

The Gathered View

National Newsletter of the Prader-Willi Syndrome Association (USA)

9th IPWSO International Conference

~ By Janalee Heinemann, Coordinator of Research & International Affairs

Representatives from 38 countries attended the 9th International Prader-Willi Syndrome Organisation (IPWSO) International Conference in Toronto, Canada! A very big thanks goes to FPWR Canada for hosting this wonderful and complex conference which consisted of multiple meetings from July 19-24.

They include:

- International Consortium to Advance Clinical Trials
- PWSA (USA) Clinical Advisory Board meeting
- IPWSO Board Meeting
- Scientific Workshop
- Scientific Conference (2 days)
- Professional Caregivers Conference (2 days)
- Scientific Poster Sessions
- Parents Conference (2 days)
- Live Life Full Camp for those with PWS & siblings
- Global PWS Community Gala
- IPWSO General Assembly Meeting

Having helped organize many complex conferences at PWSA (USA), all we can say is God bless the key organizers (Tanya & Keegan Johnson, Carole Barron, Janice Fendley) and the many, many volunteers that made this conference possible!

As always, the best part of the conference was meeting and sharing with other families, and the collaboration between clinicians and scientists from different specialties.

At the booths, PWSA (USA) distributed 310 free medical alert booklets (revised version), and IPWSO distributed free flash drives loaded with significant information in multiple languages to attendees. FPWR Canada gave out beautiful packets including program and abstract booklets.

There certainly is not room in this newsletter to give you a full report from the conference, so we will just give you glimpses of information with more to come in the future.

To view all of the scientific conference abstracts, go to www.ipwso.org

Clinical trials panel

Moderated by Dr. Theresa Strong - included representatives from Rhythm, Essentials, Alize, Zafgen, and Oxytocin.

Zafgen – beloranib –

The announcement of Zafgen ceasing development of research on PWS and beloranib happened while we were all at the meeting. The CEO of Zafgen, Tom Hughes, participated in the panel on clinical trials and discussed the situation honestly. He stated that apart from the thrombosis (blood clot)

risk, there were no other major issues, but the consequences of that risk with no realistic solution to eliminate it completely has permanently halted Zafgen's seven years of working on beloranib for PWS. Zafgen did take a proposal to the FDA about adding a prophylactic anticoagulant drug to those with PWS taking beloranib, but it was declined by the FDA. Tom stated that they would be willing to share the instruments and data they developed with other appropriate researchers to help advance PWS research in general. Zafgen is working on developing a cousin of beloranib that does not appear to have the clotting risk.

Rhythm – RM493:

targets the MC4 pathway.

Semelanotide is an 8 amino acid peptide that has to be injected once a day. It targets defects in the hypothalamus. They just had the results of their POMC deficiency patients (who also suffer from obesity and hyperphagia – the uncontrollable drive to eat) in a small study published in the New England Journal of Medicine.

Hunger and weight fell dramatically on the drug. They just completed enrollment in the PWS trial. It will be a 10-week double-blind study.

Essentialis-Diazoxide –

This drug has been used for years for insulemia in

continued on page 2



Diane Seely, New Parent Support Coordinator, and husband Rob- PWSA (USA) board member, shared info on the mission and works of PWSA (USA).

Volume 41, Number 5 ~ September-October 2016 ~ Our 41st Year of Publication

PWSA (USA) Medical and Research View – Making a Difference!

IPWSO, continued from page 1

more than 120,000 patients. It appears to blunt the central starvation signal in the hypothalamus. It may also reduce aggressiveness and impulsive behaviors and hypotonia. In their long-term extension clinical trial PCO25 on PWS, they had 13 patients ages 10-22 years for 14 weeks – 10 weeks open label and four weeks under a double-blinded study. Weight and behavior improved. The next study will involve dose ranging and have up to 12 sites with 85-20 patients ages 8-55 years old. Part of the criteria is that they be overweight with moderate to severe hyperphagia. It will be six months with an open label extension that will start early in 2017.

Alize - AZP-531

Acylated ghrelin creates appetite and unacylated ghrelin counteracts the effects of the acylated. Acylated ghrelin levels are much higher in PWS. (It has not yet been proven that ghrelin drives the hunger in PWS.) Their Phase 2 trial includes 47 patients with PWS from France, Italy and Spain. In a double-blinded two-week study the weight did not change, but there were positive changes in body composition and hyperphagia.

Oxytocin – Dr Eric Hollander – They hope to wrap up their PWS clinical trial by the end of the year. (Also see separate article on oxytocin update)

Dr. Jim Loker - Venous Thromboembolism in Prader-Willi Syndrome: A Questionnaire Survey

Dr. Loker reported on the results of the major blood clot survey completed by PWSA (USA) – We know from our mortality study that there is a 7% risk of dying from a pulmonary embolism (PE) which is a blood clot that goes to the lungs. The preliminary results from this new study suggest an increased risk of venous thromboembolism in PWS with increased age, obesity history, lower extremity edema, vasculitis, and family history of clots. Further study is needed to evaluate the effectiveness of interventions such as weight loss, anticoagulation, risks associated with genetic predisposition and PWS subtype and potential benefits of growth hormone therapy.

Jessica Bohonowych Ph.D. - Global PWS registry

She gave some early statistics: of those who have completed the global registry: - 65% were parents of children under age 10; 80% were diagnosed before a year of age; - 70% who had

a sleep study were diagnosed with sleep apnea; only 50% were compliant with the recommended CPAP use; 9% with PWS had seizures and of those 12% were deletion and 4% were UPD; the percentage diagnosed with UPD (37%) was higher than in the past. 50% of participants stayed in the NICU for more than 20 days after birth.

Dr. Harold vanBosse - Scoliosis

Babies and toddlers with PWS have arms and legs that are stronger than the core; they often need ankle orthotics. Children with PWS often have scoliosis curves that are

not obviously visible. If they are diagnosed with scoliosis before four years of age, they have a good prognosis – only 15% progress to surgery. If they are diagnosed after four years of age, 41% progress to surgery. If they have a curve of 20-25°, they should consider bracing to prevent further deterioration. If they have a curve over 45%, surgery is usually necessary. 20% have a lower bone mass density (BMD), thus, the orthopedic surgeon should be alerted. VEPTR surgery is not good for PWS because the ribs are not strong enough. The MAGEC rod uses a magnet which can link them out four times a year with no

surgery. An anterior approach for surgery should be avoided. There is a potential for serious G.I. issues post-surgery so the bowels need to be thoroughly cleaned out prior to surgery with regular x-rays of the bowel post-surgery. Children with PWS wake up hungry, but their stomach wakes up slower than the average child's. (Note: PWSA (USA) has more detailed articles by Dr. vanBosse on scoliosis and scoliosis surgery on the web site.)

Dr. Loisel Bello Ulloa and his wife Marlen - A Story from Cuba

This beautiful presentation was on their efforts to develop a PWS community in Cuba after the diagnosis of the daughter, and about how they were able to do what initially appeared impossible with the help from IPWSO. Their story was so inspirational that they received a well-deserved standing ovation. Later in the week at the IPWSO General Assembly they successfully bid that Cuba would host the 10th IPWSO conference in Havana in 2019!

Singing extraordinaire –

For me, besides meeting new and old friends from around the world, the biggest treat of the conference was the outstanding singing by Giorgio Fornasier (Italy) and Monica Fuhrmann (France) at the Gala. They sang IPWSO's two theme songs: "Fly High" and "Ich Auch (Me Too!)" Both Giorgio



Left to Right: Dr. Tony Holland (newly elected president of IPWSO), Dr. Dan Driscoll (PWSA (USA)'s CAB chair and newly appointed chair of IPWSO's Clinical Scientific Advisory Board - CSAB) Dr. Marilyn Dumont Driscoll (on PWSA (USA)'s CAB and newly elected IPWSO board member), Dr. Moris Angulo (on PWSA (USA)'s CAB and member of IPWSO's CSAB) at the reception in Toronto.

continued on page 3

PWSA (USA) Medical and Research View – Making a Difference!

IPWSO, continued from page 2

and Monica are professional opera singers and parents of adult children with PWS. They warmed hearts and brought tears to the eyes of most in the room. We're lucky to have so many talented, committed people involved with PWS! ■

Additional Reports on Conference

~ By **Kathy Clark**, PWSA (USA) Medical Affairs Coordinator
Dr. Janice Forster – When and When Not to Medicate?

I made a special note of Dr. Forster's phrase "Adaptability Deficit Disorder" as it sums up the challenges so well. She urges us to understand that the braking system is faulty for individuals with PWS. While she explained the uses of many psychotropic medications, she clarified that medications are a last resort and must be carefully chosen at the lowest doses possible. There is no medication that cannot be used but there are also no medications that are given "because someone has PWS". ■

Gala – Keynote Speaker Meagan Michie

We were all inspired by the speech given by Meagan Michie, a multiple bronze, silver, and gold medal winner in the World Special Olympic Games, and a college graduate. Meagan is a 26-year-old young woman with Prader-Willi syndrome who has determination to excel, cheerful positive energy and a focus on success. Her words and presentation were deeply moving;



IPWSO Board of Directors

she admitted to her struggles and gave thanks for her parents. Her message was one of hope and inspiration. ■

~ By **Diane Seely**, New Parent Support Coordinator

No truer words have been written. As a parent of a child with PWS, one of the first things that you can do that will prove to be enormously helpful now and in the future is to meet other families that have a child with PWS. That is what you will experience at a conference such as the 2016 IPWSO Conference.

Attending were 38 countries that came together to provide outstanding information. There is something to be said about the power of this type of mutual sharing of knowledge; I sensed a consistent thread running throughout the days - HOPE for the future.

It was a pleasure to meet so many parents. After a long day of presentations, the brain begins to go into overload. In the evenings, we could relax and chat with families. My husband and I had dinner with a lovely young couple from Canada. They have a little girl with PWS, and one on the way! The conversation turned to food; it's what is on the forefront of the minds of parents that live this thing called "life with PWS". We shared issues and ideas, including one I always found that

worked when our son was around their daughters' age is to offer the food on small plates. Many restaurants use this theme of dining called "Tapas" - offering food in smaller portions, with a beverage in between. The trick is to begin the meal with the vegetable or protein first, saving what they like for last – fruit. This way they feel as if they are getting more food than they actually are.

For me, meeting families and professionals from all over the world was the biggest joy of conference! ■

"We are more alike, my friends, than we are unlike"

~ *Maya Angelou*

Update Testing of Oxytocin in PWS

By **Rob Lutz**, PWSA (USA) Member of Board of Directors and Research Co-Chair

In May, I provided an update regarding the ongoing effort to move forward with the testing of oxytocin in PWS. As I described then, the goal is to ensure that any funding provided to do further research to test oxytocin in PWS will be as complete as possible and will enable it to be available for use as soon as possible. Unfortunately, the drug development process is never as quick as we would like, and the background situation with oxytocin is very complex.

However, there is some positive news to report. A small group of parents who have children with PWS and have experience in the pharmaceutical industry have committed to dedicating time to moving the oxytocin project forward. We are collaborating with Dr. Jennifer Miller and Dr. Dan Driscoll on this very important project.

We have a community of creative, driven, and talented individuals. I believe our involvement in this project will help accelerate the testing and development of oxytocin, so we can potentially provide another valuable therapeutic option in PWS. ■

One of the biggest problems in this era of mass communication is balancing the enthusiasm of the PWS community with reality and caution.

Welcome, Stacy Ward, to our Family Support Team

—Ken Smith, PWSA (USA) Executive Director

Once again I have good news to impart. As part of PWSA (USA)'s continuing efforts to address the needs of families of those with Prader-Willi syndrome, we have added another member to our Family Support Program.

I am very pleased to introduce Stacy Ward, our new Crisis Intervention and Family Support Counselor, who will be working with Evan Farrar and Kate Beaver.

She has worked in the disabilities field for 22 years, holding an undergraduate degree in Psychology and Human Services and a master's degree in Psychology and Applied Behavioral Analysis.

A resident of upstate New York, Stacy has been involved with PWS since 2005 and has attended New York and national conferences since then. Her connection to PWS came through Catholic Charities Disabilities Services (CCDS), her employer for many years. CCDS provides residential services, with six of their residences for PWS, ranging from one to four persons. In her interview with them, they gave her the Web site address for PWSA (USA), and her initial reaction was wanting to learn more about the syndrome.

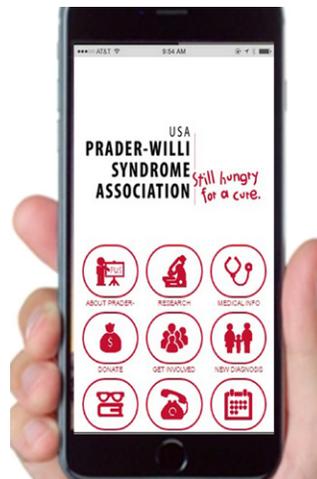
Initially at CCDS she was at first Program Manager overseeing several residences, providing direct services in their residential program and respite in their community supports programs. She was then promoted to Associate Director of residential services, doing administration and continuing to provide PWS training to new staff, day programs and schools. She is still doing some part time work for the agency.



Stacy is on the PWSA (USA) Professional Providers Advisory Board (PPAB) and serves as Residential Advisor to the New York Alliance. She finds the population of PWS to be “most rewarding, most challenging, and incredibly compassionate. Initially, it seems that ‘one type fits all’ – but in reality they are very much individuals, requiring individual services to fit their individual needs.”

In her spare time she likes to read, to play or coach soccer, and to do anything involving her two teenage boys.

For the last several years it has been her dream to work for the national association. She was very excited to have the interview and then be selected. We, too, are excited and happy to have her join us! Welcome, Stacy! ■



Carry PWSA (USA) Wherever You Go!

By Evan Farrar, M.A., PWSA (USA) Crisis Counselor

Are you carrying PWSA (USA) in your pocket? If not, why not? Because now you can by downloading the **FREE** PWSA (USA) app for your smart

phone. With this app, you will have immediate access to all the important information you need on the PWSA (USA) Web site with a touch of your phone screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

- Show your child's doctor important medical information during an appointment.
- Watch a school video with your child's IEP Team.
- Read the latest news on research and other topics of interest.
- Provide ER staff with key medical alerts during emergencies.
- Conveniently explore family support and other resources available to you.

You can also encourage all the family, friends, and professionals in your child's life to download the app so they can know what you want them to know about PWS and the support needs of your child.

So what are you waiting for? Start carrying PWSA (USA) wherever you go by downloading today the PWSA (USA) app available for Android and iPhones. ■



ATTENTION Federal Employees!

If you work for the Federal government, the Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide “all federal employees the opportunity to improve the quality of life for all.” PWSA (USA) CFC ID # is 10088

For more information about the CFC program and how it works, go to their Web site at <http://www.opm.gov/cfc/index.asp>, or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee. ■

Family Support Appeal

After 41 years, we are proud to have created the most innovative and unique



Henley

family support program in the rare genetic disorder community. As a result, when a parent of a child or adult with PWS needs support, we are ready to answer the call. Now, we ask for your support...

Our organization continues to meet the increasing demand for our support services. In 2015, we completed 2,013 support activities to assist families and people living with PWS. In the first half of 2016 we have already completed 1,443 family support activities, an increase of 43% compared to the first half of 2015.

Please help us continue to meet the demand of our family support services by donating today.

To donate, please visit www.pwsausa.org/family-support-donate ■



Jadyn

A big THANK YOU to our generous PWS community members that have raised funds and awareness by hosting an event in their local area so far this year! With your help, PWSA (USA) is able to make a big impact on a local level, throughout the nation. The more support we have, the more families we are able to help, it's that simple. We have several fundraising options so whether you have 10 minutes or 10 months to plan something, you can make a difference!

To get started, contact Leanne Gilliland at 941-487-6743 or LGilliland@pwsausa.org.

Raising Awareness with Team Skye

Angelica Morales, along with her family and friends, raised awareness and funds for PWS throughout the month of May by selling pins and buttons in honor of her new



daughter, Skye. They concluded their efforts by hosting a May 28 dance event. They plan to host an annual Zumba event in Dallas, Texas. ■



Jona "On the Move" Golf Tournament

Harry and Jean Emerson (grandparents) and Sara Dufner (mother), organized a 9-hole golf tournament this past July in honor of Jonathan Emerson Dufner. Family and friends enjoyed a fun day of golf followed by a barbeque. They plan to make this an annual fundraising event in Rathdrum, Idaho. ■

eWALK Dozens of families and individuals are already raising awareness and important funds through PWSA (USA)'s online fundraiser! eWalk is a fun and easy way for anyone from anywhere to get involved. It's easy! Click on the link below:
<http://www.firstgiving.com/pwsausa/2016-ewalk>

Rethinking Our Approach to Diet and Nutrition for the Person with Prader-Willi Syndrome

By Barb Dorn, R.N., B.S.N., Kate Beaver, M.S.W., and Margaret Burns, R.D.

Over the past several years, we have learned many new things in the area of gastrointestinal health for persons with Prader-Willi syndrome (PWS). For years, there have been many anecdotal reports of persons with PWS of all ages having problems with swallowing, choking, stomach issues and chronic constipation. Up until recently, there had only been a few research studies on these issues, specific to persons with PWS. Studies have now documented low production of saliva (6), a high risk of choking (7), a high prevalence of constipation in adults with PWS (1) and documentation of slow stomach/gastric emptying and gastric rupture (2, 3, 4). Dr. Roxann Gross, PhD. (5) reported at the PWSA (USA) 2015 conference that many persons with PWS in her study were found to have significant swallowing issues. Food was visualized on x-ray, lodged in throats, but persons with PWS were unaware of it. We know that persons with PWS have low muscle tone. **We are learning that this poor muscle tone affects their entire gastrointestinal system – mouth, esophagus, stomach and intestines.** All of these findings point to problems with feeding, nutrition and digestive health. With this new knowledge, we now need to rethink the approach to diet and nutrition for the person with PWS. It is important that any person with PWS who is experiencing problems with their gastrointestinal system, should be evaluated by a healthcare professional and, if needed, referred to a gastroenterologist (physician who specializes in diseases and problems with the gastrointestinal system). There can be many reasons for these types of problems.

So, what can be done to prevent and/or manage these problems using appropriate dietary measures for the person with PWS? Low production of saliva can impact the amount of moisture and lubrication needed for safe passage of food from the mouth to the stomach. This issue, along with poor muscle tone, may contribute to problems with food lodging in the throat and putting the individual at increased risk of choking. Another challenge arises in diet management for slow gastric emptying (gastroparesis) and constipation which contradict each other. According to the American College of Gastroenterology, a high fiber diet along with adequate fluids is recommended for prevention and treatment of constipation. In contrast, they recommend a low-fiber, low-fat diet for prevention and treatment of gastroparesis. So what diet approach should the person with PWS use when they may be at risk for both of these problems?

In the past, a low-calorie, high-fiber diet was the mainstay in management for both the child and adult with PWS. The “Red, Yellow, Green diet” was an approach that was utilized by many. However, the time has come to rethink what, when,

and how much we are feeding the child and adult with PWS. The low calorie diet must continue; however, fiber should be reduced. Since nutritional recommendations (calcium, protein, etc. needs) will vary based on **age** and **other health issues** of the person with PWS, it is important to receive specific dietary advice for a child/adult from a dietician or from PWSA (USA) nutritional publications. The examples shared in this article are **not specific** to any certain age group.

Adequate fluid intake along with good dental health can help to minimize problems with a low production of saliva. Gastroparesis is a condition where the movement and digestion of food in the stomach is slowed and in some cases, absent. Normally, contractions in the stomach help crush ingested food and move it in to the small intestine, where further digestion and absorption of nutrients takes place. It is common for a person with gastroparesis to have food remain in their stomach for a very long period of time. Retained food in the stomach can cause abnormal bacterial growth and form a mass (called a bezoar) which can cause blockage or obstruction. Diet is one of the primary treatment approaches for this problem. Foods high in fat and fiber require more work and more time for the stomach to digest and should be avoided. In most cases, fluids can pass through the stomach at a normal rate – even when gastroparesis is present. **Smaller-sized meals, foods that are semi-liquid or liquid and low fat, put less stress on the stomach and help the stomach to empty faster.** Persons with severe gastroparesis must have all food liquefied or pureed, with some requiring all nutrition be administered in a feeding tube. This is challenging for anyone; but is especially difficult for a person with PWS. A soft, lower fiber diet may be more appropriate.

Suggested Recommendations for a Soft, Lower Fiber diet for the person with PWS:

Maintain a low calorie diet.

1. Provide small, frequent meals. Avoid the three LARGE meals per day. Break up meals/snacks to three small meals and two snacks a day (six is only recommended if the person has diabetes). Reduce quantity of food being provided at one time.

2. Include more liquid or semi-liquid food items. Provide liquids during and between meals. Have person drink water or fluids between bites of food. (Helps moisten food and facilitate movement from mouth to the stomach; less work and time with food in stomach).

3. AVOID: RAW vegetables and fruits, nuts and salads. (YES, this is a change)

4. DO PROVIDE: vegetables that have been cooked (softened) and/or mashed, fruits in softer form – applesauce, fruits in natural juices, and cooked cereal.

continued on page 7

PWSA (USA) Medical and Research View – Making a Difference!

Dorn, continued from page 6

5. Soup - at least once a week (this has built-in softening and liquids)

6. Probiotic foods at least 1x daily (yogurt, kefir, sauerkraut). Helps restore and maintain healthy bacteria in the stomach.

7. Ground or cut up meat. (Ground turkey, chicken and/or beef)

8. Eggs – scrambled, fried or baked quiches

9. Schedule the last meal as early in the evening as possible.

(More time for food to be digested before going to bed)

10. Keep upright after eating. Schedule a walk or other movement. (Use gravity to help move food along)

11. HOW TO BEGIN AND PLAN: 1. Consult with dietician and determine specific calorie and nutritional needs for person with PWS. 2. Divide calories between three smaller meals and two snack times. (Suggest 6th meal time only if person with PWS has diabetes.) **THE FOLLOWING EXAMPLES HAVE BEEN PROVIDED. ■**

Sample Planning for Meals/Snacks – 1000 Calories – in a person who does not have diabetes (Check calories on individual products you purchase)			
Breakfast Goal: 225	<ul style="list-style-type: none"> o chopped hard-boiled egg (70) o 1 slice lite toast (45) o ½ TBSP margarine (25) o 3 oz. DanActive Probiotic drink (70) o 1 cup flavored water / coffee 	<ul style="list-style-type: none"> o 1 cup unsweetened cereal (100) o ½ cup unsweetened plain almond milk (15) o 1 lite cheese stick (60) o ½ cup lite applesauce (50) o 1 cup flavored water / coffee 	<ul style="list-style-type: none"> o ½ cup lite Activia yogurt (60) o ½ lite English muffin (50) o 1 TBSP lite cream cheese (30) o 1 cup V8 juice (50) o 1 cup flavored water / coffee
AM Snack Goal: 125	<ul style="list-style-type: none"> • 1 lite string cheese (60) • 3 crackers (60) • 1 cup flavored water 	<ul style="list-style-type: none"> • 1 cup lite Activia Greek yogurt (80) • ½ cup lite fruit (45) • 1 cup flavored water 	<ul style="list-style-type: none"> • 1 tortilla (80) with 1 TBSP lite cream cheese (30) • 1 cup flavored water
Lunch Goal: 225	<ul style="list-style-type: none"> o WRAP - 1 tortilla (80), 3 oz turkey lunch meat (50), 1 TBSP lite mayo (20) o ½ cup cooked green beans (20) o ½ cup lite Activia yogurt (60) o 1 cup flavored water 	<ul style="list-style-type: none"> o egg salad sandwich using light mayo & lite bread (70+30+90) o 1 cup cooked broccoli (30) o 1 dill pickle (0) o 1 cup flavored water 	<ul style="list-style-type: none"> o 2 slices ham lunch meat (30) w/ 1 slice lite cheddar cheese (50) on 1 bagel thin (100) w/ 1 tsp mustard (0) o 1 ½ cup cooked cauliflower (50) o ½ cup SF Jell-O (0) o 1 cup flavored water
PM Snack Goal: 125	<ul style="list-style-type: none"> • ½ sandwich – 1 slice lite bread (45), 2 slices ham (30) • ½ cup lite fruit cup (50) • 1 cup flavored water 	<ul style="list-style-type: none"> • ½ cup lite Activia yogurt (60) • ½ cup lite fruit cup (50) • 1 cup flavored water 	<ul style="list-style-type: none"> • 1 lite cheese stick (60) - wrap w/ham lunch meat (15) • ½ cup lite fruit cup (50) • 1 cup ice tea
Supper Goal: 300	<ul style="list-style-type: none"> o 1 cup chili soup - ground turkey, crushed tomatoes, chopped celery, chili seasoning (200) o 1 cup unsweet plain almond milk (30) o 1 cup cooked cauliflower (30) o ½ cup lite pears (50) (warm & season with cinnamon) 	<ul style="list-style-type: none"> o tacos – 1 tortilla (80) topped with 2 ounces ground beef (80) w/ taco seasoning (10) • top with ¼ cup salsa (25), ¼ cup lite shredded cheese (70), small amount shredded lettuce o 1 cup unsweet plain almond milk (30) o ½ cup SF Jell-O (0) 	<ul style="list-style-type: none"> o grilled tuna melt sandwich – 2 slices light bread (90) w/ ¼ cup tuna (50) mixed with 1 TBSP lite mayo (30) o 1 cup vegetable soup (90) o 1 cup unsweet plain almond milk (30)

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Cognitive and Adaptive Advantages of Growth Hormone Treatment in Children with Prader-Willi Syndrome

Elisabeth M. Dykens,^{1,2} Elizabeth Roof,¹ and Hailee Hunt-Hawkins¹

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J Child Psychol Psychiatry. 2016 Aug 2.

This recently-published, three-part study is on the effects of growth hormone therapy (GHT) on the cognitive and everyday adaptive functioning of children and youth with PWS. Our thanks go out to the researchers and to the families involved in this important work.

The researchers explain that it is unacceptable to conduct a randomized study (where some participants get the treatment, and others not) because GHT is now standard of care in children with PWS. Instead, they used three other approaches that took advantage of naturally occurring differences in GHT status in a large number (173) of children and adolescents with PWS.

Children with PWS completed an IQ test commonly used in children with developmental delays and parents were interviewed about their children's communication, social and everyday life skills, repetitive behaviors and hunger (hyperphagia). Although not the goal of the study, the researchers wanted to see if problems with repetitive behavior or hyperphagia related to being on or off GHT; no differences were found. As described below, however, they did find significant differences in IQ and adaptive skills. **In the first study, they compared the cognitive and adaptive functioning of children who were treated with GHT for at least 1 year to a smaller group who had never been on GHT.** Children on versus off GHT were matched on age and gender, were similar in PWS genetic subtypes, and the analyses also took into account differences in family income and education. This was important because children never on GHT came from families who were less well-educated and had lower incomes. (Unfortunately, a common finding in health care is improved access for some families, and barriers for others.) Adjusting the statistics for these differences, the researchers found that being on growth hormone had significant advantages for children in both their IQ and adaptive behavior scores. The treated group

had significantly higher Verbal and Composite IQ's (Verbal IQ averages of 81.6 versus 67.5, Composite IQ averages of 74.5 versus 62.3 composite). They also had higher communication and daily living skills scores. **The second study looked at the effects of the age of beginning GH treatment.** Most children began GHT before five years of age. Those who began GHT at less than one year of age had higher Nonverbal and Composite IQ scores than children who started treatments between 1-2 and 3-5 years old. Verbal IQ scores were not significantly different. **The third study identified the cognitive and adaptive trajectories, or changes over time, in children who were either consistently on or off GHT for a 3 -5 year period.** On average, both treated and untreated children had stable IQ and adaptive behavior scores over time. As in the first study, children remaining on GHT had higher IQ scores that remained high over time, while untreated children had lower scores that also stayed stable over time.

Take Home Messages of this Research:

- Similar to other groups of patients with growth hormone deficiencies, GHT has beneficial effects on the cognitive and everyday adaptive functioning of children and youth with PWS.
- Infants with PWS derive cognitive and developmental advantages from GHT, and motor skills and learning are connected. Even so, older children appear to derive cognitive and adaptive benefit, and studies are sorely needed on the cognitive effects of GHT in adults with PWS. Studies are also needed that document what happens to cognition and adaptive behavior after GHT is stopped, in both the short and long term.

It is time to revisit justifications of GHT in PWS based solely on linear growth or body composition. Physicians and insurers need to understand that improvements in cognition and everyday adaptive skills are also important, quality of life benefits of GHT.

As the researchers point out, studies are needed on the continued use of GHT once goals are met for linear growth, especially on doses of GHT that are safe and maintain treatment-related cognitive and adaptive advantages.

- The professional community needs to be made aware of the uneven access to GHT for children with PWS. Sadly, we see that health care in the United States is not equal for all individuals with PWS. ■

The efforts of researchers in this work, and the willingness of families to participate in these studies is the way forward.

~ Kathy Clark R.N., M.S. CS-BS
PWSA (USA) Medical Coordinator

PWSA (USA) Chapter Leaders Annual Meeting

By Crystal L. Boser, PWSA (USA) Chapter Relations Chairperson, PWSA-WI, Inc., President

The Chapter Relations Committee held their annual Chapter Leaders Meeting on July 8th-10th at the Holiday Inn hotel in Pewaukee, Wisconsin. Twenty participants from the following twelve chapters as well as the national board and office staff attended the meeting:

*-California -Florida -Illinois -Indiana -Michigan -Minnesota
-New England -New Mexico -New York -Ohio -Texas -Wisconsin*

Friday afternoon, eight Chapter Leaders participated in a tour of Prader-Willi Homes of Oconomowoc (PWHO). They visited



Saturday night dinner:

L to R front row: Heather Osterman (IL), Kristi Rickenbach (MN), Jackie Mallow (WI), Michelle Torbert (FL), Diane Seely (PWSA (USA)), Crystal Boser (WI), Cathleen Morrison (NY), Mary Raymond (NE), Amy Stuckey (OH), Julie Casey (CA), Tammie Penta (AZ)

L to R second row: Elizabeth Bystrak (NY), Rob Seely (OH), Kathryn Lucero (NM)

L to R back row: Dewey Graves (MI), Ken Smith (PWSA (USA)), Tom Noonan (TX), Brandon Watson (IN), Joshua Escher (WI), Roger Goatcher (CA)



Welcome Reception

the organization's day program, vocation program, and one of the residential homes. While at the residential home, chapter leaders were given a tour by two of the young ladies who live in the home, and chapter leaders were able to hear their personal stories about living in a residential home. This tour was a wonderful learning opportunity for chapter leaders looking at possibly creating residential homes within their state.

The weekend officially kicked off on Friday evening when the Chapter Relations Committee held the Welcome Reception in the main lobby of the hotel. Attendees spent the evening laughing, eating and drinking, sharing personal stories, and getting to know one another. We discovered many chapter leaders had never tasted frozen custard so... a run to the local custard stand was made to rectify this discovery!

On Saturday, attendees spent the day learning about the State of the Association, Research, Wyatt Special Education Advocacy, Publications, the Parent Mentor Program, Law Enforcement and Legislation/Advocacy. Saturday evening, attendees and their significant others enjoyed a social dinner at a local restaurant, Thunder Bay Grille. Afterwards, everyone relaxed by the open fire pit and chatted the night away. The evening was a wonderful opportunity for chapter leaders to continue to build on the relationships formed earlier in the weekend.

On Sunday, the leaders discussed Facebook/Web site usage along with chapter operation topics, including recruiting board members & volunteers, identifying individuals diagnosed with PWS, plus identifying physicians who are knowledgeable about PWS, boosting & retaining membership, and communicating with members. The group also discussed fundraising initiatives and how to raise awareness. By the end of the meeting, several chapter leaders

decided they would like to collaborate in the future to host a multi-state conference. Another chapter leader decided to host a fishing tournament based on some of the fundraising ideas that had been discussed. During the meeting, the dates of the 2017 National Convention and Chapter Leaders Meeting were announced as well as the location change, theme, etc.

In closing, everyone left extremely excited to learn these details, and planning for the next Chapter Leaders Meeting is already underway. ■

"Alone we can do so little, together we can do so much."

- Helen Keller

Coffee Talk with Moms, Part 1

By Denise Servais, mother to Maya, age 12

There are a number of people within the PWSA (USA) family who are great resources. One in particular is Lota Mitchell. (See sidebar)

On the eve of August 18th, three women came “together” to talk about their experiences with having a child with PWS. I was one of the moms privileged to share in this conversation, via telephone, with Kathryn Lucero (in CO) and Lota Mitchell (in PA) and me (in MN).

Given the vast differences in our children’s ages, we all shared different perspectives and unique challenges, but we also shared similar experiences in terms of the joys of raising our children. Kathryn has a 2 ½ year old son named Ronan, Lota has a 46-year-old daughter named Julie, and I have a daughter named Maya, age 12.

In this issue, the conversation between Lota and Kathryn is shared; my conversation with Lota will follow in another issue.

What are the challenges you face as a parent to a child with special needs?

Kathryn discussed initially having difficulty connecting with parents who had children with PWS in the birth to three category. She mentioned that once she connected with a parent advocate from PWSA (USA) and Dr. Jennifer Miller, she became more involved in the association and these factors helped immensely. “Now I’m dealing with typical toddler things.” Lota reported that there wasn’t the information and knowledge about PWS when her daughter was born like there is today. She talked about the first PWS conference that she attended. “It was professionals and parents in a big room and everyone asking each other questions...one great exchange of information.”

When was your child first diagnosed? Lota described her experience as a long frustrating one. She reported none of Julie’s doctors really knew what to think of Julie’s condition, whom she described as being born “limp.” In those days, there was no formal testing for PWS. Lota reported reading an article about PWS in a medical journal when Julie was five. She then saw an article on PWS in the Pittsburgh paper. “I self-diagnosed her,” Lota said. She eventually connected with the PWS national



Ronan

office and Julie was diagnosed with PWS at age 18 when lab testing became available.

Kathryn reported that Ronan was diagnosed within two weeks of birth while in the hospital. She reported at the end of her pregnancy the doctor became concerned since Ronan was not showing fetal movement; Kathryn was admitted. She had a C-section the next day. Ronan was in the NICU for 5½ weeks with a G-tube eventually placed.

What do you think has been the most helpful in terms of your ability to raise your children?

We all agreed that using our skills that we developed from our current and previous occupations, as well as experiences have helped. Lota reported that using her skills as social worker gave her the confidence to talk to professionals. When Lota wanted to start a camp for kids with PWS, she initiated talks with The Children’s Institute in Pittsburgh to get the camp started. Kathryn reported that her skills as a health coach helped her become a better advocate for her child. Lota also commented that going to PWS conferences helped her connect with other families, “It’s like coming back to this family that knows what you’re going through.”

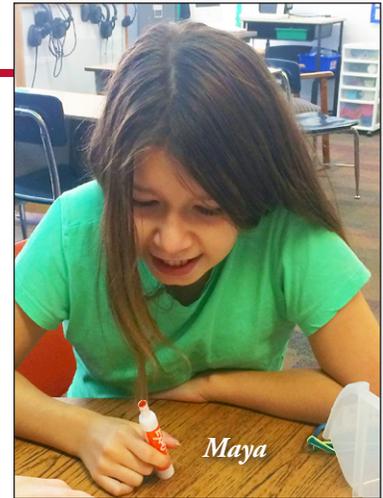
How has it been accessing services for your children where you live?

Kathryn reported that services have been easier to access since moving from New Mexico to Colorado. Her son started growth hormone at 15 months, and he currently receives early intervention, OT, and speech services. In contrast, Lota reported that there were no services when Julie was younger. Her daughter attended a separate special education school. Four years later, when the federal law required the Least Restrictive Environment, Julie then went to a regular school that had a special education class. There were no such things as IEPs!

What advice do you have for parents? All women agreed that seeking out resources and knowledge, getting involved, as well connecting with the PWS association and other parents was helpful.

Is there anything you would change since having a special needs child? “I would have enjoyed her more as a baby and a child,” Lota said. Kathryn talked about the guilt when she felt she wasn’t doing something all the time for her son. “I don’t need to be busy constantly...slow down; it’s so awesome watching him play and thrive.”

What concerns do you have for the future? Kathryn



Maya

continued on page 11

From The Home Front

Coffee Talk, Part I, continued from page 10

admitted that it was hard to think about with having such a young child, but reported having fears that her son won't have friends. However, she said she tries not to think about it as she sees many wonderful things going on right now. Lota said that Julie lives in a good group home program and is happy there – but it is 300 miles from home; she expressed concerns about being able to travel to see Julie in the future. “Julie would be willing to move if necessary...but it doesn't seem fair to uproot her.” Concerns of guardianship were also present in the discussion.



In the end, we all agreed that while each of our situations were different, the opportunity to share our experiences, joys, and concerns were worth the time we had spent. Being able to talk about our experiences with other people that “get it” is a valuable and often therapeutic tool. ■



Nolan attends a special needs school and today was his first day in a new classroom with a new teacher and new kids, so reading through his daily sheet from school I wasn't surprised to hear that he had some challenging behaviors. But I couldn't help laughing when I read that he refused to come in from recess, stating that he “needed to work on his tan.” Not sure where that came from, but considering that he is as pasty white as can be, I found that hilarious. Later, after trashing yet another pair of glasses during a meltdown, he presented the many pieces to his teacher with a huge smile on his face, as if it was a completed project, and told her excitedly, “Now I have to tell Mom!” That's my boy.

- Jennifer Kryzak, mother to Nolan, age 13
Cedarburg, Wisconsin

“Be kind for everyone you meet is fighting a battle you know nothing about.”

- Unknown

Sidebar Note: In a previous issue Andrea Glass wrote about Lota Mitchell.

Lota is one of the people who has helped shape and guide our association. When their daughter Julie was born with PWS in 1969, there was no PWSA (USA), no Internet, no personal computers, no word processors. Julie was undiagnosed, and Lota sought answers, talking to any medical person who would listen about Julie's issues. When Julie was five, a friend showed her an article in the Journal of the American Medical Association about Dr. Vanja Holm, Prader-Willi syndrome and the Prader-Willi clinic in Seattle, Washington. This was the first clinic of its kind in the world. But it was not until Julie was 18 and participated in Rob Nichols' research study on uniparental disomy, was Lota's diagnosis of PWS in her daughter confirmed.

Through the JAMA (Journal of the American Medical Association) article Lota learned about the second PWSA national conference in 1980 and attended. At the time, Lota was working on her M.S.W. degree and wrote a term paper on PWS. She found a small amount of information on PWS at the University of Pittsburgh medical library and added more from the conference. Her completed

paper, submitted to PWSA (USA), became one of the first comprehensive booklets on PWS. This early publication even made its way onto the emerging Internet. Lota went on through the years contributing to the written literature on PWS, with many PWS publications bearing her name. Lota has worked on the Publication Committee of PWSA (USA), publishing booklets, brochures, including The Gathered View. Working as an Employee Assistance Program professional for 20 years satisfied some of her desire to help people. A guiding light for our newsletter, The Gathered View, Lota passionately worked as its associate editor, then editor since 2008 [to 2014].

The international scope of PWSA (USA) has changed her worldview, seeing us all connected to one another - a PWS global family. The Gathered View publishes personal stories from around the globe as well as medical information and the latest on PWS research and is grateful for Lota's continued contributions to our association.

Honored by PWSA (USA) with a Lifetime Achievement Award at the 2013 National Conference in Orlando, she also received a Distinguished Service Award from her alma mater Muskingum College, for a lifetime of helping others, and acknowledging her contributions to PWSA (USA). ■

Functional Behavior Assessments and the Student with PWS

By Jen Bolander, PWSA (USA) Special Education Specialist

Scenario: Mrs. A receives a phone call from her child's school. It is the fourth phone call she has received in the past month. It is one of her child's teachers, calling to let her know that her child, Susie, has had another episode of serious behavior issues in the classroom. Susie has thrown her book, tipped over her chair and several other chairs, and ripped a poster off the classroom wall, all while yelling at the teacher. The teacher insists that Mrs. A come to the school and take Susie home, and the teacher also states that Susie may be suspended if these behavior issues continue. Mrs. A calls the Special Education Director for the school to discuss the situation, and the Director suggests that a "Functional Behavior Assessment" be done with Susie. Mrs. A has never heard this term before and is unsure what to do, but she feels that constantly taking her daughter out of school will not solve the behavior problems.

What should she do?

When interacting with children with PWS – especially in a school environment – it is important to remember that behavior is communication. This is especially true if the student has any trouble communicating, or is fully non-verbal. It is also true that students with PWS experience many "trigger" situations in the school environment:

- Loud and stimulating classrooms
- Complex social and/or academic situations
- School subjects which gradually increase beyond their understanding
- Unsupervised food

The student with PWS may also have constant, generalized, heightened anxiety, which then makes it harder for the student to react appropriately to any stress or frustration. Thus, there are many reasons why a student with PWS may experience mild-to-severe behavior issues at school.

A "Functional Behavior Assessment", or FBA, is a way of gathering data about:

- The environments where the behaviors occur
- How often the behaviors happen, and
- What the consequences were or what happened at the conclusion of the behavior (student spent time in the principal's office, student was sent home early).

The purpose of the FBA is to document exactly what the problem behaviors are, where/when/the environment in which they happen most frequently, and the observed outcome of the student's behaviors. The school psychologist, or a board-certified behavior analyst if the school district has one on staff, can perform the FBA, which may take a week or two to complete. Usually, only 1-2 problem behaviors are assessed.

An FBA is most effective if as much objective information as possible is gathered through:

- Indirect assessment: Interviews with teachers and staff who work with the student, to gather information about when and in what situations they have seen the behaviors occur
- Direct assessment: The school psychologist (or BCBA) will directly observe the student in their classroom or triggering environment, using an ABC chart (antecedent-behavior-consequence) or scatter plot chart to note the facts of a behavior episode.
- Data analysis: The student's IEP team meets to review the behavior data collected, to discuss the behavior patterns which emerge when looking at collected data.
- Hypothesis of functions of behaviors: IEP team creates a hypothesis, based on the data collected, as to why the student is having these problem behaviors. In other words, the team is making an informed statement as to what the "function" is of the behaviors, or what the student is trying to communicate and achieve through the behaviors.

The IEP team then creates a "Positive Behavior Intervention Plan", with the goals of:

- Addressing and eliminating triggers in the student's environment
- Making curriculum or schedule adjustments wherever needed
- Teaching the student to recognize their own stress levels, communicate that they are having difficulty, and choose a positive or preferred method to handle their stress
- Promote positive behavior choices through constant recognition and reward of preferred behaviors/good behavior choices/use of positive coping skills

It is problematic, and ineffective, for a student who is having consistent behavior issues to be repeatedly sent home from school. When these episodes originate at school, the student is communicating through their behavior that there is an aspect of the school environment with which they cannot cope appropriately. Sending the student home because of behaviors triggered by a school situation does little or nothing to address the school situation; it is a very temporary fix to an ongoing issue, one which the student will face again the very next day back at school. Parents can request that a *Functional Behavior Assessment* be initiated if their child is having repeated behavior issues at school, and should be sure to request a team meeting to discuss the data collected.

For further assistance with school situations, please visit the "School Issues" section of the PWSA (USA) Web site through this link: <http://www.pwsausa.org/school-issues/>. The article titled "Preventing Suspensions of Students with Disabilities" will be especially helpful. Assistance with **special education concerns for students with PWS is also available by calling PWSA (USA), 1-800-926-4797.** ■

Search for a Cure

By *Andrea Glass*

Right now, my son Ian (21 years with PWS) is upstairs on the computer looking for a cure for Prader-Willi syndrome. AGAIN! This time he is searching for a drug that will make him stay calm when he gets mad. He is quite concerned that his behavior gets dangerous when he is mad and he disappoints the people who love him. He is also searching for a drug that will curb his appetite. Tomorrow when we go to see the endocrinologist, he wants to discuss this topic with her. I truly can't wait to see what he comes up with... this time. He is quite good at searching on the internet.

The last time we went to the endocrinologist, Ian asked her to look up his blood type. She diligently found it for him. The next day he presented me with the Blood Type Diet. He insisted that he would stick to this diet. But, having PWS he was somewhat selective (his favorite food was on the 'no' list.) The 'no' list morphed into only those foods that he doesn't actually like. However, of course, if that's what's for dinner...guess what?

Then there was the adoption theory. If I am not 'really' his mother then he doesn't 'really' have PWS. Now he was off on a quest to find his real mother. He also suggested that he may have been switched in the hospital at birth. It was simply not him who has PWS!

Remember when your child with PWS was diagnosed? The denial stage we all go through. I think Ian is now going through the denial stage. We talk this through, but he is obstinate and rigid in his thinking. I usually can't talk any sense into him. He is very determined to find a cure. He asks everyone he knows to donate to his Firstgiving page, to help find a cure.

Then, there are the conversations that he is part of through the Department of Disability Service (DDS) who is supposed to help plan for his future. They told us there would be no residential placement, EVER (or perhaps before we are 85). This did not sit well with Ian. He absolutely envisioned a life without parents watching his every move. He immediately went upstairs and wrote to every PWS group home organization he could find. Within a week we had packets and brochures, coolers and other promotional items. We've been told there is no more funding for new residential

placements. Money is simply something Ian does not understand! What a marvelous job we have done, holding out until now. Perhaps DDS does not understand the true meaning of crisis.

The future is very frightening. Friends and family don't really understand what it means to have PWS in your life. It's the restrictions that they simply don't get. The restrictions that keep our children safe have become illegal in some states and at best, not acceptable in others. In our state (Massachusetts), the restrictions (food and behavior safety) are not considered when looking at future placements. DDS believes that everyone can be a part of the general community; period. They do not fund permanent job coaches, live-in and/or 1-1 staff. They actually seem to believe that there is no specialized care required for our children. As parents of a child with PWS we know about all the special care they require. Why won't they listen?

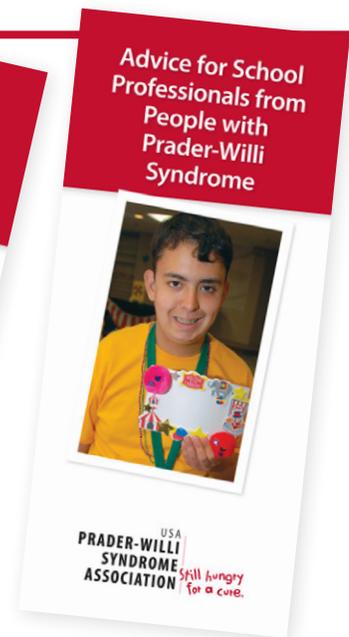
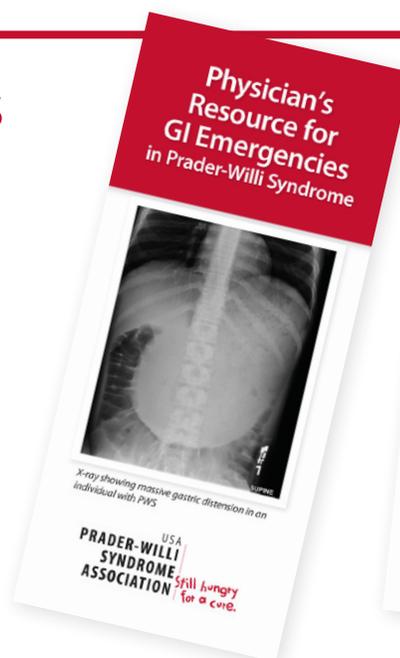
Uh oh, here he goes again. He is caught listening at the top of the stairs while we discuss the lack of adequate day programs. He vows to find something he will like and is now off on that quest. Good luck I tell him. But he is not deterred! ■

More New Publications from PWSA (USA)

In our mission to promote awareness and education to our families, healthcare community and the public, PWSA (USA) is proud to present two new publications - one is a Physician's Resource brochure focused specifically on G.I. issues, and featuring a chart for determining treatments depending on symptoms.

The other is good advice for education professionals and is written by our own PWSA (USA) Advisory Board. Both are wonderfully informative. Both brochures are available via our Web site.

Look for these brochures on the PWSA (USA) Web site! Visit: www.pwsausa.org ■





Did you Know The Top Five Issues which our Family Support Program has assisted families?

Your donations at work!

Do You know? Here are the Top Five Issues our Family Support Program has assisted families with in 2016.

- 26% School Support
- 20% Medical Support
- 16% Advocacy Support
- 14% New Diagnosis Support
- 10% Behavioral Support

Inside the Numbers: 53% of school support involved behavior issues, 42% of medical support involved answering medical questions, 35% of advocacy support involved advocating for families, 61% of new diagnosis support involved assisting parents of a child 0-3 years old, 57% of behavioral support involved challenging behaviors. 50% of contacts with families included at least one follow up activity.

- *Evan Farrar, PWSA (USA) Family Support Counselor*

Welcome and Congratulations

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We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more resources like this. Please see our web site, www.pwsausa.org

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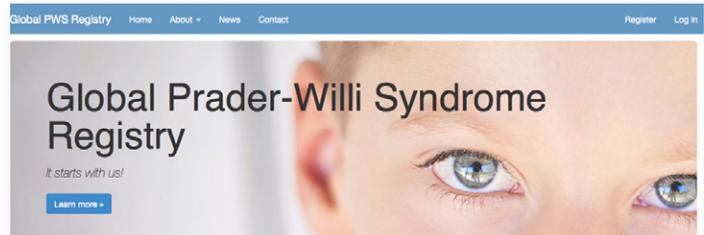
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**Deadlines to
 submit items
 to The
 Gathered View:
 Dec. 1; Feb. 1;
 Apr. 1; June 1;
 Aug. 1; Oct. 1**

Our Mission: Prader-Willi Syndrome Association (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

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The Members Only section requires a password: member20

E-mail Support Groups: We sponsor nine groups to share information. Go to: www.pwsausa.org/egroups

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Co-Chair - Mary K. Ziccardi, REM Ohio
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Liaison Member - Stacy Ward, PWSA (USA) Family Support Counselor

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 Jennifer Bolander, PWSA (USA) Special Education Specialist
 Tom Conway, PWSA (USA) Board of Directors
 Evan Farrar, PWSA (USA) Family Support Counselor

Adults with PWS Advisory Board

Shawn Cooper, Georgia
 Brooke Fuller, Michigan
 Conor Heybach, Illinois
 Kate Kane, Maryland
 Lauren Lange, Georgia
 Andy Maurer, South Carolina
 Abbott Philson, Maine
 Trevor Ryan, California

e-News...

Reminder – stay informed and stay current with PWSA (USA)'s free e-News. Sign up today at www.pwsausa.org and watch for the next update full of great info.

SAVE THE DATE!

at Caribe Royale
Orlando, FL



2017 PWSA (USA) 34th National Convention

15-16 Nov. - Chapter Leader Days

16 Nov. - Professional Providers Day

16 Nov. - Scientific Day

17-18 Nov. - General Convention

Youth Infant (age 0-6) Program (YIP)

Youth Adult (age 7 & up) Program (YAP)

Siblings (age 7-15) Program

*Watch your email and
Facebook for registration info.*

Convention Web site will be up soon.



Janalee Heinemann with with Dr. Li Ping and Tsui-Tao from Taiwan at the IPWSO Conference

In this Issue

Oxytocin Update	3
Executive Director View	
Introducing Stacy Ward	4
Rethinking Diet and Nutrition	
Including guidelines, chart, etc.	6-7
Chapter News	
Chapter Leaders National Meeting	9