



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

President: Barb Dorn
Vice President: Crystal Boser
Secretary: Jennifer Kryzak
Treasurer: Tom Hughes
Board Members: Pat LaBella,
 Jackie Mallow and Melissa Sirovina
Program Director: Mary Lynn Larson

Office Address:

PWSA of WI, Inc.
 2701 N. Alexander
 Appleton, WI 54911-2312
 Toll free: 1-866-797-2947
 Fax: call first
 Email:
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 President: Barb Dorn

Since we have so much information to share in this issue ... I will keep my message short. But please make sure to browse through this newsletter; we have lots of exciting information and opportunities' to share. We have lots of ways you can become involved. Please find something you are interested in and that you can share your time and talents.

I want to thank everyone who helped to make our 2006 Hobby Day another huge success. We had 95 persons with PWS including some family members attend this year. We have outgrown our current location at ODTC but we have begun our search for a new location. We would like to extend our sincere thanks to ODTC and Prader-Willi Homes of Oconomowoc for their generosity in services, facilities and staff. We want to thank all the volunteers for their dedication and hard work in sharing their time and talents. All who attended walked away with lots of interesting items and crafts. We have our annual golf benefit just around the corner that we would love to see you at. It provides a day of fun, sharing and even a little golf. You don't have to be a good golfer to enjoy yourself. If you are not able to attend, please consider becoming a hole sponsor or donating to our silent auction. Often times, families will go together as a group and sponsor a hole. If you want to honor someone with this ... that would be great.

And please ... mark October 11th on your calendar now. We are hosting a workshop updating you on new health information for children and adults with PWS. As a parent or caregiver, you cannot afford to miss it. There is lots of new information for you to learn. You will also receive 2 health information packets – one for you and one for the health care provider of the person with PWS. I am also proud to share that PWSA of WI, Inc has granted 3 camp scholarships and have made it possible for 3 families/caregivers to attend the national PWSA (USA) conference in New York. Thanks again for all who donate so generously. Without your help, we could not make these services possible. Well that's all for now. I tried to keep it short – and for those who know me – that can be a challenge. Take care! Barb

POISON IVY, POISON OAK AND POISON SUMAC SEASON MEDICAL ALERT

It is that time of year again and Dr. Moris Angulo has asked that parents and caregivers of people with Prader-Willi Syndrome (PWS) be particularly alert as we enter the season for Poison Ivy, Poison Oak, and Poison Sumac. People with PWS are known to scratch and pick at places on their body. This often causes large sores that can and do get infected. When caught, Poison Ivy, Poison Oak, and Poison Sumac cause the skin to become very itchy which, when scratched will not only inflame the affected area, but also spread to other parts of the body. For people with PWS who like to scratch, pick and have a high tolerance for pain, these conditions can cause serious skin infections if not caught and treated early by a dermatologist. Remember, prevention is the best cure! A walk through the woods or even an open field without protective clothing is an invitation to disaster. The above should not be considered medical advice, for that you must consult your personal medical professional.

Annual PWSA of WI, Inc. Membership Meeting

The Annual Membership meeting for members of PWSA of WI, Inc. will be held on Saturday, October 21, 2006 in Milwaukee at Children's Hospital of Wisconsin. All members are welcome to attend. More information to come as details are finalized.

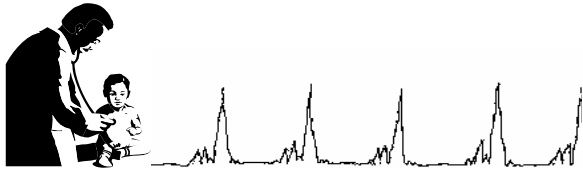
How Can YOU Help with the PWSA of WI Golf Benefit this year?

The golf benefit is PWSA of WI, Inc's biggest annual fund raiser. It will be held on August 26, 2006 at the Paganica Golf Course in Oconomowoc, WI. Funds raised help us in so many ways – Hobby Day, camp scholarships, phone bills, special projects ... just to name a few. If you or possibly a group of family members, or a business would be willing to be a hole sponsor or donate item(s) for our silent auction, we would be very grateful. Hole sponsorship is \$125. A sign will be printed and posted on one of the golf holes. Your name is posted on our "donor board" and you (or your business) will be noted in our statewide newsletter. If you are golfer ... please come join us. If not, your donation is a great way to help. For hole sponsor or donor sponsor forms either contact our state office (1-866-797-2947) or visit our website at www.pwsausa.org/WI

Volunteer Opportunity

– PWSA of WI, Inc would like to create a **newsletter for persons with PWS ages 12 years and older**. This newsletter, *Connecting You* would be a quarterly publication consisting of short features on health, social skills, nutrition and other interesting topics for adolescents and adults with PWS. We would like one person to serve as editor – recruiting contributors for the publication. We would love to have someone assist with layout; others may want to take on the printing and mailing. We are hoping to have a small team working together to make this a success. Once again, staff of PWSA of WI, Inc will be assisting.

If you are interested in offering assistance in any of these positions or have questions, please don't hesitate to contact Mary Lynn at the state office.



A Health Update on Prader-Willi Syndrome

TRAINING INFORMATION

Save the Date – Brochure to be mailed August 1st

Wednesday October 11, 2006
Quality Inn and Suites, 2969 Cahill Main,
Madison

Six Health Care Professionals to Speak on Emergency Care, Scoliosis, Respiratory Problems, Growth Hormone, Osteoporosis and other Health Concerns for Children and Adults who Have PWS. All who attend will receive 2 health information packets – one for themselves and one to share with the primary health care provider of the person with PWS.

DON'T MISS IT!!!!

Visit our website for more information today.
www.pwsausa.org/WI

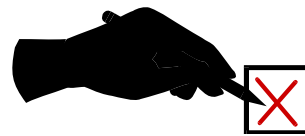


PWSA of WI, Inc. Card Club – Looking for 1 More!

We are pleased to share that we have received 1 volunteer for the start of the “Card Club” a new service we will be starting for persons with PWS. Louise Guido has offered her services to assist us with this new project. We are looking for at least 1 more person, so if you are willing to donate some time – from the comfort of your own home – please contact our office. PWSA of WI, Inc will provide you with all of the items you will need to do this. You will need to sign the cards; attach mailing labels and stamps ... and pop them in the mail. Each person will receive 6 cards per year – including one on their birthday. Everyone loves mail and PWSA of WI, Inc. plans to provide those with PWS who wish to receive more mail an opportunity to sign up. **THIS PROJECT WILL NOT BEGIN UNTIL JANUARY 1ST, 2007.** We will start off so everyone gets the same number of cards – “we will keep it fair.” We will begin recruitment in the fall – so please – share your time with us.

The Wisconsin Connection

3



Call for Nominations

It is that time of year again. PWSA of WI, Inc is actively looking for people who are willing to serve on our board. It is a great way to get involved and meet other persons involved with people who have PWS. The current positions open for the 2006-2008 term include: **TREASURER, VICE PRESIDENT AND 2 BOARD MEMBER POSITIONS.** PWSA of WI, Inc board meets 3 times a year. The location is determined by the make up of the board. We do our best to “take turns” at various locations. The following is a brief description of the duties. If you are interested, either contact Mary Lynn at the office 866-797-2947 ; Barb Dorn, president (608)-848-9597 OR check our website to file nomination papers. Do not delay – the deadline is **September 1st, 2006.**

- **TREASURER:** Prepares financial reports; provides oversight to budget preparation to program director and the organization; reports on professional audit; completes annual IRS form 990 (assistance can be provided); provides oversight to the accountant.
- **VICE PRESIDENT:** assists the president as needed; serves as chairperson for the screening and granting of all camp scholarships and grants provided by the general assistant fund
- **BOARD MEMBER:** serve on committees and special projects; provides input and votes on all issues presented to the board

Meeting for parents of young children w/ PWS aged 9 or younger

On October 21, 2006 we will be holding our annual meeting for families with children w/ PWS aged 9 yrs or younger. We have been doing this for a number of years after families reported they were hesitant to attend meetings targeting issues of adults with the syndrome. We will be meeting at Children’s Hospital in Milwaukee after the PWSA of WI Board of Directors meeting. More information will be mailed as details are finalized. Please do not hesitate to contact Mary Lynn at the state office if you have any questions. Email: Wisconsin@pwsausa.org or toll free: 1-866-797-2947.

Hobby Day 2006

Our Annual Hobby Day on April 1, 2006 proved to be another successful day of recreation, lots of laughter, and renewing friendships. We had 93 persons with PWS attend Hobby Day with a lot of assistance from the 73 parents, staff, caregivers and



volunteers who also attended. We had a special group for younger children w/ fun activities like finger painting, crafts and playing games.

Matthew, Melodee, Nolan, Olivia, and Christopher seem to be having fun catching the butterflies!

We were able to have the entire event in the classrooms and "mansion" of Oconomowoc Developmental Training Center. We had a total of nine hobby/activities: Woodworking, Eggstra Special Box, Fun with Foam, Tie-a Blanket, Painted Sun Catchers, Scented Soaps, Floral Arrangements, Beaded Necklaces and the activity group for ages 8 and under.



Wood working continues to be one of our most popular hobby activities!

Working on the Tie-A-Blanket was easier than I thought!



We had a quiet area for people who were feeling tired or overwhelmed by all the activity going on. The dance continues to be a success as we were able to chat with friends, catch up with folks we hadn't seen in a while and dance our hearts out!! As you

can see from some of these photos, the Chicken Dance and the Y-M-C-A continue to be favorites!!



Jennifer and Alex loved playing the Village People!



Who is this masked chicken??



PWSA of WI, Inc wants to extend a HUGE "Thank you!" to everyone who helped us to make this day a success! We would like to say Thanks to all our parents, volunteers, care providers, staff, family and friends! A big Thank you to Oconomowoc Developmental Training Center and Prader-Willi Homes of Oconomowoc for all their generosity and hard work behind the scenes! We could not have done without all of you!



PWSA of WI, Inc. 2005 Financial Report
SCHEDULE OF CASH RECEIPTS & DISBURSEMENTS – BUDGET VS. ACTUAL
January 1 through December 31, 2005

<u>INCOME</u>	<u>ACTUAL</u>	<u>BUDGET</u>
Membership Dues	\$ 1,440.00	\$ 2,250.00
Donations	\$ 6,083.80	\$ 6,000.00
Grants	\$ 974.50	\$ 1,500.00
Access to Community Service	\$ 4,005.91	\$ 4,100.00
United Way (Donor Choice Program)	\$ 6,480.03	\$ 3,500.00
Conference Fees	\$ 870.00	\$ 500.00
Fundraising	\$14,984.93	\$10,550.00
Designated Donations	\$ 0.00	\$ 1,000.00
Miscellaneous (Memorials/Honorariums)	\$ 1,220.00	\$ 200.00
Reimbursed Expenses	\$ 114.80	\$ 100.00
Interest	<u>\$ 381.52</u>	<u>\$ 175.00</u>
TOTAL	\$ 36,555.49	\$ 29,885.00

INCOMEEXPENSE

Payroll Expenses	\$ 9,078.00	\$13,575.00
Employee Benefits	\$ 883.64	\$ 1,303.00
Accounting Fees	\$ 4,319.83	\$ 2,350.00
Office Supplies	\$ 812.80	\$ 250.00
Printing and Publications	\$ 0.00	\$ 250.00
Telephone and Email	\$ 410.65	\$ 700.00
Postage	\$ 851.82	\$ 700.00
Membership Dues/Fees	\$ 50.00	\$ 175.00
Liability Insurance	\$ 0.00	\$ 1,400.00
National PWSA (USA) Support	\$ 2,000.00	\$ 1,000.00
Gen. Assist/Camp Scholarship Fund	\$ 2,143.91	\$ 500.00
Fundraising Expense	\$ 5,508.89	\$ 4,300.00
Board/Membership Meetings	\$ 92.35	\$ 100.00
Travel	\$ 852.60	\$ 1,250.00
Hobby/Other Supplies	\$ 506.54	\$ 650.00
Entertainment for Social	\$ 0.00	\$ 275.00
Food Expenses	<u>\$ 909.13</u>	<u>\$ 400.00</u>
TOTAL EXPENSES	\$ 28,420.16	\$ 29,778.00

NET INCOME \$ 8,135.33

Balance Information as of December 31, 2005ASSETS

Checking/Savings	
Checking – Summit Credit Union	\$4426.78
Savings – Summit Credit Union	\$5356.36
Certificate of Deposit #1	\$6194.54
Certificate of Deposit #2	\$5606.87
Money Market – Summit Credit Union	<u>\$10009.40</u>
TOTAL ASSETS	\$31,593.95

LIABILITIES & EQUITY

Equity – Opening Balance	\$ 23,119.78
Retained Earnings	\$ 338.84
Net Income	<u>\$ 8135.33</u>
TOTAL LIABILITIES & EQUITY	\$ 31,593.95

A Special Thanks to ALL of Our Donors - Making It Possible for PWSA of WI, Inc to Do So Much!

Anonymous	Virginia Johnson	Tom & Deb Schmitz	Milwaukee Heart Scan
Larry & Lori Abler	Tom & Bonnie Jones	Dennis & Sherry Schultz	Milwaukee Wave
Richard & Barbara Ausick	George Koenig	Hazel Schuster	Nashotah Clubhouse
Kate & Dan Beaver	Kimberly Kornstedt	Louis & Judy Schutz	ODTC
Richard & Jayne Becker	Jennifer Kraft	Alice Schwartz	Oconomowoc
Robert Beckman	John & Bonnie Kraft	Willi & Gudrun Sindermann	Residential Programs
Lorraine Beirl	Richard Kral	Thomas Sipin	Old World Wisconsin
Mark Bodoh	Katie Kranjac	Chad & Melissa Sirovina	Paganica Golf Course
Nicholas Bodwin	Walt & Jennifer Kryzak	Richard Stark	Panera Bread
Robert & Kathy Bomber	Carl LaBella	Wm Stege	Par Tee Pub & Grill
Clint & Crystal Boser	John & Pat LaBella	Jackie Stoner	Paragon Candles
Gary Boser	Joe LaBella	Russ & Dawn Stuczynski	Paragon Industries
Todd & Jerilyn Bramson	Rosalie LaBella	Beatrice Sturm	Platinum Realtors
Kevin & Anne Bresnahan	David & Susan Laha	Judith Sweet	Prader-Willi Homes of
Nancy & Steve Burlingame	Jeanne Langlois	Rosalie Tillman	Oconomowoc
Evelyn Burnridge	Mike & Mary Lynn Larson	Todd Trausenecker	Professional Fabrications
Ginny Cardarella	John & Cathie Lehman	Kim Tula	PWSA of WI, Inc.
Aaron Carrel, M.D.	Robin & Jenny Lucas	Leah Uttech	PWSA (USA)
Roseanna Casarez	Heidi Luebke	Todd & Betsy Van Heesch	Ruggeri's Ristorante
Eric Christensen	Al & Melodee Leuning, Jr.	Ben Van Korn	Sedwick - Claims Mgmt
Henry Clement	Allan & Kathleen Leuning	Jean Van Tuyle	SSM - Health Care of WI
Bruce Crass	Rose Lopez	Greg Wagner	TLC Homes
Karen Czebotar	Dorothy Lothe	James Wachter	Thunderbay Grille
Steven Dobbs	Wade Liljegren	Jamie & Heidi Wertjes	United Way - Brown Co.
Thomas Domanski	Marie Mae	Paul & Mary White	United Way - Fox Cities
Don & Barb Dorn	Jane Majcherek	Judith Wolter	United Way - Gr.
Elsie Dorn	Richard McNally	Rose Worden	Milwaukee
Jim & Judy Dorn	Robert Millard	Bruce & Bonnie Ziegelbauer	Virchow, Krause & Co., LLP
Mark Dorn	Michael Miller	Edmund Wegner	Washington Mutual
Gerard & Helma Drag	Virginia Mitchell	Ellen White	WI Concrete Services
Jere Fabick	Larry Morris	Ace Hardware - Verona	WLKH Radio
Dr. Anne Feldon	Dr, Marta Muller	Access to Comm. Services	X-pressions by Peggy
Charlotte Girdaukas	Mary Mulligan	Altria Employee Programs	
Gary & Martha Girdaukas	Wm Murphy	Anchor Moving	
Roger & Alice Girdaukas	Wm & Margaret Nagle	Bodoh Home Improvement	
Gary & Debbie Gostas	Dave Nagy	Boucher Chevrolet	
Louise Guido	Bob & Pat Nelson	Bramson & Assoc., LLC	
Lee Haas	Marilyn Nelson	CSI Testing, Inc.	
Larry Haas	Keith Novotny	FABCO Equipment	
Norb Haas	Wayne & Diane Nummerdor	Family Support/Resource Center	
John & Cory Hacker	Cindy Organ	Gray Jewelers	
Carolyn Haney	Leroy & Lillian Peronto	Green Bay Packers	
Paul & Karla Hansen	Lori Porte	Hughes Dental Clinic	
Charles & Diane Helman	Kevin Raether	Kimberley Clark Fdtn	
Dr. Ken Herrmann	Patricia Raffel	Kraft Foods	
Frank Hilscher	David Roemer	Kraft Foods Fed. Credit Union	
W. Hoffman	James & Angela Romig	Marshall & Ilsley Bank	
Mark Hohenwald	John & Marquerite Rupnow	Michael's House of Prime	
Dr. Jean Holder	Steve & Liz Sadzewicz	Milwaukee Brewers	
Ryan Hood	Tom & Judy Scheidegger	Milwaukee Bucks	
Tom & Agnes Hughes	Julie Scheuer	Milwaukee Electric Tool	



Sharing Resources – Helping Each Other

Frequently, as 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 MDs, dieticians, therapists, camps or other services that others with PWS can benefit from – contact us. (Toll free Phone: 1-866-797-2947 or Email: Wisconsin@pwsausa.org)



And along those lines....

I was hoping that those of you who have implemented locks in your household would be willing to share those resources and ideas so I can keep them on file whenever a family calls asking, "How do I lock this?" I have received written information as well as photos from several families but we can always use MORE!! If you are able to email me a photo of how you use locks to keep your family member safe – that would be phenomenal! I will take digital photos, regular photos, emails, written descriptions and even drawings of what works in your home! This may be something we would want to put on the web site at a later time, so I may be sending you a release of information form to sign to allow that.

THANK YOU SO MUCH!!!

Message from the Office:

By Mary Lynn Larson

We had a great turn out at our Annual Hobby Day and are busy working on getting things ready for the Golf Benefit on August 26, 2006! This is our largest fundraiser for the year...so if you have any ideas, suggestions, spare time to volunteer, or prizes to donate, please don't hesitate to contact me!! We are still looking for golfers and hole sponsors too.

We are also working on getting things ready for our Fall Health Training on October 11, 2006. We are targeting educating care providers, families and health professionals who work with persons with PWS. We have professionals speaking on Emergency Care, Scoliosis, Respiratory Problems, Growth Hormone, Osteoporosis and a variety of other health concerns. We are also supplying all attendees with health information packets that they can share with the primary care physician working with the person with PWS. This is a great opportunity for those of us who remain the primary source of information for the physicians who treat our loved ones with Prader-Willi syndrome. More information will be mailed out on this in the future.

On a personal note, life continues to remain hectic at the Larson household as I try to maintain some structure, routine and consistency during the summer months for both of my children with PWS... Essentially this means, **their** schedules rule and all else gets put on the back burner until school starts again in the fall. If you are trying to reach the state office, keep trying! Because I run the office out of our home and like to try to maintain some level of professionalism and quiet, I am usually trying to return phone calls or emails in the morning while the boys are attending summer school or on a "hit and miss" basis depending what the afternoon may hold! Thanks for your patience and understanding!!

Hugs, Mary Lynn

PWSA of WI, Inc. 2006 Calendar

July 19 - 21, 2006	PWSA (USA) conference	Grand Island, NY
August 26, 2006	6 th Annual PWSA of WI, Inc. Golf Benefit	Oconomowoc, WI
October 11, 2006	PWSA of WI, Inc. Health Update on PWS Training	Madison, WI
October 21, 2006	Board meeting, Parents of young children w/ PWS meeting, Membership meeting	Milwaukee, WI

Prader-Willi Syndrome Association of WI, Inc.

2701 N. Alexander St.

Appleton, WI 54911-2312

1.866.797.2947

email: Wisconsin@pwsausa.org