



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

Co -Presidents: Steve and Nancy Burlingame

Vice President: Crystal Boser

Secretary: Kathy Bomber

Treasurer: Tom Hughes

Board Members: Pat LaBella, Jackie Stoner, Dan Beaver & Melissa Sirovina

Program Director: Mary Lynn Larson

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PWSA of WI, Inc. is a chapter of the Prader-Willi Syndrome Association (USA).

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The Wisconsin Connection

A Note from the Co-Presidents: Steve and Nancy

Greetings, all. It's hard to believe that its newsletter time so soon. Time around the holidays seems to move even faster than through the rest of the year.

As we know, the holidays may be an especially difficult time for our loved ones with PWS. The lack of routine due to parties, decorating, buying and wrapping, time off from school, traveling or having visitors, etc., not to mention the extra challenge of sidestepping all the holiday goodies, can turn a good thing into a real nightmare. It takes extra effort and patience to try to minimize the disruptions. In our family, we've really toned down our holiday celebrations. No longer do I make several kinds of Christmas treats, and the family get-togethers are more limited than years back. But to be honest, it's less stressful for me this way, too.

This year, however, we did something very special with Kyle to kick off the holiday. Last year, our local volunteer fire department held a fundraiser. Steve and I bought Kyle a ride with Santa on the fire truck in the Waterford Christmas parade. Traditionally, the fire truck is the last thing in the parade, it stops at the library, and then Santa proceeds inside to sing carols and talk with the local kids. There are cookies and drinks for everyone. It's a real Norman Rockwell type of thing and it brings tears to my eyes every year. So this year, Kyle and I got to ride on the fire truck with Santa and Mrs. Claus. (And yes, it was the REAL Santa. Waterford's parade is held early in December so Santa still has time to attend before he gets too busy.) Kyle was made a Junior volunteer firefighter complete with shirt, and toured the firehouse before the parade. He got to hang out with three firefighters and ask numerous questions. He had a birds-eye view of the people watching the parade, and the dogs too! It was quite an event. He opted to drop off Santa and the wife and stick with the firefighters, who took us for a longer ride back to the firehouse, thankfully avoiding the cookies and drinks. So all in all, it was a very great night and a wonderful kick-off to the holiday season.

Before I end this, I want to make mention of the PWSA of WI, Inc. elections. I want to thank Mark for the superb job he's done over the years. I also want to thank all the new and returning Board members and Officers for their continued commitment to supporting PWSA of WI, Inc. And I want to encourage each of you to join us whenever and however you are able to make this organization a successful one in our mission to support, advocate, and educate for each other and our loved ones with PWS.

Happy Holidays!

Nancy

THE RESULTS ARE IN!! NEW BOARD MEMBERS/OFFICERS

Our election in November brought us some new Board members and officers who will be taking their positions just about the time you receive this newsletter. The names of the new Board members/Officers are underlined and italicized.

As of January 1, 2005, our Board Members and Officers will be:

Co-Presidents: Steve and Nancy Burlingame

Vice President: *Crystal Boser*

Treasurer: *Tom Hughes*

Secretary: Kathy Bomber

Board Members: Dan Beaver, *Pat LaBella*, *Melissa Sirovina*, and *Jackie Stoner*.

Mark Dorn has stepped down from his position as Treasurer but has promised to remain involved as we are working on a new fundraiser linked to a Milwaukee Brewer's game! (More information on that fundraiser will follow as we get it.) Tom Hughes has changed positions from Vice President to Treasurer, while Crystal Boser has taken on the Vice President role.

You will also notice that we now have **four** Board members. We have chosen to keep the entire slate of Board members who ran for election (Pat LaBella, Jackie Stoner and Melissa Sirovina) although Melissa will be a non-voting Board member to keep in with our by-laws. Many of the current Board members thought it would be a great opportunity for someone who is interested in becoming a member of the Board to get a "feel" for the workings and mission of the organization as often times they report having no real idea prior to attending a Board meeting. We want to say "THANKS" to everyone for their hard work and flexibility!!

GREAT NEWS!!

The Growth Hormone study for Infants and Toddlers with PWS has received an additional 2 years of funding from Pfizer (previously Pharmacia)!! This information was shared with participants in the study in early December 2004. Dr. Carrel also reports that they had a "one year" paper accepted for publication on the benefits of instituting GH at a young age for children with PWS!! More to come when this is officially published!!!

MORE GREAT NEWS!!

We have received a check from the Hillfarms Neighborhood Association Health Fund drive for \$964.17! This funding is made possible as a result of the LaBella's who have gotten us involved with this fund drive. Thank you John and Pat!

Caring Is Sharing Campaign
Thank you to all of our generous donors in our Caring Is Sharing campaign! To date we have received \$1400.00 in donations.

Many thanks go to:

Thomas and Debra Schmitz
Thomas, Bonnie and Kelly Jones
Susan Allison
Lori Porte
Carl Schwartz
Elsie Dorn
Beatrice Sturm
Rose Lopez
Charlotte Girdaukas
Don and Barb Dorn
Thomas Scheidegger
Nancy and Steve Burlingame
Mike and Mary Lynn Larson
Tom and Agnes Hughes
John and Cathie Lehman
Paul and Mary Smith
Jane Majcherek
Wm and Margaret Nagel
Dan and Kate Beaver
Evelyn Burnidge
Rick and Barbara Ausick
John and Bonnie Kraft
Paul and Ellen White

New Publication from PWSA(USA)

PWSA(USA) has put out a new Medical Alert Booklet that compiles life saving documents for hospitals, doctors, and care providers in a small 4.5" x 6" format. It targets issues such as: anesthesia, breathing abnormalities, stomach problems, as well as others. It is mailed to anyone who fills out the questionnaire found later in this newsletter

News from the Office by Mary Lynn Larson

I hope you all have had a safe and blessed holiday season! Ours was enjoyable but contained the many randomized moments of chaos that is “the life in the Larson household”! We spent Christmas at home but traveled to see my parents and my sister’s family for the New Year. This often requires much planning and coordinating w/ my Mom and sister about menu options as well as activities to keep the boys occupied because, often too much ‘down time’ results in many “meltdowns” yet too many activities in addition to the presents can also result in “meltdowns”. I am sure we all strive to maintain that balance in our lives...

While we were up North, we found some alarms by First Alert that use magnetic technology. You can place these small alarms on doors, windows, cabinets and numerous other places to alert you when the connection is broken. They use double sided tape making them easy to install and remove! We thought of a lot of uses for them – especially when we travel, as our families do not lock and Matthew is famous for finding food, cleaning products, and just about anything he is not supposed to have!! We were able to place them strategically around Grandma’s house and we had warning when he was “getting into things he was not supposed to”! Then before we left, we were able to easily remove them without difficulty and we can use them again. Look for more information about these later in this newsletter.

I want to thank everyone who has been so kind and generous for their donations in our Caring Is Sharing campaign. If you have not received this mailing, please let me know. If you have not yet returned yours, there is still time. We will also be sending out a mailing for membership renewal soon, so keep your eyes open for that. As always, if you have any questions, do not hesitate to give me a call or send me an email. The toll free number is 1-866-797-2947 and our email is: Wisconsin@pwsausa.org.

Take care, Mary Lynn

P. S. Don’t forget to check out the recent changes to our website. Go online at: www.pwsausa.org/WI
We can thank Jennifer for the recent updates and changes!

The following is a note from PWSA(USA):

HELP PWSA(USA) HELP YOU.... BE COUNTED!!

PWSA (USA) currently has the largest collection of information on children and adults with Prader-Willi Syndrome, but some of it is out of date and all data on families lacks essential information that could be crucial information to improve the medical care of our children. Therefore, we are going to improve our database by increasing the size and accuracy of the information.

In a perfect world, PWSA (USA) would have the names and pertinent information needed on all persons with the syndrome. ***There is power in numbers!*** If we can acquire a more comprehensive database, National Institutes of Health (NIH) and other funding sources will be more willing to help our children through funding continued research in PWS and obesity!

We have included the questionnaire form in this newsletter. We are asking that you fill it out and return it to the state office at: PWSA of WI, Inc., 2701 N. Alexander St., Appleton, WI 54911-2312. or you may fill it in online at: <http://www.pwsausa.org/population/>
We will mail all of the questionnaires in together once we have received them.

You do not need to be a member of PWSA (USA) to be included in this collection.

NEW Medical Alert booklet. This booklet will be sent FREE OF COST to all who complete this database form online or with the mailed in paper form

If you have any questions, feel free to contact Mary Lynn at our state office at our toll free number: 1-866-797-2947.

PWSA OF WI, Inc. FUNDRAISER

"Pizza With a Smile"



Wisconsin Pizza Huts have partnered with the Prader-Willi Syndrome Association of Wisconsin, Inc. (PWSA of WI, Inc.) to raise funds to benefit children and adults suffering from this challenging disability. These coupons can be used at most participating Pizza Hut locations throughout Wisconsin. To see if your local Pizza Hut is a participant, visit <http://www.WHGonline> or <http://www.phsw.net>. It's easy - all you have to do is contact the state office at 1-866-797-2947 or via email: Wisconsin@pwsausa.org to purchase a \$10 pizza card and you will receive:

- 12 FREE MEDIUM PIZZAS WITH EACH PURCHASE OF A LARGE PIZZA (a \$120.00 value) *There is no expiration date.
- A TAX-DEDUCTIBLE DONATION TO PWSA OF WI, INC!
- A BIG SMILE - EATING GREAT PIZZA, KNOWING YOU ARE HELPING PEOPLE WITH PRADER-WILLI SYNDROME RIGHT HERE IN WISCONSIN!

This is a great gift to tuck in a birthday card, thank you card; send away to a loved one at college; or remember someone "just because". The list is endless! Don't forget to get one for yourself. Please make sure to let us know if you need a receipt.

This is a year-round campaign so let us know when you need more cards!!

Thank you to everyone who purchased an Entertainment Book in support of PWSA of WI, Inc. We have raised \$151.86 in profit from your purchases! THANKS!

REMINDER.... Caring Is Sharing Campaign



Don't forget to return your Caring Is Sharing donation!! This allows us to keep supporting, educating and advocating for the person with PWS and those who are impacted by this disorder! If you need more information on this, feel free to call the office at 1-866-797-2947.

MARK YOUR CALENDARS NOW!

This year's Golf benefit will be on Saturday, September 17, 2005 with a 9am shotgun start!



Guardianship Issues

A while back, I attended a workshop on Guardianship issues. It provided a lot of ideas and thoughts I had never considered as a parent of a child w/ special needs. It really focused on **thinking about what your vision is for your child as an adult**. They stressed that we, as parents, really need to think about what we want for our child as an adult... with or without our "FULL PARENTAL CONTROL" as we might have when they are younger. And as a parent of two children with Prader-Willi syndrome, that was a dramatic eye opener!! Once your child turns 18, they are legally able to do anything any other individual is able to do.... including vote, make a contract, get married, handle finances as well as handle all of their medical care decisions without our input. If you want to restrict any of your child's activities once they turn 18, think about how you might be able to restrict those same activities of anyone else in the community. Unless you have some form of guardianship, you are unable to do this! No matter what age your child currently is.... these are issues we need to start considering **BEFORE** they become 18. To get more information on guardianship, the State Bar of Wisconsin has a variety of resources available on their web site at: www.legalexplorer.com

Product Review: First Alert Alarms

By Mike Larson

A recent problem we have had with Matthew, our four year old with PWS is keeping him out of areas of the house where he would go and make a mess. This isn't so bad during the day but in the middle of the night he would wake up and go into the bathroom and empty every container he could find. Or he would get into the refrigerator, not to search for food to eat, but to empty containers of food all over the kitchen. After chasing this active (a.k.a. mischievous) little boy all day we are usually exhausted and on some of his "midnight adventures" we would not hear him right away and would wake up to **QUITE** the mess. Ask Mary Lynn how many times you need to scrub a rug to get 4 quarts of soy sauce out (Hint...more than 6). We were not only worried about the mess he creates but we were more concerned about him getting hurt or causing a fire or something. We never had this issue with Alex, our 12 year old with PWS.

We quickly figured out how to keep him in his room at night. But what do you do during the day when he has greater access to most of the house and you want to get something done or for heavens sake, go to the bathroom? We also encountered a similar problem on a recent visit to Grandma's house. Even when sleeping with him in the same bed, he is sneaky enough to get out of bed, open the door and leave without us waking. This was very scary because he had gone through the garage entry way to get from the basement where we were sleeping to the kitchen. The temperatures were below zero and he could have easily walked outside and would have been locked out.



The problem was how to be alerted when Matthew goes where we don't want him. I had remembered seeing a commercial for some portable alarms that can go onto doors or windows. Then several weeks ago I saw them advertised at our local Shopko store. After cleaning up several dumped bottles of body oil, baby powder, and a few tubes of toothpaste on the first night of our visit to Grandma's, I ran to the local Shopko to search if they might have the alarms.

The alarm I had seen was the First Alert® Alarm. This small battery operated alarm can be added to any door, cabinet or window. The alarm is made of two pieces. The alarm is attached to the door and the matching magnet attaches to the door frame. When the alarm is triggered, a piercing ultra decibel sound is emitted indicating that the door, cabinet or window has been opened. The alarm installs easily. There are no tools or measuring required. Simply peel off the adhesive backing on the alarm unit and stick it in place.

The alarm has a 3 way switch: an alarm setting, an off setting and a chime setting. When the chime is set, it allows you to hear a single pleasant tone when a door or window is opened. It's similar to the systems used in some retail stores. Like an automatic doorbell, it let's you know that someone has just triggered the alarm. The alarm setting emits a loud persistent "siren-like" tone.

I purchased the alarms at my local Shopko store. I got a package of 4 alarms for \$9.99. They can also be purchased by calling a toll free number, 1-800-915-1580 or on their website: <http://www.first-alert-alarm-system.com/>. The web site says they will include 4 free alarms when you buy 4 for \$9.99. You only need to pay for shipping and handling.

So far they have worked well. We have purchased enough for both sets of Grandparents homes, for the school refrigerator, and to have on hand for traveling and staying in hotels. This is a quick, inexpensive way of knowing if Matthew is getting somewhere we don't want him to be. This could also be helpful in the home of a baby sitter or friend.

PWSA of WI, Inc. 2005 Calendar

January 23, 2005	PWSA of WI, Inc Board Meeting	Oconomowoc, WI
Spring 2005	Hobby Day	More to come
July 24 - 31, 2005	PWSA(USA) National Conference	Orlando, FL
September 17, 2005	PWSA of WI, Inc 5 th Annual Golf Benefit	Oconomowoc, WI

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