



IPOPI 5TH REGIONAL ASIAN PID MEETING

24-25 MARCH 2024

TOKYO, JAPAN

an **IPOPI** event

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ASIAN PID MEETING
24-25 MARCH 2024
TOKYO, JAPAN
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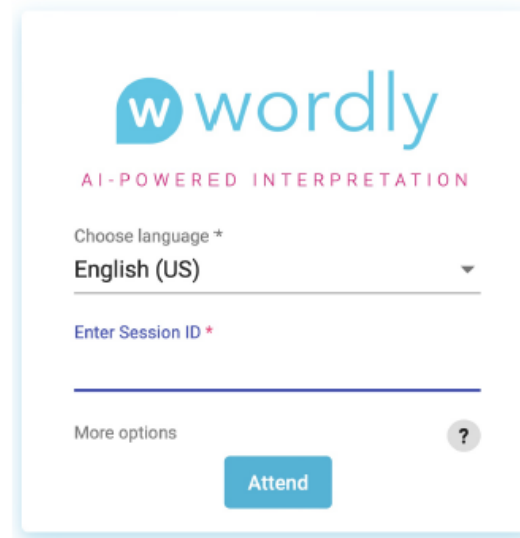
Live Translation

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 in blue. Below it, in pink, is the text 'AI-POWERED INTERPRETATION'. There are two input fields: 'Choose language *' with 'English (US)' selected, and 'Enter Session ID *' which is empty. Below these is a 'More options' link and a blue 'Attend' button. A small question mark icon is also visible.

Choose Language
Click Attend

Step 3



Read Captions on Device
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SESSION 3 | PID management and access: the Asia-Pacific context

Moderators:

Johan Prevot (IPOPI Executive Director)

Dr Adli Ali (Malaysia)



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PID Life Index – Avenues for the future in Asia

Dr Adli Ali | Malaysia



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RESEARCH

Open Access



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

Leire Solís¹, Julia Nordin¹, Johan Prevot¹, Nizar Mahlaoui^{2,3}, Silvia Sánchez-Ramón^{4,5}, Adli Ali^{6,7}, Elodie Cassignol⁸, John W. Seymour^{1,9} and Martine Pergent^{1*} 



The PID Principles of Care: Where Are We Now? A Global Status Report Based on the PID Life Index

Julia Nordin^{1†}, Leire Solís^{1†}, Johan Prévot¹, Nizar Mahlaoui^{2,3}, Helen Chapel⁴, Silvia Sánchez-Ramón^{5,6}, Adli Ali^{7,8}, John W. Seymour^{1,9} and Martine Pergent^{1*}

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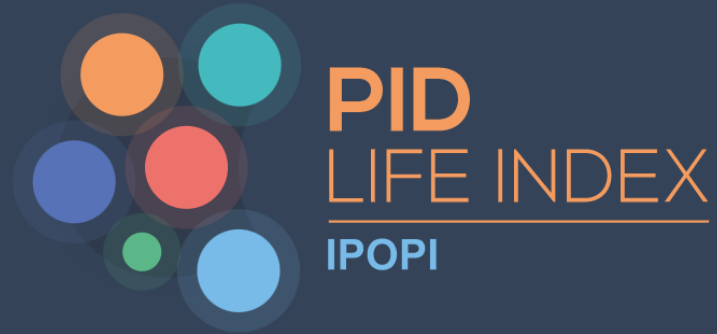
Edited by:

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Reviewed by:

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¹ The International Patient Organisation for Primary Immunodeficiencies, Donderry, United Kingdom, ² Pediatric Immunology-Hematology and Rheumatology Unit, Necker Children's University Hospital, Assistance Publique-Hôpitaux de Paris (AP-HP), Paris, France, ³ French National Reference Center for Primary Immune Deficiencies (CEREDIH), Necker Children's University Hospital, Assistance Publique-Hôpitaux de Paris (AP-HP), Paris, France, ⁴ Nuffield Department of Medicine, University of Oxford, Oxford, United Kingdom, ⁵ Department of Clinical Immunology, Instituto de Medicina del Laboratorio (IML) and Instituto de Investigación Clínico San Carlos (IdiSSC), Hospital Clínico San Carlos, Madrid, Spain, ⁶ Department of Immunology, ENT and Ophthalmology, Complutense University School of Medicine, Madrid, Spain, ⁷ Clinical Immunology Unit, Department of Paediatrics, Faculty of Medicine, Universiti Kebangsaan Malaysia Medical Centre, Kuala Lumpur, Malaysia, ⁸ Institute of IR4.0, Universiti Kebangsaan Malaysia, Bangi, Malaysia, ⁹ Department of Counseling and Student Personnel, Minnesota State University, Mankato, MN, United States



The PID Life Index aggregates information submitted voluntarily by IPOPI national member organisations and by medical contacts. While not exhaustive, the PID Life Index sheds light on the worldwide PID environment. IPOPI welcomes any feedback to help optimizing this index.

IPOPI PID Life Index :

What are the principles of care?

Registries

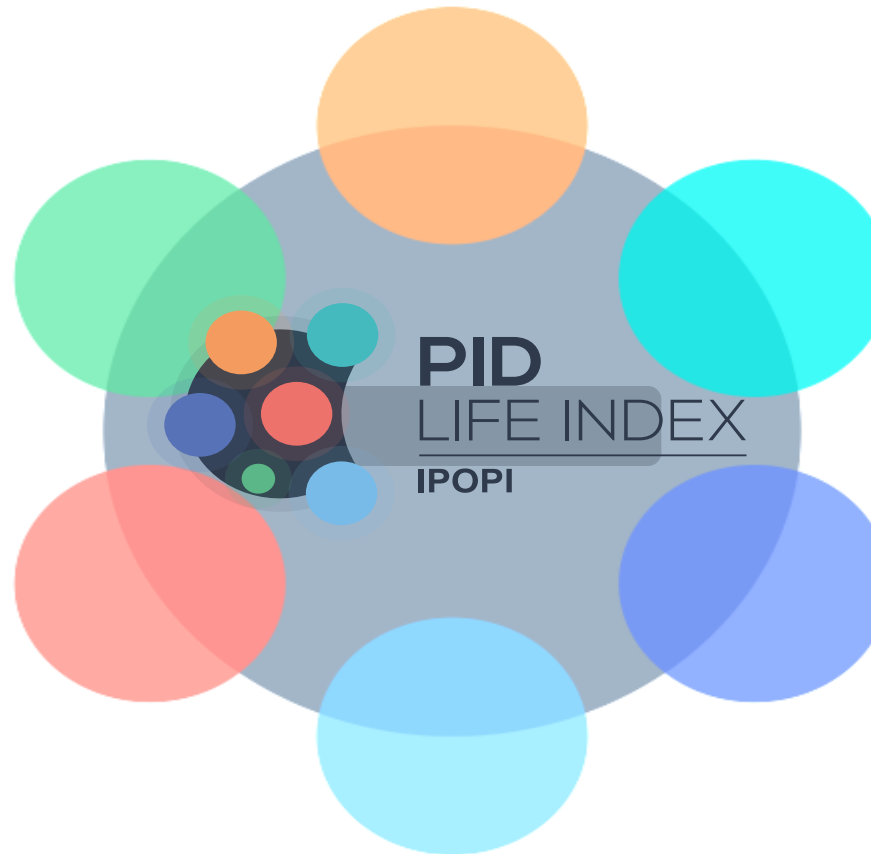
- National PID registry
- Bone marrow donor registry

National Patients Organisations

- Established national group in country
- Professional paid staff
- Main working areas

Specialised centres

- National PID specialised centre/network
- Adult PID services
- Transition care



PID Diagnosis

- Diagnosis rate
- Biological diagnosis availability
- Genetic diagnosis availability
- Prenatal diagnosis availability
- Newborn screening for SCID

Treatments

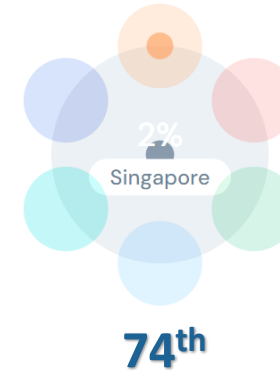
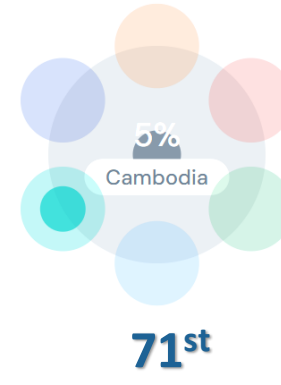
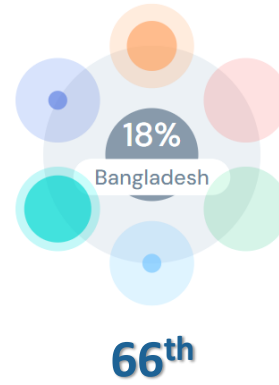
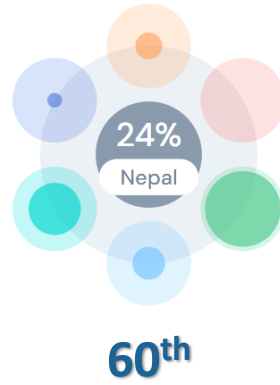
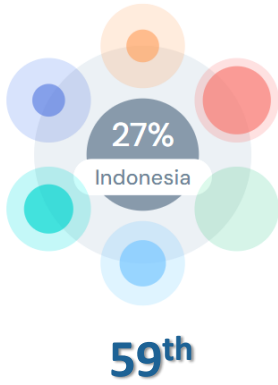
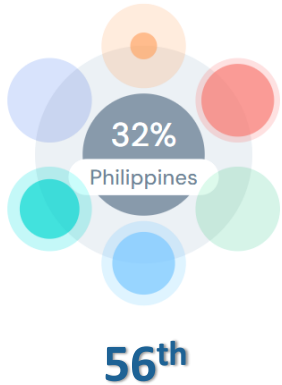
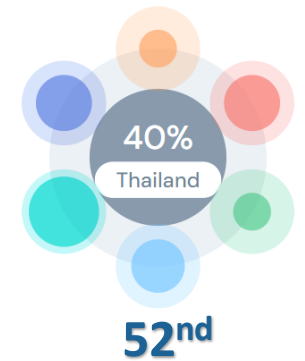
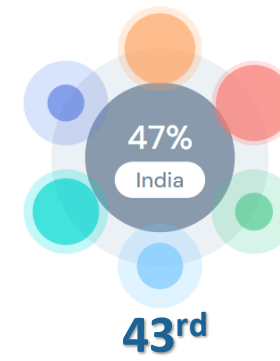
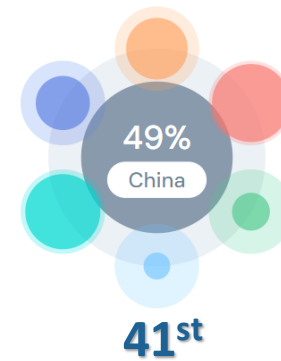
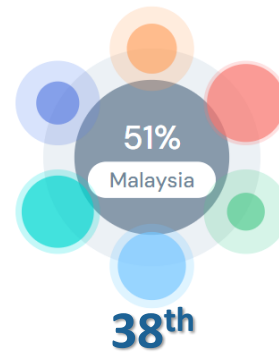
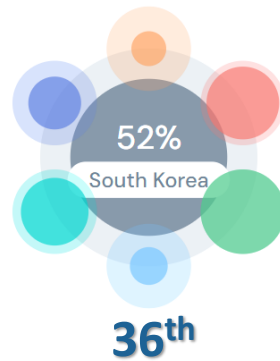
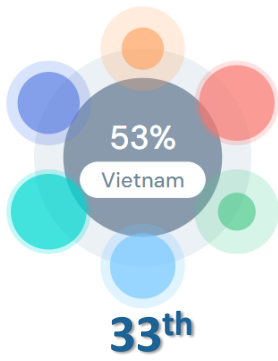
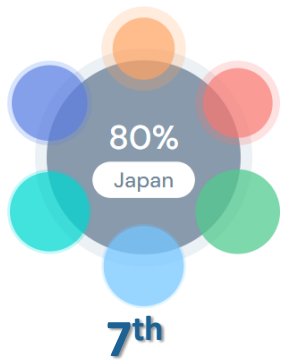
- Anti-infectious availability
- Ig availability
- Vaccines availability
- Curative treatments
- Biological and targeted therapies
- Plasma collection

Universal health coverage

- Diagnosis Reimbursement
- Treatments Reimbursement

Where are Asia Pacific in PID management?

Data from IPOPI PID Life Index





Check for updates

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SPECIALTY SECTION

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

Chee Mun Chan^{1,2}, Nizar Mahlaoui^{3,4}, Silvia Sánchez–Ramón^{5,6},
Martine Pergent⁷, Leire Solis⁷, Johan Prevot⁷ and Adli Ali^{1,2,8,9*}
on behalf of the South East Asia Primary Immunodeficiencies
(SEAPID) Consortium

PID LIFE INDEX: FOCUS ON ASIA (SEA CASE STUDIES)

DIAGNOSIS RATE

- Underdiagnosed / Misdiagnosed
- Current challenges:
 - No proper diagnosis
 - Access to diagnosis → Equity
 - Geographical challenge
 - Cross-borders issues?
- Development of CoE (IPOPI CoE?)
 - Accessible diagnostic option
 - Cost / Logistic
 - Dried blood spot / buccal mucosa

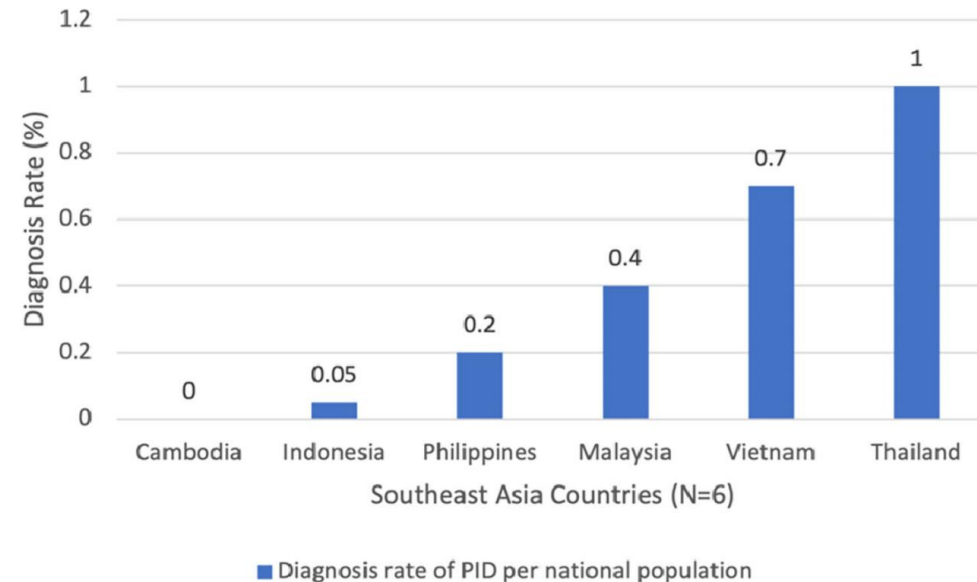


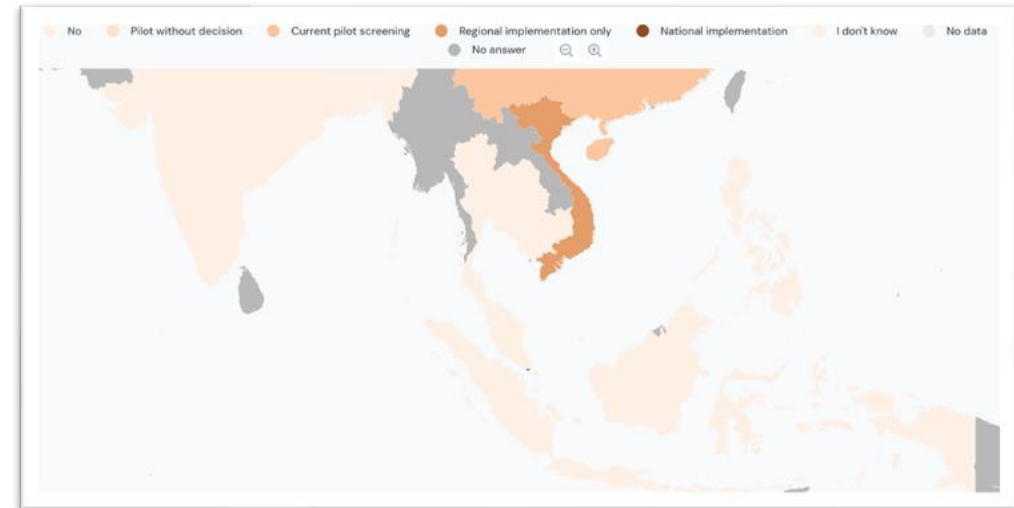
FIGURE 1

Diagnosis rate of Primary immunodeficiencies (PID) in Southeast Asia (SEA). Notes: The diagnosis rate of different countries are calculated based on the known number of patients and the theoretical number of PID patients in each country (based on a prevalence rate of 1 in 2, 000 inhabitants). The diagnosis rate is expressed in %.

PID LIFE INDEX: FOCUS ON ASIA (SEA CASE STUDIES)

DIAGNOSIS RATE

- Cheaper / logistically-accessible test
 - Introduction of LDT/ RUO tests for wider screening?
 - Functional / Protein expression panel
- Repurposing/ Expanding test indication
 - Calculated globulin/ Isohemagglutinin
- Newborn screening for SCID
 - National advocacy initiative
 - Public-private-partnership



Paving the way in implementation of SCID Newborn Screening in Resource-Constrained Nations: Feasibility Study and Strategies to Move Forward

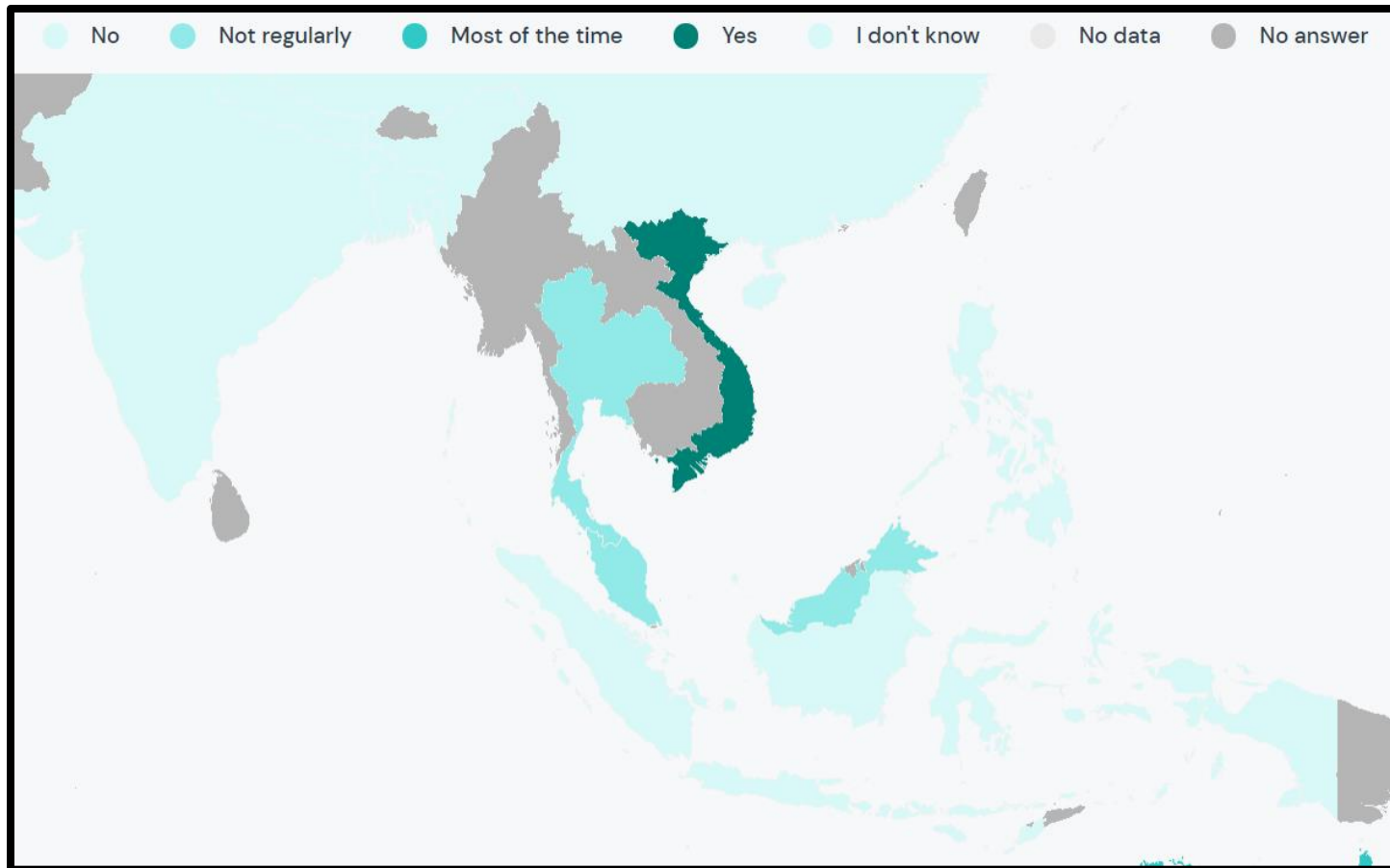
Gaayathri Kumarasamy^{1†}, Khayrin Khairiz^{1†}, Wai Leng Chang^{2,3}, Thin Thin Aye¹ and Adli Ali^{1,2,3,4,5*}

PID LIFE INDEX: FOCUS ON ASIA (SEA CASE STUDIES)

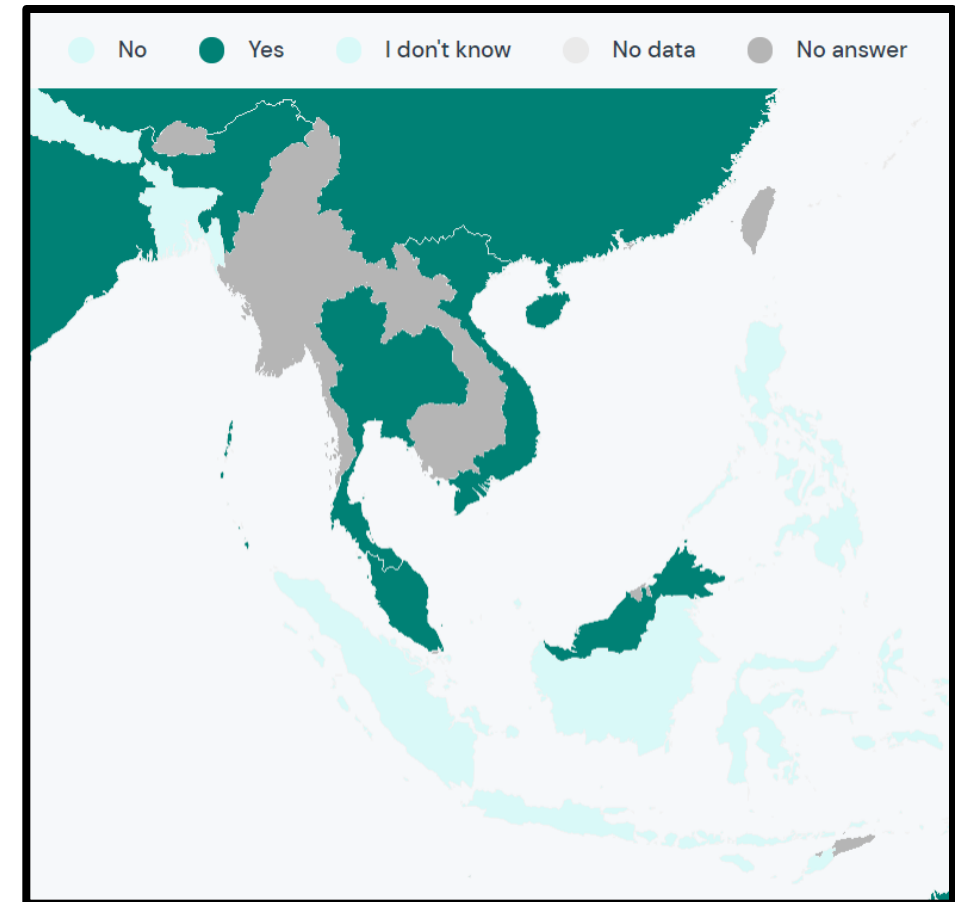
ACCESS TO TREATMENT (EXAMPLES)



Subcutaneous Ig treatment



Curative treatment (BMT/ HSCT)



PID LIFE INDEX: FOCUS ON ASIA (SEA CASE STUDIES)

ACCESS TO TREATMENT

- Regionally - available
 - Equity issues / Access: only citizen
 - international policy / trans-countries
- Cross-regional partnership
 - IPOPI/APSID/Care-for Rare/Erasmus MC
 - UNITAR-Malaysia
- Biological and targeted therapies
 - Extension indication for PID
 - Immuno-cytokine profiling for PID
- Gene therapy / Novel treatment?
 - Regional clinical trials sites?
 - Regional procurement?
 - Regional Viral Vector CDMO?

Types of treatment	Availability of treatment, N=6 (%)			
	No	Not regularly	Most of the time	Yes
A) Biological treatments				
Enzymes	0	0	0	6 (100.0)
Immunosuppressors	1 (16.7)	3 (50.0)	1 (16.7)	1 (16.7)
Monoclonal antibodies	0	4 (66.7)	1 (16.7)	1 (16.7)
Cytokines	3 (50.0)	3 (50.0)	0	0
Growth Factor	1 (16.7)	2 (33.3)	1 (16.7)	2 (33.3)
C1 inhibitor	5 (83.3)	1 (16.7)	0	0
Thrombopoietin	4 (66.7)	1 (16.7)	0	1 (16.7)
B) Routes of immunoglobulin				
IVIG	0	1 (16.7)	- ^a	5 (83.3)
SCIG	3 (50.0)	2 (33.3)	- ^a	1 (16.7)
FSCIG	4 (66.7)	2 (33.3)	- ^a	0
C) Anti-infectious				
Antibiotics	0	0	1 (16.7)	5 (83.3)
Antivirals	0	0	0	6 (100.0)
Antifungals	0	2 (33.3)	1 (16.7)	3 (50.0)
Antiparasitic	1 (16.7)	1 (16.7)	0	4 (66.7)
D) Vaccines	1 (16.7)	- ^a	- ^a	5 (83.3)
E) Curative treatments				
Bone marrow transplant	2 (33.3)	- ^a	- ^a	4 (66.7)
Gene therapy	6 (100.0)	- ^a	- ^a	0
Thymic transplant	6 (100.0)	- ^a	- ^a	0

PID LIFE INDEX: FOCUS ON ASIA (SEA CASE STUDIES)

SPECIALIZED CENTRE

- Recognized CoE for PID?
 - IPOPI Centre in PID Life Index
- Adult immunologist: inadequate
 - Pathway and recognition
- Transition care: no proper pathway
 - developing consensus/guidelines

Types of specialized centers	Availability of facilities, N=6 (%)					
	No	Yes, only one center	Yes, several uncoordinated small networks	Yes, single national network of specialized centers	Yes, some specialized centers	Yes, several centers
Adult PID service	2 (33.3)	1 (16.7)	0	0	0	3 (50.0)
National PID specialized centre/network	1 (16.7)	0	1 (16.7)	1 (16.7)	0	3 (50.0)
Transition care	0	0	0	0	3 (50.0)	0


Frontiers in Immunology

TYPE Original Research
PUBLISHED 13 July 2023
DOI 10.3389/fimmu.2023.1209315



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EDITED BY
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Transition practice for primary immunodeficiency diseases in Southeast Asia: a regional survey

PID LIFE INDEX: EXPANDING THE INDEX

Journal of Clinical Immunology
https://doi.org/10.1007/s10875-023-01463-1

ORIGINAL ARTICLE

Health-Related Quality of Life of Patients and Families with Primary Immunodeficiency in Malaysia: a Cross-Sectional Study

Ruwaydah Ahmed Meelad¹ · Intan Juliana Abd Hamid¹ · Zarina Thasneem Zainudeen¹ · Ilie Fadzil Hashim¹ · Muhd Nur Akmal Azizuddin¹ · Ernest Mangantig¹ · Fahisham Taib² · Norsarwany Mohamad² · Intan Hakimah Ismail³ · Amir Hamzah Abdul Latiff⁴ · Lokman Mohd Noh⁵

frontiers
in Immunology

ORIGINAL RESEARCH
published: 15 April 2023
doi: 10.3389/fimmu.2023.00614

Rapid Low-Cost Microarray-Based Genotyping for Genetic Screening in Primary Immunodeficiency

Narissara Suratannon^{1,2*}, Rogier T. A. van Wijck^{3,4}, Linda Broer⁴, Laixi Xue⁵, Joyce B. J. van Meurs⁴, Barbara H. Barendregt^{1,5}, Mirjam van der Burg⁴, Willem A. Dik^{1,5,6}, Pantipa Chatchatee⁷, Anton W. Langerak^{1,5}, Sigrid M. A. Swagemakers^{3,7}, Jacqueline A. C. Goos⁴, Irene M. J. Mathijssen⁴, Virgil M. A. S. H. Dalm^{1,5,6}, Kanya Suphapeetiporn^{8,10}, Kim C. Heezen¹, Jose Drabwell¹¹, André G. Uitterlinden⁴, Peter J. van der Spek^{2,5,6}, P. Martin van Hagen^{1,2,3,5} and the South East Asia Primary Immunodeficiencies (SEAPID) Consortium

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Edited by:
Antonio Condino-Neto,

frontiers
in Immunology

ORIGINAL RESEARCH
published: 21 February 2022
doi: 10.3389/fimmu.2022.825867

Pediatric Prediction Model for Low Immunoglobulin G Level Based on Serum Globulin and Illness Status

Narissara Suratannon^{1,2,3}, Phimpika Tantithummawong^{1,2}, Cameron Paul Hurst⁴, Yuda Chongpison⁵, Jongkonnree Wongpiyabovorn⁶, P. Martin van Hagen^{1,2,3,7}, Willem A. Dik^{3,8} and Pantipa Chatchatee^{1,2*}

frontiers | Frontiers in Immunology

TYPE Original Research
PUBLISHED 12 January 2024
DOI 10.3389/fimmu.2023.1308305

Knowledge, awareness, and perception on genetic testing for primary immunodeficiency disease among parents in Malaysia: a qualitative study

Ahmad Hazim Syakir Ahmad Azahari¹, Farheen Hakim Zada¹, Intan Hakimah Ismail², Intan Juliana Abd Hamid³, Bruce Wee Diong Lim⁴, Noor Akmal Shareela Ismail^{5,6} and Adli Ali^{1,5*}

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PID LIFE INDEX: FUTURE AVENUES IN ASIA

REFLECTION ON FUTURE OUTLOOK

- ❖ **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

Q&A



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Panel discussion: Empowering regional advancements: Innovations and initiatives from participating countries

Prof Kohsuke Imai (Japan), Dr Van Anh Nguyen (Vietnam),
Dr Narissara Suratannon (Thailand), Dr Dina Muktiarti (Indonesia),
Dr Jonie Tillah (Philippines), Dr Yae-Jean Kim (South Korea), Dr Dharmagat (Nepal)



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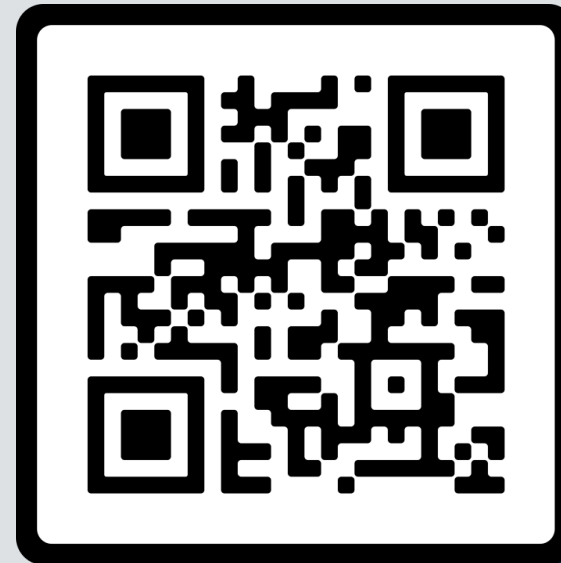
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