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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: Mike Larson

I was privileged to be the President of PWSA of WI, Inc 13 years ago. Who would have imagined all that has happened in that time? PWS is in the state statutes as a developmental disability, GH has become a standard of care for PWS, PWSA of WI, Inc. is hosting the National Conference and now, I am the President of PWSA of WI again. I need to thank Barb for bringing the organization to a new plateau. She has defined new standards and heights that state chapters of PWSA can obtain. Wisconsin continues to lead in the world of PWS advocacy.

There are probably many out there who were not around during my first "tour of duty", so just a little about me. I am now the father of two great boys with PWS. Alex our oldest is 15, in high school and almost an Eagle Scout. Our youngest, Matthew is 7, in the 2nd grade, just starting Scouts and is quite the pistol! I am very proud of both of them. Each day they teach me to face the world head on and love others for who they are. I have an engineering background and work as an Intellectual Property manager for a company in the food packaging industry.

Having two boys with PWS has its challenges, but it also has double the joys. Many of you have heard things through my wife, Mary Lynn about how chaotic our house is sometimes. From my perspective, I don't know anything other than this, so this is our normal. Yes, we have issues, but so does everyone else I know. Perhaps ours are not quite the "run of the mill" issues that most parents have, but it certainly makes life interesting. Friends seem to find our challenges very entertaining and interesting. Some say they don't know how we deal with some things, but in the back of my mind, I see the issues they deal with and I don't know how "they" do it. If I can find one thing to say about the whole thing it is; I have found the most rewarding things in life take the most work. The things that come easy are not as appreciated as the accomplishments we earn thru struggle, sweat and tears. With that in mind, I am happy to say that my boys and family are my most proud accomplishment! There is no equal love than what we share.

An accomplishment for PWSA of WI is hosting the upcoming National PWSA (USA) conference. Yes, over the past few years since we started work on this project there has been lots of struggling, sweating, and occasional crying to pull this off. Everyone involved should be extremely proud of the job they have done. It will be an outstanding experience for all who attend.

The keynote speaker is Richard Pimentel. Richard was instrumental in the passage of the Americans with Disabilities Act. I promise he will be entertaining and insightful. Other topics include Dr's Forester and Gourash addressing the challenging behaviors of children and adults with PWS. This year will also highlight some different issues of aging for persons with PWS. We will also have a panel discussion on different models of supported living environments. There will be updates on important medical issues: anesthesia, GI issues, skin picking, and GH. There will be sessions on making fitness fun, promoting successful social experiences and tips on nutrition. Among these fun and educational topics there will be many of the favorite sessions that are requested each year: PWS 101, a review of the most current scientific research, sharing sessions and being able network with professionals and experts in various fields that support persons with PWS. My favorite part of going to conference is reuniting with families that I have come to know over the years. Each time I go to conference I meet so many new people but I also get to see people that have become close friends over time. I may only see them once a year, but we have a bond through PWS that brings us closer than you could ever imagine. I promise that this year will be another fun, rewarding experience.

Peace to all of you, Mike

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.

You will want to check out the recent articles on our web site at: <http://www.pwsaofwi.org/camps.htm> for new articles on camp as you prepare to send your child to camp! These include: **Information on Summer Camps for the Camper with Prader-Willi Syndrome** and **Health Concerns and the Camper w/ Prader-Willi Syndrome: Information for Camp Staff**.

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, 2008**. 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 are camps for persons w/ physical disabilities/Respite camp for persons w/ cognitive disabilities

Business address:

101 Nob Hill Rd., Suite 301

Madison, WI 53713

Phone: 608-277-8288

Website:www.wi-easterseals.org

Email: respite1@wi-easterseals.org

Email: 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. Rates are on the high side.

Wisconsin Badger Camp

P.O. Box 240

Platteville, WI 53818-0240

Phone: 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.

Lion's Camp

3834 County Rd. A

Rosholt, WI 54473

Phone: 715-677-4761

Email: info@wisconsinlionscamp.com

Website: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 United Methodist Camps

Camping Office

P.O. Box 620

Sun Prairie, WI 53590

Phone: 608-837-3388

(ask for Special Needs Camps)

Toll Free- 1-877-947-2267

Website: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 in years past.

Archdiocese Milwaukee Adult & Family Ministry

3501 S. Lake Dr.

P.O. Box 070912

Milwaukee, WI 53207-0912

Phone: 414-769-3439 or 1-800-769-3973

Contact: Theresa Johaneck Special Needs Ministry

Website: 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

Easter Seals Kindcare Southeastern WI, Inc

Contact: Jessie Senger

1016 Milwaukee Avenue

South Milwaukee WI 53172

Phone: 414-571-5566

Website: [http://www.county.milwaukee.gov/](http://www.county.milwaukee.gov/WilOWaySummerCamp8608.htm)

[WilOWaySummerCamp8608.htm](http://www.county.milwaukee.gov/WilOWaySummerCamp8608.htm)

Camp Wil-o-way summer day camp program provides campers with opportunities for social interaction, self-expression and entertainment. The staff organizes activities of arts and crafts, games, music, nature, sports and field trips. This program helps campers maintain basic motor skills, increases recreation skills, encourages maximum use of unstructured time and increases capacities for self-expression. **Eligibility:** First priority is given to Milwaukee County residents. Residents of other counties will be accepted as space permits. Campers are ages 7-60 years old with a disability. Campers are grouped according to age and gender/group size is between 5-7 campers.

Camp Albrecht Acres of the Midwest

14775 Sherrill Rd.

Sherrill, IA 52073

Phone: 319-552-1771

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

Camp Albrecht Acres is located 8 mi. 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.

Camp Courageous of Iowa

12007 190th 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 regard-

less of ability level. They have both a summer camp as well as a respite program. They have served persons with PWS.

Wonderland Camp

18591 Miller Circle

Rocky Mount, MO 65072

Phone: 573-392-1000

Website:

www.wonderlandcamp.org

Wonderland Camp is a residential camp for children and adults with mental and physical disabilities in Rocky Mount, MO right on the Lake of the Ozarks. It is centrally located b/t Kansas City and St. Louis. It has two weeks specific to campers with Prader-Willi syndrome: June 15—20, 2008 and July 20—25, 2008. It has a specialized diet for campers with PWS and all food and kitchen areas are kept locked during these weeks. Wonderland camp cost is \$475/camper.



Find an application for funding from our General Assistance fund to attend camp on the next page.



Mark your calendars!!
PWSA of WI, Inc.'s 8th Annual
GOLF BENEFIT

Saturday August 23rd, 2008

Windwood of Watertown Golf Course

Prizes, Food, Silent Auction & Fun!

For more information, check out our web site or
contact the office toll free: 1-866-797-2947

THANK YOU!!

A BIG Thanks to the Board for People with Developmental Disabilities (previously WCDD) for their grant assisting us with our Health Education and Advocacy Training for persons with PWS which will be offered during the National PWSA (USA) conference in Milwaukee!



Prader-Willi Syndrome
Association of
Wisconsin, Inc.
2701 N. Alexander St.
Appleton, WI 54911
Office: 1-866-797-2947

APPLICATION FOR GENERAL ASSISTANCE SCHOLARSHIP

PURPOSE:

PWSA of WI, Inc. wishes to provide financial assistance for families of a person 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 WI.
2. The person with PWS, 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 _____ Return this application by **APRIL 1, 2008**
Send to: PWSA of WI, Inc., 2701 N. Alexander St., Appleton, WI 54911

Name of person w/ PWS: _____ Sex: _____ DOB: _____

Address: _____ City _____ State _____ Zip _____

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's address: _____

Dates at present job: _____ Gross annual income of household: (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, etc) _____

Specify 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 w/ 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 may make this application ineligible for funding. I authorize verification of any of the above information.

Signature _____

PWSA of WI, Inc. is sponsoring

2008 Hobby-Helping Day



Saturday April 5, 2008

9:00 AM to 3:00 PM

****NEW LOCATION****

**Prader-Willi Homes of Oconomowoc
(Oconomowoc Residential Programs)
1746 Executive Dr. Oconomowoc, WI**

NEW – THIS YEAR ONLY

Prader-Willi Syndrome Association of WI, Inc. is co-hosting the national conference on Prader-Willi Syndrome in July of 2008 and...

WE NEED YOUR HELP to make the conference a very special event.

At the national conference, we would like to present a gift to the babies and young children who attend. It will be extra special, if this gift is made by someone who has PWS or one of their siblings. So, at this year's Hobby Day, you will make a cow-printed fleece blanket that will be given to a child who attends the national conference in July.

We also want to raise some funds to help keep the cost for the national conference child care program affordable. At the 2008 conference, we plan to sell greeting cards – made by you, children and adults with PWS, and your brothers and sisters.

That's why only 2 hobbies are being offered this year. Everyone will make a cow-print fleece blanket & everyone will make greeting cards.

You will not keep either item.

However, anyone who participates in this Hobby Day will receive a "Thank You" goodie bag at the end of the Hobby Day.

We want to extend an invitation to parents, family members and caregivers to attend Hobby Day. You will have the opportunity to exchange information with each other, as well as help us in our preparation and planning for the 2008 PWSA (USA) national conference. It promises to be a day of fun, interest and a renewal of friendships for all.

See you at Hobby Day!

A registration brochure has been mailed out! Available on the web site, too!

Conference Volunteers Needed!!!

Can we "Cow-nt" on you?

We are in need of volunteers for the upcoming 2008 PWSA (USA) National conference that we are hosting in Milwaukee from July 2—4, 2008. There are numerous ways that you can help. If you are unable to attend the conference but are still interested in helping, we have plenty to do as we prepare for the event!! If you are able to attend conference and are interested in volunteering; let us know! To assist in our childcare areas, either in our Youth and Infant Program (YIP) or our Wisconsin Youth and Adult Program (WI-YAP), we do ask that you "donate a day". Change is very hard for persons with PWS so this will assist in making it a positive experience for all. We also ask that volunteers be 16 years or older. Please talk with volunteer coordinator, Crystal Boser if a volunteer is younger. We will do our best to match your request to our needs. You can find the volunteer registration form on our website at our new address: www.pwsaofwi.org. If you do not have internet access, just contact Mary Lynn at the PWSA of WI, Inc. office for a form. Our toll free number is 1-866-797-2947.

Sample the "Sundae of the Month" at Georgie Porgies in Oak Creek, WI during the month of April

Every month, Georgie Porgie's—a burger and custard hangout in Oak Creek gives 25% of the proceeds from its "sundae of the month" to a local charity or worthy cause. During the month of April 2008, PWSA of WI, Inc will receive those funds!! Melissa and Chad Sirovina are working on devising the "sundae of the month" for us - and while it is still a secret, the ingredients of caramel, whipped cream, and hot fudge HAVE been mentioned!! So if you are in the neighborhood of 9555 S. Howell #300 in Oak Creek, WI—stop in and sample it!!

Thanks for your support!!

Notes from the office.....

By Mary Lynn Larson

As you might imagine, things are getting very busy in the office as the National conference approaches. As of March 1st, there are 123 days before conference!! (Yes, I am counting down!) And with the usual day to day things of the office, such as answering the phone, getting the newsletter to print, preparing for Hobby Day as well as getting things together for Conference as well as trying to manage the Larson household with getting ready for IEPs, dealing with various school issues, and **many** doctor's appointments, life is chaotic!

With everything going on, it is time to reach out to the members/families in WI for assistance! We really need more individuals and families to work with us to put on the best National Conference ever seen! I encourage you all to go to the web site of PWSA of WI, Inc. (www.pwsaofwi.org) to sign up with the volunteer form provided there. If you are unable to access the Internet, give me a call on our toll free line (1-866-797-2947) and I will send you one in the mail! We are looking for volunteers for many different areas of the conference and if you are unable to attend the conference; we may have things you can do from your home before July! Please let me know when you can help!

In addition to the volunteers, we will need a variety of extra supplies for a wide range of things for Conference. We have put together a **WISH LIST** of things that we could really use. You can find the wish list later in the newsletter. If you are able to help in that way, we would be greatly appreciative! We are asking for a variety of gift cards as at this time, we are not certain of the exact quantity of items we might need and the gift cards are very versatile for so many things!

Thanks for all you do!

Hugs, Mary Lynn

Contributions

The following are contributions/donations we have received as of 10/15/2007 to 03/01/2008. We try to be accurate in acknowledging and recognizing contributions, and apologize for any errors or omissions. If you notice an error, please contact Melodee, Program Assistant at: WIprogram2@pwsausa.org. Please note, your name will appear only once even if you have made more than one donation in this time period.

Dan & Kate Beaver	William Stege
Madonna Kieffer	Gregory & Dianne Schwartz
Robert & Pat Nelson	Betty Schutz
John & Bonnie Kraft	Louis & Judy Schutz
James & Renee Breit	Carol Potts
Mrs. Dorothy Heniff	TLC Homes
Mrs. Elsie Dorn	Steve & Nancy Burlingame
Jayne Frazin	Roger & Alice Gir daukas
Joseph & Elaine Gareau	Alan & Kathleen Luening
Lillian Peronto	Mark Dorn
Rose Lopez	Kevin & Anne Bresnahan
Robert & Lisa Dehner	Arlan & Dottie Lothe
Gerhard & Helma Drag	Agape of Appleton
Mrs. Beatrice Sturm	Richard & Ann Knoff
John & Betty Pograd	James & Karen Plosczynski
John & Bobbi Pograd	Family Support & Resource Ctr
Neil Lucchese	PW Homes of Oconomowoc
Paul & Karla Hansen	(ORP) Oconomowoc Residential Programs Staff
Mike & Crystal Kraft	Cuba City Knights of Columbus Council #765
Patrick & Kelly Gareau	Bloomington Knights of Columbus Council #4416
Hazel Schuster	Verona Knights of Columbus Council #11155
Larry & Lorraine Abler	University Hill Farms
Tom & Bonnie Jones	KM United Presbyterian Church
Jeanne Langlois	Women of Faith—KMUPC
Cindy Kernan	Presbyterian Women—KMUPC
Todd Bickelhaupt	KMUPC Mission Board
Don & Barb Dorn	Arlen & Jill Denny
John & Cathie Lehman	Tom & Carol Ehram
John & Pat LaBella	Larry Lemmenes
Joe & Jean Van Tuyle	Bruce & Marion Pfeiffer
Gary & Marty Gir daukas	Owen & Holly Salzman
Doug Schefft	Mike & Mary Steinbauer
Al & Melodee Luening	Phyllis Warden
Walt & Jennifer Kryzak	Paul & Bonnie Wilberscheid
Jerry & Pam Offerdahl	Catherine Warden
Tom & Agnes Hughes	Wayne Ardock
Louise Guido	Donna Anderson
Evelyn Burnidge	Robert Baumann
Tim Schlafer	Carol Gunderson
Gary & Debbie Gostas	Nancy Hayden
Don & Rosalind Rahn	Karen Jensen
Jim & Judy Dorn	Kathy Lembcke
Richard Stark	Ben Van Korn
Laura Prorok	
John & Bonnie Kraft	
Charlotte Gir daukas	
Wayne & Diane Nummerdor	

ATTN: WISCONSIN PARENTS OF CHILDREN (AGED 6 YRS OR OLDER), TEENS AND ADULTS WITH PWS

2008 PWSA (USA) Conference

features



“Moo-ving Forward to Good Health & Wellness”

A 2-Day Health Education and

Advocacy Training Event for Persons with Prader-Willi Syndrome

July 3—4, 2008

Wyndham Hotel and Conference Center by the Airport, Milwaukee WI

During the 2008 PWSA (USA) Conference, while parents and caregivers are listening to national experts on PWS, there will be a 2-day health and advocacy training event specifically for older children, teens and adults with PWS! The people attending this training will be provided with learning opportunities, events and fun that will help them learn about PWS, health issues and what they can do to stay healthy and fit. The younger children will focus more on health related activities that will target nutrition, exercise and good health. Special pre-conference child care—respite services will be provided to volunteers who are providing services on Wednesday.

PWSA of WI, Inc. wants parents of all children and adults with PWS who are residents of, and reside in the state of Wisconsin to be able to participate in this great educational and support opportunity. This is a special event and service to **persons from Wisconsin ONLY!!** In addition, PWSA of WI, Inc will need volunteers to assist in many areas that are needed to execute an large event like the conference. The Board of Directors of PWSA of WI, Inc along with support of the Board for People with Developmental Disabilities (previously the Wisconsin Council on Developmental Disabilities) have joined efforts to sponsor this 2 day event

Criteria for attendees include: 1.) All participants in the training event must be resi-

dents of and reside in the state of Wisconsin. 2.) Parents of the participants must be a member of PWSA of WI, Inc. If needed, a membership scholarship can be provided. 3.) At least one parent or care giver must volunteer a minimum of 2 hours during the course of the 3 day conference. (There are pre-conference meetings and events on July 2nd.)

Cost is \$15 per person for the pre-conference (Wednesday) —including lunch and snacks plus activities and fun. This is limited to volunteers providing help **on that day ONLY**. It is \$50 per person for both Thursday and Friday—including the breakfast, lunch and snacks plus 2 days filled w/fun, learning activities and social events. **Due to limited space and volunteers, a limit of 25 participants will be allowed in the program.**

*****SORRY—This event and service is limited to WI residents only. Due to limited space, we will be prioritizing applications. REGISTRATIONS WILL NOT BE POSTED OR ACCEPTED UNTIL APRIL 1st. REGISTRATION FORMS CAN BE DOWNLOADED FROM PWSA OF WI, INC.'S WEB SITE (www.pwsaofwi.org) OR BE OBTAINED BY CONTACTING PWSA OF WI, INC. TOLL FREE AT: 1-866-797-2947.**

PWSA of WI, Inc.'s Wish List for Conference

As conference approaches, we are in need for many items. If you are able, we could use the following items as we get things ready:

- * Baskets/items for the silent auction
- * Reams of copy paper
- * Bottles of water
- * Ink jet photo printer
- * Gift cards for items from stores like:
 - * Walmart
 - * Target
 - * Shopko
 - * Costco
 - * Sam's Club
 - * Office Depot
 - * Office Max

We are hoping to use some of the gift cards for office items and food items/drinks to stock the volunteer room for our volunteers. If you have any questions, call Mary Lynn at the office.

PWSA of WI, Inc.'s Event Calendar

March 30, 2008	Conference Committee Meeting	PWHO – Oconomowoc Residential Programs Oconomowoc, WI
April 5, 2008	PWSA of WI, Inc.'s Hobby Helping Day	PWHO-Oconomowoc Residential Programs Oconomowoc, WI
April 2, 2008 AND April 9, 2008 6pm – 7pm	“Staying Fit” - Health Education Classes for teens and adults with PWS	Waisman Center Outreach Office 122 E. Olin Ave., Ste 100 Madison WI
July 2-4, 2008	30th PWSA (USA) Conference	Wyndham Airport and Convention Center, Milwaukee, WI
August 23, 2008	PWSA of WI, Inc.'s 8th Annual Golf Benefit	Windwood of Watertown Golf Course

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