



# 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

## It's time to spread awareness!

As I look out the window, see the snow melting and watch people walking through the neighborhood, I am reminded of a time not long after my son was diagnosed with Prader-Willi Syndrome (PWS) when my mother and I decided we needed to spread awareness about PWS. For almost 4 long years my son underwent testing to determine what was "wrong" with him and when he was finally diagnosed with PWS we realized most people had no idea what PWS was. We decided it was time to change that and the best way to do so was by holding some sort of awareness event. We decided since most individuals, whether diagnosed with PWS or not, needed exercise we would hold a Walk-a-thon. At the time we lived in a state that didn't have a local PWS chapter so we decided we would just hold a local walk with friends, family and co-workers. We made fliers, requested donations from local businesses and asked everyone we knew to please sponsor us for the event. Thankfully most of the people we asked to help us were very eager and helped spread the word to people they knew. In the end, we had our friends, family and co-workers, but we also had several people we didn't know personally. During the walk we ended up meeting some amazing people and the feeling of camaraderie was amazing, especially since many of the people who walked didn't even know what PWS was until this event. Our goal of spreading awareness all those years ago was met and now 12 years later I am excited to announce that the Prader-Willi Syndrome Association of WI, Inc. (PWSA-WI) is going to be hosting a Walk-a-thon this year.

On Saturday, May 14, 2011, PWSA-WI will be holding the first ever *On The Move* walk-a-thon, which will not only raise awareness about PWS, but also raise funds for both PWSA (USA) and PWSA-WI. The day will include a walk around the beautiful lake followed by a healthy lunch and music by our wonderful DJ. I am excited to personally invite each and every one of you to participate by walking on a team, pledging an individual on a team or becoming a corporate sponsor. Please refer to the inside of this newsletter or our website at [www.pwsaofwi.org](http://www.pwsaofwi.org) for a flier, registration forms or pledge forms. I hope to see all of you at the walk-a-thon so we can raise awareness, raise funds and enjoy a day of camaraderie just like I did with amazing people 12 years ago.

See you in May,  
Crystal L. Boser

### 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

### Office Address:

PWSA of WI, Inc.  
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Appleton, WI 54911-2312

**Toll free:** 1-866-797-2947

### NEW Email:

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

### NEW Website:

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

PWSA of WI, Inc. is a chapter of PWSA (USA)

8588 Potter Park Drive,  
Suite 500

Sarasota, FL 34238

**Toll free:** 800-926-4797 or

941-312-0400

### Email:

[info@pwsausa.org](mailto:info@pwsausa.org)

### Website:

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

## Family Care Advocacy Project – An Update

By Barb Dorn, Volunteer Consultant

First of all I would like to thank everyone who responded to our plea and contacted their legislators. This “plea” letter was sent to parents and guardians of adults with PWS who receive their funding support from the State of Wisconsin. Currently, our state is transforming its model of support for adults with developmental disabilities as well as the elderly. Some concerns have been shared that we fear jeopardize the assessment and reimbursement for services needed by adults with PWS. Currently, there is an audit underway by the Legislative Audit Bureau. I do not know the exact details of the audit. I am not an expert on Family Care. What I am, however; is a volunteer who is trying to stay informed and share information with you about concerns, findings and hopefully some changes that may be needed to this program.

The audit is supposed to be completed by the end of February or early March. Once the results are shared – I will do my best to communicate the findings with you. At this point in time, I am not sure what the next step will be (or needs to be).

PWSA of WI, Inc however is committed to being the voice for adults with PWS. We may be called upon to do more educating and advocating on their behalf. I have to share that your voices are being heard. I have spoken to a handful of legislative aides over the past several weeks. Some have shared their appreciation for our efforts; some have shared that we must beware that the audit may not result in changes and most likely will not result in more funds for this program. For many – Family Care has been a life saver. It has provided them with services that they were not receiving and were awaiting help while placed on a waiting list. We are not opposed to the program. We do however feel that we need to communicate our concerns so that what is broken – gets fixed. We can’t partially support our adults – they need appropriate, comprehensive services. Right now – we wait.

If you have not contacted your legislators – it is not too late. They need to hear your concerns. If you have questions, feel free to contact me. I will do my best to answer your questions however – I am still learning as well.

(Email: [barbdorn@tds.net](mailto:barbdorn@tds.net) Phone: 608-848-9597)

You’ve heard rumors and the talk... Now it’s time to SIGN UP to be a part of

**PRADER-WILLI SYNDROME  
ON THE MOVE!**



**PWSA (USA) & PWSA of WI, Inc.  
Walk-a-thon is MAY 14, 2011  
At Fowler Park in  
Oconomowoc, WI**

**Prader-Willi Syndrome *on the Move*** is the new PWSA (USA) national awareness initiative, targeted to take place annually beginning this May during PWS awareness month. The vision is that in the years ahead this campaign will be a signature event for PWS, our chapters, and PWSA (USA). IF you are not planning to do so already, we encourage you to consider participating during this inaugural year of the campaign.

We are hosting the **Prader-Willi Syndrome on the Move May Awareness Walk-A-Thon** on May 14, 2011. This is both a PWSA (USA) and a PWSA of WI, Inc. sponsored fundraising and awareness event. We are planning a 2 mile walk around Fowler Park in Oconomowoc. Registration will start at 9 am with the walk starting at 10 am. We are also hosting a lunch and entertainment after participants complete the walk. We are encouraging all walkers to get as many pledges for their efforts as possible. We have registration and pledge forms available! If you have not already received them, please contact us at the office and we will send them to you. This is a RAIN or SHINE event—so come prepared and help us to raise awareness!!

**Don’t put it off—for the sake of our children and families, contact us today and get started!**



**PRADER-WILLI SYNDROME ON THE MOVE  
MAY AWARENESS  
WALK-a-THON  
MAY 14 2011**

**FOWLER PARK • OCONOMOWOC • WI**  
PLEASE JOIN US FOR THIS NATIONAL AND LOCAL FUNDRAISING, AWARENESS EVENT  
REGISTRATION FROM 9AM - 10 AM. A TWO MILE WALK AROUND FOWLER LAKE STARTS  
AT 10AM. LUNCH / MUSIC WILL BE PROVIDED AFTER THE WALK.  
GET MORE INFORMATION ON THIS GENETIC DISORDER THAT AFFECTS 1 IN 15,000.  
**WHAT IS Prader-Willi Syndrome? go to [www.pwsausa.com](http://www.pwsausa.com).**

## Notes from the Office

By Mary Lynn Larson

Wow—there is a lot going on in the office these days! First and foremost, we have the National Walk-a-thon “**Prader-Willi Syndrome On the Move**” being sponsored by both PWSA (USA) and PWSA of WI, Inc. This is a nationwide campaign sponsored by individual state chapters and PWSA (USA). In Wisconsin, it will occur on May 14, 2011. This is an event meant to raise both awareness AND funds! We will be educating everyone we come in contact with; from those who might be donating to your walk, to those who you might be encouraging to be on a team with you; and anyone else you can make aware of the event! As many of you know, when you first say the phrase, ‘Prader-Willi syndrome’ the typical response is, “What is that? I have never heard of it before.” Occasionally, you meet someone who has heard of it, but is not certain how or where. This is your opportunity to share more information on PWS! It might just be telling the person how you are involved with someone who has PWS or it might be getting them to make a donation to our ‘worthwhile’ cause! And remember, if they ask you questions you don’t know the answer to—direct them to the web site at [www.pwsaofwi.org](http://www.pwsaofwi.org) or share the toll free number of the PWSA of WI, Inc. office!

We want everyone to start working now on getting a team together or just raising awareness by telling people about PWS and our Walk-a-thon! Encourage them to get involved by walking with you or perhaps making a donation! If you haven’t received the paperwork in the mail yet, you can go to the PWSA of WI, Inc. web site at [www.pwsaofwi.org](http://www.pwsaofwi.org) and download the registration and pledge forms. If you would like them mailed to you, contact me at the state office.

The Walk-a-thon will be held on Saturday, May 14, 2011. It is a RAIN or SHINE event, so come prepared! We will be walking around Fowler Park in Oconomowoc, WI for a total distance of 2 miles. We will be looking for a variety of people to help with a variety of tasks through out the day, so please consider volunteering! Contact Mary Lynn via the toll free number or email if you can volunteer. Walkers who pre-register by April 25th will get a commemorative water bottle and t-shirt. (Please do not forget to let us know the sizes of **everyone** on your team so we have enough shirts!) Those participants (either individual or team/family participants) who get \$100.00 in sponsorships/pledges will have one (1) individual/team member registration fee waived. The

registration fee for family or team participants is \$25.00/person while if you sign up as an individual participant, the fee is \$30.00/person. Fees are more if you register the day of the event. After the walk, we will have lunch available followed by entertainment by a DJ. If you have ANY questions regarding this event, visit the web site or call Mary Lynn at the PWSA of WI, Inc. office at 1-866-797-2947.

We are also gearing up for summer—and that means summer camp! We are interested in hearing about any positive camping experiences you or your family member with PWS has had. We would love to include the information in our list of camps that are familiar with PWS. If you or your family member with PWS has not gone to camp but you are interested in finding out more, call us. We have scholarships available to cover some or all of the cost of attending camp. If you haven’t already registered to attend this summer, do so today as most camps fill up quickly! You can apply for a scholarship using the General Assistance application included on page 7 of this newsletter. Please fill it out and return to the office by April 8, 2011.

We also are getting things ready for our annual Golf Benefit which will be held on August 27, 2011 at the Windwood of Watertown Golf course. This is our annual fundraising event for PWSA of WI, Inc. The funds raised go towards our General Assistance fund, any trainings we hold throughout the year as well as our Spring social event. We can always use your help with this event! This is a day filled with fun, laughter, prizes and friends. We even manage to get some golfing in! We are always looking for hole sponsors, prize donors, silent auction items and golfers. If you are interested in more information on any thing regarding the Golf Benefit, contact Mary Lynn at the state office. Look for a flier with specific details to be posted on our web site soon.

On a final note, PWSA (USA) is hosting a National Conference this year!! It will be held November 11-13, 2011 in Orlando FL at the Buena Vista Palace Hotel. The National Conference is an opportunity for many families to network with others across the country as well as meet with professionals who are experts in their field. Many families who have not attended a National Conference are understandably apprehensive about going; but often come back and cannot believe how connected they feel to the other attendees who are experiencing many of the same things they deal with daily. PWSA of WI, Inc offers conference scholarships to those who qualify. Contact the state office if you have questions.

Hope to see you at one of our upcoming events!  
Mary Lynn



## The Camper with Prader-Willi Syndrome Questions to Ask



For many parents and caregivers, sending a child with Prader-Willi syndrome away to camp can be filled with mixed emotions. There may be excitement that their son, daughter or resident will be able to participate in an activity that allows them some fun and friendship opportunities. There may be some fears – will they be safe; will their medical needs be met? And there may be worries– will they be successful and not have any major behavior challenges; will their dietary and food seeking needs be met? Most want to know if this is the right camp for their child or adult with Prader-Willi syndrome.

There are many camps across the State of Wisconsin that serve children and adults with disabilities. There are camps that operate day or week programs. Some offer a variety of different experiences and others may be more specialized. Some have experience in working with persons with Prader-Willi syndrome – others do not. For some, they will readily make accommodations for diet and behavior – others will not. Often times, parents begin the search in the early months of the year. Some camps have a limited number of slots or have special weeks for certain ages or disabilities. It is never too early to begin the research.

The staff at PWSA of WI, Inc. relies on parents and caregivers to share camp resources. When we do not have resources, we do our best to locate some special needs camps in your area that the parent or caregiver can contact. Each year, there may be new counselors and/or new leadership at a camp that may affect the campers' experience. One camp may be a wonderful experience for one person with Prader-Willi syndrome and a not-so-nice experience for another camper. **In all cases, it is up to the parents and caregivers to research and determine if the camp we may suggest is the right match for your son, daughter or resident. The staff at PWSA of WI, Inc are not responsible for any actions that do or do not take place at a camp.**

We would like to suggest asking questions or taking note on some areas when researching a camp:

1. **Knowledge and Experience with Campers who Have Prader-Willi Syndrome:** Have they served campers with PWS? Do they understand or are they willing to learn more about PWS? Are you willing to teach and assist in this learning?
2. **Health Services** – Do they have a nurse on duty? Who is responsible for administering medications? If a person becomes ill, what is done? Are they willing to learn about the unique health issues that may face persons with Prader-Willi syndrome?
3. **Diet and Meal-Serving Style** – Do they accommodate special diets? How are meals served? Do campers serve themselves or are portions served to them and monitored? Do they have a camp store or food opportunities that the person with PWS could access food? How much is food a part of their camp experience?
4. **Behavior Management** – Some have very strict rules about taking campers with behavior problems – you will want to know this in advance. Do counselors receive special training on behavior management? What sort of approaches or consequences do they use?

Make sure to share information about Prader-Willi syndrome and the camper with PWS with camp staff. Include suggestions on how to avoid food and behavior issues; make sure to list any strategies that you know will help the camper. Include the form- **Health Concerns and the Camper with Prader-Willi Syndrome Information for Camp Staff** and don't forget to include a health brochure so they will be sure to be aware and understand some of the unique health issues that can face this camper.

We all want the camper with Prader-Willi syndrome to have a positive, healthy experience. If you have had successful camp experiences, please share this with us. Please email us at [Wisconsin@pwsaofwi.org](mailto:Wisconsin@pwsaofwi.org) or call our toll-free number 1-866-797-2947.

## Information about Summer Camps

By Barb Dorn

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.

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 8, 2011.** 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 and phone numbers of camps our office has heard of. (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 already passed. **We have made every attempt to provide you with up-to-date contact information, internet links and email addresses.**

### ALL CAMPS LISTED BELOW HAVE EXPERIENCE IN SERVING CAMPERS WITH PWS



Camp	Address	Phone/ Website/Email	Comments
<b>Easter Seal Camp</b>  (Camp Wawbeek & Pioneer Camp)	Business address: 101 Nob Hill Rd., Suite 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:respit1@wi-easterseals.org">respit1@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 experiences for children & adults with disabilities. Low counselor to camper ratio -able 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, Wisconsin	<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 Wisconsin, 2 miles east of Rosholt, and 16 miles northeast 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 comfortable handling persons with moderate to severe (behavior) problems or those who are moderate to severe cognitively disabled.
<b>Camp Wil-O-Way</b>  <b>Easter Seals Kindcare Southeastern 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>	Serve campers with developmental disabilities ages 7 yrs – 60 yrs. 2 locations in Milwaukee Priority given to Milwaukee residents
<b>Camp Courageous of Iowa</b>	12007 190 <sup>th</sup> St. P.O. Box 418 Monticello, IA 52310-0418  Located about 5 miles 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 level. They have both a summer camp as well as a respite program.
<b>Camp Albrecht Acres of the Midwest</b>	<u>Mail:</u> PO 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 level. 24 - hour nursing staff.



Prader-Willi Syndrome  
Association of Wisconsin,  
Inc.

2701 N. Alexander St.

Appleton, WI 54911

Office: 866-797-2947

Return this application to the  
above address by April 8, 2011

**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 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, SSDI,

MA, CIP, MA): \_\_\_\_\_

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: \_\_\_\_\_

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

<b>May 14, 2011</b>	<b>PWSA of WI, Inc.'s and PWSA (USA)'s 1st Annual Walk-A-Thon</b>	<b>Fowler Park, Oconomowoc, WI</b>
<b>August 27, 2011</b>	<b>PWSA of WI, Inc.'s 11th Annual Golf Benefit</b>	<b>Windwood of Watertown</b>
<b>November 11 – 13, 2011</b>	<b>PWSA (USA) National Conference</b>	<b>Buena Vista Palace Hotel, Orlando FL</b>

Prader-Willi Syndrome Association of WI, Inc.

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