



THE WISCONSIN CONNECTION

The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.

Mission:

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

State Officers:

President:

Pat LaBella

Vice President:

Jackie Stoner

Secretary:

Mary Mankowski

Treasurer:

Tom Scheidegger

Executive Director:

Barb Dorn

Newsletter:

Brian Fendt

Office Address:

P.W.S.A. of WI, Inc.
305 Amanda Way
Verona, WI 53593
608-845-9597
Fax 608-845-9638
Email: pwsawi@itis.com

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
941-312-0400
Fax 941-312-0142
Email: pwsausa@aol.com
Website: www.pwsausa.org

A Message from the Executive Director

Barb Dorn

I always feel like I need to let everyone know how much our organization is doing .

It has been a very busy summer and we have been able to get a lot accomplished. The summer months always offer me an extra challenge to be able to keep up the momentum in answering phones and granting requests in a timely fashion. As most of you are aware, I run the office out of my home and when there is a break in school – it becomes extra challenging.

By the time you receive this newsletter, our organization will know whether or not we have received a \$5000 grant from the Wisconsin Council on Developmental Disabilities. This grant will be used to help us with our Information and Referral Initiative. With this grant, we will receive funding to help us continue to reach out to parents and professionals around the state who care for and work with persons who have PWS. It will help us cover the costs of using various telecommunications (phone, email, and fax) to support, educate and advocate for persons with this disability

and those who support them. There is no way that anyone can travel around the state and talk and meet all the needs that many of our children and adults have. We are attempting to obtain this grant along with one from the Alliant Energy foundation to help us finance this aspect of service. It is the most cost effective, time efficient way to help people spread across this big state of ours. Keep your fingers crossed.

This summer we had a situation where our organization granted some money to a parent to help the family. The money was not used for what it was earmarked for and we had to ask the person to return the money. The person became quite upset with us and felt that we were only concerned with money. I hope people don't view us this way. As I told him, we do not have a lot of money and we do our best to be very good guardians of the money we do have. We hate to have to be so concerned but unfortunately, everything comes with a cost. I know we have been asking for money lately and I know we will need to ask for more again in the future. In order to keep the organization strong, we must have funds to do this. Remember however,

Continued on Pg. 3 ➡

Notes From The President

Pat LaBella

Well, we did it! My family and I, went to the national PWSA(USA) conference in San Diego and returned to Madison, still speaking to each other. This is amazing considering the fact that we were together for 12 days straight. There were moments when hyperactivity, moodiness or extreme obsessive compulsive behaviors became almost unbearable. (And those were the behaviors from the 3 kids without PWS.) But then something humorous would happen and we'd all lighten up. All in all, the conference and trip were great. We had wonderful weather and we all learned a lot.

Over 1000 people from around the country attended this years conference. 250 of the attendees were children and adults with Prader-Willi Syndrome. Because this was the first national conference that she had attended, my daughter Beth had never seen so many people with PWS in one place. After the first day, Beth said, "Boy, it seems like everyone I meet has PWS. I think PWS is occurring much more frequently these days. Don't you Mom?"

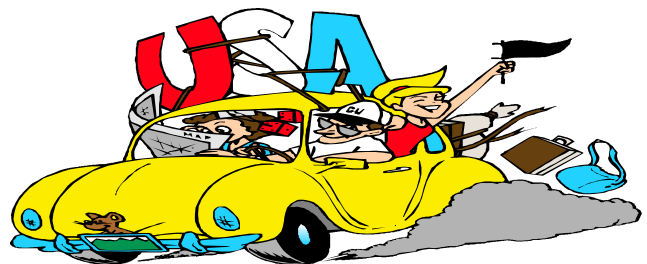
While the adults attended the conference talks, the Youth and Adult Program (Y.A.P.) sponsored a "Circus Under The Big Top" the first day. The second day the Y.A.P. went to the aquarium and to the IMAX theater. Beth and her brother enjoyed attending the YAP program and my two older daughters worked hard as chaperones.



The adult conference talks covered many areas from infancy through adulthood. Some of the topics covered were: nutrition, behavior management, information about genetic research, the use of psychotropic medications, sexuality, constructing a good IEP, transitioning into adulthood. It was good to learn new information from the talks but it was even better to share some camaraderie and stories with other adults who support a child/adult with PWS.

Thanks to all the people from PWSA (USA), the California Foundation and all the others who worked so hard to put on such a worthwhile conference. I hope to see some of you at next years national conference in Pittsburgh, Pennsylvania in July, 2000.

Pat



Thank You!

A big thank you to Mike, Mary Lynn and Alex Larson for organizing and hosting our statewide PWSA picnic. The annual fall picnic was held in Appleton. We swam at the YMCA and then we went to the Children's Museum. Four families from around the state attended as well as our friends from ODTIC, which brought total attendance up to approximately 60 people. A good time was had by all.

Message From the Executive Director Continued From Page 1

whatever money is given to us, we will be good stewards in using it to carry out the mission of the organization.

Recently, I lost a very dear friend. She was like my second mother. I have spent the past two years, helping this woman with her health and medical needs as well as being a close friend. Her battle with cancer was rough but she was a true fighter.

At her funeral, her family decided to let PWSA of WI, Inc be the recipient of funds that were donated in her memory. I made up some very tasteful memorial cards and attached them to envelopes that were addressed to our organization. These memorial cards were personalized with a message for this woman and her family. I also created a brief one-page summary of this woman's relationship to PWSA of WI, Inc and a very brief description of PWS. I did this sort of thing when my mother died as well. It was a very personal tribute to my "mothers" as well as a way for them to help me to be able to keep doing the work I am doing.

If anyone ever loses a parent, grandparent or other loved one and they too would like to do this sort of thing, our organization now has the ability to make these memorial notes and send them to you. It is one way to keep the memory of a loved one living on in the work that we do.

We haven't had many people sign up for our residential workshop on October 12th. We think we made a marketing error by including the flier in our last newsletter. We are trying to "save" the workshop by contacting residential providers to encourage them to attend. Planning and coordinating these trainings is a lot of work and we have some excellent speakers lined up. We hope we will be able to go ahead with it.

This fall we will once again be hosting a parent workshop. This year it will be held in Milwaukee. It isn't solely for parents - everyone is welcome. Our topics however are focused on issues that parents often need to face. We have attempted to reach out to young and old. I hope everyone will come out and share, and support others. Often times, that networking is the most beneficial part of these meetings. Childcare will be provided. We do however need to have everyone register so that we can make sure adequate space and volunteers are available. One topic that Pat and I will be facilitating is the topic of residential care. As parents, we have to **work together** in planning for our children's future. We won't be able to get the kind of supports our children need in a timely fashion without this sort of planning. I hope people will be able to make it.



I hope everyone has a safe holiday season. This is our last newsletter for 1999. It will be quite a change going into the new millenium. I know it will take me quite a while for me to get the hang of writing and saying 2000. Our national organization will be celebrating its 25th anniversary in 2000. We have had 25 years of discovery and progress in many areas for people with this disability.

Happy Halloween, Happy Thanksgiving, Happy Haunaka, Merry Christmas and Happy New Year to Everyone!
TAKE CARE.



A TOOTH BRUSHING TIP

Many people who have PWS, have very thick sticky saliva. Often times, we can see a white crust develop on the corners of their mouth. Many people have found Biotene toothpaste, to be very effective at preventing this crust from forming. It is a bit expensive – about \$6.50 a tube but it is very effective. It can be found at Walgreen's as well as other pharmacies.



Home Work ...A Lesson in Frustration

By Barb Dorn



Author's Comment: *Over the past 8 years, I have learned to hate the concept of homework for my son who has PWS. He is now entering eighth grade. It has only been within the past two years that I have been successful in stopping this practice. It was either stop it or allow it to destroy our family time. The following editorial article is my families' view on this common educational practice. As my son grew older, the challenges of homework grew more intense. There may be students who have PWS and families who do not face this challenge. But for those of us who do ... this article is for you.*

Homework is a task that all of us experienced as a child. A teacher taught us the material; we performed in-class exercises; and then we practiced what we learned in out-of-class work. Homework can teach many students responsibility and accountability. It can help the student transfer the learning process from school into the home environment. For many students with PWS however, transferring or generalizing what is taught in school to the home is the difficult part. Homework can create at-home chaos and emotional upheaval for the family.

Transferring learning from one environment to another is a common challenge that many students who have cognitive or learning differences experience. What that means is that a child may seem to have a clear understanding of a concept or task at school but when he or she is asked to perform that task outside of the area in which they learned it, they are often unable to do so. Add to that the fact that many of the methods of how we were taught are not the same methods used to teach our children today. So when well-meaning parents try to reinforce or re-teach a concept during homework time, the child with PWS becomes confused and anxious because the parent is explaining things in a new or different way. Battle can then begin when the student with PWS wants to complete the assignment but the parent lacks the expertise to teach the material in a consistent manner.

Many students with PWS often do not see parents as teachers (even though that can be one of our primary responsi

bilities). As parents we are very aware that many children and adults with this disability rely on the "expert or boss" in a situation for the final decision. Parents are often not viewed as the math (or reading or science...) expert.

We know that many people who have PWS are visual learners. We also know that they have poor auditory short-term memory. If exact instructions or assignments are not clearly written down, the student often can't remember how to complete the work. The parent is often placed in a "no win" situation – the parent's word against the child's word. As emotions escalate, logic and learning is lost. The end result is an evening of frustration and tears.

Many students with PWS work very hard all day long to stay focused and in control. They are faced with many challenges academically, behaviorally and socially. They view home as a time to unwind, relax and work on home-related activities. When the task of homework faces many of them, they can quickly escalate to tears, tantrums or both.

I have called teachers at home during these times to let them briefly hear and experience all that can go into a "simple misunderstanding".

Siblings often try to help out as well. This is especially true when the sibling is older than the child with PWS. Younger siblings can also quickly surpass the older child in the area of academics. At times this situation can be successful. There are other times when the whole household gets pulled into the emotions that accompany misunderstanding.

I have heard parents remark that if their child did not do homework, that they would be giving up on them. I strongly believe that we are not giving up on our children when we ask for sanity and peace in our homes. Homework often interferes with our ability to keep less stress in our family life. We face so many challenges; out-of-school work should not be one of them.

Parents become experts at interjecting learning so that the child is unaware of this practice. This is a strategy not unique to parenting a child who has PWS. We often use this on all of our children. We "sneak" ways for our child to use math skills. ("We have 4 people eating supper tonight and they each get 2 dinner rolls. How many dinner rolls should we cook?")

Continued on Pg. 5 ➡

Home Work ... A Lesson in Frustration

Continued From Page 4

We also utilize the news or a favorite TV show to point out geographic locations. Mind you, we must be very clever and sneaky in doing this teaching.

I do feel that home should be the place where we teach home-related responsibilities and expand upon social opportunities. We should be teaching and reinforcing grooming and household tasks. As the "parent-teacher", we are responsible for teaching bathing and other hygiene activities. We also instruct on bed making, laundry and cleaning responsibilities. Finding appropriate recreational opportunities is also a job we undertake.

I have always been willing to assist in "homework" such as a trip to the library to obtain a good book for recreational reading. I have also been willing to provide a structured time with my son and a few friends so that he can expand his social skills. Inviting friends for a visit can teach many valuable lessons – phone skills, speech and language skills, sharing as well as many other life skills.

When we look at our own work commitments, we all become a bit cranky when we start to do too much "work" during our family time. Most children with PWS have some degree of cognitive (learning) and/or behavior limitations. They need to have expectations in the area of homework modified – preferably eliminated. As the child and family advocate, we need to communicate the need for home time to be a time for positive social and leisure opportunities. Educators need to support the separation of schoolwork and homework. We are not giving up; we are focusing on a different yet very important areas of our child's learning .



Volunteers Needed!

Volunteers are needed for the following events. If you are able to be of help, please contact Barb Dorn at PWSA of WI, Inc. 608-845-9597.

Items needed for daycare at November Parent Meeting:

2 Bottles of Tropicana Lite Juice (any flavor)
CHILLED
2-dozen paper cups and napkins

Items needed for parents at November Parent Meeting:
2 liter bottles of soda

It really means a lot if members can pitch in and help.

Thanks.



Acknowledging and Thanking Our P.A.L.S.

We would like to thank the donors to our recent P.A.L.S. fund raising project. P.A.L.S. is the acronym used for People Are Loving Supporters. Without generous P.A.L.S. like you, we would not be able to continue our services.

Betty Schutz
Jim & Karen Plosczynski
Jeff & Laura Werner

Arlan & Dottie Lothe
Dave & Lori Fay
Jane Majcherek

We would also like to acknowledge donations that PWSA of WI, Inc. received in memorial of Virginia Hall (a dear friend of Barb Dorn)

Ruth & Leo Halverson
Kaia & Rob Dural
Ole Halverson & Kathy Lamond
Elizabeth & Scott Cooper
Ms. Josephine McDermott
Mr. Herman Grams

Chip & Cathy Halverson
LyAnne Halverson
Don & Barb Dorn
Mrs. Ruth Voss
Kenneth Danielson
Helen Grenlie

Menu Planning - Saves Time and Expense

By Barb Dorn

I remember when my son Tony began to be more "preoccupied" with food and eating. I felt like my life was consumed with talk or thoughts of food. It seemed like I was spending so much of my day trying to figure out what to cook; preparing what to cook; discussing what I was cooking and then cleaning up after I cooked.

I also had to prepare a grocery list and do the grocery shopping. There were many days that I had had enough of food and cooking.

I then figured out a way to focus my attention on food, preparation and shopping all at one time. I would sit down and prepare a menu. After I had the menu completed, I would then make up my grocery list based on the items I had chosen to make for that week. I posted the menu on the refrigerator so that if anyone had any questions about "what was for supper that night" – there was a visual reference available.

As most of us are very aware, having the menu posted and visible for the person with PWS can save us many repetitive questions and help to relieve anxiety. I think some of the first words that Tony learned to read were items from the menu. Not only does it provide a security for these people but it can also provide some sanity for us.

Another big advantage of having a pre-planned menu is that it can and does save you money at the grocery store. If you are in the habit of going to the grocery store on a daily basis because you haven't planned in advance, you end up spending more money.

For about 9 months, I worked as a nutrition counselor to a 38 year-old woman who was disabled because she had suffered a stroke as a result of high blood pressure. I was asked to help her learn how to make better choices with food and design a diet (with her dietician) to help her lose weight. This woman used food stamps and had very little knowledge of nutrition or how to read labels. She often went to the grocery store daily and would end up spending all of her food stamps by the end of the second week of the month. After working with her to plan a menu and use it to make a grocery list, she was able to make her food stamps last the entire months (and sometimes she even had some left at the end of the month). She also learned to plan menus using the basic food groups as her guide. She lost weight and began to make better choices for herself and her family in the food they were eating. Menu planning was the cornerstone to her success.

We all face the need to watch the nutrition and calories in the food that we prepare for people with PWS. Developing strategies to make it easier for us and more successful for them is well worth the efforts. Saving money; saving time; and saving tantrums can make meal time a much more pleasurable event.



Update On Summer Activities

By Pat La Bella

Our Officers and Board of Directors have been very busy during the last few months. In between raising our families and tending to issues from everyday life, we have spent many hours trying to spread the word about Prader-Willi Syndrome, *throughout the state of Wisconsin*. Barb Dorn (Executive Director) continues to run the office from her home, answering an average of 150 communications a month. She also continues to apply for grants so we can keep our state chapter running. For the last 6 months, Barb has been doing an on-going residential training at the request of an individual with PWS. So far she has spent over 50 hours, facilitating discussions between staff and client, training staff and creating an individualized training manual for staff to use when supporting this person with PWS. In June, Barb, went to *Wausau* for a consultation regarding a possible diagnosis of PWS.

In July, Jackie Stoner (Vice President), Barb and I attended the national PWSA(USA) conference in *San Diego, California*. In August, Mary Lynn Larson (PWSA - USA Vice President), Barb and I facilitated two trainings for teachers and other educators, "*Supporting the Student with PWS, Across Their Life Span*". One training was held in *Madison*, and one training was held in *Appleton*. Approximately 32 people attended those trainings. We also had our annual PWSA of WI picnic in *Appleton*, in August. In Sept., Barb was invited to speak about vocational issues at "*Supported Employment Conference*" in *Stevens Point*. We will have an Officers/Board of Directors meeting in September. We continue planning for our statewide residential training "*Caring, Conflict & Consumer Rights*" to be held in *Fond du Lac* in October. Mary Mankowski (Secretary) has made arrangements for our annual, statewide parent training to be held in *Milwaukee* in November. Jackie will be one of our presenters at this training. And last but not least, we have just finished putting the finishing touches on this quarterly newsletter.

As you can see, we have traveled throughout the state in our efforts to be true to our mission statement to, "*Support, Educate and Advocate for people with PWS, their families and professionals in meeting the challenges of this disability.*" If any of you have a passion for keeping the PWSA of WI chapter alive, please feel free to give us a call. We are always looking for new leadership. We welcome any help you can give us. Remember, this is your organization.



Thanksgiving Dinner, Some Low-Calorie Options

Compiled by: Teresa Kellermann, Prader-Willi Syndrome- Arizona Association

Note: Small portions are not always the equivalent of low-calorie portions

		<u>Regular Servings</u>	<u>Small Portions</u>	<u>Low-Calorie</u>
Turkey	6-8 oz. dark meat	400	300	
	6 oz. light, no skin			160
Gravy	Pan style	120	80	
	Broth			50
Potato	Yam Casserole	200	150	
	Baked (small)			100
Relish Tray	Olives (6)	50	30	
	Celery			5
Cranberries	Jelly	100	50	
	Jello (sugar-free)			10
Roll	Dinner style	100	50	
	Slice diet bread			40
Butter	Real or margarine	100	50	
	Fletcher's diet			5
Stuffing - 1 c.	Regular	300	150	
	Diet			60
Pumpkin pie	Reg. slice	300	150	
	Diet, no crust			50
Whipped Top.	1/2 c.	80	50	
	2 T.			20
Glass of Wine		100	80	
	Diet spark. soda			0
TOTAL				
CALORIES		1850	1140	500

According to the USDA Nutrient Database.

The average meal for a person with PWS who wants to lose weight: 250-350 Calories

The average meal for a person with PWS who wants to maintain weight: 400-450 Calories

* Visit the PWSAA on the internet: <http://www.azstarnet.com/nonprofit/pwsaa/>

* "Must see" site for kids of all ages, Miss Silli's House at: <http://www.geocities.com/HotSprings/Spa/4242/sillihouse.html>



More New Members For 1999

We would like to thank the following individuals for becoming new members since our last newsletter. Our 1999 goal was 100 paid members. We did not reach our goal. We were 5 short. If anyone sends in his or her membership for 1999 in between October and December, it will also include a 2000 membership.

WELCOME:

Dr. Ken Herrmann, Jenny Kraft, Jayne Majcherek,

Jeff & Laura Werner Ray & Carol Vidas



Prader - Willi Syndrome Association of WI, Inc. Annual Statewide Parent Training Day

“Strategies and Support for Parents of Children with PWS”

Date: Saturday, November 6, 1999

Time: 1-4 PM

Place: Children's Hospital of Wisconsin, Milwaukee, Clinic Area

Address: 8901 W. Watertown Plank Rd. Wauwatosa WI 53226

We will have a short business meeting followed by two break away sessions.
We will end the day with time for sharing and socializing

Breakaway Topics

- 1) Behavior Management Strategies for Parents of Younger Children
- 2) Residential Planning for Parents of Older Children.

Cost: Free to members. \$15 for non-members. This \$15 includes a 1 yr. membership.

Free child care will be provided along with a 100 calorie snack.

* Please do not allow children to bring other food or drinks into child care area.

Registration is necessary to insure adequate child care and adequate space for all parents.

Registration deadline: Friday, October 22, 1999

Come learn and share. Everyone is welcome!

Please return bottom to PWSA of WI, Inc., 305 Amanda Way, Verona, WI 53593

Yes, I plan to attend the PWSA Parent Training Day on Sat., November 6, 1999.

Name: _____ Address: _____

City: _____ State: _____ Zip: _____

Age of child with PWS: _____ I am a member of PWSA of WI. _____

Number of children needing childcare: _____

I am *NOT* a member of PWSA of WI. I have enclosed \$15.00 payment
made to PWSA of WI, Inc. _____

**Prader - Willi Syndrome Association of WI, Inc.
Annual Statewide Parent Training Day**



WISCONSIN

PWSA
U.S.A.

- 1999 Calendar Update**
- September 26** Officer's meeting in Madison, 1-4 PM
- October 12** "Caring, Conflict & Consumer Rights - Supporting the Person with PWS in the Residential Setting"; 8:30 - 3:30 PM, Holiday Inn, Fond du Lac. Registration required
- November 6** Parent Meeting & Training, Milwaukee Children's Hospital, 1-4 PM. Registration required.

**Prader - Willi Syndrome Association of WI, Inc.
305 Amanda Way
Verona, WI 53593**

