

PWSA | USA Bi-Weekly Pulse: August 4, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 80

August 4, 2023

www.pwsausa.org | 941.312.0400

Several 2023 Family Conference Session Recordings Now Available for Viewing!

Learn valuable information from PWS experts! Several PWSA | USA National Convention Family Conference sessions, including the clinical trials update, fireside chat with the clinicians, and supportive living options, are now available to watch at the button below. Due to limited resources and staffing, the session recordings on the webpage are the **only** recordings available from this year's Convention. If there is additional information you are looking for, please contact PWSA | USA at info@pwsausa.org.



PWSA | USA 2023
NATIONAL CONVENTION
Prader-Willi Syndrome Association | USA

[Click Here to
Watch the Session
Recordings](#)



EVENTS

2023 Moms' Retreat Applications Due August 14th!



To give the amazing moms and full-time female caregivers in our PWS community some much-deserved “me-time,” PWSA | USA will host its first-ever **Moms' Retreat** October 12-15, 2023 in Palm Springs, CA with facilitator Jessica Patay, founder and executive director of *We Are Brave Together*.

Since this is the association's first Moms' Retreat event and to provide an intimate atmosphere, 30 people will be selected to attend at random from the applications submitted. Applications are due by August 14, 2023. Learn more about the event and apply at the button below.

[LEARN MORE HERE](#)

PWS Hope United Spotlight: Kissing for a Cause



Mr. & Mrs. Steven & Tara Davis of Wilbraham, Massachusetts tied the knot this past weekend and celebrated their love by **"Kissing for a Cause"** during the reception! As a long-time friend of Melanie McDonald, mom to Josephine, 5, living with PWS, Tara wanted to raise money for PWSA | USA in honor of Josephine in a very special and unique way.

"The clinking of glasses to cue the couple to kiss felt a little too lacking in significance and more for entertainment value alone. By choosing such an important cause to

accompany the bell, it transformed each kiss into a genuine celebration in knowing we and the people we love were doing some good as well," said Tara. "We didn't need gifts to mark the occasion and wanted to find a way for our special day to be a blessing to others. PWSA | USA seemed like the perfect place to direct support. We invited Melanie to speak after our first dance to explain. We set up a bell that generous guests could ring throughout the evening indicating they had made a donation in the jar we provided, or that they had given online to our Hope United fundraising page. PWSA | USA provided a custom QR code that we put in our wedding program and displayed near the jar. We were happy to hear the bell ring so many times throughout our reception and felt great knowing that it meant PWSA | USA was getting support!" Steven and Tara raised nearly \$1,000 from their "Kissing for a Cause" fundraiser. We are sincerely appreciative to the newlyweds for their support and wish them all the best - Cheers to the Davis'!

LEARN MORE HERE



If you are interested in hosting a PWS Hope United fundraiser, click the button below and email us at hopeunited@pwsausa.org.

BECOME A HOPE
UNITED CHAMPION!



ADVOCACY

Calling All Artists Living with PWS!



The Everylife Foundation is once again accepting artwork for their **Rare Artist Program**, established in 2010. Individuals living with PWS are encouraged to submit their paintings, drawings, photography, photographed ceramics, 3D art, or poetry (new this year) to the button below by August 31, 2023. Two pieces may be submitted for consideration, but only artists can only win for one piece.

According to the Everylife Foundation's Rare Artist Program guidelines, The Rare Artist Contest awards 10 artists each year. The

program offers unique and special opportunities for award recipients including cash prizes, displaying artwork on Capitol Hill and year-round in Washington, D.C., and more!

Find all the details and the link to submit artwork at the button below.

[LEARN MORE HERE](#)

2023 YARR Leadership Academy Now Accepting Applications



Another great opportunity for our loved one's living with PWS is Everylife Foundation's upcoming **YARR Leadership Academy**.

According to Everylife Foundation's website, this program offers a series of online classes to a select group of young adults in the rare disease community. YARR Leadership Academy students will learn about the roles and opportunities for patient representation in policy-making, drug development, and the regulatory process and the steps it takes to enter those roles. Please only apply if you are between the

ages of 18 and 30 and you can commit to 8 online courses between 6 pm and 8 pm ET on Wednesday evenings between September 27 and November 15, 2023.

YARR Leadership applications are due by Friday, August 18, 2023. Find more details and the link to apply at the button below.

[LEARN MORE HERE](#)

Nominations are Now Being Accepted for the 2023 Rare Voice Awards

Consider nominating a PWS advocate for the **12th Annual Rare Voice Awards**, hosted by Rare Disease Legislative Advocates (RDLA), taking place December 13, 2023, in Washington, D.C.

According to the Everylife Foundation's website, this celebration honors advocates who help amplify the voice of the rare disease community in state and federal policy on Capitol Hill. Those in our PWS community are encouraged



to nominate individuals and organizations who have gone above and beyond to become rare disease policy leaders, having passed or catalyzed legislation for the rare disease community in 2022 and/or 2023.

Nominations close August 16, 2023. Click the button below to read more and make your nomination!

[LEARN MORE HERE](#)



FAMILY SUPPORT

What is Disenfranchised Grief and How Can PWSA | USA's Family Support Team Help?



Grief is the response to loss, particularly to the loss of someone or some living thing that has died, to which a bond or affection was formed. But what about the feelings of loss associated with living with PWS? Is this a grief individuals feel when they are faced with a loss of freedom or independence? Is it grief individuals experience when they can't reach their personal goals, when they can't have a family of their own, or when they can't own and drive a car? Yes. These are all examples of **disenfranchised grief**.

Disenfranchised grief is grief experienced when a loss occurs that is not openly acknowledged, publicly mourned, or socially supported. Any loss one experiences that is not commonly experienced by others can lead to disenfranchised grief.

It is not uncommon for people with PWS to experience grief throughout different stages of their life. PWSA | USA offers support to those experiencing disenfranchised grief. Over the past few months, we have provided support to numerous individuals with PWS, between the ages of 8- and 50-years-old, who are working through disenfranchised grief. If your loved one is experiencing a sense of loss or you believe they could use additional support related to PWS, please contact one of the family support counselors at 941-312-0400.

Community Conversations: Sibling Support Group



Siblings of loved ones living with PWS are invited to join PWSA | USA for our next Siblings Community Conversation on **August 9, 2023, at 8:00 p.m. EST**. These sibling community conversation webinars will take place the 2nd Wednesday of every month.

This discussion provides a safe space for dialogue between siblings of a person with PWS. All ages are welcome to attend! PWSA | USA team members will also be available to offer any insight and support. Register in advance at the button

below.

In an effort to ensure attendees feel comfortable to share openly, this opportunity is just for siblings. We appreciate your understanding!

[REGISTER IN ADVANCE HERE](#)



RESEARCH

Calling all PWS Parents and Caregivers!

The Chicago School of Professional Psychology is currently recruiting for a survey study to investigate caregiver perception of language patterns related to repetitive verbal behavior in PWS.



If you are the caregiver of an individual with PWS who is older than two years of age, if you are over the age of 18, and speak and read English fluently, you are eligible to participate in this study. If you complete the survey, you can choose to be entered into a raffle to win a \$25 gift card. Please also share the flyer at the button below with anyone you think may be interested in participating! To see if you qualify to participate in the study, please click the survey link below.

[SURVEY LINK](#)

[DOWNLOAD THE FLYER HERE](#)

Read Dr. Merlin Butler's Recent Published Articles About Genetic Testing in PWS and Clinical Trials Review



Dr. Merlin Butler, MD, PhD, along with other researchers, recently published multiple articles with further insight into genetic testing in PWS and current clinical trial reports. The article, [Chromosomal Microarray Study in Prader-Willi Syndrome](#), pertains to recent genetic testing results in a large PWS cohort and summarization on the types of genetic differences seen in PWS. The article, [Clinical Trials in Prader-Willi Syndrome: A Review](#), offers a review of the clinical trial reports to date and response in PWS. The article, [Prader-](#)

[Willi Syndrome and Chromosome 15q11.2 BP1-BP2 Region: A Review](#), offers a review of the clinical and genetic findings in PWS and how it impacts on the PWS phenotype.

Find these articles on PWSA | USA's PWS Articles of Interest webpage.

PWS ARTICLES OF INTEREST

Gedeon Richter Now Recruiting for KITE-PWS Clinical Trial



You or someone you love could be part of developing new therapies for PWS. Learn about [Gedeon Richter's](#) research study KITE-PWS, also known as RGH-706-003, to evaluate an experimental drug for hyperphagia in people with Prader-Willi syndrome.

Learn more and find out how you can get involved at the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

Join Our Team!



PWSA | USA is currently seeking a **Marketing and Communications Coordinator** to join our Marketing and Communications Department. The Marketing and Communications Coordinator provides brand management support and assists with the implementation of marketing, public relations, communications on our various platforms, and strategic planning. This position is available for a full-time or part-time employee and will require some travel. To apply

for this position click the button below.

[FIND THE FULL JOB DESCRIPTION HERE](#)

Get to Know PWSA Egypt & Middle East!



Individuals and families affected by PWS who are living in Egypt and the Middle East now have an established community to find help and hope. **PWSA Egypt & Middle East** was officially founded on June 1, 2023, by Walaa Mohamed, mom to Ahmed, 13, living with PWS. PWSA Egypt & Middle East will serve the entire Arab and Middle East region.

Over the past two years, PWSA | USA has assisted with laying the foundation by hosting several zoom sessions to connect specialists in the

PWS world with Walaa and several other PWS family members in Egypt. A special thank you to the International Prader-Willi Syndrome Organisation (IPWSO) for providing grant funding to start the official organization.

The organization is now in the process of finalizing its official name and registration, and is preparing for the first parent and caregiver kick-off workshop in Egypt. To learn more about PWSA Egypt & Middle East, click the buttons below.

[VISIT PWSA EGYPT & MIDDLE EAST'S WEBSITE](#)

[VISIT PWSA EGYPT & MIDDLE EAST'S FACEBOOK PAGE](#)

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope

[Donate](#)

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PWS Families - We Need Your Help! *Share Your Holiday Tips*

Summer is still in the air, but the holiday season will be upon us sooner than we realize! 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 image below to share your **Hope for the Holidays**, either through a story, a photo, a tip, or recipe from a past Halloween, Thanksgiving, Hanukkah, Kwanzaa, Christmas, New Years, or another holiday you celebrate. We will share the information submitted in PWSA | USA's September Pulse Newsletter (9/29) and on our social media pages. You can also choose to submit anonymously. Thank you!



Hope FOR THE Holidays

Click Here to
Share Your Tips!



EVENTS

**2023 Moms' Retreat Applications Now CLOSED and
Attendees Have Been Selected**



Thank you to everyone who submitted an application to attend PWSA | USA's first-ever Moms' Retreat, October 12-15, 2023, in Palm Spring, California! This afternoon, 30 applicants were randomly selected to attend the event. Our staff will be reaching out to these individuals soon to provide additional details and collect information. We will also share who was selected next week on PWSA | USA's blog and social media sites.

With the incredible interest in this retreat, we are hopeful to provide additional opportunities in the future. More details to come! We look forward to seeing our 30 attendees in sunny California soon.

Questions? Contact us at events@pwsausa.org or (941) 312-0400.

[LEARN MORE HERE](#)

Florida Residents! Enjoy Time Together at Prader-Willi Florida Association's Upcoming Family Fun Day



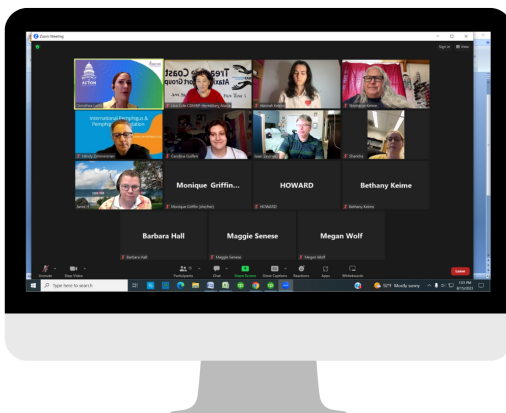
Save the date! Prader-Willi Florida Chapter will host a Family Fun Day Saturday, September 9, 2023, at the Burt Reynolds Park Waterway Pavilion in Jupiter, Florida. Please stay tuned for more details as PW Florida Association is planning this big event. Check their Facebook page [HERE](#) for event updates.

If your Chapter has an upcoming event, let us know at info@pwsausa.org so we can share it in future Pulse newsletters!



ADVOCACY

Rare Across America Recap



Over the past two weeks, several PWSA | USA advocates had the opportunity to meet with their members of congress and their staff to discuss rare diseases and ways our elected officials can continue to support the PWS community. From New Hampshire to Florida, our delegates addressed critical issues for the rare disease community, focusing on bills such as the HELP Co-pay Act, the SAFE STEP Act, the

Medical Nutrition Equity Act, the Benefit Act, and the PROTECT RARE Act. In addition to engaging in legislative efforts, our advocates once again utilized this opportunity to converse with members of Congress about our ongoing struggle to obtain FDA approval for drugs capable of treating PWS symptoms. We asked lawmakers to continue to encourage the FDA to use their regulatory flexibility when evaluating the approval of drugs to treat symptoms of PWS. PWSA | USA advocates had the opportunity to speak with the following members:

Rep. Maria Elvira Salazar (R-FL)

Rep. Gus Bilirakis (R-FL)

Rep. Daniel Webster (R-FL)

Sen. Rick Scott (R-FL)

Sen. Marco Rubio (R-FL)

Sen. Jeanne Shaheen (D-NH)

Rep. Chris Pappas (D-NH)

Sen. Maggie Hassan (D-NH)

Calling All Artists Living with PWS!



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program offers unique and special opportunities for award recipients including cash prizes, having their artwork displayed on Capitol Hill, and more!

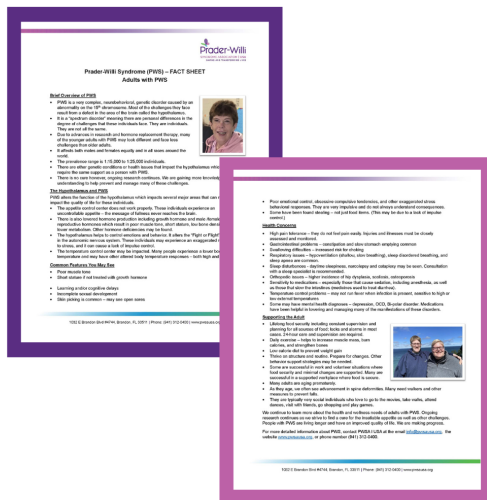
Find all the details and the link to submit artwork at the button below.

LEARN MORE HERE



FAMILY SUPPORT

New Resource Available: PWS Adult Fact Sheet



PWSA | USA has a new resource available to help give an overview of how adults living with PWS are affected by the syndrome. Click the button below to download this fact sheet, which can be shared with friends, teachers, and other interested persons to offer insight. We will also provide additional fact sheets for all age groups in the near future. A special thank you to volunteer Barb Dorn, RN, BSN, for working with the Family Support team to put these resources together.

DOWNLOAD THE FACT SHEET HERE

Community Conversations: Sibling Support Group

Siblings of loved ones living with PWS are invited to join PWSA | USA for our next Siblings Community Conversation on **September 13, 2023, at 8:00 p.m. EST**. These sibling community conversation webinars will take place the 2nd Wednesday of every month.

This discussion provides a safe space for dialogue between siblings of a person with PWS. All ages are welcome to attend! PWSA | USA team members will also be available to offer any insight and support. Register in advance at the button below.



In an effort to ensure attendees feel comfortable to share openly, this opportunity is just for siblings. We appreciate your understanding!

[REGISTER IN ADVANCE HERE](#)



RESEARCH

Help Researchers Understand the Social and Emotional Experiences of Those with PWS



Are you a parent/guardian of someone aged 12 or older, diagnosed with Prader-Willi Syndrome (PWS)?

Do you:

- Want to help researchers understand the social and emotional experiences of those with PWS?
- Want to help researchers understand the impact of the COVID-19 pandemic on those with PWS?

About the study: This study will be done completely online. If you agree to participate, you will complete an

online consent/assent form and online parent and child questionnaires, which will take about 1 hour. Upon completion of the study, participants are entered to win a raffle for \$20 Amazon gift cards.

Questions about the study? Please contact
christopher.m.daniell@vanderbilt.edu

PARTICIPATE IN THE STUDY HERE

Interested in Participating in a Research Opportunity?

COMBINEDBrain is Traveling to a Conference Near You!



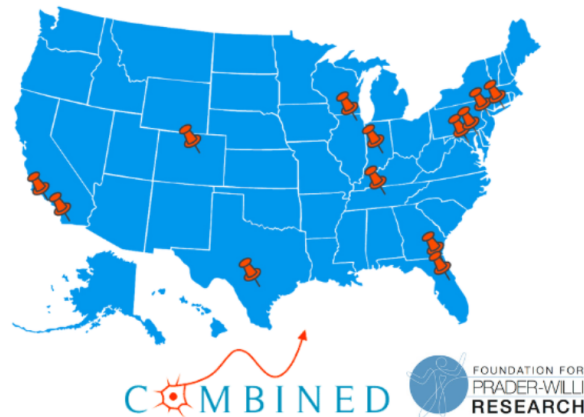
We are sharing details on behalf of The Foundation for Prader-Willi Research (FPWR) to spread the word about an upcoming and important PWS research opportunity. FPWR is collaborating with COMBINEDBrain to establish a biorepository dedicated to blood and urine samples from individuals living with PWS. This initiative aims to expedite the development of treatments for PWS, as well as other neurodevelopmental disorders.

Throughout the remainder of 2023, they will be assembling specimens at

various ROADSHOW conferences and gatherings nationwide. If you're interested, you and your loved one living with PWS have the opportunity to connect with the team during their ROADSHOW events in your vicinity and contribute a specimen that will be stored in the PWS-COMBINEDBrain Biorepository. Find more details and ROADSHOW locations below.

LEARN MORE HERE

July 19th-21st (Orlando, FL)
 July 21st-23rd (Westminster, CO)
 July 30th-August 2nd (Jacksonville, FL)
 August 3rd-6th (Queens, NY)
 Sept 22nd-23rd (Cincinnati, OH)
 Sept 29th-30th (Chicago, IL)
 Oct 5th-7th (Denver, CO)
 Oct 12th-14th (San Antonio, TX)
 Oct 15th-16th (Washington DC)
 Oct 30th-Nov 1st (Los Angeles, CA)
 Dec 1st-3rd (Orlando, FL)



Are You the Caregiver of a Loved One Between 5-17 Living with PWS? This Survey is for You!



Alanna Morrissey MA, BCBA with The Chicago School of Professional Psychology is asking for help from our PWS community. She is recruiting for a research study evaluating the impact of a behavior analytic caregiver training program on teaching caregivers how to train self-care skills to improve their child's independence.

Participation is fully remote and will take place across 8 weeks, for 1-2 hours a week. If you are 18+, speak and read English fluently, a caregiver of a child with PWS aged **5-17** who

needs help with self-care skills, and have access to the internet, you may qualify. Please share the flyer at the button below with anyone who may be interested.

[LEARN MORE HERE](#)

Aardvark Therapeutics Announces FDA Pediatric Disease Designation for PWS, Expansion of Phase 2 Clinical Trial

PWS CLINICAL TRIAL ANNOUNCEMENT



[Aardvark Therapeutics](#) recently announced the drug company has received Pediatric Disease Designation for PWS from the U.S. Food and Drug Administration (FDA), and will expand its Phase 2 clinical trial of oral ARD-101 in young adults with PWS. According to Aardvark Therapeutics, this FDA designation means the company is eligible for a Rare Pediatric Disease Priority Review Voucher when ARD-101 receives approval in PWS. ARD-101 is a first-in-class oral composition to reduce hyperphagia symptoms.

Click the button below to read Aardvark's full press release announcement.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

Adoption Spotlight



Advocates for Children and Families (ACF Adoptions) has been helping families for more than 30 years. ACF Adoptions has always worked with all children and families, but with the launch of the ACF+ Program in 2023, ACF seeks to formally ensure families involved in medically complex adoptions have all the tools and resources they need to feel safe and supported. ACF+ is focused on finding safe, healthy, and nurturing homes for children who are medically complex and/or have special needs.

Over the past few weeks, ACF+ has been working on helping identify potential adoptive families for four children with PWS. Three of these children are infants

and one of them is a toddler. In an effort to find appropriate families, they have connected with PWSA | USA to explain a bit about their program and to encourage families interested in adoption to reach out.

The ACF+ program helps families directly and also networks with other adoption professionals so they know families anywhere in the U.S. can get the help and support they need. ACF+ works hard to secure Title IV-E assistance benefits for each child in their care - a benefit most assume is only available for children adopted through foster care. The Program Coordinator is the national expert in medically complex adoption and in securing these critical benefits, which consist of a monthly stipend and Medicaid until the child reaches adulthood. Additionally, ACF+ automatically enrolls all of their families in a program, at no charge, that helps navigate and secure adoption funding, including applying for grants.

If you or someone you know is home study ready and open to medically complex adoption, please have them visit www.acfcares.org/acf and fill out the intake form. If anyone has any questions or would like more information, please email the ACF+ Program Coordinator, Jennifer Kelly, at jkelly@acfcares.org.

Show Off Your PWS Pride with Amazing Customizable Shoes!



PWS 2023 CUSTOM SHOE LINE



Inspired by **Brooklyn Marx** living with PWS and **Caden Sterns** from the Denver Broncos.



Get your very own PWS customizable Nikes and Vans! We want to thank the Marx family, their daughter Brooklyn living with PWS, Denver Broncos player Caden Sterns, and *Custom Creations by JMART* (the shoe creator) for their help in bringing this vision of PWS customizable shoes to life. Shop these shoes by clicking the button below!

[SHOP 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](#)



PWSA | USA Special Edition Pulse: August 25, 2023

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PWSA | USA Special Edition

PULSE

August 25, 2023



Looking for an Easy Way to Give Back?
Become a Hope United Champion by Hosting a Peer-to-Peer Fundraiser

Hope United Spotlight:

Kissing for a Cause



Mr. & Mrs. Steven & Tara Davis recently celebrated their union by incorporating a heartwarming Hope United fundraiser as part of their reception - **"Kissing for a Cause."** Tara and Steven are close friends of Melanie McDonald, mother to Josephine who lives with PWS, and wanted to make their big day extra special by supporting a cause close to their hearts in honor of Josephine. During the reception, guests were invited to make a donation to PWSA | USA then ring a bell, signaling Steven and Tara to share a kiss. Through "Kissing for a Cause," they raised nearly \$1,000 for the association!

Click the image above to hear details from Steven and Tara about how this innovative fundraiser was put together and how it left a lasting impression on those who participated.



Giving *Hope* Has Never Been Easier

YOU can help us become stronger and more united than ever!

As we work together building bright futures for PWS families, we are inspired by our loved ones with PWS, and motivated to take action to ensure all members of our PWS community have the benefit of passionate advocacy, exceptional family support, and life-changing research.

Now, more than ever, we are propelled forward to take action from our homes, communities, and Chapters, all across the country in fun and extraordinary ways. Where so much of our PWS journey is beyond our control, Hope United gives us the tools, the encouragement, and the opportunity to be empowered to make a difference.

**BECOME A HOPE
UNITED CHAMPION!**

Where do I start?

Check out these Hope United Fundraiser Ideas 



Special Occasions

Celebrate a birthday, wedding or special occasion by raising funds & awareness for PWSA | USA with your own customizable fundraising page.

Find Inspiration Elaine's Birthday Fundraiser



Walk, Run, Race, Play

Go solo or lead a team, each with their own fundraising page for a walk, race, or other group activity, competing for the top of our leaderboard!

Find Inspiration Gavin's Sweet 16 Run Against PWS





Do-it-Yourself

Trivia Night? Golf Tournament? Bingo? We'll provide you with a unique fundraising page for your event to collect donations & sponsorships while supporting PWSA | USA.

Find Inspiration

Answers For Audrey: Trivia Night



School/Community Group

Build community and raise awareness and funds in your workplace, school, church or other group setting.

Find Inspiration

Wear Jeans for Rare Genes



In Memory/Honor Of

Recognize someone special or honor the memory of someone you love through a Hope United fundraiser.



Upcoming Hope United Events

Several families in our PWS community will be hosting Hope United events throughout the country in the coming months! Click on the buttons below to learn more about them and find out how you can support and/or participate.



2nd Annual No Gimmies for Jimmy Charity Golf Outing

In loving memory of Jim Worthington

Where: Rock Spring Golf Club
90 Rock Spring Road
West Orange, NJ 07052

When: Friday, October 6, 2023
Check-in at 8:00 a.m. and shotgun start at 9:00 a.m.

[LEARN MORE](#)



14th Annual Hunter Lens Golf Tournament

Where: The Back Nine Club
17 Heritage Hill Dr.
Lakeville, MA 02347

When: Saturday, October 7, 2023
Golf tournament begins at 12:00 p.m.

[LEARN MORE](#)



Answers for Audrey Trivia

Where: Incarnate Word Academy
2788 Normandy Avenue
St. Louis, MO 63121

When: Saturday, October 21, 2023
Doors open at 6:30 p.m. and Trivia begins
at 7:00 pm.

[LEARN MORE](#)

*Interested in becoming a **Hope United Champion**? We will help you every step of the way! Contact us TODAY at hopeunited@pwsausa.org or (941) 312-0400.*

— THANK YOU FOR MAKING —
Hope Happen


Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES



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