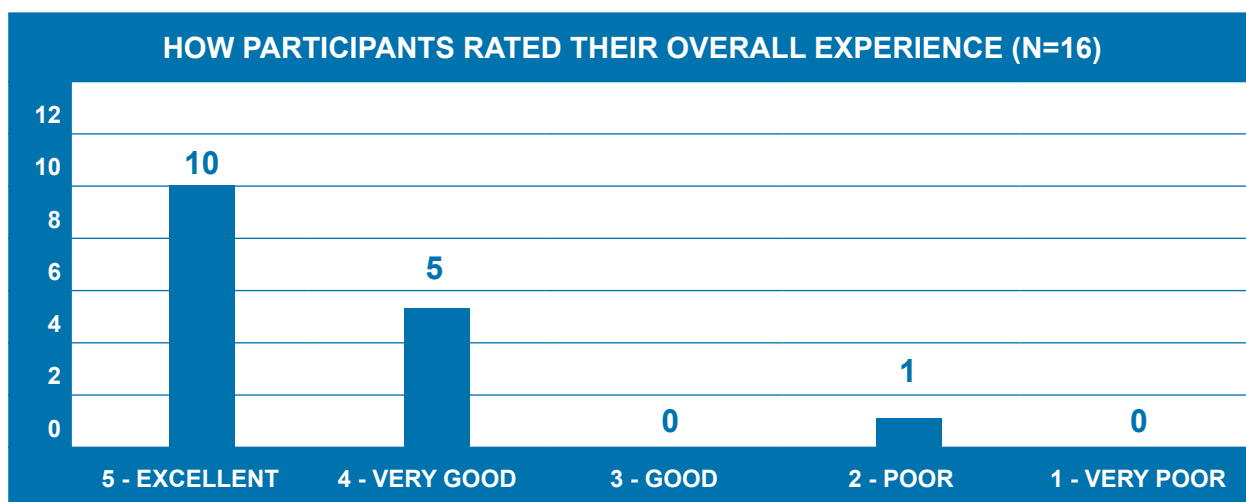
MEETING OBJECTIVES

- INCREASE AWARENESS OF PIDS AMONGST PHYSICIANS IN INDONESIA
- IMPROVE KNOWLEDGE ON DIAGNOSIS AND ACCESS TO GENETIC DIAGNOSIS
- PRESENT TREATMENT OPTIONS FOR PID, INCLUDING IGRT, HSCT AND FUTURE OPTIONS SUCH AS GENE THERAPY
- DISCUSS OPTIONS FOR PID MANAGEMENT IN THE REGION AND NATIONALLY
- IDENTIFY TREATMENT OPTIONS FOR COMPLEX CASES

PARTICIPATION OVERVIEW

TOTAL PARTICIPANTS: 218

INDONESIAN CITIES REPRESENTED: Bandar Lampung, Bandung, Banjarmasin, Bekasi, Bogor, Cirebon, Denpasar, Gorontalo, Jakarta, Karawang, Kediri, Kupang, Makassar, Manado, Mataram, Medan, Padang, Palembang, Pekalongan, Pekanbaru, Samarinda, Semarang, Sleman, South Tangerang, Surabaya, Surakarta, Tangerang, Tasikmalaya, Timika.

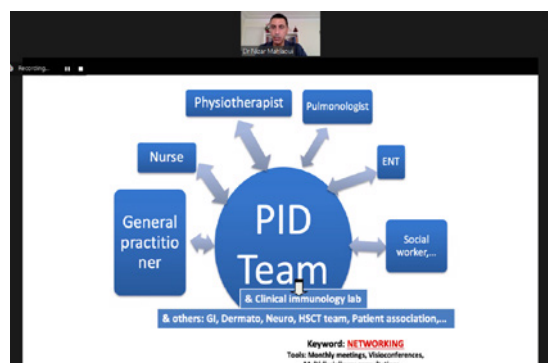
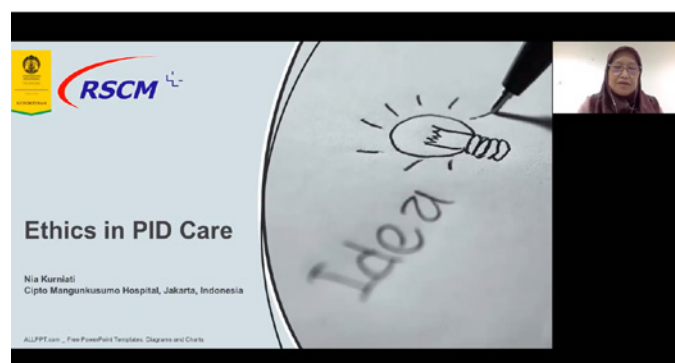


SESSION 1: OPENING KEYNOTE

MODERATED BY MS MARTINE PERGENT & DR NIA KURNIATI

- Introduction and welcome – Ms Martine Pergent, IPOPI President
- Welcome - Prof Ari Fahrial Syam, Dean of Faculty of Medicine, University of Indonesia
- Sponsor's welcome - Dr Christine Jendrsczok, Kedrion
- Ethics in Genetic Disease - Dr Nia Kurniati, Cipto Mangunkusumo Hospital, Faculty of Medicine, Universitas Indonesia
- The A to Z of PIDs - Dr Nizar Mahlaoui, Chairman IPOPI MAP, Necker Enfants-Malades Hospital, France

Ms Martine Pergent, IPOPI President, opened the meeting and warmly welcomed participants. Following this, Prof Ari Fahrial Syam, Dean of Faculty of Medicine, University of Indonesia, gave welcoming words where he highlighted the importance of early diagnosis and appropriate treatment for patients with PID. The participants were also warmly greeted by Dr Christine Jendrsczok, representing Kedrion. After the welcome the audience were introduced to Ethics in Genetic Disease by Dr Nia Kurniati, Cipto Mangunkusumo Hospital, who mentioned how high ethical standards are essential in healthcare to ensure patients are treated equally and fairly, no matter how rare their disease. This was followed by the keynote speech covering the A to Z of PIDs by Dr Nizar Mahlaoui, Necker Enfants-Malades Hospital. The main points highlighted in this interesting lecture was the importance of having a multidisciplinary team treating PID patients, that personalised immunoglobulin treatment is paramount, and that improving the diagnostic yield is needed and possible in Indonesia. In this regard Dr Mahlaoui also highlighted IPOPIs work with the WHO List of Essential In Vitro Diagnostics, emphasising that it can and should be used to ensure that public health authorities make these tests widely available.



SESSION 2: DIAGNOSIS AND MANAGEMENT OF PIDS

MODERATED BY MS MARTINE PERGENT & DR NIA KURNIATI

- How to recognize PID in adults - Prof Martin van Hagen, Vice-Chairman IPOPI MAP, Rotterdam Erasmus University Hospital, Netherlands
- Diagnosis advances in PIDs – democratising access to genetic diagnosis - Dr Narissara Suratannon, Chulalongkorn University, Thailand
- Future treatment in PIDs: HSCT & Gene Therapy - Dr Pamela Lee, The University of Hong Kong
- The role of IG replacement therapy in treating PIDs - Prof Surjit Singh, PGIMER, India

The second session continued to stress the need for improved diagnosis rates and the tools for success. It started with a lecture from Prof Martin van Hagen, Rotterdam Erasmus University Hospital, discussing how to recognise PID in adults. He emphasized that PIDs are not only paediatric diseases and that there are those more commonly diagnosed in adulthood. From Dr Narissara Suratannon, Chulalongkorn University, participants learnt about diagnosis advances in PID and how to democratise access to genetic diagnosis. She left the audience with the very important message that timely diagnosis is the most essential element in improving outcome and reducing mortality in PID. The second half of the session focused on management of those that are diagnosed, with Dr Pamela Lee, The University of Hong Kong, presenting on future treatments in PIDs, and Prof Surjit Singh, PGIMER, sharing insights on the role of IG replacement therapy. The full session provided a comprehensive overview of both diagnosis and treatment, with many interesting questions from the audience.



SESSION 3: COVID-19

MODERATED BY MS MARTINE PERGENT

- Welcome to the second day - Ms Martine Pergent, IPOPI President
- COVID-19, PIDs and autoinflammation: where do we stand? - Prof Stuart Tangye, Garvan Institute of Medical Research, Australia

Ms Martine Pergent, welcomed participants back to the second day and introduced the session covering COVID-19. Prof Stuart Tangye, from Garvan Institute of Medical Research, was the invited speaker and provided the audience with a comprehensive overview of COVID-19 and PIDs. Prof Tangye shared that even though more research is needed, recent studies have shown that many patients with PID have gone through a mild course of the COVID-19 disease, despite initial beliefs that they would suffer a more severe course. This interesting lecture sparked many questions from the audience, leading to good discussions on a very pressing topic.



Garvan Institute
of Medical Research



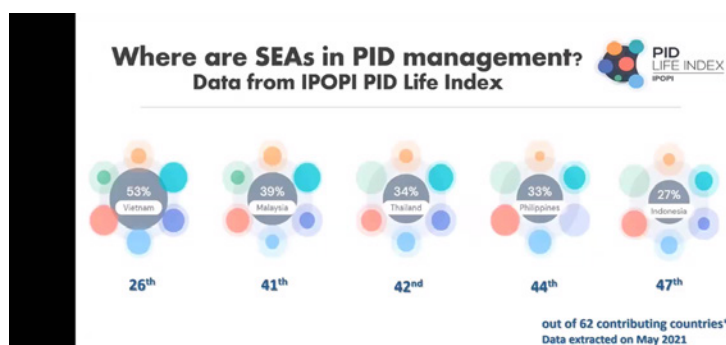
COVID19, PIDs and Autoinflammation: Where do we stand?

Prof Stuart Tangye
IPOPI Indonesian Clinical Care Meeting
19th-20th June, 2021



**PID Management
in Indonesia**

DINA MUKTIARTI
DEPARTMENT OF CHILD HEALTH
FACULTY OF MEDICINE UNIVERSITAS INDONESIA –
CIPTO MANGUNKUSUMO HOSPITAL
JAKARTA, INDONESIA



SESSION 4: PIDS IN SOUTH EAST ASIA

MODERATED BY MR JOHAN PRÉVOT & DR EVY YUNIHASTUTI

- PID management in South East Asia – Update from SEAPID - Dr Adli Ali, Universiti Kebangsaan Malaysia Medical Center, Malaysia
- PID management in Indonesia - Dr Dina Muktiarti, Cipto Mangunkusumo Hospital, Faculty of Medicine, Indonesia
- Paediatric case study: PID in Indonesia - Dr Edy Noveri, Cipto Mangunkusumo Hospital, Faculty of Medicine, Universitas Indonesia
- Adult case study: PID in Indonesia, Dr Alvina Widhani, Cipto Mangunkusumo Hospital, Faculty of Medicine, Universitas Indonesia
- Panel discussion, Dr Nizar Mahalaoui, Prof Martin van Hagen, Dr Adli Ali, Dr Evy Yuniastuti, Dr Dina Muktiarti

The final session of the Clinical Care Meeting offered an interactive format and focused on PIDs in the South East Asian region. Dr Adli Ali, Universiti Kebangsaan Malaysia Medical Center, gave the audience a status update from the region, based on data from IPOPI's interactive tool the PID Life Index. He mentioned that most of the countries in the region had seen great progress in the last five years in terms of diagnosis and care, and that continuing in this positive direction is possible and necessary. This was followed by a deep dive into Indonesian PID management, a topic presented by Dr Dina Muktiarti, Cipto Mangunkusumo Hospital. She mentioned, just as was highlighted during the first day, that diagnosis rates in Indonesia desperately need to improve. The reported cases represent less than 5% of the estimated prevalence, leaving much room for improvement on this area. The meeting ended with two interesting complex case discussions, revolving around paediatric and adult cases presented by Dr Edy Noveri and Dr Alvina Widhani from Cipto Mangunkusumo Hospital. The Panel of Experts, consisting of Dr Nizar Mahlaoui, Prof Martin van Hagen, Dr Adli Ali, Dr Dina Muktiarti and Dr Evy Yuniastuti, used their experience to guide the two presenters and advise them on the best way forward for these patients.



Points to discuss.....

- Despite current treatment, the pulmonary symptoms have not improved and the weight gain is inappropriate. Since this patient cannot undergo HSCT, What can we do?
- What monitoring tools should be done for this patient?

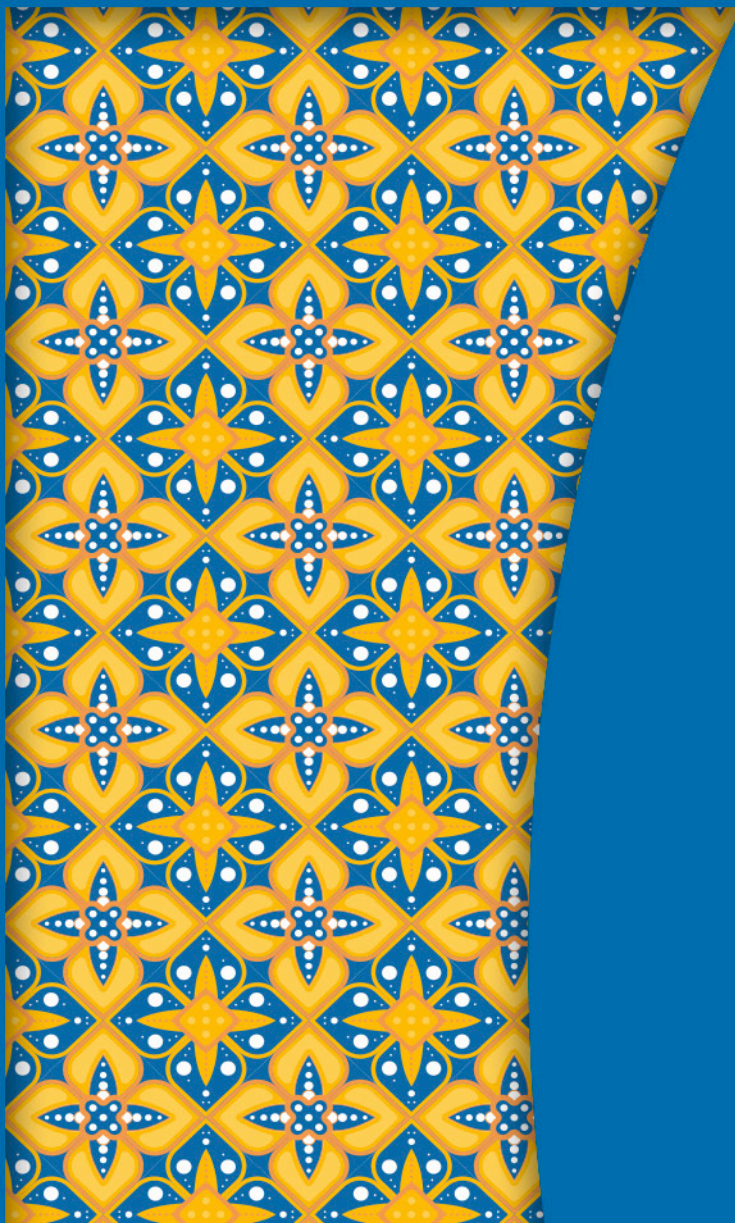
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PID PATIENTS MEETING

The second half of the conference hosted a meeting for patients with PID and their close contacts in Indonesia. It was co-organised with the Indonesian Primary Immunodeficiency Patient Society (IPIPS), IPOPI's national member organisation, who is doing a great job in supporting the patients in this country. The meeting offered two sessions, the first one covering educational presentations on PID and the second one hosting an interactive workshop on Challenges in daily life. To ease access to the meeting IPIPs had organised for the possibility to follow the meeting through their Facebook page. The two sessions were well attended and IPOPI was very pleased with the meeting.

MEETING OBJECTIVES

- INCREASE KNOWLEDGE ON PIDS AND AVAILABLE TREATMENT OPTIONS
- IMPROVE AWARENESS ON THE STATUS OF PIDS IN INDONESIA, INCLUDING PROGRESS MADE AND CHALLENGES AHEAD
- IDENTIFY AND UNDERSTAND THE MAIN CHALLENGES TO DAILY LIFE FOR PID PATIENTS AND RELATIVES IN INDONESIA
- UNDERSTAND THE PATIENTS NEED FROM THEIR NATIONAL PATIENT ORGANISATION
- IDENTIFY LONG TERM STRATEGIES TO TACKLE THESE CHALLENGES
- UNDERSTAND OPTIONS TO MEET THE CHALLENGES WITH PATIENT ADVOCACY AND AWARENESS



PARTICIPATION OVERVIEW

TOTAL PARTICIPANTS: 46



SESSION 1: OPENING KEYNOTE

MODERATED BY *MS MARTINE PERGENT & MR DIMAS SUGIHARTO*

- Welcome and opening remarks, Ms Martine Pergent, IPOPI President
- Welcome, Mr Dimas Sugiharto, Indonesian Primary Immunodeficiency Patient Society (IPIPS)
- Welcome from the sponsor, Dr Christine Jendrsczok, Kedrion
- What are PIDs and how do we treat them?, Dr Nizar Mahlaoui, Chairman IPOPI MAP, Necker Enfants-Malades Hospital, France
- PIDs in Indonesia, Dr Dina Muktiarti, Cipto Mangunkusumo Hospital, Indonesia



Ms Martine Pergent, opened the meeting and welcomed participants to the gathering. She mentioned that patients with PID sometimes feel alone, but that they exist in Indonesia, in the region and all over the world and that they should join forces to improve their situation as “we are not so rare when we come together.” This was followed by a welcome from Mr Dimas Sugiharto, President of IPOPI’s Indonesian member IPIPS, who set the scene for the day. The opening keynote was delivered by Dr Nizar Mahlaoui, Necker Enfants-Malades Hospital, who in his presentation responded to the question “What are PIDs and how do we treat them?”. Dr Mahlaoui stressed the importance of patient organisations, with both national and international cooperation to ensure success. The second presentation focused specifically on PIDs in Indonesia, presented by Dr Dina Muktiarti, Cipto Mangunkusumo Hospital. In her presentation Dr Muktiarti emphasized the role of patient groups in Indonesia and the journey IPIPS have made since their creation in 2015. IPOPI looks forward to continuing following the development of this group and support their activities as they are vital to improve the national PID environment.



SESSION 2– WORKSHOP: CHALLENGES IN DAILY LIFE

MODERATED BY MR BRUCE LIM & MR DIMAS ADHI SUGIHARTO

- Introduction - Dimas Adhi Sugiharto, Bruce Lim IPOPI / MyPOPI Malaysia
- Group discussion - Dimas Adhi Sugiharto, Bruce Lim, Hendy Wijaya Budijanto IPIPS, Lenny Susanti IPIPS
- Highlights from group discussions, Hendy Wijaya Budijanto IPIPS, Lenny Susanti IPIPS
- Meeting challenges with patient advocacy and awareness, Bruce Lim, IPOPI / MyPOPI
- Closing statements & next steps, Bruce Lim, Martine Pergent

The second half of the meeting was devoted to an interactive workshop focusing on Challenges in daily life for patients with PID, moderated by Bruce Lim, IPOPI / MYPOPI, and Dimas Sugiharto, Hendy Wijaya Budijanto and Lenny Susanti from IPIPS. During this workshop, two main challenges were identified as in need of being urgently addressed.

LACK OF MEDICAL KNOWLEDGE AND AWARENESS

The participants voiced concern about the lack of medical awareness and knowledge in the country, an issue present both in Jakarta and other parts of Indonesia. When discussing a potential solution, the participants agreed that they, under the IPIPS umbrella, should work to increase the knowledge and awareness of PIDs, not only in the big hospitals, but also in local clinics. This should be done by continuous organisation of doctors and patients' meetings, increasing awareness to support early diagnosis. The participants also mentioned the need to address health authorities and inform them about the needs of patients with PID, as they are worthy of a better quality of life.

INCREASE COVERAGE FOR PID TREATMENTS

The second main challenge highlighted was the high cost for PID treatment in Indonesia, causing great suffering for patients. The currently available national insurance does not support the cost of different PID treatments, and patients with PID thus lack financial aid. Following this the participants agreed on the need for advocating nationally to include these treatments in the national insurance scheme, to ensure patients have access to their life saving treatments. Additionally, they mentioned the need to not only make the treatments affordable but also to ensure that a wider range of treatments become available in Indonesia.

CONCLUSION

IPOPI's Indonesian PID Patient Meeting was a very successful event with high attendance. It reached its objectives to improve awareness of PIDs, diagnosis and management in Indonesia and to identify challenges and solutions for the patients in this country. It was particularly rewarding to be able to return (albeit virtually) to Indonesia and see the great progress that has been made since the last meeting, and IPOPI looks forward to continuing to support Indonesia and other countries in the Asian region in the years to come.

KEDRION
B I O P H A R M A

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



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