

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 52

June 3, 2022

www.pwsausa.org | 941.312.0400

A promotional graphic for the "HELP + HOPE" campaign. On the left is a vertical strip of five small photos showing diverse families and individuals. The main area has a light blue background with large text: "HELP + HOPE" where the plus sign is a green cross and the heart in "HOPE" is a purple outline. Below this is "TOGETHER WE'VE GOT THIS" in green and purple. A purple rounded rectangle contains the text: "Make a Difference TODAY by Donating to PWSA | USA's 2022 Family Support Campaign HERE!".

HELP + HOPE
TOGETHER WE'VE GOT THIS

Make a Difference TODAY by Donating
to PWSA | USA's 2022 Family Support
Campaign HERE!

At all ages and stages, PWSA | USA's Family Support team is always here to offer *HELP + HOPE*. YOU can help make a difference for countless families affected by PWS when you give a gift to our 2022 Family Support Campaign through July 31st!

Join us September 19-21, 2022 in Washington, D.C.!

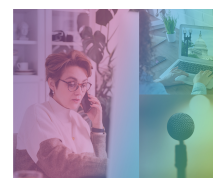


[LEARN MORE HERE](#)



SAVE THE DATE

[Upcoming Events >>>](#)



RESCHEDULED:
Advocacy in Action - We
The Patients, a preview to
RDLA in Washington, D.C.

When: June 8, 2022 at 8:00
p.m. EST

[Register in Advance Here >>](#)

If you missed PWSA | USA's recent Community Conversation where we shared an in-depth look at our new Peer-to-Peer Fundraising platform, PWS Hope United, you can watch the recording by clicking on the image above!

**VISIT THE PWS HOPE
UNITED WEBSITE HERE**



**CLICK HERE to be one of the first 20 to
register for a Hope United Fundraiser and
get a FREE shirt!**



Be one of the first **20**
to create your own
Hope United
fundraiser and receive
a Hope United t-shirt!
No matter what your
vision is, no idea or
dollar amount is too
great or too small, and
we are here to help
every step of the way.

Click the button below to get started!

Questions? Contact us at hopeunited@pwsa-usa.org.

**BECOME A HOPE
UNITED CHAMPION!**

**11th IPWSO Conference
2022**

When: July 6 - 10, 2022

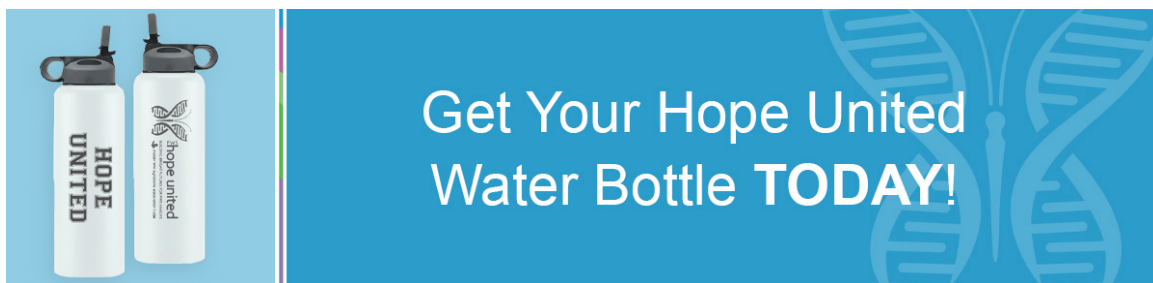
[Learn More Here >>](#)



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

When: September 19-21,
2022

[Learn More Here >>](#)



**Just in time for summer, stay hydrated in style with our brand-
new Hope United water bottles!** With every water bottle purchase,
you are also supporting PWSA | USA's 2022 Family Support
Campaign! Get yours TODAY by clicking the button below.

[PURCHASE YOUR HOPE UNITED WATER BOTTLE HERE](#)

EVENTS

Other Upcoming Events of Interest

[#WeThePatients | Washington, D.C. Fly-In 2022 | June 14-15, 2022 >>](#)

[Rare Across America 2022 | August 8 -19, 2022 >>](#)



ADVOCACY

PWSA | USA Staff Attend PWANY Conference

Last weekend, PWSA | USA's Director of Family Support Stacy Ward and Community Engagement Specialist Dorothea Lantz attended and spoke at the PWANY Conference!

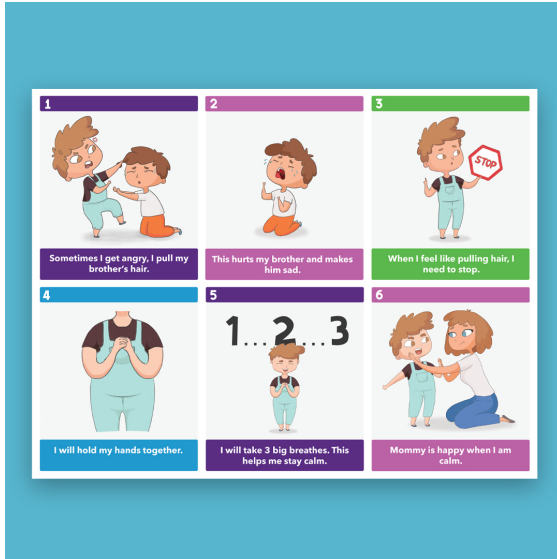
Dorothea had the privilege of being the event's keynote speaker and shared her personal journey as mom to Hunter, who is living with PWS, and some of the exciting ways our organization is participating in advocacy and awareness. Hear Dorothea's full speech by clicking the image below.





FAMILY SUPPORT

PWSA | USA's Family Support Team Offers Weekly Social Stories!



Throughout PWSA | USA's Family Support Campaign, we will launch new Social Stories each week for our community to use! They are designed to offer help for your loved ones living with PWS across all ages, races, genders, and abilities.

Click on the button below to download our first social story, which provides an exercise your loved one can use when they feel upset.

[DOWNLOAD THE SOCIAL STORY HERE](#)

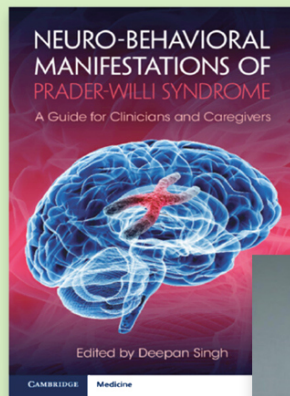
Watch PWSA | USA's School Success Resource Video *Free and Appropriate Public Education (FAPE)* by Clicking the Image Below



Prader-Willi Syndrome Association | USA



RESEARCH



**Dr. Deepan Singh to
Release New Book,
*Neuro-Behavioral
Manifestations of
Prader-Willi
syndrome***

LEARN MORE HERE

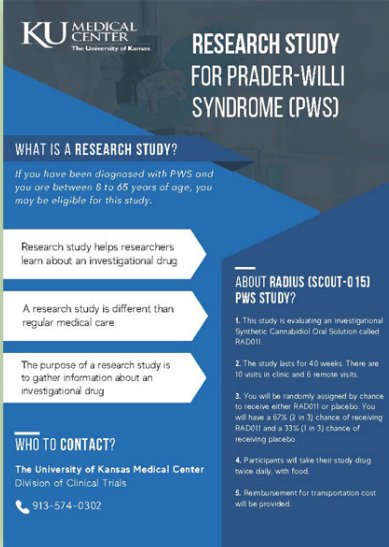


**Kasey Bedard, Ph.D.,
BCBA-D, IBA Shares
Findings from Research
Study Funded by
PWSA | USA**

LEARN MORE HERE



**Harmony Biosciences'
Phase II trial for
Pitolisant is full!
PWSA | USA is happy
to collaborate with
Harmony and look
forward to next steps.**



KU MEDICAL CENTER
The University of Kansas

RESEARCH STUDY FOR PRADER-WILLI SYNDROME (PWS)

WHAT IS A RESEARCH STUDY?
If you have been diagnosed with PWS and you are between 6 to 65 years of age, you may be eligible for this study.

Research study helps researchers learn about an investigational drug

A research study is different than regular medical care

The purpose of a research study is to gather information about an investigational drug

WHO TO CONTACT?
The University of Kansas Medical Center
Division of Clinical Trials
913-574-0302

ABOUT RADIUS (SCOUT-015) PWS STUDY?

1. This study is evaluating an investigational Synthetic Cannabidiol Oral Solution called RAD011.
2. The study lasts for 40 weeks. There are 10 visits in clinic and 6 remote visits.
3. You will be randomly assigned by chance to receive either RAD011 or placebo. You will have a 67% (2 in 3) chance of receiving RAD011 and a 33% (1 in 3) chance of receiving placebo.
4. Participants will take their study drug twice daily, with food.
5. Reimbursement for transportation cost will be provided.

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

[LEARN MORE HERE](#)

LEVO Therapeutics to Close PWS Drug Trial



This week, PWSA | USA learned that LEVO Therapeutics will close its Phase III Carbetocin study. The company is in the process of potentially being acquired. LEVO wanted to express their deepest gratitude to the PWS community for the support they received throughout this study.

We understand this is a difficult time for families, but PWSA | USA remains dedicated to supporting you and your loved ones. Learn more details by clicking the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

Welcome, Anna!



Please help us welcome Anna Landseadel as PWSA | USA's new Executive Assistant to the CEO. Learn more about Anna on our staff webpage by clicking the button below.

[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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[Prader-Willi Syndrome Association | USA](#)

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Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 53

June 17, 2022

www.pwsausa.org | 941.312.0400

Near and Far, PWSA | USA's Family Support Team is Here
to Provide Help + Hope!

HELP + HOPE
TOGETHER WE'VE GOT THIS

**MAKE A GIFT TO THE 2022 FAMILY
SUPPORT CAMPAIGN HERE!**

YOU can help make a difference for countless families affected by PWS when you give a gift to our **2022 Family Support Campaign** through July 31st!

Click on the image below to visit our Family Support Campaign Hub, which offers many features and resources! You will find downloadable social stories, which can be used to help your loved one living with PWS navigate different situations and build social and emotional skills, and first-hand stories from families and individuals in our community, who share how our Family Support Team has offered Help + Hope!

How Does Family Support Offer Help + Hope?

Watch the videos below to hear how our families and individuals affected by PWS receive support



CLICK HERE TO BE DIRECTED TO THE FAMILY SUPPORT CAMPAIGN HUB

Weekly Social Stories

Throughout the Family Support Campaign, we are launching new Social Stories each week for our community to use! These Social Stories are learning tools specifically designed for individuals living with PWS across all ages, races, genders, and abilities. They can be used to help your loved one navigate different social situations and build social and emotional skills.



Click on the buttons below to download our first social story, which provides an exercise your loved one can use when they feel upset. You will also find a blank version of this social story, allowing you to add in your own images, be it through printed pictures or drawings!

Click on the buttons below to download our second social story, which provides an exercise your loved one can use when they want to play with others. You will also find a blank version of this social story, allowing you to add in your own images, be it through printed pictures or drawings!

Click on the buttons below to download our third social story, which provides an exercise your loved one can use when other individuals are not being nice to them. You will also find a blank version of this social story, allowing you to add in your own images, be it through printed pictures or drawings!

1ST SOCIAL STORY WITH PICTURES	2ND SOCIAL STORY WITH PICTURES	3RD SOCIAL STORY WITH PICTURES
1ST SOCIAL STORY WITHOUT PICTURES	2ND SOCIAL STORY WITHOUT PICTURES	3RD SOCIAL STORY WITHOUT PICTURES

GIVING HOPE HAS NEVER BEEN EASIER

SAVE THE DATE

Upcoming Events >>>



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When: July 6 - 10, 2022

[Learn More Here >>](#)

Interested in becoming a PWS Hope United Champion but don't know where to start? Watch the video above to find some inspiration, then click on the button below to create your own fundraiser!

Giving hope has never been easier 

VISIT THE PWS HOPE UNITED WEBSITE HERE



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When: September 19-21, 2022

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Other Upcoming Events of Interest

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ADVOCACY

PWSA | USA's D.C. Fly-In Application NOW AVAILABLE!

[APPLY HERE!](#)

PWSA | USA Staff Member Dorothea Lantz, Advocacy Volunteer
Charles Conway Attend *We the Patients* D.C. Fly-In



[LEARN MORE HERE](#)



**LISTEN: *We The Patients* Gives
Recap of Event in New Podcast**

[CLICK
HERE](#)



FAMILY SUPPORT



**PWSA | USA's Family
Support Team Shares
Tips to Stay Cool
During the Hot
Summer Months**

[LEARN MORE HERE](#)

Enjoy Summer with this List of Fun Activities



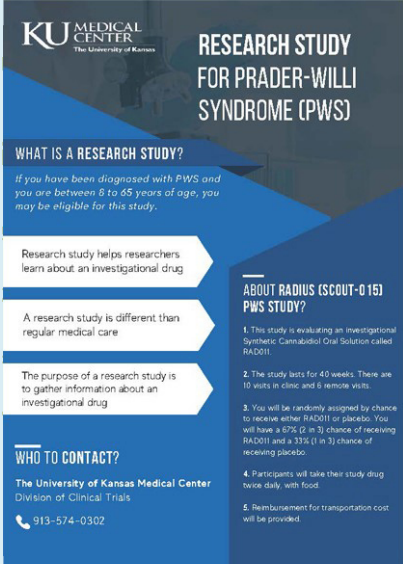
 PWSA | USA'S
SPOTLIGHT ON HOPE

Will, 14, was born with PWS and found a skill in and passion for creating beautiful works of art. You can read Will's story and find pieces of his artwork by clicking on the button below.

VISIT WILL'S WEBSITE



RESEARCH



KU MEDICAL CENTER
The University of Kansas

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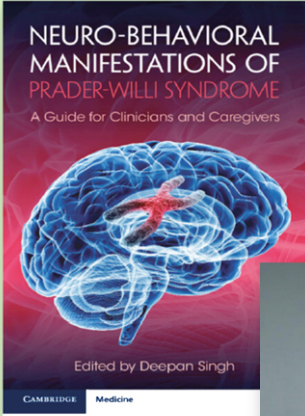
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[LEARN MORE HERE](#)



**NEURO-BEHAVIORAL
MANIFESTATIONS OF
PRADER-WILLI SYNDROME**
A Guide for Clinicians and Caregivers

Edited by Deepan Singh

CAMBRIDGE Medicine

Dr. Deepan Singh to Release New Book, *Neuro-Behavioral Manifestations of Prader-Willi syndrome*

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

Lindsay Baker's Special Olympics Debut

Lindsay Baker, 31, who is living with Prader-Willi syndrome made a splash at the 2022 Special Olympic Games in Orlando, FL by competing



and medaling in not one, but TWO swimming events!

PWSA | USA had the opportunity of speaking with Lindsay's mom, Delores, who shared her daughter's incredible journey from birth and her initial diagnosis, to finding her passion for swimming, and ultimately, her success on the U.S. Special Olympics team. Read her story by clicking the button below.

[LEARN MORE HERE](#)



Just in time for summer, stay hydrated in style with our brand-new Hope United water bottles! With every water bottle purchase, you are also supporting PWSA | USA's 2022 Family Support Campaign! Get yours TODAY by clicking the button below.

[LEARN MORE HERE](#)

Show your PWS Pride all year long with our bonfire store items! We have t-shirts, sweatshirts, mugs, water bottles, bags, and so much more featuring our beautiful PWS designs. Find



what you're looking for by clicking the button below.

[VISIT THE ONLINE SHOP](#)

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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Soar to New Advocacy Heights in Washington, D.C.!

In this June Special Edition Pulse, we are putting a spotlight on Advocacy, and more specifically, our first-ever **D.C. Fly-In** event, which will take place September 19-21, 2022 in Washington, D.C. Click on the image below to learn what this event is all about from PWSA | USA's Community Engagement Specialist Dorothea Lantz and PWS Parent / PWSA | USA Advocacy Volunteer Charles Conway.

Keep scrolling to find more advocacy resources, including how to help raise awareness by writing an op-ed piece and a registration link to our July Advocacy in Action webinar discussion on engaging with elected officials.



[REGISTER TO ATTEND THE D.C. FLY-IN HERE](#)

Raise Awareness for PWS by Writing an Op-Ed Piece



There are many ways to raise awareness for a cause you're passionate about but personal stories typically create the biggest buzz and generate the most attention. It's often difficult to find a starting point - how do I start writing my story and who do I send it to? We're here to help!

Ahead of PWSA | USA's much-anticipated D.C. Fly-In event, we are asking our community to consider writing their own op-ed piece to gain interest and momentum around this event, and in turn, our community's needs. Click the button below to learn how to write your own op-ed piece, and find out how Dorothea Lantz's op-ed piece gained the attention of Miami news station WPLG Local 10.

[LEARN MORE HERE](#)



Learn How to Engage with Elected Officials and Stakeholders



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.

[REGISTER IN ADVANCE HERE](#)



LEARN MORE
ABOUT **ADVOCACY**
AND AWARENESS
AT PWSA | USA

[Click Here](#)



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