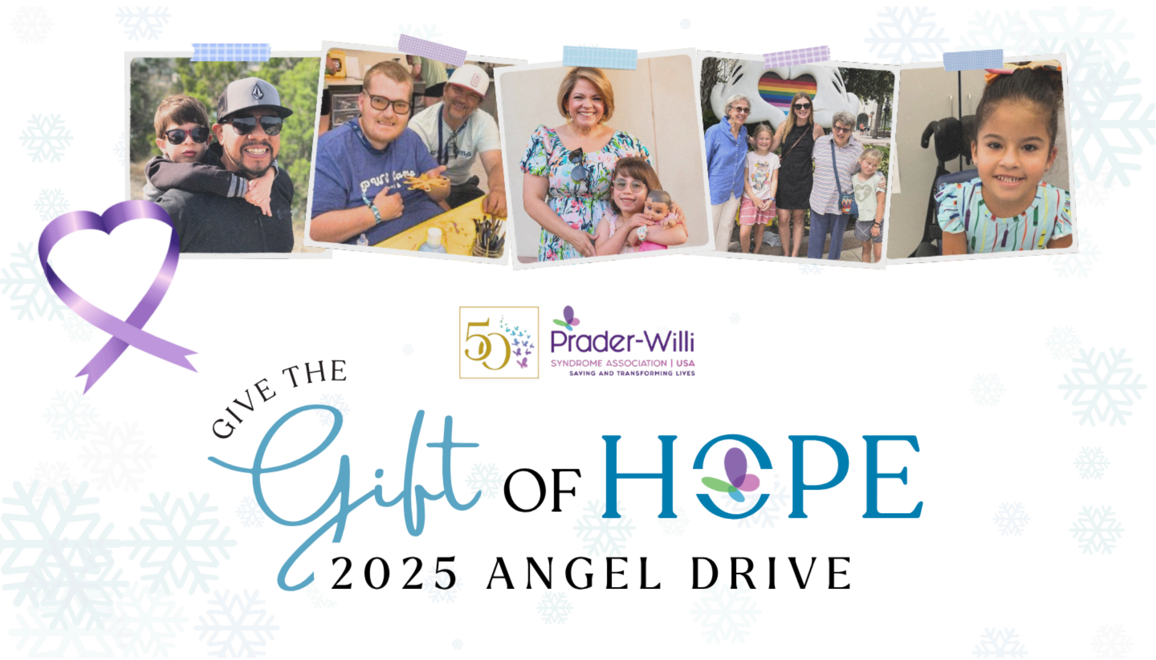
PWSA | USA Pulse Newsletter: November 7, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 134
November 7, 2025

www.pwsausa.org | 941-312-0400



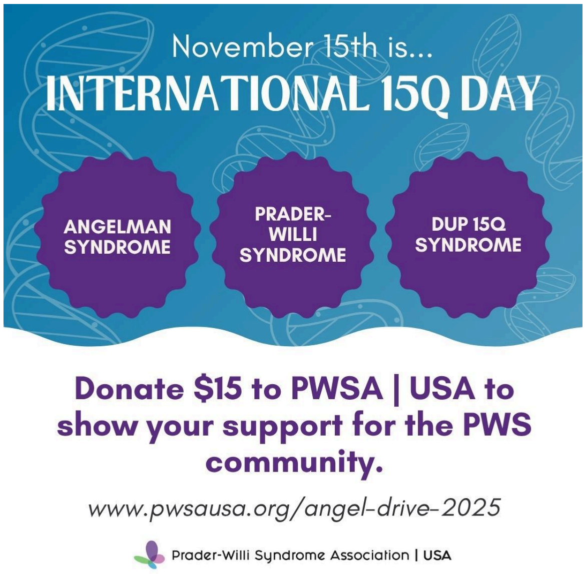
The 2025 Angel Drive Has Officially Kicked Off!

PWSA | USA’s biggest fundraising campaign of the year is here, and this one’s extra special as we celebrate 50 years of hope, progress, and community.

Your gift this season fuels what comes next: preparing for new therapies, expanding early diagnosis, and ensuring every child with Prader-Willi syndrome gets the support they deserve from day one.

The next 50 years begin now, with us. Click the button below to make an impact!

SUPPORT THE 2025 ANGEL DRIVE



November 15, International 15q Day, draws awareness to three syndromes caused by changes within the specific q11 to q13 region of chromosome 15, Prader-Willi, Angelman, and Dup15q syndromes. In honor of 15q Day and our PWS community, we encourage families to donate $15 to our Angel Drive. Please stay tuned to our socials for shareable graphics and posts on that day to encourage your community to donate.

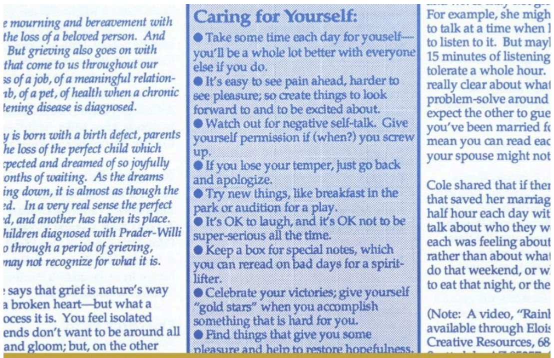
Last year’s Angel Drive campaign introduced ***Hope in Action***, a powerful video series that shares real stories of resilience, hope, and community from families impacted by Prader-Willi syndrome. Each story highlights the many ways PWSA | USA is making a difference, from school success and crisis support to advocacy and beyond, illustrating the strength of our families and the heart of our mission.

Click the image to watch the first video of our new *Hope in Action* season, featuring members

of PWSA | USA's Adults with PWS Advisory Board. Trevor Ryan, Conor Heybach, James Towle, and Abbott Philson share what self-advocacy means to them and why advocacy work is such an important part of their lives.

HOPE IN ACTION

PWSA MEMORIES



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the loss of a beloved person. And
But grieving also goes on with
that come to us throughout our
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may not recognize for what it is.

says that grief is nature's way
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and gloom; but, on the other

Caring for Yourself:

- Take some time each day for youself—you'll be a whole lot better with everyone else if you do.
- It's easy to see pain ahead, harder to see pleasure; so create things to look forward to and to be excited about.
- Watch out for negative self-talk. Give yourself permission if (when?) you screw up.
- If you lose your temper, just go back and apologize.
- Try new things, like breakfast in the park or audition for a play.
- It's OK to laugh, and it's OK not to be super-serious all the time.
- Keep a box for special notes, which you can reread on bad days for a spirit-lifter.
- Celebrate your victories; give yourself "gold stars" when you accomplish something that is hard for you.
- Find things that give you some pleasure and help to restore hopefulness.

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to eat that night, or the

(Note: A video, "Rain
available through Elo
Creative Resources, 6

The Gathered View
Vol. XVII No. 5
September-October 1993

In an article titled "Getting Through the Grief" from the September-October 1993 issue of The Gathered View, Lota Mitchell, MSW, recounted some of the key points of that year's conference session, "Bereavement: Understanding Your Grief." The session was led by Eloise Cole, a nationally known grief specialist, who first appeared as Rainbow the Clown. In the article, Lota shares some different types of grief, how mothers and fathers may experience or express it differently, and tips on how to process it in healthy ways. She included a helpful bulleted list of tips for "caring for yourself."

Read more from this article in The Gathered View, Volume XVII, No. 5, from September-October 1993 using the button below.

THE GATHERED VIEW

SHARE YOUR MEMORY

PWSA | USA'S
SPOTLIGHT ON HOPE

In 2023, Maria K. submitted a Spotlight on Hope for her son, George who is living with PWS. George is a twin and Maria shared, "His twin sister, Nicole, was reaching her milestones and Georgie was painfully behind. He was so persistent though, trying to imitate his twin sister’s every behavior. It was amazing to watch them interact." She talks about the joys of watching George with his siblings, later clarifying, "Don’t get me wrong, we had and still have the typical Prader-Willi negative situations, but my realization is that life’s most unexpected turns can lead to the most profound growth."

Read this Spotlight on Hope using the button below.

READ HERE

SHARE YOUR SPOTLIGHT

EVENTS & FUNDRAISERS

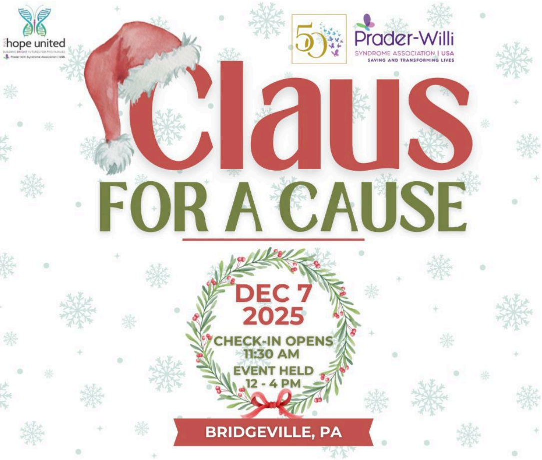
Making Spirits Bright: You're Invited to Attend Claus for a Cause

When: **Sunday, December 7th | 12 - 4 PM ET**
Where: **Bridgeville VFD Station 117 in Bridgeville, PA**

This family-friendly celebration includes pictures with Santa, a healthy meal and kid-friendly seasonal activities.

Claus for a Cause is hosted by a dedicated team of families from the greater Pittsburgh area working together to bring this magical event to life. Holidays can be especially challenging for families like ours, as the season poses unique challenges for children with PWS due to their dietary restrictions. That’s why this event focuses on what truly matters - creating joyful memories, fostering connection, and celebrating the season through togetherness and inclusion.

Every dollar raised will go directly to PWSA | USA to fund advocacy, family support, and vital research to find a treatment for PWS. Use the button below to donate and learn more.



LEARN MORE

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

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

Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

On this week's PWS United podcast episode, our team talks with two moms: Mandy Kemp, mom to Samantha (5, living with PWS) and Lynn Garrick, mom to John (almost 20, living with PWS). Some of what's discussed will resonate with families of all compositions, but some speaks specifically to single caregivers, like carrying the full mental load; feeling isolated; finding trusted care for your loved one; or simply finding time for a much-needed nap. They also talk about how and why to give yourself grace, adapting the in-home culture to fit the needs of the family and having pride in what is created. This episode is the first of our mini-series focusing on single caregivers, and it's a beautiful, insightful look into a few of the many ways families are formed.

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

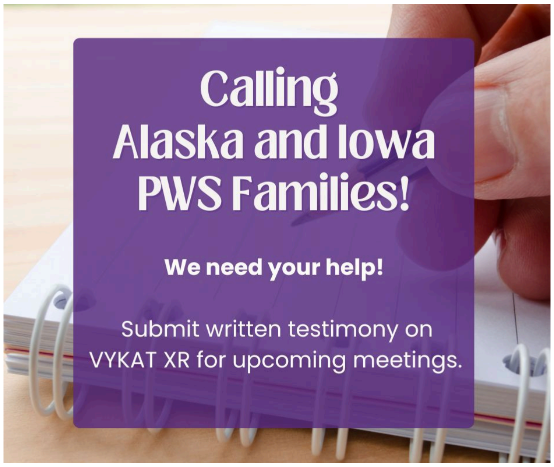
LISTEN ON PODBEAN

In this episode of the Single Caregivers Series, it was suggested that a virtual support group would be a great addition for single caregivers. We are excited to offer the new *Single Caregivers Support Group* Facebook page for single parents caregiving for individuals with PWS to share experiences - the challenges, the joys, the frustrations, the successes, and more. Click the image to check it out.

ADVOCACY

Calling All PWS Families in Alaska and Iowa - We Need Your Help!

The Iowa Medicaid Pharmaceutical and Therapeutics (P&T) Committee and Alaska Medical Assistance Drug Utilization Review (DUR) Committee need 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** or **public comment** if you attend the meeting virtually to help decision-makers understand why access to this treatment is so urgently needed. Families must live in the state they are submitting.

Iowa: Thursday, November 20, 2025
Alaska: Friday, November 21, 2025

If you are a resident of Iowa or Alaska, please use the buttons below to learn more about submitting your testimony.

IOWA P&T MEETING

ALASKA DUR MEETING

Wisconsin Families: We Need Your Voice to Support SB 203

The Wisconsin Senate is considering **SB 203**, a bipartisan bill that protects patients and local pharmacies by holding Pharmacy Benefit Managers (PBMs) accountable. This legislation is especially important for families affected by rare and chronic conditions like Prader-Willi syndrome, who rely on consistent access to medications.

To ensure SB 203 reaches a vote on Tuesday, November 18, we need more state senators to sign on. Find more details and contact information for the senators who have not co-authored SB 203 (as of Nov. 6) at the button below.

LEARN MORE

FAMILY SUPPORT

Operation Holiday Cheer Returns to Support PWS Families in 2025

Thanks to the incredible generosity of an anonymous donor, PWSA | USA is thrilled to bring back Operation Holiday Cheer for 2025!

This heartwarming initiative helps spread joy to families in need by easing the financial burden of the holiday season. Through this program, a select number of families affected by Prader-Willi syndrome will receive gift cards to assist with holiday expenses, ensuring they can focus more on celebrating with loved ones and less on financial stress. If your family could benefit from this support, we invite you to apply by completing our Operation Holiday Cheer application. **Applications are due by Monday, December 1, 2025**, so don’t miss this opportunity to bring a little extra cheer into your home this holiday season! Families will be notified by Friday, December 5, 2025.

You can download the application at the button below and email your completed application to info@pwsausa.org.

DOWNLOAD HERE

Respite & Relationship: PWS Moms' Hiking Weekends

What happened when one PWS mom invited another PWS mom out for a hike? An annual hiking trip that includes a growing number of PWS moms formed! Amy McDougall, mom to Noelle (23, living with PWS), organized the first PWS Moms' Hike in 2024 and the number of attendees doubled in 2025. There are three trips planned already for 2026, with potentially more to come. These hikes not only offer moms a respite from caregiving, but an opportunity to form connections and relationships with moms who understand this life. As one 2025 attendee said, "*The mountains, the conversations, and the community reminded me that I'm not alone on this rare disease journey. I left the retreat feeling lighter, stronger, and deeply grateful.*"

Read more about the PWS Moms' Hike by clicking the button below.

READ HERE

Community Collectives: Creating Support for Caregivers

November is National Family Caregivers Month, and we'd like to take a moment to explore what caring for caregivers may look like. 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 this blog using the button below.

READ HERE

Ask Nurse Lynn

Female, 18 years old, Deletion subtype

If my child becomes constipated, can we use Miralax to help?

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

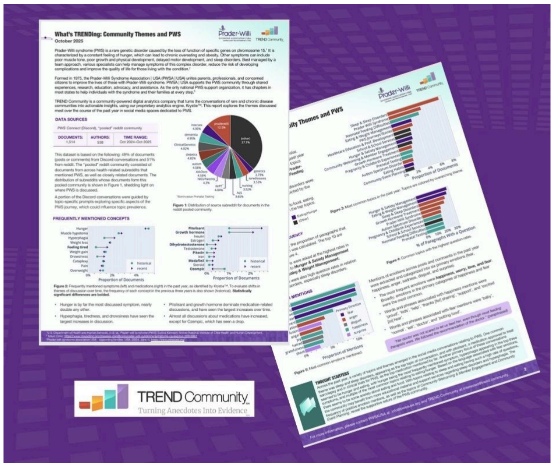
forget to ask every time you’re at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

ASK YOUR QUESTION HERE

RESEARCH

What’s TRENDing: Community Themes and PWS



TREND Community has released another report for the PWS community. 41% of the accumulated data was taken from conversations on Discord. It is important for caregivers to know that names and other identifying information is removed from what is shared in PWS Discord Connect. The conversations in the PWS Connect Discord channel are private, safe, and secure. The data collected does help researchers better understand the journey of PWS, leading to better support for the PWS community. To learn more about how you can help with PWS research and share your experiences in a safe and secure place with other caregivers of PWS, please join us on the PWS Connect channel on Discord. Use the button below to learn how.

To read the recent What's TRENDing report on "Community Themes and PWS," click the button below.

COMMUNITY THEMES REPORT

LEARN MORE AND JOIN

Aardvark HERO Clinical Trial Webinar Recording


aardvark therapeutics

HERO Trials for Treatment of Hyperphagia in PWS

Manasi Jaiman, MD and Tien Lee, MD

October 15, 2025

Watch this 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.

English: https://www.heroforpws.com/

Español: https://www.heroforpws.com/es

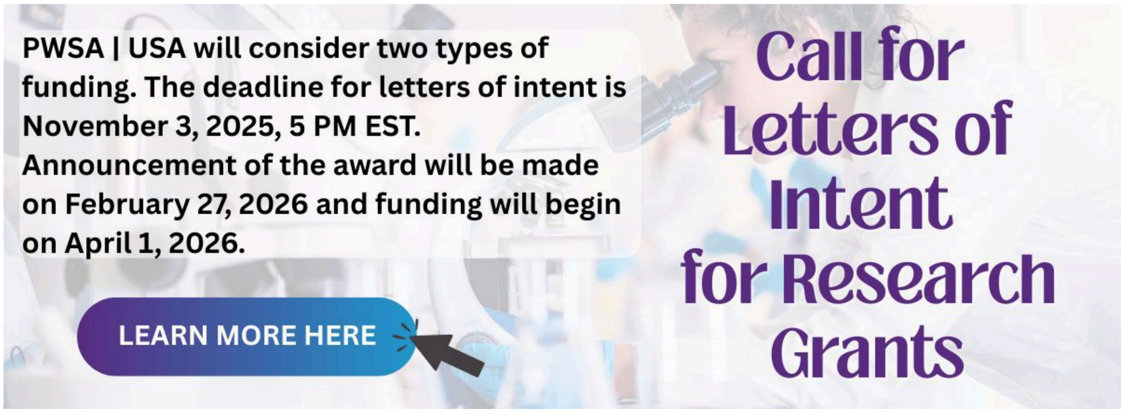
Use the button below to watch this webinar.

WATCH HERE

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.

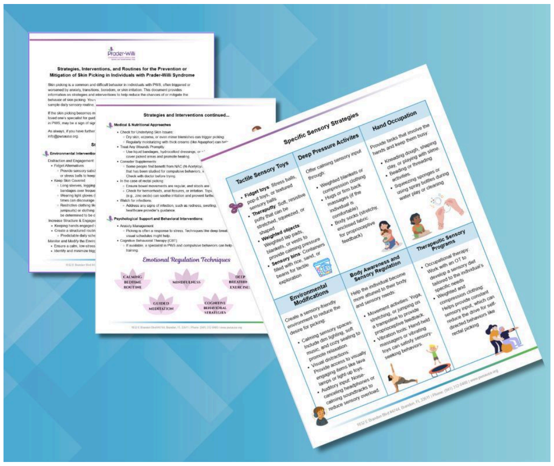


PWSA | USA will consider two types of funding. The deadline for letters of intent is November 3, 2025, 5 PM EST. Announcement of the award will be made on February 27, 2026 and funding will begin on April 1, 2026.

Call for Letters of Intent for Research Grants

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight: NEW RESOURCE!



Skin picking is a common and difficult behavior in individuals with PWS, often triggered or worsened by anxiety, transitions, boredom, or skin irritation. Skin picking behavior may appear as frequent touching, rubbing, or scratching of the skin or nails, sometimes leading to sores or other injuries. In individuals with Prader-Willi syndrome, this behavior can be repetitive and difficult to control, often linked to sensory seeking or anxiety rather than intentional self-harm. This document provides information on strategies and interventions to help reduce the chances of or mitigate the behavior of skin picking. You will also find samples of specific sensory activities and a sample daily sensory routine, all designed for individuals with Prader-Willi syndrome.

Check out our document *Strategies, Interventions, and Routines for the Prevention or Mitigation of Skin Picking in Individuals with Prader-Willi Syndrome* using the button below.

SKIN PICKING 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!

Donate

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

PWSA | USA Pulse Newsletter: November 21, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 135
November 21, 2025

www.pwsausa.org | 941-312-0400

How do we prepare for the holidays? Even in “typical” homes, preparing for the holidays can be challenging. Our planning may be filled with questions like: *who is hosting, who is bringing what dish, who is invited, which family are we visiting on which day, who gets the presents, who makes the mashed potatoes, is* *cherry pie even allowed?* When PWS is introduced to this situation, the holiday preparation stress may skyrocket to seemingly unbearable proportions.

How families prepare and navigate the holidays is unique to each family. There is no one way. We cannot expect what works for one family to work for everyone. Some families continue to avoid sugar throughout the season. Other families allow their loved one some indulgence. And some families just stay home.

It might not be easy. It might be challenging.

We can't control every situation, but we can be flexible and change our decisions as the needs of our family changes, without comparing our choices to what we may see others do. We can remember that we have the strength, the knowledge, (and sometimes the healthy snacks packed in our bags) to get through this time with relative ease and as much joy as we want to bring to the table. We can remember that we have the support of our PWS community and the staff at PWSA | USA when in need.

Below is a list of blog posts and resources to help you make informed decisions:

Celebrate Thanksgiving Safely - Prader-Willi Syndrome Association | USA

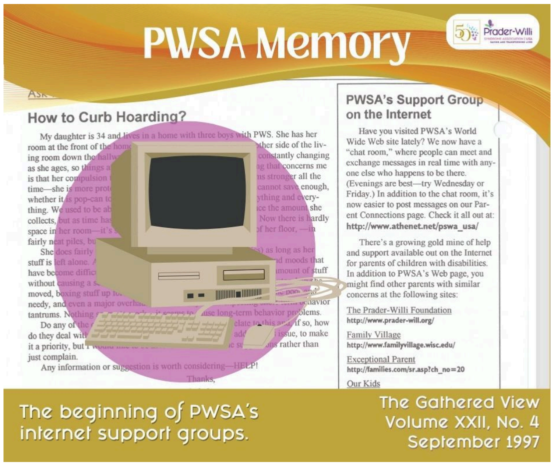
Tips and Techniques for a Safe Holiday Season - Prader-Willi Syndrome Association | USA

Cousins at Christmas: Opening the Conversation of Your Child's Special Needs - Prader-Willi Syndrome Association | USA

A Letter to Friends and Family - Prader-Willi Syndrome Association | USA

PWSA MEMORIES

Have you been in the PWS community long enough to remember when the internet chat groups began? This column from the September 1997 edition of *The Gathered View* asks readers, "Have you visited PWSA's World Wide Web site lately?" As technology advances, so too does the support people are able to tap into. Chat rooms, email threads, Facebook groups...what may be the next iteration in virtual family support?



PWSA Memory

How to Curb Hoarding?

PWSA's Support Group on the Internet

Have you visited PWSA's World Wide Web site lately? We now have a "chat room," where people can meet and exchange messages in real time with anyone else who happens to be there. (Evenings are best—try Wednesday or Friday.) In addition to the chat room, it's now easier to post messages on our Parent Connections page. Check it all out at: **http://www.athenet.net/pswa_usa/**

There's a growing gold mine of help and support available out on the Internet for parents of children with disabilities. In addition to PWSA's Web page, you might find other parents with similar concerns at the following sites:

The Prader-Willi Foundation
http://www.prader-will.org/

Family Village
http://www.familyvillage.wisc.edu/

Exceptional Parent
http://families.com/sr.asp?ch_no=20

Our Kids

The beginning of PWSA's internet support groups.

The Gathered View
Volume XXII, No. 4
September 1997

Read more from this article in The Gathered View, Volume XXII, No. 4, from September 1997 using the button below.

THE GATHERED VIEW

SHARE YOUR MEMORY

PWSA | USA'S SPOTLIGHT ON HOPE

"We try really hard to raise PWS awareness in our area, North Logan, Utah. This year, our local high school's "Latinos in Action Club" and elementary school teachers and students decided that they wanted Temi to have the same experience as other kids, but didn't want her family to have to worry about her safety. They set up a classroom door-to-door trick or treat for just her. The teachers gave her trinkets, fidgets, stuffed animals, books, puzzles, and PWS safe snacks. She had the best time, and at the end of the day, all the other kids left their candy behind and played with Temi and her toys instead. They have decided to do this every year. It is wonderful to live in a community with a school district that cares as much about her needs as we do!" - Submitted by Temi's school

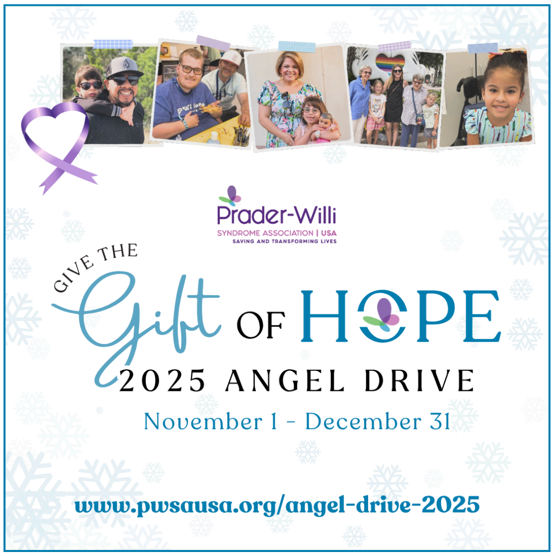
Share your Spotlight on Hope using the button below.

SHARE YOUR SPOTLIGHT

EVENTS & FUNDRAISERS

Give the Gift of Hope This Holiday Season

The 2025 Angel Drive (November 1 - December 31), PWSA | USA's largest annual fundraiser, fuels vital support and hope for individuals and families affected by Prader-Willi syndrome. This year, your gift carries extra meaning as we celebrate PWSA | USA's 50th Anniversary.



Your support powers real progress: preparing for emerging therapies across behavior, metabolism, cognition, and independence; expanding early diagnosis for every child, everywhere; and closing the gap between what families need and what's possible.

Your tax-deductible gift provides hope 24/7/365 - today, tomorrow, and for generations to come.

Thank you for standing with the PWS community. Together, we are united in hope.

MAKE AN IMPACT!

Hope in Action: Shaping the Future of PWS

For 50 years, PWSA | USA has been guided by families, leaders, and visionaries who believed in a stronger future for people living with Prader-Willi syndrome. In our next installment of PWSA's Hope in Action video series, parents David and Janice Agarwal reflect on the legacy that welcomed them into the PWS community and the spirit of passing the baton to the next generation - from advancing research to exploring new possibilities. Help shape the next 50 years of hope by supporting the 2025 Angel Drive.

WATCH HERE

Giving Tuesday, the global day of giving, is coming up on **Tuesday, December 2, 2025**. Your generosity helps PWSA | USA bring hope, support, and strength to those who need it most. More details coming soon! We can't wait to share how you can be part of this special day of hope.

You're Invited! PWS Christmas Experience near PDX

When: **Saturday, December 6, 2025** | 2 PM - 4 PM PT (The space is reserved all evening, so stay and enjoy!)
Where: Comfort Suites Portland Airport Conference Room | 12010 N.E. Airport Way, **Portland, OR,** 97220
Join PWSA of Oregon and Washington at their PWS Christmas Experience - a wonderful free opportunity to connect with other families in a relaxed and supportive environment.
Santa and his helpers will be there to give a special gift to every child and person with PWS of any age. A low-calorie snack and choice of diet drink or

bottled water will be provided for all attendees. There will be activities specially chosen for the guests. Meals are not provided, but dining options are nearby, and guest rooms have a microwave and fridge. Attendees will get the latest information on promising treatments and studies including Aardvark's HERO study and VYKAT XR. A representative from Soleno Therapeutics, the makers of VYKAT XR, will be available to answer your questions about PWS treatment and insurance coverage. Attendees will also be able to learn more about the PWSA map and receive help getting connected to this valuable resource.

Call the Comfort Suites Portland Airport at 503-261-9000 and request the *PWSA discounted rate.* **RSVP by December 3rd** to make this party and the gifts from Santa possible. Email your RSVP to pwsaorwa@gmail.com. Please include the name and age of every child and person with PWS (for Santa's gifts), along with the total number of people in your group.

Thank you to Soleno Therapeutics and Aardvark Therapeutics for sponsoring this event.

Event Recap: Prader Silly Brings Laughter and Hope to Nashville

Nearly a month later, we're still smiling from the unforgettable Prader Silly event! Hosted by Lucy Sinsheimer and Aaron Weber at Zanies Comedy Club

Nashville, the night brought together family, friends, the PWS community, and a standout lineup of comedians to celebrate their daughter, Olive (1), and raise awareness for PWS.

Thanks to everyone involved, the event raised more than $182,000 to support PWSA | USA's advocacy, family support, and research programs.

"We had everyone we love in one room getting behind a cause so near and dear to our hearts. I am so indebted to the amazing talent who donated their time to make us laugh: Brian Bates, Fiona Cauley, Dusty Slay, John Crist, Kathleen Madigan, Leanne Morgan, and Nate Bargatze. You have no idea the difference you have made in so many lives of those affected by PWS. This is not an easy journey, but Prader Silly gave us so much hope for the future."
- Lucy Sinsheimer, Mom to Olive (1)

To Lucy and Aaron, the incredible comedians, Zanies, the sponsors, and every supporter who made the evening possible, thank you for turning laughter into lasting hope for the PWS community.

Click the button below to view the photo gallery (photos by Taylor Brown | @word.doc_brown).

BONUS: *Tune in to next Tuesday's PWS United podcast episode for a special announcement from Lucy!*

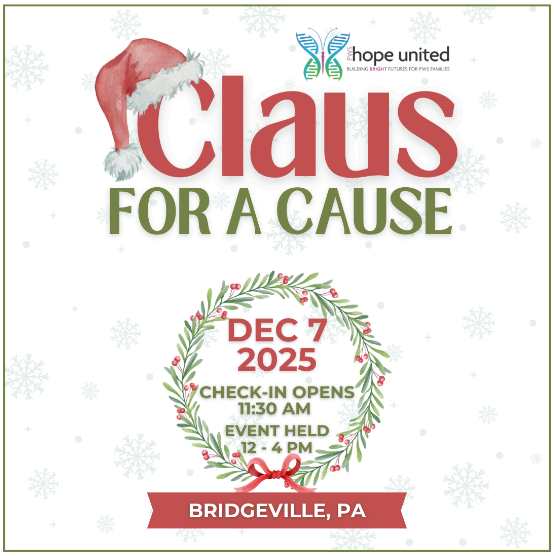
PRADER SILLY PHOTO GALLERY

Claus for a Cause Registration Closing Soon, Silent Auction Now LIVE!

Date: **Sunday, December 7, 2025**
Time: 12:00 - 4:00 PM
Check-in opens at 11:30 AM
Where: Bridgeville VFD Station 117 *(370 Commercial Street, **Bridgeville, PA** 15017)*

Join PWS families from the greater Pittsburgh area for a joyful, inclusive holiday celebration featuring photos with Santa, a healthy meal, and seasonal kids' activities - all designed with the needs of individuals living with Prader-Willi syndrome in mind.

The hosts share: *"Holidays can be challenging for families like ours, and this event is all about creating joyful memories, fostering connection, and celebrating the season together."*



Register by November 29! Every dollar raised supports PWSA | USA's advocacy, family support, and research programs and initiatives.

BONUS - the Silent Auction is now LIVE! Anyone can browse and bid on great items anytime before 3:00 PM EST on December 7.

CLAUS FOR A CAUSE REGISTRATION

CLAUS FOR A CAUSE SILENT AUCTION

Thank You, Claus for a Cause Sponsors

NORTH POLE MAGIC SPONSOR

SOLENO THERAPEUTICS

FOOD & BEVERAGE SPONSOR

BJ's RESTAURANT BREWHOUSE

TINSEL & GOLD SPONSORS

KASHURBA

PANTHER RAREX The Rare Disease Pharmacy

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

Carrie and Anne spoke with two single caregivers, Annie, mom to Adebu who is 36, and Lon, dad to Max who is 31. Both Adebu and Max are living with PWS.

This conversation dives into some challenging and very real aspects of caring for an adult with PWS. Some of it relates directly to single parents of individuals with PWS, and some of it to the cracks and growing lesions in the support systems for adults with disabilities. This is an important and beautiful episode, for its rawness, the vulnerability and willingness of the parents to share their stories, and the reality of the challenges they face when it comes to employment, relationships, obtaining services, and mental health, which Annie says is, “the hidden casualty of my life.”

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

LISTEN ON PODBEAN

We are excited to offer the new *Single Caregivers Support Group* Facebook page for single parents caregiving for individuals with PWS to share experiences - the challenges, the joys, the frustrations, the successes, and more. Click the image to check it out.

ADVOCACY

2026 D.C. Fly-In Application Coming Soon!

Mark your calendars - the 2026 PWSA | USA D.C. Fly-In will take place May 4-6, 2026, in Washington, D.C., at the Yours Truly DC Hotel! We're excited to once again bring 150 members of the PWS community, parents, siblings, supporters, and most importantly, individuals living with PWS, to Capitol Hill to share their voices directly with elected officials.

Applications will be released first to members of PWSA | USA's Advocacy Committee, with public applications opening the first week of January. Be sure to check our website and social media so you don't miss your chance - **spots will fill fast!**

This year, we're introducing travel and lodging scholarship opportunities to help make participation more accessible. Attendees will be responsible for arranging their own travel plans.

We can't wait to return to D.C. during PWS Awareness Month and continue advocating for the needs of our community! If you have any questions about the Fly-In, please contact our Advocacy team at advocacy@pwsausa.org.

Interested in sponsoring the 2026 Fly-In? *Please contact development@pwsausa.org.*

FAMILY SUPPORT

Operation Holiday Cheer Applications Closing Soon

Thanks to the incredible generosity of an anonymous donor, PWSA | USA is thrilled to bring back Operation Holiday Cheer for 2025!

This heartwarming initiative helps spread joy to families in need by easing the financial burden of the holiday season. Through this program, a select number of families affected by Prader-Willi syndrome will receive gift cards to assist with holiday expenses, ensuring they can focus more on celebrating with loved ones and less on financial stress. If your family could benefit from this support, we invite you to apply by completing our Operation Holiday Cheer application. **Applications are due by Monday, December 1, 2025**, so don't miss this opportunity to bring a little extra cheer into your home this holiday season! Families will be notified by Friday, December 5, 2025.

You can download the application at the button below and email your completed application to info@pwsausa.org.

DOWNLOAD HERE

Prader-Willi Syndrome and Diabetes

November 14th was World Diabetes Day. While diabetes is not a certain outcome of PWS, it is not uncommon for individuals with PWS to develop it over time. People with PWS may be at higher risk due to a combination of metabolic and hormonal differences that affect how their bodies use energy and manage blood sugar. The good news is that with balanced nutrition, regular physical activity, ongoing monitoring, and early interventions, individuals can lower their chances of developing diabetes and lessen its impact if it does occur. Our newest blog provides a basic overview of diabetes in people with PWS.

If you are concerned about diabetes, the most important first step is to speak with your loved one’s healthcare provider. Together, you can create a plan for prevention and wellness.

Read this article by clicking the button below.

READ HERE

¡Anuncio! Nuevo Grupo de Apoyo en Español

Hay un nuevo group en Facebook padres/madres de personas que viven con síndrome de prader willi síndrome. Está dirigido a personas que hablan español y viven en los estado unidos. Es un espacio seguro y de confianza para que los padres/madres de niños o adultos con el síndrome de Prader-Willi (SPW) puedan conectarse, compartir recursos, brindarse apoyo y celebrar a sus hijos. Si usted es padre/madre de una persona con el síndrome de Prader-Willi y desea unirse a este grupo, por favor únete al grupo haciendo clic en el botón de abajo.

Únete aquí

Ask Nurse Lynn

Female, 65 years old, Deletion subtype

My sister lives with caregivers in Calgary, Alberta. She turned 65 this year, and over the last few years she has developed a number of health issues. Due to balance issues, she has been using a walker for the last couple of years. It is hard to find any information on PW and aging and was interested when I came across the PWSA blog. In the section on accelerated biological aging, the writer refers to mUPD. What is it? Can you refer me to any other information regarding PW and aging. Thank you.

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

How to Join TREND Community and PWS Connect on Discord

TREND Community has created a "community and research platform founded on the belief that treating rare and chronic diseases starts with understanding the people who live with them." Parents are sharing experiences and engaging in valuable conversations on the PWS Connect channel on Discord. Bi-weekly "journey" prompts initiate conversations, as well as parents seeking advice or connections on the experiences of caregiving for a loved one with PWS.

JOIN PWS CONNECT ON DISCORD TODAY

What is PWS Connect?

PWS CONNECT is a private Discord community for people with PWS and their families. It's built on the belief that better care starts with truly understanding those living with the condition. By joining, you'll play a role in advancing PWS research and advocacy efforts, find supports, and make a real impact in improving how PWS is understood and treated.

Please Note: All personally identifiable information (PII) collected will be de-identified to protect your privacy while allowing researchers to analyze and share the insights produced.

TREND Community Turning Anecdotes Into Evidence X Prader-Willi SYNDROME ASSOCIATION | USA

We invite caregivers of individuals with PWS (parents, grandparents, siblings) to join us on the PWS Connect channel in Discord. Due to recent breaches of privacy in Facebook, we are taking extra measures to ensure the safety and the privacy of PWS Connect. We are limiting access to family members only. We ask for your email upon admission strictly for verification purposes. Join the conversation today! Interested? Email interested@trend.community and we'll send you a private link to join PWS Connect on Discord!

Learn more using the button below.

LEARN MORE HERE

Research Spotlight: The TEMPO PWS Clinical Trial

More Participants Needed!

If your loved one living with Prader-Willi syndrome struggles with excessive daytime sleepiness (EDS) or related behavioral challenges, Harmony Biosciences' TEMPO PWS Study is your opportunity to help drive progress!

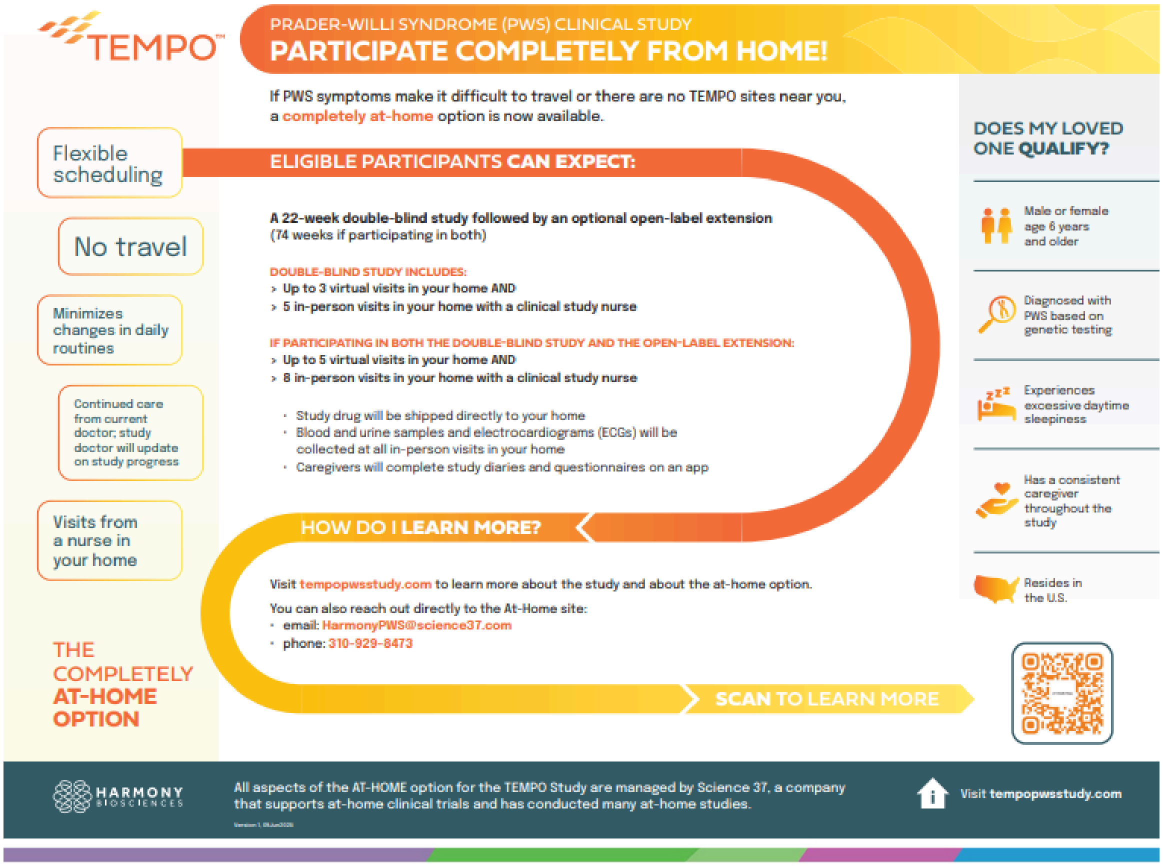
Harmony Biosciences is currently enrolling participants in its global Phase 3 clinical trial studying pitolisant, a potential treatment designed to help manage

excessive daytime sleepiness and behavioral symptoms in individuals with PWS aged 6 and older. Following a successful meeting with the FDA, pitolisant received Orphan Drug Designation, highlighting its promise for our rare disease community. Currently, no FDA-approved treatments exist for EDS in PWS, making this research critically important.

To support wider participation, the TEMPO study now offers **both in-person and fully at-home options**, with trial sites available across the country.

You can learn more about the TEMPO PWS study and its updated participation options below.

TEMPO PWS STUDY



TEMPO™

PRADER-WILLI SYNDROME (PWS) CLINICAL STUDY

PARTICIPATE COMPLETELY FROM HOME!

If PWS symptoms make it difficult to travel or there are no TEMPO sites near you, a completely at-home option is now available.

Flexible scheduling

No travel

Minimizes changes in daily routines

Continued care from current doctor; study doctor will update on study progress

Visits from a nurse in your home

THE COMPLETELY **AT-HOME OPTION**

ELIGIBLE PARTICIPANTS **CAN EXPECT:**

A 22-week double-blind study followed by an optional open-label extension
(74 weeks if participating in both)

DOUBLE-BLIND STUDY INCLUDES:
- **Up to 3 virtual visits in your home AND**
- **5 in-person visits in your home with a clinical study nurse**

IF PARTICIPATING IN BOTH THE DOUBLE-BLIND STUDY AND THE OPEN-LABEL EXTENSION:
- **Up to 5 virtual visits in your home AND**
- **8 in-person visits in your home with a clinical study nurse**

- Study drug will be shipped directly to your home
- Blood and urine samples and electrocardiograms (ECGs) will be collected at all in-person visits in your home
- Caregivers will complete study diaries and questionnaires on an app

HOW DO I **LEARN MORE?**

Visit tempopwsstudy.com to learn more about the study and about the at-home option.

You can also reach out directly to the At-Home site:
- email: HarmonyPWS@science37.com
- phone: 310-929-8473

SCAN TO LEARN MORE

DOES MY LOVED ONE **QUALIFY?**

- Male or female age 6 years and older
- Diagnosed with PWS based on genetic testing
- Experiences excessive daytime sleepiness
- Has a consistent caregiver throughout the study
- Resides in the U.S.

HARMONY BIOSCIENCES

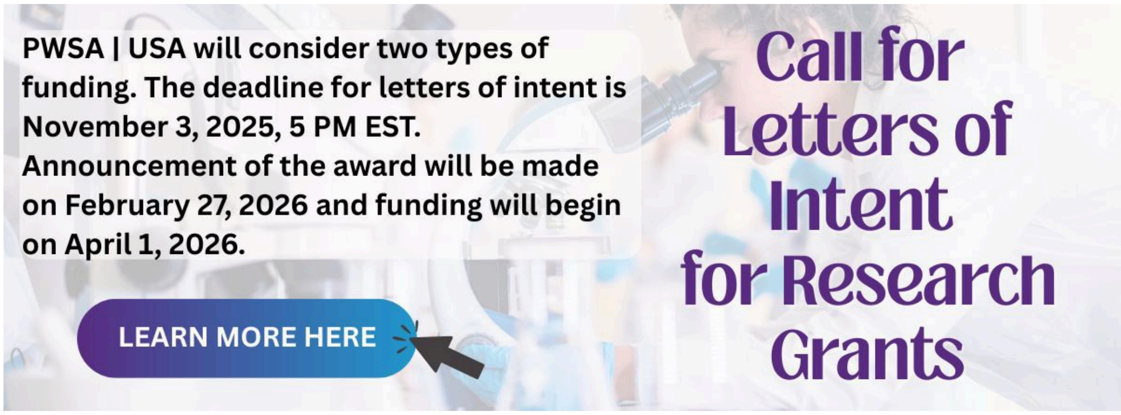
All aspects of the AT-HOME option for the TEMPO Study are managed by Science 37, a company that supports at-home clinical trials and has conducted many at-home studies.

Visit **tempopwsstudy.com**

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.



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.

Call for Letters of Intent for Research Grants

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

Central Adrenal Insufficiency Screening with Morning Plasma Cortisol and ACTH Levels in Prader-Willi syndrome

Written by Moris A. Angulo, Merlin G. Butler, Waheeda A. Hossain, Mariano Castro-Magana, and Jorge Corletto

Reviewed by PWSA | USA's Clinical/Scientific Advisory Board

Central Adrenal Insufficiency (CAI) was identified as a possible risk in PWS in 2009 by a team of researchers in The Netherlands. At that time, PWSA | USA recommended testing all individuals with PWS for this potentially life-threatening deficiency. Since 2009, researchers in other countries have published studies that did not find the high rates of CAI found in the original paper. A review paper, summarizing all such studies, was published in 2016. It suggested that CAI may not be common in the PWS population, especially in adults, but recommended that physicians continue to test for this deficiency. These authors also encouraged more research in this area.

Central Adrenal Insufficiency is caused by the deficiency of pituitary Adrenocorticotropin Hormone (ACTH). The adrenal glands make three hormones – cortisol (important for energy and sugar balance); androgens (male-like hormones that cause growth of underarm and pubic hair) and aldosterone (important in control of salt balance). ACTH controls the adrenal gland's secretion of cortisol. The adrenal glands make adrenaline independently of ACTH.

Cortisol hormone levels vary during the day, with a strong burst in the early morning and variations as needed for physical stress on the body. CAI is a very rare condition and a difficult diagnosis to make. The testing is complicated, and the most accurate tests carry risks or are unavailable in the USA. A recent study published by Angulo and Butler in 2022 confirms that morning (7-9 AM) plasma cortisol and ACTH levels in PWS are comparable with control subjects, i.e., normal. Assessment of morning cortisol and ACTH levels should be considered as initial screening for CAI. Individuals with low levels of should be referred for dynamic testing by an endocrinologist to confirm CAI.

Individuals who take Hydrocortisone (cortisol) pills daily must wear medical alert bracelets and take "stress doses" by mouth or emergency injection in cases of significant illness, injury, or surgery. There may be some individuals who produce normal daily quantities of cortisol, but who need stress dosing. If your child is currently on Hydrocortisone, you should continue this medication and discuss these new findings at your next appointment. It is dangerous to suddenly stop taking this medication. There are people with PWS who clearly have inadequate cortisol production and who benefit from this medication.

1032 E Brandon Blvd #4744, Brandon, FL 33511 | Phone: (941) 312-0400 | www.pwsausa.org

Central Adrenal Insufficiency is caused by the deficiency of pituitary Adrenocorticotropin Hormone (ACTH). Central Adrenal Insufficiency (CAI) was identified as a possible risk in PWS in 2009 by a team of researchers in The Netherlands. Since 2009, researchers in other countries have published studies that did not find the high rates of CAI found in the original paper. However, there are people with PWS who clearly have inadequate cortisol production. If you have questions or concerns, please contact your loved one's doctor for more information and possible testing.

Check out our document *Central Adrenal Insufficiency Screening with Morning Plasma Cortisol and ACTH Levels in Prader-Willi syndrome* using the button below.

READ HERE

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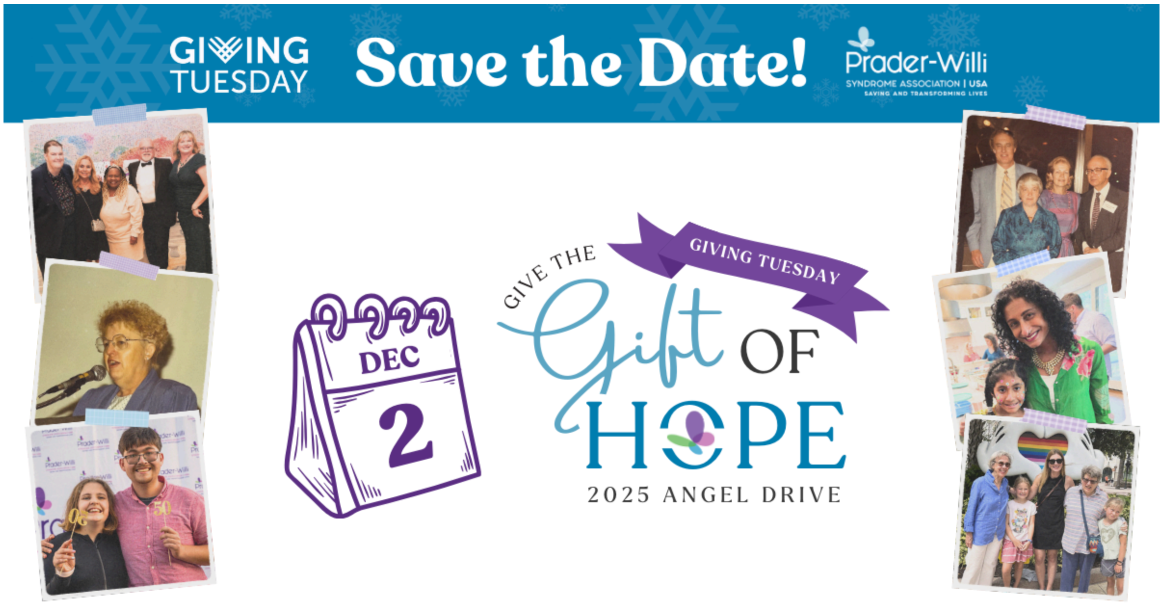
Prader-Willi Syndrome Association | USA
1032 E Brandon Blvd #4744 Brandon, FL 33511

PWSA | USA Pulse Special Edition Newsletter: November 28, 2025



Double Your Impact on Giving Tuesday – Tuesday, December 2, 2025!

Are you planning on making a year-end gift? **Giving Tuesday** is just a few days away and is the perfect opportunity to show your support! Thanks to the generosity of a group of anonymous donors, your Giving Tuesday donation made to PWSA | USA's **Angel Drive** will be **MATCHED** dollar for dollar up to **$20,000**. Make a gift anytime on ***December 2, 2025,*** and give twice the good this holiday season!

Learn How You Can Make an Impact

DONATE TODAY!

Hope in Action: Finding Strength in Community

Our next **Hope in Action** video features parents Pia and David Dorson, who share what community and support have meant for their family. As parents to seven-year-old Zahra, who is living with Prader-Willi syndrome, they've seen firsthand how essential connection, guidance, and understanding truly are.

In their story, Pia and David reflect on the many ways PWSA | USA has walked alongside them - from educational resources and IEP support to counseling, advocacy, and meaningful connections with other parents who really "get it." David speaks to the impact of finding a network of dads who understand the journey, while Pia highlights the power of advocacy and the importance of raising our voices for rare disease legislation.

Together, they remind us that no family should navigate PWS alone.

By supporting the 2025 Angel Drive, you are ensuring every family has the strength, knowledge, and community they deserve.

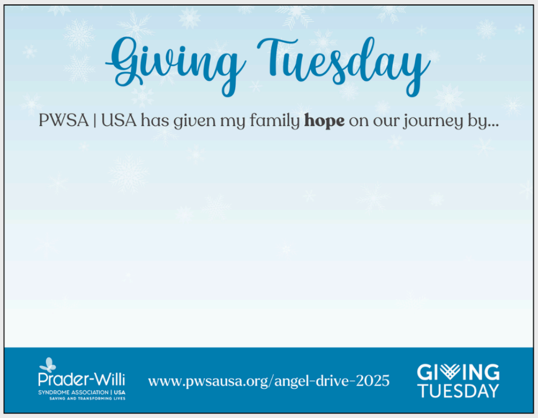
Click here to watch more Hope in Action video stories!

Calling All PWS Families!
Share Your Hope

Join the heartwarming movement by sharing your **HOPE**! Help us understand the impact PWSA | USA has had on you and your family's PWS journey. Your unique story is invaluable, and we invite you to fill out the form at the button below (when you are redirected to the webpage, scroll to the bottom to find the form). In the form, you'll find a couple of questions and an opportunity to share a cherished photo that encapsulates your journey. You can also click the images below to download our **Giving Tuesday HOPE** sign. Simply print the sign, write your message, and share a photo holding it up on your social media pages on December 2nd. Don't forget to tag PWSA | USA in your post (@pwsausa)!

As we embark on our Angel Drive campaign, these testimonials will serve as powerful beacons of inspiration, fostering hope and solidarity within our cherished community. We sincerely appreciate your participation.

Click Here to Share
Your HOPE



Giving Tuesday

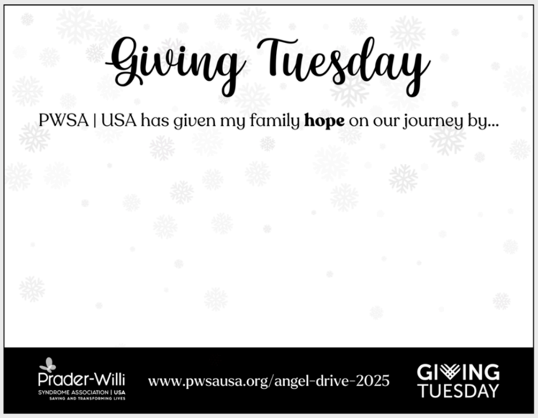
PWSA | USA has given my family **hope** on our journey by...

Prader-Willi Syndrome Association | USA Saving and Transforming Lives

www.pwsausa.org/angel-drive-2025

GIVING TUESDAY

CLICK HERE TO DOWNLOAD



Giving Tuesday

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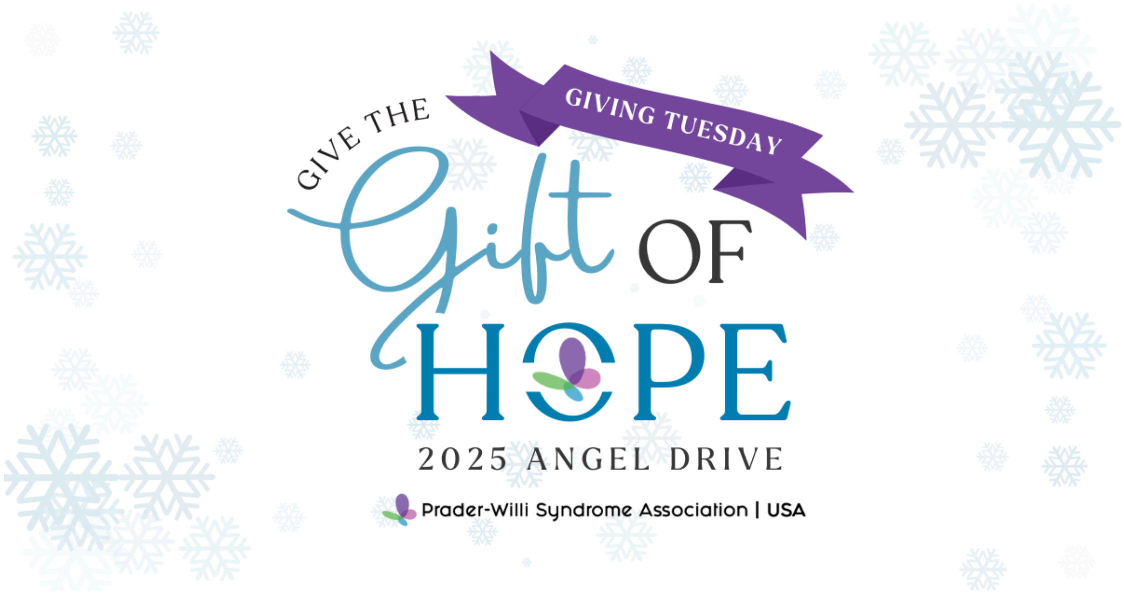
Prader-Willi Syndrome Association | USA Saving and Transforming Lives

www.pwsausa.org/angel-drive-2025

GIVING TUESDAY

CLICK HERE TO DOWNLOAD

Wishing Our Families Peace, Joy, and Love This Holiday Season!



Donate

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