



# THE WISCONSIN CONNECTION

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

## Mission:

The mission of the Prader-Willi Syndrome Association of Wisconsin, Inc. is to Support, Educate, and Advocate for persons with Prader-Willi Syndrome, their families and professionals in meeting the

## State Officers:

### President:

Pat LaBella

### Vice President:

Jackie Stoner

### Secretary:

Mary Mankowski

### Treasurer:

Tom Scheidegger

### Executive Director:

Barb Dorn

### Newsletter:

Brian Fendt

## Office Address:

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Verona, WI 53593  
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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  
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Website: www.pwsausa.org

## A Message from the Executive Director

**Barb Dorn**

I hope everyone is having a great summer. Summer can be a time of stress for many of us when the structure of things loosens up.

My job as executive director gets more challenging as well. I am not always able to be as flexible as I would like and try to be.

Our office continues to keep a steady pace of phone calls, emails and requests for information and services. We continue to support, educate and advocate for many persons with PWS and their families.

I hope you have noticed our efforts in reaching out to educators and other professionals in helping them learn how to best support children and adults with PWS. A lot of hard work and time goes into our training workshops. All of our speakers and planning members do this on a volunteer basis. We do however reimburse for mileage and expenses. We would like to encourage all professionals who work with persons with PWS to attend these workshops. Please alert professionals to these opportunities as well. We must all work together to spread the word.

Plans are also moving forward for our annual parent meeting and workshop in

November. It will be held on November 6<sup>th</sup> from 1-4 pm. Mark your calendars now.

As we approach the "Back to School" time of year again, I thought it would be a good idea to list some of the resources that might be helpful to both you and your child's teacher and other professionals. Please review the list and I hope you find resources that will be of help. If you ever have any questions or concerns, feel free to contact our office. We do our best to meet the education and advocacy needs of children and young adults with PWS.

### A Few Education Resources

**1. PWSA (USA)** The following items are available from PWSA (USA). For a complete list of products and ordering information, please call 1-800-926-4797 or visit the PWSA's web site: [www.pwsausa.org](http://www.pwsausa.org). Prices shown are PWSA (USA) member rates followed by nonmember prices and do not include shipping and handling.

Continued on Pg. 3 ➡

# Notes From The President

Pat LaBella

**M**y family and I are planning a July trip to San Diego, California for the PWSA (USA) annual conference. I look forward to this trip because, even though Beth is 19 years old, I'm still learning about Prader-Willi Syndrome. With all the current research there *are* many new things to learn. This is the first time we are taking our four children to a conference ( a learning experience right there). It's my understanding that Beth will also "learn a lot" from the other folks with PWS who will be attending the conference. (Hopefully, she will won't learn how to pick locks or learn any new strategies for stealing food or out-smarting her parents!)

When Beth was born, I remember feeling like a foreigner in this land of the disabled child. I remember saying to my Mom and Dad, "*I don't know how I'm going to handle all of this. I don't know what to do to help this child. I can't do it.*"

With love and firmness, my mother responded, "*Patti, you **have** to handle this. You are your child's advocate now and for the rest of her life. No one else has a vested interest in this child like you do. You have to learn all you can about her disability and advocate for her, because she can't advocate for herself. You can't wait for someone else to do it for you.*" While my Mom was saying these words, I wanted to put my hands over my ears to block out the sound (just like my ten year old son does to me sometimes). If I didn't hear the words, I wouldn't have to respond to them. But I did hear them and my Mom was right, I did have to respond. So I began to learn everything I could about Prader-Willi Syndrome. (Back then there was not much in writing.) Fortunately, I met Barb Dorn. We gathered a group of parents and formed a support group. Then we started the PWSA of WI, Inc..

While I continue to learn about PWS, I educate too. I challenge each of you to do the same. You have a child with or support an adult with PWS. So, right there, you know more about the syndrome than most people.

You are practically an expert. I encourage you to continue to learn about PWS by attending conferences, forming support groups, reading, doing research on the Internet. Then, educate those who help you support your child. You *do* know enough to teach people about your child's unique needs. *You* know what strategies work best to support your child. *You can* teach others about PWS. *You must* teach them. As my Mom said: "*...You are your child's advocate now and for the rest of their life. No one else has a vested interest in this child like you do. You have to learn all you can about PWS and advocate for him/her, because he/she can't advocate for himself/herself. You can't wait for someone else to do it for you.*"

Thanks Mom and Dad, for your love and support. Thanks for encouraging me to continue to learn. As my kids occasionally (and with great reluctance) say, "*OK, maybe sometimes parents are right.*" A belated Happy Mother's Day and Happy Father's Day to all you Moms and Dads out there. I'll keep you posted about what we learned at the national conference.

Have a summer filled with fun and learning.

Pat



## Message From the Executive Director Continued From Page 1

- **Management of Prader-Willi Syndrome.** This textbook is a valuable resource for people who support your child in the school setting. This book helps educate the team members using a multidisciplinary (many different professionals) approach. (\$39.95/\$45)
- **Supporting the Student with PWS Across Their Life Span.** This is a new audio tape for teachers addresses a number of different issues that affect the student with PWS from birth to 22 years of age. The accompanying handout serves as an excellent resource. (\$5.00/\$7.50)
- **Transition From School to Adult Services in PWS: What Parents Need to Know.** This booklet targets those who have children with PWS entering high school. It helps parent understand the issues to address during the high school years to best prepare their son/ daughter for life after high school. (\$10.00/\$15.00)
- **Children with PWS: Information for School Staff.** This booklet assists teachers and other school personnel who have a child with PWS in their class. (\$5.00/\$7.00)
- **The Child with PWS: Birth to Three.** This booklet is a valuable tool for parents of young children to share with early intervention teachers & school personnel. (\$5.00/\$7.50)
- **Physical Therapy Intervention for Individuals with PWS.** A good resource to share with therapists working with your child. (\$4.00/\$6.50)
- **Exercise and Crafts and activities for the Individual with PWS.** This collection of articles is valuable for a child's physical and occupation therapists, the regular education and physical education teacher. (\$6.00/\$8.50)
- **Brochures:**
  - What Educators Should Know about PWS
  - Speech and Language and PWS
  - Management of PWS in the Work Setting: A Guide for Employers and Supervisors.

### 2. Parent's Education Project (800)-231-8382

This advocacy organization specializes in educational training for parents of children with special needs in the state of Wisconsin to help them better understand their rights.

### 3. National Information Center for Children and Youth with Disabilities (NICHY) 1-800-695-0285,

**Website:** <http://www.nichcy.org>. This organization has a variety of publications available on education topics for little or no cost. They are available free on their website.

## Remember To Put The "Person" First

by Pat LaBella

**T**he other day I ran into a mother and her small child at a ball game. The little girl had really white hair and pink eyes. It crossed my mind that this young mother might be feeling alone and isolated while dealing with her child's "differences". Thinking I could be of some support to the woman, I tried to establish some common ground. I said, "I have a daughter with a disability. I know how difficult it can be sometimes. Is your daughter an albino?" The woman was obviously frustrated but she patiently responded "No she's not an albino. She's a little girl who has a condition called Albinism." I got the point. I apologized for my ignorance and thanked her for reminding me of what I already knew. The **person** is more important than the disability.

Hopefully, others can also learn from my mistake. Let's remember to put the person first when describing Prader-Willi Syndrome or any other disability. I'm not a "Prader-Willi mom". I don't have Prader-Willi. I am a mom with a child with Prader-Willi Syndrome. We aren't "the Prader-Willi family". My daughter is not a "Prader" or a "Prader-Willi". She is a person first and she happens to have a disability called Prader-Willi Syndrome. One of my goals is to retrain myself to remember the uniqueness of each person and to be more person-sensitive and person-centered when I speak. How about you?



Thanks for  
Everything



### A Big Thank You to Everyone At ODTC

On behalf of the entire Prader-Willi Syndrome Association of Wisconsin, we would like to thank the staff and residents of Oconomowoc Developmental Center for putting on a spectacular dance. We had a great time dressing for the "Western" theme. James "The Music Man" was a one cool D.J. We really enjoyed "Pingo" the clown and her face painting friends. For those who were unable to attend, you missed a great time. Once again, thanks to the folks at ODTC for all your hard work and decorations. We also want to thank the *Wisconsin State Journal - Empty Stocking Club Grant* for helping us make this

**“Caring, Conflict and Consumer Rights -  
Supporting the Person With  
Prader-Willi Syndrome In A Residential Setting”**



**Date:** Tuesday October 12, 1999

**Location:** Holiday Inn, 625 Rolling Meadows Dr., Fond du Lac, WI  
Located at the corner of Hwy 151 and Hwy 41

**Time:** 8:30 am – 3:30 pm      **Cost:** Member of PWSA of WI, Inc.:  
\$35

Nonmembers: \$45

**Target Audience:** Residential providers, case managers, parents and any others who need to gain a better understanding of PWS along with the ethical questions that go along with the measures these individuals need to remain safe and healthy in their homes.

Agenda

- 8:30 – 9:00 am      Registration
- 9:00 – 9:15 am      **Welcome** – Pat LaBella, President PWSA of WI, Inc.
- 9:15 – 10:00 am      **Overview of PWS** – Barb Dorn, Executive Director PWSA of WI, Inc.
- 10:00 – 10:15am      **BREAK**
- 10:15 – 11:00 am      **Consumer Rights and the Person the PWS** – Jim Stoner, Educator for Facilitative Learning Services Inc., Oconomowoc, WI
- 11:00 – 12:00      **Balancing Rights and Responsibilities With Challenging Behavior** – Pam Chatterton, Community Integration Specialist, Bureau of Developmental Disabilities
- 12:00 – 1:00 pm      **LUNCH** – cold lunch buffet will be provided
- 1:00 – 2:00 pm      **Nutrition and Menu Planning** – Sandy VanCalcar, Nutritionist U.W. Hospital and Clinics and Waisman Center, Madison
- 2:00 – 3:00 pm      **Behavior Incentives & Management** – Paul White, Community TIES Program, Madison
- 3:00 - 3:30 pm      **Questions and Answers** – A Time for Problem Solving

**REGISTRATION  
DEADLINE: SEPTEMBER 25<sup>TH</sup>, 1999**

**Name:** \_\_\_\_\_ **Agency (if applicable):** \_\_\_\_\_

**Address:** \_\_\_\_\_ **City:** \_\_\_\_\_ **State:** \_\_\_\_\_

**Zip:** \_\_\_\_\_ **Phone:** \_\_\_\_\_

**Are you a member of PWSA of WI, Inc.?** \_\_\_Yes \_\_\_No    **Amount Enclosed:** \_\_\_\_\_

Forward registration and payment (checks made payable to PWSA of WI, Inc) to:  
PWSA of WI, Inc  
305 Amanda Way  
Verona, WI 53593

\*\*\*Please feel free to duplicate this for each person attending. MAP ON NEXT PAGE.

# Welcome to More New Members in '99 "Better Late than Never"

We would once again like to welcome and thank our members, new and old for their support. We currently have 87 paid members. That leaves us 12 short of our goal. If you are reading this newsletter and have not sent in your membership ... it's no too late. Help us continue our efforts in supporting persons with PWS. It truly is "Better Late than Never".

Jean Ann Burke  
Louise Guido  
Richard & Victoria Kral  
ODTC - Tom Bradshaw  
ODTC - Linda Wiggins  
Paragon Industries - Lincoln Burr  
Nick & Wanda Scheidegger  
Debbie Smith

Daniel Larkin  
Mike & Mary Lynn Larson  
Dr. Diane Lytton, Ph.D.  
Laurel Mills  
Rosalie Tillman  
U.W. Waisman Center - Heidi  
Luebke  
James Wachter  
Marc Williams

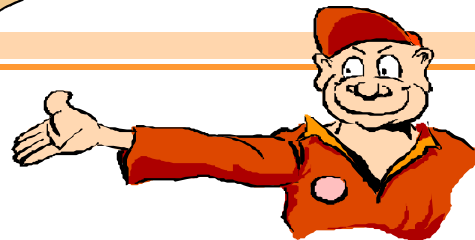
Rick Rosen  
Human Service Center- Laurie  
Groskopf  
Regina Richards

**ONLY 12  
MORE  
MEMBERS  
NEEDED!!!**



**UNTIL  
WE REACH  
OUR GOAL!!!**

## Support - It Means A Lot



Being able to help and support persons with Prader-Willi syndrome, means a lot to both the giver as well as the receiver. Sometimes it is a phone call or an email, but whatever the means, people need to remember that they are never alone. If you ever come across a question or concern, please call or write our office for answers and support.

Another way that PWSA of WI, Inc has attempted to reach out to support its members is through our General Assistance Fund. We are happy to report that we will be assisting a family with \$500 to help them cover the costs to attend the National PWSA (USA) conference that will be held in San Diego. We are glad to assist in making this trip possible.

PWSA of WI, Inc also awarded one camp scholarship to a young woman. With this assistance, she will be able to attend a 1-week camp that specializes in working with children and adults who have disabilities. Being able to assist young people in successful, social opportunities has always been one of our goals. We are once again grateful to be able to help with this support.

# Speech / Language Intervention for Young Infants and Children Birth to Three Years of Age

Mary Lynn Larson, M.A. CCC-SLP

## Pediatric Speech Therapist

P



People often wonder why a speech therapist might be working with an infant beginning as early as two or three months of age... "Surely it is months before they are expected to talk!" I usually tell parents of the children I see, "An infant begins life like a sponge, soaking up all the information the external world can provide. It is our job, as parents, therapists and caregivers, to make sure to provide the kind of information they need to soak up." With a child at risk for speech and language delays, like those with a diagnosis of Prader-Willi syndrome (PWS), we often begin therapy early to maximize their learning of language and build upon that to reduce the potential delay we might see otherwise.

An infant with Prader-Willi syndrome has a significantly reduced level of arousal – meaning they sleep too much and don't always seem to care about what is going on around them. Because of that, we want to maximize a child's/infant's ability to recognize and understand language during their alert/awake times. We want them to recognize and participate in the turn taking of language. We want them to recognize the "melody" or rise and fall of our voices when we talk to be able to determine if we are happy or sad. We want them to start recognizing the association between objects and labels so that they make the connection when we say "dog" that we are referring to the animal on four legs that barks. We want them to recognize that they can use their mouths to make a variety of sounds that at a later age they will pair together to form words in order to share ideas.

Most infants begin babbling at about two to three months of age. The first word they say usually occurs around 10 to 14 months of age. By 12 to 15 months, most children have a vocabul

ary of about 5 to 10 words. Shortly after 18 months, they develop a 10 to 20 word vocabulary and begin to combine words together such as, "more ball" or "Mommy shoe". A dramatic growth in language is noted over the next several months, as by 2 years, children will have around 200 words in their vocabulary.

### Some suggestions for parents and families to try with infants and young children to try to encourage and promote language skills include:

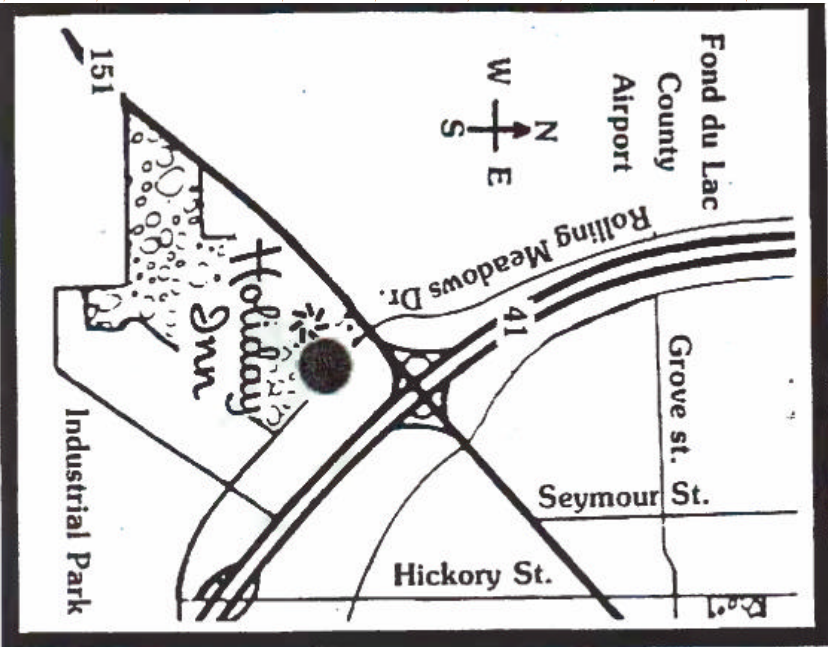
- Give your child the opportunity to view his world from different vantage points – allow them time to observe the world around them in both sitting and reclining positions. Don't forget to give him time on his tummy - although most children find this a difficult position because of the work and effort required in lifting their head and/or manipulating objects while keeping their head up.
- Place a variety of colorful toys and objects within reach to encourage independent exploration as they become able to reach out for things. Include things appropriate for them to explore in their mouths. This will encourage them to explore what they can do with their oral structures as well as play with the sounds and noises they can make.
- When talking to your child, get **ANIMATED!** Use short sentences and add inflection to your message. Inflection refers to the rise and fall of the pitch of your voice, for e.g., when asking a question, our voices tend to rise at the end of the sentence. These changes capture your child's attention and make the message more interesting.
- Allow time between your comments and questions to give your child an opportunity to respond to your message. At first, it might just be their eyes widening but as you respond to their initial subtle changes, they learn that their response can change or activate a different response in you. As parents, we tend to get more excited as they smile, coo, or clap. It is reinforcing for them so the behavior is likely to occur again.
- Make different faces and sounds while really exaggerating your facial movements. Pause and let your child offer some response if they are able. Over time, your child will begin to imitate what you are doing and likely imitate it during the pause. This is an important skill to recognize in conversation -that first you talk and then I talk.
- Call your child's name from different points in the room. Do they look for you? If initially it is only by chance, **get excited** so they will do it the next time! Over time, they will recognize and associate that name/label with themselves. This is an important step in learning new words – to associate the person or object with its respective label.
- Vary the volume of your speech when talking with your child. Expect them to react differently when you whisper vs. using normal volume. Make it a game as if you need to do things quietly and secretly when you whisper but make lots of noise in your actions when using a loud voice.
- Ask them questions like, "Where's Daddy?" as Daddy is in different parts of the room. We often target names of family members first as they are more meaningful to infants than objects. Over time, start asking about familiar objects such as, "where's your bottle?" or "where's your ball?" to expand their understanding for common objects in their environment.



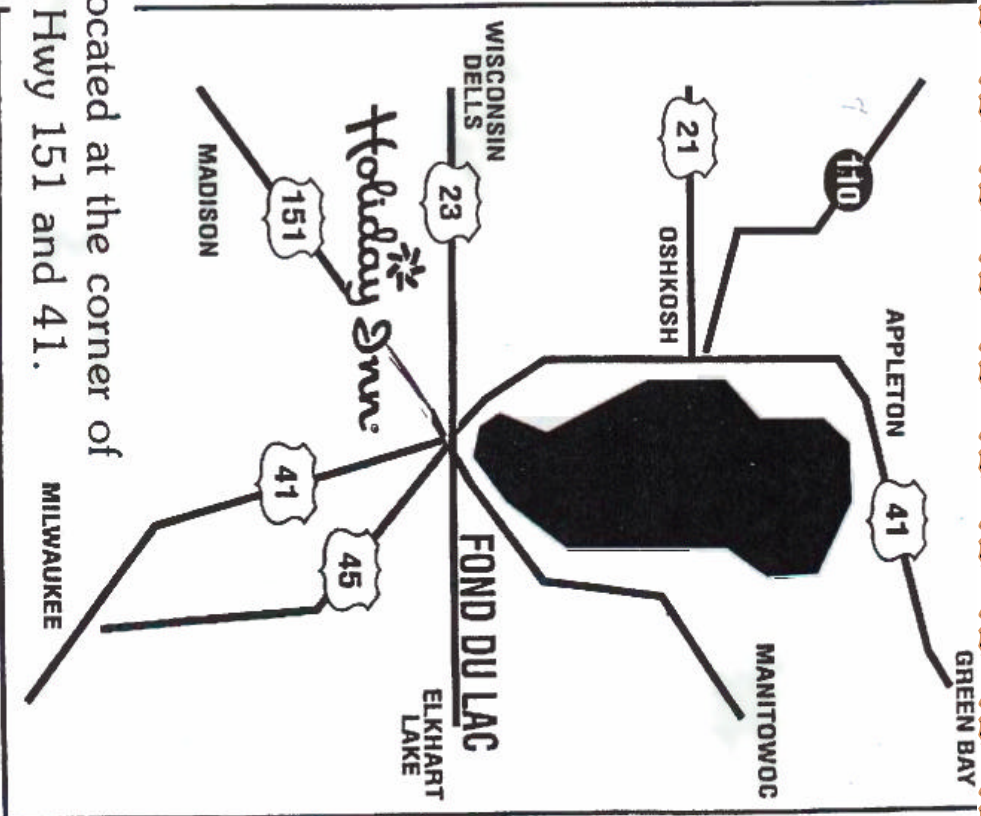
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# Holiday Inn

625 Rolling Meadows Dr.  
Fond du Lac, WI 54935



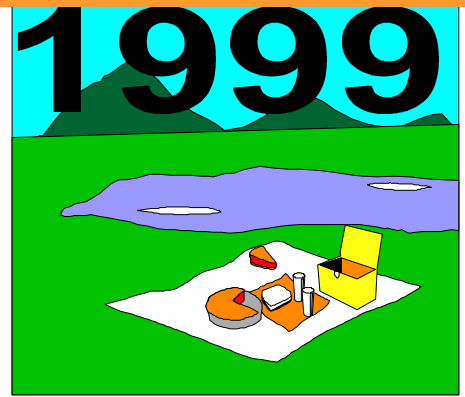
- Located at the corner of Hwy 151 and 41.



### Miles from Holiday Inn to:

Green Bay	70	Milwaukee	66
Madison	68	Sheboygan	40
Manitowoc	60	Wausau	123
Elkhart Lake	35	Wisconsin Dells	70

# PWSA of WI Summer Picnic



**When : August 28 1999**  
**Where: Appleton WI**

**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.

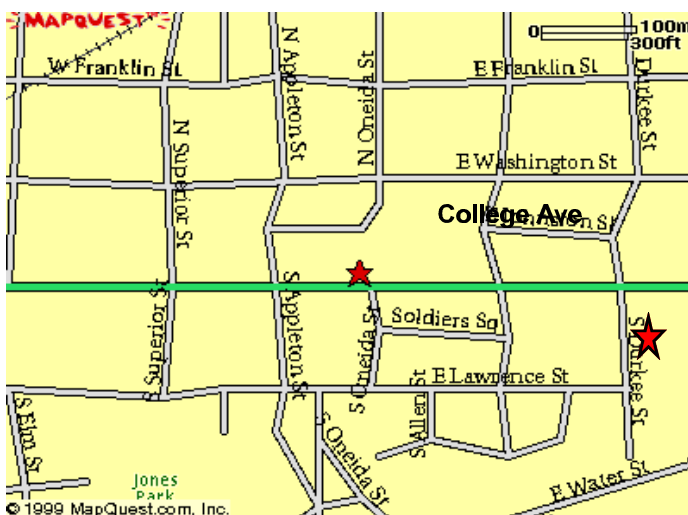
**Directions:**

**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.**

## Speech / Language Intervention for Young Infants and Children Birth to Three Years of Age Continued from page 5

- As an infant/toddler's understanding grows, they often start to imitate the words they hear us using. The first time you hear these words, it might be what your speech therapist calls an 'approximation' of the original word they are trying to say, for e.g., they might say "du" for "juice" or "wawa" for water. Rather than correcting the **way** they say it, it is best to let them know that they have the right label. You might repeat the word for them saying, "That's right, **juice**."

Now, it is important to remember that children with PWS often develop their motor skills later than their peers without PWS, which may contribute to the delays noted in their exploration of their world and their later developing language. If parents have any concerns regarding their child's development, they should speak to their child's primary care physician. If a child is under the age of 3 years, a referral to their county's Early Intervention Program may be appropriate. If the child is over the age of three, the parent can contact their local school system and ask for an assessment.

A speech therapist will assess your child's development based on their understanding and use of speech and language. After an assessment, a therapist may want to allow the child time to progress without the need for therapy and reassess them at a later date. Ask the therapist for ideas and suggestions on things you can do at home to promote their learning the necessary skills. A child may be showing signs of a delay indicating the need to initiate therapy services on a regular ongoing basis. Often the therapist will share ideas on things to try at home to continue working on the child's skills outside of therapy.

Many parents are concerned that their child will not develop language but this is not likely to be the case with a child with Prader-Willi Syndrome. In fact, once they start talking, many parents have a difficult time keeping them quiet!! It is difficult to imagine this when your 24 month old infant is not talking, but have faith... with time, patience, and intervention your child has great potential to achieve much more than most of us could imagine!



We are looking for volunteers to help us with registration at our upcoming workshops. If you are one of the lucky ones chosen, you will be able to attend the training at no cost. We will need two volunteers at the registration table for each training. Please contact Barb Dorn if you are interested at 608-845-9597.

### Our workshops include:

“Supporting the Student With PWS Across the Life Span”. The workshop is from 8:30 – 12:30 pm but the time we need your help is noted below.

- Monday August 16<sup>th</sup> from 8-9 am at the Quality Inn in Madison
- Tuesday August 17<sup>th</sup> from 8-9 am at the Paper Valley Hotel in Appleton
- Wednesday August 18<sup>th</sup> from 8-9 am at the Holiday Inn Express in Wauwatosa

“Caring, Conflict and Consumer Rights – Supporting the Person with PWS in the Residential Setting”. The workshop is scheduled from 8:30 – 3:30 pm but the time we need your help is noted below:

- Tuesday October 12<sup>th</sup> from 8:15 – 9:15 am at the Holiday Inn in Fond Du Lac.

**1999 Calendar Update**

July 8-10 <sup>th</sup>	PWSA (USA) National Conference in San Diego PWSA of WI, Inc. OFFICE CLOSED JULY 5 <sup>TH</sup> THRU 12 <sup>TH</sup>
August 1 <sup>6</sup>	"Supporting the Student With PWS Across the Life Span" (Educator Workshop) 8:30-12:30 pm Quality Inn, Madison REGISTRATION REQUIRED
August 1 <sup>7</sup>	"Supporting the Student With PWS Across the Life Span" (Educator Workshop) 8:30 - 12:30 pm Paper Valley Hotel, Appleton REGISTRATION REQUIRED
August 1 <sup>8</sup>	"Supporting the Student With PWS Across the Life Span" (Educator Workshop) 8:30-12:30 pm Holiday Inn Express, Wausau, REGISTRATION REQUIRED
August 28 <sup>th</sup>	PWSA of WI, Inc. Annual Picnic/Outing In Appleton (More Information Noted in this Newsletter)
September 8 <sup>th</sup>	Barb Dorn, Executive Director PWSA of WI, Inc. to be a speaker at "Supported Employment Conference" in Steven's Point
September	Officer's Business Meeting
October 12 <sup>th</sup>	"Caring, Conflict and Consumer Rights - Supporting the Person With PWS In a Residential Setting,
November 6 <sup>th</sup>	8:30 - 3:30 pm Holiday Inn, Fond du Lac, REGISTRATION REQUIRED Parent Training and Meeting 1-4 pm Milwaukee (More information will be available in fall)

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

