PWSA | USA Pulse Newsletter: August 1, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 128

August 1, 2025

www.pwsausa.org | 941-312-0400

August is **National Make-A-Will Month**. This milestone year, PWSA | USA's 50th anniversary, offers a special opportunity to think about the legacy you want to leave for the PWS community. For caregivers of individuals with Prader-Willi syndrome, planning ahead is especially important. Our loved ones will need support, supervision, and security throughout their lives, and having a thoughtful plan in place provides peace of mind. One deeply meaningful way to make a lasting impact is through planned giving. A bequest through your will or trust allows you to support PWSA | USA in the future, without affecting your assets during your lifetime. These gifts help sustain the vital programs, services, and advocacy work that families rely on - today and tomorrow. As we look back on five decades of progress and ahead to a hopeful future, we invite you to consider joining the many families who’ve chosen to support PWSA | USA through legacy giving.

"Ten years from now, 50 years from now, 100 years from now, I want to make sure many other generations are taken care of and always have a place they can call in to. I truly do want to help others long after my time on earth is done. I don't look at it as I have to make a world-changing event, personally. I don't have to give my entire estate. That's not what this is. This is about a level of income I know I can always count on that will go to PWSA | USA over time and that will help others who are going to need it." - John Lens, dad to Hunter (27), living with PWS

Click below to learn more about how you can make a difference.

READ HERE

PWSA MEMORIES

PWSA Conference Held with Prader-Willi California Foundation in 1999

"My husband and I attended our first PWSA | USA conference back in 1999 when it was held in conjunction with the Prader-Willi California Foundation, organized by Frank Moss (of PWCF) and Janalee Heinemann (of PWSA). Our son was just 6 months old... attending this conference truly marked the beginning of our PWS journey." - submitted by Lisa Graziano, mom to Cameron (living with PWS)

Read more of Lisa's PWSA Memory by clicking the button below.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S SPOTLIGHT ON HOPE

Our latest Volunteer Spotlight, submitted by PWSA staff member Carrie Ilijevich, celebrates Melissa Rivas - and if you know Melissa, you already know how much heart, creativity, and dedication she brings to everything she does. From designing unforgettable photo op displays at our conferences to quietly lifting up others behind the scenes, Melissa's impact on PWSA | USA has been nothing short of incredible. It's felt throughout our entire community, and we're proud to shine a light on all the ways she gives back.

Click the button below to read the full spotlight.

READ MORE HERE

EVENTS & FUNDRAISERS

2nd Annual Dance Silly for Prader-Willi

When: **Saturday, October 11, 2025**
@ 4 PM CDT
Where: **Trumbull Career and Technical Center | Warren, OH**

Join the Hampton family for the **2nd annual *Dance Silly for Prader-Willi* event**—a lively celebration to support the PWSA | USA! This special occasion honors

Jayda’s journey with PWS and the invaluable support the Hampton family has received from this organization.

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

Event Highlights:

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

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

PURCHASE TICKETS HERE

Thank You, Dance Silly for Prader-Willi Sponsors

PLATINUM SPONSOR

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GOLD SPONSORS

Jimmy and Diana Whetstone

amble

PWSA | USA's 50th Anniversary Celebration

When: **Friday, September 26, 2025 @ 6 PM CDT**
Where: **Ritz Carlton, St. Louis, MO**

After the unforgettable experience of gathering in Phoenix for the United in Hope International PWS Conference, we're excited to invite you to the next opportunity to come together in person - **PWSA | USA's 50th Anniversary Journey of Hope Gala**, which will take place Friday, September 26, 2025, at the Ritz-Carlton in St. Louis, Missouri! This milestone event will honor five decades of progress, advocacy, and community, with a cocktail reception, gourmet dinner, honoree ceremony, silent auction, and live entertainment by Griffin and the Gargoyles. It's a celebration of the people and stories that have shaped the PWS journey, and a night you won't want to miss.

Please note: Rooms at The Ritz-Carlton are almost sold out for Thursday, September 25, and Friday, September 26. If you're planning to stay at the Ritz-Carlton, we recommend booking your room soon! Gala tickets are available for purchase through September 19, 2025. For questions or help with accommodations, contact info@pwsausa.org or call (941) 312-0400. We can't wait to celebrate this historic evening with you.

Learn more and purchase tickets by clicking the button below.

JOURNEY OF HOPE GALA

THANK YOU, JOURNEY OF HOPE GALA SPONSORS

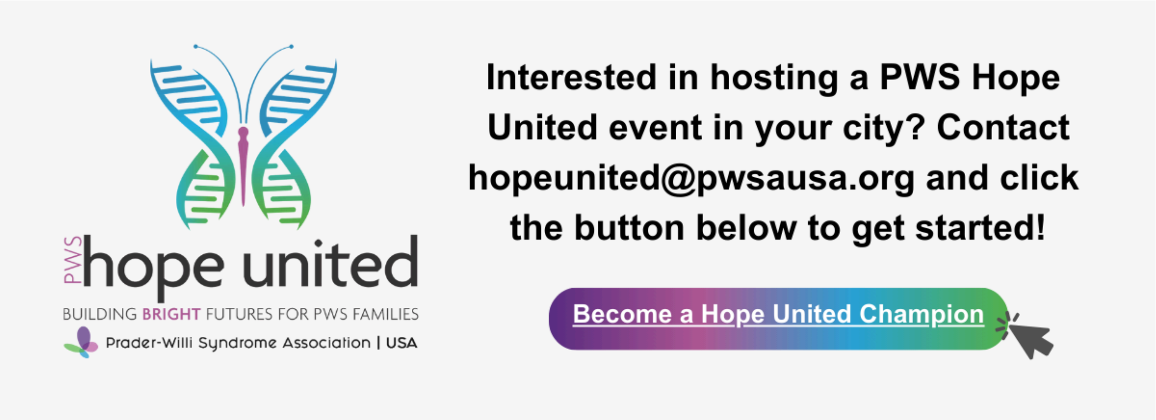
LEGACY SPONSOR

SOLENO THERAPEUTICS

PIONEER SPONSOR

5 BROTHERS PRODUCE

ACADIA



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

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

On this week's episode of PWS United, we celebrate the 35th Anniversary of the signing of the Americans with Disabilities Act. The ADA has been monumental in protecting individuals with disabilities from anti-discrimination legislation and ensuring the legal rights of individuals with disabilities to live, work, and receive services in our society.

In our discussion of the ADA, we dip briefly into the history of the modern disability rights movement that led up to the signing of the ADA, from the League for the Physically Handicapped in 1936, to Judy Heumann and the 20-day protest in 1977 that led to the late enactment of Section 504 of the Rehabilitation Act of 1973, to the inspiring Capital Crawl of 1990 just months before President Bush signed the ADA.

We invited Dorothea Lantz, PWSA's Director of Community Engagement and mom to Hunter (8, living with PWS), on to the podcast to help us better understand how new federal legislation may affect Medicaid. She'll also address the importance of getting involved in advocacy on a state level and of joining in our latest advocacy efforts.

Find this episode of PWS United on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

Exciting News! PWS Included in FY26 Department of Defense Appropriations Bill for Medical Research

We are thrilled to share that Prader-Willi syndrome has been included in the Department of Defense's (DOD) **Peer-Reviewed Medical Research Program (PRMRP)** in the 2026 Fiscal Year Defense Appropriations Bill. This is a MAJOR milestone for our community!

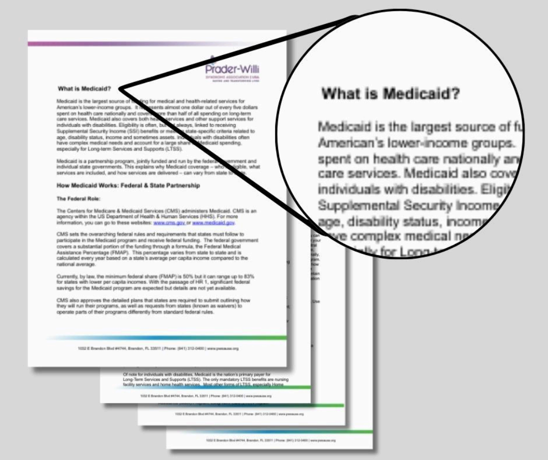
This inclusion, passed out of the Senate Appropriations Committee, is the result of tireless advocacy efforts that began with our very first PWSA | USA D.C. Fly-In in 2022. Since then, our advocates have shown up, spoken out, and shared their stories with lawmakers to push for this recognition. If signed into law, this designation will open new opportunities for federal research funding, scientific innovation, and much-needed progress in the fight against PWS.

We are so proud and grateful to every single advocate who helped make this happen. This is a testament to how much your voice is making a difference.

While this is a critical step forward, the bill still needs to pass the full Senate. We'll be sharing next steps and how you can help keep up the momentum soon. In the meantime, we encourage you to read through the DOD Appropriations Bill draft at the button below. Scroll to page 228, paragraph 1, to see Prader-Willi syndrome listed under PRMRP!

DOD APPROPRIATIONS BILL DRAFT

Understanding Medicaid



We've created a new informational sheet for our families. "What is Medicaid" offers a description overview of what Medicaid is, how Medicaid works and the differences between the state and federal roles, mandatory and optional Medicaid benefits, how to find your state's Medicaid information, as well as a list of the alternative names for Medicaid by state. It is important for families to understand what Medicaid offers and how it operates in their particular state. When we are informed, we are more capable of advocating for our loved ones and getting them the services they deserve.

Download our "What is Medicaid" PDF using the button below.

MEDICAID INFORMATION SHEET

Calling All PWS Families!

We need your voice to help make a difference! Currently, only 14 states recognize PWS as an intellectual/developmental disability (IDD), which limits access to crucial services and supports for individuals with PWS. Your personal story could help change that!

We invite you to take part in an important advocacy effort by sharing your experience with qualifying for Medicaid waiver programs and other state-funded IDD services. By filling out the form below, you'll contribute to our collective efforts to improve access to critical services for individuals with PWS across the country.

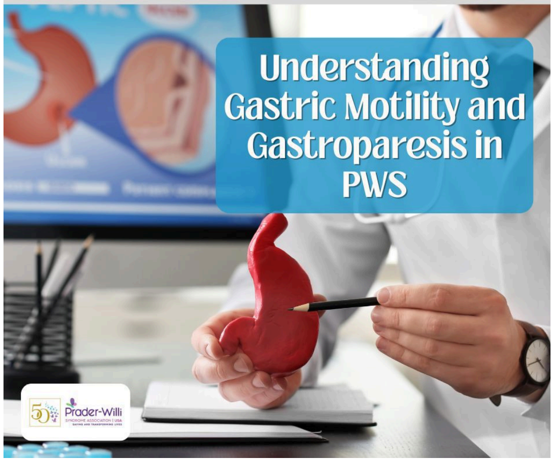
Your story has the power to make an impact! Together, we can push for change for the PWS community in your state and beyond. Share your story using the button below.

SHARE YOUR STORY

FAMILY SUPPORT

Gastroparesis Awareness Month

August is Gastroparesis Awareness Month. Gastroparesis is slow emptying of the stomach, a condition common in individuals with PWS. It is important for caregivers to understand the condition and how to recognize if the individual with PWS is experiencing symptoms. The related article, linked at the button below, was compiled and reviewed by Barb Dorn, RN, BSN, Margaret Burns, RD, Prader-Willi Homes, and Dr. Ann Scheimann, MD. It covers the definitions of gastric motility and gastroparesis, how the conditions affect children and adults with PWS, preventing and managing gastroparesis, and a food guide for the management of gastroparesis.



READ HERE

BOSS Program September Sessions Full

Accepting Applications for January Session

We had an incredible response for our September session of the BOSS (Building Our Social Skills) program and that session is now FULL. We are, however, accepting applications for the BOSS session that will begin in January, dates TBD.

The BOSS program, funded by FPWR, was created to provide a supportive, structured space for participants to build communication skills, boost confidence, and connect with peers in a fun and engaging way. This 10-week virtual program is led by experienced facilitators who understand the unique needs and strengths of people with PWS. All sessions are conducted virtually, making the program accessible no matter where you live. Learn more using the button below.

LEARN MORE AND APPLY HERE

Ask Nurse Lynn

Male, 36 years old, deletion subtype

It was suggested to me by a doctor (not a PWS specialist) that those with PWS are deficient in the hormone leptin, and that replacing it could be an alternative way of helping with hyperphagia. Have you heard of leptin supplement as a treatment for hyperphagia?

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

READ NURSE LYNN'S RESPONSE

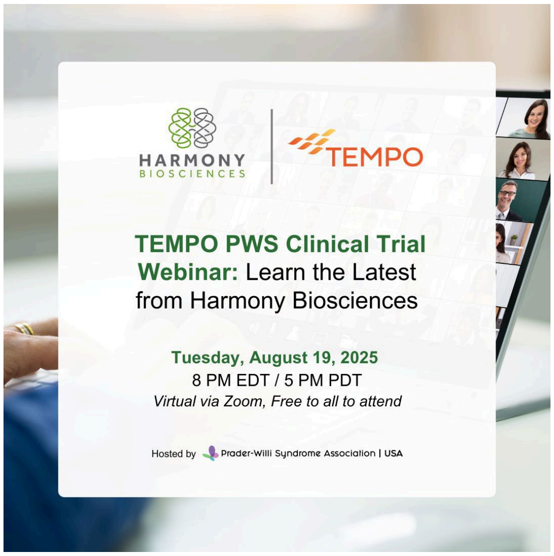
Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

ASK YOUR QUESTION HERE

RESEARCH

Hear New Details About the TEMPO Clinical Trial



HARMONY BIOSCIENCES | TEMPO

TEMPO PWS Clinical Trial Webinar: Learn the Latest from Harmony Biosciences

Tuesday, August 19, 2025
8 PM EDT / 5 PM PDT
Virtual via Zoom, Free to all to attend

Hosted by Prader-Willi Syndrome Association | USA

When: **Tuesday, August 19, 2025 @ 8 PM EDT / 5 PM PDT**
Where: **Free Virtual Webinar via Zoom,** Hosted by PWSA | USA

Join PWSA | USA and representatives from Harmony Biosciences in an upcoming free webinar to hear new information about the TEMPO PWS Clinical Trial. This global Phase 3 study is investigating pitolisant as a potential treatment for excessive daytime sleepiness (EDS) in individuals aged six and older with Prader-Willi syndrome.

Harmony will walk through updates to the trial experience, answer questions, and share how families can get involved. Several trial sites are currently open and actively recruiting participants.

Learn more about the study at: https://www.tempopwsstudy.com

REGISTER HERE

Aardvark Therapeutics HERO Phase 3 Trial Now Enrolling!

10 Active Trial Sites

Aardvark Therapeutics recently launched **HERO**, 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. Click on the button below to learn more about the open trial sites.

To learn more about the HERO Study, visit www.heroforpws.com.

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

Multiple Sites Now Open

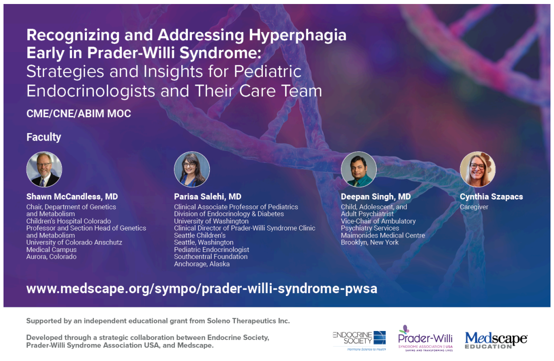
HERO Hunger Elimination or Reduction Objective

www.heroforpws.com

LEARN MORE

Two Free CME Opportunities for Medical Professionals in the PWS Community

PWSA | USA, in partnership with the Endocrine Society and Medscape Education, is excited to share two free online continuing education activities for pediatric endocrinologists, nurses, and other clinicians who care for people with Prader-Willi syndrome. These activities offer free continuing education credits (CME, CNE, and MOC) and help improve understanding and care for individuals with PWS and their families.



Recognizing and Addressing Hyperphagia Early in Prader-Willi Syndrome:
Strategies and Insights for Pediatric Endocrinologists and Their Care Team

CME/CNE/ABIM MOC

Faculty

Shawn McCandless, MD
Chair, Department of Genetics and Metabolism
Children's Hospital Colorado
Professor and Section Head of Genetics and Metabolism
University of Colorado Anschutz Medical Campus
Aurora, Colorado

Parisa Salehi, MD
Clinical Associate Professor of Pediatrics
Division of Endocrinology & Diabetes
University of Washington
Clinical Director of Prader-Willi Syndrome Clinic
Seattle Children's
Seattle, Washington
Pediatric Endocrinologist
Southcentral Foundation
Anchorage, Alaska

Deepan Singh, MD
Child, Adolescent, and Adult Psychiatrist
Vice-Chair of Ambulatory Psychiatry Services
Maimonides Medical Centre
Brooklyn, New York

Cynthia Szapacs
Caregiver

www.medscape.org/sympo/prader-willi-syndrome-pwsa

Supported by an independent educational grant from Soleno Therapeutics Inc.

Developed through a strategic collaboration between Endocrine Society, Prader-Willi Syndrome Association USA, and Medscape.

Recognizing and Addressing Hyperphagia in PWS

This activity focuses on the serious impact of hyperphagia (the constant feeling of hunger) in PWS. Health care professionals will learn about the daily challenges hyperphagia creates, its causes, and the latest treatment options, along with new and emerging therapies.

Credit: Physicians **-** Maximum of 1.25 *AMA PRA Category 1 Credit(s)™;* Nurses - 1.25 *ANCC Contact Hour(s)* (0.25 contact hours are in the area of pharmacology). Learn more details and start this training using the button below.

RECOGNIZING HYPERPHAGIA

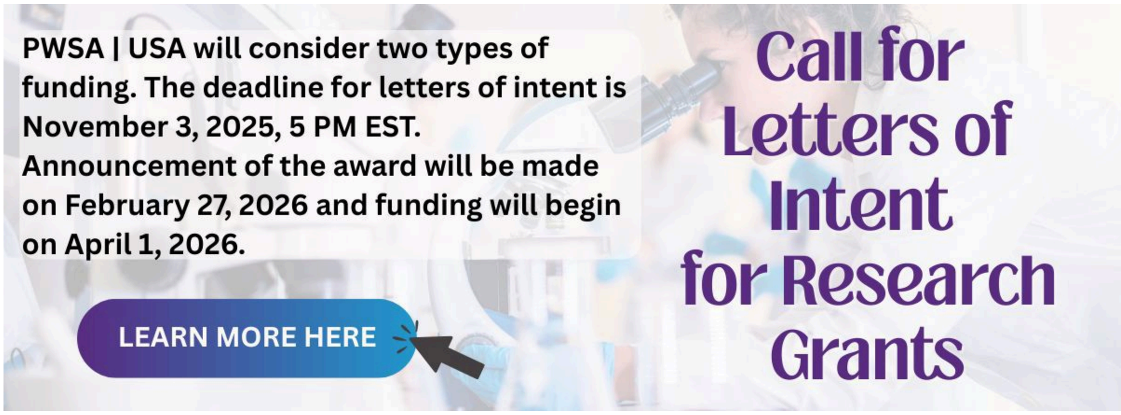
Peer-to-Peer Challenge: Interactive Case Studies in Prader-Willi Syndrome

This interactive course uses real-life case studies to help medical professionals improve how they recognize, diagnose, and manage hyperphagia as part of a comprehensive PWS treatment plan. This activity was created by and for the healthcare team.
Credit: Physicians **-** Maximum of 1.00 *AMA PRA Category 1 Credit(s)™;* Nurses - 1.00 *ANCC Contact Hour(s)* (0.25 contact hours are in the area of pharmacology). Learn more details and start this training at the button below.

PEER-TO-PEER CHALLENGE

Together, these free CME activities help ensure that more doctors, nurses, and care teams are equipped with the latest knowledge to support our PWS community. Please share these valuable resources with your care team!

Supporting PWS Research



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.

Prader-Willi Syndrome Clinical Scholarships Available

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

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

On our website, we offer various informational PDFs that can help families understand financial opportunities. One in particular is Qualifying for Social Security Disability with Prader-Willi syndrome. According to this fact sheet, "If you have a child with PWS, he or she may be eligible for help. The Social Security Administration (SSA) offers monthly financial aid for people of all ages with severe disabilities. Many people with PWS are eligible for assistance." To learn more about technical approval for disability benefits and medical qualifications for people with PWS, and find multiple links to valuable resources, download the document at the button below.

DOWNLOAD PDF

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope

Donate

they so desperately need. Thank you!

PWSA | USA Pulse Newsletter: August 15, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 129

August 15, 2025

www.pwsausa.org | 941-312-0400

This National Nonprofit Day, We're Celebrating...

50 YEARS OF HOPE

As National Nonprofit Day (August 17) approaches, we are honored and proud to celebrate 50 years of service for the PWS community!

National Nonprofit Day encourages us to recognize the hard work and dedication of the organizations that provide support to communities in need. On

August 17, 1894, the Tariff Act was signed into law. This act imposed the first federal income tax on corporations while including exemptions for non-profit corporations. On August 17, 2017, the first National Nonprofit Day was declared.

As a nonprofit organization in service to the PWS community for 50 years, we are consistently reminded of the passion and dedication of those who help our mission succeed. We honor the work done by our volunteers and staff; the passion, creativity, and fortitude of parents and caregivers; the determination of our advocates from grassroots initiatives to Congress; and the gracious contributions of our fundraisers, sponsors, and donors. They've all made it possible to support the PWS community for 50 years. On National Nonprofit Day, and every day, we want to say a huge thank you to all of you who help us support this community.

"My family continues to support PWSA | USA because the organization has been a lot of help for us, and there’s a continuing need for help. Because of the nature of it, children are born every year with Prader-Willi syndrome, so there are families behind us going back every year. We’ve been dealing with it for 33 years and there are families coming on to the scene now. The idea that PWSA | USA might not be there for them – I would be sick if that happened. So, continuing to support PWSA | USA, providing long-term support, is very important to us."

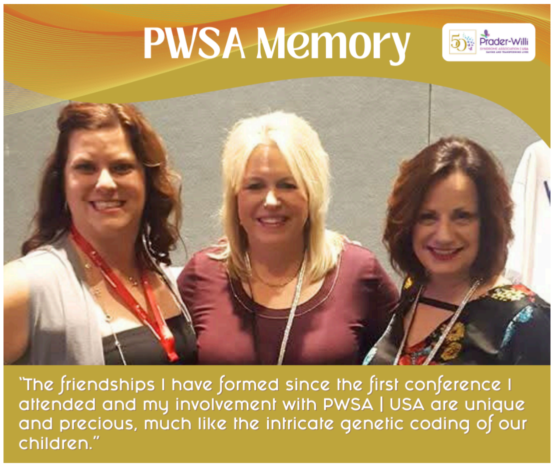
-Tim Hearn, Dad to David (33), living with PWS

Learn more about supporting PWSA | USA through Planned Giving at: [Planned Giving | PWSA USA]

PWSA MEMORIES

"In 2015, I attended my first PWSA | USA Conference in Orlando, Florida. I went alone because my son, Ronan, was just over a year old, and my husband stayed home to care for him. As the newly appointed New Mexico Chapter President, I knew a few people through Zoom, but everything else felt unfamiliar. However, once I registered and began meeting people in person, the environment became much more welcoming. Everyone was incredibly kind, asking about me, my child, and my family. Throughout the conference,

individuals would check on me to see if I needed to talk anything through, as some of the topics discussed in the breakout sessions can be very difficult to process, especially since Ronan was so young.



"The friendships I have formed since the first conference I attended and my involvement with PWSA | USA are unique and precious, much like the intricate genetic coding of our children."

The 2015 conference was a turning point in my life, introducing me to individuals who have become lifelong friends. At that time, Facebook chat groups were not as popular as they are now, so meeting face-to-face felt like reconnecting with old friends. The friendships I have formed since that conference and my involvement with PWSA | USA are unique and precious, much like the intricate genetic coding of our children. These bonds, though delicate, are strong and enduring, and I am grateful for the lasting connections we have built."

Submitted by Kat Lucero, PWSA | USA Board Member, Mom to Ronan

SHARE YOUR MEMORY

PWSA | USA'S
SPOTLIGHT ON HOPE

"I was born in Connecticut in 1950 to Millicent and Willard Booth and grew up with my younger sister, Sally. We were always happy to spend time as a family and took many trips across the USA. When I was 13 years old, I was diagnosed with Prader-Willi syndrome, and my family and myself had to learn how to manage my life going forward. My parents decided I needed a more structured living situation to help me manage my life and they found Riverbrook Residence in Stockbridge, Massachusetts. My life changed in ways I could not imagine, and I was able to

learn so many new things and get a job in the community! I was part of The Special Olympics for many, many years, I enjoyed working at Marian Father's in the greeting card department for 34 years, I volunteer at the local nursing homes, and I attend church every Sunday.

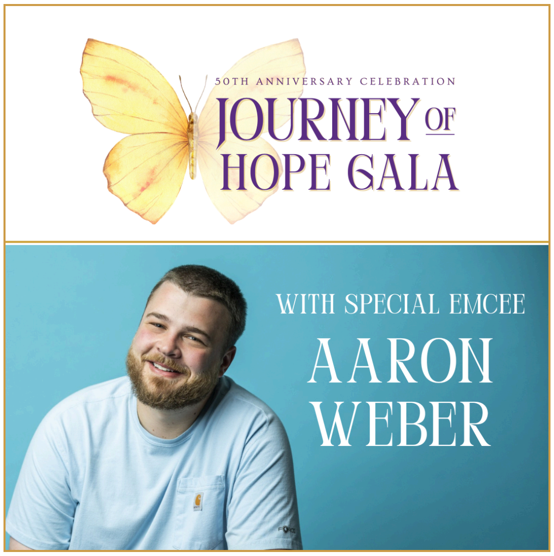
I learned that I am happy when I am busy, which helps to take my mind off of food. I enjoy puzzles, knitting, word searches, art classes, swimming, music, chair yoga, and attending community events that pique my interest. I am now 75 years old, and I am enjoying my retirement. I like to take my days a little slower, focusing my attention on my friends and family that matter the most to me. Things may seem to be hard at times, but having a good support system and having food be safely locked up is the key to my success. My family and Riverbrook helped to give me the opportunity to live my life to the fullest, despite my disabilities."

- Submitted by Susan Booth, affectionally known as Boothie (75 years old, living with PWS)

SHARE YOUR SPOTLIGHT

EVENTS & FUNDRAISERS

Journey of Hope Gala Emcee Announced!



We are thrilled to announce that Aaron Weber, nationally touring standup comedian, Grand Ole Opry regular, and proud dad to (almost) 11-month-old Olive, who is living with Prader-Willi syndrome, will be the special emcee for PWSA | USA's 50th Anniversary Journey of Hope Gala on September 26, 2025, at the Ritz-Carlton in St. Louis, MO!

Aaron has made history as the youngest standup ever to perform in the Grand Ole Opry circle, released his debut comedy special *Signature Dish* (produced by Nate Bargatze and Nateland Entertainment), and appeared on *The Tonight Show Starring Jimmy Fallon*. A co-host of *The Nateland Podcast*, Aaron blends sharp wit with heartfelt humor, and we can't wait for him to bring his signature energy to our most important night of the year.

Join us for an unforgettable evening of celebration, connection, and hope - complete with live entertainment by Griffin and the Gargoyles band, dinner, silent auction, honoree ceremony, and stories that will inspire. We hope to see you there!

PURCHASE TICKETS

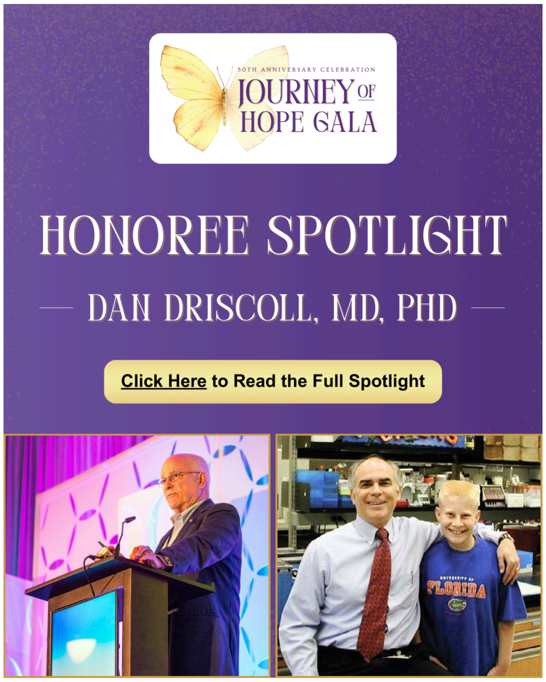
Journey of Hope Gala Honoree Spotlight Series

This year, as PWSA | USA celebrates **50 years** of hope, advocacy, and impact, we're proud to recognize the pioneers and visionaries who helped lead the way. In the weeks leading up to our *Journey of Hope Gala* in St. Louis, MO, we will share a series of blog spotlights to honor the 12 incredible individuals being recognized at the event.

These honorees have shaped the Prader-Willi syndrome landscape in profound and lasting ways – through groundbreaking research, tireless advocacy, compassionate care, and unwavering support for families and individuals living with PWS.

We hope you'll join us in celebrating their legacies by reading their stories and attending our Journey of Hope Gala. Click the images below to read our first two spotlights, featuring Dan Driscoll, MD, PhD, and Suzanne Cassidy, MD.

Visit our Journey of Hope Gala website to find the full list of honorees.



HONOREE SPOTLIGHT

— DAN DRISCOLL, MD, PHD —

Click Here to Read the Full Spotlight

HONOREE SPOTLIGHT

— SUZANNE CASSIDY, MD —

Click Here to Read the Full Spotlight

THANK YOU, JOURNEY OF HOPE GALA SPONSORS

LEGACY SPONSOR

SOLENO THERAPEUTICS

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5 BROTHERS PRODUCE

ACADIA

Get Your Tickets Now for Cocktails for a Cause!

When: **Saturday, October 18 @ 6:30 PM EDT**
Where: **Brown's Brewing Company Malt Room** *(417 River St, **Troy, NY** 12180)*

Join PWSA | USA CEO Stacy Ward and her family for an unforgettable evening of support, hope, and community. Hosted at the scenic and historic Brown's Brewing Company Malt Room, this event will bring together families, friends, and supporters for an inspiring evening of cocktails, conversation, and compassion, all aimed at raising awareness and funds for Prader-Willi syndrome.

Guests will enjoy signature cocktails, delicious hors d'oeuvres, and the unique ambiance of the Malt Room, known for its charm and exceptional service. The night will feature engaging speakers, including families impacted by PWS, as well as opportunities to learn more about the syndrome and how funds raised will directly benefit those affected by it. The event will also offer a raffle, silent auction, and other interactive ways to contribute to this important cause. Click the button below to purchase tickets and to learn more!

COCKTAILS FOR A CAUSE

Thank You, Cocktails for a Cause Sponsors

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ACADIA™

SILVER SPONSOR

CATHOLIC CHARITIES
CELEBRATING 40 YEARS
DISABILITIES SERVICES

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

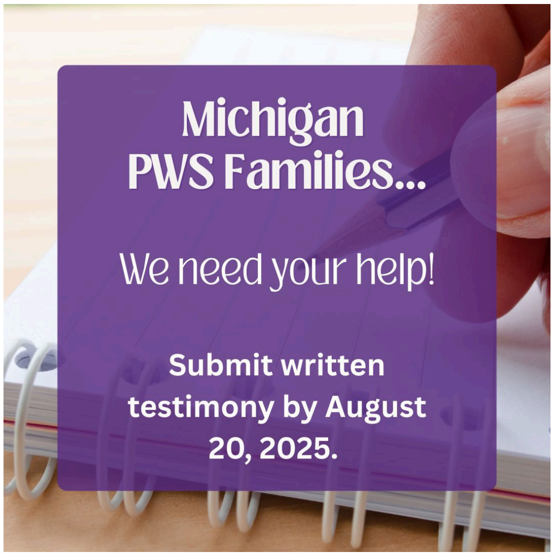
A Podcast for the PWS Community

On this week's episode of PWS United, we welcomed Destiny Pacha, Ed.D., the president of EmpowerED Solutions, an organization dedicated to providing educational consulting, IEP advocacy, and support for families and professionals navigating the complex needs of children with Prader-Willi syndrome and other genetic disorders in school settings. Dr. Pacha was a recent speaker at the 2025 United in Hope Conference and graciously offered to extend her discussion time with caregivers. She created a form for people to submit questions and then came onto the podcast to share those responses with our community. Topics included: why or why not to disclose a PWS diagnosis, service requirements in relation to public vs private schools, the differences between modifications and accommodations in an IEP, special diplomas, how to know if an IEP is being implemented, the differences between language therapy and speech therapy, and more. This discussion is a wealth of information for anyone with a child with PWS in school. Listen to this episode on your preferred Podcast streaming platform to learn more about IEP and school support, along with an upcoming training for parents from Dr. Pacha, “Empowering PWS Families in IEP Meetings.” You can also scroll below to find more details and a link to register for this training.

LISTEN ON PODBEAN

ADVOCACY

Call to Action for Michigan Families!



The Michigan Pharmacy and Therapeutics Committee will hold a Drug Utilization Review (DUR) Board meeting on **September 2, 2025**, at 6 PM. Please submit your comment by **August 20, 2025**.

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

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

LEARN MORE HERE

Federal Budget Proposals Could Undermine Critical Supports for Students with Prader-Willi Syndrome

Recent federal budget proposals may reshape how special education is funded and could pose real risks to students with Prader-Willi syndrome. These proposals could affect specific IDEA (Individuals with Disabilities Education Act) grants through eliminations or combining of grants, bringing about less targeted funding, reduced oversight, staff and program erosion, and the financial and administrative burdens shifted to families. It is critical for families to understand these changes and restructuring and stay informed of ways to act. Please know that PWSA | USA will continue to monitor these changes and how they affect our community. Together we can continue to advocate and make necessary impacts for our loved ones. Please use the button below to read the full article and learn ways you can stay informed and take action.

READ HERE

PWSA | USA Advocates Make Their Voices Heard During Rare Across America

Throughout the past week and a half, PWSA | USA staff and Advocacy Ambassadors joined rare disease advocates nationwide for EveryLife Foundation's **Rare Across America**, meeting with members of congress and their staff in more than 20 visits across the country. From sharing personal stories to urging support for critical legislation like the *Give Kids a Chance Act* and the *Accelerating Kids Access to Care Act*, our advocates, often joined by their loved ones with PWS, helped bring our community's priorities directly to lawmakers. These conversations are already making an impact, proving that when we show up and speak out, change can happen. Read more about these powerful meetings at the button below.

READ HERE

"This was my first time attending Rare Across America, though this is my 7th time advocating with my state representatives on the federal level. This has been my most active year with advocacy, and because I have met with my senator's staffer several times this year alone, we have formed a relationship. I joked when I saw her in July that I was back, and she told me, "No, please keep showing up." On our virtual meeting last week, she thanked me for showing up again because she has it on her list to ask my senator to co-sponsor the Give Kids a Chance Act / Priority Review Voucher (H.R. 1262/S.932). All of my state constituents on the Zoom were amazed by hearing that. This would be huge for our community, the senator's scorecard, and bridging the gap on the divide in politics happening right now. These were all things we discussed on the call. This was the first time that Lyra could attend a meeting with me, and Dana loved

that she could finally see her. She has watched her grow up in pictures over the years. I cannot say enough how important it is to keep showing up. One time is not enough. Two times is not enough. We have to keep showing up over and over again. My meeting during Rare Across America proved that. No matter how we meet, showing up continues to build relationships. Eventually we will make change. We have to keep trying."
- Sheri Mills, PWSA Advocacy Ambassador, Mom to Lyra

FAMILY SUPPORT

The Importance of Caring for Your Relationship

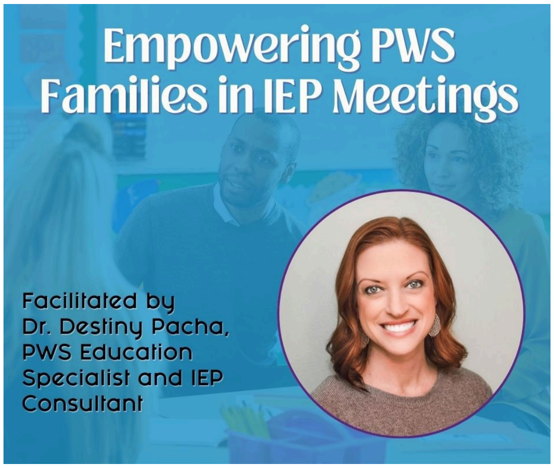
As parents and caregivers of loved ones with PWS, we know how challenging this journey can be at times. We also know the strain it may put on our marriages and relationships, though we are often not as willing to share those details. Our latest blog post is a beautiful piece from a parent who saw an opportunity to help other families. As the author reflects honestly on the end of her marriage, she weaves in insight, support, and directions on a path forward for those who find themselves struggling in their relationships.

"*Sometimes the pressure is just too much. Sometimes people grow in different directions. Sometimes grief looks like anger, or avoidance, or silence and sometimes, love just gets lost along the way... But if you're still in it with your spouse, I encourage you to look up from the daily routine and check in.*"

You can read this blog using the button below.

READ HERE

Upcoming Parent Training: Sign Up Now!


Empowering PWS Families in IEP Meetings

Facilitated by
Dr. Destiny Pacha,
PWS Education
Specialist and IEP
Consultant

Navigating the special education system can feel overwhelming, especially when your child has a rare disorder like PWS, a condition unfamiliar to most school staff. From understanding IDEA and IEP requirements to ensuring your child's medical, behavioral, and educational needs are met, parents often face a steep learning curve and emotional challenges in meetings.

The **Empowering PWS Families** training series is designed to equip parents and guardians with the knowledge, tools, and confidence they need to actively and effectively participate in their child's IEP meetings. You'll learn how to review your child's IEP, identify necessary supports and services, and advocate for your child's unique needs, all in a supportive environment led by Dr. Destiny Pacha, a PWS education specialist.

As Ron Paige once said, *"There is no more powerful advocate than a parent armed with information and options."* Join us and become a stronger advocate for your child.

"Empowering PWS Families in IEP Meetings" this coming fall will begin on Tuesday, October 14, at 7:30 PM EDT. All other meetings will be at 7 PM EDT. Space is limited so please sign up soon using the button below.

REGISTER HERE

Ask Nurse Lynn

Female, 54 years old, unknown subtype

My sister was recently in the hospital for CHF, low O2 and heart rate, and an obstruction in her stomach. She was placed on a NG tube for several days to *allow her stomach to decompress. She is now at a rehab center. She is battling huge blisters on her calves for edema and is crying in pain when she tries to have a bowel movement. The blockage in her stomach was a bowel movement at the hospital- they had to manually help her get it out. They have her on stool softeners, but it isn't getting better or easier for her. She is bedridden, so I'm sure the position isn't helping either. Suggestions?*

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

READ NURSE LYNN'S RESPONSE

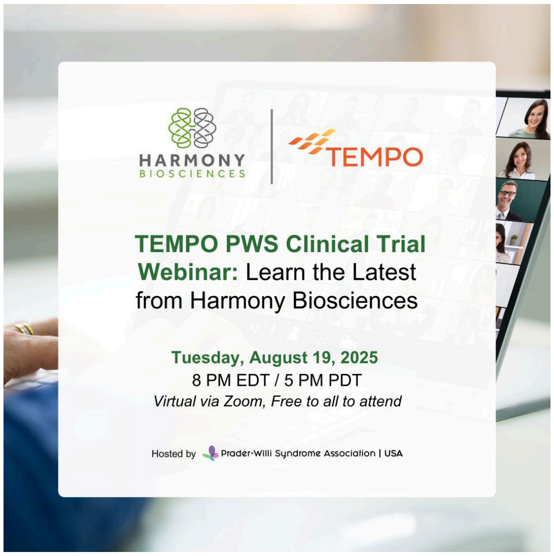
Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

ASK YOUR QUESTION HERE

RESEARCH

PWS Community! This is Your Chance to Learn About Harmony Biosciences At-Home TEMPO PWS Study



TEMPO PWS Clinical Trial Webinar: Learn the Latest from Harmony Biosciences

Tuesday, August 19, 2025
8 PM EDT / 5 PM PDT
Virtual via Zoom, Free to all to attend

Hosted by Prader-Willi Syndrome Association | USA

We're thrilled to welcome back representatives from Harmony Biosciences to share an exciting update to their TEMPO PWS Study, investigating pitolisant, a potential treatment for excessive daytime sleepiness in individuals aged six and older with Prader-Willi syndrome. This new addition is a game-changer: an **at-home clinical trial opportunity** - no travel required!

Join us for PWSA's free webinar on **Tuesday, August 19, 2025, at 8 PM EDT / 5 PM PDT** to hear all the details directly from the Harmony team.

Can't make it live? We recommend registering anyway to receive a link to the recording. But if possible, we encourage you to attend in real time so you can ask questions and get answers directly from the experts.

Learn more about the TEMPO PWS study by scrolling below or visit https://www.tempopwsstudy.com/.

REGISTER HERE

Aardvark Therapeutics HERO Phase 3 Trial Now Enrolling!

New Site Open

Aardvark Therapeutics recently launched **HERO**, 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 (PWS). 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.

New Trial Site:

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

New Site Now Open

Minneapolis, Minnesota:
University of Minnesota Masonic Childrens Hospital

Minneapolis, Minnesota
University of Minnesota Masonic Childrens Hospital
Contact: Bradley Miller, MD
Phone: (612) 624-5409
Email: mille685@umn.edu

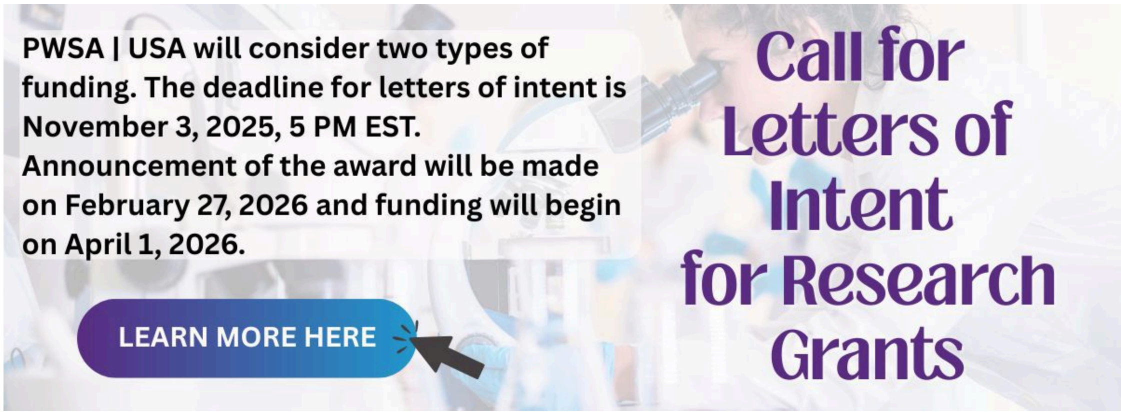
Click on the button below to learn more about the open trial sites. To learn more about the HERO Study, visit www.heroforpws.com.

LEARN MORE

Supporting PWS Research

Prader-Willi Syndrome Clinical Scholarships Available

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

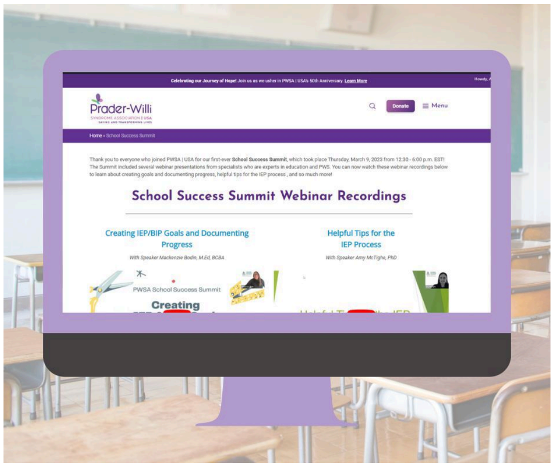


PWSA | USA will consider two types of funding. The deadline for letters of intent is November 3, 2025, 5 PM EST. Announcement of the award will be made on February 27, 2026 and funding will begin on April 1, 2026.

Call for Letters of Intent for Research Grants

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight



Celebrating our Journey of Hope! Join us as we usher in PWSA | USA's 50th Anniversary. Learn More

Thank you to everyone who joined PWSA | USA for our first-ever **School Success Summit**, which took place Thursday, March 9, 2023 from 12:30 - 6:00 p.m. EST! The Summit included several webinar presentations from specialists who are experts in education and PWS. You can now watch these webinar recordings below to learn about creating goals and documenting progress, helpful tips for the IEP process , and so much more!

School Success Summit Webinar Recordings

Creating IEP/BIP Goals and Documenting Progress

With Speaker Mackenzie Bodin, M.Ed, BCBA

Helpful Tips for the IEP Process

With Speaker Amy McTighe, PhD

August 15th is National Back-To-School Prep Day. As kids gather their supplies and look toward a new school year with excitement or trepidation, we want to make sure our families are prepared for the year ahead. The link at the button below leads to our School Success Summit webpage. There, you will find a series of webinar presentations from specialists who are experts in education and PWS. Watch these webinar recordings to learn about creating goals and documenting progress, helpful tips for the IEP process, and so much more. You will also find links to valuable downloadable material about behavior challenges, IEPs, homeschooling, special education law, and effective advocacy. Celebrate National Back-To-School Prep Day and get ready for the school year.

VISIT WEBPAGE

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the

Donate

connection, guidance, and hope they so desperately need. Thank you!

PWSA | USA Pulse Special Edition Newsletter: August 29, 2025

www.pwsausa.org | 941.312.0400 Donate

Thank You, PWS Community, for a Wonderful First Year!

We are thrilled to celebrate our 1-year anniversary of the PWS United podcast!

This podcast gives the latest news in research, advocacy, and family support by bringing together staff, volunteers, PWS treatment specialists, biotech and pharmaceutical representatives, caregivers, family members, and individuals with PWS. Our goal is to connect education, awareness, and resources with those living with PWS and their supporters. Join us in our mission to enhance the quality of life and empower those affected by Prader-Willi syndrome.

From discussions on exercise and nutrition, self-care and advocacy, PWS in the context of larger social issues and sibling relationships at home, we have created an incredible and enduring resource for the PWS community. It has been an honor to embark on the podcasting journey, and we look forward to the many incredible discussions and information sharing to come. To listen to the PWS United podcast on Podbean, click the button below, or listen on your favorite podcast app, including YouTube.

Continue scrolling to listen to some of our most popular episodes.

PWS UNITED ON PODBEAN

TOP 10 EPISODES


PODCAST EPISODE #3

ADVOCATING FOR CHANGE: A CONVERSATION WITH DOROTHEA LANTZ


PODCAST EPISODE #12

PWS PARENT CLINT HURDLE SHARES ADVICE FOR DADS, PERSONAL STORIES


PODCAST EPISODE #37

ASK NURSE LYNN: GROWTH HORMONE, SKIN-PICKING GLP-1S


PODCAST EPISODE #16

SELF-CARE, SELF-ADVOCACY, AND GRATITUDE


PODCAST EPISODE #47

NUTRITION RECOMMENDATIONS FOR PWS: CONFERENCE SESSION


PODCAST EPISODE #35

PWS AND SIBLING SUPPORT


PODCAST EPISODE #31

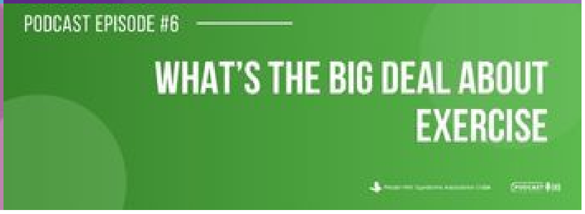
PWS AWARENESS STARTS HERE: FUNDRAISING WITH HOPE UNITED AND UNITED WE BRUNCH


PODCAST EPISODE #5

PWS BIPOC AFFINITY GROUP

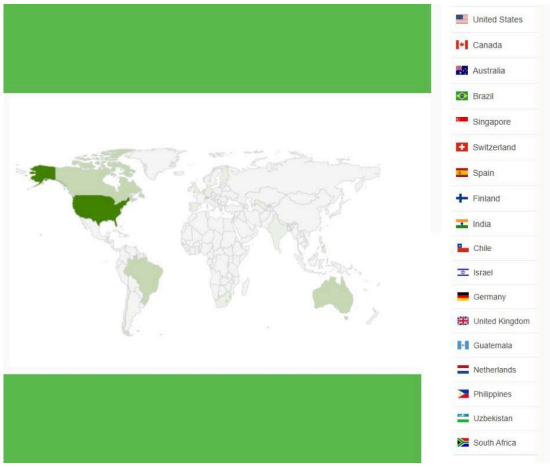

PODCAST EPISODE #14

ADULTS WITH PWS ADVISORY BOARD


PODCAST EPISODE #6

WHAT'S THE BIG DEAL ABOUT EXERCISE

A PODCAST HEARD 'ROUND THE WORLD


United States
Canada
Australia
Brazil
Singapore
Switzerland
Spain
Finland
India
Chile
Israel
Germany
United Kingdom
Guatemala
Netherlands
Philippines
Uzbekistan
South Africa

We are incredibly honored to have a podcast audience that spans the globe. By sharing our episodes weekly, we are helping spread PWS awareness and information to families in many corners of the world. Thank you to those who have shared the podcast with friends and neighbors, those who have left reviews and ratings, and those who follow us on your podcast app. All of these actions have helped our resources reach families who may be in dire need of our support. With listeners in the US, Canada, India, Israel, Hong Kong, Australia, Singapore, Uzbekistan, UK, Switzerland, Spain, Finland, Ireland, Chile, Germany, Greece, Mexico, Malaysia, and Uruguay, we are able to expand our mission worldwide.

STAFF FEEDBACK

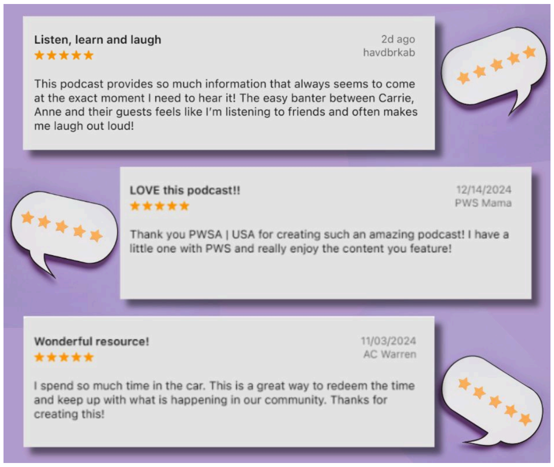
“Over the past year, this platform has become more than a podcast—it’s become a powerful voice for the Prader-Willi syndrome community. Through shared stories, expert insights, and honest conversations, we’ve reached a broader audience than ever before. Listeners around the world are learning about the complexities, challenges, and remarkable strength of those living with PWS and the families who support them. This podcast has amplified awareness, broken down stigma, and created a sense of belonging for individuals and families who often feel isolated in their journey. It has opened doors for dialogue across disciplines and inspired greater advocacy, collaboration, and understanding. Most importantly, it has helped build a stronger, more connected community—one rooted in empathy, resilience, and hope.” - Lynn Garrick, PWSA | USA's Medical/Research Coordinator, mom to John (living with PWS)

“The PWS United podcast gives our community connection, understanding and HOPE. It reminds us we are not alone in this journey.” - Kristi Rickenbach, PWSA | USA's Parent Support Coordinator, mom to Justice (21, living with PWS)

"With PWS United, we’re bringing stories and support to life in a really fresh, engaging way. Sharing knowledge across different formats is so important—because not everyone learns the same way. That’s why our podcast matters. For our community, this is more than just another resource—it’s a chance to feel connected, to hear voices that reflect their own experiences, and to know they are not alone. And let me tell you, the banter between Carrie and Anne? It’s not just fun—it keeps conversations light and real, while spotlighting so many voices from our staff and community. Their humor makes people feel welcome, while the wide range of topics and guests ensures that everyone—from families to providers to researchers—can take away something meaningful. It brings us all a little closer, and helps us all learn and grow together.” - Stacy Ward, PWSA | USA's CEO

“The PWS United podcast has been such a gift for me and for our entire community. I can’t believe it’s already been a year since we launched! It is especially helpful to listen to episodes and ‘hear’ the Pulse- rather than reading- when we’re always on the go—driving or traveling to appointments. This continues to be a source of learning, connection, and support for all of us.” - Sarah Kasaby, PWSA | USA's Information and Referral Specialist, mom to Khaled (5, living with PWS)

COMMUNITY REVIEWS



Listen, learn and laugh
★★★★★
2d ago
havdbrkab

This podcast provides so much information that always seems to come at the exact moment I need to hear it! The easy banter between Carrie, Anne and their guests feels like I’m listening to friends and often makes me laugh out loud!

LOVE this podcast!!
★★★★★
12/14/2024
PWS Mama

Thank you PWSA | USA for creating such an amazing podcast! I have a little one with PWS and really enjoy the content you feature!

Wonderful resource!
★★★★★
11/03/2024
AC Warren

I spend so much time in the car. This is a great way to redeem the time and keep up with what is happening in our community. Thanks for creating this!

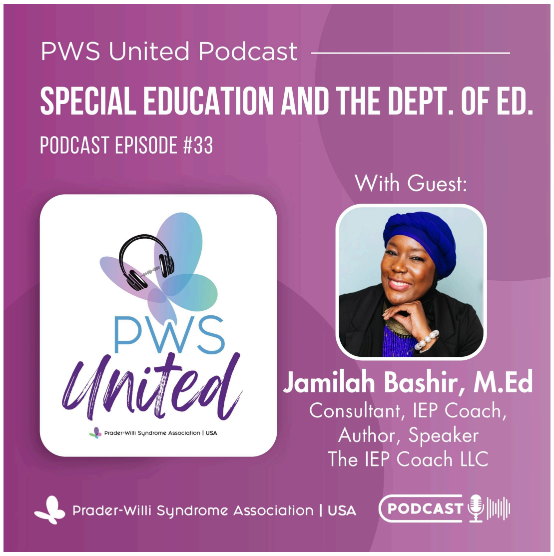
Podcasts are a unique opportunity for average people to create a platform to share their voices, their knowledge, or their stories. Podcast platforms also provide space for listeners to offer their feedback on the content, whether through a simple star-rating system or a more in-depth written review. These ratings and reviews help the podcast make its way up in the algorithms, ensuring that more people learn of the podcast. PWS United has been an exciting and innovative way to spread PWS awareness, not only to our community of family and friends, but to a broader audience around the globe. Rating our podcast and writing a review on your favorite podcast platform helps to ensure that we can continue to spread information, awareness, and hope. We are grateful to those of you who have already offered your feedback and shared your experience with our podcast. We would love to hear more. If you would like to learn more about rating and reviewing, please click the button below.

LEARN MORE

IN CASE YOU MISSED IT

In March of 2025, we published a podcast episode to help our community better understand the Department of Education. PWSA | USA’s CEO Stacy Ward sat down with educator and Individualized Education Program (IEP) coach, Jamilah Bashir to discuss special education and the state of the Department of

Education. They discussed training for special education teachers, the voucher program, where to find good information about changing policies and decisions within the Department of Education, and the path of an executive order. Jamilah clarified the different roles of the U.S. Dept. of Ed. versus the state's Dept. of Ed., focusing on funding and the accountability of states to provide services. This discussion can provide clear insight on the role of the U.S. Department of Education, why it may be critical for our loved ones with PWS, what the alternative (e.g., voucher programs and private schools) may look like, and how and why to contact your representatives on this issue. You can listen to this episode on your favorite podcast app or using the button below.



[LISTEN HERE]

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