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

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

# PWSA (USA)'s First International Hyperphagia Conference was a Big Success!

***By Janalee Heinemann, Director of Research and Medical Affairs***

Many of you will remember me writing about how impressed I have been with the similarities between the hyperphagia (the extreme unsatisfied drive to consume food) in Prader-Willi syndrome (PWS) and some of the other rare disorders. The difference is that it is not as universal in other syndromes as in PWS, but often it is just as dramatic when it does present. With the blessing of the board, Jim Kane and I decided to co-coordinate this first-ever conference bringing experts from the rare disorders together along with National Institutes of Health staff and pharmaceutical companies. Our scientific co-chairs were Dr. Tony Goldstone from the United Kingdom and Dr. Ann Scheimann from Baltimore, Maryland. The speakers specializing in the rare disorders who presented on the hyperphagia component of their syndrome were:

**Prader-Willi syndrome**
Tony Goldstone, M.D., Ph.D.,
Imperial College London, UK
**Alström syndrome**
Pietro Maffei, M.D.,
Padua University Hospital, Italy
**WAGR syndrome**
Joan Han, M.D.,
Unit on Growth and Obesity, NICHD, NIH
**Fragile X syndrome**
Randi Hagerman, M.D.,
MIND Institute of California
**Bardet-Biedl syndrome**
Leslie Bieseker, M.D.,
National Human Genome Research Inst., NIH

Our keynote speakers who presented on the overall topic of obesity, hunger and hyperphagia were from the Pennington Biomedical Research Center, Los Angeles, and are internationally recognized for their research in this area:

George A. Bray, M.D., Boyd Professor, Chief, Division of Clinical Obesity and Metabolism

Hans-Rudolf Berthoud, Ph.D., Professor, Department of Neurology and Nutrition

The afternoon involved a series of eight simultaneous roundtable discussions, and participants were able to rotate throughout the afternoon to three tables each.

Three main questions were posed to each group. The goal was to learn about the key components of hyperphagia from each other, to explore how we can enhance collaboration in research, and to generate new ideas for how to advance research on hyperphagia, hunger and obesity. Areas identified by the groups requiring more research included:

- Involvement of dopamine and reward systems in the brain
- Salivary secretion differences, taste and smell studies among the uncommon genetic disorders with hyperphagia
- Looking at the genes involved in addiction
- Comparing hypothalamic function and gene expression among the disorders
- Examining evidence of ciliary dysfunction in PWS including mouse models

*Quinn Fine Photography*

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- Within the contiguous genes syndromes identify single genes that may be responsible for increased appetite
- Identify gene targets for snoRNAs (e.g. HBII-85; HBII-52)
- Study the phenotype of BDNF gene promoter knockout mice
- Better understanding of cue-related behavior.
- Identifying critical periods in the development of obesity with progression to hyperphagia from failure-to-thrive.
- Common questionnaire across all disorders addressing and characterizing hyperphagia
- Compare and contrast gut hormone levels among the disorders

Improved understanding of hyperphagia and obesity in these rare disorders and mapping the pathophysiology may lead to an increased understanding of obesity in the general population. Rare syndromes can teach us about the architecture of eating behavior. We received very positive feedback from attendees from the various disorders and backgrounds and are delighted it was a success. PWSA (USA) is offering a Best Idea Grant (BIG) of up to $100,000 available only to those who attended the conference. For more information on the grant and the conference, go to www.hyperphagia.org. ■

***A Sampling of Comments from Those Who Were There***

*conference was fantastic...no glitches, no complaints…I really look forward to seeing what people came up with as important and salient for study…"GREAT JOB" in putting on a conference that figured out how to get people working together.*
~Jim Gardner

*…congratulations on a superbly organized and very interesting meeting.*
~ George Bray, keynote speaker

*The organizers have done a great job sending out a lot of background information and providing meeting prep materials!*
~ Chris Herold

*I found the roundtable discussions were very animated and interesting, and I learned a lot myself. I really hope this well-planned event will be a boost to research on these diseases.*
~ Hans-Rudi Berthoud, keynote speaker

*I particularly enjoyed learning more about other disorders that have hyperphagia as a feature, and I think that researchers in those areas had the opportunity to learn more about PWS. Thank you for inviting FPWR to participate.*
~ Theresa V. Strong, Ph.D.

*The whole event turned out better than I even imagined! Great speakers and a great forum for collaboration, great food, incredible hotel…It takes such a huge effort to pull this kind of thing off and I feel like everyone on the team gave 110% and made it seem effortless.*
~Kerry Headley

**Sponsor/Donors (over $1000)**

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Jim and Kit Kane

Oconomowoc

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Prader-Willi Families of Ohio

Prader-Willi Syndrome Association of Wisconsin

Prader-Willi Syndrome Association of Maryland/ Virginia/District of Columbia

Paul Verret of the Katherine B. Andersen Foundation (St. Paul)

## Collaboration and Cooperation at its Best

Although I featured the First International Hyperphagia Conference in the previous article because of its uniqueness, this does not diminish the success of all of the other events PWSA (USA) sponsored in Baltimore: **24th Annual Scientific Day Conference, Annual Providers Conference, Clinical Advisory Board (CAB) meeting, Providers Board meeting, and Scientific Advisory Board (SAB) meeting.** A lot of knowledge and collaboration of ideas flowed through the three days of events! All received very positive feedback. Everyone there worked cooperatively, and I did not hear a disgruntled word. The hotel bent over backwards to be helpful.

*Best, continued on page 3*

**Best,** *continued from page 2*

***Very special thanks go to:***

- **Jim Kane** for the tremendous amount of effort he put into this conference as overall chairperson and hyperphagia conference co-coordinator
- **Kerry Headley** for all of her behind-the-scenes organizational work
- **Barb McManus** for managing such a smooth registration process
- **Jackie Mallow** and **Mary K. Ziccardi** for their outstanding job with the Annual Providers Conference, which was extended to 1½ days

More big thanks go to **Dr. Merlin Butler** for chairing the 24th Annual Scientific Day Conference and **Dr. Dan Driscoll** for coordinating a very productive CAB meeting. We are privileged to have a great team of physicians and researchers who devote so much time to PWSA (USA). We even had Dan's wife Marilyn, also a physician, helping. Steve Leightman and his wife Michele, Jodi O'Sullivan, Evan Farrar, Jim and Joan Gardner and many others pitched in to do whatever needed to be done.

One of the focus issues at the CAB meeting was to revise and update the *Growth Hormone Consensus Statement for PWS*. Spearheaded by Dr. Jennifer Miller, this should be completed soon and will be published in *The Gathered View*. Dr. Harold van Bosse is working on scoliosis treatment guidelines. Several general and primary care issues for PWS are the focus area of Drs. Todd Porter, Marilyn Dumont-Driscoll, and Jim Loker. The psychiatric tips sheets, the outcome of the CAB meeting, were written by Drs. Linda Gourash, Jan Forster, and Elisabeth Dykens, along with Elizabeth Roof. This meeting was extended to a very full half day, and a lot of essential PWS work was done!

Volunteerism takes on a new meaning when you look at the amount of donated time it takes to make all of these meetings work. I have followed these conferences for 28 years, and I never get over being impressed with the dedication I see from professionals and parents who give of their time and talents to the cause of Prader-Willi syndrome. ■

PWSA (USA) is included in the Combined Federal Campaign. If you work for the Federal government and its agencies, use CFC ID No. 10088 to designate PWSA (USA) to receive donations. Questions? Call PWSA (USA) at 1-800-926-4797.

## *Medical and Research View*

***By Janalee Heinemann, Director of Research and Medical Affairs***

# Scientific Abstract Submissions

Presented at the 24th Annual PWSA (USA) Scientific Meeting in Baltimore, Maryland
**June 4, 2009**
**Chairperson: Merlin Butler, M.D., Ph.D.**

*Please note: Due to space limitations, we are only putting a "teaser" in this newsletter from the abstracts. To make a thorough assessment on the implications of the research below, you would need to review the entire abstract. For a complete copy, you can contact PWSA (USA) by calling 1-800-926-4797 to order a copy for only $5.00 which includes mailing.*

### Perinatal Complications in a U.S. Population with Prader-Willi Syndrome

June-Anne Gold[1], Ellen Simpson[1], Virginia Kimonis[1], Suzanne B. Cassidy[1,2]

*[1]Division of Clinical and Biochemical Genetics, Department of Pediatrics, University of California, Irvine*

*[2]University of California San Francisco*

**Conclusion:** Although the data collected may have been affected by recall bias, there is clearly a high rate of pregnancy and delivery complications, especially:

Very high caesarean section rate
Decreased fetal movements
High induction of labor rate.

Similar results were previously reported in Europe including France (Dudley et al 2007) and the UK (Whittington et al 2008). This had not been reported previously in a U.S. population. The cause of these perinatal difficulties is not known, but may relate to hypotonia and/or hormonal differences. These perinatal problems might play a role in causing characteristic early postnatal difficulties (lethargy, poor suck) and subsequent developmental and behavioral manifestations.

### Studies of the Frequency of Assisted Reproductive Technology Births and Twinning in Prader-Willi Syndrome

Chelsey Ruth[1], June-Anne Gold[1], Barbara McManus[2], Chirag Gandhi[1], Hye-Seung Lee[3], Janalee Heinemann[2], and Virginia Kimonis[1]

*Division of Clinical and Biochemical Genetics,*

*Abstracts, continued on page 4*

**Abstracts,** *continued from page 3*

*Department of Pediatrics, University of California, Irvine[1], Prader-Willi Association of USA[2], and Pediatrics Epidemiology Center, University of South Florida, Tampa[3]*

**Conclusion**: Multiple studies have concluded that the effects of ART procedures may be restricted to imprinting disorders in which the maternal allele is hypomethylated or in which an imprinting defect accounts for a significant proportion of affected cases. Two other studies did not suggest an association between PWS and ART; also an imprinting center defect in an ART-born individual with PWS has not been previously reported. The results from this study are consistent with previous results, and no increased frequency of ART-births in a PWS study population above the general population was found. Also, an increased frequency of twinning in this PWS study population was reported which was not due to ART procedures. At this time, the mechanisms causing this association have not been fully established but could be related to maternal age (Aston 2008). The possible relationship between ART, twinning, and PWS is an area of future research.

## Food Preferences in Prader-Willi Syndrome: Feeding Practices, Family Food Environment and Implications for Weight Management

Kylee M. Miller, Surekha Pendyal, Ann Wheeler

*University of North Carolina at Chapel Hill*

**Conclusion**: Children with PWS are offered a variety of foods from all food groups. Although they accept most foods well at a younger age, they develop food preferences as they get older. Notable among these is a reduced liking for vegetables which can affect compliance and success with the weight loss diet. An awareness of this behavior by families of young children with PWS may help in developing feeding practices and home food environment that is conducive to weight management.

## Central Adrenal Insufficiency in Individuals with Prader-Willi Syndrome

Jennifer L. Miller, MD[1], Anthony P. Goldstone, MD, PhD[2], Daniel J. Driscoll, MD, PhD[1]

*Department of Pediatrics University of Florida Gainesville, FL[1] and MRC Clinical Sciences Centre, Hammersmith Hospital, Imperial College London UK[2]*

**Conclusion**: Forty-seven percent of the individuals we tested had evidence of CAI demonstrated by a different stimulation test than de Lind van Wijngaarden et al (2008) used. Unlike other children with CAI, individuals with PWS had the possibility of severe hypoglycemia during the GST, which did not seem related to severe CAI. The gold-standard test for CAI, the insulin tolerance test (ITT), may be difficult to perform in children and can cause dangerously low blood glucose levels, requiring an inpatient setting, whereas the GST can be done in a clinic setting with supervision of the patient. However, the glucagon stimulation test is well recognized to be a less reliable test of ACTH reserve than the gold-standard ITT.

Further studies are warranted before a definitive estimate of the prevalence of CAI in PWS can be determined. Nonetheless, our data confirm the findings of the Dutch group that a substantial number of individuals with PWS have CAI. Therefore, we recommend that every patient with PWS undergo a dynamic stimulation test to evaluate for the presence of CAI, as some patients may benefit from physiologic doses of hydrocortisone, while others may only require stress-doses of hydrocortisone during times of illness.

## Profound Pancreatic α- and β-cell Defects Arise in Transgenic Prader-Willi Syndrome (TgPWS) Mice from Loss of the PWS-Imprinted Gene Cluster

Mihaela Stefan[1], Rebecca A. Simmons[4], Suzanne Bertera[2], Massimo Trucco[2], Farzad Esni[3], Robert D. Nicholls[1]

*Birth Defects Laboratories[1], and Division of Immunogenetics[2], Department of Pediatrics, Children's Hospital of Pittsburgh of UPMC, and Department of Surgery[3], University of Pittsburgh School of Medicine, Pittsburgh, PA; and Department of Pediatrics[4], Children's Hospital of Philadelphia and University of Pennsylvania, Philadelphia, PA*

**Conclusions**: This study indicates that the imprinted, paternally expressed gene cluster in mouse chromosome 7C, which is orthologous to the PWS domain in human chromosome 15q11.2, regulates islet endocrine cell development, survival, and function. Additionally, this mouse model reveals coordinate gene regulation for all hormones and many secretory/exocytosis polypeptides produced by the endocrine pancreas. In PWS, pancreatic insufficiency is seen with reduced insulin levels relative to the degree of obesity, reduced pancreatic polypeptide levels in response to nutrients, and with either insulin-dependent or -independent diabetes described in ~ 25% of individuals. Given our observations and the well-known growth hormone and gonadotropin deficiencies in PWS thought to be due to deficient pituitary secretion and hypothalamic GnRH release (in which Necdin has been implicated), respectively, we hypothesize that similar neuroendocrine

*Abstracts, continued on page 5*

**Abstracts,** *continued from page 4*

mechanisms underlie abnormal pancreatic, pituitary and hypothalamic hormone and peptide secretion in PWS. Understanding the molecular and genetic pathways for hormone release in PWS is essential to develop successful strategies for the treatment of PWS and other metabolic disorders such as diabetes and obesity.

### Role of snoRNA MBII-85 in a mouse model of Prader-Willi syndrome

Linyan Meng and Arthur Beaudet

*Department of Molecular and Human Genetics, Baylor College of Medicine*

**Conclusion**: The dramatic expression difference between PWS and WT mice indicates a likely repressive role of MBII-85 in regulating downstream targets. To further confirm the results and identify direct targets of MBII-85, expression profiling by mRNA-seq is under progress.

### Necdin is Required for Normal Cell Migration and Neuronal Activation

Jason R. Bush and Rachel Wevrick

*Department of Medical Genetics, University of Alberta, Edmonton, Alberta, Canada*

**Conclusion**: Neuronal migration is critical to normal brain development, and defects in migration are implicated in many genetic forms of developmental delay. The regulated migration of other cell types is also essential to prenatal development. Our results demonstrate dysregulation of cytoskeletal rearrangement consequent to loss of necdin, and provide the first evidence for an intracellular signaling defect in murine and human cellular models of Prader-Willi Syndrome.

### Molecular Function of snoRNAs Missing in Prader-Willi Syndrome

Stefan Stamm[1], Amit Khanna[1*], Zhaiyi Zhang[1], Piotr Balwierz[3], Mihaela Stefan[4], Mihaela Zavolan[3], Robert D. Nicholls[4]

*[1]Biochemistry, University of Kentucky, Lexington, USA; [2]University of Erlangen, Institute of Biochemistry, Erlangen, Germany; [3]Biozentrum Basel, Switzerland; and [4]Department of Pediatrics, University of Pittsburgh School of Medicine, Pittsburgh, USA*

**Conclusion**: In summary, our data indicate that MBII-52 is processed into smaller RNAs that associate with hnRNPs and regulates alternative splicing of numerous pre-mRNAs. The processing of snoRNAs into smaller RNAs represents a novel mechanism to generate regulatory RNAs. It also indicates that the loss of miRNA-like snoRNA derivatives could be the cause for PWS, which offers therapeutic approaches for the disease.

### Differential Gene Expression in an Imprinting Center Deletion Mouse Model of Prader-Willi Syndrome by Whole Genome Microarray Analysis

Hailing Su[1], Weiwei Fan[2,3], Pinar E. Coskun[2,3],June-Anne Gold[1], James L. Resnick[4], John H. Weiss[5], Douglas C. Wallace[2,3,6],Virginia E. Kimonis[1*]

*Division of Genetics and Metabolism, Department of Pediatrics[1] and, Center for Molecular and Mitochondrial Medicine and Genetics[2], Department of Biological Chemistry[3] Department of Neurology[5], Departments of Ecology and Evolutionary Biology[6], University of California, Irvine. Department of Molecular Genetics and Microbiology[4], University of Florida College of Medicine, Gainesville*

**Conclusions**: We found differential gene expressions in an imprinting center deletion mouse model of Prader-Willi syndrome by whole genome microarray analysis. These studies suggest that genes involved in mitochondrial energy metabolism in muscle and brain are upregulated, consistent with our mitochondrial enzyme and histology studies, and may contribute to the pathophysiology of PWS mice. Future research in this area may lead to improved future therapeutic interventions for PWS patients.

### Neural Response to Food Cues during Hunger and Satiation

Dimitropoulos, A.[1], Ho, A.[1], Kennedy, J.[1], and Tkach, J. [2, 3]

*[1]Department of Psychology, Case Western Reserve University, [2]Department of Radiology, Case Western Reserve University, [3]Case Center for Imaging Research, Case Western Reserve University*

**Results/Discussion**: Findings with lean adults indicated greater activation to HI vs. LO during fasting in the orbitofrontal cortex (OFC), superior frontal gyrus, and amygdala ($p<.01$ corrected). Direct comparison of motivational salience (HI vs. LO) by hunger state (fasting vs. satiation) indicates greater activation in the OFC and amygdala to high-calorie foods during hunger. Preliminary results for individuals with PWS indicate greater activation in the ventral striatum, superior frontal gyrus (SFG), OFC, fusiform gyrus, and dorsolateral prefrontal cortex (DLPFC; $p <.001$ uncorrected) in response to food vs. nonfood objects during fasting state. In addition, high-calorie foods yield greater activation in the insula, hippocampus, inferior frontal gyrus, and the DLPFC ($p <.001$ uncorrected). After

*Abstracts, continued on page 6*

**Abstracts,** *continued from page 5*

ingestion, individuals with PWS continue to activate the DLPFC and fusiform gyrus to foods and show deactivation in the parahippocampal gyrus (p <.001 uncorrected). The small sample sizes prevent direct group comparisons at this time. Nonetheless, these preliminary results indicate increased activation in areas involved in food regulation, taste information processing and food reward among individuals with PWS. Based on these findings, greater response in reward circuitry and areas involved in food regulation is expected among individuals with PWS in comparison to healthy weight controls during fasting state. Moreover, continued activation of these circuits after meal ingestion is anticipated for those with PWS. These preliminary results give insight into the effect of rewarding foods on the underlying neural mechanisms of food regulation during different hunger states.

### Nicotine Dependence and Cessation among Adults with Prader-Willi Syndrome: a Case Series

Janice Forster[1], Linda Gourash[1], Michael Marchese[2]

*Pittsburgh Partnership,[1] Pittsburgh PA and Latham Center,[2] Brewster MA*

**Conclusion**: Traditional smoking cessation methods failed to achieve the desired results in this case series. External controls to manage nicotine use were effective and should become part of the support plan for each person with PWS who is a smoker in the same way that food-related behaviors are a focus of restricted access and limited intake.

### Stress and Coping in Parents of Children with Prader-Willi Syndrome: Initial Assessment of a Structured Plan of Care within the Utah PWS Clinic and Care Coordination Project

Tanya Tvrdik[1], Sidney N. Thornton[2], Karin M. Dent[1], David A. Stevenson[1]

*College of Medicine, Department of Pediatrics, Division of Medical Genetics,[1] and Department of Bioinformatics,[2] University of Utah, Salt Lake City*

**Conclusion**: The introduction of a structured Plan of Care decreased stress and increased coping behaviors related to family stability for parents of children with PWS. Attention to respite care and communication support for parents of children with PWS may facilitate utilization of coping mechanisms.

### Cortisol and Stress in Prader-Willi Syndrome

**Elizabeth Roof, Miriam Lense, Tara Lerner, Elisabeth Dykens**

*Vanderbilt Kennedy Center, Nashville TN*

**Results**: In general, those with PWS, who have a normal BMI, have higher morning cortisol levels and a normal decline than those with PWS with obesity appear to have blunted, flat cortisol levels throughout the day. In addition, Hyperphagia severity scale was negatively correlated with cortisol change scores with (r's ranging from

-.43 to -.62, p<=.05 to .008). Cortisol change score was also negatively correlated with lower anxiety summary score on Achenbach Child Behavior Checklist (r's ranging from -.42 to -.55, p<=. 02 to .004).

**Discussion**: Diurnal cortisol levels in PWS may be related to BMI, hyperphagic severity and anxiety symptoms. Those with PWS who show a normal cortisol curve have lower BMI, lower hyperphagia severity and report fewer anxiety symptoms. Salivary cortisol sampling may be a novel way to relate physiological drive for food in PWS with associated stress and increases in BMI. Further analyses and discussion will include gender, PWS genetic subtype and post-prandial cortisol secretion and subtype to determine significant factors in PWS. ■

## The *Gathered View* Goes Green!

Beginning with the September/October issue of the Prader-Willi Syndrome Association's newsletter, the *Gathered View* will be e-mailed to all members for whom we have an e-mail address.

Not only will this help to save a tree and support the environment, but it will be more cost effective for PWSA.

Additional good news for members is that you will receive all the latest news faster, you will be able to forward the issues to your child's teachers and care providers, and you'll get all the pictures in beautiful, living color.

Please go to www.pwsausa.org/emailgv.htm to verify your correct e-mail address. **IMPORTANT: If you change your e-mail address, be sure to let PWSA (USA) know so that you don't miss any issues.**

If you choose the option of continuing to receive your Gathered View in printed form, you may make that choice on the Web site above, or you may call the national office 1-800-926-4797.

Thank you for helping to save our earth and save our funds—and benefit yourself at the same time! ■

## *Acting Executive Director's View*


*Evan Farrar*

# A Pressing Problem

Several years ago a Professional Provider Advisory Board (PPAB) was formed to strengthen PWSA's relationship with providers and to work together to resolve common challenges in serving people with PWS. The PPAB, which meets yearly, represents several agencies and an amazing amount of experience and expertise in working with PWS. The members of the board help us by creating and reviewing resources, assisting our crisis counselors with placement problems, and by articulating the concerns of providers in the United States.

At the most recent PPAB meeting we discussed the growing concern over the arbitrary and often abusive use of seclusion and restraint in school settings across the United States. Just prior to the PPAB meeting, the United States Government Accountability Office (GAO) released the ***first*** comprehensive report on the abusive use of restraints and seclusion in schools at the request of Congressman George Miller. Rep. Miller is the Chairman of the Education and Labor Committee of the U.S. House of Representatives. After reading the report, Rep. Miller concluded:

> *In January I asked the Government Accountability Office to investigate whether allegations of deadly and abusive seclusion and restraint in the schools are founded and widespread. Simply put, the answer is yes…in some cases, the abuse has been fatal. Though it is not limited to students with disabilities, it is happening more often to these vulnerable children."*

Some of these vulnerable children are students with PWS. The GAO report found "no federal laws restricting the use of seclusion and restraints in public and private schools and widely divergent laws at the state level." But, although no legislation is pending, the momentum is growing for Congress to finally address this basic human rights issue.

In fact, the volume of parent response to the GAO report has been so great that the Education and Labor Committee has set up a dedicated e-mail address for the purpose of collecting stories of abusive uses of restraints and seclusion, lack of parental notification, and policy recommendations. The e-mail address is seclusion-restraint-hearing@mail.house.gov

Please take a moment to send an e-mail about your child's experience! Teachers, professionals, and other concerned people should e-mail as well. The PPAB recommends we include in all e-mails these policy requests:

1. Creation of a viable, efficient, and consistent reporting method so that parents and appropriate officials are notified any time a restraint or seclusion is applied to a child
2. Implementation in all schools of a positive behavioral approach which is proven to be most effective for children with behavioral problems (and especially students with PWS!)
3. Mandatory **training for school staff and demonstrated competency in a nationally recognized crisis intervention program which focuses on preventative strategies and safe hands-on techniques for situations which present imminent danger**

Now is the time to let Congress know a significant number of Americans want federal legislation to address the use of restraints and seclusion in schools.

Sincerely,

Evan Farrar
Acting Executive Director

To read the GAO report, go to:
http://www.gao.gov/products/GAO-09-719T

## Annual Membership Meeting

The Annual Membership Meeting for 2009 will be held telephonically on Tuesday, September 1, 2009, at 8:00 p.m., Eastern Standard Time. To join the call, please dial 1-270-696-1555. The Participant Access Code is 293756. To ensure that we have sufficient lines available for all who wish to participate, please e-mail info@pwsausa.org to let us know you will be joining us. If you don't have e-mail access, simply call the office at 1-800-926-4797 and let them know.

**Production, printing and mailing of this newsletter was underwritten by CIBC Children's Miracle Day.**

**PWSA (USA)**

## Election of

**2009-2012 Board of Directors**

## Approval of

**2008 Annual Membership Meeting Minutes**

# Voting Instructions

1. Review the candidates' statements printed on the Slate of Candidates. Read the 2008 Annual Membership Meeting Minutes.

2. Cast your vote on the Official Ballot. Note any corrections necessary to the Annual Membership Meeting Minutes. Insert the ballot into the Official Ballot Envelope.

3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWSA (USA) postmarked no later than August 15, 2009.

4. If you receive the Gathered View only in an electronic form and were not provided with an Official Ballot Envelope, please mail your ballot to: Julie Doherty, Secretary, PWSA (USA) 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471. ***In the return address portion of the envelope, place your name and address and the following statement: I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote. Place your signature below this statement.*** (See sample ballot envelope below.)

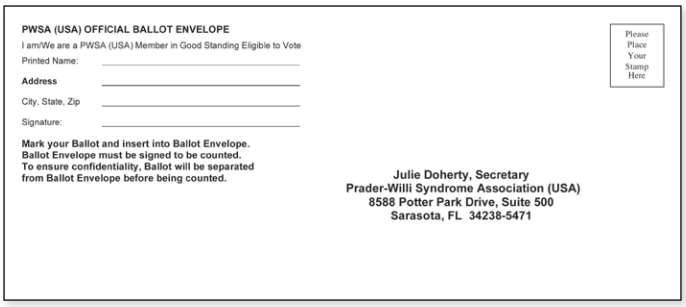
***Deadlines*:** The deadline for voting is August 15, 2009. Ballots postmarked after August 15 will not be counted.

***Confidentiality:*** Your vote will be kept confidential. PWSA (USA) staff will verify voter eligibility and separate the Official Ballot from the Ballot Envelope before the Ballots are tallied.

***Voting Criteria:*** Voting members must be Members in Good Standing with PWSA (USA). Membership dues must be current and paid in full or a dues waiver granted.

***Member Types Eligible to Vote:*** Each membership type, whether individual, family or professional, is entitled to one vote.

*sample ballot envelope*


PWSA (USA) OFFICIAL BALLOT ENVELOPE
I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote
Printed Name: _____
Address _____
City, State, Zip _____
Signature: _____
Mark your Ballot and insert into Ballot Envelope.
Ballot Envelope must be signed to be counted.
To ensure confidentiality, Ballot will be separated from Ballot Envelope before being counted.
Please Place Your Stamp Here
Julie Doherty, Secretary
Prader-Willi Syndrome Association (USA)
8588 Potter Park Drive, Suite 500
Sarasota, FL 34238-5471

## Approval of 2008 Annual Membership Meeting Minutes
## OFFICIAL BALLOT

Cast your vote for the 2009-2012 Board of Directors. Vote for five (5) of the candidates listed below.

- ☐ Greg Cherpes, M.D.
- ☐ Jackie Mallow
- ☐ James Koerber
- ☐ Lisa Thornton
- ☐ Michelle Torbert

☐ Corrections to the 2008 Annual Membership Meeting Minutes: _____

☐ No Corrections Necessary *(if neither box is checked, we will assume you have no corrections to the minutes)*

# Meet the Slate of Candidates

**Gregory L. Cherpes, M.D.,** Pittsburgh, Pennsylvania, is board certified in child and adolescent psychiatry as well as general psychiatry. He is a full-time staff member of The Children's Institute, and there he serves on the leadership team of the Prader-Willi Syndrome/Behavioral Disorders Unit, the nation's only inpatient crisis management program for individuals with PWS.

He completed his medical degree at the Medical College of Wisconsin and completed his general psychiatry residency as well as child and adolescent psychiatry fellowship training at Western Psychiatric Institute and Clinic in Pittsburgh. Since residency, he has been an advocate for the health needs of individuals with intellectual and developmental disabilities.

Since beginning at TCI in May 2006, he has worked with approximately 150 individuals with PWS as well as their families and other caregivers. He serves as a psychiatric consultant to the crisis service of PWSA (USA). He is also the medical director of Community Health Connections, a Health Care Quality Unit of the state of Pennsylvania which serves 9 counties with the mission of providing high quality training, assistance, and capacity building to benefit those with intellectual and developmental disabilities.

**Jackie Mallow** has worked in a residential setting since 1985. She has worked directly with children and adults who have been dually diagnosed and has extensive training, experience, and education in the areas of behavior/crisis management, and program/staff development.

Since 1996, she has worked exclusively with individuals with PWS, providing educational training, support, guidance and consultation nationwide. Jackie is the Admissions/Consultative Services Director for Prader-Willi Homes of Oconomowoc, the current Vice President for PWSA-Wisconsin and on their board since 1997. Extremely active in supporting the mission of PWSA (USA), she has been on its Board of Directors since 2006. As the chair for the PWSA (USA) Professional Providers Advisory Board, she takes an active role in supporting providers. Since 1997 she has shared her knowledge as a presenter at the national and international level for PWSA (USA) and IPWSO, and cherishes the opportunity to personally grow through the experience and knowledge of others that she has met over the years.

"I have worked with many children, adults, families, providers, and professionals who have had to meet numerous challenges; none of these compare to the struggles an individual with PWS and those who care for them must face. It may also be said that I have never seen a group of families, providers, and professionals be more supportive, dedicated and tireless in their efforts to making a difference in the lives of those touched by the syndrome."

Born and raised in the Oconomowoc, Wisconsin area, she enjoys the outdoors, a good book, and her family and friends. Her husband Bruce, children Nick and Samantha are the loves of her life, and her profession is her passion.

**James L. Koerber** and his wife Rita have four adult children and three grandchildren living in northern California and New York City. Their youngest daughter Alison has Prader-Willi Syndrome. She is 32 years old and lives in a group home in Citrus Heights, CA.

Jim got involved with the Prader-Willi Syndrome Association (USA) shortly after Alison was diagnosed at age nine. He served on the Board of Directors and as President of the Prader-Willi California Foundation. He also was elected to the National Board in 1997, but had to resign when he and Rita moved to Indonesia in early 1998.

Jim earned a B.S. in Mechanical Engineering from Purdue University and an M.B.A. in management from Golden Gate University. On July 1, 2007, he retired from Chevron Corporation after almost 41 years and moved from London, England to their 80-acre farm in southern

*Candidates, continued on page 10*

**Candidates,** *continued from page 9*

Indiana. During his career at Chevron he held a number of technical and management positions in the U.S. as well as international. Even with his work and travel, he maintained a strong connection with the Prader-Willi Syndrome Association. Since his retirement, he now has time to restore his 1926 Model T Ford, lower his golf handicap, contribute more time to community activities, and still be a gentleman farmer.

One of his first community activities was to provide leadership for the re-establishing of the PWSA Chapter in Indiana. He is currently serving as President.

His broad leadership experience and his desire to make PWSA (USA) the best organization it can be to serve those affected by Prader-Willi syndrome, are the reasons Jim wants to serve on the Board of PWSA (USA).

**Lisa Thornton**, Salt Lake City, Utah, is an attorney specializing in civil rights actions as well as estate planning for families with special needs.

She has served as president of the Utah Prader-Willi Syndrome Association for the last 4 ½ years. During that time she has helped raise over $100,000 and has made PWS public service television commercials airing throughout the state. She has helped secure funding from the Utah legislature and Health Department for a medical clinic and medical care manager serving the children with PWS in Utah. And she has been instrumental in developing the content for the Utah PWS software that outlines the medical, educational, and legal steps that each parent should take in caring for a child with PWS.

Sid, her husband of 18 years, is a medical scientist and has presented at PWS scientific conferences. They adore 5-year-old Kate, the one of their five children who just happens to have PWS. Lisa says that their family is "a package deal--whatever project we take on, we can always count on full enthusiasm and help from each other."

**Michelle M. Torbert**, Homestead, Florida, says: I am the mother of Leslie (age 11) who has Prader-Willi syndrome. I have been married to my husband, Tommy, for 23 years and also have 4 boys, Thomas (19), Eric (17), David (16) and Alex (14). I graduated from South Miami Senior High in 1979 and graduated from Miami Dade College with an AA degree in Criminal Justice. I attended the Miami Dade Police Academy and joined the Homestead Police Department in 1981 where I served as an officer and Sergeant until I retired in 1991 to stay home and raise my first child. I have served on many volunteer boards including the American Red Cross, the Homestead Hospital Foundation Gala Committee and The Little Angels Foundation (which raises money in the South Dade area of Florida for children with mental and physical disabilities). I am also on the Board of Trustees for Palmer Trinity School, which is the school my boys attend. I have done many fundraising events for Good Hope Equestrian Training Center (where Leslie rides horses), Baptist Health Foundation, and Prader-Willi Syndrome Association. I am currently the President for the Florida Chapter of PWS. I just co-chaired a 2- day fishing tournament for PWFA and PWSA which raised over $104,000. I feel I would be an asset to the board with my fundraising skills, as well as the fact that our daughter Leslie is my life, as is Prader-Willi syndrome, and I have a great passion and love for all the children who have the syndrome as well as their families. I would be honored to serve with the talented board that is already in place as well as being able to serve all of you in whatever you may need. ■

## Minutes of PWSA(USA) Annual Membership Meeting Wyndham Hotel, Milwaukee, Wisconsin July 3, 2008

Co-Chair Carol Hearn called the meeting to order at 12:25 p.m.

She introduced the board members and officers: Janice Agarwal, Jamie Bassel, Bill Capraro (absent), Linda Gourash, John Heybach (absent), Steve Leightman, Carolyn Loker, Jackie Mallow, Mark Ryan (absent), Ken Smith, Mary K. Ziccardi, Julie Doherty, Secretary, and Bert Martinez, Treasurer (absent.). The IPWSO Parent Delegate Susan Henoch (absent) was introduced as well as the Executive Director Craig Polhemus.

Dr. Dan Driscoll introduced the CAB. He discussed the four-hour meeting format which was utilized again this year. Four topics were covered: psychiatric medications, nutrition, central adrenal insufficiency, and an update to the growth hormone statement first issued in 1996.

Dr. Merlin Butler introduced the SAB and discussed the function of the board relating to the research grant review and award process. There were 17 abstracts and two invited keynote speakers

*Minutes, continued on page 11*

**Minutes,** *continued from page 10*

at this year's scientific conference.

Janalee Heinemann and Kerry Headley presented a Lifetime Achievement award to Dr. Merlin Butler for his work with Prader-Willi syndrome. He has made many key advances in genetics and enjoys respect worldwide for his work in this field.

*The Food, Behavior and Beyond* DVD, authored by Drs. Gourash and Forster, is available for sale with Spanish subtitles.

Julie Doherty presented the minutes from the August 2, 2007 General Membership meeting. There being no corrections, the minutes were approved as presented.

Steve Leightman, Chair of the Finance and Fund Development Committees, reported on the financial health of the organization. He highlighted the expense and revenue categories in the budget. The income in 2008 is less than this same time in 2007, which is a cause for concern but not a cause for panic. It is the desire not to spend funds from our reserve account, but to inspire additional giving and fundraising. The 2007 Annual Report was available at each table.

Craig Polhemus, Executive Director, presented his report. He noted the increase in crisis calls and the fact that we spent more than double the amount on research in 2007 than had been spent in any prior year. Families were encouraged not to wait until a crisis to call, as the office staff was available to assist with any need they have. An update on two advocacy issues was provided; one relating to SSI and one relating to Growth Hormone.

Mary K. Ziccardi, co-chair of the Leadership Development Committee, discussed the newly expanded size of the board, allowing for up to 15 members. The slate of six nominees for the six positions was presented:

**Janice Agarwal**, Zionsville, Indiana
**Carol Hearn**, Minneapolis, Minnesota
**Michael Alterman** (absent), Atlanta, Georgia
**Kerry Headley**, Columbus, Ohio
**Dr. Daniel Driscoll**, Gainesville, Florida
**Ken Smith**, Pittsburgh, Pennsylvania

Voting will be open until 5:00 p.m. today.

Sam Beltran, one of the founding members of PWSA(USA), shared his thoughts on the progress of the organization over the past 30 years. Everyone was encouraged to continue the good work.

Carolyn Loker moved to adjourn the meeting. Jim Loker seconded. Meeting adjourned at 1:15 p.m.

Respectfully submitted,
Julie L. Doherty, Secretary ■

# This is my Story

***By Andy Maurer, PWS Advisory Board Member***
***Columbia, South Carolina***

I have a very unique syndrome called Prader-Willi Syndrome. If you don't know about it, here goes.

In medical terms, people with Prader-Willi Syndrome have a deletion on chromosome 15. This means that the signal from my brain to my stomach, which tells me I am full, doesn't work. I never feel full. I can't eat as much as other people can. My food is carefully measured by staff. I am on a 1000 calorie a day diet to maintain my weight. It doesn't amount to much food, but that is what I have to do to stay alive. I also have to do a lot of exercising to help lose weight.

My father was in the hotel business, so we moved many times. Most of the time we lived in the hotel and we had to eat at the hotel restaurants for awhile until a kitchen was built in our apartment. It was hard to stay on a diet.

Over the years I have done many things. I have met some important people such as political figures like Presidents, baseball stars, foreign dignitaries, and movie and TV stars. I was interviewed by People Magazine, CNN, FOX and WIS TV a couple of years ago about Prader-Willi Syndrome and living with it. I have also been on a cruise to the Bahamas with my parents and the Henson family.

In 2003, I fulfilled a long time dream when I went to Dublin, Ireland for the Special Olympics Summer World Games. I competed in equestrian events. I didn't expect to win, but I won a Bronze Medal!

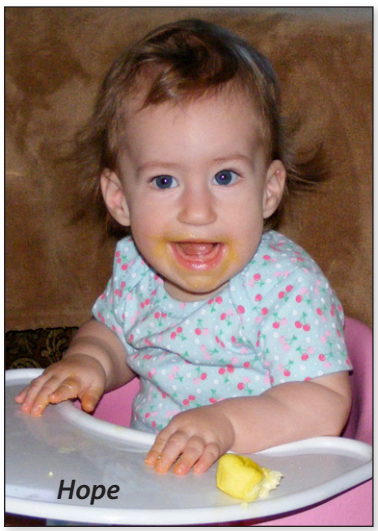
I am on the Dream Riders Board of Directors, the Prader-Willi Advisory Board and the Babcock Center Consumer Advisory Board.

These are a few of the things that I have done in my life.

I live at a Babcock Center CTH II and I am very happy. I have tried to control my weight and behavior which are part of Prader-Willi Syndrome, but sometimes it is very hard. I get compliments about how well I have done, but there is one person in my life that I want to give real special thanks to and that is my mother. She has helped me in good times and bad to deal with the problems of Prader-Willi Syndrome. I also want to thank the Babcock Center staff for all they have done for me over the years that I have been living in a group home to keep me safe, healthy and happy. They are like family. ■

# Thoughts on Healing

***By Jennifer Rinkenberger, Fresno, California***


Hope

Ordinarily (and by ordinarily I mean "for the last three weeks"), I try to keep my more religious opinion elsewhere, but this one has had me thinking. How should I respond, or should I respond to the suggestion that Hope should be "healed"?

It's taken awhile to determine my approach to the topic and something I read recently kind of brought it to mind yet again. I'm hooked on Henri Nouwen, so this week I read *Adam: God's Beloved*, a memoir/biography of the very special relationship that Henri had with the first core member of L'Arche Daybreak that he cared for. Adam could not speak, or walk, or do pretty much anything on his own and yet in him, Henri Nouwen found a spiritual guide and saw the face of God. Now obviously, the long and intimate relationship that Henri and Adam shared was built over time, it didn't just magically happen. When Henri was first assigned to Adam, he was horrified. But as he came to know the people with disabilities who lived in the L'Arche community, he began to see beyond their diagnosis and learned to relate to them as people. One particular story stood out to me on this topic:

I still remember a woman visiting the New House, walking right up to Adam, and saying, "Poor man, poor man, why did this happen to you? Let me pray over you so that our dear Lord may heal you." She motioned the assistants to make a circle around Adam to pray. But one of them gently tapped her on the shoulder and said, "Adam doesn't need any healing; he is fine. He is just happy that you came for dinner. Please join us at the table." I do not know whether this visitor was ever ready to be touched by Adam, to see his wholeness and holiness in his brokenness, but she did come to realize that everyone in the house was very happy with Adam the way he was.

I don't know that, except once, I've ever prayed for Hope to be "healed." I prayed a lot of "Dear God, not this, not this" — does that count? But I was always a little reserved in my demands, I thought I should be grateful for what I've got. Things could be much worse, let's not tempt fate. And then there is the ongoing challenge/growth process of loving Hope for who she is — every part of her, right down to her atypical 15th chromosome and all that it will entail — but not loving Prader-Willi syndrome itself because, well….it sucks. I've spent a lot of time this past year wondering whether, if I could snap my fingers and make PWS go away, would I? I've worried that to do so would mean that I really didn't love Hope, all of her. For awhile, that was the hardest question I had rolling around in my head — how do you love the baby but not the disorder, especially when the baby ***has*** the disorder?

Agh, I'm rambling….The point is I've finally gotten to the point where I can say with some certainty that if I could snap my fingers and make Prader-Willi go away, I would in a heartbeat. But praying for healing over and over again seems different. I've gone on record with God, he's quite aware of my feelings over the whole PWS-thing. I've registered my complaints, they've been duly noted. For all intents and purposes, they are beside the point. The fact of the matter is that Hope has Prader-Willi syndrome and will always have Prader-Willi syndrome. It's a part of every cell of her body. The egg that was fertilized, that became Hope, had two copies of the 15th chromosome when it should only have had one. That little glitch happened 35 years ago while I was safe in my mother's womb. That special little egg waited 34 years for its turn down the chute, and when Mr. Sperm offered his 15th, my very independent egg said, "no thanks, we're covered." If the father's 15th had been accepted and remained in every cell, a viable embryo would not have developed and there would be no Hope.

This is who Hope is. She who was knit together in my womb, she who is fearfully and wonderfully made.

For me, prayers for healing seem to shortchange Hope. As though she is somehow inherently broken, defective, less whole – and will always be so – because of her genetic condition.

I don't pray for healing anymore, I don't need to — it's a given, why belabor the point? But mostly it's because when I look at Hope I don't see somebody who needs to be fixed. I don't see a child that is broken or defective. I see a child who is different, to be sure. I see a child who brings me a level of worry I never knew imaginable. But I also see my beautiful, perfect daughter — and she is perfect…just a different kind of perfect. ■

## From the Home Front

### A Thank You from Parents

Hi Janalee. I wanted to let you know how much we appreciate the support you and the PWSA (USA) provided for us this past year. We were truly a family in crisis, and we'll always be grateful for the input and guidance you and the staff were able to offer us. Our daughter is now at Latham Centers and is doing great! It was a rocky start, but now that she's adjusted to her environment, she is thriving. We look forward to her home visit for Christmas. Although we all miss her very much, we know it has been the right decision for her. Thank you, thank you, thank you to all!! ■

~Name Withheld
for Privacy

### A Short Story

My daughter Makayla, who is 7 and in the first grade, had show and tell this week. She said, "Mom, I would like to tell my friends about Alexis." (Alexis is Makayla's cousin, age 5, who has PWS.) I said "OK, what would you like to talk about?" She did not answer me right away and went upstairs for a while. When she came down, she asked if I thought it would be all right if she took in some brochures

*Alexis, 5 and Makayla, 7*

for her teachers, a picture of Alexis and some wrist bands. I said, "That sounds like a great start, but what will you tell them about Prader-Willi syndrome?" She said to me, "Alexis is my cousin and I love her very much. I have to help her watch what she eats, because food can make her die. I play with her and we fish together, and I just want my friends to know at school that it is ok to be different."

This touched my heart. I talk a lot about PWS and set up a lot of Health Fair tables. My daughter has listened through her ears and heart. You can never start spreading awareness too early. ■

~ Cindy Galyean
Sanford, North Carolina

### Congratulations, Christine!

Christine Persanis, from New York, has at age 38 been participating in Special Olympics for 20-25 years. From time to time she has won a gold medal for an event she participated in, but never two, her goal. But she kept trying. This year in May at the Northeast Special Olympics, a regional meet, it happened! Christine won not one but two gold medals, one for the 50-yard walk and one for the softball throw. ■

### A Budding Pianist

With the help of a PWSA (USA) crisis counselor, Bridget Adley, of Plymouth, Massachusetts received a new piano from a local

*Bridget with her older brother*

foundation (for free!). She has shown a strong interest in playing the piano so she is motivated to learn. Just like other children, many with PWS are attracted to music and instruments. And, as the PWSA in England reported, "many have demonstrated skill at playing musical instruments."

Learning to play an instrument can have many benefits for a child with special needs. The American Music Therapy Organization explains, "Music Learning is used to strengthen nonmusical areas such as communication skills and physical coordination skills which are important for daily life." It can also be an important tool for socialization and interaction with the community. ■

**CHUCKLE CORNER**

When Natalie was about 4 years old she was following her Dad around the kitchen, harassing him to dress her in her Barney Halloween costume (it was the middle of summer). Exasperated, he told her, "Natalie, you're going to drive me to an early grave!" Natalie responded, "Silly Daddy. You know I can't drive...Mommy will have to take you."

~Linda Huckelberry, St. Louis, Missouri

## International View

### South Africa says Thank You!

Dear Evan,

I received information from Giorgio Fornasier re your new first 'crisis Web page'. I am the chairperson of the PWSA of South Africa and parent delegate to IPWSO. We are busy upgrading and updating the Web site of PWSA (SA) and are very excited about this project! Is it in order if we put this information and the link to the crisis Web page on our Web site? It is a very valuable service and I am considering to make use of it myself! ■

Kind regards, Rika du Plooy

### Janalee Heinemann Co-opted to IPWSO Board

The International Prader-Willi Syndrome Organization has announced that Janalee Heinemann and Jackie Waters (Deputy Chief Executive of PWSA UK) have agreed to join their board as co-opt members at least until their General Assembly and election in Taiwan in 2010.

"Co-opt" members means simply that they have been appointed rather than elected to the board. They will have the same rights, privileges, obligations and duties as the elected members.

Linda Thornton, Secretary of the IPWSO board, noted that "their expertise and knowledge will be exceedingly helpful to IPWSO, particularly at the moment when, without our dear Pam [Eisen], we need to look forward to the future and bring some good initiatives, strategies and forward planning to our members at the G.A."

In July Jackie, Mary K. Ziccardi, Jan Forster and Janalee will go to Germany to attend the Caregivers Conference. Janalee will also attend the IPWSO board meeting following. Janalee notes that her expenses will be covered by IPWSO. ■

### Swimmer from Argentina with PWS

Matias Torres, 21, from Argentina, finished a 1,500 meter swim (about ¾ mile) in a competition called, "El Reencuentro de los Delfines". Matias is a unique athlete because he has PWS.

Encouraged by his family, Torres began to swim as a little boy. "Swimming long distances was not even a thought in his mind but he did this so enthusiastically that he just let all of his obstacles go and just threw himself in the lagoon. People would just watch him swim and this generated such emotion and they knew that it could be done." says Matias' father Norbeto, who accompanied Matias to the lake where he received an ovation.

Torres already had swum distances of 400 meters. Wishing to reach a higher goal, he decided to lose weight, a difficult feat because of PWS. Assisted by a group of professionals from the Spine Foundation, he lost 32 kilos (70 pounds) in approximately 2 years.

Matias now wants to swim an even longer distance. He announced to the public, "I'm going for more!!! " ■

### A Thank You from Greece

Dear Janalee,

Thank you for your e-mail and all the helpful hints…! We are going to start the translating process and we will definitely credit your association. Your association was the first contact I made when I got my son's diagnosis (that was 8 years ago), and I will never forget all the assistance and material you had provided me…and all the e-mail support.

I would like to thank you personally and on behalf of our Greek Association. ■

Maria Papaiordanou

P.S. I'm attaching you a picture of George, he's now 8.

George

*Here are the words to the beautiful song for the worldwide family of PWS, written by Giorgio Fornasier, a former president of IPWSO.*

### FLY HIGH

We come here together
to meet with each other,
to share our life stories,
to tell of our glories;
sometimes it's not easy
to always be different,
but you are my friend here
and you understand me...

*CHORUS:*
Across the world's oceans,
across the world's skies
we join hands together
and love makes us fly high!

We're brothers, we're sisters,
we're part of the family
that binds us together
from coastland to city;
like droplets of rainfall
we flow like a river,
combining our wisdom
like powerful sea...

*CHORUS:*
Across the world's oceans,
across the world's skies
we join hands together
and love makes us fly high!

So let us stand tall now,
let's stand tall with pride.
Let's celebrate life now,
both your life and mine;
we stand on the same side
'though we live apart
just knowing you're there friend,
stays deep in my heart...

*CHORUS:*
Across the world's oceans,
across the world's skies
we join hands together
and love makes us fly high!

## *Chapter View*

*In this issue and in subsequent issues from time to time, the Spotlight will shine on a chapter or two. If you would like your chapter to be* ***In The Spotlight****, rev up your computer and send in a write-up about its activities and achievements!*

***The Spotlight Shines on…***

### Prader-Willi Syndrome Association of Ohio

Founded in 1986, the Prader-Willi Syndrome Association of Ohio became an official chapter of PWSA (USA) in 1987. Current membership includes 150+ families, special-needs service professionals, and medical professionals with the number growing all the time. Board members and officers live all around the state and attend three board meetings a year. Opportunities to take part in chapter events abound throughout the year and throughout the state.

In April the chapter held its main yearly support meeting, the annual Family Festival in Central Columbus. This year's event included carnival games and craft activities for children, swimming, a pine-box-car derby, and breakout sessions for parents with endocrinologist Dr. William Zipf and ODMRDD Family Advocate Peggy Martin.

Newsletter editor and board member Sandy Giusti writes and produces our newsletter, the "Prader-Willi Voice" 4-5 times a year. The chapter, with volunteer help, sponsors and mans a fall PWS-only Weekend Camp at Recreation Unlimited for individuals eight years old and up and pays most of the camp costs for Ohio members! This spring the chapter was also able to advocate for and raise awareness of our PWS community by helping to sponsor The ARC of Ohio Legislative Event in Columbus. The chapter is also planning an August Bowling Day for our chapter families.

Finally, chapter members have had success in fundraising. Four events in 2009 have cumulatively raised just over $25,000, plus helped raise awareness and generate support throughout Ohio. These events were coordinated by the Giustis, the Suttons, the Coulters, and the Bolanders. The chapter plans to use these funds to continue supporting our Ohio PWS community and PWSA (USA).

Please visit the chapter's Web site www.pwsaohio.org or contact through e-mail: pwsaohio@aol.com. Phone calls are also welcome at 440-716-0552.

*[Note: Ohio enjoys having two chapters! The other is Prader-Willi Families of Ohio.]* ■

And...

***The Spotlight Shines on…***

### Georgia!

On Wednesday, May 6, families in the state of Georgia met with their governor, Sonny Purdue, who presented them with a signed Proclamation recognizing May as PWS Awareness Month.

Attending the Proclamation ceremony were Georgia families Warren, Spradling, Gordon, Stakely, Arant, Bianco and World. The signing took place in the Governor's office, and the children had the extra privilege of sitting on the Governor's desk. Governor Purdue asked questions about PWS and its effects and showed genuine concern about PWS and what it means for the families in Georgia.

This event raises awareness in the state of Georgia, giving many families hope that the state will become more aware of and responsive to the needs that PWS presents. ■


Dottie Cooper, Alpharetta, Georgia writes:

*I just want to let you know what a tremendous day we have had in providing PWS training to Provider Supervisors and direct care staff, as well as Support Coordinators and parents in the state of Georgia. Debbie Lange, Georgia Executive Director, was absolutely meticulous in all the planning and preparation for the event, and everything went so smoothly. Through the gracious support from PWSA (USA), Mary K. Ziccardi was able to come in to provide the training. She did a phenomenal job, and everyone left informed, enthused, and with tools that will benefit them in supporting persons with PWS.*

*As a parent, I want to thank Mary K. Ziccardi and PWSA (USA) for its invaluable support to state chapters.* ■

## Fundraising

*The impossible just takes a little longer. ~Unknown*

### Laughter is Good Medicine

In April PWSA (USA) was presented with a donation in the amount of $12,000 for research from Zak's Promise: Progress with Support, Inc. The funds were generated from that organization's **1st Annual Laugh for the Cure,** an event organized by Zak's Promise founders, **Jamie and Jacqueline Bassel**, parents of Zak, 4 ½ with PWS. Approximately 200 guests enjoyed an evening of laughter hosted by comedian Adam Ferrara, currently performing on the Fox Network's *Rescue*. It was an incredible opportunity to make others aware of PWS and gave everyone an excuse to laugh for an amazing cause.

Established in January of 2006, **Zak's Promise: Progress with Support, Inc.** is a 501 (c) (3) charitable foundation founded in honor of the Bassels' son. Funds were also distributed to Prader-Willi Alliance of New York; The Genetic Disease Foundation with whom Zak's Promise has recently partnered to create a full-time research position to study Prader-Willi syndrome and other genetic disorders caused by the 15th chromosome; and YAI/ National Institute for People with Disabilities Network, a national leader in the provision of services, education and training in the field of developmental and learning disabilities and where Zak has been receiving treatment since birth.

Thanks to the Bassels for showing that laughter is good medicine! ■

### A Big Catch

Two fishing tournaments ran simultaneously in April and 'reeled in' $28,000 net for PWSA (USA) and $20,000 net for Prader-Willi Florida Association. **Casting for a Cause** was the idea of Florida chapter president, **Michelle Torbert**, who ran the tournament for off- and in-shore fishing with event partner TEVA (Tropical Everglades Visitors Association). TEVA also benefitted $18,000 net from the event. Torbert said she was approached by TEVA which wanted to bring a high-caliber fishing event to the area that included a charity component. They knew Torbert's daughter, Leslie, 11 ½ with PWS, well and were hoping to support PWSA. They hired a professional fishing tournament event planner and were on their way.

Two event participants, **Rorri Peaton** and **Galvin Ayers**, adults with PWS, formed a team for

the back-country division and placed second. They are Florida residents who are roommates in an independent living facility. When the pair was fishing, they didn't even think about food or ask for a snack because they just love the excitement of fishing.

She's already lifted anchor for next year with a tentative date of April 15-18, 2010. If interested in learning more, contact Torbert at pwfa2007@aol.com or home number 305.245.6484.

### The Grassroots are Growing, too!

**Barbara Emmons**, grandmother and guardian to Andrew, 10 with PWS, held ***The 3rd Annual Fun Day at the Moose*** in April to raise funds for conference grants and research. The event raised nearly $1,500. The Moose Lodge has donated their space for no charge each year and has helped Barb with advertising the event. On July 4th, Barbara plans to hold a cookout to continue raising funds.

**Ryan Thompson** and his friends ran in the ***Oklahoma City Memorial Marathon*** this year in memory of their friend **Billy Khourie III**, who died at 22 in a snowboarding accident in January. Billy's relationship with his sister Lauren, 19 with PWS, is inspiring. Ryan has raised more than $6,300 to support PWSA (USA) and PWS Oklahoma. Ryan's Firstgiving.com page says, "Anyone who knew Billy knew how much he loved his little sister. When Billy was in college, he returned home to accompany his little sister to the prom. He spent the entire evening dancing with his sister so she would have a high school prom she would cherish and remember. He would do anything for Lauren."

With people coming and going all day, **Michael Alterman**, PWSA (USA) board member and brother to Andrew, 38 with PWS, had his hands full hosting his ***2nd Annual Kentucky Derby Party***. Probably 60 people were at his house all day watching the race, bidding on their favorite horse, and hoping to beat the odds and also support PWSA (USA). Nearly $1,700 was raised, and plans to continue this event are racing ahead. ■

### Lose-A-Thon

***To all our losers 2009, great job and a hearty thanks. You're inspirational!***

## Counselors Corner

# Tips on Finding Physicians for Children with PWS

***Kate Beaver, Alterman Crisis Counselor***

"A multidisciplinary approach is needed to treat individuals with PWS, regardless of the age of the patient."

~Management of Prader-Willi Syndrome (Butler, Lee, Whitman)

In the Counselor's Corner this month we are sharing a new resource created by the PWSA (USA) Crisis Team to help parents find a physician for children with PWS. Copies of this resource are available through our Web site or by contacting the PWSA (USA) office.

Because Prader-Willi syndrome is a complex medical syndrome, it requires a multidisciplinary team approach to provide the best possible medical management. This multidisciplinary team typically includes:

| Type of Physician | Reason |
|---|---|
| Pediatrician | To treat childhood medical issues |
| Geneticist | To diagnose PWS and advise on form of PWS |
| Endocrinologist | To treat the endocrine system including evaluation of appropriateness of Growth Hormone Therapy and sex hormones |
| Psychiatrist | To treat psychiatric and/or behavioral issues |
| Neurologist | To treat neurological and nervous system issues including seizures |
| Gastrointestinal Specialist | To treat stomach and digestive problems common to PWS. |

Other physicians or health professionals (e.g., a pediatric urologist for male children, a dietician) may be needed depending on the specific needs of the child. The challenge for many parents and caregivers is to find physicians who have experience with PWS. While the number of physicians working with PWS is growing, overall the percentage of experts is quite small. So unless a child lives near a clinic that specializes in the care of people with PWS, a medical team must be developed because there is no comprehensive national database of physicians familiar with PWS.

### How should my child's medical team be structured?

If possible, identify one physician (usually a pediatrician or primary care physician) to act as the coordinator of your child's medical team. This will allow you to interact more frequently with one medical professional who can then coordinate the involvement of other medical professionals as needed. If your child is able to participate in a PWS clinic, the specialist coordinating the clinic will probably be a geneticist or endocrinologist.

### How can I find a physician?

- Contact your local PWSA state chapter which may have a list. If not, ask if they have contact information for parents who might share a physician referral with you.
- If you attend state or national PWS conferences, ask other parents you meet for suggestions.
- If you live in the region of a PWS clinic, ask if they might have a referral nearer to you for everyday care issues.
- Post a message on the appropriate PWSA Yahoo Web Group asking parents in your area for suggestions. (Note: To sign up for a Web group, contact our office.)
- Contact local agencies working with children with disabilities for a referral. Even if it is not a referral for a physician experienced with PWS, it is still better to find a physician who is interested in working with a child with a disability.

### What should I look for in a physician?

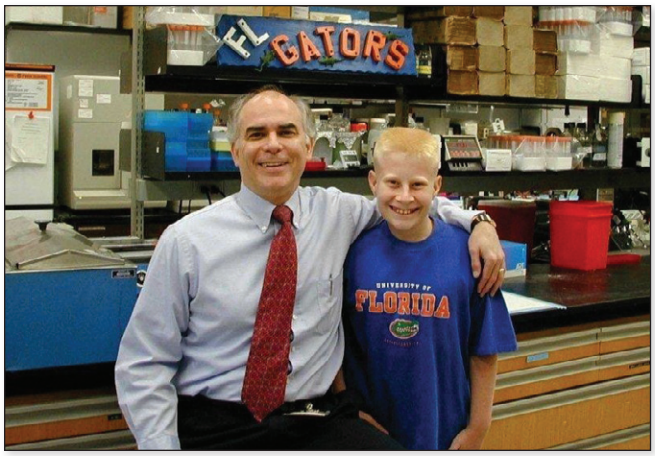
- Best scenario is to find a physician with some experience with PWS.
- In most cases, that will not be possible. Then most important is finding a physician who is willing to learn about PWS. Interview the physician with questions such as:
- Are you willing to read and review materials about PWS?
- Will you purchase the Management of Prader-Willi Syndrome book for reference? (You may want to buy it for him/her.)
- Are you willing to consult with other physicians more experienced with PWS, if needed?
- What other disabilities have you worked with?
- Are you willing to work collaboratively as the leader of my child's medical team?
- How available are you in cases of emergency?

During your first appointment with the physician, pay close attention to how the physician interacts with you and your child. Does the physician show an interest in your child as a person? Does he or she take time with you and your child? Does the physician

*Tips, continued on page 18*

**Tips,** *continued from page 17*

ask pertinent questions to learn more about PWS? The key is to feel comfortable that this is a medical professional who is willing to learn and grow with you and your child. And remember, every time a new doctor treats a child with PWS it grows the number of physicians available to other families in the future.




*Dr. Dan Driscoll & patient*

**How can PWSA (USA) help?**

- By providing educational materials for your physician. Resources, available for purchase, include a physician's awareness packet, the PWS Management book, and a DVD for health care professionals.
- By setting up free consultations for your physician, if needed, with medical professionals more experienced with PWS.
- Through our 24/7 Medical Crisis Line (800-926-4797), which is available to you and your physician in cases of emergency.
- By providing a copy of the Medical Alert book, an essential resource to help physicians quickly identify what symptoms and situations may present life-threatening medical conditions for a person with PWS. This is especially important to carry with you in your purse, glove compartment of the car, etc., should you suddenly need to go to the emergency room. It is also good to give to babysitters, teachers, and anyone else who may be caring for your child. ■

### *Washington Post* Article and Correction

The June 24 edition of *The Washington Post* included an article in the health section about the First International Hyperphagia Conference that occurred in Baltimore, Maryland on June 4-5, 2009. The article by Jennifer LaRue Huget is entitled, "Can't Stop Eating? For Some People, Obesity Is Not a Simple Failure of Self-Control." You may be able to view it at: http://www.washingtonpost.com/wp-dyn/content/article/2009/06/19/AR2009061902546.html. Janalee Heinemann, PWSA (USA) Director of Research and Medical Affairs, wanted to clarify a misquote regarding a cure for PWS and obesity. She said, *"I did not say, 'I do not think there is going to be a pill.' I said that 'I do not think it will be so simple to find the right pill as I once thought.'"*

**Visit our Web site for more pictures, regular updates and more... www.pwsausa.org**

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**Thank you for Contributions in April and May 2009**

We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

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*Contributions, continued on page 19*

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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.

PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to **www.pwsausa.org/donate**

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

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