



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.

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Hello there and welcome to 2017! It sure has been a strange and eventful start to the year weather wise here in Wisconsin. I myself am torn on the impending spring. On the one hand I am quite enjoying the bright natural sunlight shining in my office window here at PWSA of WI central (aka, my house) but the warm weather will bring leaves on the lovely trees that completely block the sun's rays! It is a real catch 22.

On the bright (see what I did there) side I have been getting to make more trips out of the office as of late to provide support for individuals in our PWS community. To go off on a side tangent, when I tell people what I do for my job I often explain that I have mixed feelings about making these forays outside. On one hand, if I need to make a trip to a place like a school, there is a good chance that someone with PWS out there is struggling and that is disheartening to hear. The more I make these trips, though, the more I realize that I am so glad that our organization exists and that the family, school, or both knew that we existed and reached out for our help. The word is getting out and we are being used as a resource more and more.

I have had the great privilege recently to be involved in assisting a number of different schools in their quest to better serve their students with PWS. It has been awesome to work with these groups of educators, administrators, and parents to help optimize the educational environment and approach. Situations have been as varied as a 6th grader who struggled with becoming a middle schooler and a 4Ker getting ready to transition into kindergarten. I even got to make a three hour trip to beautiful Northern Wisconsin to give a presentation alongside our Vice President to over twenty people who support a young gentleman in his early 20's.

Every one of these interactions leaves me full of optimism for the future of individuals with PWS here in Wisconsin. I often walk away from these meetings knowing that our folks now have a new advocate for the PWS community, even if they don't realize it.

I am so very much looking forward to the events we have coming up this spring. I think that Janice Agarwal's presentations will provide invaluable information for parents, teachers, and caregivers of individuals with PWS and we are very lucky to have her speaking here in Wisconsin. You don't want to miss it. I also can't wait for our walk-a-thon. I think it will be the biggest one yet!

Here is to a great 2017! Remember, if you need support, I am just a phone call or email away.



is Proud to Welcome

Janice Agarwal PT, CNDT



Janice is a pediatric physical therapist with over 20+ years of experience treating children birth to 3 years of age. She's a graduate of Northeastern University in Boston, MA. Janice was part of the Boston City Hospital neurodevelopmental evaluation team and the St. Mary's Hospital for Children early intervention team in Queens, NY. She received certification in Pediatric (NDT) Neurodevelopmental Training at the Bobath Center in London, England.

She has lectured nationally and internationally on Developmental Interventions and Sensory Integration (SI) for hypotonic children and children and adults with Prader-Willi Syndrome (PWS). Using techniques incorporating SI to normalize development, she now only treats children/adults with PWS. PWSA (USA), published her book *Therapeutic Interventions for Children with Prader-Willi Syndrome* in 2011.

Janice is a former 9 year member of the PWSA (USA) Board of Directors. She is the mother of two boys, Alex age 17 (PWS) and Sam, age 16.

Two Sessions Available:

“Therapeutic Interventions to Help Teens/Adults with PWS Become More Active and Help Decrease Many of Their Anxieties”

All children/adults have deficits in their sensory and motor systems. This presentation is structured to give parents and caregivers tools to identify and treat children/adults with physical and sensory delays. We want our kids/adults to be active in their community. We want them to enjoy going out and having fun. Many of our kids can't because they fear falling, or not being safe in an unknown environment. They fear loud noises or people touching them. They might not like new things. We can help them change this sensory-motor systems so that they can readjust to their environment and relax and be more active. Every participant will leave with a plan that they can use immediately with their children/adults with PWS.

“0-3 Early Intervention for the Infant with PWS. Understanding the Sensory/Motor System and Simple Strategies to Help our Children Develop Normal Milestones.”

Janice will conduct a hands on/how-to workshops on Motor/sensory development for infants/toddlers for parents of children with PWS ages 0-3. She will work with parents and their children to develop an individual plan. They will leave with a basic understanding of infant development and how they can better interact with their therapy team to optimize therapeutic services along with activities they can integrate immediately at home and in the future. Babies/children are welcome (encouraged). This will be part lecture part hands on. This is a fun, relaxed class that encourages questions and hopes to help each family and child.

***Date:* Saturday, April 8th 2017**

Time: 9:00 – 10:30 am **Teen/Adult Session**
11:30 am – 1:00 pm **0-3 Early Intervention Session**

Location: Aurora Medical Center-Summit
36500 Aurora Drive
Oconomowoc, WI 53066

Room: Draper Conference Room

Cost: \$10 parents and family members
\$15 professionals

(Scholarships are available if needed).
Contact Josh Escher at PWSA of WI, Inc.
for further information and assistance.
Phone: 1-920-733-3077

Visit pwsaofwi.org to find more information and to register. Registration deadline is April 1st.

PWSA (USA) Announces Exciting New Research Grant

Every year a portion of the money PWSA of WI raises is donated to PWSA (USA). This money often times can be earmarked towards things that our small state chapter can't possibly fund on our own. One of those things is PWS research. PWSA (USA) has recently announced a grant on "Profiling of the gut microbiome in children with PWS." The purpose of this research is to determine information on microbial composition of individuals with PWS can lead to therapies that may be able to improve metabolism and lower inflammation in children with PWS with obesity.

Profiling of the gut microbiome in children with PWS

Principal Investigator - Andrea M Haqq, MD, MHS, FRCP

University of Alberta, Canada

ABSTRACT

Individuals with a genetic condition called Prader-Willi Syndrome (PWS) are at risk for development of obesity at a young age. Children with PWS often have a very high food intake because they experience a constant feeling of hunger. However, even children with PWS who limit their food intake can still gain excessive amounts of weight. Attempts to control weight in PWS through dietary interventions have had limited success. The human gut contains bacteria that play an important role in food digestion. When the stomach and small intestine are unable to digest certain foods, gut microbes ensure nutrients are digested. Changes in gut microbes may lead to obesity, but the specific role of gut microbes in weight control in PWS and childhood obesity is not yet fully understood.

In this study, they will compare the gut microbial composition of infants and children with PWS to individuals of similar age, sex and body weight who do not have PWS. PWS infants and children and controls (ages 0-17 years) will be recruited. A stool sample will be collected during one study visit at the University of Alberta. They will assess the microbiome at different stages of development to assess whether temporal changes in the microbiome are associated with temporal change in food seeking behavior and hyperphagia.

Hypotheses

The gut microbial composition will be significantly different between PWS and matched controls.

Relevance

This proposal uses state-of-the-art technology to address a critical clinical question. It will provide novel information to design therapies aimed at reversing gut dysbiosis (a microbial imbalance or maladaptation on or inside the body) , and thereby improving metabolism and lowering inflammation in children with PWS with obesity.

Wednesday, November 15th

Chapter Leaders Meeting – Crystal Boser/Rob Seely
Chapter Leaders and New Parent Mentor Reception
Clinical Advisory Board Meeting – Dan Driscoll
Scientific Advisory Board Meeting – Merlin Butler
Professional Providers Advisory Board Meeting – Patrice Carroll/Mary K Ziccardi

Thursday, November 16th

Chapter Leaders and New Parent Mentors Meeting – Crystal Boser/Rob Seely & Lori Moline/Diane Seely
Medical & Scientific Conference – Merlin Butler supported by Dan Driscoll/Jim Loker/Kathy Clark & Ann Manzardo
Professional Providers Conference – Patrice Carroll/ Mary K Ziccardi
Medical & Scientific Reception
Welcome Reception/General Conference – Debbie Peaton

2017 PWSA (USA) National Conference November 15-18



Friday, November 17th

Rare Disease – Merlin Butler
General Gala – Debbie Peaton/Kristi Rickenbach
YAP Gala – Debbie Peaton/Kim Tula

Friday and Saturday, November 17th & 18th

PWSA (USA) General Conference – Kristi Rickenbach
Youth & Infant Program – Michelle Holbrook
Youth & Adult Program – Kim Tula
Sibling Program – Tammie and Rockie Penta

For more information and to register visit <http://www.pwsausa.org/2017-pwsa-usa-national-convention-registration/>

If you need assistance to attend the conference please contact us! We offer scholarships.

PRADER-WILLI SYNDROME ON THE MOVE MAY AWARENESS WALK-A-THON ROOSEVELT PARK OCONOMOWOC • WI MAY 13 2017

PLEASE JOIN US FOR THIS NATIONAL AND LOCAL FUNDRAISING, AWARENESS EVENT

Our 7th Annual On The Move Walk-a-thon is fast approaching! Visit our website pwsaofwi.org to find the registration packet or register online! To guarantee that you will receive an event t-shirt please register by April 10th.

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





JOIN AND EXPERIENCE THE VALUE OF **MEMBERSHIP**

WHY BECOME A MEMBER?

Members help to provide much needed revenue that supports the day to day operations of the Prader-Willi Syndrome Association of Wisconsin. PWSA of WI employs a full-time staff member who allows the organization to provide advocacy and education when called upon, a phone line for questions and other situations, and to organize our events.

YOUR MEMBERSHIP INCLUDES:

- A quarterly newsletter, The Wisconsin Connection
- Discounts on trainings or conferences
- FREE OR LOW COST social and support opportunities
- The ability to apply for scholarships and financial help
- Assurance that there will be a voice for all who have Prader-Willi syndrome. PWSA of WI, Inc. celebrated 23 years of reaching out to provide support, education and advocacy to persons with Prader-Willi syndrome and their loved ones across the State of WI.
- Every year scholarships are awarded to campers who have PWS and are in need of financial assistance so they can attend summer camp.
- Each Winter/Spring a social event is sponsored by PWSA of WI, Inc. for persons with this disability, their siblings, and those who support them. More than 100 people who have Prader-Willi syndrome attend. This is a time for making new friends, rekindling old friendships, sharing and having a great time. The unique nutritional and behavioral needs of the participants are specifically addressed.
- Once a year, a training workshop or some other educational project is conducted that helps those who work with children and adults with PWS gain a better understanding of their needs and how to make the lives of those with Prader-Willi syndrome more successful.
- Every day, information and support is provided to callers and others who seek help. Brochures and other printed material are shared at no cost.
- When requested, onsite training and consultations are conducted.

To become a member visit our website at <http://pwsaofwi.org/become-a-member/> or contact us today!



Do you have a teacher, doctor, care provider, or other professional that you think deserves to be recognized for their service to the PWS community? We want to reward them! Visit our website at <http://pwsaofwi.org/professional-service-provider-recognition/> and fill out an application today! Each winner will receive a certificate, a card, and a \$50 gift card.



Maddie Tula



Maya Luening



Makenzie Gaulke



Kameron Boser

What is the PWSA of WI, Inc. Junior Advisory Board?

PWSA of WI, Inc. realizes that engaging the growing number of interested youth is a natural step in creating the next generation of philanthropists. In 2017, the Junior Advisory Board of PWSA of WI, Inc. was developed as a way for youth ages 10-17, to learn about philanthropy and gain hands-on experience in event planning, volunteerism, program development, and fundraising within the Prader-Willi Syndrome Community. Youth will develop and lead these initiatives with the support of adult mentors from the PWSA of WI, Inc. Board of Directors.

The Junior Advisory Board will develop personal and professional skills that will prepare them for future board service and careers. The PWSA of WI, Inc. Board of Directors is extraordinarily supportive of the youth and will assist the members of the Junior Advisory Board with learning these skills.

Junior Advisory Board Program Goal

The Junior Advisory Board's goal is to empower the next generation by engaging our youth in event planning, volunteerism and program development within the Prader-Willi Syndrome community, and assist with fundraising to support the programming of PWSA of WI, Inc.

Who is eligible?

The Junior Advisory Board of PWSA of WI, Inc. is open to all youth ages 10-17 that have an interest in supporting those living with Prader-Willi syndrome.

How do I apply?

If you know someone who might be interested in joining the Junior Advisory Board of PWSA-WI, Inc. and wants to work hard, please contact Joshua Escher at prodir@pwsaofwi.org to obtain a nomination form. Space on the Junior Advisory Board is limited to 6 members, but PWSA-WI, Inc. welcomes all interested applications to volunteer at events held by the Association.

To see bios for our current board members visit our website: <http://pwsaofwi.org/junior-advisory-board/>

PWSA Board of Directors Positions Up For Election This Year

In October of 2017 we will be holding elections for the following board positions:

***President**

***Secretary**

***5 Board positions**

Each position, when elected, holds a 2 year term.

If you are interested in running for one of these positions or have questions about being a part of the PWSA of WI Board contact our program director. 920-733-3077 or Progdir@pwsaofwi.org



This year 225 people attended our Snowflake Ball. The evening started with a lovely chicken dinner. After the meal, complete with a low calorie desert, everyone let their hair down to dance to the music provided by our DJ Paul. More photos can be found on our website and were provided by RDImage.

PWSA of WI, Inc.'s Event Calendar

| | | |
|-----------------------------|--|-----------------------|
| April 8th, 2017 | Janice Agarwal PT, CNDT Therapy Presentations | Oconomowoc, WI |
| May 13th, 2017 | 7th Annual On the Move Walkathon | Oconomowoc, WI |
| August 19th, 2017 | 17th Annual PWSA of WI Golf Benefit | Watertown, WI |
| September 23rd, 2017 | 3rd Annual Strike Out PWS Bowling Event | Wauwatosa, WI |



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