

# Introduction

Welcome to Brazil's bid for the 13th International Prader-Willi Syndrome Conference in 2028.

Through Associação Brasileira da Síndrome de Prader-Willi (SPW Brasil), we unite families, professionals, and advocates worldwide under the motto: 'Together for a Lighter Way of Living.'



This presentation outlines why Brazil (and Latin America) is ready to welcome the PWS community, our conference theme and objectives, the strengths of SPW Brasil, venue and program plans, and the unique attractions of Foz do Iguaçu.

We believe hosting IPWSO's Conference 2028 in Brazil will improve and transform lives by bringing the global PWS community together in an unforgettable setting.











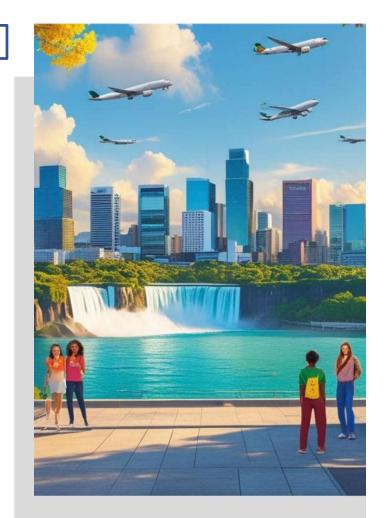


# Why Brazil?

Latin America has over 569 million people, yet PWS remains underdiagnosed. Hosting IPWSO's Conference 2028 in Brazil would expand awareness and access to information on PWS.

It is a unique chance to connect and empower communities across all the 20 countries of the region, pushing the global PWS mission forward.

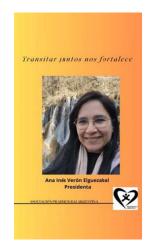
- Political, economic, and social stability
- Safe city, free from major natural disasters
- Regional gateway with access to Latin America (3 international airports)
- Cost-effective destination (e.g. 1 USD ~ 6 BRL\*)
- Home to the Iguaçu Falls a Natural World Wonder
- Visa-free for over 130 countries
- Engaging PWS awareness and education programs



\* Currency exchange rate based on May 2025

# Across Latin America, Together for PWS

















#### **OUR TEAM**

Led by President Marco Aurelio Cardoso and a dedicated Board, SPW Brasil includes parents, caregivers, medical professionals and volunteers united by personal commitment to the PWS community.

#### Board



Renata Truzzi
Acceleration Impact Director
at NESsT Global



Liane Motta
PWS Mother & Former
SPW Brasil's President



Marco A. Cardoso PWS Father & President



Roberta F. Alvarez Morsier's Mother & CHR and Board Member



Carol Passone
MD, Endocrinologist
& PWS Specialist

#### **Directors**



Marco A. Cardoso PWS Father & President



Fanny Castro Legal & Fiscal Board



Antônio Paulo Conde (AP) Finance



Mariana Sotero Bonnás Psychology



Fabio Oliveira Bonfim Fundraising



Carol Matoso Nutrition



Dra. Ruth Franco Medical



Henrique Diniz Fiscal Board



Claudia Abel Education



Anderson Degrecci Fiscal Board

#### **About SPW Brasil**

(Brazilian Prader-Willi Syndrome Association)

The Brazilian Prader-Willi Syndrome Association (SPW Brasil) was founded in 2016 as a non-profit organization. It is an association of families and professionals working together to raise awareness and inform society about PWS, support parents and caregivers, share research and medical findings, and advocate for a better quality of life for people with PWS.

#### Our goals for 2025-2028:

- Ensure growth hormone (GH) is available through Brazil's public health system (SUS).
- Guarantee a diagnosis for every newborn with PWS within 90 days.
- Identify the estimated 5,000 undiagnosed individuals (currently, 581 have been identified).
- Expand psychological support for families and caregivers.
- Develop assisted living options, which currently do not exist in Brazil.

In just a few years, SPW Brasil has built a network of hundreds of families across the country. There's still a lot to be done, but here's what we've achieved so far:

- Produced over 30 hours of PWS-related content in 55 videos.
- In May 2025, we held 7 community meetings covering essential topics: PWS Q&A, diet management tips, speech therapy, psychiatric care, diagnostics and subtypes, sleep disorders, use of Vykat, and ongoing research.
- Organized more than 50 awareness walks over the past 8 years.









We hosted a national PWS Symposium in 2023, which drew more than 150 attendees.



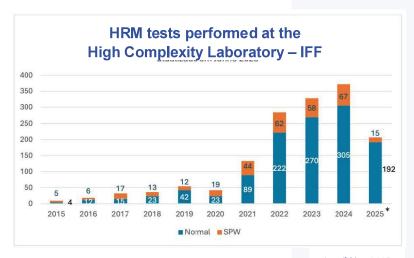
PWS multidisciplinary Symposium in 2017

Additionally, SPW Brasil organized Brazil's first-ever PWS Family Camp, bringing together 42 PWS individuals, 23 professionals and hotel kids' club staff during four days of fun, adaptive sports, educational workshops, and peer support.





• Fiocruz Partnership – Expanding Diagnosis: Since our foundation, SPW Brasil has led several landmark initiatives. Most notably, in partnership with Fiocruz – a leading Brazilian public health research institute – we launched a nationwide, free genetic testing program for PWS. Within two years, new diagnoses in Brazil increased by over 200%, allowing for earlier interventions and improved outcomes. Our efforts earned recognition from IPWSO's Scientific Committee for excellence in community service and medical collaboration. As a result, the free exam offering has been expanded to Latin American countries.



• Research & Medical Expertise: The IFF/Fiocruz High Complexity Laboratory, led by Dr. Leticia Guida, has multiple ongoing PWS research projects, including international collaborations (University of Pittsburgh, USA). This collaboration is exemplified by Dr. Robert D. Nicholls (a leading PWS researcher from Pittsburgh), who has longstanding ties with Dr. Guida's team and visited Brazil recently to share insights. Many articles have been published by our team over the past five years, some in collaboration with leaders from the US, France, and the Netherlands. Our community also works with top Brazilian specialists in genetics, endocrinology, nutrition, and psychiatry to advance PWS care.

\* until May 2025

#### We have been honored to host several world-renowned PWS experts in recent years:

#### **Prof. Tony Holland (UK)**

 outgoing IPWSO's President - has been a key advisor and advocate, fostering links between IPWSO and Brazil.



Dr. Janice Forster (USA), pediatric neuropsychiatrist; and Patrice Carroll (USA), specialized in PWS care – keynote speakers at our 2023 SPW Brasil Symposium, sharing expertise in behavioral management.





Dr. Robert D. Nicholls (USA)- a pioneer in PWS genetics - gave a special presentation at Fiocruz in Rio de Janeiro in 2025, sharing important research findings with students, doctors, and families.



**Growing Impact:** Our efforts have been translated into an all-time high PWS awareness in Brazil. Diagnoses are rising, and the average age at diagnosis is falling, a clear sign of earlier detection. Although over 5,000 patients remain undiagnosed, more families are receiving support, and healthcare professionals are increasingly being informed. We are ready to leverage the IPWSO's Conference to drive further progress in PWS care across Brazil and Latin America.

By August 2026, we will have trained at least one physician in every 27 states in Brazil in order to serve as a regional PWS reference. In total, over 60 healthcare professionals will be equipped to strengthen the national network for early diagnosis and specialized care.

**OUR STRENGTHS COMMITMENT** 

# **PWS Brazil 2025**

**Menthor Mothers (22)** 



# **Together** for a lighter way of living

#### **CONFERENCE THEME & OBJECTIVE**

Theme: Together for a Lighter Way of Living

Our motto ("Juntos por uma vida mais leve") reflects the goal of improving both physical health and emotional well-being for people with PWS. This change depends on early diagnosis and strong family support. The international congress will be crucial in advancing this initiative in the region.

#### **Conference Goal**

IPWSO 2028 in Brazil aims to unite researchers, professionals, families, and people with PWS to share knowledge and accelerate progress in care, treatments, and quality of life.

### FOZ DO IGUAÇU

#### A DESTINATION LIKE NO OTHER

A Living Symbol of Unity: At the meeting point of Brazil, Argentina, and Paraguay, Foz do Iguaçu reflects the spirit of the PWS community - diverse, inclusive, and stronger together. With over 80 nationalities, it's the perfect place to show that care knows no borders.

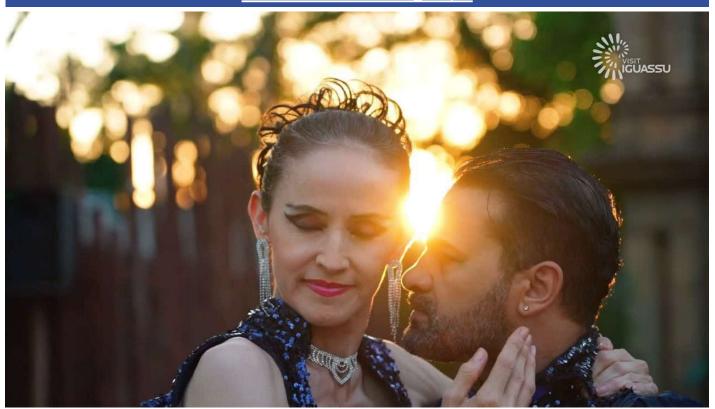
Beyond this "liquid frontier" lies top infrastructure, three international airports, excellent services, and warm hospitality. Despite its remote-sounding name, Foz is a major destination, easily accessed via São Paulo, Brasília, or Buenos Aires.

Nature here stuns: the Iguaçu Falls – UNESCO World Heritage Site and one of the New Seven Wonders – offers unforgettable moments. The surrounding rainforest and the Itaipu Dam remind us of the beauty and power of collective effort. Foz also offers safety, stability, and great value – more resources for learning, networking, and impact.

**In short:** Foz do Iguaçu is more than a venue. It's the face of Latin American unity and the perfect stage for global PWS collaboration.



# Click here and dive into the breathtaking wonders of Foz do Iguaçu!



#### SOME INCREDIBLE ATTRACTIONS IN FOZ DO IGUAÇU:



Iguaçu Waterfalls
One of the world's largest waterfall
systems, with 275 falls surrounded by lush
rainforest. A true natural wonder!



Macuco Safari
An unforgettable boat ride that takes you right under the Iguaçu Falls. Thrilling, wet, and wildly beautiful!



Yup Star Foz
Enjoy panoramic views of Foz do Iguaçu
on this 88-meter-high Ferris wheel perfect for stunning photos and sunsets.



Parque das Aves (Bird Park)
Walk among toucans, macaws, and
butterflies in this immersive sanctuary that
protects Atlantic Rainforest species.



Itaipu Binacional
One of the world's largest hydroelectric plants. Take a guided tour and witness engineering on a massive scale.



Three Borders Landmark
Where Brazil, Argentina, and Paraguay
meet. Enjoy cultural shows and views of
three nations at once.

#### CENTRE POMPIDOU EXPANDS INTO LATIN AMERICA

FOZ DO IGUAÇU WILL HOST THE FIRST INTERNATIONAL MUSEUM IN BRAZIL AND LATIN AMERICA

Pompidou in Paris, which is set to close in September for a five-year renovation, will open a satellite in Foz do Iguaçu, Brazil, in November 2027. The outpost is projected to cost \$240 million and represents the storied contemporary art institution's first foray into South America. It is supported in part by officials of the state of Paraná, in which it is to be located. Situated near the UNESCO World Heritage Site of Iguaçu Falls, near the borders of Argentina and Paraguay, the new museum will be designed by Paraguayan architect Solano Benítez.



#### RAFAIN PALACE HOTEL & CONVENTION CENTER



#### **Accommodations**

- 270 guest rooms, including 8 luxury suites:
- 1 Presidential (panoramic balcony, living room, king bed, hydro tub)
- 3 Executive (living area, full minibar, premium amenities)
- 4 Luxury (flat-screen TV, espresso machine, balcony)
- Standard rooms: Wi-Fi, A/C, safe, minibar, premium bathroom fixtures.
- Most delegates can stay on-site for maximum convenience.

#### **Convention Facilities**

- 18,015 m<sup>2</sup> modular event space with up to 44 rooms.
- Main hall fits 5,000+ (theater-style), ideal for plenaries and keynotes.
- Mid-size rooms (200 500 seats) for workshops/sessions.
- Small rooms (30 100 seats) for committees/discussions.
- All rooms with advanced AV, HD projectors, climate control.
- On-site tech staff experienced in global events.

#### Leisure & Amenities

- 63,000 m² leisure area:
- 3 pools, including lagoon-style with waterfall and loungers
- Sports: soccer, volleyball, jogging path in tropical gardens
- Accessible playground with trained staff
- Dining:
- Buffet with Brazilian/international cuisine
- 24/7 coffee shop and lounge bar
- Shopping arcade with local crafts and essentials

#### **Accessibility & Logistics**

- 10 min from downtown, 20 min from IGU Airport
- Free parking for 500 vehicles, with accessible spaces
- Fully ADA-compliant: ramps, elevators, accessible rooms
- All-in-one complex simplifies logistics for all attendees
- Rafain Palace blends world-class conference space with resort comfort - productivity meets relaxation.

# **ACCOMODATION**

Hotel Name	Rating	Rooms	Cost (USD)	Capacity	Distance from Venue
Rafain Palace Hotel & Convention Center	Lux	270	105	2-4	Onsite
Mabu Thermas Grand Resort	Lux	362	160	2-4	16 min drive
Recanto Cataratas Thermas Resort	Lux	501	120	2-4	4 min drive
Nadai Confort Hotel & Spa	Superior	130	95	2-3	12 min drive
JL Hotel by Bourbon	Superior	220	80	2-4	11 min drive
Foz Plaza Hotel	Economic	112	72	2-3	12 min drive
Wyndham Golden Foz Suites	Superior	157	68	2-4	14 min drive
Hotel Golden Park Internacional	Superior	214	45	2-4	14 min drive
Viale Iguassu Hotel	Economic	126	42	2-3	11 min drive

# PROPOSED PROGRAM OUTLINE – IPWSO 2028, BRAZIL

The four-day IPWSO's 2028 Conference will offer five parallel program tracks, tailored to the diverse needs of the PWS community - researchers, professionals, families, and individuals with PWS.

- CLINICAL & SCIENTIFIC PROGRAM (2 DAYS)
- PROFESSIONAL PROVIDERS & CAREGIVERS PROGRAM (2 DAYS)
- FAMILY PROGRAM (2 DAYS)
- ADULTS WITH PWS PROGRAM (1 DAY)
- ► CHILDREN'S PROGRAM (ONGOING)

All five tracks will run concurrently, with shared plenary sessions and a detailed, color-coded agenda to help attendees navigate the schedule.









# **UNCOVER THE COLORS, CULTURE, AND SOUL OF BRAZIL!**



Rio de Janeiro
Where nature meets city life: beaches, mountains, and iconic views.



Pantanal
A wildlife paradise – the world's largest tropical wetland.



Northeast Beaches
Golden sands, turquoise waters,
and endless sunshine.



Chapada dos Veadeiros Crystal-dear waterfalls and mystic landscapes in Brazil's highlands.



**São Paulo**Vibrant cultural and economic hub, full of energy and diversity.



**Lençóis Maranhenses**A surreal desert of sand dunes and seasonal lagoons.



Amazon Rainforest
The heart of biodiversity – a world
of rivers and jungle life.



Vale dos Vinhedos
Rolling vineyards and southem charm
inspired by European roots.



## **CONFERENCE FORMAT & ACCESSIBILITY**

We strongly encourage the global PWS community to attend in person and enjoy a "trip of a lifetime" to Brazil.

The conference will be primarily in-person, maximizing networking and direct engagement. For those who cannot travel, we will offer limited hybrid elements: select sessions live-streamed or recorded for later viewing. (We recognize the value of reaching everyone, but also the practical limits of live broadcast.)

Language: The official language will be English. We will provide Portuguese and Spanish translation; otherwise, it won't be truly a Latin American conference, as we intend it to be. Our goal is an inclusive event with as much knowledge-sharing as possible beyond the on-site experience.

#### **SOCIAL EVENTS:**

To enrich the experience, we will organize memorable social events:



**Welcome Reception:** An opening evening reception to greet delegates with Brazilian warmth. This informal gathering will feature local music and cuisine, allowing attendees to mingle and make connections from the start.

**Conference Dinner (Gala Night):** A special dinner event with entertainment, celebrating our community. This will be an opportunity to honor international contributors and local heroes, and to enjoy Brazilian culture.

Throughout the conference, we will also offer guided tours for those interested (e.g., a group visit to the Iguazu Falls, a tour to the Itaipu Dam) to experience the best of the location.



We are actively seeking sponsorships to support the conference. We have preliminary backing from local authorities (Iguassu Convention & Visitors Bureau) and interest from companies (in healthcare, nutrition, etc.) that serve the rare disease community.

Our aim is to keep registration fees affordable (with scholarships for families in need) and to possibly fund travel grants for speakers from low-income countries.

# **WE ARE READY!**

#### Brazil is ready to host IPWSO's Conference in 2028!

We offer a compelling combination of a strong PWS association, proven commitment, a fantastic venue and location, and the heartfelt enthusiasm of our community.

We are eager to work with IPWSO to create a transformative, uplifting event that will benefit individuals with PWS and families around the world.



Thank you for considering our bid.

#### We hope to welcome you to Foz do Iguaçu in 2028!









