

PWSA | USA Bi-Weekly Pulse: April 7, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS

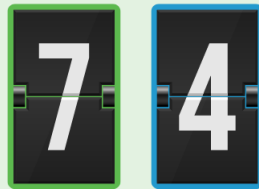


Vol. 72

April 7, 2023

www.pwsausa.org | 941.312.0400

Countdown to Convention



DAYS TO GO!

Register for the 2023

National Convention **HERE!**

PWSA | USA 37th National Convention Merchandise Now Available!



With PWSA | USA's 37th National Convention just 74 days away, we have launched a **new online merchandise store!**

Show your PWS Pride at the June 21-24, 2023 Convention with United in Hope and PWSA | USA swag including shirts, sweatshirts, coffee mugs, hats, onesies, and more! **Place your orders by May 21, 2023** to receive your items by June 15th - in time for the 2023 Convention!


[VISIT THE STORE HERE](#)

PWSA | USA 37th National Convention *Speaker Spotlight*




We are excited to have Behavior Analyst Kasey Bedard, Ph.D., BCBA-D, speak at this year's Professional Providers Conference (June 22, 2023) AND Family Conference (June 23-24, 2023)!

On day one of the Family Conference, she will host a workshop on *ABA Therapy, Potty Training, and Sleep*. Then, on day two, Dr. Bedard will join with three other behavior specialists for an ABA Therapists Panel, which will focus on *Special Topics in Behavior at Home and School*.

Three images: a large resort building, a couple in a pool, and a hotel room.

Reserve your hotel room for the 37th National Convention by May 16, 2023 to get a spot in our group room block!

BOOK NOW 

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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Prader-Willi Syndrome Association of New England
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Sir Speedy



PLANTING SEEDS OF HOPE

Take What You Need & Give What You Can

Make a difference today by donating
to PWSA | USA's **2023 Family
Support Campaign**

Double Your Donation [HERE](#)

When you join other members of our community and make a tax-deductible donation to PWSA | USA's 2023 [Family Support Campaign](#) through May 31st, YOUR IMPACT WILL BE DOUBLED up to our first \$20,000, thanks to a match from a generous PWS parent.

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.

SAVE THE DATE

[Upcoming Events >>>](#)



Sibling Community Conversation (for siblings 18+)

When: April 19, 2023

[Register in Advance
Here](#)



PWS Hope United Family Support Challenge Q & A Webinar

When: April 13, 2023 |
8:00 p.m. EST

[Register Here](#)



**37th National
Convention**



When: June 21 - 24,
2023

[*Register Here*](#)

We are also challenging individuals from all sections of our community (parents, grandparents, siblings, caregivers, physicians, therapists, and residential providers) to participate in our **PWS Hope United Family Support Challenge!** 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**](#)

Thank You for Another Amazing Hot Stove Dinner!



The **9th Annual Clint Hurdle Hot Stove Dinner** was a major success because of YOU, our PWS community! Thank you to those who sponsored the event, joined us on the island, tuned in virtually, placed bids in our auction, and participated in the Coconut Helicopter Drop and raffle.



We want to give a special shout out to Clint and Karla Hurdle. It's because of their hard work and dedication to PWSA | USA this amazing event is even possible and raises necessary funds for our Family Support programs. We would also like to say a special thanks to our event partner, Leaving Legacies Foundation. We are sincerely grateful!

[VIEW THE PHOTO GALLERY HERE](#)



ADVOCACY

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

How Can Family Support Help You?

Throughout PWSA | USA's Family Support Campaign, Director of Family Support Stacy Ward, MS, will share several ways our team can help YOU, families and individuals in our community affected by PWS. Click the image below to view the first video in this series, *Navigating the NICU*, and visit our new NICU resource webpage [HERE](#).



School Success Tip: Create a Parent Input Statement for Your Child's IEP

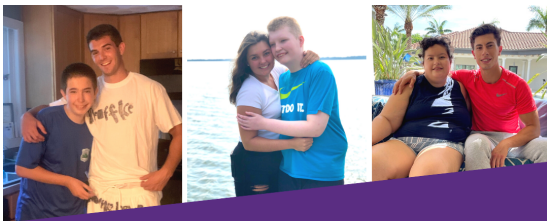
As a parent, you know your child best, and your input into the development of their Individual Education Program (IEP) is crucial. In addition to actively participating in discussions, goal development, and progress monitoring, creating a **parent input statement** is a way for you to document your child's strengths and challenges, both at home and as you see them in school.

Read more about this important resource document at the button below.



[READ MORE HERE](#)

Sibling Community Conversation



**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 Sibling 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

PWS Parents and Caregivers: Tell Your Healthcare Professionals About PWSA | USA's New ECHO Series

Introducing PWSA | USA's ECHO 4 PWS Healthcare Provider Series



Our first ECHO Webinar will take place
Tuesday, May 16, 2023 at 5:00PM CST

Topic - Genetics in PWS 101

Where - Virtual/Zoom Video

This series is for Health Care Providers only

PWSA | USA is excited to announce the launch of our new **Healthcare Provider Project ECHO Series** on May 16, 2023 at 5:00 p.m. CST. We are proud to offer this opportunity to healthcare professionals who work with patients affected by Prader-Willi syndrome (PWS) and to be the first PWS organization to implement Project ECHO in the United States.

While this ECHO series is only for healthcare providers to attend, recordings of the webinars will be made available for our PWS families on our website. We encourage you to share this opportunity with the healthcare professionals in your life! You can download our ECHO 4 PWS flyer at the button below.

[DOWNLOAD THE FLYER HERE](#)

[REGISTRATION LINK](#)



"We understand the need to further educate healthcare providers taking care of our loved ones. Through this ECHO series, we will offer access to specialists in PWS, expanding knowledge and sharing standards of care for PWS patients."

- Paige Rivard, MBA | CEO

Parents/Caregivers Invited to Participate in a Perception of Language Patterns Survey Study



The Chicago School for Professional Psychology is currently recruiting for a survey study that is investigating caregiver perception of language patterns related to repetitive verbal behavior (e.g., repetitively asking questions or making statements) in PWS.

If you are the caregiver of an individual with PWS who is older than two years of age, if you are over the age of 18, and speak and read English fluently, you are eligible to participate in this study. If you complete the survey, you can choose

to be entered into a raffle to win a \$25 gift card. Please share this flyer with anyone you may think will be interested in participating in this study. To see if you qualify to participate in the study, please click the button below.

[PARTICIPATE IN THE STUDY HERE](#)

[DOWNLOAD THE FLYER HERE](#)

PWSA | USA Offering Funding for Research Opportunities

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](#)

PWSA | USA ANNOUNCEMENTS

Remembering the Life and Impact of Ken Smith



Kenneth (Ken) Smith, 62, of Sarasota, FL, died peacefully on March 7, 2023, at Tidewell Hospice House with his life partner, Patty LaRoche, by his side. He is also survived by his mother and stepfather, Wilma and Clinton Beauford of Pittsburgh, and his sister, Kathy Smith. Ken was preceded in death by his father, Roland Smith.

For 27 years, Ken coordinated and managed specialty programs for Prader-Willi syndrome (PWS) at The Children's Institute in Pittsburgh. Ken

served on the PWSA | USA Board of Directors for 18 years and became the PWSA | USA executive director. He was greatly admired by parents, coworkers, medical professionals, and those who have PWS. In Ken's final days, the many

testimonies sent, all mentioned his intellect, great sense of humor, and his calm and caring demeanor.

There will be a private memorial on Siesta Key beach at a later date.

Testimonies

Ken will always have my utmost admiration. Besides his extraordinary knowledge of the complexities of the syndrome, Ken had a very calm and caring demeanor. Through thousands of meetings, I never saw him lose his cool or professionalism. He always listened to both sides of an issue, and never imposed his ego in the situation. In fact, Ken liked to work more behind the scenes and uplift everyone else to the public. He was adored by all the children and young adults with the syndrome and admired by their parents. Ken was a true humanitarian with a gentle soul. His light shines on.

- Janalee Heinemann, Retired

Past positions with PWSA | USA: Executive director, medical and research coordinator, board member and board president, mother of a son with PWS

For the dozens of adults with Prader-Willi syndrome who may have been an inpatient at The Children's Institute or attended a PWSA | USA Conference, Ken Smith represented one of the most recognizable and friendliest faces. What set Ken apart was his ability to recall a detail about someone's life that made them feel extraordinary. When the Adult Advisory Board first formed in 2003, Ken was one of the inaugural leaders, providing guidance and direction to adults who wanted their voices to be heard. His calm approach and sense of humor has left an unforgettable impression on the lives of many people with Prader-Willi syndrome over the years.

- Mary K. Ziccardi, Regional Director, REM Ohio, Co-chair Professional Providers Board, past member PWSA | USA Board of Directors

Ken was always a bright light in the room with his contagious smile and unwavering positive attitude with everything. We will never really know how many lives he touched, but those of us that had the honor and privilege of knowing and being around Ken have been so lucky over all the many years he was there for us and our children.

- Tammie Penta, PWSA | USA board member and mother to Victor, living with PWS

Dear Ken: It is with a very heavy heart that we write this note. Our family owes you a deep debt of gratitude, from your life saving extra effort to get Kate admitted to your clinic in Pittsburg, to your velvet hammer handling of her, which sent her off on a new safer and healthier direction, to your years of service to the PWS community, to the many years of friendship, and finally your leadership of PWSA| USA during several stressful periods of change. You dedicated your life to special "friends" as you called them and their families. Many people, families, and the world are better off from what you unselfishly committed. You will be sorely missed in this world and I'm quite sure Our Lord will welcome with open arms into his world.

- **Kit and Jim Kane** (former PWSA | USA board member), parents to Kate, living with PWS

Dear Ken: I am so very sad to know you have been battling cancer. I have missed connecting with you these past few years; you have never been far from my thoughts. I hope you can feel my genuine and deep care I feel for you, along with so many others who have known you and valued your leadership and friendship. You have touched and improved so many lives. I am proud to know you, today and always, my friend.

- **Lisa Graziano**, former PWSA | USA board member, mother to Cameron, living with PWS

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: April 21, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 73

April 21, 2023

www.pwsausa.org | 941.312.0400

Countdown to Convention



DAYS TO GO!

Register for the 2023

National Convention **HERE!**

**American Sign Language (ASL) Volunteer Interpreters
Needed!**



We are looking for two people to volunteer as ASL interpreters at the 37th National Convention Family Conference, June 23-24, 2023.

For those interested, hotel accommodations and Convention registration will be provided. Please reach out to info@pwsausa.org or call (941) 312-0400 to get more information. Thank you!



Important Upcoming 37th National Convention Deadlines

37th National Convention Hotel Room Block Deadline: **May 16, 2023**

Place your 37th National Convention Merchandise Orders by: **May 21, 2023**

PWS Camps (for children/adults living with PWS and their siblings) Registration Deadline: **May 31, 2023**

Early Bird Registration Pricing Ends: **June 1, 2023**

37th National Convention Conference Registration Deadline: **June 9, 2023**

Hope United Gala Ticket Purchase Deadline: **June 9, 2023**

In-Person EL-PFDD Meeting Registration Deadline: **June 9, 2023**

Reminder: Submit your story for the EL-PFDD Voice of the Patient Report



Reserve your hotel room for the 37th National Convention by May 16, 2023 to get a spot in our group room block!

BOOK NOW



Thank You Sponsors!

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Jamie and Tiffany

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Prader-Willi Florida Association
Georgia Association for Prader-Willi Syndrome
Minnesota Prader-Willi Syndrome Association
Prader-Willi Syndrome Association of New England
PWSA of Ohio
Texas Prader-Willi Association
Utah Prader-Willi Syndrome Association

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Family Support Campaign Update



When you join other members of our community and make a tax-deductible donation to PWSA | USA's 2023 [Family Support Campaign](#) through May 31st, YOUR IMPACT WILL BE DOUBLED up to our first \$20,000, thanks to a match from a generous PWS parent.

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.

Did you know you can DOUBLE your donation to PWSA | USA through our employer matching donation program?

See if your employer will match your donation!

Many employers sponsor matching gift programs to match charitable contributions made by their employees to deserving nonprofit organizations. When you donate to our 2023 Family Support

SAVE THE DATE

[Upcoming Events >>>](#)



37th National Convention

When: June 21 - 24, 2023

[Register Here](#)



ECHO 4 PWS - Healthcare Provider Series

"Genetics in PWS 101"

When: May 16, 2023

[Learn More Here](#)

Campaign, check to see if your employer has a matching gift program!



Hope United Family Support Challenge: Current Leaderboard

	Sujeiri Colon	\$5,000
	Jane Rosen	\$3,018
	Stacy Ward	\$800
	Laurie Skinner	\$715
	Jennifer Hill	\$410
	Sarah Kasaby	\$380
	Amy McDougall	\$250
	Anne Fricke	\$130
	Susan Gerdes	\$120

Thanks to our amazing **Hope United Family Support Challenge** fundraisers and their supporters, we are more than 70% of the way to reaching our fundraising goal for this challenge! These donations will directly benefit PWSA | USA's life-saving family support programs.

There's still time to join the effort! Click the button below to be directed to our PWS Hope United website. You can then select "Get Started" to create your Family Support Challenge page today! If you have questions, please contact us at hopeunited@pwsausa.org.

[JOIN THE FAMILY SUPPORT CHALLENGE HERE](#)



ADVOCACY

Thank You to our Amazing PWSA | USA Volunteers!

This week is nationally recognized as **Volunteer Appreciation Week**. Without our PWSA | USA volunteers, we would not be the organization we are today. YOU make an immense impact on not just the lives of the family members and individuals affected by PWS, but on our lives too. THANK YOU for everything you have done.

Below are quotes from three of PWSA | USA's longtime volunteers sharing what motivates them to give their time.



"I really appreciate volunteering with PWSA | USA. It's inspiring to see the amazing work they're doing in family support, advocacy, and research. I know firsthand how important it is for families and people living with PWS to find new ways to live well and live healthy, and I'm grateful to be a part of that."

- Emily Felt, Mom to Olivia (living with PWS)



"As the parent of an older child (adult) with PWS, I spent many years on my own, looking for information and help. Eventually a few resources became available, and then over the years PWSA | USA grew and provided more and more resources – and became a lifeline. I volunteer with PWSA | USA now to help younger families get access to the PWSA | USA lifeline, to join the fight for things the PWS community as a whole needs, and to say thank you to the organization for being there for all of us when we need you."

- Elaine Towle, Mom to James (living with

PWS)

"I enjoy volunteering as a parent mentor because even though it's been 19 years now, I remember that feeling of despair of getting the PWS diagnosis, and



I want to help parents see that there is hope, that a PWS diagnosis is manageable, and that there is a community here to support them.

I also enjoy working with the communication work group to help support the PWSA | USA staff in getting messaging out to the community and lending a parent perspective."

- Julie Casey, Mom to Ryan (living with PWS)

You Can Show YOUR Appreciation by Submitting a Volunteer Award Nomination!



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 shown throughout the past year?

Volunteer Appreciation Award nominations are now being accepted through **April 30, 2023** for the following awards:

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

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

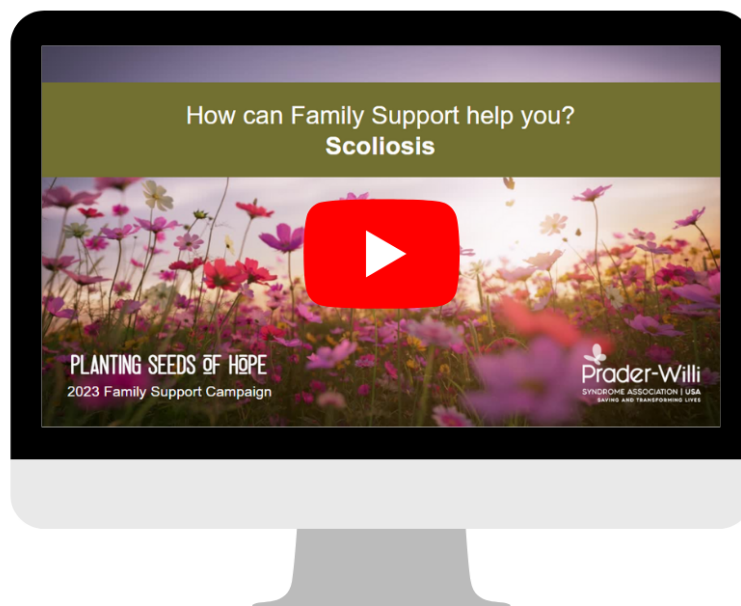
LEARN MORE HERE



FAMILY SUPPORT

How Can Family Support Help You?

Throughout PWSA | USA's Family Support Campaign, Director of Family Support Stacy Ward, MS, will share several ways our team can help YOU, families and individuals in our community affected by PWS. Click the image below to view the next video in this series, *Scoliosis*, and visit our Family Support resource video library [HERE](#).



Susan "Boothie" Booth, Living with PWS, Recently Turned 73 and Says She's Doing Great!



PWSA | USA's Alterman Family Support Counselor Kim Tula, MS, CSW recently spoke with one of the oldest known people living with PWS, Susan "Boothie" Booth, 73, to get an update!

"She is alert, healthy, and is working at her placement. She wanted me to pass along to our community that she is doing great!" Kim shares.

To learn more about Susan's life, click the button below to read (or re-read) a write up Kim put together in 2019. In it, Susan shares what has helped her all these years and gives advice to others living with PWS.

If you have a story you want to share with our Family Support Team, contact info@pwsausa.org!

[READ MORE HERE](#)



RESEARCH

PWS Parents and Caregivers: Tell Your Healthcare Professionals About PWSA | USA's New ECHO Series

Introducing PWSA | USA's ECHO 4 PWS Healthcare Provider Series



Our first ECHO Webinar will take place
Tuesday, May 16, 2023 at 5:00PM CST

Topic - Genetics in PWS 101

Where - Virtual/Zoom Video

This series is for Health Care Providers only

PWSA | USA's first **Healthcare Provider Project ECHO Series** webinar will take place May 16, 2023 at 5:00 p.m. CST. The topic discussed will be "Genetics in PWS 101" presented by Jessica Duis, MD, Associate Professor of Pediatrics and Genetics at Children's Hospital Colorado, University of Colorado, followed by a 20-minute case study on PWS presented by Shawn McCandless, MD, Chair of the Department of Genetics and Metabolism at Children's Hospital Colorado.

While this ECHO series is only for healthcare providers to attend, recordings of the webinars will be made available for our PWS families on our website. We encourage you to share this opportunity with the healthcare professionals in your life! You can download our ECHO 4 PWS flyer at the button below.

[DOWNLOAD THE FLYER HERE](#)

[REGISTRATION LINK](#)

The Deadline is Quickly Approaching to Receive Research Funding from PWSA | USA

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](#)

Research Opportunity: Prenatal Possibilities



Information provided by Hunter College and the University of North Carolina-Charlotte:

Are you pregnant AND have received a prenatal diagnosis? Do you want to know if you will be eligible for early intervention for infants and toddlers with or at risk for developmental delays or disabilities? Would you like to learn more about the types of support and resources available to you and your baby? You're invited to participate in an intervention study to help prepare you for the birth of your child and enrollment in early intervention after

your baby's birth.

Interested? Email the research team at infoprenatal@uncc.edu.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

PWSA | USA'S **SPOTLIGHT ON HOPE**



On Wednesday, April 19th, Jacob Frazier, who is the brother to Joseph Frazier (living with PWS), delivered his senior thesis entitled *The Rare Disease Dilemma*. He gave a 20-minute memorized presentation, followed by a Q&A session with a panel composed of academics and professionals.

Jacob has a heart to bring awareness to Prader-Willi syndrome and other rare diseases. His topic covered the importance of providing accessible healthcare to patients, including lowering the barrier of high costs associated with rare diseases.

Jacob's proposal was for the U.S. government to initiate a comprehensive public-private partnership to increase development and availability of specialty drugs and specialists.

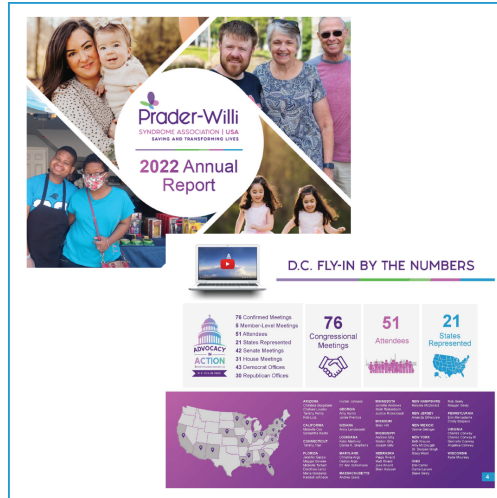
Jacob had two advisors on his project: Maria Picone, Founder and CEO of TREND Community, and Dorothea Lantz, our amazing Advocacy leader for PWSA | USA.

Congratulations, Jacob! We love seeing siblings advance the cause.

Learn about PWSA | USA's 2022 Impact in our Annual Report!

We are pleased to share our 2022 Annual Report, which gives you a look into PWSA | USA's accomplishments, impact, and growth from the past year. You can download the Annual Report by clicking the button below.

We look forward to sharing more initiatives, programs, and events with you in 2023 and beyond!



[DOWNLOAD THE ANNUAL REPORT 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!

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1032 E Brandon Blvd #4744 Brandon, FL 33511

PWSA | USA Special Edition Pulse: April 28, 2023

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YOU Can Help Shine a Light on Prader-Willi Syndrome Awareness Month!

The month of May is an important time for our rare disease community because it's recognized as Prader-Willi Syndrome Awareness Month. While advocacy efforts, the fight for research advancements, and celebration of our loved ones is important 365 days a year, the 31 days in May offer an opportunity to really show off our PWS pride. Throughout this email, we share several different ways YOU can make an impact!

**HERE'S HOW YOU CAN GET INVOLVED
THIS PWS AWARENESS MONTH**

PWS Jeopardy



To celebrate and raise awareness for PWS Awareness Month, bring your family, friends, and brain power for a fun night of PWS Jeopardy.

FREE for all to attend!

When: Monday, May 15, 2023

Games at 7:30 pm EST and
9:00 pm EST

Where: Zoom

[Click Here to Register
& Learn More](#)

Spread HOPE This PWS Awareness Month



Calling all PWS families! Send PWSA | USA a video of yourself, your family, or your loved one living with PWS saying the word "Hope" and then the phrase "United in Hope"! We will share these Hope videos on our social media pages throughout PWS Awareness Month to inspire others AND in a special video at our [37th National Convention](#).

[Click here](#) to upload your video and contact communications@pwsausa.org with any questions.

Request a Proclamation or Resolution for PWS Awareness Day (May 15th) or PWS Awareness Month (May)



One great way to help raise awareness for PWS during the month of May is by requesting a proclamation or resolution from your local and/or state government. PWSA | USA's Director of Community Engagement Dorothea Lantz shares what steps need to be taken to have PWS Awareness Day (May 15th) or May as PWS Awareness Month recognized in your area.

Click the button below to get the full details and make sure you share your proclamation journey with us at advocacy@pwsausa.org!

LEARN MORE HERE

Attend the FDA Externally-Led Patient Focused Drug Development (EL-PFDD) Meeting



YOU have the chance to
raise your voice.

The Prader-Willi Syndrome community is invited to attend our first [FDA Externally-Led Patient-Focused Drug Development \(EL-PFDD\) meeting](#) at PWSA | USA's National Convention this summer.

This meeting provides an opportunity for patients, caregivers, and advocates to share their perspectives and experiences with the FDA and drug developers. By attending this meeting, you can make your voice heard and help shape the development of new treatments and therapies for Prader-Willi syndrome. Together, we can work towards improving the lives of those affected by this rare and complex genetic disorder.

Don't miss this chance to be part of the conversation and make a difference in the future of PWS treatment options. You can attend the meeting **in-person** on June 22, 2023, at the Hilton Orlando Buena Vista Palace by registering for the [37th National Convention](#). You can also attend the meeting **virtually** by registering at the button below. Participation, both virtually and in-person, is FREE for all!

[CLICK HERE TO REGISTER FOR THE VIRTUAL MEETING](#)



“ Submit a Testimonial for the
"Voice of the Patient" Report

[CLICK HERE](#)

Wear Your Purple for PWS!

We're encouraging our PWS community to wear **purple** on May 15th! Tell your friends, family, co-workers, neighbors, anyone and everyone you know to participate, and then share your PWS pride with the world by posting photos in your purple gear. And don't forget to tag PWSA | USA so we can cheer you on!

[PWSA | USA's Facebook](#)

[PWSA | USA's Instagram](#)

[PWSA | USA's Twitter](#)

[PWSA | USA's LinkedIn](#)



15 Ways to Raise Awareness



There are many additional ways you can help raise awareness for Prader-Willi syndrome in May and all year long! We have highlighted 15 easy ways to take action, including thanking your healthcare providers, becoming a volunteer or family mentor, and hosting your own Wear Jeans for Rare Jeans fundraiser!

Click on the button below to learn more.

[LEARN MORE HERE](#)

 PWSA | USA'S
SPOTLIGHT ON HOPE



Two amazing young girls, Rose and Fiona who are both living with PWS, wanted to do something extra special to shine a light on PWS Awareness Month and support PWSA | USA. The best friends made a plan to host a t-shirt sale at their elementary school and it came together bigger and better than they expected!

"Fiona and Rose support each other in every way. They have been together since before age two sharing special times in "playdates" for OT and speech therapy, then

went on to pre-K early learning classes together, and now kindergarten. Rose and Fiona have a special bond as they face similar challenges and celebrate their victories together. They cheer each other on, spend fun moments together, and help each other not only to feel included, but to thrive. Now they have joined efforts to raise awareness about PWS at their elementary school," said Becky Hall, mom to Fiona.

With the help of their moms, the school shared a flyer promoting the t-shirts in a teacher newsletter, and the word has since spread far and wide. Not only are purchases coming in from across the U.S., but they were able to add more items than just t-shirts. Thank you notecards and onesies are now available in their shop too!

We are blown away by Rose and Fiona's awareness efforts, inspired by their incredible friendship, and grateful to them for donating proceeds from the sales to PWSA | USA's family support, advocacy, and research programs. Thank you, Rose and Fiona! You can purchase these PWS Awareness items by clicking the buttons below.





**PURCHASE ONESIES
HERE**



**PURCHASE T-SHIRTS
HERE**

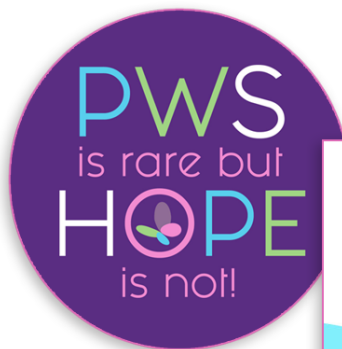


**PURCHASE CARDS
HERE**

LEARN MORE ABOUT PRADER-WILLI SYNDROME WITH PWSA | USA'S PWS FACTS TOOLKIT



DOWNLOAD THE TOOLKIT HERE



Spread Awareness on Social Media!

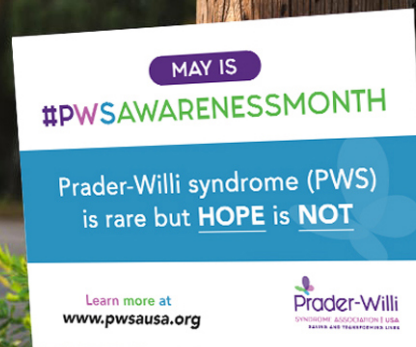


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MEDIA GRAPHICS HERE

PWS Awareness Month Yard Sign

Download PWSA |
USA's PWS Awareness
Month yard sign by
clicking the button
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We Hope You will Join us in Raising Awareness for
our Rare Disease Community Throughout the
Month of May!



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