

PWSA | USA Bi-Weekly Pulse: December 6, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS



Vol. 112

December 6, 2024

www.pwsausa.org | 941-312-0400



GIVE THE
Gift OF
HOPE
2024 ANGEL DRIVE

 Prader-Willi Syndrome Association | USA

We are **HALFWAY**
THROUGH the 2024
Angel Drive Campaign!

Thanks to your incredible support, we are halfway through our *Angel Drive: Give the Gift of Hope* campaign and halfway to reaching our fundraising goal! Your contributions ensure that PWSA | USA can continue providing critical programs and services for families, while also paving the way for exciting new events, services, and resources in 2025—our *50th anniversary!*

But we can't do it without you. Together, we can cross the finish line! Your gift today will help us meet our goal and continue empowering the PWS community. Plus, there's still time to enter our **prize raffle!** Donations made by **December 15th** will be entered for a chance to win one of four amazing prizes:

- An Apple Smart Watch
- A \$300 Amazon Gift Card
- Customizable PWS Nike Shoes
- A PWSA | USA Swag Bag

We also want to extend our heartfelt thanks to everyone who doubled their impact on Giving Tuesday and to the anonymous donors who made the \$25,000 match opportunity possible. Your generosity is a testament to the strength and spirit of our community.

Let's make this campaign a success—together!

GIVE THE GIFT OF HOPE



Samuel, 7, living with PWS

"I would like donors to know that their investment is being used appropriately. The support that the organization has for families when they're just starting and when they're in a transition period, like school, is incredible. It's a lot of support in understanding the diagnosis and that's what is the most helpful. The more you know, the more you can make change and help your grandchildren. You can help your children, too, so they're not alone and they have a safe place to land."

- Donna Stephens, grandparent to

WATCH: GRANDPARENTS' HOPE IN ACTION VIDEO

PWSA | USA'S
SPOTLIGHT ON HOPE

"Madi is now 18 years old and graduated with honors for holding a 3.6 GPA or higher for 7 semesters or more!!! She worked her butt off to keep her grades up, as she was on 4 mainstream classes junior and senior year. She is now enrolled in the GOAL program, which is a program designed to help young adults with special needs integrate into the community and find a job. They do internships at local businesses and go out into the community daily. She is thriving and I'm loving the young lady she's becoming!!!" - contributed by Madi's family

Congratulations Madi!



We want to celebrate your loved one!

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.

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 below. We're looking forward to celebrating with you!

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

2025 International PWS United in Hope Conference



June 24, 2025	June 25-26, 2025	June 26, 2025	June 27-28, 2025
PWS Clinical Workshop	Clinical & Scientific Program	Adults with PWS Program	Family Program PWS Camps
<i>Invite Only</i>	Professional Providers Program	<i>1/2 Day</i>	

The **United in Hope: International Prader-Willi Syndrome Conference** will be held at the Arizona Grand Resort and Spa in Phoenix, Arizona, from June 24-28, 2025. The event will be hosted by the [Prader-Willi Syndrome Association | USA \(PWSA | USA\)](#), the [Foundation for Prader-Willi Research \(FPWR\)](#) and the [International Prader-Willi Syndrome Organisation \(IPWSO\)](#). Our theme, “**United in Hope**” reflects this unique collaboration, which we anticipate will serve as a catalyst for the largest international PWS conference ever held.

Click the button below to register for the 2025 International PWS Conference. We hope to see you there!

REGISTER FOR THE 2025 PWS CONFERENCE

Submit Artwork Now! - Deadline Approaching

You can help your loved one's creativity for this theme with the prompts:
What do you love about birthdays? How do you like to celebrate? What do birthdays mean to you?

Through December 31, 2024, we are collecting artwork for Theme #3 of our Rare Aware Art Share to usher in PWSA | USA's 50th anniversary! Individuals living with PWS are invited to create a piece of art using the prompt: **What is your favorite birthday memory?**

We welcome anyone living with PWS to participate in this art share no matter where you live and regardless of whether or not you will be attending the 2025 conference. We also encourage those who submitted artwork for Theme #1



"What is your favorite birthday memory?"

and/or Theme #2 to submit artwork for this new theme as well! Once you have completed your art piece, please submit a digital image of your artwork using the form found at the button below.

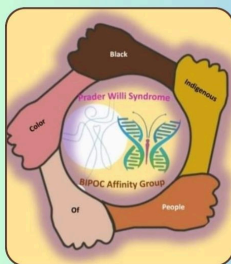


RARE AWARE ART SHARE

Join the BIPOC Diagnosis Conversation
Please note the immediate RSVP date

BIPOC PWS Diagnosis Stories

**December 8, 2024
8PM - 10PM Eastern**



On Zoom

**RSVP by Dec. 6
to
BIPOCPWS@
gmail.com**

Whether their child is 2, 22 or 52, most parents can remember their PWS diagnosis story. Among our BIPOC (Black, Indigenous, People of Color) population, we have faced unique challenges in reaching a diagnosis for our loved ones. Whether it was positive, negative, or neutral, we want to hear BIPOC PWS diagnosis stories. Let's have a conversation.

Join us on December 8, 2024 @ 8 PM - 10 PM Eastern via Zoom

If you want to share your story, if you want to hear from others, or you want more information, please email BIPOCPWS@gmail.com to RSVP by **December 7th** and receive Zoom link information.



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

Latest PWS United Episode

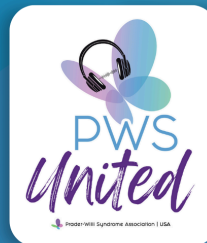
As parents and caregivers, caring for ourselves is one of the most important—and one of the most often forgotten—things we can do as a caregiver. If we neglect to take care of ourselves, we may likely find that it is more challenging to care for our loved ones. When our needs are taken care of, the person we care for will benefit, too. Recognizing that we need to take of ourselves, and actually doing that, are not always synonymous. In an effort to inspire you all to care for yourselves, we put together a "Caring for the Caregivers" podcast episode, complete with links to helpful resources.

PWS United Podcast

PWSA | USA SPECIAL EDITION PULSE: CARING FOR THE CAREGIVER

PODCAST EPISODE #19

With Hosts:



Anne Fricke
PWSA | USA
Marketing &
Communications
Coordinator,
Mom to Freya



Carrie Ilijevich
PWSA | USA
Marketing &
Communications
Director

Prader-Willi Syndrome Association | USA



Listen on your favorite podcast app or by clicking the button below.

[LISTEN ON PODBEAN](#)



ADVOCACY

Spotlight on Advocacy: A Step Forward in Georgia



This week, PWSA | USA volunteer advocates in Georgia achieved significant progress through two impactful in-person meetings with state legislators. As a result, state Rep. Katie Dempsey has invited these passionate advocates to present at the upcoming budget meeting of the Appropriations: Human Resources Subcommittee. This 15-20 minute presentation is a pivotal opportunity to highlight the needs of individuals and families affected by Prader-Willi syndrome in Georgia. It's a testament to the power of advocacy at local, state, and national levels to

create meaningful change. Together, we're amplifying the voices of the PWS community and driving progress forward!

Those in attendance included: Kelly and Clementine Guillou, Deahl and Matthew Wilson, Kara Hinkley, Government Affairs Director / Soleno Therapeutics, Alex Root, KPM, Jake Jackson, KPM, Dale, Dottie and Shawn Cooper

If you live in Georgia and are interested in joining our state advocacy team, please email dlantz@pwsausa.org.

Conway Family Featured in Soleno Therapeutics' "Our Stories" Video

For Charles and Gennelle Conway, welcoming their daughter Angelica was the start of a journey filled with love, challenges, and determination. Diagnosed with Prader-Willi syndrome before birth, Angelica's story is one of resilience and the power of advocacy.

In Soleno Therapeutics' *Our Stories* featured video, the Conways share their experiences navigating Angelica's unique needs, building a network of support, and championing her potential every step of the way.

Don't miss this inspiring glimpse into how families and communities can come together to empower a child living with PWS. [Watch the YouTube video here](#) and click the button below to read the full featured story.

“Our Stories”

Featuring Charles & Gennelle Conway, parents to Angelica (5), living with PWS

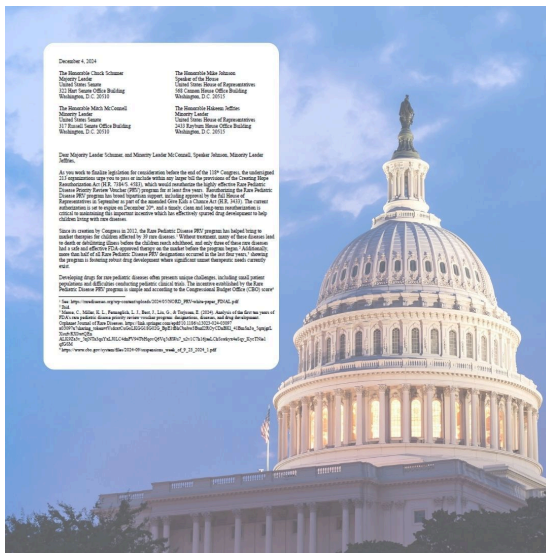


SUPPORT FOR
Prader-Willi Syndrome



WATCH HERE

Community Support Letter for the Rare Pediatric Disease PRV Program



The NORD and EveryLife teams extend heartfelt thanks to the 213 organizations that joined them in signing the support letter, urging Congress to secure a long-term extension of the PRV (priority review) Program before the December 20th deadline. The letter states, "As you work to finalize legislation for consideration before the end of the 118th Congress, the undersigned 213 organizations urge you to pass or include within any larger bill the provisions of the Creating Hope Reauthorization Act (H.R. 7384/S. 4583), which would reauthorize the highly effective Rare Pediatric Disease Priority Review Voucher (PRV) program for at least five years." PWSA | USA is one of the signing organizations of this letter for support of the extension of the PRV Program. You can read the full letter by clicking the button below.

highly effective Rare Pediatric Disease Priority Review Voucher (PRV) program for at least five years." PWSA | USA is one of the signing organizations of this letter for support of the extension of the PRV Program. You can read the full letter by clicking the button below.

READ LETTER HERE



FAMILY SUPPORT

Part 4 in the Clinical Trial Journey Blog Series

The (Sometimes Messy) Details of Life in a Clinical Trial

A Clinical Trial Journey

#4 in the Series



Prader-Willi
SYMPTOM ASSOCIATION
SAVING AND TRANSFORMING LIVES

Part 4 in the Clinical Trial Journey Series goes beyond the details of the trial appointments. Freya, a 13-year-old with PWS, is enrolled in Harmony's TEMPO PWS trial and has agreed to share the experience with the PWS community. In this blog, Freya's mom, Anne Fricke, shares the details of how they accommodate missing school for the trial, what the travel experience looks like for them, navigating food on the road (in the airport), and why math homework might be one of the biggest challenges. This series seeks to shed light on many aspects of what clinical

trials may look like for families and provide a clearer vision for families interested in enrolling. Click the button below to read the blog and find links to past blogs in the series. If you are interested in sharing your clinical trial journey, please email africke@pwsausa.org.

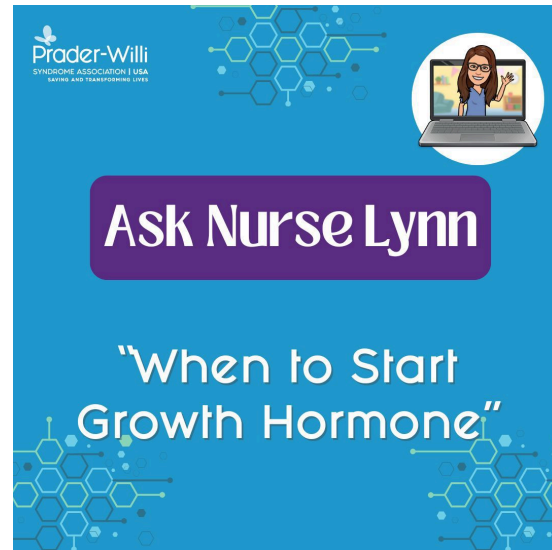
READ HERE

Ask Nurse Lynn

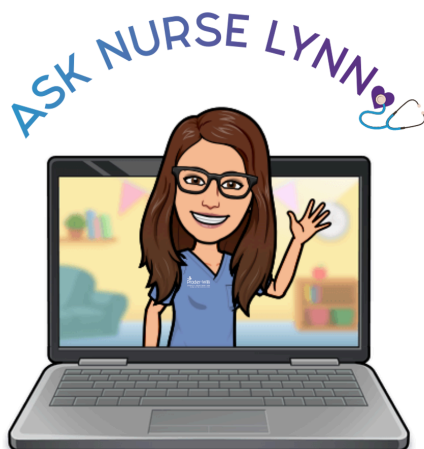
Question (*Male, 5 weeks old, Deletion subtype*):

"Our baby was diagnosed with Prader-Willi Syndrome at 3 weeks old. He is 5 weeks old, in the NICU. My family has been reading about how important growth hormone treatment is. We want to get our baby started on it but not sure if he is too little. Should we be starting that now? How do we even do that?"

Visit our blog to read Nurse Lynn's response.



[READ NURSE LYNN'S RESPONSE](#)



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

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

[ASK YOUR QUESTION HERE](#)

Family Support Webinars



We at PWSA | USA are passionate about providing support for families affected by PWS. One of the many ways we seek to fulfill this goal is by offering a monthly family support webinar, covering a variety of topics to help educate, inform, and inspire. From webinars on understanding psychosis and nurturing positive behavior, individualized education plans (IEP) and extended school year (ESY), to navigating romantic relationships for both parents and individuals with PWS, caregivers are sure to find something to help in their journey caring for an individual with

PWS. You can view the full family support webinars YouTube library at the button below.

[YOUTUBE LIBRARY](#)



RESEARCH

[Harmony Announces New Trial Site for TEMPO Trial](#)

Harmony Biosciences has announced an additional clinical trial site for its TEMPO PWS study in Houston, TX at the Texas Children's Hospital.

Harmony Biosciences' TEMPO study is a global Phase 3 trial investigating pitolisant as a potential treatment for excessive daytime sleepiness (EDS) in individuals age 6 years and older with Prader-Willi syndrome. Pitolisant is a medication that could help manage sleepiness and behavioral issues in people with PWS. Find all TEMPO trial site locations and learn more by clicking the button below.



[LEARN MORE](#)

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is open for the 2025 International PWS Conference Clinical and Scientific Program! Read more information about how to apply using the button below. Our United in Hope: International PWS Conference will shape the future of PWS care and research. This five-day event marks the first joint conference between IPWSO, PWSA | USA, and FPWR, and symbolizes a historic milestone. Register today!



Call for Abstracts

Clinical & Scientific Program Submission
Deadline: January 31, 2025

[APPLY HERE](#)

[REGISTER HERE](#)

ECHO 4 PWS Health Care Series: December Webinar Announced



Upcoming ECHO 4 PWS Webinar:

Orthopedics and PWS
with Harold van Bosse, MD

PWSA | USA is hosting an upcoming **ECHO 4 PWS** webinar.

Date: Tuesday, December 17, 2024 at 2 pm PST /

5 pm EST

Speaker: Harold van Bosse, MD

Topic: Orthopedics and PWS

Location: ZOOM

[REGISTER HERE](#)

These webinars are for health care professionals to attend only. We will have recordings of these webinars available on PWSA | USA's YouTube channel following the presentations [at this link](#). Find more information about ECHO 4 PWS at the button below.

[PROJECT ECHO](#)

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

Tis the giving season and we wanted to share with you the many ways you can help support PWSA | USA. Your generosity helps us provide critical resources, support services, and fund research aimed at improving the lives of those with PWS. Our "Make an Impact" webpage offers a variety of ways you can make a donation, including giving online, mailing a check, checking our database to see if your employer will match your donation, making a tribute gift, or setting up gifts of stocks. We are truly grateful for your generous support as we continue to enhance the quality of life and empower those affected by Prader-Willi syndrome.



Check out the "Make an Impact" resource by clicking the button below.

[LEARN MORE 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 Bi-Weekly Pulse: December 20, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS



Vol. 113

December 20, 2024

www.pwsausa.org | 941-312-0400



GIVE THE
Gift OF HOPE
2024 ANGEL DRIVE

Campaign Ends
December 31, 2024

Thank you to all of our families and friends who have donated to our **2024 Angel Drive**! Your donations help fund the many incredible ways we support individuals with PWS and their families. We could not do this without your help! Our Angel Drive ends on December 31, 2024. Please consider making a

contribution to our largest fundraiser of the year and share with your friends and family if they are looking for a worthy and valuable cause to support. We greatly appreciate all of your efforts to help us support the PWS community. Use the button below to donate.

Let's make this campaign a success—together!

GIVE THE GIFT OF HOPE

"As 2024 is coming to an end, I want to take a moment to just say thank you. I am so grateful to each of you for placing your trust in us and allowing us to walk alongside you during life's most vulnerable moments. I recognize the courage that it takes to seek help and to share your story. Your trust is a profound gift, and it fuels our commitment to provide compassionate care, resources, and support to those who need it most. Thank you for allowing us to be a part of your journey, for inspiring us every day, and for being an essential part of our mission."

Hope in Action: A Message of Gratitude and Progress from PWSA | USA



- Stacy Ward, MS, BCBA, PWSA | USA CEO

WATCH: HOPE IN ACTION

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

Klara, a 14-year-old living with PWS, recently took 3rd place in her age group in a half marathon! She ran her first 5k race at 5 years old and recently began competing in duathlons - a multi-sport endurance event. Klara enjoys participating in these events, making friends, and shining with her strengths. Klara and her family are proud of these incredible accomplishments and we at

PWSA | USA are as well! You can read more about Klara's story by clicking the button below. Congratulations Klara - let's go!

PWSA | USA'S
SPOTLIGHT ON HOPE

Klara on the Run



[READ HERE](#)

We want to celebrate your loved one!

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.

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 below. We're looking forward to celebrating with you!

[SHARE YOUR SPOTLIGHT ON HOPE](#)

EVENTS & FUNDRAISERS

Art Through the Holidays!
Rare Aware Art Share Deadline Extended

We know this time of year can be chaotic for families. With holiday preparations, traveling to see family and friends, and routines and mealtimes disrupted, many things get brushed aside. At PWSA | USA, we've been focusing on our 2024



“What is your favorite birthday memory?”



Angel Drive, moving into a momentous 50th anniversary year, and planning a birthday party at the 2025 International PWS Conference, United in Hope! We are excited to display your loved one's art at our 50th birthday party, but we need your help. To this end, and because we know how busy everyone is this time of year, we have extended the deadline for the Rare Aware Art Share Theme #3, "What is your favorite birthday memory?" Our deadline for art submissions is now **January 31st**.

You can help your loved one's creativity for this theme with the prompts: **What do you love about birthdays? How do you like to celebrate? What do birthdays mean to you?**

We welcome anyone living with PWS to participate in this art share no matter where you live and regardless of whether or not you will be attending the 2025 conference. We also encourage those who submitted artwork for Theme #1 and/or Theme #2 to submit artwork for this new theme as well! Once you have completed your art piece, please submit a digital image of your artwork using the form found at the button below.

[RARE AWARE ART SHARE](#)

2025 International PWS United in Hope Conference



June 24, 2025 PWS Clinical Workshop <i>Invite Only</i>	June 25-26, 2025 Clinical & Scientific Program Professional Providers Program	June 26, 2025 Adults with PWS Program <i>1/2 Day</i>	June 27-28, 2025 Family Program PWS Camps
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The **United in Hope: International Prader-Willi Syndrome Conference** will be held at the Arizona Grand Resort and Spa in Phoenix, Arizona, from June 24-28, 2025. The event will be hosted by the [Prader-Willi Syndrome Association | USA \(PWSA | USA\)](#), the [Foundation for Prader-Willi Research \(FPWR\)](#) and the [International Prader-Willi Syndrome Organisation \(IPWSO\)](#). Our theme, “**United in Hope**”, reflects this unique collaboration, which we anticipate will serve as a catalyst for the largest international PWS conference ever held.

Click the button below to register for the 2025 International PWS Conference. We hope to see you there!

REGISTER FOR THE 2025 PWS CONFERENCE

Save the Date for Clint Hurdle's Hot Stove Dinner!

Save the Date!

MARCH 22, 2025
Bradenton Country Club

With Special Hosts **Clint & Karla Hurdle**

Prader-Willi
 SYNDROME ASSOCIATION | USA
 SAVING AND TRANSFORMING LIVES

Clint Hurdle
HOT STOVE DINNER

Clint Hurdle

Bradenton Country Club
 Bradenton, FL & Virtual
 March 22, 2025

Island Treasure Reception 5:00 p.m. until 6:00 p.m.
 6:00 p.m. General Admission

Presented By: **Elevare**

Save the date for Clint Hurdle's annual Hot Stove Dinner, March 22, 2025, to benefit PWSA | USA. Stay tuned for more information and a link to register for this incredible event.



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

Latest PWS United Episode

Meet the PWSA | USA staff! In this episode listeners get a behind-the-scenes glimpse of the dedicated staff as we answer questions about what we do for the organization, what we love about working for PWSA and the PWS community,

and what we think you all need to know about what we offer. Find out where would Carrie travel to tomorrow, what skill Anne wishes she had, what is one (of many) of Dorothea's most memorable moments on Capitol Hill, and who does Stacy prefer - individuals with PWS or their parents? We hope you enjoy getting to know the staff and the organization as we wrap up 2024 and head into our 50th Anniversary year!

Listen on your favorite podcast app or by clicking the button below.

PWS United Podcast
PODCAST EPISODE #21

MEET THE PWSA | USA STAFF



Prader-Willi Syndrome Association | USA

PODCAST

[LISTEN ON PODBEAN](#)

ADVOCACY

Empower Change: Inclusive Advocacy in Action



Empowering Change: Inclusive Advocacy in Action

Affinity Group. Through efforts like the BIPOC Affinity Group and events like the D.C. Fly-In, PWSA | USA continues to address disparities, educate medical professionals, and ensure every family—regardless of background—has access to the support they need. Learn more about Dini's story and how PWSA | USA

Advocating for individuals with Prader-Willi syndrome means embracing every voice and every story. At PWSA | USA, we believe that expanding diversity efforts is essential to ensure every family feels seen, heard, supported, and receives their PWS diagnosis as early as possible. Dini Rao, mom to Ayoni (8 years old, living with PWS), has experienced firsthand the necessity of advocating for every individual and family with PWS and has put this need into action in D.C. and elsewhere. She is one of the co-founders of the BIPOC (Black, Indigenous, People of Color)

advocacy seeks to address the needs of every family by reading our latest blog at the button below.

If you and/or your loved one with PWS are in the BIPOC community and would like to learn more about the affinity group, email BIPOCPWS@gmail.com.

[READ HERE](#)

James and Elaine Towle Featured in Soleno Therapeutics' "Our Stories" Video

Jim and his mother, Elaine, share their journey with Prader-Willi syndrome. Through resilience, a strong community, and a positive outlook, Jim has embraced new experiences, finding ways to participate in activities that empower him toward a more independent adult life.

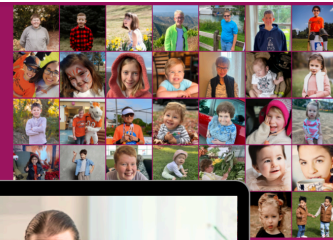
In Soleno Therapeutics' *Our Stories* featured video, Jim and Elaine's story explores the power of family, support, and commitment in overcoming the challenges of PWS.

This video serves as a reminder of what's possible with a "can-do" spirit and a supportive community. Watch the video by clicking the button below.

[WATCH HERE](#)

"Our Stories"

Featuring Elaine, a PWS Caregiver and her son, James (Aged 38)



SUPPORT FOR
Prader-Willi Syndrome



Advocating for Rare Diseases: Year-End Highlights and Uncertain Next Steps

Dorothea Lantz and Elaine Towle recently represented the rare disease community in impactful meetings on Capitol Hill with Sen. Shaheen, Sen. Hassan, Sen. Rubio, and Sen. Braun. These discussions focused on advancing key legislative priorities for 2025, including rare disease drug development,



improving Medicaid access for children, and addressing prescription drug affordability.

They also attended the in-person Community Congress Meeting hosted by the Rare Disease Legislative Advocates (RDLA), which highlighted anticipated legislative victories and strategized for the coming year.

There had been high hopes that Congress would finalize and pass a bipartisan Continuing Resolution (CR) health package, with plans for a vote before the holiday recess, however,

after bipartisan negotiations, the CR ([1,547 page version](#)) has been significantly stripped down. Several critical health provisions, once expected to pass, have been removed.

Click the button below to read what is left in the CR and what has been lost, the next steps in Congress, and what all of this means for the disability community. While this development is not the most hopeful news for our community, we will continue to push for progress in 2025 and beyond! Stay tuned for further updates.

[LEARN MORE HERE](#)



FAMILY SUPPORT

Managing Living Situations: PWS in Adulthood Blog Series

We have another fantastic blog in our "PWS in Adulthood" blog series. This blog was contributed by Elaine Towle, mom to James (38 living with PWS), and highlights the creativity, resilience, and tenacity of finding the right living situation for a loved one with PWS. As Elaine states, "Living situations for people with disabilities work great.... until they don't anymore." Elaine shares with us what those situations have looked like for James, when they knew they weren't "right" anymore, and how they navigated the path to a situation where James is happy. Please check out this latest inspiring and informative post in our "PWS in Adulthood" blog series by clicking the button below.



[READ HERE](#)

Ask Nurse Lynn

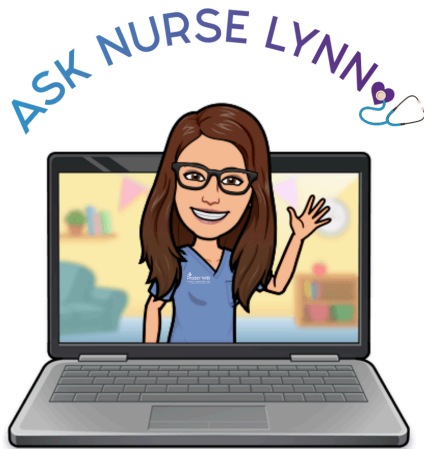
Question (Female, 66 years old, unknown subtype)

"My sister has been on 5mg Lorazepam 2 times a day for anxiety for ten years. Since this drug was added to her regimen her behaviors have been manageable with few periods of aggression. In the past she has been extremely out of control, even to the point of breaking both of her arms. Her psychiatrist for the past 2 years, who has never met her, who has never had a Prader Willi patient, is insisting on weaning her off of Lorazepam. I understand the drug is not intended for long term use, but it is working and at her age is it worth putting her through the mental torment that reducing the drug could cause? What can we, as her family, expect to occur with her behaviors? I would appreciate any advice."

Visit our blog to read Nurse Lynn's response.



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

Destiny Pacha's PWS Book Wins International Award

Destiny Pacha's book, "It Starts with Hello" has won the **International Impact Book Award** in Children's Education (December 2024). Dr. Pacha, ED. D, has worked in the public education system for more than 20 years and now works very closely with the PWS community. Her children's book follows Katie and her companions as they navigate a day at school. Katie, who is living with Prader-Willi syndrome, embraces the challenges but never allows them to hinder her enjoyment and engagement with friends. Congratulations Destiny!



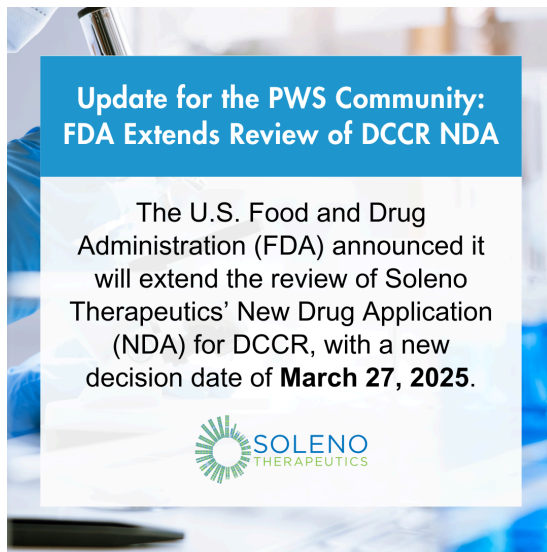
Learn more about the book and watch a video of Destiny reading "It Starts with Hello" by clicking the button below.

[READ HERE](#)



RESEARCH

Soleno Therapeutics Announced Update to DCCR's New Drug Application (NDA)



Update for the PWS Community: FDA Extends Review of DCCR NDA

The U.S. Food and Drug Administration (FDA) announced it will extend the review of Soleno Therapeutics' New Drug Application (NDA) for DCCR, with a new decision date of **March 27, 2025**.



The FDA has extended its review of the NDA for DCCR, a potential treatment for hyperphagia in individuals with PWS. The new decision date is March 27, 2025 (originally December 27, 2024), allowing the FDA additional time to review updated information. No safety, efficacy, or manufacturing concerns were cited, and DCCR remains under Priority Review, a sign of its potential importance for our community. PWSA | USA is committed to keeping the community updated throughout this process. We will share any new information as

soon as it becomes available. Learn more at the button below.

[LEARN MORE](#)

Calls for Abstracts for 2025 International PWS Conference

The abstract submission process is open for the 2025 International PWS Conference Clinical and Scientific Program! Read more information about how to apply using the button below. Our United in Hope: International PWS Conference will shape the future of PWS care and research. This five-day event marks the first joint conference between IPWSO, PWSA | USA, and FPWR, and symbolizes a historic milestone. Register today!




Call for Abstracts

Clinical & Scientific Program Submission
Deadline: January 31, 2025

[APPLY HERE](#)

[REGISTER HERE](#)

ECHO 4 PWS Healthcare Provider Series: YouTube Library for Families



ECHO 4 PWS Healthcare Webinar Series



PWSA | USA launched our Healthcare Provider Project ECHO Series, **ECHO 4 PWS**, in 2023. We are proud to offer this opportunity to healthcare professionals who work with patients affected by Prader-Willi syndrome (PWS) and to be the first PWS organization to implement Project ECHO® in the United States.

PWSA | USA's Healthcare Provider Project ECHO Series touches on a wide range of healthcare topics in the PWS space and is available for all health professionals across our network including (but not limited to):

Geneticists, Pediatric Endocrinologists, Neonatologists, Nurses, Pediatricians, Endocrinologists, Psychiatrists, Psychologists, Social Workers, Occupational Therapists, Pulmonologists, Orthopedic Surgeons, Dieticians, Physiotherapists,

Speech and Language Therapists, Medical Students and Professional Caregivers.

While our ECHO 4 PWS sessions are completed for 2024, with our latest webinar focusing on [Orthopedics with Dr. Harold van Bosse, MD](#), we look forward to offering additional ECHO 4 PWS opportunities in the future. In the meantime, we invite everyone to watch the 2024 ECHO recordings at the button below.

[ECHO 4 PWS LIBRARY](#)

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

As the holidays are well underway and many families are traveling, we thought it might be helpful to share a past blog about traveling with refrigerated medicine. Many people in our community are on growth hormone and other medications that require refrigeration. Some families will be traveling with this medication for the first time; other families may still struggle to work out the details of how. This blog offers tips for how to travel with refrigerated medicine, hopefully taking some of the stress out of your holiday travel.



Check out the "How to Travel with Refrigerated Medicine" blog by clicking the button below.

[READ HERE](#)

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope

[Donate](#)

they so desperately need. Thank
you!



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Prader-Willi Syndrome Association | USA
1032 E Brandon Blvd #4744 Brandon, FL 33511

PWSA | USA Special Edition Pulse: December 27, 2024

www.pwsausa.org | 941.312.0400

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Looking Ahead to 2025

As we wind down 2024, reflecting on the support and progress we have made toward our mission of empowering individuals and enriching the lives of those affected by Prader-Willi syndrome (PWS), we are once again reminded of how grateful we are for this community of passionate, dedicated, and motivated families, providers, caregivers, and individuals living with PWS. Through your efforts, support, guidance, acceptance, and dedication, we have had an inspiring year!

Yet, the work continues, and we are incredibly excited to move into our **50th Anniversary year!** PWSA | USA was founded in 1975 by two parents and a doctor who knew they would need a community to help individuals with PWS

live happy healthy lives. What began as an idea between a few people has now become a national organization that reaches into every corner of the PWS community. An organization that supports families all over our country and beyond. From Zoom screens in individualized education program (IEP) meetings, in-person residential trainings, family support webinars, parent mentors, and podcast episodes, to educating professional providers, advocates descending on their state capitols and gathering in D.C., and soon-to-be hosting an international PWS conference with two invaluable PWS organizations (the International Prader-Willi Syndrome Organisation and the Foundation for Prader-Willi Research), **PWSA | USA has traveled far!**

We are proud of the work we have accomplished over the last 50 years and excited to share more programs, events, and services on the horizon. This special edition Pulse offers a glimpse into what the PWS community can expect from us as we celebrate our 50th year, 2025!

EVENTS

50TH ANNIVERSARY CELEBRATION

JOURNEY OF HOPE

Prader-Willi Syndrome Association | USA

Friday, September 26, 2025

Ritz Carlton, St. Louis, MO

6 PM - 10 PM

50th Anniversary Gala: Save the Date!

Join PWSA | USA as we celebrate 50 years of support, research, and community at our *Journey of Hope Gala*.

Date: Friday, September 26, 2025, from 6 PM - 10 PM

Location: Ritz Carlton, St. Louis, MO

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.

Tickets and sponsorship opportunities coming soon—stay tuned!

International PWS Conference United in Hope

June 24, 2025	June 25-26, 2025	June 26, 2025	June 27-28, 2025
PWS Clinical Workshop	Clinical & Scientific Program	Adults with PWS Program	Family Program PWS Camps
<i>Invite Only</i>	Professional Providers Program	<i>1/2 Day</i>	

The **United In Hope: International Prader-Willi Syndrome Conference** will be held at the Arizona Grand Resort and Spa, Phoenix, AZ, from 24-28 June 2025.

The event will be hosted by the [Prader-Willi Syndrome Association | USA](#), the [Foundation for Prader-Willi Research](#) and the [International Prader-Willi Syndrome Organisation](#).

As the first joint conference between PWSA | USA, FPWR and IPWSO, it symbolizes a historic milestone in the PWS community. The power of working together and promoting our shared interests to benefit all those affected by PWS cannot be underestimated. Our theme “United in Hope” is a call to clinicians, scientists, parents, professional providers and caregivers, allied professionals and trainees, and most importantly, individuals with PWS, to bring your vision, your knowledge, your experience and your hopes, and to share and learn at this transformative gathering.

Our United in Hope Conference provides an opportunity to amplify the voice of our community. It is a time for us to renew our energies, celebrate our diversity, cultivate meaningful connections and foster groundbreaking research. And we do so in the unique and vibrant landscape that is Arizona!

[LEARN MORE AND REGISTER HERE](#)

PWSA | USA's 50th Birthday Party



When: Friday, June 27, 2025 | 6:30 PM - 9 PM

Where: Arizona Grand Resort & Spa Oasis Pool

This event is **free to attend** with a 2025 International PWS Conference registration! VIP Cabanas can be purchased when you register for the 2025 International PWS Conference.

You are invited to celebrate a milestone occasion! Join us as we commemorate the 50th birthday of PWSA | USA and the future collaborations of IPWSO, PWSA |

USA, and FPWR. Together, let's celebrate 50 years of supporting individuals and families affected by Prader-Willi syndrome, milestones achieved and memories created, and a future filled with hope, advocacy, and empowerment. Come prepared for live music, delicious food, and delightful company, as well as moments of reflection, gratitude, and celebration. Your presence will make this occasion even more special. We look forward to sharing this memorable evening with you!

[REGISTER FOR THE 2025 CONFERENCE](#)

Hope United Fundraisers

Thank you to all our donors for your incredible, steadfast support in 2024! Please watch our [Hope in Action](#) video series to learn more about the support we offer the PWS community and the difference you can make by fundraising.

As for 2025, we have an exciting year of fundraising ahead! With a new platform, more peer-to-peer fundraising opportunities, and in-person events to attend around the country, we are working to make fundraising more accessible and enjoyable. Whether you host an online fundraiser or create an event that brings together friends and family in the PWS community, fundraising is a great way to help PWSA | USA continue to support the PWS community.

Fundraise Online from the Comfort of Home!

Set up a fundraiser on [Facebook](#) or [Instagram](#) using birthdays or special events to gather donations from your friends and family. Create your own Fundraising Page on our new platform [HERE](#).

Some new fundraising events to look forward to this year are:

- Diamonds and Denim: February 1, 2025 | Springfield, IL (Register [HERE](#))
- Zahra's Night of Light: April 5, 2025 | Bedford, NY (Register [HERE](#))

**Many of our community-led fundraising events are returning for 2025!
Stay tuned for information regarding these upcoming events:**

- North Carolina Hope United 5k & Family Fun Run, May 3, 2025
- Ohio Hope United 5K & Family Run, TBD
- Answers for Audrey Trivia Night (Missouri), TBD
- 16th Annual Hunter Lens Golf Tournament (Massachusetts), October 4, 2025
- 4th Annual “No Gimmes for Jimmy” Golf Tournament (New Jersey), October 4, 2025
- Dance Silly for Prader-Willi (Ohio), October 11, 2025
- Cocktails for a Cause (New York), October 18, 2025

Explore ways to collaborate with PWSA to plan your own special fundraising event, contact us at hopeunited@pwsausa.org and get connected with a fundraising coach today! Please click the button below to learn more about our Hope United campaign.

*Giving **Hope** Has
Never Been Easier*



LEARN MORE



Remember to save the date for Clint Hurdle's Hot Stove Dinner, happening in Bradenton, FL on March 22, 2025! Tickets are **NOW AVAILABLE** for purchase at this link: [Clint Hurdle Hot Stove Dinner](#)

ADVOCACY

Empowering Advocates Through Education and Leadership

At PWSA | USA, we are dedicated to equipping our community with the tools and knowledge necessary to advocate for meaningful change. Two cornerstone initiatives are coming to our community in 2025—the PWS Advocacy Master Class and the Advocacy Ambassador Program. These new initiatives are designed to empower individuals to amplify their voices and drive impactful policy changes for those living with Prader-Willi syndrome.

Why Advocacy Matters

PWS is a complex and life-threatening condition that affects individuals and families in profound ways. Advocacy is critical to ensuring access to the life-changing therapies, services, and support our community needs. Through the PWS Advocacy Master Class and Advocacy Ambassador Program, we are empowering a new generation of leaders to champion our cause and create a brighter future for everyone impacted by PWS.

For more information or to get involved, visit our website or contact us at Advocacy@pwsausa.org today. Together, we can make a difference!

Advocacy Ambassador Program: Leading Change Across the Country

Our Advocacy Ambassador Program is a dynamic opportunity for passionate individuals to take their advocacy to the next level. Advocacy Ambassadors serve as critical connectors between the PWS community and policymakers, ensuring the voices of families affected by PWS are heard.

Program Goals:

- Build a nationwide network of trained advocates to advance policy goals.
- Eliminate barriers to accessing life-sustaining services, including restrictive IQ requirements, and advocate for PWS to be recognized as an Intellectual and Developmental Disability (IDD).
- Mobilize communities to engage in advocacy at state and federal levels.
- Collaborate with other organizations to amplify efforts and raise awareness.



Ambassador Responsibilities:

- Represent their state in advocacy efforts, including legislative meetings and public events.
- Share personal stories to humanize the impact of PWS and influence policy decisions.
- Lead grassroots efforts, including mobilizing families and organizing campaigns.

To ensure continuity, the program also includes Adjunct Ambassadors who stand ready to step in when needed, ensuring our advocacy remains strong and consistent.

Applications for our Advocacy Ambassador Program have closed and Ambassadors will be announced the first week of January!

PWS Advocacy Master Class: Learn, Advocate, Impact

Launching on **January 13, 2025**, the PWS Advocacy Master Class is a six-week program designed in collaboration with Patients Rising. It provides a robust curriculum for anyone passionate about becoming an effective advocate for PWS.

Course Highlights:

- **Congress 101:** A deep dive into how laws are made and how to engage with policymakers.
- **Pharmacy Benefit Managers & Pricing Policies:** Understand how these systems affect access to PWS therapies.

- **Effective Storytelling:** Learn how to craft and share your personal journey to inspire change.
- **Disability Rights & Clinical Trials:** Explore advocacy avenues in education, work, and treatment innovation.
- **Public Speaking & Letter Writing:** Gain confidence in presenting to legislators and writing impactful letters.
- **Final Project:** Graduates will complete either a legislator letter or an advocacy video to showcase their skills.



Participants will graduate with an e-Certificate of Completion and a working knowledge of advocacy techniques. The course combines live sessions, self-guided lessons, and practical exercises to ensure a comprehensive experience. If you or someone you know would like to participate, please click the button below to **register BEFORE January 13th!**

[REGISTER HERE](#)

FAMILY SUPPORT

Residential Provider Monthly Zoom Meetings

Residential and direct support providers are critical to the PWS community. PWSA | USA recognizes their importance and the necessity of supporting them in the work they do. To this end, we will be offering monthly Zoom meet ups for direct care staff, administrators, behavior analysts, etc. They will be facilitated by knowledgeable people from the PWS care provider community. There will be a topic discussed for each meeting, along with time for questions and sharing. These sessions will provide opportunities to brainstorm solutions to real situations and discuss what solutions have worked for others. It is our hope that these sessions not only help providers develop peer and mentor relationships amongst themselves, but that it will also strengthen the relationships between providers and PWSA | USA. We want the direct support providers in our community to feel educated, empowered, and supported.



Parent Empowerment Individualized Education Plan Training



Most parents and caregivers of school age and older individuals with PWS are familiar with the IEP process. It can be daunting, stressful, and overwhelming. PWSA | USA offers support through education, school trainings, and by attending IEP meetings (in-person or Zoom). We are excited to add to this list of support by launching our new **Parent Training Series, Empowering Families and IEP Meetings**, led by Dr. Destiny Pacha, ED.D. This comprehensive series is designed to equip parents with the tools and strategies needed to advocate

confidently for their children during IEP meetings, ensuring their unique needs are met.

Ask Nurse Lynn

We are thrilled with the success of the **Ask Nurse Lynn** series we began earlier this year. Nurse Lynn, our PWS advice nurse, has responded to questions from more than 50 families through this series alone. This number, of course, does



not include the numerous families and individuals she speaks to directly, whether on the phone, in person, or via email. Lynn Garrick, MSN, RN, is the mother of five children, including her youngest son, who has PWS. In addition to her work with PWSA | USA, she has been the Nurse and Program Director with AME Community Services, Inc., a residential provider serving adults and children with Prader-Willi syndrome, since 2007. She is also a board member of IPWSO, their professional providers and caregivers board, and the Minnesota PWS chapter. She is

an invaluable resource in the PWS community! We are excited to continue our *Ask Nurse Lynn* series, but with a new look.

We encourage any of you with a non-emergency question about PWS to submit your question to *Ask Nurse Lynn* using the button below. A response will be sent to you via email and shared (without identifying information) in our blog and on our social media platforms. The *Ask Nurse Lynn* series is a great way to spread education, awareness, and a deeper understanding of the many facets of PWS.

[SUBMIT HERE](#)

RESEARCH

PWS Behavioral Research Consortium

Kasey Bedard, Ph.D., BCBA-D, is leading the charge in understanding PWS behavior and supporting individuals with PWS. Dr. Bedard and her cohorts received grant funding from PWSA | USA to initiate their PWS Research Consortium with a focus on behavioral issues in PWS. According to the proposal, "This initiative is a strategic alliance between PWSA | USA and the PWS Behavioral Research Lab at The Chicago School, focusing on multi-disciplinary research into Prader-Willi syndrome. The partnership, led by Dr. Kasey Bedard, aims to combine clinical insights and academic research rigor. The collaboration is rooted in a mutual respect for the unique contributions of each organization. PWSA | USA brings practical, family-centered insights, while

The PWS Behavioral Research Lab offers academic expertise and research capabilities."

The consortium consists of four proposed projects:

- **PROJECT 1 | PWS HOME BASE PILOT STUDY:** Evaluating Efficacy and Encouraging Applied Learning
- **PROJECT 2 | TEACHING EMOTIONAL REGULATION SKILLS**
- **PROJECT 3 | BCBA PWS CONTINUING EDUCATION AND SUPERVISION NETWORK**
- **PROJECT 4 | FAMILY FOUNDATIONS: Navigating PWS Together**



These projects and the research gained will be wonderful additions to the understanding of PWS and provide necessary support for families in the community. Stay tuned for information on how to potentially join one of these studies.

PWS Connect Launches Journeys Project on Discord

2025



Journeys Project

Share your PWS journey and help advance PWS research and strengthen the PWS community!

In 2025, **PWS Connect** would like to learn more about your PWS journey from birth to where you are now. Throughout 2025, we will be sharing prompts on specific themes to help paint a more detailed picture of what PWS looks like for families. This information will help our organization, researchers, and specialists better understand PWS, how it affects individuals and families, and where more efforts for awareness, research, and support are needed. We encourage you all to be on the lookout for these prompts and to please participate by responding.

Your efforts will help forward research in the PWS community and offer a deeper connection with the families here.

What it will look like:

On the first and third Mondays of each month, PWSA | USA will post a theme-related prompt in the general chat of the PWS Connect channel on Discord. Members will be asked to share their experiences in the comments. While the prompt is there to inspire your thoughts on the specific theme, please feel free to include any and all details and experiences that come up. The more information the better!

Once you have completed a prompt for the month, you will receive a corresponding badge to represent your participation. We do ask that people respond to each of the two prompts in the month as they seek to draw out a different part of the experience.

In January we will be asking about PWS birth stories and hospital experiences after the birth. We know that these stories may be hard to tell for some families and would like to remind you that PWSA | USA is here to support you. Please feel free to reach out at info@pwsausa.org or call our phone line at 941-312-0400.

Your participation in the PWS Connect TREND community on Discord helps to advance PWS research and strengthen the PWS community. Please click the button below to learn more

[LEARN MORE HERE](#)

Pending DCCR New Drug Application with FDA

2025 could be an incredible year in treatments for PWS. One promising treatment is waiting on the desks of the FDA and may receive approval in the coming months. The FDA has until March 27, 2025, to decide whether or not to accept the NDA for Diazoxide Choline (DCCR). DCCR extended-release tablets are a potential treatment for individuals with Prader-Willi syndrome age 4 and older who experience hyperphagia.

It is important to remember that if the FDA does approve DCCR as a treatment option for individuals with PWS, there still may be a long road to gaining access and coverage by insurance. Know that PWSA | USA is committed to advocating for treatment options as well as the ability for families in our community to gain access to



those treatments. It may not always be an easy road but with our dedicated staff and passionate volunteers we will travel that road together.

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