

PWSA | USA Bi-Weekly Pulse - December 2, 2022

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 64

December 2, 2022

www.pwsausa.org | 941.312.0400

**Congratulations to Harold J.P. van Bosse, MD FAAOS, for
Joining the Orthopedics Team at SSM Health Cardinal
Glennon Children's Hospital in St. Louis, MO**



PWSA | USA has been informed that Harold J.P. van Bosse, MD FAAOS, joined the Orthopedics team at SSM Health/Saint Louis University/Cardinal Glennon Children's Hospital in St. Louis, MO.

"I look forward to continuing my work with patients and families of children with Prader-Willi syndrome," said Dr. van Bosse.

If you are interested in scheduling an appointment with Dr. van Bosse, he has asked our community to contact Jessica Gorman, BSN, RN, at 314-268-2700 Ext.

1163 or jessica.gorman@ssmhealth.com.

You can read SSM Health's full announcement by clicking the button below.

[LEARN MORE HERE](#)

Thank You for Supporting PWSA | USA!



Dear friends,

On behalf of PWSA | USA, I would like to extend a heartfelt thank you for your generosity on Giving Tuesday and during the first half of our Angel Drive campaign. Your outpouring of support will continue to make a difference for countless families around the world affected by PWS, propel more advocacy initiatives that will help our community, and fund important research projects to find treatments for our

loved ones. With your help, we can make an incredible impact.

As our **2022 Angel Drive** campaign continues, we have two exciting match opportunities to share. Thanks to your help and a group of anonymous generous donors, we are getting closer to reaching our match goal that kicked off on Giving Tuesday! Angel Drive contributions made through December 31st will be matched dollar for dollar up to \$38,500.

We also encourage our community to take advantage of **Facebook's new monthly recurring donor match** opportunity. Now through the end of December, we are looking for **23** people to kick-off 2023 with more HOPE! Simply sign up as a monthly PWSA | USA donor through Facebook and double your impact. The social media platform will give a 100% match up to \$100 per month for every person who participates. To qualify, you must be a new recurring donor establishing a monthly donation via our Facebook campaign [HERE](#) and make two consecutive monthly payments of \$5 or more. These funds (and the dollar-for-dollar match) will directly benefit PWSA | USA!

Thank you for your kindness and support, and for inspiring hope this holiday season.

Warmly,



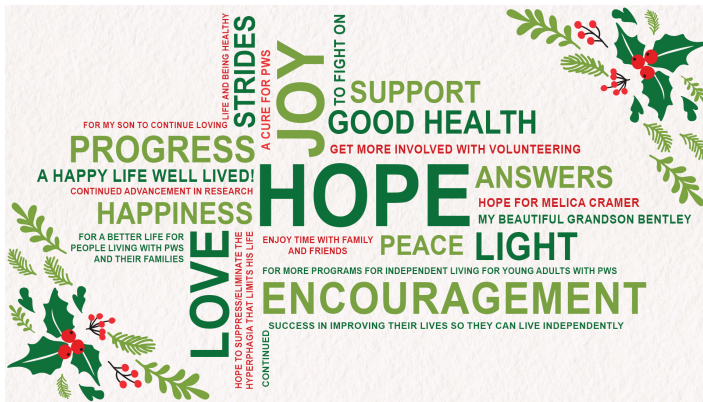
Paige Rivard, MBA | CEO
Mom to Jake (12)

HELP US REACH OUR \$38,500
MATCH BY DONATING TO THE
ANGEL DRIVE HERE



LEARN MORE
ABOUT BECOMING A
RECURRING DONOR ON
FACEBOOK HERE

Help us Continue Building our Angel Drive *Thread of Hope!*



This holiday season, we invite you to share your **HOPE** for your loved one with PWS (or the PWS community) when you fill out our online donation form. Why? Because your message of hope will become part of a thread connecting all of us near and far as we begin a new year.

Click the button below to make an impact and share your hope!



SAVE THE DATE

[Upcoming Events >>>](#)



PWSA | USA Behavior Summit

When: December 13, 2022

[Learn more here](#)



PWSA | USA Closed

When: Monday,
December 26, 2022 &
Monday, January 2, 2022

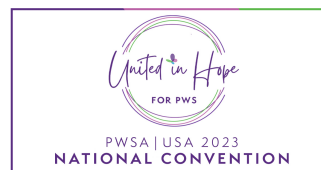


2023 Clint Hurdle Hot Stove Dinner

When: March 25, 2023



More details coming soon



37th National Convention

When: June 21 - 24, 2023

[Learn More Here](#)

Celebrate the season of giving by becoming a PWSA | USA Selfless Elf!

Tell your family and friends that taking action for PWS is at the very top of your holiday wish list. Visit hopeunited.pwsausa.org/elf to sign up as a Selfless Elf, and start encouraging donations in lieu of gifts and in honor of your loved ones. It only takes five minutes to create your own Selfless Elf page! Funds raised during our Selfless Elf campaign will support the 2022 Angel Drive.

2023 NATIONAL CONVENTION

Medical & Scientific Conference: Call for Abstracts

PWSA | USA is welcoming abstract submissions for a presentation of recent research, related scientific or medical topics on the subject of Prader-Willi syndrome for our 2023 Medical & Scientific Conference. The Medical & Scientific Conference will be held at PWSA | USA's 37th National Convention June 21-22, 2023 in Orlando, FL.

If you are interested in submitting an abstract for the medical & scientific program, click the button below and fill out our "Call for Abstracts" interest form.



We will contact you in the next couple of weeks with more details and a link to submit your abstract.

Questions? Email
info@pwsausa.org

[FIND THE CALL FOR ABSTRACTS FORM HERE](#)



ADVOCACY

PWSA | USA Selected as NFL My Cause My Cleats Charity for the Second Time



We are happy to share PWSA | USA has been selected as a charity for the [NFL's My Cause My Cleats campaign](#) for the second year in a row by Denver Broncos' player Caden Sterns. Once again, Caden has chosen our organization in honor of his friend, Brooklyn, who is living with PWS.

In light of this exciting news, PWSA | USA recently spoke with Brooklyn's parents, Kelli and Mike, who shared more about the family's connection to Caden and Brooklyn's journey living with PWS.

"It fills our heart with joy and love that Caden chooses to continue to help raise awareness for his special warrior Brooklyn, as well as everyone else in our tribe."



[READ MORE HERE](#)



FAMILY SUPPORT

Winter Holiday Tips



No matter what holidays you and your family celebrate, PWSA | USA wants to help you make it both fun *and* safe. The key is to **plan well ahead of time**, incorporating the strategies outlined in the helpful article found at the button below.

If you need any assistance navigating the holidays, you can always call our 24-Hour Support Line at (941) 312-0400.

[LEARN MORE HERE](#)

PWSA | USA to Host FREE Behavior Summit



Tuesday, December 13, 2022 | 2:00 - 7:45 p.m. EST



Stacy Ward, MS



**Patrice Carroll,
LICSW**



**Kasey Bedard,
Ph.D., BCBA-D,
IBA**



**Cindy Szapacs,
M.Ed. BCBA**

LEARN MORE & REGISTER HERE

Home Repair Loans Available for Low-Income and Rural Families



For those in our community seeking assistance, the Section 504 Home Repair program provides loans to very-low-income homeowners in rural areas to repair or improve their homes. It also provides grants to elderly very-low-income homeowners to remove health and safety hazards.

Utilizing the [USDA Eligibility Site](#), you can enter an address or search the map to review eligibility criteria. Click the button below to learn more.

[LEARN MORE HERE](#)



RESEARCH

Global PWS Registry Shares Data on Living Situations for Individuals Affected by PWS



The Global PWS Registry has released data that shares various details surrounding living situations for individuals living with PWS. Some of the information found includes how many individuals affected by PWS live with their parents, broken down by age group, are in a group home, independent-housing, or small supported living, as well as how satisfied families are with their loved one's current living situation if they are 19 years or older.

Find more details by clicking the button below.

[LEARN MORE HERE](#)

Caregiver Training - Participants Needed!



The Chicago School of Professional Psychology is looking for PWS caregivers to participate in an asynchronous computer training on medication and data collection procedures. The training is self-paced and will take less than three hours to complete.

For more information, contact Angeline Eaton, M.Ed., BCBA, LBA at Aeaton1@ego.thechicagoschool.edu.

Learn more at the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Clint Hurdle
HOT STOVE DINNER

Clint Hurdle

Key Royale Club
Anna Maria Island, FL & Virtual
March 25, 2023
Island Treasure Reception 5:00 p.m. until 6:00 p.m.
6:00 p.m. General Admission

Presented By: 

Save the Date!

CLINT HURDLE
HOT STOVE DINNER

MARCH 25, 2023
\$250 per person

Get ready for some fun in the sun! For those interested in attending the 2023 Clint Hurdle Hot Stove Dinner, you can now make your hotel reservations in our room block at the button below. The event will be held Saturday, March 25, 2023 at the Key Royale Club on Anna Maria Island, FL.

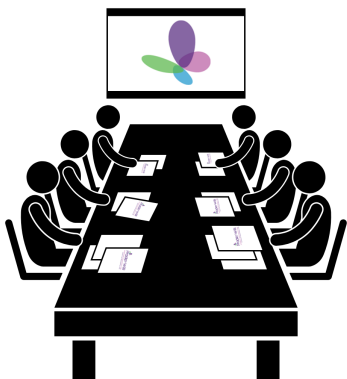
We will share more details, including registration, in the near future. We hope to see you there!

[BOOK YOUR HOTEL RESERVATION HERE](#)

Call for Nominations!

Starting in 2023, we are looking for a CPA/financial professional to fill the officer role of Board Treasurer.

If you are interested in this position or would like more information, please contact the current Board Treasurer, Pam Zambrotta at pzambro@gmail.com



or CEO, Paige Rivard at privard@pwsausa.org.

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](#)
1032 E Brandon Blvd #4744 Brandon, FL 33511

PWSA | USA Bi-Weekly Pulse - December 16, 2022

Enhancing the Quality of Life and Empowering Those Affected by PWS

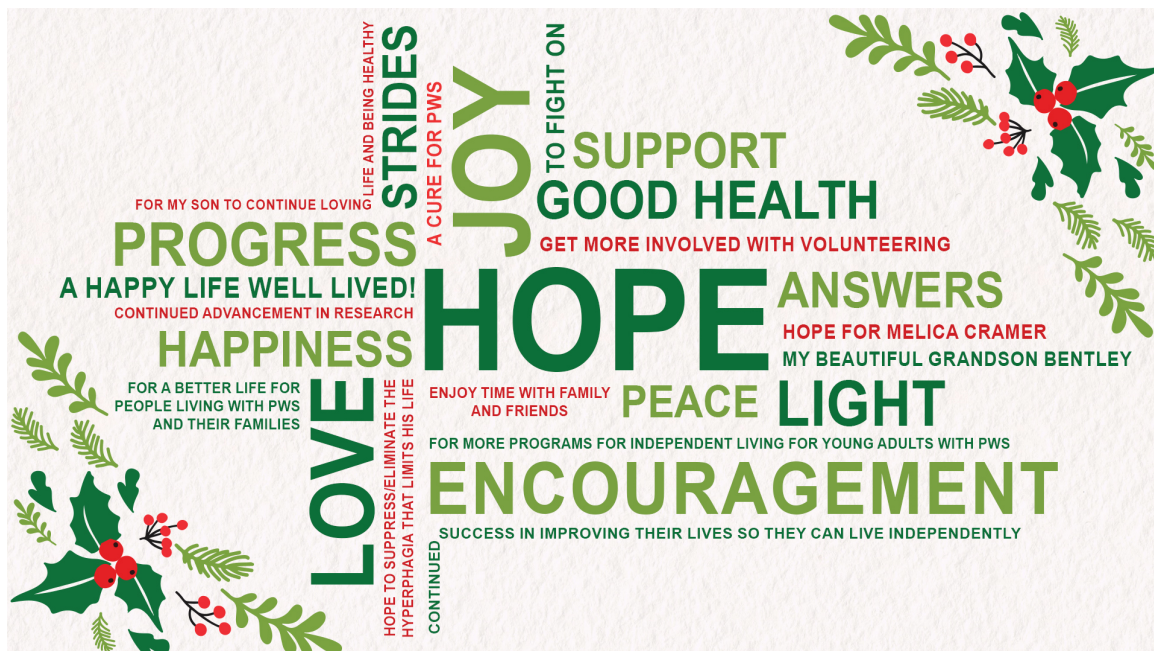


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Only *TWO WEEKS LEFT* to Make a Lasting Impact by
Donating to PWSA | USA's 2022 Angel Drive!



There are just a few weeks left to support PWSA | USA's 2022 Angel Drive campaign! Your donation will help make a **HUGE** impact in the new year as we launch several new initiatives and offer continued support to our families and loved ones. **Don't miss the chance to have your gift DOUBLED!** Thanks to a group of anonymous donors, donations made through December 31st will be matched dollar for dollar up to \$38,500.

To make a contribution, click [HERE](#) or text Angel2022 to 99129. Thank you for your generosity and for taking action to inspire **HOPE** this holiday season!



**Celebrate the season of giving
by becoming a PWSA | USA
Selfless Elf!**

It's not too late to sign up as a PWSA | USA Selfless Elf! Tell your family and friends that taking action for PWS is at the very top of your holiday wish list. Visit hopeunited.pwsausa.org/elf to sign up as a Selfless Elf, and start encouraging donations in lieu of gifts and in honor of your loved ones. It only takes five minutes to create

your own Selfless Elf page! Funds raised during our Selfless Elf campaign will support the 2022 Angel Drive.



**Register TODAY for PWSA | USA's
2023 National Convention!**

SAVE THE DATE

[Upcoming Events >>>](#)



Registration is NOW OPEN for PWSA | USA's 37th National Convention! We invite you to join us June 21 – June 24, 2023, in sunny Orlando, Florida at the Hilton Orlando Buena Vista Palace.

PWSA | USA's Convention will provide exciting opportunities to learn, connect (and reconnect), and hear about the latest PWS research. This world-class event will include Medical & Scientific, Professional Providers, and Family Conferences, as well as the newly renamed "PWS Kids Camp" for infants through adults living with PWS and their siblings. We are also honored to host and include all PWS stakeholders during our Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting, which is an FDA program.

Whether you have a loved one with PWS, are a professional provider, a physician, or scientist, the 2023 Convention has something for everyone. Register **TODAY** by clicking the button below. We hope to see you there!



PWSA | USA Closed

When: Monday,
December 26, 2022 &
Monday, January 2, 2022



PWSA | USA Behavior Summit

When: January 24, 2023

[Learn more here](#)



2023 Clint Hurdle Hot Stove Dinner

When: March 25, 2023

[Book your hotel reservation HERE](#)



37th National Convention

When: June 21 - 24, 2023



[Learn More Here](#)

**Book Your 2023 Convention
Hotel Room [Here](#)**



ADVOCACY



**[Click here to read PWSA | USA's
2022 Advocacy in Action Recap >>](#)**

*Thank you to our advocates for
your support, involvement, and
using your VOICE!*



FAMILY SUPPORT

Family Support Training Opportunities



With the start of 2023 just around the corner, we want to give a special shoutout to PWSA | USA's Family Support team. Throughout the year, they provided assistance to thousands of individuals and families in all 50 states and multiple countries. They also conducted several trainings, both virtually and in-person, to assist those who support individuals affected by PWS.

In 2022 alone, Family Support Director Stacy Ward, MS, and Alterman Family Support Counselor Kim Tula, MS, CSW, gave **18**

trainings to school professionals and residential providers around the U.S.

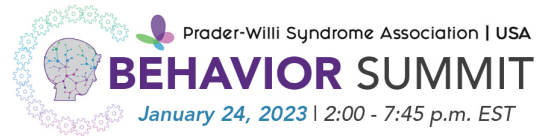
Learn more about our Educational Training opportunities at the button below.

[LEARN MORE HERE](#)

"Kim was wonderful. She was very helpful in 'normalizing' our experiences and providing recommendations and resources."

| Anonymous

**Behavior Summit RESCHEDULED for
Tuesday, January 24, 2023**



Due to circumstances beyond our control, PWSA | USA's first-ever Behavior Summit is being **RESCHEDULED** to **Tuesday, January 24, 2023** from 2:00 - 7:45 p.m. EST.

We appreciate your understanding and flexibility, and hope to see you January 24th! Learn more about this **FREE** event and find the registration links at the button below.

[REGISTER HERE](#)



RESEARCH

Caregiver Training - Participants Needed!



The Chicago School of Professional Psychology is looking for PWS caregivers to participate in an asynchronous computer training on medication and data collection procedures. The training is self-paced and will take less than three hours to complete.

For more information, contact Angeline Eaton, M.Ed., BCBA, LBA at Aeaton1@ego.thechicagoschool.edu.

Learn more at the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

ICYMI: Harold J.P. van Bosse, MD FAAOS, will Join the Orthopedics Team at SSM Health Cardinal Glennon Children's Hospital in St. Louis, MO



We are excited to share Harold J.P. van Bosse, MD FAAOS, has joined the Orthopedics team at SSM Health/Saint Louis University/Cardinal Glennon Children's Hospital in St. Louis, MO.

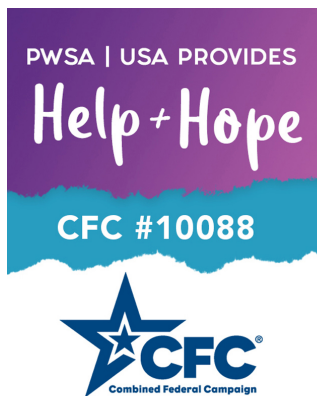
"I look forward to continuing my work with patients and families of children with Prader-Willi syndrome," said Dr. van Bosse.

If you are interested in scheduling an appointment with Dr. van Bosse, he has asked our community to contact Jessica Gorman, BSN, RN, at 314-268-2700 Ext. 1163 or jessica.gorman@ssmhealth.com.

You can read SSM Health's full announcement by clicking the button below.

[LEARN MORE HERE](#)

Are you a Current or Retired Federal Employee?



There is still time to 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 through January 14, 2023.

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](#)

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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PWSA | USA Special Edition Pulse - December 2022

www.pwsausa.org | 941.312.0400

[Donate](#)



Tomorrow is the **LAST DAY** to support PWSA | USA's [2022 Angel Drive](#) campaign! Donations can be made until **midnight** on December 31st.

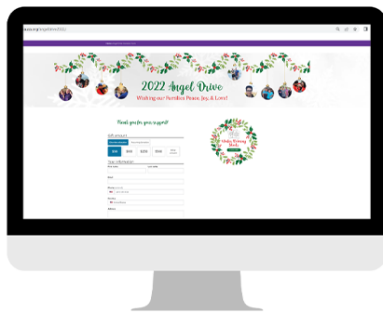
Take action to help make an impact on all of the ways PWSA | USA supports individuals affected by PWS and their families through our Advocacy, Family Support, and Research initiatives.

Your gift to the 2022 *Angel Drive* will...



Directly help those living
with PWS and their
families receive support
from PWSA | USA's
Family Support team

Support the 2022 *Angel Drive*



Make sure to share what
your **Hope** is for your
family or loved one in our
online donation form!

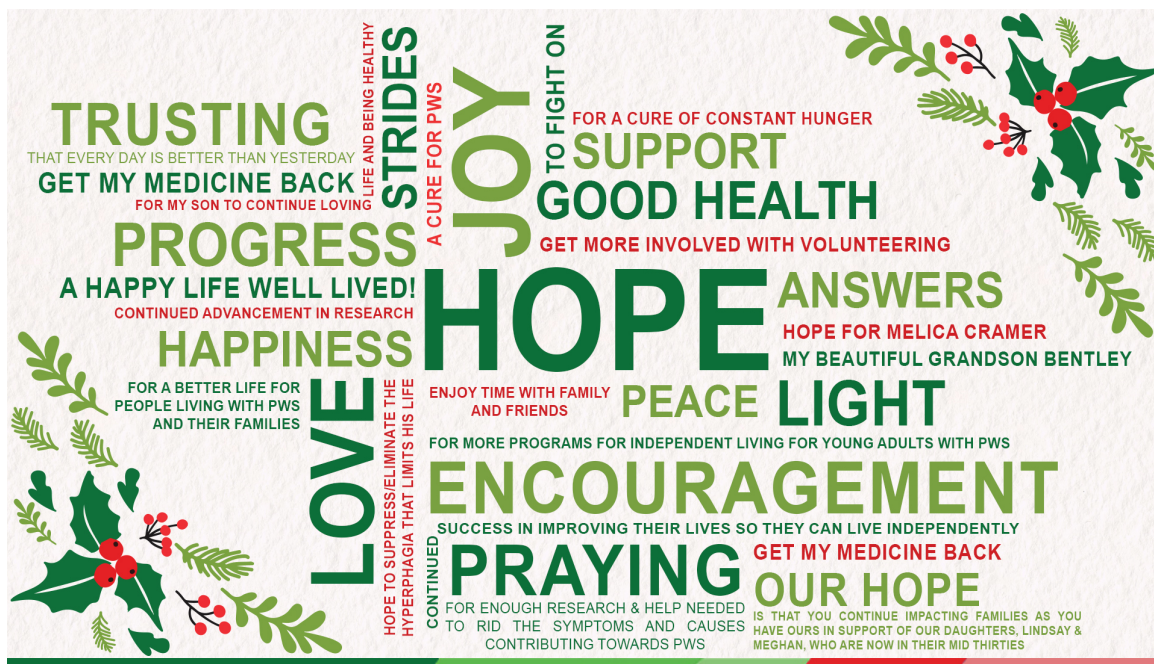
Text **Angel2022** to **99192** to
give on your mobile device



Scan the QR code to
complete your donation!



DON'T FORGET: Help us build our **Thread of Hope** by sharing
what your hope is for the new year when you make a gift [online](#)!



OUR TOP PARTICIPANTS

 Melanie R. McDonald	\$1,653
 Louise Yates	\$625
 Kendra Miller	\$405
 Kathryn Balthrop	\$200
 Kayla Guthrie	\$75



THANK YOU to our **Selfless Elves** who encouraged donations in lieu of gifts and in honor of their loved ones this holiday season. Check out the leaderboard above, and click the button below to give a gift in support of our elves.

Funds raised during our Selfless Elf campaign will support the 2022 Angel Drive.



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