

# PWSA | USA Bi-Weekly Pulse: January 5, 2024

Enhancing the Quality of Life and Empowering Those Affected by PWS



**Vol. 90**

January 5, 2024

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

## Looking Ahead to an Exciting New Year



Happy New Year to our PWS community! Click the button below to explore our reflections on the season, the rejuvenating power of rest, and uncover some of our exciting plans for 2024. Throughout January, we will share a blog series on mental wellness (read the first one by scrolling below), and get ready to join us in interactive Facebook Live events – your key to newfound self-care practices!

Plus, your insights matter! Complete our [2023 PWSA | USA Communications Feedback Survey](#) to help us tailor effective communication for your needs.

[READ MORE HERE](#)

---

**Journaling as Therapy**



Discover the transformative power of journaling in navigating the complexities of parenting a child with Prader-Willi syndrome. In the whirlwind of medical information, therapies, and emotional challenges, the article at the button below explores how journaling becomes a crucial tool for processing emotions, managing stress, and finding resilience.

From anxiety to depression, grief to stress management, the benefits of journaling are explored, providing a roadmap to emotional well-being amidst the demanding journey of caring for a child with PWS. Learn effective journaling techniques, create a space for self-reflection, and embrace the lessons that lead to growth and understanding in this insightful guide.

[READ MORE HERE](#)

## Join Us for Two Mental Wellness Facebook Live Events



### **Journal Therapy**

Wednesday, January 17, 2024 | 1:00 p.m. EST

*Facilitated by Anne Fricke, PWS mom, writer, facilitator, and PWSA staff member*

Journaling helps reduce stress and anxiety, manage depression, face fears, worries, and complex emotions, build resilience, find solutions, and lean into gratitude. Join us to learn the what, why, and how to create and nurture your own journaling practice.

[CLICK HERE TO VISIT THE FACEBOOK EVENT PAGE](#)



## Supporting Your Emotional Well-Being

Wednesday, January 24, 2024 | 8:00 p.m. EST

*Facilitated by Emily Felt, PWS mom, Mindfulness and Meditation teacher, and PWSA volunteer*

Learn valuable skills with mindfulness and meditation to help you “feel your feelings” and reroute negative thoughts to a more centered, grateful mindset, helping you to find self-compassion, awareness, and

resilience to face the obstacles on this journey with PWS.

[CLICK HERE TO VISIT THE FACEBOOK EVENT PAGE](#)

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



In the heartwarming journey of Jayda, born on schedule but faced with unexpected challenges, her family discovers resilience, hope, and the power of community. As her health took an uncertain turn, Jayda's parents navigated a complex medical landscape, finding solace and strength through the stories of

others on the PWSA | USA website. With a diagnosis that brought shock and uncertainty, Jayda's family leaned on the support of Kristi Rickenbach and a community that understood their journey intimately.

Through tough initial months and numerous milestones, Jayda's infectious smile became a beacon of joy for her family. Now, at 18 months old, Jayda's strength, coupled with unwavering love and support, paints a picture of hope that transcends the challenges they continue to face.

Read Michele Hampton's (mom to Jayda) **Spotlight on Hope** at the button below.

[READ MORE HERE](#)

## We want to celebrate your loved one with PWS!

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.

There are many challenges with PWS, and much of our focus is towards mitigating the effects of these challenges. So, PWSA | USA has created a space to share the other stories. The wins, the smiles, the milestones. The moments that bring joy and hope, a relaxing of the shoulders, and a momentary reprieve from the struggles of PWS.

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 at the button below. We're looking forward to celebrating with you!

[SHARE YOUR SPOTLIGHT ON HOPE](#)

## EVENTS

Sip, savor, and support PWSA | USA while enjoying the **10th Annual Cint Hurdle Hot Stove Dinner**, with special hosts Clint and Karla Hurdle.

The event will take place Saturday, March 23, 2024, at an exciting NEW location, the [Bradenton Country Club](#) in Bradenton, Florida. The Hot Stove Dinner can be attended in-person or virtually!

**SAVE THE DATE**  
HOT STOVE DINNER 2024  
HOSTED BY | CLINT AND KARLA HURDLE



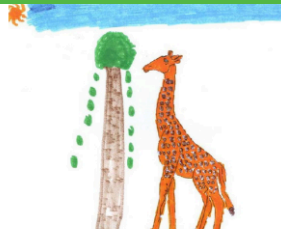
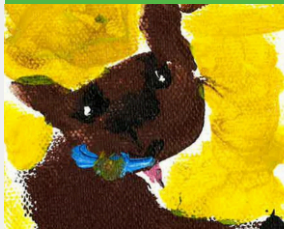
**LIVE & VIRTUAL**  
MARCH | 23<sup>RD</sup> | 2024  
BRADENTON COUNTRY CLUB

More details and registration will be available soon.



## ADVOCACY

**Introducing the Rare Aware Art Share**  
*A Virtual Art Collection to Highlight the Voices of People Living with PWS*



PWSA | USA 2024

## Rare Aware Art Share



We are excited to announce the launch of PWSA | USA's brand new initiative - **The Rare Aware Art Share!** This virtual art show aims to spotlight the voices of individuals with Prader-Willi syndrome. We hope to learn more about each individual, their lives, and their experiences as someone with PWS. Our hope is

that through this art show, our community and beyond can gain a deeper understanding of our loved ones with PWS, while offering them a space to be seen and heard. We plan to take this art show to the world outside of the PWS community, thus expanding the opportunities for support, education, advocacy, and appreciation for those living with PWS.

Click the button below to find more details, including the different artwork submission categories, dates, and where these pieces will shine!

[LEARN MORE HERE](#)

## Don't Forget! PWSA | USA's 2024 D.C. Fly-In Application Goes LIVE Next Week



PWSA | USA's **2nd D.C. Fly-In** will take place May 13-15, 2024, and the event hotel will be YOTEL Washington DC | Capitol Hill Hotel! The D.C. Fly-In application will be available on **Tuesday, January 9, 2024.**

This time around, we look forward to welcoming 100 participants to join together on Capitol Hill. Those selected to attend the Fly-In will be determined on a first-come-first-served basis.

[LEARN MORE HERE](#)

## Rare Disease Week on Capitol Hill 2024 Registration is Now Open!

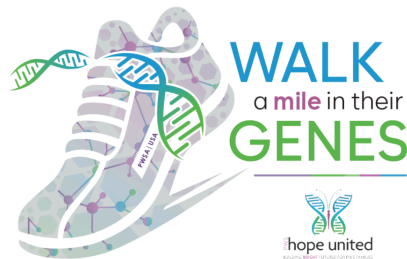
Join several PWS advocates, and other advocates from around the country, for this multi-day event, happening February 25-28, 2024 in Washington, D.C., and hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases). Rare Disease Week brings together rare



disease advocates from across the country to make their voices heard by their Members of Congress. Participants are educated on policy proposals impacting the rare disease community and provided opportunities to advocate for policy changes directly to their Members of Congress. Register to attend Rare Disease Week by clicking the button below. We hope to see you there!

[REGISTER HERE](#)

## Here's How YOU Can Support PWSA | USA's Advocacy Initiatives in 2024



We can continue to make our voices and our stories heard through advocacy and community outreach. On January 16, 2024, YOU can sign up for PWSA | USA's 2nd annual **"Walk a Mile in their Genes"** advocacy campaign. Participants will not only raise awareness about PWS, but they will raise much needed funds to enable PWSA | USA to continue to provide the services our community needs.

This virtual/in-person fitness challenge is open to all ages and fitness levels to promote health and

wellness, while supporting the Prader-Willi syndrome community.

To learn more about this opportunity and how you can participate, we will host a webinar in January. Sign up to attend this webinar at the button below. Thank you for taking action!



## FAMILY SUPPORT

### Exercise and Motivation

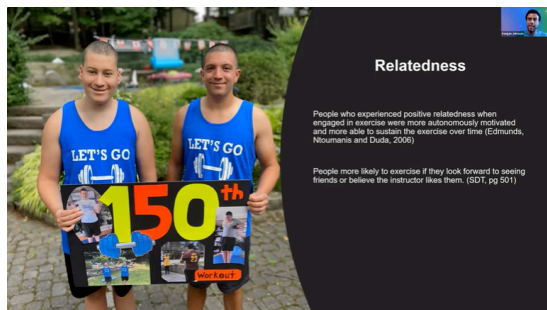
The new year can be a motivating time to implement new practices like exercise. Dante Johnson, an individual living with PWS, along with his Dad, Keegan, and cousin Mikhail, co-founded Let's Go Fitness. Let's Go Fitness is an online fitness community for people with developmental disabilities BY people with developmental disabilities. [Visit the webpage](#) to learn more about their story, how they help motivate and spread fitness education, and create job opportunities for people with developmental disabilities.



Click the image to watch

Dante and his father spoke at the 2023 PWSA | USA United in Hope Convention. Dante led the audience in a morning workout to get everyone moving and show a bit of what he does with Let's Go Fitness. Feel free to watch the opening remarks. If you're interested in getting right to Dante and Keegan, scroll to minute 12.

In this video, *Exercise and Motivation*, Keegan shares the process and inspiration for Let's Go Fitness. He provides tips for creating and nurturing autonomous motivation in our loved ones. His suggested guide points for success are to start small, build habits, develop a growth mindset, consider diet, and cultivate meaning. Watch the video recording from PWSA's 2021 Virtual Convention to learn about Dante's inspiring journey that led to reduced



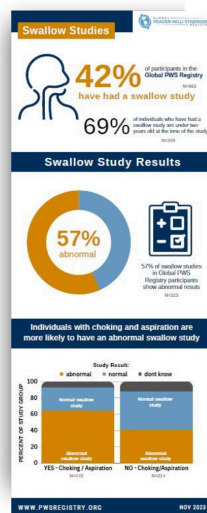


anxiety, an increase in energy levels, a confidence boost, a 50 lb. weight loss, and the founding of Let's Go Fitness.



## RESEARCH

### Swallow Studies In Individuals with PWS: Data From the Global PWS Registry



The Global PWS Registry collected patient information to create this infographic, which delves into an often overlooked aspect of Prader-Willi syndrome – dysphagia, difficulty swallowing. The data sheds light on the prevalence of dysphagia, the importance of videofluoroscopic swallow studies (VFSS), and the potential medical implications. With 42% of registry participants undergoing swallow studies, the findings emphasize the risks associated with dysphagia, including silent aspiration events. The data advocates for early intervention,

showcasing that 69% of those studied had VFSS before age two. The infographic further highlights the correlation between abnormal swallow studies and increased risks of choking or aspiration events.

The Global PWS Registry shared, *"Common treatment options for swallowing difficulties include swallowing therapy with a speech and language therapist, using special spoons, using a feeding tube, and changes to diet.*

*Recommendations during mealtime may include, but are not limited to, alternating small bites with sips of liquids, eating up right during meals, staying upright for a period of time after meals, and finishing meals with a drink."*

For more details, visit <https://pwsregistry.org/> or contact [info@pwsregistry.org](mailto:info@pwsregistry.org).

[DOWNLOAD THE INFOGRAPHIC HERE](#)

PWSA | USA ANNOUNCEMENTS

Thank You for Supporting the 2023 Angel Drive!



GIVE THE  
*Gift* OF HOPE  
2023 ANGEL DRIVE



Our 2023 Angel Drive Campaign has come to an end, and on behalf of our staff, Board of Directors, and volunteers, we want to extend a heartfelt **THANK YOU** for your donation! Your contributions will support several Advocacy, Family Support, and Research initiatives in 2024 that will greatly benefit our PWS families.

Know that through these gifts, you have made a true impact on

our community!

Warm regards,

*Stacy Ward*

Stacy Ward, MS  
PWSA | USA CEO

# Are You or is Someone You Know a CPA Looking to Get Involved?

PWSA | USA is in search of a **volunteer Treasurer**. We know many of you want to make a difference in the lives of our PWS community and we have the perfect opportunity if you, or one of your family or friends, are a CPA.

Click the image below to find the full description and needs that come with this volunteer role. Thank you for your consideration!

LOOKING FOR A WAY TO GET INVOLVED?

**PWSA | USA IS IN SEARCH OF A VOLUNTEER TREASURER**



## ABOUT THE POSITION >>>>

The treasurer is an officer of **PWSA | USA**, elected by the Board of Directors to serve a one-year term, with no limit on the number of terms, serving as an ex officio (voting) member of the Board.



### MEETINGS

- Board of Directors meetings
  - Five (5) virtual meetings per year
  - One (1) in-person meeting per year
- Monthly meetings with the CEO
- Committee meetings



### COMMITTEES

- Serves as Chair of the Finance Committee
  - Six (6) meetings per year
- Serves on the Executive Committee
  - Two (2) meetings per month



### QUALIFICATIONS

- Knowledge of basic accounting and bookkeeping procedures
- Preferably a Certified Public Accountant (CPA)
- Knowledge of nonprofit accounting
- *Not Required:* Experience with Blackbaud's Financial Edge accounting system



### RESPONSIBILITIES

- **Work closely with the CEO and accounting firm** to ensure:
  - Good financial planning
  - Decision-making
  - Sound fiscal policies
- Ensure that appropriate **internal controls, financial management policies and financial records are maintained**
- **Present prepared financial reports** to the board and answers questions as needed
- Work with the accounting firm to continue to **refine the financial procedures and reporting** utilizing Blackbaud's Financial Edge
- Review PWSA | USA's **annual budget**
- Participate in the **annual audit and Form 990 process**

If you are interested in this position or would like further information, email [Mrupnow@pwsausa.org](mailto:Mrupnow@pwsausa.org).

**LEARN MORE HERE**

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

**Donate**

they so desperately need. Thank  
you!



[Privacy Policy](#) | [Unsubscribe](#)

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

# PWSA | USA Bi-Weekly Pulse: January 19, 2024

Enhancing the Quality of Life and Empowering Those Affected by PWS

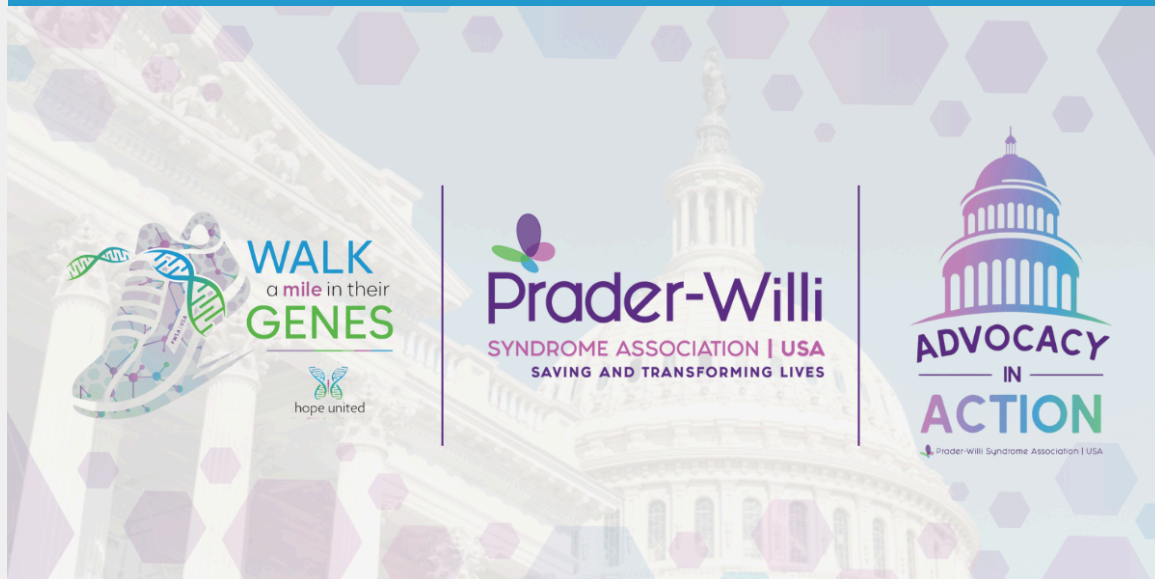


**Vol. 91**

January 19, 2024

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

Looking to Get More Involved with PWS Advocacy?



We are excited to announce the launch of PWSA | USA's 2nd annual **Walk a Mile in their Genes** advocacy campaign! By signing up as a Walk a Mile participant, you will not only spread awareness about PWS, but help raise much needed funds to enable PWSA | USA and our volunteers to effectively advocate for the unmet needs of our loved ones with PWS.

This virtual/in-person fitness challenge is open to all ages and fitness levels to promote health and wellness, while supporting the Prader-Willi syndrome community. Click the button below to get involved and learn more!

**CLICK HERE TO GET INVOLVED!**



**Want to get involved but don't know where to start?**

Watch PWSA | USA's Walk a Mile in their Genes informational session, where our staff explain how to navigate the website, create a login, and build your own page. If you have additional questions, please reach out to us at [hopeunited@pwsausa.org](mailto:hopeunited@pwsausa.org).

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



In the journey of navigating Prader-Willi syndrome (PWS), the search for understanding and connection can be isolating. Yet, through chance encounters in physical therapy, online outreach, and local connections, Silas and his family found a supportive community with other PWS families. These bonds, forged through shared experiences and mutual support, prove invaluable in celebrating milestones and navigating the challenges of PWS.

Read Jennifer Lloyd's (mom to Silas) **Spotlight on Hope** at the button below.

[READ MORE HERE](#)

[SHARE YOUR SPOTLIGHT ON HOPE](#)

## EVENTS

### 2024 Clint Hurdle Hot Stove Dinner Tickets Now Available for Purchase!

Join hosts Clint and Karla Hurdle on Saturday, March 23, 2024, on the beautiful grounds of Bradenton Country Club in Bradenton, FL, and virtually from anywhere. Together, we can create a brighter future through your continued support!

Highlights of the evening:

- Inspirational stories of what Prader-Willi Syndrome Association | USA does every day!
- Silent Auction: Bid on exclusive items and experiences, with all proceeds going towards PWS research and support programs
- Gourmet Dinner: Enjoy a delectable meal while mingling with fellow supporters and advocates
- Live Entertainment
- Raffle
- Coconut Drop | Golf Ball Drop!



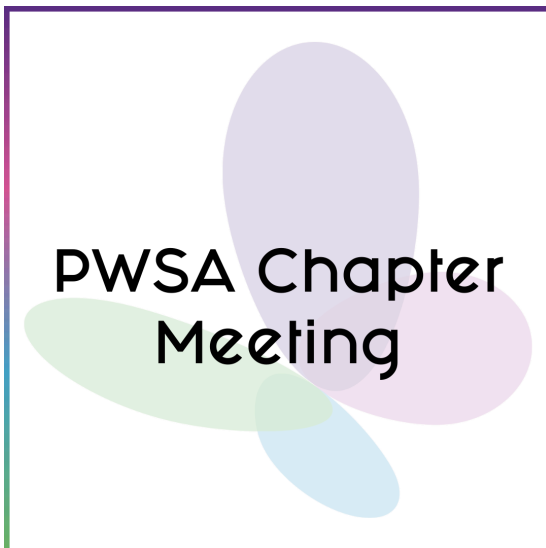
**10th Annual Hot Stove Dinner**

**Tickets on Sale Now**

**Click Link Below!**

To purchase tickets, text the keyword **Hotstove2024** to 76278 or go to [hotstove2024.givesmart.com](https://hotstove2024.givesmart.com)

**PURCHASE HOT STOVE DINNER TICKETS HERE**



### **Calling all Chapter Leaders!**

On Wednesday, January 26, 2024, at 8:00 p.m. EST, PWSA | USA will host its first Chapter Leader meeting of 2024! With all the excitement around our state qualifier initiative and the PWS therapy pipeline, it's an exciting time to engage our PWS community and we look forward to working with our Chapters this coming year. In addition to outlining our plans for 2024, we will host field liaisons from [Acadia Pharmaceuticals](#), who will discuss their Phase 3 COMPASS PWS study of carbetocin nasal spray (ACP-101) in the United States.

COMPASS PWS is a 12-week study evaluating the efficacy and safety of carbetocin nasal spray for hyperphagia in approximately 170 children and adults aged 5 to 30 years with Prader-Willi syndrome. We can't wait to see all of you! Register in advance at the button below. Please be advised, this meeting is for PWSA Chapter leaders only.

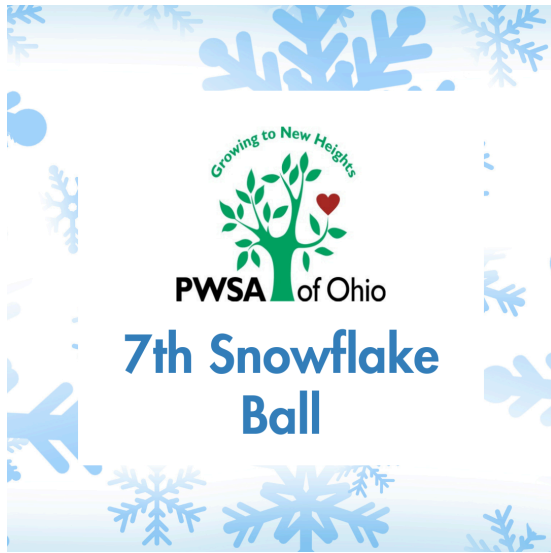
**REGISTER IN ADVANCE HERE**

### **Attention Ohio Residents!**

It's that time again to embrace the spirit of unity and celebration at the **7th Snowflake Ball** hosted by PWSA of Ohio. Enjoy an enchanting evening on Saturday, February 3, 2024, from 4:00 pm to 8:00 pm at Williams on the Lake in Medina, Ohio.

Indulge in a delightful PWS-friendly meal and let the magic unfold with a dazzling PWS Red Carpet Walk. The night continues with the joy of dancing and creating lasting memories. Be sure to RSVP by January 22, 2024. Learn more by clicking the buttons below.





[REGISTER HERE](#)

[RED CARPET FORM](#)



ADVOCACY



2024 D.C. Fly-In  
**Important  
Announcement**



**We have reached our capacity for 2024 D.C. Fly-In applications.** Anyone who submits an application going forward will be placed on a waitlist. We are thrilled to see the overwhelming interest in this event and look forward to taking

our advocacy efforts to Washington, D.C. in May! Attendee selections have been made on a first-come, first-served basis, and notifications will be sent to attendees in the next couple of weeks. Thank you all for your incredible enthusiasm and understanding!

[LEARN MORE ABOUT THE D.C. FLY-IN HERE](#)

## Spotlight on Advocacy: PWS Parent Advocates for Wisconsin Legislation to Lower Treatment, Therapy Costs for Individuals Living with Rare Diseases



On Wednesday, January 10, 2024, Katie Moureau, mom to a 9-year-old boy with PWS, was able to advocate in support of [Wisconsin State Assembly Bill 687](#) - Authorization of Value-Based Arrangements for Medicaid Programs for all rare diseases.

Assembly Bill 687 creates a platform for the Department of Health Services to enter into value-based arrangements. Value-based arrangements seek to mitigate the high costs of certain treatments and therapies, a potentially critical step

towards helping our loved ones with PWS.

Thank you, Katie, for your dedication and advocacy! Read more about her work and Assembly Bill 687 at the button below.

[LEARN MORE HERE](#)

## Join Us for Rare Disease Week on Capitol Hill 2024!

Join several PWS advocates, and other advocates from around the country, for this multi-day event, happening February 25-28, 2024, in Washington, D.C., and hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases).



Rare Disease Week brings together rare disease advocates from across the country to make their voices heard by their members of Congress. Participants are educated on policy proposals impacting the rare disease community and provided opportunities to advocate for policy changes directly to their members of Congress. Register to attend Rare Disease Week by clicking the button below. We hope to see you there!

[REGISTER HERE](#)



## FAMILY SUPPORT

### Mindfulness, Meditation, and Self-Care



Throughout January, PWSA | USA is sharing information to help our community learn and incorporate mental wellness skills into their routines through various blog posts on our website and Facebook Live events. We invite you to join us for our next Facebook Live on Wednesday, January 24th at 8:00 p.m. EST, which will focus on Supporting Your Emotional Well-Being.

Learn valuable skills with mindfulness and meditation to help you “feel your feelings” and reroute negative thoughts to a more centered, grateful mindset, helping you to find self-compassion, awareness, and resilience to face the obstacles on this journey with PWS. Our facilitator will be PWSA | USA volunteer, mom and

mindfulness/meditation teacher Emily Felt. Click the button below to read tips from Emily ahead of next week's event.

[READ MORE HERE](#)

## Does Your Loved One with PWS have a Dual Diagnosis of Autism?



If so, here is an opportunity to lend your voice to the growing knowledge of how individuals with autism are affected by co-occurring conditions, along with their needs for research and services.

The Interagency Autism Coordinating Committee, a federal panel, is interested in learning more about people with autism and co-occurring conditions. They hope to better understand the challenges and needs of these individuals as a guide for “research, services, and policy needs that may be helpful to

consider in addressing issues related to these conditions.” For more information, please visit the link at the button below.

[LEARN MORE HERE](#)



## RESEARCH

**Neuren Pharmaceuticals Announces Phase 2 PWS Study Update**

The logo for Neuren Pharmaceuticals, featuring the word "neuren" in a white, lowercase, sans-serif font inside a dark blue rounded rectangle.

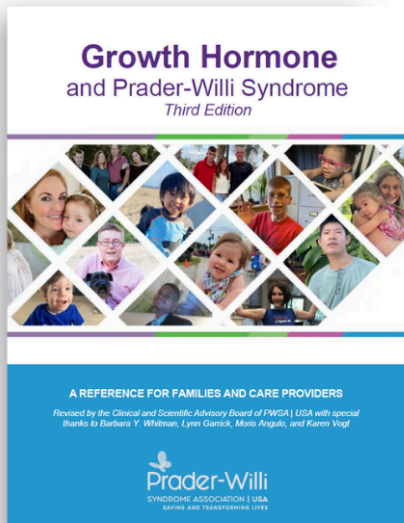
pharmaceuticals

[Neuren Pharmaceuticals](#) is pleased to announce their **second** site participating in their Phase 2, **Open Label**, PWS Study (Neu-2591-PWS-001) is now open for screening!

Important information regarding this exciting milestone:

- Two sites are now open to enrollment! Rare Disease Research (RDR), located in Atlanta, GA, and Uncommon Cures, located in Chevy Chase, MD (8 miles outside of Washington, D.C.) are now welcoming children with PWS and their families to their clinic for screening into this trial.
- A third site in Philadelphia, PA is expected to be open for screening before the end of this month.
- The duration of active treatment in this study is 13 weeks. In a preclinical study in animals, physiological and behavioral symptoms were normalized within six weeks of dosing.
- Enrollment currently continues in children diagnosed with PWS who are in the older age group (ages 8 through 12).
- After safety and tolerability data in the older group is independently reviewed (which will commence following the treatment of 3 patients in the older age group), it will be announced when children in the younger group (ages 4 through 7) can start to be screened.
- As this is an open-label study, all children who participate on this trial will receive the study drug (NNZ-2591).
- All travel and lodging for in-clinic visits (5 in total) can be fully reimbursed for patients and their families.
- If NNZ-2591 development moves into Phase 3, all children who participate in this Phase 2 study may be eligible for an Open-label Extension study that would be opened in parallel to the NNZ-2591 Phase 3 trial in PWS.

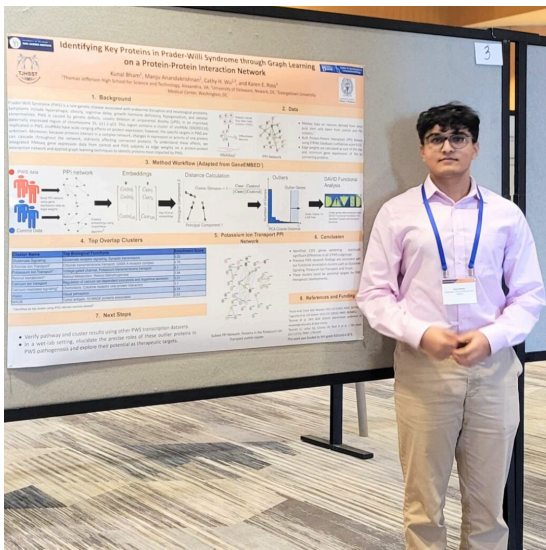
[LEARN MORE ABOUT THE STUDY HERE](#)



PWSA | USA and the Clinical/ Scientific Advisory Board have worked together to publish the Third Edition Growth Hormone Booklet. Download the booklet at the button below.

[CLICK HERE TO DOWNLOAD](#)

## Spotlight on Research: High School Student Kunal Bham Named Top Scholar for PWS Research Project



Virginia high school student Kunal Bham (18) has earned recognition as one of the [Regeneron Science Talent Search \(STS\)](#) top 300 Scholars for his impactful research on Prader-Willi syndrome. Amid fierce competition with over 2,000 applicants, Kunal's project, titled "Discovering Hidden Pathways: A Network-Centric Approach Reveals Novel Pathways Impacted by Prader-Willi Syndrome," was conducted at Georgetown last summer, and delved into uncovering new biomarkers for PWS.

The rigorous application process involved a 20-page research paper, multiple academic recommendations, and 10 essays. Kunal's dedication was rewarded with a \$2,000 prize, and as he advances to the next round, has the potential to receive a \$250,000 award. Congratulations to Kunal for this remarkable achievement in the prestigious Regeneron STS competition!

[VNS 4 PWS Clinical Trial is Now Recruiting](#)

**CLINICAL TRIAL ENROLLING SOON!**

**VNS4PWS**

Does your loved one struggle with disruptive behavior and temper outbursts? You could be eligible!

- THIS TRIAL WILL EVALUATE THE EFFECTIVENESS OF A WEARABLE MEDICAL DEVICE
- SEEKING PARTICIPANTS AGES 10-40
- HISTORY OF TEMPER OUTBURSTS OVER PAST 6 MONTHS



**ONLY 2 IN-PERSON VISITS REQUIRED!**

**VNS4PWS** is a phase 3 clinical trial evaluating the effectiveness of a Vagus Nerve Stimulation (VNS) device for improving disruptive behaviors and temper outbursts for people with PWS.

Eligible participants will wear a VNS device for 4 hours each day and the caregiver will respond daily to a short 1-3 question survey to provide data on the frequency and severity of the day's outbursts. Only two in-person visits are required for the 9-month study.

**WHO CAN PARTICIPATE IN THE TRIAL?**

- People with PWS ages 10-40 and their caregivers
- Have a history of disruptive behaviors over the past 6 months
- Medications have been stable for the past 90 days

Participants who complete the trial will have the option of enrolling in an extension study so they may continue to use the device!

If your loved one, aged 10-40, faces challenges with disruptive behavior and temper outbursts, they could be eligible for this phase 3 trial. The VNS 4 PWS trial aims to assess the effectiveness of a Vagus Nerve Stimulation (VNS) wearable device in managing disruptive behaviors and temper outbursts in individuals with a history of such incidents over the past 6 months.

Participants will wear the VNS device for 4 hours daily, and caregivers will respond to a brief 1-3 question survey each day, providing

valuable data on the frequency and severity of the day's outbursts. Only two in-person visits are required throughout the entire 9-month study duration.

Take this opportunity to contribute to advancing medical research and improving the lives of individuals with PWS. If you have questions or are ready to schedule a screening appointment, reach out to [VNS@fpwr.org](mailto:VNS@fpwr.org).

[DOWNLOAD THE INFORMATION HERE](#)

## PWSA | USA ANNOUNCEMENTS

**Tell us Your PWS Parenting Hacks!**

Ahead of PWSA | USA's January Special Edition Pulse, which will be shared on Friday, January 26th, we are collecting PWS parenting hacks from our PWS community! What are some tips/tricks that you have found work for you, your family, and/or your loved one? Here's an example from one of the moms on our team: Whenever her family goes out to eat, they always put half of her daughter's food in a to-go container to eat later. We also encourage you to share a photo if you can. Thank you for participating!



[CLICK HERE TO SHARE YOUR PARENTING HACK](#)

## Are You or is Someone You Know a CPA Looking to Get Involved?

PWSA | USA is in search of a **volunteer Treasurer**. We know many of you want to make a difference in the lives of our PWS community and we have the perfect opportunity if you, or one of your family or friends, are a CPA.

Click the image below to find the full description and needs that come with this volunteer role. Thank you for your consideration!



LOOKING FOR A WAY TO GET INVOLVED?  
**PWSA | USA IS IN SEARCH OF A VOLUNTEER TREASURER**



**ABOUT THE POSITION >>>>**

The treasurer is an officer of **PWSA | USA**, elected by the Board of Directors to serve a one-year term, with no limit on the number of terms, serving as an ex officio (voting) member of the Board.



**MEETINGS**

- Board of Directors meetings
  - Five (5) virtual meetings per year
  - One (1) in-person meeting per year
- Monthly meetings with the CEO
- Committee meetings



**COMMITTEES**

- Serves as Chair of the Finance Committee
  - Six (6) meetings per year
- Serves on the Executive Committee
  - Two (2) meetings per month



**QUALIFICATIONS**

- Knowledge of basic accounting and bookkeeping procedures
- Preferably a Certified Public Accountant (CPA)
- Knowledge of nonprofit accounting
- *Not Required:* Experience with Blackbaud's Financial Edge accounting system



**RESPONSIBILITIES**

- **Work closely with the CEO and accounting firm** to ensure:
  - Good financial planning
  - Decision-making
  - Sound fiscal policies
- Ensure that appropriate **internal controls, financial management policies and financial records are maintained**
- **Present prepared financial reports** to the board and answers questions as needed
- Work with the accounting firm to continue to **refine the financial procedures and reporting** utilizing Blackbaud's Financial Edge
- Review PWSA | USA's **annual budget**
- Participate in the **annual audit and Form 990 process**

If you are interested in this position or would like further information, email [Mrupnow@pwsausa.org](mailto:Mrupnow@pwsausa.org).

**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 Special Edition Pulse: January 26, 2024

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

Donate



## Mental Wellness



for the Caregiver



For the month of January, we dedicated our blog and two virtual Live events to the topic of mental wellness for parents and caregivers. Our intention was to provide information and education opportunities on mental wellness. We wanted to stress the importance of supporting your mental health, along with providing tips and tools on how you can do so. We at PWSA | USA know what it takes to care for someone with PWS and are here to support you and your loved one. In case you missed our efforts, we've included the blogs and Live recordings below. Please take a moment to review. We hope you learn something valuable for your own mental wellness. Also, be sure to read through to the end of this email to find some of our favorite PWS parenting hacks!



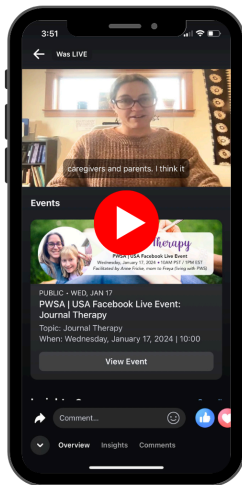
**Mental Wellness Tip: Community helps us avoid isolation. Click on the picture below to read how some families have made valuable connections!**

*"I highly encourage others to reach out to other PWS families, whether it's locally or over social media, and find support! I truly believe this has been a huge factor in my mental health as well as sharing ideas and things with each other that have worked for our littles."*

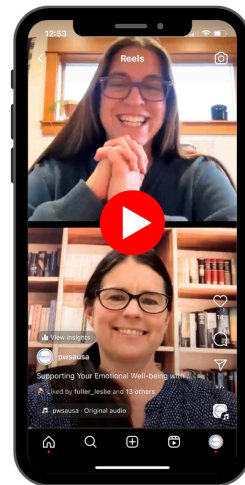


- Jennifer Lloyd, Mom to Silas (living with PWS)

## Virtual Live Events



On January 17th, we offered our first virtual Live of 2024! This event on Facebook Live was a **journal therapy workshop** taught by PWSA | USA staff member and PWS mom, Anne Fricke. She discussed the what, why, and how of creating and nurturing a journaling practice and invited attendees to try a bit of journaling on their own. Click on the image to watch the recorded session.



On January 24th, we hosted an Instagram Live with Emily Felt, PWSA | USA volunteer and PWS mom. Emily spoke on **self-care tools for parents and caregivers**; meditation, reframing our narratives, how to feel our feelings in a way that helps us move through them, the importance of community, being of service, and more. Click the image to watch the recording.

# Journaling As Therapy

Discover the transformative power of journaling in navigating the complexities of parenting a child with Prader-Willi syndrome. In the whirlwind of medical information, therapies, and emotional challenges, the article at the button below explores how journaling becomes a crucial tool for processing emotions, managing stress, and finding resilience.



From anxiety to depression, grief to stress management, the benefits of journaling are explored, providing a roadmap to emotional well-being amidst the demanding journey of caring for a child with PWS. Learn effective journaling techniques, create a space for self-reflection, and embrace the lessons that lead to growth and understanding in this insightful guide.

[READ MORE HERE](#)

## Exercise, Movement, and Mental Wellness

As parents and caregivers, we are no strangers to stress, anxiety, and even bouts of depression. There is growing evidence that these are harmful to our bodies. We also know that moving our bodies has an incredible impact on our mental health and reduces the effects of stress, anxiety, and depression. While in the PWS community we often stress the importance of exercise for our loved ones, we must remember how critical exercise and movement are for our health as well, both physical and mental. If you'd like to learn more about the evidence linking mental wellness to movement, along with the difference between exercise and movement, some ideas to get started, and more resources, please read our blog "Exercise, Movement, and Mental Health."



[READ MORE HERE](#)

## Meditation, Mindfulness, and Self-Care

PWS mom and mindfulness and meditation facilitator, Emily Felt, shared her knowledge and experience with meditation and mindfulness. Both have been valuable tools she has used in her journey raising a daughter with PWS. Science has confirmed what some have known for thousands of years, that meditation reduces stress, promotes calmness, and enhances overall happiness. Mindfulness is closely related to meditation but integrates seamlessly into life. Both can benefit your mental wellness, not only as parents and caregivers of individuals with PWS, but in life in general. Read more about mindfulness, meditation, and Emily's experience with both in her contributed blog, "Meditation, Mindfulness, and Self-Care".



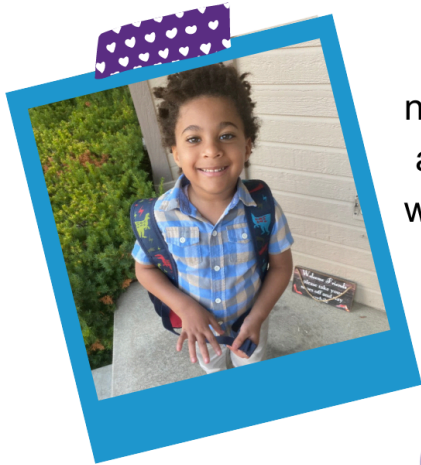
[READ MORE HERE](#)

## PWS Parenting Hacks

We've reached out to the community to share some PWS parenting hacks. Those little tips and tricks of the trade that make navigating the challenges of PWS a little easier. We hope you find something that can be helpful in your life as well. We'd love to hear your PWS parenting hacks! Please click on the button to share yours.

[Share Your PWS Parenting Hacks](#)

---



Sarah (Mom to Khaled, 4): "Buy the no sugar lollipops ahead and in bulk... and give it to the teacher or whoever will be giving away treats on whatever festive day they are having."



Melanie (Mom to Josephine, 5):  
"Out to eat? Water while we wait  
(I tell the waitress no bread in  
advance)."



Emily (Mom to Olivia, 11): "I basically just hug my child as many times a day as possible and try to remember that her life has joy and desire in everything we go through."

Kristi (Mom to Justice, 20):  
“Whenever we are going out for dinner, we always look at the menu first so she knows what to order when it is time.”



Kayla (Mom to Luella, 4 1/2):  
“When I take Luella somewhere, I do my best to find the PERFECT time to tell her our daily plan.”



Elaine (Mom to adult son James): “I use the ‘notes’ section in the iPhone and in it I have my son’s complete medical history, his current medication list, and a link to the GI algorithm on the PWSA | USA website.”







Anne (Mom to Freya, 12): “I know Freya’s ‘fight’ song (Roar by Katy Perry). Sometimes, when she shuts down and can’t (or won’t) respond, I turn on this song and start singing and dancing. It helps pull her out of herself.”



Jen (Mom to JoJo, 7): “We use visual schedules, especially when we’re changing the routine or traveling. It helps calm her mind and cuts down on questions from 1 million to 500K.”



Staishya (Mom to Axel, 2): “When it’s time to do Axel’s nightly growth hormone shot, we find it best to show him and explain what’s to come. While administering the GH, we allow him to use a tablet to help distract himself.”



If you'd like to read more about these hacks and others, or share your own, check out our recent blog post "[PWS Parenting Hacks](#)".

[READ HERE](#)



[Privacy Policy](#) | [Unsubscribe](#)

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