PWSA | USA Pulse Newsletter: February 7, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 116

February 7, 2025

www.pwsausa.org | 941-312-0400

2025 International PWS Conference: Resort Rooms are Filling Up Fast!

Our team just returned from an exciting visit to the Arizona Grand Resort & Spa in Phoenix, AZ—our 2025 International PWS Conference venue! During our annual staff retreat, we finalized key conference details, including session and program locations, signage, PWS and sibling camps, 50th birthday celebration activities, and more. The resort is truly incredible, and we can't wait for you to experience it firsthand in June. To help you get familiar with the space, we'll be sharing video previews of the resort and conference areas soon—stay tuned!

In addition to our conference work, we also had the opportunity to meet with and get to know members of the PWSA Arizona Chapter and several families in the area. We want to thank them for welcoming us with open arms and spending time with our staff.

The **2025 International PWS Conference** takes place June 24-28, 2025, and there's still plenty of time to register. However, a reminder that early bird pricing ends on **March 31, 2025**—don't miss out on these savings!

LEARN MORE & REGISTER

If you plan to stay at the Arizona Grand Resort & Spa, act fast! The hotel is **almost fully booked**, with about 20 rooms still available for Thursday, June 27. Once these rooms are gone, we won't be able to add more. If you'd like to stay on-site, we encourage you to book as soon as possible. You can make your reservation by clicking the button below.

For those seeking alternative accommodations, we now have a **hotel locator website** designed specifically for 2025 conference attendees. You can explore nearby lodging options by clicking **HERE**.

While you are welcome to stay at any of the hotels listed on the locator or find alternative lodging in the Phoenix area, please note that you'll be responsible for arranging transportation to and from the Arizona Grand Resort & Spa for all conference sessions.

We can't wait to see you in Phoenix! If you have any questions, feel free to reach out to us at info@pwsausa.org or call (941) 312-0400.

ARIZONA GRAND RESORT & SPA RESERVATIONS

"At my 3rd PWS conference, I met another mom who I now consider my PWS tribe. We connected in a way that only special needs parents can! We now plan our trips together so our families can spend time together at the conferences. We have added another family to our tribe and we have even had our separate girls weekends that I cherish so much!"

- Amy Lemmons, mom to Brock, 22, living with PWS

Thank You 2025 Conference Sponsors

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

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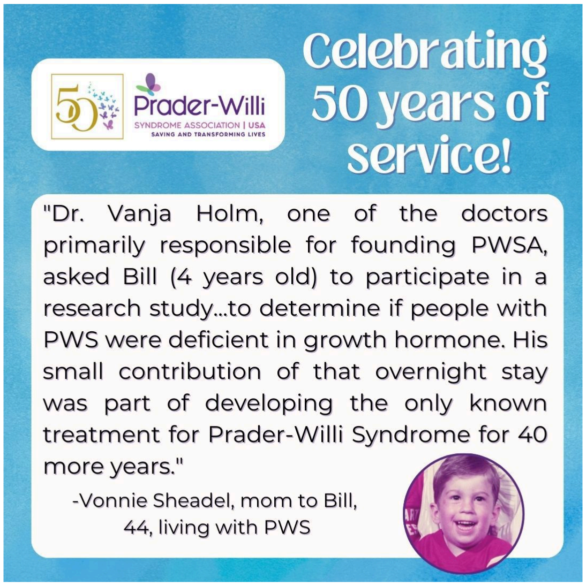
PWSA MEMORIES



Celebrating 50 years of service!

"Dr. Vanja Holm, one of the doctors primarily responsible for founding PWSA, asked Bill (4 years old) to participate in a research study...to determine if people with PWS were deficient in growth hormone. His small contribution of that overnight stay was part of developing the only known treatment for Prader-Willi Syndrome for 40 more years."

-Vonnie Sheadel, mom to Bill, 44, living with PWS

Do you have a **PWSA memory** to share? Whether it's from the beginning of the organization or just last year, we'd love to read it and share with the community! Please submit your PWSA memory at the button below.

SHARE YOUR MEMORY

PWSA | USA'S SPOTLIGHT ON HOPE

Cam was adopted from China as a baby and now lives a successful, full life with his American parents. From traveling abroad in the Mediterranean to playing sports with his peers and acting on the stage, Cam lives a fulfilling and exciting life. Sammi Hatfield, Cam's parent, wrote, "*Our children deserve to live life full, but we must fill them with things other than food! As a teacher of 28 years, I believe in being firm, fair, and consistent, and not putting lids on kids. All kids crave structure and routine! It's key to our kids' success! Praying for a cure, but until then, we strive to live full!*" You can read this Spotlight on Hope by clicking the button below.

READ HERE

We want to celebrate your loved one!

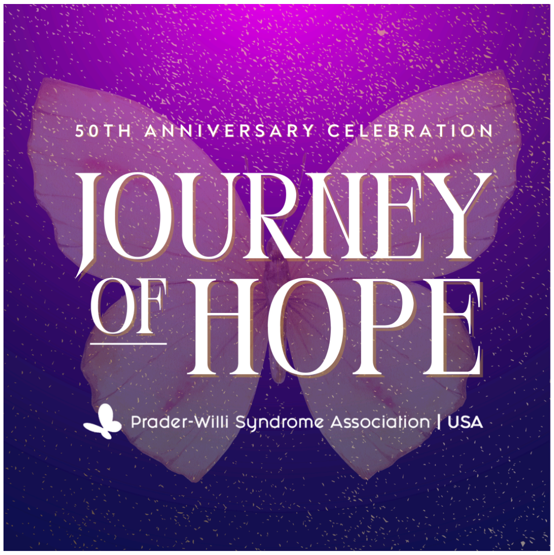
Our **Spotlight on Hope** series strives to share and celebrate the successes of our loved ones. No success is too small! Whether they took their first steps, had a great time at the school dance, made a shot in a basketball game, or are working toward a goal, we want to celebrate it all.

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!

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

PWSA | USA's 50th Anniversary Celebration: Journey of Hope Gala



When: Friday, September 26, 2025

Where: Ritz-Carlton, St. Louis, MO

Time: 6 PM - 10 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, Missouri. 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.

Stay tuned for registration and sponsorship opportunities coming soon!

Thank you to Diamonds and Denim!

We would like to say a huge thank you to the Avart family for hosting an incredible fundraiser, **Diamonds and Denim**, last weekend! Amy Avart, host of the fundraiser and mom to Esme, living with PWS, wrote "*Diamonds and Denim 2025 was a smashing success!!! We raised over $50,000 this year for PWSA!!! A huge THANK YOU to those who attended and made it just an enjoyable evening! THANK YOU to those who couldn't be there but were bidding and donating anyway! THANK YOU to Team Esme & spouses for putting your whole heart behind this cause! THANK YOU to Poe's on the Hill for an amazing venue and Chad Burton for bringing the fun! Our hearts are bursting with the amount of support and love that was on full display the weekend! There are no words!*"

You can still donate to this fundraiser in support of PWSA at the button below.

DONATE HERE

Thank you to the Diamonds and Denim sponsors, including the Diamond, Gold, Silver, and Bronze sponsors!

MIDWEST TECHNICAL INSTITUTE · SOLENO THERAPEUTICS · JOHN M. COLBERT, DMD www.JohnColbert.net FAMILY & COSMETIC DENTISTRY · MCNB · STONEBRIDGE Capital Advisors

Clint Hurdle's Hot Stove Dinner

Tickets are now on sale for the **11th Annual Clint Hurdle's Hot Stove Dinner**! This incredible event features dinner, live entertainment, raffle prizes, the always anticipated Coconut Golf Ball Drop, many exciting auction items available for in-person or virtual bidding (including a book autographed by Taylor Swift!), and the option to attend virtually if you can't make it to Florida. This fundraiser directly supports PWSA | USA. Join Clint and Karla Hurdle on March 22, 2025, at the Bradenton Country Club in Bradenton, FL, or attend virtually from anywhere in the world. To learn more, peruse the auction items, and purchase tickets, please click the button below.

CLICK HERE TO PURCHASE TICKETS!

Zahra's Night of Light

When: **Saturday, April 5, 2025 | 6 PM EST**
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 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

Rare Disease Day at Nationwide Children's Hospital

When: Saturday, March 1, 2025, 9 AM - 12 PM EST
Where: Nationwide Children's Hospital Education Center (575 South 18th St, Columbus, OH 43205)

The event is a fun, family friendly opportunity for families and patients with rare diseases to learn and network with one another. There will be an adult program/exhibition hall, and a separate youth program/activities for the kids.

Rare Disease Day

NATIONWIDE CHILDREN'S®
When your child needs a hospital, everything matters.

When: Saturday, March 1, 2025,
9 am - 12 pm
Where: Nationwide Children's Hospital
Education Center 575 South 18th St,
Columbus, OH 43205
Free, but registration required.

There will also be PWS-friendly breakfast and refreshments served during the event. Admission is free, but Nationwide Children's Hospital requests you register ahead of time.

Questions? Email RareDiseaseDay@NationwideChildrens.org or call Community Education at (614) 355-0662. Register using the button below.

REGISTER HERE

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

Terry Wilcox is the Co-Founder and Chief Mission Officer (CMO) of **Patients Rising**, the "leading grassroots patient advocacy organization seeking comprehensive policy solutions that puts the patient experience at the forefront of addressing America’s biggest healthcare access challenges." Terry sat down with our Director of Community Engagement, Dorothea Lantz, to talk about patient advocacy on state and federal levels, the importance of rare disease groups advocating together, and tips to keep in mind when advocating with representatives.

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

LISTEN ON PODBEAN

In an effort to reach more families and caregivers in the PWS community, we are growing and expanding our podcast to other platforms. PWS United is now on YouTube! We are not yet using recorded videos, but you can still listen to PWS United on YouTube and many other platforms. Use the button below to visit our channel.

PWS United on YouTube

ADVOCACY

Big Win for the PWS and Rare Disease Communities in Pennsylvania!

We are thrilled to announce that Kayla Day, a dedicated advocate and mother to 5-year-old Luella, who is living with Prader-Willi syndrome, has been appointed to **Pennsylvania's Rare Disease Advisory Council (RDAC)**! This is a historic moment—not only for the PWS community but for the entire rare disease community—as Kayla is the first PWS parent to serve on any **RDAC** in the country.

Kayla's appointment ensures the voices of PWS families are represented at the state level, influencing policies that directly impact individuals with rare diseases. Her lived experience and passionate advocacy will help shape discussions around healthcare access, support services, and legislative initiatives that benefit those affected by PWS and other rare conditions. If you are interested in learning about an RDAC in your state, visit your state's health department website. Please note that some states have RDACs listed under public health or rare disease initiatives. You can also email us at Advocacy@pwsausa.org for additional assistance.

Congratulations, Kayla! This is a huge step forward in our collective fight for awareness, resources, and better care for the rare disease community.

Victory for the PWS Community in Illinois!

We are thrilled to celebrate a major step forward for individuals living with PWS and the broader rare disease community in Illinois! On February 4, 2025, SB1651, filed by State Senator Julie Morrison, and HB2541, filed by State Representative Nicole La Ha, were introduced—marking a critical move toward better support and services for those affected by PWS. In addition to backing these bills, State Senator Neil Anderson, who represents Amy and Chris Avart, parents to Esme, living with PWS, successfully introduced and passed Senate Resolution 25, which formally recognizes Prader-Willi syndrome as a developmental disability in Illinois.

We are incredibly grateful to Senator Morrison, Representative La Ha, and Senator Anderson, and all of our dedicated advocates who continue to push for meaningful change. A few of them include: Conor Heybach (age 44, living with PWS), Sandy Noel (grandmother to Bronson, age 3, living with PWS), Nicole Tingley (administrator with DD Homes Network), and Amy and Chris Avart. Let’s keep up the momentum! If you are an Illinois resident, we encourage you to reach out to your legislators and urge them to support SB1651, HB2541. To find your state legislators, please click **HERE**.

READ MORE HERE

FAMILY SUPPORT

PWS in Adulthood Blog Series:
Steps Toward More Independent Living

Lindi Kessinger, Mom to Maddi, an adult living with Prader-Willi syndrome, shared her daughter's story into adulthood. They have tried a few different living arrangements for Maddi, adjusting the support where needed. Maddi is enrolled in the carbetocin trial. Carbetocin is Acadia Pharmaceutical's intra-nasal spray designed to treat hyperphagia. Lindi shares how they have been able to adjust Maddi's support with regards to the effectiveness of carbetocin. To learn more about the steps Maddi is taking toward a more independent life, please click the button below. There, you will also find a form to submit your own PWS in Adulthood blog, or invite your adult loved one with PWS to submit for themselves.

[READ HERE]

Ask Nurse Lynn

Question: Female, 40 years old, unknown subtype

My sister has digestive episodes (severe constipation and now vomiting, which she didn't do as child), which usually result in vasovagal episodes and her complaining of side and chest pain. There's nothing hospitals can do, but how should my parents better manage her diet?

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

READ NURSE LYNN'S RESPONSE

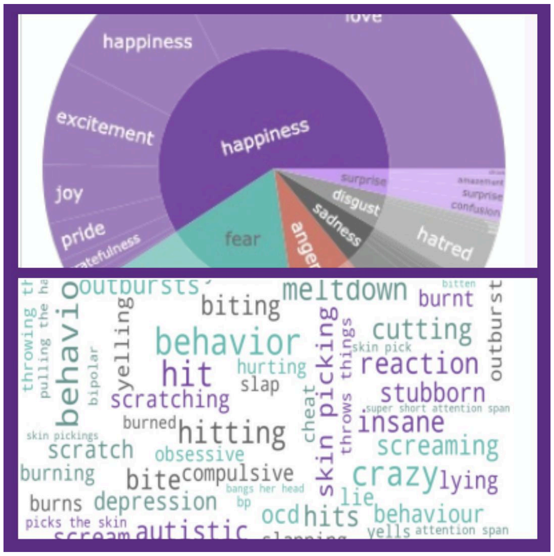
Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

ASK YOUR QUESTION HERE

RESEARCH

New TREND Report on PWS and Emotional and Behavioral Patterns



TREND Community released its latest report on PWS and Emotional and Behavioral Patterns. This report analyzed conversations parents and caregivers had on the topic of emotional and behavioral issues. In a testament to the dedication and connection of parents to their loved ones, the largest primary emotion category was “happiness," with “love” being the most commonly expressed emotion. Due to the nature of PWS, “worry” was the second largest primary emotion category, with “fear” as the largest subcategory. The report continues with an analysis of PWS-specific challenges like tantrums, meltdowns, and skin picking and covers topics related to behavior management like Behavior Therapy and Psychiatric Dosing and Pediatric Therapy Services. This report can help parents and caregivers understand the commonalities of individuals with PWS and management strategies, while providing researchers and professionals with a clearer understanding of where support and interventions are needed. Read the report at the button below.

TREND REPORT #3

Clinical Trial Perspectives on the PWS United Podcast

Justice and Kristi Rickenbach, along with Jennifer Andrews, sat down with Anne Fricke to share their experiences and perspectives on participating in Harmony Biosciences' pitolisant clinical trial. Pitolisant is being tested for its efficacy in treating excessive daytime sleepiness (EDS) in individuals with PWS. They discuss what brought them to this particular trial, details and logistics, the importance of participating in a clinical trial and research, and life before and after enrolling. PWSA | USA would like to clarify that this clinical trial is one of several available in the PWS community and future episodes will cover some of these. To learn more and find clinical trials that might be a fit for your family, please visit Clinical Trials - Prader-Willi Syndrome Association | USA.

Listen to this episode on Podbean by clicking the button below.

[LISTEN HERE]

Harmony Announces New Trial Site
Atlanta, GA

Harmony Biosciences has announced an additional clinical trial site for its TEMPO PWS study in Atlanta, GA, at Emory University. Contact Jean Luan McColl at jean.luan@emory.edu if you're interested in participating.

Harmony Biosciences' TEMPO study is a global Phase 3 trial investigating pitolisant as a potential treatment for excessive daytime sleepiness 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

Job Announcement: Administrative Assistant

JOIN THE TEAM!

Open Position:

ADMINISTRATIVE ASSISTANT

- Remote Work
- 20 hours per week
- Time-management and people skills
- Associates Degree OR 3 years comparable work experience
- Proficiency in Microsoft Office Suite

Send your resume to: sward@pwsausa.org

Full position description: www.pwsausa.org/pwsa-usa-employment

Are you highly organized, detail-oriented, and passionate about making a difference? PWSA | USA is seeking a dedicated Administrative Assistant to support our mission of empowering individuals and families affected by Prader-Willi syndrome. This dynamic role involves providing executive support to our CEO, assisting with key departmental functions like donor acknowledgments and chapter engagement, and managing essential administrative tasks to keep our operations running smoothly. Ideal candidates will have strong communication skills, a knack for technology, and experience in a nonprofit or remote work environment. If you're ready to contribute to meaningful work in a collaborative and impactful organization, apply today to join the PWSA | USA team! To find the full position description, click the button below.

To apply, please email your resume to sward@pwsausa.org.

LEARN MORE HERE

PWSA | USA Resource Spotlight
Behavior Management Resource Page

Behavior management is a key element to many of our loved ones with PWS living a successful life. While behavior challenges may be a common characteristic of PWS, PWSA | USA offers a lot of information and skill-building tools for navigating these issues. On our behavior management resource hub, you'll find PDFs on the topics of food security, behavior management guidelines, understanding how the individual with PWS thinks, creating positive behavioral

plans, strengthening boundaries and more. We encourage you to browse our behavior management resources at the button below. If you can't find what you're looking for and need more assistance with your loved one with PWS, please send us an email at info@pwsausa.org.

BEHAVIOR MANAGEMENT RESOURCES

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

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

PWSA | USA Pulse Newsletter: February 21, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

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An Important Message on Behalf of PWSA | USA

With any new administration there are changes to policy and agency staff at all levels. As things unfold with the new administration, rest assured that PWSA | USA will continue to be an organization that supports and advocates for our community. Our staff, volunteers, and advocates are working together to understand how potential changes on the federal level may impact the PWS community. We will share information and advocacy opportunities as we learn of them and will continue to be a strong voice for the PWS community. We will help you to navigate these changes and share your voice and we will continue to partner with other advocacy groups in the rare disease space. PWSA | USA supports all families in the PWS community and will continue to do so.

Friday, February 28, 2025, is **Rare Disease Day!** We encourage the PWS community to spread awareness far and wide on and leading up to this important day. To help you get started, we have created a "Rare Disease Day Hub" on PWSA | USA's website.

Click the button below to find several ways you can participate in Rare Disease Day. Here are a few highlights:

- Download our **awareness toolkit** with exclusive PWS-specific social media graphics, advocacy tips, and creative ways to get involved.
- Learn **why Rare Disease Day matters** and how Prader-Willi syndrome compares to other rare conditions.
- Find out why **zebras are the official symbol** of the rare disease community - and how you can show your stripes!
- **Support PWSA | USA** to ensure families impacted by PWS have a strong, united voice for the next 50 years.
- Host a Rare Disease Day fundraiser on our **PWS Hope United** website.

We look forward to celebrating Rare Disease Day even more on our social media pages and in our special edition pulse at the end of this month. Be on the lookout for exciting updates from Capitol Hill as our staff and volunteer advocates participate in **EveryLife Foundation's Rare Disease Week**.

RARE DISEASE DAY HUB

From February 24–26, hundreds of advocates from across the country will gather in Washington, D.C. Join us virtually to learn about the policy priorities affecting the rare disease community during the Legislative Conference and Rare Disease Congressional Caucus Briefing, and watch four featured documentaries that showcase powerful rare disease stories.

WATCH HERE

PWSA | USA'S SPOTLIGHT ON HOPE

Jenna, a teenager from New Mexico living with PWS, earned a prestigious Girl Scout award and a spot on her local news network. The Girl Scout's Gold Award is the highest achievement in Girl Scouts and recognizes members who have found solutions to issues in their neighborhood and beyond. Jenna earned her award for a video tutorial she made demonstrating how she makes rubber band bracelets. She made this tutorial for other individuals living with PWS to learn how. According to Jenna, *"It's a fidget and it gives people hand strength and gives them peace and comfort and it kind of helps them to focus."* You can watch this news article by clicking the button below. **Congratulations, Jenna!**

WATCH HERE

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!

SHARE YOUR SPOTLIGHT ON HOPE

PWSA MEMORIES

Not so long ago, when we talked about Prader-Willi syndrome, the response was often, "Prader-what?" But thanks to years of dedication from families, advocates, and PWSA | USA supporters, awareness has grown—sometimes in big, visible ways. In 2008, 3-year-old Zak Bassel, who has PWS, rang the New York Stock Exchange bell on May 30th during PWS Awareness Month, marking a proud moment for our community. Each awareness effort made by the PWS community has helped shift the conversation, bringing us closer to a future where PWS is widely understood. And the momentum continues! Scroll down to see how the PWS community was represented once again on February 13, 2025, at the NASDAQ closing bell for Aardvark Therapeutics!

SHARE YOUR MEMORY

EVENTS & FUNDRAISERS

2025 International PWS Conference:
Share a Photo of Your Loved One Living with PWS for our Special Conference Mural!

Countdown to Conference

122

DAYS TO GO!

We're creating a one-of-a-kind PWS Community Mural for the 2025 International PWS Conference, and we need your photos to bring it to life!

This mural will be the ultimate photo op spot and a powerful tribute to the incredible individuals living with PWS. Whether you're attending the conference or not, you can still be part of this special piece by submitting your favorite photos of your loved one with PWS. There's no limit—share as many as you'd like!

YOUR LOVED ONE LIVING WITH PWS IS ***BEAUTIFUL***!

United in HOPE
2025 PWS CONFERENCE

Help us celebrate them by submitting photos for our **2025 PWS Conference Mural**

June 24-28, 2025 | Arizona Grand Resort & Spa, Phoenix, AZ

Submit your photos today through our official form, which can be found at the button below. Let's make this mural a beautiful reflection of the PWS community's strength, love, and unity. Thank you for being part of this unforgettable project!

[SUBMIT PHOTOS]

The **2025 International PWS Conference** takes place June 24-28, 2025, and there's still plenty of time to register. However, a reminder that early bird pricing ends on **March 31, 2025**—don't miss out on these savings!

[LEARN MORE & REGISTER]

CONFERENCE RESORT UPDATE: Rooms on **Thursday, June 27, 2025**, are now **completely sold out**. If you don't have a room on that date and need one, we now have a **hotel locator website** designed specifically for 2025 conference attendees. For those needing accommodations Tuesday, Wednesday, Friday, and Saturday, there are still rooms at the Arizona Grand Resort & Spa available, but they are filling up very fast. If you'd like to stay on-site, we encourage you to book as soon as possible. You can make your reservation by clicking the button below.

While you are welcome to stay at any of the hotels listed on the locator or find alternative lodging in the Phoenix area, please note that you'll be responsible for arranging transportation to and from the Arizona Grand Resort & Spa for all conference sessions.

We can't wait to see you in Phoenix! If you have any questions, feel free to reach out to us at info@pwsausa.org or call (941) 312-0400.

[ARIZONA GRAND RESORT & SPA RESERVATIONS]

"Cierra is a 30-year-old happy, fun, energetic person. She has a great sense of humor and loves animals and children. Cierra loves any new opportunity to meet new people. She will be attending her first PWS

conference this year in Phoenix, Arizona. She already has her swimsuit packed and is ready for the water park!"

- Mary Lesser, mom to Cierra (30) living with PWS

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

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PLATINUM SPONSORS

SOLENO THERAPEUTICS

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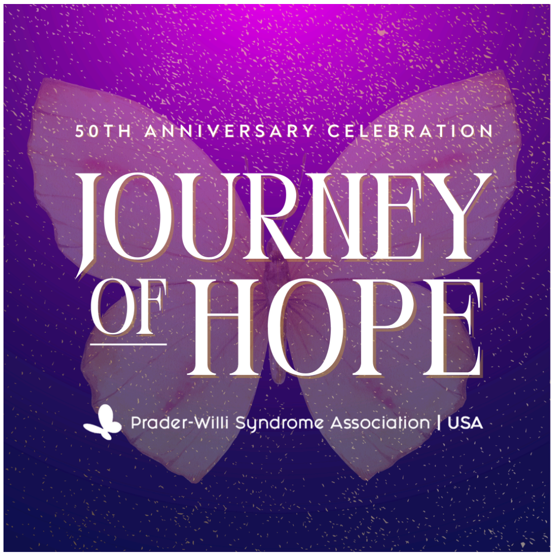
Tickets and Sponsorships are *NOW AVAILABLE* for PWSA | USA's 50th Anniversary Journey of Hope Gala



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, Missouri. 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 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+

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

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.

REGISTER HERE

The 11th Annual Clint Hurdle Hot Stove Dinner is Nearly One Month 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

Make an Impact This Rare Disease Day by Creating a PWS Hope United Online Fundraiser

Rare Disease Day is a powerful opportunity to raise awareness and support for the PWS community, and you can be a part of it! Hosting a Rare Disease Day fundraiser on our **PWS Hope United** website is quick, easy, and incredibly meaningful. Whether big or small, your efforts help fund critical programs and services for individuals and families affected by Prader-Willi syndrome.

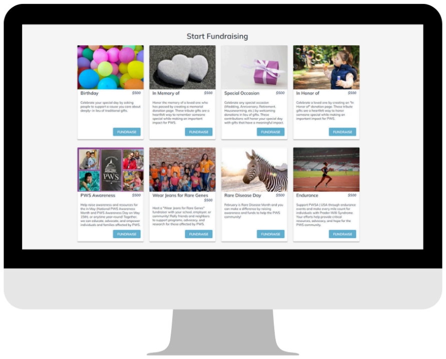
Getting started is simple:

- Visit our Hope United website at the button below and find the Rare Disease Day fundraiser option.
- Click “Fundraise” in the Rare Disease Day box and follow the easy steps to set up your page.

- Share your fundraiser with friends, family, and your network to rally support for PWSA | USA!

Every dollar raised fuels hope, support, and advocacy for the PWS community. Let’s come together and make a difference this Rare Disease Day!

Have questions? We’re here to help! Email us at hopeunited@pwsausa.org.


Start Fundraising

Birthday $500
Celebrate your special day by asking people to support a cause you care about deeply- in lieu of traditional gifts.
FUNDRAISE

In Memory of $500
Honor the memory of a loved one who has passed by creating a memorial donation page. These tribute gifts are a heartfelt way to remember someone special while making an important impact for PWS.
FUNDRAISE

Special Occasion $500
Celebrate any special occasion (Wedding, Anniversary, Retirement, Housewarming, etc.) by welcoming donations in lieu of gifts. These contributions will honor your special day with gifts that have a meaningful impact.
FUNDRAISE

In Honor of $500
Celebrate a loved one by creating an "In Honor of" donation page. These tribute gifts are a heartfelt way to honor someone special while making an important impact for PWS.
FUNDRAISE

PWS Awareness $500
Help raise awareness and resources for the in May (National PWS Awareness Month and PWS Awareness Day on May 15th), or anytime year-round! Together, we can educate, advocate, and empower individuals and families affected by PWS.
FUNDRAISE

Wear Jeans for Rare Genes $500
Host a "Wear Jeans for Rare Genes" fundraiser with your school, employer, or community! Rally friends and neighbors to support programs, advocacy, and research for those affected by PWS.
FUNDRAISE

Rare Disease Day $500
February is Rare Disease Month and you can make a difference by raising awareness and funds to help the PWS community!
FUNDRAISE

Endurance $500
Support PWSA | USA through endurance events and make every mile count for individuals with Prader-Willi Syndrome. Your efforts help provide critical resources, advocacy, and hope for the PWS community.
FUNDRAISE

PWS hope united
BUILDING **BRIGHT** FUTURES FOR PWS FAMILIES

[PWS HOPE UNITED WEBSITE]

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

Introducing ***Pioneers in PWS***, a new podcast series from PWS United in honor of PWSA | USA's 50th Anniversary!

Before there were conferences, support groups, or even a central source of information on Prader-Willi syndrome, there were pioneers. Parents, professionals, and advocates who built the foundation of the PWS community—

one connection, one breakthrough, one act of determination at a time. In honor of PWSA | USA's 50th anniversary, we're diving into their stories. *Pioneers in PWS* was originally a PWSA | USA blog series produced in 2021 by our dedicated volunteers. Throughout 2025, we'll look back on these articles to explore where we've been, how far we've come, and recognize the pioneers who made it possible.

With National Caregivers Day falling on February 21st**,** we're kicking off the series with a look back at the formation and impact of the **Professional Providers Advisory Board**. Since 2008, this group has been instrumental in shaping best practices for residential care providers supporting individuals with Prader-Willi syndrome. Join us as we revisit the history and evolution of this essential advisory board with two special guests: Jeff Covington, a founding member of the board and former co-chair (2012-2014), and Stacy Ward, CEO of PWSA | USA. Together, they'll share their insights on the challenges, milestones, and lasting impact of the board's work in improving residential care and training for professional providers worldwide.

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

LISTEN ON PODBEAN

ADVOCACY

Call to Action: Save Our Clinical Trials Letter Campaign!

PWSA | USA and FPWR have collaborated to make it easy to contact your representative about a very important issue affecting the PWS community, cuts to the NIH (National Institutes of Health). Follow the link to a pre-written letter to share with your representative. Simply type in your name, street address, zip code, phone, email, and hit send. We encourage those who are concerned to please contact their representatives and tell them:

"Please Protect Medical Research and take action to ensure that NIH funding remains intact, and that medical research remains a national priority. I ask that

you oppose any further cuts to NIH funding and restore recent reductions, support legislation that ensures stable and sufficient funding for rare disease research and advocate for transparency and accountability in the decision-making processes affecting clinical trials."

Learn more about this issue and send your letter by clicking the button below.

CALL TO ACTION

Rare Disease Legislative Advocate's State Advocacy Day in Richmond Virginia

Last week, Charles Conway and 25 other advocates from all over the State of Virginia met with over 40 members of the Virginia General Assembly to advocate on a variety of rare disease issues, including newborn screening, prior authorization, and medical debt collection practices. Their willingness and vulnerability to share their experiences, issues and concern were very impactful in helping to inform the legislators and obtain their support. As a results, all three bills passed the Virginia House of Delegates, and the fight continues in the Senate!

May this and other advocacy efforts continue throughout the United States so the rare disease, especially PWS, community can be intentionally considered in future state policy and appropriations to ensure this not so rare population is served well.

Thank you to all of the PWS advocates who continue to show up in support of our community!

PWS Awareness Heads to Wall Street and Times Square

Ringing the Nasdaq closing bell on Wall Street is an incredible opportunity to highlight a company's achievement and bring awareness to important topics like PWS. On February 13th, PWSA | USA's CEO Stacy Ward, Director of Community Engagement Dorothea Lantz, and FPWR's Executive Director Susan Hedstrom, joined Aardvark Therapeutics in this iconic ceremony. This honor was in recognition of Aardvark's IPO (initial public offering), a term used when a private company first sells shares of its stock to the public on the stock exchange.

According to an article from Fierce Biotech (Aardvark secures $94M IPO to fund appetite-suppressant trials), "the IPO should bring in gross proceeds of $94.2 million." The article also states Aardvark's intention as "to use the proceeds to advance the clinical development of ARD-101". ARD-101 is a trial drug targeting hyperphagia in individuals with PWS.

Along with the opportunity to attend the bell ringing ceremony, Stacy and Dorothea were featured on the NASDAQ Times Square Billboard! See the video of these exciting events using the button below.

WATCH HERE

FAMILY SUPPORT

Celebrating National Caregivers Day 2025!

This Feb 21, 2025, is National Caregivers Day and we'd like to take a moment to honor the caregivers in our loved one's lives. Caregivers are a critical piece to helping our loved ones with PWS live successful lives. Whether those caregivers come into our home or meet our loved ones in the community, their attention to their safety, dedication to their needs and development, and pursuit of our loved one's happiness is a balm to the challenges of this disorder. For every caregiver who comes into our lives, whether for a brief period or for decades, we are truly grateful for all of them!

To read suggestions on how to thank the caregivers in your life, self-care for you as a caregiver, and a list of the possible types of caregivers your loved one may encounter, click the button below.

READ HERE

Ask Nurse Lynn

Question: Female, 58 years old, unknown subtype

My daughter will be 58 on Jan. 14, 2025. I am interested in any information on older PWS persons. She lives in Canada. We have no APWSA anymore. She seems to be having issues with memory, confabulation, and possibly early dementia. Is this normal?

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

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

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 3 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 6 surveys today, then again in 6 months and 12 months for a total of 3 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.

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!

[LEARN MORE HERE]

Survey to Learn More About Twins and PWS

PWSA | USA is collaborating with PWSA UK to explore the genetic and environmental factors influencing Prader-Willi Syndrome (PWS) by examining twins, both fraternal and identical. By comparing identical twins, who share the same genetic makeup, with fraternal twins, who share 50% of their genes, the study could help differentiate between innate genetic factors and environmental influences on behavioral traits, health conditions, and neurodevelopment in PWS. This research could provide valuable insights into whether key characteristics of the syndrome, such as food-seeking behavior, cognitive impairments, and obesity, are primarily driven by genetics or shaped by environmental factors. We are asking parents of twins, of whom at least one has PWS, to fill out the survey at the button below.

SURVEY LINK

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

Raise Your Voice Advocacy Toolkit

The Raise Your Voice Advocacy Toolkit was created by Patients Rising Now with contributions from PWSA | USA's Director of Community Engagement, Dorothea Lants. It provides tools and tips on how to be an effective advocate. This toolkit covers meeting with and hosting an elected official, writing and calling elected officials, writing an effective Op-Ed, participating in a drug utilization review board meeting, speaking at a Town Hall, and testifying at a committee hearing. There are many ways to advocate for your loved one and the PWS community. Read through this toolkit to learn effective ways to do just that. If you have questions or are ready to dive into advocacy, please email advocacy@pwsausa.org.

ADVOCACY TOOLKIT

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

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1032 E Brandon Blvd #4744 Brandon, FL 33511

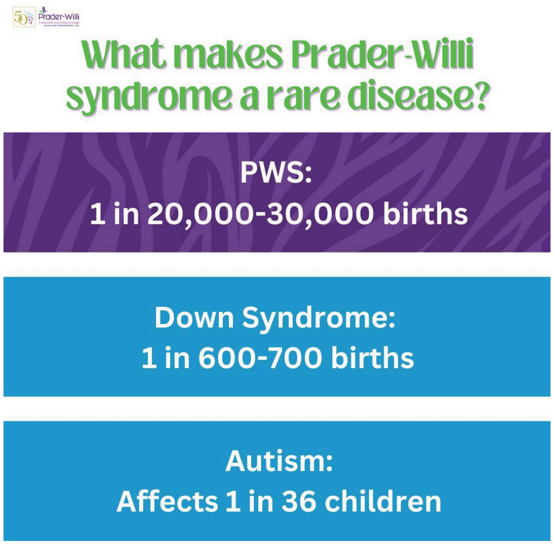
PWSA | USA February 2025 Special Edition Pulse Newsletter

www.pwsausa.org | 941.312.0400

Donate

Rare Disease Day is an incredible opportunity to spread awareness and advocate for Prader-Willi syndrome (PWS). There are 7,000+ rare diseases that collectively affect more than 30 million Americans. This day provides a platform to highlight the need for more research, better health care access, and improved policies that support rare disease communities. First launched in 2008 by EURORDIS (European Organisation for Rare Diseases) and partner organizations, the goal of Rare Disease Day is to create a common day of recognition for the millions of people living with rare diseases and to raise awareness about the challenges they face.

What Makes PWS a Rare Disease?



What makes Prader-Willi syndrome a rare disease?

PWS:
1 in 20,000-30,000 births

Down Syndrome:
1 in 600-700 births

Autism:
Affects 1 in 36 children

While it may not seem like PWS is technically a rare disease because we have such a large, active, and supportive community, PWS does meet the qualifications. A rare disease is defined in the U.S. as a condition affecting fewer than 200,000 people at any given time. PWS affects an estimated 12,000–20,000 people in the U.S. each year. Of the 7,000+ known rare diseases, more than **90%** do not have an FDA-approved treatment or cure. That means millions of people, including those with Prader-Willi syndrome, rely on supportive care, symptom management, and advocacy efforts to improve their quality of life. To learn more facts about rare diseases, visit our Rare Disease webpage at the button below.

RARE DISEASE DAY HUB

Rare disease organizations have expanded this one day of action to multiple days in Washington, D.C., where delegates from a variety of organizations meet to learn more about policies and issues affecting the rare disease community and for an opportunity to gather and meet collectively with their congressional representatives.
Thirty-five PWS advocates, including ten individuals living with PWS, were on the hill alongside Everylife Foundation, Patients Rising, and many other rare disease communities. Our advocates came from all around country to speak up for the PWS community. After presentations hosted by Everylife on Tuesday, our advocates met with their representatives on Wednesday. Every group came prepared with the same "asks" for their legislators.

The "Asks"

1. Ensuring Steady and Robust Federal Biomedical Research Funding and Public Health Agency Support
2. Reauthorize the Rare Pediatric Disease Priority Review Voucher (PRV) Program at FDA
3. Include Accelerating Kids' Access to Care Act (AKACA) in the first available legislative package
4. Ask Your Members of Congress to Join the Rare Disease Congressional Caucus

The advocacy work is already seeing results! On Wednesday afternoon, Senators Grassley and Bennet re-introduced the Accelerating Kids' Access to Care Act! The bill number is S.752.

Thank you to all of our advocates who made the trip to D.C.! We are grateful for your time, energy, and dedication to advocating for the PWS community. If you did not have the opportunity to attend the events in D.C. but would like to add your voice for the PWS and rare disease community, click on the button below to learn more about the Rare Disease Week legislative "asks" and easily send an email or phone call to your representatives.

CALL TO ACTION!

PWS Self-Advocates

Rare Disease Meetings on Capitol Hill


Don Bacon


Amy Klobuchar

Reflections from Rare Disease Advocates

We asked our rare disease advocates to share their thoughts on their experience. Below are a few insights they shared. Click the button below to read the full article with more reflections from this event.

What kind of impact do you feel you made, or what do you think was the biggest thing you did to make an impact?

"I believe the best part and most significant experience was being there to share my story and listening to others telling their stories." - James Towle (38, living with PWS), Massachusetts

"Through these meetings, we also built valuable new connections with representatives who were not fully informed about several of our advocacy priorities in Nebraska." - Sarah Kasaby, mom to Khaled (5, living with PWS), PWSA | USA Information and Referral Specialist, Nebraska

"I found the majority of our elected officials, regardless of the side of the aisle they are on, were very supportive and do not want to see cuts in funding to research." - Stacy Ward, PWSA | USA CEO, New York

"Walking the halls of Capitol Hill again with my 7-year-old son, Hunter, was more than just advocacy—it was history in the making for PWS. His voice, our story, and the power of the rare disease community came together to inspire real change. This week, we didn't just share our journey—we took a stand for a better future." - Dorothea Lantz, mom to Hunter (7, living with PWS), PWSA | USA Director of Community Engagement, Florida
"We have to keep showing up...The more people know, the harder they will fight for us." – Sheri Mills, mom to Lyra (6, living with PWS), West Virginia

"I feel like our collective voice was heard and well received. More and more people have heard of PWS and support rare disease legislation." - Lynn Garrick, mom to John (19, living with PWS), PWSA | USA Medical/Research Coordinator. Minnesota

"They asked for personal stories - stories they can use to fight against changes that may impact our loved ones. I was very encouraged." – Elaine Towle, mom to James (38, living with PWS), PWSA | USA Advocacy Specialist, Massachusetts

READ HERE

Thank you to our volunteer advocates for sharing your voice this week and representing the PWS community!

Rare Disease Day Fun Fact

Why is the Zebra the Symbol for Rare Disease Day?

The zebra is the official symbol for Rare Disease Day and the rare disease community because of the medical adage:

"When you hear hoofbeats, think horses, not zebras."

Doctors are often taught to assume common diagnoses first (horses) rather than rare conditions (zebras). However, for those living with rare diseases like Prader-Willi syndrome, this mindset can lead to delayed diagnoses, misdiagnoses, and overlooked medical needs. This Rare Disease Day, wear your zebra print and help raise awareness for the 1 in 10 Americans living with a rare disease!

PWSA | USA's Commitment to Advocacy

With any new administration there are changes to policy and agency staff at all levels. As things unfold with the new administration, rest assured that PWSA | USA will continue to be an organization that supports and advocates for our community. Our staff, volunteers, and advocates are working together to understand how potential changes on the federal level may impact the PWS community. We will share information and advocacy opportunities as we learn of them and will continue to be a strong voice for the PWS community. We will help you to navigate these changes and share your voice and we will continue to partner with other advocacy groups in the rare disease space. PWSA | USA supports all families in the PWS community and will continue to do so.

Prader-Willi
SYNDROME ASSOCIATION | Ohio
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