PWSA | USA Bi-Weekly Pulse: October 4, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 108

October 4, 2024

www.pwsausa.org | 941.312.0400

We've once again crossed the threshold of summer into autumn, ushering in another round of seemingly endless holidays and food-centered celebrations. Many families, especially families of older individuals living with PWS, may have well-established routines and adapted traditions to help them get through this season more smoothly. Other families may be facing the impending onslaught of candy-filled bags and fat-infused celebrations with trepidation and growing concern of how to navigate this food-centric season. Wherever you land on the spectrum of 'we've got this' to 'I'm freaking out,' PWSA | USA is here to offer resources and support to help you and your family not only survive these potentially treacherous holidays, but hopefully thrive and enjoy them as well.

Below are a few blogs to help prepare you for the upcoming holidays. It's never too early to start planning for fun, PWS-friendly celebrations that the whole family can enjoy!

Halloween Fun for Everyone

READ HERE

Celebrate Thanksgiving Safely

READ HERE

Celebrate Holidays Safely

READ HERE

Share Your Holiday Tips with the PWS Community

While it is important to remember that what works for one family may not work for another, it is also helpful to share our tips and strategies for navigating this PWS life. How you successfully steer through a food-laden holiday may help another family find their own alternative options or create unique traditions. Click the button below to share your **Hope for the Holidays**, either through a story, a photo, a tip, or recipe from a past Halloween, Thanksgiving, Hanukkah, Kwanzaa, Christmas, New Years, or another holiday you celebrate. We will share the tips, recipes, and stories submitted on our social media pages. You can also choose to submit anonymously.

Heads up, we are also looking for Halloween tips in your own voice to share on our PWS United podcast! You'll find that information in our podcast section of this Pulse or **HERE**.

SUBMIT HERE

PWSA | USA'S

SPOTLIGHT ON HOPE

"Lily is a 3-year-old girl diagnosed with PWS at a few weeks old. As many parents can imagine hearing our daughter's diagnosis the first time was devastating. She has shown that she is so much more than her diagnosis. She is a smart, caring, sassy, sweet little girl. She absolutely gives the best hugs. Lily has overcome so many obstacles and continues to prove how strong she is. She is our hero." - Contributed by mom, Sara B.

We want to celebrate your loved one!

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

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

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

2025 Conference Hotel Rooms Filling Up Fast! 70% FULL!

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*	

Planning to attend the 2025 International PWS Conference? Don't wait—book your stay at the Arizona Grand Resort & Spa today! With **70%** of rooms already reserved, availability is limited. In addition, there are no double queen rooms left for June 21, 2025, and only king rooms remaining on June 22, 2025. You can reserve now and cancel up to a week before the event without any charges, and you won't be billed until check-in. Secure your room now and ensure your spot at this exciting event! Book your stay at the button below or call 877-800-4888 to make a reservation.

HOTEL RESERVATIONS

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

Thank You, Garzia Family, for Hosting the Inaugural RMC Foundation Golf Outing to Support PWSA | USA!

On Monday, September 30th, Jen Garzia and her family hosted the inaugural RMC Foundation Golf Outing at the Ritz Carlton Members Only Club in Bradenton, FL. The proceeds from this event will benefit PWSA | USA's advocacy programs. You can watch Jen's heartfelt speech made during the event's luncheon by clicking the image.
"Rocco is my miracle, and I love him. I remind him daily that everyone in this room and society has problems, but Rocco and his community are not afforded the luxury of privacy. We need to tell Rocco's story and everyone who has PWS to get them the help they need so that we can adjust the system so they can access the resources they're entitled to in society. Pete and I thank you all, and all the sponsors, for being here and for your support."
- Jen Garzia, mom to Rocco

Upcoming Fundraisers

The Dance Silly for Prader-Willi event will be a FUN, FAMILY, DANCE party for any family interested! The event will take place around Halloween, a time more tough for children with PWS, so the family wants to raise awareness surrounding how we can include all individuals and how holidays don’t need to be focused on food or candy, but instead fun experiences and time together!

This fun event will include a DJ, dancing, dressing up in your favorite costume, playing games, doing a craft, kids' basket for all families registered, kid's raffles, adult raffles, dinner/snacks for all, and a memorable time with some of your favorite people!

If you, or someone you know, would be interested in being a sponsor, donating a raffle basket, or being a volunteer, please feel free to reach out to Michelle at mhampton0933@gmail.com.

Saturday, October 12th, 2024
Doors open at 4:30pm
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

New England Prader-Willi Conference

The Prader-Willi Syndrome Association's New England Chapter, together with our sponsors Acadia and Latham Centers, is delighted to host "Knowledge is Power", a conference created for PWS families and providers. The event will be

held November 2nd at the Hilton Garden Inn in Waltham Mass. **Don't miss this convenient and empowering biannual PWS event.** Whether it's getting updated on the latest therapies, networking with other parents of children with PWS, learning about everything from IEP goals to adult life, or meeting leading PWS professionals from around the country, Knowledge is Power. Space is limited so register today! Use the button below to learn more and register.

LEARN MORE HERE

PWS UNITED PODCAST UPDATES

Share Your Voice and Halloween Tips on the Podcast

Halloween is just around the corner, and with it come questions and uncertainty for our PWS families. It's only a matter of time before candy and treats will being offered in schools and throughout the neighborhoods, and we want to know your tricks! The PWS community is invited to be a part of a special upcoming PWS United podcast episode. We'd love to hear how your family navigates Halloween and share your voice on the podcast!

Here's how to do it:

- Record an audio file on your phone's voice memo app or record a video telling us how you navigate Halloween with your loved one with PWS.
- Please keep your submission under 1 minute, include age of your loved one with PWS.

- You can submit your audio or video file by clicking the button below.
- Please note that videos will likely be shared on our social media pages.
- All appropriate submissions will be shared on the podcast, social media, and/or a special Halloween blog.

SUBMIT AUDIO FILE

Latest PWS United Episode

As research and treatment options for the PWS community continue to grow, we wanted to take a closer look at clinical trials, what are they, how are they run, what trials are available for PWS families, and how you can get involved. We hear personal perspectives from families and begin the journey of one family's first foray into a particular trial in the PWS community and how they moved past their years of skepticism to finally come to the decision to enroll. This episode sheds light on the growing world of PWS clinical trials in hopes of helping families make more informed decisions.

PWS United Podcast

PWSA | USA SPECIAL EDITION PULSE: CLINICAL TRIALS

PODCAST EPISODE #10

With Hosts:

PWS United

Anne Fricke
PWSA | USA
Marketing & Communications Coordinator,
Mom to Freya

Carrie Ilijevich
PWSA | USA
Marketing & Communications Director

Prader-Willi Syndrome Association | USA

PODCAST

LISTEN ON PODBEAN

ADVOCACY

Creating Hope Reauthorization Act Goes to the Senate

The Priority Review Voucher (PRV) program has been a key driver for incentivizing drug development, particularly for rare pediatric diseases. This program allows companies that develop treatments for rare diseases to receive a priority review voucher, which can be used to expedite the FDA's review of a

future drug application or sold to other companies. This PRV program has been instrumental in accelerating the development of treatments for diseases like PWS that disproportionately affect children and other vulnerable populations in the rare disease space where the financial risk is higher due to smaller patient populations.

In September of 2024, the U.S. House of Representatives unanimously passed legislation to reauthorize the Rare Pediatric Disease PRV program through 2029. However, The **U.S. Senate** has not yet passed the needed legislation to reauthorize the **PRV Program.** A bipartisan bill, known as the **Creating Hope Reauthorization Act**, was introduced by Senators Bob Casey (D-PA) and Markwayne Mullin (R-OK). This legislation aims to extend the PRV program through **September 30, 2030**, providing longer-term stability and encouraging investment in treatments for rare pediatric diseases. The bill has garnered broad support, including endorsements from organizations like the **National Organization for Rare Disorders (NORD) and the EveryLife Foundation.** The Senate's decision in the coming weeks will determine the future of this valuable initiative. If you are interested in in knowing more, please email Advocacy@pwsausa.org to see how you can help.

FAMILY SUPPORT

PWS in Adulthood Blog Series:
The Many Factors of Independence

"The system of post-secondary education, in my opinion, was a great help in transitioning to life after school; however, once she left that educational program, it was difficult navigating the many day programs available and to ensure that it would be a good fit for my daughter, due to food issues. We've gone through many day programs, and I feel that the community-based programs are the best in gaining a sense of independence in my daughter."

Read our latest in the PWS in Adulthood blog series, this post contributed by Lynne Williams, mom to 27-year-old Jess, by clicking the button below.

READ HERE

Spreading Joy: Operation Holiday Cheer Returns to Support PWS Families in 2024

Thanks to the incredible generosity of an anonymous donor, PWSA | USA is thrilled to bring back **Operation Holiday Cheer** for 2024!

This heartwarming initiative helps spread joy to families in need by easing the financial burden of the holiday season. Through this program, a select number of families affected by Prader-Willi syndrome will receive gift cards to assist with holiday expenses, ensuring they can focus more on celebrating with loved ones and less on financial stress. If your family could benefit from this support, we invite you to apply by completing our **Operation Holiday Cheer** application. Applications are due by Friday, November 8, 2024, so don't miss this opportunity to bring a little extra cheer into your home this holiday season! Find the application at the button below.

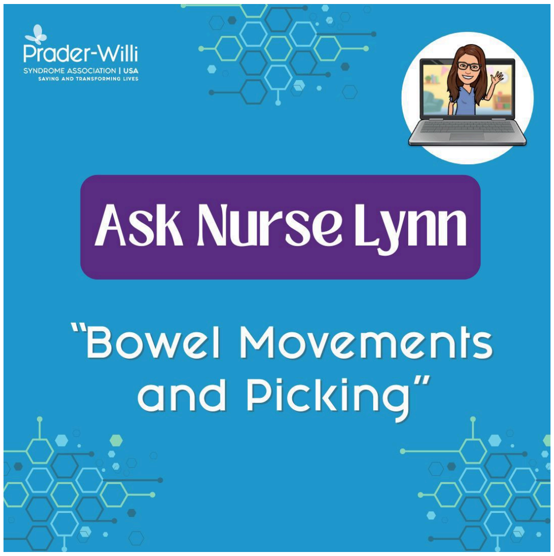
OPERATION HOLIDAY CHEER APPLICATION

Ask Nurse Lynn

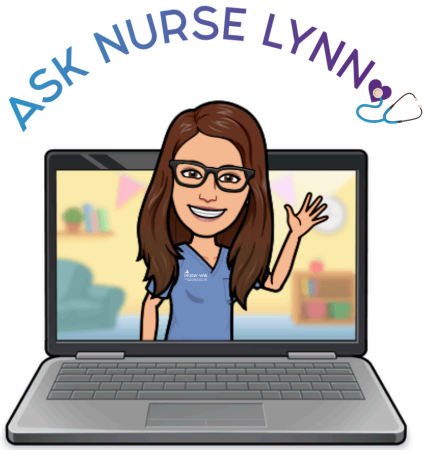
Question *(Female, 22 years old, unknown subtype):*

"I'm concerned about gastroparesis. I give my daughter one stool softener a day. Ok with her doc. She does not empty her stomach without picking at her bottom to stimulate. How do I address this issue?"

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

Support PWS Research and Create Community
When: Tuesday, October 29, 2024 |
5:00 p.m. PST / 8:00 p.m. EST

Join us for an insightful and informative webinar to learn how you can help advance PWS research while also finding and building community support. PWS parents, Maria Picone and Chris DeFelice, are excited to share how their personal journey with PWS led them to create the **PWS Connect** channel on Discord, a place where caregivers come together to share their journeys, experiences, questions, and advice to support each other and directly impact the progression of PWS research. This webinar will explain the **What, Why,** and **How** of **TREND Community** and the PWS Connect Discord group, and include time for your questions. We hope you join us for a new wave of PWS insights and growing research! Register at the button below.

REGISTER HERE

Watch the recording of our September Family Support Webinar, **Friendship and Beyond: Navigating Relationships and Sexuality in PWS** with Patrice Carroll, LICSW, at the button below.

CLICK HERE TO WATCH

RESEARCH

Update on Phase 3 COMPASS PWS Study from Acadia

Acadia Pharmaceuticals released a letter updating the PWS community on the latest news with Phase 3 of their COMPASS PWS clinical trial. This trial is studying the effectiveness of intranasal carbetocin in individuals with PWS who suffer from hyperphagia. Their update includes current and pending sites as well as letting the public know that participants who finish the 12-week trial will be eligible to enroll in a long-term open label extension study. You can read the full letter and learn more by clicking the button below.

LEARN MORE HERE

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is 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:
Two Upcoming ECHO Webinar Opportunities

PWS Health Care Providers!

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

PWSA | USA is hosting **two** upcoming **ECHO 4 PWS** webinars.

Date: Thursday, October 24, 2024 at 9:00 AM PST / 12:00 PM EST
Speaker: Deepan Singh, MD
Topic: Psychiatry and PWS
Location: ZOOM

REGISTER HERE

Date: Monday, November 11, 2024 at 2:00 PM PST / 5:00 PM EST
Speaker: Daniela Rubin, Ph.D.
Topic: Exercise Physiology
Location: ZOOM

REGISTER HERE

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 information about ECHO 4 PWS at the button below.

PROJECT ECHO

PWSA | USA ANNOUNCEMENTS

Welcome New PWSA | USA Staff Members!

Pia joined PWSA | USA as a part-time Fundraising Coach: DIY & Special Events in September 2024, after spending 20 years in Marketing. Prior to joining PWSA | USA's staff, Pia participated in our advocacy program attending the 2024 DC Fly-in on National PWS Awareness Day- where she met with elected officials on behalf of her family and others from New York. Pia believes strongly that participating in advocacy and fundraising activities is a wonderful way to give back to an organization that has been critical to her family since their daughter's Prader-Willi syndrome diagnosis in 2018. Pia has held positions where she developed and executed omni-channel strategic marketing plans, led cross-functional teams, and drove brand development initiatives. She holds a BSBA in Marketing from Boston University. Pia lives in Katonah, NY, with her husband Dave and their children, including their daughter Zahra (age 6) living with PWS. Together, they enjoy traveling, listening to music, and spending time with their extended family.

Katie joined PWSA | USA as the part-time Fundraising Coach: Team & Online Events in August of 2024. She and her family live in Baton Rouge, Louisiana. She is the mother of two boys, Samuel (7) living with PWS, and Benicio (1). Katie graduated from Louisiana State University with a bachelor’s degree in early childhood and Elementary Education. Over the past 12 years she has been an elementary school teacher, in person and virtually. She was able to virtually teach English as a Second Language to students in China for 4 years. Since her involvement with PWSA, she has become a volunteer in PWSA USA’s advocacy program since participating in both D.C. Fly-ins representing her home state of Louisiana. She has also collaborated with schools fundraising to support PWSA and has a passion for learning new ways to support the organization. In her personal life, she enjoys spending time with family, traveling, reading, and gardening.

PWSA | USA Resource Spotlight

Did you know that PWSA | USA has a YouTube channel? With over 370 videos, it's a great place to find a plethora of resources and information on PWS. From

ECHO webinars for professional care providers to family support webinars on a variety of topics, donor highlights, family interviews, and messages from our dedicated staff, you will likely learn something new and valuable about PWS. Join us over at YouTube to expand your knowledge of PWS, hear from trusted care providers and professionals, and connect with another valuable resource in the PWS community.

PWSA | USA YOUTUBE CHANNEL

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

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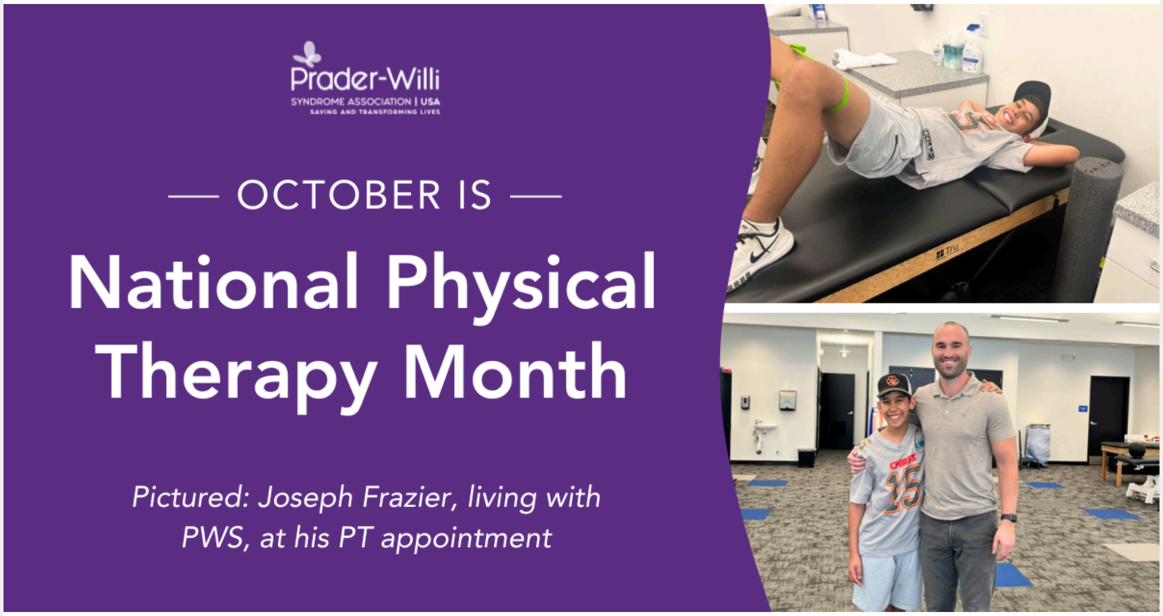


Pictured: Joseph Frazier, living with PWS, at his PT appointment

Most parents and caregivers of individuals with PWS are well-versed in the world of therapeutic interventions. Physical therapy is a valuable and important intervention to help your loved ones grow, develop, and learn how to be successful in their space. PT helps improve **gross motor skills**, which may be delayed in children with PWS. This includes activities like walking, running, and coordination. Children with PWS often have low muscle tone (hypotonia). PT can help **strengthen muscles and improve flexibility,** promoting better overall physical health. Due to an insatiable appetite, children with PWS are at risk for obesity. Regular physical activity guided by PT can help **manage weight** and promote healthy habits. PT can address **postural issues and enhance balance**, which is vital for overall mobility and can reduce the risk of falls. Engaging in physical activities can **improve social interaction and build confidence**, as children participate in group activities or sports. Early intervention through PT can lead to better **long-term health** and outcomes, helping to mitigate some of the physical challenges associated with PWS.

For some families, access to physical therapy comes easily with a diagnosis, while others have to fight for this essential service, and some find success through alternative methods. October is Physical Therapy Month, and we want to draw attention to the importance of physical therapy for your loved one, whatever that might look like.

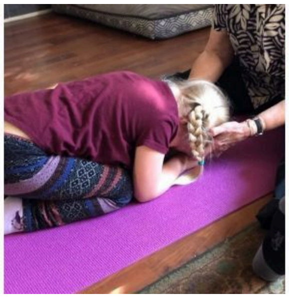
Check out "Therapeutic Interventions for the Child with Prader-Willi Syndrome" by Janice Agarwal, PT, CNDT to learn more.

We asked some PWS parents how PT has affected the life of their loved ones with PWS. Read below for what they had to say.

"Physical Therapy is important to not only help our loved ones get stronger, but it also helps with their confidence. Therapists help our kids gain the strength and confidence they need to do what comes easily for other children." - Kristi Rickenbach, mom to Justice

"I remember (when my child was) a tiny infant wondering why we needed PT at all. It felt like a waste of time.... I learned that it gave us something to do, something to push for, something to hope for. We could ALL practice these moves with her. WE were developing strength, muscle memory, a path forward." - Melanie McDonald, mom to Josephine

"My daughter had trouble learning to ride a bike. We tried to teach her for a few years without success. We took the problem to a PT who was able to break down all the movements and find ways for her to practice them separately, building strength and coordination. Within two months she was able to ride with training wheels and after another month she started to ride independently." - Emily Felt, mom to Olivia



"PT helps my son reach his age-appropriate physical milestones and helps him with balance, core strength and coordination in a safe and fun environment." - Sarah Kasaby, mom to Khaled

"Pediatric physical therapists were non-existent in our area when Freya was a baby. Thankfully we connected with an Oral and Motor Specialist trained in the Feldenkrais Method, and, a few years later, an in-home PT trained in neurodevelopmental and integrative movements. Both women brought us alternative takes on traditional physical therapy that ultimately changed the trajectory of Freya's life and helped her to be as successful as she is today." - Anne Fricke, mom to Freya

"Physical Therapy is a key part of early childhood development to help with strength, coordination, and endurance. PTs can help break down movements that most of us take for granted or easily learn into small segments to help our kids learn how to do things. Once the school started dropping PT we started Ryan with therapeutic horseback riding as a replacement, something at 20 years old, he's been doing since age 5. Though not exactly the same as PT, we found that it does continue to help with the key components of PT - strength, coordination, and endurance. Depending on the facility and specific program, you might find a place that provides hippotherapy led by a physical therapist. For us, therapeutic horseback riding has been a great therapy that doesn't seem like therapy - it's always been just a fun activity (that just happens to come with benefits). It's just one part of our overall plan to keep Ryan active." - Julie Casey, mom to Ryan

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PWSA | USA'S

SPOTLIGHT ON HOPE

"My name is Maggie Omoqui. I am 21 years old with Prader-Willi syndrome. I got into Gwynedd Mercy University into their Integrated Studies program. I am studying education and special ed. I am so happy working at variety club as a camp counselor. I love helping kids with special needs. All the kids that I work with love me." - Contributed by Maggie Omoqui

Congratulations Maggie! We wish you well on this exciting new adventure!

We want to celebrate your loved one!

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

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

50th Anniversary Party

When: Friday, June 27, 2025 | 6:30 - 9:00 p.m.
Where: Arizona Grand Resort & Spa Oasis Pool
FREE TO ATTEND! VIP Cabanas can be purchased when you register for the 2025 International PWS Conference.

You are invited to celebrate a milestone occasion! Join us as we commemorate the 50th birthday of PWSA | USA and the future collaborations of PWSA | USA,

the International Prader-Willi Syndrome Organisation (IPWSO), and the Foundation for Prader-Willi Research (FPWR). Together, let's celebrate 50 years of supporting individuals and families affected by PWS, milestones achieved and memories created, and a future filled with hope, advocacy, and empowerment. Come prepared for live music, delicious food, and delightful company, as well as moments of reflection, gratitude, and celebration. Your presence will make this occasion even more special. We look forward to sharing this memorable evening with you!

You can sign up to attend the 50th birthday celebration when you register for the 2025 International PWS Conference.

HOTEL RESERVATIONS

REGISTER FOR THE 2025 PWS CONFERENCE

Through December 1, 2024, we are collecting artwork for theme #3 of our Rare Aware Art Share to usher in PWSA | USA's 50th anniversary! Individuals living with PWS are invited to create a piece of art using the prompt: **What is your favorite birthday memory?**

Birthdays are often joyful celebrations in our lives. As PWSA | USA celebrates our 50th Anniversary/Birthday in 2025, we want to know what happy birthday memories you have. Was there a birthday when you got to go on a fun adventure or had a very special person celebrate with you? Are your favorite birthday celebrations with family and friends? Have you traveled for a birthday? Think of a birthday that made you very happy and use your art to tell us about it.

Where will the artwork be displayed: Besides our social media platforms and website, these pieces will be displayed at the 2025 International PWS Conference, specifically during the 50th Birthday Celebration party on Friday, June 27th at the Oasis Waterpark (Arizona Grand Resort & Spa).

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

RARE AWARE ART SHARE

Hurricane Support for PWS Families

PWSA | USA has established a dedicated fund to support PWS families affected by the recent hurricanes. While we have limited funds available, we are committed to helping as many families as possible during this challenging time. If you or your loved ones have been impacted by these storms and are in need of assistance, please reach out to us. For more information, contact PWSA | USA at info@pwsausa.org, or call us directly at 941-312-0400 to learn about the resources and aid available to you.

Thank You, Michele Hampton, for Hosting Dance Silly for Prader-Willi!

On Saturday, October 12th, Michele Hampton and her family hosted the Dance Silly for Prader-Willi event in Warren, OH. The proceeds from this event will benefit PWSA | USA's advocacy, family support, and research programs. You

can watch a recap video of this amazing event, including an interview with Michele and photos from the party!

"This whole event has blown up to something larger than I expected. It's just so wonderful to see families that we've known for a long time, as well as new families with Prader-Willi syndrome. We've made connections with them and some of them have become my best friends. We're very fortunate to have everyone come out." - Michele Hampton

DANCE SILLY FOR PRADER-WILLI VIDEO

PWSA | USA'S UPCOMING EVENTS

The Giving Pump

WATCH: PWSA | USA Volunteer and mom Dominique Valenti shares her and her daughter's journey with Prader-Willi syndrome and what *The Giving Pump* is all about!

A portion of The Giving Pump proceeds benefit Prader-Willi Syndrome Association | USA

We can't thank Dominique Valenti (PWSA | USA volunteer and mom to Catalina) enough for her efforts on The Giving Pump! A portion of the proceeds from The Giving Pump (located at the Mt. Ivy Country Corner Shell Gas Station: 361 Route 202, Pomona, NY 10970) will go directly to PWSA | USA. If you live in the area, we encourage you to fill up your gas tank at any of the purple-wrapped gas pumps through the end of this month! Dominique was featured in Shell USA's Giving Pump video where she shares her and her daughter's journey with Prader-Willi syndrome and what The Giving Pump is all about. You can watch this video at the button below.

We look forward to welcoming Dominique on PWSA | USA's PWS United podcast next Tuesday!

DOMINIQUE'S GIVING PUMP VIDEO

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

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- All appropriate submissions will be shared on the podcast, social media, and/or a special Halloween blog.

SUBMIT AUDIO FILE

Latest PWS United Episode

On today's episode of *PWS United*, we welcome Clint Hurdle, former Major League Baseball (MLB) manager and proud dad to Madison (22), who is living with Prader-Willi syndrome. Clint sat down with PWSA | USA CEO Stacy Ward for a heartfelt conversation, sharing his family's journey from Madison's diagnosis to connecting with PWSA | USA, along with some fun personal stories and reflections. With nearly 50 years in the MLB and over 1,000 managerial wins with the Colorado Rockies and Pittsburgh Pirates, Clint brings a unique perspective and shares powerful advice for other dads navigating a PWS diagnosis. As PWSA | USA's national spokesperson and a board member, Clint's passion and dedication to the PWS community shine through. Listen to this inspiring episode on Apple Podcasts, Spotify, or wherever you get your podcasts!

LISTEN ON PODBEAN

ADVOCACY

Opportunities to Share Your PWS Story

Soleno Therapeutics launched the first in a series of "Our Stories," a section of the website dedicated to sharing first-hand stories of individuals living with PWS and their caregivers. Starting with Kelly and her daughter Clementine, these stories will convey the joys and challenges of living with PWS and loving someone with the condition.

To inspire others within the PWS community, Kelly shares her journey as a caregiver for Clementine, who lives with PWS. Through their story, Kelly opens up about how PWS has impacted their family of six. She sheds light on their daily challenges and triumphs, illustrating that while PWS and its symptoms manifest differently for each person, the hope and resilience they hold remain constant.

To view this video and share written stories or quotes of your own, please visit www.Support4PWS.com or click the button below. This website was designed by Soleno Therapeutics as a source of hope for individuals living with PWS, their families, and loved ones. You can sign up to receive future updates from the company, including more stories like Kelly and Clementine's.

WATCH VIDEO

On October 8th, Soleno Therapeutics provided an update on DCCR, a potential treatment for hyperphagia in individuals with PWS. Following the submission of a New Drug Application (NDA) by Soleno, the FDA has granted priority review to DCCR, expediting the evaluation process. However, no advisory committee meeting will be held at this time. We continue to push for new treatments and ensure the PWS community's voice is heard.

While it appears there may not be another formal opportunity for our community to share their support for DCCR prior to the Prescription Drug User Fee Act (PDUFA) date of December 27th, we encourage you and/or your loved ones affected by PWS to contribute a written testimonial, which PWSA | USA will securely hold in the event the FDA requests additional community input. You can learn more and share your testimonial by clicking the button below.

LEARN MORE HERE

FDA Holds Public Meeting: Advancing Rare Disease Therapies Through an FDA Rare Disease Innovation Hub

On October 16, 2024, PWSA | USA and FPWR were honored to participate in the public meeting, *Advancing Rare Disease Therapies Through an FDA Rare Disease Innovation Hub*, hosted by the Reagan-Udall Foundation in collaboration with the FDA's Rare Disease Innovation Hub. The hybrid event brought together advocates, researchers, industry professionals, and other stakeholders to discuss innovative approaches for advancing treatments for rare diseases.

As part of our ongoing commitment to the PWS community, PWSA | USA and FPWR actively engaged in the meeting to represent the voices and needs of those affected by Prader-Willi syndrome. In addition, we collaborated on a written submission to the FDA, providing our recommendations on prioritizing and structuring the Rare Disease Innovation Hub. This collaboration ensures the needs and unique challenges of the PWS community are addressed within this transformative initiative.

During the meeting, key topics included approaches to enhance FDA engagement with patient groups and priority issues for rare diseases. This event reflects a significant step forward for rare disease advocacy, and we look forward to continued engagement with the FDA to expedite development and approval of safe and effective therapies for PWS and other rare conditions.

To learn more about the meeting, view the full agenda, or review the presentation slides, please visit the Reagan-Udall Foundation website. To view the written document submitted on behalf of the PWS community, click **HERE**. Thank you for your ongoing support as we work to advocate for and advance the interests of our community.

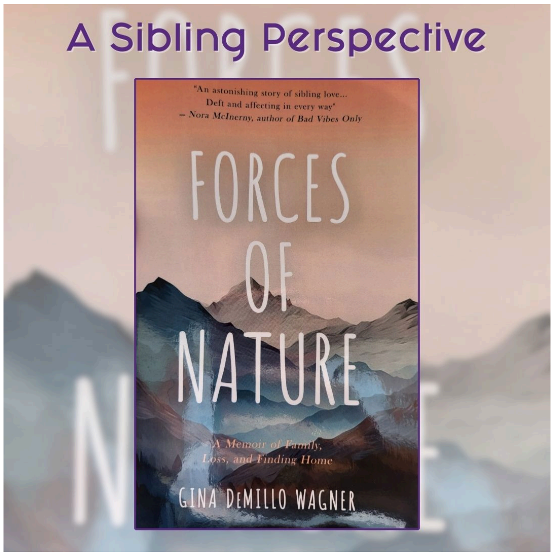
Adults with PWS Advisory Board Meeting

This week, PWSA | USA's Adults with PWS Advisory Board gathered in Phoenix, AZ, for a multi-day meeting to plan future initiatives and the half-day Adults with PWS Conference, which will take place during the 2025 International PWS Conference. In a candid interview with CEO Stacy Ward, the advisory board members shared their experiences with advocacy, self-empowerment, and hopes for the future. Click the button below to learn how the board is shaping the path forward, how you/your adult loved one living with PWS can get involved, and what the members shared about the challenges and triumphs of living with PWS.

READ HERE

FAMILY SUPPORT

PWSA | USA Blog: Forces of Nature
A PWS Book Review



Contributed by Lisa Graziano, this week's blog views a memoir written by an adult sibling of an individual with PWS who has passed away. According to Lisa, "The ideal audience for this book is the adult who has grown up with a sibling with PWS, especially one whose symptoms include(d) physical aggression. Parents may gain insight into their other children's experiences with their sibling with PWS and be reminded of the need to be present for each of our children and protect them, including, if necessary, from their sibling with PWS. Professionals who wish to gain some insight into the experiences of those who live with a sibling with PWS who has aggressive behaviors may also find the book helpful."

Please note that this book does involve the topic of death and, as Lisa emphasizes, is **not** for the parent of the young child with PWS.

If you would like to read more about *Forces of Nature* and Lisa's review, please click the button below.

READ HERE

Spreading Joy: Operation Holiday Cheer Returns to Support PWS Families in 2024

Thanks to the incredible generosity of an anonymous donor, PWSA | USA is thrilled to bring back **Operation Holiday Cheer** for 2024!

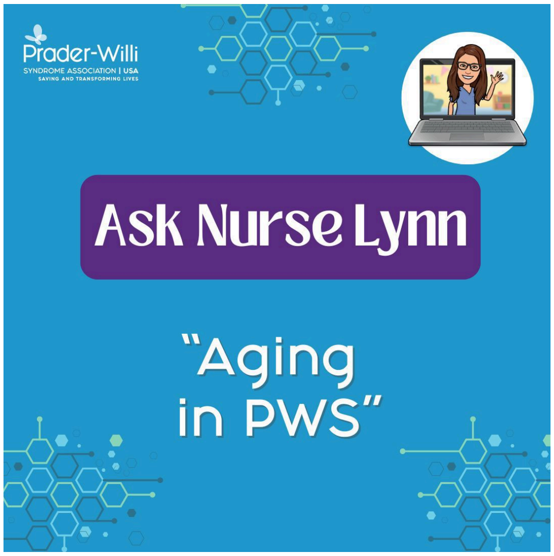
This heartwarming initiative helps spread joy to families in need by easing the financial burden of the holiday season. Through this program, a select number of families affected by Prader-Willi syndrome will receive gift cards to assist with holiday expenses, ensuring they can focus more on celebrating with loved ones and less on financial stress. If your family could benefit from this support, we invite you to apply by completing our **Operation Holiday Cheer** application. Applications are due by Friday, November 8, 2024, so don’t miss this opportunity to bring a little extra cheer into your home this holiday season! Find the application at the button below.

OPERATION HOLIDAY CHEER APPLICATION

Ask Nurse Lynn

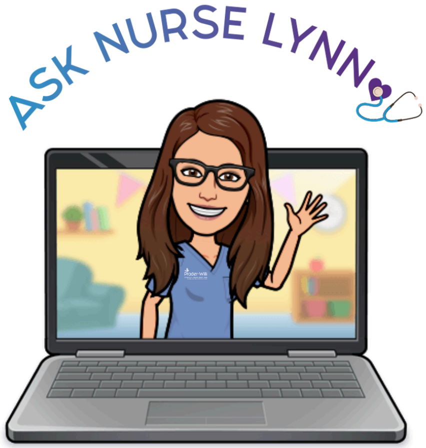
Question *(Female, 62 years old, unknown subtype):*

"My sister has PWS. We live in Quebec, Canada. There is so little information about how people with PWS age. We have reduced her meds recently due to aging (Bupropion by half, and she is now taking Lorazepam to handle side effects). She takes medicine due to pre-diabetes. She is losing weight gradually due to very careful carbs management and regular exercise. What should we watch for as she ages? Can you refer me to information or websites about aging in people 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

TREND Community
Turning Anecdotes Into Evidence

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWS Connect

SUPPORT PWS RESEARCH AND CREATE COMMUNITY

Register for our upcoming webinar:

Tuesday, October 29, 2024
5pm PST | 8pm EST

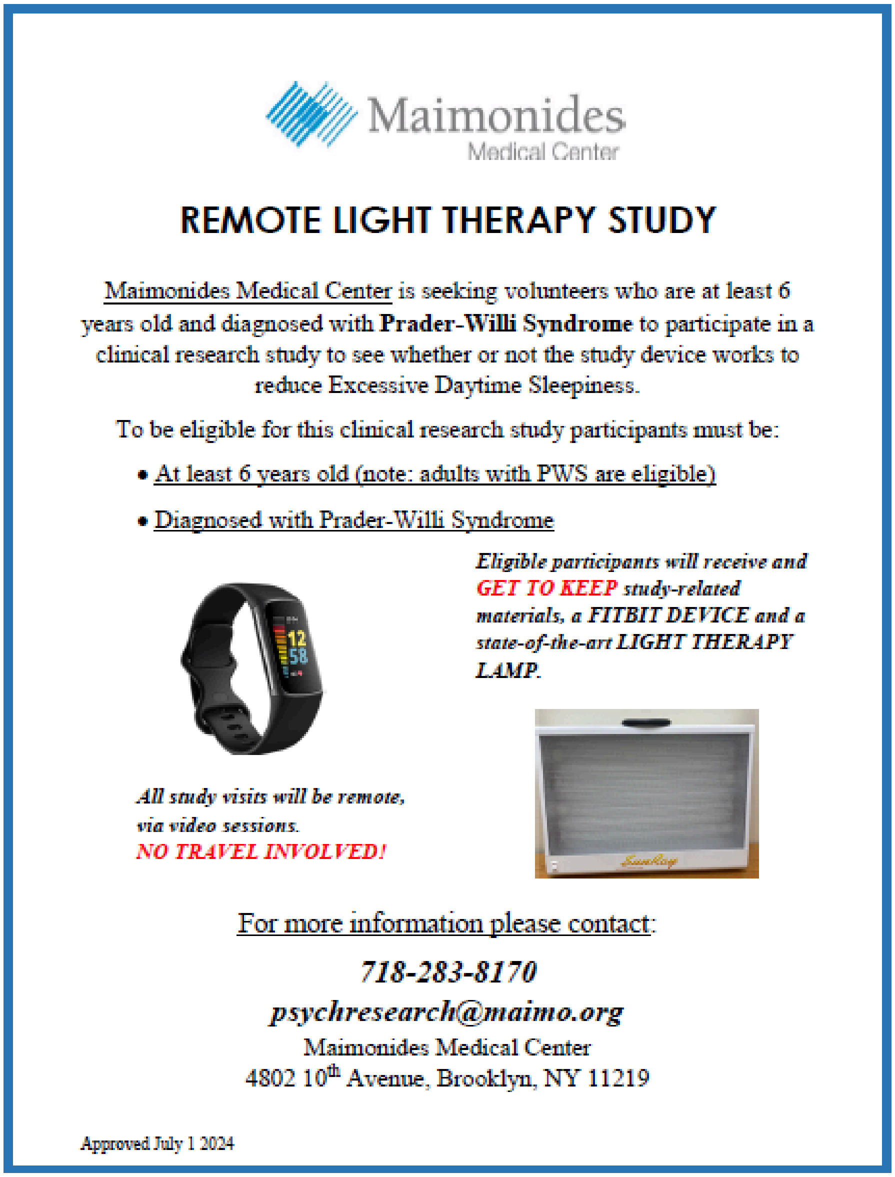
Support PWS Research and Create Community
When: Tuesday, October 29, 2024 |
5:00 p.m. PST / 8:00 p.m. EST

Join us for an insightful and informative webinar to learn how you can help advance PWS research while also finding and building community support. PWS parents, Maria Picone and Chris DeFelice, are excited to share how their personal journey with PWS led them to create the **PWS Connect** channel on Discord, a place where caregivers come together to share their journeys, experiences, questions, and advice to support each other and directly impact the progression of PWS research. This webinar will explain the **What, Why,** and **How** of **TREND Community** and the PWS Connect Discord group, and include time for your questions. We hope you join us for a new wave of PWS insights and growing research! Register at the button below.

REGISTER HERE

RESEARCH

Light Therapy Study for Excessive Daytime Sleepiness Looking for Participants



Maimonides
Medical Center

REMOTE LIGHT THERAPY STUDY

Maimonides Medical Center is seeking volunteers who are at least 6 years old and diagnosed with **Prader-Willi Syndrome** to participate in a clinical research study to see whether or not the study device works to reduce Excessive Daytime Sleepiness.

To be eligible for this clinical research study participants must be:

- At least 6 years old (note: adults with PWS are eligible)
- Diagnosed with Prader-Willi Syndrome

Eligible participants will receive and GET TO KEEP study-related materials, a FITBIT DEVICE and a state-of-the-art LIGHT THERAPY LAMP.

All study visits will be remote, via video sessions.
NO TRAVEL INVOLVED!

For more information please contact:

718-283-8170
psychresearch@maimo.org
Maimonides Medical Center
4802 10th Avenue, Brooklyn, NY 11219

Approved July 1 2024

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is 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: Two 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 **two** upcoming **ECHO 4 PWS** webinars.

Date: Thursday, October 24, 2024 at 9:00 AM PST / 12:00 PM EST
Speaker: Deepan Singh, MD
Topic: Psychiatry and PWS
Location: ZOOM

REGISTER HERE

Date: Monday, November 11, 2024 at 2:00 PM PST / 5:00 PM EST
Speaker: Daniela Rubin, Ph.D.
Topic: Exercise Physiology
Location: ZOOM

REGISTER HERE

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 information about ECHO 4 PWS at the button below.

PROJECT ECHO

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

While it is important to remember that what works for one family may not work for another, it is also helpful to share our tips and strategies for navigating this PWS life. How you successfully steer through a food-laden holiday may help another family find their own alternative options or create unique traditions. Click the button below to share your **Hope for the Holidays**, either through a story, a photo, a tip, or recipe from a past Halloween, Thanksgiving, Hanukkah, Kwanzaa, Christmas, New Years, or another holiday you celebrate. We will share the tips, recipes, and stories submitted on our social media pages. You can also choose to submit anonymously.

Heads up, we are also looking for Halloween tips in your own voice to share on our PWS United podcast! You'll find that information in our podcast section of this Pulse or **HERE**.

HOPE FOR THE HOLIDAYS

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!

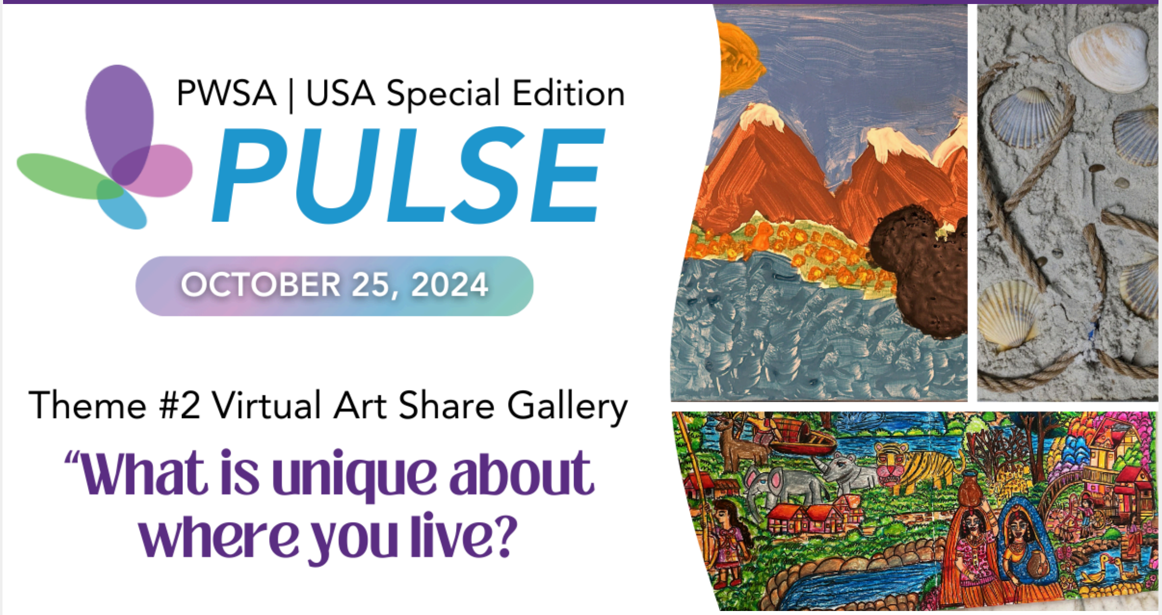
Donate

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

PWSA | USA Special Edition Pulse: October 25, 2024

www.pwsausa.org | 941.312.0400

Donate



The **Rare Aware Art Share** is an incredibly unique opportunity to learn more about individuals living with Prader-Willi syndrome and their artistic voices. Theme #2 was especially enlightening as we strongly encouraged individuals from around the world to share what is special about where they live. As we gather together in June 2025 in Phoenix, AZ, for our International PWS Conference with IPWSO, FPWR, and families from around the world, we will proudly display the beautiful and intriguing submissions that artists sent us. From India to Austria and right in our own backyards, people with PWS shared their artistic insights into what is special about their homes.

We can only share a few submissions here in this Special Edition Pulse, but all the submissions have been collected into a virtual gallery (button below) and will be posted to our social media pages over the next several weeks. If you are coming to the conference next June, please look for the Rare Aware Art Share displays.
Be sure to scroll through to enjoy some art share submissions and learn more about submitting to the current theme: ***What is your favorite birthday memory?***

VIRTUAL ART GALLERY

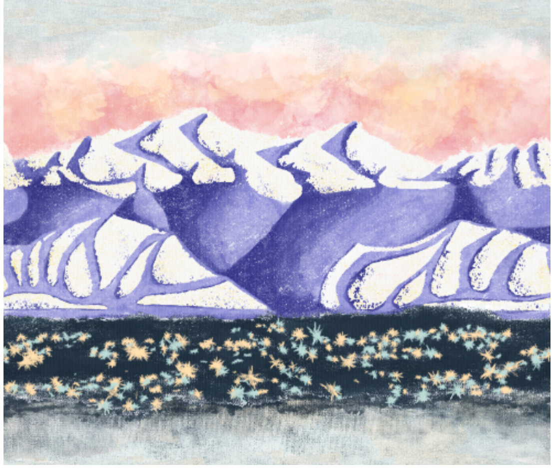
"I used to colour out mandalas but at one point this was no longer enough. I wanted to let my inspiration run free. Through my love for colours and forms in my drawings, I developed a room in which I feel I can express myself. The sense of drawing feels like home to me. Instead of taking a step outside my home, I invite other people to join me in my home."
- Patricia Hütter, 38, Austria

Theme #2 Submissions
"What is unique about where you live?"

Nicolle, 36 years old, Colorado

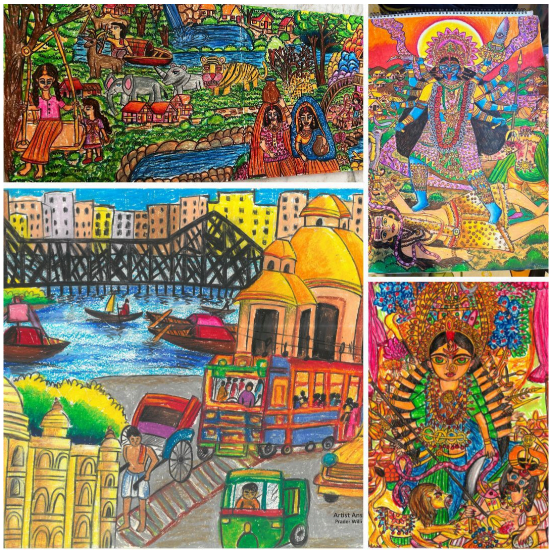
What inspired you to create your artwork? I wanted to capture the view of the stunning front range of the Rocky Mountains from Denver Colorado.
What is something you wish people knew about you? I think often people don't see the many things I struggle with, it's easy for people to assume my struggles with my weight, or easily getting fatigued is from lack of will power, or just being lazy.

On the flip side despite the challenges and struggles I've had and continue to deal with because of PWS, they've also made me who I am. Everyone has their



own challenges in life, and this one is mine, I don’t want to be felt sorry for, my life may look different, but beautiful and full.

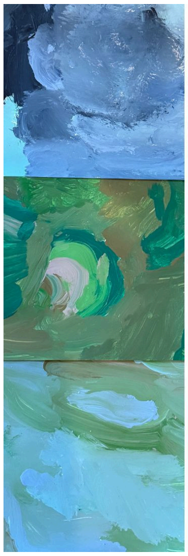
Ansh, 20 years old, India



Explain the Artwork (Materials used? If people in your art, who are they?): I have drawn a picture of my city Kolkata in India. The unique thing about my city is electric trams, black and yellow iconic taxis and the famous Howrah bridge. I have used oil pastels (crayons) to colour the picture. The famous festivals celebrated in my city Kolkata are Goddesses Durga and Kali, they are powerful and stood to destroy evil. **What inspired you to create your artwork?:** I love to draw and it’s my passion to create whatever I see on my drawing sheets. I love vibrant colors in my drawings. I love to draw pictures of cities and Indian Gods and Goddesses.

Lyra, 6 years old, West Virginia

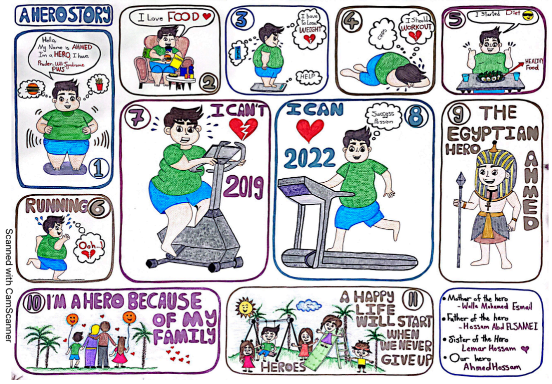
Explain the Artwork (Materials used? If people in your art, who are they?) This piece explains what it's like living on the side of the blue ridge mountains, and next to the Shenandoah River. The colors are amazing. The river is represented with blues and greens. The mountains in the middle with a variety of greens, and the blue sky above the mountains. Just like John Denver's song, West Virginia. "Blue ridge mountains, West Virginia..."



What is something you wish people knew about Prader-Willi syndrome? Lyra pays a lot of attention to the beauty of this world. She sees the beauty of it. She's not bogged down with a lot of stress that some kids her age are. She's in her own world, and we believe PWS makes her a kinder and sweeter person.

What is something you wish people knew about you? I love my family! Especially my Poppop!

Ahmed, 16 years old, Egypt



Explain the Artwork (Materials used? If people in your art, who are they?) My art is my story with PWS. I use paper and coloring pencils.

What inspired you to create your artwork? My mother helped me and inspired me to turn my story into a work of art that I share with my friends to support them.

What is something you wish people knew about Prader-Willi syndrome? Life with PWS is not easy, but it is full of wonderful challenges. With PWS, your life changes for the better.

What is something you wish people knew about you? I am handsome, wonderful, and funny. I love all people, but I ask them to help me so that I can face all these challenges every day.

Lenny, 11 years old, Texas

Explain the Artwork (Materials used? If people in your art, who are they?) This is a picture created with marker pens. This artwork is a heartfelt birthday gift from Lenny to his mother. The vibrant piece depicts a powerful dragon and a determined warrior, symbolizing the deep connection between mother and son. The dragon represents Lenny, born in the Year of the Dragon, while the warrior stands for his mother, showcasing their mutual reliance and unwavering support

for one another. The bold colors and dynamic composition reflect the strength and love in their relationship.

What inspired you to create your artwork? Lenny was born in China and was diagnosed with PWS at the age of 5. He and his mother spent seven difficult years in China and immigrated to the United States at the age of 7.

What is something you wish people knew about Prader-Willi syndrome? I hope that more and more people around the world can pay attention to PWS. I also hope that more people can know more about PWS.

What is something you wish people knew about you? My genes are missing, but my soul is complete. I want to be a famous artist!

Ashley, 16 years old, Massachusetts

Explain the Artwork (Materials used? If people in your art, who are they?) First you take the blank canvas and picture what you want to see. Then you ask Brittni to hot glue the stuff on. I used sand, beach grass, shells, rope, and a whale.

What inspired you to create your artwork? Brittni said that I should make a craft about Cape Cod so I did.

What is something you wish people knew about Prader-Willi syndrome? Everything will be okay.

What is something you wish people knew about you? Sometimes I like to act.

Now Accepting Artwork for Theme #3

What is your favorite birthday memory?

Through December 1, 2024, we are collecting artwork for Theme #3 of our Rare Aware Art Share to usher in PWSA | USA's 50th anniversary! Individuals living with PWS are invited to create a piece of art using the prompt: **What is your favorite birthday memory?**

Birthdays are often joyful celebrations in our lives. As PWSA | USA celebrates our 50th Anniversary/Birthday in 2025, we want to know what happy birthday memories you have. Was there a birthday when you got to go on a fun adventure or had a very special person celebrate with you? Are your favorite birthday celebrations with family and friends? Have you traveled for a birthday? Think of a birthday that you have had that made you very happy and use your art to tell us about it.

Where will the artwork be displayed: Besides our social media platforms and website, these pieces will be displayed at the 2025 International PWS Conference, specifically during the 50th Birthday Celebration party on Friday, June 27th at the Oasis Waterpark (Arizona Grand Resort & Spa).

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

LEARN MORE HERE

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