PWSA | USA Bi-Weekly Pulse: August 2, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 104

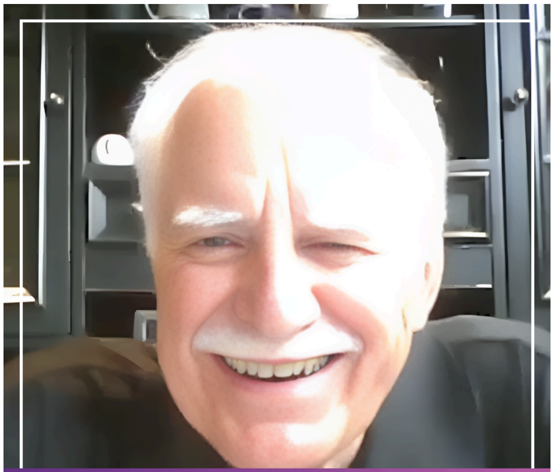
August 2, 2024

www.pwsausa.org | 941.312.0400

August is National Make-a-Will Month. Planning for a future in which you have passed on may not be a pleasant task, but it is a necessary one. It is especially important for caregivers of individuals with PWS, as our loved ones will need security, supervision, and guidance throughout their lives. National Make-a-Will Month encourages us to see to the tasks of planning for the future. An incredibly impactful way to support the Prader-Willi Syndrome Association | USA (PWSA | USA) and leave a lasting legacy for PWS families is through an endowment gift.

A common form of such a gift is a bequest, which allows you to contribute through your will or trust. This means the transfer of funds to PWSA | USA occurs after your lifetime, ensuring that you can enjoy the asset during your lifetime. As a non-profit organization, PWSA | USA is incredibly grateful for the contributions of families in the PWS community. Planned giving is a wonderful way to show your support. Learn more by clicking the button below.

LEARN MORE HERE


Jim Koerber, Former PWSA | USA Board Member and PWS Parent

"Like many of us, when someone does something good for you, you want to return that good deed. In my case, I volunteered my time, talent, and treasures. I no longer serve on any of the chapters or the PWSA | USA national board, however, I continue to make donations and have established a planned gift. Our goal has always been for our child to be the best Prader-Willi syndrome person she can be, and through the help of the association, we've accomplished that – with our ups and downs, of course. I hope others consider this long-term aspect of planned giving and the long-term benefits it has."

Read our National Make-a-Will Month blog at the button below.

NATIONAL MAKE-A-WILL MONTH

PWSA | USA'S SPOTLIGHT ON HOPE

This week's Spotlight on Hope was submitted by Jeremy Lanning, the father of a baby with PWS. Jeremy shared with us the story of Lucas' birth, receiving a diagnosis of Prader-Willi syndrome, a glimpse of life in the first few months in the NICU, admiration for his wife, and how he came to the resolve that his son

is "less than no one." Along with his story, Jeremy sent a video of a song he wrote for his son during this time, called "I'll Be Your Lullaby." Jeremy and his wife, Melissa, have created "Less Than No One" PWS gear. Proceeds help support PWSA | USA. You can email pwsaware@gmail.com to learn how you can get your gear. To read Jeremy's story, along with hearing the beautiful song written for Lucas, please click the button below.

READ BLOG HERE

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

2025 International United in Hope PWS Conference

June 24, 2025	June 25-26, 2025	June 26, 2025	June 27-28, 2025
PWS Clinical Workshop	Clinical & Scientific Program	Adults with PWS Program	Family Program PWS Camps
Invite Only	Professional Providers Program	*1/2 Day*	

Register for the **2025 International Prader-Willi Syndrome Conference** in Phoenix, Arizona! PWSA | USA, FPWR, and IPWSO are coming together to bring you the most up-to-date medical information, help and HOPE for parents and caregivers, a safe and fun space for your loved ones with PWS and their siblings, and a time to connect with other families. Space at the camps is limited; once they are full, we will close registration. Mark your calendars and register early! Scholarships are available by submitting an application **here**.

2025 Conference Camps:

Little Tikes Camp (0-24 months) - 43% capacity
Junior Adventure Camp (2-6 years) - **FULL**
Sibling Camp (6-14 years) - **FULL**
Adventure Camp (7+) - 81% capacity

VISIT CONFERENCE WEBSITE

With the 2025 International PWS Conference approaching, we're creating a special mural to showcase the diversity and beauty of our incredible PWS community. This mural will be on display during the 2025 conference at the Arizona Grand Resort & Spa. We want photos of your loved one to be a part of it! Submit a picture of your PWS warrior, even if you can't join us in person, at the button below. The pictures shared will help create a display of hope that everyone can take pride in. Let's come together to celebrate and inspire!

SUBMIT PHOTO HERE

PWSA | USA's Residential Providers Conference: Registration Closing Soon!

PWSA | USA's 2024 Residential Providers Conference, Empowerment Heroes: Reveal Your Superpowers, will offer a variety of lectures and workshops in a collaborative space where professionals can exchange practice-driven knowledge and actively contribute their experiences. The conference will take place **August 18-20, 2024**, both virtually via ZOOM and in-person at the Kimpton Brice Hotel in Savannah, GA. The goal of this event is to enhance the care provided to individuals and develop new methods of support on a range of topics like research, relationships, technology, the role of therapies, diagnostic instruments in behavior management, autonomy, aging, and more. Whether you have daily or occasional involvement as a professional caregiver of people with PWS, we invite you to join!

*

Registration for in-person attendance has been extended to **August 7th** (please note, attendees registering during this extension period are not guaranteed swag).

*

Registration for virtual attendance will close on **August 16th**.

REGISTER HERE

Upcoming Fundraisers

Tee off for a great cause at RMC's annual golf tournament, benefiting innovative research and community support initiatives. Enjoy a round of golf at the Ritz Carlton Members Club while making a positive impact on those living with Prader-Willi syndrome. The RMC Foundation works to provide funding to PWSA | USA's Advocacy programs. These programs help enrich the lives of people living with Prader-Willi syndrome.

Register TODAY at the button below.

When: **Monday, September 30, 2024, 8:30am shotgun start**
Where: **Ritz Carlton Members Club, Bradenton, FL**

REGISTER TO ATTEND

PWSA | USA'S UPCOMING EVENTS

Become a Hope United Champion and host an event in your community! Learn more below.

HOST A FUNDRAISER

ADVOCACY

PWSA | USA Files Congressional Letter of Support with the FDA

PWSA | USA has submitted our "Congressional Letter of Support" to the FDA with 27 signatures from U.S. Congress members! This letter pushes for urgent development and approval of treatments for Prader-Willi syndrome. A big thank you to our advocates who shared this ask during the 2024 D.C. Fly-In and to the team leads who worked diligently to follow up with their members of Congress. Your dedication is making a difference.

Thank you to the members of Congress who showed their support for our community by signing the letter! Together, we're bringing hope and a better quality of life to those affected by PWS.

READ NAMES AND LETTER

Are you a Military Family Affected by PWS?

We need your help to support an important initiative that could significantly benefit military families affected by Prader-Willi syndrome (PWS). As part of PWSA | USA's advocacy program, one of our key legislative asks is that Prader-Willi syndrome be added as a topic area to the Peer Reviewed Medical Research Program (PRMRP).

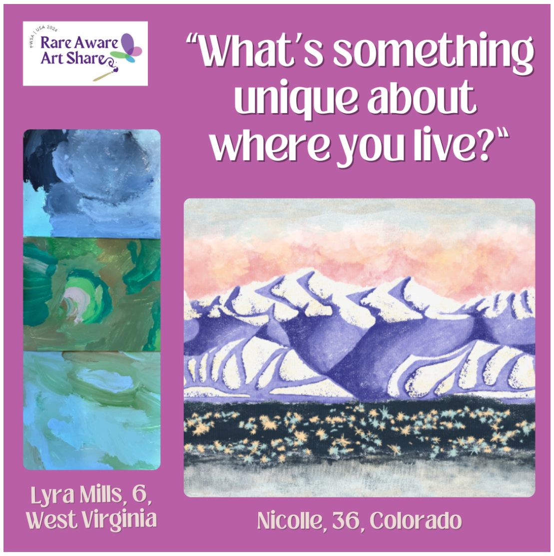
Established in 1999 under the U.S. Department of Defense, the PRMRP has funded a wide range of research aimed at enhancing the health and well-being of military service members, veterans, retirees, and their families. To strengthen our petition that PWS be added as a recognized topic area, it's crucial for us to gather data on how many U.S. military families within our community are affected by PWS.

If your family is part of the military—whether active, inactive, or retired—please take a moment to fill out the form at the button below. Your participation will provide the essential information we need to advocate effectively for research and policies that support the unique needs of military families dealing with PWS.

Thank you for your support and for helping us make a difference! If you have any questions, please contact us at info@pwsausa.org.

MILITARY FAMILY FORM

Rare Aware Art Share Deadline Extended!
Submissions Open until September 15



Our Rare Aware Art Share is an international opportunity to showcase the artistic voices of individuals living with PWS. As we are preparing to gather with our international community in June of 2025, we are seeking the voices of individuals around the world to share with us something that is unique about where they live. This is a wonderful opportunity to learn about individuals with PWS in a variety of cultures and places worldwide. To give this theme it's proper due and provide ample time for word to spread to artists to submit pieces, we are extending the submission deadline to September 15. Please share this opportunity with your PWS community and let's encourage individuals from all over the world to share their artistic voice! Learn more and submit artwork using the button below.

SUBMIT HERE

THEME #1 GALLERY VIDEO

FAMILY SUPPORT

PWS Blog: Interdependence
PWS in Adulthood Blog Series

"From a young age, we chose to work toward 'interdependence,' which we define as having the individual with PWS actively participate in making informed decisions about their future; however, being reliant on relational interactions with a guardian for ultimate decision-making responsibility." Amy McDougall, mom to Noelle (21), shares some of her experience caregiving for an adult with PWS. Read our latest blog post, "Interdependence," by clicking the button below.

READ BLOG HERE

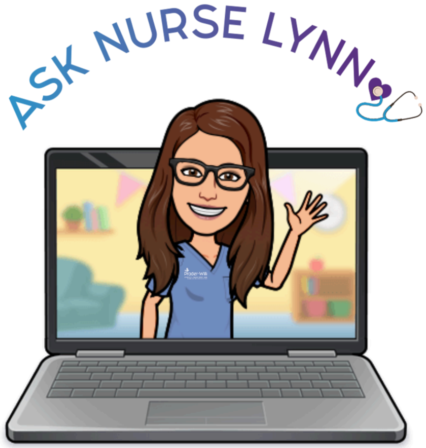
Ask Nurse Lynn

Question *(Male, 2.5, UPD):*

"My son has had a decrease in appetite (eats breakfast and lunch but not dinner) but has been drinking regularly the past two days. His BMs are a lighter brown/tan/beige color, and he has had smelly gas. His stomach at night looks slightly distended but is gone by morning. The stomach bug has hit my husband and I over the last week. Should I be concerned about a blockage? Or any other GI complications?"

Visit our blog to read Nurse Lynn's response and find links for the mentioned 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

Family Support Webinars

PWS Aging Research and Health Update Webinar Series: Comprehensive Insights and Strategies for Caregivers

Join us for the PWS - Aging Research and Health Update Webinar series, featuring Lynn Garrick, RN, MSN, and Barb Dorn, RN, BSN, Part 2, on Tuesday, August 6, 2024, at 8:00 p.m. EST. We will continue the discussion from session 1, focusing on respiratory issues, weight gain/obesity, low bone density, cardiac issues, mobility challenges, and mental health concerns. Attendees will gain insights into prevention and management strategies for these health topics.

REGISTER FOR PART 2

Session 1 of our **PWS Aging Research and Health Update Webinar Series: Comprehensive Insights and Strategies for Caregivers**, featuring Lynn Garrick, RN, MSN, and Barb Dorn, RN, BSN.

RECORDING COMING SOON

RESEARCH

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is now open for the 2025 International PWS Conference Clinical and Scientific Program and the Professional Providers and Caregivers 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 5-day event marks the first joint conference between IPWSO, PWSA | USA, and FPWR, and symbolizes a historic milestone! Register today!

Call for Abstracts

Professional Providers Program Submission Deadline: November 5, 2024

Clinical & Scientific Program Submission Deadline: January 31, 2025

APPLY HERE

REGISTER HERE

ECHO 4 PWS Health Care Series:
Three New ECHO Webinars Planned for 2024

Project ECHO®

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS Health Care Providers!

Register for PWSA | USA's **Upcoming ECHO 4 PWS Webinars**

PWSA | USA is hosting **four** upcoming **ECHO 4 PWS** webinars. On August 15, 2024, at 5:00 p.m. EST, Jim Loker, MD, will discuss “Cardiac Concerns,” which accounts for 16% of all deaths in PWS, and share the unique features of PWS that may predispose individuals to cardiovascular problems. On September 11th, join us for a webinar on “Feeding and Swallowing” with Roxann Diez Gross, PhD, CCC/SLP, and Ann Scheimann, MD, MBA. This presentation will enhance the knowledge of PWS assessment and management, focusing on feeding and swallowing issues through a multidisciplinary approach. On October 24th at 1:00 p.m. EST, join Deepan Singh, MD, for a "Psychiatry and PWS" ECHO webinar. Then, on November 11th, Daniela Rubin, Ph.D., will lead a webinar on “Exercise Physiology,” with more details coming soon. These webinars are for health care professionals to attend only. We will have recordings of these webinars available on PWSA | USA's website following the presentations. Find more details and registration links for these webinars at the button below.

PROJECT ECHO

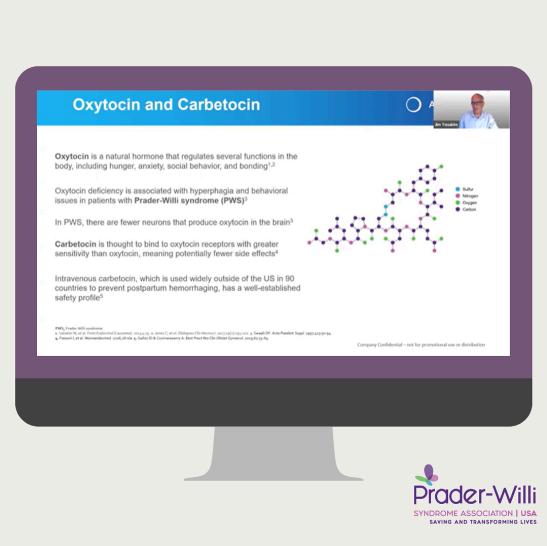
VNS4PWS Clinical Trial Webinar

PWSA | USA and FPWR are hosting a webinar for families to learn more about the VNS4PWS Clinical Trial. "VNS4PWS is a phase 3 clinical trial evaluating the effectiveness of a Vagus Nerve Stimulation (VNS) device for improving disruptive behaviors and temper outbursts for people with PWS. If your loved one is between the ages of 10 and 40, you may be eligible to participate!" (fpwr.org) The VNS4PWS Clinical Trial webinar will be on **Thursday, August**

22nd, at 8:00 p.m. Eastern, 5:00 p.m. Pacific. Click the button below to register.

REGISTER HERE

Acadia Webinar Recording: Clinical Studies for Hyperphagia in Prader-Willi Syndrome



Oxytocin and Carbetocin

Oxytocin is a natural hormone that regulates several functions in the body, including hunger, anxiety, social behavior, and bonding[1,2]

Oxytocin deficiency is associated with hyperphagia and behavioral issues in patients with **Prader-Willi syndrome (PWS)**[3]

In PWS, there are fewer neurons that produce oxytocin in the brain[3]

Carbetocin is thought to bind to oxytocin receptors with greater sensitivity than oxytocin, meaning potentially fewer side effects[4]

Intravenous carbetocin, which is used widely outside of the US in 90 countries to prevent postpartum hemorrhaging, has a well-established safety profile[5]

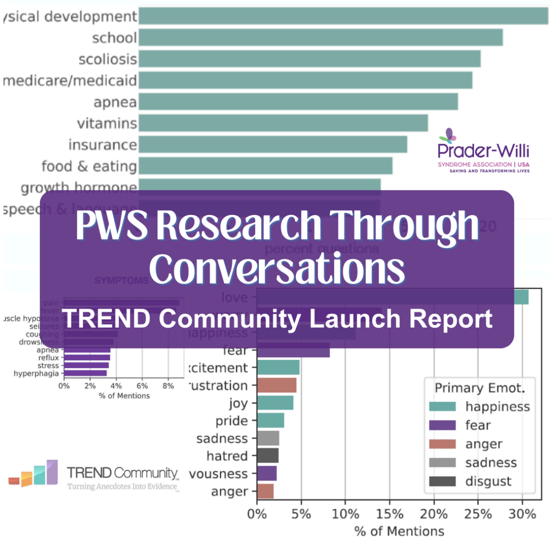
Company Confidential – not for promotional use or distribution

Watch this webinar recording from Acadia Pharmaceuticals to learn more about the COMPASS PWS Study, which aims to investigate the drug Carbetocin (nasal spray) as a treatment for PWS, specifically to help address hyperphagia symptoms. Discussion includes details about the drug and their Phase 3 study openings, requirements, and more!

This webinar was presented by James Youakim, MD and facilitated by PWSA | USA. James Youakim, MD, is a Vice President of Clinical Development Acadia Pharmaceuticals, focusing on medications that treat rare diseases. In that role he oversees the clinical studies of carbetocin nasal spray for hyperphagia in PWS. Dr. Youakim trained as a psychiatrist and has worked in the pharmaceutical industry for over 18 years. He most recently worked in a treatment of Rett Syndrome, a rare nuerodevelopmental disorder.

WATCH WEBINAR HERE

TREND Community: PWS Launch Report



PWSA | USA partnered with TREND Community to help further PWS research through conversations. For two years, TREND collected data from Facebook group conversations to gain important insight into the issues families were facing. Please note that there was no personal information attached to the data that was collected, but merely the keywords and topics that were being discussed. Some of this data has already fostered and shaped ongoing PWS trials. You can now read and review the Launch Report that came from two years of data collecting from social media groups. Click the button below.

READ HERE

New Site Announced for TEMPO Clinical Trial

Harmony Biosciences has announced an additional clinical trial site for its TEMPO PWS study at Dr. Singh's office in Brooklyn, New York. Harmony Biosciences' TEMPO study is a global Phase 3 trial investigating pitolisant as a potential treatment for excessive daytime sleepiness (EDS) in individuals aged six years and older with Prader-Willi syndrome. Pitolisant is a medication that could help manage sleepiness and behavioral issues in people with PWS. Find all eight (8) TEMPO trial site locations and learn more at the button below.

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

Request for Prader-Willi Syndrome Research and Mini-Fellowship Grant Applications

PWSA | USA is currently seeking research project applications with direct impacts on individuals and families affected by PWS. We are offering mini-fellowship grants to support providers in enhancing their understanding of PWS through clinical proctorships. Research priorities include expanding knowledge about PWS, applying therapies, and attracting new providers and investigators to the field. Funding opportunities include grants of up to $100,000 for 12 months, with potential renewal, smaller grants of up to $10,000, and mini-fellowships of up to $25,000. Applications and inquiries can be directed to Stacy Ward at sward@pwsausa.org or by calling (941) 312-0400. The deadline to submit a Letter of Intent is September 1, 2024, 5:00pm EDT. Click the button below to learn more and to read additional guidelines.

LEARN MORE HERE

PWSA | USA Resource Spotlight

August is Gastroparesis Awareness Month. Gastroparesis may affect individuals with PWS. This condition occurs when there is a delay or slowing in the contraction of the stomach muscle. Because of this delay, stomach contents build up and distention can occur. Caregivers should be aware of the symptoms of gastroparesis and other GI conditions and know the steps to getting your loved one into the proper care if symptoms arise. PWSA | USA offers some valuable information about gastroparesis on our website, including an informative article by Barb Dorn, RN, BSN, "Gastroparesis, Gastric Dilatation, with Gastric Necrosis and PWS, What Do We Know?" This article, found on our Medical Issues A-Z page, can be accessed by using the button below.

READ ARTICLE 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

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

PWSA | USA Bi-Weekly Pulse: August 16, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 105

August 16, 2024

www.pwsausa.org | 941.312.0400

In celebration of **National Nonprofit Day** on August 17, 2024, PWSA | USA proudly reflects on nearly 50 years of dedicated service to the Prader-Willi syndrome community. As a national nonprofit, we've worked to provide essential support, education, advocacy, and research to empower individuals living with PWS and their families. Your unwavering support has been instrumental in our journey, and we invite you to continue spreading the word and contributing to our mission. Together, we can make a difference—donate today to help us continue supporting families with PWS.

READ MORE

DONATE TO PWSA | USA

We are thrilled to announce the upcoming launch of ***PWS Connect*****, a brand-new podcast from PWSA | USA**, debuting **Friday, August 30, 2024**, on all major podcast platforms. *PWS Connect* will be your go-to source for the latest news, research, advocacy, and family support in the Prader-Willi syndrome community. This podcast brings together voices from across the PWS landscape, offering valuable insights and practical advice to empower and support those affected by PWS.

On August 30th, check our website, social media, and Special Edition Pulse email newsletter for information on how to listen. Episodes will air every Tuesday and include valuable content to inform, inspire, and empower. We invite you to join us on this new journey!

PWS CONNECT PODCAST

PWSA | USA'S

SPOTLIGHT ON HOPE

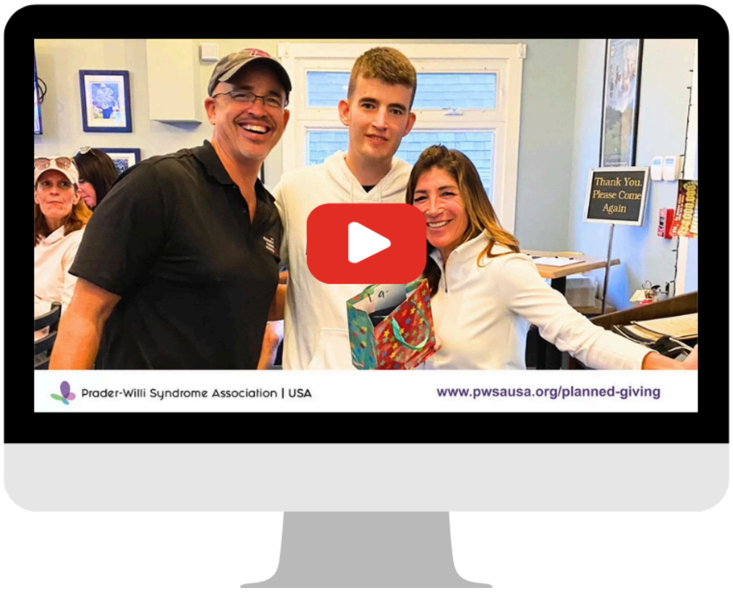
"Olivia will be two years old in September, and we received her diagnosis when she was two months old. She was in the NICU for three weeks and we were sent home with a feeding tube and no answers. After we received her diagnosis, I immediately began my research so we could help her to thrive in the life she was given. PWS is hard, but our baby is such a blessing. She is the sweetest baby, and she is so smart! We have met some amazing families through Olivia's journey, and everyone is so nice and helpful."

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

Leave a Lasting Legacy with PWSA | USA

Planning for the future can be overwhelming, especially for families navigating the challenges of Prader-Willi syndrome. In our latest video, John Lens, a devoted father and PWSA | USA board member, shares his personal journey and the peace of mind that planned giving has brought to his family. Discover how your legacy can provide hope, support, and resources for generations to come. Watch the video by clicking the image below and learn how you can make a lasting impact through planned giving with PWSA | USA.



CLICK HERE TO MAKE AN IMPACT THROUGH PLANNED GIVING!

2025 International United in Hope PWS Conference

United in HOPE
2025 PWS CONFERENCE
Prader-Willi Syndrome Association | USA · IPWSO International Prader-Willi Syndrome Organisation · Foundation for Prader-Willi Research

PWSA | USA 2024
Rare Aware Art Share

Our Rare Aware Art Share is an international opportunity to showcase the artistic voices of individuals living with PWS. As we are preparing to gather with our community at the 2025 International PWS Conference next June, we are seeking the voices of individuals around the world to share with us something that is unique about where they live. This is a wonderful opportunity to learn about individuals with PWS in a variety of cultures and places worldwide. The deadline to submit artwork is September 15th. Please share this opportunity with your PWS community and let's encourage individuals from all over the world to share their artistic voice! Learn more and submit artwork using the button below.

RARE AWARE ART SHARE

REGISTER FOR THE 2025 PWS CONFERENCE

Join Us in Creating a Tribute: Submit Your Photo for the 2025 PWS Conference Mural

With the 2025 International PWS Conference approaching, we're creating a special mural to showcase the diversity and beauty of our incredible PWS community. This mural will be on display during the 2025 conference at the Arizona Grand Resort & Spa. We want photos of your loved one to be a part of it! Submit a picture of your PWS warrior, even if you can't join us in person, at the button below. The pictures shared will help create a display of hope that everyone can take pride in. Let's come together to celebrate and inspire!

SUBMIT PHOTO HERE

We Look Forward to Connecting with Residential Providers at This Weekend's Inaugural Conference!

PWSA | USA is thrilled to welcome residential providers from across the country to our first annual **Residential Providers Conference** in beautiful Savannah, GA, this weekend! This event marks an exciting milestone as we come together to share knowledge, exchange best practices, and strengthen our collective efforts in supporting individuals with Prader-Willi syndrome. We are eager to

collaborate with attendees and explore innovative ways to enhance the quality of care and improve the lives of those we serve. We look forward to making this inaugural conference a truly unforgettable experience!

Registration for both in-person and virtual conference attendance is now closed.

Upcoming Fundraisers

Dance Silly for Prader-Willi event T-shirts are now being sold to raise additional funds for PWSA | USA! adult shirts are $22 and youth shirts are $15. If you are not attending the event, or don't live near where the event is occurring, you can still order! If you would like your shirt(s) sent to you a week after the event (estimated ship date: October 18th), please add on $6 to the total to cover shipping costs. **For shirts to be sent out by October 18th, please have the form (found at the button below) completed by Friday, September 13th.** If you have any questions, please email Michele at mhampton0933@gmail.com. Thank you for supporting PWSA | USA!

Ohio residents: Register TODAY for the Dance Silly for Prader-Willi event! Hosted by parent Michele Hampton, mom to Jayda who is living with PWS, the evening will include a DJ, dancing, dressing up in your favorite costume, playing games, doing a craft, a kid's basket for all families registered, a kids' raffles, an adult raffle, dinner/snacks for all, and a memorable time with some of your favorite people.

When: **Saturday, October 12, 2024, at 4:30 p.m.**
Where: **Trumbull Career & Technical Center** (528 Educational Hwy. NW,

Warren, OH 44483)

REGISTER TO ATTEND

PWSA | USA'S UPCOMING EVENTS

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

ADVOCACY

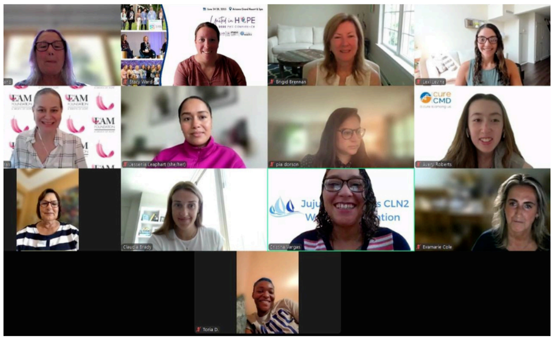
Advocating for Change: PWSA | USA's Impact in Rare Across America 2024

PWSA | USA along with several of our dedicated volunteer advocates has been actively participating in congressional meetings as part of EveryLife Foundation's Rare Across America 2024. This initiative provides a powerful platform to raise awareness about Prader-Willi syndrome and advocate for policies that support the rare disease community. By sharing personal stories and discussing the unique challenges faced by those living with PWS, our advocates are helping to ensure the voices of our community are heard at the highest levels of government. Together, we're making a meaningful impact for all individuals affected by PWS.

Here's what Erin Carter, PhD, mom to Victoria who is living with PWS, and our CEO Stacy Ward had to say about their experiences participating in Rare Across America 2024:

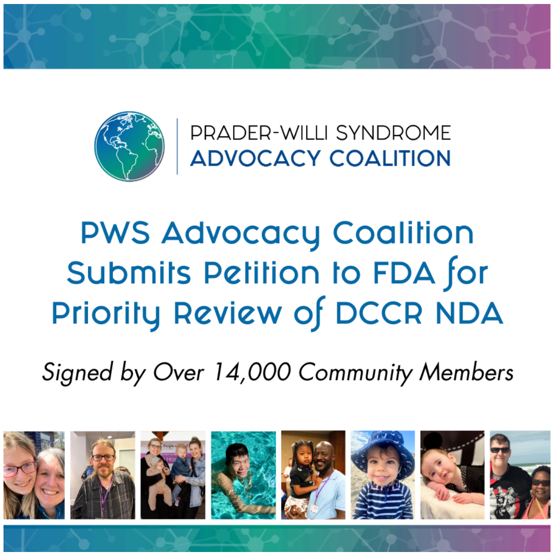
"I asked Victoria if she wanted to go to the meeting and she was visibly apprehensive. Certainly part of that was that she didn't fully understand what it was, or what she would be expected to do. I told her that we were going to see our friend Joel at Congressman Miller's office and that all she needed to do was to talk with him and thank him for helping us. She asked if she could also read him a book. When we arrived, she was very excited! Once the meeting began, I started talking about our asks and after a bit she chimed in and said "when are you going to be done talking, mom?" It was hilarious. So I turned the floor over to her and she got the most nervous I'd ever seen her. But Joel asked about her school and where we live, and then she had her moment to shine and "read" him the 5 Little Monkeys (she isn't reading yet, but has the book memorized). She was so proud of herself and I was and am so proud of her. She is still talking about our friend Joel. For the virtual Senate meetings, I had her join to say hello to the staffers I have been working with for the past couple years. It was nice for them to get a chance to put a cute face to the stories I've been telling them." - Erin Carter, PhD, mom to Victoria (6) (OH)

"Meeting virtually with Senator Chuck Schumer's office, alongside other rare disease advocates, was an incredible experience. Senator Schumer's staff truly listened to our concerns and demonstrated a genuine commitment to the rare



disease community. It's crucial that we continue these conversations with our elected officials to raise awareness about Prader-Willi syndrome and advocate for the policies and resources that our community needs. Every meeting is a step closer to ensuring that those living with PWS receive the support and care they deserve." - Stacy Ward, CEO of PWSA | USA

The PWS Advocacy Coalition Submitted a Petition to the FDA for Priority Review of the DCCR New Drug Application



PRADER-WILLI SYNDROME
ADVOCACY COALITION

PWS Advocacy Coalition Submits Petition to FDA for Priority Review of DCCR NDA

Signed by Over 14,000 Community Members

On August 2, 2024, the PWS Advocacy Coalition submitted a petition to the FDA, urging the priority review of Soleno Therapeutics' drug DCCR. The petition, supported by 14,271 members of the PWS community, highlights the critical need for this treatment. While the FDA's review process remains confidential, this achievement marks a significant step forward. We will keep the community updated as we learn more about the FDA's review and decision. Find the downloadable petition at the button below.

FDA PETITION

FAMILY SUPPORT

PWS Blog: Aging Research in PWS

As individuals with Prader-Willi syndrome are living longer, thanks to advancements in care and management, we are increasingly recognizing the

unique health challenges associated with aging in our community. While our improved understanding has enabled us to address hormone deficiencies, manage diets, and expedite early diagnosis and treatment, research on aging in PWS adults remains limited.

This week's Family Support blog spotlights, contributed by Barb Dorn, RN, BSN, share findings from two surveys on the health issues experienced by PWS adults age 30 and older, and a recap from Barb's webinar series, *PWS Aging Research and Health Updates*. Click the buttons below to read more.

SURVEY RESULTS

AGING RESEARCH IN PWS BLOG

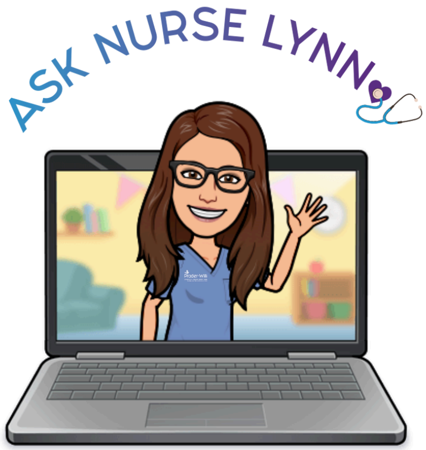
Ask Nurse Lynn

Question *(Male, 29 years-old, UPD):*

"My son is currently on oxygen and is having several health issues.
Our biggest concern is weight loss and finding a doctor in Florida who can help him as an adult with PWS."

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

Family Support Webinars

Creating an Individualized Health Plan with Destiny Pacha

When: Tuesday, August 27, 2024 | 5:00 p.m. PST / 8:00 p.m. EST

Join us for an informative webinar on Individualized Health Plans (IHP) for Students with Prader-Willi syndrome (PWS) as a vital supplement to an Individualized Education Program (IEP). This session will dive into the unique health needs of students with PWS and how an IHP can provide essential supports, ensuring their safety and well-being in the school environment. We'll discuss the collaboration between educational and healthcare teams, key components of an effective IHP, and strategies to seamlessly integrate it with the IEP to maximize student success. Whether you're a parent, educator, or school nurse, this webinar will equip you with the knowledge and tools to advocate for and implement comprehensive plans that address both the educational and health needs of students with PWS.

REGISTER HERE

Friendship and Beyond: Navigating Relationships and Sexuality in PWS

When: Tuesday, September 17, 2024 | 5:00 p.m. PST / 8:00 p.m. EST

This session on friendships, relationships and sexuality will focus on the unique challenges that people with PWS face in forming and maintaining friendships as well as navigating their sexuality. Discussions will center around healthy relationships, addressing social deficits and creating an appropriate education in relation to sexuality. An emphasis will be on the importance of effective education, communication, and the dignity of risk.

REGISTER HERE

Share a Message to Celebrate National Grandparents Day!

Show some love for the grandparents in your loved one's life by sharing a photo and a quote at the button below! You can share a memory, a way they support your loved one and family, or simply a thank you message.

We will share these submissions on PWSA | USA's social media pages on National Grandparents Day, September 8th!

SHARE A MESSAGE

RESEARCH

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is now open for the 2025 International PWS Conference Clinical and Scientific Program and the Professional Providers and Caregivers 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 5-day event marks the first joint conference between IPWSO, PWSA | USA, and FPWR, and symbolizes a historic milestone! Register today!

Call for Abstracts

Professional Providers Program Submission
Deadline: November 5, 2024

Clinical & Scientific Program Submission
Deadline: January 31, 2025

APPLY HERE

REGISTER HERE

ECHO 4 PWS Health Care Series: Three Upcoming ECHO Webinar Opportunities

Project ECHO®

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS Health Care Providers!

Register for PWSA | USA's
Upcoming ECHO 4 PWS Webinars

PWSA | USA is hosting **three** upcoming **ECHO 4 PWS** webinars. On September 11th, join us for a webinar on "Feeding and Swallowing" with Roxann Diez

Gross, PhD, CCC/SLP, and Ann Scheimann, MD, MBA. This presentation will enhance the knowledge of PWS assessment and management, focusing on feeding and swallowing issues through a multidisciplinary approach. On October 24th at 1:00 p.m. EST, join Deepan Singh, MD, for a "Psychiatry and PWS" ECHO webinar. Then, on November 11th, Daniela Rubin, Ph.D., will lead a webinar on “Exercise Physiology,” with more details coming soon. These webinars are for health care professionals to attend only. We will have recordings of these webinars available on PWSA | USA’s YouTube channel following the presentations at this link. Find more details and registration links for these webinars at the button below.

PROJECT ECHO

VNS4PWS Clinical Trial Webinar

PWSA | USA and FPWR are hosting a webinar for families to learn more about the VNS4PWS Clinical Trial. "VNS4PWS is a phase 3 clinical trial evaluating the effectiveness of a Vagus Nerve Stimulation (VNS) device for improving disruptive behaviors and temper outbursts for people with PWS. If your loved one is between the ages of 10 and 40, you may be eligible to participate!" (fpwr.org) The VNS4PWS Clinical Trial webinar will be on **Thursday, August 22nd, at 8:00 p.m. Eastern, 5:00 p.m. Pacific**. Click the button below to register.

REGISTER HERE

New Sites Announced for TEMPO Clinical Trial

Harmony Biosciences has announced **three** additional clinical trial sites for its TEMPO PWS study:

- **San Diego, CA** | Rady Children's Hospital
- **San Ramon, CA** | Tri-Valley Sleep Center
- **Bronx, NY** | Montefiore Medical Center

Harmony Biosciences' TEMPO study is a global Phase 3 trial investigating pitolisant as a potential treatment for excessive daytime sleepiness (EDS) in individuals aged six years and older with Prader-Willi syndrome. Pitolisant is a medication that could help manage sleepiness and behavioral issues in people with PWS. Find all 11 TEMPO trial site locations and learn more at the button below.

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

The Deadline to Submit an Application for a PWSA | USA Mini-Fellowship Grant is Approaching!

PWSA | USA is currently seeking research project applications with direct impacts on individuals and families affected by PWS. We are offering mini-fellowship grants to support providers in enhancing their understanding of PWS through clinical proctorships. Research priorities include expanding knowledge about PWS, applying therapies, and attracting new providers and investigators to the field. Funding opportunities include grants of up to $100,000 for 12 months, with potential renewal, smaller grants of up to $10,000, and mini-fellowships of up to $25,000. Applications and inquiries can be directed to Stacy Ward at sward@pwsausa.org or by calling (941) 312-0400. **The deadline to submit a Letter of Intent is September 1, 2024, 5:00pm EDT.** Click the button below to learn more and to read additional guidelines.

LEARN MORE HERE

PWSA | USA Resource Spotlight

PWSA | USA's **School Success Toolkits** are invaluable resources designed to support students with Prader-Willi syndrome in achieving their full potential in educational settings. These comprehensive toolkits offer practical strategies, customized guidance, and essential tools for educators, parents, and caregivers to address the unique needs of students with PWS. From managing behavioral challenges to adapting learning environments and fostering effective communication, our toolkits provide actionable insights to enhance academic success and overall well-being. By equipping schools with the right resources and knowledge, PWSA | USA is committed to ensuring that every student with PWS has the opportunity to thrive in their educational journey. Find our school success toolkits at the button below.

SCHOOL SUCCESS TOOLKITS

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

PWSA | USA Special Edition Pulse: August 30, 2024

www.pwsausa.org | 941.312.0400

Donate

We are excited to announce the launch of our new podcast, ***PWS United,*** across all major podcast platforms. The *PWS United* podcast will be your go-to source for the latest news, research, advocacy efforts, and family support in the Prader-Willi syndrome community.

At PWSA | USA, our mission has always been to empower and support individuals with PWS and their families, and this podcast is an extension of that commitment. Each episode will bring together a diverse range of voices, including our dedicated staff, passionate volunteers, leading PWS treatment specialists, biotech and pharmaceutical experts, caregivers, family members, and individuals living with PWS.

PWS United is more than just a podcast—it's a platform for education, awareness, and connection. Whether you're looking for updates on PWSA | USA's services and events, the latest research, insights into advocacy, or practical advice for family support, this podcast has something for everyone in the PWS community. Our goal is to bridge the gap between information and those who need it most, ensuring that everyone affected by PWS has access to the resources and knowledge they need to thrive.

How to: Listen, Follow, Rate and Review

Podcasts have been around for almost two decades, but for those who are new to the concept, follow the button below for some basic instructions to help you navigate this new platform. Please note that following the podcast, downloading episodes, rating, leaving a review, and sharing the podcast or specific episodes on social media or with friends are crucial to getting our podcast seen by a larger audience. Through the growth of this podcast, we hope to reach even more families in the PWS community who may be struggling and looking for necessary support.

READ HERE

Advocating for Change: A Conversation with Dorothea Lantz

In this episode of *PWS United Podcast*, we sit down with Dorothea Lantz, Director of Community Engagement at PWSA | USA, for an insightful discussion about recent and upcoming advocacy efforts. Dorothea offers a recap of the May 2024 D.C. Fly-In and discusses the recent steps taken to advance our congressional requests made during the event. Looking ahead, she outlines exciting initiatives and programs for advocacy in 2025. Dorothea also discusses the crucial steps needed to ensure access to DCCR, Soleno Therapeutics' drug to treat hyperphagia, if it receives FDA approval. The episode concludes with heartwarming reflections on the special mission moments that continue to inspire and drive the community's advocacy work.

LISTEN HERE

BIPOC Affinity Group: With Dini Rao and Gennelle Conway

"If you don't pay attention to the specific needs of people of color, whether it's education or health, the outcomes are always poorer for the people of color."
- Dini Rao, Mother to Ayoni (living with PWS)

We spoke with PWS parents and advocates Gennelle Conway and Dini Rao about the growing PWS BIPOC (Black, Indigenous, People of Color) Affinity Group. We discussed the experiences and challenges of people of color in the medical and PWS world, implicit bias, personal prejudice, and systemic racism, and how people can be allies in their own lives and public spaces. We also mention a variety of valuable and informative resources, so please be sure to check out the links below! If you are a person of color or raising a person of color in the PWS community and are interested in joining Dini and Gennelle and the growing BIPOC Affinity community, email bipocpws@gmail.com.

"A good advocacy point is that we're considered when it comes to access to drugs, access to health, access to the things that we need to do when it comes to genetic testing."

- Gennelle Conway, Mom to Angelica (living with PWS)

LISTEN HERE

Back to School:
PWSA | USA Special Edition Pulse

We want to make sure the PWS community is aware of the multiple resources offered by PWSA | USA to help you and your loved one with PWS have a successful school year. From suggestions to help ease back to school anxiety for both individual and caregiver, tips for individualized education plans (IEPs), our School Success Summit and more, this episode, along with the relevant links, supports your family in having a happy, successful, and confident school year.

LISTEN HERE

Edition 104: PWSA | USA Pulse

Carrie and Anne, from PWSA | USA's Communication Dept., share the news and resources from PWSA | USA's Pulse newsletter, edition #104. Our Pulse covers upcoming fundraising events and conferences, advocacy highlights and actions, family support resources and offerings, the latest in research, trial opportunities and more. The Pulse newsletter is published digitally every other Friday. Future podcast Pulse episodes will air the following Tuesday.

LISTEN HERE

New Episodes Every Tuesday

Be sure to follow or subscribe to the PWS Connect podcast on your podcast app or platform of choice to be notified when we publish new episodes. Next week's episode, "What's the Big Deal About Exercise?" is a conversation with PWSA | USA Board Member Kat Lucero and PWSA | USA's CEO Stacy Ward.

Please remember to like the podcast, leave us a rating and review, and share with your community. Look for us every Tuesday on your podcast app!

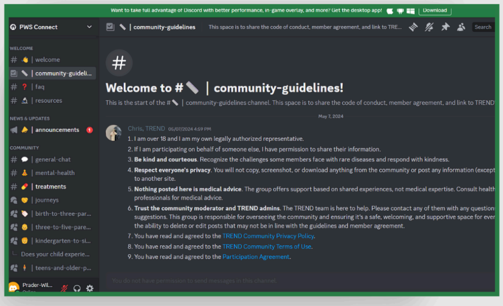
If you would like to make suggestions on future content or have questions about the podcast, please email us at pwsconnectpodcast@gmail.com.

Happy Listening!

We Invite You to Continue the Conversations in our Discord Groups

We invite you to continue the conversations and connect directly with other PWS community members in our PWS Connect Discord Groups! PWS Connect on Discord (a free internet social platform) is a community and research initiative led by PWSA | USA in partnership with TREND Community for those living with PWS and their families. Due to recent Facebook policy updates and limitations, TREND Community has shifted its research efforts to Discord. As part of the PWS Connect online community, you can share your experience on your own time and interact with other PWS parents, including privately in age-appropriate groups, to advance the understanding of the condition. We need your input to continue this amazing work! Please click the button below to join our discussion groups today.

Discord



Welcome to # | community-guidelines!

This is the start of the # | community-guidelines channel. This space is to share the code of conduct, member agreement, and link to TREND

May 7, 2024

Chris, TREND 05/07/2024 4:59 PM

1. I am over 18 and I am my own legally authorized representative.
2. If I am participating on behalf of someone else, I have permission to share their information.
3. **Be kind and courteous**. Recognize the challenges some members face with rare diseases and respond with kindness.
4. **Respect everyone's privacy**. You will not copy, screenshot, or download anything from the community or post any information (except to another site.
5. **Nothing posted here is medical advice**. The group offers support based on shared experiences, not medical expertise. Consult health professionals for medical advice.
6. **Trust the community moderator and TREND admins**. The TREND team is here to help. Please contact any of them with any question suggestions. This group is responsible for overseeing the community and ensuring it's a safe, welcoming, and supportive space for ever the ability to delete or edit posts that may not be in line with the guidelines and member agreement.
7. You have read and agreed to the TREND Community Privacy Policy.
8. You have read and agreed to the TREND Community Terms of Use.
9. You have read and agreed to the Participation Agreement.

You do not have permission to send messages in this channel.

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