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.”
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.

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.
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**

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

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**THERE ARE**

11 **Trial Sites Around the US**

Travel expenses to the site most convenient to you will be reimbursed by Harmony Biosciences

**Current Sites:**
- San Diego, CA
- San Ramon, CA
- Wilmington, DE
- Gainesville, FL
- Chicago, IL
- Baltimore, MD
- Nashville, TN
- Houston, TX
- Salt Lake City, UT
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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JOIN OUR TEAM!

PWSA | USA is hiring a full-time Development Specialist. This remote role is responsible for administrative, research, planning, and event support for all fundraising activities that help to sustain our programs to enhance the quality of life of those affected by PWS. For more info and instructions on how to apply, click the button below.

CLICK HERE FOR MORE INFORMATION
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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
THE BACK NINE CLUB
17 HERITAGE HILL - LAKEVILLE, MA

PROCEEDS BENEFIT
Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

REGISTER HERE

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.

Visit Us Online!
www.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!

Give Now
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 >>](#)

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**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.

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Harmony Biosciences recently announced the acquisition of HBS-102, a potential first-in-class molecule with a novel mechanism of action, from ConSynance Therapeutics, Inc. 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. Sleep abnormalities, including narcolepsy and cataplexy, are a common feature of Prader-Willi syndrome.

Read the full press release announcement here >>

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VOLUNTEER APPLICATION

EVENTS
8th Annual Hot Stove Dinner with Clint Hurdle

March 26, 2022

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

*Limited number of rooms available

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

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

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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.

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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
Show Your Support for the STAT Act!

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

Homeschooling 101:
How You Homeschool Your Child With PWS
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**Letters of Intent (LOI) submissions will be accepted starting September 1, 2021 with a due date of November 8, 2021.**

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

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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
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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, FOOD, LIVE MUSIC, 50/50 RAFFLES & SILENT AUCTION

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

where: INCARNATE WORD ACADEMY
7700 NORMANDY AVE, ST. LOUIS, MO 63130

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

REGISTER HERE
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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!
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
Webinar: Become an Advocate for PWSA | USA

If you didn't get a chance to join our Advocacy Webinar, the recording is available by clicking the image above. Special thank you to Community Engagement Coordinator Dorothea Lantz for sharing how our community can help bring awareness to PWS.

Description: 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 governments and the federal government both play a unique and irreplaceable role in supporting these efforts. Join our team of advocates and learn how you can help!

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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
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)

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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.”

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17 HERITAGE HILL - LAKEVILLE, MA

**PROCEEDS BENEFIT**

Prader-Willi Syndrome Association USA
Saving and Transforming Lives

**REGISTER HERE**

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**YOU'RE INVITED!**

**(trivia) ANSWERS FOR AUDREY**

**what:** TRIVIA NIGHT
Open Bar (Beer/Chowder) | 50/50 Raffles | Silent Auction

**when:** FRIDAY OCTOBER 22ND, 2021
Doors open at 6:30PM / Trivia begins at 7PM

**where:** INCARNATE WORD ACADEMY
2050 NORMANDY AVE, ST. LOUIS, MO 63131

**why:** Help fund research that provides life-changing treatments for Prader-Willi Syndrome

**Prader-Willi Syndrome Association USA**
Saving and Transforming Lives

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