PWSA | USA Pulse Newsletter: January 3, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 114

January 3, 2025

www.pwsausa.org | 941-312-0400

As we step into 2025, PWSA | USA is proud to celebrate **50 years** of supporting the Prader-Willi syndrome community! Over the past five decades, we've witnessed remarkable progress, from our early days as a small grassroots organization to becoming the national leader in advocacy, education, and support. In our latest blog post, we take a moment to reflect on some of the milestones that have shaped our journey, highlighting the countless community efforts that helped us grow. We also share exciting new programs and initiatives we’re launching this year to further our mission. To mark this special year, we’re thrilled to announce our **50th Anniversary Celebration Gala** in September, an event that will honor our community’s resilience and our shared journey of hope. Click the button below to find out how you can be a part of this historic year and help us continue to empower families impacted by Prader-Willi syndrome.

50 YEARS OF HOPE

"As we celebrate 50 years of progress, I am deeply humbled by the unwavering support of our community. From the parents, professionals, and volunteers who have made this journey possible to the individuals and families we serve, each of you has played a vital role in shaping our shared mission. This milestone is not just a reflection of our past, but a testament to the hope and strength we continue to build together. As we look to the future, I am excited for the next chapter in our journey and the many new ways we will continue to empower families and make a lasting impact on the lives of those affected by Prader-Willi syndrome."

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

PWSA | USA’S SPOTLIGHT ON HOPE

Lenny Shang, a 12-year-old living with PWS, has been passionate about art since he was 4 years old. Over the years, his dedication has led to several international awards, and his art has become not just a creative outlet but also a way for him to give back to the community. This year, in collaboration with Art Spark Texas, Lenny exhibited 11 of his artworks and raised $50,000 for charity. Most recently, Lenny participated in a local Children’s Business Fair, where he showcased his entrepreneurial spirit and commitment to hard work. Click the

button below to read Lenny's Spotlight on Hope, contributed by his mom, Cocoa Ma.

READ HERE

We want to celebrate your loved one!

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

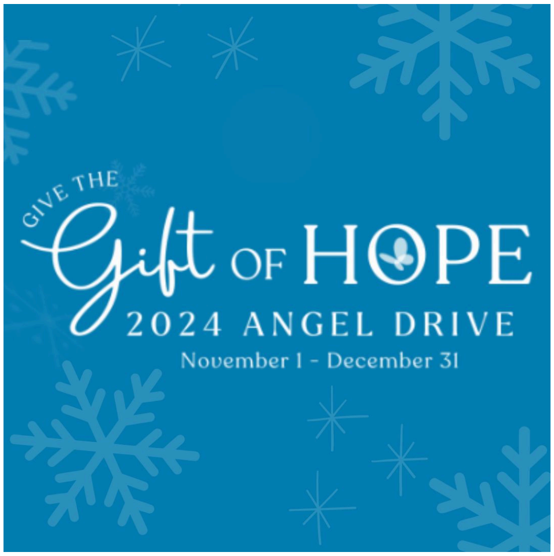
If you'd like to honor your loved one and share their success story with the PWS community, please fill out our Spotlight on Hope form below. We're looking forward to celebrating with you!

SHARE YOUR SPOTLIGHT ON HOPE

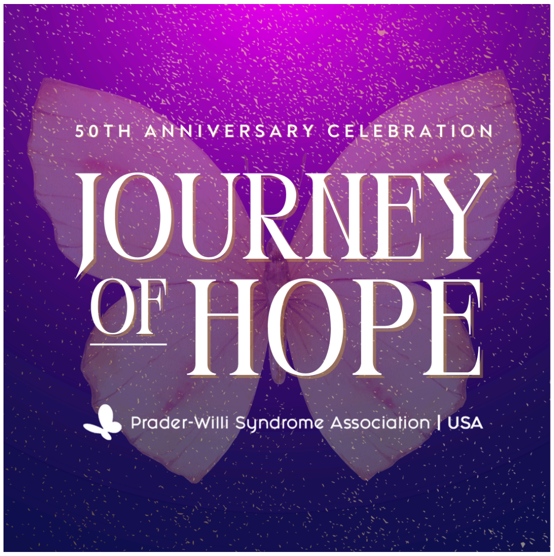
EVENTS & FUNDRAISERS

Thank You for Supporting the 2024 Angel Drive!

A heartfelt thank you to everyone who contributed to our **2024 Angel Drive**! Your generous donations are helping to sustain and grow the vital programs and services that support individuals and families impacted by Prader-Willi syndrome. As we enter 2025, our 50th anniversary year, your support ensures we can continue making a meaningful difference in the lives of those we serve. While we are still finalizing the total raised, we are deeply grateful for your commitment to our mission. We'll also be announcing the four winners of our special prize raffle drawing soon, so stay tuned!



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



When: Friday, September 26, 2025
Where: Ritz-Carlton, St. Louis, MO
Time: 6pm - 10pm CST

This September, we invite you to join us for the **50th Anniversary Celebration Gala: The Journey of Hope** on Friday, September 26, 2025, at the Ritz-Carlton in St. Louis, Missouri. This special evening will honor the incredible progress we've made together while celebrating the people who have shaped our journey over the past five decades.

Stay tuned for registration and sponsorship opportunities coming soon!

PWS Art Need for 50th Birthday Celebration

We are excited to display your loved one's art at our 50th birthday party, but we need your help. Please encourage your loved one with PWS to create art for our Rare Aware Art Share Theme #3, "What is your favorite birthday memory?" Our deadline for art submissions is **January 31st.**

You can help your loved one's creativity for this theme with the prompts: **What do you love about birthdays? How do you like to celebrate? What do birthdays mean to you?**

We welcome anyone living with PWS to participate in this art share no matter where you live and regardless of whether or not you will be attending the 2025 conference. We also encourage those who submitted artwork for Theme #1 and/or Theme #2 to submit artwork for this new theme as well! Once you have completed your art piece, please submit a digital image of your artwork using the form found at the button below.

[RARE AWARE ART SHARE]

2025 International PWS United in Hope Conference

The **United in Hope: International Prader-Willi Syndrome Conference** will be held at the Arizona Grand Resort and Spa in Phoenix, Arizona, from June 24-28, 2025. The event will be hosted by the Prader-Willi Syndrome Association | USA, the Foundation for Prader-Willi Research, and the International Prader-

Willi Syndrome Organisation. Our theme, “**United in Hope,**” reflects this unique collaboration, which we anticipate will serve as a catalyst for the largest international PWS conference ever held.

Click the button below to register for the 2025 International PWS Conference. We hope to see you there!

REGISTER FOR THE 2025 PWS CONFERENCE

Diamonds and Denim

When: **Saturday, February 1, 2025 | 5:30pm CST**
Where: **Poe's On the Hill, Springfield, IL**

Get ready for a night of delicious food, lively dancing, and exciting entertainment. DJ Chad Burton will keep the energy high throughout the evening. Explore the silent auction items, available for browsing and bidding all night, and don’t miss the live auction kicking off at 8pm!

Dress to impress in your best "diamonds" or keep it relaxed in "denim" - either way, you’re in for a fantastic time.

Event Details:

- **Tickets:** $60 per person | $110 per couple
- **Dinner Options:** Prime Rib or Cavatappi with Alfredo Chicken
  Includes a decadent dessert buffet!
- **Doors Open:** 5pm

Bring some cash for 50/50 draws, raffles, and other fun games. Mark your calendar and join us for an evening you won’t want to miss!

LEARN MORE HERE

PWS hope united

BUILDING BRIGHT FUTURES FOR PWS FAMILIES

Prader-Willi Syndrome Association | USA

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

Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

With more than 20 episodes in our podcast library, we wanted to check in and make sure families know that we have been producing a podcast for the PWS community! With episodes on the latest in PWS news, PWSA events, advocacy, research, and family support offerings, including interviews with parents, professionals, caregivers, and individuals with PWS, you're sure to find something inspiring, educational, and enjoyable to listen to!

Are you new to podcasts and not sure how to listen? Want to know what we mean when we ask you to follow or rate and review? Check out our blog post "PWS United Podcast: How to Listen, Follow, Rate and Review."

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

LISTEN ON PODBEAN

We are grateful for your reviews and feedback. Please take a moment to leave a rating and review on your favorite podcast app or platform.

"This podcast is truly wonderful for our community and for others to learn about PWS too. I love the banter and realness of the hosts. It makes me feel less isolated, in fact it makes me feel so seen and understood, like I'm part of a big community that is there for me and my family 24/7 if we need them. I'm glad to know PWSA | USA exists and all of the services. Love listening every week. Therapy." - Review from CraftonMommy on Apple Podcasts

ADVOCACY

PWS Advocacy Master Class:
Register Before January 13th!

Launching on **January 13, 2025**, the PWS Advocacy Master Class is a six-week program designed in collaboration with Patients Rising. It provides a robust curriculum for anyone passionate about becoming an effective advocate for PWS.

Course Highlights:

- **Congress 101**: A deep dive into how laws are made and how to engage with policymakers.
- **Pharmacy Benefit Managers & Pricing Policies**: Understand how these systems affect access to PWS therapies.
- **Effective Storytelling**: Learn how to craft and share your personal journey to inspire change.
- **Disability Rights & Clinical Trials**: Explore advocacy avenues in education, work, and treatment innovation.
- **Public Speaking & Letter Writing**: Gain confidence in presenting to legislators and writing impactful letters.
- **Final Project**: Graduates will complete either a legislator letter or an advocacy video to showcase their skills.

Participants will graduate with an e-Certificate of Completion and a working knowledge of advocacy techniques. The course combines live sessions, self-guided lessons, and practical exercises to ensure a comprehensive experience. If you or someone you know would like to participate, please click the button below to join the Patient Rising Community **BEFORE January 13th**! The course will be available in the Circle app portal on January 13th.

If you have any questions, email Dorothea Lantz at dlantz@pwsausa.org or reach out directly to Jim Sliney at Patients Rising via email at jsliney@patientsrising.org

REGISTER HERE

FAMILY SUPPORT

A Global Network of Hope: How PWSA Egypt & Middle East is Transforming Lives

Imagine facing a rare diagnosis without the support or resources you need. For families in the Middle East affected by Prader-Willi syndrome, this was their reality - until Walaa Mohamed, mom to Ahmed, founded PWSA Egypt & Middle East in 2023 with the support of PWSA | USA and IPWSO. This new organization is bringing critical resources, health care guidance, and a sense of community to families across the region.

Click the button below to learn how this initiative is changing lives and offering hope to those who once felt alone in their journey.

READ HERE

Ask Nurse Lynn

Question: Female, 3.5 years old, UPD subtype

Hello, I'm from Ontario Canada. We just received a diagnosis a couple of weeks ago. I see most of the children on this support group are being diagnosed within weeks of birth. Is PWS routine testing with your newborn screen? Just curious as I knew something was wrong from the start and was told she's fine. Thank you.

Visit our blog to read Nurse Lynn's response.

READ NURSE LYNN'S RESPONSE

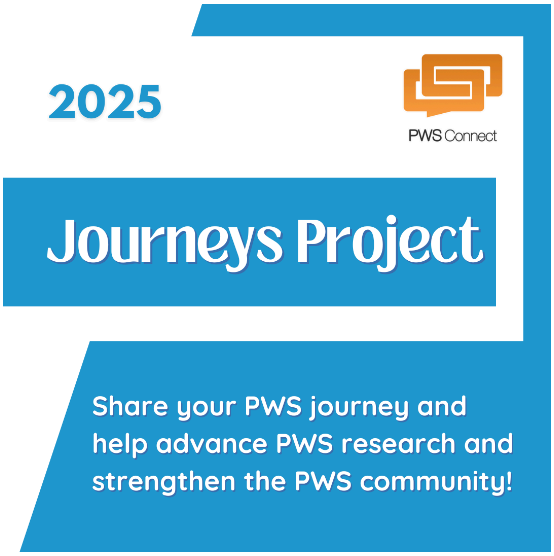
Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

ASK YOUR QUESTION HERE

RESEARCH

Participate in PWS Research Through PWS Connect Journeys Project



In 2025, PWS Connect would like to learn more about your PWS journey from birth to where you are now. Throughout 2025, we will share prompts on specific themes to help paint a more detailed picture of what PWS looks like for families. This information will help our organization, researchers, and specialists better understand PWS, how it affects individuals and families, and where more efforts for awareness, research, and support are needed. We encourage you all to join the PWS Connect community on Discord! Your efforts will help forward research in the PWS community and offer a deeper connection with the families who participate.

LEARN MORE

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is open for the 2025 International PWS Conference Clinical and Scientific Program! Read more information about how to apply using the button below. Our United in Hope: International PWS Conference will shape the future of PWS care and research. This five-day event marks the first joint conference between IPWSO, PWSA | USA, and FPWR, and symbolizes a historic milestone. Register today!

Call for Abstracts

Clinical & Scientific Program Submission
Deadline: January 31, 2025

APPLY HERE

REGISTER HERE

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight
Parent/Family Mentor Program

For many of us, our child's diagnosis is the first time we hear the term "Prader-Willi syndrome." Not only are we getting to know this new member of our family, but we must also learn to navigate a world of medical speak and therapeutic interventions that we have never visited. PWSA | USA offers support in many ways, including pairing up new families with "veteran" parents. Our Parent Mentor Program pairs families with mentors who have shared similar experiences. Parent Mentors are carefully chosen with each family's specific needs in mind and are committed to ensuring newly diagnosed families have access to the most up-to-date research material, educational literature, and nutrition and therapy best practices.

Learn more about our Parent Mentor Program by emailing info@pwsausa.org.

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: January 17, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 115

January 17, 2025

www.pwsausa.org | 941-312-0400

2025 International PWS Conference: Join Us in Phoenix for this Historic Event!

Countdown to Conference

158

DAYS TO GO!

We're excited to introduce the ***Countdown to Conference*** section of our Pulse newsletter! As we count down the days to the **2025 International PWS Conference**, taking place June 24-28 at the Arizona Grand Resort and Spa in Phoenix, AZ, each newsletter will highlight new details, exciting features, reminders, and more about this once-in-a-lifetime event.

This year's conference is truly historic—it's the first time PWSA | USA, The International Prader-Willi Syndrome Organisation (IPWSO), and the Foundation for Prader-Willi Research (FPWR) are coming together to host an International PWS Conference. Even more special, it coincides with PWSA | USA's 50th anniversary!

Don't forget: **Early bird pricing ends March 31, 2025!** Register now to save $50 on your program registration—whether you're attending the Family Program, Clinical & Scientific Program, Professional Providers Program, or the Adults with PWS Half-Day Program. We also highly recommend booking your stay at the Arizona Grand Resort & Spa as soon as possible. Days are filling up fast and rooms are almost sold out on Tuesday, June 24. **Click here to book your hotel reservation**. One additional reminder is that our **PWS and Siblings Camps are completely full.** Registration is still open for the Adults with PWS Half-Day Program (taking place Thursday, June 26).

Click the button below to register and learn more about the incredible programs and events we have planned. We can't wait to celebrate this milestone with you in Phoenix!

LEARN MORE & REGISTER

Interested in Sponsoring the 2025 International PWS Conference?

Join us in creating a brighter future for individuals with Prader-Willi syndrome by sponsoring the 2025 *United in Hope: International PWS Conference.* For the first time ever, PWSA | USA, IPWSO, and FPWR are uniting to host this extraordinary event, bringing the global PWS community together like never before.

Your sponsorship will:

- Support access to cutting-edge research and education for the PWS community.
- Help foster connections among families, experts, and advocates.
- Align your brand with a cause that inspires hope and impacts lives worldwide.
- And so much more!

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

Thank You 2025 Conference Sponsors

DIAMOND SPONSOR

aardvark therapeutics

PLATINUM SPONSOR

SOLENO THERAPEUTICS

GOLD SPONSOR

ACADIA™

PWSA | USA'S

SPOTLIGHT ON HOPE

"Potty training...It's a big milestone, and one that is hard for our kids." In this Spotlight on Hope, Sheri Mills, mom to Lyra, living with PWS, shares their family's journey with potty training. As her quote implies, it was not a quick or easy journey, until it was. Thankfully, with the right services and support, they were able to help Lyra reach this very exciting milestone! Check out the latest Spotlight on Hope and learn what supports helped Lyra by clicking the button below.

READ HERE

We want to celebrate your loved one!

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

If you'd like to honor your loved one and share their success story with the PWS community, please fill out our Spotlight on Hope form below. We're looking forward to celebrating with you!

SHARE YOUR SPOTLIGHT ON HOPE

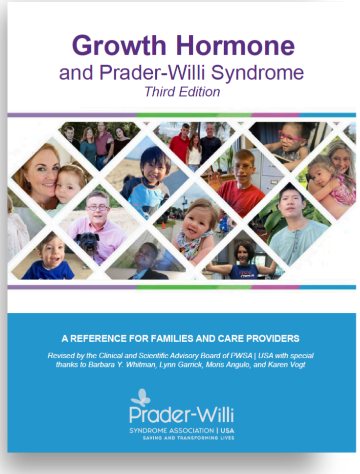
PWSA | USA ANNOUNCEMENTS

Support for Our Families in LA and Beyond

PWSA | USA wants to remind our community that we are here to provide service where we can. To our families affected by the devastating wildfires in LA, please know that we are here for you. If you would like help connecting to resources or would like to speak with someone on our Family Support team, please reach us at our email at info@pwsausa.org or call 941-312-0400. We also have an "Emergency Preparedness Checklist" to help families prepare for supporting their loved one with PWS during a crisis or natural disaster. We hope that all of our families are safe and reach out for help if needed.

EMERGENCY CHECKLIST

PWSA | USA Resource Spotlight



Growth Hormone
and Prader-Willi Syndrome
Third Edition

A REFERENCE FOR FAMILIES AND CARE PROVIDERS

Revised by the Clinical and Scientific Advisory Board of PWSA | USA with special thanks to Barbara Y. Whitman, Lynn Garrick, Moris Angulo, and Karen Vogt

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

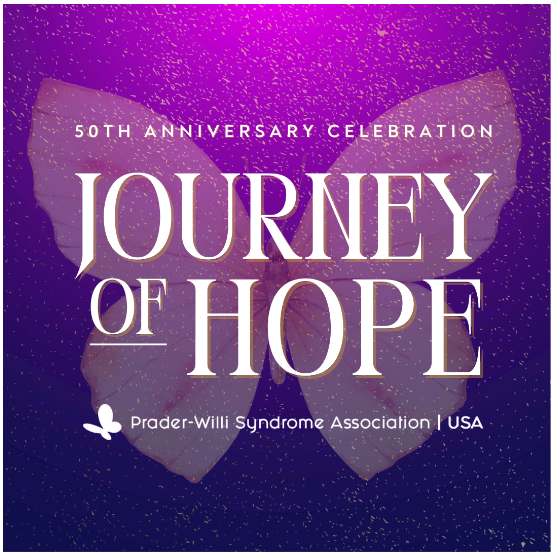
Growth hormone (GH) is a valuable and vital treatment for the management of PWS. Clinical experience suggests that GH treatment can be beneficial for an individual with PWS as early as 2-3 months of age. Treatment intended to increase height needs to begin prior to the normal age of puberty and earlier treatment (often prior to age 2) seems to offer the best opportunity for improvements in body composition and acquisition of motor milestones. Since 2000, the use of GH has become the standard of care for individuals with PWS when prescribed by an experienced endocrinologist. In infants and children with PWS, GH can help with height, weight, body mass, strength and agility, and also may help with attention and cognitive development. In addition, studies of the use of human GH in adults with PWS have shown positive results in the areas of bone strengthening, improved body composition including improved lean muscle mass, greater energy and endurance, and modest improvements in cognition.

If you have questions about growth hormone or need assistance in asking your doctor to prescribe GH for your loved one, please call us at 941-312-0400 or email info@pwsausa.org. Use the button below to download our third edition growth hormone booklet to learn more.

DOWNLOAD HERE

EVENTS & FUNDRAISERS

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



When: Friday, September 26, 2025
Where: Ritz-Carlton, St. Louis, MO
Time: 6pm - 10pm CST

This September, we invite you to join us for the **50th Anniversary Celebration Gala: The Journey of Hope** on Friday, September 26, 2025, at the Ritz-Carlton in St. Louis, Missouri. This special evening will honor the incredible progress we've made together while celebrating the people who have shaped our journey over the past five decades.

Stay tuned for registration and sponsorship opportunities coming soon!

PWS Art Needed for 50th Birthday Celebration

The deadline to submit art, **January 31st**, is approaching fast! We're excited to display the contributions of your loved ones with PWS at our 50th birthday party at the 2025 International PWS United in Hope Conference in June.

How can your loved one get involved?
Ask your loved one to create a piece of art on the theme "What is your favorite birthday memory?" or to send a Happy Birthday wish to PWSA | USA by making

a birthday sign with words or pictures. Take a photo of your loved one's art, or a photo of them holding their sign, and submit at the button below.

You can help your loved one's creativity for this theme with the prompts: **What do you love about birthdays? How do you like to celebrate? What do birthdays mean to you?**

We welcome anyone living with PWS to participate in this art share no matter where you live and regardless of whether or not you will be attending the 2025 conference. We also encourage those who submitted artwork for Theme #1 and/or Theme #2 to submit artwork for this new theme as well!

RARE AWARE ART SHARE

Clint Hurdle's Hot Stove Dinner

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES
Clint Hurdle
HOT STOVE DINNER
Bradenton Country Club
Bradenton Country Club
Bradenton, FL & *Virtual*
March 22, 2025
Island Treasure Reception 5:00 p.m. until 6:00 p.m.
6:00 p.m. General Admission
Presented By:
Elevare Foundation

Save the Date!

MARCH 22, 2025

Bradenton Country Club

With Special Hosts Clint & Karla Hurdle

[CLICK HERE TO PURCHASE TICKETS!]

Diamonds and Denim

When: **Saturday, February 1, 2025 | 5:30pm CST**
Where: **Poe's On the Hill, Springfield, IL**

Get ready for a night of delicious food, lively dancing, and exciting entertainment. DJ Chad Burton will keep the energy high throughout the evening. Explore the silent auction items, available for browsing and bidding all night, and don't miss the live auction kicking off at 8pm!

Dress to impress in your best "diamonds" or keep it relaxed in "denim" - either way, you're in for a fantastic time.

Event Details:

- **Tickets:** $60 per person | $110 per couple
- **Dinner Options:** Prime Rib or Cavatappi with Alfredo Chicken
- **Doors Open:** 5pm

Bring some cash for 50/50 draws, raffles, and other fun games. Mark your calendar and join us for an evening you won't want to miss!

[LEARN MORE HERE]

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

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

Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

This episode is an edited recording of a past webinar explaining how parents can help advance PWS research while also finding and building community support. PWS parents Maria Picone and Chris DeFelice shared how their personal journey with PWS led them to create the PWS Connect channel on Discord, a place where caregivers come together to share their journeys, experiences, questions, and advice to support each other and directly impact the progression of PWS research. This episode explains the What, Why, and How of TREND Community and the PWS Connect Discord group. Join PWS Connect on Discord for a new wave of PWS insights and growing research!

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

LISTEN ON PODBEAN

We are grateful for your reviews and feedback. Please take a moment to leave a rating and review on your favorite podcast app or platform.

"Thank you PWSA | USA for creating such an amazing podcast! I have a little one with PWS and really enjoy the content you feature!"- Review from PWS Mama on Apple Podcasts

ADVOCACY

Celebrating Leadership and Welcoming New Opportunities: Changes at FDA's Center for Drug Evaluation and Research

PWSA | USA and FPWR would like to take a moment to acknowledge a significant leadership transition at the U.S. Food and Drug Administration (FDA). As Dr. Patrizia Cavazzoni steps down as Director of the Center for Drug Evaluation and Research (CDER), we express our deepest gratitude for her remarkable contributions to the rare disease community. At the same time, we are thrilled to welcome Dr. Jacqueline Corrigan-Curay as the incoming Director, bringing renewed hope and optimism to our mission. Read more by clicking the button below.

READ HERE

FAMILY SUPPORT

Volunteer Spotlight

Leadership and Vision: Over 20 Years of Service

Volunteers are a critical part of the work we do at PWSA | USA! We are incredibly grateful and inspired by the people who step up and offer their time, energy, wisdom, and support to help the families and individuals in the PWS community. For 2025, we have created a space to celebrate our volunteers. This first spotlight is on Michelle Torbert, mom to Leslie, living with PWS. Michelle has been a dedicated volunteer with PWSA | USA for more than 20 years. She has led the Florida Chapter, served as a Board of Directors member, held the position of Board Chair for several years, and has been a part of numerous committees and work groups. Her vision and strategic guidance have strengthened PWSA | USA's foundation and outreach. Thank you, Michelle, for all of your dedication and hard work. To read more about Michelle's volunteer work with PWSA | USA, click the button below.

You can submit your own Volunteer Spotlight **HERE.**

READ HERE

Ask Nurse Lynn

Question: Male, 19 years old, Deletion subtype

My son is on sertraline (Zoloft) and has been on quite a low dose, so under 25 mg for quite a while, in November we put his dose up by 2ml every week so now he is on 50 mg, one pill in the morning and one at night. The sertraline is to reduce anxiety, perseveration, and to help with difficulty sleeping when he gets stuck. Often over the years, when we put the dose up, we wondered if it was adding to his anxiety and ramped up behaviours, so we were *very slow to increase. So now, having upped the dose quite quickly, he settled for a week or two, and now is ramped up again. It is December, school schedule is all over the map with special activities, etc., but I wonder if we should go UP or DOWN. He is hyper, prior to dose increase he seemed depressed.*

Visit our blog to read Nurse Lynn's response.

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.

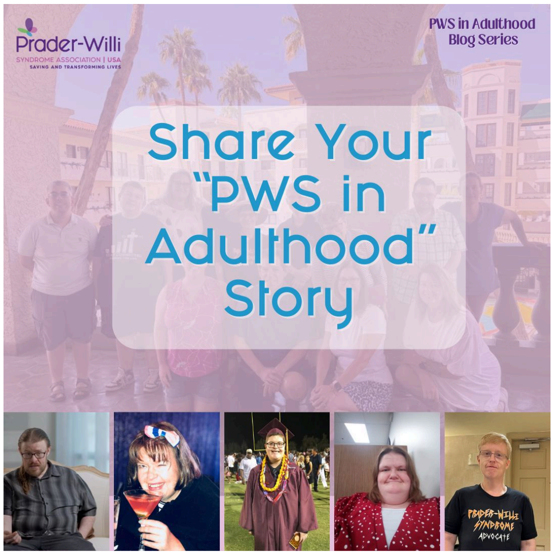
ASK YOUR QUESTION HERE

NEW PWS in Adulthood Blog Submission Form

We've created an easier way to share your experiences caring for your adult loved one with PWS! We want to know: What did the transition into adulthood look like? How is their living situation managed? What supports do they have in place? Do they have successful romantic or platonic relationships? What does it look like to work or volunteer in the community? And more.

Adults with PWS are invited to share their own story! We would love to amplify more voices of individuals living with PWS, so please share this opportunity with your loved one. Whether you are a caregiver, parent, or individual with PWS, we hope that you share your adulthood story with our community to spread knowledge and awareness of PWS in adulthood and celebrate the lives of those adults living with Prader-Willi syndrome.

To share your PWS in Adulthood story, click the button below.

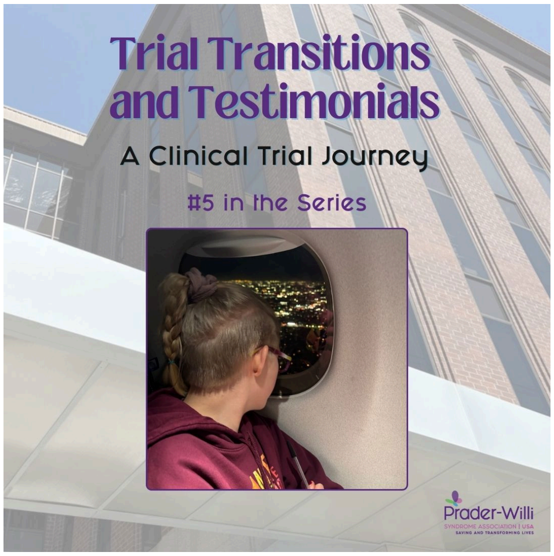


SUBMIT HERE

RESEARCH

Trial Transitions and Testimonials

#5 in the Clinical Trial Journey Blog Series



How should families manage their expectations in a clinical trial? Number 5 in our Clinical Trial Journey blog series walks through some of the transition details from the double-blind portion of the trial (where Freya, 13, with PWS, was receiving either the treatment or the placebo) to the open-label extension (where Freya is knowingly receiving the treatment). Freya's mom, Anne, explores what her expectations have been thus far and the wisdom and need for potentially shifting those expectations, while also holding on to the hope gained from the "success" stories of other families. Read the latest in our Clinical Trial Journey blog series by clicking the button below.

Email africke@pwsausa.org to share your clinical trial experience.

LEARN MORE

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is open for the 2025 International PWS Conference Clinical and Scientific Program! Read more information about how to apply using the button below. Our United in Hope: International PWS Conference will shape the future of PWS care and research. This five-day event marks the first joint conference between IPWSO, PWSA | USA, and FPWR, and symbolizes a historic milestone. Register today!

Call for Abstracts

Clinical & Scientific Program Submission
Deadline: January 31, 2025

APPLY HERE

REGISTER 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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PWSA | USA January 2025 Special Edition Pulse Newsletter

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PWSA | USA turns 50! To help commemorate our 50th birthday, PWSA | USA now has a webpage celebrating our past 50 years of service. You'll find a timeline of events in PWSA history, information on activities to celebrate throughout the year, links to special blogs and podcast projects and a way to share your PWSA memories. This webpage is a comprehensive commemoration on 50 years of service, dedication, education, and awareness, along with a promise to continue this work in the decades to come.

Check out our new webpage below and scroll this email for some highlights of what you will find.

VISIT WEBPAGE

MOMENTS IN TIME

Prader-Willi Syndrome Parents and Friends, soon to be renamed *Prader-Willi Syndrome Association*, was established by Gene and Fausta Deterling, parents of a son with PWS, with the support of Dr. Vanja Holm, of the Child Development and Retardation Center in Seattle, Washington.

"*Since we first discovered our son had Prader-Willi syndrome we have been eager to learn everything we can about it in order to make life a happy one. We soon found that there was very little information available and felt there must be numerous other parents with similar circumstances and desires as ours. We, therefore, decided to form an organization that could serve to act as a vehicle for communication and work toward the betterment of those with this syndrome*." - Gene Deterling, from Vol. 1 of **The Gathered View**.

PWSA MEMORIES

Throughout our 50-year celebration, we'd love to honor the moments that mean the most to you. Have you been to a PWSA | USA conference, advocated in Washinton during our DC Fly-in, made connections with other families through a Hope United fundraiser, or received a valuable service from our staff members? Please share your PWSA | USA memory to help us celebrate 50 years of

service. Submit your memory using our form below so we can highlight it throughout the year.

Submit your memory at the button below. We would love to see pictures with these memories as well!

SHARE HERE

PIONEERS IN PWS SERIES

This year our Pioneers in PWS Blog Series meets the PWS United podcast! Pioneers in PWS highlights parents and professionals who have been leaders in the growth of PWSA | USA as well as those who have furthered our advancement in knowledge and research of PWS. At times, it is a history lesson as well as a sincere thank you to all who have helped PWSA | USA become the leader in supporting persons with PWS. We will be revisiting this blog series with some added flare and reflection in this special podcast series.

Building on the theme of National Caregivers Day (February 21st), our first Pioneers in PWS podcast episode will honor residential and professional care providers in the PWS community. Please follow the podcast on your favorite podcast app so you don't miss when these episodes come out. You can also listen and follow at the button below.

LISTEN HERE

EVENTS

50th Anniversary Gala: Save the Date!

Join PWSA | USA as we celebrate 50 years of support, research, and community at our *Journey of Hope Gala.*

Date: Friday, September 26, 2025, from 6 PM - 10 PM
Location: Ritz Carlton, St. Louis, MO

Together, we will reflect on the milestones we've achieved and the lives we've touched, all while raising crucial funds to continue our journey of hope for the next 50 years. This event will feature **inspiring stories**, **special tributes**, **live entertainment**, and a **silent auction**, all in support of PWSA | USA's mission: Enhancing the quality of life and empowering those affected by Prader-Willi syndrome.

Tickets and sponsorship opportunities coming soon—stay tuned!

PWSA | USA's 50th Birthday Party

When: Friday, June 27, 2025 | 6:30 PM - 9 PM
Where: Arizona Grand Resort & Spa Oasis Pool

This event is **free to attend** with a 2025 International PWS Conference registration! VIP Cabanas can be purchased when you register for the 2025 International PWS Conference.

You are invited to celebrate a milestone occasion! Join us as we commemorate the 50th birthday of PWSA | USA and the future collaborations of IPWSO, PWSA | USA, and FPWR. Together, let's celebrate 50 years of supporting individuals and families affected by Prader-Willi syndrome, milestones achieved and memories created, and a future filled with hope, advocacy, and empowerment. Come prepared for live music, delicious food, and delightful company, as well as moments of reflection, gratitude, and celebration. Your presence will make this occasion even more special. We look forward to sharing this memorable evening with you!

REGISTER FOR THE 2025 CONFERENCE

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