

THE WISCONSIN CONNECTION

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*The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.
Supporting, Educating and Advocating for Persons with Prader-Willi Syndrome and All who
are Impacted by this Disorder*

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.

A Letter from the Office



Hello from the office! I am writing this in 2017 but you are probably reading this in 2018 so happy New Year! It was a very busy end to the year for me here at PWSA of WI. In October and November I made numerous advocacy trips to support folks with PWS in their schools. Then in November I traveled to the PWSA (USA) National Convention.

This was my second convention and I came away from it with lots of great experiences, knowledge, and relationships.

While I did not meet any new Wisconsin families this time around Wisconsin was very well represented! We granted scholarships to five different families to assist them financially so they would be able to attend.

If you have never attended a national convention before I strongly encourage you to attend. PWSA (USA) brings dozens of experts in the PWS field to one location to give us the opportunity to learn from them. I had the opportunity to be educated about different topics such as ideal diet (spoiler, find what works for you because everyone is different), different physical therapy philosophies, and preparing for IEP's. All of this knowledge has better equipped me to serve all of you!

As always, remember I am here in the office to help you. If you need assistance with something do not be afraid to ask. Even if I can't provide you with what you need I will help you find out who can. Cheers to a great 2018!

Did you know?

PWSA of WI hosts a private Facebook group for parents of children from ages 0-9. This group allows those parents to share information and bounce ideas off of each other. They have also taken a group trip to the Madison Zoo each of the last two years! If you are interested in being a part of this group contact us today!



Olivia Luening, a young lady with PWS here in Wisconsin, and three fellow Girl Scouts recently built a buddy bench for one of the Prader-Willi Homes of Oconomowoc group homes.

How can a buddy bench affect the lives of people who struggle with Prader-Willi Syndrome? We tried to figure this out because we have a special connection to these people. We were inspired to do this project by a fellow classmate and friend Olivia Luening. The people in this home have a special place in our hearts because they share the same syndrome as her. Prader-Willi Syndrome (PWS) is a genetic disorder that involves the 15th chromosome. PWS affects 1 in 15,000 people, and everyone reacts to it differently. We felt that the buddy bench could be involved in the lives of the people at the home by helping their social skills and creating a safe place for them to share their feelings. In addition to the buddy bench, we recreated their garden into something more manageable, giving them something to do outside other than lounging. We also swept and cleaned their patio so they have a clean place to sit outside. This patio also had a number of overgrown plants that we either relocated or simply dug up creating a more spacious area. During our time we spent at the home, we raked leaves, rolled rocks, swept the patio, and interacted with the members of the home by watering plants with them and showing them how to care for the plants we planted. This project has brought us closer to our friend Olivia by making us realize the problems and challenges people with PWS face everyday. By exposing us to people with different backgrounds and mindsets, this experience truly changed us as people.

Written by: Grace Hill



Join us for a Madison Capitols game February 3rd! The game is at 6:05 PM. A percentage of each ticket sale will be donated back to our organization. Tickets are only \$8 and everyone who purchases with the link will be in the same section so we can have our own little PWS hockey party!

**To purchase tickets use the link:
<http://mm1.glitnirticketing.com/mmticket/web/loggingroup1.php>
 Password:wili**



The Junior Advisory Board had a busy Summer and Fall preparing for the 34th PWSA National Convention. In August, the four members met to make 15 blankets for the participants in the Youth and Infant Program (YIP). In September, they got together and made 110 bracelets that would be handed out to each participant in the Youth and Adult Program (YAP). The group also met to distribute 50 pounds of cornstarch into small zip lock bags, which was used for activities in YAP. Three of the four Junior Advisory Board members also traveled to Florida to participate in the National Convention. Makenzie and Maddie volunteered in YAP while Maya participated in the Sibling Program. They all worked very hard and were excellent representatives for PWSA-WI, Inc.

After returning from the National Convention, the group met to start working on flowers for the upcoming PWSA-WI, Inc. Snowflake Ball. Makenzie, Maya, Maddie and Kameron spent the afternoon putting together 45 corsages and 78 boutonnieres. They will be meeting again in January to finish this project so every individual with PWS who attends the Ball will receive a flower arrangement.

The PWSA-WI, Inc. Board is very proud of the hard work this group has been putting in and we look forward to seeing what goals they will accomplish in 2018.

Thank you Claudine!

PWSA of WI would like to thank our outgoing board member Claudine Hoverson for 2 wonderful years of service. **Thank you Claudine!**

Welcome to our new board members!



Lynn Ann Parrish

Ms. Parrish lives in Verona, WI and is the mother of a 25 year old daughter. As the Corporate Secretary for First Business Financial Services, Inc. (FBIZ) she is responsible for overseeing the Company's corporate governance framework, ensuring compliance with stock exchange listing standards and SEC reporting and compliance, implementing decisions made by the board of directors and overseeing shareholder relations. Prior to joining FBIZ, Ms. Parrish worked at CUNA Mutual Group in the Governance, Risk and Assurance department; as a branch manager at both State Bank of Cross Plains and Park Bank; Executive Director of the Cross Plains Business Association and, as a Research Coordinator for the Dean Foundation for Health Research and Education. Ms. Parrish is active in the community as a volunteer for Susan G. Komen Wisconsin and United Way of Dane County Women's Leadership. Ms. Parrish is a member of the Society for Corporate Governance and the National Association of Corporate Directors. Ms. Parrish is interested in serving on the Board of PWSA of WI because of Sarah Hughes. Ms. Parrish met Sarah through her sister, Carolyn Jahnke, and looks forward to the opportunity to use her unique experiences in corporate governance, fundraising, and community involvement to give back to the Association that has done so much for Sarah Hughes and her family.



Ryan Finkenbinder

I worked at Prader-Willi Homes of Oconomowoc from 2009 to 2017. In that time, I've done everything from being a 3rd shift staff, a 1:1 direct support staff, a 1st shift medical staff and a Program Manager for one of the group homes, beginning in 2012. I thoroughly enjoyed my time interacting with all of the clients company wide and prided myself on taking the time to get to know and building a solid rapport with as many of the individuals that resided in the company as I possibly could. I tried to help out as often as possible because when they were happy, I was happy. Some of my favorite memories were just doing simple things like taking someone on a personal outing or playing a game because it was during those moments I really felt I could give that person my undivided attention and really listen to them. Those bonding moments were something I will always cherish.



Hippotherapy and Prader-Willi Syndrome

Hippotherapy is the use of horses to perform physical, occupational, or speech therapy treatments. This type of therapy has gained a great deal of popularity in recent years. The American Hippotherapy Association says that the use of horses “promotes the use of the movement of the horse as a treatment strategy in physical, occupational and speech-language therapy sessions for people living with disabilities.”

There are many things that make hippotherapy a great option for individuals with PWS. The physical act of riding a horse is a very active situation. There is a constant need for the body to react and adjust to the

horse and its movements. For individuals with PWS who have low tone and balance issues due to limited trunk strength this can be incredibly beneficial, especially for young children.

The Principles of Hippotherapy

- ✦ The horse’s movement promotes active responses in the patient.
- ✦ Variations in the horse’s movement, as directed by the therapists, promote variations in the patient’s response.

Patient responses are intended to affect function.

Specific Benefits of Hippotherapy

- ✦ Arousal and attention
- ✦ Balance strategies
- ✦ Belief in one’s functional capabilities
- ✦ Bilateral integration

- ✦ Body awareness
- ✦ Circulation
- ✦ Dynamic postural stability
- ✦ Endurance
- ✦ Expressive and/or receptive speech and language
- ✦ Midline orientation
- ✦ Mobility of pelvis, spine, and hip joints
- ✦ Modification of muscle tonus
- ✦ Motivation
- ✦ Muscle strength
- ✦ Musculoskeletal alignment
- ✦ Neurogenic bladder
- ✦ Neuromotor function
- ✦ Oral-motor function
- ✦ Posture
- ✦ Problem-solving movement strategies
- ✦ Respiratory function
- ✦ Self-confidence
- ✦ Sensorimotor integration
- ✦ Symmetry and alignment

Timing and coordination of motor strategies
From AHA, Inc. Hippotherapy Treatment Principles Level I Manual, copyrighted 2015 5th edition.

Hoodies, t-shirts, and coozies can be purchased from our webstore by visiting <http://tiny.cc/PWSAWIstore>



JOIN AND EXPERIENCE THE VALUE OF MEMBERSHIP

WHAT IS PWSA-WI?

The Prader-Willi Syndrome Association of WI, Inc. (PWSA-WI) is a chapter of the national organization, PWSA (USA), and is an independent organization whose mission is 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. People contact the office via phone or email. Staff answer questions, provide support and connect callers to resources. Through the quarterly newsletter, The Wisconsin Connection, new information is shared with families and professionals. When requested, staff and/or volunteers help educate others through consultations and trainings. PWSA of WI, Inc. is frequently called upon to advocate for persons with PWS. It has become the voice of all who are impacted by this disability.

WHAT IS PRADER-WILLI SYNDROME?

Prader-Willi syndrome (PWS) is the most common known genetic cause of life-threatening obesity in children. Although the cause is complex it results from an abnormality on the 15th chromosome. It occurs in males and females equally and in all races. Prevalence estimates have ranged from 1:8,000 to 1:25,000 with the most likely figure being 1:15,000.

PWS typically causes low muscle tone, short stature if not treated with growth hormone, incomplete sexual development, motor and social development delays and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity. The food compulsion makes constant supervision necessary.

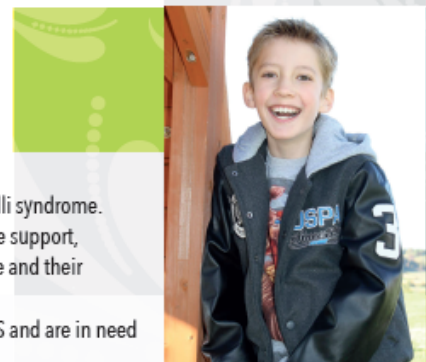
Children with PWS can be sweet and loving, but they display characteristics of the Prader-Willi personality that can cause social and behavioral problems. They also have many complex and unique medical issues.

With knowledge, support and understanding, persons with PWS can and do become valued members in our communities. They need to be supported by parents, care givers and professionals who have the knowledge and tools needed to assist them in doing this. PWSA of WI, Inc. provides a variety of services to make this possible.

WHY BECOME A MEMBER?

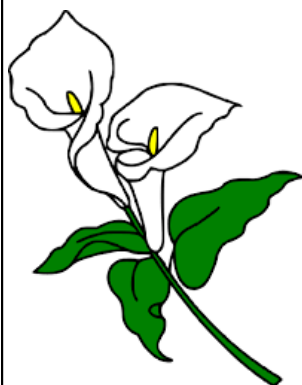
Your Membership Includes:

- A quarterly newsletter, The Wisconsin Connection
- Discounts on trainings or conferences
- FREE OR LOW COST social and support opportunities
- The ability to apply for scholarships and financial help
- Assurance that there will be a voice for all who have Prader-Willi syndrome. PWSA of WI, Inc. celebrated 23 years of reaching out to provide support, education and advocacy to persons with Prader-Willi syndrome and their loved ones across the State of WI.
- Every year scholarships are awarded to campers who have PWS and are in need of financial assistance so they can attend summer camp.
- Each Winter/Spring a social event is sponsored by PWSA of WI, Inc. for persons with this disability, their siblings, and those who support them. More than 100 people who have Prader-Willi syndrome attend. This is a time for making new friends, rekindling old friendships, sharing and having a great time. The unique nutritional and behavioral needs of the participants are specifically addressed.
- Once a year, a training workshop or some other educational project is conducted that helps those who work with children and adults with PWS gain a better understanding of their needs and how to make the lives of those with Prader-Willi syndrome more successful.
- Every day, information and support is provided to callers and others who seek help. Brochures and other printed material are shared at no cost.
- When requested, onsite training and consultations are conducted.



To learn more and register to become a member visit our website at

<http://pwsaofwi.org/become-a-member/>



Many donations were made over the last quarter in loving memory of loved ones who have been lost. PWSA of WI sends our deepest condolences to the families of **Kara Harper, Sue LaBella, and Joseph VanTuyle**. Their memories live on in all of you.





GLOBAL PRADER-WILLI SYNDROME REGISTRY

WWW.PWSREGISTRY.ORG

TOPIC HIGHLIGHT: SLEEP

61%

of respondents report having **AT LEAST** one sleep related issue

FREQUENCY OF SLEEP ISSUES



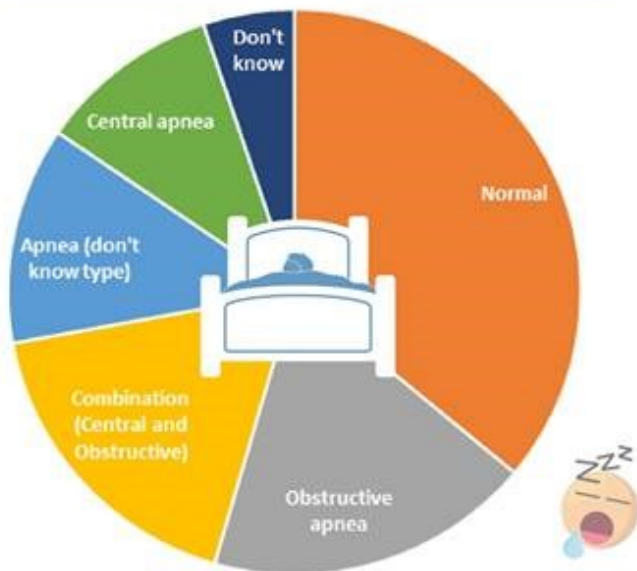
SLEEP STUDY RESULTS

87%

of respondents have had a sleep study

59%

who completed a sleep study reported apnea



Data as of December, 2017

Global Prader-Willi Syndrome Registry

The Global Prader-Willi Syndrome Registry is an endeavor that has been taken up world wide to compile data to get a detailed idea of the broad range of challenges individuals with PWS and their families and caregivers face. This collection of data will be help to expedite the completion of clinical trials, and to determine areas of needed research and treatments to improve the lives of those affected by PWS. The registry is open to anyone with PWS and the surveys can be completed by the parent or guardian of the individual with PWS or the individual themselves.

When you respond to questionnaires and surveys on the registry to will immediately get to see breakdowns of how others have responded as well.

If you are interested in finding out more about the registry check out www.pwsregistry.org.



Did you know PWSA of WI has a card club for individuals with PWS?!



Contact our program director at progdir@pwsaofwi.org to have birthday cards and seasonal cards sent to your loved one with PWS!

Do you know someone with Prader-Willi who no longer has family to provide them with gifts on their birthday or Christmas?



PWSA of WI has a gift giving program for these folks! Please contact us for more information so we can make their day.



7th Annual Snowflake Ball

A special evening of elegance... Just for You

SATURDAY, JANUARY 27, 2018

From 4 pm to 7:30 pm

Registration from 4-5pm • Dinner starting at 5pm • Dancing to follow

\$15 for Individuals with PWS; \$20 for Members; \$30 for Non-Members*

*Save on registration by becoming a member! Please go to pwsaofwi.org for more info.

WATERTOWN COUNTRY CLUB

1340 N Water Street • Watertown, WI 53098

A fancy dinner will be followed by
an evening of dancing and fun.

Dress attire is preferred



If you would like to attend our 2018 Snowflake Ball you can get the registration form by visiting our website at PWSAofWI.org or by contacting our program director either via phone 920-733-3077 or email progdir@pwsaofwi.org.

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 Web site: www.pwsaofwi.org

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Permit #75



PWSA of WI, Inc.'s Event Calendar		
Watertown Country Club, Watertown, WI	7th Annual Snowflake Ball	January 27th, 2018
Oconomowoc, WI	On the Move Walkathon	May 12th, 2018
Watertown, WI	PWSA of WI Golf Benefit	August 18th, 2018