

THE WISCONSIN CONNECTION

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PWSA of WI, Inc. is a
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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.



Program Directors Corner

By: Joshua Escher

As I write this, March has been very kind to us! The weather is as warm as we could usually hope here in Wisconsin this time of year. The sun is still playing a lot of peek-a-boo with us but the nice weather is at least making it easy to get outside and enjoy some rays when we can. Many folks can be negatively effected by the shorter days of winter. When we get to this time of year, our bodies are starved for that warm sunlight. This is called seasonal affective disorder (or SAD). This can be characterized by things like depression, fatigue, hopelessness, and social withdrawal. Take

advantage of this mild spring and go out for a walk!

This time of year often brings unique challenges for individuals with Prader-Willi. Behaviors that haven't been seen before can sometimes appear seemingly out of nowhere! The good news is, I can help you with that! If you or a caregiver or educator are struggling to figure out how to deal with a certain behavior, contact me. Sometimes just getting a fresh perspective is exactly what you need to figure why it is happening and how you can avoid it. Don't be afraid to call, I'm happy to help. Heck, let me know about your successes too! If you don't feel comfortable calling, you can also text our phone 920-733-3077, email me progdir@pwsaofwi.org, or even find my Facebook page and message me there Joshua Escher Pwsa-wi, or message our PWSA of WI, Inc Facebook page.

In Loving Memory



Joseph Gareau

Barb Nobile

Robert Bomber

Dr. Marta Muller

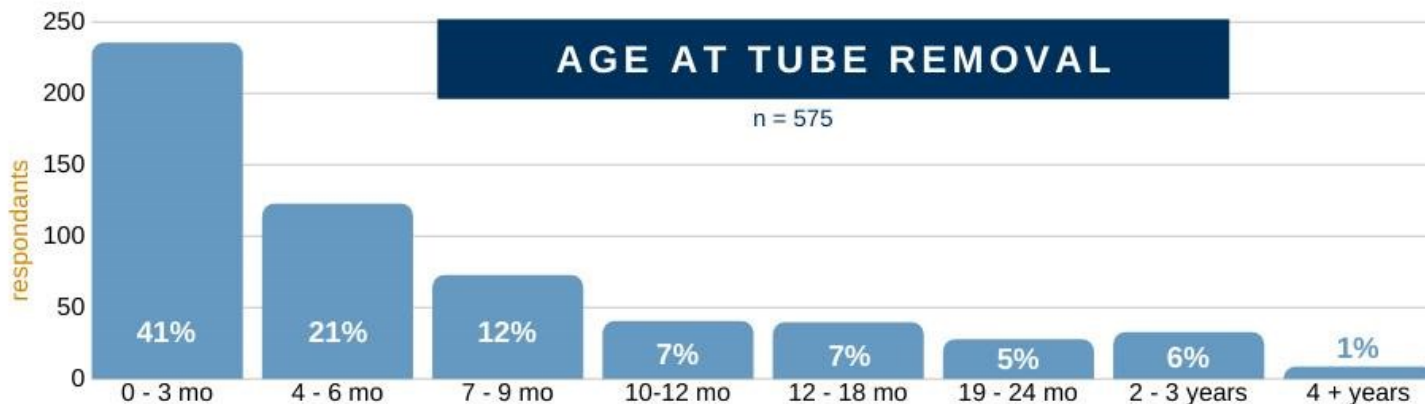
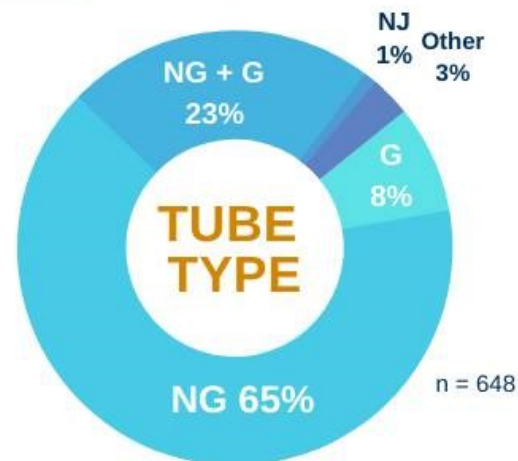
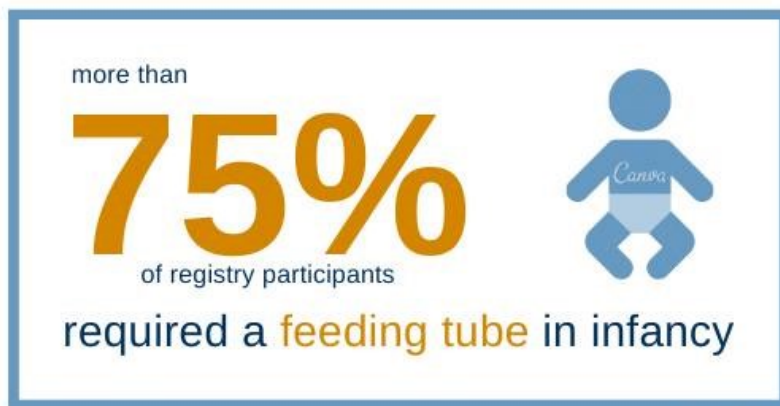


Generous donations were made to honor the memory of loved ones lost recently.



At our Snowflake Ball this year five members of our Junior Advisory Board were awarded with certificates thanking them for the 24 volunteer hours each of them contributed during the 2019 PWSA (USA) Convention. Kameron Boser, Makenzie Gaulke, Maddie Tula, Eva Glass, and Josaphine Glass all worked diligently to provide childcare, leadership in the YIP and YAP programs, as well as support for the sibling program. Without their work, many parents might not have had the ability to attend the convention.

FEEDING TUBES & PWS





Focus on: Exercise and Prader-Willi, information for gyms and trainers

Why is exercise important for people with Prader-Willi syndrome (PWS)?

Physical activity can provide a number of benefits to people living with PWS, including management of common symptoms such as obesity, reduced muscle tone and anxiety. A particularly important aspect of PWS that an individualized exercise plan can assist with is balancing the amount of energy in (eating) with the amount of energy out (exercise).

Reduced muscle tone is often a symptom of PWS. This can occur across a wide range of severity, so not all individuals with PWS will experience this to the same extent. Lower muscle tone can affect coordination and balance and result in generalized weakness. Exercise is an effective way of improving muscle tone, which is associated with general improvements in strength and energy levels.

Daily exercise in people with PWS can help maintain a healthy weight and improve physical strength and overall health. 30 minutes of physical activity each day is the recommended average. This can improve health and well-being, and is especially important for people with PWS for the management of their weight and improving muscle tone.

What are common difficulties people with PWS may face with exercise programs?

People living with PWS can face some additional challenges which should be considered when designing an exercise program. For example, they may have low muscle tone which can contribute to poor coordination, balance and strength. This can often be coupled with the physical strain of obesity and the common symptom of scoliosis, which is an abnormal curvature of the spine. Scoliosis occurs in approximately 45% of people who have PWS, and can have negative effects on flexibility, strength and posture.

Children with PWS may also have behavioral difficulties. These can include anxiety, a tendency to lose interest quickly, difficulties in adapting to change, emotional outbursts and mood swings. A preoccupation with food and acquiring the next meal may distract the person from engaging with the activity. These difficulties can further deter people with PWS from participating in physical exercises. However a well-tailored exercise regime which meets the needs of people living with PWS can be an important aspect in encouraging a healthy lifestyle.

What should be considered when tailoring an exercise program for someone with PWS?

As the syndrome is characterized by a broad spectrum of symptoms, the abilities of different people with PWS may differ. Generally, people living with PWS have reduced muscle strength, power and mass. This may also impact reaction-time, speed and coordination.

Participation in a wide-range of exercises that engage all muscle groups is an effective way to manage weight gain. For people with PWS, resistance and weight bearing activities can be effective at improving muscle tone. Lifting light weights, using stationary machines such as a bicycle or rowing machine, and activities involving jumping or throwing can all be suitable. However, those with scoliosis may be at increased risk of injury or find weight bearing exercises particularly difficult. The person's physician should be consulted for advice if there are any concerns.

Moderate aerobic exercises are helpful in losing, as well as maintaining weight. Walking, jogging, cycling and any other activities that produce a mild increase in heart rate and breathing can be useful activities for most people with PWS. People living with PWS may be at particularly high risk of sprains and joint pain from high impact activities such as running and jumping at a high intensity. In addition, aerobic capacity may be lower in people with PWS, reducing the time for which aerobic exercises can be comfortably maintained. Care should therefore be taken to begin training programs at a light intensity, and built up according to personal progress.

Suggested conversations for a trainer, parent and person with PWS when developing an exercise plan

Personal trainers and gyms can be a great asset in planning and implementing any fitness plan. Communication is the most important aspect of creating an individualized training program for a person who has PWS. Everyone has different abilities and enjoys different things, so having a mutual understanding of this can improve the experience. For any items of medical concern, the person's doctor may also need to be consulted.

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We recommend the trainer or gym, the person who has PWS and their parent or carer discuss the questions below to ensure the program is designed in a way that best suits the individual and that there is transparency in the complex needs of the person with PWS:

- What PWS symptoms should I be aware of?
- Is task-switching an issue? If so, are there any techniques you have found useful for this?
- What kind of activities does the person enjoy most?
- Are there any kinds of activities that the person finds particularly difficult
- Are there certain times of the day when the person tends to be happiest or more readily engaged?
- Is there anything in particular that calms the person down if they become distressed?
- What techniques do you find most useful in giving instructions?
- Is routine favored over variety? As the person progresses and improves with training, what is the best way to introduce changes to the training program?
- What are the benefits of exercise you'd most like to see? (e.g. weight loss, weight maintenance, strength building, improved muscle tone, social benefits etc).

How can exercise programs be designed to be accessible and enjoyable for people with PWS?

It is important to gain an understanding of common difficulties faced by people with PWS. Starting slowly and gently can be an effective way to engage a person with PWS in physical exercise. Intensity of exercise can then slowly be increased as muscle tone, confidence and enjoyment builds. Everyone has different interests, so communicating with the person on which activities they enjoy most can encourage enthusiasm.

People with PWS may have difficulty adapting to change or following complex instructions. Exercise training programs should aim to be well-defined, easy to accomplish (as per individual abilities) and broken down into small steps. For some people who have PWS, it may be beneficial to follow a planned routine they can become familiar and comfortable with, which further minimises the stress related to anticipation. However, it is also important to be flexible and willing to adapt.

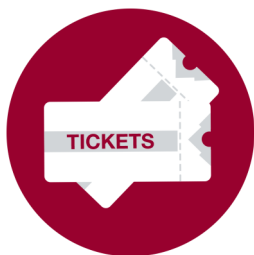
Incorporating strength training and aerobic exercises with games can be helpful in engaging children with PWS. Throwing, catching, skipping and dancing within or between exercises can be a simple way of keeping things entertaining.

Devising a training program that suits the individual abilities and interests of the person is the best way to build confidence and therefore decrease any aversion to exercise. Showing patience and enthusiasm while explaining exercises in a clear and simple step-by-step manner can make activities less stressful. Active communication and mutual respect between the person who has PWS, the parent and trainer is an important aspect of achieving this.

This post was written by four University of Melbourne science communication students, Jessica, Jinia, Elena and Frances. Each is a Masters-level research active science student and undertook this work under the guidance of their course coordinator Dr Jenny Martin and our volunteer director of science communication Melanie Carem. You can read more about the University of Melbourne Science Communication subject here.

This post originally appeared on the praderwilli.org.au blog September 17th, 2016

PWSA of WI is always looking for donations that can be used for raffles and silent auction items for our golf, gala, and bowling events. You can donate these types of items any time during the year! Examples of items can be anything from gift cards to golf balls, or larger items like sports tickets, resort stays, and autographed memorabilia. No donations are too big or too small. To donate or if you have any questions, contact our program director Josh at 920-733-3077.



10th ANNUAL PRADER-WILLI SYNDROME ON THE MOVE MAY AWARENESS WALK-A-THON RIVERSIDE PARK WATERTOWN • WI MAY 9 2020

Online registration available at our website: <https://pwsaofwi.org/event-3663940> .

We will also have a fundraising site where you can set up your own fundraising page and share with your friends!

Please note, only registered service dogs are allowed in Riverside park.

Easy Burrito Bowls



INGREDIENTS:

- 1 cup uncooked rice
- 1 cup salsa, homemade or store-bought
- 3 cups chopped Romaine lettuce
- 1 (15.25-ounce) can whole kernel corn, drained
- 1 (15-ounce) black beans, drained and rinsed
- 2 Roma tomatoes, diced
- 1 avocado, halved, seeded, peeled and diced
- 2 tablespoons chopped fresh cilantro leaves

FOR THE CHIPOTLE CREAM SAUCE

- 1 cup sour cream
- 1 tablespoon chipotle paste*
- 1 clove garlic, pressed
- Juice of 1 lime
- 1/4 teaspoon salt, or more, to taste

DIRECTIONS:

1. To make the chipotle cream sauce, whisk together sour cream, chipotle paste, garlic, lime juice and salt; set aside.
2. In a large saucepan of 1 1/2 cups water, cook rice according to package instructions; let cool and stir in salsa; set aside.
3. To assemble the bowls, divide rice mixture into serving bowls; top with lettuce, corn, black beans, tomatoes, avocado and cilantro.
4. Serve immediately, drizzled with chipotle cream sauce.

Makes 6 servings

Ninth Annual Snowflake Ball



On February 1st Red Circle Inn & Bistro in Nashotah opened their doors to our 224 guests and 21 volunteers for our Snowflake Ball. It was a lovely evening of dinner and dancing and we had so much fun with our PWS family!



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.

Exercise and Behavior

You've heard exercise is good for physical health, but did you know research also shows exercise is beneficial to mental health and mood? According to the Mayo Clinic, physical activity stimulates endorphins in the brain that elevate mood and encourage relaxation.

Exercise can fend off depression and anxiety in individuals with PWS and can even combat unwanted behaviors like physical aggression, self-injury, and destruction of material goods.

- If an individual has general anxiety, 60 minutes of physical activity a day is often enough to help them feel better.
- Individuals with higher levels of anxiety might need more regular periods of exercise throughout the day to feel better.
- Individuals that tend to be more explosive and aggressive might respond to regularly scheduled activities like playing basketball or running to help with emotional regulation.
- Exercise in the form of fun physical activities can also be helpful in redirecting unwanted behavior such as skin picking. If your loved one is skin picking, engage him or her in a game of catch or other physical activity which requires the use of their hands.
- Individuals with PWS and Sensory Processing issues can also benefit from exercise to help regulate their systems and decrease unwanted behaviors. The exercise routine should be based on the individual's particular need for sensory input. For example, if your loved one needs more physical input, like joint compression or heavy muscle work, using light weights, running, playing basketball, or performing wall pushups can help meet these needs. If your loved one needs more movement to help regulate, walking, rolling on a stability ball, or jumping on a trampoline may be more helpful.

How can you encourage someone with PWS to exercise?

- Don't call it exercise!!
- Make the activity fun.
- Do the activity with them.
- Make it part of the routine day.
- Use creative wording. Instead of, "It's time for our walk," try "Let's take a hike to look for birds!"
- Play tag, follow the leader, or engage in playful competition.

Exercise, while good for nearly everyone, can be a fun and interactive way to help individuals with PWS physically, mentally, emotionally, and behaviorally.

This article previously appeared on the PWSAUSA.org website

**Help you and those around you stay healthy!
Practice good hygiene. Cover your mouth
when you cough, and wash your hands!!**



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PWSA of WI, Inc.'s Event Calendar		
Riverside Park, Watertown, WI	On the Move Walkathon	May 9th, 2020
The Oaks, Cottage Grove, WI	PWSA of WI Golf Benefit	September 27th, 2020
Red Circle Inn & Bistro, Nashotah, WI	2nd Annual Sparkle and Shine Gala	October 17th, 2020