



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

My Second Family

In April 2000, I moved to Wisconsin after accepting a new job with my mother's company. When I arrived I was a single parent of a 5 year old son with Prader-Willi Syndrome (PWS) and I didn't know anyone except my mother. I was very apprehensive about meeting people who would understand the special circumstances that having a child with PWS can bring about. Thankfully, the geneticist we saw at Children's Hospital of Wisconsin referred me to the Prader-Willi Syndrome Association of Wisconsin, Inc. (PWSA-WI) and within a few weeks I had found our new "family". I wouldn't truly realize until 8 years later how much the organization really was part of our "family" and how the combined knowledge of the members would benefit me.

In June 2008, I found myself facing one of the most difficult situations a parent of someone with PWS can face. My son had ended up in a psychiatric facility due to aggressive behavior and the physicians wanted to commit him to a long-term mental institution, which I knew was the worst place he should be. I had absolutely no idea how to wade through the legal or mental health world so I turned to the association for guidance and assistance. Within a few hours of contacting the Program Director and several of the board members I had a general idea of how to start working on getting my son released to a group home rather than to a long-term mental institution. Within a few days, I had answers on how to get a case worker assigned and I had the contact information for the group home I was interested in having my son placed. Within weeks I had waded through the system and my son was moving into his new room at Oconomowoc Developmental Training Center (ODTC). During those weeks, the members of PWSA-WI not only helped me by sharing their knowledge, but they helped mentally support me as well. I knew that I could call one of the board members 24 hours a day 7 days a week if I needed to talk, ask a question or just plain cry. Throughout the 8 years prior to this, the board had assisted my family by answering general questions that arose or by providing financial assistance when I wanted to send my son to camp, but never in my life was it so apparent that this organization was truly there to support their members no matter what the situation or event.

I decided to share this story with everyone because I recently had an individual tell me that they really didn't feel they needed to be involved with the organization much because everything with their child was going really well and they just couldn't see a time when things would be "that bad". Well I can assure everyone that for 8 years things with my son went fairly well and I only needed the occasional question answered. I can also assure you that I would never have imagined that things would ever get "that bad", but one morning things were worse than "that bad". If you get the chance to be involved with the organization, whether it is a fundraising benefit or just answering the questions on a survey, I encourage you to do so...you never know when you might need the expertise or support of the organization and the members. And you never know what changes the answers to those surveys might prompt that will help you or some other member in the future.

Happy Fall.

Crystal

Board of Directors:

President: Crystal Boser

Vice President: Jackie Mallow

Treasurer: Tom Hughes

Board members: Melissa Sirovina, Al Luening, Don Dorn, Candace Lipski and Katherine Girdaukas

Program Director: Mary Lynn Larson

Assistant Program Dir: Melodee Luening

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PWSA of WI, Inc's 10th Annual Golf Benefit

"What a gorgeous day!!"

What luck! August 28th had perfect weather—which was convenient as we held our 10th Annual PWSA of WI, Inc. Golf Benefit at Windwood of Watertown Golf Course on that day! We had 93 golfers attending and 7 volunteers helping with the event. A huge thanks goes to our golf committee (which consists of Jackie Mallow, Crystal Boser, Don



Dorn, Candace Lipski as well as any other volunteers we can pull in), who did a great job of getting prizes, golfers and pulling everything together for the



Crystal and Jackie are working on making sure everything turns out just right...

event!! We had terrific prizes donated this year! We could not do all this without you! We had 48 generous Hole Sponsors!! Thanks so much to both our new golfers and those who continue to join us each year! We could not do it without you all nor would we have as much fun!

We had our first



Golfer Jay Neider on the 17th hole where he scored a 'hole-in-one'! Congratulations Jay, sorry it wasn't on the 13th hole for the car!!

'hole-in-one' this year on hole 17 — although unfortunately for Jay Neider, it was not on the 13th hole where anyone scoring a hole-in-one there could have won a new car. Maybe next year??

Thank you to our prize donors!!

- | | |
|-------------------------------------|--------------------------|
| Cave of the Mounds | Safe House |
| Lake Michigan Car Ferry | Paint Ball Dave's |
| Don & Barb Dorn family | German Fest |
| Milwaukee County Zoo | Road America Inc. |
| UW-Milwaukee Athletics | Sybaris Pool Suites |
| Quality Candy/Buddy Squirrel | Milwaukee Wave |
| Prime Quarter Steak House | WTMJ-TV |
| Barbara Ausick | Fun World |
| Sprecher Brewing Co. | Jennifer Kryzak |
| Al & Melodee Luening | Linda Wiggins |
| Walgreens | Worzella Photography |
| Sunset Playhouse | Riveredge Nature Center |
| Green Bay Packers | Mequon Country Club |
| Applebee's | Goebel Woodwork Inc. |
| Joe & Elaine Gareau | Al Stark |
| Build-A-Bear Workshop | Milwaukee Bucks |
| Alan Luening, Sr. | Cheesecake Factory |
| Rocky Rococo Restaurant | Bristol Renaissance Fair |
| Windwood of Watertown | Milwaukee Admirals |
| Xpression by Peggy | Berres Brothers |
| Legacy Bakehouse | Mike Laur |
| Betty Brinn Children's Museum | Mike Pierson |
| Milwaukee Public Museum | Panera Bread |
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| Bartolotta Restaurants | Milwaukee Brewers |
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| Mike & Mary Lynn Larson | Papa Murphys |
| Racine Danish Kringle | Becky Soderholm |
| John & Marquerite Rupnow family | Summerfest |
| Mike Hassler Art & Scenes | Bobbie Beson-Crone |
| Tailgaters Sports Bar & Grill | Felt-Up Designs |
| John & Bobbi Pogrant | Apple Automotive |
| Lynn Ann Miller | Paradise Tan Inc. |
| Westridge Neighbors | Mike Miller |
| Jim & Renee Breit | James Jones |
| Bruce & Jackie Mallow family | Crystal Boser |
| John & Candace Lipski | FM 106.1 |
| Chad & Melissa Sirovina family | Nancy Burlingame |
| John & Betty Pogrant | Dennis Schultz |
| Donna Munnik—Mary Kay | Daniel Copp |
| Bruce & Cindy Opsal | Susie Forde |
| Klement's Sausage | Festa Italiana |
| Prader-Willi Homes of Oconomowoc | |
| Welcome Home Bed & Breakfast | |
| Lake of The Torches—Resort & Casino | |

THANK YOU HOLE SPONSORS!!

- Tosa Pediatrics
- In Honor of Beth LaBella — The Ausick Family
- In Honor of Peter Frazin
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- In Honor of Tony Dorn — Laurence, Leslie & Brodie Hall
- In Honor of Tony Dorn — Dan & Shirley Kealey
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- In Honor of Tony Dorn — Mark Dorn & Laurie Grinnell
- In Honor of Tony Dorn — "Westridge Friends"
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- In Honor of Jefferson Kennedy — Owen Kennedy
- In Honor of Katherine C. Baker — Sam & Diana Baker

Notes from the Office...

By Mary Lynn Larson

Happy Fall! I can't believe its fall already!! My family LOVES autumn—with the cooler temperatures, football season, and especially the return of the consistency of school! I suspect this is a common theme in the homes of families living with Prader-Willi syndrome! It was a bit tougher this year with Alex having his recent spinal fusion surgery the week before school started... but he has recovered so amazingly well! We are finally getting him back for a few half days of school starting this week!! It's time!! He was beginning to start telling me everything I did wrong around the house, "in his eyes"... GRRRR! It's a very good thing though as things are getting busier in the office!

We are busy getting ready for our training, "Special Tricks on Treating Prader-Willi Syndrome: A Behavioral Approach" with speaker Dr. Linda Gourash on October 15, 2010 which should provide all attendees with some great ideas and strategies!! Dr. Gourash is a dynamic, entertaining speaker who has years of experience dealing with individuals with PWS and is sure to have lots to share with us! We hope to see you there!

We are also interested in sending out a survey to our members. We want to know what we, as an organization, can do for you. We have tried several things over the years, but our attendance at events seems to wax and wane. What are the things that you benefit most from? Does it help to meet with other families who might be dealing with similar issues? Do you prefer networking with other families online? Do you need resources for the school personnel working with your child? Do you like just attending the spring social events? We will be sending a short survey form in the mail in the next few weeks. We would love for you to share what things work best for you and your family. Please help us out.

We are also looking for persons willing to serve on the Board of Directors of PWSA of WI, Inc. Are you interested? It doesn't require a large time commitment and we just ask you be willing to share your ideas and opinions. Are you open to being a voice for persons with Prader-Willi Syndrome? Please review the duties and responsibilities and see if this might be a good match for you. If you have any questions, feel free to contact one of the current Board members or Mary Lynn at the office.

Enjoy Autumn. Mary Lynn

Call for Nominations PWSA of WI, Inc.

Officers and Board Members

Its that time of year again when PWSA of WI, Inc. is looking for dedicated individuals to serve in the following roles for a 2 year term of office. If you have any questions regarding the roles or responsibilities, feel free to contact the PWSA of WI, Inc. office or any current officer or board member.

VICE PRESIDENT: may be delegated by the president to perform his/her duties in event of the president's temporary disability or absence from meetings, and shall have such other duties as the president may assign.

TREASURER: shall be responsible for the financial integrity of the organization. He/she shall keep an account of all moneys received and expended for the use of the organization and shall report to the National office and the membership on the financial status of the organization. The treasurer shall establish the necessary controls and checks for the handling and accounting of all financial transactions for the organization.

BOARD MEMBER: (*need 2 for 2010 elections*) Serves as advisor in providing governance to the organization. Assists in projects, committees and other capacities as needed.

OVERVIEW OF BOARD MEMBER RESPONSIBILITY: The following is a brief outline of major events and activities PWSA of WI, Inc. sponsors annually.

BOARD MEETINGS: The board of directors meets three times a year. The meetings are typically in February, early June and October. The exact dates, times and locations are determined at the previous meeting. We typically meet from 11 am to 3 pm. Every attempt is made to work around board members' preferences and location. We try to meet at a central location if possible. We have tried many approaches and currently schedule it on the same day as our fall training workshop prior to the annual membership meeting.

BOARD MEMBER INVOLVEMENT: We encourage Board members to become involved in **at least one activity or project** per year. The following is a list of our current activities and projects. Dates and types of events are discussed and determined at Board Meetings.

Annual Social-Training Day This event typically occurs in the spring of the year. We have tried various approaches, activities and locations for this event. The primary focus has been hobby activities in the morning with a dance - social activity for children and adults

with PWS in the afternoon. We also provide either a training or support opportunity for parents and/or professionals. The event is one day, however the planning and preparation goes on year-round.

Annual Charity Golf Benefit – This event typically occurs in the late summer or early fall. It has recently occurred at Windwood Golf Course in Watertown. The date is dependent upon availability. Jackie Mallow is the chairperson and she works with a committee of volunteers. All board members are asked to obtain 2-3 hole sponsors, seek out door prizes and disseminate fliers and recruit golfers for the event. They are also expected to attend/assist at the event if able.

Annual Training Workshop or Education Project PWSA of WI, Inc tries to sponsor some sort of training workshop or educational project on an annual basis. The topic, speakers and location vary. In the past, some board members have been speakers, worked at the registration table or assisted in other ways. As an alternative, we may chose to do an education and/or awareness project. A board member may be willing to offer their expertise in some aspect of a project.

PWSA of WI, Inc. Newsletter – The Wisconsin Connection The newsletter is published and distributed 4 times a year. Currently the program director solicits articles, prepares layout and has it printed. We have a volunteer fold, secure, apply mailing labels and stamps and mail them out. Board members are encouraged to submit an article or help with any aspect of this.

Packet of Hope Program All genetics clinics in Wisconsin are given 5 copies of our Packet of Hope each year. We contact each of them and replenish their supplies annually. Packets need to be compiled and mailed. Help is needed in replenishing and distributing these packets.

PWSA of WI, Inc.'s Annual Mail Fund Raiser Once a year, we conduct a mail fund raiser typically in the fall of the year. Currently the program director creates the letter and prepares it for mailing. Any board member (or volunteer) who is interested in any aspect of the creation of this annual mail fund raising letter is graciously appreciated. The program director assists with the production of labels and any other supplies that may be needed. (We are always looking for creative people!)

PWSA of WI, Inc. Website We continue to look for help in upgrading our website exposure.

Annual Meeting for Parents of Young Children In the past few years, we have sponsored an annual meeting specifically for parents of young children. Two parents of young children have made all the arrangements for this event.



**PWSA of WI, Inc.
CANDIDATE APPLICATION - 2010**

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Email: _____

Date of Application: _____

Position You Are Interested In Running for:

- ◇ Vice President (2 year term)
- ◇ Treasurer (2 year term)
- ◇ Board Member (2 year term) ** There will be 2 Board positions open.

**Tell us briefly about yourself and the strengths or skills you feel you are bringing to this position?
(We will be using this information as your bio to inform the membership of your interest, background and qualifications)**

**You can also get this form in electronic format by sending an email request to: wisconsin@pwsaofwi.org
Please return this form by October 15, 2010 to:**

**PWSA of WI, Inc.
2701 N. Alexander St.
Appleton, WI 54911-2312
Toll free: 1-866-797-2947
Email: Wisconsin@pwsaofwi.org**



Shoo the Flu – Colds, “The Flu” and the Person with PWS

By Barb Dorn, RN, BSN

Author’s Note: This article is meant to help identify and manage the symptoms of upper respiratory infections in the child or adult with PWS. It is NOT intended to replace the recommendations of your health care provider. Contact this person for any questions or concerns you may have.

Introduction

We are now approaching the cold days of winter. Many of us will be facing colds, flu and other viruses. Many children and adults with Prader-Willi syndrome may be more susceptible to respiratory infections. Because of weak chest muscles and obesity, they are often at increased risk for developing complications when they do contract these illnesses. Many people with PWS also have other chronic health problems (like asthma and diabetes) which can also complicate the management of upper respiratory infections.

How Do You know if it is a Cold or the Flu?

Cold and flu symptoms often resemble each other but they tend to differ in intensity. Major influenza is a flu that affects a person’s respiratory system. It is not the one that affects ones’ stomach or intestinal tract.

COLD	FLU
<ul style="list-style-type: none"> Often starts off slow with sniffles, sneezing Symptoms: head & nose congestion, sore throat, minor cough, low grade fever Can usually continue with work and school. 	<ul style="list-style-type: none"> Tends to come on fast Symptoms: persistent cough which can proceed into pneumonia, headache, joint and muscle pain, high fever Often makes one too ill to go to work or school

What Can Be Done to Help these Symptoms?

What should you do to help the child or adult with PWS who has an upper respiratory infection? Here is a quick reference to help with some of the common problems that they face.

Problem	What Might Help
Fatigue	<ul style="list-style-type: none"> Encourage rest but do not let the child/adult sleep too long. When ill, persons with PWS tend to sleep more and move less. Can lead to onset of pneumonia.

Problem	What Might Help
Cough or Lung Congestion	<ul style="list-style-type: none"> Encourage the person to get up and move around every 1-2 hours. This helps to expand their lungs. Encourage deep breathing and coughing up secretions. (Even crying & yelling can help to expand their lungs.) Encourage fluids in moderation. This helps to keep lung secretions thin & watery. (Warm broth &/or warm sugar-free lemonade are often soothing) Administer cough medicine as advised by your health care provider.
Fever	<ul style="list-style-type: none"> Take temperature every 3-4 hours. Because many children and adults with PWS have difficulty with temperature control, a fever may or may not be present when they have a serious infection. Administer medication to lower fever as directed by your health care provider. In children, DO NOT USE ASPIRIN.
Headache &/or Body Aches	<ul style="list-style-type: none"> Dress in lightweight clothes and do not cover with too many blankets if fever is present. Take pain-relieving medication as directed by your health care provider.

When Should I Contact my Health Care Provider?

Often times the best indicator of a more serious infection can be a change in behavior, an increase in sleepiness and/or a decrease in appetite. However, persons with PWS often do not exhibit a change in appetite

Notify your health care provider if the person with PWS has:

- Nasal secretions or is coughing up mucous that is yellow, green or gray.
- A persistent cough that keeps them awake.
- Chest pain or persistent facial or head pain.
- Presence of a high fever (above 101 degrees)

Trust your instincts. When in doubt, call for advice.

Who Should Receive the Influenza Vaccine?

The Center for Disease Control has set up guidelines to assist in identifying those persons who are at high risk. This fall there are no reports of a shortage of the flu vaccine. The vaccine should be available for the general patient population.

High risk has been defined as:

- People over 65 ears or older
- Children or teens on long-term aspirin therapy
- People of any age with chronic diseases of the heart, lung and kidneys or who have diabetes, severe anemia, or immunosuppression .
- Women in their 2nd or 3rd trimester of pregnancy during the flu season
- People who live in a house hold with high-risk people.

Should Persons With PWS Receive the Flu Vaccine?

Unless otherwise advised, persons with PWS who have a chronic health problem (asthma, diabetes, heart problems...) should receive this vaccine. Many physicians also recommend it for persons with PWS because of their weak chest muscles and poor muscle tone. Don't hesitate to discuss this with your health care provider.

Continuing their generosity**Knights of Columbus Council 607 of Appleton**

We have been very fortunate over the last several years to receive a generous donation from the Knights of Columbus, Council 607 of Appleton, WI through their Tootsie Roll Fundraiser held in the Spring of the year. This year, they donated a check for \$719.40. We are very fortunate to have some personal connections with Council 607, including Larry Abler and Mike Larson, parents to sons with Prader-Willi Syndrome.



Persons in photo (L to R): Brian Kubiak (Deputy Grand Knight, Council 607), Larry Putzstuck (Trustee, Council 607), Mary Lynn Larson (Program Director of PWSA of WI, Inc.), and Glenn Wiegand (Treasurer, Council 607).

**Thank You!**

Dear PWSA of WI, Inc Board Members,

I am writing to **thank you so much** for the camp scholarship you gave me and making it possible for me to go to Badger Camp this year. I really had a good time.

I was part of a "travel camp" where I was able to go to the Wisconsin Dells. I stayed in a cabin with 2 other campers and a counselor. I wanted to share some of the things I did and things I liked the best:

- My favorite part was being able to go to the Dells and riding on the Ducks.
- I also really liked seeing and riding on the train (in North Freedom).
- It was really cool that – the counselors cooked all of our meals on a campfire. (Except one day for breakfast we had Cheerios).
- The food was great – I had pancakes, cake, appetizers (string cheese and crackers) and S'Mores.
- We went to the Tommy Bartlett's Robot museum – it was really cool.
- I got to swim in a pool at the camp ground.
- I slept on the top bunk in my cabin (and I didn't fall out).
- I danced with some girls at the "Badger Ball".
- I did karaoke as part of a talent show on Friday morning before we left ... and I wasn't scared.

Thanks again for making it possible for me to do this. I am going to work very hard again this year so I can save to go to camp again next year. My mom and dad told me it gets more expensive every year and I was really lucky to have PWSA of WI help me so I could do this.

Sincerely,
Tony Dorn

P.S. My mom helped me write this letter but everything in this letter is the truth.

PWSA of WI, Inc.'s Event Calendar

October 14, 2010	Annual Membership meeting Meet and Greet 7PM	Country Springs Hotel & Conference Center Waukesha, WI
October 15, 2010	PWSA of WI, Inc.'s "Special Tricks on Treating Prader-Willi Syndrome: A Behavioral Approach"	Country Springs Hotel & Conference Center Waukesha, WI
November 14, 2010	PWSA of WI, Inc. Board meeting 9:30am	PWHO Corporate offices Oconomowoc, WI

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