



PWSA | USA's 37th National Convention Schedule

Medical and Scientific Conference, Professional Providers Conference, and the Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD)

June 21-24, 2023 • Hilton Orlando Buena Vista Palace



PWSA | USA 2023
NATIONAL CONVENTION

Wednesday, June 21, 2023

Medical and Scientific Conference / DAY 1

8:00 a.m. - 6:00 p.m.

During this one and a half day event, scientists, researchers, and medical professionals from different disciplines share ideas and report on progress. This opportunity helps 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. Parents and students are welcome to register to attend the Medical and Scientific Conference as observers.

8:00 a.m. - 9:30 a.m.

- Welcome to the Medical and Scientific Conference - James Loker, MD and Ann Manzardo, PhD
- CSAB Overview - Ann Scheimann, MD, MBA
- Keynote Presentation - Tony Holland, MD

9:30 a.m. - 12:00 p.m.

Presentations from Deepan Singh, MD and Moris Angulo, MD (*Topics coming soon*)

1:00 p.m. - 3:30 p.m.

- Medical Practice Update
- Oral Abstract Presentations

4:00 p.m. - 6:00 p.m.

Medical and Scientific Conference Reception and Poster Abstract Presentations

Thursday, June 22, 2023

Medical and Scientific Conference / DAY 2

8:00 a.m. - 11:30 a.m.

8:00 a.m. - 10:30 a.m.

- Welcome to Day Two of the Medical and Scientific Conference - James Loker, MD and Ann Manzardo, PhD
- Presentation from Jessica Duis, MD (*Topic coming soon*)
- PWS Clinical Trial Endpoints Roundtable

10:30 a.m. - 11:30 a.m.

- Oral Abstract Presentations
- Closing Remarks

FDA Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD)

Landmark meeting to bring together the PWS patient voice.

12:00 p.m. - 4:30 p.m.

Free for all Convention attendees

12:30 p.m. - 2:45 p.m.

Patient Panels

- Person with PWS open panel
- PWS clinical trial discussion

2:45 p.m. - 4:30 p.m.

- Testimonials and facilitated discussion
- PFDD-driven clinical trial design in PWS
- Stakeholder panel discussion
- Closing remarks

Thursday, June 22, 2023 (cont.)

Professional Providers Conference

8:00 a.m. - 4:30 p.m.

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

8:45 a.m. - 9:00 a.m.

Welcome to the Professional Providers Conference - Stacy Ward, MS, Lynn Garrick, RN, and Jen Dayton

9:00 a.m. - 2:00 p.m.

- Staff Burnout / Caregiver Fatigue - Jessica Zielske, MA, MS
- When Someone is their Own Guardian - Tony Holland, MD
- Behavior / Skin Picking - Kasey Bedard, PhD, BCBA-D
- Multi-Disciplinary Teams and Aging - Mary Cataletto, MD and Lynn Garrick, RN
- Internet / Social Media Access - Patrice Carroll, LICSW and Brittini Kliment M.Ed

2:00 p.m. - 4:30 p.m.

Small group sharing sessions: Maximizing your Rates, Sexuality / Relationship Building, Internet Safety, Smart Homes - Using Technology, Doing More with Less Money, Day Supports



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Family Conference and PWS Camps

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Thursday, June 22, 2023 (cont.)

Family Conference Kick-Off Events

4:30 p.m. - 9:00 p.m.

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, learn from top specialists and authorities on PWS, and 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.

4:30 p.m. - 6:30 p.m.

Dad's Den

6:30 p.m. - 7:00 p.m.

First-Time Convention Attendee
Welcome Reception

7:00 p.m. - 9:00 p.m.

Family Conference Welcome Reception

Friday, June 23, 2023

Family Conference / DAY 1

8:30 a.m. - 5:00 p.m.

8:30 a.m. - 10:15 a.m.

Welcome & Keynote Presentation

- Hear uplifting stories from people with PWS
- Keynote Speaker: Cristol O'Loughlin, Founder/CEO, ANGEL AID CARES

Day 1 Sessions

- Medical and Scientific Conference recap
- Standards of care
- Dad's panel
- GI issues
- Finding your tribe
- Orthopedic issues
- Therapeutic journaling
- Pathway to independence
- ABA therapist panel
- Behaviors at home and school
- Living options
- Avoiding legal issues
- Caring for the caregiver
- And more!

4:00 p.m. - 6:00 p.m.

Dad's Den

6:00 p.m. - 9:30 p.m.

Hope United Gala - Dueling Pianos,
silent and live Auction

6:00 p.m. - 9:30 p.m.

A Night Under the Stars Gala

Children and adults living with PWS and
their siblings (7 years and up)

Saturday, June 24, 2023

Family Conference / DAY 2

8:30 a.m. - 5:00 p.m.

Day 2 Sessions

- Nutrition/diet
- Special need trusts
- Behavior medication management
- Sleep schedule and potty training
- Mental health
- Sibling panel
- Speech and physical therapy
- IEP and IFSP's
- Disordered sleep
- Fireside Chat: Q & A with PWS experts
- And more!

12:30 p.m. - 1:30 p.m.

Family Conference Luncheon

Announcement of PWSA | USA's
Volunteer Awards

3:45 p.m. - 5:00 p.m.

Closing Ceremony

5:00 p.m. - 7:00 p.m.

Family Den

PWS Camps • June 23-24, 2023

PWS Camp Opportunities

8:00 a.m. - 4:30 p.m.

Friday and Saturday

Little Tikes (0-24 months)

(Formerly referred to as YIP Infants) During Little Tikes Camp, your loved one will be cared for by staff that have worked in either the healthcare or childcare fields. There will be a variety of age-appropriate activities, along with quiet rest times throughout the day. This camp is available to both children with and without PWS.

Junior Adventure Camp (2-6 years old)

(Formerly referred to as YIP) Junior Adventure Camp will provide fun and entertaining activities for children with and without PWS, supported by staff that are experienced and trained in caring for individuals with PWS.

Adventure Camp (7 years and up)

(Formerly referred to as YAP) Adventure Campers will be in groups with others their age and supported by staff that are experienced and trained in caring for individuals with PWS.

Sibling Camp (7-16 years old)

This camp will allow your child to participate in numerous activities, make friends with other siblings, and share their experiences. The Siblings Camp may participate in offsite activity. More information on this will be available soon.

PWS Camp Activities

- Social time
- Arts & crafts
- Dancing
- Self esteem games
- Bingo
- Movies
- Scavenger hunt
- Sensory bins
- Soccer
- And more!