



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: Crystal Boser

Wow, half way through 2012 and PWSA-WI, Inc. has been busy helping to support, educate, and advocate for individuals with PWS and their families. In addition, we have been raising funds for both PWSA-WI and PWSA (USA).

On May 12th, PWSA-WI in conjunction with PWSA(USA) hosted our 2nd Annual *On the Move* walk-a-thon at Fowler Park in Oconomowoc. This year the weather was beautiful when almost 250 people participated in a 2-mile walk around the lake. Again, participants received a complimentary t-shirt, water bottle and had the chance to obtain an OTM tattoo. In addition, Prader-Willi Homes of Oconomowoc (PWHO) Art Club donated painted pots that were available in exchange for a donation to PWSA-WI. Several sponsors supported the event by providing us with a healthy lunch and drinks while our favorite DJ, Scott of Wileman Mobile DJ provided music. Thank you to everyone who participated or supported the event through donations/sponsorships. We couldn't have done it without you!! Remember to mark your calendars for next year's event on May 11, 2013.

We have also been hard at work planning the 12th Annual Golf Benefit, which is being held Saturday, August 25th at the Windwood of Watertown golf course. This event includes 18 holes of golf followed by a luncheon where hole prizes, goody bags, and door prizes are given out. A silent auction is open throughout the event with amazing items such as a Green Bay Packer Signature Football. I hope to see you all there; however, if you are not a golfer but still want to participate please feel free to sponsor a hole or donate an item to be used as a door prize or in the silent auction. Together with your help we can make this event a HUGE success.

We are working diligently on the upcoming November 3rd conference "**Planning for the Future –Strategies to Support our Children's Lifelong Needs**", which will be held in Appleton. This event will address various topics such as guardianship, wills, trusts, and possibly more. Childcare will be provided as well a continental breakfast and lunch. Continue reading for additional information on this event.

I would like to close this letter by announcing three new projects that are currently in the works. First, PWSA-WI is in the process of creating an exciting new Facebook page that will also utilize Pinterest as a way for Parents of Young Children to interact and support each other. If your child is 9 years of age or younger please keep an eye out for an official invite or check out our website periodically for more details. Second, PWSA-WI recently created a holiday and birthday assistance program to help individuals with PWS who do not have close family to provide gifts and/or funds for these special events. This program is different from our general assistance program and our camp scholarships so please feel free to contact the office if you are interested in more details. Lastly, I am proud to announce that I was recently asked to join a State Leader Team, which will primarily help other states grow stronger. It is our hope that eventually all 50 states will have a chapter that will help support, educate, and advocate for individuals with PWS. I am extremely honored to have been chosen to be part of this team and I will do my best to keep you all updated on our progress. Until next time....Crystal

Board of Directors:

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Second Annual On The Move Walkathon

Our Second Annual *On the Move* Walkathon and Awareness event was held on May 12, 2012 at Fowler Lake Park in Oconomowoc. We had **GREAT** weather and a **GREAT** response/turnout!! This



fundraiser is held in conjunction with PWSA (USA) and not only allows us to raise funds, but raise awareness as well!

We walked the 2 miles around Fowler Lake and then arrived

back to have lunch and dance or just listen to music from our favorite DJ!!

There were also decorated pots to purchase that the



PWHO Art Club donated to help us raise



funds! We can't begin to thank everyone who participated, but know:

We are forever grateful!!



THANKS to our On The Move Walkathon Sponsors!!

We would like to take this opportunity to say "Thank you!" to our sponsors for our Second Annual *On The Move* Walkathon for their support and generosity! Thanks to GFS, Kwik Trip, Piggly Wiggly, PWSA (USA), Prader-Willi Homes of Oconomowoc, and Nasco! They were kind enough to offer great discounts or donate items or services for the walk! We could not have achieved this level of success without their support!

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



Notes from the Office.....

By Mary Lynn Larson

Summer is here! In the Larson household that means getting ready for things like summer school (Matthew), summer camp (Matthew), summer job (Alex), helping with football practice (Alex) and going to the family cottage any chance we get!

In the office, it means a variety of other things: We are busy getting ready for our upcoming golf outing on August 25th at the Windwood of Watertown Golf Course! Do you, family, or friends golf? If you have not received our golf registration form and would like to join us, contact the office!! If you are not a golfer but have some connections with items for door prizes or our silent auction, contact the office!! If you just want to help, contact the office!! We can find you something to do!

We are also working on our upcoming conference “Planning for the Future—Strategies to Support our Children’s Life-long Needs” We will be holding this in Appleton and will have several speakers addressing issues like Wills, Trusts, Guardianship, Important Legal Documents to Have, as well as funding sources like SSI and SSDI. We will have care for youth and adults with PWS provided while family members are at the conference. Look for more information on our web site as we finalize things. If in your preparation for your loved one entering adulthood, you have come across issues or questions you wanted answered, let us know—as many of us have the same questions and we are hoping we can find the answers to some of them for you!

Mary Lynn



PWSA of WI, Inc.’s Annual Charity Golf Benefit Saturday, August 25th

We will be hosting our 12th Annual Golf Benefit on Saturday, August 25, 2012 at the Windwood of Watertown Golf Course. This is a great day of food, fun and friends—and we are in need of your help! The proceeds raised in this event help to maintain programs that assist persons with Prader-Willi syndrome as well as the persons who support them. We are always looking for golfers, hole sponsors and prize donations. Are you or your company willing to sponsor a hole? Hole sponsorships are \$125.00 and include donor recognition on the specific hole sponsored plus notice of your generosity on our donor board, in our statewide newsletter and on our website. The deadline for hole sponsorship is **August 19, 2012**. Golfers who register before July 1st will receive a free raffle ticket for our fourteenth hole drawing (a \$10 value). If you are unable to attend please consider sponsoring a hole for your business or in honor/memory of someone special. Silent auction and door prize donations are also needed and greatly appreciated. Corporate sponsorship provides a unique marketing opportunity and is available upon request.

Information is available on our web site at www.pwsaofwi.org. If you have any questions about the benefit or how you could help, call Mary Lynn at the office at 1-866-797-2947 or Jackie at 1-262-569-5515 ext. 2708.

Is There a Role for Psychopharmacology in Treating People with Prader-Willi syndrome?

On Wednesday, May 23, 2012, Dr. Ken Herrmann, M. D., a psychiatrist who works with many individuals with PWS addressed a group of family members and professionals at the Waisman Center on how science and medication might offer solutions to the challenges persons with



PWS may face. PWSA of WI would like to take this opportunity to thank both Dr. Herrmann and the staff at the Waisman Center for their support and assistance in helping us to offer this event.



Dr. Ken Herrmann

Families of children with PWS ages 9 years or younger...

A message to families with younger children with PWS, (age 9 or younger) - we are in the planning process of a Face Book page specific



to you and the issues you deal with. Over the years, we have recognized that families with younger children with PWS deal with different issues than those who have loved ones with PWS in their teenage years or older. We have tried having regular meetings to network and try to address the specific challenges you might be facing—but with variable success. Recently it was brought to our attention that many families of children with PWS in this target age range use Face Book and other social media sites to get information rather than relying on face to face networking that was popular years ago. We are hoping to create a Face Book account that is a closed group, meaning that you can join the group by invite only. In conjunction with Face Book, Pinterest can also be used... For those who are unfamiliar with Pinterest, it is a picture sharing platform that is set up in such a way to create themed boards to pin pictures to. You can also pin videos and begin discussion groups specific to certain topics. This Face Book group and Pinterest sites would both have a moderator. We will be sending out a mailing and/or email to determine which families might be interested in this. If you have ideas, please feel free to contact the office: 866-797-2947 or email: Wisconsin@pwsaofwi.org More info to come.

Congratulations

Dale and Dottie Cooper
 who have been named Interim Executive Directors of PWSA (USA) by the Board of Directors

Upcoming Events

Planning for the Future: Strategies to Support our Children's Lifelong Needs

As a parent or family member of someone with a developmental disability, a lot of questions arise! Will they be able to work and sustain themselves? Can they get insurance? Should we gain guardianship? How do we support our loved one with PWS once we are gone? Do we need a special will? A trust? How do we do that?

PWSA of WI, Inc. is hosting a training to try and answer some of these many questions we all have as our loved one gets older. We have an attorney who will speak on wills and trusts; as well as other important legal documents to have. We have other speakers talking about guardianship, social security disability income (SSDI) and supplemental security income (SSI). We recognize that many of our members may not have children or loved ones near adult age, but it is so important to make plans before you reach the point of needing it!

Date: Saturday, November 3, 2012

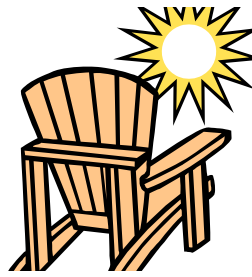
Time: 8am—3:30pm

Cost: To be determined

Location: First English Lutheran
Church, North site; 6331 N. Ballard
Road,
Appleton WI

We will be sending a mailing out soon!

Notes from the Office...



So, how is your summer going so far? I wish I could say mine is like this deck chair with a tropical drink...but alas! It is a crazy time in our household as we struggle with summer school or work, schedule a variety of lessons or play time, attempt to maintain some type of schedule and structure, and just try to enjoy the summer!

In the office, we are gearing up for our upcoming Golf Benefit! I am getting all sorts of things in the mail from donors (like a signed Green Bay Packer football), as well as questions via phone or email. We have a variety of golfer registration forms, hole sponsor forms or prize donation forms on our web site at www.pwsaofwi.org for download. And, yes, we are still looking for golfers and prizes! If you have any questions, don't hesitate to give me a call on the toll free line at 866-797-2947.

We are also getting things ready for our fall conference which will be hosted here in Appleton on Saturday November 3rd, titled **Planning for the Future: Strategies to Support our Children's Lifelong Needs**. It is targeting a lot of issues faced as our loved one with PWS approaches adulthood—but by NO means is it meant only for families of young teens or adults! (As a parent who has an adult child AND a school age child, I can assure you, the questions can change based on your child's capabilities or even on how the current 'system' works!) I think most families who attend will walk away with something useful! The topics being addressed are not specific to PWS either but to supporting anyone with lifelong needs. As we get more things in place, we will be mailing out information on this soon!

Take some time and enjoy the gorgeous weather with family and friends—because we know all too soon, it will be changing! Please don't hesitate to contact us if you have any questions or concerns that we might be able to help with.

Stay cool,

Mary Lynn

The following donors have made contributions to PWSA of WI, Inc. between 01/01/2012 through 05/31/2012. We want to thank you for your continued support.

We try to be accurate in recognizing our contributors and apologize for any errors or omissions. If you note an error, please do not hesitate to contact us so we might correct it.

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Prader-Willi Homes of Oconomowoc

In memory of Thomas Grady

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Lillian Peronto

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Honoring the wedding of Larry and Vivian

Bob and Marge Miller

Honoring the 50th Anniversary of Leo and Esther Bethke

PWSA of WI, Inc.'s Event Calendar

August 25, 2012	PWSA of WI, Inc.'s 12th Annual Golf Benefit	Windwood of Watertown Golf Course
November 3, 2012	PWSA of WI, Inc.'s Training: Planning for the Future: Strategies to Support our Children's Lifelong Needs	First English Lutheran Church, North site, Appleton, WI
May 11, 2013	PWSA of WI, Inc.'s 3rd Annual <i>On the Move</i> Walkathon	Fowler Park Oconomowoc, WI

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