



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: Barb Dorn

A Mother's Day Message - "So Proud"

I am the mother of two young men – yes men. Tony, who has Prader-Willi syndrome (PWS), is 22 years old. Tyler, “my baby” is 20 years old. In all honesty, it is hard to believe “my boys” are now men. Where have the years gone?

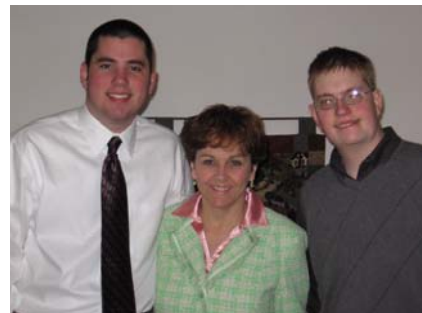
As parents, we want all of our children to grow up to be successful, safe, healthy and happy. Tyler lives in Milwaukee, in a home he rents with two other young men. He is now a sophomore at the University of Wisconsin – Milwaukee. He is majoring in accounting and finance and seems to know he wants to do something in the field of business. He is studying hard and has made the Dean's list every semester so far. He has a good head on his shoulders and it appears that my husband and I now do know a little bit about life. Tyler also works part-time. He is healthy ... and he seems happy. He makes me so proud.

Tony lives in Oconomowoc, in a home with seven other young men who have PWS. He works two jobs – one at Paragon Industries, a more supported worksite and one at Duct-O-Wire, a job out in the community. He earns a paycheck that helps him afford the many activities he likes to do. He is supported by staff that really seems to care about Tony as an individual. His life is structured and balanced with home responsibilities as well as social opportunities. His weight is under control. He is healthy ... and he seems happy. He makes me so proud.

I am very blessed. I have two sons who are very successful, safe, healthy and happy. Like all parents, my husband and I have faced our bumps in the road. At times, there were pebbles and at times, there were boulders. Both boys have offered us parenting challenges in their own ways. They have also given us numerous joys, positive memories and many life lessons.

My job as a mother will never end. (Sorry about that boys!) It is a job that has always been very important to me as well as a big priority. I think they both know – family is the center of our life. It is nice to be able to sit back now and reflect on what great young men both of them are becoming. I am so proud to be their mom.

I want to wish all moms and dads a very happy Mother's Day and Father's Day. You have a very important job. You are very special people to some very special children. *Barb*



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Hobby Day 2007

This year 95 children and adults with Prader-Willi syndrome, and their siblings, did hobbies. Over 75 parents, siblings, friends and staff from Prader-Willi Homes of Oconomowoc (PWHO) volunteered their time and had a blast! This is



like a statewide annual convention for those with PWS and their families. The morning was spent working on a variety of hobby tasks while the afternoon was a time for dancing!!

Parents were able to spend the afternoon making contact with other families who are dealing with similar issues. Siblings of those with PWS were happy to be able to meet other siblings. There was a special area targeting activities for children under the age of 8—for both those with and without PWS). A GREAT time was had by all! Thanks



Making things from wood is always a lot of FUN!!



to everyone for helping us make it such a success!

It was a day of

friendship, fun and great memories. The participants enjoyed spending time with old friends and making new ones. We want to thank all of the parents, family members, staff and everyone else who helped to make this our best Hobby Day ever! We couldn't do this without you!



What is a dance without doing the "CHICKEN dance"?

THANK YOU!!



HELP NEEDED!!

We are looking for someone with sewing experience !!!

For the upcoming 2008 conference, we thought it would be fun to have many of the adults w/ PWS from around the state of Wisconsin work on some “baby” blankets and present to the infants/toddlers as a gift they could take home at the end of the conference. Because the “tie-a-blankets” we have at Hobby Day are such a success and not difficult to do—we thought these would be a good choice! We are hoping to have several “workshops” around the state and have persons with PWS arrange to help. In order for this to work smoothly, we need some assistance in getting these ready for tying. If you are either interested or available to assist—please contact Mary Lynn at the state office.

Prader-Willi Syndrome Awareness month: May 2007

Information about PWS featured on “The Morning Show” in the Milwaukee area

Those of you who are in the Milwaukee Channel 4 viewing area need to keep a look out as Melissa Sirovina (a board member and mother of a child with PWS), her daughter, Kayla Sirovina (a teen with PWS) and Barb Dorn (PWSA of WI, Inc. President) will be featured on the show, the Morning Blend on Friday May 4th. The show starts at 10 am and we are not sure exactly when they will be featured, but we wanted to let you know in case you are around. This is yet another way to increase awareness about the syndrome. **THANKS to Melissa, Kayla and Barb for working hard to put this together!!**

Keep the following dates open:

July 13—15, 2007

Take me out to the ball game!!

Milwaukee Brewers Game

We have an potential opportunity to work raising money for PWSA of WI, Inc at a Brewer’s home game against the Colorado Rockies! The Rockies have been a big supporter of fundraising for Prader-Willi syndrome as their manager, Clint Hurdle has a daughter, Madison who has been diagnosed with PWS. Clint served as the National spokesperson for PWSA (USA) in 2006 and has been supportive of our attempts to work out some awareness and fundraising activities during their series with the Milwaukee Brewers this year. We have not yet determined all the specifics, however, we are hoping Clint is able to speak and raise awareness to the attending crowd—and we sure hope to have tickets available so that we, our loved ones with PWS and families might attend! Please watch for updated news in a mailing later in the upcoming months and/or on our website at www.pwsausa.org/WI

Camp Scholarships Awarded!

Each year as an organization, PWSA of WI, Inc. awards General Assistance Scholarships to persons with PWS wanting to attend summer camp. This year, we are able to grant two scholarships for two individuals to attend a day camp this summer. Each year, we make our membership aware of our intent to award these scholarships and request that families fill out their applications by a specified date. The only requirements we have is that the person w/ PWS or their family be a member of PWSA of WI, Inc. and the person with PWS be a WI resident. 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 and behavioral issues that need to be addressed).

Notes from the Office -

By Mary Lynn Larson

As I was thinking about my note for this month's newsletter, I realized I usually open with how busy things are in the office...because they usually are!. Well, that may change soon—we have recently hired a new Assistant Program Director to help out!!! Please welcome Melodee Luening, {mom to Olivia, (age 4 with PWS) and Maya, age 1 and wife to Board member, Al} who has agreed to take on this position. This will allow me to delegate some of the many things on my "to do" list... (THANK YOU!! It makes me feel guilty when items have been on there for awhile!) She might also help with the task of collating, labeling, stamping and mailing of the newsletter,

(which I suspect might disappoint Alex as he has gotten a lot of community service hours for assisting with that job) as well as updating entries into the database and other odd jobs that need doing. Over the years, Melodee has helped with the meeting we have for families with young children with PWS as well as volunteering at our golf benefit. **WELCOME MELODEE!!**

The Wisconsin 2008 Conference Committee continues to work on things for the 2008 National conference that we, as a chapter are hosting in Milwaukee on July 2—4, 2008. We are still in the planning stages for many things—but we are *always* on the look out for willing volunteers and donors! We only recently had the conference logo approved and are working on the next stages of planning. If you are interested in helping with any part of it or want to help but are not sure where you might 'fit in', please do not hesitate to contact me on the toll free number at 1-866-797-2947. We can discuss the many areas where we will need some assistance and see what you might be interested in!

Don't forget that we also have our 7th Annual Golf Benefit coming up on August 25, 2007 at a **new location!!** This is our biggest fundraiser throughout the year—so please mark the date and come join us!! We will be at Windwood of Wauertown Golf Course. If you are interested in getting some friends together to golf, want to make a donation to our Silent Auction or perhaps, want to be a Hole Sponsor—you can either contact me via the toll free number or check out our web site at www.pwsausa.org/WI. Hugs, Mary Lynn

2008 PWSA (USA) National Conference Update

“Moo-ving Forward”

By Mike Larson, conference committee
co-chair

For those who did not know, the 2008 National PWSA (USA) conference is going to be held July 2—4, 2008 here in Wisconsin! The conference site has been selected to be the Four Points Sheraton Hotel in Milwaukee. It has fantastic conference facilities, plenty of rooms for attendees and a *great* location for people to get to either driving or flying in. The conference theme will be “Moo-ving Forward”. This theme was chosen as a play on Wisconsin being the dairy state and “Forward” being the Wisconsin state motto. The logo for the conference was created by Al Luening. Father to 4 yr old Olivia with PWS and a current Board of Directors member. As well as a dairy theme, the conference spans into the 4th of July weekend lending to a patriotic theme also.

We are very excited to have obtained a very dynamic keynote speaker for the 2008 conference. His name is Richard Pimentel. He is a disabled Vietnam veteran that was very instrumental in the passage of the

Americans with Disabilities Act. He is also the subject of an upcoming movie called: “Music Within”. Look for it in theaters in late fall of 2007. We will be sharing more details of conference highlights in upcoming newsletters as well as on the web site at www.pwsausa.org/WI. There will be a great need for volunteers so stay tuned for opportunities to step up and help us show the PWS world how Wisconsin can host a party!!

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.

Please 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.

Wisconsin's Family Support Program: A Service you may not know about...

By Melodee Luening, Assistant Director

The Family Support program was developed to provide individual services and supports to families that include a child with severe disabilities. The program offers help in funding, locating services and utilizing community resources. There is funding to buy needed goods and services that cannot be purchased through other sources. Example: hippo therapy, specialty shoes, respite care funds and so much more. This program is also a great resource to help families connect with other families within their area for support.

The Program Guidelines simply state: "The foundation of the Family Support Program is the belief that parents of children who have severe disabilities know best what they need." Now with that being said, when meeting with your Family Support Coordinator, you as the parent and the coordinator work together to pick a plan to best maximize the funds and offer the best services for your child.

How does this Program work? Families apply for the services through their local County Family Support Program. The application process includes an eligibility determination and a needs assessment. Information is gathered from a variety of sources, which may include interviews with the family, educational records and a complete medical history. Once eligibility has been determined, a coordinator will come out to your home to do a "home visit". As a team, the family and the coordinator set up a plan that will best suit your child.

Personally this program has really opened up some avenues for Olivia and our family by providing services and goods to help us to improve her quality of life on a daily basis. She loves going to



the stables to ride "Painters" the horse for her Hippo therapy sessions. Hippo therapy is designed to strengthen the core muscles of the abdomen and improve balance so – not only does she have a blast but she gets a great workout as well. It is alternative programs like these that are not routinely covered by insurance that really promote confidence and pride in our children. This program, in particular would be difficult for us to afford if not for the help of Family Support funds.

In addition to the funding, Family Support also is just that, 'support'. As any parent of a child with a disability knows, having others to share stories with and communicate with is very important to our own "mental" health. Now that you know what Family Support is; here is how you can apply: Your first step is to contact your local county government to find out the Family Support Coordinator in your area or call Wisconsin First Step at 1.800.642.7837. This is a great service that Wisconsin has for families in need. You can also check out their web site at www.dhfs.wisconsin.gov/bdds/fsp.htm

Mark your calendars!!

PWSA of WI, Inc.'s

7th Annual

GOLF BENEFIT

Saturday August 25th, 2007

New Location

Windwood of Watertown

Golf Course

Prizes, Food, Silent Auction &

Most of All Fun!

For more information, check out our web site or contact the office toll free:

1-866-797-2947

Some Interesting New Products We Have Recently Found

We have recently discovered some more new products we thought our membership would be interested in. The ones we have found include:

General Mills Fruit Ripples

These are individual packets of items like apple chips. They come in these flavors: Cinnamon Apple and Strawberry Apple. Each pouch is 50 calories.

Diet Coke Plus

This is Diet Coke that is fortified with vitamins and minerals. These include vitamins B3, B6, and B12 and the minerals zinc and magnesium.

Pro-Namel toothpaste

This toothpaste help protects your teeth against the growing problem of acid erosion. Dentists have reported a growing dental health concern due to changing modern diets: acid erosion or acid wear. Even teeth without cavities can be affected. Acids in everyday food such as some fruit and acidic drinks like orange juice and wine can dissolve minerals from our teeth, softening the enamel surface which is then more easily worn away. As the enamel becomes thinner, teeth can become visibly less white, weaker and sensitive. Teeth sensitive to hot and cold foods can be an early sign of acid wear.

New Sensodyne ProNamel toothpaste is spe-

cially formulated for people with sensitive teeth to help protect against acid wear. As it contains fluoride it also provides the benefits of a regular daily toothpaste. For people whose tooth enamel is deteriorating, dentists often recommend using a straw when drinking carbonated beverages such as soda to lessen contact w/ tooth enamel.

If you find any products that are helpful in meeting the diet plan for persons with PWS or work well for you, your family member with PWS and/or your family, let Mary Lynn know at the state office via phone: 1-866-797-2947 or email:

wisconsin@pwsausa.org. Thanks



REQUEST FOR EMAIL ADDRESSES

We are wondering if we have your most current email address in our database. We often like to send out an email if an important event is coming that we were unable to inform you about in the most recent newsletter. If you are uncertain, drop me an email from the address you would like to receive the notes. We will be sending out information soon regarding the Brewers/Rockies baseball game—so don't delay. The office email is: wisconsin@pwsausa.org

PWSA of WI, Inc.'s Event Calendar

August 1-3 2007	29th PWSA (USA) Conference	Intercontinental Hotel Dallas, TX
August 25, 2007	PWSA of WI, Inc.'s 7th Annual Charity Golf Benefit	Windwood Golf Course, Watertown, WI
July 2-4, 2008	30th PWSA (USA) Conference	Four Points Sheraton, Milwaukee, WI

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