



IPOPI
LATIN AMERICAN
PID PATIENTS'
MEETING

OCTOBER 19-20, 2023
MEXICO CITY, MEXICO

an **IPOPI** event

SESIÓN 2

COLLABORATION



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GRIFOLS





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IDPs: América Latina hoy PIDs: Latin America today

Moderadora: Roberta Anido de Pena

Moderator: Roberta Anido de Pena

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Abordar los desafíos y oportunidades de las IDPs en América Latina

Addressing the Challenges and Opportunities for PIDs in Latin America.

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Perspectiva médica Physician perspective

Prof Gesmar Segundo | Presidente de LASID, Brasil
Prof Gesmar Segundo | LASID President, Brazil

Primer desafio

- Paises heterogeneos
- Diferente formacion medica
- Diferentes sistemas sanitarios
 - Publico
 - Privado



population: 666.463.929 (Sep 2023)

Mexico in North America; Guatemala, Honduras, El Salvador, Nicaragua, Costa Rica and Panama in Central America; Colombia, Venezuela, Ecuador, Peru, Bolivia, Brazil, Paraguay, Chile, Argentina and Uruguay in South America; and Cuba, Haiti, the Dominican Republic and Puerto Rico

Desafios

- Concientización sobre la IDP: profesionales sanitarios/población
 - Pocos centros de referencia
 - Muy pocas pruebas de laboratorio especializadas
 - Acceso a los tratamientos
-
- **Centros IDP sólo en grandes ciudades (grandes distancias)**



population: 622,257,054

Mexico in North America; Guatemala, Honduras, El Salvador, Nicaragua, Costa Rica and Panama in Central America; Colombia, Venezuela, Ecuador, Peru, Bolivia, Brazil, Paraguay, Chile, Argentina and Uruguay in South America; and Cuba, Haiti, the Dominican Republic and Puerto Rico

Concientización: cómo abordarla

Educación médica

- Facultades de medicina
- Programas educativos locales

Sensibilización de la población

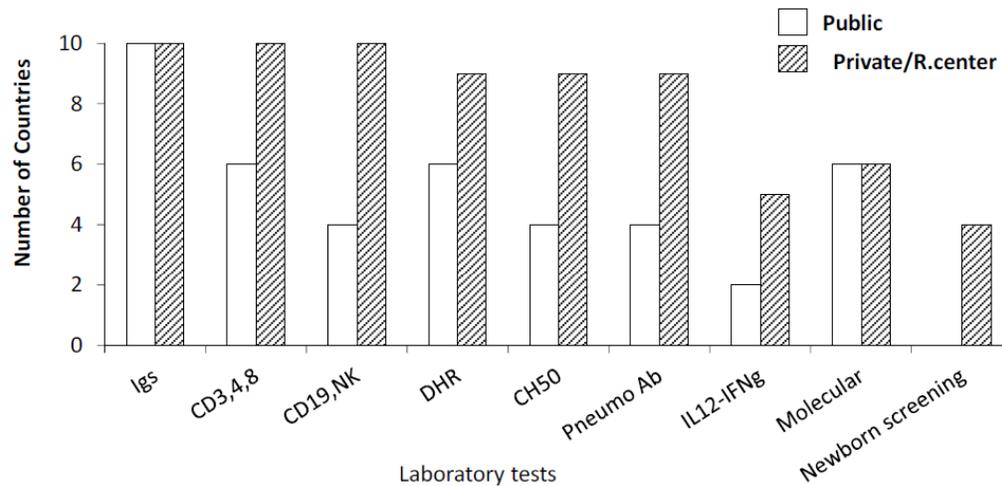
- Social Media (cuantos seguidores temenos?)
- Publicidad en via publica
- Radio/TV – muy costoso

Madrinas o padrinos influyentes



Desafíos de laboratorio

- Pruebas de laboratorio disponibles en centros públicos y de referencia/laboratorios privados de 10 países: Argentina, Brasil, Chile, Colombia, Costa Rica, Honduras, Guatemala, México, Paraguay y Perú.

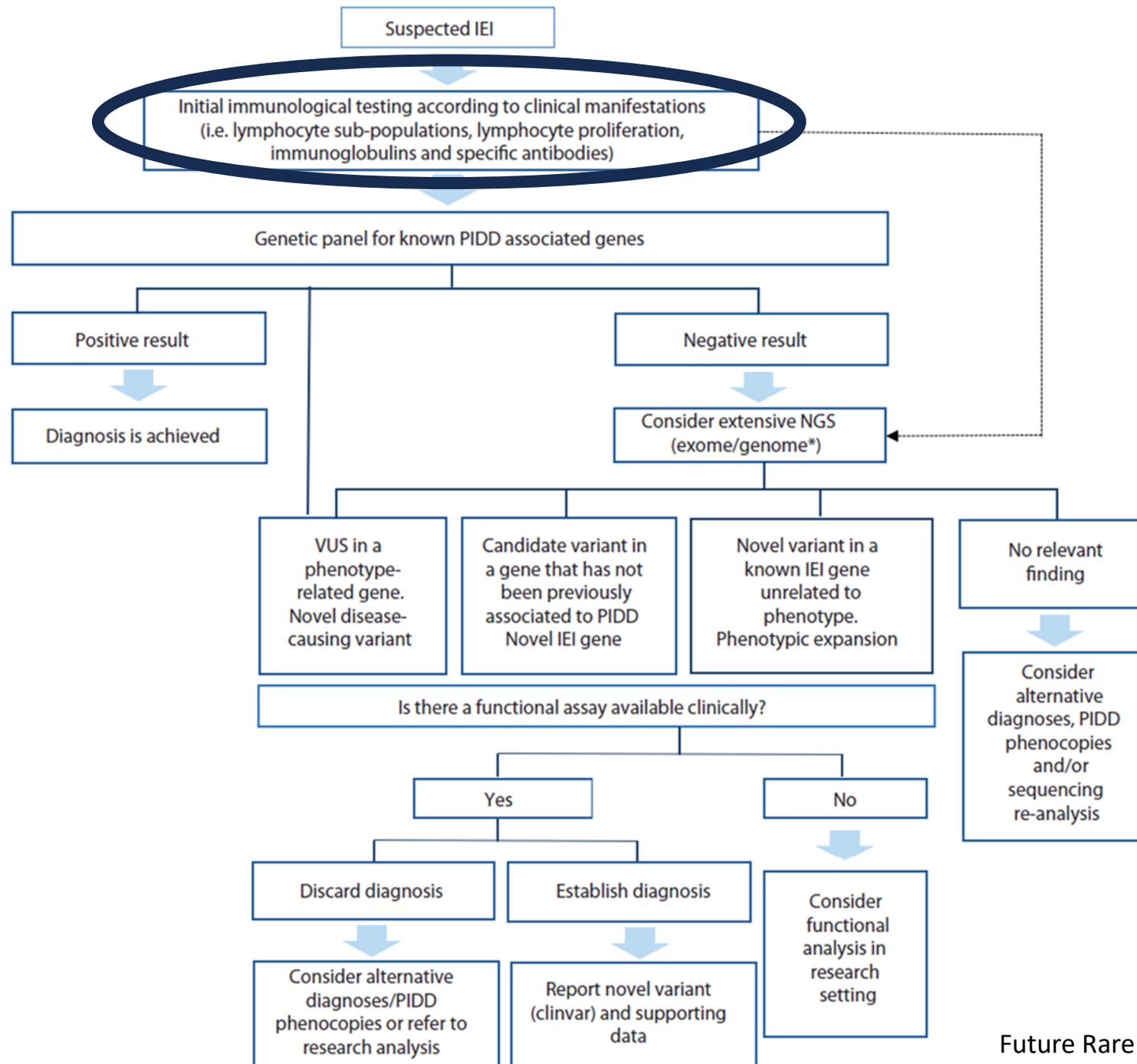


- Sólo en programas de investigación
- Fenotipo de células B
- Fenotipo de células T (excepto células T naïve)

Latin American challenges with the diagnosis and treatment of primary immunodeficiency diseases. Expert Rev Clin Immunol. 2017;13(5):483-489.

Afrontar los desafíos del laboratorio

- Las pruebas funcionales de laboratorio son caras
- No es viable para laboratorios comerciales
- Que hacer??
 - Aumentar las pruebas básicas
 - Mejorar el acceso a las pruebas genómicas (los precios están bajando, los programas de acceso, por ejemplo, Jeffrey insights)



Afrontar los desafíos del laboratorio

- Newborn screening for SCID
 - Salva vidas
 - Pero se necesita infraestructura para tratarlos

Desafío en el acceso al tratamiento

- Distintos estatus según los países
 - Regulación del acceso a las inmunoglobulinas
 - Inmunobiológicos y moléculas pequeñas (cada vez utilizamos más)
 - Trasplante de médula ósea: pocos centros y camas para enfermedades no malignas
- En algunos países: enormes diferencias entre lo público y lo privado

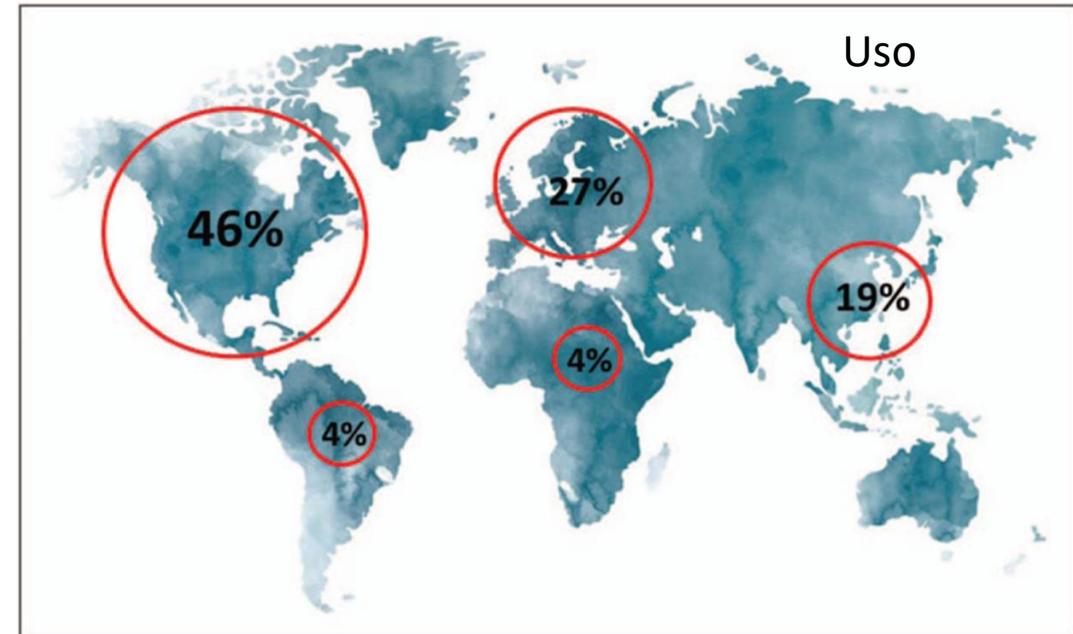
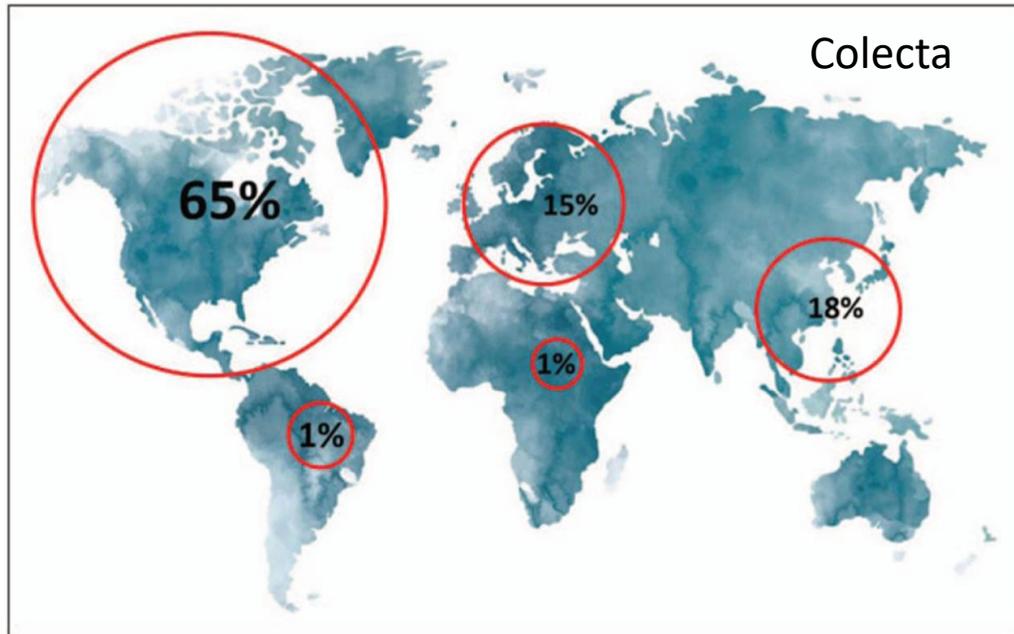
Desafío en el acceso al tratamiento

- Depende de los primeros pasos
 - Mejorar el conocimiento y el diagnóstico
- Advocacy
- Los pacientes y la asociación de médicos trabajan juntos
 - Agencias médicas reguladoras
 - Politicos

Desafío en el acceso al tratamiento

Immunoglobulinas....

- Necesitamos mejorar la colecta de plasma en América Latina



Resumen

- Mucho trabajo por hacer por nuestros pacientes
- Las asociaciones locales de pacientes y médicos deben colaborar
- Identificar los problemas específicos de cada país
 - Mejorar el conocimiento de los sistemas sanitarios reglamentarios For diagnosis
 - Acceso al tratamiento
 - Estrategias para alcanzar objetivos
 - Administrativas
 - Políticas
- Apoyo de las sociedades regionales e internacionales



Thank you Muchas Gracias

Contact: gesmar2@gmail.com
gesmar@ufu.br



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Perspectiva de representantes de pacientes Patient representatives' perspective

Roberta Anido de Pena | Responsable regional en la Junta de IPOPI
Roberta Anido de Pena | IPOPI Regional Board Member

Some Concepts...

- New group vs establish NMO
- Experience
- Local priorities
- Patients needs
- Knowledge of the health system
- Conviction
- Time
- Support
- Resources

6 Principles of care



PID diagnosis



National Patient Organisations



Registries



Specialised centres



Treatments



Universal health coverage

1- PID Diagnosis

Genetic diagnosis

Biological diagnosis

New born screening for SCID

Diagnosis rate

Prenatal diagnosis

2- National Patient Organisations

Working medical awareness/ information

Data collection

Cooperation with medical professionals

Ensure the effectiveness and safety of treatments & involment in research-clinical trials

Patient empowered, psychological , financial & patient support

Advocay/ access to right and legal support

Be part of the decision-making tables

Training and patient terapheutic education

3- Registries

National PID registry

Bone marrow donor registry

Epidemiological indicators

Resource map

Actions planning

Medication policy

4- Specialized centres

Diagnosis and management facilities of PIDs

Multidisciplinary services/training of medical and nursing personnel

Transition care from pediatric to adult services

Identify specialists and centers/formal recognition by entities

Training and training program

Hematopoietic cell transplant / neonatal screening/ gene therapy

5- Treatments

- Biological and targeted therapies
- Immunoglobulin replacement therapy
- Anti-infections
- Plasma collection
- Vaccines
- Enzyme therapies, growth factors & immunosuppressants
- Curative Treatments

6- Universal Health Coverage- UHC

IG reimbursement

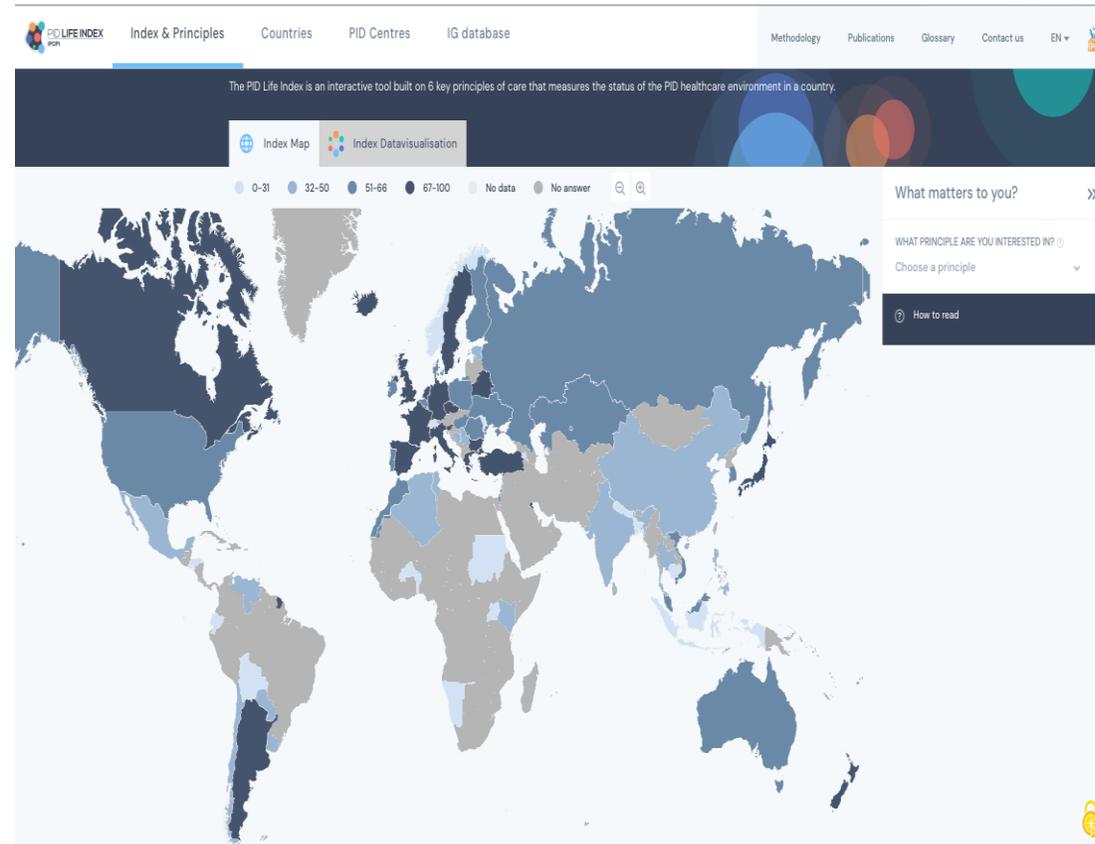
Curative treatments reimbursement

Anti-infections reimbursement

Diagnosis reimbursement

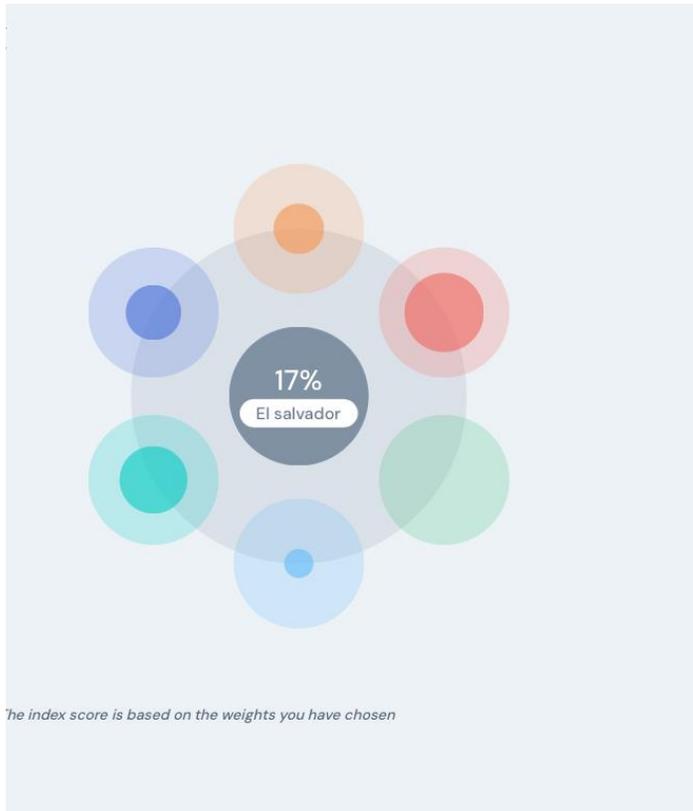
Vaccines reimbursement

PID Life Index



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

PID Life Index



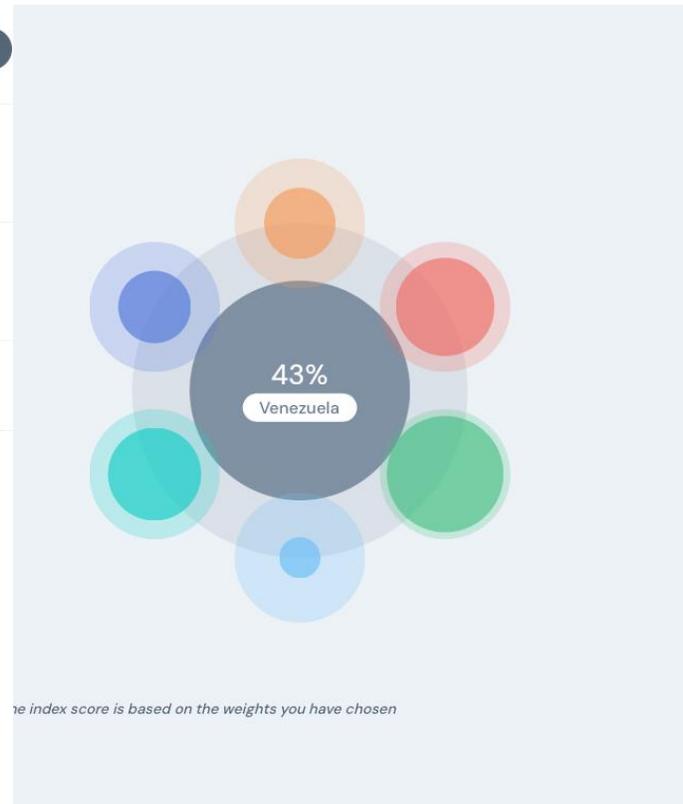
El salvador

[See country page](#)

CONTINENT **America**
 SUB-REGION **Latin America, Central America**
 LAST UPDATE **24/04/2023**

POPULATION **6,486,201 (World Bank data)**
 NUMBER OF KNOWN PATIENTS **0**
 POPULATION BASED ON THEORETICAL PREVALENCE **3,243**

17% **67th**
 GLOBAL SCORE RANK



Venezuela

[See country page](#)

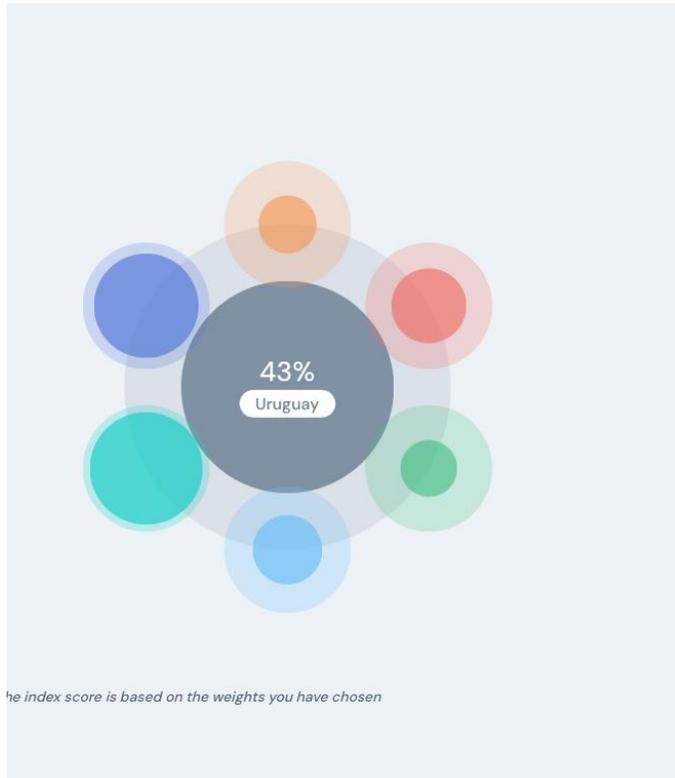
CONTINENT **America**
 SUB-REGION **South America, Latin America**
 LAST UPDATE **25/07/2023**

POPULATION **28,435,943 (World Bank data)**
 NUMBER OF KNOWN PATIENTS **134**
 POPULATION BASED ON THEORETICAL PREVALENCE **14,218**

43% **45th**
 GLOBAL SCORE RANK



PID Life Index



Uruguay

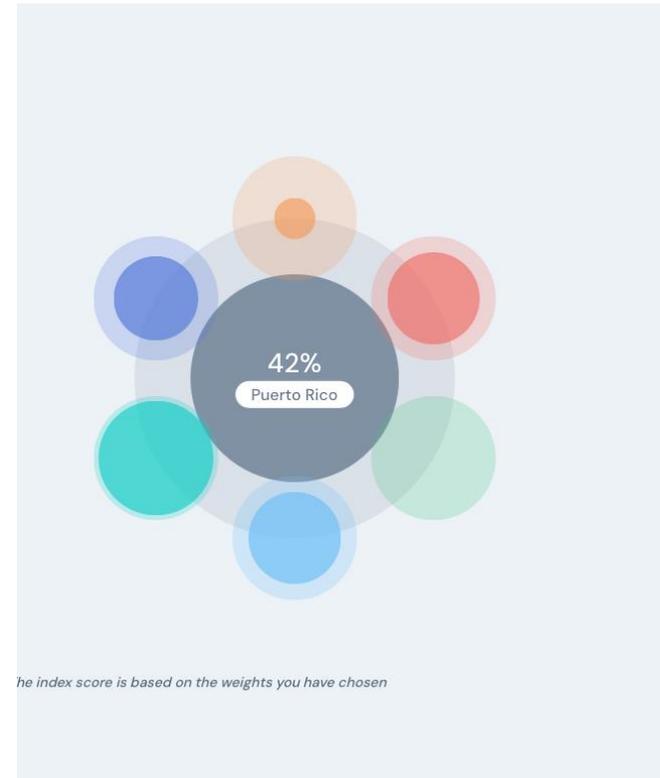
[See country page](#)

CONTINENT **America**
 SUB-REGION **South America, Latin America**
 LAST UPDATE **07/09/2020**

POPULATION **3,473,727** (World Bank data)
 NUMBER OF KNOWN PATIENTS **110**
 POPULATION BASED ON THEORETICAL PREVALENCE **1,737**

43%
GLOBAL SCORE

47th
RANK



Puerto Rico

[See country page](#)

CONTINENT **America**
 SUB-REGION **Latin America, Caribbean**
 LAST UPDATE **06/04/2020**

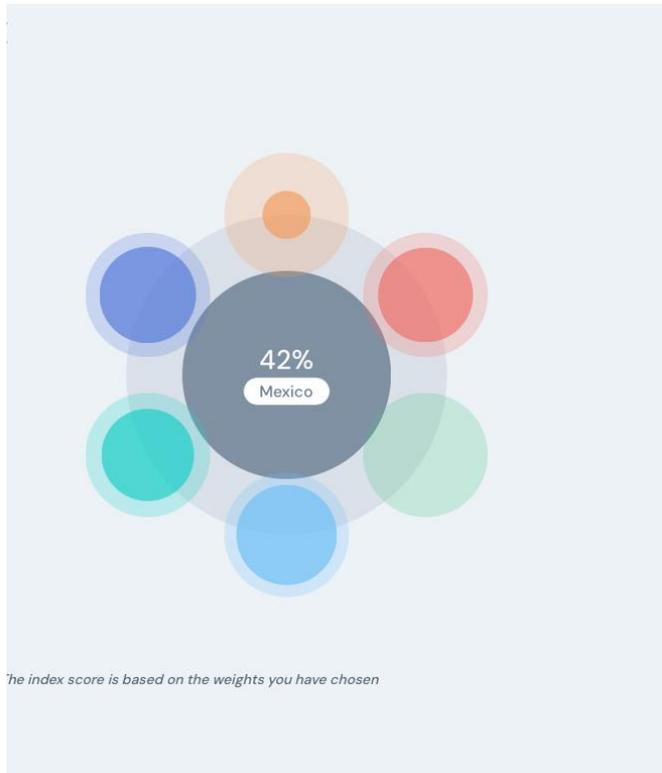
POPULATION **3,194,034** (World Bank data)
 NUMBER OF KNOWN PATIENTS **140**
 POPULATION BASED ON THEORETICAL PREVALENCE **1,597**

42%
GLOBAL SCORE

49th
RANK



PID Life Index



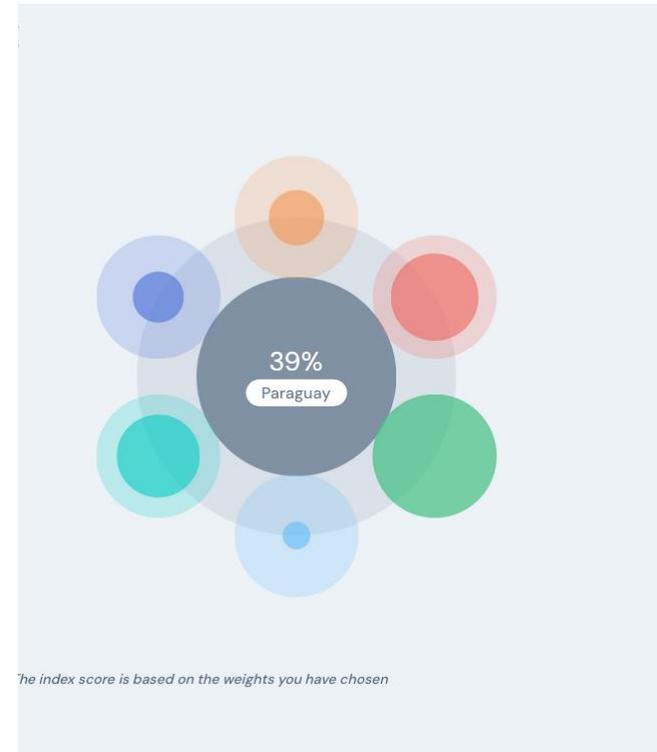
Mexico

[See country page](#)

CONTINENT America
 SUB-REGION Latin America, Central America, APEC member
 LAST UPDATE 09/01/2020

POPULATION 128,932,753 (World Bank data)
 NUMBER OF KNOWN PATIENTS 1,238
 POPULATION BASED ON THEORETICAL PREVALENCE 64,466

42% GLOBAL SCORE
48th RANK



Paraguay

[See country page](#)

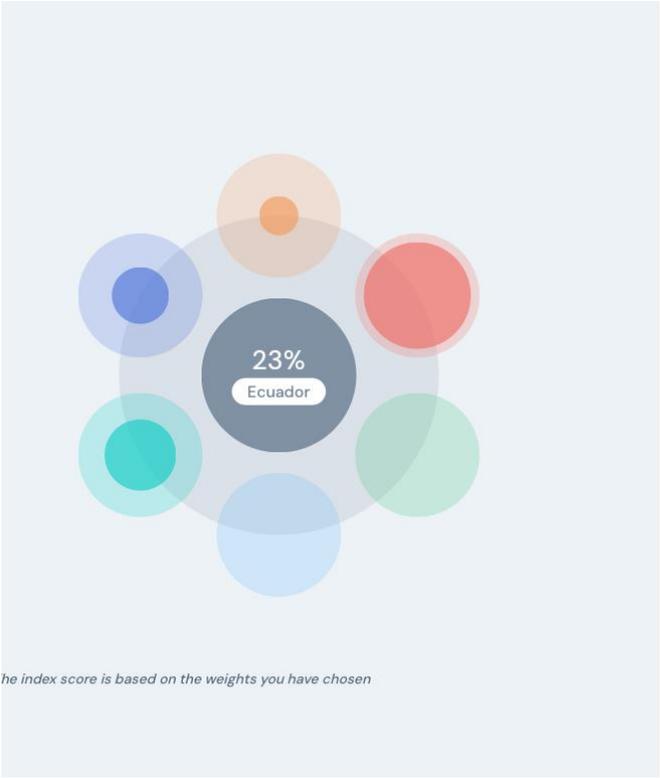
CONTINENT America
 SUB-REGION South America, Latin America
 LAST UPDATE 23/06/2020

POPULATION 7,132,530 (World Bank data)
 NUMBER OF KNOWN PATIENTS 110
 POPULATION BASED ON THEORETICAL PREVALENCE 3,566

39% GLOBAL SCORE
52th RANK



PID Life Index



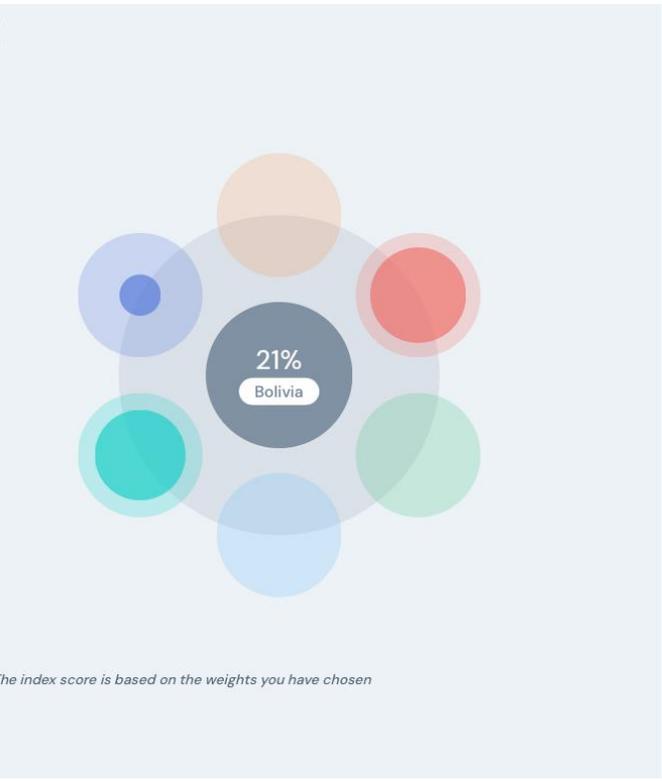
Ecuador

[See country page](#)

CONTINENT America
 SUB-REGION South America, Latin America
 LAST UPDATE 17/07/2023

POPULATION 17,643,060 (World Bank data)
 NUMBER OF KNOWN PATIENTS 90
 POPULATION BASED ON THEORETICAL PREVALENCE 8,822

23% GLOBAL SCORE
60th RANK



Bolivia

[See country page](#)

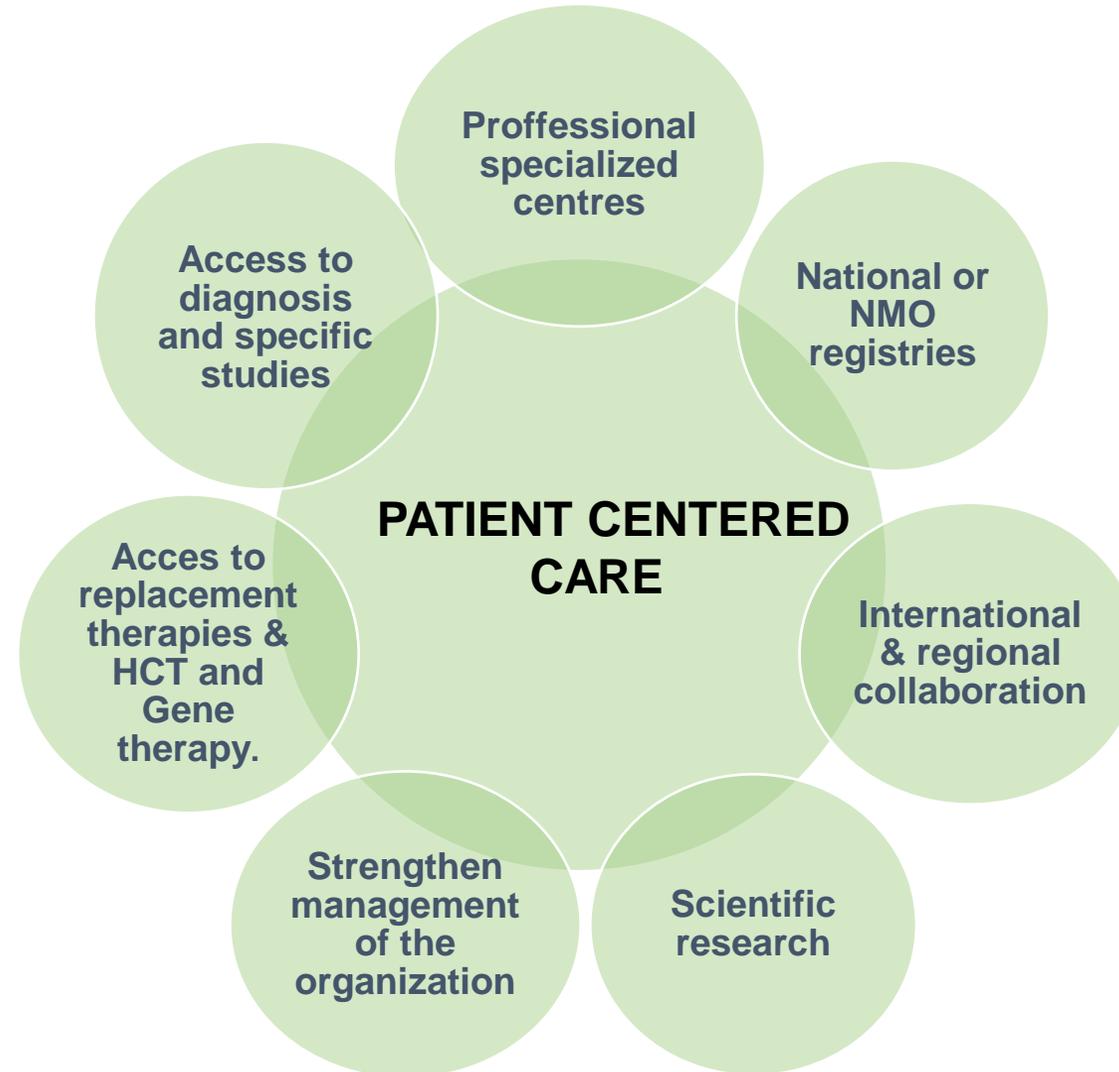
CONTINENT America
 SUB-REGION South America, Latin America
 LAST UPDATE 24/04/2023

POPULATION 11,673,029 (World Bank data)
 NUMBER OF KNOWN PATIENTS 80
 POPULATION BASED ON THEORETICAL PREVALENCE 5,837

21% GLOBAL SCORE
61th RANK



Conclusions



Conclusions

- **Ask IPOPI for support**
- **Use IPOPI website**
- **Participate in IPOPI webinars**
- **Participate at IPIC - IPOPI GPM- Latin American PID Patient's Meeting**
- **Leaflets**
- **PID LIFE INDEX**

Thanks

Together we are much stronger!

Muchísimas gracias.

Juntos somos más fuertes!

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Identificación y debate sobre cómo afrontar juntos los desafíos

Identify and Resolve: Tackling challenges together

Roberta Anido de Pena

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INTERVALLO BREAK 30 MIN

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