



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

“When running isn’t a form of exercise”

(If this seems familiar, it is because this is a revision of a note Crystal wrote a few years ago.)

Have you ever been in a store and turned your back for just one minute then when you turned around your child was missing only to be found hiding under the nearest clothes rack? Or has your child ever gotten overwhelmed with emotions and instead of managing those emotions they ran out of the house only to be found hiding in a bush nearby? Most of the time when this occurs a parent is certain they will find the child immediately once they are called for, but as the seconds turn into minutes the feeling of dread starts to take over and the parents voice becomes filled with panic. It is at this moment the child realizes they need to come out of hiding because they have clearly upset their parent and when they do we as parents are filled with elation. Now imagine having a child run away and not come out of hiding or not be found for several hours. During this time the dread mounts and everything becomes chaos as everyone realizes the situation has become dire. Unfortunately, this exact situation occurred in October when an individual with Prader-Willi syndrome (PWS) in Indiana went missing for almost 28 hours before being found. It was during those missing hours that I remembered a similar situation that occurred in Wisconsin a few years ago and I realized how important it is for everyone to be informed or reminded of how to properly prepare for this type of crisis situation.

Being properly prepared means parents, relatives, school personnel, childcare workers and all others involved in the individual’s life need to have proper pre-planning. Since many individuals with PWS don’t know their proper contact information being prepared starts with making sure there is an emergency contact list in the individuals backpack, purse or wallet. In addition, parents or guardians should educate community members, such as the fire department, police department, hospitals, schools and surrounding neighbors. In the event that your child runs away these agencies will most likely be involved in a search and rescue so having them properly informed about PWS is of key importance. Parents or guardians should also have a crisis support plan and a current flier prepared with the individual’s most recent photo. A crisis support plan should include who to contact in the event of an emergency, individuals to enlist for a search party, a map of the surrounding area and noted food locations, a list of local businesses, and local media outlets who can get the flier on television immediately. Since many individuals with PWS also attend school it is vitally important to have an “in the event of” plan as part of the child’s Individualized Education Plan. The “in the event of” plan should spell out exactly how school personnel should proceed if an individual runs away from the school property. In addition, it is a good idea to include all the components of the crisis support plan as it pertains to the school location.

It is my hope that no one ever has to experience what it is like to find out that your child has run away, but we all know it can happen. By having a plan in place before this occurs, there is a better chance the child will be found quickly and safely.

Happy Holidays.
Crystal



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President: Crystal Boser

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PREVENT A HOLIDAY HEALTH EMERGENCY: Keep a Watchful Eye!!

As we approach the holiday season, there can be many more opportunities for children and adults with PWS to gain access to food and binge. We must be extra vigilant and have watchful eyes to that these individuals do not overeat. Binge eating can result in a life threatening situation. Overeating can result in overextension fo the stomach which can either rupture or put pressure on nearby vital organs which interferes with their functioning.

In addition to careful supervision, *encourage the individual with PWS to tell if they overeat. They must not be punished—or why would they tell?*

If any of the following symptoms appear, the person should be evaluated by a health care professional immediately.

- Their stomach becomes bloated or distended. (this can be hard to detect if they are overweight).
- They vomit (This is rare but if it occurs, it could indicate a serious health situation).
- They complain of “not feeling well” or have stomach pain. (Pain is not always present.)

What you should do:

- Take the child/adult to see a health care professional immediately.
- Bring along a medical alert booklet or brochure. If you do not have one, download a copy from our web site. (Click on MEDICAL ALERT information.)
- If you do not have a knowledgeable health care professional and you need advocacy help, contact PWSA (USA): 1-800-926-4797
- Don't be afraid to advocate that this individual be closely evaluated to rule out a gastric necrosis or rupture.

CHOKING can also occur more frequently because individuals with PWS may steal food and eat it very fast to avoid being caught. If you do not know how to do the Heimlich maneuver—learn. You may be saving a life.

Most important, remember to keep food locked and/or supervised. We know the holidays offer more challenges in this area. We all want everyone to have a happy, healthy holiday season.

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

On November 3, 2012, PWSA of WI, Inc. hosted a conference at the First English Lutheran Church - North site in Appleton focusing on **Planning for the Future: Strategies to Support our Children's Lifelong Needs.** We had 25 parents/



family members attend the day long event with lunch being provided. Our speakers included attorney Chris J. Mares SC who talked about Wills and Trusts as well as important legal documents to have or consid-

er having in place. Mary Hammer from the Coalition of Wisconsin Aging Groups spoke on Guardianship issues and things to consider when determining if your loved one with PWS might need a guardian. Julie Dixon-Seidl, an SSI Managed Care External Advocate Project Coordinator from Disability Rights Wisconsin spoke about Social Security Disability Income and Supplemental Security Income and the differences between them. It was a very fact filled day with a large amount of information and ideas being shared.

We had 8 individuals attend the child/adult care program with 7 dedicated volunteers working to make sure they had a fun filled day! The annual PWSA of WI, Inc. membership meeting was also held at the end of the day after the conference.

Notes from the Office.....

By Mary Lynn Larson

Wow, another year is almost over! We (PWSA of WI, Inc., that is) had an absolutely amazing 2012!! We started the year with a new event: our Snowflake Ball—an event where persons with PWS got all dressed up, and along with their families and friends come to a fancy dinner followed by an evening of fun and dancing! It was such a huge success—that we have chosen to make it a tradition! We are hosting the 2nd Snowflake Ball on Saturday January 26, 2013 from 4pm to 7:30pm at the PWHO Gymnasium, 1746 Executive Drive in Oconomowoc. Please contact the office if you haven't received the mailing on this event. We would love to have you join us!!

When spring came along, PWSA of WI, Inc. hosted our 3rd annual *On the Move* Walkathon at Fowler Park in Oconomowoc which helps raise funds supporting both PWSA of WI and PWSA(USA). This is a two mile walk around Fowler Lake followed by lunch and entertainment. Again, our members and families have made this a GREAT event which raises funds supporting both organizations! We can't begin to thank you enough for participating!

In August, we hosted our 12th Golf Benefit... WOW, we have so many generous supporters, donors, volunteers and golfers. It has grown so much we had to move to the larger area upstairs at the golf course! The funds raised at this event allow us to continue our mission of supporting, educating and advocating for persons with PWS and those who



support them. We could not do all that we do as an organization without the generosity of everyone involved!

On November, 3, 2012 we hosted a training on **Planning for the Future: Strategies to Support our Children's Lifelong Needs.** This was a topic we feel everyone should think about and make plans for prior to the point your loved one with PWS reaches the age of adulthood and regularly thereafter as your own life circumstances might change.

We already have plans in the works for 2013 and we will be mailing information out as we get it available. In the meantime, enjoy the holiday season with family and friends. May God's Blessings be abundantly showered upon you in the new year. Mary Lynn



So, do you have your teams ready?

We're looking ahead to our **3rd Annual *On the Move* Walkathon** to be held May 11, 2013 at Fowler Park in Oconomowoc!!

We offer a box lunch, a lot of fun and entertainment! We want you to start getting your teams ready and make your pledge donors aware so that this can be our best walk yet! Its sure to be a great time! A mailing will be sent soon.



Prader-Willi Syndrome Association of Wisconsin, Inc.
“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, Hanukah, 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 special 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. The “Holiday-Birthday Special Assistance Program” 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 the State of 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.



**Prader-Willi Syndrome Association of Wisconsin, Inc.
 "Holiday-Birthday Special Assistance Program"**

APPLICATION FORM

**APPLICATION FOR HOLIDAY-BIRTHDAY
 SPECIAL ASSISTANCE PROGRAM**



Prader-Willi Syndrome
 Association of
 Wisconsin, Inc.

2701 N. Alexander
 St.

Appleton, WI 54911

Phone: 1-866-797-
 2947

PURPOSE:

PWSA of WI, Inc. believes everyone with PWS should feel special and continue to have special memories and gifts – no matter what their age. As many adults with PWS are aging, they are often outliving parents and family members. These individuals have no one to provide them with a gift or card on special occasions such as Birthdays or Holidays. PWSA of WI, Inc. has developed the Holiday – Birthday Special Assistance Program to help meet this unique need of these individuals.

ELIGIBILITY:

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 the holiday or birthday celebration.

The adult with PWS must reside in the State of Wisconsin.

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

Date of request _____

Name of person completing application: _____

Address _____ City _____ State _____ Zipcode _____

Email address: _____ Phone: _____

Name of person w/ PWS: _____ Sex _____ DOB: _____

Address for person with PWS: _____

Relationship to person with PWS: _____

Occasion for request: Holiday: _____ Birthday: _____

The above named adult with PWS no longer has family members who can provide for his/her holiday and/or birthday celebration needs and would benefit from the gift card being provided by PWSA of WI, Inc. I certify that all of the information given above is true and correct. I understand that any false or incomplete statements in this application may make this application ineligible for funding.

Signature: _____

Return this application to: PWSA of WI, Inc.
 2701 N. Alexander St.
 Appleton, WI 54911-2312

A gift card will be sent to the above applicant, not the person with PWS at the address above. 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!)

A special evening of elegance... just for you

2nd Annual Snowflake Ball

We would love to see you... Please join us!!

Date: Saturday, January 26, 2013

Time: 4:00pm to 7:30pm

Registration from 4pm—5pm

Dinner starting at 5pm

Dancing to follow.

Cost: \$10.00 per person

Place: PWHO Gymnasium

1746 Executive Dr.

Oconomowoc, WI

A fancy dinner served by the PWSA of WI, Inc. Board of Directors and volunteers will be followed by an evening of dancing and FUN.

Dress attire is preferred.

If you need more information or a registration form, call the office at 1-866-797-2947 or find it on our web site at www.pwsaofwi.org

Web site update

We are currently in process of updating our web site! We have done many things to update/upgrade our site over the past few years and the Board of Directors wants to keep it current and informative. At this time, we are relying on things we hear from our Board members, and email or phone contacts to the office in getting ideas on what might be of interest or helpful to you... but we recognize that is somewhat limited. Can you give us some input?



We are looking for ideas, suggestions, recipes, stories, or photos from our members and families to help keep it pertinent to you and your needs! What do you search the web for? What questions do you have? Let us know what you need or are interested in as it relates to Prader-Willi syndrome or supporting a loved one with PWS.

The PWSA of WI, Inc. web page address will not change. It remains at www.pwsaofwi.org. We intend to have the opportunity to download grant applications for the general assistance fund, links to our newsletters, the chance to make online donations or even register for upcoming events available online when our new site is up and running!!

We are really excited about it but would like your input on what your need and what works best for you! Keep watching for it and let us know your thoughts! Thanks!

Contributors/Donors

The following donors have made contributions to PWSA of WI, Inc. between 09/01/2012 through 11/30/2012. 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.

Daniel and Jacinda Konczal
 James and Angela Romig
 Clint and Crystal Boser
 Karen and James Plosczynski
 Heidi and Jamie Wertjes
 US Bancorp Fdtn Matching Gift Program
 Thomas Grall
 Dan and Kate Beaver
 Mike and Mary Lynn Larson
 Judy Crespi
 Bob and Kathy Bomber
 United Way Metro Chicago
 Richard Becker
 John and Wendy VanElk
 John and Bobbi Pogradt
 Prader-Willi Homes of Oconomowoc
 Don and Barb Dorn
 Al and Melodee Luening
 Karent Shackleton
 Tom and Agnes Hughes
 WellsFargo Community Support Program
 Melissa Sirovina
 Lillian Peronto
 St. Andrew Knights of Columbus Council



PWSA of WI, Inc.'s Event Calendar

January 26, 2013	PWSA of WI, Inc. Winter Ball 4pm to 7:30pm	PWHO Gym, 1746 Executive Dr. Oconomowoc, WI
May 11, 2013	PWSA of WI, Inc.'s 3rd Annual <i>On the Move</i> Walkathon	Fowler Park Oconomowoc, WI
August 24, 2013	PWSA of WI, Inc.'s 12th Annual Golf Benefit	Windwood of Watertown Golf Course
November 7-9, 2013	PWSA (USA) National Conference	Buena Vista Palace Hotel, Orlando FL

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