

Bi-Weekly Pulse: February 3, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 68

February 3, 2023

www.pwsausa.org | 941.312.0400

Do you have Questions About PWSA | USA's 37th National Convention? We will Share the Answers!

Join with several members of PWSA | USA's staff **Tuesday, February 21, 2023 at 8:00 p.m. EST** to learn the ins and outs of our 37th National Convention! We are excited to share more details and answer questions about this year's Convention events, speakers, opportunities for families, caregivers, and health professionals, and how you can participate and bring your voice to the highly-anticipated FDA Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting. We will also walk through and answer any questions to help you navigate the registration process.



You won't want to miss this informative, FREE webinar as we get ready to gather together again in-person, June 21-24, 2023 at the Hilton Orlando Buena Vista Palace in Orlando, FL. Click the button below to register in advance. We hope to see you there!

[REGISTER FOR THE COMMUNITY CONVERSATION HERE](#)

[REGISTER FOR THE 37TH NATIONAL CONVENTION HERE](#)



We know that many of you want to make a difference in the lives of members of our PWS Community – and we have the perfect opportunity if you, or one of your family or friends, are a CPA.

Our fabulous treasurer is retiring in March after many years of excellent service to our association. There are staff members in place that provide the day-to-day duties in regards to finance, so this volunteer position will oversee the preparation of the Form 990, and actively participate in various virtual meetings such as the Finance and Executive Committee meetings. It is estimated that the time commitment is 15-20 hours per month.

A Certified Public Accountant is preferred, with experience in nonprofit accounting and tax laws. Experience with Blackbaud's Financial Edge software is a plus. We know that someone in our community – or in their

SAVE THE DATE

[Upcoming Events >>>](#)



Advocacy in Action: Arizona State Qualifier Campaign

When: February 16, 2023

[Learn More Here](#)



Community Conversation: 2023 National Convention Q & A

When: February 21, 2023

[Register in Advance Here](#)



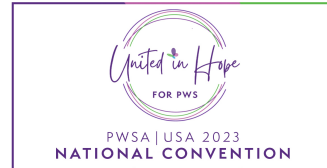
2023 Clint Hurdle Hot Stove Dinner

network of friends and family members – is the ideal fit for this position. Please contact CEO Paige Rivard, privard@pwsausa.org, for more information or to apply.

When: March 25, 2023

In-person tickets are SOLD OUT but you can still attend virtually by clicking [here](#)

*Thank You for
Your Interest!*



37th National Convention

When: June 21 - 24, 2023

[Register Here](#)



ADVOCACY



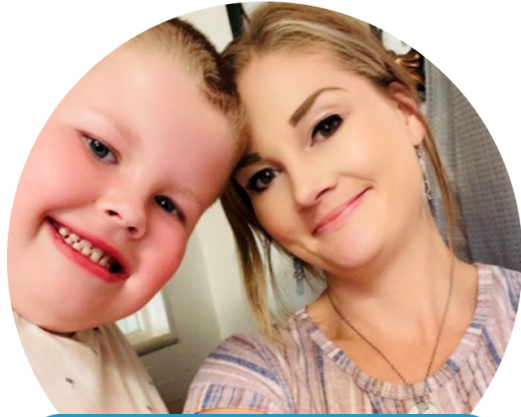
Advocacy in Action Webinar: Arizona State Qualifier Campaign

Thursday, February 16, 2023 | 8:00 p.m. EST

Register TODAY for PWSA | USA's free February Advocacy in Action webinar, where several PWSA Arizona Chapter leaders will discuss the **Arizona State Qualifier Campaign**. PWS is only recognized in 14 states as an automatic qualifying condition. Join us as we bring you the leaders of our Arizona State Chapter who are fighting to make Arizona the 15th! Crissy Burgstaler, Chelsea Loucks, Lisa Lamb and Tammie Penta will walk us through their Arizona campaign and help educate our community on the steps they've taken to make this happen.



Crissy Burgstaler
Mom to Amalia, 3, living
with PWS



Chelsee Loucks
Mom to Stanley, 8, living
with PWS



Lisa Lamb
Mom to Makenna, 12, living
with PWS



Tammie Penta
Mom to Victor, 29, living
with PWS

[LEARN MORE AND REGISTER HERE](#)

Walk a Mile in Their Genes in Support of Rare Disease Day 2023

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!

[SIGN UP AS A WALK A MILE IN THEIR GENES PARTICIPANT](#)

When you enter the Walk a Mile in their Genes website, select "Get Started" to join as a new participant. You will then be prompted to fill out our Hope United form to set up your personal Walk a Mile in their genes fundraiser page.

IMPORTANT NOTE: There will be 1st, 2nd, and 3rd place prizes for the top three campaign fundraisers!

| | | |
|---|---|---|
|  <p>One 37th National Convention Family Conference Registration</p> <p>One Convention Kids Camp Registration</p> <p>One Hope United Gala Registration</p> |  <p>One 37th National Convention Family Conference Registration</p> |  <p>One Hope United Gala Registration</p> |
|---|---|---|

OUR TOP PARTICIPANTS

| | |
|------------------|---------|
| Jennifer Garzia | \$2,830 |
| Lisa Lamb | \$900 |
| Michelle Cox | \$390 |
| Dorothea Lantz | \$250 |
| Jessica Kempa | \$100 |
| Valerie Selinger | \$100 |
| Maggie Andrews | \$100 |



“Family and friends began to ask how they can help my son Rocco live his best life. My first thought was to increase research through fundraising. Melanie at PWSA | USA was my first call and she had Rocco’s Walk a Mile in their Genes page up and running within minutes. PWS has invested in a system that is user friendly and time efficient. I’m looking forward to utilizing the fundraising app with Melanie’s help for future events!”

- Jennifer Garzia, Mom to Rocco living with PWS

**PWS Advocates are Getting Ready to Raise Awareness for
our Rare Disease Community on Capitol Hill!**



Between February 28th and March 2nd, **14** PWS advocates will gather on Capitol Hill for RARE Disease Week! Now in its 12th year, **Rare Disease Week on Capitol Hill** empowers and inspires hundreds of advocates each year. The connections you make during the week will impact rare disease patients for generations to come. Hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases), the multiday event brings together rare disease advocates from across the country to make

their voices heard by their Members of Congress. Participants are educated on policy proposals impacting the rare disease community and provided opportunities to advocate for policy changes directly to their Members of Congress. No matter one's connection to rare disease or their advocacy experience level, all are welcome.

If you are interested in attending, there is still time to register at: [Rare Disease Week 2023 - EveryLife Foundation for Rare Diseases](https://www.everylifefoundation.org/rare-disease-week-2023). Registration closes on February 17, 2023! If you register, please email Advocacy@pwsausa.org so that we may include you in our group activities.



FAMILY SUPPORT



Prader-Willi Syndrome Association | USA

BEHAVIOR SUMMIT

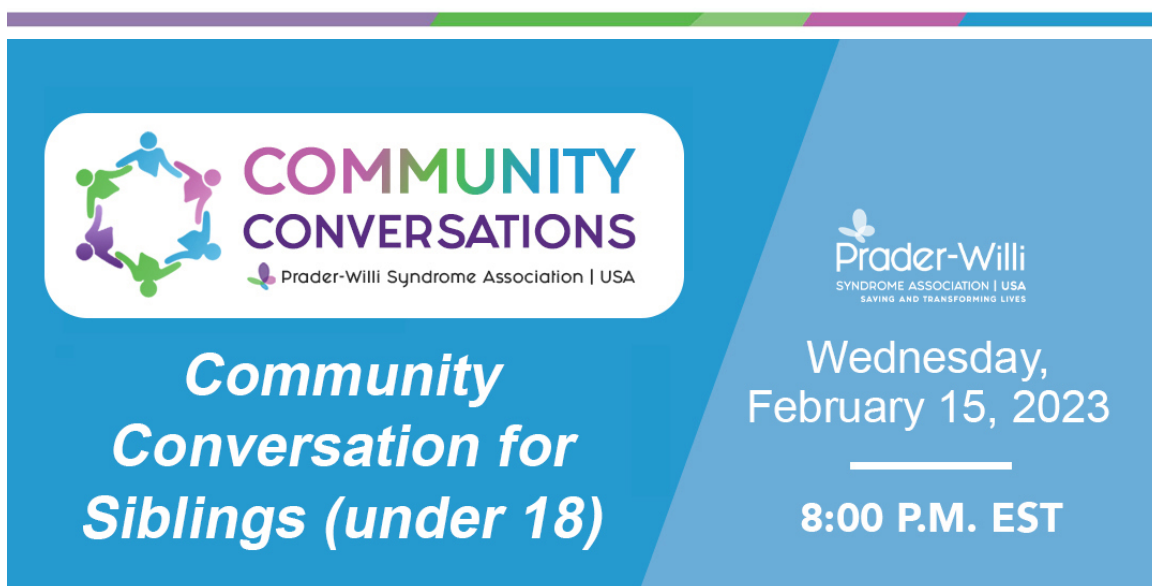
Webinar Recordings Now Available!



Thank you to those who joined PWSA | USA's first-ever Behavior Summit last week! All four recordings and downloadable presentations are now available at the button below.

A special thank you to our incredible speakers for sharing their knowledge and expertise with the PWS community.

[WATCH BEHAVIOR SUMMIT RECORDINGS HERE](#)



The banner features a blue background with a white rounded rectangle on the left containing the 'COMMUNITY CONVERSATIONS' logo and the text 'Prader-Willi Syndrome Association | USA'. To the right of this rectangle, the text 'Community Conversation for Siblings (under 18)' is written in white. Further right, the date 'Wednesday, February 15, 2023' and time '8:00 P.M. EST' are displayed in white. The Prader-Willi Syndrome Association logo is also present on the right side of the banner.

Siblings (aged 18 and under) of loved ones living with PWS are invited to join PWSA | USA for our February Siblings Community Conversation, February 16, 2023 at 8:00 p.m. EST. This webinar will provide an open space for dialogue between siblings in this age group. PWSA | USA Family Support members will also be available to offer any insight and support.

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

[SIBLINGS CAN REGISTER IN ADVANCE HERE](#)

**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

Messages of Hope



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!

[Share your Message of Hope Here](#)



RESEARCH

Call for Abstracts: Submission Deadline EXTENDED to February 17, 2023



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 has been extended to Friday, February 17, 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.

**Click Here to Submit
an Abstract**

Calling All PWS Parents and Caregivers



The Chicago School of Professional Psychology is asking parents and caregivers in the PWS community to participate in a brief survey to investigate challenges that parents have when completing daily self-care skills with their child with PWS. This survey is for parents and caregivers with a child between the ages of 12-25 living with PWS. To learn more and to participate in the survey, please click the button below. Thank you!

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

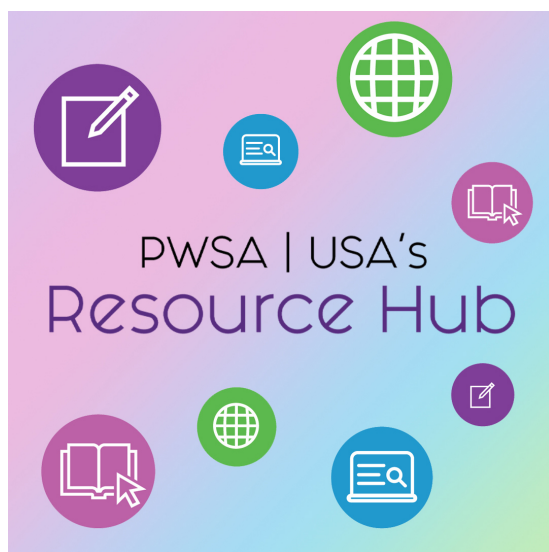


2023 Clint Hurdle Hot Stove **Coconut Helicopter Drop** golf balls and **raffle tickets** are now available for purchase for both in-person and virtual attendees!

CLICK HERE TO LEARN MORE!

In-person tickets for the 2023 Clint Hurdle Hot Stove Dinner are **SOLD OUT** but Virtual tickets are still available! Purchase yours TODAY by [clicking here](#).

Find Many Helpful PWS Publications in PWSA | USA's New 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.

Click the button below to see what PWSA | USA's Resource Hub has to offer!



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](#)



[Privacy Policy](#) | [Unsubscribe](#)

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

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Enhancing the Quality of Life and Empowering Those Affected by PWS



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Countdown to Convention



DAYS TO GO!



Join with several members of PWSA | USA's staff **February 21, 2023 at 8:00 p.m. EST** to learn the ins and outs of our 37th National Convention! We are excited to share more details and answer questions about this year's Convention events, speakers, opportunities for families, caregivers, and health professionals, and how you can participate and bring your voice to the highly-anticipated FDA Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting. Learn more and register in advance at the button below.

37th National Convention Q & A



[Click Here to Register for the Convention
Q & A Community Conversation](#)

Thanks to the generosity of an anonymous donor, PWSA | USA is offering scholarships for the 2023 National Convention. Guidelines for submitting a scholarship application are as follows:

- You must be a first-time PWSA | USA National Convention attendee
- Scholarship funds can be applied toward a Conference registration, the Hope United Gala, A Night Under the Stars Gala, PWS camps for your children and/or adults living with PWS and their siblings, and your hotel stay
- **There are limited scholarship opportunities available**



**PWSA | USA is Accepting
National Convention
Scholarship
Applications**

You can access our Convention scholarship application at the button below. Please submit your application to info@pwsausa.org no later than **Tuesday, February 28, 2023**. If you have questions, contact us at info@pwsausa.org or (941) 312-0400.

Click Here to Download PWSA | USA's Convention Scholarship Application

PWSA | USA is excited to share a first-look at our **37th National Convention schedule**. Download the document below to find information about the Medical and Scientific, Professional Providers, and Family Conferences, as well as events that will take place between June 21-24, 2023 in Orlando, FL.

*Be on the lookout for our **FULL** Convention schedule, which will be unveiled soon!*

| PWSA USA's 37th National Convention Schedule | | | | PWSA USA's 37th National Convention Schedule | | | |
|---|--|--|--|--|--|---|--|
| Medical and Scientific Conference, Professional Providers Conference, and the Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD) | | | | Family Conference and PWS Camps | | | |
| June 21-24, 2023 • Hilton Orlando Buena Vista Palace | | | | June 21-24, 2023 • Hilton Orlando Buena Vista Palace | | | |
| Wednesday, June 21, 2023 | Thursday, June 22, 2023 | Thursday, June 22, 2023 (cont.) | Thursday, June 22, 2023 (cont.) | Friday, June 23, 2023 | Saturday, June 24, 2023 | PWS Camps • June 23-24, 2023 | |
| Medical and Scientific Conference / DAY 1 8:00 a.m. - 6:00 p.m. During this one and a half day event, scientists, researchers, and medical professionals from different disciplines share ideas and report on progress. This opportunity helps to meet the ever-present goal to support research that will identify effective treatment and improve the quality of life for individuals diagnosed with PWS. Parents and students are welcome to register to attend the Medical and Scientific Conference as observers. 8:00 a.m. - 9:30 a.m. Welcome to the Medical and Scientific Conference - James Laker, MD and Ann Manzardo, PhD CME Overview - Ann Schumann, MD, MBA Keynote Presentation - Tony Holland, MD 9:30 a.m. - 12:00 p.m. Presentations from Deepan Singh, MD and Morte Angeli, MD (Topics coming soon!) 1:00 p.m. - 3:30 p.m. Medical Practice Update Oral Abstract Presentations 4:00 p.m. - 6:00 p.m. Medical and Scientific Conference Reception and Poster Abstract Presentations | Medical and Scientific Conference / DAY 2 8:00 a.m. - 11:30 a.m. Welcome to Day Two of the Medical and Scientific Conference - James Laker, MD and Ann Manzardo, PhD Presentation from Jessica Doh, MD (Topic coming soon) PWS Clinical Trial Endpoints Roundtable 10:30 a.m. - 11:30 a.m. Oral Abstract Presentations Closing Remarks FDA Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD) Landmark meeting to bring together the PWS patient voice. 12:00 p.m. - 4:30 p.m. Free for all Convention attendees 12:30 p.m. - 2:45 p.m. Patient Panels Person with PWS open panel PWS clinical trial discussion 2:45 p.m. - 4:30 p.m. Symposium and facilitated discussion PFDD-driven clinical trial design in PWS Stakeholder panel discussion Closing remarks | Professional Providers Conference 8:00 a.m. - 4:30 p.m. This is an opportunity for Educational, Social Services, Vocational and Residential professional providers to come together to discuss identified and supported best practice and standard of care approaches, as well as to provide a critical in-person, solutions-oriented exchange of ideas for specific concerns that can be addressed by experts in the field. 8:45 a.m. - 9:00 a.m. Welcome to the Professional Providers Conference - Stacy Ward, MS, Lynn Garrick, RN, and Jen Dayton 9:00 a.m. - 2:00 p.m. Staff Burnout / Caregiver Fatigue - Jessica Zarate, MA, MS When Someone is their Own Guardian - Tony Holland, MD Behavior / Skin Picking - Kirsty Sedard, PhD, BCBA-D Multi-Disciplinary Teams and Aging - Mary Catalano, MD and Lynn Garrick, RN Internet / Social Media Access - Porrice Carroll, LICSW and Britt Klement M.Ed. 2:00 p.m. - 4:30 p.m. Small group sharing sessions: Maximizing your Rates, Security / Relationship Building, Internet Safety, Smart Homes - Using Technology, Doing More with Less Money, Day Supports | Family Conference Kick-Off Events 4:30 p.m. - 9:00 p.m. This two-day event attracts parents, grandparents, caregivers, and professionals. The attendees are skillfully guided through a series of modules learning topics covering an array of topics that can be tailored to their individual preferences. It is a time to build relationships with other families, learn from top speakers and authorities on PWS, and have fun. Experts in the field provide attendees with up-to-date information and resources for addressing the very complex needs of supporting and caring for an individual diagnosed with PWS. 4:30 p.m. - 6:30 p.m. Dad's Den 6:30 p.m. - 7:00 p.m. First Time Convention Attendee Welcome Reception 7:00 p.m. - 9:00 p.m. Family Conference Welcome Reception | Family Conference / DAY 1 8:30 a.m. - 5:00 p.m. 8:30 a.m. - 10:15 a.m. Welcome & Keynote Presentation Hear uplifting stories from people with PWS Keynote Speaker: Christa O'Laughlin, Founder/CEO, ANGEL, 400 CARES Day 1 Sessions Medical and Scientific Conference recap Standards of care Dad's panel Q&A Finding your tribe Crispedes, Meets Therapeutic journaling Pathway to independence Behaviors at home and school Living options Avoiding legal issues Caring for the caregiver And more! 4:00 p.m. - 9:30 p.m. Hope United Gala - Dazzling Performances, Silent and Live Auction 6:00 p.m. - 9:30 p.m. A Night Under the Stars Gala Children and adults living with PWS and their siblings (7 years and up) | Family Conference / DAY 2 8:30 a.m. - 5:00 p.m. Day 2 Sessions Nutritionist Special needs travel Behavior/medication management Deep schedule and policy training Mental health Sibling panel Speech and physical therapy IEP and IEP's Overheard deep ABA therapist panel Friends Chat: Q&A with PWS experts And more! 12:30 p.m. - 1:30 p.m. Family Conference Luncheon Announcement of PWSA USA's Volunteer Awards 3:45 p.m. - 5:00 p.m. Closing Ceremony 5:00 p.m. - 7:00 p.m. Family Den | PWS Camp Opportunities 8:00 a.m. - 4:30 p.m. Friday and Saturday Little Stars (2-5 years old) Formerly referred to as PWS Junior Adventure Camp, your child will be able to be cared for by staff that have worked in either the healthcare or childcare fields. There will be a variety of age appropriate activities, along with meals and snacks throughout the day. This camp is available to both children with and without PWS. Junior Adventure Camp (6-14 years old) Formerly referred to as PWS Junior Adventure Camp, your child will be able to be cared for by staff that have worked in either the healthcare or childcare fields. There will be a variety of age appropriate activities, along with meals and snacks throughout the day. This camp is available to both children with and without PWS. Adventure Camp (17 years and up) Formerly referred to as PWS Adventure Camp, your child will be able to be cared for by staff that have worked in either the healthcare or childcare fields. There will be a variety of age appropriate activities, along with meals and snacks throughout the day. This camp is available to both children with and without PWS. Sibling Camp (7-14 years old) This camp will allow your child to participate in numerous activities, make friends with other siblings, and share their experiences. The Sibling Camp may participate in office activity. More information on this will be available soon. PWS Camp Activities • Social time • Kick baseball • Arts & crafts • Drawing • Safe online games • Movies • Scavenger Hunt • Group Yoga • Soccer • And more! | |

Click Here to Download PWSA | USA's 37th National Convention Schedule

Thank You Sponsors!

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

DIAMOND SPONSOR



PLATINUM SPONSORS



BRONZE SPONSORS

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PARTNER IN HOPE SPONSORS

AME Community Services, Inc.
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Latham Centers, Inc.

EL-PFDD SPONSORS



The Steele Family
Jamie and Tiffany

PWSA CHAPTER SPONSORS

Partner in Hope Sponsors

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

Friend in Hope Sponsors

PWSA of Arizona
Prader-Willi Alliance of New York



In-person tickets for the 2023 Clint Hurdle Hot Stove Dinner are sold out but **Virtual tickets are still available!**

Support PWSA | USA's Family Support programs while enjoying the 9th Annual Clint Hurdle Hot Stove Dinner on **March 25, 2023** surrounded by family from the comfort of your home.

Virtual attendees have the opportunity to take part in all of the events that will happen on the island, including the Coconut Helicopter Drop, live auction, purchase raffle tickets, and view a special virtual program. Virtual guests will also enjoy the musical talents of country music artist Max Flinn AND receive a link to a virtual swag bag!

Learn more about this amazing event and purchase your tickets by clicking the button below.

SAVE THE DATE

[Upcoming Events >>>](#)



Community Conversation: 2023 National Convention Q & A

When: February 21, 2023

[Register in Advance Here](#)



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](#)

**PURCHASE YOUR
TICKETS HERE TODAY**



37th National Convention

When: June 21 - 24, 2023

[Register Here](#)



ADVOCACY

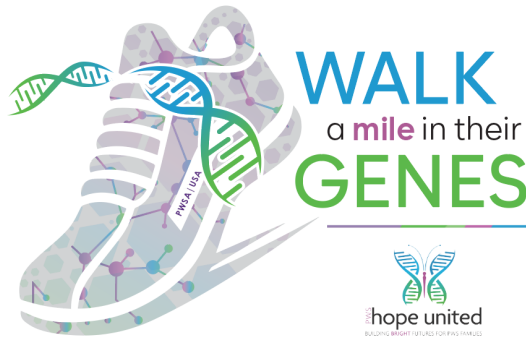
**WATCH: Advocacy in Action's Arizona State Qualifier
Campaign Webinar Recording Now Available**



If you missed Thursday's **Advocacy in Action** webinar highlighting the Arizona State Qualifier Campaign, the recording is now available by clicking the image above. A big thank you to PWSA Arizona Chapter Leaders Crissy Burgstaler, Chelsee Loucks, Lisa Lamb and Tammie Penta for walking us through their Arizona campaign and helping to educate our community on the steps they've taken to make this happen.

Rare Disease Day 2023

Walk a Mile in their Genes in Support of Rare Disease Day 2023



This is YOUR opportunity to raise awareness for Rare Disease Day 2023 and support your loved one living with PWS! 🧬❤️

PWSA | USA's Walk a Mile in their Genes advocacy fundraiser is a virtual/in-person fitness challenge that is open to all ages and fitness levels to promote health and wellness, while supporting the

Prader-Willi syndrome community. Here's a look at our current leaderboard - a big thank you to these amazing individuals for their support.

Current Leaderboard

| | |
|------------------|---------|
| Jennifer Garzia | \$3,030 |
| Lisa Lamb | \$2,250 |
| Erin Carter | \$1,185 |
| Maggie Andrews | \$1,180 |
| Jessica Kempa | \$1,065 |
| Jamie Prentice | \$863 |
| Valerie Selinger | \$836 |
| Michelle Cox | \$440 |
| Dorothea Lantz | \$250 |
| Lisa Stover | \$200 |

[CLICK HERE](#) to create your own Walk a Mile in their Genes fundraiser through **February 28, 2023!**

When you enter the Walk a Mile in their Genes website, select "Get Started" to join as a new participant. You will then be prompted to fill out our Hope United form to set up your personal Walk a Mile in their Genes fundraiser page.

IMPORTANT NOTE: There will be 1st, 2nd, and 3rd place prizes for the top three campaign fundraisers!



PWSA | USA Advocate Receives Proclamation for Rare Disease Day



Congratulations to one of our amazing PWS advocates, Sujeiri “Sue” Colon, on receiving a **Rare Disease Day Proclamation** from the mayor of Monroe Township, NJ! Sue originally contacted her local mayor's office in hopes they would be willing to participate in "Light Up" for Rare Disease Day. Upon being informed they don't have the ability to participate, the mayor offered to present her with a proclamation declaring February 28, 2023, as Rare Disease Day in the Township of Monroe. Thank you, Sue, for your hard work and dedication to our community!

If you are interested in having your local government do something similar, the best place to start is by asking. Call your municipal and/or city mayor's office, or feel free to reach out to your city commissioner and ask if they would also be willing to show their support for Rare Disease Day. It's as simple as a phone

call, and we are always here to help. If you have any questions or would like additional guidance, please contact PWSA | USA at Advocacy@pwsausa.org.

Today is the LAST DAY to Register for Rare Disease Week on Capitol Hill



Between February 28th and March 2nd, **14** PWS advocates will gather on Capitol Hill for RARE Disease Week! Now in its 12th year, **Rare Disease Week on Capitol Hill** empowers and inspires hundreds of advocates each year. The connections you make during the week will impact rare disease patients for generations to come. Hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases), the multiday event brings together rare disease advocates from across the country to make

their voices heard by their Members of Congress. Participants are educated on policy proposals impacting the rare disease community and provided opportunities to advocate for policy changes directly to their Members of Congress. No matter one's connection to rare disease or their advocacy experience level, all are welcome.

If you are interested in attending, there is still time to register at the button below. Registration closes **TODAY**, February 17, 2023! If you register, please email Advocacy@pwsausa.org so that we may include you in our group activities.

[REGISTER TO ATTEND HERE](#)

Light Up for Rare!



Join the effort to light up a landmark on Rare Disease Day! PWSA | USA staff has received confirmation the Bob Kerrey Bridge and Hubbard Center for Children in Omaha, NE will illuminate in Rare Disease Day colors (purple, pink, blue, and green) on February 28th.

Find helpful documents that will encourage landmarks near YOU to shine a light on our rare disease community at the button below.

[LEARN MORE HERE](#)



FAMILY SUPPORT



**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**

We invite you to join us 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](#)

February is National Children's Dental Health Month



Individuals of all ages affected by Prader-Willi syndrome (PWS) will eventually experience challenges with dental health. That's why we are putting a spotlight on National Children's Dental Health month by sharing resources to help your loved one living with PWS practice healthy dental care.

Click the buttons below to be directed to a variety of dental resources, compiled by PWSA | USA staff, volunteers, and medical professionals. You can also find more Medical resources on our

[Medical A-Z web page](#). If you have additional questions, our Family Support Team is available to help. Contact info@pwsausa.org or call (941) 312-0400.

[Dental Health in Children and Adults with PWS](#)

[Dental Care Tips for Children and Adults with PWS](#)

[Oral Disorders in Children with PWS](#)

Creating Your Child's Education File



Have you ever walked away from an Individualized Education Program (IEP) meeting and thought to yourself, “That’s not what they told me during the last meeting” or “Why are we having the same discussions each meeting; this is a waste of time?” Having an organized file that encompasses all documents regarding your child’s education will help alleviate the frustration you feel during these meetings.

PWSA | USA's Family Support Team outlines how to build this organized education file and gives tips on

navigating IEPs at the button below.

[READ MORE HERE](#)



RESEARCH

Today is the LAST DAY to Submit an Oral or Poster Abstract Presentation for PWSA | USA's 37th National Convention

Don't miss the opportunity to submit an Abstract for a poster 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, Florida. Today, February 17th, is the last day we will be accepting Abstract submissions.

[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.



[CLICK HERE TO SUBMIT AN ABSTRACT](#)

ICYMI: Neuren Pharmaceuticals Announces FDA Approval for Phase 2 of PWS Drug Trial



In case you missed it, Neuren Pharmaceuticals recently announced it has received FDA approval for an Investigational New Drug (IND) application for NNZ-2591 in patients with Prader-Willi syndrome. This will allow Neuren to proceed with a Phase 2 clinical trial study in children living with PWS. Positive effects from a previous study of NNZ-2591 included improved cognition and motor function, reduced anxiety, and prevention of seizures. Read Neuren's full press release announcement at the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

PWSA | USA Joins Forces with Other Rare Disease Nonprofits to Bring Back AmazonSmile



Earlier this year, Amazon announced the company plans to end its giving program, AmazonSmile. The program allowed customers to purchase products through a special AmazonSmile link, with a percentage of the purchase cost donated to a nonprofit of their choice.

The organization **Global Genes** launched a petition to bring back AmazonSmile, which has benefitted countless nonprofits over the years - PWSA | USA included. To support this endeavor, PWSA | USA joined 180 other rare disease nonprofit

organizations by signing this petition.

Click the button below to learn more and to read the letter Global Genes sent to Amazon CEO, Andy Jassy.

[LEARN MORE HERE](#)

Adoption Spotlight

On behalf of the Gladney Center for Adoption:

The Gladney Center for Adoption is currently seeking an adoptive family for a baby boy named Sashen. He was born on November 2, 2022 in Houston, Texas to a young couple that are new to the US and are without adequate support to parent the child. The family is from India originally and the baby was born with Prader-Willi syndrome.

Sashen is eating and sleeping well, growing stronger each day. He is up to 10 pounds and on NeoSure 22 calories. He has been seen by a physical therapist (PT) and occupational therapist (OT) while in the hospital and is continuing



those services in the temporary home he lives, located in Dallas, Texas. No medications or home health needs are required. The process of adoption subsidy has been started, and all legal relinquishments have been obtained from the birth parents. Besides PT and OT services, the baby has follow-up appointments with genetics, endocrinology, urology and cardiology.

The birth parents are hoping for a semi-open relationship through occasional pictures and updates.

They are a very nice, loving couple who just want what's best for Sashen.

If interested in learning more about Sashen and the adoption process, please contact:

Tanya Houk

Director of Child Advocacy
The Gladney Center

Tanya.houk@gladney.org

817-922-6078

PWSA | USA is Looking for a Volunteer Treasurer



We know that many of you want to make a difference in the lives of members of our PWS Community – and we have the perfect opportunity if you, or one of your family or friends, are a CPA.

Our fabulous treasurer is retiring in March after many years of excellent service to our association. There are staff members in place that provide

the day-to-day duties in regards to finance, so this volunteer position will oversee the preparation of the Form 990, and actively participate in various virtual meetings such as the Finance and Executive Committee meetings. It is estimated that the time commitment is 15-20 hours per month.

A Certified Public Accountant is preferred, with experience in nonprofit accounting and tax laws. Experience with Blackbaud's Financial Edge software

is a plus. We know that someone in our community – or in their network of friends and family members – is the ideal fit for this position. Please contact CEO Paige Rivard, privard@pwsausa.org, for more information or to apply.

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

February Special Edition Pulse: February 24, 2023

www.pwsausa.org | 941.312.0400


[Donate](#)




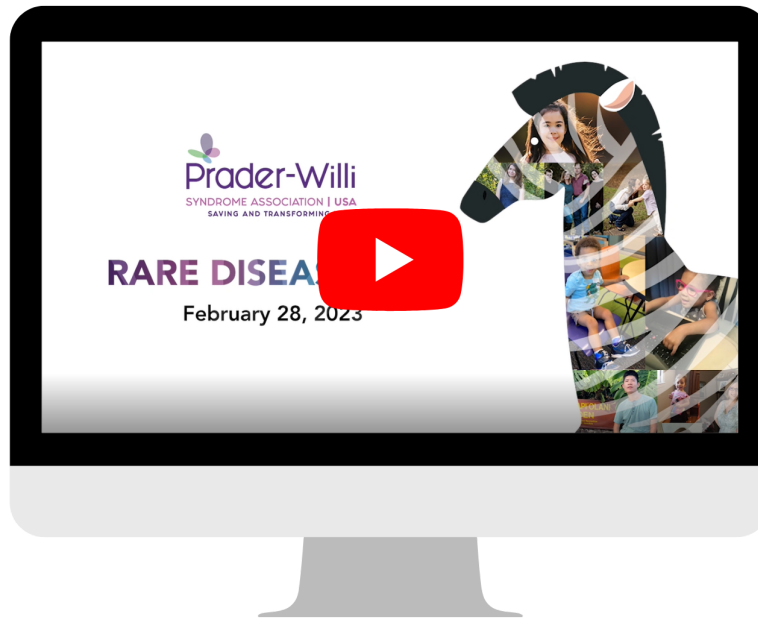
Only four days until Rare Disease Day!
How will YOU participate?

DID YOU KNOW



 Rare Disease Day began in 2008 as an international campaign to raise awareness among the general public, healthcare professionals, and policy makers for people living with a rare disease.

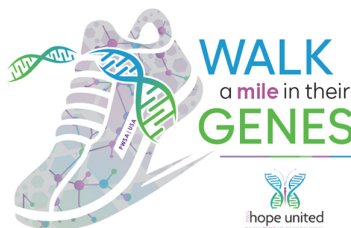
 Rare Disease Day takes place on the last day of February each year with thousands of events held in more than 100 participating countries!



PWSA | USA celebrates Rare Disease Day with our amazing PWS Community!

To shine a light on the message behind Rare Disease Day, Family Support Director Stacy Ward shares the history and why it's so important from a community perspective, not just on February 28th but all year long. *Watch by clicking the image above.*

February 28th is the LAST DAY to Sign Up as a Walk a Mile in their Genes Participant!



Now, more than ever, we are propelled forward to take action from our homes, communities, and Chapters, across the country in fun and extraordinary ways. There's still time to sign up for PWSA | USA's **Walk a Mile in their Genes** campaign to raise awareness for PWS and celebrate **Rare Disease Day 2023!**

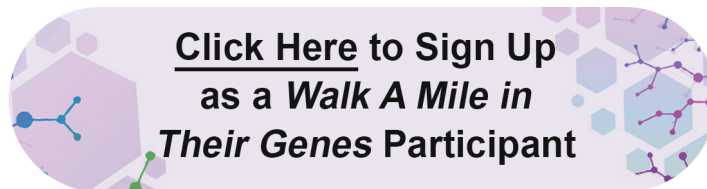
By joining our Walk a Mile in their Genes advocacy campaign, participants will not only raise awareness about PWS, but also raise much needed funds that



will 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 syndrome community.

Signing up is easy as 1, 2, 3 and will take around 5-minutes to create your own Walk a Mile in their Genes fundraiser page! Sign up closes Tuesday, February 28th and the last day to fundraise is Sunday, March 12th **(We are only 25% from our**

fundraising goal!). Learn more by clicking the button below.



When you enter the Walk a Mile in Their Genes website, select "Get Started" to join as a new participant. You will then be prompted to fill out our Hope United form to set up your personal Walk a Mile in their genes fundraiser page.

DON'T FORGET: There will be 1st, 2nd, and 3rd place prizes for the top three campaign fundraisers!



One 37th
National
Convention
Family Conference
Registration

One Convention Kids Camp
Registration

One Hope United Gala
Registration



One 37th National
Convention Family
Conference Registration



One Hope United Gala
Registration



Current Leaderboard

| | |
|------------------|---------|
| Jennifer Garzia | \$3,030 |
| Lisa Lamb | \$2,350 |
| Jennifer Andrews | \$1,871 |
| Maggie Andrews | \$1,680 |
| Erin Carter | \$1,595 |
| Jamie Prentice | \$1,318 |
| Valerie Selinger | \$1,181 |
| Jessica Kempa | \$1,065 |
| Michelle Cox | \$485 |
| Dorothea Lantz | \$250 |

**Contact your City Officials to have Rare Disease Day
Recognized in your Hometown!**

Rare Disease Day helps shine a light on more than 7,000 recognized rare diseases. To assist in this effort, we have been asking our community to tell us how you "share your rare" for Prader-Willi syndrome. One unique and impactful way we have heard from families is how they've received a **Rare Disease Day Proclamation** from their local city officials.

Thank you to Sue Colon and Leslie and Corey Fuller for their advocacy efforts and for sharing the steps they took to make this happen.



"Our local mayor's office contacted us almost right away and offered their full support. We had a meeting with Mayor Stephen Dalina (Monroe Township, New Jersey) and discussed PWS symptoms, the challenges, and our need for awareness."

It was a very empowering experience to be the voice for my daughter and so many other individuals living with

PWS and any other rare disease."

- Sue Colon, mom to Shealynn (3) living with PWS

[READ MORE HERE](#)

Pay your experience forward; we're all individuals! We are all so much more alike than different. It feels good and healthful to share PWS.

The best first step, is to take a step. Call, email, or write your local government officials, representatives, and senators. It's not nearly as intimidating as you think.



- Leslie Fuller, mom to James living with PWS

[READ MORE HERE](#)

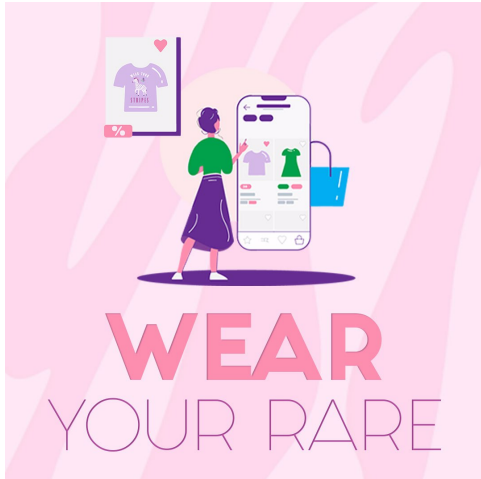


In just a few days, several PWS advocates will gather on Capitol Hill for RARE Disease Week! Now in its 12th year, **Rare Disease Week on Capitol Hill** empowers and inspires hundreds of advocates each year.

Hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases), the multiday event brings together rare disease advocates from across the country to make their voices heard by their Members of Congress.

We can't wait to share photos and a recap from PWS advocates attending in our March newsletters!

Here are a Few Other Ways YOU Can Raise Awareness for PWS and Support PWSA | USA this Rare Disease Day

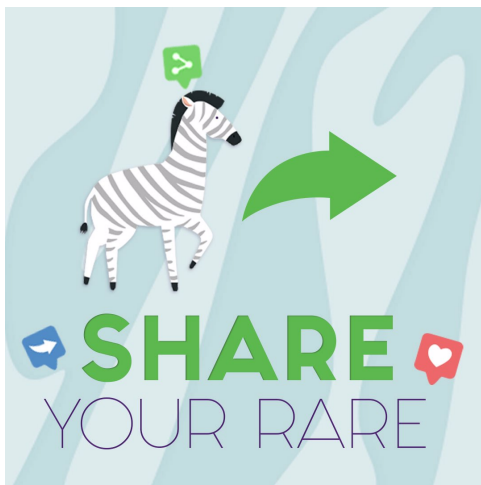


Show your PWS pride and wear your rare **YEAR-ROUND** with our PWSA | USA Merchandise! Shop a variety of Rare Disease Day inspired shirts, sweatshirts, onesies, mugs, water bottles, bags, and MORE when you click the button below.

**WEAR YOUR
RARE HERE**

Be part of a global chain of lights to recognize Rare Disease Day! We encourage our community to light your own home in Rare Disease Day colors (blue, green, pink and purple) on February 28th, and encourage your friends and neighbors to do the same!

LIGHT UP FOR
RARE HERE

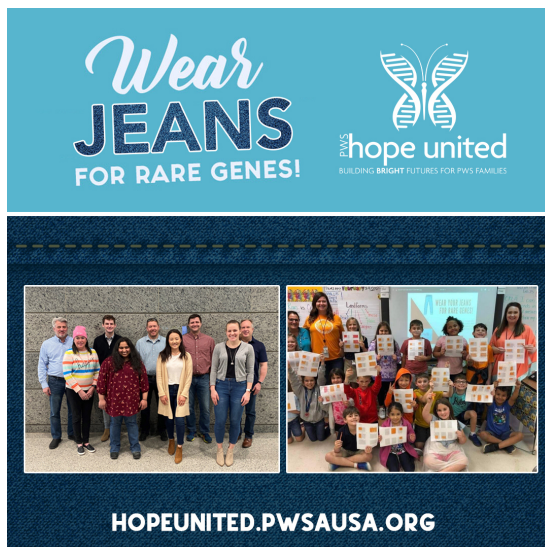


We are asking our PWS community to share your rare! This can be through telling your PWS journey, sharing a quote that inspires you, or a picture of you and your loved one. Thank you for helping us shine a light on Rare Disease Day!

SHARE YOUR
RARE HERE

Another easy way to recognize Rare Disease Day AND support PWSA | USA is to host a PWS 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 download helpful, customizable documents to



start the process. Contact us at hopeunited@pwsausa.org with any questions.

Wear Jeans for Rare Genes Letter



Wear JEANS FOR RARE GENES

Formal Salutation
Name of Place
Address 1
Address 2
City, State, Zip

Salutation,

I am reaching out to ask for your <<school/workplace/church/etc>> partnership to help raise awareness for Prader-Willi syndrome (PWS), a rare disease that affects families in our community. You all know <<name of individual with PWS>>, but did you know that Prader-Willi Syndrome (PWS) is one of over 7,000 rare diseases that affects over 300 million people globally? More than 30 million Americans (one in 10) live with one or more rare diseases and 95% of rare diseases have no FDA approved treatment or cure. It is also a fact that 50% of rare disease patients are children, and sadly, 30% of children with a rare disease won't live to see their 5th birthday.

This year, I'm working to raise awareness for PWS and to celebrate our <<school/office/church/etc>> as a welcoming, safe, and supportive place for those living with a rare disease and their caregivers. Participating is as easy as 1, 2, 3 and your involvement can have a great impact!

- 1) **Pick a Day and let us know!** Pick any day on the calendar and make it a day to "Wear Jeans for Rare Genes." If you usually dress up, wear a uniform, or your "Sunday best," encourage people to wear jeans on this special day. Make it a fun and special occasion! Email us at hopeunited@pwsausa.org to let us know when you will be participating!
- 2) **Ask participants to donate** (\$1, \$5, \$10, or whatever is comfortable) for the opportunity to participate. Consider a friendly competition between <<classes, departments, branches>> perhaps? Each dollar collected will help PWS families living with rare disease get the specialized support they need.
- 3) **Celebrate and share your success!** Take a photo and email it to hopeunited@pwsausa.org so that we can celebrate your efforts and use your success to inspire others!

As a member of the PWS community and the <<school/workplace/church/etc>>, I am happy to help coordinate this as a volunteer in whatever ways would be supportive. At the conclusion of your event, you can simply mail your donations in one check to the address below or make your donation through our online portal at <https://www.pwsausa.org/get-involved/donate> and PWSA | USA will send a tax acknowledgement!

If you or any of your staff are interested in learning more about Prader-Willi syndrome and how this rare disease affects the lives of families throughout the world, please let me know as I would be delighted to provide you with additional information.

Sincerely,
<<Your Name>>
Mom/Dad to <<Child's Name>> (Age << >>)

Melanie McDonald
PWSA | USA Dir. of Development,
Mom to Josephine (Age 3)

Prader-Willi Syndrome Association | USA
1032 E Brandon Blvd #4744, Brandon, FL 33511
941.312.0400 | www.pwsausa.org | info@pwsausa.org

Wear Jeans for Rare Genes Flyer



Wear JEANS FOR RARE GENES

Join us at <<insert name of school/workplace>>
On <<insert date(s)>>

As we all Wear Jeans for Rare Genes in support of Prader-Willi Syndrome (PWS) - a rare diagnosis affecting one in 15,000 births every year.

To participate, simply wear your jeans on this day and bring <<recommended amount>> [\$1 for schools, \$5-\$25 for workplaces] to show your support! All donations we collect will be sent to Prader-Willi Syndrome Association | USA to advance research to treat individuals with PWS.

Together we can make a difference!

Learn more about PWSA | USA and Prader-Willi syndrome by scanning the QR code

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SAVES AND TRANSFORMS LIVES
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