



IPOPI 4TH REGIONAL ASIAN PID MEETING

19-20 NOVEMBER 2022
KUALA LUMPUR, MALAYSIA

an IPOPI event

CARE FOR RARE
GLOBAL ALLIANCE EDUCATIONAL SEMINAR



SUPPORTING ORGANISATIONS

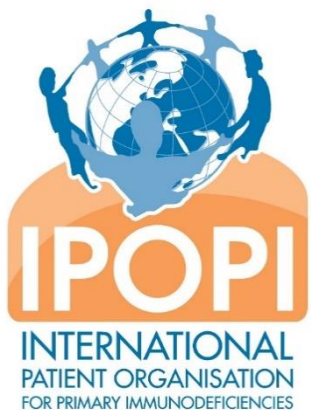


SUPPORTED BY



Asian regional meeting Doctors' meeting

Kuala Lumpur, 19 November 2022



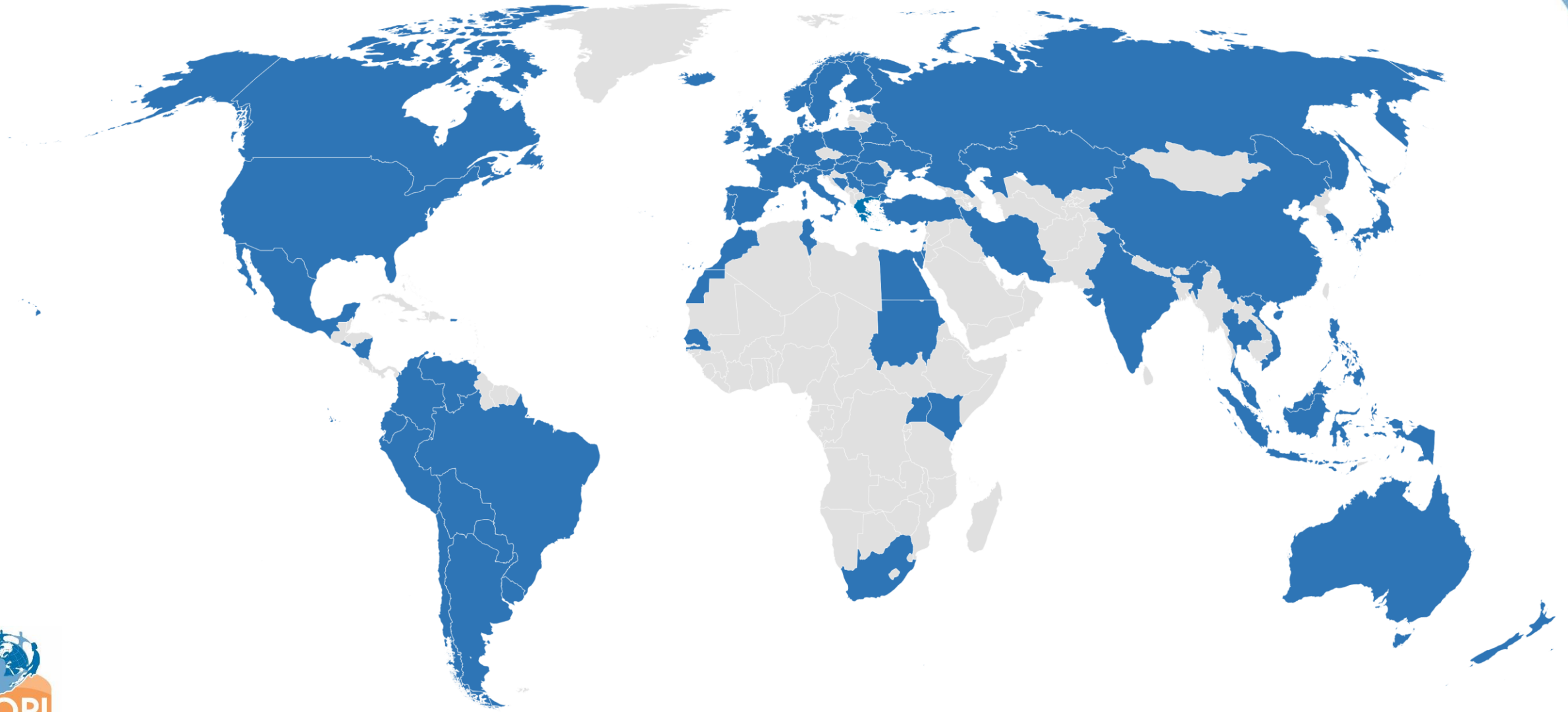
Martine Pergent
IPOPI President



What is IPOPI?

- **The International Patient Organisation for Primary Immunodeficiencies (IPOPI)**
 - a non-profit international organisation
 - the leading advocate for primary immunodeficiency (PID) patients worldwide
 - working in collaboration with patients, healthcare professional, politicians, regulators, pharmaceutical industry and other relevant stakeholders.
- **Our mission: IMPROVING PID PATIENTS' LIVES. WORLDWIDE.**

A growing membership (69 countries)



A vibrant global Community



A committed IPOPI 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)

Andrea Gressani (IT)

Cynthia Olotch (KEN)

John Seymour (USA)

Otilia Stanga (RO)



A multi-tasking IPOPI Staff



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Executive Director
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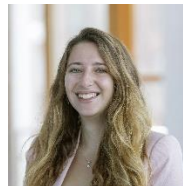
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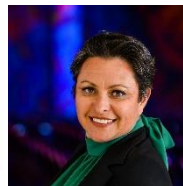
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A supportive IPOPI Medical Advisory Panel (MAP)

- Dr Nizar Malhaoui, Chairman (FR)
- **Prof Martin van Hagen, Vice-Chair (NL)**
- **Dr Adli Ali (MAL)**
- Dr Tadej Avcin (SLO)
- Prof Aziz Bousfiha (MOR)
- Dr Charlotte Cunningham-Rundles (USA)
- Dr Virgil Dalm (NL)
- Prof Tandakha Dieye (SEN)
- Prof Alain Fischer (FR)
- Prof Elie Haddad (CA)
- Professor Steven Holland – (USA)
- **Dr Pamela Lee**
- Prof Isabelle Meyts (BEL)
- Prof Antonio Condino-Neto (BRA)
- Dr Olaf Neth (SP)
- Dr Cecilia Poli – (CL)
- Dr Elizabeth Rivers – (UK)
- Dr Silvia Sanchez-Ramon (SP)
- Prof Ana Shcherbina (RU)
- **Prof Surjit Singh (IND)**
- **Prof Stuart Tangye (AUS)**
- Prof Klaus Warnatz (GER)

Our strategic priorities – Horizon 2025

1. **Improve access to early diagnosis & patient-centred care** through advocacy and awareness
2. **Build capacity and support IPOPI's national member organisations** to improve living conditions for people living with PID
3. **Educate, promote knowledge and data sharing** to increase understanding of PID, improve clinical care and advance research
4. **Strengthen multi-stakeholder cooperation** to optimize all programmes and activities

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

Regional PID meetings

- Regional meeting organised in parallel to regional scientific societies



Educational tools

IPOPI educational leaflets

- Patient or doctors information leaflets on key PID topics
- [Visit the website](#)



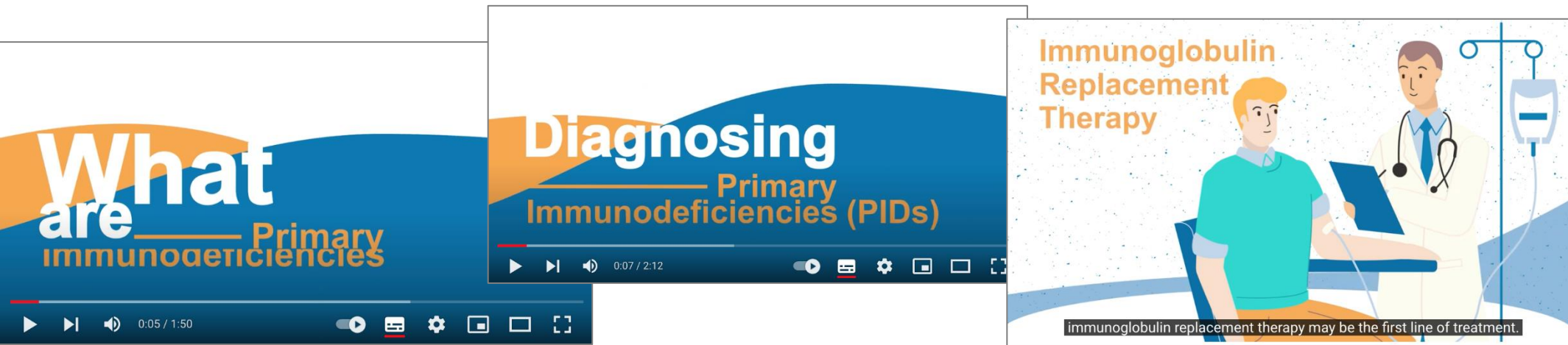
Educational tools

IPOPI Clinical Care Webinars

- PID expert speakers
- For health care professionals and patient representatives

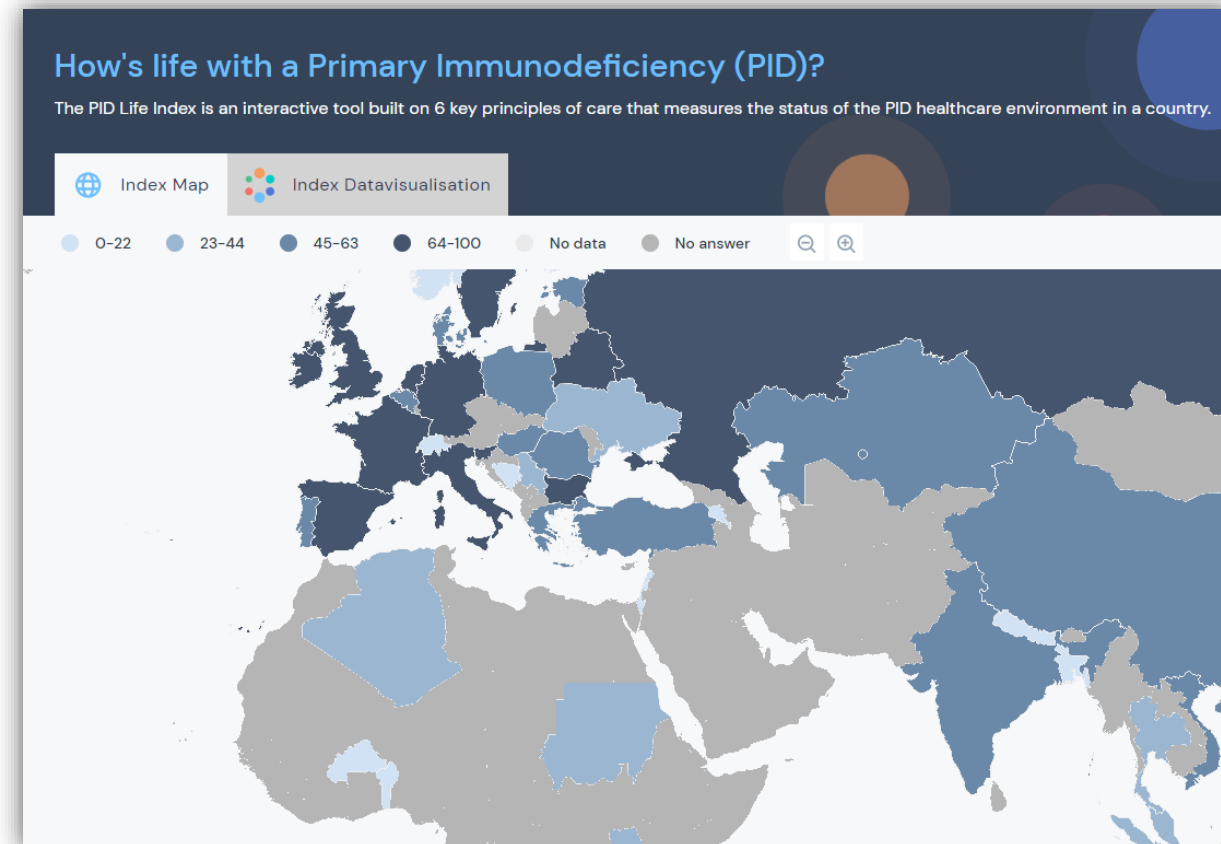
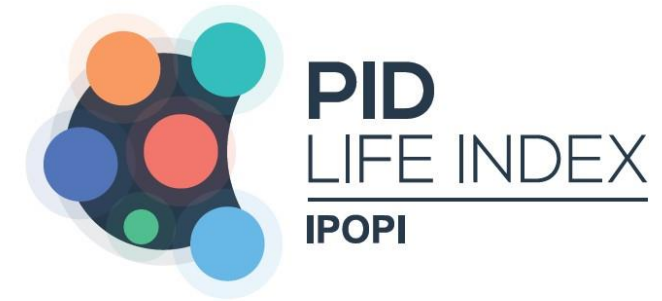
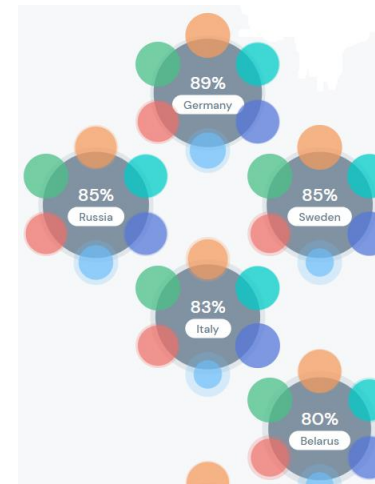


IPOPI new video series on PIDs



PID Life Index

- Index built on 6 key principles of care that measures the status of the PID healthcare environment across the globe
- Large set of data, provided by IPOPI member organisations and physicians
- **Useful tools for advocating for improved diagnosis and treatment in each country**
- <https://pidlifeindex.ipopi.org>



Advancing Research & ERN work

- IPOPI partnering in several research programmes
- Provide patient input in research and development process





IPIC2023

INTERNATIONAL
PRIMARY
IMMUNODEFICIENCIES
CONGRESS

DIAGNOSIS AND
CLINICAL CARE

NOVEMBER 8-10, 2023

ROTTERDAM, THE NETHERLANDS

- A unique approach to its scientific programme
- Focus on patient-centred care
- A CME-accredited clinical programme





Thank you!