

# The *Gathered View*

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

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

## Counselors Corner

### Report from the 2016 Annual Meeting of the Adults with PWS Advisory Board

By *Evan Farrar, M.A. Crisis Intervention and Family Support Counselor, PWSA (USA)*

In January, the Adults with PWS Advisory Board held its annual meeting in Sarasota, Florida. Attending were all advisory board members – Andy Maurer, Lauren Lange, Conor Heybach, Shawn Cooper, Abbott Philson, Brooke Fuller, and Kate Kane. We also welcomed Trevor Ryan as a new member of the Advisory Board.

The Adults with PWS Advisory Board is a group that works hard when it meets to serve its mission to help PWSA (USA) by sharing their perspective as people living with PWS. At this year's meeting the Advisory Board:

- Completed a Self-Advocate research questionnaire to provide feedback on their experience living with PWS and research needs at the request of the Foundation for Prader-Willi Research. One interesting result was Advisory Board members' response to the question - "are you happy with your lives?" The Board responded with a unanimous "yes" and listed many reasons why – family and other relationships, work and volunteer activities, hobbies, sense of being part of a community, and more.



*L to R: Shawn Cooper, Trevor Ryan, Brooke Fuller, Lauren Lange, Abbott Philson, Kate Kane, Conor Heybach, Andy Maurer*

- Provided feedback on the 2015 PWSA (USA) national conference and recommendations for the future.
- Participated in an activity with attorney Michelene Bajakian to provide first person information to help PWSA (USA)'s Family Support program's response to situations where a person with PWS is involved with law enforcement.
- Shared updates with each other about their lives and activities since last meeting.
- Took a break from working hard to visit Sarasota's Jungle Gardens to enjoy seeing many of Florida's most interesting animals and birds.

Finally, the Advisory Board created plans for their own e-letter – with their own content – to spread awareness about PWS and the Advisory Board's work. The first issue, planned for PWS Awareness month this May, will include:

- Their hopes and dreams for the PWS community.
- Answers to questions from the PWS community submitted via social media.
- Articles written by Advisory Board members and more. Stay tuned!

As always, we are very grateful for the time and energy the Advisory Board takes to help PWSA (USA). It is an outstanding group of people who represent the PWS community with pride and distinction. ■

**MAY 19-21  
2016**

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CASTING FOR A CAUSE  
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**Volume 41, Number 2 ~ March-April 2016 ~ Our 41st Year of Publication**

## 2015 PWSA (USA) National Conference Scientific Program

- Scientific Day Chair - Merlin G. Butler, M.D., Ph.D.
- Guest Speaker -- Sue Carter, Ph.D., Director of the Kinsey Institute, and Rudy Professor of Biology at Indiana University presenting on “*Review and Current Understanding of Oxytocin*”
- 15 Scientific presentations by meeting attendees

*Note: This is the second of a two-part series of a review of the presentations at the recent PWSA (USA) National Conference. The complete version of the PWSA (USA) 2015 Scientific Abstract Booklet may be purchased through the PWSA (USA) website shop section or calling 800-926-4797. Janalee Heinemann, M.S.W., Coordinator of Research & International Affairs, PWSA (USA)*

### **Inhibition of Histone H3K9 Methylation Unsilences Imprinted Prader-Willi Syndrome Candidate snoRNA Cluster**

*Yuna Kim<sup>1,8</sup>, Hyeong-Min Lee<sup>4,5,8</sup>, Yan Xiong<sup>6</sup>, Noah Sciaky<sup>5</sup>, Xinyu Cao<sup>1</sup>, Jian Jin<sup>6</sup>, Bryan L. Roth<sup>5,7</sup>, Yong-Hui Jiang<sup>1,2,3</sup>*  
*<sup>1</sup>Department of Pediatrics and <sup>2</sup>Neurobiology, <sup>3</sup>Program in Genomics and Genetics, Duke University, Durham, NC; <sup>4</sup>Department of Cell Biology & Physiology, University of North Carolina School of Medicine, Chapel Hill, NC; <sup>5</sup>Department of Pharmacology, University of North Carolina School of Medicine, Chapel Hill, NC; <sup>6</sup>Department of Structural and Chemical Biology, Department of Oncological Sciences, Department of Pharmacology and Systems Therapeutics, Icahn School of Medicine at Mount Sinai, New York, NY; <sup>7</sup>Program in Neuroscience and Division of Chemical Biology and Medicinal Chemistry, and NIMH Psychoactive Drug Screening Program, University of North Carolina School of Medicine, Chapel Hill, NC; <sup>8</sup>These authors contributed equally to this study*

**Introduction/Background:** Prader-Willi syndrome (PWS) is a neurodevelopmental disorder caused by the deficiency of human chromosome 15q11-q13. The loss of genes responsible for clinical features of PWS occurs at the paternal chromosome, while maternal copies remain intact but silenced by epigenetic modification. In this study, we aimed to identify the small molecules that can modify the epigenetic status of PWS imprinted domain and unsilence the repressed PWS candidate genes from the maternal chromosome.

**Conclusions:** Our study suggests the unsilencing effect of G9a inhibitors on imprinted PWS genes and the G9a-mediated histone modification as a target for PWS therapeutic intervention. ■

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### **The Loss of SNORD115 can be Compensated with an Oligonucleotide that Inhibits Food Intake**

*Zhaiyi Zhang<sup>1</sup>, Paul Gresch<sup>2</sup>, Ronald Emerson<sup>2</sup>, Stefan Stamm<sup>1</sup>*

*<sup>1</sup>Department of Biochemistry and Molecular Biology, College of Medicine, University of Kentucky, Lexington, KY;*

*<sup>2</sup>Department of Molecular Physiology & Biophysics, Vanderbilt University, Nashville, TN*

**Introduction/Background:** The loss of SNORD115 and SNORD116 expression contributes to Prader-Willi syndrome. Recently, we found that SNORD115 promotes inclusion of the

alternative exon Vb of the serotonin receptor 2C. This receptor forms at least 25 protein isoforms due to a combination of RNA editing and alternative splicing. Pre-mRNA splicing generates two isoforms, RNA1 and RNA2. RNA1 encodes a truncated receptor that is located intracellularly. Heterodimerization of the truncated receptor with the full-length receptor, encoded by RNA2, leads to a sequestration of the full-length receptor inside the cell, which switches off serotonin signaling. In the hypothalamic arcuate nucleus, the serotonin receptor 2C regulates food intake. PWS patients have more RNA1 than RNA2 in the hypothalamus, indicating a decrease of serotonin signaling.

**Conclusions:** The ratio of serotonin receptor 2C isoforms is regulated by SNORD115 and deregulated in PWS, as SNORD115 is missing. The deregulation of the serotonin receptor 2C isoforms impacts on food intake and likely contributes to hyperphagia. The strongest deregulation is seen in the pituitary, where the full-length form is absent, which could contribute to the low growth hormone levels, and possibly the elevated ghrelin levels. The serotonin receptor isoforms in the pituitary and the levels of SNORD115 in the pituitary are influenced by the feeding of animals, suggesting that the loss of SNORD115 exaggerates a natural ‘sensor-function’ of SNORD115. The loss of SNORD115 can be substituted with an oligonucleotide through injection, offering a treatment option for PWS. SNORD116 seems to use a similar molecular mechanism, but has more targets. It is possible that a combination of oligonucleotides could compensate SNORD116 loss. ■

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### **Prader-Willi Syndrome Genetic Subtypes and Clinical Neuropsychiatric Diagnoses in Adults in Residential Care**

*Nicolette E. Weisense<sup>1,2</sup>, Janice Forster<sup>3</sup>, Sheryl Ayala<sup>1</sup>, Ann M. Manzardo<sup>4</sup>, Waheeda Hossain<sup>4</sup>, Merlin G. Butler<sup>4</sup>*

*<sup>1</sup>Marian University, Fond du Lac, WI; <sup>2</sup>Prader-Willi Homes of Oconomowoc, LLC, Dousman, WI; <sup>3</sup>Pittsburgh Partnership, Pittsburgh, PA; <sup>4</sup>University of Kansas Medical Center, Kansas City, KS*

**Introduction/Background:** Prader-Willi syndrome (PWS) is a complex genetic disorder characterized by a range of mental, behavioral and physical findings. PWS results from

continued on page 3

### Scientific Abstracts, continued from page 2

loss of expression of paternal genes from the chromosome 15q11-q13 region under the control of an imprinting center. It is classified into three genetic subtypes: deletion, typically a paternal deletion of the 15q11-q13 region (about 70% of cases) comprising two forms (larger Type I or smaller Type II); non-deletion maternal disomy (UPD) 15 (about 25%) and imprinting defects (about 1-5%). Many adults with PWS are diagnosed based on clinical presentation and not genetic findings which limits opportunities for genetic subtype-specific psychometric investigations and treatment. Prader-Willi Homes of Oconomowoc, LLC (PWHO) is the largest USA-based group home system specializing in the management of PWS and the majority of residents have not been genetically confirmed. The goal of our study was to determine the PWS genetic subtypes in PWHO residents and characterize the relationship with neuropsychiatric diagnoses.

**Results/Discussion:** Psychotic features were present in 23% of participants. The total number of psychiatric diagnoses was inversely correlated with age among deletion subtypes with Type I deletion mean of 4.3 which was significantly greater than mean of 3.6 in Type II deletion when controlling for age ( $p < 0.03$ ). No other statistically significant differences in the rates of co-morbid psychiatric illnesses achieved statistical significance.

**Conclusions:** The results of our preliminary investigation of genetic subtype and psychiatric co-morbidity in PWS identified uniformly high rates of psychiatric co-morbidity in PWS with subtype-specific trends in psychiatric disorders. Confirmation and further characterization of clinical features and psychiatric co-morbidities related to PWS genetic subtypes will advance understanding of PWS-associated psychopathology, facilitate the development of genetic subtype-specific treatment protocols to alleviate distress and improve quality of life in PWS. ■

### Polyembolokoilamania in Prader-Willi Syndrome: A Case Series

*Janice Forster, Linda Gourash  
Pittsburgh Partnership, Pittsburgh, PA; Latham Centers,  
Brewster, MA*

**Introduction/Background:** Polyembolokoilamania is a behavior disorder characterized by insertion of foreign bodies into body orifices. Children who accidentally ingest represent the largest group with boys more than girls. Batteries and magnets present the greatest challenge for management. Body insertion among adolescents reflects risk-taking, attention-seeking and poor judgment. Adults with polyembolokoilamania are more likely to have a desire for sexual stimulation, mental illness, delusional hypochondriasis, factitious disorder or malingering. The authors present a case series of individuals with PWS who display symptoms of this disorder. Polyembolokoilamania can be a severe and life threatening

problem precipitating medical intervention, requiring a special skill set for management in PWS.

**Conclusions:** A comparison of this case series with the literature reveals that oral ingestion is also the leading form of polyembolokoilamania in this case series of persons with PWS. This underscores the risk for choking and gastrointestinal morbidity associated with PWS. In all cases, a team approach to behavioral programming is essential, involving EMS, ED, nursing, the psychiatrist, the person and their legal guardian. ■

### Transcranial Direct Current Stimulation Reduces Food-Craving and Measures of Hyperphagia in Participants with Prader-Willi Syndrome

*Ann Manzardo<sup>1</sup>, Albert Poje<sup>1</sup>, Gabriela Bravo<sup>2</sup>, Iago Perissinoti<sup>2</sup>, Bianca Marcondes<sup>2</sup>, Mauricio Villamar<sup>2</sup>, Laura Luque<sup>2</sup>, Jean-Francois LePage<sup>2</sup>, Diane Stafford<sup>3</sup>, Felipe Fregni<sup>2</sup>, Merlin Butler<sup>1</sup>*

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**Introduction/Background:** The dorsolateral prefrontal cortex (DLPFC) is associated with decision-making and appears to be a key structure in the regulation and processing of food motivation and satiety signaling. Transcranial direct current stimulation (tDCS) is an emerging technique utilizing a nine-volt radio battery to provide a safe, painless, inexpensive non-restrictive and non-invasive method to modify neuronal functioning through the application of a weak electric current to the scalp. tDCS applied to the DLPFC has been shown to influence cognitive processes and modulate decision-making including cue-induced food craving in healthy adults. We assessed the efficacy of anodal tDCS, applied over the right DLPFC, in the activation of inhibitory control pathways modulating food craving and hyperphagia in lean, obese and PWS participants.

**Conclusions:** PWS was associated with significantly elevated baseline hyperphagia rating scores relative to healthy-weight control (HWC) and consistent with the expected chronic severe phenotype associated with this disorder supporting the hypothesis of primary disturbances in cognitive and emotional aspects and food preoccupation in PWS. Obese participants showed deficits in baseline inhibitory control but were otherwise similar to HWC. The use of tDCS among HWC, obese and PWS participants was generally well tolerated. The results support sustained neuromodulatory effects and efficacy of tDCS to reduce food drive and behaviors impacting hyperphagia in PWS. tDCS did not appear to impact neuropsychological functioning or processing speed supporting the specificity for food motivated behaviors without disruptive effects on central executive functions. Transcranial direct current stimulation

continued on page 4

## PWSA (USA) Medical and Research View – Making a Difference!

Scientific Abstracts, continued from page 3

may represent a promising straight-forward, low risk and low cost method to improve care, management and quality of life in individuals with PWS. ■

### Effects of Growth Hormone Treatment on Intelligence Test Results and a Consideration of Genetic Subtypes in Prader-Willi Syndrome

June-Anne Gold<sup>1,2</sup>, Naomi Matthews<sup>2</sup>, Abhilasha Surampalli<sup>2</sup>, Marie Wence<sup>2</sup>, Virginia Kimonis<sup>2</sup>, Suzanne Cassidy<sup>3,2</sup>

<sup>1</sup>Department of Pediatrics, Loma Linda University, Loma Linda, CA; <sup>2</sup>Pediatrics Division Genetics and Genomics, University of California, Irvine, Orange, CA; <sup>3</sup>Pediatrics, University of California, San Francisco, San Francisco, CA

**Introduction/Background:** Although previous studies have shown a positive effect of early intervention with growth hormone (GH) treatment on body composition, energy and activity, it remains unclear whether GH treatment improves intelligence in individuals with PWS. The aim of this project was to examine intelligence in individuals with PWS in those treated with GH and those who have not received GH. Furthermore, we will compare those with maternal uniparental disomy (UPD) versus paternal deletion and treated with or without GH.

**Results/Discussion:** Comparison between the UPD and deletion subject groups revealed no significant difference in intelligence scores when comparing both genetic subtype groups. The cohort showed a significantly higher intelligence level in the GH treated group specifically in the vocabulary section of the Stanford-Binet test ( $p=0.02$ ), there was no significant difference

however in the other categories of the test. Age was evaluated and no statistical significance between the groups was seen.

**Conclusions:** Larger studies may determine whether GH treatment does affect the intelligence scores of those with PWS having the deletion or UPD genetic subtype. This is being examined more closely by the Rare Disease Consortium on Prader-Willi syndrome (RDCRN) in a larger cohort of well-characterized individuals with PWS. ■

### Improvement in Motor Proficiency in Youth With Prader-Willi Syndrome After 24 Weeks of Participating in a Home-based Physical Activity Program

Daniela A. Rubin<sup>1</sup>, Debra J. Rose<sup>1</sup>, Kathleen S. Wilson<sup>1</sup>, Lenny D. Wiersma<sup>1</sup>, and Marilyn Dumont-Driscoll<sup>2</sup>

<sup>1</sup>California State University Fullerton, Fullerton, CA; <sup>2</sup>University of Florida Gainesville, Gainesville, FL

**Introduction/Background:** In Prader-Willi syndrome, motor proficiency (Lam et al. 2013) and participation in physical activity (PA) are below average (Castner et al. 2014). This study aimed to determine if participation in a 24-week parent-led PA intervention improved gross motor proficiency (MP) in youth with and without PWS. Preliminary analyses are reported.

**Conclusions:** This parent-led game-based PA program resulted in positive changes in both components of gross MP in youth with and without PWS. Likely, the progressive nature of the games provided opportunity for the intervention group to practice and develop skills related to coordination. Participation in a skill-based PA program at home shows promise to improve MP in obese youth and in youth with PWS. ■

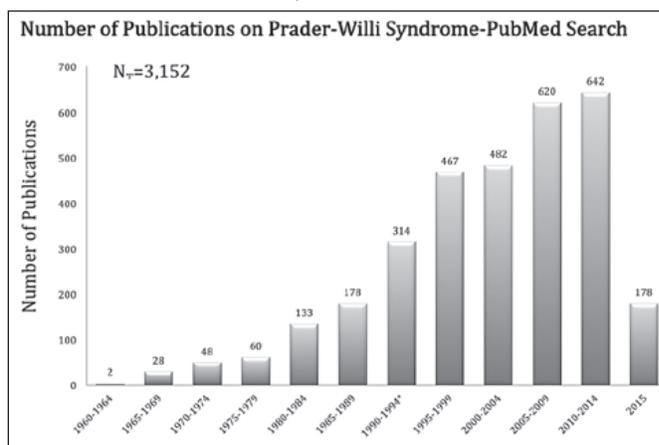
## Did You Know?

# Pediatric publications and Prader-Willi syndrome

A historical perspective of pediatric publications by Quinn et al. in 2013 (Pediatrics 132:406-412) reported on a bibliometric analysis of 497,240 peer-reviewed articles published in 191 journals dedicated to pediatrics between 1945-2010.

An article on Prader-Willi syndrome (PWS) was found to be the 53<sup>rd</sup> most cited (Holm VA, Cassidy SB, Butler MG, Hanchett JM, Greenswag LR, Whitman BY, Greenberg F. Prader-Willi syndrome—consensus diagnostic-criteria. *Pediatrics*. 1993;91(2):398-402).

The PWS article was cited 618 times with a range of the top 100 most cited articles between 2284 and 457 citations. ■



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

# Growth Charts for Prader-Willi Syndrome During Growth Hormone Treatment

By Bonnie L. Shelley, Ph.D., Coordinator of Medical Affairs, PWSA (USA)

Many of our readers are familiar with Dr. Merlin Butler, a geneticist, who chairs the PWSA (USA) Scientific Advisory Board. Dr. Butler is also one of the most published researchers on PWS in the world. We are pleased to share this abstract of his most recent work and published article. The author(s) disclosed of the following financial support or the research, authorship, and/or publication of this article: Prader-Willi Syndrome Association (USA) and the Angelman, Rett and Prader-Willi Syndromes Consortium.

**Abstract:** The purpose of the current study was to develop syndrome-specific standardized growth curves for growth hormone-treated Prader-Willi syndrome (PWS) individuals age 0 to 18 years. Growth-related measures for comparison of a person's size, form, and functional capacities were obtained on 171 subjects with PWS who were treated with growth hormone for at least 40% of their lifespan. They had no history of scoliosis. PWS standardized growth curves were developed for 7 percentile ranges using the LMS\* method for weight, height, head circumference, weight/length, and BMI along with normative 3<sup>rd</sup>, 50<sup>th</sup>, and 97<sup>th</sup> percentiles plotted using control data from the literature and growth databases. Percentiles were plotted on growth charts for comparison purposes. **Growth hormone treatment appears to normalize stature and markedly improves weight in PWS** compared with standardized curves for non-growth hormone-treated PWS individuals.

**Conclusions:** The recognition and

confirmed diagnosis of PWS in early infancy has led to the need to develop standardized growth charts to closely monitor growth before and during growth hormone therapy. The use of syndrome-specific growth charts is vital to optimize medical care and treatment not only during infancy but also later to improve quality of life and monitor clinical outcomes in PWS. Caloric intake and individualized exercise plans should be in place to maximize the impact

*The use of syndrome-specific growth charts is vital to optimize medical care and treatment not only during infancy but also later to improve quality of life and monitor clinical outcomes in PWS.*

of growth hormone therapy and assist the clinician and dietitian to avoid the onset of obesity and related medical co-morbidities. Syndrome-specific standardized growth charts can be used to guide the care and treatment in regulating growth hormone dosages and growth response, monitor orthopedic problems such as scoliosis or other clinical features related to obesity to meet the growing need to improve care and outcomes in PWS.

The authors encourage the use of these syndrome-specific standardized growth charts in those with PWS treated

with growth hormone from infancy to 18 years of age in the evaluation, follow-up and medical management of obesity and short stature, cardinal features seen in this rare obesity-related genetic disorder, as well as for comparison of others similarly affected in relationship to normative data. In addition, previous standardized growth charts for non-growth hormone-treated PWS infants and those between 3 and 18 years of age have been reported and in use clinically for the medical care and treatment of individuals with PWS. Some of the observations were interesting, particularly the final height and weight positive effects at 18 years as a result of GH treatment.

**References:** Butler M.G., Lee J., Cox D.M., et al. *Growth Charts for Prader-Willi syndrome During Growth Hormone Treatment*. Clinical Pediatrics. 2016, 1-18.

**Previous published research articles:** Butler M.G., Lee J., Manzardo A.M., et al. *Growth Charts for Non-growth hormone Treated Prader-Willi syndrome*. Pediatrics. 2015;135:e126-e135.

Butler, M.G., Sturich J., Lee J., et al. *Growth Standards of Infants with Prader-Willi syndrome*. Pediatrics. 2011;127:687-695.

\*Lambda-Mu-Sigma (LMS) is a popular method to obtain smoothed centile curves, particularly for cross-sectional data. These are commonly used to obtain percentile curves for various growth parameters in children. ■

## PWSA (USA) Phone App on all mobile devices!

Thank to the Settles family, enjoy freedom to browse any and all information on our website from the ease of using your phone app. Visit: <http://www.pwsausa.org/introducing-pwsa-usas-phone-app/> ■

# Call for Nominations for PWSA (USA) Board of Directors and Volunteers for Committee Service

The source of PWSA (USA)'s strength lies in its membership - parents, extended family members, professionals, and others committed to promoting research, education, and support for families affected by Prader-Willi syndrome.

We are currently seeking candidates for the 2016-2019 Board of Directors and volunteers for Committee service. We have specific needs for talented individuals in the areas of:

- Finance
- Fundraising
- Public relations/marketing

Board and committee membership is open to family members and interested professionals.

Please contact us if you or someone you know possesses the qualities necessary to be an effective Board of Director:

- Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group
- Membership in PWSA (USA)
- Commitment to serve a 3-year term (unless nominated to fill a shorter term)
- Willingness to attend Board and committee meetings and other special events; ask questions; take responsibility for a given assignment; support the Association as generously as your financial resources allow and assume shared responsibility for generating resources to meet Association goals; open doors in the community
- Possess willingness to learn skills such as understanding financial statements; cultivating and soliciting funds; cultivating Board members and other volunteers
- Possess honesty, sensitivity to and tolerance of different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a sense of values; concern for the Association's development; a sense of humor

### What will you gain in return for your service?

- A sense of pride as you work to better the lives of all persons affected by PWS
- Input into decisions and policy-making that affects persons with PWS
- Increasing your knowledge about PWS and its treatment and management strategies
- Increasing your exposure to professionals who work with individuals with PWS

To nominate yourself or someone else, please contact Leadership Development Committee Co-Chairs Lisa Graziano or Tammie Penta via the PWSA (USA) office at 800-926-4797 or 941-312-0400 or [info@pwsausa.org](mailto:info@pwsausa.org) or by fax to 941-312-0142. *The deadline for nominations is May 15, 2016.*

*To continue to grow as a vibrant, effective organization, PWSA (USA) also needs volunteers for fundraising, advocacy, and family and research support, among other areas. If you are able to free up time to help, please email us at [info@pwsausa.org](mailto:info@pwsausa.org). There is no deadline, as volunteers are always welcome. ■*

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## Ann Siegel: Volunteer and Friend



Have you been to the National office on a Friday morning? If so, you may have met Ann! Married for over 60 years with four sons (one deceased), nine grand- and five great-grandchildren, Ann was born and raised in Brooklyn, New York. Residing in Connecticut for over 45 years, she and her husband, Jerry were snowbirds to Sarasota for five years; full-time residence in Sarasota began two years ago.

Having a son with learning disabilities and later diagnosed with Asperger's syndrome, Ann became very involved with disabilities groups, spending 30 years with the Learning Disabilities Association, serving on boards at local, state (as chairman) and national levels. She returned to college for a Master's degree in special education and was a resource teacher and parent advocate for ten years.

Ann and her husband became owners of a condo on Midnight Pass Rd. in Sarasota. Never one to sit still, on a 10-minute walk from their condo, she noticed the PWSA (USA) office and recognized the name. Ann stopped in, met Janalee (then Executive Director) and offered to volunteer; that was 15 years ago. Since then, Ann is the Friday a.m. volunteer and has enjoyed mutual support of staff and a pleasant environment to donate her time and talents.

On the go, Ann has four different morning volunteer jobs; Wednesday is her day off! When not working as a volunteer, her "retirement" hours are spent on sewing and quilting projects for the local Red Cross, a local quilt guild, and cancer support groups.

PWSA (USA) is so grateful and appreciative of Ann's years of service for the organization. ■

## Organization News

# Kate Beaver: 10 Years of Making a Difference



By *Evan Farrar, M.A. Crisis Intervention and Family Support Counselor, PWSA (USA)*

In 2007, when I first began working for PWSA (USA), I'd never heard of Prader-Willi syndrome (PWS). I knew if I was going to learn to be effective in helping the PWS community, I would need good teachers to help me along the way. One of my best teachers from the start was Kate Beaver, who this year celebrates her 10th anniversary as a PWSA (USA) Crisis Intervention and Family Support Counselor.

When Kate joined PWSA (USA)'s staff, as a parent of a child with PWS, she brought with her an enormous knowledge of how PWS impacts people with the syndrome, their families, and the support professionals who work with them. In addition, she also brought to this job the professional training she earned with her Master's of Social Work (MSW) and extensive experience working in other social service settings. So Kate brings the best of both worlds – personally and professionally - to the important task of serving families in the PWS community and enhancing the Family Support Program at PWSA (USA). Over the years, she's helped transform the lives of many people living with PWS and their families and PWSA (USA)'s ability to deliver services in new and creative ways.

During this time, I've observed and appreciated Kate's many clinical skills as a very effective counselor. Her organizational gifts, her ability to conceptualize cases, formulate and implement support plans, approach parents and families non-judgmentally, and offer a supportive person-centered presence

are exceptional qualities she has consistently demonstrated. She also is able to remain calm in a crisis and help families and professionals in a way that encourages creative and successful problem solving. Most importantly, I always know when a family is working with Kate they are in good hands.

In addition to working directly with families, Kate's served as an integral part of our Family Support team helping us to craft new family support initiatives in a range of areas including working with providers of services, managing behavioral issues in all settings, and enhancing our ability to support families and professionals with a range of school issues. Kate has also authored some of our most significant written resources – including the groundbreaking book she recently co-authored with Barb Dorn to help parents and professionals with the crucial task of helping young people with PWS successfully transition into adulthood.

Serving as a Crisis and Family Support Counselor with PWS is a unique job. It is a job I've never done without working with Kate. Over the years, we've spent countless hours talking about cases, sharing strategies, discussing new resources and programs and – as important as any of these – offering personal and professional support to each other as we navigate the sometimes very challenging terrain of helping to assist children and adults with PWS who are in crisis. For me, knowing we are there for each other is one of the best parts of this job. I've often told Kate I can't imagine working at PWSA (USA) without her. This remains true! So, while we celebrate her 10<sup>th</sup> anniversary with great joy and thanksgiving, I also look forward to continuing our work together.

In closing, I don't want to miss this important opportunity to say thanks to Kate for all she's done for the families we serve, the PWS community, and for me.

**Happy 10<sup>th</sup> Anniversary, Kate!** ■

## International View

# Save The Date- Ninth IPWSO Conference



**July 20-24,  
2016  
Toronto,  
Ontario**

Every three years, IPWSO holds an international PWS conference held in a member country. IPWSO conferences are unique! Scientists, researchers, psychiatrists, psychologists, geneticists, endocrinologists, physicians and all other

medical professionals are our delegates. Jeremy Veenstra-VanderWeele, M.D. is the keynote speaker. Dr. Veenstra-VanderWeele is the Mortimer D. Sackler, M.D., Associate Professor of Psychiatry at Columbia University, the New York State Psychiatric Institute, the Sackler Institute for Developmental Psychobiology and the New York Presbyterian Hospital Center for Autism and the Developing Brain. Professional caregivers and residential managers, parents, teachers caregivers, relatives and friends attend. Children, babies, and adults with PWS, their siblings, and volunteer caregivers all

enjoy IPWSO's fantastic international conferences.

This conference (hosted by the FPWR) in Canada will offer the latest research presented by scientists, the best possible strategies to help parents, caregivers and teachers support the person with PWS, and a platform for professional caregivers and professional residential providers to meet and expand their already internationally acclaimed "Best Practice Guidelines for Residential Care". ■

**To register:** <http://bit.ly/1OUJua9>

**To learn more:** <http://bit.ly/1MVStKF>



## Events

FL	OTM WALK	5/1
WI	OTM WALK	5/7
IL	I HEART MOMMA TRAIL RACE	5/8
MI	OTM WALK	5/14
IN	OTM 5K	5/14
MN	GOLF SCRAMBLE	5/20
UT	OTM WALK	5/21
MA	HUNTER LENS GOLF TOURNEY	6/4

Don't see an *On the Move* event in your area? Why not host your own! *On the Move* events aren't just for chapters. Many individuals have hosted very successful events in their local areas. So why not give it a try! We will help you throughout the entire process. An *On the Move* event can take place ANYTIME of the year and can be anything from a walk or golf tournament to a dress down day at your child's school. Help us spread awareness while raising funds. If you are interested in hosting an event, please contact Leanne Gilliland at 941-312-0400 or lgilliland@pwsausa.org. ■

## Other 2016 Chapter Events

IN	PIRATES GAME IN INDIANAPOLIS	4/2
IN	BOWLING FUNDRAISER	4/16
CA	SOUTHERN CA WALK	4/24
WI	DR. ANN SCHEIMANN PRESENTATIONS	4/29
CA	NORTHERN CALIFORNIA SUPPORT GROUP	4/30
NY	STATE CONFERENCE IN ALBANY	5/13-5/14
NY	GOLF FOR PWS IN MT. SINAI	5/16
IN	MIDWEST CONFERENCE - INDIANAPOLIS	October



Kyle and Kayla

## The Snowflake Ball

PWSA-WI, Inc. hosted their Fifth Annual Snowflake Ball Saturday, January 30, at Turner Hall in Watertown, Wisconsin. The blue and silver decorations, some made personally by those with PWS, created a winter wonderland. Over 230 people attended the Ball, dressed to the hilt, ranging from ball gowns to tuxedos. Corsages and boutonnieres, made with love by PWSA-WI, Inc. board members, were proudly worn by individuals with the syndrome, along with their siblings. Twenty-five amazing volunteers helped serve a delicious sit-down dinner, with a special toast given by the organization's vice president. Following dinner, the real fun began...DANCING! Favorites such as the *Locomotion*, *Uptown Funk* and *YMCA* got everyone to their feet and brought smiles to everyone's faces. Friendships old and new were enjoyed and made. This special evening was magical. We're already looking forward to next year! ■



The Gaulke Family

## 2016 eWalk



Have you ever wanted to plan an event to raise money for Prader-Willi syndrome but just never have had the time to do so? We have great news!! *eWalk* is just the thing for you! Now within minutes, you can start raising awareness and funds by reaching out using social media and other online communications. It's fast, easy and fun! Just go to <https://www.firstgiving.com/pwsausa/2016-ewalk> and click register. Fill out a few simple steps and easily create your own fundraising page. Now all you have to do is share your page with everyone you know on social media and by email. All someone will have to do is click on your post and donate to your page. It's that easy! If you have any questions, please contact Donny Moore at 941-487-6729 or email: dmoore@pwsausa.org. ■

## eWalk/On The Move Webinar

PWSA (USA) introduces a new webinar! It features Evan Farrar, our Family Support Counselor, Lori Moline, our New Parent Support Specialist and Diane Seeley, our New Parent Support Coordinator. They went into great detail explaining all the important services we provide to our community, future services, and how important fundraising is towards continuing providing these lifesaving services. Listen to Donny Moore and Leanne Gilliland of the development team, discuss the fundraising options PWSA (USA) provides. Learn how you can become a part of a successful event. Our team can help you every step of the way! Haven't seen the webinar yet? Visit our Facebook page <https://www.facebook.com/PWSAUSA/?fref=ts> or website <http://www.pwsausa.org/>. If you have questions about the webinar or fundraising, please contact Donny Moore or Leanne Gilliland at 941-312-0400. ■

## The Silver Lining

By John Carey

Audrey is my granddaughter, the sweetest 7-year-old you could ever know, with bright blue eyes, hair of gold and a heart to match. She also has Prader-Willi syndrome. On a July morning during 2011, a month after Audrey turned four, my wife and daughter sat me down and said, “We have something to tell you.” My immediate reaction was “It’s about Audrey, isn’t it?”

Prior to this time, I was led to believe only that Audrey was born with low muscle tone. This was quite evident, as I knew my daughter was using a feeding tube when Audrey was an infant. Later I knew of the low dose shot of Human Growth Hormone (HGH) my daughter administers to Audrey’s upper leg each night.

Other symptoms I became aware of when Audrey was about three were her appetite, cleaning her plate of food, her twirling endlessly a little set of toy spoons on a key ring, and the slowness of her speech to develop.

Christmas 2008 was our turn to have my sister and her family over. Audrey was a year and a half and had only begun to crawl a few months earlier. Her cousin Sean, born around the same time as Audrey, was already walking. I noticed Audrey crawl off to the den, and I followed her. As I watched, I saw her make a valiant effort to stand. Her weak muscle tone, however, sent her back down on all fours. I quickly scooped her up in my arms. She put her arm around my neck, smiled and seemed to say, “It’s OK, Pop-Pop; I’ll get there.” Sure enough, a few months later, Audrey was walking.

Nothing, however, prepared me for that July morning when my wife and daughter informed me of Audrey’s genetic defect. Their reason for keeping this secret from me was simple and appreciated. Why give me additional years of concern when it wasn’t necessary?

Audrey is such a caring and sharing child. She seems to get more enjoyment from serving food to her older sister Hannah (11) and younger brother Thomas (5) before eating herself. One night I said I didn’t feel like cooking and suggested we order out; Hannah and Thomas were upset, but Audrey with concern on her face, asked, “Are you OK, Pop-Pop?” All three children are a blessing to our lives, and, as many have said, the nearness of grandchildren is the principal benefit of growing old.

The low muscle tone also affects Audrey’s speech. At school she uses an electronic device that aids her in forming her words. With each year her speech continues to improve. Well loved at school, she attends the Applied Academics Classroom with children with other disabilities. A class picture of her leaning over and embracing her friend confined to a wheelchair is etched in my mind.

This afternoon my wife and I have been watching Audrey, and now it’s time to take her home. My trip will encompass 10



miles through typically beautiful New England countryside featuring gently rolling hills, white steeple churches and red barns.

It’s near the end of September. Some trees are starting to turn color and soon will be aglow in the copper, red and golds that only a New England autumn can provide. A chilly light rain is falling, and I know Audrey will nap in the car, what she calls her “baby shush.” Not more than two blocks from our home and already she’s fast asleep. I reach across the console and place my hand on hers and squeeze lightly, my aging hand showing the wrinkles of time on top of her soft young skin.

As the rain continues to fall, I squeeze a little tighter and fall deep into thought.

“Audrey, life has not dealt you a level playing field. It will present you with a challenge each and every day. I’m sure with your kind heart and happy spirit you will accept that challenge and succeed. No one can tell what the future holds, honey. Medical breakthroughs are always possible, and I pray you can live as close to a normal life as possible. I’m not the one to say how long your Pop-Pop will be around to share my life on earth with you, but one thing is certain, my darling child, my spirit will feel your every breath, be your every heartbeat, and I will go on loving you forever and ever. You are all that is good about life.”

Now the clouds have passed and a lovely sunset is forming, the setting sun casting a celestial golden glow to the surroundings, the distant clouds encased in a heavenly silver lining.

Audrey, c’mon, wake up sweetheart, we’re home. ■

## Executive Director View

There are many exciting changes that have come recently to the newly designed Family Support and Medical sections of the PWSA (USA) website, and we want our members to know about them! Bookmark and visit regularly as new content is added frequently and information is constantly being updated.

A click on **Family Support** takes you to a wealth of information about common issues and concerns for families with a person with PWS from birth all the way through adulthood. Its pages include topics such as Positive Behavioral Support, Weight Management, and Residential Placement.

Let's take School Issues as an example. A click takes you to resources like Info for School Staff, Food Security in the Educational Environment, and Information for School Transportation, many of which can be printed out, plus links to other helpful information and a video on Tips for Teachers that you can watch.

In addition, it outlines the ways our

Family Support Counselors can assist you. If you feel the need for more information or assistance, person-to-person help is available through our highly trained Family Support Counselors, Monday through Friday, 10 a.m. to 5 p.m. EST, at 1-800-926-4797.

A page dedicated to Adult Issues including employment, placement and more is in the works to be added soon.

A click on **Medical** takes you to a page, which has Medical Issues from A to Z – Anesthesia to Water Intoxication. No “Z” yet! This includes most of the text of the small Medical Alert booklet which should be in everyone's glove compartment — plus more items not listed in the Alert. New information is added as it becomes available. The page also has a list of Physician Resources.

Then there is the **Shop**, where you can order Accessories, Apparel, Books and Publications, and CDs and DVDs. Do you want a book on, say, siblings, or nutrition

for children, or for grandparents? They're all there! There are logo items from \$1.00 post-it notes, \$3.00 pens to books on PWS to \$45.00 iPad Smart Covers—and lots in-between!

Last but not least, there is now a **mobile app for your iPhone or Android**. You can download the app from the App store, which will then allow you to download information from the whole website on your phone. The app allows you to easily navigate around different sections that work off our website so you can quickly get the information you need and want. You will also receive special updates on research, crisis support, fundraising, medical and any other important information we have to share.

Now you know! Go to: [pwsausa.org](http://pwsausa.org) and browse. Find the information you want or need – and use it! ■

~ **Ken Smith, Executive Director**  
**PWSA (USA)**

## Personalizing Your Medical Alert Booklet

By **Barb Dorn, R.N., B.S.N.**

Do you worry that all members of your family do not know the health needs, medications, allergies and other health information for the person with PWS? Does the person with PWS ever stay with other family members or come for a visit and people may not be able to accurately inform or educate about important health information in case he/she requires medical care? Do all parties have a medical alert booklet at their fingertips? If the answer to any of these questions is no, consider the following recommendation.

Recently, my son Tony with PWS had an overnight visit with his brother in a different city. I got to thinking, if Tony needed medical care, did his brother have the necessary information to inform and educate the health care provider about his medical needs including his current

medications and allergies? The answer? NO!

I took steps to make sure that in the future, everyone was equipped with this important information – including myself. I purchased four newly revised Medical Alert booklets from PWSA (USA). In the blank pages at the end of the booklet, I created several charts that included the following information:

- List of Tony's current medications and medical problems
- Tony's allergies AND type of reactions
- Immunization Record
- Contact information for all of his physicians and specialists
- Contact information to his home and his parents/guardians

These charts and information were taped to the blank pages at the end of the booklet. I placed each booklet in a sealed bag. I shared a booklet with each person who might have Tony for



an extended visit. The Medical Alert booklet now included personal information about Tony as well as information to educate any health care professional who needs education about the health concerns associated with PWS.

The challenge will be to keep this information up to date. Fortunately, Tony does not have many medication changes. All this information is on my computer. Parents and others can easily write this information on the blank pages and update as needed. This personalized booklet may be helpful to parents who are divorced and share custody of the person with PWS. It may also be helpful to parents and/or family members when they bring their loved one on a home visit. (When you are not giving the medications on a daily basis, you may not recall all medications and/or their dosages). This is a simple strategy to help others who want to make sure we **ALL** have health information available, just in case it is needed. ■

# Texas Prader-Willi Association

By Tom Noonan, member, Board of Directors, PWSA (USA) and June Finnerty

The Texas Prader-Willi Association (TXPWA) was founded in 2009. A consolidation of small parent groups from around Texas including Lindi Kessinger, Jan Rosenfeld, and Cheri Wood, from the Tyler area, who consulted with leaders from other states, researched by-laws, organizational and mission statements, and attained its non-profit status. Our mission was established to 'improve the quality of all lives affected by PWS' by providing education, respite, crisis intervention, and inroads towards residential living.

TXPWA held a successful, well-attended 2010 conference in Houston. Expert speakers addressed resources available, behavioral interventions, housing, diet, etc. A second conference, the Texas Roundup in 2013, was a sell-out. Many in the group held a long-term goal of providing a Prader-Willi-specific camp to give our kids a true camping experience while providing respite for the parents, and especially the siblings. The first fundraiser, a 2011 golf tournament sponsored by Molly's Pubs, Houston accomplished this. With a goal of raising \$10,000, a week before the tournament we'd barely accumulated \$3,000. With a final push, \$34,000 was raised! Finding the camp proved more challenging. Luckily, Cheri Wood found a camp that would accommodate our very specific needs, and we provided our own nurse. TXPWA's sixth *People With Smiles* Camp to be held July 8-10, 2016 at Peaceable Kingdom Retreat. Camp is open to any person with PWS over the age of eight.

Two 2016 fundraisers are planned. First, the sixth annual the Molly's Pub Charity Golf Tournament and charity auction benefiting the TXPWA is Monday, May 16th, at the

Cypresswood Golf Club in Humble. Later in the spring, Alana Finnerty, an older sibling of a child with PWS, is planning an *On the Move* walk in the Fort Worth area with her sorority.

With only one residential home previously servicing PWS in Texas, Cheri and Lindi were successful in starting a PW specific home Longview. Pace Opportunity Centers Inc., a provider of services to individuals with intellectual and developmental disabilities since 1985, has developed an active treatment facility and beautiful environment for people with PWS in the Piney Woods of East Texas, just North of Longview. This six-person Intermediate Care Facility (ICF) was developed on a five-acre plot with its own dayhab, walking trail, large covered sports/recreation communal area, greenhouse, and circuit exercise gym. Two more Home and Community-Based Services (HCS) homes are in Longview, which have dayhab at this facility. The focus of this program is to provide a safe, fun environment for those who need consistent supervision of their intake and access to food, and to provide specialized staff trained to care for this special needs population.

Another state support here is Rock House Support Services. Since 1979, Rock House helps individuals with IDD with a goal for them to live as independently as possible. The Eastland location currently serves over 20 individuals with PWS in ICF/ID and HCS group homes. In 2013, their Georgetown location began specializing in PWS as well, with specialized training for staff and professionals to learn about the dangers/special needs of one with PWS. Admissions can be accepted without an IDD diagnosis, as PWS is a related condition.

continued on page 12

*Our mission was established to 'improve the quality of all lives affected by PWS' by providing education, respite, crisis intervention, and inroads towards residential living.*



Addressing legislative issues in our state is a full-time job. Obtaining resources and having PWS recognized by the State like in other states is an ongoing challenge. Cheri Wood is our legislative person and is on a first-name basis in Austin!

The HealthBridge connection to our association is very strong. Chris Elem, the Program Director at HealthBridge Children's Hospital, is a board member and almost all of our board has had a child spend time in the Prader-Willi program there. Chris works directly with parents to get their children admitted and get the help they need in the complex aspects of weight, behavior, and medication management.

The current TXPWA Board of Directors are: President: Tom Noonan, Keller, TX, Vice President: June Finnerty, Spring, TX, Treasurer: Faye Westwood, Richmond, TX. Board members are: Jan Rosenfeld, Tyler, TX, Chris Elem, Houston, TX, Jennifer Arcaya, Austin, TX, Ashley Banks, Austin, TX, and Cindy Yelverton, Houston, TX. For more information, please go to: txpwa.org. Our website (being updated!) is designed to reach out to all families in Texas coping with PWS. ■



## Every Person Matters

### Register Now Global Prader-Willi Syndrome Registry

If you are a parent or guardian of a person with PWS, join the movement today to build the Global Prader-Willi Syndrome Registry by visiting [www.pwsregistry.org](http://www.pwsregistry.org) ■

**Become a part of the world's largest PWS advocacy community.**

**Join our family!  
Become a member today, go to:  
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### **PWSA (USA) Member Benefits include:**

- 20% discount on merchandise
- *Gathered View* newsletter
- Members only online access
- Webinar registration discount



## The Resource Challenge

*By Kathryn Lucero*

I have been told for many years that change is good and one should strive to allow change into their lives. For me, I do not deal well with change, which is somewhat strange considering my son has Prader-Willi syndrome. In early January 2016 a big change occurred; my husband was offered a wonderful job opportunity. We did not have a lot of time to decide if this was going to be a good fit, so I did what any parent of a special needs child would do; I began researching resources in this possible new place we will call "home." I have come to realize that there is no easy way to find resources, however tapping into resources that we already know are priceless. I first contacted a college friend who has a special needs son with sensory processing disorder. From there the journey to resources started. She connected with friends who provided me with recommendations. During this time, I contacted the PWSACO Chapter, who connected me with the Children's Hospital along with some wonderful parents that I had the opportunity to speak with on the phone. One thing I have learned is that you have to follow up with people if you want something done. Don't just think it is getting done because it's probably not. I have been worried about Ronan's Early Intervention services and am waiting for a call back. Fingers crossed they have had a lot of new patients and not that they have set his paperwork aside. Looks like I may be making some phone calls...

This journey has not been easy and it is far from being over with getting things set for Ronan when we get there. So when they say it takes a village they are not kidding! I am trying to be excited about this change that is about to occur, but one thing I can say is that I am looking forward to a new journey with my family.

*Editors' Note: Every day can be a challenge, some are better than others. I look forward to hearing from Kathryn and how her family is settling into their new environment. ■*



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# 125

I believe too often we underestimate children.

Let me explain.

As part of Nick's transition to his new school, it was agreed that a PWS presentation would be offered to his entire 8th grade class. This, I believed, was important so fellow students could understand how to relate better to Nick.

The idea arose from the inclusion success we experienced last year at his previous school. You may recall Nick's sixth grade teachers asking me to speak to their students about inclusion and the tremendous response that occurred once the children were enlightened. To learn more, read here. <http://onalifelessperfect.blogspot.com/2013/11/a-sixth-grade-introduction-to-prader.html>

Nick's new school however, was not interested in allowing me to speak to their kids. In fact, parental involvement has always been vehemently discouraged in this school district. So instead, it was suggested a PWS "expert" present the show. I decided it really didn't matter who gave the discussion, as long as the children were educated, so I agreed.

A speaker was hired and scheduled to visit the school in November. A letter was sent out to parents informing them of the upcoming assembly and providing an opportunity for those students who were not interested to opt out.

A few days before the big event, I received a call from the special ed coordinator. She informed me that the "expert" expressed deep reservations about speaking to middle school children. She feared that students at this level would not want to help. She feared that Nicholas would be bullied.

Since this was an "expert" making these statements, the coordinator canceled the speaking engagement and begged me to reconsider my request.

I used only one word to answer her: NO.

I told her "the so-called expert" seriously underestimated these students.

I told her I knew this because I had done this before. I had spoken to teens about inclusion and experienced spectacular results. I described how last year's students became enthused about inclusion and wanted to help. I told her how several teens expressed how they were no longer afraid and appreciated learning about how to relate to children diagnosed with special needs. I told her how the experience moved students, teachers, and administrators to embrace change.

Still, she did not believe. "Middle school children are different," she said.

"No," I argued, "They will surprise you."

She disagreed. But since my request was written up as part of Nick's IEP, she had no choice but to comply.

She agreed to move forward but requested that SHE give the presentation. She asked to use the PWS PowerPoint slides I had presented to the staff. She asked if I would attend the assembly as her assistant, there only to answer any medical questions.

But I had no idea how well she could speak.

The PowerPoint presentation was my baby, my blood, sweat and tears. Would she do it justice? Did she have an ability to connect with an audience, particularly one she didn't trust?

I was worried. When suddenly I was struck by an idea.

I realized I had a chance to enlighten not just the children but this "nonbelieving" special ed coordinator too. I couldn't resist. "Let's do it!" I told her.

The big day arrived. The coordinator was nervous. I told her not to worry and that she would be pleasantly surprised by the students' response. I told her she was about to change the world.

Still, she did not believe.

We entered the empty auditorium where the PowerPoint projector was prepped and ready for our use. Unfortunately, however, the remote control to change the slides was missing.

Luckily, the assistant principal entered the room. I asked her if she or one of the 8th grade teachers could kindly help us to switch slides?

She laughed in my face at my audacious request and told me that I should be grateful they were attending at all. It was clear from her tone that the teachers were NOT interested in this inclusion presentation. They were not convinced that this would work and resentful to be asked to participate in such a ridiculous farce.

I ignored her behavior and told the coordinator I would switch the slides.

Slowly, the students began to enter the auditorium. They were excited and animated, speaking loudly among themselves. More and more students arrived, filling the room to its capacity, most of them sitting directly up front. Nicholas and I were seated before the crowd.

The assistant principal stood beside us and held up her hand, "Quiet down," she barked, "We are here today to learn more about one of our new students".

The boisterous crowd became silent.

continued on page 14

The coordinator who was standing quietly behind the podium, began to speak. She was nervous and spoke very softly. In an effort to finish, she breezed through the slides too quickly.

I began to worry that she was losing the audience, neglecting to pause after each slide to give the crowd a moment to reflect.

But the presentation was filled with powerful images and it appeared that folks were listening.

“Sometimes real superheroes live in the hearts of small children fighting big battles”.

She finished the show in record speed and asked, “Does anyone have any questions?”

There was complete silence. No one moved.

The coordinator’s shoulders sank, her worst fears realized, the kids, she believed, were not ready for this.

The assistant principal smiled smugly.

But I knew better.

I sprung from my chair to speak directly to the children.

“I know what you’re thinking. This is scary stuff. I was scared once too. And I am Nick’s mother. But right now we have an opportunity, a chance to learn all about this frightening stuff. In fact, once you ask your questions, I am sure you will find that it’s not so scary after all. You will find that Nick is the BEST friend you could ever have. He will not talk behind your back. He will never say an unkind word. He will ALWAYS be happy to see you. So, please raise your hands and ask the questions you want to ask.”

I looked beside me and asked Nick if he wanted to say anything to the children. He smiled and turned his head to the side, telling the kids,

“Aw Mum, I’m too shy.”

That was all it took. One by one, a few hands went up.

The coordinator, using a microphone, walked over to the students and asked them to speak their questions directly into the hand piece.

“Will Nick always have this?” A brave boy asked.

“What is a seizure?” another one said.

“Where is Nick’s classroom located?”

“Is he coming with us to Camp Kiev?”

And pretty soon a sea of hands shot up from the crowd, a mighty collection of boys and girls, all wanting to know more. The coordinator ran from one side of the room to the other trying to keep up with all the questions. The students were motivated and engaged, anxious to learn exactly how they could help Nicholas.

I was surprised to see a few teachers raise their hands.

The assistant principal’s jaw dropped open wide as she stood speechless beside me.

Soon, we ran out of time. The bell rang to signal the end of our time together.

The coordinator announced loudly to the students that before they left, there was a sign-up sheet located up front for anyone who was interested in visiting Nicholas in his classroom.

In one collective movement, all of the students rose and headed toward the front. No one left.

Lines and lines of giggling students clogged the aisle-ways.

All of them interested in one thing, getting to know Nick.

The response was overwhelming.

The coordinator and assistant principal scurried out of the room to rustle up more pens and paper so more children could enlist.

What was immediately noticeable, at least to me, were the smiles on the students’ faces.

The kids, I believe, were inspired, hopeful to have an opportunity to make a difference and become empowered.

It was a beautiful bonding experience for the entire room of participants. The energy was electrifying.

Surprisingly, on the face of the special ed coordinator....a tear.

I thanked her for her bravery.

The very next day, I received an email from her. She told me that a boy she did not know approached her in the hallway and said,

“Nice speech!”

She told me the assistant principal made a special effort to describe the energized climate at the staff meeting held shortly after the presentation. At the meeting the teachers were inspired and exuberant, anxious to discuss ways of including Nicholas into their classes.

And the number of students who signed up to come visit Nick’s classroom you ask?

125. ■

*This story was written and shared by Lisa Peters. Her blog chronicles of her family life raising two children, Nicholas 13, diagnosed with Prader-Willi syndrome and Weston 16, diagnosed with Autism/Asperger’s/ADHD.*

<http://onalifelessperfect.blogspot.com/>

Thank you Lisa. – Editor



My son Jonathan age 6 when asked by his doctor during a check up “can you show me where your heart is, Jonathan, so I can listen to it?” says to the doctor: “you are the one who went to medical school; you show me where my heart is.” The doctor was cracking up and so was I!

*-Marina Jones, Perry, Georgia*

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

**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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- Sue Myers, M.D., St. Louis University, St. Louis, MO
- Todd Porter, M.D., M.S.P.H., Children's Medical Center, Denver, CO
- Douglas Rose, M.D., Cincinnati Children's Hospital Medical Center, Cincinnati, OH
- Ann Scheimann, M.D., M.B.A., Johns Hopkins School of Medicine, Baltimore, MD
- Harold J.P. van Bosse, M.D., Shriners Hospital for Children, Philadelphia, PA
- Barbara Y. Whitman, Ph.D., St. Louis University, St. Louis, MO

**Liaison Members**

- Suzanne B. Cassidy, M.D., Scientific Advisory Board
- Janalee Heinemann, M.S.W., Coordinator of Research and International Affairs, PWSA (USA), Vice President, IPWSO
- Ken Smith, Executive Director, PWSA (USA)

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- Kate Beaver, PWSA (USA), Sarasota, FL
- Patrice Carroll, Latham Centers, Brewster, MA
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- B. J. Goff, Goff Associates Disability Consultants, Springfield, MA
- Kim Stevens, Volunteers of America, Tulsa, OK
- Mary K. Ziccardi, REM Ohio, Inc., Valley View, OH

**Special Education Advisory Board (SEAB)**

- Chair** - Amy McTighe, Tammie Penta
- B.J. Goff, Mary K. Ziccardi
- Tanya Johnson
- Liaison Members:** Kate Beaver, PWSA (USA) Family Support Counselor
- Jennifer Bolander, PWSA (USA) Special Education Consultant
- Tom Conway, PWSA (USA) Board of Directors
- Evan Farrar, PWSA (USA) Family Support Counselor

**Adults with PWS Advisory Board**

- Shawn Cooper, Georgia
- Conor Heybach, Illinois
- Lauren Lange, Georgia
- Abbott Philson, Maine
- Brooke Fuller, Michigan
- Kate Kane, Maryland
- Andy Maurer, South Carolina
- Trevor Ryan, California

## e-News...

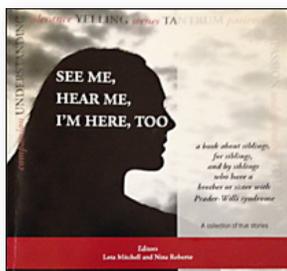
Reminder – stay informed and stay current with PWSA (USA)'s free e-News. Sign up today at [www.pwsausa.org](http://www.pwsausa.org) and watch for the next update full of great info.

## The Sibling Book: See Me, Hear Me, I'm Here Too

*Edited by Lota Mitchell and Nina Roberto*

Brothers and sisters growing up with an individual with PWS have unique challenges. *See Me, Hear Me, I'm Here, Too*, is "a book about siblings, for siblings and by siblings who have a brother or sister with Prader-Willi syndrome", and emphasizes that they are important, also.

Unlike a smaller collection of stories written by siblings in the *Packet of Hope* for parents of newly diagnosed, this 76-page resource is invaluable. Stories specifically look at how it affected some writers as children and, in many cases, as adults. It considers the benefits as well as the negatives, and offers what was (or is) helpful to them. This book includes priceless, experienced advice to other siblings and parents. Parents, too, have unique challenges in this situation, and will find useful tips for them. The book addresses what information an adult sibling needs if the primary caregiver is no longer there, and the question of should siblings be genetically tested. A siblings section also writes about when the brother or sister with PWS has died. To purchase (\$15 ea): <http://www.pwsausa.org/product/see-me-hear-me-im-here-too/>



## Join the Fun for a Great Cause!

**7th Annual Hunter Lens Golf Tournament, dinner, auction**

**When: Saturday June 4th 1:00pm**

**Where:** Back 9 Golf Club (<http://www.thebacknineclub.com/>) If unable to attend, you may donate online by using the link below, or mail a check written out to PWSA (USA) to the Sarasota address. (Place Hunter in the memo line.) **For more info or to register, visit:**

<http://www.firstgiving.com/pwsausa/7th-annual-hunter-lens-golf-tournament>

Thank you for supporting Hunter and PWSA (USA)!  
 John & Lori



## In this Issue

### 2015 Conference Scientific Abstracts

Part 2 of 2..... 5

### The Silver Lining

A Grandfather's Story .....9

### Executive Director View

Family Support on our Website..... 10

### Chapter Spotlight

The Big State of Texas..... 11