

NOV 2025



IPWSO LATIN AMERICA

Prepared for the IPWSO Board of Trustees – November 2025

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Main Goal

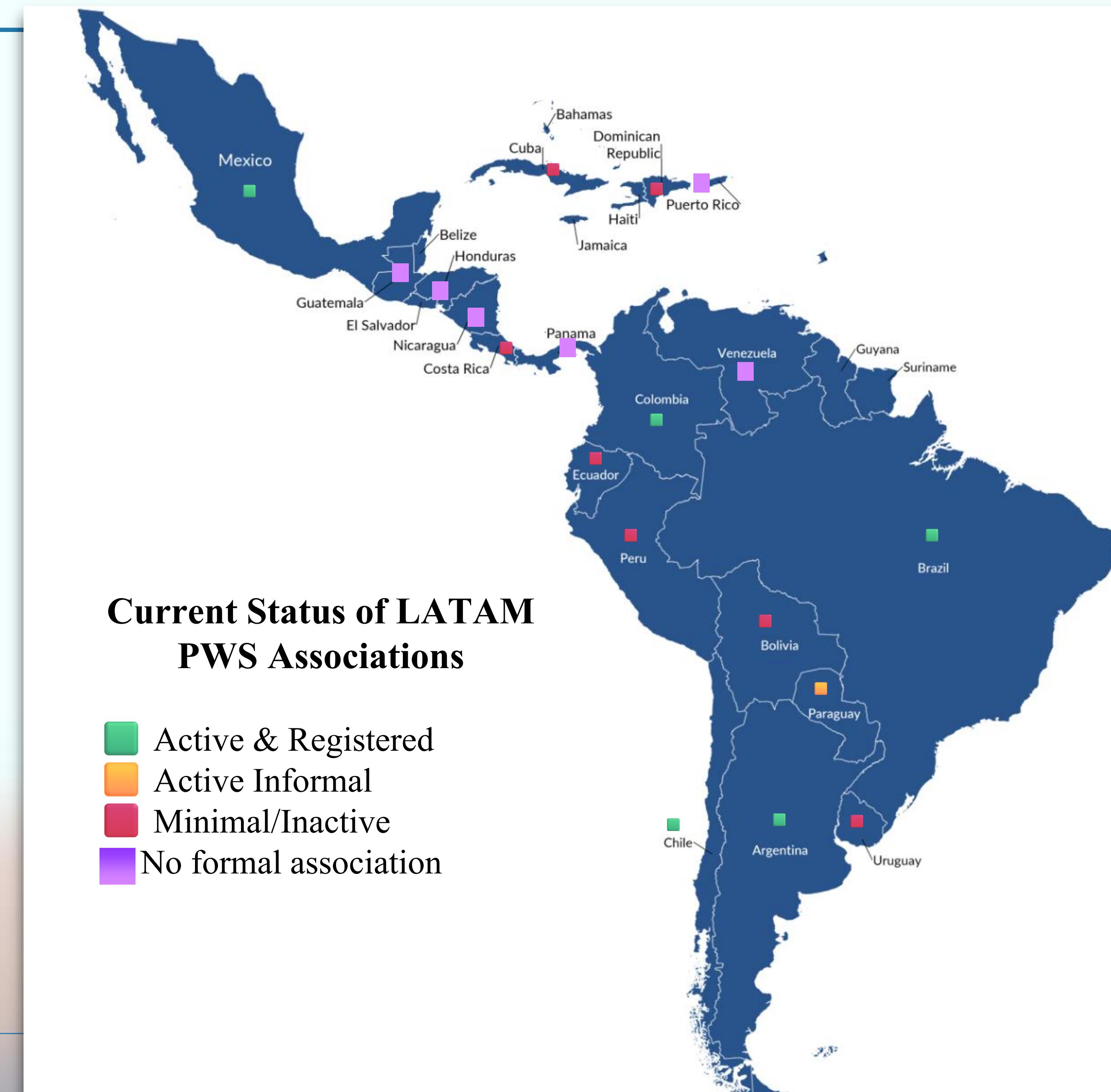
- Map current status of LATAM PWS associations
- Identify achievements, gaps, and needs
- Understand priority support needed
- Online questionnaire sent to national associations

Current Status of LATAM PWS Associations

- **15 survey responses from 14 countries:** Argentina (2 organizations), Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, El Salvador, Mexico, Paraguay, Peru, Uruguay.
- These are mostly parent-led PWS associations or family groups, plus a couple of newer foundations.
- **No responses** were received from **6 countries:** Venezuela, Guatemala, Honduras, Nicaragua, Panama, and Puerto Rico.

In some cases, isolated families or informal parent groups exist, but without legal structure or sustained advocacy.

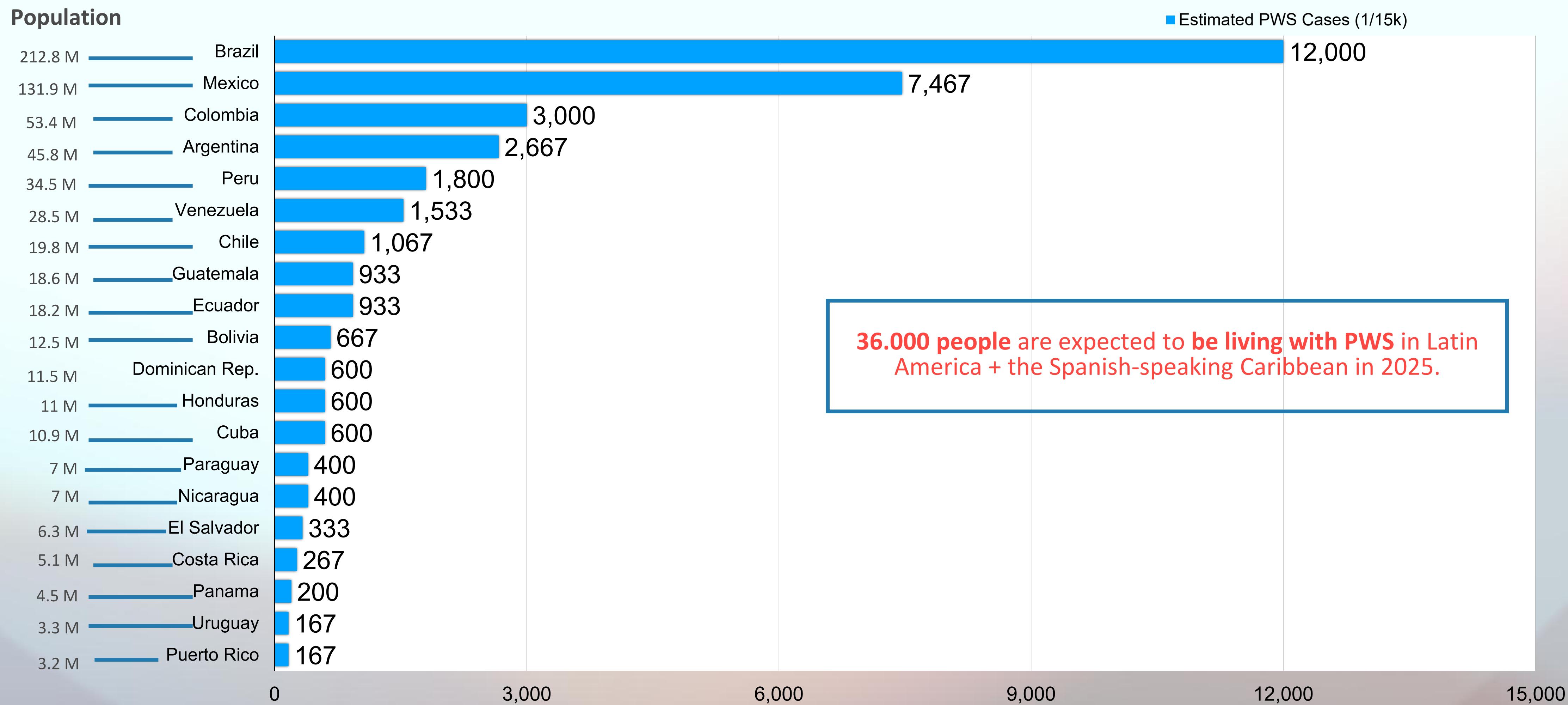
Significant gap in Central America and the Caribbean, where efforts are still needed to foster national PWS networks and family organizations.





Latin America PWS Prevalence

(1 out of 15.000 cases) Population **under 55 years**



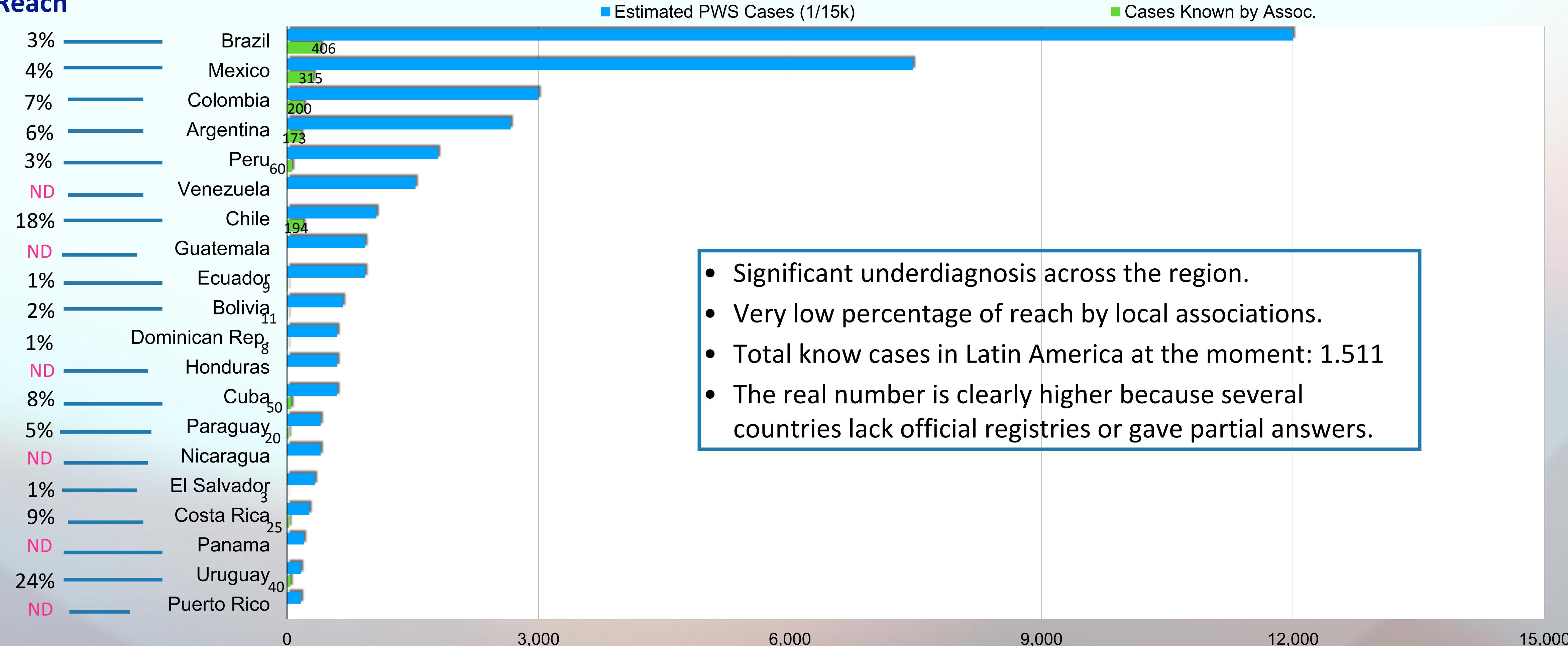
*Population <55 estimates are derived from country-specific age distributions.



Cases Known by LATAM Associations vs PWS Prevalence

(1 out of 15.000 cases) Population **under 55 years**

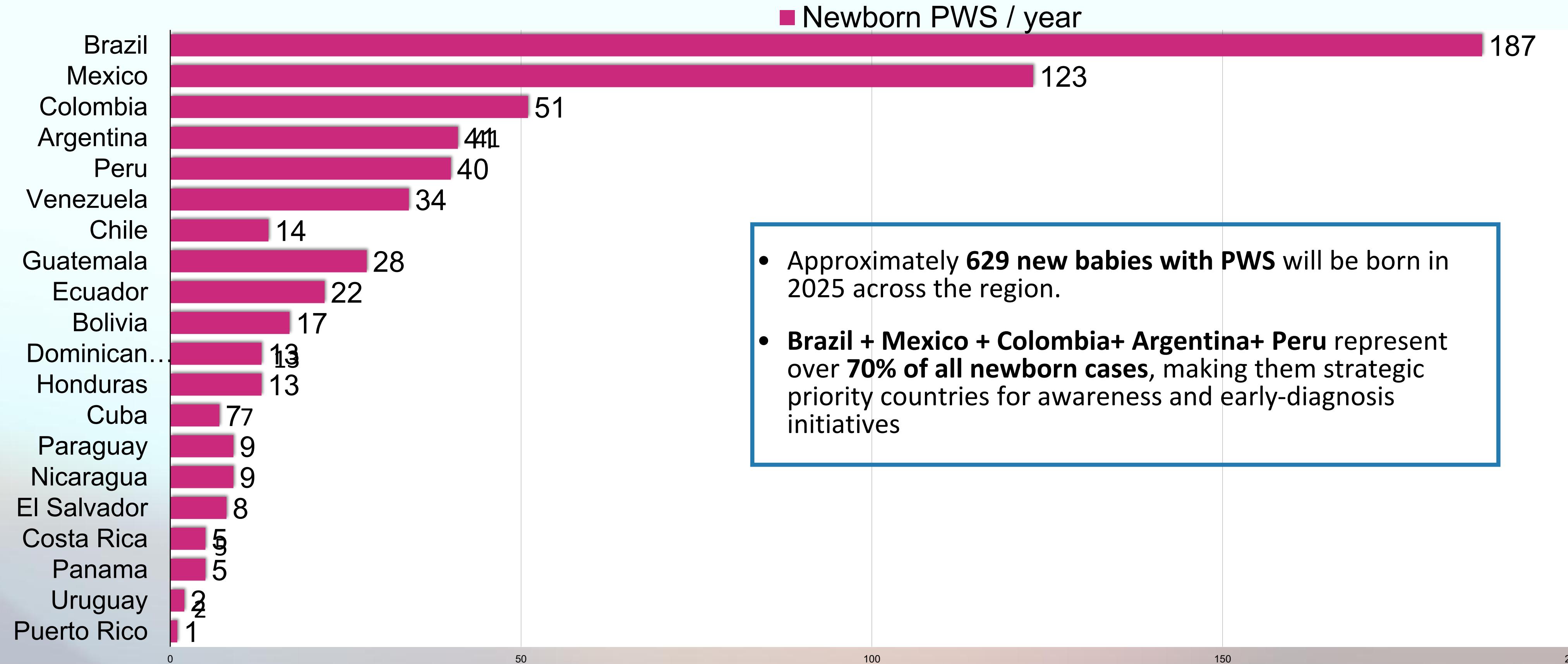
% Reach





LATAM Newborn PWS Prevalence per Year

(1 out of 15.000 cases - Birth-based new cases)





Legal status, Activity and Governance

Active associations:

- 10 say they are currently active and functioning.
- 4 say they are not active or in transition

Legally registered & with a Formal Board

- 10 are legally constituted in their country.
- 4 are *not* yet formally registered (some are informal family groups).

ACTIVE ASSOCIATIONS	NOT ACTIVE ASSOCIATIONS	NO ASSOCIATION	IPWSO MEMBERS
ARGENTINA BOLIVIA BRAZIL CHILE COLOMBIA COSTA RICA CUBA MEXICO PARAGUAY PERU	ECUADOR EL SALVADOR DOMINICAN REPUBLIC URUGUAY	VENEZUELA GUATEMALA HONDURAS NICARAGUA PANAMA PUERTO RICO	ARGENTINA BRAZIL CHILE COLOMBIA COSTA RICA MEXICO DOMINICAN REPUBLIC BOLIVIA

**Cuba, Paraguay and Peru said to be IPWSO members*



PWS LATAM Growth Hormone Treatment

- **Subsided by the government** in 2 countries: Colombia, Costa Rica.
- **GH Partial/Private Access:** Mexico, Brazil, Argentina, Chile, Peru, Uruguay, Dominican Republic, Ecuador
- GH is denied to patients after they stop growing.
- GH was approved in Bolivia in June 2025 but it is not yet accessible to patients.

Barriers: delays, long interruptions, irregular supply, inequities, adult-care gaps, lack of professional training, government bureaucracy

Despite GH being the standard of care worldwide for PWS

! Only ~1% of children with PWS in Latin America receive Growth Hormone

✓ Total estimated PWS cases under 18 across 20 countries: ~17,236

✓ Total children receiving GH based on data gathered ~164

! GH treatment starts very late — often **after ages 3 to 7**

Many doctors refuse to initiate GH until they see obesity.

! Adults with PWS are not receiving growth hormone treatment in Latin America

An opportunity for IPWSO LATAM to help the associations to:

- **Advocate for continuity of GH treatment** across the lifespan
- Push for national-level GH coverage reforms
- **Educate** clinicians about **non-growth-related benefits**
- Promote improvement on supply chains and authorization processes
- **Support families** with formal guidance and policy language



Processes and Strategic Planning

ALLIANCE WITH HEALTH PROFESSIONALS

- **Health professionals formally linked to the association:**
 - 8 say yes
 - 7 say no

DATABASES

- **Patient/family database:**
 - 10 associations keep a database of patients/families.
 - 5 do not.

STRATEGIC PLANNING

- 5 associations said they **have some kind of strategic plan or institutional plan** (sometimes called “*Institutional Project*” or planning through 2028).
- Around 9 say **no** or “**not formally**”, or are only just starting to build a plan.

Many associations are **collecting data and have some structure**, but **long-term strategic planning is still weak in most associations**.



MAIN CHALLENGES FOR FAMILIES

- **Lack of awareness and knowledge** about PWS among doctors, schools and society in general.
- **Few specialists** (especially psychiatrists, endocrinologists and behavioral health professionals) with PWS expertise.
- **Insufficient health services** for people with PWS, especially in the public system.
- Limited access to growth hormone and therapies in several countries.
- **Lack of specialized centers** for adolescents and adults; very few residential or day-program options.
- **Economic barriers**: families cannot afford private therapies or treatments.
- **Lack of information** for families at the time of diagnosis and through the lifespan.
- **Political/health system instability** and changes in disability / health policies are mentioned as a serious obstacle.



PRIORITY SUPPORT REQUESTED FROM IPWSO

- **Strategic support** to help **identify more cases** and strengthen the associations.
- **Administrative and organizational support** to build stronger, more useful associations (governance, strategic planning, fundraising).
- Institutional support for dialogue with governments, universities and pharma.
- More information and materials in Spanish (and Portuguese for Brazil), including scholarships for professionals to attend conferences.
- Support to increase training for health professionals and expand access to genetic testing and growth hormone.
- Some explicitly say: “We feel we have already received a lot of support from IPWSO and want to continue that collaboration.”
- Newer or smaller groups simply answer: “All types of support”, “Health”, or “Accompaniment”.



- Founded ~2014
- **315 known PWS families**
(mostly mid-low income)
- No formal board of directors
- **Only 3 people** conform the Association

Medical & Diagnosis

- **GH not subsidized**; uneven access
- Less < 30% (80 people) receive **GH**.
- GH treatment begins around ages 3–4. Prescribed until signs of obesity appear.
- **Average diagnosis age 3–8 yrs.**
- Free diagnosis available through Anolab pharmaceutical

Programs & Activities

- **Regional meetings every 2 yrs**
(7 so far)
- Virtual PWS events
- Virtual psychology support, family consultations
- Quarterly newsletter

Main Challenges

- Limited capacity to execute projects and campaigns.
- Few newborns are diagnosed with PWS. In need of early diagnosis
- Limited access to trained doctors.
- Access to medications.
- Promote GH treatment.
- Diagnosis acceptance.
- In need for school and social PWS awareness



- Founded ~2019
- **200 known PWS families** 12% reach
- Formal board of directors
- Use of **regional committees** to decentralize work

Medical & Diagnosis

- **GH** is fully government **subsidized** but it is commonly discontinued at age 16.
- **100 PWS patients receive GH.**
- Significant **increase in early diagnosis** of children with PWS in recent years

Main Achievements

- **Rapid expansion** of their PWS DB
- **Partnerships** with universities & medical associations
- **Increase in PWS early diagnosis**
- **Education** and training on PWS for families and healthcare professionals

Strategic Plan

- Obtain PWS **mandatory newborn screening** within the next 3 years.
- Diversifying **funding** sources.
- Comprehensive care and clinical guidelines.
- Scientific partnerships and research.
- Corporate governance.
- Training for caregivers and families



- Delivered phase 1 of a 10-week Virtual Therapeutic Caregivers training to over 700 attendees across Latin America. Recording available on their YT channel.

In the words of one participant, “now I feel that I can properly care for a person with PWS”



- Completed the 2nd in-person phase of the Therapeutic Caregiver Training Course for PWS.
- 12 Colombian healthcare professionals trained by Fundación Spine (Argentina). Who provided consultation based on their learning to PWS patients at the end of the session.
- Builds a future national training network to expand specialized PWS care.
- A historic milestone enabling future projects: Reference Center, Residences, Support Centers, Camps.



AR Association SPW Argentina

- Founded ~2002
- **173 known PWS families**
6% reach
- Formal board of directors
- **2005** - Argentina hosted IPWSO conference.

Medical & Diagnosis

- **Growth Hormone (GH):** It used to be subsidized by the government, but not anymore.
- Families now must **enter legal processes** in order to continue receiving GH treatment.

AR Foundation SPW Argentina

Overview

- **Newly formed** in **2025**, composed of 10 families

Strategic Plan

Short-Term Goal (2 years)

- Create a **Day Center/ Respite for adults (18+ years)**

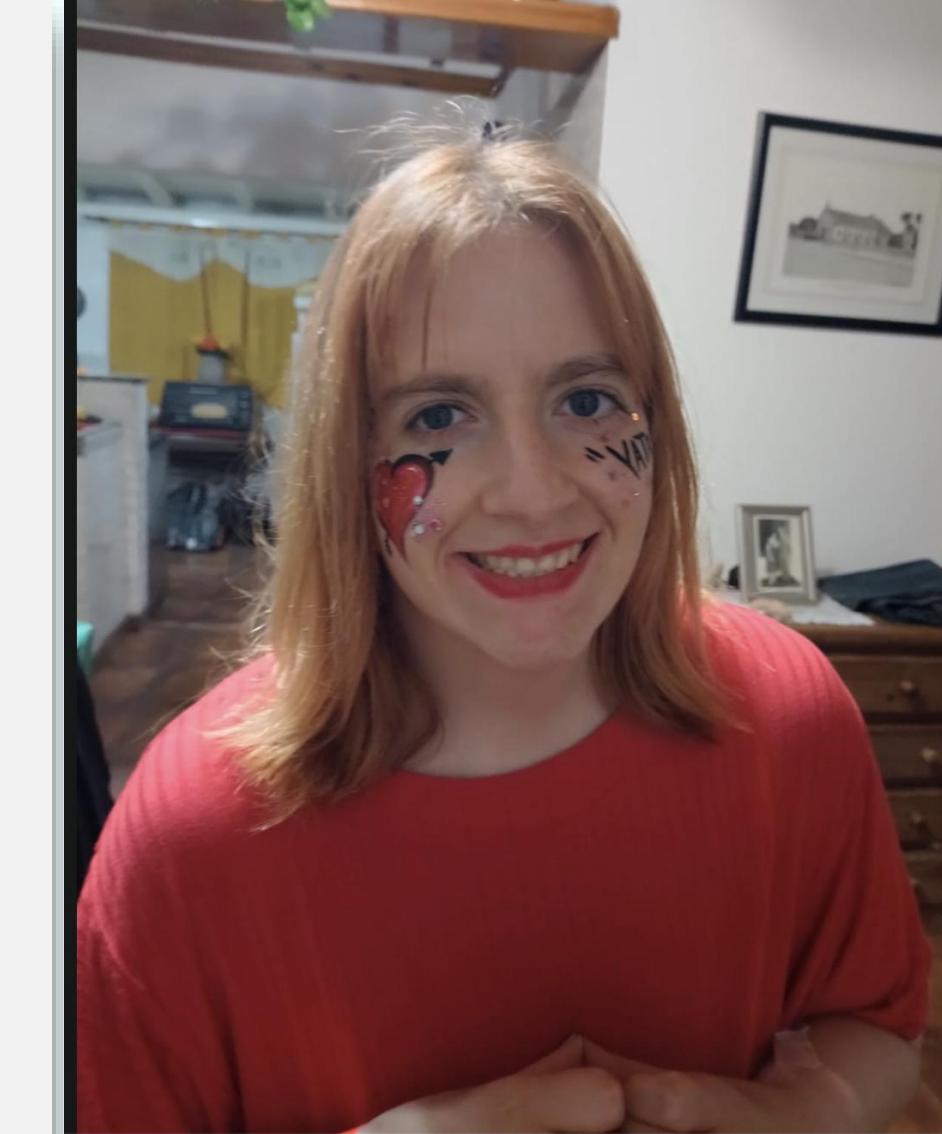
Long-Term Goal (5 years)

- Establish a **PWS Residential Home** for up to 10 individuals with PWS

Hoping to receive state subsidies and pharmaceutical donations.

Key Needs

- **Training** for caregivers and professionals.
- **Increased inclusion** and community opportunities.





LATAM REGIONAL CONCLUSIONS

Key Regional Findings

- Low diagnosis rates and uneven access to GH and multidisciplinary care.
- Strong momentum toward **earlier detection** of PWS in several countries.
- Many associations operate with **limited volunteer capacity**, slowing growth.
- Expanding collaborations with **universities, medical societies, and research teams**.
- Increasing training initiatives: **workshops, bootcamps, regional meetings, and virtual trainings**.

Community Dynamics

- In some countries, **parallel PWS groups have emerged** because families feel underserved (adults vs. children, obesity vs. typical weight, GH vs. no GH).
- Highlights the need for **inclusive, unified national structures**.



STRATEGIC PRIORITY: LATAM MENTORING PROGRAM

Establish a **regional mentoring model** where **robust, experienced associations** (e.g., Colombia, Mexico, Brazil, Argentina) support **younger or emerging associations**.

Focus areas of mentorship:

- **Best practices** in organization, data collection, outreach, and advocacy
- **Creating and implementing strategic plans**
- **Strengthening governance and leadership**
- **Building sustainable funding models**

This program would accelerate growth, reduce fragmentation, and create a **stronger, more coordinated LATAM network**.