PWSA | USA Pulse Newsletter: April 4, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 120

April 4, 2025

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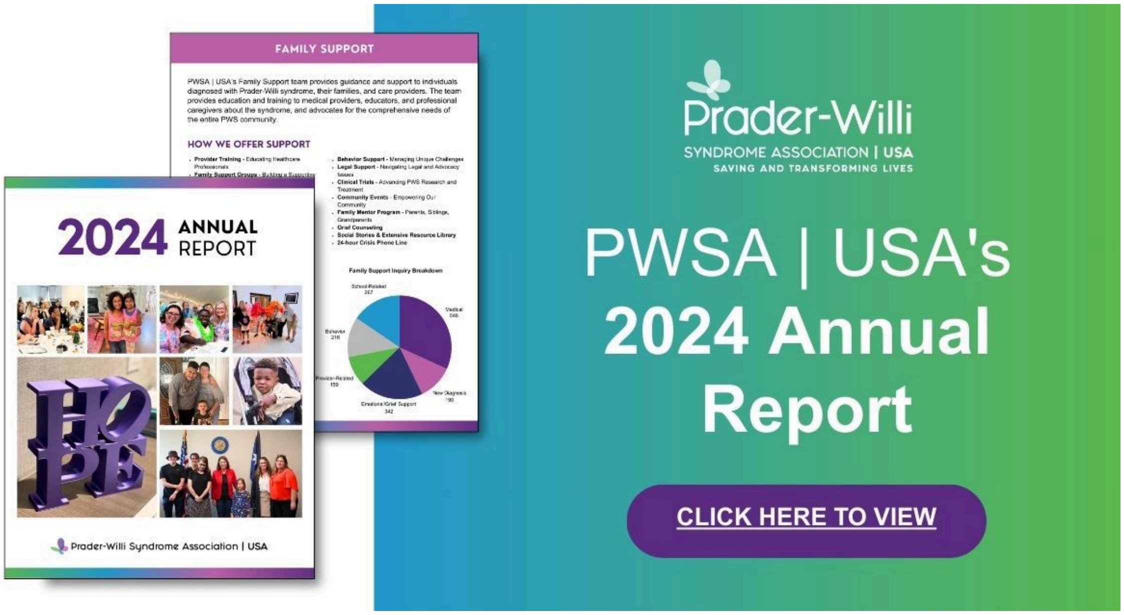
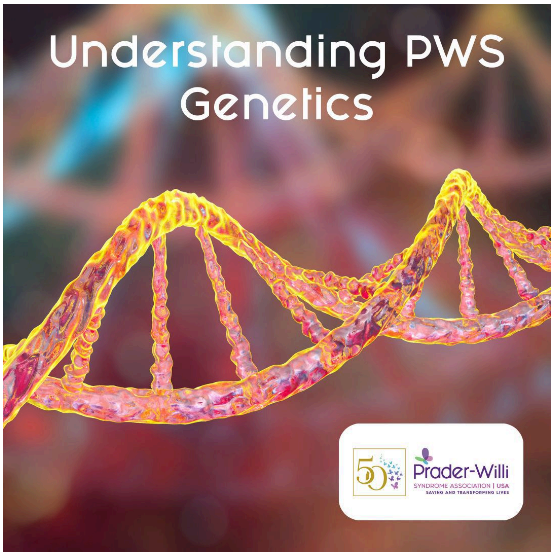


PWSA | USA's 2024 Annual Report is Here!

2024 was a year of progress, advocacy, and impact for the PWS community. From groundbreaking treatment milestones to expanded family support and advocacy efforts, our Annual Report highlights the incredible strides we've made, together. Discover how your support has driven real change. Read about our key initiatives, inspiring stories, and the future we’re building for individuals with PWS. Read the full report by clicking the image above.

PWSA MEMORIES



Merlin G. Butler, MD, PhD, FFACMG, known affectionately to some as the Wizard, is a retired Physician Scientist, Clinical Geneticist and Clinical Cytogeneticist who worked at the University of Kansas Medical Center and as a prominent researcher in the PWS community. He is a member of PWSA | USA's Clinical and Scientific Advisory Board and incredibly helpful with genetics questions that our staff and providers have. "*In the early 1980s, he was the first to report the genetic cause of this syndrome, a chromosome 15 deletion, was donated by the father only. Later in the same decade, he teamed up with investigators from Harvard University using advanced DNA technology and determined about one-third of Prader-Willi cases were the result of maternal disomy 15, when a mother passes two copies of chromosome 15 to her child with Prader-Willi syndrome instead of one copy.*" - Pioneering geneticist Merlin G. Butler, M.D., Ph.D., keeps pushing the boundaries of science

With the help of researchers like Dr. Butler, the medical community is able to have a better understanding of PWS, symptoms, and the most effective way to move forward with treatment options. We offer our sincere gratitude to Dr. Butler and all of the clinical and scientific professionals who work to help enhance the lives of our loved ones with PWS.

Read some of Dr. Butler's work by clicking the button below.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S

SPOTLIGHT ON HOPE

Call for Spotlight on Hope Stories

Our **Spotlight on Hope** series strives to share and celebrate the successes of our loved ones. No success is too small! Whether they took their first steps, had a great time at the school dance, made a shot in a basketball game, or are working toward a goal, we want to celebrate it all.

There are many challenges with PWS, and much of our focus is toward mitigating the effects of these challenges. So, PWSA | USA has created a space to share the other stories. The wins, the smiles, the milestones. The moments that bring joy and hope, a relaxing of the shoulders, and a momentary reprieve from the struggles of PWS.

If you're looking for inspiration, please browse our past Spotlight on Hope stories to read just how capable and inspiring our loved ones with PWS truly are!

READ SPOTLIGHTS HERE

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

2025 International PWS United in Hope Conference Welcomes International Families

We are thrilled to welcome PWS families from around the world to the 2025 United in Hope Conference, hosted by IPWSO, PWSA | USA, and FPWR! Families will be joining us from Japan, Ireland, Hungary, Canada, United Kingdom, Australia, Dominican Republic, Sweden, Norway, Kenya, Germany, Belgium, Bulgaria, Costa Rica, Israel, Congo, France, Argentina, Netherlands, Nigeria, Switzerland, and, of course, the United States. This historic event is an exciting opportunity to make connections and spread support for PWS. We hope you will join us as we extend a very warm welcome to our international families.

Online registration will remain open until Tuesday, June 17, 2025. Walk-up registration will not be available on-site.

Booking Your Stay: As a reminder, rooms at the Arizona Grand Resort & Spa are completely sold out on Thursday, June 26, 2025. There are still rooms available for the remaining conference days, but if the booking website shows no availability, we encourage you to call the resort directly to receive help or be placed on a waitlist. Call 877-800-4888. **Click here** to visit the Arizona Grand Resort & Spa's booking site. We also have a Hotel Locator Website specifically for 2025 International PWS Conference attendees. **Click here** to be directed to that page. *(Please note: If you stay off-site, you'll need to arrange transportation to and from the Arizona Grand Resort & Spa for all conference sessions.)*

Don't miss this incredible opportunity to connect, learn, and celebrate coming together in person!

Register for the 2025
International PWS Conference

Thank You 2025 Conference Sponsors

To learn more about sponsorship opportunities, contact us at development@pwsausa.org. Together, we can make a lasting impact!

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USA friends of IPWSO

VYKAT XR (formerly known as DCCR) Approved by FDA! Soleno Hosts Informational Webinar

When: **Wednesday, April 16th at 9:15 AM PT | 12:15 PM ET**

medlive
Education that empowers

VYKAT XR
(diazoxide choline) extended-release tablets

Soleno's Heartfelt Thanks to the Prader-Willi Syndrome Community

Live Online Presentation
April 16, 2025 12:15pm ET / 9:15am PT

Register Now
www.Medlive.com/v/PWScommunity

[FREE TO PARTICIPATE]

What You'll Learn:

- How to recognize hyperphagia in people living with Prader-Willi syndrome
- How VYKAT XR helps hyperphagia as the first and only FDA approved treatment for hyperphagia in Prader-Willi syndrome
- A caregiver's story of their loved one's experience with VYKAT XR
- How to get started with VYKAT XR

In Partnership With:

Foundation for Prader-Willi Research
Prader-Willi Syndrome Association | USA
Saving and Transforming Lives

Featured Speakers:

Kathryn Obrynba, MD
Pediatric Endocrinologist

Deahl Wilson
Caring for a loved one with PWS

Stacy Ward
CEO Prader-Willi Syndrome Association | USA

Susan Hedstrom
Executive Director
Foundation for Prader-Willi Research

Brennen Fields
Senior Director, Patient Access Solutions Soleno Therapeutics

The PWS community is celebrating a big victory with the FDA approval of VYKAT XR (formerly known as DCCR in clinical trials). While we celebrate, it is important to learn all that we can about VYKAT XR and the next steps for this as a potential treatment option. Registration is NOW OPEN for Soleno Therapeutics & MedLive's free, live webinar! We highly encourage everyone in the PWS community to attend this virtual event to learn more about VYKAT XR (formerly known as DCCR) and how it addresses hyperphagia in individuals with Prader-Willi syndrome. If you are unable to make it, the webinar will be recorded.

What You'll Learn:
- How VYKAT XR helps manage hyperphagia as the first and only FDA-approved treatment
- A caregiver's firsthand experience with VYKAT XR
- How to get started with treatment

Download the webinar flyer **HERE**. Register for the webinar at the button below.

REGISTER HERE

VISIT THE OFFICIAL VYKAT XR WEBSITE

PWANY Mini-Conference and Family Fun Day: Book Your Hotel TODAY (April 4), Last Day for Early Bird

When: **May 2-3, 2025**
Where: Hyatt Place Albany (82 Montgomery Street, **Albany, NY**)

Prader-Willi Alliance of New York (PWSANY) is hosting its Spring Mini Conference and Family Fun Day, May 2-3. Friday evening will be a "Meet & Greet" at 7 PM ET. Conference sessions will be on Saturday from 8 AM until 12 PM ET. An activity room will be available for individuals with PWS and their siblings during the Meet & Greet and presentations. On Saturday afternoon (12 PM - 4 PM ET), there will be a Family Day at Huck Finn's Playland (check out their website at [Huck Finn's Playland | HUCK FINN’S PLAYLAND 72nd SEASON]).

Fees:

- Conference Registration: $25 per family (There is no charge for the activity room. Meals are not included.)
- Huck Finn's Playland: $15 per person (Thanks to one of our sponsors, we can offer this EARLY BIRD rate until April 4, 2025. Prices after this date will be subject to availability.)

Prader-Willi Alliance of New York, Inc.
Advocacy • Support • Hope

Spring
Mini Conference
&
Family Fun Day
May 2-3, 2025

ANNOUNCING OUR PRESENTERS

NEW YORK STATE OF OPPORTUNITY.
Office for People With Developmental Disabilities

Diane Woodward
Director of Clinical and Policy Support in OPWDD’s Division of Statewide Services

Dr. Moris Angulo
Pediatric Endocrinologist, Geneticist and well known PWS Expert

Dr. Judith Lucas
Developmental-Behavioral Pediatrician with over 30 years of experience in the medical field

Conference Registration
ONLY $25 per family
Come to learn and connect,
stay to play at
Huck Finn’s Playland!
Early Bird pricing
$15/person.
*Group rate subject to availability.
Register NOW!

CONFERENCE REGISTRATION

or Visit Our Website
www.prader-willi.org/events

Dorothea Lantz & Stacy Ward
PWSA | USA’s Director of Community Engagement and parent of a child with PWS, along with the CEO of PWSA | USA

SPONSORED BY
ACADIA
SOLENO THERAPEUTICS

DON’T WAIT!!
Conference Rate of
$179/ night expires
April 4th!!

HOTEL RESERVATIONS

Hyatt Place Albany/Downtown
82 Montgomery Street
Albany, New York 12207

To reserve a room at the hotel and take advantage of the conference rate ($179/ night), use the following link BEFORE April 4, 2025: [PWANY Block at Hyatt Place]

Please be aware that if you reserve after April 4 or make your own arrangements, you will not be guaranteed the conference rate.

Click the button below to learn more and register for this exciting event!

[REGISTER HERE]

Zahra's Night of Light, April 5:
Bid Now on Auction Items!

When: **Saturday, April 5, 2025 |**
6 PM CT
Where: Historical Hall, 608 Old Post Road, Bedford, New York

Zahra's Night of Light in Bedford, NY, is fast-approaching! The event will take place tomorrow, April 5th, at the Historical Hall at 608 Old Post Road. If you can't make it to the event, you can still support Zahra, her family, and the PWS community by donating **HERE** or by bidding on incredible auction items using the button below.

Every dollar raised will go directly to PWSA | USA to fund advocacy, family support, and vital research to find a treatment for PWS.

ZAHRA'S NIGHT OF LIGHT
april 5 | bedford, ny

Auction Items - Bid Now!

BID HERE

United We Brunch: Awareness in Every State

At PWSA | USA, we believe that raising awareness for Prader-Willi syndrome starts in our own circles - with friends, family, neighbors, and colleagues. As PWS Awareness Month approaches this May, we are excited to introduce the **United We Brunch (UWB)** initiative, a nationwide effort designed to bring people together to connect, share experiences, and gain the resources and support our community needs.

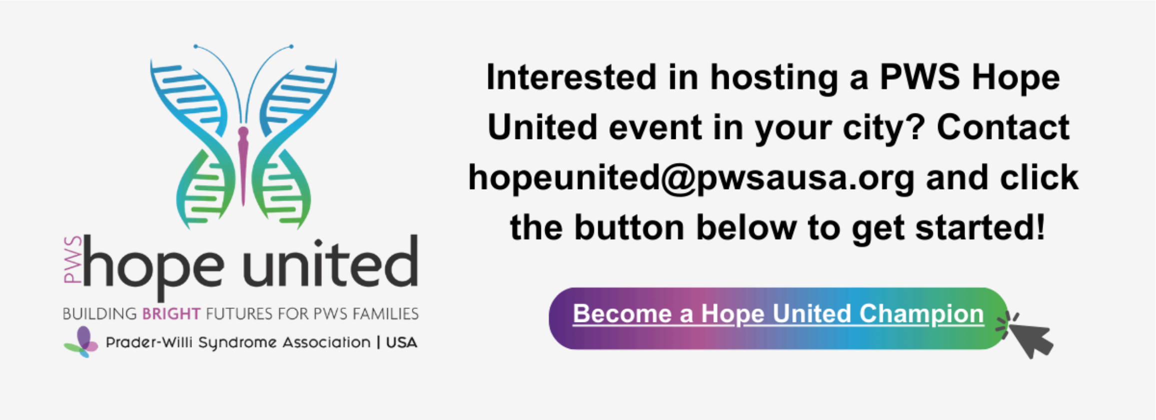
United We Brunch is all about raising awareness, fostering hope, and gathering resources - one brunch, one state, and one family at a time - uniting communities and creating a ripple effect across the U.S. Anyone can host a UWB event! It's easy and can be as casual or fancy as you'd like. From having friends over for muffins and coffee to catering a high-tea and arranging flowers, your time and imagination are the only limits.

We've made getting involved easy!

1. Download our **United We Brunch toolkit HERE**
2. Register to create your UWB page at the button below.
3. Name your event: Include the state and date
4. Start planning and reach out to **hopeunited@pwsausa.org** for help and support!

GET STARTED!

VISIT THE PWS AWARENESS MONTH HUB



Interested in hosting a PWS Hope United event in your city? Contact hopeunited@pwsausa.org and click the button below to get started!

Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

Our latest *PWS United* episode features our beloved Parent Support Coordinator Kristi Rickenbach, along with Board members Denise Servais and Lisa Lamb, and Marketing and Communications Coordinator, Anne Fricke. They are all parents of multiple children, including a child with Prader-Willi syndrome.

In their conversation, they discussed feelings of getting it wrong - of over-managing social situations and lives, letting siblings take on perhaps too much responsibility, over-compensating for the challenges of PWS and time spent with the child with PWS, and other feelings of inadequacies. They discuss the importance of quality time, ensuring siblings feel heard, validating their feelings, being vulnerable and fair, understanding the difference between equality and equity, and why PWS parents should have honest conversations with their children.

Listen to the latest episode of *PWS United* on your preferred podcast app or by clicking the button below.

[LISTEN ON PODBEAN](#)

ADVOCACY

PWS Awareness Month Proclamation Toolkit – Now Available!

ADVOCACY IN ACTION

Prader-Willi Syndrome (PWS) Awareness Month

Proclamation Toolkit

Created by PWSA | USA's Advocacy Team

4-Step Guide on How to Request a Proclamation or Resolution 2

Sample Cover Letter - EXAMPLE 1 3

Make an impact this May by securing a PWS Awareness Month or PWS Awareness Day (May 15th) proclamation in your city or state! Our Proclamation Toolkit provides everything you need to take action, including step-by-step guidance, sample cover letters for reaching out to local and state officials, and inspiring success stories from PWS families who have done it before.

This is an easy yet powerful way to raise awareness for Prader-Willi syndrome in your community, and we encourage everyone to get involved! If you receive a proclamation, be sure to share it with us so we can celebrate with you.

For questions, email: advocacy@pwsausa.org
Send proclamation photos to: communications@pwsausa.org

Let’s work together to make PWS awareness visible across the country!

PROCLAMATION TOOLKIT

Call for Stories from Illinois PWS Community!

We have been working with a small group of advocates in Illinois to get PWS recognized as a condition for Medicaid disability services. In the last couple of weeks, it has become apparent that there are elements of the process for families seeking services that are not working as designed. We need your help to learn more.

We are looking for stories from Illinois families who need services from the state and have been denied. We are also interested in families who have been granted services but have been unable to obtain them. These real-life examples of challenges with the Illinois system for obtaining disability services are important to our continued advocacy.

Please reach out to Elaine at etowle@pwsausa.org or 941-487-6720 to share your story. All stories are important to help us – and Illinois officials – better understand what is happening as PWS families seek necessary services.

We look forward to hearing from you. Please **respond by Wednesday, April 9**, and thank you in advance for your help.

FAMILY SUPPORT

Supporting Siblings for National Siblings Day and Everyday!

Sibling Support Guide

Featuring Resources for Parents and Siblings of a Loved One Living with Prader-Willi Syndrome

Contributed by: Kristi Rickenbach, Denise Servais, and Lisa Lamb

April 10 is National Siblings Day! As parents and caregivers, we recognize the challenges that siblings of individuals with PWS face and the need for specialized support for those siblings. With this in mind, we are continuing to grow our resources for the siblings in the PWS community. Our new **Sibling Support Guide**, created with contributions from moms Kristi Rickenbach, Denise Servais, and Lisa Lamb, is designed to help both parents/caregivers and siblings navigate this unique experience.

This guide provides practical support for parents in fostering understanding and communication, while also offering direct guidance and encouragement for siblings themselves. Inside, you'll find valuable insights, including *10 Tips for Helping Siblings Thrive*, *How Siblings May Feel*, and *What is PWS (for siblings)*. Whether you're a parent looking for ways to support your children or a sibling seeking understanding, this guide is here for you.

We also have a sibling blog from Mallory Servais. You can read that blog **HERE**. We are excited to share the sibling perspective and are looking for more blogs. If your sibling would like to share their experience, please email africke@pwsausa.org.

Are you attending the 2025 International PWS Conference? Be sure to check out the sibling panel to hear more from the siblings in our community and what kind of support they need.

DOWNLOAD SIBLING GUIDE HERE

"A Loving School Is Vital"
PWS in Adulthood Blog Series

This blog was contributed by Lois Schults, father to Laura, a 38-year-old living with PWS. He wrote about the challenges of Laura's behavior and the decision to place her in a group home, why this was a good decision for their family, and how Laura thrived. Today, she is in a good home with lots of friends and loving staff and volunteer work that she enjoys. Read the blog to learn more about Laura and Lois's advice for raising and supporting a child with PWS.

READ HERE

Ask Nurse Lynn

Female, 23 years old, UPD subtype

My 23-year-old daughter with UPD is just now developing some food-foraging behaviors. I am assuming this is not uncommon, but I am just wondering if this is typical to start at this age. We have never locked our cabinets because we never had to, so I am wondering if this is the direction we are headed. Thank you so much.

Visit our blog to read Nurse Lynn's response and find links to connected resources.

READ NURSE LYNN'S RESPONSE

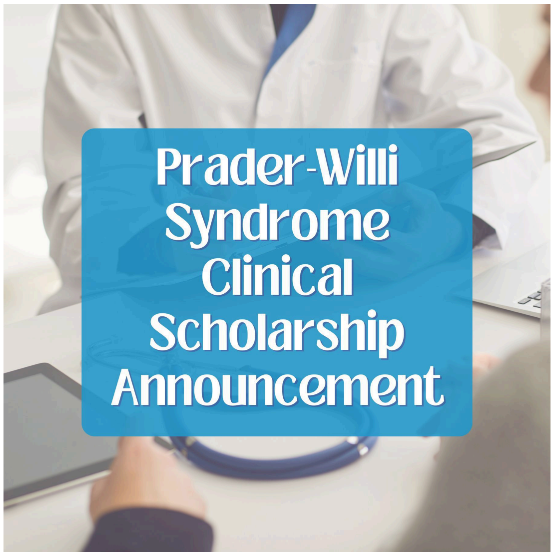
Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

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

ASK YOUR QUESTION HERE

RESEARCH

PWS Clinical Scholarship Announcement



We are proud to offer scholarships of up to $25,000 USD to support providers in enhancing their understanding of Prader-Willi syndrome through clinical proctorships with experts in the field. The scholarship supports providers who are currently in practice in the United States and who presently care for or plan to care for patients with PWS to deepen their knowledge of Prader-Willi syndrome through directed clinical proctorship with experts in the field. **Special consideration** will be given to **new or early-stage providers to PWS, as well as those in underserved geographic areas or serving underserved populations** (e.g., adults, diverse populations, rural communities).

Read the details of the scholarship and learn how to submit your application by clicking the button below.

LEARN MORE HERE

Call for Letters of Intent for New PWS Research Grants

The PWSA | USA research priorities are to gather knowledge about PWS, support the application of therapies, and recruit new investigators to the field.

Regarding research topics, a broad range of areas will be considered, from societal and behavioral to biological, particularly in understudied areas such as adult health, quality of life, positive health outcomes, and diverse populations. Priority will be given to clinical studies, but we are open to other types of research as well as funding pilot projects and supporting clinical innovations to support individuals with PWS.

PWSA | USA will consider two types of funding:

1. Applicants may request up to $150,000 USD to fund research on Prader-Willi syndrome. The term of the award is 12 months, with the possibility of a second grant period of 12 months of funding upon competitive renewal.

2. Applicants may choose to request a smaller budget and/or shorter duration. Awards of up to $25,000 USD may be considered on an individual and rolling basis.

The deadline for letters of intent is August 1, 2025, 5 PM EST. Announcement of the award will be made on November 14, 2025 and funding will begin on January 1, 2026 (release of funds to awardee is contingent upon IRB approval of the proposal).

Learn more about this call for LOIs and how to submit yours by clicking the button below.

[LEARN MORE HERE]

PWSA | USA ANNOUNCEMENTS

PWSA | USA Welcomes New Staff Member!

Charles Conway, Jr., Executive Administrative Assistant

Charles was born and raised in Hope, Arkansas (currently resides in Woodbridge, Virginia). He is a retired Army Logistics Officer (Lieutenant Colonel). He served for over 24 years in numerous leadership and support staff position across the United States including 4 deployments overseas (Afghanistan and Iraq). He earned his BS in Civil Engineering Technology from Alabama A&M University and MSA in General Administration/Human Resources from Central Michigan University. In his free time, Charles enjoys spending time with his family, playing and watching basketball, tennis & football (especially The Dallas Cowboys), listening to music, running, lifting weights and most importantly being the voice for his children especially his youngest daughter Angelica who has PWS. Since retirement, Charles has been a big supporter of PWSA | USA's mission as he serves as a member of the Advocacy Committee, Communications Working Group, Family Support Working Group as well as a Parent Mentor and Dads' group organizer. He also co-organizer the PWS Black, Indigenous and People of Color (BIPOC) Affinity Group. Charles is committed to helping raise awareness about PWS, educating others (including federal, state, and local government) and mentoring, encouraging, and supporting families impacted by PWS. He is married to the beautiful Gennelle. They have six adorable children (the late Ja'Brea, Nicholas, Jaeda, Angelica, Charles III, and Gabriel).

PWSA | USA Resource Spotlight

Questions and Answers about PWS Brochure

Our Mission

To enhance the quality of life and empower those affected by Prader-Willi syndrome.

Q: What causes the appetite and obesity problems in PWS?

Q: Does the overeating associated with PWS begin at birth?

Q: What kinds of behavior problems do people with PWS have?

Q: How does growth hormone therapy help?

Q: What does the future hold for people with PWS?

Q: How is PWS diagnosed?

Q: What is known about the genetic abnormality?

Q: What is Prader-Willi syndrome (PWS)?

Q: Is PWS inherited?

Q: How common is PWS?

Questions and Answers

About Prader-Willi Syndrome

As we look ahead to PWS Awareness Month in May, we wanted to share a resource to help spread information and awareness about our loved ones. Our downloadable brochure, *Questions and Answers about Prader-Willi Syndrome*, provides insight into some of the more common questions about PWS; What is it? How common is PWS? What causes appetite and obesity problems? How does growth hormone help? What does the future hold? and more. Prepare for PWS Awareness Month by downloading this free resource and sharing with your community.

Q & A ABOUT PWS BROCHURE

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 Pulse Newsletter: April 18, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 121

April 18, 2025

www.pwsausa.org | 941-312-0400

Important Update: Limited Spots Remain for the 2025 Family Program

Due to the overwhelming response to the 2025 International PWS Conference, we are now in the position of needing to implement a capacity limit for the Family Program (June 27 & 28, 2025) to ensure we remain in compliance with the Arizona Grand Resort & Spa's fire code regulations. This measure is necessary to prioritize the safety and comfort of all attendees. As of today **53** spots remain available for the Family Program. If you plan to participate in the Family Program and haven't yet registered, we encourage you to do so as soon as possible to secure your spot. Thank you for your understanding and continued support. We look forward to seeing our community come together in Phoenix soon!

REGISTER HERE

Professional Providers High-Level Schedule Now Available for Download!

June 24-28, 2025 · Arizona Grand Resort & Spa

2025 International PWS Conference

Professional Providers Program

High-Level Schedule

Professional Providers Program | Wednesday, June 25, 2025 - Thursday, June 26, 2025

Wednesday, June 25, 2025 | *DAY ONE*

9:00 AM - 5:30 PM

Breakfast on your own *(6:30 AM - 9:00 AM - Food Trucks at Conference Center Pavilion)*

9:00 AM - 9:30 AM	Opening and Welcome *Arizona C, D (Copperwood, Desert Willow)*
9:30 AM - 10:15 AM	PWS Residential Services Across the Globe *Arizona C, D (Copperwood, Desert Willow)*
10:45 AM - 11:30 AM	A New Resource: 'Practical Portions for Prader-Willi Syndrome' *Arizona C, D (Copperwood, Desert Willow)*
11:30 AM - 12:00 PM	Poster Presentations *Arizona C, D (Copperwood, Desert Willow)*
12:00 PM - 1:00 PM	Lunch
1:00 PM - 1:50 PM	The Development of a PWS Specific Respite Service *Arizona C, D (Copperwood, Desert Willow)*
1:50 PM - 2:40 PM	Musculoskeletal Issues of Prader-Willi Syndrome: A Few Things to Know *Arizona C, D (Copperwood, Desert Willow)*
3:10 PM - 3:55 PM	Looking Beyond Poor Lean Mass and Growth Hormone Deficiency, Why is Exercise More Difficult for People with PWS? *Arizona C, D (Copperwood, Desert Willow)*
3:55 PM - 4:40 PM	Caregivers' Forum *Arizona C, D (Copperwood, Desert Willow)*
4:40 PM - 5:30 PM	A Simple and Humane Approach to Minimizing Behavioral Outbursts for People Living with PWS: What to Do and Why *Arizona C, D (Copperwood, Desert Willow)*

Thursday, June 26, 2025| *DAY TWO*

8:30 AM - 6:30 PM

Breakfast on your own *(6:30 AM - 9:00 AM - Food Trucks at Conference Center Pavilion)*

8:30 AM - 10:30 AM | ***WORKSHOP I***
- Supporting People with PWS with Very Challenging Behavior
  Arizona B (Bougainvillea)
- ABA and PWS: Tailoring Applied Behavior Analysis for Individuals with Prader-Willi Syndrome
  Arizona C, D (Copperwood, Desert Willow)

11:00 AM - 1:00 PM | ***WORKSHOP II***
- Effective Communication with People with PWS
  Arizona B (Bougainvillea)
- Aging in PWS
  Arizona C, D (Copperwood, Desert Willow)

1:00 PM - 2:00 PM - Lunch

2:00 PM - 4:00 PM | ***WORKSHOP III***
- The Experience of Grief for Residents and Staff in a PWS Residential Setting
  Arizona B (Bougainvillea)
- Caregivers Working with the Family of the Person with PWS
  Arizona C, D (Copperwood, Desert Willow)

4:30 PM - 6:30 PM | ***WORKSHOP IV***
- Friends, Partnerships, and Sexuality
  Arizona B (Bougainvillea)
- Promoting and Fostering Self-Advocacy
  Arizona C, D (Copperwood, Desert Willow)

Exciting news! A high-level look at the **2025 International PWS Conference Professional Providers schedule** is now available for download. Professional Providers are invited to join PWSA | USA, FPWR, and IPWSO on Wednesday, June 25, and Thursday, June 26, 2025, for an incredible lineup of expert-led sessions covering key topics, including:

- PWS Residential Services Across the Globe
- The Development of a PWS Specific Respite Service
- Looking Beyond Poor Lean Mass and Growth Hormone Deficiency, Why is Exercise More Difficult for People with PWS?
  …and so much more!

Each session and workshop is designed to support Professional Providers in the PWS space, and offer opportunities to connect, learn, and grow. A finalized agenda with our speakers will be released closer to the conference.

PROFESSIONAL PROVIDERS PROGRAM SCHEDULE

FAMILY PROGRAM SCHEDULE

Thank You 2025 Conference Sponsors

To learn more about sponsorship opportunities, contact us at development@pwsausa.org. Together, we can make a lasting impact!

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epm Therapeutics

USA friends of IPWSO

PWSA MEMORIES

In January of 1976, The Gathered View, the newsletter for Prader-Willi Syndrome Parents and Friends (PWSA | USA's original name) celebrated the first international members to the organization. The article reads as follows, *"Prader-Willi Syndrome Parents and Friends now has an international membership. Among our new members, we welcome two from England and one from Australia. Our English members live in the same county and have already become acquainted. Total membership is now fifty-one." (Volume II, Number 1)*

editor has had no journalism training and

The editor does not have time to individually answer the letters received, so she says, "Thank you, and please write again."

PRADER-WILLI SYNDROME PARENTS AND FRIENDS IS INTERNATIONAL

PRADER-WILLI SYNDROME PARENTS AND FRIENDS now has an international membership. Among our new members we welcome two from England and one from Australia. Our two English members live in the same county and have already become acquainted. Total membership is now fifty-one.

IN APPRECIATION

THE GATHERED VIEW is typed in preparation for publication by Mrs. Lyn Willow Ekern of Kent, Washington, who performs this work as a contribution. It is an exacting task, as the material must go to the printer as camera-ready copy. The printer has commented frequently on the high quality of Mrs. Ekern's work. Our thanks to her for the fine service she performs.

Since then, the number of families outside of the United States that PWSA | USA helps has grown exponentially; countries include Egypt, Morocco, Tunisia, Algeria, Lybia, Sudan, Israel, Saudi, Emirates, Qatar, Kuwait, Syria, Palestine, France, Canada, Italy, Belguim, Australia, Ukraine, China, Columbia, Mexico, and India. With organizations like PWSA | USA and IPWSO (International Prader-Willi Syndrome Organisation), PWS families around the world can stay updated on research, knowledge, and growing standard practices of care. We are happy to support and celebrate our growing PWS community.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S
SPOTLIGHT ON HOPE

Hello PWS community! We wanted to share our proud moment in honor of our daughter Addy, 5 years old, who completed her first race yesterday!! She took off at the start line, and pushed hard running! I was by her side, coaching her to pace herself, breathe, and motivate her to keep going. I know she was tired, but this girl never stopped and quitting was NOT an option for her. She kicked it into high gear toward the end to cross the finish line and earn her medal!!

She never gives up, continues to fight daily, and believes in herself, as we do. We must advocate for our loved ones and always remind them what they are truly capable of, despite the obstacles that may come their way. We want to thank PWS America for always being there as support and guidance for our families. The sky is the limit, and we can only get better from here. May this be the first of many finish lines for Addy Rae! - Submitted by Adelynn Uriegas

SHARE YOUR SPOTLIGHT ON HOPE

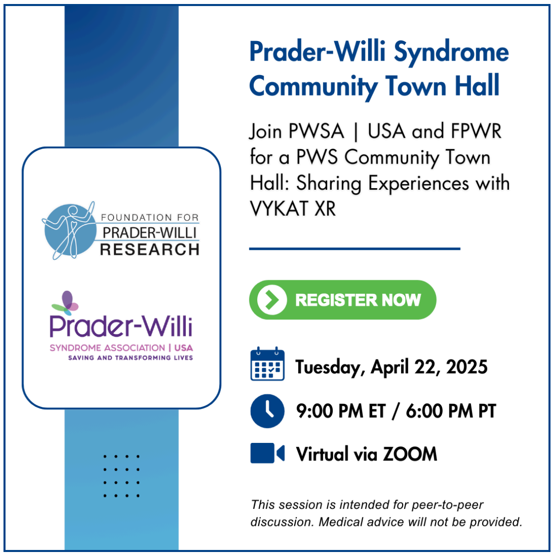
EVENTS & FUNDRAISERS

PWS Community Town Hall: Sharing Experiences with VYKAT XR

When: **Tuesday, April 22 @**
9 PM EDT | 6 PM PDT

PWS families and caregivers are invited to a virtual town hall focused on VYKAT XR, the first FDA-approved medication for treating hyperphagia in individuals with Prader-Willi syndrome, ages 4 and older. This informal, community-led town hall is a no-host forum, designed as a space for families and caregivers to share their personal experiences with VYKAT XR, ask questions, and learn from one another.

Please note: This session is intended for peer-to-peer discussion. Medical advice will not be provided. This town hall is intended for U.S.-based caregivers of individuals with Prader-Willi syndrome. To ensure a safe and supportive environment, PWSA | USA and FPWR will verify all registrants to confirm caregiver status. Registration will be approved only once verification is complete. For the privacy of our attendees, the town hall will not be recorded.



Prader-Willi Syndrome Community Town Hall

Join PWSA | USA and FPWR for a PWS Community Town Hall: Sharing Experiences with VYKAT XR

Tuesday, April 22, 2025

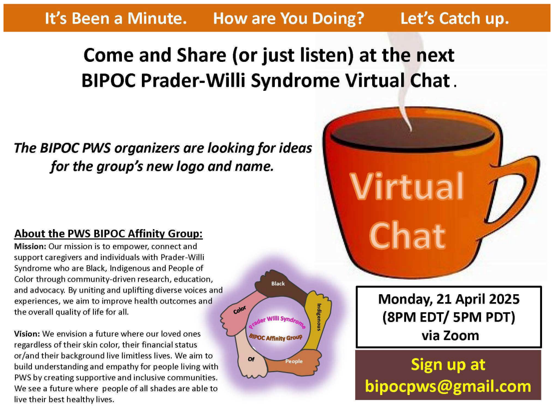
9:00 PM ET / 6:00 PM PT

Virtual via ZOOM

This session is intended for peer-to-peer discussion. Medical advice will not be provided.

[REGISTER HERE]

BIPOC Affinity Group Virtual Chat



It's Been a Minute. How are You Doing? Let's Catch up.

Come and Share (or just listen) at the next BIPOC Prader-Willi Syndrome Virtual Chat.

The BIPOC PWS organizers are looking for ideas for the group's new logo and name.

About the PWS BIPOC Affinity Group:

Mission: Our mission is to empower, connect and support caregivers and individuals with Prader-Willi Syndrome who are Black, Indigenous and People of Color through community-driven research, education, and advocacy. By uniting and uplifting diverse voices and experiences, we aim to improve health outcomes and the overall quality of life for all.

Vision: We envision a future where our loved ones regardless of their skin color, their financial status or/and their background live limitless lives. We aim to build understanding and empathy for people living with PWS by creating supportive and inclusive communities. We see a future where people of all shades are able to live their best healthy lives.

Monday, 21 April 2025
(8PM EDT/ 5PM PDT)
via Zoom

Sign up at
bipocpws@gmail.com

When: **Monday, April 21 @ 5 PM PDT | 8 PM EDT**

The PWS BIPOC (Black, Indigenous, and People of Color) Affinity Group is hosting their virtual event next Monday, April 21, on Zoom to catch up, connect, and get your input on our group's name and future logo. Your voices matter and are needed!!

Interested BIPOC or caregivers of BIPOC individuals are asked to RSVP to bipocpws@gmail.com to obtain the meeting link. On behalf of PWS BIPOC Affinity Group Organizers (Charles, Gennelle, Karine and Dini), we hope to see and meet you soon.

Creating Financial Security for a Loved One with PWS
Financial Planning Webinar

When: **Wednesday, May 14 @**
12 PM EDT | 9 AM PDT

Join us for this educational workshop to learn more about special needs planning. Topics covered will include an overview of Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), Medicaid and Waivers, ABLE accounts, special needs trusts, and other important considerations to help family members better understand how planning for a child with special needs is different both legally and financially. This webinar is presented by Ivailo Grigorov, a Financial Advisor and special needs parent to Lucca, who is 8 years old and has a diagnosis of Prader-Willi syndrome. Ivailo realized that families like ours can benefit from a comprehensive plan that can guide them through the years and can ultimately maximize a child's overall quality of life. Ivailo's team primarily works with families who have a loved one with disabilities who will require some support not only now but in the distant future. Ivailo's goal is to serve as the quarterback for the family's planning, educate on most efficient ways to save, optimize and protect our loved ones' futures and ultimately provide piece of mind. Register for this webinar using the button below.

REGISTER HERE

Zahra's Night of Light Shines Bright

On April 3rd, the Dorson Family, Pia, Dave, Zahra, Ronin, and Zoe, hosted the inaugural *Zahra's Night of Light* at the Historic Hall in Bedford, NY. The evening brought together family and friends for a beautiful celebration benefiting children like Zahra who are living with Prader-Willi syndrome. Guests enjoyed live entertainment, delicious food and drinks, a silent auction, and a heartfelt sense of purpose.
Thanks to the Dorsons' efforts and the generosity of their community, the event raised more than **$70,000** to support PWSA | USA's family support, advocacy, and research programs. We are incredibly grateful!

Click the button below to see photos from this unforgettable night.

PHOTO GALLERY

North Carolina 5K and Family Fun

Hope United Event

When: **Saturday, May 3 @ 9 AM EDT**
Where: **Greater Wilson Rotary Park | 1901 Branch St. NW, Wilson, NC 27893**

Register to ATTEND or SPONSOR the NC Hope United 5K & Family Fun Run in support of individuals living with Prader-Willi Syndrome! Proceeds from this event will benefit PWSA | USA's Advocacy, Family Support, and Research programs to find a treatment for PWS. Learn more, register, and/or donate by using the button below.

REGISTER HERE

United We Brunch: Awareness in Every State

At PWSA | USA, we believe that raising awareness for Prader-Willi syndrome starts in our own circles - with friends, family, neighbors, and colleagues. As PWS Awareness Month approaches this May, we are excited to introduce the **United We Brunch (UWB)** initiative, a nationwide effort designed to bring people together to connect, share experiences, and gain the resources and support our community needs.

United We Brunch is all about raising awareness, fostering hope, and gathering resources - one brunch, one state, and one family at a time - uniting communities and creating a ripple effect across the U.S. Anyone can host a UWB event! It's easy and can be as casual or fancy as you'd like. From having friends over for muffins and coffee to catering a high-tea and arranging flowers, your time and imagination are the only limits.

We've made getting involved easy!

1. Download our **United We Brunch toolkit HERE**
2. Register to create your UWB page at the button below.
3. Name your event: Include the state and date
4. Start planning and reach out to **hopeunited@pwsausa.org** for help and support!

GET STARTED!

VISIT THE PWS AWARENESS MONTH HUB

PWS hope united
BUILDING BRIGHT FUTURES FOR PWS FAMILIES
Prader-Willi Syndrome Association | USA

Interested in hosting a PWS Hope United event in your city? Contact hopeunited@pwsausa.org and click the button below to get started!

Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

On this episode we brought in Lynn Garrick, PWSA | USA's Medical and Research Coordinator and the woman behind Ask Nurse Lynn. We pulled three previous submissions to discuss on this episode, based on some common questions that families in the PWS community have. Nurse Lynn discussed when and why to start growth hormone, tips for helping your loved one with skin-picking issues, and what are GLP-1s and why they may or may not work on individuals with PWS.

Listen to the latest episode of *PWS United* on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

PWS Awareness Month Proclamation in New Hampshire

"Governor Kelly Ayotte of New Hampshire recently signed a Proclamation declaring May 2025 as Prader-Willi Syndrome Awareness Month in the state of New Hampshire. We are delighted to have her support to raise awareness of PWS and the New Hampshire families living with it. Requesting a Proclamation was really easy. First, identify who you want to ask – your state Senator or Representative, or the Governor. Then, use the tools in the [PWS Awareness Month Proclamation Toolkit]() to craft a letter. Give the office you contact at least 2 or 3 weeks' notice and ask for a formal presentation and photo op. We haven't been successful with that last part yet, but I'll keep trying!" - Submitted by Elaine Towle, PWSA | USA's Advocacy Specialist and mom to James, living with PWS.

PWS Awareness Month Proclamation in New York

We're thrilled to share that New York state is officially recognizing PWS Awareness Day thanks to a resolution filed by Senator Jake Ashby! This is an incredible step forward in raising awareness for Prader-Willi syndrome. Even more exciting — Stacy Ward, Jeff Covington, Amy, Harry, Noelle, and Logan McDougall will be present in Albany on May 15 to witness the resolution's acceptance during the Senate session. What a powerful moment for the PWS community!

Our Proclamation Toolkit provides everything you need to take action, including step-by-step guidance, sample cover letters for reaching out to local and state officials, and inspiring success stories from PWS families who have done it before. Access by clicking on the image.

For questions, email: advocacy@pwsausa.org
Send proclamation photos to: communications@pwsausa.org

ADVOCACY IN ACTION

Prader-Willi Syndrome (PWS) Awareness Month

Proclamation Toolkit

Created by PWSA | USA's Advocacy Team

FAMILY SUPPORT

Celebrating Occupational Therapy Month

April is National Occupational Therapy (OT) Month. Occupational therapy empowers people with complex diagnoses, including Prader-Willi syndrome, to build skills, confidence, and independence at every stage of life. In honor of OT Month, Kristi Larsen, MS, OTR/L, an occupational therapist in Madison, WI, shares how OT supports sensory needs, behavior regulation, early intervention, and lifelong well-being - offering practical insight for families and caregivers.

Click the button below to read her full contributed blog article.

[READ MORE]

Post a Message for Mother's Day

Mothers are incredible! Often the life-force of the family; the caretaker, nurturer, nurse, teacher, therapist, and more. Mothers are providers, secretaries, shuttle drivers, homework assistants, cooks, housekeepers, social confidantes, the ones children go to for emotional support or when they're feeling ill, and still more.

We are grateful for our mothers and know that you are as well! For this Mother's Day, we're offering space to share words of appreciation, gratitude, and celebration for the PWS mom in your life.

PWSA | USA would like to share a photo and a special message for your PWS Mom on our social media leading up to and on Mother's Day. Share with the world what it is that you appreciate about her. Ask your loved one for a special message about what she means to them. Share with our community what you appreciate about your PWS Mom.

Please submit your photo and message **no later than May 6** by using the button below.

SUBMIT HERE

Ask Nurse Lynn

Male, 38 years old, unknown subtype

I am an LPN. We currently have an individual with PWS, we are running into several problems, one of the biggest being hygiene. This individual refuses to shower, averaging about 1 weekly. He has a very large, growing rash across his abdominal folds. While we are here to support the individual's rights, it's becoming a health scare. This is new over the past few months; hygiene has not always been a problem. He has also faced several changes, such as a new home and new roommates/staff.

Visit our blog to read Nurse Lynn's response and find links to connected 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.

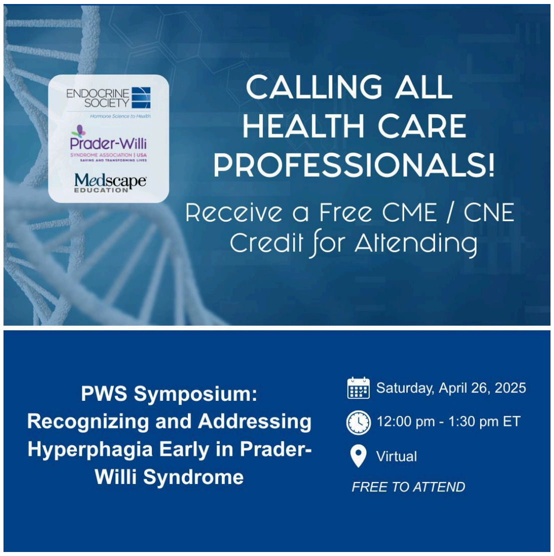
ASK YOUR QUESTION HERE

RESEARCH

Receive a FREE CME/CNE for attending the upcoming **Symposium: Recognizing and Addressing Hyperphagia Early in Prader-Willi Syndrome**

When: **Saturday, April 26 @ 12 PM - 1:30 PM EDT**
Where: **Virtual**

Join PWSA | USA, the Endocrine Society, and Medscape Education for this live symposium on Prader-Willi syndrome, where experts will explore the huge burden that hyperphagia represents for patients with PWS, their families, and their caregivers. They will delve into the pathophysiology and complications of



PWS Symposium: Recognizing and Addressing Hyperphagia Early in Prader-Willi Syndrome

Saturday, April 26, 2025
12:00 pm - 1:30 pm ET
Virtual
FREE TO ATTEND

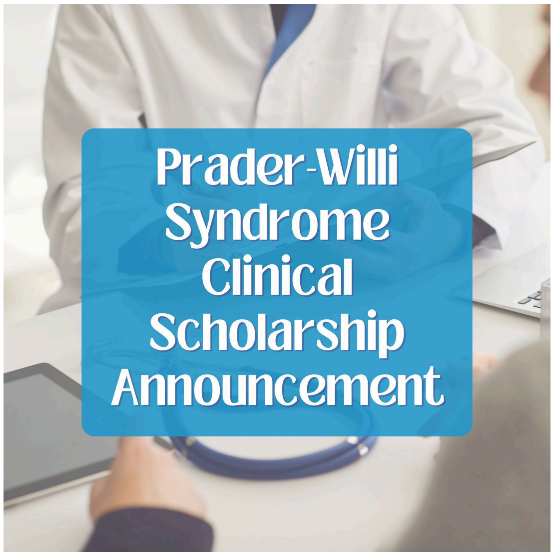
hyperphagia and look to the future in a discussion around the current and emerging treatment options for hyperphagia in PWS. By incorporating patient case examples and the latest data, the faculty will exchange ideas around best practices to ensure improved quality of life for patients with PWS and those around them. There will be an opportunity for attendees to ask questions of the experts during this symposium.

Please note: This is only for health care professionals to attend (pediatricians, endocrinologists, psychiatrists, geneticists, nurse practitioners, physician assistants, nurses, and other clinicians who care for patients with PWS in the United States). PWS families - Please share this opportunity with the health care professionals in your life!

This event is free to attend. Register using the button below.

REGISTER HERE

PWS Clinical Scholarship Announcement



We are proud to offer scholarships of up to $25,000 USD to support providers in enhancing their understanding of Prader-Willi syndrome through clinical proctorships with experts in the field. The scholarship supports providers who are currently in practice in the United States and who presently care for or plan to care for patients with PWS to deepen their knowledge of Prader-Willi syndrome through directed clinical proctorship with experts in the field. **Special consideration** will be given to **new or early-stage providers to PWS, as well as those in underserved geographic areas or serving underserved populations** (e.g., adults, diverse populations, rural communities).

Read the details of the scholarship and learn how to submit your application by clicking the button below.

LEARN MORE HERE

Call for Letters of Intent for New PWS Research Grants

The PWSA | USA research priorities are to gather knowledge about PWS, support the application of therapies, and recruit new investigators to the field.

Regarding research topics, a broad range of areas will be considered, from societal and behavioral to biological, particularly in understudied areas such as adult health, quality of life, positive health outcomes, and diverse populations. Priority will be given to clinical studies, but we are open to other types of research as well as funding pilot projects and supporting clinical innovations to support individuals with PWS.

PWSA | USA will consider two types of funding:

1. Applicants may request up to $150,000 USD to fund research on Prader-Willi syndrome. The term of the award is 12 months, with the possibility of a second grant period of 12 months of funding upon competitive renewal.

2. Applicants may choose to request a smaller budget and/or shorter duration. Awards of up to $25,000 USD may be considered on an individual and rolling basis.

The deadline for letters of intent is August 1, 2025, 5 PM EST. Announcement of the award will be made on November 14, 2025 and funding will begin on January 1, 2026 (release of funds to awardee is contingent upon IRB approval of the proposal).

Learn more about this call for LOIs and how to submit yours by clicking the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight
Find Your Voice Webinar Series

Check out our series of four webinars on Advocating for PWS Health Care on our YouTube channel. Topics include health advocacy (strategies, tools, and resources), common urgent health topics (high pain threshold, respiratory concerns, temperature regulation problems, GI problems, fragile bones, skin picking, food seeking, weight management), concerns for the hospitalized person with PWS (ER information, anesthesia, post-op monitoring, medication sensitivity, food security), mental health crises and getting help (differentiating between typical PWS behaviors and a mental health diagnosis, identifying and treating serious mental health issues). Click the button below to watch this webinar series.

[FIND YOUR VOICE](#)

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](#)