

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

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 70

March 3, 2023

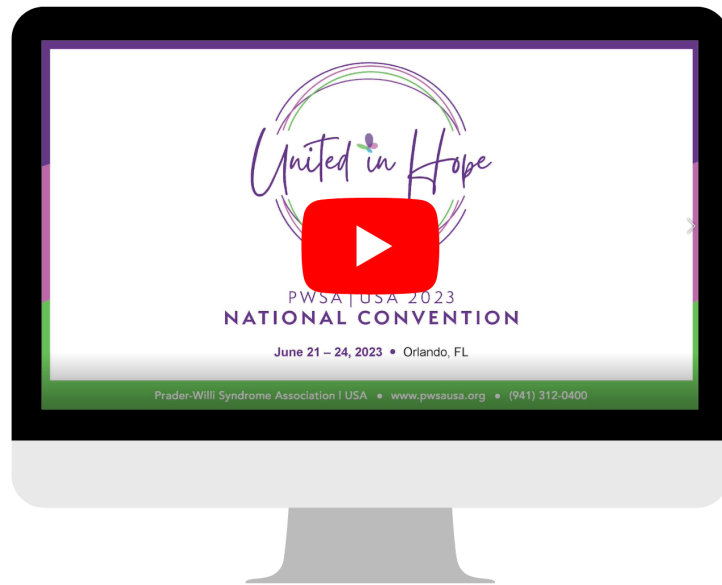
www.pwsausa.org | 941.312.0400

Countdown to Convention



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.

SAVE THE DATE

[Upcoming Events >>>](#)



School Success Summit

When: March 9, 2023

[Learn More 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

[Register Here](#)

**PURCHASE YOUR
TICKETS HERE TODAY**



ADVOCACY

PWS Advocates Share Their Voice at Rare Disease Week on Capitol Hill



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!



WV Legislative Photography, Photo by Will Price

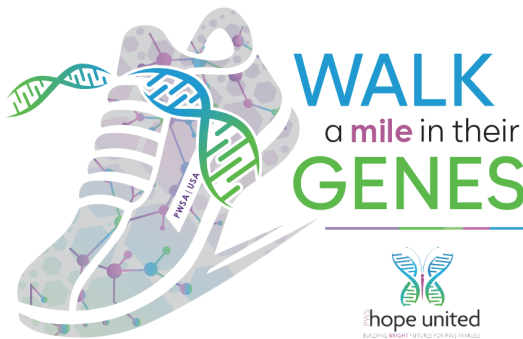
Rare Disease Day Spotlight

Congratulations to PWS parent, Sheri, and her daughter, Lyra, for receiving a Rare Disease Day Proclamation from the state of West Virginia!

"We walked away with an official document from the state of West Virginia, and so much hope. I look forward to the future and what it may bring."

[READ MORE HERE](#)

Walk a Mile in their Genes Sign Up has Ended, but There's Still Time to Show your Support!



we're 93% of the way there!

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** -

[SHOW YOUR SUPPORT HERE](#)

Current Leaderboard

Jennifer Garzia	\$3,030
Lisa Lamb	\$2,625
Jennifer Andrews	\$2,071
Maggie Andrews	\$2,005
Timothy Kelleher	\$1,765
Erin Carter	\$1,720
Jamie Prentice	\$1,354
Valerie Selinger	\$1,241
Jessica Kempa	\$1,115
Michelle Cox	\$535



FAMILY SUPPORT

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](#).



[READ MORE HERE](#)

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.

[READ MORE HERE](#)

Register TODAY for PWSA | USA's FREE Virtual School Success Summit



**SCHOOL
SUCCESS
SUMMIT**

Prader-Willi Syndrome Association | USA

Thursday, March 9, 2023 | 12:30 - 6:00 p.m. EST



**Mackenzie
Bodin, M.Ed,
BCBA**



**Amy McTighe,
PhD**



**Elizabeth
Eynon-Kokrda**



**Amy McDougall,
MS**

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



RESEARCH

PWSA | USA Research Funding Opportunity

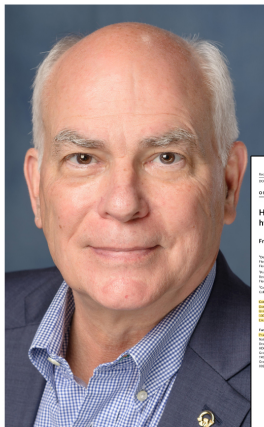
PWSA | USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with PWS. PWSA | USA is seeking to fund two projects that will each receive **\$25,000** for a one-year grant support.

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 HERE](#)

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.

[READ THE ARTICLE HERE](#)

Submit a Testimonial for the FDA Externally-Led Patient-Focused Drug Development Meeting



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*,

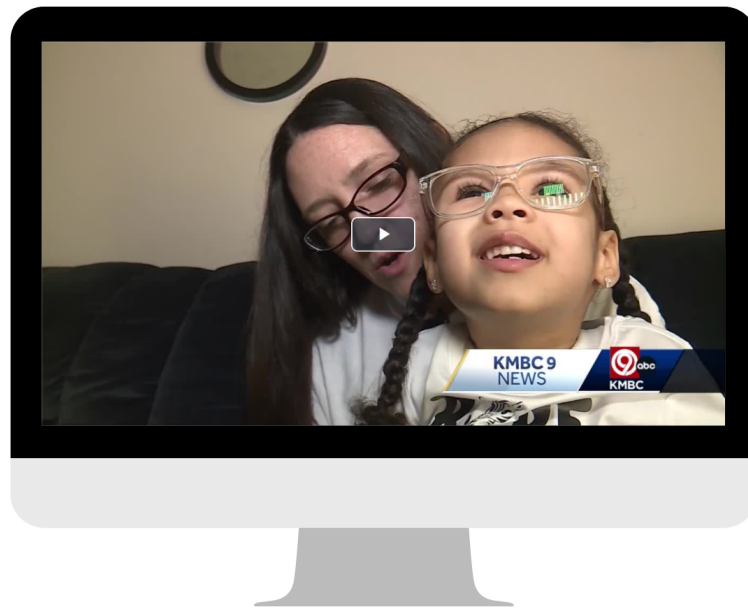
which become published papers. This will allow pharmaceutical companies to access the report, so they can develop protocols that best fit our community's needs. With this report, **WE** can help with the development of drugs to help our entire community.

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

[SUBMIT YOUR TESTIMONIAL](#)

PWSA | USA ANNOUNCEMENTS

 PWSA | USA'S
SPOTLIGHT ON HOPE



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!

[Donate](#)



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

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

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 71

March 17, 2023

www.pwsausa.org | 941.312.0400

Countdown to Convention

9 5

DAYS TO GO!

Register for the 2023
National Convention **HERE!**

PWSA | USA 37th National Convention

Community Spotlight

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.



[READ MORE HERE](#)



SUBMIT A TESTIMONIAL FOR THE EL-PFDD MEETING

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.

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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!

SAVE THE DATE

[Upcoming Events >>>](#)



Sibling Community Conversation (for siblings 18+)

When: April 19, 2023

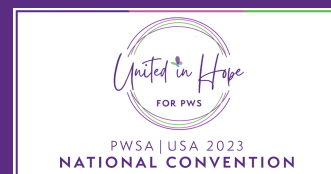
[Register in Advance Here](#)



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

[Register Here](#)

FAMILY SUPPORT CHALLENGE 2023



PLANTING SEEDS OF HOPE

Take What You Need & Give What You Can



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!

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

[REGISTER HERE](#)

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

[REGISTER HERE](#)



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!



Our PWS advocates and team members of our Advocacy Work Group have been the undeniable champions of our first ever Walk-a-Mile campaign.



These individuals continue to take on the challenges of our community and have dedicated themselves to creating a better world for all of our loved ones with PWS.

- Dorothea Lantz, PWSA | USA Director of Community Engagement

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



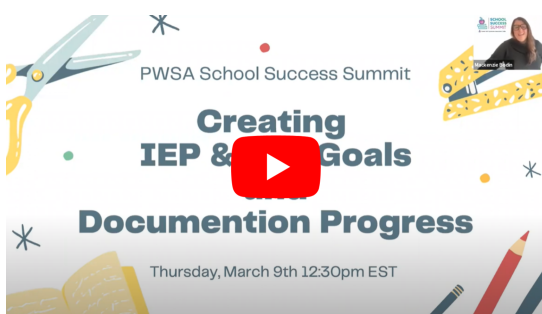
FAMILY SUPPORT

School Success Summit Webinar Recordings Now Available!

Click the images below to watch each webinar

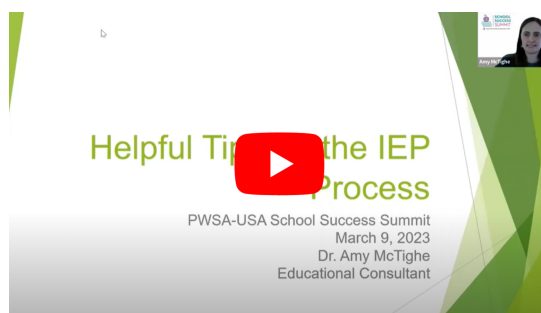
Creating IEP/BIP Goals and Documenting Progress

With speaker Mackenzie Bodin, M.Ed., BCBA



Helpful Tips for the IEP Process

With Speaker Amy McTighe, PhD



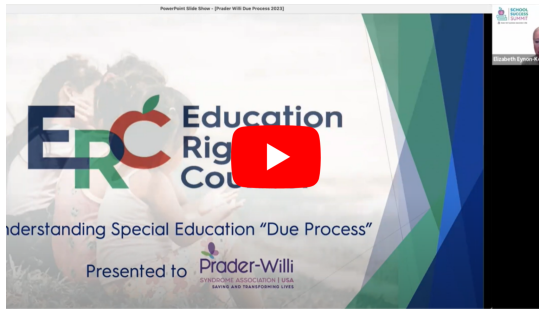
DOWNLOAD PRESENTATION

Due Process

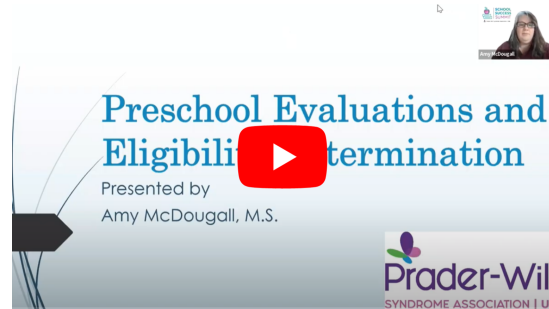
With Speaker Elizabeth Eynon-Kokrda

Preschool Evaluations

With Speaker Amy McDougall, MS



[DOWNLOAD PRESENTATION](#)



[DOWNLOAD PRESENTATION](#)

Sibling Community Conversation





COMMUNITY CONVERSATIONS
Prader-Willi Syndrome Association | USA

Sibling Community Conversation
(for siblings 18+)

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](#)



RESEARCH

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.

[LEARN MORE HERE](#)

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.

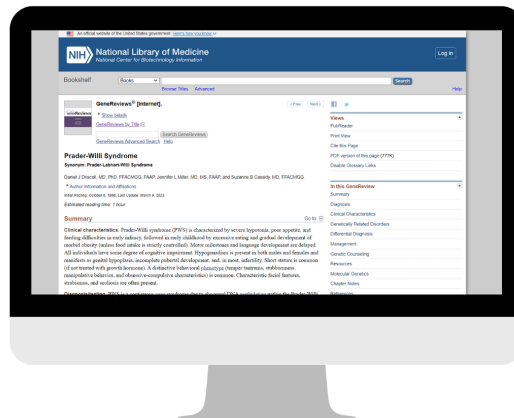
Please consider completing the REDCap Survey by [clicking here](#), and learn more information about the purpose of this survey at the button below.

LEARN MORE HERE

Prader-Willi Syndrome Article Published in GeneReviews

Daniel Driscoll, MD, PhD, FFACMGG, FAAP, Jennifer Miller, MD, MS, FAAP, and Suzanne Cassidy, MD, FFACMGG 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.



[READ THE ARTICLE 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 Special Edition Pulse: March 31, 2023

www.pwsausa.org | 941.312.0400

[Donate](#)



Take what you need and give what you can... Help us plant seeds of HOPE!

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](#)



Prizes Awarded to the Top Three Fundraisers!



**2025 Family
Conference
Registration**

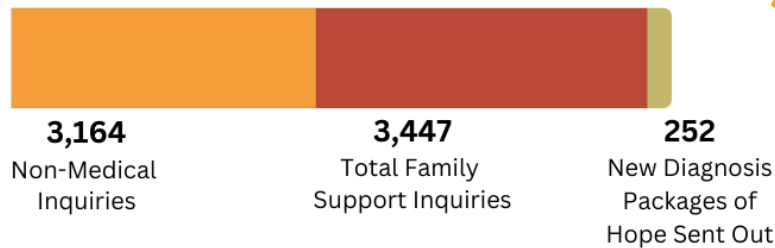


**2025 Gala
Registration**

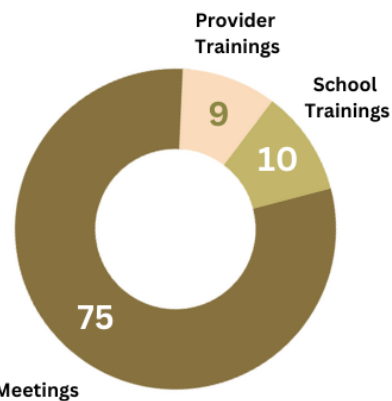


**\$100 Amazon
Gift Card**

Family Support 2022 Impact



Top Family Support Inquiries





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