Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

Vol. 17
May 7, 2021

WEBINAR OPPORTUNITY

Introduction to Compensatory Education

PRESENTED BY
Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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

PWS Awareness Month - Hope Is Here

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

Having a rare disorder like PWS can be stressful and challenging for individuals and families. At Prader-Willi Syndrome Association | USA we believe amid the stress and challenge there is tremendous resiliency and hope for the future.

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**

Click here for more resources.

Hi, my name is Aran (pronounced Aaron), and I am part of the Prader-Willi Syndrome family. I was diagnosed at three weeks old. I was fortunate that my state has a fantastic Early Intervention program, and I

was able to start physical and occupational therapy within the fourth week. That work was tough, but it helped me to be my very best. Sure, I was late on all of my milestones, but I sat up, crawled, and even walked by the time I was three!! Everybody told my Mom and Dad that I would get there on MY time, not the schedule that everybody laid out for kids my age. I added a speech therapist along the way because I struggled to form my sounds into words. It didn't take too long (longer than Mom and Dad wanted to wait though!!) and I was making syllables, and eventually words. I still struggle with certain sounds and longer words, but I keep working hard, and it is coming.

Read more stories of Hope here.

Chalk Your Walk and Win!

Create a chalk masterpiece on your driveway, sidewalk, or a fence in your yard for PWS Awareness Month this May!

Submit your creation on Facebook by tagging Prader-Willi Syndrome Association USA, Instagram @PWSAUSA and Twitter @PWSA | USA using the hashtags **#ChalkYourWalk, #HopeIsHere,** and **#PWSAwareness.**

Win! We will select the 3 most creative entries to win a $25 Target gift card!

A Special PWS Awareness Month Fundraiser

SHOW YOUR PWS PRIDE
& STAY HYDRATED THIS SUMMER!

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of each bottle
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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

Teacher Appreciation Week

May 2 - May 9, 2021

Here are some ideas to recognize the teachers in your life:

- Send a thank you card telling them all the ways that they have impacted your child's learning.
- Have your child draw or color a picture for their teacher.
- Create a certificate of appreciation.
- Create a video, thanking your

child’s teacher and email to them.
- Share social media posts using the hashtag #ThankATeacher

Read more here.

Virtual National Convention

What Are You Waiting For?

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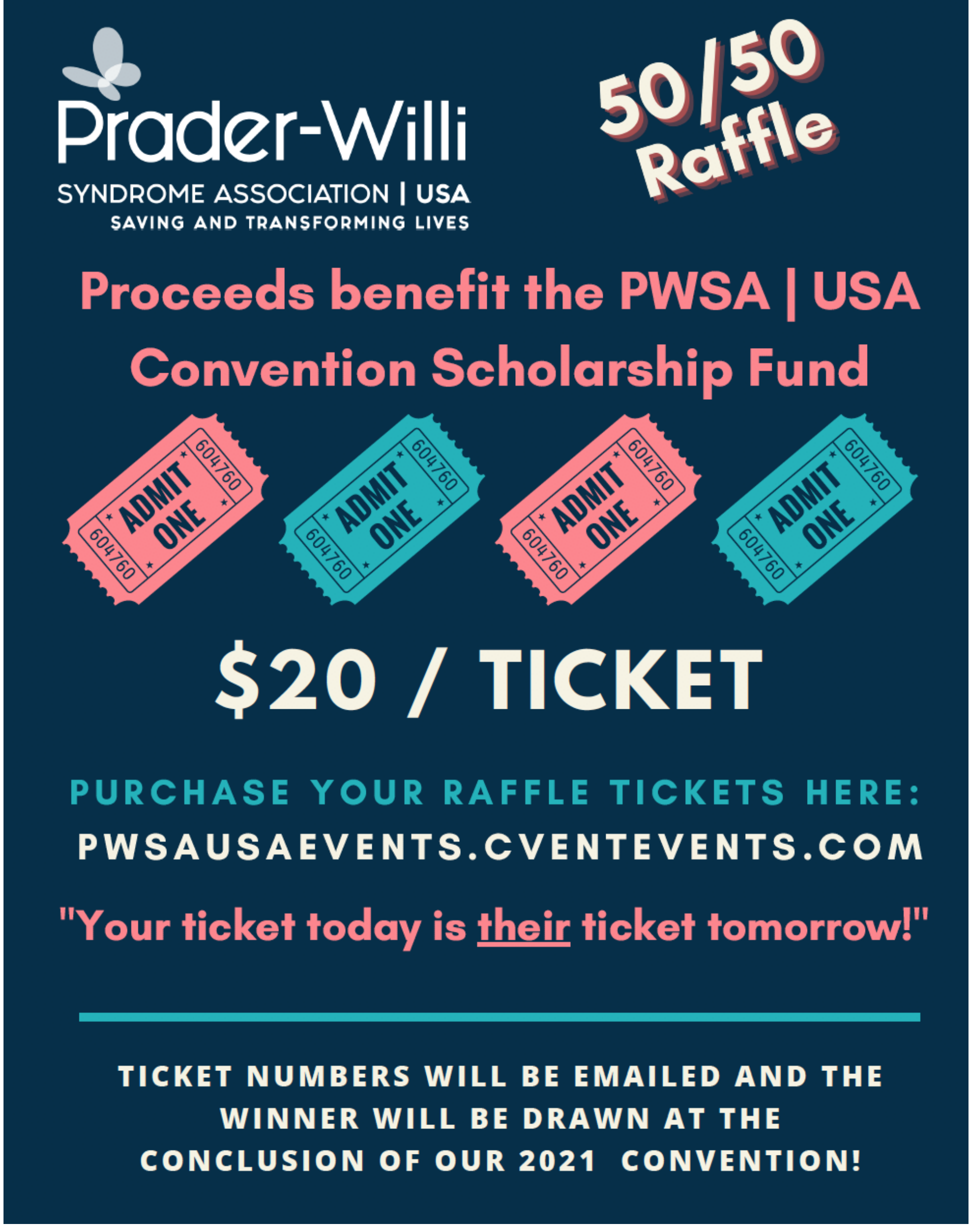

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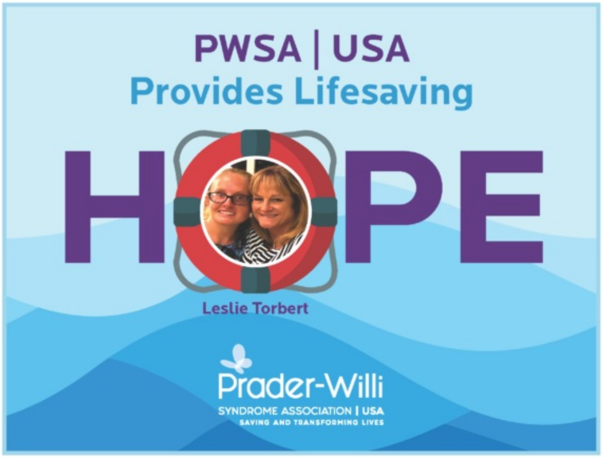

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Learn more ***here****.*

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Prader-Willi California Foundation

Save the Date

Prader-Willi Syndrome (PWS) 2nd DCCR Town Hall

When: May 20, 2021 at 4:30 p.m.
Where: This virtual event is open to the public and we encourage you to attend.

This is a continuation of the first Town Hall and an additional chance to help understand the current DCCR situation and get up-to-date information, as well as continue to collect patient and caregiver stories. Once again, speaking opportunities will be open and we encourage you to share your PWS related experiences in this open public forum.

Pre-register to speak:

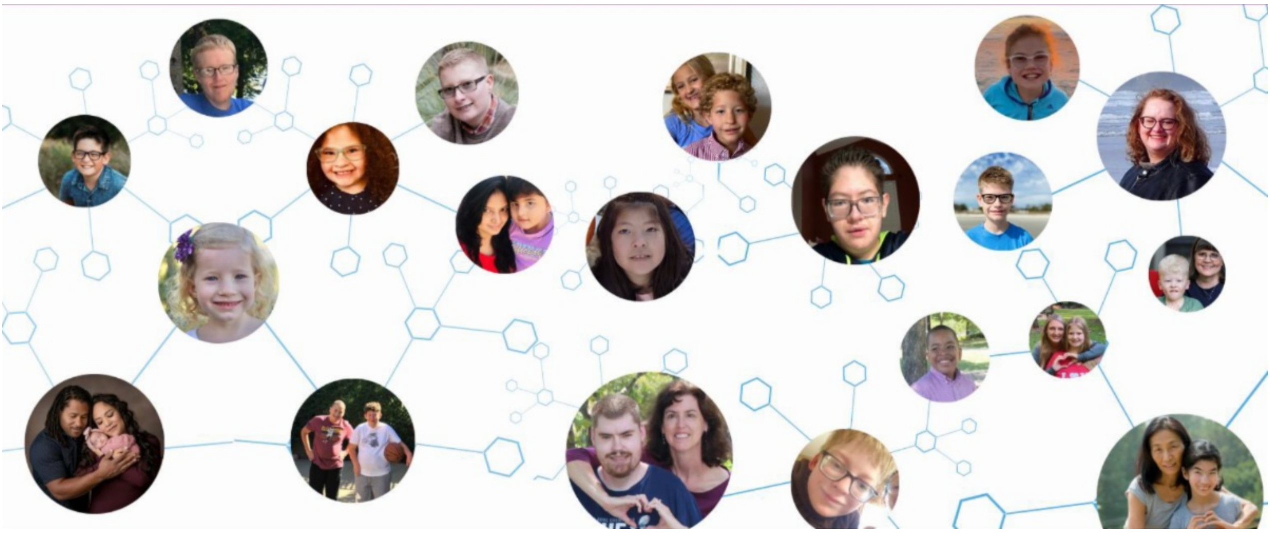
Preference will be given to a family member or child with experience on DCCR

https://tinyurl.com/PWSSPEAKER2

For questions and/or media requests, email pwsadvocates@gmail.com

Advocacy

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

Pioneers in PWS

Pioneers in PWS - The Delegates to IPWSO

This article began as an acknowledgement of the nearly 30 years of PWSA | USA elected delegates to IPWSO, the International Prader-Willi Syndrome Organisation, but rapidly became much more than that. PWSA | USA was actually instrumental in the founding and development of IPWSO. The mission and vision of IPWSO is similar to that of PWSA | USA but with the added responsibility of assisting those in countries where Prader-Willi syndrome was often unknown to physicians and struggling families who needed diagnosis for their challenging child.

Click here to read more.

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.

Research

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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

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**.

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.

Important Message About This Newsletter

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Give Now

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Vol. 18
May 14, 2021

PWS Awareness Month - Hope Is Here

How did May become Prader-Willi Syndrome Awareness Month?

Republican Congressman Ed Royce and Democratic Congresswoman Jane Harman co-sponsored the original House Resolution thanks to efforts by Amy Porter whose niece Abby has PWS, and Tom and Renay Compere (whose son William has PWS) who brought this important cause to their attention. The House Resolution passed in December 2009, which then led to the Senate bill being passed on May 27, 2010, thereby establishing National Prader-Willi Syndrome Awareness Month!

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**

Click here for more resources.

#HopeIsHere - Ethan and Mason

"Our reality is that Prader-Willi syndrome is not our lives. Our boys are our lives. My life is spent feeling so, so, so incredibly blessed and humbled that I was given these special little lives to raise. Prader-Willi syndrome helped shape our family. It has given us SO much more than it will ever take from us."

~Tessie

Click here to read more.

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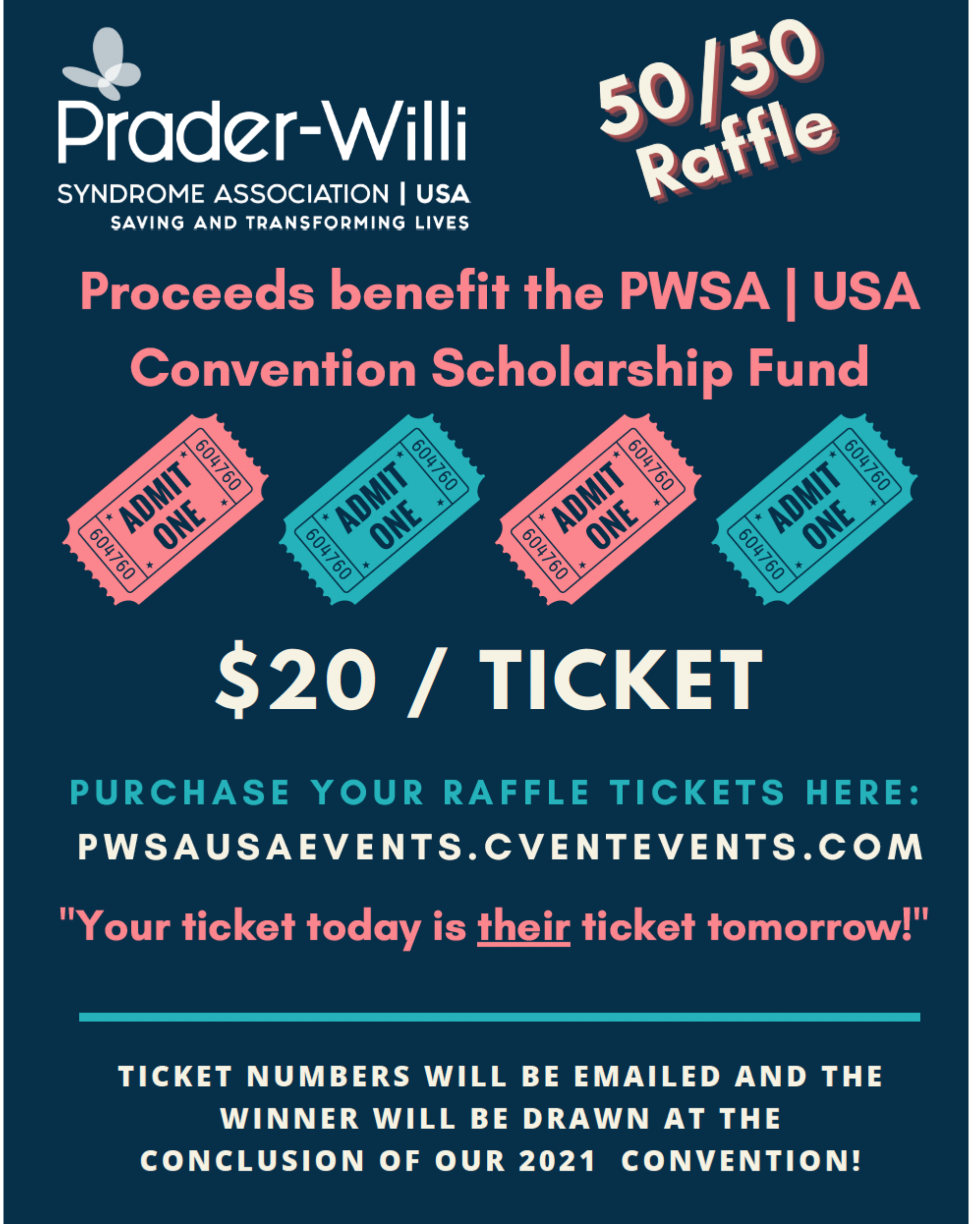

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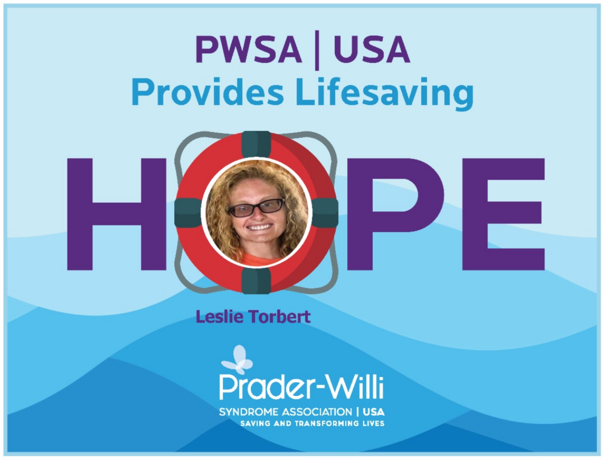

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PWS patients, Cade and Bridget, with Dr. Jennifer Miller

Pioneers in PWS

Pioneers in PWS - The Crisis Intervention Counselors

Many of you have called the PWSA | USA office in need of guidance for your child's IEP, support for behaviors that are out of control, information on a supportive living placement and many other subjects. You've no doubt been met with the calm, reassuring and knowledgeable voice of a Crisis Intervention Counselor. Unless you've been a part of our organization for many years, you do not have an understanding of how this very important program evolved.

Click here to read more.

Research

Saniona Voices: Lynn Garrick

Saniona’s Community Voices video series spotlights those living with rare diseases, their caregivers, and their medical professionals. For Prader-Willi Syndrome (PWS) Awareness Month, Paul Pereira, Vice President, Saniona, interviewed Lynn Garrick, the mother of a 13-year-old son living with PWS, about her son and family’s experience managing the condition.

Click here to watch the videa.

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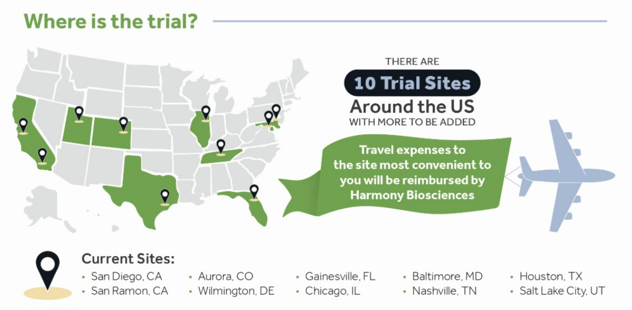

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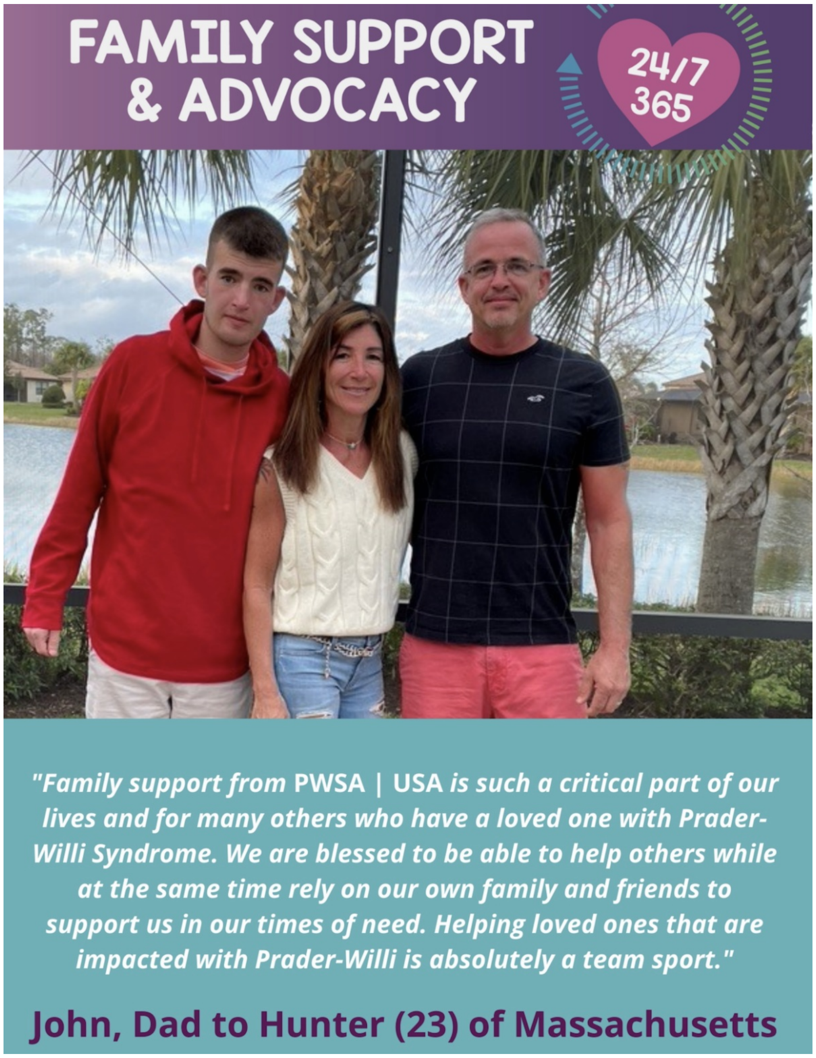
Vol. 19
May 21, 2021



"Family support from PWSA | USA *is such a critical part of our lives and for many others who have a loved one with Prader-Willi Syndrome. We are blessed to be able to help others while at the same time rely on our own family and friends to support us in our times of need. Helping loved ones that are impacted with Prader-Willi is absolutely a team sport."*

John, Dad to Hunter (23) of Massachusetts

"Through Family Support at PWSA, we are constantly reminded we are not alone on this journey; parent mentors guided us in the beginning, staff educated and helped us start in the school system, and facebook groups connect me with families facing the same challenges. It's comforting to know that Family Support at PWSA will always be there by our side helping us navigate each aspect of PWS as Bridget grows older."

Maggie, Mom to Bridget (3) of Florida

To help sustain our life-saving Family Support Program, give generously below!

DONATE NOW

Staff Announcement

Carrie Larsen

We are pleased to announce that Carrie Larsen has joined PWSA | USA as Marketing and Communications Specialist. In this role, she will coordinate our social media efforts, create marketing and communication strategies, and work closely with the PWSA | USA network to share stories that offer help and hope. Carrie graduated from the University of Wisconsin-Whitewater with a B.A. in Broadcast Journalism and a Marketing minor. For three years, she worked as a multimedia journalist and weekend anchor for news stations in Topeka, KS and Madison, WI. Carrie left the news industry to take on a role with a behavioral healthcare nonprofit in Cleveland, OH, where she worked as their Marketing and Communications Coordinator for three and a half years. Carrie lives in Cleveland, Ohio with her fiancé Steve and

their Cavapoo, Henry.

Breaking News

PWSA | USA Expands Capacity to Serve With Transition of the Prader-Willi Care Coordination Program from The Children's Institute of Pittsburgh

Read the full press release here.
May 19, 2021

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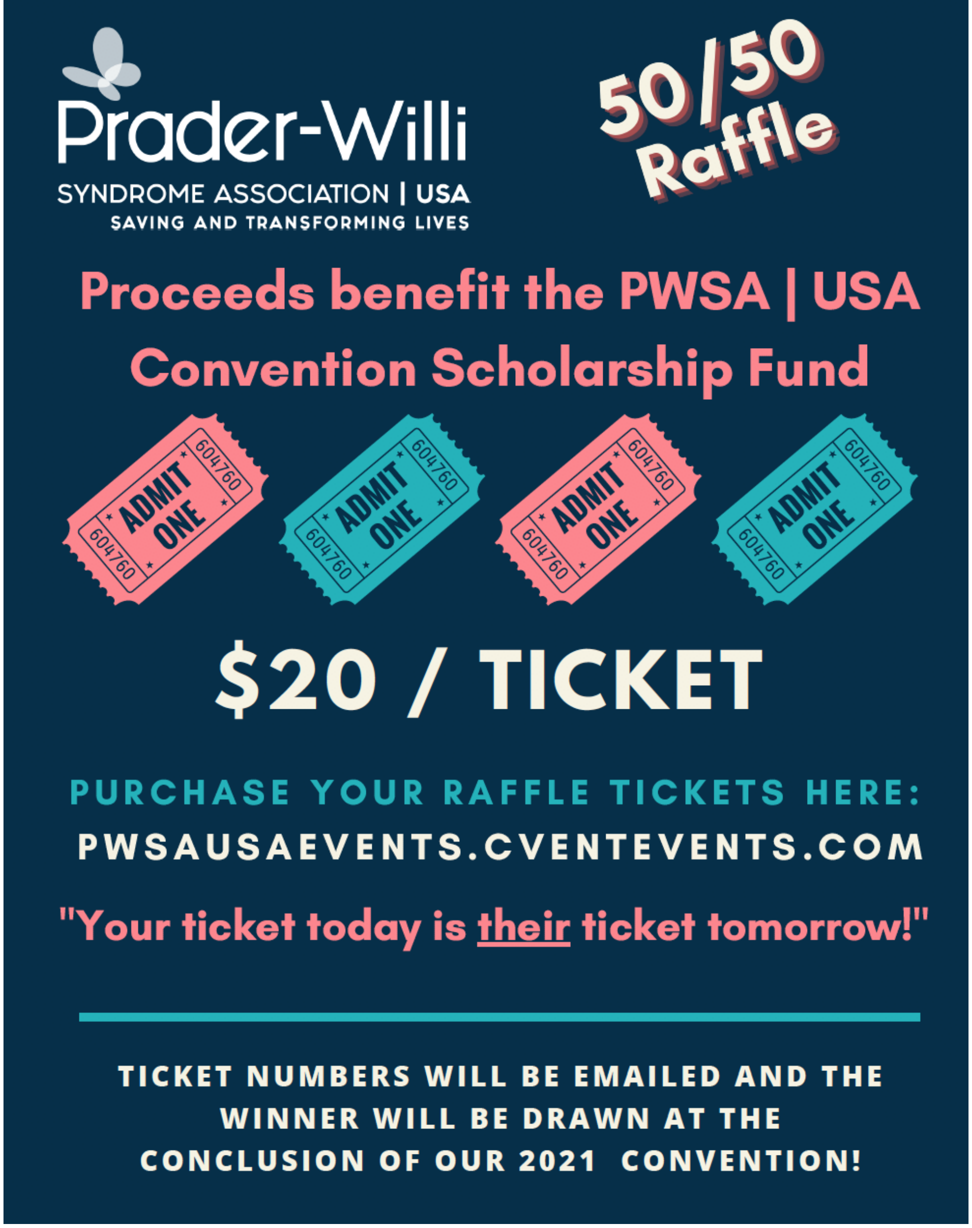

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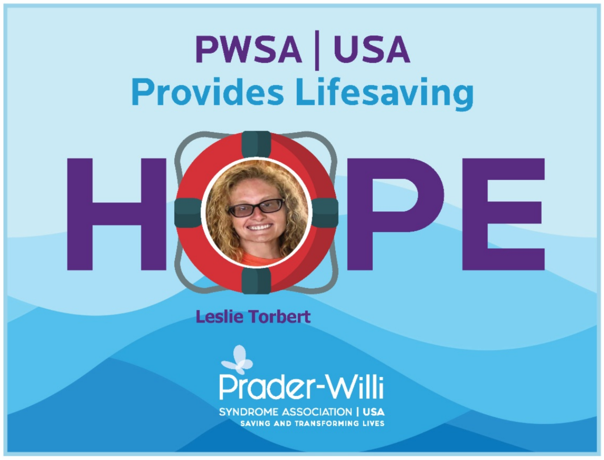

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Advocacy

Inform and Educate Your Elected Officials on the Importance of DCCR

Our PWS community recently learned that the FDA is recommending an additional clinical trial for DCCR (Diazoxide choline controlled-release tablet), which is manufactured by Soleno Therapeutics.

DCCR is a therapy that our community desperately needs and we hope that it can quickly become available to anyone with PWS who would benefit from it. While the PWS community might not have the resources of groups with greater numbers, change is still possible!

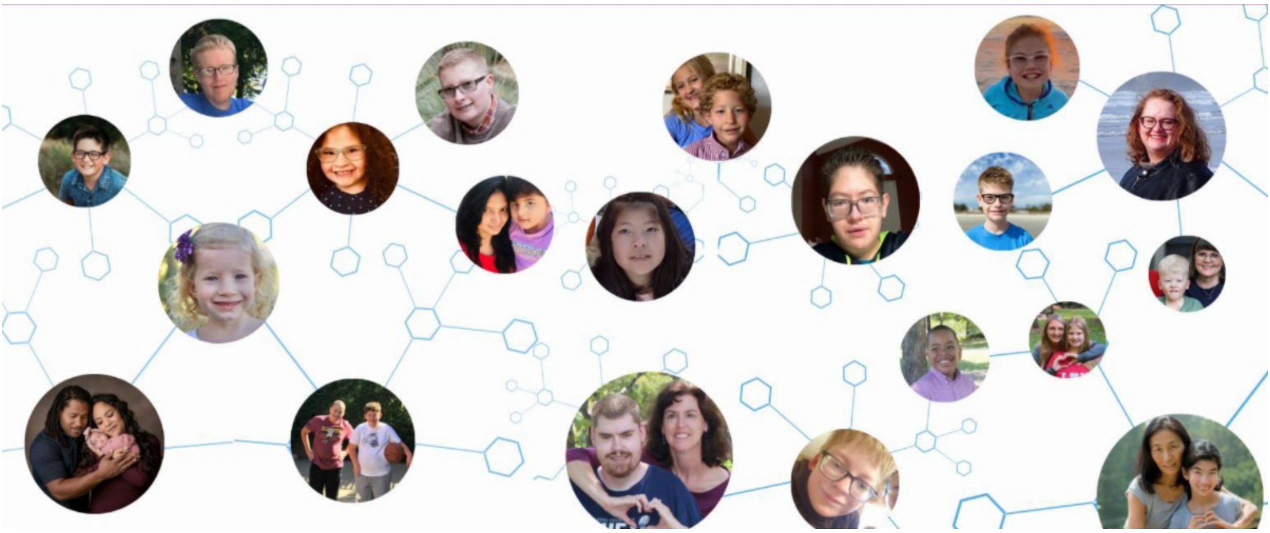
Please take the time to contact your elected officials TODAY and inform them of this issue facing our community.

2nd DCCR Town Hall Recap

In case you missed the second DCCR Town Hall last Friday, it is now available on YouTube.

Click here to watch the recording.

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

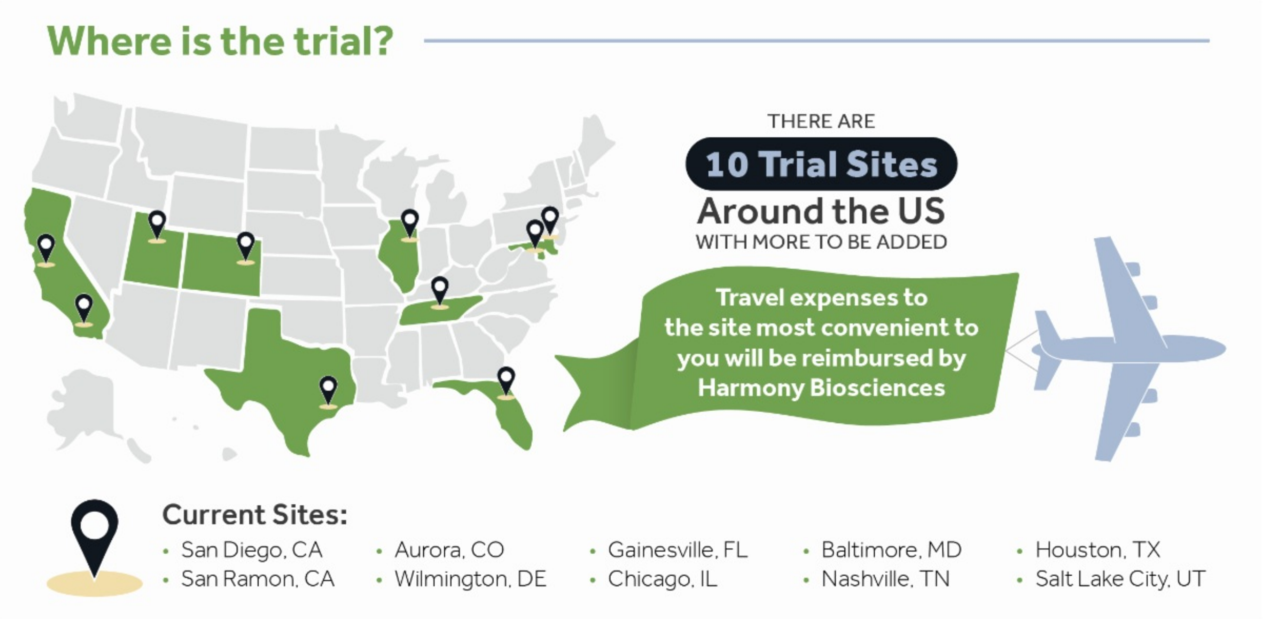
Research

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.



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

View as Webpage

Prader-Willi
SYNDROME ASSOCIATION | USA
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PWSA | USA
THE PULSE

Vol. 20 | May 28, 2021

FAMILY SUPPORT & ADVOCACY

24/7
365

"I appreciate the Family Support provided by PWSA | USA. *The medical alert booklet has been extremely helpful when my son has been hospitalized. As a board member of Prader-Willi Syndrome Association of New England, I am grateful to be able to refer parents and providers to* PWSA | USA *for support, and confident they will receive it."*

Mary, Mom to Davis (24) in Massachusetts

www.pwsausa.org/get-involved-donate/

"PWSA | USA *has been our backbone of support since we discovered them nearly four years ago. Whether we've needed doctors, advice, help with preparing our son for school or even just a strong shoulder to cry on,* PWSA | USA *has always stood right by our side. We will be forever grateful to this outstanding organization for always being there for us!"*

Dorothea, Mom to Hunter (3) in Florida

www.pwsausa.org/get-involved-donate/

To help sustain our life-saving Family Support Program, give generously below!

DONATE NOW

FAMILY SUPPORT

PWS Awareness Month - *Hope Is Here*

Chalk Your Walk and Win!

This is the **last weekend** to create a chalk masterpiece on your driveway, sidewalk, or a fence in

"When we initially received Noelle's diagnosis, we grieved the loss of all the typical long-term dreams that we had for our only daughter and acknowledged that we were going to need to live our lives differently."

Read More About Noelle's Journey

your yard for PWS Awareness Month! Submit your creation on Facebook by tagging Prader-Willi Syndrome Association USA, Instagram @PWSAUSA and Twitter @PWSA | USA using the hashtags **#ChalkYourWalk**, **#HopeIsHere**, and **#PWSAwareness**.

WIN! We will select the 3 most creative entries to win a $25 Target gift card. ***The winners will be announced in next week's Pulse.***

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

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

REGISTER HERE

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]().

Join us for a night of family fun for *ALL AGES* and a chance to WIN a PWSA Summer Fun Prize Pack!

The Superhero Bingo Family Fun Night, June 26th from 6-8pm EST, is ***ABSOLUTELY FREE*** for PWS Families and Residential Homes. If you register between now and **June 4th**, you will be entered to win!

REGISTER HERE

WIN A FAMILY SUMMER FUN KIT!

- PWSA | USA Logo Beach Tote
- 2 Towels
- 2 Waterbottles!
- Beachball

SUPERHERO BINGO FAMILY FUN NIGHT

SATURDAY, JUNE 26TH | 6-8PM EST

To participate, you must be registered by June 20th

Presented by: Leaving Legacies Foundation

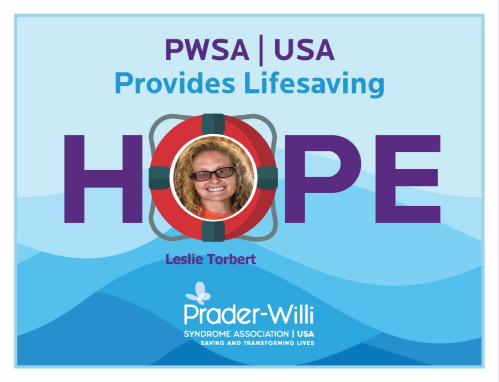
- ★ BINGO
- ★ Live Entertainment
- ★ Superhero Guests
- ★ Prizes + Trivia

ADVANCED REGISTRATION REQUIRED FOR VIRTUAL EVENT

- ★ 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 costumes!

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!

Explore All That Our Convention Has To Offer



PWSA | USA
Provides Lifesaving
HOPE

Leslie Torbert

Prader-Willi
SYNDROME ASSOCIATION | USA
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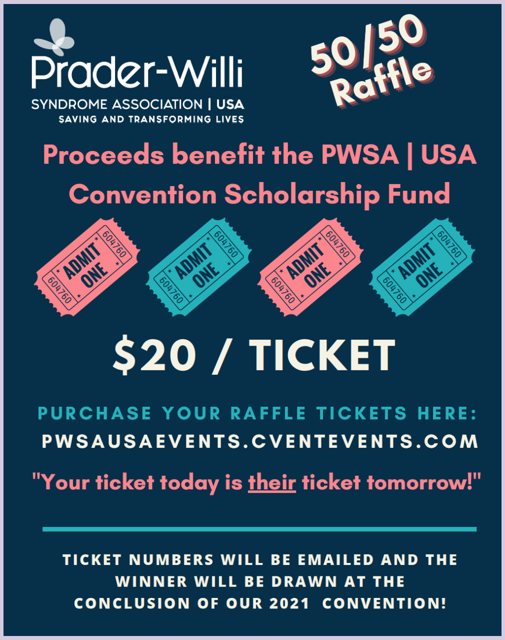
Recognize your loved one or family member with a Lifesaving Hope display image to be showcased during the 2021 Virtual National Convention for just $30!

LEARN MORE HERE



Prader-Willi
SYNDROME ASSOCIATION | USA
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50/50 Raffle

Proceeds benefit the PWSA | USA Convention Scholarship Fund

$20 / TICKET

PURCHASE YOUR RAFFLE TICKETS HERE:
PWSAUSAEVENTS.CVENTEVENTS.COM

"Your ticket today is their ticket tomorrow!"

TICKET NUMBERS WILL BE EMAILED AND THE WINNER WILL BE DRAWN AT THE CONCLUSION OF OUR 2021 CONVENTION!

PURCHASE RAFFLE TICKETS

Thank You to Our Convention Sponsors!

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ADVOCACY & AWARENESS

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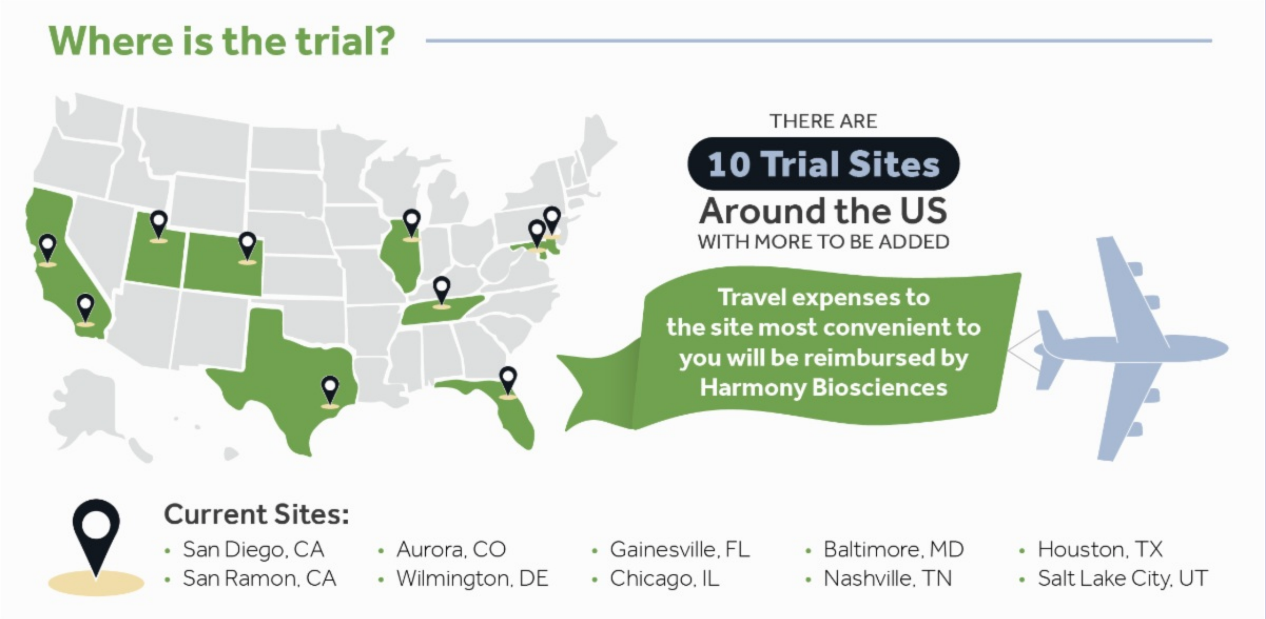

Where is the trial?

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

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