

# The *Gathered View*

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

USA  
PRADER-WILLI SYNDROME ASSOCIATION  
*Still hungry for a cure.*

## on the **MOVE**

PRADER-WILLI SYNDROME ASSOCIATION (USA)

Spring is just around the corner and most of you know what that means..... It is Prader-Willi Syndrome Awareness Season! Spring is the main time that families and friends around the country spring into action for PWSA (USA), so that our organization can continue to make a positive difference in the lives of people and families living with PWS.

**On The Move** is an awareness and fundraising campaign that:

- is designed to increase awareness of PWS and raise **essential** funds for PWSA(USA) and state chapters.

- grows support of the PWS community as a whole and PWSA (USA)'s many vital family support services.

- includes an element of physical activity.

- is undertaken by state chapters, affiliates, individuals and groups.

**On The Move** is very important in raising awareness of PWS and funding for PWSA (USA)'s key operations of support, research, education, awareness and advocacy. **Medical advocacy is one of the most essential things we do** and crucial for our children's physical

survival. We respond to medical crises and medical questions. Medical information is faxed or emailed to hospitals, doctors, parents, and various other care providers. Consultation is arranged with complex situations.

In the last year alone PWSA (USA) was able to do the following with the money raised from **On The Move** activities:

- Participate in **IEP meetings** for students with PWS across the country (by phone or in person) to answer questions and recommend PWS appropriate educational and behavioral strategies.

- Distribute hundreds of **informational packets** to care providers, medical, and school professionals.

- Write hundreds of **advocacy letters** to support access to benefits for people with PWS.

- Offer an understanding and **supportive ear** when parents need a place to talk.

- Create the new e-letter

*School Times* which in four months has a subscription list of over 400 parents and school professionals.

- Create and complete the **Wyatt Special Education Advocacy Training** - the first national PWSA (USA) Special Education Training.

- Utilize **Educational and Residential consultants** to provide expert training to schools and residential programs across the country.

- Assist children and adults in **crisis** to receive treatment at the PWS program at The Children's Institute in Pittsburgh.

- Design creative **new resources** such as the Older Child Package for families and caregivers.

- Join **advocacy efforts** to promote the support needs of people with PWS and their families.

- Spend over **\$1,000,000 on Prader-Willi syndrome research** (in a five-year period).

- Sponsor over **50 research projects** in the past 10 years.

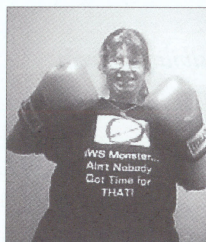
Your involvement in OTM as an event organizer, fundraiser, and/or participant empowers you and educates others. A great thing about **On The Move** is you get to choose where your funds go! If you want 100% to go to support, great! If you want 100% to go to research, perfect! If you want to split the funds between different services, no problem!

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*Vanessa Child's story, see page 8*

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## PWSA (USA) Creating Professional Awareness and Education in 2013

*By Janalee Heinemann, MSW, Director of Research & Medical Affairs, PWSA (USA), Vice President, IPWSO*

### Endo 2013 - San Francisco, June 2013

Our PWSA (USA) Scientific Advisory Board member and IPWSO president, Dr. Suzanne Cassidy, was able to acquire a free booth for PWS at the conference, and she hosted me in her home. We both worked the booth. It was a collaborative effort between our International Prader-Willi Syndrome Organisation (IPWSO) and PWSA (USA). We distributed educational materials to more than 278 endocrinologists. Dr. Cassidy was able to experience firsthand the work it takes to organize and work an awareness booth, but also the excitement in educating so many endocrinologists on PWS in a matter of a few days. ■

### ESPE 2013 – Milan, Italy, September 2013

Thanks to a generous sponsorship IPWSO received from Pfizer Europe, we had an awareness and educational booth at ESPE (European Society for Paediatric Endocrinology). This year it was a joint meeting with Societies for Paediatric Endocrinology from all over the world with over 5,000 participants. Besides ESPE, it included the Pediatric Endocrine Society (PES), Australasian Paediatric Endocrine Group (APEG), Asia Pacific Paediatric Endocrine Society (APPEs), African Society for Paediatric and Adolescent Endocrinology (ASPAE), Japanese Society for Pediatric Endocrinology (JSPE), and the Sociedad Latinoamericana de Endocrinología Pediátrica (SLEP). Giorgio and I ran the IPWSO booth along with his wife Maurizia and his son Daniele (with PWS), who was in charge of scanning bar codes of all doctors calling at our booth. We distributed hundreds of specialized packets on PWS. We also had medical alert booklets in multiple languages including Chinese and Arabic. Fortunately, Giorgio can greet people in multiple languages and communicate fluently in several languages. All Daniele had to do was smile, and he melted hearts.

With your support, we can continue to develop the knowledge of professionals on PWS and save lives. Please consider donating for this cause or to one of our many other support programs. Albert Einstein said, *"I believe we are here to do good. It is the responsibility of every human being to aspire to do something worthwhile, to make the world a better place than the one we found."* ■

### Obesity week – Atlanta, November 2013

PWSA (USA) had an awareness booth at the Obesity Week conference, one of the world's largest gatherings of obesity professionals covering the full scope of obesity issues. This inaugural meeting brought together scientists, clinicians,

surgeons, physicians, integrated health professionals and policymakers from around the world. The American Society for Metabolic and Bariatric Surgery (ASMBS) and The Obesity Society (TOS) brought their resources together to hold both annual meetings under one roof.

This gave us the opportunity to educate obesity specialists from a variety of backgrounds on PWS. As always, we had extensive packets of information to distribute. It was especially important to have information about PWS and bariatric surgery due to the large number of attendees from ASMBS. A surgeon from Saudi Arabia gave a lecture stating he had success with bariatric surgery in children with PWS. I was able to discuss our concerns and get his information in order that we can further assess his outcomes. It also was an opportunity to discuss collaboration with researchers in the area of obesity.

I met with a group of interested professionals and the key coordinators of Obesity Week regarding pursuing a PWS symposium at the 2014 Obesity Week conference in Boston. Thanks to the assistance of Jack Yanovski, M.D., Ph.D. (Director of the NIH Unit on Growth and Obesity), our application is in, and we are waiting to hear if our proposal will be accepted.

*A special thanks to our wonderful PWS volunteers, Dottie and Dale Cooper, for helping me host the booth and hosting me in their home. Because our funding is limited, their support made this conference a viable option.* ■

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## Combating Obesity – An Exciting PWS Clinical Trial

*By Janalee Heinemann, MSW, Director of Research & Medical Affairs, PWSA (USA), Vice President, IPWSO*

Hopefully you have all read the exciting news either in the *New York Times* article on Prader-Willi syndrome or in the press release by the pharmaceutical company Zafgen about the clinical trial results on the phase 2 study of Beloranib in patients with PWS. The study results were very encouraging with reduced body-fat content while allowing patients with PWS to eat more food without gaining weight, and hunger-related behaviors improved.

This is just one example of how we can impact research on PWS besides direct funding to research. In 2012 I helped the president and CEO of Zafgen to coordinate a meeting during our hyperphagia conference in Baton Rouge at Pennington. The goal was to put together a collaborative team that could move a clinical trial forward. We had that meeting in November 2012. For those of you that don't know much about research, getting approval from the FDA, working with the appropriate clinical and research sites, getting IRB approval, recruiting appropriate candidates for the research, dealing with the complexity of a placebo-controlled, randomized double-

*continued on page 3*



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

### Clinical Trial, continued from page 2

blind study, and calculating the results is a HUGE project that often takes several years. To go from our first meeting in November 2012 to have in the results publicized less than 14 months later is an incredible victory for Zafgen, the researchers (principal investigator was Dr. Jennifer Miller who is on our PWSA (USA) Clinical Advisory Board), and for our families with PWS.

Zafgen is now in the process of working with the FDA to determine a path forward in continuing the development of Beloranib. Once the details are worked out, we will give you an update. I do want to clarify that at this point they are not ready to decide on who will be eligible for any future study. **I can report, though, that the initial trial on Beloranib is the most encouraging progress I have seen regarding a medication to potentially help with the obesity and hyperphagia (uncontrollable drive to eat) in PWS! ■**

## Results of PWSA (USA) Grant Published

An article entitled “Brain-derived neurotrophic factor in human subjects with function-altering melanocortin-4 receptor variants” was recently published in the International Journal of Obesity (2013) describing the findings of a study funded by the PWSA (USA) 1<sup>st</sup> Hyperphagia Conference Best Idea Grant that was awarded to NIH researchers, Joan Han, M.D., and Jack Yanovski, M.D., Ph.D. The authors examined brain-derived neurotrophic factor (BDNF) concentrations in blood samples from patients with genetic variations of the melanocortin-4 receptor (MC4R). Patients with decreased MC4R function have excessive appetite and weight gain. In mice, MC4R appears to regulate BDNF concentrations in the brain. Patients with genetic defects affecting BDNF also have hyperphagia and obesity, and patients with PWS have been reported to have decreased blood concentrations of BDNF, suggesting a possible role of BDNF in PWS. In this article, the researchers reported that blood BDNF concentrations are similar in people with and without MC4R defects, suggesting that blood BDNF concentrations may not directly reflect levels of BDNF in the regions of the brain that are important for appetite regulation. Thus, while global deficits in BDNF throughout the body may be associated with lower blood BDNF concentrations, patients with MC4R defects may only have BDNF deficits in isolated regions of the brain, while blood concentrations still remain normal. ■

## Orphan Disease Research

Thanks in large part to the determination of patient organizations like Taylor's Tale, a non-profit which funds research

at top institutions like the University of North Carolina, rare disease (also called orphan disease) research is hotter than ever before.

Generous gifts have allowed prestigious universities to create institutes focused on rare disease.

Government initiatives such as the Therapeutics for Rare and Neglected Diseases program at the NIH have been developed to promote rare disease research. Taylor's Tale, co-founded by the sister of a little girl with the fatal brain disorder, Batten disease, has been part of advancing important rare disease legislation in U.S. Congress.

Drug companies that used to run screaming from small-population diseases have learned from success stories like Genzyme, which built its entire foundation on developing drugs for orphan diseases. One-third of the 39 drugs approved by the FDA in 2012 were for orphan diseases, and worldwide, the market for orphan drugs is expected to skyrocket from \$86 billion in 2012 to \$112 billion in 2017. Large drug companies like GlaxoSmithKline now have dedicated programs for rare diseases.

[Ed. Note: A “rare disease” is any disease that affects a small percentage of the population. Most are genetic and no single cutoff number has been agreed upon.] ■

## Obesity Biology and Integrated Physiology

**Obesity | VOLUME 22 | SUPPL. 1 | FEBRUARY 2014**  
[www.obesityjournal.org](http://www.obesityjournal.org)

### Hyperphagia: Current Concepts and Future Directions Proceedings of the 2nd International Conference on Hyperphagia

This 16-page supplement to the prestigious Obesity Journal has been a long time coming post our 2012 conference, but now it is officially out. They even have a parent's perspective on PWS by Jim Kane – which I'm sure is unusual in this journal. The positive outcome of the conference goes on and on.

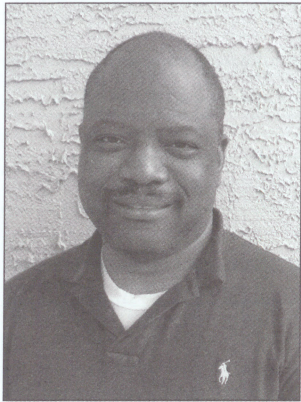
I am also happy to report that I just got word that our proposal for a **PWS symposium at the 2014 Obesity Conference** has been approved! It is exciting to see how far we are expanding outside our world of PWS to educate physicians and entice researchers and pharmaceutical companies to see PWS as the “Window of Opportunity” to find the answers to combat all obesity and hyperphagia (the uncontrollable drive to eat).

~ Janalee Heinemann, MSW, Director of Research & Medical Affairs, PWSA (USA), Vice President, IPWSO ■

We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this.  
Please see our web site, [www.pwsausa.org](http://www.pwsausa.org)



## On The Move 2014!



Ken Smith, Executive Director

For around 30 years of my life, I have been involved in various aspects of the Prader-Willi syndrome community. During that time the needs of the individuals and the families of those with PWS for various services have not changed much, including support, research, education, information and advocacy. But the cost for providing— and indeed increasing— those services has grown and grown.

Money raised through **On The Move** helps fund those services. Did you notice the new logo? Take a look and see that the figures aren't sitting still; they are active and in motion. You might say that they are **On The Move**!

Our newsletter, *The Gathered View*, has been running a series of articles about “How Our Organization Helped”, or **HOOH**. Let's take a look at some of their stories, both long and short.

- There was Madison, 4, who was in the hospital; PWSA (USA) faxed information to the hospital regarding respiratory distress in kids with PWS—which helped her doctor determine a treatment plan for her.
- Matthew, 29, was approved to go to The Children's Institute until his sodium levels were found to be too low; PWSA (USA) sent inquiries to endocrinologists around the country for their opinions about the possible cause tracked down drinking excessive amounts of water. Matthew's water intake was cut, his sodium went back to normal, and he went to TCI.
- Information about PWS and anesthesiology was dispatched by PWSA (USA) to the anesthesiologist when Julie, 44, was facing oral surgery.
- Louise, 80, was still caring for Charlotte, 50, at home, but management was getting more and more difficult;

*“Set a goal to achieve something that is so big, so exhilarating that it excites you and scares you at the same time. It must be a goal that is so appealing, so much in line with your spiritual core, that you can't get it out of your mind. If you do not get chills when you set a goal, you're not setting big enough goals.”*

— Bob Proctor

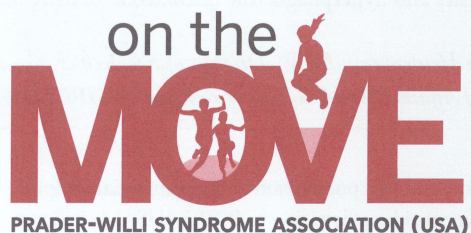
- contributed by Clint Hurdle

PWSA (USA) Crisis Counselor Evan Farrar sent many letters of support to get needed services as well as provided encouragement and guidance to Louise through the process. Charlotte is now in a good residential program.

- Sixth-grader Brian was having lots of behavioral problems at school; Mary K Ziccardi was sent by PWSA (USA) to do an in-service for the school staff, causing important changes for Brian's benefit.

You can read two more **HOOH** pieces in this issue about Cami, 15, and Trace, 10, who were having meltdowns at school and how they were helped through PWSA (USA) services. **On The Move** provides much of the financial foundation for these services. It's a little bit like a house: PWSA (USA) has to have a foundation (financial) in order to put up the walls (services).

We look forward to celebrating this **On The Move** season with you and our entire PWS community as we build the foundation for the services that are so badly needed by so many! ■



PWSA (USA) began with a historic movement to begin a membership organization that could provide education, support, and research for families and professionals in need. The need is still there – in fact growing every day – so we need a new movement to provide the financial support to meet that need. Together with your family and your friends, or your chapter, be a part of that movement by sponsoring an **On The Move** event this spring!



# I am Just a Girl

by Lisa Peters



The greatest challenge I face, as a parent of a child diagnosed with Prader-Willi syndrome, is my inability to face my fear.

I am afraid.

I am afraid that if I neglect appointments, therapies or new treatment options, my son's life will suffer.

I am afraid if I do not make a better effort to manage his anxiety and

his resulting behavior, he will become a monster.

I am afraid, if I do not secure our home, he will wander the neighborhood searching for food and instead find harm and danger.

I am afraid if I am not a "good enough" parent, my son will die.

I have been running away from this fear all of his life.

It has finally caught up with me.

When my son Nicholas was first diagnosed with this monstrous syndrome, I experienced a type of shock. I buried my fear by devoting my life to a constant state of movement. I figured if I stayed busy enough, I wouldn't have time to feel anything. Nick's complex medical needs made this warped philosophy a convenient reality.

I became selfless, devoting myself completely to my weakened child. This chaotic lifestyle took me to a lonely place where few folks in my life could relate. I lost friends and family members. But still I persevered. I tried to make sense of my suffering by researching many forms of religion and spirituality. Here, I was interested to learn that most if not all of these beliefs shared a similar philosophical promotion of selflessness and a belief in its path to peaceful living and enlightenment.

The only problem was...I didn't feel enlightened.

All I felt was tired.

After much soul searching, I have discovered that perhaps my selfless intentions are somewhat misguided.

Am I being selfless because I truly want to be selfless?

Do I enjoy it and feel energized by the experience?

Or am I staying busy just to hide my fear?

These are difficult questions but I believe the answer is....

I am afraid.

I am afraid if I allow myself to feel this fear, it will consume me.

So, I don a new persona. I compare myself to the likes of superheroes and soldiers and in the process I begin to lose myself. I bury my hopes, my dreams, and my health, so that I can better care for my son. I have become a cartoon

caricature and not a human being.

Last week I got my wake-up call. A visit to my primary physician indicated that I may be headed down the dreadful path of self-destruction. My blood pressure has begun to increase. I have always had low blood pressure. This shocking news made me think of my father who passed away suddenly from a stroke shortly after my first son was born. Realizing there was a good chance that I could face a similar fate, I did some soulful reflecting and found that my previous motto of "to do" needs to be replaced with a healthier "to be" philosophy. If I do not find a more relaxed mindset and do not take better care of myself, who will care for my children? This is, of course, my biggest fear.

I need to find my peace. I realize however, that this will take some time. I am considering things like exercise, meditation, and creating new hobbies. I am also visiting with a mental health professional who is well versed in the stresses associated with raising children with special needs.

I am learning that...

Before I can give selflessly to another, I must first be fearless in my understanding of myself.

I must realize that I am not a superhero or soldier, I am just a girl.

I am a girl with a very big responsibility. I am responsible for the quality of life of a medically fragile child.

This responsibility often makes me tired and scared.

It is very OK to feel this way.

My son Nicholas has endured many medical, physical and emotional difficulties and yet he faces each one of these challenges with a sense of calm acceptance and fearless resilience. It is this spirit that I need to embrace.

Ironically, it is my son who makes me want to become a better, more accepting human being. ■

## iHOLA!

*By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.*

iHola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que necesitan informacion y ayuda. Les quiero dirigir a [www.pwsausa.org](http://www.pwsausa.org) donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, [ninaroberto@verizon.net](mailto:ninaroberto@verizon.net). iHablamos pronto! ■





# "Bowlieve" It!

## fundraiser

for Prader-Willi Syndrome Association (USA)

Bowling is a good old-fashioned fun time for all, young and old, small and tall, rain or shine, anytime!

Let the good times roll while you strike up funds for the Prader-Willi Syndrome Association (USA).

### Let's get started on an unbowlievable event!

- ☐ Contact your local bowling alley for available dates and times.
- ☐ Decide if you need supplemental insurance
- ☐ Finalize date and send event form to PWSA (USA) national headquarters
- ☐ Publicize your event
- ☐ Support materials and forms available
- ☐ Any Questions?

**Contact:** Pamela Ferrara at pferrara@pwsausa.org for more information. ■

### Be an Advocate For

#### On The Move:

For more information on how you can advocate for **On The Move**, call Ben Karp,

Communications Specialist for PWSA (USA) at 941-487-6730 or email bkarp@pwsausa.org .

Order Your **On The Move** Logo Items Today!

The PWSA (USA) **On The Move** logo items are a unifying symbol of hope and awareness in our community. Last year, hundreds of **On The Move** logo items were distributed nationwide and were worn by advocates just like you in support of PWS Awareness.

This year we have a new logo and new products that we are sure you will enjoy!

To order today, contact Pam Ferrara at 941-312-0400 or email pferrara@pwsausa.org .



PRADER-WILLI SYNDROME ASSOCIATION (USA)

## Shout Out!

### The New Jersey "Kick It Up For Kids" Dinner Dance and Auction

held on November 16th not only was a wonderful evening for those who attended, but also raised a GRAND total of \$29,551 for Prader-Willi causes. A third of this, over \$9000, will be sent to the National Office to help fund the many ways they serve individuals with PWS and their families. The remaining \$20,000 will help fund New Jersey Chapter activities. Thank you go to the awesome committee who worked so hard to make the event so successful, planning it, soliciting donations of food and the over 100 baskets that were raffled, selling tickets, and running the event, as well as those who donated baskets. Committee members included Christie Bevacqua and her family, who have been holding these events for many years. ■

### The 2014 Giving Challenge is

*coming soon!* Mark your calendar for May 6. This challenge is a **24-hour online event** from Tuesday, May 6 at 12:00 noon through Wednesday, May 7 at 11:59 a.m. **We have 24 hours to make a difference!** All it takes is one click & a minimal donation of \$25. [www.givingpartnerchallenge.org](http://www.givingpartnerchallenge.org) . This url goes live noon ET May 6<sup>th</sup> through noon ET May 7<sup>th</sup>. Please share this to raise awareness and funds for PWSA (USA). ■

### On The Move, continued from page 1

Through **Firstgiving.com** you can set up your event, ask participants for donations online through emails and social media, and registrations are automated through the process.

### If you are having an OTM Event:

- ☐ **Get and** Submit your PWSA (USA) OTM Event Agreement to bkarp@pwsausa.org .
- ☐ We will create a FirstGiving event at [www.firstgiving.com/PWSA \(USA\)](http://www.firstgiving.com/PWSA(USA)) and send you a log-in & password.
- ☐ Log-in and add event information and pictures to customize your event page.
- ☐ Send emails or post to your social network using the easy to use tools for registration and donations.

### Fundraise Online:

Want to raise awareness and money for PWS, but you don't have time for an event? Fine! Firstgiving.com makes it

easy to spread awareness and fundraise whether you are having an **On The Move** event or not.

If you want to set up your own fundraiser/awareness page online for FREE:

- ☐ Go to [FirstGiving.com/PWSAUSA](http://FirstGiving.com/PWSAUSA).
- ☐ Click "Start Fundraising" button.
- ☐ Select "PWSA **On The Move** 2014".

Set up your own fundraising page and start sharing with friends and family through the simple email and social media tools.

See extra info on page 10 on how we can help YOU with your own event in the fight for PWSA (USA)!

### Already hosting an event? Tell us about it!

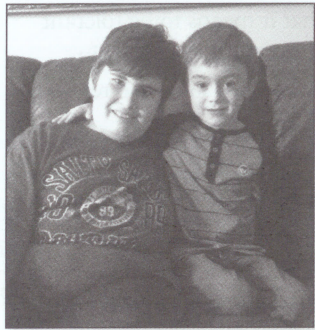
- ☐ Submit your event to bkarp@pwsausa.org or call 941-487-6730, and we will post it on our website and share it in our community blog. ■



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## How Our Organization Helped Trace's Meltdowns

John Bloom was very frustrated. His ten-year-old grandson, Trace Gallo, with PWS, was having a difficult time in school. "He was having meltdowns. I tried to get across to the school what PWS is and the behaviors...the school wouldn't listen," Bloom explained. "They (school) didn't try to figure out what was causing the meltdowns."



*Trace with brother Tanner.*

Trace's special education teacher believed Trace's behaviors were purposeful. Bloom asked the teacher on numerous occasions to call the national PWSA (USA) office for information that would help Trace. At the end of November 2013, the school agreed to talk to someone from PWSA (USA) and was put in touch with Kate Beaver.

Beaver recommended that the school perform a Functional Behavioral Assessment (FBA). A FBA is used to determine the underlying cause or purpose of a behavior so that an effective plan may be developed. An IEP meeting was scheduled with Beaver in attendance via a conference call. Based on the results of the FBA, Beaver gave input into developing a behavioral plan.

"Kate walked the teacher through everything," reported Bloom. Changes were made to meet Trace's academic and social needs. "Lunch was hard. Now Trace gets to eat in the classroom with an adult and a friend...Trace's quality of life is much better," concludes Bloom.

Next year, Trace will be in 6<sup>th</sup> grade and in a new school. Beaver has suggested to Trace's grandfather that he talk with the new school staff when the time comes to go over Trace's needs and how Prader-Willi syndrome affects Trace.

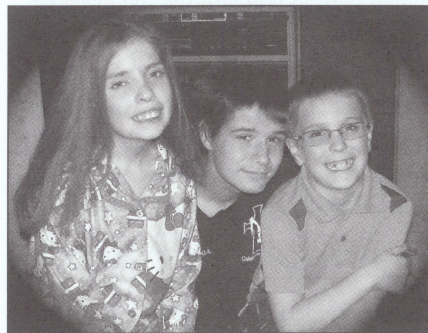
Trace lives with his grandparents, his mother Valerie, and his younger brother Tanner. Bloom adds, "Trace loves going places. He is a joy. Everyone loves him. He's like the mayor, everyone knows him." Trace and his family live in Fort Wayne, Indiana. ■

with distinct answers, this syndrome doesn't have answers that always work. Her name is Cami (Camille Grundy), our daughter who was born with Prader-Willi syndrome (PWS).

Monitoring how much food she eats and eliminating opportunities for her to get food are a daily challenge. The constant, uncontrollable hunger that Cami and individuals with PWS feel causes them to forage for food and do almost anything to get it. We have awakened in the morning to find our daughter in bed with empty plates and containers from leftovers from the trash, which we had forgotten to lock the night before. Yes, we lock our refrigerator, food pantry, trash, and anything with any type of eatables; otherwise, her compulsion will cause her to eat it all. The feeling we have when this happens is like a monster pouring out of us, coating us with sadness and fatigue. We constantly remind ourselves that it is not her fault. We had our kitchen framed in with a locking door so that Cami cannot get into the kitchen at night to forage for food.

The last few years at school were complicated as Cami's behavior turned into daily tantrums with spikes of rage that seem out of her control. Her classmates, who love her dearly, became afraid of her. This, coupled with her paranoia, made teaching and learning very difficult and challenging. Very often after such episodes, extreme remorse and guilt is felt by those with PWS; then they are ready to get back to the task at hand.

In 2009 we were at wits end so we called PWSA (USA) for advice and help. Through tears and anguish in our hearts we explained what we were dealing with Camille. We got more than we could have imagined when speaking to the kind people at PWSA (USA). Evan Farrar and the team have been so supportive and encouraging, introducing us to Mary K Ziccardi who has been our educational consultant, sounding board and, most importantly, friend.



*Cami, with brothers Cody and Cavan*

Mary K introduced us to The Children's Institute (TCI) in Pittsburgh, PA, which helps children and adults with PWS. Many patients there are extremely overweight with serious behavioral

challenges. Cami spent two months there from December 27, 2011 – February 28, 2012. The day we left her there was one of the hardest days of our lives. (We live 10 hours away.) Cami is only 4'5" and weighed 118 pounds. She was placed on a strict diet of 800 calories/day, plus a daily exercise routine. She was taught strategies to deal with how she was feeling and how to process her behaviors. Cami's behaviors were strictly monitored,

**continued on page 8**

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## How Our Organization Helped Cami's Story ~ It Takes A Village

This beautiful fifteen-year-old girl will love you the moment she meets you, but her syndrome is as complicated as the toughest math problem. However, unlike math problems



and she received medications to help with those behaviors.

We are eternally grateful to TCI and particularly Ken Smith, admissions director at that time and now Executive Director at PWSA (USA). Also Dr. Cherpes, psychiatrist, as well as all the nurses, dieticians, teachers, therapists and staff, helped us while Cami was there. Her stay at TCI was a game changer for her and our family.

While there, we learned that Cami had extreme scoliosis. TCI staff suggested we call Dr. van Bosse at Schreiner's Hospital in Philadelphia; on the PWSA (USA) Clinical Advisory Board, he treats children who have PWS and severe scoliosis. After a year of visits to and from Philadelphia, Cami had spinal fusion July 26, 2013. Our family is forever grateful for the care that our precious daughter received from Dr. Van Bosse, surgeon, Marcia, nurse practitioner, and the many other nurses and staff who helped Cami during her stay there.

Over the last two years we have maintained the 1000-calorie diet and exercise routine that Cami started at TCI. In 2012 she lost 45 pounds and maintained her weight at 75 pounds. We recently bought her first pair of skinny jeans – A SIZE ZERO!!

Cami made the transition to high school this year and is a freshman. The best educational model for Cami is to be in the same room for most of the day. The school staff at Fitch High have done a great job in taking the steps necessary to understand PWS and how to handle Cami in both the good and more difficult times during the day.

Our support system is most certainly a blessing. Camille has two great brothers, Cody, 17, and Cavan, 8, who play with her, read to her and exhibit a great deal of patience with her. Cody would tell you that “it is not easy and you have to take your time with her, but when you do you will see the loveable side of Cami.”

Cami has very special grandparents, especially her paternal grandmother, Sharon, who gets her ready for school every day, goes on field trips with her, picks her up from school when she is sick and is always there to help whenever needed. We are also thankful to our close friends and church family who have offered support, encouragement, prayers, babysitting, and financial assistance.

The past two years have provided many new opportunities for Cami. She attends Camp Horizons, a special needs camp; such a blessing its staff has been. Cami also joined the Special Olympics team with the Town of Groton, Connecticut (our home town), competing in Track and Field. In two years she has become one of the top 800-meter walkers for her age division, knocking two minutes off her time.

Because of the great care Cami has been given, we want to give back. Cami will be in the first-ever swallow study sponsored by PWSA (USA) on people with PWS. Dr. Gross

and Dr. Cherpes at TCI are conducting this study. This is Cami's first visit back since she left. She can't wait for the doctors and staff to see her and how much weight she has lost.

Our very special daughter has opened our eyes and hearts to people we would have never experienced and had the pleasure of getting to know had she not had PWS. Cami absolutely loves everyone she meets, greeting all with a smile and huge hug. She loves animals, especially dogs, and is very drawn to people that most of us would automatically not be. She cares for those who are physically and emotionally hurting, offering a “Cami” hug and a warm smile. In this world of intolerance, Cami has shown us what it means to be tolerant and accepting, and that it is alright to talk to strangers in wheelchairs or to those who “look different.” She also regularly reminds us to pray for these people.

The many layers to Cami's story are challenging, exhausting, inspiring and uplifting -- but thanks to a “village” of compassionate and caring people, Cami has blossomed into a happy and loving young woman. ■

Gratefully,

Larry and Kim Grundy for our daughter, Cami



## A Person with Prader-Willi Syndrome Speaks Out

My Name is Vanessa Child I'm 25 yrs old I'm an intelligent, loving caring individual who enjoys life But I battle my Own personal demon Known

as Prader Willi Syndrome it is very difficult living with this syndrome But I am strong and found a way to help me cope with it. I Refer to PWS as a Monster and defeat him day in day out with the help of My red Boxing gloves that I wear for continuing My battle against my monster I have ignored HIM for over a Year but it doesn't change anything my hunger pains are worse now than when I gave him what he wanted and my belly hurts more. I can say no to people offering me food but it's hard I Have Him who tells me I am Hungry and the hunger itself that I Call the “Bear” it sounds like an Angry momma grizzly and feels like someone punched me. I've ignored His cravings but it's still hard. Last Year Everything Changed In February I got under 200 lbs what I refer to as ONE-derland but I didn't just get there for me. it was a Promise I Made to My Cousin

**continued on page 9**



# People Who Make a Difference

By Janalee Heinemann, MSW, Director of Research & Medical Affairs, PWSA (USA), Vice President, IPWSO

Since the death of their 17-year-old son Jeremy on December 26, 2004, Pete and Gayle Girard (formerly of Orlando, Florida, now Townsend, Tennessee) have volunteered at our national conference throughout the years. They also donated computer equipment and assistance with our computers at PWSA (USA). Pete and Gayle generously funded the printing of our *Medical Alert* booklets. Jeremy died from a stomach rupture; they attribute his death to the ER physicians' lack of understanding the potential serious nature of his eating binge on Christmas Eve as a major risk factor. Their mission is to ensure that all PWS families carry the *Medical Alert* booklet with them at all times. ■



*Sometimes out of the ashes of grief  
great works of kindness are created.*



Heard at a Pennsylvania Chapter meeting:

Parents of Shane, age 8, related that he had been having some instruction at school about using 911 and emergency situations. When asked what he would do if his house was on fire and his parents had passed out, his immediate response was "Go to the kitchen!"

## Grandmother's Testimony

By Sally Taylor



Addison

In January 2010 I learned that my son and his wife were expecting a long-awaited second child. In March they gave birth to a beautiful baby girl, Addison Rose Taylor. She was so tiny and frail with muscle tone so weak she did not even have the strength to cry. Life itself seemed to exhaust her, and she slept all the time. Anxiety that something was wrong with Addie was mounting. In May I helplessly witnessed Michelle and Curtis's hopes shatter as Addison was diagnosed with Prader-Willi syndrome. When I got the call, my thoughts hung in disbelief. With jumbled emotions all I could do was cry.

Part of me grieved for the life my poor weak little granddaughter would never experience.

Part of me grieved over lost dreams and the perfect life our family would never have together.

And to be honest, part of me saw her as an intruder into the perfect world my kids had worked so hard to create.

Addison is only three, and I have already witnessed different devils at different levels as each stage of her life brings with it new physiological challenges. I have watched my children fight for their daughter's life. Addison has overcome challenges that can last a lifetime in many PWS cases such as sleep apnea, hearing loss, and low muscle tone. She has just recently been able to walk without braces and is starting to

Vanessa, continued from page 8

Lacy who got her angel wings in November of 2012 after a battle with Cancer and the meaning that Being ONE-Derland holds is the Reason Why I Haven't allowed HIM to Return. I Refuse to Give Up but I will Always Be Hungry for a Cure And Make Others Aware Of Prader Willi Syndrome. ■

~ Vanessa Child  
Mexico, Maine

*I know a woman who is strong, courageous, dedicated, intelligent, willful and powerful. This woman battles Prader-Willi syndrome daily and refers to PWS as her "monster." She defeats him on a day-to-day basis and refuses to quit fighting. She is constantly getting the word out about PWS through fundraising, posting links on awareness on her facebook page...and about the always present struggles a person with PWS experiences. That woman is my sister.*

*Our family wears red bracelets that say "Prader-Willi Syndrome, Still Hungry for a Cure."*

*~Emily Child, full time student with a full time job*

continued on page 10



# The Wayne Miller Family Story

By Lota Mitchell, Editor, *The Gathered View*

At the beginning of December I received a call from a good friend and classmate from Muskingum College days in New Concord, Ohio. It was Wayne Miller, better known as “Frenchy”, with a request.

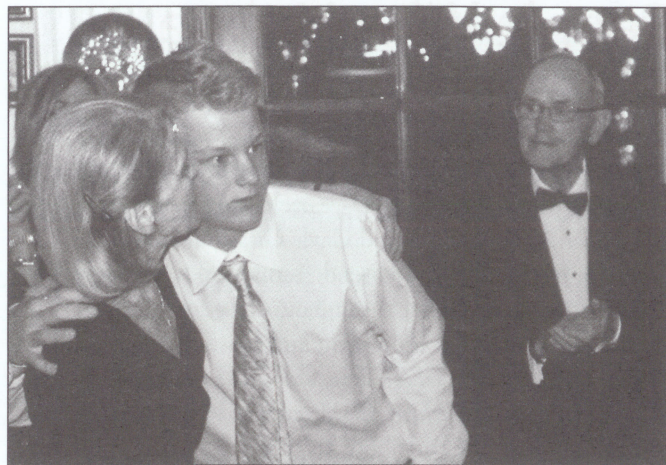
Each December he and his wife Barbara host their annual IFO (Immediate Family Only) dinner with their two sons and daughter and their families. For that dinner a particular charity has been selected for everyone to learn about and support. This year Prader-Willi Syndrome Association (USA) was the chosen charity. Could we send information? Cindy Beles at the national office and I selected brochures, booklets, newsletters, and handouts to go into packets, one for each person attending the dinner.

At the beginning of February I received a letter and pictures from Frenchy. Following are excerpts from his letter:

*“This year we asked grandson, Blake Miller, age 14 and a freshman in high school, to research Prader-Willi and to make the presentation before dinner. He did a great job.”*

Excerpt from Blake’s presentation:

*...“It is tough to have this disease start when you are an infant and follow you for the rest of your life, thereby putting strict external controls on your everyday activities.*



Barbara, grandson Blake, and Wayne “Frenchy” Miller

*“As you all know, we are an extremely blessed family, and some people right now are having a constant life-threatening battle against Prader-Willi syndrome. SO, this year we as a family are each donating \$20 to help stop this epidemic. In conclusion, sick people are waiting for support from people all around the world, and I’m glad to say that the members on the IFO of 2013 are donating to help save people’s lives.”*

Frenchy goes on to say,

*“The results were rewarding – the six younger grandkids donated \$20 each, or \$120, and the two older ones and their guests donated \$40 each or \$160 for a total of \$280 from the cousins. Barbara and I matched it with our donation of \$1,000 for a*

*grand total of \$1,280 going to a great cause.”*

What a wonderful way to fund raise, increase awareness, and establish a culture of giving—AND have a great time doing it with family! ■



## Grandmother, continued from page 9

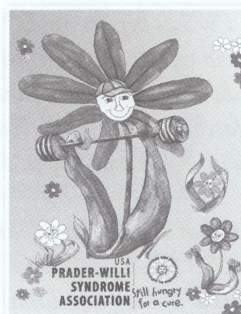
pronounce her words. Every milestone of her success is a blessing.

However, we live each day preparing for the monster in the closet who wants to rise up, steal, and destroy our little Addie. The monster’s name is hyperphagia (extreme unsatisfied drive to consume food). This stage of PWS can begin any time after the age of two and lasts throughout life.

We live with the faith that in Addison’s lifetime PWS research will finally hunt down and destroy this cruel monster. Until then our family will remain vigilant to insure a long healthy life for our little girl.

I must confess that I first feared a broken life for my kids, but in truth Addison has given all of

us a life of greater significance and value. [www.sallyhelencreations.com](http://www.sallyhelencreations.com) is dedicated to finding a cure for PWS in her lifetime. You can help by purchasing any Wild Blossom product. 10 percent of the cost of your purchase will be donated to finding a cure. ■





# Chapter Spotlight on - Indiana

**Prader-Willi Syndrome Association of Indiana**  
by Jim Koerber, Past President (2008-13) and Amy Pfeiffer, Executive Director

The Indiana chapter, re-established in 2007 and very active, operates under the PWSA of Indiana by-laws. It has officers, board of directors and an executive director. The Chapter is organized exclusively for educational, literary, scientific and charitable purposes with our own exempt status under Section 501(c)3 of the Internal Revenue Code. The Chapter currently has close to 100 members, consisting of individuals with PWS, parents, grandparents, and providers.

Each October, the Chapter holds an annual membership meeting and social event. Annual meetings are educational with guest speakers as well as time for family sharing, e.g., the 2013 annual meeting was followed by a hayride and pumpkin painting for the kids.

The Chapter held the first Prader-Willi Syndrome Midwest Regional Conference in Indianapolis on October 6, 2012. In addition to letting people know what was happening in the organization, the conference provided an opportunity for professionals and families to get together to learn and to share with each other. Four subjects were covered: Endocrinology, Gastroenterology and Nutrition, Individual Education Program (IEP) and School-Related Issues, and Special Needs Estate Planning.

The Chapter has many on-going projects, including an active Advocacy Committee. The Advocacy goal is to change the current legislation in order to recognize PWS as a developmental disability. The Chapter also works with the State of Indiana Department of Developmental Disabilities to immediately help those with PWS prior to any legislative changes. Additional work by the Advocacy committee and the Care Home committee is to influence the development of more appropriate residential options for adults with PWS in the state and to develop a network of local advocates to help with school issues. They are working on a presentation about PWS and the specialized needs of individuals with PWS for the Indiana Department of Developmental Disabilities.

For medical support, Indiana is fortunate to have Bryan Hainline, M.D., Ph.D., a physician at Riley Children's Hospital in Indianapolis who is on the Clinical Advisory Board at PWSA (USA). His group works with many Indiana families.

The Chapter is very active with fundraising. They have held **On The Move** 5K Walk/Run events each year since 2011 during the month of May. The average fundraising amounts to more than \$20,000 each year, of which 50% is donated to PWSA (USA). Last year they provided every individual with



PWS that participated in the **On The Move** event an iPad mini. In addition, they have provided financial assistance to families attending the National Conference and to PWS children and adults attending Wonderland Camp.

For more information about PWSA of Indiana, please refer to their website at: [www.pwsaindiana.org](http://www.pwsaindiana.org).

**Mission Statement:** Prader-Willi Syndrome Association of Indiana is an organization of families and professionals working together to raise awareness, offer support, provide education, lobby and advocate, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

**Vision Statement:** Every individual with Prader-Willi syndrome will achieve their maximum potential through our awareness, support, education, lobbying, advocacy and research.

**Our Goals:** We will achieve our Mission and Vision by:

- **Awareness:** Instilling a sense of compassion and understanding through our dedication to providing awareness and enlightened knowledge about Prader-Willi syndrome.
- **Support:** Providing emotional support to families and caregivers, and nurturing a sense of hope, strength and connection as we strive together to improve the quality of life of individuals with Prader-Willi syndrome.
- **Education:** Attending conferences, bringing specialists to our chapter meetings, thus providing education and resources in order to improve the quality of life for everyone with the syndrome as well as the people who support them.
- **Lobbying:** Lobbying and working with State officials and agencies to develop legislation that supports individuals with Prader-Willi syndrome.
- **Advocacy:** Advocating for individuals with Prader-Willi syndrome and helping provide more residential living options for those individuals.
- **Research:** Raising funds to support research; this will ultimately lead to a cure. ■

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School student-sponsored "Spirit Week" Fundraiser in Greenville, South Carolina.



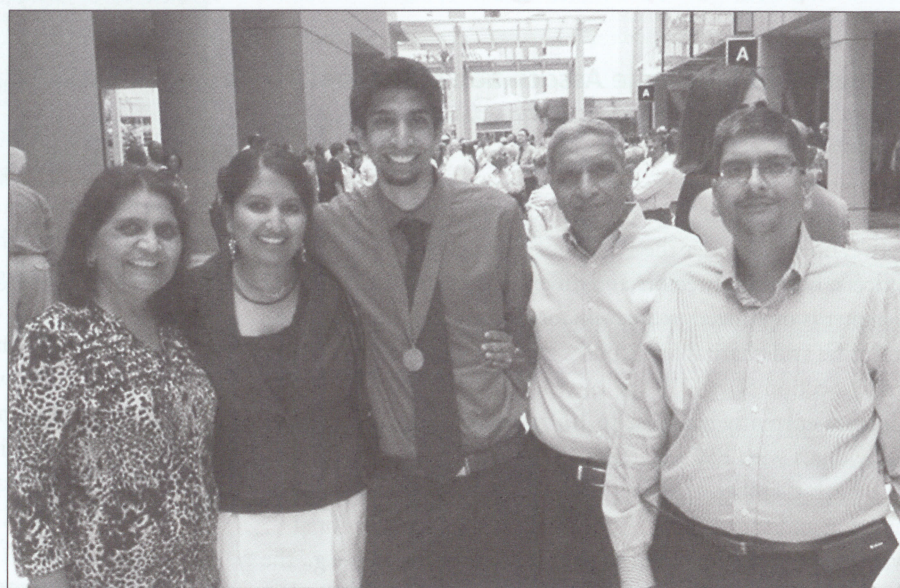
# Filled with Inspiration and Infinite Possibilities

By Neil Patel and Neha Patel, DO  
Developmental & Behavioral Pediatrics  
Fellow, Oklahoma LEND Fellow,  
Oklahoma University Child Study  
Center

Growing up with an older brother with Prader-Willi Syndrome (PWS) has been challenging at times for my younger brother, Neil, and myself. We definitely had family situations that were marked with frustration, misunderstandings, and tears. But, though some people may think having a sibling with a developmental disability imposes a unique set of challenges that would negatively impact our own lives, we know that our lives would not have been as rewarding and fulfilling had we not had a brother with PWS.

Neil and I were blessed to have an older brother that was our staunchest supporter. No matter what obstacles we were facing, Amit unfailingly offered words of encouragement. He cheered Neil on in his baseball games, voiced his good luck for my debate competitions, and he continues to be someone we can look to for unconditional love. His diagnosis of PWS did not limit our ability to fully participate in activities that were important to our family, but instead strengthened our family ties. Amit has always been our older brother first, with his diagnosis coming in a far second.

Having grown up with a brother with a developmental disability, it was no surprise to anyone that Neil and I both decided to go to medical school. Our home life nurtured this choice and we felt that we had much to offer in the way of experience. With the help and guidance of our parents, we did well in college and were accepted into medical school. This career path would be difficult for anyone to follow, but I think we had a better time of it because of our childhood experience. It was comforting to know that no matter what challenges



In the picture from left to right: Suman Patel (mother), Neha Patel (sister), Neil Patel (brother), Arvind Patel (father), and Amit Patel (brother).

*We see our life as  
siblings of a brother  
with PWS filled  
with inspiration and  
infinite possibilities.*

were in our way, we could always come home to our family and find comfort there.

I pursued a career in pediatrics while Neil decided internal medicine was his calling. And, while the journey has not always been smooth, we still were able to accomplish our goals. We discovered that PWS was not our obstacle, but our motivator instead. It challenged us to work harder, to think outside the box, and to think of others first. We learned not to prematurely place limitations on our shoulders, especially when we had a

brother who had no limitations in what he could do. And, we realized that no goal was unattainable regardless of the situation.

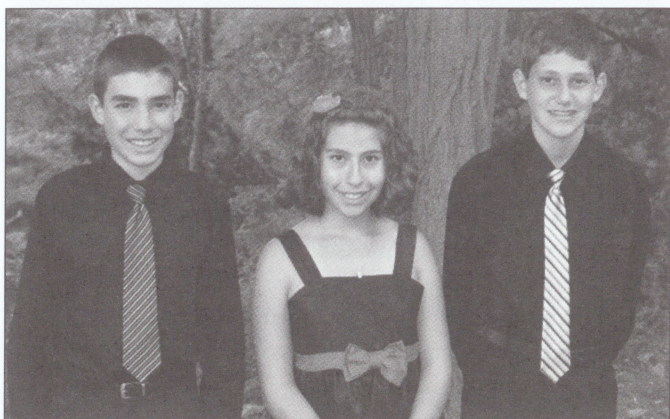
Neil and I know that we could have used Amit's diagnosis of PWS as a reason to limit our expectations of ourselves. But, then we would be limiting his expectations of us, and that we could not do. We see our life as siblings of a brother with PWS filled with inspiration and infinite possibilities. We have fulfilled many goals and we continue to set new ones. In the future, we will have families of our own but Amit will always be a part of it, as a brother, as a friend, and hopefully as a beloved uncle. Our life may have been different if we were not affected by PWS, but I know we are better people because of it. ■

on the  
**MOVE**  
PRADER-WILLI SYNDROME ASSOCIATION (USA)

To order **On the Move** products today, contact Pam Ferrara at 941-312-0400 or email [pferrara@pwsausa.org](mailto:pferrara@pwsausa.org)







## Honor Roll Recognition

*By Ann Baird, mother*

I want to share some wonderful news with you. Rebecca has always been a hard worker and it has paid off...Rebecca made the honor roll!

Rebecca is 12 years old and in the 5th grade (we had her repeat Kindergarten). She has ELA and Math in a small resource room and goes to her regular class for Social Studies, Science and all her specials. An aide from the resource room goes into the classroom with her to oversee her and other kids in the class. Rebecca used to have a 1:1 aide when she was younger. As she's getting older, we want her to become as independent as she can be and she's shown us all that she can do it. We know anything can change at any time, but for now, she is doing better than we ever imagined and we couldn't be happier!

I'm also happy to report that Rebecca is not seeking food, does not always eat everything on her plate, and will tell us she's full after eating.

Not sure if it's the conditioning we've done with her all these years telling her that we are all full after we eat, so she says she's full, but whatever the reason is that she's doing so well, we'll take it! ■

## The Faith of a Champion

*By Amy McDougall, mother*

Noelle (age 11), our middle child and only daughter, has PWS. At first glance, she seems like a "girly girl" who loves to be dressed in her own style and loves animals. We have fostered a strong work ethic in all of our children with the stance that accomplishments aren't what is truly important, rather the level of effort that you give. Noelle rises to this challenge every day: in her schoolwork (which doesn't come easily), in therapies (many of which she no longer qualifies for), and importantly, how she advocates for herself.

What you don't see is her determination and strong-willed nature. Noelle can explain how PWS affects her and will ask for opportunities to educate others as to how others can best support her, particularly in dealing with hyperphagia.

Her participation in normal activities such as dance, soccer, cheerleading, etc. over the years has pushed her to grow even more. This year (2013?) Noelle was recognized as the Reserve Champion for her division (Lead Line) at the local horse show series, based on her place in points for the shows this past summer. Her trainer alone was aware she had received motor therapies starting in infancy, and there were no accommodations made for her at shows. This accomplishment is all her own and we couldn't be more proud of Noelle and all her hard work! ■

"The adventure of life is to learn. The goal of life is to grow. The nature of life is to change. The challenge of life is to overcome. The essence of life is to care. The secret of life is to dare. The beauty of life is to give. The joy of life is to love!"

*William Arthur Ward (1921-1994);*

Author, Educator, Motivational Speaker



## Aloha

*By Clinton Soo, father*

At the Hawaii 5210 Let's Go! Keiki Run 2014, a Great Aloha Run event, Corbin, age 10 and in the 4th grade, showed determination, pushed the limits and utilized the support team to help realize the thrill of victory in a win for Waikiki School. From four Soo Family participants, \$15 from each registration will be going back to Waikiki School for a total of \$60. We believe in the cause to continue promoting healthy eating and active living in Hawaii schools and families. ■





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## Counselors Corner

### Update on *Older Child* eBook

By Kate Beaver, M.S.W.

We are having so many positive responses to the *Older Child* eBook that was developed to help parents raising children and young adults who have PWS. The feedback is that this eBook contains lots of one- and two-page articles on all the subjects parents call us about for help: Food, Behavior, School, and Medical; it also contains the *Growth Hormone* Booklet. We have had many positive comments about the food section with ideas on brown bag lunches, sample menus and food list. The behavior section has stress trigger charts and how to avoid tantrums, plus great articles by other parents on behavior and food. All of the articles can be printed off when you need them and shared with those who also help to support your child. The eBook is available on a zip drive or a hard copy. If interested, call 800-926-4797 and order your copy today! ■

### School Times eLetter

By Evan Farrar, Crisis Intervention Counselor

Great News! Thanks to Ben Karp's help with getting our second issue of *School Times* out in early January, we already have over 40 new subscribers to the e-letter. Our new subscribers include parents and school professionals as well as parents from the PWS communities in Belgium and South Africa. It is exciting to see this unique school resource grow and evolve to meet the needs of students with PWS. Soon we will have over 400 subscribers after only two issues of *School Times*! ■



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## We Remember

**Ellen (Heath) Magenis, M.D.**, 88, a pioneer in the field of human genetics, died Feb. 4, 2014, at home with her family in Portland. She was married to Dr. Thomas Magenis, had seven children and later divorced. She became the director of the Oregon Health & Science University Cytogenetics Laboratory in 1977 and grew it into an entity recognized internationally for its quality. She also directed her own research laboratory and the genetics clinic for the majority of her 40 years at OHSU. A founding fellow of the American College of Medical Genetics, she served on many editorial boards and became a Professor Emeritus in 2011. Her devotion as an advocate for patients and their families was evident locally and nationally by her efforts on the board of PRISMS (national Smith-Magenis syndrome association

- the syndrome named for her), the Angelman Syndrome Association, PWSA (USA), the Multnomah County Prader-Willi Project Advisory Group and the Prader-Willi Parent Support Group of Oregon. The family would appreciate donations to patients and researchers interested in PRISMS or PWSA (USA).

#### A Personal Tribute

This week we lost Dr. Ellen Magenis. She died at the age of 88, surrounded by her family. She was a mom, a ground-breaking geneticist and physician, an excellent teacher, advocate, and friend.

I first met Ellen 25 years ago, when we took our then 4-year-old daughter to see her, in the PWS clinic at Oregon Health and Science University. Meagan did not have the deletion in the 15<sup>th</sup> chromosome that was considered necessary at that time to be diagnosed with PWS.

As years went by, Meagan, my husband, and I participated in genetic testing. And eventually Dr. Magenis and several colleagues invented a test allowing them to tighten focus on our genetic information to the point where they could see that there should have been a deletion but my genes had transmutated to match 15 as closely as they could and filled the hole. I would tell Ellen, "I'm a true co-dependent-even my genes see a hole and try to fill it." That always made her laugh.

She was so approachable and ever-ready to teach. She supported PWS of Oregon for years before we came along--encouraging parents, researching, and providing support, both emotional and financial.

She had a wonderful mind and heart. She will be greatly missed. Thank you, Ellen. ■

Lennae Elkington  
PWSA Oregon



# USA PRADER-WILLI SYNDROME ASSOCIATION

*Still hungry  
for a cure.*

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[www.pwsausa.org](http://www.pwsausa.org)

**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.

## Staff and Key Contacts

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### MEMBERS ONLY:

Access our website, [www.pwsausa.org](http://www.pwsausa.org), for downloadable publications, current news, research, and more. The Members Only section is now available to everyone and the password is "pws."

Note: If you have difficulty logging in, please contact [info@pwsausa.org](mailto:info@pwsausa.org).

E-mail Support Groups:

We sponsor nine groups to share information.

Go to: [www.pwsausa.org/egroups](http://www.pwsausa.org/egroups)

### The Gathered View (ISSN 1077-9965)

Editor, Lota Mitchell  
Associate Editor & GV Designer, Sara Dwyer  
Andrea Glass, Denise Servais

The Gathered View is published bimonthly by PWSA (USA). Publications, newsletters, the website, and other forms of information and communication are made possible by our generous donors. Consider a donation today to help ensure the continuation of these resources.

Medical information published in *The Gathered View* is not a substitute for individual care by a licensed medical professional.

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

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USA  
**PRADER-WILLI SYNDROME ASSOCIATION**  
*Still hungry for a cure.*

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Reminder – stay informed and  
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Sign up today at [www.pwsausa.org](http://www.pwsausa.org)!

**Did you know?**  
PWSA (USA), which is  
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support services for  
families and people with  
PWS in the world.



**Contributions to  
The Association**  
The staff is pleased to announce that the  
publication of the list of donors and sponsors  
will be included in the online "e-version"  
of *The Gathered View* for this issue. These  
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continue to support and enrich the families,  
professionals, and chapters who rely on our  
services and resources to make a difference to  
those who need our help.

■ Thank you for your support.

## PRADER-WILLI SYNDROME ASSOCIATION (USA) Attend 2014 OTM Events Across The Country



March 29 - Running Of The Bears 5k - Vestal, NY  
April 6 - Florida Prader-Willi Syndrome *On The Move* - River Ranch, FL  
May 3 - 1st Annual Fighter Jhett Classic - Indianapolis, IN  
May 3 - *On The Move* Michigan - Jackson, MI  
May 3 - P<sup>W</sup>AN<sup>Y</sup> Walk - Syracuse, NY  
May 10 - 4th Annual *On The Move* - Oconomowoc, WI  
May 10 - I Heart Momma 5k - Chicago, IL  
May 17 - PWSA of Indiana *On The Move* - Indianapolis, IN  
May 17 - Walk N Roll - Middletown, CT  
May 18 - Rockin' For A Cure - Queens, NY  
May 31 - Hunter Lens 5th Annual PWSA Golf Event - Lakeville, MA  
June 1 - *On The Move* Walk - New Brunswick, NJ  
Watch for other upcoming *On The Move* Events! To see all the events across the  
country, visit: <https://www.firstgiving.com/pwsausa.org>.