



# 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

**2012** is shaping up to be an extremely busy year for PWSA-WI, Inc. We kicked off the year with our 1<sup>st</sup> Annual Snowflake Ball on January 28<sup>th</sup>, 2012 at the Prader-Willi Homes of Oconomowoc gymnasium. This event allowed individuals with PWS and their families an opportunity to dress up in "fancy" clothes complete with a beautiful boutonniere or corsage, eat a delicious sit down meal, and groove to music provided by our favorite disc jockey: Wileman Mobile DJ. In addition, participants were able to take home a winter themed activity packet, a decorative snowflake pencil, and a photo album that included a special photo of the participant and his or her family/friends. The night was filled with lots of smiles, tons of laughter, and several requests for us to do it again next year. If anyone is interested in seeing pictures from the event feel free to visit our website at [www.pwsaofwi.org](http://www.pwsaofwi.org). I would like to take this moment to say thank to the members of our planning and decorating committee: Melodee Luening, Mary Lynn Larson, Candi Lipski, Jackie Mallow, Melanie Ignatowski, Linda Wiggins, Lynn Ann Miller, and Steve Steffen for helping to make this event such a success!!

The next event PWSA-WI, Inc. will be hosting is the 2<sup>nd</sup> Annual PWS *On the Move* walk-a-thon and I would like to personally invite all of you to attend. The event includes a 2 mile walk around Fowler Park in Oconomowoc with lunch and dancing to follow. In addition, participants will be able to take home an *On the Move* water bottle and t-shirt plus they will be given the opportunity to visit our awesome art table. This event will allow participants to not only raise funds for PWSA-WI, Inc. and PWSA(USA), but also raise awareness about PWS. If you are interested in learning more about this event and how you can participate please see the enclosed article or visit our website. I look forward to seeing you all there!!

Happy Spring everyone!! (Yes I'm aware it's only March, but the weather outside has been quite spring-like).

Crystal L. Boser

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**Vice President:** Jackie Mallow

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# Snowflake Ball

On Saturday, January 28, 2012 magic descended upon the gymnasium at



Prader-Willi Homes of Oconomowoc and it was transformed into an elegant

winter wonderland for our Snowflake Ball. Everyone was wearing some of their finest clothes and were ready for an evening of fun with family and



friends. Dinner was served by some of our favorite volunteers including family, friends and

supporters of PWSA of WI, Inc. After dinner we had an opportunity to re-



new old friendships and make new friends

while we enjoyed music, dancing and camaraderie.



## Second Annual PWSA of WI, Inc. *On The Move* Walkathon

The Second Annual PWSA of WI, Inc. *On the Move* Walkathon will be on May 12, 2012 at Fowler Lake Park in Oconomowoc, WI. We are in the process of getting everything set for another successful fundraiser for both PWSA of WI and PWSA (USA).

## Notes from the Office.....

By Mary Lynn Larson

Wow! Our Snowflake Ball turnout was AMAZING!! Those of us who worked on getting things set up were so excited to see everyone all dressed up and having FUN! It is something very different from our usual socials—and we think it went pretty well—but let's hear from you! What are your thoughts about it?

Now we are gearing things up for the *On The Move* Walkathon coming in May, but we will need your support and your energy! Please start getting your teams and pledges together because we want to see you there!

I know it is only coming into March—but you need to start getting your camp applications in if you plan on going to camp this summer. We have a list of camps that are familiar with campers and PWS, but if you know of others, call me at the office at 1-866-797-2947.

We also want our members to know about two upcoming trainings! The first is about **Psychopharmacology and PWS**. It will be held at the Waisman Center Outreach office in Madison on Wednesday, May 23, 2012 where Dr. Ken Herrmann will be the speaker. The second is **Planning for the Future: Strategies to Support Our Children's Lifelong Needs**. Topics we hope to cover include: Wills, Trusts, Guardianship, Social Security, Disability, Medicare, Medical Assistance and much more. It will be held Saturday, November 3, 2012 in Appleton at First English Lutheran Church, North Site.

Look for more info to come!

Mary Lynn

## Summer Camp



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

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

If your decision to attend camp is based on finances—or lack of, don't hesitate to apply for a scholarship! PWSA of WI Inc. sets aside funds each year to assist a child or adult attend camp. Any person with PWS living in WI, 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, 2012.** A copy of the application form is included on the next 2 pages or can be downloaded from our website ([www.pwsaofwi.org](http://www.pwsaofwi.org)).

**NOTE:** There is a week at Lion's Camp for young adults aged 18-25 with Mild Cognitive Disabilities. This year it is August 12-17, 2012. Families are encouraged to get more information on eligibility requirements by visiting the Lion's camp website at: [www.wisconsinlionscamp.com](http://www.wisconsinlionscamp.com).

On the following page we have compiled names and contact information of camps with experience dealing with PWS. If you know of more, let us know! Some do not have staffing and 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 passed.



We try to make every attempt to provide you with up-to-date contact information, internet links and email addresses.

### Summer Camps (continued)

Camp	Address	Phone/Website/Email	Comments
<b>Easter Seal Camp</b> (Camp Wawbeek and Pioneer Camp)	<u>Business address:</u> 101 Nob Hill Rd., Suite 301 Madison, WI 53713  Located on wooded 400 acres site near WI Dells, WI.	<u>Phone:</u> 608-277-8288 or <u>Toll free:</u> 800-422-2324 <u>Web:</u> <a href="http://www.wi-easterseals.org">www.wi-easterseals.org</a> <u>Email:</u> <a href="mailto:respitel@wi-easterseals.org">respitel@wi-easterseals.org</a> or <a href="mailto:wawbeek@wi-easterseals.org">wawbeek@wi-easterseals.org</a>	Camp Wawbeek serves those w/ physical disabilities. Provides experiences for disabled children & adults. Low counselor to camper ratio to handle those with higher needs.
<b>Wisconsin Badger Camp</b>	<u>Mail:</u> P.O. Box 240 Platteville, WI 53818-0240  Located 10 miles south of Prairie Du Chein, WI.	<u>Phone:</u> 608-348-9689 <u>Web:</u> <a href="http://www.badgercamp.org/">www.badgercamp.org/</a>	Serves developmentally challenged individuals regardless of severity. Have well trained staff & medical personnel.
<b>Camp Wil-O-Way Easter Seals Kindcare Southeastern WI, Inc.</b>	1016 Milwaukee Avenue South Milwaukee, WI 53172	<u>Phone:</u> 414-482-0133j <u>Web:</u> <a href="http://www.county.milwaukee.gov/WilOWaySummerCamp8608.htm">www.county.milwaukee.gov/WilOWaySummerCamp8608.htm</a>	Serves campers w/ developmental disabilities aged 7—60 yrs. 2 locations in Milwaukee. Priority given to Milwaukee residents.
<b>Lion's Camp</b>	3834 County Road A Rosholt, WI 54473  Located 2 miles east of Rosholt and 16 miles north-east of Stevens Point WI.	<u>Phone:</u> 715-677-4761 <u>Web:</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 charge for this camp.**	Serves mild/borderline cognitively disabled youth & young adults. Do not feel comfortable handling persons w/ moderate-severe behavioral issues or those who are moderate-severe cognitively disabled.
<b>Camp Courageous of Iowa</b>	12007 190th St. P.O. Box 418 Monticello, IA 52310-0418 Located about 5 miles south of Monticello IA.	<u>Phone:</u> 319-465-5919 <u>Web:</u> <a href="http://www.campcourageous.org">www.campcourageous.org</a>	Serves all people regardless of ability level. They have both a summer camp as well as a respite program.
<b>Camp Albrecht Acres of the Midwest</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, IA.	<u>Phone:</u> 319-552-1771 <u>Web:</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 level. 24-hour nursing staff.





Prader-Willi Syndrome  
Association of Wisconsin,  
Inc.

2701 N. Alexander St.  
Appleton, WI 54911

Office: 866-797-2947

## APPLICATION FOR GENERAL ASSISTANCE SCHOLARSHIP

### PURPOSE:

PWSA of WI, Inc. wishes to provide financial assistance for families of an individual with PWS to help meet the unique needs of these individuals and their families.

### ELIGIBILITY:

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

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

**Date of request** \_\_\_\_\_

Name of person w/ PWS: \_\_\_\_\_ Sex \_\_\_\_\_ Birth date \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zipcode \_\_\_\_\_

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 Phone \_\_\_\_\_ Cell phone \_\_\_\_\_

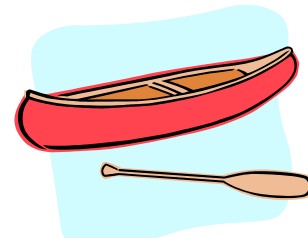
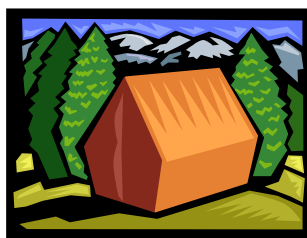
Parent/guardian's employer \_\_\_\_\_ Current Position \_\_\_\_\_

Employer address \_\_\_\_\_

Dates at present job \_\_\_\_\_ Gross monthly income \_\_\_\_\_

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

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.)

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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, 2012** \_\_\_\_\_

Send to: PWSA of WI, Inc.  
2701 N. Alexander St.  
Appleton, WI 54911



## PWSA of WI, Inc.’s 12th Annual Golf Benefit



Start thinking about our upcoming golf benefit scheduled for Saturday August 25, 2012! Mark it on your calendar and make plans to join us! It will be at the Windwood Golf Course in Watertown, WI! We are always looking for golfers, donations, and hole sponsors... It is always a day of friends and fun! PLEASE join us!!



## Upcoming Educational Events

### Is There a role for Psychopharmacology in Treating People with Prader-Willi syndrome?



Mood swings, obsessions, violence, anxiety, lack of focus, depression and psychosis are all seen in people with PWS. Can science and medicine in particular offer any solutions? This presentation will provide information to help answer this question. A discussion of what medication might be useful for which symptoms will be discussed. Questions will be welcome.

**Date:** Wednesday, May 23, 2012      **Time:** 12pm—2pm  
**Cost:** \$10.00 (no charge for persons w/ PWS)  
**Location:** Waisman Center Outreach location, 122 E. Olin Ave, Suite 100, Madison, WI  
**To register:** <http://cow.waisman.wisc.edu/traincon.html> or call: 608-265-8440 Ext. 440



### Planning for the Future: Strategies to Support our Children’s Lifelong Needs

As a parent or family member of someone with a developmental disability, a lot of questions arise! Will they be able to work and sustain themselves? Can they get insurance? Should we gain guardianship? How do we support our loved one with PWS once we are gone? Do we need a special will? A trust? How do we do that?

**Date:** Saturday, November 3, 2012      **Time:** 8am—3:30pm  
**Cost:** To be determined  
**Location:** First English Lutheran Church, North site; 6331 N. Ballard Road, Appleton

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

<b>May 12, 2012</b>	<b>PWSA of WI, Inc.'s 2nd Annual <i>On the Move</i> Walkathon</b>	<b>Fowler Park, Oconomowoc, WI</b>
<b>May 23, 2012</b>	<b>Is There a Role for Psychopharmacology in Treating People with Prader- Willi Syndrome?</b>	<b>Waisman Center Outreach Location 122 E. Olin Ave Suite 100 Madison, WI</b>
<b>August 25, 2012</b>	<b>PWSA of WI, Inc.'s 12th Annual Golf Benefit</b>	<b>Windwood of Watertown Golf Course</b>
<b>November 3, 2012</b>	<b>PWSA of WI, Inc.'s Training: Planning for the Future: Strate- gies to Support our Children's Lifelong Needs</b>	<b>First English Lutheran Church, North site, Appleton, WI</b>

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