Don't Miss the Opportunity to Gather Together Again In-Person!

Register TODAY for PWSA | USA’s 37th National Convention! We invite you to join us June 21 – June 24, 2023, in sunny Orlando, Florida at the Hilton Orlando Buena Vista Palace.

PWSA | USA’s Convention will provide exciting opportunities to learn, connect (and reconnect), and hear about the latest PWS research. This world-class event will include Medical & Scientific, Professional Providers, and Family Conferences, as well as the newly renamed "PWS Kids Camp" for infants through adults living with PWS and their siblings. We are also honored to host and include all PWS stakeholders during our Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting, which is an FDA program.

Whether you have a loved one with PWS, are a professional provider, a physician, or scientist, the 2023 Convention has something for everyone. Register at the button below. We hope to see you there!
On behalf of PWSA Arizona:

PWSAA is fundraising to send selected Arizona parents/caregivers to PWSA | USA's National Convention in Orlando, Florida! Priority will be given to those who have never been or would be unlikely to attend otherwise.

Click the button below to learn more and to make a contribution. Thank you!

LEARN MORE HERE
Our 2022 Angel Drive Campaign has come to an end, and on behalf of our staff, Board of Directors, and volunteers, we want to extend a heartfelt **THANK YOU** for your donation! Your contributions will support several Advocacy, Family Support, and Research initiatives in 2023 that will greatly benefit our PWS families.

Know that through these gifts, you have made a true impact on our community!

Warm regards,

Paige Rivard, MBA | CEO
Mom to Jake (12)
2022 was a groundbreaking year for PWSA | USA's Advocacy efforts and it's thanks to you, our amazing community and volunteers. As we step into a new year, we are excited to share more advocacy opportunities on the horizon.

Please join us Tuesday, January 17, 2023, at 8:00 p.m. EST with PWSA | USA's Director of Community Engagement Dorothea Lantz for our first 2023 Advocacy in Action webinar. Dorothea will share details about upcoming initiatives and the much-anticipated launch of PWSA | USA's *Walk a Mile in Their Genes*! We can't wait to show you what's in store.
Register in advance by clicking the button below.

REGISTER IN ADVANCE HERE

Shine a Light on Rare Disease Day!

Tuesday, February 28, 2023, is Rare Disease Day and we are asking YOU, our PWS community, to help once again shine a light on this important day! You can be part of a global chain of lights in recognition of Rare Disease Day either by helping to light up monuments or buildings near you in Rare Disease Day colors (blue, green, pink, and purple). You can even light your own home in these colors and encourage your friends and neighbors to do the same!

Our ask to the PWS community is if you receive approval from a landmark in your area, or if you simply light up your home in Rare Disease Day colors, please share a picture with us at communications@pwsausa.org. Through this effort, we can show the world just how important Rare Disease Day is to our community.

LEARN MORE HERE

FAMILY SUPPORT

There's Still Time to Register for PWSA | USA's First-Ever Behavior Summit
There's still time to register for PWSA | USA's first-ever Behavior Summit, which will be held **Tuesday, January 24, 2023 from 2:00 - 7:45 p.m. EST**! The Summit will include several webinar presentations from specialists who are experts in behavior issues, and is for both parents and healthcare providers.

During this FREE virtual event, you will learn about the ABCs of behavior, how to prevent challenging behaviors, and so much more! Click the button below to register **TODAY**!

**REGISTER HERE**

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**SAVE THE DATE**

**Thursday, March 9, 2023 | Virtual Event**

**More details and registration coming soon!**

**RESEARCH**

**Calling All PWS Health Professionals!**
PWSA | USA is welcoming Abstract submissions for a presentation of recent research, related scientific or medical topics on the subject of Prader-Willi syndrome for our 2023 Medical & Scientific Conference. The Medical & Scientific Conference will be held at PWSA | USA's 37th National Convention June 21-22, 2023, in Orlando, FL. The deadline to submit an Abstract is January 31, 2023.

Click here to view the step-by-step process on how to submit an Abstract. We also encourage you to click here to read through our Abstract Submission Guidelines.

CALL FOR ABSTRACTS

Calling All PWS Caregivers!

The Chicago School of Professional Psychology is looking for PWS caregivers to participate in an asynchronous computer training on medication and data collection procedures. Upon completion, you will be entered to win a $50 Amazon gift card!

Click the button below to learn more about this opportunity and to find the training link. Thank you!
PWSA | USA ANNOUNCEMENTS

PWSA | USA Closed Friday, January 13th for Staff Event

We want to let our community know that PWSA | USA will be closed Friday, January 13, 2023, for a Staff Retreat. We will have limited availability to phone and email, and will return any missed calls.

We appreciate your understanding and flexibility as we take this opportunity to gather as a team!

PWSA | USA will also be closed Monday, January 16, 2023, in observance of Martin Luther King Jr. Day. If you are in need of assistance, our 24-Hour Support Line will be open at (312) 941-0400.

There is Just ONE WEEK LEFT to Support PWSA | USA in This Year's Combined Federal Campaign (CFC)

Are you a current or retired federal employee? The CFC is a program through which you can give to the charity of your choice through January 14, 2023.

The campaign’s mission is to provide “all federal employees the opportunity to improve the quality of life for all.” Please consider supporting PWSA | USA as we continue to provide help and hope to families around the world.

PWSA | USA’s CFC ID # is 10088
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
It Pays to Plan Ahead: Don't Miss Out on National Convention Early Bird Prices!

Are you planning to attend PWSA | USA’s 37th National Convention? Don't wait to register!

Early bird pricing for Convention registration is available through May 31, 2023! Prices will increase between $25-$50 (depending on the type of registration) beginning June 1, 2023. You won't want to miss this opportunity to gather together in-person to connect (and re-connect) with other PWS parents and families, health professionals, and our loved ones living with PWS.

The 2023 National Convention will be held June 21st - 24th in sunny Orlando, FL at the Hilton Orlando Buena Vista Palace. Learn more about the Convention, book your hotel, and register for Conferences, the Hope United Gala, and Kids' Camps at the button below. We hope to see you there!
Introducing PWS Camp - A fun and safe space for your loved one living with PWS (children AND adults) and their siblings to connect with peers and make new friendships. The PWS Camp is available throughout the Family Conference (June 23 & 24, 2023)

Click here to learn more >>

Tickets for the 9th Annual Clint Hurdle Hot Stove Dinner are NOW AVAILABLE for Purchase!

PWSA | USA Behavior Summit

When: January 24, 2023

Learn more here
The 9th Annual Clint Hurdle Hot Stove Dinner, which benefits PWSA | USA, will take place on Saturday, March 25, 2023. We are excited to have you join us at the Key Royale Club on beautiful Anna Maria Island in Florida.

Tickets and donations are now available online at the button above, and there is even a virtual ticket for those of you that can’t attend or prefer to enjoy the event from the comfort of home! Get your tickets, consider an event sponsorship, and tell all your friends.

To those that have participated or donated in the past... THANK YOU. Your generous support has helped many PWS families. If everyone can lend a hand, we can make a huge difference in the lives of our families and children.

Get to Know PWSA | USA’s Newest Advocacy Initiative!

We can continue to make our voices and our stories heard through advocacy and community outreach. By joining PWSA | USA’s “Walk a Mile in their
"Genes" advocacy campaign, participants will not only raise awareness about PWS, but they will raise much needed funds to enable PWSA | USA to continue to provide the services our community needs. This virtual/in-person fitness challenge is open to all ages and fitness levels to promote health and wellness, while supporting the Prader-Willi community. You can sign up as a Walk a Mile in their Genes participant or make donations through March 19, 2023, at the button below. Thank you for taking action!

Learn more about this exciting initiative by clicking the image below to watch Tuesday’s Advocacy in Action webinar.

Wear Jeans in Support of Rare Genes to Recognize Rare Disease Day!

Have you been looking for an easy way to raise awareness and funds to support PWSA | USA in your workplace, school, or community group?
In recognition of **Rare Disease Day**, February 28, 2023, we encourage members of our PWS community to host a Hope United "Wear Jeans for Rare Genes" fundraiser! YOU can help PWSA | USA provide care for families in our community by simply wearing your jeans and donating a few dollars. Pick a date to host a "Wear Jeans for Rare Genes" fundraiser with your employer, your child’s school, church fellowship, etc.

Click the images below to learn how easy it is to host a "Wear Jeans for Rare Genes" fundraiser, and to download helpful, customizable documents to start the process. Contact us at hopeunited@pwsausa.org with any questions.

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**Wear Jeans for Rare Genes Letter**

**Wear Jeans for Rare Genes Flyer**
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There's Still Time to Register for PWSA | USA's First-Ever Behavior Summit

Don't forget to join us Tuesday, January 24, 2023 from 2:00 - 7:45 p.m. EST for PWSA | USA's first ever Behavior Summit. The Summit will include several webinar presentations from specialists who are experts in behavior issues, and is for both parents and healthcare providers.

During this FREE virtual event, you will learn about the ABCs of behavior, how to prevent challenging behaviors, and so much more! Click the button below to register TODAY!

Calling all PWS Parents, Siblings, Grandparents, and Caregivers: Send in Your Messages of Hope

PWSA | USA's Family Support Team is asking the PWS community to share Messages of Hope that will be featured in our New Diagnosis Package. This important publication will be sent to new families who receive a PWS diagnosis. It is our hope that your messages will encourage families to see past the diagnosis and see their child through their own eyes, and not a definition of PWS.

By sharing our community's stories and experiences, others will feel embraced and supported in their journey. One of the biggest gifts from PWS is our community: the fact that we are NOT alone in this. We have a community that celebrates every victory, and applauds even the smallest successes!
Time is Running Out to Submit an Abstract for PWSA | USA's National Convention!

PWSA | USA is welcoming Abstract submissions for a poster presentation and/or oral presentation of recent research, related scientific or medical topics on the subject of Prader-Willi syndrome for our 2023 Medical & Scientific Conference. The Medical & Scientific Conference will be held at PWSA | USA's 37th National Convention June 21-22, 2023, in Orlando, FL. The deadline to submit an Abstract is January 31, 2023. 

Click here to view the step-by-step process on how to submit an Abstract. We also encourage you to click here to read through our Abstract Submission Guidelines.
We are deeply saddened by the passing of Megan Lynn McKenny, who passed away on December 8, 2022, at the age of 28.

According to Megan's obituary, "Megan attended Holy Rosary School and graduated from St. Benedict of Auburndale, class of 2013. She loved volunteering at church and being with friends and family."
The family requests that any donations in Megan’s memory be sent to PWSA | USA, 1032 E. Brandon Blvd. #4744 Brandon, FL 33511, or be made at the button below.

DONATE

PWSA | USA GRIEF COUNSELING AVAILABLE

Grief can occur with any loss and grieving is a necessary step in the healing process. PWSA | USA offers grief support to individuals diagnosed with PWS and to parents, family members, and caregivers who may be dealing with any type of grief. If you are interested in receiving grief counseling, please give us a call at 941.312.0400.

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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Prader-Willi Syndrome Association | USA
1032 E Brandon Blvd #4744 Brandon, FL 33511
Introducing PWSA | USA's Resource Hub!

PWSA | USA has been hard at work building a Resource Hub for our PWS community, and while it mostly includes helpful publications for parents, siblings, grandparents and caregivers, these resources are available for anyone and everyone.

Publications in the Resource Hub are free to download and use. They were created by members of our Family Support Team and volunteers over the years, now compiled into one easy-to-navigate space! The Resource Hub will continue to grow, with new documents, booklets, brochures, cards, etc. being added on a regular basis.

Scroll below to see what PWSA | USA's Resource Hub has to offer!
Behavior Management Resources

The Behavior Management resource page includes several publications including *Behavior and the Collaborative Problem-Solving*, *Behavior Management Guidelines*, *Preventing Challenging Behavior*, and more!

Booklet Resources

The Booklet resource page includes several publications including *Medical Reference Guide for Parents*, *Grandparent eBooklet*, *Supporting Adults in Residential Settings*, and more!
Brochure Resources
The Brochure resource page includes several publications including *Helping All Families and Professionals*, *Q&A About PWS*, *Supporting Someone with PWS*, and more!

Card Resources
Find various helpful cards on this resource page including the PWS Customizable I.D. Card and IEP Meeting Card.

Diagnosis & Testing Resources
The Diagnosis & Testing resource page includes two documents: *The Genetics of PWS* (an explanation for

Diet & Nutrition Resources
The Diet & Nutrition resource page includes several publications including *Seven Nutritional Phases*
the rest of us) and *PWS and Obesity, and PWS Look-Alikes.*

**Family & Sibling Resources**

The Family & Sibling resource page includes several publications including *A Life Less Perfect, Being a Dad,* and more! You can help us grow our family and sibling resources by sharing your PWS journey with PWSA | USA. **Click Here** if you're interested in sharing your story.

**Financial Literacy Resources**

The Financial Literacy resource page offers an interactive map to Medicaid Waivers in your state, videos about financial management, special needs trusts, and financial planning for special needs families, as well as helpful documents provided by the Global Genes Global Advocacy Alliance.
Food Security Resources

The Food Security resource page includes two documents: *Follow the Principles of Food Security* and *Food Security Locks and Alarms*.

Legal Resources

The Legal resource page includes several publications including *PWS and Theft, Allegations of Abuse and/or Neglect in the Person with Prader-Willi syndrome* and more!

Medical Resources

The Medical A-Z resource page includes several publications on various topics including dental issues, breathing/respiratory concerns, GI problems, scoliosis, and more!

NICU Resources

Our Navigating the NICU resource page is available to help families who are newly diagnosed. You will find information about communication in the NICU, a letter for NICU doctors, a NICU overview, and more.
School Success Resources

The School Success resource section has many helpful tips, tricks, and tools for navigating the education system - whether it is at home or in-person. Find information about PWS challenges and solutions, Individualized Education Program (IEP), homeschooling, effective advocacy, and more!

If you are in need of additional support or have any questions, our 24-Hour Support Line is always available at (941) 312-0400