

PWSA | USA Bi-Weekly Pulse: May 3, 2024

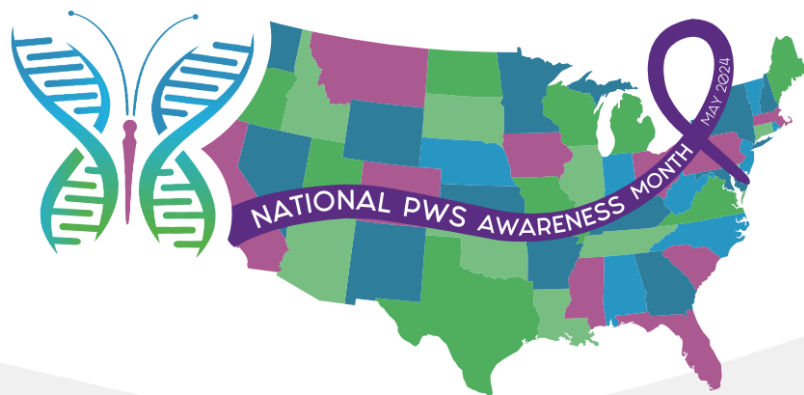
Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 98

May 3, 2024

www.pwsausa.org | 941.312.0400



May is PWS Awareness Month!

[Click here](#) to access our awareness month resources webpage.

Happy PWS Awareness Month! May is an important time for our rare disease community because it is recognized as PWS Awareness Month. While advocacy efforts, the fight for research advancements, and the celebration of our loved ones are important 365 days a year, the 31 days in May offer an opportunity to show off our PWS pride. We have created a PWS Awareness Month resource hub which offers downloadable graphics and tools to help YOU spread awareness all month long. Please visit our resource hub and help spread PWS awareness and pride! Are you celebrating PWS Awareness Month in a unique way and want to share it with the community? Email communications@pwsausa.org and let us know how.

Please note that due to the Communications Staff attending the D.C. Fly-In, our next Pulse will be postponed a week.

Look for the next Pulse on May 24th!

PWSA | USA'S SPOTLIGHT ON HOPE



James Towle, a 38-year-old living with Prader-Willi Syndrome, plays with the Great Blizzards of Massachusetts, Inclusive Ice Hockey. He recently had the opportunity to speak publicly about his experiences with hockey, some of the challenges of having PWS, and how he has overcome those to get out on the ice. The radio show, *Breaking the Ice, Let's Talk Inclusion*, is a weekly broadcast to "discuss topics that are important to our inclusive community and highlight

the talents and achievements of our community members." (thegreatblizz.org) Read the full Spotlight on Hope, along with a contribution from James himself, and find a link to listen to the radio show below.

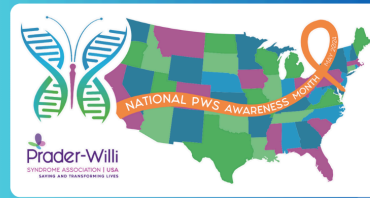
[READ BLOG HERE](#)

EVENTS & FUNDRAISERS

Awareness Month Virtual Meet-Up

Taking action to raise awareness for PWS in the month of May can be simple, fast, and fun with PWSA's Awareness Month Tool Kit! Come lunch and learn as we tour through this brand-new digital resource that has something for everyone to utilize. Whether this is your very first PWS Awareness month with your little

one, or you are just looking for some new ideas, this free info session will empower you with new tips, tricks, and techniques to raise awareness like a pro! Register in advance by clicking the button below.



PWS Awareness Month: Take Action Now!

Virtual Meet-Up
May 7 @ 12 noon EST

[REGISTER HERE](#)

Registration Open for Residential Providers Conference

RESIDENTIAL PROVIDERS Conference

Empowerment Heroes: Reveal Your Superpowers | IN-PERSON & VIRTUAL



August 18-20, 2024



Savannah, Georgia
Kimpton Brice Hotel

Thank you to our sponsors



As residential providers and caregivers are integral to the health and well-being of those living with PWS, it is critical that they have access to the latest information. **PWSA | USA's 2024 Residential Providers**

Conference, *Empowerment Heroes: Reveal Your Superpowers*, will offer a variety of lectures and workshops in a collaborative space where professionals can exchange practice-driven knowledge and actively contribute their

experiences. The Conference will take place **August 18-20, 2024**, both virtually via ZOOM and in-person at the Kimpton Brice Hotel in Savannah, GA. The goal of this event is to enhance the care provided to individuals and develop new methods of support on a range of topics like research, relationships, technology, the role of therapies, diagnostic instruments in behavior management, autonomy, aging, and more. Whether you have daily or occasional involvement as a professional caregiver of people with PWS, we invite you to join!

[REGISTER HERE](#)

Make a Difference by Supporting PWSA | USA's 2024 Family Support Campaign



Help & Hope, our Family Support Campaign, is underway! We will be collecting donations through May 31st.

The funds raised in this campaign directly support our work in family support. We offer personal family support through our Package of Hope and mentoring program, assistance with the individualized education program (IEP) process as well as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) claims, training 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.

Please share the donation link with your friends and family and consider making a gift so we can continue to be a source of **Help & Hope** to our community.

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

"PWS is hard on everyone, and I'm grateful there are people like those on the Family Support team who pick us up and let us know we're not alone."

- Anonymous



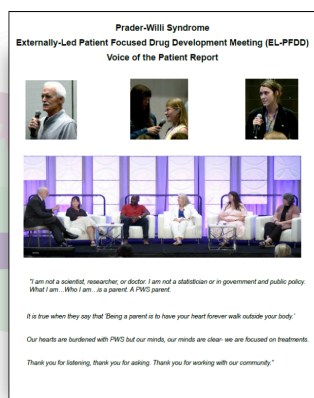
Another way to support PWSA | USA's Family Support Campaign is by hosting a **Hope United** fundraiser! In just minutes, you can create a personalized fundraising page in honor of a birthday, PWS Awareness Month, or even in memory of someone special. Click the button below to get started!

BECOME A HOPE UNITED CHAMPION!



ADVOCACY

The PWS Voice of the Patient Report has Been Filed with the FDA!



To kick off PWS Awareness Month, the **Voice of the Patient Report** was officially filed with the FDA! This timely filing marks a significant moment for the Prader-Willi syndrome community. The report gives crucial insights that amplify the perspective of individuals and families affected by PWS and sheds light on aspects of PWS that may not be fully captured in drug trials alone. Integrating the patient's voice throughout the drug approval process for PWS treatments is essential for the U.S. Food and Drug



Administration's (FDA) comprehensive understanding and impactful decision-making.

The Voice of the Patient Report was created following the June 2023 PWS Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting and is compiled of testimonials shared during the EL-PFDD meeting, as well as those submitted virtually.

PWSA | USA, FPWR, and IPWSO extend heartfelt gratitude to the entire PWS community for contributing to the success of this project. You can read the Voice of the Patient Report by clicking the button below.

[READ MORE HERE](#)

Urgent Call to Action for DCCR Petition!

We are rallying behind a critical petition urging the FDA to take action on DCCR (diazoxide choline) for individuals living with PWS. Soleno Therapeutics' investigational drug has shown remarkable promise in improving hyperphagia, reducing fat mass, and addressing challenging PWS-associated behaviors in clinical trials. This is a "petition to request that the FDA file, grant priority review, and review the application for DCCR for people living with Prader-Willi syndrome (PWS)". We encourage our community to sign the petition by May 23rd here. To learn more about the DCCR petition, watch our [PWS Community Advocacy Webinar HERE](#).

OUR MESSAGE TO THE FDA:

**FILE DCCR'S NEW
DRUG APPLICATION!**



SIGN ON NOW

DEADLINE: MAY 23, 2024



Scan the QR code to
learn more and access
the petition link



PRADER-WILLI SYNDROME
ADVOCACY COALITION

[CLICK HERE TO SIGN ON!](#)

DC Fly-In Hill Day Tips & Tricks



The D.C. Fly-In is less than two weeks away. Advocates are meeting weekly to discuss the legislative asks and how they are going to tell their stories to represent the PWS community. Meeting with a government official and representative can seem like an intimidating experience. If you are attending the Fly-In as an advocate, we've curated some Hill Day Tips and Tricks to help prepare you for your meeting and hopefully calm some of the nervousness you may be feeling. There is also still time to meet with our Community Engagement Specialist, Dorothea Lantz, to run through any questions or concerns you may be having about the Fly-In. Her office hours are Mondays from 12:00-2:00pm EDT and Fridays from 3:00-5:00pm EDT. Click [HERE](#) meet with her during these open office hours.

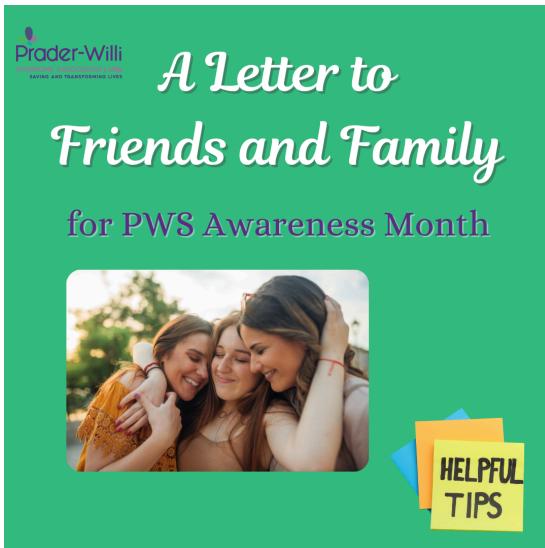
[DOWNLOAD THE TIPS & TRICKS DOCUMENT HERE](#)



FAMILY SUPPORT

A Letter to Friends and Family

In our world where we must actively advocate for our loved one and our family, it's good to ask for help. Hopefully sharing this letter with your friends and family can bring more awareness to your community and add to your foundation of support. This letter provides bullet-pointed tips on helping families avoid isolation, how to create a PWS-friendly environment, the importance of self-education, advocacy, and remembering the siblings, offering support during



stressful behavior moments, and more. Share this blog with your community, add any personal touches you deem necessary, and let your people know how they can help support you and your family.

[READ BLOG HERE](#)

Ask Nurse Lynn

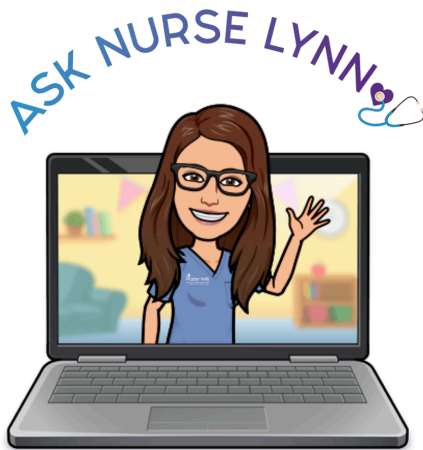
Question (Male, Newborn, Subtype unknown):

"How soon should a person who has been diagnosed with PWS start hormone therapy (specifically HGH)?"

One of the important first steps when receiving a diagnosis of PWS is learning about the use of growth hormone. To learn more about growth hormone therapy, read Nurse Lynn's response to this submission, and find important resource links, visit the blog "When to Start Growth Hormone Therapy."



[READ NURSE LYNN'S RESPONSE](#)



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

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

[ASK YOUR QUESTION HERE](#)

Family Support Webinars

Let's face it, even the strongest marriages are tested by the multitude of challenges that PWS throws at us. This month's Family Support Webinar will explore the science of human connection, focus on the unique stressors on our PWS marital and partnership relationships, and provide a multitude of strategies you can immediately practice to deepen your connection and closeness with your partner. Our host is Lisa Graziano, M.A., LMFT, parent of a 25-year-old son with PWS, long-time PWS advocate, and practicing Marriage and Family Therapist with over 30 years' experience specializing in marital and family therapy.

Family Support Webinar

Romancing the PWS Parent: Strategies to Create a Strong and Healthy Marriage

Facilitated By:
Lisa Graziano, MA, LMFT

Tuesday, May 28
5 pm Pacific, 8 pm Eastern

[REGISTER HERE](#)



Watch the recording of our April Family Support Webinar, **Everything You Need to Know About Extended School Year** with Dr. Destiny Pacha, at the button below.

[CLICK HERE TO WATCH](#)

Aging Health and Wellness Survey for Residential Care Providers 2024



PWSA | USA Volunteer Barb Dorn, RN, BSN, is seeking participants for a survey on aging and wellness.

"People with PWS are living longer than ever predicted. Research has begun to identify the effects of aging for these individuals, but we still have a lot to learn. I will be doing a webinar on Aging in July of 2024, and I need your help. In addition to sharing the current research, I would also like to focus on issues and concerns individuals 30 years and older are facing. I would greatly appreciate hearing from you regarding what health and wellness

challenges you are seeing in the individuals you support. I have kept this survey short. I hope it won't take much of your valuable time." Click on the button below to take the survey.

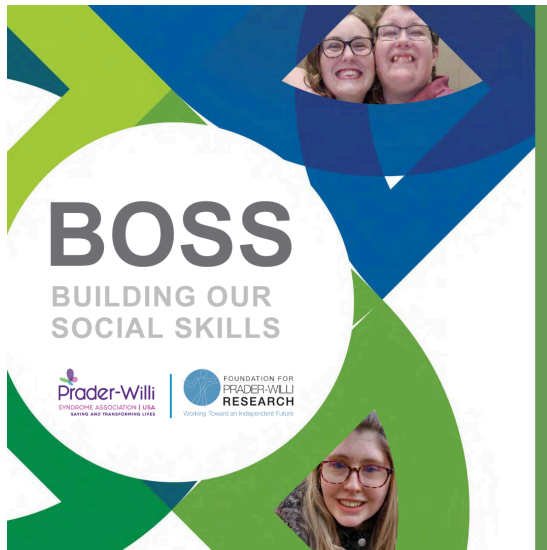
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BOSS Curriculum Sessions Pushed to July. Applications accepted through June!

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.

Due to a lack of registration, BOSS curriculum sessions have been pushed to July. We will be accepting applications through the month of June. These sessions will be held via zoom. All sessions are mandatory, and participants must be able to communicate vocally without assistance in order to participate in these virtual sessions. Please click the button below to find our application and 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](#)



RESEARCH

Request for Prader-Willi Syndrome Research and Mini-Fellowship Grant Applications

PWSA | USA is currently seeking research project applications with direct impacts on individuals and families affected by PWS. We are offering mini-fellowship grants to support providers in enhancing their understanding of PWS through clinical proctorships. Research priorities include expanding knowledge about PWS, applying therapies, and attracting new providers and investigators to the field. Funding opportunities include grants of up to \$100,000 for 12 months, with potential renewal, smaller grants of up to \$10,000, and mini-fellowships of up to \$25,000. Applications and inquiries can be directed to Stacy Ward at sward@pwsausa.org or by calling (941) 312-0400. The deadline to



submit a Letter of Intent is
September 1, 2024, 5:00pm EDT.
Click the button below to learn more
and to read additional guidelines.

[LEARN MORE HERE](#)

DCCR Update!

Soleno Therapeutics has announced a groundbreaking achievement: DCCR has been granted Breakthrough Therapy Designation by the FDA for Prader-Willi syndrome (PWS). This marks a significant milestone as the FIRST-EVER designation for a drug developed for PWS. The designation underscores the FDA's recognition of PWS as a serious condition and the potential for DCCR to offer substantial improvement for patients with hyperphagia. While this is a major step forward, it's important to note that DCCR's approval is still pending. However, Soleno plans to submit its New Drug Application (NDA) in mid-2024. To help ensure the FDA pays attention to this NDA, we encourage our community to sign the petition by May 23rd [HERE](#).

Read Soleno's full press release announcement by clicking below.

UPDATE ON DCCR



[READ ARTICLE HERE](#)

Harmony Biosciences' TEMPO PWS Study Announces New Trial Site



[Harmony Biosciences](#) has announced a third Clinical Trial Site for TEMPO PWS Study. You can find the specific study details and updates at the button below.

New Location information:
Texas Valley Clinical Research, LLC
Weslaco, TX

Coordinator contact:
Preston Hale
hale.rn@tvcrmail.com
(956) 647-2552

[VISIT THE LINK HERE](#)

Congratulations Dr. Butler, Highly Ranked Scholar!


Congratulations to Dr. Merlin Butler for being recognized as a ScholarGPS Highly Ranked Scholar. Dr. Butler works out of the Kansas University Medical Center as the Director of the Division of Research and Genetics, Professor Emeritus of Psychiatry, Behavioral Sciences and Pediatrics, and an ABMG Certified Clinical Geneticist and Clinical Cytogeneticist. "ScholarGPS celebrates Highly Ranked Scholars™ for their exceptional performance in various Fields, Disciplines, and Specialties. (The) prolific publication record, the high impact of (his) work, and the outstanding quality of (his) scholarly contributions have placed (him) in the top 0.05% of all scholars worldwide." Dr. Butler ranked #1 for Prader-Willi Syndrome and #16 for Medical Genetics for accomplishments spanning his career. Congratulations Dr. Butler and thank you for your contributions to the PWS community!



PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

Did you know that PWSA | USA has detailed fact sheets designed to focus on typical issues for specific age groups. These printable fact sheets provide important and easy to read information about PWS, health concerns, and ways to support your loved one. Share these fact sheets with your doctors, specialists, teachers, friends, and family to help them learn more about your loved one. We provide fact sheets for Infants, Toddlers, School Age to Young Adult, and Adult as easy ways to help spread awareness and support families in the PWS community. Click on the button below to check them out.



Prader-Willi Syndrome (PWS) – FACT SHEET

Infants with PWS

Brief Overview of PWS

- PWS is a very complex, neurobehavioral, genetic disorder caused by an abnormality on the 15th chromosome. Most of the challenges these infants face result from a defect in the area of the brain called the hypothalamus.
- It affects both males and females equally and in all races around the world.
- The prevalence range is 1:15,000 to 1:25,000 individuals.
- There are other genetic conditions or health issues that impact the hypothalamus, which may require the same support as a person with PWS.
- It is a "spectrum disorder" meaning there are personal differences in the degree of challenges that these infants face. They are individuals. They are not all the same.
- Due to advances in research and hormone replacement therapy, many infants have experienced significant health and developmental benefits from growth hormone.
- There is no cure however, ongoing research continues. We are gaining more knowledge and understanding to help prevent and manage many of these challenges. There is hope for a cure.

Common Features You May See

- Infants with PWS are beautiful, happy babies.
- All experience poor muscle tone which often results in delayed developmental milestones. They may be slower to hold up their heads, roll over, crawl, and walk. However, you will see progress as their muscles grow stronger.
- They have weak muscles in their face and mouth, so they have a poor suck resulting in the need for specialized feeding techniques. Some may have a temporary feeding tube.
- Feeding and introducing solid foods takes time and patience. Nutrition is very important but, because of their muscle weakness, it often takes them time to master eating. It is important to provide a high fat diet. A nutritious high fat diet is important for all infants to assist in brain development.
- They tend to sleep a lot. They rarely cry and when they do, it may be weak.

Health Concerns

- Growth Hormone (GH) deficiency. There are numerous benefits for an infant to begin GH as soon as they complete an evaluation by a pediatric endocrinologist.
- It can be challenging for the infant to gain weight. Your primary care provider may have your baby come in for more frequent visits to make sure they are gaining weight and growing.
- Infant boys may experience undescended testicles. Discuss with the health care provider. A referral to a pediatric surgeon or urologist is recommended.
- Temperature regulation problems. They may not run fever when infection is present, and they are sensitive to high or low external temperatures.
- Respiratory issues – hypoventilation (shallow, slow breathing), sleep disordered breathing, and sleep apnea may be seen in some infants.

TOUL & BRIDGES 800-84-1414, BRIDGES, FL 32011 | PHONE: (904) 274-0900 | WWW.PWSUSA.ORG

PWS FACT SHEETS

Rare Aware Art Share Printify Shop



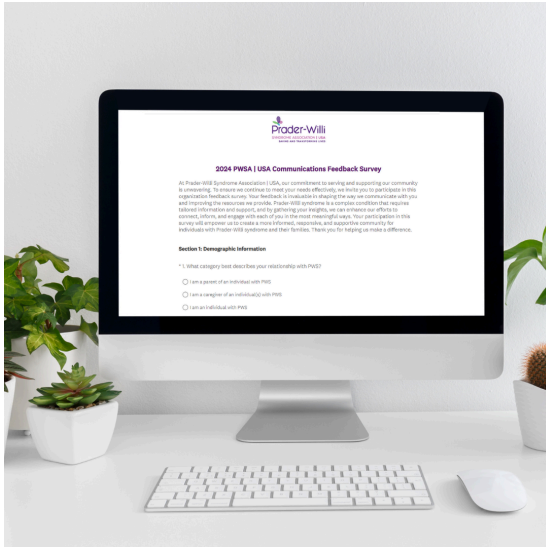
We have created a way for you to proudly wear and display art created by our participating artists living with Prader-Willi syndrome. Printify is our print-on-demand (POD) platform that allows you to choose from a wide range of products. Creating a product from our Rare Aware Art Share is a chance to support art that you enjoy and is a unique and lighthearted way to start those conversations that spread awareness and education on PWS to your community. Check out our Printify shop to see what products are ready for purchase or visit our virtual gallery to learn about designing your own and explore the art submitted for our theme "What is your superpower?"

PRINTIFY STORE

RARE AWARE ART SHARE GALLERY

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](#)

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 Bi-Weekly Pulse: May 24, 2024

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 99

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Thank you to Soleno Therapeutics for providing PWS Awareness center stage in New York City! People with PWS were invited to share their picture to help spread awareness that people with PWS are Determined, Resilient, Hopeful, Beautiful, Powerful, and Loved. Check out the project and how they are asking for support for PWS at Support4PWS.com. As we wind down PWS Awareness Month, we hope that you all have had an opportunity to educate your community on this rare genetic disorder, let people know how they can support you and your family, and remind them that your loved one is capable of so much. If you haven't taken advantage of our PWS Awareness Month hub and the resources for spreading awareness, there is still time. (And of course awareness doesn't end when the month does.) We encourage you all to let your

communities know that awareness matters and that our loved ones with PWS deserve to be seen and understood.

[WATCH TIMES SQUARE VIDEO](#)

Thank you for supporting PWS Awareness!



 PWSA | USA'S
SPOTLIGHT ON HOPE

In honor of PWS Awareness Day, dedicated PWS parent Heather James took the stage at the Kiwanis Club in Texarkana, TX, to share an enlightening presentation about Prader-Willi syndrome. Heather's passion and knowledge truly shined, leaving everyone informed and inspired. The audience was captivated, and the positive feedback was overwhelming! Thank you, Heather, for your incredible advocacy and for spreading much-needed awareness about PWS. Together, we can make a difference!



Spreading PWS Awareness

EVENTS & FUNDRAISERS

Campaign Ending Soon!

Help us Reach our Goal and Support PWSA | USA's 2024
Family Support Campaign



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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.

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- Anonymous

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[BECOME A HOPE UNITED CHAMPION!](#)

Registration for 2025 International PWS Conference Opens June 1st!



United in HOPE

2025 PWS CONFERENCE



2025 INTERNATIONAL PWS CONFERENCE | PHOENIX, AZ



June 24-28, 2025



Arizona Grand Resort & Spa

[Learn More Here](#)

Registration for Residential Providers Conference

RESIDENTIAL PROVIDERS Conference

Empowerment Heroes: Reveal Your Superpowers | IN-PERSON & VIRTUAL

Thank you to our sponsors



SOLENO
THERAPEUTICS

HB HARMONY
BIOSCIENCES



August 18-20, 2024



Savannah, Georgia
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[REGISTER HERE](#)



ADVOCACY

DC Fly-In Recap Coming Next Week!



With almost 150 members of the PWS community present, we had an incredible and inspiring few days in Washington, DC. We met with the representative offices of 31 states, participated in panel discussions, listened to motivated speakers, and enjoyed the company of those living with PWS, other parents and caregivers, and supporters of our community. We have many heartwarming stories to share, and impactful statistics to relate and we look forward to doing so in next week's special edition Pulse. Stay tuned for a detailed recap into an incredible trip to DC!

A reminder to those who attended: Please upload any photos you took during the Fly-In to our shared Google Drive.

[UPLOAD PHOTOS](#)



FAMILY SUPPORT

Nutrition Discourse in the PWS Community



There are many factors that go into the decisions that families make around food, and many reasons why we, as a community, need to have healthy, respectful conversations on nutrition and food security. It is incredibly important for caregivers to have access to information about nutrition and tips for controlling access to food. Discussions on recipes and meal ideas can help broaden a caregiver's scope of food and nutrition choices, help grow their education around nutrition, and help ease the stress of constantly having to think about and prepare food.

Respectful, open, and knowledgeable conversations about food are a great way to support one another. Read our blog "Nutrition Discourse in the PWS Community" to learn more about the factors that go into our food choices (like socioeconomics, education, beliefs, cultural identities, etc.) and how we, as a community, can support one another.

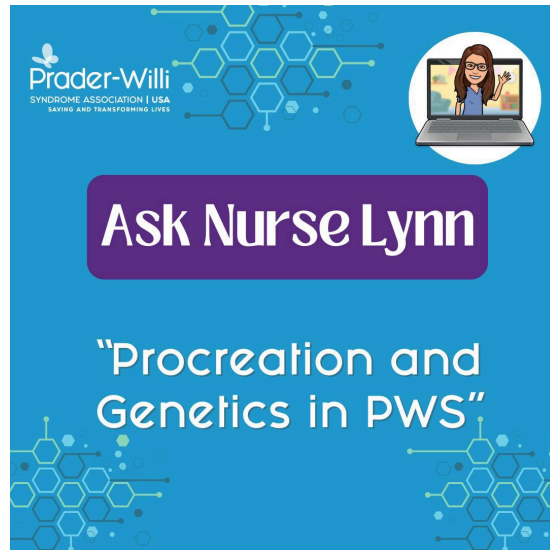
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Ask Nurse Lynn

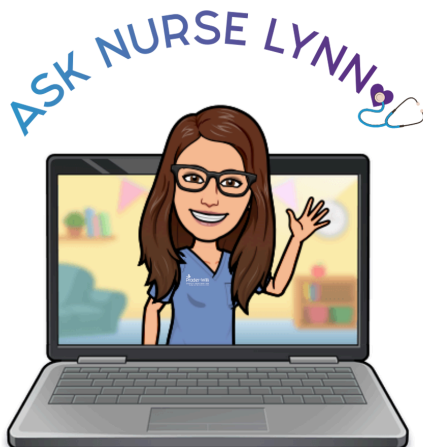
Question (Female, 34 Deletion):

"My daughter continues to wonder how/why some ladies with PWS have been able to conceive, give birth. As a teenager, an ultrasound determined that she had 'follicles,' but she's not ever menstruated. She continues to want to investigate the possibility of becoming pregnant. We've explained that this is highly unlikely, but she's learned of a handful of women with PWS who have ... Your thoughts, please."

Visit our blog to read Nurse Lynn's response about procreation and genetics in PWS.



[READ NURSE LYNN'S RESPONSE](#)



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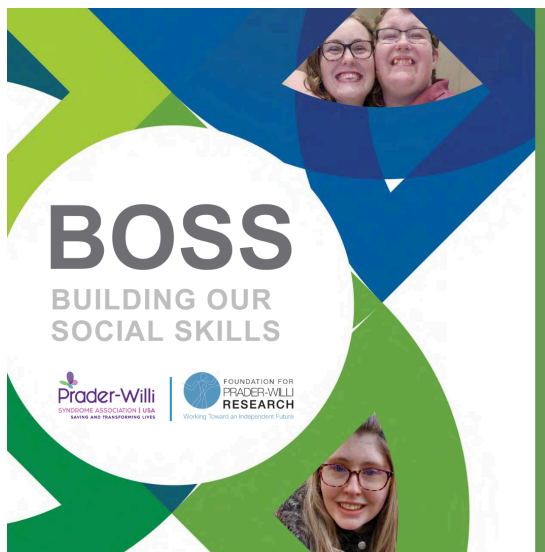
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PWSA | USA is thrilled to offer more sessions for the **Building Our Social Skills (BOSS) curriculum**, a highly effective social skills intervention program created at Vanderbilt University. The BOSS curriculum provides tailored social groups to teens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

Due to a lack of registration, BOSS curriculum sessions have been pushed to July. We will be accepting applications through the month of June. These sessions will be held via zoom. All sessions are mandatory, and participants must be able to communicate vocally without assistance in order to participate in these virtual sessions. Please click the button below to find our application and 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](#)



RESEARCH

Request for Prader-Willi Syndrome Research and Mini-Fellowship Grant Applications

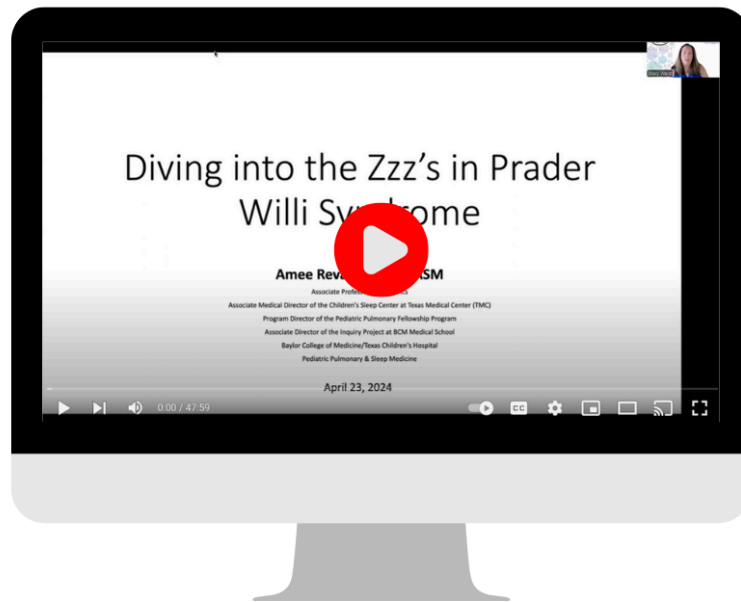


PWSA | USA is currently seeking research project applications with direct impacts on individuals and families affected by PWS. We are offering mini-fellowship grants to support providers in enhancing their understanding of PWS through clinical proctorships. Research priorities include expanding knowledge about PWS, applying therapies, and attracting new providers and investigators to the field. Funding opportunities include grants of up to \$100,000 for 12 months, with potential renewal, smaller grants of up to \$10,000, and

mini-fellowships of up to \$25,000. Applications and inquiries can be directed to Stacy Ward at sward@pwsausa.org or by calling (941) 312-0400. The deadline to submit a Letter of Intent is September 1, 2024, 5:00pm EDT. Click the button below to learn more and to read additional guidelines.

[LEARN MORE HERE](#)

**Sleep ECHO with Dr. Ameer Revana Webinar
Recording Now Available**



**Funding for this
program is provided by
a grant from Harmony
Biosciences**

PWSA | USA ANNOUNCEMENTS

PWSA | USA Welcomes New Staff Member!

Kasey Vogler, our new Development Specialist: Peer 2 Peer Fundraising, comes to her work at PWSA from a very strong sales background where she was recognized for her natural abilities as well as her tremendous skill in coaching others and helping them succeed. Kasey is very excited to provide support, encouragement, and new tools to help our volunteer fundraisers reach and exceed their goals. She connected with PWSA | USA when her son Cooper (aka "Coop") was diagnosed with PWS at only 8 days old. She is grateful for the HOPE and the world of resources available through our organization and is excited to give back! Kasey is also an accomplished runner and has multiple half-marathons under her belt (one full marathon too). Although Kasey never imagined finding herself on a PWS journey, she couldn't be prouder to serve

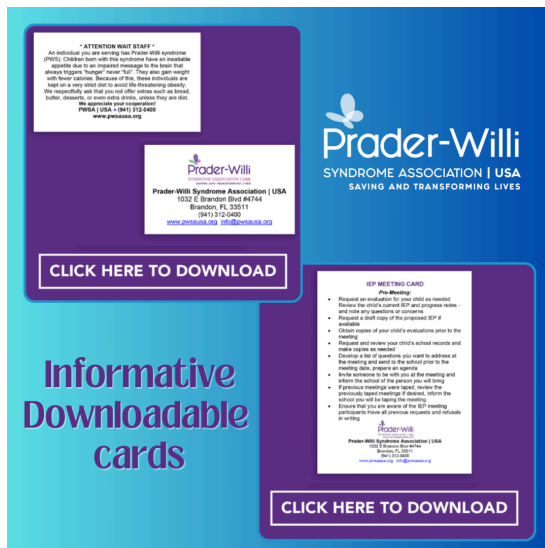


such a deserving community. She has an unwavering passion to support and lead fellow PWS families into the light and to foster that sense that we are all stronger when we work and fight together.

Kasey is devoted wife to Ben, and mother to two beautiful children, Collins (5), and Cooper (infant) living with PWS. She's also doggy mama to Deacon, Bart, and Keller. Kasey and her family live in North Carolina.

PWSA | USA Resource Spotlight

Did you know that PWSA | USA has downloadable cards for important occasions when quick reminders or a brief, but necessary introduction to PWS can support caregivers and help keep our loved ones safe? We have a customizable and downloadable ID card to share with those meeting your loved one. Download and print cards for law enforcement or the wait staff at a restaurant to provide critical information important to keeping your loved one safe and secure. You can also download a handy card to take with you to your next IEP, helping you remember appropriate and necessary steps and requests during your meeting.



[PWS CARDS](#)

Rare Aware Art Share Printify Shop

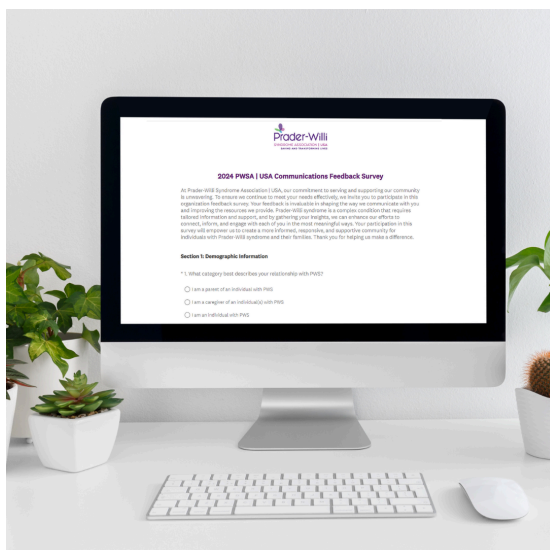


We have created a way for you to proudly wear and display art created by our participating artists living with Prader-Willi syndrome. Printify is our print-on-demand (POD) platform that allows you to choose from a wide range of products. Creating a product from our Rare Aware Art Share is a chance to support art that you enjoy and is a unique and lighthearted way to start those conversations that spread awareness and education on PWS to your community. Check out our Printify shop to see what products are ready for purchase or visit our virtual gallery to learn about designing your own and explore the art submitted for our theme "What is your superpower?"

[PRINTIFY STORE](#)

[RARE AWARE ART SHARE GALLERY](#)

Survey Closing Soon! 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](#)

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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PWSA | USA Special Edition Pulse: May 31, 2024

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PWSA | USA Special Edition

PULSE

FRIDAY, MAY 31, 2024



D.C. FLY-IN 2024



From Dorothea Lantz, Director of Community Engagement

From May 13th through 15th, the Prader-Willi Syndrome Association (PWSA) | USA held its second biennial DC fly-in to celebrate PWS Awareness Day. This event was a resounding success, drawing 139 dedicated advocates from 31 states across the nation. Together, these advocates attended a remarkable total of 131 Congressional meetings, highlighting the widespread support and commitment to advancing our cause.

Congressional Meetings Overview

Our advocates engaged in meaningful discussions, ensuring that the voices of those affected by Prader-Willi syndrome were heard loud and clear on Capitol Hill. We gathered congressional support for adding Prader-Willi syndrome to the Department of Defense Peer Reviewed Medical Research Program, gathered co-sponsors for the Promising Pathway Act, and obtained congressional support for PWS research and development with the FDA.

Policy Dive Panel Discussion

A key highlight of the fly-in was our in-depth policy dive, featuring a distinguished panel discussion. The panel included:

- Chris Jones: Senior Policy Advisor for Representative Gus Bilirakis, of Florida
- Jacob Chebowski: Legislative Assistant for Senator Mike Braun, of Indiana
- Terry Wilcox: CEO and Co-founder of Patients Rising

The panelists provided valuable insights into health care policies affecting the rare disease community, with a particular focus on the Promising Pathway Act 2.0. Their expertise and perspectives helped our advocates understand the legislative landscape and the importance of continued advocacy for improved health care policies.

Impact and Takeaways

The fly-in was an inspirational and educational experience for all involved. Our advocates left with a renewed sense of purpose and a deeper understanding of the legislative process. Our efforts on the Promising Pathway Act 2.0 made a direct impact and helped Senator Braun file this legislation with revised language the week following our event! The connections made, relationships we continue to foster, and the knowledge gained will undoubtedly strengthen our ongoing efforts to support individuals with Prader-Willi syndrome and their families.

We are immensely proud of the commitment and enthusiasm shown by our advocates and are grateful for the support of the Congressional members and their staff who took the time to meet with us. Together, we are making significant strides toward better, more inclusive health care policies for rare diseases and greater awareness for Prader-Willi syndrome.

Thank you to everyone who participated and contributed to the success of our 2nd PWSA | USA DC Fly-in. We look forward to continuing this vital work and building on the momentum we have created. If you are interested in joining our advocacy team, please email Advocacy@pwsausa.org.

131

Congressional
Meetings



139

Attendees

31

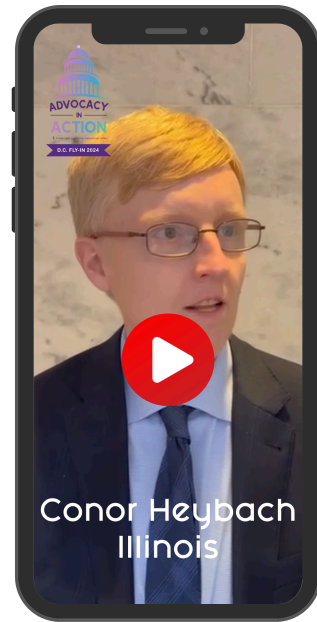
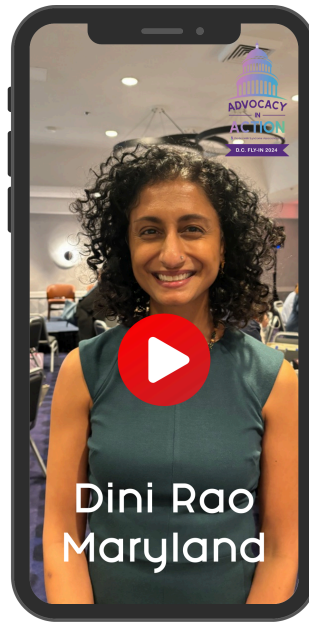
States &
Districts
Represented



- Congressional meetings: 131
- Member level meetings: 13
- Attendees: 139
- States represented: 31
- Senate meetings: 67
- House meetings: 64
- Democrat offices: 74
- Republican offices: 55
- Independent offices: 2



DC Testimonials



James Towle, Massachusetts, living with PWS

What do you want to get across to your representatives?

"The low muscle tone. I struggled with that a lot when I was younger and the fact that I was watching a lot of the time, watching my friends and peers participating in physical activities and sports and stuff, watching them from the sidelines more often than participating. It was a struggle. I wanted to participate but just couldn't because I didn't have the muscle strength to do that. If the research continues, and if the medications and therapies increase, and the openness for services increases, I hope that it will eventually become easier for others to do that and get more into physical activities and building muscle structure."



Vonnie Sheadel, Washington, Mom to Bill, 44, living with PWS

What are you most compelled to fight for?

"The Promising Pathway Act, to me, is the biggest one. We've been waiting for 44 years for a treatment. He's been in different research studies for drugs that were absolutely successful. You could see in our home our whole life was better... calmer, easier, he was happier - but they just never were passed through the FDA. So, I see the promise of it and I'm just waiting for the one that gets passed."





Charles Conway, Virginia, Dad to Angelica, 4, living with PWS

Do you have advice for people who may want to attend the next fly-in?

"Do it, because once you do it one time you get comfortable. We're not only talking at the national level. You'll be able to do it at the state level. What people need to understand is once we get stuff done and approved through congress and FDA, that's the easy part, to me, honestly. Now you got to go to the state level who is tied to approving diagnosis lists, who has to work with Medicaid and Medicare to get drugs approved. They have to work with insurances so at the higher level through congress, once we get that approved, now it's really time to go to work. Now we got to get the states to get involved."



Photo Gallery



[CLICK HERE TO VIEW
THE PHOTO GALLERY](#)

Thank You Gregg Harper



Former Congressman Gregg Harper from Mississippi spoke to our fly-in attendees about advocating for our loved ones with PWS. He is the father of an adult living with Fragile X syndrome and an experienced Rare Disease advocate. With his friendly demeanor and extensive experience of DC, he shepherded our community into the halls of congress and helped us feel

welcome. Thank you, Congressman Harper, for sharing your story, inspiring our advocates, and setting us on the path to our representatives.

Thank You Sponsors

We want to extend a heartfelt thank you to our amazing sponsors for their support - [Aardvark Therapeutics](#), [Acadia Pharmaceuticals](#), [Harmony Biosciences](#), and [Solenio Therapeutics](#). We are truly grateful for what you bring to the PWS community and the many ways that you support our efforts and our loved ones with PWS. Thank you for actively believing that our loved ones deserve options and pathways to a better life. Thank you for being on this journey with us!



Continuing Advocacy

While in D.C., PWS advocates presented their representatives with an "ask" to sign on to the Promising Pathway Act 2.0 (bill number [S. 4426](#)). The Promising Pathway Act 2.0, recently introduced to Congress on May 23, 2024, will create a conditional approval pathway for drugs intended to treat rare, progressive and congenital diseases. The PWS community, with many unmet needs, has long awaited treatment options. This bill will open pathways for promising treatments

PROMISING PATHWAY ACT

=

Hope

Introduced to Congress

to reach individuals living with PWS. Promising Pathway 2.0 was introduced by Senator Mike Braun, Senator Kirsten Gillibrand, Senator Kevin Cramer, Senator Joe Manchin, Senator Eric Schmitt, Senator Alex Padilla, Senator J.D. Vance, Senator Cory Booker, Senator Josh Hawley, Senator Peter Welch, and Senator Lisa Murkowski.

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