



IPOPI  
LATIN AMERICAN  
PID PATIENTS'  
MEETING

OCTOBER 19-20, 2023  
MEXICO CITY, MEXICO

an **IPOPI** event

# SESIÓN 2

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# SESIÓN 2

## IDPs: América Latina hoy PIDs: Latin America today

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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

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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

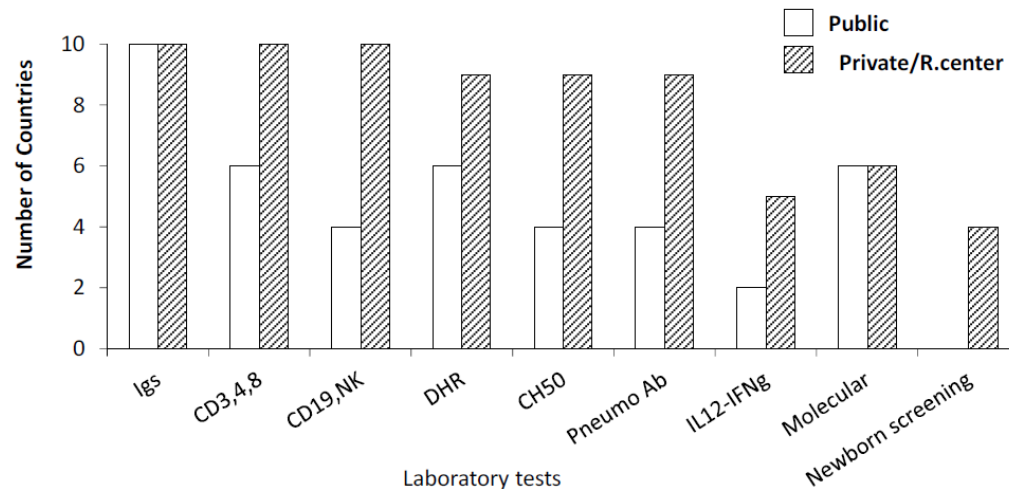
- Social Media (cuántos seguidores tenemos?)
- Publicidad en vía pública
- Radio/TV – muy costoso

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.



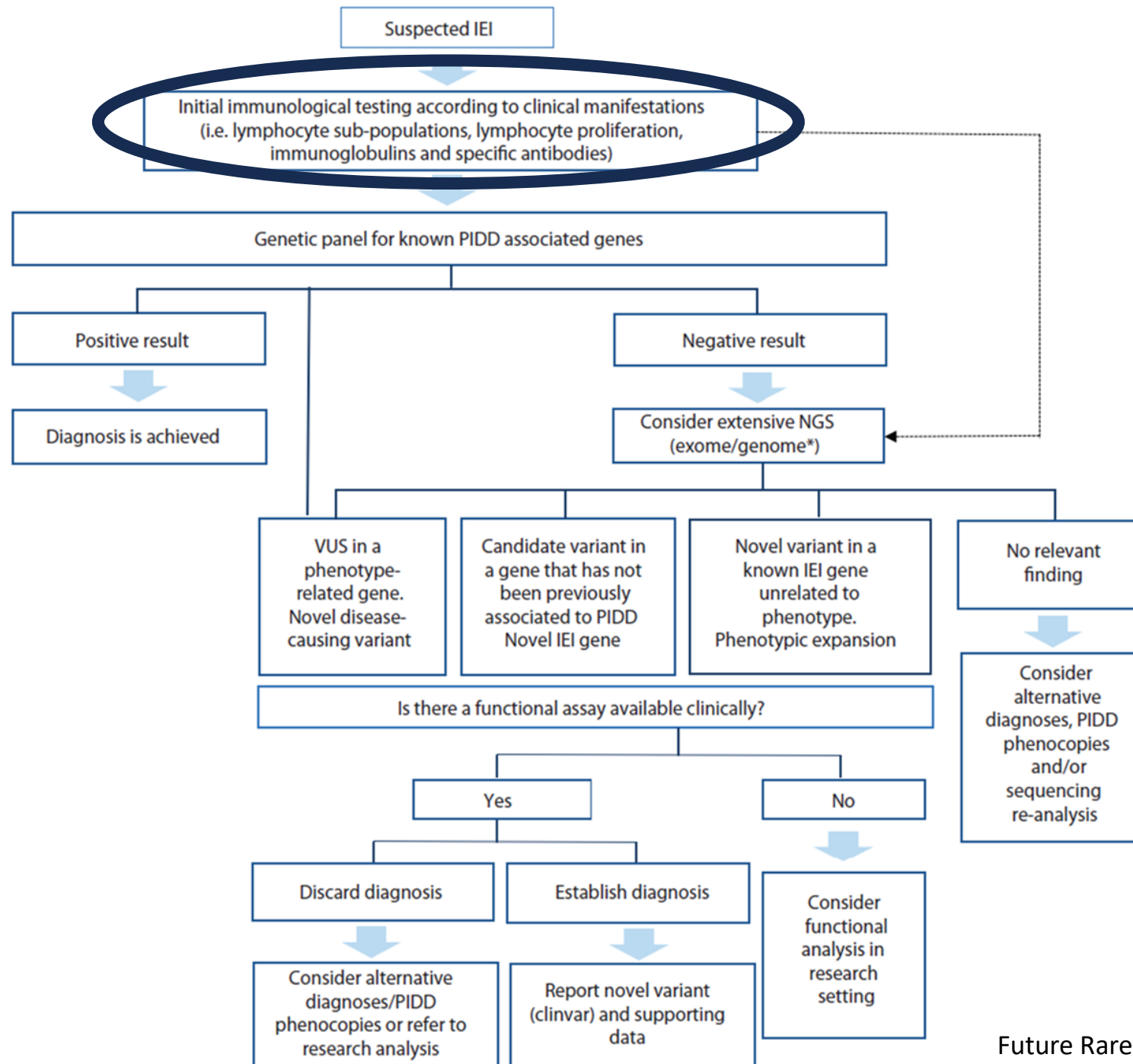
- Sólo en programas de investigación
- Fenotipo de células B
- Fenotipo de células T (excepto células T naïve)

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 desafios 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

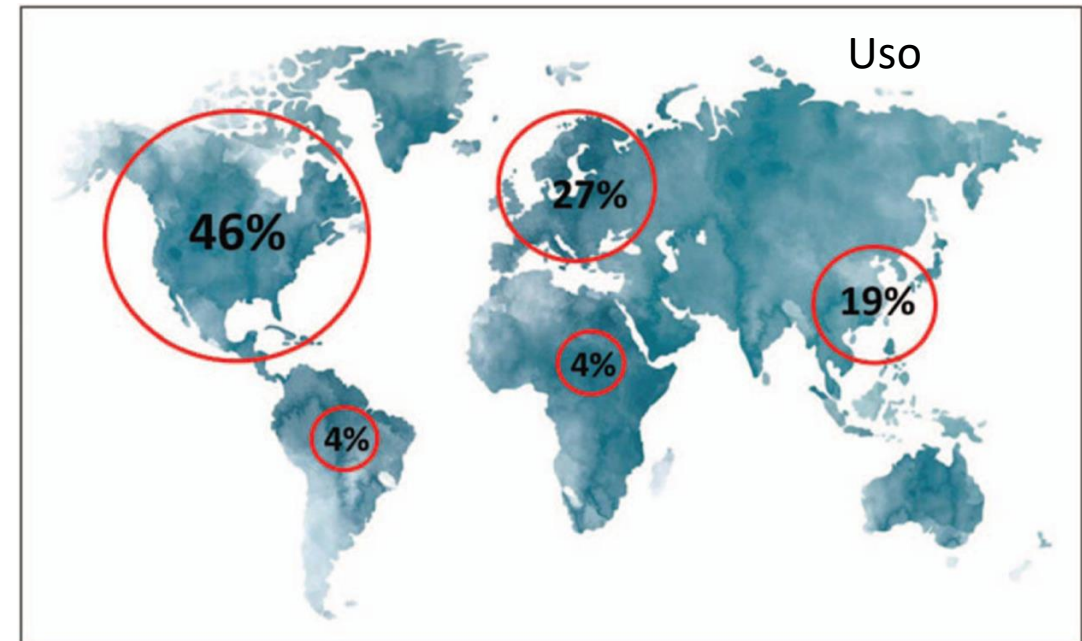
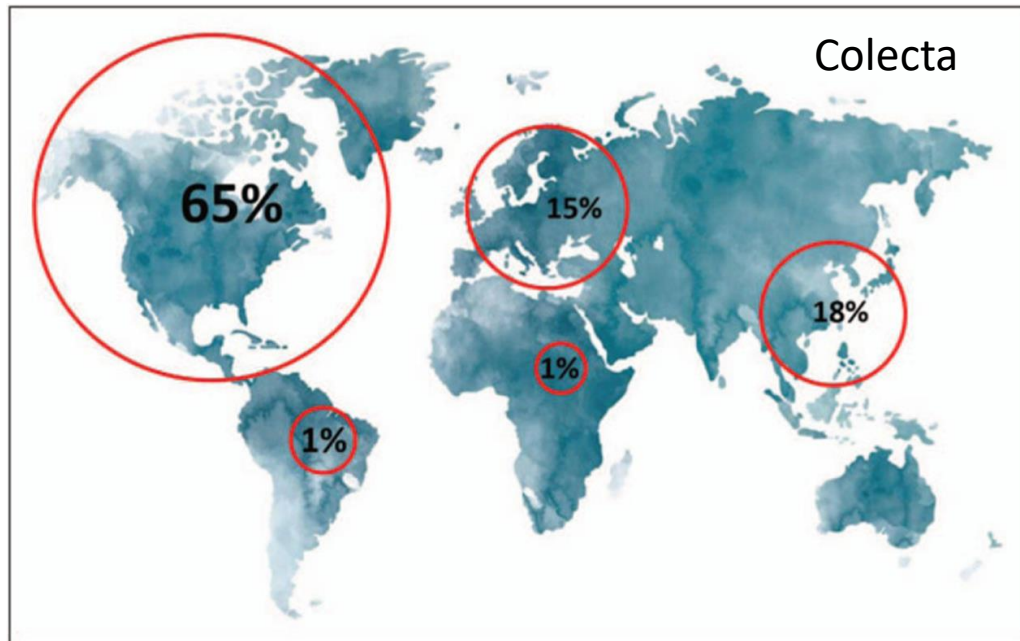
# Desafío en el acceso al tratamiento

- 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](mailto:gesmar2@gmail.com)  
[gesmar@ufu.br](mailto:gesmar@ufu.br)



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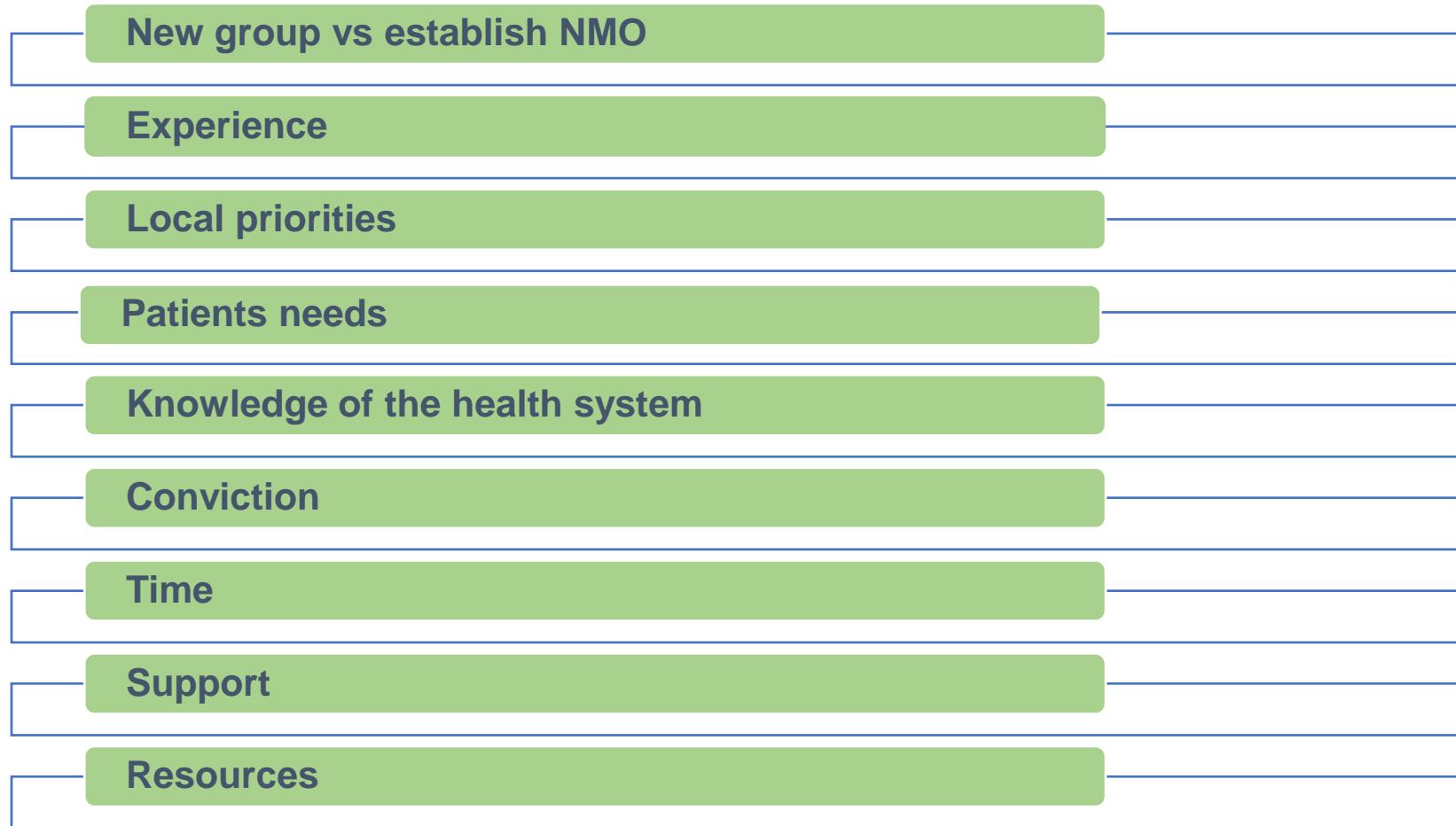


# Perspectiva de representantes de pacientes Patient representatives' perspective

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

# Some Concepts...



# 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 & involvement in research-clinical trials

Patient empowered, psychological , financial & patient support

Advocacy/ access to right and legal support

Be part of the decision-making tables

Training and patient therapeutic 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**

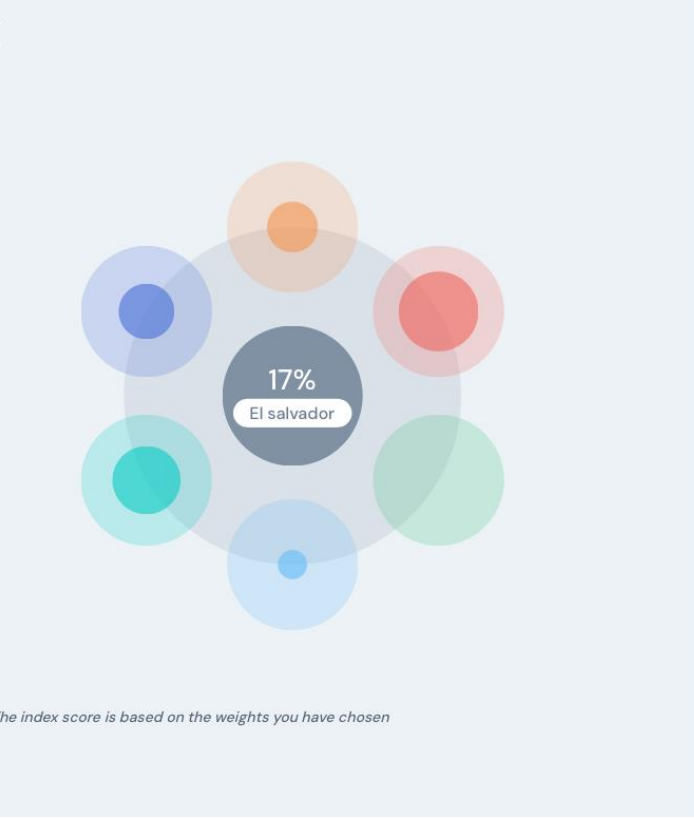
**Vaccines reimbursement**

# PID Life Index



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

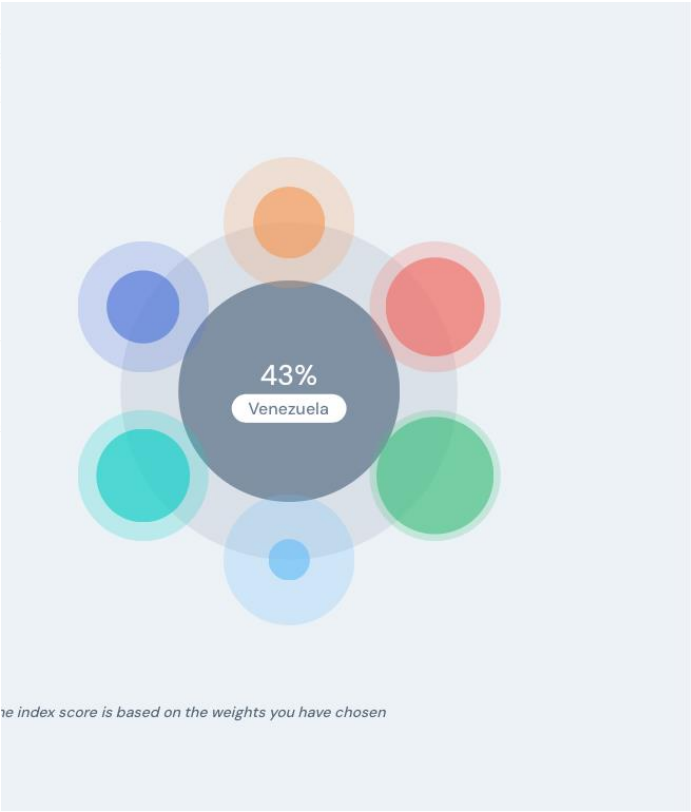
# PID Life Index



## 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
GLOBAL SCORE	17%
RANK	67th
PID diagnosis	15%
National Patient Organisations	37%
Registries	0%
Specialised centres	5%
Treatments	27%
Universal health coverage	18%

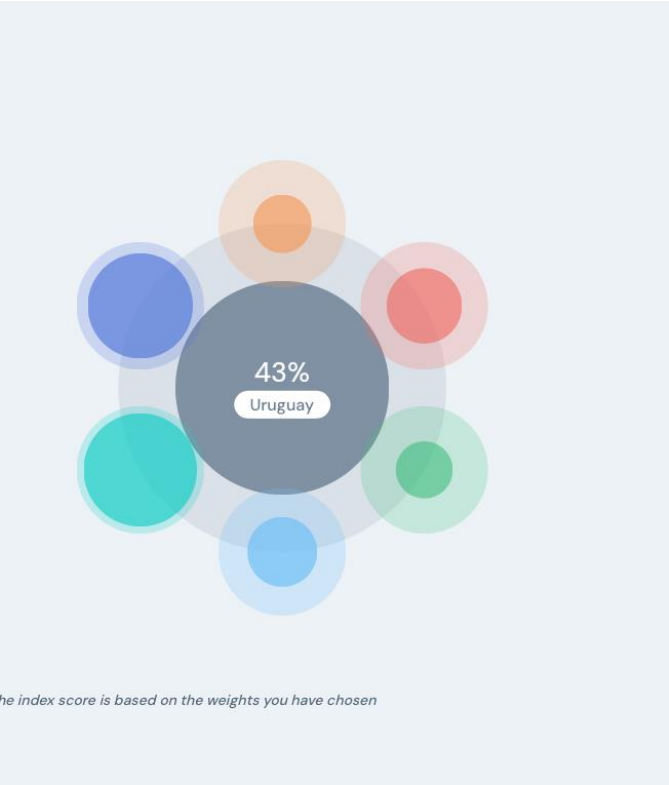


## Venezuela

[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
GLOBAL SCORE	43%
RANK	45th
PID diagnosis	30%
National Patient Organisations	57%
Registries	80%
Specialised centres	10%
Treatments	51%
Universal health coverage	31%

# 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

PID diagnosis

21%

National Patient Organisations

35%

Registries

20%

Specialised centres

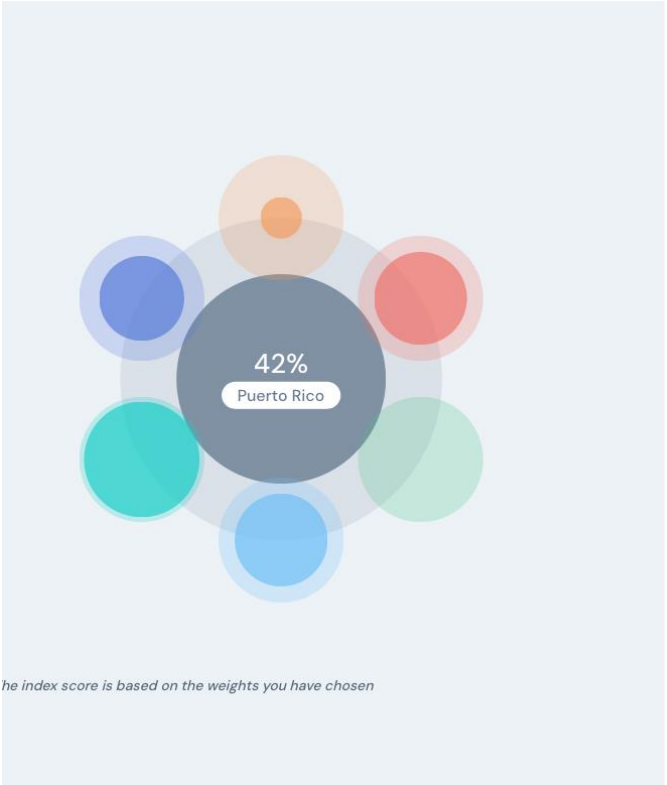
30%

Treatments

79%

Universal health coverage

68%



### 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 diagnosis

11%

National Patient Organisations

55%

Registries

0%

Specialised centres

55%

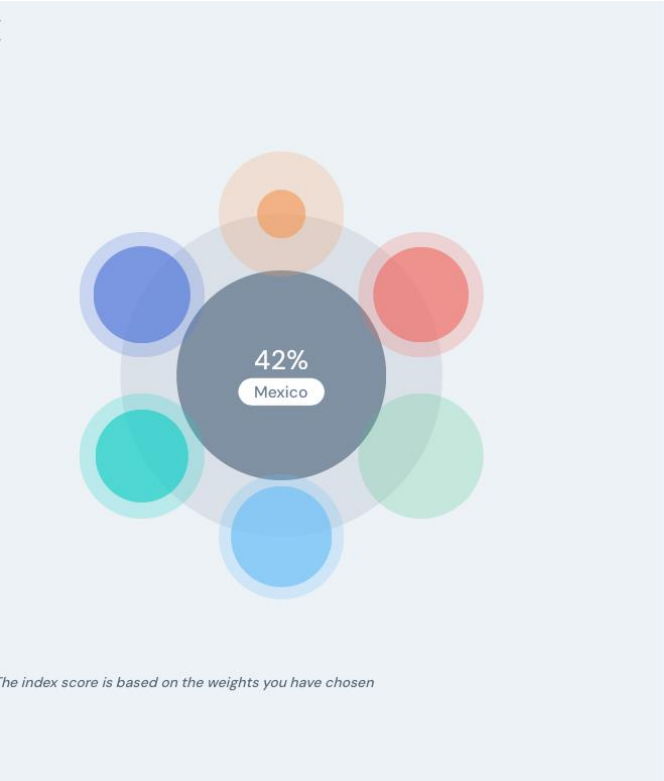
Treatments

85%

Universal health coverage

46%

# PID Life Index



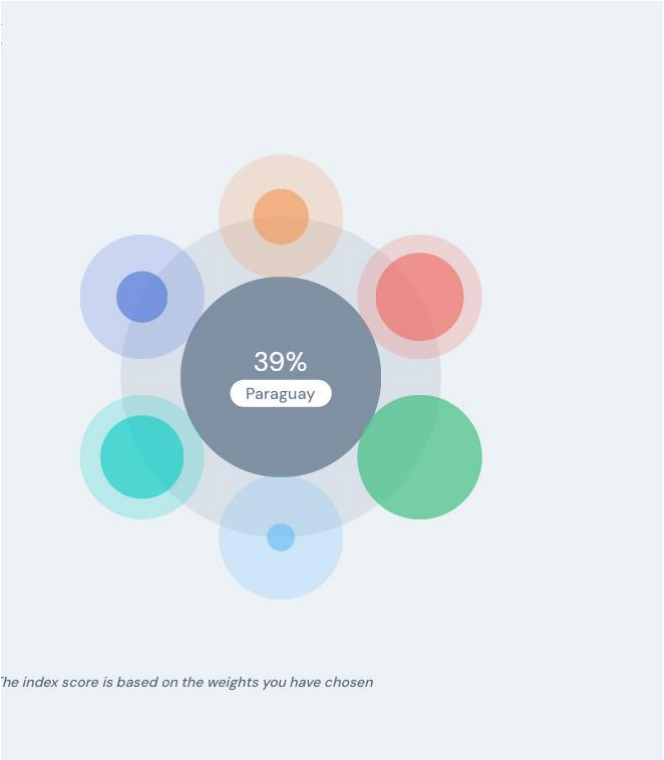
## Mexico

[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



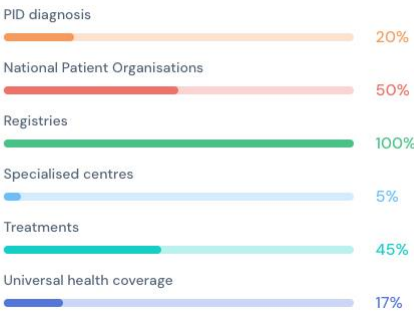
## Paraguay

[See country page](#)

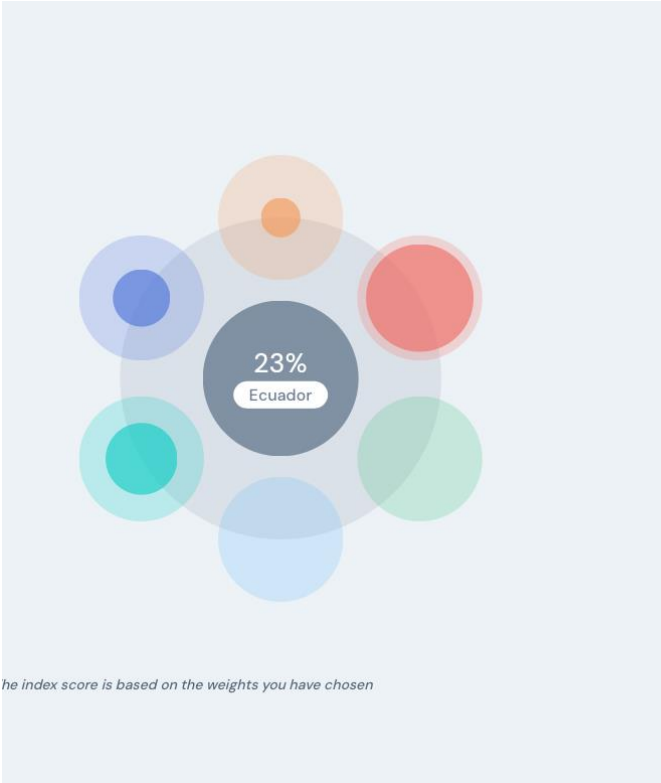
CONTINENT America  
SUB-REGION South America, Latin America  
LAST UPDATE 23/06/2020

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

PID diagnosis

10%

National Patient Organisations

74%

Registries

0%

Specialised centres

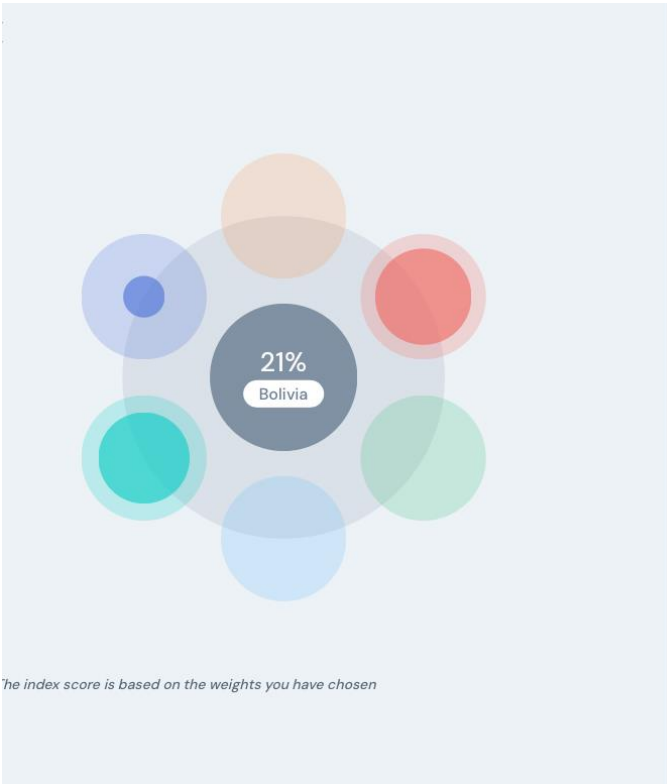
0%

Treatments

33%

Universal health coverage

21%



### 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

PID diagnosis

0%

National Patient Organisations

59%

Registries

0%

Specialised centres

0%

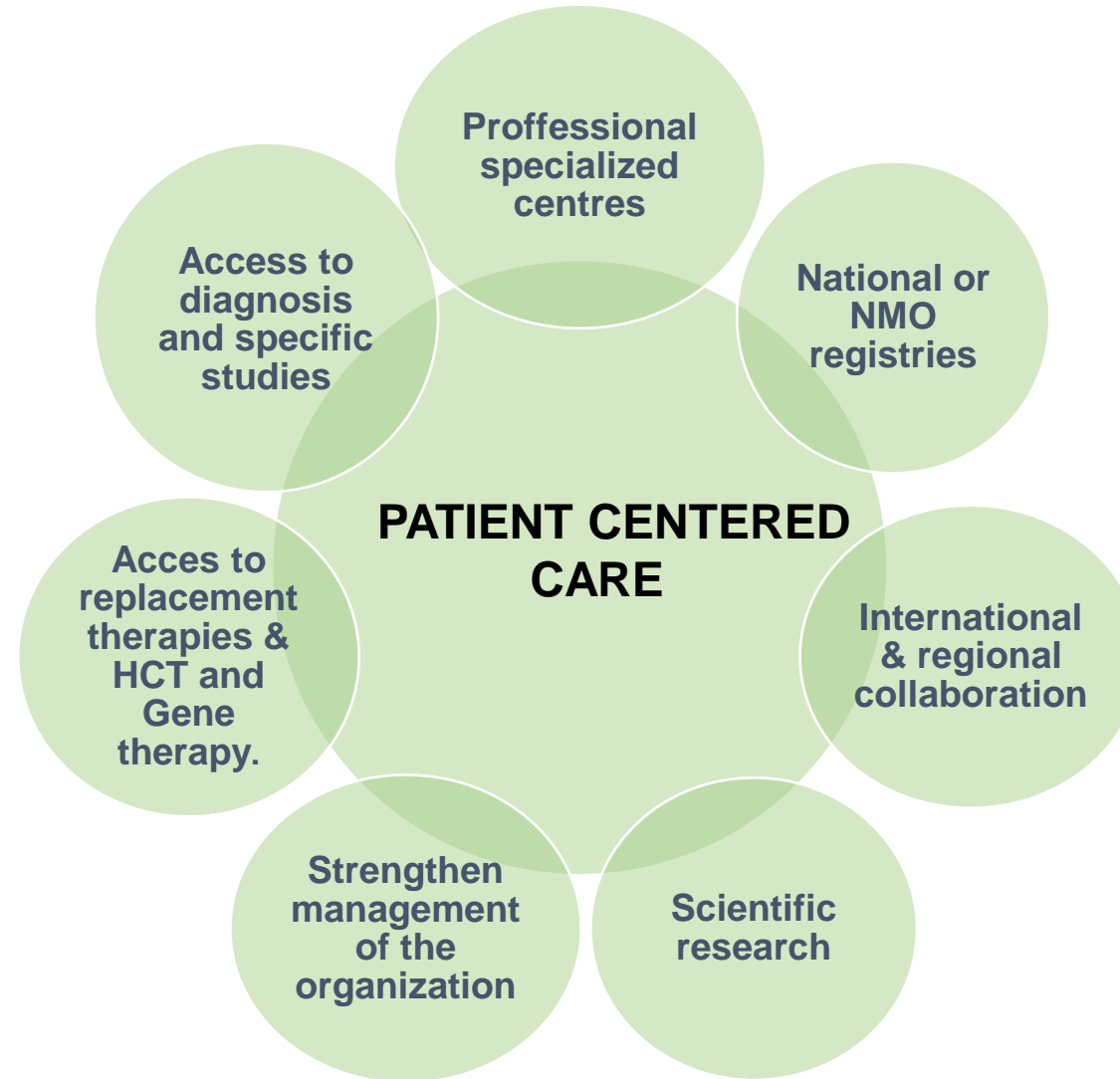
Treatments

53%

Universal health coverage

11%

# Conclusions



# Conclusions

- **Ask IPOPI for support**
- **Use IPOPI webiste**
- **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!

Muchisimas 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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# INTERVALO BREAK 30 MIN

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