PWSA | USA Pulse Newsletter: March 7, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 118

March 7, 2025

www.pwsausa.org | 941-312-0400

2025 International PWS Conference -
Key Details and Reminders

We’re thrilled to partner with the Foundation for Prader-Willi Research (FPWR) and the International Prader-Willi Syndrome Organisation (IPWSO) to host the **2025 International PWS Conference** from June 24-28, 2025, at the Arizona Grand Resort & Spa in Phoenix, AZ!

REGISTER FOR THE 2025 INTERNATIONAL PWS CONFERENCE

Help us Plan Ahead - Register Early! Early bird registration is available until **March 31, 2025.** Online registration will remain open until June 17, 2025. Walk-up registration will not be available on-site.

Booking Your Stay: As a reminder, rooms at the Arizona Grand Resort & Spa are completely sold out on Thursday, June 26, 2025. There are still rooms available for the remaining conference days, but if the booking website shows no availability, we encourage you to call the resort directly to receive help or be placed on a waitlist. Their number is 877-800-4888. **Click here** to visit the Arizona Grand Resort & Spa's booking site. We also have a Hotel Locator Website specifically for 2025 International PWS Conference attendees. **Click here** to be directed to that page. *(Please note: If you stay off-site, you’ll need to arrange transportation to and from the Arizona Grand Resort & Spa for all conference sessions.)*

What Food is Included with Conference Registration?

- Two snack breaks and lunch each day (breakfast and dinner are on your own).
- **Food Options:**

- We’re bringing in partnering food trucks for breakfast—stay tuned for details!
- If you're staying in a villa, you’ll have access to a full kitchen, and there are nearby grocery stores if you’d like to prepare your own meals.
- Want to explore dining options? **Click here** to find restaurants on the Arizona Grand Resort & Spa property. **Click here** to explore additional restaurant recommendations in the surrounding area.

For Campers: Each day, campers will receive two snacks and lunch. Parents will receive the menu once it's available. *(A reminder that all PWS and Sibling Camps are completely sold out.)*

Beating the Heat! We know Phoenix summers can be hot, and we’re working on ways to help attendees, especially our loved ones living with PWS, stay cool. We’ll be sharing a blog article soon with details on what to expect—air-conditioned spaces, cooling stations, and more!

Don’t miss this incredible opportunity to connect, learn, and celebrate coming together in person!

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

HARMONY BIOSCIENCES

GOLD SPONSOR

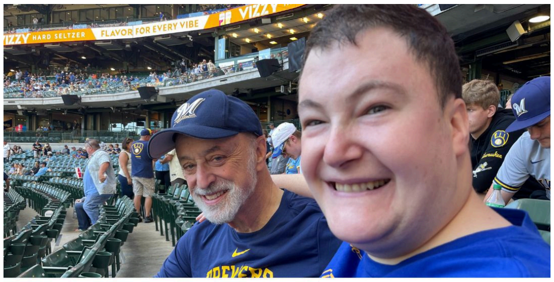
ACADIA™

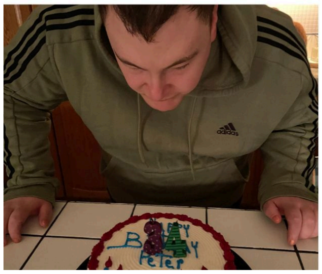
STAR SPONSORS

ConSynance THERAPEUTICS

USA friends of IPWSO

PWSA MEMORIES





Submitted by Jayne Jeffery, mom to Peter (34, living with PWS)

Peter was not definitely diagnosed with PWS until he was three years old in 1994. He was born on 1/21/91. Peter, Larry (my husband), and I visited The Cleveland Clinic where we finally got answers from an extremely dedicated specialist, Dr. Suzanne Cassidy. After blood workups, she diagnosed Peter with uniparental disomy (UPD).

We were very proactive parents after Peter was born, enrolling him in St. Francis Children's Center for physical, occupational, and speech therapy at six weeks of age. I was a firm believer that he would benefit from

Prader-Willi SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

early intervention. He was then referred to a PWS specialist at the UW Hospital and Clinics in Madison, WI, where Peter was included in a “human growth hormone therapy” program. That doctor was Aaron Carroll, M.D. Peter grew taller and became leaner.

Today, Peter is living in Madison, WI, where he is flourishing. Peter lives a life full of joy and loves all animals. He is always the first to introduce himself to new people who become part of his life.

Keep donating, learning, and sharing your own personal stories with “the PWS tribe.” But most importantly, never ever lose hope... We are all in this together and are on the right track. Stay strong and educated, because every day, strides are being made for our PWS individuals!

Thanks for your time,

Jayne Jeffery (loving and proud mom of Peter & Daniel)

SHARE YOUR MEMORY

PWSA | USA’S

SPOTLIGHT ON HOPE

"Last week, Khaled and I had the incredible opportunity to travel to Washington, D.C., to advocate alongside other families during Rare Disease Week! Khaled is my greatest motivation and inspiration, and this year was extra special because, at five years old, he was able to actively participate. He met with representatives, took photos, and most importantly—we shared his story. When policymakers see him and hear about his journey, the challenges of rare disease become more than just statistics; they become personal and urgent.

Beyond advocacy, this trip gave us the chance to connect with an amazing community. Khaled met new friends who are also battling Prader-Willi syndrome and others facing different rare conditions. Seeing these incredible kids together, sharing smiles and strength, was a reminder that while each journey is unique, we are never alone in this fight. It was an unforgettable experience, and we are so grateful to be part of this movement. Thank you to everyone working *tirelessly for change—together, we make a difference!*"- submitted by Sarah Kasaby, mom to Khaled (5, living with PWS)

SHARE YOUR SPOTLIGHT ON HOPE

We want to celebrate your loved one!

Our **Spotlight on Hope** series strives to share and celebrate the successes of our loved ones. No success is too small! Whether they took their first steps, had a great time at the school dance, made a shot in a basketball game, or are working toward a goal, we want to celebrate it all.

If you'd like to honor your loved one and share their success story with the PWS community, please fill out our Spotlight on Hope form below. We're looking forward to celebrating with you!

EVENTS & FUNDRAISERS

Exciting Webinar Opportunity – Learn About Harmony Biosciences' TEMPO Phase 3 Clinical Trial!

We invite the PWS community to join us for a **FREE** and **important** webinar with Harmony Biosciences on **Tuesday, March 11, 2025**, at 5 PM PST / 8 PM EST on Zoom!

This is your chance to:
- Learn about the TEMPO Phase 3 clinical trial of pitolisant, a potential treatment for excessive daytime sleepiness (EDS) and behavioral disturbances in PWS.
- Find out where trial sites are located *(ALL sites are now open and actively enrolling participants)*.
- Ask your questions directly to the Harmony Biosciences team.

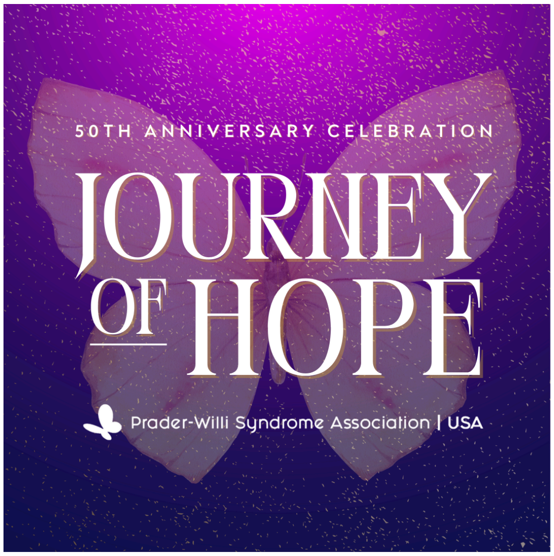
With the help of our community, this groundbreaking treatment could move one step closer to FDA approval, bringing hope and new options to those who need it most.

Don't miss this opportunity to be part of the future of PWS treatment! Click the button below to register.

Mark your calendar and spread the word!

REGISTER HERE

Tickets and Sponsorships are *NOW AVAILABLE* for PWSA | USA's 50th Anniversary Journey of Hope Gala



When: Friday, September 26, 2025
Where: Ritz-Carlton, St. Louis, MO
Time: 6 PM - 11 PM CST

This September, we invite you to join us for the **50th Anniversary Celebration Gala: The Journey of Hope** on Friday, September 26, 2025, at the Ritz-Carlton in St. Louis, MO. This special evening will honor the incredible progress we've made together while celebrating the people who have shaped our journey over the past five decades.

Please note the **RSVP date is September 1.**

PURCHASE TICKETS HERE

Equity and Prader-Willi Syndrome: A Series of Listening Sessions

The BIPOC Prader-Willi Syndrome Affinity Group is hosting listening sessions for Black, Indigenous, and/or People of Color who have been impacted by Prader-Willi syndrome and would like to create a more equitable Prader-Willi syndrome community. They want to learn about your challenges, successes and needs to shape their efforts. There are four sessions in March and all are virtual. If you are only able to come to one, that's okay! We would like to hear from you!

We hope you will join us at one or more of these times:

March 4 (Tues) at 12 PM ET - focus on ages 0-12
March 13th (Thurs) 7 PM ET - focus on ages 0-12
March 20th (Thurs) 12 PM ET - focus on ages 13+
March 25th (Tues) 7 PM ET- focus on ages 13+

Do you want your loved ones with PWS to have the best options for care?

Come Join Us! We want to hear from you!

The PWS BIPOC Affinity Group is hosting a series of Listening Sessions.

If you are a family who identifies as Black, Indigenous, or other People of Color, **we want to hear from you!** The goal of these sessions is to learn about your challenges, successes, and needs to guide our efforts.

Please join us (virtually) at one or more of these times:
March 4 (Tues) at 12pm ET - focus on ages 0-12
March 13th (Thurs) 7pm ET - focus on ages 0-12
March 20th (Thurs) 12pm ET - focus on ages 13+
March 25th (Tues) 7pm ET- focus on ages 13+

Families of color, and those who parent people of color can sign up with the QR code or email bipocpws@gmail.com

About the PWS BIPOC Affinity Group

Our mission is to empower and connect Black, Indigenous and other People of Color with Prader-Willi Syndrome and their caregivers through community-driven research, education, and advocacy. By uniting diverse voices and experiences, we aim to improve health outcomes and the overall quality of life for all.

Thank you to Acadia Pharmaceuticals and Soleno Therapeutics for sponsoring these sessions.

REGISTER HERE

The 11th Annual Clint Hurdle Hot Stove Dinner is Nearly Two Weeks Away - Get Your Tickets Now!

Don’t miss this incredible event supporting PWSA | USA’s family programs and services! Join Clint and Karla Hurdle on **March 22, 2025**, at the **Bradenton Country Club in Bradenton, FL**, for an unforgettable evening featuring dinner, live entertainment, raffle prizes, and the always-anticipated Coconut Golf Ball Drop. Can't make it in person? You can still attend virtually!

Even if you can’t join the event, you can still take part in the excitement - bidding is NOW OPEN on an amazing selection of auction items! Some highlights include Apple AirPods Pro 2, Jimmy Choo designer sunglasses, a Henry Golden Boy rifle, a Mario Lemieux signed helmet, and even a book autographed by Taylor Swift!

Click the button below to start bidding, purchase raffle tickets, and grab your Coconut Golf Ball Drop entries. Don’t wait! Be part of this special night and help make a difference.

PURCHASE TICKETS

BID ON AUCTION ITEMS

Upcoming Hope United Fundraiser: Zahra's Night of Lights!

When: **Saturday, April 5, 2025 | 6 PM CST**
Where: Historical Hall, 608 Old Post Road, Bedford, NY

Join us for the inaugural **Zahra’s Night of Light** at the Historical Hall in Bedford, NY! This community event brings us together to support children like Zahra, living with Prader-Willi syndrome. Enjoy an evening filled with entertainment, food and drinks, a silent auction, and more.

Please visit the event page using the button below to see the ticket price options which include a variety of sponsorship opportunities. Every dollar raised will go directly to the Prader-Willi Syndrome Association (PWSA | USA) to fund advocacy, family support, and vital research to find a treatment for PWS.

LEARN MORE HERE

PWS hope united

BUILDING **BRIGHT** FUTURES FOR PWS FAMILIES

Prader-Willi Syndrome Association | USA

Interested in hosting a PWS Hope United event in your city? Contact hopeunited@pwsausa.org and click the button below to get started!

Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

PWS Awareness starts here! In our latest episode of the PWS United Podcast, we dive into the power of peer-to-peer fundraising with PWS Hope United—PWSA | USA's platform that lets community members create fundraisers that fit their passion and comfort level.

You'll hear from:
- PWSA | USA's Development Team talking all things PWS Hope United.
- Kat Lucero – PWS mom & board member, sharing her online fundraising success and the exciting launch of "United We Brunch" (a great way to get involved during PWS Awareness Month)
- Michele Hampton – PWS mom & host of Dance Silly for Prader-Willi, a fun-filled event making a big impact!

Whether you're looking for inspiration to start your own fundraiser or just want to hear some incredible stories of community support, this episode is for you.

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

LISTEN ON PODBEAN

ADVOCACY

United for Change: PWSA | USA Advocates Make a Powerful Impact During Rare Disease Week 2025

Our advocates had a busy and impactful week for Rare Disease Week in Washington, D.C., and elsewhere. From gathering together to build connections and raise awareness, taking a deep dive into legislative policy, and advocating for critical issues like the reauthorization of the Rare Pediatric Disease Priority Review Voucher (PRV) Program, our advocates represented the PWS community alongside several other rare disease communities. PWSA | USA's Director of Community Engagement, Dorothea Lantz, also attended the official opening of the FSU Institute for Pediatric Rare Diseases (IPRD)—a groundbreaking new center dedicated to advancing research and treatment for pediatric rare diseases. Read more about the exciting advocacy events and how you can participate in advocacy from your home by clicking the button below.

READ HERE

Breaking Barriers: Texas Moves to Eliminate IQ Requirement for PWS Medicaid Waivers!

We are thrilled to announce a major milestone in our advocacy efforts! Texas State Representative Elizabeth “Liz” Campos has officially filed **HB 3891**, groundbreaking legislation that will remove the IQ requirement as a barrier to Medicaid waiver eligibility for individuals living with Prader-Willi syndrome.

Additionally, Senator Judith Zaffirini, PhD, the esteemed Dean of the Texas Senate, will be filing the companion bill in the Senate, marking another key step forward for our community!

For far too long, the outdated IQ-based eligibility criteria have prevented individuals with PWS from accessing the critical services and supports they need to thrive. HB 3891 ensures that a PWS diagnosis alone will be sufficient for qualification under a Section 1915(c) Medicaid waiver program, eliminating unnecessary obstacles for families seeking essential care.

This achievement would not have been possible without the tireless dedication of our incredible PWSA | USA advocates. Your voices, your persistence, and your unwavering commitment to the PWS community have made this legislative progress a reality. Together, we are breaking down barriers and creating a more inclusive future for Texans living with PWS!

Now, we turn our focus to the next step: rallying support for HB 3891 and its Senate companion bill. Stay tuned for updates on hearings, calls to action, and ways you can help ensure the passage of this crucial legislation.

THANK YOU to all who have championed this cause—we are making history together!

Advocacy Action Needed in Illinois: Fill Out a Witness Slip to Support House Bill 2541!

Illinois families, your voice is needed! The Illinois House of Representatives Human Services Committee is holding a hearing on House Bill (HB) 2541 on **Wednesday, March 12, 2025**, at 8 AM CT, and we need as many witness slips submitted as possible to show support for this important bill.

What is a Witness Slip?

A witness slip is a simple online form that lets lawmakers know you support HB 2541. It’s a quick and powerful way to advocate for our families and loved ones. Those living in Illinois are encouraged to click the button below to fill out and submit a witness slip.

Why This Bill Matters

HB 2541, filed by State Rep. Nicole La Ha, would officially recognize Prader-Willi syndrome as a developmental disability in Illinois law and add PWS to the state's list of developmental disabilities. This would help ensure that individuals with PWS qualify for essential services regardless of IQ.

Take Action Today!

- Fill out your witness slip online (click the button below).
- Encourage other Illinois residents to do the same - every submission counts!
- Attend the hearing in person if you're able (March 12, 8 AM CT, Room C-1, Stratton Building, Springfield, IL).

Your support can make a real difference in securing the services and recognition our community needs. Let's make our voices heard!

WITNESS SLIP

PWS Awareness Month Now in Illinois!

Representative La Ha from Illinois just filed a House Resolution declaring the month of May 2025 PWS Awareness Month in Illinois. Representative Coffey, Jr. co-sponsored this resolution what states, "...we declare May 2025 as Prader-Willi Syndrome Awareness Month in the State of Illinois; and be it further resolved, that we express our support for raising awareness and educating the public about Prader-Willi Syndrome and increasing research and funding into the causes and treatments of the disease." You can read the full document by clicking the button below.

READ HERE

FAMILY SUPPORT

Her Own Home with Family Nearby:
PWS in Adulthood Blog Series

Julia is a 55-year-old woman living with PWS in Queensland, Australia. She lives with another woman and receives full-time support. She enjoys volunteering at a local puppy rescue and going out for BINGO and country music nights. While she does have a lot of support in place, she values having her own home and knowing that her family is not far away. To read more about Julia, her life as an adult with PWS, and her twin sister's advice for how to prepare a loved one with PWS for adulthood, please click the button below. You can also submit your own PWS in Adulthood blog while there.

READ HERE

Ask Nurse Lynn

Male, 20 years old, UPD

Our son, 20 years old, UPD, since his childhood presented one of the characteristics of the syndrome: skin picking. We have treated him with multiple creams and therapeutic aids. But now, he started with the anal skin picking, and it is very difficult for us to handle these situations and, above all, to try to avoid them. Do you have any suggestions or advice? Thank you very much.

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]

I Am Full - Stories for Jacob Free Book Club Guide

Canadian publisher *Signature Editions* is happy to let members of the PWSA | USA community know that Dan Yashinsky's book *I Am Full – Stories for Jacob* is now available on Amazon. It's a thoughtful, poignant, and funny reflection on his son Jacob's life. It's also a grief memoir, written as a way to celebrate Jacob's extraordinary courage, wit, and wisdom as someone living with PWS. Jacob died in 2018 at age 26, and his father Dan decided to become his "storykeeper."

Dan began to write down Jacob's sayings and doings in his imagined voice. He also gathered many of Jacob's own writings: poems, love letters, apology letters (no surprise for PWS parents!), and an inspiring advocacy speech Jacob gave at a PWS fundraiser just two months before his death (the speech can also be seen on Youtube by googling “I AM Jacob Zavitz”). With the book now available in the U.S., Dan is hoping to lead book clubs for groups of parents, caregivers, and all members of the PWS community.

After a discussion with the Arizona PWS Association, Crissy McGann wrote: *The book talk based on "I Am Full – Stories for Jacob," was a wonderful experience. It was heartwarming to discuss with others in the PWS community and hear the ways we could all relate to different aspects of Jacob’s story. The author read some favorite passages which added even more depth to a book that felt so personal for us all. One participant commented how the book would stay with her and I couldn’t agree more. Since reading it, I am constantly revisiting the imagery and magic of a unique life so beautifully depicted. I plan on revisiting it many times in my own journey with PWS.*

We look forward to connecting with you individually or in a group. Please write to dan_yashinsky@hotmail.com if you’d like a copy of the Book Club Discussion Guide, or to talk about your own experiences in the world of PWS.

"I AM FULL" ON AMAZON

RESEARCH

TREND Report: Gastrointestinal Issues in the PWS Community

TREND Community released its latest report on Gastrointestinal Issues in the PWS Community. This report expresses some of the most common topics involving GI issues, including constipation and bowel movements, vomiting/spitting up/gagging, prune juice and other foods, reflux, and community support. This report looked at the conversations to determine different emotions in relation to GI discussions, with fear being the most common emotion in the presence of a GI tract finding. Constipation concerns affected caregivers across the age groups. Caregivers asked a lot of questions regarding management of constipation, showing a prevalent concern and need for information regarding the topic. To read this report and learn more about TREND Community, please click the button below.

[TREND REPORT]

Global PWS Registry: New Project Seeks to Identify Characteristics that Predict Challenging Behaviors in PWS

EARLY INDICATORS OF CHALLENGING BEHAVIORS

COMPLETE **6 SURVEYS** IN THE GLOBAL PWS REGISTRY **3 TIMES** OVER 1 YEAR

Surveys include:

- Diagnosis
- Psychological and Mental Health
- Anxiety and Distress
- Inventory of Feelings and Experiences
- Routines Inventory
- Strengths and Difficulties

PARTICIPANTS WHO COMPLETE THE 6 SURVEYS BY MARCH 31, 2025 WILL BE ENTERED TO WIN 1 OF 4 $100 AMAZON GIFT CARDS!

A new study by Dr. David Evans at Bucknell University aims to identify early risk factors for certain behavioral challenges in PWS. The project will examine how behaviors may change over time within each individual and across age and genetic subtypes. Parents are asked to complete surveys three times over a year. Information from this study will help identify the earliest signs of challenging behaviors in PWS so they can be addressed as soon as possible and support parents and clinicians in developing earlier and more individualized interventions. Seeking caregivers of people with PWS ages 2+ to complete the six surveys today, then again in six months and 12 months for a total of three times. Responses will help identify the earliest signs of challenging behaviors, with the goal of identifying those at highest risk who might benefit most from individualized interventions and management. Learn more about the study and how you can participate at the button below.

[LEARN MORE HERE]

Harmony Biosciences Announces Two Additional Clinical Trial Sites

Harmony Biosciences has announced two additional clinical trial sites for its TEMPO PWS study; Children's Hospital of Wisconsin in Milwaukee, WI, and Ann and Robert H. Lurie Children's Hospital of Chicago in Chicago, IL.

Harmony Biosciences' TEMPO study is a global Phase 3 trial investigating pitolisant as a potential treatment for excessive daytime sleepiness (EDS) in individuals age 6 years and older with Prader-Willi syndrome. Pitolisant is a medication that could help manage sleepiness and behavioral issues in people with PWS. Find all TEMPO trial site locations and learn more by clicking the button below.

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

Call for Nominations to PWSA | USA Board of Directors

PWSA | USA is looking for bright, motivated people who think clearly and creatively, work well with others, are sensitive to different points of view, and who are dedicated to improving the lives of individuals with PWS and their families. Be an active contributor on a committee or project prior to being nominated for service on the Board of Directors.

The following areas have been identified as priorities for additional bench strength:
Human Resources (Generalist) | Philanthropy | Fund Development | Research Expertise | Medical Expertise | Legal Expertise | Financial Expertise

Have one of these specialized skills or know someone who does?
Communications and Media | Website | Research | Financial Expertise

Or do you "simply" have passion, dedication, and follow-through to bring to a committee?

To learn more about committee work or to learn how your specialized skill set can help families and professionals, contact Stacy Ward, CEO, at sward@pwsausa.org. To nominate yourself or someone else for the Board of Directors contact Lisa Graziano, Leadership Development Committee Chair, at LisaGrazianoLMFT@gmail.com.

For more information contact PWSA | USA · 800-926-4797 · info@pwsausa.org

PWSA | USA Resource Spotlight
Community Publications

We've recently added a new page to our website called, "Community Publications." This page hosts a variety of creations from and for the PWS community. Here you will find links to children's books, informative memoirs and manuals, articles, YouTube videos, and podcasts created by caregivers in the PWS community. These publications can help educate you and your community about the intricacies of PWS, offer guidance on the ways to discuss PWS with your family, friends, and loved ones, and help create a stronger sense of belonging and bond within this community. Please visit the page using the button below. If you or someone you know has released a publication that you think belongs on this page, please email communications@pwsausa.org.

COMMUNITY PUBLICATIONS

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the

Donate

connection, guidance, and hope they so desperately need. Thank you!

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

PWSA | USA Pulse Newsletter: March 21, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 119

March 21, 2025

www.pwsausa.org | 941-312-0400

March offers us a lot to celebrate and curate awareness around. Awareness months, weeks, and days are great opportunities to learn more about an issue we are interested in or to spread information and personal stories about issues that affect us. Many awareness campaigns have fresh themes each year, providing a path to follow and curate stories around. PWSA | USA seeks to promote and encourage our community through these awareness events, bringing information to our community and learning more about ourselves along the way. We hope that you continue to find inspiration and encouragement from these opportunities. Below are the awareness opportunities for March.

National Nutrition Month, "Food is our connection"

When we first learn about PWS, many of us concentrate on hyperphagia. Parents and caregivers often share concerns about the struggles with nutrition, food security, and the affected behaviors. If there’s any community where the theme "food is our connection" truly resonates, it’s the PWS community. This awareness month encourages us to continue to educate ourselves about healthy nutrition and how food is connected to our lives. Learn more about PWS nutrition in our blog, **Nutrition in the PWS Family,** written by dietician Michael Tan. For a friendly guide on how to have healthy and respectful conversations on nutrition, check out **"Nutrition Discourse in the PWS Community."**

National Developmental Disabilities Awareness Month

As with any awareness celebration, it is not about a limited moment in time, but a way to draw attention to issues, people, and groups that are in our society every day. This year's Developmental Disability Awareness Month theme is "We're Here All Year." As parents and caregivers of individuals with PWS, we know that developmental disabilities do not go away when the awareness focus shifts. To learn more about this awareness month, visit the site for **National Association of Councils on Developmental Disabilities.**

Women's History Month

This year's women's history month theme is "Moving Forward Together: Women Educating and Inspiring Generations." There have been and continue to be many incredible women educating and inspiring the PWS community and beyond. We can't possibly list them all, but for a glimpse at some of these PWS Pioneers, please check out our blog "**Women in PWS: Moving Forward Together."**

Neurodiversity Celebration Week

Neurodiversity, a term coined by Australian sociologist Judy Singer in the mid-1990s, is a social justice movement that seeks to bring awareness, equality, and inclusion to people of various neurological abilities, including those with PWS. With neurodiversity, "there is no one 'right' way of thinking, learning, and behaving, and differences are not viewed as deficits." **What is neurodiversity? - Harvard Health.** You can read more about "Neurodiversity and Prader-Willi Syndrome" in our past blog at **Neurodiversity and Prader-Willi Syndrome - Prader-Willi Syndrome Association | USA.**

PWSA MEMORIES

Prader-Willi Syndrome Parents and Friends, later renamed **Prader-Willi Syndrome Association**, was established by Gene and Fausta Deterling, parents of a son with PWS, with the support of Dr. Vanja Holm, of the Child Development and Retardation Center in Seattle, Washington. This week, we are recognizing the incredible work and dedication of Dr. Holm and her contributions to the PWS community.

"*As a pediatrician who specialized in developmental disorders (conditions that included slower development and intellectual disability) at the University of Washington's specialized center for developmental disability, Dr. Holm established and directed one of the very first clinical programs dedicated to children (and later also adults) with Prader-Willi syndrome. This was a multi-disciplinary clinic that included many specialties relevant to people with PWS, and it served as a model for similar clinics in other medical centers and universities. She also organized one of the first medical conferences dedicated to PWS, which included multiple speakers from many institutions each of whom contributed a chapter about a particular aspect of PWS that Dr. Holm collected into the first book about PWS, published in 1981.*" - Dr. Suzanne Cassidy.

To read more about Dr. Holm and her contributions to the PWS community, please click the button below for a beautiful tribute to an influential woman.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S
SPOTLIGHT ON HOPE

Ronin Dhar turned 11 years old on January 1, 2025. In lieu of gifts from his friends for his party, he asked them all to donate to a page he created for his sister Zahra, 7, living with PWS. His goal was $200, but after posting it to Facebook, he raised over $1,000!

"As parents, we are constantly concerned about our PWS child but also how the disease affects the other siblings. Some of the side effects are positive, though. Like empathy! Ronin knows that our expectations are for him to be thankful and kind, and to give back to the community. I'm overjoyed that he's doing it!" – Pia Dorson, mom to Ronin and Zahra

SHARE YOUR SPOTLIGHT ON HOPE

We want to celebrate your loved one!

Our **Spotlight on Hope** series strives to share and celebrate the successes of our loved ones. No success is too small! Whether they took their first steps, had a great time at the school dance, made a shot in a basketball game, or are working toward a goal, we want to celebrate it all.

If you'd like to honor your loved ones and share their success story with the PWS community, please fill out our Spotlight on Hope form below. We're looking forward to celebrating with you!

EVENTS & FUNDRAISERS

2025 Conference Early Bird Registration and Family Program Schedule

We're thrilled to partner with the Foundation for Prader-Willi Research (FPWR) and the International Prader-Willi Syndrome Organisation (IPWSO) to host the

2025 International PWS Conference from June 24-28, 2025, at the Arizona Grand Resort & Spa in Phoenix, Arizona!

Our high-level Family Program schedule is now available for download!

United in HOPE
2025 PWS CONFERENCE

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: 9:15 AM - 4:30 PM

Breakfast on your own *(6:30 AM - 9:00 AM - Food Trucks at Conference Center Pavilion)*

9:15 AM - 10:30 AM - Welcome to the International PWS Conference *(Main Ballroom, All Ages)*

10:45 AM - 11:45 AM
- What's Happening in PWS Research *(Main Ballroom, All Ages)*
- The Orthopaedics of Prader-Willi Syndrome *(Arizona A - Acacia, All Ages)*
- The Importance of Exercise for People Living with PWS *(Arizona B - Bougainvillea, Ages 12+)*
- Prader-Willi Syndrome: Nutrition Guidance and Recommendations *(Arizona C, D - Copperwood, Desert Willow, Ages 0-11)*

11:45 AM - 1:00 PM - Lunch *(Canyon Ballroom)*

1:00 PM - 2:00 PM
- Aging: Cognitive, Physical and Social Health *(Main Ballroom, Ages 18+)*
- Understanding the Sibling Experience in Prader-Willi Syndrome *(Arizona A - Acacia, All Ages)*
- Clinical & Scientific Program Recap *(Arizona B - Bougainvillea, All Ages)*
- Dynamic Movement Interventions *(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)*
- Healing, Hope, and Acceptance *(Arizona A - Acacia, Ages 0-3)*
- IPWSO's Family Support Services: FAMCARE *(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, poolside movie ("Encanto") at 8:00 PM, Drone Show at 8:45 PM

Saturday, June 28, 2025 | *DAY TWO* Sessions: 9:15 AM - 4:30 PM

Breakfast on your own *(6:30 AM - 9:00 AM - Food Trucks at Conference Center Pavilion)*

9:15 AM - 10:15 AM
- PWS Around the World *(Main Ballroom, All Ages)*
- Finding Joy Amidst Grief *(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)*

10:30 AM - 11:30 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+)*

11:45 AM - 12:30 PM - Lunch *(Canyon Ballroom)*

12:30 PM - 1:30 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+)*

1:45 PM - 2:45 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+)*

3:00 PM - 4:00 PM - Trailblazers: Stories of Inspiration from Leaders in Our Community *(Main Ballroom, All Ages)*

4:00 PM - 4:30 PM - Closing Remarks *(Main Ballroom, All Ages)*

DOWNLOAD HERE

Help us Plan Ahead - Register Early! Early bird registration is available until **Monday, March 31, 2025**. Online registration will remain open until Tuesday, June 17, 2025. Walk-up registration will not be available on-site.

Booking Your Stay: As a reminder, rooms at the Arizona Grand Resort & Spa are completely sold out on Thursday, June 26, 2025. There are still rooms available for the remaining conference days, but if the booking website shows no availability, we encourage you to call the resort directly to receive help or be placed on a waitlist. Call 877-800-4888. **Click here** to visit the Arizona Grand Resort & Spa's booking site. We also have a Hotel Locator Website specifically for 2025 International PWS Conference attendees. **Click here** to be directed to that page. *(Please note: If you stay off-site, you'll need to arrange transportation to and from the Arizona Grand Resort & Spa for all conference sessions.)*

What Food is Included with Conference Registration?

- Two snack breaks and lunch are included each day (breakfast and dinner are on your own).
- **Food Options:**
    - We're bringing in partnering food trucks for breakfast - stay tuned for details!
    - If you're staying in a Villa, you'll have access to a full kitchen, and there are nearby grocery stores if you'd like to prepare your own meals. All Arizona Grand Resort & Spa rooms are equipped with a refrigerator.
    - Want to explore dining options? **Click here** to find restaurants on the Arizona Grand Resort & Spa property. **Click here** to explore

  additional restaurant recommendations in the surrounding area.
  - In addition, the Arizona Grand Resort & Spa offers room service (Breakfast: 6:30 AM – 11 AM; all day dining: 11 AM – 10 PM)

For Campers: Each day, campers will receive two snacks and lunch. Parents will receive the menu once it's available. *(A reminder that all PWS and Sibling Camps are completely sold out.)*

Beating the Heat! Scroll below to our "Family Support" section to find ways we're making sure attendees, especially our loved ones living with PWS, stay cool in the Phoenix heat.

Don’t miss this incredible opportunity to connect, learn, and celebrate coming together in person!

Register for the 2025
International PWS Conference

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

HARMONY BIOSCIENCES

GOLD SPONSOR

ACADIA™

STAR SPONSORS

ConSynance THERAPEUTICS

USA friends of IPWSO

Celebrating the 2025 Clint Hurdle Hot Stove Dinner This Weekend!

Tomorrow, Saturday, March 22nd, the **11th annual Clint Hurdle Hot Stove Dinner** will take place at the Bradenton Country Club in Bradenton, Florida! Hosted by the wonderful Clint and Karla Hurdle, parents to Madison (living with PWS), this event has been a longstanding tradition in support of PWSA | USA's Family Support programs and services.

We are continuously grateful to the Hurdles for their dedication to the PWS community and for bringing people together year after year to make a difference. Many of our PWSA | USA staff members will be attending, and we look forward to celebrating with the families and supporters in attendance.

We can’t wait to share photos and highlights from this special evening following the event!

Upcoming Hope United Fundraiser: Zahra's Night of Light!

When: **Saturday, April 5, 2025 | 6 PM CST**
Where: Historical Hall, 608 Old Post Road, Bedford, New York

Join us for the inaugural **Zahra’s Night of Light** at the Historical Hall in Bedford, New York! This community event brings us together to support children like Zahra, living with Prader-Willi syndrome. Enjoy an evening filled with entertainment, food and drinks, a silent auction, and more.

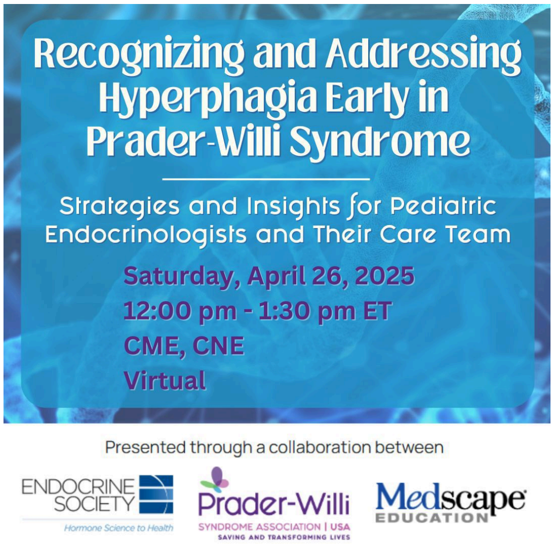
Please visit the event page using the button below to see the ticket price options which include a variety of sponsorship opportunities. Every dollar raised will go directly to the Prader-Willi Syndrome Association (PWSA | USA) to fund advocacy, family support, and vital research to find a treatment for PWS.

LEARN MORE HERE

Live Symposium on Hyperphagia for Medical Professionals

When**: April 26, 2025; 12 PM - 1:30 PM ET**
Where: **ZOOM**

This educational activity is intended for an audience of pediatricians, endocrinologists, psychiatrists, geneticists, nurse practitioners, physician assistants, nurses, and other clinicians who care for patients with PWS in the United States. Expert faculty will explore the huge burden that hyperphagia represents for patients with PWS, their families, and their caregivers. They will delve into the pathophysiology and complications of hyperphagia and look to the



Recognizing and Addressing Hyperphagia Early in Prader-Willi Syndrome

Strategies and Insights for Pediatric Endocrinologists and Their Care Team

Saturday, April 26, 2025
12:00 pm - 1:30 pm ET
CME, CNE
Virtual

Presented through a collaboration between

future in a discussion around the current and emerging treatment options for hyperphagia in PWS. By incorporating patient case examples and the latest data, the faculty will exchange ideas around best practices to ensure improved quality of life for patients with PWS and those around them.

CME's Available!

For Physicians
Medscape, LLC designates this live activity for a maximum of 1.0 *AMA PRA Category 1 Credits*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

For Nurses
Awarded 1.0 contact hour(s) of nursing continuing professional development for RNs and APNs.

REGISTER HERE

United We Brunch: Awareness in Every State

At PWSA | USA, we believe that raising awareness for Prader-Willi syndrome starts in our own circles - with friends, family, neighbors, and colleagues. As PWS Awareness Month approaches this May, we are excited to introduce the **United We Brunch (UWB)** initiative, a nationwide effort designed to bring people together to connect, share experiences, and gain the resources and support our community needs.

United We Brunch is all about raising awareness, fostering hope, and gathering resources - one brunch, one state, and one family at a time - uniting communities and creating a ripple effect across the U.S. Anyone can host a UWB event! It's easy and can be as casual or fancy as you'd like. From having friends over for muffins and coffee to catering a high-tea and arranging flowers, your time and imagination are the only limits.

We've made getting involved easy!

1. Download our **United We Brunch toolkit HERE**
2. Register to create your UWB page at the button below.
3. Name your event: Include the state and date
4. Start planning and reach out to **hopeunited@pwsausa.org** for help and support!

LEARN MORE

PWS hope united
BUILDING BRIGHT FUTURES FOR PWS FAMILIES
Prader-Willi Syndrome Association | USA

Interested in hosting a PWS Hope United event in your city? Contact hopeunited@pwsausa.org and click the button below to get started!

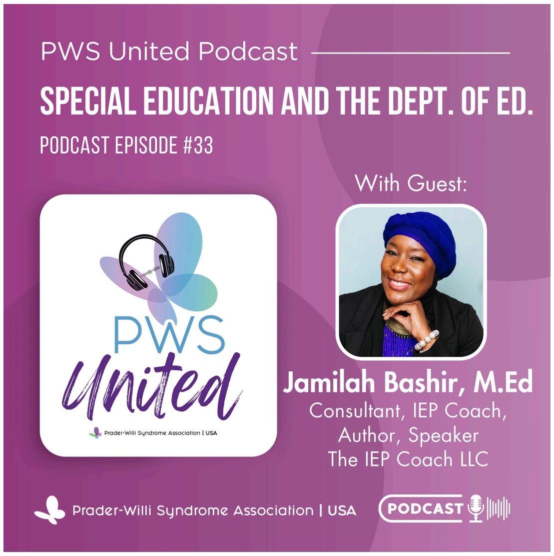
Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

PWSA | USA's CEO Stacy Ward sat down with educator and IEP coach, special education consultant, author, and sibling of an individual with an intellectual disability, Jamilah Bashir, M.Ed., to discuss special education and the current state of the Department of Education. They discussed training for special education teachers, the voucher program, where to find good information about changing policies and decisions within the Department of Education, and the path of an executive order. Jamilah clarified the different roles of the U.S. Dept. of Education versus the state's Dept. of Education, focusing on funding and the accountability of states to provide services. This discussion can provide clear insight on the role of the U.S. Department of Education, why it may be critical for our loved ones with PWS, what the alternative may look like, and how and why to contact your representatives on this issue.

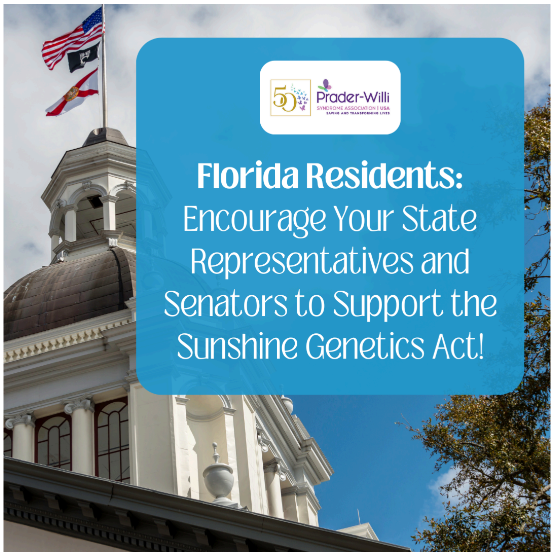
Listen to the latest episode of *PWS United* on your preferred podcast app or by clicking the button below.



LISTEN ON PODBEAN

ADVOCACY

Voices Needed from Florida PWS Community!



Help ensure early genetic screening for Prader-Willi syndrome by urging your Florida state legislators to support the Sunshine Genetics Act (HB 907 / SB 1356)! This bill would establish newborn genetic testing, leading to earlier diagnoses, better care, and reduced healthcare costs for families affected by rare diseases.
- Early detection = life-changing interventions
- Delayed diagnosis leads to severe health & financial burdens
- Florida can be a leader in genetics & precision medicine

If you live in Florida, take action now! Visit this link at the button below to learn more and to send a letter to your state representatives and senators.

LEARN MORE HERE

PWS Siblings & Families in the Spotlight: Share Your Story for PWS Awareness Month

From Soleno Therapeutics:

As we look ahead to May and PWS Awareness Month (quickly approaching!), we are reminded of the incredible opportunity we had last year to showcase the faces and stories of individuals living with PWS. Your participation last year made such a powerful impact, bringing greater awareness and understanding to this community.

This year, we are excited to continue this journey together, celebrating the strength, love, and resilience that define the PWS community. In particular, we want to pull back the curtain on an often-invisible, but deeply important perspective: *the role of family members, including siblings, cousins, and special loved ones.*

SOLENO
THERAPEUTICS

We know that a family plays a vital part in the caregiving journey, and their experiences deserve to be shared. We would love to highlight their collective voices by sourcing stories and photos of family members together, and sharing them on Support4PWS.com and other public marketing channels (like social media, billboards and digital screens in public spaces). If you would like to participate, please email stories@soleno.life with the following items.

- A photo of family members together that are navigating PWS in the family (this can include siblings, cousins, or other special loved ones impacted by PWS).
- Responses to these two questions:
    - What is one challenge you've experienced as a family member of someone with PWS?
    - What is one hope you have for your loved one's future?
- Your first name, last initial, and the state you live in.
- A completed photo release form:
    - For minor siblings/family members (multiple names can be added)
    - For adult siblings/family members (if any)

    - If there are two siblings where one is a minor and one is an adult, please have the parent/caregiver fill out the first form with one minor's name and the adult sibling fill out hte second form in their own name.

Your stories help educate, inspire, and connect our community and the public in meaningful ways. In the coming weeks, you will also be hearing from us more regularly. If you have not already done so, we invite you to sign up for updates here.

Thank you for considering this opportunity. We are so grateful for each of you!

RELEASE FORM FOR MINORS

RELEASE FORM FOR ADULTS

FAMILY SUPPORT

How to Beat the Arizona Heat and Stay Cool at Conference

As we count down the days to the United in Hope: International PWS Conference in Phoenix, Arizona, our excitement at gathering with so many families from the PWS community grows! We'll be spending time with old friends, making new ones, and collectively sharing information, guidance, support, great conversations, maybe some tears and certainly some laughs. Another thing we'll all be sharing is the HEAT. Phoenix in June will be hot, and as we know about our loved ones with PWS, temperature regulation and staying cool in the heat is a challenge. But don't worry, we've got you covered! Check out this week's blog to learn about the measures we're taking at conference to help you and your loved stay cool. You'll also find tips from Arizona families on how to keep your loved one safe in the Arizona heat.

READ HERE

Ask Nurse Lynn

Male, 7 months old, unknown subtype

He has a cough, congestion, and I have the humidifier with Vicks vaporizer going and been using the nose sucker by Frida to help clear his airway. But I’m so worried at night especially knowing now he has sleep apnea. He’s having a hard time breathing. I really can’t sleep worried about him. Any advice?

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

READ NURSE LYNN'S RESPONSE

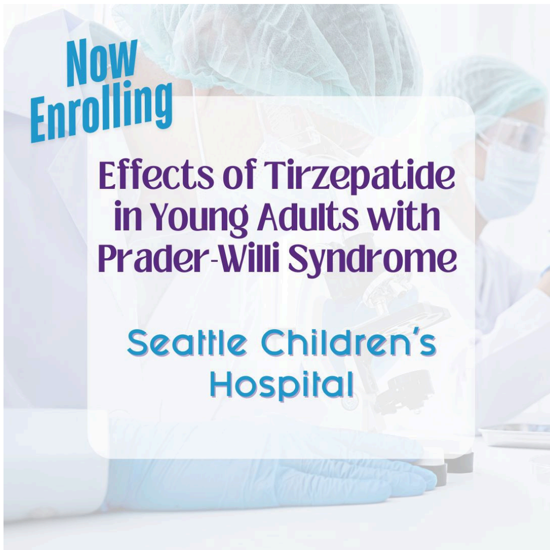
Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you’re at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

ASK YOUR QUESTION HERE

RESEARCH

New Research Study Designed to Treat Obesity in Specialized Populations with Tirzepatide



This is a multi-site, open-label, non-randomized pilot study to investigate the efficacy of tirzepatide to promote reduction of body BMI in obese young adults with 1) PWS, 2)HO, or 3)GNSO. The primary aim will be to evaluate the percent change in weight and BMI from baseline during 48 weeks of treatment with tirzepatide. This will be a 48-week trial using tirzepatide that includes 6 in person study visits, 4 telehealth visit, and an additional visit 8 weeks after stopping medication.

This study might be a good fit for you if you:

- Are age 18-26.
- Have Prader-Willi Syndrome, Hypothalamic Obesity, or Obesity unrelated to a genetic syndrome or medical condition.

If you/your child decide to take part in the research study, you/your child would:

- Participate for approximately 56-60 weeks.
- Receive tirzepatide for once-weekly dosing.
- Complete 6 in-person SCH study visits
- Complete 4 telehealth visits.

Complete the following research procedures:

- Medical Record Review
- Vital Signs
- Anthropometry (e.g., height, weight, waist measurements)
- Physical Exams

- Laboratory Tests (e.g., fasting blood draws, urine test)
- Dual-Energy Absorptiometry (DXA) scans
- Questionnaires

We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include a decrease in your appetite and your weight which can improve your overall health. Participants who take part get $50 gift cards for each in-person and telehealth visit to thank them for their time.

To take part in this research study or for more information, contact the Endocrine Research Team
at EndocrineResearch@seattlechildrens.org or 206-987-2540.

Recording of Harmony Biosciences TEMPO Phase 3 Trial Informational Webinar

Harmony Biosciences held a free webinar to help the PWS community learn more about the TEMPO Phase 3 clinical trial of pitolisant, a potential treatment for excessive daytime sleepiness (EDS) and behavioral disturbances in PWS. You can also learn where the trial sites are located (ALL sites are now open and actively enrolling participants), and webinar participants had the option to ask questions directly to the Harmony Biosciences 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. Watch the recording of this webinar using the button below.

WATCH HERE

PWSA | USA ANNOUNCEMENTS

Call for Nominations to PWSA | USA Board of Directors


Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES

CALL FOR NOMINATIONS TO THE BOARD OF DIRECTORS

and VOLUNTEERS WITH SPECIALIZED SKILL SETS

The following areas have been identified as priorities for additional bench strength:

Human Resources (Generalist) | Research Expertise
Philanthropy | Medical Expertise
Fund Development | Legal Expertise

Have one of these specialized skills or know someone who does?

Communications and Media | Financial Expertise
Website Management | Research

PWSA | USA is looking for bright, motivated people who think clearly and creatively, work well with others, are sensitive to different points of view, and who are dedicated to improving the lives of individuals with PWS and their families. Be an active contributor on a committee or project prior to being nominated for service on the Board of Directors.

The following areas have been identified as priorities for additional bench strength:
Human Resources (Generalist) | Philanthropy | Fund Development | Research Expertise | Medical Expertise | Legal Expertise | Financial Expertise

Have one of these specialized skills or know someone who does?
Communications and Media | Website | Research | Financial Expertise

Or do you "simply" have passion, dedication, and follow-through to bring to a committee?

To learn more about committee work or to learn how your specialized skill set can help families and professionals, contact Stacy Ward, CEO, at sward@pwsausa.org. To nominate yourself or someone else for the Board of Directors contact Lisa Graziano, Leadership Development Committee Chair, at LisaGrazianoLMFT@gmail.com.

For more information contact PWSA | USA · 800-926-4797 · info@pwsausa.org

PWSA | USA Resource Spotlight
Early Intervention Therapy: Know Your Rights

Early Intervention (EI) is a systematic program of therapy, exercises, and activities designed to address developmental delays that may be experienced by children with Prader-Willi syndrome or other disabilities. These services are mandated by a federal law called the Individuals with Disabilities Education Act (IDEA). The law requires that states provide EI services for all children who qualify, with the goal of enhancing the development of infants and toddlers and helping families understand and meet the needs of their children. Download our "What is Early Intervention" guide to learn more about the legal requirements of

early intervention, who pays for it, and how to sign your loved one up to receive the service.

EARLY INTERVENTION GUIDE

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 March 2025 Special Edition Pulse Newsletter

Donate

www.pwsausa.org | 941.312.0400

Host a United We Brunch Event in Your State and Help Spread PWS Awareness!

United We Brunch (UWB) is all about raising awareness, fostering hope, and gathering resources - one brunch, one state, and one family at a time - uniting communities and creating a ripple effect across the U.S. Now that VYKAT XR (formerly known as DCCR) has been approved by the FDA, let's roll up our sleeves (even farther) and keep working. Raising awareness and gathering donations helps us continue to advocate for treatment options and accessibility.

Host a Brunch in Your State!

Anyone can host a UWB event! It’s easy and can be as casual or fancy as you’d like. From having friends over for muffins and coffee to catering a high-tea and arranging flowers - your time and imagination are the only limits.

It's PWSA | USA’s goal to grow this initiative so that every May, during PWS Awareness Month, there will be a wave of support that increases in momentum with every year. Imagine knowing that every May, nationwide, new groups are gathering to help shine a light on PWS for all of us. It starts here, it starts now, it starts with you...

Help spread awareness and have a great time doing it!

LEARN MORE

PWS United

Click Here to Listen to PWSA | USA’s *PWS United* Podcast Episode: *Fundraising with Hope United & United We Brunch*

"Our dollars are going towards something incredible for our kids. The impact is really there, especially when you get involved through fundraising efforts. So much of our PWS journey is out of our hands. This is a place we can make a difference.” - Kat Lucero, mom to Ronan

"I think for me, PWS Awareness Month, as important as it is to our community, it can feel really heavy for families with younger kids. It can feel like a lot. You're reminded of all the things your child may or may not already be experiencing. With this initiative, we're basically saying, get a bunch of people together who love you and who have an opportunity to learn about PWS. It can be as simple as brew a pot of coffee at home and bake a dozen muffins, or if you have the energy and excitement, it can have a theme. You can really do it in whatever way and on whatever scale feels appropriate and feels right for you and your family, and where you are in your PWS journey." - Melanie Zalman, PWSA | USA Director of Development, mom to Josephine

How to Host a Brunch

We've made it simple for you to create and host a United We Brunch fundraiser!

Sample Brunch Theme/Menu/Décor Inspiration

BRUNCH IDEAS

1. **Garden Party Brunch -** Floral decor, pastel colors, and fresh garden-to-table dishes.
2. **Jazz & Mimosas Brunch -** Live jazz music and a mimosa bar.
3. **Southern Comfort Brunch -** Biscuits, gravy, shrimp & grits, and sweet tea.
4. **Parisian Cafe Brunch -** Croissants, crepes, and café au lait with a chic French atmosphere.
5. **Around the World Brunch -** Food stations featuring brunch items from different countries.
6. **Pajama Brunch -** Guests wear cozy PJs while enjoying classic comfort
7. **Farm-to-Table Brunch -** Locally sourced, organic foods with a rustic

(Example 1 / CALL TO ACTION)

Join me in on <<May __>> for United We Brunch to celebrate PWS Awareness Month and support PWSA | USA! Your donation helps improve lives through advocacy, education, and resources for families affected by #PWS. Let's raise awareness and make a real impact together! 💙 #UnitedWeBrunchPWS #PWSAwareness [Insert donation link]

(Example 2 / MOMENTUM)

This May, I'm hosting a United We Brunch event to celebrate PWS Awareness Month and raise funds for PWSA | USA! Your support helps make a real difference for [loved one's name] and others affected by #PWS. Every donation brings us closer to a world where individuals with PWS have the resources and support they need. Your generosity means everything to us—thank you for being part of this important cause! 💙 #UnitedWeBrunchPWS #PW reness

Pajama Brunch Theme (Cont.)

Decor Ideas:

- Cozy Atmosphere: Use blankets, plush pillows, and soft lighting to create a relaxed setting.
- Breakfast-in-Bed Style Tables: Arrange trays with mini vases and candles for a cozy feel.
- Pajama Dress Code: Encourage guests to wear their favorite PJs for a fun and laid-back vibe.
- Fluffy Slipper Party Favors: Provide guests with small, cozy slippers as keepsakes.
- Themed Signage: Fun quotes like "Brunch So Hard" and "Snooze & Mimosas" on chalkboards or banners.
- Self-Serve Coffee & Cocoa Bar: A cute station with different creamers, toppings, and syrups.
- Photo Booth: A backdrop with pillows, blankets, and oversized coffee mugs for playful pictures.

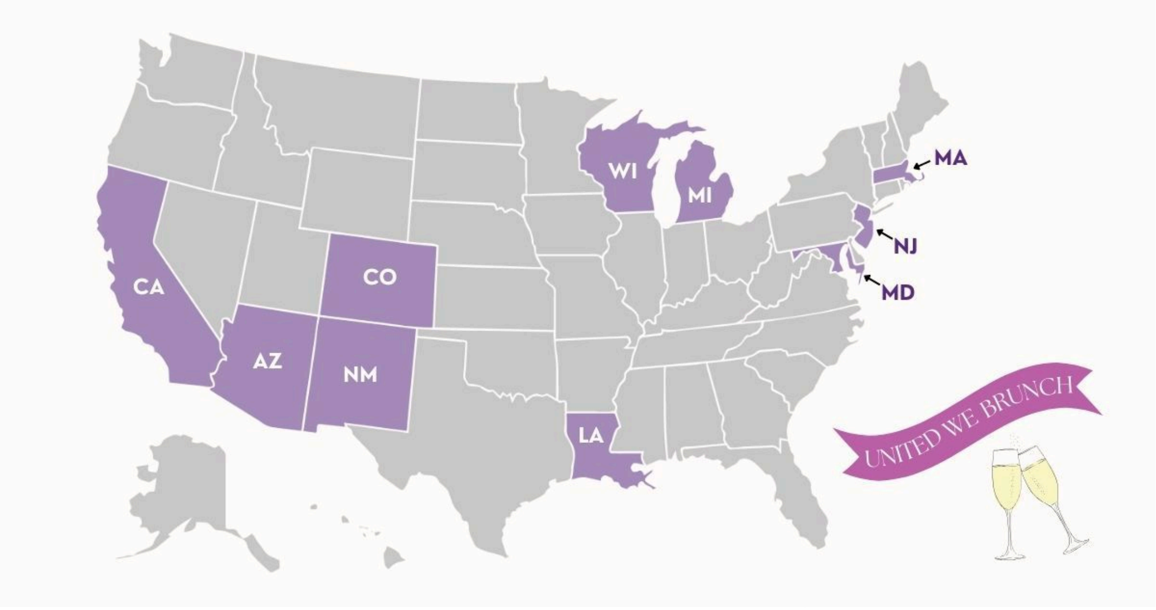
Here's how:

1. Download our **United We Brunch toolkit HERE**
2. Register to **create your UWB page**
3. Name your event, and include the state and date in your event title.
4. Start planning and reach out to hopeunited@pwsausa.org for help and support.

In our toolkit, you'll find event promotion and logistics, social media content ideas, sample email language, fundraising tips, sample brunch themes, menus, and decor and more. Check out the toolkit by clicking on the button below.

UNITED WE BRUNCH TOOLKIT

Help us fill in the map below by hosting a United We Brunch fundraiser in your state!



Support a Brunch

Magnolias and Mimosas!

When: **April 24, 2025**
Hosted by: Kat Lucero, mom to Ronan

Magnolias & Mimosas is not just a Ladies Brunch; it is a celebration of hope, strength, and community. This fundraiser aims to raise awareness about Prader-Willi Syndrome and generate funds to support research, resources, and families affected by PWS. The event will feature a variety of activities, including a raffle, fun back drop for pictures, PWS education and delicious food and drinks.

“I'm asking people to donate at least $15 for the 15th chromosome. I'm having people dress in their Sunday best for kind of like a Southern thing. I'm going to have information around tables about Prader-Willi syndrome. I also thought about doing a little game for attendees with questions about Prader-Willi syndrome, and then they would win a prize. It's not going to be this big gala event. It's just going to be really casual where other women can meet. And if people want to give more, then they give more. I'm just really excited that this has come, and I'm going see where it goes this year." - Kat Lucero

LEARN MORE & DONATE

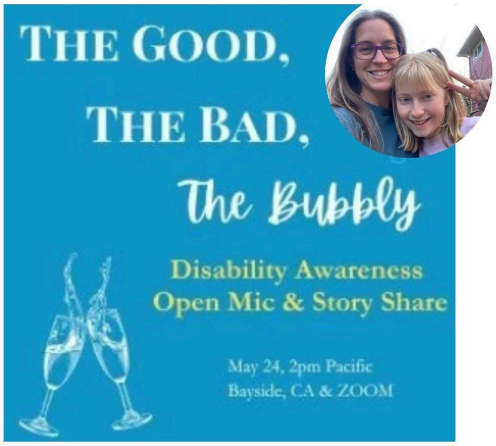
Hummus and Tahini!

When: **Saturday, May 17, 2025**
Where: **American Muslim Institute, Tri-faith Campus**
Hosted by: Sarah Kasaby, mom to Khaled

You are invited to attend my special United We Brunch "Hummus & Tahini” event in support of PWS Awareness Month this May! My event is taking place on Saturday May 17th at the American Muslim Institute located on the Tri-faith Campus. Whether you’re able to attend in person or participate from afar, your involvement helps raise vital awareness and foster hope for families impacted by Prader-Willi syndrome.

NEBRASKA

[LEARN MORE & DONATE]



CALIFORNIA

The Good, The Bad, The Bubbly; Disability Awareness Open Mic & Story Share

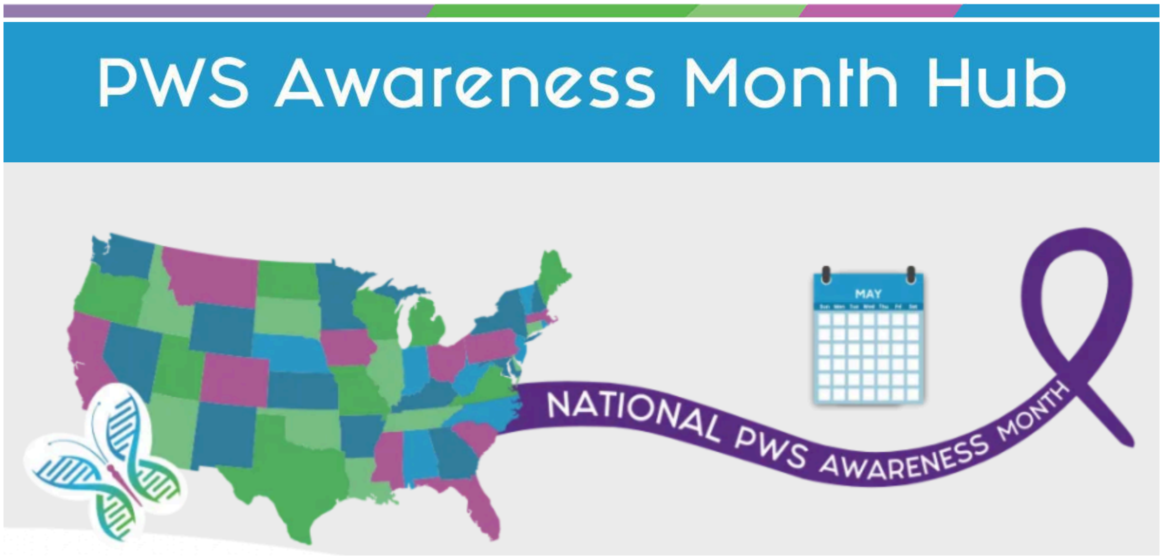
When: **Saturday, May 24, 2025, 2 PM Pacific**
Where: **Humboldt Unitarian Universalist Fellowship and Zoom**
Hosted by: Anne Fricke, mom to Freya

Gather together to share your stories and poems (or songs and comedy bits) about living with a disability or caring for someone who lives with a disability. The in-person event ends at 4pm. (Zoom will end around 3pm) We will host an open mic for folks who would like to share about their experience as an individual with a disability or the caregiver or parent of someone with a disability. We encourage community members to join us and hear our lived experiences.

Attending over Zoom?

For those who would like to attend from afar, we are offering a chance to watch over zoom. Unfortunately, we do not have the capabilities to allow shares over zoom at this time, but you can still enjoy the beautiful shares from this community. A donation of $15 will get you access to the zoom link before the event, along with my heart felt gratitude!

LEARN MORE & DONATE



As PWS Awareness Month approaches (May), we encourage you to check out our PWS Awareness Month Hub. You'll find links to share your story, buy PWS shwag, a PWS awareness month tool kit, and 15 ways to help spread awareness. We've made it easy for you to share awareness of PWS to your community and beyond.

VISIT THE PWS AWARENESS MONTH HUB HERE

Prader-Willi
SYNDROME ASSOCIATION | Ohio
SAVING AND TRANSFORMING LIVES

DONATE HERE

f 🐦 ◎ in YouTube