



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
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A Note from the President: Barb Dorn

A Special Thank You to Our Valuable Volunteers

PWSA of WI, Inc would not be the great organization it is today without the numerous volunteers that help us in so many ways. First of all I want to personally acknowledge and thank Dr. Dan Beaver for his recent presentation to physicians, medical students and other health care professionals at Waukesha Memorial Hospital. Dr. Beaver is an emergency room physician and father of Hana who has PWS. He volunteered his time and expertise in an effort to educate health care professionals about the unique health issues that may be seen in PWS. Since there are over 69 adults with PWS residing in this area, PWSA of WI, Inc. decided to begin its health education efforts at this community. (There is a residential agency, Prader-Willi Homes of Oconomowoc that supports adults with PWS in Oconomowoc and surrounding communities.) I also attended this presentation and I can say in all honesty that Dr. Beaver did an excellent job in helping to make health providers more informed. Thanks again.

In the next week, we will be hosting our annual Hobby Day and Social. As I write this message, we have 99 persons with PWS plus siblings signed up to attend. In addition, we have 80 volunteers to assist. We have dedicated people who are willing to share their talents so that these young people can experience success and a good time. I want to gratefully thank **ALL** who help to make this day a continued success.

Our officers and board of directors contribute numerous hours, attending meetings, managing finances, developing our website, providing consultations and raising funds so that our organization can continue its ongoing efforts of helping persons with PWS. Hats off to you.

If you are reading this thinking – “Gee, I’d like to get more involved”, I have **2 NEW OPPORTUNITIES** for you to consider.

#1 - We are hoping to create a **Card Club** – a service to persons with PWS of all ages. Everyone loves mail – especially fun mail. Members of the Card Club will be sent 6 greeting cards over the course of 1 year. Interested individuals will be asked to sign up for this club and our goal is have the club up and running by January 1st, 2007. Volunteers will assist in sign up, organizing the information collected; and purchasing and mailing cards. The staff of PWSA of WI, Inc. will assist in creating a database and providing mailing labels. All expenses will be covered. It something one or many volunteers can do.

#2 – 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.

So ... if you have some extra time and a willingness to share it with us – please contact Mary Lynn at our office 1-866-797-2947. We want to expand our services to persons with PWS and with your help – we can do it. Once again, I would like to say thanks to everyone who makes PWSA of WI, Inc – the best!!!

Take care, Barb

PWSA of Illinois Punt, Pass, Kick Competition with the Chicago Bears

By Alex R. Larson

Hi, my name is Alex Larson. On March 25, 2006 my family and I went to Lake Forest, IL for a trip to meet some of the Chicago Bears! We got everything we needed ready; like cameras, DVDs, DVD players, and our footballs all packed up and ready to go. I was able to watch several DVDs on the ride, and so did my brother Matthew. We stopped on the way and got a snack and drink. We got into town and stopped



Roberto Garza with Matthew and Alex Larson

at Trader Joe's Grocery store and had lunch at TGIFriday's. We accidentally passed the street that led us to the practice field (the Walter Peyton Center at Halas Hall) but we turned around

and finally got there. We registered and everyone was given a PWSA of Illinois/Chicago Bears T-shirt! We met up with other families with kids with PWS. I got to see a cowboy named "Wild Willy" (who Mom says was at the last PWSA (USA) conference).



Rex Grossman showing the fine art of passing to Matt

We met a bunch of the Chicago Bear players (Rex Grossman, Charles Tillman, Mark Bradley, Roberto Garza, Airese Currie, Lennie Friedman and Alfonso Marshall) and they taught us how to be a Quarterback, Defensive Back, Guard, and Wide Receiver on the team. Then we were able to show them what we had learned.

We then got to take part in the Punt, Pass, Kick competition. All of the players stayed after the competition to autograph pictures and things for the kids! I had them sign a



Matt kicking off in the competition

football for me! After the event, we were all given a Chicago Bears baseball cap and a Victory medal. A lot of the kids got together and sang "My Name's Not Willy" with Wild Willy before we left. I had a great time working with the Chicago Bears and it was TONS of fun!



Wild Willy came all the way from Texas to be part of this special event.

Message from the Office...

By Mary Lynn Larson

Happy Spring!! I hope things are going well at your house as the pleasant weather approaches! The Larson household remains "hectic" ... although I am quite certain that is because I work out of our home – which is **NEVER** quiet! (With two *very talkative* children with PWS who happen to have a mom who is a speech therapist – how could it be?) ...

In December 2005, I was nominated to the Board of Directors of **Disability Rights-Wisconsin** (previously known as the Wisconsin Coalition for Advocacy). It has been a great experience to date! The people involved with that organization have a wealth of information about so many things! In the short time I have been involved, I have come across several resources that I think may be of interest to our membership!

One resource that I thought would be of interest is: **Able Trek Tours** which is an organization which provides chaperoned and integrated tours for people with developmental disabilities and others who need assistance traveling. The organization is owned by Don Douglas (who was previously the Executive Director of Wisconsin Badger Camp for a number of years) and is located in Reedsburg, WI

Able Trek Tours has trips throughout Wisconsin, the United States, Canada and even trips to Europe! Obviously, there are many individual issues that may need to be addressed depending upon a person's needs and personal preferences but this could allow many young teens and adults the opportunity to travel either with family/friends or alone. I have a friend who spent several weeks during her college years, traveling with clients she was working with at a supported living environment. She speaks highly of her experiences with **Able Trek Tours**.

For a book on their vacation packages for 2006 or more information, you can contact them at:

Able Trek Tours

P.O. Box 384
Reedsburg, WI 53959
Phone: 608-524-3021
Toll free 1-800-205-6713
www.abletrektours.com

Another resource to keep checking on is the PWSA of WI, Inc web site at:
www.pwsausa.org/WI

Our web master, Jennifer continues to add new ideas and resources regularly. If you come across a neat idea or resource that we could add, don't hesitate to let us know!! You can send me a note via email at: wisconsin@pwsausa.org or toll free: 1-866-797-2947. Look forward to hearing from you!

Hugs, Mary Lynn

Thanks to the following listed below for renewing their membership for 2006

Laurel Mills	Jessica Schroeder
Erich & Carol Schultz	Tom & Bonnie Jones
Jim & Judy Dorn	Elsie Dorn
Richard Stark	Dan & Nancy Gulling
Jim & Karen Plosczynski	Madonna Kieffer
Tom & Judy Scheidegger	Jane Majcherek
Dianne Schwartz	Virginia Johnson
Michelle Olson	Rosalie Tillman
Ken Peters	Jane Fritsche
Kate & Dan Beaver	Charlotte Girdaukas
Louise Guido	James Wachter
Janice Zwettler	Rose Lopez
Louis & Judy Schutz	Judi Sweet
Bonnie Kraft	Jennifer Kraft
Mark Dorn	Lori Porte
Jeanne Langlois	Susan Allison
Dr. Jean Holder	Beatrice Sturm
Karen Shackleton	Bob & Kathy Bomber
Paul & Karla Hansen	William Stege
Kevin & Anne Bresnahan	Kim Tula
Nancy & Steve Burlingame	Rena Mills
Al & Melodee Leuning	Dr. Aaron Carrel
Wayne & Diane Nummerdor	John & Cory Hacker
Judy Wolter	Jeff Wiggins
Marquerite Rupnow	Dr. Marta Muller
Lizabeth Moser-Sadzewicz	Hollie McIntosh
Rose Worden	Mark Hohenwald
Robert & Patricia Nelson	Jolene Lemerond
Eric & Heidi Schoenberger	Paul White
Jerry & Pam Offerdahl	Larry & Lori Abler
Roger & Alice Girdaukas	John & Pat LaBella
Don & Barb Dorn	Jackie Mallow
Chad & Melissa Sirovina	Walt & Jennifer Kryzak
Clint & Crystal Boser	Tom & Agnes Hughes
Mike & Mary Lynn Larson	Joe & Elaine Gareau
Lee & Shirley Larson	Heidi Luebke

NEW NAME SAME AWARD WINNING ADVOCACY

The Wisconsin Coalition for Advocacy has changed its name to: **Disability Rights Wisconsin**

There were a number of factors that led to the decision to change the agency's name:

- It's a more self explanatory name that makes the disability rights focus clearer.
- There was some confusion with other multi-organization coalitions.
- People with disabilities and families who needed help often experienced difficulty in finding and recognizing this was an organization that could help them.
- The media were sometimes confused about the organization which only increased the public's confusion.

Other changes to note:

There is a new web site address:

www.disabilityrightswi.org

although the www.w-c-a.org site will be available until construction on the new site is complete.

New TTY number for all three offices:

888-758-6049.

Other contact information remains the same:

Madison:

16 North Carroll St. Suite 400

Madison, WI 53703

Voice: 608-267-0214

Fax: 608-267-0368

Toll free: 800-928-8778

Milwaukee:

6737 W. Washington St. Suite 3230

Milwaukee, WI 53214

Voice: 414-773-4646

Fax: 414-773-4647

Toll free: 800-708-3034

Rice Lake:

801 Hammond Ave.

Rice Lake, WI 54868

Voice: 715-736-1232

Fax: 715-736-1252

Toll free: 877-338-3724



**Remember to
keep
Saturday,
August 26,
2006 open so
you can join us for
PWSA of WI, Inc.'s 6th
Annual Golf Benefit!!
Contact Mary Lynn at:
1-866-797-2947 or
Wisconsin@pwsausa.org
if you have ideas for
prizes, hole sponsors,
etc... or if you just want
to volunteer your time!**

MARK YOUR CALENDARS NOW!

WEDNESDAY OCTOBER 11, 2006

HEALTH UPDATE ON PWS

Place: Quality Inn and Suites
Madison, WI

Time: Registration begins at 8 am
Workshop ends at 3:30 pm

Plans are under way. We are confirming speakers now. We have learned so much more about health issues in children and adults with PWS. Come and listen to health care experts. All attendees will receive a health information packet for themselves and one to share with the primary health care provider who cares for the person with PWS. Don't miss this great opportunity.

More details will be shared at a later time.

Skin Care – A Few Tips to Share

Skin picking can be a very challenging behavior to manage and control. It can become so problematic that a person can develop severe infections – some as deep down into the bone. Many ask why so many persons with PWS do this sort of thing. Some believe it is a strong compulsive behavior. Others disagree. There is no clear reason – only that it is seen in many (not all) persons with PWS. Parents and caregivers struggle with helping the child and/or adult keep their skin free from sores. There is no simple solution. Most strategies focus on diversion and supervision. The following are some strategies that many people use to help prevent and treat this problem. Feel free to email our office with more ideas so we can share them in future newsletters.

Wisconsin@pwsausa.org

Prevention

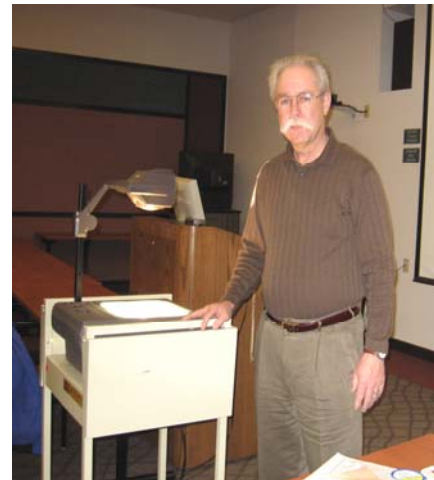
- Apply mosquito repellant before going outdoors. Preventing a bite is easier than treating one.
- Have the person wear a lightweight long-sleeve shirt before going on a walk in a wooded area. This too may help prevent insect bites.
- Provide diversion during high risk times – while watching TV, use handheld games, wear socks or light weight gloves; keep hands busy with coloring or shuffling cards.
- Some report rubbing a smooth surfaced object – a rock, piece of steel during sedentary times.
- Keep skin lotion available at various locations around their home and work. Teach and encourage them to apply lotion when they feel the urge to pick. Allow the person to pick out their favorite lotion. (Lotion provides diversion and keeps the skin soft and hydrated so it is more difficult to pick/scratch open).
- Keep nails short. Establish a weekly routine of cutting nails.
- In general – keeping the person with PWS busy and engaged in activities can be a very effective strategy in preventing this problem.

Treatment

Now comes the real challenge – treating the open sores and trying to get them healed. In severe cases, supervision must take place in all environments – including bathing and going to the bathroom. Infection of the skin and in some cases – the bone can result. Vigilant attention must be given to some.

- If sores become excessive or look infected (red streaking, sores with yellow or creamy drainage) – they should be evaluated by a medical professional.
- Keep areas clean and covered. Try different Band-Aids that provide coverage and protection. Some report using the clear liquid Band-Aide solutions on high-risk areas in addition to an outer bandage.
- There is some research to suggest that the medication Naltrexone has been helpful for those with severe skin picking. (This is not 100% and should be discussed with your health care provider).
- Some people with PWS want to have gloves applied at bedtime. Some report it helps them so they don't pick while they are sleeping. Using gloves should be a joint decision.

There are no easy solutions. We welcome your ideas and suggestions.



Dr Dan Beaver prepares to present important health information to physicians, medical students and other health professionals at Waukesha Memorial Hospital.

DID YOU KNOW: that pear and apricot nectar (NOT juice) is an excellent beverage to assist in bowel management? Some say it is better than prune juice.

Membership Renewal

Have you sent in your membership renewal for 2006?

If not, there is still time. An annual membership of \$25.00 provides you with our quarterly newsletter, *The Wisconsin Connection*, discounts on trainings or conferences, free social and support opportunities, as well as the ability to apply for scholarships and financial assistance. We also offer Associate memberships that allow sponsoring members to provide others such as grandparents, teachers, physicians, etc. the *Wisconsin Connection* newsletter which shares the latest information about the syndrome, upcoming statewide events and the like for \$15.00. The associate member has no voting privileges. If you have any questions about membership, please contact Mary Lynn at 1-866-797-2947 or via email at wisconsin@pwsausa.org

Volunteer Opportunities

We have 2 volunteer opportunities!

#1 - PWSA of WI, Inc. is hoping to create a **Card Club** - a service to persons with PWS of all ages. Members of the Card Club will be sent 6 greeting cards over the course of 1 year. Interested individuals will be asked to sign up for this club and our goal is have the club up and running by January 1st, 2007. Volunteers will assist in sign up, organizing the information collected; and purchasing and mailing cards. The staff of PWSA of WI, Inc. will assist in creating a database and providing mailing labels. All expenses will be covered. This is something one or many volunteers could do.

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

28th Annual Prader-Willi Syndrome Association (USA) and 16th Annual Prader-Willi Alliance of New York, Inc. Conference July 19 - 21, 2006



Wild about you!
Grand Island, New York

PWSA of WI, Inc. has General Assistance Scholarships Available for WI members to attend the 2006 PWSA (USA) conference

We are happy to announce that PWSA of WI, Inc. has once again allocated funds for a family of someone w/ PWS to attend the National PWSA (USA) conference in Grand Island, New York from July 19-21, 2006. If you are interested, please fill out the General Assistance Scholarship paperwork and mail it to the state office as soon as possible! If you have any questions, contact Mary Lynn at the state office via email: wisconsin@pwsausa.org or toll free: 1-866-797-2947. You can find information about the National conference on the PWSA (USA) web site at www.pwsausa.org



Prader-Willi Syndrome
Association of
Wisconsin, Inc.

2701 N. Alexander St.
Appleton, WI 54911

Office: 866-797-2947

APPLICATION FOR GENERAL ASSISTANCE SCHOLARSHIP

PURPOSE:

PWSA of WI, Inc. wishes to provide financial assistance for families of an individual with PWS to help meet the unique needs of these individuals and their families.

ELIGIBILITY:

Eligibility is based on financial need of the person with PWS. Financial need being equal, the second consideration would be given to those who could benefit most from attendance (respite intervention or personal/behavioral issues that need to be addressed).

1. Any person with PWS who resides in the state of WI.
2. The person with PWS or the caregiver or a family member of the person with PWS must be a member of the state chapter of the PWSA of WI, Inc.

Date of request _____

Name of person w/ PWS: _____ Sex _____ Birth date _____

Address _____ City _____ State _____ Zipcode _____

Phone (_____) _____ Does individual reside in WI? ____ Yes ____ No

Contact person _____ Phone (_____) _____

Is individual, family member or caregiver a member of PWSA of WI, Inc.? ____ Yes ____ No

Specific dates funds are needed by:: _____ Amount Requested: _____

What will funds be used for? _____

Why would this scholarship be helpful to you? How will funds improve the quality of life for the individual with PWS? (Financial need, need for respite, etc.) Use reverse side or attach additional paper if needed.

Return this application by: __ASAP_____

Send to: PWSA of WI, Inc.
2701 N. Alexander St.
Appleton, WI 54911

PWSA of WI, Inc. 2006 Calendar

April 1, 2006	Hobby Day	Oconomowoc, WI
June 3, 2006	PWSA of WI, Inc Board of Director's Meeting	Oconomowoc, WI
July 19 - 21, 2006	PWSA (USA) conference	Grand Island, NY
August 26, 2006	6 th Annual PWSA of WI, Inc. Golf Benefit	Oconomowoc, WI
October 11, 2006	Health Update Training	Quality Inn and Suites Madison, WI

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