



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 recently saw an ad for Harley Davidson that struck me. It was a black and white photo of a motorcycle parked in front of a house. The caption read, "The richest people on earth don't necessarily have the most money." I'm not trying to promote Harley's, but they are a fine Wisconsin made product. If I did own one, I probably wouldn't have to worry about having a lot of money anymore either. I found the caption and idea of not equating wealth with money interesting. I have often written here about finding the balance in life. A balance between work, family, money, and all that life throws in your path. And making decisions about what is important and what you need to carry to survive in the world today. I feel that living a rich life is a huge part of finding the balance.

We get hung up many times in the chaos of school, work, extra curricular activities, shopping, cooking, cleaning, and everything else. I don't think many people will contest that we live in a materialistic world. The demands of these things can weigh heavily on each of us. Sometimes work demands can be quite heavy, like a giant weight on the low end of a seesaw and you are sitting way up on the high end not able to touch the ground with your legs swinging wildly, trying desperately to touch something to give you some stability. That weight is huge. And it feels like it controls us in a way that there isn't much we can do to overcome it. There are many things that seem to pile up every day on that other side of the seesaw causing us to wiggle in the air trying to get a foot hold back on the ground.

Balance... That is the whole thing behind the seesaw. Sometimes, I think we give the things on the other side of the seesaw too much weight and it makes us feel we have no control. But funny things happen, sometime through no fault of our own, that make us shift things in our lives. We may experience a crisis where we may lose or come close to losing something that is very important to us, a loved one, a home, health, a job. It seems **then** we start putting into perspective what truly is important to us. God, Family, happiness... those things start carrying more weight than having a new car, a vacation, trying to "keep up with the Joneses". When things are getting overwhelming, out of the blue, Matthew often comes to me, gives me a big hug and tells me he loves me. The weight of the outside world becomes much less. My feet touch the ground again and I hug him back. The big important things from earlier suddenly seem to have much less weight. My balance gets better. I'm less likely to sweat the small stuff. Easy to say, hard to do. When I give more weight to the truly important stuff and put those things first, the things on the other end of the seesaw aren't as heavy and I seem to have more control over them as well as the things on my end of the board.

So maybe living rich is not so much about how much money you have but how much value you have. Give more weight to the important things and try not to give so much weight to the rest. Maybe asking "how much weight are you going to give it?" not how much weight it has on you may help keep the balance. Keep your feet on the ground.

Live rich.

Mike

Board of Directors:

President: Mike Larson

Vice President: Jackie Mallow

Treasurer: Tom Hughes

Board members: Melissa Sirovina, Crystal Boser, Al Luening and Don Dorn

Program Director: Mary Lynn Larson

Assistant Program Dir: Melodee Luening

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Appleton, WI 54911-2312

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**PWSA of WI, Inc.
9th Annual Golf Benefit**

The 9th Annual Golf Benefit for PWSA of WI, Inc. was held Saturday, August 22nd at Windwood of Watertown Golf Course. Wonderful weather + great golf games (or not) + family and friends = yet another successful benefit and fun filled day on the course to support persons and families affected with PWS in Wisconsin.

There were 90 golfers, 40 hole sponsors and a long list of donors and volunteers to make this a great event. Thanks to all that participated in one-way or another. There were a lot of laughs and memories made. We hope to see you there next year. We do not yet have a date but will let you know in our next newsletter so you can mark your calendar.



Crystal and Melanie are two of our die hard volunteers! We LOVE you!



We love seeing our golfers come back each year!



We all need a little practice, right?

Thanks to all our donors, golfers and helpers!!



**PWSA of WI, Inc.
9th Annual Golf Benefit
Hole Sponsors**

- | | |
|--|--|
| The Ausick Family | Hughes Dental Clinic |
| Riegel Law, S.C. | Candoco Ziegelbauer |
| Jim's Marina | Mark Dorn & Laurie Grinnell |
| Tosa Pediatrics | Honoring Jimmy Jones |
| "Westridge Friends" | Dan & Shirley Kealey |
| R D Image | In Honor of Peter Frazin |
| The Larson family | Sells Printing Company |
| CSI Testing | Chuck & Karen Dorn |
| The Lipski Family | LaBella Consulting, Inc. |
| Cathy H. & Mary S. | Dick & Jayne Becker |
| The Dall family | Laurence & Leslie Hall |
| Keith Novotny | Pantheon Industries |
| Don & Barb Dorn | Greg & Cindy Heinemann |
| Gierach Family | The Ignatowski Family |
| Turner Hall | The Health Care Solutions Team |
| Rena Mills | Women's International Pharmacy |
| FABCO | Prader-Willi Homes of Oconomowoc |
| In Honor of Olivia Luening—Uncle Color & Nannie | In Honor of Sophie Coggeshall—Jay & Susan |
| Landscape Maintenance & Services - Josh Rupnow | Oconomowoc Developmental Training Center |

**PWSA of WI, Inc.
9th Annual Golf Benefit
Prize Donors**

- | | |
|---|-------------------------------|
| Todd & Sue Morris Family | Milwaukee Bucks |
| Don & Barb Dorn family | WTMJ—TV |
| Cost Cutters—Oconomowoc | PWSA (USA) |
| John & Candy Lipski | Rosatti's |
| Milwaukee County Zoo | Rookies—Okauchee |
| Clit & Crystal Boser family | Starbucks |
| Wild Wings Sportsman's Club | Green Bay Packers |
| Ralley Time—Watertown | Milwaukee Wave |
| Pantheon Industries | Northside Auto |
| Milwaukee Brewers | Bob Miller |
| Clear Communications | WTMJ |
| Xpressions by Peggy | Panera Bread |
| Wigwam Mills | YMCA—Feith family |
| Milwaukee Admirals | Turner Hall |
| Potosi Brewing Co. | Tom & Agnes Hughes |
| Steve & Nancy Burlingame | Felt-Up Designs |
| Al & Melodee Luening | Sue Dowling |
| Windwood of Watertown | Goebel Woodwork, Inc. |
| Dave Nagy family | Welcome Home |
| Todd's Grill—Oconomowoc | Chili's |
| Bruce & Jackie Mallow family | |
| John & Marguerite Rupnow family | |
| Lakerz Sports Bar & Grill—Oconomowoc | |
| Pick N Save—Oconomowoc | |
| Prader-Willi Homes of Oconomowoc | |
| Berres Brothers Coffee Roasters, Inc. | |

Notes from the Office.....

By Mary Lynn Larson

It's been a long and somewhat strange summer at the Larson house. When someone asks "How's your summer been?" I am inclined to answer, "I feel like I am being pecked to death by ducks!!" This is due to a number of factors like parenting 2 children w/ PWS; many household projects gone awry; running to numerous MD appointments and scheduling minor surgery for Matthew; - and part of it is my two children asking what the schedule is, wanting reassurance on their current and next activities, and just having to verify everything! I also ended up having a week of vertigo—(definition: a feeling of dizziness that occurs when your sense of balance has been disrupted) as a result of grinding/clenching my teeth; likely as a result of my trying to inhibit what I say to my children to ensure it does not backfire on me! This Mom is SOOO ready for school to start and the return of structure, routine and consistency to be someone else's responsibility rather than mine!

As I get my trainings for school staff ready, I need to add another item to the top of my "TO DO" list—respite time for Mom and Dad!! Over the years, Mike and I have recognized that when we are over-stressed and anxious, our boys also become stressed and anxious which leads to more struggles and meltdowns. Other families report a similar occurrence. Matthew is quick to ask me, "Are you angry with me?" whenever he thinks I am out of sorts. Our children quickly pick up our mood and emotion and often times match it.... (Remember the last time your child escalated? Were you also emotional so that they fed off your emotion?)

As with so much of our parenting, we need to be proactive with respite for ourselves too! Knowing to take a break and refresh yourself is so important to everyone's mental health!! We, as parents, need to connect with our local resources for respite care... check with your County's Family Support program. They often have funds available for families to pay for respite care. But call now—as the funds are depleted quickly. When you make contact with the Family Support Program in your county, you also get noted as a family who will likely need case management—especially if your developmentally disabled child gets into a crisis mode.

Many families who have a child getting into a medical/behavioral crisis often have not made contact with the county prior to that point and have a bit of a time lag getting a case manager unless their

child is becoming a danger to others or themselves requiring immediate intervention such as hospitalization or jail. It then becomes necessary to educate the case manager on the complexities of the syndrome so your child can get the services they truly need. And often, as parents, we have all had professionals unfamiliar with the syndrome look at us as if we have completely lost our mind when we describe some of the issues our children struggle with. Educating staff providing support to your child within the county program is as important as educating those in the school system!! The county staff need to know of the kinds of challenges our children struggle with so that they can make sure we/they have that support when our child needs it!

Another area to look for respite services might be the gym/library/class where your child may be taking classes for the summer! Many times teachers of swim lessons, gymnastics, summer school programs and the 'Y' are required to take "training" classes in CPR or first aid if they are working with the public... and don't you want the person caring for your child to have those skills? Maybe you have another child in karate or some other class... are the staff their looking for extra cash and willing to offer respite? Talk to the director of the program and see if any of the staff are interested.

We have also become part of a larger network in our community of families who have children with disabilities and we frequently share names of young persons who we rely on for respite services. Some of our best care providers are young teens who happen to be siblings to other young teens who have a disability. Another area we have found to be invaluable is Alex himself.... He has been in a "Life Skills" class since he started high school which has 'normal' students paired with the disabled students. The students work together to 'teach' specific areas of the curriculum targeting life skills. It is a great learning experience for both sets of students—and yet another area we can find some great respite care providers!!

As the school year starts and you are getting the school personnel ready to work with your child, don't forget about **you** as the parent! Look for potential respite service providers; allow siblings time with their friends without having to worry about their brother or sister with PWS; plan a night out for you and your spouse; and just take some time to re-group!! As the saying goes in our house, "If Mama ain't happy, ain't **NOBODY** happy!!" So take some time for yourself—and get HAPPY!!

Wishing you all a quiet, productive school year!!
Mary Lynn

PWSA of WI, Inc.

CANDIDATE APPLICATION - 2009

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Email: _____

Date of Application: _____

Are you a member of PWSA of WI, Inc. _____ Yes _____ No

Position You Are Interested In Running for:

- _____ President (2 year term)
- _____ Secretary (2 year term)
- _____ Board Member (2 year term)

Tell us briefly about yourself and the strengths or skills you feel you are bringing to this position? (We will be using this information as your bio to inform the membership of your interest, background and qualifications)

Please return this form to:

PWSA of WI, Inc.
 2701 N. Alexander St.
 Appleton, WI 54911-2312
 Toll free: 1-866-797-2947
 Email: Wisconsin@pwsaofwi.org

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CALL FOR NOMINATIONS 2009 OFFICERS & BOARD MEMBER - PWSA of Wisconsin, Inc.

PWSA of WI, Inc is once again looking for dedicated individuals to serve in the following roles for a 2 year term of office. If you have any questions regarding these roles or responsibilities, feel free to contact the PWSA of WI, Inc office or any current officer or board member.

The PRESIDENT is the principal officer of the organization and presides at meetings of the organization's membership. This officer communicates to the association such matters and makes such suggestions that may in his/her opinion tend to promote the welfare and increase the usefulness of the association, and shall perform such other duties as are necessary incident to the office of president. The president serves as a member of the Chapter Advisory Board for the Prader-Willi Syndrome Association (USA).

The SECRETARY has the responsibility to give notices, to keep a record of proceedings (minutes), to attest documents and perform such other duties as are usual for such an official as may be duly assigned.

The BOARD MEMBER serves as advisor in providing governance to the organization. He/she will assist in projects, committees and other capacities as needed.

What to Do ... When?

Please obtain and complete a candidate form. You can download this from our website: at www.pwsaofwi.org or call our office at the toll free number: 1-866-797-2947.

Submit completed form to the WI office by email or US mail **no later than October 2nd 2009**.

A ballot will be mailed to all primary members the week of October 5, 2009.

Return of all ballots are needed by November 9, 2009. Ballots will also be available at our annual membership meeting which will be held in Milwaukee. (exact time and location being determined).

Overview of Board Member

Responsibilities:

The following is a brief outline of some of the major events and activities that PWSA of WI, Inc. sponsors on an annual basis. We have outlined these activities so that board members and officers learn what activities they might choose from in their involvement with our organization.

BOARD MEETINGS: The board of directors meets 2-3 times a year. The meetings are typically in February, (early June as needed) and October. The exact dates, times and locations are determined at the previous meeting. We typically meet from 11 am to 3 pm. Every attempt is made to work around board members' preferences and location. We try to meet at a central location if possible.

BOARD MEMBER INVOLVEMENT: We encourage all board members to become involved in some way in at least one activity or project per year. The following is a list of our typical activities and projects. The dates and types of events are discussed and determined annually.

- **Annual Hobby Day, Social-Training Day:** This event typically occurs in the spring of the year. We have tried various approaches, activities and locations for this event. The primary focus has been hobby activities in the morning with a dance - social activity for children and adults with PWS in the afternoon. We also provide either a training or support opportunity for parents and/or professionals. The event is one day, however the planning and preparation goes on year-round.
- **Annual Charity Golf Benefit:** This event typically occurs in the late summer. It recently moved to Windwood of Watertown golf course in Watertown. The date has been dependent upon availability. Jackie Mallow has been the chairperson and she works with a committee of volunteers. All board members are asked to obtain 2-3 hole sponsors, seek out door prizes and disseminate fliers and recruit golfers for the event. They are also expected to attend/assist at the event if able.
- **Annual Training Workshop/Education Project:** PWSA of WI, Inc tries to sponsor some sort of training workshop or educational project on an annual basis. The topic, speakers and location vary. In the past,

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some board members have been speakers, worked at the registration table or assisted in other ways. As an alternative, we may choose to do an education and/or awareness project. A board member may be willing to offer their expertise in some aspect of a project.

- **PWSA of WI, Inc. Newsletter – The Wisconsin Connection:** The newsletter is published and distributed 4 times a year. Currently the program director solicits articles, prepares layout and has it printed. We have a volunteer fold, secure, apply mailing labels and stamps and mail them out. Board members are encouraged to submit an article or help with any aspect of this.
- **Packet of Hope Program:** All genetics clinics in the State of Wisconsin have been given at least 5 copies of our Packets of Hope. On an annual basis, we make contact with each of them and replenish their supplies if needed. Packets need to be compiled and mailed. Any board member who may be interested in assisting with this can work with the program director to do so.
- **PWSA of WI, Inc.'s Annual Mail Fund Raiser:** Once a year, we conduct a mail fund raiser. This is typically in the late fall of the year. Currently the program director has created the letter and prepared them for mailing. Any board member (or volunteer) who is interested in any aspect of the creation of this annual mail fund raising letter is graciously appreciated. The program director assists with the production of labels and any other supplies that may be needed. (We are always looking for creative people!)
- **Annual Meeting for Parents of Young Children:** Over the past few years, PWSA of WI, Inc has sponsored an annual meeting specifically for parents of young children with PWS. Any board members or parents of young children who are interested can help in the planning and arrangements for this event.

If you have any questions or concerns about nominating someone or potentially running for a position for Officer or Board Member: do not hesitate to contact any of our current Board Members or the state office.

Mark Your Calendars!!

PWSA of WI, Inc. works on holding an educational training on a regular basis. We have a training planned for October 15, 2010 on many of the behavioral and medical challenges that we often have to deal with living with someone with PWS. We have Dr. Linda Gourash, renowned national and international speaker on PWS scheduled to be our key note speaker. We will keep you informed as things progress!

Handouts for Back to School

As school approaches, we work on getting all the professionals in school working with our child 'up to speed' on the unique needs of our child. In anticipation of this, Barb Dorn has put together a variety of handouts for school staff. There is one titled Back to School Checklist; which is for families to help get their child ready for the changes in schedule and routine. Another titled Info for School Staff is letting the variety of staff some of the unique issues our children face as well as strategies that are useful in assisting them. There is one titled Health Concerns which is found later in this newsletter. The last one is titled School Transportation which targets the bus driver, cab driver or bus aide who work on transporting your child to school. If you are interested in copies, they are available on the PWSA of WI, Inc. web site at www.pwsaofwi.org or you can contact the office at 1-866-797-2947 to request copies.



Work Place Giving—

Remember PWSA of WI, Inc.

It is that time of year again, when many employers offer employees the opportunity to sign up for payroll deductions that will benefit the charity of their choice. Please make PWSA of WI, Inc. one of those charities. If you work for the State of Wisconsin, City of Madison, Madison Metropolitan School District, Madison Teachers Inc., Dane County, Monona School District, or Madison Area Technical College you can easily make this donation through the Combined Campaign or Partners in Giving Program. PWSA of WI, Inc is a member of the umbrella, Access to Community Services and we are listed as a recipient organization (#511). If you do not work for one of these organizations, you may still be able to list our organization in the "donor choice" area. In most cases, all you need to do is to list PWSA of WI, Inc along with our address – 2701 N. Alexander St., Appleton, WI 54911. Also, check the box that you would like to be notified by the organization. This is an assurance that your donation has reached us. Thanks to the generosity of our members, their families and friends, PWSA of WI, Inc has been able to receive donations from many work place campaigns. If you have any questions, please feel free to contact our office. Your generosity counts in helping us to continue our support, education and advocacy efforts.

Health Concerns and the Student w/ Prader-Willi Syndrome - Information for School Staff

The student with Prader-Willi syndrome (PWS) may experience some unique health issues. It is important for school staff to be aware of these issues to help ensure that the student has a safe, healthy educational experience. Health concerns and some strategies are summarized below.

Health Concern	Strategies
<p>Altered Pain Threshold – Decreased Pain Sensitivity/High Pain Threshold <i>Pain may be diminished or absent - even in severe injuries. Fatigue or irritability may be a sign of illness. Increased bruising & swelling is common.</i></p>	<p>All injuries should be assessed by an adult. Report all injuries or changes in behavior to the parent or caregiver. Elevate and apply ice to injuries as needed. Student may require examination by a physician to rule out fracture or other health problem.</p>
<p>Altered Temperature Regulation <i>Common to see unexplained high and low temperatures Little or no fever may be present with illness. Often experience low tolerance to high or low outside temperatures.</i></p>	<p>Limit time outdoors during very warm and/or humid temperatures. If extreme redness of the face and sweating is noted, remove to cool area; encourage cool water and/or utilize cooling measures. In colder climates make sure student is appropriately dressed and limit exposure to cold temperatures. If illness is suspected, notify parent.</p>
<p>Increased Food Drive/Food Seeking/Low Metabolism <i>Because of hypothalamic abnormality, students with PWS do not register the feeling of fullness. There is varying degrees of food seeking. Many sneak and/or steal food – are at great risk for choking. Gain weight on ½ calories of other students; require calorie restricted diet & supervision around all food.</i></p>	<p>Receive/follow prescription from health professional for calorie-restricted diet. Supervise student around all food sources. Keep food out of sight. Avoid use of food in classroom activities or as reward. Promptly empty garbage cans that contain discarded food. Train staff in the Heimlich maneuver. Have plan for how to handle food treats & other food issues in the classroom.</p>
<p>Osteoporosis <i>High risk due to hormone abnormalities & dietary limitations.</i></p>	<p>At high risk for fracture – assess injuries for possible sprain/fracture. May require x-ray to rule out fracture.</p>
<p>Daytime Sleepiness <i>Common to see in students. Often symptom of sleep apnea. May be result of weak chest muscles-poor air exchange.</i></p>	<p>Physical therapy evaluation for muscle strengthening. Get student up and moving if fatigue is noted. May require a rest time during the school day. Communicate problem to parent & health care provider.</p>
<p>Strabismus <i>Often seen in younger students. Poor muscle tone/control in eyes Glasses, patching and in some cases surgery is needed.</i></p>	<p>Look for signs during vision screening. Refer to eye specialist if needed Make sure students wears glasses and/or patches if needed.</p>
<p>Skin Picking <i>Common problematic behavior seen in students of all ages. Open sores common. May pick at various openings of body</i></p>	<p>Provide diversion activities – keep hands busy. Encourage liberal application of lotion. Incentive program often needed to keep wound covered. Teach self care of wound if able. Monitor frequent trips to bathroom. Set time limits; supervise in bathroom if needed.</p>
<p>Behavior – Emotional Problems <i>Students with PWS have problems regulating their emotions. Most do not handle change well. Some exhibit obsessive-compulsive tendencies, exaggerated emotional responses and extreme anger. Some take medications to assist with mood stabilization.</i></p>	<p>Minimize changes. When they do occur – prepare if possible. Teach ways to appropriately share feelings and emotions. Practice and reinforce these strategies frequently. State behavior you want to see. Avoid using word “don’t”. Make sure to administer medications at the appropriate times.</p>
<p>Severe Stomach Illness – Lack of Vomiting <i>Severe stomach illness has been noted in students who have had a binge eating episode. Symptoms: abdominal bloating, vomiting, pain may or may not be present, general feeling of not feeling well. Rare for a person with PWS to vomit.</i></p>	<p>If symptoms of stomach illness are present, notify parent. Student should be urgently evaluated by a health care professional. Report any incidence of vomiting to the parent. Encourage the student to share honestly if they have had a binge episode. The student should not be punished if this has occurred.</p>
<p>Increased Sensitivity to Medications <i>More sensitive to medications causing sedation or sleepiness</i></p>	<p>Be aware of all medications that student is taking. Report any problems to parents.</p>
<p>Scoliosis and Other Spine Problems <i>Common to see scoliosis/other spine deformities in students’ w/PWS. Often difficult to detect if obese. May require bracing.</i></p>	<p>If found, refer to orthopedic specialist. Support and assist if brace is needed. Adaptive measures may be needed for physical education. Physical therapy evaluation for muscle strengthening.</p>
<p>Dental Problems – Dry Mouth <i>Common problems: thick, sticky saliva, teeth grinding, rumination and cavities</i></p>	<p>Teach and encourage good dental care and water. Assist in referral to dentist if needed.</p>

PWSA of WI, Inc.'s Event Calendar

Fall 2009	Board meeting Mtg of Parents of young children w/ PWS	
Spring 2010	Spring social	
Late summer 2010	10th Annual Golf Benefit	Windwood of Watertown
October 15, 2010	PWSA of WI, Inc.'s Behavior Training	

Prader-Willi Syndrome Association of WI, Inc.

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NEW Web site: www.pwsaofwi.org

