

The *Gathered View*

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

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

Hand-to-Hand Across America

~By Jodi O'Sullivan

Development/Communications

Last year we kicked off our inaugural year of Prader-Willi Syndrome *On The Move*SM with 14 events occurring nationally. This second year our goal is to double that number. Ideally, soon we'll see *On The Move*SM events in every state, with "Mo", the move character, a more easily recognized symbol for PWS.

The benefits of a cohesive campaign include increased visibility and solidarity, and more funding. Those involved with the PWSA (USA) organization have had a vision of raising public consciousness about PWS through an organized nationwide effort for many years. With the help of dedicated volunteers, it's been taken from idea to reality, and it's being offered to you.

I remember when I was a kid, I visited my family in Ohio. My aunt announced that we were going to participate in Hands Across America. If you're not familiar, Hands Across America, according to Wikipedia.org, was a benefit event and publicity campaign staged on Sunday, May 25, 1986, in which approximately 6.5 million people held hands in a human chain for fifteen minutes along a path across the continental United States. Many participants donated ten dollars to reserve their place in line; the proceeds were donated to local charities to fight hunger and homelessness and help those in poverty. Hands Across America raised \$34 million. The idea was conceived by one man who took it from idea to reality.

That reality was something in which I partook. I remembered feeling like part of something really big, something that mattered. *On The Move*SM is like that—being part of something big to accomplish more than what one person could do alone. Chapter and individual involvement is vital. *Our* chain is stronger and covers more distance when

there are more who participate. We move closer to reaching our campaign goals to raise awareness, grow support, raise funds, improve health, inspire, and remind (go to www.pwsausa.org/onthemove to see those goals in more detail).

Anyone who participated in the campaign's first year will tell you they are glad they did it for a number of reasons. The most important reason is that it is entirely for the benefit of those who live with the syndrome. It is for their future. It is for their lives.

*On The Move*SM was created thoughtfully to require movement-based activity which is important for those who have PWS, and to occur in May, which is PWS Awareness Month.

The full list of states where events are officially registered is: CA, CT, FL, MA, NY, OH, WI (as of print date); we'll be announcing more soon.

The seeds are planted and now need tending. In this case, the degree to which we all nurture and toil by planning an *On The Move*SM event or supporting one already scheduled is what will ultimately determine what will grow in the garden to come. Let's work for a wondrous Eden, by working hand-to-hand across America together, and take this even further from idea to reality.

To join our movement or for more information, visit www.pwsausa.org/onthemove or call PWSA (USA) at 800.926.4797. ■



On The Move

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Volume 37, Number 2 ~ March-April 2012 ~ Our 37th Year of Publication

Presentations at the 25th Annual PWSA (USA) Scientific Meeting in Orlando, Florida – Nov 2011

The 2011 Scientific Co-Chairs

Keynote speakers:

Maïthé Tauber, M.D., Ph.D., *Toulouse, France spoke on "The French Reference Centre for PWS and Pertinent Endocrine Issues in PWS"*
Cary R. Savage, Ph.D., *Kansas University Medical Center spoke on "Functional MRI studies in PWS and Obesity"*

Here are more of the abstracts presented at Scientific Day at the national conference. In the issue is **The Behavior/Neuropsychiatry Review** and **The Medical/Nutrition Review**. The complete abstract booklet can be bought by calling the PWSA (USA) office at 800-926-4797 or emailing Cindy Beles at cbeles@pwsausa.org. The cost is \$10 for members and \$15 for non-members.

The Behavior/Neuropsychiatry Review

Social Functioning in Prader-Willi Syndrome

Anastasia Dimitropoulos

Department of Psychological Sciences, Case Western Reserve University, Cleveland, Ohio

Introduction/Background: In addition to a well-described behavioral phenotype that includes hyperphagia, obsessive-compulsive symptoms, disruptive behavior, and cognitive delays, research also suggests that some persons with Prader-Willi syndrome (PWS) have repetitive behavior and social deficits reminiscent of autism spectrum disorders (ASD). Although repetitive behavior has been well characterized in this population, social functioning has not been well studied thus far. The few findings that have been reported indicate that social problems are common in PWS with individuals with PWS exhibiting more problems with social competence and making fewer gains in competence with age compared to individuals with other neurodevelopmental disorders (Rosner et al., 2004). Further examination of social functioning in PWS is also warranted in light of findings implicating the 15q11-q13 region as a genetic susceptibility region for idiopathic autism. In addition, research to date indicates individuals with the maternal uniparental disomy (m-UPD) subtype of PWS are at greater risk for autistic symptomatology than those with paternal deletions (DEL) of 15q11-q13. The purpose of this research is to examine social competence and responsiveness in individuals with PWS in direct comparison to individuals with ASD and to examine those abilities with respect to PWS genetic subtypes.

Their findings indicate individuals with PWS have difficulty initiating social interaction and may be prone to social hesitancy or withdrawal similar to those with

ASD (autism spectrum disorders). Prosocial behaviors such as generosity, empathy, and helpfulness were more evident in those with DEL (deletion) subtype than in individuals with m-UPD or ASD.

This research was funded by a grant from the PWSA (USA)

Psychiatric Symptoms in Prader-Willi Syndrome

Elizabeth Roof, Carolyn Shivers, Lauren Deisenroth and Elisabeth Dykens

Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN

Results: Those with the mUPD subtype versus Deletion subtype of PWS showed a significant increase of psychotic symptoms with delusions, magical thinking and other perceptual disturbances being the most commonly endorsed features. In addition, age is positively correlated with brief reactive psychosis.

Those with Imprinting Mutation subtype of PWS are also scoring significantly higher on the psychotic subtype, suggesting they may share some common psychiatric features with those who have the UPD subtype.

The Effect of Residential Placement on Weight Control of Individuals with Prader-Willi Syndrome: An Outcome Evaluation

L. Spanbauer¹ and K. Stote²

¹Consultant for Catholic Charities Disabilities Services, Albany, NY, Adjunct Instructor, State University of New York, Empire State College, Center for Distance Learning, Saratoga Springs, NY; ²Assistant Professor State University of New York, Empire State College, Center for Distance Learning, Saratoga Springs, NY

Results: Study participants (N=8) had a mean age of 30 years (range: 38 to 18) and an average pre-admission BMI of 39±14

kg/m². The mean amount of time since admission into the approved facility was 6.3±5 years. With the exception of only one participant, all those included in the study sample experienced weight loss and a decrease in BMI. The mean amount of weight loss by study participants was 22kg. The greatest amount of weight loss was 65kg, however; one individual was noted to have a 7 kg weight gain since admission. In addition to weight loss, across all those study participants who lost weight (7 of 8) BMI was noted to decrease by 42%, resulting in a mean BMI of 26.4 kg/m² (compared to the mean pre-admission BMI of 39±14 kg/m² prior to residing in the food secure environment).

Conclusion: Among those females with PWS included in the study, the introduction of a supervised, food secure environment for people with PWS results in overall weight loss and improvement in BMI.

Parental Role in Physical Activity among Children with Prader-Willi Syndrome

Jie Weiss, Michele Mouttapa and Daniela Rubin

California State University, Fullerton

Introduction/Background: It has been demonstrated that parents play a role in influencing their children's health-related behaviors. Physical activity is vital to the management of Prader-Willi Syndrome (PWS). One of the determinants of youth physical activity (PA) is the parents' own PA. Cognitively, parents' views of the consequences of PA among children predict the child's PA level. This study examined associations between parents' self-reported physical activity (PA) and PA of their children with PWS. This study also explored relationships between parents' perceived consequences of their child's PA, and child's actual PA involvement, using the Multi-

- Janalee Heinemann

Attribute Utility (MAU) decision making model as the theoretical framework.

Conclusion: The observed positive influence of parental PA on children's PA suggests that one potentially effective strategy to increase PA among children with PWS may be through promotion of PA among parents. Because children with PWS are more dependent on their parents compared to children without PWS, they may especially benefit from parental support for a healthy lifestyle.

The Relationship between Early-Onset Obesity and Behavior

Krista S. Garner^{1,2}, Jennifer L. Miller², Jonathan J. Shuster³, John H. Kranzler¹ and Daniel J. Driscoll^{2,4}

¹Department of Special Education, School Psychology, and Early Childhood, College of Education; ²Department of Pediatrics, College of Medicine; ³Department of Health Outcomes and Policy, College of Medicine; Center for Epigenetics, ⁴University of Florida, Gainesville, FL

Results/Discussion: The results of the present study indicate that (according to parent, teacher, and self-report) individuals with early-onset morbid obesity (EMO) and individuals with PWS tend to behave similarly, on average, and their behavior tends to be more problematic than typically developing individuals. For example, both the individuals with EMO and the individuals with PWS scored significantly worse than their typically developing sibling controls across raters on the Atypicality, Withdrawal, Somatization, Adaptability, Social Skills, and Leadership scales.

These findings suggest that individuals with EMO and individuals with PWS tend to display more strange or odd behaviors, tend to be more withdrawn, pessimistic, or sad, tend to display more health-related concerns, tend to be less adaptable to changing conditions, tend to have more difficulty complimenting others and making suggestions for improvement in a tactful and socially acceptable manner, and tend to have more difficulty making decisions, being creative, and getting others to work together effectively than typically developing individuals.

Surprisingly, not only did the individuals with EMO typically score more similarly on the BASC-2 to the individuals with PWS than to their normal weight sibling controls across raters, but they also often scored significantly worse than the individuals with PWS. The reasons behind these findings need to be explored further.

Preliminary Results of Strengths and Weaknesses in Neuropsychological Testing in Children with Prader-Willi Syndrome

Marnie Hutchison¹, Wing Sze Wence Leung¹, Michelle L. Mackenzie², Andrea M. Haqq² and Jacqueline Pei¹

¹Department of Educational Psychology, University of Alberta, Edmonton, AB, Canada; ²Department of Pediatrics, University of Alberta

Results/Conclusions: The study sample demonstrated an uneven profile suggesting certain areas of strength and weakness and that children's IQ does not wholly account for performance on these measures. On average, children with PWS obtained abbreviated intelligence scores in the extremely low range. Participants' verbal and nonverbal working memory scores are comparable to their IQ. Results from the TOVA indicate that these children demonstrate significant difficulty maintaining attention for sustained periods of time and show signs of fatigue and impulsivity. On the NEPSY-II, children with PWS demonstrated relative strengths on Animal Sort and Response Set but showed relative and normative weaknesses on Auditory Attention and Inhibition. On the BRIEF, parents reported children with PWS to have relative strengths with organizing materials, initiating tasks, and holding information in memory. Parents reported normative and relative weaknesses controlling their emotions, changing tasks, resisting impulses, regulating their behaviour, and self-awareness. Although a small sample size limits our ability to generalize results and make detailed conclusions, this preliminary information can begin to inform practice. As such, we will also discuss implications for intervention and support based on this early information.

The Medical/Nutrition/Endocrine Review Hormonal and Metabolic Responses to Endurance Exercise in Prader-Willi Syndrome

Daniela A. Rubin¹, Daniel A. Judelson¹, Susan S. Clark², Diobel M. Castner, Joane Less², and Jason Ng¹

¹Department of Kinesiology, California State University, Fullerton; ²Department of Endocrinology, Children's Hospital of Orange County

Introduction: Prader-Willi syndrome (PWS) is characterized by several hormonal and metabolic abnormalities resulting in excessive body fat. The purpose of this study was to determine differences in endocrine and

metabolic responses to exercise between youth with PWS and those without, accounting for differences in adiposity.

Discussion: Despite baseline differences in IGF-1 and testosterone, youth with PWS respond similarly to acute exercise compared to youth without PWS for several hormones (insulin, glucagon, IGF-1, cortisol, and testosterone). Metabolically, PWS present lower glucose concentrations than NW (normal weight) and OB (obese); however, glucose concentrations do not seem to limit the rate of glycolysis during exercise as indicated by similar lactate responses. Youth with PWS present similar rate of lipolysis as NW and OB in response to acute exercise. Thus, it appears that in childhood and adolescence, PWS does not drastically affect some hormonal and metabolic responses to acute endurance exercise.

Postprandial Cardiac Autonomic Function is Impaired in Prader-Willi Syndrome

Louise Purtell¹, Lisa Sze², Arthur Jenkins³, Alexander Viardot¹, Herbert Herzog⁴, Amanda Sainsbury-Salis⁴, Ellie Smith⁵, Georgina Loughnan⁶, Katharine Steinbeck^{6,7} and Lesley V. Campbell⁸

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Introduction: Prader-Willi syndrome (PWS) is a leading genetic cause of obesity, characterised by hyperphagia and endocrine and behavioural complications. The syndrome is associated with increased cardiovascular morbidity and early mortality. Autonomic tone, measurable by analysis

continued on page 4

Presentations, continued from page 3

of heart rate variability, has been shown to be a cardiovascular risk predictor, and is closely associated with adiposity. It has been suggested that an impairment in autonomic nervous system (ANS) responsiveness could be a cause of cardiovascular morbidity in PWS. However, no differences have been found between people with PWS and BMI-matched controls during orthostatic manoeuvres. Postprandial ANS responsiveness in PWS has not yet, to our knowledge, been studied. Further, due to the relationship between autonomic tone and adiposity, it is desirable to eliminate fat distribution as a confounding factor by matching groups for total and abdominal adiposity. This study assesses basal and postprandial ANS responsiveness in PWS independent of adiposity

Conclusion: There was a postprandial defect in ANS responsiveness in adults with PWS. While this impairment had no apparent effect on heart rate, a robust and important predictor of cardiovascular morbidity, the meal-related abnormality we found may contribute to some appetite regulation impairments in PWS.

Phenomenology of Malignant Hypothermia in PWS

Janice Forster¹, Francie McDougall², Jacqueline Durette² and Linda M. Gourash¹

¹Pittsburgh Partnership, Pittsburgh PA;

²Latham Centers, Brewster MA

Background: Persons with PWS have difficulty maintaining core body temperature when ambient temperature changes. In addition to faulty homeostatic mechanisms in the hypothalamus, there is reduced transmission of temperature sensation from the skin; impaired judgment that interferes with selection of appropriate clothing to match the weather; and cognitive inflexibility that interferes with compliance for seasonal changes in clothing. A few individuals have had episodes of sustained (malignant) hypothermia <92°F, severe enough to be life threatening, and these individuals appear to be susceptible to experiencing subsequent episodes.

Conclusions: Malignant hypothermia is a life threatening problem seen in PWS. Investigation of an underlying medical cause is essential considering iatrogenic etiologies. All individuals with PWS are at risk for mild hypothermia because of impaired peripheral somatosensory and central thermoregulation,

poor judgment and cognitive inflexibility. Aging individuals with PWS are at greater risk for malignant hypothermia. Physicians, families and residential providers must learn about the risks of hypothermia in PWS. Recommendations include greater supervision and behavioral reinforcement for wearing appropriate clothing, early detection by monitoring vital signs in cold weather, and ongoing monitoring of body temperature in those who have already experienced an episode of malignant hypothermia.

Cases of Survival and Death from Gastric Dysmotility in PWS

*Linda M. Gourash and Janice Forster
Pittsburgh Partnership, Pittsburgh, PA*

Introduction/Background: Abnormalities of smooth muscle are clinically significant in many persons with PWS. Gastric necrosis, rupture and death are described in the literature beginning in 1997 but other important clinical details are still emerging. Additional descriptions of cases of persons who survive gastric dilation are needed in order for clinicians to respond correctly and to guide our surgical colleagues.

Conclusion: All persons with PWS hospitalized for any reason should be weighed daily and require 1 to 1 supervision at all times both to guarantee no extra food acquisition and to mediate between healthcare providers and the patient. Inappropriate communications with adults with PWS include discussions of uncertain medical possibilities, ambiguous test results and offhand comments or discussions about food or diet which introduce additional uncertainty, stress and behavioral problems. Communications should be done privately with guardians or caretakers who should then interpret to the patient. Prevention for susceptible individuals appears to include careful monitoring of intake and daily bowel patterns and ongoing daily management of constipation. Other factors, no doubt, exist. Continued sharing of crucial clinical details in these cases will guide other clinicians when they are involved in what is often their first experience with this life threatening condition. More detailed but concise information about PWS and gastric dysmotility for the surgical community is needed.

Autonomic Nervous System (ANS) Dysfunction in PWS and Childhood Obesity: Preliminary Findings

Lawrence P. Richer¹, Darren S. DeLorey², Arya M. Sharma³, Felix Kreier⁴, Michael

Freemark⁵, Michelle L. Mackenzie¹ and Andrea M. Haqq¹

¹Department of Pediatrics, University of Alberta, Edmonton, AB, Canada; ²Faculty of Physical Education and Recreation, University of Alberta; ³Department of Medicine, University of Alberta, Edmonton, AB, Canada; ⁴Department of Pediatrics, University of Amsterdam, The Netherlands; ⁵Department of Pediatrics, Duke University, Durham, NC, USA

Background: A number of clinical features in PWS suggest congenital ANS dysfunction, including: viscous saliva, altered gastrointestinal motility and temperature control, hypoglycemia, sleep disturbances, increased pain threshold and a specific neurocognitive profile. Moreover, common causes of mortality in PWS differ from traditional obesity-related causes and may be linked to ANS dysfunction that is unique from the ANS dysfunction associated with general obesity.

Conclusion: These preliminary findings suggest possible important differences in autonomic cardioregulatory mechanisms between normal control subjects and the children with PWS. Additional subjects are needed for study of ANS dysfunction in PWS. The confirmation of ANS dysfunction in PWS could lead to novel treatment strategies to improve quality of life and prevent premature mortality.

Growth Hormone Effects in Adults with Prader-Willi Syndrome

Merlin G. Butler¹, Bryan Smith², Jaeboon Lee³, Candy Schmoll⁴, Wayne Moore⁴ and Josephe E. Donnelly²

¹Departments of Psychiatry & Behavioral Sciences and Pediatrics, University of Kansas Medical Center, Kansas City; ²Center for Physical Activity & Weight Management and ³Center for Research Methods and Data Analysis, University of Kansas, Lawrence; ⁴Department of Pediatrics, Children's Mercy Hospital, Kansas City, Missouri

Conclusions: The beneficial effects of growth hormone treatment noted in treating children with PWS were identified in our adults during the 12 months growth hormone treatment interval but body composition and physical activity measures and both HDL and IGF-1 levels regressed to baseline after treatment cessation for 12 months. The growth hormone treatment had no apparent effect on energy expenditure.

Serum IGF-1 Levels Do Not Correlate with Growth Hormone Dose in

Medical and Research View

Children with Prader-Willi Syndrome

Diane E. J. Stafford

Children's Hospital, Boston, Harvard Medical School, Boston, MA

Conclusion: Growth hormone therapy has been shown to benefit children with Prader-Willi syndrome in a variety of aspects. Appropriate dosing of growth hormone for these children, however, has remained difficult to determine and clinical practice is variable. Based on this review of 67 patients with Prader-Willi syndrome, serum IGF-1 levels in those treated with growth hormone are highly variable whether dosing is based on body weight or body surface area. This data supports the need to individualize growth hormone dosing based on measurement of IGF-1 levels. Serial measurements are necessary in individuals when growth hormone doses are altered as there is frequently no linear correlation between dose and IGF-1 level, even in the same patient. Clinicians who prescribe growth hormone therapy for PWS should adjust growth hormone dose based on serum IGF-1 in addition to longitudinal growth rate and body weight.

Hyperghrelinemia Begins Early in Prader-Willi Syndrome

Frederick A. Kweh, Jennifer L. Miller, Carlos R. Sulsona and Daniel J. Driscoll
College of Medicine and Department of Pediatrics, University of Florida, Gainesville

Discussion: Serum ghrelin levels were measured in individuals with PWS from 2 months to 36 years of age. We found that ghrelin levels were significantly elevated beginning in early infancy in PWS well before the onset of obesity and hyperphagia. Given that ghrelin levels were the highest in PWS in infants still in the poor appetite phase (i.e., 1a) it seems unlikely that elevated ghrelin levels are causing the switch to the hyperphagic phases of PWS. However, it has been shown in mice that ghrelin can also act to increase fat mass independent of its effect on appetite (Perez-Tilve et. al, FASEB J. 25:2814, 2011). Therefore, it is likely that the elevated ghrelin levels are causing the increased fat mass seen in infants with PWS compared to normal infants with similar body mass indices (BMI)

Two More Children Born to Women with Prader-Willi Syndrome, One Normal, One with Angelman

Suzanne B. Cassidy and Divya Vats
Division of Medical Genetics, Department

of Pediatrics, University of California, San Francisco

Discussion/Conclusion: These cases represent the 3rd and 4th reported females with PWS who brought a pregnancy to term. All were on behavioral medications (SSRIs or antipsychotics) at the time they became pregnant, possibly stimulating their FSH and LH response and increasing the likelihood of ovulating and establishing a pregnancy. Three of the four with fertility had significant weight loss prior to pregnancy; the other was never obese. Thus it appears that infertility is not a consistent feature in females with PWS and that there is a variable degree of reduced fertility in untreated females with PWS of any molecular genetic etiology. Though hypogonadism is an important diagnostic feature, it should not preclude the possibility of pregnancy without testing, and sex education and discussion of contraception should be part of management of women with PWS.

Effects of Early Growth Hormone Therapy in Individuals with Prader-Willi Syndrome

Carolina Vac¹, Jennifer Miller², Jonathan Shuster³ and Daniel J. Driscoll^{1,4}

¹College of Medicine University of Florida; ²Department of Pediatrics, University of Florida; ³Department of Biostatistics, University of Florida; ⁴Center for Epigenetics, University of Florida

Results and Conclusions: Those who began GH therapy before 1 year of age had a BMI Z-score that was significantly lower than those who started GH later in life. Additionally, those who began treatment before 1 year of age had a lower total percentage of body fat at the time of analysis and a higher resting energy expenditure than those who began GH at an older age. Consistent with previous analysis of effects of early GH treatment, those who were treated prior to age 1 had higher verbal skills than those treated later.

However, GH treatment prior to age 1 did not have a significant effect on GIA, TIA, working memory, cognitive efficiency, or BSI. Although there was a trend towards higher GIA with early GH treatment, this association was not significant on ANCOVA analysis. Further data will be forthcoming on the entire cohort followed under the auspices of the NIH-funded Rare Disease Consortium. ■

**Your Association
needs YOUR support
and participation
in this campaign.**



*This is my
Association.*

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

Thank you.

**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.**

2nd International Conference on HYPERPHAGIA

The Mechanism – The Research – The Treatment

and 26th Annual PWSA (USA) Scientific Day Conference

and PWSA (USA) Professional Providers Conference

October 17-20, 2012

Pennington Biomedical Research Center - Louisiana State University

Baton Rouge, LA, USA

Hyperphagia Conference

Wednesday, Oct. 17, 6:30 p.m. – 9:30 p.m.

Thursday, Oct. 18, 8:30 a.m. – 9:15 p.m.

Friday, Oct. 19, 8:30 a.m. – 1:00 p.m.

PWSA (USA) Professional Providers Conference

Thursday, Oct. 18, 8:30 a.m. – 5:30 p.m.

Friday, Oct. 19, 8:30 a.m. – 12:00 p.m.

26th Annual PWSA (USA) Scientific Day Conference

Friday, October 19, 1:00 p.m. – 8:00 p.m.

Saturday, October 20, 8:30 a.m. – 12:00 p.m.

HYPERPHAGIA CONFERENCE

- Join top international scientists in the field of appetite research for a thought-provoking program designed to:
- Expand your understanding of hyperphagia
- Generate points of contact and collaboration
- Create research initiatives for hyperphagia
- The conference will feature top international scientists in the field of appetite and obesity research. Over the three-day conference, participants will present the latest information on various aspects of appetite control including:
 - Intracellular nutrient control of hunger
 - Common and novel genetic causes of hyperphagia
 - Animal and cell models of hyperphagia
 - Addictive behavior and hyperphagia
 - Novel investigative approaches to study hyperphagia

We're hungry for a solution to obesity. Imagine that one source could provide breakthrough insight with Prader-Willi syndrome as that "Window of Opportunity". As the most

common known genetic cause of life-threatening obesity, Prader-Willi syndrome features extreme problems related to genetics, hormones, brain structures, psychology and appetite control. Research on the extremes of PWS is the "Window of Opportunity" for breakthroughs applicable to the general population.

For information on submitting an abstract for a poster go to www.pwsausa.org -- Deadline July 1st

PWSA (USA) PROFESSIONAL PROVIDERS CONFERENCE

This conference is designed for all who work in homes, residential facilities, vocational programs, educational programs, health and human service agencies, and other community programs that provide assistance and education to persons who have Prader-Willi syndrome and their families.

Consider attending the PWSA (USA) Scientific Conference immediately following.

26TH ANNUAL PWSA (USA) SCIENTIFIC DAY CONFERENCE

These sessions are designed for physicians and researchers in the field of Prader-Willi syndrome. Presentations will be made by world-renowned scientists, medical specialists and other professionals.

We are pleased to announce that **Professor I. Sadaf Farooqi** (University of Cambridge, United Kingdom) and **Professor George A. Bray** (Pennington Biomedical Research Center, Baton Rouge, Louisiana), both internationally known experts, have accepted our invitation as keynote speakers at the Scientific Day Conference. Professor Farooqi will be speaking on the genetics of obesity while Professor Bray will discuss causation of obesity, weight gain and energy expenditure.

For Information about the Scientific Conference including requests for abstracts go to www.pwsausa.org.

Hyperphagia Conference Agenda

Wednesday, October 17

6:30 p.m. – 9:30 p.m.

Introduction to Meeting

Steven Heymsfield, M.D.

Dinner and Keynote Presentations

“Hypothalamic, Brainstem and Intracellular Nutrient Signals Controlling Food Intake”

Randy Seeley, Ph.D.

“Defining Hyperphagia”

Jack A. Yanovski, M.D., Ph.D.

Thursday, October 18

8:30 a.m. – 9:15 p.m.

Welcome and Conference Overview

Phillip Brantley, Ph.D.

Causes of Hyperphagia

“Prader-Willi Syndrome - The Window of Opportunity”

Daniel J. Driscoll, M.D., Ph.D.

“Common Genetic Variants Causing Hyperphagia and Obesity”

Ruth Loos, Ph.D.

“Novel Genetic Defects Causing Hyperphagia”

I. Sadaf Farooqi, M.D., Ph.D.

“Craniopharyngioma and Hyperphagia”

Christian L. Roth, M.D.

“SIM1 Gene and Hyperphagia”

Andrew Zinn, M.D., Ph.D.

Developing Treatments - Pros and Cons Panel Facilitated Discussions

Drugs vs. Behavior

“Best Practice for Treating Hyperphagia will involve Drugs in addition to Control of the Food Environment and Behavioral Modification”

Tony Goldstone, M.D., Ph.D., George Bray, M.D.,
Linda Gourash, M.D.

Bariatric Surgery

Pros and Cons: “Bariatric Surgery is an Appropriate Treatment Option for Patients with Genetic or Hypothalamic Obesity”

Tony Goldstone, M.D., Ph.D., Christian Vaisse, M.D.,
Ph.D., Ann Schieman, M.D., M.B.A.

Developing Treatments - Pharmaceutical Interventions

“How to Run a Clinical Trial for Genetic and Hypothalamic Obesity with Hyperphagia”

Maïthé Tauber, M.D., Ph.D.

“Developing Drugs for Genetic and Hypothalamic Obesity with Hyperphagia: Role of Regulatory Authorities” - To be determined

Animal and Cell Models of Hyperphagia

“How can Animal Models for Prader-Willi Syndrome help us find Treatments for Hyperphagia?”

Rachel Wevrick, Ph.D.

“Hyperphagia in Animal Models of Bardet-Biedl Syndrome”

Val Sheffield, M.D., Ph.D.

Poster Session, Social Hour and Dinner with Presentation

“Addictive Behavior and Hyperphagia”

Nicole M. Avena, Ph.D.

Friday, October 19

8:30 a.m. – 1:00 p.m.

Novel Techniques for Investigating Obesity

“Novel Genetic and Neuroanatomical Techniques to Dissect Feeding Pathways in Animal Models”

Joel Elmquist, D.V.M., Ph.D.

“Using Induced Pluripotent Stem Cells to Investigate Neuronal Phenotypes in Genetic Obesity”

Rudy Leibel, M.D.

Research Challenges

“Panel Facilitated Discussion of Research Challenge Questions and Research Agenda”

George Bray, M.D., Tony Goldstone, M.D., Ph.D.

Lunch and Learn – Guided Tour of Pennington Biomedical Research Center with Lunch

Hyperphagia Organizing Sponsors

Prader-Willi Syndrome Association (USA)

Pennington Biomedical Research Center (PBRC)

Foundation for Prader-Willi Research (FPWR)

Scientific & Providers Organizing Sponsors

Prader-Willi Syndrome Association (USA)

Pennington Biomedical Research Center (PBRC)

Note: Parent observers are welcome to attend the Scientific and Hyperphagia Conferences

For More Information Contact:

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t: 1-410-321-9788

e: hyperphagia2012@verizon.net

www.hyperphagia.org

www.pwsausa.org

Do you know of a child who does not test out as PWS but is very obese and/or has the PWS-like appetite?

Early-onset Morbid Obesity (EMO) Recruitment through the PWS-EMO Rare Disease Natural History Study funded by NICHD as part of the RDCRN

Background: Many children who become obese before the age of 4 are referred to either genetics or endocrinology to evaluate for possible identifiable etiologies of their obesity. Very little is known about the etiology of early childhood obesity. A few genes have been described which can cause early childhood obesity, but the vast majority of patients are undiagnosed at this point.

Rationale: The diagnosis of PWS is often entertained in children who develop obesity early in life. We refer to individuals who develop obesity before the age of 4 as the Early-onset Morbid Obesity (EMO) population. *Many of the EMO children have similarities to PWS*, including developmental delay, learning problems, and behavioral problems. However, several of the *EMO children also have distinct differences from PWS*, including tall stature, a large head circumference, lack of hypotonia, and lack of neonatal failure-to-thrive.

Specific Aim: To determine the natural history of Early-onset Morbid Obesity (EMO)/"Prader-Willi Like" patients with respect to birth history, medical problems, age of onset of obesity, appetite, learning difficulties, psychiatric/behavioral problems and physical features.

Inclusion/Exclusion criteria: The **EMO group** will be selected solely based on a documented medical chart history of their weight having exceeded 150% of Ideal Body Weight (IBW) or a Body Mass Index (BMI) of greater than 97% before 4 years of age. Participants will be **excluded** from this part of the study if they have a chromosomal aneuploidy (i.e., an extra or missing whole chromosome) or Fragile X as the cause of their obesity. All EMO patients will have had a chromosomal (or a chromosomal microarray) analysis, DNA methylation testing for PWS, *MC4R* mutation analysis and a serum leptin prior to entry to the study.

Study Recruitment: Information about the participating research centers can be found at the following link: <http://rarediseasesnetwork.epi.usf.edu/arpwsc/studies/pw-5202.htm>

Note: PWSA (USA) is a collaborative member in this Rare Diseases Clinical Research Network (RDCRN) ■

Low Sodium in PWS

Q: Can Psychotropic Medications Cause Low Sodium?

I had two calls from parents whose adult children who have Prader-Willi syndrome experienced a very low drop in sodium. Both were on more than one psychotropic medication – primarily Prozac, Seroquel and Trileptal. I went to our experts (all members of our PWSA (USA) Clinical Advisory Board), and the following was their responses – Janalee

Dr. Greg Cherpas, The Children's Institute -- Hyponatremia (low sodium) is a potential complication of fluoxetine (Prozac) and other SSRI use, and I have definitely seen it before (though not often). There may be an increasing risk with advancing age.

Dr. Jan Forster, Pittsburgh Partnership -- The Prozac and/or Seroquel can cause hyponatremia alone and with greater incidence in combination. All of the SSRI's and the atypical antipsychotic medications can do this.

Dr. Linda Gourash, Pittsburgh Partnership -- Every single person I put on oxcarbazepine (Trileptal) developed low sodium when the dose exceeded about 900-1200 mg. per day. I am certain that the problem with this young man is the oxcarbazepine, and they should drop his dose to 1200 mg. and recheck his sodium. The effect is dose-related but not linear. I had this experience with about 12 patients. Otherwise it's a great drug, but I do not trust people to use it carefully enough. Sometimes the sodium is low but not dangerously low; you have to keep checking it. It can drift down slowly over weeks or months. We learned this the hard way. Even though I warned the outside physicians about the problem, two patients were allowed to drop so low they had seizures (which generally occur when the sodium is below 130, depending on how quickly it drops) We also had two patients (one had an atypical deletion) develop low platelets. One was dangerously low and recovered as soon as we stopped the Trileptal. ■

Investing – in Lives

By David Crump
Interim Executive Director

When I was a child, my parents taught me to set aside money to put in a savings account. Even from my weekly allowance I was to take a certain amount and *invest* it in savings. This early training served me well, helping me form a lifelong habit of building that proverbial “nest egg” for a specific need or for the future.

The idea of investing is to create or achieve something that is of value to you. Putting money into a savings account – or currently, some other more lucrative investment tool – is intended to put your money to work making more money. Yet the real goal is not the money itself but something else of value that your money can get for you: a particular product, an education or secure future for your child, healthcare for yourself and your family, retirement, etc.

If you are like me, in your mail almost every day is a letter (or two) asking you to support some good cause. When we respond, we often do so thinking in terms of “giving a gift” or “making a donation” to the organization. But what is it that motivates us to give? Isn't it that, in one way or another, that organization has conveyed to us that they are doing something that we value? We certainly wouldn't send a gift to an organization whose mission and work we rejected or disagreed with.

So, giving to our favorite cause is a kind of investing. Our gift is not so much about the money (or our time volunteering) but about the *value* that is achieved through the gift. **We give to an organization because we know that they are doing something in people's lives and in our world that we believe in.**

If you are reading this newsletter, probably someone you know was born with Prader-Willi syndrome. PWSA (USA)'s Board Chair, John Heybach, is fond of saying: “*The PWS community is an exclusive club that no one wants to be a member of... but it's our family now.*” Because of this connection it is important to you that this community and particularly the person and family you are connected with have the resources and support they need. And it is important to you that research is being done to find appropriate treatments and ultimately a cure for PWS.

The Prader-Willi Syndrome Association (USA) at the national level and through its state Chapters is here for this purpose. The kind of value PWSA (USA) offers is illustrated, in part, by the following case. Names have been changed to ensure anonymity.

Carol, who has 5 children, was referred to PWSA (USA) by a Chapter president. Her oldest daughter, Ann, is 15 and has PWS. Carol and her husband are divorced; when Ann visits her dad, he lets her eat what she wants. When Carol contacted us, Ann weighed 350 pounds and was on a C-pap machine 24/7. We worked with the mom first to get the food issues under control. We sent locks along with information for a 3-week menu, and set up a plan for a weekly follow-up call with her. We also sent out a packet for the dad and teachers. We worked with Carol on strategies for exercise and for helping Ann accept the new menu. Once the menu was posted for Ann to see, she discovered that she actually had more to eat than before. The food was lower calorie with a nice variety. Dad, too, is doing better about the food after reading the information about how to help Ann. Now, after two months, Ann has lost 15 pounds. We are also working on having her go to The Children's Institute in Pittsburgh where she can continue the weight loss.



David Crump

In the past year PWSA (USA)'s Family Support staff spoke with families, doctors, school officials and others on more than 2,000 occasions, providing information and support, helping manage crises, and helping find solutions to challenges. We were contacted by 125 families who had just received the diagnosis that their child has PWS. We offered them encouragement; assured them that we are here for any questions or support needs they have; sent them the Package of Hope full of resources and information; and for those who wanted it, assigned new parent mentors. We have also responded to numerous inquiries from families in other countries, seeking help and information. We funded research, in partnership with the Foundation for Prader-Willi Research as well as through PWSA (USA)'s Best Idea Grants focused on the hunger drive. We also planned and hosted the biennial Family, Provider, and Scientific conference in Orlando that was attended by more than a thousand members of our community.

If what you have read here is something you value, if these are things you believe in for our community, then I invite you to consider a gift to PWSA (USA). These are not easy economic times for any of us. Some of us are in a position to give more than others. But here at PWSA (USA), we, too, are feeling our budget stretched at a time when the demand for services is actually increasing. So I invite you, at the level and to the extent that you are able, to consider an *investment* for the sake of your loved one and for families across this country and around the world impacted by Prader-Willi syndrome. If you have questions or want more information, feel free to contact me at 941-312-0400, or at dcrump@pwsausa.org. Thank you! ■

Men and Grief

We thank Linda Thornton, from New Zealand, Secretary of the International Prader-Willi Syndrome Organisation, and parent of an adult daughter with PWS, for being an active contributor to The Gathered View. This was sent to her by a father who had submitted it for a magazine she was editing at the time.

I had been looking forward to the birth of our first child. For months I had been fascinated by her movements inside her mother; at the beginning a little fluttering and then as the months passed, stronger, more vigorous movements.

I was present at my daughter's birth, an experience that defied words. All stories and films that had the birth of a child in them made much of the initial birth cry. I was absolutely unprepared for our experience; she arrived without a sound. I have a clear picture of the doctor holding her up, her little mouth shaped like a cry, but there was no sound. I am unable to describe what came over me at that moment. Words like "shock, disbelief" do not even hint at what I felt.

My overwhelming reaction was what I can only call resignation; whatever would be, would be, and I had no power whatever to change any of it. I was devoid of feeling. That stayed with me for months. The only thing that broke through my lack of emotion in those early days was a kind of subdued elation when our little girl would actually swallow milk from an eye-dropper, which was the only way we could feed her. Eventually our efforts weren't enough, and she had to be tube-fed at hospital.

At work, I was an automaton. I have little recall as to whether I was happy or sad, warm or cold. I had no appetite. I used to enjoy a drink. I never tasted the stuff from this time for months afterwards.

At the hospital, testing continued to determine what the condition might be. I became aware of how differently my partner [wife] was responding. She saw all tests as a challenge. I was indifferent to the various tests. As each eliminated

this or that possibility, she saw all these as major victories. The diagnosis at this state was "benign hypotonia". I was conscious that I was unsupportive. My partner's hopes were constantly undermined by my skepticism, actively negative, and yet I could not break out of the "what will be, will be" mindset. While my wife wanted to talk about progress and development and testing, I just wanted to be left to myself. I had closed off—little outside myself held any interest.

A friend was a good listener, but I could only share at a superficial level. Talking was not helping as the overriding feature of "all this talk will not change anything" undermined any chance of healing.

The second stage was marked by my waking one day and noticing the sun was shining. I felt warm for the first time in months. This time pin-pointed another stage: anger. Wild mood swings, optimism (that our little girl would be "normal", that she would outgrow this strange condition), followed by depression caused by the uncertainty of what the condition would mean long term. I cried more now—most nights. Sleep was full of curious dreams, and I would wake up exhausted. But there was less of "what will be, will be". By now our little girl was drawing me more and more into her life. I felt I was able to share more of my partner's hopes. The future seemed much less fixed.

Eventually our daughter's strange condition was diagnosed as Prader-Willi syndrome. It took me a long time to accept this. I read all I could about the syndrome. After a time, I noticed a shift in what I was feeling. The crippling resignation had given way to a hope that what was now did not have to be in the future. My wife was already planning counter-measures for our daughter to run against the classic symptoms—extra help for learning, exercises to firm up the little muscles, games to keep her stimulated.

Sometimes it seems a long time ago; more often, it feels like yesterday. A kind of emotional evenness came when she was five and a wholeness at seven. The

anniversary is still hard, but my partner eases me through it each year.

Yes, we men do cope with grief differently. Education should enable us to cope better. I hope so. ■

Stephanie's Amazing Story!

By Lota Mitchell, Editor

Fifteen years ago Stephanie Tanner, an Arkansas native, was 27, out of college with a major in English with Writing Emphasis and minor in psychology. Neither Prince Charming nor her dream job of doing hospital social work had come along, so, influenced by having a cousin with PWS, she took a job at a facility for developmentally delayed adults.

Then she learned about a baby in California with PWS. Would she take him? She flew to California and brought him back when he was five months old. Kaelin had lots of serious medical problems, but Stephanie believes that God uses everything for His purposes. He turned 15 in January, weighs 90 pounds, does his own IEP, calculates his calories, and struggles with the teenage angst "but all the other kids..."

Kaelin was just the beginning. Another call came when he was eight months old. Would she take a four-month-old baby girl with Down's? She got Reagan when she was four months old, now 14, who became a heart transplant recipient.

A year later the next call came, this time about a six-year-old in Oregon with autism and Down's. Mark, the oldest, is now 19; a year ago he developed seizures.

Next came Allie from Georgia, who had an unpronounceable syndrome which cut off her blood and oxygen at birth, a brain stem injury. She could do almost nothing, but would let them know her wishes through her eyes. Allie passed away at age seven from the flu. For Stephanie, the loss of Allie was a life-changing, terribly painful experience.

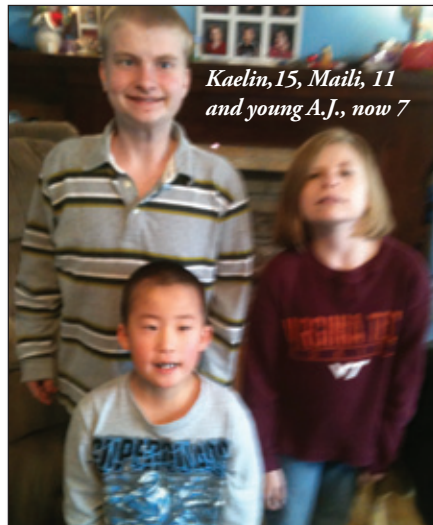
continued on page 11

Stephanie, continued from page 10

Maali, now 11, came next when she was 17 months old. Her birth mother gave her up because she needed too much care. She has severe scoliosis and has had three back surgeries. She has an odd variation of PWS, does no food seeking but likes to eat, although at times they have to encourage her. She weighs 50 pounds now. Stephanie describes her as a “charmer”, but is self-injurious with severe behavior problems. “Maali” is the Russian spelling for Mollie, which means precious; the English spelling means bitter.

Another call—would she take a baby from Kentucky who was difficult to place? He has CHARGE syndrome, in which every letter stands for an anomaly, like deafness. Carson, now eight, arrived at two months. He’s happy all the time. He and Reagan are taught at home by a teacher who comes in because of their disabilities.

Her “Asian sensation” is A.J.,



*Kaelin, 15, Maili, 11
and young A.J., now 7*

from New York, coming to her at eight months and now seven years old. He has textbook PWS, plus egg, wheat and milk allergies, and weighs 40 pounds. All three with PWS have deletion and ask questions constantly.

Right after she got A.J., Prince Charming arrived through eHarmony in the form of Robert. He was from Long Island but moved to Arkansas, and they

were married in October, 2009. He is semi-retired from Wall Street, has his own small business, and four kids of his own, one of whom, age 23, has some special needs, too. Perhaps that helped to prepare him! She laughs that they have “dates” now at the house on the couch; she fixes her hair and dresses up, just like going out to dinner.

Number seven is their own baby, Charlie, now 15 months, who is just fine. And to complete the family, there are three dogs.

She has an interesting technique which she says prevents a lot of stress at holidays. Food is scheduled daily without variation, including two snacks. A snack can be traded (i.e., passed up and not eaten) for a popsicle stick; then the stick or sticks can be traded in for a special treat, like a piece of pie. They have to learn to use their sticks wisely.

Stephanie’s is a life that not many of us could handle—but she says she wouldn’t trade it for anything. For her, it is filled with love and joy. ■

Barb McManus is Retiring!

Andrea: We hear you are retiring your full-time position at PWSA (USA). How long did you work here?

Barb: I worked six years as a full-time employee for PWSA (USA). Before that, I did contract work and volunteered many hours for the organization.

Andrea: How did you first become interested in the organization?

Barb: I made my first call to PWSA (USA) in 1996 when my granddaughter, Jessika, was diagnosed with PWS. At that time there were only a few people working in the office, and the website had only a few pages of information. I called and ordered one of every publication they had. That was a very scary time in our lives. I’m glad that we found accurate and dependable information through PWSA (USA).

Andrea: What types of volunteer

work did you do over the years?

Barb: As a volunteer, I served on the board of directors of PWSA (USA) and was the secretary for a few years.

Andrea: What was the scope of your full-time positions?

Barb: My original responsibilities were office computers, servers and software. Through those years, I flew to Florida from Buffalo, New York many times to work (sometimes through the night) on the computers.

I created and maintained all the various databases in the office, as well as the research database online at www.pwsausa.org/population. I managed the national Web site which has grown to over 2,000 pages of information. In more recent years I managed the National Conference registrations, the communication supports for the



state chapter leaders, new parent mentoring and family support. This part has been very rewarding, helping the States with organization and communications (like Yahoo groups). There is still so much work to be done to ensure families can reach out to others.

Andrea: How can others volunteer?

Barb: Everyone has some talent or resources that will help PWSA (USA). You can register to volunteer at <http://www.pwsausa.org/help/volunteer.asp>.

Andrea: What’s next for you?

Barb: Jessika will always be my granddaughter, my reason for doing all that I have done and will do for PWSA (USA). At this time of my life I want to play more golf, dance, learn pickle ball and enjoy my new life in Florida. ■

~ This interview was conducted by *The Gathered View* volunteer Andrea Glass.

How Kids with Prader-Willi Survive College

By Colleen McMaster

Hi everyone, my name is Colleen and I am 20 years old. I was born with Prader-Willi Syndrome. The worst part of having PWS is being hungry all the time. I found support is the best way to deal with the hunger issues, but when I was in high school, it was hard to get all the support I needed. I wasn't able to tell others that I had PWS. I graduated in 2009 with a high school diploma. After I graduated, I was hired at Lifetime Assistance where I scanned documents for car dealerships. I worked there for two years when I learned about a program known as LifePrep at Nazareth College, Rochester, New York.

I have been in this program since September and I just love it. The teachers teach in a fun way and I get all the support I need with PWS. I was able to share with my teachers and peers that I have PWS. Since they know, I am able to refrain from getting food from vending machines and the cafeteria.

I have a job at the Nazareth College box office. They have a terrific theater program and I am able to attend one performance a semester for free. I finished my first college course, Psychology for the Exceptional Individual. There was a peer who attended the class with me, and I would send her my homework to make sure I was on the right track. She only made spelling changes. I belong to two clubs. Gerontology Club where I played Bingo with the elderly. I also belong to the Dance Club.

I have made many friends on campus and learned there is more freedom in college than in high school. I am able to ask for and receive support, and the teachers are flexible allowing me to do a power point versus a paper. I love college and I am learning a lot. Going to



college through a special program gives me the added support I needed. The advice I would like to give you is to go to college, don't stress yourself out, and tell others that you have PWS, whether it is your teachers or friends you can trust. The support keeps you distracted from buying food when you shouldn't. Try it, I guarantee it works! ■

LifePrep@Naz

The LifePrep@Naz program is a program designed to provide individuals, 18 years and up, with disabilities with an opportunity to go to college. This program is created through the collaborative relationship among Nazareth College, Victor Central School District and The Arc of Monroe County. The curriculum is created to be an inclusive program with 50% of the student's time with same-aged peers without disabilities. LifePrep@Naz students are also supported by peer mentors who are Nazareth College students. Mentors provide academic support to students and promote the inclusiveness of LifePrep students in the campus community. For more information or questions about LifePrep@Naz please contact:

Jaime Dermody, Community Outreach Coordinator
The Arc of Monroe County
2060 Brighton Henrietta Townline Road
Rochester, NY 14623
Phone: (585) 730-6037
Email: Jdermody@arcmonroe.org

Volunteer bereavement support needed

In the past at PWSA (USA) we had our dear volunteer Norma (now deceased) do both calls to the families after the death of their child and create bereavement booklets to send to each family. It adds to a family's grief not to have anyone to talk to after the death of their child or sibling who understands the syndrome plus all of the issues of grieving. I would like to put out an appeal to our PWS community for two volunteers:

- 1) Someone with an understanding of grief to call families – preferably with a counseling background and/or an understanding due to the loss of their own child.
- 2) Someone with computer graphic skills who would be willing to put together personalized bereavement booklets. We can supply examples.

If you are willing to be one of our next "support angels", call Janalee Heinemann at 800-926-4797. ■



A good many years ago, we were planning to attend our second

National Conference at Overland Park, Kansas. Joyce seemed to be happily excited. As we boarded our flight for the trip to Kansas, Joyce announced, "I want to see the yellow brick road!"

- Sarah Abell, Kentucky

Miranda

I want to share one of the most memorable moments of my life-- at a Miranda Lambert concert in Charlottesville, Virginia.

In May 2010 Miranda Lambert was on "Extreme Makeover Home Edition", lending both a hand and her voice to the Starkweather family of Tulsa, Oklahoma. The Starkweathers' son, Ethan, then nine, was diagnosed with PWS shortly after birth. I watched the show, being a HUGE fan of both Miranda and the ABC show; little did I know that one week later I would receive a phone call confirming our daughter Addison's diagnosis of PWS. Ever since, it has been my mission in life to fundraise and spread awareness for our cause. I wear a red awareness bracelet everywhere I go, hoping that someone will ask me so I would have an opportunity to speak about it.

My BFF Michelle and I were in the pit, very close to the stage. I decided to do everything in my power to reach Miranda and give her my bracelet. Early in the show Miranda knelt down on the stage close to where we were. I reached over a couple of people standing in front of me to hold up my bracelet. Once Miranda spotted me, she reached down, grabbed the bracelet and put it on! I mouthed "for my daughter"; then she flipped the bracelet over and read it. She finished the last verse of "More Like Her", blew me a kiss--and wore that red bracelet for the remainder of the concert!!!

Miranda may never know how much what she did meant to me. In the flood of emotion since receiving the diagnosis to all the therapies, doctor appointments and worries for my daughter's future and safety, seeing Miranda wear that bracelet for me, for my daughter, for all the loved ones and people living with PWS, that I cannot put into words! I will be forever grateful

to Miranda; she is an amazing talent and equally an amazing person! ■

*~ Anne Taylor
mom to Darryn, 9, and
Addie, 22 months with PWS*

Whit Park and the Lemonade Stand

Winter is almost over, but how will the people of Nichols Hills, Oklahoma, know when it is summer? Why, when Whit Park opens his lemonade stand, of course!



Whit, born in October 1983, was diagnosed with PWS when he was five months old. When he was six, he started the stand. His mother Penny Park says, "Whit...and his friends would sit outside and visit and hold up signs, and people would stop because there was such a bevy of little friends having fun."

Now 27, he lives most of the year at Woods School in Pennsylvania, but as soon as he gets home for his annual month-long visit in the summer he opens the stand.

To begin with, cups of lemonade were 25 cents each, and more than 20 years later, they are still the same price. However, police and firefighters get theirs free, Whit's way of saying thanks for their services.

People will stop by for a cup of his

product, which he says is "very cold and very sweet", visit with Whit, catch up on what he is doing and share what they have been doing, and leave with smiles on their faces.

Each year he hopes to make enough money to buy some particular item, like a cellphone or iPad, but each year he falls short. But he still has a great time with his lemonade stand and visiting with all the friends, family and fellow Oklahomans who stop by. And maybe that is really what it is all about. ■

Some Conference Thanks

... we loved the conference in Orlando! It was our first one and hopefully not the last. Our son Rich was thrilled to meet so many other people with PWS and the content of the meetings was great. The group who organized and managed the YAP programming deserves kudos for a job especially well done. ■

... thank you again for the opportunity for Ben to attend the YAP program. He had a wonderful time! He was so happy to be involved in something "independent" of his Dad and myself! It was quite a new experience for us. We thoroughly enjoyed the time we spent as well! It was reassuring to meet others who face the very same challenges we do, finally! ■

My family and I had a great time. More so, Jane got a lot of mental support from the conference. My granddaughter Sara experienced for the first time that there are others like her and that it is OK to be less than perfect. Going forward, she wants to attend all conferences. Thank you for making it happen. ■

I am the mother of Kourtney, a 14-year-old female with PWS. Kourtney recently attended the PWS Conference in Florida. I really enjoyed being a part

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Chapter View



State Leaders Day at Conference

November 11, 2011

By Jennifer Bolander

As part of the 31st PWSA (USA) National Conference, approximately 26 chapter and state group leaders gathered to get to know one another, talk about their recent activities and events, learn more about the workings of PWSA (USA), and discuss many other topics of importance. They shared advice—and got reassurance that leading a chapter or group can sometimes be challenging!

Who all attended?

Alaska (Lindsay Smith)	New Jersey (Sybil Cohen)
California (Julie Casey)	New York (Amy McDougall, Nina Roberto)
Colorado (Lynette Hosler)	Ohio (Jennifer Bolander)
Connecticut (Jeannette & Tom Young)	Pennsylvania (John & Donna Forster)
Florida (Michelle Torbert)	Tennessee (Dianne Bryden, Steve Asbury)
Georgia (Debbie Lange)	Texas (Lindi Kessinger)
Idaho (Jim Wells)	Utah (Lisa Thornton)
Indiana (Jim Koerber, Amy Pfeiffer)	Wisconsin (Crystal Boser)
Michigan (Eric Macks)	
Minnesota (Jim Gardner)	
Nebraska (Paige Rivard)	

John Heybach, chair of the PWSA (USA) board and Ken Smith, vice-chair, sat in on a portion of the morning session. Interim Executive Director David Crump, Family Support Coordinator Barb McManus, Development/Communications Associate Jodi O’Sullivan, and PWSA (USA) board members Steve Leightman and Jim Koerber not only attended the entire day but were of great assistance with the planning and implementation of the day’s agenda.

What was the day’s agenda?

Volunteers Jennifer Bolander and Jim Koerber, with the help of *On The Move* Committee members David Crump, Michelle Torbert, and Jodi O’Sullivan, walked the group through a slide presentation covering “PWS On The MoveSM” 2012 Fundraising and Awareness Campaign. Attendees were able to cover this topic in depth with many questions answered and many details discussed. Family Support Coordinator Barb McManus delivered an excellent presentation covering Advocacy, providing attendees with information to take back to their chapters and groups such as “Ten Steps to Effective Self-Advocacy” and copies of her presentation.

Director of Research and Medical Affairs Janalee Heinemann generously shared her lunch hour with attendees and provided a thorough report on the topics and projects being worked on in the area of PWS research.

Barb McManus and Jennifer Bolander led a presentation covering the topic of “Growing and Expanding Your Chapter”, which was helpful especially for those participants whose groups or chapters are just starting or are re-starting.

Steve Leightman led a discussion of the relationships chapters and state groups have with PWSA (USA), which aspects of those relationships work well and which may need improvement.

It was a day packed full of useful information and great discussion. A heartfelt “Thank You” to everyone who helped to make it a success for all who attended! ■

Thanks

From Joan and Jim Gardner, PWSA (USA) Lifetime Achievement Award recipients (along with Jim Kane) at the National Conference

Jim and I would like to thank PWSA (USA) for the special recognition, which we received at the national conference. We feel quite unworthy and humble. It is all of you, the members, who should receive this honor. We have been privileged to



work with you and meet so many new friends through Prader-Willi syndrome. Thank you for this gift. ■

Thanks, continued from page 13

of the 6-12 year-old group and received valuable information and sometimes just comfort in reading others’ stories. Thank you! ■

Contributions

Thank you for Contributions in December 2011 and January 2012. We try to be accurate in recognizing contributions above \$25, and apologize for any errors or omissions. If you notice an error, please tell us.

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Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers.

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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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The Gathered View (ISSN 1077-9965)
 Editor, Lota Mitchell
 Andrea Glass, Denise Servais
 GV Designer, Sara Dwyer

Published bimonthly by PWSA (USA) as a membership benefit. Annual U.S. membership: \$50 (individual, family, or agency/professional). Annual membership outside the U.S.: \$60 (individual, family, or agency/professional). We never deny parents membership for any reason.

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**Deadlines to submit items
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Counselors Corner

It's Time to Think about Summer Camp!

Summer camp is a great time for both youth and adults who have PWS. It can be a fun-filled exciting time that allows your child to develop some social skills and meet new friends. It also allows time for everyone to have a bit of respite. Knowing what camp and at what age is best for your child is a decision that each parent/provider needs to make.

Sending a child to summer camp may cause some anxiety about the camp and concern about the safety of your child--will the dietary and food-seeking needs be met?

There are many camps in the U.S. that serve children and adults with disabilities. Some offer a variety of programs; some may be more specialized. Some even have weeks that are just for people who have PWS.

Because most camps have a limited number of slots, the earlier in the year

you start the research, the better chance you have that there will be an opening for your loved one.

Here are some questions to ask when researching a camp:

Knowledge & Experience with campers with PWS - Have they served campers with PWS? Do they have a PWS-specific program or week? Do they understand or are they willing to learn more about PWS? Are you willing to teach and assist in this learning?

Health Services - Do they have a nurse on duty? Who is responsible for administering medications? If a person becomes ill, what is done?

Diet and Meals-Serving Style - Do they accommodate special diets? How are meals served? Will they serve and monitor food for the person with PWS?

Is there food that is easily accessible to the person with PWS?

Behavior Management - Some camps have very strict rules about behavior issues. You will want to know this in advance. Do counselors receive special training on behavior management? What type of approach and consequences do they use? Are the consequences negative reinforcement or positive reinforcement?

Send information about PWS and your child to the camp staff. Let them know what works for your child and what doesn't. Include suggestions on how to avoid food and behavior issues and how to apply strategies that will help the camper.

Include a health brochure so they will be sure to be aware and understand some of the unique health issues that the camper may face. ■

- Kate Beaver
Crisis Counselor