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PWSA of WI, Inc. is a chapter of PWSA (USA)

Website: www.pwsausa.org

The mission of the Prader Willi Syndrome Association of Wisconsin, Inc. is to Support, Educate and Advocate for persons with Prader-Willi Syndrome, their families and professionals in meeting the challenges of this disability.

Looking Ahead – 2024

Happy New Year!

We are very excited for 2024! While change seemed to be the theme for 2023, it appears as though growth is going to be the theme for 2024.

At the beginning of January, we said good-bye to long-term board member, **Amber Gaulke**, as she stepped down after serving eight years as the board's secretary. We also said good-bye to **Sherita Greer**, who stepped down after serving five years on the board. Although we are going to miss Amber and Sherita, we wish them luck in the future and know we will see them at upcoming events.

As mentioned in our Fall newsletter, as of January 1st, we also welcomed **Tessie Hurd, Kristen Rathkamp and Jessica Sheldon**. With the addition of these three, our board is now comprised of 15 dedicated individuals who are looking forward to an exciting and productive year ahead. Plans include hosting our annual **Walk in the Park** and **Formal Ball**. In addition, we are bringing back past favorites, such as the **Family Fun Day at Henry Vilas Zoo** and the **Golf Outing**. We will also be continuing our advocacy and training efforts with plans to do additional law enforcement trainings, amongst others, throughout Wisconsin. If there is something you would like to see the Association focus on in 2024, please do not hesitate to reach out to me.

As I've said previously, we are all very excited about the upcoming year and the continued growth of not only our board, but also the services and opportunities we are planning to provide to the PWS community.

Happy New Year! I look forward to seeing you all soon!

Crystal L. Boser

Crystal L. Boser
President

Hypothermia in Person's with PWS

Because of a problem in the area of the brain called the hypothalamus, people with PWS do not always regulate their body temperature safely.

- Their normal body temperature is often times lower than normal (98.6).
- Their body may not warm itself properly and it may be worse when the outside temperature is low, and it is very cold.
- Even when it is not extremely cold outside – people with PWS often feel cold (and have a low body temperature). Many don't always use good judgment in picking appropriate dress for the weather.

HYPOTHERMIA - A POTENTIAL HEALTH EMERGENCY	
What is it?	A very low body temperature that occurs when the body is unable to keep itself warm. If left untreated, it can lead to unconsciousness and death.
Signs	<ul style="list-style-type: none">• Shivering• Numbness• Glassy stare• Apathy, lack of interest in what is going on around them• Weakness• Confusion- impaired judgment• Drowsiness/Loss of consciousness / Fainting

WHAT CAN YOU DO TO HELP THE PERSON WITH PWS?

Frequently, persons with PWS complain of feeling cold and may require more layers of warm clothing.

- Allow persons to wear warmer clothes unless it is very warm outside.
- Know the person's baseline temperature. (Check it 2 times per month or more often if you wish).
- Keep the thermostat in your home at a reasonably warmer temperature.
- Make sure they do not sleep in a cold bedroom. Apply extra blankets and/or flannel sheets.
- Encourage to wear warm pajamas.
- Make sure that when a person with PWS leaves the home for any outings during colder weather, they are dressed appropriately to face those conditions. The individual should wear a hat, gloves, and a coat as well as being dressed in winter clothing.
- Stress the importance of bringing items in case a vehicle breaks down or other unforeseen situation occurs.
- If an individual refuses to wear appropriate clothing - **avoid a power struggle**. Bring items along and try again later.
- In the event of snow accumulation, icy conditions or extreme cold parents or caregivers should err on the side of caution. Activities that are not of an immediate nature (such as outings, activities, unimportant appointments etc.) should be cancelled and rescheduled for another time when weather conditions are better.
- If hypothermia is the result of being out in the cold too long, move to a warm place. Wrap resident in a warm blanket.
- If person has wet clothing, remove it.
- Drink warm liquids that do not contain caffeine or alcohol.
- Warm up slowly.
- If confusion or loss of consciousness occurs, **call 911**.

Homestead Credit Act – Questions and Answers

Compiled by Barb Dorn, RN, BSN

Note from Editor: This article is intended to inform families, guardians and persons with PWS about a program that may provide them with a tax refund related to their rental payments. PWSA of WI, Inc. is NOT providing tax advice but is providing information and resources to investigate this program.

What is the Homestead Credit Act?

The Homestead Credit is a refund for low-income tenants or homeowners if their income is under \$24,680 (2023 income) as a household. The person must have lived in a Wisconsin property for part or all of the tax year. It is designed to soften the impact of taxes and rent on persons who have a low income. Many persons with PWS qualify for this program..

What Needs to be Done to File for It?

According to the State of Wisconsin IRS, if you file a Wisconsin income tax return, you should attach Schedule H or H-EZ to the return. If you are not required to file an income tax return, you may file the Homestead Credit by itself.

Steps you will need to take:

1. Obtain and complete the Schedule H or H-EZ form. (See link below)
2. Include all household income.
3. Sign and date the form.
4. Obtain your property tax bill or rent certificate. (Request a rent certificate from your landlord. If you pay a residential care provider or Family Care agency, they will deduct funds allocated for food and other necessities. Your rent certificate may not be the sum total of your monthly room and board payments.)
5. If you are disabled and under age 62, you will need to attach a statement verifying you were disabled in 2023. (See the link below for more information.)

How Much Will I Receive?

The maximum amount of Homestead Credit allowed in Wisconsin for 2023 is **\$1,168**. However, **the actual amount of credit you receive depends on your income, rent or property taxes, and other factors.**

Where Do I Learn More About It?

For more information, including the Schedule H & H-EZ form, click on the link enclosed:

2023 I-016a Schedule H & H-EZ Instructions - Wisconsin Homestead Credit

Wisconsin Wayfinder

On November 2nd, 2023, the Wisconsin Department of Health Services has launched Wisconsin Wayfinder, a free service that aims to connect families of children with specific health care needs or conditions with resources. Wisconsin Wayfinder: Children's Resource Network includes a user-friendly website and toll-free helpline that lets families easily connect with real people – dedicated children's resource guides – who will help navigate through the essential services and supports that will enable their children to thrive.

A statewide, user-friendly website, dhs.wi.gov/wiscway, and toll-free number, 877-WiscWay (877-947-2929), provide families with convenient, direct access to compassionate and knowledgeable children's resource guides. All contacts will be confidential and interpretation services are available.

The project builds on partnerships with providers and care systems throughout the state, fostering a seamless approach for families seeking help.

Wisconsin Wayfinder is funded by American Rescue Plan Act dollars; about \$4 million was devoted to the creation and launch of the service. These ARPA funds are projected to support Wisconsin Wayfinder through 2024. DHS will explore other funding sources to continue the service after that time. Find more information at dhs.wi.gov/wiscway or call toll-free 877-WiscWay (877-947-2929).

Questions and Answers on Extended School Year for the Student with PWS in the State of Wisconsin

Compiled by Barb Dorn, RN, BSN

Note from Editor: This article may look familiar. It should, it was featured in the Winter Issue of the "Wisconsin Connection" 2023. It is worth sharing it again. There are no new findings for 2024 so feel free to use this information to guide you with this process in 2024.

Many students with PWS benefit from services under terms of Extended School Year (ESY). As the mid to end of the academic year approaches, many parents and advocates are involved in IEP's where this topic should be discussed. The information shared below is taken from the State of Wisconsin Department of Public Instruction Informational Bulletin Number 10.02 which specifically addresses ESY. (Information Update Bulletin 10.02 | Wisconsin Department of Public Instruction) The following are some questions and answers on ESY, along with some advocacy tips on this important topic.

What are ESY Services?

ESY services are "special education and related services provided pursuant to an IEP beyond the limits of the school term." According to the Individuals with Disabilities Education Act (IDEA), all students with a disability must be provided a free appropriate public education (FAPE). The student is entitled to special education services and related services (ex. speech, occupational, physical therapies, transportation) as outlined in their IEP. Federal guidelines provide each state discretion in determining ESY services, as long as it includes FAPE.

Is ESY the Same as Summer School?

NO. Summer school is typically an optional program provided beyond the regular school year. Schools can opt in or out of operating summer school. In many cases, summer school programs teach new content or enrichment and/or offering recreational or academic opportunities not present during the regular school year. Special education students can attend summer school and they can utilize programs to maintain learned skills or prevent loss of critical skills. For ESY, the IEP team determines the need and extent of services needed to meet the unique needs of the child. If services are not provided, a child's skills can be temporarily or permanently lost, jeopardizing progress. The decision to receive ESY is dependent on the needs identified in an individual's IEP; not on what services are available.

What Criteria Determines if a Student Qualifies for ESY?

According to the Wisconsin DPI Bulletin 10-02, "In most cases, courts consider regression during an interruption in services and recoupment of skills after services resume in determining eligibility for ESY services. The Seventh Circuit Court of Appeals, which includes Wisconsin, has held that states should engage in a multi-factored determination of eligibility for ESY services, including "the likelihood of regression, slow recoupment, and predictive data based upon the opinion of professionals." *Todd v. Duneland Sch. Corp.*, 229 F.3d 899, 907 (7th Cir. 2002). Several other Courts of Appeals have articulated a similar standard for determining whether a child requires ESY services. Specifically, in *Alamo Heights Independent School District v. Texas Board of Education*, the Fifth Circuit Court of Appeals explained:

[I]f a child will experience severe or substantial regression during the summer months in the absence of summer programming, the handicapped child may be entitled to year-round services. The issue is whether the benefits accrued to the child during the regular school year will be significantly jeopardized if he is not provided an educational program during the summer months. 790 F.2d 1153, 1158 (5th Cir. 1986).[1]"

"Consistent with the Seventh Circuit, the Tenth Circuit explained in *Johnson v. Independent School District Number 4*, 921 F.2d 1022 (10th Cir. 1990), that multiple factors are relevant in considering a child's need for ESY services. The court listed possible factors to consider, including but not limited to:

... the degree of impairment, the degree of regression suffered by the child, the recovery time from this regression, the ability of the child's parents to provide the educational structure at home, the child's rate of progress, the child's behavioral and physical problems, the availability of alternative resources, the ability of the child to interact with nonhandicapped children, the areas of the child's curriculum which needs continuous attention, the child's vocational needs, and whether the requested service is extraordinary for the child's condition, as opposed to an integral part of a program for those with the child's condition. This list is not intended to be exhaustive, nor is it intended that each element would impact planning for each child's IEP."

Accordingly, the Wisconsin Department of Public Instruction, it is recommended that school districts consider all appropriate factors in determining whether the benefits accrued to a child during the regular school year will be significantly jeopardized if the child is not provided ESY services.

Questions and Answers on Extended School Year for the Student with PWS in the State of Wisconsin (Cont.)

Compiled by Barb Dorn, RN, BSN

What Does Regression and Recoupment Mean?

Regression is the return to a lower level of learning or loss of what was learned.

Recoupment is to regain what is lost. It can be normal to lose some skills when they are not used.

Do all students with PWS Qualify for ESY?

NO. Students with PWS have varying abilities, needs and challenges. Some students do not require special education or related services year-round in order to prevent regression or problems with recoupment. Students with significant learning challenges; those with extreme behavior issues, and those with speech or fine/gross motor delays often do qualify.

Can a Student Just Receive Related Services for ESY?

YES. A student may have a need for some or all related services to prevent regression or recoupment of certain skills but not require special education services.

How Long Are ESY Services Guaranteed?

ESY services are only guaranteed for 1 year and are not automatically renewed. The IEP team must evaluate the student's needs and determine services every year.

What Are Some Examples Where Students with PWS Have Qualified for ESY?

Many students with PWS have qualified for ESY to prevent regression of academic skills that they have acquired during the school year. This can be supported by documentation of regression or the need for "relearning" after breaks or vacations in the school year. When a student with significant learning challenges has a 3 month break in their learning environment, it can reasonably be assumed that there will be a loss of skills learned. For many, the time to recoup these skills can be lengthy.

Students with PWS who have significant behavioral challenges, may demonstrate a regression in managing their behavior management skills during extended breaks from school and qualify for ESY.

Frequently, continued progress in speech, fine and/or gross motor skills can be maintained through ESY.

Young adults who are employed and supported in jobs through their vocational program with goals outlined in their IEP, could risk losing their job and employment skills if not enrolled in ESY.

A Few Advocacy Tips for ESY?

The following are some tips in advocating for the student with PWS for ESY:

- Watch for regression and recoupment during breaks in school – weekends, vacations. Document and share your findings.
- Ask therapists what the likelihood of regression will take place if no therapies are provided for 3 months. (If the student has significant challenges in these areas, no intervention for 3 months would most likely cause significant regression)
- For those with more behavioral issues, emphasis on the importance of ongoing, uninterrupted strategies are needed to have the student successfully gain these skills.
- Make sure ESY is on your list of topics to be discussed at the IEP meeting. If needed, there may be time for documentation and justification to be obtained.

Many students with PWS benefit from uninterrupted time from their education services that helps them with their academic, behavioral, physical and/or social progress and prevents regression. ESY may be part of the solution.



HAPPY BIRTHDAY TO YOU!

DECEMBER

Ben V. Cody J.
Kelsey O. Katherine B.
Ethan H.

JANUARY

Olivia L. Paige S.
Alexis O. Karen S.
Katie S. Travis L.
Carley V. Greysen G.
Aiden D. Laura G.
Greg B. Siena S.
Kevin S. Jessica K.

FEBRUARY

Joel A. Tom A.
Sophie H. Kyle P.
David B. Beth L.
Nick R. Tiffany N.
Andy C. David G.
Jennifer K. Phongseeyu L.
Kevin T.

Spotlight on Success



Jackson D.

In 2018, Jackson got the opportunity to start swimming for the Monona Swim and Dive team that participates in the All City Swim and Dive League. He swims with the team at the summer practices during the week and competes in meets on the weekends against other unified swimmers. He also has had the chance to swim at the All City meets competing against swimmers from teams all over the Madison area.



This fall Jackson joined the boys swim team at Monona Grove High School. He practices every day with the team with the help of his coaches. This has been an amazing opportunity for him to participate and compete in a school sport and a way for him to be included in the high school environment. Jackson loves to swim and it is a great way for him to workout which can be a struggle. With getting this exercise he sleeps better and it is something he constantly looks forward to, while helping with his mood. He works so hard every day to become a faster swimmer since his biggest motivation is winning! He has so much fun and is so happy to be a part of the team and we are very grateful to have had this opportunity for him.

Do you want to share a success story of an individual with PWS to be featured in future Wisconsin Connection newsletters? Please email your story and photo to Barb Dorn at bdorn84@gmail.com.

SUBMIT YOUR SUCCESSES!

PWSA of WI Shares Free Tickets to Country Christmas Light Display

The PWSA-WI, Inc. Board of Directors is very thankful for our entire PWS community. In order to show our appreciation, the Association gave away 76 free tickets to the Country Christmas light display at The Ingleside Hotel located in Pewaukee, Wisconsin. We are very excited that several families, residential group home providers, residents, and professional providers were able to enjoy this special event.



"Thank you to PWSA of WI for sharing these tickets with us. We have lived in the Oconomowoc area for over 3 years and we have driven by these lights almost every year. This year, thanks to your generosity, we took our grandson on this Christmas adventure. It was awesome! My favorite part was the rotating light tunnel. You helped to make our Christmas a little extra special this year."
(Barb and Don Dorn)



If you're interested in having birthday and seasonal cards sent to your loved one with PWS or have a change of address, please contact Bobbi Pogrnt at Pogrnt1@msn.com with the name, address, and birth date of the individual with PWS.

Exercise Ideas for the Winter

It can be extra challenging to find NEW exercise and movement options in the winter time. It can be fun to change things up once in a while. Here are some options to consider.

Chair Yoga

Chair yoga is becoming a very popular way for people of most ages to keep moving in a safe, low impact way. Chair yoga has been noted to promote flexibility, improve strength, improve mental clarity, help with pain management and improve proprioception (your ability to judge where your body is). Many of these exercise really help strengthen the core muscles and area that many children and adults need to improve. This type of yoga is becoming more popular especially for the elderly and the disabled. Here are some options to get you started – all that can be done in the comfort of your warm home.



On Your Computer:

- Sit and Stretch: Free Chair Yoga Exercises for Senior Wellness (exercisedaily.com)
- Yoga for Seniors Using a Chair for Support (yogajournal.com)

On YouTube:

- Gentle Chair Yoga for Seniors and Beginners - Gentle Chair Yoga for Seniors and Beginners: 18 Minutes (youtube.com)
- Wheelchair Yoga - Wheelchair Yoga - Gentle Chair Yoga Routine (youtube.com)
- Chair Yoga for People with Special Needs: <https://www.youtube.com/watch?v=vMi8lvts4Aw>

Handouts / Articles:

- 5 Free Printable Chair Yoga Exercises for Seniors to Improve Their Health and Well-being | Nao Medical
- Yoga for Kids with Special Needs - Yoga for Children with Special Needs (6 Awesome Poses!) - Special Learning House

Music

Music can also be a way to keep the person with PWS moving on those cold winter days. Dancing is a very popular activity – some like it slow; others like it fast. They key is to make it fun using videos, streaming music or music found anywhere.

For little ones, there are songs that encourage movement. Do a search for CD's for kids that promote movement.

The following are a list of some popular songs:

- The Hokey Pokey
- The Chicken Dance
- 5 Little Monkeys
- The Wheels on the Bus
- Head, Shoulders, Knees and Toes

Besides these, you can always take to the outdoors – snowshoeing, sledding and/or walking in the snow (maybe even make a few snow angels). No matter what, do what you can to keep the person with PWS moving.

Exercise, Movement, and Mental Health

In the PWS community, we emphasize the importance of exercise and movement as management strategies and life-saving habits for people living with PWS. With the complications of hyperphagia and a slower metabolism, exercise is critical for care. But our loved ones are not alone in this. Physical fitness is incredibly valuable and needed for parents and caregivers as well. This resource from PWSA (USA) explains the benefits of exercise on our mental health.

<https://www.pwsausa.org/exercise-movement-and-mental-health/>



SAVE THE DATES:



05/11/24

PWSA of WI - A Walk in the Park

Come help us spread awareness and raise funds for Prader-Willi Syndrome, spend some time with family and friends, enjoy lunch and dancing!

Roosevelt Park • Oconomowoc, WI



07/20/24

PWSA of WI Family Fun Day – Henry Vilas Zoo

A fun casual meetup for families. A stroll through the zoo is followed by a picnic lunch in the park.

Henry Vilas Zoo • Madison, WI



08/24/24

PWSA of WI Golf Benefit

Golfers of all abilities gather together for a round of golf followed by a luncheon, door prizes and a silent auction.

Western Lakes Golf Club • Pewaukee, WI



Tentative Date: 11/9/24

PWSA of WI Annual Ball

An evening of elegance for individuals with Prader-Willi syndrome and their families and friends. It is a fun and safe evening with dinner and dancing that many look forward to all year.

Venue to Be Determined

WATCH OUR FACEBOOK PAGE FOR MORE INFO TO COME!

Bring Zebra Hop to Your Local Brewery for Rare Disease Day 2024!

NORD is thrilled to partner with **Component Beer of Milwaukee, Wisconsin** on the release of a new CraftBeer called **Zebra Hop** that benefits NORD and the Rare Disease community! Zebra Hop aims to raise awareness and funds for research, treatments, and support services. Proceeds from the sales will directly support NORD's mission to empower rare disease patients, caregivers, and families.

Join the Movement, Raise a Glass, Make a Difference!

Bring Zebra Hop to your local brewery to raise awareness for Rare Diseases on Rare Disease Day – February 29, 2024. Visit the Zebra Hop website at <https://zebrahop.com/> for information.

Raise awareness for the
1 in 10
Americans living with
a rare disease.

Bring Zebra Hop to a brewery near you!

NORD
National Organization
for Rare Disorders

COMPONENT
BEER CO.

Mark Your Calendars!!

Please mark your calendars for the 2024 calendar of events the PWSA of WI Board of Directors have been busy planning!

A Walk In The Park

Join us at Roosevelt Park in Oconomowoc, WI on Saturday, May 11th for our annual PWS May Awareness event: A Walk in the Park. Come help us spread awareness about Prader-Willi Syndrome and raise money for the Prader-Willi Syndrome Association of Wisconsin, Inc. In addition, spend time with family and friends, enjoy a healthy lunch... and dancing!

Family Fun Day

This year, PWSA of WI will be hosting the family fun day at Henry Vilas Zoo in Madison, WI. This is a fun casual meetup for all families and friends. Enjoy stroll through the free zoo, while visiting with others and meeting new families. After the zoo, there will be a picnic lunch at the park nextdoor.

Golf Benefit

The PWSA of WI Golf Benefit is back this year on Saturday, August 24th at a new location: Western Lakes Golf Club in Pewaukee, WI. A fun day of golf at a beautiful golf course! Get together a scramble team and come help us raise money for our organization. Golfers of all abilities are welcome. After hitting the course, there will be Lunch, Prizes, and raffles! Sponsorship opportunities are available if you are interested in helping make this event a success!

The Annual Ball

Tentative date is November 9, 2024 and a venue to be determined. This fun annual social event is one you don't want to miss! An evening of elegance with a fancy meal, followed by a night of dancing!

Thank You Donors! We appreciate YOU!

For over 20 years, PWSA of WI has worked hard to support, educate and advocate for persons with Prader-Willi syndrome, their families and professionals in meeting the challenges of this disability. We strive to help parents, families and professionals gain a better understanding of the unique needs of children and adults with Prader-Willi syndrome.

PWSA of WI has received so many generous gifts over the years through donations, sponsorships, employee matching, memorial gifts, Amazon Smile, purchasing items off our wish list, and the most valuable of all, through your time and volunteerism. Some contributions come to us anonymously or without notification on who to thank (examples include Amazon Smile and Employee Matching), and we want to mention we appreciate your support! **THANK YOU!**

With your contribution, we are able to provide annual social events for people living with PWS, educational training and support, scholarships and general assistance programs, the PWS card club, and much more.

Here at PWSA of WI, we cannot thank you enough. Our supporters are the reason we are able to make any difference at all. It is because of you that we can make the lives of people living with Prader-Willi syndrome a little bit brighter.

If you have specific questions about how your gift is being used, or you want further information on how to continue your support, please don't hesitate to contact us at ProgDir@pwsaofwi.org or visit pwsaofwi.org/WaysToGive

Scholarships and General Assistance Programs

Did you know PWSA of WI offers different types of assistance in order for families of a person with Prader-Willi syndrome to help meet the unique needs of these individuals and their families?

It is easy to apply for these programs at pwsaofwi.org/Scholarships These programs are outlined below:

Membership Scholarships

We offer our services to all. We request a membership registration so that we send information only to those who wish to receive our mailings. We ask that you update your contact information with our office once a year so we can ensure our information gets to you.

Holiday/Birthday Special Assistance Program

PWSA of WI, Inc has created a program to reach out to adults with PWS who are 18 years or older who no longer have family to help them celebrate holiday or birthday events. The "Holiday-Birthday Special Assistance Program" is a program that attempts to make all adults with PWS feel special and be able to continue to have special memories and gifts - no matter what their age.

Workshop or Conference Scholarships

Please see registration form for workshop or conference you would like to attend for more information on how to apply for a scholarship. Every year, PWSA of WI, Inc. sponsors a social and/or workshop for persons with Prader-Willi syndrome as well as families and others who support them. Scholarships are always available for those in need.

Camp Scholarships

Every year, the Board of PWSA of WI, Inc. sets aside funds to assist children and adults with Prader-Willi syndrome so that they can attend summer camp. These camping experiences provide a time of fun and adventure for the camper as well as a time of respite for parents and caregivers.

General Assistance

The Board of Directors allocates funds to assist persons with Prader-Willi syndrome as well as those who support them in areas that help them manage some of the extra costs they may incur because of their disability. In addition, the Board provides funds for families to attend conferences or other workshops, for respite, home modifications or other requests. Unfortunately, because our funding is limited, we are not able to approve all requests our organization receives.

Educating and Advocating – PWSA of WI Efforts Continue

Volunteers continue their efforts in supporting, educating and advocating for persons with PWS in a variety of settings. **Barb Dorn** continues to help residential, care managers and day programming staff as they support two young adults in Madison. She participates in monthly meetings and helps everyone learn more about PWS with a focus on advocating for the individual needs of these individuals.



Board member, **Melissa Sirovina**, continues to assist a family as they navigate various challenges within their child's school environment. Melissa attended the child's most recent IEP meeting where she was able to share some strategies that could be used to support this child while at school. President, **Crystal Boser**, continues to work with residential providers and care managers to ensure they understand the unique needs of individuals with PWS. Crystal participates in a variety of meetings where she shares resources with those who serve and support members of the PWS community.

It Starts With Hello — A Book Review

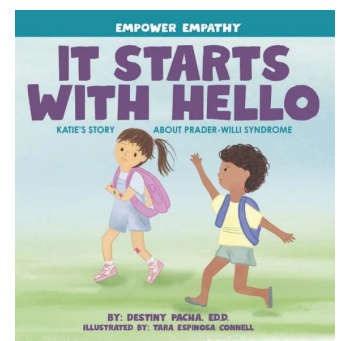
A Little Bit About the Author - Dr. Destiny Pacha, Ed.D

Dr. Pacha is a PWS Education Specialist with over 20 years of experience in the education field. She focuses on working with families and school personnel in understanding the needs of the student with PWS. Dr. Pacha provides consultative services through PWSA | USA.

"It Start with Hello - Katie's Story About PWS"

... is a wonderful, heartwarming story about Katie, a young girl who has PWS. This book highlights some of the challenges she faces and provides simple explanations of why Katie may need help in some areas. Each page ends with a question – engaging the reader with the topics being discussed. These questions help the reader understand how Katie's differences may be more similar to all of us than we realize. This book is great to use to when educating classmates or other children about PWS. – Barb Dorn (Editor, mom to Tony Age 38 with PWS)

... is a heartwarming and enlightening journey that beautifully captures the resilience and strength of individuals facing Prader-Willi Syndrome. Pacha's compassionate storytelling not only provides valuable insights into the challenges of this condition but also inspires empathy and understanding. This book is a testament to the power of connection and the importance of embracing differences, making it a must-read for anyone seeking a touching narrative that fosters compassion and awareness. - Katie Moureau (Mom to 5 Boys, Cade Age 9 with PWS)



PWS Clinical Trials

To learn more on the latest trial opportunities, please visit www.fpwr.org.

Currently Recruiting Drug Studies

VNS4PWS (ages 10 - 40)

Does your loved one struggle with disruptive behavior and temper outbursts? Vagus Nerve Stimulation (VNS) uses brief electrical impulses to stimulate areas of the brain that are important for controlling emotions and behavior. Initial studies of VNS therapy in people with PWS demonstrated that VNS was safe and effective at reducing temper outbursts (both in number and severity).

Participants in the VNS4PWS clinical trial will wear a tVNS device for 4 hours a day, for 9 months. The time required to wear the device can be split into shorter periods throughout the day, or worn continuously for the full 4 hours. The device is small and portable allowing the participant to go about their regular routine while the device is working.

The VNS4PWS trial will enroll people with PWS ages 10-40 with a history of temper outbursts over the past 6 months. To learn more or to schedule your screening appointment, go to <https://www.fpwr.org/>

THE NEMOS tVNS DEVICE

- Small and portable
- Electrode attaches to ear
- Wear for 4 hours/day



CARBETOCIN FOR HYPERPHAGIA IN PWS

In this Phase 3 study, carbetocin nasal spray or placebo will be inhaled through the nose three times each day. This study will last approximately 19 weeks and will involve up to 5 in-person visits to the study center. Upon completion of the study treatments, participants are invited to join a long-term extension study in which all participants will receive carbetocin nasal spray for up to 36 months.

NNZ-2591 FOR THE POTENTIAL TREATMENT OF PWS BEHAVIORS

This Phase 2 study will evaluate the safety and effectiveness of NNZ-2591 (an oral solution) in treating PWS behaviors. The study is currently enrolling children with PWS ages 8 - 12. Enrollment for children ages 4 - 7 will open soon. This 13-week study requires 5 in-person study visits. Several sites are available across the U.S.

ARD-101 FOR THE POTENTIAL TREATMENT OF PWS

This Phase 2, open-label study, will investigate the effects of ARD-101 in people with Prader-Willi Syndrome. This study is looking to enroll 12 individuals between the ages of 17 and 65 years. Participants will take ARD-101 orally, twice daily for 28 days. This study is taking place at Stanford, CA, and Children's Hospital, CO.

Coming Soon

PITOLISANT FOR EXCESSIVE DAYTIME SLEEPINESS IN PWS

This Phase 3 study will be available for people with PWS ages 6+ who struggle with excessive daytime sleepiness.

Study Programs for Caregivers

WELLCAST: Supporting Wellbeing of Caregivers Via Telehealth

If your loved one with PWS is between the ages of 2 and 35, you may be interested in participating in Project Wellcast: an opportunity to receive free therapy or resources that is 100% remote!

PWS SMART START: Behavioral training for caregivers of children with PWS

If your child with PWS is between the ages of 3 and 12 and engages in at least one disruptive behavior, you may be interested in participating in this study. Caregivers will participate in a 15-week caregiver training program. Training, testing and surveys will be done entirely online.