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ADDRESS**

Email: progdir@pwsaofwi.org

Website: www.pwsaofwi.org

Facebook: www.Facebook.com/PWSAofWI

Twitter: www.twitter.com/PWSAofWI

Instagram: www.instagram.com/PWSAofWI

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.

PWSA of WI, Inc. Annual Report

Despite the challenges that the Covid pandemic presented to everyone, PWSA of WI, Inc continued its mission of supporting, educating and advocating for persons with Prader-Willi syndrome (PWS) across our state. Despite hurdles, the following are some of the highlights of the activities and services that were provided.

Staying Connected and Providing Some Fun

Three separate virtual Family Bingo events were conducted. 149 individuals participated in these events. Even though in-person social opportunities were not possible, PWSA of WI reached out to provide 3 evenings of fun and diversion from the challenges of isolating and quarantine. In addition, a virtual Pub Quiz also provided entertainment and a little diversion for 13 individuals.

Many people with PWS love to get mail. PWSA of WI, Inc sends out cards to 135 individuals to celebrate birthdays, holidays and just to let

them know we care. Staying connected was extra important this year.

Training and Education

PWSA of WI, Inc. continues to strive to educate others about the many unique health challenges that can face persons with PWS. Pandemic or not, PWSA of WI, Inc provided this experience to forty parents, guardians, family members, medical providers and residential care providers. Dr. Ann Scheimann, a national gastroenterologist with an expertise in PWS, shared a virtual presentation, "GI Issues in Prader-Willi Syndrome", a comprehensive overview of gastrointestinal issues in people with Prader-Willi Syndrome.

Fundraising

The dedication and commitment of golfers was not stifled by social distancing and the extra precautions taken to conduct the PWSA of WI Annual Golf Benefit. Although attendance was down, thirty-six golfers enjoyed the event at The Oaks Golf Course in Cottage Grove.

Prader-Willi Syndrome of Wisconsin, Inc. 2021 Financial Breakdown

Income		Expenses	
Membership Dues	\$2,320.00	Payroll & Benefits	\$39,683.32
Donations	\$13,791.23	Accounting Fees	\$3,520.22
Grants	\$8,055.00	Administrative Costs	\$3,549.22
Fundraising Events & Campaigns	\$36,536.83	National PWSA Support	\$2,500.00
Miscellaneous	\$2,683.01	General Assistance/Camp Scholarship	\$100.00
		Fundraising & Event Expense	\$5,119.19
		Staff & Speaker Travel	\$310.78
		Miscellaneous Expenses	\$1,681.05
		Card Club	\$482.89
Total Income	\$63,386.07	Total Expenses	\$56,946.67
Net Operating Income/Loss \$6,439.40			



THE PRADER-WILLI SYNDROME ASSOCIATION OF WI

SPARKLE & SHINE Gala

BE THE REASON FOR THE SPARKLE IN THEIR LIVES

Sparkle & Shine Gala

78 family members and friends of the Prader-Willi community gathered at the Red Circle Inn & Bistro on Saturday, September 24th to raise funds for the Prader-Willi Syndrome Association of Wisconsin, Inc. The evening began with a cocktail hour where attendees enjoyed a variety of hors d'oeuvres and drinks while engaging in conversation and fellowship. Several attendees also participated in a wine cork pull where they took home bottles of wine including Moscato, Pinot Grigio and Sauvignon Blanc. In addition, many participants started the bidding on numerous silent auction items, such as: Brewers tickets, a Green Bay Packers signature football, a Tuscan vacation and assorted baskets.

Supporters of the event then moved into the dining room where they dined on filet mignon,

stuffed green peppers, and baked chicken followed by a menagerie of dessert bars. After dinner, several people hit the dance floor where disc jockey, Rebecca Cox, played the Cupid Shuffle, Macarena, and the Cha Cha Slide among other songs.

Thank you to Prader-Willi Homes for being our Platinum Sponsor, **Sandy & David Nagy** for being our Emerald Sponsor, and **Thomas & Agnes Hughes** for being our Ruby Sponsor. Also, thank you to our Shining Star and Fairy Dust sponsors as well as to everyone who attended, bid on a silent auction items, participated in the cork pull or made a donation. We couldn't have raised almost \$8,000 without all of you! Also a huge thank you to **Tom Davenport from RD Image** for capturing this evening of elegance!!





Masquerade Ball

Saturday, October 29th, was an evening to remember for those who attended the Masquerade Ball!

Our reimagined **Masquerade Ball** replaced the previous years Snowflake Ball. Similar to past years, this event provided individuals with PWS the opportunity to participate in a prom-like experience that includes a sitdown dinner, professional photos and dancing.

Attendees came dressed to the nines ready for fun and comradery. Masquerade masks were provided to those who wished to wear one, while some came adorned with their own masks.

The Ball was held at a new venue, the Ingleside Hotel, which did not disappoint. The hotel was

the epitome of elegance, the service was amazing, and the food was top notch. The Ball was a huge success!

Thank you to the Pixie Dust Table Sponsors **Carolyn Hughes** and **Judith Scheidegger** (2 tables), which provided scholarships for those who may not be able to afford to come to the Masquerade Ball.

A special thank you to the **Stackner Foundation**, who granted PWSA of WI \$5,000 towards the Masquerade Ball! We are very thankful!

Thank you to all those who attended and we look forward to seeing everyone next year!



Food Security – Holiday Tips

Compiled by Barb Dorn

As we approach the upcoming holidays, it's important to be extra diligent. It's not only important to monitor calories, it's also important to monitor the quantity of food consumed.

OVEREATING and BINGE EATING can result in over-extension of the stomach. This can either put pressure on nearby vital organs, interfering with how they work or rupture of the stomach causing acidic contents to spill in to the abdominal cavity. This can be life-threatening. **CHOKING** is another health emergency that frequently occurs with individuals with PWS. They may steal food and eat it very fast to avoid being caught.

PREVENTION:

- Assign one person to provide supervision at holiday gatherings. Don't assume someone is watching – make sure someone is.
- Have low calorie snack alternatives.
- Space out the timing for snacks. Make a plan. Provide the plan in writing. Set a timer.
- Encourage the individual with PWS to tell if they overeat. They must not be punished (or why would they tell).
- Use strategies to help the person with PWS slow down eating. Have them put their eating utensil down between bites; limit quantities of food served.
- Make them take sips of water between bites. ("Pace and Chase")
- Make sure you know how to do the Heimlich maneuver. You may be saving a life.

Symptoms of a Possible "Gastric" Medical Emergency:

If you see any of the following symptoms, the person with PWS should be evaluated by a health care professional immediately.

- Their stomach becomes bloated or distended. (This can be hard to detect especially if they are overweight)
- They vomit. (This is rare but if it occurs it could indicate a serious health situation)
- They may complain of "not feeling well" or have stomach pain. (Pain is not always present)

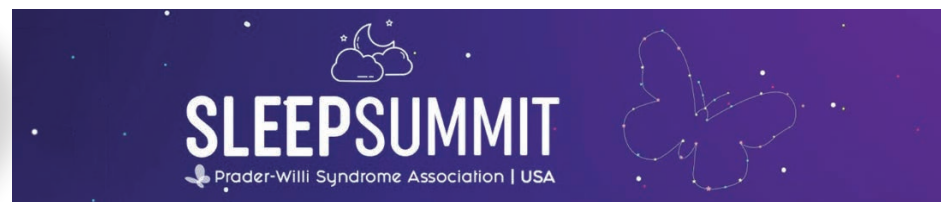
What you should do:

- **Take the child/adult with PWS to see a health care professional immediately.**
- Bring along a medical alert booklet or GI chart. If you don't have one, download a copy from the PWSA I USA website. www.pwsausa.org (Click on Resources, Medical Issues A-Z, **MEDICAL ALERT booklet AND GI chart**)
- If you encounter a health care professional who is not knowledgeable and you need advocacy help, contact PWSA (USA) at **1-941-312-0400**. Help is available 24/7.
- Don't be afraid to educate and advocate for evaluation and monitoring to rule out a gastroparesis or a ruptured stomach.

Most important, remember to keep food locked and/or supervised. We know the holidays offer more challenges in this area. We all want everyone to have a happy, healthy holiday season.

"I wish I knew more about...."?

Send an email to **Barb Dorn** at bdorn84@gmail.com and let us know what you want us to help you learn about.



Presentations Are Now Available

On Tuesday September 27th, 2022, PWSA I USA hosted 8 hours of medical experts in the field of sleep disorders and PWS. The topics and speakers were very informative and worthwhile in viewing. If your loved one with PWS struggles with daytime sleepiness and/or sleep apnea, there are several experts who discussed this issue. To access these presentations, go to: <https://www.pwsausa.org/sleepsummit/>

Medicare Dual Advantage Program for Adults with PWS on Medicare and Wisconsin Medicaid

Compiled by Barb Dorn



There is a Medicare Dual Advantage Program for adults with PWS who are Wisconsin residents and are currently on Medicare and Medicaid. The program is called My Choice Wisconsin Medicare Advantage plan. The monthly premium is \$0. This program has a 5 out of 5-star rating from Medicare.

Who Can Enroll?

This plan is available in 38 Wisconsin counties and this number keeps growing. You must be a Wisconsin resident and be receiving benefits from Medicare and Wisconsin Medicaid. For more information on eligibility go to: Medicare Dual Advantage - Eligibility & Other Resources | My Choice Wisconsin

Can I Still Keep My Same Doctors?

Visit the website for this program at www.mychoicewi.org/medicare-dual-advantage/. Click on the "Provider" link and see if your current providers are listed. Or you can click on the "Joining and Enrollment" link where you can arrange to speak to an advisor. The advisor will help you determine if your physicians and dentist are part of this program.. The list of providers continues to grow.

Does it Include Dental Care?

This plan covers many dentists across the state of Wisconsin. If your dentist is not in network, you may be able to see an out of network dentist after authorization. Once again, you can check to see if your dentist is on their authorized list. They just partnered with DentaQuest, an established network of dental professionals. The plan provides \$2500 annual dental benefits that includes many services not covered under

Medicaid. This means there are less dental out-of-pocket expenses for members.

Is There a Drug Program?

Yes, this plan includes its own drug program. You can check the pharmacy and drug coverage link to see if your medications are covered or an advisor can also assist you in providing this information. If not on the list, there is a way to ask for a prior authorization.

What Other Benefits Does It Offer?

Some of the additional benefits include:

- Home and bath safety items and modifications (such as grab bars) up to \$300 a year.
- Over-the-counter medication coverage - up to \$100 per month with rollover coverage. There is a catalog that includes many OTC medications and other products (toothbrushes, scales, oximeters...)
- Eyeglasses up to \$150 a year.
- An emergency response button.

Learn more about this program by either visiting their website (www.mychoicewi.org/medicare-dual-advantage/) or call 1-800-963-0035 and ask to speak to a Medicare Advisor.

(NOTE: We recently signed up for this program for our son, Tony who is 37 years old. Most of his physicians were on the list and all of his medications were covered. He did have to get a new eye doctor. All of his over-the-counter medications are covered at his home and he has purchased sunscreen and dental products. So far, we are very pleased.)

YOU make all the difference

It's that time of year for the PWSA of WI, Inc.'s annual "Caring is Sharing" fundraiser.

Your gift, your generosity helps PWSA of WI, Inc. provide support, education and social opportunities to children and adults with PWS, as well as all who support them. **We need you to make the difference.** No amount is too small.

MAKE A GIFT:

By Mail:

PWSA of WI, Inc.
PO Box 226, Oconomowoc, WI 53066

Online:

pwsaofwi.org/WaysToGive



**YOU MAKE ALL THE DIFFERENCE
CARING IS SHARING**

Prader-Willi Syndrome Association | USA
BEHAVIOR SUMMIT
December 13, 2022 | 2:00 - 7:45 p.m. EST

www.pwsausa.org/behaviorsummit



Spotlight on Success



Addy P.

PWSA-WI, Inc. would like to congratulate **Addy P.** on her recently acquired work positions through her school's Community Work/Volunteer Program. Her school works with community partners to provide jobs with support during school hours to develop vocational skills. Addy has been working at Goodwill Industries, Lambeau Field Stadium, and as an Administrative Assistant for a Power and Energy Supplier. Her work coordinators have shared that Addy has been very successful in the work environment and is a very hard worker. Addy has nothing but positive things to say about her experiences and hopes to keep developing new skills.

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!

Recent Trainings, Awareness, and Advocacy Efforts



On Friday September 30, 2022, Don, Barb and Tony Dorn traveled to North Chicago and did a presentation to approximately 30 medical students at Rosalind Franklin School of Medicine and Science. The presentation focused on providing a quick overview of PWS; educating them about some of the major medical issues often seen in people with PWS. Barb also shared some of the challenges faced by the Dorn family over the years. Tony shared personal things about his family, his life in residential care, his job, as well as his day program. The students enjoyed asking him about his favorite topic, Harry Potter. Barb emphasized the need for the students to always take the time to learn about a rare disorder; to listen to parents; and to take the time to engage and interact with the patient with PWS. She pointed out what amazing people they will get to know when they do this. This presentation was another step that PWSA of WI, Inc. is taking in helping to educate the medical community.

Barb has also continued her education and advocacy efforts by participating in team meetings and providing ongoing education on PWS to the staff of Vital Honor, one of the newest adult family homes in Madison who supports individuals with PWS.



Katie Moreau, mom to Cade who has PWS, recently traveled to Washington D.C as part of PWSA USA's D.C. Fly-in where she was one of 51 advocates who met with legislators to educate and advocate on 3 key issues. The issues included asking for a resolution declaring May 15th as PWS Awareness Day; advocating for co-sponsorship for Orphan Drug Covid-19 Mitigation Act (HR 8641); and adding PWS as a recognized topic area for DOD research under the Congressionally Designated Medical Research Program's Peer Reviewed Research Program (PRMRP.) Katie met with legislative representatives from Wisconsin including Senator Tammy Baldwin and Representative Mark Pocan's office. She and Cade will be meeting with a representative from Senator Johnson's office in the upcoming weeks. Thank you, Katie, for sharing the voices of persons with PWS in the State of Wisconsin.



HAPPY BIRTHDAY TO YOU!

SEPTEMBER

Tommy N.	Katelyn S.
Ian D.	Lisa T.
Nathan B.	Brian H.
Jamil M.	Jackson D.
Natalie B.	Beth H.

OCTOBER

Mason H.	Chelsea C.
Tim S.	Teresa B.
Wayne B.	Eli H.
Richard D.	Alexander L.
Nick L.	Lisa G.
Kayla S.	Sameea S.
Lucy W.	David C.
Brandon W.	

NOVEMBER

Bella A.	Mykenna P.
Julie H.	Sarah C.
Jon C.	Dallas H.
Kai H.	Kate K.
Tiffany M.	



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.

Welcome to the Board!!

We are so happy to welcome the following to the PWSA of WI Board of Directors:



**Pam Toepfer,
Machesney Park, IL**

I have had the pleasure of working with individuals with diverse limitations for the past 8 years. My professional background is knowledge of how to manage

finances for these individuals as well as providing insight to their guardians and representative payees. I also have assisted in fundraising efforts within the company I work, from planning to speaking on how the individuals are benefitted by supporters. I became involved with PWSA-WI when I met board member, Melissa Sirovina. This has been valuable to me in my profession as we do service a few individuals with PWS, but also on a personal level. I have volunteered for the Snowflake Ball in the past and have attended several events. In addition, Volunteering with PWSA-WI has been a pleasure and I would like to utilize my talents more with them.



Eva Glass, Nashotah, WI

I have served on the junior advisory board for many years and I am now interested in joining the regular board because I have a desire to do more. I love the organization and have

a passion for helping people in need. I feel I can bring a different perspective as a young person and I can help encourage people my age to get involved. During my time on the board, I volunteered at the PWSA|USA National conference, Snowflake Ball, Sparkle & Shine gala, walk-a-thon, bowling event, and golf outing. In addition, I work part time for residential care facilities that services individuals with Prader-Willi Syndrome.



**Josaphine Glass,
Nashotah, WI**

I have served many years on the junior advisory board, and now want to join the regular board. I want to help share what

we do for people with Prader-Willi Syndrome and to help recruit other young members to join both the junior advisory board and regular board. Throughout my time on the junior advisory board, I have volunteered at the Snowflake Ball, bowling event, Sparkle & Shine gala, golf outing, PWSA|USA National conference, golf outing and walk-a-thon.



**Gavin Johnson,
Oconomowoc, WI**

I have worked for going on 6 years next month as a Direct Support Professional in a group home with those with PWS and I have participated in the Snow-

flake Ball, walk-a-thon and golf outing. I would like to continue making a difference in the lives of those with PWS on a higher level. the people who participate. And learning more about the experiences, medications, symptoms, milestones, and other aspects of PWS is key to advancing our understanding and discovering new therapies and treatments.

Fitness Fun

by Brandon Schmidt

Hi everyone! My name is Brandon Schmidt and I am the Athletic Director at Abilities Midwest, Inc. and a board member of PWSA-WI. My job is to support the athletic program at Abilities Midwest. I'm a Certified Personal Trainer and my specialty is working with the individuals with PWS at Abilities Midwest. As the winter months are approaching (hello, there was snow on October 14th?!), it's time to create a fitness plan to help keep your loved one active during the winter.

While there is the option to workout indoors via exercise machines such as a treadmill or by lifting weights, there are other creative ways to stay active while having fun indoors. Here are a few ideas:

- Swimming! Many hotels that have pools allow the community members to use the pool for a small fee.
- Indoor walking tracks! Some schools even allow community members to use indoor tracks before or after school hours.
- Wii Games: Just Dance and Wii Sports are great options to burn some calories while having fun playing the Wii.
- Fitness Classes: Fitness classes are a great way to incorporate both fitness and community integration. Many gyms offer these classes. I would recommend starting with a short, beginners class. Zumba is a great, fun option!
- Indoor Basketball: Does your loved one enjoy shooting hoops? Many large gyms and/or community centers have indoor basketball courts for you to enjoy.

Now let's talk about motivation. If you are struggling to motivate your loved one to work out during the winter months, try a motivational program. One idea is to use a star-incentive program. For every time the individual completes a workout, provide them with a star sticker on their chart (having a visual is huge!). After 5-10 stickers are earned, head out on a fun outing with the individual to celebrate them working to stay healthy this winter!

Have fun, and stay warm this winter. Thanks for reading!! - Brandon Schmidt

Your Fall 2022
newsletter has arrived!

The Newsletter of the Prader-Willi Syndrome Association of WI, Inc.

THE
WISCONSIN
Connection