



# 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 Educate, Advocate and Support persons with Prader-Willi Syndrome, their families and professionals in meeting the challenges of this disability.

**State Officers:**

**President:**

Mike Larson

**Vice President:**

Jenny Lucas

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Pat LaBella

**Treasurer:**

Tom Scheidegger

**Executive Director:**

Barb Dorn

**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](mailto: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](mailto:pwsausa@aol.com)  
Website: [www.pwsausa.org](http://www.pwsausa.org)

## SPECIAL BACK TO SCHOOL ISSUE

### Starting middle school.

*One family's approach to preparing a new school and staff for their daughter with PWS*  
By Linda Keder

When Stephanie Baker enters Mayfield Woods Middle School this month, she and everyone else will be ready, thanks to the groundwork laid by her parents, Bob and Peggy Baker of Elkridge, Maryland. If all goes according to plan, one week before school begins, the Bakers and their pediatrician will have the undivided attention of the school principal, assistant principal, their daughters, special education teachers, her key support staff (speech therapist, occupational therapist, and adapted P. E. aide), the related arts staff ( art, music, and P.E. teachers), the cafeteria workers, and even the school custodians.

First the medical doctor will present the basic information about Prader-Willi syndrome and answer the school staff's questions. Then Bob and Peggy-and possibly Stephanie herself-would give the staff more specific information about how PWS affects Stephanie and what the school team can do to prevent problems related to her disability. The doctor's presence provides a high level of credibility and reinforcement to their staff training, Bob explains. Its best to have a doctor who knows your child well, but, basically, any professional

who knows about PWS is better than no professional when it comes to convincing schools about the needed measures, he says.

The staff training meeting is only one step in the process, however. The Bakers began last spring to prepare for Stephanie's transition to Middle School by observing several times in the new school, meeting with the middle school guidance counselor and special education support staff, having a special education team leader from the Middle School observe Stephanie and talk with her elementary school team, meeting with the new principle to set up the staff training meeting, and making sure Stephanie's IEP (Individualized Education Program) was appropriate for the next year. The Baker's often take a doctor with them to IEP meetings, as well, and this year they also engaged an independent educational consultant to review the IEP. The consultant helped them pare down the number of goals and make sure they were achievable and measurable.

Although all these professionals cost money, the Bakers say that it's worth it to ensure that Stephanie gets the supports she needs, especially her classroom aide, who monitors and assists her throughout the day and instructs her in basic life skills.

**Continued on page 2 see Middle School**

## Notes from the President

By Mike Larson

From the national conference comes exciting news! PWSA of WI, Inc.'s very own Barb Dorn has been elected as President of the National PWSA(USA) and myself as a member of the National Board of Directors.



**National PWSA President Barb Dorn and newly elected Board member Mike Larson**

I feel this is great that representatives from WI can broaden the circle of influence that they have started here in WI to help persons with PWS and their families across the country. What does that mean for PWSA of WI? It means we need others to step in where Barb and I have been involved. There will be elections for PWSA of WI officers in November. We need nominations for officers. To date, we do not have nominations for Secretary and President. This is an opportunity for someone to step forward and be involved. Some say that they won't know what to do. These positions do not require any prior experience or knowledge. There will be people to help every step of the way. This is a way to learn more about PWS, and be proactive in living with this disability.

I recently attended an event where the keynote speaker was Ralph Nader. During Mr. Nader's speech, he briefly spoke about volunteerism. He spoke about the need for each of us to be active in the local organizations that support our needs. We cannot wait for the government or the system to take care of us, but we need to be proactively supporting ourselves and seeking out answers and services that are there. We just need to find them because they won't find us. He said that the reason most people give for not being involved in a volunteer organization is that they won't have time for a social life. His response was, "What better place to have a social life? Where else would you be able to meet genuine, caring people that have similar interests?"

I find what Mr. Nader said to be true. I have met more people that have become close friends through the PWSA of WI organization. And I believe they will be my friends for the rest of my life. I have learned more about PWS and how I can best help my son live with this disability. I have learned that knowledge is power. And with this power I can take a proactive approach to PWS and not just letting PWS control how we live. I have learned about using the systems and programs to our best advantage and not being dependent on the system telling me what to do. Having this approach improves the quality of life for a PWS family.

What you need to do is get involved and nominate yourself for an officer position or volunteer to help with a special project for PWSA of WI. **Step forward, the chapter needs you right now! If you don't do it, who will?**

## Back to School Blue Jean Blues

By Barb Dorn



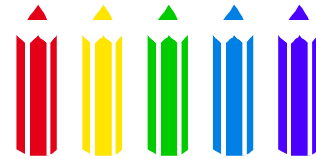
Are you approaching the school year with that dreaded fear of trying to find blue jeans that not only fit but also look good on your child? Here are a few recommendations of stores and/or catalogs.

For younger children, many discount stores have a bigger selection of jeans with elastic at the waist. Some have elastic all the way around while others have it on the side. Examples include K-Mart, Shopko, Walmart, and Target. Not only are they easier to find

but often times less expensive.

Once your child is in the adult sizes, the selection is often more limited and difficult to find. Two sources that I have found include Eddie Bauer catalog and JC Penney catalog. In the Eddie Bauer catalog, the jeans have elastic around the entire waist and you can order them to your exact length specifications.

I have not been able to find these at their store – only through the catalog. (1-800-426-8020). The Fall and Winter 1998 JCPenney catalog also has some elastic waist jeans TWILLS (pg. 389). The inseams are a bit longer and you can't order them to fit but the price is a bit lower. Well, good luck with your back to school clothes shopping.



## Middle School (Continued from page 1)

The Bakers have created a school information packet about PWS – including the Management textbook, a PWSA video, articles, booklets, and brochures – which stays at Stephanie's school for staff reference.

One final bit of strategy that the Bakers recommend is to be visibly involved in and supportive of the school. To that end, Peggy Baker regularly volunteers at her daughter's school - not necessarily in Stephanie's classroom, but often in the media center, which provides a central location from which to meet teachers and monitor school happenings. The Bakers have found that they can best advocate for their child when they know the school and its programs and can suggest ways for her to fit in.

## Educating the Educator

By Barb Dorn, RN BSN, Executive Director PWSA of WI, Inc.

It's hard to believe how fast the summer months go. For some of us, the start of another school year is a time of returning to structure, routine and relief. It can also be a time of hard work in trying to get educators and other professionals to understand our child and the unique needs they have. I have found that I need to conduct a training on an annual basis to help educators learn about my son and Prader-Willi Syndrome. It is just one of the many hats I wear as the parent of a child with this disability.

If you think this article looks familiar, it should. This is a revision of an article from the July-August 1993 issue of *The Gathered View*. Over the past few years, I have gained more experience in presenting to school staff as well as coming up with some new ideas and strategies. (Most of these ideas have come from parents and educators.) This article is meant to help parents get organized and give suggestions in where to begin when "educating the educators".

### Where to Begin

- ◆ Ask the building principal or special educator to set up the meeting. If you find resistance, you may want to try asking for staff training in your child's IEP.
- ◆ Figure out the main concerns you want to focus on.
- ◆ Gather pictures of your child so no one forgets the individual child you are discussing. (You can bring pictures in frames or make a poster board with them mounted on)
- ◆ Gather written information to distribute to staff at the meeting. Make sure to focus on your priorities.

### The Meeting Format

The following format is one I have found to be very successful:

1. Welcome the staff and state the purpose of the meeting. Thank them for attending.
2. Describe your child as an individual, focusing on his/her strengths and interests. Show the photos or display.
3. Present a general overview of PWS including the genetic cause (keep this part brief), the two distinct stages ("failure to thrive" and "thriving too well") and health risks. Your child's educators may need to know about the complications of obesity, hypoventilation (which could result in falling asleep), skin picking, a high pain threshold as well

as any other health concerns your child may have.

4. Share recommended behavior management strategies for the specific characteristics of PWS that may interfere with their learning process. (See enclosed chart for suggestions)
5. Describe how PWS affects individual teachers, such as regular education or special education teachers, art teacher, physical education teacher as well as any others.
6. Summarize your points and thank the staff.
7. Encourage them to purchase the textbook, *Management of Prader-Willi Syndrome*. It is a valuable resource.

### Other Items to Share

Many educators have misconceptions about the child's ability to gain control of their food drive, their rigid thinking, being flexible, or other problematic behaviors associated with the syndrome. Parents need to make sure they explain that PWS is a brain dysfunction that prevents affected children from developing these inner controls. (There are 2 handouts in the new *Behavior Management for Persons With PWS* booklet that I have found to be very helpful. This is now available through PWSA (USA).)

Rather than trying to eliminate the behaviors, teachers need to find ways to adapt the environment. It is my belief that "the key to success in school as well as all settings is providing supports in their environment in order for students with PWS to function effectively (and in some cases, survive). I have found that I have to emphasize realistic goal setting. The goal may need to be for "Tony to decrease the frequency and intensity of tantrums – maybe not to eliminate them". Adaptations in the environment may include foreshadowing, providing visuals and setting up behavior contracts. I've advocated for some students who were receiving supports in all areas except the lunchroom. It was obvious that the staff did not understand this child's needs.

Teachers need to be reminded of the type of learning style your child uses to succeed. Many students with PWS are visual learners and do better when material and behavior contracts/strategies are presented in this format. Many of these students learn best in the morning with a strength often seen in reading. The art teacher



may need to be informed of fine motor weaknesses as well as the need to avoid using food items in art projects. The gym teacher needs to be aware of motor weaknesses and their risk for injury. The physical education teacher may need to modify activities and direct the child to stop before reaching his/her endurance limits. Both the physical and occupational therapist can also be resources to teachers who need help in modifying these areas.

### **Make it Individualized**

Each parent needs to tailor their talk to their child. Share strategies that you know work for your child. After each presentation that I do, I continue to be amazed and learn more strategies that parents have found useful in managing some of the behavior concerns in their child. Parents, you are the experts about your child and it is often up to you to be their advocate as well as the educator for those who work with him or her.

Remember the most effective presentation should be personal, accurate, informative, and practical.

### **Some Information Resources**

#### Pamphlets:

- ◆ \*What Educators Should Know about PWS
- ◆ \*Questions and Answers about PWS
- ◆ \*PWS Behavior and Weight Management
- ◆ \*Management of PWS in the Work Setting – A Guide for Employers & Supervisors (if appropriate)

#### Booklets:

- ◆ \*"Directions" (if your child is under age 5 years.)
- ◆ The Child with PWS: Birth to Three (Available from Visible Ink Inc. (1-800-358-0682))
- ◆ "Children with Prader-Willi Syndrome: Information for School Staff" (Available from Visible Ink Inc. (1-800-358-0682))

#### Other:

There are pamphlets available on \*Speech and Language as well as Physical Therapy (Visible Ink) if your child needs these services. Don't forget the most valuable resource, the \* *Management of Prader-Willi Syndrome* textbook.

\*Denotes items available through PWSA (USA) at 1-800-926-4797.

Good luck and have a great education adventure.

## **EDUCATION RESOURCES**

The following are resources both in the state of Wisconsin as well as nationally.

### **The Parent Education Project of Wisconsin (PEP-WI)**

serves parents of children with disabilities by helping them become more informed of their child's rights in the area of education. They offer one-on-one telephone information, support and referrals. The sponsor workshops and training, which provide participants with skills, knowledge and confidence to be their child's best advocate in the complexities of special education and related services. They are also a big resource of written materials related to these topics. They have district advocates located throughout the state. Call their main office for the advocate closest to you. **1-800-231-8382**

**Wisconsin Family Ties**, is a unique agency begun by families providing services to and with families that include children and adolescents with emotional, behavioral and mental disorders. It is a support, education, advocacy, information and referral organization which provides a voice for the most underserved disability group. They have skilled staff and volunteers throughout the state that are there to respond to families. For more information contact; **1-800-422-7145**

**WI Families On-Line** is an information web site for Wisconsin families which is designed for parents of children with disabilities to provide relevant information on Wisconsin events, resources and linkages to state and national information resources that are available in electronic format. The Wisconsin Council on Developmental Disabilities provided the Early Intervention Program at the Waisman Center the funding to make this possible.

<http://www.waisman.wisc.edu/earlyint/wis-fam/>

**NICHCY (The National Information Center for Children and Youth with Disabilities)** is one of the best sources of information for both parents and educators. To order a publications list, call **1-800-695-0285**  
**For information on the new revisions to Individuals with Disabilities Education Act (IDEA) Public Law 105-17**

**National Parent Network Disabilities:**

<http://www.npnd.org>

**Council for Exceptional Children:**

<http://www.cec.sped.org>

**For Information regarding new guidelines in the state of Wisconsin PI-11, Wisconsin Administrative Code contact:**

Paul Halverson at Dept. of Public Instruction  
608-266-1781 or 1-800-441-4563

## Information for School Staff Supporting the Student Who Has Prader-Willi Syndrome

Common Characteristics In Students With PWS	Possible Management Strategies
<p style="text-align: center;"><b>Rigid Thought Process</b></p> <p>It is common for people with PWS to receive and store information in a very orderly manner. There is a strong need for routine, sameness, and consistency in the learning environment.</p>	<ul style="list-style-type: none"> <li>● Foreshadow changes and allow for discussion</li> <li>● Use visuals; put things in writing – lists, schedules</li> <li>● If possible, communicate changes in personnel ahead of time</li> <li>● Don't make promises you can't keep</li> <li>● Give warning of ending (“Ten more minutes...”)</li> <li>● Breakdown procedures into concise, orderly steps</li> </ul>
<p style="text-align: center;"><b>Perseverative Thinking</b></p> <p>This is the tendency to get “caught” on one issue or thought to the point where it overshadows the main theme of the learning or social event. Perseveration can lead to loss of emotional control.</p>	<ul style="list-style-type: none"> <li>● Use reflection – have student restate what you said</li> <li>● Set limits. “I’ll tell you 1 more time, then we move on to next topic”</li> <li>● Put it in writing; use visuals</li> <li>● Avoid power struggles and ultimatums</li> <li>● Ignore (if possible)</li> </ul>
<p style="text-align: center;"><b>Tenuous Emotional Control</b></p> <p>Any combination of life stressors can lead to emotional “discontrol” as evidenced by tantrums – yelling, swearing, aggression, destruction, self-injury. Recovery of control takes time and is often followed by sadness, remorse, and guilt.</p>	<ul style="list-style-type: none"> <li>● Provide positive attention and praise when person is maintaining control, especially in difficult situations</li> <li>● Prevent loss of control by encouraging communication and acknowledging feelings</li> <li>● Anticipate build up of frustrations and help him/her to remove self to “safe area” where he/she can share feelings</li> <li>● Don't try reasoning during times when out of control</li> <li>● Have a plan in place if student becomes more violent. Consistency in approach in how this is handled is imperative</li> <li>● Provide positive closure. Don't hold a grudge.</li> </ul>
<p style="text-align: center;"><b>Difficulty with Peer Interactions</b></p> <p>While children want and need other children and value friends, it may be difficult for them to be exposed to the unpredictability of others for long periods. The need for order often translates into fairness issues and comparing themselves to others, often resulting in anger.</p>	<ul style="list-style-type: none"> <li>● Many do better in small groups and at times alone</li> <li>● Preplan outings. Keep time short</li> <li>● “Supported recess” – planned activities with a friend</li> <li>● Include child in planning activities that are of interest to him/her (board games, puzzles, computer games...)</li> <li>● Provide social skill classes that emphasize sharing, taking turns...</li> </ul>
<p style="text-align: center;"><b>Food Craving and Diet Restrictions</b></p> <p>For people with PW, the craving for food is unusually strong, and food is metabolized at a rate that causes extraordinary weight gain. Food must be monitored and the individual supervised.</p>	<ul style="list-style-type: none"> <li>● Supervision in the lunchroom and in all food related areas – including vending machine areas. In some cases, student may need to eat in classroom (with peer/friend)</li> <li>● Many require supervision in hallways or near unlocked lockers</li> <li>● Address any stealing or trading in private. Do not punish</li> <li>● Follow guidelines for treats or eating of extra food</li> <li>● Don't delay snack or lunch; if necessary discuss ahead</li> <li>● Don't leave alone in areas of food. Be aware of candy dishes or sources of food</li> <li>● PRAISE situations where student does not take food when you see they could have.</li> </ul>
<p style="text-align: center;"><b>Poor Stamina</b></p> <p>People with PWS tire more easily and may fall asleep during the day. Morning is typically their optimal learning time, when energy level is highest.</p>	<ul style="list-style-type: none"> <li>● Get the person up and moving. Send on errand. Take a walk. Schedule high energy, mobilizing activity after lunch</li> <li>● Offer items /activities which stimulate large muscles and breathing (balloon blowing, party blowers)</li> <li>● Provide scheduled rest time</li> </ul>
<p style="text-align: center;"><b>Scratching and Skin Picking</b></p> <p>These two behaviors are often seen in individuals with PWS and may be worse during times of stress. Combined with the higher pain threshold, these behaviors can result in tissue damage if not controlled.</p>	<ul style="list-style-type: none"> <li>● Provide activities to keep hands busy (coloring, computer time, play dough, hand-held games...)</li> <li>● Provide supervision. Reward and praise for not picking</li> <li>● Cover area with band aide or similar covering</li> <li>● Keep nails short. Apply lotion liberally.</li> <li>● Apply mosquito repellent before any walks or outside activity</li> </ul>

## MODIFICATIONS BASED ON INDIVIDUAL NEED CAN HELP ENSURE A SUCCESSFUL SCHOOL EXPERIENCE

by Pat LaBella

Our daughter, Beth, is an 18 year old with Prader-Willi Syndrome. She will be in 12th grade next year. She plans to stay in school through her 21st year. That way, she will be supported by the school district in both school and vocational settings. Throughout her school years we have had some successes and many failures. It has taken her educational team (including her parents) 16 years to develop an appropriate educational program for Beth. But over the last two years we developed an excellent program that works well for her.

In order for Beth to be successful within her educational setting, she needs many modifications. Most of these modifications cost little or no money. Some of them can be implemented at any grade level. Some of them are easier to implement within a middle school or a high school, where the school day is more flexible and the class scheduling is a little bit more individualized. All of these modifications help Beth to trust that she has the external support she needs, to get through the school day, with as little anxiety as possible. When Beth's anxiety is low, everyone's day goes better.

- Beth is transported to and from school by private car every day. The school district reimburses us for her transportation.
- She is assigned a one to one teacher to be with her throughout the school day.
- Her teacher meets Beth at the entrance door in the morning and stays with her at the exit door until she goes home in the afternoon.
- On a good day, Beth arrives at school 5-10 minutes later than rest of the students.
- She is dismissed from her last class a few minutes early.
- Beth leaves the building approximately 5 minutes earlier than the main student body.
- She transitions from one class to the another just before or just after the major traffic in the halls.
- Beth's teacher carries a cell phone at all times, in case she needs back up support.
- Prior to the first day of school, there is an inservice training for all adults who may be in contact with Beth throughout her day (principal, teachers, special teachers like Art, Music, Librarian and Gym, teaching assistants, therapists like OT/PT, nursing staff, security guards, custodian, cafeteria staff.)
- Nursing staff monitors Beth's medications and daily health and tracks her weight.
- Beth takes a scheduled daily nap in the nurses office.
- Beth and her teacher have been given a small

classroom (former storage area) for her private use. (Even in elementary school Beth had a small room designated for "calming down").

- Her locker is located in a quiet area directly across from her private classroom.
- The first period of her school day is a "free" period where she gets organized for the day, checking the calendar and reviewing the daily schedule. The schedule is written on the board.
- This "free" period allows Beth to have a flexible arrival for days when she is having a rocky start at home. If she arrives late, she has not missed any academic work.
- Because of her extreme Obsessive Compulsive behavior, Beth is NEVER given homework.
- She finishes all left over schoolwork, and gets extended time on tests, during study halls or in her private classroom.
- She functions best when she is included in self-contained, special education classes with other students who are Cognitively Disabled.
- All academic curriculum is modified.
- Beth never takes a school lunch. She always brings a lunch from home.
- She eats her lunch with her teacher and some other special education students and staff in a special education classroom.
- She never purchases items from the general school store.
- Once a week she is allowed to purchase prizes (sometimes low calorie snacks) with earned points from the special education classroom.
- Home suggests to school staff, that snacks and food rewards be given no more than once per week and be no more than 100 calories.
- A notebook is sent from home to school and back home again every day. Daily communication is critical because issues carry over from one environment into the next.

Beth has a classic textbook case of Prader-Willi Syndrome. She needs structure, foreshadowing and routine. What works for Beth may not work for everyone with P.W.S. But everyone with P.W.S. functions better when their individual needs are met. We are lucky that the current administration is extremely open to supporting Beth and meeting her needs.

Do you have some modifications that have worked for your child with P.W.S.? Please share your ideas with us, so that we can share them with others. We would love to hear from you.

# PWSA of WI Summer Picnic

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When: August 22, 1998

Where: Appleton, WI

1



Plans Include:

10:30 -12:00

Swimming – Appleton YMCA

12:30 - 1:00

Lunch - Bring your own lunch. We will eat at facilities provided by the Children's Museum.

1:00 - 3:00

Children's Museum

1. Appleton YMCA (Swimming)  
218 E. Lawrence  
Appleton, WI
2. Appleton Children's Museum  
100 W. College Ave.  
Appleton, WI  
Parking Garage available from S. Appleton Ave.

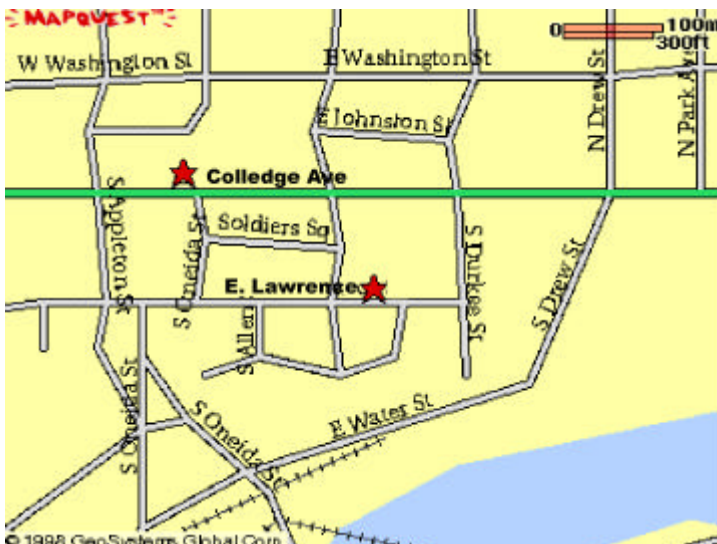
## Directions:

### From Highway 41

1. Exit Highway 41 on College Ave
2. Go approx. 5 miles east to downtown area.
3. Turn south onto S. Durkee St.
4. Turn west onto E. Lawrence.

### From Highway 441

5. Exit Highway 441 on College Ave
6. Go approx. 5 miles west to downtown area.
7. Turn south onto S. Durkee St.
8. Turn west onto E. Lawrence.



↳ Parents & care providers: You must stay with the person(s) with PWS at this event. We cannot be responsible for those who are dropped off and left without supervision.

## MARK YOUR CALANDER

The next Meeting of the PWSA of WI.

November 7, 1998

Parents Training Day

This will be a special day designed for parents of individuals with PWS.

Place: RFDF Community Living  
2875 Fish Hatchery Rd  
Madison, WI 53713  
608-274-4353

Date: Saturday November 7, 1998  
Time: 9:30 am- 3:00 p.m.

Cost: Free to members / \$15 to nonmembers but will include 1 yr membership

Registration deadline: Friday October 23, 1998

*\*More registration information will be sent.*

**Come, Learn and Share. Everyone is welcome!**

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