

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

Enhancing the Quality of Life and Empowering those Affected by PWS



**Vol. 102**

July 5, 2024

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



Accepting Submissions  
for Theme #2

**"What's something  
unique about where  
you live?"**



We are now collecting artwork for our Rare Aware Art Share Theme #2, "What's something unique about where you live?" We will be collecting artwork from individuals with PWS on this theme through August 15, 2024. This prompt was inspired by our upcoming 2025 United in Hope International PWS Conference and submissions for this theme will be displayed at the conference. As we gather together from homes around the world, it offers us an opportunity to learn more about the world outside our own.

This virtual art show aims to spotlight the voices of individuals with Prader-Willi syndrome. We hope to learn more about individuals, their lives, and their experiences as people living with PWS. We hope that through this art show, our community and beyond can gain a deeper understanding of our loved ones with PWS while offering them a space to be seen and heard. We plan to take this art show to the world outside the PWS community, thus expanding the opportunities for support, education, advocacy, and appreciation for those living with PWS.

We welcome anyone living with PWS to participate in this art share no matter where you live and regardless of whether or not you will be attending the 2025 Conference. Once the art piece is completed, please submit a digital image of your artwork using the form at the button below.

[SUBMIT ARTWORK HERE](#)

## PWSA | USA'S SPOTLIGHT ON HOPE



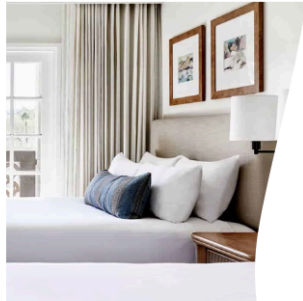
Declan just turned one in June!! He is from Farmingdale, New York, where he lives with his two older brothers, Connor and Riley, his mom and dad, and his four-legged puppy sisters, Evie and Mirabel. In the past year, Declan has battled all the battles including many hospitalizations, coming off the NG tube, hypotonia, hydrocephalus, pericardial effusion, and respiratory failure. He has OT, PT, speech/feeding therapy, a nutritionist, an at-home special education teacher, a social worker, a home nurse, and a team of 15 specialized doctors!

He is the definition of a warrior and will continue the fight in this beautiful life! Declan's first year has been a blessing and every minute out of the hospital has been pure joy, especially celebrating his first holidays, going to Disney World for his first haircut, and meeting Mickey Mouse. But, honestly, just being home and daily life with him is something we will never take for granted.

SHARE YOUR SPOTLIGHT ON HOPE

# EVENTS & FUNDRAISERS

## 2025 United in Hope International PWS Conference




United in HOPE  
2025 PWS CONFERENCE



**2025 Conference Resort  
Rooms are Filling Up  
Quickly!**

 Arizona Grand Resort & Spa  
Phoenix, AZ

 June 24 - 28, 2025

Are you planning to attend the 2025 International PWS Conference? Consider booking your room at the Arizona Grand Resort & Spa soon! 45% of the resort rooms are already reserved for the week of the conference, June 24 - 28, 2025. You can cancel your hotel room up to a week before the event without any charges, and you won't be billed until check-in. Secure your room today and register for the 2025 conference at the button below.

Due to space and occupancy allowances, once the camps are full, registration for the camps will be closed, no exceptions.

[VISIT CONFERENCE WEBSITE](#)

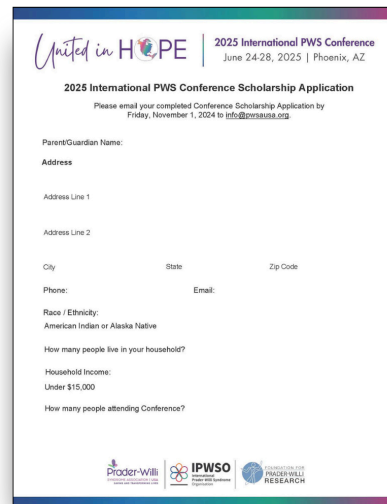
### 2025 Conference Camps:

**Little Tikes Camp (0-24 months) - 43% capacity**  
**Junior Adventure Camp (2-6 years) - FULL**  
**Sibling Camp (6-14 years) - FULL**  
**Adventure Camp (7+) - 67% capacity**

### 2025 Conference Scholarships Available

PWSA | USA is now accepting scholarship applications for the 2025 International PWS Conference. The guidelines for submitting a scholarship application are as follows:

- You must be a first-time PWS conference attendee.
- Scholarship funds can be applied toward a conference program registration (Family Program, Clinical & Scientific Program, or Professional Providers Program), "A Night Under the Stars Gala" registration for loved ones aged 7 and older, and your hotel stay.
- There are limited scholarship opportunities available.



The image shows a screenshot of a scholarship application form titled "2025 International PWS Conference Scholarship Application". The form includes the following fields and instructions:

- Parent/Guardian Name:** [Blank field]
- Address:** [Blank field]
- Address Line 1:** [Blank field]
- Address Line 2:** [Blank field]
- City:** [Blank field]
- State:** [Blank field]
- Zip Code:** [Blank field]
- Phone:** [Blank field]
- Email:** [Blank field]
- Race / Ethnicity:** American Indian or Alaska Native
- How many people live in your household?** [Blank field]
- Household Income:** Under \$15,000
- How many people attending Conference?** [Blank field]

At the bottom of the form, there are logos for Procter & Gamble, IPWSO, and the University of Arizona Center for Procter & Gamble Research.

You can access our 2025 conference scholarship application at the button below. Please submit your application to [info@pwsausa.org](mailto:info@pwsausa.org) no later than Friday, November 1, 2024. If you have questions, contact us at [info@pwsausa.org](mailto:info@pwsausa.org) or (941) 312-0400.

[APPLY HERE](#)

## Registration for Residential Providers Conference

**Attend  
Virtually!**

**RESIDENTIAL  
PROVIDERS** *Conference*

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

Thank you to our sponsor



August 18-20, 2024  
Savannah, Georgia  
Kimpton Brice Hotel



Residential providers and caregivers are integral to the health and well-being of those living with PWS and 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](#)

## Upcoming Fundraisers

**Calling all New Englanders** – Join the Lens family for a full afternoon of fun activities!

The 15th Annual Hunter Lens Golf Tournament will take place Saturday, October 5, 2024, at 12:00 p.m. EST at the Back Nine Club (17 Heritage Hill Dr., Lakeville, MA 02347).



Enjoy time with family and friends while participating in golf, a silent auction, prize drawings, and a delicious dinner. Meet Hunter (26, living with PWS), learn more about PWS and how PWSA | USA works to help families across the U.S., and enjoy a day on a beautiful course with great company! **Register TODAY at the button below.**

**When: Saturday, October 5, 2024, 12:00 p.m. EST**

**Where: Back Nine Club (17 Heritage Hill Dr., Lakeville, MA 02347)**

[LEARN MORE & REGISTER TO ATTEND](#)

[PWSA | USA'S UPCOMING EVENTS](#)

**Become a Hope United Champion and host an event in your community! Learn more below.**

[HOST A FUNDRAISER](#)



**ADVOCACY**

**Are you a military family affected by PWS?**

**We need your help to support an important initiative that could significantly benefit military families affected by Prader-Willi syndrome (PWS).** As part of PWSA | USA's advocacy program, one of our key legislative asks is that Prader-Willi syndrome be added as a topic area to the Peer Reviewed Medical Research Program (PRMRP).

Established in 1999 under the U.S. Department of Defense, the PRMRP has funded a wide range of research aimed at enhancing the health and well-being

of military service members, veterans, retirees, and their families. To strengthen our petition that PWS be added as a recognized topic area, it's crucial for us to gather data on how many U.S. military families within our community are affected by PWS.

If your family is part of the military—whether active, inactive, or retired—please take a moment to fill out the form at the button below. Your participation will provide the essential information we need to advocate effectively for research and policies that support the unique needs of military families dealing with PWS. Thank you for your support and for helping us make a difference! If you have any questions, please contact us at [info@pwsausa.org](mailto:info@pwsausa.org).



**MILITARY FAMILY FORM**

## Soleno Files NDA for DCCR!

### UPDATE ON DCCR



Exciting News from Soleno Therapeutics! On Friday, June 28th, Soleno announced the company has officially submitted a New Drug Application (NDA) to the FDA for DCCR (diazoxide choline) extended-release tablets. This new treatment targets Prader-Willi syndrome (PWS) in individuals aged 4 and older with hyperphagia.

CEO Anish Bhatnagar, MD, says, “Submission of the DCCR NDA to the FDA marks a significant milestone not only for Soleno, but for people living with PWS. This

*regulatory submission advances us one important step closer to our goal of bringing to market a new therapeutic for individuals with PWS that addresses the life-threatening hyperphagia and other key aspects of this serious and rare condition. We look forward to working with the FDA throughout the review process. We extend sincere gratitude to the team at Soleno, investigators, study*

*site teams, advocacy organizations, and most importantly, the individuals with PWS and their families who were instrumental in completing our DCCR development program.”*

With Breakthrough, Fast Track, and Orphan Drug Designations, Soleno hopes for a Priority Review to expedite the FDA's process. Read the full press release below.

[READ HERE](#)



## FAMILY SUPPORT

### PWS in Adulthood Blog Series

As our loved ones with PWS become adults, they want the same things as anyone else. They want to feel listened to, valued, have friendships/romantic relationships, have a sense of purpose, and live independently. We need to consider how we can accomplish this while considering our loved one's individual abilities and needs. Click the button below to read this PWS in Adulthood blog, contributed anonymously by the parent of an adult living with PWS. If you would like to share your advice and caregiving experiences for your adult with PWS, please email [africke@pwsausa.org](mailto:africke@pwsausa.org).



[READ BLOG HERE](#)

### New Resource for School Psychologists

Congratulations to Stacy Ward (CEO of PWSA | USA), Kasey E. Bedard, Destiny Pacha, and Annette K. Griffith for publishing their article, "Prader-Willi



## Prader-Willi Syndrome: A primer for school psychologists



Syndrome: A Primer for School Psychologists," in the *Children and Youth Services Review*. As the abstract states, "This paper provides a primer for school psychologists, introducing the physiological, educational, and behavioral differences experienced by children with PWS. As the symptoms of PWS are widespread, the impacts of common physical and neurological differences on specific learning abilities, adaptive skills, and overall functioning in the classroom setting are discussed in detail. While PWS is a spectrum, and each child will

experience symptoms and challenges differently, this article aims to provide a foundation for the development and facilitation of support services to assist educators in not only maintaining the health and safety of their students with PWS, but also in capitalizing on their strengths, and building a plan to help them succeed." Read the full article by clicking the button below.

[READ ARTICLE HERE](#)

## Ask Nurse Lynn

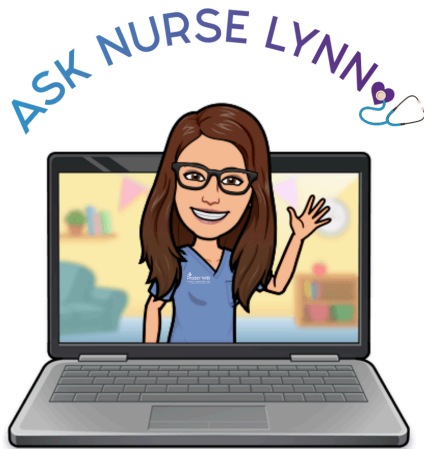
### Question (Female 40, Deletion):

Is there anything to worry about if someone with PWS is having a Colonoscopy?

Visit our blog to read Nurse Lynn's response about colonoscopies and PWS and how to help prepare your loved one for the procedure.

A blue graphic with a white hexagonal pattern and circuit-like lines. In the top left, it features the Prader-Willi Syndrome Association | USA logo with the tagline 'SAVING AND TRANSFORMING LIVES'. In the top right, there is a circular icon of a woman with glasses on a laptop screen. A large purple button in the center contains the text 'Ask Nurse Lynn'. Below the button, the word 'Colonoscopy' is written in white, enclosed in quotation marks. The bottom corners of the graphic also feature the hexagonal pattern and circuit lines.

## 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



### PWS - Aging Research and Health Update Webinar Series

### PWS Aging Research and Health Update Webinar Series: Comprehensive Insights and Strategies for Caregivers

Join us for the PWS - Aging Research and Health Update Webinar series, featuring Lynn Garrick, RN, MSN, and Barb Dorn, RN, BSN. Part 1, on Tuesday, July 30, 2024, at 8:00 p.m. EST, will highlight current research on aging in PWS and common health issues reported by caregivers. The speakers will cover risk factors, screening tools, and strategies for dental concerns, choking,

constipation, and diabetes. Part 2, on Tuesday, August 6, 2024, at 8:00 p.m. EST, will continue the discussion, focusing on respiratory issues, weight

gain/obesity, low bone density, cardiac issues, mobility challenges, and mental health concerns. Attendees will gain insights into prevention and management strategies for these health topics.

[REGISTER FOR PART 1](#)

[REGISTER FOR PART 2](#)



Watch the recording of our June Family Support Webinar, **What's the BIG Deal About Exercise** with Kathryn Lucero, at the button below.

[CLICK HERE TO WATCH](#)



## RESEARCH

**ECHO 4 PWS Health Care Series:  
Three New ECHO Webinars Planned for 2024**



***PWS Health Care Providers!***

Register for PWSA | USA's  
**Upcoming ECHO 4 PWS  
Webinars**

PWSA | USA is hosting three upcoming ECHO 4 PWS webinars. On August 15, 2024, at 5:00 p.m. EST, Jim Loker, MD, will discuss “Cardiac Concerns,” which accounts for 16% of all deaths in PWS, and share the unique features of PWS that may predispose individuals to cardiovascular problems. In September, join us for a webinar on “Feeding and Swallowing” with Roxann Diez Gross, PhD, CCC/SLP, and Ann Scheimann, MD, MBA. This presentation will enhance the knowledge of PWS assessment and management, focusing on feeding and swallowing issues through a multidisciplinary approach. In November, Daniela Rubin, Ph.D., will lead a webinar on “Exercise Physiology,” with more details coming soon. These webinars are for health care professionals to attend only. We will have recordings of these webinars available on PWSA | USA’s website following the presentations. Find more details and registration links for these webinars at the button below.

[PROJECT ECHO](#)

## Harmony Announces New Trial Sites

Harmony Biosciences has announced two additional clinical trial sites for its TEMPO PWS study in Wilmington, Delaware and San Antonio, Texas. Harmony Biosciences' TEMPO study is 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. Pitolisant is a medication that could help manage sleepiness and behavioral issues in people with PWS. You can find all seven (7) TEMPO trial site locations and learn more by clicking the button below.



[LEARN MORE HERE](#)

**Help Needed: Caregivers of Children with Prader-Willi Syndrome and Repetitive Verbal Behavior**



Kasey Bedard, PhD, and her team at The Chicago School are seeking caregivers of children diagnosed with Prader-Willi syndrome (PWS) who exhibit repetitive verbal behavior to participate in a research study. This study, part of a dissertation project, aims to test interventions that caregivers can implement at home.

If interested, please contact Dr. Bedard at [Kbedard1@thechicagoschool.edu](mailto:Kbedard1@thechicagoschool.edu) or Chante Dix, MA, BCBA, LBA at [Cnr4994@ego.thechicagoschool.edu](mailto:Cnr4994@ego.thechicagoschool.edu). Please share this information with anyone who might be

interested.

#### **Study Details:**

- Duration: 2-3 weeks
- Frequency: 1-3 sessions per day
- All sessions will be recorded
- Caregivers will participate in training activities

#### **Eligibility Criteria:**

- Caregiver is 18 years or older
- Access to a computer or device with internet
- Proficient in English
- Child is 4-8 years old, diagnosed with PWS
- Child uses vocal communication
- No severe challenging behaviors in the child's history

[DOWNLOAD THE FLYER](#)

## **Help Needed: Caregivers Needed to Participate in a New Play Skills and PWS Study**

A doctoral student at The Chicago School is seeking participants for a Dissertation study to evaluate the impact of a virtual caregiver training program on transition behavior in play of children with PWS. Participation is fully remote and will take place across 10 weeks. This study is for children between the ages of 4 and 9. Participants will receive a \$50 Amazon gift card following completion

of all phases of the study. If you are interested in participating, please contact Kelly Krukowski, MA, BCBA at [Kkrukowski@ego.thechicagoschool.edu](mailto:Kkrukowski@ego.thechicagoschool.edu) or click on the button see if you qualify.

## PLAY SKILLS & PWS

I am a Doctoral student at The Chicago School seeking participants for a Dissertation study to evaluate the impact of a virtual caregiver training program on transition behavior in play of children with PWS. Participation is fully remote and will take place across 10 weeks. All caregiver training sessions will be video recorded for data collection purposes.

### We Invite you to participate if:

- You are at least 18 years of age
- You have a child with PWS between the ages of 4 and 9 and live in the same home as your child
- You speak and read English
- You have access to a device with videorecording and videoconferencing capabilities
- Your child demonstrates challenging behaviors when asked to transition between activities in play

Participants will be provided with a \$50 Amazon gift card following completion of all phases of the study.

Please share this flyer with anyone you know who may be interested in participating

### Find out if you qualify!

Visit: <https://owslab.questionpro.com/r/AW7apZ2f4>

Contact:  
Kelly Krukowski, MA, BCBA  
[Kkrukowski@ego.thechicagoschool.edu](mailto:Kkrukowski@ego.thechicagoschool.edu)  
IRB #: IRB-PV24-46



## PLAY SKILLS SCREENING

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



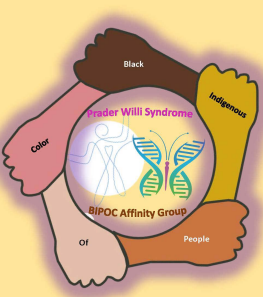
PWSA | USA is currently seeking research project applications with direct impacts on individuals and families affected by PWS. We are offering mini-fellowship grants to support providers in enhancing their understanding of PWS through clinical proctorships. Research priorities include expanding knowledge 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](mailto: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

## PWSA | USA ANNOUNCEMENTS

### Empowering Diversity and Inclusion for the PWS Community



1:15,000 children are born with PWS. How many children of color are diagnosed? How are they and their families affected?

**Want to meet more PWS families of color?**

- ❖ Every person with PWS is different. We share our experiences and lessons learned. As caregivers, it's natural to seek out success stories that reflect our children.
- ❖ The purpose of this BIPOC Affinity group is to connect people of color, living with or affected by Prader-Willi Syndrome (PWS) to be empowered and live their best lives.
- ❖ If you are a person of color diagnosed with PWS or raise children of color, email [BIPOCPWS@gmail.com](mailto:BIPOCPWS@gmail.com) to sign up for our email list and group chat on Signal.

*Let's encourage a conversation that brings about a standard of care that considers all shades/cultures of people living with PWS.*

In a significant step towards fostering equity and inclusion within our Prader-Willi syndrome (PWS) community, we are pleased to announce a collaborative initiative aimed at improving the standard of care and support for marginalized individuals living with PWS and their families. This initiative, undertaken with the active involvement of several community members, seeks to ensure that every person living with

PWS, regardless of their background, can access better care and harbor hope for the future. As an initial measure, the community members established a BIPOC (Black, Indigenous, and People of Color) affinity group. This group is dedicated to people of color living with PWS and their caregivers, providing a platform to share experiences, offer mutual support, and develop necessary resources. We urge all PWS service providers to assist in spreading the word about this vital initiative to families of color within the PWS community. Your support is crucial in reaching those who will benefit most from these efforts. For any questions or further information, please contact the BIPOC organizer group - Charles Conway, Karine Kabundi, and Dini Rao - at [bjpocpws@gmail.com](mailto:bjpocpws@gmail.com).

## PWSA | USA Resource Spotlight

This week's Website Spotlight features PWSA's brochures, offering a wide array of resources for PWS families and health care providers. Some of the brochures

include "Supporting Someone with PWS," "Q & A About PWS," "Management of PWS in Work Settings," "What Educators Should Know," and more! These resources are essential for families to utilize as they provide crucial information and support for managing the unique challenges associated with PWS.



[VISIT WEBPAGE](#)

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: July 22, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS



Vol. 103

July 22, 2024

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

United in HOPE  
2025 PWS CONFERENCE



Why attend  
conference?

June 24 - 28, 2025  
Phoenix, AZ



In June of 2025, three PWS organizations, PWSA | USA, IPWSO (International Prader-Willi Syndrome Organization), and FPWR (Foundation for Prader-Willi Research), are coming together to bring the community the **United in Hope International PWS Conference**. With specialized sessions for clinicians, researchers, providers and families, and camps for individuals with PWS and their siblings, this conference has something for all facets of the PWS

community. If you're still deciding whether or not to make the trip to Phoenix, AZ, next June, here are some reasons to attend:

- \*Connect with other PWS families and build your community.
- \*Learn the latest research in PWS management.
- \*Meet PWS specialists from around the world.
- \*Enjoy the amenities (spa, golf course, pool, and water slides) of the venue.
- \*Have an "ah-ha" moment in understanding PWS.
- \*Receive support as a parent and caregiver.
- \*Access information to share with your community at home.
- \*Relax and have fun with people who can relate to your experiences.
- \*Create an opportunity for your loved one to meet other individuals with PWS.
- \*Help PWSA | USA celebrate 50 years!

Consider booking your room at the [Arizona Grand Resort & Spa](#) soon! 50% of the resort rooms are already reserved for the week of the conference, **June 24 - 28, 2025**. You can cancel your hotel room up to a week before the event without any charges, and you won't be billed until check-in. Secure your room today and register for the 2025 conference at the button below. [Scholarships](#) are available for first-time attendees.

Due to space and occupancy allowances, once the camps are full, registration for the camps will be closed, with no exceptions.

[VISIT CONFERENCE WEBSITE](#)

### 2025 Conference Camps:

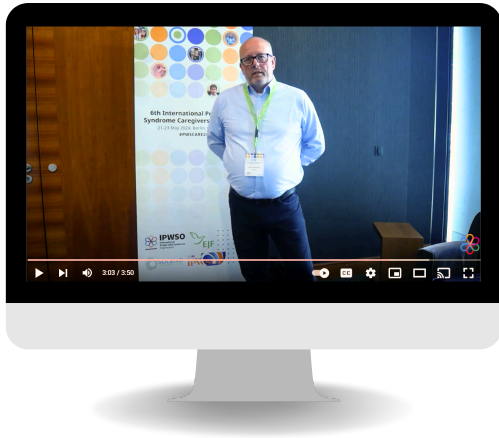
**Little Tikes Camp (0-24 months) - 43% capacity**

**Junior Adventure Camp (2-6 years) - FULL**

**Sibling Camp (6-14 years) - FULL**

**Adventure Camp (7+) - 78% capacity**

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IPWSO held its **6th International PWS Caregivers' Conference** in Berlin, Germany on May 22, 2024. Click the button to watch a video of delegates explaining why they encourage people to attend an IPWSO conference.

[WATCH HERE](#)

With the 2025 International PWS Conference approaching, we're creating a special mural to showcase the diversity and beauty of our incredible PWS community. This mural will be on display during the 2025 conference at the Arizona Grand Resort & Spa. We want photos of your loved one to be a part of it! Submit a picture of your PWS warrior, even if you can't join us in person, at the button below. The pictures shared will help create a display of hope that everyone can take pride in. Let's come together to celebrate and inspire!



[SUBMIT PHOTO HERE](#)

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



*"Luella is a beautiful 5-year-old girl who was diagnosed with Prader-Willi syndrome at about 6 months old. She is so very sweet, smart, and loving to all she meets. She is truly a beacon of light for her friends and family. Luella has been through so much in her short 5 years. She is so strong and courageous, teaching others life lessons daily. Along with PWS, Luella has a diagnosis of narcolepsy with cataplexy. Our sweetest girl does not let anything stop her or define her. She is an amazing little lady and the best big sister! We could not be more proud of this beautiful soul. We are*

*truly blessed to be her parents!"*

SHARE YOUR SPOTLIGHT ON HOPE

## EVENTS & FUNDRAISERS

PWSA | USA's Residential Providers Conference is Only One Month Away!

Attend Virtually!

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



Residential providers and caregivers are integral to the health and well-being of those living with PWS and 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

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](#)

## Upcoming Fundraisers

**1ST ANNUAL GAVIN GILL CLASSIC GOLF TOURNAMENT**  
— DRIVING FOR A CURE —

**CALLING ALL NEW ENGLANDERS!**  
Join the Gill Family for a full morning of fun activities!  
The 1st Annual Gavin Gill Classic Golf Tournament - Driving for a Cure, will take place on Saturday, September 7, 2024, at 9:00 a.m. EST at North Hill Country Club (29 Merry Avenue, Duxbury, MA 02332).  
Enjoy time with family and friends while participating in golf, a silent auction, prize drawings, and a delicious lunch.  
Meet Gavin (18, living with PWS), learn more about PWS and how PWSA | USA is working to help families across the U.S., and enjoy a day on a beautiful golf course with great company!

PROCEEDS FROM THE GAVIN GILL CLASSIC BENEFIT Prader-Willi Syndrome Association | USA

**Calling all New Englanders** – Join the Gill family for a full morning of fun activities!

The 1st Annual Gavin Gill Classic Golf Tournament - Driving for a Cure, will take place on Saturday, September 7, 2024, at 9 a.m. EST at North Hill Country Club (29 Merry Avenue, Duxbury, MA 02332).

Enjoy time with family and friends while participating in golf, a silent auction, prize drawings, and a delicious lunch.

Meet Gavin (18, living with PWS), learn more about PWS and how PWSA | USA is working to help families across the U.S., and enjoy a day on a beautiful golf course with great company!

**Register TODAY at the button below.**

**When: Saturday, September 7, 2024, 9 a.m. EST**

**Where: North Hill Country Club (29 Merry Avenue, Duxbury, MA 02332)**

[LEARN MORE & REGISTER TO ATTEND](#)

[PWSA | USA'S UPCOMING EVENTS](#)

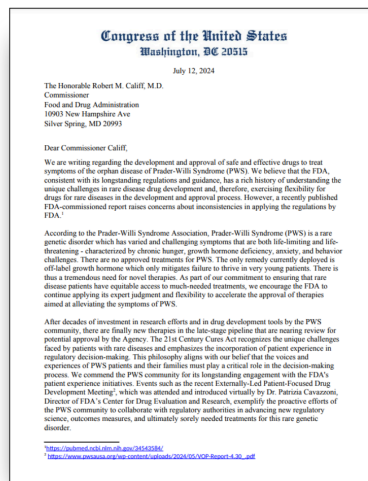
**Become a Hope United Champion and host an event in your community!  
Learn more below.**

**HOST A FUNDRAISER**



**ADVOCACY**

## **PWSA | USA Files Congressional Letter of Support with the FDA**



**Exciting Advocacy News! PWSA | USA has submitted our "Congressional Letter of Support" to the FDA with 27 signatures from U.S. Congress members! This letter pushes for urgent development and approval of treatments for Prader-Willi syndrome. A big thank you to our advocates who shared this ask during the 2024 D.C. Fly-In and to the team leads who worked diligently to follow up with their members of Congress. Your dedication is making a difference. You can read the letter by clicking the button below.**

**Together, we're bringing hope and a better quality of life to those affected by PWS. Stay tuned for updates!**

**READ THE LETTER**

## **Are you a Military Family Affected by PWS?**

**We need your help to support an important initiative that could significantly benefit military families affected by Prader-Willi syndrome (PWS). As part of PWSA | USA's advocacy program, one of our key legislative**

asks is that Prader-Willi syndrome be added as a topic area to the Peer Reviewed Medical Research Program (PRMRP).

Established in 1999 under the U.S. Department of Defense, the PRMRP has funded a wide range of research aimed at enhancing the health and well-being of military service members, veterans, retirees, and their families. To strengthen our petition that PWS be added as a recognized topic area, it's crucial for us to gather data on how many U.S. military families within our community are affected by PWS.



If your family is part of the military—whether active, inactive, or retired—please take a moment to fill out the form at the button below. Your participation will provide the essential information we need to advocate effectively for research and policies that support the unique needs of military families dealing with PWS. Thank you for your support and for helping us make a difference! If you have any questions, please contact us at [info@pwsausa.org](mailto:info@pwsausa.org).

**MILITARY FAMILY FORM**

## D.C. Fly-In Recap Video from Believe Limited

### 2024 PWSA | USA D.C. Fly-In Documentary



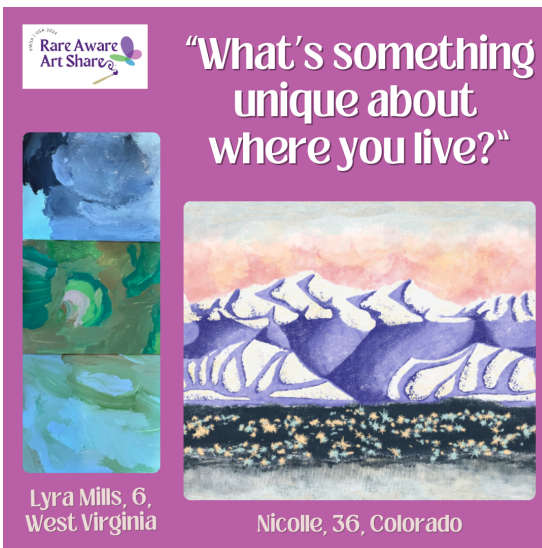
We were fortunate to have PWSA | USA's 2024 D.C. Fly-In event captured in a unique and authentic way. Please enjoy this mini-documentary of our time on Capitol Hill, where nearly 150 parents, caregivers, siblings, family members, and individuals living with PWS came together to advocate for our community's needs. We are sincerely grateful to those who stepped in front of the camera lens to share their story. Together, we are driving change and making a lasting impact for those affected by PWS.

Thanks to Soleno Therapeutics for sponsoring the production of these videos.  
Produced by Believe Limited: The Patient People.

[WATCH VIDEO](#)

## Rare Aware Art Share Deadline Extended! Submissions Open until September 15

Our Rare Aware Art Share is an international opportunity to showcase the artistic voices of individuals living with PWS. As we are preparing to gather with our international community in June of 2025, we are seeking the voices of individuals around the world to share with us something that is unique about where they live. This is a wonderful opportunity to learn about individuals with PWS in a variety of cultures and places worldwide. To give this theme it's proper due and provide ample time for word to spread to artists to submit pieces, we are extending the submission deadline to September 15. Please share this opportunity with your PWS community and let's encourage individuals from all over the world to share their artistic voice! Learn more and submit artwork using the button below.



[SUBMIT HERE](#)

[THEME #1 GALLERY VIDEO](#)



**FAMILY SUPPORT**

**PWS Blog: Growing Up Rare**





Justice Rickenbach is a 20-year-old living with PWS. She is a vocal member of the community and a fierce advocate. As she states, "Having a lot of medical issues has not stopped me from doing what I love. I may need to stop and take breaks or do things a little differently than others, but I manage. Riding horses, weightlifting, long bike rides, hiking, reading, and art are all some of my favorite things to do. When I was born, the doctors told my parents most of these things would not be possible, but I proved them wrong." Read her blog, "Growing up Rare," by

clicking the button below.

[READ BLOG HERE](#)

## Ask Nurse Lynn

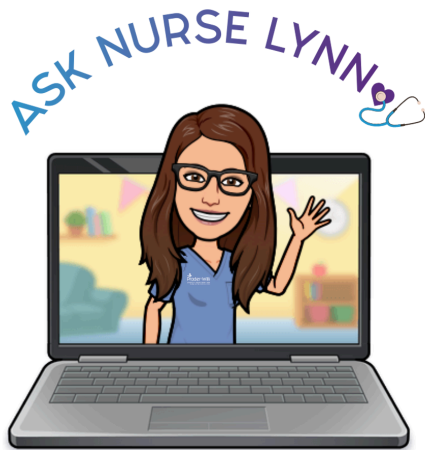
### Question (*Female 33, Deletion*):

"My daughter went through several programs of weight loss in Pittsburgh. Their program saved her life. They don't offer that program anymore. Are there any other programs that can help us with her weight? She's very heavy again. When Covid hit, it got out of control again and I feel like I failed my daughter."

Visit our blog to read Nurse Lynn's response and find links for the mentioned resources.



[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



**PWS - Aging Research and Health Update Webinar Series**

### **PWS Aging Research and Health Update Webinar Series: Comprehensive Insights and Strategies for Caregivers**

Join us for the PWS - Aging Research and Health Update Webinar series, featuring Lynn Garrick, RN, MSN, and Barb Dorn, RN, BSN. Part 1, on Tuesday, July 30, 2024, at 8:00 p.m. EST, will highlight current research on aging in PWS and common health issues reported by caregivers. The speakers will cover risk factors, screening tools, and strategies for dental concerns, choking,

constipation, and diabetes. Part 2, on Tuesday, August 6, 2024, at 8:00 p.m. EST, will continue the discussion, focusing on respiratory issues, weight gain/obesity, low bone density, cardiac issues, mobility challenges, and mental health concerns. Attendees will gain insights into prevention and management strategies for these health topics.

REGISTER FOR PART 1

REGISTER FOR PART 2



Watch the recording of our June Family Support Webinar, **What's the BIG Deal About Exercise** with Kathryn Lucero, at the button below.

CLICK HERE TO WATCH



## RESEARCH

### Acadia Webinar: Tuesday, July 23, 2024

Join PWSA | USA and the team from Acadia Pharmaceuticals on Tuesday, July 23 at 8:00 p.m. EST / 5:00 p.m. PST to learn more about the COMPASS PWS Study, which aims to investigate the drug Carbetocin (nasal spray) as a treatment for PWS, specifically to help address hyperphagia symptoms. Acadia representatives will give details about the drug and discuss their Phase 3 study openings, requirements, and more! They will also be available for a Q & A discussion for any questions you have.

ACADIA COMPASSPWS

**FREE WEBINAR OPPORTUNITY!**

**Acadia Pharmaceuticals -  
Clinical Studies for Hyperphagia  
in Prader-Willi Syndrome**

**Tuesday, July 23, 2024**  
8:00 p.m. EST / 5:00 p.m. PST | Virtual via ZOOM

**WITH PRESENTER:**  
**James Youakim, MD**  
Vice President of  
Clinical Development,  
Acadia Pharmaceuticals

This webinar will be presented by James Youakim, MD and facilitated by PWSA | USA. James Youakim, MD, is a Vice President of Clinical Development Acadia Pharmaceuticals, focusing on medications that treat rare diseases. In that role he oversees the clinical studies of carbetocin nasal spray for hyperphagia in PWS. Dr. Youakim trained as a psychiatrist and has worked in the

pharmaceutical industry for over 18 years. He most recently worked in a treatment of Rett Syndrome, a rare neurodevelopmental disorder.

We invite you to sign up for this free webinar opportunity you won't want to miss! Register TODAY.

[REGISTER HERE](#)

## ECHO 4 PWS Health Care Series: Three New ECHO Webinars Planned for 2024



# ***PWS Health Care Providers!***

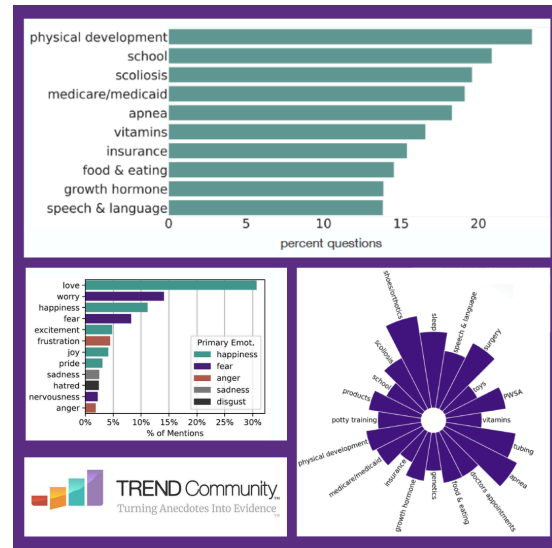
## **Register for PWSA | USA's Upcoming ECHO 4 PWS Webinars**

PWSA | USA is hosting three upcoming ECHO 4 PWS webinars. On August 15, 2024, at 5:00 p.m. EST, Jim Loker, MD, will discuss "Cardiac Concerns," which accounts for 16% of all deaths in PWS, and share the unique features of PWS that may predispose individuals to cardiovascular problems. In September, join us for a webinar on "Feeding and Swallowing" with Roxann Diez Gross, PhD, CCC/SLP, and Ann Scheimann, MD, MBA. This presentation will enhance the knowledge of PWS assessment and management, focusing on feeding and swallowing issues through a multidisciplinary approach. In November, Daniela Rubin, Ph.D., will lead a webinar on "Exercise Physiology," with more details coming soon. These webinars are for health care professionals to attend only. We will have recordings of these webinars available on PWSA | USA's website following the presentations. Find more details and registration links for these webinars at the button below.

## PROJECT ECHO

### Research Data from TREND Community

For 2.5 years PWSA | USA has been partnering with TREND Community to turn our online support groups into a source of real-world evidence. By collecting the most frequently discussed terms in the Facebook group discussions, TREND was able to gather insights that shed light on under-recognized symptoms and our community's unmet needs, fueling critical research for our community. Our privacy is always protected. Only non-identifying data is used for research, with progress shared within the community.



"A high priority of caregivers in the community appears to be understanding the role of PWS in their children's futures. A common theme of conversation was milestones and development (e.g., topics: speech & language, physical development). These conversations likely have some association with worry, where future and kids were associated terms, and physical growth had more questions than any other topic. Another primary focus for the community seems to be management. Many themes in discussions included an array of management techniques (growth hormone, vitamins, shoes/orthotics, etc.). The positive emotions described in the community (e.g., love, support) demonstrate the supportive nature of the groups regarding their interactions with one another. The community may benefit from enhanced support services and educational programs, particularly those focusing on navigating critical stages of early life (e.g., school, developmental milestones, etc.)."

Due to recent Facebook policy updates and limitations, TREND Community has shifted its research efforts to PWS Connect on Discord. We are inviting the PWS community to join us there!

[JOIN NOW](#)

[HOW TO SET UP DISCORD FOR MOBILE](#)

## HOW TO SET UP DISCORD FOR COMPUTER

### 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 [ward@pwsausa.org](mailto:ward@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.

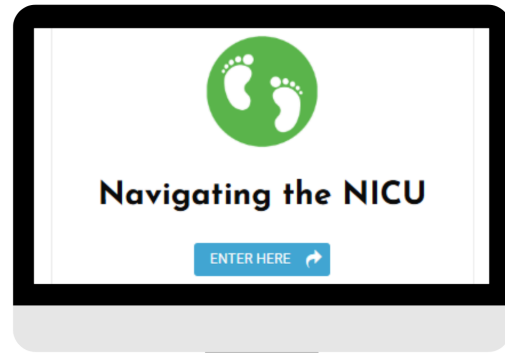
[LEARN MORE HERE](#)

## PWSA | USA ANNOUNCEMENTS

### PWSA | USA Resource Spotlight

This week's Website Spotlight features our "Navigating the NICU" webpage. This page offers a variety of touching and important resources for parents who are learning how to navigate the NICU with their babies. Documents include "Communication in the NICU", "Doctor Letter NICU", "NICU Overview", "Testing

and Diagnosis", "Family Support NICU", "Dads in the NICU Blog V2", "Standard NICU Tests and Procedures", and more. Click the button to visit the webpage.



[VISIT WEBPAGE](#)

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: July 26, 2024

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

[Donate](#)



PWSA | USA Special Edition  
**PULSE**  
JULY 26, 2024

It's that time of year again when many families are preparing to send their loved ones off to school. We know that can be both a daunting and exciting experience. There are many factors that parents and caregivers have to think about as the school year approaches. Will our loved ones have the proper support? Will they be able to keep up with the schoolwork? Will they find things they enjoy? Will they make friends? Will they be safe? These are questions most parents concern themselves with, PWS or not. But, as with most things there are special considerations for PWS: necessary additions to IEPs, educating school staff, and helping our loved ones with their peer relationships. We are dedicating this special edition Pulse to helping families navigate the experience of going back to school.

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***“Over the years, we have relied on PWSA | USA’s support for our frequent IEP meetings. Navigating the educational system with the support of PWSA | USA has made a world of difference in our***



*son's programming placement. We are forever grateful to the PWSA | USA IEP team for sharing their in-depth knowledge, out-of-the-box thinking, and sincere drive for all PWS individuals to reach their full potential." - Jen Garzia, mom to Rocco (19)*

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PWSA | USA offers an extensive array of resources for families around the country. We provide trainings for school staff, assistance with the IEP process, webinars on how to advocate for your child, downloadable information documents to share with teachers, as well as an incredible library of resources on our website (including our [School Success Toolkit here](#)). We are able to offer this support in part from the generous donations of our community. If you would like to help with PWSA | USA's efforts in supporting families, please consider donating today. Your donations are greatly appreciated!

[DONATE HERE](#)

## What should I put in the IEP?

Individualized Education Plans (IEPs) are legal documents defining specialized services and support students will receive while in school. While IEPs are outlined according to the distinct needs of each individual student, there are many important additions for our loved ones with PWS. We reached out to the community for advice on what members have found to be a critical element of an IEP. Below are some suggestions for what has worked for other families. PWSA | USA is here to assist any families needing help defining or advocating for these services.

\*Mandatory PWS training for everyone who interacts with the individual with PWS. Include a staff Q&A session with parents so the staff can learn the specifics about their child.



\*Food security. All snacks, food, lunch boxes, etc., should be locked away in a cabinet in the classroom. There should also be supervision during any mealtime or when food is present.

\*Monitored water intake during snack and lunch (to ensure the individual drinks enough water).

\*Access to a safe space that is quiet and calm.

\*Always include extra time and a countdown for transitions from one activity to another.

\*Include alternatives for recess or Physical Education (PE) when it is too hot or cold.

\*Approval for the use of stress balls or fidget spinners during class.

\*Use of audiobooks for reading assignments.

\*Prior notification of any class parties or celebrations where food will be involved.

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***"Alternative PE and recess when it's too hot/ cold or even his scoliosis brace makes the needed movement difficult. (Not just sending him to the library - a staff member plays games indoors or walks with him around the halls so he's still getting movement and exercise.)" - Amy Voelker Watson***

## Celebrations in the Classroom

Celebrations involving food are an inevitable aspect of our society, whether in school or out. It is important that we learn and teach our loved ones how to



navigate these situations. While they are in school, we should ensure the teachers and staff understand the dangers of not having food security and how they can help keep our loved ones safe. Below are some ways that families have brought food security and healthy choices into the classroom.

\*Include in the IEP that no food should be given to the individual unless it is provided by the family.

\*Provide the classroom with alternative options (like healthy

snacks or non-food items) to give to the student when sugary treats are handed out.

\*Volunteer to bring in healthy treats for the whole class or to be present during celebrations for added food security.

\*Include the option for the student to participate in an alternative activity out of the classroom (i.e. join another class or visit the library) during the food part of the celebration.

\*Encourage art activities in the classroom rather than sweet treats (i.e. decorating felt gingerbread characters rather than gingerbread cookies).

\*Give the student half portions when it is a treat.

\*Allow the student to participate in the activity but notify the family so they can adjust the other meals throughout the day.

---

***I make many different “junk foods” as healthy as possible. Savory muffins in place of cupcakes, beet chips in place of bags of chips, homemade gold fish crackers, homemade popsicles, hint water “juice boxes,” etc. Then, I send everything in at the beginning of the year so Luella has something available anytime there is a party or something that was a surprise or unplanned. - Kayla Day***

## Navigating Peer Relationships

As parents and caregivers, we want to see our loved ones successful in their relationships. Making connections with peers is a valuable part of adolescence and being in school. Some of the characteristics of PWS can make this challenging. Struggles with transitions, egocentrism, slower processing, excessive daytime sleepiness, and, of course, food concerns, can sometimes get in the way when our loved ones are navigating relationships. PWSA | USA's Kim Tula and Kristi Rickenbach offered insights for families to help their loved ones navigate and nurture these relationships. Read our blog by clicking the button below.



[READ BLOG HERE](#)

## Parent Advocacy Training

## Upcoming Parent Training Series: Empowering Families in IEP Meetings



outcomes for your child's education. Details, including training dates, will be announced soon. Spots will be limited, so stay tuned for more details!

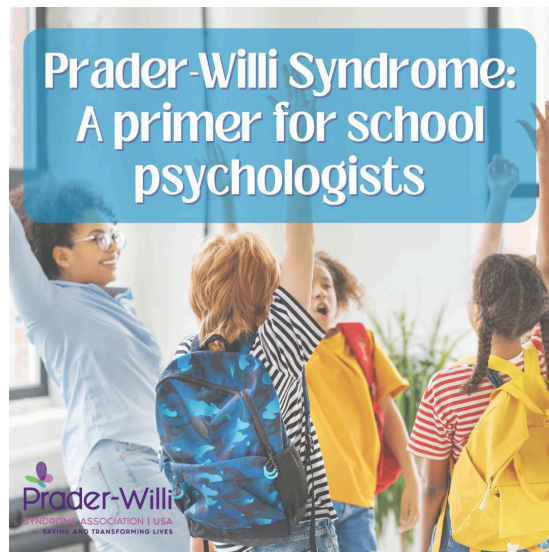
Get ready for an upcoming training series presented by Dr. Destiny Pacha, PWS Education Specialist, designed specifically for parents and families of children with PWS! This series will provide in-depth knowledge about the specifics of an IEP and your child's educational rights. Plus, how to incorporate specific services, strategies, and accommodations to ensure your child has a safe and successful school year. You will gain the confidence and skills needed to actively participate and advocate effectively for your child in IEP meetings, ensuring the best possible

## Resource for School Professionals

Stacy Ward (CEO of PWSA | USA), along with Kasey E. Bedard, Destiny Pacha, and Annette K. Griffith, recently published an article, "Prader-Willi Syndrome: A Primer for School Psychologists," in the Children and Youth Services Review. As the abstract states, "This paper provides a primer for school psychologists, introducing the physiological, educational, and behavioral differences experienced by children with PWS. As the symptoms of PWS are widespread, the impacts of common physical and neurological differences on specific learning

abilities, adaptive skills, and overall functioning in the classroom setting are discussed in detail. While PWS is a spectrum, and each child will experience symptoms and challenges differently, this article aims to provide a foundation for the development and facilitation of support services to assist educators in not only maintaining the health and safety of their students with PWS, but also in capitalizing on their strengths, and building a plan to help them succeed." If you

### Prader-Willi Syndrome: A primer for school psychologists



would like to read the "Prader-Willi Syndrome: A Primer for School Psychologists" article, please contact Stacy Ward at [sward@pwsausa.org](mailto:sward@pwsausa.org) or Dr. Destiny Pacha at [drpacha@empoweredolutions.org](mailto:drpacha@empoweredolutions.org) to receive a copy.



PWSA | USA's

## Website Spotlight



**SCHOOL  
SUCCESS  
SUMMIT**

PWSA | USA's **School Success Summit** includes several webinar presentations from specialists who are experts in education and PWS. These webinar recordings focus on creating goals and documenting progress, helpful tips for the IEP process, due process and more. You can watch the recordings by visiting the webpage at the button below.

[VISIT WEBPAGE](#)



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