PWSA | USA Pulse Newsletter: January 2, 2026

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 138
January 2, 2026

www.pwsausa.org | 941-312-0400

Parents and Caregivers: Begin the New Year by Participating in Important PWS Research, Paid Opportunity

As we start the New Year, PWSA | USA, in partnership with our research partner MedPanel, is inviting parents and caregivers of individuals living with Prader-Willi syndrome to participate in a paid research opportunity. This study seeks to better understand real-life experiences and challenges, helping inform future treatments and support resources for the PWS community.

Important Note: If you have already taken the eligibility screener or completed the survey, thank you for your participation. Please do not take it again, as each person may complete the survey only once and receive one $50 thank-you check.

What Participation Involves:

- A brief online eligibility screener
- A 15-minute online survey for those who qualify
- A $50 check as a thank-you for completing the survey

Privacy & Confidentiality:

Participation is voluntary and double-blinded. Personal information is kept confidential and is not shared with the study sponsor. MedPanel collects contact information only to issue the honorarium.

If you have not yet participated, this is an **easy way to make an impact from the comfort of your home**. Click below to take the eligibility screener. Eligible participants will be automatically directed to the full survey. If you start the survey but need to step away before finishing, please do not return to the original screener link. Instead, MedPanel will send you a new, unique link by email so you can continue where you left off. If you don’t see that email, be sure to check your spam or junk folder. The message will come from elawson@us.imshealth.com.

Thank you for starting the year by supporting progress for the PWS community!

TAKE THE ELIGIBILITY SCREENER

SPOTLIGHT ON PWS

We're rebranding our Spotlight on Hope for a more inclusive approach to sharing the stories of PWS! Spotlight on PWS is a place to share the everyday moments of PWS, whether an exciting success or a challenging moment. We want to get to know more about individuals with PWS, celebrate with them, share in the frustrations, and provide support when and where we can. Perhaps your challenging situation can help others learn how to meet similar challenges with more preparation. Perhaps your loved one’s success will inspire others to see their goals through. There is no PWS story too big or too small to share here.

Please submit your loved one's PWS story using the button below.

SHARE YOUR SPOTLIGHT

EVENTS & FUNDRAISERS

Announcing PWSA | USA's 2026 Events - Save the Dates!

May 4-6, 2026

Washington, D.C.
Yours Truly DC Hotel

ADVOCACY
IN
ACTION
D.C. FLY-IN 2026

D.C. Fly-In registration will open Monday, January 5, 2026.

PWSA | USA'S 2026
RESIDENTIAL PROVIDERS
Conference

August 21-22, 2026

Savannah, GA
Kimpton Brice Hotel

Residential Providers Conference registration will open Monday, February 2, 2026.

October 16-17, 2026

Park City, UT
Grand Hyatt Deer Valley

PWSA | USA 2026 MOMS' RETREAT
MOMENT
AN UPLIFTING PAUSE
October 16-17, 2026 Park City, Utah

Moms' Retreat registration will open Saturday, February 14, 2026.

United in Hope
FOR PWS
PWSA | USA 2027
NATIONAL CONVENTION

July 14-17, 2027

Orlando, Florida
Caribe Royale Orlando

2027 United in Hope Conference registration will open Wednesday, July 1, 2026.

Thank You for Giving the Gift of Hope

Because of you, the 2025 Angel Drive was a huge success, and more importantly, families impacted by Prader-Willi syndrome are stepping into 2026 with hope, support, and a community they can count on.

Every gift, no matter the size, strengthens our ability to remain a trusted lifeline, fueling programs, advocacy, and connections for families from diagnosis through adulthood.

From all of us at PWSA | USA, thank you for believing in this community, investing in hope, and helping ensure no one ever faces PWS alone.

We couldn't do this without you.

"When we got the diagnosis, thankfully our doctor and another friend that I connected with told us about PWSA | USA. Kristi activated the whole Prader-Willi parent network. What I really needed to hear as soon as possible was to know that Kenzie would be okay. So, just to hear from person after person, whose kids were all in their teens and 20s, that their kids were all doing so well gave me so much more peace and reassurance that, yes, we're going to have some challenges we didn't expect, but we can do this. And if we can't do this, we know who to call to help us do this."

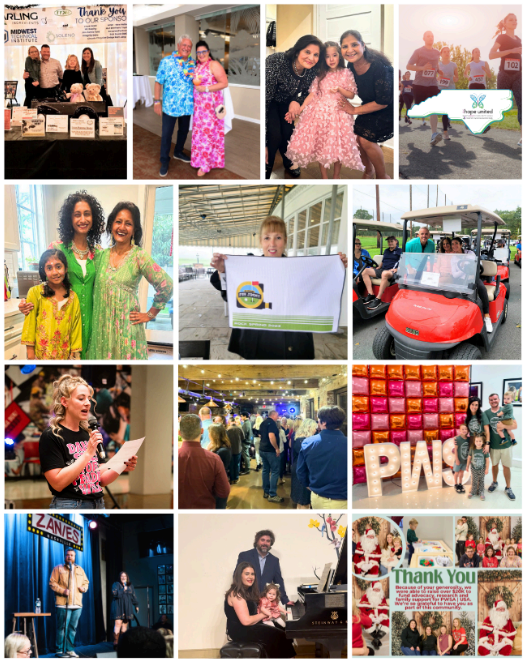
- Annie Kuo, mom to Kenzie (3) living with PWS

Watch our last 2025 Hope in Action video and check out our full YouTube playlist at the buttons below.

WATCH ANNIE'S STORY

HOPE IN ACTION PLAYLIST

Thank You! PWS Hope United Events Raised Record Funds in 2025



As we wrap up an incredible year, we're feeling so grateful for everyone who hosted and supported the 2025 PWS Hope United peer-to-peer fundraising events.

Across the country, families, friends, and volunteers came together to put on meaningful events, including the successful launch of *United We Brunch* during PWS Awareness Month. From first-time fundraisers to those hosting an event for the 2nd, 5th, and even 16th year, these community-led efforts were nothing short of inspiring.

Together, PWS Hope United fundraising events raised nearly **$700,000** in 2025, helping fuel PWSA | USA's critical programs and services. Thank you to everyone who gave their time, energy, and heart - your impact reaches families every single day.

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

2025 was a year of growth, innovation, and strengthened commitment. We expanded family support, enhanced clinical and crisis services, grew our advocacy and education efforts, and continued advancing critical research.

This episode is a message from PWSA | USA CEO Stacy Ward about the incredible work done by PWSA | USA staff, volunteers, and supporters throughout this past year, along with our deep and heartfelt gratitude.

Listen to PWS United on your favorite podcast app or by clicking the button below.

LISTEN ON PODBEAN

In 2026, PWS United will be searching the PWS community for musicians to create new podcast theme music. Tune those guitars, dust off those piano keys, tighten those drum skins, and stay tuned (pun intended) for details to the 2026 PWS United podcast music contest.

ADVOCACY

EveryLife Foundation's Rare Disease Week

Mark your calendars! The EveryLife Foundation’s Rare Disease Week on Capitol Hill returns **February 24–26, 2026**, in Washington, D.C., and we're encouraging our PWS community to be part of it.

Rare Disease Week brings together patients, families, advocates, and organizations from across the country to raise awareness, share lived experiences, and meet directly with lawmakers to advance policies that impact the rare disease community. It’s a powerful opportunity to ensure the voices of individuals and families affected by a rare disease, including Prader-Willi syndrome, are heard on Capitol Hill.

Registration opens Wednesday, January 7, 2026, and can be accessed using the button below.

RARE DISEASE WEEK 2026

Want a glimpse of what to expect? Click on the image to watch PWSA | USA advocates in action at Rare Disease Week 2024 and see how our community shows up, speaks out, and drives change together.

FAMILY SUPPORT

Sibling Spotlight: Ella Frazier's Heart for Service

We're starting off 2026 with a beautiful Sibling Spotlight, submitted by PWSA | USA's Event Coordinator, Angela Frazier. If you've ever received a New Diagnosis Care Package from PWSA | USA, there's a good chance it was carefully prepared by Ella Frazier. Ella is the sister of Joseph (JoJo), who lives with Prader-Willi syndrome, and from the very beginning, she has played an important role in his journey. Her care and compassion shine through in every box she helps assemble.
Thank you, Ella, for your time, your compassion, and your support of families in our community.

Read this blog using the button below.

READ HERE

Rare Aware Art Share Back for 2026:
PWS Advocacy and Awareness

The Rare Aware Art Share is back for 2026! The Rare Aware Art Share is an opportunity for individuals living with Prader-Willi syndrome to use art as a powerful form of expression, advocacy, and awareness. Through this annual virtual art experience, artists share their perspectives and lived experiences – helping others better understand life with PWS and amplifying voices that deserve to be seen and heard.

The **2026 theme is Advocacy and Awareness**, inviting artists living with PWS to explore what it means to speak up, tell their story, and help create understanding through creativity.

Artwork submissions will be accepted January 15–March 15, 2026. Submissions are accepted in **digital format only**.

Artwork will be showcased throughout May (PWS Awareness Month) across PWSA | USA platforms, and at our 2026 D.C. Fly-In event, helping extend each artist’s voice beyond the PWS community and into broader conversations around inclusion, education, and advocacy. Learn more and submit using the button below.

LEARN MORE HERE

Ask Nurse Lynn

Female, 30 years old, UPD subtype

Should a person with PWS use the same BMI ranges as someone without PWS? We are trying to figure out a good goal weight range for my loved one. Currently, her BMI is around 20 – which her PCP says is normal. Is this a good measurement to use in determining the healthiest weight for her, or should her BMI be lower than “typical” ranges due to hypotonia?

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

PWSA | USA's 2025 Research Year in Review

2025 was a landmark year for PWS research and care. From the FDA approval of the first medication to treat hyperphagia in individuals with PWS to global collaboration at the International *United in Hope* Conference, momentum across PWSA | USA's Medical and Research efforts continued to grow. Learn how experts, advocates, and families worked together to advance care, expand research, and strengthen support for the PWS community - and what's ahead in 2026.

Read the full 2025 research wrap-up at the button below.

READ MORE

PWSA | USA ANNOUNCEMENTS

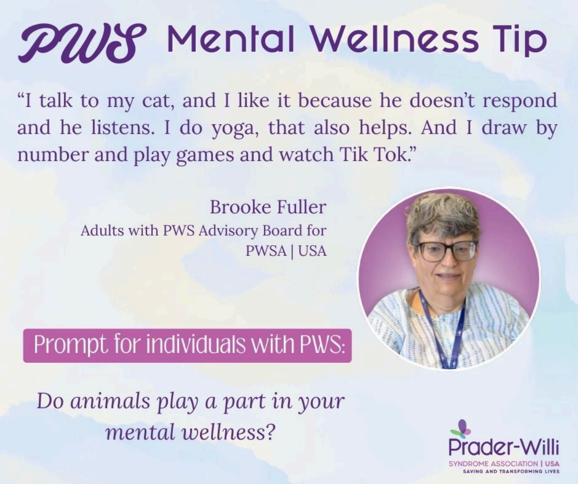
PWSA | USA Resource Spotlight

January is Mental Wellness Month. While we know that mental wellness matters every month, this is a great opportunity to discuss and recognize the many ways we can support our mental health.

"The American Psychology Association recognizes that exercise can decrease the effects of stress on the body, improve a person's mental health and mood, and even enhance the brain's ability for memory and cognition. The right kind of stress, like exercise, may help make the body more resilient by allowing it to practice coping with stress and building stronger and necessary communication pathways between the body's physiological systems."

To learn more about how physical activity benefits your mental wellness, use the button below to read our blog.

READ HERE



PWS Mental Wellness Tip

"I talk to my cat, and I like it because he doesn't respond and he listens. I do yoga, that also helps. And I draw by number and play games and watch Tik Tok."

Brooke Fuller
Adults with PWS Advisory Board for
PWSA | USA

Prompt for individuals with PWS:

Do animals play a part in your mental wellness?

For Mental Wellness Month, we're asking members of our Adults with PWS Advisory Board how they support their mental wellness. Check out our social media every Monday for their tips. If you're loved one with PWS would like to contribute a tip, please email africke@pwsausa.org or leave a comment in the posts.

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

Donate

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

PWSA | USA Pulse Newsletter: January 16, 2026

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 139
January 16, 2026

www.pwsausa.org | 941-312-0400

The Rare Aware Art Share is NOW LIVE!

Theme: Advocacy and Awareness

We're thrilled to announce the resurgence of our Rare Aware Art Share campaign in 2026! Our submission period is January 15-March 15. This year's theme is in honor of our upcoming D.C. Fly-In. We are asking individuals with Prader-Willi syndrome to make artwork on the theme of Advocacy and Awareness using the prompts:

How do you advocate for yourself?
How do you bring awareness to your community about PWS?

This art share is open to any and all individuals with PWS. There are no restrictions on age, skill level, or where they are in the world. We welcome all art (as long as it can be sent to us digitally)!

The art submissions will be shared virtually on our social media pages and in an art gallery on our website. A video showcasing these submissions will be made for YouTube and available to show at various awareness events during PWS Awareness Month in May. All or select pieces will be used in print material for various events at the D.C. Fly-In.

We invite individuals living with PWS to show what advocacy and awareness look like in *their* lives – big or small, public or personal. Not everyone makes a trip to Washington, D.C., or their state capital to advocate for policy. Sometimes advocating looks like demanding better food security at a group home or reminding a teacher that supervision is required during meals. Awareness may be speaking about PWS at a big event or sharing your story with a classmate or community member.

There is no "right" way to advocate or raise awareness. **Every voice matters, and every action counts.**

Learn more and submit artwork using the buttons below.

LEARN MORE HERE

SUBMIT ARTWORK HERE

SPOTLIGHT ON PWS

Our first Spotlight on PWS was submitted by María G. Padron in honor of her daughter Ashley (9, living with PWS).

Prader-Willi Syndrome Association | USA

"Soy mamá hispana de una niña 9 años. Desde que nació me la diagnosticaron con PWS. Yo como madre está rota sin saber nada al respecto. Hoy puedo decir siempre hay algo que podamos hacer por ellos. Ella es mi luz y la niña más dulce del mundo. Busca ayuda si estás en esta situación."

Translation: "I am a Hispanic mom of a 9-year-old girl. From the moment she was born, she was diagnosed with PWS. As a mother, I felt broken, not knowing anything about it. Today I can say there is always something we can do for them. She is my light and the sweetest girl in the world. Seek help if you are in this situation."

Please submit your loved one's PWS story using the button below.

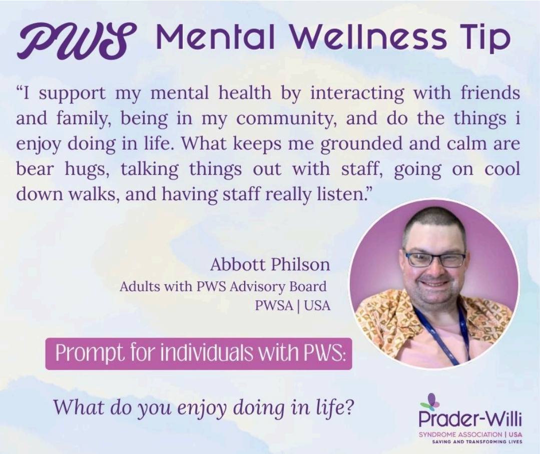
SHARE YOUR SPOTLIGHT

PWS RESOURCE SPOTLIGHT

As caregivers know, there may be an overwhelming number of things to remember about PWS, and that list changes as our loved ones age and transition to new developmental stages. Our PWS Fact Sheets are a quick guide to basic facts and concerns common in various life stages: Infant, Toddler, School Age and Young Adult, and Adults. Each fact sheet offers a brief overview of PWS, common features, health concerns, and specific ways you can support your loved one during this stage of life.

Download these PWS Fact Sheets using the button below.

READ HERE



PWS Mental Wellness Tip

"I support my mental health by interacting with friends and family, being in my community, and do the things i enjoy doing in life. What keeps me grounded and calm are bear hugs, talking things out with staff, going on cool down walks, and having staff really listen."

Abbott Philson
Adults with PWS Advisory Board
PWSA | USA

Prompt for individuals with PWS:

What do you enjoy doing in life?

For Mental Wellness Month, we're asking members of our Adults with PWS Advisory Board how they support their mental wellness. Check out our social media every Monday and Thursday for their tips. If you're loved one with PWS would like to contribute a tip, please email africke@pwsausa.org or leave a comment to our social media posts.

EVENTS & FUNDRAISERS

REGISTRATION NOW OPEN!

CLINT HURDLE HOT STOVE DINNER
Saturday, March 21, 2026
Bradenton Country Club | Bradenton, FL

With Special Hosts Clint & Karla Hurdle

Registration is NOW OPEN for the 12th Annual Clint Hurdle Hot Stove Dinner! Join hosts Clint and Karla Hurdle on **Saturday, March 21, 2026**, on the beautiful grounds of **Bradenton Country Club** in Bradenton, Florida – or participate virtually from anywhere – and help make a meaningful difference for those affected by Prader-Willi syndrome.

This special evening brings together the PWS community, friends, and supporters to raise critical funds for PWSA | USA through inspiring stories, a silent auction featuring exclusive items and

SAVE THE DATE

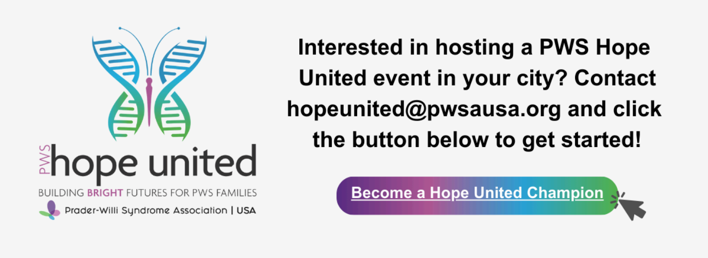
Upcoming Events >>>

D.C. Fly-In
May 4-6, 2026
Washington, D.C.
Apply Today!

experiences, a gourmet dinner, live entertainment, a raffle, and the ever-popular Coconut Drop (Golf Ball Drop).

Your attendance and support fuels PWSA | USA’s vital Family Support services and programs. Together, we can create a brighter future for individuals and families affected by PWS.

CLINT HURDLE HOT STOVE DINNER



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

Residential Providers Conference
August 21-22, 2026
Savannah, GA
Registration Coming Soon!

Moms' Retreat
October 16-17, 2026
Park City, UT
Registration Coming Soon!

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

Stacy Ward, PWSA | USA's CEO, sat down with key figures of the Global PWS Registry: Dr. Theresa Strong, Director of Research for FPWR; Dr. Jessica Bohonowych, Associate Director of Research for FPWR; Lisa Matesevac, Study Coordinator for FPWR; and Lynn Garrick, Medical/Research Coordinator for PWSA | USA. They discussed the many surveys available and the importance of gathering this data from families. Not only are these surveys helping to inform the medical and research community on the many nuances of PWS, but they can also serve as a living medical record for families. The Global PWS Registry has been updated to a more intuitive platform, making it easier for families to complete surveys and view the information submitted by the community. The commentators also discuss the exciting implications for the upcoming VYKAT XR survey, which will help document in real-time the effects of the first-ever FDA-approved treatment for hyperphagia in PWS.

Listen to PWS United on your favorite podcast app or by clicking the button below.

LISTEN ON PODBEAN

GLOBAL PWS REGISTRY

ADVOCACY

PWSA | USA and Soleno Therapeutics are Partnering to Bring PWS Awareness to the 2026 Super Bowl!

We are thrilled to share that PWSA | USA has partnered with Soleno Therapeutics on an exciting new awareness initiative that will be featured during this year's Super Bowl - an ad in the Super Bowl printed program! The powerful message — *"No end zone. No final whistle. Just goal posts that keep moving."* — brings national attention to the realities of Prader-Willi syndrome, including the relentless challenges of hyperphagia and the constant drive for food experienced by so many in our community.

This collaboration reflects our shared commitment to elevating the voices of individuals and families living with PWS, increasing public understanding, and pushing forward the visibility and advocacy this community deserves. We are deeply grateful to Soleno for helping bring PWS to one of the largest stages in the world.

Above is a preview image of the ad that will be featured. A link to download the ad for free will be available one week prior to the Super Bowl.

THE GOAL POSTS KEEP MOVING.

Prader-Willi syndrome (PWS) is a rare genetic disorder that can cause growth hormone deficiency, behavior challenges, and hyperphagia — characterized by feeling of intense, persistent sensation of hunger accompanied by food anxiety, constant thoughts about food, and an extreme drive to seek and consume food.

No end zone. No final whistle.
Just goal posts that keep moving.

Learn more about PWS here:

PWSA USA

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

SOLENO
THERAPEUTICS

Soleno Therapeutics, Inc. © 2026 | All Rights Reserved
C-US-PWS-00152 v1 01/2026

Together, we are moving the goal posts toward greater awareness, stronger advocacy, and a future filled with possibility for every individual living with PWS.

Advocate for the PWS Community's Needs at
PWSA | USA's 2026 D.C. Fly-In

Click the image below to apply today

2026 D.C. FLY-IN

APPLICATION NOW AVAILABLE!

CLICK HERE

MAY 4-6, 2026

WASHINGTON, D.C. | YOURS TRULY DC HOTEL

ADVOCACY
IN
ACTION

D.C. FLY-IN 2026

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

EveryLife Foundation's Rare Disease Week - Registration Now Open!

Registration is now open for the EveryLife Foundation’s **Rare Disease Week on Capitol Hill**, taking place February 24–26, 2026, in Washington, D.C. We encourage the PWS community to be part of this powerful opportunity to ensure the voices of individuals and families affected by Prader-Willi syndrome are heard on Capitol Hill.

This free, multi-day event, hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases), brings together patients, families, and advocates from across the country to raise awareness, learn about key policy proposals impacting the rare disease community, and advocate directly with Members of Congress. Participants will receive advocacy training and take part in meetings with lawmakers to help advance meaningful policy change.

The Rare Disease Week Agenda Overview is also now available, and you can find the agenda, registration, and additional event details by clicking the button below. We hope to see you there!

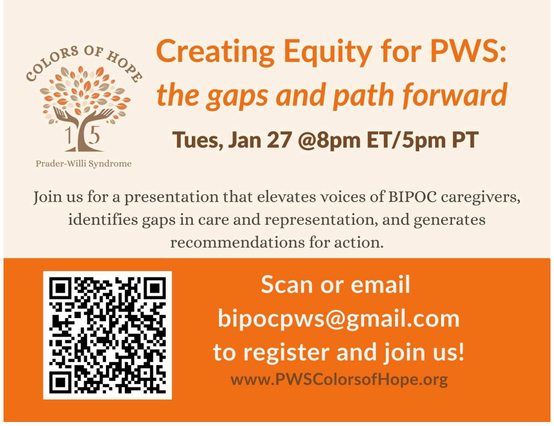
RARE DISEASE WEEK 2026

Colors of Hope Listening Session Open to All

When: **Tuesday, January 27**
@ 8pm ET | 5pm PT
Where: ZOOM

Want to know how we can **improve outcomes for more people in our PWS Community**? Come join the Colors of Hope group as they present findings from a series of Listening Sessions and surveys with the families of color affected by Prader-Willi syndrome. The goal of this presentation is to create a shared understanding of the challenges and opportunities ahead.

Register to join the presentation using the button below.



COLORS OF HOPE
15
Prader-Willi Syndrome

Creating Equity for PWS:
the gaps and path forward
Tues, Jan 27 @8pm ET/5pm PT

Join us for a presentation that elevates voices of BIPOC caregivers, identifies gaps in care and representation, and generates recommendations for action.

Scan or email
bipocpws@gmail.com
to register and join us!
www.PWSColorsofHope.org

REGISTER HERE

PWSA NJ is updating their family registry and would like to have your most current information on file so they can provide support and community. Please use the button to complete the form.

UPDATE HERE

FAMILY SUPPORT

How Individuals with PWS Can Use Social Media Safely

At first glance, social media looks to be an excellent way for persons with PWS to connect with and enjoy the company of others. There are many platforms always readily available for our loved one to connect, share, and interact with someone in some virtual community somewhere in the world.

The challenge is that most kids and adults with PWS lack the skills required to use social media responsibly and safely. PWS interferes with executive functioning skills and social functioning skills. The loss of these skills makes

using social media not just challenging, but potentially dangerous. This article, submitted by Lisa Graziano, M.A., LMFT, and mom to Cameron, living with PWS, explores what these skills look like, how the lack creates challenges for social media use, and tips for helping your loved one stay safe while also staying connected.

Read this blog using the button below.

READ HERE

Ask Nurse Lynn

Male, 34 years old, UPD subtype

Our son has never taken growth hormone (GH). One day, his endocrinologist noticed he had high hemoglobin levels, the highest being 18. Because of this, the doctor referred him to a hematology specialist. The doctors checked his lungs, kidneys, and liver, and everything was fine. Seeing that everything was okay, they are now checking if he has any bone marrow disease. The doctors are planning to perform a lumbar puncture and take a biopsy, but there was also the option of drawing blood and using a reagent to test for bone marrow abnormalities. We are wondering if high hemoglobin is common in PWS (unfortunately, the doctors here are not familiar with this condition) and what recommendations you have?

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

READ NURSE LYNN'S RESPONSE

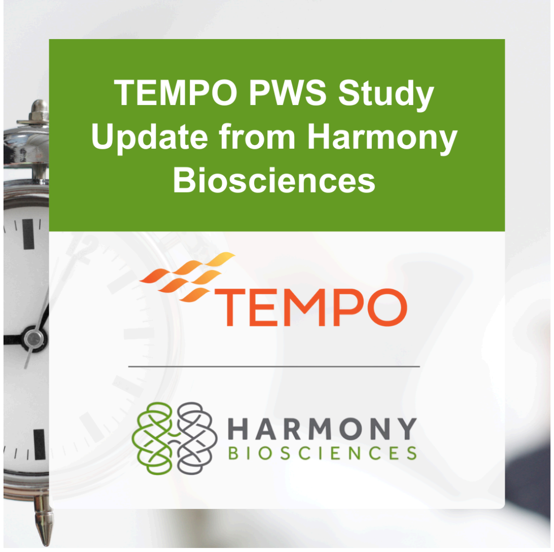
Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

[ASK YOUR QUESTION HERE]

RESEARCH

Harmony Biosciences Confirms TEMPO PWS Study Phase 3 Results Expected in 2026



This week, Harmony Biosciences announced a major corporate update highlighting continued growth of their WAKIX® (pitolisant) franchise, and importantly for our community, they confirmed that the TEMPO Phase 3 clinical trial of pitolisant in Prader-Willi syndrome remains on track, with topline data expected in the second half of 2026.

Pitolisant is already FDA-approved for narcolepsy, and the TEMPO study represents an important step in exploring its potential to address excessive daytime sleepiness and related symptoms in individuals with PWS.

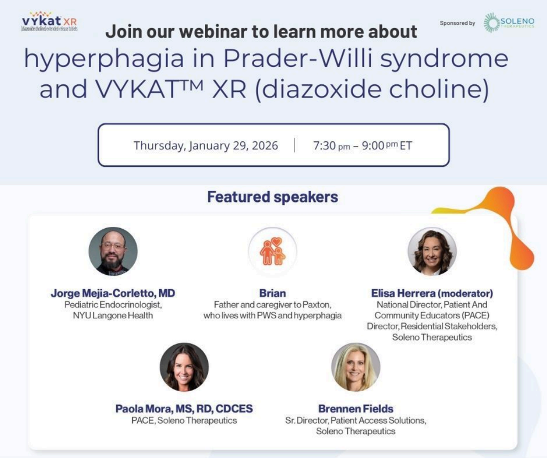
While this is not an approval announcement, it is a meaningful sign of continued progress and investment in PWS-focused research. PWSA | USA will continue to share updates with the community as they become available.

You can read Harmony's full press release announcement at the button below.

[READ MORE]

VYKAT XR Webinar from Soleno Therapeutics

When: Thursday, January 29
@ 7:30 - 9pm ET | 4:30 - 6pm PT



vykat XR

Join our webinar to learn more about

hyperphagia in Prader-Willi syndrome and VYKAT™ XR (diazoxide choline)

Sponsored by SOLENO THERAPEUTICS

Thursday, January 29, 2026 | 7:30 pm – 9:00 pm ET

Featured speakers

Jorge Mejia-Corletto, MD
Pediatric Endocrinologist,
NYU Langone Health

Brian
Father and caregiver to Paxton,
who lives with PWS and hyperphagia

Elisa Herrera (moderator)
National Director, Patient And
Community Educators (PACE)
Director, Residential Stakeholders,
Soleno Therapeutics

Paola Mora, MS, RD, CDCES
PACE, Soleno Therapeutics

Brennen Fields
Sr. Director, Patient Access Solutions,
Soleno Therapeutics

In 2026, Soleno Therapeutics, the makers of VYKAT XR will be hosting a series of caregiver webinars. Each webinar will have a mini-theme related to important moments in the PWS community. On January 29, the webinar will review the signs and symptoms of hyperphagia in Prader-Willi syndrome, what VYKAT XR may offer as a treatment option for patients 4 years and older, and how to get started. Speakers include Jorge Mejia-Corletto, MD, Pediatric Endocrinologist, NYU Langone Health; Paola Mora, MS, RD, CDCES, PACE, Soleno Therapeutics; Brennen Fields, Sr. Director, Patient Access Solutions, Soleno Therapeutics; Brian, Father and caregiver to Paxton; and Elisa Herrera, National Director, Patient and Community Educators (PACE) Director, Residential Stakeholders, Soleno Therapeutics; as moderator.

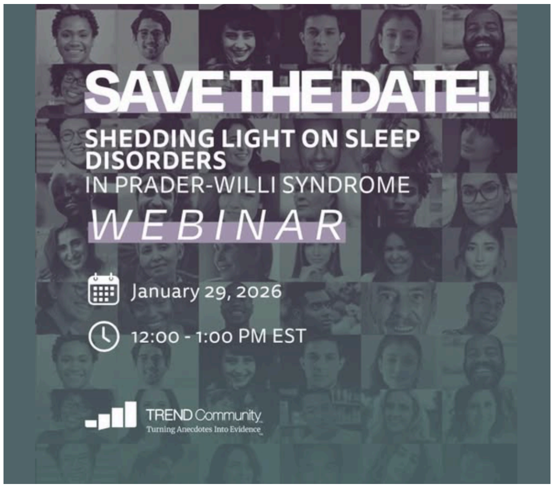
Register for this webinar using the button below.

REGISTER HERE

Shedding Light on Sleep Disorders: TREND Webinar

When: Thursday, January 29, 2026 @ 12 – 1pm ET

Sleep challenges are a real — and often misunderstood — part of life with Prader-Willi syndrome.
Join TREND Community for "Shedding Light on Sleep Disorders in Prader-Willi Syndrome," a webinar centered on caregiver experiences and clinical insight, with a focus on listening, learning, and understanding the real-world impact of sleep issues in PWS.



SAVE THE DATE!

SHEDDING LIGHT ON SLEEP DISORDERS IN PRADER-WILLI SYNDROME

WEBINAR

January 29, 2026

12:00 - 1:00 PM EST

TREND Community
Turning Anecdotes Into Evidence

This is not a traditional lecture. It’s an honest conversation about what families see, feel, and wish they had known sooner — paired with guidance from clinicians who help translate lived experience into care.

RSVP using the button below.

RSVP

PWSA | USA ANNOUNCEMENTS

Do You Have a Skill That Could Help Strengthen PWSA | USA?

PWSA | USA is built on the dedication of families, caregivers, and supporters who believe in advancing care, advocacy, and resources for individuals with Prader-Willi syndrome. In addition to lived experience, the organization relies on professional expertise to remain strong, sustainable, and forward-thinking.

This is an opportunity not only for parents and caregivers, but also for extended family members, friends, and professional allies who want to support the mission in a meaningful way. If you've ever wondered how your skills could make a difference beyond a donation, this is a powerful way to contribute.

PWSA | USA welcomes individuals who are willing to share their expertise in the following areas:

- Communications & Media
- Financial Expertise
- Fund Development
- Human Resources (generalist)
- Legal Expertise
- Philanthropy
- Website / Digital Expertise

Volunteering your professional skills helps strengthen the organization's infrastructure and allows PWSA | USA to better serve families nationwide. Contributions of time and talent — whether ongoing or project-based — play a vital role in advancing this important work.

If you, or someone you know, has experience in any of these areas and is interested in learning more, please contact Stacy Ward, CEO, at info@pwsausa.org and type “I have a skill” in the subject line.

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

Donate

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

PWSA | USA Pulse Special Edition Newsletter: January 30, 2026

We've been celebrating **Mental Wellness Month** throughout January! If you haven't been keeping up with the mental wellness tips online from our advisory board or weekly blogs, here is your chance to catch up. This Special Edition Pulse is dedicated to Mental Wellness Month. While our new social content focused on individuals with PWS themselves, we'd like to remind you that caregiver mental health is just as important. Below are some past resources focused on helping caregivers support and nurture their own mental wellness. Scroll to the end of this email to learn more and listen to our latest PWS United podcast episode, *Ep77: Limits, Perspective, and Mental Wellness* with Denise Rickenbach. We encourage you to read through, listen, and watch these resources and prioritize your mental wellness, along with helping your loved one with PWS find ways to support theirs as well.

"You are worth the quiet moment. You are worth the deeper breath. You are worth the time it takes to slow down, be still, and rest."

- Morgan Harper Nichols

Mental Wellness Blogs:
Exercise, Movement, and Mental Health
Simple Tools for Managing Stress
Self-Care for Caregivers
PWS United Podcast:
Ep16 Self-Care, Self-Advocacy, and Gratitude | PWS United
PWSA YouTube:
An Invitation To Self Care and the PWS Journey
PWSA | USA Facebook Livestream Event: Journal Therapy

Mental Wellness Tips from our Adults with PWS Advisory Board

"I talk to my cat, and I like it because he doesn't respond and he listens. I do yoga, that also helps. And I draw by number and play games and watch Tik Tok."

Brooke Fuller

Victor Penta

"I support my mental health by going somewhere where it is quiet, usually my room. I watch TV or play video games. I also like to be with friends and laugh. It makes me happy. Things that help me feel calm are going for a walk or being in a quiet area."

"I support my Mental Health by talking to my family, talking to friends, interacting with Support Staff. asking for help when needed, eating healthy meals, playing games, & going out in the Community.

If I am upset I try to walk away from the situation and try to calm myself down and just breathe. I try to stay calm or grounded by talking to my parents and/or staff to let them know how I feel and what is going on - we talk it out.

It always helps to find someone who is a good listener. If someone needs help, they can reach out to one of us on the PWS Advisory Board and we can just talk it out."

Shawn Cooper

Abbott Philson

“I support my mental health by interacting with friends and family, being in my community, and do the things I enjoy doing in life. What keeps me grounded and calm are bear hugs, talking things out with staff, going on cool down walks, and having staff really listen.”

“The way I keep my mental health in check is when one of my peers at my group home talks negatively to me, I just don’t engage any further. Other than that, I work out 🏋️‍♀️ 2-3 times a week at a gym where I’m a member. And my trainer is my very very Best Friend and I feel I can confide in her... And sometimes when I’m in a grumpy mood from a peer or a staff I wind up going to work out and I feel better afterward.”

Kate Kane

Conor Heybach

"I see my therapist every two weeks, and my psychiatrist every six months. I am currently in two dialectical behavior therapy groups which have been very helpful. I am currently working with a therapist to help me find ways to work through those emotions instead of acting upon them. I am currently working through my emotions by journaling, writing letters, and socializing with friends. I am looking into other ways to meet new people. Yes, at first it may be hard to talk to others about feelings you may be experiencing. But remember they are just feelings and they will pass. If you feel alone, always remember you have the Adults with PWS Advisory Board for inspiration."

Social Media Use and PWS

At first glance, social media looks to be an excellent way for persons with PWS to connect with and enjoy the company of others. There are many platforms always readily available for our loved one to connect, share, and interact with someone in some virtual community somewhere in the world.

The challenge is that most kids and adults with PWS lack the skills required to use social media responsibly and safely. PWS interferes with executive functioning skills and social functioning skills. The loss of these skills makes using social media not just challenging, but potentially dangerous. This article, submitted by Lisa Graziano, M.A., LMFT and mom to Cameron, living with PWS, explores what these skills look like, how the lack creates challenges for social media use, and tips for helping your loved one stay safe while also staying connected.

Read this article by clicking the button below.

READ HERE

Conor Heybach, a member of the Adults with PWS Advisory Board for PWSA | USA, shared some great information on why individuals with PWS should be cautious about social media use, what some of the dangers may be, and how individuals with PWS, along with their friends and family, can use social media responsibly. As Conor wrote, "*You are in control of what online content you post. Recognize which content is unhealthy and report it. Find healthy ways to use social media that you are passionate about.*"

Read this blog, along with tips from other adults on the advisory board, by clicking the button below.

READ HERE

PWS United Podcast: Limits, Perspective, and Mental Wellness

Denise Rickenbach is an Adlerian-trained Licensed Marriage and Family therapist as well as a Licensed Alcohol and Drug Counselor (LADC). Denise's interests include addiction, codependency, family systems, anxiety, depression, obsessive compulsive disorder, grief, life transitions, and strained relationships. She was a speaker at the 2025 United in Hope conference and is the sister of PWSA | USA's beloved family support coordinator – Kristi Rickenbach.

Kristi and Denise both joined Carrie Larsen and Anne Fricke from PWSA | USA on this episode on mental wellness to talk about what addictive behavior may look like and why parents of individuals with disabilities are perhaps more likely to develop these. They also discuss caregiver burden, setting limits – why and how, negative comparison vs. perspective taking, disenfranchised grief, and more.

Listen to this episode by clicking the button below.

Remember to subscribe or follow on your favorite podcast platform so you never miss an episode!

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