

PWSA of WI, Inc.'s Event Calendar

May 14, 2011	PWSA of WI, Inc's and PWSA (USA)'s 1st Annual Walk-A-Thon	Fowler Park, Oconomowoc, WI
August 27, 2011	PWSA of WI, Inc.'s 11th Annual Golf Benefit	Windwood of Watertown
November 11 – 13, 2011	PWSA (USA) National Conference	Buena Vista Palace Hotel, Orlando FL
May 12, 2012	PWSA of WI, Inc's and PWSA (USA)'s 2nd Annual Walk-A-Thon	Fowler Park, Oconomowoc, WI

Prader-Willi Syndrome Association of WI, Inc.
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 Web site: www.pwsaofwi.org



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

Awareness at its BEST!

I am proud to announce that on Saturday, May 14th, the Prader-Willi Syndrome Association of Wisconsin, Inc. (PWSA of WI, Inc.) in conjunction with Prader-Willi Syndrome Association (USA) successfully hosted our 1st Annual *On the Move* Walk-a-thon and Fundraising event. Although it was chilly, windy and overcast, almost 300 people gathered at beautiful Fowler Park in Oconomowoc to participate in a 2 mile walk around the lake. Each individual who participated was given a complimentary t-shirt, water bottle and a fun ribbon when crossing the finish line. In addition, individuals were able to receive an *On the Move* tattoo and several were interested in purchasing flower pots painted by persons with PWS who are part of Prader-Willi Homes of Oconomowoc Art Club. After the walk, everyone was able to enjoy a healthy lunch provided by Piggly Wiggly of Brown St., Oconomowoc and then enjoy dancing with music provided by Scott of Wileman Mobile DJ. Friends who have been part of the PWSA-WI family were able to visit and catch up while new friends who were just finding out about PWS were welcomed with open arms and wide smiles. This event was truly Awareness at its BEST!!

We would like to thank our Corporate Sponsors for their generous donations and helping to make this event a success. They include:

- | | |
|-------------------------------------|---------------------|
| Prader-Willi Homes of Oconomowoc | PWSA (USA) |
| Piggly Wiggly of Oconomowoc | PWSA of WI, Inc. |
| Wileman Mobile DJ | RD Images |
| Gordon Food Services (GFS) | Ascedia |
| Kwik Trip of Oconomowoc | Pantheon Industries |
| Lakeview Specialty Hospital & Rehab | |

I would also like to formally invite everyone to our next major event... the 11th Annual PWSA of WI, Inc. Golf Benefit!! This event is being held on Saturday, August 27th at the Windwood of Watertown Golf Course. If you are interested in this event, look on the PWSA of WI, Inc web site at www.pwsaofwi.org for more information or call Mary Lynn at the office. This is a day full of fun and laughter — we would definitely love to see you there.

Have a wonderful summer. Crystal

Board of Directors:
President: Crystal Boser
Vice President: Jackie Mallow
Treasurer: Tom Hughes
Board members: Melissa Sirovina, Al Luening, Don Dorn, Candace Lipski and Katherine Girdaukas
Program Director: Mary Lynn Larson
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Toll free: 800-926-4797 or
 941-312-0400

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Website:
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PRADER-WILLI SYNDROME ON THE MOVE!



PWSA (USA) and PWSA of WI, Inc. Walk-a-thon was a GREAT SUCCESS!!

Despite the clouds and forecast for rain, sunshine was noted on the faces of all the participants of our Walkathon/Fundraiser! It was a huge success thanks to our walkers, donors, families, corporate sponsors and volunteers! We had approximately 300 individuals walk the 2 mile course around Fowler Lake in Oconomowoc on May 14, 2011! Walkers received a t-shirt, *On The Move* water bottle just for participating!! *On The Move* logo tattoos were also available Tom Davenport of RD Images was available to take photos of all the events of the day!! Once the walkers had completed the walk, they were provided lunch and music by our favorite DJ, Scott of Wileman Mobile DJ.



Prader-Willi Syndrome *On The Move* is the new national awareness initiative of PWSA (USA) and local chapters



as a way of targeting awareness and fundraising. We have already raised over \$10,000 without counting our expenses. These funds will be shared with PWSA (USA) and PWSA of WI, Inc. in our joint effort to support, educate and advocate for persons with Prader-Willi syndrome, their families and the professionals who support them in meeting the challenges of this disability.



We would like to say "Thank you" to our corporate sponsors who supported us. They include: Ascedia, Gordon Food Service (GPS), Kwik Trip Stores, Lakeview Specialty Hospital and Rehab, Pantheon Industries, Piggly Wiggly-Oconomowoc, Prader-Willi Homes of Oconomowoc (PWHO), PWSA of WI, Inc., PWSA (USA), and RD Images.



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

Notes from the Office...

By Mary Lynn Larson

Wow, the past several months have been very busy here at the office/Larson house! We have been preparing for the Walk-a-thon, a graduation and the upcoming Golf Benefit! As you can see earlier in the newsletter, the Walk-a-thon was a HUGE success; 'Thanks' to our very generous sponsors, members, families and friends who donated and worked so hard to support us! Those of us on the organizing committee were regularly touched and amazed at all everyone did to get involved! Our walkers were out in full force despite the gloomy, chilly weather and we were very fortunate that it did not rain the day of the event until about 10 minutes after we were done with the clean up! I would like to say a huge "Thank you" to our organizing committee who spent many hours on conference calls and behind the scenes making this a successful event!

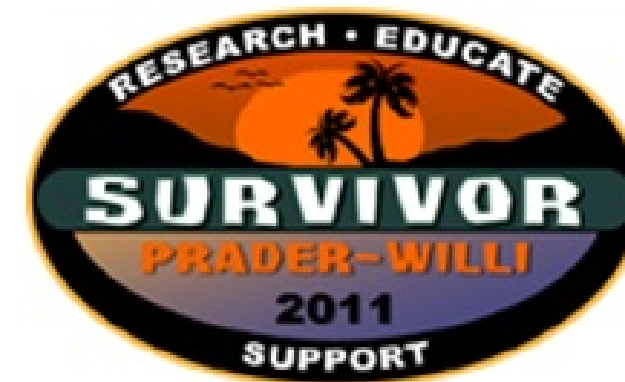
And the next event in our personal lives is Alex's graduation on June 2nd. Alex chose to continue with his schooling until age 21 but wanted to "walk" graduation with his class. We are continuing to work on his classes for next year and what that will entail—but he is able to achieve that "milestone" that is a "right of passage" for us all. As we have been focusing on this "milestone", we have been using it as a tool to promote adult responsibilities and chores for Alex to learn and participate in. He is learning how to do laundry, how to clean various rooms in the house and coordinating/planning things into his schedule so he is not double-booked!!

At the office, we are beginning our focus on the 11th Annual Golf Benefit which is right around the corner! We need our members, families and friends to save the date (08/27/11) and start getting their golfing teams together!! We are always looking for new golfers, door prizes and silent auction items. This is our biggest fundraiser of the year and supports our

day to day programs, so we need your help! If you have some ideas of items to donate for our silent auction or perhaps door prizes, let me know! We are also looking for Hole Sponsors. Consider sponsoring a hole in honor of a loved one or family member, or maybe get a group together to sponsor a hole! Hole Sponsorships are \$125. If you need more information about the golf outing, either call Mary Lynn at the office at 1-866-797-2947 or go to our web site at www.pwsaofwi.org.

I look forward to seeing you there! Don't look for me golfing, I have too much fun doing the 'behind the scenes' work!

Take care. Mary Lynn



PWSA(USA) National Conference Survivor: Prader-Willi November 11-13, 2011 Buena Vista Palace Hotel Disneyworld, Florida

Registration will be open in late summer. Check the PWSA (USA) web site for regular updates. The general conference is November 12-13, 2011 and will include the Infant and Youth program (YIP), the Youth and Adult program (YAP), and the Siblings program. HOPE TO SEE YOU THERE!!

Save the date!! PWSA of WI, Inc.'s 11th Annual Golf Benefit is Saturday August 27th, 2011!!

We are getting things ready for our 11th annual Golf Benefit on August 27th at Windwood of Watertown's Golf Course. This annual event is guaranteed to be a day of fun and friendly competition. The proceeds raised in this event help to maintain programs

that assist persons with Prader-Willi syndrome as well as those who support them. We are always looking for golfers, hole sponsors and prize donations. 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.



PWSA of WI
Annual Golf Benefit
SUPPORT • EDUCATE • ADVOCATE

Are you or your company willing to sponsor a hole? Hole sponsorships are \$125.00 and includes 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, 2011. 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.

PWSA of WI, Inc.'s 11th Annual Golf Benefit Prizes, Goody bags, Lunch, Refreshments and Silent Auction will happen Rain or Shine

Check In @ 8:30am

Shotgun start @ 9:00am

Foursome/Scramble

GOLFER REGISTRATION

\$90 PER PLAYER

(\$30 is a tax-deductible donation)

PRIMARY CONTACT PERSON:

Name: _____

Address: _____

City: _____ State: _____

Zip: _____ Phone: _____

Email: _____

Other golfers on your team:

Name: _____

Address: _____

City: _____ State: _____

Zip: _____ Phone: _____

Email: _____

Name: _____

Address: _____

City: _____ State: _____

Zip: _____ Phone: _____

Email: _____

Name: _____

Address: _____

City: _____ State: _____

Zip: _____ Phone: _____

Email: _____

**Deadline for Golfer Registration :
August 19, 2011**



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Our heartfelt thanks go out to all of you who supported us in some way. The committee who worked on this event has been truly touched by all the dedication, kindness and generosity of all who were in some small way a part of this event.

Thanks for being our sunshine on a cloudy day!

PWSA (USA) Medical Crisis Counselor Availability

We wanted to be sure our membership was aware that the hours of the PWSA (USA) Medical Crisis Counselor have changed. Previously PWSA (USA) had someone available after hours to answer calls related to medical emergencies. This is not the case any longer. The information on the web site reads:

If a person with PWS is experiencing a medical crisis or problem we can help in the following ways:

- A Medical Crisis Counselor is available to assist you with medical calls and questions during the hours of 10—5pm EST Monday through Friday by calling 800-926-4797 or 941-312-0400.

Note: Any voicemail messages left after the PWSA (USA) office is closed will be returned promptly the next business day. If you are calling about a medical emergency please seek medical attention immediately from your local physician or emergency room or by dialing 911.

- Important medical alerts and other medical information useful during medical crisis is available on the website 24/7.
- Through contacting the Medical Crisis Counselor, medical information can be faxed or e-mailed to physicians and other medical professionals and facilities. In some situations, PWSA (USA) may be able to set up a "physician to physician" consultation.
- A copy of the PWSA (USA) Medical Alert Booklet which includes many of the most important medical alerts to share with physicians and Emergency Room staff. If a family cannot afford the cost of the Medical Alert booklet, a copy can be provided for free. A copy of the medical alert booklet can also be downloaded off the National website at www.pwsausa.org

Board Positions opening in fall

We will be having some PWSA of WI, Inc. Board of Director positions opening in the fall. We know for certain the Secretary position will be available—so we want you to start thinking now if this is something you might be interested in. We do not require you are a parent of a person with PWS to become a member of the Board, so the position is open to anyone. Think about it! More information will be on the web site and in the next newsletter.

Family Care: Updates By Barb Dorn

I want to thank everyone who has shared their stories; asked their questions and shared their perspectives on Family Care. On Saturday April 30th, PWHO and PWSA of WI, Inc co-hosted an informational meeting and sharing session on Family Care. Several parents from around the state whose children are served by PWHO attended. I am summarizing and sharing recent updates and concerns that have been raised—not only at this meeting but also by others who have persons with PWS being served by this program. I did not spend time explaining Family Care so if anyone needs further information—please feel free to contact me.

Questions and Concerns Shared along with Suggested Action Items: (A “Member” is the person receiving services.)

1. There are some interdisciplinary teams who are making contacts; doing assessments and/or making adjustments with members without their guardian or other representative present. We all know there are many persons with PWS who may have a different perception of a situation or a need than what is reality. Some team members have asked the member if they would like to have a credit card; or if they would like to stop working; or have a less restrictive environment?
- **Suggested Action Item: Parents/guardians should draft a letter and have the “member” sign it indicating that the member wants their guardian or other designated person to be notified and present when any assessment or conversations take place with any member of the assessment team. If adjustments or updates are made to functional screens, guardians should be notified.**
2. Care plans developed by Interdisciplinary teams are not being shared with providers and/or parents or guardians. Care Management Organizations (CMO’s) must receive approval for the care plan. How can a provider make sure all needs are being addressed when they do not have access to this important document?
- **Suggested Action Item: Parents/guardians should also include a request to have a copy of the care plan shared with them as well as the provider. Include this request in the letter noted above.**
3. Interdisciplinary teams may have little or no knowledge or understanding of PWS. (Team

members must only have knowledge of 1 of the 3 populations served under Family Care.)

- **Suggested Action Items: Make sure to personally educate the team members about PWS. If you do not have brochures or written information—contact PWSA of WI, Inc. for assistance. Make sure to share personal information about how PWS has impacted the member.**
- **PWSA of WI, Inc. will make attempts to make sure information is available to DHS as well as Care Management Organizations about PWS. If possible, we would like to do an in-service about PWS,**
- 4. Budgets are, and have been strained. The current budget proposal includes \$500 million in cuts to Medicaid—which means cuts to Care Management Organizations and providers. This funding crisis has significantly impacted services in Wisconsin. Providers are being forced to change their service models and in some cases—some are being forced to close their doors. Currently, expansion of Family Care is on hold.
- **Suggested Action Item: Contact your legislators (again) and ask them to NOT cut funding to Family Care. IF you do not know who or how to contact them—contact Barb Dorn.**
- 5. “Bed Holds”, “Holding Days” and/or “Vacation Days” are now being added to some contracts and limit the ability of members to visit family members and/or take vacations without a financial penalty.
 - A. “Bed Holds” are days when a member is hospitalized, in a nursing home or rehabilitation center when the provider is not able to receive any Medicaid funding (the primary source of funding for Family Care). If this time is an extended period of time, providers may only be able to “hold” a bed for a limited time or their budget is adversely impacted.
 - B. “Holding Days” and/or “Vacation Days” are days in which the member may be on a home visit, vacation or other non-medical leave from their home/placement. In the past, a person could be gone 14 consecutive days or less without the county limiting funding. There are some Managed Care Organizations adding these days to contracts so a provider receives zero payments for any days when the member is away thus significantly impacting their budget and their ability to plan for and fund services. Some members may be asked to pay a fee when they visit family or spend non-medical time away from their home.

- **Suggested Action Item: We are currently waiting to see these items put in to writing. So far, these items have been requested but not communicated to members, parents/guardians in writing. PWSA of WI, Inc. is already in contact with the Family Care Ombudsman from Disability Rights Wisconsin to see if this is a violation of the member’s rights to a least restrictive living condition. If you have received notice of this change—please contact me (Barb Dorn) so that we can do our best to advocate for the member’s rights and needs.**

The Results of the Legislative Audit

On Wednesday, April 27, 2011 the Legislative Audit Bureau released its report on Family Care. The full report is over 80 pages and the shortened version is 4 pages. Both can be found on the PWSA of WI, Inc website (www.pwsaofwi.org). I am summarizing some of the highlights as well as a few of my perceptions of the report. I learned more about this program—its goals, its components, its problems and recommendations after reading the audit.

***The audit has asked Dept of Health Services (DHS) to report to the Joint Legislative Audit Committee by September 1, 2011 on these concerns.

- Nearly 60% of program participants receive care in their own homes.
- ***Residential services costs represent 44.3% of the MCO’s expenditures. There is talk of establishing uniform rates for participants with similar needs within and across counties. This is controversial and there is question if this will lower reimbursement for higher cost participants. Also, MCO’s want to have the ability to negotiate rates. (If I understand this correctly, currently some of the fees or payments of others help to pay for the higher costs and fees of those with higher needs and costs.)
- ***There have been some concerns over the financial solvency of some MCO’s, as well as some fraudulent payments and noncompliance. Some CEO’s from these companies have salaries greater than \$200,000.00.
- ***There is a need for the formation of regional long-term committees.
- ***Certified screeners are RN’s or Social Workers who must have experience in working with one of the populations served—the frail elderly, the physically disabled or the developmentally

disabled. Screeners may have little or no experience in working with many of the members they are asked to assess. They are required to take part in training however, many screeners had not been tested and many of those who were tested scored below the passing grade. Caseloads also vary (and they sound extremely large.)

- DHS is aware of certain high cost participants—persons with PWS are listed as such. It does not appear (from my review of the functional screen tool) that the needs of these high cost individuals are being adequately assessed and captured in this assessment tool. The audit does not seem to address the reliability of the functional screen tool.
- There is increasing provider dissatisfaction because rates are being reduced with little or no notice. (I was very surprised to learn that many MCO’s do not provide providers with long term contracts. How can any business budget and plan when their economic security changes and is not guaranteed?)
- If a member does not feel their needs and budget adequately meet their needs, an appeal process can take place. (This may be an avenue that more members need to take advantage of). The member will be asked to complete a service evaluation form and more information is being asked to know how personal data outcomes will be used to improve service quality.
- By August 2012, the Joint Legislative Audit committee is requesting DHS to report on the status of Family Care including any changes in participation rates and costs as well as any administrative rules it has promulgated or any statutory changes enacted as part of the 2011-2013 biennial budget.

Final Comment: I fully support the philosophy of Family Care. I think all people who have a developmental disability, or a physical disability or are a frail elderly should receive the care and supports they need in a prompt manner. However, without the economic supports to pay for these supports the system will fail and providers will close their doors and our loved ones care will be jeopardized. I will continue to do my best to advocate for the needs of persons with Prader-Willi Syndrome and keep you informed of what YOU need to do to advocate as well. Stay informed and we need to keep the lines of communication open between all parties.