

THE WISCONSIN CONNECTION

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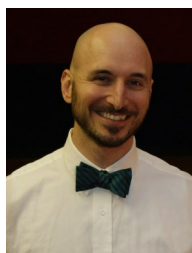
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*The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.
Supporting, Educating and Advocating for Persons with Prader-Willi Syndrome and All who
are Impacted by this Disorder*

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



As I write this, the sun is shining and March is already sliding down to its end. Unfortunately that bright shiny sun is not quite yet accompanied by the warmth of spring but hey, we have to take what we can get here in Wisconsin right?

As a former teacher this time represented a bittersweet time. It means the end of the school year was fast approaching. That meant sending my kids on to the next grade level that hopefully I had prepared them for. As many teachers will probably agree, this is hard because they are *OUR* kids and we become so invested in them and want to make sure each one of them succeeds. It also meant lots of behavior issues as the year winds down, the weather gets nicer, and the class schedule gets more and more messed up by holidays, school assemblies, end of the year activities, and the like.

Our young folks with Prader-Willi are not immune to these challenges and this can be a very difficult time of the year for them. We can often be more willing to overlook behavior changes at the end of the school year because we know that they will soon not be an issue as that last school bell tolls for the year. Talk to your child's teacher about the importance of keeping their schedule as consistent as possible. Work with them to help foreshadowing the inevitable changes that will be happening. Being proactive is the best solution.

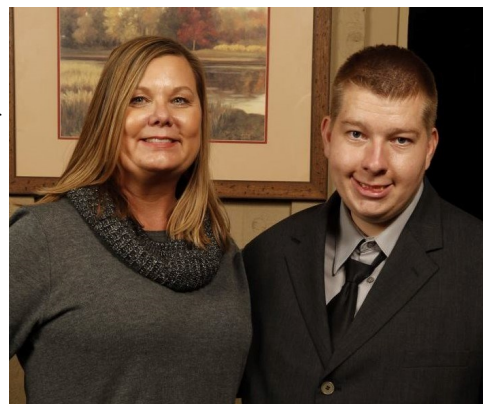
This time of year is also the perfect time to start working on transitioning into next year. If the school is able to tell you who will be their teacher next year (sometimes these decisions aren't made until after the school year is over and contracts are signed) have your child meet them. Get a tour of their classroom. Find out where their new locker will be. By eliminating the unknown we can limit the anxiety of the changes to come.

As always, please let me know if you need assistance. I am able to come to your child's school free of charge to assist! Happy Spring!

Save The Date!

June 23rd, 2018

Tammy Penta, a retired police officer and mom of Victor, a young man with PWS, will be coming to Wisconsin to do two presentations. One will be for parents and caregivers and one for police personnel. She is the treasurer of the Arizona chapter of PWSA (USA) and also a board member for PWSA (USA) and works with the national organization to help train law enforcement in how to deal with individuals with PWS and what to expect.





Do you have a physician you love? We would love to hear about them! PWSA of WI often gets inquiries from parents and caregivers looking for primary care physicians and other specialists in their areas. Currently we will reach out to families in those areas to ask for recommendations but we would love to get an up to date list together. If you have a doctor you would like to recommend to us, please email us at progdir@pwsaofwi.org or call 920-733-3077.

Drawing Blood In Children With PWS

Individuals with Prader-Willi syndrome may have difficulties with blood draws. The hypotonia and increased subcutaneous fat may make finding landmarks more difficult for the phlebotomist. These are some hints that may help.

- 1) If your child has had difficulty in the past with blood draws, warn the lab tech that an experienced person will be needed because your child is a “hard stick.” The usual guideline is that the phlebotomist should try twice. If he or she is unsuccessful after two tries; then someone else should try. Do not be afraid to ask up front for the most experienced individual. That individual may not be present at the time, so depending on what labs are needed, you might ask if the blood draw can be postponed until that person is present. In most children’s hospitals, the phlebotomist would have the most experience with little children. On occasion the parents might wish to ask for a neonatal nurse to come down for the draw. In smaller hospitals, the parents might be able to request a pediatric/newborn nurse, who may have more experience than the phlebotomist, and the hospital may be better able to comply with that request.
- 2) 2) Request a prescription from your doctor for EMLA cream to help numb the area. EMLA should be placed on the skin 45 minutes prior to lab draw.
- 3) 3) Give your child plenty to drink several hours before the visit to the hospital/doctor. If the weather is cold, bundle them warmly on the way for the blood draw. Ask for warm packs to place on the blood draw site.

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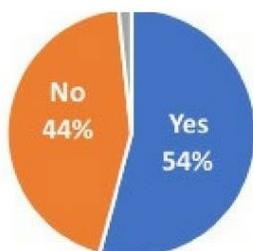
PWS PROTIP!

When your child has a blood draw done, take a picture of the successful stick so you can show to future phlebotomists and nurses. This might make their job a little easier and your life a little less stressful!



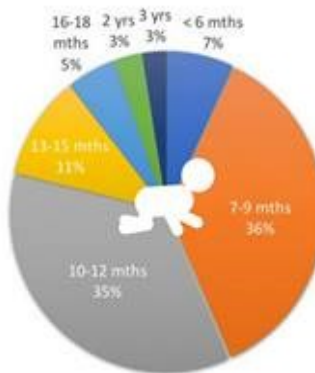
VOMITING

MORE THAN **50%** OF PARTICIPANTS HAVE **VOMITED**



MILESTONE AGE

CRAWLING AGE



WALKING AGE



Data reported from the registry compares favorably with historic reports of motor development in PWS. This is likely a reflection of earlier diagnosis and more infants receiving growth hormone therapy.

CHOKING

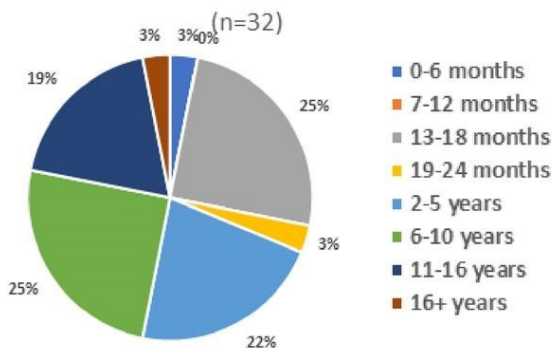
OF PARTICIPANTS HAVE **18% CHOKED**



50% OF CHOKING INCIDENTS WERE SEVERE ENOUGH TO REQUIRE THE

HEIMLICH

Choking is still a concern past the toddler years. For participants age 5+ who have had a choking incident, more than 50% happened at age 6 or older

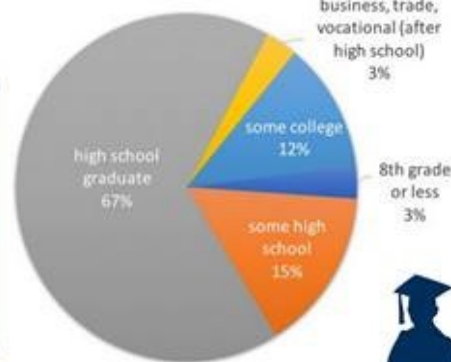


HIGHEST LEVEL OF COMPLETED EDUCATION



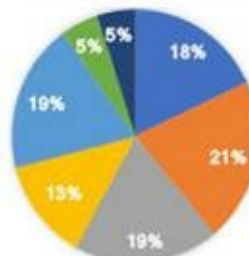
ages 18+

81% of participants have graduated high school.



GROWTH HORMONE USE

AGE STARTED GH



91% of participants have used GH



Data as of February, 2018

Data as of January, 2018



Wisconsibs is an organization in Wisconsin that supports the brothers and sisters of individuals with disabilities. We sometimes forget that siblings go through their own struggles. The only people who can truly understand those challenges are other siblings. Wisconsibs works to provide support to siblings through activities and events across the state of Wisconsin.

Wisconsibs provides support to siblings of all ages. While we may usually think of younger sibs when considering these challenges, older sibs are often part of the “sandwich” generation. These sibs are often finding themselves having the responsibility of both caring for their aging parents as well as their sibling.

Some things the organization provides:

- Workshops
- Camps
- Social Events
- Summer Programs
- Volunteer Training
- Discussion Groups

To learn more about this amazing organization visit wisconsibs.com



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



PRADER-WILLI SYNDROME ON THE MOVE
MAY AWARENESS WALK-A-THON
ROOSEVELT PARK
OCONOMOWOC • WI
MAY 12 2018

PLEASE JOIN US FOR THIS NATIONAL AND LOCAL FUNDRAISING, AWARENESS EVENT
GET MORE INFORMATION ON THIS GENETIC DISORDER THAT AFFECTS 1 IN 15,000.
WHAT IS PRADER-WILLI SYNDROME? go to www.pwsaofwi.org

Online registration can be found at:
<https://www.firstgiving.com/event/pwsaofwi/on-the-move-walkathon-2018>





FIVE-SPICE TURKEY & LETTUCE WRAPS

This recipe appears on eatingwell.com

Ingredients

- ½ cup water
- ½ cup instant brown rice
- 2 teaspoons sesame oil
- 1 pound 93%-lean ground turkey
- 1 tablespoon minced fresh ginger
- 1 large red bell pepper, finely diced
- 1 8-ounce can water chestnuts, rinsed and chopped
- ½ cup reduced-sodium chicken broth
- 2 tablespoons hoisin sauce, (see Note)
- 1 teaspoon five-spice powder, (see Note)
- ½ teaspoon salt
- 2 heads Boston lettuce, leaves separated
- ½ cup chopped fresh herbs, such as cilantro, basil, mint and/or chives
- 1 large carrot, shredded

Directions

1. Bring water to a boil in a small saucepan. Add rice; reduce heat to low, cover and cook for 5 minutes. Remove from the heat.
2. Meanwhile, heat oil in a large nonstick pan over medium-high heat. Add turkey and ginger; cook, crumbling with a wooden spoon, until the turkey is cooked through, about 6 minutes. Stir in the cooked rice, bell pepper, water chestnuts, broth, hoisin sauce, five-spice powder and salt; cook until heated through, about 1 minute.
3. To serve, divide lettuce leaves among plates, spoon some of the turkey mixture into each leaf, top with herbs and carrot and roll into wraps.

Make Ahead Tip: Prepare the filling (through Step 2), cover and refrigerate for up to 1 day. Serve cold or reheat in the microwave.

Tips: Hoisin sauce is a spicy, sweet sauce made from soybeans, chiles, garlic and spices. It will keep in the refrigerator for at least a year.

Often a blend of cinnamon, cloves, fennel seed, star anise and Szechuan peppercorns, five-spice powder was originally considered a cure-all miracle blend encompassing the five elements (sour, bitter, sweet, pungent, salty). Look for it in the supermarket spice section.



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 <http://pwsaofwi.org/professional-service-provider-recognition/> and fill out an application today! Each winner will receive a certificate, a card, and a \$50 gift card.



On January 27th we held our annual Snowflake Ball at the Watertown Country Club. Over 230 individuals with PWS, parents, family members, and friends attended the yearly event. The goal is to provide an elegant night that gives those in our community a wonderful opportunity to socialize and have great fun! The night was started off with a healthy low calorie dinner and was finished with dancing to music provided by a DJ.

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PWSA of WI, Inc.'s Event Calendar		
Roosevelt Park, Oconomowoc, WI	On the Move Walkathon	May 12th, 2018
Windwood of Watertown	PWSA of WI Golf Benefit	August 18th, 2018
AMF Bowlero, Wauwatosa, WI	Strike Out PWS Bowlation	September 22nd, 2018