



THE WISCONSIN CONNECTION

*The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.
Supporting, Educating and Advocating for Persons with Prader-Willi Syndrome and All who
are Impacted by this Disorder*

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

A Message from the President: Barb Dorn

Passing the Torch - Again

Once again, I will be passing the torch of leadership for PWSA of WI, Inc. It is a torch I have passed before ... and received back again. I always feel fresh new blood is good – new ideas, new energy, and new views on how to best meet the needs of our diverse membership. Our new president, Mike Larson, has also carried this torch before. This upcoming year, I think you will be so glad you have a person like Mike as your leader. He is very dedicated, a hard worker and puts his heart and soul into making the world a better place for people with PWS as well as those who support them. Mike and his wife, Mary Lynn have two (**yes two**) children with PWS – one by birth; one by adoption. Mary Lynn also serves as our program director. Don't worry, the Board of Directors has taken steps to make sure Mike and Mary Lynn will remain married and Mike won't get to boss his wife around (any more than he usually does). This couple will do a dynamic job working to meet the needs of our organization.

2008 PWSA of WI, Inc Board of Directors' Election Results

- **Mike Larson – President**
- **Melissa Sirovina – Secretary**
- **Al Luening – Board Member**

This next year, our organization has taken on an extra challenge. By now, I hope you are aware that PWSA of WI, Inc will be co-hosting the national PWSA conference. It is quite an adventure. I am proud to say that we have a great group of people who are working very hard at organizing and executing it. This is an event that takes many devoted unselfish people. I am so proud to work with each and every one of them.

This newsletter is devoted to informing you about the 2008 PWSA (USA) conference. I hope you can find some way to become involved. In the past year, I have gotten to meet people I don't believe I would have met had we not done this conference. Our little Addison, the child in the cow suit, is our poster child. Her mother, Bobbi (and her husband) and her employer have donated the use of her image and printing services so we can help to spread the word. Please find a way for you to become involved. If you cannot attend, but want to support our efforts – check out our wish list area. I am sure you can find some way – big or small to become a part of this statewide effort.

In closing, I want to thank you for allowing me to serve as your president. I will continue to remain involved and devoted to this organization and I was honored you put your confidence in my leadership abilities. Join us as we "Moo-ve Forward" not only in 2008 but in the many years to come. Take care, **Barb**

Background Information About PWSA (USA) Annual Conferences

Annually, PWSA (USA) sponsors a multidisciplinary conference which in reality is 4 conferences or meetings rolled in to one. 2008 will be their 30th annual conference. The conference includes:

- A 1-day scientific meeting for researchers, physicians and other professionals.
- A 1-2 day conference for residential providers;
- A 1-day meeting for chapter presidents and representatives;
- A 2 day conference for parents, care givers and others who support persons with PWS.

On the odd years, PWSA (USA) staff and volunteers coordinate and organize all aspects of conference. They provide child-adult care services to siblings and persons with PWS of all ages - YIP (Young Infant Program) and YAP (Youth and Adult Program).

On the even years, PWSA (USA) collaborates with a state chapter or group in hosting the conference and work together in coordinating and organizing this conference. In order to help limit the demands on the hosting chapter/group, child care is limited to care of children and siblings 5 years and younger, (YIP). During this collaborative conference, the decision to provide additional child care services for older children and/or adults is up to the discretion of that chapter or group. If the chapter or group decides to provide these additional services, they have total responsibility for all aspects of their program (YAP) including financial.

PWSA of WI, Inc wants parents of all children and adults with PWS who reside in the State of Wisconsin to be able to participate in this great educational and support opportunity. In addition, PWSA of WI, Inc will need parents of children and adults of all ages to assist in many volunteer areas that will be needed to execute an event like this. The Board of Directors of PWSA of WI, Inc has agreed to support a child-adult care program (YAP) for children and adults who reside in the State of Wisconsin.

PWSA of WI, Inc. to Host 2008 National PWSA (USA) Conference

"Moo-ving Forward"

SAVE THE DATES!!!

WHEN: July 2—4, 2008

WHERE: The Wyndham Milwaukee Airport Hotel & Convention Center (Formerly Sheraton Four Points), Milwaukee, WI

****PLEASE — DO NOT make your reservations yet. We will have special instructions so that you can receive the lowest rate. We will inform you as soon as this is known!!!**

PWSA of WI, Inc. has joined forces with PWSA (USA) in hosting the 2008 National Conference on Prader-Willi syndrome. It promises to highlight advances in knowledge and research that are taking place in the field of Prader-Willi syndrome. Experts from all over the world will be attending.

The conference, titled "**Moo-ving Forward**" will focus on the progress and hope we are making in creating a better world for children and adults with Prader-Willi syndrome. This is a unique opportunity for professionals, parents and all who are impacted by this disorder to listen and learn from experts.

The conference is really 4 conferences or meetings rolled in to one:

- 1-day Scientific Meeting for Researchers and other Professionals
- 1 ½ day Residential Providers meeting
- 1-day meeting for chapter and other groups
- 2-day General conference

We plan to welcome our visitors to Wisconsin with open arms and hearts.

INFORMATION ABOUT OUR KEYNOTE SPEAKER:

Richard Pimentel



Richard Pimentel

Richard Pimentel is one of the leading experts in the nation on attitude change in education, disability issues on the workplace, disability management, job placement of special needs students, job recruitment and the Americans with Disability Act.

First Impressions Really Do Count! ...And that is why we have asked Richard to be our keynote speaker. He is not only technically proficient; he is also an exceptional communicator whose audiences praise his ability to combine information, humor, metaphor and storytelling. His vast and penetrating knowledge about issues related to

disability and people of difference is communicated with humor and conviction. His opening presentation promises to be enlightening.

This fall, Mr. Pimentel had a motion picture of his life released. "The Music Within" is being debuted nationwide.

Volunteer Needs and Descriptions

Putting on a conference like this takes a lot of work and resources. We want to make it possible for as many families in our state to attend. There is so much to learn – so much to gain for those who attend. In order to make this possible – **we need your help.** The following is a list of possible volunteer opportunities. As we get closer to the event, I am sure this list will grow. We have created a volunteer sign up form that can be downloaded from our website at (www.pwsausa.org/WI) or you can call our toll free number (1-866-797-2947). Review the list – find some way to help.

A-V Assistant – Assist with computer and A-V needs. Experience and knowledge required.

Clerical – Assist with copying, stuffing packets, (Tues July 1st).

Hospitality Suite Assistants – Make sure snacks and beverages

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are stocked in the volunteer suite (Weds., Thurs., and Fri.).

Breakfast Distributor – Assist in distributing boxed breakfasts to YIP & WI-YAP participants (Thurs. & Fri.).

Exhibitor Set Up – Direct and assist vendors to tables (Weds. July 2nd).

Information Table (Newcomer Greeters) – Distribute welcome packets; assist with directions and scheduling of meetings/rooms; answer questions (Tues. evening, Weds., Thurs. and Fri.).

Conference Registration – Assist with check in of providers, physicians, parents and other conference attendees.

Post Conference Thank You Letters – Assist with sending out thank you letters following the conference.

Room Monitors – Introduce speakers, provide assistance to speakers in case of equipment needs or room temperature needs.

Silent Auction Assistant – Work with chairperson in setting up items donated for silent auction; monitor items during their display; collect items following auction closure; receive payments and distribute items purchased.

Volunteer Check-In – Meet and greet all volunteers and direct them where to store personal

items and direct them to their appointed volunteer assignment.

Welcome Reception – Assist with pre-planned activities for families of children and adults with PWS.

YIP and WI-YAP Check-In – Assist with check in of children and adults participating in these programs.

YIP and WI-YAP Program Volunteers – Assist with providing child care/respite services to infants, children, teens and adults with PWS as well as siblings. We ask that you donate 1-day (no partial shifts).

****HOLIDAY ALERT****

As the holidays approach, we want to remind families of the recent unexpected deaths of individuals with PWS over the last several years due to food-binging episodes. In many cases, the person with PWS was slim and had no weight concerns. Remember that someone with PWS who has good weight control does not mean they have **total food control**. When a person eats, the stomach stretches. It may become "over stretched" or distended when one overeats. We know that persons with PWS do not have the normal mechanism of registering fullness as they eat. They are at a very high risk of over distending their stomachs.

Many of these individuals were at holiday festivities in large groups with many people "watching". It is believed that the person with PWS over distended their stomach, and stretched it to the point that it cut off its blood supply causing necrosis (the stomach tissue dies). This resulted in rupturing of the stomach with highly acidic gastric juices leaking into the chest and abdominal cavity. This is a life threatening situation if it is not quickly diagnosed and treated. Unfortunately, most of these cases have resulted in death and been diagnosed in a postmortem examination.

Information about the Wisconsin Youth and Adult Program (WI-YAP)

PWSA of WI, Inc wants parents of all children and adults with PWS who reside in the State of Wisconsin to be able to participate in this great educational and support opportunity. In addition, PWSA of WI, Inc will need parents of children and adults of all ages to assist in many volunteer areas that will be needed to execute an event like this. The Board of Directors of PWSA of WI, Inc has agreed to support a child-adult care program (YAP) for children and adults who reside in the State of Wisconsin. Young Infant Program (YIP) is also a part of conference programming. This service is available to all who attend who have infants and children 5 years old and younger.

Overall Objectives of the Wisconsin YAP Program is to:

Provide age appropriate care and supervision of children (6 years and older) and adults with PWS, along with their siblings so that parents can confidently attend the 2008 PWSA (USA) conference and assist with the volunteer needs that this conference will require.

Address the unique nutritional, health and behavioral needs that children and adults with PWS require.

Provide fun-filled, positive, social opportunities and experiences for all who participate in the program.

Criteria:

Child/adult must reside in the State of Wisconsin.

Parents of participants must be a member of PWSA of WI, Inc. If needed, a membership scholarship can be provided.

At least one parent must volunteer a minimum of 2 hours during the course of the 4-day conference event.

Considerations:

All participants must complete an application form so that all health, nutritional and behavioral needs can be assessed and accommodated if indicated.

All medications and/or special treatments **must** be administered/performed by the parent.

Due to limited space and volunteers, a limit of 25 participants will be allowed in to the program. Priority will be given to children of volunteers who are serving in leadership positions (chairpersons, committee chairs etc).

The conference chairperson and WI-YAP chairperson will evaluate participants who have extreme challenges in the area of health and/or behavior. They will determine if the volunteers in the WI-YAP program can safely meet the individual's needs.

If a participant in the program demonstrates extreme challenges and the conference chairperson and WI-YAP chairperson feel volunteers can no longer maintain a safe environment, the parent will be contacted to come and pick up the individual.

Cost:

Every attempt will be made to keep the cost for this service low; outside grants and/or donations will be solicited to assist with this.

A final daily fee will be determined by the spring of 2008.

Separate payment for this program will be made to PWSA of WI, Inc.

Fees for conference chairs and committee chairs will be minimized and/or waived if possible.

OUR WISH LIST

The following is the start of our wish list.

If you are able to help out with a donation, it will help us keep costs down. I am sure this list will grow as we continue to learn what our needs will be. We are "Udderly Grateful" to all of you.

Gift Cards (so we can purchase the needed items)

- Office Max/Office Depot - (paper, office supplies) We will need lots of copy paper and a variety of office supplies.
- Shopko/K-Mart/Walmart - (various supplies for YIP and WI- YAP).
- Sam's Club/Costco/Grocery store - (Snacks, food items and beverages for our volunteers).

Items for YIP Program

- Baby and Toddler DVD's
- Baby CD's
- Books - for both infants and toddlers
- Boom Box w/ CD player
- Riding toys
- Dolls
- Portable baby swing

Items for our Volunteer Area (We will have a suite where volunteers can take a break).

- Bottled water
- Bottled Ice tea
- Soda - diet and regular
- Snack bags

- Coffee
- Creamer, sugar packets

Please check our website

www.pwsausausa.org/WI for further updates on our wish list. We are so grateful for your support.

Notes from the Office....

By Mary Lynn Larson

Greetings!! Have you decided what tasks you might be able to do to help us put on the **BEST** National Conference ever in July 2008?? We are **really** in need of volunteers to help with just about everything! We have a great group of core volunteers on the Conference committee – but we will need a lot of help! We know that many people might have plans for the Fourth of July weekend and may not be available— but if you are not able to assist with the conference itself, we have a lot of things that need to be done before, during and after! It might be something like putting out a mailing, helping with sewing the fleece blankets together before Hobby Day, or picking up some copy paper! If you are unable to find time to do specific tasks, we have a large "Wish list" that you might want to consider making a donation of some of the listed items! Or maybe you have a friend or family member who would be willing to share a day of volunteering at some of the tasks or who works at an organization that could assist... There are so many things that need to be done that are not on the list – so if you have an idea, call the office and we can talk about it! The toll free number is 1-866-797-2947 and we can come up with some ideas.

Have a safe and blessed holiday season!

Mary Lynn

HOBBY DAY

A NEW APPROACH IN 2008

We are planning a different approach to Hobby Day this year because of the upcoming Annual Conference that we will be hosting in July 2008. We are hoping that people coming to Hobby Day would be willing to help us out! Here is what we are hoping to do:

THINGS THAT WILL BE DIFFERENT:

We will focus on 2 "helping" hobby events:

- Making Cow-Fleece Baby Blankets
Attendees will help make cow-themed baby blankets that will be given to all infants and little ones with PWS who attend the 2008 conference. This will be a special baby gift from the great people of Wisconsin who have PWS.
- Creating Pictures that will be transformed into greeting cards. Participants will be asked to draw pictures that will be used on greeting cards which will be sold at the 2008 conference. Profits made from these cards will be used to help with the costs incurred in hosting the conference.
- **ALL PARTICIPANTS WILL RECEIVE A THANK YOU GIFT BAG AT THE END OF THE DAY.** We know it may be difficult for some people with PWS to share the items they have made so we will share a thank you gift bag for all of their hard work and generosity.

THINGS THAT WILL BE THE SAME:

- Low calorie snacks and lunch will be served.
- DJ will provide music for the afternoon dance.
- It will be a time to see old friends and make new ones.
- It will be the same great fun time like we always have.
- We will have a separate program for kids under 9 years of age.
- Parents will have a separate time to help with planning for the 2008 conference.

The exact location, time and details will be shared at a later time.

... Stay tuned for more updates.

Membership Renewal

You will be receiving a mailing soon to renew your annual membership with PWSA of WI, Inc. Please don't forget to send it in so you continue receiving our newsletter and keep updated on the latest news about Hobby Day, the upcoming conference and so much more!

PWSA of WI, Inc.'s Event Calendar

January 26, 2008	Conference Planning meeting	Location and time to be determined
Date to be determined	Hobby Day 2008	Location to be determined
July 2-4, 2008	30th PWSA (USA) Conference	Wyndham Milwaukee Airport Hotel & Convention Center

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