

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 54

July 1, 2022

www.pwsausa.org | 941.312.0400



Stephen Leightman,
Grandfather to Joslyn



Henry, Brother to Josie

HELP + HOPE
TOGETHER WE'VE GOT THIS

Make a Difference **TODAY** by Donating
to PWSA | USA's 2022 Family Support
Campaign [HERE!](#)



PWS hope united
BUILDING BRIGHT FUTURES FOR PWS FAMILIES
Prader-Willi Syndrome Association | USA

SAVE THE DATE

[Upcoming Events >>>](#)



GIVING HOPE HAS NEVER BEEN EASIER



Interested in becoming a PWS Hope United Champion but don't know where to start? Watch the video above to learn how to host your own Wear Jeans for Rare Genes fundraiser, then click on the button below to create your own fundraiser!

Giving hope has never been easier 💜

**VISIT THE PWS HOPE
UNITED WEBSITE HERE**

OTHER UPCOMING EVENTS OF INTEREST

Advocacy in Action: How to Engage with Elected Officials

When: July 25, 2022

[Learn More Here >>](#)



PWSA | USA Washington, D.C. Fly-In

When: September 19-21,
2022

[Learn More Here >>](#)

Rare Across America 2022

RARE
ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS

When: August 8th to August 19th
Virtual and In-Person Meetings

LEARN MORE HERE



ADVOCACY

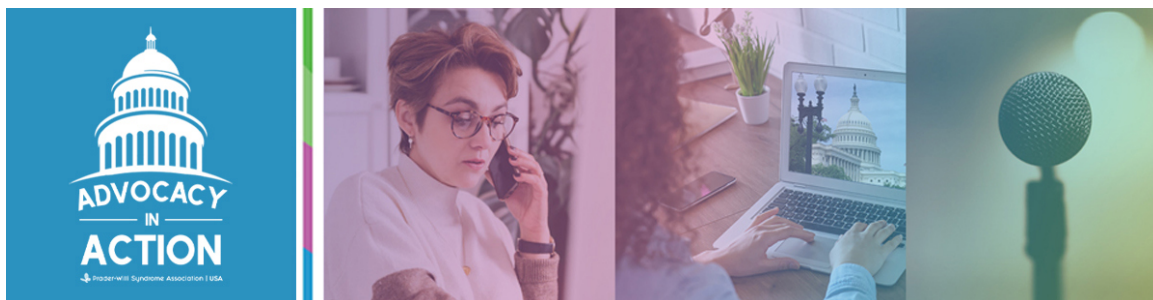
**Submit Your PWSA | USA D.C. Fly-In Application by
Monday, July 4, 2022!**

If you are interested in joining us for our first-ever D.C. Fly-In, September 19-21, 2022 in Washington, D.C., please submit your application to advocacy@pwsausa.org by Monday, July 4, 2022. Find the application and learn more information by clicking on the button below.



[APPLY HERE!](#)

Join us for our July Advocacy in Action Webinar



PWSA | USA is excited to bring our community a virtual roundtable and panel discussion on effective communication with elected officials and stakeholders.

The ability to work with lawmakers is one of the most important skills that advocates must employ. Join us on July 25, 2022 at 2:00 p.m. EST to hear directly from elected officials and their staff, and explore some of the basic dos and don'ts when engaging with elected officials.

Register in advance by clicking on the button below.

[LEARN MORE HERE](#)



Happy 4th of July weekend!

While you and your loved ones are enjoying the holiday, here are some tips from our Family Support Team to stay cool and safe in the summer heat:

🌡️ Capitalize on the cooler temperatures in the early morning and evening and plan your outdoor activities during those times

☂️ Carry an umbrella with you to block out the sun's direct rays

🧴 Always wear sunscreen!

💧 Always keep frozen water bottles or cold drinks with you

🚗 Cool your car down before getting into it

🔋 Keep battery operated fans in your car and larger fans in your home

✈️ When traveling, keep a cooler with ice packs, wet towels, and water bottles with you in case of a heat-related emergency

If you have any questions, please contact us at 941-312-0400 or info@pwsausa.org.



Residential Spotlight: Mainstay Life Services

PWSA | USA's Family Support team shares their second feature story in our Residential Spotlight Series, a look into Mainstay Life Services group homes in Pittsburgh, PA. Read the full article by clicking the button below.

[LEARN MORE HERE](#)



RESEARCH

An infographic for a research study. It features a dark blue background with white and yellow text. The top section is titled 'KU MEDICAL CENTER The University of Kansas' and 'RESEARCH STUDY FOR PRADER-WILLI SYNDROME (PWS)'. Below this, it asks 'WHAT IS A RESEARCH STUDY?' and provides a definition. It then lists 'ABOUT RADIUS (SCOUT-015) PWS STUDY?' with five numbered points. The bottom section is titled 'WHO TO CONTACT?' and provides contact information for The University of Kansas Medical Center, Division of Clinical Trials, including a phone number.

KU Medical Center Now Recruiting for Radius (SCOUT-015) PWS Study

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

PWSA | USA Receives Grant from Global Genes

PWSA | USA is honored to have been selected as a recipient of Global Genes' Financial Advocacy in RARE Patient Impact Grant! Learn more



about this amazing opportunity by clicking the button below.

[LEARN MORE HERE](#)

IN MEMORY OF



We are deeply saddened by the passing of Kimberly Lovern, who passed away on February 19, 2022 at the age of 30.

According to Kimberly's obituary, "She graduated from Burroughs High School in 2010. She loved going to the local mountains with her family on hunting and camping trips and their annual trips to Lake Mead every spring. She participated in the Gymkhana horse shows for several years and helped with raising many animals her family had. Immanuel Baptist Church teen club was one of

her favorite places to attend.

After moving to Palm Desert in 2012, she attended Desert Arc where art was her favorite pastime. Her happy smile, laughs, and sense of humor will be greatly missed.

Any donations can be made to Prader-Willi Syndrome Association | USA in Sarasota, Florida."

[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

Enhancing the Quality of Life and Empowering Those Affected by PWS



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HELP + HOPE
TOGETHER WE'VE GOT THIS

PWSA | USA's Family Support Team is *always* here to offer **HELP + HOPE** to families and individuals affected by PWS. You can ensure these vital programs continue by donating to our **2022 Family Support Campaign**.



GIVING HOPE HAS NEVER BEEN EASIER

Fundraising has never been easier with PWSA | USA's new peer-to-peer fundraising platform - PWS

SAVE THE DATE

Upcoming Events >>>



Hope United

There are many ways you can make an impact. Draw inspiration from fundraisers that have already launched on our Hope United website, including "Tri-Harder for Belle." In the image below, Holly and Greg are training for a triathlon in honor of their daughter Annabelle's 1st birthday, while sporting some Hope United t-shirts. Way to go, Holly and Greg!

Find out how YOU can start your own fundraiser by clicking the button below.

[BECOME A HOPE UNITED CHAMPION!](#)



Advocacy in Action: How to Engage with Elected Officials

When: July 25, 2022

[Learn More Here >>](#)



PWSA | USA Washington, D.C. Fly-In

When: September 19-21, 2022

[Learn More Here >>](#)

PWSA | USA Attends IPWSO Conference in Ireland



Between July 6-10, 2022, PWSA | USA was represented at the 11th IPWSO Conference, which took place in Limerick, Ireland. CEO Paige Rivard along with Medical Coordinator Lynn Garrick and others had the incredible opportunity to attend, speak, and host a table on behalf of our national organization. It was a great week meeting families and new friends from around the globe!

OTHER UPCOMING EVENTS OF INTEREST

Rare Across America 2022



When: August 8th to August 19th
Virtual and In-Person Meetings

[LEARN MORE HERE](#)

6th Annual Snowflake Barn Dance

Hosted by



When: Saturday, July 23, 2022
4:00 - 8:30 pm EST | Gahanna, OH

[LEARN MORE HERE](#)

ADVOCACY

Join us for our July Advocacy in Action Webinar



PWSA | USA is excited to bring our community a virtual roundtable and panel discussion on effective communication with elected officials and stakeholders.

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[LEARN MORE HERE](#)

FAMILY SUPPORT

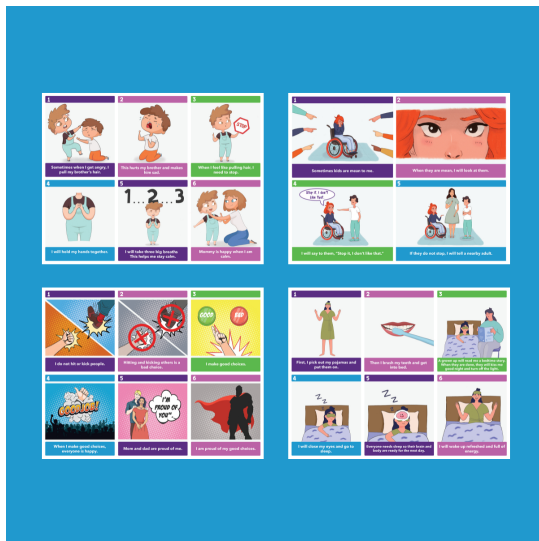
How to Develop Positive Relationships with Your School District

Navigating the special education process world can be intimidating, overwhelming, and sometimes downright scary for parents. Building a positive and collaborative relationship with the school district will benefit your student, you, and district officials.

It's important to remember that there will be differences of opinions, mistakes, and difficult conversations throughout the school years. When you have created a positive working relationship based on open and honest communication, working through those challenges will be easier.

To learn more about developing positive relationships with your school district, watch the video below and find more details in PWSA | USA's article [Getting](#)

[To Yes - Negotiating Agreement Without Giving In.](#)



Social Stories

Don't forget - as part of our 2022 Family Support Campaign, PWSA | USA's Family Support Team is releasing new social stories each week to help your loved one living with PWS. Click the button below to download our first seven social stories and be on the lookout for more!

[LEARN MORE HERE](#)

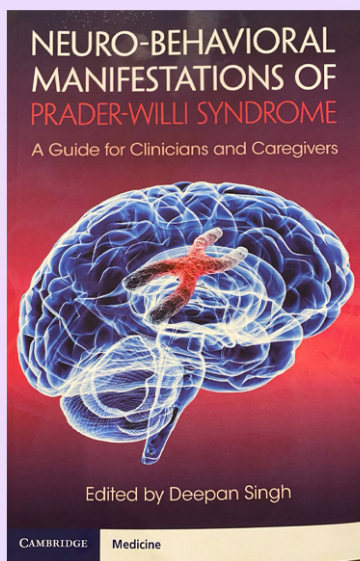


RESEARCH

RADIUS®

Radius Health
Announces New
Details Regarding
SCOUT-015
Clinical Trial

[LEARN MORE HERE](#)



Dr. Deepan Singh's New
Book is Now Available,
and Includes a Quote
from PWSA | USA CEO
Paige Rivard

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

Join our Team!

Join our team! PWSA | USA is currently looking for a Development Database Coordinator. We are headquartered in Sarasota, FL, but this will be a remote position.



This critical support role provides administrative, research, data, and strategic support for all constituent management functions that sustain our services to enhance the quality of life of those affected by Prader-Willi syndrome.

Read the full job description and find out how to apply by clicking the button below.

[APPLY 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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[Donate](#)



Get Ready for Back to School!

The end of summer is just around the corner and once again, it will be time to grab the backpacks and schoolbooks!

Whether it is in the classroom or at home, school can come with many challenges for our rare disease community. As you start preparing for your loved one's return to learning, PWSA | USA is here to offer helpful tips and reminders about the education-focused resources available for our PWS families.



We encourage our PWS families to utilize PWSA | USA's Tips for School Success Toolkits! Explore six school success toolkits that share how your child can be successful while navigating learning - whether it's at home or in the classroom.

Get to know the School Success Toolkits

PWS Challenges and Solutions



This toolkit includes videos and resources that outline the unique educational and environmental needs of students with PWS.

[ENTER HERE](#)

Individualized Education Program (IEP)



This toolkit includes videos to aid in preparing your child's IEP at every transition period, sample IEPs and supporting documentation.

[ENTER HERE](#)

Homeschooling



Thinking about homeschooling? This toolkit is for you. It includes a video by two veteran homeschool parents as well as several resources.

[ENTER HERE](#)

Behavior Challenges



This toolkit includes videos and resources that outline the school's legal responsibility when responding to behavioral challenges in the school district.

[ENTER HERE](#)

Effective Advocacy



This toolkit includes videos that teach parents how to be effective advocates while building a positive relationship with their child's school, sample letters to use when communicating with the school as well as templates to share information regarding your child.

[ENTER HERE](#)

Special Education Law



This toolkit includes videos that explain special education law, IDEA and FAPE in laymen's terms. You can also find a copy of IDEA 2004 [here](#).

[ENTER HERE](#)



Interested in learning more? Visit our School Success blog feed for additional resources.

[CLICK HERE](#)



New Guidances Released for Disciplinary Action in School

[Click here to learn more >>](#)

Download PWSA | USA's Customizable PWS Health Identification Card

To help our communities better understand Prader-Willi syndrome, how it affects those



diagnosed, and what symptoms require immediate medical attention, PWSA | USA has created a customizable PWS Health Identification Card. This Health ID card can be printed and shared with anyone in your community, e.g. school officials, medical providers, family members, etc.

Learn more and download your customizable card at the button below.

[DOWNLOAD OUR CUSTOMIZABLE CARD HERE](#)

HELP + HOPE
TOGETHER WE'VE GOT THIS

"PWSA | USA's Family Support Team was with me throughout my daughter's IEP process to help advocate for her needs. With their help, we now have a plan we all feel good about and our daughter is thriving at school."

| Mom, New Hampshire

YOU can ensure PWSA | USA's Family Support services including IEP assistance, special education advocacy, behavior support, and more remain available for current PWS families and those who have yet to receive their life-changing diagnosis.

DONATE



Make a donation to our **Family Support Campaign**
by clicking the button below.



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