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Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

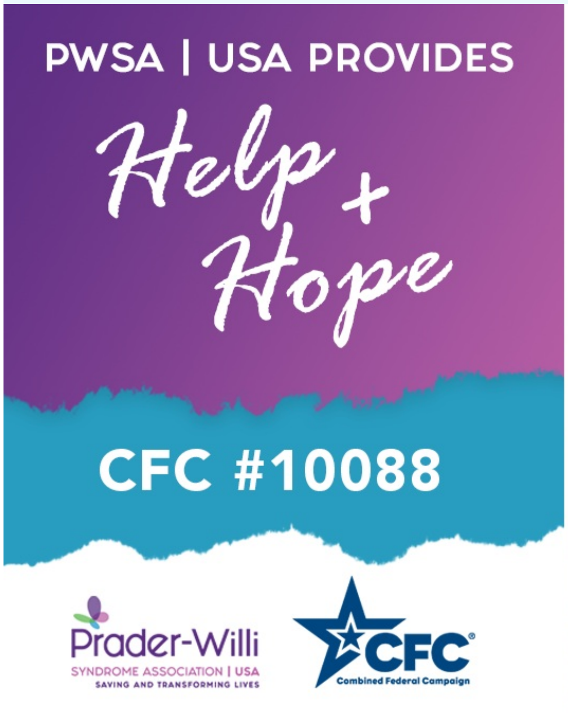
PWSA | USA

THE PULSE

Vol. 32 | September 3, 2021

www.pwsausa.org | **Donate**

Attention Current & Retired Federal Employees!



Between ***NOW*** 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

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!*

Show Your Support for the STAT Act!

Patients like me need an FDA Rare Disease Center of Excellence to help our community achieve better access to therapy development and coordination of policies and stakeholders involved in rare. I asked my Members of Congress to support the STAT Act, because it can change the landscape of rare disease for the better.

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 for 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 one-two 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 - September 2, 2021

92 NEW ADVOCATES

287 Total Legislator Connections

Thank you for using your voice to spark change!

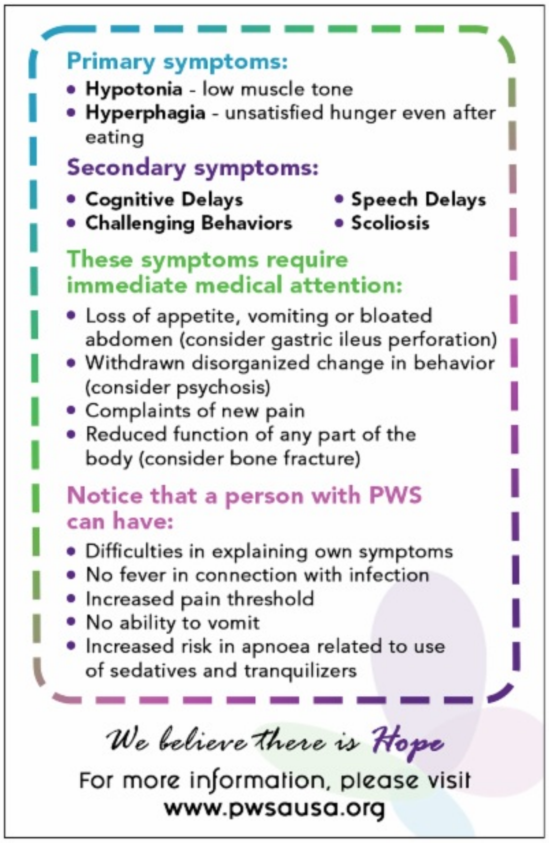
FAMILY SUPPORT

NEW Customizable PWS Health Identification Card!

Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES

Hi, my name is Jake

And I have Prader-Willi syndrome (PWS)



Primary symptoms:

- **Hypotonia** - low muscle tone
- **Hyperphagia** - unsatisfied hunger even after eating

Secondary symptoms:

- **Cognitive Delays**
- **Challenging Behaviors**
- **Speech Delays**
- **Scoliosis**

These symptoms require immediate medical attention:

- Loss of appetite, vomiting or bloated abdomen (consider gastric ileus perforation)
- Withdrawn disorganized change in behavior (consider psychosis)
- Complaints of new pain
- Reduced function of any part of the body (consider bone fracture)

Notice that a person with PWS can have:

- Difficulties in explaining own symptoms
- No fever in connection with infection
- Increased pain threshold
- No ability to vomit
- Increased risk in apnoea related to use of sedatives and tranquilizers

We believe there is Hope

For more information, please visit
www.pwsausa.org

To help our communities better understand Prader-Willi syndrome, how it affects those diagnosed, and what symptoms require immediate medical attention, PWSA | USA has created a customizable PWS Health Identification Card. This Health ID card can be printed and shared with anyone in your community, e.g. school officials, medical providers, family members, etc. Download the customizable card by clicking the button below and add your own image and name, like in the example above. We have also included a "how to customize" document for your convenience. If you have any questions, please contact **info@pwsausa.org**.

DOWNLOAD THE CUSTOMIZABLE PWS HEALTH ID CARD HERE

HOW TO CUSTOMIZE YOUR PWS HEALTH ID CARD

RESEARCH

PWSA | USA CALL FOR LETTERS OF INTENT (LOI)

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

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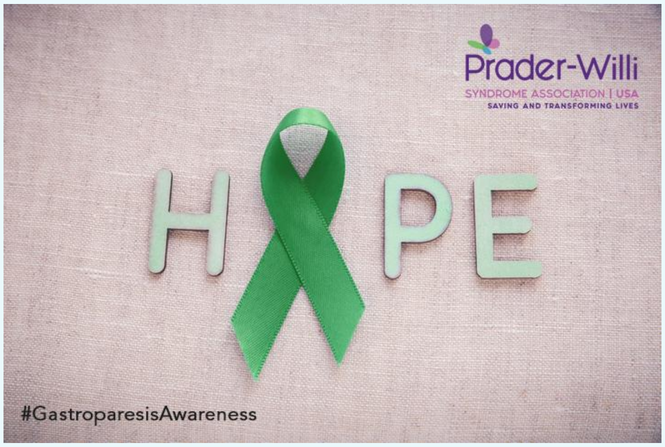
DOWNLOAD GRANT SUBMISSION GUIDELINES HERE

Understanding Gastric Motility and Gastroparesis in PWS



To raise awareness of Gastric Motility and Gastroparesis, PWSA | USA volunteers Barb Dorn, RN, BSN and Margaret Burns, RD, Prader-Willi Homes, along with Board member Ann Scheimann, MD share the most up-to-date information.

Read their full article 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

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

Join The Volunteer Gratitude Team!

Are you good at putting a smile on peoples face? If so, we need YOU! At PWSA | USA we want to ensure that our members, donors, volunteers, and partners feel loved and appreciated. We are looking for volunteers to hand write personalized cards for birthdays,

welcome home, welcome new baby, just thinking of you postcards, encouragement and more! The time commitment is up to you and materials will be provided by PWSA | USA. If you or someone you know is interested in joining our Gratitude Team, please email Dorothea at volunteer@pwsausa.org.

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

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SATURDAY, OCTOBER 2ND,2021 - 1 PM

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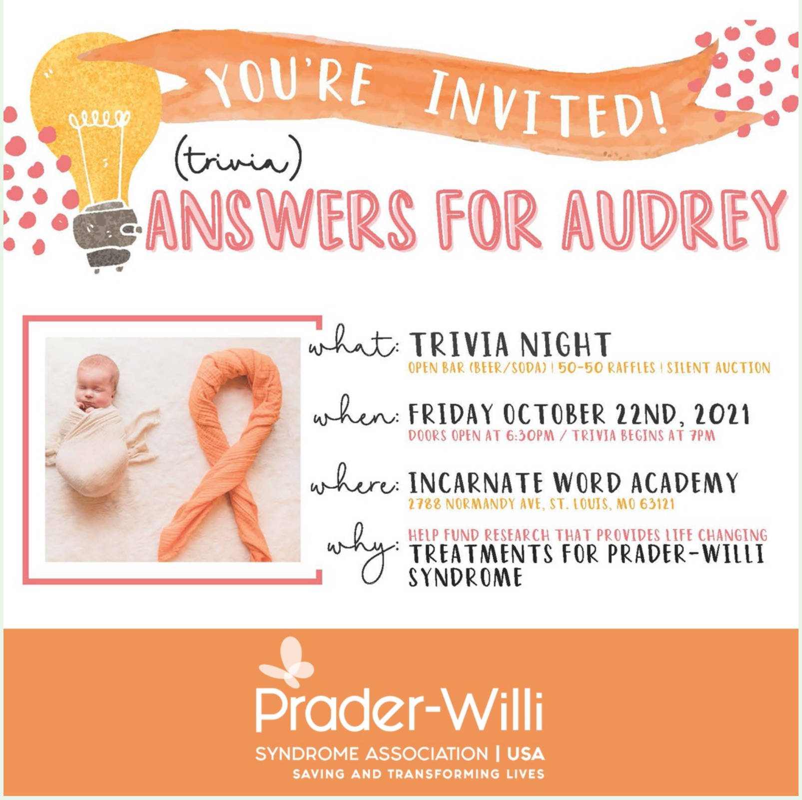

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(trivia)

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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

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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
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REGISTER HERE

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Important Message About This Newsletter

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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!
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Give Now

View as Webpage

Prader-Willi
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PWSA | USA
THE PULSE
Vol. 33 |
September 10, 2021

www.pwsausa.org | Donate

We've heard from many of you in our PWS community about the concerns regarding Dr. van Bosse leaving Shriner's Hospitals for Children. We would like to take this opportunity to have a conversation and help in any way we can. Please join PWSA | USA's CEO Paige Rivard, Family Support Director Stacy Ward, and Parent Support Coordinator Kristi Rickenbach for a discussion. We will not have specific information on Dr. van Bosse, but want to hear your particular needs, and offer assistance where we can.

REGISTER IN ADVANCE HERE

RESEARCH

FDA Advisory Committee to Review LEVO's Carbetocin as a Treatment for PWS

We are excited to share that LEVO's New Drug Application

(NDA) for carbetocin as a treatment for PWS will be discussed at a public meeting of the Psychopharmacologic Drugs Advisory Committee, which will be held November 4, 2021.

Learn more here >>

Soleno Therapeutics Announces Positive Data Showing Continued Significant Improvements in Symptoms of PWS following One Year Treatment with DCCR

The data shows:

- Statistically significant reduction in hyperphagia and all other PWS behavioral parameters in Study C602
- Statistically significant improvements compared to natural history of PWS from the PATH for PWS Study
- On track for data submission to the FDA in Q3 2021

Learn more here >>

Promising PWS Treatment Granted Orphan Drug Designation by FDA

We are excited to share that Neuren Pharmaceuticals has been granted Orphan Drug designation by the US Food and Drug Administration (FDA) for NNZ-2591 to treat PWS. Orphan Drug designation is a special status that the FDA may grant to a drug to treat a rare disease or condition. Amongst other incentives, Orphan Drug designation qualifies the sponsor of the drug for seven years of marketing exclusivity, plus six months if approved for pediatric use, as well as waiver of the prescription drug user fee for a marketing application. PWSA | USA will continue to provide updates as more information becomes available.

Learn more about NNZ-2591 here >>

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

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ADVOCACY

Show Your Support for the STAT Act and BENEFIT Act!

THE STAT ACT

THE BENEFIT ACT

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.

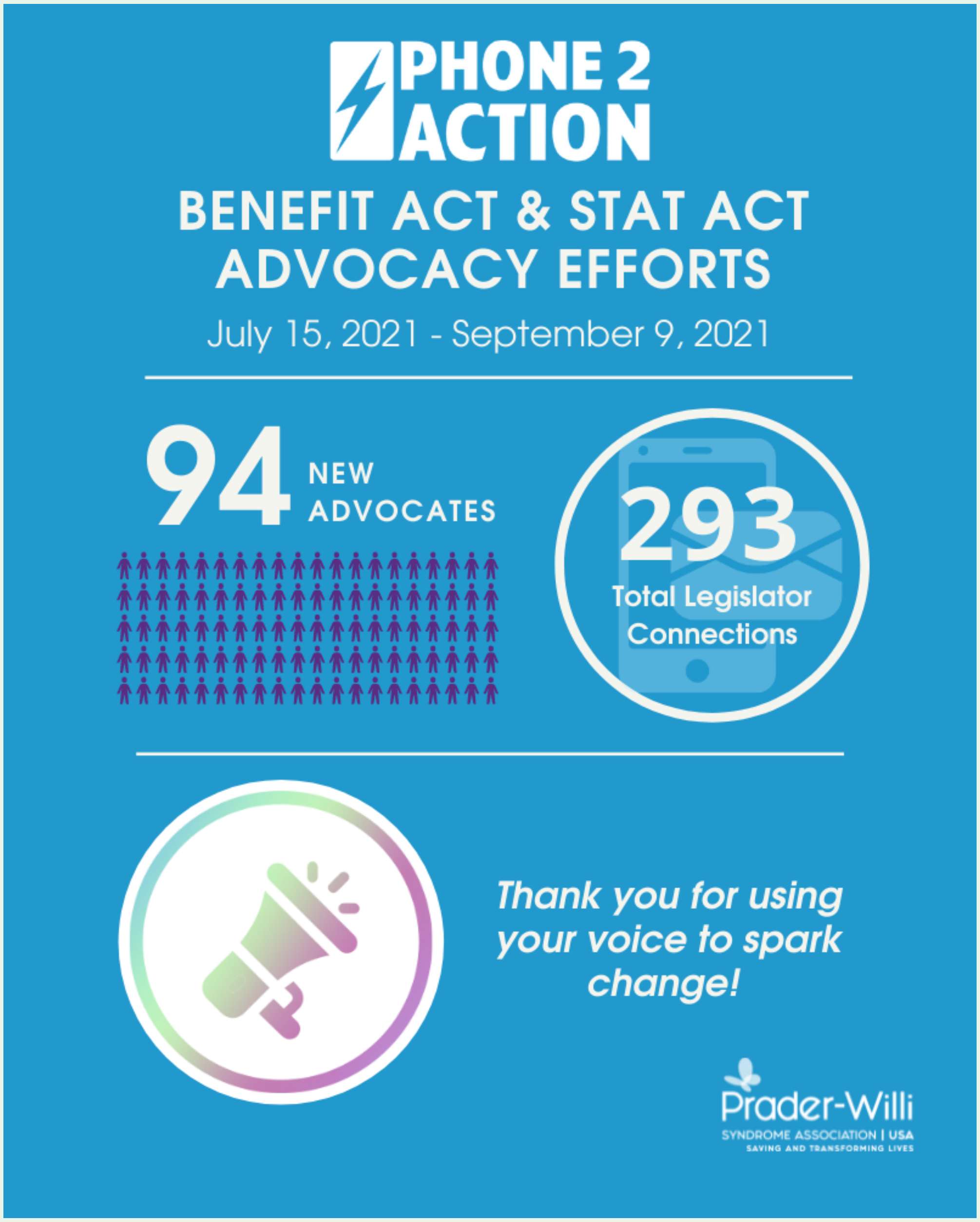
The BENEFIT Act would require that the FDA disclose whether and how patient experience and/or preference data was used in the benefit risk assessment of a new drug. It will ensure that patient voices are being heard and allow for patient stakeholders to continue to work with the FDA to refine the data that they need to make decisions.

LEARN MORE ABOUT THE STAT ACT HERE

LEARN MORE ABOUT THE BENEFIT ACT HERE

SUPPORT THE STAT ACT HERE

SUPPORT THE BENEFIT ACT HERE



FAMILY SUPPORT

Creating Your Child’s Special Education File

School is back in session and PWSA | USA Family Support Director Stacy

Ward shares how you can create a special education file for your child. This file will not only keep you organized and aid you in preparing for all interactions with the school district but will give you a clearer understanding of your child's special education needs and progress.

Read the full article here >>

A "Beary" Happy Story

Lia (pictured) has attended Victory Justice Camp in North Carolina six times and each summer has been gifted a new stuffed bear through the camp's Bear Necessities program. With dreams of becoming a first grade teacher, Lia recently shared the special way she will tie in her camp experience for years to come - by using the bears as an audience for her future students to read to!

Find Lia's inspiring story here >>

About Victory Justice Camp

Victory Justice Camp is located in Randleman, North Carolina and is considered a 'Serious Fun' camp for disabled and seriously ill kids. They provide medically-safe camp experiences filled with discovery, friendship and a lot of laughter. Always at no cost to families. Learn more here >>

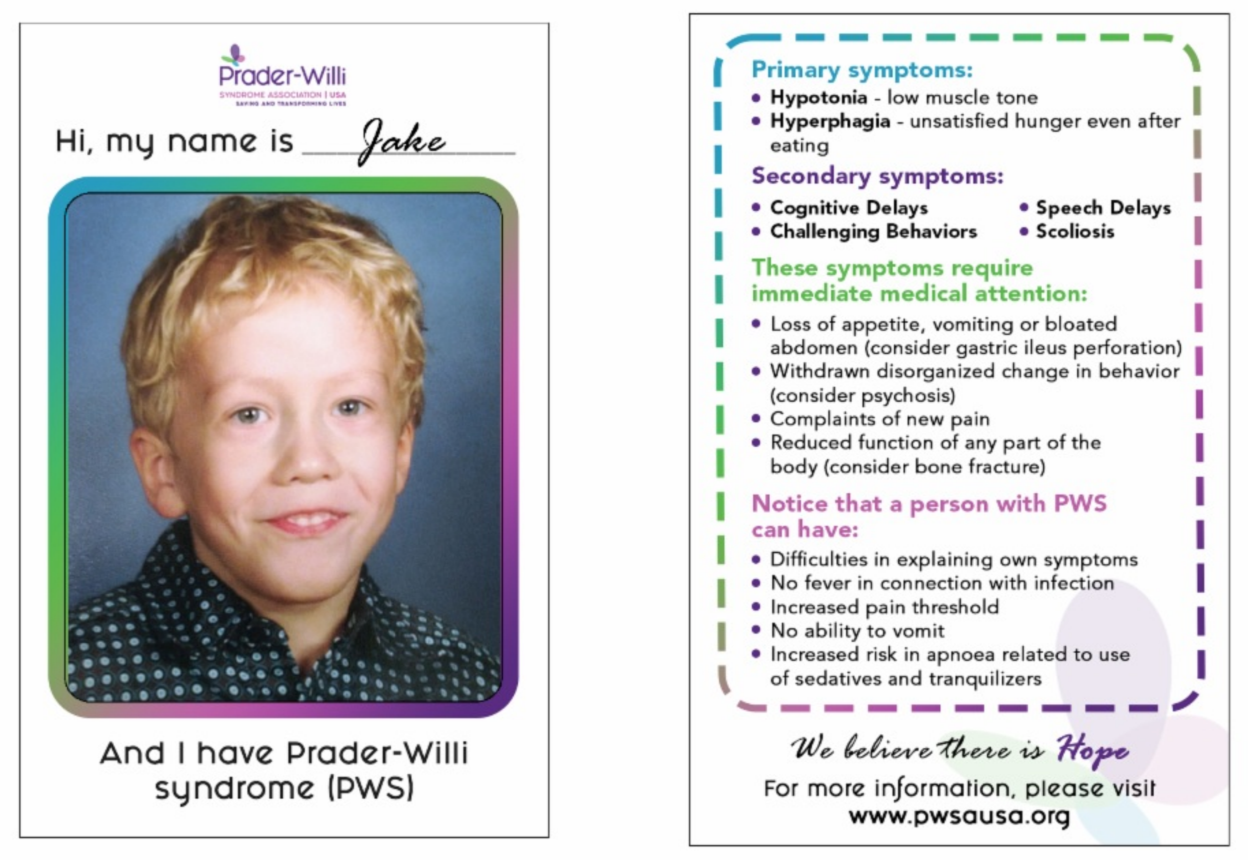
Texas Prader-Willi Association Opens First Group Home in Conroe, Texas

On behalf of June Finnerty President of the Texas Prader-Willi Association:

"I'm enormously grateful to announce the opening of our first Texas Prader-Willi Association group home in Conroe, Texas. After purchasing the home, remodeling, fundraising, renovating yet again after Storm Uri, we were able to accomplish this long-term goal. I am profoundly thankful for the amazing generosity from benefactors, vendors and volunteers who supported this project. Our mission is to provide more group homes in Texas for individuals with PWS. Your generosity made this

possible."

Customize Your Own PWS Health Identification Card!



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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HOW TO CUSTOMIZE YOUR PWS HEALTH ID CARD

PWSA | USA ANNOUNCEMENTS

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PWSA | USA's CFC ID # is 10088

LEARN MORE HERE

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VOLUNTEER APPLICATION

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"Watching how hard she needs to work to do things that my body can do so easily is gut-wrenching. As I prepare for this high endurance challenge of running 100 miles in 24 hours, my sister's life-long struggles have inspired me each step of the way."

LEARN MORE AND DONATE HERE

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Day Camp

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Recreation Unlimited
7700 Piper Road
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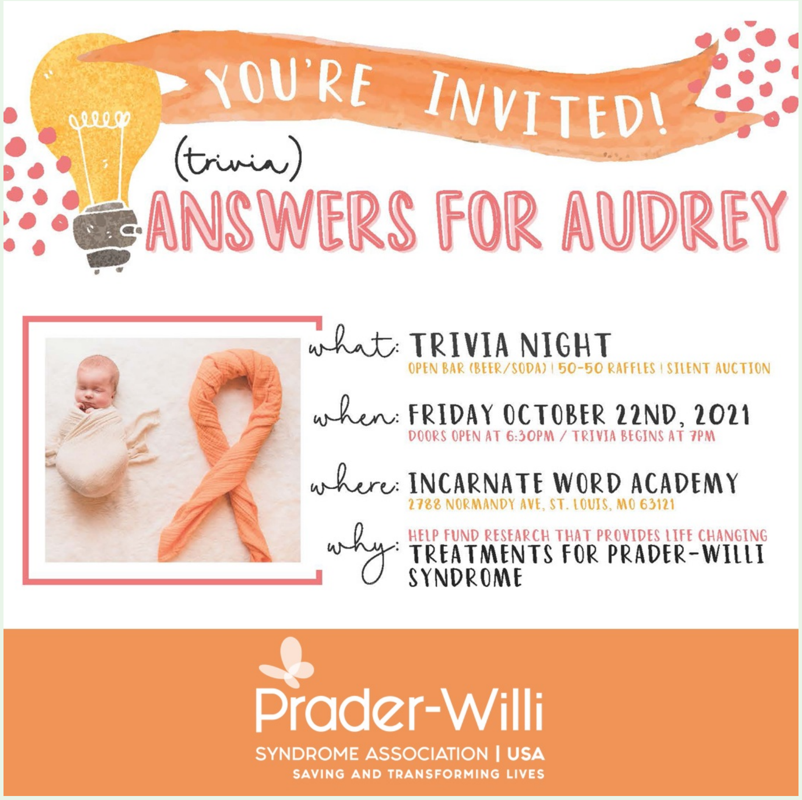

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Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

REGISTER HERE

11th ANNUAL MOLLY'S PUB 2021 CHARITY GOLF TOURNAMENT AT CYPRESSWOOD

MONDAY OCTOBER 4TH

SAVE THE DATE!

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

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!
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Give Now

View as Webpage

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PWSA | USA
THE PULSE

Vol. 34 |
September 17, 2021

www.pwsausa.org | **Donate**

PWSA | USA Family and Friends: We Need Your Help!

We are working on a special project for our PWS community and are in need of pictures of you and your loved ones. We are creating a PWSA 2022 Calendar, which will be available in the next couple of months, and will include photo collages on each page. If you have a loved one living with PWS, please fill out PWSA | USA's Media Release Form (download below) and send it, along with your picture, to *news@pwsausa.org*.

Learn More Here >>

DOWNLOAD MEDIA CONSENT FORM HERE

ADVOCACY

BY THE NUMBERS

BETTER CARE BETTER JOBS ACT

3.2 MILLION
more people with disabilities (including kids) and seniors will get the care they need, like home nursing and support, in their homes and communities instead of institutions. Right now, nearly a million people are stuck on waiting lists for care and even more qualify for help.

1.1 MILLION
unpaid family caregivers would be able to return to work, knowing their loved ones are getting the care they need at home.

500,000
new home care jobs will be created, and wages raised for caregivers - the average salary is currently just $12 an hour.

CLICK HERE to let your legislators know that Care Can't Wait!

Prader-Willi SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

ONE VOICE, ONE MESSAGE, ONE GOAL
WWW.PWSAUSA.ORG/WHAT-WE-DO/ADVOCACY

RESEARCH

World Narcolepsy Day is September 22nd. Narcolepsy is a chronic neurological condition that impairs the brain's ability to regulate the sleep-wake cycle. It affects about one in 2,000 people. Continued research suggests that children and adults with PWS experience sleep disorders including chronic insomnia and narcolepsy with cataplexy to a greater extent than the general population.

To learn more about narcolepsy, watch this Convention panel presentation moderated by Maria Picone, Co-Founder and CEO of TREND Community, with expert panelist Dr. Glaze of Texas Children's Hospital and featuring Kristi and Justice Rickenbach, a family navigating life with narcolepsy, cataplexy, and PWS.

FDA Advisory Committee to Review LEVO's Carbetocin as a Treatment for PWS

We are excited to share that LEVO's New Drug Application (NDA) for carbetocin as a treatment for PWS will be discussed at a public meeting of the Psychopharmacologic Drugs Advisory Committee, which will be held November 4, 2021.

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FAMILY SUPPORT

Introducing PWSA | USA's Tips for School Success Toolkits!

PWSA | USA's Family Support team is excited to introduce our Tips for School Success! Explore six school success toolkits that share how your child can be successful while navigating learning - whether it's at home or in the classroom. Our variety of topics include:

- **PWS Challenges and Solutions**
- **Individualized Education Program**
- **Homeschooling**
- **Behavior Challenges**
- **Effective Advocacy**
- **Special Education Law**

ENTER HERE

COMMUNITY CONVERSATIONS

Prader-Willi Syndrome Association | USA

RECAP

For Families to Discuss the Impacts of Dr. van Bosse leaving Shriner's Hospitals

Prader-Willi
SYNDROME ASSOCIATION | USA
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On Tuesday evening, PWSA | USA hosted a Community Conversation bringing together members of the PWS community to informally share concerns, ideas, and updates on Dr. van Bosse's recent departure from Shriners Hospitals. Read the full recap from Tuesday's online event and find helpful resources by clicking the button below.

COMMUNITY CONVERSATION RECAP

This Community Conversation was such a success that PWSA | USA has decided to host them monthly. Join us on the second Tuesday of every month at 7pm CST. **The next Community Conversation will be Tuesday, October 12th focused on Guardianship!**

Thank You Direct Support Professionals!

This week is nationally recognized as Direct Support Professionals Week, but we want these incredible individuals to know they are appreciated every day. Make sure to thank a direct support professional in your life!

Read the full article here >>

PWSA | USA ANNOUNCEMENTS

Attention PWS Community!

To ensure that you receive the care and support you need from us, PWSA | USA is working to update contact information for those in our PWS Community! We ask that you please fill out our new contact information form by clicking the button below.

If you have any questions, please reach out to info@pwsausa.org. Thank you!

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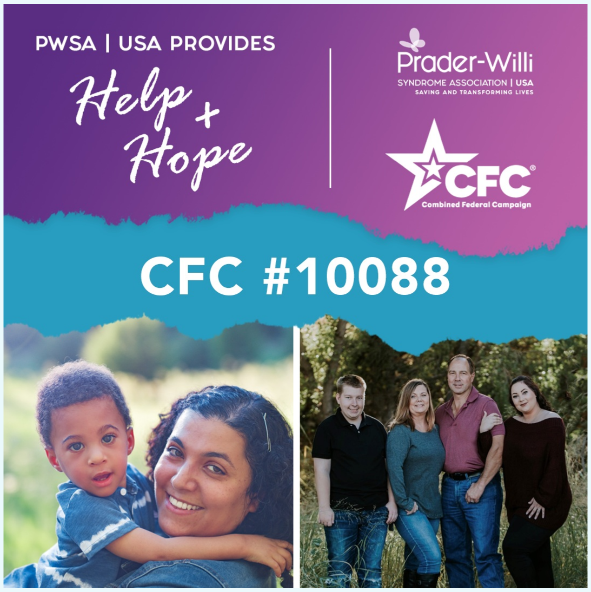

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LEARN MORE AND DONATE HERE

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

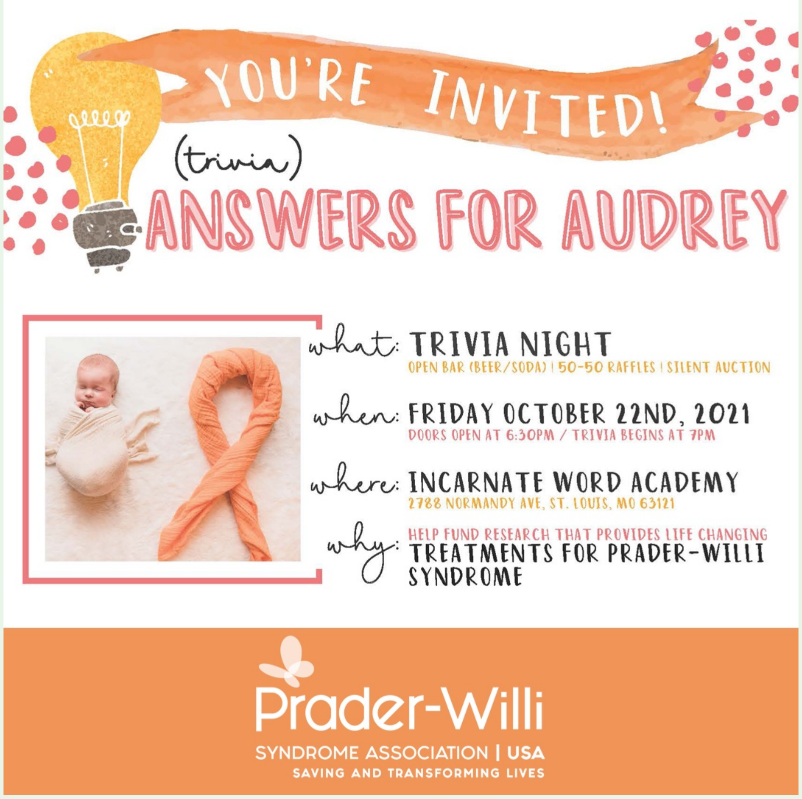
THE BACK NINE CLUB

17 HERITAGE HILL - LAKEVILLE, MA

PROCEEDS BENEFIT

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

REGISTER HERE



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

REGISTER HERE

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

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

PWSA | USA
THE PULSE
Vol. 35 |
September 24, 2021

www.pwsausa.org | Donate

WORLD NARCOLEPSY DAY SEPTEMBER 22

HARMONY BIOSCIENCES

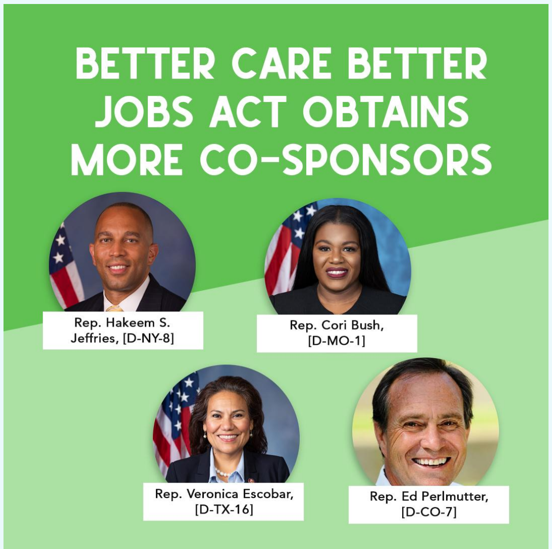
Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES

PWSA | USA ANNOUNCED AS ONE OF HARMONY BIOSCIENCES' *2021 PATIENTS AT THE HEART* RECIPIENTS

Funds from this grant will be used to foster creation of free and accessible tools and resources informed by focus groups and PWS sleep best practices, as well as a PWSA | USA Virtual Sleep Summit.

LEARN MORE HERE >>

ADVOCACY



BETTER CARE BETTER JOBS ACT OBTAINS MORE CO-SPONSORS

Rep. Hakeem S. Jeffries, [D-NY-8]

Rep. Cori Bush, [D-MO-1]

Rep. Veronica Escobar, [D-TX-16]

Rep. Ed Perlmutter, [D-CO-7]

WATCH: Click the image above to hear from PWSA | USA's Community Engagement Coordinator Dorothea

The Better Care Better Jobs Act, HR 4131, just obtained more bipartisan support in the US House of

Lantz as she shares details about what is happening with the Orphan Drug Tax Credit and how you can help save it.

Learn more >>

SAVE THE ORPHAN DRUG TAX CREDIT >>

Representatives! We first alerted our community to show their support for this piece of legislation less than a week ago. Since then four new representatives have joined forces with 132 other members of Congress to show their continued support for the rare disease community.

Learn more >>

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 are now being accepted through November 8, 2021.

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

DOWNLOAD CALL FOR LETTERS OF INTENT HERE

DOWNLOAD GRANT SUBMISSION GUIDELINES HERE

FAMILY SUPPORT

School Success: PWS Challenges and Solutions

Last week, we unveiled six different School Success Toolkits that share how your child can be successful while navigating learning - whether it's at home or in the classroom.

Get to know the School Success Toolkit - PWS Challenges and Solutions. This toolkit includes videos and resources that outline the unique educational and environmental needs of students with PWS. You will find helpful information about food in the classroom, a medical overview for school nurses, information for transportation personnel, and an IEP worksheet.

ENTER HERE >>

INTERESTED IN LEARNING MORE?

VISIT THE SCHOOL SUCCESS BLOG HERE

PWSA | USA ANNOUNCEMENTS

Attention PWS Community!

To ensure that you receive the care and support you need from us, PWSA | USA is working to update contact information for those in our PWS Community! We ask that you please fill out our new contact information form by clicking the button below.

If you have any questions, please reach out to info@pwsausa.org. Thank you!

Download PWSA | USA's Contact Information Form Here

PWSA | USA Family and Friends: We Need Your Help!

We are working on a special project for our PWS community and are in need of pictures of you and your loved ones. We are creating a PWSA 2022 Calendar, which will be available in the next couple of months, and will include photo collages on each page. If you have a loved one living with PWS, please fill out PWSA | USA's Media Release Form and send it, along with your picture, to *news@pwsausa.org*.

Learn More Here >>

DOWNLOAD MEDIA CONSENT FORM HERE

PWSA | USA FACE MASKS BACK IN STOCK!

PWSA | USA face masks are back in stock to keep you safe! As more mask recommendations and mandates take effect around the country, we decided to offer PWSA masks once again. Purchasing PWSA | USA store items directly benefits our organization, and allows us to provide help and hope to families and PWS individuals in need. **CLICK HERE** to be directed to our online shop and buy your own PWSA | USA face mask today!

We are grateful to have recently been selected as one of **Ragdollz NFTs'** community-backed charities to receive a generous donation! As part of the *Ragdollz Gives Back* program, the company is donating $10,000 to community backed charities for every 1,000 Ragdollz sold. A very special thank you to Debra and Rob Lutz for nominating PWSA | USA as a partnering nonprofit organization.

EVENTS

Click here for PWSA | USA's Calendar of Events

Support Mattyofit's Miami Endurance Run for PWS!

Matheus Oliveira will be running in this year's Miami Ultra 100 Marathon **TOMORROW** and we want to wish him the best of luck! Matty is not running just for himself, he's also running for his sister Ana Beatriz (16) who has struggled with Prader-Willi syndrome all of her life. ***Show your support for Matheus and Ana by clicking the button below.***

"Watching how hard she needs to work to do things that my body can do so easily is gut-wrenching. As I prepare for this high endurance challenge of running 100 miles in 24 hours, my sister's life-long struggles have inspired me each step of the way."

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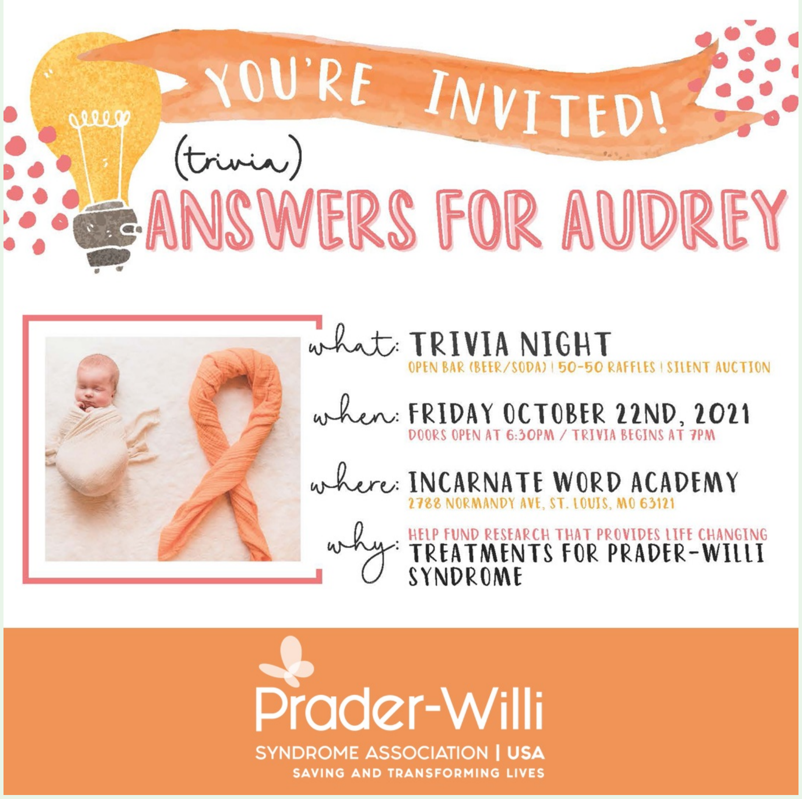

YOU'RE INVITED!

(trivia)

ANSWERS FOR AUDREY

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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!

BENEFITING
TEXAS PRADER-WILLI ASSOCIATION
www.txpwa.org

REGISTER HERE

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

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Prader-Willi
SYNDROME ASSOCIATION | USA
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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