



# 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*

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**Consultant:** Barb Dorn

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## Website:

www.pwsaofwi.org

PWSA of WI, Inc. is a  
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The Wisconsin Connection

**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

I was recently talking to some individuals from another state about being the president of PWSA-WI, Inc. & someone asked me the following question, "You donate so much of your time to PWSA-WI, Inc., but how have they directly helped you & your family?" I decided to share the following stories with her, & now with all of you. It is my hope to shed some light on what PWSA-WI, Inc. has done, not just me, but for so many individuals, ... offer support, guidance, and knowledge!

In June of 2008, my son was admitted to a psychiatric hospital because his aggressive behavior was out of control & we could no longer keep him or those around him safe. Throughout the next 3 weeks he received in-patient treatment & during this time I was forced to make the toughest decision of my entire life...Bring him home & risk someone getting hurt or place him in a residential facility that could attend to his needs & keep everyone safe. My family & I decided to place him in a residential facility; however, in order to do so we had to file a request for protective placement, attend several court hearings, & meet with lawyers, guardian ad litem, & county case managers. The entire process was extremely overwhelming & many times I had no idea what I was doing. During this time, several members of PWSA-WI, Inc. shared their knowledge to help make this situation go as smooth as possible. But just as importantly, many members were there to offer moral support when I wasn't sure I could survive giving up my son to someone else's care.

Fast forward 4 ½ years & I am again leaning on the members of PWSA-WI, Inc. for support & guidance. On February 19<sup>th</sup>, my son is going to turn 18 years old, which is a monumental milestone for most children. However, while many parents are happily planning their child's impending graduation & looking forward to them going off to college or obtaining full-time employment, I am planning to obtain guardianship & meeting with various individuals to discuss how to best ensure my son will continue to receive the services he needs to be successful. Although I have more knowledge than I did several years ago, I am quickly realizing there are many things I don't know about this transition period. Again, members of PWSA-WI, Inc. have been there to help answer my numerous questions, like:

- What forms do I need to fill out to obtain guardianship?
- What do I need to do to transition from child services to adult services?
- Are individual Managed Care Organizations better than IRIS?
- Which Managed Care Organization is best?

Every step of the way, someone has been willing & able to share their experiences & guide me in making the best decisions for my son. Without the employees & members of PWSA-WI, Inc., I would never have been able to survive the roller coaster ride I have been on throughout the years.

So I will close with this, the organization does so much more than just host social events, educational trainings, & offer financial support. The staff, board, & members offer their invaluable knowledge & unending support whenever it is needed. Please do not hesitate to reach out to others within this organization when you are in need....they will offer whatever they can to help you out.

Crystal

# Snowflake Ball 2013— Success!!

Wow! What a night!! Our second Snowflake Ball was held Saturday, January 26, 2013 at the Oconomowoc Gym. Our dedicated volunteers spent hours transforming the gym into a wonderland of white and gold with the final result looking like this: Boutonnieres and wrist

**This is how it looked...**



corsages were created and provided to our attendees. Guests arrived dressed up and ready to have some fun! We got to see our old friends, meet new ones and get to know one another all over again!



**Kayla and Kyle enjoying a dance together!**

The night began with a special toast followed by a great dinner served by a great group of volunteers! It included a few members of the PWSA of WI, Inc. Board of Directors, staff at Prader-Willi Homes of Oconomowoc and other friends. All attendees were able to have a



**These are some of our volunteer friends...**

special photo keepsake taken of themselves with their friends or family that they could take home! The wonderful photographer who did this for us was our friend Tom Davenport!!  
**Thanks so much, Tom!!**



**Tom Davenport**

The evening of fun continued with dancing! Music was provided by our favorite DJ—  
Scott Wileman of Wileman Mobile DJ! And

**Scott, our DJ!**



because Scott knows us so well, he was sure to include some of our favorites like The Chicken Dance, the Macarena, and the YMCA.

As you can see, Scott brings costumes so we can enjoy things to the fullest!! And these photos show you just how much your friends were enjoying themselves!! **Thanks Scott!!** I think we all had a great time!



We must take a moment to Thank everyone for all they did to help make this event a success! We could not have done this without the cooperative work of everyone involved!!

**THANK YOU** to everyone who helped:

- |                                |                           |
|--------------------------------|---------------------------|
| <b>Dr. Nicolette Weisensel</b> | <b>Linda Wiggins</b>      |
| <b>Natasha Riley-Glassman</b>  | <b>Al Luening</b>         |
| <b>Melodee Luening</b>         | <b>Crystal Boser</b>      |
| <b>Jackie Mallow</b>           | <b>Melanie Ignatowski</b> |
| <b>Candace Lipski</b>          | <b>Mary Lynn Larson</b>   |
| <b>Agnes Hughes</b>            | <b>Rachel Gross</b>       |
| <b>Randy Dorn</b>              | <b>Gretel Evans</b>       |
| <b>Ben Ambroch</b>             | <b>Cheri Gullicksen</b>   |
| <b>Katie Gullicksen</b>        | <b>Cal Gullicksen</b>     |
| <b>Alixee Rheeve</b>           | <b>Jacinda Konczal</b>    |
| <b>Marguerite Rupnow</b>       | <b>Maura Coffey</b>       |
| <b>Jonah Rupnow</b>            | <b>Denise VanCuyk</b>     |
| <b>Deb Levine</b>              | <b>Rich Levine</b>        |
| <b>Max Levine</b>              | <b>Sam Levine</b>         |
| <b>Alec Billingsley</b>        |                           |
| <b>Jessica Kadow</b>           |                           |
| <b>LynnAnn Miller</b>          |                           |
| <b>Bob Miller</b>              |                           |
| <b>Marge Miller</b>            |                           |
| <b>Tom Davenport</b>           |                           |
| <b>Emily Jones</b>             |                           |
| <b>Dr. Tom Hughes</b>          |                           |
| <b>Jason Rieve</b>             |                           |
| <b>Ava Rieve</b>               |                           |
| <b>Sabrina Garner</b>          |                           |
| <b>Sue Morris</b>              |                           |
| <b>Dave Nagy</b>               |                           |





**PWSA of WI, Inc.**  
**Lunch and Learn Training Events**



**Nutritional Management of Common Health Issues Seen In Persons with Prader-Willi Syndrome**

**Presenters:** Barb Dorn, RN, BSN, Consultant and Training Event Coordinator—PWSA of WI, Inc. and Margaret (Peggy) Burns, RD Registered Dietician—Prader-Willi Homes of Oconomowoc

**Training Outcomes:** Persons who attend this training event will:

- Gain a better understanding of the nutritional needs of persons with PWS.
- Obtain guidance in calorie determination, diet and meal planning for the person with PWS.
- Be able to briefly explain three common health conditions often seen in persons with PWS—**Gastroparesis, Constipation and Diabetes.** Obtain guidance in dietary measures needed to manage persons with PWS who are experiencing these conditions.

**Target Audience:** Parents and Care Givers who are responsible for diet and menu planning for persons with PWS who need a basic understanding of the nutritional needs of persons with PWS as well as 3 common health conditions often seen in these individuals.

**Lunch:** A boxed lunch including a 6 inch turkey sub sandwich, chips, and a cookie from Subway is included (sorry no substitutions) along with a beverage. Feel free to bring your own lunch if this does not meet your nutritional needs.

**When/Where: (3 locations across the state)**

- Monday April 15th, 2013—Oconomowoc Residential Programs, 1746 Executive Drive, Oconomowoc, WI
- Wednesday May 8th, 2013—UW Waisman Center Community Outreach 122 E. Olin Avenue, Suite 100, Madison, WI

**Special Note:** To register: <http://cow.waisman.wisc.edu/traincon.html> Or call 608-265-9440 ext. 440

- September 2013 (Exact date and location to be determined)

**Time:** 11am to 1:30 pm

**Cost:** \$25 member of PWSA of WI, Inc. (Scholarships are available if needed)  
 \$35 Nonmembers

**SPEAKER INFORMATION:**

**Barb Dorn, RN BSN** is a Registered Nurse in the UW Health—University Station Internal Medicine Clinic in Madison, WI. She has over 35 years of experience as a nurse. She is the past president of PWSA of WI, Inc. and PWSA (USA). Barb has extensive experience as a consultant, advocate and Crisis counselor for persons with PWS. She currently serves as a consultant and Training Event Coordinator for PWSA of WI, Inc. She has created and contributed many articles and handouts on the care and management of persons with PWS especially in the area of education and health. She has been a speaker at many conferences on topics supporting the person with PWS. Barb is the parent of two sons, Tyler age 26 and Tony age 28 who has PWS.

**Margaret (“Peggy”) Burns, RD, LD** is a Registered Dietician who works for Prader-Willi Homes of Oconomowoc where she provides nutritional services for over 80 adults with Prader-Willi syndrome. Peggy has over 26 years of experience as a dietician. She received a Bachelor of Science degree in General Dietetics and Nutritional Care (1986) and a Masters degree in Health Care Administration (1996). Affiliations: American Dietetic Association, Wisconsin Dietetic Association, Milwaukee Dietetic Association, Prader-Willi Syndrome Association (USA) and Prader-Willi Syndrome Association of WI, Inc. Peggy is the proud parent of two teenage children.

## Notes from the Office by Mary Lynn Larson

Did you miss the Snowflake Ball? I hope not as we all had a BLAST!! First, I want to say, it was GREAT seeing everyone! I also have to give a big THANK YOU to everyone who helped with the planning, preparations, implementation, and all that went along with it! Thanks to our DJ, Scott, and photographer, Tom, for all the work you put in. All of our volunteers: YOU ROCK!! We could not have had such a successful event without you!! Thank you!! Thank you!! Thank you!!

We are now looking forward to our 3rd Annual *On the Move* Walkathon promoting fundraising and awareness of Prader-Willi syndrome. The walk will be held on Saturday, May 11, 2013 at Fowler Park in Oconomowoc. We are getting things ready to mail out and will have it on our web site as soon as it goes to print. Start working on getting pledges from family and friends and getting your team together... As always, if you are interested in volunteering with set up, obtaining sponsors, clean up or any part of getting things ready, and/or the day of, PLEASE send me an email or give me a call in the office! We can always use another set of hands!



We are starting to gear up for the 13th Annual Golf Benefit which will be held August 24, 2013 at Windwood of Watertown Golf Course. The proceeds from this event allow us to maintain our programs assisting persons with PWS and those who support them. We are again looking for golfers, hole sponsors and prize donations. Some past ideas for prizes include: coolers, lawn chairs, lawn games, gift certificates of any kind, grilling supplies and golf items.



Are you or your company willing to sponsor a hole? Hole sponsorships include donor recognition on the specific hole sponsored plus notice of your generosity on our donor board, in the newsletter and on our web site. We also need silent auction and door prize donations. Corporate sponsorship is another way to support the organization and provides a unique marketing opportunity. If you have any questions about participating in any of the opportunities above, check our web site or give me a call.

Take Care, Mary Lynn

## Nutritional Management of Common Health Issues Seen in Persons with Prader-Willi Syndrome

**\*\*Registration for Oconomowoc Location ONLY!  
Please fill out, detach and mail in.**

Name: \_\_\_\_\_

- ◇ Parent, Family member or Friend
- ◇ Professional (Type) \_\_\_\_\_

Agency: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State \_\_\_\_\_ Zip code: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Training Location:

- ◇ **Monday April 15, 2013:** Oconomowoc Residential Programs, 1746 Executive Drive, Oconomowoc, WI 53066
- ◇ **To register for Madison location, you MUST go to <http://cow.waisman.wisc.edu/traincon.html> Or call 608-265-9440 extension 440**

**Cost:**

- ◇ \$25 each—Member of PWSA of WI, Inc.
  - ◇ \$35 each—Non-member
- \_\_\_\_\_ Number of People Attending

\_\_\_\_\_ Total Amount Enclosed

- ◇ I would like to apply for a scholarship. You will be contacted by someone from the PWSA of WI, Inc. organization. You must be a member to receive a scholarship.

**Make check payable to : PWSA of WI, Inc.**

**Deadline: April 1, 2013 (Oconomowoc training)**

**Mail to:** PWSA of WI, Inc.

2701 N. Alexander St.

Appleton, WI 54911

**Questions: Contact PWSA of WI, Inc. office at toll free 866-797-2947 or via email:**

**[Wisconsin@pwsaofwi.org](mailto:Wisconsin@pwsaofwi.org)**

## Information on Summer Camps

Compiled by Barb Dorn



Summer camp can be a fun-filled, exciting time for youth & adults with PWS. Knowing what camp & at what age is best for your child to attend is a decision that each parent/care provider needs to make. Camp can offer a week filled with activities, adventures, & social opportunities. It can also be time where families (esp. siblings) get a break from the monitoring & challenges that we face.

Over the years, PWSA of WI, Inc. has compiled a list of some camps that parents & care providers of children & adults who have PWS have attended. If you have further questions, contact PWSA of WI, Inc.'s office at 1-866-797-2947 or contact the camp directly. Everyone has different opinions & views. **You** need to make the final decision. Many camps fill up early.

If your decision to attend camp is based on finances (or lack of), don't hesitate to apply for PWSA of WI, Inc.'s Camp Scholarship. This year, we have once again set aside funds to help a child or adult attend camp. Any person with PWS, living in Wisconsin, young or old, is eligible. You must be a member of our organization to be a recipient. Membership scholarships are also available. **DEADLINE IS APRIL 1, 2013.** A copy of the application form is included in this newsletter; can be downloaded from our website ([www.pwsaofwi.org](http://www.pwsaofwi.org)) or be mailed to you.

The following are the names, addresses & phone numbers of camps our office has heard of. (If you know of more...let us know). Some do not have staffing & support for special needs children but others do. We may be able to help. BUT don't delay. Many deadlines for camp registrations are approaching soon or may have already passed. **We have made every attempt to provide you with up-to-date contact information, internet links & email addresses.**

**ALL CAMPS LISTED BELOW HAVE EXPERIENCE IN SERVING CAMPERS WITH PWS.**

Camp	Address	Phone/ Website/Email	Comments
<b>Easter Seal Camp (Camp Wawbeek and Pioneer Camp)</b>	<u>Business address:</u> 101 Nob Hill Rd., Ste 301, Madison, WI 53713 Located on a wooded 400 acre site near Wisconsin Dells.	<u>Phone:</u> 608-277-8288 or <u>Toll free:</u> 800-422-2324 <u>Website:</u> <a href="http://www.wi-easterseals.org">www.wi-easterseals.org</a> <u>Email:</u> <a href="mailto:respite1@wi-easterseals.org">respite1@wi-easterseals.org</a> <u>Email:</u> <a href="mailto:wawbeek@wi-easterseals.org">wawbeek@wi-easterseals.org</a>	Camp Wawbeek—serves persons w/ physical disabilities. Provides experi- ences for children & adults with disa- bilities. Low counselor to camper rati- oable to handle some higher need campers.
<b>WI Badger Camp</b>	<u>Mail:</u> P.O. Box 240 Platteville, WI 53818-0240 Located 10 miles south of Prairie du Chien, WI	<u>Phone:</u> 608-348-9689 <u>Website:</u> <a href="http://www.badgercamp.org/">www.badgercamp.org/</a>	It serves developmentally challenged individuals regardless of severity. Have a well-trained staff and medical personnel.
<b>Lion's Camp</b> 	3834 County Rd A Rosholt, WI 54473 Located in central WI, 2 mi. east of Rosholt & 16 mi. NE of Stevens Point.	<u>Phone:</u> 715-677-4761 <u>Website:</u> <a href="http://www.wisconsinlionscamp.com">www.wisconsinlionscamp.com</a> <u>Email:</u> <a href="mailto:info@wisconsinlionscamp.com">info@wisconsinlionscamp.com</a> **There is no cost for this camp	Serves mild/borderline cognitively disabled youth and young adults. They have designated weeks for youth (Ages 9-17). Do not feel com- fortable handling persons with behav- ioral issues or those with moderate— severe cognitive disabilities.
<b>Camp Wil-O-Way Easter Seals Kind- care Southeast- ern WI, Inc</b>	1016 Milwaukee Avenue South Milwaukee WI 53172	<u>Phone:</u> 414-482-0133 <u>Website:</u> <a href="http://www.county.milwaukee.gov/WiLOWaySummerCamp8608.htm">www.county.milwaukee.gov/ WiLOWaySummerCamp8608.htm</a>	Serves campers with developmental disabilities ages 7—60 yrs. 2 locations in Milwaukee. Priority giv- en to Milwaukee residents
<b>Camp Courageous of Iowa</b>	12007 190th St. P.O. Box 418 Monticello, IA 52310-0418 Located about 5 mi. south of Monticello, Iowa	<u>Phone:</u> 319-465-5919 <u>Website:</u> <a href="http://www.campcourageous.org">www.campcourageous.org</a>	Serves all people regardless of ability levels. They have both a summer camp and a respite program.
<b>Camp Albrecht Acres of the Mid- west</b>	<u>Mail:</u> P.O. Box 50 Sherrill, IA 52073 <u>Location:</u> 14775 Sherrill Rd. Sherrill, IA 52073 Located 8 miles north of Dubuque,	<u>Phone:</u> 319-552-1771 <u>Website:</u> <a href="http://www.albrechtacres.org">www.albrechtacres.org</a> <u>Email:</u> <a href="mailto:info@albrechtacres.org">info@albrechtacres.org</a>	Serves all people regardless of ability levels. 24 hour nursing staff. 

### APPLICATION FOR GENERAL ASSISTANCE SCHOLARSHIP



**Purpose:** PWSA of WI, Inc. wishes to provide financial assistance in order for families of persons with PWS to help meet the unique needs of these individuals and their families.

**Eligibility:** Eligibility is based on financial need. Financial need being equal, the second consideration would be given to those who could benefit most from funds (respite intervention or personal/behavioral issues that need to be addressed).

1. Any person with PWS who resides in the state of Wisconsin.
2. The person with PWS or caregiver/family member of the person with PWS must be a member of the state chapter of PWSA of WI, Inc.

Date of request: \_\_\_\_\_

Name of person with PWS: \_\_\_\_\_ Sex: \_\_\_\_\_ DOB: \_\_\_\_\_

Address: \_\_\_\_\_

Is individual, family member or caregiver a member of PWSA of WI, Inc.? \_\_\_\_\_ Yes \_\_\_\_\_ No

Does individual reside in WI? \_\_\_\_\_ Yes \_\_\_\_\_ No Parent/guardian: \_\_\_\_\_

Home phone: \_\_\_\_\_ Work : \_\_\_\_\_ Cell : \_\_\_\_\_

Parent/guardian's or person w/ PWS's employer if not residing at home: \_\_\_\_\_

Current position: \_\_\_\_\_

Employer's address: \_\_\_\_\_

Dates at present job: \_\_\_\_\_

Gross annual income: (select one) \_\_\_\_\_ < \$15,000; \_\_\_\_\_ \$15,000—\$ 29,000; \_\_\_\_\_ \$30,000—\$41,000  
 \_\_\_\_\_ \$42,000—\$59,000; \_\_\_\_\_ \$60,000—\$119,000; \_\_\_\_\_ over \$120,000

Average monthly amounts of other income: (Please specify sources, ie. SSI, MA, CIP) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Specific dates funds are needed by: \_\_\_\_\_

Amount requested: \_\_\_\_\_

What will funds be used for" \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Why would this scholarship be helpful to you? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How will funds improve the quality of life for the individual with PWS? (Financial need,, need for respite,, etc.) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**I certify that all of the information given above is true and correct. I understand that any false or incomplete statements in this application may make this application ineligible for funding. I authorize verification of any of the above information .**

**Signature:** \_\_\_\_\_

Return this application by April 1, 2013 to PWSA of WI, Inc., 2701 N. Alexander St., Appleton, WI 54911

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

<b>May 11, 2013</b>	<b>PWSA of WI, Inc.'s 3rd Annual <i>On the Move</i> Walkathon</b>	<b>Fowler Park Oconomowoc, WI</b>
<b>August 24, 2013</b>	<b>PWSA of WI, Inc.'s 13th Annual Golf Benefit</b>	<b>Windwood of Watertown Golf Course</b>
<b>November 7-9, 2013</b>	<b>PWSA (USA) National Conference</b>	<b>Buena Vista Palace Hotel, Orlando FL</b>

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