



# 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.**

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The Wisconsin Connection

## A Note from the President: Barb Dorn

### PWSA of Wisconsin to Host 2008 PWSA (USA) National Conference

I am very proud to share some exciting news. Wisconsin has been approved to host the 2008 PWSA (USA) national conference. It will be held at the Sheraton Four Points in Milwaukee. This hotel is located down the street from Mitchell International Airport. The hotel's layout, rooms and conference accommodations will make for a perfect site. We have a big job on our hands but I am confident that our membership and their family members will assist us in this great honor. The dates for the conference include:

**Wednesday July 2<sup>nd</sup>** – Scientific Researchers Meeting, Residential Providers Conference and Chapter Presidents Meeting.

**Thursday and Friday July 3<sup>rd</sup> and 4<sup>th</sup>** – General Conference for Parents, Care Providers and All Interested Parties.

Researchers from around the world will gather to discuss and share their progress in learning more about many issues and concerns that face children and adults with PWS. PWSA (USA) has always felt it was important to facilitate this meeting – to keep researchers talking and sharing about the progress and new information we continue to learn.

PWSA (USA) has adopted an "alternate year" child-adult care services during their conference. **On the odd years**, the national conference offers day support services for persons with PWS of all ages. It is referred to as the YAP program (Youth and Adult –also includes infants and children). They hire professionals with an expertise in PWS to plan and care for persons with PWS. Parents and caregivers can attend the meetings and the children and adults with PWS are cared for and entertained during the day. **On the even years**, chapters provide the planning and assistance for conference with a smaller Youth and Infant – YIP program. Child care is provided for infants and children up to and including age 5. **Care in all years** includes the care of siblings as well as those with PWS. This service is limited in the even years in order to make hosting a conference more manageable for a chapter. PWSA (USA) has made it a priority to support parents of young children who are often just facing a new diagnosis. In addition, **the hosting chapter offers child care for persons with PWS of all ages from their state** so that parents and families can attend the conference as well as assist in various volunteer capacities.

Every year, the conference covers topics for persons with PWS of all ages. This is an exciting opportunity for Wisconsin to show and share what a great state we have; and for health care professionals, parents, and care givers to see and listen to expert speakers in the field of PWS.

On Saturday November 11, 2006 we will be hosting our first "official 2008 conference planning meeting". It will be held at the offices of Prader-Willi Homes of Oconomowoc at 9:30 am. At that time, we will be identifying our needs; establishing committees; making timelines and beginning our recruitment of volunteers. **WE WILL NEED YOUR HELP!**

If you are the creative sort of person, you may be able to give us ideas on a theme. Since the conference will take place over the Independence Day holiday – we may want to include this in our theme. We also feel it would be nice to pull in the State of Wisconsin in some sort of way. We will be hosting an opening reception. We will need someone who is creative who can plan activities for young children and families – focusing on welcoming everyone to our great state. A gala or special dinner is also a part of the festivities. We will be looking for people to assist with table decorations and in other ways to make this a special event.

As you can see, there will be lots to do for all sorts of people with different gifts and talents. So stay tuned for many more updates. We welcome your ideas, input and support.

*Barb*



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

### 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"> <li>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.</li> </ul>

Cough or Lung Congestion	<ul style="list-style-type: none"> <li>Encourage the person to get up and move around every 1-2 hours. This helps to expand their lungs.</li> <li>Encourage deep breathing and coughing up secretions. (Even crying &amp; yelling can help to expand their lungs.)</li> <li>Encourage fluids in moderation. This helps to keep lung secretions thin &amp; watery. (Warm broth &amp;/or warm sugar-free lemonade are often soothing)</li> <li>Administer cough medicine as advised by your health care provider.</li> <li>Take temperature every 3-4 hours.</li> </ul>
Fever	<ul style="list-style-type: none"> <li>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.</li> <li>Administer medication to lower fever as directed by your health care provider. In children, DO NOT USE ASPIRIN.</li> </ul>
Headache &/or Body Aches	<ul style="list-style-type: none"> <li>Dress in lightweight clothes and do not cover with too many blankets if fever is present.</li> <li>Take pain-relieving medication as directed by your health care provider.</li> </ul>

### 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 years 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 2<sup>nd</sup> or 3<sup>rd</sup> 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.

## Holiday Alert

As the holidays approach, we want to remind families of the recent unexpected deaths of individuals with PWS over the last several years due to food-binging episodes. In many cases, the person with PWS was slim and had no weight concerns. Remember that someone with PWS who has good weight control does not mean they have **total food control**. When a person eats, the stomach stretches. It may become "over stretched" or distended when one overeats. We know that persons with PWS do not have the normal mechanism of registering fullness as they eat. They are at a very high risk of over distending their stomachs.

Many of these individuals were at holiday festivities in large groups with many people "watching". It is believed that the person with PWS over distended their stomach, and stretched it to the point that it cut off its blood supply causing necrosis (the stomach tissue dies). This resulted in rupturing of the stomach with highly acidic gastric juices leaking into the chest and abdominal cavity. This is a life threatening situation if it is not quickly diagnosed and treated.

Unfortunately, most of these cases have resulted in death and been diagnosed in a postmortem examination.

## Join PWSA of WI, Inc.'s NEW "Card Club"



We are starting a new "card club" for everyone with PWS throughout the state!! Everyone who registers with Mary Lynn at the state office will receive a card 6x a year. Cards will be mailed out for your birthday, Valentine's Day, Spring Holiday, Mid Summer Holiday, Fall Holiday and Winter Holiday! **We will be mailing a registration letter to everyone with PWS in our database in December, 2006. Please do not send me your registrations before December 2006.** If you have any questions, feel free to call me at: 1-866-797-2947 or send me an email at:

[wisconsin@pwsausa.org](mailto:wisconsin@pwsausa.org)



## UPCOMING MEMBERSHIP RENEWAL CAMPAIGN

In the upcoming months, watch for paperwork on renewing your membership with PWSA of WI, Inc.! We are targeting mailing this out around the first of the year. If you do not receive the initial paperwork mailing after January 1, 2006 – let Mary Lynn know at the state office: toll free at 1.866.797.2947 or email:

[wisconsin@pwsausa.org](mailto:wisconsin@pwsausa.org)



## Getting Bigger and Better... Our annual golf benefit, that is!!

Well, we've done it again! Our 6<sup>th</sup> Annual Golf Benefit for PWSA of WI, Inc was our best yet!! We had 87 golfers and made a profit of **\$8452.60!!** We can't begin to put into words how grateful we are for your enthusiasm, participation, and support for making this event so successful! We couldn't possibly continue to do all we do to support, educate and advocate for persons with PWS in Wisconsin without the generous people who support US through all of our fundraising efforts! Thank You!

### Thanks so much to the following Hole Sponsors:

1. Virchow, Krause & Company, LLP
2. CSI Testing Plymouth, MN
3. CSI Testing Plymouth, MN
4. Jim's Marina
5. BACZ Arts & Crafts LLC
6. John and Pat LaBella Family
7. Oconomowoc Developmental Training Center
8. Paragon Industries
9. Rd Image – Ianine Rozina
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11. Sedgwick–Claims Management Services, Inc.
12. Prader-Willi Homes of Oconomowoc
13. "Friends of Olivia" – The Jahns
14. Hughes Dental Clinic- Cassville, WI
15. For Olivia from the Mitchells
16. Tosa Pediatrics
17. Unicus Promotions – Mike Stock
18. Financial Partners/Networth – Scott Layeux
19. The Dorn Family - Don, Barb, Tony & Tyler
20. Alliance Capital – Ben VanKorn
21. The Jayne & Dick Becker Family
22. Milwaukee Heart Scan
23. Keith N.- Friend to PWSA-WI
24. John, Marguerite, Jabin, & Jonah Rupnow
25. Bodoh Home Improvements- Dousman, WI

26. FABCO Equipment Inc.
27. St. Clare Hospital – Baraboo
28. In Honor of Alex and Matthew Larson
29. Mark Dorn & Laurie Grinnell
30. William & Carolyn Murphy Family
31. "Friends of Tony Dorn – Chuck, Karen, & Kimberly"
32. PromHagen – Promotional Marketing By Jeff Verhagen

### Thank you to our generous prize donors!!

- PWSA of Wisconsin, Inc.
- PWSA – USA
- Thomas Hughes Family
- Thunderbay Grille
- WKLH Radio
- Milwaukee Electric Tool
- Machine Shed Restaurant - WKLH
- John & Pat LaBella Family
- John & Bonnie Kraft Family
- Balistreri's Blue Mound Inn -WKLH
- Suzy's Cream Cakes - WKLH
- The Comedy Café - WKLH
- Gray Jewelers
- Fireworks City - WKLH
- Milwaukee Brewers -WKLH
- Green Bay Packers
- Paragon Candles
- Prader-Willi Homes of Oconomowoc
- Paganica Golf Course
- Sybaris Pool Suites – WTMJ
- BACZ Arts & Crafts LLC
- Kryzak Family
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- Dave & Sandra Nagy Family
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- Goebel Woodwork, Inc.
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- Panera Bread
- Avon
- Bruce & Jackie Mallow Family
- Gordie Boucher Ford
- Milwaukee Wave
- The Safe House
- Ragazza
- Wigwam Mills, Inc
- City Screen Print
- Robb Beckmann
- Gail Sylvan

We were very fortunate to have members of the organization who worked with family and friends to get T shirts printed for all of our golfers! They had the PWSA of WI, Inc logo and looked FANTASTIC!!

We also want to thank everyone who golfed, volunteered and just helped to make the day a great success! **Thanks to you all!! We could not do this without your support!**

**Mark your calendars now –  
Our 7<sup>th</sup> Annual Golf Benefit  
will be August 25, 2007.  
We will be mailing out  
more information about  
the golf benefit as details  
become finalized.**



## Election Results

The results are in!! The following people were elected to these Officer and Board positions:

**Vice President: Crystal Boser**

**Treasurer: Tom Hughes**

**Board members: Jackie Mallow, Betsy Van Heesch, Al Leuning**

The new Board members will start their positions in January 2007.

We would like to thank outgoing Board member Pat LaBella for her time and talent during her Board position. We know that Pat will not be idle in this organization just because she is no longer on the Board. We already have some ideas on other tasks she can help us with...

**Thanks so much Pat!!**

## Colleen's Angels for Prader-Willi Syndrome

**Sunday November 19,  
2006**

**3:00PM – 9:00PM**

**Gaelic Park  
6119 147<sup>th</sup> St.  
Oak Forest, IL**



Colleen Doherty was a young woman who resided in Oconomowoc and who lost her life on December 27th, 2005. In her memory, Colleen's family and their Irish American family are holding a benefit event for the Prader-Willi Syndrome Association (USA) and PWSA of WI, Inc. Funds raised from this event will be used for medical awareness, support and other projects that are close to the family. Had there been more medical awareness, perhaps, Colleen might still be alive today. There will be **live entertainment** by: Velvet Green; Pat Daly and the Sounds of Green; and Frank O'Connor; all the way from San Francisco, CA.

There will also be a **ticket raffle with fantastic prizes** including cash and a surround sound home system, as well as a 50/50 raffle and silent auction with more spectacular items. The cost at the door will be \$25.00 per person and will include food and entertainment.

**Come ... be one of Colleen's Angels.** Colleen's legacy, which her family and friends are now honoring, was to make the world aware of this very serious syndrome. We hope that you will join Colleen's family in remembering Colleen and help those still living with PWS by attending this event. Please give your support and give those with PWS a life that they deserve.

**For more information about this event, please contact Connie and Bill Devitt at (219) 322-0228 or (708) 372-1737 or John O'Connell at (708) 489-6727.**

### About Colleen

Colleen was a beloved individual whose purpose in life was to make people happy. She loved life, wanted to be with her family, sit around and talk, and have a cup of coffee. She was in love with a man where she lived at a residential care facility and she was a typical girl giddy over a guy. She is sadly missed.

## How PWSA of WI, Inc Helps Our Members

As an organization, PWSA of WI, Inc. strives to support, educate, and advocate for persons with PWS, their families and those who support them. We do this through our general assistance fund, discounts and scholarships we offer for conferences, membership scholarships, and camp scholarships – just to name a few. Each year the Board of Directors of PWSA of WI, Inc. sets aside funds to assist in providing financial assistance for families of a person w/ PWS to help meet the unique needs of this disorder. The person w/ PWS, a family member or care giver must be a member of PWSA of WI, Inc and the person w/ PWS must be a Wisconsin resident. Eligibility is based on financial need of the person w/ PWS. We currently have a limited amount of funds left for 2006 but if you or your loved one with PWS has specific needs that qualify through any of these programs, let us know.



### A Health Update on Prader Willi Syndrome

Our Health Update on Prader-Willi Syndrome training was held Wednesday, October 11, 2006 at the Quality Inn and Suites in Madison. We had over 50 people in attendance at this training: We had five physicians and Barb Dorn, (RN crisis counselor for PWSA (USA), parent, advocate, and President of PWSA of WI, Inc.) speaking on a wide variety of topics including scoliosis, respiratory issues, growth hormone, osteoporosis, emergency care, dental health, eye concerns, skin care, water issues, constipation, and the ever popular – diet and exercise.

Everyone in attendance received two health information packets providing parents and caregivers information and tools to be effective health advocates for persons with PWS. One packet was to provide the person attending the training with information while the second was to share with the primary health care professional treating the person with PWS. We plan to distribute more of these packets to our membership who were unable to attend this training. An additional mailing will be done in January 2007.

The Wisconsin Connection

## Planning Meeting for 2008 PWSA (USA) Conference Hosted by Wisconsin

We will be having our 1st official planning meeting for the 2008 Conference on Saturday November 11, 2006 at the Corporate Office of PWHO - Oconomowoc Residential Programs. The Corporate Office is located at 1746 Executive Drive, Oconomowoc, WI 53066. Our meeting will begin at 9:30 am. We will get more information compiled and available prior to this meeting, however - please mark your calendars. Let Mary Lynn at the state office know if you would like more information or have any ideas or suggestions. Contact her via email at [wisconsin@pwsausa.org](mailto:wisconsin@pwsausa.org) or via phone, toll free at 1-866-797-2947.

### Sharing Resources - Helping Each Other



Frequently, the program director for PWSA of WI, Inc. - Mary Lynn receives calls requesting the names of various types of physicians and other professionals who may have patients with PWS and who have knowledge and experience with the many aspects of this disability. We rely on YOU - to share names and contact information about these professionals in your area. Many families use the same professionals on purpose - hoping that with more than 1 patient/client with PWS, this professional will feel motivated to learn more. PLEASE SHARE THOSE NAMES AND RESOURCES WITH US - SO WE CAN SHARE THEM WITH OTHERS. There is no way we can know who is knowledgeable if you don't tell us. So if you have physicians, dieticians, therapists, camps or other services that others with PWS can benefit from - contact us via our toll free number: 1-866-797-2947 or Email:

[Wisconsin@pwsausa.org](mailto:Wisconsin@pwsausa.org)

## Message from the office...

From Mary Lynn Larson

**Wow...** we have been working on so many different things here over the last several weeks, I have to make lists of my lists to keep them straight!! We had a **GREAT** response with the Golf Benefit in August and the Health Update training in October was very well received!! Thanks to everyone who helped us make these events such a success! We have had a great response to our call for volunteers to assist with the Card Club which will be beginning in 2007 and we are hoping for a similar response as we start preparations for the upcoming PWSA (USA) National conference that Wisconsin is hosting in 2008.

Our membership, families and friends have always been there to assist us with these projects – and we are **so grateful** to you. Over the years that I have been part of the state organization, it has always been encouraged of our Board members and volunteers to “do what you can – but if something comes up with family that requires you to step back for a bit, let us know” and at that point, usually one of the others will step up to assist. We recognize that this strategy has made it possible for us to become such a strong and productive chapter.

Take note, in the next few months; you will be receiving several different mailings targeting the Caring Is Sharing campaign as well as our annual membership renewal campaign. Please contact me if you do not receive these mailings by the end of January 2007. You can either send me an email or contact me on the toll free phone line.

As we begin the planning stages for the 2008 National conference, we are looking at a large project like this and trying to break it down into manageable steps to achieve our ultimate goal. As this is such a large undertaking, we can use any number of volunteers doing any number of things over the next 22 months. We are looking for people with contacts and skills as we start making plans. For example, things we are looking might include: large potential donors; activities to use in the YIP program; ideas of a

potential logo and theme for the conference; obtaining office supplies to be used before and during the conference; people and young adults to assist with the set-up, implementation and clean-up of the hotel site for the YIP program; and **SOOO** many more things! We have not yet had our first planning meeting for the conference, (that is scheduled for November 11, 2006) yet we are beginning to make notes of ideas we might need or want to implement during the conference, things we might want to have available during the conference, etc... As these ideas are presented to me, I keep encouraging people to write them down and send them to me so I can pass them onto the appropriate people.

Thanks for your time, treasure and talent in helping us to be a strong chapter. We could not do this without your support!

Hugs, **Mary Lynn**

## Good Search: a new search engine that helps PWSA(USA)

A new search engine (like Google or Yahoo) that works the same as all the others, but you raise a penny for PWSA (USA) for every search you do on the web. Now you can raise money for PWSA (USA) just by searching the Internet at GoodSearch.com. You use it like any other search engine — the site is powered by Yahoo! — but each time you do, money is generated for PWSA (USA). Here's how it works:

1. Go to [www.goodsearch.com](http://www.goodsearch.com)
2. Type PWSA into the "I support" box and click on "verify" then scroll to PWSA (Sarasota, FL)
3. Search the Internet just like you would with any search engine
4. Since GoodSearch shares its advertising revenue with charities and schools, every time you search the Internet at GoodSearch, you'll be earning money for PWSA (USA).

GoodSearch also has a toolbar you can download from their homepage so that you can search right from the top of your browser. The graphics and details are on the PWSA (USA) website at <http://www.pwsausa.org/goodsearch/index.htm>

## PWSA of WI, Inc. 2006 Calendar

<b>November 11, 2006</b>	Planning Meeting for 2008 National Conference hosted by Wisconsin	Oconomowoc, WI
<b>November 19, 2006</b>	Colleen's Angels Benefit for Prader-Willi Syndrome	Gaelic Park, Oak Forest, IL
<b>August 1-3, 2007</b>	PWSA(USA) 29 <sup>th</sup> Annual Conference	Dallas, TX
<b>August 25, 2007</b>	7 <sup>th</sup> Annual Golf Benefit	Oconomowoc, WI

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