



# THE WISCONSIN CONNECTION

*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 Message from the President: Crystal Boser

## Keeping Up With The Times

I recently had a conversation with a group of women about Prader-Willi Syndrome. During this conversation one of the women asked me a particular question that has stuck in mind over the past few weeks. The question was this: "How do you stay so well educated and up-to-date with all of the events and changes in relation to Prader-Willi Syndrome?" I thought for a moment then methodically listed all of the ways in which I stay informed, but when I was done I could tell by the look on her face that she was clearly amazed. Her response was simply this, "Wow, I would have never guessed there were so many ways to stay educated about PWS." Until that moment it had never occurred to me how many different ways there were to gain information about Prader-Willi Syndrome now as opposed to in the past. So with that being said, I would like to take this opportunity to share all of the ways that you, our members, can stay informed about PWS.

You can stay informed about the on-going changes in relation to PWS in the following ways:

- Become a member of **both** PWSA of WI, Inc. **and** PWSA (USA);
- Routinely visit the chapter or national maintained websites at: <http://www.pwsaofwi.org> and <http://www.pwsausa.org>;
- Become involved with PWS e-groups such as <http://health.groups.yahoo.com/group/pwsa-wi>;
- Follow PWS on social networking sites such as: Facebook and Twitter;
- Attend annual events such as: the annual membership meeting, the Spring Social, the Parents of Young Children's meeting and the Golf Benefit;
- Attend educational trainings and state or national sponsored conferences.

As you can see there are many different ways in which people can learn and keep up with the many changes in relation to PWS and I encourage all of you to take advantage of these various opportunities.

I would also like to take this moment to personally invite all of you to attend the upcoming Wisconsin and Illinois co-sponsored conference titled, "Special Tricks on Treating Prader-Willi Syndrome: A Behavior Approach". This event, which is being held on Friday October 15, 2010, will feature nationally renowned guest speaker Dr. Linda Gourash along with a variety of other speakers. These speakers will be focusing on the behavior challenges individuals with PWS face at home, school, work and in their own communities. Please visit our website: [www.pwsaofwi.org](http://www.pwsaofwi.org), or call our main office at 866-797-2947 to find out more information and how to register for this conference.

I hope to see you all at the upcoming golf benefit in August and at the conference in October.

Crystal

### Board of Directors:

**President:** Crystal Boser

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**Program Director:** Mary Lynn Larson

**Assistant Program Dir:** Melodee Luening

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### Website:

[www.pwsausa.org](http://www.pwsausa.org)

## Did 'Ya Know?

Do you have any information, situations, products that you would like to share with others on our membership list? If yes, please feel free to send it to Mary Lynn at the office email: [wisconsin@pwsaofwi.org](mailto:wisconsin@pwsaofwi.org) so we can share it with everyone.

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Did you know that there is a program out there for people who have no dental care and have problems finding a dentist who takes Medical Assistance (MA)? It is called Donated Dental Services. It is a part of the Wisconsin Dental Association Foundation. As many of us are very aware - it is very hard to find a dentist who takes Medical Assistance. Some dentists would rather donate their services than take that program on. To apply for the program, there is an application to complete and there is a waiting list. If your dentist is willing to take you on - the wait is basically non-existent. For more information go to: [www.wda.org](http://www.wda.org) and search for Donated Dental Services in the search box. You can download an application. Or call toll free: South and East WI: 1-888-338-6852 Greater Wisconsin 1-866-812-9840.

### **Request for Email Addresses or Updates**



Would you be willing to receive your newsletter by email? This could be a great cost savings for our organization. Are you receiving all of our last minute updates and information? Often times, our office receives information that we pass on to our membership via email. This is also a cost-savings way to keep you informed. Please drop us a note to let us know your email or inform of us of any changes. We strive to keep you updated on issues of concern.

**CONTACT:** [wisconsin@pwsaofwi.org](mailto:wisconsin@pwsaofwi.org)

## **Notes from the Office.....**

**By Mary Lynn Larson**

Our golf outing is not far away and our chairpersons are hard at work as always! We can still use your help!! Do you have friends who love to golf? Invite them to join us!! Don't worry if you don't have a foursome, we can help you out with that!

If you have family or friends who are interested in supporting you and your loved one with PWS, ask them to become a hole sponsor! If the cost of the hole sponsorship is too much for one friend or family member, encourage several to join together to sponsor a hole —to “honor” your loved one with PWS! I have a sample letter available to anyone who is interested in this concept! It was put together a few years ago by another member of the organization—and was a huge hit!! We were able to get 40 Hole Sponsors for our event last year and are hoping to beat that! Help us out!

In order to make this golf outing a success, we need prizes for our golfers and silent auction! Some past ideas for prizes include: coolers, lawn chairs, lawn games, gift certificates of any kind, grilling supplies, and golf items. Remember, this is NOT an all inclusive list so if you have other ideas either for golf prizes or silent auction items, let us know!

The other event causing activity in the office is our Fall Behavior training featuring Dr. Linda Gourash. Dr. Gourash is a developmental pediatrician who has over 30 years of experience working with persons with PWS. We are very excited she will share her insights into dealing with some of the behavior challenges of PWS. Our conference will be at the Country Springs Hotel and Water Park in Waukesha, WI. We, as an organization, are not offering child/adult care at the conference but many of us involved with the planning have made arrangements to include our kids/loved one with PWS so we can spend some “fun” time with them at the water park outside of the conference. We are hoping this will be an opportunity for you to spend some “fun” time and learning time with your loved one with PWS. Please be aware that we are offering scholarships for those who have financial constraints. Just contact me at the office via phone or email and I will send you an application form to fill out. We are hoping this will encourage ALL families to take advantage of the chance to learn more about dealing with behavioral challenges. Hope to see you there!

Enjoy!

Mary Lynn

# The Spring Carnival was a BLAST!

"We had so, so much fun, Mom!" was Matthew's comment as we loaded into the van to head back home after the Carnival held by PWSA of WI, Inc. at the Oconomowoc Residential Programs Gymnasium on April 24, 2010. From the fishing game, to kicking a soccer goal, to the Pencil pull, bowling, duck pond—and my



favorite, the 'Corn Balls of Fury', it was an exciting day!

A HUGE "Thank You" to Melodee and Jackie for all the work they—and their "helpers", did to make this event such a suc-



cess! We appreciate it more than you know! It was really great to see old friends and meet new ones! I hope you were able to 'catch up' with some of your friends!



After the Carnival stations and lunch, we were treated to juggling—and much more which was provided by one of our newer Board members, Katherine G. and her juggling partner.



We were then treated to an amazing Magic Show provided by Andrew and Lynette Baerlocher!! Andrew



was able to keep us entertained and always guessing with his card tricks, balloon animals and levitation tricks. How did he get Amanda to float in the air like that? And how did



he make Lynette disappear in that box? I hope you enjoyed the magic show as much as I did; although I am still wondering how all those tricks worked! We also need to take a moment to thank all of the families and friends who attended and helped us to make this year's event a HUGE success!! We would like to thank the staff at PWHO for their participation and letting us use their facilities. Thanks to all our volunteers for jumping in and making it happen without a glitch! And to those who participated, it was seeing the fun you had and the smiles on your faces that make us work so hard at this each year! Thanks so much!!

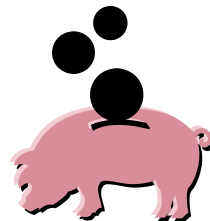


## PWSA of WI, Inc. Pick 'n Save WE CARE PROGRAM



Do you shop at Pick 'n Save? Did you know that PWSA of WI, Inc. can benefit from your shopping purchases? Designate our organization on your Pick 'n Save Advantage Card.

**PWSA of WI, Inc's number is 622600**



- Q: What to do if I don't have an Advantage card:
- A: Just go to the service desk and apply for one. There is no fee. It will offer you all kinds of savings plus a certain percentage will be donated to our organization. Please designate our organization as one of your WE CARE organizations. **Remember # 622600.**
- Q: How do I add/change what I have designated?
- A: Just go to the service desk and ask for a change form. Add our organization to your list.

**Please share this information with family and friends. Help us raise funds that will benefit all who have Prader-Willi Syndrome!**



**PWSA of WI, Inc and Prader-Willi Syndrome Assoc. IL Chapter  
Are Proud to Host**

## **Special *Tricks* on *Treating* Prader-Willi Syndrome: A Behavioral Approach**

**Featuring Guest Speaker Dr. Linda Gourash, MD, a Developmental  
Pediatrician and National & International Expert on  
Prader-Willi Syndrome.**

**Friday October 15, 2010  
Country Springs Hotel Water Park & Conference Center,  
Waukesha WI**

Dr. Linda Gourash, MD, is a board certified Developmental and Behavioral Pediatrician. She has over 30 years of experience in working with children and adults with developmental disabilities who have behavior and medical disorders. She is a past Medical Director of the Prader-Willi Syndrome (PWS) and Behavior Disorders unit at the Children’s Institute in Pittsburgh, PA. Dr. Gourash is co-founder of her current practice in the Pittsburgh Partnership. She has authored many articles and publications on practical management of challenges faced by individuals with PWS. She serves on boards for both PWSA (USA) and the International Prader-Willi Syndrome Organization (IPWSO). Dr. Gourash is a dynamic speaker and has years of experience as a consultant in helping those who support persons with PWS.

Children and adults with Prader-Willi syndrome often face behavior challenges at home, school, work and in their community. This conference will provide those who support these individuals with information, tools and networking that will help them gain a better understanding of how and what they can do to prevent and/or minimize these challenges.

Other Speakers Include:

Gus Ludwig OTR: Occupational Therapist from Oconomowoc Developmental Training Center who has training and experience in Sensory Integration Sensory Regulation.

Barb Dorn, RN, BSN: Volunteer Consultant on Prader-Willi Syndrome and parent of 25 year old son with PWS.

Peggy Burns, RD: Staff dietician for Prader-Willi Homes of Oconomowoc who provides nutritional services for over 70 persons with PWS.

**NO CHILD/ADULT CARE SERVICES WILL BE PROVIDED**

LODGING: Country Springs Hotel in Waukesha has provided PWSA organizations with very reasonable hotel room rates. Visit their website [www.countryspringhotel.com](http://www.countryspringhotel.com). Make sure to mention “PWSA” when registering or you will not receive these reduced rates. Hotel Contact: Toll free: 1-800-247-6640 or locally 1-262-547-0201

ROOM	SINGLE/DOUBLE RATE – WITHOUT WATERPARK	SINGLE/DOUBLE RATE – WITH WATERPARK *Includes 4 passes to 45,000 water park
Standard	\$95	\$115
Executive Suite	\$155	\$175
Governors Suite	\$216	\$235

**COST:**        **\$35** (for members of PWSA of WI, Inc or PWSA – IL)  
                  **\$45** (for non-members)  
                  Scholarships are available for members

**\*Certificates of Attendance will be awarded to social workers, educators and other professionals.**

## “What can we do??”

### I’m BORED”

I’m not sure about the rest of you—but I **DREAD** summer! Summer vacation hits and suddenly all the work of keeping a structured, consistent, and **FUN** routine falls on my shoulders! And lets not forget that many of our kids are much better behaved if we can maintain consistency and routine throughout the rest of our plans!

Don’t forget, Matthew still has 5 weeks of **ESY** (extended school year) that has to be accounted for, and then the week of summer camp both boys attend, and we definitely want to head up to our family’s cottage for some long weekends, and the boys are continuing the swim lessons through the summer... but for the rest of summer the message is: **MAKE IT FUN, Mom!!** So, how do we go about doing that??

Some basics we use in the Larson house are—each morning we follow the ‘morning school routine’ (with a somewhat later start time) unless otherwise negotiated or planned for. The boy’s have their general morning chores—make their bed, dress, brush teeth, feed cats, and breakfast; with activities like showering or using the treadmill thrown in on specific days noted by a ‘chore chart’ in each of their rooms. During the weeks Matthew is at school, the mornings with Alex consist of light chores, errands or him working on his required summer reading and book reports while I work on my own activities.

On the weeks when **ESY** is not in session, we look at events like heading to the library, biking, going on walks, going on a picnic, doing crafts, visiting a park or playground, or swimming. Other ideas you might want to investigate include activities at the local **YMCA**, free community concerts, or farm markets. We try to limit the “larger” active events to one per week with smaller, less strenuous things happening thru the rest of the week. It might be worthwhile to go online and ‘google’ topics like, “free community activities” to get some other ideas of things going on in your neighborhood. Some other activities we have had available to us in our community include: special needs T-ball through the Challenger or Miracle Leagues, special needs soccer thru a local school district, vacation bible school, and activities through our local Sibshops program.

When things are getting a bit hectic at home but I still need to run errands, I try to make a list of things I need and make it like a scavenger hunt or memory game. “First, we need to stop at the pharmacy and pick up a prescription and some Band-Aids. Sec-

ond, we have to go to the post office, next we pick up the dry cleaning while last, we need to go to the bank.” I used to use this type of strategy when we would go on walks by giving them a short list of things we needed to find. Sometimes just the change of scenery can be enough to break the cycle of an argument! If you have some other interesting ideas that you use, share them with me. We could all use ideas on some of the things you do during the summer to avoid the dreaded “I’m bored” comment.

## PWSA of WI, Inc’s 10th Annual Golf Benefit

Keep August 28, 2010 open to attend PWSA of WI, Inc.’s 10<sup>th</sup> Annual

Golf Benefit to be held at Windwood of Watertown! This is

our biggest fundraiser of the year and we

need your help and participation!! We are looking for golfers, prizes, volunteers to help out and hole sponsors! For more information, contact Mary Lynn at the PWSA of WI, Inc office at 1-866-797-2947 or visit the web site: [wisconsin@pwsaofwi.org](mailto:wisconsin@pwsaofwi.org)



## Getting ready for school



I know, the kids just started their summer vacation it seems—but now is the time to start thinking about what your child will need for and from the school in the fall. I usually start by making a list of all the things I want for my children during the upcoming school year, knowing that I won't likely be able to get them all! In our house, some of the

most obvious things to think about include diet and food accessibility, bussing, behavior and academics.

**Diet and Food Accessibility**—Does the school know your child's diet restrictions? You may want to get your physician to write a prescription stating just how many calories your child is allowed each day. It may help to break it down per meal, for example, 300 calories for breakfast, 100 calories per snack allowing 2 snacks per day, 300 calories for lunch, etc. Once the school has the prescription from the physician, they must follow it.

It is also important to think about the potential for food accessibility during your child's day. Do they have a cooking class or snack? How are the calories consumed here determined? How is this conveyed to you, the parent? What about holiday parties or birthday treats? How will these situations for food be handled? Discuss this ahead of time so that everyone at the school including the classroom teacher and your child know what to expect!

**Bussing**—Does your child receive bussing as part of their school day? Are their issues at school that need to be carried over on the bus such as the concern for food accessibility? If your child's school day includes bussing to and from school—the same issues of safety should be addressed on their bus ride!

Another area to consider is the chance of food or snacks being consumed by students on the bus. Does your child have access to their lunch? Will they consume it during the bus ride to school? Will other students on the bus share their snacks or lunch with your child? Do they need to leave their lunch bag and/or backpack with the bus driver dur-

ing the trip to or from school?

**Behavior**—Do you have a Behavior Intervention Plan in place at school to help keep your child safe? A *Behavior Intervention Plan (BIP)* takes the observations made in a Functional Behavior Assessment (FBA) and turns them into a concrete plan of action for managing a student's behavior. A BIP may include ways to change the environment to keep behavior from starting in the first place, provide positive reinforcement to promote good behavior, employ planned ignoring to avoid reinforcing bad behavior, and provide supports needed so that the student will not be driven to act out due to frustration or fatigue. When a behavior plan is agreed to, the school and staff are legally obligated to follow it, and consequences of not following it should not be inflicted on the student. This may take a lot of vigilance, advocacy, and battling by parents to make sure that everyone who is to take these interventions into account does so in a complete and informed way. This plan should have the necessary interventions the staff should implement when they see negative behaviors occurring with your child but it should also include a section where your child is being taught strategies to reduce the negative behaviors as well as learning to demonstrate appropriate behavior during times of stress and anxiety. These interventions should be taught and reviewed when your child is calm and NOT having a meltdown and then practiced regularly—especially before anxiety or behaviors are starting to escalate.

**Academics**—One of the most obvious areas to address will be academics. Is your child being taught subject areas he or she will need to know during their life? During the elementary school years, the obvious choices of reading, writing and arithmetic are important, but what else? Science? Social studies? Social skills? This can be much more of a challenge after the elementary years. It may require you sitting down with your child and finding out some of their personal goals. Do you want your child to have the skills for leisure activities such as art, music, or even photography? Is there a possibility of taking a class on health and basic first aid? Do you want your child to know some of the basics of government so they can be knowledgeable in the voting process? It is never too early to start thinking about what you envision for your child as a young adult as NOW is the time to start to help them prepare. Good luck!

## Olivia's Run

By Al Luening

It never ceases to amaze me that a child deemed so unable to thrive, continues to develop and strive especially when faced with all the adversities of typical childhood development. Over the last few years, I've given a lot of thought as to what we are all capable of and I suppose when faced with the reality of having a child with different needs we are all faced with the same sort of thought. Can I do this? Will I make a mistake?

Two years ago I decided to find out what I was capable of doing when I opted to train for and complete a full marathon (26.2 miles). I've never been one to really push myself to those types of limits before, but watching Olivia grow and struggle with every step, I figured my temporary pain would be minimal compared to her lifelong hunger. Every time I felt like quitting, I would think of her miraculous first steps at the age of two and I would just keep going. During the marathon, she was there, cheering and ringing the cowbell, keeping me going. Little did I realize that as much as she inspired me, I was doing the same for her.

A few days after the marathon, she started asking if she could run a race like mine too. Always the optimist, I said, "maybe when you're older." Why not? Running, unlike a lot of team sports is mostly about competing with yourself; pushing harder, tolerating punishment and always looking to improve. Olivia already likes taking a little walk now and then. What's stopping her from running a short distance?

While researching the Green Bay Marathon, for my own challenge, I noticed that they had a kid's mini race that was about a half mile. The course for all the races that weekend included a lap inside Lambeau Field. Melodee and I talked to Olivia about it and she was a little more than excited. We immediately signed her up. Olivia loves to tell people about all the news in her life, so as soon as she knew she was going to run, so did everyone at her school. Her gym teacher started working with her on keeping a good pace and some teachers and fellow students got a "walking" club together so they could go around the track during lunch recess at school. Olivia and I got out a few times to "run" around the block so I could make sure she didn't forget to breathe deep. Watching her persistence really put so much in perspective for me. For all the limitations that are supposed to keep her down, when she sets her mind to doing something, she really puts in her all.

May 15th at 10:45 am, Olivia and I set off on our lap of Lambeau. The start was just outside the south side of the stadium and as we trotted through the players tunnel, the mass of 7 year olds we were running with, thinned down to Olivia, me and the "pace" guy. Egging her on and keeping her focused wasn't as hard as I thought it would be. I wanted her to have fun and enjoy the experience. As we trotted out onto the field, into the light, the small group of people sitting in the south end zone stands erupted into cheers and wild screams of Olivia's name. We saw the bright purple and pink "GO OLIVIA" signs that I

### Olivia with her 'cheering' section!



made for family members to hold up. As we paced ourselves along the west side of the field to the north and then around to the east heading back south toward the cheering fans, I looked back at Olivia's eyes and saw them welling up with tears. I braced myself for a meltdown, but to my astonishment, she smiled at me through her tears and ran a little faster, waving and clapping at all those holding her signs. We went back through the tunnel with workers and the "pace" guy cheering her on. She continued to run even though we were the last ones on the course. Coming out of the tunnel with just two more turns to make, she was tiring a little but quickly snapped to attention with the smell of hot dogs on a grill. "Dad, I get a hot dog when we're done, right?" I reassured her that there would indeed be hot dogs and a cool drink waiting for her right after the race. As we came around the last turn, family and friends cheering among the



countless others that we had never met before, Olivia smiled, put her head down and finished. I couldn't

have been more proud of my little fighter. A few days later we talked about writing this story together and I decided (because she's so busy all the time) that I would interview her instead. It's short but sweet.

### Interview with Olivia:

Q: Why did you want to run the race?

A: Because I wanted to do something hard.

Q: What did you do to train for your run?

A: I practiced running around the gym and started a walking club with my friends at school for recess.

Q: How many miles was the race?

A: A half a mile, right?

Al: 26.2 miles actually. A little longer than a half.

Olivia: Yeah!!

Q: How did it make you feel to finish?

A: Happy, proud, really good.

Q: When we were running, I thought I saw you getting a little teary eyed. Was it the wind?

A: (Laughs nervously) It was happy crying when I saw all those people.

Q: Did you have a lot of family there?

A: Yes, and they all held up signs that you made for me dad. Remember?

Q: Was it fun?

A: Yes, but very tiring.

Q: Do you plan on running again?

A: Yes, maybe next year with my sister.

Q: What was the most fun part of the race?

A: Running with you, dad.

Al: Well that's nice of you to say.

Olivia: And the Gatorade and the hot dog.

Al: But, we got to run on Lambeau field, wasn't that cool too?!

## PWSA of WI, Inc.'s Event Calendar

<b>August 28, 2010</b>	<b>PWSA of WI, Inc.'s 10th Annual Golf Benefit</b>	<b>Windwood of Watertown</b>
<b>October 15, 2010</b>	<b>'Special Tricks on Treating PWS: A Behavioral Approach'</b>	<b>Country Springs Hotel &amp; Conference Center, Waukesha, WI</b>

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