



The Wisconsin Connection

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

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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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Table of Contents

Notes from the President.....	2
How To: Better Cope with a Family Member's Disability.....	3
1997 Donations.....	4
Conference Updates.....	5
Speech and Language Development.....	6
Kids Say the Cutest Things.....	7
Getting Ready for Summer ... Summer Camps.....	8
Camp Scholarship Application.....	9
Is It Time to Eat?.....	10
Meeting Notice.....	11
1998 Calendar of Events.....	12



LEGISLATIVE UPDATE: WE DID IT - PWS ADDED TO WISCONSIN STATUTES

by Barb Dorn

On Monday December 15, 1997 friends, family members and persons with Prader-Willi Syndrome gathered in our state capitol to watch Governor Tommy Thompson sign Assembly Bill 403 in to law. This signing added PWS to Chapter 51 of the Wisconsin statutes which defines a developmental disability. This addition is a clarification for those service providers who are not familiar with PWS. This change will make it easier for all persons who have PWS to receive the necessary evaluations

and services that they need to live and work in our communities.

Over the past few years, we have had isolated cases in which persons with PWS were denied access to evaluations because they were "not mentally retarded". After advocating and informing these providers, our office was able to secure services for them. The confusion occurs in the fact that forty percent of persons with PWS do not have mental retardation. They do however receive treatment and supports as if they were. It is these individuals who often times run in to delays when trying to access residential and/or vocational services.

(Continued on page 4)

Notes from the President

Does admitting that you are crazy make you saner? Recently a caring friend was asking about how we were doing. They commented that from their point of view, we have a lot to deal with and they were worried how we were handling things. In our house we live with PWS, diabetes, and multiple sclerosis along with the daily stresses of raising a family in the nineties, both parents working, day care, school, taking care of a house, rental property, personal finances, family commitments, working with the state and national PWSA organizations and trying to have a regular social life with friends. I'm not really sure what they expected but the standard response of "Oh, we're just fine" was given. I don't know how this person would have reacted if I had told him the truth; that most days we are absolutely, undeniably, and certifiably CRAZY!! Who wouldn't be with all this? I don't know about most parents of children with PWS, but most days I feel like I am walking a fine line between being a responsible, civic minded adult or losing control and "going on a rampage". There always seems to be a struggle to "keep the balance".

One thing that keeps threatening to disrupt my balance, pushing me over the emotional edge, is playing the "What's going to happen in the future" game. (Playing "What's going to happen in the future" is a favorite game of mine. Somehow, no matter how much I play, I still lose every time I play it. You would think that I would get better the more I play, but I keep finding ways of beating myself.) This is a very difficult game because we don't know the future and we always play out the worse possible scenarios over

and over in our mind. I don't know who doesn't worry about how the "hand they have been dealt" in life will play out, but this is not a good game to play and is designed to surely push you over this emotional edge. If I start playing this game, I feel lucky when, rather than going over the edge, I just feel like I'm going crazy! And traditionally- when you're crazy, you've lost the game... or have you?

They say that if you think you are crazy, you're really not. I have the greatest concerns about people who say they have everything under control. Either they are lying or they are the real nut cases. I can't say I know of any other parents of kids with PWS that aren't, in their own way, crazy - to some degree. Most parents of 'normal' kids generally venture in and out of this state of emotional instability, but manage to hold on to some semblance of normalcy by today's standard.

My personal way of dealing with life the past few years has been to tip the scales and admit to myself that, "I really AM crazy! I would be crazy NOT to think I am crazy!" And that this is alright. I have a crazy life. I am going to live in a house with other crazy people and a lot of strange and crazy things are going to happen there. Many of the things are so strange that an outsider would call the nice young men in their clean white coats to come and take me away (ho-ho) if they knew they were happening! I **will** struggle living with PWS and there **will** be times when I just want to cry. And there **will** be times I can't stand it any more and burst out laughing at something an outsider would not find in the least bit funny. I **will** do just what I have to do not to "lose" my balance and

maintain my sometimes tenuous hold on my sanity. So, what I'm trying to say is "If you feel like you are going crazy, maybe you are doing all right handling your own situation." Maybe it's okay to allow myself to be 'crazy' and to keep a 'balance' in life, rather than going over the edge.

So, all you friends and relatives who might read this.... Yes, we are crazy! This helps us to hold onto our sanity.

Keep the cards and letters coming.

Mike Larson
2701 N. Alexander St.
Appleton, WI 54911-2312
Phone: 920-749-1174
Fax: 920-749-0906

Medical Definitions from the Home for the Bewildered:

Clinical depression: The print your behind makes on the doctor's examination table.

Derange: Kitchen appliance. Usually sits right next to de fridge.

Bonding: What chewing gum does between your shoe and the pavement.

Repressing: What you'll be doing to your pants after a thirteen-hour car trip.

Healing process: Teaching your dog to walk beside you.

How To: Better Cope With a Family Member's Disability

Perceptions are the ways we view things in our lives. Changing the way you think about a challenging event may help you feel better about that event. It may even give you additional strength to make improvements in your family's life. Research has shown a link between perceptions and successful functioning.

Basically, four types of perceptions can make you feel better and improve your family's functioning.

1. The view that your child's special needs exist because of some specific cause or reason. This is called causal attribution. For instance, you may feel your child's disability is the result of something you did (or did not do). Or what a health care professional did (or did not do). Or that genetics, a special purpose, or even fate caused the disability.

"God has his reasons and never gives you a burden too heavy to carry."

"Well, it's not my fault. It's something that is passed down through the family."

"Others before me have dealt with this, so can I"

"Now that I know what my child's diagnosis is, I can move forward and do what needs to be done."

Identifying a cause makes people feel more in control of their situation. That control gives them strength. (Do you think your child's disability is the result of some cause? If so, what? Does that make you feel better in any way?)

2. The view that you can control some things that happen in the life of your child with special needs. This is called mastery. If you think you can do something, you have a far better chance of doing just that than the person with no confidence.

You can gain a sense of greater control by gathering as much information as possible. You may have heard the phrase "Information is power." There is truth in that old saying.

Some people may join a parent advocacy group to make sure their child is fully included in daily school or renovate their house for their child with special needs. Taking direct action makes people feel better about their life.

I didn't just sit there singing the blues. I went down to my local library and went through all their stuff. They even ordered some books for me. Then I talked with other doctors and compared what they said to my books.

I wrote letters to my legislators when there was a bill going to be passed that I didn't like. I even joined the advisory board of my child's early intervention program. Sitting around isn't going to help my child or me.

(What have you actually done for your child with special needs? Did that make you feel better? Is there something else you can do for your child?)

3. The view that your situation - when compared with that of another individual - is better than that of the person you compared yourself with. This is called social comparison.

Some parents compare themselves with other parents who seem to be handling their lives well. In doing so, these parents get encouraged by the good job they see. (*"If they can do it, well, so can I."*) Then again, parents may compare themselves with others who are doing about the same. (*"At least we are not alone."*)

If parents compare themselves with people whose lives seem more difficult, they may actually feel fortunate about a situation that had previously seemed difficult. Along this same line, people often say about their own lives: *"It could have been worse."* This view makes them more accepting of life circumstances.

(Do you ever compare yourself with somebody else who has a child with special needs who is coping very well? What do you think makes that person cope with the situation better? How

about your child?: Could that child's condition be worse than it is today? If so, aren't you glad that it isn't?)

4. The view that your child with special needs contributes in a good way to your family and others. This is called positive contributions. Have you ever seen someone look at you in pity when that person notices your child for the first time? Or heard someone say, "I'm sorry," when you tell them about your child? When people react that way it is because they think a child with a disability is a burden; they see only the negative, not the good.

But, your child may have taught your family patience, brought your family together, enlightened the family with a new perspective--a number of contributions. Your child, too, may have a beautiful singing voice, cheerful attitude, brilliant mind, or a host of other impressive talents or characteristics.

(How has your child changed your family for the better? What is one positive trait your child has? Would your family be better or worse off if your child was not with you?)

If you are interested in more information or other issues concerning families who have children with disabilities, please contact the Beach Center on Families and Disability at 3111 Haworth, University of Kansas, Lawrence, KS 66045 (913) 8647600 for related products, including The Cognitive Coping Workshop Manual; Cognitive Coping, Families, and Disability (available from Brookes Publishing); The Kansas Inventory of Parental Perceptions; What Research Says About How Viewing Disability in Different Ways Aids Positive Coping Skills, etc.

Permission granted to photocopy these guidelines. Please credit The Beach Center on Families and Disability

**LEGISLATIVE UPDATE: WE DID IT
- PWS ADDED TO WISCONSIN
STATUTES (continued)**

According to the State of Wisconsin statutes, Chapter 51, a Developmental Disability means " a disability attributable to brain injury, cerebral palsy, epilepsy, autism, mental retardation or **condition closely related to mental retardation or requiring treatment similar to that required for mental retardation, which has continued or can be expected to continue indefinitely and constitutes a substantial handicap to the affected individual.**" Persons with PWS have always met the state definition but those who did not have mental retardation often had hurdles to overcome before receiving the help they needed. Now, there should be no more hurdles. PWS has been added to this list.

In 1995, the Bureau of Developmental Disabilities Services and our organization collaborated by disseminating information about this disability as well as by clarifying that these individuals did in fact meet the definition. On February 10, 1995 Secretary Gerald Bourne distributed a memo to service providers across the state. Things improved ... for a while. Then however, we started to receive calls again.

In 1996, our organization approached Senator Joe Wineke and Representative David Brandemuhl requesting their support in adding PWS to Chapter 51. It seemed like the only way to guarantee services for persons with this disability.

Dr. Thomas Hughes and Barb Dorn began their journey in working with these legislators to do the things that were needed to make this process a success. Meetings were held, testimonies were given to both the Senate and Assembly health committees. Representative John

Lehman (Racine) found this legislation near and dear to his heart. It was through this process that we discovered that he was the father of a young woman with PWS. He candidly shared his personal story with his colleagues and testified about the experiences he faced in securing services for his daughter. Pat LaBella also contributed to testimony. It became a real family venture.

The journey was long and a real learning experience but ... did it. Thanks to all of you who called or wrote to your legislators. We have surely increased awareness about this disability as well as made a significant change that will benefit ALL persons with PWS.

PWSA of Wisconsin is in need of a few good people to volunteer as committee chairpersons for the 1998-99 association events, dance, picnic, training day, awareness day. Call headquarters today and do your part



Uncle Willi Wants YOU!

for your country (I mean your association...sorry I got carried away!) We would like to express our sincere thanks to all who made donations to PWSA of Wisconsin in 1997. It is only through the generosity of our contributors and our volunteers that we can fulfill

1997 Donations

our mission: to educate and assist families and professionals in dealing with individuals with Prader-Willi Syndrome.

United Way of Greater Milwaukee
United Way of Brown Co. (Mary Lynn Larson)

Dorothy and Arian Lothe
United Way of Greater Milwaukee
(Sharon Zagorski)

United Way of Greater Milwaukee
Duane & Emma Spice
Dave & Sandy Seether
Dan & Sarah Larkin

United Way of Greater Milwaukee
In Memory of John Gustafson
(grandfather of Katie Scheidegger)

Peter & Jane Majcherek
Richard Larson

United Way of Greater Milwaukee
Judy Schutz in name of Eddie & Wanda Gretz

Gary Ziegelbauer & Sue Polaski
United Way of Brown County
Valmet, Inc. Appleton Division
Rosalie (Sue) LaBella

Cathy Van Tienhouen Van Humbolt (in honor of Laura Schutz)
United Way of Greater Milwaukee

And a BIG THANKS to the
Empty Stocking Grant!
Conference Updates

It's a Family Affair from Parent to Parent

* February 9th, 7:00 p.m.

Grace Presbyterian Church
215 Gould

Beaver Dam, Wisconsin

* February 16th - 7:00 p.m.

Midvale Community Lutheran Church

4329 Tokay Blvd.
Madison, Wisconsin

The impact that a child with a chronic illness of disability has on the entire family, family relationships will be explored and suggestions offered on how to meet the special challenges that parents and siblings face. (Free childcare is available.)

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

Anger Management with Children and Adolescents, presenter Jerry Wilde, PhD.

* March 19th - 9:00 a.m. - 4:00 p.m.
Registration 8:30 a.m., Fee \$89
Sheraton Madison Hotel
706 John Nolen Dr.
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 action are shared and discussed. This presentation is filled with practical techniques.

Managing Difficult Behaviors in School-Age Children, presenter Jerry Wilde, PhD

March 20th - 9:00 a.m. - 4:00 p.m.
Registration 8:30 a.m., Fee \$89
Sheraton Madison Hotel
706 John Nolen Dr.
Madison, WI

This workshop presents practical, down-to-earth methods of dealing with the most difficult behaviors of school-age children. Learn how to analyze a child's behavior and discover the payoff for misbehavior. In addition to learning effective techniques for dealing with difficult behaviors, you'll also learn how your behavior influences the behavior of difficult children.

For more information on these two workshops, call Ann Whitaker, Programs in Health and Human Issues, 608-262-4509 or 1-800-442-4617.

A Comprehensive Approach to Supporting Individuals with Challenging Behaviors, Instructors: Chris Heimerl and Paul White.

* March 26th, Spring Green
* April 1st, Green Bay
* May 13th, Milwaukee
Times: 8:30 a.m. to 3:30 p.m.
Registration Fee: \$59

In this workshop you can learn about new tools for information gathering, assessing issues and options. You will learn from case histories, from people who face the same kinds of issues you face day to day. You can also learn:

- * How to develop a problem list of stresses and pressures that lead to loss of control, with examples and descriptions of the behaviors of concern.
- * How to look for stages of adaptive behaviors and supports, pointing toward way to deal with each stressor.
- * How to deal with the "red flags" in the situation
- * How to ask systematic questions to bring order to what looks like chaos.
- * Bringing the team to consensus by finding what good things each individual is already doing.
- * Knowing when to "back off"; when and how to get the team process "un-stuck".
- * What to do when a team member feels undermined by others or entire process.
- * How to recognize and escape vicious cycles in the group; how to divide problems into manageable pieces.

For more information, contact the Health Promotion Project at 608-265-4079.

Promoting Dental Health for People with Developmental Disabilities

An Interactive Video Conference presented at eight locations throughout Wisconsin

* Feb. 3rd & 17th, 1:00 - 2:30 p.m.

Caregivers and support providers who know simple techniques for oral health

promotion can help prevent many of the dental problems that seem so difficult. This statewide video conference will show you what you can do and how to do it.

Hosted by Dr. Robert Dwyer, D.D.S. of the Northern Wisconsin Center, the workshop will take place in two 1 ½ hour sessions. Each session will feature three short video segments and follow-up questions and answers with Dr. Dwyer.

For more information, contact Reghan Walsh at UW-Madison/Extension, 608-265-2233.

Sexuality and Relationships: Teaching Strategies for Groups and Individuals

* February 6th, 9:00 a.m. - 4:00 p.m.,
Registration at 8:30 a.m., Fee \$69
Advocap of Neenah
181 East Northwater Street
Neenah, Wisconsin
* March 27th, 9:00 a.m. - 4:00 p.m.,
Registration at 8:30 a.m., Fee \$69
Kenosha Achievement Center
1218 79th Street
Kenosha, Wisconsin

This workshop will use the STARS (Skills Training for Assertiveness, Relationship Building and Sexual Awareness) guidebook. The STARS model and activities are suitable for people who may have difficulty with abstract concepts and who require more concrete ways of learning. You will use practical group and one-to-one techniques for learning, discussing, and teaching sexuality issues. For more information, contact Cheryl Rompa at 608-262-6492, Reghan Walsh at 608-265-2233, or Health Promotion Project at 608-265-4079

Speech and Language Development

By Mary Lynn Larson, MA CCC-SLP
Pediatric Speech Therapist

It is believed that man is born with the innate ability to learn language. This means a built-in capacity to understand and learn the language of

his environment, whether that is English, French, or Navajo. Unfortunately, when a child is born with Prader-Willi Syndrome, the development of these skills is affected significantly by a number of factors, including but not limited to - their level of cognitive skills, the degree of hypotonia, and the implementation of early intervention programming. Hypotonia and cognition are responsible for many of the difficulties seen with speech and language issues in individuals with PWS. The hypotonia may affect a child's oral motor structures in ability and functioning, whether as it relates to feeding or speech/language. Muscle weakness may be responsible for some of the unintelligibility / imprecision in the child's utterances, which might also be referred to as an articulation or phonological disorder. Low tone may also contribute to the degree of hypernasality that might be noted in their utterance. Hypernasality is usually a direct result of inadequate velopharyngeal closure or the inadequate closure of the oral and nasal cavities using the velum and pharynx. Closure of the velopharyngeal port results in directing airflow to the oral cavity and closes off the nasal cavity. A child suffering from hypernasality often sounds like they are "talking through their nose".

A delay in language development might initially be attributed to a cognitive delay as the child is unable to demonstrate their understanding of what is spoken to them due to a delay in their motor skills. How can a child demonstrate they understand a two step directive such as "Put the cup on the table" if they do not have the motor skills to reach for the cup and perhaps the ability to balance while standing to place it on the table? How can a child explore their world and the

wonderful objects about them if they have difficulty maintaining a sitting balance or difficulty with two handed midline play? Most of us explore new items with both hands, in front of our bodies while perhaps using our fine motor skills to turn and rotate the object for visual (sight), tactile (touch), auditory (hearing), olfactory (smell) and sometimes oral (taste) exploration. It is often appropriate for the Physical Therapist/ Occupational Therapist/Speech Therapist to work in joint sessions with the child to help them explore their motor abilities AND language skills. As a child becomes more mobile, they might often put their language on hold until they are comfortable with their newfound mobility skills and then after a period, you see gains in their language skills also. I often tell parents of the children I work with that children are a sponge and need to soak up what we are striving to teach them for a period of time and then, after a while, they show us that they really were listening and paying attention!

Our cognitive skills (sometimes referred to as our mental skills, problem solving skills, or thinking skills) very closely match our language skills as you cannot (or perhaps shouldn't) talk above the level of your knowledge base. In other words, you can't use language you don't know, referring to grammar, vocabulary, etc... A language delay because of a cognitive deficit requires working with the child on using these forms -of grammar or vocabulary and modeling the use of these structures. It might include expanding their vocabulary base from 10 words to a more age appropriate expressive vocabulary through modeling and exposure to age appropriate vocabulary words and language structures. The speech

therapist and the classroom teacher will often work together in addressing the targeted goals for the child.

One of the issues with many children is their unintelligibility - or how easy or difficult it is to understand them when they speak. The most common issue affecting a child's intelligibility is their articulation skills. A child may not be using sounds correctly and often substitute easier sounds in their place, for example they might say "tup" for "cup". A therapist might refer to a child's articulation difficulties as a "phonological processing" disorder. This refers to a child's learning the 'rules' or classification of sounds. For example, some sounds are made in the front of your mouth, (like /t, p, d, b/) where some are made in the back, (/k, g/). A child might not always recognize this 'rule' and use some of the "front" sounds for "back" sounds. Some sounds might be described as "long" sounds (as therapists, we refer to them as continuants /s, z, Th, sh, f, v/ because they continue) while others are "short" sounds (these are referred to as stops /p, d, t, k, b, g/). If a child does not know the 'rules' of sounds, they will not know when to use each of these different classes. Using sounds from another class makes it difficult for us as listeners to try to figure out what the child is saying. If a child uses a different sound than needed but it is from the same class, it is much easier to guess what they are trying to tell us. As a therapist, knowing why the articulation problem occurs, (i.e. Not knowing the 'rules' of sounds) calls for a different approach to therapy and the progress of the child can vary dramatically!

One of the many questions parents ask is what they can do for or with their child at home. Depending on the

nature of the problem the child is experiencing, carryover/home activities can vary dramatically. Some basics include modeling language you want your child to imitate, using gesture or visual cues to help their understanding, and rewarding or praising them when language is successful! Talk with your child's therapist and get some ideas for home carryover that are appropriate to the situation. But remember, you are the parent, not the therapist and they look to you to love them and 'make it all better' when things go wrong. Many parents find that their child does not respond well to them taking on the therapist role. Try to avoid doing the activities in a drill routine and try to incorporate them into everyday conversational activities. Talk with your child's therapist about things that you can do to help facilitate their communication attempts outside of treatment. Let the therapist know what works best for your child when they are not in treatment and what you have tried that has been successful and what hasn't worked!

The following are some print and internet resources for good information on Speech and Language:

"Speech and Language and Prader-Willi Syndrome" brochure from PWSA(USA)

Akefeldt, A. (1997) Voice, speech and language characteristics of children with Prader-Willi syndrome. Journal of Intellectual Disability Research, 41(Pt. 4), 302-11.

"Out of the Mouths of Babes" by Shelia Frick, et.al., from PDP Press (on suck/ swallow/ breath synchrony, not specifically written on PW, but is one of the problems associated with PW)

"The Caring Connections that Help Children Communicate" (Copyright 1986, Revised 1990, Revised 1997 for the world wide web) has been taken from "IT TAKES TWO TO TALK", a Hanen Early Language Parent Guidebook (Manolson, 1985, Revised 1992) ISBN 0-921145-02-0.

Excerpts from the book listed above are available on the internet at:
<http://www.hanen.org/carconn.html>

And here are a few more Internet resources:

The American Speech Language and Hearing Association:
<http://www.asha.org/consumers/consumers.htm>

Pragmatic Language Tips:
http://www.kidsource.com/ASHA/language_tips.html

Kids Say the Cutest Things

Contributed by Jenny Lucas

This was sent to me without the author's name, but it could have been any one of our adorable children that this story is about.

My Son's Prayer

Last week I took my children to a restaurant. My six year old son asked if

he could say grace. As we bowed our heads he said, "God is good. God is great. Thank you for the food, and I would even thank you more if mom gets us ice cream for dessert. And Liberty and justice for all! Amen!"

Along with the laughter from the other customers nearby I heard a woman remark, "That's what's wrong with this country. Kids today don't even know how to pray. Asking God for ice-cream! Why, I never!"

Hearing this, my son burst into tears and asked me, "Did I do it wrong? Is God mad at me?" As I held him and assured him that he had done a terrific job and God was certainly not mad at him, an elderly gentleman approached the table. He winked at my son and said, "I happen to know that God thought that was a great prayer." "Really?" my son asked. "Cross my heart." Then in theatrical whisper, he added (indicating the woman whose remark had started this whole thing), "Too bad she never asks God for ice cream. A little ice cream is good for the soul sometimes."

Naturally, I bought my kid's ice cream at the end of the meal. My son stared at his for a moment and then did something I will remember the rest of my life. He picked up his sundae and without a word walked over and placed it in front of the woman. With a big smile he told her, "Here, this is for you. Ice cream is good for the soul sometimes and my soul is good already."

Getting Ready for Summer...Summer Camps

by Barb Dorn

It's hard to think of summer when many of us are still trying to recover from Christmas but...camp applications may start to arrive any day and spots fill up quickly.

Summer camp can be a fun-filled, exciting week for both youth and adults with PWS. Knowing what camp and at what age is best for your child is a decision that each parent/careprovider needs to make.

I have compiled a listing of some of the camps that parents of children and adults who have PWS have attended. You can call the state office (608-845-9597) if you have questions or contact the camp directly with your questions or concerns. Everyone has different opinions and views. You need to make the final decision...but don't delay.

If your decision to attend camp is based on finances them (or lack of), don't hesitate to apply for PWSA of WI, Inc's Camp Scholarship. This year, we will be awarding two of them. Any person with with PWS, living in Wisconsin, young or old, is eligible. DEADLINE IS MARCH 15, 1998.

Camp can offer a week filled with activities adventures, and social opportunities. It can also be a week where families (especially siblings) get a break from the monitoring and challenges that we all face.

The following are the names, addresses and phone numbers of camps our office has heard of (If you know of more...let us know). I also have a book of camp listings for about 65 camps in the state of Wisconsin. Some do not have staffing and support for special needs children but others do. Contact our office if you are looking for a camp in your area. We may be able to help. BUT don't delay; many deadlines for camp registrations are approaching soon or may have already passed.

Short Camp Listing

Lion's Camp
3834 County Rd. A
Rosholt, WI 54473
715-677-4761

*This camp is for mild/borderline cognitively disabled youth, and adults. They have designated weeks for youth (ages 9 -17) and adults. They do not feel comfortable handling persons with moderate to severe (behavior) problems or those who are moderate to severe cognitively disabled. They have served children and adults with PWS and their diet is managed by "portion control".
THERE IS NO COST FOR THIS CAMP.

Badger Camp
P.O. Box 240
Platteville, WI 53818-0240
608-348-9689

*Wisconsin Badger Camp serves developmentally challenged individuals regardless of severity. They have a well trained staff and medical personnel. They have certain weeks devoted to different ages.
***NOTE: we have received some reports of easy access to food in kitchens that are not locked and located in the campers dormitory area. our office plans to offer financial assistance to make at least one dormitory "more accessible" for the camper who has PWS. We have also heard of some medication administration incidents.

Easter Seal Camp (Camp Wawbeek and Pioneer Camp) Business address:
101 Nob Hill Rd., Suite 301 Madison,
WI 53713

*Camp is located on a wooded 400-acre site near Wisconsin Dells. This camp provides experience for children and adults with physical disabilities. They have certain weeks for different ages. PWSA of WI does not know of their knowledge or experience with persons with PWS. They also offer respite weekends but the cost is pretty high.

Camp Albrecht Ares of the Midwest
14775 Sherrill Rd.
Sherrill, IA 52073
319-552-1771

*Although it is not located in Wisconsin, this camp may be accessible for those living in south western Wisconsin. The camp is designed for the mentally and physically disabled. They have 24 - hour nursing staff. They do have some experience in working with children and young adults with PWS. It is "family style" eating but staff will monitor for portion control. They have a lot of opportunities/weeks available for adults.

Trade Lake Camp
Business Address:
127 E. County Road C, Unit 3
St. Paul, MN 55117
612-481-8036
Camp Location:
Hwy 87
Grantsburg, WI
715-488-2690

*This camp has designated weeks for persons with PWS. They welcome campers with PWS at any session however. They are acquainted with PWS and the dietary and behavioral concerns that must be addressed. *** NOTE: we have received reports of concerns in the area of nursing supervision as well as medication administration. You may also want to inspect the pool and make sure it is being maintained.



Prader-Willi
 Syndrome
 Association
 of Wisconsin

●
 305 Amanda Way
 Verona, WI 53593
 ●

Office: 608-845-9597
 Fax: 608-845-9638

APPLICATION FOR CAMP GRANT

PURPOSE: The Prader-Willi syndrome Association of WI, Inc., has money available to assist a child or adult with Prader-Willi Syndrome, in covering the expenses of attending an organized summer camp.

ELIGIBILITY: Any person with PWS, who resides in Wisconsin, and has a financial need is Eligible for the grant. If financial need is equal between several applicants, secondary Consideration will be given to those who would benefit most from attendance (example: respite intervention or personal/behavioral issues needing to be addressed).

Date of request _____

Campers Name: _____ Sex _____ Birthdate _____

Address _____ City _____ State _____ Zipcode _____

Phone (_____) _____ Wisconsin Resident _____ Yes _____ No

Contact person _____ Phone (_____) _____

Name and address of camp you plan to attend: _____

Cost of Camp _____ How much of this cost can you pay yourself? _____

Why would this grant be helpful to you? (Financial need, need for respite, etc.)

Return this application by March 15, 1998

To: PWSA OF WI, Inc.
 305 Amanda Way
 Verona, WI 53593

* You will be notified by mail if you are awarded the grant. PWSA of WI will send the grant money directly to the camp.

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. This month we only have space for one cookbook review.


RECIPES FOR LIFE, from the Kitchen of Healthy Choice Foods. .

I have long been a fan of Healthy Choice frozen foods. They are very low calorie, low in fat, and usually full of vegetables. In my opinion, they are the best frozen meals on the market. So naturally when I found their web site, which includes a "recipe box", I was excited. And then, to my delight, I found they have published a cookbook. So I had to buy it. It's a little pricey (\$24.95), but well worth it. The book starts out with a section called "Nutrition for Life", which explains the Food Guide Pyramid, how to read the nutrition facts labels, nutrient listings, and tips for reducing fat. There is a 22 page "Healthy Menus" section that will help you to balance your nutritional intake while still presenting an eye pleasing, well rounded dinner.

The recipe section contains 200 pages of recipes with full color pictures for each, clear, concise directions and, best of all, "Nutrition Facts" in the popular USDA format that you find on all of the food packaging. It also shows the "Diet Exchanges" for those using

the exchanges method of dieting.

In case you can't already tell, I really like this cookbook. I highly recommend it to everyone who has ever tried and enjoyed one of the Healthy Choice frozen meals, and would like to serve the whole family healthy meals.

I rate this cookbook only because of the price. If it were more reasonable, I  would definitely give it a 4! I did, however, just come across another Healthy Choice cookbook in the current Avon catalog for \$9.95, with 60 recipes. A nice starter cookbook for those on a budget.

Here is a recipe I tried from **Recipes for Life**:

Turkey Tetrazzini

Serves 8, Cal. 241, Total Fat 7 g.

8 oz. Uncooked spaghetti, broken into 2-inch lengths
 ½ cup margarine, divided
 1 cup sliced fresh mushrooms
 ½ cup celery, sliced
 1 clove garlic, minced
 3 Tablespoons all-purpose flour
 2 ½ cups skim milk
 ¼ teaspoon salt
 ¼ to ½ teaspoon pepper
 1 ½ cups cubed fully cooked turkey (¾ inch cubes)
 ⅓ cup shredded low-fat Swiss cheese
 1 jar (2 oz.) Sliced pimento, drained

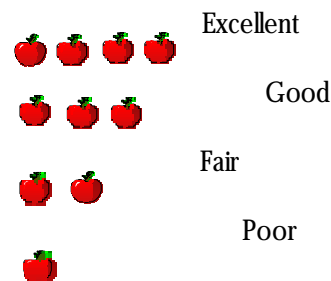
Prepare spaghetti as directed on

package, rinse and drain. Set aside.

Heat oven to 350 degrees. In 2 quart saucepan, combine 1 tablespoon margarine, the mushrooms, celery and garlic. Cook over medium heat for 5 to 7 minutes, or until celery is tender-crisp, stirring occasionally. Stir in remaining 3 tablespoons margarine until melted. Stir in flour. Cook for 30 seconds to 1 minutes, or until mixture bubbles.

Blend in milk, salt and pepper. Cook over medium heat for 10 minutes, stirring frequently. Reduce heat to low and cook for 2 to 5 minutes longer, or until sauce thickens and bubbles, stirring occasionally. In 2 quart casserole, combine sauce, spaghetti and remaining ingredients. Bake for 30 to 35 minutes, or until hot.

Call 1-800-328-3895 to order Recipes For Life or for more information. Or visit their web site at <http://www.healthychoice.com>



MEETING NOTICE

You 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! We had one very successful meeting in November, 1997 and this is a follow-up meeting to organize a possible PWSA chapter in Milwaukee.

Event: Parent Connections Meeting

Date: Saturday, April 4, 1998

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

*Place: Children's Hospital at the
Children's Health Systems
Office Building
9000 W. Wisconsin Avenue
Milwaukee, Wisconsin*

*Meeting room: 5th Floor
Educational Service Classroom*

*Children's room: Lobby
Conference Room*

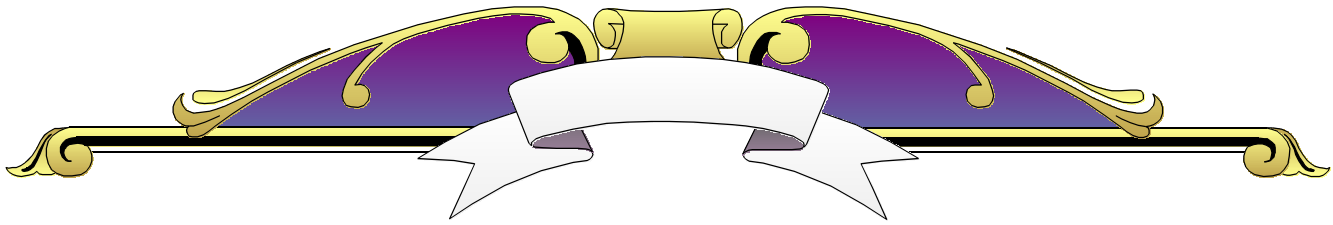
Parking adjacent to Office Bldg.

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!

IF ANYONE IN THE MILWAUKEE AREA CAN PROVIDE EXPERIENCED CHILD CARE VOLUNTEERS, PLEASE CONTACT BARB DORN, EXECUTIVE DIRECTOR, PWSA OF WI, AT 608-845-9597, AS



**PWSA OF WISCONSIN
1998 Calendar of Events**

Sat., February 1st.....Business Meeting in Beaver Dam
Sat., April 4th...Parent Connections Meeting, Milwaukee
Sat., April 25th...Spring Dance, ODTC, Oconomowoc
July 22- 25...PWSA(USA) National Conference, Columbus, OH
Sat., Aug 22nd...Summer Picnic, location to be determined
Sat., November 7th... Election, location to be determined

***Jot these dates down on your calendar now...and watch for details in the next
Issue of Wisconsin Connection***



SOON AS POSSIBLE.

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