

FAMILY SUPPORT & ADVOCACY



"In the beginning, Prader-Willi syndrome diagnosis can truly be an overwhelming experience. PWSA | USA's Family Support Team has been there for us since the beginning, helping us and supporting us through the journey. Our son is now 18 months old, and just knowing that the family support team is just a phone call away 24/7 is something we are grateful for."

Sarah, Mom to Khaled (18 months) of Nebraska

pwsausa.org/get-involved/donate



"PWSA | USA and their family support team has helped us at times where we were desperate for assistance. Their immediate response for help with medical issues have made the difference between a critical medical issue and immediate help to resolve and correct the problem. No words can say how appreciative we always will be."

Tammie, Mom to Victor (27) of Arizona

pwsausa.org/get-involved/donate/

We have the amazing opportunity to extend our Family Support Campaign through July 15th, in an effort to help sustain our lifesaving Family Support Program.

Please give below to ensure our families receive the help they need!

DONATE NOW

BREAKING NEWS

PWSA | USA and FPWR Share Community Update on FDA Patient Listening Session

PRADER-WILLI SYNDROME

FDA PATIENT LISTENING SESSION

HIGHLIGHTS FROM JUNE 17, 2021



PWSA | USA and FPWR held a joint Patient Listening Session with the FDA on June 17, 2021 advocating for new treatments for PWS. Read highlights from our meeting by clicking the button below.

[READ MORE](#)

FAMILY SUPPORT

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
- Technology is advancing and that includes body cooling technology. **Invest in a cooling vest, frogger towel, or cooling gel pads**, which can all be found in your local sporting goods store

**THANK YOU FOR ATTENDING THE
2021 PWSA | USA VIRTUAL NATIONAL
CONVENTION!**

For those who attended, we hope



you enjoyed everything the 2021 Virtual PWSA | USA National Convention had to offer!

Recordings of the Convention sessions will be available on our website (www.pwsausa.org) in the coming weeks. We will send out a notification when they are uploaded and ready to be viewed.

Lifesaving Hope

Thank you to those who donated and sent in pictures of your loved ones for our **Lifesaving Hope Video!**



Share your National Convention pictures and let us know what this year's Convention meant to you!



**SHARE YOUR PICTURES AND QUOTES
HERE**

[Click Here](#) to Order *2021* Convention Gear and new PWSA | USA Swag



THANK YOU to everyone who participated in **Superhero BINGO** and congratulations to all of our winners! We had so much fun and hope you did too. A special thank you to Leaving Legacies Foundation for partnering on this epic event, to Super Neil Fuentes for being our super host, and to our Superhero guests, including Actor Dean Cain!

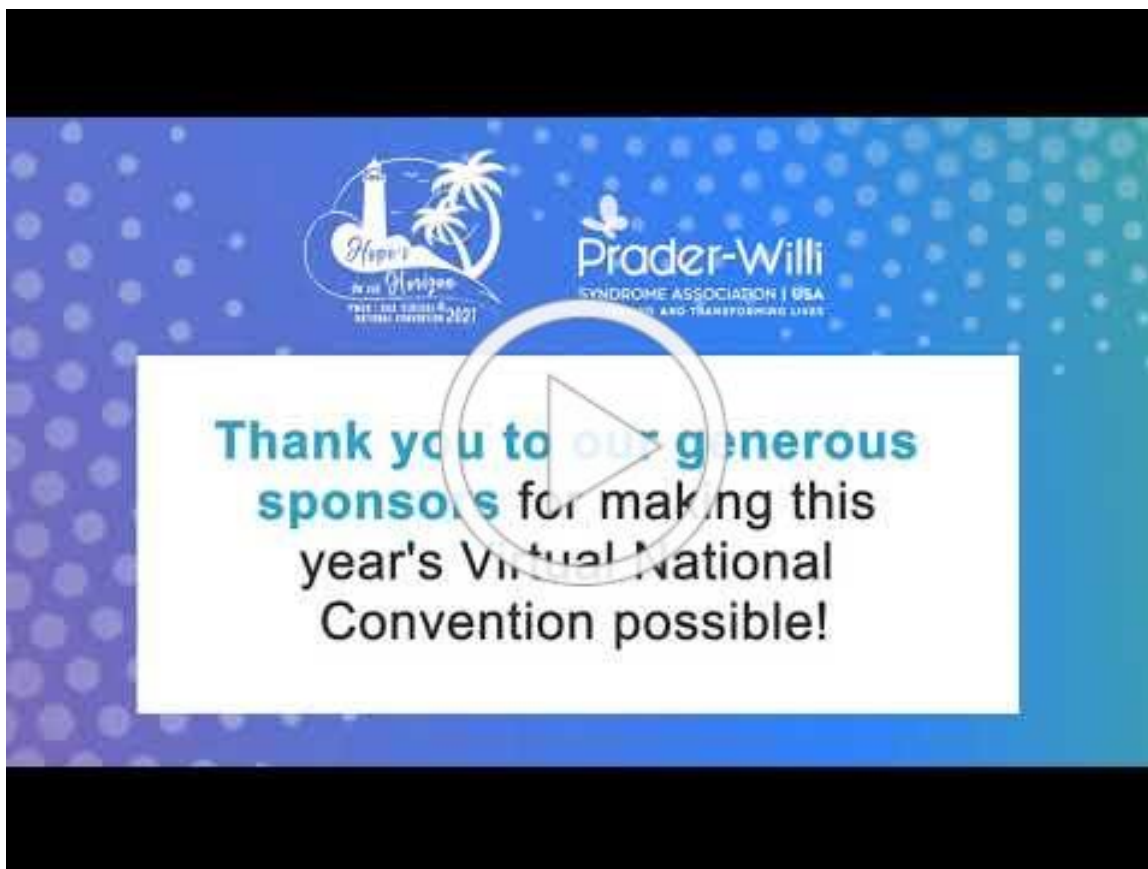


**Thank you to everyone who bid on our Superhero
BINGO Silent Auction Items!**

Congratulations to our Silent Auction Winners:

Getaway to Montana - Michelle Torbert
Room Makeover Package - Janice Agarwal
Game Time Teen Boy Package - Gennelle Conway
Lilly Pulitzer & Nordstrom Package - Christine Miller
Hello Summer! Family Fun Package - Melissa Estrada
IPAD Air 4th Generation - Kit and Jim Kane
Private Virtual Voice Lessons - Christina Argo
Virtual Family Fitness Classes - Kimberly Storr
Introductory Kit of doTERRA - Gennelle Conway
Two Large Customizable Bottles - Janice Agarwal
Super Dad Package - Janice Agarwal

Thank You to Our Convention Sponsors!



Calling all New Englanders!

THE 12TH ANNUAL

HUNTER LENS GOLF TOURNAMENT

SATURDAY, OCTOBER 2ND 2021 - 1 PM

THE BACK NINE CLUB

17 HERITAGE HILL - LAKEVILLE, MA



TO REGISTER:

WWW.PWSAUSA.ORG/LENSGOLF/

\$150 / Adult Golf & Dinner

\$80 / Youth (16 + under) Golf & Dinner

\$60 / Dinner Only

Can't Attend? Donations are Welcome!

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Prader-Willi Syndrome (PWS) is a rare, lifelong, non-inherited, genetic disorder. It is the most common known genetic cause of life threatening obesity. Currently, there is no cure but early diagnosis and intervention saves lives.

Proceeds Benefit:



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

REGISTER HERE

ADVOCACY & AWARENESS



DCCR COMMUNITY EFFORTS

May 27, 2021 - June 30, 2021

118 NEW
ADVOCATES



Join the Voices for Change and Contact Your Elected Officials on the Importance of DCCR

Our PWS community recently learned that the FDA is recommending an additional clinical trial for DCCR (Diazoxide choline controlled-release tablet), which is manufactured by Soleno Therapeutics.

DCCR is a therapy that our community desperately needs and we hope that it can quickly become available to anyone with PWS who would benefit from it. While the PWS community might not have the resources of groups with greater numbers, change is still possible!

Please take the time to [contact your elected officials TODAY](#) and inform them of this issue facing our community.



RESEARCH

Harmony Biosciences is seeking people with PWS between the ages of 6 – 65 to enroll in Clinical Trial

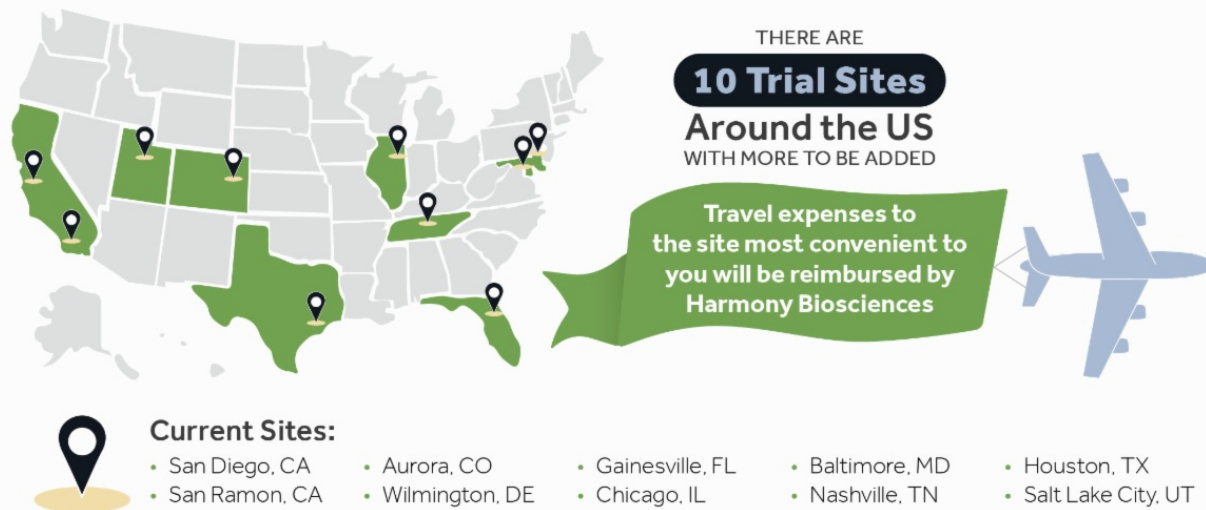


Harmony Biosciences will be studying the safety and impact of an investigational medication on excessive daytime sleepiness, cognition, and behavioral function in people with PWS.

Participation in the trial lasts approximately four months. During that time, there are five planned visits.

Read more [here](#).

Where is the trial?



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Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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[Visit Us Online!](http://www.pwsausa.org)
www.pwsausa.org

[Give Now](#)



FAMILY SUPPORT & ADVOCACY



"The birth of our first child, Josephine, and the weeks that followed in the NICU often brought to mind the term "brutiful." We were so immediately deeply in love with Josephine and quickly so scared as well. Those days were so hard, but also full of beauty when we could see it. When we found PWSA | USA, the "brutiful" slowly turned into beautiful. It is because of PWSA | USA that we thrive as a family."

Jennifer, Mom to Josephine of Minnesota

pwsausa.org/get-involved/donate



"The Family Support staff at PWSA | USA have always been there for my son and our family. Whether it was questions about potty training, school issues, behavior challenges or health concerns, they have been there to listen and share information and strategies to help us with whatever questions we had."

Barb, Mom to Tony (36) of Wisconsin

pwsausa.org/get-involved/donate/

CLINICAL ANNOUNCEMENTS

FDA Grants Priority Review for Levo Therapeutics' New Drug Application for LV-101 (Intranasal Carbetocin) for the Treatment of Prader-Willi Syndrome

We are excited to announce that the FDA has granted priority review for Levo Therapeutics, Inc.'s LV-101 (Intranasal Carbetocin) new drug application as a treatment for hyperphagia and behavioral distress associated with Prader-Willi syndrome.

The logo for levō, featuring the word in a lowercase, sans-serif font. The 'o' has a small orange horizontal bar above it.[READ MORE](#)

Soleno Therapeutics Provides Update on DCCR for the Treatment of PWS

The FDA has agreed to review additional data from Soleno Therapeutics' DESTINY PWS trial and C602 extension study to determine if the data sufficiently supports a potential NDA request for DCCR.

[READ MORE](#)

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Thank You to Our Convention Sponsors!



**Thank you to our generous
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year's Virtual National
Convention possible!**

ADVOCACY



RARE DISEASE WEEK

July 14, 2021 - July 22, 2021

**RARE DISEASE
LEGISLATIVE ADVOCATES
TIP SHEET**

**CLICK
HERE**

**WHY ADVOCACY
MATTERS**

**CLICK
HERE**

**ECONOMIC BURDEN
OF RARE DISEASE**

**CLICK
HERE**

**RARE DISEASE WEEK
THE "ASK"**

**CLICK
HERE**

**Every Voice
MATTERS**



July 14th - 22nd (Virtual)

REGISTRATION NOW OPEN

REGISTER HERE FOR RARE DISEASE WEEK

If you are interested in learning more about how to engage with your elected officials, please contact Dorothea Lantz at Dlantz@pwsausa.org.

PWSA | USA ADVOCACY EFFORTS



DCCR COMMUNITY EFFORTS

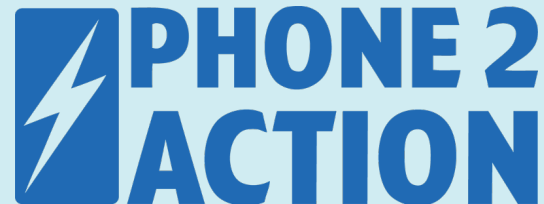
May 27, 2021 - July 8, 2021

125 NEW
ADVOCATES



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UPCOMING EVENTS

THE 12TH ANNUAL

HUNTER LENS GOLF TOURNAMENT

SATURDAY, OCTOBER 2ND, 2021 - 1 PM

THE BACK NINE CLUB

17 HERITAGE HILL - LAKEVILLE, MA



TO REGISTER:

WWW.PWSAUSA.ORG/LENSGOLF/

\$150 / Adult Golf & Dinner

\$80 / Youth (16 + under) Golf & Dinner

\$60 / Dinner Only

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Proceeds Benefit:



Prader-Willi

SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

REGISTER HERE

RESEARCH

Harmony Biosciences is seeking people with PWS between the ages of 6 – 65 to enroll in Clinical Trial

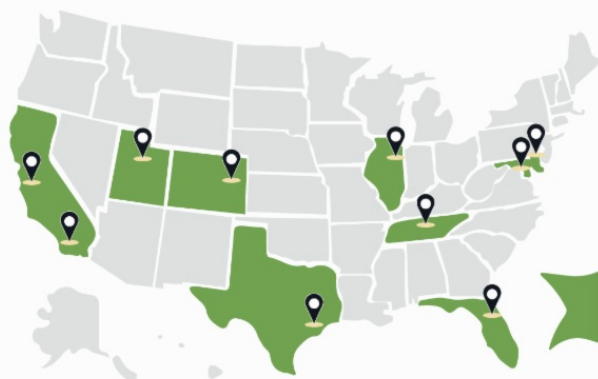
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Participation in the trial lasts approximately four months. During that time, there are five planned visits.

Read more [here](#).

Where is the trial?



THERE ARE
10 Trial Sites
Around the US
WITH MORE TO BE ADDED

Travel expenses to
the site most convenient to
you will be reimbursed by
Harmony Biosciences



Current Sites:

- San Diego, CA
- San Ramon, CA
- Aurora, CO
- Wilmington, DE
- Gainesville, FL
- Chicago, IL
- Baltimore, MD
- Nashville, TN
- Houston, TX
- Salt Lake City, UT

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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!

[Visit Us Online!](http://www.pwsausa.org)
www.pwsausa.org

Give Now



FAMILY SUPPORT & ADVOCACY



We want to thank everyone who donated to our Family Support Campaign, and all of our PWS families for sharing how PWSA | USA's Family Support Team has supported you and your loved ones over the years! We are truly grateful to continue providing help and hope.

A video player thumbnail for a video titled "FAMILY SUPPORT & ADVOCACY". The video features a woman smiling and holding a young child. A large white play button is centered over the image. The video player includes a Prader-Willi Syndrome Association | USA logo in the top left corner and a "24/7 365" support graphic in the top right corner. The video content includes a quote from Sarah, Mom to Khaled (18 months), and a link to the PWSA | USA website.

FAMILY SUPPORT & ADVOCACY

"In the beginning, Prader-Willi syndrome diagnosis can truly be an overwhelming experience. PWSA | USA's Family Support Team has been there for us since the beginning, helping us and supporting us through the journey. Our son is now 18 months, and just knowing that the Family Support Team is just a phone call away 24/7 is something we are grateful for."

Sarah, Mom to Khaled (18 months)
www.pwsusa.org/get-involved/donate/

ANNOUNCEMENTS

Billions in Funding Allocated to Schools Nationwide in an Effort to Help Students with Disabilities

More than \$3 billion in funding is



set to be dispersed to schools around the country to meet the needs of students with disabilities after the fallout from COVID-19.

Some of the funding will be used to support:

- Special Education programs for students between three and 21 years old
- Preschool offerings, specifically for infants and toddlers with disabilities

[LEARN MORE HERE](#)

FAMILY SUPPORT

Brooklyn's Story

"We will forever be grateful for the services PWSA | USA provided. Without them I don't know where we would be. They were my lifeline when I felt like I was drowning."



Read Brooklyn's Story by clicking the button below.

[READ MORE](#)

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WATCH CONVENTION SESSION
RECORDINGS HERE

Purchase NEW PWSA | USA + National
Convention Swag Through July 31st!



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Convention Gear and
new PWSA | USA Swag



Thank You to Our Convention Sponsors!



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year's Virtual National
Convention possible!

ADVOCACY

It's **Rare Disease Week 2021!** Share the image below on your social media or print it, take a selfie and post it to help us spread awareness for PWS.

I AM A RARE DISEASE ADVOCATE!



#RAREDC2021

[DOWNLOAD IMAGE HERE](#)

Reach Out To Your Elected Officials!

RARE DISEASE
LEGISLATIVE ADVOCATES
TIP SHEET

CLICK
HERE

WHY ADVOCACY
MATTERS

CLICK
HERE

ECONOMIC BURDEN
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RARE DISEASE WEEK
THE "ASK"

CLICK
HERE

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PWSA | USA ADVOCACY EFFORTS



DCCR COMMUNITY EFFORTS

May 27, 2021 - July 16, 2021

134 NEW
ADVOCATES



1,017

Total Legislator
Connections



*Thank you for using
your voice to spark
change! With your
continued support
and efforts, the
possibility of DCCR
becoming
available to our
loved ones is in
reach!*



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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Prader-Willi

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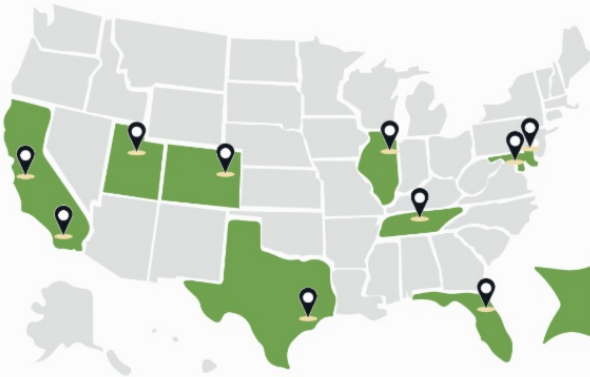
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Read more [here](#).

Where is the trial?



THERE ARE

10 Trial Sites

Around the US

WITH MORE TO BE ADDED

Travel expenses to
the site most convenient to
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Current Sites:

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Prader-Willi

SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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!

Visit Us Online!
www.pwsausa.org

Give Now





This has been an incredible week for PWSA | USA and the rare disease community. In collaboration with [RDLA and the EveryLife Foundation](#), PWSA | USA took part in Rare Disease Week on Capitol Hill.

We had the opportunity to represent our community and meet with Congressmen Tonko, Delgado, Bacon, and Senators Schumar, Gillibrand, Fischer, Rubio, and Scott.

Finally, our CEO, Paige Rivard, had a one-on-one with Senator Ben Sasse. We raised our voices in support of the **STAT Act** and the **BENEFIT Act**, both of which have the potential to be life-changing for caregivers, families, and individuals with PWS.



THE STAT ACT

The STAT Act will allow patients with a rare disease speedy access to therapies, inform rare disease policies and actions by creating a Rare Disease and Condition Drug Advisory Committee and fund regulatory science and related activities to support the development of therapies to treat rare disease populations.

[STAT Act Proposed Legislation >>>](#)

**SUPPORT THE
STAT ACT HERE**



THE BENEFIT ACT

The BENEFIT Act would require that the FDA disclose whether and how patient experience and/or preference data was used in the benefit risk assessment of a new drug. It will ensure that **patient voices are being heard** and allow for patient stakeholders to continue to work with FDA to refine the data that they need to make decisions.

[BENEFIT Act Proposed Legislation >>>](#)

**SUPPORT THE
BENEFIT ACT HERE**

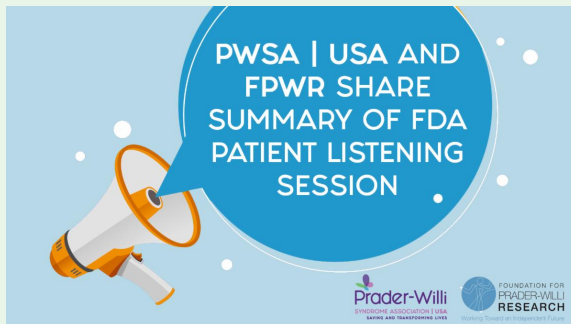
We encouraged members of congress to co-sponsor and support both pieces of bipartisan legislation and look forward to working with our elected officials to continue to advocate on behalf of the PWS community.



"Rare Disease Week on Capitol Hill is a unique opportunity to bring together policy experts and the rare disease community to help educate all on the important issues facing the rare disease community. PWSA | USA participated in the many sessions held during the week, and we met with Congressmen and Senators from several states. It was an honor to represent the PWS community, share and advocate on behalf of Prader-Willi syndrome and bring awareness and our voice to Capitol Hill!"

- Paige Rivard, PWSA | USA CEO

CLINICAL ANNOUNCEMENTS



PWSA | USA and FPWR Share Combined FDA Patient Listening Session Summary

We are excited to present a summary of PWSA | USA and FPWR's June 17th Patient Listening Session meeting with the FDA. PWSA | USA and FPWR compiled meeting notes and presentation points into an educational and informative document for the public.

[READ THE SUMMARY HERE](#)

Radius Health Announces Plans for Global Prader-Willi Syndrome Pivotal Study

Radius Health, Inc. announced Wednesday, July 21, 2021 that its drug RAD011, a synthetic cannabidiol oral solution utilized for the treatment of Prader-Willi syndrome, will go through a pivotal Phase 2/3 global study. Based on the feedback and meeting minutes from a June Type C meeting with the FDA, the Phase 2/3 Study, otherwise known as "SCOUT," will be initiated by the end of 2021 or early first quarter of 2022.

PWS TREATMENT ANNOUNCEMENT

[LEARN MORE](#)

AGENCY NEWS

JOIN OUR TEAM!

PWSA | USA is hiring a full time Development Specialist. This remote role is responsible for administrative, research, planning, and event support for all fundraising activities that help to

sustain our programs to enhance the quality of life of those affected by PWS. For more info and instructions on how to apply, click the button below.

**CLICK HERE FOR MORE
INFORMATION**

**NOW
HIRING!**


Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES



Make a Difference by Becoming a PWSA | USA Volunteer!

Do you want to get more involved with PWSA | USA? We are looking for energetic, passionate individuals to help us carry out our mission and support those affected by PWS. Please click the button below to access our Volunteer Application. If you have any questions, please reach out to volunteer@pwsausa.org.

**VOLUNTEER
APPLICATION**

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PROCEEDS BENEFIT
Prader-Willi
SYNDROME ASSOCIATION | USA
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[REGISTER HERE](#)



YOU'RE INVITED!
(trivia)
ANSWERS FOR AUDREY

what: **TRIVIA NIGHT**
OPEN BAR (BEER/SODA) | 50-50 RAFFLES | SILENT AUCTION

when: **FRIDAY OCTOBER 22ND, 2021**
DOORS OPEN AT 6:30PM / TRIVIA BEGINS AT 7PM

where: **INCARNATE WORD ACADEMY**
2708 NORMANDY AVE. ST. LOUIS, MO 63121

why: **HELP FUND RESEARCH THAT PROVIDES LIFE CHANGING TREATMENTS FOR PRADER-WILLI SYNDROME**



[REGISTER HERE](#)

To plan your custom PWSA | USA fundraiser, contact
events@pwsausa.org.

RESEARCH

PWSA | USA partners with Autism Brain Network (ABN) to help facilitate the collection of postmortem brain tissue from individuals

with PWS. ABN collects, processes, stores, and then distributes collected donations as requested to qualified researchers worldwide.

“Postmortem brain tissue is an invaluable resource for advancing our knowledge of and identifying treatment options that can significantly improve the quality of life of individuals with PWS and their families. PWSA | USA’s partnership with Autism Brain Network is a way to honor the memories of our loved ones while providing hope for a brighter future for our community.”

- Paige Rivard, PWSA | USA CEO



AutismBrainNet

Advancing research through the gift of brain donation.



Linda Keder, mom to a child with PWS who passed away, recently worked with the Autism Brain Net and shared the below quote with PWSA | USA CEO Paige Rivard.

“I really appreciated our conversation and your connecting me with the Autism Brain Net. I was very impressed with the perseverance of Carolyn Hare to help us make the brain donation happen.”

- Linda Keder

Learn more information and find out how to donate by clicking the button below.

LEARN MORE

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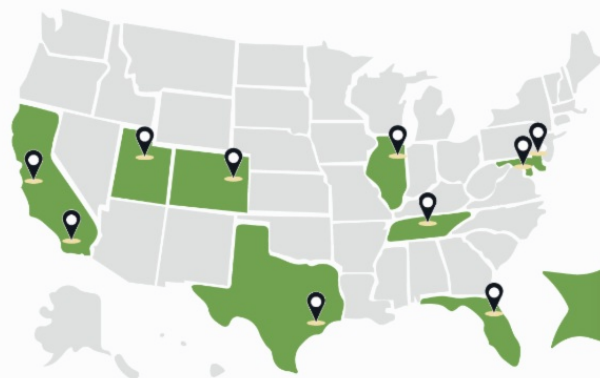


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SAVING AND TRANSFORMING LIVES

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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