



# IPOPI 5<sup>TH</sup> REGIONAL ASIAN PID MEETING

24-25 MARCH 2024  
TOKYO, JAPAN

an **IPOPI** event

COLLABORATION



SUPPORTED BY



# WELCOME TO IPOPI 5<sup>TH</sup> REGIONAL ASIAN PID DOCTORS' MEETING



IPOPI  
5<sup>TH</sup> REGIONAL  
ASIAN PID MEETING  
24-25 MARCH 2024  
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COLLABORATION



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# WI-FI

User: **SCCC\_RoomA**  
Password: **solacity01**



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IPOPI.ORG

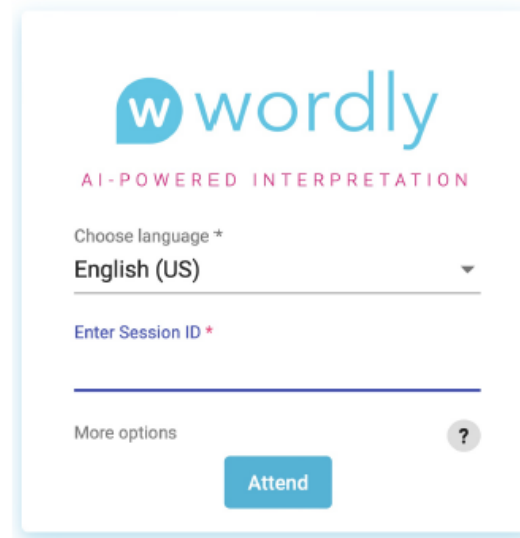
# Live Translation

## Step 1



Scan QR Code or Go To:  
<https://attend.wordly.ai/join/KPYA-6720>

## Step 2

A screenshot of the Wordly app interface. At the top is the 'wordly' logo with a blue 'w' icon. Below it, in pink, is 'AI-POWERED INTERPRETATION'. There are two input fields: 'Choose language \*' with 'English (US)' selected, and 'Enter Session ID \*' with a blue underline. At the bottom left is 'More options' and at the bottom right is a blue 'Attend' button and a small grey circle with a question mark.

Choose Language  
Click Attend

## Step 3



Read Captions on Device  
Use Headset for Audio

# WELCOME SESSION

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Moderator:

Mrs Martine Pergent | IPOPI President



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#### COLLABORATION



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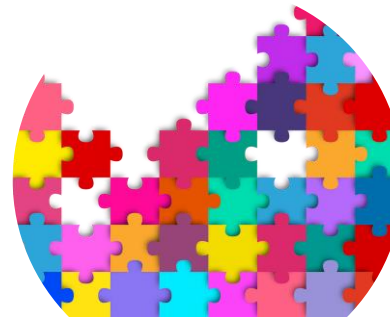


# What is IPOPI?

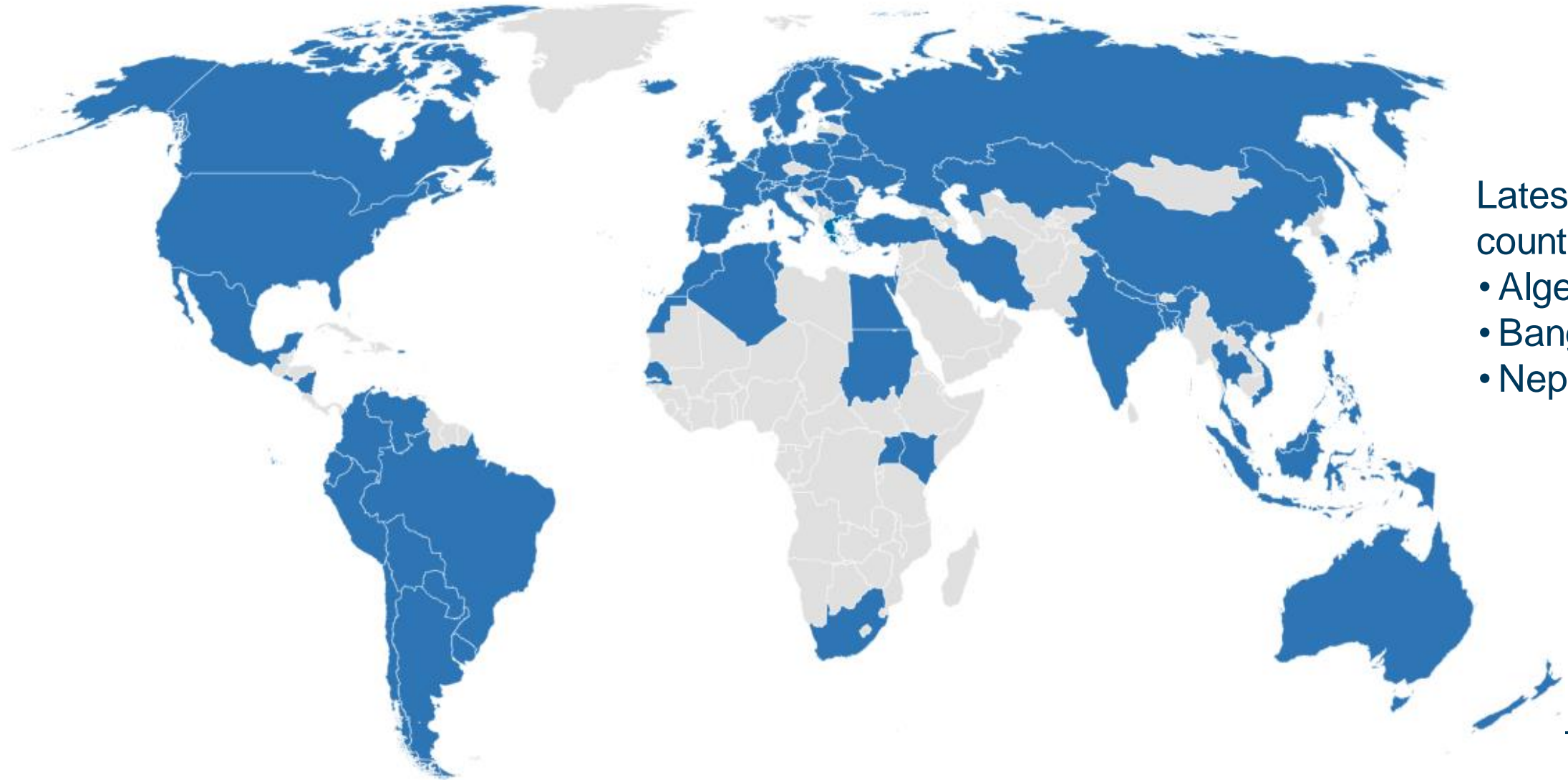
- a **non-profit international** organization
- the **leading advocate** for primary immunodeficiency (PID) patients worldwide
- working in **collaboration** with patients, doctors, politicians, regulators, pharmaceutical industry and other relevant stakeholders.

# Our mission

To improve awareness, access to early diagnosis and optimal treatments for primary immunodeficiency patients **worldwide** through global **collaboration**.



# Our members: **73 national patient organisations**



Latest countries:

- Algeria
- Bangladesh
- Nepal

# IPOPI works as an umbrella organisation

A vibrant global  
community





# A committed Board of Directors

- Martine Pergent, Chair (FR)
- **Bruce Lim, Vice-Chair (MAL)**
- Otilia Stanga, Treasurer (RO)
- Roberta Anido de Pena (ARG)
- Whitney Ayoub Goulstone (CA)
- Jose Drabwell (NL/UK)
- Cynthia Olotch (KEN)
- John Seymour (USA)
- Otilia Stanga (RO)
- Johan Prévot (BEL) ex-officio
- Nizar Mahlaoui (FR) ex-officio
- Martin van Hagen (NL) ex-officio

# IPOPI dynamic Staff



**Executive Director**  
**Johan Prevot**

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**Events & Logistics Assistant**  
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**Leire Solis**

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# IPOPI Medical Advisory Panel (MAP)



Dr Nizar Mahlaoui,  
Chairman (FR)



Prof Martin van Hagen,  
Vice-Chair (NL)



IPOPI LeBien AWARD

- **Dr Adli Ali (MAL)**
- Dr Tadej Avcin (Slovenia)
- Prof Aziz Bousfiha (Morocco)
- Dr Charlotte Cunningham-Rundles (USA)
- Dr Virgil Dalm (Netherlands)
- Prof Tandakha Dieye (Senegal)
- Prof Alain Fischer (France)
- Prof Elie Haddad (Canada)
- Professor Steven Holland – (USA)
- **Dr Pamela Lee (Hong-Kong)**
- Prof Isabelle Meyts (Belgium)
- Prof Antonio Condino-Neto (Brazil)
- Dr Olaf Neth (Spain)
- Dr Cecilia Poli – (Chile)
- Dr Elizabeth Rivers – (UK)
- Dr Silvia Sanchez-Ramon (Spain)
- Prof Ana Shcherbina (Russia)
- **Prof Surjit Singh (India)**
- **Prof Stuart Tangye (Australia)**
- Prof Klaus Warnatz (Germany)

# Our context, for now and tomorrow ...

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Presenter



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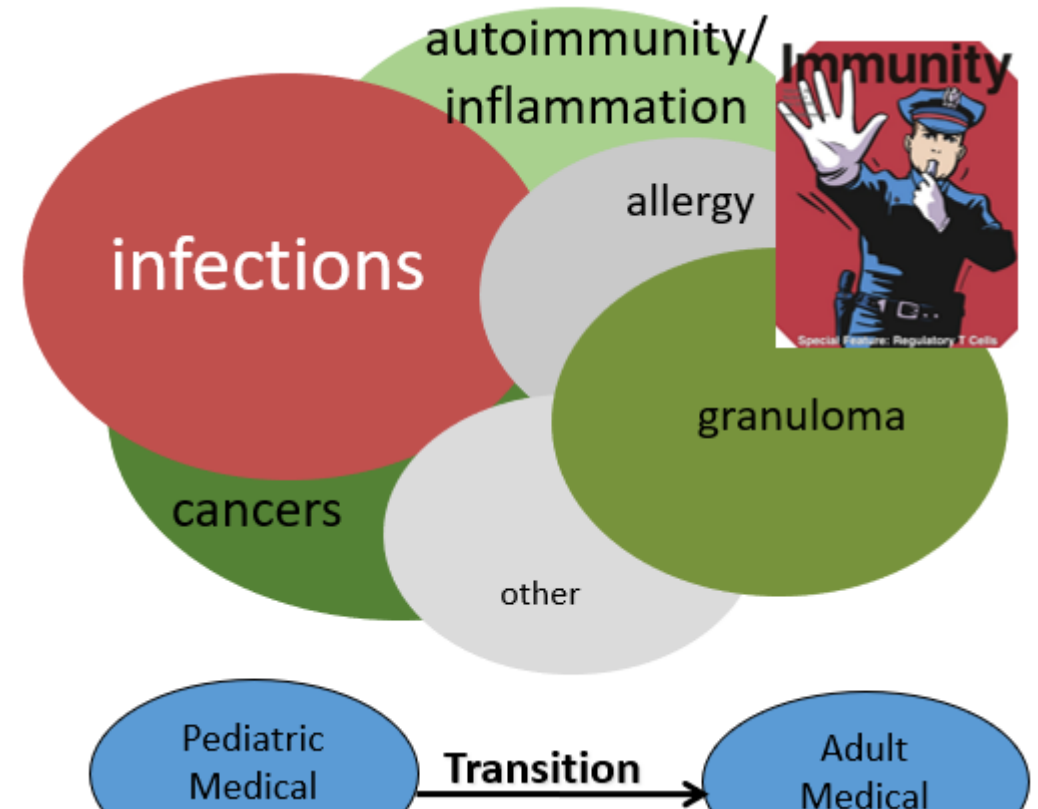
# Primary immunodeficiencies (Inborn errors of immunity)

PIDs are no longer defined by tendency for infections alone

Clinical presentation is variable

PID patients with non-infectious complications are increasingly recognised with features of immune dysregulation:

- Autoimmunity
- Inflammation
- Lymphoproliferation
- Allergy
- Malignancy



# Landscape, our common challenges/opportunities

## A fast-expanding field with crossovers

- 1000 PIDs by 2030?

## Plasma collection, IG

- Supply and coverage
- SCIG

## Availability, Access & Coverage

- Diagnosis & treatment
- Lab facilities and reagents
- Medical devices

## Advances in diagnostics and treatment

- Personalised medicine
- Centres of expertise
- Disruptive innovations (AI, genomics, mRNA, ...)

## Data

- Epidemiology, registries, PROMs

## Mental health

- Quality of life
- Social and psychological support

## Newborn screening

- For SCIDs ... and more PIDs in the future

## Transition care

- Childhood >Adulthood
- Ageing

## Training of immunologists

- for children & adult
- Immunology as sub-speciality

## Medical awareness and education on PIDs

- Organ specialists, ...

## Threats and pandemic preparedness

- AMR, emerging viruses, counterfeit products, conflicts

## Secondary immunodeficiencies

- A growing patient population



Improve access to early  
diagnosis & patient-centred care

an IPOPI event

# IPOPI

activities & projects

=> 2025



Build capacity and support IPOPI's  
national member organisations



Educate, promote knowledge  
and data sharing



Strengthen multi-stakeholder  
collaboration



[IPOPI.org](http://IPOPI.org)

# Thank you for your kind attention!

Thank you to  
our sponsors  
for making this  
important  
meeting  
possible

どうもありがとう

매우 감사합니다

太感谢了

धेरै धेरै धन्यवाद

Terima kasih banyak-banyak

आपका बहुत-बहुत धन्यवाद

ကျေးဇူးတင်ပါသည်

Cảm ơn bạn rất nhiều

তোমাকে অনেক ধন্যবাদ

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# Improve access to early diagnosis and patient centred care

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Presenter

Strategic Objective 1



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# Newborn screening for SCIDs



“Neonatal screening is much more than just a simple test.”



screen4rare

What is NBS? MEP Interest Group Resources and other activities About Us

CONTACT

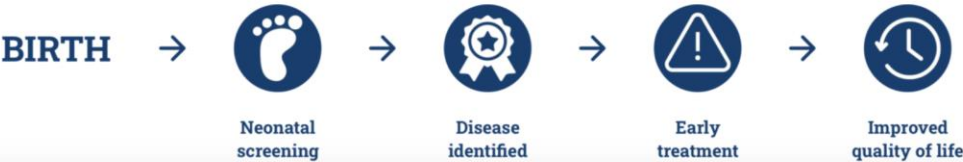
## What is NBS?

Home / What is NBS

## What is newborn screening?

### WHAT DOES NEONATAL SCREENING MEAN FOR PATIENTS?

Timely access to diagnosis, treatment and care!



# Global advocacy – Calling for more plasma collection

## SAFE Task Force releases two position statements

KEY PUBLICATIONS, NEWS

The Supply and Access for Everyone (SAFE) Task Force and IPOPI position statements on 2 key topics of relevance to patients with



### Patients with PID need sustained access to their Ig therapies

Primary immunodeficiencies (or PIDs) are chronic and rare diseases where components of the immune system do not work properly or not at all. Patients need immunoglobulin replacement therapies (Igs) throughout their lives to maintain antibodies within a “suitable” threshold to fight life-impairing or life-threatening infections if alternative treatments are available for these patients.

**Igs are plasma-derived medicinal products (PDMPs)** that require plasma either through plasmapheresis (source plasma) or from pooled plasma for the development of these medicines<sup>1</sup>.

**Each Ig is a unique biological medicine.** The different manufacturers ensure individual patients' tolerability to a given therapy<sup>2</sup>.

**Igs are not generic medicines and cannot be interchanged.**



### Managing demand for immunoglobulins: PIDs are a priority indication at all times

The global demand for immunoglobulin (Ig) replacement therapies is growing annually at 6–8% across a broad range of indications. Whilst strategies to manage Igs demand are urgently needed and should be swiftly implemented in all countries, the fact remains that some countries are still struggling to get access to Ig therapies. Ensuring appropriate, equitable and stable access to Igs in all countries require both increased plasma supply with much more regionally balanced plasma collection and improved fractionation technology to optimize yield from each litre of plasma<sup>4</sup>.

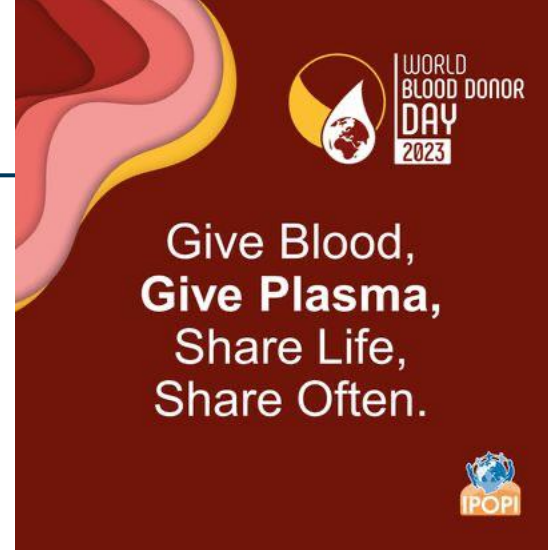
Igs are plasma derived medicinal products (PDMPs) used in the treatment of several diseases and conditions.

Around 60% of patients with primary immunodeficiencies (PIDs) need Igs throughout their lives to keep the levels of antibodies within a “suitable” threshold to fight infections and prevent mortality.

No alternative treatments are available for patients with PIDs requiring Ig therapies<sup>1</sup>.

# Awareness Campaigns

Universal Health Coverage  
Vaccination, ...



Plasma collection  
IG availability

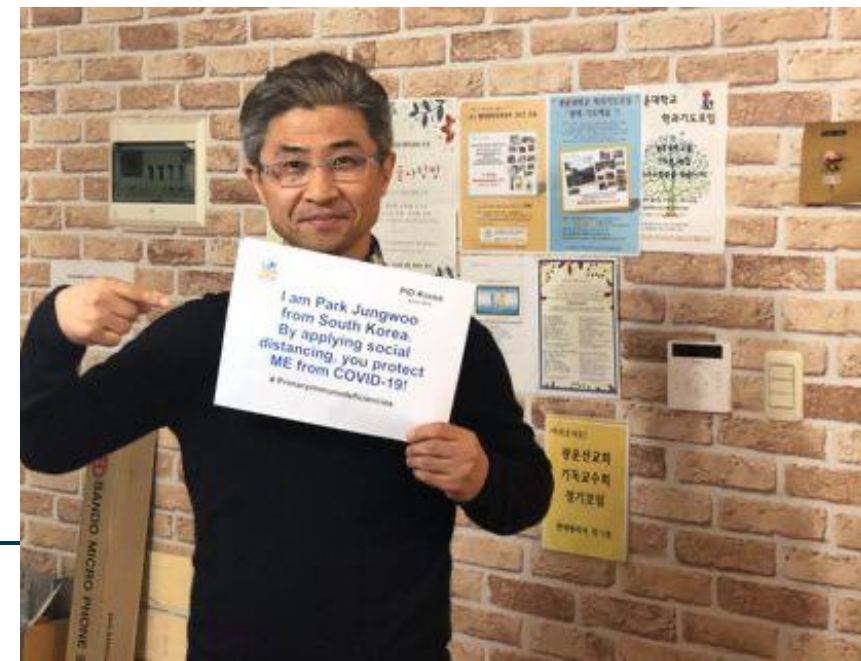


Lack of access to UHC is a  
global problem.

**Let's tackle it together.**

Join us on Universal Health Coverage Day to make  
healthcare a universal right.

## Antimicrobial resistance



# Advocacy World Health Organisation



**IGs** included in the WHO list of essential medicines

**PIDs diagnostic tests** included in the WHO Model List of Essential In vitro Diagnostics

# Addressing PID patients needs

## bringing the patient perspectives on medicines, shortages, clinical trials, ...

- at EMA (European medicine Agency)
- at APEC  
(Blood Policy Forums and APEC Rare Disease Forums)
- at Asia Pacific Plasma Leaders Network (APPLN)
- hopefully at AMA (African medicine Agency)



EDUCATION

EVENTS

RESOURCES

LECTURE CATALOG

PRINT CERTIFICATE

## UNMET NEED FOR PLASMA DERIVED MEDICINAL PRODUCTS IN APAC: THE PID PATIENT'S PERSPECTIVE

PUBLICATION DATE: 13 October 2023

CONTINUING EDUCATION UNITS: 0.5 hours

### LECTURE DESCRIPTION:

In this lecture, Johan Prevot, Executive Director of the International Patient Organisation for Primary Immunodeficiencies (IPOPI), describes the organization and provides an overview of the evolving use of immunoglobulins. His presentation

# Have PIDs on the political agendas



Meetings at the European parliament chaired by members of Parliament on diverse topics

- Digital health
- Collection of plasma, supply of IGs
- Cross border care

At the Brazilian Parliament



# Build capacity and support IPOPI's National Member organisations

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Presenter

Strategic objective 2



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# Patient community momentum

## Global Patients Meeting

- Biennial meeting open for all NMOs, organised in parallel to ESID & INGID congresses
- Next meeting in Marseille (France), October 2024
- 2-day meeting with educational sessions, skills building workshops and exchange of experiences
- Hosts the PID Champions Awards

## Regional PID meetings

- Regional meeting open for all NMOs from the region, organised in parallel to regional scientific societies (ASID, LASID, APSID/SEA) & INGID congresses

## Webchats

- Community online regular meetings



# Help our members take action



## COVID-19 and PIDs FAQs

Updated April 29, 2020

*This is a compilation of answers to questions received from IPOPI's national member organisations via email, social media and during IPOPI's COVID-19 webchats.*

**New statement: A PID causing a heavy burden of disease must always be recognised as a disability**



Training sessions with play roles

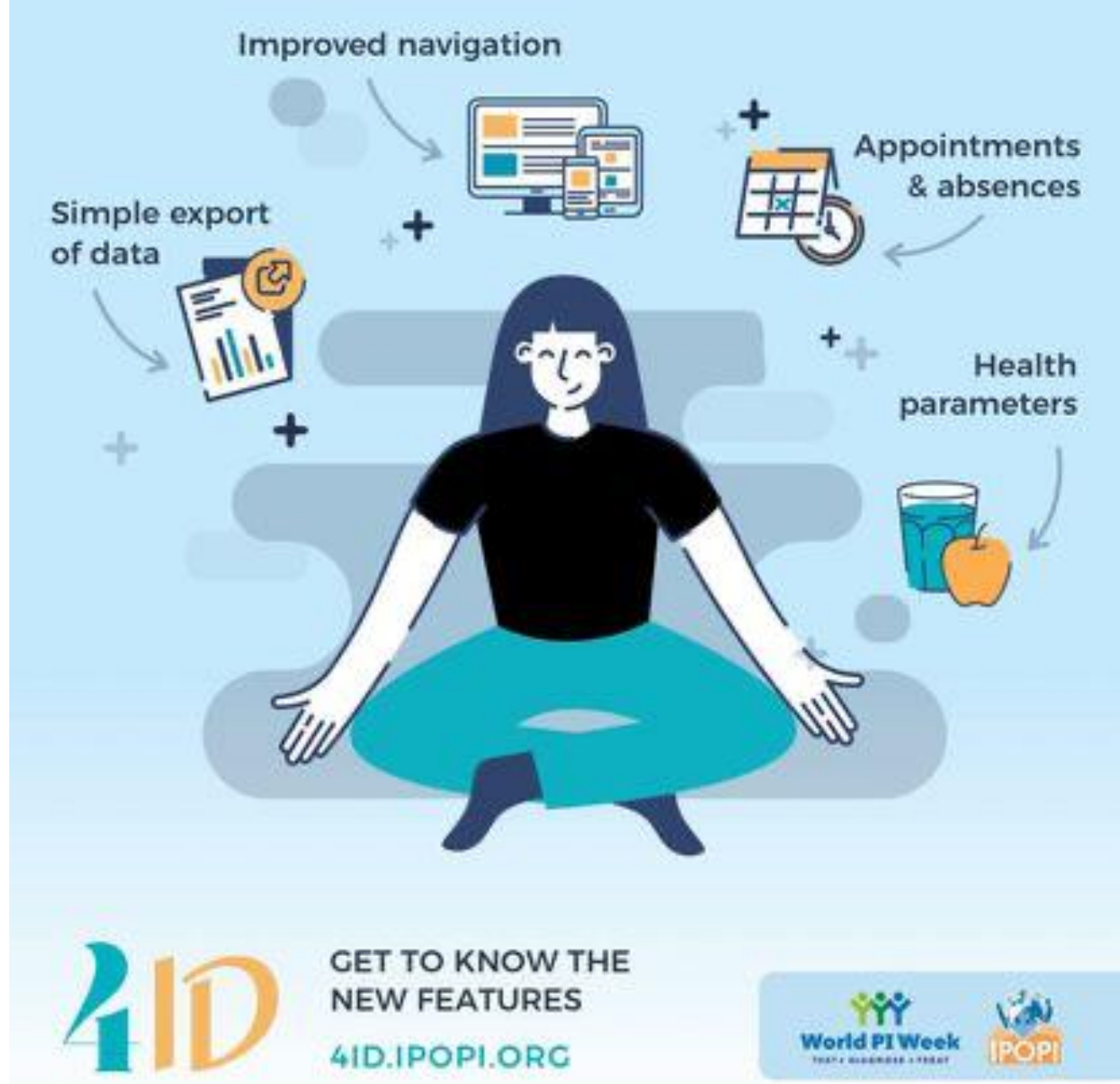
In Asia



In Africa

# 4ID app.

- A health calendar ...  
A source of information  
when you visit your  
specialist
- A Source a patients'  
real-life data



# World Primary Immunodeficiencies Week 22-29 April every year

すべての原発性免疫不全患者に対するケアへのアクセス、どこでも

Let's make early diagnosis & timely access to quality treatment a reality worldwide

#WorldPIWeek



  
**World PI Week**  
TEST • DIAGNOSE • TREAT

2024 年 4 月  
22 ~ 29 日

# Educate, promote knowledge & data sharing

Presenter

Strategic objective 3



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## Educational material

Leaflets  
Webinars

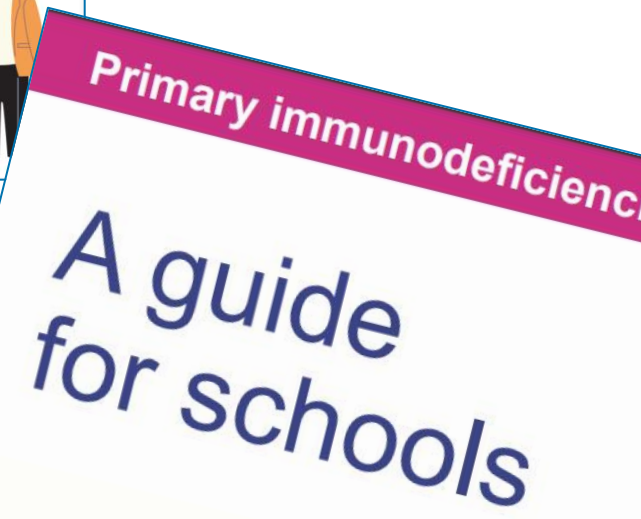
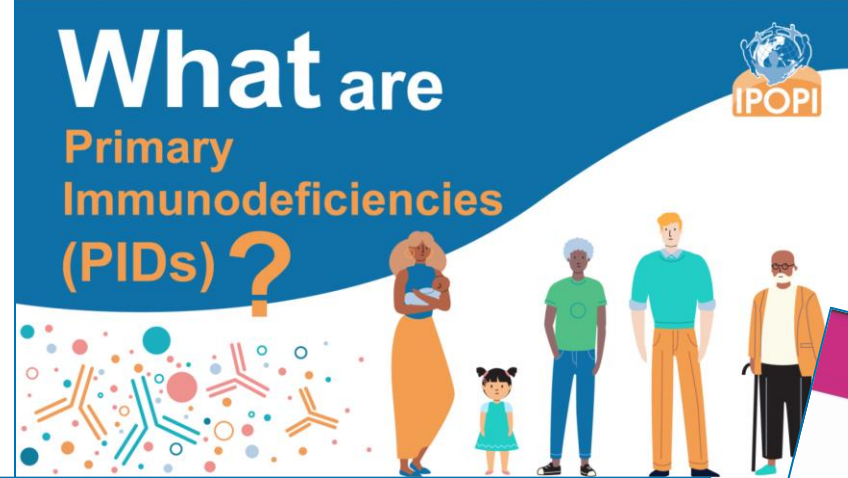
- For health care professionals



an IPOPI event

# Educational material

- For patients
- For the general public



Mini-documentary



# INVITATION



an IPOPI event

# IPIC2025

INTERNATIONAL  
PRIMARY  
IMMUNODEFICIENCIES  
CONGRESS

DIAGNOSIS  
AND CLINICAL CARE

PRAGUE, CZECH REPUBLIC  
5-7 NOVEMBER 2025

[ipic2025.com](https://ipic2025.com)

## PIDetect: Training programme

Indonesia > Erasmus, Rotterdam

Bangladesh > PGIMER Chandigarh, India

Moldova > Timisoara, Romania



# IPOPI Latest Publications

Solis et al. *Orphanet Journal of Rare Diseases* (2022) 17:11  
<https://doi.org/10.1186/s13023-021-02161-0>

Orphanet Journal of Rare Diseases

RESEARCH Open Access

## The PID Life Index: an interactive tool to measure the status of the PID healthcare environment in any given country

Leire Solís<sup>1</sup>, Julia Nordin<sup>1</sup>, Johan Prevot<sup>1</sup>, Nizar Mahlaoui<sup>2,3</sup>, Silvia Sánchez-Ramón<sup>4,5</sup>, Adli Ali<sup>6,7</sup>, Elodie Cassignol<sup>8</sup>, John W. Seymour<sup>1,9</sup> and Martine Pergent<sup>1\*</sup>

**Abstract**

**Background:** The 'Primary Immunodeficiencies (PIDs) principles of care' were published in 2014 as the gold standard for care of patients with PIDs, setting a common goal for stakeholders to ensure that patients with PID have appropriate care and good quality of life. Since then, IPOPI (the International Patient Organisation for Primary Immunodeficiencies), has been working with national PID patient organisations as well as collaborating with scientific medical institutions and experts to bring these principles closer to the day-to-day life of individuals with PID.

**Method:** The six PID Principles of Care were revised to consider advances in the field, as well as political developments that had occurred after their initial publication in 2014. Based on this revision the list was updated, an principle was added. The six established principles were: diagnosis, treatment, universal health coverage, special centres, national patient organisations and registries. Each principle was structured and measured through a criteria, and was given the same weight, as they have been considered to all be equally important. Specific criteria were attributed to the criteria depending on their relevance and importance to quantify the principle. The criteria were translated into a survey for data collection: initially involving data from selected countries for a pilot, followed by a nationwide survey of data from IPOPI's national member organisations and key countries.

**Results:** The PID Life Index was developed in 2020 to assess the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care.

**Conclusion:** The PID Life Index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care.

Orphanet Journal of Rare Diseases

RESEARCH Open Access

## Global immunoglobulin supply: steaming towards the iceberg?

Johan Prevot<sup>a</sup> and Stephen Jolles<sup>b</sup>

**Abstract**

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The Lancet Regional Health - Europe  
2022;00: 100311  
Published online xxx  
<https://doi.org/10.1016/j.lanepe.2022.100311>

## Newborn screening as a fully integrated system to stimulate equity in neonatal screening in Europe

Maurizio Scarpa<sup>a,\*</sup>, James R. Bonham<sup>b</sup>, Carlo Dionisi-Vici<sup>c</sup>, Johan Prevot<sup>d</sup>, Martine Pergent<sup>d</sup>, Isabelle Meyts<sup>e</sup>, Nizar Mahlaoui<sup>f</sup>, and Peter C.J.J. Schielen<sup>g</sup>

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frontiers | Frontiers in Immunology

TYPE Original Research  
PUBLISHED 30 March 2023  
DOI 10.3389/fimmu.2023.1151355

## Primary immunodeficiencies (PID) Life Index in Southeast Asia: A comparative analysis of PID Principles of Care (PoC)

Chee Mun Chan<sup>1,2</sup>, Nizar Mahlaoui<sup>3,4</sup>, Silvia Sánchez-Ramón<sup>5,6</sup>, Martine Pergent<sup>7</sup>, Leire Solís<sup>8</sup>, Johan Prevot<sup>9</sup> and Adli Ali<sup>1,2,8,9\*</sup>

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International Journal of Neonatal Screening

REVIEW

## Towards Achieving Equity and Innovation in Newborn Screening across Europe

Jaka Sikonia<sup>1,2,\*</sup>, Uth Groselj<sup>1,2,\*</sup>, Maurizio Scarpa<sup>3</sup>, Giancarlo la Marca<sup>4,5</sup>, David Cheillan<sup>6</sup>, Stefan Köllker<sup>7</sup>, Rolf H. Zetterström<sup>8,9</sup>, Viktor Kožich<sup>10,11</sup>, Yann Le Cam<sup>12</sup>, Gulcin Gunus<sup>12</sup>, Valentina Bottarelli<sup>12</sup>, Mirjam van der Burg<sup>13</sup>, Eugenie Dekkers<sup>14</sup>, Tadej Battelino<sup>1,2</sup>, Johan Prevot<sup>15</sup>, Peter C. J. I. Schielen<sup>16</sup> and James R. Bonham<sup>16,17,\*</sup>

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Qualitative Research in Medicine & Healthcare 2020; volume 4:117-131

## It's long-term, well it's for life basically: Understanding and exploring the burden of immunoglobulin treatment in patients with primary immunodeficiency disorders

Georgina I. Jones<sup>1</sup>, Eva Brown Hajdukova<sup>2</sup>, Esme Hanna<sup>3</sup>, Rosie Duncan<sup>4</sup>, Brendan Gough<sup>1</sup>, Jane Hughes<sup>4</sup>, Debbie Hughes<sup>5</sup>, Fran Ashworth<sup>5</sup>, Johan Prevot<sup>6</sup>, Jose Drabwell<sup>7</sup>, Leire Solís<sup>8</sup>, Nizar Mahlaoui<sup>9</sup>, Anna Shrimpton<sup>9</sup> on behalf of the International IgBoT study team

**Abstract**

**Background:** The 'Primary Immunodeficiencies (PIDs) principles of care' were published in 2014 as the gold standard for care of patients with PIDs, setting a common goal for stakeholders to ensure that patients with PID have appropriate care and good quality of life. Since then, IPOPI (the International Patient Organisation for Primary Immunodeficiencies), has been working with national PID patient organisations as well as collaborating with scientific medical institutions and experts to bring these principles closer to the day-to-day life of individuals with PID.

**Method:** The six PID Principles of Care were revised to consider advances in the field, as well as political developments that had occurred after their initial publication in 2014. Based on this revision the list was updated, an principle was added. The six established principles were: diagnosis, treatment, universal health coverage, special centres, national patient organisations and registries. Each principle was structured and measured through a criteria, and was given the same weight, as they have been considered to all be equally important. Specific criteria were attributed to the criteria depending on their relevance and importance to quantify the principle. The criteria were translated into a survey for data collection: initially involving data from selected countries for a pilot, followed by a nationwide survey of data from IPOPI's national member organisations and key countries.

**Results:** The PID Life Index was developed in 2020 to assess the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care.

**Conclusion:** The PID Life Index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care.

frontiers | Frontiers in Immunology

TYPE Original Research  
PUBLISHED 18 April 2023  
DOI 10.3389/fimmu.2023.1166198

## COVID-19 vaccination in patients with primary immunodeficiencies: an international survey on patient vaccine hesitancy and self-reported adverse events

Martine Pergent<sup>1\*</sup>, Filomee Haerynck<sup>2,3</sup>, Levi Hoste<sup>2,3</sup> and Ann Gardulf<sup>4,5,6</sup>

**Abstract**

**Background:** The 'Primary Immunodeficiencies (PIDs) principles of care' were published in 2014 as the gold standard for care of patients with PIDs, setting a common goal for stakeholders to ensure that patients with PID have appropriate care and good quality of life. Since then, IPOPI (the International Patient Organisation for Primary Immunodeficiencies), has been working with national PID patient organisations as well as collaborating with scientific medical institutions and experts to bring these principles closer to the day-to-day life of individuals with PID.

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frontiers | Frontiers in Immunology

TYPE Original Research  
PUBLISHED 30 March 2023  
DOI 10.3389/fimmu.2023.1151355

## Initial presenting manifestations in 16,486 patients with inborn errors of immunity include infections and noninfectious manifestations

Julian Thalhammer, MD,<sup>a,b,\*</sup> Gerhard Kindl, MD,<sup>a,\*</sup> Alexandra Nieters, PhD,<sup>a</sup> Stephan Rusch,<sup>a</sup> Mikko R. J. Seppänen, MD,<sup>c</sup> Alain Fischer, MD,<sup>d,e</sup> Bodo Grimmacher, MD,<sup>a,f,g,h</sup> David Edgar, FRCP, FRCPATH,<sup>i,j</sup> Matthew Buckland, MD,<sup>k,l</sup> Nizar Mahlaoui, MD, MPH, PhD,<sup>d,e</sup> and Stephan Ehl, MD,<sup>a,g</sup> for the European Society for Immunodeficiencies Registry Working Party<sup>†</sup>

**Abstract**

**Background:** The 'Primary Immunodeficiencies (PIDs) principles of care' were published in 2014 as the gold standard for care of patients with PIDs, setting a common goal for stakeholders to ensure that patients with PID have appropriate care and good quality of life. Since then, IPOPI (the International Patient Organisation for Primary Immunodeficiencies), has been working with national PID patient organisations as well as collaborating with scientific medical institutions and experts to bring these principles closer to the day-to-day life of individuals with PID.

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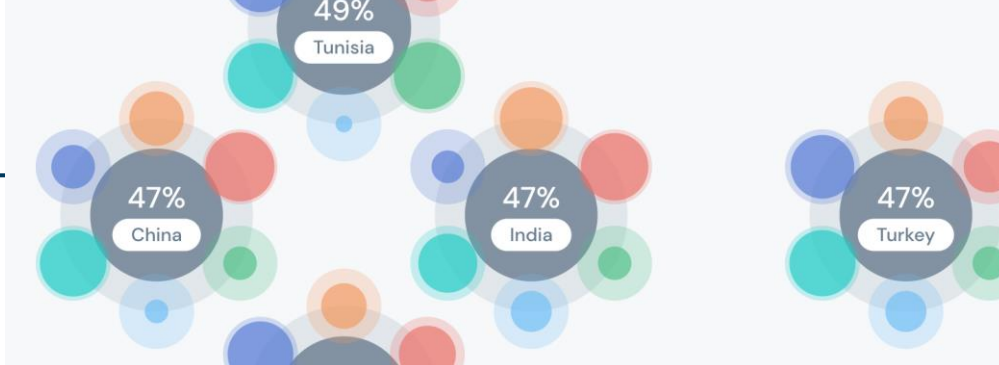
**Results:** The PID Life Index was developed in 2020 to assess the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care.

**Conclusion:** The PID Life Index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care. The index is a tool to measure the status of the PID environment and the implementation of the 6 principles of care.

# Data: the PID Life Index

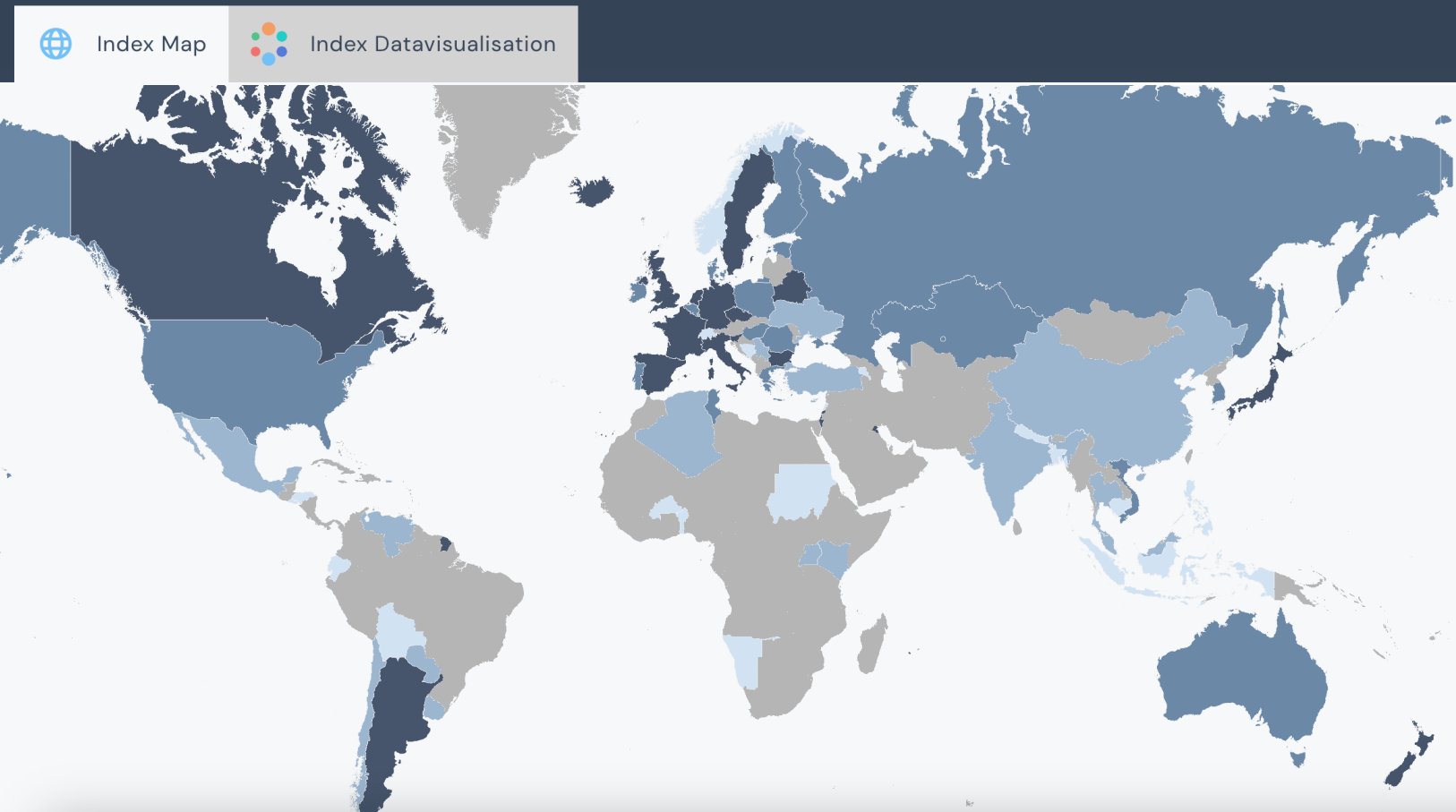
- built on 6 key principles of care
- It measures the status of the PID healthcare environment across the globe

<https://pidlifeindex.ipopi.org>



## How's life with a Primary Immunodeficiency (PID)?

The PID Life Index is an interactive tool built on 6 key principles of care that measures the status of the PID healthcare environment in a country.



# Strengthen multi-stakeholder collaboration

Presenter

Strategic objective 4



COLLABORATION



SUPPORTED BY



# Red Cross blood collection centres, hospital teams



in Thailand



In Indonesia



Prof Chean Sôphal, Cambodia



Dr Yae-Jean Kim, Korea

# Research

**IPOPI active in several research programmes:**

- Recomb,
- 3D-GATA2
- INTEGRATE-ATMPs
- JAKI consensus



# UNITAR SIGNS A MEMORANDUM OF UNDERSTANDING WITH IPOPI



IPOPI

14 August 2023, Geneva, Switzerland - We are pleased to announce that UNITAR, the United Nations Institute for Training and Research, and IPOPI, the International Patient Organization for Primary Immunodeficiencies, have entered into a new Memorandum of Understanding (MoU). This agreement represents a strong commitment to collaborating and cooperating to make a positive impact on access to plasma-derived therapies worldwide.

The MoU enhances our existing collaboration, elevating it to a true partnership. It promotes cooperation through various means, such as knowledge sharing, innovative education, training, capacity-building solutions, and raising awareness to improve access to healthcare in the field of plasma-derived therapies.

Through this collaborative endeavour, UNITAR and IPOPI aim to make significant strides in advancing healthcare and capacity-building initiatives. The partnership's collective efforts will lead to tangible and sustainable impacts, benefitting communities worldwide.

We look forward to embarking on this journey together and remain committed to fostering a meaningful and lasting

## Global initiatives with national pilots



# Launch of the International Coalition for Safe Plasma Proteins (ICSPP)

Organizations join with ISBT to advance global access to safe plasma proteins



The ISBT Working Party on Global Blood Safety initiated the ICSPP as a global coalition to advance access to safe plasma proteins in Low- and Middle- Income Countries. In cooperation with the World Health Organization, this coalition was established to address the global insufficiency of plasma-derived medicinal products that are unavailable or unaffordable in many low- and middle- income countries (LMIC) and the consequent suffering and early mortality of patients



International Society  
of Blood Transfusion



World Health  
Organization



WFH

WORLD FEDERATION OF HEMOPHILIA



PLASMA PROTEIN  
THERAPEUTICS  
ASSOCIATION

Global initiatives with national pilots



# Looking towards the future (What's Up in 2030)



## OPEN ACCESS

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## The PID Odyssey 2030: outlooks, unmet needs, hurdles, and opportunities — proceedings from the IPOPI global multi-stakeholders' summit (June 2022)

Susan Tadros<sup>1</sup>, Johan Prévot<sup>2</sup>, Isabelle Meyts<sup>3,4</sup>,  
Silvia Sánchez-Ramón<sup>5</sup>, Nahla H. Erwa<sup>6</sup>, Alain Fischer<sup>7,8,9,10</sup>,  
Guillaume Lefevre<sup>11,12</sup>, Matthew Hotchkiss<sup>13</sup>, Peter M. Jaworski<sup>14</sup>,  
Helen Leavis<sup>15</sup>, Cornelis Boersma<sup>16,17,18</sup>, Jose Drabwell<sup>2</sup>,  
Martin van Hagen<sup>19,20</sup>, Samya Van Coillie<sup>2</sup>, Martine Pergent<sup>2</sup>,  
Siobhan O. Burns<sup>1</sup> and Nizar Mahlaoui<sup>2,7,8\*</sup>

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<sup>2</sup>IPOPI, Brussels, Belgium, <sup>3</sup>Department of Pediatrics, University Hospitals Leuven, KU Leuven,  
Leuven, Belgium, <sup>4</sup>Department of Microbiology, Immunology and Transplantation, KU Leuven,  
Leuven, Belgium, <sup>5</sup>Department of Immunology, Health Research Institute of the Hospital Clínico San  
Carlos (IdiSSC), IML and IdiSSC, Madrid, Spain, <sup>6</sup>Faculty of Medicine, University of Khartoum,  
Khartoum, Sudan, <sup>7</sup>Pediatric Hematology-Immunology and Rheumatology Unit, Necker-Enfants  
malades University Hospital, Assistance Publique-Hôpitaux de Paris (AP-HP), Paris, France, <sup>8</sup>French  
National Reference Center for Primary Immune Deficiencies (CEREDIH), Necker-Enfants malades  
University Hospital, Assistance Publique-Hôpitaux de Paris (AP-HP), Paris, France, <sup>9</sup>Collège de France,  
Paris, France, <sup>10</sup>Imagine Institute, UMR Inserm 1163, Paris, France, <sup>11</sup>Univ. Lille, Inserm, CHU Lille,  
U1286 – INFINITE Institut de recherche translationnelle sur l'inflammation, Lille, France, <sup>12</sup>Institut  
d'Immunologie, CHU Lille, Lille, France, <sup>13</sup>Marketing Research Bureau, Inc., Yakima, WA, United States,  
<sup>14</sup>Strategy, Ethics, Economics, and Public Policy, McDonough School of Business, Georgetown  
University, Washington, DC, United States, <sup>15</sup>Department of Rheumatology & Clinical Immunology,  
University Medical Center (UMC), Utrecht University, Utrecht, Netherlands, <sup>16</sup>Health-Ecore B.V.,  
Zeist, Netherlands, <sup>17</sup>Unit of Global Health, Department of Health Sciences, University Medical Center  
Groningen (UMCG), University of Groningen, Groningen, Netherlands, <sup>18</sup>Department of Management  
Sciences, Open University, Heerlen, Netherlands, <sup>19</sup>Department of Internal Medicine, Division of Allergy  
& Clinical Immunology, Erasmus University Medical Center Rotterdam, Rotterdam, Netherlands,  
<sup>20</sup>Department of Immunology, Erasmus University Medical Center Rotterdam, Rotterdam, Netherlands

IPOPI held its first Global Multi-Stakeholders' Summit on 23-24 June 2022 in  
Cascais, Portugal. This IPOPI initiative aims to bring together experts from various fields to discuss the future of PID research and care.

# In the pipes...

COLLABORATION



SUPPORTED BY



# In the pipes

## **The SIDE Project: Secondary ImmunoDeficiency**

- to assess whether specific subsets of SID patients could be represented by IPOPI

## **AI Rare**

- Exploring the potential of artificial intelligence

## **IPOPI Research Grants**

- to promote scientific and clinical research in the field of immunodeficiencies.

## **IPOPI Collaborative Centres**

- Expert centres will be recognized for their commitment to a patient-centred collaborative approach in accordance with the values and principles upheld by IPOPI.

# Thank you for your kind attention!

Thank you to  
our sponsors  
for making this  
important  
meeting  
possible

どうもありがとう

매우 감사합니다

太感谢了

धेरै धेरै धन्यवाद

Terima kasih banyak-banyak

आपका बहुत-बहुत धन्यवाद

ကျေးဇူးတင်ပါသည်

Cảm ơn bạn rất nhiều

তোমাকে অনেক ধন্যবাদ

COLLABORATION



SUPPORTED BY



GRIFOLS

# Welcome to Tokyo

Ms Emi Homareda | PID Tsubasa-no-Kai



IPOPI  
5<sup>TH</sup> REGIONAL  
ASIAN PID MEETING  
24-25 MARCH 2024  
TOKYO, JAPAN  
an IPOPI event

#### COLLABORATION



#### SUPPORTED BY



# Welcome from APSID

Prof Hirokazu Kanegane | Japan



IPOPI  
5<sup>TH</sup> REGIONAL  
ASIAN PID MEETING  
24-25 MARCH 2024  
TOKYO, JAPAN  
an IPOPI event

#### COLLABORATION



#### SUPPORTED BY





# Ten-year prospective for the region (APSID role)

**Hirokazu Kanegane**

*Professor*

Tokyo Medical and Dental University (TMDU)

*President-elect*

Asian Pacific Society for Immunodeficiency (APSID)

*Vice President*

Japanese Society for Immunodeficiency and  
Autoinflammatory Diseases (JSIAD)

*Representative Medical Advisor*

PID Tsubasa-no-kai

## COLLABORATION



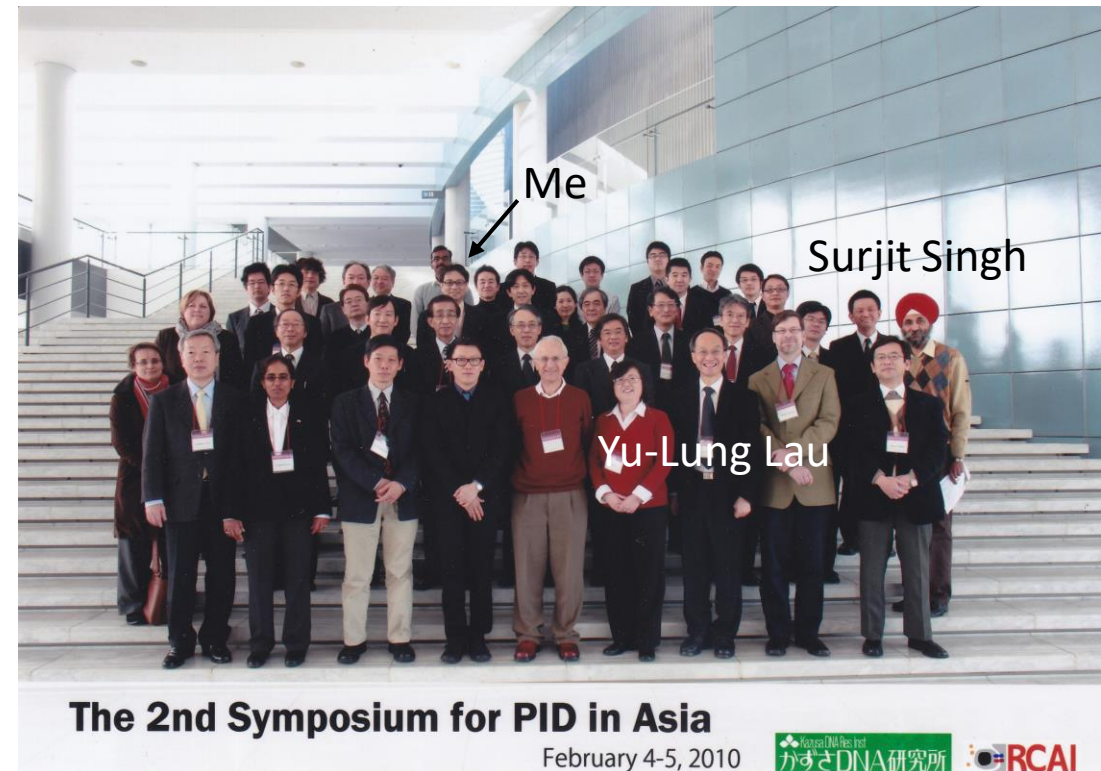
## SUPPORTED BY



## Asian PID network was started from “Symposium for PID in Asia”



Yokohama, 2009



Chiba, 2010



**Asia Pacific Society for Immunodeficiencies  
(APSID) Preparatory Meeting**  
16–17 April 2015 • Osaka, Japan

Country	Surname	Name
Bangladesh	MAHBUBUL	Hoque
China Mainland	JIANG	Min
	LU	Meiping
	MAO	Huawei
	NONG	Guangmin
	SONG	Hongmei
	WANG	Wei
	WANG	Xiaochuan
	YANG	Xi
	YANG	Xiqiang
	ZHAO	Xiaodong

Hong Kong	CHAN	Chi Fung Godfrey
	CHUNG	Hon Yin Brian
	LAU	Yu-Lung
	LEE	Pui-Wah Pamela
	LEUNG	Chi Wai
	WU	Yuet Zoe
India	SINGH	Surjit
Indonesia	KURNIATI	Nia
	MUKTIARTI	Dina
Japan	NONOYAMA	Shigeaki
	HARA	Toshiro
	KANEGANE	Hirokazu
	IMAI	Kohsuke
	NUNOI	Hiroyuki
	MORIO	Tomohiro
	OHARA	Osamu
	HEIKE	Toshio
	NISHIKOMORI	Ryuta
Korea	KANG	Eun Sook
	KANG	Ziman
	KIM	Joong-Gon
	KIM	YaeJean
	SON	Sohee
	YU	Shinae

Malaysia	ABDUL LATIFF	Amir Hamzah
	ISMAIL	Intan Hakimah
	LOKMAN	Mohd Noh
Myanmar	LINN	Kyaw
	ZAYAR	Kyaw Win
Philippines	OCAMPO	Jonie Tilah Santos
Singapore	LIEW	Woei Kang
	SOH	Jian Yi
Taiwan	CHIEN	Yin-Hsiu
	LEE	Wen-I
Thailand	PANTIPA	Chatchatee
	MANUYAKORN	Wiparat
	SUWAT	Benjaponpitak
	SURATANNON	Narissara May
	TRAKULTIVAKORN	Muthita
	WASU	Kamchaisatian
USA	OCHS	Hans
Vietnam	HUONG	Le Thi Minh
	QUANG	VU VAN
	NGUYEN	Dzung Dang
	NGUYEN	Van Anh
	TAM	Nguyen Thi Minh

# We pledge together to establish the ASPID

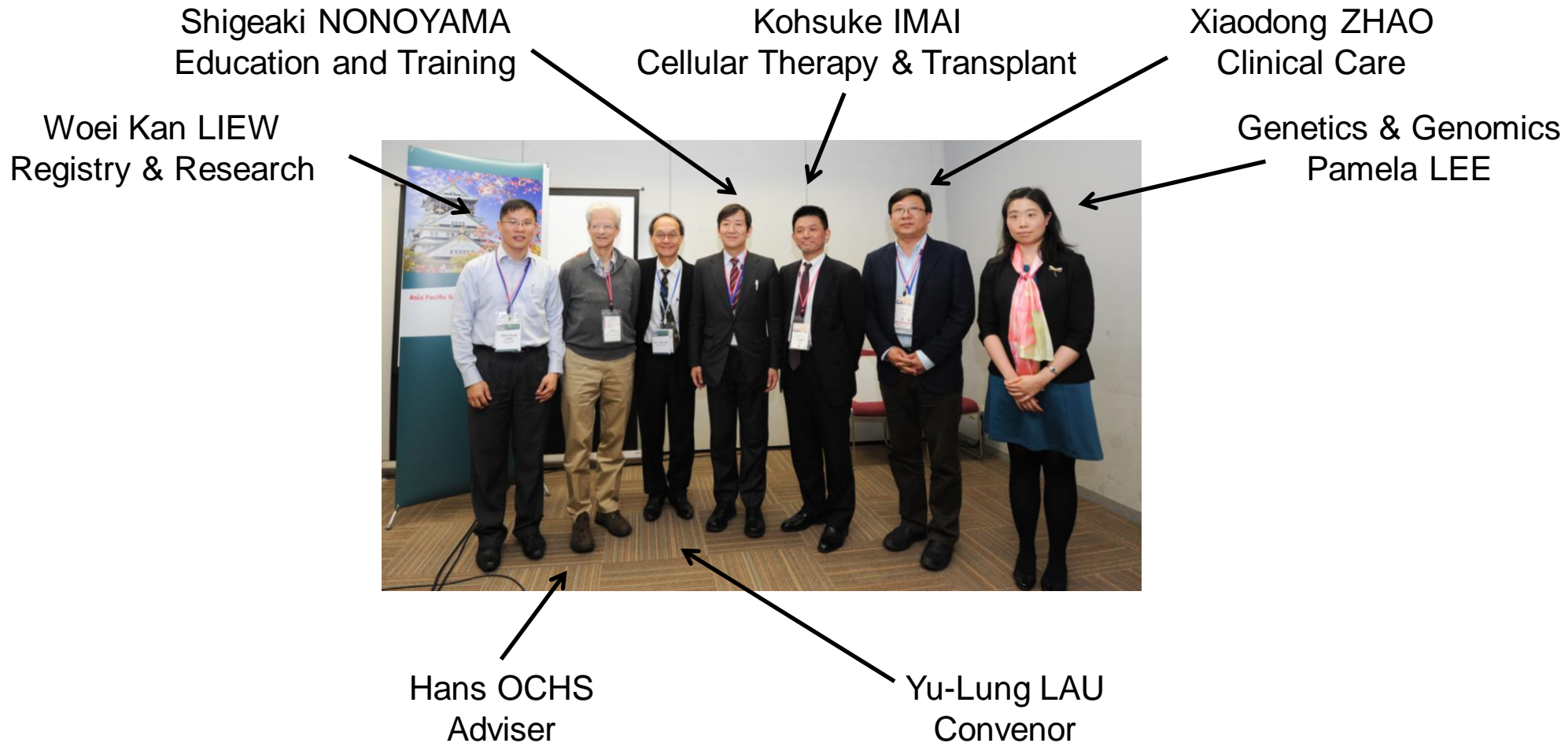
11th Asian Society for Pediatric Research (ASPR) Congress, April 14-18, 2015, Osaka, Japan



> 60 Asian  
pediatricians  
met in Osaka,  
April 2015

- Establish **APSID** with the following missions:
- To **care and cure patients** with PID
- To share our **PID experience** to promote collaboration and education
- To improve **PID management** through understanding its genetics and pathogenesis
- To **advocate and advance** in the care of PID through engaging governments, patient organization and industry

## Decisions of Osaka Group 2015



## Education and Training: APSID School from 2015



1<sup>st</sup> APSID Winter School in Hanoi, Nov 2015

International Faculty

Prof Hans Ochs

Prof Yu-Lung Lau

Prof Reinhard Seger

Prof Shigeaki Nonoyama

Prof Roger Kobayashi

Dr Daniel Suez

29 young pediatricians from 10 Asian countries

# 1<sup>st</sup> APSID Congress in Hong Kong, 28<sup>th</sup> April – 1<sup>st</sup> May 2016



**Prof Andrew Cant**

President of ESID

**Prof Luigi Notarangelo**

Immediate Past President of CIS

**Prof Hans Ochs**

Advisor of APSID

**Mrs Jose Drabwell**

President of IPOPI

**>150 participants**

# Executive Board members (updated)



Prof Surjit Singh  
President (2020-2024)



Prof Hirokazu Kanegane  
President-elect (2023-2024)



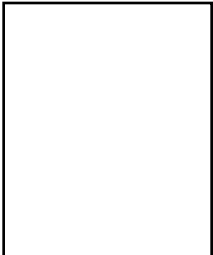
Prof Yu-lung Lau  
Advisor to the Executive Board  
Founding President (2016-2020)



Prof Amit Rawat  
Secretary (2023-2026)



Dr. Jaime Sou Da Rosa Duque  
Treasurer (2024-)



Cellular Therapy and Transplant Working Party (2024-)



Prof Huawei Mao  
Genetics & Genomics Working Party (2024-)



Dr Vignesh Pandiarajan  
Registry & Research Working Party (2024-)



Prof Yaejean Kim  
Clinical Care Working Party (2024-)



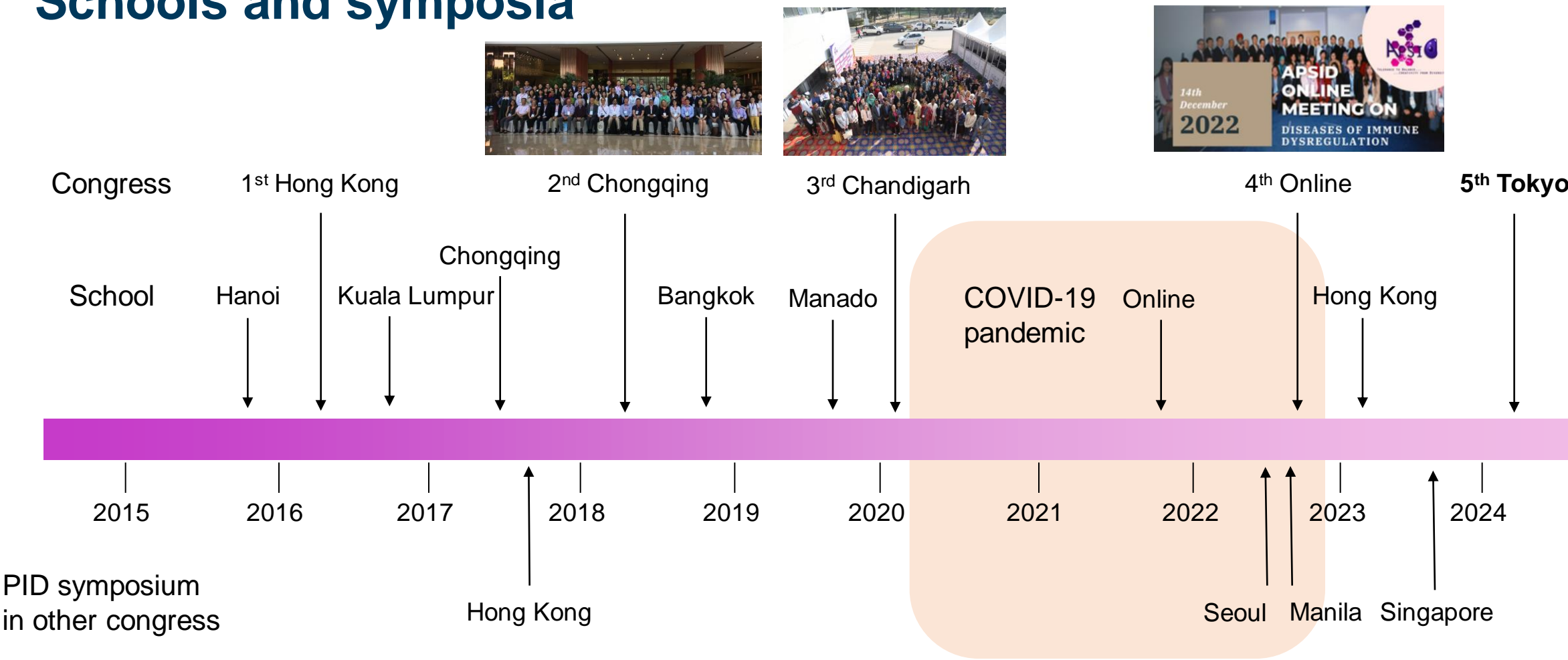
Dr Zarina Thasneem Zainudeen  
Junior Members Working Party (2024-)



Dr Narissara Suratannon  
Education and Training Working Party Chair (2023-2026)



# Schools and symposia



## PID school

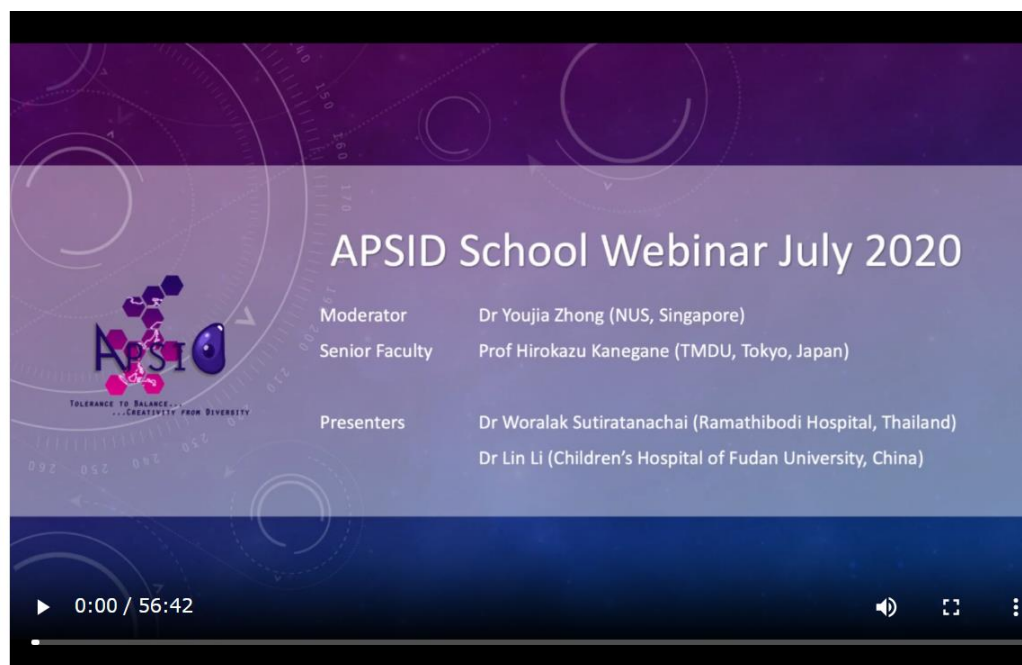


@Manado, Indonesia in 2019



@Shingapore in 2023

# APSID School Webinar was started in July 2020



	Faculty/Moderator
2020/9	Yu-Lung Lau/Vignesh Pandiarajan
2020/12	Intan Juliana Abd Hamid/Lokman M Noh Zarina Thasneem Zainudeen
2021/5	Surjit Singh/Gilbert Chuo
2021/6	Kohsuke Imai/Ankur Jindal
2021/9	Amit Rawat
2023/9	Satoshi Okada/Vignesh Pandiarajan
2024/1	P.M. van Hagen/Narissara Suratannon

# Centers of excellence (CoE)

## APSID-sponsored fellowship for junior members

### **Aim of the fellowship:**

- Identify gaps in clinical service, diagnostic/therapeutic procedures or lab techniques in primary immunodeficiency at the home institution (can be clinical or laboratory)
- Identify an APSID CoE that provides this service routinely
- Targeted learning at the host centre to transfer the expertise to the home institution

# APSID CoE

- Postgraduate Institute of Medical Education and Research, Chandigarh, India
  - Beijing Children's Hospital, Beijing, China  
&
  - The University of Hong Kong, Hong Kong, China
  - Hiroshima University, Hiroshima, Japan
- 



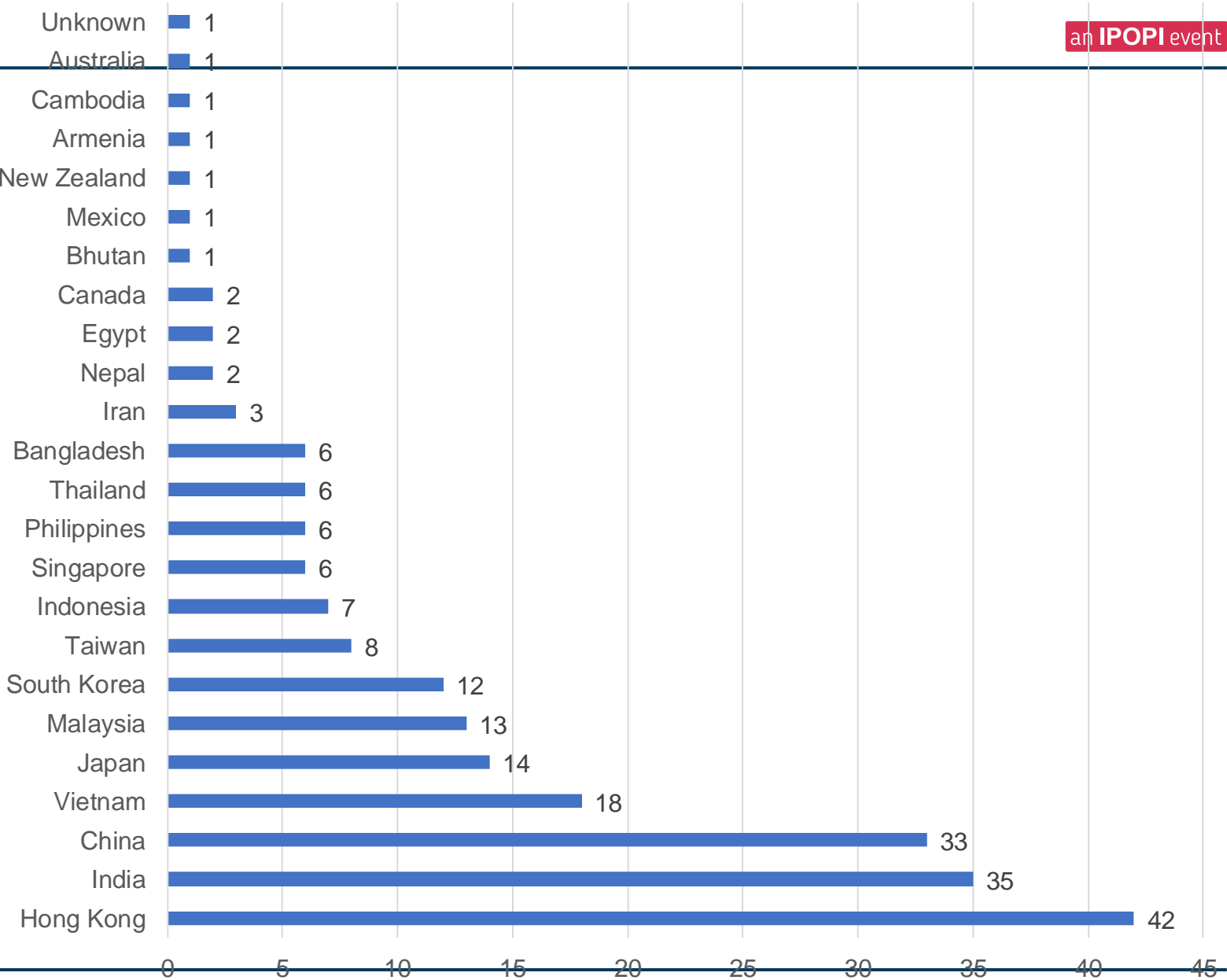
HIROSHIMA UNIVERSITY



**HKU  
Med**

School of Clinical Medicine  
Department of Paediatrics  
& Adolescent Medicine  
香港大學兒童及青少年科學系

# APSID members in each country



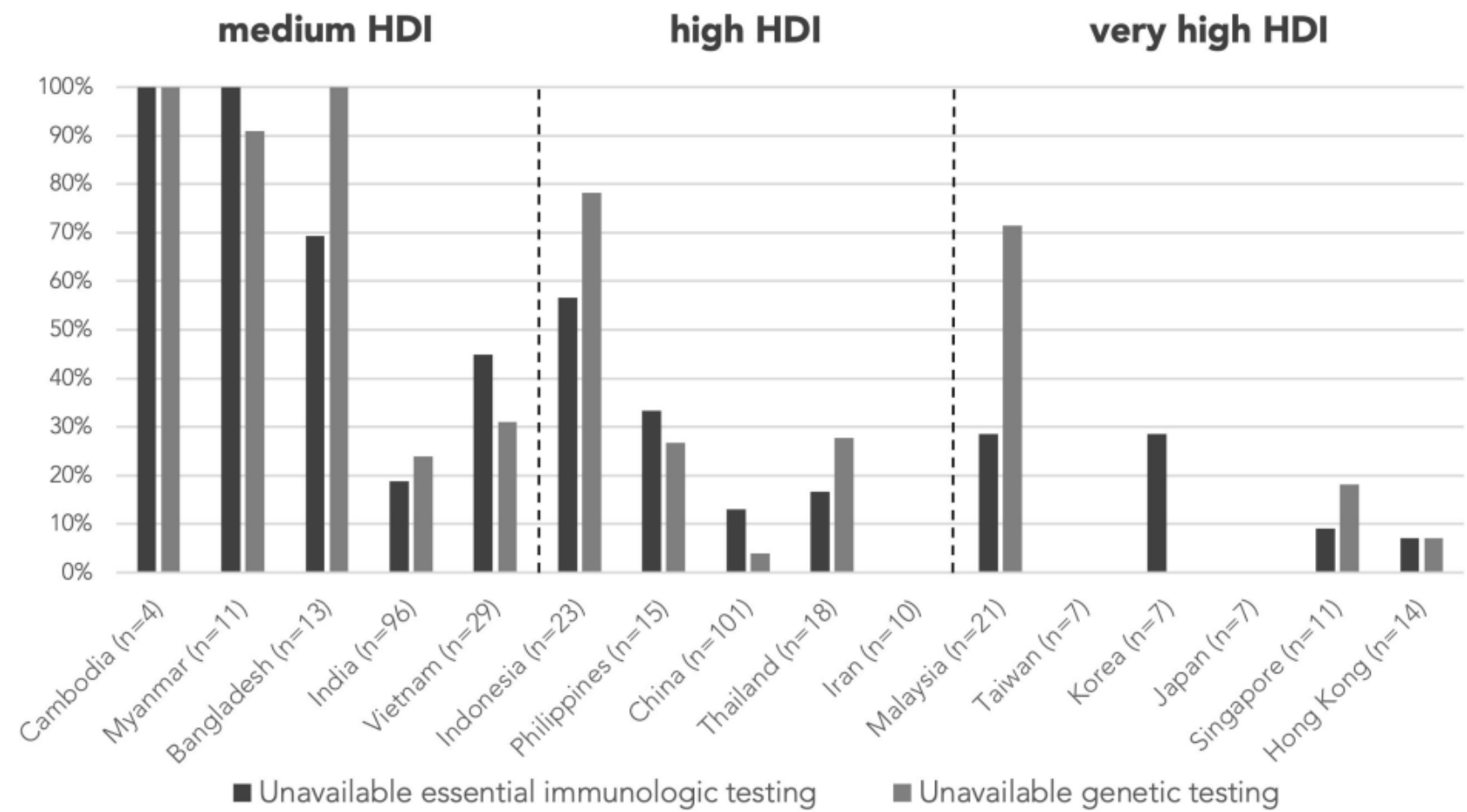


# Current Perspectives and Unmet Needs of Primary Immunodeficiency Care in Asia Pacific

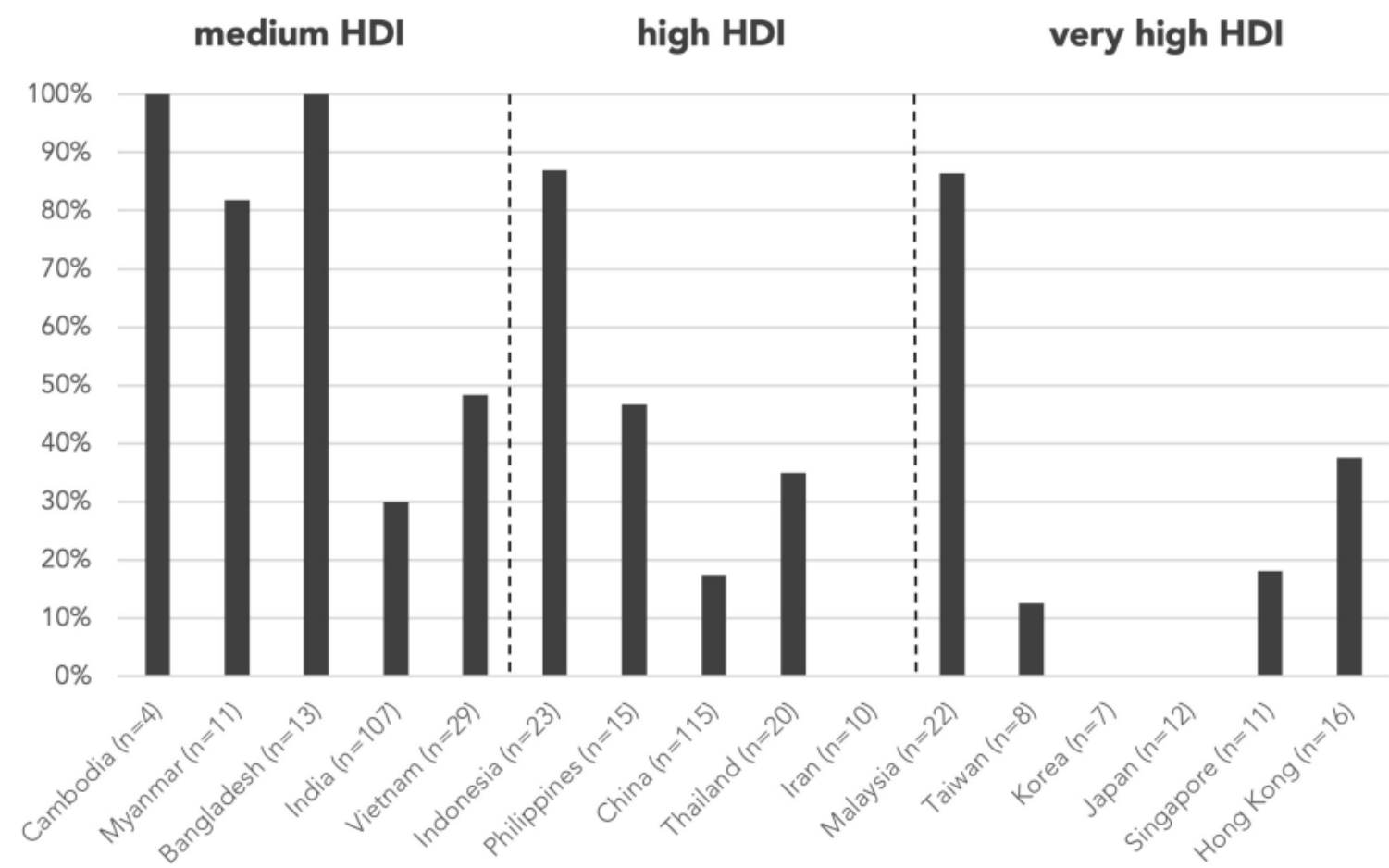
*Daniel Leung<sup>1†</sup>, Gilbert T. Chua<sup>1†</sup>, Alric V. Mondragon<sup>2</sup>, Youjia Zhong<sup>3</sup>, Le Nguyen-Ngoc-Quynh<sup>4</sup>, Kohsuke Imai<sup>5</sup>, Pandiarajan Vignesh<sup>6</sup>, Narissara Suratannon<sup>7</sup>, Huawei Mao<sup>8</sup>, Wen-I Lee<sup>9</sup>, Yae-Jean Kim<sup>10</sup>, Godfrey C. F. Chan<sup>1</sup>, Woei Kang Liew<sup>11</sup>, Le Thi Minh Huong<sup>4</sup>, Hirokazu Kanegane<sup>12</sup>, Dina Muktiarti<sup>13</sup>, Xiaodong Zhao<sup>8</sup>, Fatima Johanna Santos-Ocampo<sup>14</sup>, Amir Hamzah Abdul Latiff<sup>15</sup>, Reinhard Seger<sup>16</sup>, Hans D. Ochs<sup>17</sup>, Surjit Singh<sup>6</sup>, Pamela P. Lee<sup>1\*</sup> and Yu Lung Lau<sup>1\*</sup>*

Level	Presence of any one of these tests
0	No laboratory tests performed
1	CBC, IgG/A/M
2	IgE, C3, C4, CH50, AH50, functional antibody response including to tetanus, polio, hepatitis B vaccine
3	Basic lymphocyte subset analysis (CD3, CD4, CD8, CD19, CD20, CD16, CD56), dihydrorhodamine test, nitroblue tetrazolium test
4	Lymphocyte cell marker CD45RO/RA, TREC qPCR, lymphocyte proliferation test, NK cytotoxicity studies
5	Comprehensive T or B cell subset with markers other than those mentioned in levels 3 and 4, protein expression of PID genes (e.g., WASP, BTK, CD40L by flow cytometry), assays of pathway activation (e.g., pSTAT3 by Western blot or flow cytometry), cytokine production (e.g., IFN-gamma level by ELISA)

*CBC, complete blood count, TREC, T-cell receptor excision circle; qPCR, quantitative polymerase chain reaction.*



HDI, Human Development Index.



Cambodia  
Myanmar  
Bangladesh  
India  
Vietnam

Indonesia  
Philippines  
China  
Thailand  
Iran

Malaysia  
Taiwan  
Korea  
Japan  
Singapore  
Hong Kong

HDI	Diagnostics	Therapeutics
Medium	<ol style="list-style-type: none"> <li>1. CBC</li> <li>2. IgG/A/M/E</li> <li>3. Lymphocyte subset (CD3, CD4, CD8, CD19/20, and CD16/56)</li> <li>4. NBT test or DHR test</li> <li>5. C3, C4, CH50, and AH50</li> <li>6. Functional antibody response to tetanus, polio, and hepatitis B vaccine</li> <li>7. Sanger sequencing for <i>BTK</i>, <i>WAS</i>, <i>IL2RG</i>, and <i>CYBB</i></li> </ol>	<ol style="list-style-type: none"> <li>1. Antimicrobials</li> <li>2. IMG</li> </ol>
High	<ol style="list-style-type: none"> <li>1. Naive and memory T cell marker CD45RO/RA</li> <li>2. TREC qPCR</li> <li>3. Lymphocyte proliferation test</li> <li>4. NK cytotoxicity study</li> <li>5. C1 esterase inhibitor level and function</li> <li>6. Targeted PID NGS panel</li> <li>7. WES</li> </ol>	<ol style="list-style-type: none"> <li>1. Commonly used biologics</li> <li>2. HSCT</li> <li>3. SCIG</li> </ol>
Very high	<ol style="list-style-type: none"> <li>1. Comprehensive T or B cell subset with markers other than those mentioned (CD3, CD4, CD8, CD19/20, CD16/56, CD45RO/RA)</li> <li>2. Protein expression of PID genes (e.g., WASP, BTK, CD40L by flow cytometry)</li> <li>3. Assays of pathway activation (e.g., pSTAT3 by Western blot or flow cytometry)</li> <li>4. Cytokine production (e.g., IFN-gamma level by ELISA)</li> <li>5. SCID NBS (TREC qPCR)</li> <li>6. WGS</li> </ol>	<ol style="list-style-type: none"> <li>1. Complete access to biologics</li> <li>2. Gene therapy</li> </ol>

## Conclusion

- Different countries/regions in Asia Pacific are at different stages of development in the **care** and **training** related to PID, depending on their **HDI**.
- APSID will continue to serve as an important platform for the sharing of **experiences** and **resources** to improve PID care in the Asia Pacific region.

Thank you for your kind attention.

COLLABORATION



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# Welcome from SEAPID

Dr Adli Ali | Malaysia



**IPOPI**  
**5<sup>TH</sup> REGIONAL**  
**ASIAN PID MEETING**  
24-25 MARCH 2024  
TOKYO, JAPAN  
an **IPOPI** event

#### COLLABORATION



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# SEAPID (South East Asia PID) Network



# The initiative



International Patient Organisation for Primary Immunodeficiencies



# The First Care-for-Rare European-South-East Asian PID-Meeting: From Bench to The Bedside (26 Jan 2015)



**1<sup>ST</sup> CARE-FOR-RARE  
EUROPEAN-SOUTHEAST ASIAN  
PRIMARY IMMUNODEFICIENCY (PID) MEETING  
FROM BENCH TO BEDSIDE**

**JANUARY 26, 2015**  
MONGKOLRAJAVAN HALL, 5TH FLOOR BUILDING,  
CHULALONGKORN UNIVERSITY, BANGKOK, THAILAND

VENUE	CONFIRMED SPEAKERS
Mongkolrajav Hall, Floor 10, Sor-Kor Building King Chulalongkorn Memorial Hospital Chulalongkorn University, Bangkok, Thailand	<ul style="list-style-type: none"> <li>● Prof. Dr. Christoph Klein (Germany)</li> <li>● Prof. Dr. Martin van Hagen (the Netherlands)</li> <li>● Dr. Adi Bin Ali (Malaysia)</li> <li>● Prof. Le Huong (Vietnam)</li> <li>● Dr. Kanya Suphacheeporn &amp; Dr. Narissara Surattanon (Thailand)</li> <li>● Dr. Liew Wei Kang (Singapore)</li> </ul>

SCIENTIFIC PROGRAMME	
MORNING	AFTERNOON
● <b>9.00 - 10.30</b> Clinical Challenges and Novel Diagnostic Tools Including NGS & New Therapies (Prof. Dr. Christoph Klein)	● <b>13.30 - 14.45</b> Current Status PID in Southeast Asia: Examples from Malaysia, Vietnam, Singapore, and Thailand (Dr. Adi Bin Ali, Prof. Le Huong, Dr. Liew Wei Kang, Dr. Kanya Suphacheeporn, and Dr. Narissara Surattanon)
● <b>10.30 - 11.00</b> Coffee Break	● <b>14.45 - 15.15</b> Coffee Break
● <b>11.00 - 12.30</b> Antibody Deficiencies from Bench to the Bedside (Prof. Dr. Martin van Hagen)	● <b>15.15 - 16.15</b> Round Table Discussion: Access to Diagnostics and PID Care in Southeast Asia
● <b>12.30 - 13.30</b> Lunch	● <b>16.30 - 17.30</b> The Importance of Stakeholder Collaboration and International Collaborations
	● <b>17.30 - 18.00</b> Launch of PID Southeast Asian Network & Further Collaboration

**PRE-REGISTRATION:**  
<http://goo.gl/Fu3L07>

**FOR MORE INFORMATION:**  
E-mail: [Dr. Rungnapha.Hitwut@runghapah@yahoo.com](mailto:Dr. Rungnapha.Hitwut@runghapah@yahoo.com)  
PHONE: +66 2 2564000 ext. 3354








# 6 Founders: SEAPID network

Thailand

Malaysia

Singapore

Vietnam

Indonesia

The Philippines



# SEAPID Network: Mission

1. **Education:** Educational efforts should be put into place to increase the expertise on PIDs in the South East Asia region
2. **PID Registries:** National PID registries should be established in all South East Asian countries.
3. **Early diagnosis:**
  - a) Support South East Asian healthcare providers to facilitate the early diagnosis of PIDs
  - b) Provision of basic PID blood tests – to be done in facilities compliant with internationally recognized standards.
  - c) To further develop PID genetic diagnostics and these be made accessible and timely

# Acknowledgment



# Acknowledgment



# Acknowledgment



# Keynote lecture: Ten-year prospective for the region (APSID role)

Prof Hirokazu Kanegane | Japan



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# Q&A



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# COFFEE BREAK

## 15 MIN

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