

PWSA | USA Bi-Weekly Pulse: November 3, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 86

November 3, 2023

www.pwsausa.org | 941.312.0400

Give the Gift of Hope This Holiday Season!

PWSA | USA's **2023 Angel Drive** campaign kicked off yesterday, which is the perfect opportunity to support families and individuals affected by PWS! You can **Give the Gift of HOPE** to ensure we can continue taking action in the new year.

Whether it's helping families and individuals navigate the challenges associated with PWS or working with volunteer advocates to raise our voices with legislators in Washington, D.C. about issues that matter most, your year-end, tax-deductible gift ensures that PWSA | USA can continue to provide **HOPE** 24/7/365! Click the image below to learn more and to make your donation today.



[CLICK HERE](#) to Make an Impact TODAY!

By donating to the Angel Drive, you are helping families like Erin and Victoria's receive help and hope.

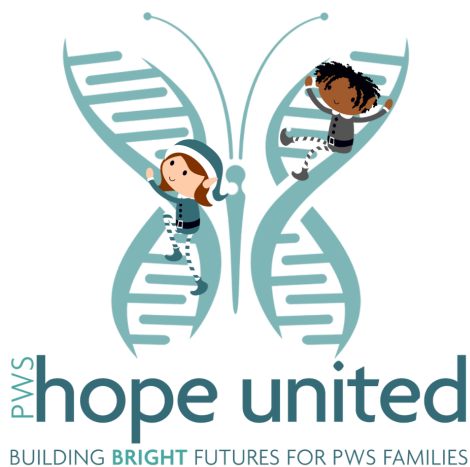
Hear their journey with PWS and what inspires Erin to be an advocate.



Become a 'Selfless Elf' and Give Hope Rather than Get Gifts

Tell your family and friends that taking action for PWS is at the very top of your holiday wish list. **[CLICK HERE](#)** to sign up as a **Selfless Elf** and start encouraging donations in lieu of gifts and in honor of your loved ones. It only takes five minutes to create your own Selfless Elf page!

If you are interested in becoming a Selfless Elf but don't know where to start, we have the perfect opportunity! PWSA | USA staff and past participants will be on-



hand to share their experiences and encourage others to host their own peer-to-peer fundraiser this holiday season. We will offer TWO webinar opportunities - **Thursday, November 9, 2023 at 12:00PM EST** and **Tuesday, November 14, 2023 at 7:00PM EST**. You only need to join one on the date and time that fits your schedule best. Register for the webinar of your choosing at the buttons below. We hope to see you there!

Thursday, November 9, 2023 at 12:00PM EST

[**REGISTER HERE**](#)

Tuesday, November 14, 2023 at 7:00PM EST

[**REGISTER HERE**](#)

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



In his newly published book, ***I Am Full - Stories for Jacob***, Dan Yashinsky reflects on the life of his son Jacob who lived with Prader-Willi syndrome. Despite the challenges Jacob faced, his extraordinary sense of humor, kindness, and generosity shone through, leaving a lasting impact on those around him.

Tragically, Jacob passed away at the age of 26, prompting Dan to compile a collection of Jacob's writings and his own recollections, preserving his spirit in a book that aims to inspire

others. Through Jacob's voice and Dan's narration, the book serves as a tribute to his life, offering a glimpse into the richness, meaning, and love that defined his journey.

Read more about Jacob's inspiring journey, including his own words from a speech he gave in 2018, and purchase a copy of *I Am Full - Stories for Jacob* at the buttons below.

[READ MORE HERE](#)

[PURCHASE A COPY OF "I AM FULL - STORIES OF JACOB"](#)

EVENTS

Thank You, Spring Family, for Hosting the Third Annual Answers for Audrey Trivia Event!



We want to share a big **THANK YOU** to the Spring family for hosting another incredible Answers for Audrey Trivia Night in St. Louis, MO! It was an amazing turnout with a large silent auction, food, fun and, of course, trivia! We also want to thank those who sponsored, attended, and donated to this 3rd annual event in honor of Audrey Spring who is living with PWS. If you were not able to attend but would like to show your support for the Springs, click [HERE](#).

If you are interested in hosting a PWS Hope United fundraiser in honor or in memory of a loved one, click the button below.

[BECOME A HOPE UNITED CHAMPION HERE](#)



ADVOCACY

Join us for the Upcoming Webinar
*Advocacy in Action - DC Debrief: What You Need to Know
and How You Can Help*

— WITH SPEAKERS —



Dorothea Lantz



Jen Garzia



Andrew Gilly



Jennifer Andrews



Elaine Towle



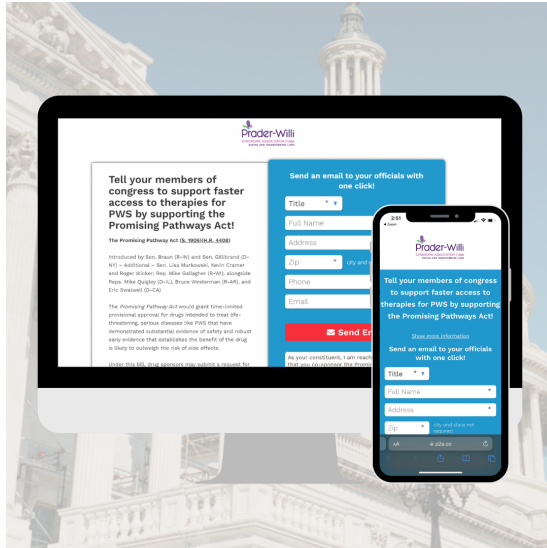
When: Thursday, November 16, 2023 at 8:00PM EST

Where: Zoom (free for all to attend)

Join PWSA | USA as we feature four of our volunteer advocates who will share how the advocacy work they are doing in Washington, D.C. will benefit our entire PWS community and how **YOU** can help. Everyone is encouraged to listen in to this virtual event - You won't want to miss how we are making sure the PWS voice is heard on Capitol Hill! Register in advance at the button below.

[REGISTER IN ADVANCE HERE](#)

Tell Your Members of Congress to Support the Promising Pathway Act!



The **Promising Pathway Act (PPA)** proposes time-limited provisional approval for drugs aiming to treat life-threatening, serious conditions such as PWS. This provisional approval would require substantial evidence of safety and strong initial indications that the benefits outweigh potential side effects. This means our loved ones living with PWS would have access to new treatments quickly!

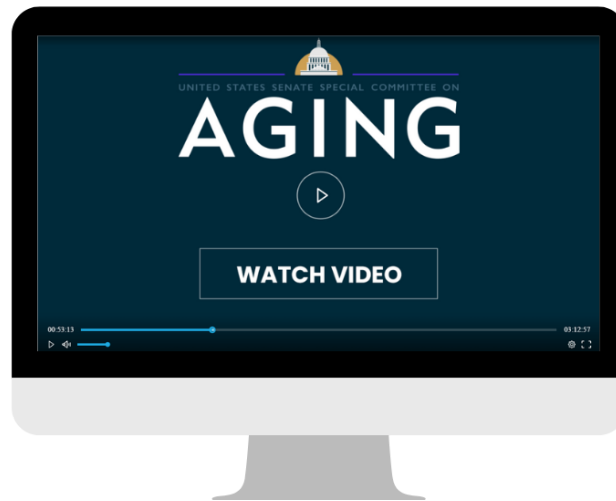
Find a pre-written digital letter you can send to your elected officials at the button below. Simply fill in your

name, address, phone, and email and click "Send Email." We encourage everyone to take a minute to do this as our collective voices make one big impact with lawmakers on Capitol Hill. Thank you!

[SEND YOUR DIGITAL LETTER HERE](#)

ICYMI: Watch the Senate Committee on Aging's Hearing on the Promising Pathway Act

Click here
to watch the
recording



Last week, the U.S. Senate Committee on Aging held a congressional hearing titled, ***Unlocking Hope: Access to Therapies for People with Rare, Progressive, and Serious Diseases***, to discuss the benefits of the Promising Pathway Act. PWSA | USA advocates were in attendance to represent the PWS community. Soleno Therapeutics CEO Anish Bhatnagar, MD, gave a testimony during the hearing to shine a light on PWS and how individuals affected by the syndrome would benefit from the Promising Pathway Act. Click the image above to watch the full hearing.

Rare Disease Company Coalition (RDCC) Shares Recap of Last Week's Capitol Hill Briefing

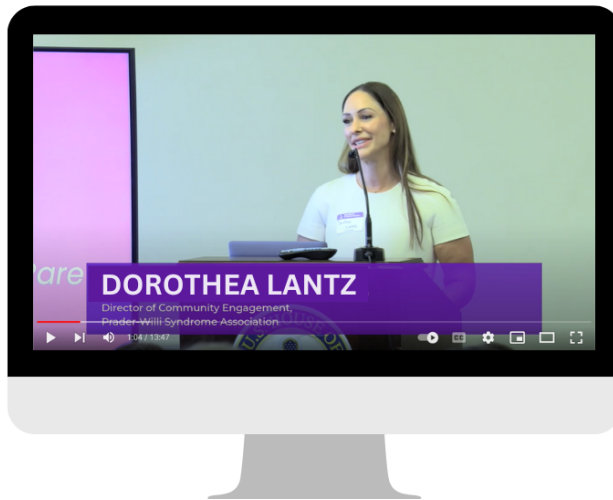
Another important event that took place in D.C. last week was a briefing held by the **Rare Disease Company Coalition**. The coalition presented a white paper on the challenges faced by rare disease companies due to policy uncertainty and highlighted the urgent need for stable policies to support rare disease research and development.

PWSA | USA's Community Engagement Director Dorothea Lantz spoke on a panel during the briefing. *"Even the smallest shift in public policy can leave our loved ones with no hope for treatment. As a rare disease community, we understand the costs and the risk of rare disease research and development."*

Read the full recap, along with the RDCC's white paper at the button below.

[READ THE FULL RECAP HERE](#)

Watch Dorothea's
RCDD Briefing
Speech by
clicking here



FAMILY SUPPORT

2023 Operation Holiday Cheer Applications
Now Being Accepted



Due to the generosity of an anonymous donor's gift, PWSA | USA is once again able to bring holiday cheer to families in need this holiday season! We will identify a select number of families to receive gift cards to be used to help ease the financial stresses of the holidays. To be considered, please fill out our Operation Holiday Cheer application at the button below. **Applications are due no later than Friday, November 24, 2023.**

[DOWNLOAD THE APPLICATION HERE](#)

Next Sibling Community Conversation: November 8th



Siblings of individuals living with PWS are invited to join PWSA | USA for our next Sibling Community Conversation on **Wednesday, November 8, 2023 at 8:00 p.m. EST.**

This discussion provides a safe space for dialogue between siblings of a person with PWS. All ages are welcome to attend! PWSA | USA team members will also be available to offer any insight and support. Register in advance at the button below.

[REGISTER IN ADVANCE HERE](#)



RESEARCH

Make Your Voice Count: Shape the Future of College Programs for Students with Intellectual Disabilities



For students with intellectual disabilities (ID), the opportunity to go to college after leaving high school is very limited. The Center for Transition and Career Innovation (CTCI) at the University of Maryland College Park wants to hear from YOU - students, families, and educators about your interest, knowledge and desire for college programs for students with ID. They will not collect any personal information from you. The hope is to take the general information they get from the survey responses and present

them to state legislators, apply for grants, and develop partnerships.

Anyone can participate - This is the chance for your voice to be heard!

Please take 5 minutes to complete the survey at the button below.

[TAKE THE SURVEY HERE](#)

PWSA | USA Announced as Harmony Biosciences' 2023 *Patients at the Heart* Grant Recipient

We are excited to share that PWSA | USA has been selected as one of Harmony Biosciences ***Patients at the Heart*** funding award recipients! This grant allows us to create a new program, ***PWS Sleep Within Reach Resources***. The program aims to educate health care professionals, caregivers of people with PWS, as well as residential and educational staff, on the most misunderstood forms of sleep disorders, including those among people with PWS. More details coming soon!

[LEARN MORE HERE](#)



This initiative underscores our commitment to fostering collaborative care, involving professionals, caregivers, and educational staff. Through project elements like 'PWS ECHO Sleep Within Reach' and 'ECHO Debrief,' alongside the development

of educational toolkits, we reaffirm our dedication to making a meaningful impact in the lives of those affected by this rare and challenging condition, as well as their loved ones.

- Stacy Ward, MS, Interim CEO



PWSA | USA ANNOUNCEMENTS

PWSA | USA is Looking for a Volunteer Treasurer

In Search of a
Volunteer Treasurer
for PWSA | USA



Looking for a way to get involved? PWSA | USA is in search of a **volunteer Treasurer**. We know that many of you want to make a difference in the lives of our PWS community and we have the perfect opportunity if you, or one of your family or friends, are a CPA.

Click the button below to find the full description and needs that come with this volunteer role. Thank you for your consideration!

[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](#)



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

PWSA | USA Bi-Weekly Pulse: November 17, 2023

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Give Twice the Good on Giving Tuesday



Are you planning on making a year-end gift? **Giving Tuesday** is quickly approaching and is the perfect opportunity to show your support and **DOUBLE** your impact!

Thanks to the generosity of a group of anonymous donors, your Giving Tuesday donation will be **MATCHED** dollar for dollar up to **\$15,000**. Make a gift any time on **November 28, 2023** and give twice the good this holiday season!

[DONATE TO THE ANGEL DRIVE HERE](#)

Thank You to PWSA | USA's Selfless Elves!



Sujeiri Colon (New Jersey)

Angela & Joseph Frazier (Texas)

**Melanie & Henry McDonald (New
Hampshire)**

Jared Payne (Florida)

Rhonda Williams (Indiana)

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than Get Gifts**

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If you are interested in becoming a Selfless Elf but don't know where to start, click the image below to hear from Development Director Melanie McDonald on how to set up your own page. If you have any additional questions, email us at hopeunited@pwsausa.org.



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

"Sienna started horse therapy at 4 years old and fell in love with it immediately. She has gotten more comfortable with it over the years to the point that this year, at 8 years old, she asked us to switch her to a more challenging program. She is now able to ride backwards, on her knees, and trot unassisted. It has been amazing for her strength and endurance. She now does 90-minute sessions with zero complaints! One of the best parts has been seeing her confidence grow."

"There is also something incredibly healing about horses that seems to center Sienna. She has even chosen to delay her meal times just to spend more time grooming the horses! I'm continually amazed by my little cowgirl's determination."



- Allyson Jeans, Mom to Sienna (8)
living with PWS

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS

Join Clint & Karla Hurdle at the 10th Annual Hot Stove
Dinner!

Sip, savor, and support PWSA | USA while enjoying the **10th Annual Clint Hurdle Hot Stove Dinner**, March 23, 2024, at an exciting NEW location, the [Bradenton Country Club](#) in Bradenton, Florida. This event can be attended in-person or virtually! More details and registration will be available soon.



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Clint Hurdle
HOT STOVE DINNER

Bradenton Country Club
Bradenton, FL & Virtual
March 23, 2024
Island Treasure Reception 5:00 p.m. until 6:00 p.m.
6:00 p.m. General Admission

Presented By: 

Save the Date!

MARCH 23, 2024

Bradenton Country Club

WITH SPECIAL HOSTS
CLINT & KARLA HURDLE





ADVOCACY

Be on the Lookout for an Important Advocacy Email in Your Inbox Next Week!







On Friday, November 24, 2023, PWSA | USA will share several important Advocacy updates in our Special Edition Pulse newsletter, including:

- Two exciting opportunities in December where we will widely spread awareness for PWS, including participation at the **Alexion, AstraZeneca Rare Disease RareConversations** and the **RDLA Community Congress Annual Meeting**
- The recording of yesterday's **D.C. Debrief webinar**, which featured several of our volunteer advocates who shared how they are making a difference on Capitol Hill and how YOU can help
- An update on the **PWS State Qualifier Campaign**
- More details about our **2024 D.C. Fly-In**
- How you can **support** PWSA | USA's Advocacy initiatives in 2024

PWSA | USA's advocacy efforts have made major strides over the past couple years, largely in part due to our incredible volunteer advocates. We are sincerely grateful for everything they have done and continue to do for the PWS community!

Tell Your Members of Congress to Support the Promising Pathway Act!



The **Promising Pathway Act (PPA)** proposes time-limited provisional approval for drugs aiming to treat life-threatening, serious conditions such as PWS. This provisional approval would require substantial evidence of safety and strong initial indications that the benefits outweigh potential side effects. This means our loved ones living with PWS would have access to new treatments quickly!

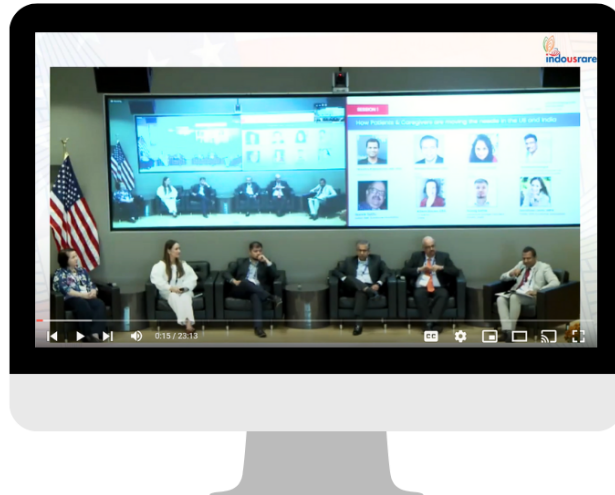
Find a pre-written digital letter you can send to your elected officials at the button below. Simply fill in your

name, address, phone, and email and click "Send Email." We encourage everyone to take a minute to do this as our collective voices make one big impact with lawmakers on Capitol Hill. Thank you!

SEND YOUR DIGITAL LETTER HERE

WATCH: Dorothea Lantz Spoke at the 2023 Indo US Bridging Rare Summit to Share Information About PWS

Watch Dorothea speak at the Indo US Bridging Rare Summit by clicking here



Last month, Community Engagement Director Dorothea Lantz had the opportunity to speak at the Indo US Bridging Rare Summit in Virginia, alongside a panel of fellow rare disease organization representatives. She shared information about PWS, detailed our community's needs, and how PWSA | USA is working to help individuals and families. Click the image above to watch the panel discussion, titled "How Patients and Caregivers are moving the needle in US and India."



FAMILY SUPPORT

Only One Week Left to Submit an Operation Holiday Cheer Application

Due to the generosity of an anonymous donor's gift, PWSA | USA is once again able to bring holiday cheer to families in need this holiday season! We will identify a select number of families to receive gift cards to be used to help ease the financial stresses of the holidays. To be considered, please fill out our Operation Holiday Cheer application at the button below. **Applications are due no later than Friday, November 24, 2023.**



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Celebrate Thanksgiving Safely!



Holidays are a time for gathering, connecting, and celebrating – but are also typically centered on food, which often places *enormous* stressors on families of a child or adult with PWS. We hope the tips found at the button below will help make your Thanksgiving celebration safer, less stressful, and more enjoyable for every member of your family.

Happy Thanksgiving from all us of at PWSA | USA!

[LEARN MORE HERE](#)

Food Security on a Budget



Whether we are prepared or not, PWS eventually demands that we secure the food in our homes. When we implement food security, we help keep our loved one safe. Though food security will ultimately help create relative safety and peace in our lives, planning for it may be a daunting and overwhelming task. But it doesn't have to be.

For some families, this job is outsourced to a professional kitchen renovator. For others, homeowners and renters alike, budget and space are a challenge. If this is you, we

have compiled some ideas to hopefully ease the burden of planning and help you attain food security. Click the button below to learn more.

[LEARN MORE HERE](#)



RESEARCH

The Chicago School Shares Promising Results from PWS Behavior Study

Exciting news! We are thrilled to share a glimpse of groundbreaking results from The Chicago School's **PWS Smart-Start Program**, which was made possible through a grant from PWSA | USA. Tailored for caregivers of children aged 3 to 14 with Prader-Willi syndrome, this innovative behavioral training initiative has demonstrated significant positive impacts.

Over a 10-week period, 34 caregivers participated in online live video-coaching sessions, leading to remarkable transformations. Preliminary findings reveal substantial improvements in child behavior, a decrease in parental stress and burnout, and enhancements in parenting practices, parent-child relationships, and overall family quality of life.

The promising outcomes suggest that the PWS Smart-Start program not only supports children with PWS through behavioral challenges but also acts as a beacon for reducing caregiver stress and elevating various facets of family life. Read the full results at the button below.



[READ MORE HERE](#)

Make Your Voice Count: Shape the Future of College Programs for Students with Intellectual Disabilities



For students with intellectual disabilities (ID), the opportunity to go to college after leaving high school is very limited. The Center for Transition and Career Innovation (CTCI) at the University of Maryland College Park wants to hear from YOU - students, families, and educators about your interest, knowledge and desire for college programs for students with ID. They will not collect any personal information from you. The hope is to take the general information they get from the survey responses and present them to state legislators, apply for

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[Donate](#)



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PWSA | USA Special Edition Pulse: November 24, 2023

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[Donate](#)



PWSA | USA Volunteer Advocates Give Insight Into Their Advocacy Efforts

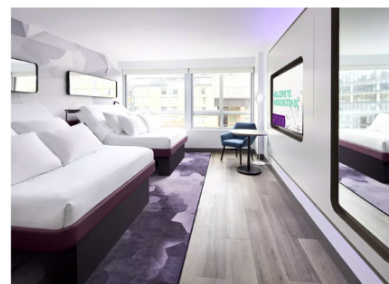
Last week, PWSA | USA hosted the webinar, ***Advocacy in Action - DC Debrief: What You Need to Know and How You Can Help***. Several of our volunteer advocates shared how the advocacy work they are doing in Washington, D.C. will benefit our entire PWS community and how YOU can help.

In case you missed this informative virtual event, the recording is now available for our community to view. Click the image below to be directed to the video link.


[CLICK HERE](#)
TO WATCH THE
RECORDING



2024 D.C. Fly-In Hotel Announcement and Application Release Date



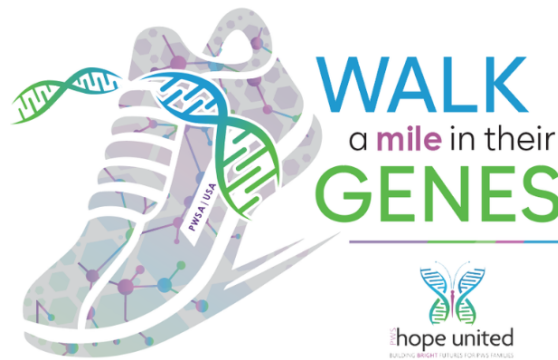
We are excited to share PWSA | USA's 2nd D.C. Fly-In will take place **May 13-15, 2024**, and the event hotel will be **YOTEL Washington DC | Capitol Hill Hotel** (415 New Jersey Ave NW, Washington, DC 20001)! During the Fly-In, we will learn about Policy affecting the PWS community, hear from policy makers, and continue our advocacy efforts by coming together on May 15th for a "Day on the Hill" to celebrate National PWS Awareness Day!

The D.C. Fly-In application will be available on **Tuesday, January 9, 2024**. Be on the lookout for an email from PWSA | USA when it is ready. This time around, we look forward to welcoming 100 participants to join together on Capitol Hill.

Those selected to attend the Fly-In will be determined on a first-come-first-served basis.

[CLICK HERE TO EXPLORE THE YOTEL WASHINGTON DC](#)

Here's How YOU Can Support PWSA | USA's Advocacy Initiatives in 2024



We can continue to make our voices and our stories heard through advocacy and community outreach. On January 16, 2024, YOU can sign up for PWSA | USA's 2nd annual **"Walk a Mile in their Genes"** advocacy campaign. Participants will not only raise awareness about PWS, but they will raise much needed funds to enable PWSA | USA to continue to provide the services our community needs.

This virtual/in-person fitness challenge is open to all ages and fitness levels to promote health and wellness, while supporting the Prader-Willi syndrome community.

To learn more about this opportunity and how you can participate, we will host two webinars in January. Sign up to attend one of these webinars at the buttons below. Thank you for taking action!

Tuesday, January 9, 2024 | 7:00 PM EST

[REGISTER HERE](#)

Thursday, January 11, 2024 | 12:00 PM EST

[REGISTER HERE](#)

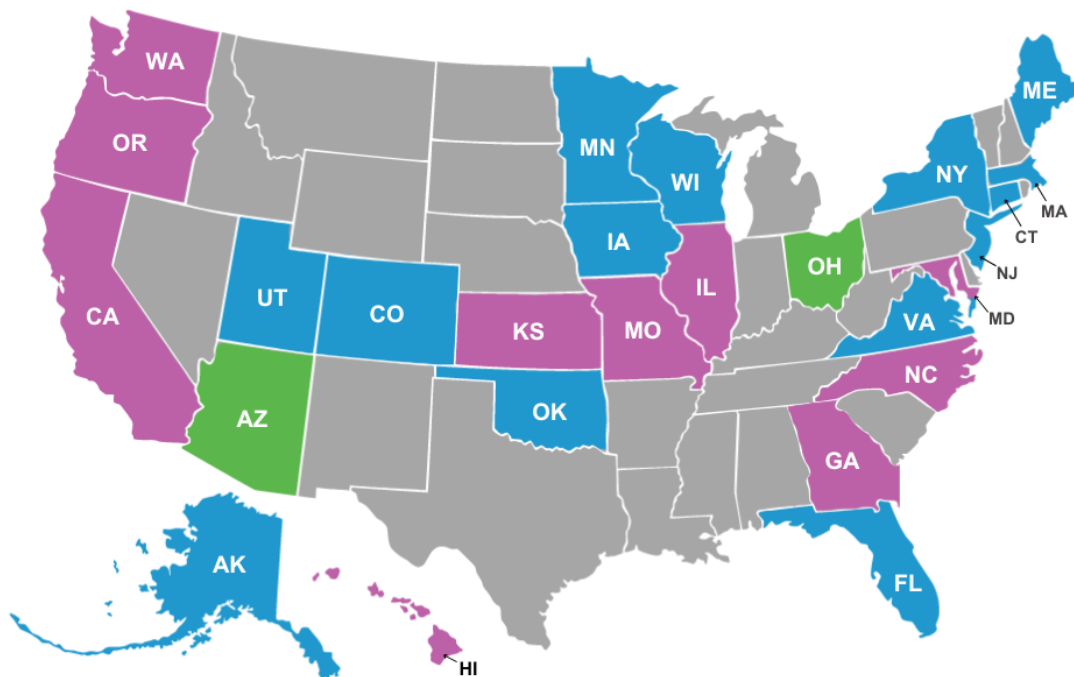
Arizona Residents - We Need Your Help Getting PWS Added as a State Qualifier

Important request for Arizona residents: Some individuals with PWS are being denied access to the support and services they need. PWSA | USA is working with our Arizona Chapter to better understand the obstacles you face when seeking approval for state Medicaid ALTCS/AHCCCS and DDD services. Please take a few of minutes and participate in the survey at the button below to help us gather the data we need. Everyone's experiences are important in this effort!

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

PWS State Qualifier Campaign Update: We are excited to share that community members in Kansas are now in the beginning stages of having PWS added to their state's list of developmental disabilities. Currently, there are advocates in Ohio and Arizona working to make PWS a qualifying condition, and additional advocates in Georgia, Maryland, North Carolina, Oregon, California, Hawaii, Illinois, Washington and Missouri who are starting the process!

**Here's a look at the current PWS State
Qualifier Campaign map:**



■ States that recognize PWS
 ■ States in the process of recognizing PWS
 ■ States beginning to organize the recognition of PWS

Interested in organizing the recognition of PWS in your state? [Click here](#) to find inspiration from one PWS mom leading the charge in Ohio, and reach out to PWSA | USA at advocacy@pwsausa.org to get started.

Attention Individuals Living with PWS and Caregivers: Participate in TREND's PWS Study

TREND Community is conducting an interview research study on Prader-Willi syndrome and is seeking participation from individuals living with PWS and their caregivers. The study aims to identify symptoms, challenges, and impacts of living with PWS, with the goal of understanding current needs for future clinical studies.

TREND is looking to for the following participants to complete their study:

- **>6 months old**, male, non-white
- **3-8 years old** male, never been on GH, imprinting defect
- **9-12 years old**, 2 males, never been on GH and imprinting defect



- **13-17 years old**, 2 females, 1 deletion, 1 imprinting, never been on GH
- **18+ years old**, 1 female, 2 male, 2 deletion, 1 imprinting, never been on GH, <1 years old

Participants must agree to a 1-hour audio-recorded interview, have access to a phone/computer, and may participate in English or Spanish with a translator if needed. Those interested can email research@trend.community to

participate and contribute to advancing PWS research. Click the button below to find more details.

[CLICK HERE TO LEARN MORE](#)

PWSA | USA Community Engagement Director to Represent the PWS Voice at Alexion, AstraZeneca Rare Disease RareConversations Event



On December 5th from 8:30AM - 12:15PM EST, PWSA | USA's Director of Community Engagement Dorothea Lantz will join Annie Kennedy of EveryLife Foundation, Jason Resendez of the National Alliance for Caregiving, and Heidi Ross of NORD in representing the rare disease community voice at **Alexion, AstraZeneca Rare Disease RareConversations**.

This half-day policy forum will discuss how to spur more rapid, patient-centered development and access to innovative treatments in a sustainable rare disease ecosystem.

Additional panelists and presenters will include patient advocates, leaders of other committed stakeholder groups, and regulatory and legislative staff, as well as a leading member of Congress.

If you will be in the D.C. metro area and are interested in attending, please click the text below. There will not be a virtual option for this event, but a recording of

PWSA | USA's presentation will be available following the event.



**Click here to download the
Alexion, AstraZeneca Rare Disease
RareConversations Flyer**

PWSA | USA to Participate in RDLA's Community Congress Annual Meeting



As a member of RDLA's Community Congress with [The EveryLife Foundation](#), PWSA | USA will join fellow Community Congress members on December 14th to take part in a comprehensive 2023 year-in-review and to establish collective policy priorities for 2024. This in-person event will take place at the National Press Club in Washington, D.C. and includes presentations, panel discussions, table brainstorming sessions and group breakout sessions on topics including:

- 2023 highlights
- Policy updates and working group activity
- Political outlook and implications for rare disease policy
- Opportunities to improve consistency in regulatory decision making
- Optimizing new rare disease data for diagnostic
- Regulatory and access policy solutions
- Data deep dives: Economic impact, pipeline analysis model expansion, and more
- 2024 priorities breakout discussions

Click the button below to find more details about this important event.

[CLICK HERE TO LEARN MORE](#)

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Prader-Willi
SYNDROME ASSOCIATION | USA
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