



# CONVENTION INFORMATION

June 23-26 | Orlando, FL

“Friends are like Lighthouses, with the sources of light coming from their hearts.”

– Tom Baker



On behalf of PWSA | USA,  
 our sincere gratitude for  
 helping us make a difference,  
 and providing lifesaving HOPE  
 for those whose lives are impacted  
 by Prader-Willi syndrome.




## WHAT IS PRADER-WILLI SYNDROME?

Prader-Willi syndrome is a complex genetic disorder that typically causes low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behaviors, and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity.

It is estimated that one in 12,000 to 15,000 people are born with Prader-Willi syndrome. Although considered a “rare” disorder, PWS is one of the most common conditions seen in genetics clinics and is the most common genetic cause of obesity that has been identified. PWS is found in people of all sexes and all races.



## WHAT IS PRADER-WILLI SYNDROME ASSOCIATION | USA

Prader-Willi Syndrome Association | USA is the largest education, support, research, and advocacy organization for people and families living with PWS in the United States. This convention provides a unique opportunity to access a cross section of families, providers, scientists, and medical professionals who care for people born with this complex syndrome.



Organized in 1975, PWSA | USA is headquartered in Sarasota, Florida. PWSA | USA is a member of the International Prader-Willi Syndrome Organisation (IPWSO). Together, these organizations collectively create a voice for those with, and affected by, PWS worldwide.

## ABOUT THE CONVENTION

PWSA | USA is deeply committed to providing education about PWS and truly understands the value of meeting in person. The first national conference took place in 1979 in Minnesota. Now over 1,200 people from around the world walk the main hall during this elaborate four-day event. The national convention includes concurrent parts — shown on following pages.



## Medical & Scientific Conference

During this two-day event, Scientists, Researchers, and Medical professionals from different disciplines share ideas and report on progress, helping to meet the ever-present goal to support research that will identify effective treatment, and improve the quality of life for individuals diagnosed with PWS.



## Professional Providers Conference

Educational, Social Services, and Residential professional providers come together to discuss identified and supported best practice and standard of care approaches, as well as to provide a critical in-person, solution-orientated exchange of ideas for specific concerns that can be addressed by experts in the field.

## General Conference

This two-day event attracts parents, grandparents, caregivers, and professionals. The attendees are skillfully guided through a choice of multiple learning tracks covering an array of topics that can be tailored to their individual preferences. It is a time to build relationships with other families, attend educational sessions and support groups, meet with top specialists and authorities on PWS, and just have fun! Experts in the field provide attendees with up-to-date information and resources for addressing the very complex needs of supporting and caring for an individual diagnosed with PWS.



## Chapter Leaders Meeting

This is a special opportunity for the leadership of the organization's network of chapters. Attendees receive training and updates on current national developments and projects, share information about their chapter's activities, work collaboratively to address challenges, provide support to each other and set direction to maintain and improve upon the level of service offered by chapters and the national headquarters.



## Parent Mentor Meeting

This is an opportunity for our PWSA | USA mentors to collaborate on information and support systems available for the families and individuals to whom they provide ongoing support and guidance. Attendees receive training and updates on current national developments, work collaboratively to address challenges, provide support to each other and set direction to maintain and improve upon the level of service offered by the mentoring group.

## Young Infant Program (YIP) 6 weeks to 24 months

While it is hard for our young families to feel comfortable with having their infant too far from their sight, this warm, nurturing nursery allows parents the opportunity to gain support and valuable education needed for raising their precious little one. The nursery is staffed with individuals who are caring in addressing their specific needs, all within a short distance from their loving parents.



## Youth & Infant Program (YIP) 2-6yrs old

Little ones with PWS, or young siblings of those with PWS, just want to have fun, laugh and explore, and this two-day program was developed with that particular goal in mind. Arts, Crafts, Story Telling, Puppets, Music, Magic and more will light up their faces as they participate in structured play and staff-guided activities.



## Youth and Adult Program (YAP) 7yrs and up

Filled to capacity each year, children and adults diagnosed with PWS, ages 7+, are involved in an innovative structured program, carefully designed to meet their unique medical, physical, and emotional needs.

This program is a wonderful opportunity for friendships to develop, fun to be had, and to be a part of a peer group that truly understands one another. The individuals are divided into eight groups based on age and are supported by highly trained and experienced staff members who understand their unique challenges. For two days, they are motivated, praised and encouraged to try new activities all within a safe and therapeutic environment.



## Sibling Program

While their brothers or sisters are busy in YIP or YAP, this program was developed to enhance their individuality and reinforce their sense of importance. For most kiddos whose brother or sister has PWS, their home life revolves around the complexities of their sibling's environmental and care needs. This program allows them to have fun, meet and develop relationships with others who are in similar situations, explore new possibilities and share experiences with one another.



## General Gala

For most families who support a loved one with PWS, they find it challenging to participate in social functions, as they generally need to be so vigilant in monitoring any unrestricted food access their child may encounter. While their 7-year-old and older child participates in their own highly structured YAP Gala event, they are able to socialize, make new connections, have a date night with their significant other or just enjoy some well-deserved down time.

## Youth & Adult Program (YAP) Gala

A separate event with spectacular lights, theme decorations, music and smiles for all. This Youth & Adult Program Gala is open to all individuals diagnosed with PWS from 7 years old and up. Trained support staff ensure food security, while the participants are able to enjoy social time with their friends, eat a healthy but special dinner, and then move on to dancing the night away to their favorite tunes. Families love joining in the festivities later on in the evening, as they hit the dance floor with their kiddos.



## Exhibit Hall

Attendees look forward to visiting and exploring the exhibitors' section to learn more about products and services as they relate to PWS. There are treatment facilities, residential programs, camps, food security, healthy living, supports and many other vendors represented.



## PWSA | USA Bookstore

Organizers ensure that related resources, informational pamphlets, and educational material are available for review and purchase. A staff member will assist attendees in making suggestions based on their individual needs or pertaining to an area of interest. If an attendee wants to show their association pride, logo merchandise can also be purchased in this one-stop shop.



## Hilton Hotel Buena Vista Palace, Orlando, FL

Come for the Convention and stay for a perfect family vacation. This beautiful hotel is located right across the street from Disney Springs and has its own lazy river to relax and enjoy.

