PWSA | USA Pulse Newsletter: October 3, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 132
October 3, 2025

www.pwsausa.org | 941-312-0400

What a night! Nearly 200 guests from across the country joined us at The Ritz-Carlton, St. Louis on September 26th to celebrate **PWSA | USA's 50th Anniversary Journey of Hope Gala**. From heartfelt Pioneer Award tributes and inspiring speeches to a lively cocktail hour, dancing, and laughter led by emcee Aaron Weber, it was truly an evening to remember.

We are deeply grateful to our sponsors, honorees, attendees, and supporters who made this historic celebration possible. Thank you for standing with us as we honor five decades of grit and grace, and look ahead to PWSA | USA's next 50 years.

Relive the highlights by reading our full recap blog, which can be found at the button below.

50TH GALA RECAP

50th Anniversary Tribute Video

Click the image below to watch!

THANK YOU, JOURNEY OF HOPE GALA SPONSORS

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SEMINOLE Hard Rock HOTEL & CASINO HOLLYWOOD, FL

PIONEER SPONSORS

5 BROTHERS PRODUCE

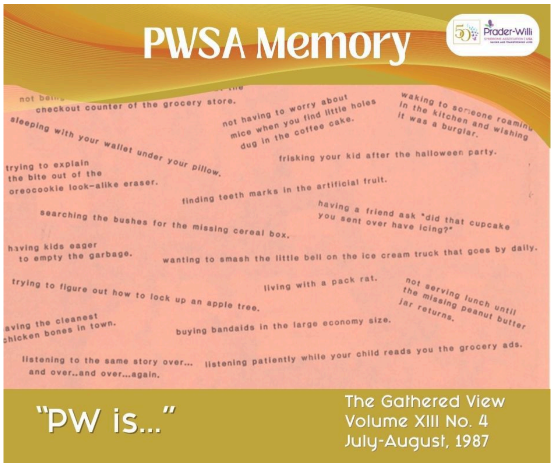
ACADIA

PWSA MEMORIES

Parents, at a 1987 PWS Conference in Texas, were given the partial sentence "PW is..." Parents who submitted responses seemed to veer toward a light, more humorous tone with suggestions like:

- "Finding teeth marks in the artificial fruit."
- "Listening to the same story over ... and over ... and over ... again."
- "Having the cleanest chicken bones in town."

You can read more responses in The Gathered View, Volume XIII, No. 4 (page 8), from July-August 1987 using the button below.



PWSA Memory

not bei

checkout counter of the grocery store.

sleeping with your wallet under your pillow.

not having to worry about mice when you find little holes dug in the coffee cake.

waking to someone roaming in the kitchen and wishing it was a burglar.

frisking your kid after the halloween party.

trying to explain the bite out of the oreocookie look-alike eraser.

finding teeth marks in the artificial fruit.

searching the bushes for the missing cereal box.

having a friend ask "did that cupcake you sent over have icing?"

having kids eager to empty the garbage.

wanting to smash the little bell on the ice cream truck that goes by daily.

trying to figure out how to lock up an apple tree.

living with a pack rat.

not serving lunch until the missing peanut butter jar returns.

aving the cleanest chicken bones in town.

buying bandaids in the large economy size.

listening to the same story over... and over..and over...again.

listening patiently while your child reads you the grocery ads.

"PW is..."

The Gathered View
Volume XIII No. 4
July-August, 1987

[THE GATHERED VIEW](#)

[SHARE YOUR MEMORY](#)

PWSA | USA'S
SPOTLIGHT ON HOPE

"Ollie is pictured with her two new friends, a pair of sisters (ages 13 and 10), one of whom is in Ollie's grade at school. After really hitting it off with the sisters, Ollie has been enjoying attending their softball team games on weekends. Although Ollie has at times struggled to make friends at school, it turns out that when the connection is there it comes quite naturally. These girls are "besties" who take care of each other inside and outside of school." - Submitted by Emily Felt, mom to Ollie (13, living with PWS)

Share your Spotlight on Hope using the button below.

SHARE YOUR SPOTLIGHT

EVENTS & FUNDRAISERS

2nd Annual Dance Silly for Prader-Willi!

When: **Saturday, Oct. 11 | 3:30 PM EDT**
Where: **Trumbull Career and Technical Center | Warren, OH**

Join the Hampton family for the 2nd annual Dance Silly for Prader-Willi event—a lively celebration to support PWSA | USA! This special occasion honors Jayda's journey with PWS and the invaluable support the Hampton family has received from the organization.

Get ready for a FUN, FAMILY, DANCE PARTY like no other! Set against the backdrop of Halloween—a season that poses unique challenges for children with PWS due to their dietary restrictions—this event aims to spotlight inclusivity and emphasize that holidays are about more than just treats. It's all about creating joyous, memorable experiences and cherishing time together.

Event highlights:

- Dance to the beats with our energetic DJ
- Rock your favorite costume for a festive twist
- Enjoy exciting games and a creative craft station
- Sport fun and colorful face painting
- Participate in kids and adults raffles for fabulous prizes
- Savor a delicious family dinner

Whether you're looking to sponsor, donate a raffle basket, or volunteer, we would love your support. Reach out at mhampton0933@gmail.com to get involved. Donate or purchase tickets using the button below.

LEARN MORE

Thank You Sponsors

Platinum

ACADIA

SOLENO THERAPEUTICS

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Jimmy and Diana Whetstone

ACURA of Boardman

amble

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

We are beginning a new podcast series, Sibling Advocacy, in which we will be speaking with siblings about how they show up for their loved one with PWS, whether at the kitchen table, at school, in friend groups or government, or any place where their sibling may need them.

This week's episode is led by Elaine Towle, PWSA | USA Advocacy Specialist and mom to Jim (39, living with PWS), who speaks with Rockie Penta. Rockie is the younger sibling of Victor Penta, a man well-known in the PWS community. Victor is on

PWSA | USA's Adults with PWS Advisory Board and has traveled to Washington, D.C. to advocate for the PWS community.

Rockie shares how she speaks up for Victor when needed, how she avoids caregiver burn out, and how she navigated PWS growing up and what it looks like now having him as a roommate and live-in uncle to her children. Spoiler alert, it seems to be going well!

With a diagnosis as challenging as PWS can be, we hope families will find this episode, and this series, refreshing and insightful. Thank you to all the siblings advocating and showing up for their loved one with PWS!

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

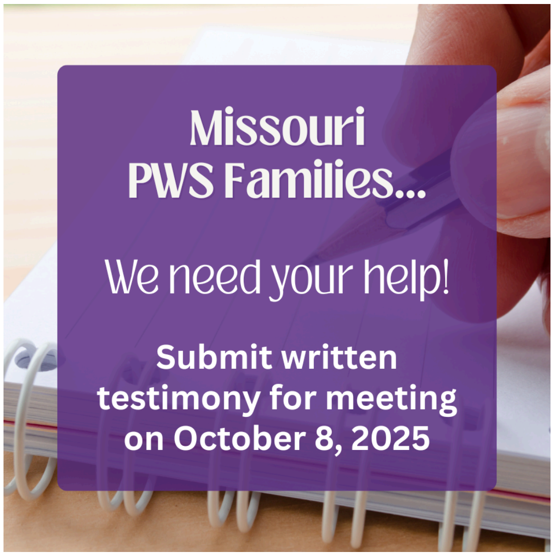
LISTEN ON PODBEAN

Looking for Podcast Guests for November Episode

November is **National Family Caregivers Month**. As parents and caregivers ourselves, we recognize and value the incredible dedication, work, and support that family caregivers provide. In November, we will honor all family caregivers but would like to emphasize single caregivers. In a society that increasingly requires more than one household income for basic needs, being a single caregiver becomes more and more challenging. As part of our work for the PWS community, we are hoping to bring together some single caregivers for a heartfelt and insightful podcast episode.
The intention of the episode is to create a safe space for single caregivers to share their experiences so they may feel less alone and find valuable advice. It's also to give others a better understanding of the experiences of single caregivers, thus offering insight into how our community might offer better support. If you are a single caregiver or know of someone who is a single caregiver for an individual with PWS and would be willing to share on our podcast or through a blog, please reach out to Anne at africke@pwsausa.org.

ADVOCACY

Calling Missouri PWS Families for Written Testimony on Hyperphagia for October 8th RDAC Meeting



The Missouri Rare Disease Advisory Council will be meeting **Wednesday, October 8, 2025**, from 10:30 AM – 2 PM CDT.

The Missouri Rare Disease Advisory Council needs to hear directly from you – the parents, caregivers, and family members who understand the real-life impact of hyperphagia (excessive hunger) in PWS. One of the medications under review is VYKAT XR, the first-ever hyperphagia treatment specifically for individuals living with PWS that was approved by the FDA in March 2025.

We're asking families to submit written testimony to help decision-makers understand why access to this treatment is so urgently needed. Learn more using the button below.

LEARN MORE

Calling Indiana PWS Families for Testimony on Hyperphagia for October 17th Indiana DUR Board Meeting

On **Friday, October 17, 2025**, at 10:00 AM EDT, the Indiana Medicaid Drug Utilization Review (DUR) Board will meet to review several medications, including VYKAT XR.

This is a critical opportunity for families in Indiana to share their voices. Families can participate by submitting written testimony or registering to provide public comment virtually during the meeting.

Important: If you plan to participate, you must read the full article, found at the button below, for details on how to register, submit testimony, and follow the Board's specific participation requirements.

LEARN MORE

FAMILY SUPPORT

Intervening with a Bully, One Family's Experience

PWSA Blog

October is **National Bullying Prevention Month.** One of the frustrating and sad realities of our society is that individuals with disabilities and special needs are more likely to be bullied, including our loved ones with PWS. It is essential that we, as parents and caregivers, are aware of the potential for bullying, recognize its signs, and understand how to intervene to prevent and stop this behavior. This blog shares one family's experience with their loved one's struggles at school and how they navigated the challenging situation, along with some quick tips and resources for bullying prevention.

Read this blog using the button below.

READ HERE

Ask Nurse Lynn

Female, 13 years old, Deletion subtype

My daughter started the estradiol patch about 4 months ago. She hasn't really gained much weight or gotten bigger, but she is getting stretch marks across her butt and her upper thighs. Is this common with estrogen spikes or does it have something to do with PWS? Is there anything she should or could be putting on them to lessen the severity?

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

What’s TRENDing: Birth Stories and PWS

TREND Community has released its latest one-pager report, Birth Stories and PWS. TREND Community is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights. This report explores the stories about birth — before, during, and after — that parents of children with PWS shared on PWS Connect, a discord channel started by TREND Community. These conversations help sharpen the understanding of PWS and provide valuable insight for researchers, specialists, and organizations like PWSA | USA to help bring more support to the PWS community. We invite all parents of individuals with PWS to meet us over at [PWS Connect on Discord](#) to share the stories and experiences that have shaped your PWS journey. By sharing your journey, you can participate in research and help expand the support provided to the PWS community. Learn more about TREND Community and read the latest report using the buttons below.

[LEARN MORE ABOUT TREND](#)

[TREND BIRTH AND PWS REPORT](#)

Acadia Pharmaceuticals Primary Endpoint Not Met

We are deeply saddened to share that Acadia Pharmaceuticals has announced that its Phase 3 COMPASS PWS carbetocin trial for Prader-Willi syndrome did not meet its primary goal in reducing hyperphagia. In a letter to the PWS community Acadia wrote, "*We are deeply disappointed by the results of this clinical trial, knowing the incredible need for treatment options to address hyperphagia in Prader-Willi syndrome, and are profoundly grateful to the patients, families, and investigators who have participated in this clinical trial for their dedication and contributions to advancing scientific understanding.*"

Dear Prader-Willi Syndrome Community,

Today Acadia announced top-line results from the company's Phase 3 COMPASS PWS trial evaluating the efficacy and safety of intranasal carbetocin in patients with hyperphagia in Prader-Willi syndrome. Intranasal carbetocin did not demonstrate significant improvement over placebo on the study's primary or secondary measures.

We are deeply disappointed by the results of this clinical trial, knowing the incredible need for treatment options to address hyperphagia in Prader-Willi syndrome, and are profoundly grateful to the patients, families, and investigators who have participated in this clinical trial for their dedication and contributions to advancing scientific understanding.

Acadia does not intend to investigate intranasal carbetocin further and we plan to share an organized plan to discontinue the open-label extension trial with our study investigators this week. For those who are participating in the ongoing trial, please reach out to your study coordinator or investigator for additional information next week.

We are committed to sharing a summary of the data at a future scientific forum to ensure our efforts contribute to future scientific understanding of Prader-Willi syndrome.

The heart and passion of this community have inspired us, and we value the relationships that we have formed with you. We sincerely appreciate the opportunity to learn from you and to share in your journey.

All our best,
Acadia

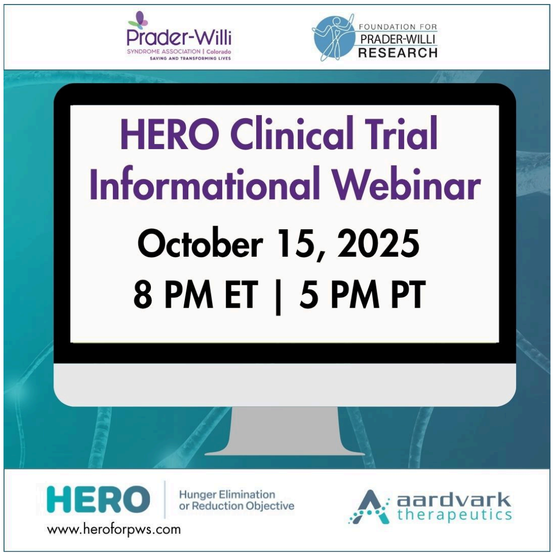
You can read more details and find a link to Acadia's press release using the button below.

We know this news is difficult for our families, and we want to acknowledge the incredible dedication of everyone who participated in this trial. If you need support, PWSA | USA is here for you. Please reach out at (941) 312-0400 or info@pwsausa.org.

READ HERE

News from Aardvark's HERO Clinical Trial

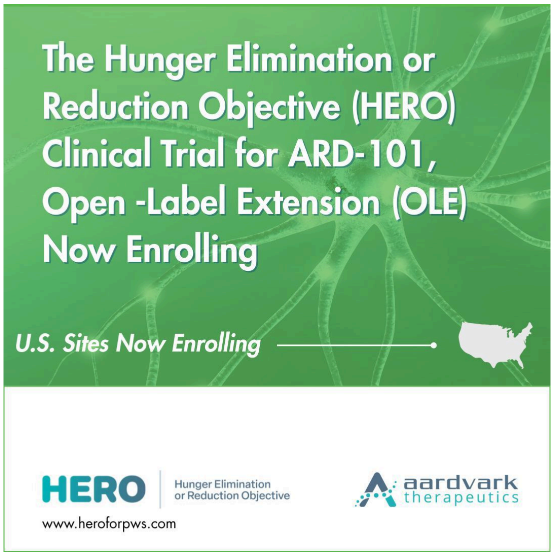
When: **Wednesday, October 15, 2025 @ 5 PM PDT | 8 PM EDT**
Where: **ZOOM** *(Link to register below)*



Join us for an information webinar to learn more about Aardvark Therapeutics HERO clinical trial of ARD-101, jointly hosted by PWSA | USA and FPWR. This trial is a global Phase 3 clinical trial investigating ARD-101, an innovative, orally administered treatment designed to help reduce hyperphagia (excessive hunger) and food-seeking behaviors in individuals with Prader-Willi syndrome. This randomized, double-blind, placebo-controlled trial is an important step toward identifying a potential new treatment option for the PWS community, and now, trial sites across the United States are actively enrolling participants.

Join PWSA | USA, FPWR, and Aardvark Therapeutics for this informational webinar by clicking the button below.

REGISTER HERE



Aardvark Therapeutics Now Offering Open-Label Extension for HERO Clinical Trial ARD-101

Aardvark Therapeutics has begun the Open-Label Extension (OLE) of their HERO Clinical Trial for ARD-101, an innovative, orally administered treatment designed to help reduce hyperphagia and food-seeking behaviors in individuals with Prader-Willi syndrome. Participants who have completed treatment on the AVK-101-301 study through Week 12/End of Treatment will have the option to join the OLE AVK-101-302 study, to receive ARD-101 for up to 12 months. Learn more about the HERO trial and the open-label extension by clicking the button below. To learn more about the HERO Study, visit www.heroforpws.com.

New Trial Site:

Mineola, New York
NYU Langone Children’s Ambulatory Care Center
Contact: Jorge Mejia-Corletto, MD
Phone: (516) 663-4600
Email: jorge.mejia-corletto@nyulangone.org

LEARN MORE

¡Ahora en Español!

Estudio Hunger Elimination or Reduction Objective (HERO, Objetivo de eliminación o reducción del hambre) para el tratamiento de la hiperfagia en el síndrome de Prader-Willi (PWS)

HERO, Phase 3 Clinical Trial for ARD-101, Now Enrolling

New Site Now Open

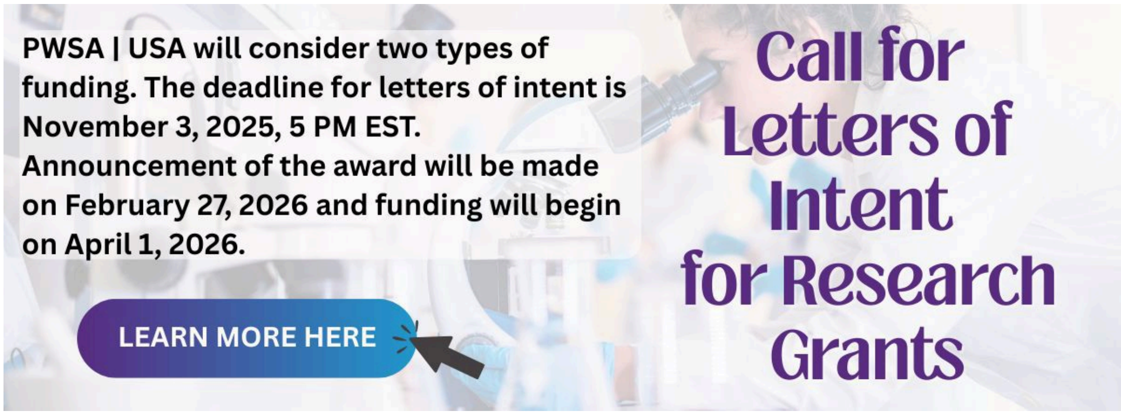
Fort Worth, Texas:
Cook Children's
Medical Center

Supporting PWS Research

Prader-Willi Syndrome Clinical Scholarships Available

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

LEARN MORE HERE



PWSA | USA will consider two types of funding. The deadline for letters of intent is November 3, 2025, 5 PM EST. Announcement of the award will be made on February 27, 2026 and funding will begin on April 1, 2026.

LEARN MORE HERE

Call for Letters of Intent for Research Grants

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

We have an incredible resource to share for National Physical Therapy Month (October); *Therapeutic Interventions for the Child with Prader-Willi Syndrome*, by Janice Agarwal, PT, CNDT. This booklet explains what a pediatric physical therapist is and covers topics like early intervention, typical development through the years, sensory integration, the vestibular, proprioceptive, tactile, and oral-motor systems, as well as calming techniques, sleeping strategies and more. This booklet is a great resource for every family in the PWS community, from birth through adulthood.

Click the button below to view the booklet.

THERAPEUTIC INTERVENTIONS BOOKLET

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: October 17, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 133
October 17, 2025

www.pwsausa.org | 941-312-0400

On Wednesday, October 22, 2025, the iconic Zanies Comedy Club will host Prader Silly: A Night of Rare Laughs — a one-night-only comedy fundraiser benefiting the PWSA | USA hosted by PWS parents Aaron Weber and Lucy Sinsheimer of Nashville. This is more than a comedy show. It's a night of gathering, giving, and gut-busting laughter — featuring a powerhouse lineup of top-tier comedians, a silent auction packed with unforgettable prizes, and several surprise guest performers.

This incredible event is sold out but, thankfully, you can still participate from home!

Auction items include a Pensacola beachfront getaway, a private tour of Project Chimps, a chimp rehabilitation center in Georgia, the ultimate Grand Ole Opry experience, a night out on Broadway, 4 tickets to a Nashville Sounds baseball game, a 60-minute massage at Third Coast Salt, a Bourbon Lover’s Dream Package, and so much more.

The auction CLOSES on Wednesday, **October 22, 2025, at 7:00 PM CDT**. Winners will be notified by email or text via the auction platform.

How to Participate in the Silent Auction:

1. Click the button below.

2. Login with your email (guests create an account).

3. Add your payment info via the “Cart” button.

4. Bid & set max bids to auto-increase.

VISIT AUCTION SITE

Thank You Prader Silly Sponsors!

HEADLINER SPONSORS

NATELAND

ZANIES COMEDY NIGHT CLUB

Anne & Mike Sinsheimer

LAUGH LEGEND SPONSOR

OUTBACK PRESENTS

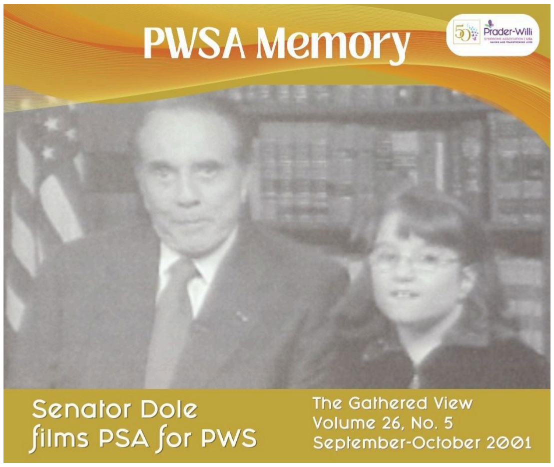
PUNCHLINE SPONSOR

SOLENO THERAPEUTICS

PWSA MEMORIES

"Sen. Bob Dole filmed a public service announcement (PSA) about Prader-Willi syndrome on August 2, 2001 in Washington, D.C., at the Republican Party Studio. Appearing with him is Amanda Diaz, age 7, who has PWS." Susan Wheeler, the sister of Pamela Tobler, (mom to Nathan, with PWS), helped coordinate this recording. At the time, Pamela served on the national board of directors for PWSA | USA as the public relations liaison.

Read more from this article in The Gathered View, Volume 26, No. 5, from September-October 2001 using the button below.



THE GATHERED VIEW

SHARE YOUR MEMORY

PWSA | USA'S
SPOTLIGHT ON HOPE

With Halloween coming up soon, this week's Spotlight on Hope shares how one PWS family celebrated the holiday in a fun and PWS-friendly way. On October 11, families and friends gathered in Warren, Ohio, for the 2nd Annual *Dance Silly for Prader-Willi* -- a festive Halloween fundraiser hosted by Michele Hampton and her family. For Michele, whose 3-year-old daughter, Jayda, is living with Prader-Willi syndrome, the event is about more than costumes and music. "*Halloween and parties don't have to be all about candy and food – it can be about the time with friends and family,"* Michele shared. This celebration also holds a special meaning for Michele's family. "*This event is really all about Jayda. She loves to dance, and we're just so happy to highlight how well she's doing and come together to enjoy our day,*" she said. Click the button below to read how Michele and her community turned a night of dancing, laughter, and connection into a celebration of hope and awareness for PWS.

Read more about this wonderful event using the button below.

READ HERE

SHARE YOUR SPOTLIGHT

EVENTS & FUNDRAISERS

2nd Annual RMC Foundation Golf Outing

When: **November 17, 2025 @ 8:30 AM**
Where: **Ritz-Carlton Members Club | Bradenton, FL**

The RMC Foundation

2nd Annual
RMC Foundation Golf Outing

November 17, 2025
8:30am Shotgun Start
Lunch Included (12:15 pm)
Ritz Carlton Members Club
Bradenton, FL

Tee off for a great cause at RMC's annual golf tournament, benefiting education, awareness, and resources for the Prader-Willi community. Enjoy a round of golf while making a positive impact. The RMC Foundation works to provide funding to PWSA | USA's Advocacy programs. These Programs help enrich the lives of people living with Prader-Willi syndrome.

Learn more about this event using the button below.

LEARN MORE

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

This episode is from a session held during the International United in Hope PWS Conference and was recorded on June 28, 2025.

”Teaching Emotional Regulation in Individuals with Prader-Willi Syndrome: ABA Strategies for Lasting Success,” was presented by Kasey Bedard, PhD, BCBA-D assistant professor at The Chicago School. Kasey discusses why emotional regulation is challenging for people with PWS, why tantrums occur, self-regulation vs co-regulation, how to teach emotional regulation skills, and more.

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

LISTEN ON PODBEAN

ADVOCACY

Cuts to Department of Education Affect Individuals with PWS, Call to Action!

Extreme cuts to the Department of Education have forced debilitating layoffs to critical offices including the Office of Special Education Programs, the Rehabilitation Services Administration, the Office for Civil Rights, and the Office of Elementary and Secondary Education. Our loved one's educational opportunities are at risk!

Click the button below to learn more and download a powerful letter from PWS educational leader and advocate Dr. Destiny Pacha to share with your representatives. Please note that at the time of publishing, a judge has temporarily put a halt to these cuts, however, it is very important that we continue to reach out to our representatives on this issue.

Our loved ones matter and they need our voices!

LEARN MORE

FAMILY SUPPORT

PWS Families Gather in Egypt for the Nile Hope Workshop and Camp

Between October 1-4, 2025, PWSA Egypt and the Middle East held their first-ever PWS event in the heart of Egypt. Thanks to a grant from Friends of IPWSO, the Nile Hope Workshop and Camp was able to host more than 120 people (30 families) from across the Arab world, both virtually and in-person, for an incredibly meaningful experience families can carry with them on their PWS journey. Sarah Kasaby, PWSA | USA's Information and Referral Specialist and catalyst for our organization's international efforts, traveled to the Nile Hope Workshop and Camp to help facilitate the event and finally meet the families she's supported over the past four years.

Read more about this event and Sarah's experience in our recent blog by clicking the button below.

READ HERE

Soleno Therapeutics Invites Families to a PWS Community Day!

Soleno Therapeutics invites you to

PWS Community Day

in collaboration with Prader-Willi Syndrome Association | USA, Saving and Transforming Lives; Foundation for Prader-Willi Research

Saturday, October 25, 2025
11:00 AM - 2:00 PM

Please Touch Museum
4231 Avenue of the Republic,
Philadelphia, PA 19131

An afternoon of connection, care, and fun for families in the Prader-Willi syndrome (PWS) community

Families will have access to the museum from 10:00–11:00 AM.

Food will **NOT** be provided during our event, but please feel free to pack a snack or lunch from home. A separate, secure space to dine will be available.

Meet our speakers

Jorge Mejia-Corletto, MD
Pediatric endocrinologist at NYU Langone Health

Caregiver
To a loved one living with hyperphagia in PWS treated with VYKAT XR

SOLENO THERAPEUTICS

vykat XR (diazoxide choline) extended-release tablets

When: **Saturday, October 25, 2025 @ 11 AM - 2 PM ET**
Where: **Please Touch Museum (4231 Avenue of the Republic, Philadelphia, PA)**

Soleno Therapeutics, in collaboration with key advocacy groups, is excited to bring families together to learn, interact, and feel supported by one another. With caregiver sessions and supervised activities for your individuals with PWS and their siblings, this will be a great opportunity for parents and caregivers to network, recharge, learn about VYKAT XR, and strengthen community.

Download a flyer for more information at PWS-Community-Day-Invite.pdf.

Space is limited so please be sure to register using the button below.

REGISTER HERE

Ask Nurse Lynn

Male, 40 years old, deletion subtype

My son turned 40 in December 2025. I feel his memory is getting shorter. Forgetting a lot. Also, talking to himself. He never really did this, but seems to be doing it a lot lately. Is this normal for adults. We are going to his primary soon. Should he have any test done?

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.

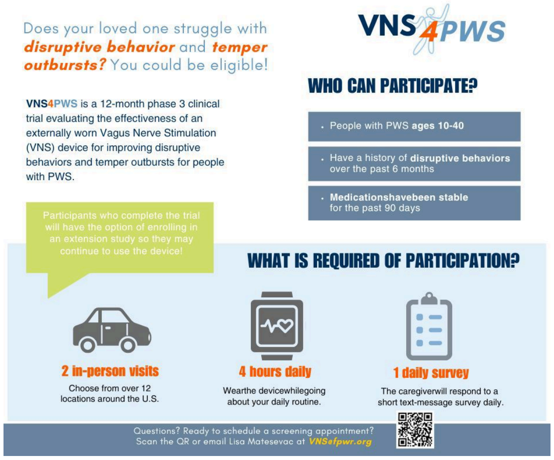
Now you can **Ask Nurse Lynn,** PWSA | USA's very own PWS Nurse.

[ASK YOUR QUESTION HERE]

RESEARCH

FPWR Seeking Participants for VNS Trial

VNS4PWS is a 12-month phase 3 clinical trial evaluating the effectiveness of an externally worn Vagus Nerve Stimulation (VNS) device for improving disruptive behaviors and temper outbursts for people with PWS. FPWR is seeking participants ages 10-40 with a history of temper tantrums over the past 6 months to enroll in this trial. Spots are filling up quickly so please reach out today if you are interested in enrolling your loved one with



Does your loved one struggle with ***disruptive behavior*** and ***temper outbursts?*** You could be eligible!

VNS4PWS is a 12-month phase 3 clinical trial evaluating the effectiveness of an externally worn Vagus Nerve Stimulation (VNS) device for improving disruptive behaviors and temper outbursts for people with PWS.

Participants who complete the trial will have the option of enrolling in an extension study so they may continue to use the device!

WHO CAN PARTICIPATE?

- People with PWS **ages 10-40**
- Have a history of **disruptive behaviors** over the past 6 months
- **Medicationshavebeen stable** for the past 90 days

WHAT IS REQUIRED OF PARTICIPATION?

2 in-person visits
Choose from over 12 locations around the U.S.

4 hours daily
Wearthe devicewhilegoing about your daily routine.

1 daily survey
The caregiverwill respond to a short text-message survey daily.

Questions? Ready to schedule a screening appointment?
Scan the QR or email Lisa Matesevac at ***VNS@fpwr.org***

PWS. Please use the button below to learn more.

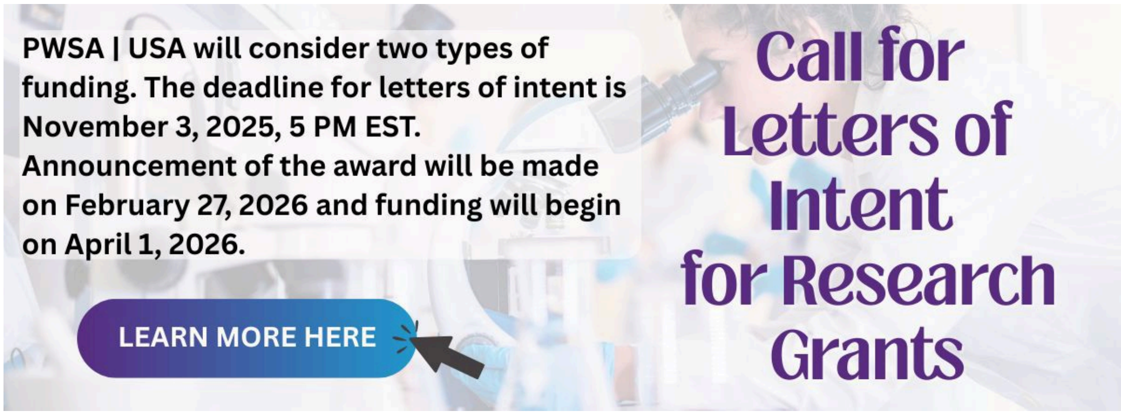
LEARN MORE

Supporting PWS Research

Prader-Willi Syndrome Clinical Scholarships Available

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

LEARN MORE HERE



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LEARN MORE HERE

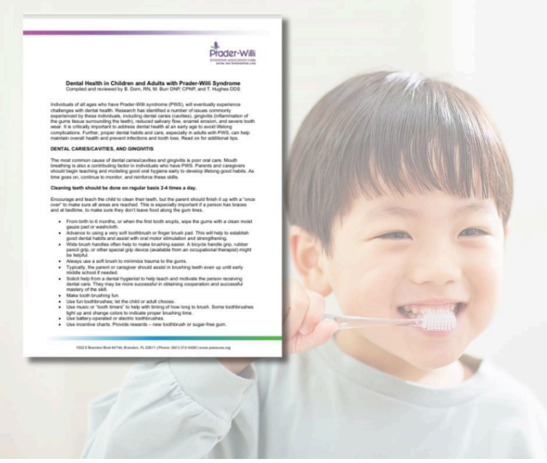
Call for Letters of Intent for Research Grants

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

Individuals of all ages who have PWS will eventually experience challenges with dental health. Research has identified a number of issues commonly experienced by these individuals, including dental caries (cavities), gingivitis (inflammation of the gums tissue surrounding the teeth), reduced salivary flow, enamel erosion, and severe tooth wear. It is critically important to address dental health at an early age to avoid lifelong complications. Further, proper dental habits and care, especially in adults with PWS, can help maintain overall health and prevent infections and tooth loss.

Check out our document *Dental Health in Children and Adults with Prader-Willi Syndrome*, compiled and reviewed by medical professionals B. Dorn, RN, M. Burr DNP, CPNP, and T. Hughes DDS, using the button below.



Dental Health in Children and Adults with Prader-Willi Syndrome
Compiled and reviewed by B. Dorn, RN, M. Burr DNP, CPNP, and T. Hughes DDS

Individuals of all ages who have Prader-Willi syndrome (PWS), will eventually experience challenges with dental health. Research has identified a number of issues commonly experienced by these individuals, including dental caries (cavities), gingivitis (inflammation of the gums tissue surrounding the teeth), reduced salivary flow, enamel erosion, and severe tooth wear. It is critically important to address dental health at an early age to avoid lifelong complications. Further, proper dental habits and care, especially in adults with PWS, can help maintain overall health and prevent infections and tooth loss. Read on for additional tips.

DENTAL CARIES/CAVITIES, AND GINGIVITIS

The most common cause of dental caries/cavities and gingivitis is poor oral care. Mouth breathing is also a contributing factor in individuals who have PWS. Parents and caregivers should begin teaching and modeling good oral hygiene early to develop lifelong good habits. As time goes on, continue to monitor, and reinforce these skills.

Cleaning teeth should be done on regular basis 2-4 times a day.

Encourage and teach the child to clean their teeth, but the parent should finish it up with a "once over" to make sure all areas are reached. This is especially important if a person has braces and at bedtime, to make sure they don't leave food along the gum lines.

- From birth to 6 months, or when the first tooth erupts, wipe the gums with a clean moist gauze pad or washcloth.
- Advance to using a very soft toothbrush or finger brush pad. This will help to establish good dental habits and assist with oral motor stimulation and strengthening.
- Wide brush handles often help to make brushing easier. A bicycle handle grip, rubber pencil grip, or other special grip device (available from an occupational therapist) might be helpful.
- Always use a soft brush to minimize trauma to the gums.
- Typically, the parent or caregiver should assist in brushing teeth even up until early middle school if needed.
- Solicit help from a dental hygienist to help teach and motivate the person receiving dental care. They may be more successful in obtaining cooperation and successful mastery of the skill.
- Make tooth brushing fun.
- Use fun toothbrushes; let the child or adult choose.
- Use music or "tooth timers" to help with timing of how long to brush. Some toothbrushes light up and change colors to indicate proper brushing time.
- Use battery-operated or electric toothbrushes.
- Use incentive charts. Provide rewards – new toothbrush or sugar-free gum.

[DENTAL HEALTH DOCUMENT]

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!

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PWSA | USA Pulse Special Edition Newsletter: October 31, 2025

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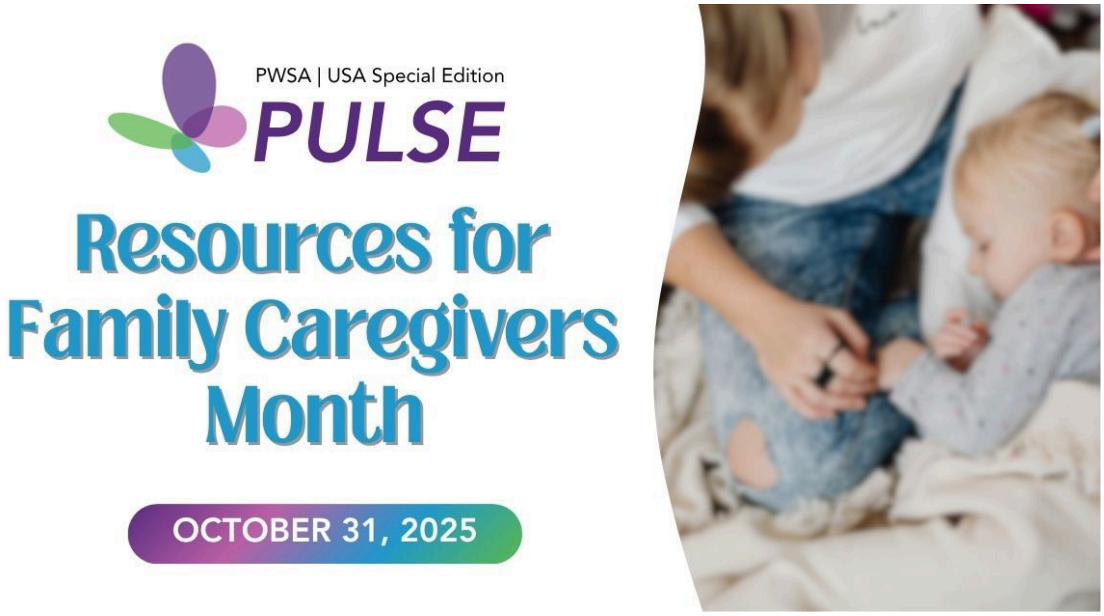


November is National Family Caregivers Month, a great opportunity for our community to reflect, discuss, and take action on caring for our caregivers. Family caregivers are the parents, grandparents, siblings, and other family members who care for individuals with PWS in the home. We celebrate this month, not to dwell on the challenges of being a family caregiver, but to recognize the need of caring for the caregiver as well.

In a time when the term "self-care" gets tossed around as an often elusive anti-dote to a lack of community and resources, our latest blog looks at how families can come together to create spaces of shared respite and resources, freeing one another for some of that much needed self-care.

We also share easy and affordable self-care tips, along with some of our staff's favorite ways to unwind and recharge. For National Family Caregivers Month, we encourage our caregivers to get creative and resourceful, nurture your community connections, and learn how you can ask for help before it’s needed. Read our latest blog using the button below. Keep scrolling to find valuable resources to care for the caregiver, from babysitter and respite care guides, self-care blog posts, informative webinars, and inspiring podcast episodes. Happy National Family Caregivers Month to all of the incredible, valuable, and loved caregivers in our community!

READ HERE

Care Guide for Babysitters

For many families and caregivers, taking time for yourselves, or even to run necessary errands is hindered by a lack of child or respite care. If and when caregivers do find someone willing and capable to take on that role, the job of educating about the specific needs of a loved one with PWS may seem overwhelming. PWS parent and PWSA | USA volunteer Julie Casey shared with us how she manages this obstacle and we made it into an accessible document for families. This packet helps you easily create an informative and potentially life-saving folder designed for the specific needs of your loved one with PWS. We hope this guide helps families feel more comfortable receiving care for your loved one so that you may have a moment to care for yourselves.

Check out our downloadable information packet for babysitters and respite workers by clicking the buttons below.

CARE GUIDE WITH RESOURCE DOCUMENTS

CARE GUIDE WITH DOWNLOADABLE LINKS

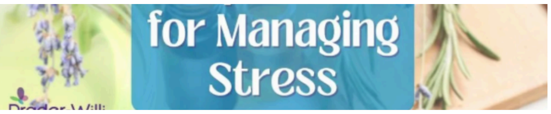
Babysitter and Care Provider Training

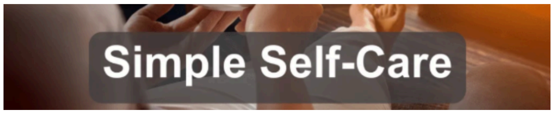
Facilitated by marriage and family therapist Lisa Graziano and mom to Cameron (living with PWS), this training will help your babysitter, respite worker, and even relatives better understand how to care for your child or adult more safely, giving YOU a greater opportunity to enjoy date nights, self-care moments, and even weekends away! The webinar underscores the need to follow parents care exactly and offers strategies to provide food security, decrease arguing, and increase cooperation. Click the button below to watch the webinar and share it with your care providers.

WATCH HERE

Blogs on Self-Care

PWSA | USA offers a growing list of blog articles focused on caregiver support. Below is a curated list of some of those articles. We hope you take a moment to read through these blogs and find some ways to help support yourself as a caregiver. Click on the button to visit our Blog page and see what other articles we offer. From blogs on how some families navigate PWS in adulthood to holiday preparation and gift guides, to advocacy initiatives in Washinton, D.C. and research opportunities for the community, you'll find a variety of





helpful and informative articles on the many aspects of caregiving for someone with PWS.

[Self-Care for Caregivers]

[Simple Tools for Managing Stress]

[Exercise, Movement, and Mental Health]

[Meditation, Mindfulness, and Self-Care]

[Simple Self-Care]

[Journaling as Therapy]

PWSA BLOG

Caregiver Podcast Episodes

As parents and caregivers, caring for ourselves is one of the most important, and most often forgotten, things we can do as a caregiver. If we neglect to take care of ourselves, we may likely find that it is more challenging to care for our loved ones. When our needs are taken care of, the person we care for will benefit, too.

We talk with Emily Felt (mom to Olivia, living with PWS) about what caregiver burnout may look like, various ways to practice meditative activities and why, the importance of self-advocacy and external support, what gratitude does for perspective and mental health, and how and why to keep showing up for yourself.

Our PWS United podcast is dedicated to keeping the PWS community informed on the latest in PWS research, advocacy, and family support offerings. For the month of November, we are dedicating our non-Pulse episodes to single caregivers. We're asking single caregivers about their journeys, their challenges, where they need support, and what advice or "PWS hack" they'd share with other single caregivers. PWSA | USA recognizes that families come in a beautiful variety of shapes and size and we honor and support all families in the PWS community.

Listen to the PWS United podcast on your favorite podcast platform, including YouTube, or on Podbean by using the button below.

LISTEN HERE

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