



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 President

Happy Fall Everyone!

2017 has been an extremely busy year for PWSA-WI, Inc! We hosted our 6th Annual Snowflake Ball, which brought in friends from Arizona, Florida, Indiana, Ohio, Maryland and New Hampshire (Sorry if I missed anyone from other states). We also hosted our 7th Annual On the Move Walk-a-thon, 17th Annual Golf Benefit and 3rd Annual Strike Out PWS bowling event. In addition, we hosted our 3rd Annual Henry Villa Zoo trip in Madison for our families with younger children. Janice Agarwal, PT, CNDT also traveled to Wisconsin and presented on therapeutic interventions to help teens and adults with PWS become more active and decrease many of their anxieties as well as a how-to workshop on motor/sensory development for infants/toddlers. These fun and educational events were made possible thanks to generous donations from our membership, friends, family and corporate sponsorship.

Thanks to everyone's generosity, our Program Director has also been very busy helping various families throughout Wisconsin with regard to ISP's, BIP's, residential placements, and hospitalizations. We've also been able to award several scholarships to help families attend the upcoming National Convention, the largest convention in the world focused on PWS, and we were able to award a few scholarships to help families with medical needs and transportation.

I'm proud to announce, we also formed the Junior Advisory Board which is made up of 4 youth who are passionate about spreading awareness and raising funds for PWS. They have met several times since Spring, making blankets and bracelets for the kiddos who will be attending YIP & YAP at the upcoming National Convention. In addition, we also created our Professional Service Provider Recognition Program, which acknowledges someone who goes above and beyond to help support individuals with PWS whenever possible. So far we've recognized one provider as a PWS champion, but have received additional nominations we plan to review.

Again, I would like to thank everyone who has supported PWSA-WI, Inc. throughout the year by making a donation or giving up their valuable time and volunteering. It is your support that has allowed us to succeed with the aforementioned accomplishments and fulfill our mission of supporting, educating and advocating for individuals with PWS and their families. Together, we can **ALL** make a difference!

Sincerely,

Crystal L. Boser
President





PHILLY CHEESESTEAK STUFFED PEPPERS

Prep time: 20 mins Cook time: 20 mins Total time: 40 mins

Serves: 4 servings

Preheat oven to 350 degrees F and arrange bell pepper halves on a baking sheet and sprinkle 3 tablespoons mozzarella in the bottom of each half.

In a large skillet, heat oil over medium heat. Once oil is heated, add onion and cook 3-4 minutes; add mushrooms and cook an additional 4-5 minutes or until mushrooms are soft and onion is translucent. Add garlic and saute 30 seconds or until fragrant. Add roast beef, Worcestershire, salt, and pepper; cook 4-5 minutes mixing well.

Divide the roast beef mixture into each of the 4 pepper halves, firmly pressing contents down to fit; top each half with an additional 3 tablespoons mozzarella.

Bake for 20-24 minutes or until the cheese is golden brown and peppers are soft.

NOTES

Recipe adapted from Little Family Adventure

NUTRITION INFORMATION

Serving size: 1/2 stuffed pepper Calories: 252 Fat: 11.8 Carbohydrates: 13.3 Sugar: 5.0 Sodium: 743 Fiber: 2.8 Protein: 24.8 Cholesterol: 48

Recipe and image from <http://preventionrd.com>

INGREDIENTS

- 2 green bell peppers, halved and seeds removed
- 1 1/2 cups part-skim mozzarella cheese, shredded and divided
- 1 Tbsp olive oil
- 1 onion, diced
- 8 oz mushrooms, sliced
- 2 cloves garlic, minced
- 8 oz shaved deli roast beef, thinly sliced
- 2 Tbsp Worcestershire sauce
- 1/4 tsp salt
- 1/4 tsp black pepper

INSTRUCTIONS

BEYOND ACCESSIBILITY

Home Modification Ideas for Children with Down, Angelman and Prader-Willi Syndromes.



Improve how you live with customized solutions to everyday problems at home.

IDEAS FOR EVERYONE

There are many common features of these genetic syndromes that may influence home modification needs:

Concern: Changing needs (childhood to adulthood)

- > Families report having to adjust to the specific needs at each age, size, and developmental stage of their child, with a need for frequent reassessments and modifications

Concern: Decreased motor skills (including low tone, ataxia, poor balance, decreased strength, and limited endurance)

- > Zero-step entry or wider/bigger steps at entry
- > Additional handrails or grab bars at entrances, toilet and bathing areas, stairs, and in hallways
- > Nonslip surfaces on stairs and steps (carpet may be safer)
- > Level yard areas and walkway to vehicles, including bus
- > Wider sidewalks, big enough for 2 people or adaptive equipment (walker or wheelchair)
- > Remove hazards in walking areas, such as rugs and screen doors
- > Clearly mark changes in walking surface to be easily visible
- > Bathing area ideas
 - Replace tub with shower or walk-in tub
 - Built-in or portable bath seat
 - Non-skid floor or mat
 - Water-resistant and slip resistant flooring in any potentially wet areas
- > Obesity- common in both childhood and adulthood
 - Need space for exercise indoors and outdoors
 - Bidet on toilet to help with cleaning after using the toilet
 - Larger shower spaces and/or seat in shower

Concern: Safety and ability during daily tasks.

- > Correct size toilet, with foot rest if needed (or squatty potty)
 - Seat: sometimes smaller or larger depending on personal size
 - Height: may be shorter or taller depending on personal size
- > Faucets that are easy to reach and turn on/off
- > Faucet extenders
- > Handheld shower (can help a lot with hair washing)
- > Easy to open fridge and storage areas in kitchen
- > Lever handles throughout the home on doors and faucets
- > Hooks to hang coats, bags, and towels
- > Creating a bathing space that is water-proof (or a "wet room")
- > Places to sit while dressing and while putting off/on shoes
- > Clear and accessible storage and organization in play areas, bedrooms, and for school work to support independence
- > Clear and accessible storage and organization in areas of daily care, such as closet and bathrooms

Concern: Positioning needs for alignment and support in daily tasks (such as spinal issues or low tone concerns)

- > Space for specialty seating equipment in dining, living, and bathing areas
- > Room for specialty beds or hospital beds
- > Temporary or permanent need for adaptive equipment, such as walkers or wheelchairs (see notes under Prader-Willi)
- > Room in home for larger furniture, such as chairs and beds

beyondaccessibility.com



Information is solely for informational purposes and is not intended as medical or building advice. Please consult a professional. Activities or modifications are done at your own risk.

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But Weight, There Is More

As we all know anxiety is a huge factor in the day to day quality of life and behavior of individuals with PWS. One thing that has been found to help with anxiety is the use of a weighted blanket. Unfortunately weighted blankets can come at a cost. Often times a good weighted blanket can cost anywhere from \$100.00 to well over \$300.00! That normally leaves you with two options, take out another mortgage on your house or make one yourself. Thankfully a third option exists because there are amazing people in this world! There is a website sharingtheweight.org. You put in a request for a blanket and pay for shipping (about \$15) and they will make you a blanket free of charge. It can take them up to a year to get you the blanket because they have volunteers doing the work, but for those on a budget this can be a great option! They are a non-profit so they also take donations if you want to support their cause.

Weighted blankets can help with many things:

- ◆ Helps relieve anxiety (like a big long hug)
- ◆ Can help calm an agitated state
- ◆ Helps alleviate sensory disorders
- ◆ Can eliminate insomnia

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





You're a Doll!

One of our members recently got one of these really cool dolls from fbfdolls.org.

They are called Feel Better Friends and are hand made and donated. They are designed to look just like your child and will even include specific details such as scars or medical devices they need to wear.

What are Feel Better Friends?

Feel Better Friends are handmade dolls stuffed with love and well wishes. Shanon Fouquet, artist/designer from Shanonigans, came up with the idea when she saw a picture of a little girl, Berkeley who was battling cancer and holding her American Girl doll. Like most little girls who have this popular doll, Berkeley was “twinning”, or dressing identically to her doll.

Shanon looked at this particular photo of this brave little girl who was proud to be going ‘wigless’ to her doctor’s appointment that day and Shanon couldn’t help but wonder if Berkeley would like for her doll to be able to go ‘wigless’ too. It was then that Shanon decided to come up with a handmade doll created just for Berkeley with a wig and matching clothes that could go ‘wigless’ just like her!

Shanon had so much fun making Berkeley’s doll that she decided to make more dolls for other children suffering from cancer and other illnesses, who would like the comfort of a Feel Better Friends doll custom made with their own likeness and characteristics.

To request a doll visit their website. Because they are created by volunteers they can sometimes take a few months but they sure look like they would be worth the wait!

**I SUPPORT A SAFER,
HAPPIER HALLOWEEN**



TEALPUMPKINPROJECT.ORG
#TEALPUMPKINPROJECT

The Teal Pumpkin Project is a movement to promote awareness to food allergies and the special needs of those from whom Halloween can be a challenging holiday to celebrate because of the food treats handed out. This is a concern shared by the PWS community so we encourage you to let the folks in your neighborhood know about this amazing idea. The concept is basically that homes displaying a teal pumpkin will have non-food items to hand out in place of the usual candy. Some ideas for items might be glow sticks, pencils, necklaces, bracelets, bubbles, bouncy balls, and so much more! Many of these types of items can be found at very reasonable prices from online vendors such as www.orientaltrading.com.

Tealpumpkinproject.org has lots of printable materials and great information to help you get this movement off the ground in your area.



In loving memory of Elsie Dorn. Elsie was the grandmother of Tony, who has PWS. She was a huge supporter of our organization throughout the years. She will be dearly missed by all who knew her and we send our love to her family.



Best Practices in Support Levels for Students with Prader-Willi syndrome

By Jennifer Bolander, PWSA (USA) Special Education Specialist

One of the three main goals of the Individuals with Disabilities Education Act [IDEA] is to promote independence. For the child who is developing neurotypically, who does not have a medical diagnosis or health issue which affects their brain function, increased independence which culminates in their fully caring for themselves and making independent life decisions is a logical goal. Most students with Prader-Willi syndrome, however, require an adjusted understanding of and expectations for appropriate school environments and independence. There are at least four areas or situations where close support of the student with PWS is often a necessity and imperative in order for that student to benefit from their education:

- **Academics:** Students with PWS have diagnosis-based, ongoing, academic challenges. Slowed processing speed, short-term memory challenges, and being easily distracted mean that the student will possibly require prompts and redirection frequently, especially when placed in a highly distracting classroom without appropriate support. Classrooms with a large number of students (18 – 25) are settings where students can easily become distracted and lose learning opportunities, leading to frustration. Increased frustration often leads to increased behavior problems, which also decrease the student’s learning time.
- **Food security:** The intense interest in food experienced by those with PWS is a manifestation of the diagnosis and is not something they can control. For most individuals with PWS, the only factor preventing them from accessing extra food or going into trash cans within the school setting is the arm’s-length proximity of the trained aide. Simply having other school staff in the classroom is not adequate prevention, especially in a general education classroom which will have 18-25 students (several of whom may also have IEPs and need assistance). Thus, the provision of close support for the student with PWS will allow that student to function successfully in their classroom and throughout the school environment where there is food in multiple areas. Exposure to unauthorized food can be life threatening for the student due to the risk for choking and stomach rupture. It also causes the student to feel hopeful that they will get access to unauthorized food, which in turn increases their anxiety and increases the potential for behavior problems. When food is secure and there is no exposure to unauthorized food, the student’s anxiety is reduced and they are better able to focus on the academic program to the best of their ability.
- **Physical security:** Students with PWS can potentially be “runners”, meaning that for reasons which sometimes are clear only to them at that moment, they may take the opportunity to run out of a classroom and even out of the school building. This is a problematic situation for the student and staff, and can also become a safety issue if the student moves quickly enough to leave school property. There are multiple running triggers in each and every school day for the student with PWS. As mentioned with food security above, often the only factor preventing a student from using running as a coping option is the arm’s length presence of a staff person who is trained to recognize the student’s agitated state and potential for running and redirect the student appropriately.
- **Behavioral support:** People with PWS have mild to severe intellectual impairments. Some behavioral and academic challenges can be prevented or managed with proper programming and support. Many students with PWS have functional behavior assessment [FBA] data and a positive behavior intervention plan [PBIP] attached to their IEP. Often the key to the successful implementation of a PBIP is the consistent presence of an aide, teacher, or school staff person who is trained in “PWS best practices”, has gotten to know the student from prolonged daily contact, and has an understanding of how the brain functions for the student with PWS. They can assist the student in processing and managing their feelings of anxiety, rather than the student turning to perseverating, or engaging in escalating controlling and disruptive behaviors, in an attempt to manage the anxiety on their own.

It is important to note, that “independence” and the support needs of each student with PWS will vary, and will change depending on each specific setting in school. The times and situations in the school day when additional close support is generally necessary (i.e. not negotiable) for the student include (but are not limited to) coming into the school and exiting the school at the beginning and end of the day, getting to their classroom, transitioning between classrooms, and during any food-related situations (lunches, snack times, parties). At the same time, when the school staff and IEP team members have been in close communication with each other and have gotten to know the student, it will be apparent what other parts of the day can be times of check-in support. Supervision needs can change but they should be an area of constant collaboration and observation by all members of the IEP team.

It is also important to note that we encourage the concept of “supervised” or “perceived” independence, where the student is taught and encouraged to do as much for themselves as they can safely do. It is crucial that all aides, paraprofessionals, or school staff working with the student throughout his/her educational years keep a focus on long-term capabilities and functional goals.

While it is common for individuals with PWS to transition into supported living after completing their education, and most parents will pursue legal guardianship of their son/daughter, it is also true that the student’s overall self-esteem and self-confidence will depend a great deal on their ability to function independently in as many areas as possible. The child’s parents and IEP team members should keep in constant and productive communication so that all are fully informed about the student’s individual needs for varying levels of support.

Lastly, we strongly encourage all school districts to fully train all school staff personnel working with students with PWS, including aides and paraprofessionals. Aide/para support staff will be working closely with the student and will need to know the student’s behavior plan, the student’s signs of growing frustration/agitation, and all of the “PWS best practices” known by the teachers. Aides/paraprofessionals should also be present for team meetings held to create and review the child’s behavior plan, so that they are fully informed of which behaviors the team is working to encourage, and which behaviors are non-preferred and how to respond to them.

Ultimately, each student with PWS will need some variety of supervision during their school day. For some students, dedicated 1:1 paraprofessional support from 1-2 consistent staff people is an absolute necessity. For other students, proximal or check-in support for some times of the day is possible. Food security for those who are food-seekers, physical security for students who elope, and behavioral support are needs inherent to the PWS diagnosis, and the IEP team should communicate closely regarding the student’s other individual needs.

©2017 This document has been reviewed and approved by the Special Education Advisory Board. Please contact PWSA (USA) for further assistance (1-800-926-4797). Many helpful resources are also available at www.pwsausa.org.

Reprinted from a resource of the Prader-Willi Syndrome Association (USA).

Wednesday, November 15th

Chapter Leaders Meeting – Crystal Boser/Rob Seely
 Chapter Leaders and New Parent Mentor Reception
 Clinical Advisory Board Meeting – Dan Driscoll
 Scientific Advisory Board Meeting – Merlin Butler
 Professional Providers Advisory Board Meeting – Patrice Carroll/Mary K Ziccardi

Thursday, November 16th

Chapter Leaders and New Parent Mentors Meeting – Crystal Boser/Rob Seely & Lori Moline/Diane Seely
 Medical & Scientific Conference – Merlin Butler supported by Dan Driscoll/Jim Loker/Kathy Clark & Ann Manzardo
 Professional Providers Conference – Patrice Carroll/ Mary K Ziccardi
 Medical & Scientific Reception
 Welcome Reception/General Conference – Debbie Peaton

**2017 PWSA (USA) National Conference
 November 15-18**



Friday, November 17th

Rare Disease – Merlin Butler
 General Gala – Debbie Peaton/Kristi Rickenbach
 YAP Gala – Debbie Peaton/Kim Tula

Friday and Saturday, November 17th & 18th

PWSA (USA) General Conference – Kristi Rickenbach
 Youth & Infant Program – Michelle Holbrook
 Youth & Adult Program – Kim Tula
 Sibling Program – Tammie and Rockie Penta

For more information and to register visit <http://www.pwsausa.org/2017-pwsa-usa-national-convention-registration/>

If you need assistance to attend the conference please contact us! We offer scholarships.

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PWSA of WI, Inc.'s Event Calendar		
Watertown, WI	PWSA of WI Golf Benefit	August, 2018
Oconomowoc, WI	On the Move Walkathon	May 12, 2018
Watertown, WI	PWSA of WI, Inc. Winter Ball	January 27, 2018