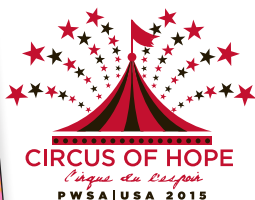


The Gathered View

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



Watch for full coverage of the 2015 National Conference in the 2016 January-February Gathered View!



A Message from Bonnie L. Shelley, Ph.D. Coordinator of Medical Affairs

The two stories below are two recent examples shared by mothers of children with PWS which reflect their positive beliefs in their children. Tessie Hurd is the mother of Mason who is now one year old. Kathy Slabaugh is the mother of Brooke who is now 18 years old.

Professionals, especially teachers, working with children know they develop and learn in different ways. Acquiring skills is easier for some children; they reach milestones sooner while others progress more slowly. Parents with more than one child typically will observe this in their own children.

Children who enter this world with genetic or inherited conditions typically face global developmental delays, that is, delays in more than one area. Such conditions include Down syndrome,

autism, Fragile X syndrome and Prader-Willi syndrome. We know these children can develop and learn despite experiencing developmental delays and, like "normal" children, they will learn in different ways and at different rates.

How is this information important to the parents and families of children with PWS? It is because the expectations of parents for their children to succeed are directly proportional to their belief in their children's abilities. A parent's encouragement for a child to be all he can be, without imparting a sense of entitlement, is critical to a child's view of himself and his development of self-worth.

It is also important that parents are not ashamed of their children's differences. I have yet to meet a parent of a child with developmental delays who has not grieved this awareness at the child's birth. For the sake of both parents and child, grief

has to be acknowledged and set free in order to allow this child to grow up to be the best person he or she can be. Children rise to the expectations and positive regard they receive for who they are.

It is rewarding for me to communicate with a parent or family member after a medical crisis has passed or advice/assistance has been requested. These parents or family members are relieved and grateful. I'm relieved and grateful as well. Medical questions, concerns and crises are part of the life of a child with PWS. Developmental and intellectual concerns are so often compounded by physical and psychological illness. Most people with whom I speak want and attempt to do everything they possibly can do to enable their children with PWS to grow, learn, and develop into healthy, happy, well-functioning adults. I am fortunate to talk with parents who reflect this standard.

MASON

When Mason was born, we knew something was different. There was no crying and he was breathing hard and wouldn't move a muscle. All he wanted to do was sleep. Feeding issues became a focal point. At a good feeding, he'd take 8 cc's and that was always exciting. At 18 days, he was to be discharged from NICU with an NG tube and the prospect of a G tube in the near future. However, two days before discharge, Mason finished his first 48 cc bottle (with a little cheek support) and things just got better! He began finishing more and more bottles and at 8 weeks old, we received permission to remove the NG tube. Many appointments followed and lots of therapy but Mason began to thrive. His head control improved; he began rolling over and he was the happiest baby!



continued on page 2

BROOKE

I knew something was different and missing from the first cry of life. Brooke looked angelic and many commented on this. People told me she was just a floppy baby who was sent home very weak. There were no answers as to why her body temperature dropped fast. We were then sent to University of Michigan Hospitals and still had few answers. Within a few days, a muscle biopsy was completed and several mitochondrial disorders were identified. They gave us little hope. But every day I held Brooke, she showed me her will to stay with us.

I prayed as I sat and read about rare diseases, looking for an answer about Brooke's condition and I kept going back to Prader-Willi syndrome. The FISH blood test was negative for PWS. I continued my research and eventually found



continued on page 2

Volume 40, Number 6 ~ November-December 2015 ~ Our 40th Year of Publication

At 5 months, things changed dramatically and our world crashed down around us. Mason stopped gaining weight, got sick, started having seizures, and returned to the hospital.

*I finally felt there
was help for us
and I wasn't alone.*

Dealing with such a rare condition as PWS in the hospital and ER was overwhelming. One nurse told me he looked malnourished because of his low tone and doctors were uncertain how to treat our child. I felt lost and that's when I turned to PWSA (USA) for help. Without delay, they emailed information to our pediatric hospitalist, sent booklets and pamphlets about PWS to the ER and to me. They also continued to follow up with me to see how Mason was doing. It was amazing! I finally felt there was help for us and I wasn't alone.

After Mason's discharge and multiple follow-up appointments, Mason went back on the NG tube. An EEG came back abnormal, followed by an MRI which revealed some brain abnormalities. I feared this would hold Mason back and things would go downhill from there. Fortunately, Mason proved us wrong again! He came off the NG tube in two weeks, started growth hormone 6 weeks later and he's now finally gaining weight but still a peanut. At 10 months old, he was sitting up on his own, started to weight bear on his arms, scooted all over the place on his back, and rolled around to get into EVERYTHING. He tries to beat us to all the cords and plastic bags and definitely keeps us on our toes. He continues to surprise us as well as his doctors. Nothing's going to stop this kid and I can't wait to see what else he overcomes. ■

a lab in Chicago that used a newly-developed test. Our geneticist agreed to Methylation test and the results were positive for PWS. I had wanted a diagnosis and when received, my hope became belief that we would find an answer to this devastating syndrome.

Life has been hard for Brooke with many ups and downs; I chose to pursue alternative therapies for her which seemed to help tremendously. I went without food for several days, experiencing the feeling of starvation to better understand Brooke's emotions and moods. I have always told Brooke we will never give up. God put her here to love, share and give and that's what happiness is about.

Brooke has had many setbacks, including stuttering. We discovered the Speech Easy Device which literally stopped her stuttering. After several years of training, she stutters rarely, when stressed. She has had gastric problems, allergies, eye problems. We climb one mountain to the top, then another appears.

Brooke's schooling has been difficult to say the least. PWS is rare and many educators aren't familiar with it or related issues. PWSA (USA) provided much information to aid in Brooke's learning. Living in a small town with few special needs students, we kept Brooke in regular school as she would gain much from being included. She was in plays, cross country and track, Girls on the Run, and band. As her programming at the local high school was not meeting her needs, Brooke was enrolled at the Petoskey Schools where she received education better suited to meet her IEP. Changing schools meant that Brooke was not able to graduate with a Certificate of Completion with the class she had been a part of most of her school life. Her 12th grade dream was to graduate and walk the stairs like her brother, Kole. We wanted Brooke's dream of

a graduation ceremony to be fulfilled and we chose to make it happen. I arranged with Harbor Springs Schools to rent the football stadium where Brooke could fulfill her dream to walk the stairs of accomplishments. We put together a graduation ceremony with her brother and his friends walking her down the stairs to Commencement! The Harbor Springs High School band (Brooke had been a member) played "Pomp and Circumstance" which was touching and inspiring. May 30, 2015, a beautiful ceremony was attended by many. Brooke's kindergarten teacher and advocate, Jan McDonald, presented a touching tribute of Brooke's accomplishments. During the ceremony, an eagle circled the stadium most appropriately; one of Brooke's favorite songs, "An Eagle Will Rise Again" was played. *If an eagle appears, it bestows freedom and courage to look ahead and inspires one to reach higher and become more than one thinks she can.* It was a magical evening and Brooke's dream was fulfilled, reinforcing our belief we can accomplish anything in this life together.

To commemorate this evening and her achievements, Brooke received a mustard seed necklace. Matthew 17:20 – "Because of your faith, I say to you, if you have faith like a grain of mustard seed, you will say to this mountain, move from here to there, and it will move, and nothing will be impossible for you." We also gave her a compass by Walt Whitman – "Now Voyager, sail thou forth to seek and find".

Brooke and I speak often of her life's journey and we describe it as a path to unknowns. We have met many angels along the way and we know God is with us, showing us our way. We want to encourage others to not lose hope and to hold strong onto faith and belief in tomorrow.

I am grateful to say the staff at PWSA (USA) has been supportive in every way and we appreciate their huge hearts and help. ■

An Old Problem Reappears

In the mid 1990s, a time of increasing use of group homes, especially for persons with PWS, certain standards--and controversy--arose regarding those individuals' "rights." For those with PWS, the specific issues that questioned the violation of their "rights" were strict dietary management and restricting access to money (limiting ability to buy food).

In 1998 the PWSA (USA) Board of Directors approved a policy paper entitled "Adults with PWS and Decisions Regarding Least Restrictive Environment and the Right to Eat." This is a strongly-worded document in response to several deaths and many others with huge obesity-related crises occurring in the preceding three years as a result.

Today those issues are arising again, powerfully fueled by the "Final Rule of Medicaid Home and Community-Based Services" published in the Federal Register on Jan. 16, 2014. A critical requirement states: "Individuals [must] have access to food at all times." These **Federal Statutes are mandating access to food at will, a situation with potentially disastrous consequences for those with PWS that we love.**

California is experiencing some enforcement of these Statutes with resulting attendant medical disasters. For example, one individual, 26, currently weighs about 400 pounds,



Ken Smith, Executive Director

can no longer live in his home but is in a skilled nursing facility where he needs assistance to walk even ten feet, is wearing diapers because he can't get himself to the bathroom, and needs a ventilator two hours a day and oxygen.

However, for some providers waivers can be achieved allowing for locks when necessary. Exactly what type of provider (Group Home? Supported Living?) can get these waivers is not entirely clear. PWCF (Prader-Willi California Foundation) is and will continue working with state agencies, group homes and supported living agencies to educate them about PWS and brainstorm how to keep within the intent of the new Federal Medicaid regulation, while ensuring the health and safety of the residents with PWS they serve.

In Georgia, Debbie Lange, executive director of the state chapter, describes the Georgia Department of Behavioral Health and Developmental Disabilities as "stringent" in their management of provider contracts, which include day programs as well as residential ones. No agencies in Georgia providing services are PWS-dedicated. Most provider agencies are doing well and implement some sort of food security, but others don't know or understand PWS. One 35-year-old in a day program has gained 50 pounds in seven months with two bingeing episodes. Debbie was invited to do training at

one such agency, but partway through her presentation she was stopped and ejected from the premises! Money from states requires "free access to food."

Waivers of standards are available "for health and safety issues". These require papers submitted by the provider agency plus agreement with guardian or parent. Debbie feels strongly that providers not only need education about PWS but must "buy into" the PWS condition to make the necessary effort to get the waiver. She recommends that parents get help if they feel their child is not being protected from food.

She also notes that the application for a "waiver of standards" is useless unless the individual service plan (ISP) and supporting documents clearly reflect why there is a need (PWS) and what type of food security (global environmental restrictions - locks, money, etc.) is needed. If a parent is made aware of the importance of the ISP, and it is written to support PWS, it will go a long way to documenting our position.

The Advocacy Committee of PWSA (USA) would like to work with all state chapters and interested stakeholders in addressing this very important issue, but states and members have to provide the information for a plan to be developed to deal with this threat to the health of our adults with PWS. This is an ongoing problem which will require vigilance on the part of parents and guardians. Let your state chapter know, let national know. Please contact us. ■

*Best wishes for a holiday season filled
with joy, love and peace*



Maddox

Angel Campaign

Watch your mailbox for this year's angel solicitation. This is our largest campaign of the year, and your donation will help us meet the quickly growing demands of our PWS community in 2016. Please give generously. ■

Oxytocin Phase 2 Study Update

As of this printing, over \$400,000 has been raised for this exciting and potentially life-changing research study for our children with PWS. Drs. Miller and Driscoll from the University of Florida will lead this multi-site dosing study that will begin in 2016. ■



Completed Events:

Many thanks to our dedicated PWS community members that made the following events so successful! Your hard work and commitment to PWSA (USA) is appreciated beyond measure. Funds raised will support many different programs

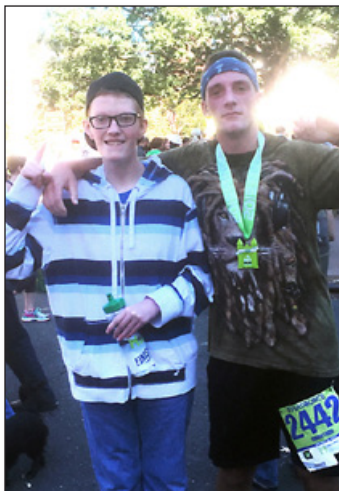
for those affected by PWS on a local and national level.

Idaho "On The Move" Walk: \$5,000

Hosted by the Idaho chapter at Ann Morrison Park on September 5 (*above*)

Sarasota "On The Move" Walk:

\$4,000 Hosted by PWSA (USA) at JD Hamel Park on September 19 (*below*) ■



Fundraiser Spotlight:

Leo McCarthy: Raising Funds while Running

Leo, a student at the University of Vermont, ran the Hartford Marathon in Connecticut on October 10th in honor of his little brother Gregory who turns 17 this month. Leo says, "Sometimes I find it hard to get along with my brother but I really do care about him and I wanted to do something that he would appreciate". Leo has raised over \$1,100 by setting up an



online, personalized fundraising page and making it easy for his friends, family and community members to donate to his cause. Leo is an awesome example of how an individual can make an impact by raising funds and awareness for PWS.

Running a marathon is just one of the

many different ways to fundraise. To set up your own online fundraising page or more information on ways to make an impact in your community, please contact Leanne Gilliland at Lgilliland@pwsausa.org or 941-487-6743. ■

Fundraising

We Have A New Website!



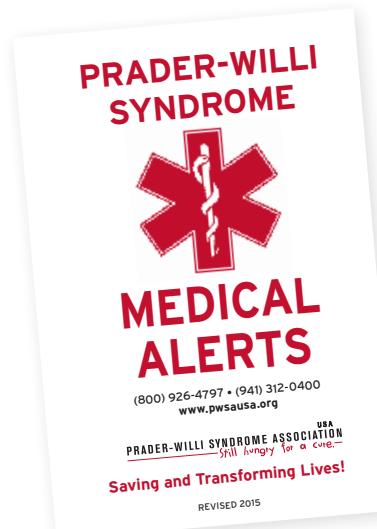
We are proud to announce the new PWSA (USA) website is live. The new look and feel is the result of much development and planning, designed especially for our community. You may navigate easily around the site with user-friendly technology across all device platforms (desktop, laptop, tablet and mobile). Our new site is easier to browse – new search bar features make searching for pages a snap! Family Support, Medical, and Research sections are more user-friendly and you can find the information you want faster. You can even sign up for one of our fundraisers (*On The Move* or *eWalk*), with our registration forms in our “Support Us” section.

Exclusive! PWSA (USA) members will enjoy the “Members Only” section. It’s eye-catching and searching through past issues of *The Gathered View* and other exclusive publications is easy. Enjoy browsing the new online shop featuring PWSA (USA) apparel, accessories and publications for purchase at your member discounted rate. Thank you for all of your support and we hope you enjoy the new PWSA (USA) website! ■

Hot off the Press!

Medical Alerts

by PWSA (USA)
**20% discount
for members**



A newly revised **LIFESAVING** medical resource for parents/caregivers! This is crucial medical information along with the GI lifesaving

chart to be handed to doctors, ER staff, EMTs and all caregivers. The content was written by our medical professionals. **It’s imperative that this pocket-sized medical booklet be with you at all times.** The lifesaving **Medical Alerts** Booklet (\$3.00 ea) features a new, large foldout G.I. algorithm chart. This algorithm will help direct ER medical staff what to look for and do, when GI problems are presented in PWS.

Publications available via the website, visit: <http://pwsausa.org/product-category/books-publications/>. ■

Our New Mobile App Is Going Live!

Please look for our new PWSA (USA) phone app in the iPhone and Google Play stores. The app will work on all mobile devices and will give fast information at your fingertips, and allow you to go direct to our website for certain information without leaving the app.

Our gratitude goes to Rick and Kim Settles, in memory of their son Patrick for their donation to help PWSA (USA) create an iPhone app. We hope you find this useful and enjoy! ■

Bang! It’s Amy!



On the set of Big Bang Theory with the stars!



This bottom picture includes Salideen Patterson, Celika’s college friend who is a writer/co-producer for the Big Bang Theory.

Submitted by Leon Caldwell. A PWSA (USA) board member, Leon currently is a Senior Research Associate at The Annie E. Casey Foundation in Baltimore, MD.

Our family went to LA in August and got to meet the stars of the *Big Bang Theory*. My wife, Celika, is old college friends with one of the *Big Bang Theory*’s writers and co-producer, Saladin Patterson. (They were at MIT together – interesting career change from engineer to writer and producer.)

The trip was awesome. Mayim was great and really enthusiastic and knowledgeable about PWS. Mayim Bialik (Amy in the show) has been doing some awareness PR for us and did her PhD thesis on PWS!

Here is the link to her video about PWS: <https://youtu.be/1XIVk1U-E04>

Educating Endocrinologists Around The World

By Janalee Heinemann, M.S.W.,
PWSA (USA) Coordinator of Research
& International Affairs



Mariona Nadal with a doctor from Morocco

Thanks to an unrestricted educational grant from Pfizer, our Prader-Willi syndrome international organization, IPWSO, was again able to provide an extensive amount of educational materials on Prader-Willi syndrome (PWS) to physicians at the European Society for Paediatric Endocrinology (ESPE) Conference that was held in Barcelona, Spain in October 2015. It was the 54th annual ESPE meeting. To show how much the interest in PWS has grown around the world, we had 460 flash drives with educational materials [much of it provided by PWSA(USA)] in multiple languages that we distributed, and all were gone before the end of the conference. We also distributed medical alert booklets in 17 languages. It is wonderfully encouraging to know we can make such a difference in a short period of time. As we have seen in the past, physicians from many countries were also very grateful to learn about our free diagnosis for countries that do not have the option of DNA methylation testing. IPWSO provides this service in collaboration with the Baschirotto Institute for Rare Disorders

(BIRD). Some new countries that were especially appreciative of this option were Vietnam, Bahrain, and South Korea.

Dr. Maité Tauber, one of our PWS experts in France, gave two presentations on the syndrome, and there were 17 posters presented on PWS – more than in any ESPE conference in the past. There was also a great interest from several pharmaceutical companies who are doing clinical trials, or are interested in doing clinical trials, on drugs for the syndrome. Most of them are working on drugs that have the potential to help the obesity and hyperphagia (uncontrollable drive to eat) so we are certainly happy to educate and work with them!

Some interesting facts from France that Maité presented are:

- The mean age of diagnosis was 17 days in 2013
- They have 54% with deletion and 43% with UPD (a higher rate of UPD than most studies have shown in the past) and 3% with translocation
- The prevalence at birth in France is one in 19,000

Our awareness booth was hosted by me, Giorgio Fornasier from Italy, and Mariona Nadal from Spain. Marguerite Hughes from Ireland also assisted prior to the conference in some of the organizational details and creating the flash drive. Mariona is a PWS sibling who is on our IPWSO board. This is the 1st conference in which she assisted us, and she was a tremendous help! Besides putting together some of the materials that had to be created in Spain, she was able to communicate with the many endocrinologists from Spanish-speaking countries, plus she also speaks French fluently. She was also able to explain the IPWSO android App for PWS called Prader-Willi World (PWW) – because she created it. I am always impressed by Giorgio's fluency in multiple



Giorgio Fornasier with a physician from Bahrain

languages and his understanding of the politics and cultural issues in so many countries. My expertise is in the medical and research field, so the 3 of us made a good combination of skills needed to communicate.

Mariona was able to see first hand what Giorgio and I have known for years – even though we have 3 days of long hours at ESPE, not including the massive amount of work it takes before the conference to get it organized, seeing what a difference we will eventually make in the lives of so many PWS families always revitalizes our spirit and enthusiasm.

Each physician from the 41 countries who visited our booth will go back and share this information with other physicians who will then have the education and materials they can use that will help every PWS family they eventually treat. We cast our net wide upon the waters of the world and lives will be saved thanks to PWSA (USA)'s collaboration with IPWSO – and thanks to Pfizer for making this possible through their funding. ■



The Global Prader-Willi Registry: Join the Movement!

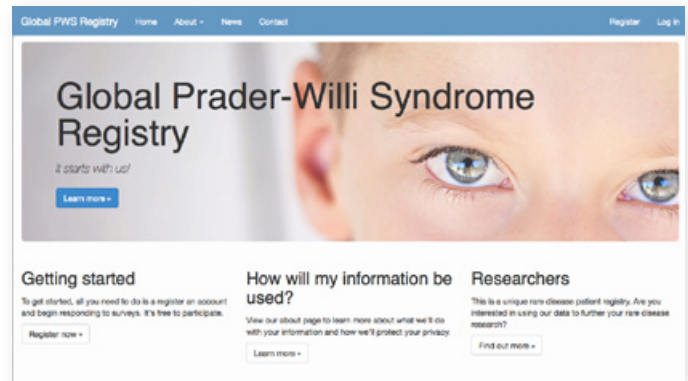
By Evan Farrar, PWSA (USA) Family Support Counselor

I recently represented PWSA (USA) at the Foundation for Prader-Willi Research (FPWR)'s national conference for parents and families in Austin, TX. It was a great gathering and I was honored to help lead a session on special education advocacy with my colleague, Tanya Johnson, who is a member of the PWSA (USA) Special Education Advisory Board.

It was also my first opportunity to really learn about the Global Prader-Willi Syndrome Registry – a project that is critically important to the entire PWS community because it will advance PWS research faster than ever by providing researchers with comprehensive, accurate, and research-ready data that is easily accessible. The Global PWS Registry is a secure database compliant with U.S. Health Information privacy laws, and FDA regulations that will:

- Document the full range of PWS characteristics – across the lifespan.
- Expedite completion of clinical trials.
- Drive unmet research and treatments.
- Guide standards of care.
- Improve the lives of those affected by PWS.

But to achieve these goals, and create the most robust PWS registry possible, every person with PWS should be included in the registry. Through a series of electronic



surveys, the registry collects information on a wide range of topics including developmental history, medical complications, and quality of life issues. So whether your loved one with PWS is 2, 15 or 52 we need your help in making sure they are included to provide a complete picture of the PWS community. This is a great way people with PWS – of all ages – can help advance research, develop new treatments and improve the quality of life of the entire PWS community. It is also a powerful reminder that every person with PWS matters – and so does their unique life experience. So if you are a parent or guardian of a person with PWS, join the movement today to build the Global Prader-Willi Syndrome Registry by visiting www.pwsregistry.org ■

The following is to help our members understand the differences between the various registries/medical database:

Global Prader-Willi Syndrome Registry – explained in Evan's article above.

RDCRN registry – Rare Diseases Clinical Research Network (RDCRN) is an extensive ten-year natural history registry that was created and compiled by the PWS centers involved with this extensive NIH (National Institutes of Health) project. All of the information was inputted by medical staff, so it would be considered to have the most accurate data. But, the RDCRN grant is now completed and the registry will not continue, but the information will soon be available for other medical professionals and researchers.

PWSA (USA) medical database – thanks to over 1900 PWS families, we have an extensive historical medical database that has been extremely helpful for medical professionals, researchers, and pharmaceutical companies. This medical database will not continue in order to encourage families to participate in the new global registry, but this valuable information will remain available. ■

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 directar a 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. iHablamos pronto! ■

PWSA (USA)'s Focus on Saving Lives – A New G.I. Grant Approved

By: Janalee Heinemann, M.S.W., Coordinator of Research & International Affairs

Due to the fact we receive the medical crises calls at PWSA (USA) and study the deaths, we have a special interest in finding the cause and prevention of serious G.I. complications, aspiration, and choking. With this goal in mind, PWSA (USA) has approved funding of a grant submitted by Dr. Karla Au Yeung, “*Prevalence Of Dysphagia In Prader-Willi Syndrome With GE Reflux As A Contributing Factor*”. This study will complement the swallowing research we are sponsoring by Dr. Roxann Gross. The following is a short explanation of the Yeung grant.

Prader-Willi Syndrome (PWS) is a complex genetic condition that presents with multiple factors throughout a child's life predisposing him/her to **gastroesophageal reflux disease** (GERD) causing potentially life-threatening complications. For example, in infancy, hypotonia may prevent normal feeding due to poor strength and coordination of sucking and swallowing. This leads to poor weight gain which affects development and further feeding problems, and may lead to complications of GERD causing laryngeal chemoreflexes and risk for apnea or aspiration. As the child ages, obesity is a complicating factor that aggravates GERD. There are complications related to obstructive sleep apnea (OSA) which may be exacerbated by GERD and lead to apnea and/or aspiration of oral contents in infants and older children. Finally, salivation is diminished in PWS patients compared to controls which contributes to dysphagia (swallowing difficulties) symptoms.

There is no data available on the severity of GERD in PWS, but the prevalence of dysphagia in PWS has been documented by Dr. Gross in her recent study supported by PWSA (USA). Through the Yeung grant, they will examine

the relationship that may exist between these problems. As is often the case with GERD, it can be silent and increase severity of another disorder even though the disorder alone would not cause as much morbidity. Furthermore, choking deaths have been reported in 5%-8% of individuals with PWS. What component of dysphagia is due to GERD is unknown.

Multichannel intraluminal impedance (MII) monitoring is a tool that is utilized with pH measurement in the esophagus to measure the frequency of gastroesophageal reflux as well as the acidic nature of the contents in the esophagus refluxed from the stomach. MII/pH is considered the gold standard for measuring gastroesophageal reflux. The instrument can also be used to correlate whether or not swallowing dysfunction symptoms occur when reflux happens.

The first aim is to send out a dysphagia symptom questionnaire to patients identified with PWS to discover the prevalence of dysphagia in PWS and compare to tests results of GERD or dysphagia when they are available. The second aim of this study is to evaluate the severity of GERD in children by obtaining reports from those patients who have already undergone testing with 24-hour pH/impedance continuous monitoring, and any other prior testing done to assess swallowing dysfunction or GERD such as video

fluoroscopic swallow studies, esophagrams, and upper endoscopy with biopsies. This study will be done in cooperation and collaboration with Dr. Ann Scheimann. ■

(Note: Recently, the daughter of one of our longtime active members choked to death. She was slim and doing well in supportive living. When her caregiver went into the bathroom, she slipped out into the garage and got in the garbage. Although it was only a couple of minutes, her caregiver was not able to revive her. I was just reporting on the study of death at a couple of meetings, and included the eating binges and choking deaths. As I told the attendees – although complications from morbid obesity are still the leading cause of death, hyperphagia without obesity still is a major risk factor. This death is a sad example of why we need to keep moving forward regarding a better understanding of the PWS G.I. and swallowing issues.)

...we have a special interest in finding the cause and prevention of serious G.I. complications, aspiration, and choking.

“Be the Seed. Seeds surrender themselves to the ground so they can be used for a greater purpose. Wherever you work, decide to plant yourself where you are and allow yourself to be used for a greater purpose. When you plant yourself and make a difference you grow into the person you were born to be and produce a harvest that will benefit others and change the world. New morning means a new beginning, a new struggle, a new endeavor, but with God by our side, we can overcome any challenges and turn obstacles into stepping stones.”

– John Gordon contributed by Clint Hurdle

We are all Warriors!

By Janalee Heinemann, M.S.W., PWSA (USA) Coordinator of Research & International Affairs

In October I attended the Rare Diseases and Orphan Products Breakthrough Summit 2015. One of the speakers was 10-year-old Hunter Pague, who has SMARD, a very rare disease significantly affecting both spine and lungs. – 12 in the US and only 80 worldwide. He said, “*SMARD is not who I am, it is only a part of me. Be the voice of hope – what we have done is not only for us, but for everyone with this disease.*” In speaking about all rare disorders, Hunter said, “*We are all warriors, achievers, and champions!*” In spite of needing support to breathe and being in a wheelchair, Hunter is a strong advocate – and indeed a champion for rare disorders.

There are over 6800 rare disorders. 50-75% begin in childhood and of those, 30% will not live to see their 5th birthday.

A speaker pointed out that everyone is walking around with a life-threatening gene...it just may not be visible yet. You do not have to understand all of the science – but there’s still something you can do to advocate for your own rare disorder: tell your story. He said, “*We can read 100 times in a textbook about your disorder, but if you tell us your story it will be what is burned in our memory.*”

This meeting featured over 20 speakers from the FDA with participation from over 80 patient organizations and from the Pharma/Biotech industry’s foremost experts in orphan products. There was extensive talk about the issues of drug development, which is very expensive -- \$5 billion per drug on an average, and the failure rate is 95%. Also, a trial put on clinical hold creates a risk to additional studies.

For the FDA, the big ethical dilemma is, “How do you balance risk versus benefit of a clinical trial?” One speaker

acknowledged that at the end of the day much of the benefit-risk assessment is a value judgment. This is why the input of patients and patient advocacy groups dealing with the rare disorder is so valuable in their decision-making. There has been a major evolution in the FDA thinking; now the big emphasis is that the researcher must have a partnership with the patient organization and their families. This patient engagement has become more and more important to the FDA, which is evident through a major funding source, the Patient Centered Outcomes Research (PCOR) grants.

The speaker for the National Center for Advancing Translational Sciences (NCATS) said it usually takes 1 to 1½ years to get a clinical trial started. They want to reduce this time significantly. One example is their effort to centralize universities and hospitals internal review board (IRB) approval. When a clinical trial involves more than one site, the process of getting each center’s IRB approval can be incredibly burdensome and time-consuming.

Today’s better understanding of biology and genetics makes it easy to work on an actual targeted drug. Gene therapy is on the cusp of being a reality – just not for PWS yet because of PWS being a multigene issue. Another very positive advancement for rare disorders is that now we can know what’s going on in the world of PWS instantly, thanks to global connections through the Internet. You are not so alone when you can communicate daily with the world.

The keynote speaker at this conference was Jono Lancaster who has Treacher Collins syndrome (which can cause significant facial deformities). His story was very candid and inspiring, but it deserves to stand alone in a future article. Jono eventually learned to accept who he was. He said, “*My face didn’t change – my attitude changed. I learned to believe in myself. A bad attitude is more disabling than anything.*” ■

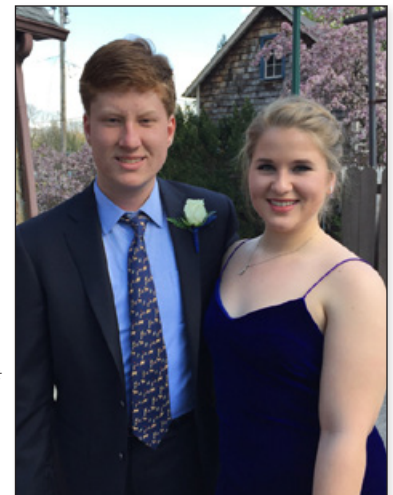


ATTENTION Federal Employees!

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. ■

Mr. Alex Argawal attended the Zionsville Community High School Best Buddies Prom with his best buddy Miss Isabella Goodwin May 2, 2015, held at the Lions Club Clubhouse, Zionsville, IN



From 2015 National Conference



Synopsis of a Seminar: Dr. Stephen Porges, Polyvagal Theory

By Andrea Glass

Always interested in alternative medicine and therapies, I attended the seminar given by Stephen W. Porges, Ph. D. from the Kinsey Institute. Dr. Porges taught us about his Polyvagal Theory. This may sound familiar to you, as you may recall research in the UK on vagal nerve stimulation. Dr. Porges spent some time during our conference observing and speaking with parents and individuals with PWS.

His wife, Dr. Sue Carter, is also now involved in PWS through her studies on Oxytocin. During his seminar he touched briefly on the possible connection between the characteristics of people with PWS and atypical autonomic regulation. He is considering including PWS individuals in his studies. One of Dr. Porges' goals is to apply to PWS an intervention he developed using computer altered vocal music to improve autonomic regulation and social engagement behaviors.

The Polyvagal theory encompasses the concept of autonomic regulation. Polyvagal Theory gets its name from the two branches of the vagus, the cranial nerve that is the predominant regulator of the parasympathetic nervous system. One branch is associated with the regulation of the heart and the muscles of the face and head. The other branch is linked to the regulation of the gut and other organs located below the diaphragm. The theory describes a "Social Engagement System" that involves the branch of the vagus involved in cueing and detecting social cues. When the Social Engagement System is dysregulated, a cluster of behavioral and autonomic features emerge that are coincident with many of the behavioral and autonomic characteristics of PWS. The Social Engagement system is neurologically how we connect to others. He speaks about true connection. Not just 'hugs' but HUGS. In his

seminar he shows pictures of one person connecting with another or an animal. He asks us to focus on the eyes as he emphasizes the "face-heart connection" in typical persons. Now he shows some pictures of individuals with PWS. We can observe the difference in the social engagement system responses. The noticeable deficits include lack of prosody (intonation of voice); gaze; facial expressivity; mood and affect; posture during social engagement; state regulation; ingestion problems; and sound hypersensitiveness. The slides show pictures of the connection between the corticobulbar pathways (neural pathways from the cortex to the brainstem that regulate muscles of the face, head and neck) and the vagus nerve. The connection is a critical component of the social engagement system. It "provides a portal to exercise the neural regulation of physiological state via face-to-face social interactions."

Dr. Porges' slides describe Polyvagal Theory as:

- 1. Evolution** provides an organizing principle to understand neural regulation of the human autonomic nervous system.
- 2. Three neural circuits** form a phylogenetically-ordered response hierarchy that regulate behavioral and physiological adaptation to safe, dangerous, and life-threatening environments. [When evolutionary newer circuits are unsuccessful in maintaining a state of safety, we use older circuits that evolved for defense].
- 3. Neuroception** of danger or safety or life threat trigger these adaptive neural circuits. [Our nervous system evaluates risk without awareness].

He is basically describing my child with PWS, showing that there is a connection between the behaviors I see in my child and the Social Engagement System. The inability to suck and swallow as a

baby; the lack of eye contact (connection); the muted facial expressions in his adorable face; the lack of prosody in his voice; his inability to read social cues, such as personal space. I also make a connection to his defensive strategies such as shutdowns (evolutionary freeze strategies) and tantrums. All these behaviors are a reflection of difficulties in the neural circuits defining the Social Engagement System.

Dr. Porges is conducting research on a listening protocol in which he presents acoustic stimulation, such as

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The Social Engagement System is neurologically how we connect to others.



Andrea Glass with son Ian, at the 2015 PWSA (USA) National Conference YAP Dance Gala

Porges, continued from page 10

computer-altered vocal music, to exercise the Social Engagement System. In research with children with autism, the protocol improves several features of the **Social Engagement System**, including improvements in the vagal regulation of the autonomic nervous system. The connection between the corticobulbar pathways regulating the muscles of the face and head (including muscles in the middle ear that dampen auditory hypersensitivities and improve auditory processing) and the vagus nerve may lead to music therapies that can help our children with PWS improve their social engagement system. I'm hoping we will be hearing more about this concept in the near future. ■

CHUCKLE
CORNER

We were out of town and left our daughter with PWS home with her elderly favorite baby sitter. I called daily to check on her and hear about their fun adventures. One day I called and the sitter exclaimed that all was fine and the fire department was just leaving. Ready to fly home immediately, I asked her if my daughter was alright. The sitter said that she was, but that she, the sitter, had put the bicycle lock on backwards on our side by side refrigerator and it had to be cut off! Needless to say, I had to visit the fire department upon my return to explain the necessity of a lock on the refrigerator!

~ Mimi Bush
Olmsted Falls, Ohio

Flashback 2008–2015

By Sara Dwyer, Editor, *The Gathered View*

Then and Now.

In 2008 *The Gathered View* team was comprised of editor Lota Mitchell, me as graphic designer, writers Andrea Glass and Denise Servais, and others. Personally, seven years of learning about PWS by osmosis pales in comparison to attending a National Conference. Overwhelming? Yes, but what a joyous time - meeting many I'd only read, written, admired and conversed with electronically for years; I loved every minute! What was your favorite part about conference? Oops, that's for the next issue. Let's take a look back...

2008 Our organization grew in size and service with 30 chapters plus PWS support groups. PWSA (USA) began a proactive movement to help every family affected by PWS find support either through a local chapter or in focus groups. Through a pilot project launched in 2007, families had access 24 hours a day, 7 days a week, to emergency medical counseling and referral. PWSA (USA) doubled spending on research in 2007. Families were encouraged not to wait until a crisis to call, as the office staff was available to assist with their needs.

A PWSA (USA) delegation attended the **First International Caretaker's Conference** in Herne, Germany, sponsored by the International Prader-Willi Syndrome Association (IPWSO). IPWSO president **Pam Eisen**, from Wormleysburg, PA, lost her battle with pancreatic cancer.

The **PWSA (USA) 2008 National Conference** was held in Milwaukee, WI.

Eastside High School, Greenville, SC, presented a \$224,575.59 check to PWSA (USA). Raised from the school's

week of fundraising, this PWSA (USA) fund will provide crisis and support services for families affected by PWS.

2009 An electronic task force, the **Advocacy eGroup**, was created. **Research** studies included two by the Pacific Graduate School of Psychiatry, funded by PWSA (USA); these focused primarily on the parents and family system with another on siblings. Surveys gathered data with 1,747 families responding to the first survey/questionnaire. The "crown jewel" of membership benefits, **New Parent Mentoring**, initiated by Carolyn Loker and Janalee Heinemann, matched families new to PWS with families, who through life experience, became empathetic experts.

The **first International Conference on Hyperphagia** was held in Baltimore, MD, in June. The 24th Annual Scientific Day Conference, Annual Providers Conference, Clinical Advisory Board (CAB), Providers Board, and Scientific Advisory Board (SAB) also met then. PWSA (USA) announced two BIG (Best Idea Grants) awards on Hyperphagia: Leptin resistance in mouse models of hyperphagia, and Brain-Derived Neurotrophic Factor in Prader-Willi Syndrome and MC4R Function-Altering Mutations. Webinar "The Truth About Consequences" was presented.

The **second International Caretaker's Conference** was held, thanks to Norbert Hödebeck-Stuntebeck and Dr. Hubert Soyer. Two new lectures will be part of every Caretaker's Conference: the Pam Eisen Memorial Lecture and the International Lecture. PWSA (USA) co-sponsored an awareness booth with IPWSO at the **world's largest endocrinology conference** in New York. The PWSA (USA) Tribute Dinner honored national spokesman **Clint Hurdle** in Denver, Colorado.

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40 Year Flashback

Flashback, continued from page 11

2010 The Oklahoma family of Ethan Starkweather was selected for ABC's popular *Extreme Makeover: Home Edition*. Dr. Suzanne Cassidy presented webinar "Prader-Willi Syndrome: An Overview for Parents of Young". Chapter development grew, and many support groups moved toward chapter status. National Institutes of Health (NIH) awarded **\$117 Million for Rare Disorders Grant** including Prader-Willi syndrome research. A **national Prader-Willi Syndrome Awareness Month** is official! **IPWSO 7th Scientific Conference** in Taiwan was followed four months later with Dr. Loisel Bello holding the **first PWS meeting in Cuba**.

2011 The *On The Move* campaign was launched, as well as more grassroots events and a Facebook page for PWSA (USA), The **Willett Fund donation** helped provide school staffing assistance and enabled patients to be admitted to The Children's Institute. The **Best Practices Guideline** publication was introduced. The **Family Support team** added Nina Roberto for our Spanish-speaking members, plus programs for Parent Mentoring, Medical Support and Crisis Intervention. The Children's Institute, whose PWS program began 30 years ago, expanded their PWS Unit. The **National Conference 2011** moved to Orlando. Five Hyperphagia grants were sponsored by PWSA (USA).

2012 The **Hurdle Endowment for PWS Support** was established. The first **FDA Patient Advocacy Conference** was attended by Janalee Heinemann. NIH Partners in Progress were awarded to Dan Driscoll and Janalee Heinemann. The **second Hyperphagia Conference** was held in Baton Rouge, LA. Dottie and Dale Cooper, whose daughter Shawn has PWS, became Interim Executive Directors.

2013 saw the first two-day **Wyatt Special Education Advocacy Training** (WSEAT), an **IPWSO Conference** in Cambridge, UK, the death of **Marge Wett**, first executive director for PWSA (USA), the **School-Times e-letter** launched, the opening of a **PWS inpatient facility at Healthbridge Children's Hospital** in Houston, TX, and "**Teacher Tips**" added to YouTube. The **Nicholls Ride for Research** fundraiser finished at "Survivor – Orlando", the **PWSA (USA) 2013 National Conference** in Orlando, where Lota Mitchell received a lifetime achievement award.

2014 **Ken Smith** became **Executive Director**. Beloved Volunteer Crisis counselor and friend to all, **David Wyatt** passed away on April 7. The **David Wyatt Crisis Fund** was set up in his memory. Fundraising events grow with *On The Move*, Angel Campaign, 5Ks, marathons, fishing tournaments, AMAZON Smile, and chapter events. A PWS Medical database survey was developed. The **Chapter Relations Committee** was formed, led by Crystal Boser (PWSA (USA) -WI chapter president). A PWS team made a

presentation with a Q&A to the FDA. Significant interests by pharmaceutical companies lead to other drug studies underway. **Medical Affairs Coordinator** Bonnie Shelley and **Director of Fund Development** Jack Hannings joined the National office. The **Federal ABLÉ Act** passed.

2015 75-80% of every dollar raised goes directly to family programs and services. **PWS growth charts** were published with funding by PWSA (USA) and NIH-RDCRN. New **e-Walk** fundraising began online. Webinars for Beloranib and Oxytocin Phase 2 were given. The Flow (algorithm) chart for GI complaints was created. A new **Special Education Advisory Board** (SEAB) was created to help parents and school professionals work together to support students with PWS. An **iPhone app** is soon to be released. A very successful "Circus of Hope" **2015 PWSA (USA) Conference** was held in Orlando, with a special honor presented to conference co-chair Jackie Mallow.

Actress **Mayim Bialik** brought a new level of awareness to PWS with her video and posts to social media.



Jackie Mallow, with Lori Moline and Ken Smith

No words can give proper gratitude and commendation deserving to all, then and now, who made and continue making life-changing differences for children with PWS. ■

Do you Self-Care?

By Kathryn Lucero

Self-care is defined as "care of the self without medical or other professional consultation." Do you self-care? For many of us this may be a loaded question. You think to yourself, when do I have time? There not enough hours in the day for me. As parents and caregivers we put others before ourselves. Some may consider this wrong, but I consider this life. We think to ourselves, if I take time for me then everything else will fall apart.

...Or will it? If you take just 10 minutes a day for yourself to clear your head or do something for yourself, imagine how you will feel. Ten minutes is not a lot of time, but when you feel as if you don't have the time, it's so valuable. In just 10 minutes or less you can meditate, sit outside and breathe in the crisp air, close your eyes and clear your head, go for a walk, read, or journal. Some people even like to cook or bake. In that short span of time you can care for yourself. I tell people I work with that if you cannot take care of yourself, then how will you care for your loved one?

The people we care for are important to us, so why don't we show them that it's important to take care of ourselves,

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too? We want to be the best role models, and by taking care of ourselves that is how it's accomplished.

What do you do for self-care? Take a few minutes and write down some things you can do to take care of yourself. After you do this, take one of those ideas and try doing it once a week. That's it, just once. Small steps can accomplish big things. Good luck and ask yourself: Do you self-care? ■

Reference: American Psychological Association (APA): self-care. (n.d.). Dictionary.com Unabridged. Retrieved October 27, 2015, from Dictionary.com website: <http://dictionary.reference.com/browse/self-care>



We Remember Life According to Kim: 1963 - 2015

By Judy Ipsen

For 52 years, I thought this was my story — my life of raising and caring for a person with Prader-Willi syndrome. My husband was as involved as I, but I will express my own perspective and seek his approval. In reality, this is Kim's story — a story of survival in a world where we expect everyone to be normal according to our own definition of the word.

Who are we when our bodies are not perfect? "What kind of life is that?" is a question we ask *before* a disability comes into our life. Not after. When I looked down at that tiny four-pound bundle placed in my arms, my first thought was "perfect!" It was others' opinions that tried to cloud my perception. "Mrs. Ipsen, we think your child is premature, and these babies sometimes don't survive." One look into Kimberly's eyes told me all I needed to know—this child would live. Whenever doubt crept in, an interlude on my knees in prayer at my bedside gave me all the assurance I needed.

I recall a frustrated doctor counseling me when he thought I was not paying attention: "Mrs. Ipsen, I am trying to tell you your daughter may not live. We don't know what is wrong with her — it could be one of many things, but she may not survive." I looked at him in wonder, "He doesn't understand. He really does not know that not only will

she live — she will live a full life!" That began what I thought was MY story — my commitment to see that Kim had every opportunity to reach her full potential, whatever potential might be.

Judith Kimberly Ipsen was born in 1963, when PWS was unknown by much of the professional world. Some of the best hospitals in the world could not diagnose her. She was finally diagnosed at age ten — by a pediatrician who read the article published in a medical journal. My life changed because I now had an idea of what I was dealing with.



After her diagnosis, the first specialized physician said, "Some of us in the profession aren't convinced of the syndrome. Just take her on regular hikes up the mountain." We moved to Miami shortly thereafter, where a physician told me, "Yes, we are familiar with PWS. But these kids don't live past their 20s. They die of weight-related problems.

There is nothing you can do — you might as well give up and let her enjoy what life she has."

This deflated my sails temporarily, but when she quickly gained ten more pounds, I got my second wind and decided we were on our own. In spite of our constant care and my optimism, Kim came close to death multiple times from the moment she was born. We almost lost the battle at age 12 when she weighed 162 pounds. Pittsburgh's Children's Institute had doctors with some experience with PWS. With their intervention, we were able to change the course of Kim's weight gain. It took time and a tough battle, but with the advance in research and specialized PWS group homes, we were able to reduce and maintain her weight at 105 pounds.

With weight loss, her health was restored in many areas, and she lived over 30 more years. She would have lived longer had not her compulsion to grab and gorge food come at an unexpected opportunity. Sadly, she choked on some chicken at a time in her life when her compulsions appeared to lessen somewhat — a reminder that behaviors may appear modified, but the compulsion remains, waiting for an opportunity.

Kim was what I consider a typical case of PWS, with every characteristic including mild retardation (IQ in the 70s). We dealt, unsuccessfully, with locked fridges and cupboards. Holidays and socials were a nightmare for me — Kim loved them. That's the difference I

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Kim, continued from page 13

have come to realize, why this is Kim's story. All those years we worked hard to make life better for her were indeed work, battling for services such as group homes and related facilities to see that Kim and others like her could enjoy a better life. What I missed to a large extent was that Kim WAS enjoying life. Sure, she got frustrated. Yes, she was dependent on us. Don't we all experience daily frustration and aren't we all dependent on each other? Are we really *that* different?

I didn't fully realize until I was putting together a collage of pictures for Kim's funeral what a full life she really lived! She didn't live MY life — she lived her own life! Kim's book is filled to the brim with activities she participated in regularly -- drama productions, field trips, family outings, dates, and countless parties of every kind -- with friends or family, and her countenance is as radiant as her big smile. Her favorite was the annual Christmas party sponsored by Enable-Utah, a sheltered workshop, where the Jazz Bear became more important than Santa Claus. She worked at Enable for 27 years where they encouraged her in multiple ways and gave her a sense of worth. She looked forward to each paycheck, which she believed provided her food and shelter. She had more than 150 medals from Special Olympics, which she participated in regularly in bowling, swimming, bocce ball, toss ball, and walking.

Kim lived in typical residential housing with two other girls and staff who came on shifts to provide structure, companionship, meals, and behavior counseling. She loved to come home often for visits, but she was always ready to return. I think it represented independence to her. She considered the staff her friends perhaps because they allowed her to be herself. I was "mother with the watchful eye." We found as Kim aged, she mellowed in some of her compulsive behaviors.

She was more fun to be around. Perhaps we all mellowed. We still had to watch her closely, but I learned to relax somewhat. Life seemed to get better for all of us.

The day Kim died, Frank and I took her to lunch during which she recounted her recent experiences at Camp Kostopolus (something she looked forward to each summer), horseback riding, canoeing, and crafts she had made for dad's upcoming birthday. Perhaps Kim's legacy is that she taught us all about what is really important in our own lives. I miss her daily phone calls. Now, when I send a little prayer up to heaven, I say to Kim, "Well, it was tough, wasn't it? But it was worth it." I think Kim just laughs

at me and says, "What was so tough about it? It's time for my snack."

Note: My attitude has been greatly influenced by Amanda Dickson, author of "Change it Up!" She wrote, ***"After we receive a diagnosis that limits us, how do we break through those limitations? We run for the cure. We sponsor someone else who can run for the cure. We donate our time or our money or our ability to a cause. We show our children or parents or coworkers how to live with joy after a loss. We roll with the changes."***

Kim's story shows that we've come a long way, but there is still much to be done. Each of us has the opportunity to make a difference. Kim's life has made a difference. ■

WE REMEMBER

Lorrie Ann Prettyman

A remembrance by Lorrie's family

Lorrie Ann Prettyman, 55, of Delaware passed away peacefully on August 7, 2015 at Seasons Hospice at Christiana Hospital.

Born July 19, 1960, to Ken and Ruth (Paskey) Prettyman, Lorrie didn't let her disability of PWS affect her life and spirit. She was a joy to everyone she met. Lorrie enjoyed word searches, reading, participating in Special Olympics, working at Citibank, and visits from her dear family and friends. Lorrie was the recipient of dedicated care from Chimes Delaware for over 20 years.

She appreciated the little things in life, things many of us take for granted. A fighter always bouncing back after critical situations, Lorrie taught and showed us love, patience, tolerance, determination, strength and compassion.

Lorrie and her family enjoyed attending many Prader-Willi conferences, allowing Lorrie to travel and see many places in the U.S. Conferences were fun for her as she enjoyed seeing her yearly friends, dances, and the field trips that were

taken. One conference Lorrie served on a panel of adults with PWS; she will be remembered for stating, "I am not workshop material!"



She was able to achieve a job at Citibank going through the envelopes looking for forgotten checks. We were amazed at the number of checks she found—and the amounts written on them.

Lorrie and her mother Ruth had a very special relationship. For 55 years Ruth was Lorrie's advocate, cheerleader, confidant, best friend, ally, care giver and loving mother. Lorrie called her mom every day after each meal to report what she ate and what she left for the cat. Those calls will be missed.

Her dad Ken lovingly composed a poem which space does not allow to be printed in its entirety, but the last verse said "Our angel looks down upon us every day. May the Lord bless her in every way". ■

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 Dec. 1; Feb. 1;
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The Gathered View (ISSN 1077-9965)

- Sara Dwyer, Editor
- Lota Mitchell
- 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.

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