



# THE WISCONSIN CONNECTION

THE NEWSLETTER OF THE PRADER-WILLI SYNDROME ASSOCIATION OF WISCONSIN, INC.

Volume I, Number 1

October 1994

**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.

**State Officers:**

**President:**

Barb Dorn

**Vice President:**

Pat LaBella

**Secretary:**

Bonnie Jones

**Treasurer:**

Tom Scheidegger

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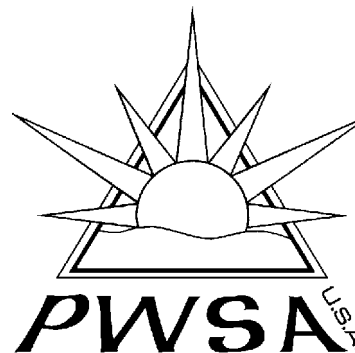
## First Annual PWSA National Awareness Day

This year on April 29 will be the first annual PWS Awareness Day. During this week state chapters throughout the United States will be promoting PWSA fund raisers and other events that create awareness of PWS and our purpose. Money from the fund raisers will be split with the national office. Eventually it is desired that this will become a nationally recognized day promoting PWS awareness. To have our Awareness Day nationally recognized it takes an act of Congress (no really!) There are plans to have a bill proposed as legislation to recognize National PWS Awareness Day. This year a letter was drafted at the National Conference in Atlanta, written to President and Mrs. Clinton, telling them about this disability and efforts of the National and state chapters. All persons attending the conference and all individuals with PWS signed the letter to be received by the Clintons on National PWS Day. Further details of the PWS Awareness Day will be discussed at our next meeting.

## New Look for PWSA (USA)

In the near future you will notice a new look from the National PWSA office. PWSA(USA) has adopted a new logo and have new sets of stationary and literature packages printed up. With the national office moving to St.Louis and hiring a new Executive Director, it was felt an entire new look and image was appropriate. With so many new things happening at the PWSA National Office it was looked at as "A New Day for PWSA".

As Don Goranson (VP of PWSA) explained, "Our new logo is neither simplistic nor abstract and comes with very definite symbolism. The designer wanted the spikes of the sunburst to pierce a known shape, to break through the boundaries or limitations of that shape. We chose the triangle because it symbolizes the PWS body shape, the food pyramid, the mountain to be scaled, and even the pyramid of power, with many supporting few.



(Cont. on page 4 see LOGO)

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## A MESSAGE FROM YOUR PRESIDENT - BARB DORN

**F**irst of all, this will be the last newsletter that you will be receiving a message from me as your president. The duties and responsibilities in running the state office are growing on a daily basis. We are receiving more calls and there isn't a day that goes by that I don't have at least one message on my answering machine that needs my attention. This is good news however. I feel our organization and this disability are starting to become more well known in the State of Wisconsin. We have accomplished a lot in 2 short years. I also feel my job as a mother is becoming increasingly more demanding. Even though Tony is only 9 years old, we are facing many experiences that demand more of my attention. For all of us, the balancing act is very difficult. I am offering my services as the secretary as well as continued manager of the state office. Bonnie Jones will be my co-secretary to help me with mailings and other areas. I hope to be able to get the state office better organized in hopes of saving myself a lot of repetitious work in the future. My dear husband Don has also offered to help me in this area. Right now I am in the process of taking my first computer course (ever). I am learning so much. In this newsletter, once again, I have so much to share with all of you. First of all I want to thank all of the officers who have volunteered their valuable time to keep this organization viable and moving forward. For those of you who are paid members, you also have a ballot enclosed. If anyone wants to offer their services, please feel free to add your name. We appreciate all your support. A BIG THANKS!!

Our summer picnic was a big success. We had a day filled with bubbles, face painting and an afternoon of bowling. Tom and Bonnie Jones were very gracious hosts. Thanks to ALL who helped make this another successful event.

We just completed our first residential conference that this organization has ventured to sponsor with the State of Wisconsin Dept. of Developmental Disabilities. It was a great deal of work and I could have never pulled it off without the help of Pat LaBella. Also a big thanks to Ginny Cardarella, Paul White, Pat LaBella, Josh Lapin, & Craig Hoffman for their help in stuffing folders and packets for the conference. I believe our final total attendance was 108. We had parents, case managers, residential provides attend as well as others. Russ Myler, the executive director from National PWSA was also in attendance. My initial review of the evaluations were very good. Speaker requests have also been increasing. In July, Ginny Cardarella spoke to a group of students at the U.W. Madison - Waisman Center about being the parent of a child with PWS. In August, Ginny and Pat LaBella spoke at a conference in Wisconsin Dells about *PWS: A Supportive*

*Perspective.* Both Pat and Ginny received outstanding reviews. On October 28, 1994 Pat LaBella and I will be speaking at the Wisconsin School Psychologists Association 1994 Fall Convention. Our topic will be *Educational Considerations for Working with Students with PWS.*

In early September, Mike and Mary Lynn Larson, Lori Abler as well as other volunteers distributed pamphlets & addressed questions at the state convention for Special Olympics. As you can see, we have all been working hard to spread the word.

Mike Larson has an article highlighting the 1994 National PWSA conference that was held in Georgia. The National office has a new logo and is gearing up for the 1st National PWS Awareness Day on April 29, 1995. Our state organization will be discussing changing our logo to show unity with our parent organization. 1995 offers us a lot of excitement and work as well. Keep reading this newsletter so you won't miss out on anything. A BIG THANKS TO ALL OF YOU AND YOUR SUPPORT DURING MY TENURE AS PRESIDENT; IT HAS BEEN A HEARTWARMING, and EXCITING VENTURE ON MY PART. Take Care!!!!!!

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### OUR NEXT MEETING

**WHEN:** Saturday November 5, 1994      **TIME:** 1:30 - 4:00 P.M.

**PLACE:** St. Albert the Great Catholic Church  
2420 St. Alberts Dr. SUN PRAIRIE  
(MAP ENCLOSED)

**TENTATIVE AGENDA:** Elections, Discuss plans/calendar for 1995, discuss PW Awareness day, Share Highlights from 1994 PWSA convention, SHARE!!

\*\*\*CHILD CARE WILL BE PROVIDED but we are asking for a small donation so we can provide our child care providers with a small thank you gift.

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## POSSIBLE GROWTH HORMONE STUDY UPDATE

**A**fter many phone calls, I was finally able to get an update on exactly where things are at for the possible GH study. It is not as promising however as I had hoped. Apparently Dr. David Allen, the pediatric Endocrinologist is having difficulty getting a pharmaceutical company to fund the study. As you recall, the doctors wanted to do a 5 year study and would not consider anything less than 2 years. They have not given up. They are still trying. At this time, however I am not sure if or when this might occur. Keep your fingers crossed. This would be a great opportunity for our children.

## SPRING FUND RAISER

**A**s of October 1, 1994 the total funds raised in our Spring Mail-a-thon Fund Raiser are \$2087. This amount does not include those who participated in a matching funds program. This event was truly a success. Once again, we are printing the following list so that members can personally thank these contributors for their generous donation. We have started to use these funds to support our recent workshop as well as purchasing current books and pamphlets about PWS.

## THANKS TO THE FOLLOWING CONTRIBUTORS:

Donald & Rosalind Rahn	Bonnie & John Kraft
Kevin & Linda Mulcrone	Duane & Emma Spice
Willi & Gudrun Sindermann	Mary & Orville Endres
Bonnie & Tom Jones	Jane Majcherek
William & Deborah LaLor	Marcella Gross
School Sisters of Notre Dame	Carol Graham
Delmar & Lois Schmidt	Jean Burke
Ruth Helmig & Barb Williams	Rosalie LaBella
Modern Solutions/Jeff & Renee Cardarella	

## ELECTIONS

**F**or those of you who are paid members of P.W.S.A. of WI., Inc, you have a ballot enclosed for you to help select officers for 1994 - 1996. They will serve a 2 year term and will give up this term in November of 1996. Feel free to insert a write in. Please return it to the state office or in person to our November meeting. The following is a list of candidates.

PRESIDENT: Mike Larson (Appleton) Mike is the parent of 2 year old Alex with PWS.

VICE-PRESIDENT: Pat LaBella (Madison) Pat is the parent of 14 year old Beth with PWS. This will be Pat's second term in this position.

TREASURER: Tom Scheidegger (Sun Prairie) Tom is the parent of 8 year old Katie with PWS. This will be Tom's second term in this position.

SECRETARY: Barb Dorn/Bonnie Jones Barb is the parent of 9 year old Tony with PWS. She is past president PWSA of WI., Inc. Bonnie is the parent of 13 year old Kelly with PWS. This will be Bonnie's second term in this position.

## HIGHLIGHTS FROM 1994 NATIONAL PWSA CONFERENCE

by Mary Lynn Larson

**T**he biggest news from the 1994 National PWS Conference was the unveiling of the new National logo. It represents optimism and hope for the future. It encourages our making a move toward a more professional and business-like attitude both with the National organization and our state chapters.

Other highlights included Dr. Merlin Butler providing an overview of the latest techniques to diagnose genetic disorders and to locate genetic markers on the chromosomes. Dr. Kari Storhaug presented a talk on the oral health problems in individuals with PWS that she has encountered in her practice in Oslo, Norway. She wonders if orthodontic treatment should begin at an earlier age in children with Prader-Willi Syndrome.

The sessions on Friday separated us into groups based upon the age of our child. The topics they focused on included medical, nutrition, psychological/behavior, legal/education, education/work/transition, social security/estate planning, living alternatives, and employment. This was also an opportunity to talk with parents of other children with PWS to see if they were experiencing many of the things we were going through.

## NEW & OLD ITEMS AVAILABLE FOR SALE

**T**he following is a list of new and old items available for sale through the state office. Some items we may only have a few copies of so if the demand is great, I will order more and get them to you as soon as possible. We also have some items that we have many copies of so we have lowered the price on these items in order for more people to obtain them. We also don't want to have large volumes of these items on hand when new, more updated materials become available. If you can wait until our meeting to purchase them, please do. I will bring copies along and this will save on postage.

PAMPHLETS (All pamphlets 1-20 \$0.25/each, 21 or more \$0.20/each)

My Child has PWS Now What?

Education for Parents  
 Medical Alert  
 What Educators Should Know  
 Behavior & Weight Mngment  
 Late Teens & Young Adults  
 Shelly  
 Guide For Employers & Supervisors  
 Someone You Know Has PWS  
 Speech & Language

**BOOKS/BOOKLETS**

Management of PWS, Greenswag, Alexander	\$32.00
Directions (Handbook for birth - 5yrs)	\$ 5.00
Sometimes I'm Mad Sometimes I'm Glad	\$ 4.00
PW & You - Feelings	\$ 4.00
Development of Placement for PWS	\$10.00
Overview of PWS, Mitchel	** \$ 2.00
Directory of Services for PWS	** \$ 3.00
PWS: Residential Options in West Canada	* \$ 8.00
PWS Home, School and Community	* \$26.00
PT Intervention for Individuals with PWS	
	\$ 5.00-(member) \$6.00- (non)
Children with PWS:Info for School Staff	
	* \$ 5.00 (member)\$6.00 (non)

\* DENOTES NEW PUBLICATIONS

\*\*price lowered

**PACKETS**

Behavior packet	
(a few articles addressing topic)	\$1.00
Diet & Weight Management	\$3.00
Residential	\$3.00

**OTHER**

We have FREE copies available of the new publication, *The Forum*, a newsletter linking people to people and people to information. Copies will be available at our next meeting as well.

**LOGO** (continued from page 1)

The sun exudes warmth and depicts new days and also the concept of one day at a time. The spikes show breakthroughs and, therefore, hope, progress, reaching out, the future, and optimism. The colors (orange and gold in the full-color logo) are warm and cheerful.

Finally, we have used at the base of the triangle a line depicting an uneven horizon to symbolize the ups and downs of dealing with individuals with Prader-Willi syndrome. But remember this: the sun is rising, representing the uplifting thoughts of the new day, of promise and hope."

Provisions have been made for the state chapters to incorporate the new logo into logos for each chapter to use. Look forward to seeing a new look for PWSA of WI also.

**A Special Note:**

The United Way drive is now underway. Even though PWSA of WI does not get funding through the United Way you can still contribute to PWSA of WI through payroll deduction and the United Way. On your enrollment form there will be an area for directed contribution. If you fill this out designating Prader-Willi Syndrome Association of WI and the address. The United Way will direct your contribution to PWSA of WI. However, the United Way does take a small percentage for paperwork and administration fees. So if you have a problem with this it is still best to direct your donations directly to PWSA. But the convenience of payroll deduction is a definite advantage. If you have any questions regarding this your United Way chairperson should be able to help you.

A SPECIAL THANKS TO MIKE AND MARY LYNN LARSON FOR HELPING LAYOUT THIS NEWSLETTER