



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.

Board of Directors

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PWSA of WI, Inc. is a chapter of the Prader-Willi Syndrome Association (USA).
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A Note from the Co-Presidents: Steve and Nancy

Hi everyone -

Well, Hobby Day has come and gone. It was a wonderful success - thanks to all who participated and/or supported this event. In fact, it was the best one that I have ever attended!

Summer is just around the corner and we are already making summer plans. This is my favorite season. It always seems that it is easier for me to control weight in the summer. It's a season of lighter eating, with lots of fruits and veggies and salads around, instead of heavier, calorically saturated casseroles and sweetbreads everywhere you look. And it is so much easier to get fun exercise in the summer.

The warm weather invites us to go to the parks, go for walks, go swimming and horseback riding. Somehow all of this combines to help take the heat off (weight-wise) just a bit for a short while.

Don't forget that the national conference will be coming up the end of July. For anyone who has not attended one of these, it is a wonderful experience and you should truly consider attending. Check out the national website for all the details. It's a great opportunity for learning and for fellowship.

Wishing you all a great summer -

Nancy

HOBBY DAY



Hobby Day 2005 was a day of stamping, woodworking, painting, beading, framing and creating! We had 80 people signed up for

hobbies, 63 volunteers consisting of parents, siblings, friends, staff of Prader-Willi Homes of Oconomowoc and a choice of 10 different hobbies to select from.

After everyone had a chance to work at 2 of their selected hobbies, each participant was able to take home their completed project!



The afternoon was set aside for renewing old friendships, making new ones and DANCING!!



From the photos here; it looks like everyone was enjoying

themselves!! Parents and caregivers were able to spend this time listening to Lois Rentmeester, an attorney who spoke on guardianship issues.



Thank you!! Thank you!!

We would like to extend a **HUGE** "THANK YOU!" to everyone who helped make our Hobby Day a big success! We want to thank all our volunteers and family members who volunteered their time, treasure and talent! You made a huge difference in the lives of individuals with PWS!



Lois Rentmeester, an attorney and Nancy Burlingame, PWSA of WI, Inc. president during Hobby Day 2005

Thanks go to Lois Rentmeester, the attorney who spoke to family and caregivers about guardianship in the afternoon.

Thanks also to Home Depot, Walmart and Michael's Craft Stores for donating some of the supplies.

We want to extend a special thank you to **Prader-Willi Homes of Oconomowoc (PWHO)** who donated the afternoon soda, the decorations, the cost of the DJ, the cost of the rental of tables and chairs! They also assisted in providing their staff as some of our volunteers for the day!

Special thanks also go to **Oconomowoc Developmental Training Center (ODTC)** for letting us use their facility!

**We could not do this without all of you!
Thank you!!**

Parents of children w/ PWS aged 9 or younger:

Each year we try to have a meeting targeting families with children aged 9 years or younger. This year we have it tentatively scheduled for Saturday, October 8, 2005. We are hoping to hold this in the Milwaukee area this year as we have several newly diagnosed families in this area over the last few years. If you are willing to assist with this, please contact Mary Lynn at the state office to discuss some of the arrangements. Call toll free: 1-866-797-2947 or send an email: Wisconsin@pwsausa.org.



National PWSA (USA) Conference 27TH ANNUAL CONFERENCE "A Brand New Me" July 27 – 29, 2005

Sheraton World Resort in Orlando, FL
For more information, contact PWSA (USA) toll free at 1-800-926-4797 or via the web at: www.pwsausa.org

General Assistance Scholarships Available

We are happy to announce that PWSA of WI, Inc. has allocated funds for a family of someone w/ PWS to attend the National PWSA (USA) conference in Florida from July 27-29, 2005. If you are interested, please fill out the General Assistance Scholarship paperwork and mail it to the state office as soon as possible! You can find information about the National conference on the PWSA (USA) web site at www.pwsausa.org

PWSA of WI, Inc. Memberships

The following people/families have renewed their memberships for 2005:

Louise Guido
 Jim and Judy Dorn
 Beatrice Sturm
 Karen Shackleton
 Rosalie Tillman
 Ken Peters
 Mary Mulligan
 Elsie Dorn
 Richard Stark
 Tom and Judy Scheidegger
 TLC Homes
 John and Cathie Lehman
 Mark Dorn
 Mrs. Dorothy Lothe
 Gary and Debbie Gostas
 Jane Majcherek
 Ginny Cardarella
 Heidi Luebke
 Rose Lopez
 Gerard and Helma Drag
 Russ and Dawn Stuczynski
 Tom and Bonnie Jones
 John and Pat LaBella
 Bob and Kathy Bomber
 Steve and Nancy Burlingame
 Clint and Crystal Boser
 Dan and Kate Beaver
 Jackie Stoner
 Tom and Agnes Hughes
 Chad and Melissa Sirovina
 Roger and Alice Girdaukas
 Lori Porte
 Robert and Pat Nelson
 Julie Scheuer
 Family Support and Resource Center
 Jean Van Tuyle
 Cindy Organ
 Aaron Carrel
 Robin and Jenny Lucas
 Judith Sweet
 James Wachter
 Wayne and Diane Nummerdor
 Eugene and Virginia Johnson
 Charlotte Girdaukas
 John and Cory Hacker

Todd and Betsy Van Heesch
 Katie Kranjac
 Jeanne Langlois
 Paul and Mary White
 Kevin and Anne Bresnahan
 Jennifer Kryzak
 Heidi and Jamie Wertjes
 Michelle Anderson
 Jacqueline Alexander
 Michelle Olson
 Alicia Picchiottino
 Larry and Lori Abler
 Judith Wolter
 Dr. Anne Felden
 Kim Tula
 Marguerite Rupnow
 Rose Worden
 Mark Hohenwald
 Liz Moser-Sadzewicz
 Dr. Marta Muller
 Jennifer Kraft
 Louis and Judy Schutz
 Gary and Marty Girdaukas
 Lillian Weigand
 Pastor Greg Fairrow
 Madison Police Dept.
 Fitchburg Police Dept.
 Verona Police Dept.
 Town of Madison Police Dept.
 Don and Barb Dorn
 Mike and Mary Lynn Larson
 Joe and Elaine Gareau
 Lee and Shirley Larson
 Dave and Cathy Hennig
 Patti Kelley-Huff

Have you sent in your 2005 membership yet? If you aren't sure, feel free to call or email Mary Lynn at the state office. She can be reached toll free at 1-866-797-2947 or by email: Wisconsin@pwsausa.org



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 _____

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: _____

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

Speaking About Memberships...

Recently, someone asked me why we, as a family, were members of PWSA(USA).... It got me to thinking....how would I answer that if a member of PWSA of WI, Inc. asked me, "Why are you a member of PWSA of WI, Inc **and** PWSA(USA)?"

In the 12 years since Alex's diagnosis, Mike and I have been involved with both the state and National organizations because of all that they can do for us! We have both held positions at the state and National levels which have allowed us to see how essential they are to one another - **and to us** – both at the individual level and the state level! Without either of these organizations, we would not have received some of the early information that Barb Dorn created as PWSA of WI, Inc. "Packets of Hope" that families of newly diagnosed children receive! Barb initiated this in Wisconsin when she ran the WI office and National thought it was a phenomenal idea that they have started sending out their own packet of hope! We have learned so much from both organizations about so many of the pertinent medical issues that seem to touch many of our children at a variety of levels. PWSA (USA) has also afforded us friendships with other families who have been crucial in our struggles... as mentors as well as our support system! It was because of some of these friendships that Mike and I had made which led to the decision to bring Matthew, our second son with PWS, into our family!

Here is what a membership of PWSA (USA) can provide.... Recently National has initiated the only national database system on PWS which can help direct research. They have contact with all of the world-wide "experts" on PWS and will put you or your personal physician in touch with them if a medical issue arises. Membership gets you copies of The Gathered View, which offers vital medical information, the latest in research, personal stories from families that we all relate to at some level... How can you NOT afford to be a member?

Remember, **NO PARENT IS EVER DENIED MEMBERSHIP.** If you cannot afford to pay the membership fee, simply call PWSA (USA) toll free 1-800-926-4797 and tell the staff. No questions are asked.



**Remember to
keep
Saturday,
September 17, 2005
open so you can join us
for PWSA of WI, Inc.'s
5th Annual Golf
Benefit!! Contact Mary
Lynn at: 1-866-797-
2947 or
Wisconsin@pwsausa.org
if you have ideas for
prizes, hole sponsors,
etc... or if you just want
to volunteer your time!**

Caring Is Sharing Campaign

Thanks to recent donors in our Caring Is Sharing Campaign! Recent donations came from:

Mr. and Mrs. LeRoy Peronto
Robert and Pat Nelson
Larry and Lori Abler
Paul and Karla Hansen

From the Office....

By Mary Lynn Larson

Things have been quite busy over the last several months with the membership campaign, getting things ready for Hobby Day, the regular phone calls from families and care givers with questions or concerns, as well as the day to day things of trying to keep everyone in my own family on track!

In the last two months, we have had to work on both boys IEPs... which was quite a bit more work than I had anticipated. Usually they coincide with their birthdays (October and May, respectively) but we have had some issues that required a revisiting of Alex's IEP. Alex is transitioning from elementary school to middle school!! And I have heard that often, this is one of the toughest times - both for the child, and for the parent! Unfortunately, in the two months leading up to Alex's IEP, we were also dealing with some... "inappropriate sexual behaviors" within the school environment. (Side note: How do you explain to a caring, social child that it is inappropriate to hug your classmates in school? Or explain why they should not put their arm around a classmate who has been hurt - whether they are boys or girls?) So, we have been having regular meetings with school personnel, as well implementing a Behavior Support Plan to try to reduce or eliminate these behaviors.

Over the last several years, I have found it useful to plan ahead of time what issues I want to include in the boy's IEPs by reviewing the publication: The Student With Prader-Willi Syndrome - Information for Educators by Barb Dorn and BJ Goff. This publication has concise divisions of behaviors commonly seen in the elementary, middle school or high school age levels. They also offer ideas on things that may assist in addressing these behaviors - all within the appropriateness of the age level of the child!! It also talks about a variety of other things that may come into play - depending upon your child's personality. It was certainly something I felt imperative to include in the packet of information that will be sent on with Alex as he enters middle school! If anyone is interested in a copy, please give me a call!

Enjoy the coming summer months!
Mary Lynn

Camp Scholarships Awarded

We are happy to announce that PWSA of WI, Inc. has awarded three camp scholarships this year! The recipients of the camp scholarships include: Kayla Sirovina, Robin Wolk, and Megan Allen. Camp is an opportunity for activities, adventure 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. Enjoy your time at camp, girls!

THANKS FOR SHOPPING AT PICK 'N SAVE!!

Thank you to all who shop at Pick n Save and designate PWSA of WI, Inc as one of their **WE CARE** organizations! We received a check for \$56.93 for your efforts! If you shop at Pick 'n Save and would like to designate PWSA of WI, Inc as one of your **WE CARE** organizations; our number is 622600. Stop at the service counter and ask for assistance. Thanks!!

Anyone Interested in Attending a Brewers Game?

PWSA of WI, Inc. has 50 tickets to the September 25, 2005 Brewers game against the St. Louis Cardinals. This is a Sunday game at 1:05pm. The tickets are located in Section 112, Rows 18, 19 and 20. The tickets are \$50.00 a piece and PWSA of WI, Inc. gets a portion of this! If you are interested, please contact Crystal via email at: crystalpmhs@aol.com or call the state office at 1-866-797-2947. Checks should be made payable to PWSA of WI, Inc. This is a great chance to support PWSA of WI, Inc, enjoy time with family and friends and cheer on the Brewers!!

PWSA of WI, Inc. 2005 Calendar

July 27 - 29, 2005

PWSA(USA) National Conference Orlando, FL

September 17, 2005

PWSA of WI, Inc 5th Annual Golf Benefit Oconomowoc, WI

September 25, 2005

Brewers game against the St. Louis Cardinals 1:05pm, Milwaukee, WI

October 8, 2005

PWSA of WI, Inc., Board Meeting, Milwaukee, WI

October 8, 2005

Parents of Young children w/ PWS meeting, Milwaukee, WI

More info to come

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