



THE WISCONSIN CONNECTION

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

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.



I hope this newsletter finds everyone well here at the end of the year! As I write this Mother Nature has decided to bestow a lovely cold snap upon us. Sometimes working from home has its advantages and not having to venture out into the cold is definitely one of them!

It is hard to believe that it is already two months since I was in Florida for the PWSA (USA) National Convention. This was my third convention and I can honestly say that it was the best one I have been to. From the chapter leaders meeting to the closing ceremonies, this was easily my favorite across the board.

I started the conference meeting with leaders from other state chapters from all over the country. We had the opportunity to network and share strategies that will help make all of us better.

PWSA (USA) also gave us a number of ideas that will make us more successful.

Those first two days of meetings were followed by two amazing days of breakout sessions during the general convention. Every session had something useful to offer and helped build my knowledge. I got updates on GI issues and behavior management from previous conventions. I learned about some of the legal planning for individuals with PWS and their families as well as transitional planning in schools. I even received an overview of some psychotropic medicines and their use in individuals with PWS.

As always, meeting families was a big part of the convention as well. There were no families from Wisconsin this year that I had not met before but I did meet numerous people who neighbor our state and others who might be a great resource to me going forward when I don't have answers to someone's questions.

We have hit that time of year where schools start to think about IEPs and making changes. If you would like someone to provide support during this process, please let me know! If your child is struggling at school, this is a great time to give the school some training and assistance to try to turn things around. I am available to travel to them to do this so do not be afraid to reach out.

Our Snowflake ball will be here before we know it. I can't wait to see everyone's smiling faces. Have a wonderful holiday season and please feel free to reach out if you need anything!

Joshua Escher

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

Website: www.pwsausa.org

Save the Date:

PWSA (USA) 36th National Convention will be held June 22-26th, 2021 at Hilton Orlando Buena Vista Palace



CAREPWS

Clinical Study Recruiting for Prader-Willi syndrome (PWS)

CARE-PWS is a clinical study evaluating an investigational medicine for the treatment of Prader-Willi syndrome (PWS) in 7-18 year olds. People with PWS have a constant feeling of hunger, known as hyperphagia. Find out more.

www.carepwsstudy.com

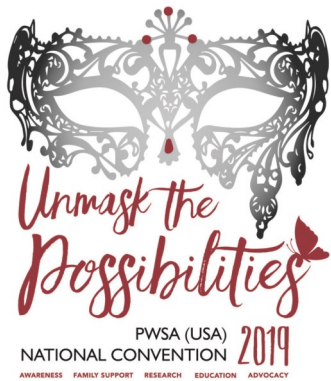


On October 12th we were joined by 137 friends, family, and individuals with PWS at the Bowlero in Wauwatosa. Everyone had a great time bowling, laughing, competing for raffle prizes, and meeting new friends! It was the biggest Strike Out PWS event yet. We can't wait for next year.



We would like to thank our two lane sponsors from this event. **Root Connections Consultative Services** and **Prader-Willi Homes a MyPath Company.**





A few of our Junior Advisory Board members traveled to Florida to volunteer at the PWSA (USA) National Convention. We asked them to share their thoughts. We are so proud of all of them. They really set the bar high in the programs they worked!

Going to the National Prader-Willi Conference in Florida this year had me feeling very excited to see all the participants again. The group I was working with I was put full of wonderful individuals with Prader-Willi and some amazing missionaries to help up with the activities. It was amazing to watch the missionaries interact and help the kids when they needed it. I am so grateful that I get to be a part of these events and get to celebrate a little bit of my life with them. I also love doing these events because my little sister has disabilities and sometimes she thinks she doesn't fit in. It is important to

us to tell her she is perfect and will always be able to do what she wants to no matter the challenge. My favorite event in Florida was us learning a dance to perform in front of all the parents and just share how these kids can do everything else we can do and just seeing their faces with smiles on them makes me happy.

-Josaphine Glass

I enjoy volunteering at the PWSA national convention in Florida because it helps me get closer to the residents and just have a good time. My little sister has hip dysplasia and a muscle defect, so I grew up with disabilities in my home. I volunteer because I like to watch them have a good time and connect with each other in a safe environment. My favorite part of the convention is the parade at the end I love watching them all dance for their parents it puts a huge smile on our face. I am so excited for next time to reconnect with my kiddos from this year's group and hopefully make some new friends.

-Eva Glass

October 23-26, 2019 was a rewarding and fun time for me as I volunteered for PWSA USA. I volunteered to provide childcare for the parent mentor and chapter leaders so they could attend meetings when their children were taken care of and having a great time. I also volunteered in YAP as a crew leader for the youngest participants. Working with these kids with PWS is always so rewarding. I love helping them learn new crafts and games, and seeing the smiles on their faces when they are just being kids and having fun. They are so fun, caring, and loving. Volunteering and working with people with PWS is my true passion. I can't wait to have some of the same kids in my group in 2021 and to meet new ones!

-Maddie Tula

My name is Makenzie Gaulke and this year I had the honor for my second time to volunteer at the Prader Willi Convention. My first two days I helped watch the little kids as the parent mentors had their meeting. I was happy to spend time and get to know so many more young kids like my brother. It also helped me see how every child is different and faces different challenges. My second two days I got to work with younger adults with Prader Willi, along with assisting at the Gala. Working with the older individuals I have really gained a better understanding at what my brother's future looks like and has really helped me prepare for the future. I really enjoy helping and look forward to helping again.

-Makenzie Gaulke

On October 23rd, I flew to Florida to volunteer during the PWSA National Convention. For the first two days I helped provide child care so Chapter Leaders and Parent Mentors could attend their respective meetings and evening social. The kids and I played games, watched movies and got out some of our energy by taking walks. During the last two days of the Convention, I worked in YAP with Jamie. We helped the participants with a variety of activities, such as creating masks, parade signs, and calming bottles. We also helped them learn the dance that everyone would perform at the closing ceremony. During the YAP gala, I helped to serve food to all of the attendees and helped to ensure the peeps were safe and having fun. I also did a lot of heavy lifting whenever anything needed to be moved throughout the time I was there volunteering. It was an honor to represent the PWSA-WI, Inc Junior Advisory Board and I truly enjoyed my time working with all of the individuals with PWS who attended the programs I worked in.

-Kameron Boser

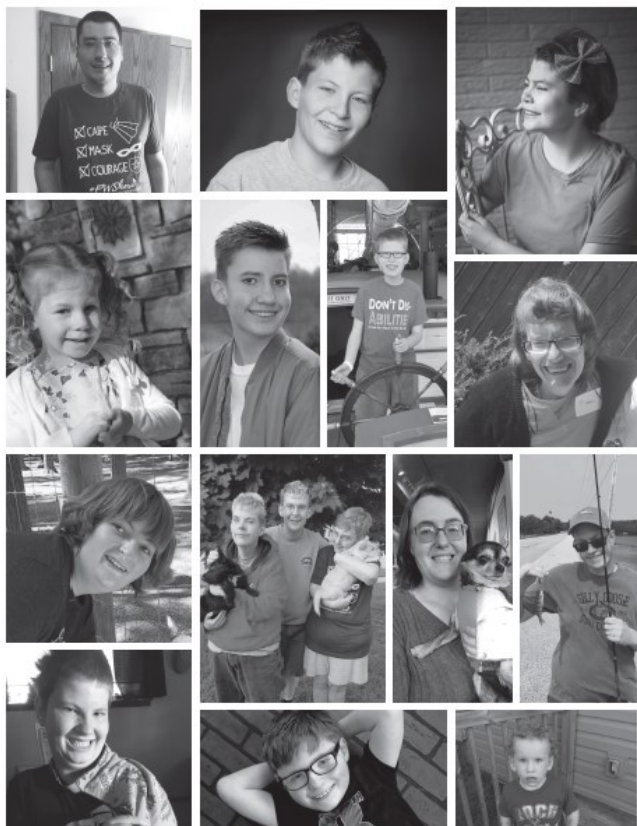
Ninth Annual Snowflake Ball

A special evening of elegance... Just for You

To register head over to pwsaofwi.org and click on the Snowflake Ball event.

SATURDAY, FEBRUARY 1, 2020

From 4 pm to 7:30 pm



The difference **YOU** can **MAKE:**

YOU MAKE ALL THE DIFFERENCE • CARING IS SHARING

\$25,000

Allows you to host the Annual Snowflake Ball, a safe and fun dinner and dance cost-free to over 100 individuals with Prader-Willi syndrome.

Our annual Caring is Sharing fundraising drive plays a big role in providing the financial support we need to fund the programs and services we offer. Please, if you haven't already, consider donating!

\$2,500

Allows PWSA of WI to host quarterly PWS-expert presentations for families.

\$250

Ensures 5 families have the money for travel to necessary doctors' appointments.

You can donate by mailing a check to PWSA of WI, Inc PO Box 324 Menasha, WI 54952 or by visiting our website pwsaofwi.org/donate

\$25

Sends 5 Packets of Hope to families with a new diagnosis or education materials to schools that have a student with Prader-Willi syndrome.



Thank You!

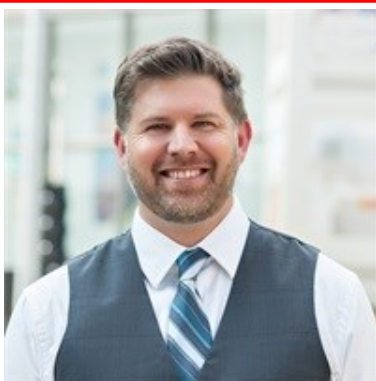
We would like to thank Ryan Finkenbinder and Lynn Ann Parrish for their two years of service on our Board of Directors. They may be stepping away but they will always be a part of our family!



Welcome!

We would like to welcome Angela Catteruccia to the Board of Directors for the 2020-22 term! Angela is very excited to be involved with our organization. We wanted to share her application so you all could get to know her a little better.

My adventure with PWSA, WI began in 2016 when I helped plan and execute the PWSA Snowflake Ball at Watertown Country Club. Since then, I have worked with the membership in the planning and execution of three VERY successful Snowflake Balls and the first Annual PWSA WI Gala that was held just a few weeks back at The Red Circle Inn. My interactions with Crystal, Kim, Jackie and the entire team lead me to wanting to know and do more for such a great foundation. I believe that my attention to detail, enthusiasm, energetic attitude, and positivity would flourish amongst the PWSA WI membership. My previous employment never lent much time for volunteering or participating in anything outside of my daily grind of the workplace. I feel that I have the time and will be 100% dedicated to the board and membership. Being involved...engaged in the activities and events that are associated with the foundation are more than intriguing to me and absolutely love being part of it. I am not far from the big ol' 50 and I would like to look back and say to myself, "Hey self, you finally did something important with your time and you made a difference in someone's life!" Interacting with the kiddos of PWSA WI from the start and I don't know how to put it in words, but...fulfilled, made me happy, excited, and my heart was full knowing that they all felt the same way. My fiancé and I don't have any kiddos with PWS, but our eldest son, Anthony, was diagnosed with bi-polar at an early age and we went through the mania, out bursts, and the not-knowing what would happen next on a day to day basis. He is older now and is an amazing artist and is doing well. We also have two other children. Andrew, he plays semi-pro football and is also currently pursuing a career in law enforcement. Our daughter, Kalin...well unless you have two weeks of spare time I can certainly dive into her and our past, but think I will save you the agony and just say that she is truly a free spirit and is 150% a force to reckon with! My fiancé and I are empty nesters aside from our four-legged fur-son, Tanner. He's a 13 year old Pibble and living life as a very happy house hippo. Needless to say, now that I no longer have little kiddos to take care of, there is now time for me and I would love nothing more than to put extra time into PWSA WI.



Patrick MacGrath from **Private Wealth Management Group LLC** has been providing us with written pieces about financial planning needs for individuals with special needs and their families. Patrick would like to continue this series but he wants to know that you the reader are getting something out of it. Let us know! progdir@pwsaofwi.org or 920-733-3077

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On September 29th fifteen brave golf teams thumbed their noses at mother nature and played through a misty/rainy day. Our new location at The Oaks in Cottage Grove provided us with a well drained course to play upon. We followed up with a wonderful lunch and a few really awesome raffle prizes. We already look forward to an even bigger and better event next year!



We would like to thank our Beverage Cart Sponsor **Affeldt Law Offices, S.C.**



Asian Chicken Thighs

Prep: 15 min. Cook: 50 min. Makes 5 servings

Ingredients

- 5 teaspoons olive oil
- 5 bone-in chicken thighs (about 1-3/4 pounds), skin removed
- 1/3 cup water
- 1/4 cup packed brown sugar
- 2 tablespoons orange juice
- 2 tablespoons reduced-sodium soy sauce
- 2 tablespoons ketchup

- 1 tablespoon white vinegar
- 4 garlic cloves, minced
- 1/2 teaspoon crushed red pepper flakes
- 1/4 teaspoon Chinese five-spice powder
- 2 teaspoons cornstarch
- 2 tablespoons cold water
- Sliced green onions
- Hot cooked rice, optional

recipe and image from tasteofhome.com

Directions

- 1) In a large skillet, heat oil over medium heat. Add chicken; cook 8-10 minutes on each side or until golden brown. In a small bowl, whisk water, brown sugar, orange juice, soy sauce, ketchup, vinegar, garlic, pepper flakes and five-spice powder. Pour over chicken. Bring to a boil. Reduce heat; simmer, uncovered, 30-35 minutes or until chicken is tender, turning chicken occasionally.
- 2) In a small bowl, mix cornstarch and cold water until smooth; stir into pan. Bring to a boil; cook and stir 1 minute or until sauce is thickened. Sprinkle with green onions. If desired, serve with rice. **Freeze option:** Cool chicken. Freeze in freezer containers. To use, partially thaw in refrigerator overnight. Heat slowly in a covered skillet until a thermometer inserted in chicken reads 165°, stirring occasionally and adding a little water if necessary.

Nutrition Facts

1 chicken thigh (calculated without rice): 292 calories, 14g fat (3g saturated fat), 87mg cholesterol, 396mg sodium, 15g carbohydrate (13g sugars, 0 fiber), 25g protein. Diabetic Exchanges: 3 lean meat, 1 starch, 1 fat.

The following is an excerpt from the article “**Hypothermia and Prader-Willi Syndrome-An Overview**” written by Barb Dorn, RN, BSN for PWSA (USA). The full piece can be found on their website pwsausa.org.

Over the years, there have been reports and research studies done on persons with PWS that have provided a mixture of results in supporting the premise that individuals with PWS have a defect in temperature regulation.

Factors Contributing to Hypothermia

- ◆ Age – Infants and older persons are at greater risk
- ◆ Exposure to cold temperatures
- ◆ Inadequate heating in home or workplace – conditions do not have to be extreme.
- ◆ Inappropriate dress – not wearing adequate warm clothing.
- ◆ Falling in cold water
- ◆ Medications – Opioids (pain medications), certain anti-hypertensive medications, anesthetics, some atypical antipsychotics and antidepressants.
- ◆ Certain medical conditions – stroke, spinal cord injuries, hypothyroidism, severe arthritis, Parkinson’s disease, dehydration, other nerve disorders.

Symptoms of Hypothermia

Early/Mild Hypothermia:

Shivering, dizziness, nausea, increased breathing and heart rate, slurred speech or difficulty talking, slight confusion or lack of coordination, fatigue, cold, pale or blue gray skin

Moderate/Severe Hypothermia:

Shivering (decreases and stops as it progresses), weak pulse, slow respirations, increased confusion, drowsiness (progresses to loss of consciousness), infants may appear limp, weak cry, cold, red skin

To purchase PWSA of WI merchandise visit pwsaofwi.org/merchandise



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PWSA of WI, Inc.'s Event Calendar		
Red Circle Inn & Bistro, Neshotah, WI	PWSA of WI, Inc 9th annual Snowflake Ball	February 1st, 2020
Riverside Park, Watertown, WI	On the Move Walkathon	May 9th, 2020
The Oaks, Cottage Grove, WI	PWSA of WI, Inc's Annual Golf Benefit	September 27th, 2020