PWSA | USA Pulse Newsletter: July 4, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 126

July 4, 2025

www.pwsausa.org | 941-312-0400

The 2025 United in Hope International PWS Conference was a success! Families, providers, and researchers from around the globe converged on the Arizona Grand Resort and Spa in Phoenix, bringing knowledge, experience, dedication to the community, and a desire to connect and help improve the lives of those living with Prader-Willi syndrome.

One attendee shared, *"It was such an amazing conference. It was very informative, the breakout sessions discussed great topics. It felt like a big family reunion, getting to see and catch up with our PWS families. Thank you for everything!!"*

Another attendee touched on the positivity that permeated the conference. "*The highlight of my experience was the feeling of Unity and Hope. We all know the struggles and worries - but I left with a real feeling of all the possibilities."*

With nearly 850 attendees taking part in the family conference, there were sessions and resources designed for the whole family, from nutrition and endocrinology sessions to sibling and PWS camps, to the dad's meet up and the Serenity room, which provided a place for families to get some peace and quiet. *"It was a great family experience. We have more tools and knowledge of PWS that definitely will help us to improve our management with our PWS son."*

And, of course, the ultimate goal of our United in Hope conference was to foster just that, the hope that every family deserves. *"Thank you for organizing this. The energy around was so hopeful, from other families, doctors, and sponsors. It can feel so lonely when a diagnosis is delivered and is thought about purely clinically. Thank you for the hope."*

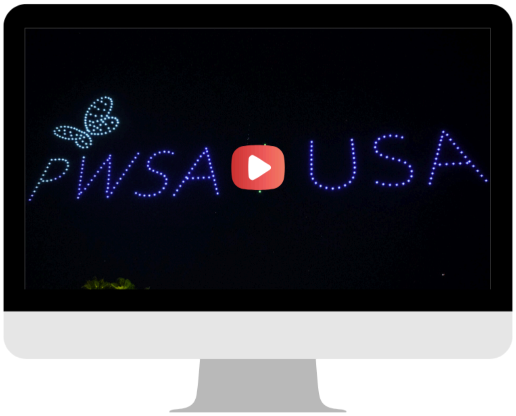
Representatives of the residential provider Prader-Willi Homes wrote a lovely article of their experience at the conference. "*There was an undeniable energy throughout the conference — an eagerness to grow, to challenge norms, and to innovate in ways that uplift those we serve*." You can read more in the article, United in Hope—and Action: Reflections from the International Prader-Willi Syndrome Conference.

We're looking for conference attendees who would like to share their experience on PWSA | USA's PWS United Podcast! Recording sessions, held Wednesday, July 9th, 1 PM - 3 PM ET (10 AM - 12 PM PT), will be 5-10 minutes long. If you would like to participate, please email Anne at africke@pwsausa.org.

We also have the Family Conference Main Ballroom sessions now available for viewing. Special thanks to Blake Brenneman for capturing these informative sessions and speakers! Watch them all on our United in Hope conference YouTube playlist at the button below. We look forward to sharing more photos from the event soon!

WATCH: MAIN BALLROOM SESSIONS

Celebrating 50 Years in Style!



On Friday evening, families and fellow PWS community members gathered at the Oasis Water Park on the resort grounds for an evening of birthday fun and celebration! Guests floated down the lazy river, tumbled in the wave pool, shot down the towering water slides (Conor, we're talking about you!), and enjoyed refreshments and celebratory music. The evening culminated in an incredible drone show celebrating 50 years of PWSA | USA! We want to give a huge shout out to Jeff Ward for such a fascinating and exciting spectacle and to Soleno Therapeutics for sponsoring this fun event for the PWS community. Thank you! You can watch the drone show on YouTube by clicking the button below.

DRONE SHOW

Thank You Conference Sponsors!

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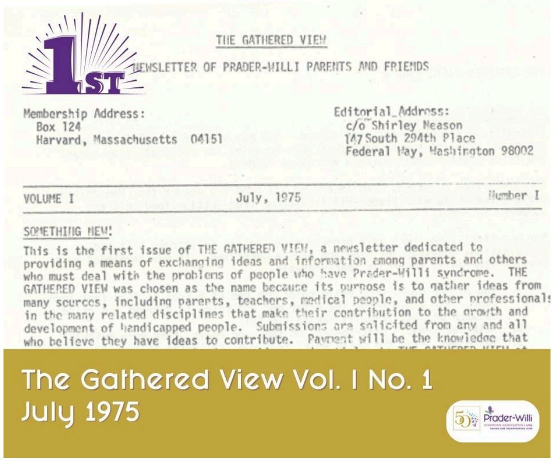
PWSA MEMORIES



THE GATHERED VIEW

NEWSLETTER OF PRADER-WILLI PARENTS AND FRIENDS

Membership Address:
Box 124
Harvard, Massachusetts 04151

Editorial Address:
c/o Shirley Neason
147 South 294th Place
Federal Way, Washington 98002

VOLUME I July, 1975 Number I

SOMETHING NEW!

This is the first issue of THE GATHERED VIEW, a newsletter dedicated to providing a means of exchanging ideas and information among parents and others who must deal with the problems of people who have Prader-Willi syndrome. THE GATHERED VIEW was chosen as the name because its purpose is to gather ideas from many sources, including parents, teachers, medical people, and other professionals in the many related disciplines that make their contribution to the growth and development of handicapped people. Submissions are solicited from any and all who believe they have ideas to contribute. Payment will be the knowledge that

The Gathered View Vol. I No. 1
July 1975

In July 1975, Prader-Willi Parents and Friends (later to be known as PWSA | USA) published the first edition of The Gathered View, a newsletter for the PWS community. "The Gathered View was chosen as the name because its purpose is to gather ideas from many sources, including parents, teachers, medical people, and other professionals in the many related disciplines that make their contribution to the growth and development of handicapped people." You can read Vol. 1 No. 1 of The Gathered View by clicking the button below.

The Gathered View helped inform the PWS community for decades and later became what is now the "PWSA | USA's Pulse Newsletter."

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S SPOTLIGHT ON HOPE

Submitted by Sarah Kasaby, mom to Khaled (living with PWS)

Families from around the world were invited to submit their comic stories and artwork — stories of strength, resilience, and imagination — all centered around our incredible PWS heroes and their battles against monsters, including the infamous Chromosome 15 Monster and his sneaky companions. These heartfelt contributions were put together into a colorful comic-style booklet, now also available in Spanish, Greek, and Arabic!

Today, Khaled received the Arabic version of the book he requested, and it featured one of his best friends, our very own hero Ahmed. Known as the Fitness Pharaoh, Ahmed shared his inspiring journey on how he managed to combat the monster and lose the weight! Even more special? The drawings were lovingly created by his amazing mom, capturing Ahmed's strength and determination in every line.

Special thanks to IPWSO, Sarah-Jane Judge and Neil Bratchpiece for all of their love, creativity, and contribution into bringing this comic book to life — and for making it available in different languages! Receiving a copy of this comic as a gift touched our hearts. It's more than just a book — it's a celebration of our children's strength, imagination, and uniqueness. Thank you for making our kids feel seen, valued, and powerful.

This project was funded by and gifted in collaboration with IPWSO.

If you'd like to honor your loved one and share their success story with the PWS community, please fill out our Spotlight on Hope form using the button below. We're looking forward to celebrating with you!

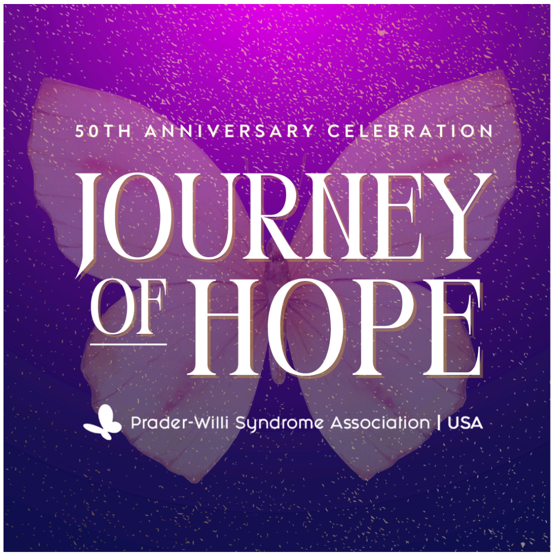
SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

The 50-Year Celebration Continues

When: **Friday, September 26, 2025, at 6 PM CT**
Where: **Ritz Carlton, St. Louis, MO**

Let's keep the celebration going! Join us in St. Louis for our 50th Anniversary Gala. Together, we will reflect on the milestones we've achieved and the lives we've touched, all while raising crucial funds to continue our journey of hope for the next 50 years. This event will feature inspiring stories, special tributes, live entertainment, and a silent auction, all in support of PWSA | USA's mission: Enhancing the quality of life and empowering those affected by Prader-Willi syndrome. We are proud to honor individuals in recognition of their lifelong contributions and unwavering dedication to the organization. Learn more and purchase tickets using the button below.



CELEBRATE 50 YEARS!

Get Your Tickets Now for the 16th Annual Hunter Lens Golf Tournament

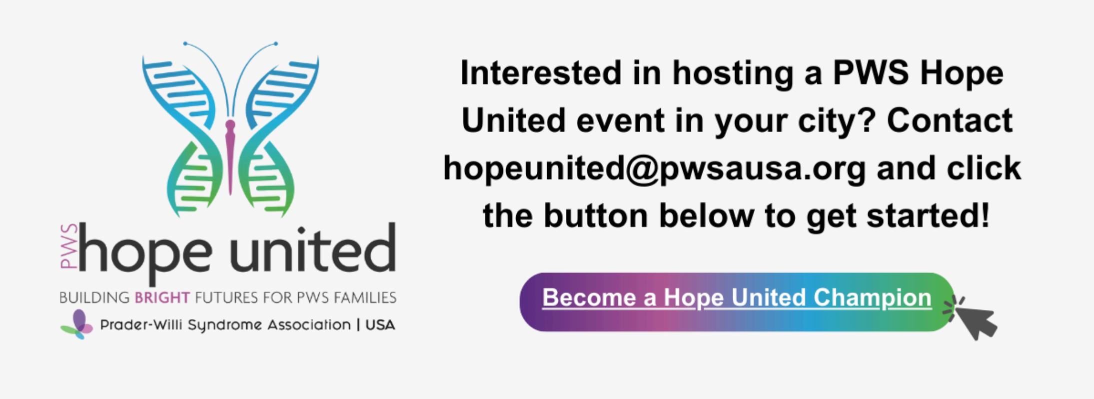
When: **Saturday, September 13 @ 1 PM ET**
Where: **Heritage Hills Golf Club, 17 Heritage Hill Drive, Lakeville, MA**

Join the Lens family for a day of golf, good spirits, and great friends as you golf and dine at Heritage Hills Golf Club in Lakeville, MA. This event is celebrating its 16th year raising critical funding for PWSA | USA, an organization that serves individuals living with PWS, their families, caregivers, and more through family support, advocacy, and research.

Hunter Lens (27, living with PWS) leads a happy, active life despite his daily challenges. He has friends, a loving family, and his weight is under control. Supporting PWSA | USA, a non-profit, will open more doors for Hunter and others who live with PWS, which ultimately means a better life. Hunter deserves a better life. Please join the Lens family on this special day in honor of Hunter to benefit PWSA | USA's mission.

Learn more and get tickets using the button below.

[HUNTER LENS GOLF TOURNAMENT]



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

This episode is a recording from the 2025 United in Hope International PWS conference in Phoenix, AZ. "Nutrition Recommendations for Children and Families with PWS" was presented by Michael Tan, registered dietitian at the University of Florida. This session is an overview of traditional nutrition recommendations, current recommendations and guidance, and how everyone in the family plays a role. View the slides from Michael's session by clicking the button below.

If you attended the 2025 United in Hope Conference and would like to share a brief testimonial on the PWS United podcast, please email africke@pwsausua.org.

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

NUTRITION SLIDES

LISTEN ON PODBEAN

Dr. Destiny Pacha presented two sessions at this year's conference: "First Steps to School Success: Navigating the IFSP-to-IEP Transition" and "PWS IEP Roadmap: Essential Components for School Safety and Success." Both sessions focused on essential points and challenging hurdles for families in the PWS community. As with many of the sessions, participants have more questions than what the time allows and often meet up with the presenters afterward. Dr. Pacha is generously offering her time outside of the conference as well. She has created a document for families to submit additional questions or to follow up on something that was shared. These questions will then be answered in a special episode of the PWS United podcast! Please submit your question by **July 11th.** Submit using the QR code featured or clicking the button below.

SUBMIT QUESTIONS

ADVOCACY

Advocacy in Action: Elevating Voices, Driving Change — A Standout Session at the 2025 PWSA | USA United in Hope Conference

One of the most powerful moments of the 2025 United in Hope Conference was the standing-room-only session, Advocacy in Action: Elevating Voices, Driving

Change, where the PWS community came together to celebrate the role of advocacy in shaping brighter futures for individuals living with Prader-Willi syndrome.

Led by PWSA | USA's Director of Community Engagement Dorothea Lantz and Advocacy Specialist Elaine Towle this inspiring session featured five of PWSA's dedicated Advocacy Ambassadors, each bravely sharing their personal experiences and perspectives on advocacy across the lifespan. The panel included:

- Jessica Kempa, mom to Kaia, her 6-year-old son living with PWS
- Paige Rivard, mom to Jake, age 14 living with PWS
- Jennifer Garzia, mom to Rocco, age 20 living with PWS
- Justice Rickenbach, a 21-year-old self-advocate living with PWS
- Elaine Towle, mom to James, age 39 living with PWS

Representing different life stages — from early childhood to adulthood — their stories highlighted the challenges, victories, and evolving needs that come with navigating health care, education, social services, and long-term care systems. Their heartfelt reflections served as a reminder that while the journey isn't always easy, change is possible when we raise our voices together.

The session also included a special appearance by Anish Bhatnager, CEO of Soleno Therapeutics. Dr. Bhatnager delivered a powerful message about the critical need for cross-collaboration between advocacy organizations, industry, researchers, and families across the PWS community. He emphasized that when we unite behind shared priorities, we amplify our collective impact and accelerate progress for all individuals living with PWS.

The energy in the room was undeniable as families, self-advocates, and professionals engaged in a meaningful dialogue about how advocacy can — and does — lead to real change. The panel explored everything from accessing early intervention and school supports to advocating for Medicaid waivers, housing, and federal legislative priorities like attending PWSA's D.C. Fly-In. Through it all, one message rang clear: The collective voices of the PWS community are stronger together.

We are deeply grateful to our Advocacy Ambassadors, Dr. Bhatnager, and every family who shared their experiences during this memorable session. Your stories are the foundation of our movement, and together, we are building a future of hope, inclusion, and opportunity for all individuals living with PWS.

FAMILY SUPPORT

New Blog Post: Conference Recap from a Grateful Mom and a Happy Daughter

Anne Fricke and her daughter, Freya (13, living with PWS) wrote about their experience at the 2025 United in Hope Conference. Freya shared about the new friends she made, the entertaining activities at camp, and having fun at the water park. Anne, who has seen how her daughter sometimes struggles with being the only one in the room with PWS, shared what it felt like to watch her daughter in that space where most people have PWS, "...*that realization that she isn't alone in the world means everything*." Many families found comfort and inspiration in the community that gathered in Phoenix last week. For some families, it was the first time they were around other families with PWS. "*Thank you PWSA | USA, IPWSO, and FPWR for an incredible conference! For bringing so many of us together so that we parents, grandparents, siblings, and especially our loved ones with PWS, can truly know what it feels like to not be alone.*" You can read this blog by clicking the button below.

READ BLOG HERE

Developing Residential Site Offers Options and Meaningful Futures for Young Adults with PWS

C-15 Foundation, a registered 501(c)(3) organization dedicated to creating opportunities for individuals living with PWS, is announcing the creation of a Live, Work, Play, and Thrive community in Chattahoochee Hills, GA, approximately 20 minutes from the Atlanta Airport.

This first-of-its-kind, dedicated PWS development will be home to "high-functioning" PWS young adults (current ages of 20-30) who have the desire and ability to reach greater heights of independence and self-development. The 108-

acre C-15 campus is proposed to provide a genuine opportunity to live a more self-supportive life, while still receiving guidance and light oversight from on-campus coaches. Additionally, all residents will be required to have a part-time job on or off campus.

The campus will offer 24 private, kitchenless apartments consisting of a large private bedroom and bathroom with connected common areas, an ultra-secure dining hall, activity center that includes a pool, walking track, and more, and a working farm.

C-15 Foundation expects to begin conducting resident interviews in 2026 with a goal to open in mid-2027. Please visit the website, which can be found at the button below, for more information in the coming months and to follow the construction progress. If you believe your loved one with PWS has the desire and ability to live in a semi-independent environment, please reach out to the foundation.

LEARN MORE

Interactive Map for Washington | Oregon PWS Families

Shared on behalf of the Oregon and Washington Chapter of PWSA | USA

The Oregon and Washington Chapter of PWSA | USA is proud to launch the PWS Link Map, a new platform designed to be a life-changing resource for our community.

This map allows families to find other families who choose to “join” the Map. They will be able to securely message one another through the platform's messaging system. To protect privacy, the contact information and exact location is never revealed. Participants can choose to share that information directly through a message and meet outside the map platform if they desire to. This initial version is just the beginning, and the plan is to introduce additional search options as the platform's population grows.

A Vision for National Connection.

The primary challenge for national expansion is moderation. To be successful, each state requires a dedicated moderator to ensure the map remains a focused resource, free from spam or unrelated content. Here in the Northwest, our knowledge of local families allows us to moderate effectively. We are eager to brainstorm with other state leaders to develop a sustainable national model. Another option is for individual states to join. Contact us if you are interested in brainstorming with us. For any questions, feedback, or assistance with logging in, please contact **pwsawaor@gmail.com**.

A Powerful Tool for Research

Beyond its role as a connection hub, the PWS Link Map has the potential to be a valuable tool for researchers. Data could provide invaluable insights into the prevalence of service needs, the geographic distribution of PWS subtypes, age group demographics, and more. Mass messaging by businesses or researchers will not be permitted.

Visit the map by clicking the button below.

LEARN MORE

Ask Nurse Lynn

Female, 31 years old, UPD subtype

Do people with PWS age at an accelerated rate compared to those who do not have this syndrome? My 31 year old daughter was just diagnosed with arthritis in her knee. As I look back on her health history, I can see how many of her conditions are related to accelerated aging….everything from losing baby teeth at 4 or 5, to a bone age of 12 when she was 9, to varicose veins in her 20s, to arthritis at 31 (and many other issues as well). If so, what kind of life span can I expect? When she was younger, I was told obesity-related *conditions would severely limit her lifespan. As she got older, I was told if her health and weight were monitored closely, she could live a normal life span. Now, I am wondering what the current thinking is. Thank you for your insights.*

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

Harmony Biosciences Now Offers TEMPO Clinical Trial At-Home!

Harmony Biosciences is offering the opportunity for people to participate in their TEMPO clinical trial from home. The TEMPO clinical trial is assessing an investigational medication for excessive daytime sleepiness in people 6 years of age or older with PWS. This is a 22-week double-blind study with an open-label extension for those who choose to continue. You can learn more about this study by clicking the button below. If would like to contact the At-Home site directly, please email HarmonyPWS@science37.com or call 310-929-8473.

TEMPO™

PRADER-WILLI SYNDROME (PWS) CLINICAL STUDY

PARTICIPATE COMPLETELY FROM HOME!

If PWS symptoms make it difficult to travel or there are no TEMPO sites near you, a completely at-home option is now available.

Flexible scheduling

No travel

Minimizes changes in daily routines

Continued care from current doctor; study doctor will update on study progress

Visits from a nurse in your home

THE COMPLETELY **AT-HOME OPTION**

ELIGIBLE PARTICIPANTS **CAN EXPECT:**

A 22-week double-blind study followed by an optional open-label extension
(74 weeks if participating in both)

DOUBLE-BLIND STUDY INCLUDES:
- **Up to 3 virtual visits in your home AND**
- **5 in-person visits in your home with a clinical study nurse**

IF PARTICIPATING IN BOTH THE DOUBLE-BLIND STUDY AND THE OPEN-LABEL EXTENSION:
- **Up to 5 virtual visits in your home AND**
- **8 in-person visits in your home with a clinical study nurse**

- Study drug will be shipped directly to your home
- Blood and urine samples and electrocardiograms (ECGs) will be collected at all in-person visits in your home
- Caregivers will complete study diaries and questionnaires on an app

HOW DO I **LEARN MORE?**

Visit tempopwsstudy.com to learn more about the study and about the at-home option.

You can also reach out directly to the At-Home site:
- email: HarmonyPWS@science37.com
- phone: 310-929-8473

SCAN TO LEARN MORE

DOES MY LOVED ONE **QUALIFY?**

- Male or female age 6 years and older
- Diagnosed with PWS based on genetic testing
- Experiences excessive daytime sleepiness
- Has a consistent caregiver throughout the study
- Resides in the U.S.

HARMONY BIOSCIENCES

All aspects of the AT-HOME option for the TEMPO Study are managed by Science 37, a company that supports at-home clinical trials and has conducted many at-home studies.

Visit **tempopwsstudy.com**

LEARN MORE

Aardvark Therapeutics HERO Phase 3 Trial Now Enrolling!

2 New Sites Open

HERO, Phase 3 Clinical Trial for ARD-101, Now Enrolling

2 New Sites Now Open

Prader-Willi Syndrome Association | USA

San Diego, California: Rady Children's Hospital

Atlanta, Georgia: Emory University School of Medicine

HERO Hunger Elimination or Reduction Objective

www.heroforpws.com

aardvark therapeutics

Aardvark Therapeutics recently launched **HERO**, a global Phase 3 clinical trial investigating ARD-101, an innovative, orally administered treatment designed to help reduce hyperphagia (excessive hunger) and food-seeking behaviors in individuals with Prader-Willi syndrome (PWS).

This randomized, double-blind, placebo-controlled trial is an important step toward identifying a potential new treatment option for the PWS community, and now, trial sites across the United States are actively enrolling participants. Click on the button below to learn more about the open trial sites.

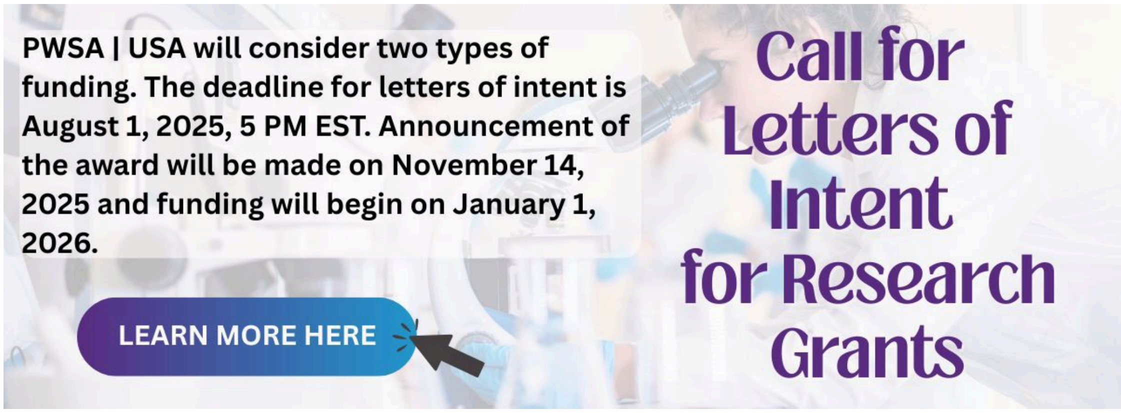
To learn more about the HERO Study, visit www.heroforpws.com.

LEARN MORE

Supporting PWS Research

Prader-Willi Syndrome Clinical Scholarships Available

$25,000 USD to support providers in enhancing their understanding of PWS through clinical proctorships with experts in the field. Available to providers currently in practice in the US and who presently care or plan to care for patients with PWS.



PWSA | USA will consider two types of funding. 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.

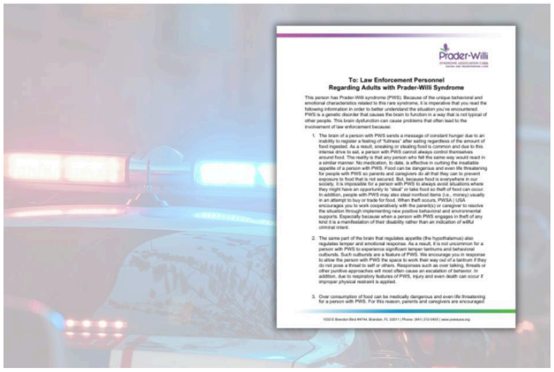
Call for Letters of Intent for Research Grants

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

Reaching out to local police stations and law enforcement establishments to educate them about Prader-Willi syndrome may be a critical step in providing safety and security for your loved one with PWS. Whether your loved one is an eloper, or prone to behavioral melt downs in public, it is important that your local law enforcement officers know your loved one with PWS and have an understanding of some of the behaviors they may witness, and how to interact with an individual with PWS. Educating law enforcement officers can help keep your loved one safe. We have provided a letter to help share necessary information so you can begin the conversation with your local precinct. Including personalized information about your loved one, along with a photo or meeting them in person, is important as well. You can download the letter using the button below.

Letter to Law Enforcement Personnel



To: Law Enforcement Personnel
Regarding Adults with Prader-Willi Syndrome

This person has Prader-Willi syndrome (PWS). Because of the unique behavioral and emotional characteristics related to this rare syndrome, it is imperative that you read the following information in order to better understand the situation you've encountered. PWS is a genetic disorder that causes the brain to function in a way that is not typical of other people. This brain dysfunction can cause problems that often lead to the involvement of law enforcement because:

1. The brain of a person with PWS sends a message of constant hunger due to an inability to register a feeling of "fullness" after eating regardless of the amount of food ingested. As a result, sneaking or stealing food is common and due to this intense drive to eat, a person with PWS cannot always control themselves around food. The reality is that any person who felt the same way would react in a similar manner. No medication, to date, is effective in curbing the insatiable appetite of a person with PWS. Food can be dangerous and even life threatening for people with PWS so parents and caregivers do all that they can to prevent exposure to food that is not secured. But, because food is everywhere in our society, it is impossible for a person with PWS to always avoid situations where they might have an opportunity to "steal" or take food so theft of food can occur. In addition, people with PWS may also steal nonfood items (i.e., money) usually in an attempt to buy or trade for food. When theft occurs, PWSA | USA encourages you to work cooperatively with the parent(s) or caregiver to resolve the situation through implementing new positive behavioral and environmental supports. Especially because when a person with PWS engages in theft of any kind it is a manifestation of their disability rather than an indication of willful criminal intent.

2. The same part of the brain that regulates appetite (the hypothalamus) also regulates temper and emotional response. As a result, it is not uncommon for a person with PWS to experience significant temper tantrums and behavioral outbursts. Such outbursts are a feature of PWS. We encourage you in response to allow the person with PWS the space to work their way out of a tantrum if they do not pose a threat to self or others. Responses such as over talking, threats or other punitive approaches will most often cause an escalation of behavior. In addition, due to respiratory features of PWS, injury and even death can occur if improper physical restraint is applied.

3. Over consumption of food can be medically dangerous and even life threatening for a person with PWS. For this reason, parents and caregivers are encouraged

1032 E Brandon Blvd #4744, Brandon, FL 33511 | Phone: (941) 312-0400 | www.pwsausa.org

DOWNLOAD HERE

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: July 18, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 127

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www.pwsausa.org | 941-312-0400

Keep the Celebration Going - Join Us for PWSA | USA's 50th Anniversary Journey of Hope Gala

After an unforgettable time together in Phoenix at the United in Hope International PWS Conference, it's clear how powerful it is to gather, learn, and celebrate as a community. Let’s keep that momentum going!

We’re excited to invite you to our next big event (and it's coming soon): the PWSA | USA 50th Anniversary Journey of Hope Gala. On Friday, September 26, at the Ritz-Carlton in St. Louis, MO, we will honor five decades of progress, advocacy, and unwavering support and hope for the Prader-Willi syndrome community.

Get all the details, find our list of incredible honorees, and learn how you can be part of the celebration at the button below.

JOURNEY OF HOPE GALA

PWSA MEMORIES

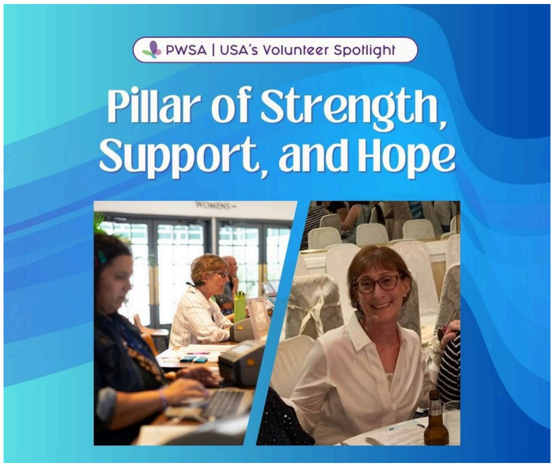
According to The Gathered View, Volume 33, Number 4, from July - August 2008, PWSA | USA's sharing of information was an important part of growth hormone approval for PWS families in Australia. Barry Greensmith, president of PWSA of Australia, shared his gratitude in this issue, stating, "Yesterday morning, I was notified (verbally from Pfizer) that Growth Hormone for PWS was passed here in Australia. I wish to thank you for all the data you supplied to us here in Australia; I believe that if not for this data we would not have GH passed here. It has been a long battle, and after 9 years, we have got there finally. Thanks again." You can find this issue of The Gathered View using the button below.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S

SPOTLIGHT ON HOPE



Sybil Cohen has been a dedicated volunteer for PWSA | USA for many years, serving in numerous vital roles, including chapter leader, board member, and parent mentor. She volunteered and worked the check-in desk at the recent United in Hope conference for the entirety of the event. Sybil's efforts did not go unnoticed; countless families, new and returning, commented on how her kindness made their experience more welcoming and meaningful. Her dedication, approachability, and deep compassion are a true reflection of the spirit of the PWSA | USA community. We are truly grateful for her commitment to this organization and the PWS community.

READ MORE HERE

EVENTS & FUNDRAISERS

Relive the Best Moments From the 2025 United in Hope International PWS Conference!

Thank you to everyone who joined us for the 2025 United in Hope International PWS Conference - the largest PWS gathering yet! We're excited to share the official Conference Recap, where you'll find:

- A snapshot of how many people attended and from where they traveled.
- A link to our full photo gallery to relive your favorite memories.
- A chance to watch the special 50th Birthday Drone Show video again.
- Access to main ballroom session recordings...and more!

SUMMARY

1,330
Total Number
of Registrants

NUMBER OF ATTENDEES BY EVENT

Clinical & Scientific Program 413	Professional Providers Program 161
Adults with PWS Program 59	Family Program 823
SYS Program 22	PWS Camps 187
50th Birthday Party 720	Night Under the Stars Gala 73

CLINICAL & SCIENTIFIC PROGRAM

Number of Sessions Offered: 60
Oral Abstracts: 32
Lightning Talks: 20
Poster Abstracts: 95
Number of Speakers: 61

PROFESSIONAL PROVIDERS PROGRAM

Number of Sessio
Number of Speake
Poster Abstracts:

FAMILY PR

Number of Sessio
Number of Speake

WHERE IN THE WORLD DID ATTENDE

We Welcomed 146 International

- Argentina
- Austria
- Australia
- Belgium
- Brazil
- Bulgaria
- Canada
- China
- Congo (Democratic Republic)
- Costa Rica

- Egypt
- Dominican Republ
- France
- Germany
- Greece
- Hungary
- Ireland
- Japan
- Kenya
- Malaysia

United in HOPE
2025 PWS CONFERENCE

UNITED IN HOPE INTERNATIONAL
PWS CONFERENCE RECAP

JUNE 24-28, 2025 | PHOENIX, AZ

We hope this recap helps you look back on an inspiring few days of learning, connection, and celebration - and keeps the momentum going until we gather again. Check it out using the button below!

[2025 CONFERENCE RECAP]

Click the button below to watch our conference highlight video and revisit some of the incredible moments from this historic event. A heartfelt thank you to our generous sponsors for making this historic event possible - we couldn't do it without you!

Get Your Tickets Now for No Gimmes for Jimmy

When: **Saturday, September 6 @ 12:30 PM ET**
Where: **Heron Glen Golf Course, 110 State Highway 202 & 31, Ringoes, NJ**


4TH ANNUAL
No Gimmes For Jimmy Charity Golf Outing

Saturday, September 6, 2025
Heron Golf Course | Ringoes, NJ

- 12:30 PM: Sign in & Warm up!
- 1:30 PM Shotgun Start
- 6/6:30 PM Awards Dinner and Raffle

No Gimmes for Jimmy is held in honor of Jim Worthington. While he survived being directly under Tower 1 on 9/11, he eventually lost his battle with leukemia on October 16, 2021. He loved to play golf when he could get out — which was not often. He loved his family even more, including his son with Prader-Willi syndrome.

A “gimme” in golf is usually a short putt that is excused by one’s opponent for playing because it is considered too easy to miss. Jim was as generous on the golf course as he was in life, and his wish was that any “gimmes” go to helping those individuals and families with PWS.

The *No Gimmes for Jimmy Annual Charity Golf Outing* is an event to raise money and awareness for PWS, while having some fun and remembering a great family man. Please contribute a “gimme” in Jim’s honor to PWSA and join in for a day of fun on the course in his honor!

Learn more about signing up for this event, sponsoring, or donating by clicking the button below.

NO GIMMES GOLF EVENT

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

This episode is a recording from the 2025 United in Hope International PWS conference in Phoenix, AZ. "Endocrine Issues in Teens and Adults" was presented by Dr. Diane Stafford. In this session, Dr. Stafford discusses the issues of growth and pubertal development through the pre-teen and teen years in those with PWS, including the effects of growth hormone therapy and sex steroids. She also discusses the indications for the use of growth hormone therapy in those who have completed their growth, including risks and possible benefits and the indications for ongoing sex steroid therapy in adults with PWS. In this discussion you can learn more about growth hormone monitoring and deficiency, delayed or absent puberty, adrenarche vs puberty, and more.

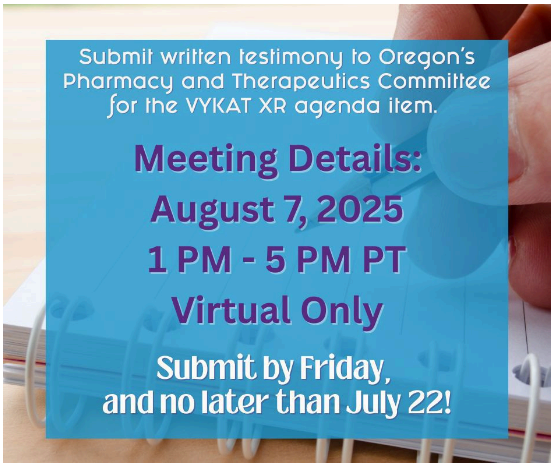
Find the latest episode of PWS United on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

Call to Action for Oregon Families!

Oregon's Pharmacy and Therapeutics Committee will be discussing "New Drug Evaluation/Prior Authorization Criteria" for VYKAT XR at their August 7th meeting. Your actions can help secure Medicare/Medicaid coverage for VYKAT XR in Oregon. PWS families in Oregon, especially Medicare/Medicaid/Medicaid Waiver recipients, are strongly encouraged to share their written testimony.



Submit written testimony to Oregon's Pharmacy and Therapeutics Committee for the VYKAT XR agenda item.

Meeting Details:
August 7, 2025
1 PM - 5 PM PT
Virtual Only

Submit by Friday, and no later than July 22!

Please send testimonials to OSUPharm.DI@oregonstate.edu. Submissions are due no later than Tuesday, July 22, but families are strongly encouraged to submit by Friday, July 18. You must include a completed "Conflict of Interest" Form (which can be found at the button below).

Writing Guide:

- My name is:
- I live in:
- My child living with PWS is ___ years old and receives Medicaid in the state of Oregon.
- Thank the members of the committee for the work they do.
- How do the unmet needs of PWS affect your family?
- If your son/daughter IS taking VYKAT XR, explain how access to the drug has changed your lives?
- If your son/daughter IS NOT taking VYKAT XR, how will having access to an approved drug to treat hyperphagia in PWS change their life and what their future looks like?
- What is your hope for the approval of drugs to treat hyperphagia in PWS?

Learn more about submitting public comment and find the link to join the meeting at the button below.

CONFLICT OF INTEREST FORM

LEARN MORE/MEETING LINK

PWSA | USA Helps Usher in New Era of Rare Disease Research with Launch of Florida's Sunshine Genetics Act

On July 9, 2025, leaders in science, medicine, and policy gathered at Florida State University's Interdisciplinary Research & Diagnostic center to celebrate a transformational step in pediatric health care, the launch of the Sunshine Genetics Act. This act is a first-of-its-kind initiative offering free, voluntary, whole genome sequencing for all newborns. PWSA | USA was honored to stand at the forefront of this historic moment for rare disease families, represented by Jennifer Garzia, Florida PWSA Chapter President and mom to Rocco (20, living with PWS) and Dorothea Lantz, PWSA | USA's Director of Community Engagement and mom to Hunter (7, living with PWS). Read more about this act and the event by clicking the button below.

READ HERE

FAMILY SUPPORT

BOSS (Building Our Social Skills) Program Begins Again, Apply Now

PWSA | USA is excited to announce the return of the Building Our Social Skills (BOSS) program this fall. We know how important social development is for individuals with PWS and how challenging it can be. BOSS, funded by FPWR, was created to provide a supportive, structured space for participants to build communication skills, boost confidence, and connect with peers in a fun and engaging way.

This 10-week virtual program is led by experienced facilitators who understand the unique needs and strengths of people with PWS. The next session of BOSS begins on Monday, September 8, 2025, and will meet three times a week - Mondays, Wednesdays, and Thursdays at 4:00 PM EST. All sessions are conducted virtually, making the program accessible no matter where you live. Learn more using the button below.

LEARN MORE AND APPLY HERE

PWSA | USA Offering Scholarships of Up to $25,000 USD to Clinicians

Prader-Willi Syndrome Clinical Scholarships Available

$25,000 USD to support providers in enhancing their understanding of PWS through clinical proctorships with experts in the field. Available to providers currently in practice in the US and who presently care or plan to care for patients with PWS.

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. Providers who may apply for a scholarship include but are not limited to physicians, nurse practitioners, physician assistants, nurses, physical therapists, occupational therapists, speech therapists, mental health counselors, behavior analysts, and educators.

The scholarship funds are intended to be used for the following, although other appropriate expenses will be considered as well:

1. Reasonable expenses related to travel and lodging for the applicant to shadow a provider with expertise in PWS.
2. Reasonable expenses and fees related to hosting the applicant on-site.

Funding will be made directly to each institution according to the approved budget.

Awardees are required to provide a written progress report at the end of the proctorship and a long-term impact statement one year after completion. **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** (eg: adults, diverse populations, rural communities).

LEARN MORE / SUBMIT

Ask Nurse Lynn

Male, 15 months old, UPD subtype

My son has esotropia and amblyopia primarily affecting his right eye but intermittently seen in his left eye as well. Surgical correction has been discussed and currently we have been instructed to patch his dominant eye (left) for two hours daily. We would like to pursue the interventions that are most likely to promote binocular vision and preserve ocular sensory input in both eyes. Our questions with regard to his ocular issues are:

1.) For best results do you recommend patching for a solid two hours or intermittently throughout the day for a total of two hours?
2.) Are there treatments or therapies for esotropia and amblyopia specifically geared to individuals with PWS?
3.) Are there any clinics or clinicians who specialize in treatment of ocular disease in PWS individuals

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

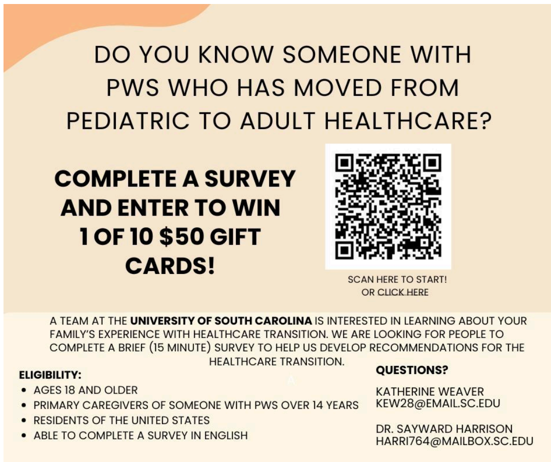
RESEARCH

Research Study Invitation for Parents of Individuals with PWS 14 Years and Older

Are you a parent or guardian of a person with PWS who is 14 years or older? If so, please consider taking part in a new study on the pediatric-to-adult transition for individuals with PWS. Researchers from the University of South Carolina are conducting a brief survey of parents and guardians of individuals with PWS to learn more about their experiences with the pediatric-to-adult health care transition.

The anonymous online survey takes less than 15 minutes to complete. The findings will help us better understand challenges and opportunities for improving care for our loved ones with PWS as they move from pediatric to adult care. Ten participants will be randomly selected to receive a $50 gift card for their participation! The study has been approved by the Institutional Review Board at the University of South Carolina. For questions, please reach out to Dr. Sayward Harrison at harri764@mailbox.sc.edu.

To learn more and/or complete the survey, click the button below.



DO YOU KNOW SOMEONE WITH PWS WHO HAS MOVED FROM PEDIATRIC TO ADULT HEALTHCARE?

COMPLETE A SURVEY AND ENTER TO WIN 1 OF 10 $50 GIFT CARDS!

SCAN HERE TO START!
OR CLICK HERE

A TEAM AT THE **UNIVERSITY OF SOUTH CAROLINA** IS INTERESTED IN LEARNING ABOUT YOUR FAMILY'S EXPERIENCE WITH HEALTHCARE TRANSITION. WE ARE LOOKING FOR PEOPLE TO COMPLETE A BRIEF (15 MINUTE) SURVEY TO HELP US DEVELOP RECOMMENDATIONS FOR THE HEALTHCARE TRANSITION.

ELIGIBILITY:

- AGES 18 AND OLDER
- PRIMARY CAREGIVERS OF SOMEONE WITH PWS OVER 14 YEARS
- RESIDENTS OF THE UNITED STATES
- ABLE TO COMPLETE A SURVEY IN ENGLISH

QUESTIONS?

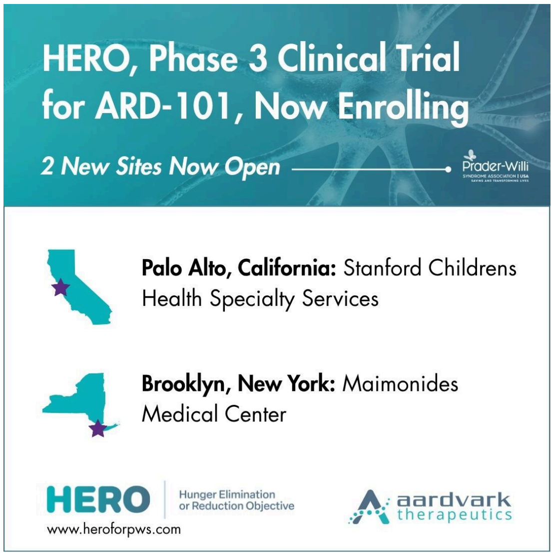
KATHERINE WEAVER
KEW28@EMAIL.SC.EDU

DR. SAYWARD HARRISON
HARRI764@MAILBOX.SC.EDU

LEARN MORE

Aardvark Therapeutics HERO Phase 3 Trial Now Enrolling!

2 New Sites Open



HERO, Phase 3 Clinical Trial for ARD-101, Now Enrolling

2 New Sites Now Open

Palo Alto, California: Stanford Childrens Health Specialty Services

Brooklyn, New York: Maimonides Medical Center

HERO Hunger Elimination or Reduction Objective

www.heroforpws.com

Aardvark Therapeutics recently launched **HERO**, a global Phase 3 clinical trial investigating ARD-101, an innovative, orally administered treatment designed to help reduce hyperphagia (excessive hunger) and food-seeking behaviors in individuals with Prader-Willi syndrome (PWS).

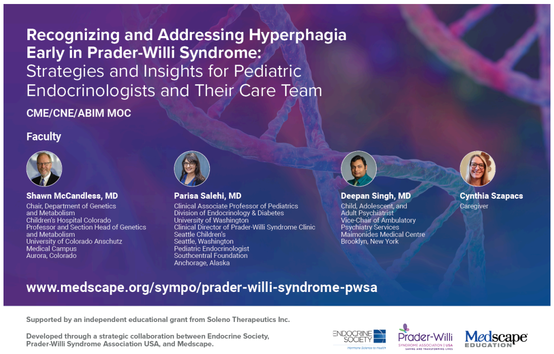
This randomized, double-blind, placebo-controlled trial is an important step toward identifying a potential new treatment option for the PWS community, and now, trial sites across the United States are actively enrolling participants. Click on the button below to learn more about the open trial sites.

To learn more about the HERO Study, visit www.heroforpws.com.

LEARN MORE

Two Free CME Opportunities for Medical Professionals in the PWS Community

PWSA | USA, in partnership with the Endocrine Society and Medscape Education, is excited to share two free online continuing education activities for pediatric endocrinologists, nurses, and other clinicians who care for people with Prader-Willi syndrome. These activities offer free continuing education credits (CME, CNE, and MOC) and help improve understanding and care for individuals with PWS and their families.



Recognizing and Addressing Hyperphagia Early in Prader-Willi Syndrome:
Strategies and Insights for Pediatric Endocrinologists and Their Care Team

CME/CNE/ABIM MOC

Faculty

Shawn McCandless, MD
Chair, Department of Genetics and Metabolism
Children's Hospital Colorado
Professor and Section Head of Genetics and Metabolism
University of Colorado Anschutz Medical Campus
Aurora, Colorado

Parisa Salehi, MD
Clinical Associate Professor of Pediatrics
Division of Endocrinology & Diabetes
University of Washington
Clinical Director of Prader-Willi Syndrome Clinic
Seattle Children's
Seattle, Washington
Pediatric Endocrinologist
Southcentral Foundation
Anchorage, Alaska

Deepan Singh, MD
Child, Adolescent, and Adult Psychiatrist
Vice-Chair of Ambulatory Psychiatry Services
Maimonides Medical Centre
Brooklyn, New York

Cynthia Szapacs
Caregiver

www.medscape.org/sympo/prader-willi-syndrome-pwsa

Supported by an independent educational grant from Soleno Therapeutics Inc.

Developed through a strategic collaboration between Endocrine Society, Prader-Willi Syndrome Association USA, and Medscape.

Recognizing and Addressing Hyperphagia in PWS

This activity focuses on the serious impact of hyperphagia (the constant feeling of hunger) in PWS. Health care professionals will learn about the daily challenges hyperphagia creates, its causes, and the latest treatment options, along with new and emerging therapies.

Credit: Physicians **-** Maximum of 1.25 *AMA PRA Category 1 Credit(s)™;* Nurses - 1.25 *ANCC Contact Hour(s)* (0.25 contact hours are in the area of pharmacology). Learn more details and start this training using the button below.

RECOGNIZING HYPERPHAGIA

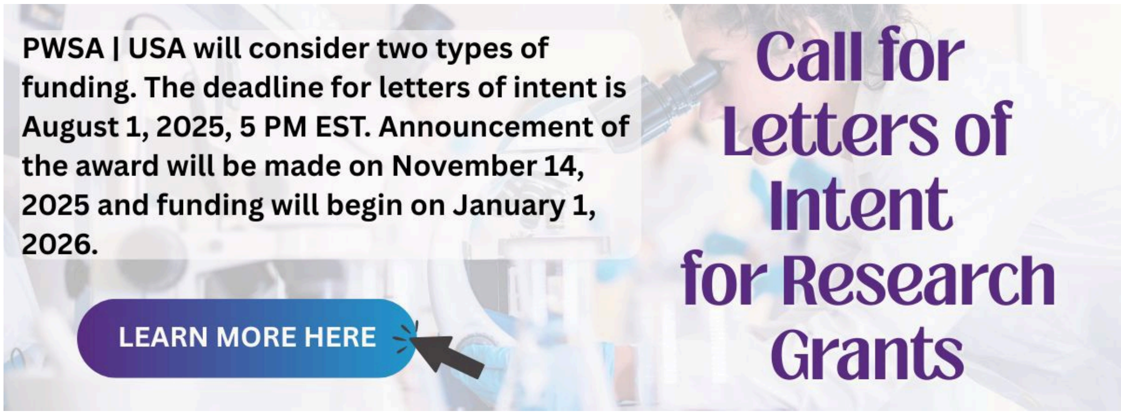
Peer-to-Peer Challenge: Interactive Case Studies in Prader-Willi Syndrome

This interactive course uses real-life case studies to help medical professionals improve how they recognize, diagnose, and manage hyperphagia as part of a comprehensive PWS treatment plan. This activity was created by and for the healthcare team.
Credit: Physicians **-** Maximum of 1.00 *AMA PRA Category 1 Credit(s)™;* Nurses - 1.00 *ANCC Contact Hour(s)* (0.25 contact hours are in the area of pharmacology). Learn more details and start this training at the button below.

PEER-TO-PEER CHALLENGE

Together, these free CME activities help ensure that more doctors, nurses, and care teams are equipped with the latest knowledge to support our PWS community. Please share these valuable resources with your care team!

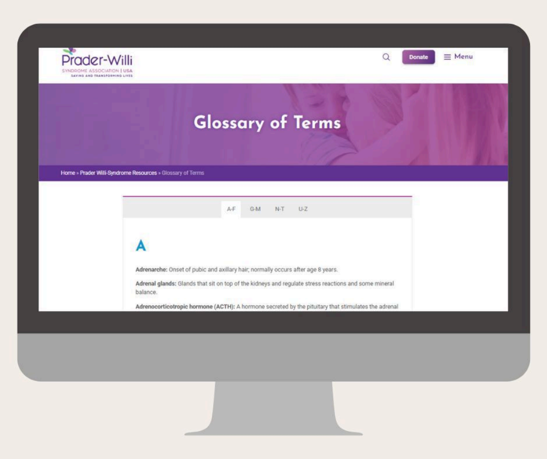
Supporting PWS Research



PWSA | USA will consider two types of funding. 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.

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight



Glossary of Terms

Home » Prader Willi-Syndrome Resources » Glossary of Terms

A

Adrenarche: Onset of pubic and axillary hair; normally occurs after age 8 years.

Adrenal glands: Glands that sit on top of the kidneys and regulate stress reactions and some mineral balance.

Adrenocorticotropic hormone (ACTH): A hormone secreted by the pituitary that stimulates the adrenal

When navigating the world of PWS, the majority of us are introduced to words we've never heard of before. Not only are we asked to decipher the many nuances of this disorder but also to learn a new set of vocabulary. From *adrenarche* to *uniparental disomy*, parents may become lost in the terrain of medical speak, struggling to truly understand what they are learning about PWS. If you find this is you, please note that we have a glossary of terms on our website that you can access at any time. Use the button below to check it out.

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

PWSA | USA July 2025 Special Edition
Pulse Newsletter

www.pwsausa.org | 941.312.0400

Donate

Americans with Disabilities Act Celebrates 35 Years!


We Shall Overcome
ACCESS IS A CIVIL RIGHT

Above photo credit: Tom Olin 1990

Thirty-five years ago, the disability community had a momentous victory on the hill! On March 12, 1990, almost 60 individuals with disabilities climbed the near 100 capitol steps in Washington, DC, to draw attention to the lack of accessibility for individuals with disabilities. This historic event, known as the “Capitol Crawl”, fiercely encouraged congress to sign the Americans with Disabilities Act (ADA) into law just a few months later. (When the 'Capitol Crawl' Dramatized the Need for Americans with Disabilities Act | HISTORY)

On July 26, 1990, President George H. W. Bush signed the Americans with Disabilities Act, an act that sought inclusion for those with disabilities and accountability from the society in which they live. As a community in the disability space, we owe our gratitude for those who pushed this bill forward. Without such laws, the future of our loved ones would not be so bright. This special edition Pulse is meant to be a tribute to those advocates who crawled, marched, and fought for these rights, offer an explanation of what the ADA is and how it affects our loved ones, and, perhaps most importantly, serve as a call to action for the many advocacy efforts still needed, especially with Medicaid. As those advocates before us built the foundation for an inclusive society, it is now in our hands to continue their work and push for a society not just of inclusion, but of belonging.

To learn more about the history of the disability rights movement, read our blog "Road to the Americans with Disabilities Act (ADA)" using the button below.

READ HERE

photo credit: Tom Olin

photo credit: Jeff Markowitz

WHAT IS THE ADA?

“The Americans with Disabilities Act (ADA) is a law that protects people with disabilities from discrimination.” (What Is the Americans With Disabilities Act

(ADA)? | ADA National Network) It ensures equal opportunities for individuals with disabilities in various areas, including employment, public accommodations, transportation, and telecommunications. The act is separated into 5 distinguishing sections each focused on a specific aspect of our society and disability rights.

Denise Servais, PWSA | USA Board Member and mom to Maya (living with PWS), wrote about how this act specifically helped individuals with disabilities in communication. *"When the Americans with Disabilities Act (ADA) passed in 1990, it didn't just mandate ramps and parking spaces, it did something just as critical: it made communication access a civil right. Before the ADA, people who couldn't speak clearly or used communication devices were often ignored. Hospitals weren't required to provide interpreters, schools didn't have to support AAC, and employers could legally turn someone away for using a voice output device.*

The ADA changed all that. It established that communication with individuals with disabilities must be 'as effective' as communication with everyone else. Today, students can use AAC in classrooms, receive therapy in schools and hospitals, and advocate for themselves in ways that were once unimaginable. It's a powerful reminder that communication is connection and everyone deserves access to it."

Title I:
Protects against workplace discriminiation.

Title II:
Mandates accessibility for use of programs or services run by state and local governments

Title III:
Guarantees access to public accommodations, like hotels and restaurants.

Title IV:
Guarantees equal access for telecommunication services for those challenged with speech and hearing.

Title V:
Ensures the rights of person asking for their ADA rights and prohibits retaliation.

TITLES OF THE ADA

Timeline of Key Moments of the ADA

1973: Rehabilitation Act of 1973 signed into law.

1977: Section 504 of the Rehabilitation Act of 1973 finally enacted after activists staged a 20-day protest.

1986: The National Council on Disability (NCD) proposed the first "comprehensive" equal opportunity law for people with disabilities, according to disability rights organizations.

1988: The first version of the ADA was introduced in Congress.

July 26, 1990: The ADA was signed into law by President George H.W. Bush.

1991: Regulations for Titles I, II, III, and IV of the ADA were issued, covering employment, state and local government services, public accommodations, and telecommunications.

1999: The Supreme Court narrowed the definition of "disability" in several ADA cases.

2008: The ADA Amendments Act (ADAAA) was signed into law, expanding the definition of disability and counteracting the Supreme Court's rulings.

2014: The U.S. Access Board and the Department of Justice issued updated guidelines and rules related to the ADA.

2015: The ADA celebrated its 25th anniversary.

MEDICAID AND ADVOCACY TODAY

What is Medicaid?

Medicaid is the largest source of funding for medical and health-related services for America's lower-income groups. It represents almost one dollar out of every five dollars spend on health care nationally and covers more than half of all spending on long-term care services. Medicaid also covers both health services and other support services for individuals with disabilities. Eligibility is often, but not always, link to receiving Supplement Security Income (SSI) benefits or meeting state-specific criteria related to age, disability statue, income and sometimes assets. Individuals with disabilities often have complex medical needs and account for a large share of Medicaid spending for Long-Term Services and Supports (LTSS).

Medicaid is a partnership program, jointly funded and run by the federal government and individual state governments. This explains why Medicaid coverage - who is eligible, what services are included, and how services are delivered - can vary from state to state.

How Medicaid Works: Federal and State Partnership

The Federal Role

The Centers for Medicare & Medicaid Services (CMS) administers Medicaid. CMS is an agency within the US Department of Health & Human Services (HHS). For more information, you can go to these websites: www.cms.gov or www.medicaid.gov.

CMS sets the overarching federal rules and requirements that states must follow to participate in the Medicaid program and receive federal funding. The federal government covers a substantial portion of the funding through a formula, the Federal Medical Assistance Percentage (FMAP). This percentage varies from state to state and is calculated every year based on a state's average per capita income compared to the national average.

Currently, by law the minimum federal share (FMAP) is 50% but it can range up to 83% for states with lower per capita incomes. With the passage of HR 1, significant federal savings for the Medicaid program are expected but details are not yet available.

CMS also approves the detailed plans that states are required to submit outlining how they will run their programs, as well as requests from states (known as waivers) to operate parts of their programs differently from standard federal rules.

The State Role

Participation in Medicaid is voluntary, but every state, the District of Columbia, and the US territories currently choose to participate. Within the broad federal guidelines, each state has considerable flexibility to design and administer its own Medicaid program.

States decide:

- Who is eligible.
- What services are covered. States must cover certain mandatory services but can choose from a list of optional services to include in their benefit

package.
- How services are delivered. States determine the delivery system, choosing between traditional fee-for-service or various Managed Care models.
- How much providers are paid.

States can also apply for waivers to cover different groups or services than typically allowed under standard rules. This flexibility through state plans and waivers is a core feature of Medicaid, allowing programs to be tailored to state needs but also creating variations in coverage and access that beneficiaries experience across the country.

States contribute significant funding to jointly finance the program with the federal government. They are also responsible for the day-to-day operations, including processing applications, enrolling members, and ensuring program integrity.

Mandatory & Optional Medicaid Benefits

Federal law requires that all state Medicaid programs provide a specific set of essential health benefits to most eligible enrollees to receive federal funding. These are known as mandatory benefits. Mandatory benefits include hospital care; physician & clinic services; lab & x-ray; long-term services & supports (nursing home care, home health services); child health; family planning & maternity; transportation; substance use disorder treatment; clinical trials.

States have the option to cover a wide range of additional health care services under their Medicaid programs. The most common and significant optional benefits that states may choose to cover include: prescription medications; dental & vision care (adults); therapy services (PT, OT, speech); mental health & substance use disorder services; long-term services & supports (Home and Community-Based Services (HCBS), personal care service, hospice care, intermediate care facility services for individuals with intellectual disabilities (ICF/IID), self-directed personal assistance services (1915(j)); other medical services (ex: podiatry, optometry, respiratory care for ventilator-dependent

individuals); devices & equipment; care coordination & management; health-related social needs (housing instability or nutrition insecurity); and others.
Of note for individuals with disabilities, Medicaid is the nation's primary payer for Long-Term Services and Supports (LTSS). The only mandatory LTSS benefits are nursing facility services and home health services. Most other forms of LTSS, especially Home and Community-based Services (HCBS) that allow individuals to receive care in their homes or communities rather than institutions, are optional benefits. States typically provide HCBS through waivers (like 1915(c) waivers) or other state plan options. Because these are often optional and may operate under waivers, states can sometimes limit the number of people serviced or maintain waiting lists for HCBS programs. This means access to services crucial for remaining in the community is highly dependent on state policy choices and available funding.

Finding Your State's Medicaid Information

Renew Your Coverage

Check your Medicaid notice or contact your state Medicaid office for more information.

Given the significant variations from state to state, the single most important step you can take to understand your specific Medicaid coverage is to consult official resources for your state. Start with the official federal website, Medicaid.gov. This site serves as a central hub and should contain links or tools to help you find information specific to your state, often through sections labeled "State Overviews" or similar navigational aids.
Additionally, you should contact your state agency, responsible for administering its Medicaid program. This agency is the definitive source for information about eligibility, covered benefits, how to apply, and finding providers. State agencies handle the actual administration of the program, including eligibility determinations and enrollment. These websites often contain detailed benefit manuals, provider directories, application portals, and contact information.

Medicaid Source Information

The information on Medicaid was compiled in part using a website from govfacts.org. Use the button below to visit the website.

SOURCE INFORMATION

Alternative Medicaid Names by State

If you aren't sure whether you or your loved one are receiving services and benefits through Medicaid, it may be because it is not called "Medicaid" in your state. Here is a list of some of the alternative names Medicaid is called in various states. Please note that this is by no means a comprehensive list and your state may have more alternative names for Medicaid.

- Alabama: Alabama Medicaid
- Alaska: DenaliCare
- Arizona: Arizona Health Care Cost Containment System (AHCCCS)
- Arkansas: Health Care
- California: Medi-Cal
- Colorado: Health First Colorado
- Connecticut: Husky Health, Husky C (for aged, blind, or disabled persons)
- Delaware: Diamond State Health Plan (Plus)
- Florida: Statewide Medicaid Managed Care Program (SMMC), Managed Medical Assistance (MMA) Program, Long-Term Care) (LTC) Program
- Georgia: Georgia Medicaid
- Hawaii: Med-QUEST
- Idaho: Idaho Medicaid Health Plan
- Illinois: Medical Assistance Program, HealthChoice Illinois
- Indiana: Hoosier Healthwise, Hoosier Care Connect, M.E.D. Works, Health Indiana Plan (HIP)
- Iowa: Iowa Medicaid, IA Health Link
- Kansas: Kansas Medical Assistance Program (KMAP), KanCare
- Kentucky: Kentucky Medicaid
- Louisiana: Louisiana Medicaid, Healthy Louisiana (formerly Bayou Health)
- Maine: MaineCare
- Maryland: Medical Assistance
- Massachusetts: MassHealth
- Michigan: Michigan Medicaid
- Minnesota: Medical Assistance (MA)
- Mississippi: Mississippi Coordinated Access Network (MississippiCAN)
- Missouri: MO HealthNet
- Montana: Montana Medicaid
- Nebraska: Nebraska Medical Assistance Program (NMAP)
- Nevada: Nevada Medicaid
- New Hampshire: NH Medicaid, Medical Assistance
- New Jersey: NJ FamilyCare
- New Mexico: TurqioseTurquoise Care (formerly Centennial Care)
- New York: New York State Medicaid, Medicaid Managed Care
- North Carolina: NC Medicaid
- North Dakota: North Dakota Medicaid
- Ohio: Ohio Medicaid, MyCare Ohio
- Oklahoma: SoonerCare
- Oregon: Oregon Health Plan (OHP)
- Pennsylvania: Medical Assistance (MA)

- Rhode Island: RI Medical Assistance Program
- South Carolina: Healthy Connections
- South Dakota: South Dakota Medicaid
- Tennessee: TennCare
- Texas: STAR+PLUS
- Utah: Utah Medicaid
- Vermont: Green Mountain Care
- Virginia: Cardinal Care
- Washington: Apple Health
- Washington, DC: DC Medicaid
- West Virgnia: West Virginia Medicaid
- Wisconsin: Forward Health
- Wyoming: Wyoming Medicaid, Equality Care

CHECK YOUR STATE HERE

HR-1: What is it and how does it affect Medicaid?

HR-1, also known as the One Big Beautiful Bill Act, passed the House on July 3, 2025, and was signed by President Trump on July 4, 2025. This bill has a sweeping and varied effect on multiple areas of federal and state government agencies, decreasing spending in some areas and increasing in others. The effects will be varied and vast, some having an immediate effect and other changes taking place over the next few decades, making the effects more challenging to predict. With changes on the horizon, it is important for families and advocates to stay informed and ready to use their voice when needed. PWSA | USA will continue to share information as it comes and advocate for our families. We will call upon you at times to share your stories, call your representatives, or visit their offices. Together we will continue to fight for access to necessary services and the inherent rights to the dignity and quality of life our loved ones deserve.

Major Medicaid Changes by Phase

1. Work & Reporting Requirements (Rolling Out 2026–2028)

- **Who's affected?** Able-bodied adults aged 19–64 in ACA expansion coverage. Some states (e.g., those with waivers like Wisconsin) may include others.
- **What's required?** 80 hours/month of work, volunteering, or education—with periodic reporting.
- **State difference:** Only expansion states are directly affected (accounting for over half of the savings). Non-expansion states may see impact if they maintain similar adult eligibility groups.

2. More Frequent Eligibility Redeterminations (Starts ~2026)

- States move from annual to biannual redeterminations for expansion enrollees.
- States with high churn could see higher administrative burdens and greater coverage loss risk.

3. Curtailing Provider Taxes & State Directed Payments (Phased 2028–2031)

- Caps provider taxes at 3.5% by 2031 (down from current 6% in many states)
- Limits state-directed supplemental payments (e.g., hospital wraps from 100–110% of Medicare, depending on expansion status) starting 2028.
- State variation:
    - High-impact: states reliant on provider taxes like California, NY, FL, TX.
    - Supplemental funding cuts hit states with large hospital/discharge wrap programs hardest.

4. Coverage & Eligibility Reforms (Implementation Now–2026)

- Retroactive coverage cut to 1 month (down from 3)
- Home equity cap now flat at $1 million—no inflation updates
- Co-pays up to $35 for incomes >100% FPL; providers can deny service if co-pay unpaid.
- Other restrictions:
    - Bar federally funded Planned Parenthood; litigation ongoing.
    - Adds a 5year wait for green card holders, limits gender affirming care and immigrant coverage.

5. Rural Hospital Fund (2026–2031)

- $50 billion over 5 years to support rural hospitals—important, but small relative to projected losses.
- Backloaded cuts: ~76% of Medicaid spending cuts will occur 2030–2034, leaving states time to adjust.

State-by-State Impacts

- Expansion vs. Non Expansion States

    - Only expansion states face the bulk of work/reporting, redetermination, and provider tax constraints (~$526 B of savings from expansion states alone).
    - Non-expansion states are less affected—though they share some consequences like coverage reforms and co-pays.

- State Funding Reliance

    - States with high provider tax and hospital wrap utilization (e.g., Illinois, Louisiana, Oregon, Nevada) may lose ≥ 19% of federal Medicaid funding over the decade.
    - States with lower reliance (or with strong limits on provider taxes) face smaller proportional cuts.

- Rural States

    - Despite dedicated funds, permanent cuts may still squeeze rural hospitals reliant on Medicaid—a shortfall relative to support.

Timeline Overview for Advocates

Phase	Timeline	Key Actions
Immediate	Now–Early 2026	States update policies on retroactive coverage, co-pays, home equity, and coverage restrictions
Phase I	2026–2028	Rollout of work mandates, eligibility redeterminations, rural hospital funding begins
Phase II	2028–2031	Provider tax caps and state-directed payment limits take effect
Phase III	2030–2034	Most of the $911 B in federal Medicaid spending reduction hits

Advocacy Takeaways

1. Know Your State's Profile

    - Does your state have Medicaid expansion, provider taxes, or supplemental payment programs? High reliance means higher impact.

2. Prepare for Eligibility Shocks

    - Support for enrollees to comply with work/reporting, and proactive outreach around more frequent renewals will be critical.

3. Engage on Funding Shifts

    - Hospital and provider groups and rural advocates should highlight how cuts to wrap funding and provider revenues threaten local services.

4. Track Timing Closely

- Many key deadlines are state-driven—advocates must push for transparent implementation plans and reporting from health agencies.

Bottom Line

Medicaid changes are layered and phased—working eligibility rules, financial reforms, and administrative constraints each roll out over 2025–2034. State differences matter significantly: expansion status, funding structures, and provider relationships shape both the timeline and the depth of impact.

Source Information

The button below links to a website created by the Kaiser Family Foundation. It allows folks to click on additional resources that are more state specific and helps provide additional clarity on HR1.

INFORMATION SOURCE

CALL TO ACTION: MEDICAID STORIES

Meet with Your Representative, Share Your Medicaid Story

As parents and caregivers of individuals with disabilities, you have an opportunity to make your voice heard. It is important to share your experiences of receiving or being denied services and how that has affected your loved one and your family. We need to ensure that our representatives hear our stories, understand our situations, and urge them to vote in support of access, services, and inclusion for our loved ones. We invite you to take part in an important advocacy effort by sharing your experience with qualifying for Medicaid waiver programs and other state-funded IDD services. By filling out the form at the button below, you'll contribute to our collective efforts to improve access to critical services for individuals with PWS across the country. Your story has the power to make an impact! Together, we can push for change for the PWS community in your state and beyond.

LEARN MORE HERE

Medicaid Testimonials from the PWS Community

How Medicaid Helped Our Family and Why It Still Matters

submitted by Denise Servais, mom to Maya

When our daughter, Maya, was diagnosed with Prader-Willi Syndrome, we knew life would look different, but we didn't fully grasp how expensive different could be.

Thankfully, Medicaid became a lifeline.

Through Medicaid, Maya received critical services: speech therapy, occupational therapy, mental health counseling, growth hormone, and even medical equipment that insurance didn't cover. Because of Medicaid, she saw specialists without us worrying how we'll pay the bill.

Most importantly, Medicaid gave us peace of mind. We didn't have to sell our house or drain retirement accounts to meet her needs. We could focus on being her parents instead of constantly acting like insurance case managers.

But here's what people don't talk about enough: Medicaid also comes with frustrating red tape.

We've had to re-prove Maya's eligibility multiple times. Services have been denied for no clear reason, only to be approved after appeals. Some of the best providers won't take Medicaid due to low reimbursement. And coverage varies dramatically by state, what's available in Minnesota might not be in Texas. And now, with political debates over cuts and work requirements, we worry that even this essential support might one day change.

Different States, Different Evaluations and Access

submitted by Jen Garzia, mom to Rocco

As a parent of a child with Prader-Willi syndrome, I witnessed firsthand how the lack of Medicaid waiver access in Pennsylvania left my son without the support he desperately needed. Rocco was experiencing frequent restraint and seclusion at school due to the behavioral symptoms of his syndrome. Although he was receiving Medicaid for medical benefits, he was not enrolled in a waiver program, which would have provided essential home and community-based services tailored to his needs.

In Pennsylvania, Rocco was subjected to repeated restraint and seclusion at his special needs school—one incident was so severe that he experienced distressed breathing and had to be rushed to the hospital. Despite these serious events, our requests for Medicaid waiver support were denied. We were told we did not meet the "crisis" criteria, even though the harm he endured was clearly traumatic. The evaluation process felt entirely subjective and dismissive. However, when we moved to Florida and shared the same incident history, the state recognized it as a crisis and placed Rocco on the Medicaid waiver. This difference in state response illustrates how access to life-changing support is inconsistently applied and unfairly withheld depending on geography and interpretation, not actual need.

Multiple Denials Based on Income

submitted by Sue Colon, mom to Shealynn

I applied for state benefits twice, once when Shealynn was born and again about a year ago. Both times we got denied. Originally it was for income, then we were informed there is a state waiver program which we can apply for, but they don’t know how helpful it will be given the fact there is a waitlist. The wavier also only covers home health aide services. We currently don’t receive any assistance in any fashion. We have had to carry the burden of all copayments, all non-covered expenses from our commercial insurance and so on.

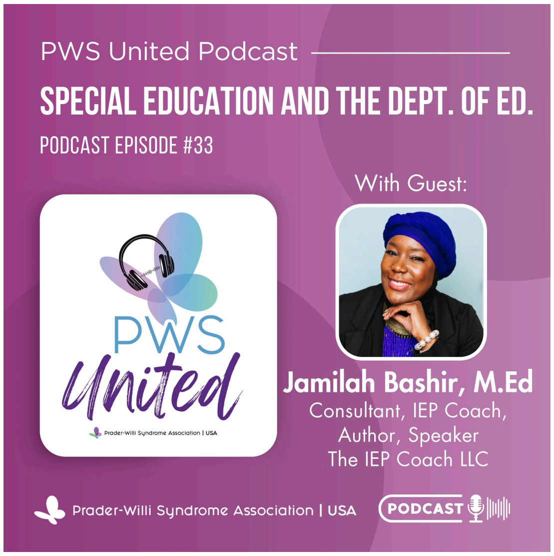
We currently do not receive any state benefits. We have applied numerous times, denied based on income. The only state wavier program offered we have been on the wait list for 4 years and the only wavier services offered in NJ is a home health aide. The entire process to even receive this information has been daunting and long.

SAVE THE DATE

We're excited to share the dates for PWSA | USA's next D.C. Fly-In event, taking place May 4-6, 2026, in Washington, D.C. We will share more details, including our attendee application and hotel location, in the coming months so keep an eye on your email and social media feeds! In the meantime, we invite you to take a trip down memory lane - click on the image to watch our 2024 D.C. Fly-In recap video, sponsored by Soleno Therapeutics.

IN CASE YOU MISSED IT

In March of 2025, we published a podcast episode to help our community better understand the Department of Education. PWSA | USA's CEO Stacy Ward sat down with educator and IEP coach, Jamilah Bashir to discuss special education and the state of the Department of Education. They discussed training for special education teachers, the voucher program, where to find good information about changing policies and decisions within the Department of Education, and the path of an executive order. Jamilah clarified the different roles of the U.S. Dept. of Ed. versus the state's Dept. of Ed., focusing on funding and the accountability of states to provide services. This discussion can provide clear insight on the role of the U.S. Department of Education, why it may be critical for our loved ones with PWS, what the alternative (ie voucher programs and private schools) may look like, and how and why to contact your representatives on this issue. You can listen to this episode on your favorite podcast app or using the button below.



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