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

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

PWSA (USA) has a new Executive Director



Soon after PWSA (USA)'s 2013 national conference in Orlando in November, two important things happened.

The first was that, as of the conference, Dottie and Dale Cooper stepped down as Interim Executive Directors, a position they had held since April 2012. It is difficult to express enough gratitude to them for their work over this period of time.

The second was the announcement from the PWSA (USA) Board of Directors of the appointment of a new Executive Director, Ken Smith, effective immediately. The board is delighted to have a seamless transition to a permanent executive director.

Michelle Torbert, board chair, states: "PWSA (USA) needed an Executive Director that understood the challenges and needs of the PWS families and community. Ken Smith was the perfect choice for this position with his many years serving the PWS community both as a PWSA (USA) board chair and member as well as his extensive history with The Children's Institute in Pittsburgh. We are thrilled that he accepted the Board's offer and look forward to this organization doing great things in the coming years."

Ken is a familiar figure to the PWS family in so many ways – his 18 years of service on the board of directors, his 27 years of work with the PWS program at The Children's Institute, his involvement with the Prader-Willi Advisory Board and the PWSA (USA) crisis program. A hearty welcome goes to Ken in his new job with PWSA (USA), and a request to all of our membership to give him everyone's full support.

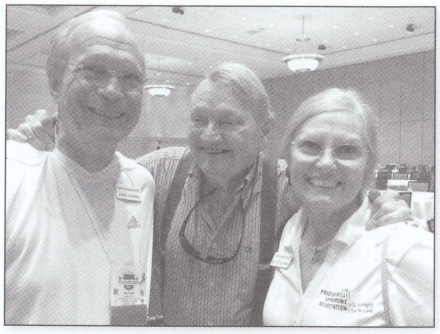
[Editor's note: Many years ago Bea Maier designed and implemented the brand-new PWS program at the then-named Rehabilitation Institute, now The Children's Institute, of Pittsburgh. It grew so quickly that she soon needed help, and one day she commented to me, "I've hired a young man to work with me. I hope he works out." We wish Bea were still with us to see how well he has "worked out!"] ■



Rob Nicholls receives congratulations in Orlando as he finishes his almost-3,000-mile bicycle ride from California to Florida to raise funds for Prader-Willi syndrome research. Donations are still being accepted and can be sent to the national office.

The Coopers and David Wyatt moments after the conference ended.

To see more photos from the 2013 conference see page 8.





A Little All-Star

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

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Volume 39, Number 1 ~ January-February 2014 ~ Our 39th Year of Publication

Presented at the 8th International Prader-Willi Syndrome Organisation Conference - 2013 University of Cambridge, UK

Intervention and Changing Clinical Perspectives in PWS

by Daniel Driscoll, M.D., Ph.D., University of Florida College of Medicine, Gainesville, Florida, USA

PWS as a Multi-Staged Syndrome

- PWS has been **historically known as a two stage syndrome**, with the first stage characterized by hypotonia (low muscle tone) and poor feeding in infancy, and the second stage exhibiting hyperphagia (an uncontrollable drive to eat) combined with weight gain on fewer calories. Current research through an extensive natural history study has shown that PWS is more of a multistage syndrome.
- The initial nutritional phase, **PHASE 0**, occurs *in utero* with decreased birth weight, length and fetal movements. In the **FIRST PHASE** the infant is hypotonic and not obese. Sub-phase 1a (median age range = 0-0.75 years) is characterized by poor appetite, feeding, and weight gain. Sub-phase 1b (median age range = 0.75-2.08 years) occurs when the infant is growing steadily along a growth curve and appears to be growing at a normal rate with an improving appetite.
- The **SECOND MAIN PHASE** occurs when the weight starts to increase and crosses growth percentile lines. This generally begins between 18-36 months of age. Sub-phase 2a (median age range = 2.08-4.50 years) is when the child's weight increases such that they cross 1-2 or more growth percentile lines without a significant increase in calories. During this phase the children do not have an increased appetite or increased interest in food.
- **Sub-phase 2b** (median age range = 4.5-8.0 years) occurs when the child has increased their daily calories and has become more overweight/obese if the diet is not appropriately regulated. Individuals in this sub-phase have an abnormally increased appetite and interest in food and typically do some food seeking, but they do not yet have the insatiable appetite and frequent food seeking exhibited in phase 3.
- The **THIRD PHASE** (median age of onset is 8.0 years and lasts into adulthood) is the development of an insatiable appetite accompanied by very aggressive food-seeking. This is the classical phase that most people typically associate with PWS, but its onset is actually quite variable in PWS. It may appear as early as 3 years of age or as late as 15 years of age.
- The **FOURTH PHASE** may occur in later adulthood when an individual who was previously in phase 3 no longer has an insatiable appetite and can feel full. Families and caretakers note a significant improvement in appetite and weight control. Most adult individuals with PWS have not yet entered this phase, and may never do so.

Most individuals go through all the phases to phase 3, but there are some individuals that skip some phases and some rare few that never progress to phase 3. Phase 4 only occurs in a minority of adults. ■

Dr. Driscoll is the chairperson of the PWSA (USA) Clinical Advisory Board.

An Open-Label Pilot Study of N-Acetylcysteine for Skin-Picking in Prader–Willi Syndrome

by Jennifer L. Miller, M.D., M.S., Dept of Pediatrics-Endocrinology, University of Florida, Gainsville, Florida, and Moris Angulo, M.D., The PWS Center at Winthrop University Hospital-Pediatrics, Mineola, New York

Skin-picking can result in serious and potentially life-threatening infections. Recent evidence suggests that the excitatory neurotransmitter glutamate is dysregulated in obsessive-compulsive behaviors, and modulation of the glutaminergic pathway may decrease compulsive behaviors, such as recurrent hair pulling or skin-picking behaviors. Nacetylcysteine (NAC), a derivative of the amino acid cysteine, is thought to act either via modulation of NMDA glutamate receptors or by increasing glutathione in pilot studies. Thirty-five individuals with confirmed PWS (ages 5–39 years, 23 females/12 males) and skin-picking behavior for more than 1 year were treated with Nacetylcysteine (Pharma-NAC) at a dose of 450–1,200 mg/day. Skin-picking symptoms and open lesions were assessed after 12 weeks of treatment by counting and measuring lesions before and after the medication. All 35 individuals had improvement in skin-picking behaviors. Ten (29%) individuals (six males and four females) did not have complete resolution of skin-picking behavior, but had significant reduction in the number of active lesions. Longer-term, placebo-controlled trials are needed to further assess the potential benefit of this treatment.

(**Post note**: Nacetylcysteine can be bought without a prescription and

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Skin-Picking, *continued from page 2*

there are various brands. Dr. Miller states Pharma-NAC is a good brand because it does not degrade. It should not be started without first talking to your child's doctor, making sure there are no drug interactions with any of his/her prescribed medications, and getting a starting dose recommendation.) ■

Am J Med Genet Part A 9999:1–4. Drs. Miller & Angulo are members of PWSA (USA) Clinical Advisory Board

PWSA (USA) Awards Research Grant on Comprehensive Oxytocin Study

by Janalee Heinemann

We are excited to report that PWSA (USA) is collaborating with the National Institutes of Health (NIH) on funding a randomized, double-blind, placebo-controlled clinical trial of oxytocin in Prader-Willi syndrome (PWS). The study will be done under the auspices of the Rare Disease Center Research Network (RDCRN) at the four institutes doing research on PWS (University of Florida, Kansas University, Vanderbilt University, and University of California, Irvine).

This is an extremely important study for individuals with PWS, as oxytocin administration has the potential to possibly ameliorate several problematic aspects of PWS, including hyperphagia/drive to eat and issues with socialization. This study will evaluate for any adverse effects of treatment with intranasal oxytocin in children with PWS, as well as for impact of this treatment on appetite and behavior. Children with PWS, ages 5-11 years, will be asked to participate in a randomized, double-blind, placebo-controlled crossover study to investigate the effects of oxytocin on their appetite and behavior. They will be asked to come for a seven-day stay at the participating institution of their choice and be randomized to receive either intranasal oxytocin or placebo for 5 days. During their stay, they will have safety labs monitored, as well as be evaluated in terms of their appetite and behavior. They will then return home and return to the institution approximately one month later for the alternate treatment of either oxytocin or placebo.

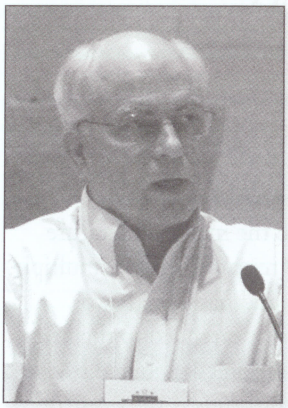
There have been two other studies done on oxytocin in other countries, one in France in adults with positive results, and one in Australia on adults with minimal results. Additionally, there is a study in infants with PWS that is being done in France currently. There is another PWS study currently sponsored in our country to be led by a researcher who is not a PWS expert, but who has done an oxytocin study on another disability (i.e., autism).

There have been very positive anecdotal reports on oxytocin by parents of children with PWS, some by parents who are physicians. Our researchers think it is important to look at optimal dosing, ages included in the study, and the outcome on both behavior and appetite. There is a lot of understandable excitement about oxytocin, so we need to fill in the gap of studies needed to give this drug an honest and fair evaluation of its effects in PWS. We believe that the collective PWS knowledge and data of the four institutes involved with this study will give us the answer.

(A very special thank you to Russell and Jane DeFauw who donated $15,000 towards this research project in honor of their grandson, Nicholas Joncas.) ■

PWSA (USA) National Conference Enhances Medical Knowledge and Research

This report does not begin to give the width and depth of knowledge dispersed at our 2013 conference, but I have tried to give some highlights that I thought might be of particular interest to a broad range of parents and professionals. Once our new website is completed, we will have the entire abstract booklet from the scientific conference available online.
~ Janalee Heinemann



Clinical Advisory Board report by Chairperson Dan Driscoll, M.D., Ph.D.

Dr. Driscoll has been conducting clinical and laboratory research on Prader-Willi syndrome since the late 1980s. He has been a major contributor to the understanding of the genetics of Prader-Willi syndrome (PWS) and genomic imprinting in the PWS region, as well as to revealing insights into the natural history of PWS.

SNORD 116 Deletion patients: Dr. Driscoll is starting to get chromosomal microarrays on all of his patients to evaluate the size of the deletion. In PWS there's a loss of function in at least 10 genes. What is the function of each gene? SNORD 116 is a major gene/locus of obesity and hyperphagia.

G.I. issues and PWS: I asked the CAB to discuss this issue because I hear so often that when a person with PWS is taken to the ER, they do an x-ray and find bowel impaction--and then conclude that this is the problem. But I think our people with PWS are probably impacted most of the time. The problem with

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CAB Reports, *continued from page 3*

this "diagnosis" is that they then do not get to the core of the real problem

The CAB discussed a possible G.I. study

- Should we consider supporting a retrospective study of 50 – 75 children and adults with PWS who were taken to the ER and had an x-ray of the bowels?
- And/or do a retrospective study of those that had x-rays of the bowel prior to surgery?
- If we find out that constipation/impaction is the norm with PWS, a publication documenting this fact might reduce the under-reaction of ER staff, which can have fatal consequences.

Should we be more specific about the use – and misuse – of G-tubes?

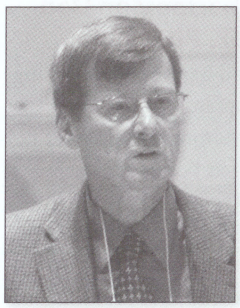
A new parent recently said to me that, when they argued against a G-tube, the NICU physician said, "What are you trying to do, kill your baby?" There is more of a tendency in this day and age for a NICU physician to put a G-tube in an infant with PWS in order to get them out of the hospital quicker, plus they feel more assured that the baby will get adequate nutrition. But there are potential long-term consequences having a G-tube. It was decided that in our new NICU publication we should give clear guidelines about when and if a G-tube should be used versus an NG tube or other means of oral feeding.

General G.I. comments from Dr. Ann Scheimann

- The PWS stomach is thin-walled, doesn't produce a lot of fluid, and often has delayed emptying.
- To avoid constipation, use MiraLAX if they drink a lot of fluid -- and milk of magnesia if they do not and have normal kidney function.



Abstracts Presented at Scientific Day at the Conference



Scientific Conference Report to the general membership by Chairperson Merlin G. Butler, M.D., Ph.D.

Dr. Butler has contributed significantly to the medical literature with over 400 research articles, multiple book chapters and has edited two textbooks. His research led to the first observation of the chromosome 15 deletion contributed by the father and recognition of genomic imprinting as the cause of PWS.

Keynote speaker: Professor Anthony Holland, University of Cambridge, UK

- We now differentiate more between behavior and mental illness in PWS.
- With UPD, 60% may experience mental illness/psychosis versus 16% with deletion, but the psychosis is treatable.
- Features of psychotic illness in UPD versus deletion differ – more hypermania symptoms – other symptoms more the same, i.e., delusions, persecution, paranoia, hallucinations.

Scientific Presentations:

Comparison of Body Mass Index and Antipsychotic use between Genetic Subtypes in Patients with PWS

Gregory L. Cherpes[1], Jennifer Padden Elliott[2], Khalid M. Kamal[2], Elizabeth Bunk[2], Megan Cockroft[2], Rachel Marini[2], Ashley Modany[2], Ishveen Chopra[2]

Conclusion: Although we did not observe a significant difference in BMI between patients with deletion versus UPD, we did observe a statistically significant difference in the frequency of antipsychotic prescribing, with patients with UPD being more likely to be prescribed an antipsychotic. We also observed that lighter patients in both subtypes and those with UPD have more behavioral and psychiatric problems requiring antipsychotic therapy.

Startle-Response Test to Assess Transcranial Direct Current Stimulation-induced Modulation of Hyperphagia in PWS

Gabriela L. Bravo[1], Laura Luque[1], Iago Perissinotti[1], Bianca Fernandes[1], Jean-Francois LePage[1], Mauricio Villamar[1], Diane Stafford[2], Felipe Fregni[1], Albert B. Poje[3], Kelly M. Usrey[3], Merlin G. Butler[3,4]

Conclusion: Visual processing of food stimuli was assessed through an emotion-modulated startle response test. In preliminary results, there was no decreased craving and drive for food in the healthy group, little in the obese group, but those with PWS who had the transcranial direct current stimulation had a significant decrease in craving and drive for food.

The Effect of Atypical Antipsychotic Medications on Body Temperature in Patients with PWS

Gregory L. Cherpes[1], Jennifer Padden Elliott[2], Khalid M. Kamal[2], Elizabeth Bunk[2], Megan Cockroft[2], Rachel Marini[2], Ashley Modany[2], Ishveen Chopra[2]

Conclusion: Atypical antipsychotics (AAP) are often prescribed to treat behavioral & psychiatric disorders in patients with PWS.

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Scientific Abstracts, *continued from page 4*

AAP use & PWS have both independently been associated with impaired thermoregulation In a chart review at the time of admission to The Childrens Institute, it was found that exposure to AAP did not have a significant impact on the mean body temperatures of pediatric and adult patients with PWS in this study. None of the patients experienced hyperthermia, and although rare, hypothermia was experienced at similar rates between adult and pediatric subjects, regardless of AAP exposure. Temperatures less than or equal to 95° F on admission were seen in approximately 1.4% of the entire sample population. (Note: Because hypothermia is listed as a potential side effect of some drugs, this still must be considered by the doctor.)

Function Abilities of Children with PWS on the BRIEF

Marnie Hutchison[1], Jacqueline Pei[1], Michelle L. Mackenzie[2], Melanie D. Hicks[3], Audrey Thurm[4], Joan C. Han[3], Andrea M. Haqq[2]

Conclusion: Overall, their results suggest that many parents see Executive Functioning (e.g., purposeful problem solving) difficulties as a common issue in children with PWS. It appears that the metacognitive components of EF in children with UPD may be more severely impaired than in children with the deletion subtype of PWS.

Comparisons of Cognitive Ability and Academic Achievement Profiles of Individuals with PWS

Matthew L. Daley[1,2], Krista S. Garner[1,2], Carlos R. Sulsona[2], Jennifer L. Miller[2], John H. Kranzler[1,2], Daniel J. Driscoll[2]

Conclusion: This study has identified strengths and weaknesses in the academic and cognitive profiles of individuals with PWS. Examination of overall academic under-achievement indicates that individuals with PWS are several years behind, but this is not a global deficit. The results indicate no significant differences in cognitive and achievement abilities between the main two deletion subtypes (i.e., T1D and T2D). UPD scored higher in verbal. Scores are higher in general than in the past. More deficiency in achievement with age. This study is part of the NIH funded Rare Disease Clinical Research Network, where we have a sample size of 269 individuals > 6 years of age.

Understanding the Impact of Hypotonia in PWS across the Lifespan

Janice L. Forster, Linda M. Gourash

Results/Conclusions: Early treatment with growth hormone has demonstrated a significant impact on symptoms of hypotonia and contributed to improved sensory motor integration and cognitive function during the developmental period. Early intervention services provide physical therapy, occupational therapy, speech/language therapy and cognitive stimulation. However, unlike children with more typical developmental delays, *individuals with PWS require life-long intervention.* Special strategies that improve attention to movement through mirroring or physical touch can improve motor function at any age. Individualized assessment of sensory needs is essential, and the prescription of a sensory diet helps to manage behaviors driven by sensory hunger. The regular, supervised implementation of these activities provides ongoing opportunities to improve sensory motor integration throughout the lifespan and to increase adaptive behavior in persons with PWS.

Nutrient Intake and Diet Quality of Children with Prader-Willi Syndrome

Jasmeena Gill[1], Michelle Mackenzie[2], Diana Mager[1,2], Andrea M. Haqq[2]

Conclusion: Despite relatively high scores for overall diet quality, children with PWS are at risk for suboptimal intake of important nutrients such as vitamin D, calcium, folate, zinc and iron. This suggests that micronutrient supplementation may be warranted in children with PWS. Further research is needed to guide specific nutritional recommendations in children with PWS.

Beloranib, a Novel Methionine Aminopeptidase 2 (MetAP2) Inhibitor, Appeared Safe and Showed Dose Responsive Weight Loss Over 12 Weeks in Interim Analysis of Phase 2 Trial

Dennis D. Kim, James E. Vath, Alice Chen, Thomas E. Hughes

Introduction/Background: Beloranib is a MetAP2 inhibitor that reduces hunger and restores balance to the production and utilization of fat. Previous studies in obese women showed ~ 4% BW loss with 1-3 mg beloranib over 4 weeks. Beloranib treatment for 12 weeks was generally well-tolerated, resulting in rapid and sustained clinically meaningful body weight loss of up to ~10%, improved sense of hunger and cardiometabolic risk markers in this interim analysis of a Phase 2 study.

Trial of PWS just completed – 17 patients injected 2x weekly. -- randomized double-blind trial.

Funded by Zafgen, Inc.; ClinicalTrials.gov

¡HOLA!

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.

¡Hola! 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 nececitan 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. ¡Hablamos pronto!

How Our Organization Helped

It Was Time

by Evan Farrar

I have some really good news on a case I've been working on for 9 months with Florida resident Louise*, 80, who has cared for her daughter Charlotte*, 50, at home.

When Louise contacted me at the beginning of 2013, she was in true crisis. She was unable to control Charlotte, and so Charlotte was heavily medicated to keep her behaviors under control. This meant Charlotte literally slept most of the day. Louise grieved that she had to keep Charlotte so medicated, but, at her age, if Charlotte became aggressive, she could seriously injure Louise. Meanwhile, for Charlotte, this meant a life of little quality and even less hope that she would ever be able to live more fully again.

When Louise contacted us, she did not know what to do. She was not connected with needed services in Florida. Over time, we helped connect Charlotte with an emergency Medicaid waiver through APD. Through this painstaking process, I wrote many letters of support over 9 months and made countless phone calls to her service coordinator to keep things moving. At one point, I had to go above the service coordinator's head when she was not cooperative to get things back on track. Through this process we also connected Louise with the ARC in Gainesville so we could work with their social worker to obtain placement for Charlotte in their PWS program.

My job during this time period was to help Louise whenever she was frustrated or not sure what to do. If she was stuck, or the process bogged down, she would call me and we would figure out together what pressure point to push to get things moving again.

Today Louise called to thank me for my assistance and to let me know yesterday Charlotte began living at the ARC program in Gainesville. She said Charlotte is thrilled because this is what she wanted all along. When I asked Louise how she felt, she said, "I feel like I've been let out of prison.'

I share this because for me – at the end of the day – this story exemplifies the core mission of PWSA (USA). Assisting people and families living with PWS is not always pretty and fun. Sometimes it is downright ugly and frustrating. Many times it doesn't work the way we hope it will. But for Charlotte and her mom, because we were here to answer the call for help, give direction, provide advocacy, explain and understand the syndrome, and encourage Louise to believe in herself and not give up – Charlotte today is in a supportive program with her peers, experiencing what it means to be fully alive again. And I am reminded again of why we do what we do at PWSA (USA). ■

**names changed*

How Our Organization Helped

Mason Meets the President

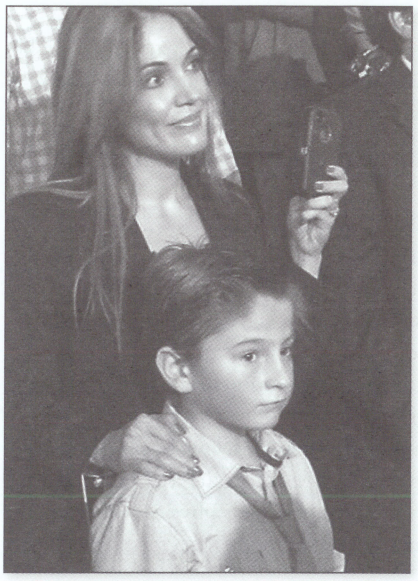
by Laura Ferreira

Mason has been a tenacious, sweet and loving boy. I remember after he was diagnosed, my husband and I said we would give anything to take that diagnosis away. Six years later I can honestly say that I wouldn't change anything about Mason, including his diagnosis. Does he exhibit extremely difficult behaviors at times? Certainly! Is it a challenge to constantly monitor his appetite and diet? Most definitely! However, the reward of having such a beautiful human being for a son far outweighs any struggles we have had. He has made me a better parent and definitely a better person.

The biggest challenge I feel we encountered was the stress of losing our health insurance two years ago. My husband switched jobs and I am self-employed with no access to private insurance. To maintain the insurance we had was more than my mortgage payment, but I was afraid that we wouldn't qualify for anything else because of Mason's pre-existing condition. Fortunately, we live in Massachusetts which has offered state insurance for years. The relief in knowing that Mason's medication will continue to be covered and we can never be denied coverage is immeasurable. We were asked to attend an event in Boston for the Affordable Health Care Act where Mason got to meet the President. The Health Connector, which is Massachusetts' computer portal for health insurance, gave our names to the governor's office as a success story for affordable healthcare in Massachusetts.

President Obama was wonderful to Mason. He bent down and held his hands and asked his name. I was so nervous that Mason wouldn't speak. Sometimes, because





of his speech delay he is silent because he is afraid the person will not understand him. He did respond, and the President asked his age and

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Executive Director View

First of all, I would like to thank you all for your kind letters and emails. I am truly gratified by the sheer number of positive communications received since assuming this position a month ago. I am truly honored and humbled to be assuming the role of Executive Director of PWSA (USA).

For those of you who are not familiar with me, I have spent the majority of my adult life (28 years) supporting individuals with PWS and their "caregivers". By caregivers I mean parents, grandparents, siblings, therapists, physicians, educators, residential providers and community support personnel. I have also had the pleasure of serving on PWSA (USA)'s board of directors on and off since 1995. In many ways I believe that my experience over nearly three decades has specifically prepared me for this new role.

After leaving my previous job in Pittsburgh early this year, my primary goals were to stay closely involved with PWSA (USA) and to assist organizations in developing new treatment alternatives for persons with PWS – specifically, the creation of new regional inpatient and outpatient treatment alternatives for persons with PWS and related conditions.

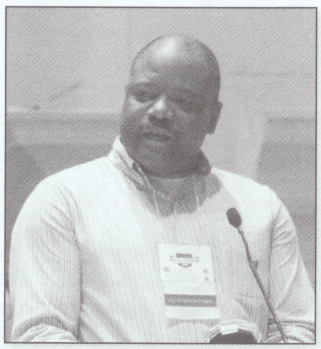
The creation of a specialized inpatient treatment program at HealthBridge Children's Hospital in Houston, Texas was my first consultation in pursuit of this goal. It is my hope that individuals with PWS in need of treatment will be able access services closer to their home communities.

Here are my initial goals for the upcoming year:

Chapter Support. PWSA (USA)'s board chair Michelle Torbert and I will be reaching out to all of our chapter leaders directly during the first quarter of 2014.

Completion of PWSA (USA)'s website upgrade during the first quarter of 2014.

Formulation of a **comprehensive fund development plan**. I will be working closely with our Board Development chair Rob Lutz and Finance co-chair Steve Leightman.



Ken Smith, Executive Director

Assessing and enhancing **staffing for the national office**, particularly as it relates to pursuing our goal of raising awareness, offering support, providing education and advocacy, and promoting and funding research to enhance the quality of life of those affected by Prader-Willi syndrome. Michelle Torbert will be working very closely with me on this.

Develop and enhance **PWSA (USA)'s relationship with the Foundation for Prader-Willi Research**. I am proud to report that the relationship between our organizations improved markedly during my tenure as board chair and vice chair. Designated individuals from each organization will be assisting me in cultivating this relationship. We enthusiastically look forward to working with the FPWR board and leadership team.

In conclusion, I look forward to the New Year with great enthusiasm. I also hope to speak with many of you over the course of the year. ■

Too often we underestimate the power of
the smallest act of caring,
which in itself has the potential
to turn a life around.
~Leo Buscaglia

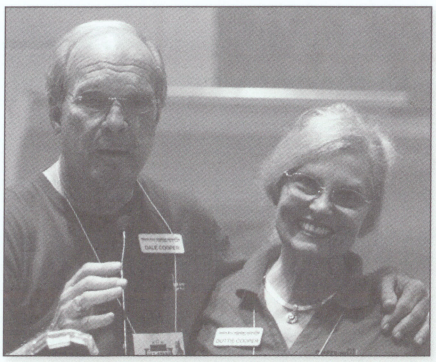
Mason, *continued from page 6*

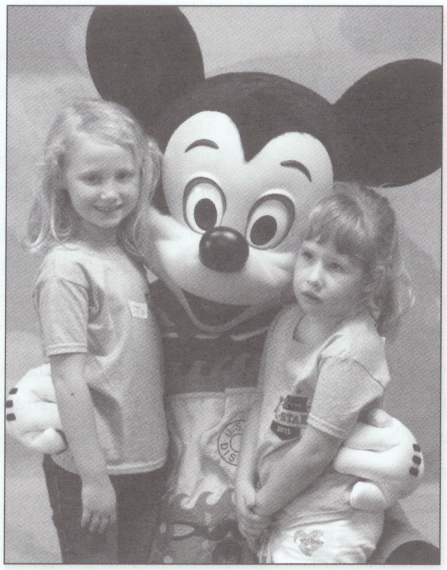
grade in school and what he wanted to be when he grew up. He told the President he wanted to be a pro wrestler.

I was thrilled because I had the opportunity to tell the President that the fight for affordable healthcare is worth it, and we wouldn't have insurance if he didn't eliminate pre-existing condition discrimination and thank you. As a hair stylist, I meet people of many different political backgrounds, I know a lot of people are opposed to healthcare reform. Regardless of political beliefs, ensuring that children AND adults with pre-existing conditions can never be denied healthcare is such important legislation. The opportunity to express that publicly and the thrill for Mason to meet the President of the United States was amazing.

When Mason was diagnosed with PWS, having access to PWSA (USA) was a Godsend. They spent hours talking to my husband and me about the reality of what to expect. We were referred to Dr. Angulo and were offered hope. He was the first doctor who really understood PWS. I was referred to a parent who spoke to me about her daughter. This was wonderful because I could see that while the diagnosis would be challenging, Mason would be able to do many things that a typical child can do. He does; he plays piano, does karate, swimming lessons and horseback riding.

Even now the support we have received through PWSA is immeasurable. When Mason began having behavior difficulty last year at school, Evan helped with resources and information that have been invaluable. Even today, he wrote a letter to Mason's school to help get additional support in his classroom, which happened. I cannot begin to express my appreciation to PWSA (USA) for the support and genuine concern for the PWS community! ■







I LOVED sitting with families from my same state.





Registered Attendance at Conference

General Conference - 350
Providers - 62
YIP - 26
Chapter Leaders Day - 39
+ circa 100 volunteers

Scientific - 77
YAP - 96
Siblings - 19

EXCELLENT – Thank you! Well organized for parents, PWS kid and their siblings. Information was well delivered.



I always leave these national events feeling so grateful for all the professionals that devote their lives to improving the lives of our children....whether it be the care that they provide or the research that they conduct.



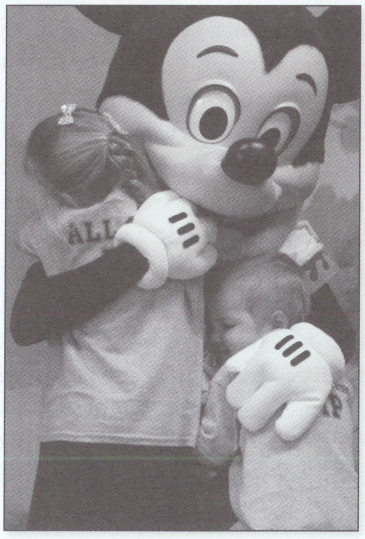


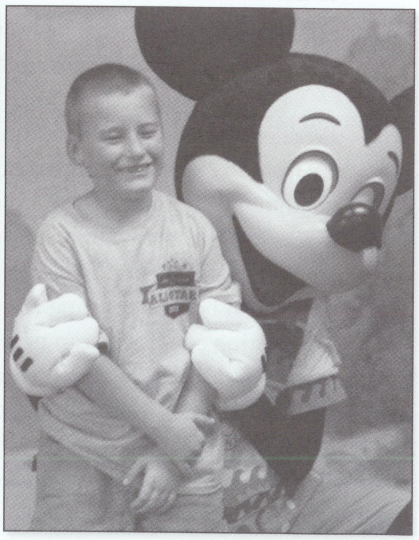




I enjoy the conferences for several reasons: 1, sense of belonging and being surrounded by people who "get it", feeling of not being alone, 2, ability to talk to experts, 3, socializing/sharing with other families, 4, learning new info or being reminded of things we need/ should do.



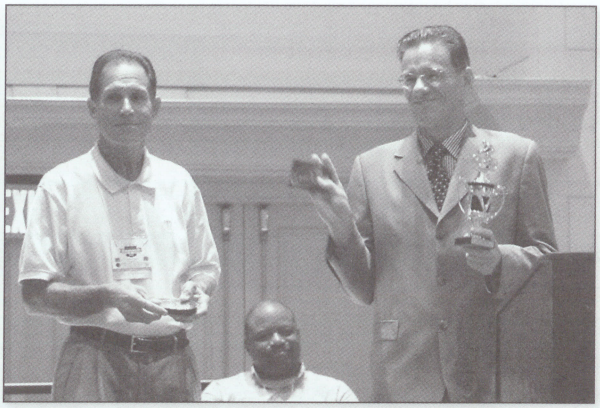






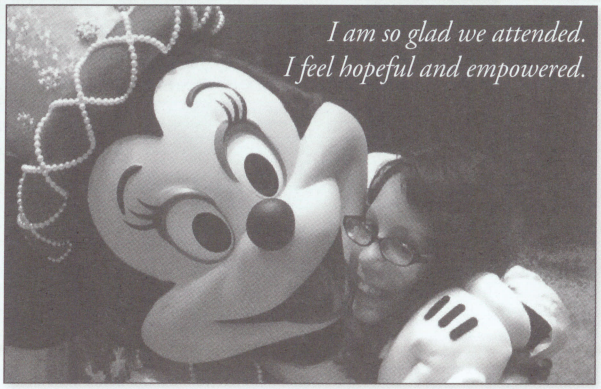












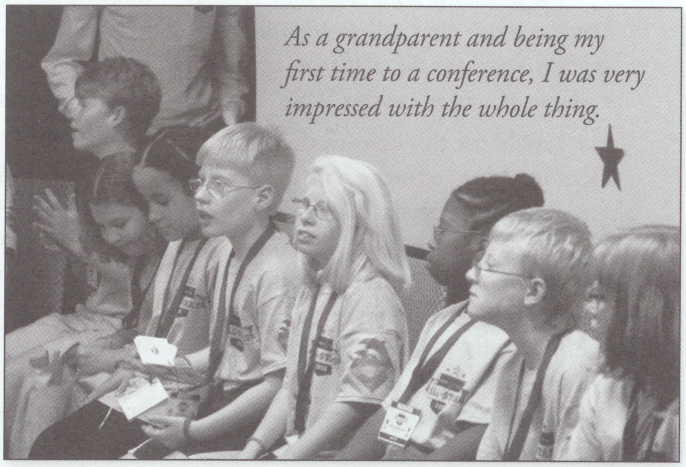


Networking with other parents, good medical info, feeling united – we're not alone!



Conference was impressive, informative, educational, emotionally gratifying and amazing.

















More News on *A Book of Bullies*

by Katherine Stanley

Katherine Stanley, the 17-year-old author who has PWS, brought her books to the national conference for a book signing--and sold out of them. It is a valuable resource to have. You can purchase a copy through our national store - PWSA (USA). Retail cost is $17.

The current issue of *Parenting Special Needs* Magazine features an essay written by Katherine. The magazine is available online, and her article is on page 52 - "Proud of Myself". Both PWSA (USA) and Grateful Steps Publishing are mentioned. ■





Katherine, author of the Bullying book, dancing at conference to her favorite singer Katy Perry.

Sibling View

The following is an essay that Lindsay Douglas wrote for a college admission application about the challenges of being a sibling of someone with PWS.

I could use this essay to complain about hardships of living with a "special needs" brother, specifically Prader-Willi syndrome (PWS), but I find it more appropriate to express the profound impact Jacob has had on my life. Because of him, I've become a compassionate, understanding, and responsible person. I've learned to see differences between people with and without limitations, to which others may not be as sympathetic. I understand the dependence some must have on those of us who are independent. I've matured faster than my peers, and Jacob's syndrome has also influenced my desire to study genetics to help those like him in the future.

Many teenagers expect others to be invincible, self-reliant. They don't realize people like my brother struggle with simple tasks the rest of us take for granted. With PWS, my brother battles never-ceasing hunger. Another person may realize, "I'm not really hungry," but Jacob can't; he's as emotionally attached to food as many teens are to modern technology. Watching him struggle to live unburdened by this tether has allowed me to be aware of and compassionate towards others' constraints.

Many acquaintances have told me how mature I am compared to "normal" teenagers. I believe this comes from helping Jacob simply make it through his day-to-day life, which has made me more responsible. Dealing with his seemingly miniscule but actually burdensome issues puts my personal issues into perspective, usually on the smaller end of the spectrum. I'm more open to approaching people with disabilities than most, and I want to help as many of them as possible, driven by my relationship with my brother.

After volunteering to take care of children with disabilities at summer camps, I've led my own camp for "typical' kids. The stress of managing totally dependent children makes coordinating activities for more capable children comparatively easy. Observing the lack of opportunities children with special needs have makes me aware of those opportunities normal children do have. People who haven't interacted with special needs most likely haven't investigated the science behind disabilities, either.

The effects of living with my brother not only impact my day-to-day life but also my education. I never would've been intrigued by genetics if not for living with genetics gone awry. Like others, I'm amazed tiny chromosomes create such complex individuals. Further, I know firsthand that a deletion [on] a minute chromosome can cause enormous changes. I aspire to study genetics so less people are faced with complications accompanying what I see as potentially curable genetic disorders.

Growing up with Jacob has enabled me to see distinctiveness in everyone. I've developed patience and understanding, with "normal" as well as disabled people, and realized how self-reliant I can be, compared to the total dependence my brother has on our family. I've seen that not everyone develops the same, and I yearn to discover what causes these differentiations. I know there aren't many people who share my experiences, so I plan to make my impact on this world a unique one. ■

Happy Birthday, Justice Faith!

by Kristi Cole Rickenbach

On December 18, 2003, our lives were forever changed. As I held our sweet baby in my arms for the first time, I wondered if we would ever take her home. Those first few hours I longed to hear her cry or to see her move. The first few days I prayed for her to eat, to stay awake. When we finally took her home, I cried during those long sleepless nights, listening to make sure she was still breathing. It seems like just yesterday we were running to so many doctors trying to get an answer, something, anything to explain why our baby was so weak.

A month later when we finally got the diagnosis of PWS, our world stopped. We knew the heartache and struggles that came with this diagnosis, we knew, we had read, we had done research. The medical books were very clear on what to expect. Our world was filled with a whole new vocabulary that in the past I never cared to learn. Words like Methylation, Uniparental Disomy, NG Tube, failure to thrive, aspiration and so many more that I could fill an entire page with them.

I was so angry that I figured that if I learned everything I could about PWS I could somehow fix it. It took me a while to come to the realization that I couldn't. At first I screamed Why me? Why my baby? But then one day it all became clear. Justice Faith's future was not determined by a text book. We decided that as a family we were going to do anything and everything to ensure that Justice had every opportunity to prove the text books wrong. Today as we celebrated her 10th birthday, my heart swelled as I listened to her read all of her birthday cards out loud. I could barely contain my joy as I watched her interact with her friends, laughing and talking about what they will wear tomorrow, just like any other 10-year-old. My heart melted again just like it did 10 years ago



Justice Faith

as I held her before she climbed into bed.

I cried again today but not because of what Justice is not, but because of all she is. Justice is an amazing, beautiful, smart, compassionate, funny, sweet little girl that has brought us more joy than I could have ever imagined. ■

Happy Birthday, Sophie!

by Lori Moline



Sophie, holding her new baby nephew. She is a very proud auntie!

Today my beautiful girl, the one the doctors told me was profoundly deaf and blind, who they said would likely never walk or even sit normally…the one I was told to take home from the hospital and love "for the time you have her with you"...turned TWELVE YEARS OLD. So far, she's kicked every one of those predictions of gloom and doom to the curb. She no longer needs hearing aids, she not only walks and sits, she is on a "typical" sports team, set to take a spring tournament by storm. She's smart and kind and so funny there are days that all we do is laugh. She has a tenderness for animals and babies that is truly amazing, and they respond to her as if they know she "gets" them. I would love to make a list of all the incredible things this girl has done, WITH PICTURES, and mail it to the geneticist who handed me a list 12 years ago of all the things she would never do. So far she has climbed mountains, hiked deserts, swam in two oceans and the Mediterranean sea, she has given me far less trouble than her typical brothers, become my "partner in crime" and my bestest traveling buddy ever. Yes, we've had struggles--no, things haven't always been easy and trouble free. But 12 years of this sweet, floppy little baby, now strong, accomplished young woman, who wakes up with a smile EVERY morning, makes every struggle worth it.. She is a blessing to everyone who gets to know her. I can't believe how fast 12 years can go by. ♥

CHUCKLE CORNER

Molly was with her older sister in the van and they were driving down the highway. In front of them was a semi full of pigs. Molly asked Kira where they were taking all those pigs. Kira was really worried about how to handle the question so was as delicate as she could be. She told her, 'well, Molly, they take those pigs to a place where they kill them and turn them into things like sausage, bacon...." Molly quickly interupted, grabbed her sisters leg and said, "hurry Sissy, catch that truck... I want sausage". Only our kids!

~ Teresa Price
Amboy, Indiana

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.

Counselors Corner

By Kate Beaver, M.S.W.

Communication Consistency

Children who have PWS usually have a processing delay as part of their problems with communication. We have found that working with the school and parents to create a consistent form of communication has helped children at home and at school. One of the reasons that consistent communication helps is that the child doesn't have to struggle with processing directions from different people who have different communication styles.

Remember, children with PWS have a delay in processing the information you give them. Most children will take between 3-5 seconds to understand what you say. If too many instructions are given or the instructions are generalized, they can miss the middle part of what you said and misunderstandings occur. Instead of saying "go get ready for bed", or "go get ready to go home", try breaking the process down into steps; It's time to brush your teeth", or "it's time to put your book away", wait 3-5 sec. before repeating the request. If after the second request they do not comply, do the task with them before asking that they do the next step.

Problem-solving skills are also often impaired. This is in part due to the processing problem and not being able to put things in order of how they should be done, which also creates anxiety. Children become frustrated and anxious trying to do what you want them to without being able to know what to do first and what all it entails. Again, having a set of short clear steps for them to follow will help with the child's anxiety and help them to process the information.

Working with teachers and parents to come up with common language to use with the child is very helpful. Decide how steps should be broken down and what common words will be used. Decide on how much time the child needs to process a step--is it 3 seconds? 5 seconds? Each child can be different. ■

Lota Mitchell Receives a Lifetime Achievement Award

by Andrea Glass

For those of you that read the PWSA (USA) timeline in the newsletter two years ago, it was no surprise to find Lota Mitchell's name pop up a few times. Lota served on the Board of Directors of our association for 12 years from 1980 to 1992, the last five years as Chairman of the Board. Later she served as President for three years beginning in 2001.

Lota has been a guiding light for our newsletter, *The Gathered View*, as associate editor and then editor since 2008. She is one of the people who have helped shape and guide our association. Lota was honored by PWSA (USA) with a Lifetime Achievement Award at the 2013 National Conference in Orlando. This award goes next to a Distinguished Service Award that she received from her alma mater Muskingum College for a lifetime of helping others, acknowledging her contributions to PWSA (USA).

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



Through the JAMA (Journal of the American Medical Association) article Lota learned about the second PWSA national conference in 1980 and attended. At the time, Lota was working on her M.S.W. degree and wrote a term paper on PWS. She found a small amount of information on PWS at the University of Pittsburgh medical library and added more from the conference. Her completed paper, submitted to PWSA (USA), became one of the first comprehensive booklets on PWS. This early publication even made its way onto the emerging Internet. Lota went on through the years contributing to the written literature on PWS, with many PWS publications bearing her name.

Perhaps Lota should have been a journalist. She has worked on the Publication Committee of PWSA (USA) since those early years, publishing booklets, brochures and contributing to *The Gathered View*. Working as an Employee Assistance Program professional for 20 years satisfied some of her desire to help people. Lota has a passion for people, so working as our GV editor has helped fulfill that passion. She is

continued on page 13

A First Visit to Honduras 24 – 29 October 2013

by Giorgio Fornasier





Introduction:

I was trying to get contacts with professionals and parents in Honduras since many years but with no success. My good friend Patricia Ynestoza, journalist at Vatican Radio in Rome and who was born in this country, introduced me to Guillermo Anderson, a very famous singer in Honduras who was performing concerts in Rome the same days I was performing mine. He promised to help me and introduced me to Prof. Ramon Alvarenga, president of the National Paediatric Society, endocrinologist and the only geneticist existing in this country. Once I received his enthusiastic answer, I decided to change my flights and add a visit to Honduras, too, soon after Cuba. I asked Dr. Moris Angulo to join me and give scientific talks about the syndrome. He accepted immediately and willingly, as always.

Here is my Report to the International Prader-Willi Syndrome Organisation (IPWSO) Board.

A First Step in Honduras

I left Cuba with my wife Maurizia and my son Daniele [who has PWS] on October 24th, with destination Tegucigalpa in Honduras. Dr. Alvarenga with another doctor were waiting for us and Dr. Moris Angulo arriving from New York. Our meeting in person confirmed the friendship we had established already by email.

On 25 October at 6:45 [a.m.] we went to the faculty of Medicine of the local University, which is close to the major paediatric hospital in the capital city, where Moris gave a talk about genetics in different diseases to many doctors crowding the conference room. At the end I introduced IPWSO briefly and explained the reason of our visit to the country. As Moris introduced me also as a singer, I sang a song of mine I translated in Spanish about parents hiding their disabled children at home for shame. The impact Moris and I had first in the morning was quite strong.

Soon after, we joined a group of parents with their children in a room at the hospital. We met 7 families among the 10 known to have children with PWS in Honduras. Doctors participating to the meeting were quite surprised and touched because it was the first time families gathered together and knew each other. I talked to them in Spanish about IPWSO mission and our history and experience as parents. They [had] many questions and asked also Daniele to tell them about his life and job, who surprised them all the way he answered half in Italian and half in Spanish. Some of them had children who did not talk yet. The presence of my family there was really inspiring because they could verify in person a positive case of an adult with PWS, giving them hope for the future.

I encouraged them to meet together again and asked the doctors to create awareness to identify other cases as soon as possibile. At the end they decided to establish a national PWS Association soon, and a mother who speaks English accepted to become parent delegate, completing the team with Dr. Alvarenga. We had dinner with doctors in the evening where Moris gave a presentation about PWS and I showed a power point presentation on IPWSO. At the end I sang our song "Ich auch" which touched the hearts of all participants. The day after, our meetings and professional conversations with doctors continued, and Moris was invited to give a talk about PWS during next national paediatric meeting in Honduras in November 2014.

Moris and I found a very poor country, somehow worse than Cuba, with old structures and technologies at the hospitals. But the big heart of all doctors we met covered this gap. We are sure that this important first step will lead to a similar successful development we had in Cuba. ■



Dr. Angulo, Giorgio, Daniele, and Dr. Alvarenga

Lota, *continued from page 12*

also one of four teachers for a large adult Sunday School class at her church, always beginning her lesson with a funny story. She says work on the GV and the Sunday school classes keep "the brain cells banging together!" (along with some occasional bridge).

The international scope of PWSA (USA) has changed her world view. She sees us all as connected to one another, a PWS global family. *The Gathered View* publishes personal stories from around the globe as well as medical information and the latest on PWS research. The Home Front and Chuckle Corner were her brainchildren. Lota will continue to make contributions to our association through her work as *The Gathered View* editor. A perfect fit for her current lifestyle, she enjoys working from home and staying connected. She encourages all members to send more personal stories and chuckles for publication in *The Gathered View.* ■

Fundraising like the Pros

By Andrea Glass



Walkers from the last New England Walkathon.

Most families who have children born with PWS find themselves wanting to help find the cure. Our PWS community goal is to raise as much money for research and PWS support programs as we possibly can. Many families have run successful fundraisers; one family has even started a non-profit business that funds research. Perhaps you, too, can use these ideas to start your own yearly fundraiser or business.

The Wells Family from New England

Cindy and Jarod Wells came home from their first New England PWS Association meeting knowing that they needed to help make the Chapter thrive. The Chapter had been struggling and did not have the funding to help local families with PWS specific issues. That was five years ago. The Wells family leadership of the PWS New England Walkathon has been an incredible source of funds for both the local Chapter and National. Each year they have raised between $20,000 and $30,000.

According to Cindy, they raise 50% on line before the walk through participants' Firstgiving accounts and the other 50% during the walk. There is a silent auction with donations coming from restaurants, entertainment venues, sports teams, retail and service establishments, and the travel industry. Cindy and Jarod contact over 500 potential donors during the course of the year leading up to the walk. The chapter is a 501(c)3 charitable organization which makes it easier to obtain the silent auction items. Many companies have specific rules regarding when you can solicit donations, and they have specific guidelines and forms. This information is typically on company websites in the investor relation area. They will fill out forms, email or snail mail a letter explaining PWS and the activities the Chapter has funded in the previous year. They will also state their vision for the future and, of course, send a picture of their daughter Mady. The quality and quantity (over 100 items!) of these auction items raises a significant portion of the funds.

The place for the event is also very important. Cindy and Jarod chose a state park setting that has a low cost, plenty of parking, beautiful safe walking paths, and a large area for the free activities. They have face painting, a clown, arts and crafts, and music and giveaways. The park is booked 9 to 12 months ahead and easily accommodates the 300 participants that have made the walk successful.

If you would like assistance on this type of fundraiser, feel free to contact the Wells at cmjwells@yahoo.com.

Colette's Castile Soaps

Colette and Eric Joncas decided that instead of just asking their family and community to donate money to support PWS research, they would sell something of value. In November 2013, the Joncas family incorporated a non-profit company that donates 100% of the company profits to PWS research. They produce a beautiful, premium castile soap product that makes an ideal gift to give or receive. Both Colette and Eric have full time jobs, children (including Nick, age 4 with PWS) and now a new business. They spend evenings cooking and molding soaps that take 30 days to cure. The soaps are all handcrafted using only the finest all natural ingredients. Each bar bears a tag informing recipients that their gift has helped fund PWS research.

The soaps are sold through an ecommerce site and farmers markets. You may purchase soap on the company website, www.colettescastilesoaps.com. ■

How Our Organization Helped

School Challenges

by Denise Servais

It was becoming an all too familiar occurrence for Amy Lemmons. "Last May, 2013, Brock was having a lot of behavioral problems at school. He was bolting from the classroom and having tantrums…He wasn't like this at home. It was hard to believe we were talking about the same kid." Brock is currently a 6th grader at the K-12 school in Valparaiso, Indiana.

Amy knew she needed help so she called the crisis line at PWSA (USA) and was put in touch with Mary K Ziccardi. After several long phone calls with Mary K and the special education teacher, Mary K offered to come to Brock's school and do an in-service for the school staff.

"Our school is K-12, so all the general and special education teachers were there," Amy reported. "Mary K did a general overview of PWS and behavioral issues. She increased awareness. The staff could ask questions at the end." Amy reported that the in-service was well received, and the principal and special education teacher played an integral part in getting things changed based on Mary K's suggestions.

"By August, we had a 1:1 assigned to Brock, and now we have started the ground work for the transition to middle school," Amy said. She added, "We have an awesome support system at the national association."

Amy lives in Valparaiso, Indiana, with her husband, Brock and three other younger children. ■

USA
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Still hungry for a cure.

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

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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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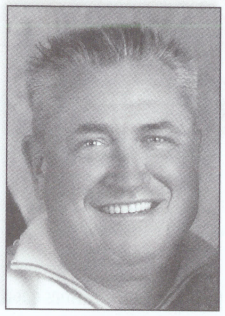
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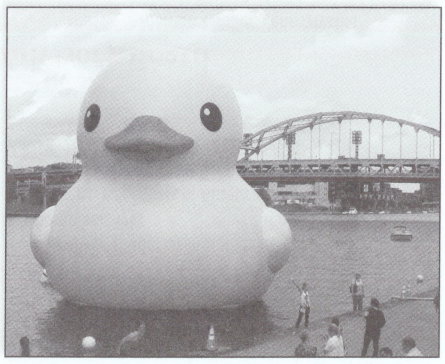


Congratulations!

Clint Hurdle, Manager of the Year

By Lota Mitchell, Pittsburgh, Pennsylvania

In October, Pittsburgh, Pennsylvania, was a happy city. Delighted Pittsburgh-area residents flocked to Point State Park to see the giant yellow rubber duck, four stories high and three stories wide, moored on the Allegheny River for three weeks.



Just to look at it made people smile!

Delighted Pittsburgh-area residents flocked to PNC Park to see the Pittsburgh Pirates play, and tickets became hard to come by. After 20 long years in baseball basement with not one winning season, this sports-happy city (Steelers football, Penguins hockey) was thrilled with the Pirates 94-68 season, five players going to the All Star Game, and a wildcard spot in the playoffs, losing to the St. Louis Cardinals in the fifth game.

Then Clint Hurdle, manager of the Pirates, national spokesperson for PWSA (USA), and father of Maddie, age 11 with PWS, was voted Manager of the Year in the National League. In a landslide vote, the Baseball Writers Association of America gave him 25 first place votes out of a possible 30.

He was the first Pirate manager to receive this honor since Jim Leyland in 1992 (and 1990) and only the second Pirate manager to win it. One writer commented that he created an environment where his players could thrive. Congratulations, Clint! ■

[In 2012 Clint and his wife Karla had the Hurdle Endowment for Prader-Willi Syndrome Support established in their name. Its overall goal is to support the highest possible quality of life for each and every person affected by PWS, both now and in the future. To contribute to the Hurdle Endowment, you can send a check to PWSA (USA) with Endowment Fund in the memo line, or donate online at http://pwsausa.org/support/donations.asp.]

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