



# 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

As I sit down to write this I am amazed that fall is already upon us. I am also amazed at how busy the organization has been throughout this year so far. In addition to our 1st Annual Snowflake Ball in January and our 2nd Annual On the Move walk-a-thon in May, we also held our 12th Annual Golf Benefit on August 25th. This event was once again held at the lovely Windwood of Watertown golf course, and I am excited to announce we had an all time high of 130 golfers!! Everyone enjoyed 18 holes of golf followed by a wonderful lunch, a silent auction and everyone left with a nice door prize. I would like to extend a sincere, heart felt thank you to Dave Nagy of Oconomowoc Residential Programs for his immense generosity not only this year, but also in years past. Without the generosity from people like Dave, our event would not be as successful as it is. Thanks Dave!! Also, thank you to everyone who participated in or donated items to the event!! Make sure to mark August 24th, 2013 on your calendars now so you can plan to join us next year.

Throughout the past several months the organization has also been busy preparing for the upcoming "Planning For the Future: Strategies to Support Our Children's Lifelong Needs" seminar that is being held in Appleton on Saturday, November 3rd. This is a wonderful chance to hear knowledgeable speakers share information about wills, trusts, guardianship, and social security disability versus supplemental security income. Child/adult care will be provided by experienced volunteers so we hope to see you all there.

In addition to the aforementioned events, the organization has also been busy working to make some changes to the organization as a whole. In September, the board of directors voted to add two more board member positions, which brings the total to five. The board also voted to hire Ascedia, a web design company, to re-design our current website. We are hoping to have a new and improved look within the next few months. We have also been working diligently to keep our Facebook page updated, and we have started a Facebook page for children of young parents. This new Facebook page works in conjunction with Pinterest so interested parties can share various ideas and interests. If you have a child with PWS who is ten years old or younger and you are interested in joining this special Facebook page, please contact our Program Director, Mary Lynn Larson. We are very excited about all of these changes and believe they will help continue to move the organization forward. If you have any ideas you would like the board of directors to consider please don't hesitate to share them with us.

Have a wonderful fall and I hope to see you in November.

Crystal L. Boser



### Board of Directors:

**President:** Crystal Boser

**Vice President:** Jackie Mallow

**Treasurer:** Tom Hughes

**Board members:** Don Dorn, Candace Lipski, Melanie Ignatowski, Bobbi Pogrnt

**Program Director:** Mary Lynn Larson

**Assistant Program Dir:** Melodee Luening

### Office Address:

PWSA of WI, Inc.  
2701 N. Alexander St.  
Appleton, WI 54911-2312

**Toll free:** 1-866-797-2947

### Email:

wisconsin@pwsaofwi.org

### Website:

www.pwsaofwi.org

PWSA of WI, Inc. is a chapter of PWSA (USA)

8588 Potter Park Drive,  
Suite 500

Sarasota, FL 34238

**Toll free:** 800-926-4797 or  
941-312-0400

### Email:

info@pwsausa.org

### Website:

www.pwsausa.org



## PWSA of WI, Inc.'s Annual Charity Golf Benefit

We had beautiful weather for our 12th Annual Golf Benefit on Saturday, August 25th - and it seemed everyone had a great time! We had 130 golfers (YEAH!! A new record!) attend and after a gorgeous day on the course, they enjoyed lunch upstairs with a variety of prizes being given out and the silent auction!. We also took a moment to say "Thanks!" to a tremendous supporter of PWSA of WI, Inc.—Dave



Nagy. Dave has always done so much to make our golf benefit and other

events a success - and without our generous supporters, we could not do all we do. Thank you!! Thank you all so very much!!

Mark your calendars now for next year's event

**August 24, 2013**

Hope to see you all there!



Thank you to the following individuals and businesses that donated to this year's event!

### 2012 Prize Donors

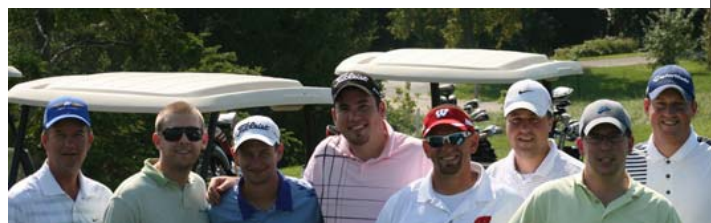
- |                                       |                         |
|---------------------------------------|-------------------------|
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## Notes from the Office:

By Mary Lynn Larson

It's crazy busy in the office!! It seems we just finished up the golf outing and we are deep into plans for our upcoming conference:

### **"Planning for the Future: Strategies to Support Our Children's Lifelong Needs"**

which we are hosting in Appleton. This will be a great learning opportunity for everyone—no matter where you are in the process of planning for your loved one! We have speakers addressing wills and trusts, SSI and SSDI, as well as guardianship. Register today—check our web site at [www.pwsaofwi.org](http://www.pwsaofwi.org) if you need more information about the conference, the child/adult care or overnight lodging in the area! Or call Mary Lynn at the state office.

### **MORE GOOD NEWS!!**

PWSA of WI, will be hosting their 2nd annual Snowflake Ball on January 26, 2013 in Oconomowoc! We are eager to do this because of the tremendous turn out and positive response we received from so many of our attendees and members! So mark the date on your calendar and look for the details to be mailed out shortly!

*Got your teams ready yet??*

We are looking ahead to our **3rd Annual *On the Move* Walkathon** which will be held on May 11, 2013 at Fowler Park in Oconomowoc! It's a day of fun, exercise and friends.



We offer a box lunch, a lot of fun and some entertainment! We want you to start getting your teams ready and make your pledge

donors aware so this can be our best walk yet! Its sure to be a great time!

Please take a moment to consider taking part in the Vanderbilt survey for adolescent siblings. It also requires parent participation to be eligible for the Target gift card. The complete information is located on page 7 of this newsletter.

Will we see you in Appleton in November? Mary Lynn

## SAVE THE DATES

January 26, 2013

PWSA of WI, Inc.'s  
2nd Annual  
Snowflake  
Ball



May 11, 2013

PWSA of WI, Inc.'s  
3rd Annual *On the  
Move* Walkathon  
Details to follow!

## 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:** \$30 for PWSA of WI member  
\$40 for non members  
\$15 for child/adult care

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

**The Annual PWSA of WI, Inc.  
membership meeting will be  
held following the conference.**

**Are you interested in staying overnight the night before the conference?** A block of rooms has been reserved at the Cambria Suites Hotel. Rooms include a king size bed and pull out couch and are available for \$99 + taxes for Friday November 2nd. Make sure to mention PWSA of WI to get a discounted rate.

**Deadline: October 12th!**

Cambria Suites—Appleton

3940 N Gateway Dr., Appleton, WI

Toll Free: 1-866-430-2692



**And the  
results are  
in...**

Thanks to everyone who returned their ballot in the election. I would like to take this moment to say Thanks to one of our 'retiring' members who has served as our Treasurer for a long time, Tom Hughes. Please make sure to let him know of your appreciation for his years of work and dedication to the organization the next time you see him!!

We are happy to welcome the new faces and grateful that others stepped up/into their new role... Welcome the following individuals to the PWSA of WI, Inc. officer and Board of Directors positions:  
Vice President: Don Dorn  
Treasurer: Lynn Ann Miller  
Board Members: Jackie Mallow, Steve Steffen and Nancy Burlingame.  
Welcome to the Board and Thank you for your support!

**The following donors have made contributions to PWSA of WI, Inc. between 06/01/2012 through 08/31/2012. 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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## Survey Participants Needed!

Adolescent siblings in families with 2 or more children—both children must be between the ages of 12—18 years.


**Description:** We are interested in how having a brother or sister impacts adolescents. We invite parents and siblings to fill out an online survey. Families with and without children with disabilities are welcomed to participate.

**Compensation:** For your participation, you will be entered in a drawing for one of 40 \$50 Target gift cards. You will have approximately a 1 in 10 chance of winning the gift card.

**Study requirements:** completion of one survey—20 min for parents , 15 min for adolescents.

**Survey link:** <https://redcap.vanderbilt.edu/surveys/?s=RbeQdw>

## PWSA of WI, Inc.'s Event Calendar

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
January 26, 2013	 PWSA of WI, Inc.'s 2nd Annual Snowflake Ball	PWHO Gym Oconomowoc, WI
May 11, 2013	PWSA of WI, Inc.'s 3rd Annual <i>On the Move</i> Walkathon	Fowler Park Oconomowoc, WI

Prader-Willi Syndrome Association of WI, Inc.

2701 N. Alexander St.

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Toll free: 1-866-797-2947

Email: [Wisconsin@pwsaofwi.org](mailto:Wisconsin@pwsaofwi.org)

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