



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.

Our cover letter this quarter comes to us from Alex Larson. Alex is 22 and graduated from high school in 2011 and then proceeded onto the Project Search program which he graduated from in 2014. We asked him to share what he has been up to now that he is done with school.



*Since I finished high school and graduated from Project Search, I started volunteering at the hospital by entering patient surveys for the Quality Management Department for couple months. I continued meeting with Matt Busch, my Job Finder Specialist from Valley Packaging Inc. and Megan Banik from the Department of Vocational

Rehabilitation. I did a job assessment at Aramark Uniform Services as the Hanger Cady Recycling Specialist. Then I found out that the job I was hoping to get at Aramark was just a temporary job placement and they were not ready to hire a permanent employee for that position.

Many of the staff of Project Search and Valley Packaging, Inc. saw that I was a really hard worker and thought I would do great at Valley Packaging. I started working at Valley Packaging as their Clean Room Sanitation Coordinator. I enjoy working at Valley Packaging, but I have had some ups and downs while working there. They brought in a job coach to help me and we are working out the bumps in the road together. I want to continue to work to earn money to go to college for theatre. I am hoping to find some support networks for the future.*

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Educating Health Care Professionals – A Special Thanks to You By Barb Dorn RN



Over the years, PWSA of Wisconsin has sponsored many initiatives to help educate health care professionals. Physicians have presented at Grand Rounds at hospitals in Madison, Waukesha and Oconomowoc. Conferences have taken place to help educate parents, guardians and caretakers on health issues so that they can help to inform and educate professionals on the unique health issues that many persons with PWS can face. Health Education packets were compiled and information disseminated. I have to say, educating my medical colleagues can be a very challenging process. Physicians, Nurse Practitioners, Physician

Assistants as well as other health care providers have limited time to devote to formal education. The demands of their clinical practice often limits their ability to be away from their patients to attend a day-long conference. However, many do take time to attend “Grand Rounds” typically a 1-hour educational meeting that focuses on one health issue, disease or topic. We have been working with the Medical College of Wisconsin in Milwaukee to welcome Dr. Ann Scheimann MD, MBA, a pediatric gastroenterologist from Johns Hopkins School of Medicine, Baltimore, Maryland who also serves as adjunct faculty at Baylor College of Medicine directing the Prader-Willi Syndrome Clinic at Texas Children’s Hospital. Dr. Scheimann’s focus of research and interest has been in nutrition and obesity with special areas of interest in PWS and nonalcoholic fatty liver disease. In addition, she serves on both the PWSA (USA) Scientific and Clinical Advisory Boards. She has been very devoted to helping professionals as well as parents gain a better understanding of gastrointestinal problems often seen in persons with PWS.

The date and time for Dr. Scheimann’s Grand Rounds presentation was in the process of being finalized when a conflict occurred. We are now working on rescheduling. PWSA of WI, Inc. will be providing all of the financial support for this great educational opportunity. We wanted to let you know that PWSA of WI, Inc. remains committed to advancing the knowledge and understanding of all health care providers who care for adults and children with PWS. This is just one example of how we are using your generous donations to improve the lives of persons with PWS. Thank you for helping us make opportunities like this possible.

Did you know PWSA of WI has a card club for individuals with PWS?!



Contact our program
director at
progdir@pwsaofwi.org
to have birthday cards
and seasonal cards
sent to your loved one
with PWS!

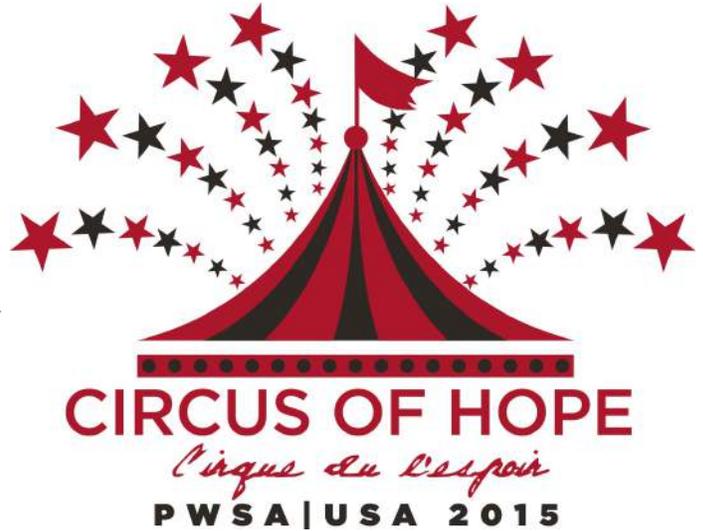
With the 2015 PWSA USA National conference fast approaching we asked our president Crystal Boser to share her personal experience of her first time at the national conference.

*My son, Kyle, was diagnosed with Prader-Willi Syndrome when he was 4 years old and just a month later I attended my first PWSA (USA) national conference. It was life changing because I met several other families who had children with PWS and

were facing the same challenges I was. In addition, I learned about groundbreaking research with regard to growth hormone and I learned about a variety of therapeutic approaches I could consider for Kyle. Nine years later, I had the pleasure of participating in the 2008 conference when PWSA-WI, Inc. hosted the national conference right here in Wisconsin. Not only did I reconnect with families I met at my first conference in 1999, but I also met several new families who I still keep in touch with today. If you haven't had a chance to attend a PWSA (USA) national conference, I highly recommend you do so.

November 4-7th, PWSA (USA) will be celebrating its 40th year as the largest support, research and advocacy organization for people and families with Prader-Willi syndrome in the United States. During this year's conference, families will have the opportunity to learn about a variety of topics such as: Special Education Advocacy; Transition Planning; Growth Hormone and Other Medical Considerations for Infants & Children; Aging & Behavior; Basics of Speech, Language and Oral Motor Skill Development; Therapeutic Interventions; Parenting Success with Less Stress. Families can attend the topics that are of interest and appropriate for their specific children and they can meet other families who have similar experiences. It can be a life changing experience for those who have never attended and it can be a rejuvenating experience for those of us who have attended before.

If you are interested in learning more about the 33rd PWSA (USA) National Conference, please visit <http://www.pwsausa.org/conference>. In addition, if you are in need of financial assistance, please contact Joshua Escher to find out more about the scholarships that are available. *



Call for Nominations for PWSA of WI, Inc. Officers and Board Members

PWSA of WI, Inc. has four board positions whose terms are coming to an end. Those positions are President, Secretary, and two other board positions.

The PRESIDENT is the principal officer of the organization and presides at meetings of the organization's membership. This officer communicates to the association such matters and makes such suggestions that may in his/her opinion to promote the welfare and increase the usefulness of the association, and shall perform such other duties as are necessary incident to the office of president. The president serves as a member of the Chapter Advisory Board for the National Prader-Willi Syndrome Association.

The SECRETARY has the responsibility to give notices, to keep a record of proceedings (minutes), to attest documents and perform such other duties as are usual for such an official as may be duly assigned.

The BOARD MEMBER serves as advisor in providing governance to the organization. He/she will assist in projects, committees, and other capacities as needed.

If you are interested in applying for one of these positions please contact the office either by phone (1-866-797-2947) or email (progdir@pwsaofwi.org).

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

PWSA of WI, Inc. is also searching for a volunteer accountant. Please contact the office if you would be interested in volunteering your time in this role!



on the MOVE

PRADER-WILLI SYNDROME ASSOCIATION (USA)

Our 2015 On the Move Walkathon was a huge success! On May 9th 351 walkers converged on Roosevelt Park in Oconomowoc, WI to raise awareness for Prader-Willi Syndrome here in Wisconsin. This was our largest turnout ever! We hope next year the event will be even bigger!

We would like to thank all of our corporate sponsors for their support of this years walk.



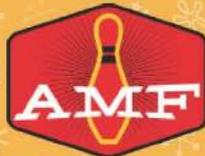
PMS 268
C: 91 M: 94 Y: 0 K: 23.5
R: 79 G: 38 B: 131

STRIKE OUT PWS

A FUNDRAISER TO BENEFIT THE PRADER-WILLI SYNDROME ASSOCIATION OF WI, INC.

JOIN US SATURDAY,

OCTOBER 17, 2015



Bowlero Lanes

REGISTRATION:
1:00-1:30 PM
BOWLING:
1:30-3:30 PM

11737 WEST BURLEIGH • WAUWATOSA, WI 53222

**REGISTER
YOUR
TEAM
TODAY!**

REGISTER TODAY ONLINE AT PWSAOFWI.ORG OR BY MAIL

\$20 PER PERSON ENTRY FEE INCLUDES 2 HOURS OF BOWLING AND SHOE RENTAL

PRIZES FOR THE TOP 3 BOWLERS! • SILENT AUCTION AND A 50/50 RAFFLE

BOWLERS WHO COLLECT OVER \$100 IN PLEDGES WILL BE ENTERED

INTO A RAFFLE TO WIN A FIT BIT CHARGE ACTIVITY WRISTBAND !!!

Can't attend, but wish to donate to help PWSA-WI?

Please see pwsaofwi.org to learn how you can sponsor a lane, donate to the silent auction or make a cash donation.



**Prader-Willi Syndrome
Association of WI, Inc.
15th Annual Golf Benefit**



PWSA of WI
Annual Golf Benefit
SUPPORT · EDUCATE · ADVOCATE

Saturday, August 22nd, 2015

Windwood of Watertown Golf Course



Our 15th Annual Golf Benefit is fast approaching. Don't waste any time getting your team registered. You don't want to miss this amazingly fun event. Every golfer gets some sort of door prize and the course is full of challenges and opportunities to win things like our 50/50 putting raffle and a heavy duty Milwaukee radio. We also have a silent auction with items like Disney park tickets, a Pepsi golf bag, jewelry, a signed Dean Koontz book, and much more! After golfing the fun isn't over because we also provide a luncheon where we will keep the good times rolling.

To get registered for our outing you can head to our website to download a brochure or register online at tiny.cc/2015golf. Golfing costs \$90 per person and if you would like to just attend the luncheon and auction you can do so for just \$30.



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.



PWSA of WI, Inc.'s Event Calendar

August 22, 2015	PWSA of WI, Inc. 15th Annual Golf Benefit	Windwood of Watertown Watertown, WI
October 17, 2015	Strike Out PWS Bowling Event	AMF Bowlero Lanes, Wauwatosa, WI
January, 2016	PWSA of WI, Inc. Winter Ball	



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