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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.

Letter from the President

Welcome to our Spring edition of the Wisconsin Connection newsletter!

This year is flying by and we've been quite busy since our last edition of the newsletter; therefore, I would like to take this opportunity to highlight the various activities we've been focused on. In addition, I'd like to share some exciting news about what we'll be working on in the coming months.

In March, our treasurer, **Jamie Milaeger** attended the **Oconomowoc Rotary Club** meeting. During this meeting, Jamie gave a Powerpoint presentation about Prader-Willi Syndrome and the mission of our Association. Club members were able to ask questions and learn how they could get more involved in the Association. We are looking forward to applying for a grant through the Oconomowoc Rotary Club and looking for more ways we may be able to partner with them. Speaking of partnership, PWSA-WI, Inc and **Vino Etcetera** partnered to raise funds, increase awareness and have fun during Bingo Night at Vino Etcetera. Throughout the evening, several board members and our volunteer Events Coordinator shared several Prader-Willi Syndrome facts and answered questions from those in attendance. We are definitely looking forward to working with the owner, **Brian Borkowski**, and his staff in the future.

As you may know, May is Prader-Willi Syndrome Awareness month and the Association celebrated by hosting its annual **Walk in the Park** at Roosevelt Park in Oconomowoc. Attendees learned information about Prader-Willi Syndrome as they walked along the 2 mile trail then enjoyed lunch and dancing with both old and new friends. We've included some pictures from the event and will be sharing more on our PWSA-WI, Inc. Facebook page in the near future.

In addition to fundraising and awareness events, one of our volunteers has also done a significant amount of advocacy and training throughout the past few months. There have been a few new residential providers who have opened their doors to residents with Prader-Willi Syndrome and although this is wonderful news, these providers do require training on this unique syndrome. These trainings have included both in person and virtual presentations focused on diet/nutrition, exercise/activity, behavior management and person-centered care. I'd like to extend a huge thank you to **Barb Dorn** for all she has done to help set our individuals with Prader-Willi Syndrome up for success in their new homes.

In the coming months, PWSA-WI, Inc. plans to continue its awareness and advocacy efforts. On August 2nd and 3rd, PWSA-WI, Inc. will be welcoming former law enforcement agent, **Tammie Penta**. Tammie will be conducting multiple trainings for law enforcement agencies where individuals with Prader-Willi Syndrome live. In addition, she will be providing a similar training geared toward parents, guardians and providers. Although we do not have all of the details worked out at this time, we anticipate sharing additional information in the coming weeks. To stay up to date on all of our upcoming activities and events, please visit our website at www.pwsaofwi.org or follow us on our PWSA-WI, Inc. Facebook page.

If you have any questions regarding anything related to PWSA-WI, Inc., please feel free to reach out to me via email at crystal.boser@aol.com, phone or text at 414-403-1935 or Facebook Messenger.

Sincerely,

Crystal L. Boser

Crystal L. Boser
President

Bingo Event

Oh what a night - for playing BINGO.

On Monday April 3rd, 2023, the establishment of **Vino Etcetera** and **PWSA of WI, Inc.** partnered to raise funds, increase awareness, and have a great time. The place was packed as community members joined right in with enthusiasm and enjoyed a great time.

Thanks to the owner, **Brian Borkowski** and bar manager, **Amy Raabe** for their hospitality in making this event a success. In addition, several volunteers from PWSA of WI, including board members **Sarah Glass**, **Eva Glass**, **Josaphine Glass** and **Jamie Milaeger** helped with all aspects of setting up; selling cards and sharing lots of information about PWS. **Andrea Kane**, the new Events Coordinator and **Corrie Mosely** all pitched in to help PWSA of WI raise \$800.

We look forward to partnering again with **Vino Etcetera**.





A Walk In The Park

On Saturday, May 13th, close to 200 members of the Prader-Willi Syndrome community joined PWSA-WI, Inc. at Roosevelt Park in Oconomowoc for our annual Walk in the Park.

Of these participants, 62 champions with PWS walked, ran, and wheeled down the paved path filled with signs that highlighted basic PWS facts and words of encouragement from our amazing footprint sponsors. Once completing the two mile walk, attendees enjoyed lunch consisting of wraps, chips, bananas, and flavored water. Participants then danced the early afternoon away to tunes provided by disc jockey, Rebecca Cox from Let's Duet. At the conclusion of the event, everyone left with a PWSA-WI, Inc. tote

bag. A huge thank you to all of the volunteers who work hard to make this event special!

We'd also like to thank our corporate sponsors who helped us walk our way toward our fundraising goal. A huge thank you to Boucher Automotive, Satko Oral Surgery Implant Center, Municipal Well & Pump, TW Metals, Element Style, Jim O'Connor Select Auto, The Lounge, The Etcetera Bar & Grill, Lucky Mutts Bakery, Athena Legal Solutions, Prader Willi Homes, Love Your Skin Spa Room, Kwik Trip, Costco, Sentry Foods of Delafield, Stretch Zone, and Dorn Chiropractic!

Thanks to the efforts of everyone, we raised over \$20,000!!



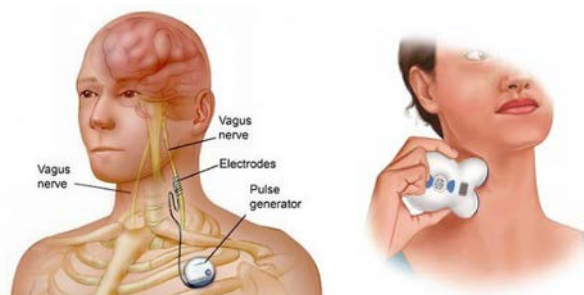
Vagus Nerve Stimulation: Preliminary Research Shows Help to Manage Maladaptive Behavior

Compiled by Barb Dorn, RN, BSN

PWS is a spectrum disorder. Some individuals face extreme challenges in food seeking, emotional and behavior control. For those who do, it often impacts their quality of life and interferes with their ability to be successful and happy. Parents and caregivers often try many behavior management strategies and/or medications with minimal improvements. A new treatment approach is now under investigation. It is called Vagus Nerve Stimulation (VNS).

What is VNS?

VNS is a treatment which sends very low-grade electrical impulses to a key nerve, the vagus nerve, that runs through the neck. A device can be surgically implanted under the skin on the chest and be connected to the vagus nerve. A non-invasive vagus nerve stimulation device does not require surgical implantation and it delivers these impulses outside, on top of the skin. It is known as transcutaneous VNS (t-VNS). These treatments have been primarily used to treat epilepsy (seizures), depression and in some cases – pain.



What Has the Research Shown So Far?

In 2015, a group of researchers in the United Kingdom began to research VNS, initially investigating the effects of overeating in PWS. In this study, three individuals with PWS had VNS devices implanted. The results showed that changes in their eating behavior was uncertain and questionable. However, there was surprising improvements and changes in two of three of these individuals in the area of maladaptive behavior, temperament, and social behavior. This study helped encourage further investigation for improvement in these behaviors.

(REFERENCE: Manning KE, McAllister CJ, Ring HA, Finer N, Kelly CL, Sylvester KP, Fletcher PC, Morrell NW, Garnett MR, Manford MR, Holland AJ. Novel insights into maladaptive behaviours in Prader-Willi syndrome: serendipitous findings from an open trial of vagus nerve stimulation. *J Intellect Disabil Res.* 2016 Feb;60(2):149-55. doi: 10.1111/jir.12203. Epub 2015 May 27. PMID: 26018613; PMCID: PMC4950305.)

In 2019, these same researchers focused more intensely on the effects of transcutaneous VNS on behavior. After a baseline phase, participants received four-hours of t-VNS daily for 12 months, followed by one month of daily t-VNS for two-hours. The primary outcome measured the mean number of behavioral outbursts per day. Secondary outcomes included findings from behavioral questionnaires and both qualitative and goal attainment interviews. Four of the five participants who completed the study exhibited a statistically significant reduction in number and severity of temper outbursts after approximately nine months of daily four-hour t-VNS. Subsequent two-hour daily t-VNS was associated with increased outbursts for all participants, two reaching significant issues. There were no serious safety issues reported. It appears that t-VNS is an effective, safe intervention for chronic temper outbursts in PWS. These findings challenge the present biopsychosocial understanding of such behaviors suggesting that there is a single major mechanism that is modifiable using t-VNS. (REFERENCE: Manning KE, Beresford-Webb JA, Aman LCS, Ring HA, Watson PC, Porges SW, Oliver C, Jennings SR, Holland AJ. Transcutaneous vagus nerve stimulation (t-VNS): A novel effective treatment for temper outbursts in adults with Prader-Willi Syndrome indicated by results from a non-blind study. *PLoS One.* 2019 Dec 3;14(12):e0223750. doi: 10.1371/journal.pone.0223750. PMID: 31794560; PMCID: PMC6890246.)

How Can I Learn More About Having the Person with PWS Participate in this Research Trial?

More research is now being planned to evaluate this treatment further. To stay updated on when and where this trial may be available, go to the Foundation for Prader-Willi Syndrome Research at PWS Clinical Trials (fpwr.org).

 **The Foundation for Prader-Willi Research**

Vagus Nerve Stimulation (VNS) has shown promise in improving behavior and quality of life PWS. Preparations are nearly complete for our upcoming VNS 4 PWS clinical trial. This \$1.6 million study will enroll 50-100 people with PWS. This study will be FPWR's first 100% led and funded clinical trial for people with PWS and are excited to begin trial enrollment mid-year 2023. Learn more about our impact in our 2022 Impact Report. <https://fpwr.us/3kFrezf>

Devices Offer New Opportunities

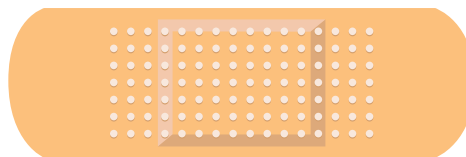


In 2022, FPWR developed  a new clinical trial, **VNS 4 PWS**, that will launch mid-2023 with the aim of bringing a new treatment for behavior to our loved ones with PWS.

Picky, Picky, Picky - Skin Concerns And the Person with PWS

by Barb Dorn, RN, BSN

- Many people with PWS pick at their skin and many openings of their body (nose, rectum, nails...).
- Preventing, treating, and managing this problem can be very challenging. Pain is often not a factor.
- Wounds can become chronic and severe. They can also be confused as a sign of abuse. (Some sores may resemble cigarette burns).
- Insect bites or contact with poisonous plants (poison ivy, poison oak) can often create or make a problem worse.
- Know the signs of a wound infection. (The person may not complain of pain).
 - o Redness, warmth and/or drainage
- Many also have very fair skin and can experience sun burning very easily.
- Many are also on medications which make sun burning even easier.



Things You Can Do:

1. Keep hands busy.
 - o Provide stress balls, handheld games, magazines, lotion, putty, puzzles, word search books, card games, art projects and any other measures that help prevent picking.
2. Supervise. Limit time alone.
3. Use shower gloves while bathing.
4. Keep nails short. Apply lotion to keep skin hydrated.
5. Some persons may require supervision when bathing and/or going to the bathroom.
6. Cover with bandage, clothing (or both).
7. In some cases, medication may be tried.
8. Seek medical care if an infection is suspected.
9. If the sores are being confused as evidence of abuse:
 - o Access the PWSA (USA) handout – Allegations of Abuse and Neglect in Persons with PWS
10. Apply sunscreen about 30 minutes before going out in the sun. Reapply frequently – especially if the person is in and out of the water.
11. Stay out of the sun during peak sun/heat time – 12 noon until 3 pm.
12. When going on a hike or stroll in the woods, have the person with PWS wear long pants and/or long-sleeved shirt. Tuck pants into socks so ticks cannot bite around the ankles. If a tick bite is suspected, watch area closely and consult a health care professional for monitoring.
13. If there has been known contact with any poisonous plants, use care when removing these items of clothing. Plant residue may be left behind.
 - o Launder clothing as soon as possible.
 - o Shower immediately after exposure to wash away plant residue.
14. Oatmeal soaks may be helpful and soothing. Consult a health care professional if severe.

We Are Only a Phone Call Away!

If you have questions, call us at (920) 733-3077 and Board Member Emeritus, Nancy Burlingame. Nancy will answer your questions or direct you to someone that can help.



(920) 733-3077

HAPPY BIRTHDAY

HAPPY BIRTHDAY TO YOU!

MARCH

Molly P. Amanda C.
Johnny E.

APRIL

Toby S. Tom B.
Brian L. Kate J.
Lucas B. Eden D.
Alex P. Barb L.
Tony D. James S.
Sarah H. Austin W.

MAY

Addyson M. April K.
Morgan B. Nicholas T.
Ellie S. Amelia B.
JoAnn E. Jeff B.
Karen B. Quemont Gr.
Kimberly N. Elizabeth J.
Nick B. Rachel K.
Jefferson K. Matthew L.



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 Pogradt at Pogradt1@msn.com with the name, address, and birth date of the individual with PWS.

State Guardianship Training Requirement

As of Jan. 3, the University of Wisconsin-Green Bay, in partnership with the Wisconsin Department of Health Services, launched the **required Act 97 FREE, online training for guardians**. The training is an online course that includes topics such as the limits to guardianship decision-making authority, the rights of wards, and best practices regarding your ward's wishes in decision-making.

To enroll in this FREE, online, self-paced course, visit www.uwgb.edu/guardianship-training. It's accessible 24/7.

Save the Dates:

06/23/23 - 06/24/23
PWSA-USA 2023 National Convention
Orlando, Florida

PWSA | USA's Convention will provide exciting opportunities to learn, connect (and reconnect), and hear about the latest PWS research.

REGISTER TODAY!
<https://www.pwsausa.org/convention2023/>

SCHOLARSHIPS AVAILABLE! <https://pwsaofwi.org/AssistApplication>

08/02/23 for Law Enforcement only
08/03/23 for Providers, Parents, & Guardians

Police Training Times and Locations coming soon!

PWSA of WI will be providing a FREE training for Law Enforcement, Providers, Parents, & Guardians

Please watch our Facebook page and website for details coming soon!

10/05/23 - 10/07/23
FPWR Family Conference
Denver, CO

*Research Symposium will be held Oct 5-6;
Family Conference will be held Oct 6-7 and their Live Life Full Gals will be held Oct 7th.*

For more information and to register, go to:
2023 Research Symposium & Family Conference (fpwr.org)



We are in the planning stages!

Please watch the PWSA of WI Facebook page and website for more events to come!



PWSA | USA 2023
NATIONAL CONVENTION

Spotlight on Success



Greysen G.

Greysen, age 9, being the youngest, has grown up watching his two older sisters play many sports. He has watched them win trophies and medals and was eager to be on a team of his own. At the time we just happened to be at a dance performance of his sister and I saw a booth for the Special Olympics. I had always planned on getting him involved and the timing was perfect. He asked me to be on a basketball team however at the time it was bowling so he joined the bowling team. He had a blast and the people were amazing. Greysen was excited for what was next he was going to be a part of a basketball team. He got a uniform and a team bag with his name on it. He couldn't have been any happier.

In April, Greysen had the honors of going to state after he went to regionals. His entire school was cheering him on. They posted signs that were made for him by his Special Olympics coach. They announced it over the loudspeaker on the morning of the event. Everyone knew Greysen was going to state. He was so proud and excited. It was all he could talk about. Greysen tried so hard and showed amazing sportsmanship; cheering on his fellow teammates and his fellow competitors. Greysen's time had come for his moment to shine! He won 3rd place getting a bronze medal which he can proudly put next to his sisters.

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!

Exercise and Prader-Willi syndrome

We know that exercise is important for all of us; but it is especially important for children and adults with PWS.

Here is a handout that outlines all the questions and answers on this important topic published by IPWSO (International Prader-Willi Syndrome Organization).

Follow the link:

Exercise for people with Prader-Willi Syndrome - IPWSO

This is also available in a printer friendly format so it can be shared. Exercise for the person with PWS is a daily life skill that needs to be taught and practiced. It is a skill that can and should be included in a student's IEP.


EDUCATE
PATIENTLY


ADVOCATE
PASSIONATELY


INSPIRE
CONSISTENTLY

PWSA of WI, Inc is committed to providing education and advocacy for those who need it. Over the past few months, volunteers have been busy doing just that. Volunteers have ...

- Participated in team meetings for those in residential care, providing support and education to new providers caring for people with PWS.
- Coordinated and provided training and handouts to new residential care providers.
- Provided support to parents who were experiencing stress related to the discharge of their loved one with PWS from a residential care program and assisted in locating alternate, appropriate housing for them.
- Sent free Medical Alert booklets to new residential care providers.
- Provided support in connecting a parent who had a loved one who was experiencing a life-threatening health situation with a medical health professional with the expertise in PWS.

PWSA | USA School Success Summit

Navigating the challenges in educating the student with PWS can be complex and sometimes overwhelming. PWSA | USA hosted its first School Success Summit on Thursday March 9th. It provided attendees with experts on various education topics and lots of strategies to help the student as well as the parent who may be assisting the student.

Topics and speakers included:

"Creating IEP/BIP Goals and Documenting Progress" - Mackenzie Bodin, M.Ed, BCBA.

You can access her presentation by clicking on this link - School Success Summit: Creating IEP/BIP Goals and Documenting Progress - YouTube

"Helpful Tips for the IEP Process" - Dr. Amy McTighe, Educational Consultant.

You can access her presentation by clicking on this link - School Success Summit: Helpful Tips for the IEP Process - YouTube

"Due Process" - Attorney Elizabeth Eynon-Kokrda

You can access her presentation by clicking on this link - School Success Summit: Due Process - YouTube

"Pre-School Evaluations" - Amy McDougall, MS

You can access her presentation by clicking on this link - School Success Summit: Pre-School Evaluations - YouTube

For more information about these topics as well as access to handouts, go to the PWSA | USA website at www.pwsausa.org Click on Events; then click on School Success Summit. There are several other educational handouts and resources available.



PWSA | USA ECHO 4 PWS Health Care Provider Series



PWSA | USA has announced the launch of a new Healthcare Provider Project ECHO Series on **May 16, 2023, at 5:00 p.m. CST**. They are proud to offer this opportunity to healthcare professionals who work with patients affected by Prader-Willi syndrome (PWS) and to be the first PWS organization to implement Project ECHO® in the United States.

"We understand the need to further educate healthcare providers taking care of our loved ones. Through this ECHO series we will offer access to specialists in PWS, expanding knowledge and sharing standards of care for PWS patients," said Paige Rivard, MBA, PWSA | USA CEO.

The first healthcare ECHO topic will be "Genetics in PWS 101" presented by Jessica Duis, MD, Associate Professor of Pediatrics and Genetics at Children's Hospital Colorado, University of Colorado, followed by a 20-minute case study on PWS presented by Shawn McCandless, MD, Chair of the Department of Genetics and Metabolism at Children's Hospital Colorado.

PWSA | USA's Healthcare Provider Project ECHO Series will touch on a wide range of healthcare topics in the PWS space and will be available for all health professionals across our network including (but not limited to): Geneticists, Pediatric Endocrinologists, Neonatologists, Nurses, Pediatricians, Endocrinologists, Psychiatrists, Psychologists, Social Workers, Occupational Therapists, Pulmonologists, Orthopedic Surgeons, Dieticians, Physiotherapists, Speech and Language Therapists, Medical Students and Professional Caregivers.

While this ECHO series is only for healthcare providers to attend, recordings of the webinars will be made available for our PWS families on our website. PWSA of WI, Inc. will have those links available as soon as they are shared.

For more information and to share this with a health care professional go to: [Introducing PWSA | USA's ECHO® 4 PWS Healthcare Provider Series - Prader-Willi Syndrome Association | USA \(pwsausa.org\)](https://www.pwsausa.org)