



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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PWSA of WI, Inc.

Information & Referral

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Wisconsin@pwsausa.org

Website:

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

Website: www.pwsausa.org

A Note from the Co-Presidents: Steve and Nancy

Here it is June already and time for our summer issue of the newsletter. For all of you who attended this spring's Hobby / Social Day, I think you'll agree that it was a very successful event and that everyone involved enjoyed themselves tremendously. Every year it seems to get better! I want to thank everyone that participated, especially our volunteers. If you've never volunteered to help out at our Socials, I encourage you to do so. It's a real warm-fuzzy, feel-good experience when you see the "kids" having such a great time, renewing old friendships, learning new skills, and boogying down to the music.

Our next big event is the Golf Outing, coming up on September 18. Some great door prizes and raffle items have already been collected, and the recruitment of recruiting golfers for the day has begun. Steve and I have marked the event on our calendars and I hope that many of you have too, or will do so **soon**. PWSA of WI, Inc. has many members that we've not yet had the opportunity to meet, and this event is a fun way to get to know each other while enjoying golf, good food, wonderful prizes and a treasured reprieve from the responsibilities of everyday life. And no counting calories here!! Come join us!

Until next time, thanks again to everyone who supports our loved ones with Prader-Willi Syndrome through their support of PWSA of WI, Inc.

See you in September -
Nancy

Editor's note: While this column reads '*...from the Co-Presidents*' these notes usually come from Nancy. She assures me that Steve does some of the "behind the scenes" work while she takes the "photo op-" jobs as he thinks she is more photogenic...MLL

SSRI's Linked to Bleeding Problems in Orthopedic Surgery

Researchers in the Netherlands found the use of SSRI's (the group of medications used to help with Obsessive Compulsive disorder and depression known as **selective serotonin reuptake inhibitors**) in 520 patients who had orthopedic surgery increased the need for blood transfusions during orthopedic surgery. Even though the study did not look at persons with PWS specifically, we felt it was important to share the findings of this study with our readers since many persons with PWS take medications in this drug classification and may need to have orthopedic surgery. It is believed that SSRI's may inhibit or lessened the activation of platelets, the part of our blood, which is responsible for controlling bleeding.

If a person with PWS is undergoing surgery for scoliosis or other orthopedic reasons and they are taking a SSRI medication, parents and caregivers should make sure that the surgeon is aware of this.

SSRI Medications Include:

Celexa (Citalopram)	Lexapro (Escitalopram)
Prozac (Fluoxetine)	Luvox (Fluvoxamine)
Paxil (Paroxetine)	Serzone (Nefazodone)
Zoloft (Sertraline)	

(Source: "Relationship of Serotonergic Antidepressants and Need for Blood Transfusion in Orthopedic Surgical Patients". *Archives of Internal Medicine*, K. Movig, et al., October 27, 2003)

PWSA OF WI, INC. CONTACT INFORMATION UPDATE

Clip and Save:

PWSA of WI, Inc

Toll free: 1-866-797-2947

Email: Wisconsin@pwsausa.org

2701 N. Alexander St.

Appleton, WI 54911-2312



**National PWSA(USA) Conference
June 30 – July 2, 2004**

**At the Lodge at Sawmill Creek
In Sandusky OH**

"Explore the Possibilities"

**Thursday, July 1 2004 all day – July 2, 2004
until 2:30pm**

General Sessions and Youth/Infant Program

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

www.pwsausa.org

NEW HANDOUTS AVAILABLE TO PARENTS AND RESPITE WORKERS



Every year, PWSA of WI, Inc strives to increase the knowledge and understanding of parents and professionals who care for and work with people with PWS. This year, Barb Dorn has created two informational handouts. One form highlights some of the issues and strategies needed in providing respite to a person with PWS. Another fill-in form is available that helps parents communicate person-specific information. Both forms are available FREE to all members who would like one. A copy of these resources will also be sent to all respite agencies in the State of Wisconsin in the next few months. As we all know, respite workers are precious. We must do everything we can to make this experience a positive one for both the person with PWS as well as the respite worker. To receive your copy, contact Mary Lynn at the Wisconsin office.

Thanks Barb for all you do for us!!



We took some time out during Hobby Day to say "Thanks!" to Barb Dorn who has spent so much of her time, talents and energy working to support, educate and advocate for persons with Prader-Willi syndrome. Barb was one in the initial group of parents and families that helped establish PWSA of WI, Inc. in 1992. Barb is seen here receiving a plaque expressing our thanks from Chapter President, Nancy Burlingame. The plaque reads: **"PWSA of WI, Inc. recognizing Barbara Dorn for providing outstanding leadership and service on behalf of its members 1992-2003.**

When someone needed a hand, yours was the first to reach out."

Thanks again, Barb!! While hers is no longer the voice on the phone you first hear when you call the state office, Barb has assured us she will continue to be available to us – she is now taking some time for her family and herself!

Mark your calendars for September 18, 2004!!

Our 4th Annual Golf Benefit at Paganica Golf Course in Oconomowoc, WI.

Steve and Nancy will be there... will you?



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 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 birthday or 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 TIME



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

Hobby Day 2004 A Day of Hard work, Hobbies, and Humor

This year on April 24, 2004 we had a day of hard work, hobbies and LOTS of humor!! It was our annual Hobby Day/Spring social. We had 73 individuals with PWS in attendance as well as 47 adult volunteers (parents, staff, friends, family). Hobbies included wood working; making dream catchers; beads, beads, and more beads; making eyeglass chains; fleece pillows, puffy paint T-shirts, and model cars. From the photos here, it looked like most everyone enjoyed themselves!

I love painting these T-shirts!



Steve is leading this group in how to make those model cars



Do you know who this is?

And why is he wearing this chicken disguise?

Jackie is leading us all in the Macarena! Go girl!

These fleece pillows are sure soft!



“Everybody do the locomotion....”



Here are some of the guys doing woodwork!



Sarah is enjoying the beads, beads workshop.



We want to say “**Thank you**” to everyone who attended Hobby Day. Thanks to all who helped in some way to make this another successful event. We were glad to see everyone and especially glad that everyone had a good time!

Prader-Willi Syndrome Association of Wisconsin, Inc. – 2003 Financial Report
SCHEDULE OF CASH RECEIPTS & DISBURSEMENTS – BUDGET VS. ACTUAL
January 1 through December 31, 2003

<u>INCOME</u>	<u>ACTUAL</u>	<u>BUDGET</u>
Membership Dues	\$2210.00	\$ 2250.00
Donations	\$6776.60	\$ 4700.00
Grants	\$3306.03	\$14975.00
Access to Community Service	\$4167.97	\$ 2800.00
United Way (Donor Choice Program)	\$3688.45	\$ 2800.00
Training / Social /Conference Fees	\$ 745.00	\$ 870.00
Golf Benefit	\$7130.00	\$ 5200.00
Caring is Sharing – Mail Fundraiser	\$1355.00	\$ 1600.00
Calendar fundraiser	\$ 0	\$ 2000.00
Designated Donations	\$ 520.00	\$ 500.00
Memorials/Honorariums	\$1150.00	\$ 200.00
Rebates	\$ 0	\$ 10.00
Miscellaneous (Book proceeds)	\$4792.00	\$ 0
Reimbursed Expenses	\$ 195.64	\$ 700.00
Interest	<u>\$ 177.45</u>	<u>\$ 325.00</u>
TOTAL INCOME	\$36214.14	\$42030.00
<u>EXPENSE</u>		
Payroll Expenses	\$14160.00	\$15780.00
Employee Benefits	\$ 1343.24	\$ 1472.00
Audit	\$ 1800.00	\$ 1800.00
Payroll Processing /Accounting Fees	\$ 490.00	\$ 532.00
Office Supplies	\$ 258.13	\$ 1100.00
Printing and Publications	\$ 6899.34	\$ 6950.00
Telephone and Email	\$ 1021.67	\$ 1200.00
Postage	\$ 569.97	\$ 900.00
Membership Dues/Fees	\$ 174.00	\$ 140.00
Liability Insurance	\$ 0	\$ 1400.00
National PWSA (USA) Support	\$ 1000.00	\$ 1000.00
Gen. Assist/Camp Scholarship Fund	\$ 250.00	\$ 1000.00
Golf Benefit	\$ 3120.42	\$ 2535.00
Caring is Sharing Fundraising Expense	\$ 211.44	\$ 150.00
Board/Membership Meetings	\$ 83.95	\$ 80.00
Staff/Board Training	\$ 307.00	\$ 0
Speakers/Staff/President Travel	\$ 1138.74	\$ 1900.00
Hobby Supplies	\$ 627.63	\$ 1200.00
Entertainment for Social	\$ 250.00	\$ 375.00
Food Expenses	<u>\$ 376.56</u>	<u>\$ 475.00</u>
TOTAL EXPENSES	\$34,124.09	\$40,947.00
NET INCOME	\$2,090.05	\$ 1083.00

Balance Information as of December 31, 2003

ASSETS

Checking/Savings	
Checking – Summit Credit Union	\$ 6470.19
Savings – Summit Credit Union	\$ 6260.55
Certificate of Deposit	<u>\$ 5398.82</u>
TOTAL ASSETS	\$18,129.56

LIABILITIES & EQUITY

Equity – Opening Balance	\$ 23119.78
Net Income	<u>\$ 2090.05</u>
TOTAL LIABILITIES & EQUITY	\$18,129.56

PWSA of WI, Inc.'s Sincere Appreciation

PWSA of WI, Inc. wishes to thank all who have generously cared & shared with us in 2003.

Individual and Family Donors

Lawrence & Lorraine Abler
 Agape of Appleton
 Sam & Sue Allison
 Brian Balestrieri
 Matt Balestrieri
 Dan & Kate Beaver
 Richard & Jayne Becker
 Lorraine Beirl
 Brenda Bickelhaupt
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 James Wachter
 Greg Wagner
 Ryan Weinetz
 Marc Williams
 John & Claudia Williamson
 K. Wisniewski
 Tom & Gladys Yuenkel
 Candice Ziegelbauer
 Janice Zwettler

Honorariums: In honor of Colleen Doherty: Peter & Chelsea Hoff, Dawn & Richard Castillo, Desire Koser, Constance Devitt

Memorials: In Memory of Mary Wall: Frank Wall In Memory of Anne Burlingame: Steve & Nancy Burlingame

Corporate Donors

Access to Community Services	Milwaukee Electric Tool	Principal Financial Group
Altria Group	Milwaukee Heart Scan	Raymond Rentals
Anchor Moving	Mykel Wade Hair Design	Regent Mental Health
Certification Services Inc.	Nashotah Clubhouse	Rookies All-Star Bar & Grill
Clear Channel WISN Radio	North Shore Insurance Agency Inc.	State Collection Services, Inc.
Employees' Mutual Benefit Assoc	Oconomowoc Developmental Training Center	Virchow, Krause & Co, LLP
EWH Small Business Accounting, SC	Oconomowoc Residential Programs	Willow Glen Academy
Flint Inc.	Olympia Resort & Conference Center	Wisconsin Video
Gray Jewelers	Paganica Golf Course	WKLH Radio
Homes for Independent Living	Panera Bread	Woodman's Food Market, Inc
Hughes Dental Clinic	Paragon Industries	WTMJ TV
Kraft Foods	Plunkett Rayisch Architects, LLP	Xpressions by Peggy
Meissner, Tierney, Fisher & Nichols S.C.	Prader-Willi Homes of Oconomowoc	
M & I Bank	PWSA (USA)	

NEW Playstation Interactive Games Provide Exercise and Fun

We all worry that our children do not get enough exercise. And ... trying to find an activity that burns calories and is fun can be challenging. Many kids and adults love to play various video games, which do not provide any activity or exercise in their life. Playstation 2 now has an interactive game that provides an upper body exercise workout and fun – all at the same time.

“Eye Toy”

The Eye Toy game comes with a small video camera that goes on the top of your television set and hooks up to the Playstation 2 entertainment device. Once turned on, the player becomes an active part of the games. The player even turns on and selects the game by reaching and touching various button and parts on the TV screen.

Eye Toy comes with 8 different games and is a fun game for all ages. (Even parents get a great workout!) Because there is some eye-hand coordination that goes along with learning to use this game, it may take a short time for the player to get the hang of it. However, it isn't long before the player is reaching and moving and getting quite a work out.

The cost of the game is \$49.99 and is available where video games are sold. At this time, Playstation 2 is the only video system that has this game.

“Dance Dance Revolution”

Another interactive video game with “work out” benefits is Dance Dance Revolution by Konami Digital Entertainment – America. The player stands on a 3 foot square platform or mat with an arrow on each side of the square, pointing up, down, left and right. The player faces a video screen that has arrows scrolling upward to the beat of a song chosen by the player. During the game, as an arrow reaches the top of the screen, the player steps on the corresponding arrow on the mat. The game increases in difficulty by throwing out combinations of multiple arrows and speeding up the pace. The game is as challenging and vigorous as a high impact aerobics class.

Fans report the game is addictive and expensive. In an arcade, it can cost from \$1 to \$1.50 for about six minutes. It can become more addictive as players realize they are losing pounds and inches. While DDR originally began as an arcade game, it quickly became marketed for home play as the addiction of both playing the game and weight loss spread! Reports of weight loss vary. Some players report a loss of 20 pounds while others have lost over 100 pounds with DDR, better eating habits and weight training to improve their health.

Dr. Richard Adler, of the University of Tennessee Health Science Center in Memphis, said he likes the game because it “gets kids off their butts and they lose weight.” One possible down side is that it may cause discomfort in the joints of

players who are heavy and have arthritis. As always, each person should have a check up with their personal physician before beginning any exercise program.

Dance, Dance Revolution's home version costs about \$40 for the game and \$40 for the plastic dance pad and is available with Playstation. It also includes a “workout mode” that can track how many calories the user burns while playing.

Entertainment Books: a fundraiser for PWSA of WI, Inc.

Melissa Sirovina, Mom to Kayla who has PWS, has been strategic in setting up an opportunity to raise funds for PWSA of WI, Inc. Melissa works for Washington Mutual, a mortgage and loan company committed to encouraging volunteerism. They have chosen to assist in raising additional funds for PWSA of WI, Inc through the sale of Entertainment Books.

The committee responsible for coordinating the volunteer/fundraising at Washington Mutual will handle setting everything up and monitoring a website for ordering books online. The website allows access by people not employed by Washington Mutual to help support **our** cause by purchasing a book. The committee has asked that we notify members of the association, friends, and family members so they may participate in the fundraiser to maximize the donation potential to be made to our group.

Online ordering would be available from August until December 2004. The books are good from August 2004 through November 2005 and are around \$35.00. For each book that is purchased \$7.00 goes to PWSA of WI, Inc. The Entertainment book consists of coupons for businesses in your local area including sports teams, restaurants, cinema's etc. The good thing is that you can order them for any area (just make sure to specify your local area) or even friends in a different state. For example, if you have family in Texas, they can go online and order a book for themselves for their area and still have the donation go to PWSA of WI, Inc. or you could order a book as a gift for them and it would be specific for their area.

Once the fundraiser is over, Entertainment Books sends proceeds earned to the PWSA of WI, Inc. The committee at Washington Mutual wants us to get the word out to our members so we can maximize our return. This type of fundraiser allows us to reap the benefits without doing the work!! The only work involved is you placing your order! More info to follow!

PWSA of WI, Inc. 2004 Calendar

June 30-July 2, 2004	National PWSA(USA) Conference	Sandusky, OH
September 18, 2004	PWSA of WI, Inc. 4th Annual Golf Benefit	Oconomowoc
October 9, 2004	PWSA of WI, Inc Board Meeting 10am Meeting for Parents of Children w/ PWS age 8 and younger Annual Membership Meeting	Appleton (Times and location to be determined)

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