



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
Vice President: Crystal Boser
Secretary: Kathy Bomber
Treasurer: Tom Hughes
Board Members: Pat LaBella, Jackie Stoner, Dan Beaver & Melissa Sirovina
Program Director: Mary Lynn Larson

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A Note from the Co-Presidents: Steve and Nancy

Greetings to all of you –

Well, the summer is winding down. The national conference is behind us, and the golf outing is just around the corner – September 17, 2005. I hope that I will see many of you there. This year we will again have a silent auction and are planning a shotgun start, which is new this year. Thanks to Jackie and Crystal for all their hard work in planning this event.

Personally, I am quite busy making final arrangements for Kyle, my grandson, to attend the Waterford school district. So far, the school system has been very cooperative in working with me to develop the IEP, Kyle and myself have met with his special ed teacher for a tour through the school and playground areas, and now I am working with the school nurse to develop an IHP – Individualized Health Plan. The teachers and administrators have all watched the video **Prader-Willi Syndrome – Overview for Health Professionals** (obtained through PWSA-USA) and we have discussed the educator’s packet (**The Student with Prader-Willi Syndrome**, co-authored by Barb Dorn, Wisconsin). In addition, we will have a “refresher” meeting to review all of it and allow for questions. Despite all of this and although Kyle says he “really likes the new school” I have some ambivalence as the start of school approaches. I could certainly use some well-deserved hours of respite, but let’s face it – our kids just don’t handle change very well. However, I am comforted to know that I’ve done what I believe I can to optimize the situation by utilizing the tools provided to me by the state and national organizations. I can’t imagine how difficult it must have been prior to the formation of these organizations. I am eternally grateful for that expertise and support, which is so freely given.

So, with thoughts of gratitude and hope, I’ll close. See you in September.

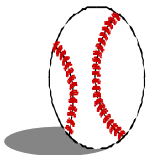
Nancy

Keep September 17, 2005 open for PWSA of WI, Inc.'s 5th Annual Golf Benefit!

We are looking for golfers, prizes and hole sponsors!

For more information, contact Mary

Lynn at the PWSA of WI, Inc office at 1-866-797-2947.



**Take Me Out to the
Ballgame ...To the Brewer
Ballgame**

**Friends, Families and Supporters of
PWSA of WI, Inc - Join Us for an
Afternoon of Fun**

When: Sunday September 25th, 2005
Game Time: 1:05 pm
Where: Miller Stadium, Milwaukee
**Cost: \$35/ticket (A portion of sales
will go to PWSA of WI, Inc.)**

Brewers vs. St. Louis Cardinals
Tickets are located in Section 112
Rows 18, 19, and 20

Advanced tickets can be purchased from
Crystal Boser via email:

crystalpmhs@aol.com or PWSA of WI,
Inc at 1-866-797-2947.

Make check payable to PWSA of WI, Inc.

**What better way to have a great time and
help PWSA of WI, Inc?**

**RESEARCH ON EDUCATIONAL
ISSUES:**

**Students with Prader-Willi ,
Williams, Down
or Fragile-X Syndromes**

The UCLA Behavioral-Genetics Clinic along with the UCLA Lili Claire Family Resource Center is conducting a needs assessment of teachers and parents of children with specific genetic disorders. We are seeking your participation in answering our research questionnaire about your child's educational strengths and limitations, behavior concerns, and the degree to which your child's school program is tailored to his/her specific needs. The questionnaire should take no more than 30-40 minutes to complete.

For more information or to participate in the study, please contact:

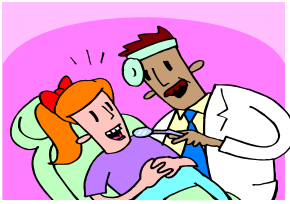
Rebecca Cox, Ph.D.
Technical Support Coordinator
Rm. 58-218E
760 Westwood Blvd.
Los Angeles, CA 90024

Or call 310-794-9516 (Lili Claire Family Resource Center)

Or contact us by email at
GENESTUDY@mednet.ucla.edu

Principal Investigator-Bhavik Shah, M.D.,
UCLA Department of Psychiatry

UCLA IRB# G03-01-073-02
Expiration Date: 11/28/05



Dental Problems and PWS

By Dr. Tom Hughes, DDS
Orthodontist, Treasurer PWSA of WI, Inc
and Parent of Sara w/ PWS

Most dental problems with PWS are related to decrease salivary flow and mouth breathing. These two concerns combined, promote tooth decay, periodontal disease and crowded arches. What can be done? First, make sure the child or adult has either a fluoridated water supply or fluoride tablets (1 mg/day) to help fight tooth decay. Have them brush with a fluoride toothpaste after each meal and then before bedtime. Parents will need to check their teeth after brushing, especially at night so that they don't leave food along their gum lines. This leads to decay and periodontal disease. Persons with PWS also have a tendency towards dry mouth because of their mouth breathing which leads to thicker saliva, which promotes both decay and periodontal disease. Normal saliva is thin and washes the teeth clean, while thick saliva sticks to the teeth and harbors bacteria that cause tooth decay and periodontal disease. Finally, as a result of mouth breathing during their early years, individuals with PWS have a greater chance of developing narrow arches which causes crowded teeth. Getting orthodontic care early (age 6-9) to help develop the arches to a more normal shape can make it easier to keep the teeth clean, which helps prevent tooth decay and periodontal disease. It can also help reduce their tendency to mouth breath, which would decrease tooth decay and periodontal disease. Professional dental cleanings every 3 to 6 months is also a big help in keeping the teeth and gums clean and healthy.

Ask the Dentist

The following are common questions regarding dental issues for persons with PWS. Dr. Hughes has provided us with some answers.

QUESTION 1: Sealants are often used in protecting a child's teeth from the formation of cavities. Is this something an adult with PWS could have done? Yes, an adult can have this done but this only protects the biting surfaces from decay. Along the gum lines is where most decay due to dry mouth and thick saliva occurs. In these cases, only proper brushing with fluoride toothpaste and topical fluoride rinses or varnish is effective.

QUESTION 2: Is there anything a dentist can do to help this be covered by the person's insurance? The Wisconsin Medical Assistance program covers sealants on permanent posterior teeth (which are the only ones that need sealants) the problem with the program is that it is under funded and difficult to work with. That is why many dentists don't accept it in their practices. (Please contact your state assembly and senate person and ask them to fund this program better.) Some insurances may cover this if a preauthorization is completed however, each insurance may be different.

QUESTION 3: Is there anything to help address the thick sticky saliva that is often seen in persons with PWS? Would scheduling "water snacks" at certain intervals help? The reason for thick saliva is mouth breathing for the most part and less fluid intake secondly. "Water snacks" (a glass of water 4-6 oz.) might help but too much water is bad also. (Water intoxication can occur if a person drinks a very large amount of fluids in a short period of time. The large amount of fluid washes away the sodium in their system and can result in a serious health emergency). However, if this was done twice a day mid morning and mid afternoon it could help. (Many parents also report the use of Biotene toothpaste has been helpful.)

QUESTION 4: Is it true that chewing gum after meals helps to prevent tooth decay? If so, is there any special gum that helps more than others? Chewing gum could help clean the teeth, but here again you have to be careful. Use sugar free gum and only let them chew 1 (one) piece. This can last from breakfast to lunch or lunch to dinner or dinner to bedtime. But as we know, many people with PWS will try to eat many pieces either at a time or one after another as the flavor goes away. If they eat many pieces of gum containing sugar, it can have the opposite effect and cause cavities and weight gain.

QUESTION 5: Is it true that there are certain foods (like apples or carrots) that can actually assist in removing the build up of plaque? Foods with hard textures do help clean the teeth of plaque. But again you have to use them in moderation because they still have calories and eating all day long produces plaque buildup.

QUESTION 6: Are there foods that should be avoided that may be contributing to the development of cavities? Any food that is soft, sticky and sugary (raisins, "gummy anything", candy ...) should be avoided.

QUESTION 7: It is often common to see white crusting on the sides of the mouth in person's w/PWS - what causes this and can anything be done to prevent this? This is dried saliva from mouth breathing. If your child has crowded teeth and narrow arches (need a dentist to assess this) having orthodontic treatment to widen the arches might help with their ability to breathe through their nose instead of their mouth. Also have their tonsils and adenoids checked because if they are enlarged this causes mouth breathing also.

QUESTION 8: Are there any special considerations that parents and dentists need to be mindful of when considering orthodontia for a person w/PWS? The biggest problem is keeping the teeth cleaned. Parents will have to help their children keep their teeth cleaned during orthodontic therapy.



Dental Tips and Tricks

Start teaching tooth care at a young age. Cleaning teeth should be done twice daily, beginning as soon as the first teeth appear.

- Start cleaning teeth in infants and toddlers with a very soft toothbrush, a washcloth or finger toothbrush pads. Not only will this help establish good dental habits and prevent tooth decay – this may help with oral motor stimulation and strengthening.
- Wide brush handles often make brushing easier. There are many brands and styles. One trick is to insert a bicycle handle grip, rubber pencil grip or other special grip device (available from an Occupational Therapist) on to the toothbrush handle.

- Ask your dental hygienist to help teach and motivate the person receiving dental care. (Many often do more to please others than they do to please parents.)
- Use a SOFT brush to prevent or minimize trauma to gums.
- Typically the parent should assist in brushing teeth up until early middle school. Encourage and teach the child to do it ... but the parent should finish it up with a "once (or twice) over" to make sure all areas have been reached.
- Make tooth-brushing fun. Don't be afraid to vary things to keep it fun as well as novel. There are many fun toothbrushes. Ones with:
 - Movie and cartoon characters. Let the child choose!
 - Music (so the child/person learns to stop brushing when the music stops).
 - Batteries – "Electric" toothbrushes.
- Use good tasting toothpaste w/ fluoride. Always provide supervision with toothpaste use to prevent the child from overeating it. Toothpaste in small amounts will not hurt you.
- 1-2 times a week, use tablets or a stain to check for plaque build up. Your dental care provider may be able to assist you with obtaining tablets or a small amount of food coloring on a Q-tip works well too.
- Make tooth care a game. Establish a routine. "Count 20 brushes on the top right; 20 on the top left; 20 on the bottom right; 20 on the bottom left; and don't forget the areas behind the upper and lower front teeth and tongue". Post the sequence on a small index card and post it to the mirror or other nearby spot so everyone who may be assisting uses the same approach.
 - Make a chart ... use incentives for good habits and cooperation. (Possibly reward with a new toothbrush, sugar-free gum...)
 - Use a tooth-brushing timer so that adequate time is spent doing the brushing. (See side box)
- Teach and encourage flossing. There are flossing instruments available at most pharmacies and other stores to help make this easier.
- Limit sugar and/or use sugar free products. (Sugar + Bacteria = Acid Production Acid + teeth = Cavities)

Visit a dental professional every 6 months for cleaning and monitoring

Finding a Dentist for the Person with PWS

- Select a dentist who is not only a good professional but one that also makes your child and the experience a positive one.
- Don't be afraid to shop around. Talk to other parents in your community. Get a referral. Choose a dental team that works well with children/adults who have cognitive limitations.

Finding dental professionals that take Medical Assistance is very challenging. Since the reimbursement rate is very low, dental practices often chose not to take this type of insurance. If your child/young adult has been receiving dental care from a dentist for many years and then begins to be covered under MA, talk to him/her to see if they would be willing to continue to care for your child. A dental practice can dictate how many patients they serve with MA and if you have a long-term relationship with this professional, he/she may consider doing this. Some dental care providers have opted to donate their services in lieu of filing with MA.

In planning for your child's future, you may want to budget funds so that your son/daughter can receive adequate dental care. Even with dental insurance, there are many services that are either only partially covered or not covered at all.

PRODUCT SHARING

1. **"TOOTH TIMER"** is a fun device that helps patients brush their teeth for 2 minutes, the proper time for brushing. NO batteries needed.
COST: \$9.99 + \$4.95 for standard shipping. Available at Open Wide catalog at 1-800-232-4244 or on line at www.OpenPlease.com Just write "timer" in the search box (item # CM940)
2. **BIOTENE** (toothpaste, mouthwash & gum) are products that help decrease bacteria and found to be very effective in decreasing the white ring and/or crusting often seen around the mouths of persons with PWS. It is expensive and not available at all stores. (Walgreen's carries it) ... and it is worth it.

Contact PWSA of WI office to share a product or trick you use to help with tooth care.

Did You Know???

Water with fluoride is available in plastic disposable bottles. If your water source does not contain fluoride, feel free to use it not only to drink but also with your recipes, juices, and/or Kool-Aid.

In addition to cavities, gum disease and periodontal disease, poor oral care can lead to other health problems. Bacteria can break away from the teeth and gums and travel to other parts of the body causing infections.

Back to School is Just Days Ahead. Is Your Child's Educational Staff Ready?

PWSA of WI, Inc has Educational Packets available to educators of children with PWS. These packets include numerous resources including the book, **The Student with Prader-Willi Syndrome – Information for Educators** co-written by Barb Dorn RN, BSN and B. J. Goff, Ed.D. . In addition, the packet includes brochures, articles and handouts that attempt to help the education team about the needs of the student with PWS and strategies to encourage success. There is no cost however, we do ask for a small donation of \$10 to cover shipping and mailing costs.

Can the Student with PWS Receive a Special Meal at School?

The question frequently arises "Can the student with PWS receive a special meal at school"? And ... the answer is yes. The need for a modified diet however must be included in the student's IEP. A written prescription from the student's health care provider is also needed. This prescription should include the student's diagnosis (PWS) along with a calorie amount for each meal. (Some students eat breakfast and lunch at school.) Because all schools received federal funding for their nutrition – lunch program, they must make reasonable efforts to accommodate this. Generally, schools may use nonfat milk, low calorie bread, fresh or lite fruit and extra vegetables. The use of these items is not an excessive request.

Work Place Giving

Soon many businesses will be asking their employees if they wish to make donations as part of their annual work place giving campaign. Keep PWSA of WI, Inc in mind. For those in the Madison area, PWSA of WI, Inc. is a part of the Access To Community Services umbrella. If you or someone you know is an employee of State of WI, Dane County, City of Madison, MATC, Madison Metropolitan School District or Monona School District, a donation can be made as part of your payroll deduction. In other parts of the State, many employee work place giving programs allow you to make a donation to our organization as part of a donor choice. Just fill in PWSA of WI and you will help us to continue our services to you. If any questions, feel free to contact our office. Also, check the box that you would like to be notified by the organization. This is an assurance that your donation has reached us.

Call for Candidates – 2005-2007

Are you looking for a way to get involved and help all with PWS? We have a way to meet this need. We have 3 Board positions open this fall, each for a two-year term. If you or someone you know is interested in serving our organization, please contact our office for filing papers. You can and will make a difference in the lives of persons with PWS. We can't do this alone – we need your help. Please feel free to contact any of our Board Members with questions or for more information. **Papers should be received by September 15, 2005.** A ballot is sent to all members in mid-September. These are the positions open.

PRESIDENT: Primary representative of PWSA of WI, Inc. Serves as Board chairperson. Calls Board meetings and sets agenda. Works closely with program director in completing necessary business items that require signature and/or input. Participates in organizational activities as able. Represents PWSA of WI, Inc at annual chapter president's meeting at the national PWSA (USA) conference. (Expenses are reimbursed.)

SECRETARY: Responsible for recording minutes at Board meetings and annual membership meeting. Distributes minutes to all board members as well as sends requested items to PWSA (USA). Participates in organizational activities as able.

BOARD MEMBER: Serves as advisor in providing governance to the organization. Assists in projects, committees and other capacities as needed. Participates in organizational activities as able.

Overview of Board Member Responsibilities:

The following is a brief outline of major events and activities PWSA of WI, Inc. sponsors annually. We attempt to present these with time frame and responsibilities that are expected from Board members or volunteers. We hope this helps you to make an informed decision about becoming a member of the board and decide where you might become more involved.

BOARD MEETINGS: The Board of Directors meets twice a year. The first meeting is typically the end of January so we are able to complete necessary items as we prepare for the calendar year. The exact day, time and location is determined at the previous meeting. We typically meet from 11 am to 3 pm. We attempt to work around Board Members' preferences and meet at a central location if possible. The second meeting is in the fall. We have tried many approaches and currently schedule it on the same day prior to the annual membership meeting.

BOARD MEMBER INVOLVEMENT: We encourage Board members to become involved in at least one activity or project per year. The following is a list of our current activities and projects. Dates and types of events are discussed and determined at our Board Meetings.

- **Annual Social-Training Day** - This event typically occurs in the spring of the year. We have tried various approaches, activities and locations for this event. The primary focus has been a Hobby-day with a social activity for children/adults with PWS. We also provide training and/or support opportunities for parents and/or professionals. This event is one day; however the amount of preparation time varies.
- **Annual Charity Golf Benefit** – This event usually occurs in the late summer/early fall. It has occurred at Paganica Golf course in Oconomowoc. The date is dependent upon availability. Jackie Stoner and Crystal Boser are the primary coordinators. All board members are asked to obtain 2-3 hole sponsors, seek out door prizes, disseminate fliers and recruit golfers for the event. They are also expected to attend/assist at the event if able.
- **Annual Training Workshop or Education Project** - PWSA of WI, Inc has sponsored some sort of training workshop/educational project annually. The topic, speakers and location vary. In the past, Board members have been speakers, worked at the registration table or assisted in other ways. As an alternative, we may choose to do an education/awareness project. We welcome anyone willing to offer expertise in any aspect of the project.
- **PWSA of WI, Inc. Newsletter – The Wisconsin Connection** - The newsletter is published and distributed 4 times a year. Program directors solicit articles, prepare layout and mail it. Any one willing to submit an article or help with some aspect of this is encouraged.
- **Packet of Hope Program** - All genetics clinics in the State of Wisconsin are given 5 copies of our Packet of Hope each year. We contact each of them and replenish their supplies annually. Packets need to be compiled and mailed. Help is needed in replenishing/distributing these packets.
- **PWSA of WI, Inc. Annual Mail Fund Raiser** - We conduct a mail fundraiser annually. This is typically in the spring of the year. Currently program directors create the letter and prepare them for mailing. Anyone interested in creating this fund raising letter should contact our office. Program directors assist with the production of labels and any other supplies that may be needed. (We are always looking for creative people!)
- **Meeting for Parents of Young Children** - In the past few years, we have sponsored an annual meeting specifically for parents of young children. Two parents of younger children have made all the arrangements for this event. We are planning this year's meeting in the Milwaukee area.

Conference Scholarship Awarded

PWSA of WI, Inc was happy to award a conference scholarship to the Kryzak family so that Jennifer and Nolan could attend their first conference! Jennifer stated that it was a very rewarding, informative yet very emotional experience. We had plenty of time to talk about it and many other things during our delay waiting for a flight leaving from Orlando to Milwaukee! Jennifer has promised to put some things together for a newsletter article in the near future.

News from the Office...

Things in the PWSA of WI, Inc. office had been relatively quiet before the National conference in July – but now everyone is thinking of school, fall fundraisers and the phone is ringing all the time! We have been getting things together for presentations to schools that may be getting a new student with Prader-Willi syndrome as well as sending updated information to families who have already made presentations to their schools and just want some new information.

And I am frantically working on my own presentations to our schools – especially now that Alex is moving onto Middle School while Matthew is going to an Integrated Kindergarten in the school Alex has spent the last 10 years attending.

In addition, we are getting things ready for the golf benefit on September 17th, as well as the Brewer game on September 25th! I hope to see many of you at one or maybe both of these events! They are a lot of fun and a great way to support PWSA of WI, Inc.

We are also getting things ready for elections for Board and Officer positions. Is this something you might be interested in? We are always looking for eager and enthusiastic people who might be interested in helping on our Board of Directors. It only requires you have an interest and commitment to the organization's mission to support, educate and advocate for anyone impacted by PWS.

Feel free to contact me if you have any questions about these upcoming events on the toll free line at 1-866-797-2947.

Hugs
Mary Lynn

Camp Scholarships Awarded...

PWSA of WI, Inc was able to fund several camp scholarships this year. Camp is such a fun time for kids to make friends, learn new skills and just have fun! It also allows families a chance for respite and some time away from their family member with PWS. We were able to help Robin Wolk, Megan Allen and Kayla Sirovina all attend camp!! We heard a lot about the fun they had; and Kayla sent us this note:

August 13, 2005

Dear PWSA Board Members:

Thank you so much for my scholarship to camp Wil-O-Way. I can't thank you enough because this summer was the best summer of my life! Being away from school was great. I have to admit that camp was a blast. This summer, I was spending the hot days out in the pool. The water was always cold to cool us down. We took hikes on the bike trails, to the play ground at picnic area 7,8,9 and last but not least to Lake Michigan. Now that was cool.

I thought if I put in my Camp Wil-O-Way song it would give you a little idea about camp. This is the song:

Welcome to Wil-O-Way to start off a great day
Welcome to Wil-O-Way where fun is a step away.
Make new friends and throw all your cares away
here at Wil-O-Way.
We're from Wil-O-Way; couldn't be prouder.
If you can't hear us we'll shout a little louder.

Every week we went on field trips. Our field trips were to the zoo, Holler Park swimming pool, Italian Community Center, bowling, and the Milwaukee Museum. The last one was to the State Fair. Mom went to the State Fair with me.

I had so much fun this summer that I hope to go back next summer.

Thanks a lot!!!

Love

Kayla



PWSA of WI, Inc. 2005 Calendar

September 17, 2005	PWSA of WI, Inc 5 th Annual Golf Benefit	Oconomowoc, WI
September 25, 2005	Milwaukee Brewers vs. St. Louis Cardinals 1:05pm	Miller Park Milwaukee, WI
October 8, 2005	PWSA of WI, Inc Board Meeting Meeting of Parents of Young Children with PWS	Milwaukee, WI Details to follow
July 19 - 21, 2006	PWSA (USA) conference	Grand Island, NY

Prader-Willi Syndrome Association of WI, Inc.

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