Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 46

March 4, 2022

www.pwsausa.org

941.312.0400

Donate

Help us honor our PWSA | USA volunteers!

Do you know someone who deserves to be recognized for their service and dedication to PWSA | USA's mission and the PWS

SAVE THE DATE

Upcoming Events >>>

PWS
Prader-Willi Syndrome
Association of New England

community? **2022 Volunteer Appreciation Award** nominations are now being accepted through March 15, 2022. PWSA | USA will give out the four awards: The Advocacy and Awareness Award, the Family Support Award, the Research Award and the Volunteer of the Year Award.

The award recipients will be announced during the recognition dinner at PWSA | USA's upcoming **Volunteer Summit** (more information below). Click on the button below to download the 2022 Volunteer Appreciation Award Nomination Form.

Prader-Willi Association of New England's Trivia Night

When: March 11, 2022

Learn More Here >>

11th Annual IPWSO Conference 2022

When: July 6 - 10, 2022

Learn More Here >>

EVENTS

In-person tickets for the 8th Annual Clint Hurdle Hot Stove Dinner are sold out but you can still attend the event virtually!

Join us on **March 26, 2022** for the 8th Annual Clint Hurdle Hot Stove Dinner 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 the entire live program. Virtual guests will also enjoy the musical talents of Max Flinn! Learn more about this amazing event and purchase your tickets by clicking the button below.

PURCHASE YOUR TICKETS HERE TODAY

The **8th Annual Clint Hurdle Hot Stove Dinner Auction** items are available for bidding! Enjoy a one night stay at the Eau Palm Beach Resort and Spa, display a priceless football signed by Green Bay Packers' quarterback greats Bart Starr, Brett Farve, and Aaron Rodgers, take home beautiful Kendra Scott jewelry, and SO much more. Click the button below to find a complete list of items, and place your bids TODAY!

We are excited to share this amazing opportunity to cheer on one of our PWS community members! Joe Gill will race in the upcoming 2022 Boston Marathon in honor of his brother Gavin, who is living with PWS. His goal is to raise $16,000 by

race day, April 18th, to celebrate Gavin turning 16 this year! Proceeds from Gavin's Sweet 16 Run Against PWS will directly benefit PWSA | USA. Learn more and show your support for Joe and Gavin by clicking the button below.

SUPPORT GAVIN'S RUN HERE

Have you been looking for an easy way to fundraise in your workplace, school, or community group?

Wear jeans for rare genes **ALL YEAR LONG**! 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" event with your school, community group, coworkers, church, etc. to help raise money for PWSA | USA! Find all of the information you need to start your own "Wear Jeans for Rare Genes" event, including a customizable letter and flyer, by clicking the button below. If you have any questions, please reach out to us at events@pwsausa.org.

LEARN MORE

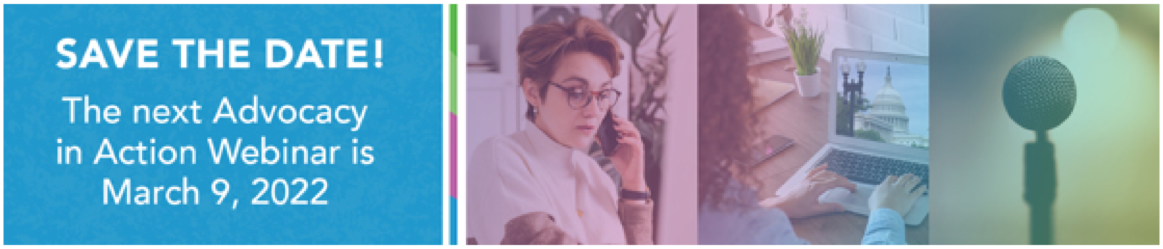
We want to give a heartfelt thank you to our community for showing up this Rare Disease Day! Whether you shared your story or an image of your loved one, submitted a request for a landmark to join in the chain of lights, or supported PWSA | USA by purchasing our Wear Your Rare merchandise, we are extremely grateful for you - our PWS community. Click the images below to see how we came together on this special day to shine a light on Rare Disease Day and PWS.

CLICK HERE TO FIND OUT HOW OUR COMMUNITY LIT UP FOR RARE

CLICK HERE TO FIND OUT HOW OUR COMMUNITY SHARED THEIR RARE

PWSA | USA Staff Participate in Rare Disease Week on Capitol Hill

Rare Disease Week on Capitol Hill wrapped up this week, with more than 600 rare disease advocates in attendance from around the country. Hosted by the Everylife Foundation, Rare Disease Week on Capitol Hill gives the rare disease community opportunities to meet with their elected officials and advocate for their needs. Several PWSA | USA staff members attended these meetings to raise awareness for PWS and to share our community's needs.



Join PWSA | USA for our next Advocacy in Action webinar on March 9, 2022 at 8:00 p.m. EST, where we will welcome one of our Advocacy Committee members as guest presenter, Maureen Tracey, who is the Founder and CEO of Four Seasons Behavioral Solutions. Learn more and register in advance by clicking the button below.

REGISTER IN ADVANCE HERE

FAMILY SUPPORT

PWSA Sleep Issues Survey

You can help PWSA | USA by taking our Sleep Issues Survey. The purpose of this research is to better understand how issues related to sleep impact the daily lives of people diagnosed with PWS and their caregivers. PWSA | USA will use this information to inform the areas of interest for our 2022 Sleep Summit, which will take place in September. Participate in the survey by clicking the button below. Thank you for your time!

TAKE SURVEY HERE

COMMUNITY CONVERSATIONS

Prader-Willi Syndrome Association | USA

Sleep Issues in Prader-Willi syndrome

Tuesday, March 15th

8:00 p.m. EST

Join PWSA | USA's Family Support team on March 15, 2022 at 8:00 p.m. EST for our next Community Conversation. CEO Paige Rivard, Director of Family Support Stacy Ward, Parent Support Coordinator Kristi Rickenbach and Alterman Family Support Counselor Kim Tula will host a discussion focused on sleep issues in Prader-Willi syndrome. Click the button below to register in advance.

REGISTER IN ADVANCE

RESEARCH

NEW SURVEY

Complete your

FEEDING TUBE SURVEY

in the Global PWS Registry

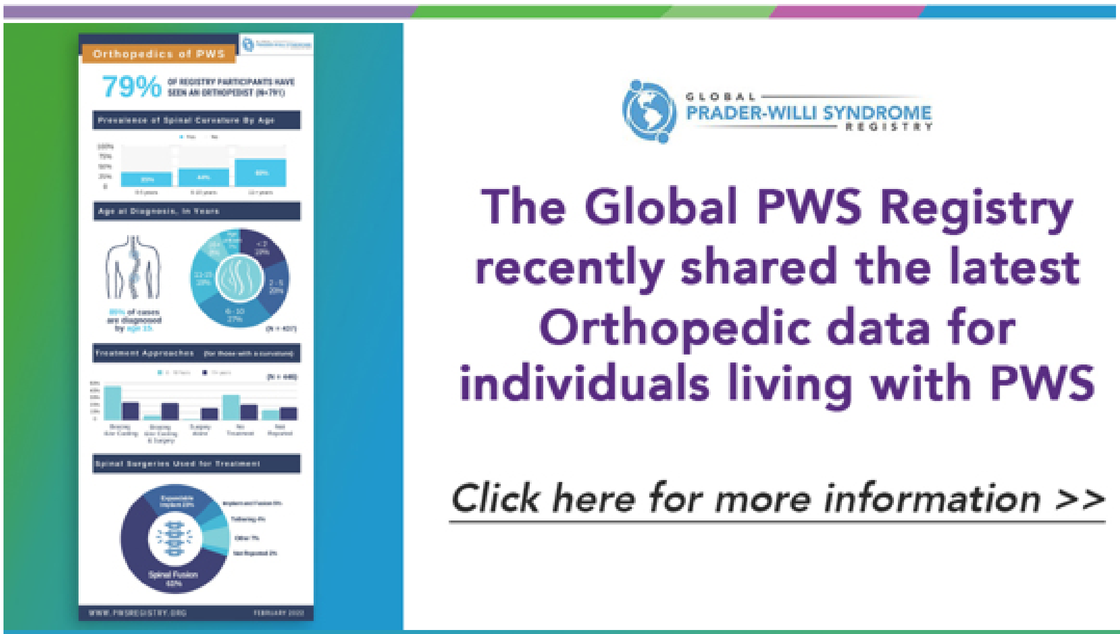
This survey only takes a few minutes to complete and provides invaluable insight into the use of feeding tubes in our loved ones with PWS.

- What type(s) of feeding tubes were used?
- How long was the feeding tube used?
- Why was the feeding tube put in place?
- Did you experience any complications related to the feeding tube?

www.pwsregistry.org

If your child used a feeding tube, you can help the Global PWS Registry by completing their new ‘**Feeding Tube Use and Complications**’ survey. According to the Global PWS Registry, this survey will help PWS experts in the newly formed PWS-CLIC (PWS **Cl**inical **I**nvestigation **C**ollaborative) learn more about how often feeding tubes are used in the PWS population, complications from feeding tube use, and duration of use. Learn more and find out how you can participate by clicking the button below.

LEARN MORE HERE



The Global PWS Registry recently shared the latest Orthopedic data for individuals living with PWS

Click here for more information >>

PWSA | USA ANNOUNCEMENTS

PURCHASE YOUR PWSA | USA RARE MERCH TODAY!

You can be one step ahead for next year's Rare Disease Day and purchase your Wear Your Rare merchandise right now! It's always time to show off your stripes! There are SO many amazing items to choose from featuring our brand new graphics: Shirts, sweatshirts, water bottles, coffee mugs, bags, hats - even a child's cape! Purchase your items TODAY by clicking the button below.

Purchase Your Rare Merch Here!

PWS STORIES

Read the inspiring story of Daniel, who is living with PWS and just celebrated his 65th birthday with an exercise-themed party at his day program! A special thank you to Daniel's sister, Miriam, for sharing his story with our PWS community.

READ DANIEL'S STORY HERE

We are excited to welcome author and teacher Jen Pastiloff as a speaker at PWSA | USA's first-ever Volunteer Summit, which will be held April 29-May 1 in Dallas, TX! Jen was recently interviewed by Katie Couric and shared information about her nephew who is living with PWS in the article below.

"My nephew has a rare genetic disorder called Prader Willi Syndrome, a deletion or partial deletion of the 15th chromosome. It affects the hypothalamus in the brain and sends a signal that tells the person they're starving. It's the cruelest and most heartbreaking thing and my sister has to padlock the fridge and alarm all the cupboards. It's caused me to really rethink how I think about hunger and food. We get to have hunger. We get to satisfy that hunger. My nephew never does. May we have compassion."

You can read the full article by clicking the button below.

READ MORE

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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Purchase your virtual tickets by *MARCH 23, 2022* to enjoy the 8th Annual Clint Hurdle Hot Stove Dinner from the comfort of your home!

Support PWSA | USA's Family Support program while enjoying the 8th Annual Clint Hurdle Hot Stove Dinner on **March 26, 2022**

SAVE THE DATE

Upcoming Events >>>

"No Gimmes for Jimmy" Annual Charity Golf

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 artist Max Flinn!

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

Outing

When: Friday, May 6, 2022

Learn More Here >>

WE'RE ALL IN THIS TOGETHER
11TH INTERNATIONAL
PRADER-WILLI SYNDROME
ORGANISATION CONFERENCE
In collaboration with pwsai

11th Annual IPWSO Conference 2022

When: July 6 - 10, 2022

Learn More Here >>

The **8th Annual Clint Hurdle Hot Stove Dinner Auction** items are available for bidding! Enjoy a Kentucky Estate Getaway for up to 25 people, display a priceless football signed by Green Bay Packers' quarterback greats Bart Starr, Brett Farve, and Aaron Rodgers, take home beautiful Kendra Scott jewelry, and SO much more. Click the button below to find a complete list of items, and place your bids TODAY!

Important reminder: *You don't need to purchase a virtual event ticket to bid on Auction items, secure your "Coconut" for the Helicopter Drop, or raffle tickets!! It's an opportunity for **anyone** to support PWSA | USA!*

EVENTS

In April 2022, PWSA | USA will host the "Find Your Voice: Advocating for PWS Health Care" webinar series to provide helpful tools and resources on health care advocacy for our PWS community. Because there are very few health care professionals in our communities who have knowledge of the unique health issues of infants, children, and adults with PWS, especially in urgent and/or emergency situations, it falls to the parents and caregivers to be the primary educators and advocates on health issues and needs for people with PWS.

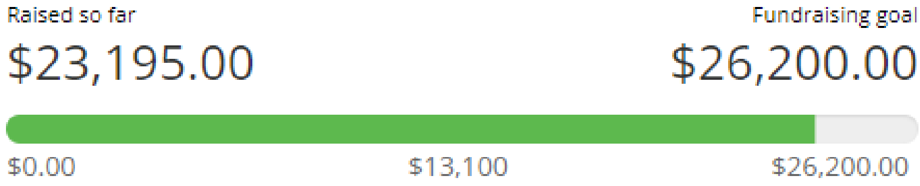
Led by PWS healthcare professionals (some of whom are parents of children with PWS), our four-part webinar series provides strategies and resources to help you advocate in the prevention, diagnosis, and management of the many health concerns and behaviors experienced by those with PWS. Find the full webinar series schedule and register in advance by clicking the button below.

LEARN MORE AND REGISTER HERE

Gavin's Sweet 16 Run Against PWS

A special update from Joe Gill regarding Gavin's Sweet 16 Run Against PWS: *"We are incredibly grateful for everyone who has helped us to reach our initial goal of the big *16* in honor of Gavin's birthday. Can we make it the full 26.2? We hit the birthday, now let's try for the mileage!"*

Proceeds from Gavin's Run will directly benefit PWSA | USA. Learn more and show your support for Joe and Gavin by clicking here.



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Wear jeans for rare genes **ALL YEAR LONG**! 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" event with your school, community group, coworkers, church, etc. to help raise money for

PWSA | USA!

Find all of the information you need to start your own "Wear Jeans for Rare Genes" event, including a customizable letter and flyer, by clicking the button below. If you have any questions, please reach out to us at events@pwsausa.org.

LEARN MORE

ADVOCACY

ADVOCACY IN ACTION

WATCH: March 9th Advocacy in Action Webinar with Speaker Maureen Tracey

Parents first response!

What Happened!?

As Parents we can usually tell by the story where it went wrong!

Change

Food Access

Someone not following the Rules

Lawmakers Review Several Legislative Proposals Intended to Accelerate Innovation of Therapies, Including the STAT Act

Learn more here >>

FAMILY SUPPORT

Texas Prader-Willi Association Opens New PWS Group Home

We are excited to share the Texas Prader-Willi Association has recently opened a new group home for PWS individuals. It currently houses three women living with PWS. The association is now looking to open a second home for men living with PWS.

Learn more by clicking the button below.

LEARN MORE

PWSA Sleep Issues Survey

You can help PWSA | USA by taking our Sleep Issues Survey. The purpose of this research is to better understand how issues related to sleep impact the daily lives of people diagnosed with PWS and their caregivers.

PWSA | USA will use this information to inform the areas of interest for our 2022 Sleep Summit, which will take place in September. Participate in the survey by clicking the button below. Thank you for your time!

TAKE SURVEY HERE

RESEARCH

What Type of Research Matters to You?

We want to know what PWS research matters to you most! Please take a moment to help inform our next phase of research efforts and related programming by taking a brief five-minute survey to share your thoughts and preferences for the type(s) of research PWSA | USA should support moving forward.

Find the survey link by clicking the button below.

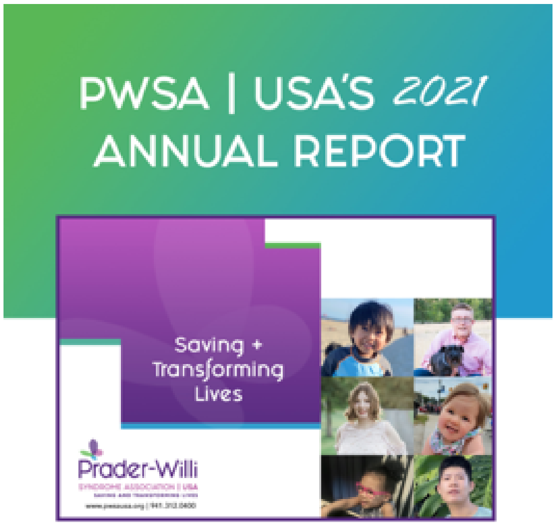
LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

SPOTS AVAILABLE IN LET'S GO FITNESS PROGRAM!

Reach your true potential with a fitness community that understands your diverse abilities

Spots are still available in our Let's Go Fitness Program! PWSA | USA has partnered with Let’s Go Fitness, an online fitness community that celebrates diverse abilities, to provide free virtual exercise classes for individuals living with Prader-Willi syndrome who are 14 years or older. We have a few additional spaces open for this exciting opportunity and will select program participants from the applications submitted. Those selected will receive a free one-year membership to Let’s Go Fitness! Learn more and apply by clicking the image above.



We are pleased to share our 2021 Annual Report, which gives you a look into PWSA | USA's accomplishments, impact, and growth from the past year. You can download the Annual Report by clicking the button below.

We look forward to sharing more initiatives, programs, and events with you in 2022 and beyond!

VIEW PWSA | USA'S ANNUAL REPORT

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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8588 Potter Park Drive, Suite 500 Sarasota, FL 34238

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March is Nationally Recognized as Sleep Awareness Month

Sleep health is essential for everyone. It is just as important to take care of ourselves as parents and caregivers as it is for those living with Prader-Willi syndrome (PWS). We understand that disordered sleep has implications for cognitive outcomes, mental and physical health, work, and school performance. Sleep disturbances can occur from many factors, including weight, metabolic variations, and types of genetic imprinting. There are additional concerns to be aware of when it comes to individuals diagnosed with PWS.

Sleep-wake patterns are often disrupted for those diagnosed with PWS. Frequently, excessive daytime sleepiness presents difficulties when attending school and work. Many of our children have built-in rest periods during the day, both at school and work. Those that require these rest periods during the day may have their academic and work progress suffer.

The importance of employing a combination of methods to address sleep health in our loved ones cannot be understated. Speak with your doctor about testing for Obstructive Sleep Apnea (OSA), sleep-related hypoventilation, narcolepsy, or the need for having tonsils/adenoids removed to improve the quality of sleep.

Other methods, including weight control, medication, and establishing a sleep schedule with sleep routines can improve overall sleep health. Keeping a sleep log will be useful when speaking with healthcare providers about any sleep concerns you may have. The Centers for Disease Control (CDC) recommends that infants get on average 14-16 hours of sleep per day. For children 1-12 years of age, 11-14 hours is recommended. For ages 13-18, 8-10 hours is recommended. Finally, adults should get seven or more hours of sleep per day. Please be aware of any changes to sleep patterns and report them to your healthcare provider.

To learn more about sleep issues in individuals living with PWS, PWSA | USA is hosting a six-month program entitled *Sleep Issues in Prader-Willi Syndrome: A Deep Dive for Parents & Practitioners*, which includes monthly focus group discussions led by a trained facilitator. The program will conclude with a full day PWSA | USA Virtual Sleep Summit, which will be held on September 27, 2022. The Sleep Summit will include four webinar presentations from physicians for both parents and healthcare providers. Be on the lookout for a registration link to join us in the coming months.

Right now, you can help PWSA | USA by taking our Sleep Issues Survey. The purpose of this research is to better understand how issues related to sleep impact the daily lives

of people diagnosed with PWS and their caregivers.

PWSA | USA will use this information to inform the areas of interest for our 2022 Sleep Summit. Participate in the survey by clicking the button below. Thank you for your time!

PARTICIPATE IN THE SLEEP SURVEY HERE

Sleep-Related Symptoms and How they Affect an Individual Living with PWS

To learn more about sleep-related symptoms that affect individuals living with PWS, watch this Convention panel presentation moderated by Maria Picone, Co-Founder and CEO of TREND Community, with expert panelist Dr. Daniel Glaze of Texas Children's Hospital, and featuring PWSA | USA's Family Support Coordinator Kristi Rickenbach and her daughter Justice who is living with narcolepsy, cataplexy, and PWS.

GATHERING DEEPER INSIGHTS

AN ANALYSIS OF CONVERSATIONS RELEVANT TO SLEEP ISSUES

When my child really laughs, her head and eyelids drop as if she is falling asleep. It's like she loses all control. I would love a explanation!

We have tried Vyvanse, concerta, Mod (provigil) and now Armodafinil (Nuvigil).

We tried to get pitolisant, but our insurance would not approve it

We were told by a neurologist that his unresponsive episodes are narcolepsy, and rop attacks are cataplexy.

ould fall and hit something on the down. It was really scary."

CONFIDENTIAL © TREND COMMUNITY ALL RIGHTS RESERVED

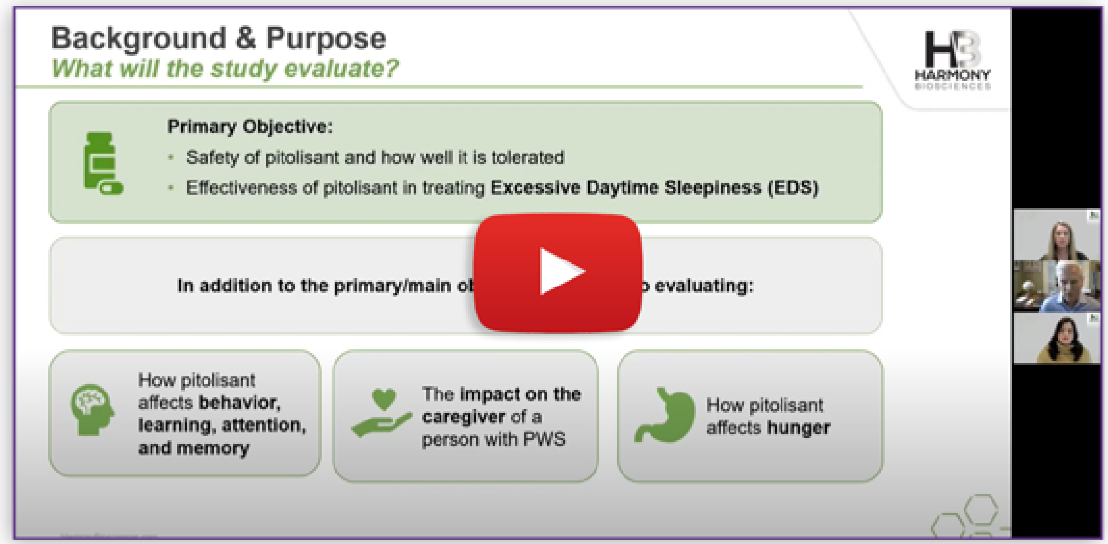
To further explain her personal struggles with sleep-related symptoms while living with PWS, Justice Rickenbach wrote a blog post that is featured on TREND's website. We encourage you to read her thoughtful and informative article by clicking the button below.

READ THE ARTICLE HERE

WATCH: Learn More About Harmony Biosciences' Drug Pitolisant to Treat Excessive Daytime Sleepiness

Last month, PWSA | USA participated in a webinar discussion surrounding Harmony Biosciences Phase 2 study of its drug Pitolisant. Harmony Biosciences representatives share information about Pitolisant, including its effectiveness in treating Excessive Daytime Sleepiness (EDS), behavioral issues, cognitive issues, and hunger. Watch the recording of this webinar by clicking on the image below.

Harmony Biosciences is currently in its Phase 2 clinical trial of Pitolisant. If you are interested in getting more information, please contact clinicaltrials@harmonybiosciences.com.



Background & Purpose

What will the study evaluate?

Primary Objective:

- Safety of pitolisant and how well it is tolerated
- Effectiveness of pitolisant in treating **Excessive Daytime Sleepiness (EDS)**

In addition to the primary/main ob

evaluating:

How pitolisant affects **behavior, learning, attention, and memory**

The **impact on the caregiver** of a person with PWS

How pitolisant affects **hunger**

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Prader-Willi Syndrome Association | USA

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