

Enhancing the Quality of Life and Empowering Those Affected by PWS



**Vol. 58**

September 2, 2022

[www.pwsausa.org](http://www.pwsausa.org) | 941.312.0400



### 2022 Sleep Summit Speakers



Registration is now available for PWSA | USA's **FREE** Virtual Sleep Summit! The Sleep Summit will be held Tuesday, September 27, 2022 from 12:30 - 8:00 p.m. EST, and will include several webinar presentations from top specialists who are experts in sleep issues. Our speakers include:

**Amee Revana, DO FAASM - Welcome to Sleep and Sleep Disorders in Children with PWS**

**Deepan Singh, MD - Sleep**

**Abnormalities Associated with Behavioral Problems in Prader-Willi Syndrome**

**Althea Shelton Robinson, MD & Olivia Veatch, PhD - Genetics of Sleep and Sleep Disorders in PWS**

**Jessica Duis, MD - Presentations and Management of Sleep Disorders in Prader-Willi Syndrome**

**Aliana Weavers - Assessing the Efficacy of an Applied Behavior Analytic (ABA) Treatment Protocol to Treat Sleep Concerns in Children with PWS**

This summit is for both parents and healthcare providers. To learn more and to register, please click on the button below. We hope to see you there!

[LEARN MORE AND REGISTER HERE](#)



**GIVING HOPE HAS NEVER BEEN EASIER**



PWS parent Elaine Towle shares how easy it was to start her own Hope United birthday fundraiser in support of PWSA | USA. If you are interested in becoming a Hope United Champion, no idea or goal is too great or too small and we are here to help every step of the way.

Get started TODAY by clicking the button below!

**SAVE THE DATE**

[Upcoming Events >>>](#)



**PWSA | USA Washington, D.C. Fly-In**

When: September 19-21, 2022

[Learn More Here >>](#)



**Virtual Sleep Summit**

When: September 27, 2022

[Learn More Here >>](#)

**BECOME A HOPE  
UNITED CHAMPION!**

## OTHER UPCOMING EVENTS OF INTEREST



### **PWSA of Ohio Family Activity Day**



Hosted by Prader-Willi Syndrome  
Association of Ohio

**When: September 24, 2022**

*Ashley, OH*

[LEARN MORE HERE](#)

### **COUNTRY FOR A CURE**

Featuring

## **THE FRONTMEN**

PRADER-WILLI  
SYNDROME  
ASSOCIATION

Hosted by Prader-Willi Syndrome  
Association of Colorado

**When: October 1, 2022**

*Greenwood Village, CO*

[LEARN MORE HERE](#)



## ADVOCACY

### D.C. Fly-In Office Hours

We are less than three weeks away from our first ever D.C. Fly-In! We have more than 51 advocates joining from 19 states, and 74 meetings with members of congress have been requested.

PWSA | USA and our advocates are energized and ready to promote our mission! For those of you who are attending, please don't forget that our Community Engagement Specialist Dorothea Lantz is hosting open office hours each week prior to



the fly-in to work with advocates, answer questions, work through your story or just help settle down jitters.

Office hours are Monday's from 12:00 - 2:00 p.m. EST and Friday's from 3:00 - 5:00 p.m. EST. You can save the link at the button below and drop in during Dorothea's office hours to get help with anything you need in preparation for our trip.

[OFFICE HOURS LINK](#)



## FAMILY SUPPORT

### Residential Placement Opportunity for Adult Living with PWS



PWSA | USA has received information that the Evergreen Meadow Adult Foster Care Home in Ada, Michigan is anticipating a rare opening in the very near future. Find more details and how to contact Evergreen Meadow at the button below.

[READ MORE HERE](#)

September 8, 2022 is World Physical Therapy Day

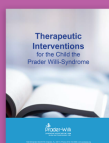




Did you know that in 1996 the World Confederation for Physical Therapy established World Physical Therapy (PT) Day as September 8th?

Physical therapists are an integral part of the multidisciplinary team that supports individuals with Prader-Willi syndrome (PWS). PT treatments improve gross and fine motor skills, balance, coordination, strength, and endurance (Janice Agarwal, 2011).

Learn more about physical therapy and PWS by downloading our Therapeutic Interventions booklet at the button below.



**Download PWSA | USA's  
Therapeutic Interventions  
Booklet**

## Thank You Direct Support Professionals!



National Direct Support Professionals Week is September 11 - 17, 2022. This is a week to recognize and show appreciation for the work of providers who are supporting individuals with developmental and intellectual disabilities to maximize their independence.

Learn more by clicking the button below.

[READ MORE HERE](#)

## September Community Conversation for Siblings



COMMUNITY  
CONVERSATIONS

Prader-Willi Syndrome Association | USA



## Community Conversation for Siblings

TUESDAY,  
SEPTEMBER 22

8:00 P.M. EST

[REGISTER IN ADVANCE HERE](#)

### Thank You for Supporting PWSA | USA's 2022 Family Support Campaign!



*We are sincerely appreciative to our amazing PWS community for your commitment and support of PWSA | USA's Family Support services. The funds raised during our 2022 Family Support Campaign, June 1 - July 31, 2022, are critical to ensuring **HELP + HOPE** is available for our families on a day-to-day basis.*

*We have such a fantastic team that is extremely dedicated to our mission of enhancing the quality of life and empowering those affected by Prader-Willi*

*syndrome.*

*If you are in need of support, please contact us at [info@pwsausa.org](mailto:info@pwsausa.org) or (941) 312-0400.*

*Paige Rivard*

Paige Rivard, MBA | CEO  
Mom to Jake (12)



## RESEARCH



Is your loved one living with PWS affected by daytime sleepiness? Harmony Biosciences is now recruiting caregivers and their care recipients to take part in a 60-minute interview, with a goal to help inform how medicines for people with PWS are studied in the future. Reimbursement for your participation is available.

Learn more and find out how to participate by clicking the button below.

[LEARN MORE HERE](#)

## PWSA | USA ANNOUNCEMENTS

**Support the 2023 National Convention by Donating Items to the PWS Kids Camp**

With [PWSA | USA's 2023 National Convention](#) just one year away, we are starting to collect items for our children and adults camp! YOU can help secure the items we need to make this a successful event for our loved ones living with PWS. Find the list at the button below. Thank you for your help!



**Support the 2023  
Convention by purchasing  
items for the PWS Camp  
for Children and Adults!**

**SHOP OUR AMAZON WISHLIST**

**Make a Lasting Impact with Planned Giving!**



In honor of last month being recognized as National Make-A-Will Month, we want to remind our community that you can make a lasting impact by including PWSA | USA in your planned giving. Click the button below to learn more about this process and how one of our families is putting this into action.

[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](#)

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Enhancing the Quality of Life and Empowering Those Affected by PWS



**Vol. 59**

September 16, 2022

[www.pwsausa.org](http://www.pwsausa.org) | 941.312.0400



PWSA | USA's first-ever Virtual Sleep Summit will be held Tuesday, September 27, 2022 from **11:30 a.m. EST - 8:00 p.m. EST. More speakers have been added to the Sleep Summit agenda to inform our community!** The event will now include six webinar presentations from top specialists who are experts in sleep issues. The Summit is for both parents and healthcare providers.

During this **FREE** virtual event, you will learn about the genetics of sleep disorders in PWS, how to manage sleep disorders for those affected by PWS, and so much more.

[LEARN MORE AND REGISTER HERE](#)

*Our Sleep Summit speakers include:*





**Maria Picone, CEO/**  
Co-Founder, TREND  
Community



**Ameer Revana, DO**  
FAASM, Associate  
Professor of Pediatrics,  
Texas Children's  
Hospital



**Deepan Singh, MD,**  
Vice-Chair of  
Ambulatory Psychiatry  
Services at Maimonides  
Medical Center



**Althea Shelton  
Robinson, MD,**  
Associate Professor,  
Neurology, Vanderbilt  
University Medical Center



**Olivia J. Veatch, Ph.D.,**  
Psychiatry and  
Behavioral Sciences,  
The University of Kansas  
Medical Center



**Jessica Duis, MD,**  
Associate Professor of  
Pediatrics and Genetics,  
Children's Hospital  
Colorado, University of  
Colorado



**Aliana Weavers,**  
Master's Student, The  
Chicago School of  
Professional Psychology



**PWSA | USA's 37th National Convention will take place on June 21 – June 24, 2023, in Orlando, Florida at the Hilton Orlando Buena Vista Palace!**

Parents, grandparents, siblings, and individuals with Prader-Willi syndrome (PWS) will come together to experience this transformational conference of **HOPE**.

## SAVE THE DATE

*Upcoming Events >>>*



**PWSA | USA Washington,  
D.C. Fly-In**

When: September 19-21,  
2022

[Learn More Here >>](#)





Get excited because we are putting a fun twist on our 2023 National Convention Gala event! Attendees are invited to join us for the **Hope United Gala**, which will take place the evening of Friday, June 23, 2023. Bring your best singing voice because our special entertainment will be performed by "Fun Pianos," with their amazing **Dueling Pianos for Prader-Willi syndrome**. Heavy hors d'oeuvres and drinks will be served, and attendees will have the chance to bid on amazing items in our silent and live auctions.

Learn more about what the 37th National Convention has in store at the button below.

[LEARN MORE HERE](#)

### Community Conversation for Siblings

When: September 22, 2022

[Learn More Here >>](#)



### Virtual Sleep Summit

When: September 27, 2022

[Learn More Here >>](#)

## OTHER UPCOMING EVENTS OF INTEREST



### PWSA of Ohio Family Activity Day

Hosted by Prader-Willi Syndrome  
Association of Ohio

**When: September 24, 2022**  
Ashley, OH

[LEARN MORE HERE](#)



Hosted by Prader-Willi Syndrome  
Association of Colorado

**When: October 1, 2022**  
Greenwood Village, CO

[LEARN MORE HERE](#)



We are just a few days away from our first-ever D.C. Fly-In! We have more than 51 advocates joining from 21 states (see the map below), and 74 meetings with members of congress have been requested.

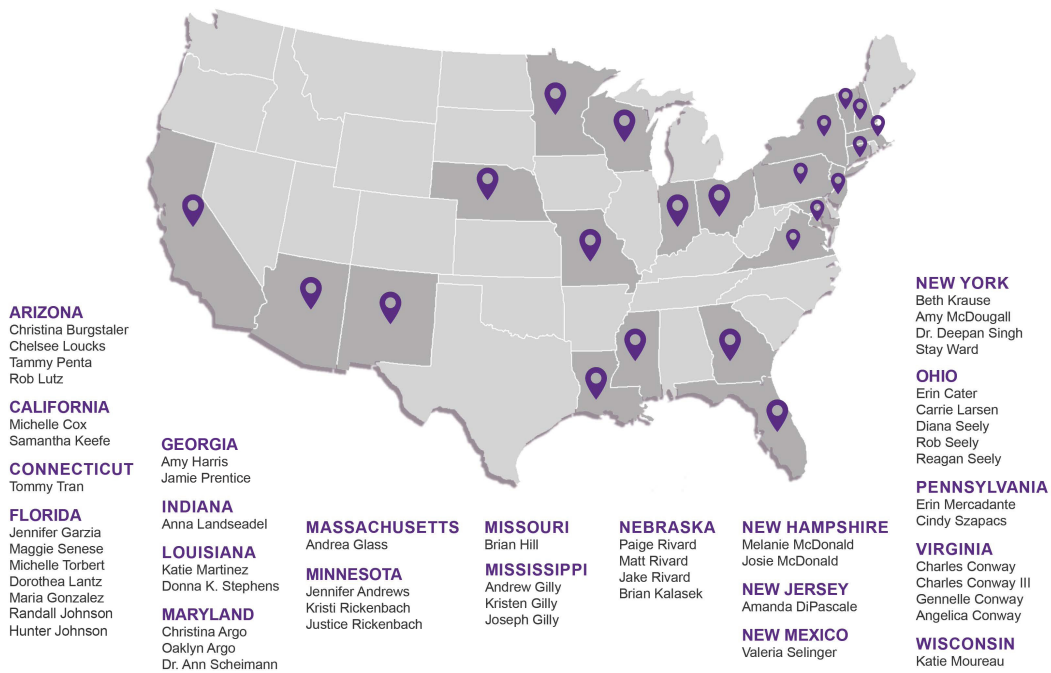
PWSA | USA and our advocates are energized and ready to promote our mission!

We encourage our community to check out the D.C Fly-In event agenda by clicking the button below. Also, make sure to read through next week's Special Edition Pulse, which will be sent Friday, September 23rd, for a recap of our time in D.C.

We look forward to seeing everyone who is flying in on Monday!


[VIEW THE AGENDA HERE](#)


## D.C. Fly-In Participant Locations



## FAMILY SUPPORT

### Residential Spotlight Series





**PWSA | USA's  
Residential  
Spotlight Series**

**Camelot Society**  
Inspiring Hope, Fostering Growth

Get to know Camelot Society, a PWS-specific group home, in PWSA | USA's fourth installment of our Residential Spotlight Series, contributed by Alterman Family Support Counselor Kim Tula, MS, CSW.

[READ MORE HERE](#)

## Thank You Direct Support Professionals!



This week, September 11 - 17, 2022, is recognized as **National Direct Support Professionals Week**. This is a week to recognize and show appreciation for the work of providers who are supporting individuals with developmental and intellectual disabilities to maximize their independence.

Learn more by clicking the button below.

[READ MORE HERE](#)

## September Community Conversation for Siblings



**COMMUNITY  
CONVERSATIONS**  
Prader-Willi Syndrome Association | USA



**TUESDAY,  
SEPTEMBER 22**  

---

**8:00 P.M. EST**

*Community  
Conversation for  
Siblings*

Do you have a sibling with PWS? Are you 13 years or older? If you answered yes to both of these questions, we invite you to join us on Thursday, September 22nd at 8:00 p.m. EST for our first-ever Sibling Community Conversation!

This Community Conversation will be an opportunity to meet other siblings, discuss the positive and challenging parts of having a sibling with PWS, and learn from one another. PWSA | USA wants to create a safe place for siblings to

share openly and honestly, and to ensure that, we will not be permitting parents to attend this community conversation. We appreciate your understanding!

[REGISTER IN ADVANCE HERE](#)



## RESEARCH

### Share your Experience about Quality of Life and Mood in PWS

DO YOU HAVE **5** MINUTES TODAY?



Complete your  
**QUALITY OF LIFE & MOOD SURVEYS**  
in the Global PWS Registry

Measuring physical and mental wellness can provide a meaningful way to identify areas of unmet medical need and understand the impact of treatments. Please complete the Quality of Life (PROMIS) and the Mood (Glasgow) surveys so we can establish a baseline for comparison to future studies.



[www.pwsregistry.org](http://www.pwsregistry.org)

Quality of life and mood are important aspects of living with PWS that need to be better understood. To address this, two new surveys have been launched in the Global PWS Registry. We are asking you to take 5 minutes of your time to complete the 'PROMIS' and the 'Glasgow' surveys which will ask questions about your loved one's physical and mental wellness and overall mood. These are important for our community because the data will provide a basis for assessing the impact of new treatments for PWS.

You can contribute to this research easily from the comfort of your home. Simply login to your account in the Global PWS Registry [www.pwsregistry.org](http://www.pwsregistry.org) and click the 'Take Surveys' button to begin. These surveys can be found under the 'Initial Surveys' tab.

[VISIT THE GLOBAL PWS REGISTRY WEBSITE HERE](#)

## PWSA | USA ANNOUNCEMENTS





**Save the Date!**

**CLINT HURDLE  
HOT STOVE DINNER**

**MARCH 25, 2023**  
\$250 per person

*More information coming soon!*

## PWSA | USA'S SPOTLIGHT ON HOPE



Lara Pullen and her son Kian (18), who is living with PWS, recently shared their unique story with PWSA | USA's Family Support Director Stacy Ward, MS.

Over the summer, Kian moved away from his family in Chicago to attend college in Minnesota, where he is now living independently. In this audio story, Lara and Kian share the

struggles and triumphs of this decision and how important this learning experience has been for both of them.

[SHARE YOUR SPOTLIGHT ON HOPE STORY HERE](#)



## PWSA | USA Welcomes Two New Members to our Board of Directors



**Lisa Lamb**  
Gilbert, AZ



**Kathryn Lucero**  
Colorado Springs, CO

PWSA | USA recently welcomed two new Board of Director members, Kathryn Lucero and Lisa Lamb. Get to know Kathryn and Lisa by visiting our Board of Directors webpage, which can be found by clicking the button below.

We also want to thank our two outgoing Board members, Rob Lutz and Jim Kane, for their many years of commitment and dedication to PWSA | USA and the PWS community. They will both remain involved with our mission in different capacities.



**Jim Kane**  
Baltimore, MD



**Rob Lutz**  
Phoenix, AZ

## Thank You to our Outgoing Board of Director Members

[LEARN MORE HERE](#)

## Staff Spotlight

Help us give a big congratulations to PWSA | USA's Director of Marketing & Communications Carrie Larsen (Ilijevich), who married her now husband, Steve, over Labor Day weekend!



We are so excited for this next journey in her life. Best wishes to the happy couple!

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!

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

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## Special Edition Pulse - September 23, 2022

[www.pwsausa.org](http://www.pwsausa.org) | 941.312.0400

[Donate](#)



### THE D.C. FLY-IN

This week, PWSA | USA took our advocacy efforts to new heights! ✈️

On Monday, September 19th, 51 of our advocates touched down in Washington D.C. for PWSA | USA's first-ever D.C. Fly-In! We hosted a welcome reception Monday evening for our attendees, which offered an opportunity to get to know each other and connect about Tuesday's meetings on Capitol Hill.

Everyone woke up bright and early Tuesday morning to catch a bus to the congressional offices. Our teams divided and conquered more than 70 meetings with elected officials from around the country. During each meeting, our advocates touched on three key items:

\*Asking for a resolution declaring May 15th as PWS Awareness Day



\*Asking congressional members to co-sponsor the Orphan Drug COVID–19 Mitigation Act (HR 8641)

\*Adding Prader-Willi syndrome as a recognized topic area for DOD research under the Congressionally Designated Medical Research Program's Peer Reviewed Medical Research Program (PRMRP)

We ended the day with a participant dinner and reflected as a group on what the event meant to everyone. You can learn more about this incredible event and hear from our advocates in attendance about their experience by clicking on the image below.



[\*\*CLICK HERE TO VIEW OUR LIST  
OF D.C. FLY-IN CONGRESSIONAL  
MEETINGS\*\*](#)

ORPHAN DRUG RESEARCH



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## PWSA | USA Offered Unique Opportunity to Meet with Members of the FDA and CDER

During the D.C. Fly-In, PWSA | USA had the honor of an in-person meeting with several members of the Food and Drug Administration's (FDA) Center for Drug Evaluation and Research (CDER).

We were joined by Dr. Patrizia Cavazzoni (Director of CDER), Theresa Mullin (Associate Director for Strategic Initiatives at CDER) and Robyn Bent (Director of the Patient-Focused Drug Development (PFDD) Program). During the meeting, we were able to discuss the rare disease drug approval process, bringing the "voice of PWS" to the table, and opportunities where our community could add value to the process and collaborate with the FDA.

We will share more details from this meeting in the next few weeks.







## THANK YOU SPONSORS!

The **2022 D.C. Fly-In** would not have been possible without the generous support and funding from:



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