PWSA | USA Pulse Newsletter: December 5, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 136

December 5, 2025

www.pwsausa.org | 941-312-0400

Thanks to your incredible support, we are halfway through our *Angel Drive: Give the Gift of Hope* campaign and halfway to reaching our fundraising goal! Your contributions ensure that PWSA | USA can continue providing critical programs and services for families, while also paving the way for exciting new events, services, and resources in 2026 and beyond.

But we can’t do it without you. Together, we can cross the finish line! Your gift today will help us meet our goal and continue empowering the PWS community.

You can make a tax-deductible donation to the 2025 Angel Drive campaign through December 31st at the button below.

MAKE AN IMPACT

We also want to extend our heartfelt thanks to everyone who doubled their impact on Giving Tuesday and to the anonymous donors who made the $20,000 match opportunity possible. Your generosity is a testament to the strength and spirit of our community. Click on the image to hear our CEO Stacy Ward's message of gratitude!

Hope in Action: Carol's Story

When Carol and Tim Hearn first learned their son David had Prader-Willi syndrome more than 30 years ago, hope was hard to find. In our newest *Hope in Action* video, Carol reflects on those early days, the limited guidance families once received, and how PWSA | USA became a lifeline of trusted information, support, and connection.

Now, 50 years later, Carol sees just how far the PWS community has come and how much brighter the future is for newly diagnosed families today. Her story is a powerful reminder that progress is built one family, one advocate, and one generation at a time.

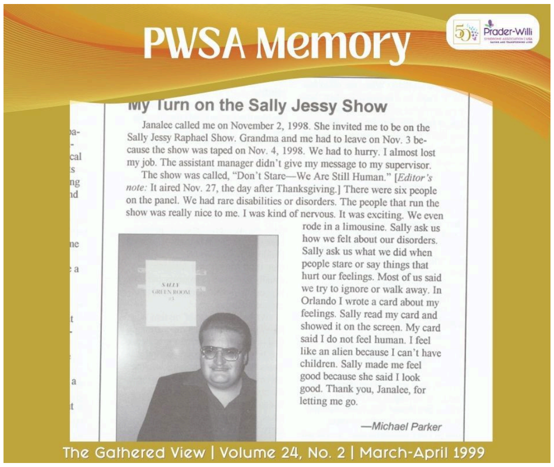
This video is part of our *Hope in Action* series for the 2025 Angel Drive campaign. Your support helps ensure families receive not just a diagnosis - but real hope and real help.

Watch the video below and support the 2025 Angel Drive today!

WATCH HERE

PWSA MEMORIES

On November 27, 1998, the Sally Jessy Raphael Show aired an episode titled, "Don't Stare--We are Still Human." Michael Parker, a young man with Prader-Willi syndrome, was on the 6-person panel sharing his journey as someone with



PWSA Memory

My Turn on the Sally Jessy Show

Janalee called me on November 2, 1998. She invited me to be on the Sally Jessy Raphael Show. Grandma and me had to leave on Nov. 3 because the show was taped on Nov. 4, 1998. We had to hurry. I almost lost my job. The assistant manager didn't give my message to my supervisor.

The show was called, "Don't Stare—We Are Still Human." [*Editor's note:* It aired Nov. 27, the day after Thanksgiving.] There were six people on the panel. We had rare disabilities or disorders. The people that run the show was really nice to me. I was kind of nervous. It was exciting. We even rode in a limousine. Sally ask us how we felt about our disorders. Sally ask us what we did when people stare or say things that hurt our feelings. Most of us said we try to ignore or walk away. In Orlando I wrote a card about my feelings. Sally read my card and showed it on the screen. My card said I do not feel human. I feel like an alien because I can't have children. Sally made me feel good because she said I look good. Thank you, Janalee, for letting me go.

—Michael Parker

The Gathered View | Volume 24, No. 2 | March-April 1999

a disability. In the Volume 24, No. 2 issue of *The Gathered View* from March-April 1999, Michael was praised for spreading awareness about PWS on a national stage.

Read this article of *The Gathered View* by clicking the button below.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S SPOTLIGHT ON HOPE

In December of 2023, we released a Spotlight on Hope video with the Saacks family. We spoke with Sharon (mom to Andrea, living with PWS) and Andrea's sister, Leora. The sisters grew up in South Africa and, at the time of the video, lived in Philadelphia. Sharon and Leora talked with us about their relationship growing up, how education on PWS affected their lives, and how their relationships with Andrea have evolved. Like many families, Leora says hers has greatly benefitted from PWSA | USA – the family support, resources, advocacy, and all we offer our community.

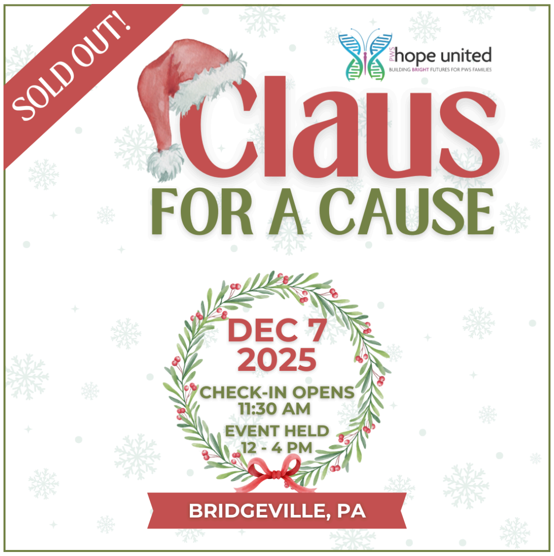
"I think the Prader-Willi Syndrome Association is phenomenal. It's literally been a lifesaver for my family. I think having resources and people who really understand what the needs of a Prader-Willi person and the needs of a Prader-Willi family are has been invaluable,"

Read this Spotlight on Hope and watch the interview by clicking the button below.

READ | WATCH HERE

EVENTS & FUNDRAISERS

Claus for a Cause is Just Days Away!



This festive holiday event, hosted by several PWS families in the greater Pittsburgh area, is officially **SOLD OUT**! Claus for a Cause, benefiting PWSA | USA, will be held on Sunday, December 7th, at the Bridgeville Volunteer Fire Department Station 117 in Bridgeville, PA.

For registered attendees, here's a glimpse of what's in store:

- Check-in: 11:30 AM
- Lunch: 12–2 PM
- Santa photos: 1–4 PM
- Face painting & therapy pup fun: 1–3 PM
- Silent auction closes: 3 PM

Please visit the registration desk upon arrival. If your guest list has changed, contact the organizers at pghpws@gmail.com. Full details and FAQs are available here: Claus for a Cause FAQs

Not registered? You can still support Claus for a Cause by donating or bidding in the silent auction.

A note from the organizers:
"Your generosity and support help lighten burdens, fuel hope, and remind families navigating Prader-Willi syndrome that they are not alone. Every donation, bid, share, and kind word makes a meaningful difference this holiday

season and beyond. From our families to yours, thank you for helping us move closer to a brighter future."

WATCH THANK YOU MESSAGE

Thank You, Claus for a Cause Sponsors

NORTH POLE MAGIC SPONSOR

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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

We're excited to share our latest **Sibling Advocacy** episode on *PWS United*. In this ongoing series, we talk with siblings about how they show up for their loved ones with PWS, whether at the kitchen table, at school, among friends, in government spaces, or anywhere their sibling may need support.

This episode is hosted by Elaine Towle, PWSA | USA's Advocacy Specialist and mom to James, living with PWS. Elaine spoke with Joe Gill, the older brother of Gavin, an almost 20-year-old living with PWS. Joe talks about growing up with

PWS in the house, what inclusion looks like for Gavin, the need for opportunities for adults, and offers some advice for other siblings on this journey. In 2022, as part of raising funds and awareness, Joe ran the Boston Marathon.
Find this episode of *PWS United* on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

A Milestone for Hope: U.S. House Passes the Give Kids a Chance Act

We're celebrating a monumental victory for the rare disease community! On December 1, 2025, the U.S. House of Representatives passed the *Give Kids a Chance Act*, a landmark step toward restoring critical incentives for developing treatments for children with pediatric cancers and rare diseases - including Prader-Willi syndrome.

What does this mean for the PWS community, and why is the Senate vote so critical? In our latest advocacy blog post, PWSA | USA's Director of Community Engagement, Dorothea Lantz, breaks down why this legislation is a potential game-changer for our families, and why our advocacy must continue.

Click the button below to learn what’s next and how you can help.

READ MORE

FAMILY SUPPORT

Reflections from PWSA | USA's Visit to PANTHERx Rare Pharmacy

Last month, a few of our PWSA | USA staff members spent a meaningful day with the PANTHERx Rare Pharmacy team - sharing lived experiences, exchanging insights, and connecting on what it truly means to support individuals and families affected by PWS.

The conversations were emotional, honest, and full of hope. Click the button below to read each staff member’s personal reflection in our latest blog post.

READ HERE

"The visit to PANTHERx Rare Pharmacy was truly unforgettable. Their branding and logo immediately stood out, so thoughtful and polished, but it was their warmth and genuine hospitality that really made an impact. What moved me most was their deep desire to understand the lived experience of people with PWS. As we shared stories, you could feel how much it resonated, and seeing both their team and ours brought to open tears is something I’ll never forget. One of the most touching moments was watching them embrace Josie, Melanie’s 7-year-old daughter living with PWS - the kindness, curiosity, and compassion they showed her spoke volumes. It was a beautiful reminder of the heart behind this work and the power of true connection."

- Stacy Ward, MS, BCBA, PWSA | USA CEO

Adoption Spotlight: Meet Santino

Shared on behalf of The Children's Home of Pittsburgh

Santino is a Caucasian 2 month old baby boy. Santino has a diagnosis of the genetic disorder Prader Willi Syndrome. He has a G-tube and is currently doing well overall. Santino has hypotonia, for which he is receiving speech, PT, and OT. He has follow-up appointments with specialists at UPMC Children's Hospital of Pittsburgh.

Santino's birthparents are making a private adoption plan. They would like for his name to be kept. They prefer a family that practices Catholicism or Christianity. The birthparents would like ongoing contact with the adoptive family. While this is a private adoption, due to Santino's medical needs, there are minimal fees involved. To learn more about Santino, contact Erika Schmitt at The Children's Home of Pittsburgh at eschmitt@chomepgh.org or 412-441-4484.

Ask Nurse Lynn

Male, 32 years old, deletion subtype

My son has been taking testosterone for 18 years, but his LH blood test is 1.1 low. Is it normal for him?

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

HERO Study Update: FDA Expands Trial Access for Individuals with PWS

Exciting clinical trial news! Earlier this week, the FDA officially approved Aardvark Therapeutics' protocol amendment to their Phase 3 HERO clinical trial for ARD-101, expanding eligibility and opening the door for younger individuals living with PWS to participate. This update means:

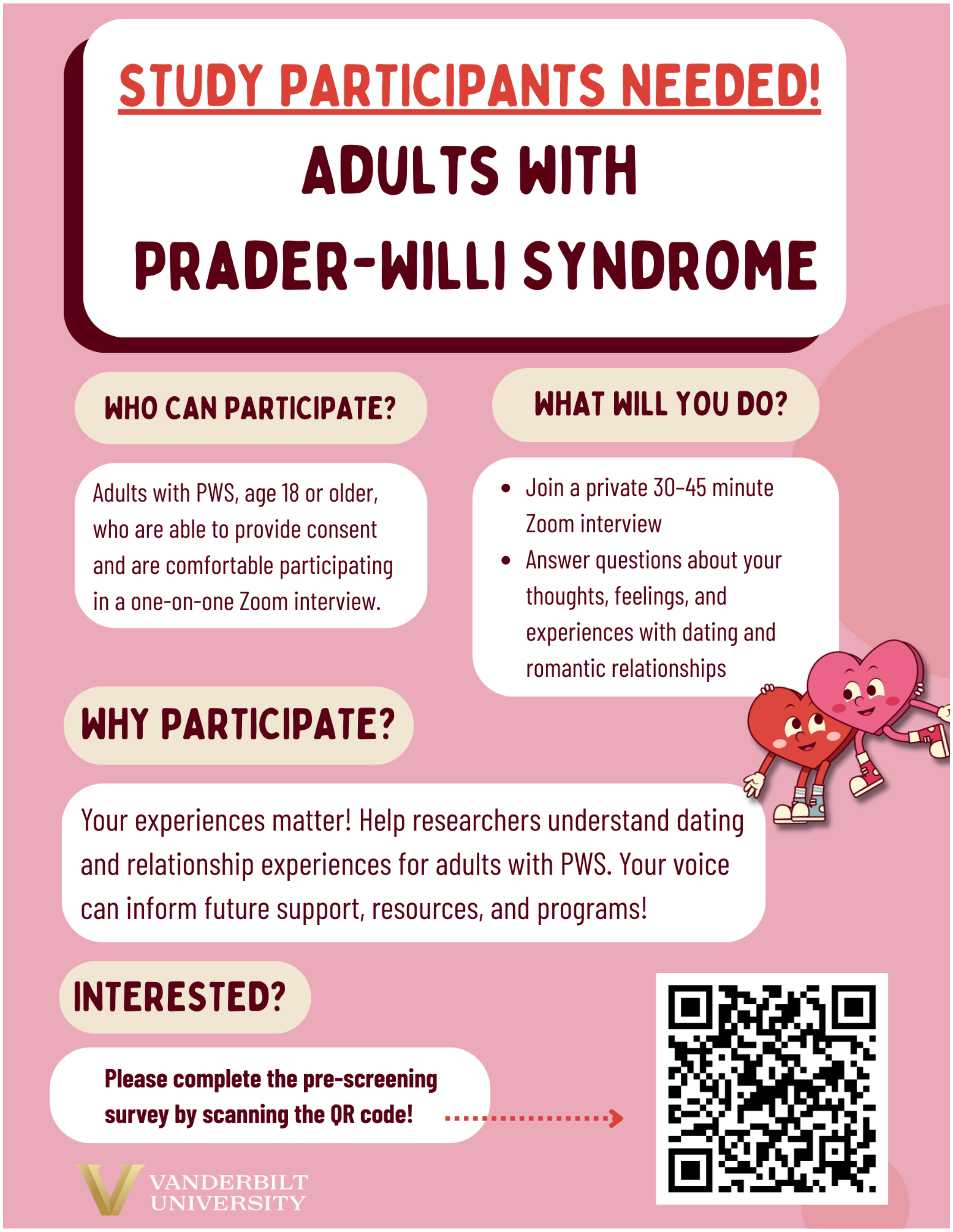
- Individuals aged 10 and older can now enroll
- Those previously on the waitlist (between the ages of 10-12) are now eligible to join
- More opportunities for early intervention and expanded access

We are encouraged by this important step forward and what it means for individuals and families in the PWS community. ARD-101 is an investigational therapy being studied to help manage hyperphagia in individuals with PWS.

Click the button below to learn more.

LEARN MORE

Adults with PWS Invited to Share Their Perspectives



STUDY PARTICIPANTS NEEDED!

ADULTS WITH PRADER-WILLI SYNDROME

WHO CAN PARTICIPATE?

Adults with PWS, age 18 or older, who are able to provide consent and are comfortable participating in a one-on-one Zoom interview.

WHAT WILL YOU DO?

- Join a private 30-45 minute Zoom interview
- Answer questions about your thoughts, feelings, and experiences with dating and romantic relationships

WHY PARTICIPATE?

Your experiences matter! Help researchers understand dating and relationship experiences for adults with PWS. Your voice can inform future support, resources, and programs!

INTERESTED?

Please complete the pre-screening survey by scanning the QR code! →

VANDERBILT
UNIVERSITY

DOWNLOAD THE FLYER

Call for Caregivers of Children with PWS to Participate in Play Skills Study

The Chicago School is looking for participants to learn more about the effects of caregiver training on play skills for children with PWS.

The purpose of this study is to evaluate the effects of virtual caregiver training to teach caregivers to use behavioral interventions to improve social skills in play in children with PWS. Caregivers will participate in a 5- to 7-week virtual caregiver training program, complete pre and post training surveys, and video record play sessions with their child. Participation in this study will require between 60 minutes and 2 hours per week. The training and surveys will be done entirely online via Zoom and QuestionPro. Participants will be provided with a $300 Visa gift card upon completion of this study.

To participate:

- You must be at least 18 years of age.
- Have a child with PWS between the ages of 5 and 10 and live in the same home as your child.
- Speak and read English.
- Have access to a device with videorecording and videoconferencing capabilities.
- Your child must have at least one deficit in social play skills (e.g., sharing, turn taking, communicating during play).

Use the button below to find out if you qualify. For questions, please contact: kkrukowski1@thechicagoschool.edu

TAKE ELIGIBILITY SCREENER

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.

IN MEMORY OF

In Loving Memory of

Fausta Deterling

10/17/1931 - 11/23/2025

PWSA | USA Co-Founder, Mom to Curtis (living with PWS)

We are deeply saddened to share the passing of **Fausta Margaret Deterling**, co-founder of the Prader-Willi Syndrome Association, who passed away peacefully on November 23, 2025, at the age of 94.

Fifty years ago, alongside her husband, Gene, Fausta helped create and build PWSA | USA (then known as Prader-Willi Syndrome Parents and Friends). At a time when very little was known about PWS and families had few places to turn for guidance or support, Fausta stepped forward with courage and determination. As the devoted mother of Curtis, who is living with Prader-Willi syndrome, she transformed both personal challenge and professional skill into a lifelong mission of advocacy, education, and hope. What began as a mother's desire to help her own son grew into an international beacon of support for thousands of families around the world.

Fausta helped lay the foundation for the PWS community we know today. Her legacy lives on not only through PWSA | USA, but through the countless lives touched by her strength and compassion, and through Curtis, who recently celebrated his 54th birthday in good health.

Fausta will be deeply missed by the entire PWS community. We hold her family close in our hearts during this time of loss.

We invite you to read more about Fausta's remarkable life and legacy at the button below.

READ MORE

A memorial service is being planned for after the holiday travel disruptions, with further information to come. In lieu of flowers, memorials preferred to the Prader-Willi Syndrome Association at https://www.pwsausa.org/.

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

As the holidays fast approach, we're re-sharing our holiday gift guide that focuses not on ages, but on sensory needs and desires. Gift shopping for the holidays can be stressful and overwhelming. Sifting through gift guide after gift guide that categorizes by age group and the developmental assumptions that go along with those can bring even more frustration. This sensory level-inspired gift guide can help you curate a successful, appropriate, and fun list for your holiday shopping. Check out this blog post 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 Newsletter: December 19, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 137

December 19, 2025

www.pwsausa.org | 941-312-0400

Time is Running Out to Support the

2025 ANGEL DRIVE!

Less than two weeks remain to support PWSA | USA's 2025 Angel Drive!

For 50 years, families affected by Prader-Willi syndrome have turned to PWSA | USA as a lifeline — when a diagnosis arrives, when fear sets in, when answers feel out of reach. Because of supporters like you, help has been there: steady, compassionate, and unwavering.

As we mark the end of this milestone year, we're reminded that the heart of our mission has never changed: ensuring no family walks this journey alone, and doing everything we can to help those living with PWS thrive. We're close to our Angel Drive goal, but we can't cross the finish line without you.

Your gift today honors 50 years of hope and carries that legacy forward for the next generation of families who will need us tomorrow. Please consider making a tax-deductible gift through December 31st.

The next 50 years begin now, with us.

MAKE AN IMPACT

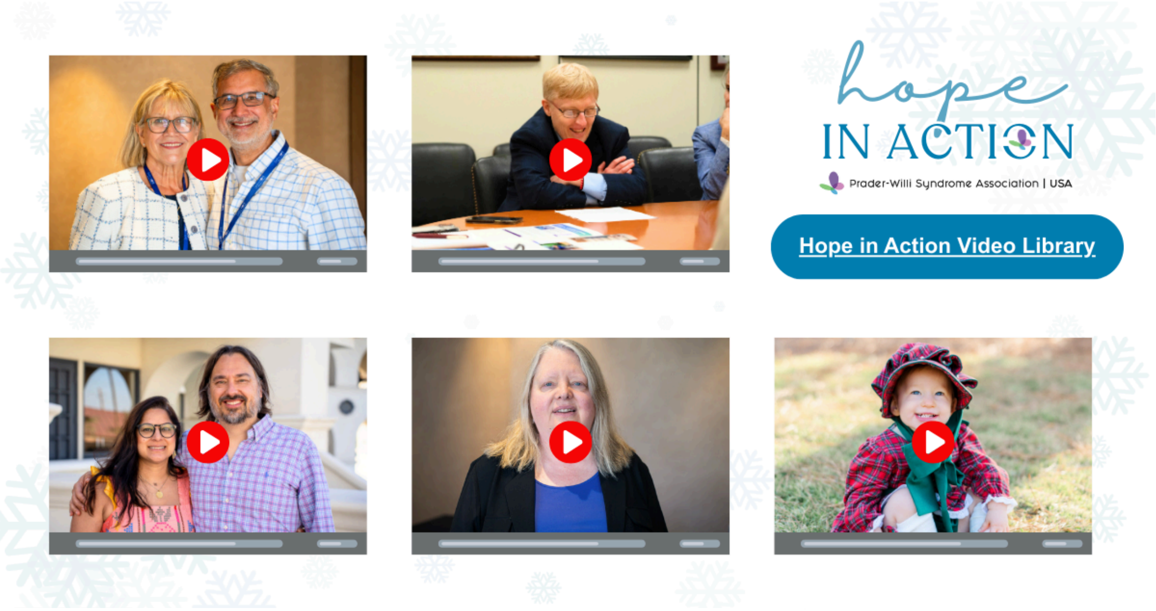
How Your PWSA | USA Angel Drive Gift Supports Newly Diagnosed Families

How Your **Angel Drive** Gift Supports Newly Diagnosed Families

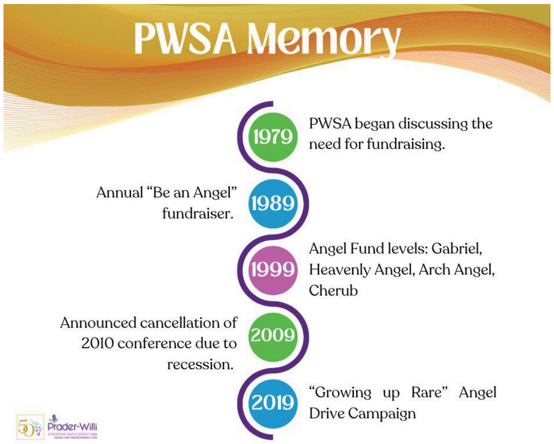
When a family receives a Prader-Willi syndrome diagnosis, PWSA | USA is often their very first contact. From crisis support and family mentors to care packages and community connection, we are there from the very beginning. Your gift of hope helps ensure no family ever faces those first steps alone.

Watch the video at the button below to see this support in action!

WATCH HERE



PWSA MEMORIES



PWSA Memory

1979 PWSA began discussing the need for fundraising.

1989 Annual “Be an Angel” fundraiser.

1999 Angel Fund levels: Gabriel, Heavenly Angel, Arch Angel, Cherub

2009 Announced cancellation of 2010 conference due to recession.

2019 “Growing up Rare” Angel Drive Campaign

As we close out our 50th Anniversary year and turn the final corner for our 2025 Angel Drive Campaign, we wanted to look back at some of the fundraising memories of PWSA | USA.

In 1979, The Gathered View announced the beginning of the fundraising discussion, emphasizing the growth of the organization and the need to raise funds to support the work. Up until this point, Gene and Fausta Deterling, co-founders of this organization, were handling all the paperwork. Then, fundraising chairman for PWSA Marge A. Wett asked the question, “What have we done as an organization and as individuals?...If I am going to be successful as a Fund Raiser for the National Organization, I need a Board of Directors, and a full membership that is doing their part.”

In 1989, The Gathered View announced the launch of the annual “Be an Angel” fundraiser with the opportunity to receive $10,000 in matching funds if the goal

was met.
The 1999 Gathered View celebrated donors for the various tiers of the Angel Fund, those being Gabriel, Heavenly Angel, Arch Angel, and Cherub.
In 2009, PWSA sadly announced the cancellation of the 2010 conference. This was due to effects of the recession; decrease in donations, inability to secure new grants, lack of funds for families to travel to conference, diminished budgets for researchers and professionals to travel.
The 2019 Gathered View promoted that year's Angel Drive Campaign as *Growing Up Rare* and stating, "Of all the things you can do to raise awareness, few are more valuable and beneficial than telling your story."
In 2025, we are continuing the work set forth by the founders 50 years ago, with far more resources than those original families had access to. We reach families in the PWS community around the country and in many corners of the world. We offer support for families and individuals with PWS, funding for research, education to caregivers and professionals, advocacy at the highest levels, and a place for PWS families to find connection and support. We are grateful to all our donors for their generosity and contributions to the incredible work done by this organization.

PWSA | USA'S
SPOTLIGHT ON HOPE

"Hayden absolutely loves people! He's never met someone he hasn't instantly become friends with. He will ask family, friends, the grocery store cashier, etc., 'How is your day going?'; 'Did you have a good day at work?'; 'Did you have a fun weekend?' We love how friendly he is and how he really listens to people's responses when he asks them these questions. Such an amazing little boy!"

- Submitted by Rebecca Woods, mom to Hayden (living with PWS)

Submit your own Spotlight on Hope using the button below.

SUBMIT SPOTLIGHT

EVENTS & FUNDRAISERS

Family Zoo Day for Florida PWS Families

When: **February 21, 2026 | 10 AM - 5 PM ET**
Where: **Zoo Miami, Miami FL**

The Prader-Willi Florida Chapter is excited to invite you to a special Family Zoo Day at Zoo Miami.
Join families from the Florida chapter of PWSA | USA at 10 AM at Zoo Miami, where together you'll enjoy a fun, inclusive, and community-building experience as families explore the zoo’s incredible exhibits and take part in engaging group activities designed to bring families closer and strengthen the PWS community.

Admission is $10 for adults, $5 for kids ages 4-12, and children 3 and younger are free.

Learn more about this event and purchase tickets by clicking the button below.

LEARN MORE

Buenas noticias para los residentes de Florida!

Ahora pueden visitar y beneficiarse del sitio web del Capítulo de Florida en español.

VISITA EL SITIO WEB

A Bow for Áine Mirella: Night of Music, Joy, and Hope for Prader-Willi Syndrome

On November 21, 2025, friends, family, and supporters gathered at the Main Line Unitarian Church in Devon, Pennsylvania, for an unforgettable evening: A Bow for Áine Mirella – Performance for PWS. The concert was a beautiful celebration of music, community, and love – all in support of PWSA | USA. Katie Martinez, PWSA | USA's Fundraising Coach, attended the event and wrote a beautiful recap about the meaning behind the event name, the music played, and the intention behind coming to an event like this. Read Katie's recap by clicking the button below.

READ HERE

Thank You, A Bow for Áine Mirella Sponsors

VENUE SPONSOR

Main Line
Unitarian
Church

CONCERTO SPONSOR

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THERAPEUTICS

ENCORE RECEPTION SPONSOR

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www.grazendecor.com

Thank You, Claus for a Cause Attendees & Supporters!

Shared on behalf of the Claus for a Cause organizers

Thank You

Because of your generosity, we were able to raise over $20K to fund advocacy, research and family support for PWSA | USA. We're so grateful to have you as part of this community.

Thank You, Claus for a Cause Sponsors

NORTH POLE MAGIC SPONSOR

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BJ's RESTAURANT BREWHOUSE

TINSEL & GOLD SPONSORS

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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

We're excited to share our latest **Sibling Advocacy** episode on *PWS United*. In this ongoing series, we talk with siblings about how they show up for their loved ones with PWS, whether at the kitchen table, at school, among friends, in government spaces, or anywhere their sibling may need support.

This episode is hosted by Dorothea Lantz, PWSA | USA's Director of Community Engagement and mom to Hunter, living with PWS. Dorothea spoke with 15-year-old Christian Garzia, the younger brother of

Rocco, a 21-year-old living with PWS. Christian brings some humor to this conversation and talks about what fairness looks like in their family dynamic, why he's not worried about the future with Rocco, and how advocacy looks like protection.
Find this episode of *PWS United* on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

PWSA | USA at the EveryLife Community Congress: Looking Back at 2025 and Mobilizing for 2026

PWSA | USA recently participated in the EveryLife Foundation for Rare Diseases' Community Congress end-of-year convening in Washington, D.C. This two-day gathering brought together rare disease advocates, policy experts, and community leaders to reflect on state-level legislative progress in 2025, assess emerging challenges, and begin shaping a coordinated strategy for 2026. This was a great opportunity for advocates to build connections across the rare disease community, focus on access and reimbursement issues, and also discuss obstacles and advocacy efforts moving forward.

As Dorothea Lantz, PWSA | USA's Director of Community Engagement and mom to Hunter (living with PWS) states, *"Advocacy is rarely a straight line. There are moments of progress, moments of pause, and moments—like this one—that call on us to reorganize and recommit. In 2026, we will take what we've learned, strengthen our partnerships, and continue showing up—because access, equity, and dignity for people living with PWS are always worth fighting for."*

Read the full recap using the button below.

READ HERE

Advocating for Housing and Funding for PWS Residential Programs in New York

Submitted by Stacy Ward, CEO of PWSA | USA

On Tuesday, I had the opportunity to meet with New York State Assemblyman Angelo Santabarbara to shine a light on a growing and urgent crisis: the severe shortage of housing and sustainable funding for Prader-Willi syndrome–specific residential programs in New York State. As individuals with PWS age into adulthood, families are finding that appropriate residential options - those with trained staff, consistent supervision, and an understanding of the unique medical and behavioral needs of PWS and the required food security in place, are simply not available. Without intentional investment and policy attention, too many adults with PWS are left without safe, appropriate places to live, and families are left navigating an impossible system with few viable choices.

I was honored to be joined by Cynthia and Chip Whiting and Dan Maillet, all parents of adult children with PWS, whose personal stories underscored just how real and immediate this crisis is. They spoke candidly about the strain on aging parents, especially those facing their own medical crisis, the lack of long-term planning options, and the fear that comes with knowing your adult child's needs may outlive your ability to provide care. Their voices transformed this conversation from policy to people and made clear that PWS-specific residential programs are not a luxury, but a necessity. We are grateful to Assemblyman Santabarbara for engaging in this discussion, and we remain committed to working with state leaders to advance solutions that ensure adults with PWS can live safely, with dignity, and with the supports they need to thrive.

FAMILY SUPPORT

Adapting Holiday Traditions

Many main-stream winter holiday traditions fall short of being PWS-friendly. From leaving cookies for Santa and hot cocoa after ice skating to gingerbread houses and deep-fried latkes, it can be challenging for some families to adapt these traditions to fit the needs of Prader-Willi syndrome. Some traditions simply need some small changes and others may need to be discarded for new ones entirely. In our latest blog, staff and volunteers share some of their practices and ideas on adapting and creating PWS-friendly holiday traditions.

Read this blog by clicking the button below.

READ HERE

Melanie's Air-Fryer Chanukah Latkes
(PWS-Friendly Potato Pancakes)

Melanie Zalman, PWSA | USA's Director of Development and mom to Josephine (living with PWS), shares her adapted recipe for latkes, a Chanukah tradition for her family. As Melanie writes, "When Josephine was born, I worried a lot about what our Jewish holiday traditions would look like and how (more like IF) I would be able to make them PWS-friendly. When she began to eat solid food, I made the decision that I would do my very best to find healthy alternatives to my traditional holiday treats so that she could enjoy the tastes of the season with the rest of us. I still work each season to refine things and to adopt healthier alternatives for the whole family."

You can read more from Melanie and find this recipe using the button below.

READ HERE

Ask Nurse Lynn

Male, 22 years old, Deletion subtype

My son was diagnosed with Prader-Willi when he was born. I'm wondering whether or not I should place him in a group home where he can get help. He’s currently living at home & it’s getting out of control with his weight gain & diabetes. Please help. 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

NURSE LYNN

Prader-Willi Syndrome Association | USA

Lynn Garrick, RN, MSN

PWSA | USA Medical / Research Coordinator

Mom to John, living with PWS

ASK YOUR QUESTION HERE

RESEARCH

New Research Study Seeks Caregiver Insights on PWS

Paid Opportunity!

PAID RESEARCH OPPORTUNITY

PWS Caregivers Needed

- ✓ 15-Minute Online Survey
- ✓ Caregivers of Individuals Aged 4+ Diagnosed with PWS
- ✓ $50 Compensation for Your Time *(if you qualify)*

MedPanel

After a brief pause to review initial responses, our research partner, MedPanel, has reopened enrollment for the Prader-Willi syndrome (PWS) study shared earlier this month. This paid survey aims to better understand PWS-related experiences. The insights gathered will help shape future treatment approaches and support resources for the PWS community. **If you think you might qualify and have not yet completed the survey, we encourage you to participate.**

If you have already completed the survey or previously checked your eligibility, thank you – please do **not** take it again.

Important note for those taking the survey for the first time:
Please click the button below to access the eligibility screener and determine whether you qualify to participate in the study. Eligible participants will move directly into the online survey and will receive a $50 compensation check for completing it.

If you begin the survey but need to step away before finishing, please do not return to the original eligibility screener link.

Instead, elawson@us.imshealth.com will automatically send you a new, unique link by email so you can continue where you left off. If you don't see this follow-up link in your inbox, please check your spam or junk folder.

TAKE ELIGIBILITY SCREENER

About the Study

What Participation Involves:

- A brief online screener to determine eligibility
- A 15-minute online survey (including the screener)
- A $50 check as a thank-you for completing the survey

Is This Survey Private?

Participation is voluntary and double-blinded. Your personal information is confidential and never shared with the study sponsor. Our research partner, MedPanel, collects contact information only to issue the $50 honorarium.

Would You Like to Participate?

Click here to take the brief screening survey. Eligible participants will be automatically directed to the full survey.

Reflections on the End of a Trial
Clinical Trial Journey Entry #6

Anne Fricke, mom to Freya (14, living with PWS), shares her reflections on the close of their on-site clinical trial experience with Harmony Bioscience's TEMPO trial of pitolisant, a medication to treat excessive daytime sleepiness. In this blog series, Anne has shared the emotional, practical, and logistical details of participating in this trial - from questioning whether she made the right choice in enrolling her daughter, to the gratitude she feels today, this blog series captures one family's experience in PWS research.

You can read this blog submission and find links to the other entries by clicking the button below.

READ HERE

Holiday Greetings: Consider Participating in PWS Research!

Shared on behalf of Harmony Biosciences

As we move into the holiday season, we all look forward to the meaningful moments that make this time of year special: time spent together, family traditions, and a chance to settle into a quieter winter rhythm. For those supporting someone with PWS, the day-to-day challenges of excessive daytime sleepiness can make enjoying these moments to the fullest more challenging.

As a new year approaches, please consider taking part in the TEMPO clinical study to further research focused on excessive daytime sleepiness in PWS. With the **completely at-home study option**, you can contribute to PWS research entirely from the comfort of your home!

Alternatively, you may choose to participate at one of our **18 clinical study sites** around the country, and be rest assured that all your travel needs are fully covered such as transportation, parking, meals.

Qualified participants:

- Are 6 years of age or older
- Have a diagnosis of Prader-Willi syndrome
- Have excessive daytime sleepiness

To learn more about the TEMPO clinical study, visit **www.tempopwsstudy.com**. You can find out if your child is eligible to participate by answering 7 simple questions in our **eligibility questionnaire**. Please note that the questionnaire is not a complete list of eligibility requirements and completing the questionnaire does not mean that a care recipient agrees to participate in the study.

Wishing you and your family a joyful holiday season!

- The Team at Harmony Biosciences

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 ANNOUNCEMENTS

PWSA | USA Resource Spotlight

We know that our families may face many obstacles and frustrations to having a safe and joyful holiday season. How to navigate gatherings with food, manage behavior issues with disrupted schedules, find ways to enjoy the holiday spirit with PWS can be challenging. For some valuable insight and suggestions on

how to navigate this time, please read our blog *Tips and Techniques for a Safe Holiday Season* 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

PWSA | USA Pulse Special Edition Newsletter: December 26, 2025

Dear PWS Community,

As we close out another meaningful year - a milestone year - I want to speak directly to you: our families, donors, partners, and advocates. Thank you. Your generosity, belief in our mission, and dedication to the Prader-Willi syndrome (PWS) community are the heart of everything we do.

This year, we celebrated 50 years of PWSA | USA. What began as a small, parent-led effort has grown into a national network of support. One built on a powerful foundation of families refusing to walk this journey alone and doing everything they can to help their loved ones with PWS thrive.

That same spirit still guides us today.

Because of you, 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.

Newly diagnosed families had someone to call. Caregivers in crisis received expert guidance. And children and adults with PWS were better understood and supported in their homes, schools, and communities.

Thank you for helping make all of this possible.

Important Milestones in 2025

In 2025, our **Family Support services** ensured parents, caregivers, and individuals with PWS had compassionate guidance at every stage - from diagnosis through adulthood and beyond. Our team provided support, resources, and more to over 4,500 families and individuals, not only across the country but around the world.

Our **24-Hour Crisis Phone Line** (941-312-0400) and **Medical Support Services** remained a lifeline during emergencies, offering clinician-to-clinician consultation, behavioral and emotional support, safety planning, and critical intervention when families needed it most. These are often unseen but truly life-changing moments.

We also continued to ensure that no family begins this journey alone - sending **more than 100** New Diagnosis Care Packages to families newly navigating life with PWS, offering comfort, resources, and connection from the very start.

Our **Education and Training programs** continued to grow as well, equipping schools, caregivers, residential providers, and clinicians with the tools they need to support individuals with PWS safely and effectively. Strong communities begin with informed, empowered people, and your support made that possible.

We made powerful strides in **advocacy and public policy**. At the state level, we worked tirelessly to ensure Prader-Willi syndrome is recognized as an eligible diagnosis for waiver services, opening access to critical supports individuals with PWS need and deserve. We also launched our new Advocacy Ambassador Program, expanding PWS awareness and policy advocacy efforts across the country through the voices of our community.

And after years of hard work, we achieved a **long-awaited victory** with the inclusion of Prader-Willi syndrome in the Department of Defense's **Peer-Reviewed Medical Research Program** House Appropriations Bill - a powerful milestone that, if passed by the Senate, will help advance PWS research for years to come.

This year also marked a truly historic moment of hope with the **FDA approval of VYKAT XR**, the first-ever treatment for hyperphagia in Prader-Willi syndrome. This breakthrough represents not only scientific progress, but the collective strength and perseverance of our entire community - families, clinicians, researchers, advocates, and supporters working together toward meaningful change.

This was also a landmark year for **research and scientific advancement**. Through our support of the Global PWS Registry, natural history studies, collaborations with industry partners, and continued investment in research initiatives and ongoing clinical trials, your generosity helped accelerate progress toward new treatments and improved clinical understanding. Breakthroughs that once felt distant now feel closer than ever.

We also strengthened connection and storytelling across the PWS community through powerful shared experiences. Our **PWS United podcast** celebrated its first anniversary on September 1st, continuing to elevate voices, share stories, and bring our community closer together.

We commemorated our 50th anniversary in a truly special way at our **Journey of Hope Gala**, where we honored 12 extraordinary individuals who helped shape PWSA | USA into the trusted, essential organization it is today. It was a powerful reminder that our history is

built on the dedication and love of so many.

This year, we were honored to co-host the **“United in Hope” International PWS Conference**, alongside IPWSO and FPWR. The conference saw a record-breaking 1,330 families, professionals, and advocates from around the world. The energy, education, connection, and inspiration that filled the Arizona Grand Resort and Spa that week will stay with us for years to come. I’m also proud to share that during the conference, PWSA | USA’s Adults with PWS Advisory Board hosted its first-ever Adults with PWS Conference, where nearly 60 individuals living with PWS came together to learn from one another and build lasting connections.

And across the country, we saw incredible momentum through our **PWS Hope United** peer-to-peer fundraising events, including the successful launch of the United We Brunch campaign throughout May (PWS Awareness Month). These community-led efforts were nothing short of inspiring - driven by volunteers hosting events for the first time, and others for their 2nd, 5th, even 16th year. In total, Hope United fundraising events raised nearly **$700,000** in 2025 to support PWSA | USA’s critical services. We are deeply grateful to every individual who gave their time, energy, and heart to make these events possible.

Beyond programs, policies, and progress, what your support truly provides is hope.

Hope for newly diagnosed families feeling overwhelmed.
Hope for adults with PWS seeking independence.
Hope for caregivers who need to know they’re not alone.
Hope for a future shaped by understanding, compassion, and progress.

As we celebrate 50 years of PWSA | USA, your impact is unmistakable. From our early beginnings to a national network of care, advocacy, and guidance, you have helped build the foundation families rely on every day.

Looking ahead, there is still work to do, but we are stronger and better prepared because of you. Your generosity, your voice, and your belief in this community continue to move us forward.

As our Angel Drive campaign continues through December 31st, we invite you to consider a year-end gift. Your support ensures that when a family reaches out, whether for a new diagnosis, a crisis, or guidance, we are ready to answer.

From all of us at PWSA | USA, thank you for walking with us. We wish you and your loved ones a peaceful holiday season and a hopeful New Year.

Donate to the Angel Drive

Stacy Ward

Stacy Ward, MS, BCBA
PWSA | USA CEO

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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