



# 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.**

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## A Note from the President: Barb Dorn

I would like to wish everyone a very Happy New Year. For many of us, the holidays are a time of mixed emotions. It is always nice to see family members who we may not see very often, however the need for constant surveillance when there seems to be food every where you turn; makes for an exhausting time. Hopefully everyone is now all nestled back into their routine and structured snacks and meals. I can't help but reflect back on 2006 and look forward to a new and exciting 2007. As an organization, we have a lot to be proud of – a lot to be thankful for. We are so fortunate to have dedicated staff and volunteers who make it possible for us to do so much for persons with PWS as well as those who support them. Every year, PWSA of WI hosts a Hobby Day where persons with PWS as well as siblings and family members gather for a day of fun. They are able to create 2 wonderful craft projects; have lunch and snacks and enjoy the entertainment from a local DJ. Family members also get a chance to meet and talk with other parents. This past year, we had more young ones attend. Historically, this has not been the case. We want children and adults of all ages to feel welcome so we plan to change a few aspects to make sure our little ones and their families feel welcome.

In addition, we hosted a gathering for parents of young children in the fall. This is an opportunity for families to get together and share some of their joys and challenges in raising a youngster with PWS. Thanks to many committed volunteers and golfers, we had another very successful Golf Benefit that was held in Oconomowoc. This is our biggest fund raiser and probably our most fun one as well. It is a day of play, food, celebration and raising money for a very good cause. We gratefully thank everyone who helps to make this event a big success. Because of the funds raised at this event as well as from other generous donors, we are able to provide assistance to young and old who have PWS so that they can attend summer camp. We were also able to provide financial assistance so a family could attend the national PWSA (USA) conference that was held in New York.

A major focus in 2006 and 2007 has been and will be educating parents, care providers and health care professionals about the health issues and concerns of persons with PWS. Special packets have been made and are in the process of being distributed. We also hosted a conference, *A Health Update on PWS* in the fall which featured six health care professionals who provided up-to-date information on new developments and treatments for conditions often seen in children and adults with PWS. I also want to thank the Devitt family for a recent fundraiser they conducted that was in memory of Colleen Doherty, a young woman who died from health complications last year. Funds raised by “**Colleen's Angels**” will be used to help us support our health education project. They raised \$6925.01

We also have many new things to look forward to in 2007. We have begun recruiting for our new Card Club. This club began on January 1<sup>st</sup>. Persons with PWS will receive 6 different greeting cards by mail every year. We are grateful for the volunteers – Louise Guido, Katie Kranjac, Sandie Stoner, Judy Scheidegger and Heidi and Lucas Wertjes for helping us to get this new club launched. If you haven't registered yet - don't delay. We don't want anyone with PWS to miss out on this fun opportunity. We are also planning to expand our health education efforts to young teens and adults who have PWS. A simple brochure will be created along with training classes.

And ... we will continue our planning and excitement for the 2008 National PWSA (USA) conference. I am looking forward to making this an opportunity to work with lots of new faces here in Wisconsin. I see this as an opportunity to share the many talents of our chapter while bragging up all the good things we have to offer here in Wisconsin. Please see that 2008 Conference Update article to see where you may be of help.

Barb

## A Fond Farewell to Pat LaBella

On behalf of the membership and Board of Directors of PWSA of WI, Inc., we want to acknowledge and thank Pat LaBella for her service as a Board Member. Pat is the kind of person who will always pitch in and help. She has (and will continue) to serve as the chairperson for our annual Hobby Day celebration. She has also volunteered as YIP chairperson, the day care service we will provide as part of the 2008 National Conference. Pat and her husband, John have also been very generous in donating funds, door prizes and other items that help to keep our organization progressive and strong! Our heartfelt "Thanks" for all you do, Pat!!

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### Attention: Residential Providers

We are trying to update our Wisconsin Resources. Even if you do not have any vacancies for residential support for persons with PWS with your agency, we are asking you to complete a short informational report about yourself or your agency. Please go to [www.pwsausa.org](http://www.pwsausa.org); click on English; click on Providers; then click on the Provider database. This information may be used by case managers, parents as well as other providers. It is a great marketing tool or a way for others to contact you with questions. It also allows PWSA (USA) and PWSA of WI, Inc to keep you informed of any new information we may receive that you may want or need.

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### Attention: Parents and Care givers – Health Care Provider Resources

Frequently we receive calls asking for a referral to a physician or other health care professional who has experience in caring for a child or adult with PWS. We are attempting to compile a list of health care providers that you can recommend (or that you would NOT recommend). We have included a form in all membership renewals that are being mailed out and it is posted on our web site: [www.pwsausa.org/WI](http://www.pwsausa.org/WI). Help us... to help you.

## Health Education Packets Available

Often times, when a health professional has more than one patient with PWS, they are more apt to become more educated about the health risks. There are also many instances in which parents and care givers must be the primary educators and health advocates to a new physician or a professional that has limited knowledge about PWS. If you have not received a health packet for the primary health provider for the person with PWS that you support, please contact our office so we can assist in sending one to him/her. We also have a separate packet of information for the parents and care givers that we can mail to you. **Please – only one packet per person with PWS.** We want to make sure we have enough. We want to graciously thank the Devitt family for a recent fund raiser ("Colleen's Angels") which raised almost \$7000 for this cause. We are trying to prevent premature death in all persons with PWS. The Devitt's are family members of Colleen Doherty, a young woman with PWS who lost her life to a medical complication last year. We are very grateful to this family for all they have done to honor Colleen as well as support the needs of all who have Prader-Willi Syndrome.

## MEMBERSHIP RENEWAL

In the upcoming weeks, watch for paperwork on renewing your

membership with PWSA of WI, Inc.! We are targeting mailing this out around mid January. If you do not receive the initial paperwork mailing after January 31, 2007 – let Mary Lynn know at the state office: toll free at 1.866.797.2947 or email: [wisconsin@pwsausa.org](mailto:wisconsin@pwsausa.org)





## Information on Summer Camps for the camper with PWS

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 hundreds of camps across the United States that serve children and adults with disabilities. There are camps that operate day, week or extended monthly 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 (USA) 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. **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 (USA) 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 – does the camper 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 consequences or approaches 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; 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 [cis@pwsausa.org](mailto:cis@pwsausa.org) or call our toll-free number 1-800-926-4797.

## Join PWSA of WI, Inc.'s NEW “Card Club”



Have you registered for PWSA of WI, Inc.'s **Card Club??** We began it in January 2007 but it is **NOT** too late to join!! Everyone who registers with Mary Lynn at the state office will receive a card 6x a year. Cards will be mailed out for your birthday, Valentine's Day, Spring Holiday, Mid Summer Holiday, Fall Holiday and Winter Holiday! **We mailed a registration letter to everyone with PWS in our database in December, 2006 but if you did not receive one, let me know!!** If you have any questions, feel free to call me at: 1-866-797-2947 or send me an email at: [wisconsin@pwsausa.org](mailto:wisconsin@pwsausa.org)

## It's That Time of Year Again ... Information on Summer Camps Compiled 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.

Over the years, PWSA of WI, Inc. has compiled a list of some of the camps that parents of children and adults who have PWS have attended. You can call the state office Toll Free at 1-866-797-2947 if you have questions or contact the camp directly with your questions or concerns. Everyone has different opinions and views. **You** need to make the final decision...but don't delay.

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, 2007.** A copy of the application form is included in this newsletter.

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.

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. **Please note some internet links and email addresses may have changed.**

### Easter Seal Camp

(Camp Wawbeek and Pioneer Camp)  
Camp Wawbeek – for persons with physical disabilities/Respite camp for persons with cognitive disabilities

Business address:  
101 Nob Hill Rd., Suite 301  
Madison, WI 53713  
608-277-8288

Website: [www.wi-easterseals.org](http://www.wi-easterseals.org)  
Email: [respit1@wi-easterseals.org](mailto:respit1@wi-easterseals.org)  
Email: [wawbeek@wi-easterseals.org](mailto:wawbeek@wi-easterseals.org)

Easter Seals Wisconsin has a respite program as well as various summer camp sessions. The camp is located on a wooded 400-acre site near Wisconsin Dells. This camp provides a variety of experiences for children and adults with disabilities. They do have experience in serving persons with PWS. They also offer respite weeks and weekends. They have a low counselor to camper ratio so they are able to handle some higher need campers. Their rates are on the high side

The Wisconsin Connection

### Wisconsin United Methodist Camps

Camping Office  
P.O. Box 620  
Sun Prairie, WI 53590  
Phone: 608-837-3388 (ask for their Special Needs Camps)  
Toll Free- 1-877-947-2267

Website: <http://www.wisconsinumc.org/camps/>  
Wisconsin United Methodist Camp has 3 locations. Byron Center is located southwest of Fond du Lac on County F near Brownsville, WI. Pine Lake is located northwest of Westfield near Hwy 51 between Portage and Stevens Point. Whispering Pines is located in the northwest part of the state about 75 miles from the Twin Cities near Frederic, WI. All three have weeks that serve three age level programs. Their Children's Program serves children ages 8-14; their Youth Program serves youth 15-21; and their Adult Program serves adults 22 and up. All campers must be able to care for their own basic daily needs and have a diagnosis of mild to moderate mental retardation. They do not serve individuals with severe mental retardation or mental illness. We have received a positive report from one camper who attended this camp previously.

### Wonderland Camp

18591 Miller Circle  
Rocky Mount, MO 65072  
573-392-1000



Website: <http://www.wonderlandcamp.org>  
Email: [info@wonderlandcamp.org](mailto:info@wonderlandcamp.org)

The mission of Wonderland Camp is to provide a fun, educational camp experience for mentally and physically challenged individuals, to offer a respite from daily care giving for family members and health care workers and to provide and nurture a personal development experience for volunteers and staff. Wonderland Camp is located on the Lake of the Ozarks in MO. They are familiar with PWS and have a week devoted specifically to campers w/ PWS. This year it is June 10 – 15, 2007.

### Lion's Camp

3834 County Rd. A  
Rosholt, WI 54473  
715-677-4761

Email: [info@wisconsinlionscamp.com](mailto:info@wisconsinlionscamp.com)  
Website: <http://www.wisconsinlionscamp.com/>

Lion's Camp is located in central Wisconsin, 2 miles east of Rosholt, and 16 miles northeast of Stevens Point. \*This camp serves the needs of mild/borderline cognitively disabled youth, and young adults. They have designated weeks for youth (ages 9 –17). They do not feel comfortable handling persons with moderate to severe (behavior) problems or those who are moderate to severe cognitively disabled. They have served children with PWS and their diet is managed by "portion control". **THERE IS NO COST FOR THIS CAMP.**

**Wisconsin Badger Camp**

P.O. Box 240  
Platteville, WI 53818-0240  
608-348-9689

Website: <http://www.badgercamp.org/>

\*Wisconsin Badger Camp is located 10 miles south of Prairie du Chien, Wisconsin. It serves developmentally challenged individuals regardless of severity. They have a well-trained staff and medical personnel. They have certain weeks devoted to different ages. They have served many young adults and adults with PWS. They fill up very fast so don't hesitate to get your application in soon.

**Camp Albrecht Acres of the Midwest**

14775 Sherrill Rd.  
Sherrill, IA 52073  
319-552-1771

Camp Albrecht Acres is located 8 miles north of Dubuque on the Sherrill blacktop road. This camp may be accessible for those living in southwestern Wisconsin. It is designed for all who are disabled. They have a 24 - hour nursing staff. They have some experience in working with children and young adults with PWS. It is "family style" eating but staff will monitor for portion control.

**Archdiocese of Milwaukee –  
Adult and Family Ministry**

3501 S. Lake Dr.  
P.O. Box 070912  
Milwaukee, WI 53207-0912  
Phone: 414-769-3439 or 1-800-769-3973  
Website: [www.archmil.org](http://www.archmil.org)

You must be a resident of Milwaukee County to attend. We have received positive reports from one camper who has been attending this camp for several years. It has a low counselor to camper ratio.

**Camp Wil-O-Way (Day and Respite Camp)**

Easter Seals Kindcare Southeastern WI, Inc  
Contact: Susan Klawien  
1016 Milwaukee Avenue  
South Milwaukee WI 53172  
414-571-5566  
Website: <http://wi-se.easterseals.com>

Camp Wil-O-Way is a day camp program that provides campers with opportunities for social interaction, self-expression and entertainment. It is currently offered at 2 locations: Milwaukee Holler Park and Waukesha Schuetze Recreation Center for individuals with disabilities ages 7 to 21 these programs are available for 10 weeks during the summer, with operating hours Monday through Friday from 7:30 am to 6:00 pm. These programs are also staffed on a 4 participant to 1 staff member ratio.

**Camp Courageous of Iowa**

12007 190<sup>th</sup> St. P.O. Box 418  
Monticello, IA 52310-0418  
Phone: 319-465-5919

Website: <http://www.campcourageous.org/>

Camp Courageous of Iowa is located about 5 miles south of Monticello, Iowa. It serves all people regardless of ability level. They have both a summer camp as well as a respite program. They have served persons with PWS.



**If families or care providers know of other camps that have been successful for campers with PWS, please share the contact information with Mary Lynn at the state office and we can share it with others!!**

**We Need Your Help – Database Update on Health Care Professionals**

We have all been in a situation where we have had more knowledge than the health care professional caring for our loved one with PWS. It is so reassuring to see a health care provider who knows about PWS and has cared for others with this disability. PWSA (USA) needs your help in getting the names and contact information for health care professionals that people are using to care for a child or adult with PWS. Go to <http://pwsausa.org/HealthProf/input.asp> and fill in the requested information. If you don't have all of the information, please fill in as much as possible so we can contact them and obtain the missing data we need. With your help, PWSA (USA) can be a better resource to you by providing a referral to a health care professional who has an understanding of PWS.



Prader-Willi Syndrome  
Association of  
Wisconsin, Inc.

2701 N. Alexander St.  
Appleton, WI 54911

Office: 866-797-2947  
Wisconsin@pwsausa.org

**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 \_\_\_\_\_

Phone (\_\_\_\_\_) \_\_\_\_\_ Does individual reside in WI? \_\_\_\_ Yes \_\_\_\_ No

Contact person \_\_\_\_\_ Phone (\_\_\_\_\_) \_\_\_\_\_

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

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.) Use reverse side or attach additional paper if needed.

Return this application by: **April 1, 2007**

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

## 2008 Conference Update: "Moo-ving Forward"

On Saturday, November 11, 2006 twelve dedicated volunteers met to begin planning a conference that will provide parents and professionals in Wisconsin and across the United States, an opportunity to see and hear researchers and experts in the area of Prader-Willi syndrome. These professionals will meet to share research findings and educate us all on the new advances in the field of PWS. This conference also provides lots of time and opportunities for parents to meet others who walk in the parenting shoes. PWSA of WI, Inc is hosting the 2008 National conference in Milwaukee from July 2 – 4, 2008. We plan to organize and orchestrate a conference that we will all be proud in saying that we are from Wisconsin.

The conference has a team of co-chairs that will be working hard – together – to plan and execute this event. Co-chairs include: Barb and Don Dorn, Mike Larson, and Chad and Melissa Sirovina. We have most (but not all) leadership positions filled. At this time, we continue to get organized and identify needs. We are still in need of 4 chairpersons. A brief summary of these positions and responsibilities are noted below. PLEASE if you have talents in any of these areas and are willing to assist us; contact Mary Lynn at our office (1-866-797-2947 or email at [Wisconsin@pwsausa.org](mailto:Wisconsin@pwsausa.org))

1. Chairperson(s) for Welcome Reception – If you are good at planning a birthday party, you would be great in this role! We need your help in organizing a 1 hour reception where there are planned activities for families to meet each other and have a good time.
2. Chairperson(s) for Closing Ceremony – Are you creative and willing to work with little ones in creating a closing activity that unites the children in our daycare program with their parents and families to say "it's been a great conference time!" On Friday July 4<sup>th</sup>, we need someone to come up with a closing ceremony to end the 2008 conference.
3. Exhibitor Co-chairperson – Work with Jodie O'Sullivan of PWSA(USA) in planning and organizing exhibitors for the conference. Most exhibitors are pharmaceutical or service organization representatives that attend yearly.
4. Corporate Contributions/Gift Chairperson(s) – We are looking for someone who is good at writing letters and not afraid to ask for donations and/or

gifts. Anyone who is willing to share this talent – we need you!

(If you know someone that you could co-chair any of these positions with; we are open to this too.)

We are going to need volunteers with different talents and abilities. If you have an interest or talent that you think we may be able to use, let us know. We will need typists; people who like to decorate and/or make centerpieces, childcare leaders and assistants, room monitors to introduce and assist speakers along with many more that we are still identifying. Please keep the week of June 30-July 4<sup>th</sup>, 2008 open to learn and help with this event.

### How Did We Choose the Theme "Moo-ving Forward"?

Wisconsin prides itself on being Americas' Dairy Land. We hope to highlight and proclaim this famed statewide industry. Our State motto: "Forward" reflects Wisconsin's continuous drive to be a national leader. We hope this will also give those who attend the message that research, support and the future for persons with PWS is progressing and moving forward; and life with PWS can be positive and fulfilling. This theme lends itself to playful and educational opportunities so that people from around our nation will have a fun-filled, positive experience at the 2008 conference.

### Message from the Office....

By Mary Lynn Larson

Wow... things are even busier at the office as we begin to make preparations for the 2008 National conference, get ready for our upcoming Hobby Day, work on mailings for a number of different projects and try to answer the toll free number providing support, education and advocacy to families and professionals calling for assistance!

We are asking for volunteers for a number of different positions for the conference... and if you are interested or have questions regarding some of the specifics, feel free to give me a call. We may not know the answer but will search for it! We are looking for talented, innovative ideas and energy...can you help us out with that? If so, contact me at 1-866-797-2947. Mary Lynn

## **PWSA of WI, Inc. 2007 Calendar**

<b>January 28, 2007</b>	<b>PWSA of WI, Inc. Board Meeting</b>	<b>Verona, WI</b>
<b>February 3, 2007</b>	<b>2008 Conference Planning Meeting</b>	<b>Four Points Sheraton Hotel, Milwaukee, WI</b>
<b>March 24, 2007</b>	<b>Hobby Day</b>	<b>Oconomowoc, WI</b>
<b>August 1-3, 2007</b>	<b>29th Annual PWSA(USA) Conference</b>	<b>Dallas, TX</b>
<b>August 25, 2007</b>	<b>7th Annual PWSA of WI, Inc. Golf Benefit</b>	<b>Paganica Golf Course, Oconomowoc, WI</b>
<b>July 2 – 4, 2008</b>	<b>30th Annual PWSA (USA) Conference</b>	<b>Four Points Sheraton Hotel, Milwaukee, WI</b>

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