KEYNOTE SPEAKER ANNOUNCED FOR PWSA | USA'S 2023 NATIONAL CONVENTION!

Cristol Barrett O’Loughlin
Founder and CEO of A Nonprofit Group Enriching Lives, Inc.

Keynote Title: Caring for the Caregivers: From brokenhearted to belonging using the Raregivers™ Emotional Journey Map

LEARN MORE HERE >>
Federal Employee?

Ask them to support PWSA | USA via the Combined Federal Campaign!

Between NOW and January 14, 2023, you can support PWSA | USA during this year's Combined Federal Campaign (CFC)! The CFC is a program through which you can give to the charity of your choice. The campaign’s mission is to provide “all federal employees the opportunity to improve the quality of life for all.” Please consider supporting PWSA | USA as we continue to provide help and hope to families around the world.

PWSA | USA’s CFC ID # is 10088

LEARN MORE HERE

SAVE THE DATE

Upcoming Events >>>

Rare(ly) Missed Opportunities: Your PWS Financial Guide

When: October 11, 2022

Learn More Here >>

2023 Clint Hurdle Hot Stove Dinner

When: March 25, 2023

More details coming soon

ADVOCACY

PWSA | USA’s D.C. FLY-IN THANK YOU ADVOCATES!

Last month, PWSA | USA took our advocacy efforts to new heights!
Between September 19-21, 2022, 51 of our advocates touched down in Washington, D.C. for PWSA | USA’s first-ever D.C. Fly-In! We hosted a welcome reception Monday evening for our attendees, and on Tuesday, conquered more than 70 meetings with elected officials from around the country.

See our full event recap by clicking on the image below. A special thank you to our sponsors Harmony Biosciences, Saniona, and Horizon for funding this opportunity.

Learn about PWSA | USA's Newest Resource - Your PWS Financial Guide

Join us Tuesday, October 11th at 8:00 p.m. EST to learn about PWSA | USA's newest initiative "Rare(ly) Missed Opportunities: Your PWS Financial Guide." During this free interactive webinar, we will walk you through navigating our newest web based resource to find waivers in your state, financial literacy webinars and downloadable documents. Click the button below to register for this webinar event.
A special thank you to Global Genes for funding this new resource for our community.

Thank you to those who attended PWSA | USA's Virtual Sleep Summit!

Click the button below to access the session recordings, along with various presentations and sleep resources. We also want to give a big thank you to our incredible speakers for sharing their expertise with our community, and to Harmony Biosciences for funding this virtual event.

Radius Health to Close its RAD011 Trial

PWSA | USA received the news that Radius Health has decided to end its
phase 2/3 clinical trial to evaluate RAD011 as a potential treatment for Prader-Willi syndrome (PWS). Radius was recently purchased by Gurnet Point Capital who shared it will begin winding down the SCOUT-015 study throughout the month of October.

We know the past year has been tough on our community from a clinical trial standpoint, and PWSA | USA is here to support our families. Please reach out to us if you need assistance or support at 941-312-0400 or www.info@pwsausa.org.

Solenotm Therapeutics Announces Start of Randomized Withdrawal Study for PWS Drug DCCR

This week, Soleno Therapeutics announced it has initiated the next phase of its DCCR clinical trial (C602 Study), which is a randomized withdrawal period that will affect patients currently enrolled over the next four months.

Learn more about this announcement by clicking the button below.
Halloween is just around the corner and with it comes questions and uncertainty for our PWS families. In the next few weeks, candy and sweets will be offered in schools and throughout neighborhoods, and we are here to offer a few tricks to conjure up new treats! Click the button below to hear from families who have found new ways to navigate the spooky season.

We are also working to collect more alternative options or unique traditions on Halloween. At the button below, we encourage you to fill out our Halloween Tips + Tricks form to share your own stories from Halloweens and/or suggestions for other families that you have found to be successful.

**LEARN MORE HERE**

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**Help us Welcome Andrea Hughes to PWSA | USA's Staff!**

We want to give a warm welcome to our newest team member Andrea Hughes, who will serve as the organization's Development Database Coordinator.

We are excited to have her join our PWSA | USA family! Get to know Andrea better by visiting our Staff webpage at the button below.

**VISIT THE STAFF WEBPAGE**
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!
Do YOU know a Current or Former Federal Employee?

Ask them to support PWSA | USA in this year's Combined Federal Campaign!

Between NOW and January 14, 2023, you can support PWSA | USA during this year's Combined Federal Campaign (CFC)! The CFC is a program through which you can give to the charity of your choice. The campaign’s mission is to provide “all federal employees the opportunity to improve the quality of life for
all.” Please consider supporting PWSA | USA as we continue to provide help and hope to families around the world.

**PWSA | USA’s CFC ID # is 10088**

LEARN MORE HERE

Congratulations to two of our **Hope United Champions** for hosting amazing events in October! Thank you to John Lens and his family, and Michelle Spring and her family for helping to raise funds for PWSA | USA in honor of their loved ones living with PWS. Click on the images below to learn more.

**13th Annual Hunter Lens Golf Tournament**

**2022 Angel Drive**
When: November 1 - December 31, 2022
More details coming soon

**2023 Clint Hurdle Hot Stove Dinner**
When: March 25, 2023
More details coming soon

**SAVE THE DATE**
Upcoming Events >>>
37th National Convention
When: June 21 - 24, 2023

Learn More Here

2nd Annual Answers for Audrey

BECOME A HOPE UNITED CHAMPION!

WE HAVE MOVED!

New Address:
PWSA | USA
1032 E Brandon Blvd #4744
Brandon, FL 33511

ADVOCACY
As part of PWSA | USA's D.C. Fly-In, our advocates were able to share their personal stories with elected officials and their staffers. Several individuals living with PWS attended these meetings as well, including Reagan Seely and Justice Rickenbach, who gave insight into their own journeys living with the syndrome.

Reagan and Justice wanted to give our entire community the opportunity to read what they shared on Capitol Hill. You can find their letters by clicking on the images below. Thank you, Reagan and Justice, for your courage and strength.

Learn about PWSA | USA's Newest Resource - Your PWS Financial Guide

Click on the image below to watch the recording of last week's webinar "Rare(ly) Missed Opportunities: Your PWS Financial Guide." Family Support Director Stacy Ward walks you through navigating our newest web-based resource to find waivers in your state, financial literacy webinars, and downloadable documents.
A special thank you to Global Genes for funding this new resource for our community.

**Rare(ly) Missed Opportunities: New PWS Financial Guide**

**VISIT THE PWS FINANCIAL GUIDE WEBSITE HERE**

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**Halloween Fun for Everyone**

**Halloween** is just around the corner, and with it come questions and uncertainty for our PWS families. PWSA | USA’s Family Support Team is here to offer tips and tricks to keep your loved one safe while still having fun! Click the button below to learn more.

**LEARN MORE HERE**

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**Attention PWS Caregivers - We Need Your Input!**
We are looking for caregivers who have helped their loved one living with PWS through toilet training.

Click the button below to learn more about this survey and to see if you qualify. Thank you!

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

Marine Locks are Back in the PWSA | USA Shop!

We are excited to share that Marine Locks are now available for purchase in our online shop in white, black, and stainless! The marine lock offers easy installation, keeps your items very secure, and comes with a replaceable padlock. Order yours today by clicking the button below!

ORDER HERE
With the holiday season just around the corner, PWSA | USA is working to create a library of tips, stories, and recipes to help our community navigate this fun, but often stressful time of year. You can help fellow parents, caregivers, and family members find inspiration and ideas by sharing what you have done for your loved one living with PWS as alternative options or unique traditions.

Click the button below to share your **Hope for the Holidays**!

**SHARE YOUR HOPE FOR THE HOLIDAYS**

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
1032 E Brandon Blvd #4744 Brandon, FL 33511
Holiday Safety for Your Loved One Living with PWS

With Halloween just a few days away and the busy holiday season quickly approaching, we know it can be a fun, but often stressful time of year for our PWS community. PWSA | USA's Family Support Team and volunteers are here to offer helpful tips and tools to make trick-or-treating, holiday parties, and gift giving more manageable for your family and loved one living with PWS.

Click the images below to learn more!
Thank you to those who have participated in our Hope for the Holidays by sharing a story, tip, or recipe! Scroll below to learn some of the different ways PWS families have found success. YOU can help us continue to build a library of information that gives hope to families and helps them navigate the holidays.

SHARE YOUR HOPE FOR THE HOLIDAYS
"Plan ahead! Zoey does really well through the holidays when we plan ahead and can fill her in on those plans. She likes knowing what to expect so planning ahead and discussing it with her helps to soothe a lot of her anxiety."

- Jamie Cox, Mom to Zoey (12)

"My son loves spooky things! On Halloween, he wears his costume to eat dinner in a restaurant. We used to come home after and play a spooky game or watch a spooky movie, but now a car wash near us does a haunted car wash!"

- Cindy Szapacs, Mom to Daschel (15)

"My daughter Chassidy, 29, was diagnosed with PWS at 18-months-old. We don’t do Halloween because of the candy and temptation. Thanksgiving is with family members who support our guidelines on food security. Christmas is the same. I bring dessert that is sugar free. I make sure that Chassidy is supervised and has something to do while getting together with our loved ones."

- [Mom to Chassidy]
“The holidays tend to be a busy time. Instead of trying to fit more in, I try to look at what I can remove from our list of activities and obligations. I also try to take extra time off work and build in spaces for down-time. This helps relieve stress and gives us more space to deal with whatever challenges come up, because they always do!”

- Emily Felt, Mom to Olivia (10)
and swerve some of the healthy options below. Switch things up every year to make treats exciting and fun year after year!”

- Lisa Graziano, Mom to Cameron (23)