



IPOPI 5TH REGIONAL ASIAN PID MEETING

24-25 MARCH 2024
TOKYO, JAPAN

an IPOPI event

MEETING REPORT

COLLABORATION



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Introduction

During the Sakura season, IPOPI hosted the **IPOPI 5 th Regional Asian PID Patients and Doctors Meeting on March 24-25, 2024**, held in parallel with the 5 th Asia-Pacific Society for Immunodeficiency (APSID) Congress and the 7 th Annual Scientific Meeting of the Japanese Society for Immunodeficiency and Autoinflammatory Diseases (**JSIAD**).

Over two days, we engaged in **insightful discussions** on key aspects of **effective primary immunodeficiency (PID) patient care, diagnosis challenges**, and the **rapidly evolving landscape of immunodeficiencies**. We explored the **latest regional initiatives** from both patient representatives and physicians, sparking interesting and fruitful discussions.

The meeting provided a **successful platform for valuable knowledge exchange and fortified connections** between healthcare professionals, IPOPI members, and other relevant stakeholders, laying the groundwork for fruitful collaborations in the years ahead.

The meeting was held in English and Japanese, with the use of an AI translation service, to allow the participation of all our delegates from the region.

Meeting objectives

- Improve knowledge on diagnosis and treatment for PIDs
- Practice how to raise awareness and advocate on a subject
- Identify and address the challenges of living with a PID in Asia
- Learn from NMO's and other healthcare professionals' best practices in the region
- Strengthen regional cooperation

Participation overview

Total of participants: 50

Countries represented: Bangladesh, Cambodia, China, India, Indonesia, Japan, Malaysia, Nepal, Philippines, Singapore, South Korea, Thailand, and Vietnam.



NEPAL

INDIA

BANGLADESH

THAILAND

CAMBODIA

MALAYSIA

SINGAPORE

CHINA

SOUTH KOREA

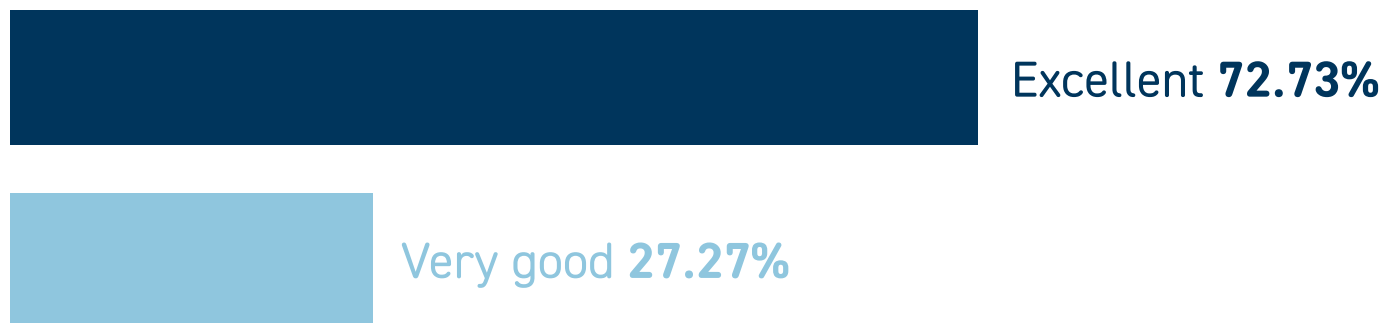
JAPAN

VIETNAM

PHILIPPINES

INDONESIA

Participation feedback (11)



What was the most valuable session for you, and why?

“The workshop was very useful, where we can exchange our ideas with our members from different countries”

“The sessions selected are currently hot topics for PID. It's very informative and valuable for me.”

“Primary and secondary immunodeficiency session. Because the lecture provided up- date therapies for PID patients, that was really open-minded for me”

”

Meeting programme

The full meeting programme is available [here](#).

Presentations available

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

Pictures available

Check out selected pictures from this meeting [here](#).

Report

This report captures key lessons and action points from this two-day meeting, aimed at empowering patient organisations and stakeholders to enhance PID patient care in Asia. Rather than summarising all presentations, it focuses on actionable takeaways.

We encourage patient representatives and stakeholders to prioritise these points and collaborate effectively to improve PID patients' lives in their countries.

Programme

Click on topics you're interested in to learn more.

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Day 1 | March 24 - PATIENTS MEETING

01 Session

Welcoming words

Moderated by Ms Martine Pergent (IPOPI President)

- Welcome remarks and introduction to IPOPI - Ms Martine Pergent, IPOPI President.
- Welcome to Tokyo from PID Tsubasa-no-Kai - Ms Emi Homareda, on behalf of Mr Shun Kimura, PID Tsubasa-no-Kai (Japan).
- Welcome remarks from sponsors - Takeda, Pharming, Grifols and Chiesi.
- Inspire & Connect: Regional updates - IPOPI NMOs (National Member Organisations) and Ms Miriam Ferreira (IPOPI NMO Programmes Officer)
- PID development in the last 2 years in Asia - Dr Adli Ali (Malaysia)

Check out this session's presentations [here](#).

Welcome session

The first day of the Asia meeting kicked off with a welcome session that underscored the **importance of collaboration and the exchange of initiatives/experiences from various countries**, to enhance the diagnosis, care, and treatment of patients with primary immunodeficiency (PID). Ms Pergent highlighted the powerful role of the patients' voices in driving improvements.

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Inspire & Connect NMOs

IPOPI's NMOs showcased **impactful initiatives** from the past two years addressing national challenges, such as:

- **Neonatal screening programs:** Inclusion of PIDs in national neonatal screening programs.

- **Awareness campaigns:** Improved PID diagnosis through targeted awareness campaigns.
- **Access to treatment:** Enhanced access to immunoglobulin treatment, via successful video campaigns.

Advances in PIDs

Dr Ali shared the significant progress made over the past two years, such as:

- **Therapies and treatments:** Advances in the development of therapies and treatments for PIDs.
- **Neonatal screening:** Implementation of neonatal screening programs for early detection.
- **Early diagnosis:** Improved access to early diagnosis for better patient outcomes.

Future outlook

Dr Adli provided insights into the future status of PIDs in Asia over the next two years, expressing optimism about continued progress and collaboration. We look forward to continuing to work together to achieve these goals and enhance PID patients' lives in Asia.

FUTURE OUTLOOK: PID STATUS IN ASIA IN THE NEXT 2 YEARS

- ❖ **Registries:** Standardized / Wider-national-based / Comparable data
- ❖ **Patients Organisation :** More structured and proactive organisations
- ❖ **Specialized Centre :** Integrated adult care with transition pathway
- ❖ **PID Diagnosis :** accessible cost-effective option / trans-countries COE (Reviving SEA6)
- ❖ **Treatment :** Improving equity / earlier access to novel treatment (Clinical Trial in Asia?)
- ❖ **Health Coverage :** ASEAN-WHO AP engagement / Commercial Insurance partnership



Patient leaders from 9 countries introducing their inspiring initiatives to address challenges for PID patients in their countries. (left Dimas Sugiharto, Indonesia; right, Jessie Qu, China).

Other related resources:

- [IPOPI PID Life Index](#)

02 Session

Effective PID Patient Care

Moderated by Mr Johan Prevot (IPOPI Executive Director)

- A Last developments on the state of the art treatment in PIDs - Dr Pamela Lee (Hong Kong).
- Panel discussion: Achieving optimal patient care for PID patients. Doctors: Prof Surjit Singh (India) and Dr Nizar Mahlaoui (France); Patient representatives: Mr Bruce Lim (Malaysia) and Ms Jitchanwichai Narumon (Thailand).
- How to manage daily life with a PID? - Dr Intan Hakimah (Malaysia) and Mr Bruce Lim (IPOPI Vice-President)

Check out this session's presentations [here](#).

Dr Lee provided a very interesting lecture, showcasing the latest developments in PID treatments. Key insights were:

- **Advancements in stem cell transplantation for PIDs**, particularly for severe combined immunodeficiencies (SCIDs): improvement in procedures and increasing success rates for haploidentical transplantation widen access to haematopoietic stem cell transplantation (HSCT) for PID patients.
- **Better understanding of genetic immune disorders**: identification of novel genetic mutations and deeper understanding of underlying mechanisms lead to more targeted and personalized treatments.
- **Improved diagnostic and therapeutic approaches**: advanced diagnostic tools, such as next generation sequencing and functional immune assays; new curative and targeted therapies, such as HSCT, gene therapy and biological or small molecules.
- **Evolution towards precision medicine and personalised approaches**: facilitate more precise management strategies and improved patient care.

Panel discussion: Achieving optimal patient care for PID patients, key elements were highlighted by our panel of doctors and patient representatives:

- **Collaboration:** Optimal care requires joint efforts of patients, doctors, and policymakers.
- **Early diagnosis:** Physicians' training in clinical immunology is crucial for early identification of PIDs.
- **Access to treatment:** Address the availability and affordability of treatments, such as immunoglobulin therapies.
- **Quality of life:** Important aspects are convenient treatment schedules, local access to therapy, and comprehensive support.
- **Awareness and advocacy:** Raising awareness among healthcare providers and advocating for policy changes are essential.



Panel discussion on achieving optimal patient care for PID patients (left to right: Mr Bruce Lim, Ms Jitchanwichai Narumon, Prof Surjit Singh and Dr Nizar Mahlaoui.

How to manage daily life with a PID? Insights from Dr Hakimah, Mr Lim, and participants in the group discussion.

- **Self-management:** Patients must manage their medication and treatment routines, and participate in shared decision-making regarding their health.
- **Holistic health:** Prioritize nutrition, adequate sleep, stress management, and regular exercise.
- **Support:** Overcome stigma through awareness and education.



Group discussions aimed at addressing how to manage daily life with a PID

Other related resources:

- IPOPI leaflet on [“Genetic Diagnosis of PIDs”](#), [“Targeted Therapies for PIDs”](#), [“PIDs and psychological management”](#), and [“A Guide for schools”](#).
- IPOPI video series [“What is a PID?”](#), [“Diagnosing PIDs”](#), and [“Treating PIDs”](#).

03 Session

PID Action Planning Workshop

Moderated by Ms Miriam Ferreira (IPOPI NMO Programmes Officer) and Dr Samya Van Coillie (IPOPI Medical Affairs Project Manager)

- A Workshop development - IPOPI NMOs
- Summary remarks - Ms Martine Pergent and Mr Bruce Lim

Check out this session's presentations [here](#).

This workshop aimed to empower our National Member Organisations (NMOs) with the skills and knowledge essential to create comprehensive action plans independently. Using a country case study, participants developed action plans from start to finish.

Lessons learned:

- **Strategic planning:** Define priorities. You can't tackle all challenges at the same time. Set clear short-term and long-term goals to measure progress and stay focused.
- **Volunteer engagement:** Involve stakeholders for valuable support and manpower, such as : medical student associations like [AMSA](#); volunteer professionals (ex : journalist or writers) ; assign specific roles ; recognise and reward volunteers for their contributions effectively.
- **Awareness campaigns:** Raise awareness to gain government and general public support through social media, interviews with doctors, TV, radio, and conferences.
- **Advocacy and policy change:** Start with achievable goals to build momentum. Use tools like international publications (ex : the [WHO essential diagnostics and medicines lists](#)), real data (ex : [IPOPI PID Life Index](#)), and patient stories for effective advocacy.
- **Fundraising:** Estimate annual funding needs and explore diverse sources, including government grants, donations, and membership fees. Consider platforms like [Azure.com](#) for significant funding.
- **Collaboration and sharing knowledge:** Participate in international meetings and webchats to learn from other organisations and share successful strategies.

- **IPOPI resources:** Use IPOPI tools and resources for effective advocacy and awareness campaigns.



Patient leaders collaborating with doctors to develop specific action plans to tackle challenges in a country.

Other related resources:

- [IPOPI educational leaflets for healthcare professionals and patients](#)
- [IPOPI mini-series videos and mini-documentaries](#)
- IPOPI’s statement:
 - [IPOPI’s new statement on “Patients with PIDs should have access to safe, efficacious and high-quality immunoglobulin therapies”](#)
 - [IPOPI’s statement on “A PID causing a heavy burden of disease must always be recognised as a disability”](#)
 - [IPOPI’s statement on “Patients with PIDs need sustained & continued access to their Ig therapies!”](#)
 - [IPOPI’s statement on “Managing demand for immunoglobulins: PIDs are a priority indication at all times”](#)

04 Session

IPOPI/APSID Joint Session - PID Life Odyssey - the Patient Journey

Moderated by *Dr Nizar Mahlaoui (IPOPI MAP Chair)* and *Prof Martin van Hagen (IPOPI MAP Vice-Chair)*

- Lectures and Panel Discussion - Ms Martine and Mr Bruce Lim, and Mr Shun Kimura, (PID Tsubasa-no-Kai President, Japan).
- Closure of the day - Ms Martine Pergent

Check out this session's presentations [here](#).

This session focused on the challenges and progress on primary immunodeficiency, and how PID patient organisations have tackled them in Asia. Key insights from the session included:

- Patient organisations should prioritise knowledge and data sharing to **raise awareness of PID among healthcare professionals and the public.**
- **Collaboration** with healthcare professionals, patient organisations, policymakers, and other stakeholders is crucial for advocating for PID patients.
- **Implementing newborn screening for PIDs** is essential for early diagnosis and timely treatment.
- **Patient organisations play a key role** in providing support and resources for PID patients, including educational materials and platforms for data sharing.
- **Establishing specialised centers for PID** with knowledgeable healthcare professionals is vital for improving patient care.
- **Transitioning PID patients** from pediatric to adult care requires a smooth and safe process, emphasising the need for **specialised medical care for patients of all ages.**



Panel discussion on the PID Life Odyssey - the Patient Journey



Participants

Other related resources:

- [IPOPI leaflets : “Value of SCID newborn screening” and “Moving from child to adult care”](#)
- [List of PID specialised centres in the world.](#)
- [International neonatal screening day, on June 28.](#)

Day 2 | March 25 - DOCTORS MEETING

Welcome Session

Moderated by *Ms Martine Pergent*

- Welcome remarks and introduction to IPOPI - Ms Martine Pergent
- Welcome from sponsors - Takeda, Pharming, Grifols and Chiesi
- Welcome to Tokyo - Ms Emi Homareda, on behalf of Mr Shun Kimura, PID Tsubasa-no-Kai (Japan)
- Welcome from APSID and SEAPID - Prof Hirokazu Kanegane (Japan) and Dr Adli Ali (Malaysia)
- Keynote lecture: Ten-year prospective for the region (APSID role) - Prof Hirokazu Kanegane (Japan)

Check out this session's presentations [here](#).

The second day meeting aimed to engage healthcare professionals from Asia. It commenced by warmly welcoming participants, highlighting the importance of the topics, and encouraging active involvement.

Keynote Lecture - Ten-year Prospective for the Region (APSID Role) - Prof Kanegane main insights:

- **Future focus on training and education:** focus on providing training and education through annual congresses, PID schools, and webinars for healthcare providers in the region, to ensure continuous engagement with the latest developments in PID care.
- **Advocacy and policy influence:** strengthen advocacy by collaborating with governments, patient organisations, and industry to improve PID care standards and accessibility.
- **Centers of excellence:** expand and establish centers to enhance expertise in PID care.

- **Increasing collaboration:** foster greater collaboration among Asian countries, leveraging the strengths of high Human Development Index (HDI) countries to support those with lower HDI.
- **Research:** advance research in genetics and pathogenesis to develop innovative treatments and enhance diagnostic capabilities.
- **Addressing disparities:** prioritise ongoing training and education for regional healthcare providers through annual congresses, PID schools, and webinars, ensuring they stay updated with the latest developments in PID care.



Prof Kanegane providing the keynote lecture on the ten-year prospective for the region (APSID role)

Other related resources:

- Educational opportunity by attending IPOPI's International Primary Immunodeficiencies Congress, on 5-7 November, 2024, in Prague, Czech Republic. Travel grants for Junior Doctors and NMOs will be available
- Keep updated through the [Asian Pacific Society for Immunodeficiencies website](#).

01 Session

The fast-evolving field of immunodeficiency

Moderated by *Dr Nizar Mahlaoui (France)* and *Prof Kohsuke Imai (Japan)*

- The role of auto-inflammation in primary immunodeficiency - Prof Ryuta Nishikomori (Japan).
- The crossover between primary and secondary immunodeficiencies - Prof Martin van Hagen (the Netherlands).
- The growing demand for plasma products: Balancing regional needs and evolving therapeutic indications - Dr Renf Błchel (Switzerland).
- Challenging clinical cases (APSID + SEAPID): APDS Diagnostics - Prof Intan Hakimah (Malaysia); HSCT in congenital neutropenia - Dr Jia Hou (China)
- Panel: Case discussion - Prof Hirokazu Kanegane (Japan), Prof Martin van Hagen (the Netherlands), Dr Ewen Munro (Pharming) and Dr Van Anh Nguyen (Vietnam).

Check out this session's presentations [here](#).

This session provided a comprehensive analysis of the fast-evolving field of immunodeficiencies, with the following highlights:

- Prof Nishikomori's lecture highlighted the **complex interplay of auto-inflammatory processes on immune system dysregulation** and the importance of comprehending this process for developing new targeted treatments.
- Prof van Hagen's presentation featured **real patient cases**, providing valuable insights into the **commonalities between primary and secondary immunodeficiencies**, emphasising the sharp increase in drug-induced secondary antibody deficiency and the need for a holistic understanding to effectively address this growing concern.
- Dr Büchel's discussion underscored the **increasing demand for plasma derived products** and the **challenges of balancing regional needs** while adapting to evolving therapeutic indications, reflecting the dynamic nature of the field.

Challenging clinical cases:

- Prof Hakimah's presentation and following discussion highlighted the critical importance of **accurate and timely diagnostics in identifying and addressing APDS**, emphasising the need for specialised testing and expertise to effectively diagnose this rare immunodeficiency.
- Dr Hou's presentation and following discussion on HSCT in congenital neutropenia showcased the **potential of hematopoietic stem cell transplantation as a promising therapeutic approach for addressing this specific immunodeficiency**, providing valuable insights into its potential benefits in clinical practice.



Panel of experts discussing challenging cases on APDS diagnosis and HSCT for congenital neutropenia for the region (APSID role)

Other related resources:

- IPOPI leaflets: “Autoimmunity and autoinflammation”, “Rheumatological, Autoimmune & Autoinflammatory Crossovers”, Plasma-derived therapies, “APDS - Activated PI3K Delta syndrome”, and “Hematopoietic stem cell transplantation”
- IPOPI Mini Documentary - A closer look at Primary and Secondary Immunodeficiencies
- International Plasma Awareness Week, first week of October
- IPOPI call for increased plasma collection to ensure patients with PIDs have access to their therapies, on IPAW 2020
- IPOPI Clinical Care Webinar: [The A to Z of APDS](#)
- IPOPI Hard Talks: [APDS Diagnosis](#)

02 Session

Asian Perspectives on PID diagnosis and screening

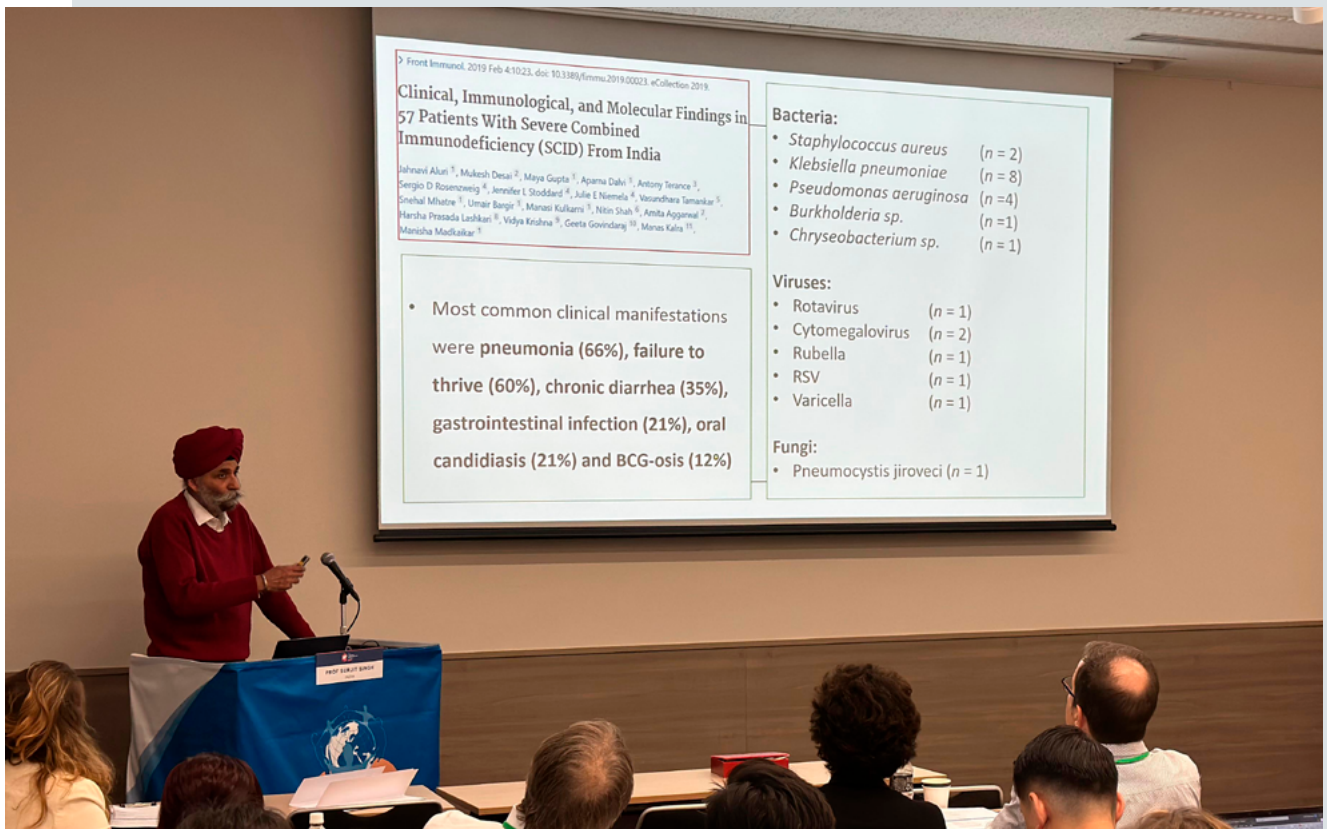
Moderated by **Mr Bruce Lim (IPOPI Vice-President)** and **Dr Narissara Suratannon (Thailand)**

- Specific infectious agents relevant to PID in the Asian region - Prof Surjit Singh (India).
- Flow Cytometry for Diagnostics: Value, Context, and Sustainability - Dr Jaime Sou da Rosa Duque (Hong Kong).
- Tailoring Newborn Screening for Severe Combined Immunodeficiency in Asian Context: Insights from Japan - Dr Manabu Wakamatsu (Japan); Insights from Malaysia - Dr Adli Ali (Malaysia).

Check out this session's presentations [here](#).

This session shed light on the critical aspects of PID diagnosis and screening in the Asia-Pacific region, emphasizing the need for early detection, comprehensive clinical management, and technological advancements to enhance diagnostic accuracy.

- Prof Singh explained the **diversity of infections** faced by patients with different types of PID across the globe, emphasizing the need for **regionally tailored approaches** based on the **local experience**.
- Dr Duque highlighted the **advances in flow cytometry technology** and its **crucial role in the accurate diagnosis of PID**.
- Dr Wakamatsu and Dr Ali highlighted the **vital role of early PID diagnosis**, underscoring the need for **efficient newborn screening** to identify individuals before severe infections, thereby enhancing patient outcomes and reducing long-term complications.



Prof Surjit Singh providing a lecture on specific infectious agents relevant to PID in the Asian region

Other related resources:

- IPOPI leaflet on “Essential of PID Diagnosis” and “Value of SCID newborn screening”
- World Antimicrobial Resistance (AMR) Awareness Week, 18-24 November, 2024.
- International Neonatal Screening Day, on June 28.

03 Session

PID management and access: the Asia-Pacific context

Moderated by **Mr Johan Prévot (IPOPI Executive Director)** and **Dr Adli Ali (Malaysia)**

- [PID Life Index](#) - Avenues for the future in Asia - Dr Adli Ali (Malaysia).
- Panel discussion: Empowering regional advancements: Innovations and initiatives from participating countries - Prof Kohsuke Imai (Japan), Dr Dina Muktiarti (Indonesia), Dr Van Anh Nguyen (Vietnam), Dr Jonie Tillah (Philippines), and Dr Yae-Jean Kim (South Korea).
- Panel discussion and recommendations for the way forward - Prof Surjit Singh (India) and Dr Adli Ali (Malaysia).
- Closure of the day.

Check out this session's presentations [here](#).

The final session provided a deeper conversation on the PID landscape and its future, having Dr Ali's presentation and following panel highlight the current challenges and key recommendations to improve the future prospects of PID management in the Asia-Pacific region.

Current status

- The need for **increased awareness** and **improved training** for diagnosis and treatment of PID, especially in certain Asian regions.
- Lack of **access to treatment and equity** in healthcare.
- **Limited access to biological targeted treatments**, due to availability and coverage issues.
- The importance of **improving networking and public-private partnerships** in PID management.

Recommendations for the way forward:

- Establish comprehensive care programs that **include adult integrated care** and **newborn screening initiatives** to improve early diagnosis and management of PID.
- Develop pathways and **recognition for adult-related subspecialties** to contribute to PID management and address the specific needs of adult patients.
- **Create transition care guidelines** in Asia-Pacific countries to ensure continuity of care for PID patients as they transition from pediatric to adult care.
- **Use artificial intelligence solutions** to simplify diagnosis and improve access to expertise for managing PID and related disorders.



Panel discussion on the regional advancements (left to right - Dr Yae-Jean Kim, Dr Jonie Tillah, Dr Van Anh Nguyen, Dr Dina Muktiarti and Prof Kohsuke Imai)

Conclusion

The **IPOPI Regional Asian PID Patients and Doctors** meeting in **Tokyo** was a **vibrant gathering** with active participation from patient representatives, healthcare professionals and other relevant stakeholders from the region.

The meeting **marked a significant step towards enhancing collaboration**, sharing best practices, and educating on advances in the field of primary immunodeficiencies. The enthusiasm and dedication of all attendees underscored a shared commitment **to advance care and treatment for those living with primary immunodeficiencies in the Asian region.**

IPOPI wishes to thank **APSID, JSIAD, SEAPID** (Southeast Asia Primary Immunodeficiencies Society), and **Tsubasa-no-Kai** (IPOPI member in Japan) for their valuable support to organise this meeting. We would like to particularly acknowledge the dedication and commitment of Mr Shun Kimura, President of Tsubasa-no-Kai.



Day 1



Day 2

The meeting marked a significant step towards enhancing collaboration, sharing best practices, and educating on advances in the field of primary immunodeficiencies.

IPOPI would like to thank Takeda, Pharming, Grifols and Chiesi for their generous support towards this meeting.



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