



# 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  
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## Office Address:

PWSA of WI, Inc.  
 Information & Referral  
 2701 N. Alexander  
 Appleton, WI 54911-2312  
 Toll free: 1-866-797-2947  
 Fax: call first

Email:

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

Website:

[www.pwsausa.org/WI](http://www.pwsausa.org/WI)

PWSA of WI, Inc. is a chapter of the Prader-Willi Syndrome Association (USA).  
 5700 Midnight Pass Road  
 Suite 6  
 Sarasota, FL 34242  
 800-926-4797 or  
 941-312-0142  
 Fax: 941-312-0142

Email: [national@pwsausa.org](mailto:national@pwsausa.org)

Website: [www.pwsausa.org](http://www.pwsausa.org)

## **A Note from the Co-Presidents: Steve and Nancy**

Fall always seems to put me in a reflective mood. With school starting, the weather changing, and short days upon us, I sense a “settling in” as we prepare for another winter. Due to some recent challenges we have encountered lately, I’ve been reflecting on the changes our family has experienced due to the presence of PWS in our lives.

A few months back, we noticed Kyle having some increased anxiety, with more hand-wringing, temper outbursts and perseveration. Crystal contacted his psychiatrist and medication changes were initiated. This seemed to help and we all thankfully went about our business, grateful for the easy fix. Then we stumbled on food foraging and sneaking. Despite the fact that our family is quite well-informed about the syndrome, when we first noticed a slight weight gain, we attributed it to too many birthday parties, family gatherings, etc... over the summer. Then I found a canister top awry with a lone raisin on the floor nearby. Eventually, I walked in on an empty box of Rice Krispie Treats, numerous empty wrappers, and a kid with chipmunk jowls chewing like crazy! Kyle has always been so good about following his ‘snack-meal-snack-meal-snack-meal’ routine - that I was shocked! Isn’t that silly? A person with PWS sneaking food should not be shocking – isn’t that what they do? We had been warned that during the pre-teen and teen years, problems may change and / or become more pronounced (and really, what pre-teen or teen doesn’t develop some problems – with or without PWS?) but for some reason, when the reality occurred, I felt saddened once again by what this syndrome is. For me, there is always a period of sadness prior to acceptance. This is the first time we’ve had to look at installing refrigerator and cupboard locks. It’s something I’d hoped we could avoid. But in the big scheme of things, it’s just not that big a deal. If locking things up can keep Kyle safe from himself and that haunting hunger, and take the burden off him of trying to control the uncontrollable, it’s OK. After modifications with medications and Kyle’s environment, things have settled down a bit and he is once again his happy, gentle self. And that’s what really matters.

As we’ve gone through the years; we’ve had a lot of ups and downs. But the struggles are miniscule in comparison to the joys and blessings of life with Kyle. In fact, in so many ways he is my light, my mentor, my inspiration. I hope that sharing our struggles will prove useful to some of you when changes and challenges strike your family and your loved one with PWS. I’m certainly grateful that there are those who have shared with me. Isn’t that what this organization is all about?

Until next time, thank you for supporting our loved ones with PWS through your support of PWSA of WI, Inc.  
 – Nancy

# 4<sup>th</sup> Annual Golf Benefit a HUGE Success!!



Kara was one of the sponsors from the Moser-Sadzewicz family.

The PWSA of WI, Inc. 4<sup>th</sup> Annual Golf Benefit was held Saturday, September 18, 2004 with gorgeous weather

and generous friends and family!!



What a gorgeous day to enjoy some golf!!

Our event continues to grow thanks to a dedicated group of committee members who work on getting us the hole sponsors, prizes, and golfers! We had 66 golfers joining us this year. The event raised over \$6000! Some new items featured this year were our silent auction and a raffle. There were autographed footballs with some very familiar names to anyone who is a Packer fan, a smoker (for smoking meats), a boom box, a Mountain bike and much more!

Here are some of the autographed footballs...

Recognize any names?



Here is a sampling of some of the prizes...

PWSA of WI, Inc. would like to thank all of the hole sponsors for supporting this year's benefit:

- 1) Virchow, Krause & Company, LLP
- 2) CSI Testing Plymouth, MN
- 3) CSI Testing Plymouth, MN
- 4) ParTee Pub
- 5) Mark Dorn
- 6) Fabco-Cat
- 7) The John and Pat LaBella Family
- 8) Oconomowoc Developmental Training Center
- 9) First Associated Insurance
- 10) Paragon Industries
- 11) Medinet
- 12) The Moser-Sadzewicz Family
- 13) Milwaukee Heart Scan, LLC
- 14) Prader-Willi Homes of Oconomowoc
- 15) Keith N.- Friend to PWSA-WI
- 16) The Don Dorn Family
- 17) WKLH Radio
- 18) Hughes Dental Clinic- Cassville, WI
- 19) The Nashotah Clubhouse
- 20) Principal Financial Group
- 21) The Luening Family
- 22) EWH Small Business Accounting S.C.
- 23) Bodoh Home Improvements- Dousman, WI
- 24) Bob and Kathy Bomber Family
- 25) Todd Bramson, CFP
- 26) Dick and Jayne Becker Family
- 27) Grandparents of Olivia L.
- 28) Capital Alliance



Here are some of the hole event prizes



Here is a group of happy golfers!!

We also could not have had such a successful day without the wonderful prizes donated by the following companies and individuals:

- Six Flags Great America
- PWSA (USA)
- Menard's
- Family Land Water Park W.D.
- Glen Erin Golf Club- Janesville, WI
- Hollywood Video
- WKLH Radio
- Milwaukee Electric Tool
- Nashotah Club House
- Anchor Moving
- John & Pat LaBella Family
- Kraft Foods
- Wigwam Mills
- Doug Meek
- The Milwaukee Bucks
- The Milwaukee Admirals

- Gray Jewelers, Gladstone, MI
- Xpressions Salon
- The Green Bay Packers
- The Milwaukee Waves
- Crystal Boser and Family
- Paragon Candles
- Prader-Willi Homes of Oconomowoc
- PWSA of WI, Inc.
- Nancy & Steve Burlingame
- Paganica Golf Course
- John Hawks Pub
- Suzy's Cheesecakes
- Camille's Trattoria
- The Thunder Bay Grille
- Virchow Krause & Company
- WTMJ-TV
- FM 106
- WTMJ-Radio
- Gail Sylvar
- Lynn Ann Seeger

We also want to say "Thank you" to everyone who helped us set things up, worked the registration table, cleaned up and just offered a helping hand!! We may not have been able to say "Thank you" at that time, but know that we appreciate all you do!

Below are some of "the crew" who helped in getting things ready for the golf benefit.



**MARK YOUR CALENDARS NOW!**  
**Next year's Golf benefit will be on**  
**Saturday, September 17, 2005 with a**  
**9am shotgun start!**

**Fundraising: Entertainment Books**

Do you buy one of the Entertainment Books each year to benefit from the buy 1, get 1 free coupons and other discounts? Your purchase could now benefit PWSA of WI, Inc. We have teamed up with Melissa Sirovina's employer, Washington Mutual who has a committee of people who head up a variety of volunteer/fundraising efforts, (The CAN committee). They have provided us with this opportunity. You can order an Entertainment Book for your area by logging onto the website at: [www.entertainment.com/support](http://www.entertainment.com/support). You then need to enter your zip code so they can determine which book you can use in your local area. Enter our account number which is **857299** and make the purchase using your credit card. You do not need to live in the state of Wisconsin to buy an Entertainment Book and our organization can still reap the benefits. Online ordering is available until December 2004. The books vary in cost depending upon where you live but average about \$35.00 per book. The coupons in the book are good now until November 2005. Coupons are from a variety of businesses including sports teams, restaurants, cinemas, and various events throughout the year. If you do not have access to the Internet, need assistance or have questions, give Mary Lynn a call at the state office at: 1-866-797-2947. She may be able to assist you.

## WHAT MAKES AN ADJUSTED ADULT WITH PWS?

By: Janalee Heinemann,  
Executive Director, PWSA(USA)

During our thirty-year-old son Matt's recent visit home at Thanksgiving, I was again touched at what a good person he has become, and knowing intimately about all of the crisis situations we get at the office, had to ask myself again, "Why?" I am grateful he is doing so well, but what makes the difference between Matt and some other young adults with Prader-Willi syndrome (PWS) who have good parents, yet are such a challenge? In my searching for answers, right or wrong, I have come up with the following possibilities:

**Medication** – Personally, I think that lower doses of psychotropic medications in combination are very beneficial in treating the many emotional and behavior issues that are inherent to the syndrome. Unfortunately, there is no magic bullet in treating our "kids." And since their major issues vary (as well described in the recent article written for us by Dr. Gourash and Dr. Forster, and in past articles by Barb Whitman, Ph.D.) and they all respond differently to medications, we do not have an easy prescription plan. I cannot help but think though that there has to be a better roadmap of "most likely to succeed" medications that we can share with professionals. This

was our goal in mind by approving research money that will be focused in this particular area.

**Genetics** – Although Matt has the classic deletion, and has had all of the classic characteristics including years of varying levels of challenging behaviors, the picking compulsion, and a significant and creative ability to forge for food, I have certainly known worse in the degree of the problem. This brings us to the new revelation of two categories of deletion reported by Dr. Merlin Butler at our PWSA (USA) 2003 conference in Orlando (see the Sept-Oct Gathered View or buy our abstract booklet for more details) In their research at Children's Mercy Hospitals and Clinics, Kansas City, a very simplistic interpretation is what Dr. Butler is calling Type I (T1) deletion has more of a deletion of genetic material – and significantly more maladaptive behavior. Whereas Type II (T II) deletion has less of a deletion – and generally less maladaptive behavior than either Type 1 or in some areas, those with UPD.

**Age** – In another study reported at conference this summer by Elisabeth Dykens, Ph.D., of UCLA, people with PWS typically significantly improve in behavior in their 30' and 40's. (See the Nov-Dec edition of the Gathered View) I can see a gradual change in Matt over the last ten years in that he is much more accepting of who he is and in what he can or cannot do.

**Management** – Although I feel we did a lot right in Matt's behavior and food management in the earlier years, and I have written on this topic, I do not think this is the entire answer. I do know though that I still believe in my philosophy that no matter what our children's problems are, we must challenge them to be decent human beings. Society will not be all-forgiving like a parent, and many, many people with significant disabilities end up expelled from school and in jail – including some with PWS. A child with PWS must learn that no matter how upset they are, hitting, hurting and destroying others property is never OK!

I also have to give great credit to Matt's staff at Open Options. Some have been with him the entire ten years he has been living in Open Options supportive living homes. Matt has won awards at work and also for "Client of the Year" (Actually was "Consumer of the Year" which is the current phrase, but I hate that term since our children "consume" too much.) Although Matt gave the staff great grief that first year, both Matt and the staff (they were fairly new at the PWS challenges back then) grew in their understanding and love for each other.

**Letting Go – And Letting Him Grow --** I think one of the biggest challenges for our parents is learning how to avoid sabotaging supporting living placement once their child with PWS moves away from home. You spend your life advocating for your child and protecting them from the hurts of the world, and then you are supposed to turn them over to strangers when they become a

young adult. It is an understatement to say that this is difficult to do. One of the advantages we had was my years of exposure to seeing how parents often inadvertently and unintentionally sabotaged their adult child's placement by over-involvement post placement. I compare it to a divorce situation where the child learns to play one parent against the other. I think it is crucial that from the beginning, a strong direct line of communication is set up between staff and parents – and not have the person with PWS be the link between.

Of course, when Matt first went into placement, he tried every trick in the book. I remember one call where he was upset because the staff did not make his favorite meals. When I asked him what that was (since I thought they were all his favorite) he said, "lobster bisque and quiche lorraine." I said, "Matt, what are you talking about? I have never made either of those dishes in my life!" We decided early on that we would screen his calls. We told Matt that he had to learn to relate to the staff and resolve his differences with them, and after days of upset calls, told him we would only respond when he had positive things to say. This may seem harsh, but we did listen to his woes on the answering machine, and if we thought there might be a real issue, would discreetly call his staff to work on the issues without him knowing we had done so. I knew it was absolutely crucial for him to learn how to resolve his issues and not to be dependent on us to do so for him.

Sometimes I do not think we give our adult children with PWS credit for having the ability to resolve issues, or give them the opportunity to really grow up. Would you call the president of their university or their landlord for your other adult children once they leave home? Hopefully not. Of course, a parent may say, "But my child with PWS is more vulnerable and dependent on his/her caregivers." That is true, but as I said above, they still have to be the best they can be. As a parent, after placement, you have to decide what battles with staff are important and which ones can be let go. Most important is to not play the role of rescuer. Your adult child will use you and abuse the staff. The staff will resent you and not establish the needed relationship with your child. Have an agreement with the managing agency who you should go to with issues, and what the back up plan is if that does not work. Again, go to them without your child knowing you did so. Then help your child brainstorm ways they can resolve their own problem. Once they have learned to do this (or at least think they did it on their own) they will feel empowered to do so in the future. Also, for every time you have to privately criticize staff, make sure you have spent double that time complimenting them for what they did right.

We think the world of Matt and his key staff. Has every staff person been appropriate? No. But, Matt has leaned to get along with about everyone – and whom he can do to within the agency if he has a problem. Is there one answer for why Matt is doing so well? No, but there are some obvious pieces to the puzzle, and we can continue to work towards finding where the other pieces fit in. I want every

parent feel the pride and peace we feel about were Matt is with his life.

**Side bar:**

Another separate but positive report: Matt has been on the adult growth hormone research study in St Louis for about seven months, and the positive changes are remarkable. He had been gaining weight, but since on the study, he has gone from 192 pounds to 140. He is now under goal weight! Of course, his body shape has changed dramatically and he went from having quite a belly to having a flat stomach. Beside the obvious physical, the most noticeable change we observed was that his energy level dramatically improved. More subjective is that it appeared he was more satisfied with his diet. His tremendous interest in food was still there, but he appeared less intent at getting more food. We will be very interested in following the results of this study.



**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.*

**Introduction**

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> </ul>
Fever	<ul style="list-style-type: none"> <li>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.</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 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 2<sup>nd</sup> or 3<sup>rd</sup> trimester of pregnancy during the flu season
- People who live in a house hold 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.



National PWSA(USA) Conference  
July 24 – July 31, 2005

Orlando, Florida

For more information, contact:

**Prader-Willi Syndrome Association (USA)**

5700 Midnight Pass Road  
Suite 6

Sarasota, FL 34242

Telephone: 800-926-4797 or 941-312-0400

Fax: 941-312-0142

email: [national@pwsausa.org](mailto:national@pwsausa.org)

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**PWSA OF WI, Inc.  
FUNDRAISER  
"Pizza With a Smile"**



Wisconsin Pizza Huts have partnered with the **Prader-Willi Syndrome Association of Wisconsin, Inc.** to raise funds to benefit children and adults suffering from this challenging disability. These coupons can be used at most participating Pizza Hut locations throughout Wisconsin. To see if your local Pizza Hut is a participant, visit <http://www.WHGonline> or <http://www.phsw.net>

It's easy - all you have to do is contact the state office at 1-866-797-2947 or via email:

[Wisconsin@pwsausa.org](mailto:Wisconsin@pwsausa.org) to purchase a \$10 pizza card and you will receive:

- 12 FREE MEDIUM PIZZAS WITH EACH PURCHASE OF A LARGE PIZZA (a \$120.00 value)  
\*There is no expiration date.
- A TAX-DEDUCTIBLE DONATION TO **PWSA OF WI, INC!**
- A BIG SMILE - EATING GREAT PIZZA, KNOWING YOU ARE HELPING PEOPLE WITH PRADER-WILLI SYNDROME RIGHT HERE IN WISCONSIN!

This is a great gift to tuck in a Christmas stocking, a thank you card; send away to a loved one at college; or remember someone "just because". The list is endless! Don't forget to get one for yourself.

Please make sure to let us know if you need a receipt.

\*\*\* REMINDER \*\*\*

### MEMBERSHIP RENEWAL



Don't forget to send in your membership renewal! If you did not receive the initial paperwork mailing – let Mary Lynn know at the state office: toll free at 1.866.797.2947 or email: [wisconsin@pwsausa.org](mailto:wisconsin@pwsausa.org)

## Notes from the office...

by Mary Lynn Larson

I started getting things ready for the newsletter about a week ago and had a "Note from the office..." already started talking about how things had finally settled down in our house after the initial chaos of the school year beginning as both of the boys were getting ready for new rules, new classrooms and new routines. Then three days later, Alex (our almost 12 yr old) did not show up at home at his usual time after school. (We only live 2 blocks from school.) He had decided to go home with a new friend – without letting anyone know. After a very disconcerting 90 minutes of trying to locate him involving school personnel, friends, and neighbors – he was located safe and sound!! This incident made me realize that we were so busy working on the **NEW** rules, routines and schedules that we neglected to remind him of the rules that **HAD NOT** changed; such as making sure that Mom or Dad always knows where you are and who you are with!! Later, as I spoke with friends about the incident, I was reminded about how we need to regularly reinforce things with our boys. Things like: the rules, how proud I am when they make good choices, or demonstrate good behavior. I had forgotten to "find them doing good things and compliment or praise them on it!!"

I am now trying to make it a point that Alex and I have some 'alone' time during the week where we can review the week and talk about the good and bad things that may have happened; – whether we are running errands, visiting the library or driving to an appointment together. It's important for all of us to hear when we are recognized doing something good or making good choices... I had just forgotten – and apparently let Alex forget also. Hoping the chaos in your lives does not allow you to forget...

Take care,

Mary Lynn

**Ballots for electing new Board Members and Treasurer should be in the mail soon. Don't forget to return your ballots before November 6, 2004.**

**PWSA of WI, Inc. 2004 - 2005 Calendar**

<b>October 9, 2004</b>	PWSA of WI, Inc Board Meeting	Appleton Medical Center, Appleton, WI
<b>November 6, 2004</b>	12:30pm Parents of young children w/ PWS meeting 1:30pm Membership meeting	Appleton Medical Center, Appleton, WI
<b>July 24 - 31, 2005</b>	PWSA(USA) National Conference	Orlando, FL
<b>September 17, 2005</b>	PWSA of WI, Inc 5 <sup>th</sup> Annual Golf Benefit	Oconomowoc, WI

**Prader-Willi Syndrome Association of WI, Inc.**

2701 N. Alexander St.

Appleton, WI 54911-2312

1.866.797.2947

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