



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*

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Vice President: Don Dorn

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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: Crystal Boser

Let me start by saying I cannot believe it is September already!! Clearly the saying, "Time flies when you're having fun" is true!! And the Board of Directors, staff, and volunteers of the organization have definitely been having fun planning and hosting a variety of events throughout the year. Our most recent event, the 13th Annual Golf Benefit, was held at the wonderful Windwood of Watertown golf course. The weather was beautiful, the smiles were plentiful, and the amazing gift of giving was in abundance. This year the 4th and 7th place teams, who both won prize money, voted unanimously to donate their team winnings back to PWSA of WI, Inc.; generous supporter, Dave Nagy of Oconomowoc Residential Programs once again helped sponsor several golfers so they could participate in the event; and Barb & Don Dorn secured numerous golf teams and hole sponsors. Without the immense generosity of these individuals, our event would not be as successful as it is. Thank you Dave, Barb, Don, and everyone else who participated in or donated items to this event!! Make sure to mark August 23rd, 2014 on your calendars now so you can join us at next year's event.

Although the organization has been having a great time working hard to improve the lives of individuals with PWS and their families, we are sad to announce that an important member of our team will be leaving us. In August, our Assistant Program Director Melodee Luening decided to leave her position in order to concentrate more on her family. Melodee spent many, many hours planning the Snowflake Ball and OTM walk-a-thon events in addition to helping support the organization in numerous ways. Thank you, Melodee, for all of your hard work and dedication throughout the years! You will be missed immeasurably!! In order to continue to move our organization forward, PWSA-WI is planning to restructure the office to best meet the numerous tasks and responsibilities set forth by our association. Stay tuned as we move forward with our support, education and advocacy efforts, as it takes a community to move mountains. Together we accomplish more!

Crystal L. Boser

PWSA of WI, Inc.'s 13th Annual Golf Benefit

Once again, the weather cooperated with us and we had an absolutely beautiful day for our event!



We had 35 teams registered, 135 golfers, and 45 Hole Sponsors!! We continue to be amazed at the generosity of those of

you who support us! We saw LOTS of familiar faces and quite a few new ones, and we remain grateful to all of you!



Once golfing was completed, our teams came back to the clubhouse and enjoyed a luncheon, prizes and a chance to bid on

some great items from our Silent Auction! We had a wide range of sports items, gift certificates, hotel/trip packages and so much more. If you have a chance, take a minute to review our



donor list and thank our donors for their generosity! We could

not do it without them! Many of our cash prize winners even donated their cash prizes back to the organization! We cannot thank you enough for making this event a success!

We also need to thank our golf committee for all the time and effort they put into making this a great—and successful

event! I know they work on this event ALL year long!!



THANK YOU TO OUR HOLE SPONSORS:

Pantheon Industries
Prader-Willi Homes of Oconomowoc
Hughes Dental Clinic
CGC, Inc.
Larry, Lori & Tom Abler
Independent Printing Co., Inc.
RD Image, LLC
Sedona Smiles
Al & Kathleen Luening, Sr.
Genesee Lake School
Waggin Tails Dog Spa
Satko Oral Surgery—Western Springs, IL
Tosa Pediatrics
Riegel Law, S.C.
The Ignatowski family
Constantine Stamatelakys DDS—
Periodontics & Implant Services—Greenfield,

In honor of Jean Burke—George & Mary Hayes
In honor of Addy Pogrart—Love Mom & Dad
In honor of Addy Pogrart—Appleton Control Systems
In honor of Tony Dorn—Dick & Jayne Becker
In honor of Katie Scheidegger—Tom, Judy, Maggie, & Jeff Scheidegger
In honor of Martha Lehman—Love Mom & Dad
In honor of Tony Dorn—Cynthia & Greg Heinemann
In honor of Beth LaBella—The LaBella Family
In honor of Tony Dorn—Tyler Dorn
In honor of Dave Nagy—Friend of PWHO
In honor of Beth LaBella—The Ausick family
In honor of Tony Dorn—Dick & Jayne Becker
In honor of Jim Jones—Love Dad
In memory of Ann Burlingame
In honor of Tony Dorn—Leslie & Brodie Hall
In honor of Tony Dorn—Dan & Shirley Kealey
In honor of Sarah Hughes—Detlef & Rochelle Moore
In honor of Tony Dorn—Larry & Mary Dall
In honor of Tony Dorn—John Rockenbach
In honor of Teresa Bacigalupo—Love Dad
In honor of Tony Dorn—Love Mom & Dad
In honor of Katherine C. Baker—Sam & Diana Baker
In honor of Tony Dorn—Laurie Grinnell & Mark Dorn
In honor of Alex & Matthew—Mike & Mary Lynn Larson
In honor of Tony Dorn—"Westridge Friends"
In honor of Tony Dorn—Grall, Hazzard, Boebel, Bryant & Schneider Families
In honor of Tony Dorn—Opsal, Leonard, Bryan & Jim Becker & Bramson Families
In honor of Sophie Coggeshall—Love Mom & Dad
In honor of Tony Dorn—Collentine, Cahill, Espie & Koerner Families

THANK YOU TO OUR GENEROUS DONORS!!

Thomas Hughes, DDS	Don & Barb Dorn family	Pizza Hut
Milwaukee Wave	Wisconsin Hospitality Group	Al & Melodee Luening
Richfield Napa	Papa Murphy's	John & Bobbi Pogrart
Green Bay Packers	Mike Hassler Art & Scenes	Milwaukee Bucks
Kelley Benson	Wigwam Mills	Dave Nagy
Wines for Humanity	John & Candace Lipski	Outerwall Redbox
Saz's Catering	Tina Kroepflin	Panera Bread
Bruce & Jackie Mallow family	Touch of Class Hairstyling	The Club Tap
Windwood of Watertown	Pantheon Industries	Shedd Aquarium
Xpression by Peggy	Mike & Mary Lynn Larson	Walt Disney World
Clint & Crystal Boser	Sheild Family Dentistry	TJ Maxx
Nancy Burlingame	Bob & Marge Miller	Build A Bear
Milwaukee County Zoo	CVS Pharmacy	Cheese Cake Factory
Buffalo Phil's Pizza	Tabitha Kukes	Kapco Inc.
Moosejaw Pizza	Eve Boutique	Roger Pumphrey
Joseph & Mary Elaine Gareau	Napa Auto Parts	Melanie Ignatowski
Goebel Woodwork, Inc.	Lebanon Sport Haus	Dennis Schultz
Turner Hall—Watertown	Mike Fitzgerald	Bryan & Jessie Becker
Jim & Janice Becker	YMCA of Ozaukee	Dave & Carol Hirn
Milwaukee Admirals	Bits & Pieces	Steve & Debra Boebel
Mike Collentine	Heidi Luebke	
Cathy Hazzard	Jerry Koerner	
Jean & Joe Van Tuyle	Anonymous	
Joan Lohneis	Thomas Grall	
Jim's Septic Service	Thomas Conlin	
Jim & Mary Schneider	Festa! Italiana	
Bruce & Cindy Opsal	Wayne Bryant	
Marilyn Klingele	Pamela Hansen	
John Ziegelhagen	Ken Leonard	
John & Barbara Cahill	Ed Talbott	
Todd & Jerilyn Bramson	Jason Parsell	
Enterprise Services, Inc.	John Espie	
Prader-Willi Homes of Oconomowoc		
Lake of the Torches—Resort & Casino		
John & Marguerite Rupnow family		
Rachel Pipp—Pashion for Fashion		
Dr. Nicolette Weisensel, MD		

***Save the date next year August 23,
2014 Hope to see you there!***



Changes in the Bylaws

In July, the PWSA of WI, Inc. Board of Directors sent out a letter and ballot to the membership asking for a vote on the proposed changes to our bylaws:

1. Free membership to anyone requesting it; and
2. Eliminating term limits for the President and Vice President positions.

As an organization, we feel everyone should have the most current information about this syndrome. We keep our membership aware of the latest information about the syndrome many times through our newsletter. There is currently a fee for membership which may limit some individual's access to this information. We proposed that membership be free to anyone requesting it. The membership voted in agreement to this change.

The bylaws read that the president and/or vice president shall not assume his/her position for more than 2 consecutive terms. No other term limits are in place. This becomes an issue as we do not have a lot of people willing to take on these roles and many times we alternate between a few persons who are willing to fill the positions. We proposed that the term limits of 2 consecutive terms for both the President and Vice President be eliminated. The membership voted in agreement to this change also. Thank you to our membership for responding in a timely manner to this issue.



REMINDER: ELECTIONS

Please remember to return your election ballots to the office by October 11, 2013!!

PWSA(USA) 'SCHOOL TIMES' E-LETTER

Have you seen the new resource put out by PWSA (USA)? It is an e-letter called *School Times*—all about PWS school-related issues!! The first one came out in August. It will be published bi-monthly by PWSA (USA) and is the first publication to focus solely on school issues for the PWS community! It will feature topics like Special Education Advocacy, Special Education Law, Discipline, and have guest expert columns on things like behavior management and SO MUCH MORE! To sign up, contact Evan Farrar at cic3@pwsausa.org

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

Notes from the Office.....

By Mary Lynn Larson

Things remain hectic here in the PWSA of WI, Inc. office/Larson household! And, yes, I realize I say that most times—but it is always so very true! Both boys have started off the school year with success! Read about Alex's last year of high school where he is participating in Project SEARCH (you will find it later in the newsletter). Matthew is in 8th grade this year but he is more focused on moving onto high school... He thinks he can 'date' once he gets in high school but that is another story!

In the office, we have had another successful golf benefit! Thanks so much to everyone who came to golf, donated items, worked at the event or assisted in any way! We could never pull off an event this large without your assist! Please be sure to review the list of donors and if you are able, THANK them personally for their generous support!

We had to cancel our "Lunch and Learn" event in Appleton scheduled for Monday, September 16, 2013. We felt we could not justify our two speakers' travel, time and effort for the limited number of registrations we had received. We know the topic, "Nutritional Management of Common Health Issues Seen in Persons with Prader-Willi Syndrome" was one that many of you are/were interested in—and we are sorry! This is the second of three scheduled "Lunch and Learn" training events planned that we

have had to cancel... (we also cancelled the April 2013 training scheduled in Oconomowoc). We are struggling with how best to serve our membership/families with trainings. We try to alternate our events from occurring during the week or on a weekend so that we can get both families and professionals to attend. We target topics which have been suggested by families and/or professionals. We try to host them throughout the state so we can reach everyone... but we are feeling frustrated that low attendance continues to occur. We are hoping the membership can assist us with trying to figure out how to best serve them through training events. Feel free to share your thoughts and ideas via email at: Wisconsin@pwsaofwi.org or call the office at 1-866-797-2947.

The office is currently in a transition mode - so please bear with us. Melodee has left her position as Assistant Program Director last month to devote more time and energy to her family. We want to thank Melodee (—and her family) for everything she and they have done for the organization over the last 6 years! She **promises** she will still be involved as much as life allows. This means I will be doing a lot of everything over the next few months while we try to figure out what direction this will take the organization. Be aware that I may need reminders on things as if I don't write things down, I forget! If I do not return contacts you have made via phone or email in a timely manner... please be patient—but do not be hesitant to make the contact again if I have not responded within a day or two.

So, what can you do to help us during this transition period? First off, if you happen to have some spare time or skills that might be of benefit to us and are willing to volunteer—feel free to give me a call or shoot me an email!! There are *always* projects that we have going that we could use assist with... it might be stuffing and labeling envelopes, pulling brochures and information together for outgoing folders, helping with the Card Club, or helping to organize with an upcoming event! Let us know.

Mary Lynn



Holiday-Birthday Special Assistance Program

No matter what age, we all like to celebrate and feel special during the holidays and on our birthday. Whether it is Christmas, Hanukkah, Kwanza, or a birthday – no one should ever feel alone and not have a gift or card to open.

As adults with PWS are aging, many of them are outliving their parents and/or family members. Some have no close friends to provide them with a gift or card on these spe-

cial occasions. There are fewer resources for care providers to provide gifts and/or funds for special celebrations. Programs and resources such as Toys for Tots, faith-based organizations, churches and holiday giving trees often provide assistance for children and families. There are few if any to assist aging adults with PWS who may be left alone.

PWSA of WI, Inc. has created a program to reach out to adults with PWS who are 18 years or older who no longer have family to help them celebrate holiday or birthday events. This is a new program that attempts to make all adults with PWS feel special and be able to continue to have special memories and gifts – no matter what their age.

Who Can Participate?

- Any adult with PWS 18 years or older who no longer has family members or friends who can provide them with a present, card or some sort of gift for a holiday or birthday celebration.

- The adult with PWS must reside in Wisconsin. If children with PWS 17 years and younger need assistance, a family member or responsible adult should contact PWSA of WI, Inc. to check on assistance through our General Assistance Fund.

How Many Times Can One Person Participate in One Year?

An adult with PWS can participate 2 times in one year for this program - one holiday and one birthday request per year.

What Needs to be Done to Participate?

- A responsible adult – case manager, home manager ... can request, complete and submit an application.
- The adult with PWS cannot complete the application but can assist a responsible adult in doing so.
- ONE application should be submitted for each holiday or birthday request unless the holiday and birthday fall on the same date.
- The responsible adult will be informed within 10 days of PWSA of WI, Inc. staff receiving the application.

The application will be reviewed by a committee comprised of at least 1 staff member and 2-3 board members.

What Sort of Gifts Can a Person Receive? How Does this Work?

- The responsible adult will be sent a gift card which can either be used to purchase gift items or be given as the gift itself.
- A \$50 gift card will be awarded as a holiday gift.
- A \$25 gift card will be awarded as a birthday gift.

What Needs to Be Done After Receiving the Gift?

- A thank you note should be sent to PWSA of WI, Inc. acknowledging the receipt of the gift(s) within 30 days of the holiday or birthday. If this does not take place, no further assistance will be provided.

PWSA of WI, Inc. wants assurance that the adult with PWS has received the gift card or gifts. (Photos would be wonderful).

This application is for ONE holiday or birthday request. A separate application should be submitted unless the holiday and birthday fall on the same date.



(Continued)



Project SEARCH

By Mary Lynn Larson

Our oldest son, Alex has been offered a unique opportunity for his last year of high school. A group of community partners joined together and initiated Project SEARCH within the Appleton community. These partners include St. Elizabeth Hospital; Wisconsin Department of Workforce Development; Appleton Area School District; Valley Packaging Industries, Inc.; and Community Care. Project SEARCH was developed in 1996 by Nurse J. Erin Riehle, then the Director of the Emergency Department at Cincinnati Children's Hospital Medical Center. As the flagship program, Cincinnati Children's Hospital provides technical assistance for replication and overall leadership to Project SEARCH worldwide.

The Project SEARCH High School Transition Program is a unique, business led, one year school-to-work program that takes place entirely at the workplace. Total workplace immersion facilitates a seamless combination of classroom instruction, career exploration, and hands-on job-skills training through strategically designed internships. The goal for each student participant is competitive employment. The program provides real-life work experience combined with training in employability and independent living skills to help youths with significant disabilities make successful transitions from school to productive adult life. The Project SEARCH model involves an extensive period of training and career exploration, innovative adaptations, long-term job coaching, and continuous feedback from teachers, job coaches, and employers. As a result, at the completion of the training program, students with significant intellectual disabilities are employed in nontraditional, complex and rewarding jobs. The presence of a Project SEARCH High School Transition Program can bring about long-term changes in business culture that have far-reaching positive effects on attitudes about hiring people with disabilities and the range of jobs in which they can be successful.

Project SEARCH serves students with significant intellectual and developmental disabilities. Typically these are students who are on an Individual Education Program (IEP) and in their last year of high school eligibility. The most important criterion for ac-

ceptance into Project SEARCH is a desire to achieve competitive employment.

Students attend the program for a full school year in the host business/hospital. The business provides access to an on-site classroom that can accommodate up to 12 students. The site is staffed by a special education teacher and one to three job coaches to meet the educational and training needs of the students.

The first few weeks of the program are focused on new employee orientation, hands-on skill assessment and familiarization to a business environment. As the year progresses, the students work on employability and functional skills during the classroom time focusing on a wide range of topics including team building, interviewing, workplace safety, social skills, money management, job search skills and keeping a job. The students will be enrolled in three targeted internships where they will acquire competitive, marketable, transferable skills to enable them to apply for related positions. Students are required to interact with their supervisors via telephone and written communications to arrange a job interview to secure each rotation. A department mentor is identified at each site. The mentor interacts with the instructor, job coaches, and the student as a consistent source of guidance and feedback. Students spend approximately five hours each day at the internships including a 30 minute lunch. Working from a task list, they acquire the core skills necessary to be hired in an entry-level position at the host business site or in the community. Job coaches and department staff collaborate to provide support for students. The Project SEARCH staff delivers the training and develops job accommodations and standard work procedures. Once the students master the core skills, additional skills are layered on to improve their marketability.

During the last few months of the program, emphasis is on refining skills, achieving the career goal, and carrying out individualized job placement. The Vocational Rehabilitation Counselor becomes an even more important part of the team as the job search process begins. Job development and placement occurs based on the student's experiences, strengths, and skills. Linkages to appropriate services in the community are critical at this stage, as students prepare to graduate from the program, to ensure a successful transition to employment and adult life. Services are identified in the community that provide assistance with necessary adaptations required to perform a specific job, job coaching, and long-term follow along are arranged usually through the local Developmental Disability organization. Upon satisfactory completion of the program (95% or better attendance, good attitude, successful skill acquisition

at each job site) students receive a Career Portfolio. The contents of the packet will vary among replicated program sites, but generally the packets contain a resume, letters of recommendation, a competency profile, any awards or special recognition received while in the program.

To date, this has been a GREAT program for Alex! He takes the city bus to and from the hospital. The students went through a day where they worked with one of the staff on community transit specifics. Alex takes a bus which several of his peers ride so they watch out for one another. I was initially concerned about the patient confidentiality part—but Alex has proven he understands it! One night, Mike's sister was over visiting and mentioned one of her coworkers had seen and chatted briefly with Alex in the halls while she was at the hospital visiting a patient... Later I asked him, "Did you see Kristy at the hospital today?" He replied, "Mom, you know I can't tell you that!"

I was able to meet with the entire Project SEARCH staff prior to the start of the school year and shared with them the specifics of PWS and how it presents in Alex. We discussed issues that may be of concern (things like interning in the cafeteria and access to areas containing food items or money) as well as provided them with suggestions on how to handle some of the potential issues related to rigidity, inflexibility and misperception of what is being conveyed. As the school year has progressed, we have maintained regular contact over various topics and things are going well! Alex starts his first work/job rotation next week and is very excited! He told me this morning that he is working on being 'flexible'. "I have the last lunch period of the entire group because of the department I will be working in! No one else has it as late as me, I am being flexible!" he explained with a grin! We will keep you informed how things go as the year progresses!

To learn more about the Project SEARCH program, go to their web site at: <http://www.projectsearch.us/>

Like us on Facebook at
[www.facebook.com/](http://www.facebook.com/PWSAofWI)
PWSAofWI

MEMBERS, WE NEED YOUR HELP...

We get many calls in the office and often times, families are often looking for experienced physicians or other related health care professionals who might have some familiarity and knowledge of treating persons with Prader-Willi syndrome. We all know that we will have to educate our physicians and health care professionals on how PWS might specifically affect our loved one, but if that professional already knows some of the basics of PWS—that is a bonus! They may have had previous experience with individuals with PWS years prior—and that may make them willing to take on our loved one as a patient!

We are hoping you can share with us names and contact information of any physicians or other related health care professionals who are familiar with PWS and who you recommend to others who have loved ones with PWS. Because we are a state organization, I would love to have names of medical professionals all over the state... Many of our families report they are willing to travel - especially if the physician/health care professional is familiar with some of the idiosyncrasies of the syndrome. With the insurance regulations being put into place, we are always looking for names—especially for mental health care providers!! Please feel free to shoot me an email or call me on the toll free number to share contact information.

Email: Wisconsin@pwsaofwi.org
 Toll free: 1-866-797-2947

PWSA of WI, Inc.'s Event Calendar

September 16, 2013	Nutritional Management of Common Health Issues Seen in Persons w/ PWS Lunch and Learn	First English Lutheran Church – North site 6331 N. Ballard Rd Appleton, WI
November 7-9, 2013	PWSA (USA) National Conference	Buena Vista Palace Hotel, Orlando FL
January 2014	PWSA of WI, Inc. Winter Ball	
August 23, 2014	PWSA of WI, Inc. 14th Golf Benefit	Windwood of Water- town Golf Course Watertown, WI



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