

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.

The holiday season is upon us and that can make for big challenges in the Prader-Willi world. Schedule changes, new people visiting, and time off of school. All of these things can cause anxiety in the PWS population. This can make for frustrating times and dangerous situations (see page 5 of this newsletter for some great holiday tips from PWSA (USA)).

What this might mean for you as a parent or caregiver is that you may run into situations you have never dealt with in the past. PWSA of WI can help! Sometimes just a little additional training or even a sympathetic ear can make a huge difference. Don't be afraid to reach out to us.

This is also the time of year where we start thinking about reviewing IEPs at school. If you are worried about this process, we can help with that too! Our program director can be there to provide support and knowledge to help make sure your child's needs are being met. We provide this service free of charge!

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PWS Funnies



Most weekends I chat with my grandson, Kyle, and I always ask about his plans. The group home where he resides frequently has fun off-grounds activities, and he tells me all about what they are doing. This weekend he said they were planning on a movie - Rap City. I'd never heard of it so I asked more detail. He said, "It's weird. It's not about rap music. I guess it's about rock." I was quite puzzled till the lightbulb went off - LOL. I said, "Could it be Rhapsody? Bohemian Rhapsody?" Sure enough - that was it! -Nancy *PWS Grandma*

Do you have a Prader-Willi related funny story to share? Email them to us, progdir@pwsaofwi.org

Delivering Your Ultimate P.R.O.M.I.S.E.

This is part two of our financial planning series featuring Patrick McGrath CHFC, CHSNC and President and CEO of Private Wealth Management in Appleton, WI.

Today’s installment of our P.R.O.M.I.S.E series centers on Preparing a Clear Vision. This is by far the most challenging element of any form of planning, in that it dictates a decision that we are going to get something done, and hopefully in a timely fashion. Here is where the rubber meets the road! If we are being honest with ourselves, many of us haven’t articulated what we want out of life, at least to the point where we have a roadmap on what we want to do in this life! We all have dreams, desires, things we want to accomplish, and often enough in a family with a special needs loved one, those dreams often get pushed aside until a date in the future. Why is it that if you want to build a house, you need a get a blueprint of the home and have the building inspector and other government agencies approve your home design? You can’t build the home without their permission! So, why do we take it for granted that someday in the future we will get to the planning needed in order for me and my family to live the life we envisioned, and worked for, and have a special needs plan for our loved one incorporated into that plan? In reality? It’s too damn hard! Too many moving parts! Too many things to consider! Not enough information! My financial advisor knows stocks and bonds, he or she doesn’t know about the myriad of obstacles we face with a loved one with special needs! How am supposed to think outside the box and think about what I want when I can barely get through the day, and when I do, I feel blessed that I did! Another day down, on to the next. We all look back and think where did the time go?

How many of us grew up with Legos? The intricate little pieces that according to the picture convinced us that there is no way we are going to be able to put this together! But, what did we also find inside...a step-by-step instruction guide to help us complete the task. Some areas were more complex, some a bit easier. Some areas we could complete in a short amount of time, others took a bit longer to piece together. But sure enough, we were able to get through what once was a seemingly insurmountable task and were left a large, Transformer-like figure complete with 500 pieces! We know that if we follow the instructions and we understand the path, we can accomplish anything.

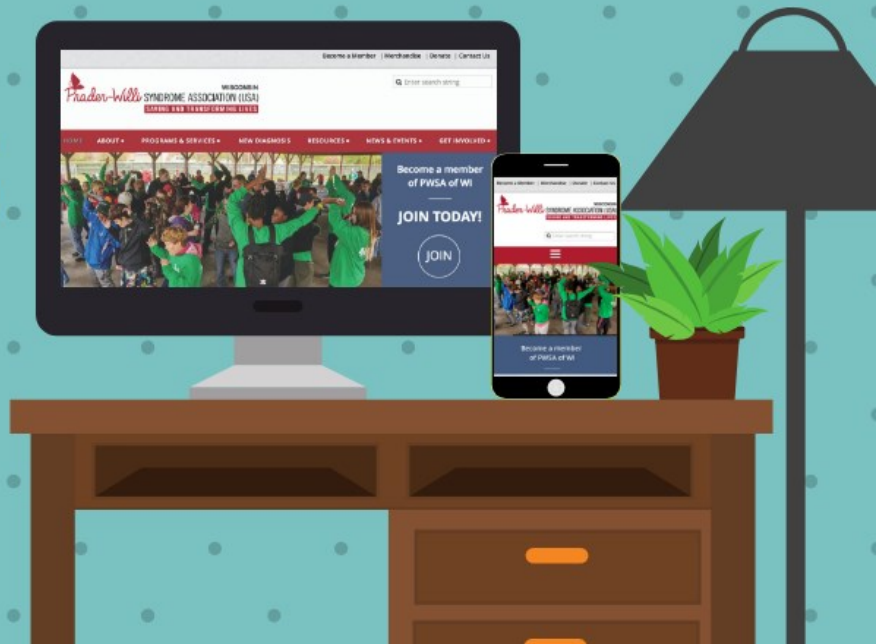
Ask any kid, “how do you eat an elephant?” and what do they say? One bite at a time...

Why is any of this important? The sad reality is that more and more individuals are being diagnosed with special needs, the government resource pool is always shrinking, the cost of the services we want our loved one to have access to is getting higher and higher, and at the end of the day, if you aren’t your child’s biggest advocate for a life well-lived, then nobody will come to your rescue. Guess what? On top of all of that, how do we begin the process of our own financial plan based on what we want our future to look like? Wait a minute, we have a future? Go ahead and laugh, its good for the soul. But its accurate, and your child’s future security is grounded in your ability to take the reins, do the hard work and set forth a plan of action that makes sense.

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**OUR NEW
WEBSITE IS
ONLINE
NOW!**

pwsaofwi.org/



Continued from Page 2:

We as parents, siblings, caregivers of loved ones have to realize that if we don't do the appropriate foundational planning, then the future of our loved one will suffer as well. In my family's own experience, my parents didn't have to do too much planning for Heather. Back then, the programs so relevant today were not so readily available, and in order to maintain future benefits for Heather, she was essentially disinherited. Sounds harsh, but that's what it was like. Today, Heather is 40 and still lives with my folks in Florida. While my parents didn't really have access to "Special Needs Planning" they knew enough to constantly contribute to their retirement accounts, they had life insurance just in case, they took the time to do a will and completed some basic estate planning documents. Unbeknownst to them, they kept the foundation in place, just in case. We all need these things, not just those families with special needs loved ones.

Special Needs Planning is complex, it marries up the traditional wealth planning ideas and strategies and overlays it with the confusing world of government benefits and social programs. How do we know where to begin? First, find a financial advisor who understand special needs planning. To tell you the truth, there are not that many of us out there. Sure, there are lots of really good financial planners, but do they know how SSI works and how that may affect your particular situation? Do these advisors have an idea as to how the estate plan should look like when your loved one can't have any assets in excess of \$2,000? Finding an attorney who is experienced with special needs trust and understands the vast nuances of disability law is also of utmost importance. The Social Security Administration governs and oversees the application of special needs trusts, so it makes sense to have an ally who understands how they work and what a special needs trust can and cannot do. Oh, and there are different types of trusts too. Very confusing legal elements all around. Another individual who is vitally important is an individual who understands government benefits and future care planning costs. It is really hard to determine how much your child's future care is going to cost, but those experts are out there. Building a "Dream Team" will help you through all the issues that are sure to arise as the plan evolves, and it will evolve. My parents, now in their 70's, have finally gotten around to creating a Special Needs Trust for Heather. It only took me YEARS of harping on them to get one in place, and I'm in the financial planning world! But that's a story for a later article.

Here's your homework if you find yourself agreeing with a few of the points in this note. Take a few minutes with your spouse and talk about what you want your future to look like, what makes you happy, what values you want to pass along to your kids, what kind of legacy do you want them adhere to? If you knew that your child would be well taken care of, what do the next decades look like? Once you have an idea to these questions, you've taken the first important steps! Tony Robbins is famous for stating, "start with the end in mind"! And you know what, it doesn't have to be the plan that lasts forever, its just a starting point. Spend a few moments and think about what your family's life would look like if you weren't around. Each and every one of us who is a parent wants to give our children the security they deserve, and all it takes is a few minutes and maybe a nice glass of wine. After that, we can help.

Stay tuned for the next installment of P.R.O.M.I.S.E where we dive into the Researching Your Options chapter, a deeper look at governmental programs like SSI, SSDI, waiver programs and more that are integral part of your child's current and potential future planning.



Save The Date(s)

June 8th, 15th, and 22nd PWSA of WI will be featuring Patrick MacGrath CHFC, CHSNC and a member of the academy of special needs planners. Patrick will be presenting his 7 step P.R.O.M.I.S.E. special needs planning guide and answering your questions as well.

The reason we have three dates is that we are holding this event in three different cities (Madison area, Milwaukee area, and the Fox Valley) to hopefully make it convenient for you! Exact details are forthcoming, keep an eye on our website, social media, and the next newsletter. This presentation is not PWS specific so let your other special needs parent friends know!



Turkey Stroganoff

Recipe By: Diabetic Living Magazine

Ingredients

- 4 ounces dried whole-wheat or plain noodles
- 1 (8 ounce) carton light dairy sour cream
- 2 tablespoons all-purpose flour
- 1 tablespoon olive or canola oil
- 1 pound turkey breast tenderloin, cut into bite-size slices
- 8 ounces sliced fresh mushrooms
- 2 cups fresh broccoli florets
- 1½ cups reduced-sodium chicken broth
- ½ teaspoon onion powder
- ¼ teaspoon ground pepper

Serving size: 1 cup turkey mixture and about ½ cup cooked noodles

Per serving: 372 calories; 11 g fat(4 g sat); 5 g fiber; 34 g carbohydrates; 37 g protein; 65 mcg folate; 90 mg cholesterol; 3 g sugars; 469 IU vitamin A; 42 mg vitamin C; 116 mg calcium; 3 mg iron; 328 mg sodium; 783 mg potassium

Nutrition Bonus: Vitamin C (70% daily value)

Carbohydrate Servings: 2½

Exchanges: 4 lean protein, 2 starch, 1 vegetable

Directions

- 1-Cook noodles according to package directions. Drain; keep warm. Stir together sour cream and flour in a small bowl; set aside.
- 2-Meanwhile, heat oil in a large skillet over medium-high heat. Add turkey. Cook and stir for 4 to 5 minutes or until browned and no longer pink inside. Remove from skillet. Add mushrooms to skillet. Cook and stir for 3 minutes. Add broccoli. Cook and stir for 2 minutes more or until mushrooms are browned and tender and broccoli is crisp-tender.
- 3-Add broth, onion powder and pepper to skillet. Bring to boiling. Whisk in reserved sour cream mixture. Cook and stir until thick and bubbly. Cook and stir 1 minute more. Stir turkey into mixture in skillet; heat through.
- 4-Serve turkey mixture with warm noodles.

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WE NEED YOUR HELP

We're looking for **500 people** with Prader-Willi syndrome **age 5 to adult** to participate in PATH for PWS.



PARTICIPANT CRITERIA:

CONFIRMED DIAGNOSIS OF PWS



LIVE IN THE U.S., CANADA OR AUSTRALIA



ENROLLED OR WILLING TO ENROLL IN THE PRADER-WILLI SYNDROME REGISTRY



HAVE ACCESS TO THE INTERNET TO ENTER STUDY DATA



➤ Learn more at www.PATHforPWS.com and **enroll today.**

HAPPY HOLIDAYS

Dear Friends,

The holidays are typically a food fest in our country – and can be a time of stress for our PWS families. With good planning, it is possible to make it a happy holiday for all.

- If you will be with relatives, carefully plan ahead of time and communicate the importance of food control with all involved. Make sure all attending know the “rules of engagement” and agree to cooperate. See that someone at all times is clearly in charge of your child with PWS. Clearly define when you are “changing guards”. As Dr Linda Gourash states, “When everyone is in charge – no one is in charge.”
- If your child is old enough, rehearse the “rules” before the special day and come to a mutual agreement on what your child will be allowed to eat. You can barter, i.e. “Do you want a little extra turkey and dressing, or do you want a piece of pie as your special treat?”
- It is okay to request that Grandma and other relatives tuck away tempting items during your visit and to discreetly check with you prior to offering your child a treat.
- Make sure you know what everyone is bringing, so there are no surprises on what the choices will be.
- Grandpa and Grandma, or aunt and uncle may want to bring a special gift toy to compensate for the food they have to deny your child.
- Go over with the hostess or your family the plan to contain accessibility to food. This will help prevent your child from sitting near bowls of food, rolls, or condiments. Many people do not consider how many calories children can consume with the extras – sugar, butter, ketchup, etc.
- After eating when people are just visiting make sure food is put away or, if left out, someone is responsible for guarding it.

Your child must have the security of knowing you will be strong in your commitment to keep them protected from food – in spite of themselves. Giving in, even once, means several battles ahead. Consistency is the key. Of course, each family must judge their own situation based on their child’s food drive and their own regulations on treats. Some families are raising their children to never have any sweets – no exceptions. Others (like ours) just go by calories and the weight of the child, trying to keep the diet less in quantity with more variation of food. Often, the most important thing is to prevent food sneaking or food demands. There is a large variance in the food drive of children with PWS. Some will ask or beg for more food, but make no significant attempts to sneak food. On the other hand, some will go to great extremes to get food, and are incredibly clever at doing so.

HOLIDAY ALERT FOR PRADER-WILLI SYNDROME

There have been several holiday seasons where some of our pre teens, teens and adults with Prader-Willi syndrome have had unexpected deaths due to food binging episodes that led to necrosis of the stomach wall and a perforation (tear) in the stomach. In several of the deaths, the person with PWS was slim, so there was no great concern about weight gain.

They were all in festive group situations, where “everyone was watching” which meant no one was watching. Keep in mind that even if a person with PWS is slim, it does not mean they have total food control. Add too many food temptations around, the lack of feeling full, and the high pain threshold, and you have the potential of filling the stomach dangerously full. Also add to the risk factors that in a study sponsored through PWSA (USA), a significant portion of people with PWS in the study had delayed stomach emptying, and in another recent study sponsored by PWSA (USA), virtually all in the study had an undetected swallowing problem which can lead to choking and/or aspiration.

We know that there are many food binging episodes of our children and adults with PWS – most not having such disastrous results, but we feel obliged to forewarn parents, grandparents, and caregivers of the potential risks. We want this to be a happy holiday season for all of our wonderful children and adults and their families.

Please help us keep them safe!

Sincerely,

Prader-Willi Syndrome Association (USA)

pwsausa.org



Save The Date

PWSA (USA) National Convention

Date: October 23rd – 26th, 2019

Hotel: Caribe Royale

Location: Orlando, Florida

Agenda of Events

Chapter Leaders Meeting - October 23rd & 24th

Medical & Scientific Conference – October 23rd & 24th

New Parent Mentors Meeting – October 24th

Professional Providers Conference – October 24th

Welcome Reception – October 24th (6pm – 9pm)

PWSA (USA) General Conference – October 25th & 26th

Youth & Infant Program

Youth & Adult Program

Sibling Program



PWSA (USA)
 NATIONAL CONVENTION **2019**



PWSA of WI provides scholarships to Wisconsin members. Visit our website pwsaofwi.org for more details or contact our program director progdir@pwsaofwi.org or 920-733-3077.

COME OUT TO A FUN CAPITOLS GAME WITH PWSA OF WI

Saturday, March 16th at 7:05pm
Bob Suter's Capitol Ice Arena
Middleton, WI

\$5 from every ticket sold goes back to PWSA of WI.

Use the ticket link to buy your \$15 fundraiser ticket!



<http://mm1.glitnirticketing.com/mmticket/web/loggingroup1.php>
Password: willi

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



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PWSA of WI, Inc.'s Event Calendar		
Red Circle Inn & Bisto, Neshota, WI	PWSA of WI, Inc. Snowflake Ball	February 2nd, 2019
Roosevelt Park, Oconomowoc, WI	On the Move Walkathon	May 12th, 2019
TBD - Milwaukee, Madison, and Fox Valley Locations	P.R.O.M.I.S.E. Financial Planning	June 8th, 15th, and 22nd, 2019