



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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Treasurer: Tom Hughes

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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

As I write this I am reminded that fall is fast upon us as the wind is whipping outside, the temperature is hovering around 62 degrees, the kids are back in school and college football is playing on the television. The summer has now come and gone with our organization remaining busy throughout it all.

On August 27th, PWSA-WI, Inc held its 11th Annual Golf Benefit at the lovely Windwood of Watertown golf course. Contrary to today, there were blue skies, a light wind and moderately warm yet not too hot weather. The golfers enjoyed 18 holes of golf followed by a wonderful lunch, a silent auction and everyone left with a nice door prize. I am excited to announce that due to the amazing turn out of this event each year we will be moving to the upper level of the club house which means more room to accommodate even more golfers. Make sure to mark August 25th, 2012 on your calendars now so you can plan to join us next year. Thank you to everyone who participated in or donated items to the event!!

Some members of our organization have also been busy throughout the summer working with the people at PWSA (USA) in preparation for the upcoming 31st National Conference being held in Orlando, Florida. The conference is being held at the Buena Vista Palace Hotel November 11th-13th and is channeling the "Survivor" theme from the popular show of the same name. In addition to the general conference there will also be a Youth & Adult Program, Youth & Infant Program and a Siblings Program. If you are interested in attending this event please visit <http://www.pwsausa.org/> for more information. Please keep in mind that PWSA of WI, Inc. does offer scholarships to assist in covering a portion of the costs to attend conference. For more information about this option please visit the PWSA of WI, Inc. website at <http://www.pwsaofwi.org/>.

Within the next few weeks we will be holding our annual board member elections and we are currently looking for 2 board members to fill open positions. Since many of the current board members have served in one capacity or another throughout the years we would love to see some new additions. If you are interested in running for one of the open positions please feel free to visit the website or contact our Program Director, Mary Lynn Larson.

Have a wonderful fall and hopefully I'll see you in November at the conference.

Crystal

PWSA of WI, Inc.'s 2011 Golf Benefit

By Mary Lynn Larson

Saturday, August 27th was a picture perfect day! The sun was shining and friends were all around at the 11th Annual



PWSA of WI Golf Benefit! We had a record number of golfers participate and many friends present to join the fun! It was great to see established friends and

meet new ones after not having been able to attend the Golf Benefit last year! (And many thanks to you who offered me sun screen... you were all very kind!) The Windwood of Watertown Golf Course was a great venue for our benefit, as usual! Thanks to the staff at Windwood for all their help and support! We also need to



say a BIG Thank You to our friends and families for their continued strong support by donating prizes, cash, time and funding. You can see a list of all our donors on the next page. We had 42 Hole Sponsors this year. A listing of all those who were Hole Sponsors is

also listed on the next page. We continue to be amazed at all you do for our organization!

We had an opportunity to win a prize package of golf clubs and other items on the 14th hole. Many of our golfers were very generous in donating to participate in their chance to win. It was won by John Lipski! Our congratulations to John!



After the 18 holes of golf, the participants had an opportunity to come inside for a luncheon and prizes! What a great day!!



PWSA of WI, Inc. 2011 Golf Outing Prize Donors

Dave & Carol Hirn	Susan Morris
John & Pat LaBella	KAPCO, Inc.
Don & Barb Dorn Family	Pizza Hut
Mike Hassler Art & Scenes	Erin Norris
Thomas J. Hughes, DDS	Milwaukee Wave
YMCA—Keelyn Lyon	Papa Murphy's
Al & Melodee Luening	Green Bay Packers
Pantheon Industries Inc.	Barbara Ausick
Milwaukee Bucks	Kelley Benson
Dave & Sandy Nagy	Wigwam Mills Inc.
John & Candace Lipki	Milwaukee Brewers
Racine Danish Kringle	Applebee's
Thomas & Sandra Grall	Bob & Marge Miller
Charle & Gisele Harvey	Melanie Ignatowski
Alice & Wayne Bryant	Berres Brothers
Jerry & Penny Koerner	James & Judy Dorn
Westridge Neighbors	Festa! Italiana
Joe & Elaine Gareau	Nancy Burlingame
Xpression by Peggy	Greg Wegner
Clint & Crystal Boser	Frank Hilscher
Milwaukee Admirals	Dennis Schultz
Goebel Woodwork Inc.	Andy Branski
James & Angela Romig	Sean Mlenar
Bill & Bernadette Townsend	
Welcome Home Bed & Breakfast	
Tina Kroeplin & Rick Schmid	
Amber DeGroot—Thirty One Gifts	
Wisconsin Hospitality Group	
Tailgaters Sports Bar & Grill	
John & Marguerite Rupnow Family	
Prader-Willi Homes of Oconomowoc	
Lake of the Torches—Resort & Casino	
Mike & Mary Lynn Larson	
Bruce & Jackie Mallow Family	
Windwood of Watertown	
Bartolotta Restaurants	

PWSA of WI, Inc. 2011 Golf Outing Hole Sponsors

Dan & Shirley Kealey	Tosa Pediatrics
Fauerbach Automotive	Riegel Law, S.C.
CSI Testing, Inc.	James Jones
Westridge Friends	CGC, Inc.
Detlaf Moore & Rochelle Bast	
The Ignatowski Family	
Larry & Mary Dall	
John Rockenbach	
Waggin Tails Dog Spa	
Sam & Diane Baker	
Joe & Jen Reed Family	
Cathy Hazzard & Mary Schneider	
KAPCO, Inc.	
Dick & Jayne Becker Family	
Don & Barb Dorn	
Women's International Pharmacy	
John & Pat LaBella	
Laurence & Leslie Hall Family	
Sells Printing	
Richard M. Lofthouse Sr., DDS	
Mark Dorn & Laurie Grinnell	
Dayne Piehl at Hall Imports	
Prader-Willi Homes of Oconomowoc	
Pantheon Industries, Inc.	
Greg & Cynthia Heinemann Family	
Candy Ziegelbauer	
Friend of PWHO—Jayne Gierach	
R & R Insurance Services	
Satko Oral Surgery—Western Springs, IL	
Special Friends to the Dorn Family	
Mike & Mary Lynn Larson	
In Memory of Ann Burlingame	
The Ausick Family	
American Advantage Insurance	Stoecker & Assoc., Inc.
Oconomowoc Developmental Training Center, LLC	
Constantine Stamatelakys DDS —	
Periodontics and Implant Services Greefield, WI	

Notes from the Office.....

By Mary Lynn Larson

School has finally started in our district in the last few weeks (yeah!!) and, of course, my boys have been looking forward to it for quite a while! (Me too!) I can now focus more on events in the office rather than on planning summer activities for the boys! And things are getting busy!

We had a very successful golf benefit earlier this month. We appreciate all our donors and volunteers who helped make this another successful year! The money raised from the Golf Benefit supports the majority of our programs throughout the year. We would like to say a huge **Thank You** to our Golf Committee for all their time and effort to make this happen.

Now our plans are focusing on events in 2012. We have the Winter Ball in January and our Walkathon coming in May! The Winter Ball is a dance/social event to be held on January 28, 2012 in Oconomowoc. Not all the details are in place yet—but we are sure it will be filled with friends and fun! We will have more information mailed out to the membership as soon as we have more specifics.

The 2nd Annual PWSA (USA) *On the Move* Walkathon will happen on May 12, 2012 at Fowler Park in Oconomowoc. This is a national event with PWSA (USA) to raise awareness of Prader-Willi Syndrome and raise funds. We are looking for energetic walkers so get ready!! Our event this past year was a BLAST!! We will have a mailing out with more details on this after the first of the year.

We are also getting ready for Board elections. We are looking for people to fill the positions of President, Secretary and a Board of Directors position. The Board of Directors meets 3—4x a year and asks each Board member to work on one of our annual events. If anyone is interested in learning more about these opportunities, give me a call at the state office and I can send you more information about the duties and responsibilities of each position. Ballots will be mailed out in the next few weeks.

The PWSA (USA) National Conference is also coming soon. It will be held November 11—13, 2011 in Orlando Florida at the Buena Vista Palace Hotel. The National Conference is a time when families come together and can chat and learn from world renowned experts in Prader-Willi syndrome. It also allows you a chance to meet other families who are experiencing many things that people not living with PWS don't seem to understand. If you have not been to a National Conference, I would encourage you to attend. If you need financial assistance, PWSA of WI, Inc can offer support through our General Assistance fund. You can go to our web site at www.pwsaofwi.org or call me for a General Assistance fund application.

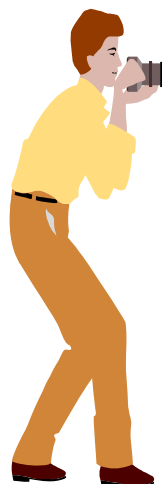
As the school year starts, if you are looking for resources to share with your child's teachers on PWS or experiencing challenges with staff, please contact me and I can share information addressing some of the concerns. We also have people available to do trainings for those working with your child. We want to make this a successful school year for all involved. If you ever just have questions or concerns, don't hesitate to contact us.

Happy Fall, **Mary Lynn**

Looking for photos....

Friends and families —

We are always looking for photos of loved ones with PWS. We are currently looking for photos of our older adults (aged 40 years or older) to be used in an educational presentation on aging issues with Prader-Willi syndrome.



You can email:
barbdorn@tds.net
 or send a hard copy to:
 Barb Dorn
 1017 Gateway Pass
 Verona, WI 53593

We LOVE our kids and it's time to share our JOY....

By Melodee Luening

Everyone has trying times. We've all felt the terror of a behavioral meltdown or the frustration of answering the same questions again and again, "When do I get to eat?" , "When is snack time?" However, when our kids shine they remind us that inside of our flawed selves, we are all deeply human. Regardless of condition, ability or drive, every person is an emotional and sometimes irrational being. That being said, it is this divine human spirit that can defy odds and overcome obstacles. Stories like these put the lump in our throats and cause us to smile, cheer and rejoice in the beautiful glow that is LIFE. Hard times pass leaving us with a renewed sense of what's really important. That's what we wish to share here.

Joy. Pass it on...

The Power of a Parent's Pride! Let's share our stories...

I'll start...

My daughter Olivia is 8 1/2 years old (in her words). She has been dancing for the last 3 years with a local German dance group. This has changed our whole family forever. Olivia has been dancing with a group of wonderful kids that welcomed her with open arms and made her feel apart of the team. Not only does she get to learn

a bit of her heritage and language with singing songs, she also gets to dance (exercise) and show off her beautiful smile on stage. We are, of course so proud of her, but most of all, she is proud of her self.

Olivia is a planner like most of



our kids, she has been watching every move the adults in the dance group do. She has made it known that she will be dancing one day with her instructors.

This has shown us that finding different and creative ways to get Olivia on a healthy path of life will provide her with a life long drive and sense of importance to dance (exercise) and feel proud of what she can accomplish throughout her lifetime. We are so proud of her dedication and the hard work she continues to show us.

Please share with us your stories of pride. It is a perfect way for all of us to be reminded of what our kids do to make us so proud. They are doing it everyday and we would love to share your stories!!

**Please send them to:
Wisconsin@pwsaofwi.org**

“Dapper Dean” – Still Going Strong at Age 60 Interview by Barb Dorn



Recently, I had the privilege of spending some time with Dean Plon – the oldest person with PWS that PWSA of WI, Inc has on record in their database. It was a joy and an honor being able to talk with him and reminisce about “old times”. Dean turned 60 years old on his last birthday. For the most part, Dean remains healthy and active. He is an engaging, bright man who is very willing to share his memories and experiences.

Dean and I talked a bit about baseball. For those of you who know me, baseball has become a personal and family favorite topic. Dean shared his memories of the Milwaukee Braves. He told me how sad he was when they moved to Atlanta. He talked about going to games at Milwaukee County Stadium. He told me he continues to be a Brewer fan however he still has a special place in his heart for the Braves.

I asked Dean what he is doing now that he is retired. He shared that he continues to attend a program at the Madison Area Rehabilitation Center (MARC). “On some days I still do a little work. On other days we get to go on trips – out for coffee and shopping”. Dean has been a volunteer at a voting site for years. In the last election, he got paid as well. I asked him if he likes his life these days and he smiled and said “yes”.

One thing he did share that has been hard is that both of his parents have died. He still has a guardian that helps him with decisions; however I could see on his face that this loss was something he still grieves.

About one year ago, Dean and his long-time housemate moved in to a different duplex where he continues to receive 24 hour support from the staff of Community Living Connections. Dean shared that he really likes this home better than his previous one and he is very pleased with the support and help he receives from his staff. Dean has always taken pride in contributing to making his home look nice. He has loved to mow the lawn in the summer and shovel the snow in the winter.

I have known Dean for many years. He may have a few more wrinkles but he still has that twinkle in his eye and a sense of humor that I hope will continue for many years to come.

...GETTING READY?



On The Move

The PWSA of WI, Inc. Second *On the Move* Walkathon and Awareness Event is scheduled for May 12, 2012 at Fowler Park in Oconomowoc, WI! We want you to start getting your teams ready, ‘cuz - we want to see you there!

CALL FOR NOMINATIONS 2011 OFFICERS & BOARD MEMBERS

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: President, Secretary and Board member. This commitment entails attending 3 Board meetings a year with support at Chapter events when able. There are occasional email communications as needed. We ask our Board members take an active role in one of our annual events as able. 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.

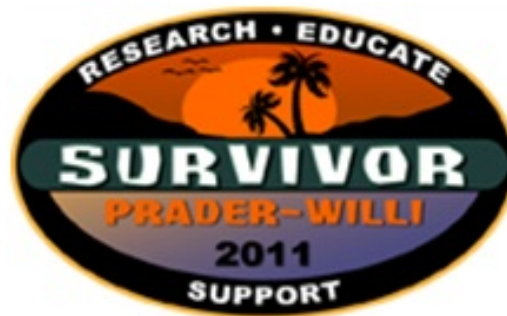
What to Do ... When?

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 1, 2011.**

A ballot will be mailed to all primary members the week of October 3, 2011.

Return of all ballots are needed by November 1, 2011.



PWSA(USA)

National Conference

November 11—13, 2011

Buena Vista Palace Hotel

Disneyworld, Florida

SIGN UP TODAY!!!

Registration is open!! Its filling up FAST! Check the PWSA (USA) web site for registration details. The general conference is November 12—13, 2011 and includes the Infant and Youth program (YIP), the Youth and Adult program (YAP), and the Siblings program. Unfortunately, at this time, the Youth and Adult Program (YAP) which supports children and adults age 8 and older is **full!** It filled up quickly as they accepted only the first 60 participants due to staffing. The YIP program is only accepting applications until October 25, 2011 or until it reaches its capacity.

Conference is such a unique experience for families of children with PWS... you're somewhere that the people around you "get it"!! All the struggles, joys and challenges of PWS—because they are living a life not unlike your own. Many previous attendees will tell you that your 1st conference is filled with a wide range of emotions, but it gives you all sorts of tools and strategies to hopefully, make life easier.

If you need assistance to attend conference, PWSA of WI, Inc. offers a variety of assistance to help. Contact Mary Lynn at the PWSA of WI, Inc. office via email at Wisconsin@pwsaofwi.org or call the toll free number 1-866-797-2947.

PWSA of WI, Inc.'s Event Calendar

November 11 – 13, 2011	PWSA (USA) National Conference	Buena Vista Palace Hotel, Orlando FL
January 28, 2012	PWSA of WI, Inc. Winter Ball	
May 12, 2012	PWSA of WI, Inc. 2nd Annual <i>On the Move</i> Walkathon	Fowler Park, Oconomowoc, WI
August 25, 2012	PWSA of WI, Inc.'s 12th Annual Golf Benefit	Windwood of Watertown Golf Course

Prader-Willi Syndrome Association of WI, Inc.

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