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.

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!
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
When: August 8th to August 19th
Virtual and In-Person Meetings
Learn More Here

Country for a Cure
Hosted by Prader-Willi Syndrome Association of Colorado
When: October 1, 2022
Greenwood Village, CO
Learn More Here
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](#)

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**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
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:
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
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:
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.

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

When: September 19-21, 2022

Learn More Here >>

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**Virtual Sleep Summit**

When: September 27, 2022

Learn More Here >>
DOWNLOAD THE FORM 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

Country for a Cure

Hosted by Prader-Willi Syndrome Association of Colorado
When: October 1, 2022
Greenwood Village, CO

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.
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
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
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!

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!
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.

**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

Time: 2:30 - 3:30 p.m.
Sleep Abnormalities Associated with Behavioral Problems in Prader-Willi Syndrome with speaker Deepan Singh, MD

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

REGISTER HERE

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

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

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.
97% of respondents were parents

72% report that their loved one experiences restless sleep

67% report that their loved one has difficulty staying asleep

37% report that their loved one has difficulty falling asleep

70% report that their loved one is a mouth breather while sleeping

49% report that their loved one snores

49% report that their loved one closes their eyes while eating

49% report that their loved one experiences sudden muscle weakness while eating

32% report that their loved one has pauses in breathing or gasps for air while sleeping

Donate

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1032 E Brandon Blvd #4744 Brandon, FL 33511