



THE WISCONSIN CONNECTION

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

Website: www.pwsausa.org

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.



Letter From the Office

Program Director

Joshua Escher

Happy New Year! I know this is the Winter *21* newsletter but honestly, it makes sense that it would come out a little late because, well, these days we have to be ready to zig when you are supposed to zag! Unfortunately we were forced to postpone our Snowflake Ball but we are determined to hold it in some form this year. Combine that with our On the Move Walkathon we are definitely planning to see your smiling faces in person this year.

Parents, it is that time of year again. IEP reviews are coming fast. Some of you might even have them scheduled already! If you would like some support with them, let me know. I can attend meetings with you or look over the IEP before you sign it. Maybe you just want to have someone to bounce ideas off of beforehand. I am here for that too!

I have heard from a few folks in the last couple months that have been looking for options for things like respite. Staffing is down across the board so many of the usual suggestions are unable to accommodate. If you have some ideas for me, please let me know! I hope everyone is staying warm. The days are already getting longer and before we know it spring will be here. As always, don't hesitate to reach out if you need anything!

THANK YOU!

PWSA of WI often gets donations through employee match programs and other programs that allow you to donate directly from your paycheck. Oftentimes we are not given the information to be able to properly thank those donors. If you are one of them, thank you! We greatly appreciate your support!

Many employers have programs to encourage their employees to support non-profit organizations. Speak with your HR people to get more information and let us know if you need our information or help to make that happen.



Thank You Kim!

Kim Tula leaves our board of directors after 5 wonderful years. She spent a portion of that time as Vice President of the organization. Kim has pledged to continue volunteering but she will be greatly missed nonetheless!

We would like to welcome a number of new faces (and one returning face) to our board of directors for the 2022 to 2024 term.



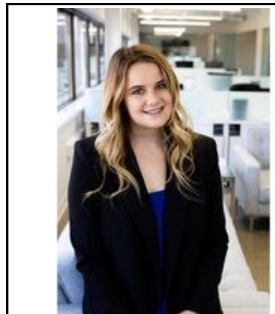
Sarah Glass: After watching my sister Jamie Milaeger and daughters Josaphine and Eva Glass participate with this group, I have seen the joy that comes from their interactions. I have found this disorder fascinating the more I learn about it and would love to see others learn from it as well.

I have first hand knowledge of raising a child with special needs (though not PW) and raising a family of 4 total children I understand the importance of knowledge and education for ourselves and others in order to find new treatments, support and new opportunities for individuals with Prader-Willi or any disability to live a more comfortable life.

I participated for four years on our schools PTO board as VP of Fundraising finding new ideas of things we could do to help engage our community with our school at the same time.



Melissa Sirovina: My daughter, Kayla, is 27 years old and lives at Downing House. I was on the PWSA of WI board while my children (all 3 girls) were still at home. I left the board to pursue a degree in business as well as coach the kids' basketball teams, travel for sports, and be the active/supportive parent in their interests while including them in mine. Now that they are grown, I again have time to devote to being an advocate for our individuals with Prader-Willi. I enjoy the comradery with others as well as the chance to educate anyone from the new parent to our family to a doctor who has questions on Prader-Willi. I've been through fighting the education system in order to give Kayla all the chances she deserved as well as getting through the government red tape to get her into the Prader-Willi Homes. I believe my experiences will be a benefit to the board.



Katelyn Schmidt: I am the owner of Abilities Midwest, a new PWS-specific residential provider located in River Falls, WI. Opening Abilities Midwest was a dream come true for me. I first learned about Prader Willi when I was a child when my cousin was diagnosed with it. It was my cousin having PWS and my interest in what his life may look like over the years that later caused me to come across a group home provider called Stepping Out, which is located in Hastings, MN. Upon coming across their website, I saw they were hiring for Direct Care Staff. I applied, and ended up spending over 6 years there, working directly with adults with PWS. I later went on to go to school for Human Services, and eventually started working as a Behavioral Modification Assistant for the MN Department of Human Services. However, I still couldn't leave Stepping Out. Through my experience at both jobs, I learned what I thought worked well, as well as what I believe didn't. I knew over the years that I wanted to open up my own group home, so I took my experiences along with my husband and we opened Abilities Midwest.

Although it was not easy starting our company from scratch, I have truly enjoyed loved my career path. The saying "Do what you love and you'll never work a day in your life." couldn't be more true for me! Outside of work, I enjoy spending time with my husband, two rescues dogs, and our foster children.

By joining PWSA-WI I believe I can provide a lot of prospective as a provider, as well as contribute from my experience working in a number of roles within the Human Services field. I am passionate about advocating for individuals with Prader Willi and continuing to help increase services whenever and wherever I can.



Brandon Schmidt: I am the co-owner of Abilities Midwest, where my primary position is the company's Athletic Coordinator. My job is to conduct initial and ongoing fitness assessments, where I determine each resident's strengths and weakness to develop fitness plans. I then assist each resident with their nearly daily exercise routines. I also help coordinate other athletic opportunities for our residents, such as Special Olympics participation while educating others on the components of PWS. I strive to ensure they are receiving a good workout, while also learning to love fitness to in return live a healthy, happy life! I first learned about Prader Willi from my wife, who has a cousin with the syndrome. My wife always spoke about how much she enjoyed her job. At that time, I wasn't happy in my career path and chose to make a complete change to the Human Services field. I began working at a Prader Willi specific provider in Minnesota in order to gain direct PWS experience while my wife and I worked to open up our own group home. Watching our company come together was an amazing experience, and I look forward to watching it continue to grow.

Outside of Abilities Midwest, I coach high school soccer and play recreational softball. I enjoy ending time with my wife, our dogs, and being a foster dad.

I believe I would be a good addition to PWSA-WI as I can provide prospective as a provider and a former direct care staff. I also would love to help families however I can with finding athletic opportunities for their loved ones to help them too live a healthy, happy life.

Saniona Initiates Phase 2b Clinical Trial of Tesomet for Prader-Willi Syndrome

PRESS RELEASE

December 28, 2021

Saniona (OMX: SANION), a clinical-stage biopharmaceutical company focused on rare diseases, today announced the initiation of a Phase 2b clinical trial of Tesomet in patients with Prader-Willi syndrome (PWS). Tesomet is an investigational fixed-dose combination therapy of tesofensine, a triple monoamine reuptake inhibitor, and metoprolol, a beta-1 selective blocker. Data from the trial are expected in the first half of 2023.

“The initiation of this Phase 2b clinical trial of Tesomet in Prader-Willi syndrome follows our recent initiation of a Phase 2b clinical trial of Tesomet in hypothalamic obesity – two serious diseases with high unmet need,” said Rudolf Baumgartner, M.D., Chief Medical Officer and Head of Clinical Development at Saniona. “In addition to these two trials, we are also conducting a Phase 1 clinical trial of SAN711, which means Saniona is ending 2021 with three clinical trials ongoing. This is a significant achievement and represents the hard work and expertise of our clinical, regulatory, technical operations and quality teams.”

The Phase 2b clinical trial in PWS includes a randomized, double-blind, placebo-controlled 16-week treatment period followed by a 36-week open-label extension period. The trial is expected to enroll approximately 120 patients with genetically-confirmed PWS. Initially, the trial will enroll adults (18 to 65 years of age) and then, following confirmation by the data monitoring committee and by the FDA, the trial is planned to expand into adolescents (13 to 17 years of age). During the 16-week double-blind period, participants will be randomized to receive daily dosing with Tesomet at one of three dose levels or a placebo. During the 36-week open-label extension period, participants who wish to continue treatment, including those who originally received placebo, will receive the highest tolerated dose of Tesomet as established during the double-blind period. The primary objective of the study will be change in hyperphagia at week 16 as measured by the Hyperphagia Questionnaire for Clinical Trials (HQ-CT), a caregiver-reported survey that evaluates food-seeking behavior, such as frequency of sneaking food or time spent talking about food, and which has been used as the primary outcome measure for most PWS clinical trials. Secondary endpoints include change in body weight, change in caregiver impression of hyperphagia, change in clinician impression of overall disease severity, and change in clinician impression of overall clinical status.

The clinical trial is being conducted at multiple sites around the world including in the United States, New Zealand, Australia, and in multiple countries in Europe including the United Kingdom, Sweden, Italy, Spain and others. More information is available at www.praderwillisyndromestudy.com or www.clinicaltrials.gov.

“Currently, there are no approved treatments for hyperphagia, the uncontrollable hunger that is one of the most debilitating symptoms of PWS,” said Paige Rivard, CEO of Prader-Willi Syndrome Association USA. “We are encouraged to see Saniona addressing hyperphagia, and we look forward to working with them to support this clinical trial through education and outreach amongst our community.”

“As a physician scientist with over 40 years of clinical practice experience, I have researched PWS extensively and cared for many patients and families afflicted by this disorder,” said Merlin G. Butler, M.D., Ph.D., Professor of Psychiatry, Behavioral Sciences and Pediatrics, and Director of the Division of Research and Genetics and the KUMC Genetics Clinic at the University of Kansas Medical Center. “The complex presentation of PWS has made it a difficult target for drug developers, but I am encouraged by the initial Tesomet data and look forward to the data from this clinical trial.”

Saniona previously evaluated Tesomet in a randomized, double-blind, placebo-controlled initial Phase 2 trial in adults and adolescents with PWS. Adult patients receiving Tesomet achieved a statistically significant reduction in hyperphagia, as well as a reduction in body weight. Adolescent patients demonstrated dose-dependent reductions in hyperphagia and body weight in open-label extensions of the study. Tesomet received orphan drug designation in PWS from the FDA, who also confirmed that Tesomet may be advanced via the 505(b)(2) regulatory pathway. Saniona is partnering with the Foundation for Prader-Willi Research (FPWR), the Prader-Willi Syndrome Association USA (PWSA-USA), and the International Prader-Willi Syndrome Organisation (IPSWO) to inform the clinical trial design and clinical development processes, and to raise awareness within the PWS community.

Saniona is also evaluating Tesomet in a Phase 2b clinical trial for hypothalamic obesity (HO). The FDA granted Tesomet orphan drug designation in HO in July 2021.

For more information, please contact

Trista Morrison, Chief Communications Officer, Saniona. Office: + 1 (781) 810-9227. Email: trista.morrison@saniona.com

National Awareness!

On December 5th, Denver Broncos Safety Caden Sterns wore cleats during his game against the Kansas City Chiefs adorned with the logo of the Prader-Syndrome Association USA. He wore the cleats as part of the NFL's annual 'My Cause My Cleats' campaign.

Caden's friend and mentor has a daughter named Brooklyn who has PWS. Brooklyn attended the game and was awarded with the cleat that also featured her name after the game.

Thank you for your support Caden!



Since we have postponed our Snowflake Ball to an as yet to be determined date we have decided to bring back the Family Virtual Bingo nights! This is a free event for the whole family! Join our program director Josh as he calls the letters and numbers and gives out prizes to the winners.

You can register for the event by going to this web address.

<https://cutt.ly/1IwmPaz>

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!



on the
MOVE
 PRADER-WILLI SYNDROME ASSOCIATION (USA)

Save the date:

Saturday May 7th

Roosevelt Park in Oconomowoc

We can't wait to see everyone in person!



Zucchini Noodles with Avacado Pesto & Shrimp

Ingredients

- 5-6 medium zucchini (2 1/4-2 1/2 pounds total), trimmed
- 3/4 teaspoon salt, divided
- 1 ripe avocado
- 1 cup packed fresh basil leaves
- 1/4 cup unsalted shelled pistachios
- 2 tablespoons lemon juice
- 1/4 teaspoon ground pepper
- 1/4 cup extra-virgin olive oil plus 2 tablespoons, divided
- 3 cloves garlic, minced
- 1 pound raw shrimp (21-25 count), peeled and deveined, tails left on if desired

- 1-2 teaspoons Old Bay seasoning

Directions

- 1) Using a spiral vegetable slicer or a vegetable peeler, cut zucchini lengthwise into long, thin strands or strips. Stop when you reach the seeds in the middle (seeds make the noodles fall apart). Place the zucchini "noodles" in a colander and toss with 1/2 teaspoon salt. Let drain for 15 to 30 minutes, then gently squeeze to remove any excess water.
- 2) Meanwhile, combine avocado, basil, pistachios, lemon juice, pepper and the remaining 1/4 teaspoon salt in a food processor. Pulse until finely chopped. Add 1/4 cup oil and process until smooth.
- 3) Heat 1 tablespoon oil in a large skillet over medium-high heat. Add garlic and cook, stirring, for 30 seconds. Add shrimp and sprinkle with Old Bay; cook, stirring occasionally, until the shrimp is almost cooked through, 3 to 4 minutes. Transfer to a large bowl.
- 4) Add the remaining 1 tablespoon oil to the pan. Add the drained zucchini noodles and gently toss until hot, about 3 minutes. Transfer to the bowl, add the pesto and gently toss to combine.

Nutrition Facts

Serving Size:

1 3/4 cups each

Per Serving: 446 calories; protein 25.9g; carbohydrates 15.8g; dietary fiber 6.6g; sugars 6.6g; fat 33.2g; saturated fat 4.7g; cholesterol 158.8mg; vitamin a iu 1143.9IU; vitamin c 54.7mg; folate 112.3mcg; calcium 140.8mg; iron 2.4mg; magnesium 109.6mg; potassium 1271.2mg; sodium 712.9mg; thiamin 0.2mg.


This recipe originated from eatingwell.com

February is Rare Disease Month and February 28th is this year's Rare Disease Day. Make sure to share some information about Prader-Willi syndrome to spread awareness!

Graphic created by the KAT6A Foundation



Do you have a teacher, doctor, care provider, or other professional that you think deserves to be recognized for their service to the PWS community? We want to reward them! Visit our website at <https://pwsaofwi.org/ProRecognition> and fill out an application today! Each winner will receive a certificate, a card, and a \$50 gift card.



80 % of rare diseases are genetically based.

Many rare diseases result in premature death of infants & young children or are fatal in early adulthood.

Families & private foundations provide about 3% of all medical research funding in the U.S.

90% of healthcare providers must treat the majority of rare disease patients with non-FDA approved drugs.

1 in 10 Americans has a Rare Disease 30 million people have a serious, lifelong condition.

More than half are children

Holding hands, they would circle the globe about 1.5 times

7,000 Rare diseases exist, with less than 500 FDA-approved treatments → **5%** of rare diseases have treatments.

RARE DISEASE DAY

WHAT IS A RARE DISEASE? Any disease, disorder, illness or condition affecting fewer than 200,000 people in the United States is considered RARE.

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





Wonderland Camp is a summer camp in Missouri that provides a place for kids with disabilities to have an awesome camp experience in a safe environment. Wonderland camp provides a Prader-Willi specific week each summer. This year they will be holding that during the week of June 12-17th and has a Magic theme! You can check them out by visiting wonderlandcamp.org.

WONDERLAND
Camp EST. 1969

Scholarships to attend camps are available for PWSA of WI members who may not be able to afford them on their own. You can find more information about that here:

<https://pwsaofwi.org/Scholarships2>

Behavioral Training for Caregivers of Children with Prader-Willi Syndrome

We are looking for research study participants!

Help us learn about the effects of a behavioral caregiver training program for caregivers of children with PWS

Caregivers must be at least 18 years of age, must speak and read English, and live in the home with their child with PWS.

Caregivers must be able to participate in an online program with both live and recorded sessions.

Children must be aged 2-12, have a diagnosis of PWS, have no other diagnoses, and engage in at least one disruptive behavior. Children must have a caregiver who will also participate in the study.

Caregivers will participate in a 10-week caregiver training program, complete pre and post training surveys and testing, and collect child behavior data.

Including pre-testing and post-testing, the study will take 12-13 weeks in total, and will require between 30min -2hours per week.

The training, testing, and surveys will be done remotely using Zoom and Qualtrics.

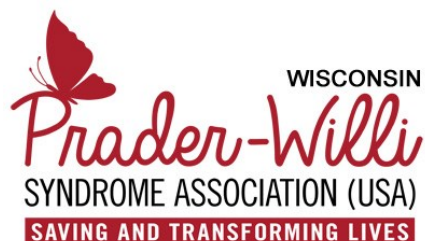
Participants will be compensated with a \$500 Visa gift card following the completion of the study. Assistance with computer and internet access may be available for a limited number of participants who need it to participate.

For more information, contact
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Permit #75



PWSA of WI, Inc.'s Event Calendar		
From the comfort of your own home.	Saturday January 29th, 2022	Virtual Bingo Bash
Roosevelt Park, Oconomowoc, WI	Saturday May 7th, 2022	On the Move Walkathon
	Postponed, TBD	Snowflake Ball