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# 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*

**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 challenges of this disability.**

## A Letter From Our President

Happy New Year!!

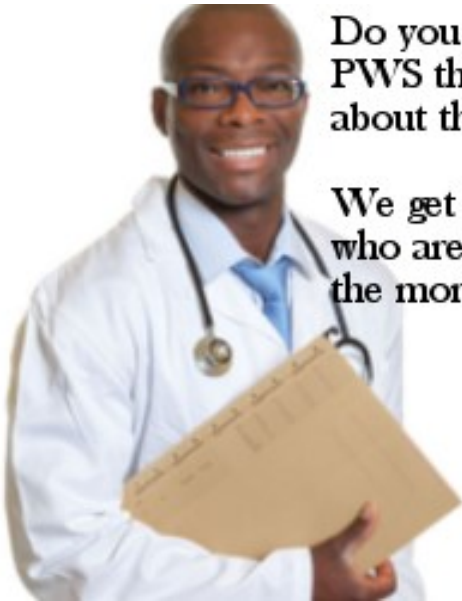
2015 was an extremely busy year for PWSA-WI, Inc. We held our 4th Annual Snowflake Ball, 5th Annual On The Move walk-a-thon, 15th Annual Golf Benefit and 1st Annual Strike Out PWS bowling event. In addition, our program director and I attended the 33rd Annual Prader-Willi Syndrome Association (USA) National Conference in Orlando, Florida.

For those of you who have never had the opportunity of attending a conference, it is a time when parents, providers, chapter leaders, educators and experts can share new information about PWS and learn from each other. During my first two days of conference, I had the pleasure of meeting with representatives from PWSA (USA), the Prader-Willi Syndrome Association of Australia Inc. and chapter leaders from around the United States. Many of the chapter leaders in attendance had been involved with their state chapter for several years and others were just beginning their journey as a chapter leader. Throughout the first day, we discussed topics such as research, bereavement, the studies of death, law enforcement, legislation, and advocacy. In addition, we learned about the new transition resource released this past fall by PWSA (USA). The topics we covered were very interesting and I believe the information our program director and I brought back will be beneficial to the members of PWSA-WI, Inc.

Throughout the second day, we discussed topics such as chapter operations, local and national fundraising, the new PWSA (USA) website, and the rejuvenated parent mentor program. We were all given the opportunity to share our experiences as chapter leaders and, as a group, we brainstormed new ideas to help the members in each of our chapters. In addition, chapter leaders shared ideas about existing events that were successful in their chapters so other chapter leaders didn't need to "recreate the wheel". For example, many chapter leaders were interested in learning more about the Snowflake Ball so our program director and I were able to share the information so they could hold a similar event in their chapters. At the end of the meeting, I left with the feeling that we were all working together toward one common goal, which was to continue to positively impact the PWS community as a whole throughout the country.

Our program director and I also had the opportunity to meet with several Wisconsin families during the welcome reception. Although we had met a few of the families prior to the conference, we were able to meet others we did not know previously and we were able to get to know everyone better. I was so happy we, as an organization, were able to help send a few families to the conference and I want to thank everyone who donated to PWSA-WI, Inc. throughout the year as you are the reason we were able to help these families attend the conference!!

As the new year begins I want to take a moment to tell you all how thankful I am to be part of our incredible PWS family. Together we have spread awareness about this rare syndrome, raised much needed funds for research and support, and continued to improve the lives of individuals of PWS and their families. Together the sky is the limit and I look forward to seeing what we can all accomplish in 2016!!



**Do you have a caregiver that knows PWS that you love? Let us know about them!**

**We get contacted often by families who are looking for suggestions and the more we know about the better.**



**Prader-Willi Syndrome Association of WI Is proud to welcome Dr. Ann Scheimann, MD, MBA.**

Dr. Scheimann will be in Milwaukee at Children's Hospital to give her presentation "Best Practices In GI Issues in Persons with Prader-Willi Syndrome" to local physicians and we have set up an opportunity for parents and caregivers to receive some of the same information as well as ask her questions. We will be providing free child care to hopefully accommodate anyone interested in attending.

### **Save the Date!**

**Friday April 29th**

**10-11:30 am**

**Cost for parents will be \$10 and \$15 for providers. (Scholarships are available)**

**Registration will be mailed out soon and also will be available on our website.**

Dr. Ann Scheimann MD received her doctorate of medicine at the University of Cincinnati, School of Medicine and completed her pediatric residency and pediatric gastroenterology and nutrition fellowship at Baylor College of Medicine/Texas Children's Hospital. She was full time faculty within the Division of Pediatric Gastroenterology and Nutrition at Baylor College of Medicine until 2000 when she moved to join the full time faculty within the Department of Pediatrics/Division of Pediatric Gastroenterology at Johns Hopkins School of Medicine but remained adjunct faculty at Baylor College of Medicine directing the Prader-Willi Syndrome Clinic at Texas Children's Hospital. Dr. Scheimann completed a Masters in Health Sciences Management at Johns Hopkins School of Business in 2005. Dr. Scheimann's focus of research interest has been in nutrition and obesity with special areas of interest in Prader-Willi syndrome and nonalcoholic fatty liver disease. She has authored or co-authored to date approximately 50 peer-reviewed publications, in addition to book chapters and meeting presentations.



## Notes from the Office

2015 was an incredibly eventful year for me here at PWSA of WI. It marked my first experiences with our Snowflake Ball and the On the Move Walkathon. I celebrated my first anniversary as Program Director with the organization and have enjoyed every minute of it. I have seen a little bit of everything this year from visiting schools to help the staff better understand how to serve a student to making contact with hospitals to disseminate information so their doctors and nurses are able to perform their duties with respect to individuals with Prader-Willi. Our events allowed me to see so many of the smiling faces that are really what this organization is all about. The On the Move Walkathon alone brought out 351 people all to spread the word about what Prader-Willi Syndrome is and who we are.

One of the greatest experiences I had this year occurred in November when I had the opportunity to attend the PWSA USA national conference in Florida. I truly got to be inspired by individuals affected by this disease from all across the globe. As someone who has no historical connection to PWS prior to employment with PWSA of WI I often feel like I am on the outside looking in when it comes to understanding all the challenges that the disease can present. Being at this conference I was able to participate in numerous presentations and discussions where I got to hear many different points of view from folks with many different experiences and ideas having to do with PWS.

Of all the amazing things I experienced in Florida, the most genuinely uplifting was having the chance to meet some of the great families we have right here in Wisconsin. Hearing what they go through on a daily basis and seeing the determination to provide an amazing life for their children really drove home to me that I am doing exactly what I should be with my career.

I am looking forward to everything 2016 holds. I hope that each of our events is even bigger than it was last year. Our numbers for the Snowflake ball are already well over where they were last year and I am currently still getting rsvp's! Please always remember that when something challenging comes up, I am here. Heck, if something awesome happens, call me then too! I love hearing about everyone's successes because ultimately those are the things that keep us going.

Please be aware that I will be moving this spring so that means the office will as well. The organization has purchased a PO Box so that the address will remain consistent from here on out. That address is PO Box 324 Menasha, WI 54952. Happy 2016!



I would like to thank PWSA-Wisconsin for the generous scholarship so Cade and I could attend the PWSA-USA Conference. This experience was the most amazing experience I have had at a conference. I have attended numerous conference for work, but never as a parent before. Attending as a parent was a whirlwind of an experience. I had so many emotions running through me. Traveling with a 10 month old baby by myself, was a bit stressful.

Even though I was stressed I was beyond excited to get down to Florida! We made it to the conference with the help of a lovely family I had met through the Facebook group PWSA Birth to 3. I was so excited to be meeting families, whom I have talked with for several months, yet have never seen in person, and I was nervous doing this by myself.

Despite being with Cade by myself and having to pump every 4-6 hours I did not miss much of the conference. There were so many great speakers for all different age groups. I was amazed at the amount of information I left with. Most of the sessions I went to pertained to the 0-3 year age range but no matter the session I attended I walked away feeling happy and amazed at the information I took in.

The number of parents I met amazed me! I have so many words that I could use to describe them but the one that wraps it up in one word is family. The lovely mom's I met have become my best friends. We talk over Facebook every day. We are each others' supports. I am so thankful for each of them.

Last, but not least the professionals! I cannot say how proud I am to have these professionals fighting in Cade's corner. They treated us like family. They are the most friendly and down to earth professionals I have ever worked with, let alone seen. One of those professionals Dr. Jennifer Miller, who just happens to be Cade's Endocrinologist, was able to see his progress and how well he is doing. I have never seen so much love from a doctor. Listening to her talk about the high hopes she has for all her children with PWS, is so heartwarming. to know that her and others in the field are working hard on research to find a cure, and at the very least make our children's life manageable and positive!

If I have the opportunity to attend another conference in the future I will. It is the most loved I have felt for Cade and I, as well as, the amount of information I have received will be extremely beneficial to Cade and others I have been able to share it with. I can not say enough about this amazing experience, please go if you ever have the opportunity!

Katie-Mom of Cade



**Do you know someone with Prader-Willi who no longer has family to provide them with gifts on their birthday or Christmas?**

**PWSA of WI has a gift giving program for these folks! Please contact us for more information so we can make their day.**



# Thank you to all of our donors and supporters of 2015!

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**Growing Old with Prader-Willi Syndrome:  
Health and Safety Issues and Concerns**

We continue to learn more about health and safety issues that affect adults with Prader-Willi syndrome (PWS) as they age. Most issues are not unique to persons with PWS, however we are seeing them occur at an earlier age than the nondisabled population. Topics covered will include:

1. Slow Gastric Emptying and Constipation,
2. Urinary Incontinence,
3. Low Bone Density - Osteoporosis
4. Mobility Challenges and Fall Prevention.

An overview of these topics will be presented along with measures to prevent, minimize and/or manage them will be shared.

**Target Audience:** Direct care givers, case managers and anyone who cares for the adult with Prader-Willi syndrome

**When:** Friday April 1<sup>st</sup>, 2016

**Time:** 10:30 – 12 noon

**Location:** Waisman Center Outreach Program  
122 E. Olin Ave, Madison, WI

**To Register:** Go to: <http://cow.waisman.wisc.edu/traincon.html>

**Registration Fee:** \$12 for Dane Co. DD Service Providers/\$24 any other

**Objectives:** Attendees will be able to:

- Share what researchers are learning about aging and persons with PWS.
- Describe normal aging issues for the following health concerns:
  - Gastrointestinal system
  - Urinary Tract system
  - Bone Density
- Identify aging issues and safety concerns for the adult with PWS
- Describe preventative and treatment strategies that can be utilized in supporting the aging adult with PWS

**Barb Dorn, RN, BSN:** Barb is a Registered Nurse who recently retired from the University of WI Hospital and Clinics - University Station Internal Medicine Clinic in Madison, WI. She has over 37 years of experience as a nurse. Over the past 24 years, Barb has served as the past president of PWSA of WI, Inc. and PWSA (USA). She has extensive experience as a consultant, advocate, educator and counselor for persons with PWS. She currently serves as a Consultant and Training Coordinator for PWSA of WI, Inc. She has created and contributed many articles and handouts on the care and management of persons with PWS especially in the areas of health and education. She has been a speaker at many conferences on topics supporting the person with PWS. Barb Dorn is the parent of two sons, Tyler age 28 and Tony age 30 who has PWS.



Hoodies, t-shirts, and coozies can be purchased from our webstore by visiting <http://tiny.cc/PWSAWIstore>

A collage of four items available for purchase: a grey hoodie with a red Wisconsin map, a blue PWSA Wisconsin coozie with a sun logo, a black t-shirt with a Wisconsin map made of text, and a grey hoodie with a white Wisconsin map.

## **PWSA of WI offers many services to support the Prader-Willi community in Wisconsin.**

**We provide an advocate who can visit schools for the purpose of attending IEP meetings, consulting on behavior management, and educating staff on the nuances of PWS.**

**Our phone line is available to provide support, information, and a caring ear in crisis situations as well as those times when people just need someone to listen.**

**We provide scholarships for summer camps, conferences, family needs such as school supplies and clothing, and various other things we feel may benefit an individual with PWS or their family that they might not be able to afford on their own.**

**We create and distribute many publications and informational materials. These include but are not limited to: medical alert booklets, educator informational DVD's, and our quarterly newsletter.**

# **Caring Is Sharing**

Without the support of people like you PWSA of WI couldn't exist to provide services and support to the PWS community here in Wisconsin. Our Caring is Sharing fundraising drive has just begun and you can donate today. It is easy, just send a check made out to PWSA of WI, Inc to Po Box 324 Menasha, WI 54952 or you can head to our website where you can make an online donation at this address: [pwsaofwi.org/cis](http://pwsaofwi.org/cis)



## PWSA of WI, Inc.'s Event Calendar

January 30th, 2016	PWSA of WI, Inc. Winter Ball	Turner Hall, Watertown
April 29th, 2016	Dr. Ann Scheimann GI presentation	Children's Hospital, Milwaukee
May 7th, 2016	On the Move Walkathon	Roosevelt Park, Ocono- mowoc
August 20th, 2016	16th Annual Golf Benefit	Windwood of Water- town
September 17th, 2016	2nd Annual Strike Out PWS Bowling Event	Bowlaero, Wauwatosa



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