



IPOPI 4TH REGIONAL ASIAN PID MEETING

19-20 NOVEMBER 2022
KUALA LUMPUR, MALAYSIA

an **IPOPI** event

IN COLLABORATION WITH



MEETING REPORT

SUPPORTING ORGANISATIONS



SUPPORTED BY



INTRODUCTION

IPOPI was delighted to be back in person in Asia and welcome **50 participants** to the 4th **Regional Asian PID Meeting**, held **November 19-20, 2022**, in Kuala Lumpur, Malaysia.

At this two-day meeting, patient representatives and healthcare professionals from 11 countries from the Asia-Pacific region (Cambodia, China, India, Indonesia, Japan, Malaysia, Nepal, Philippines, South Korea, Thailand, and Vietnam) gathered to discuss with and learn from both **international and regional primary immunodeficiencies (PID) experts** on the **latest developments in Asia**.

An overview was provided of the current and future possibilities and challenges of **diagnostic methods, genetic testing, immunoglobulin replacement therapy, targeted therapies**, and **management of infectious diseases related to PIDs**. Areas for improvement in the Asian region were identified and entail comprehensive PID management as defined by the **PID life index**, the need to increase plasma collection and processing to ensure future regional-sufficiency, and improved availability and use of national and regional registries.

The doctors' meeting was initially scheduled to take place on November 19, and the patients' meeting on November 20. Due to the unexpected last minute national elections in Malaysia on November 19, after careful consideration, IPOPI decided to modify the allocation of sessions on the programme, to ensure we could organise this meeting in the most effective way possible for our participants, faculty, supporting organisations and sponsors. This new format allowed for more doctors to also attend our educational patients' meeting and interact with the patient leaders from the region. IPOPI could not be more pleased with the outcomes of the meeting.

PARTICIPATION OVERVIEW

Total participants: 50

Countries represented: 11 (Cambodia, China, India, Indonesia, Japan, Malaysia, Nepal, Philippines, South Korea, Thailand, and Vietnam).

PROGRAMME EVALUATION (n=13)





I really enjoyed the conference in Malaysia. It motivated me to care and find PIDs in my country.

Really honoured to be part of this meeting. I really enjoyed it a lot. More knowledge and new learnings. Big thank you



PRESENTATIONS AVAILABLE

Authorised presentations provided at this meeting are available on the [meeting webpage](#) for educational purposes.

SESSION 1: State of the art of PID diagnosis and treatment

Moderated by **Ms. Martine Pergent**, IPOPI President

- Introduction and welcome, **Ms. Martine Pergent**, IPOPI President
- Welcome to Malaysia, **Mr. Bruce Lim**, MyPOPI President (Malaysia), IPOPI Vice-Chair
- Keynote lecture: PID diagnosis and treatment in Asia, **Prof. Narissara Suratannon** (Thailand)
- Genetic testing – what does it mean for patients?, **Dr. Adiratna Mat Ripen** (Malaysia)
- IVIg & SCIg – Lifestyle considerations, **Prof. Martin van Hagen** (The Netherlands)
- Looking ahead: advanced therapies in Asia, **Dr. Virgil Dalm** (The Netherlands)
- Transition care, **Dr. Virgil Dalm** (The Netherlands)
- Question & Answers



Ms. Martine Pergent



Prof. Narissara Suratannon



Dr. Adiratna Mat Ripen



Prof. Martin van Hagen



Dr. Virgil Dalm

The first day started with the PID patients' meeting for IPOPI's national member organisations in the region. The meeting was opened with an introduction and warm welcoming words from IPOPI President **Ms. Martine Pergent**. She expressed gratefulness to be hosting this meeting for the fourth time, and gratitude to all organisations who have supported the preparation of this meeting and contributed to its success: **Care4Rare**, **MyPOPI**, **SEAPID** and **APSID**.

Following a brief presentation of IPOPI and MyPOPI, the participants enjoyed a fruitful session on the status and developments of the PID diagnosis and treatment in Asia. **Prof. Narissara Suratannon** from Chulalongkorn University, Thailand, presented her keynote scientific presentation on PID diagnosis and treatment in Asia, outlining that 87% of PID cases are diagnosed by taking into account the 10 classical warning signs of PIDs, the family history, live vaccine infections, opportunistic infections, and syndromic characteristics. **Dr. Adiratna Mat Ripen** explained the process of genetic testing, and highlighted its impact for PID patients in Asia. **Prof. Martin van Hagen** followed with a thorough explanation of the impact of IVIg and SCIg therapies on patients' lifestyle. Looking at the future, **Dr. Virgil Dalm** provided a clear perspective on advanced therapies to look forward to in Asia and followed with an insightful presentation of the challenges of transition care from pediatric to adult management in Asia. Dr. Dalm drew attention to the need to establish a well-organised transition policy with a dedicated team able to follow up with the patient from early adolescence rather than close to the age of 18 years. The four speakers contributed to five excellent presentations and provided a comprehensive snapshot of the region.



Dr. Adiratna Mat Ripen (Malaysia) presenting

SESSION 2: ACCESS TO TREATMENT IN ASIA

Moderated by **Mr. Bruce Lim**, IPOPI Vice-Chair

- Access to treatment, an overview based on the PID Life Index, **Dr. Adli Ali** (Malaysia)
- Panel discussion on access to treatment in Asia, **Mr. Bruce Lim** (MYPOPI, Malaysia), **Mr. Adhi Sugiharto** (IPIPS, Indonesia), **Ms. Jessie Qu** (PID Care, China), **Dr. Adli Ali** (SEAPID, Malaysia), **Prof. Narissara Suratannon** (SEAPID, Thailand) and **Prof. Martin van Hagen** (Erasmus MC, the Netherlands)



Mr. Bruce Lim



Dr. Adli Ali



Mr. Adhi Sugiharto



Ms. Jessie Qu



Prof. Narissara Suratannon



Prof. Martin van Hagen

The second session explored access to treatment in Asia, moderated by **IPOPI Vice-Chair Mr. Bruce Lim**. **Dr. Adli Ali** started by providing an important overview of access to treatment in Asia based on the IPOPI PID Life Index. He highlighted that PID management in SEA has progressed significantly over the last 6 years, however, national patient organisations together with SEAPID doctors need to continue to strategy to ensure broad access to treatment for PID patients. Following, presentations from three patient representatives were welcomed. **Mr. Bruce Lim** (MYPOPI, Malaysia), **Mr. Adhi Sugiharto** (IPIPS, Indonesia), **Ms. Jessie Qu** (PID Care China) explained their experience with access to treatment in their respective countries. Key challenges were identified: insufficient access and reimbursement of IVIG nationwide; supporting facilities to PID patients; no access to SCIG; lack of PID experts. These challenges were further discussed with a panel of experts: **Dr. Adli Ali**, **Prof. Narissara Suratannon**, and **Prof. Martin van Hagen**.



Mr. Bruce Lim (IPOPI) presenting, with Prof. Narissara Suratannon, Dr. Adli Ali, Ms. Jessie Qu, Mr. Adhi Sugiharto and Prof. van Hagen (left to right)

SESSION 3: SUCCESSES AND CHALLENGES FOR PID PATIENT ORGANISATIONS

Moderated by **Mr. Bruce Lim**, IPOPI Vice-Chair and **Ms. Miriam Ferreira**, IPOPI NMO Programmes Officer

- NMO presentations: Recent successes and challenges, **Ms. Lenny Susanti** (IPIPS, Indonesia), **Mr. Rakesh Chawla** (IPSPI, India), and **Mr. Harris Baraguir** (PhilPOPI, Philippines).
- Workshop on developing concrete action plans to overcome the national patient organisations' main challenges.



Mr. Bruce Lim



Ms. Miriam Ferreira



Ms. Lenny Susanti



Mr. Rakesh Chawla



Mr. Harris Baraguir

On the last session of the patients' meeting, we invited **Ms. Lenny Susanti** (IPIPS, Indonesia), **Mr. Rakesh Chawla** (IPSPI, India), and **Mr. Harris Baraguir** (PhilPOPI, Philippines), three patient representatives who featured their organisations' main recent successes and challenges. The participants were divided into small working groups, based on three main challenges identified by our Asian NMOs through a survey: membership related; interaction with physicians; and fundraising. This was a very engaging workshop that allowed the patient leaders to brainstorm ideas and identify concrete action plans to take home and overcome their challenges with their members and IPOPI.

STRATEGIC ACTION PLANS

MEMBERSHIP

- Provide a brochure on what PIDs are, to promote patients' understanding of their disease.
- Create a WhatsApp group or similar with all patients.
- Organise a Family Meeting Day, so patients and families may share their main concerns.
- Share personal experiences on social media to engage more volunteers.
- Create a patient organisation info brochure, highlighting the benefits of taking part in activities (e.g., to raise awareness and develop an advocacy plan for better treatment access), as well as how to become a member.

INTERACTION WITH PHYSICIANS

- Have regular meetings between patient representatives and medical advisors (physicians and nurses), to discuss patients' main challenges.
- Have a WhatsApp group or similar with patient representatives and a group of medical advisors, for urgent questions.
- Create a template for patients on how to consult with their physician, explaining for example how to prepare notes and questions, to optimize their time with the physician.
- Provide a brochure/booklet for physicians with practical tools explaining the diagnosis of PIDs.

FUNDRAISING

- Create a stakeholders' map, identifying private and public entities that may have a shared interest in PIDs.
- Prepare a structured plan for any project (objectives, timeline, and budget) and send a final report to the sponsor.
- Contact other patient groups and join forces, for example, other rare diseases groups.
- Create a godparent programme, on which private donors may connect and contribute to a patient's treatment.
- Be aware of the fundraising rules applying in your country/region, such as governance or tax laws.



Working group

DAY 1, AFTERNOON PID DOCTORS MEETING

19 NOVEMBER

Welcome Session

Moderated by **Ms. Martine Pergent**

- Welcoming words, **Dr. Kent Woo**, President of MSAI (Malaysian Society for Allergy and Immunology),
- Welcoming remarks and introduction to IPOPI, **Ms. Martine Pergent**, IPOPI President



Ms. Martine Pergent



Dr. Kent Woo

The doctors' meeting opened with an introductory session. The welcoming remarks were given by **Dr. Kent Woo**, thanking IPOPI for their work in the region on raising awareness and fostering collaboration through such meetings. **Ms. Martine Pergent** followed by thanking for the great collaboration with MSAI and other stakeholders in the region and by providing a short introduction to IPOPI.

SESSION 1: CARE-FOR-RARE GLOBAL ALLIANCE EDUCATIONAL SEMINAR

Moderated by **Prof. Amir Hamzah** and **Prof. Christoph Klein**

- The many faces of IEI (Inborn Errors of Immunity) - from infection to immune dysregulation, **Prof. Christoph Klein**, Care-for-Rare
- Global Alliances in practice: How regional doctors and scientists can benefit - the example of SEAPID and APSID, **Dr. Adli Ali** (Malaysia), **Dr. Dina Muktiarti** (Indonesia), **Prof. Surjit Singh** (India), **Prof. Christoph Klein** (Germany)
- Question & Answers



Prof. Amir Hamzah



Prof. Christoph Klein



Dr. Adli Ali



Dr. Dina Muktiarti



Prof. Surjit Singh

The first session focused on the importance of global cooperation. This seminar organised by Care-4-Rare, was introduced by **Prof. Christoph Klein** who explored the many facets of IEI, providing an overview from infection to immune dysregulation. The second part of this session provided an inspiring panel discussion between doctors from the SEAPID and APSID regions **Dr. Adli Ali**, **Dr. Dina Muktiarti**, **Prof. Surjit Singh**, and **Prof. Christoph Klein** for improvement in the Asian region were identified, such as personalised PID management, the need to increase plasma collection and processing to ensure future regional self-sufficiency and improved availability, and finally the use of national and regional registries.



Prof. Christoph Klein (Germany) presenting. Dr. Adli Ali, Dr. Dina Muktiarti, Prof. Amir Hamzah and Prof. Surjit Singh (from left to right)

SESSION 2: THE IMPORTANCE OF DATA COLLECTION/REGISTRIES

Moderated by Dr. Virgil Dalm and Dr. Adli Ali

- Introduction: The value of registries (national and regional, ESID registry example), **Dr. Virgil Dalm** (The Netherlands)
- APSID/SEAPID regional registry update: Where are we and where would we like to be?, Professor **Prof. Surjit Singh** (India)
- Panel discussion: **Prof. Noh Lokman** (Malaysia), **Prof. Surjit Singh** (India), **Dr. Areum Shin** (South Korea)
- Day 1 Closing Keynote Lecture: Advanced therapies: The future of BMT in Asia, **Prof. Hirokazu Kanegane** (Japan)



Dr. Virgil Dalm



Dr. Adli Ali



Prof. Surjit Singh



Prof. Noh Lokman



Dr. Areum Shin



Prof. Hirokazu Kanegane

Dr. Virgil Dalm opened the session with a well-rounded presentation that highlighted the importance of registries to understand PID diseases, through diagnostic rate, natural history, comorbidities, and the main description of therapies. **Prof. Surjit Singh** contributed with the APSID/SEAPID perspective, explaining the advances of the APSID/SEAPID registry and through it an overview of PIDs in these countries. Following these lectures, we welcomed a fruitful panel discussion with **Prof. Noh Lokman**, **Prof. Surjit Singh**, and **Dr. Areum Shin**, who highlighted the need to strengthen regional collaboration in the development of current registries and the development of new ones.

The closing keynote lecture was given by **Prof. Hirokazu Kanegane** who provided an updated overview of bone marrow transplantation for PIDs in Asia and shared exciting unpublished findings on a clinical trial for HSCT in 14 XLA patients, that show that HSCT may be an effective and safe treatment option for XLA patients with severe complications and allow for the discontinuation of Ig replacement therapy. This was followed by closing words of our first day of the meeting from **Ms. Martine Pergent**, who thanked the participants on behalf of IPOPI and invited them to the next day's meeting.



Prof. Surjit Singh (India) presenting

DAY 2, MORNING PID PATIENTS' MEETING

20 NOVEMBER

SESSION 3: PID diagnostics in Asia

Moderated by **Ms. Martine Pergent**

- Opening remarks, **Ms. Martine Pergent**
- Keynote Opening Lecture: State of the art of PID diagnosis in Asia, **Prof. Narissara Suratannon** (Thailand)
- Cytokine auto-antibodies: from regulation to disease, **Dr. Wim Dik** (the Netherlands)
- IPOPI PIDetect programme: Experiences from Bangladesh and India, **Dr. Laila Kamrul** (Bangladesh)
- Newborn screening for rare diseases – real-life experiences and future opportunities, **Ms. Martine Pergent** (French experience), and **Dr. Adli Ali** (Malaysian experience & Screen4Rare)



Ms. Martine Pergent



Prof. Narissara Suratannon



Dr. Wim Dik



Dr. Laila Kamrul



Dr. Adli Ali

The participants were greeted back on the second day by **Ms. Martine Pergent**. **Prof. Narissara Suratannon** kick-started the day with an in-depth overview of the current panorama of PID diagnosis in Asia, focusing on the development of the original 10 warning signs of PID patients, the screening tools for low IgG, and the approach to PID- tests. **Dr. Wim Dik** followed, giving a presentation on a newly discovered disease (anti-IFN γ autoantibodies associated immunodeficiency syndrome) which is predominantly seen in the Asian population.

The next presentation was provided by **Dr. Laila Kamrul**, IPOPI's awardee of the IPOPI PIDetect programme scholarship 2021 who explained her experience training at the Post Graduate Institute of Medical Education & Research, Chandigarh, India, supervised by Prof. Surjit Singh, focusing on the new techniques and skills learned to diagnose PID patients. Ms. Pergent emphasized how important diagnosis is, as the starting point of making PID patients visible.

In the last part of this session, the participants had the opportunity to hear from two perspectives on newborn screening in France and Malaysia. **Ms. Martine Pergent** explained the SCID screening process in France, from its advocacy to the implementation discussions and conditions, as well as the lessons learned. **Dr. Adli Ali** followed with a presentation of the phases of implementation of SCID newborn screening in Malaysia, and a presentation of the treatment options provided. These were important presentations, that highlighted on one hand, the feasibility and effectiveness of SCID newborn screening, and on the other hand, the need to adapt its process to the national and regional requirements.



Prof. Narissara Suratannon (Thailand) presenting

SESSION 4: Optimal PID management

Moderated by **Dr. Intan Juliana** and **Mr. Johan Prevot**, IPOPI Executive Director

- The role of IG replacement therapy in treating PIDs: SCIg in focus, **Prof. Martin van Hagen** (the Netherlands)
- Management of infectious complications, **Dr. Intan Hakimah** (Malaysia)
- Plasma collection and products in Asia – where are we and where are we going, **Dr. René Buechel**, Takeda
- Question and Answers
- Highlight: A new gene candidate in PID - and what now? **Dr. Verna Zhou** (the Netherlands)



Dr. Intan Juliana



Mr. Johan Prevot



Prof. Martin van Hagen



Dr. Intan Hakimah



Dr. René Buechel



Dr. Verna Zhou

The fourth session was introduced by **Prof. Martin van Hagen**, who in his presentation provided a comprehensive overview of the Ig replacement therapy in PIDs, touching upon the importance of personalized IgG therapy options, and advanced therapies such as gene therapy and gene editing. **Dr. Intan Hakimah** explored the management of infectious complications, explaining the main patterns and factors of infections associated with PIDs, and the best practices to manage them. After understanding the clinical needs for the optimal management of PIDs, **Dr. René Buechel** highlighted the necessity for the Asian region to become self-sufficient when it comes to plasma collection and processing, with 80% of the plasma fractionation capacity being situated in the US and Europe. He also emphasised that future efforts should focus on increasing plasma apheresis, and on overcoming barriers in legislation and infrastructure to meet patients' need for plasma and plasma-derived therapies. These presentations inspired a lively Question & Answer session where the speakers continued to share their appreciated knowledge. To wrap up this meeting IPOPI invited Dr. Verna Zhou who shared the results of her latest publication on the subject of "Did variants in inborn errors of immunity genes contribute to the extinction of Neanderthals?".



*Dr. Verna Zhou (China/The Netherlands) answering
Dr. René Buechel and Mr. Johan Prevot (from left to right)*

CONCLUSION

This was a successful meeting, focusing on the overall journey of a PID patient from diagnosis to treatment, highlighting the importance of multistakeholder partnerships to further improve the life of PID patients in the Asian region. The meeting was very well received by the participants. It was a pleasure to welcome back our NMOs representatives from the region, colleagues, and friends from countries such as Cambodia and Nepal, and we look forward to continuing working closely with all in the years to come.



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



