

# PWSA | USA Bi-Weekly Pulse: November 1, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS



**Vol. 110**

November 1, 2024

[www.pwsausa.org](http://www.pwsausa.org) | 941.312.0400

**YOU Can Support PWSA | USA's Programs and Services by Donating to the 2024 Angel Drive Campaign TODAY Through December 31st!**



GIVE THE  
*Gift* OF HOPE  
2024 ANGEL DRIVE

November 1 - December 31



[CLICK HERE TO MAKE AN IMPACT!](#)

The **2024 Angel Drive** is PWSA | USA's largest annual fundraising campaign, dedicated to bringing hope and essential support to families and individuals impacted by Prader-Willi syndrome. This year, the Angel Drive not only supports our life-changing programs—like school advocacy, medical crisis support, and caregiver resources—but also marks the beginning of our 50th anniversary celebration! Your donations **directly** fuel our mission, helping families access vital services, empowering individuals, and fostering a connected and resilient PWS community.



You can give your **Gift of HOPE** through December 31st by clicking [HERE](#), or by mailing a check to:

**PWSA | USA**  
**Attn: Angel Drive**  
1032 E. Brandon Blvd #4744  
Brandon, FL 33511

***Together, let's ensure PWSA | USA is here to support families for another 50 years and beyond.***

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***BONUS! If you contribute by December 15th, you'll be entered for a chance to win one of four exciting prizes: An Apple Smart Watch, a \$300 Amazon gift card, customizable PWS Nike shoes, and a PWSA | USA swag bag***



## Hear How PWSA | USA Turns Hope into Action

We are excited to launch our [Hope in Action](#) video series, which will share powerful stories of resilience and hope from the Prader-Willi syndrome community, highlighting the many ways PWSA | USA is making a difference. From school support to crisis assistance, advocacy, and more, each story showcases the real-life impact of our programs and the strength of our families.



Created as part of our 2024 Angel Drive, this series celebrates the support PWSA | USA provides to families, caregivers, and individuals with PWS—and the difference you can make by joining us in giving the gift of hope. Tomorrow, November 2nd, we will share the first video in this series - School Success, featuring mom Sue Colon and CEO Stacy Ward - in an email and on our social media pages!

**HOPE IN ACTION SERIES**

PWSA | USA'S  
**SPOTLIGHT ON HOPE**

## Way to go, Kinsler!



*"My son, Kinsler, recently lost 21lbs with the guidance, encouragement, and insights from Dr. Sani Roy and her team at the MPoWER clinic at the Cook Children's Prader-Willi Center in Fort Worth. We are extremely proud of the hard work Kinsler has put in not only to lose the weight but continuing to drop the pounds. These photos are the before and after. The before was taken at our first time at the MPoWER Clinic on June 25, 2024. Kinsler weighed 134 lbs. at the time of the picture. The after picture was taken at a follow up appointment with Dr. Roy on October 3, 2024. Kinsler weighed*

*in at 112 lbs.!"* - Contributed by Cecily Kirby

### 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 International PWS Conference Registration



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
<i>Invite Only</i>	Professional Providers Program	<i>1/2 Day</i>	

As the first joint conference between **PWSA | USA, FPWR and IPWSO**, this event symbolizes a historic milestone in the PWS community. The power of working together and promoting our shared interests to benefit all those affected by PWS cannot be underestimated. Our theme “United in Hope” is a call to clinicians, scientists, parents, professional providers and caregivers, allied professionals and trainees, and most importantly, individuals with PWS, to bring your vision, your knowledge, your experience and your hopes, and to share and learn at this transformative gathering.

Our **United in Hope Conference** provides an opportunity to amplify the voice of our community. It is a time for us to renew our energies, celebrate our diversity, cultivate meaningful connections and foster groundbreaking research. And we do so in the unique and vibrant landscape that is Arizona!

Together, let us embark on this journey of knowledge exchange and collaboration to help shape a brighter, more inclusive future for everyone affected by PWS.

**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?**

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



**RARE AWARE ART SHARE**

## Hurricane Support for PWS Families



### HURRICANE SUPPORT For PWS Families

CALL OR EMAIL PWSA | USA



(941) 312-0400



info@pwsausa.org



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](mailto:info@pwsausa.org), or call us directly at 941-312-0400 to learn about the resources and aid available to you.



## Thank You, Michelle Spring, for Hosting Answers for Audrey!



Spring

On Saturday, October 12th, Michelle Spring and her family hosted the 4th Annual Answers for Audrey trivia night in Bel-Nor, MO. Online donations from this event benefit PWSA | USA's advocacy, family support, and research programs.

*"The 4th Annual (Trivia) Answers for Audrey is in the books! Thank you to everyone who attended, volunteered, and donated to our cause! We have such a loving and generous community and were able to raise right around \$13,750 for Prader Willi Syndrome! Thanks for loving our girl as if she was your own!" - Michelle*

### 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](mailto:hopeunited@pwsausa.org) and click the button below to get started!

[Become a Hope United Champion](#)

## PWS UNITED PODCAST UPDATES

Latest PWS United Episode

PWSA | USA's Adults with PWS Advisory Board recently met in person at the site of the 2025 International PWS conference. Stacy Ward, CEO of PWSA, interviewed board members to share more about the work they do, how they began, what it's like living with PWS, advice for families, and what strengths they are looking for as they seek a new advisory board member.

Advisory Board members include Conor Heybach, Shawn Cooper, Abbott Philson, Kate Kane, Victor Penta, Trevor Ryan, and Brooke Fuller. Thank you, board members, for all that you do for the community and being such inspiring and motivated members!

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

[LISTEN ON PODBEAN](#)

PWS United Podcast  
**ADULTS WITH PWS ADVISORY BOARD**  
PODCAST EPISODE #3  
With Guests:  
Adults with PWS Advisory Board  
Prader-Willi Syndrome Association | USA  
PODCAST

## **ADVOCACY**

### **PWSA | USA Advocates on Capitol Hill, NORD Breakthrough Summit**

In a powerful week of advocacy, Dorothea Lantz, Director of Community Engagement at PWSA | USA, represented Prader-Willi syndrome (PWS) on Capitol Hill and at the 2024 NORD (National Organization for Rare Disorders) Breakthrough Summit in Washington, D.C., from October 20–22. The Summit gathered leaders across the rare disease community, including patient advocates, health-care providers, researchers, and policymakers, all united to tackle issues in rare disease advocacy, research, and healthcare policy. Key discussions covered equitable health-care access, regulatory challenges, and the need for more inclusive health-care solutions for rare disease patients. To read more about this event, click the button below.



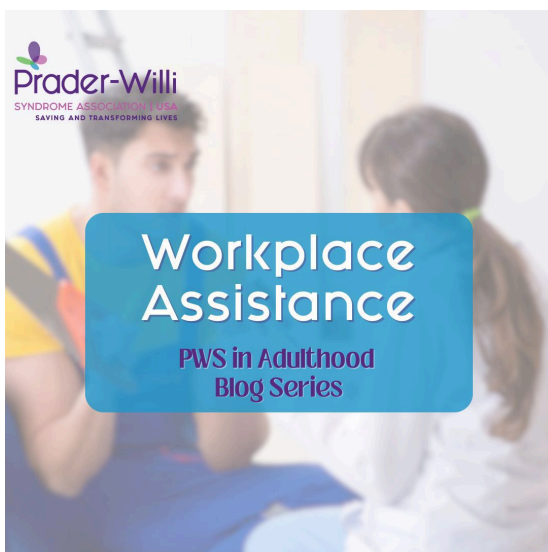


[READ HERE](#)



## FAMILY SUPPORT

### PWS in Adulthood Blog Series



The PWS in Adulthood blog series seeks to document the variety of ways adults with PWS find their version of independence, or interdependence, and how they participate in their families and communities through school, work, relationships, and more. As younger families look toward the future, they may be comforted to read how adults with PWS are living rich, fulfilling lives. As caregivers of adults with PWS read these blogs, they may be inspired to learn how other adults are navigating life in the older years. This blog, contributed by Jill Boughton, is

yet another glimpse into the possibilities of what it may look like living with PWS in Adulthood.

READ HERE

### Is your loved one an adult with PWS?

1. What steps did you take to prepare for their life as an adult?
2. What does independence look like for them?
3. What supports do they have in place?
4. Do they have romantic relationships and how are those maintained?
5. Do they work or volunteer in their community and what does that look like?
6. Do you have advice for parents on how and when to prepare for adulthood?

Share your story for our PWS in Adulthood Blog series by emailing [africke@pwsausa.org](mailto:africke@pwsausa.org).

## Applications Due Soon! Friday, November 8



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

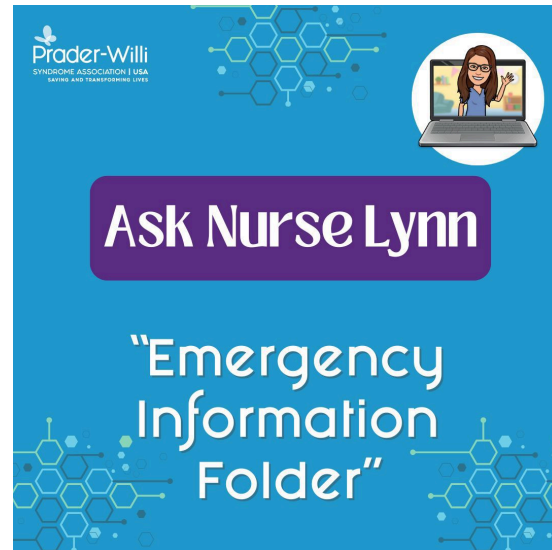
support, we invite you to apply by completing our **Operation Holiday Cheer** application. Applications are **due by Friday, November 8, 2024**, so don't miss this opportunity to bring a little extra cheer into your home this holiday season! Find the application at the button below.

## OPERATION HOLIDAY CHEER APPLICATION

### Ask Nurse Lynn

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

*"Does the association have a letter or document of some type that could be given to a doctor in an emergency situation, in order to give them a quick understanding of PWS and the potential medical impacts? Perhaps it could even be attached to a PWS patient's medical record so that all medical staff interacting with the patient could have the information. Before writing something up, I wondered if PWSA already has something like this available. Thank you."*



Visit our blog to read Nurse Lynn's response.

[READ NURSE LYNN'S RESPONSE](#)

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

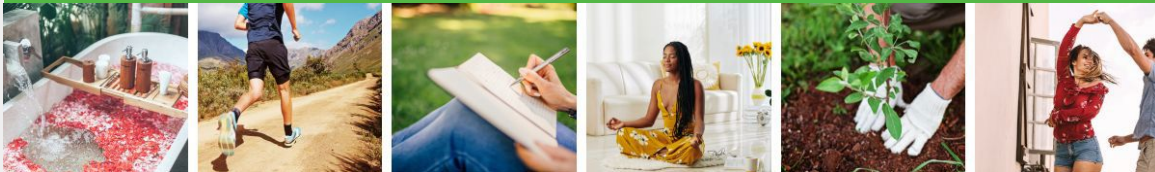
Now you can **Ask Nurse Lynn**, PWSA | USA's very own PWS Nurse.

ASK NURSE LYNN



ASK YOUR QUESTION HERE

## November is National Family Caregiver Month



November is National Family Caregiver Month. We want to let all of you parents and caregivers know that you are doing an amazing job! We know how challenging it can be at times to care for someone with PWS. Please remember that PWSA | USA is here to support you and your family. Stay tuned to our social media channels throughout the month for tips, tools, tricks, and treats to help support and honor you as a caregiver. See the following sections for a few of our Family Caregiver Month offerings now open for registration: *"Babysitter and Care Provider Training"* and *"Journaling and Story Sharing Workshop"*. To get started on celebrating this month, check out our blog on **"Self-Care for Caregivers"** at the button below.

READ HERE

Family Support Webinars



Family Support Webinar

## Babysitter and Care Provider Training

Facilitated By:  
Lisa Graziano, MA, LMFT

Tuesday, November 19  
5 pm Pacific/ 8 pm Eastern

### Babysitter and Care Provider Training

When: Tuesday, November 19, 2024 |  
5:00 p.m. PST / 8:00 p.m. EST

This live webinar, facilitated by Lisa Graziano, M.A. LMFT, will help your babysitter, respite worker, and even relatives better understand how to care for your child or adult more safely, giving YOU greater opportunity to enjoy date nights, self-care moments, and even weekends away! The webinar underscores the need to follow parents care exactly and offers strategies to provide food security,

decrease arguing, and increase cooperation. Register for this webinar using the button below.

[REGISTER HERE](#)



PWS Connect

Watch the recording of our October Family Support Webinar, **Support PWS Research and Create Community** with Maria Picone and Chris DeFelice, at the button below.

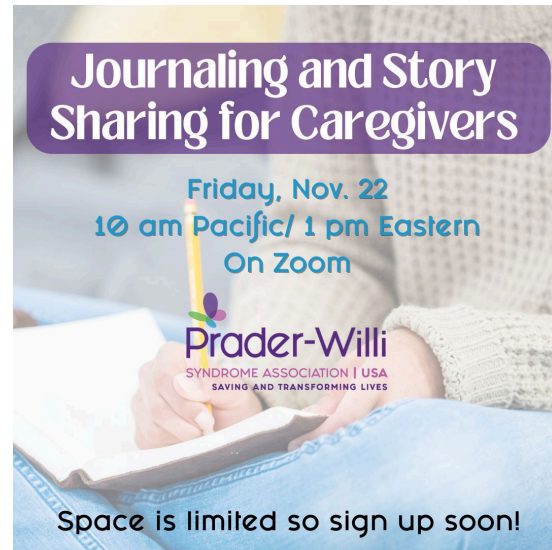
[CLICK HERE TO WATCH](#)

## Journaling and Story Sharing

*“Writing Therapy (WT) is defined as a process of investigation about personal thoughts and feelings using the act of writing as an instrument, with the aim of promoting self-healing and personal growth.”— [National Library of Medicine.](#)*

Journaling can help develop understanding, acceptance, growth, and healing in your life. Journaling in a group can magnify this experience while also helping you make connections, build your community, and find comfort in the sharing of experiences. For National Family Caregiver Month, we would like to offer you an opportunity to meet with other PWS caregivers in an intimate journaling and story sharing experience on **Friday, November 22, 10 am Pacific/ 1 pm Eastern**. In this workshop, Anne Fricke, PWSA | USA Communications

Coordinator, writer, and PWS mom, will briefly cover some journaling tips, provide a collective prompt and writing session, with time for participants to share. The intention is to create a space for caregivers to reflect on their experiences and discover the ways they succeed or the areas of needed improvement while also forming connections and deepening relationships with other caregivers. Space is limited so register soon by sending an email to [africke@pwsausa.org](mailto:africke@pwsausa.org)!



## RESEARCH

A Personal Account from a Clinical Trial Journey



This blog, contributed by Anne Fricke, continues to document one family's experience with a clinical trial, the details of what to expect at the appointments, the process of participating in a clinical trial, and the excitement, thoughts, and sometimes complicated emotions that come along for the ride. *"Her questions probed at places I didn't know were tender, brushed dirt away from griefs and habits I was beginning to bury. Each microscopic examination of Freya's behavior reminded me of how "not typical" this life is. All of the accommodations and adaptations*

*that have become a part of our daily routine were spread across an open table, displayed in focus for me to see."*

Read this blog and find links to previous blogs in the series at the button below.

[READ HERE](#)

## Harmony Biosciences Announces New Trial Site for TEMPO Trial

Harmony Biosciences has announced an additional clinical trial site for its TEMPO PWS study in Indianapolis, IN at the Riley Children's Hospital.

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 TEMPO trial site locations and learn more by clicking the button below.



[LEARN MORE](#)

## Calls for Abstracts for 2025 International PWS Conference



### Call for Abstracts

Professional Providers Program Submission  
Deadline: November 5, 2024

Clinical & Scientific Program Submission  
Deadline: January 31, 2025

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!

[APPLY HERE](#)

[REGISTER HERE](#)

**ECHO 4 PWS Health Care Series:  
1 Upcoming Session, Date TBD**





*Upcoming*

# ECHO 4 PWS Webinar:

Exercise Physiology  
Daniela Rubin, PhD

**Rescheduled: TBD**

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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**



**ECHO 4 PWS Webinar:**  
*Psychiatry*

**Recording Available**



**WATCH HERE**



## ECHO 4 PWS Webinar: Cardiac Concerns

Recording  
Available



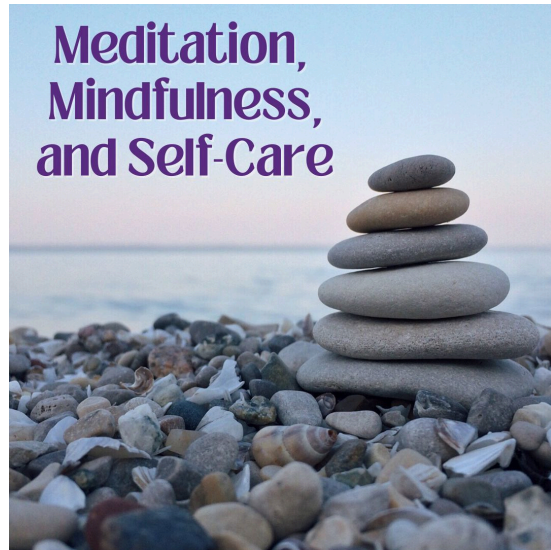
WATCH HERE

## PWSA | USA ANNOUNCEMENTS

### PWSA | USA Resource Spotlight

In keeping with the theme of National Family Caregiver Month, we'd like to point you in the direction of a blog and Facebook Live recording from PWS mom and mindfulness teacher, Emily Felt. As Emily states, *"Scientific studies confirm that meditation reduces stress, promotes calmness, and enhances overall happiness. Mindfulness is closely related to meditation but seamlessly integrates into daily life. It revolves around cultivating greater awareness of your actions, feelings, emotions, as well as your surroundings and interactions."* To learn more about meditation, mindfulness, and self-care, read Emily's blog or watch the Facebook Live interview by clicking the button below.

### Meditation, Mindfulness, and Self-Care



LEARN MORE 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: November 15, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS



Vol. 111

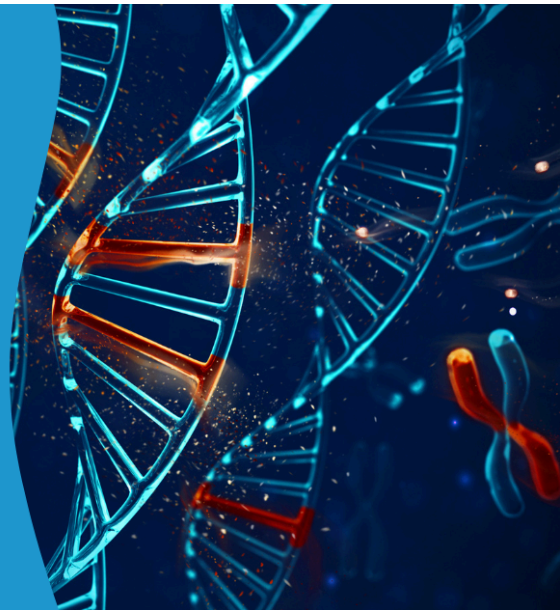
November 15, 2024

[www.pwsausa.org](http://www.pwsausa.org) | 941-312-0400



— NOVEMBER 15TH IS —  
**International  
15q Day**

*Prader-Willi Syndrome  
Angelman Syndrome  
Dup15q Syndrome*



International 15q Day is a day to recognize and spread awareness of three syndromes caused by abnormalities on the 15th chromosome: **Prader-Willi syndrome, Angelman syndrome,** and Chromosome 15q11.2-13.1 duplication syndrome (**Dup15q syndrome**). While they are unique in what causes each of these disorders, they display many similar characteristics and symptoms. There are no cures for any of these three syndromes and share the need for more

research and treatment options. To learn more about these genetic disorders, please read our blog at the button below.

In honor of International 15q Day, we're asking the PWS community to participate in this awareness effort and help us raise money for our Angel Drive. **Donate \$15 for International 15q Day!** Share with 15 friends and ask them to help support the efforts of PWSA | USA by donating \$15 for 15q. Your donation helps support much-needed research, advocacy efforts, and family support services like school trainings, parent mentors, medical advocacy and more. Every amount helps!

To donate \$15, whether a one-time donation or recurring, please follow the link below. Click on the "other amount" box and add your intended amount. We are grateful for the support of our community.

[READ 15Q BLOG](#)

[DONATE \\$15 FOR 15Q!](#)



*"Having this organization and other PWS families to speak to, give me ideas, and help me through the process has been the biggest gift I could have ever received. I personally want to thank anyone who's donated to PWSA | USA. We've been using their services for a long time, not just for IEPs but for medical difficulties too. I've needed their guidance through it all. Your donation is going to impact and change people's lives on a daily basis the way it has mine."*

*- Sue Colon, mom to Shealynn, 4, living with PWS*

 PWSA | USA'S  
**SPOTLIGHT ON HOPE**

*"Jamal has been going from strength to strength all while smiling. We spent a month in the NICU before he got the diagnosis as he turned 7 months. By this time, he had already gotten rid of his feeding tube, had two surgeries, and was enjoying PT & OT.*

*It's been amazing to watch him take his first bottle, enjoy his first solid meal and learning how to roll and sit up by himself. Jamal's now focused on learning how to walk, having started his growth hormone treatment and we can't wait to celebrate more milestones. Learning how to swim is his favorite thing in the world, as well as going for walks in the rain.*



*His love for people is huge so anything we need to do outside takes that much longer since Jamal will smile, wave, and interact with many. I feel so blessed to be this angel's mom and am so very proud of him." - Contributed by Mom, Monira Saleh*

### **We want to celebrate your loved one!**

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

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

**SHARE YOUR SPOTLIGHT ON HOPE**

## **EVENTS & FUNDRAISERS**

**FPWR Offers Travel Fellowship for  
2025 United in Hope Clinical and Scientific Program**

The Foundation for Prader-Willi Research (FPWR) will offer a limited number of \$1,000 USD travel awards to support trainees attending the 2025 International PWS Conference's Clinical and Scientific Program (June 25-26, 2025) in Phoenix, Arizona. Travel funds can be applied to the conference registration fee, economy airfare, hotel, meals, and ground transportation. Applications must be completed in English. The application deadline is January 31, 2025.

Applicants will be notified by March 14, 2025. Award funding will be disbursed after the conference by FPWR, upon receipt of a travel reimbursement form and accompanying receipts. For any queries regarding this application, please contact: [caroline@fpwr.org](mailto:caroline@fpwr.org). Learn more by clicking the button below.



[LEARN MORE HERE](#)

[REGISTER FOR THE 2025 PWS CONFERENCE](#)

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**We want to thank everyone who submitted an application for PWSA | USA's conference scholarship. We appreciate your interest in attending the 2025 International PWS Conference - United in Hope, and are grateful for the opportunity to help families attend. The scholarship application process has ended and those selected to receive a scholarship will be notified by December 1, 2024.**

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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?**

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

PWSA | USA 2024

Rare Aware  
Art Share

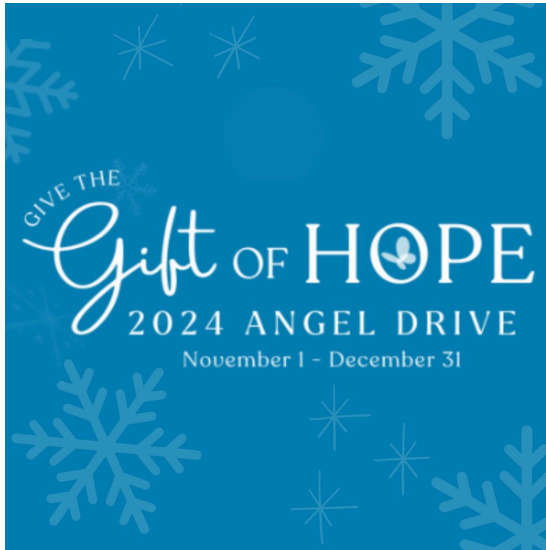


completed your art piece, please submit a digital image of your artwork using the form found at the button below.

**RARE AWARE ART SHARE**

**YOU Can Support PWSA | USA's Programs and Services by  
Donating to the *2024 Angel Drive Campaign* TODAY  
Through December 31st!**





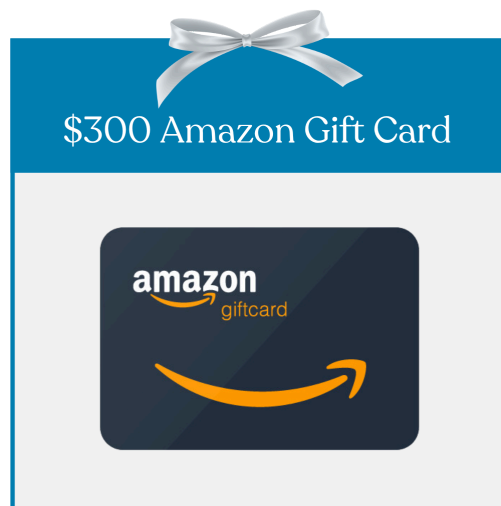
The **2024 Angel Drive** is PWSA | USA's largest annual fundraising campaign, dedicated to bringing hope and essential support to families and individuals impacted by Prader-Willi syndrome. This year, the Angel Drive not only supports our life-changing programs—like school advocacy, medical crisis support, and caregiver resources—but also marks the beginning of our 50th anniversary celebration!

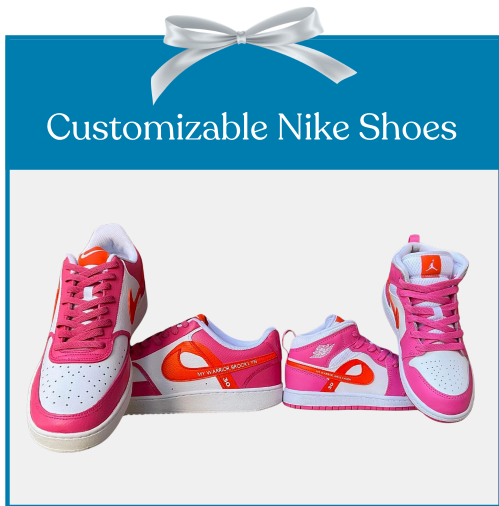
Your donations **directly** fuel our mission, helping families access vital services, empowering individuals, and fostering a connected and resilient PWS community.

[DONATE HERE](#)

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***BONUS! If you contribute by December 15th, you'll be entered for a chance to win one of four exciting prizes: An Apple Smart Watch, a \$300 Amazon gift card, customizable PWS Nike shoes, and a PWSA | USA swag bag.***

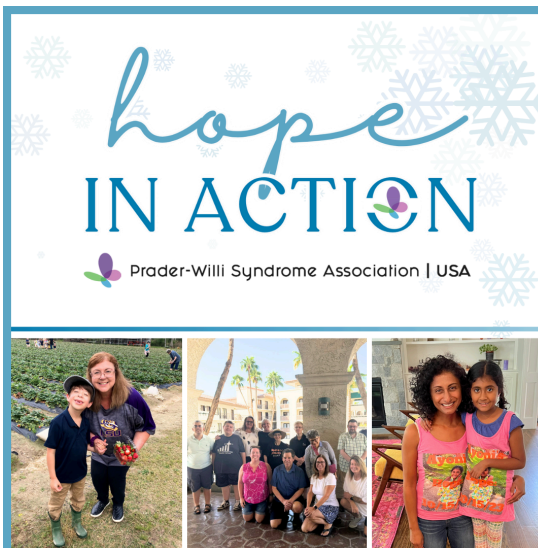




## Hear How PWSA | USA Turns Hope into Action

Our [Hope in Action](#) video series, which shares powerful stories of resilience and hope from the Prader-Willi syndrome community, highlights the many ways PWSA | USA is making a difference. From school support to crisis assistance, advocacy, and more, each story showcases the real-life impact of our programs and the strength of our families.

Created as part of our 2024 Angel Drive, this series celebrates the support PWSA | USA provides to families, caregivers, and individuals with PWS—and the difference you can make by joining us in giving the gift of hope. We will release new videos throughout the duration of our 2024 Angel Drive. You can watch the first couple *Hope in Action* stories at the button below.



[HOPE IN ACTION SERIES](#)

## PWSA of Washington and Oregon will Host a PWS Christmas Party



**When: December 14, 2024 | 1 pm - 2:30 pm and beyond**

**Where: Footprints Church (formerly Pleasant View Church) | 801 NE 194th Street | Ridgefield, WA 98642**

**PWSA | USA of Washington and Oregon** are hosting a PWS Christmas Party. Festivities include a visit from Santa from 1 pm - 2:30 pm with gifts for children and PWS guests. Guests will also receive a low-cal Christmas snack and diet beverage. There will be Christmas

music and activities. From 2:30 pm - 3:30 pm, there will be a brief meeting hosted by PWSA of Oregon & Washington members. Parents are welcome and encouraged to join to hear about the exciting new PWS map and upcoming events. You can also stay longer to visit other parents.

Many attendees will dine out together afterward at nearby restaurants. Resource materials will also be available. If you are in need of hotel accommodations Friday and/or Saturday night, families are encouraged to book a room at La Quinta Inn & Suites by Wyndham, 1500 NE 134th St, Vancouver, WA 98685. You can call the hotel directly at 360-566-1100 to reserve your room. This is a free event, though donations are gratefully accepted. Please RSVP to ensure there will be enough snacks, activities, and gifts. **RSVP** to Vonnie Sheadel at [vsheadel@gmail.com](mailto:vsheadel@gmail.com) or **360-609-5197**.

## PWSA | USA Texas Hosts 2025 Bi-Annual Statewide Conference

**When: February 1, 2025 | 8 am-5 pm (Registration: 7:15 am)**

**Where: Spring Branch Presbyterian Church | 1215 Campbell Rd. | Houston, TX 77055**

Join the **Texas Prader-Willi Syndrome Association** community for a special one-day event - the Bi-Annual Statewide Conference.

- Listen to medical professionals specific to PWS.

- Learn from behavior experts.
- Attend breakout sessions on transition, wills and trusts, working with educators, and more.
- Find out the latest on clinical trials.
- Network with parents/caregivers coping with PWS.
- Meet a variety of exhibitors and representatives from PWSA USA and FPWR.
- And more!

Lunch will be provided.

Infants/toddlers registered for child care must bring their own food. PWS individuals registered for child care will receive a meal that meets PWS guidelines or you can provide your own. Admission is \$50 for an individual and \$25 for child care.

For more information, email [executivedirector@txpwa.org](mailto:executivedirector@txpwa.org) or call 713-253-9032, and follow [Texas Prader-Willi Association Facebook page](#) or [txpwa.org](http://txpwa.org) for updates.

**REGISTER HERE**



**Interested in hosting a PWS Hope United event in your city? Contact [hopeunited@pwsausa.org](mailto:hopeunited@pwsausa.org) and click the button below to get started!**

**Become a Hope United Champion**

**PWS UNITED PODCAST UPDATES**

**Latest PWS United Episode**

PWSA | USA's communication team, Carrie and Anne, speak with PWS mom Emily Felt about self-care for caregivers. We talk about what caregiver burnout may look like, various ways to practice meditative activities and why, the importance of self-advocacy and external support, what gratitude does for perspective and mental health, and how and why to keep showing up for yourself.

Whether your self-care routine is a walk in the forest, yoga stretches in the morning, a campfire with friends, or all of the above, we hope this conversation helps you better understand the need for self-care as a caregiver, ways to bring more of it into your life, and how to truly show up for yourself.

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

[LISTEN ON PODBEAN](#)



PWS United Podcast  
**SELF-CARE, SELF-ADVOCACY, & GRATITUDE**  
PODCAST EPISODE #16  
With Guest:  
  
**Emily Felt**  
PWSA | USA  
Volunteer, Mom to Olivia  
Prader-Willi Syndrome Association | USA  
PODCAST



## ADVOCACY

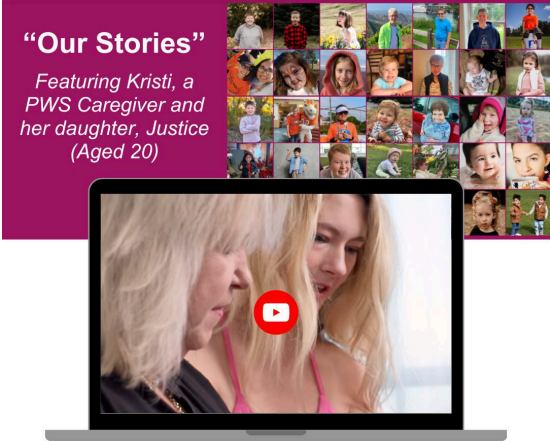
### PWSA | USA's Dorothea Lantz Appointed to 2025 Rare Disease Legislative Advocates Advisory Committee

We are thrilled to announce that Dorothea Lantz, PWSA | USA's Director of Community Engagement, has been selected to join the RDLA (Rare Disease Legislative Advocates) Advisory Committee for 2025! As a member of this distinguished group, Dorothea will collaborate with other rare disease advocacy leaders to elevate the voices of those impacted by rare diseases, including Prader-Willi syndrome, in key legislative and policy discussions. Her role will include providing essential guidance on RDLA activities, participating in advocacy events like Rare Disease Week on Capitol Hill, and engaging advocates across the country. Congratulations, Dorothea, on this well-deserved recognition and opportunity to make a difference for the rare disease community!



## Kristi and Justice Rickenbach Featured in Soleno Therapeutics' "Our Stories" Video

In a new 'Our Stories' spotlight, created by Soleno Therapeutics, PWSA | USA Parent Support Coordinator Kristi Rickenbach and her daughter, Justice (20), share the journey of transitioning into adulthood with PWS. Justice's story reflects her desire for independence and the steps she takes to manage PWS while working toward autonomy. This video testimonial captures the balancing act of nurturing independence while providing the support Justice needs to thrive as an adult. To stay informed and connected, sign up for updates at [www.Support4PWS.com](http://www.Support4PWS.com), a platform by Soleno Therapeutics, created to bring hope to families affected by PWS.



SUPPORT FOR  
Prader-Willi Syndrome



You can watch this video on YouTube at the button below.

WATCH HERE



## FAMILY SUPPORT

### PWSA | USA Hope in Action: A Lifeline for Families in Crisis



Managing daily life with Prader-Willi syndrome is challenging, and when crisis strikes, PWSA | USA's medical and family support services are **always** here as a lifeline. Our expert team offers compassionate and educated guidance and resources when families need it most.



In May 2024, Gracie turned to PWSA | USA when her daughter Angel (11) experienced a medical emergency. With immediate help from our Family Support team, Gracie felt reassured knowing she wasn't alone. Ultimately, the guidance given to the ER doctors

by Senior Family Support Counselor Kim Tula helped save Angel's life.

Read the full story at the button below of how Gracie and Angel were supported in their moment of need—and learn how the [Angel Drive](#) helps families like theirs every day.

[READ HERE](#)

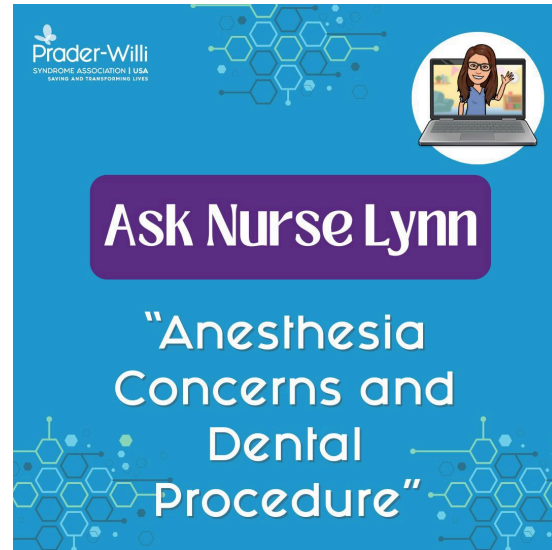
[WATCH THIS 'HOPE IN ACTION' VIDEO](#)

PWSA | USA's 24-Hour Emergency Crisis Line: 941-312-0400

Ask Nurse Lynn

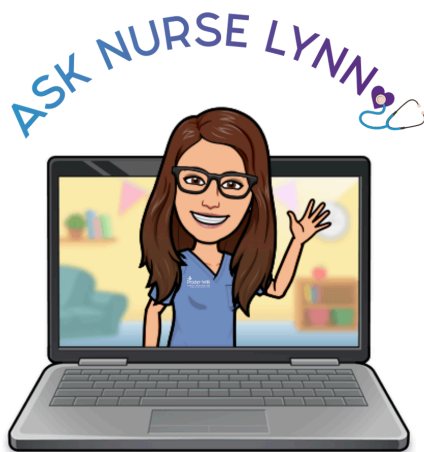
**Question** (*Female, 38 years old, Deletion subtype*):

*"Our daughter has significant dental issues and needs to have multiple procedures. The dentist has recommended that we tackle the issues all at once in a hospital setting with anesthesia. I am immediately concerned by all the possible complications but also recognize the need to try and save some of her teeth. We were unaware of the deterioration of her dental health until we recently had her braces removed and were able to visualize the extent of the enamel erosion. Is there a consensus among the health experts as to the safest way to manage major dental procedures?"*



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



When: **Tuesday, November 19, 2024**  
| **5 pm PST / 8 pm EST**

This live webinar, facilitated by Lisa Graziano, M.A. LMFT, will help your babysitter, respite worker, and even relatives better understand how to care for your child or adult more safely, giving YOU greater opportunity to enjoy date nights, self-care moments, and even weekends away! The webinar underscores the need to follow parents care exactly and offers strategies to provide food security, decrease arguing, and increase cooperation. Register for this webinar

using the button below.

[REGISTER HERE](#)



PWS Connect

Watch the recording of our October Family Support Webinar, **Support PWS Research and Create Community** with Maria Picone and Chris DeFelice, at the button below.

[CLICK HERE TO WATCH](#)

## Journaling and Story Sharing

When: **Friday, November 22, 2024** | **10 am PST / 1 pm EST**

Journaling can help develop understanding, acceptance, growth, and healing in your life. Journaling in a group can magnify this experience while also helping you make connections, build your community, and find comfort in the sharing of experiences.

For National Family Caregiver Month, we would like to offer you an opportunity to meet with other PWS caregivers in an intimate journaling and story sharing experience. In this workshop, Anne Fricke, PWSA | USA Communications Coordinator, writer, and PWS mom, will briefly cover some journaling tips, provide a collective prompt and writing session, with time for participants to share. The intention is to create a space for caregivers to reflect on their experiences and to discover the ways they succeed or the areas of needed improvement while also forming connections and deepening relationships with other caregivers. Space is limited so register soon by sending an email to [africke@pwsausa.org](mailto:africke@pwsausa.org)!

**Journaling and Story Sharing for Caregivers**

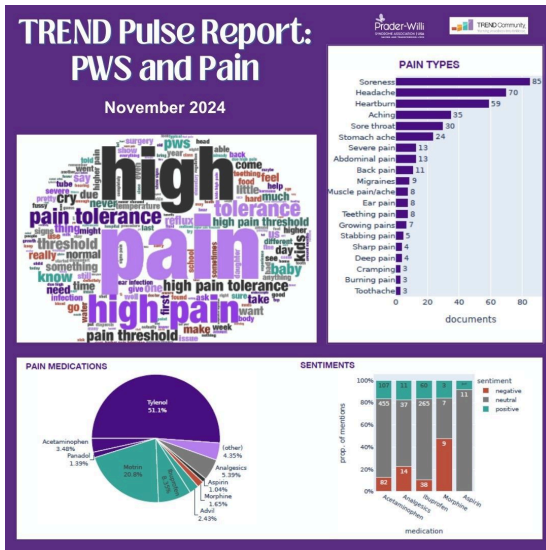
Friday, Nov. 22  
10 am PST / 1 pm EST  
On Zoom

Prader-Willi  
SYNDROME ASSOCIATION | USA  
SAVING AND TRANSFORMING LIVES

Space is limited so sign up soon!  
email [africke@pwsausa.org](mailto:africke@pwsausa.org) to reserve a spot

# RESEARCH

## TREND Releases New Report on Pain



We are excited to share the next PWS Pulse Report that focuses on pain. TREND looked at the most common types of pain and the affected body parts. TREND also analyzed the types of pain medications discussed, as well as the associated sentiments. Finally, TREND explored the experience of reduced pain sensitivity in individuals with PWS. TREND Community is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights. PWSA | USA partnered with TREND

Community to help further PWS research through conversations. To learn more about TREND and read the latest report, please click the button below.

[READ HERE](#)

## Harmony Announces New Trial Site for TEMPO Trial

Harmony Biosciences has announced an additional clinical trial site for its TEMPO PWS study in Sacramento, CA at the Center of Excellence in Diabetes and Endocrinology.

Harmony Biosciences' TEMPO study is a global Phase 3 trial investigating pitolisant as a potential treatment for excessive daytime sleepiness (EDS) in individuals age 6 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 TEMPO trial site locations and learn more by clicking the button below.



[LEARN MORE](#)

## Participate in a Virtual Hyperphagia Study

We're excited to announce a new opportunity for individuals age 10 and older with Prader-Willi syndrome to participate in a study aimed at measuring hunger—and we need your help! This simple, semi-structured Zoom interview allows people with PWS to share their experience with hunger and its impact on their lives, providing valuable information, which will present to the FDA. Participation is easy: parents or caregivers simply click the button below, complete a brief questionnaire, and the individual with PWS fills out a quick assent form. Then, a trained interviewer will schedule a 10–15 minute meeting with the participant, using clear, standardized prompts to ensure understanding. With your help, we hope to reach 150 participants so the FDA can use this data to support effective treatments for hunger in people with PWS. Please consider sharing this opportunity with your networks to help us reach families everywhere!

## Virtual Study on Hyperphagia



Contact:  
elizabeth.roof@vanderbilt.edu  
615-343-3330

[CLICK HERE TO PARTICIPATE](#)

[STUDY FLYER](#)

## Calls for Abstracts for 2025 International PWS Conference

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



### Call for Abstracts

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:  
December Webinar Announced**



*Upcoming*  
**ECHO 4 PWS Webinar:**  
**Orthopedics and PWS**  
with Harold van Bosse, MD

PWSA | USA is hosting an upcoming **ECHO 4 PWS** webinar.

**Date: Tuesday, December 17, 2024 at 2 pm PST /  
5 pm EST**

Speaker: Harold van Bosse, MD

Topic: Orthopedics and PWS

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](#)



## ECHO 4 PWS Webinar: *Psychiatry*

Recording  
Available



WATCH HERE



## ECHO 4 PWS Webinar: *Cardiac Concerns*

Recording  
Available



WATCH HERE

## PWSA | USA ANNOUNCEMENTS

### PWSA | USA Resource Spotlight

Last year, we shared a unique gift guide tailored for individuals with PWS, and with the holidays quickly approaching, we're resurfacing it to help make this season's shopping easier and more meaningful. Instead of age-based categories, this guide offers gift ideas organized by sensory levels, making it easier to find items that truly match your loved one's needs. With links to special shopping resources like Fat Brain Toys and Enabling Devices, you'll find options to support individual growth and enjoyment at every stage.



Read the full guide below to get started on your holiday list!

[LEARN MORE 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

## November 2024 Special Edition Pulse

[www.pwsausa.org](http://www.pwsausa.org) | 941.312.0400

Donate



### *Caring for the Caregiver*



November is **National Family Caregiver Month**. We want to remind parents and caregivers that you are doing an amazing job! We know how challenging it can be at times to care for someone with PWS. Please remember that PWSA | USA is here to support you and your family. This special edition Pulse newsletter is dedicated to you, the caregiver. Here you will find links to resources, new and old, that can help you navigate being a caregiver for someone with PWS, while also considering and caring for your own needs.

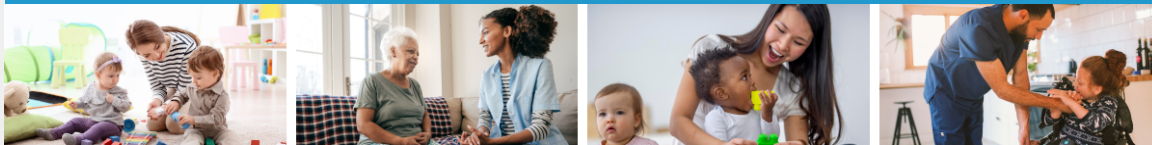
Before we get into the resources we offer, we'd like to mention **Employee Assistance Programs (EAP)** frequently offered by employers as a service to those who work outside the home. According to the [U.S. Office of Personnel Management](#), "An Employee Assistance Program (EAP) is a voluntary, work-based program that offers free and confidential assessments, short-term counseling, referrals, and follow-up services to employees who have personal and/or work-related problems. EAPs address a broad and complex body of issues affecting mental and emotional well-being, such as alcohol and other substance abuse, stress, grief, family problems, and psychological disorders." If



you or your spouse work outside the home, please be sure to check with your employer to learn more about the EAP program that is offered.

***"If your compassion does not include yourself, it is incomplete."***  
**- Jack Kornfield**

## Respite Workers and Babysitters



Sometimes we know exactly what kind of help we need, and that involves having someone else care for our loved one with PWS. This is not always an easily accomplished task. We may not have reliable family members living near us, or friends with the time and space to help supervise our loved one while we take some much-needed respite. Thankfully, there are programs to help families find respite workers and care providers. These programs vary from state-to-state, so you'll need to learn the programs available to you. A good place to start is with your government-funded services office, local university, or a potentially helpful site, [National Respite Locator Service](#).

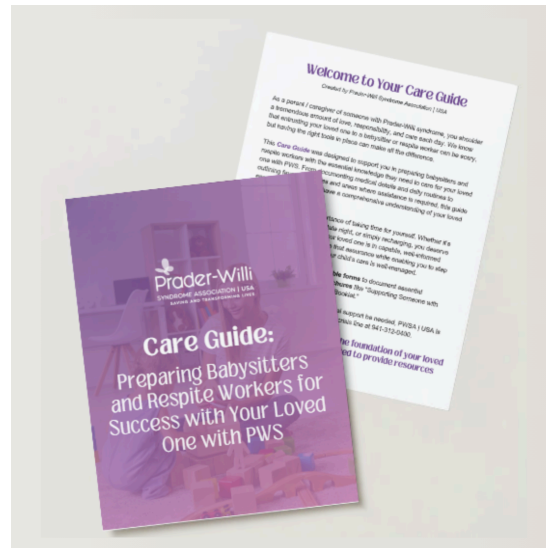
Finding someone trustworthy to care for our loved one is only part of the challenge. We also have to ensure they are well-versed in the challenges of PWS and the specific needs of our loved ones. Where to begin and how to successfully impart the necessary information may seem like immovable roadblocks on the path to finding proper help. While this Pulse newsletter may not be able to list all the respite service programs in every state, we can provide easy and accessible information to those respite workers to help ease your burden.

## Care Guide for Babysitters and Respite Workers

Check out our downloadable information packet for babysitters and respite workers. This packet helps you easily create an informative and potentially life-saving folder designed for the specific needs of your loved one with PWS. Thank you to Julie Casey, PWSA | USA volunteer and mom to Ryan (living with PWS) for creating this resource and letting us share it with the PWS community!

*"Time alone with your partner is so important. It helps make sure you stay connected to each other and also gives you a break from caring for your child. I*

*held off on respite for a long time, and didn't utilize the service until my son was a teen. I wish I had done it sooner because it's so nice to have regular date nights with my husband; we can actually have uninterrupted conversations! One reason I waited so long was because I felt uncomfortable leaving Ryan with other people, so to help me feel better about that and to make sure his caregivers are prepared, I put together a packet of information. One of my personal passions now is raising awareness for PWS, so the packet also serves that purpose as the contents help educate the providers about PWS, and it gives me peace of mind knowing the right information is there in the event of an emergency." - Julie Casey*



**CARE GUIDE WITH RESOURCE DOCUMENTS**

**CARE GUIDE WITH DOWNLOADABLE LINKS**

## Babysitter and Care Provider Training



Facilitated by Lisa Graziano, M.A. LMFT, and mom to Cameron (living with PWS), this training will help your babysitter, respite worker, and even relatives better understand how to care for your child or adult more safely, giving YOU greater opportunity to enjoy date nights, self-care moments, and even weekends away! The webinar underscores the need to follow parents care exactly and offers strategies to provide food security, decrease arguing, and increase cooperation. Click the button below to watch the webinar and share it with your care providers.

WATCH HERE

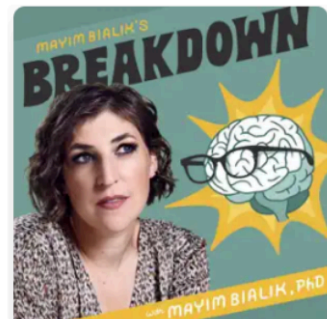
## Self-Care for the Caregiver

### Self-Care App Suggestions from Staff and Volunteers

Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. If we neglect to take care of ourselves, we may likely find that it is more challenging to care for our loved ones. When our needs are taken care of, the person we care for will benefit, too. Recognizing that we need to take care of ourselves, and actually doing that, are not always synonymous. In an effort to inspire you all to care for yourselves, and make it a little easier, we asked our staff and volunteers, **"What is your favorite self-care app?"** You'll find their picks below. Please note that clicking on the photo will take you to the app websites.

"Mayim Bialik's Breakdown. I love podcasts and hers is a mix of humor, education, and science."

- Stacy Ward, CEO of PWSA | USA



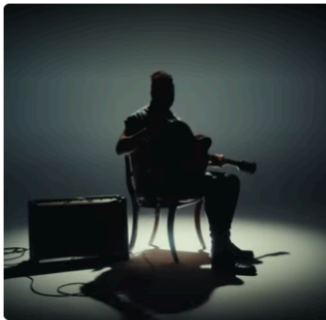
"For self-care I listen to our podcast. I also like the CALM meditation app."

- Melanie McDonald, PWSA | USA's Director of Development, mom to Josephine (living with PWS)

This app focuses on sleep, stress and anxiety, and mindfulness.

"I like Insight Timer. It has guided meditations plus sound baths, music, yoga and you can track lots of things including naps."

- Emily Felt, PWSA | USA volunteer and mom to Olivia (living with PWS)



"I like to listen to music. That's what I do to remain calm. This is a new favorite in our house. It has become an anthem."

Hard Fought Hallelujah by Brandon Lake

- Kristi Rickenbach, PWSA | USA's Family Support Coordinator, mom to Justice (living with PWS)

"I recommend the Peloton app (paid subscription) for guided workouts that fit any schedule and Medito (free) for mindfulness and stress relief. Both offer valuable tools to help recharge and refocus, essential for anyone caring for loved ones!"

- Carrie Ilijevich, PWSA | USA's Director of Marketing & Communications

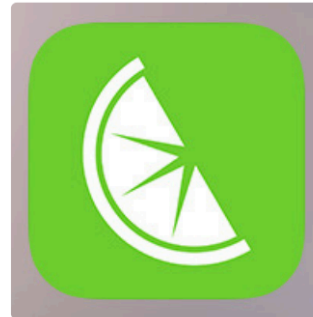


"Kindle App to read when I find a quiet moment and music to squash the loud thoughts when they get too much."

- Kristen Starkey, PWSA | USA's Accounting Clerk

“Mealime helps figure out what’s for dinner - something I love of doing. They have a variety of recipes and even help make the shopping list.”

- Anne Fricke, PWSA | USA’s Marketing and Communications Coordinator, mom to Freya (living with PWS)



## PWS United Episode on Self-Care for Caregivers

PWSA | USA's communication team, Carrie and Anne, spoke with PWS mom, Emily Felt, about self-care for caregivers. They talked about what caregiver burnout may look like, various ways to practice meditative activities and why, the importance of self-advocacy and external support, what gratitude does for perspective and mental health, and how and why to keep showing up for yourself. Whether your self-care routine is a walk in the forest, yoga stretches in the morning, a campfire with friends, or all of the above, we hope this conversation helps you better understand the need for self-care as a caregiver, ways to bring more of it into your life, and how to truly show up for yourself.

The podcast cover has a purple background. At the top, it says "PWS United Podcast" and "SELF-CARE, SELF-ADVOCACY, &amp; GRATITUDE" in white. Below that is "PODCAST EPISODE #16". On the left is the PWS United logo, which includes a stylized blue and purple flower with headphones. On the right is a photo of two women, one of whom is Emily Felt. Below the photo, it says "With Guest: Emily Felt, PWSA | USA Volunteer, Mom to Olivia". At the bottom, there are logos for the Prader-Willi Syndrome Association | USA and a "PODCAST" icon with a microphone.

[LISTEN HERE](#)

## Blogs for Caregivers

PWSA | USA offers a growing list of blog articles focused on caregiver support. Below is a curated list of some of those articles. We hope you take a moment to read through these blogs and find some ways to help support yourself as a caregiver. Click on the button to visit our Blog page and see what other articles we offer. From blogs on how some families navigate PWS in adulthood to holiday preparation and gift guides, to advocacy initiatives in D.C. and research



opportunities for the community, you'll find a variety of helpful and informative articles on the many aspects of caregiving for someone with PWS.

[Self-Care for Caregivers](#)

[Simple Tools for Managing Stress](#)

[Exercise, Movement, and Mental Health](#)

[Meditation, Mindfulness, and Self-Care](#)

[Simple Self-Care](#)

[Journaling as Therapy](#)

PWSA | USA's BLOG

## National Adoption Month

November is also National Adoption Month, a time to draw awareness and support for the caregivers who provide homes, open arms, and unconditional love to children in need of a family. We are honored to share the stories of two families who have adopted a loved one with PWS. Thank you for telling your story. And for all the adoptive families in our community, the families who chose to open their homes and their hearts to an individual with PWS, we are truly grateful for you. You chose to be here, and we salute you for it!

### An Adoption Story

Jordan Zak, mom to Sawyer (living with PWS), graciously shared her family's journey to adoption. After the tragic loss of their son, Jordan and her husband found their way to adoption for the first time. They have been building their support system with other PWS families, recognize their challenges, appreciate

how happy of a child Sawyer is, and have since grown their family. To read this beautiful story of Jordan, Sawyer, and their growing family, please click on the button below.



[READ HERE](#)

**Adoption Story on PWS United Podcast**

PWS United Podcast

**NATIONAL ADOPTION MONTH, ADOPTING A LOVED ONE WITH PWS**

PODCAST EPISODE #18

With Guest:



**Rachel Aazzerah**

Mom to Michael (6) with Prader-Willi Syndrome



Prader-Willi Syndrome Association | USA

PODCAST

With a focus on National Adoption Month, we have a lovely PWS United podcast episode with guest Rachel Aazzerah, the mom of Michael, a 6-year-old with PWS. She speaks with Stacy about her family's experience in adopting Michael as a baby, what open adoption looks like, and offers advice and suggestions for how families can look into adoption for themselves. This conversation steers around to how people can support adoption causes - like donating to local foster care closets, being a respite home for infants, and even donating airline miles for things like

medical trips. Rachel and Stacy also discuss the challenges of adoption, like the emotional roller coaster and having to invite social workers into your home, how and where to find your people for support, and how Rachel knew Michael was her baby the first time she held him.

**LISTEN HERE**

## Help Us Continue to Help PWS Caregivers with Giving Tuesday

Giving Tuesday is just around the corner—mark your calendars for December 3, 2024! This global day of giving is your chance to make a life-changing impact for families affected by Prader-Willi syndrome through PWSA | USA's Angel Drive campaign. This Giving Tuesday, every dollar you donate to PWSA | USA will be matched dollar for dollar—up to \$25,000! That means your gift goes twice as far in helping us provide critical support services, advocacy, and resources that families count on every day.



### Give Twice the Good

when you donate to **PWSA | USA** on Tuesday, December 3, 2024!





When you donate, you will also be entered into a drawing to win one of four exciting gifts!

- An Apple Watch
- A \$300 Amazon gift card
- Customizable PWS Nike shoes
- A PWSA swag bag

Click the button below to learn more about doubling your impact for Giving Tuesday and how you can participate via social media to show your support for PWSA | USA.

[LEARN MORE HERE](#)

[FACEBOOK EVENT](#)



[DONATE HERE](#)



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[Prader-Willi Syndrome Association | USA](#)

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