



# THE WISCONSIN CONNECTION

Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.  
Vol. 3 No. 5  
October 1997

Mission: The mission of the Prader-Willi Syndrome Association of Wisconsin, Inc. is to educate and assist families and professionals in dealing with individuals with Prader-Willi Syndrome.

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## Legislative Update

by Barb Dorn

We are continuing our journey down the road to add Prader-Willi Syndrome to the list of developmental disabilities as cited in Chapter 51 of the Wisconsin Statutes. On Tuesday, August 19, 1997, Barb Dorn, Pat LaBella,

Rep. John Lehman (Racine), Dr. Tom Hughes, Rep. David Brandemuhl, and Senator Joe Wineke went before the Assembly Health Committee to give testimony as to the merits of adding our disability to the statutes/ Many personal stories were shared along with facts about Prader-Willi Syndrome.

We did this same procedure with basically the same participants on Wednesday, August 27, 1997 before the Senate Health Committee. As most of you are aware, the legislature has been stalled in approval of the state budget. Until the budget issues are resolved, we can go no further in our venture. We are hoping that this legislation will go before the Assembly and senate in early Fall and be voted on and easily approved.

This has been a 3 year project which is finally reaching an end. Thanks to all

who have contacted their legislators. Thanks to all who have come to the state capitol and have personally testified in order that all persons with Prader-Willi Syndrome receive the services they so desperately need and deserve. I hope to write one more article in our next newsletter saying . . . "We did it!!!"

## Wisconsin Chapter of PWSA (USA) celebrates Five Years



Executive Director Barb Dorn proudly displays 5 Year Plaque from PWSA(USA). The first five are the hardest, Barb!

## Notes from the President

Probably one of the most frequently asked questions I get is from parents and professionals wondering where can they find information on Prader-Willi Syndrome. So many people are amazed when I tell them where they can find the medical basics of the syndrome; answers to commonly asked questions; diagnostic criteria; and so much more. People can obtain names and addresses for all the state chapters; information on the upcoming national conference; articles published in professional journals; a place they can meet other parents either by leaving a message or chatting live in the Chat Room, as well as locating many other sources where they can find information on PWS. And best of all, this information can be accessed instantaneously from anywhere in the world. Where is this information found? The Prader-Willi Syndrome Association World Wide Web page on the Internet.

We all hear so much hype about the Internet. It truly is a great informational tool. The PWSA(USA) web page has reached out to people all over the world. In the first year almost 10,000 people accessed the web page and the numbers are quickly increasing. The foremost medical institutions have links to the PWSA(USA) web page. Among these are Johns Hopkins University, Mayo Clinic, and the American Medical Association. There are also many links from more than a dozen different countries to the PWSA(USA) web page. Some people ask "What good does that do for me? I don't access the Internet." Even if you don't have access, many of the people who you want to know about PWS do. Schools, public libraries, counselors, health care professionals, friends and families. How many times have you spent your time and money telling people all about the basics of PWS? This can be used as a great tool for people who need to know about PWS to serve your child or client that has PWS. By giving these people the web page address anyone can have this information immediately. It can be printed out and/or given out as reference materials. The

address for the PWSA web page is:

[http://www.athenet/~pwsa\\_usa/index.html](http://www.athenet/~pwsa_usa/index.html)

There are plans for expansion of the web pages to include many of the following:  
 Select articles from the Gathered View (National newsletter)  
 Family stories  
 Message boards that anybody can leave messages or ask questions  
 Listings of PWS medical clinics  
 Summer Camp listings  
 Latest reports from PWSA's annual Scientific Day on PWS  
 Booklets and information packets  
 Latest news from around the country and all parts of the world about PWS.

What we need from you is your comments and feedback as to what you would like to see on the PWSA web page. Wisconsin even has it's own Internet page:

[http://www.athenetnet/~pwsa\\_usa/WI/wihome.htm](http://www.athenetnet/~pwsa_usa/WI/wihome.htm)

Please send any comments or suggestions you have to me, Mike Larson at: [pwsa\\_usa@athenet.net](mailto:pwsa_usa@athenet.net)

There are many other resources about PWS for parents and professionals. The upcoming training day on October 10th is another great resource. This training day is sponsored by PWSA of WI, Inc. and has an agenda equal to any conference on PWS you will find anywhere! It is targeted at parents and professionals who would like to know more about PWS, from the basics to more involved issues. Everyone is welcome. Brochures were sent to everyone on our mailing list, but if you would like more information you can call the State office at 608-845-9597. The cost is \$25.00 for non-members and \$15.00 for members. Parent scholarships are available by calling the State Office.

And as always, the PWSA(USA) National office is another resource. They are there to help in any way they can. The toll free number for the National office is 1-800-926-4797. The phone in the national

office rings at least once every ten minutes. They help in finding local and state contacts, sending out information packets, and keeping members informed on regional and national issues regarding PWS research and legislation. They also sponsor the National Conference every July. The 1998 conference will be in Columbus, Ohio. Financial assistance, in the way of grants, is available for persons wishing to apply for it. Just call the national office for information.

These are just a few of the resources available for persons wanting to know more about PWS. Your State and National organizations are working for you. We need your support in the way of volunteering and your voice on important issues. Please step forward and join others in helping.

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## Help Wanted

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Statewide membership association needs self-starter to fill the volunteer position of **Dance Chairperson**. No experience necessary. Just a desire to create some fun for our kids and young adults. Must be well organized, yet not too serious.

Statewide membership association needs self-starter to fill the volunteer position of **Picnic Chairperson**. No experience necessary. Just a desire to create some fun for our kids and young adults. Must be well organized, yet not too serious.

Statewide membership association needs motivated, well organized individual to fill the volunteer position of **Training Day Chairperson**. No experience necessary. Training and support provided.

Statewide membership association needs independent thinker to fill the volunteer position of **Awareness Day Chairperson**. No experience necessary. Just a desire to educate the public about Prader-Willi Syndrome.

For more information on any of these positions, contact the PWSA of WI office today at 608-845-9597.

## Conference Updates

Parent to Parent, a support program for parents and other adults involved in caring for children and young adults with disabilities or limitations of any type, presents....

Last One Picked, First One Picked On,

October 13th - 7:00 p.m. in  
Beaver Dam, WI  
October 20th - 7:00 p.m. in  
Madison, WI

Rejections and teasing - painful parts of childhood for almost all kids, but especially those with disabilities that set them apart. Learn how to help your child cope with difficult situations.

Tips, Tricks and Techniques For Positive Parenting,

November 10th-7:00 p.m. in  
Beaver Dam, WI  
November 17th - 7:00 p.m. in  
Madison, WI

Helping your child grow to his or her full potential means giving them a foundation of self awareness, self respect and self esteem. The speaker will focus on this critical aspect of parenting.

*For more information, call Jane Boltz, Program Director, 608-833-8888 or 800-657-4929*

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Stress Solutions, Workshop for Women

Nov. 3rd, 9:00 a.m. - 4:00 p.m.,  
Sheraton Madison Hotel  
Nov. 5th, 9:00 a.m. - 4:00 p.m.,  
Milwaukee Best Western Midway -  
Airport  
Nov. 4th, 9:00 a.m. - 4:00 p.m.,  
Pewaukee Country Inn Hotel

Course Objectives:  
To equip you with simple stress management skills that will help you:

\*Stay calm and collected in anxious moments

\*Deal with stressful people, assertively and positively  
\*Learn to manage your personal stressors with grace and confidence  
\*Live more energetically and work more productively - in spite of the pressures at home and on the job

*For more information or registration, contact CareerTrack, 1-800-334-6780*

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Rational Emotive Behavior Therapy and its use with special client populations.

October 15th, 9:00 a.m. - 4:00 p.m.  
Stevens Point - Best Western Royale Inn  
November 3, 9:00 a.m. - 4:00 p.m.  
Madison, J.F. Friedrick Center

Rational emotive behavior therapy (REBT) is the original multi-modal, cognitive-behavior therapy. Learn how REBT can teach clients to not only cope with their presenting problems, but also how to apply the methods to just about any problems they encounter throughout their lives.

Anger redefined - Myths, misconceptions and methods of change

October 16, 9:00 a.m. - 4:00 p.m.  
Stevens Point, Best Western Royale Inn  
November 4, 9:00 a.m. - 4:00 p.m.  
Madison, J.F. Friedrick Center

Anger is perhaps one of the most destructive yet least understood human emotions. Falsehoods about managing its varying manifestations abound. This program provocatively questions much of the conventional wisdom about anger and replaces it with strategies that contribute to long-range happiness and survival.

*For more information, contact Ann Whitaker, Programs in Health and Human Issues, 608-262-4509 or 800-442-4617.*

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**Is it Time to Eat?**


By Jenny Lucas

Finding low calorie, low fat recipes that satisfy our hungry children is not always easy to say the least. Contrary to popular belief, people with Prader-Willi won't eat just anything. It's got to taste good and seem like a lot of food or you, the cook, are in big trouble! So, I've searched the cookbooks, tried the cooking software, and come up with some winners and some losers. Here I will tell you, in my opinion, how they rate.

The first cooking software that I evaluated is MasterCook Deluxe, v 3.0, by Sierra, at a cost of \$40.00. This user friendly software not only has 1,250 recipes, it has nutrition information, a shopping list function, cost analysis, a menu plan and a meal planning calendar. There are four cookbooks within the program and you can add more of your own recipes or your own cookbook.

While all of this is helpful, I didn't find a lot of low calorie recipes that had fewer than 20 ingredients and were simple to prepare. The heading of "Healthwise" contains only 46 recipes. But, add your own recipes to the database and you've got a good product. The format is good, it's easy to use, and inexpensive. They've already released with v 4.0 and have dropped the price to just \$35.00. For more info or ordering, call Sierra, 800-757-7707.

Overall, I give it

Here's a quick  recipe from MasterCook for you to try for yourself....

Broccoli Casserole

Servings: 8, Cal.: 124, Total Fat: 9 g.

- 2 tablespoons butter
- 2 tablespoons flour
- 1 cup milk
- 3 oz. cream cheese -- softened
- 1/4 cup blue cheese, crumbled
- 20 oz. frozen chopped broccoli
- 1/3 cup fresh bread crumbs

Melt butter. Stir in flour and cook 1 minute. Add milk and continue cooking, stirring, until thickened. Add cheeses and cook until cheese melts and mixture is smooth.

Cook and drain broccoli according to package instructions. Stir cheese mixture into broccoli. Turn into a buttered 1/2-quart casserole dish. Sprinkle with bread crumbs. Bake at 350 degrees for 30 minutes.

*Editor's Note: You can save 55 calories and 3.75 g. fat per serving by substituting diet margarine, skim milk, and fat free cream cheese. I don't know that you can do anything different with the blue cheese.*

The first hard copy cookbook (that's a book, rather than computerized) is "Healthy Cooking for people who don't have time to Cook", by Jeanne Jones, retail price \$27.95. Just the title of the book intrigued me enough to try it. I'm sure you can all relate!

I found the layout of this book to be very time saving too. It's has a short intro that includes a section on stocking your pantry for healthy cooking, understanding nutrition labels, and how to arrange your kitchen for maximum efficiency. These topics are great for newly diagnosed parents who've never had the pleasure of dieting. Then, the recipes are categorized by how much time they take to prepare. The

Chapter Three is "From Start to Finish in 15 minutes". Especially good for those of us who's children want to eat NOW! Chapter Four is "On the Table in 30 minutes", good for those leisure times when you can actually plan ahead a bit!

The portions are generous and the calories and fat are nice and low. Most main dish recipes are under 300 calories per serving, although there were a few that were up around the 500 calorie range.

The only thing I disliked about this cookbook is that it has lots of pretty pictures of the food (which is important to me...I'm a very visual person), but, the pictures were scattered all throughout the book and didn't correspond with the recipes.

I rate this cookbook

Here's one of the recipes from "Healthy Cooking for people who don't have time to Cook" that I tried and everyone in the family likes,



Vegetarian Lasagne

Servings: 8, Cal.: 245, Total Fat: 4 g.

- 1 jar (26 oz.) fat-free meatless spaghetti sauce
- 1 pound fresh mushrooms, sliced
- 1 medium onion, chopped
- 3 small zucchini, sliced
- 15 oz. fat-free ricotta cheese
- 1/2 cup chopped fresh parsley
- 1 egg
- 1/2 teasp. salt
- 1/4 teasp. black pepper
- 1 cup shredded part-skim Mozzarella cheese, divided
- 4 tablespoons shredded fresh Parmesan cheese, divided
- 6 no-boil lasagna noodles

1. Preheat the oven to 350 degrees. Coat a 13" x 9" dish with non-stick vegetable cooking spray.

2. In a large saucepan, combine the spaghetti sauce, mushrooms, onions and zucchini. Bring to a boil over medium-high heat. Reduce the heat to low, cover and cook for 10 minutes.

3. In a large bowl, combine the ricotta, parsley, egg, salt and pepper. Mix well. Stir in 3/4 cup of the mozzarella and 2 tablespoons of the Parmesan.

4. Place a third of the sauce mixture in the bottom of the prepared dish. Top with half of the ricotta mixture and 3 of the uncooked noodles (space about 1/2 " apart). Repeat the layering.

5. Top with the remaining sauce. Sprinkle with the remaining 1/4 cup mozzarella and the remaining 2 tablespoons Parmesan.

6. Cover with a lid or aluminum foil and bake for 40 minutes. Uncover and bake for 20 minutes, or until lightly browned.

Excellent

Good

Fair



Poor



"  Do's & Don'ts" for  
F  ostering Social  
C  ompetence

*excerpted from "Teacher's Guide to*

*Learning Disabilities and Social Skills”  
with Richard Lavoie*

Please note the key at the end of each suggestion:

P = appropriate for parent use

T = appropriate for teacher use

P/T = can be effectively utilized by parents or teachers

## DO

... observe your child in a wide variety of social situations (e.g., classroom, scout meetings, free play). This will enable you to gain a deeper understanding of his social strengths and weaknesses. (P)

... design an unobtrusive "signal system" with the child to use in social situations. For example, if the child tends to perseverate (talking about only one topic which often is not of interest to the listener) design a signal (touch your nose with your finger, cross your arms) that tells him to change the topic or cease the discussion. In this way, you can halt troubling behaviors without causing undue embarrassment or conflict. (P/T)

... establish reward systems to reinforce and recognize appropriate social behavior. Be willing to recognize and reinforce even the smallest signs of progress and growth. (P/T)

... enroll the child in group activities and pursuits. When selecting these activities, consider the child's interests and abilities. If you are fearful that the child may be rejected by the others because of his negative reputation, enroll him in activities in another neighborhood or town. Thereby, he can begin with a "clean slate". (P)

... continually reinforce social information. Many social skill deficits

are caused by a lack of basic social information (e.g., all odd numbered houses are on one side of the street; mayonnaise must be refrigerated; mail deliveries are made only once daily). Never miss an opportunity to teach this invaluable information to a child. View every car ride or trip to the store as a "classroom" for social information. (P/T)

... encourage all members of the family to assist in the creation of a support system for the child. Siblings play a particularly important role in such a system. Create a non-competitive home (and school!!) environment wherein the child learns to celebrate his own small victories. The child must learn to view his progress as compared to his own previous performance, not the performance of others. (P)

... make transitions easier for the child. Students with social skill deficits often have difficulty "changing gears" from one activity to another. This is particularly true when going from an enjoyable activity (e.g., a game) to a less pleasurable one (e.g., math drills). In order to ensure a smoother transition, be certain to "wind down" the enjoyable activity by providing a warning signal several minutes prior to the end of the activity. As each minute passes, inform the child of how much time remains before the activity will conclude. (P/T)

... make modifications and adjustments to accommodate for the child with a learning problem. For example, if he is unable to participate effectively in the homework program because he constantly forgets his books, simply issue him two texts with instructions to keep one at home and one in school. (T)

... work on one behavior or social skill at a time. By focusing the child's attention and efforts on a single skill for a period of time, he is less confused and more responsive to your intervention. (P/T)

... assist the child in expressing his feelings during emotionally charged social situations. (e.g., "I am sure that you feel angry and jealous when Daniel and Sean go fishing and don't invite you.") (P/T)

... teach empathy. Encourage the child to be more understanding of the feelings of others. Use role playing to help him "walk in another's shoes". (P/T)

... utilize "real life" or television shows to teach valuable social skills. Discuss the behaviors of significant, high status people (e.g., "On that TV show, how did the policeman make the frightened woman feel more comfortable and at ease?") (P)

... provide the child with choices whenever possible. (e.g., "I want you to clean your room now. Do you want to pick up your toys or make up your bed first?") This approach fosters independence and problem solving skills. It also increases the child's ownership of the task or activity. (P)

... provide the child with a positive model of appropriate social skills. Be certain that your behavior mirrors the skills that you are teaching your students. (e.g., temper control, courteous listening). (P/T)

## DON'T

... necessarily discourage the child from establishing relationships with students who are a year or two younger than he is. He may be

seeking his developmentally appropriate level. By befriending younger students, he may enjoy a degree of status and acceptance that he does not experience among his peers. (P/T)

. . . force the child to participate in large groups if he is not willing or able. If the child responds well when working with another student, plan activities wherein he has ample opportunities to do so. Then add a third person to the group, then another and so on, until the group approximates the entire class. (T)

. . . place the child in highly-charged competitive situations. These are often a source of great anxiety and failure for students with learning problems. Rather, focus upon participation, enjoyment, contribution and satisfaction in competitive activities. Emphasis should be placed on the development of skills and strategies - not on winning or losing. (P/T)

. . . assume that the child understood your oral directions or instructions because he did not ask any questions. Ask him to repeat the instructions in his own words before beginning the activity. (P/T)

. . . scold or reprimand the child when he tells you about social confrontations or difficulties that he has experienced. He will respond by refusing to share these incidents with you. Rather, thank him for sharing the experience with you and discuss optional strategies that he could have used. (P)

. . . attempt to teach social skills at times of high stress. Rather, approach the child at a time when he is relaxed and receptive. (e.g., "Meghan, next

week you will be going to Jilly's birthday party. Let's practice how you will hand her your gift and what you will say when she opens it and thanks you.") (P)

. . . view praise as the only verbal reinforcer - interest works, too! Expressing a genuine and sincere interest in a child can be as positive and motivating as praise. (e.g., "I watched you playing soccer at recess, Adam. Do you play at home with your brothers?") (P/T)

. . . encourage the frustrated child to relieve his stress via pointless physical activity (e.g., punching a pillow). Rather, teach him to relieve stress through an activity which has definable and observable goals. (e.g., shoot ten baskets, run five laps, write a one-page letter) (P/T)

### What about punishment?

(P/T)

DON'T expect punishment or negative reinforcement to have a meaningful or lasting impact upon your child's social skill deficits. Punishment may stop specific behaviors in specific settings, but positive reinforcement is the only effective strategy for meaningful and lasting social skill improvement.

Overuse of punishment is largely ineffective because:

- a) it does not teach appropriate behavior- the child merely learns what he should not do;
- b) the child often becomes passive in the face of punishment and merely avoids situations similar to those in which he makes social errors (e.g., visiting grandmother, going to the store);
- c) the child may develop a concurrent set of inappropriate behaviors, such as lying, cheating, or blaming others, in order

to

avoid punishment;

d) the child may adapt to punishment, which will require you to intensify the level and severity of the punishments.

DO use punishment only for behaviors that are intolerable; dangerous to the child or others; and seemingly unaffected by a well-planned positive discipline approach. Punishment should be applied immediately following the offending behavior and should be consistently applied. Fair warning should always be given (e.g., "If you belch again at the table, you will be told to eat in the kitchen.") Avoid giving a great deal of attention to the child when applying the punishment and tell him briefly why he is being punished. Avoid numerous threats and never take away something that you had previously given or promised as a reinforcer for positive behavior.

*Richard Lavoie, M.A., M.Ed. has worked in special education since 1972, as a teacher, administrator, author, and consultant. He is currently Executive Director of Riverview School, a residential school for children with learning disabilities, in East Sandwich, Massachusetts. His award-winning programs include:*

*How Difficult Can This Be?: The F.A.T. City Workshop 1989*

*Learning Disabilities and Social Skills: Last One Picked, First One Picked On 1994*

*Learning Disabilities and Discipline with Richard Lavoie: When the Chips Are Down...Strategies for Improving Children's Behavior (1997)*

*For further information on these and other video series, contact:: By phone: 703/998-3293, By fax: 703/998-3405, By mail: WETA Video, P.O. Box 2626, Washington, D.C. 20013*

## MEETING NOTICE

**Y**ou asked for it! You got it! Many families in your area have asked for a meeting to be held in Milwaukee. So with the help of Children's Hospital Genetics Clinic, we've done it!

*Event: Parent Connections Meeting*

*Date: Saturday, November 1, 1997*

*Time: 1:00 to 4:00 p.m.*

*Place: Children's Hospital at the  
Children's Health Systems Office  
Bldg.*

*9000 W. Wisconsin Avenue  
Milwaukee, Wisconsin*

*Meeting room: 5th Floor Educational Service  
Classroom*

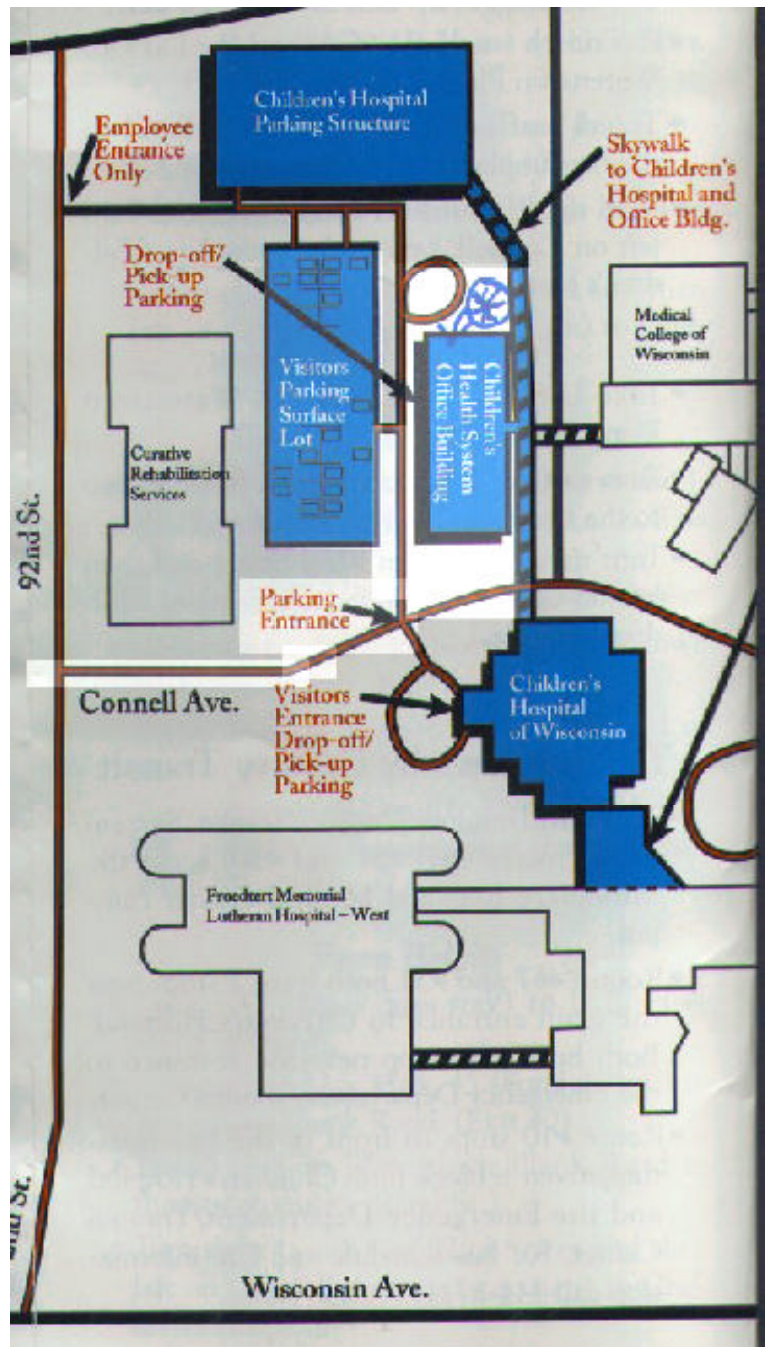
*Children's room: Lobby Conference Room*

*Parking adjacent to Office Bldg.*

Experienced babysitters will be provided by the association, along with toys, a video, and of course, a 100-calorie snack.

You don't need to be a member to attend. Come and see what it's all about! Decide for yourself how the association can work for you in your area of the state, and in your areas of concern about Prader-Willi Syndrome.

**SEE YOU THERE!**



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HEADLINE NEWS - HEADLINE NEWS - HEADLINE NEWS - HEADLINE NEWS - HEADLINE NEWS

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## BY POPULAR DEMAND, PWSA OF WISCONSIN HOLDS NOVEMBER MEETING IN MILWAUKEE!!!

We've been gently persuaded, cajoled, implored, induced, urged to hold a membership meeting in the Milwaukee area, s-o-o-o-o . . .

NOVEMBER 10th, 1997. . . WE'RE THERE! PLEASE DON'T MISS IT!

*See details on PAGE 7.*

Prader-Willi Syndrome Association of Wisconsin, Inc.  
305 Amanda Way  
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