

PWSA | USA Bi-Weekly Pulse: March 1, 2024

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 94

March 1, 2024

www.pwsausa.org | 941.312.0400

Celebrating Nutrition Education



National Nutrition Month®, a nutrition education and information campaign sponsored annually by the Academy of Nutrition and Dietetics, started in 1973 as National Nutrition Week, and became a month-long observance in 1980 in response to growing interest in nutrition. With nutrition being a huge factor in managing PWS, we thought it would be an appropriate time to share some information and resources to support families navigating the nutritional needs of our loved ones. To learn more about the academy, National Nutrition Month®, and find a valuable collection of nutrition resources, visit their website at eatright.org.

[LEARN MORE HERE](#)

Healthy Meal Building Tips from Kim Tula, PWSA | USA's Alterman Family Support Counselor

Choose one (or more) from each group.

Vegetables

- Carrots
- Cucumbers
- Green beans
- Broccoli
- Cauliflower
- Spinach
- Lettuce
- Tomatoes
- Celery
- Zucchini
- Yellow squash
- Asparagus
- Bell peppers
- Onions
- Brussel sprouts
- Artichoke
- Cabbage
- Kale
- Snap peas
- Okra
- Collards
- Bok choy
- Eggplant
- Spaghetti squash
- Swiss chard
- Turnips

Proteins

- Beef
- Pork
- Chicken
- Turkey
- Salmon
- Tuna
- White fish
- Shrimp
- Crab
- Lobster
- Scallops
- Clams
- Eggs
- Greek yogurt
- Nuts
- Seeds
- Cottage cheese
- Duck
- Soy
- Tofu
- Tempeh
- Lamb
- Goat

Carbohydrates

- WHOLE grain bread
- WHOLE grain pasta
- Quinoa
- Brown rice
- Wild rice
- Barley
- Oatmeal
- Black beans
- Kidney beans
- Pinto beans
- White beans
- Lima beans
- Chickpeas
- Green peas
- Hummus
- Black-eyed peas
- Edamame
- Lentils
- Sweet potato
- Potato
- Whole grain couscous
- Farro
- Millet
- Pumpkin
- Butternut squash
- Acorn squash
- Popcorn
- Buckwheat
- Amaranth

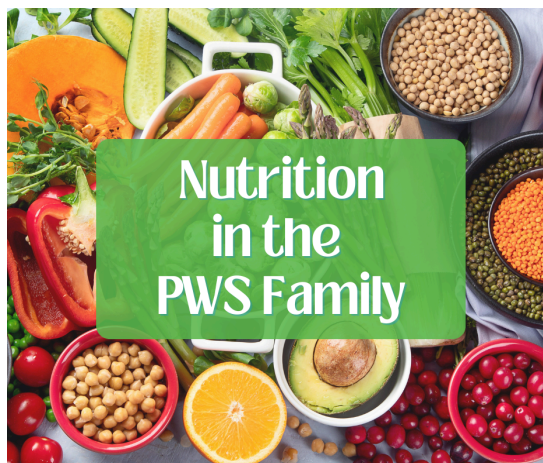
[DOWNLOAD THE DOCUMENT HERE](#)

- **Ensure there is a source of Fat at each meal as well, preferably Unsaturated Fat (oils, nuts, seeds, avocado, fish, etc.).**

- Fruit can be included with the meal as well, but only 2 servings per day of fruit. If using canned fruits, make sure there is no added sugar or syrup.
- No carb only snacks. If carb is included in a snack, ensure there is a protein and/or fat with it.

Nutrition in the PWS Family

Michael Tan, MS, RD, LDN, is a Dietitian at the University of Florida Health. Alongside Dr. Jennifer Miller, he sees and advises many families in the PWS community. We reached out with some general questions about PWS and nutrition. What does a balanced meal look like? How do we meet the nutrition needs of our loved ones with PWS, as well as their growing siblings? Should we try low-carb diets or intermittent fasting as diet strategies for our loved ones with PWS? Check out our blog at the button below to read his responses to these questions and more.



[READ BLOG HERE](#)

PWSA | USA'S SPOTLIGHT ON HOPE

Through dedication and hard work, Mira, a 12-year-old from Colorado who is living with PWS, qualified to participate in a spelling bee at the district level. She was one of only three students from her school who were able to qualify. Mira was focused and organized in preparing for the district level spelling bee and had the help of her family to practice. Her family is very proud of her hard work, ability to remain calm and happy during the stress of the spelling bee, and look forward to seeing how she will succeed again in the future. Read Mira's full Spotlight on Hope at the button below.



[READ MIRA AND THE BEE HERE](#)

EVENTS

Limited Tickets Remain for the 2024 Clint Hurdle Hot Stove Dinner - Get Yours TODAY!

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!

**Join Clint and Karla Hurdle
At The 10th Annual
Hot Stove Dinner**

Bradenton Country Club
March 23, 2024

**LIMITED TICKETS
REMAIN!**

To purchase tickets, text the keyword Hotstove2024 to 76278 or go to hotstove2024.givesmart.com.

Note: You don't need to attend the Hot Stove Dinner to purchase golf balls for the Coconut Golf Ball Drop or raffle tickets. These items can be purchased by anyone at the button below!

PURCHASE HOT STOVE DINNER TICKETS HERE



Recap: Rare Disease Week on Capitol Hill

Click the image below to watch our Rare Disease Week on Capitol Hill recap video! PWSA | USA staff and our volunteer advocates were grateful for the opportunities the [Everylife Foundation](#) and [Rare Disease Legislative Advocates](#) provided throughout the week. We had many successful meetings with elected officials and their staffers, shared our stories and shined a light on PWS/our community's needs, and built relationships with fellow rare disease advocates. We can't wait to return to Capitol Hill in May for our D.C. Fly-In and continue to fight for our loved ones and families.

Rare is many, rare is strong, rare is proud!



Step Up for PWS Advocacy



Join PWSA | USA in our 2nd Annual **Walk a Mile in their Genes** advocacy campaign to raise awareness for PWS. Take action from your home, community, or Chapter to support families affected by this rare disease. By becoming a participant, you not only advocate for the PWS community but also raise crucial funds for PWSA | USA to continue providing necessary services. This virtual/in-person fitness challenge is open to all ages and fitness levels, promoting health and wellness while supporting those with Prader-Willi syndrome. The

campaign runs until March 18, 2024, and signing up is quick and easy through the link at the button below.

[CLICK HERE TO GET INVOLVED!](#)













Help us Reach our Goal!

\$14,824

\$50,000

30%

[Click here](#) to support our *Walk a Mile in their Genes* participants!

- | | | | |
|----|---|---|---------|
| 1 |  | Loving and Living for Leslie
Michelle Torbert | \$3,295 |
| 2 |  | Little Louie Fighters
Lindsey Lipton | \$2,050 |
| 3 |  | Creating Change for Clementine
KELLY GUILLOU | \$1,600 |
| 4 |  | Elaine's Advocacy Efforts for PWS
Elaine Towle | \$1,250 |
| 5 |  | Pentas Speak Out For PWS
Tammie Penta | \$1,100 |
| 6 |  | United in Hope to change lives.
Sue Colon | \$1,000 |
| 7 |  | Miles for Maya
Denise Servais | \$825 |
| 8 |  | Help Chris Advocate for His Friends
Maggie Andrews | \$660 |
| 9 |  | Raising for Ronan
Kat Lucero | \$550 |
| 10 |  | Lolli's Little Guy
Julie Lopez | \$550 |
-

If you have additional questions, please contact us at hopeunited@pwsausa.org.

Advocacy Gear



Are you looking for another way to show your support for PWS Advocacy? Are you going to the D.C. Fly-In and want to represent your work in the PWS community? Advocacy gear is now available through our Bonfire site at the button below. Crew-neck and V-neck t-shirts, hoodies, and long-sleeved tees in a variety of sizes and colors are available. Proceeds will benefit PWSA | USA's advocacy efforts.

[SHOP ADVOCACY GEAR HERE](#)

Highlighting the Artistic Voices of PWS



Artwork created by Victor Penta (living with PWS)

Calling all individuals living with PWS! We are collecting artwork for our 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.

The global art share will last for the entirety of 2024 and will be separated into three distinct themed sessions. Each session will have a specific date range for when we are accepting submissions. Submissions

will be accepted in digital format only. Click the button below to find the artwork submission form, as well as answers to frequently asked questions.

Between **February 1 - March 15, 2024**, we are collecting artwork for Theme 1 - **PWS Awareness**. Create your artwork using the prompt:

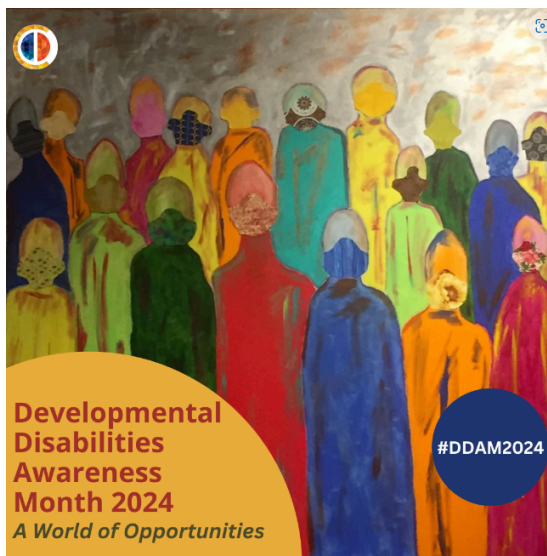
**“What is your superpower?
What are you capable of?”**

[SUBMIT ARTWORK HERE](#)



FAMILY SUPPORT

**National Developmental Disabilities Awareness Month
"A World of Opportunities"**



National Developmental Disabilities Awareness Month is a campaign to promote inclusion and recognize the strong, diverse communities that are formed when people with and without disabilities come together. It is a time to acknowledge the successes of including people with disabilities in society, as well as generating awareness on the many struggles people with disabilities still face.

***"A World of Opportunities" –
We're celebrating people and
working together to remove
obstacles. Our goal is to build a***

***community that's committed to creating a world where everyone can do
well and succeed. Join us in making a world where all kinds of people
have the chance to thrive."***

To learn more about National Developmental Disabilities Awareness Month and the National Councils on Developmental Disabilities, click the button below.

[LEARN MORE HERE](#)

Ask Nurse Lynn

Nurse Lynn received a question about a 34-year-old female with PWS UPD.

Q: *Is there some age at which it will be appropriate for our daughter to stop taking female hormones (in the form of birth control pills)?*

A: *The issue of Hormone Replacement Therapy (HRT) is more complicated than one would think. Hypogonadism is common in PWS and is believed to be caused by hypothalamus dysfunction. It is important to understand the difference between treatment of hypogonadism and birth control management.*

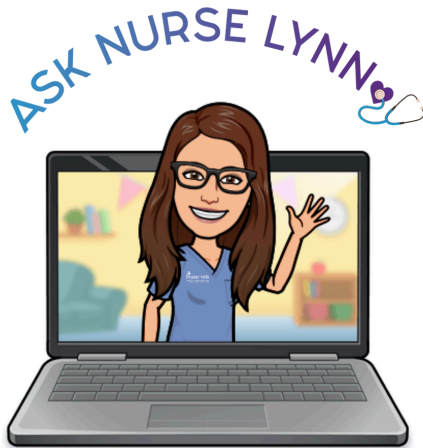
Read the Nurse Lynn "Birth Control and Hypogonadism" blog at the button below to learn more about this topic and find a link to Lynn's suggested reading resource.

[READ MORE HERE](#)



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](#)



Upcoming Family Support Webinar

Family Support Webinar

PSYCHOSIS IN PWS:
EARLY SIGNS, DIAGNOSIS, AND TREATMENT

Facilitated by: Elizabeth Roof, M.A., H.S.P.

Tuesday, March 26, 2024
5pm PST/ 8pm EST

Join PWSA | USA and Elizabeth Roof, MA, HSP, on **Tuesday, March 26th** to learn more about *Psychosis in PWS: Early Signs, Diagnosis, and Treatment*. The webinar will begin at **5pm PST/ 8pm EST**. Elizabeth Roof is a Senior Research Associate at Vanderbilt University Department of Psychology and has been licensed as a Health Service Provider in Tennessee since 1994. She currently directs several research programs with children and adults with Prader-Willi syndrome alongside Elisabeth

Dykens. For over 30 years, Elizabeth has followed longitudinally over 400 children, teens, and adults with PWS in research studies. She has a wealth of knowledge and experience with PWS and has valuable insights to offer in the realm of psychosis in PWS. Register for the webinar below.

[REGISTER HERE](#)

Wonderland Camp Accepting PWS Campers

Wonderland Camp, founded by the parent of an individual with PWS, is an overnight camp for people with disabilities. While the camp accepts campers with PWS for other sessions, June 9-14, 2024, is designated specifically for people with PWS. Located on the Lake of the Ozarks in Rocky Mount, MO, Wonderland Camp has adaptable activities including challenge elements like a giant swing, rock wall, and tight rope bridge. They also have a pool, archery, arts and crafts, paddle boats, kayaks, pontoon boats, fishing, and more. The camp accepts campers as young as six and never age out, hosting campers in their 60's, 70's, and even 80's. The camp has nurses 24 hours a day who can inject growth hormone and dispense any other medications.



Wonderland Camp is located in a tourist area. Campers come from multiple states with their parents who take a week off and enjoy the resorts and other places there to stay.

The summer camp is \$1,050 and there is some funding left to assist with the cost. To learn more and register, visit wonderlandcamp.org.

REGISTER HERE



RESEARCH

PWS Parents and Caregivers: Tell Your Healthcare Professionals About PWSA | USA's Next ECHO Webinar, *Sleep with Dr. Amee Revana*



ECHO 4 PWS

Date: Thursday, March 14, 2024

Time: 6:00 PM EST

Topic: Sleep with Dr. Amee Revana

PWSA | USA's next **Healthcare Provider Project ECHO Series** webinar will take place March 14, 2024, at 6:00 p.m. EST. The topic discussed will be **Sleep** presented by Amee Revana, DO FAASM, Associate Professor of Pediatrics, Texas Children's Hospital, followed by a 20-minute case study on PWS (*speaker to be determined*).

While this ECHO series is only for healthcare providers to attend, recordings of the webinars will be made available for our PWS families on our website. We encourage you to share this opportunity with the healthcare professionals in your life! You can learn more details and find the registration link at the button below.

ECHO 4 PWS INFORMATION

PWSA | USA ANNOUNCEMENTS

Share Your Feedback! Participate in PWSA | USA's Communications Survey

At PWSA | USA, our commitment to serving and supporting our community is unwavering. To ensure we continue to meet your needs effectively, we invite you to participate in this organization feedback survey. Your feedback is invaluable in shaping the way we communicate with you and improving the resources we provide. Prader-Willi syndrome is a complex condition that requires tailored information and support, and by gathering your insights, we can enhance our efforts to connect, inform, and engage with each of you in the most meaningful ways. Your participation in this survey will empower us to create a more informed, responsive, and supportive community for individuals with Prader-Willi syndrome and their families. Thank you for helping us make a difference.



[CLICK HERE TO PARTICIPATE IN THE SURVEY](#)

Get Your Own PWSA | USA Handcrafted Tumblers!



Introducing **PWSA | USA Tumblers**, which are handcrafted by Kim Tula, a dedicated member of the PWSA | USA team. Each tumbler boasts a stunning marbled tie-dye effect, showcasing the vibrant hues of PWSA | USA's signature colors and making every piece a unique masterpiece.

No two tumblers are alike, ensuring that yours will be one-of-a-kind. You also can personalize your tumbler with your/your loved one's name, adding a touch of individuality and charm.

With each purchase, you are supporting PWSA | USA's advocacy, family support, and research programs and initiatives. Learn more and order yours today at the buttons below!

[ORDER TUMBLERS WITH CUSTOMIZATION](#)

ORDER TUMBLERS WITHOUT CUSTOMIZATION

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: March 15, 2024

Enhancing the Quality of Life and Empowering Those Affected by PWS



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National Sleep Awareness Week



Sleep related issues occur often in individuals with PWS. Central sleep apnea, obstructive sleep apnea, excessive daytime sleepiness (EDS), narcolepsy, and cataplexy are conditions common in this population. It is important to properly diagnose and treat these conditions. Sleep studies are recommended as standard care for people with PWS. It is important to note, however, that standard sleep tests do not cover the potential needs of our loved ones. Sleep tests need to include testing for central apnea and end tidal CO₂, not just obstructive sleep apnea. In honor of National Sleep Awareness Week, we wanted to remind families of the importance of understanding and treating any sleep-related issue your loved one may be having. Learn more about Sleep Problems/Tiredness on our [Resource Hub](#). You can also learn more by reading a past article from PWSA | USA's Lynn Garrick, RN.

[READ ARTICLE HERE](#)

Tips for Sleep Studies from a PWS Mom

A diagnosis of PWS requires families to learn all sorts of new things, among them medical procedures we may not be familiar with. A fairly common one, the sleep study, can be a little daunting when you don't know what to expect. Prader Willi Syndrome can manifest with a variety of sleep problems, starting with obstructive and central sleep apnea even in early infancy as well as later in life. It is important to have your loved one assessed for sleep issues. While the thought of a sleep study may seem scary or overwhelming, this blog from PWS mom Jennifer Andrews provides relevant tips and advice to help prepare you and your loved one for what to expect.



[READ BLOG HERE](#)

PWSA | USA's Donor Spotlight

PWSA | USA is incredibly grateful for donors like Your Journey Team, powered by AMR Real Estate Indianapolis. Your Journey Team was founded by Niki Fuller in 2012. Her nephew, James, was born in 2020. In honor of James and his diagnosis of PWS, the Your Journey Team contributes a portion of their real estate commissions to PWSA | USA. Learn more about James, his life, and his aunt's inspiring support of him and the PWS community.



[LEARN MORE HERE](#)

EVENTS



Exciting announcement for the PWS community! PWSA | USA is pleased to announce a new partnership with the Foundation for Prader-Willi Research and the International Prader-Willi Syndrome Organisation to host **United in Hope – an International PWS Conference** to be held June 24-28, 2025 at the Arizona Grand Resort & Spa in Phoenix, Arizona!

The conference theme, “United in Hope” reflects this unique collaboration, which we anticipate will serve as a catalyst for the largest international PWS

conference ever held. Please mark these dates in your calendars! Further information will be made available soon.

Click the button below to learn more about the Arizona Grand Resort & Spa and to find a link to our hotel booking website.

[LEARN MORE HERE](#)

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- Coconut Drop | Golf Ball Drop!

To purchase tickets, text the keyword Hotstove2024 to 76278 or go to hotstove2024.givesmart.com.

Note: You don't need to attend the Hot Stove Dinner to purchase golf balls for the Coconut Golf Ball Drop or raffle tickets. These items can be purchased by anyone at the button below!

[PURCHASE HOT STOVE DINNER TICKETS HERE](#)



Hope United Ohio 5K & Family Fun Run

Saturday, April 20, 2024
11:00am - 2:00pm

Glacier Ridge Metro Park
Plain City, OH



Calling all Ohio residents!

Register to ATTEND or SPONSOR the **Hope United Ohio 5K & Family Fun Run** in support of Prader-Willi syndrome! Proceeds from this event will benefit PWSA | USA's Advocacy, Family Support, and Research programs.

The Hope United Ohio 5K & Family Fun Run will take place Saturday, April 20, 2024, at the Glacier Ridge Metro Park in Plain City, OH. The event will include food, vendors, a 5K run/walk, kids games, kids' run, and more!

If you're interested in being a participant or sponsor for this event, please register at the button below. You can also fundraise on your own to support this event by clicking [HERE](#). We hope to see you there!

REGISTER FOR THE OHIO 5K & FAMILY FUN RUN HERE



ADVOCACY

Rare Aware Art Share Deadline Extension

We are extending the Rare Aware Art Share deadline a few more days. 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. We will be taking submission for **Theme #1 "What is your superpower? What are you capable of?"** through March



17th. These submissions are for individuals with PWS only. We have greatly enjoyed the art and question responses we have received so far and look forward to more! Please invite your loved one with PWS to create an art piece, or find one they have already made that they feel compelled to share, and submit using the button below. Submissions for Theme #1 accepted through March 17th.

Theme #2 Submissions Accepted

July 1, 2024 - August 15, 2024. "What is something unique or special about where you live?" We will begin accepting submissions for Theme #2 on July 1, 2024, running through August 15, 2024. This theme is in honor and preparation of the PWS community gathering from around the globe in Phoenix, AZ, June 2025, for the United in Hope International PWS Conference. Learn more about the Rare Aware Art Share by scrolling to the FAQs at the bottom of the page on the button below.

SUBMIT FOR THEME #1 HERE

Recap: Rare Disease Week on Capitol Hill

Click the image below to watch our Rare Disease Week on Capitol Hill recap video, which includes advice from attendees to those coming to our D.C. Fly-In in May! PWSA | USA staff and our volunteer advocates were grateful for the opportunities the [Everylife Foundation](#) and [Rare Disease Legislative Advocates](#) provided throughout the week. We had many successful meetings with elected officials and their staffers, shared our stories and shined a light on PWS/our community's needs, and built relationships with fellow rare disease advocates. We can't wait to return to Capitol Hill with many more PWS advocates during PWS Awareness Month and continue to fight for our loved ones and families.

Rare is many, rare is strong, rare is proud!



D.C. Fly-In Open Office Hours Starting April 1st

We know many of our dedicated advocates are gearing up for [PWSA | USA's 2nd D.C. Fly-In!](#) We have 150 parents, siblings, grandparents, and individuals living with PWS planning to make the trip to Capitol Hill and promote our mission.

For those of you who are attending, we invite you to join Community Engagement Specialist Dorothea Lantz during her **open office hours beginning April 1, 2024**. Dorothea

will be available to answer questions, work through your story, or just help settle down jitters.

Office hours will take place Monday's from 12:00 - 2:00 p.m. EST and Friday's from 3:00 - 5:00 p.m. EST. You can save the link at the button below and drop in during Dorothea's office hours to get help with anything you need in preparation for our trip.

[CLICK HERE TO ACCESS THE OFFICE HOURS ZOOM LINK](#)

Only a Few Days Left to Support PWSA | USA's Advocacy Efforts!













The 2nd Annual **Walk a Mile in their Genes** advocacy campaign is almost over! March 18th is the LAST DAY to support our Walk a Mile fundraising champions. To make a contribution, simply click the button below and give to any of the Walk a Mile fundraising pages!



This is your opportunity to take action from your home, community, or Chapter to support families affected by this rare disease.

[CLICK HERE TO TAKE ACTION!](#)

Walk a Mile Leaderboard

1		Loving and Living for Leslie Michelle Torbert	\$3,295
2		Little Louie Fighters Lindsey Lipton	\$2,150
3		Creating Change for Clementine KELLY GUILLOU	\$1,600
4		Mojo for Jojo in Advocacy Action Jennifer Andrews	\$1,485
5		Elaine's Advocacy Efforts for PWS Elaine Towle	\$1,350
6		Pentas Speak Out For PWS Tammie Penta	\$1,100
7		United in Hope to change lives. Sue Colon	\$1,000
8		Help Chris Advocate for His Friends Maggie Andrews	\$880
9		Miles for Maya Denise Servais	\$850
10		Lolli's Little Guy Julie Lopez	\$700

If you have additional questions, please contact us at hopeunited@pwsausa.org.

Advocacy with Rare Conversations

PWSA | USA's Director of Community Engagement, Dorothea Lantz, was featured in the Rare Conversations 2023 report. Dorothea has been a vocal advocate for her son Hunter and the rest of the PWS community. In December of 2023, she had the opportunity to speak at Rare Conversations, where representatives from a variety of rare diseases were given the microphone. Dorothea spoke about the issues regarding legislative policies and how they can negatively impact the development of beneficial and much-needed treatments for those living with rare diseases. To learn more about Rare Conversations and read the article about Dorothea's talk, "Hear Our Voices: Advocating for Our Community" follow the link below.



READ MORE HERE



FAMILY SUPPORT

Travel Blog Series

With the diagnosis of PWS, families must consider the many aspects of their lives and how PWS will affect them. For many, traveling may seem like a daunting and unfathomable opportunity. While adjustments do need to be made and travel details considered intently through the lens of PWS, traveling is still a possibility for most families. We hope that our travel blog series offers insightful remedies for some of the more challenging aspect of travel and PWS. And with the exciting announcement of the United in Hope 2025 PWS Conference in Phoenix, AZ, we hope you find the encouragement and confidence you may need to make the trip.



How To Travel with Refrigerated Medication

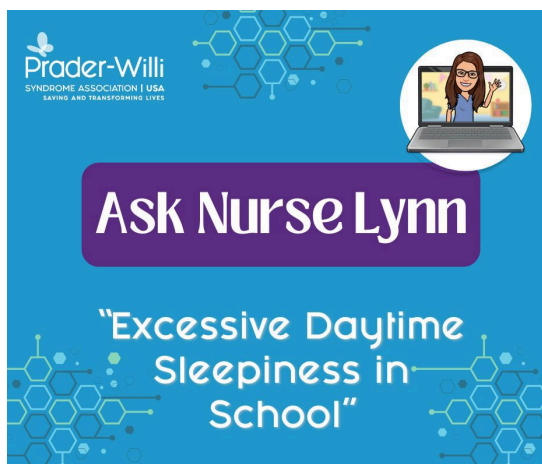
[READ BLOG HERE](#)

Ask Nurse Lynn

In honor of Sleep Awareness Week, we're sharing a Nurse Lynn submission regarding excessive daytime sleepiness and young children in school.

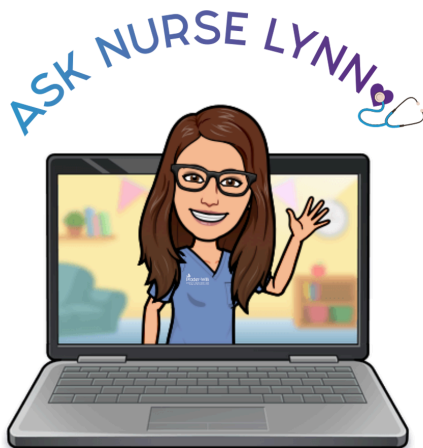
Q: Any tips or tricks to help when our little ones get tired throughout the school day, besides a nap? Not all schools will allow for a student to take a nap during the regular school day.

You can find Lynn's response and suggested resources in the blog "Excessive Daytime Sleepiness in School".



[READ MORE HERE](#)

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](#)



Upcoming Family Support Webinar

Family Support Webinar

PSYCHOSIS IN PWS:
EARLY SIGNS, DIAGNOSIS, AND TREATMENT

Facilitated by: Elizabeth Roof, M.A., H.S.P.

Tuesday, March 26, 2024
5pm PST/ 8pm EST

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Dykens. For over 30 years, Elizabeth has followed longitudinally over 400 children, teens, and adults with PWS in research studies. She has a wealth of knowledge and experience with PWS and has valuable insights to offer in the realm of psychosis in PWS. Register for the webinar below.

[REGISTER HERE](#)



Watch the recording of our February Family Support Webinar, **Unlocking Potential: Harnessing Strengths to Transform Behavior Webinar**, with Patrice Carroll, LICSW, at the button below.

[CLICK HERE TO WATCH](#)

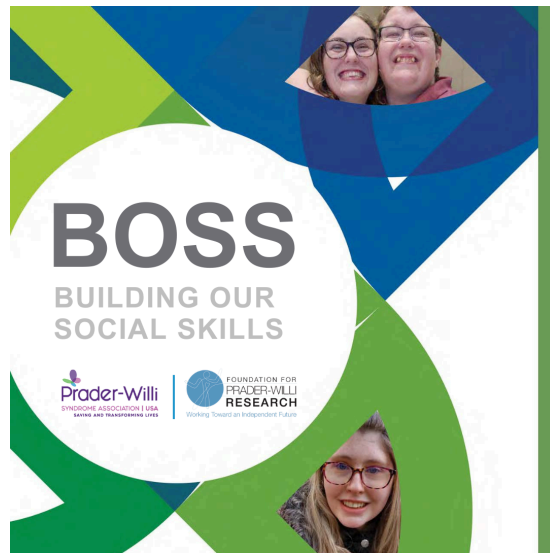
BOSS Application for May Sessions Now Available!

PWSA | USA is thrilled to offer more sessions for the **Building Our Social Skills (BOSS) curriculum**, a highly effective social skills intervention program created at Vanderbilt University. The BOSS curriculum provides tailored social groups to teens and adults with PWS, empowering them to enhance their social interactions and build meaningful connections.

If you are interested in joining our next BOSS curriculum sessions, which will take place every Monday, Tuesday and Thursday at 5:00pm EST, May 6 – July 19, 2024, using ZOOM, please click the button below to find our application. All sessions are mandatory and participants must be able to communicate vocally without assistance in order to participate in these virtual sessions. Please send your completed application to info@pwsausa.org.

Thank you to The Foundation for Prader-Willi Research for funding the BOSS curriculum.

[LEARN MORE HERE](#)



Upcoming Interactive Map for Pacific Northwest

The Washington and Oregon Chapters of PWSA are working on a new interactive map for PWS families. This map will not share personal information



but be a way for families in the two states to find each other, potentially along with providers and resources in their area. PWSA | USA will keep you updated on the progress of this upcoming new resource for families in the Pacific Northwest. Read blog to learn more.

[READ HERE](#)



RESEARCH

IMPORTANT UPDATE: PWSA | USA's Sleep ECHO Will Now Take Place Tuesday, April 23, 2024



ECHO 4 PWS

Date: Tuesday, April 23, 2024

Time: 6:00 PM EST

Topic: Sleep with Dr. Amee Revana

PWSA | USA's next **Healthcare Provider Project ECHO Series** webinar will now take place on April 23, 2024, at 6:00 p.m. EST. The topic discussed will be **Sleep** presented by Amee Revana, DO FAASM, Associate Professor of Pediatrics, Texas Children's Hospital, followed by a 20-minute case study on PWS (*speaker to be determined*).

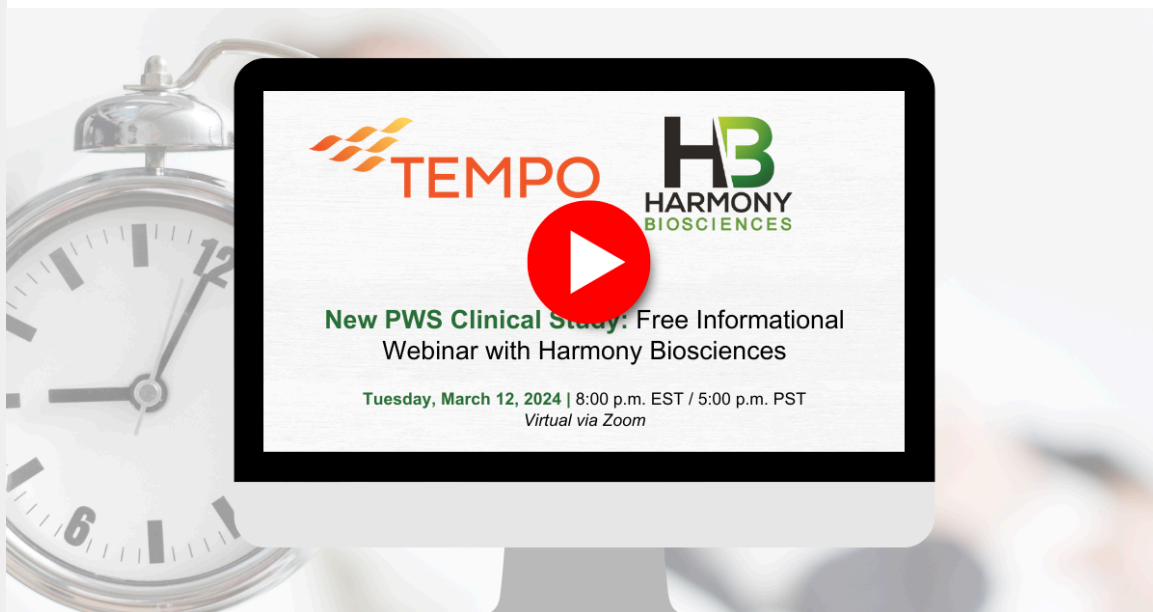
While this ECHO series is only for healthcare providers to attend, recordings of the webinars will be made available for our PWS families on our website. We encourage you to share this opportunity with the healthcare professionals in

your life! You can learn more details and find the registration link at the button below.

ECHO 4 PWS INFORMATION

WATCH: Harmony Biosciences Informational Webinar on New PWS Study, TEMPO

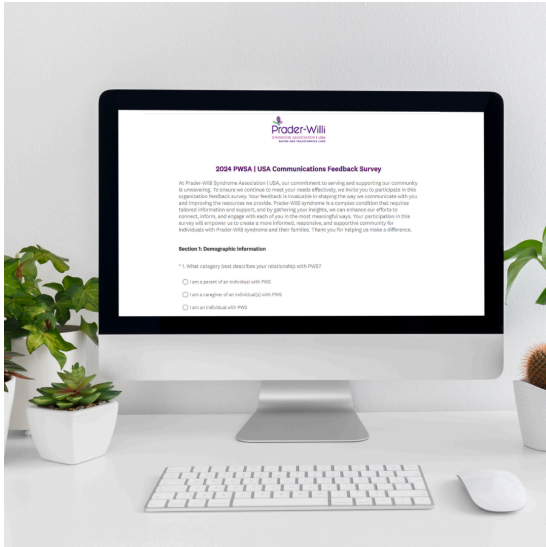
Harmony Biosciences, through PWSA | USA, offered an informational webinar to discuss the upcoming TEMPO study trial of the drug Pitolisant. Pitolisant has the potential to help patients with PWS who suffer from the symptoms of EDS (Excessive Daytime Sleepiness). They plan to open test sites by the end of the month. Watch the recording of their webinar to learn more about the study and how you can participate.



PWSA | USA ANNOUNCEMENTS

Share Your Feedback! Participate in PWSA | USA's Communications Survey

At PWSA | USA, our commitment to serving and supporting our community is unwavering. To ensure we continue to meet your needs effectively, we invite you



Prader-Willi syndrome and their families. Thank you for helping us make a difference.

[CLICK HERE TO PARTICIPATE IN THE SURVEY](#)

Get Your Own PWSA | USA Handcrafted Tumblers!



Introducing **PWSA | USA Tumblers**, which are handcrafted by Kim Tula, a dedicated member of the PWSA | USA team. Each tumbler boasts a stunning marbled tie-dye effect, showcasing the vibrant hues of PWSA | USA's signature colors and making every piece a unique masterpiece.

No two tumblers are alike, ensuring that yours will be one-of-a-kind. You also can personalize your tumbler with your/your loved one's name, adding a touch of individuality and charm.

With each purchase, you are supporting PWSA | USA's advocacy, family support, and research programs and initiatives. Learn more and order yours today at the buttons below!

[ORDER TUMBLERS WITH CUSTOMIZATION](#)

[ORDER TUMBLERS WITHOUT CUSTOMIZATION](#)

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!

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

PWSA | USA Special Edition Pulse: March 29, 2024

www.pwsausa.org | 941.312.0400

[Donate](#)



MARCH 29, 2024



PWSA | USA's Family Support Team is Here for You and Your Loved One 24/7

HELP & HOPE
TOGETHER WE'VE GOT THIS

adulthood, and the growing experiences of PWS in the later years of life, we are available every step of the way. We offer personal family support through our mentoring program, assistance with the IEP process, as well as SSI and SSDI claims, trainings for schools and residential providers, connections and information on PWS specific providers, informative webinars, community-engaging conferences, a blog that focuses on the variety of PWS experiences, and a 24-hour crisis hotline. We are honored to be here for your family and the rest of the PWS community. **On April 1, 2024, we will begin taking donations**

Family Support is the cornerstone of PWSA | USA. From those first days in the NICU, finding specialists and deciphering insurance claims, to sending your child off to school, navigating independence and

for our Family Support Campaign. Please consider donating so we can continue to be a source of **Help and Hope** to our community.

FAMILY SUPPORT PAGE

DONATE TO THE FAMILY SUPPORT CAMPAIGN

15 Reasons to Call PWSA | USA's Family Support Team

- 1** To know I am not alone.
- 2** When I read information about PWS on Google, it is overwhelming. I need support.
- 3** What should be on my child's IEP?
- 4** How/what am I supposed to feed my child?
- 5** My baby is in the NICU, what do I need to know?
- 6** I want to do a training at my child's school. What should they know?
- 7** How do I set up a fundraiser to support PWSA | USA?
- 8** I need help with my child's behavior issues.
- 9** My newborn was just diagnosed with PWS and I am at a loss.
- 10** I have specific medical questions/concerns about my child.
- 11** I would like to get more involved with advocacy efforts. Where do I start?
- 12** I would like to connect with other parents who have a child diagnosed with PWS.

13 We are in crisis, in the middle of the night,
and authorities are now getting involved.

14 My child's school is not following their IEP.

15 How do I explain PWS to my family?



**PWSA | USA's
24-Hour Crisis
Hotline:**

(941) 312-0400

Family Mentoring Program

Our mentoring program offers comprehensive support and education to families who have received a PWS diagnosis. It connects new families with "veteran" parents, grandparents, and siblings. Our mentors are committed to ensuring that newly diagnosed families have the most up-to-date research materials, educational literature, counseling, nutrition and medical information.

Our mentors are selected with each family's needs in mind to offer intentional guidance and support. If you are interested in finding a mentor, please reach out to Kristi Rickenbach, PWSA | USA's Family Support Coordinator, at krickenbach@pwsausa.org.



School Success

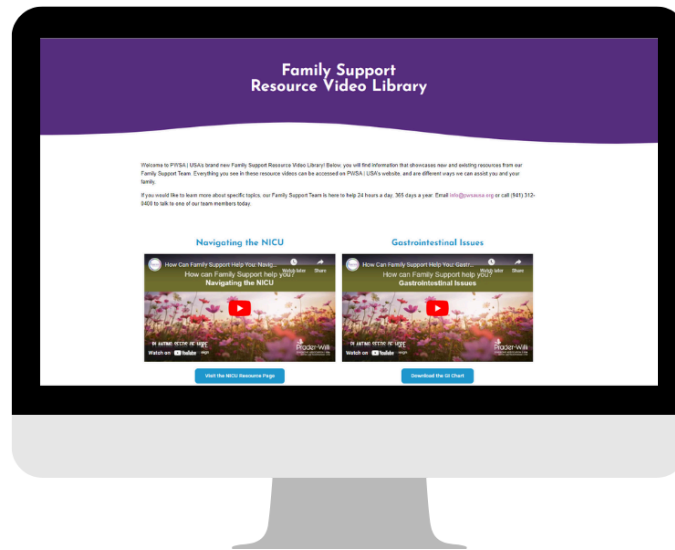


PWSA | USA knows how challenging the school environment can be for your loved one. We have created a multitude of resources to help families and caregivers navigate the school years so your loved one can receive the skills and benefits their education offers. Our website hosts a catalogue of information for parents, teachers, specialists, and administrators to learn more about the specifics of PWS, the challenges that arise in a school setting, and the many ways your loved one can be successful in the school environment. We also have staff

available to advocate for your child, whether that is writing letters to your child's school, attending IEP meetings virtually, or providing necessary trainings to school staff. Sending your child to school can be a nerve-wracking experience. We want families to know that PWSA | USA is here to support you. To learn more about our School Success toolkits, click on the button below.

SCHOOL SUCCESS

Resource Video Library



From navigating the NICU, helping parents understand their role in the IEP process, to learning more about scoliosis, executive functioning disorder, and more, our Family Support Resource Video Library offers a variety of videos with information focused on PWS. These videos showcase new and existing resources from our Family Support Team and are a great way to dive deeper into some of the challenging issues of PWS. If you decide you'd like to learn more about specific topics, our Family Support Team is here to help 24 hours a day, 365 days a year. Email info@pwsausa.org or call (941) 312-0400 to talk to one of our team members today!

VIDEO LIBRARY

Trainings and Consultations

PWSA | USA provides 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. When it comes to school trainings, we focus on the complexities of PWS and how they can impact the student's ability to learn, the need for food security, and common behaviors



with a focus on positive behavior support. We also review IEPs and behavior plans. Training for residential providers is focused on many different areas, including the genetics and medical overview of PWS, supporting someone with PWS, common behaviors and approaches to behavior management, dignity and respect, activity planning, food security, diet and nutrition, and working with families.

[LEARN MORE HERE](#)

Social Stories

Social stories can be used to help your loved one with PWS navigate different social situations and build social and emotional skills. PWSA | USA's Family Support Team designed social stories specifically for individuals with PWS across all ages, races, genders, and abilities. Our social stories cover topics like what your loved one can do when they are upset, how to ask someone if they want to play, making good choices, how to properly brush their teeth, and more. You can download these social stories, with pictures or without (so your loved one can draw their own) by clicking on the button below.



[SOCIAL STORIES](#)

Facebook Support Groups



PWSA | USA provides
Help & Hope

Make a difference TODAY at
www.pwsausa.org/get-involved/donate

 **Prader-Willi Syndrome Association USA**
13K followers · 123 following

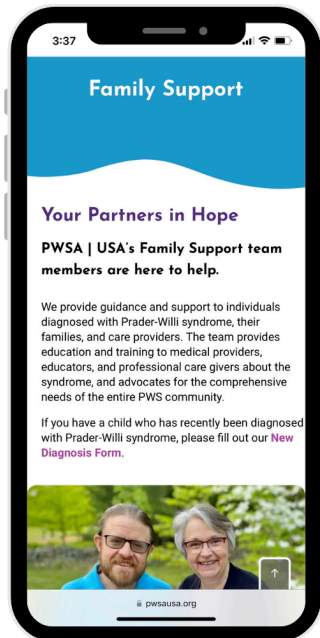
[Donate](#) [Following](#) [Message](#)

PWSA | USA hosts a variety of Facebook groups designed for families of all stages on their PWS journey. We also keep the community informed about new blog posts, upcoming webinars, study trials and research alerts, conference news, and dates to remember on our main Facebook page. If you're looking to connect with other families, whether as a parent, grandparent, sibling, or other loved one, we have a Facebook group for you.

FACEBOOK

Along with these helpful resources and programs, we offer education and guidance on behavior issues, weight management, medical issues, providers and residential homes, and so much more.

Find important documents, brochures, booklets, and more at our [Resource Hub](#). Easily locate specific medical information on our Medical A-Z page. Watch informative webinars and read our PWS-focused blog on a variety of subjects. The list continues. We encourage you to explore our comprehensive website to learn more about all of the ways we support the PWS community!



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