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
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
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

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.
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.
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

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

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!

Jennifer Hill, CPA
Director of Accounting

Angela Frazier
Events Coordinator
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

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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

PWSA | USA PULSE

Vol. 43
January 21, 2022

www.pwsausa.org
941.312.0400

WITH SPECIAL HOSTS CLINT & KARLA HURDLE

LIVE & virtual EVENT
MARCH 26, 2022

CLICK HERE TO REGISTER TODAY!

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!
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 MORE HERE
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.

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
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

Saniona Launches TM006 Study Website to Advance Testing Efforts for Tesomet

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
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!
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.

**READ ABOUT THE HISTORY OF THE HOT STOVE DINNER HERE**

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**JOIN US ON THE ISLAND OR ONLINE!**

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!