Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 56

August 5, 2022

www.pwsausa.org | 941.312.0400



We are excited to share that **PWSA | USA's 37th National Convention** will take place 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**.

Registration for the 37th National Convention will be available in the coming months. Learn more by clicking the button below.

LEARN MORE HERE



Are you interested in presenting at PWSA | USA's 37th Family Conference?

Now through September 1, 2022, you may submit your topic and contact information to info@pwsausa.org to be considered. All selections will be finalized and speakers notified by October 1, 2022.

GIVING HOPE HAS NEVER BEEN EASIER

A big congratulations and THANK YOU to Holly and Greg for completing their Olympic Triathlon (1500m swim / 26.4 mile bike ride / 6.2 mile run), in Boulder, Colorado in honor of their daughter Annabelle (1) who is living with PWS! 💜

You can support this amazing family through their Hope United fundraiser **Tri-Harder for Belle.**

Consider becoming a Hope United Champion TODAY by clicking the button below.

BECOME A HOPE UNITED CHAMPION!

SAVE THE DATE

Upcoming Events >>>



Advocacy in Action: How to Craft Your Story

When: August 10, 2022

Learn More Here >>

Community Conversation for Siblings

When: August 16, 2022 | 8:00 p.m. EST

Learn More Here >>







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 >>

OTHER UPCOMING EVENTS OF INTEREST

Rare Across America 2022

RARE ACROSS AMERICA
EVERY VOICE, IN EVERY DISTRICT, MATTERS

When: August 8th to August 19th
Virtual and In-Person Meetings

LEARN MORE HERE



Hosted by Prader-Willi Syndrome Association of Colorado

When: October 1, 2022
Greenwood Village, CO

LEARN MORE HERE

ADVOCACY

Join us for our August Advocacy in Action Webinar to Learn How to Craft Your Story!



Join PWSA | USA for our next Advocacy in Action webinar, Wednesday, August 10th at 8:00 p.m. EST, where we will welcome Jim Sliney with Patients Rising to help our community craft their story.

This presentation will give insight into writing your own op-ed piece and the best way to share your story with media outlets, elected officials, and others outside of our rare disease community.

Register in advance by clicking the button below.

REGISTER HERE

FAMILY SUPPORT

Thank You for Making a Difference!

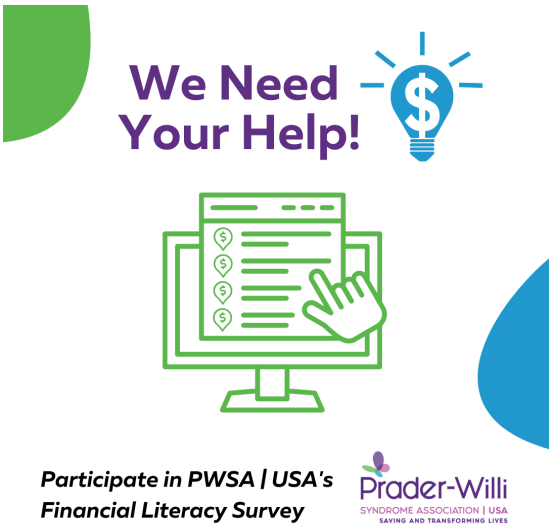


We want to share a big ***thank you*** to our PWS community for supporting PWSA

| USA's Family Support services during our 2022 Family Support Campaign. Your generous gifts mean the world to us and will make an impact on many families and individuals affected by PWS.

We are always here to offer **HELP + HOPE!** If you have any questions or are in need of assistance, contact us at info@pwsausa.org or (941) 312-0400.

Participate in PWSA | USA's Financial Literacy Survey



Most PWS caregivers have not navigated through the state or federal benefits eligibility and application process prior to becoming a parent/guardian to an individual with PWS. Since PWS presents as a spectrum diagnosis with symptoms that continue to unfold well into adulthood, there is not consistency in presentation or presumption of eligibility for services or financial benefits.

PWSA | USA is looking to gather information from you, our PWS community, through this survey in an effort to grow the list of responsive tools and resources aimed at strengthening the financial well-being and literacy of our PWS community. Share your feedback by clicking the button below.

Thank you!

TAKE SURVEY HERE

SAVE the DATE

September 27, 2022

SLEEPSUMMIT

Prader-Willi Syndrome Association | USA

Supported in part by a grant from

HARMONY BIOSCIENCES

Click here to learn more >>

RESEARCH

RADIUS®



Radius Health Releases Helpful Resources for SCOUT-015 Clinical Trial

LEARN MORE HERE



PWSA | USA is excited to share a clinical trial opportunity for our community with **Aardvark Therapeutics**.

Learn more about their drug Oral ARD-101 and how you can participate by clicking the button below.

LEARN MORE HERE

Participate in a PWS Specific Sleep Study



The Chicago School of Professional Psychology is conducting a sleep study for individuals affected by PWS, who are between three and seven years old.

If you are interested in learning more about the qualifications and how to participate, click on the button below.

TAKE SURVEY HERE

PWSA | USA ANNOUNCEMENTS

As part of our transition to a virtual office, PWSA | USA has a new address! If you plan to send us any mail going forward, please use our new mailing address:



1032 E Brandon Blvd #4744
Brandon, FL 33511

If you have any questions, you can contact us at info@pwsausa.org.

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!

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

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 57

August 19, 2022

www.pwsausa.org | 941.312.0400



Registration is now available for several PWSA | USA Virtual Sleep Summit presentations! The Sleep Summit will be held on **Tuesday, September 27, 2022 starting at 12:30 p.m. EST**, and will include several webinar presentations from top specialists who are experts in sleep issues. This Summit is for both parents and healthcare providers.

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

A few of our speakers include:



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



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



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



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

LEARN MORE AND REGISTER HERE



PWSA | USA's 37th National Convention will take place 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**.

The Professional Provider Conference will be held June 22nd, which gives residential service providers, case managers, community support providers, employment specialists and so many more the opportunity to share and learn from each other. **PWSA | USA is accepting proposals for Convention topics until November 1, 2022.** For those interested, please complete the form at the button below and return it to info@pwsausa.org.

SAVE THE DATE

Upcoming Events >>>



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

When: September 19-21, 2022

Learn More Here >>

SLEEPSUMMIT
Prader-Willi Syndrome Association | USA

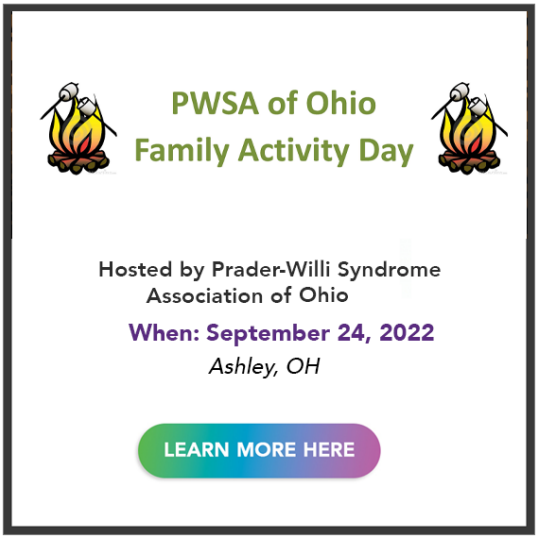
Virtual Sleep Summit

When: September 27, 2022

Learn More Here >>

DOWNLOAD THE FORM HERE

OTHER UPCOMING EVENTS OF INTEREST





ADVOCACY

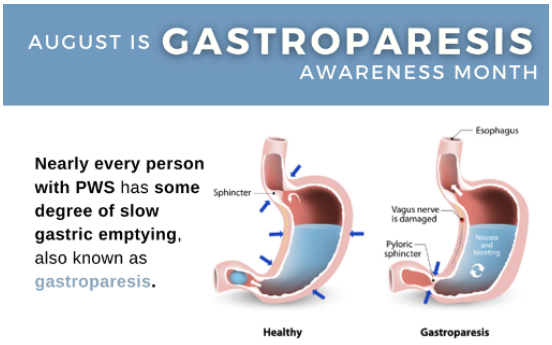
WATCH: Learn How to Craft Your Story

If you missed last week's Advocacy in Action webinar with special guest Jim Sliney (Patients Rising), you can watch the recording below. A special thank you to Jim for sharing his insight on how to craft your own story and share it with those outside of our rare disease community.



FAMILY SUPPORT

August is Gastroparesis Awareness Month



Gastroparesis, also known as delayed gastric emptying, is a chronic condition that affects the stomach muscles and prevents proper movement of food from the stomach to the small intestine. Find helpful information about GI Issues in individuals affected by PWS by clicking the buttons below.



Download the article *"Understanding Gastric Motility and Gastroparesis in PWS"*



Download the article *"A Comprehensive Overview of GI Issues in Prader-Willi Syndrome"*

Residential Spotlight: The Arc of Alachua County

PWSA | USA's Family Support



team shares their third feature story in our Residential Spotlight Series, a look into The Arc of Alachua County group home in Gainesville, FL. Read the full article by clicking the button below.

READ MORE HERE

Don't Forget about our Back-to-School Resources!



The end of summer is upon us and once again, it's time to grab the backpacks and schoolbooks!

Whether it is in the classroom or at home, school can come with many challenges for our rare disease community. As your loved one returns to learning, PWSA | USA is here to offer helpful tips and reminders about the education-focused resources available for our PWS families. Click the button below to find our School Success Toolkits.

VISIT THE SCHOOL SUCCESS TOOLKITS

RESEARCH

RADIUS®



Radius Health Releases Helpful Resources for SCOUT-015 Clinical Trial

LEARN MORE HERE



PWSA | USA is excited to share a clinical trial opportunity for our community with **Aardvark Therapeutics**.

Learn more about their drug Oral ARD-101 and how you can participate by clicking the button below.

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

PWSA | USA Receives Support from The Giving Pump

PWSA | USA is honored to be recognized as a charity beneficiary of The Giving Pump! For those in our community who live in the Yonkers



area of New York, we encourage you to fill up your tank at the Shell Gas station located at 1 Enterprise Blvd., Yonkers, NY. Through October 31st, a portion of your gas purchase will support PWSA | USA!

A special thank you to PWS parent Dominique Valenti and Chris Singleton at Capitol Petroleum Group for their hard work to make this opportunity happen!

Learn more about The Giving Pump by clicking the button below.

LEARN MORE HERE

Become a Hope United Champion!

PWS hope united
BUILDING BRIGHT FUTURES FOR PWS FAMILIES
Prader-Willi Syndrome Association | USA

Giving hope has never been easier, and you can make it happen! Start your own fundraiser on behalf of PWSA | USA and help us become stronger and more united than ever as a community. No matter what your vision is, no fundraising idea or dollar amount is too great or too small, and we are here to help every step of the way. Click the button below to get started.

Hope is here to stay!

GET STARTED TODAY!

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

DONATE

they so desperately need. Thank you!

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

www.pwsausa.org | 941.312.0400

Donate



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 - 6:30 p.m. EST, and will include several webinar presentations from top specialists who are experts in sleep issues. The Summit is for both parents and healthcare providers.

During the **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!

Click on the image below to hear from Family Support Director Stacy Ward, who shares details about Sleep Summit topics, speakers, and why it's important for our PWS community to attend.



VISIT THE SLEEP SUMMIT WEBSITE

Sleep Summit Agenda

Time: 12:30 - 2:00 p.m.

Welcome from PWSA | USA CEO Paige Rivard, MBA

Introduction to Sleep and Sleep Disorders in Children with PWS





with speaker Amee Revana, DO FAASM

REGISTER HERE



Time: 2:30 - 3:30 p.m.

Sleep Abnormalities Associated with Behavioral Problems in Prader-Willi Syndrome with speaker Deepan Singh, MD

REGISTER HERE





Time: 4:00 - 5:00 p.m.

Genetics of Sleep Disorders in PWS with speakers Althea Shelton Robinson, MD and Olivia J. Veatch, Ph.D.

REGISTER HERE



Time: 5:30 - 6:30 p.m.

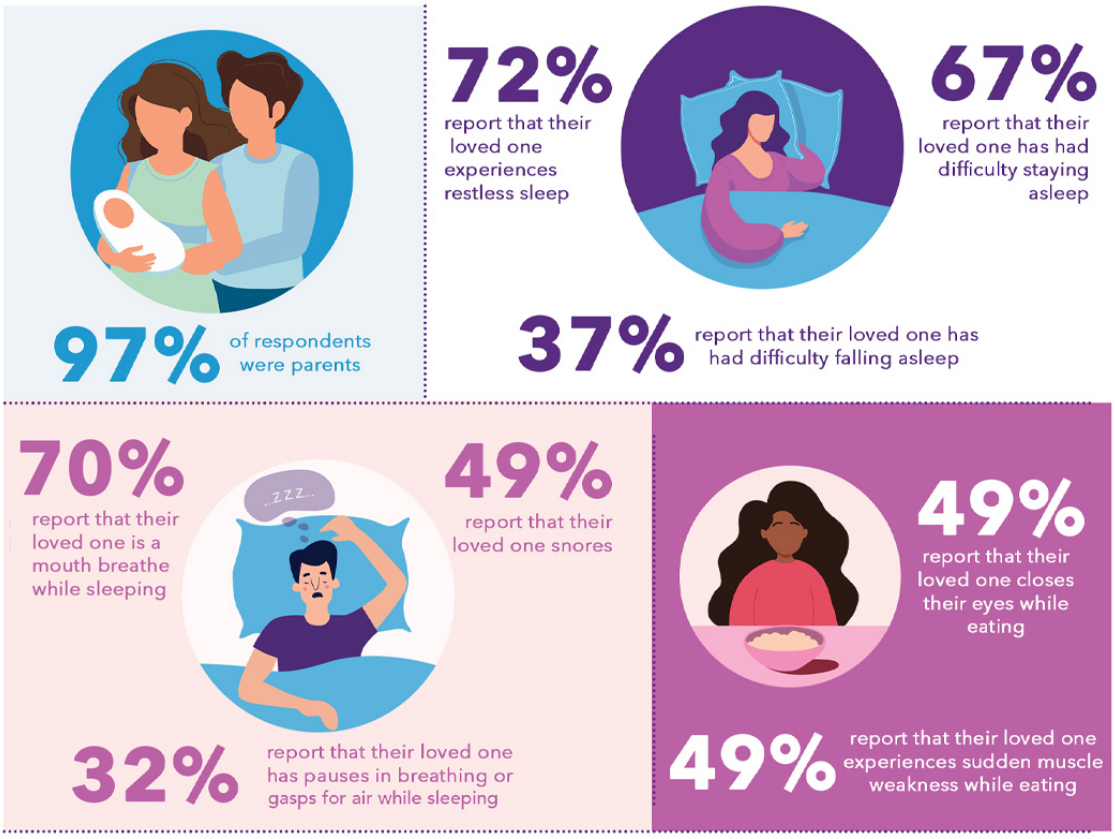
Presentations and Management of Sleep Disorders in Prader-Willi Syndrome with speaker Jessica Duis, MD

REGISTER HERE

Thank You to our PWS Community for Participating in PWSA | USA's Sleep Issues Survey!

The purpose of this research is to better understand how issues related to sleep impact the daily lives of people diagnosed with PWS and their caregivers. Below are some of the survey findings, which will continue to be shared on PWSA | USA's social media pages, the Sleep Summit website, and discussed during the September 27th Virtual Sleep Summit.





Donate

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