Countdown to Convention

109 DAYS TO GO!

Register for the 2023 National Convention HERE!
If you missed our recent Convention Q & A Community Conversation, you can view the recording by clicking on the image above. Several members of PWSA | USA's staff share details and answer questions about this year's Convention events, speakers, and opportunities for families, caregivers, and health professionals. They also walk through the registration process step-by-step.

If you have questions of your own, contact us at info@pwsausa.org or (941) 312-0400.

__Spots are still open__ for our 37th National Convention PWS Camps (formerly known as YIP and YAP). The Little Tikes (0 - 24 months), Junior Adventure Camp (2 - 6 years old), Adventure Camp (7 years and up), and Sibling Camp (7 - 16 years old) serve as fun and safe spaces for your loved one living with PWS (children and adults) and their siblings to connect with peers and make new friends!

The PWS Camps are available throughout the Family Conference, which will take place June 23-24, 2023, at the Hilton Orlando Buena Vista Palace in Orlando, FL.
Learn more about the PWS Camp options and register HERE!

Thank You Sponsors!

If you are interested in sponsoring PWSA | USA’s 2023 National Convention, contact Paige Rivard at privard@pwsausa.org.

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Here’s How YOU Can Enjoy the 9th Annual Clint Hurdle Hot Stove Dinner

#1 Purchase tickets for our Virtual event! On March 25, 2023, enjoy the Hot Stove Dinner and country music artist Max Flinn from the comfort of your home. Virtual attendees will also have the opportunity to see and hear everything happening on the island!

#2 Participate in our Raffle and Coconut Helicopter Drop! The winner of the Coconut Helicopter Drop will receive a two-night stay at the Compass by Margaritaville Resort on Anna Maria Island, FL and a prize packed Yeti Roadie 24 Hard Cooler. There will also be ten raffle winners with prizes including Hit the Links and Le Creuset prize packs, a Lottery/Gift Card Tree, and so much more.

#3 Bid on many amazing auction items! A few of these items include a Steph Curry signed jersey and tribute, a must-have beach set with items from Neiman Marcus, Kate Spade, and more, AND a Magic Johnson autographed jersey.
This past week, 13 PWS advocates, including five people living with PWS, joined RDLA (Rare Disease Legislative Advocates), the EveryLife Foundation, and more than 500 other rare disease advocates from across the country to share their voice for rare disease awareness and support on Capitol Hill in Washington, D.C.

PWS community advocates attended meetings with the FDA and NIH and encouraged congress to sign on to a letter incorporating the patient experience into the drug approval program.

PWSA | USA is grateful to our amazing advocates for their dedication, hard work, and tenacity and we thank our community members who continue to fight for our loved ones with PWS!
Walk a Mile in their Genes Sign Up has Ended, but There's Still Time to Show your Support!

Thank you to everyone who signed up to fundraise for PWSA | USA's first-ever Walk a Mile in their Genes campaign to support our Advocacy and Research initiatives!

While the time to create an individual fundraising page has passed, donations are still being accepted through March 12, 2023. Help us reach our goal of raising $20,000 - we're 93% of the way there!

SHOW YOUR SUPPORT HERE
Sleep Disturbances in Prader-Willi Syndrome

Sleep health is essential for everyone. It is just as important to take care of ourselves as parents and caregivers as it is for those living with PWS. PWSA | USA’s Medical/Research Coordinator Lynn Garrick, RN, shares the various ways we can experience sleep disturbances, along with methods to help address and manage them to get a better night’s rest. Learn more by clicking the button below.

To find additional resources and helpful information from health professionals who specialize in sleep issues, visit our Sleep Summit webpage.
Residential Spotlight: Abilities Midwest in Wisconsin

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

Register TODAY for PWSA | USA's FREE Virtual School Success Summit
Time is running out to register for PWSA | USA’s first-ever School Success Summit, which will be held Thursday, March 9, 2023 from 12:30 - 6:00 p.m. EST! The Summit will include several webinar presentations from specialists who are experts in education and PWS, and is for both parents and school professionals.

During this FREE virtual event, you will learn about creating goals and documenting progress, helpful tips for the IEP process, and so much more! Click the button below to find registration links.

LEARN MORE AND REGISTER HERE

PWSA | USA Research Funding Opportunity

PWSA | USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with PWS. PWSA | USA is seeking to fund two projects that will each receive $25,000 for a one-year grant support.

Letters of Intent (LOI) submissions can be submitted to Paige Rivard at privard@pwsausa.org through Monday, May 1, 2023 at 12:00 p.m. EST.
Congratulations to Dr. Dan Driscoll for Getting PWS Research Manuscript Published

We are pleased to share Daniel J. Driscoll, MD, PhD, FAAP, FFACMGG recently had his manuscript, Hyperinsulinemia is a probable trigger for weight gain and hyperphagia in individuals with Prader-Willi syndrome, published in the journal Obesity Science and Practice. Dr. Driscoll said "funding from a recent PWSA | USA grant on Dissecting the Various Nutritional Phases of the Prader-Willi Syndrome was instrumental in completing this work."

According to Dr. Driscoll, the results show promise in helping Soleno Therapeutics get their drug DCCR approved by the FDA. You can read the full manuscript by clicking the button below.
Your voice matters! We have the incredible opportunity to bring together the PWS patient voice at PWSA | USA's 37th National Convention during the EL-PFDD meeting.

Ahead of the event, we will be collecting testimonials from our PWS community. You can share your personal story, the struggles your family and loved one living with the syndrome have faced, or anything else you want others to consider. These testimonials will be included in our Voice of the Patient Report, which become published papers. This will allow pharmaceutical companies to access the report, so they can develop protocols that best fit our community’s needs. With this report, WE can help with the development of drugs to help our entire community.

You can submit your testimonial at the button below. Thank you!
To help raise awareness for our rare disease community on Rare Disease Day, one PWS mom shared her daughter Journey’s story with a local Kansas City news station. Watch this heartfelt and hopeful spotlight by clicking the image above.

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
Countdown to Convention

9 5

DAYS TO GO!

Register for the 2023 National Convention HERE!
We are excited to come together again in-person for the 37th PWSA | USA National Convention, June 21-24, 2023 in Orlando, FL! Leading up to this much-anticipated event, members of our PWS community are sharing their Convention memories and why it’s beneficial for others to attend!

In our first Convention Spotlight, PWS parent Julie Casey gives details about her past National Convention experiences with her son Ryan. She also shares advice for other families, especially those planning to attend Convention for the first time. Read more from Julie at the button below.
Your voice matters! We have the incredible opportunity to bring together the PWS patient voice at PWSA | USA's 37th National Convention during the EL-PFDD meeting.

Ahead of the event, we will be collecting testimonials from our PWS community. You can share your personal story, the struggles your family and loved ones living with the syndrome have faced, or anything else you want others to consider. These testimonials will be included in our Voice of the Patient Report, which become published papers. This will allow pharmaceutical companies to access the report, so they can develop protocols that best fit our community's needs. With this report, WE can help with the development of drugs to help our entire community.

You can submit your testimonial at the button below. Thank you!

SUBMIT A TESTIMONIAL HERE

Thank You Sponsors!
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Just One Week Left to Place Your 2023 Hot Stove Dinner Auction Bids!

We are excited to see our community come together next weekend for the 2023 Clint Hurdle Hot Stove Dinner! Whether you are attending on the island or virtually online, we sincerely appreciate your support.

All proceeds from the Hot Stove Dinner directly impact PWSA | USA’s Family Support programs, which help countless families receive the care they need to help their loved one living with PWS thrive. Another way you can participate in the Hot Stove Dinner is by bidding on our amazing auction items! Click the button below to view the full list, and place your bids TODAY!

Sibling Community Conversation (for siblings 18+)
When: April 19, 2023
Register in Advance Here

2023 Clint Hurdle Hot Stove Dinner
When: March 25, 2023
In-person tickets are SOLD OUT but you can still attend virtually by clicking here

37th National Convention
When: June 21 - 24, 2023

Join us for a quick online call to learn about how YOU can participate in our first-ever Family Support Challenge! In just five minutes, you can be up and running.
and have a great way to raise awareness of PWS *just in time* for PWS awareness month this May!

There are two opportunities to participate and learn more. To register for this free, online event, click your preferred day/time below. Can't attend, but still want to get involved? Email us at [hopeunited@pwsausa.org](mailto:hopeunited@pwsausa.org)!

March 28, 2023 at 5:00 p.m. EST

[REGISTER HERE](#)

March 30, 2023 at 12:30 p.m. EST

[REGISTER HERE](#)

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### ADVOCACY

**Thank You to our Walk a Mile in their Genes Fundraising Champions!**

A little over seven weeks ago, PWSA | USA launched the Walk a Mile in their “Genes” campaign, a new fundraising initiative to raise funds for our advocacy and research programs. We are ecstatic to report that because of YOU, our amazing community, we not only raised our monetary goal of $20,000, but surpassed it!
Congratulations to our Walk a Mile in their Genes Winners!

1st Place: Jennifer Garzia, who raised $3,180
2nd Place: Timothy Kelleher, who raised $2,675
3rd Place: Lisa Lamb, who raised $2,625

Nominations Now Being Accepted for PWSA | USA's 2023 Volunteer Awards

Help us honor our PWSA | USA volunteers!

Do you know someone who deserves to be recognized for their service and dedication to PWSA | USA's mission and the PWS community?

2023 Volunteer Appreciation Award nominations are now being accepted through April 30, 2023. PWSA | USA will give out six awards this year:

- 2023 Advocacy in Action Star
- Family Support Champion
- Research Star
- Peer-to-Peer Fundraiser of the Year
- Legislative Champion 2023 (Elected Official)
Volunteer of the Year 2023

The award recipients will be announced during our 37th National Convention Family Conference. Click on the button below to download the 2023 Volunteer Appreciation Award Nomination Form. Please submit your completed form to volunteer@pwsausa.org. Thank you!

DOWNLOAD NOMINATION FORM HERE

School Success Summit Webinar Recordings Now Available!

Click the images below to watch each webinar

Creating IEP/BIP Goals and Documenting Progress
With speaker Mackenzie Bodin, M.Ed., BCBA

Helpful Tips for the IEP Process
With Speaker Amy McTighe, PhD

Due Process
With Speaker Elizabeth Eynon-Kokrda

Preschool Evaluations
With Speaker Amy McDougall, MS
Sibling Community Conversation

Siblings (aged 18 and older) of loved ones living with PWS are invited to join PWSA | USA for our Siblings Community Conversation on April 19, 2023, at 8:00 p.m. EST.

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

In an effort to ensure attendees feel comfortable to share openly, this opportunity is just for siblings. We appreciate your understanding!

REGISTER HERE

PWSA | USA Research Funding Opportunity
PWSA | USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with PWS. PWSA | USA is seeking to fund two projects that will each receive $25,000 for a one-year grant support.

Letters of Intent (LOI) submissions can be submitted to Paige Rivard at privard@pwsausa.org through Monday, May 1, 2023 at 12:00 p.m. EST. Learn more by clicking the button below.

Parents/Guardians Invited to Participate in a PWS Research Study

Are you a parent/guardian of someone age 12 or older, diagnosed with Prader-Willi Syndrome (PWS)?

Do you:

- Want to help researchers understand the social and emotional experiences of those with PWS?
- Want to help researchers understand the impact of the COVID-19 pandemic on those with PWS?

About the study: This study will be done completely online and if you agree you will complete an online consent/assent form and complete online parent and child questionnaires taking about 1 hour. Upon completion of the study participants are entered to win a raffle for $20 Amazon Gift Cards.
Questions about the study? Please contact christopher.m.daniell@vanderbilt.edu

PARTICIPATE IN THE STUDY HERE

DOWNLOAD THE FLYER HERE

Attention PWS Medical Providers!

The PWS clinic at Children's Mercy Kansas City is seeking input from medical providers who treat infants less than 1 year of age with PWS, related to sleep assessments and management of growth hormone therapy.

Please consider completing the REDCap Survey by clicking here, and learn more information about the purpose of this survey at the button below.

LEARN MORE HERE

Prader-Willi Syndrome Article Published in GeneReviews

Daniel Driscoll, MD, PhD, FFACMG, FAAP, Jennifer Miller, MD, MS, FAAP, and Suzanne Cassidy, MD, FFACMG recently collaborated to write an updated and detailed article about Prader-Willi syndrome in the widely used point-of-care resource website GeneReviews.

This article can be viewed by clinicians and health care providers around the world to better understand PWS and its symptoms. The article can be accessed publicly, and we encourage our community to share it with your health care professionals. You can learn more at the button below.
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!
Tomorrow, April 1, 2023, is the kick-off to PWSA | USA's Family Support Campaign! As we work together to ensure every member of our Prader-Willi syndrome community has access to the support, expertise, and resources needed to help our loved ones thrive, we need your help. Whether you have just begun your PWS journey or are well along your way, join us to help ensure PWSA | USA's responsive and ever-evolving services and resources are always available to all.

When you join other members of our community and make a tax-deductible donation to our Family Support Campaign (tomorrow through May 31st!), YOUR IMPACT WILL BE DOUBLED up to our first $20,000, thanks to a match from a generous PWS parent.
Learn more about the Family Support Campaign from Director of Family Support Stacy Ward, MS, in the video below.

“My motivation to donate to PWSA | USA was due to the tremendous amount of help and support they gave my family and I in such a difficult and dark time in our lives. Also, all the support they gave the NICU staff. I can truly say that without their guidance, I don’t know where things would have gone or where we would be today.”

- Sue Colon
Mom to Shealynn (3) living with PWS
Participate in the Family Support Challenge!

As we embark on our 2023 Family Support Campaign and head into PWS Awareness Month in May, we are challenging individuals from all sections of our community (parents, grandparents, siblings, caregivers, physicians, therapists, and residential providers)! YOU have the opportunity to participate in our PWS Hope United Family Support Challenge to help raise critical funds to sustain important resources for the entire PWS community.

Creating a Family Support Challenge fundraising page is quick and easy (5 minutes!) and you can use it to reach out to your family, friends, neighbors, and colleagues. You can even utilize the Facebook integration to amplify your efforts via social media. Click the image below to get started today!

If you are interested in learning more, join us on April 13th at 8:00 p.m. EST for a Family Support Challenge Q & A webinar! Register in advance at the button below.

REGISTER IN ADVANCE HERE

JOIN THE FAMILY SUPPORT CHALLENGE 2023!

CLICK HERE
Prizes Awarded to the Top Three Fundraisers!

1. 2025 Family Conference Registration
2. 2025 Gala Registration
3. $100 Amazon Gift Card

Family Support 2022 Impact

- 3,164 Non-Medical Inquiries
- 3,447 Total Family Support Inquiries
- 252 New Diagnosis Packages of Hope Sent Out

Top Family Support Inquiries:
- Medical: 283
- New Diagnosis: 252
- Emotional/Grief Support: 205
- Provider-Related Concerns: 190
- Behavior: 167
- School-Related Concerns: 120

IEP Meetings: 75
Provider Trainings: 9
School Trainings: 10