

# The Gathered View

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

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

## PWSA (USA) Moving Research Forward!

### 2<sup>nd</sup> International Conference on Hyperphagia 26<sup>th</sup> Annual PWSA (USA) Scientific Day

**The Hyperphagia Conference** = 22 invited speakers/presenters from around the country and world all known for their research expertise on hyperphagia (the uncontrollable drive to eat), hunger and obesity. Attended by 102, many of whom are also experts in the field, and 5 pharmaceutical companies. The ideas, collaboration and energy produced at this conference are guaranteed to move this important aspect of research forward!

**Best Idea Grants (BIG)** = opportunities for research funding now being announced. BIG is another outcome of the conference – to encourage ongoing research in the area of the hyperphagia, hunger and obesity in PWS. These grants are the collaborative efforts of FPWR and PWSA (USA) with funding from One Small Step.

**Location** = Pennington Biomedical Research Center, the world’s largest obesity research center. A special thanks to the staff at Pennington for this year and half long collaboration, and to all involved on the committee. Anyone who took the tour of Pennington had to be impressed with their extensive campus and state-of-the-art equipment! We see this as the start of a long and fruitful relationship between PWSA (USA) and Pennington.

### The PWSA (USA) 26<sup>th</sup> Scientific Day =

23 who presented on their research that involves and/or impacts all of the diverse aspects of PWS. Attended by 95, many of whom also attended the hyperphagia conference, and some new to our world of PWS.



Steven Heymsfield, M.D., Pennington



L to R: Debi Applebee and Dale Cooper, PWSA (USA); Anne Haney, Pennington; Dottie Cooper, Kate Beaver and Hope Mays, PWSA (USA)

### Feedback from the Experts =

- “I thought the meeting was masterfully organized and conducted, and ideal for learning a lot - which I did. My students too!”
- “I completely agree that this was an outstanding conference and I learned quite a bit from the other speakers, too. I hope that we can meet once again to further explore this important topic that I think is under-investigated in the field of obesity.”
- “I wanted to write to express my appreciation for the amazing work that the leadership of PWSA (USA) did to organize and run the Hyperphagia conference, in conjunction with the Scientific, Service Providers, and State Leaders conferences, this year. I am really hoping the conferences stimulate the scientists who attended for the first time to think more about how to study and treat hyperphagia.”



George Bray, M.D., Pennington

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Our Angel, Jessika

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Jack Yanovski, M.D., Ph.D., NIH

- “Everything was very well done and with lots of class. Makes me very proud to be part of this organization! *Kudos to all the organizers!*”



Tony Goldstone, M.D., Ph.D., Imperial College, London

### Lay Abstract

## Pilot study examining swallowing function in persons with Prader-Willi Syndrome

*Principle Investigator: Roxanne Diez Gross, Ph.D., CCC/SLP*

*Co-Principle Investigator: Gregory Cherpes, M.D.*

Several research studies from the USA and around the world have found that lung infections (pneumonia) and choking on food are frequent causes of premature death in persons with Prader-Willi syndrome (PWS). Because swallowing impairments are known to cause these serious problems, it is very possible that persons with PWS have unrecognized swallowing impairments. Shockingly, there are no published research studies that have examined swallowing function in persons with PWS. Research that will examine swallowing ability and identify risk factors for swallowing problems in this unique population is urgently needed.

In this research study, we will directly observe the swallowing function of persons with PWS using videofluoroscopy (a moving x-ray). Using this method, we will be able to see food and drink that is inside of the mouth, throat and esophagus before, during and after eating and drinking. We will be able to identify the presence of swallowing problems and risks for choking and aspiration (food and drink getting into the airway to the lungs). To make comparisons between swallows and people, we will control the amount and rate of food and drink given for some of the swallows. To see if behavioral factors influence swallowing safety, we will allow each participant to eat and drink a fixed amount freely for some of the swallows. Furthermore, because disordered breathing/swallowing patterns can put people at risk for choking and aspiration, we will also simultaneously measure breathing and swallowing coordination.

Based upon what is known about PWS, we expect that the x-rays will reveal undetected symptoms of swallowing impairment and/or signs of increased risk for aspiration and choking. Understanding swallowing function in those with PWS has great potential to improve quality of life by reducing the number of lung infections that may be caused by aspiration and preventing deaths from choking.

*This study is generously sponsored by a grant from PWSA (USA). ■*

## PWSA (USA) Scientific Abstracts

**Presented at the 26<sup>th</sup> Annual  
PWSA (USA) Scientific Meeting  
in Baton Rouge, LA  
October 19 and 20, 2012 ~  
Chairperson Merlin G. Butler,  
M.D., Ph.D.**

*Note: Because the amount of scientific information presented at both the Hyperphagia and Scientific conferences could be overwhelming – and far more than we can print in The Gathered View, I have selected for this edition a few studies from the Scientific Conference that would potentially have a more immediate and direct impact on our children and adults with PWS. More will be reported*

*in the future and/or on our Web site. What is reported here is just the introduction/background and conclusions. To review all abstracts including methods, discussion & results, you can order them at [sales@pwsausa.org](mailto:sales@pwsausa.org) or call 800.926.4797.*

*– Janalee Heinemann*

## Obestatin is Elevated in Young Children with Prader-Willi Syndrome

*Andrea M Haqq,<sup>1</sup> Michael J Muehlbauer,<sup>2</sup> Huaxia Cui,<sup>2</sup> Daniela A. Rubin,<sup>3</sup> Michelle L Mackenzie,<sup>1</sup> and Michael Freemark,<sup>2</sup>*

*<sup>1</sup>Pediatrics, University of Alberta, Edmonton, Alberta, Canada; <sup>2</sup>Sarah*

*W. Stedman Nutrition & Metabolism Center and Pediatrics, Duke University, Durham, NC, USA; and <sup>3</sup>Dept. of Kinesiology, California State University Fullerton, Fullerton, CA, USA*

**Background:** Ghrelin levels are elevated in children and adults with PWS but are normal in infants prior to the development of hyperphagia. Obestatin is derived from the proteolytic cleavage of preproghrelin. Obestatin initially was described as having anorexigenic (causing loss of appetite) effects, but other studies have failed to confirm these findings. Recent studies suggest that obestatin inhibits water intake more profoundly than it affects food intake. Since infants with PWS

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have been found to have reduced water intake, an alteration in obestatin levels might contribute to their unusual drinking behavior

In this study, obestatin levels were higher in infants with PWS than in controls. This finding might indicate increased processing of ghrelin preprohormone by prohormone convertase 2 in PWS. The possibility that obestatin might contribute to the reduced water intake or failure to thrive commonly seen in infants with PWS should be further explored. ■

## Hypoglycemia in Prader-Willi Syndrome

*Rena Harrington, Jennifer Miller and David Weinstein  
Department of Pediatrics, University of Florida, Gainesville, FL*

**Introduction/Background:** Hypotonia, feeding difficulties and poor growth are common characteristics of infants with Prader-Willi syndrome, but may also be findings associated with hypoglycemia. Hypoglycemia in PWS infants may go unrecognized due to the overlap of signs associated with these conditions. As frequent hypoglycemia in infancy has been associated with developmental delay, determining the presence and characteristics of hypoglycemia in infants with PWS is crucial to improving patient care and outcomes. For this reason, we performed a chart review to assess the frequency of documented hypoglycemia in infants with PWS.

**Discussion:** We found that hypoglycemia is occurring in a significant number of infants with PWS. This has not been reported previously. It is interesting that patients with hypoglycemia less than 40 mg/dl were more likely to have deletion compared to the whole sample group, suggesting that hypoglycemia in infancy may explain differences between subtypes in verbal and cognitive development. Through further studies of hypoglycemia in PWS, we hope to gain insight into the impact of hypoglycemia on neuro-cognitive development and hormone regulation in this patient population. ■

## Vagus Nerve Stimulation as a Treatment for Hyperphagia in Prader-Willi Syndrome

*Katherine E. Manning<sup>1</sup>, Catherine J. McAllister<sup>1</sup>, Howard A. Ring<sup>1,2,3</sup>, Nicholas Finer<sup>4,5</sup>, Karl Sylvester<sup>5</sup>, Anthony J. Holland<sup>1,2,3</sup>  
<sup>1</sup>CIDDRG, Department of Psychiatry, University of Cambridge, UK; <sup>2</sup>IHR CLAHRC for Cambridgeshire and Peterborough, UK; <sup>3</sup>Cambridgeshire and Peterborough NHS Foundation Trust, UK; <sup>4</sup>Department of Medicine, University College London, UK; <sup>5</sup>Addenbrooke's Hospital, Cambridge, UK*

**Background:** Prader-Willi syndrome (PWS) is a

genetic disorder involving hyperphagia arising from aberrant satiety signaling, for which there are currently no successful treatments. The central involvement of the vagus nerve in satiety, alongside serendipitous weight loss observed during Vagus Nerve Stimulation Therapy® (VNS; Cyberonics, TX, USA) for other conditions (Pardo et al. 2007), suggests that enhancing vagus signaling may be beneficial in PWS. The safety, acceptability and efficacy of VNS as a novel therapeutic intervention for hyperphagia in PWS are assessed.

**Conclusions:** Preliminary findings indicate that VNS is safe and acceptable in PWS. To date, effects on the characteristic overeating in PWS are unclear. More strikingly, positive effects on mood and behaviour have been reported which demand further investigation. ■

## Study of Body Composition Variables and Bone Mineral Density in Patients with Prader-Willi Syndrome

*Manaswitha Khare<sup>1</sup>, June-Anne Gold<sup>1,2\*</sup>, Marie Wencel<sup>1</sup>, Andrea Pontello<sup>3</sup>, Pietro Galassetti<sup>3</sup>, Suzanne Cassidy<sup>4</sup>, Virginia Kimonis<sup>1</sup>*

<sup>1</sup>Department of Pediatrics, Division of Genetics and Metabolism, University of California, Irvine, CA; <sup>2</sup>Department of Pediatrics, Division of Clinical Genetics, Loma Linda University, Loma Linda, CA; <sup>3</sup>Institute for Clinical & Translational Science, UC Irvine, CA; <sup>4</sup>Division of Medical Genetics, Department of Pediatrics, University of California, San Francisco, CA

**Introduction:** Some individuals with Prader-Willi syndrome (PWS) show evidence of low bone mineral density (BMD) and changes in body composition variables. Previous studies have reported improved body composition variables and BMD in children with PWS who are treated with growth hormone. There is limited consensus regarding comparison between the molecular subclasses and the management of bone mineralization problems in individuals with PWS.

**Conclusion:** This is the largest study that compares BMD and body composition variables in deletion and UPD subclasses of PWS. In UPD there was a lower Body Mass Index (BMI), however BMD was higher compared to individuals with deletion. Individuals treated with growth hormone had favorable body composition variables. Osteopenia/osteoporosis was seen in 45% of individuals with PWS. This points to the importance of evaluating bone mineralization status regularly. Supplementation with calcium, vitamin D and/or bisphosphonates to prevent fractures needs to be considered. Larger longitudinal studies are required to evaluate the natural history, effects of growth hormone and genetic subtype on bone mineralization in individuals with PWS. ■



Abstracts, continued from page 3

### The Effect of Atypical Antipsychotic Medications on Metabolic Parameters in Patients with Prader-Willi Syndrome

Gregory L. Cherpes<sup>1</sup>, Jennifer Padden Elliott<sup>2</sup>, Khalid M. Kama<sup>1</sup>, Chelsea Harrison<sup>2</sup>, Brandon Herk<sup>2</sup>, Matthew McCrossin<sup>2</sup>, Mary Riedy<sup>2</sup>, Ishveen Chopra<sup>2</sup>

<sup>1</sup>The Children's Institute of Pittsburgh; <sup>2</sup>Duquesne University Mylan School of Pharmacy, Pittsburgh, PA

**Introduction:** Atypical antipsychotics (AAP) are often used to treat behavioral and psychiatric disorders in patients with Prader-Willi syndrome (PWS). AAP are associated with metabolic risks such as increased body mass index (BMI), total cholesterol (TC), triglycerides (TG) and hemoglobin A1C, and thus the study objective was to evaluate the effect of AAP on metabolic parameters in patients with PWS.

**Conclusion:** There were no differences in metabolic parameters at time of admission between adult patients with and without prior AAP exposure. The only statistically significant difference in metabolic parameters observed in pediatric patients was with respect to BMI, with those exposed to AAP having lower BMI at time of admission. Further research is warranted on the effect of AAP on metabolic parameters. ■

### Growth Hormone Receptor (GHR) Gene Polymorphism and Impact on Growth in Prader-Willi Syndrome

Merlin G. Butler, Jennifer Roberts, Jena Hayes, Xiaoyu Tan, Ann Manzardo

University of Kansas Medical Center, Kansas City, MO

**Introduction/Background:** When treated with growth hormone (GH), individuals with Prader-Willi syndrome (PWS) respond favorably in stature and body composition with decreased fat and increased muscle mass. The exon-3 deletion polymorphism (*d3*) in the growth hormone receptor (*GHR*) gene is reported to occur in about 50% of Caucasians in the general population. This polymorphism is reportedly associated with an increased growth response to GH therapy in non-PWS patients. The aim of our study was to assess whether *GHR* alleles impact height, weight, head circumference and body mass index (BMI) in PWS at baseline prior to GH treatment and the rate of growth during treatment.

**Conclusions:** The *d3* allele was associated with significantly increased BMIs in our cohort of PWS subjects prior to GH treatment but not for height or weight alone. The

growth rate was positively impacted by the *GHR* genotype with *fl/d3* or *d3/d3* subgroups having nearly twice the rate of growth compared with the *fl/fl* subgroup. The presence of the *d3* allele and its impact on BMI before GH treatment and growth rate during treatment in PWS may influence the care and surveillance and should be addressed in expanded studies. ■

### Valproic Acid Related Hyperammonemia among Individuals with Prader-Willi Syndrome: a Case Series

Nicolette E. Weisense<sup>1</sup>, Janice L. Forster<sup>2</sup>

<sup>1</sup>Prader-Willi Homes of Oconomowoc, Oconomowoc, WI;

<sup>2</sup>Pittsburgh Partnership, Pittsburgh, PA

**Background:** Valproic acid related hyperammonemia (VRH) occurs in 20-50% of children and adults with seizure disorders and is more likely to occur with antiepileptic polytherapy and longer duration of valproic acid (VPA) therapy. There is a linear relationship between ammonia level, VPA level, and VPA dose; hepatic enzymes may not be elevated. Symptomatic VRH is termed valproic acid related encephalopathy (VRE) and clinical symptoms can include lethargy, ataxia, hypotonia, slowed cognition, confusion, agitation and encephalopathy (confirmed by EEG.) In the majority of cases, elevated levels of ammonia and clinical symptoms of VRE are reversible when the dose of VPA is reduced or discontinued.

VPA is used to treat mood instability and aggressive/impulsive behavior occurring in individuals with Prader-Willi syndrome (PWS). The incidence of VRH in PWS has not been reported. This study explores the incidence of VRH among individuals with PWS residing in a series of group homes in Oconomowoc, WI.

**Discussion/Conclusions:** Given that 11 out of 12 individuals with PWS in this case series (91%) had documented VRH, we recommend monitoring ammonia levels during VPA treatment. Because individuals with PWS have preexisting cognitive deficits, excessive daytime sleepiness, motor coordination problems, and mood and behavioral lability, it can be difficult to decide if VRH is resulting in neurobehavioral toxicity. Therefore, if ammonia levels are elevated, it is strongly advised to consider reducing VPA dose or discontinuing VPA therapy.

The cause of VRH is not known. Potential etiologies include mitochondrial dysfunction, abnormalities of urea metabolism and high protein diet. Individuals with PWS are typically on calorie-restricted diets, many of which limit protein content, and this may serve as a protective factor. Serum carnitine levels have been found to be inversely proportional to serum ammonia levels; therefore carnitine supplementation has been recommended. More research is needed. ■

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## Success of the Hyperphagia Conference: Jim Kane – *The Man Behind the Scenes*

By *Janalee Heinemann*

It is no surprise that the volunteer who took the leadership role on both the 1<sup>st</sup> and 2<sup>nd</sup> International Hyperphagia Conferences was Jim Kane, chair of PWSA (USA) Research Advocacy.

Jim has been involved with PWSA (USA) since his 31-year-old daughter, Kate, was eight. Kate got a clinical diagnosis of PWS in 1986 and then had this diagnosis verified with the UPD form, thanks to Dr. Dan Driscoll. In fact, Kate was the motivation behind Dr. Driscoll seeking an answer for those children who obviously had PWS but did not test out with regular chromosome testing, and developing the DNA methylation test which is now the gold standard for initial testing for PWS.

Jim became the association's treasurer in 1991 and board chair in 1993. After being board chair for six years, Jim stepped down – but never stepped down from his commitment to PWSA (USA) and research to find a cure for the hunger/hyperphagia. His daughter, Kate, is very bright and charming – but very food-driven. Although she is slim and content with her life, he knows how much that limits her freedom.

Among many other things, Jim was the source to acquiring the funding for the Bear Study by Dr. Ralph Nelson, who is now deceased. This compares the hyperphagia vs. non-hyperphagia phases of bears with the same phases in PWS. (More on this at a later date.) I have known Jim throughout his many years with PWSA (USA) and can honestly say that Jim has done more behind the scenes than almost anyone involved with the association (besides our editor Lota Mitchell, but more on her in the next GV). He never looks for recognition or thanks – just for ways to move forward on supporting our children. God bless the unsung heroes in our PWS family. ■



*“Be the change you wish to see in the world!”*  
-Gandhi

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## Providers Collaborate and Learn in Baton Rouge

By *Mary Kay Ziccardi*

The Professional Providers Advisory Board (PPAB) planned and presented a day and a half of opportunities for providers to listen to the most current information on several new topics and to share common experiences. Providers Day kicked off with lectures regarding sensory integration, psychiatric issues and staff training curricula. Following the lectures, providers worked in small groups to discuss scenarios on a range of topics, from behavioral issues to

sexuality to parent relationships, to name a few. All of the scenarios and potential solutions were verbally shared with the entire group. Each provider left with a complete set of the scenarios to be used for training their own staff.

Annual national conferences are one way that providers can share ideas and support each other. PWSA(USA) membership, attending state chapter meetings, joining the Yahoo provider group, and participating in webinars

are other ways to stay involved and informed. The PPAB recognizes the scheduling and financial challenges faced by providers today. We want to hear from all providers and to learn how we can best meet your needs. We welcome your input so that we can plan for 2013 and beyond. Please send any suggestions and comments to the PPAB Co-chairs, Patrice Carroll (PCarroll@lathamcenters.org) or Jeff Covington (jeffc@ccdservices.org). ■



Dale and Dottie Cooper

## 2013 will be an exciting year!

In the last GV, we reviewed our history – a step back in time. How nostalgic that was! Well, now 2012 is part of our history as well.

2012 was a year of building - we built a relationship with researchers on the topic of Hyperphagia, established the State Leaders Team and identified leaders in almost every state, converted to a new IT system, began an initiative to upgrade our Web site, and upgraded volunteer and resource databases.

All of that preparation has positioned us for some exciting initiatives in 2013. You will be hearing more about how PWSA (USA) is:

- **Rocking with Research** – You could see light bulbs going off in the minds of the world-renowned researchers at the 2<sup>nd</sup> *International Conference on Hyperphagia* this past October, hosted by PWSA (USA) and Pennington Biomedical Research Center in Baton Rouge. Their collaboration promises to result in additional researchers and research on the mystery of PWS.

- **Fearless with Family Support** – A new initiative for Education Advocacy, Parent Mentors, and additional parent/caregiver information on behavior and food security.

- **Synchronized with State Leaders** – A national campaign to mentor each state in pursuing its goals for their families and raising the funds to propel them forward .

- **Awesome with Awareness** – A national campaign that builds awareness in the medical, provider, and general public audiences.

- **Prolific with Publications** – Several new publications are being planned, to increase the help we give to families, caregivers, and the general public in supporting the person with PWS.

- **Coordinating THE Conference** – The biennial PWSA (USA) National Conference occurs this November in Orlando! A day of Scientific, Providers, and State Leaders collaboration, as well as the Parent/Caregiver conference and the programs for persons with PWS (YIP = Youth and Infant Program, and YAP = Young Adult Program) and siblings. Everyone who possibly can will be there, as it is filled with information, support, and energy!

- **Fun with Fundraising** – Look for a new fundraising campaign that all the states can have fun participating in. In addition, we are positioned to support the great ideas emanating from ON-THE-MOVE and your grassroots efforts.

- **Voracious with Volunteers** - What are the needs in your state - respite services, educational advocacy, a PWS Clinic, supported living, supported employment ...? Perhaps there is something you need and are willing to help push for - whatever you can and would like to do. An added benefit is the opportunity to get to know each other better and learn from each other's successes, experiences, strength, and hope.

**This is a call to action!** Each of us can be a volunteer – particularly in joining together to host a fundraiser that will benefit both your state and the national momentum. Will you volunteer to donate your talent, time, money, products, and/or effort to PWSA (USA)?

**You can do it!** Go to our Web site under the **“Get Involved”** tab and sign up to be a volunteer.

Also, on our Web site under the **“Contact Us”** tab are the names and contact information for the state leader in your state, as well as the State Leaders Team Mentor for your state. Get with your state leader and let us know what you would like to do and see accomplished.

Be part of the action and part of our collective drive towards solutions for the future of our loved ones with PWS. Who knows, whether through research or support, what additional ways of positively impacting the lives of persons with PWS will emerge?

**Yes, 2013 will be an exciting year!!** ■

*Be part of the action  
and part of our  
collective drive towards  
solutions for the future  
of our loved ones  
with PWS.*



## Sibling View

# The Wedding Day and PWS

by Katherine Crawford  
reprinted with permission from the  
Prader-Willi California Foundation

In the final two weeks, Jackson and I realized that there was a final element that we hadn't planned for: the incredible heat wave hitting the Midwest, where our outdoor wedding was taking place in July 2012. We told our officiant that if the temperature was to be over 90°, the wedding would be set up in the alternate indoor location. He immediately gave a sigh of relief.

My brother Michael, 23, like many with PWS, has trouble regulating his core body temperature. About ten years ago, this nearly resulted in catastrophe when, during a family trip to Florida, he developed such advanced heat stroke that he fell into a coma and was hospitalized for a week. This I would not repeat.

In the early hours on our wedding day, a light rain shower passed over our city. The temperature dropped; against all odds, it was going to be pleasant. Soon I was waiting with my dad for our big entrance cue. My usher gave a nod, "It's time." He guided my dad and me around the corner in the garden and proudly gave my train a final *floof* so it trailed behind me just so. I began the final walk up the aisle.

Everyone was in high spirits after the wedding and headed for the mid-day cruise. The lake breeze was refreshing. Michael sat with his caretaker, Brian, during most of the cruise. This was the hardest part for him, due to the buffet-style hors d'oeuvres which the captain was cheerfully pushing everyone to try. Brian handled so many little challenges, from food spills to well-needed pleasantly distracting conversation.

After the cruise was a two-hour break before the evening reception.



Brian took Michael home for a rest. When Michael arrived at the reception fifteen minutes after the original scheduled Grand March, he thought he missed being part of it because he slept in. He felt terrible. What had actually happened was that we had re-arranged the schedule of the Grand March. But... no one told Michael. As he stood in front of me sniffing back tears, I gave him a big hug as I told him, "Michael, we couldn't have a Grand March *without* you!" and he smiled with relief.

Dinner was served, no buffet. One surprising complication came up beforehand regarding the cake. There were multiple layers of flavor to account for allergies and preferences. Whoops. My dad was worried that Michael would insist on eating one of each, but I told dad that I'd take care of it. I called Michael three weeks beforehand and asked, "What slice would you like: vanilla, lemon poppy seed, or double chocolate cake with peanut butter cup whipped filling?" Of course, he picked chocolate (just like my husband!) and had no problem with eating only one slice because he had advance notice.

Day-of, I discovered that the "double-chocolate cake" included two vanilla layers of cake. I heard Michael start to get upset: he'd ordered double-chocolate cake, not chocolate and *vanilla* cake. Suddenly, a moment of

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## PWSA Bulletin Board

### NEW BEREAVEMENT SUPPORT EMAIL GROUP

PWSA (USA) provides support for our families throughout their child's life – and beyond. For many years we have offered bereavement support to our PWS families through phone support and booklets. Now we have added an email support group. If you know any parents that have lost a child (of any age) and may want to join, have them send an email to [PWSA-USA-Bereavement-subscribe@yahoogroups.com](mailto:PWSA-USA-Bereavement-subscribe@yahoogroups.com). They may also call the PWSA (USA) office and ask for Amy for guidance in this process.

### WANTED - for *The Gathered View*

Submissions for consideration: articles, stories, Chuckle Corner material, pieces by persons with PWS/siblings/grandparents/relatives/friends, pictures. Email to [news@pwsausa.org](mailto:news@pwsausa.org).

### PWSA (USA) NATIONAL CONFERENCE 2013

**Where:** Orlando, Florida

**When:** November 7-9, 2013

**What:** "PWSA (USA) – All Stars"

### INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION 8<sup>TH</sup> IPWSO CONFERENCE

**Where:** Fitzwilliam College,  
Cambridge, UK

**When:** July 17-21, 2013

**What:** "From Research through to Practice"

### NEW! CALENDAR OF EVENTS

PWSA (USA) has implemented a Calendar of Events on the Web site at <http://www.pwsausa.org/events>. The calendar can be used to register fundraising events, chapter and support group events and conferences. Please register your local events on the link provided. To see a summary of all events, click on Agenda at the top right side of the calendar. Let's fill this calendar with all the events going on around the country.

A big Thank You to Barb McManus, for developing this!

# PWSA (USA) – On The Move in 2013!

In many ways PWSA (USA) is a wealthy organization – our coffers are filled with the wealth of medical information on our PWS Web site, bountiful with the support of professionals who lend their expertise to helping families and persons with PWS, and overflowing with the energy and passion of a small staff but large army of volunteers from states across the nation.

Now we will be focusing on **funding** that will support the needs of our families so PWSA (USA) and our State Chapters can continue to do their good works and meet the needs of those impacted by PWS in 2013 and beyond. What are those financial needs? Consider the following:

### RESEARCH

Funding the promising research that will take us to the next level.

### SUPPORT

**Counseling, Medical, and Crisis support** that enhances and even saves the lives of those persons with Prader-Willi syndrome.

The **PWSA (USA) 2013 National Conference** costs and grants to sponsor families who otherwise would not be able to attend.

Costs associated with launching the new **Special Education Advocacy Training** initiative, as well as sponsoring attendees to subsequently travel to states and train others.

**Awareness** materials, booths, and presentations for auxiliary conferences.

**Publications** - printing costs for over 30 publications and for the bi-monthly **Gathered View** that is so valuable to our many families.

**PWSA (USA) Web site** upgrade – a new initiative that will be underway in 2013 to provide families, caregivers, and medical professionals, as well as state leaders easier and greater access to the information they need.

**PWSA (USA) State Leaders** meetings, initiatives (such as Education Advocacy, Clinics, state advocacy, etc.), and respite support, as well as financial support for crisis needs.

### *How are we going to do this?*

This year we are taking a strong strategic approach, creating a solid fundraising campaign designed to generate much-needed revenue to support our outreach and support goals. We will be adding innovative online fundraising methods along with an annual schedule of events developed by proven fundraising and marketing professionals. This approach will allow PWSA (USA) to focus concentrated efforts in making the most out of our fundraising initiatives along with advocating for PWS and those it affects on a daily basis.

We have heard your suggestions and feedback and have worked hard to put in place detailed plans and guides for events that have been developed and created for you ... including sponsorship packages, marketing materials, donation form letters,

interactive fundraising websites with social media and more. We are ready to kick up our fundraising to the next level and understand each chapter and supporter needs the proper tools to help. **Stay tuned for our 2013 Fundraising Packet and Event Guide which will be available Spring, 2013.**

In addition to the above, we invite you to participate in our National Fundraising campaign – **On The Move - 2013!** Last year we focused on walks, and they are still a popular activity.

Please call our National Office at 800-926-4797 or access our Web site [www.pwsausa.org/onthemove](http://www.pwsausa.org/onthemove) for guidance and assistance in starting or registering your walk. ■



You know your daughter has PWS when...each room in her WEBKINZ play land has a bed and at least three refrigerators. No other furniture required. When asked “why does this WEBKINZ have three refrigerators in her room?” the answer is, of course, “for all the food...she needs a lot of food.”

~ Cheryl Gagne  
Kelowna, BC

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



## The Thrilling Birthday Party

By Carlos Molinet

Past President of the Chile PWS Association

It was 20:00 hours, all the guests to the birthday party were at the events room at the 5<sup>th</sup> floor of our building, waiting for [my daughter] the little princess Pia Macarena of Jesus.

Everything was a beautiful surprise; most important, there was a special guest for her, her boyfriend Esteban, who along with his parents had traveled from Vina del Mar to be with her.



At the set time, we went to the 5<sup>th</sup> floor. A little nervous and excited, she had been waiting for this moment for a long time and did not stop saying – Dad, when is my birthday? I think that is

important for her in order to avoid us forgetting her birthday.

When we got to the events room, we covered her eyes and SURPRISE! She was very happy. Everybody kissed her, and she did not stop looking everywhere. Who was she searching for? Esteban, hidden behind the door. When she saw him, she hugged him and passionately kissed him. Seeing this beautiful image of pure, clear, naïve and sincere love, we thrilled as well. How many times we saw her, suffering when she was a little girl, and now so different, a woman, so beautiful and happy.

Later, the dinner started. She was very happy, seated close to Esteban; she looked to him and kissed him. He was a little bit shy and only laughed.

Before having dessert, her brother Jean Pierre, 19, invited Esteban to go down to the first floor. A little later our



son calls – everything is ready. Then I tell Pia and all the guests to go with me. We started going down and listening to music, trumpets and guitars. I looked to my daughter, and her chest was jumping in emotion, crying and very excited. She saw a wonderful love scene, her boyfriend with a big Mexican hat and with him a group of “Charros” singing a beautiful serenade for her.

Pia did not stop crying and the guests as well. She was so thrilled. Esteban’s parents were also happy to see their son singing to his girlfriend. Pia went down from the balcony and hugged and kissed him. It was so thrilling and wonderful to see that scene; there are no words to describe how happy we were.

Later the “Charros” go to the 5<sup>th</sup> floor; they sing with Pia and Esteban, then Pia sings to him and soon we were singing with them.

It was a wonderful birthday; we had never seen her so thrilled. She hugged us and said – Thanks, Mom, thanks, Dad. “Happy 24 years, Pia Macarena of Jesus.”

*Dear friends, Mommies and Daddies with kids like ours, I just wanted to share with you, this beautiful and positive moment. I think they are the light and hope for all of us, we only have to see and feel with their eyes. This is so important, what I feel in this moment in my heart makes me stronger to go on helping her and helping any other who needs it, too. – Carlos ■*

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### Wedding Day, continued from page 7

brilliance occurred to me. There was a thin strip of chocolate frosting in between the two vanilla layers. “Oh, Michael,” I said, “it *is* double-chocolate. Look: chocolate *here*” I point to the chocolate cake part, “and chocolate *here*” I point to the chocolate frosting between the vanilla layers. For once, I was saved by a technicality!

The Grand March was a big hit and kicked off a lively dance. Michael was particularly exuberant in his dancing,

singing along with the Elvis songs and spinning around the dance floor. Midway through the dance, Brian noticed that Michael was overheating and took him aside to sit down and take off the outer jacket of his tux for a while. He got Michael a cool compress for his forehead, and a half hour later Michael was feeling better. Once again, Brian saved the day by being a helping hand with Michael.

As the dance was winding down, Michael went to the DJ to ask for the microphone. He gave the final toast of that evening, dressed to the nines in his

tailed tux and red vest, standing tall and strong. Tears of happiness welled up in my eyes. I thought of all that we’d been through together as siblings. Years of mischief and make-believe, successes and failures, laughter and sorrow all went through my mind. I am so proud Michael is part of my family. He’s the best brother I could have ever asked for. ■

*Katherine is Family Support Coordinator of the Prader-Willi California Foundation, an Affiliate of Prader-Willi Syndrome Association (USA).*

# State Chapter Leaders Meeting

By Lisa Thornton, Chair of National State Leaders Team, President of the Utah PWS Chapter, PWSA (USA) Board member, and best of all, Mom to Kate, with PWS

On October 20, 2012, PWSA (USA) hosted a State Leaders Conference in Baton Rouge, Louisiana in conjunction with the Hyperphagia Conference. Thirty-nine leaders from your states came together as a vibrant team moving forward to help families dealing with PWS, to be trained and share, many coming at great sacrifice. For example, one new state leader team rented a van and drove 16 hours for the conference. In a show of unity, many states provided financial support to new state leaders who haven't had the chance to do fundraising. We have many new state leaders who have stepped up in the last few months and agreed to serve you in states that have previously had no formal leadership. This new surge is exciting.

I began the conference with the theme "If you add a little to a little, and do it often enough, that little will become great." We stressed throughout the day that our small consistent efforts pay off grandly at the state level. The Baker family from Utah prepared the following wonderful video presentation about their daughter Lindsay and how a state organization has changed their lives. <http://youtu.be/Ne83-wDtal>. Lindsay's mother commented, "There are probably a lot of Lindsays around the country who would benefit from having a chapter in their state." This is why state leaders do what they do!

Dale and Dottie Cooper followed with a summary of the

National Association and how it can help states. **Kate Beaver** presented on crisis intervention and the new Resource Database that will soon be available to all states. The state leaders were given a "tour" of the Pennington facility and its work on obesity through the eyes of **Dr. Phil Brantley**. Utah's PWS State Educational Consultant and national board member **Michelle Holbrook** presented on educational advocacy and provided each state leader with a packet that will help each family with their child's education. **Crystal Boser** presented an enlightening session on how to conduct successful fundraising. **Deb Peaton** followed with How to Run a State Chapter, and **Debbie Mason**, Utah's Medical Care Manager for the Utah PWS Clinic, provided in-depth information on how to start a medical clinic in your state.

**Jim Koerber and Debbie Lange** presented on State Legislative and Funding Efforts. I provided materials to states to enable them to hold a legal planning session where families can meet together and complete their special needs trusts. **Jim and Deana Wells**, new state leaders from Idaho, were the

lucky winners of the free special needs trust! Best of all were the sharing sessions held throughout the day.

To top off the day, the state leaders were rewarded with an "Ask the Professionals" hour where several professionals attending the Hyperphagia Conference made themselves available to answer questions about our children. We ended the conference with an appropriate **Louisiana Saturday Night** celebration on the Bayou with Cajun style dining and music. Contact your state leader and ask how you can help move your state forward in the great cause of helping our children and families. ■

Contributed by Clint Hurdle:

"If your actions inspire others to dream more, learn more, do more and become more, you are a leader."

~ John Quincy Adams

## WE REMEMBER

The sympathy of the PWSA (USA) family goes out to Sam (Delphin) Beltran, M.D., on the loss of his wife Sylvia, nicknamed Tibby.

Sam, whose daughter Sarah, now 31, has PWS, served as the first president of PWSA.

Sam and Sylvia's was a late-life marriage after both were widowed. They first met in kindergarten and he may or may not have dipped her pigtails in the inkwell in third grade to show his affection for her. Many years later they met again, and the romance was rekindled. ■



It's not too late...

Your Angel Fund contribution is vital to support those whose lives have been affected by PWS.

To make a gift, contact us at 1-800-926-4797 or donate online at [www.pwsausa.org](http://www.pwsausa.org)

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# Homework... A Lesson in Frustration

*Revised from The Gathered View,  
September-November 1999  
by Barb Dorn, Consultant and Training  
Coordinator, PWSA of WI, Inc.*

*I recall the days when homework was a nightmare for our family. As my son Tony, with PWS, grew older; the challenges of homework grew more intense. For many (but not all) homework can destroy family time. There may be students who have PWS and families who do not face this challenge. But for those of you who do...this article is for you, a view on this common educational practice.*

Homework is a task that all of us experienced as students. A teacher taught us the material; we performed in-class exercises; then we practiced what we learned in out-of-class “home” work. Homework can teach many students responsibility and accountability. It can help students transfer the learning process from school into the home environment. But...there are a variety of reasons that homework can cause tremendous stress in the home life of students with PWS.

**Difficulty in transferring learning** to different environments causes frustration in many students with PWS as well as those with other cognitive or learning differences. Most have difficulty transferring or generalizing what is taught in school to the home or other environment. A child may seem to have a clear understanding of a concept or task at school, but when he or she is asked to perform that task outside of the area in which they learned it, they are often unable to do so.

**Changes and new ways of teaching** have taken place since the

times when parents learned many concepts. In addition, many students with PWS require special modifications and approaches that parents have never learned. Well-meaning parents try to reinforce or re-teach a concept during homework time. The child with PWS becomes confused and/or anxious because the parent is explaining things in a different way. Battles often begin when this student then wants to complete the assignment, but the parent hasn't the ability to teach the material in a consistent manner. This results in at-home chaos and emotional upheaval for the entire family.

**Role confusion** also contributes to frustration. Many students with PWS do not see parents as teachers (even though that can be one of their undercover responsibilities). Many children and adults with this disability rely on the “expert” for the final decision. Unfortunately, the parent is not always viewed as this expert. Siblings often try to help out as well. There are situations where this is successful. There are other times when the whole household gets pulled into the emotions of frustration and misunderstandings that accompany this role confusion.

**Poor auditory and short-term memory** is often seen in many students with PWS. If exact instructions or assignments are not clearly written down, the student is often unable to remember how to complete the work. The parent is often placed in a “no win” situation--the parent's word against the child's word. Emotions can escalate; logic and learning is lost.

**Home can and should be a safe-haven** where students with PWS can unwind, relax, and work on home-related and social activities. Many students with PWS work very hard all day long in order to stay focused and in control of their emotions and behavior. The school environment can present them with many challenges academically,

behaviorally, and socially. Lowering stress levels for all who support these students should be a priority. A “no homework” expectation asks for sanity and peace in their homes. Parents face so many challenges; out-of-school work should not be one of them.

**“Home work” should focus on different learning experiences.** Parents can become experts at teaching the student with PWS life skills, home-related responsibilities, exercise and social skill activities. Parents should be teaching and reinforcing grooming and household tasks. The “parent-teacher” is responsible for teaching bathing and other hygiene tasks, instructing on bed making, laundry, and other cleaning responsibilities. Parents also orchestrate appropriate recreational and social opportunities. Arranging community experiences, providing structured time with friends, expanding social skills, practicing phone skills...and making sure food security is in place are all examples of many valuable life lessons and “home work” that parents provide.

**Homework should be eliminated or modified.** Students with PWS have some degree of cognitive (learning) and/or behavior limitations. As the child-and-family advocate, parents need to feel confident in requesting that home time be a time of positive social and leisure opportunities. Educators need to support the separation of school work and home work. Parents are not giving up; instead they are focusing on different yet very important areas of the student's learning needs. ■

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## WE REMEMBER

### Donna Marie Cillo

Donna Marie Cillo passed away suddenly on Sept. 8, 2012. She was 44 years old, weighed only 105 pounds, but had developed a serious heart problem the year before. For the short time she lived, she made an everlasting impression on everyone she met or knew.



Donna truly loved family celebrations and was always the first one on the dance floor with the best dance moves and the biggest smile.

To avoid skin picking, which was a major medical issue for Donna, she kept her hands occupied as much as possible. You could always see her working on latch hook kits, beads, puzzles, and crafts, which she would materialize into lovely gifts and delight in giving them to people.

What we will miss the most is her beautiful cheerful smile, her phone calls at 7:30 a.m. singing “Happy Birthday to You” on your birthday, seeing how excited she got when coming home for holidays with bags of gifts for everyone that she personally selected and beautifully wrapped, sharing fun times and milestones with her nephews Dustin and Louis, watching scary movies together and seeing her face glow when taking a trip to Dunkin’ Donuts with her sister Kim for her very favorite de-caf skim latte.

She had a deep sense of compassion and sincere capacity of caring for people. Many friends, staff and family have told us how she touched their lives in some way - “a character”, “hot stuff”, “a true lady”, “a challenge”, “life of the party”, “heart of gold”. But her boyfriend Brian said it best - “Donna always made me feel better when I talked to her - she always knew just what to say to help me through the difficult times.”

No parent should ever know the pain of losing a child. There are no words that can truly speak to the sorrow of such an unimaginable loss. The love we shared will always be a part of us, and she will be eternally in our hearts. You did your best while on this earth, Donna, now you can Rest in Peace.

*-Kathleen and Louis Cillo  
Ardley, NY*

## The Media of PWS

*By Andrea Glass*

It never ceases to amaze how much information we can find on PWS NOW. I just saw a copy of the second *Gathered View* from September 1975—written, of course, on a typewriter. Can you imagine what parents did in those days to connect with other parents of children with PWS? How they were fortunate enough to find each other without a strong national association and a widespread internet is really beyond my 2012 imagination.

Today the *Gathered View* goes out to more than 5000 people in 42 countries. The PWSA(USA) Web site during the year 2011 had 600,746 visitors with 471,688 from the U.S., and the remainder from 200 other countries. That’s incredible. Just think for a moment, 600,000 people had an interest in PWS. These people visited the PWSA(USA) site for a number of reasons, including helping loved ones with the syndrome; providing medical and caregiver services; reviewing research; requesting research grants; seeking self-help publications; connecting with other parents and providers; seeking crisis, legal and IEP support.

Let’s not forget the power of the printed word. There are over 50 books and pamphlets written on PWS. Many are translated into Spanish. There are also 13 CDs/DVDs, all available from PWSA(USA).

It is incredible how many people take to the Internet on a daily or weekly basis to write about their lives with PWS. Just search “My son has PWS” or “My daughter has PWS”. Go to Facebook and connect with many more who are very gifted writers and bloggers.

Our world and our people are connected by the power of the **Internet**. Take a virtual cruise around the world one evening and view the IPWSO, Australia, and England PWS Web sites. Use a translator and view the Web site from Japan.

In 2011, there were over 2000 people who logged into the email support groups at [www.pwsausa.org/egroups/index.htm](http://www.pwsausa.org/egroups/index.htm). These 65 e-group connections are a lifeline for so many people. Have a few quiet hours on your hand to explore current and past research studies on PWS? Search out sites of organizations such as PWSA(USA), FPWR, NIH, Pubmed. Today you can find over 2500 abstracts on-line. It is uplifting to find all this research that will one day help our children.

PWSA(USA) reaches out to 90 countries through email, fax and phone, spreading awareness, developing connections and providing crisis support. Some of these countries do not have the media opportunities that we take for granted in the U.S. Some countries are just now identifying PWS. Families in these countries are now being connected with each other for the first time. These families join ours, and they are no longer alone in their journey. Through media connections we are one voice striving for the same goals. ■

## How Does a Person With PWS Think?

Persons with PWS are generally concrete thinkers. Terms like, “Hop to it!” may not be understood to mean “Begin the task immediately” and may cause confusion, anxiety, and result in an unwanted behavior.

Persons 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”, try breaking the process down into steps. For example, “It’s time to brush your teeth”, then wait 3-5 seconds 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 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.

Short-term memory is often poor.

Long-term memory is usually excellent (thanks to ghrelin) so that once something is learned, it’s remembered forever.

### PWS is about Anxiety

Persons with PWS typically feel high levels of anxiety – all the time.

Maladaptive, unwanted behaviors are often attempts to reduce the level of anxiety the individual with PWS is feeling: skin picking (also done when feeling bored); repeated questions; excessive talking; controlling, oppositional or argumentative behavior; sleeping.

**If you can reduce or eliminate the cause of the anxiety, you’ll reduce or eliminate the behavior problem!** The best start is to remember they have a processing delay and they want to please you. ■

*~Kate Beaver, Crisis Counselor*

## Collaboration with Pfizer to Educate Endocrinologists

We are pleased to announce that Pfizer is donating \$10,000 to fund a PWSA (USA) 2013 project to educate all pediatric endocrinologists in the nation about Prader-Willi syndrome and medical issues. This project will involve re-printing of our growth hormone booklet, creating a PWS growth chart for ages 2-12 (we have an infant toddler one thanks to Dr. Butler) plus basic medical information and a brochure of the services offered by PWSA (USA). Pfizer will then help us distribute the materials to all of the pediatric endocrinologists around the nation. This will be a tremendous service to our families. Thank you, Pfizer! ■

## 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](http://www.pwsausa.org) donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718)846-6606 o email, [ninaroberto@verizon.net](mailto:ninaroberto@verizon.net). ¡Hablamos pronto! ■

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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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**New Password:** pws

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

E-mail Support Groups:

We sponsor nine groups to share information.

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

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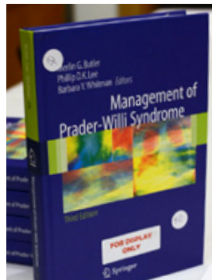
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## Sights from the Hyperphagia Conference



### Couldn't attend but want to learn more?

Several of the researchers who gave presentations at the Hyperphagia Conference have given permission for us to put their presentation on our PWSA (USA) Web site. To order the abstracts from both the Hyperphagia and Scientific Conferences, see Note: for the Abstracts article on page 2. ■



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