



# 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 and assist families and professionals in dealing with individuals with Prader-Willi Syndrome.

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## LEGISLATIVE UPDATE

by Barb Dorn

First of all, a big thank you to all of you who have contacted your legislators asking them for their support in our legislative venture. If you haven't done this yet... it's not too late. Both the Senate Bill (SB # 175) and the Assembly Bill (AB # 403) have not made it to their floors, so no votes have been taken yet.

The spring legislative session focuses primarily on the state budget. Our bills continue to move forward in health committees. We will be presenting our proposals to health committees in both the Senate and the Assembly. Once this is done, the bills will then go on to their respective floors for a vote.

Your phone call and/or letter does make a difference! As you know, most people do not know about PWS. Your contact increases your legislator's awareness about this disability and elicits his/her support on a bill he/she might not otherwise pay attention to. Your action can make a difference!! We have the endorsement of Secretary LEEAN, who is the head of the Department of Health and Family Services. His support is very important and another big step forward in our quest. A summary of the sponsors and co-sponsors of each bill is listed below:

Assembly Bill # 403 sponsored by:  
Brandemuehl, Bock, Skindrud,  
Wasserman, Huber, Lorge, Robson,  
Hanson, Sykora, Plouff, Notestein, J.,  
Lehman, R. Young, and Boyle.

Co-sponsored by: Wineke, Rude, Schultz, and Grobschmidt.

Senate Bill # 175 sponsored by:  
Wineke and Schultz.

Co-sponsored by: Brandemuehl, J. Lehman, Bock, Hanson, Urban, Boyle, Notestein, Powers, Hasenohrl, Lorge, Sykora, R. Young, Skindrud, and Williams.

If you haven't contacted your legislator, do it NOW! It will make a difference. Remember, this bill will help to expedite services for those persons with PWS who are not mentally retarded.

*Note: During our process of changing this statute, we found out that we have an assemblyman who has a daughter with Prader-Willi Syndrome. He has offered to help us continue to learn all the "ins and outs" that are needed in making this change possible.*

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## Conference Updates

Parent Education Project of Wisconsin presents...**Advanced Advocacy Institute of 1997**  
September 18, 19, 20, 21, 1997 in Mosinee, WI

The Advanced Advocacy Institute of 1997 provides extensive, multi-faceted training in informal conflict resolution, conflict management, communication, and negotiation skills to experienced volunteer and paid advocates who work with parents of children with disabilities.

If Interested, contact Pep-WI  
Advanced Advocacy Institute-North  
2192 South 60th Street  
West Allis, WI 53219  
414-328-5520

### **Anger Management with Children and Adolescents**

September 15, 1997, Sheraton Madison Hotel, Madison, WI

This workshop examines one of our most pressing issues: angry and violent kids. Learn some of the causes of anger and the health risks associated with hostility.

Intervention based on cognitive, emotive and behavioral techniques are described and demonstrated. Methods for how to help children and adolescents distract themselves in order to gain time before acting are shared and discussed. This presentation is filled with practical techniques you'll be able to use every day with clients and students.

For program information contact Ann Whitaker 608-262-4509 or 800-442-4617

### **Cognitive-Behavior Therapy with Children and Adolescents**

September 16, 1997, Sheraton Madison Hotel, Madison, WI

Cognitive-behavior therapy is becoming increasingly popular with counselors due to its practical, problem-solving focus. This workshop presents an analysis of rational emotive behavior therapy (REBT), one of the more commonly used forms of cognitive-behavior therapy. Learn to use REBT with young clients, especially for depression and anxiety and the important distinctions of working with children and adolescents.

For program information contact Ann Whitaker 608-262-4509 or 800-442-4617

### **The Arc-Wisconsin State Conference**

September 19, 20, 1997, Paper Valley Hotel, Appleton, WI

Who should Attend?

Parents, self-advocates, siblings, grandparents, other family members, advocates, health and social service professional, guardians, teachers and policy makers.

Tentative Topics include:

- Keynote Speaker: Quincy Abbot, President of The Arc-US.
- What keeps People Safe?
- Friendship Building
- Ins and Outs of Social Security & SSI
- Special Olympics - Families are Its Biggest Resource
- Americans with Disabilities Act and Childcare
- Demystifying the Legal System: Your Rights and Responsibilities
- Promoting Independence Through Friendship & Housing
- Internet Introduction: Window to the World
- Alzheimers and Persons with Developmental Disabilities
- Running a Successful Sibshop
- What Should I Wear?

For questions about registration and membership call The Arc-Wisconsin 608-251-9272

**A Madison-based residential agency has an opening in a Supportive Home Care setting for an individual with Prader-Willi Syndrome.** The three-bedroom duplex is located on the south side of Madison in Dane County. Currently living there is a 23 year-old woman with PWS, with two more individuals with PWS living on the adjacent side of the duplex.

The structure includes 24 hour staff with a program coordinator, full-time live-in, and weekend respite. Staff are trained in the aspects of serving individuals with PWS, including behavioral strategies, nutrition and exercise. Consumers are involved in a structured yet comfortable environment, with daily planned activities in the community.

For further information please contact:

Ginny Cardarella  
RFDF Community Living  
2875 Fish Hatchery Road  
Madison, WI 53713  
608-274-4353, ext. 3017

or: Dan Rossiter  
Dane County Community Services Manager  
608-242-6500 or 608-242-6473

## Can Water Be Harmful?

This Spring we had an unpleasant experience with our 26 yr old son (who has PWS) and which we would like to share.

While at work, he had convulsions twice and became unconscious and he had vomited phlegm. He was sent home by taxi, but when he had further convulsions, the staff immediately took him to hospital where he remained in a coma for several hours.

The next morning the doctor informed me that the level of salt in his blood was too low and that they had been obliged to put him on a drip containing salt water. Two days later, when his level of salt was back to normal, he was allowed to leave the hospital, a little tired perhaps, but otherwise back in shape. If I understood the doctor correctly, this could happen to anyone who drank obsessive amounts of fluids rapidly and did not urinate. The "body fluid" was then diluted which meant that that level of salt was lowered and this in turn influenced the nervous system. She guessed that Anders must have drunk 6-9 litres of water to cause such a reaction and recommended a maximum of 3 litres per day. However, Anders strongly denied drinking more than usual. After specific questioning by Anders' regular doctor, the group staff told him that for a long time Anders had been drinking more water than average. However, the amounts were not larger than what many people take in without problems.

Why did Anders react this way?

Sven Martinsson

Response from:  
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"The most probable explanation is that for a few months he was on medication with Haldol (Haloperidol) for psychiatric symptoms which had mostly receded. It is known that in rare instances this drug can cause an

over-secretion of antidiuretic hormone which prevents the kidney getting rid of excess water.

For a person with PWS who might decide to drink in order to reduce eating, this might cause water intoxication as in Anders' case. It may also be speculated that people with PWS may have a slightly deranged regulation of the antidiuretic hormone which is produced in the hypothalamus. This part of the brain also includes other functions that are abnormal in PWS: appetite control, regulation of growth hormone secretion, temperature, gonadotropins and pain threshold setting.

In any case, PWS patients on haloperidol should be supervised as to their water consumption."

## Things We Can Learn From a Dog

- Never pass up the opportunity for a joy ride.
- Allow the experience of fresh air and the wind in your face to be pure ecstasy.
- When loved ones come home, always run to greet them.
- When it's in your best interest, practice obedience
- Let others know when they've invaded your territory.
- Take naps and stretch before rising.
- Run, romp and play daily.
- Eat with gusto and enthusiasm.
- Be loyal.
- Never pretend to be something you're not.
- If what you want lies buried, dig until you find it.
- When someone is having a bad day, be silent, sit close by and nuzzle them gently.
- Thrive on attention and let people touch you
- Avoid biting when a simple growl will do.
- On hot days, drinks lots of water and lie under a shady tree.
- When you're happy, dance around and wag your entire body.

### FREE TO A GOOD HOME!

Exercise Bicycle  
 Contact Barb Dorn at the State Office  
 608-845-9597  
 FIRST COME.....FIRST SERVE



## Ask the Professionals

*"I do not understand exactly what a 'low metabolic' rate means and what affect this has on an individual with Prader-Willi Syndrome..."*

We asked Dr Peter Davies (Associate Professor, School of Human Movement Studies at Queensland University of Technology, Australia) for his opinion. He responded:

"The notion that an individual with Prader-Willi Syndrome has low metabolic rate has been around for many years. The fact that there is some confusion about this issue, is due to a number of reasons, not least that we scientists have not been able to explain this matter simply and easily. I think in order to understand the situation I should begin by giving you some straight forward facts.

All individuals use up energy during the day. An average male in their twenty's for example would use around 2,500 calories of energy a day. What you have to remember is that this energy is used for different purposes. The largest amount of this 2,500 calories is used up by our basal metabolic rate. This is the energy that our body needs to just 'tick over', and exist. The energy is used for example, to keep the heart beating, to keep our lungs breathing and all our other vital organs functioning well.

Think of the analogy of a motor car. Our basal metabolic rate is comparable to a car's engine being on but just ticking over, the car is not going anywhere. A very small amount of our 2,500 calories is used to keep our body warm. Don't forget we are warm blooded creatures and therefore we need to expend some energy in maintaining our body temperature at about 37oC. The rest of our 2,500 calories are used because of physical activity. Obviously, once we put our car into gear and move forward, we are using more petrol or in the case of a human more energy.

Some people have suggested, that in children and adults with Prader-Willi Syndrome their basal metabolic rate is lower than the individuals without the syndrome. Recent research has shown that this is absolutely not the case. The basal metabolic rate or the 'tick over' energy requirements are the same in an individual with Prader-Willi Syndrome as

in anyone else.

The energy required by an individual with Prader-Willi Syndrome to maintain their body temperature, again is no different than that of any other individual.

However, it does seem that individuals with Prader-Willi Syndrome are less physically active on average than individuals without the syndrome and therefore the amount of energy used due to physical activity is less than in people without the syndrome. The important point therefore, is that there is no fundamental reduction in basal metabolic rate in this syndrome.

This is very important in that, if we can increase somebody's physical activity level, their energy expenditure will have to go up and therefore they would be using up more calories. If an individual is using up the calories, obviously their body is unable to store that energy as fat.

The concept therefore that being overweight or even obese in Prader-Willi Syndrome is unavoidable because the person has a low metabolic rate, is simply not the case. We can do something about it.

## Olestra's Effect on Carotenoids

*What are carotenoids and how does olestra affect them?*

Much has been written about a family of chemicals called "carotenoids," found in fresh fruits and vegetables. Some carotenoids are fat-soluble. If you consume snacks containing olestra in sufficient quantity at the same time as fresh fruits and vegetables, then it could result in a reduction of carotenoid absorption, due to these chemicals latching onto olestra and being carried out of the body with it. However, the FDA determined that the effect of Olean® snacks on carotenoids is insignificant. This decision is supported by the Director of Cancer Prevention at the National Cancer Institute and the Director of the National Eye Institute.

# PWSA of WI Summer Picnic

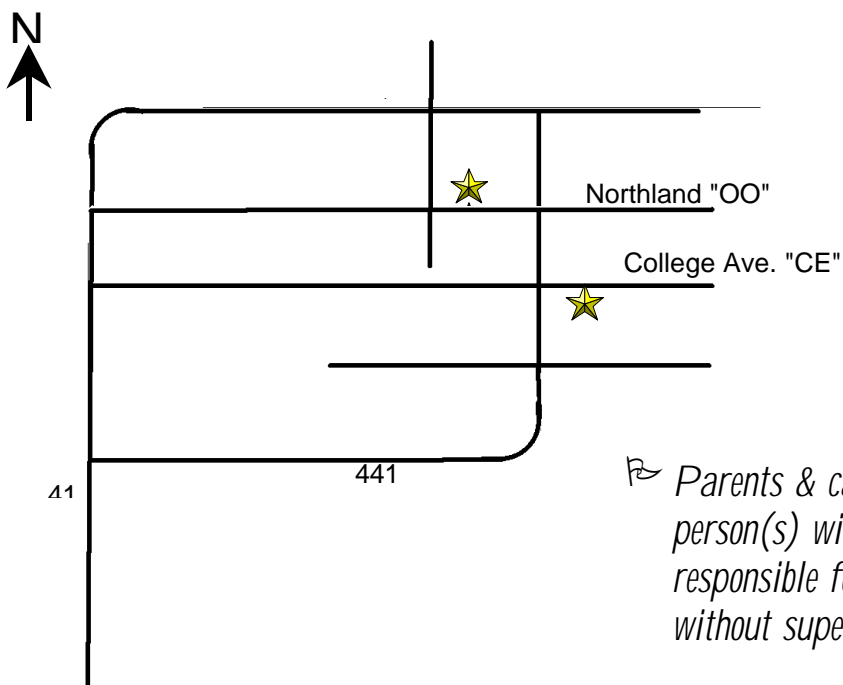
## Miniature Golf and Bowling Outing

When: August 23, 1997

Where: Appleton, WI

### Plans Include:

- |              |  |
|--------------|--|
| 10:30 -12:00 | Miniature Golf - Badger Sports Park<br>E. College Ave "CE" & Hwy 441 |
| 12:00 - 1:00 | Lunch - Bring your own lunch and blankets                            |
| 1:00 - 3:00  | Bowling - Super Bowl Lanes<br>2222 E. Northland Ave "OO"             |



**NO COST!!  
EVERYONE IS WELCOME!!**

*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 1, 1997  
Tentatively scheduled in the Milwaukee Area

Come, Learn and Share. Everyone is welcome!

Look for more details soon!  
Or call 608-845-9597

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