

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

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 96

April 5, 2024

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



**HELP & HOPE**  
TOGETHER WE'VE GOT THIS  
Prader-Willi Syndrome Association | USA

## Family Support Campaign

PWSA | USA's Family Support Fundraising Campaign kicked off on Monday, April 1, and runs through May 31! The campaign will focus on sharing all of the valuable ways PWSA | USA offers **Help & Hope** to the PWS community. We offer support for all families of individuals with PWS in all the various stages of life. You can learn more about how PWSA | USA supports our community by reading our recent blog post "How Family Support Helps Your Family."

[READ ARTICLE HERE](#)

DONATE TO HELP & HOPE HERE

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

## Own Your Story



Advocacy has many faces. Sometimes it wears the face of a seasoned advocate confidently shaking hands in the halls of D.C. Sometimes it is a lone parent facing a board of teachers and specialists across a table piled with IEP notes and assessments. Other times it is a parent sharing their family's story and vulnerability from a podium. Denise Servais is one of those advocates. You can read about Denise's experience and what inspired her to step up and own her story.

[READ BLOG HERE](#)

## EVENTS

## SPECIAL ANNOUNCEMENT!

# United in HOPE

2025 PWS CONFERENCE



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](#)

## Hope United Ohio 5K & Family Fun Run

Saturday, April 20, 2024  
11:00 a.m. - 2:00 p.m. EDT

Glacier Ridge Metro Park  
Plain City, Ohio



### Calling all Ohio residents!

Register as a PARTICIPANT (in-person or virtual) or SPONSOR for 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

### Open Office Hours for D.C. Fly-In Participants

### D.C. Fly-In Open Office Hours Have Begun!

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**. Dorothea is offering assistance now until the date of the Fly-In via ZOOM to answer questions, work through your story, or just help settle down jitters.

Office hours will take place Mondays from 12:00 p.m. - 2:00 p.m. EDT and

Fridays from 3:00 p.m. - 5:00 p.m. EDT. You can save the ZOOM 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](#)

## Scholarship for Adults with Rare Disease

This year, the **#RAREis Scholarship Fund**, in partnership with the EveryLife Foundation for Rare Diseases, will be awarding \$5,000 scholarships to 88 adults (17+) living with a rare disease. Applications are open until April 22 at [Rarescholarship.org](https://rarescholarship.org). Recipients and non-recipients will be notified this summer and payment will be provided directly to the educational institution for Fall 2024. For more detailed information, visit: <https://everylifefoundation.org/rare-scholarship> or click the button below to read about who is eligible and how to apply.

## #RAREis Scholarship Fund

Powered by the EveryLife Foundation

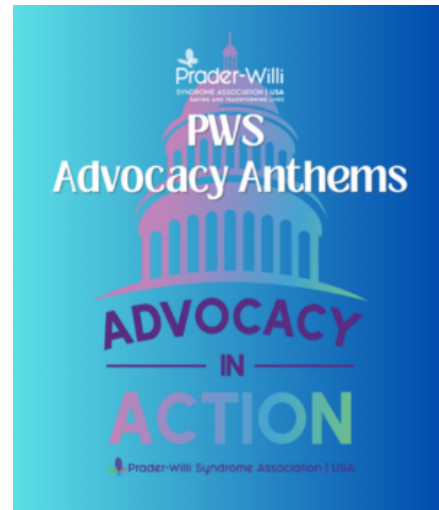
**APPLICATIONS  
CLOSE APRIL 22, 2024  
AT 2:00 PM ET**

[RareScholarship.org](https://rarescholarship.org)

[LEARN MORE HERE](#)

## PWS Advocacy Anthems

As PWSA | USA staff and volunteers prepare to head for Washington, D.C., in May, let's revel in the inspiring power of music! We are curating a list of songs to empower, inspire, and remind people that their stories matter and should be heard! While out on your daily walk, cooking dinner, driving to work, or packing for D.C., join others in the PWS community as we let these influential rhythms and melodies inspire our resolve. You can listen to this growing list of songs by searching PWS Advocacy Anthems on Spotify or click below.



[ADVOCACY ANTHEMS](#)



## FAMILY SUPPORT

### Travel Blog Series

A common worry among families after receiving a diagnosis is how much life will change. Will we be able to go out to restaurants or celebrate birthdays? Will we be able to have a vegetable garden or go to neighborhood barbecues? Will we ever be able to travel? Every family must manage the challenges of PWS in the way that works for them and their loved one. For many families, travel is still a vibrant and exciting part of life. We are collecting and sharing these tales and travel tips to help educate and inspire those families wondering how travel can still be a part of their future. Click on the button below to read one family's cruising adventure and travel tips, and find the form to share your own.

# Cruising with Grace

PWS Travel Tale



[READ BLOG HERE](#)

## Ask Nurse Lynn

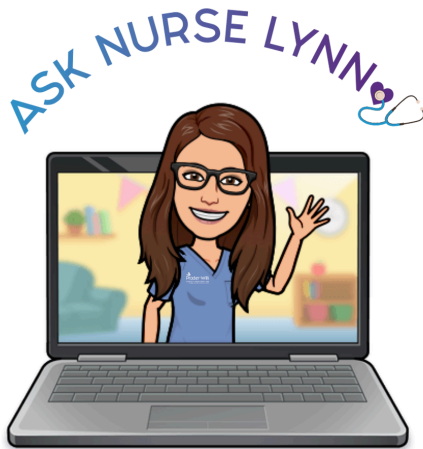
### Question (Female, 15, Deletion):

Do you happen to know of any standard of care as far as hormone support or instigating a menstrual cycle in females with PWS? Is there any harm in waiting to initiate a cycle? I know a lot of women and girls with PWS never start their period without medical intervention, but many do start, just later than most. We're getting a lot of pressure to get started with these things, but there are lots of indications that my girl may start her cycle at any time (hormone levels/physical development). I'd like to see that happen if it is possible and not problematic.

You can read Nurse Lynn's response in the blog "Menstruation and Hormone Support."



READ THE ANSWER 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

## Family Support Webinars

Join PWSA | USA and Dr. Destiny Pacha for our April Family Support webinar, "Everything You Need to Know About Extended School Year." The webinar will be held on Tuesday, **April 23, 2024 at 5:00 p.m. PST / 8:00 p.m. EDT**. Dr. Destiny Pacha is an Educational Consultant with more than 20 years of experience in the educational field. She is also the author of the children's book "It Starts with Hello: Katie's Story About Prader-Willi Syndrome." Register for the webinar below.

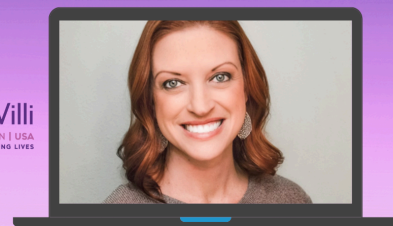
Family Support Webinar

### EVERYTHING YOU NEED TO KNOW ABOUT EXTENDED SCHOOL YEAR

Facilitated by: Dr. Destiny Pacha

Tuesday, April 23, 2024  
5pm PST/ 8pm EST

 Prader-Willi  
SYNDROME ASSOCIATION | USA  
SAVING AND TRANSFORMING LIVES





[REGISTER HERE](#)



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

[CLICK HERE TO WATCH](#)

Watch the recording of our March Family Support Webinar, **Psychosis in PWS, Early Signs, Diagnosis, and Treatment** with Elizabeth Roof, MA, HSP, at the button below.

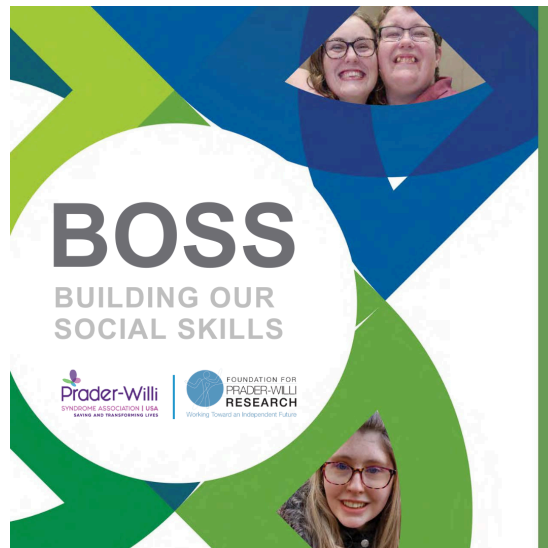


[CLICK HERE TO WATCH](#)

## 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 5:00 p.m. EDT, 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](mailto:info@pwsausa.org).

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

[LEARN MORE HERE](#)

## Upcoming Sibling Community Conversation



PWS Siblings! If you are between the ages of **12 - 18** and have a sibling of any age with PWS, please join us for PWSA | USA's next Sibling Community Conversation on **Wednesday, April 10 at 5:00 p.m. PST / 8:00 p.m. EDT**. This discussion provides a safe place for dialogue between siblings of a person with PWS. PWSA | USA team members will also be available to offer insight and support. Register in advance by clicking the button below. We hope to see you there!

[REGISTER HERE](#)

## PWS Aging Health and Wellness Survey

Barb Dorn, a former PWSA | USA Family Support counselor and current member of PWSA Wisconsin board is seeking parents of adults with PWS over the age of 30 for a survey on the aging health and wellness of individuals with PWS. Barb plans to do a presentation on aging in July to share information about current research on this topic as well as discuss some of the issues and concerns that people have been seeing. Her goal is to receive at least 50 responses. If you are interested and fit the criteria, please follow the button below to this brief, one page survey.



[TAKE SURVEY](#)

## Grief and Bereavement in Children with Intellectual Disability Study

**UNIVERSITY of MARYLAND BALTIMORE**

**Has your child with an intellectual disability experienced the death of someone in their life?**

Looking for parents/guardians for important research study

We are conducting a study to understand more about how children with intellectual disabilities grieve after the loss of someone in their life. If your child has experienced such a loss, we invite you to participate in this study to help us learn how to support other children in similar situations.

Participants will be interviewed for approximately one hour and will receive a \$25 gift card as a token of appreciation. Interviews will be conducted by video or phone.

Your child may optionally join for a short portion of the interview.

Please email [arlengaines@umaryland.edu](mailto:arlengaines@umaryland.edu) or call 240-242-7424 for more information.

**Who may be eligible?**

- Parents/guardians over 18 who have a child with an intellectual disability.
- The child was between the ages of 5-17 when they experienced the death of someone significant in their life (such as a parent, sibling, grandparent, or friend).
- The death was at least 6 months ago and no longer than 3 years ago.

IRB # HP-0108903, Date Approved 02/05/2024

*On behalf of the University of Maryland, Baltimore*

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LEARN MORE HERE



## RESEARCH

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



### ECHO 4 PWS

**Topic: Sleep with Dr. Ameer Revana**

Date: Tuesday, April 23, 2024

Time: 3:00 p.m. PST / 6:00 p.m. EDT

Location: ZOOM



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

PWSA | USA's next **Healthcare Provider Project ECHO Series** webinar will now take place on April 23, 2024, at 6:00 p.m. EDT. The topic discussed will be **Sleep** presented by Ameer 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

## Harmony Biosciences Announces Study Sites for Pitolisant Study, TEMPO



Harmony Biosciences is seeking participants for its TEMPO study, a global Phase 3 trial investigating pitolisant as a potential treatment for excessive daytime sleepiness (EDS) in individuals aged six years and older with Prader-Willi syndrome (PWS). Pitolisant is a medication that could help manage sleepiness and behavioral issues in people with PWS. There are two trial sites currently open and accepting patients: Santa Monica, CA and Atlanta, GA. Click on the button to learn more.

[LEARN MORE HERE](#)

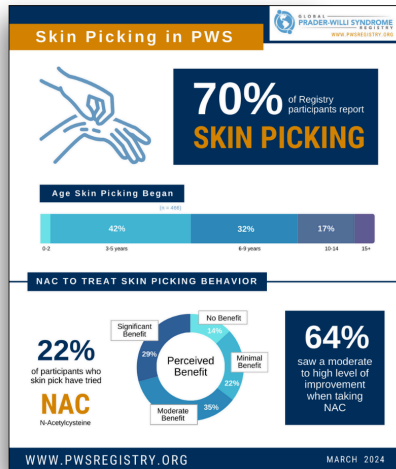
## FAM-PWS 2024 A Study of Families Living with PWS

Psychology Researchers at the University of Galway in Ireland are seeking parents and guardians of individuals with PWS to consider taking part in their study. Their study will examine the experiences and well-being of families living with PWS. The study survey can be completed online in around 20-25 minutes. Their intention is to give voice to parents and siblings of individuals with PWS, validate their experiences, and to paint a richer picture of the lives of families who live with PWS.



LEARN MORE HERE

## Global PWS Registry Shares Data from Skin Picking Survey



Skin picking is a common issue among individuals with PWS, often starting in childhood. It can lead to physical harm, including scarring and infections. Data from a recent Global PWS Registry survey suggests various causes, including obsessive-compulsive tendencies and self-stimulation behaviors. Behavioral approaches, like redirecting attention, and preemptive measures, such as moisturizing the skin, are recommended. Some families have reported benefits from the dietary supplement N-acetyl cysteine (NAC), but consulting a physician is advised.

The Global PWS Registry underscores the widespread occurrence of skin picking, highlighting the need for tailored treatment approaches. For more information or to participate in the registry, visit [pwsregistry.org](https://pwsregistry.org) or contact [info@pwsregistry.org](mailto:info@pwsregistry.org).

DOWNLOAD THE INFOGRAPHIC HERE

## 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

## IN MEMORY OF



*Contributed by Shannon's family*

God gave Shannon to us on June 3, 1984. A beautiful daughter that would change our lives. Through laughter, love and even tears we enriched each other's life.

She started school in Colorado Springs. At the age of 6 we moved to Tucson AZ where she then attended school and graduated in 2006 from Rillito Center. Through those years, the Christian congregation played an important role in forming the young lady she would become.

She loved people (especially babies), a close second was her love of animals. She was fearless in talking to people. No hang-ups or barriers would stop her from approaching a stranger, who would soon become a friend. She loved to smile and laugh with anyone who would spend time with her.

Yet, beneath it all, it was a challenge for Shannon due to her rare disease of Prader-Willi Syndrome. Sad to say, due to complications of this syndrome, her life ended on March 14, 2024. Far too soon. But she is in our hearts and God's memory.

*Our hearts are with Shannon and her family. May she rest in peace and her family find comfort on the memories of their lives together. The family have asked their friends and community to make donations to PWSA | USA's Family Support in honor of Shannon.*

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: April 19, 2024

Enhancing the Quality of Life and Empowering Those Affected by PWS



**Vol. 97**

April 19, 2024

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

## National Volunteer Week



As we head into National Volunteer Week (April 21-27) we'd like to take a moment to acknowledge the many wonderful volunteers who help the PWS community through PWSA | USA. Our volunteers help us to continue striving to meet the needs of families across the country and beyond. Together, we strengthen and uplift our community and our loved ones with PWS. Click on the button below to learn more about the types of volunteers who support the PWS community through PWSA | USA and learn how you can participate. To all of our volunteers, past, present, and future, **we thank you!**

[READ BLOG HERE](#)

[DONATE TO HELP & HOPE HERE](#)

## PWSA | USA'S SPOTLIGHT ON HOPE



Kristi Rickenbach, PWSA | USA's Parent Support Coordinator, was featured in an article on Patient Worthy®, a valuable online resource for the rare disease community. In her "Rare Community Profiles" feature she spoke about PWS specifically and shared a bit of her own story about being the mother to a daughter with PWS. She also talked about growth hormone and the need for more treatments for our loved ones, along with how to advocate for getting those treatments. Kristi continues to be a voice of hope for the PWS

community, and we are grateful for her! You can read Kristi's feature by clicking the button below.

[READ FEATURE HERE](#)

## EVENTS & FUNDRAISERS

**Register to Attend the Upcoming PWS Advocacy Webinar to Learn How You Can Help Unlock Access to PWS Treatments**

Join us **Thursday, April 25, at 4:30pm Pacific/ 7:30pm Eastern**, for a webinar to learn more about advocating for new treatments for PWS and prepare for several important initiatives to support access to approved treatments for PWS.

This webinar, brought to you by the PWS Advocacy Coalition, will be presented by James Valentine and Larry Bauer, from Hyman, Phelps & McNamara, who are both experts in helping bring patient and caregiver voices into the drug development process and FDA decision-making. James and Larry will review the FDA's drug review process and discuss where patients and caregivers may have input into that process. We will also discuss the upcoming launch of a community petition to encourage the FDA to file the New Drug Application (NDA) for DCCR (Diazoxide Choline). Register in advance at the button below.

## PWS COMMUNITY ADVOCACY WEBINAR

Learn more about advocating for new treatments for PWS and prepare for several important upcoming initiatives.



THURSDAY, APRIL 25  
7:30 PM ET

REGISTER NOW

Hosted by the PWS Advocacy Coalition



[REGISTER HERE](#)

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

**HELP & HOPE**  
TOGETHER WE'VE GOT THIS  
Prader-Willi Syndrome Association | USA



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!](#)

**Residential Providers Conference**


## RESIDENTIAL PROVIDERS: SAVE THE DATE!

# RESIDENTIAL PROVIDERS Conference

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

Thank you to our sponsors



 August 18-20, 2024

 Savannah, Georgia  
Kimpton Brice Hotel



More details and registration coming soon!



## The Ohio 5K & Family Fun Run is Happening TOMORROW!

### Hope United Ohio 5K & Family Fun Run

Saturday, April 20, 2024  
11:00 a.m. - 2:00 p.m. EDT

Glacier Ridge Metro Park  
Plain City, Ohio



### Calling all Ohio residents!

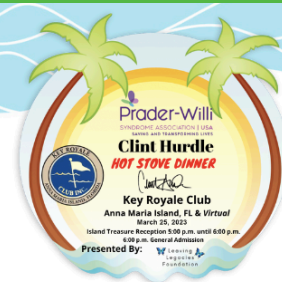
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interested in being a participant or sponsor for this event, please register at the button below. You can also fundraise on your own to support this event by clicking [HERE](#). We hope to see you there!

[REGISTER FOR THE OHIO 5K & FAMILY FUN RUN HERE](#)

## Thank You Hosts, Participants, and Donors!



Thank you to hosts Clint and Karla Hurdle, Leaving Legacies Foundation, and everyone who attended and participated in this year's **Clint Hurdle Hot Stove Dinner!**

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



## ADVOCACY

### Introducing PWSA | USA's D.C. Fly-In Legislative Asks

#### Legislative Ask #1

### Promising Pathway Act (PPA) 2.0

The Promising Pathway Act 2.0 would allow the FDA to grant time-limited conditional approval for drugs intended to treat only rare, progressive, and congenital diseases that have demonstrated evidence of safety and early evidence of effectiveness. Patients would be able to access the conditionally

approved drugs through their insurance. Sponsors must bring conditionally approved drugs to market within a reasonable time frame.

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### Legislative Ask #2

## Peer-Reviewed Medical Research Program (PRMRP)

By adding Prader-Willi syndrome as a recognized topic area for the U.S. Department of Defense's research under the Congressionally Directed Medical Research Program's PRMRP, scientists, researchers, and patient advocacy groups would have an opportunity to fast-track multiple research projects that may lead to therapies for our loved ones with PWS.

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### Legislative Ask #3

## Congressional Letter of Support for PWS to the U.S. Food and Drug Administration

PWSA | USA advocates are asking members of Congress to sign a letter encouraging the FDA to prioritize the development and approval of safe and effective drugs to treat Prader-Willi syndrome. The letter emphasizes the urgent need for novel therapies to address the varied and challenging symptoms of PWS, the importance of prioritizing orphan drugs targeting these symptoms, and underscores the potential for improving patients' quality of life and offering hope for a better future.

## Open Office Hours for D.C. Fly-In Participants

### D.C. Fly-In Participants! Attend PWSA | USA's Open Office Hours for Answers to Any Questions

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**. Dorothea is offering assistance now until the date of the Fly-In via ZOOM to answer questions, work through your story, or just help settle down jitters.





Office hours will take place Mondays from 12:00 p.m. - 2:00 p.m. EDT and Fridays from 3:00 p.m. - 5:00 p.m. EDT. You can save the ZOOM 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](#)

## PWSA | USA Joins Rare & Ready Coalition

We joined Rare & Ready to lend our voices for better access to therapies. Rare & Ready is a coalition of advocates pushing for state policies that mitigate Medicaid program hurdles to ensure that patients with rare and genetic conditions get access to the care they need. Whether you are a patient, caregiver, healthcare provider or member of a patient advocacy group, Rare & Ready welcomes everyone. Share with the coalition your story about how hard it is to access FDA-approved therapies through your state Medicaid. Check out their website at [www.rareandready.org](http://www.rareandready.org)

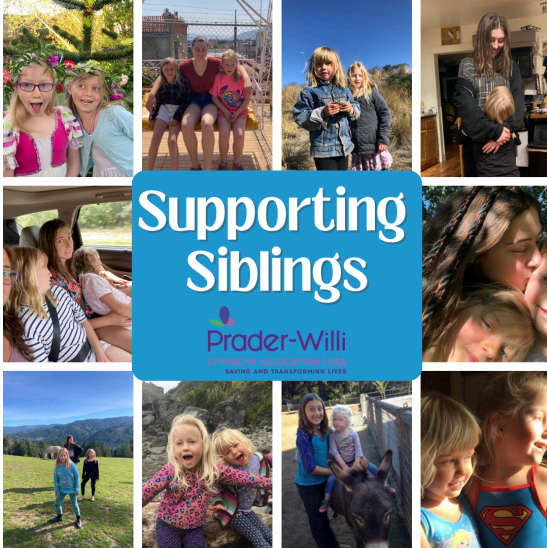


[VISIT WEBSITE](http://www.rareandready.org)



## FAMILY SUPPORT

### Supporting Siblings Blog



Setting aside our own needs is, of course, a typical trait of parenting but amplified by the challenges of PWS. Often, our loved ones with PWS are not our only children, and we must find previously unknown reserves to balance the unique demands of PWS and the typical needs of our other children. At times, we fall short. Thankfully, there are resources to help support the siblings of children with PWS. Read the blog to learn more about siblings and find resources to help support your sibling.

[READ BLOG HERE](#)

### Ask Nurse Lynn

**Question** (Male, 11, Deletion):

My grandson has behavioral issues, and we try to help as much as possible when he is over. He is on medication, but his behavior seems worse at times. For instance, when he gets mad because he can't get what he wants, especially in a store, will sit down and cry and most times it's hard to get him to stop. He has terrible times at school which get out of control. He does take Lithium and at first it seemed to help but now his attitude can get out of control. His parents are divorced and that hasn't

Prader-Willi  
SYNDROME ASSOCIATION | USA  
SAVING AND TRANSFORMING LIVES

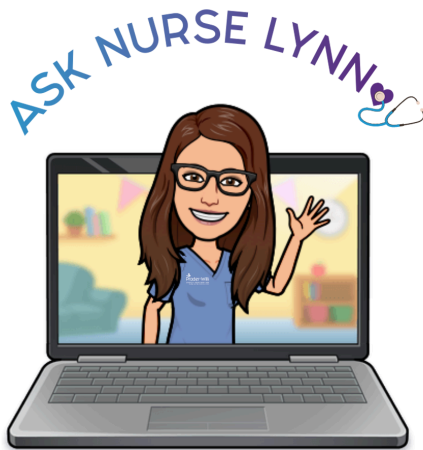
Ask Nurse Lynn

"Supportive Grandparents"

been the best for him. I love my grandson more than anything and it hurts when my son starts saying he may have to go to a home. Is there anything we can try or do to help him? He is a sweet boy and very smart but sometimes it is difficult to keep him occupied. Any advice?

You can read Nurse Lynn's response, along with resource links, in the blog "Supportive Grandparents."

[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

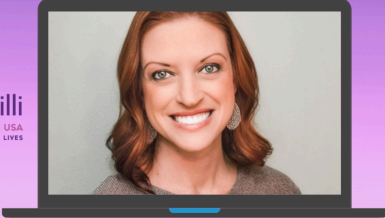

Join PWSA | USA and Dr. Destiny Pacha for our April Family Support webinar, "Everything You Need to Know About Extended School Year." The webinar will be held on Tuesday, **April 23, 2024 at 5:00 p.m. PST / 8:00 p.m. EDT**. Dr. Destiny Pacha is an Educational Consultant with more than 20 years of experience in the educational field. She is also the author of the children's book "It Starts with Hello: Katie's Story About Prader-Willi Syndrome." Register for the webinar below.

Family Support Webinar

## EVERYTHING YOU NEED TO KNOW ABOUT EXTENDED SCHOOL YEAR

Facilitated by: Dr. Destiny Pacha

Tuesday, April 23, 2024  
5pm PST/ 8pm EST



[REGISTER HERE](#)



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

[CLICK HERE TO WATCH](#)

Watch the recording of our March Family Support Webinar, **Psychosis in PWS, Early Signs, Diagnosis, and Treatment** with Elizabeth Roof, MA, HSP, 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

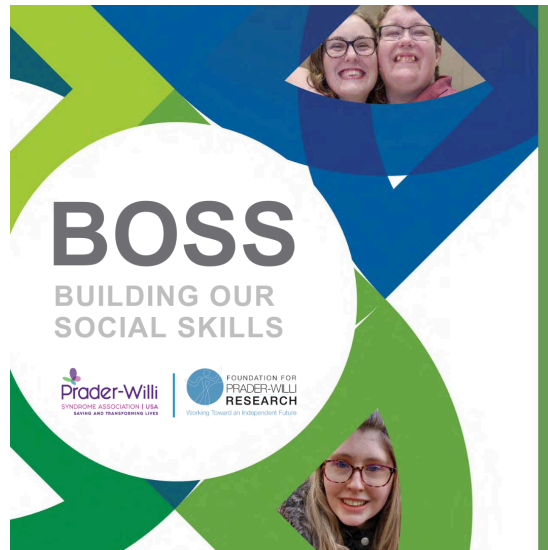
created at Vanderbilt University. The BOSS curriculum provides tailored social groups to teens and adults with PWS, empowering them to enhance their social interactions and build meaningful connections.

If you are interested in joining our next BOSS curriculum sessions, which will take place every Monday, Tuesday and Thursday at 5:00 p.m. EDT, 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](mailto:info@pwsausa.org).

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

[LEARN MORE HERE](#)



## PWS Aging Health and Wellness Survey

PWSA | USA volunteer Barb Dorn, RN, BSN, is seeking participation from parents of adults with PWS over the age of 30 for a survey on the aging health and wellness of individuals with PWS. Barb plans to do a presentation on aging in July to share information about current research on this topic as well as discuss some of the issues and concerns that people have been seeing. If you are interested and fit the criteria, please follow the button below to this brief, one page survey.



TAKE SURVEY



## RESEARCH

Health Care Professionals! Register to Attend PWSA |  
USA's Upcoming Sleep ECHO



### ECHO 4 PWS

**Topic: Sleep with Dr. Ameer Revana**

Date: Tuesday, April 23, 2024

Time: 3:00 p.m. PST / 6:00 p.m. EDT

Location: ZOOM



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

PWSA | USA's next **Health Care Provider Project ECHO Series** webinar will now take place on April 23, 2024, at 6:00 p.m. EDT. The topic discussed will be **Sleep** presented by Ameer 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 health care 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 health care professionals in your life! You can learn more details and find the registration link at the button below.

ECHO 4 PWS INFORMATION

## Dr. Miller Speaks Out About GH Shortage on NPR

Dr. Jennifer Miller, Pediatric Endocrinologist, PWS specialist, and vocal advocate for those living with Prader-Willi syndrome spoke with National Public Radio (NPR) about the growth hormone shortages affecting the community. Individuals with PWS are suffering from the lack of growth hormone, physically and mentally, and the process of prior authorizations causes incredible challenges to receiving this treatment. To read more about the effect of the shortage on individuals, the challenges to procuring treatment, and how Dr. Miller and pharmacy companies are responding, click the button below.



[READ ARTICLE HERE](#)

## Harmony Biosciences' TEMPO PWS Study Now Available on clinicaltrials.gov!



[Harmony Biosciences](#) has announced that information about its TEMPO PWS Study (Pitolisant drug trial) can now be found on clinicaltrials.gov. You can find the specific study details and updates at the button below.

[VISIT THE LINK HERE](#)

## New Trial Site Open for Enrollment



Radys Children's Hospital (Site 401) located in San Diego, CA is now open for enrollment. Any families interested in visiting the site for screening may reach out to our central recruitment coordinator Henry Nickson at [PWStrialreferral@precisionformedicine.com](mailto:PWStrialreferral@precisionformedicine.com). This is a Phase II study looking at the safety, tolerability, and efficacy of NNZ-2591 in the treatment of children with Prader-Willi syndrome. This is an open-label study which means that every participant (and caregiver) will know they are receiving active treatment. This study

investigates an oral medication called "NNZ-2591", which aims to improve the impaired connections and signaling between brain cells that are involved in Prader-Willi syndrome. Learn more at by clicking the button below.

[LEARN MORE HERE](#)

## PWSA | USA ANNOUNCEMENTS

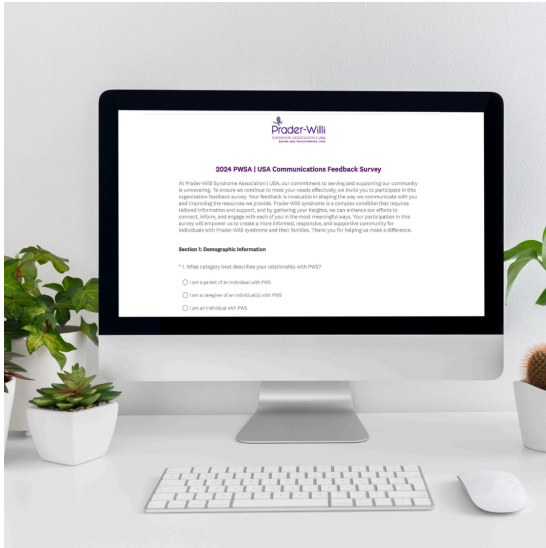
### PWSA | USA Welcomes New Staff Member

PWSA | USA would like to give a warm welcome to our newest staff member! Amy Maust is stepping into the role of Accounting Director. We look forward to working with her and introducing her to our community.





## 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 marble 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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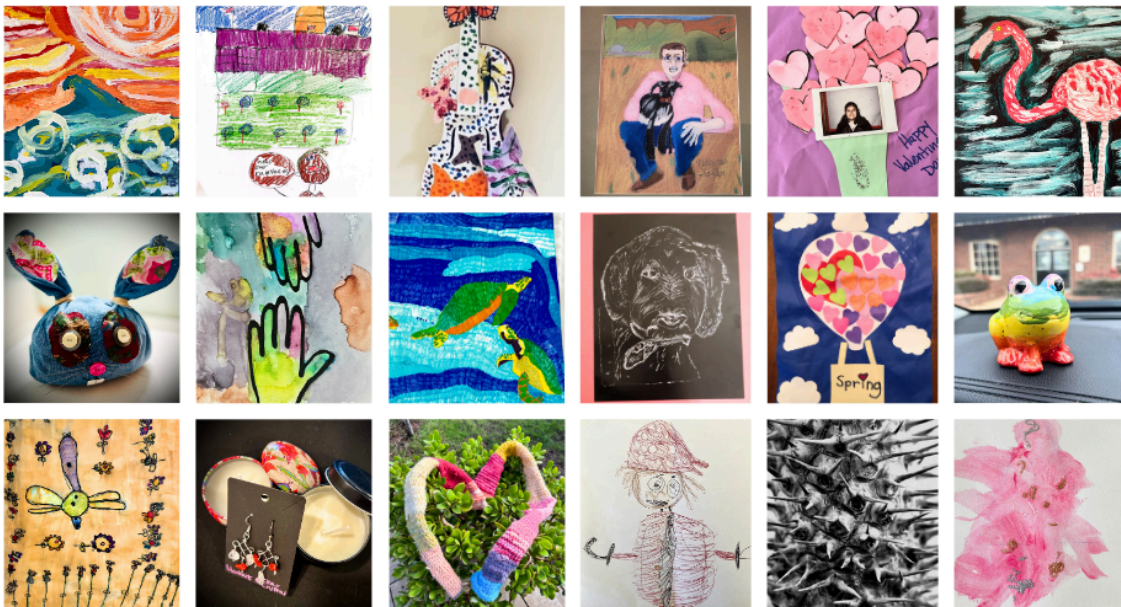
# PWSA | USA Special Edition Pulse: April 26, 2024

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

Donate



FRIDAY,  
APRIL 26, 2024



## 2024 Rare Aware Art Share

In the beginning of this year, PWSA | USA launched an exciting new project to help share the artistic voices of individuals living with Prader-Willi Syndrome! This virtual art show is open to all individuals living with PWS and seeks to offer



an opportunity to learn more about each individual, their lives, and their experiences as someone with PWS. Along with their art submission, individuals are asked to voluntarily answer questions about who they are and what people should know about PWS. Our hope is that through this art show, our community and

beyond can gain a deeper understanding of our loved ones with PWS, while offering them a space to be seen and heard.

Our first theme of 2024 was, **"What is your superpower?"** We've uploaded all of the submissions to our virtual Rare Aware Art Share Gallery. There you can view all of the submissions and read the artists' responses.

[VIRTUAL ART SHARE GALLERY](#)

## Create Customized Art Share Products



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.

### How it works

- Visit the Rare Aware Art Share pop-up shop on Printify at <https://rare-aware-art-share.printify.me/products>
- Browse the collection of already designed products and purchase one if you like it.

- If you don't see something you like, browse the catalogue of products that Printify offers. Be sure to get the product number, size, and color.
- Decide which art piece you would like to print on this product.
- Email [communications@pwsausa.org](mailto:communications@pwsausa.org). Include your name, email, phone number, the information about the product and which art piece you would like to print on this product. If possible, please share pictures and screenshots with us.
- We will create the product of your choice, upload it to the store, and then notify you when it is available for purchase. All of the customer service needs regarding the product, once it is created and ordered, will go through Printify.

*\*Please note that the prices set are simply for manufacturing and shipping the product. There is no profit being made by the artist or PWSA | USA.*

## PRODUCT GALLERY

# Artist Spotlights

## Kyle Gallagher

**Kyle Gallagher**, 38 years-old,  
Pennsylvania

***Explain the artwork you shared:***

I submitted 2 works at this time. The first is my Poison Dart Frogs and the second a Flamingo. I find that art calms me and helps with my mood. I enjoy creating beautiful art pieces and I especially love animals. Animals are my go-to subject. Amphibians and reptiles are among my favorite things to paint. The

Poisonous Dart across is amongst my favorite piece. I really took my time with this and it sold within minutes of being posted online. I am especially proud of that piece for it went to a very special friend of mine.



***What inspired you to create your artwork?***

I'm inspired by a lot of things but most of the time an idea pops in my head and I just draw it. I get an idea, research it for reference then sketch it out deciding what medium I will use. I work primarily with acrylics but I will explore just about anything. I have recently started making jewelry with my teachers at ArtWorks and I love it!!

***What is something you wish people knew about Prader-Willi syndrome?***

This is a hard one. I want people to know that people with PWS can enjoy a special treat with moderation.

***What is something you wish people knew about you?***

I like to be challenged and experiment with new things. I want people to know that even people with PWS or a disability can do anything they put their heart to...

**Lyra Mills**



**Lyra Mills**, 5 years-old, West Virginia

***Explain the artwork you shared:***

My mommy traced my hands on canvas, then I painted with watercolor.

***What inspired you to create your artwork?***

Everyone tells me I give the best hugs.

***What is something you wish people knew about Prader-Willi syndrome?***

I have so much love to give.

***What is something you wish people knew about you?***

I love to play and dance.

**Ahmed Hosam**



**Ahmed Hosam**, 15 years-old, Egypt

***Explain the artwork you shared:***

A picture of a fish seller. I loved him very much. He is a kind and simple man. I used my mobile phone, and my father helped me.

***What inspired you to create your artwork?***

I love photography, because I will preserve these special moments.

***What is something you wish people knew about Prader-Willi syndrome?***

I hope they know I'm very hungry.

***What is something you wish people knew about you?***

I hope they know that I have lost a lot of weight, and that I exercise in the gym.

**Kinsley Reasor**

**Kinsley Reasor**, 10 years-old,  
Oklahoma

***Explain the artwork you shared:***

I made a frog with sparkly paint & water. I used paintbrushes. It was sprayed in the oven to make it shiny. I made it at the Olympics.

***What inspired you to create your artwork?***

I wanted to make it in a rainbow. It inspired me because I like rainbows so much.

***What is something you wish people knew about Prader-Willi syndrome?***



Popcorn can make me choke. Sometimes I have candy like Halloween. I can do different things than other people. Like puzzles & games. I bite my nails & scratching. Make me bleed. I love unicorns & rainbows. I can't eat a lot of stuff. It makes my tummy hurt.

***What is something you wish people knew about you?***

I play puzzles & games. I have movie night & snuggle. I play Olympics bocce ball & basketball & cheer & art & corn hole. And it's so fun I can play with friends. That's what I like about the Olympics.

## Harmony Plum



**Harmony Plum**, 37 years-old, Pennsylvania

***Explain the artwork you shared:***

I enjoy crocheting. My mom taught me how to crochet. I love to make blankets, hats, scarves and many other things. Especially gifts for others. I have also submitted my jewelry I made in my classes at ArtWorks along with the hats I made. I use U-Tube a lot for lessons on crocheting and what materials I would need for a project. I used yarn for knitting and we used stones, wire and other mediums. I love making jewelry and selling it in the gallery. I have sold a few pieces already. I also paint. I love to do all kinds of art and learn from my amazing teachers. We researched how to make candles and alongside my staff I enjoyed creating candles. We melted wax and added drops of liquid to make them smell good and used dried flowers inside the wax for decoration. Mixed media is my favorite but all around I just love to do art.

***What inspired you to create your artwork?***

My inspirations just pop up. I get a lot of help for ideas from my teachers they are great with helping and utilize reference photos for my painting's. Sometimes the ideas just come to me.

***What is something you wish people knew about Prader-Willi syndrome?***



I would like people to know that it is an interesting thing to learn about but very hard to diagnose. Just make sure your friends, family and staff are aware of your diets so you remain healthy.

***What is something you wish people knew about you?***

I am a very fun and nice, caring type of person.

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**Be sure to visit our virtual Rare Aware Art Share gallery to see submissions from all participating artists!**



Nilo Mohadjer, 18, Washington

[VIEW GALLERY HERE](#)



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**Rare Aware Art Share Theme #2**

**What is something unique or special about where you live?**

The Rare Aware Art Share Theme #2 was inspired by our preparations for the United in Hope International PWS Conference in June of 2025. As we prepare to gather together from communities around the world, we have an opportunity to learn more about the world outside of our own. This is an opportunity to share what is unique or special about where you live and share it with the rest of the PWS community and beyond. Besides our social media and print-on-demand site, these submissions will be displayed at the 2025 conference.

We will take submissions for Theme #2 "What is something unique or special about where you live?" from July 1- August 15.

[LEARN MORE HERE](#)



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