

PWSA | USA Bi-Weekly Pulse: February 2, 2024

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 92

February 2, 2024

www.pwsausa.org | 941.312.0400

**PWSA | USA is Now Accepting Artwork for the
Rare Aware Art Share**



We are excited to announce the launch of PWSA | USA's brand new initiative – **The Rare Aware Art Share!** This virtual art show aims to spotlight the voices of individuals with Prader-Willi syndrome. We hope to learn more about each individual, their lives, and their experiences as someone with PWS.

The global art share will last for the entirety of 2024 and will be separated into three distinct themed sessions. Each session will have a specific date range for when we are accepting submissions. Submissions will be accepted in digital

format only. Click the button below to find the artwork submission form, as well as answers to frequently asked questions.

Between **February 1 - March 15, 2024**, we are collecting artwork for Theme 1 - **PWS Awareness**. Create your artwork using the prompt:

**“What is your superpower?
What are you capable of?”**

[CLICK HERE TO SUBMIT ARTWORK](#)

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



Justice, 20 living with PWS, has been a member of the Young Adult Rare Representative (YARR) since January 2023 and recently had the opportunity to learn more about one of the things she is passionate about, Advocacy. Justice plans on taking what she has learned to make a difference not only for the PWS community but for all rare diseases. Read our newest Spotlight on Hope to learn more about the EveryLife Foundation and Justice's experience as a YARR.

[READ MORE HERE](#)

[SHARE YOUR SPOTLIGHT ON HOPE](#)

EVENTS

2024 Clint Hurdle Hot Stove Dinner Tickets Now Available for Purchase!

Join hosts Clint and Karla Hurdle on Saturday, March 23, 2024, on the beautiful grounds of Bradenton Country Club in Bradenton, FL, and virtually from anywhere. Together, we can create a brighter future through your continued support!

Highlights of the evening:

- Inspirational stories of what Prader-Willi Syndrome Association | USA does every day!
- Silent Auction: Bid on exclusive items and experiences, with all proceeds going towards PWS research and support programs
- Gourmet Dinner: Enjoy a delectable meal while mingling with fellow supporters and advocates
- Live Entertainment
- Raffle
- Coconut Drop | Golf Ball Drop!

To purchase tickets, text the keyword **Hotstove2024** to 76278 or go to hotstove2024.givesmart.com

PURCHASE HOT STOVE DINNER TICKETS HERE



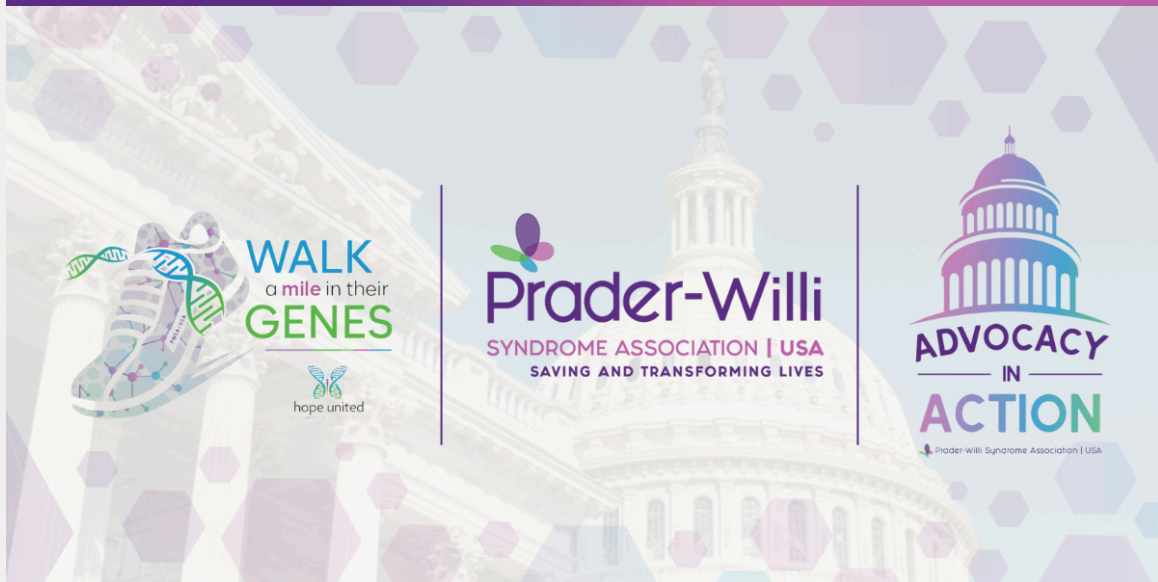
Sibling Community Conversation

If you are between the ages of 12 and 17 and have a sibling of any age with PWS, please join us for PWSA | USA's next **Sibling Community Conversation, Wednesday, February 14th at 8:00 p.m. EST**. This discussion provides a safe space for dialogue between siblings of a person with PWS. PWSA | USA team members will also be available to offer any insight and support. Register in advance at the button below. Our next meeting will be held on Wednesday, March 13th at 8:00 p.m. EST for siblings who are 18 years and older.



[REGISTER IN ADVANCE HERE](#)

ADVOCACY



Step Up for PWS Advocacy

Join PWSA | USA in our 2nd Annual **Walk a Mile in their Genes** advocacy campaign to raise awareness for Prader-Willi syndrome (PWS). Take action



from your home, community, or Chapter to support families affected by this rare disease. By becoming a participant, you not only advocate for the PWS community but also raise crucial funds for PWSA | USA to continue providing necessary services. This virtual/in-person fitness challenge is open to all ages and fitness levels, promoting health and wellness while supporting those with Prader-Willi syndrome. The campaign runs until March 18, 2024, and signing up is quick and easy through the link at the button below.

[CLICK HERE TO GET INVOLVED!](#)

Want to participate in the ***Walk a Mile in their Genes Advocacy Campaign*** but don't know where to start? PWSA | USA staff members share what steps to take in this video.

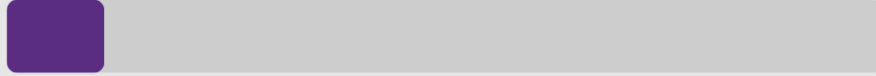


If you have additional questions, please contact us at hopeunited@pwsausa.org.

Our Progress









\$4,850

\$50,000



Fundraising Leaderboard

[Click here](#) to support our *Walk a Mile in their Genes* participants!

1		Creating Change for Clementine KELLY GUILLOU	\$1,500
2		Elaine's Advocacy Efforts for PWS Elaine Towle	\$1,150
3		Pentas Speak Out For PWS Tammie Penta	\$1,000
4		Hope for Hunter Dorothea Lantz	\$500
5		Walking with Freya Anne Fricke	\$450
6		Pedaling for PWS Carrie Ilijevich	\$175
7		Raising for Ronan Kat Lucero	\$50
8		Help Chris Advocate for his Friends Maggie Andrews	\$25

Movement and Motivation for our Loved Ones with PWS

It is common knowledge in the PWS community how important it is for our loved ones with PWS to regularly participate in movement and exercise. Knowing the importance and being able to get our loved ones involved in movement activities are not always connected. Tactics like helping them to determine a fitness goal, creating a visually pleasing schedule, or joining families for our Walk a Mile campaign and watching the movement miles add up are all possible ways to



motivate your loved one to work on their fitness. Read this week's blog, [Movement and Motivation for our Loved Ones with PWS](#), to learn more.

[READ MORE HERE](#)

Major Milestone: PWS Qualifier Bill Advances Unanimously in Arizona State Senate Committee



We are thrilled to announce that, on January 30th, the PWS qualifier bill ([SB 1191](#)) in Arizona unanimously passed the State Senate Health and Human Services Committee! This marks a crucial and initial step towards having PWS recognized as a developmental disability in the state of Arizona. We are also delighted to share that this bill is scheduled for a hearing in front of the Senate Appropriations Committee on February 6th at 2:00 PM in SHR 109. If you reside in Arizona and wish to get involved, please email Crissy Burgstaler at

crissymcgann@gmail.com. You can also stay updated on its progress by tracking the bill through the Arizona legislative process by clicking [here](#). A big thank you to Crissy and all our PWSA Arizona Chapter Leaders for their unwavering dedication in advancing this cause in 2024!

Calling All New England Residents!



PWSA New England is trying to better understand the obstacles we face when seeking approval for Medicaid and/or Disability services for our loved ones with PWS. If you live in one of the New England states (Massachusetts, Maine, New Hampshire, Vermont, Rhode Island), please complete this quick survey. All of our experiences are important to this work!

For questions about the survey, please contact Elaine at eltowle@gmail.com.

[CLICK HERE TO PARTICIPATE](#)

Empowering Hope: Kayla Day's Journey as a PWS Advocate



Meet Kayla Day, a dedicated advocate and mother to Luella, a 4-year-old living with PWS. In this week's **Spotlight on Advocacy**, Kayla shares her family's journey with PWS and the steps she's taken to get PWS recognized as a developmental disability in Pennsylvania.

Kayla's recent meeting with Pennsylvania Senator Pat Stefano underscores her commitment to educating the public and the medical field, ensuring proper care and treatment options for the PWS

community. Kayla's mission is to make a difference and spread hope in

Pennsylvania, where PWS may be rare, but hope is not. Read more about Kayla's meeting with Senator Stefano at the button below.

[READ MORE HERE](#)

Join Us for Rare Disease Week on Capitol Hill 2024!



Join several PWS advocates, and other advocates from around the country, for this multi-day event, happening February 25-28, 2024, in Washington, D.C., and hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases).

Rare Disease Week brings together rare disease advocates from across the country to make their voices heard by their members of Congress. Participants are educated on policy proposals impacting the rare disease community and

provided opportunities to advocate for policy changes directly to their members of Congress. Register to attend Rare Disease Week by clicking the button below. We hope to see you there!

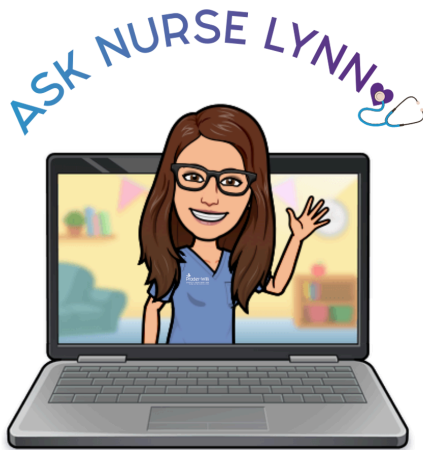
[REGISTER HERE](#)



FAMILY SUPPORT

Ask Nurse Lynn Your Non-Emergency PWS Medical Questions!

Do you have a non-emergency medical question about Prader-Willi syndrome (PWS)? 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.

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. PWSA | USA has been a significant resource since the birth of her son, and she is honored to help the community through her personal and professional knowledge.

How it works:

Please submit your non-emergency medical questions to the form found at the button below or email questions to communications@pwsausa.org with the subject line **Attn: Ask Nurse Lynn**. We will then send your question to Nurse Lynn. Lynn’s response will be posted anonymously on our social media platforms, as well as sent to you via email. Please keep questions appropriate for an all-ages social media audience.

[SUBMIT YOUR QUESTIONS HERE](#)

PWS Parenting Hacks

We’ve reached out to the community to share some PWS Parenting hacks. Those little tips and tricks of the trade that make navigating the challenges of PWS a little easier. We hope you find something that can be helpful in your life as well. We’d love to hear your PWS Parenting Hacks! Please click on the button to share yours.

[CLICK HERE TO SHARE YOURS](#)



Michelle (Mom to Samantha, 5):
 “If you are dealing with frequent insurance denials or coverage limitations, ask to be assigned a case manager from the insurance company. Always formally request the authorization, never verbally, through customer service. When you receive a denial letter, read it and follow the steps to appeal.”



Tuscon Residence Foundation (ages 49 and 51): “We check the restaurant menu by the app and decide 1st choice of the meal and then a 2nd choice just in case the meal is not available.”



Rachel (Mom to Michael, 6): “When preparing for the school year, create an ‘All About (Your Child’s Name)’ packet. Include copies of the PWSA | USA medical reference guide. Meet the classroom teacher and specialists to go over diet, medical concerns, temperature regulation, behavior, and how social studies and a visual schedule can be helpful. Help educate them about how PWS kids are wonderful! If needed, contact PWSA | USA for help with IEPs and 504 plans.”



RESEARCH

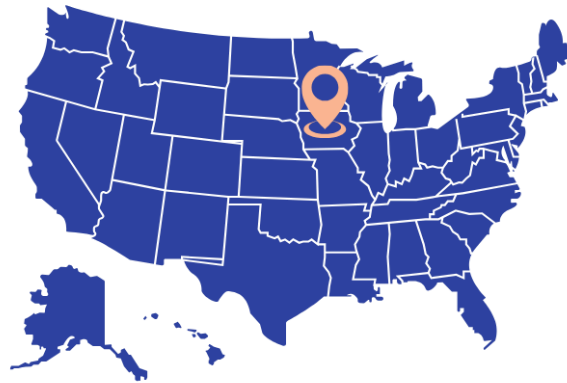
Acadia Pharmaceuticals Announces New Clinical Trial Site for COMPASS PWS Study



COMPASSPWS

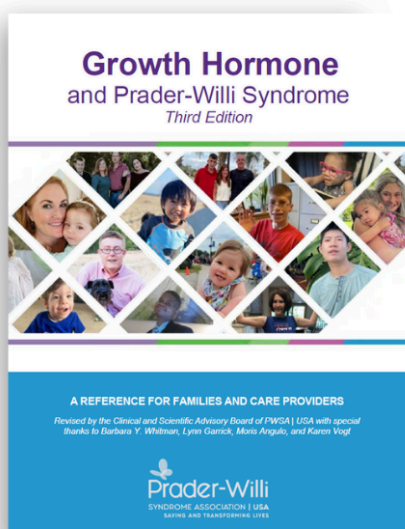
Acadia Pharmaceuticals

has announced the opening of a new clinical trial site for its COMPASS PWS study (carbetocin nasal spray/ACP-101) at the University of Iowa Hospitals and Clinics – Stead Family Children’s Hospital (Iowa City, IA).



[LEARN MORE HERE](#)

ICYMI: Third Edition Growth Hormone Booklet is Now Available!



PWSA | USA and the Clinical/Scientific Advisory Board have worked together to publish the Third Edition Growth Hormone Booklet. Download the booklet at the button below.

[CLICK HERE TO DOWNLOAD](#)

PWSA | USA ANNOUNCEMENTS

Join the PWSA | USA Team!



PWSA | USA is looking to hire two passionate individuals to join our team as the new Development Specialist and Director of Accounting.

Full Time Development Specialist (Remote):

Do you have a passion for cultivating relationships and supporting those affected by PWS? Here is your opportunity! PWSA | USA is on the lookout for a dynamic individual to join our growing development team! As the Development Specialist, you'll

play a crucial role in special projects, grassroots support, and donor engagement. Ready to spearhead strategies and tactics to welcome new donors? Exciting opportunities await, including managing the organization's Just Giving Peer-to-Peer fundraising platform and creating custom forms for DIY events. In addition, this individual will manage small project grants, online auctions, solicitation campaigns, recurring donation initiatives and cause

marketing/merchandising. Take the next step in your career and contribute to our impactful initiatives. Click [HERE](#) to learn more.

To apply, email your resume to mmcdonald@pwsausa.org by **February 12, 2024**. No phone calls please.

Director of Accounting (30 hours per week, remote):

We're currently seeking a qualified professional to join our team as the Director of Accounting. In this role, you will be responsible for overseeing the operation and management of the accounting information and control department. Key responsibilities include reviewing and scrutinizing financial information, ensuring adherence to set deadlines, assisting with annual program budgets, assessing organizational progress against the budget, and managing monthly and annual close processes on an accrual basis. If you have a strong background in accounting and are meticulous in adhering to guidelines and procedures, we invite you to explore this opportunity further. Click [HERE](#) to learn more.

To apply, email your resume to sward@pwsausa.org by **February 21, 2024**.

EMPLOYMENT OPPORTUNITIES

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: February 16, 2024

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PWSA | USA Advocacy in Action is Heading to D.C. for Rare Disease Week!



PWS Advocates are heading to Washington, DC to celebrate Rare Disease Week (February 25-28)! Advocates will have the opportunity to learn more about policy proposals affecting the rare disease community, as well as meet with members of Congress to have their voices heard. There are over 10,000 rare diseases, PWS being one of them. Rare Disease Week is an incredible opportunity for the rare disease community to come together and advocate for

our loved ones. If you're interested in learning more, or reading about the ways you can participate in Rare Disease Week at home, please check out our blog.

[READ MORE HERE](#)

PWSA | USA'S SPOTLIGHT ON HOPE



Meet CBC Saskatchewan Future 40 winner Ryan Kendall

Ryan Kendall, 24, is a 2016 Future 40 winner

for CBC News - Posted: Mar 17, 2016 6:00 PM CDT | Last Updated: March 17, 2016



Contributed by Brian Kendall

Ryan is 32-years-old and lives with PWS. He has an incredible voice and utilizes his talent to uplift communities by performing at care homes and special needs events. Not only does he captivate audiences with his original inspirational songs, but he also demonstrates a profound commitment to philanthropy, having raised over \$13,000 for a local charity. His remarkable contributions have been recognized on a national level, as evidenced by his receipt of the CBC Future 40 Under 40 award from the Canadian Broadcasting Corporation (CBC).

[SHARE YOUR SPOTLIGHT ON HOPE](#)

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- Coconut Drop | Golf Ball Drop!

To purchase tickets, text the keyword **Hotstove2024** to 76278 or go to hotstove2024.givesmart.com

PURCHASE HOT STOVE DINNER TICKETS HERE



PWSA of New Mexico Valentine's Day Party

On behalf of PWSA of New Mexico:

Attention all families of individuals with Prader-Willi Syndrome (PWS)! We're excited to invite you to a Valentine's Day Party on Saturday, February 17th, from 1:00 pm to 3:30 pm, hosted at Christ United Methodist Church located at 6200 Gibson Blvd SE, Abq, NM 87108. Please park on the west side of the building. Please note that no food will be served during the event. However, there will be plenty of fun activities including crafts, a photo booth, music, and goodie bags



for everyone to enjoy! Kindly RSVP to Maggie Andrews at 205-527-4414 or via email at maggie@pwsanm.com. We can't wait to celebrate with you!

[DOWNLOAD THE FLYER HERE](#)

A banner for advocacy. The top section is purple with a white lightbulb icon and the word "ADVOCACY" in white. Below this is a light blue section with a background image of a classical building. On the left is the "WALK a mile in their GENES" logo, which includes a running shoe and a DNA helix. In the center is the Prader-Willi Syndrome Association | USA logo, featuring a butterfly and the text "Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES". On the right is the "ADVOCACY IN ACTION" logo, which includes a dome-shaped building and the text "ADVOCACY IN ACTION". At the bottom is a green section with the text "Step Up for PWS Advocacy" in white.

ADVOCACY

WALK
a mile in their
GENES

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

ADVOCACY
IN
ACTION

Step Up for PWS Advocacy

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from your home, community, or Chapter to support families affected by this rare disease. By becoming a participant, you not only advocate for the PWS community but also raise crucial funds for PWSA | USA to continue providing necessary services. This virtual/in-person fitness challenge is open to all ages and fitness levels, promoting health and wellness while supporting those with Prader-Willi syndrome. The campaign runs until March 18, 2024, and signing up is quick and easy through the link at the button below.

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Fundraising Leaderboard

- | | | | |
|----|---|---|---------|
| 1 |  | Loving and Living for Leslie
Michelle Torbert | \$2,520 |
| 2 |  | Creating Change for Clementine
KELLY GUILLLOU | \$1,600 |
| 3 |  | Elaine's Advocacy Efforts for PWS
Elaine Towle | \$1,150 |
| 4 |  | Pentas Speak Out For PWS
Tammie Penta | \$1,100 |
| 5 |  | Little Louie's Fighters
Lindsey Lipton | \$1,000 |
| 6 |  | United in Hope to change lives.
Sue Colon | \$1,000 |
| 7 |  | Raising for Ronan
Kat Lucero | \$550 |
| 8 |  | Hope for Hunter
Dorothea Lantz | \$500 |
| 9 |  | Walking with Freya
Anne Fricke | \$460 |
| 10 |  | Help Chris Advocate for His Friends
Maggie Andrews | \$390 |
-

Want to participate in the
Walk a Mile in their Genes
Advocacy Campaign but don't
know where to start?
PWSA | USA staff members
share what steps to take
in this video.



***If you have additional questions, please contact us at
hopeunited@pwsausa.org.***

Advocacy Gear

Are you looking for another way to show your support for PWS Advocacy? Are you going to the DC Fly-In and want to represent your work in the PWS community? Advocacy gear is now available through our Bonfire site. Click the button or follow the link on the home page of our [Walk a Mile in their Genes](#) advocacy fundraising campaign. Crew-neck and V-neck t-shirts, hoodies, and long-sleeved tees in a variety of sizes are available. Proceeds will benefit PWSA | USA's advocacy efforts.



[SHOP ADVOCACY GEAR HERE](#)

Highlighting the Artistic Voices of PWS



Calling all individuals living with PWS! We are collecting artwork for our new initiative - **The Rare Aware Art Share**. This virtual art show aims to spotlight the voices of individuals with Prader-Willi syndrome. We hope to learn more about each individual, their lives, and their experiences as someone with PWS.

The global art share will last for the entirety of 2024 and will be separated into three distinct themed sessions. Each session will have a specific date range for when we are accepting submissions. Submissions

will be accepted in digital format only. Click the button below to find the artwork submission form, as well as answers to frequently asked questions.

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**“What is your superpower?
What are you capable of?”**

[SUBMIT ARTWORK HERE](#)

Another Milestone: PWS Qualifier Bill Advances in Arizona State Senate Committee on Appropriations

We are thrilled to announce that on February 6th, the PWS qualifier bill ([SB 1191](#)) in Arizona has now passed the State Senate Committee on Appropriations! This marks yet another crucial step towards having PWS recognized as a developmental disability in the state of Arizona. A big thank you to Crissy Burgstaler and all our PWSA Arizona Chapter Leaders for their unwavering dedication in advancing this cause in 2024!



Protecting Healthcare for All Patients Act Passes in House of Representatives

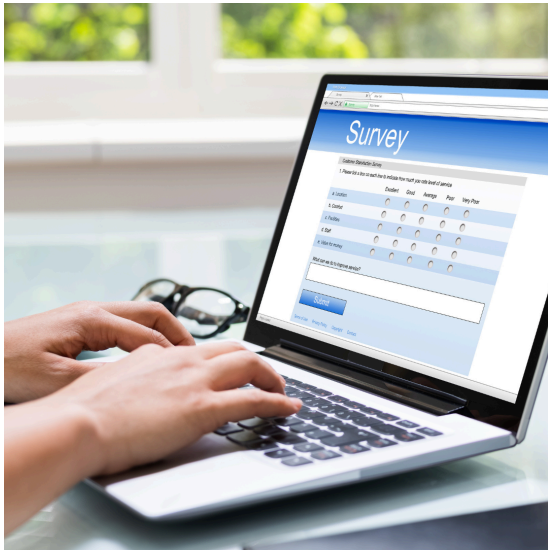
The Protecting Healthcare for All Patients Act, [H.R. Bill 485](#), narrowly passed in the House of Representatives, but it stands as a monumental victory for the patient and disability rights communities! Here's how H.R. 485 will make a difference:

- Bans the use of [QALY](#) and similar tools in federal healthcare programs.
- Ensures treatment decisions are based on medical need, not discriminatory metrics.
- Promotes equity and fairness in healthcare access for all.



We will continue to provide updates on this legislation as it moves forward in the approval process.

Calling All New England Residents!



PWSA New England is trying to better understand the obstacles we face when seeking approval for Medicaid and/or Disability services for our loved ones with PWS. If you live in one of the New England states (Massachusetts, Maine, New Hampshire, Vermont, Rhode Island), please complete this quick survey. All of our experiences are important to this work!

For questions about the survey, please contact Elaine at eltowle@gmail.com.

[CLICK HERE TO PARTICIPATE](#)



FAMILY SUPPORT

Today, February 16th, is National Caregivers Day



February 16th is National Caregivers Day and PWSA | USA would like to first extend our gratitude and support to all caregivers in the PWS community. We would like to further recognize the incredible work and determination of those who care for our loved ones in residential settings, along with honoring those parents who are in the unexpected territory of caring for adults with PWS. Today, and every day, we thank you! To read more about parents caring for adults, some of the wonderful residential facilities in the PWS community, and ways to show your

gratitude to caregivers, please check out our blog, "Gratitude for Caregivers on National Caregivers Day."

[READ MORE HERE](#)

Register for PWSA | USA's Family Support Webinar with Patrice Carroll, *Unlocking Potential: Harnessing Strengths to Transform Behavior*



Join Patrice Carroll, LICSW and the PWS community on **February 27, 5pm Pacific/ 8pm Eastern** for an insightful webinar on behaviors in PWS and effective ways to interact with these behaviors. This webinar will help to define the challenges that lead to unwanted behaviors and help to reframe your responses for more positive outcomes. We will take a deeper dive into why challenging behaviors occur and will give you the skills needed to help your child be the best that they can be!

[REGISTER FOR THE WEBINAR HERE](#)

New Support Avenue for Families: Ask Nurse Lynn

PWSA | USA invites parents and caregivers in the PWS community to reach out to our staff nurse, Lynn Garrick, with non-emergency medical questions. You can read a few of her responses here and submit your question below.



Ask Nurse Lynn



Male, 4 months old, UPD, NM:

My son recently caught Covid, I feel like it's taking him longer to get over it, he's been hospitalized twice, his lungs sound ok, is on iv fluids. First time he didn't really get to rest it off nurses would constantly come in room and messed with him. He is GTube fed. Is it pretty normal or common for it to take longer to recover or act pretty much normal?

I am sorry to hear that your son was in the hospital. It is true that hospitals are not the best places to get good rest. Unfortunately, I don't have any timeframes for you. Each person recovers differently. But, from what I've seen, it can take our folks longer to recover. His little body is working hard to grow, meet milestones and all those things. We know that our loved ones take longer to do typical things so I would wager that it could take your son longer to recover. Give him time and watch for signs for distress indicating he may need to go back to be evaluated.



M, 37, UPD, Ireland:

Habit of going to bed and not easily getting up. Used be to avoid issues. Now over adult years it's happening regular. Stays 3 days in bed. Mood flat. Food no longer priority.

Have there been changes to the daily routine? Is there a daily schedule that he follows? Oftentimes, a daily schedule is helpful for them. Building in rewards or preferred activities can also be useful. Having your son be a part of the weekly planning can be empowering and help him with accountability of task completion. Lastly, has he been evaluated by a mental health professional? It can be difficult to differentiate behavioral issues with true mental health diagnosis. There is a great PWS association in Ireland. They would also be a great resource for you. <https://nwsai.ie/>

...could also be a great resource for your hyperphagia.

Do you have a non-emergency medical question about Prader-Willi syndrome (PWS)? 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 NURSE LYNN](#)

PWS Parenting Hacks

Do you have a tip or simple parenting tool that helps you navigate the challenges of PWS parenting? Are you willing to share with the community so other parents may learn from you and gain ideas for the challenges they may face? We'd love to hear your PWS Parenting Hacks! Please click on the button to share yours.

[CLICK HERE TO SHARE YOURS](#)



RESEARCH

PWS Parents and Caregivers: Tell Your Healthcare Professionals About PWSA | USA's Next ECHO Webinar, *Sleep with Dr. Amee Revana*



ECHO 4 PWS

Date: Thursday, March 14, 2024

Time: 6:00 PM EST

Topic: Sleep with Dr. Amee Revana

PWSA | USA's next **Healthcare Provider Project ECHO Series** webinar will take place March 14, 2024 at 6:00 p.m. EST. The topic discussed will be **Sleep** presented by Amee Revana, DO FAASM, Associate Professor of Pediatrics, Texas Children's Hospital, followed by a 20-minute case study on PWS (*speaker to be determined*).

While this ECHO series is only for healthcare providers to attend, recordings of the webinars will be made available for our PWS families on our website. We encourage you to share this opportunity with the healthcare professionals in your life! You can learn more details and find the registration link at the button below.

[ECHO 4 PWS INFORMATION](#)

New Trial Sites Open

New Trial Site Open



Fort Worth, Texas

Acadia Pharmaceuticals opens a new trial site for the Compass PWS Study at Cook Children's Medical Center in Fort Worth, Texas. Compass PWS is a Phase III trial testing the effectiveness of a carbetocin nasal spray (ACP-101). The purpose of the COMPASS PWS study is to learn more about a study drug in participants with Prader-Willi syndrome (PWS) who have hyperphagia (excessive appetite).

[LEARN MORE HERE](#)

Neuren Pharmaceuticals has announced a third trial site opening for their Phase II, **Open Label**, PWS Study (Neu-2591-PWS-001). Suburban Research in Philadelphia is now welcoming children with PWS and their families to their clinic for screening into this trial. Rare Disease Research (RDR), located in Atlanta, GA, and Uncommon Cures, located in Chevy Chase, MD (8 miles outside of Washington, D.C.) are the other participating trial sites. Click the button to learn more about the trial.



[LEARN MORE HERE](#)

Lynn Garrick Celebrates New Article: Full-time Care Services Vital for PWS Community



New article published by our very own Lynn Garrick, MSN, RN!

Full-time care services are essential to overall care for many living with PWS and their families. This article looked at full-time care services for people with PWS from six countries and around 200 individuals with PWS. The findings support what many already know. Specialized services in PWS dramatically improve BMI and behaviors of concern. These improvements are apparent quickly and improve over time.

We hope that this article will pave the way for additional studies about how specialized support services make a positive impact on the lives of those living with PWS and their families. We are also hopeful that this study can be used to support the need for funding and opening more specialized homes for those living with PWS.

[READ THE ARTICLE HERE](#)

Kasey Bedard Publishes New Paper on Skin-Picking

Kasey Bedard, PhD, BCBA-D, along with Annette K. Griffith and Kelly Krukowski, have published a new paper called "Caregiver-Implemented Behavior Analytic Treatment Package for Skin-Picking in PWS: A Pilot Study". Skin-picking is a self-injurious behavior that is common in individuals with PWS. This paper discusses the results of a study involving caregivers and behavior strategies implemented to help lessen the occurrence of skin-picking. Read the article to learn more. Email Kasey at kbedard@thechicagoschool.edu to receive the full PDF.

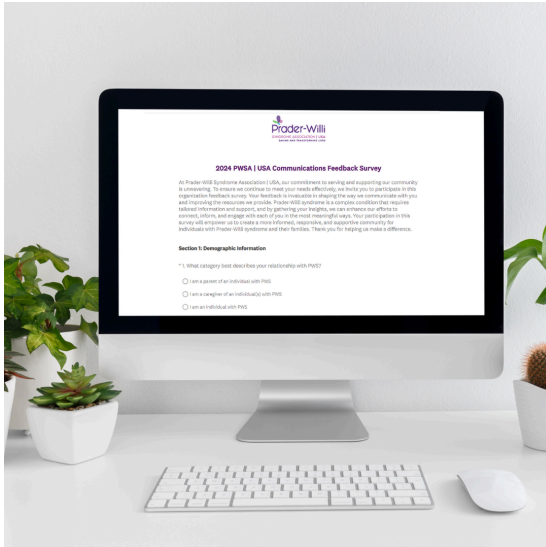


[READ THE ARTICLE HERE](#)

PWSA | USA ANNOUNCEMENTS

Share Your Feedback! Participate in PWSA | USA Communications Survey

At PWSA | USA, our commitment to serving and supporting our community is unwavering. To ensure we continue to meet your needs effectively, we invite you to participate in this organization feedback survey. Your feedback is invaluable



in shaping the way we communicate with you and improving the resources we provide. Prader-Willi syndrome is a complex condition that requires tailored information and support, and by gathering your insights, we can enhance our efforts to connect, inform, and engage with each of you in the most meaningful ways. Your participation in this survey will empower us to create a more informed, responsive, and supportive community for individuals with Prader-Willi syndrome and their families. Thank you for helping us make a difference.

[CLICK HERE TO PARTICIPATE IN THE SURVEY](#)

Join the PWSA | USA Team!



PWSA | USA is looking to hire two passionate individuals to join our team as the new Development Specialist and Director of Accounting.

Full Time Development Specialist (Remote):

Do you have a passion for cultivating relationships and supporting those affected by PWS? Here is your opportunity! PWSA | USA is on the lookout for a dynamic individual to join our growing development team! As the Development Specialist, you'll



play a crucial role in special projects, grassroots support, and donor engagement. Ready to spearhead strategies and tactics to welcome new donors? Exciting opportunities await, including managing the organization's Just Giving Peer-to-Peer fundraising platform and creating custom forms for DIY events. In addition, this individual will manage small project grants, online auctions, solicitation campaigns, recurring donation initiatives and cause

marketing/merchandising. Take the next step in your career and contribute to our impactful initiatives. Click [HERE](#) to learn more.

To apply, email your resume to mmcdonald@pwsausa.org by **February 29, 2024**. No phone calls please.

Director of Accounting (30 hours per week, remote):

We're currently seeking a qualified professional to join our team as the Director of Accounting. In this role, you will be responsible for overseeing the operation and management of the accounting information and control department. Key responsibilities include reviewing and scrutinizing financial information, ensuring adherence to set deadlines, assisting with annual program budgets, assessing organizational progress against the budget, and managing monthly and annual close processes on an accrual basis. If you have a strong background in accounting and are meticulous in adhering to guidelines and procedures, we invite you to explore this opportunity further. Click [HERE](#) to learn more.

To apply, email your resume to sward@pwsausa.org by **February 29, 2024**.

EMPLOYMENT OPPORTUNITIES

Get Your Own PWSA | USA Handcrafted Tumblers!



Introducing **PWSA | USA Tumblers**, which are handcrafted by Kim Tula, a dedicated member of the PWSA | USA team. Each tumbler boasts a stunning marbled tie-dye effect, showcasing the vibrant hues of PWSA | USA's signature colors and making every piece a unique masterpiece.

No two tumblers are alike, ensuring that yours will be one-of-a-kind. You also can personalize your tumbler with your/your loved one's name, adding a touch of individuality and charm.

With each purchase, you are supporting PWSA | USA's advocacy, family support, and research programs and initiatives. Learn more and order yours today at the buttons below!

[ORDER TUMBLERS WITH CUSTOMIZATION](#)

[ORDER TUMBLERS WITHOUT CUSTOMIZATION](#)

IN MEMORY OF



We are saddened to share the passing of beloved Carol "Tati" Diane Jamieson (Aug. 6, 1973 - Feb. 3, 2024), who peacefully passed away at 50 in Columbus, Ohio, with her mother by her side. Overcoming the challenges of Prader-Willi syndrome, Carol found joy in dance classes, Special Olympics, horseback riding, and Camp Sue Osborn. A member of the Sisukas Finnish Folk Dancing Group, she cherished time with family and friends, adored Disney princesses, and deeply embraced her faith. She is survived by her parents, sisters, nieces, and beloved

dogs, Buddy and Webster. A Celebration of Life will be held on Feb. 11, 2024, at Jefferson Country Club, Blacklick, Ohio, and on Feb. 17, 2024, at Camp Burton, Burton. Read her full obituary at the button below.

[READ MORE HERE](#)

PWSA | USA GRIEF COUNSELING AVAILABLE

Grief can occur with any loss and grieving is a necessary step in the healing process. PWSA | USA offers grief support to individuals diagnosed with PWS and to parents, family members, and caregivers who may be dealing with any type of grief. If you are interested in receiving grief counseling, please give us a call at 941.312.0400.

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](#)



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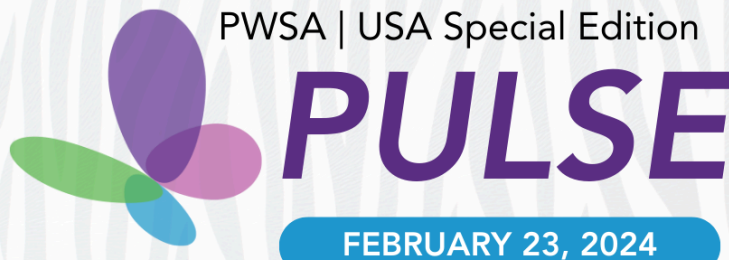
[Prader-Willi Syndrome Association | USA](#)

1032 E Brandon Blvd #4744 Brandon, FL 33511

PWSA | USA Special Edition Pulse: February 23, 2024

www.pwsausa.org | 941.312.0400

[Donate](#)



Rare Disease Day

February 29th, **Rare Disease Day**, is just around the corner! PWSA | USA and PWS advocates will be meeting in Washington, D.C. to make their voices heard at Everylife Foundation's [Rare Disease Week on Capitol Hill](#). To date, there are over 10,000 rare diseases, 95% of which are without FDA approved treatments. Roughly 70% of genetic rare diseases start in childhood, and the average time it takes to get an accurate rare diagnosis is 6-8 years! Overall, there are 400 million people worldwide affected by a rare disease.

These numbers are staggering! Rare Disease Week is an incredible opportunity for the rare disease community to come together and advocate for our loved ones. PWSA | USA is excited and grateful to participate in this event. The PWS community will be well represented.

[READ MORE HERE](#)

"Thank you to all our hard-working advocates for taking this opportunity to share your voices; your relentless persistence to change the face of PWS and all rare disease is inspirational, and we are grateful for all you do."

- Dorothea Lantz, Director of Community Engagement at PWSA | USA

Watch our **2024 Advocacy in Action** video, featuring three of our dedicated volunteer advocates who share why they raise their voice.



Live Coverage of Rare Disease Week

Join PWSA | USA as we bring you live updates straight from Washington, D.C. during Rare Disease Week! Follow us on our social media platforms to stay in the loop.

Here's what you can expect:

1. **Live Check-Ins:** Catch us on Facebook and Instagram for live updates and insights between Monday, February 26th and Wednesday, February 28th. We'll be sharing our experiences in real-time as we navigate Rare Disease Week.

2. **Exclusive Content:** Dive deeper into the heart of our mission with behind-the-scenes photos, compelling interviews, and highlights of the impactful work taking place within the rare disease community on Capitol Hill.
3. **Recap in Pulse Newsletter:** Missed out on any of the action? Don't worry! In next week's Pulse newsletter, we'll provide a recap of our experiences, ensuring you're up-to-date with all the latest developments and insights from Rare Disease Week.







[FOLLOW US ON FACEBOOK](#)

[FOLLOW US ON INSTAGRAM](#)

Rare Disease Day Webinar

#RAREis
A program by **AMGEN**

#RAREis One Webinar
February 29, 2024 | 11:30 a.m. ET

 Michelle Rivas Notestine Senior Manager, Product Communications Amgen	 Dorothea Lantz Director of Community Engagement Prader-Willi Syndrome Association USA
 Daniel DeFabio Menkes Syndrome Dad Director of Community Engagement, Global Genes, Co-Founder, The Disorder Channel	 Anton Morkin Founder & CEO TBI4Life

PWSA | USA's Director of Community Engagement, Dorothea Lantz, will be a panelist at the upcoming **#RAREis One** webinar to share her family's experience with PWS.

#RAREis One, a program from Amgen, one of the world's leading biotechnology companies, will focus on elevating the faces, voices, and unique experiences of those living with or caring for someone with a rare disease. Through the

presentations of diverse storytellers, you will gain an understanding of what life is like in different parts of the globe for the 400 million people impacted by rare diseases and the challenges they've encountered and overcome.

To register for this webinar, click the button below.

[REGISTER IN ADVANCE HERE](#)

Reflection on Advocacy



Stepping into the role of "advocate" for a community may seem daunting. As much as we want to create change and a safer world for our loved ones, speaking in a public forum may be intimidating, especially if someone does not know what is expected. Jen Andrews shares with us her journey to becoming a prominent advocate in the PWS community, the steps she took to get there, what is expected of advocates when they enter the realm of legislation, and the many ways to

advocate for our loved ones with PWS from home. For anyone considering taking up advocacy work, this is an encouraging and enlightening blog to help get you on the path.

[READ MORE HERE](#)

Ways to Participate In Rare Disease Day

- [Click here](#) to create a **Walk a Mile in their Genes** advocacy campaign page and help raise money and awareness for PWSA | USA's 2024 Advocacy initiatives and programs. You can also donate to existing Walk a Mile in their Genes participant fundraisers.
- **Wear zebra stripes** to show your support. Talk to your child's class or invite friends to ask questions about PWS and your loved one.

- **Share your rare story on social media** to help spread awareness of rare diseases like PWS, the need for research funding and policy changes, and the immense challenges the rare disease community faces every day.
- Join PWSA | USA's advocacy work group! Contact advocacy@pwsausa.org
- Participate in Global Genes “**Zebra Tales**” initiative. [Click here](#) to learn more!
- Call or write your representatives to share your experience with PWS, and what they can do to help. Click on the “Write a Letter to a Representative” button on [PWSA | USA's Advocacy](#) page for a link to automatically send emails to your legislators. It's that easy.
- **Express your gratitude** to the advocates on the front lines of the fight for recognition, research, policy change, and treatment options.
- Let your community know that you are a part of the rare disease community and invite them to share their support.
- Encourage your loved one living with PWS to participate in PWSA | USA's Rare Aware Art Share! [Click here](#) to learn more.



PWSA | USA Advocacy Shirts Now Available!

Another way to show your PWS pride AND support PWSA | USA is by purchasing our new advocacy shirts. They come in a variety of colors and styles, including sweatshirts, long sleeve t-shirts, short sleeve t-shirts, and more! Visit the homepage of our [Walk a Mile in their Genes](#) fundraising campaign, or our Bonfire site at the button below, to order yours. Proceeds will benefit PWSA | USA's Advocacy efforts.

[PURCHASE ADVOCACY SHIRTS HERE](#)

Advocacy in Action



Sue Colon's (mom to Shealynn, living with PWS) efforts were successful in getting New Jersey Governor Phil Murphy to officially proclaim **March 4, 2024, as Rare Disease Day in the state of New Jersey**. This is a huge step in the fight for recognition and awareness of rare diseases. Congratulations, Sue!



Crissy Burgstaler and the PWSA Arizona Chapter leaders were instrumental in getting the **PWS qualifier bill (SB 1191)** passed by the State Senate Health and Human Services Committee, marking a critical step in the fight to get PWS recognized as a developmental disability in the state of Arizona. Congratulations to Crissy and the PWSA AZ Chapter!

Spotlight on Walk a Mile in their Genes Participants



Miles for Maya

"This event isn't just about logging miles; it's about making a difference in the lives of those affected by Prader-Willi syndrome, including my daughter, Maya. Maya's journey with Prader-Willi syndrome has been one filled with challenges and triumphs, and every step I take in this fundraiser is a testament to her resilience and strength."



Participating in this fundraiser isn't just about raising funds; it's about raising awareness and spreading hope. It's about advocating for greater understanding and support. It's about ensuring that every individual living with Prader-Willi syndrome, like Maya, has the resources and opportunities they need to grow."

- Denise Servais, Mom to Maya (living with PWS)

[Visit MILES FOR MAYA Here](#)

Raising for Ronan

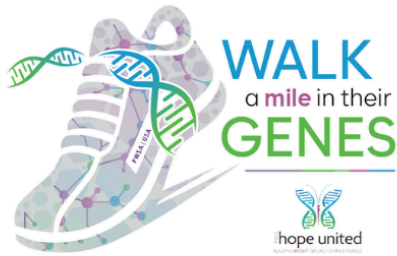


"As we work together building bright futures for PWS families, we are inspired by our loved ones with PWS, and motivated to take action to ensure all members of our PWS community have the benefit of passionate advocacy, exceptional family support, and life-changing research.

Now, more than ever, we are propelled to take action all across the country in fun and extraordinary ways. Where so much of our PWS journey is beyond our control, Hope United gives us the tools, encouragement, and opportunity - empowering us to make a difference together."

- Kat Lucero, Mom to Ronan (living with PWS)

[Visit RAISING FOR RONAN Here](#)



Help us Reach our Goal!

\$12,600

\$50,000



Fundraising Leaderboard

Michelle Torbert	\$2,795
Lindsey Lipton	\$1,700
Kelly Guillou	\$1,600
Elaine Towle	\$1,250
Tammie Penta	\$1,100
Sue Colon	\$1,000
Denise Servais	\$575
Kat Lucero	\$550
Dorothea Lantz	\$500
Maggie Andrews	\$460

It's not too late to start your Walk a Mile in their Genes fundraising campaign and raise money for PWSA | USA's advocacy efforts. Click the button below to get started!

[START YOUR PAGE HERE](#)

Spotlight on Advocacy



For Rare Disease Day 2024, PWS mom and PWSA | USA staff member Melanie McDonald wanted to take the opportunity to raise awareness right in her community of Jaffrey, New Hampshire. Melanie's children, Henry (12) and Josephine (5 w/ PWS), love their town library and see it as a great place for families to gather for educational offerings. Melanie reached out to Library Director Julie Perrin who hadn't heard of PWS and didn't know about Rare Disease Day. The library team was immediately excited and began drafting plans for events and programs in anticipation of National PWS Awareness Day (May 15, 2024), as well as looking towards Rare Disease Day 2025! The McDonald family purchased an additional copy of Dr. Destiny Pacha's book *"It Starts With Hello: Katie's Story About Prader-Willi Syndrome"* and arranged to gift it to the Jaffrey Public Library in Josephine's honor. The library staff were excited to receive it and even wore zebra stripes to welcome Josephine!

[About "It Starts With Hello: Katie's Story About Prader-Willi Syndrome"](#)

Written by Destiny Pacha, ED.D., the book follows Katie, a spirited character navigating school life while living with PWS. Through Katie's journey, readers gain insights into the challenges and triumphs of individuals with PWS, fostering empathy and understanding. *"It Starts With Hello: Katie's Story About Prader-Willi Syndrome"* underscores the importance of inclusivity and connection, reminding us all of the power of a simple greeting to initiate meaningful relationships.

If you feel inspired to purchase and donate a copy of this book to your library, school, or any other community center, click the button below.

[PURCHASE THE BOOK HERE](#)



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