Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Vol. 15
April 23, 2021

Call for Nominations

PWSA | USA is looking for bright, motivated people who think clearly and creatively, work well with others, are sensitive to different points of view, and who are dedicated to improving the lives of individuals with PWS and their families.

Be an active contributor on a committee or project prior to being nominated for service on the Board of Directors.

To learn more about committee work, contact Stacy Ward, Director of Family Support, at sward@pwsausa.org.

To nominate yourself or someone else for the Board of Directors contact Lisa Graziano, Leadership Development Committee Co-chair, at info@pwsausa.org.

Staff Announcement

PWSA | USA is pleased to announce that Dorothea Lantz will be joining the staff on May 3, 2021 in the role of Community Engagement Specialist.

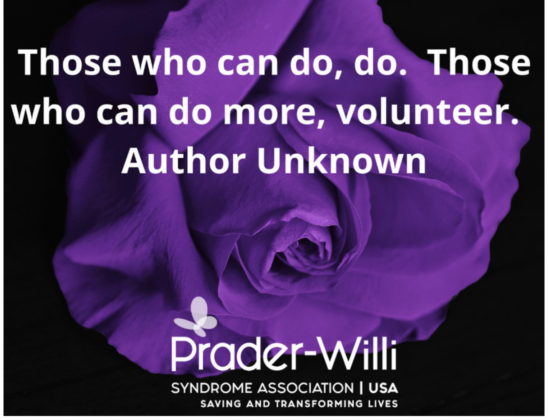
Dorothea Lantz is lifetime resident of Miami, Florida. In 2017, she and her husband were blessed with their son, Hunter, who was diagnosed with PWS at 16 days old. Dorothea has an extensive background in real estate, public service, government administration and is a contributing member of the South Florida and PWS community. She has been a Parent Mentor with PWSA | USA since 2019 and also serves on the Advocacy Committee. 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. Dorothea is a licensed Real Estate Broker with ONE Sotheby's International Realty.

Volunteer Recognition Week

Gandhi said, “selfless action is a source of strength” and by that measure we are the strongest organization around!

Whether you volunteer hundreds of hours per year or two hours during an event, you are making a difference. We are so grateful to all of our volunteers who are the backbone of PWSA | USA.

This week we celebrated the wonderful volunteers and recognized the Volunteer of the Year award winners.



Please join us in congratulating the following winners:

Name: Rachel Azzerah
Category: Family Support

Name: Christina Argo
Category: Awareness

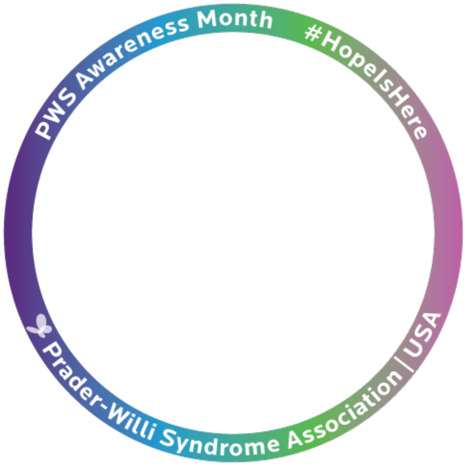
Name: Kelly Guillou
Category: Research

Name: Clint and Karla Hurdle
Category: Fundraising

- Prader-Willi California Foundation in the category of Education
- PWSA Wisconsin in the category of Awareness
- PWSA Utah in the category of Family Support
- PWSA Texas in the category of Advocacy
- PWSA New England in the category of Fundraising

Get Ready for PWS Awareness Month

May is Prader-Willi syndrome (PWS) awareness month, and we're excited to partner with YOU to spread the word!



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During PWS Awareness month, we will share factual information to raise awareness as well as messages of hope, kindness, and resilience from the PWS community. **#HopeIsHere**

Don't forget to customize your Facebook profile pic with the PWSA | USA profile frame!

Advocacy

Policy Alert from NORD's Rare Action Network

The **Safe Step Act (H.R. 2163/S. 464)** has been reintroduced in Congress! This legislation would ensure that rare disease patients have access to treatments they need by improving step therapy protocols.

Step therapy, often called "fail first," is a process that requires patients to take one or more alternative medications before they can access the medication prescribed by their doctor. While this is done to control high drug costs, step therapy has been increasingly applied without sufficient regard for a patient's medical history.

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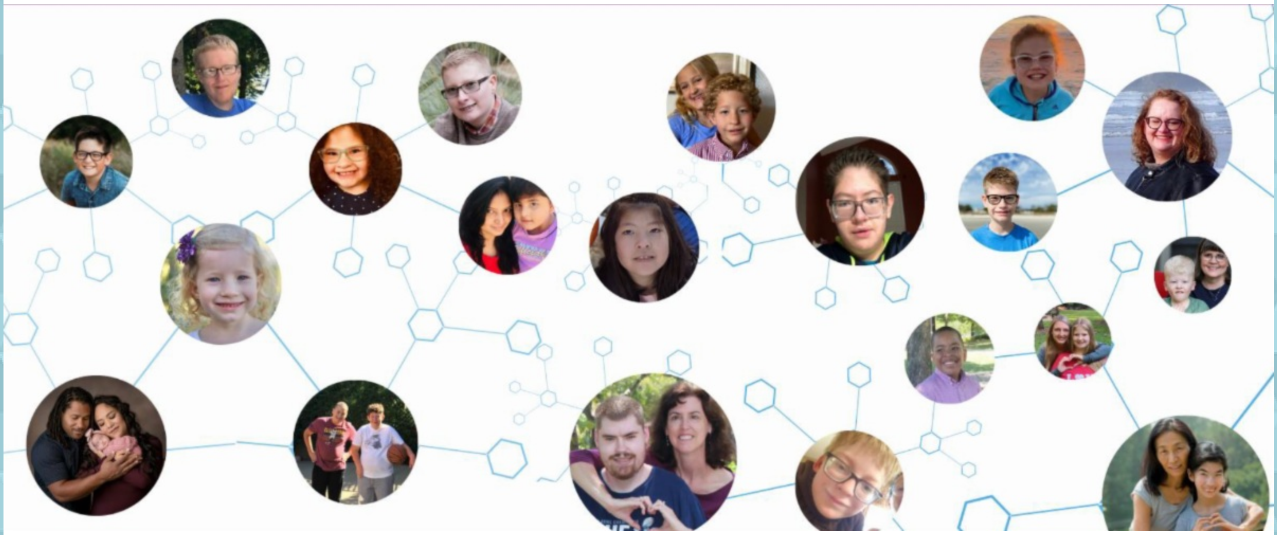
Take action by asking Congress to support the Safe Step Act - click here.

PWS Community Voice



Our Request to the Food & Drug Administration: Apply Regulatory Flexibility and Review an NDA for DCCR, a Potential Treatment for Prader-Willi Syndrome.

Thank you to all who provided feedback and participated in the DCCR Advocacy Survey. Your voice is being heard.

Click the link below to download the comprehensive joint response from PWSA | USA and FPWR. We will continue to keep you informed of any developments as we move forward in this process together.

Download the Report

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PWSA | USA Virtual National Convention

Don't Forget to Register in Advance

For the first time ever, admission to the General Conference is FREE for all to attend!

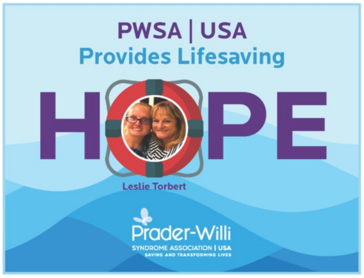
PWSA | USA's **virtual** National Convention will be held **June 22-26, 2021.** Our dedicated staff and convention volunteers are hard at work putting together an exciting lineup of educational, informative, and fun sessions for the PWS community.

Download the Convention flyer here, and don't forget to share with your loved one's medical and care providers! Watch the Convention video here.

To learn more about sponsorship and exhibitor opportunities, click here.

Register Now

Lifesaving Hope



Recognize your loved one or family member with a Lifesaving Hope display image to be showcased during the 2021 Virtual National Convention for just $30!

Learn more here.

Thank You to Our Convention Sponsors!

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Prader-Willi SYNDROME ASSOCIATION | Utah SAVING AND TRANSFORMING LIVES

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PWSA Florida
Prader-Willi California Foundation

Pioneers in PWS

Pioneers Devoted to Educating and Supporting Residential Care and Education Professionals

In 2008, a group of residential care professionals formed the PWSA I USA Professional Providers Advisory Board to help educate and support residential providers. Over the years, not only did they help to develop care standards for providers in the USA, they also worked with IPWSO to help providers in many other countries around the world.

Click here to read more.

Current Members of PWSA I USA Professional Providers Advisory Board

		
Patrice Carroll	Mary K Ziccardi	B. J. Goff
		
Marguerite Rupnow	Mark Lister	Stacy Ward

Research

CDISC and NORD Partner to Develop Data Standards for Rare Diseases

NORD®
National Organization
for Rare Disorders

Danbury, CT and Austin, TX – April 22, 2021 – CDISC and the National Organization for Rare Disorders (NORD®) have announced a partnership to develop global data standards for rare diseases.

The data standards will be released in a **Therapeutic Area User Guide** that will be available at no cost on the CDISC website for researchers to leverage in studies to maximize data's full potential.

Read the full press release **here**.

Announcement from Saniona

Saniona has updated their Tesomet Clinical Development timelines based on manufacturing feedback from the U.S. FDA.

Read the full press release **here**.

Harmony Biosciences - Two New Trial Sites

Harmony Biosciences has announced the opening of two new trial sites - the University of Utah and the University of Florida.

This concludes the opening of Harmony's 10 original trial sites, but they will continue to pursue others in an effort to make the trial as geographically diverse as possible.

Visit the link below to learn more.

A Phase 2 Study to Evaluate the Safety and Efficacy of Pitolisant in Patients With Prader-Willi Syndrome, Followed by an Open Label Extension - Tabular View - ClinicalTrials.gov

An Update on the Status of DCCR from Soleno

Soleno Therapeutics recently shared **this letter** regarding the status of DCCR.

We are grateful for our partnership with Soleno and their continued commitment to the PWS community.

Chapter Event Alerts

A New Series from Prader-Willi California Foundation

Register today for a brand new PWS behavior management training series presented by Lisa Graziano, M.A., LMFT. This seven-part series will explore the different aspects of PWS behaviors and introduce various techniques you can implement to manage these behaviors.

Session 1: It All Begins with Food Security, Anchoring Your Self and Empathy
Date and Time: Sunday, April 25 | 10:00 - 11:00 AM PST

Each session is an hour in duration and will occur once a month until October 2021.

Click here to view the series flyer, including all future session dates.

Click here to register.

PWSA Colorado Derby Day - May 1, 2021

The PWS Derby is the annual fundraising party for PWS in Colorado. The Derby takes place on the first Saturday in May. This year the event will be held on May 1, 2021 from 4-9 pm at Marjorie Park at Fiddler’s Green.

What better excuse than a global pandemic to change up this year’s Derby event? We are excited to invite you to the 2021 Derby Day fundraiser. Visit the event page here for up-to-the-minute details about this year's event!

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.

Prader-Willi
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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!

Visit Us Online!
www.pwsausa.org

Give Now

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Vol. 16
April 30, 2021

WEBINAR OPPORTUNITY

Introduction to Compensatory Education

PRESENTED BY
Prader-Willi
SYNDROME ASSOCIATION | USA
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Saturday May 8, 2021

12:00 PM – 1:30 PM EST

Due to the pandemic, some IEP services were unable to be provided, and some students did not meet IEP goals. Through Compensatory Services, ESY, Remote Learning Plans or IEP amendments, learn what you need to know to make sure your child is set up for success going forward.

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ERC Education Rights Counsel

REGISTER IN ADVANCE:

https://us02web.zoom.us/webinar/register/WN_tKjP9CL6TzyXr7hNagezxg

Elizabeth Enyon-Kokrda

Managing Attorney for Education Rights Council

Elizabeth Eynon-Kokrda focuses her practice on education issues. As an education attorney for over 20 years, she has served as the Chair of the National Council of School Attorneys and President of the Nebraska Council of School Attorneys. In addition to her private practice, she currently serves as Managing Attorney for Education Rights Counsel, a non-profit advocating for the special education and due process rights of children and families. Elizabeth's extensive legislative experience has developed her passion for working to improve education laws at the state and federal level. Elizabeth is licensed to practice in Nebraska, Iowa and before the United States Supreme Court.

Register in Advance

PWS Awareness Month - Hope Is Here

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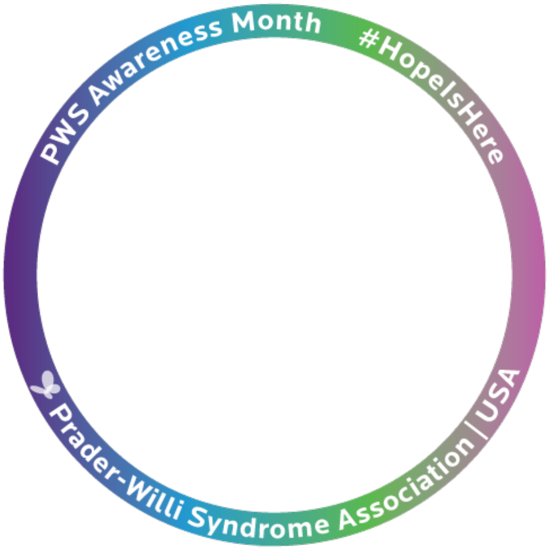

It's not too late to customize your Facebook profile picture with our PWSA | USA #HopeIsHere PWS Awareness Month Photo Frame!

1) Click on your Facebook Profile Picture
2) Click "Add Frame"
3) Search for the frame called "PWSA | USA PWS Awareness"
4) Select this frame and spread the word!

Stay tuned to your email and our Facebook page for other easy ways to participate in PWS Awareness Month.

A Special PWS Awareness Month Fundraiser

SHOW YOUR PWS PRIDE
& STAY HYDRATED THIS SUMMER!

Prader-Willi
SYNDROME ASSOCIATION | USA
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$15 of each bottle sold benefits PWSA | USA

PWS AWARENESS MONTH
CUSTOM WATERBOTTLE
FUNDRAISER

Place Your Order Today!

1) Visit www. store.zagfundraising.com
2) Enter Seller ID# 84854424
3) Click "SHOP" and browse
4) Pick 1 of 9 available colors!
5) Personalize (name, hashtag, or logo)
6) Pay (Orders will arrive in 3-4 weeks)

*Free Shipping on orders $75+

CLICK HERE TO ORDER

Virtual National Convention

What Are You Waiting For?

This year's National Convention **Hope's on the Horizon** has gone VIRTUAL!

There's so much to learn and so many ways to connect (and reconnect) with our PWS community. Whether you have a loved one with PWS, are a professional provider, a Physician, or Scientist . . . this year's convention has something for everyone!

Over 500 individuals have already registered and remember - this year, **registration to our General Conference is FREE**!

PWSA | USA's **virtual** National Convention will be held **June 22-26, 2021.** Our dedicated staff and convention volunteers are hard at work putting together an exciting lineup of educational, informative, and fun sessions for the PWS community.

Download the Convention flyer here, and don't forget to share with your loved one's medical and care providers! Watch the Convention video here.

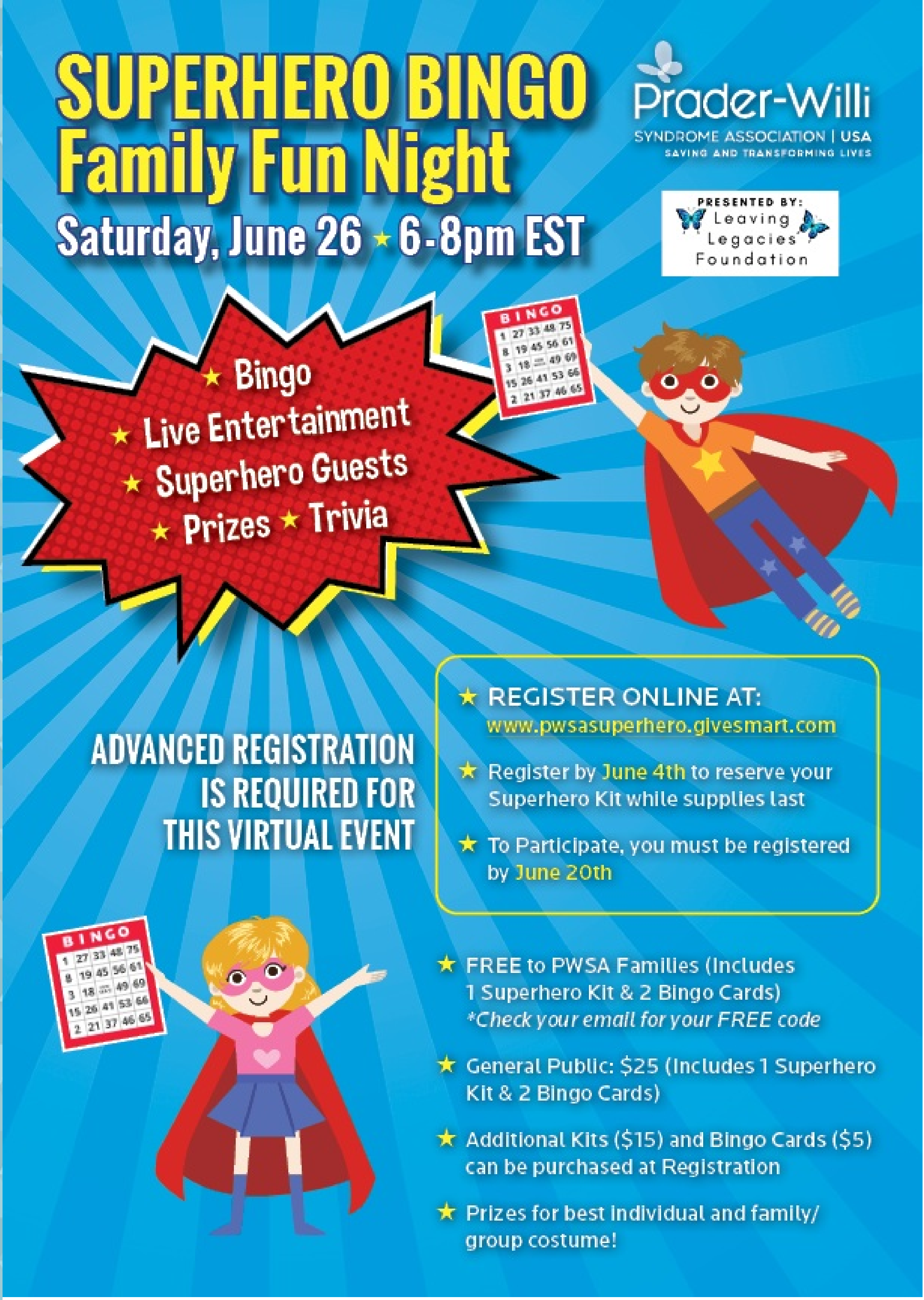
To learn more about sponsorship and exhibitor opportunities, click here.

Register Now

Our Superhero Bingo Family Fun Night on June 26th is ABSOLUTELY FREE for PWS Families and Residential Homes!

To register as a family, select 1 Superhero Deluxe Kit and enter discount code **"BAM"** at checkout.

To register a group at a residential facility, contact Stacy Ward at sward@pwsausa.org for your special free registration code!



SUPERHERO BINGO Family Fun Night

Saturday, June 26 ★ 6-8pm EST

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PRESENTED BY:
Leaving Legacies Foundation

- ★ Bingo
- ★ Live Entertainment
- ★ Superhero Guests
- ★ Prizes ★ Trivia

ADVANCED REGISTRATION IS REQUIRED FOR THIS VIRTUAL EVENT

- ★ REGISTER ONLINE AT: www.pwsasuperhero.givesmart.com
- ★ Register by June 4th to reserve your Superhero Kit while supplies last
- ★ To Participate, you must be registered by June 20th

- ★ FREE to PWSA Families (Includes 1 Superhero Kit & 2 Bingo Cards) **Check your email for your FREE code*
- ★ General Public: $25 (Includes 1 Superhero Kit & 2 Bingo Cards)
- ★ Additional Kits ($15) and Bingo Cards ($5) can be purchased at Registration
- ★ Prizes for best individual and family/group costume!

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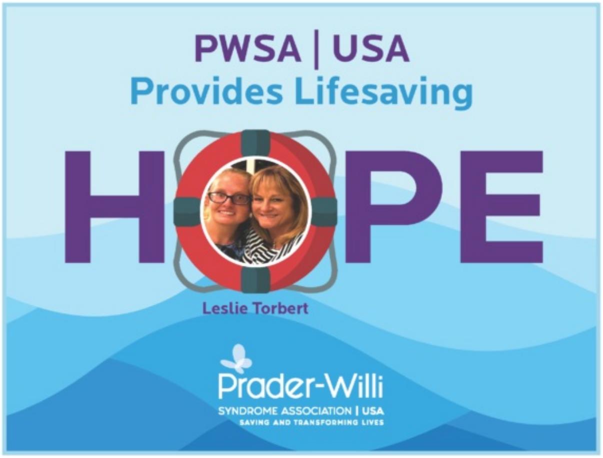

Learn more [here](#).

Thank You to Our Convention Sponsors!

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PWSA Ohio	PWSA Florida
PWSA Texas	Prader-Willi California Foundation
PWSA Wisconsin	

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Download the Report

FOUNDATION FOR PRADER-WILLI RESEARCH
Working Toward an Independent Future

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Pioneers in PWS

Pioneers Who Cared for Persons with PWS in Medical and/or Psychiatric Crisis

2000 Staff from the Children's Institute

Despite our growing understanding and knowledge of the management of Prader-Willi syndrome (PWS), there are still persons with PWS who experience life-threatening complications due to obesity; and others who require inpatient treatment for severe, challenging behaviors. There are a handful of professionals who became experts in caring for these individuals at a time when they were very ill, either physically or behaviorally. For many, it was probably the most stressful time in their lives. Because of their experiences, these pioneers helped us learn about the seriousness of such health emergencies and the urgency in preventing and treating problems before they become fatal. Most of these professionals conducted research, wrote papers and shared their knowledge with other professionals who cared for persons with PWS from around the world. We have highlighted just some of the team members who have given so much to the world of PWS. We are truly grateful for their focus on those who truly needed their expertise.

Click here to read more.

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Research

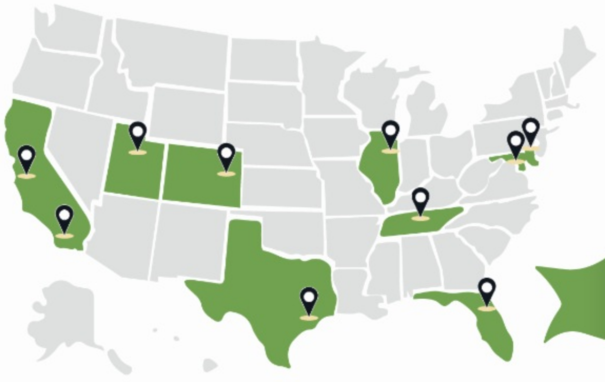
Harmony Biosciences is seeking people with PWS between the ages of 6 – 65 to enroll in Clinical Trial

Harmony Biosciences will be studying the safety and impact of an investigational medication on excessive daytime sleepiness, cognition, and behavioral function in people with PWS.

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

Read more here.

Where is the trial?



THERE ARE

10 Trial Sites

Around the US

WITH MORE TO BE ADDED

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

Current Sites:

- San Diego, CA
- San Ramon, CA
- Aurora, CO
- Wilmington, DE
- Gainesville, FL
- Chicago, IL
- Baltimore, MD
- Nashville, TN
- Houston, TX
- Salt Lake City, UT

CDISC and NORD Partner to Develop Data Standards for Rare Diseases

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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!

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