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Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWSA | USA
THE PULSE
Vol. 28 | August 6, 2021

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WEBINAR OPPORTUNITY

Homeschooling: What You Need to Know

Monday, August 9th
7:30 p.m. EST

FREE VIRTUAL EVENT YOU DON'T WANT TO MISS!

The COVID-19 pandemic forced parents to make difficult decisions regarding their children's education. Join **Julie Casey** and **Danielle Warmuth** to learn from veteran homeschoolers about curricula, services, and socialization.

REGISTER HERE

Julie Casey

Julie Casey has been homeschooling her 17-year-old son Ryan (PWS) for the last 11 years. This September, she will begin her 12th year with Ryan as a High School Senior. Before becoming a stay-at-home mom, Julie, who holds a BA in Behavioral Sciences and a MA in Organizational Management, worked in the Insurance and Risk Management Industry. Shortly after Ryan was born in 2004, Julie got involved with both PWSA | USA and PWCF. She is a past Board President for PWCF and remains on their Fund Development Committee. Julie is a member of the PWSA | USA Communications and Editorial Committee, the Chapter Relations Committee, and is a Parent Mentor.

Danielle Warmuth

Danielle Warmuth has been homeschooling for 21 years and has three children, ages 30, 27, and Andrew, age 14 (PWS). She served as Secretary for the Prader-Willi syndrome, Indiana Chapter for 10 years. She is a multidisciplinary major in International Studies from Michigan State University, holds minors in Earth Sciences, Archaeology, and Anthropology, and speaks French and Japanese. Danielle retired from the airlines in 2012 to stay home with Andrew. Together, they co-author the website Moving Mountains Daily. It was a homeschool project that grew way beyond what they intended! Outside the classroom, exercise and life adventures are a big part of their school day. Experiences like hospital stays, learning to pump gas, scouting, living with the nomads in Mongolia, or watching a flatboat navigate the Ohio River locks all count as "school." Their family life motto is "Progress not Perfection."

ADVOCACY

THE STAT ACT RECEIVES MORE BI-PARTISAN SUPPORT

Rep. Josh Gottheimer
(D-NJ)

Rep. David Kustoff
(R-TN)

The STAT Act, HR 1730 / S 670, just obtained more bi-partisan support in the US House of Representatives! Representative David Kustoff (R-TN) and Representative Josh Gottheimer, (D-NJ) have joined forces with 19 other US representatives to show their continued support for the rare disease community. The STAT Act will allow patients with a rare disease speedy access to therapies, inform rare disease policies and actions by creating a Rare Disease and Condition Drug Advisory Committee and fund regulatory science and related activities to support the development of therapies to treat rare disease populations.

Help encourage your elected officials to support the rare disease community by sending a letter of support.

SUPPORT THE STAT ACT HERE

LEARN MORE ABOUT THE STAT ACT HERE

If you are interested in spreading awareness of PWS, engaging elected officials, and traveling with fellow PWSA | USA supporters, **YOUR time has come**! PWSA | USA is looking for volunteers from each state to participate in launching a special project to promote PWS awareness throughout the United States. For more information, please contact Dorothea Lantz at **Advocacy@pwsausa.org** for an application.

FAMILY SUPPORT

PWSA | USA Family Support Impact

April 2021 - July 2021

339

TOTAL FAMILY SUPPORT INQUIRIES

- 194 Calls
- 40 Letters
- 102 Emails
- 3 Meetings

Whether it is a compassionate call of support after your child's diagnosis, or a resource-filled consultation when your loved one is entering a new phase of development, PWSA | USA is here for you and your family **24 hours a day, 7 days a week, 365 days a year.**

LEARN MORE ABOUT FAMILY SUPPORT HERE

RESEARCH

Harmony Biosciences adds Cincinnati, OH site to its Phase 2 Clinical Trial

Harmony Biosciences is currently in its Phase 2 clinical trial of Pitolisant, studying the safety and impact of an investigational medicine for excessive daytime sleepiness, cognition, and behavioral function in people with PWS. This week, they added an 11th location to their list of trial sites around the U.S. The trial site will be located at CTI Clinical Trial and Consulting Services, Inc. in Cincinnati, OH and will be led by Dr. James Maynard, who is board certified in both neurology and sleep medicine.

Participation in the trial lasts approximately four months. During that time, there are five planned visits.

Read more here.

PWSA | USA ANNOUNCEMENTS

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VOLUNTEER APPLICATION

EVENTS

A reminder that our 2021 Virtual Convention Session Recordings are available on PWSA | USA's Website! Click the button below to access the videos.

WATCH CONVENTION SESSION RECORDINGS HERE

THE 12TH ANNUAL

HUNTER LENS GOLF TOURNAMENT

SATURDAY, OCTOBER 2ND,2021 - 1 PM

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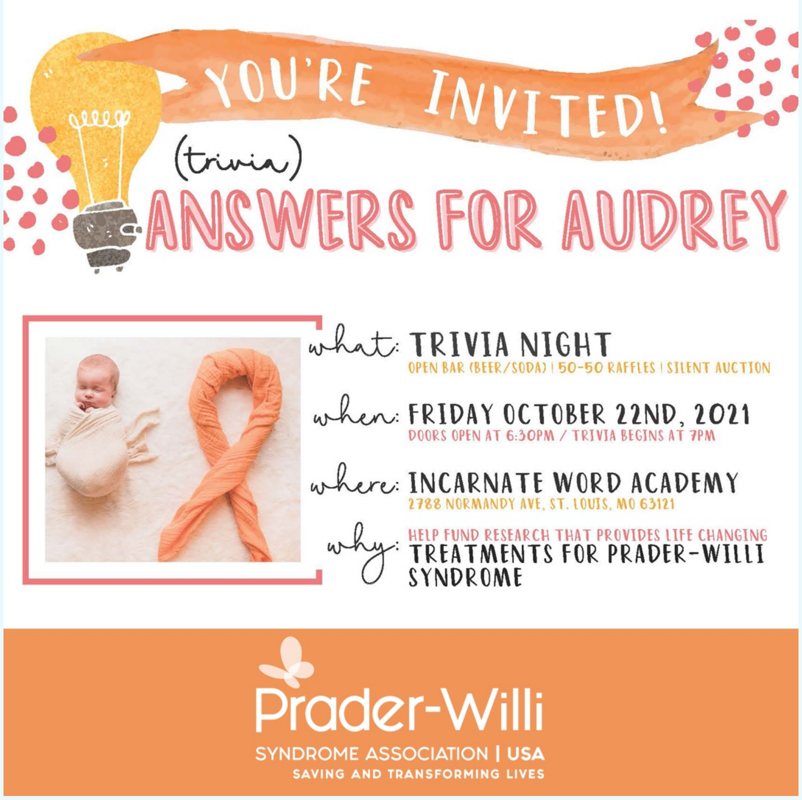

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(trivia)
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OPEN BAR (BEER/SODA) | 50-50 RAFFLES | SILENT AUCTION

when: FRIDAY OCTOBER 22ND, 2021
DOORS OPEN AT 6:30PM / TRIVIA BEGINS AT 7PM

where: INCARNATE WORD ACADEMY
2788 NORMANDY AVE, ST. LOUIS, MO 63121

why: HELP FUND RESEARCH THAT PROVIDES LIFE CHANGING TREATMENTS FOR PRADER-WILLI SYNDROME

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To plan your custom PWSA | USA fundraiser, contact events@pwsausa.org.

Important Message About This Newsletter

The information provided in this email is intended for your general knowledge only and is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this publication.

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Vol. 29 | August 13, 2021

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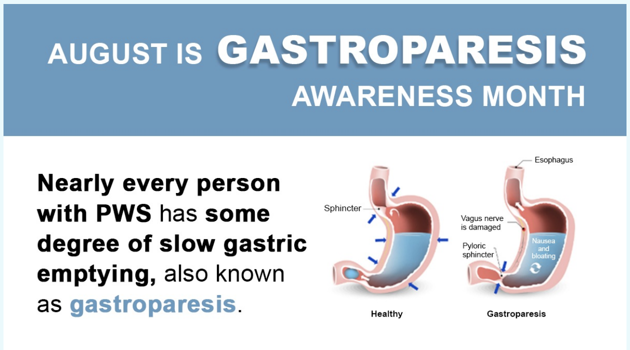
AUGUST IS **GASTROPARESIS** AWARENESS MONTH

Nearly every person with PWS has **some degree of slow gastric emptying,** also known as **gastroparesis**.

August is **Gastroparesis Awareness Month**. Gastroparesis, also known as delayed gastric emptying, is a chronic condition that affects the stomach muscles and prevents proper movement of food from the stomach to the small intestine.

Nearly every person with PWS has some degree of slow gastric emptying. This month, in honor of gastroparesis awareness, we are asking our PWS community to complete the gastrointestinal history survey in the Global PWS Registry. This survey will ask if your loved one has ever been examined by a gastroenterologist and if they have been diagnosed with any GI issues. Your participation will help us better define GI issues in PWS and how often they typically occur.

Visit the registry here >>

ADVOCACY

THE BENEFIT ACT

The BENEFIT Act, HR 4472 / S373, has received a bill number in the US House of Representatives! Representative Doris Matsui (D-CA) introduced the BENEFIT Act mid-July, but with a bill number it's now easier than ever to ask your elected officials to sign on and support this life-changing piece of legislation. The BENEFIT Act is a bi-partisan piece of legislation that would require that the FDA disclose whether and how patient experience and/or preference data was used in the benefit risk assessment of a new drug. It will ensure that patient voices are being heard and allow for patient stakeholders to continue to work with FDA to refine the data that they need to make decisions. With everything our community has experienced throughout the last year, we know it's more important than ever to have the FDA consider patient experience as a part of their approval process. Help the voices of our community be heard and encourage your elected officials to co-sponsor this bill today!

Help encourage your elected officials to support the rare disease community by sending a letter of support.

SUPPORT THE BENEFIT ACT HERE

LEARN MORE ABOUT THE BENEFIT ACT HERE

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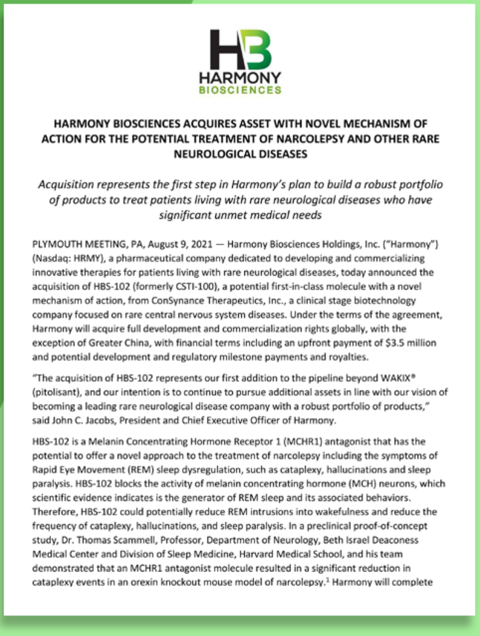
RESEARCH

Harmony Biosciences Acquires Asset with Novel Mechanism of Action for the Potential Treatment of Narcolepsy and other Rare Neurological Diseases

READ MORE



HARMONY BIOSCIENCES

HARMONY BIOSCIENCES ACQUIRES ASSET WITH NOVEL MECHANISM OF ACTION FOR THE POTENTIAL TREATMENT OF NARCOLEPSY AND OTHER RARE NEUROLOGICAL DISEASES

Acquisition represents the first step in Harmony's plan to build a robust portfolio of products to treat patients living with rare neurological diseases who have significant unmet medical needs

PLYMOUTH MEETING, PA, August 9, 2021 — Harmony Biosciences Holdings, Inc. ("Harmony") (Nasdaq: HRMY), a pharmaceutical company dedicated to developing and commercializing innovative therapies for patients living with rare neurological diseases, today announced the acquisition of HBS-102 (formerly CSTI-100), a potential first-in-class molecule with a novel mechanism of action, from ConSynance Therapeutics, Inc., a clinical stage biotechnology company focused on rare central nervous system diseases. Under the terms of the agreement, Harmony will acquire full development and commercialization rights globally, with the exception of Greater China, with financial terms including an upfront payment of $3.5 million and potential development and regulatory milestone payments and royalties.

"The acquisition of HBS-102 represents our first addition to the pipeline beyond WAKIX® (pitolisant), and our intention is to continue to pursue additional assets in line with our vision of becoming a leading rare neurological disease company with a robust portfolio of products," said John C. Jacobs, President and Chief Executive Officer of Harmony.

HBS-102 is a Melanin Concentrating Hormone Receptor 1 (MCHR1) antagonist that has the potential to offer a novel approach to the treatment of narcolepsy including the symptoms of Rapid Eye Movement (REM) sleep dysregulation, such as cataplexy, hallucinations and sleep paralysis. HBS-102 blocks the activity of melanin concentrating hormone (MCH) neurons, which scientific evidence indicates is the generator of REM sleep and its associated behaviors. Therefore, HBS-102 could potentially reduce REM intrusions into wakefulness and reduce the frequency of cataplexy, hallucinations, and sleep paralysis. In a preclinical proof-of-concept study, Dr. Thomas Scammell, Professor, Department of Neurology, Beth Israel Deaconess Medical Center and Division of Sleep Medicine, Harvard Medical School, and his team demonstrated that an MCHR1 antagonist molecule resulted in a significant reduction in cataplexy events in an orexin knockout mouse model of narcolepsy.[1] Harmony will complete

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Read the full press release announcement here >>

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VOLUNTEER APPLICATION

EVENTS

HOT STOVE DINNER

A Fundraiser to Benefit PWSA | USA

Save the Date

March 26, 2022

8th Annual

Hot Stove Dinner with Clint Hurdle

Reserve your Stay at *Compass by Margaritaville* on Anna Maria Island, FL

**Limited number of rooms available*

BOOK HERE

COMPASS BY MARGARITAVILLE

ANNA MARIA SOUND, FL

THE 12TH ANNUAL

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SATURDAY, OCTOBER 2ND,2021 - 1 PM

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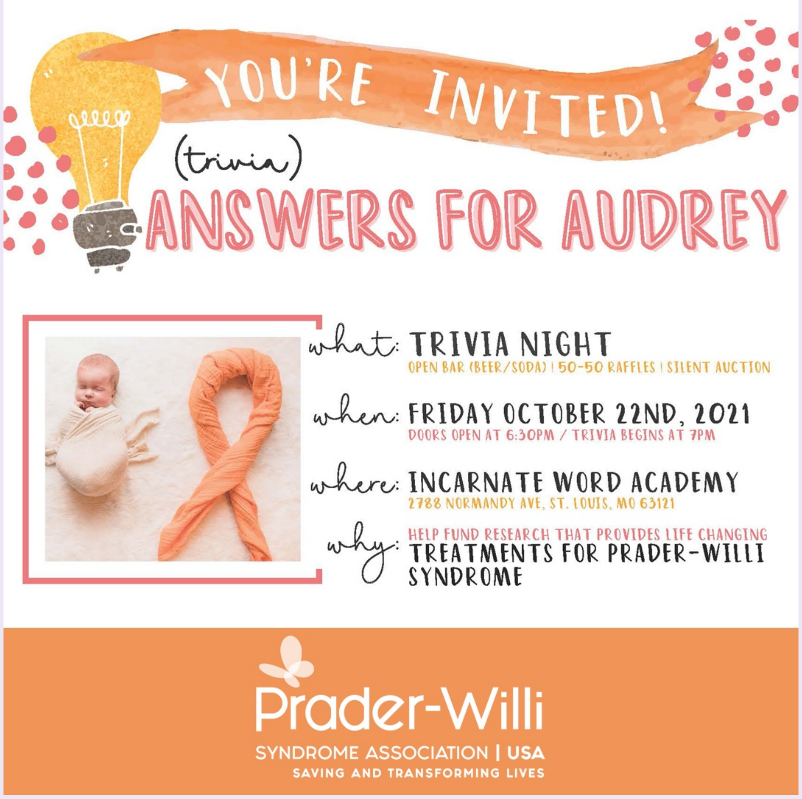

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PWSA | USA
THE PULSE
Vol. 30 | August 20, 2021

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INTRODUCING PWSA | USA'S 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 are able to provide help and hope through our family support, advocacy, and research efforts. To celebrate and honor your generosity, each month, we will share a **Donor Spotlight** and story to reveal the dedication, gratitude, and optimism that defines us as a PWS community!

PWSA | USA recognizes Huma Onorato as this month's Donor Spotlight!

"Keeping my promise to continually learn, give passionately to my community, and live purposefully."

| Huma Onorato, Mom to Lily

READ LILY'S STORY HERE

ADVOCACY

WEBINAR OPPORTUNITY

Become an Advocate for PWSA | USA

Monday, August 26
8:00 PM EST

Advocacy is not just for lobbyists. Anybody can be an effective advocate. Join PWSA | USA and learn how you can help bring PWS awareness to states throughout the country. At PWSA | USA we understand that State and Federal governments both play a unique and irreplaceable role in supporting these efforts. Join our team of advocates and learn how you can help!

"The journey of a thousand miles begins with a single step" ~ Tao Te Ching

REGISTER IN ADVANCE HERE

Speaker: Dorothea Lantz

Dorothea Lantz is the Community Engagement Specialist for PWSA | USA, a licensed Real Estate Broker with ONE Sotheby's International Realty and a lifetime resident of Miami, Florida. In July of 2017, she and her husband were blessed with their son, Hunter, who was diagnosed with PWS at 16 days old. Dorothea has an extensive background in public service, government administration and is a contributing member of the South Florida and PWS community. She has been a Parent Mentor with PWSA | USA since 2019. In addition, Dorothea is an appointed member of the City of South Miami Environmental Review and Preservation Board and a Mentor with the ACE Foundation Women's Leadership Institute.

The BENEFIT Act, HR 4472 / S373, has obtained more bipartisan support in the US House of Representatives! Representative Doug LaMalfa (R-CA) has signed on to show his continued support for the rare disease community. The BENEFIT Act is a bipartisan piece of legislation that would require that the FDA disclose whether and how patient experience and/or preference data was used in the benefit risk assessment of a new drug. It will ensure that patient voices are being heard and allow for patient stakeholders to continue to work with FDA to refine the data that they need to make decisions. With everything our community has experienced throughout the last year, we know it's more important than ever to have the FDA consider patient experience as a part of their approval process. Help the voices of our community be heard and encourage your elected officials to co-sponsor this bill today!

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Abbey,
rare disease patient

Make your voice heard…STAT! The EveryLife Foundation for Rare Diseases is seeking advocates to share quotes, photos, and/or videos to express their support the Speeding Therapy Access Today Act, or STAT Act. Advocates are encouraged to share how their specific rare disease journey will be positively impacted by a specific aspect of the STAT Act. Please send a 1-2 sentence quote and photo and/or video (no longer than 60 seconds) to Dorothea Lantz, PWSA | USA’s Community Engagement Specialist, at Advocacy@pwsausa.org as soon as possible. Your quote, photo and/or video will be shared on Everylife’s and PWSA | USA’s social media and website and in presentations and communications to stakeholders and policymakers.

LEARN MORE ABOUT THE STAT ACT HERE

SUPPORT THE STAT ACT HERE

PHONE 2 ACTION

BENEFIT ACT & STAT ACT ADVOCACY EFFORTS

July 15, 2021 - August 19, 2021

75 NEW ADVOCATES

227 Total Legislator Connections

Thank you for using your voice to spark change!

Prader-Willi SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

FAMILY SUPPORT

Prader-Willi SYNDROME ASSOCIATION | USA
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Homeschooling 101:

How You omeschool
Your Child With PWS

PWSA | USA Webinar: Homeschool - What You Should Know

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RESEARCH

PWSA | USA CALL FOR LETTERS OF INTENT (LOI)

PWSA | USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with PWS. PWSA | USA is seeking to fund projects for a one- to two-year grant support aimed at discovering and developing treatments and technologies benefiting those with PWS.

Letters of Intent (LOI) submissions will be accepted starting September 1, 2021 with a due date of November 8, 2021.

The current focus of PWSA | USA research is supporting projects that have the potential for immediate and high impact for the PWS community. Therefore, PWSA | USA will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical application. The goal is to fast-track better treatment for the syndrome.

Learn More About PWSA | USA's Research Grant Program Here >>

DOWNLOAD CALL FOR LETTERS OF INTENT HERE

DOWNLOAD GRANT SUBMISSION GUIDELINES HERE

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PWSA of Ohio Family

Day Camp

Join us at Recreation Unlimited**
for a day of fun activities

SATURDAY, SEPTEMBER 25, 2021
From 9 am to 6 pm

Registration Starts at 9:00

Lunch and Dinner provided

RSVP BY SEPTEMBER 17

Cost : Members - $15 per family
Non-member - $15/person

Recreation Unlimited
7700 Piper Road
Ashley, OH 43003
http://www.recreationunlimited.org/

LEARN MORE HERE

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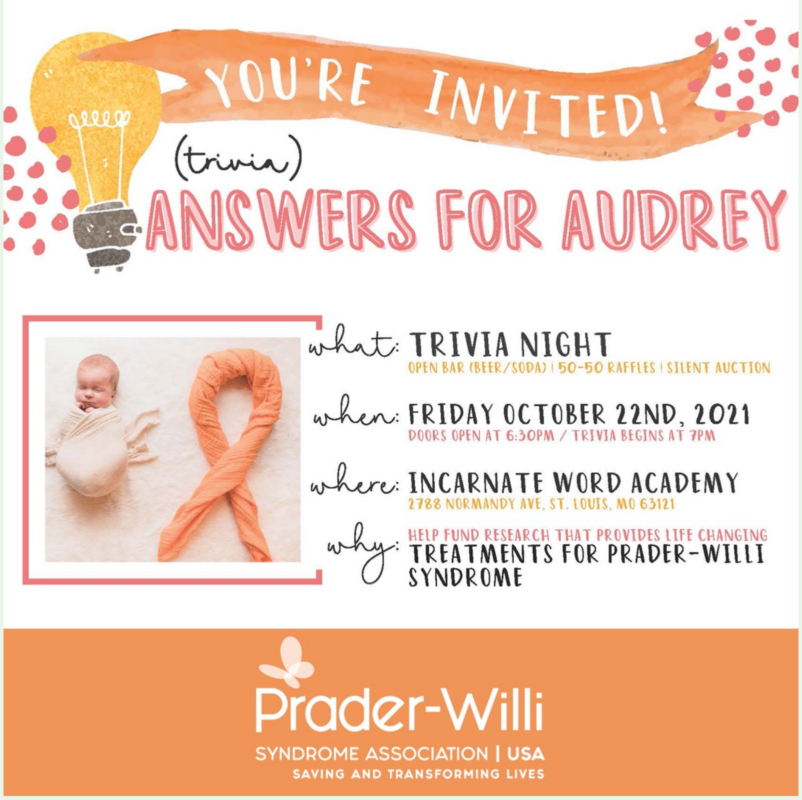

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THE PULSE

Vol. 31 | August 27, 2021

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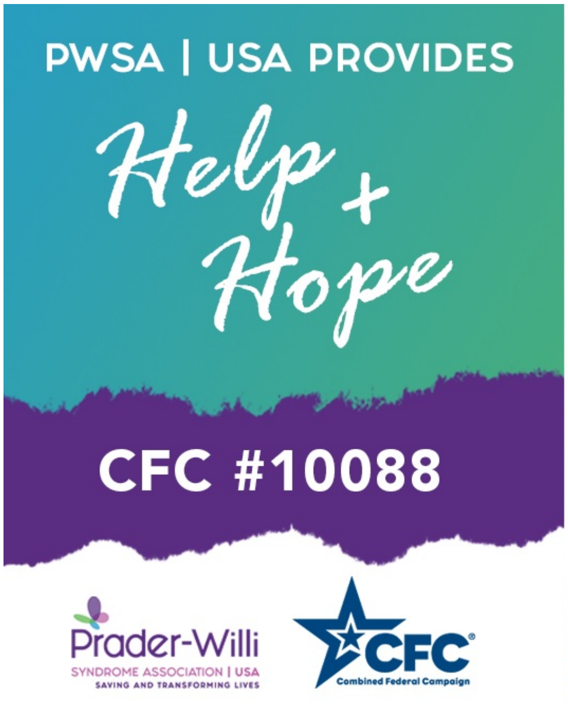

Attention Federal Employees!

Between September 1, 2021 and January 21, 2022, 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

ADVOCACY

Webinar: Become an Advocate for PWSA | USA

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FAMILY SUPPORT

We Are Brave Together

Founded in 2017 by Jessica Patay, mother to a 17-year-old son with Prader-Willi syndrome, **We Are Brave Together (WABT)** is a nonprofit organization whose mission is to support caregiving mothers to children, any age, with any

WE ARE BRAVE together™

diagnosis, disability, or challenge, including learning differences, ADHD, and mental health issues. This international community includes over 1350 moms in 45 states and 10 countries. Passionate about serving and encouraging moms of special needs children everywhere, Jessica wishes she could look every mom in the eyes and tell her, “You are not alone.”

LEARN MORE HERE

RESEARCH

PWSA | USA CALL FOR LETTERS OF INTENT (LOI)

PWSA | USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with PWS. PWSA | USA is seeking to fund projects for a one- to two-year grant support aimed at discovering and developing treatments and technologies benefiting those with PWS.

Letters of Intent (LOI) submissions will be accepted starting September 1, 2021 with a due date of November 8, 2021.

The current focus of PWSA | USA research is supporting projects that have the potential for immediate and high impact for the PWS community. Therefore, PWSA | USA will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical application. The goal is to fast-track better treatment for the syndrome.

Learn More About PWSA | USA's Research Grant Program Here >>

DOWNLOAD CALL FOR LETTERS OF INTENT HERE

DOWNLOAD GRANT SUBMISSION GUIDELINES HERE

PWSA | USA ANNOUNCEMENTS

Welcome Spring Velazquez!

We are pleased to welcome Spring Velazquez as PWSA | USA's new Development Specialist. With over 25 years of non-profit management experience from higher education to human services, Spring is thrilled to join PWSA | USA as our Development Specialist. Most recently she spent eight years with Make-A-Wish which helped her develop a deep understanding of families with children who have been diagnosed with rare or critical childhood illnesses. Prior to working at Make-A-Wish, Spring was the Director of Donor Relations at Widener University and was responsible for managing all aspects of donor and alumni giving. Spring brings a wide range of skills and knowledge of fundraising and development to help PWSA | USA fulfill our mission to enhance the quality of life of and to empower those affected by Prader-Willi syndrome. She lives outside of Philadelphia, PA with her husband, her dog, and six cats. When she's not busy working, Spring is volunteering with other non-profits that serve children, and working on her final project in the Penn State Master Gardener's program with a focus on "providing gardening as therapy for children with different abilities."

Changes in PWSA | USA Membership

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWSA | USA is continuously looking for ways to be as inclusive as possible for our community, families, and individuals living with PWS. One of the ways this can be accomplished is by revamping our membership criteria. Going forward, we will open our membership up to anyone who shares our mutual interest in helping individuals and families impacted by Prader-Willi syndrome. We will offer our materials and services to all, not just members. With this change, PWSA | USA hopes to expand its community and provide services to a wider range of families and individuals, better serving our mission. We thank you for your support and understanding as we make this transition and ask that you reach out to info@pwsausa.org with any questions you may have.

Make a Difference by Becoming a PWSA | USA Volunteer!

Do you want to get more involved with PWSA | USA? We are looking for energetic, passionate individuals to help us carry out our mission and support those affected by PWS. Please click the button below to access our

Volunteer Application. If you have any questions, please reach out to volunteer@pwsausa.org.

VOLUNTEER APPLICATION

EVENTS

PWSA of Ohio Family

Day Camp

Join us at Recreation Unlimited**
for a day of fun activities

SATURDAY, SEPTEMBER 25, 2021
From 9 am to 6 pm

Registration Starts at 9:00

Lunch and Dinner provided

RSVP BY SEPTEMBER 17

Cost : Members - $15 per family
Non-member - $15/person

Recreation Unlimited
7700 Piper Road
Ashley, OH 43003
http://www.recreationunlimited.org/

LEARN MORE HERE

THE 12TH ANNUAL

HUNTER LENS GOLF TOURNAMENT

SATURDAY, OCTOBER 2ND, 2021 - 1 PM

THE BACK NINE CLUB

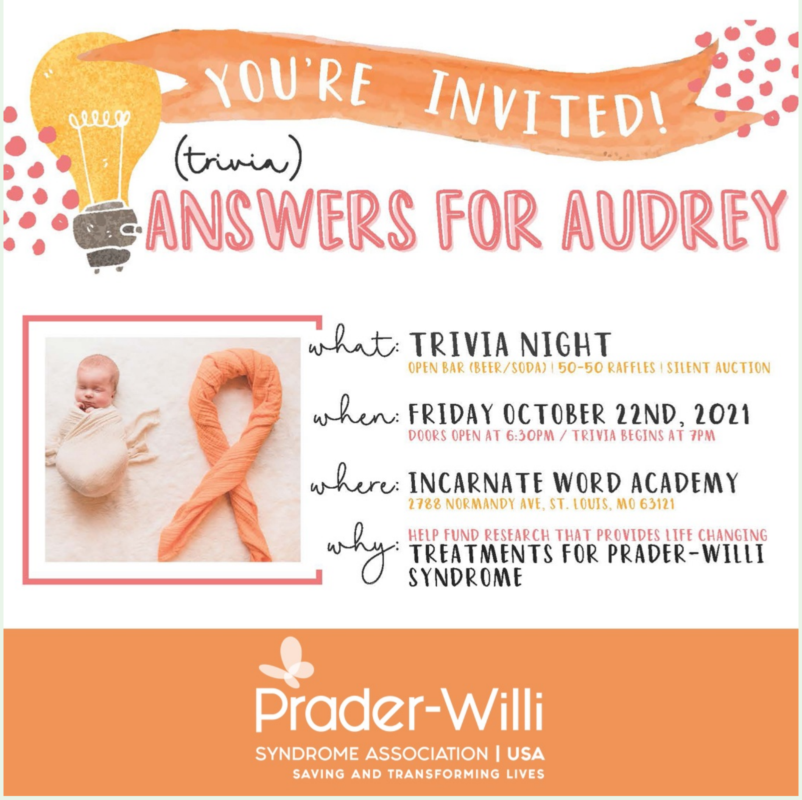
17 HERITAGE HILL - LAKEVILLE, MA

PROCEEDS BENEFIT

Prader-Willi SYNDROME ASSOCIATION | USA

SAVING AND TRANSFORMING LIVES

REGISTER HERE



YOU'RE INVITED!

(trivia) ANSWERS FOR AUDREY

what: TRIVIA NIGHT

OPEN BAR (BEER/SODA) | 50-50 RAFFLES | SILENT AUCTION

when: FRIDAY OCTOBER 22ND, 2021

DOORS OPEN AT 6:30PM / TRIVIA BEGINS AT 7PM

where: INCARNATE WORD ACADEMY

2788 NORMANDY AVE, ST. LOUIS, MO 63121

why: HELP FUND RESEARCH THAT PROVIDES LIFE CHANGING TREATMENTS FOR PRADER-WILLI SYNDROME

Prader-Willi SYNDROME ASSOCIATION | USA

SAVING AND TRANSFORMING LIVES

REGISTER HERE

11th ANNUAL MOLLY'S PUB
2021 CHARITY GOLF TOURNAMENT
AT CYPRESSWOOD
MONDAY OCTOBER 4TH
SAVE THE DATE!
Traditions Course
BENEFITING
TEXAS PRADER-WILLI ASSOCIATION
www.txpwa.org

REGISTER HERE

To plan your custom PWSA | USA fundraiser, contact events@pwsausa.org.

Important Message About This Newsletter

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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!

Visit Us Online!
www.pwsausa.org

Give Now