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bdorn84@gmail.com

PWSA of WI, Inc.

PO Box 226

Oconomowoc, WI 53066

(920) 733-3077

**NEW
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

As the world continued to navigate the Covid pandemic and determine what the new "normal" was for everyone, PWSA of WI, Inc. continued its mission to support, educate and advocate for persons with Prader-Willi syndrome (PWS) across the state of Wisconsin. Despite various challenges, the following are some of the highlights of activities and services the Association provided throughout 2022.

Staying Connected

The beginning of the year started off with a virtual Family Bingo event where 60 individuals from across the country signed up and participated. This event provided an evening of fun and a diversion from the challenges of isolating and social distancing. Later in the year, as in-person events resumed, 18 families participated in a Family Fun Day with activities and lunch provided by the Association. The year ended with 135 individuals dancing the night away at the Masquerade Ball. In addition to these events, PWSA of WI, Inc. sent out birthday and holiday cards to 135 individuals with PWS living throughout Wisconsin. Staying connected with these individuals and letting them know we care about them is extremely important to the Association.

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. Members and volunteers of the Association, conducted five trainings for several newly established residential group homes in the Madison and Lake Country area. These trainings included "Overview of PWS", "Health Concerns", "Behavior Management", "Activity Planning and Exercise", and "Nutrition, Diet and Menu Planning". A volunteer of the Association, along with her son who has PWS, presented information about PWS to medical students at the Center for Genetic Disorders. PWSA of WI, Inc. also provided IEP training for multiple families with school aged children, and supported families dealing with grief due to the sudden loss of a loved one. Training videos, educational articles, and other resources were shared through quarterly newsletters, social media, and the Association's website.

Fundraising

In May, 228 individuals with PWS, family members and friends reunited in person for our annual walk-a-thon. In addition to these participants, 10 corporate sponsors and 12 people who purchased "footprints" supported this event, resulting in almost \$20,000 raised. Toward the latter half of the year, 78 family members and friends of the Prader-Willi community gathered for the Sparkle & Shine Gala, which raised roughly \$8,000.

(Continued on page 9)

Law Enforcement Training Summary

Oh No Five-0 and The Dark Web

On Wednesday, August 2nd, retired police sergeant **Tammie Penta** provided a two hour training to law enforcement agents belonging to the City of Oconomowoc and Village of Chenequa Police Departments. During her training, Tammie shared introductory information on Prader-Willi Syndrome and how to best deal with a situation involving an individual with PWS. According to the officers who attended the training, the information was very informative, especially because there are several individuals living with PWS in their jurisdictions.

On Thursday, August 3rd, Tammie hosted a two hour in-person training session for a group of residential providers and professionals from a vocational school serving individuals with PWS. In addition, she provided a virtual training to several residential providers located in northern Wisconsin. Throughout this session, Tammie shared introductory information on how to best prepare for an incident involving a resident or staff and law enforcement. In addition, Tammie discussed the dark web, social media concerns and device usage. Tammie also distributed several resources regarding internet apps, gaming safely, sexting, and cyberbullying. Please click [HERE](#) to download from our website to view the resources.

During all three sessions, Tammie discussed what she calls "**The Blue Form**". This form contains important information that can be printed on blue card stock and provided to law enforcement officers when they are called to a situation involving a person living with PWS. The form is tailored to each individual and provides a quick "snapshot" for police. Information may include the individual's diagnoses, IQ, persons functional age, a brief description about possible behavior officers can expect from the individual and ways to respond to said behavior. The form also includes information about food safety. If you are interested in a "**blue form**", please click [HERE](#) to download from our website.

PWSA-WI, Inc. would like to thank **Tammie Penta** for sharing her vast knowledge and for agreeing to return for additional trainings in the future. We would also like to thank board member, **Jamie Milaeger**, for allowing us to use her company's board room for the trainings. Lastly, we would like to thank the officers, providers and professionals who attended these trainings.



OH NO FIVE-0 AND THE DARK WEB!
A guide to prevention and education with Law Enforcement, legal concerns and victimization on the web.



Ready, Set, Go!

Getting Ready for the New School Year

by Barb Dorn, RN, BSN

It is that time of the year for preparing the student with PWS to return to school. This can be an exciting and sometimes a stressful time. Many students with PWS are “anxiety sensitive” and change is often the number one source of this anxiety.

If the student with PWS is starting in a new school or having a new teacher, there are some things you can do to lower his/her anxiety.

- **VISIT** the school a few days before classes begin, when the building is quiet.
 - o Find their classroom; meet the teacher and locate other popular locations (bathroom, therapy room, gym – just to name a few).
 - o Some families have found it helpful to visit more than once before school begins.
- **SHARE** information about the student and about PWS. Make it personal. Help educators to get to know the student and how to have a successful experience.
 - o Inform educators about topics or subjects that are his/her favorite, successful strategies and things that can be problematic.
 - o Provide handouts about PWS. Help new staff understand PWS.
 - o Create a 1-page handout about your student. Include personal “tips for success” – especially how to prevent and manage food situations. Educators LOVE to have this resource.
- **REVISIT** your child’s IEP. If questions or concerns about any aspect, request and schedule a time or meeting to meet.
 - o Be sure health information is up to date.
- **EDUCATE** school staff about the unique needs of students with PWS. Share the Medical Alert booklet as well as the Health Concerns handout.
 - o If your child has any allergies or additional health concerns, make sure the school nurse and/or office staff are informed.
 - o Create the PWS Health Identification Card from PWSA | USA.
 - o **NEW Customizable PWS Health Identification Card! - Prader-Willi Syndrome Association | USA (pwsausa.org)**

If you have any additional questions or needs, contact PWSA of WI, Inc. Email: progdir@pwsaofwi.org or call: 1-920-733-3077.

Here are some resources for you to access:

1. Back to School Checklist: [Back-to-School-Checklist.pdf \(pwsaofwi.org\)](#)
2. General Information on School Success: [School Success: PWS Challenges and Solutions - Prader-Willi Syndrome Association | USA \(pwsausa.org\)](#)
3. Information on the Individual Education Plan (IEP): [School Success: Individualized Education Program - Prader-Willi Syndrome Association | USA \(pwsausa.org\)](#)
4. Food in the Classroom: [Food-In-the-Classroom.pdf \(pwsausa.org\)](#)
5. Health Concerns in the Student with PWS: [Health Concerns and the Student w/ Prader-Willi Syndrome \(pwsausa.org\)](#)
6. Information for Transportation Personnel: [Information-for-Transportation-Personnel.pdf \(pwsausa.org\)](#)

A Brief Overview: Hypogonadism in Prader-Willi Syndrome (PWS)

Compiled by Barb Dorn, RN, BSN

PWS is a complex, multisystem genetic disorder that impacts many aspects of health and wellness in the person with PWS. We continue to learn more about the impact of several hormone deficiencies and how they impact the quality of life in persons with PWS.

Hypogonadism refers to a condition where there is little or no production of male or female hormones by the testes or ovaries. Hypogonadism is a common clinical feature seen in both males and females with PWS. Studies have shown that there may be more than one cause for this condition. It has been found that there may be a problem in the hypothalamus as well as a problem with the function of ovaries and testicles.

What Do We See?

Males	Females
Scrotal Hypoplasia (small, underdeveloped)	Hypoplasia of labia and/or clitoris (small, underdeveloped)
Cryptorchidism (undescended testicles)	Delayed puberty and breast development
Small penis	Few or no menstrual periods
Low levels of testosterone	Low levels of estradiol
Precocious puberty (early, incomplete start of hair growth and breast development) is common	

Therapy for these conditions focuses on hormonal therapy to replace deficient, low hormone levels. Frequently, this is prescribed and monitored by an endocrinologist. Infant boys may be prescribed human chorionic gonadotropin (hCG) to help the testicles descend. If this does not work, surgical intervention is often done.


Currently there are no specific guidelines for the treatment of hypogonadism but clinicians are using hormone replacement therapy to bring hormone levels closer to normal. Males often receive testosterone and females receive estrogen and progesterone.

Parents and caregivers are encouraged to begin discussing this topic and encourage closer evaluation when the child with PWS is in early adolescence. Since the onset of puberty may not be evident, this typically occurs around the age of 12 years.

Hypogonadism is a lifelong condition that requires monitoring and treatment from infancy into the adult years. It helps to prevent bone density problems including osteoporosis as well as improves muscle mass and endurance. It can make an extreme difference in the quality of life for an individual, especially as they grow older.

References:

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For more information, download this booklet:
[Hypogonadism_in_Prader-Willi_Syndrome_Download \(fpwr.org\)](https://fpwr.org)

Why I Advocate for Those with Prader-Willi Syndrome

by Katie Moureau, Mother to Cade with PWS



Cade & Katie meeting with Senator Roys

I advocate for those with Prader-Willi syndrome (PWS) (and rare disorders) because I believe that everyone deserves access to quality healthcare, regardless of their diagnosis. People with PWS often face significant challenges, including lack of awareness, limited access to care, and high cost of care. Advocacy can help to address these challenges and improve the lives of people with rare diseases, especially PWS.

I have a personal connection to PWS. My son, Cade was both with PWS. When he was diagnosed, I was shocked and scared. I did not know anything about rare diseases or PWS, and I did not know where to turn for help.

I started by doing research online. I learned that there are over 7,000 rare diseases, and that each one is unique. PWS happens to about 1 in 15,000 births. I also learned that there are many patient organizations that provide support and resources to people with rare diseases and their families.

I joined PWSA – Wisconsin. Through this amazing organization, I met other parents of children with the same diagnosis. We share our experiences and learned from each other. We also worked together to advocate for our children's needs.

As a result of my advocacy, Cade has access to better care. He received early intervention services and he has made great progress and continues to move mountains daily. I am grateful for the opportunity to advocate for my son and other children with rare diseases. On May 1, 2023, while I was in Washington DC, I had the opportunity to go and meet with our Wisconsin legislators on the Benefit Act 2023 S. 526 and H.R. 1092 and have them get to know our family better and current treatments in the pipeline for PWS.

Next on May 17, 2023 Cade and I were able to participate in meetings with our state level legislators in Madison, WI for Rate State Advocacy Day. Cade and I met with 2 state senators and 5 assembly members. We were able to educate them on PWS and talk about Cade's story and talk about what life is like for Cade. We had to requests - #1 Newborn Screen Act, making Wisconsin in the Recommended Uniform Screening Panel (RUSP) alignment, and #2 Co-pay adjustments.

Most recently, Cade participated in Rare Disorder Legislative Advocacy Kids and Tenn Advocacy du throughout the month of June. He was able to share a bit about himself and PWS and asked that Senators Baldwin and Johnson, as well as Representative Pocan consider co-sponsoring the Accelerating Kids Access to Care Act. He also asked if they would join the Rare Disease Congressional Caucus.

I encourage you to get involved in advocacy. There are many ways to get involved, such as:

- Joining PWS of WI and other Rare Disease Organizations
- Volunteering your time
- Writing to your elected officials
- Donating to research

Together, we can make a difference!



Cade preparing to meet with legislators

COME JOIN OUR BOARD OF DIRECTORS!

Are you interested in being involved in PWSA of WI's mission? Consider running for a board member position! PWSA of WI will have 11 open board positions to begin in January of 2024 and we would love to see some new additions! Board positions are 2 year positions, but we do have three 1 year positions available this time around. The elections are held each October and are a key part of determining the direction of our organization as we try to best serve the PWS community here in Wisconsin.

If you are interested in running for a board position please visit our website to download an application at pwsaofwi.org/Volunteer. If you would like more info, please contact Crystal at progdir@pwsaofwi.org. Board Applications must be submitted by Sept. 15th.



HAPPY BIRTHDAY TO YOU!

JUNE

- | | |
|-------------|------------|
| Victoria L. | Brielle S. |
| AJ L. | Jim J. |
| Michael G. | Jack B. |
| Oliver M. | Daniel S. |
| Nolan K. | Jillian C. |
| Jason F. | Tony S. |

JULY

- | | |
|--------------|-------------|
| Julien J. | Ania B. |
| Claudia H. | Jennifer M. |
| Haylee Jo B. | Renee R. |
| Dan S. | Addy P. |
| Elizabeth G. | Marcus O. |
| Robin W. | Anna L. |
| Hana B. | |

AUGUST

- | | |
|-----------|-------------|
| Laura S. | Adam B. |
| Elaine Y. | Jackson G. |
| Jeff K. | Sydney V. |
| Martha L. | Meredith W. |



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.

Spotlight on Success



Ethan H.

When Ethan moved in with us as a foster child in 2018, I wasn't sure what our lives would look like in the future. He struggled big time with boundaries, food, and basic everyday skills. If you were to tell me 5 years later we'd have a high school graduate, I'd call you crazy!

Ethan has had a TON to overcome in his life. Despite trying to navigate the foster system, with Prader-Willi Syndrome, he's managed to come out on top, even without all the early childhood interventions most other

individuals with PWS receive. Ethan has succeeded, and defied odds all along the way! We adopted Ethan in 2019, and he is now the oldest of 5, and loves to be a helper. He likes to make sure everyone stays in line, and does what they're supposed too (which doesn't always bode well with the little bros). From holding his little sisters hand, and "directing cars" in parking lots to keep her safe, to making sure his autistic brother has a full sippy all hours of the day, Ethan loves helping his siblings.

In the fall, Ethan will start at ACE Academy and work on life skills, and community involvement. I'm so incredibly proud of how he's persevered to get here, and I can't wait to see where the next couple years take 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!

Save the Dates:

09/12/23

Special Preview Benefit for PWSA of WI of the documentary "The Life You're Given"

The Towne Cinema • 310 E. Main St. • Watertown, WI

"The Life You're Given" is a feature length documentary about a family's experience raising a daughter born with Prader-Willi syndrome, from her birth thirty five years ago to the present. It presents an unusually intimate, honest look at their individual and collective joys and struggles, with hope ever present.

Admission by donation of any amount, all gratefully accepted.

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 info and to register, go to: [2023 Research Symposium & Family Conference \(fpwr.org\)](https://2023researchsymposiumandfamilyconference.org)



10/07/23

PWSA of WI Casino Night Fundraiser

The Cornerstone • Oconomowoc, WI Stay tuned for more information to come!

A fundraiser for PWSA of WI with hors d'oeuvres, music, and plenty of casino games, prizes, and fun!

11/04/23

PWSA of WI Annual Ball

The Ingleside Hotel • Pewaukee, WI Stay tuned for more information to come!

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.

Movement and Exercise for the Little Ones

by Barb Dorn, RN, BSN

As we all know, exercise is good for everyone – especially those who have PWS. Due to poor muscle tone and some developmental delays, finding exercise options for little ones can sometimes be a challenge. A few key points to keep in mind are – make it fun, silly, and full of laughter. Also, make it a part of their daily routine. Exercise helps the person with PWS in so many ways. Here are a few ideas to promote movement and hopefully a few smiles.



Walking is a popular activity that many people of all ages can enjoy.

- o Try out different routes. “Explore” the neighborhood.
- o Create scavenger hunts – look for stones, leaves, “things that are green ...” to add a little excitement.
- o Use a pedometer and “see if you can add 1 more step every day”.
- o Try some little nursery rhyme type chants to go along with your walk. (Count to 8 with each step; stop and kick one foot to the left saying “we”; then kick the other foot to the right saying “are”. Then bend your knees saying “a little bit” and then bend forward at the waist ending with “CRAZY”! Repeat.



Swimming, running through a sprinkler or splash pad and playing in water are fun ways to promote movement and keep everyone cool.

Take a trip to the park. Parks are a fun, free way to get young ones moving. Climbing slides, swinging on swings, and exploring other equipment provide fun-filled adventures and activities.



Toys and games can provide lots of movement. Pull and push toys including walkers, strollers and tricycles can be a fun way to promote movement. There are games that make kids get up and move around including some long-time favorites like “ring around the Rosie”, “duck, duck, goose”, “hide and seek”, and “tag”.

No matter what, be creative and find ways to keep your loved one with PWS moving. Make it a family affair. We can all benefit from this.

Thank You Donors! We appreciate YOU!

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

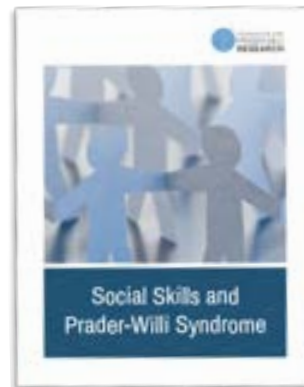
Building Social Skills in Persons with PWS

Helping people with PWS build social skills can be complex and challenging for some. In a survey conducted by FPWR, people with PWS reported that they wanted more friends and to feel less lonely. The following are resources that can be downloaded to help parents and clinicians with this task.

DOWNLOAD the BOSS Curriculum and Guide for Parents Today (fpwr.org)



DOWNLOAD Social Skills and Prader-Willi Syndrome (fpwr.org)



PWSA | USA Conference Wisconsin Volunteers

On Wednesday, July 24th, current PWSA-WI, Inc. board members Crystal Boser, Jamie Milaeger, Eva Glass and Sarah Glass along with board member emeritus, Nancy Burlingame, and former junior advisory board member, Makenzie Gaulke, arrived in Orlando, Florida to volunteer for four days at the 37th PWSA | USA National Convention.



As the registered nurse, Nancy was tasked with assessing and treating any children or adults who became ill or injured throughout the conference. This was Nancy's third time volunteering in this role at the convention and, according to her, this experience is extremely rewarding. Not only does she love seeing all of the kids who visit her, she also knows many parents feel comfortable leaving their children to attend sessions because there are nurses and physicians available if a medical need arises.



Crystal, Jamie, Eva and Makenzie volunteered in the PWS Adventure Camp where 118 individuals with Prader-Willi Syndrome ages 7 and up, enjoyed two days full of fun activities and friendship. Jamie and Eva were each responsible for a group of roughly 15 camp attendees. Their main duties were to guide their respective groups to the various activities being offered and to assist each individual as needed while completing the activities. Makenzie was responsible for helping to lead one of the activities the camp attendees participated in. Crystal once again served as the assistant to camp director, Kim Tula, and helped wherever needed. Sarah volunteered in the PWS Junior Camp where 56 individuals with Prader-Willi Syndrome ages 6 and under, spent two days playing with each other and the various volunteers. Crystal, Jamie, Eva and Makenzie have all volunteered at past conferences, but this was Sarah's first time volunteering. According to her, she had an absolute blast with the kids!

Wisconsin was also well represented at the PWS Adventure Camps overseen by Kim Tula, former PWSA of WI board member and current PWSA | USA Family Support Counselor, along with volunteers Lydia J., Chase J., Caleb E., Haley E., Lissa B., Don B., Maddie T., Colton D., Matt B., Sam "Alex" F., Sarah N., Kenley N., Angie L., Rosie L., Jackie M., Krissy G., Stephanie K., and Jonah R. PWSA | USA Board Chair Marguerite Rupnow, also from Wisconsin, was in attendance. Thank you to everyone who helped make this years Conference a success!

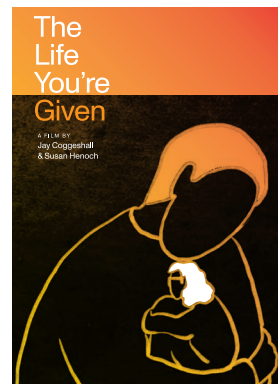


Volunteer of the Year Award Presented to Barb Dorn, RN, BSN

Barb Dorn, RN, BSN has impacted so many lives over the course of many years and works incredibly hard to support our mission. As the mother of two

sons, one of whom is 38 and living with PWS, Barb first began to display her dedication to our PWS community in 1992 when she established PWSA of WI. Since then, she has continued to dedicate her time to advocating on the state and federal level on behalf of our community. She has written countless articles, presents locally as well as at many of our National Conferences, and constantly seeks to educate and provide training for medical staff, case managers, teachers and caregivers on how to work with and treat people with PWS. She was a significant player in the fight to have growth hormone approved for our PWS population and led the charge to have Prader-Willi syndrome added to Wisconsin's definition of Developmental Disability. She continues to assist our community and PWSA | USA, most recently by facilitating the Health Care Advocacy Webinar series and updating and editing the PWS Medical A-Z documents. Her energy is endless and her dedication to our PWS community over the past three decades has not only shown remarkable leadership, assertiveness, and integrity, but it clearly defines her deep level of compassion and commitment to PWSA | USA's mission.

New Documentary to be Released



"The Life You're Given" is a feature length documentary about a family's experience raising a daughter born with Prader-Willi syndrome, a rare genetic disorder, from her birth thirty five years ago to the present. It presents an unusually intimate, honest look at their individual and collective joys and struggles, with hope ever present.

Special preview benefit for the Prader-Willi Syndrome Association WI, Inc.

Tuesday, September 12 at 6:00 P.M.

**The Towne Cinema
310 E. Main Street
Watertown, WI**

Admission by donation of any amount, all gratefully accepted.

PWSA of WI, Inc. Annual Report

(Continued from page 1)

Prader-Willi Syndrome of Wisconsin, Inc. 2022 Financial Breakdown

Income		Expenses	
Membership Dues	\$1,515.00	Payroll & Benefits	\$34,767.89
Donations	\$8,030.01	Accounting Fees	\$4,759.10
Fundraising Events & Campaigns	\$58,523.20	Administrative Costs	\$4,980.86
Social Events	\$4,670.00	Fundraising Events & Campaigns	\$14,635.56
Grants	\$5,000.00	Social Events	\$7,877.28
Miscellaneous	\$3,541.15	Travel	\$418.11
		Miscellaneous Expenses	\$110.41
		Card Club	\$256.33
		Website	\$2,052.00
Total Income	\$81,279.36	Total Expenses	\$69,857.54
Net Operating Income/Loss \$11,421.82			