PWSA | USA Pulse Newsletter: May 2, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 122

May 2, 2025

www.pwsausa.org | 941-312-0400

National PWS Awareness Month is here! We're wishing you all a lovely month of spreading awareness and education, and in doing so, extending your foundation and community of support. As a reminder, we have our PWS Awareness Month hub for anyone wishing to participate in social media campaigns, fundraisers or legislative actions for proclamations, or wishing to buy PWS merchandise. Please visit our awareness month hub using the button below.

PWS AWARENESS HUB

Family Program at Capacity — Registration Now Closed

We are officially at capacity for the 2025 International PWS Conference Family Program, taking place June 27–28, 2025, at the Arizona Grand Resort & Spa in Phoenix, AZ. Due to fire safety regulations and our commitment to providing a comfortable experience for all, we are no longer able to accept new registrations for the Family Program. However, if you'd like to be added to the waitlist, please contact us at (941) 312-0400 or email info@pwsausa.org. We will reach out if space becomes available.

Here's a quick breakdown of what's still open (and what's now closed) for conference registration:

- Professional Providers Program (June 25 & 26) - Open *(for professional providers only)*
- Clinical & Scientific Program (June 25 & 26) - Open *(family members may attend as observers)*
- Family Program (June 27 & 28) – Closed
- PWS & Sibling Camps (June 27 & 28) – Closed
- 50th Birthday Party Celebration (June 27) – Free & Open to All Attendees
- Night Under the Stars Gala (June 27) – 33 spots remaining – reserve your seat soon! *(for individuals living with PWS and their siblings ages 7+)*

If you haven't yet registered for the Clinical & Scientific or Professional Providers programs and would like to attend, we encourage you to sign up soon while space is still available.

REGISTER HERE

Thank You 2025 Conference Sponsors

To learn more about sponsorship opportunities, contact us at development@pwsausa.org. Together, we can make a lasting impact!

DIAMOND SPONSOR

aardvark therapeutics

PLATINUM SPONSORS

SOLENO THERAPEUTICS

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Innovation through medicinal chemistry

PWSA MEMORIES

In December of 2009, the House passed a resolution to establish a National PWS Awareness Month. This resolution was brought to the U.S. House of Representatives by Republican Congressman Ed Royce and Democratic Congresswoman Jane Herman, both of California, thanks to efforts by Amy Porter (aunt to Abby with PWS) and Tom and Renay Compere (parents to William with PWS). The bill then went to the Senate and was passed on May 27, 2010, making May the official National PWS Awareness Month!

Thank you to those families who worked hard and fought to get Prader-Willi syndrome recognized on a national level. You paved the way for more awareness, advocacy, and hope around this country and beyond!

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S

SPOTLIGHT ON HOPE

Cameron Graziano, a 26-year-old living with PWS, began Tae Kwan Do when he was just 9 years old and could barely balance on one foot. He stuck with it and earned his black belt at 17. After years of dedication and some physical setbacks, like a foot injury and months of physical therapy, Cameron is back at it. He is working toward a new black belt. He also created his own curriculum called "Karate with Cameron" and teaches this martial art to other individuals with PWS through the Prader-Willi California Foundation (PWCF). Read more about Cameron and his years of mastering karate by clicking the button below.

READ HERE

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

Creating Financial Security for a Loved One with PWS
Financial Planning Webinar

When: **Wednesday, May 14 @**
12 PM EDT | 9 AM PDT

Join us for this educational workshop to learn more about special needs planning. Topics covered will include an overview of Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), Medicaid and Waivers, ABLE accounts, special needs trusts, and other important considerations to help family members better understand how planning for a child with special needs is different both legally and financially.

This webinar is presented by Ivailo Grigorov, a Financial Advisor and special needs parent to Lucca, who is 8 years old and has a diagnosis of Prader-Willi syndrome. Ivailo realized that families like ours can benefit from a comprehensive plan that can guide them through the years and can ultimately maximize a child's overall quality of life. Ivailo's team primarily works with families who have a loved one with disabilities who will require some support not only now but in the distant future. Ivailo's goal is to serve as the quarterback for the family's planning. He aims to teach the most efficient ways to save, optimize and protect our loved ones' futures and, ultimately, to provide peace of mind. Register for this webinar using the button below.

REGISTER HERE

NC 5K and Family Fun Run Happening Saturday! Thank You Sponsors!

When: **Saturday, May 3 | 9 AM ET**
Where: **Greater Wilson Rotary Park | 1901 Branch St. NW, Wilson, NC 27893**

On Saturday, May 3, friends and families from the PWS community will gather and run for the North Carolina 5K and Family Fun Run. Proceeds from this event will benefit PWSA | USA's Advocacy, Family Support, and Research programs to find a treatment for PWS. We'd like to offer a big THANK YOU to our sponsors: Acadia (Platinum), Freedom Family Medicine (Gold), AQWA (Bronze), Ridgeline and TREND Community (Emerald), and our Ruby sponsors, Cups of Joy, Lori Thomas, Agent from NC Farm Bureau, Mickey Adams Flooring Co., Eastern Carolina Chiropractic Center, and Wilson Signs & Graphics. You can still make a donation to this event in support of the PWS community by clicking the button below.

DONATE HERE

United We Brunch: Awareness in Every State

Magnolias and Mimosas, Colorado!

On April 26, the first United We Brunch fundraiser was held in Colorado by Kat Lucero. Magnolias & Mimosas was not just a Ladies Brunch, but also a celebration of hope, strength, and community. The event featured a variety of activities, including a raffle, a fun backdrop for pictures, PWS educational activities, and delicious food and drinks. Kat thanked Melanie and her team for helping to make her event easy to host from start to finish, and followed up with, **"Honestly, the hardest part for me was picking out a dress and making sure I could get my ideas not to look like a Pinterest FAIL."** Congratulations, Kat, on a wonderful event, and thank you for spreading awareness about PWS.

Find upcoming United We Brunch events and learn how to host your own by clicking the button below.

GET STARTED!

Interested in hosting a United We Brunch event for PWS Awareness Month?

Start planning and reach out to hopeunited@pwsausa.org for help and support!

Click the button below to download our United We Brunch Toolkit to get started!

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

In our latest episode of *PWS United*, we explore the science and hope behind Aardvark Therapeutics' ARD-101, an investigational treatment currently in its Phase 3 clinical trial for Prader-Willi syndrome. Our guests, Dr. Tien Lee, CEO of Aardvark Therapeutics, and Dr. Manasi Jaiman, Chief Medical Officer, break down the difference between hunger and appetite, and how ARD-101 targets gut-brain signaling to reduce hyperphagia.

Dr. Lee and Dr. Jaiman also share insights into Aardvark's uniquely compassionate approach to clinical trials, including their close engagement with the PWS community. Tune in to learn how this innovative therapy could impact the future of care for individuals living with PWS.

We're proud to recognize Aardvark Therapeutics as our Diamond Sponsor for the 2025 International PWS Conference – United in Hope. Visit their exhibitor table and meet many members of their team in person!

Listen to the latest episode of *PWS United* on your preferred podcast app or by clicking the button below.

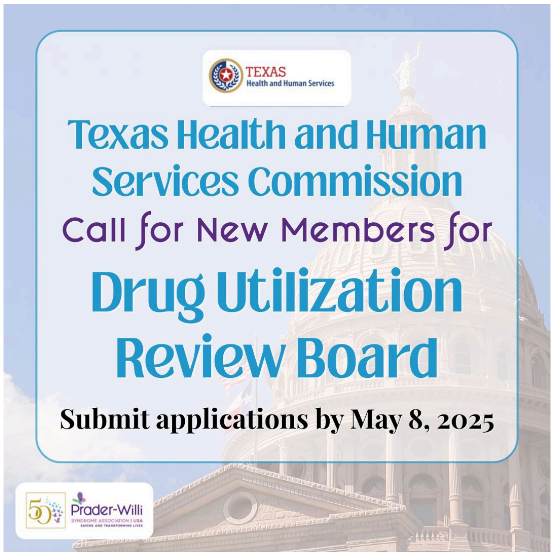
LISTEN ON PODBEAN

ADVOCACY

Call for New Members for Texas Drug Utilization Review Board

Texas Health and Human Services Commission is looking for new members for the Drug Utilization Review Board, including reps from the Medicaid enrollee community. If you're interested in the Statewide Medicaid Drug Utilization Review Program, you may want to apply. The Texas Health and Human Services Commission Executive Commissioner will appoint members to the board to serve a term expiring Aug. 31, 2028.

Applications are due by 11:59 PM CT, May 8, 2025.



Texas Health and Human Services Commission

Call for New Members for

Drug Utilization Review Board

Submit applications by May 8, 2025

Learn more at by clicking on button below.

LEARN MORE HERE

PWS Awareness Day Proclamation in Florida

PWS families in the state of Florida celebrated a victory on Thursday. The Florida Senate signed a proclamation recognizing May 1st as PWS Awareness Day. The day began with a press conference outside the Senate chambers at the Florida Capitol. After the press conference, Republican Senator Ana Maria Rodriguez took to the Senate floor to officially proclaim May 1st as PWS Awareness Day in Florida! Thank you to all the PWS families who helped push this Proclamation Day through the Florida legislature and were there to celebrate and represent our community.

Our Proclamation Toolkit provides everything you need to take action, including step-by-step guidance, sample cover letters for reaching out to local and state officials, and inspiring success stories from PWS families who have done it before. Access by clicking on the image.

For questions, email: advocacy@pwsausa.org
Send proclamation photos to: communications@pwsausa.org

ADVOCACY IN ACTION

Prader-Willi Syndrome (PWS) Awareness Month

Proclamation Toolkit

Created by PWSA | USA's Advocacy Team

FAMILY SUPPORT

Adults with PWS Advisory Board Spotlight

In honor of PWS Awareness Month, we are spotlighting our Adults with PWS Advisory Board, made up of individuals living with PWS. Victor Penta is 31 years old and lives with Prader-Willi syndrome. He resides in Arizona and has been on the Adults with PWS Advisory Board since 2019. In an effort to learn more about our adults with PWS, and to shine a light on their lives and experiences, we asked our Advisory Board members some questions about their lives and what they want people to understand about PWS.

"Because I struggle with PWS, it makes me understand others who have other disabilities and their struggles. It makes me more caring for other people." - Victor Penta

Learn more about Victor by clicking the button below.

READ MORE

Post a Message for Mother's Day

Mothers are incredible! Often the life-force of the family; the caretaker, nurturer, nurse, teacher, therapist, and more. Mothers are providers, secretaries, shuttle drivers, homework assistants, cooks, housekeepers, social confidantes, the ones children go to for emotional support or when they're feeling ill, and still more.

We are grateful for our mothers and know that you are as well! For this Mother's Day, we're offering space to share words of appreciation, gratitude, and celebration for the PWS mom in your life.

PWSA | USA would like to share a photo and a special message for your PWS Mom on our social media leading up to and on Mother's Day. Share with the world what it is that you appreciate about her. Ask your loved one for a special message about what she means to them. Share with our community what you appreciate about your PWS Mom.

Please submit your photo and message **no later than May 6** by using the button below.

SUBMIT HERE

Join Focus Group to Develop Content for New Family Resource Program

The Behavioral Innovations for Rare Diagnosis (BIRD) Lab at The Chicago School is working in collaboration with PWSA | USA to develop a Family Resource Program.

We will be holding a series of focus groups to get your input on a variety of topics, including:

- The most important knowledge and information needs for individuals with PWS and their families.
- The daily challenges and successes you experience as a caregiver.

- The kinds of emotional, behavioral, and medical supports that are most needed.
- What helps (or hinders) you in navigating education, healthcare, and social systems.
- The best ways to deliver support – live, pre-recorded, one-on-one, or in groups.

Your perspective will help us build a program that supports families like yours-at every stage of life. If you have questions, please contact Dr. Annette Griffith at agriffith@thechicagoschool.edu.

For information on joining our focus groups, please click the buttons below.

PARENTS AND CAREGIVERS

SIBLINGS OF INDIVIDUALS WITH PWS

Ask Nurse Lynn

Female, 2 years old, unknown subtype

My daughter has had a very high fever for the last two days. There are lots of viral things going around here so I am thinking that it is that. Is it normal that kids with PWS get fevers? I have read before that usually they don't break out in a fever.

Visit our blog to read Nurse Lynn's response and find links to connected resources.

READ NURSE LYNN'S RESPONSE

Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

Now you can **Ask Nurse Lynn,** PWSA | USA's very own PWS Nurse.

ASK YOUR QUESTION HERE

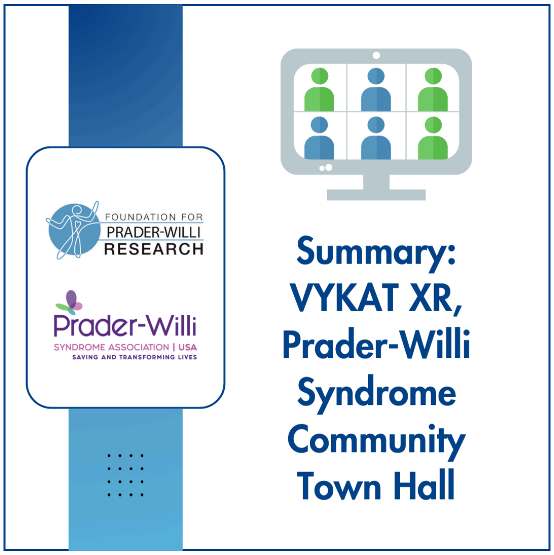
RESEARCH

VYKAT XR Town Hall Summary

At our recent town hall with FPWR, families shared encouraging experiences from the Phase 3 clinical trial of VYKAT XR, describing noticeable improvements in behavior, reduced food-related anxiety, and better metabolism for their loved ones with PWS.

While some side effects were noted, parents emphasized the importance of patience and close monitoring, and many reported a smooth experience receiving the medication.

Read our full blog for highlights, helpful resources, and how your voice can shape what we learn next through the Global PWS Registry.



READ HERE

Looking for Survey Study Participants!

New Research Opportunity

Educational Trends of Students with PWS

Chance to Win a $50 Amazon Gift Card

Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES

INTERESTED?

Find Out if You QUALIFY!

Visit: https://pwslab.questionpro.com/PWSeducation

Help us learn about the current trends in school placement, specialized instruction, related services, and educational supports provided to students with Prader-Willi syndrome (PWS) under the Individuals with Disabilities Education Act (IDEA). At the completion of the survey, you can enter to win one of four $50 Amazon gift cards.

Caregivers will complete a 20–25-minute online survey on Questions Pro about their child's education, IEP, and food security at school. To participate, caregivers must be at least 18 years old and speak and read English. Additionally, they must be the parent or guardian of a child who is school-aged (3-22 years old) at the time of the survey, has a diagnosis of PWS, and lives in the United States.

Find out if you qualify by clicking the button below. For questions, contact: Destiny Pacha, EdD at dpacha@thechicagoschool.edu

[TAKE THE SURVEY]

Aardvark Launches Website for ARD-101 Clinical Trial!

Aardvark Therapeutics has created a website for families to learn more about the HERO (Hunger Elimination or Reduction Objective) Study, the ARD-101 Phase 3 clinical trial. ARD-101 is being studied to see if it can help the body release certain gut hormones that may help reduce excessive hunger and food-seeking behaviors in people with PWS. Families can explore the website to find more details about the study including trial site locations, requirements to participate, FAQs, and more. Click on the button below to visit the website.

Hunger Elimination or Reduction Objective (HERO) Study for Treatment of Hyperphagia in Prader-Willi Syndrome (PWS)

Eligibility

- Documented diagnosis of Prader-Willi Syndrome (PWS)
- Age 13 years old or older
- Primary caregiver that can commit to the trial requirements for 12 weeks

Study Details

- Eligible participants will either receive study drug or placebo (no active study drug ingredients).
- Study drug will be taken orally twice daily for 12 weeks
- Approximately 4 in-person clinic visits and 3 telehealth visits are required
- Travel expenses and lodging (if required) for the participant and a primary caregiver will be covered
- No fasting required
- All participants who complete the HERO study will have the option to participate in a follow up study where everyone will receive active study drug.

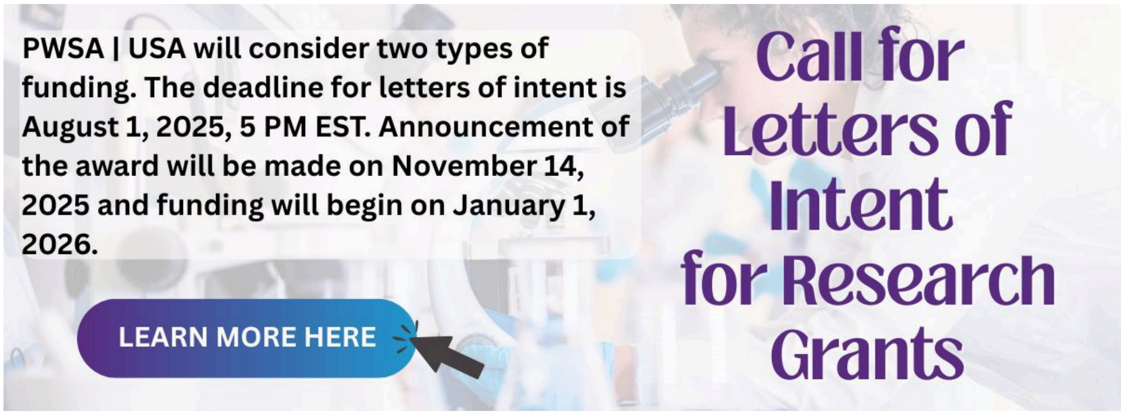
Study Locations

- Find the clinical site nearest you

[LEARN MORE HERE]

Supporting PWS Research

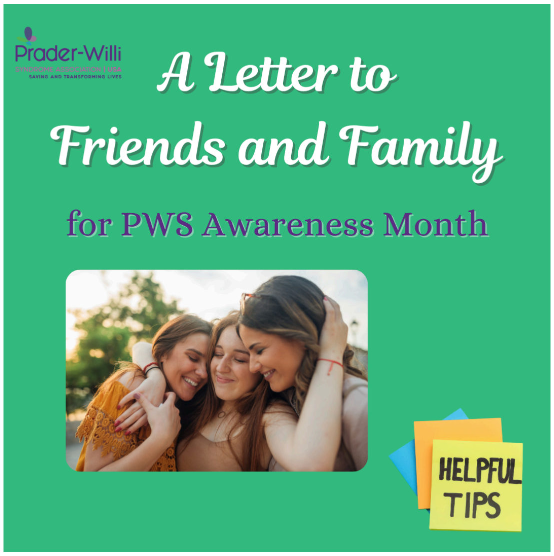
$25,000 USD to support providers in enhancing their understanding of PWS through clinical proctorships with experts in the field. Available to providers currently in practice in the US and who presently care or plan to care for patients with PWS.


PWSA | USA will consider two types of funding. The deadline for letters of intent is August 1, 2025, 5 PM EST. Announcement of the award will be made on November 14, 2025 and funding will begin on January 1, 2026.

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

A Letter to Friends and Family



As part of PWS Awareness Month last year, we created a letter to be shared with friends and family. We know PWS may be challenging to discuss, especially with those closest to you. Our hope is that this letter covers the vital information you need your community to know and can serve as a tool for learning and connecting. Topics include how to help families with PWS avoid isolation, creating a PWS-friendly environment, reliable resources for PWS information, how to support the PWS siblings, behavior challenges and strategies, helping caregivers find a break, and the importance of the village. Share this letter with your community for PWS Awareness Month as a way to spread awareness and grow your foundation of support.

LETTER TO FRIENDS & FAMILY

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope they so desperately need. Thank you!

Donate

Privacy Policy | Unsubscribe
Prader-Willi Syndrome Association | USA
1032 E Brandon Blvd #4744 Brandon, FL 33511

PWSA | USA Pulse Newsletter: May 16, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

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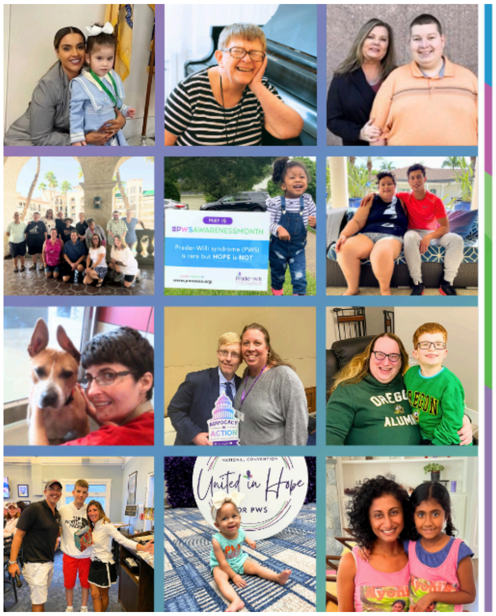


15 May
PRADER
WILLI SYNDROME
AWARENESS DAY

Thank you PWS community for another successful PWS Awareness Day and continuing awareness efforts for Awareness Month! We are honored and proud to be a part of such a connected, strong, creative, and advocacy-oriented community. Thank you to all who are spreading awareness by hosting United

We Brunch fundraisers, by sharing the PWS Facts posts, by telling your personal stories, or finding other ways by thinking outside the box! If you are interested in ways to participate in PWS Awareness Month, please visit our PWS Awareness Month Hub. Read on for some unique ways families are helping spread awareness and support for the PWS community.

PWS AWARENESS HUB

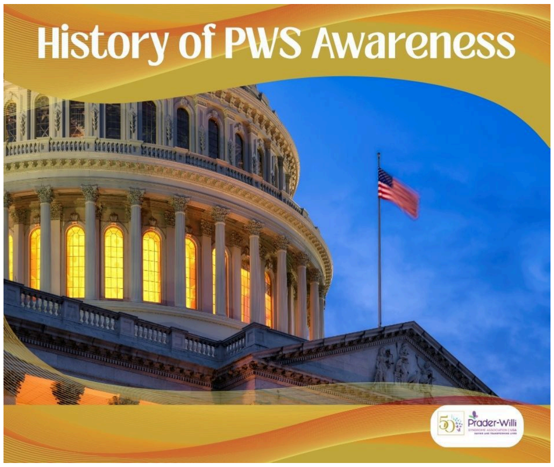
Awareness in West Virginia

"I've done this 6 years now. I decided when Lyra was 10 months old, to use my talent for good. People often don't like to just give money, and I gift afghans all the time just because I love making them. I combined the two, and each $1 donated gets 1 chance into a drawing to win a custom afghan made by me. The pattern is called 'Better Together', which is perfect because we are better due to those who invest in our Prader-Willi community. The pattern calls for 4 colors, but I've done 2-6, and the colors are chosen by the winner. So, it's customized to them. My drawing for the afghan is June 1." - Sheri Mills, mom to Lyra (living with PWS) Enter drawing and donate HERE.

Awareness in New Hampshire

Elaine Towle, mom to James (39, living with PWS) and PWSA | USA's Advocacy Specialist, donated a PWS book to the Chester Public Library in Chester, NH. The book she donated was recently released by Miriam Chernick, the sibling of an adult with PWS. *The Zuzu Secret*, told in alternating points of view, is about Josie, a 12-year-old aspiring veterinarian, and Abe, her 15-year-old baseball-loving brother born with a rare disease called Prader-Willi syndrome, as they learn the risks of keeping secrets and the value of family while staying true to their dreams. Order HERE.

PWSA MEMORIES



On May 2, 1995, the president and vice president of the United States and their wives, Bill and Hillary Clinton and Al and "Tipper" Gore, along with members of both the House and Senate, learned about Prader-Willi syndrome as part of the first-ever National Prader-Willi Syndrome Awareness Week. Read the full article in the February 1995 issue of The Gathered View (Volume XX, Number 1) by clicking the button below. Years later, U.S. Congressman Paul D. Tonko (D-NY) and Congresswoman Maria Elvira Salazar (R-FL) filed a joint resolution declaring May 15, 2023, and every May 15th thereafter, Prader-Willi Syndrome Awareness Day in the U.S.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S

SPOTLIGHT ON HOPE

Photos by Megan Grace Photographs

PWS mom Jamie Caldwell has found a unique way to celebrate her daughter, Lydia (3, living with PWS) and PWS Awareness Month. She teamed up with Kristina Rieger, owner and founder of Dalyas Dreamers, a “program designed to promote inclusivity, bring awareness to the families of children with special needs and their incredible journeys, and to support the organizations that serve these families.” Through this business, families can design an outfit based on their loved one’s personality, participate in a photo session with Megan Grace Photographs, and help financially support an organization of their choice. "The families that participated in the photo sessions were able to choose a foundation or organization that 10% of the sales of all items would be donated to. In addition, Lydia and I were able to design a dress that we felt best represented her but also other children living with PWS. All proceeds from this specific dress design will go to PWSA.” – Jamie Caldwell. You can learn more about Dalyas Dreamers, view the dress designs, and read more about Jamie and Lydia's story by clicking the button below.

READ HERE

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

Countdown to Conference: 38 Days to Go!

The countdown is on! In just 38 days, we'll come together in Phoenix, AZ, for the **2025 International PWS Conference: United in Hope**, a powerful gathering of families, professionals, and researchers from around the world.

We're excited to announce that the high-level Family, Clinical & Scientific, and Professional Providers Program schedules are now all available for download! Stay tuned - detailed schedules with speakers will be released soon.

As a reminder: The Family Program and PWS/Sibling Camps are now at full capacity, and we are no longer accepting registrations for those portions of the conference. However, registration remains open for the Clinical & Scientific and Professional Providers Programs, and spots are still available!

Attendees, keep an eye on your inbox! In the coming weeks, we'll be sharing important conference information, including access to our mobile app, an in-depth attendee welcome packet, and more to help you prepare for an unforgettable experience.

June 24-28, 2025 Arizona Grand Resort & Spa

2025 International PWS Conference

Family Program

High-Level Schedule

Family Program | Friday, June 27, 2025 - Saturday, June 28, 2025

Friday, June 27, 2025 | *DAY ONE* Sessions: 9:00 AM - 4:30 PM

Breakfast on your own *(7:00 AM - Food Trucks at Conference Center Pavilion)*

9:00 AM - 10:00 AM - Welcome to the International PWS Conference *(Main Ballroom, All Ages)*

10:15 AM - 11:15 AM

- What's Happening in PWS Research (*Main Ballroom, All Ages)*
- Musculoskeletal Issues of Prader-Willi Syndrome: A Few Things to Know *(Arizona A - Acacia, All Ages)*
- The Importance of Exercise and Nutrition Guidance and Recommendations for People Living with PWS (*Arizona B - Bougainvillea, Ages 12+)*
- Nutrition Recommendations for Children and Families with PWS (Arizona C, D - Copperwood, Desert Willow, Ages 0-11)

11:15 AM - 12:45 PM - Lunch *(Canyon Ballroom)*

1:00 PM - 2:00 PM

- Aging: Cognitive, Physical and Social Health (*Main Ballroom, Ages 18+)*
- Dynamic Movement Interventions *(Arizona A - Acacia, All Ages)*
- Clinical & Scientific Program Recap *(Arizona B - Bougainvillea, All Ages)*
- Understanding the Sibling Experience in Prader-Willi Syndrome (*Arizona C, D - Copperwood, Desert Willow, Ages 0-5)*

2:15 PM - 3:15 PM

- The Role of Medications for the Management of Behavior Issues in PWS (*Main Ballroom, Ages 6+)*
- Dads Panel *(Arizona A - Acacia, PWS Dads and male caregivers only)*
- International Perspectives *(Arizona B - Bougainvillea, Open to all)*
- Starting Out Right: Behavioral Strategies for the Early Years and Beyond (*Arizona C, D - Copperwood, Desert Willow, Ages 0-5)*

3:30 PM – 4:30 PM

- Clinical Trial Panel (*Main Ballroom, All Ages)*
- IPWSO's Family Support Services: FAMCARE *(Arizona A - Acacia, Ages 0-3)*
- *Healing, Hope, and Acceptance (Arizona B - Bougainvillea, Open to all)*

6:00 PM - 8:30 PM - Night Under the Stars Gala *(Main Ballroom)*
For individuals with PWS and their siblings; Ticketed event; Dinner included

6:30 PM - 9:00 PM - 50th Birthday Celebration Party *(Oasis Waterpark)*
Free to attend; Drone Show at 8:45 PM; Dinner not included

Saturday, June 28, 2025 | *DAY TWO* Sessions: 9:00 AM - 4:45 PM

Breakfast on your own *(7:00 AM - Food Trucks at Conference Center Pavilion)*

9:00 AM - 10:00 AM

- PWS Around the World (*Main Ballroom, All Ages)*
- Finding Joy in the Journey *(Arizona A - Acacia, Ages 0-2)*
- From First Steps to School Success: Navigating the IFSP-to-IEP Transition (*Arizona B - Bougainvillea, Ages 3-5)*
- Advocacy in Action (*Arizona C, D - Copperwood, Desert Willow, All Ages)*

10:15 AM - 11:15 AM

- Keeping Your Relationship Intact: Strategies to Create a Strong and Healthy Marriage or Partnership (*Main Ballroom, All Ages)*
- Sleep Disorders in PWS *(Arizona A - Acacia, All Ages)*
- PWS IEP Roadmap: Essential Components for School Safety & Success (*Arizona B - Bougainvillea, Ages 3+)*
- Endocrine Teens & Adults (*Arizona C, D - Copperwood, Desert Willow, Ages 10+)*

11:15 AM - 12:45 PM - Lunch *(Canyon Ballroom)*

1:00 PM - 2:00 PM

- Endocrine Infants & Children (*Main Ballroom, Ages 0-9)*
- Caring for the Caregiver *(Arizona A - Acacia, All Ages)*
- Supporting People with PWS to Move Out of the Family Home (*Arizona B - Bougainvillea, All Ages, International Attendees)*
- Making and Keeping Friends (*Arizona C, D - Copperwood, Desert Willow, Ages 16+)*

2:15 PM - 3:15 PM

- Legal & Financial Planning (*Main Ballroom, All Ages)*
- Update on GI Issues and Management in Prader-Willi Syndrome *(Arizona A - Acacia, All Ages)*
- Mental Health Challenges in People with PWS (*Arizona B - Bougainvillea, Ages 10+)*
- Teaching Emotional Regulation in Individuals with Prader-Willi Syndrome: ABA Strategies for Lasting Success (*Arizona C, D - Copperwood, Desert Willow, Ages 5+)*

3:30 PM - 4:30 PM - Trailblazers: Stories of Inspiration from Leaders in Our Community *(Main Ballroom, All Ages)*

4:30 PM - 4:45 PM - Closing Remarks *(Main Ballroom, All Ages)*

On Friday, June 27, and Saturday, June 28, 2025, the **Family Program** will offer an incredible lineup of expert-led sessions covering key topics, including:

- What's Happening in PWS Research
- Aging: Cognitive, Physical & Social Health
- Starting Out Right: Behavioral Strategies for Early Years & Beyond
- Clinical Trial Panel
- Finding Joy in the Journey
- Sleep Disorders in PWS
- Caring for the Caregiver
- Mental Health Challenges in People with PWS
- Trailblazers: Stories of Inspiration from Leaders in Our Community

…and so much more!

Each session is designed to focus on specific age groups of those living with PWS, and parents and caregivers are encouraged to attend sessions based on their loved one's age.

DOWNLOAD

June 24-28, 2025 Arizona Grand Resort & Spa

2025 International PWS Conference

Clinical & Scientific Program

High-Level Schedule

Clinical & Scientific Program | Wednesday, June 25, 2025 - Thursday, June 26, 2025

Wednesday, June 25, 2025 | *DAY ONE*

8:30 AM - 6:00 PM

Breakfast on your own *(6:30 AM - Food Trucks at Conference Center Pavilion)*

8:30 AM - 10:15 AM	I. Opening Session *Main Ballroom (Ironwood Doors Entrance)*
10:15 AM - 10:45 AM	BREAK
10:45 AM - 11:45 AM	II. Genetics & Epigenetics *Main Ballroom (Ironwood Doors Entrance)*
11:45 AM - 12:45 PM	Networking Lunch *Room TBD*
12:45 PM - 1:45 PM	III. Medical Session *Main Ballroom (Ironwood Doors Entrance)*
1:45 PM - 1:55 PM	BREAK
1:55 PM - 2:40 PM	IV. Oral/Poster Lightning Talks Session 1 *Main Ballroom (Ironwood Doors Entrance)*
2:40 PM - 3:00 PM	BREAK
3:00 PM - 4:00 PM	V. Oral/Poster Lightning Talks Session 2 *Main Ballroom (Ironwood Doors Entrance)*
4:00 PM - 6:00 PM	VI. Poster Presentation Session Light refreshments will be served. *Arizona E, H (Eucalyptus, Honeysuckle)*

Thursday, June 26, 2025| *DAY TWO*

8:15 AM - 4:30 PM

Breakfast on your own *(6:30 AM - Food Trucks at Conference Center Pavilion)*

8:15 AM - 10:00 AM	VII. Neuroscience, Cognition & Mental Health *Main Ballroom (Ironwood Doors Entrance)*
10:00 AM - 10:15 AM	BREAK
10:15 AM - 11:00 AM	VIII. Invited Speaker *Main Ballroom (Ironwood Doors Entrance)*
11:00 AM - 12:00 PM	IX. Clinical/Clinical Trials Session *Main Ballroom (Ironwood Doors Entrance)*
12:00 PM - 1:00 PM	LUNCH *Canyon Ballroom*
1:00 PM - 2:30 PM	Concurrent Sessions X. Clinical Care *Main Ballroom (Ironwood Doors Entrance)* XI. Molecular Session *Arizona A (Acacia)*
2:30 PM - 3:00 PM	BREAK & POSTER VIEWING *Arizona E, H (Eucalyptus, Honeysuckle)*
3:00 PM - 4:00 PM	XII. Closing Session *Main Ballroom (Ironwood Doors Entrance)*
4:15 PM - 4:30 PM	XIII. Outstanding Young Investigator Presentations & Close *Main Ballroom (Ironwood Doors Entrance)*

Scientists, researchers, and medical professionals are invited to attend the **Clinical & Scientific Program**, taking place Wednesday, June 25, and Thursday, June 26, 2025. Topics discussed will include:

- Genetics & Epigenetics
- Medical
- Oral/Poster Lightning Talks
- Clinical Care

…and so much more!

Each session and workshop is designed to deepen the understanding of Prader-Willi syndrome from a medical, clinical, and scientific perspective, while also offering opportunities to connect, learn, and network.

DOWNLOAD

June 24-28, 2025 Arizona Grand Resort & Spa

2025 International PWS Conference

Professional Providers Program

High-Level Schedule

Professional Providers Program | Wednesday, June 25, 2025 - Thursday, June 26, 2025

Wednesday, June 25, 2025 | *DAY ONE*

9:00 AM - 5:30 PM

Breakfast on your own *(6:30 AM - Food Trucks at Conference Center Pavilion)*

9:00 AM - 9:30 AM	Opening and Welcome *Arizona C, D (Copperwood, Desert Willow)*
9:30 AM - 10:15 AM	PWS Residential Services Across the Globe *Arizona C, D (Copperwood, Desert Willow)*
10:45 AM - 11:30 AM	A New Resource: 'Practical Portions for Prader-Willi Syndrome' *Arizona C, D (Copperwood, Desert Willow)*
11:30 AM - 12:00 PM	Poster Presentations *Arizona C, D (Copperwood, Desert Willow)*
12:00 PM - 1:00 PM	Lunch
1:00 PM - 1:50 PM	The Development of a PWS Specific Respite Service *Arizona C, D (Copperwood, Desert Willow)*
1:50 PM - 2:40 PM	Musculoskeletal Issues of Prader-Willi Syndrome: A Few Things to Know *Arizona C, D (Copperwood, Desert Willow)*
3:10 PM - 3:55 PM	Looking Beyond Poor Lean Mass and Growth Hormone Deficiency, Why is Exercise More Difficult for People with PWS? *Arizona C, D (Copperwood, Desert Willow)*
3:55 PM - 4:40 PM	Caregivers' Forum *Arizona C, D (Copperwood, Desert Willow)*
4:40 PM - 5:30 PM	A Simple and Humane Approach to Minimizing Behavioral Outbursts for People Living with PWS: What to Do and Why *Arizona C, D (Copperwood, Desert Willow)*

Thursday, June 26, 2025| *DAY TWO*

8:30 AM - 6:30 PM

Breakfast on your own *(6:30 AM - Food Trucks at Conference Center Pavilion)*

8:30 AM - 10:30 AM | ***WORKSHOP I***
- Supporting People with PWS with Very Challenging Behavior
  Arizona B (Bougainvillea)
- ABA and PWS: Tailoring Applied Behavior Analysis for Individuals with Prader-Willi Syndrome
  Arizona C, D (Copperwood, Desert Willow)

11:00 AM - 1:00 PM | ***WORKSHOP II***
- Effective Communication with People with PWS
  Arizona B (Bougainvillea)
- Aging in PWS
  Arizona C, D (Copperwood, Desert Willow)

1:00 PM - 2:00 PM - Lunch

2:00 PM - 4:00 PM | ***WORKSHOP III***
- The Experience of Grief for Residents and Staff in a PWS Residential Setting
  Arizona B (Bougainvillea)
- Caregivers Working with the Family of the Person with PWS
  Arizona C, D (Copperwood, Desert Willow)

4:30 PM - 6:30 PM | ***WORKSHOP IV***
- Friends, Partnerships, and Sexuality
  Arizona B (Bougainvillea)
- Promoting and Fostering Self-Advocacy
  Arizona C, D (Copperwood, Desert Willow)

Professional Providers are invited to attend the **Professional Providers Program** on Wednesday, June 25, and Thursday, June 26, 2025, for an incredible lineup of expert-led sessions covering key topics, including:

- PWS Residential Services Across the Globe
- The Development of a PWS Specific Respite Service
- Looking Beyond Poor Lean Mass and Growth Hormone Deficiency, Why is Exercise More Difficult for People with PWS?

…and so much more!

Each session and workshop is designed to support Professional Providers in the PWS space, and offer opportunities to connect, learn, and grow.

DOWNLOAD

PWS BIPOC Affinity Group Pre-Conference Discussion

Mission: Our mission is to empower, connect and support caregivers and individuals with Prader-Willi Syndrome who are Black, Indigenous and People of Color through community-driven research, education and advocacy. By uniting and uplifting diverse voices and experiences, we aim to improve health outcomes and the overall quality of life for all.
Vision: We envision a future where our loved ones regardless of their skin color, their financial status or/and their background live limitless lives. We aim to build understanding and empathy for people living with PWS by creating supportive and inclusive communities. We see a future where people of all shades are able to live their best healthy lives.

Please join the
BIPOC PWS Affinity Group
for a Virtual
PRE-CONFERENCE
DISCUSSION
MAY 18th, 2025
@ 6PM EDT/ 3PM EDT

If you are a person of color diagnosed with PWS, or care for a person of color with PWS, come out to learn about the 2025 United in Hope conference topics, get some conference lessons learned, or share your questions with attendees to ask on your behalf. Whether this is your first conference, your fifth conference, or you are unable to attend this year. This will be a great opportunity you don't want to miss.

Email BIPOCPWS@gmail.comto RSVP and you will get the ZOOM link via email by 16 MAY.

When: **May 18th, 2025 @ 6 PM EDT | 3 PM EDT**

PWS families in the BIPOC community! Come out to learn about the 2025 United in Hope conference topics, get some conference lessons learned, or share your questions with attendees to ask on your behalf. Whether this is your first conference, your fifth conference, or you are unable to attend this year. This will be a great opportunity you don't want to miss.

Email **BIPOCPWS@gmail.com** to RSVP and you will get the ZOOM link via email by May 16.

Newly Diagnosed Nashville Family Celebrates National PWS Awareness Day by Launching Fundraising Event

Parents Aaron Weber and Lucy Sinsheimer, whose daughter Olive is newly diagnosed with PWS, are diving right into the PWS community! They have already created an incredible opportunity for awareness and fundraising, along with enjoyment and laughs.

"Join Aaron Weber and a (**TOP SECRET**) celebrity lineup of nationally acclaimed comics for an evening of laughs for a cause! This is more than a comedy show. It's a night of gathering, giving, and gut-busting laughter — featuring a powerhouse lineup of top-tier comedians, a silent auction packed with unforgettable prizes, and several surprise guest performers we're keeping tucked in our back pocket (Shhh...). Whether you come for the laughs, the love, or the chance to stand up for a rare cause, this is your invitation to show up — for PWS families and others on a rare disease journey."

Learn more about "Prader Silly: A Night of Rare Laughs" and how you can participate by clicking the button below.

VISIT WEBSITE

Lucy and Aaron went on WSMV4, a local Nashville channel, to talk about the Prader Silly event and spread awareness about Prader-Willi syndrome. They both gave an incredible nod to PWSA | USA's support as they begin their PWS journey. You can watch that interview by click the photo below.

United We Brunch: Awareness in Every State

Desi Tea for Prader-Willi, Maryland

Dini Rao, mom to Ayoni (8, living with PWS) hosted a very successful United We Brunch fundraiser for PWS Awareness Month. Desi Tea for Prader-Willi was on May 4th at the Rao home in Maryland. Neighbors, community members, and local PWS families gathered together for samosas, pakoras, chai, PWS awareness, and community. *"We had over 50 people attend and I feel we met our goal of creating more awareness and empathy for those living with Prader Willi Syndrome. I'm so grateful I had the chance to host, as it truly filled my cup!*" – Dini Rao

Read her full recap, see pictures from the event, find upcoming United We Brunch events and learn how to host your own by clicking the buttons below.

DESI TEA RECAP

GET STARTED!

Interested in hosting a United We Brunch event for PWS Awareness Month?

Start planning and reach out to hopeunited@pwsausa.org for help and support!

Click the button below to download our United We Brunch Toolkit to get started!

Download Toolkit Here

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

PWSA | USA staff members Sarah Kasaby, Melanie Zalman, Charles Conway, Elaine Towle, and Kristi Rickenbach, are parents of loved ones with PWS. On this episode of PWS United, they share their PWS origin stories, how things have changed since the early days of their PWS journey, and their favorite ways to spread PWS awareness. Honesty, wisdom, support, pride in their loved ones, and hope for the future permeate this episode - an inspiring way to celebrate PWS Awareness Month for all of May, focusing on May 15 as PWS Awareness Day!

PWS United Podcast

PWS ORIGIN STORIES, SUCCESS, AND AWARENESS

PODCAST EPISODE #41 | WITH GUESTS:

Sarah Kasaby
Information and Referral Specialist,
mom to Khaled

Melanie Zalman
Director of Development,
mom to Josephine

Charles Conway
Executive Administrative Assistant, dad to Angelica

Elaine Towle
Advocacy Specialist, mom to James

Kristi Rickenbach
Parent Support Coordinator, mom to Justice

Listen to the latest episode of *PWS United* on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

PWS Advocates Represent Disability Needs and Rights in DC

From May 5th–8th, six of our PWSA | USA Advocacy Ambassadors joined forces with the Council of Parent Attorneys and Advocates (COPAA) and key partners from the rare disease industry to advocate for critical issues affecting individuals with Prader-Willi syndrome and the broader rare disease community on Capitol Hill.

Over the course of several days, our ambassadors met with members of Congress and their staff to advance the following priorities: Protecting Medicaid for Individuals with Disabilities, Preserving Federal Education Funding, Safeguarding the Rare Pediatric Disease Priority Review Voucher (PRV) Program, and Supporting the Orphan Drug Tax Credit (ODTC).

Call to Action!
One of the most powerful tools we have in advocacy is your story. Personal experiences help lawmakers understand the real-world impact of their decisions. We invite you to share your PWS journey with us using the link in our article. Stories submitted will be shared with elected officials to drive home the urgent need for support and services.

Read this article by clicking the button below.

READ HERE

PWS Awareness Day Proclamation in New York

On April 29, 2025, the New York State Senate adopted Resolution J809, introduced by Senator Jake Ashby, officially designating May 15, 2025, as Prader-Willi Syndrome (PWS) Awareness Day in New York state. Senator Ashby

used to work with adults with PWS, so this resolution aiming to raise public awareness about PWS, is close to home for him.

The resolution also acknowledges the vital role of organizations such as the Prader-Willi Alliance of New York, Inc., and the national Prader-Willi Syndrome Association | USA, in providing support, promoting awareness, and facilitating research. These organizations have been instrumental in advocating for individuals with PWS and their families, offering resources, and fostering a community of support. The resolution highlights the leadership of individuals like Stacy Ward, CEO of PWSA | USA, and Jeffrey Covington, a board member representing New York and Amy McDougall, President of Prader-Willi Alliance of NY in advancing the mission of these organizations. (NYSenate.gov)

By proclaiming May 15 as Prader-Willi Syndrome Awareness Day, New York state demonstrates its commitment to supporting individuals with PWS and their families, promoting research for effective treatments, and fostering an inclusive society that recognizes and addresses the challenges faced by those living with this condition.

Joining Stacy in the Senate Gallery when Senator Ashby spoke to the importance of the Resolution were Amy and Harry McDougall and their children Noelle (living with PWS) and Logan, Sarah and Matthew Bernas and their daughter Lexie (living with PWS) and PWSA | USA Board member, Jeff Covington.

Our Proclamation Toolkit provides everything you need to take action, including step-by-step guidance, sample cover letters for reaching out to local and state officials, and inspiring success stories from PWS families who have done it before. Access by clicking on the image.


4-Step Guide on How to Request a Proclamation or Resolution 2
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ADVOCACY IN ACTION
Prader-Willi Syndrome Association | USA

Prader-Willi Syndrome (PWS) Awareness Month

Proclamation Toolkit

Created by PWSA | USA's Advocacy Team

@pwsausa
Prader-Willi Syndrome Association | USA

For questions, email: advocacy@pwsausa.org
Send proclamation photos to: communications@pwsausa.org

FAMILY SUPPORT

Adults with PWS Advisory Board Spotlight

Conor Heybach is 44 years old and lives with Prader-Willi syndrome. He resides in Chicago and has been on the Adults with PWS Advisory Board since 1996. In an effort to learn more about our adults with PWS, and to shine a light on their lives and experiences, we asked our Advisory Board members some questions.

"I teach and coach chess at Altus Academy in Chicago, IL. I have advocated on the State and Federal level for PWSA | USA." - Conor Heybach

Learn more about Conor by clicking the button below.

READ MORE

Financial Planning Webinar Recording: Creating Financial Security for a Loved One with PWS

Watch this educational webinar to learn more about special needs planning. Topics covered include an overview of Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), Medicaid and Waivers, ABLE accounts, special needs trusts, and other important considerations to help family members better understand how planning for a child with special needs is different both legally and financially. This webinar was presented by Ivailo Grigorov, a Financial Advisor and special needs parent to Lucca, who is 8 years old and has a diagnosis of Prader-Willi syndrome. Watch this webinar by clicking the button below.

WATCH HERE

Join Focus Group to Develop Content for New Family Resource Program

BIRDLAB
RESEARCH & PRACTICE
TheChicagoSchool

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

The Behavioral Innovations for Rare Diagnosis (BIRD) Lab at The Chicago School is working in collaboration with PWSA | USA to develop a Family Resource Program.

We will be holding a series of focus groups to get your input on a variety of topics, including:

- The most important knowledge and information needs for individuals with PWS and their families.
- The daily challenges and successes you experience as a caregiver.
- The kinds of emotional, behavioral, and medical supports that are most needed.
- What helps (or hinders) you in navigating education, healthcare, and social systems.

- The best ways to deliver support – live, pre-recorded, one-on-one, or in groups.

Your perspective will help us build a program that supports families like yours-at every stage of life. If you have questions, please contact Dr. Annette Griffith at agriffith@thechicagoschool.edu.

For information on joining our focus groups, please click the buttons below.

PARENTS AND CAREGIVERS

SIBLINGS OF INDIVIDUALS WITH PWS

Ask Nurse Lynn

Female, 7 years old, Unknown deletion

Does the identification of PWS by genetic testing PWS give conclusive results? In other words, your child either has or doesn’t have PWS?

Does a child with PWS gain weight event if her caloric intake is restricted? Would a “less than normal” caloric intake still result in weight gain?

Visit our blog to read Nurse Lynn's response and find links to connected resources.

READ NURSE LYNN'S RESPONSE

Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you’re at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

Now you can **Ask Nurse Lynn,** PWSA | USA's very own PWS Nurse.

ASK YOUR QUESTION HERE

RESEARCH

Webinar for Aardvark's HERO Clinical Trial of ARD-101

When: **Tuesday, May 20, 5 PM PT | 8 PM ET**
Where: **Zoom | Registration is free!**

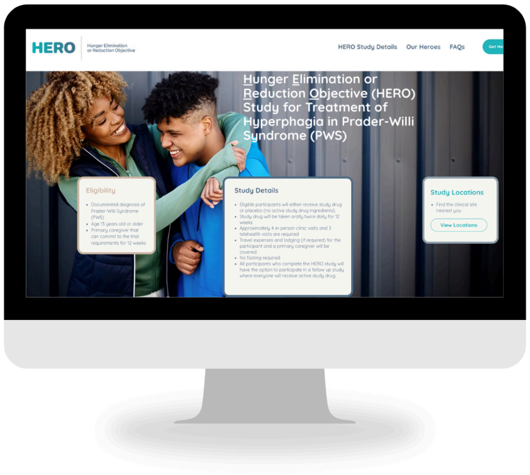
Join us for an informational and important webinar to learn more about Aardvark's HERO clinical trial for ARD-101, a potential treatment for hyperphagia and behavioral disturbances in PWS.

This is your chance to:
– Learn about the HERO Phase 3 clinical trial of ARD-101, a potential treatment for hyperphagia and behavioral disturbances in PWS.
– Find out where trial sites are located and which are currently open and actively enrolling participants.
– Ask your questions directly to the Aardvark team.

With the help of our community, this groundbreaking treatment could move one step closer to FDA approval, bringing hope and new options to those who need it most. For more information on the HERO Study, please see their website at www.heroforpws.com.

Don’t miss this opportunity to be part of the future of PWS treatment! Register for this webinar using the button below.

REGISTER HERE



Hunger Elimination or Reduction Objective (HERO) Study for Treatment of Hyperphagia in Prader-Willi Syndrome (PWS)

Eligibility

- Documented diagnosis of Prader-Willi Syndrome (PWS)
- Age 13 years old or older
- Primary caregiver that can commit to the trial requirements for 12 weeks

Study Details

- Eligible participants will either receive study drug or placebo (no active study drug ingredients).
- Study drug will be taken orally twice daily for 12 weeks
- Approximately 4 in-person clinic visits and 3 telehealth visits are required
- Travel expenses and lodging (if required) for the participant and a primary caregiver will be covered
- No fasting required
- All participants who complete the HERO study will have the option to participate in a follow up study where everyone will receive active study drug.

Study Locations

- Find the clinical site nearest you

Aardvark Therapeutics has created a website for families to learn more about the HERO (Hunger Elimination or Reduction Objective) Study, the ARD-101 Phase 3 clinical trial. Families can explore the website to find more details about the study including trial site locations, requirements to participate, FAQs, and more.

HERO TRIAL WEBSITE

Looking for Survey Study Participants!

Help us learn about the current trends in school placement, specialized instruction, related services, and educational supports provided to students with Prader-Willi syndrome (PWS) under the Individuals with Disabilities Education Act (IDEA). At the completion of the survey, you can enter to win one of four $50 Amazon gift cards.

Caregivers will complete a 20–25-minute online survey on Questions Pro about their child's education, IEP, and food security at school. To participate, caregivers must be at least 18 years old and speak and read English. Additionally, they must be the parent or guardian of a child who is school-aged (3-22 years old) at the time of the survey, has a diagnosis of PWS, and lives in the United States.

Find out if you qualify by clicking the button below. For questions, contact: Destiny Pacha, EdD at dpacha@thechicagoschool.edu


New Research Opportunity

Educational Trends of Students with PWS

Chance to Win a $50 Amazon Gift Card

INTERESTED?

Find Out if You QUALIFY!

Visit: https://pwslab.questionpro.com/PWSeducation

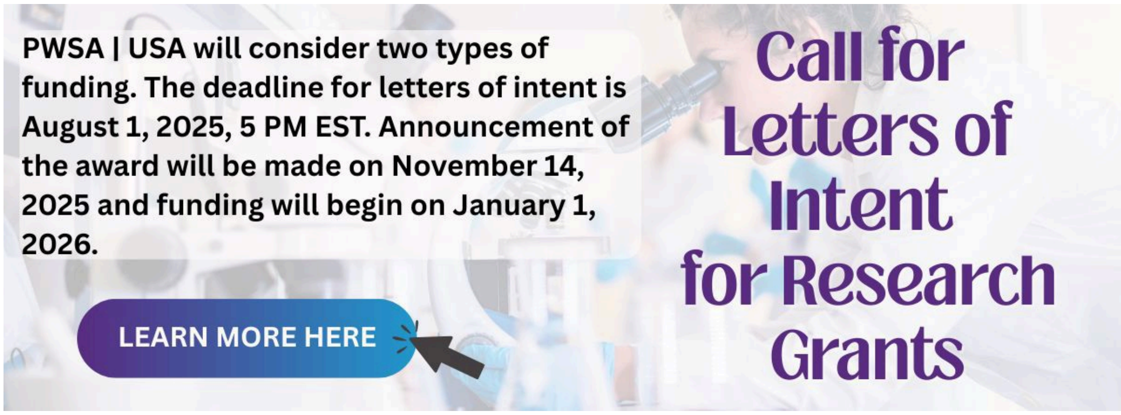
[TAKE THE SURVEY]

Supporting PWS Research


Prader-Willi Syndrome Clinical Scholarships Available

$25,000 USD to support providers in enhancing their understanding of PWS through clinical proctorships with experts in the field. Available to providers currently in practice in the US and who presently care or plan to care for patients with PWS.

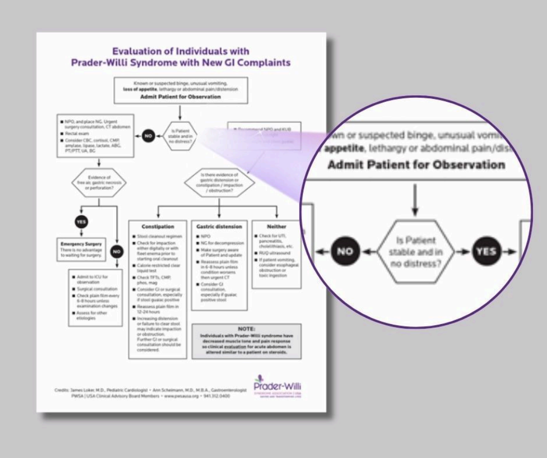
LEARN MORE HERE



PWSA | USA will consider two types of funding. The deadline for letters of intent is August 1, 2025, 5 PM EST. Announcement of the award will be made on November 14, 2025 and funding will begin on January 1, 2026.

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight



Evaluation of Individuals with Prader-Willi Syndrome with New GI Complaints

Gastrointestinal (GI) issues are common in individuals with PWS. From a young age, there are signs and symptoms parents and caregivers must become aware of. Vomiting, diarrhea, and belly aches can all be signs that something more serious is happening with your loved one. This is not meant to be a cause for alarm, but an opportunity for education and action. PWSA | USA has a GI algorithim chart to help families and medical providers determine the best plan of action if your loved one is showing symptoms of GI issues. Download the chart below.

DOWNLOAD GI ALGORITHIM

IN MEMORY OF

We are deeply saddened to share the news of the passing of Jim Gardner, a beloved and instrumental figure in the history of PWSA | USA. Jim's unwavering

dedication and tireless advocacy laid the foundation for much of the work we continue today. As one of the organization’s earliest champions, Jim helped shape PWSA | USA into a national voice for individuals with Prader-Willi syndrome and their families—at a time when few resources or support networks existed. Jim served as a PWSA | USA board member from 1995 – 2004, three of those years serving as treasurer.

“Jim Gardner was not an upfront and center stage person but was a part of the bedrock foundation of PWSA | USA. With a background in banking, I counted on him as treasurer for years to keep our finances (and me) in line. Jim was not one to look for glory. I will always remember him as the faithful person behind the booth selling PWSA logo items at conferences for many years and then helping Joan with the IPWSO booths. They were not only PWS parents devoted to Larry, but also partners in all things PWS.” Janalee Heinemann

Jim, along with his wife Joan, hosted the first PWSA | USA and IPWSO combined conference in 2001. They were integral to the creation of the PWSA Minnesota Chapter and partnered with Fausta and Gene Deterling to support the Oakwood Residence an agency providing residential care to individuals with PWS. Many of their programs are now operated by AME Community.

Jim's legacy is one of compassion, vision, and leadership. His work helped bring together a community of families, professionals, and advocates who remain connected through the mission he so strongly believed in. His passing is a profound loss, but his impact will continue to guide and inspire us for years to come.

Memorial service: Monday, June 2, 2025, 11 AM at St. John in the Wilderness Episcopal Church (2175 1st Street, White Bear Lake, MN)

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope they so desperately need. Thank you!

Donate

PWSA | USA May 2025 Special Edition
Pulse Newsletter

www.pwsausa.org | 941.312.0400

[Donate]()

The 2025 United in Hope International PWS Conference is Almost Here!

As June rounds the bend of 2025, we at PWSA | USA , along with our co-hosts at IPWSO and FPWR, are excitedly gearing up for the **[United in Hope International PWS Conference]()** in Phoenix, Arizona! We have many exciting updates to share in this Pulse so please read through to be informed of all the opportunities and preparations for this year's conference.

We recognize that there are many factors that determine whether or not a family can attend conference, but we don't want families unable to attend to miss out on the knowledge and education this conference will provide. To that end, we have a few ways to share the conference with you at home. Sessions in the main ballroom will be recorded for our YouTube channel. Unique to this year, we will also have our PWS United podcast in attendance to record a few of the conference sessions. Follow PWS United on your favorite podcast app to be notified when those sessions air. And there's more! Scroll to learn how you can tune in and participate live in a conference session.

Upcoming Materials

CONFERENCE MOBILE APP & ATTENDEE WELCOME PACKET COMING SOON!

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5 Conference Schedule
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24 Before You Travel
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For registered attendees, please keep an eye on your inbox next week for some exciting pre-conference material. Next week you will have the opportunity to read through a detailed schedule of the Family Program. We strongly encourage you to read through each session and make note of the ones you would like to attend. Once you arrive at conference, there will be many people to connect with and sites to see, so develop your plan before go.

We will also be sending out an Attendee Welcome Packet. This packet will include all things conference to help you plan for your trip. If you prefer to listen, our recent PWS United podcast episode, aptly named "All Things Conference," with PWSA | USA staff members Angela Frazier and Kristi Rickenbach, covers many of the questions attendees have reached out to us with. You can listen to that episode on your favorite podcast platform or at **PWS United on Podbean**. Stay tuned to PWS United next week for an episode with the organization leaders from the conference hosts, Stacy Ward from PWSA | USA, Marguerite Hughes from IPWSO, and Susan Hedstrom from FPWR.

Along with the Attendee Welcome Packet and the detailed Family Conference schedule, you will receive instructions on downloading the conference app. We will be using a uniquely designed mobile app for all conference details during the event. With the mobile app, you will have access to detailed conference and speaker schedules, maps of the conference site, information about our sponsors and exhibitors, and opportunities to connect and message with other attendees. Remember to check those spam boxes if you don't see an email by Friday.

First Time Attendee Meeting

First-Time Attendee Info Session: What to Expect at the 2025 International PWS Conference!
When: *Wednesday, June 4, 2025 | 12:00 PM ET / 9:00 AM PT*
Where: *Online via ZOOM*

Is this your first time attending a PWS Conference? Wondering how the Family Program works or what exciting events are planned? We've got you covered! Join Kristi Rickenbach, PWSA | USA Parent Support Coordinator, and Stacy Ward, PWSA | USA CEO, for a special info session designed just for first-time attendees. They'll walk you through the Family Program schedule, share helpful tips, and highlight some of the can't-miss moments at this year's conference in Phoenix.

The first portion of the webinar will be recorded, including the overview and tips from Stacy and Kristi. However, the live Q&A that follows will not be recorded, so be sure to join us live to ask your questions! This is your chance to get answers, connect with other new attendees, and feel confident and excited heading into conference week. Use the link at the button below to join us on June 4 at 12:00 PM ET.

ZOOM LINK

PWS United at Conference

The PWS United Podcast is going to conference for the first time! As a newer project of PWSA | USA (since August of 2024) this will be our first time hosting and attending conference with a podcast platform. We are excited for the opportunities this creates and how we can bring the conference to families all around the world. We have selected a few sessions from the conference to record as podcast episodes to be released at a later date. Follow the podcast or stay tuned to social media for when those episodes will air.

Something perhaps even more exciting will be our first ever livestream! That's right, we'll be airing a live podcast episode straight from a conference session. Tune in to **PWS United on the Podbean** app on **Saturday, June 28 at 1:15 PM PT | 4:15 PM ET** for “Teaching Emotional Regulation in Individuals with Prader-Willi Syndrome: ABA Strategies for Lasting Success,” presented by Kasey Bedard, PhD, BCBA-D, Assistant Professor from The Chicago School. This session will provide valuable tools and understanding for individuals with PWS of ages 5 and older and will explore why emotional regulation is challenging for people with PWS, and why common strategies for teaching this skill often don't seem to help PWS children and adults. The presentation will further explore how Applied Behavior Analysis (ABA) strategies can be used to effectively teach emotional regulation skills.

To join us for this **PWS United livestream**, you'll want to download and/or update the Podbean Podcast app and follow PWS United to listen on your phone. If you'd like to listen from a browser on your computer, and you don't already have an account with Podbean, be sure to log on a few minutes early to set up with your one-time sign in. Once the livestream begins, you'll be able to listen in and share comments with fellow online listeners in the chat. For full details and the link for the June 28th livestream, please click the button below for the "How to Join a PWS United Livestream" article.

READ ARTICLE HERE

PWS UNITED PODCAST

Have you always wanted to hear your voice on a podcast? Are you coming to conference? PWS United's co-host, Anne Fricke, will be wandering the crowds of the conference, looking for people willing to share their experiences for future podcast episodes. So tune up those voices and look for Anne when you're there. Feel free to let her know you'd like to claim your moment of fame on the podcast.

Meet TREND Community

TREND Community
Turning Anecdotes Into Evidence

TREND Community is coming to Phoenix! We're on a mission to spread the word about PWS Connect on Discord. Come find us to learn more and join the movement to generate insights that fuel breakthroughs and transform the lives of people living with PWS. Let's do this—together!

Get a jump start—download Discord in 3 easy steps:

1. Visit discord.com/download
Choose your platform (desktop or mobile) and download the app.

2. Create an account
Follow the prompts to sign up using your email address.

3. You're in!
Once your account is created, you'll be ready to join PWS Connect (we'll provide the invite link when we see you in Phoenix!).

To learn more, visit trend.community or email us at research@trend.community.

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