



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.

Board of Directors

Co -Presidents: Steve and Nancy Burlingame
Vice President: Crystal Boser
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Program Director: Mary Lynn Larson

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A Note from the Co-Presidents: Steve and Nancy

This is my last official letter as the President of PWSA of WI, Inc. As I turn over the reins to Barb Dorn, one of the founders of this organization, I am grateful for the extra time I will have available to focus on some personal health challenges which have come my way. There is no more experienced an individual than Barb to accept this role, and her experience and passion will be welcome. Being a rookie in the position, I didn't exactly understand what I was getting in for when I took on the position as President. In fact, I would only consider it by sharing the role as co-President with Steve, my husband. But I must say that it has been a rewarding experience, and I encourage all of you to consider volunteering to serve as an officer of this great organization.

I want to thank all of the Board members and officers for their continuing hard work, and I especially want to thank our one-and-only employee, Mary Lynn, for all the gentle nudges, reminders, and guidance she has provided to me.

Although I will be leaving the organization as President, I'll warn you – you haven't seen the last of me. I will still be there on Hobby Day to tie fleece (or whatever else might be needed) and to golf (if you can call it that!) and will continue to volunteer to serve in whatever capacity might be needed. I look forward to seeing you all at these events. And once again, I encourage you all to get more involved in your organization.

Nancy

Prader-Willi Homes of Oconomowoc “Otherwise known as PWHO”

By Jackie (Stoner) Mallow



Many of you may have heard of Prader-Willi Homes of Oconomowoc for their “behind the scenes” support to Prader-Willi Syndrome Association of Wisconsin, Inc. (PWSA of WI, Inc.) on many of our annual events and fund raisers; or maybe they have touched your lives personally; however we thought it was important to recognize their support to us as an Association.

Prader-Willi Homes of Oconomowoc (**PWHO**) along with their sister companies Paragon work services and Oconomowoc Developmental Training Center have been providing residential, vocational, and educational services for individuals diagnosed with Prader-Willi syndrome for over thirty years.

PWHO continues to be committed not only to providing quality care for people, but also to developing support systems, strengthening skill development, and enriching their community involvement. These opportunities have enhanced the quality of life for the individuals who reside in their local neighborhood homes. “Providing Homes with a Heart” is not just a slogan but a way of thinking. For many of the employees, who collectively have hundreds of years of supporting individuals diagnosed with Prader-Willi syndrome and their families, it is a passion.

PWHO sees great importance in supporting and assisting with the state and national PWSA chapters, as well as the importance of PWSA of WI Inc.’s mission to support, educate and advocate. The educational and training opportunities for their staff members, has assisted in developing a strong foundation in which to provide specialized services for those individuals in their care. It has also provided the individuals they support with the opportunity to socialize with others throughout the Wisconsin Area.

For many families, Prader-Willi Homes of Oconomowoc provides them the ability to have some peace of mind and the knowledge that their family member can live a happy, productive and meaningful life.

RESEARCH ON EDUCATIONAL ISSUES:

Students with Prader-Willi , Williams, Down or Fragile-X Syndromes

The UCLA Behavioral-Genetics Clinic along with the UCLA Lili Claire Family Resource Center is conducting a needs assessment of teachers and parents of children with specific genetic disorders. We are seeking your participation in answering our research questionnaire about your child’s educational strengths and limitations, behavior concerns, and the degree to which your child’s school program is tailored to his/her specific needs. The questionnaire should take no more than 30-40 minutes to complete.

For more information or to participate in the study, please contact:

Rebecca Cox, Ph.D.
Technical Support Coordinator
Rm. 58-218E
760 Westwood Blvd.
Los Angeles, CA 90024

Or call 310-794-9516 (Lili Claire Family Resource Center)

Or contact us by email at
GENESTUDY@mednet.ucla.edu

Principal Investigator-Bhavik Shah, M.D.,
UCLA Department of Psychiatry

UCLA IRB# G03-01-073-02
Expiration Date: 11/28/05



PWSA of WI, Inc. has a successful 5th year Golf Benefit!!!

On September 17, 2005, family, friends, generous donors and supporters of PWSA of WI, Inc. descended upon the Paganica Golf Course in Oconomowoc for our 5th annual Golf Benefit. We began at 9AM with a shotgun start with 59 golfers. There were prizes to be won, friends to mingle with and lots of good times experienced by all. This year's event raised over \$6000.00!!

We would like to thank our Hole Sponsors for their support in making this event a huge success:

1. Virchow, Krause & Company, LLP
2. CSI Testing Plymouth, MN
3. CSI Testing Plymouth, MN
4. ParTee Pub Bar & Grill
5. FABCO Equipment Inc.
6. The John and Pat LaBella Family
7. Oconomowoc Developmental Training Center
8. Paragon Industries
9. Wisconsin Concrete Services – Delafield WI
10. Dan VanKorn
11. Sedgwick – Claims Management Services, Inc.
12. St Marys – SSM Health Care of WI
13. Prader-Willi Homes of Oconomowoc
14. Keith N.- Friend to PWSA-WI
15. Platinum Realtors, Watertown WI
16. Kevin Raether
17. Hughes Dental Clinic- Cassville, WI
18. The Nashotah Clubhouse
19. Bodoh Home Improvements- Dousman, WI
20. Bramson & Associates, LLC
21. John, Marguerite, Jabin, & Jonah Rupnow
22. Don, Barb, Tony & Tyler Dorn
23. "Friends of Kayla"
24. Dick & Jayne Becker Family
25. Milwaukee Heart Scan
26. M&I Marshall & Ilsley Bank
27. Professional Fabrications Inc.
28. Mike & Mary Lynn Larson



Wow, look at that form.... Imagine what I could do if you won those new clubs for me, Dad!!



"This is what it is all about! Right Kyle and Crystal?"



The Norb Haas foursome are regulars at this event!! Thanks for your continued support!



Dan Beaver takes time out for fun with family and friends on this beautiful day!



"Stop laughing, or you will make me lose count!" says Barb Dorn as she makes change.



Jackie is grateful for her family and friends as they offer support for this event. Besides, they always have fun when they are together!

The Hughes family always has a good time at this event!



Al Leuning, Jr. is having a pensive moment as he watches his shot... Is it good? Is it good?



It's nice to see the LaBella men out having a great time on the golf course!



Don't worry about the score, silly! Remember Chad, it is all about the fun we are having..... Remember that!!



Chad wonders, "Are we having fun yet?"

Thank you to our generous donors who help us in making this a great day for all involved:

- PWSA - Wisconsin
- PWSA - USA
- Old World Wisconsin
- Thomas Hughes Family
- Thunderbay Grille
- WKLH Radio
- Milwaukee Electric Tool
- Anchor Moving
- John & Pat LaBella Family
- Kraft Foods
- Michael's House of Prime
- Milwaukee Bucks
- Milwaukee Major Indoor Soccer League
- Gray Jewelers
- X-Pressions by Peggy
- Ruggeri's Ristorante
- Mike & Mary Lynn Larson
- Green Bay Packers
- Panera Bread
- Clint & Crystal Boser Family
- Paragon Candles
- Prader-Willi Homes of Oconomowoc
- Paganica Golf Course
- Ace Hardware, Verona WI
- Boucher Chevrolet
- Chad & Melissa Sirovina Family
- Bonnie Ziegelbauer
- Dorothy Hawke

MARK YOUR CALENDARS NOW! NEXT YEAR'S GOLF BENEFIT IS SCHEDULED FOR AUGUST 26, 2006!!

ELECTION RESULTS!! AND THE WINNER IS...

In October, members of PWSA of WI, Inc. received a mailing for the election of Board members and Officers. The votes are all in and the winners are:

President: **Barb Dorn**
Secretary: **Jennifer Kryzak**
Board member: **Melissa Sirovina**

Just for the record, Melissa had a voice but no "vote" while she served on the Board of Directors this past year. With this election, she now may vote on motions made during the Board meetings.

Brewer's Game 2005

On September 25, 2005, the Prader-Willi Syndrome Association of WI, Inc. teamed up with the Milwaukee Brewers for a combined outing and fundraiser. PWSA of WI, Inc. sold tickets to the game for \$35.00 each, of which \$17.50 was donated to the association. The funds raised, totaling over \$600.00, will be used for such events as hobby day, scholarships, and awareness.

Although the weather outside was gloomy, Section 112 was alive and ready for the game between the Brewers and St Louis Cardinals. After all, the Brewers had already beaten the Cardinals Friday and Saturday night and were on the verge of going over .500. We even got to see our name on the scoreboard. Thanks to a generous donation from a couple of our members; several adults and caretakers from Prader-Willi Homes of Oconomowoc (PWHO) got to join family and friends at the game.

Unfortunately, our Brewers lost 0-2 but the game was exciting. Everyone had a lot of fun. It was a chance to relax, talk, and reconnect. Due to the success of this years event, we will be having another outing next year in late spring or early summer. Watch upcoming issues of the Wisconsin Connection for details.

Notes from the Office...

I hope all is going well for you and yours! Things remain busy and chaotic in the Larson household which usually translates into that things are also hectic in the office. We have had some great success with events this fall!! The Golf Benefit took in over \$6000.00; the Brewers game was a success, despite the loss to St. Louis; and the meeting of families with young children w/ PWS had its largest turnout ever!!

I want to thank everyone who made these events such a huge success!! Without caring and dedicated individuals and families; PWSA of WI, Inc. could not accomplish all it does!! We are so fortunate to have you; as are the children and adults affected with this syndrome! Thank you!

In the upcoming months, we will be working on getting things together for the upcoming year. We have our annual Hobby Day event scheduled for Saturday, April 1, 2006. This is continues to be a successful day for all involved! If you have skills, talent and/or enthusiasm that would allow you to assist us by leading or 'teaching' a hobby, please contact us at the state office! We like to add new hobbies/activities each year so we may all gain some new skills and ideas!

I also want to say "Thanks!!" to our outgoing officers/Board members! It has been a pleasure to work with you all! These folks have shared a lot of time, effort and dedication with this organization! It is because of individuals like you that we have become a strong organization and voice for those who have Prader-Willi syndrome.

I hope you all have a safe and blessed Holiday season,
Mary Lynn



Shoo the Flu” – Colds, “The Flu” and the Person with PWS

By Barb Dorn, RN, BSN

Author’s Note: This article is meant to help identify and manage the symptoms of upper respiratory infections in the child or adult with PWS. It is NOT intended to replace the recommendations of your health care provider. Contact this person for any questions or concerns you may have.

We are now approaching the cold days of winter. Many of us will be facing colds, flu and other viruses. Many children and adults with Prader-Willi syndrome may be more susceptible to respiratory infections. Because of weak chest muscles and obesity, they are often at increased risk for developing complications when they do contract these illnesses. Many people with PWS also have other chronic health problems (like asthma and diabetes) which can also complicate the management of upper respiratory infections.

How Do You know if it is a Cold or the Flu?

Cold and flu symptoms often resemble each other but they tend to differ in intensity. Major influenza is a flu that affects a person’s respiratory system. It is not the one that affects ones’ stomach or intestinal tract.

COLD	FLU
<ul style="list-style-type: none"> • Often starts off slow with sniffles & sneezing • Symptoms: head and nose congestion, sore throat, minor cough, low grade fever • Can usually continue with work and school. 	<ul style="list-style-type: none"> • Tends to come on fast • Symptoms: persistent cough which can proceed into pneumonia, headache, joint and muscle pain, high fever • Often makes one too ill to go to work or school

What Can Be Done to Help these Symptoms?

What should you do to help the child or adult with PWS who has an upper respiratory infection? Here is a quick reference to help with some of the common problems that they face.

Problem	What Might Help
Fatigue	<ul style="list-style-type: none"> • Encourage rest but do not let the child/adult sleep too long. When ill, persons with PWS tend to sleep more and move less. This can lead to the onset of pneumonia.
Cough or Lung Congestion	<ul style="list-style-type: none"> • Encourage the person to get up and move around every 1-2 hours. This helps to expand their lungs. • Encourage deep breathing and coughing up secretions. (Even crying & yelling can help to expand their lungs.) • Encourage fluids in moderation. This helps to keep lung secretions thin & watery. (Warm broth &/or warm sugar-free lemonade are often soothing) • Administer cough medicine as advised by your health care provider.
Fever	<ul style="list-style-type: none"> • Take temperature every 3-4 hours. Because many children and adults with PWS have difficulty with temperature control, a fever may or may not be present when they have a serious infection. • Administer medication to lower fever as directed by your health care provider. In children, DO NOT USE ASPIRIN.
Headache &/or Body Aches	<ul style="list-style-type: none"> • Dress in lightweight clothes and do not cover with too many blankets if fever is present. • Take pain-relieving medication as directed by your health care provider.

When Should I Contact my Health Care Provider?

Often times the best indicator of a more serious infection can be a change in behavior, an increase in sleepiness and/or a decrease in appetite. However, persons with PWS often do not exhibit a change in appetite

Notify your health care provider if the person with PWS has:

- Nasal secretions or is coughing up mucous that is yellow, green or gray.
 - A persistent cough that keeps them awake.
 - Chest pain or persistent facial or head pain.
 - Presence of a high fever (above 101 degrees)
- Trust your instincts. When in doubt, call for advice.



Who Should Receive the Influenza Vaccine?

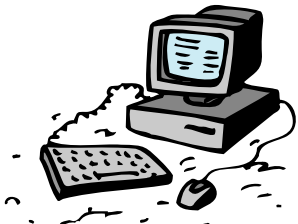
The Center for Disease Control has set up guidelines to assist in identifying those persons who are at high risk. This fall there are no reports of a shortage of the flu vaccine. The vaccine should be available for the general patient population.

High risk has been defined as:

- People over 65 ears or older
- Children or teens on long-term aspirin therapy
- People of any age with chronic diseases of the heart, lung and kidneys or who have diabetes, severe anemia, or immunosuppression.
- Women in their 2nd or 3rd trimester of pregnancy during the flu season
- People who live in a household with high-risk people.

Should Persons With PWS Receive the Flu Vaccine?

Unless otherwise advised, persons with PWS who have a chronic health problem (asthma, diabetes, heart problems...) should receive this vaccine. Many physicians also recommend it for persons with PWS because of their weak chest muscles and poor muscle tone. Don't hesitate to discuss this with your health care provider.



Request for Email Addresses or Updates

Are you receiving all of our last minute updates and information? Often times, our office receives information that we pass on to our membership via email. Please drop us a note to let us know your email or inform of us of any changes. We strive to keep you updated on issues of concern.

Contact Mary Lynn at the state office on the toll free number at 1-866-797-2947 or via email: wisconsin@pwsausa.org

Special Words of Thanks

The membership, Board and staff of PWSA of WI, Inc. would like to extend their sincere appreciation to Nancy and Steve Burlingame, Kathy Bomber, and Dan Beaver for their dedication and service as Board members and/or Officers during their terms. These individuals have been instrumental in the planning, supporting and assisting with so much the organization has accomplished during the past several years! Once again - a Special Thanks to all of you!



New and updated web site...
www.pwsausa.org/WI

In the past several weeks/months, the web site for PWSA of WI, Inc has undergone some dramatic changes, thanks to Jennifer Kryzak! Jennifer was kind enough to take on the role of "webmaster" for our site when she moved to Wisconsin! She has updated many of the items and added tons of links and information!! She has included such things as our newsletter: *The Wisconsin Connection* for the last several months, links to a number of resources, upcoming conferences and events that may be of interest and so much more!!

Check it out and if you have ideas or suggestions on things we may want included, contact Mary Lynn at the office via phone: 1-866-797-2947 or email: wisconsin@pwsausa.org .

PWSA of WI, Inc. 2006 Calendar

February 4, 2006	PWSA of WI, Inc Board of Director's meeting	To be determined
April 1, 2006	Hobby Day	Oconomowoc, WI
July 19 - 21, 2006	PWSA (USA) conference	Grand Island, NY
August 26, 2006	6 th Annual PWSA of WI, Inc. Golf Benefit	Oconomowoc, WI

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