

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 42

January 7, 2021

www.pwsausa.org | [Donate](#)



HELPING YOU FOCUS ON

Health & Wellness in 2022



This year, we are putting a focus on **Health & Wellness** by offering a resource library for our PWS community! Click on the image above to be directed to our Health & Wellness Hub where you will find several resources on a variety of topics including:

- [Exercise](#)

SAVE THE DATE

[Upcoming Events >>>](#)

- [Mindfulness & Meditation](#)

- [Motivation & Coaching](#)

- [Nutrition](#)

We also want to know what helps **YOU** stay well! If there is a wellness blog you follow, a phone application or website that encourages you maintain self-care, a podcast that lifts your spirits, a healthy recipe - anything that helps you and your family stay well - we want to know! It may help others on their wellness journey.

[SHARE YOUR WELLNESS TIPS HERE](#)

LET'S GO FITNESS
PROGRAM APPLICATION
NOW AVAILABLE!

APPLY HERE
TODAY!

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

With a new year, comes exciting opportunities! 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. Applications are **NOW AVAILABLE** and are due by **Wednesday, January 26, 2022**. PWSA | USA will select 20 individuals from the applications submitted to each receive a free one-year



Texas Prader-Willi
Association Conference

When: January 29, 2022

[Learn More Here >>](#)



8th Annual Clint Hurdle Hot
Stove Dinner

When: March 26, 2022

[Learn More Here >>](#)



11th Annual IPWSO
Conference 2022

When: July 6 - 10, 2022

CALL FOR ABSTRACTS:

Clinical & Scientific
Conference

Professional Providers and
Caregivers Conference

[Learn More Here >>](#)

membership to Let's Go Fitness. Learn more by clicking the image above.



Shine a Light on Rare Disease Day!

Monday, February 28, 2022 is Rare Disease Day and we are asking YOU, our PWS community, to help shine a light on this important day! There are many ways we can come together even if we don't do so physically. Being part of a global chain of lights in recognition of Rare Disease Day is one example. You can be part of it either by helping to light up monuments and 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! PWSA | USA has already received confirmation that The Bob Kerrey Pedestrian Bridge in Omaha, Nebraska will light up in recognition of Rare Disease Day on February 28th!

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.

[JOIN THE EFFORT HERE!](#)

Please join PWSA | USA for the kickoff of our 2022 Advocacy Campaign on January 12th at 8PM EST. We will roll out our exciting advocacy plan for 2022, including exclusive speakers, educational opportunities, legislative priorities, and our first-



ever Washington DC Fly-in event. Please register by clicking the button below.

[REGISTER IN ADVANCE HERE](#)



FAMILY SUPPORT



Share Your Thoughts on PWSA | USA's School Success Toolkits!

You can help PWSA | USA's Family Support Team by sharing your thoughts on our School Success Toolkits. If you have not had an opportunity to look through this library of resources, [click here](#) to be directed to our School Success homepage. Your input is invaluable to the continuation of this critical program! Take the survey by clicking the button below. Thank you!

[TAKE THE SCHOOL SUCCESS SURVEY HERE](#)



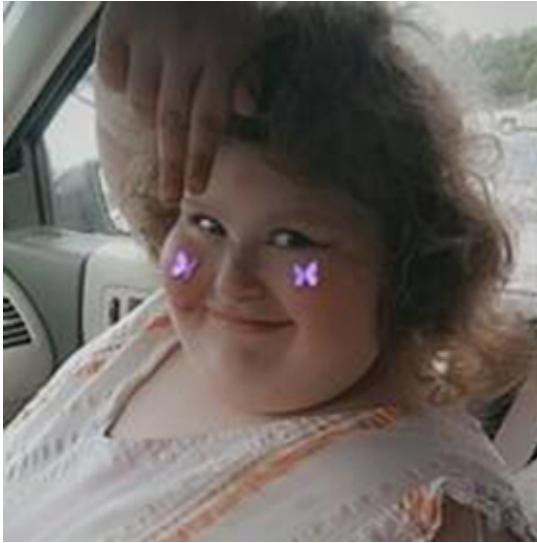
Tuesday, January 18th | 8:00 p.m. EST

We have heard from many of you in the PWS community regarding guardianship. Please join PWSA | USA's CEO Paige Rivard, Family Support Director Stacy Ward, Parent Support Coordinator Kristi Rickenbach, and Alterman Family Support Counselor Kim Tula for a discussion regarding guardianship and the challenges parents face.

[REGISTER IN ADVANCE HERE](#)

Remembering Sophia Erdely (10) and Karina Vela (24)

We are heartbroken to share the passing of two beautiful lights in our PWS family, Sophia Erdely and Karina Vela. If you would like to extend your condolences to the Ederly or Vela families, please click the buttons below to sign their digital guest books.



[SIGN SOPHIA'S GUEST BOOK](#)



[SIGN KARINA'S GUEST BOOK](#)

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.

Honoring our Loved Ones

PWSA | USA is here for our families every step of the PWS journey including during the most heartbreaking moments. Help us honor your loved one forever by filling out the form below. Our Forever in our Hearts Memorial page will serve as a digital space that gives friends and family a powerful way to celebrate their loved one's unique story.

[HONOR YOUR LOVED ONE HERE](#)



RESEARCH



[LEARN MORE HERE](#)

National Research Study Seeks Participation from Parents of Adults with Intellectual and/or Developmental Disabilities

Participate in an online survey and/or interview! Share your experiences with providing and finding care for your adult son or daughter with IDD.

[Take the survey by clicking here >>](#)

[Interested in being interviewed? Click here >>](#)

Questions?

Email: Kelli.Sanderson@csulb.edu

CLINICAL TRIAL UPDATE



Saniona Initiates Phase 2b Clinical Trial of Tesomet for Prader-Willi Syndrome

Exciting news from Saniona! The company announced that it has initiated Phase 2b clinical trial for the drug Tesomet, which is being studied as a treatment for hyperphagia. Learn more by clicking the button below.

[READ MORE](#)

PWSA | USA ANNOUNCEMENTS

We want to give a big, heartfelt

THANK YOU to those who supported PWSA | USA in our 2021 Angel Drive Campaign!

Your donations will support several Advocacy, Family



Support, and Research initiatives in 2022 that will greatly benefit our PWS families. Know that through these gifts, you have made a true impact on our community!

SNOWFLAKE COLORING CONTEST WINNERS!

We also want to extend a heartfelt thank you to those who participated in our Angel Drive Snowflake Coloring Contest! We are excited to announce the two winners chosen at random to receive a \$25 Target Gift Card:

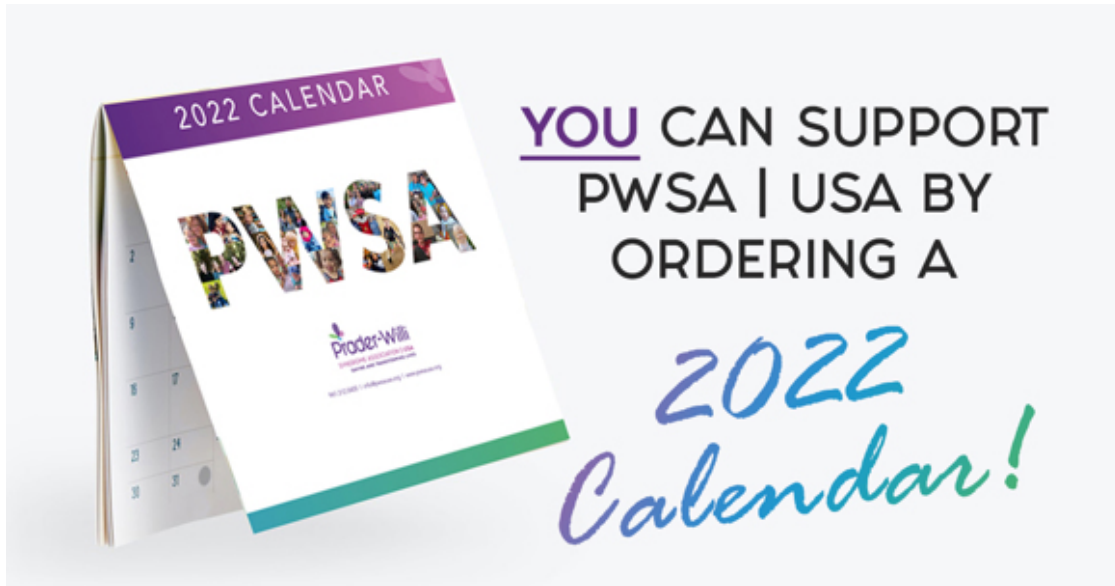
Congratulations Ryan Damm & Kinsley Reasor!



It's not too late to purchase a 2022 calendar!

The 2022 PWSA calendar provides more than 50 beautiful smiles of our loved ones throughout the seasons, is a special calendar filled with reminders of important dates, holidays, and days of significance for the PWS community, and proceeds from the sales help us fulfill our mission to enhance the quality of life and empower those affected by Prader-Willi syndrome!

[PURCHASE YOUR CALENDAR HERE TODAY!](#)



WELCOME NEW PWSA | USA STAFF MEMBERS!



We are very excited to have two new PWSA | USA staff members join our team! Please help us welcome Angela Frazier, who will serve as our Events Coordinator, and Jennifer Hill, who will serve as our Director of Accounting. Get to know them more by clicking the button below.

[READ MORE HERE](#)

DONOR SPOTLIGHT



PWSA | USA is special because of **YOU**, our donors, who passionately give to support our mission. It is because of your generous gifts that we can provide help and hope through family support, advocacy, and research efforts. To celebrate and honor your generosity, each month we will spotlight a donor and their story showcasing the dedication, gratitude, and optimism that defines us as a PWS community!

Our January Donor Spotlight is **Rob Lutz**, who is a PWSA | USA Board Member and longtime supporter of our organization.

[READ 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](#)

[Privacy Policy](#) | [Unsubscribe](#)

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

8588 Potter Park Drive, Suite 500 Sarasota, FL 34238

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 43

January 21, 2022

www.pwsausa.org

941.312.0400



[Donate](#)

A promotional poster for a "LIVE & virtual EVENT" on March 26, 2022. The poster has a blue background. On the left, there is a circular graphic with a rainbow and two palm trees. Inside the circle, it says "Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES", "Clint Hurdle HOT STOVE DINNER" with a signature, "Key Royale Club Anna Maria Island, FL & Virtual March 26, 2022", and "Island Treasure Reception 5:00 p.m. until 6:00 p.m. 6:00 p.m. General Admission". Below the circle, it says "Presented By: Leaning Legacies Foundation". On the right, the text "LIVE & virtual EVENT" is in large, stylized letters, followed by "MARCH 26, 2022". At the bottom right, a white button says "CLICK HERE TO REGISTER TODAY!".

**WITH SPECIAL HOSTS CLINT &
KARLA HURDLE**

SAVE THE DATE

[Upcoming Events >>>](#)



We are excited to announce that tickets are **NOW ON SALE** for the 8th Annual Clint Hurdle Hot Stove Dinner, March 26, 2022! Sip, savor, and support PWSA | USA while enjoying this outdoor event on the beautiful grounds of the Key Royale Club, Anna Maria Island, FL. This event may be attended in-person or virtually!

[Learn More About the Clint Hurdle Hot Stove Dinner Here!](#)



Rare Disease Day

When: February 28, 2022

[Learn More Here >>](#)



11th Annual IPWSO Conference 2022

When: July 6 - 10, 2022

[Learn More Here >>](#)



We are excited to welcome our



Advocacy in Action guest presenter for the month of February, Guy Stephens, who is the Founder and Executive Director for the Alliance Against Seclusion and Restraint (AASR).

Join us February 9, 2022 at 8:00 p.m. EST for our next Advocacy in Action webinar, as part of our continuous series to raise awareness and promote advocacy for PWS and PWSA | USA! Learn more about Guy and his organization Alliance Against Seclusion and Restraint by clicking the button below.

[LEARN MORE AND REGISTER HERE](#)



Take Part in the RARE Compassion Program!

The RARE Compassion Program offers an opportunity to bring medical students and rare disease communities together to develop stronger connections and a greater knowledge of individual and family needs.

According to the leader of this effort, Global Genes, participants "will build meaningful connections with medical students helping them to better advocate for and recognize patients living with a complex rare condition."

Learn more about how you can participate by clicking the button below.

Learn About Rare Disease Firsthand

The RARE Compassion Program matches eligible medical students with a rare disease patient or family, giving you an opportunity to personally learn more about:

- Rare disease diagnosis journeys
- Unique challenges faced daily by rare disease patients
- How to connect with the larger rare disease community including medical experts working in rare

Applications for the RARE Compassion Program will be open January 18, 2022 until February 25, 2022.

Learn more and apply today!

DAVID R. COX
SCHOLARSHIP

Global Genes®
RARE Compassion Program

[LEARN MORE HERE](#)



FAMILY SUPPORT

**LET'S GO FITNESS
PROGRAM APPLICATION
NOW AVAILABLE!**

**APPLY HERE
TODAY!**



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

With a new year come exciting opportunities!

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. The program application is now available and is due by **Wednesday, January 26, 2022**. PWSA | USA will select 20 individuals from the applications submitted to each receive a free one-year membership to Let's Go Fitness. Learn more by clicking on the image.



RESEARCH



Levo Therapeutics announced this week that they have received a complete response letter from the FDA regarding the new drug application for Carbetocin, which is being studied as a treatment for hyperphagia, anxiousness, and distress associated with PWS. Read the full response by clicking the button below.

[LEARN MORE HERE](#)

Following Saniona's announcement that the company is initiating its Phase 2b clinical trial for Tesomet, which is being studied as a treatment



**Saniona Launches TM006
Study Website to Advance
Testing Efforts for
Tesomet**

for hyperphagia in Prader-Willi syndrome, the company has launched a website to help advance testing efforts for the drug. Visit the website by clicking the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS



Welcome New Staff!

We are very excited to have a new PWSA | USA staff member join our team! Please help us welcome Paige Jackson, who will serve as our Web and Graphic Designer. Get to know Paige better on our staff page 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](#)

[Privacy Policy](#) | [Unsubscribe](#)

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

8588 Potter Park Drive, Suite 500 Sarasota, FL 34238

www.pwsausa.org | 941.312.0400



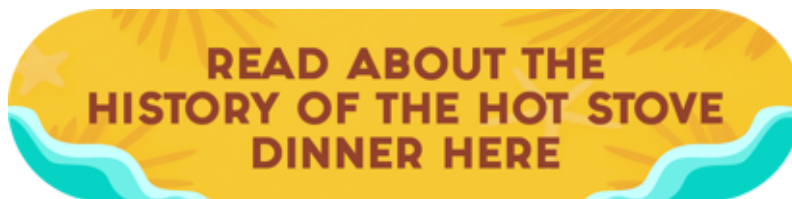
**Purchase your tickets
today for the 8th Annual
Clint Hurdle Hot Stove
Dinner, March 26, 2022!**

YOU can support PWSA |
USA's Family Support programs
while enjoying this outdoor
event on the beautiful grounds
of the Key Royale Club, Anna
Maria Island, FL. This event
may be attended in-person or
virtually!

**PURCHASE YOUR
TICKETS HERE TODAY**



The **Hot Stove Dinner** is hosted annually by Clint and Karla Hurdle, longtime supporters of PWSA | USA, who work tirelessly to serve the PWS community, particularly in the advancement of funding for family support programs to benefit new and existing PWS families. Clint shared with us his family's passion for putting on this annual event and all of the exciting features and activities this year's Hot Stove Dinner will bring! Click on the image above to watch an interview with Clint and click on the button below to learn about the history of this great event.



Sip, savor, and support PWSA | USA on the island or online! Sway to

the sounds of the Steel Drum Band, learn about the extraordinary ways PWSA | USA empowers the PWS community through shared experiences, research, education, advocacy and support. Your generous contributions will enable the only national PWS support organization in assisting individuals with the syndrome, and their families, every step of the way!



In-Person Hot Stove Dinner Tickets | Guests who attend the event on the island will receive one drink ticket and plated meal, have the opportunity to bid on once-in-a-lifetime experiences and luxury trips in the Live Auction, the opportunity to participate in the "Coconut Helicopter Drop," and purchase raffle tickets. PLUS, each guest will receive a swag bag to take home!

Virtual Hot Stove Dinner Tickets | Virtual guests will be able to participate in the events and activities offered on the island, but from the comfort of your home! Virtual tickets include the opportunity to bid on once-in-a-lifetime experiences and luxury trips in the live auction, participate in the "Coconut Helicopter Drop," purchase raffle tickets, and enjoy entertainment by country music artist Max Flinn. Virtual guests will also be mailed a swag bag!



**PURCHASE YOUR
TICKETS HERE TODAY**



[Privacy Policy](#) | [Unsubscribe](#)

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

8588 Potter Park Drive, Suite 500 Sarasota, FL 34238