

PWSA | USA Bi-Weekly Pulse: December 1, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 88

December 1, 2023

www.pwsausa.org | 941.312.0400



Thank You for
Giving Twice the Good
This Giving Tuesday!

We are extremely grateful to **YOU**, our PWS community, for supporting PWSA | USA on Giving Tuesday! A special thank you to our generous anonymous donors who matched gifts dollar for dollar up to \$15,000.

Still want to make a year-end gift? There's time! **PWSA | USA's Angel Drive campaign** lasts through **December 31st**. All donations will make

a direct impact on the lives of those living with PWS and their families, and will support Advocacy, Family Support, and Research initiatives in the new year.

DONATE TODAY!

Become a 'Selfless Elf' and Give Hope Rather than Get Gifts

Tell your family and friends that taking action for PWS is at the very top of your holiday wish list. Click the button below to sign up as a **Selfless Elf** and start encouraging donations in lieu of gifts and in honor of your loved ones. It only takes five minutes to create your own Selfless Elf page! All donations made to your Selfless Elf campaign will directly benefit PWSA | USA's 2023 Angel Drive.

Click Here to Become
a Selfless Elf



Need help getting started?

Watch this video to learn how to build your own Selfless Elf page. If you have additional questions, email us at hopeunited@pwsausa.org.



PWSA | USA 2023 SELFLESS ELF PARTICIPANTS

Sujeiri Colon

New Jersey

Angela & Joseph Frazier

Texas

Melanie & Henry McDonald

New Hampshire

Jared Payne

Florida

Rhonda Williams

Indiana

Sabrina Hadro

Minnesota

Derek Montelcalvo

Massachusetts

PWSA | USA'S SPOTLIGHT ON HOPE

"Our daughter, Lindsay, 17 years old with PWS is going to graduate high school this year. During the years, she was determined to complete all her assignments, homework, and projects. She participated in Animal Rescue Club and volunteered to help dogs at shelters. She is a member of the local swim team and swims three times a week. She also participates in hip hop and Zumba classes.



She loves to walk her dog during her free time and enjoys her routine exercises. During the high school year, she lost 20 pounds by eating healthy and exercising. She has many friends and enjoys her social life with them. She went to her last homecoming dance with her friends."

- Shared by Lindsay W.'s Parents

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

**Join Clint & Karla Hurdle at the
10th Annual Hot Stove Dinner**

Sip, savor, and support PWSA | USA while enjoying the **10th Annual Clint Hurdle Hot Stove Dinner**, Saturday, March 23, 2024, at an exciting NEW location, the [Bradenton Country Club](#) in Bradenton, Florida. This event can be attended in-person or virtually! More details and registration will be available soon.

Save the Date!
MARCH 23, 2024
Bradenton Country Club

WITH SPECIAL HOSTS
CLINT & KARLA HURDLE

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES
Clint Hurdle
HOT STOVE DINNER
Bradenton Country Club
Bradenton, FL & Virtual
March 23, 2024
Island Treasure Reception 5:00 p.m. until 6:00 p.m.
6:00 p.m. General Admission
Presented By: Leaving Legacies Foundation



ADVOCACY

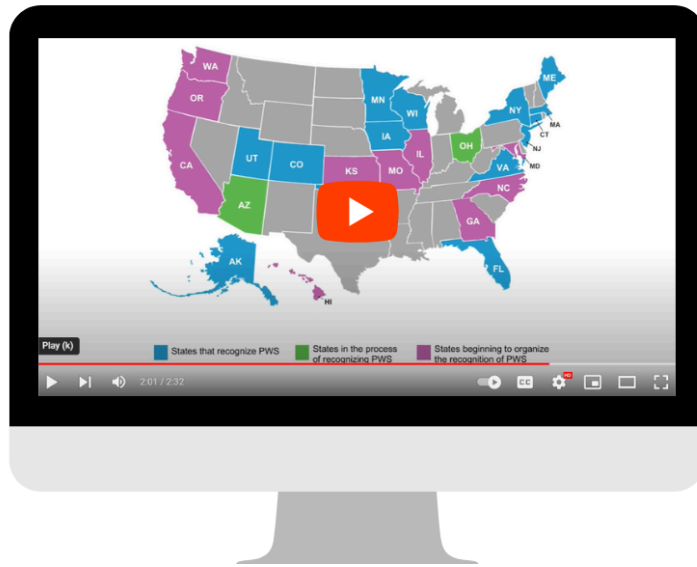
Joint Legislation Filed to have PWS Recognized as a Developmental Disability in Ohio

PWSA | USA is excited to announce that thanks to the dedication and hard work of our Advocacy Ambassador, Dr. Erin Carter-Cooper, PhD, Ohio Representative Rose Sweeney (D - District 16) and Representative Gayle Mannin (R - District 52) have jointly filed legislation that will make Prader-Willi syndrome a recognized developmental disability in the state of Ohio!

[House Bill 337](#) was introduced earlier this month and has already garnered support from both sides of the aisle. With 11 co-sponsors already signed on, this is the 2nd state this year that has introduced legislation to support our PWS community. Advocates like Erin are making a difference and moving the needle throughout the country.

If you or someone you know is interested in getting involved, please email Dorothea at Advocacy@pwsausa.org for more information.

WATCH: Click the image below to hear from Erin as she explains the first steps she took to get PWS added to Ohio's list of developmental disabilities.



ICYMI: 2024 DC Fly-In Hotel Announcement and Application Release Date



We are excited to share 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** (415 New Jersey Ave NW, Washington, DC 20001)! During the Fly-In, we will learn about Policy affecting the PWS community, hear from policy makers, and continue our advocacy efforts by coming together on May 15th for a "Day on the Hill" to celebrate National PWS Awareness Day!

The D.C. Fly-In application will be available on **Tuesday, January 9, 2024**. Be on the lookout for an email from PWSA | USA when it is ready. 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.

[CLICK HERE TO EXPLORE THE HOTEL](#)

Sign the Petition! Global Advocacy Alliance Launches Campaign Urging Airlines to Prioritize Disability Travel

Information shared by the Global Genes Global Advocacy Alliance:

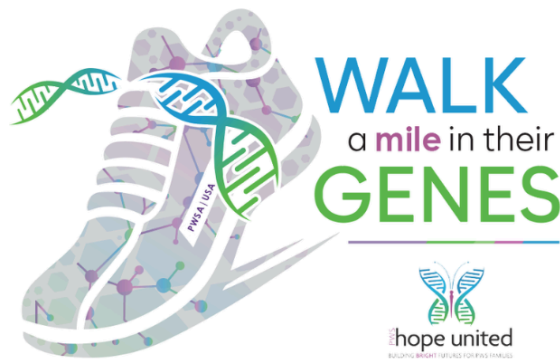
The Global Advocacy Alliance is calling on ALL airlines to acknowledge, respect, and act on improving the needs of those traveling with a disability and their vital medical equipment. These fragile and highly expensive devices are all too often mishandled and damaged, resulting in passengers with rare disease being stranded without a method of mobility.



The Global Advocacy Alliance has started a petition to push leaders in the travel industry to take the responsibility and opportunity to create policies to support all travelers, establish procedures, and educate all employees on how to transport mobility devices and medical equipment. To sign and support this cause, click the button below.

[SIGN THE PETITION 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 two webinars in January. Sign up to attend one of these webinars at the buttons below. Thank you for taking action!

Tuesday, January 9, 2024 | 7:00 PM EST

[REGISTER HERE](#)

Thursday, January 11, 2024 | 12:00 PM EST

[REGISTER HERE](#)



FAMILY SUPPORT

Holiday Gift Ideas: Sensory Edition

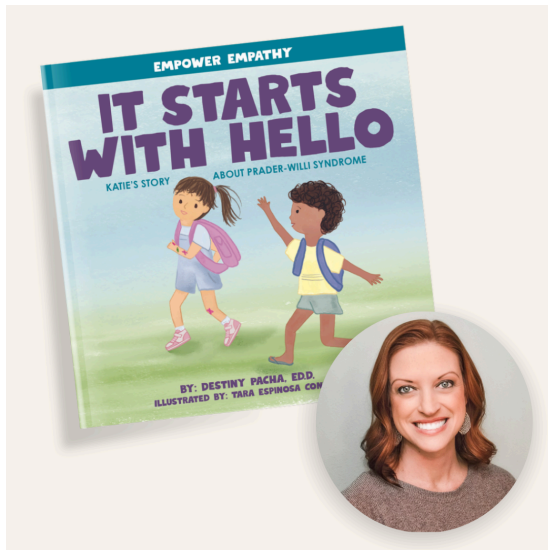


The gift-giving holidays are quickly approaching and we know gift shopping for the holidays can be stressful and overwhelming.

Our team and helpful community members have come up with a sensory level-inspired gift guide that can help you curate a successful, appropriate, and fun list for your holiday shopping! Find these ideas at the button below.

[FIND GIFT IDEAS HERE](#)

New PWS Children's Book Now Available for Pre-Sale!



We are excited to share that a new children's book centered around PWS is now available to pre-order! *It Starts with Hello: Katie's Story about Prader-Willi Syndrome* was written by Destiny Pacha, Ed.D., who has worked in the public education system for more than 20 years. The story follows Katie and her companions as they navigate a day at school. Katie, who is living with Prader-Willi syndrome, embraces the challenges but never allows them to hinder her enjoyment and engagement with friends.

Throughout the experience, you'll discover the unique aspects that make Katie distinct from others, while also recognizing shared qualities. Cultivating these connections fosters empathy and empowerment, and it all begins with a simple "Hello!" "Your children and grandchildren inspire me each and every day, and it is because of them I continue to fight for a safe and secure educational environment for all children. By continuing to spread PWS Awareness, we can Empower Empathy," said Destiny.

[PRE-ORDER THE BOOK HERE](#)

Simple Self-Care for Caregivers



Find simple ways to incorporate self-care into your busy life! While November, which is nationally recognized as Family Caregivers Month, may have come to an end, supporting caregivers **never** should. We hope the article linked at the button below will be a reminder of the importance of self-care and our encouragement to seek it out.

PWS caregivers - you are amazing!

[LEARN MORE HERE](#)



RESEARCH

Acadia Pharmaceuticals has Announced the Initiation of its Phase 3 Study for Nasal Carbetocin to Treat Hyperphagia



This week, Acadia Pharmaceuticals announced the initiation of its Phase 3 COMPASS PWS study! This study focuses on evaluating the efficacy and safety of carbetocin nasal spray (ACP-101) for treating hyperphagia in Prader-Willi syndrome. The COMPASS PWS trial is a 12-week, double-blind, randomized, placebo-controlled global Phase 3 trial, with approximately 170 participants aged five to 30 years.

Stay tuned for updates as we eagerly anticipate the Phase 3 trial outcomes and the potential for a

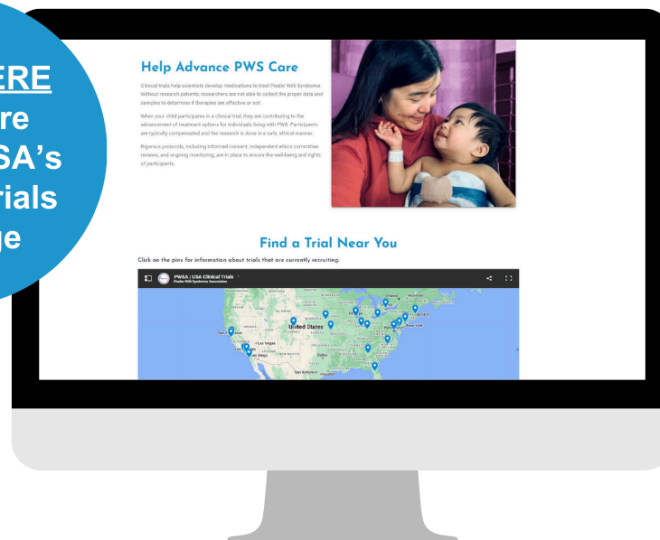
groundbreaking treatment option for those living with PWS. Learn more about the COMPASS PWS study at the buttons below.

[LEARN MORE HERE](#)

[READ ACADIA'S LETTER TO THE PWS COMMUNITY HERE](#)

Learn More About PWS Clinical Trials by Exploring PWSA | USA's New Website Addition

[CLICK HERE](#)
to explore
PWSA | USA's
Clinical Trials
webpage



At PWSA | USA, we're thrilled to announce the launch of our new **PWS Clinical Trials webpage**, a dedicated space providing essential information for the Prader-Willi syndrome community. This platform is a valuable resource, offering insights into current PWS drug trials, their locations nationwide, and a comprehensive guide to understanding the various stages of clinical trials.

We're committed to keeping this webpage up-to-date, incorporating new trial locations and introducing emerging drugs as they arise. We urge the PWS community to explore this dynamic resource and learn about the significance of drug trials. By staying informed and actively participating, you can play a crucial role in advancing PWS research. Click the image above to explore!

PWSA | USA ANNOUNCEMENTS

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.

LEARN MORE HERE

Adoption Spotlight: 9-Year-Old Boy Living with PWS in Philadelphia is Seeking a Loving Foster Family

Kyle (not his real name) is a vibrant 9-year-old boy with PWS, hypothyroidism, obstructive sleep apnea, morbid obesity, and albinism, and is seeking a loving foster family. Currently living in a structured environment near Philadelphia, Kyle is making progress with weight loss. Despite occasional challenges, Kyle is an active, inquisitive child who loves reading, scary movies, sing-a-longs, walks, and swimming. His teacher praises his behavior and academic achievements in a special education classroom. If you have experience with PWS and can provide a caring home for Kyle, contact his child advocate attorney Shannon Sherwood at ssherwood@sccalaw.org or social worker Cathy Behar at cbehar@sccalaw.org to learn more about this delightful young boy.



Find more details at the button below.

[LEARN MORE HERE](#)

IN MEMORY OF



We are deeply saddened to share the passing of Stephanie Ann Knoll, who was 29 years old living with PWS. According to her obituary, Stephanie passed away at Eastern Maine Medical Center in Bangor, on October 21, 2023, after a brief illness, surrounded by many people whom she loved.

"Stephanie loved to play soccer, dancing with the Wii and baking with her mom. She had a yearly tradition of going to the Father-Daughter Dance with her cousin, Tim. She looked forward to dressing up and

spending quality time with the love of her life, Tim. When Tim couldn't take her Uncle Brian or stepdad, Joey, would step in and take her. One of her favorite past times was to go ATVing with her mom and stepdad, where she learned to drive a side by side. She also loved to take walks or play in the rain with her mom. Stephanie was a proud Special Olympics athlete. She was a fierce competitor in swimming. She had the support of her cousins, Pamela and

Robin, who swam with her, cheering her on. Stephanie had so much love to give and loved her family immensely. She was taken far too early."

Read Stephanie's full obituary and find out how you can support her family at the button below.

[LEARN MORE HERE](#)

PWSA | USA GRIEF COUNSELING AVAILABLE

Grief can occur with any loss and grieving is a necessary step in the healing process. PWSA | USA offers grief support to individuals diagnosed with PWS and to parents, family members, and caregivers who may be dealing with any type of grief. If you are interested in receiving grief counseling, please give us a call at 941.312.0400.

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: December 15, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 89

December 15, 2023

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Time is Running Out! 



The last day to support PWSA | USA's **2023 Angel Drive** campaign is **December 31, 2023!** With the gift-giving season in full swing, now is the perfect time to make a donation that will impact families and individuals affected by PWS. You can **Give the Gift of HOPE** to ensure we can continue taking action in the new year.

Whether it's helping families and individuals navigate the challenges associated with PWS or working with volunteer advocates to raise our voices with legislators in Washington, D.C. about issues that matter most, your year-end, tax-deductible gift ensures that PWSA | USA can continue to provide **HOPE** 24/7/365!

DONATE TODAY!

By donating to the Angel Drive, you are helping families, like the Saacks', receive the support they need.

Hear their journey with loved one, Andrea (52), who is living with PWS.



Make your Angel Drive donation a gift for a loved one this holiday season! Did you know with your 2023 Angel Drive donation, you can instantly download our customizable **“Gift of HOPE” certificate**? This symbol of generosity serves as a memorable keepsake or a unique present for loved ones. Add a personal touch with your own message, making this heartfelt gesture a lasting memory of warmth and affection.

Click Here to Download the
“Gift of Hope” Certificate

There's Still Time to Become a 'Selfless Elf' and Give Hope Rather than Get Gifts

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PWSA | USA 2023 SELFLESS ELF PARTICIPANTS

Sujeiri Colon

New Jersey

Angela & Joseph Frazier

Texas

Melanie & Henry McDonald

New Hampshire

Jared Payne

Florida

Rhonda Williams

Indiana

Sabrina Hadro

Minnesota

Derek Montelcalvo

Massachusetts

PWSA | USA'S SPOTLIGHT ON HOPE

This week's **Spotlight on Hope** shares the remarkable journey of Madison (Madi) Nicole, a beacon of resilience and triumph. From the initial uncertainty of a potential syndrome to the unexpected diagnosis of Prader-Willi syndrome at 12, Madi defies odds and embraces life. Overcoming challenges, she conquers high school, engages in activities like cheerleading and dance, and runs her own goat soap business, *The Fancy Nanny*. Now 21, Madi radiates joy while working on a small farm and contributing to her mother's salon. Her story is a



testament to the power of love, acceptance, and the extraordinary potential within every individual.

Read Madi's complete Spotlight on Hope story at the button below, which was shared by her mother, Patricia.

[READ MORE HERE](#)

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

[SHARE YOUR SPOTLIGHT ON HOPE](#)

EVENTS

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



LIVE & VIRTUAL
MARCH 23RD 2024
BRADENTON COUNTRY CLUB



Prader-Willi
Clint Hurdle
HOT STOVE DINNER
Presented by: 

Sip, savor, and support PWSA | USA while enjoying the **10th Annual Clint 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! More details and registration will be available soon.



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.



December has Been Another Exciting Month for PWS Advocacy!

On December 6th, Director of Community Engagement Dorothea Lantz was the keynote and opening speaker for the first annual **Rare Conversations**. This rare disease policy forum was organized by Alexion AstraZeneca Rare Disease and focused on how to advance the needs of people living with rare disease and their caregivers by working with state and federal officials. Also in attendance for this important conversation surrounding rare disease was Annie Kennedy, Chief of Policy, Advocacy & Patient Engagement at EveryLife Foundation, Heidi Ross, Vice President of Policy and Regulatory affairs at the National Organization for Rare Disease, Representative Cathy McMorris Rodgers (R-WA), Jason Resendez, President and CEO at National Alliance for Caregiving, congressional staff and the U.S. Food and Drug administration.



Rare Conversations provided an opportunity to not only stimulate the knowledge of our community's needs, but it also provided specific recommendations for policy change.



This week, Dorothea was invited to represent our organization and our PWS community at [EveryLife Foundation's Community Congress](#) year-in-review in Washington, D.C. This annual, in-person event provided an opportunity for members to participate in a comprehensive review of 2023, and to establish our rare disease collective policy priorities for 2024.

The event was attended by patient advocacy organizations, policymakers' industry, and governmental agencies. The agenda included presentations, panel discussions, table brainstorming sessions and group breakout sessions.

The Community Congress is dedicated to bringing patient organizations, industry leaders, and other rare disease stakeholders together. The Congress acts as a coalition of collaborators with shared priorities, providing strategic guidance and insight on policy issues and Foundation programs. PWSA | USA is honored to represent the "voice" of our community and will continue to fight for PWS initiatives!

PWS State Qualifier Campaign Update in West Virginia



West Virginia State Senator Patricia Rucker has agreed to sponsor efforts on adding Prader-Willi syndrome as an approved diagnosis for IDDW (Intellectual Developmental Delay Waiver)!

Every state has diagnoses listed in different ways, and each state has a different approach to how they will recognize rare diseases. Most states have it written into a certain bill, but it does not appear to be that way in West Virginia. Sen. Rucker has agreed to find out how and where this can be accomplished in her state so we can push our agenda into open session, which runs the month of February.

Sheri Mills, a resident of West Virginia and mom of five-year-old Lyra with PWS, met with Sen. Rucker to discuss the initial steps ahead of open session in February. This will be a lot of preparation in a short amount of time, but both Sheri and Patricia are ready for this challenge. Sheri recommends meeting in-person with your elected officials to discuss the issues you are having in your state, and discuss how they can help, should you also want to have your state recognize PWS.

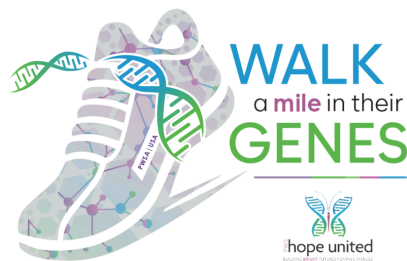
West Virginia Residents: We Need Your Help!

Some of our West Virginia PWS families are being denied access to the supports they need. We are trying to better understand the obstacles we all face when seeking approval for state assistance, specifically regarding IDDW services. All of our experiences are important in this effort. We thank you for your participation!



[TAKE THE SURVEY 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.

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[REGISTER HERE](#)

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FAMILY SUPPORT

Supporting the PWS Community Through Training



PWSA | USA supports the PWS community in a multitude of ways. This includes providing training to residential home and school staff. These trainings are an essential component of educating schools, homes, and providers to help our loved ones live safer, healthier lives. Alterman Family Support Counselor Kim Tula recently traveled to a number of places to provide these trainings. We asked her to share details about her work in the community. You can find her answers at the button below.

[READ MORE HERE](#)

Locking the Fridge: Community Stories

As a follow up to a recent blog post PWSA | USA staff member Anne Fricke wrote about her daughter Freya's positive reaction to having the fridge locked in their home, we have collected quotes from other families who shared what this experience was like for them and the reactions shown by their loved ones living with PWS. We sincerely appreciate those who contributed their stories, which can be read at the button below.



Locking the Fridge, Community Stories

[READ MORE HERE](#)



RESEARCH

Join the Interest List for a Groundbreaking Clinical Trial

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!

Does your loved one struggle with disruptive behavior and temper outbursts? A new clinical trial (VNS 4 PWS) will evaluate the effectiveness of a wearable medical device to reduce temper outburst behavior. The VNS 4 PWS clinical trial is expected to be ready for enrollment in early 2024. If you have a loved one aged 10-40 with PWS and temper outbursts, you are encouraged to join the interest list by sending an email to vns@fpwr.org. By signing up, you will be among the first to be contacted when the study opens.

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

PWSA | USA Will be Closed January 4-5, 2024 for a Staff Retreat



We want to let our community know that PWSA | USA will be closed January 4, 2024 and January 5, 2024 for a Staff Retreat. We will have limited availability to phone and email, and will return any missed calls.



We appreciate your understanding and flexibility as we take this opportunity to come together as a team!



With various holidays coming up this month, we want to remind our community about PWSA | USA's 24-Hour Support Phone Line. The support line is available 24-hours everyday, 365 days a year. Our knowledgeable and resourceful Family Support team members can help answer questions, offer guidance, or simply be there to talk. This support line will also be open and available during our Staff Retreat in January. In addition, you can reach out to us via email at info@pwsausa.org.

24-Hour Support Line phone number: (941) 312-0400

We are here for YOU!

Looking for a Last Minute Holiday Gift?



Looking for the perfect holiday gift? Your family and friends can show off their PWS pride with amazing customizable shoes! We want to thank the Marx family, their daughter Brooklyn living with PWS, Denver Broncos player Caden Sterns, and Custom Creations by JMART (the shoe creator) for their help in bringing this vision of PWS customizable shoes to life. Shop these shoes at the button below.

Disclaimer: These shoes can take up to 10 weeks to create and ship, as they are hand-crafted by JMART to perfectly capture your vision.

ORDER YOUR CUSTOM SHOES HERE

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!

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ABOUT THE POSITION >>>>

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 - 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.

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



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

PWSA | USA Special Edition Pulse: December 29, 2023

www.pwsausa.org | 941.312.0400

Donate



Time is Running Out!



Sunday is the **LAST DAY** to support PWSA | USA's 2023 Angel Drive campaign! Donations can be made until **midnight** on December 31st.

Take action to help make an impact on all the ways PWSA | USA supports individuals affected by PWS and their families through our Advocacy, Family Support, and Research initiatives. Your year-end, tax-deductible gift ensures we can continue to provide **HOPE** 24/7/365!

DONATE TODAY!

As we bid farewell to 2023 and usher in a new year, our team has united with a shared purpose: to enhance understanding about our organization and the support we provide. Dive into the insights of our committed staff by clicking on the two images below.

WATCH: What PWSA | USA's staff wish more people knew about our organization



WATCH: What PWSA | USA's staff say is the most rewarding part of their job



Looking Ahead to an Exciting New Year



Explore the depths of our reflections on the season and the rejuvenating power of rest. Click the button below to uncover our exciting plans for 2024, including powerful advocacy, family support, and captivating artistic expressions. Throughout January, we will share a blog series on mental wellness, and get ready to join us in interactive Facebook Live events – your key to newfound self-care practices!

Be part of the PWS community's journey by following us on Facebook ([@PWSAUSA](#)) and Instagram

([@pwsausa](#)). Plus, your insights matter! Complete our [2023 PWSA | USA Communications Feedback Survey](#) to help us tailor effective communication for your needs. Wishing you a magical New Year celebration – see you in 2024!

[READ MORE HERE](#)

Thank You, Selfless Elves!

Sujeiri Colon

New Jersey

Angela & Joseph Frazier

Texas

Melanie & Henry McDonald

New Hampshire

Jared Payne

Florida

Rhonda Williams

Indiana

Sabrina Hadro

Minnesota

Derek Montelcalvo

Massachusetts

THANK YOU to our **Selfless Elves** who encouraged donations in lieu of gifts and in honor of their loved ones this holiday season. We encourage you to click the button below to give a gift in support of our elves, who are listed above.

Funds raised during our Selfless Elf campaign will support the 2023 Angel Drive.



PWS **hope united**
BUILDING BRIGHT FUTURES FOR PWS FAMILIES

[SUPPORT OUR SELFLESS ELVES](#)

Thank You for Your *Support*


Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES



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