



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

24-25 MARCH 2024

TOKYO, JAPAN

an **IPOPI** event

COLLABORATION



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# WI-FI

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



**IPOPI**  
**5<sup>TH</sup> REGIONAL**  
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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 AI-Powered Interpretation interface. It features the Wordly logo at the top, followed by the text 'AI-POWERED INTERPRETATION'. Below this is a dropdown menu labeled 'Choose language \*' with 'English (US)' selected. There is a text input field labeled 'Enter Session ID \*' and a 'More options' link with a question mark icon. At the bottom is a blue 'Attend' button.

Choose Language  
Click Attend

## Step 3



Read Captions on Device  
Use Headset for Audio

# SESSION 3 | PID Action Planning Workshop

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Moderators:

Ms Miriam Ferreira (*IPOPI NMO Programmes Officer*)

PhD Samya Van Coillie

(*IPOPI Medical Affairs Project Manager*)



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## 3 Steps for Effective Planning



**DEVELOP:**  
50 minutes



**PRESENT:**  
5 minutes per  
sub-group

# Implementation of the 6 principles of care: *practical take-home tools*

Moderators:

PhD Samya Van Coillie (*IPOPI Medical Affairs Project Manager*)

Ms Miriam Ferreira (*IPOPI NMO Programmes Officer*)



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# DIAGNOSIS

Estimated PID incidence – How does it compare to the diagnostic rates in your country?

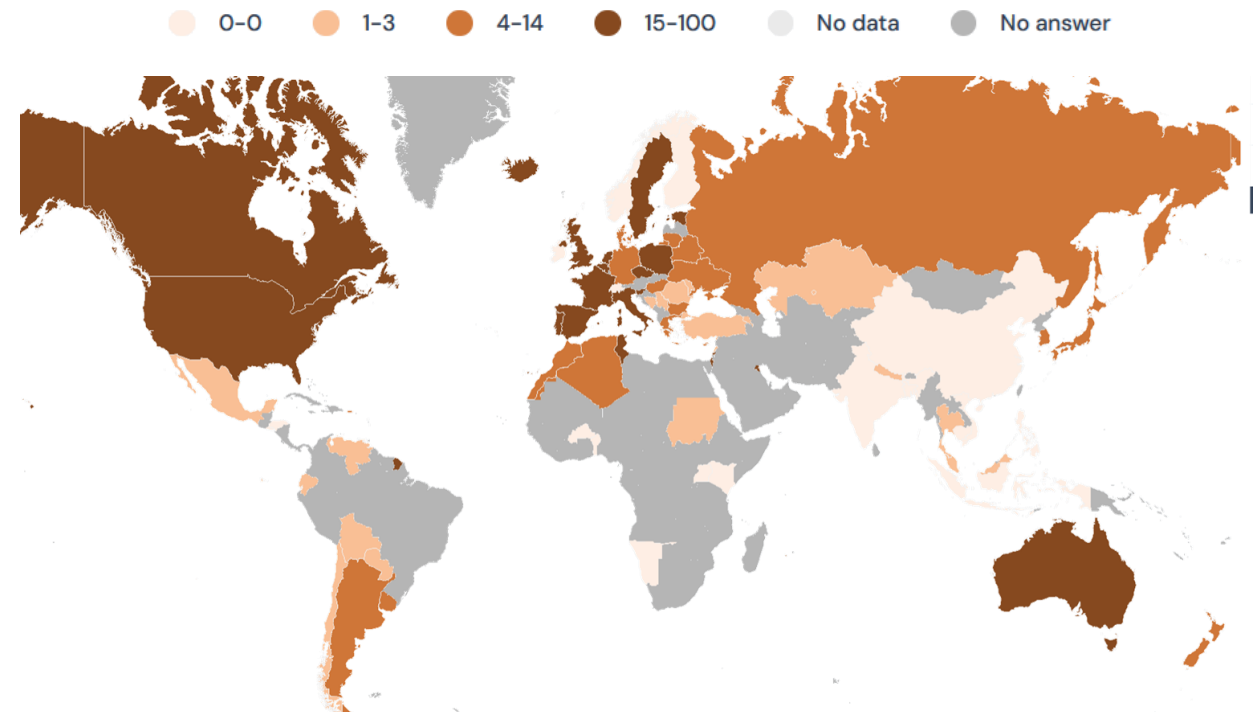
~ 6 million people worldwide

~ 1/2000 worldwide

PID Life Index – Diagnostic Rate

~ less than 3% for most Asian countries

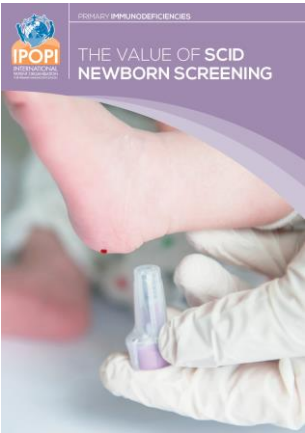
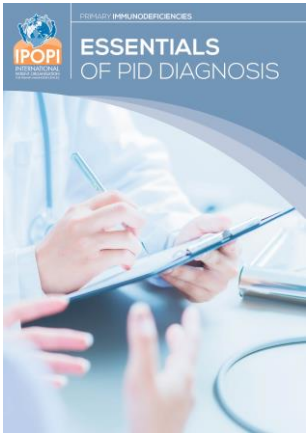
→ Many patients are not yet diagnosed!



# DIAGNOSIS

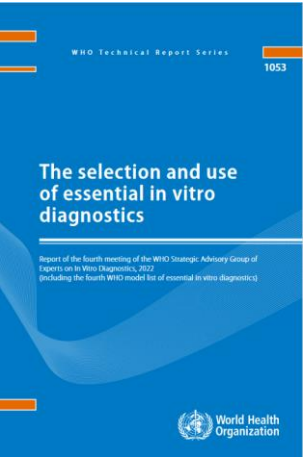
## Educational Tools

- IPOPI leaflets on (genetic) diagnosis
- IPOPI leaflet on SCID newborn screening
- IPOPI leaflet on PID warning signs across medical specialties



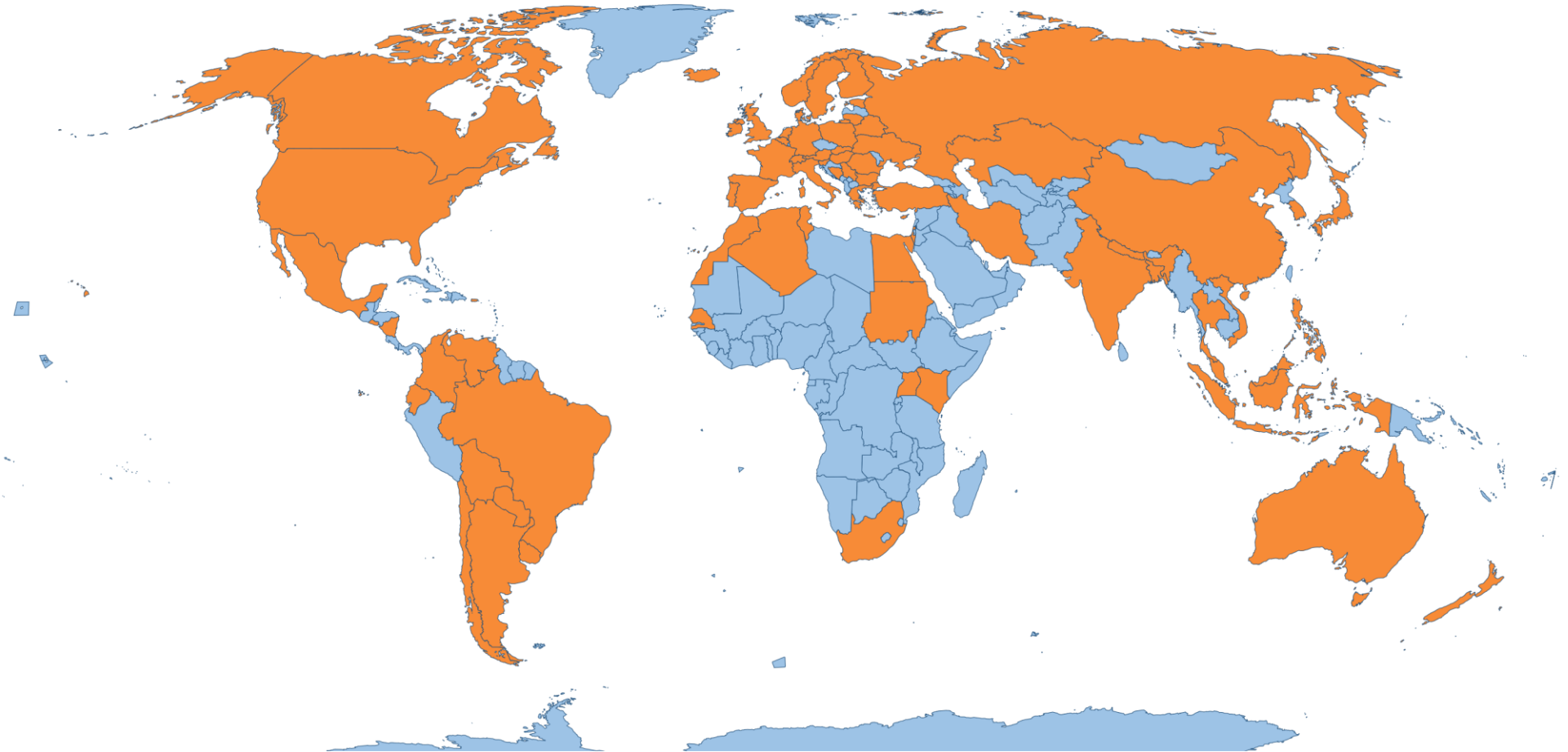
## Advocacy Tools

- WHO Essential Diagnostics List
- International Neonatal Screening Day



II.b. Disease-specific IVDs recommended for use in clinical laboratories <i>continued</i>						
Disease	IVD test	Test purpose	Assay format	Specimen type	WHO prequalified or recommended products	WHO supporting documents
Primary immunodeficiencies	HIV 1/2 antibody (anti-HIV Ab)	For differential diagnosis of primary immunodeficiencies	RDT	Oral fluid Capillary whole blood Venous whole blood	N/A	N/A
	Plasma immunoglobulin levels (IgG, IgA, IgM)	To identify patients with low plasma immunoglobulin levels and to monitor replacement	Radial immunodiffusion (RID) Immunoassay	Serum Serum Plasma	N/A	N/A
	Lymphocyte subtype enumeration: CD3, CD4, CD8, B cells CD19 and/or CD20, CD16/56 T cells and NK cells (Refer to HIV infection for enumeration of CD4 cells only)	To aid in the diagnosis of primary and secondary immunodeficiencies	Flow cytometry	Venous whole blood	N/A	

# NATIONAL MEMBER ORGANISATIONS

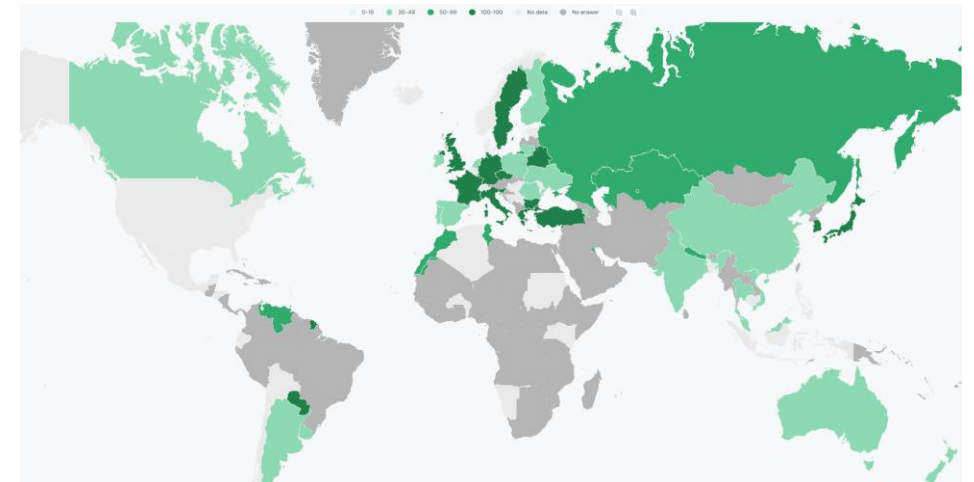


# REGISTRIES

A medical registry is **an organised database** that collects data about a population defined by a particular disease, condition, or exposure, and that is followed over time.

## Medical registries are invaluable tools

- For a disease analysis such as assessing prevalence, measuring incidence, detecting low-diagnostic areas, highlighting diagnostic delays, and studying specific populations.
- For improving patient care, advancing multi-centric medical research, and informing healthcare policy decisions.
- For supporting advocacy efforts and healthcare system decisions.



# REGISTRIES

## Current registries in the Asian region

- **APSID Registry**
  - Registry working party (2020-2024 – Prof Yae-Jean Kim, South Korea).
- **SEAPID** organised a survey on PIDs in 2016 but does not have yet a PID registry.

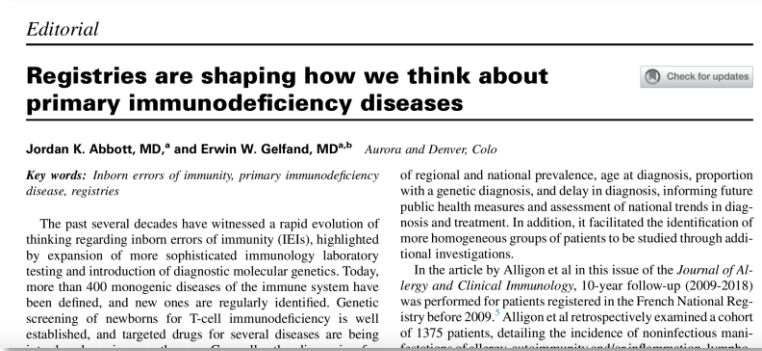


Username

Password

## Educational Tools

- [“Registries are shaping how we think about primary Immunodeficiency diseases”](#)



- [“So You Want to Build Your Disease’s First Online Patient Registry: An Educational Guide for Patient Organizations Based on US and European Experience”](#)

So You Want to Build Your Disease’s First Online Patient Registry:  
An Educational Guide for Patient Organizations Based on US  
and European Experience

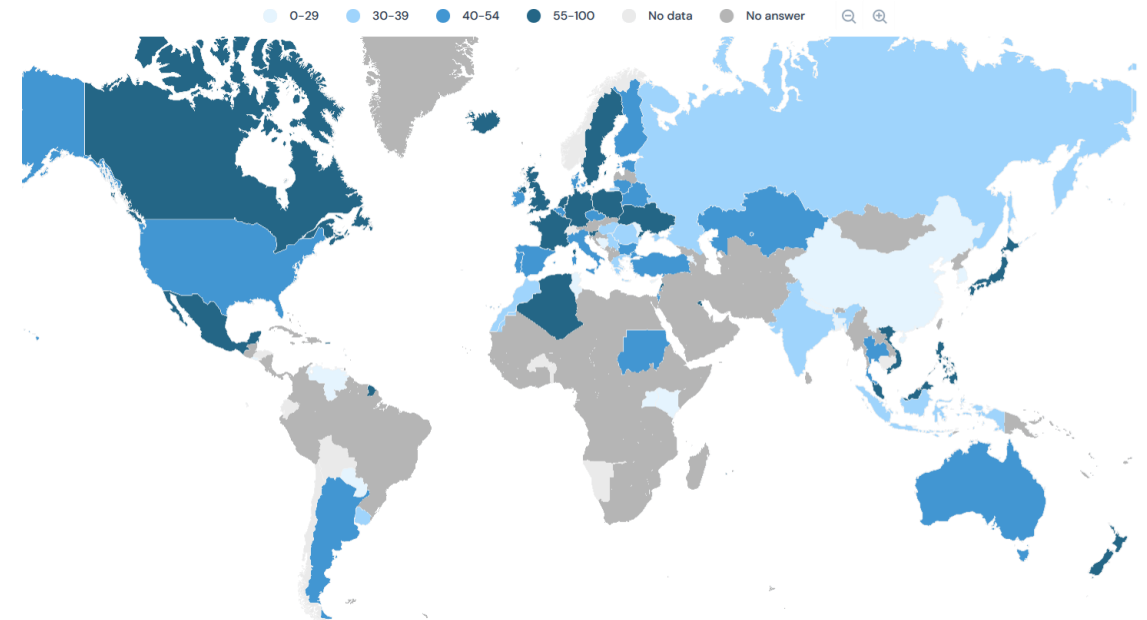
Paul Wicks<sup>1</sup> · Lindsey Wahlstrom-Edwards<sup>2</sup> · Sam Fillingham<sup>3</sup> · Andrea Downing<sup>4</sup> · Elin Haf Davies<sup>5</sup>

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# SPECIALISED CENTRES

How do PID care centers in your country compare to the rest of the world?

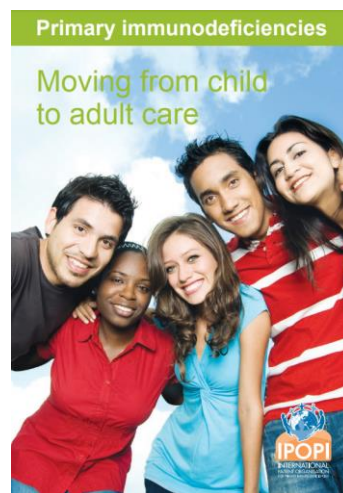
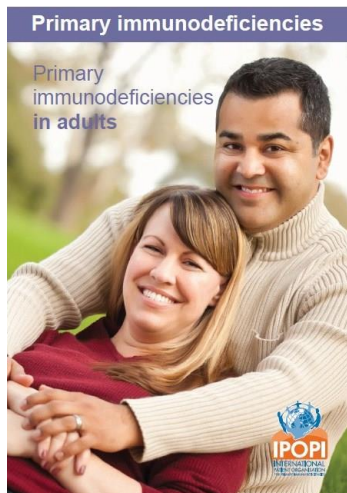
- Established centers specialising in PID?
- Coordinated network of specialised PID centers?
- Adult PID services available?
- Established process for guiding transition from paediatric to adult services?



# SPECIALISED CENTRES

## Educational Tools


- IPOPI leaflet on PID in adults
- IPOPI leaflet on transition care




## Clinical Trials


- ClinicalTrials.gov
- International Clinical Trials Registry Platform (ICTRP)


ClinicalTrials.gov is a place to learn about clinical studies from around the world.

 The U.S. government does not review or approve the safety and science of all studies listed on this website. [Read our full disclaimer](#) for details.


**Focus Your Search** (all filters optional)

**Condition/disease** 


**Other terms** 

**Intervention/treatment** 

**Location**  
Search by address, city, state, or country and select from the dropdown list

**Study Status** 

☒ All studies  
☐ Recruiting and not yet recruiting studies

**More Filters** 

[Search](#)

 World Health Organization

 International Clinical Trials Registry Platform Search Portal

[Home](#) [Advanced Search](#) [List By](#) [Search Tips](#) [UTN](#) [ICTRP website](#) [Contact us](#)

Example: liver cancer OR breast cancer NOT genetic [Search](#) [Search tips](#)

☐ Restrict to COVID-19  
☐ Search for [clinical trials in children](#)  
☐ Without Synonyms

**Phases** are 

☐ With results only  
☐ Rare diseases / orphan drugs  
☐ Genome editing

# TREATMENTS

Which different types of treatment are available in your country?

Vaccines

Preventative use, to avoid severe illness caused by infectious pathogens

Antimicrobials

Specific treatment of an infectious pathogen: antibiotics, antivirals, antifungals, antiparasitic drugs

Immunoglobulin replacement therapy

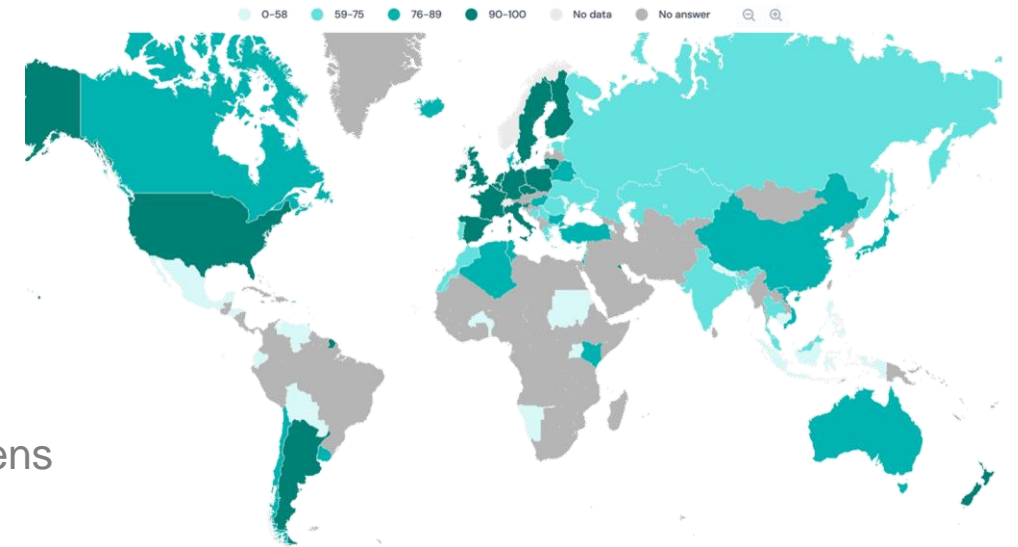
Compensation/supplementation of the patient's defective immunoglobulin production

Biologicals and Targeted therapies

Specifically targeting the molecular or cellular pathways underlying a disease (e.g., monoclonal antibodies, JAK inhibitors)

Curative treatment

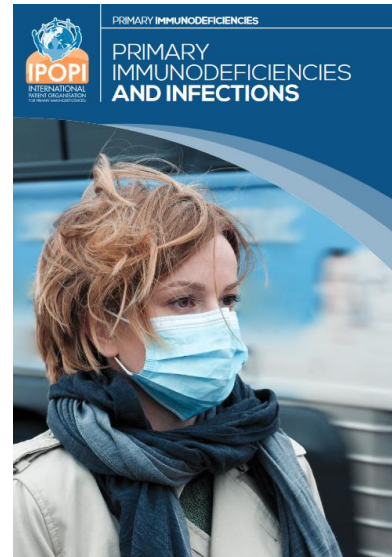
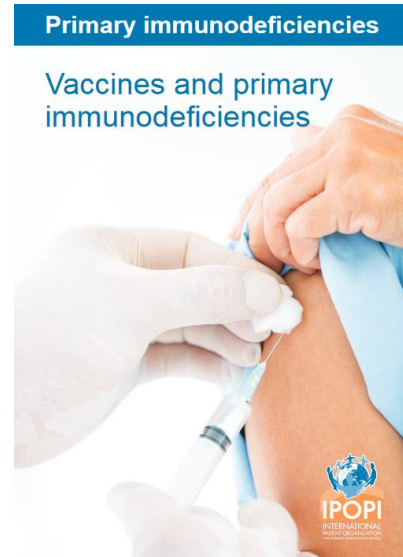
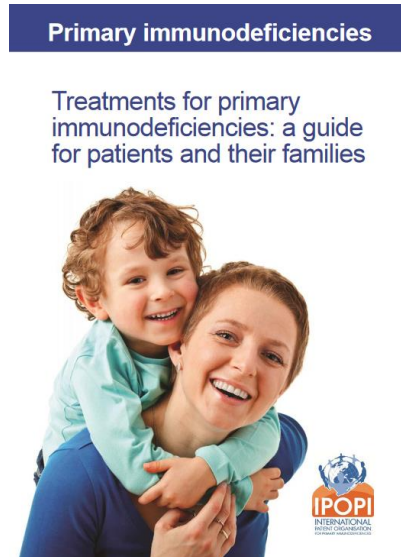
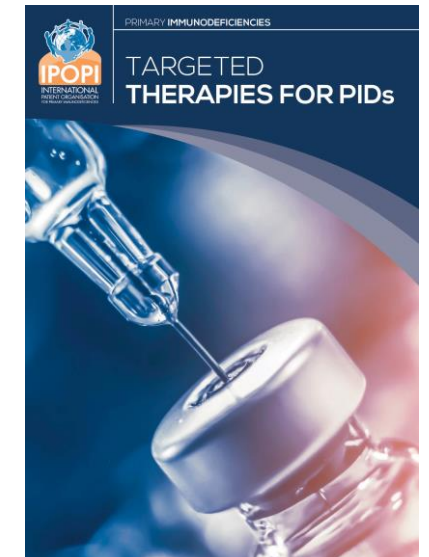
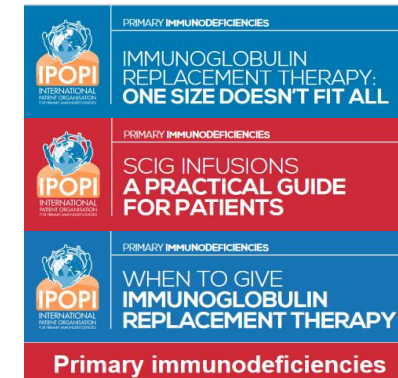
Permanent elimination of the underlying genetic immune defect (e.g., haematopoietic stem cell transplantation, gene therapy)



# TREATMENTS

## Educational Tools

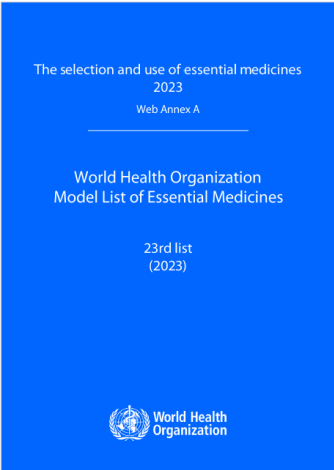
- IPOPI leaflets on various treatment options
- IPOPI leaflets on specific PIDs (see [IPOPI website](https://www.ipopi.org/))



# TREATMENTS

## Advocacy Tools

- WHO Essential Medicines List



whole blood	
<b>11.2 Plasma-derived medicines</b>	
All human plasma-derived medicines should comply with the WHO requirements.	
<b>11.2.1 Human immunoglobulins</b>	
anti-D immunoglobulin	<b>Injection:</b> 250 micrograms in single-dose vial.
anti-rabies immunoglobulin	<b>Injection:</b> 150 IU/mL in vial.
anti-tetanus immunoglobulin	<b>Injection:</b> 500 IU in vial.
<b>Complementary List</b>	
normal immunoglobulin	<b>Intramuscular administration:</b> 16% protein solution. <b>Subcutaneous administration:</b> 15%; 16% protein solution. – Primary immune deficiency.  <b>Intravenous administration:</b> 5%; 10% protein solution. – Primary immune deficiency – Kawasaki disease – Langerhans cell histiocytosis

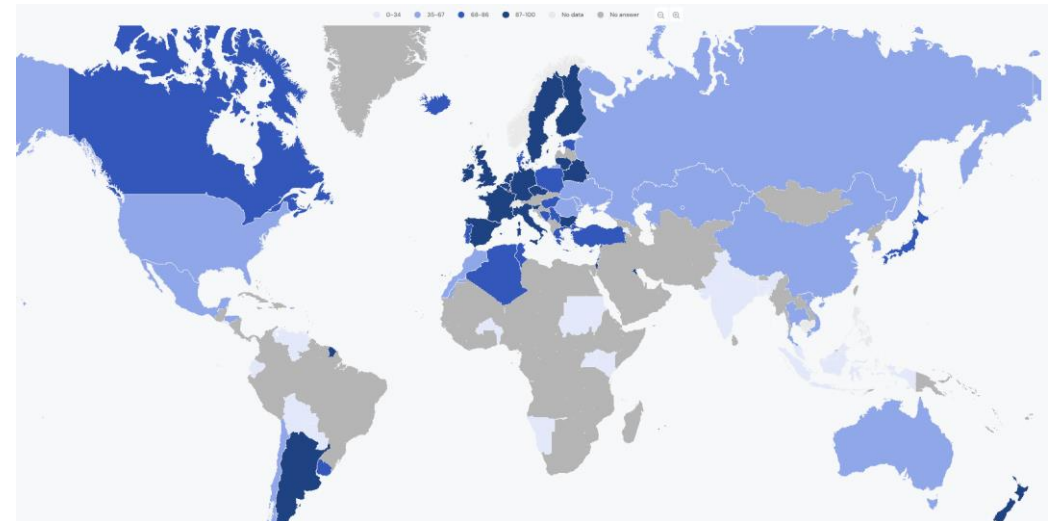
- IPOPI position statements on treatment access
  - [Patients with PIDs should have access to safe, efficacious and high-quality immunoglobulin therapies](#)
  - [Patients with PID need sustained & continued access to their Ig therapies!](#)
  - [Managing demand for immunoglobulins: PIDs are a priority indication at all times](#)

# UNIVERSAL HEALTH COVERAGE

**Universal Health Coverage** ensures that all people everywhere have access to quality health services they need, without financial hardship.

How does Universal Health Coverage in your country compare to the rest of the world?

- Immunoglobulin reimbursement
- Curative treatment reimbursement
- Anti-infectious Reimbursement
- Diagnosis Reimbursement
- Biological and targeted therapies (including biosimilars and generics) reimbursement
- Vaccines reimbursement



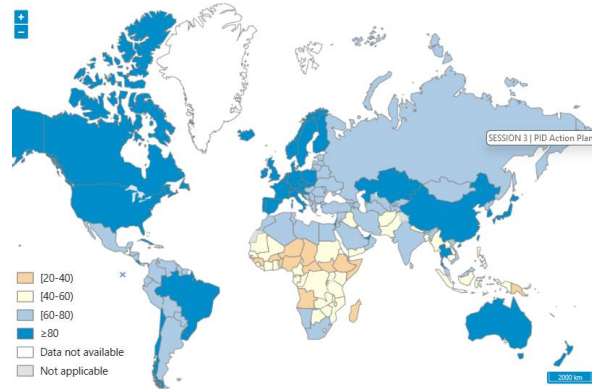
# UNIVERSAL HEALTH COVERAGE

## Important international commitments

- Universal Declaration of Human Rights, article 25 in 1948
- Sustainable Development Goals (SDGs) in 2015
- United Nations General Assembly High-Level Meeting on UHC in 2019 and 2023

## Data Tools

- World Health Organisation
  - [Tracking Universal Health Coverage: 2021 Global monitoring report](#)
  - [UHC index tracker](#)
- [IPOPI PID Life Index](#)

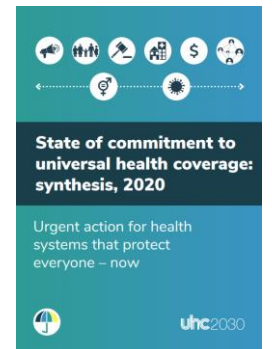


## Advocacy Opportunity

- Universal Health Coverage Day, on December 12.

## Advocacy Tools

- [UHC2030: State of Commitment to UHC report](#)
- [universalhealthcoverageday.org/](https://universalhealthcoverageday.org/)
- [Health for All Advocacy Toolkit](#)
- [#UHC4RareDiseases Toolkit](#)



## REFERENCES

### PID incidence estimates:

Tangye SG et al. Human Inborn Errors of Immunity: 2019 Update on the Classification from the International Union of Immunological Societies Expert Committee. J Clin Immunol. 2020 Jan;40(1):24-64. doi: 10.1007/s10875-019-00737-x.

Bousfiha AA et al. Primary immunodeficiency diseases worldwide: more common than generally thought. J Clin Immunol. 2013 Jan;33(1):1-7. doi: 10.1007/s10875-012-9751-7.

van Zelm MC et al. Editorial: Primary Immunodeficiencies Worldwide. Front Immunol. 2020 Jan 22;10:3148. doi: 10.3389/fimmu.2019.03148.

Meyts I et al. Primary Immunodeficiencies: A Decade of Progress and a Promising Future. Front Immunol. 2021 Feb 18;11:625753. doi: 10.3389/fimmu.2020.625753. PMID: 33679719; PMCID: PMC7935502.

Nordin J et al. The PID Principles of Care: Where Are We Now? A Global Status Report Based on the PID Life Index. Front Immunol. 2021 Nov 18;12:780140. doi: 10.3389/fimmu.2021.780140.

### PID Life Index:

<https://pidlifeindex.ipopi.org/#/en/principles/world-map>

# THANK YOU FOR PARTICIPATING!

To further enhance the quality of our meetings, we kindly request a few moments of your valuable time to provide your feedback.

Please scan the QR Code:



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# COFFEE BREAK

## 30 MIN

### COLLABORATION



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