PWSA | USA Bi-Weekly Pulse - January 6, 2023

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 66

January 6, 2023

www.pwsausa.org | 941.312.0400

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!

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

BOOK YOUR HOTEL ROOM FOR THE 2023 NATIONAL CONVENTION!

Hilton Orlando Buena Vista Palace
Orlando, FL

BOOK YOUR STAY HERE

2023 National Convention Scholarship Fundraiser

Organized by:

Prader-Willi Syndrome
Arizona Association

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

Thank you for making an impact!

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

Paige Rivard, MBA | CEO
Mom to Jake (12)

SAVE THE DATE

Upcoming Events >>>

Advocacy in Action Webinar

When: January 17, 2023

Register in Advance Here

Prader-Willi Syndrome Association | USA
BEHAVIOR SUMMIT

PWSA | USA Behavior Summit

When: January 24, 2023

Learn more here

School Success Summit

When: March 9, 2023

More details coming soon!

THANK YOU to our **Selfless Elves** who encouraged donations in lieu of gifts and in honor of their loved ones this holiday season.

Top Participants

Melanie McDonald	$1,830
Louise Yates	$725
Kendra Miller	$405
Kathryn Balthrop	$200
Kayla Guthrie	$75

Save the Date!
CLINT HURDLE
HOT STOVE DINNER
MARCH 25, 2023
$250 per person

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES
Clint Hurdle
HOT STOVE DINNER
Key Royale Club
Anna Maria Island, FL & *Virtual*
March 25, 2023
Island Treasure Reception 5:00 p.m. until 6:00 p.m.
6:00 p.m. General Admission
Presented By: Leaving Legacies Foundation

2023 Clint Hurdle Hot Stove Dinner

When: March 25, 2023

[Book your hotel reservation HERE]

United in Hope
FOR PWS
PWSA | USA 2023
NATIONAL CONVENTION

37th National Convention

When: June 21 - 24, 2023

[Learn More Here]

ADVOCACY

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

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.

Click Here to Submit an Abstract

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!

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

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

STAFF RETREAT
Unlocking Our Success **2023**

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

LEARN MORE HERE

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope they so desperately need. Thank you!

DONATE

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1032 E Brandon Blvd #4744 Brandon, FL 33511

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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!

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

PWSA NATIONAL CONVENTION
PWS CAMP
20 23

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!

PURCHASE YOUR TICKETS HERE TODAY

SAVE THE DATE

Upcoming Events >>>

Prader-Willi Syndrome Association | USA
BEHAVIOR SUMMIT

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.

PWSA | USA School Success Summit

When: March 9, 2023

More details coming soon

2023 Clint Hurdle Hot Stove Dinner

When: March 25, 2023

Purchase Tickets Here

United in Hope
FOR PWS
PWSA | USA 2023
NATIONAL CONVENTION

37th National Convention

When: June 21 - 24, 2023

Learn More Here

ADVOCACY

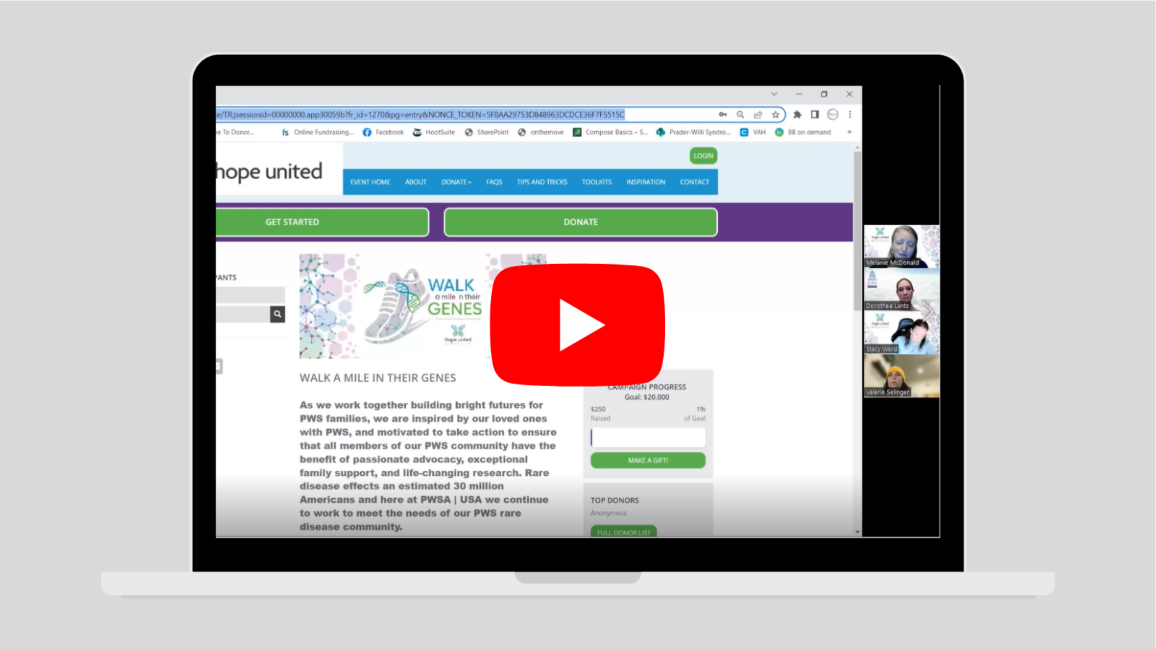
Get to Know PWSA | USA's Newest Advocacy Initiative!

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.

[SIGN UP TO WALK A MILE IN THEIR GENES]



WALK A MILE IN THEIR GENES

As we work together building bright futures for PWS families, we are inspired by our loved ones with PWS, and motivated to take action to ensure that all members of our PWS community have the benefit of passionate advocacy, exceptional family support, and life-changing research. Rare disease effects an estimated 30 million Americans and here at PWSA | USA we continue to work to meet the needs of our PWS rare disease community.

CAMPAIGN PROGRESS
Goal: $20,000
$250 Raised
1% of Goal

TOP DONORS
Anonymous

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

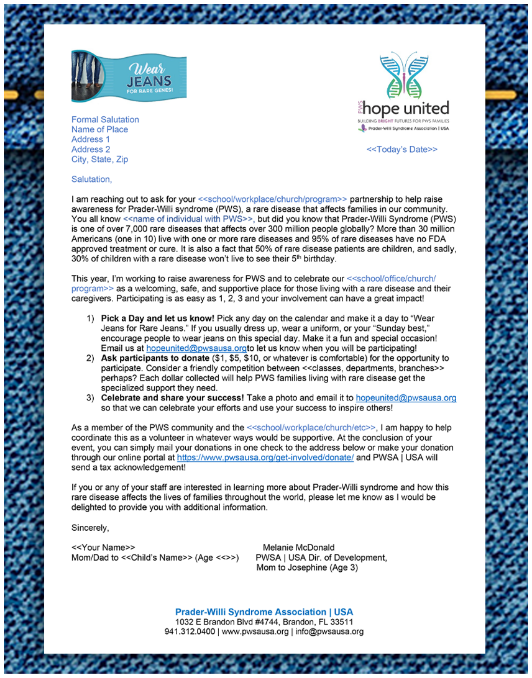
Have you been looking for an easy way to raise awareness and funds to support PWSA | USA in your workplace, school, or community group?

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.

Wear Jeans for Rare Genes Letter

Wear Jeans for Rare Genes Flyer



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

<<Today's Date>>

Salutation,

I am reaching out to ask for your <<school/workplace/church/program>> 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/program>> 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 Jeans." 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.orgto 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

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 effecting 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

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES
hopeunited.pwsausa.org
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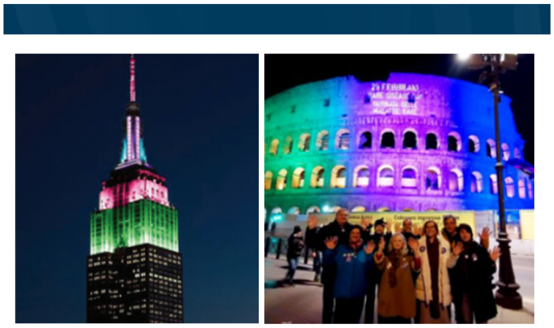
Shine a Light on Rare Disease Day!



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LEARN MORE HERE

FAMILY SUPPORT

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**!

REGISTER 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 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

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**.

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Click Here to Submit an Abstract

PWSA | USA ANNOUNCEMENTS

Donor Spotlight: Sujeiri Colon

PWSA | USA recognizes Sujeiri Colon as this month's Donor Spotlight!

"My motivation to donate to PWSA | USA is due to the tremendous amount of help and support they gave my family and I in such a difficult and dark time in our lives."

Read Sujeiri's Donor Spotlight Here

IN MEMORY OF

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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PWSA | USA Special Edition Pulse - January 27, 2023

www.pwsausa.org | 941.312.0400

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!

PWSA | USA's

Resource Hub

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!

Enter Here

Booklet Resources

The Booklet resource page includes several publications including a *Medical Reference Guide for Parents*, *Grandparent eBooklet, Supporting Adults in Residential Settings*, and more!

Enter Here

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!

Enter Here

Card Resources

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

Enter Here

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*.

Enter Here

and Sub-Phases, *Meals and Snack Ideas for PWS*, and more!

Enter Here

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.

Enter Here

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.

Enter Here

Food Security Resources

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

Enter Here

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!

Enter Here

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.

Enter Here

Enter Here

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!

Enter Here

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

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