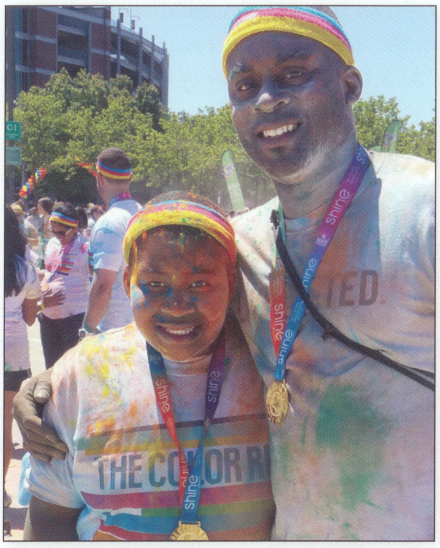
USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

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

Executive Director View
Calling All Fathers!



Dr. Caldwell, with son Kahlil

We all know what a mother with a child with PWS is likely to be like. She may be researching for answers, involved in leading or participating in a support group in person or online, stressed, overwhelmed, busy making sure that her child has whatever it takes to help him or her to reach full potential, helping to raise money for research – some or all of those descriptions and more, but she is "all in."

We know a lot less about fathers and male caregivers of individuals with PWS. There is very little research regarding fathers of special needs children and none about fathers of sons and daughters who have PWS. But there is enough research regarding the role of fathers of typical children to be able to say how important they are to the development of those children. Those at the national conference heard Clint Hurdle, manager of the Pittsburgh Pirates and father of Maddie, age 13 with PWS, speak about how essential the involvement of fathers of those with PWS is.

PWSA (USA), seeing the need and moving ahead in this new area, has approved a grant for a survey on the needs and issues of fathers and other male caregivers of individuals with PWS.

Leading the study will be Dr. Leon Caldwell, who is uniquely qualified for this role. A member of the PWSA (USA) board, he is a professional researcher and a father himself of a son, Kahlil, age 12, with PWS. Dr. Caldwell, currently a Senior Research Director at ThinkShift, a Washington, D.C. social innovation collaborative of the DeBruce Foundation, has a Bachelor's degree in Economics, a Master's degree in Education, and a Doctorate in Counseling Psychology. He has written and researched about fatherhood and produced a documentary about black fathers.

The purpose of this study is to learn about the coping and parenting styles of male caregivers and to provide information to PWSA (USA) regarding how the organization can best support them (see more details on page five).

When the opportunity comes to sign up for this important survey, we encourage all fathers and male caregivers to participate. And we encourage all mothers and female caregivers to encourage their male counterparts to take part in this ground-breaking study! ■

~ Ken Smith, PWSA (USA) Executive Director

A Colorful Glimpse from the 2015 Conference



In this one-time commemorative issue, *The Gathered View* shares a varied collection of conference articles to read and photos of our sessions, presentations, workshops, children's activities. Attendees left with friendships and knowledge to take home to their communities. ■

Attendee feedback shared: "Comraderie with others in the same situation. Able to speak with the thought leaders and actual clinicians in the PWS arena. Meeting the true pioneers in the PWS movement – the founders & promoters of PWS, "the original fighters". It is awe-inspiring!"





Volume 41, Number 1 ~ January-February 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 first 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)*

Cardiovascular Complications in Prader-Willi Syndrome

James Loker
Department of Pediatrics, Pediatric Cardiology, Bronson Methodist Hospital, Western Michigan University, Kalamazoo, MI

Introduction/Background: Increased morbidity and mortality in Prader-Willi syndrome (PWS) is often associated with obesity related cardiorespiratory problems. PWSA (USA) maintains a database of cause of death in over 470 individuals with PWS. This detected a disproportionately high rate of pulmonary embolus as a cause of death. Interestingly cardiomyopathies and congenital heart disease are uncommon. Understanding the pathophysiology of these cardiac problems in Prader-Willi syndrome will help with reducing the death rate.

Conclusions: Cardiac problems in PWS are primarily related to the obesity. There does not seem to be an increased risk of congenital heart disease or cardiomyopathy as seen in other syndromes. There is an unusual increased risk of pulmonary embolism and there may be factors in Prader-Willi syndrome that increase their risk for deep venous thrombosis more than the general population. Further investigation into the incidence of deep venous thrombosis (DVT) in PWS is needed. DVT prophylaxis may be indicated in those individuals that are at risk. ■

Diagnosing Prader-Willi Syndrome in Infancy Delays Onset of Obesity

Virginia Kimonis[1,2], Roy Tamura[3], June-Anne Gold[1,4], Abhilasha Surampalli[1], Jennifer Miller[5], Elizabeth Roof[6], Elisabeth Dykens[6], Merlin Butler[7], Daniel Driscoll[5]
[1]Department of Pediatrics, University of California, Irvine, CA; [2]Children's Hospital of Orange County, Orange, CA; [3]Health Informatics Institute, University of South Florida, Tampa, FL; [4]Department of Pediatrics, Loma Linda University Medical School, Loma Linda, CA; [5]Department of Pediatrics, University of Florida, Gainesville, FL; [6]Vanderbilt Kennedy Center for Research on Human Development, Vanderbilt University, Nashville, TN; [7]Departments of Psychiatry & Behavioral Sciences and Pediatrics, University of Kansas Medical Center, Kansas City, KS

Introduction/Background: Our consortium involved an NIH funded RDCRN (Rare Diseases Clinical Research Network) for Prader-Willi research. The long-term data were accrued from 351 individuals with PWS recruited for a 10 year RDCRN natural history study and represent the best characterized cohort in the world.

Because of large variability in age of diagnosis (range from 1 month to 47 years old), the age of diagnosis was categorized into three categories. Both the age of diagnosis and the race were significant factors for the age when the child first became heavy.

Conclusions: We propose that technology currently exists to perform newborn screening using filter cards that are routinely in use at the state level. This technology could be applied and would be critical for PWS to be detected in the newborn period to avoid costly invasive diagnostic work-ups and permitting early GH treatment to prevent obesity and associated co-morbidities. ■

Subclinical Hypothyroidism in Prader-Willi Syndrome

Abhilasha Surampalli[1], June-Anne Gold[1,2], Vy Dang[1], Marie Wencel[1], Shawn McCandless[3], Suzanne Cassidy[1,4], Virginia Kimonis[1,5]
[1]Department of Pediatrics, University of California Irvine, Irvine, CA; [2]Department of Pediatrics, Loma Linda University, Loma Linda, CA; [3]Department of Genetics and Genome Sciences, Case Western Reserve University, Cleveland, OH; [4]Department of Pediatrics, University of California San Francisco, San Francisco, CA; [5]Children's Hospital of Orange County, Orange, CA

Introduction/Background: There is very limited literature on the thyroid function in PWS. The aim of the current study is to determine thyroid function in common PWS subtypes, deletion and UPD and to evaluate the therapeutic effects of growth hormone (GH) treatment on thyroid profile in a large cohort of 64 subjects.

Conclusions: We found two individuals with hypothyroidism, one male previously diagnosed and treated and one new female (2/52= 3.85%). We did not find any significant difference in thyroid function between genetic subtypes or between subjects who were treated versus not treated with GH. This confirms that people with PWS should be screened regularly for thyroid insufficiency and treated with levothyroxine depending on the results regardless of genetic cause or GH treatment. ■

continued on page 3

Scientific Abstracts, *continued from page 2*

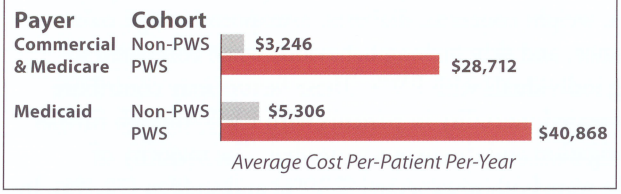
Analysis of Direct Medical Costs of Prader-Willi Syndrome Using Administrative Claims

Andrew J. Shoffstall[1], Julia A. Gaebler[1], Nerissa Kreher[2], Timothy Niecko[3], Diah Douglas[1], Theresa V. Strong[4], Jennifer L. Miller[5], Diane Stafford[6], Merlin G. Butler[7]
[1]Health Advances LLC, Weston, MA; [2]Zafgen, Boston, MA; [3]Niecko Health Economics LLC, St. Pete Beach, FL; [4]Department of Medicine, University of Alabama at Birmingham, Birmingham, AL; [5]Division of Pediatric Endocrinology, University of Florida College of Medicine, Gainesville, FL; [6]Harvard Medical School, Division of Endocrinology, Boston Children's Hospital, Boston, MA; [7]Division of Research and Genetics, Departments of Psychiatry & Behavioral Sciences and Pediatrics, Kansas University Medical Center, Kansas City, KS

Introduction/Background: While clinical awareness and early diagnosis are improving in the medical field, understanding of the natural history and financial and social burden of this condition remains low. Few studies have characterized medical resource utilization (MRU) among patients with PWS. We hypothesized these costs would be higher relative to a matched non-PWS control group, and tested this by assessing MRU among PWS patients using U.S. claims data.

Conclusions: Direct MRU was considerably higher among patients with PWS than members without the condition. Effective treatments for PWS are needed to reduce the financial burden on patients, their families and payers. ■

Fig.1 Total mean medical costs per patient per year (sum of costs for medications, outpatient and inpatient care).



A Descriptive Case Series Correlating Clinical Information With Neuropathology in Post Mortem Brains of Persons With Prader-Willi Syndrome

Janice Forster[1], Linda Gourash[1], Patrick Hof[2]
[1] Pittsburgh Partnership, Pittsburgh, PA; [2]Fishberg Department of Neuroscience, Icahn School of Medicine, Mount Sinai, NY

Introduction/Background: Our current state of understanding of the brain in Prader-Willi syndrome (PWS) is derived from phenomenology, electrophysiology and brain imaging studies. Functional magnetic resonance imaging (fMRI) has provided information about reward and loss of cortical inhibition, while resting state MRI has elucidated dysfunction in brain networks. Neuropathological study of postmortem brain has revealed characteristic findings of vascular inflammation and heterotopias of grey matter. Swaab reported senile plaques in a few brains. However, there are no studies correlating clinical state with brain neuropathology.

Conclusions: These 11 cases represent an aging population of persons with PWS with significant medical morbidity. BMI was significantly elevated despite supervised living. However, despite elevated BMI, only 5 individuals had diabetes, suggesting that half of the cohort had a protective metabolic phenotype. The medical records revealed that obesity hypoventilation was a chronic condition in these cases, and it was not managed appropriately despite repeated hospitalizations at academic medical centers. Edema was severe (up to the breast level in one patient) and was inappropriately treated with high dose diuretics. Several people were receiving > 2 liters of oxygen in an attempt to decrease elevated CO_2 levels. This suggests that the unique physiology of PWS contributing to rising lymphedema and insensitivity to carbon dioxide levels was not appreciated by medical teams managing these critically ill patients. The number of psychotropic medications was high among those who received them, but there was no correlation with age, as studies of psychopathology in adults with PWS might predict. One of the three oldest individuals had clinical evidence of behavioral deterioration compatible with dementia, and she had neuronal inclusions on neuropathology. This aging cohort of individuals who died as a result of complications of the syndrome provides an overview of medical and psychiatric morbidity and the presence of underlying neuropathology that has not been possible before. ■

Subclinical Dysphagia is a Likely Contributor to Premature Death in Prader-Willi Syndrome

Roxann Diez Gross[1], Ronit Gisser[1], Gregory Cherpes[1], Katie Hartman[1], Rishi Maheshwary[2]
[1]The Children's Institute of Pittsburgh, Pittsburgh, PA; [2]West Penn Allegheny Health System, Pittsburgh, PA

Introduction/Background: It is well-documented that premature deaths from choking and pulmonary infection occur within the Prader-Willi syndrome population at alarmingly high rates. It has been postulated that the high frequency of pneumonia and respiratory compromise could be related to "unrecognized aspiration." Probable causes for the increased choking risk in persons with PWS are thought to be neurobehavioral issues such as rapid eating and incomplete chewing. A thorough review of the literature identified at least ten reports of premature and/or sudden death from choking or pulmonary infection, but we could not find a single study that examined the swallowing function in persons with PWS of any age. Because swallowing impairment is linked to choking and aspiration, it seemed plausible that subclinical dysphagia could be a significant, yet unknown, contributing factor to the high premature or sudden death rate in PWS. To begin

continued on page 4

Scientific Abstracts, *continued from page 3*

to address this clinical gap, the purpose of this investigation was to determine if dysphagia and/or risk factors for prandial aspiration are present in persons with PWS. We also sought to determine if eating behaviors contribute to choking and aspiration risk. We hypothesized that dysphagia and risk factors for prandial aspiration would be revealed under videofluoroscopy, and that risk factors would increase when persons with PWS ate and drank spontaneously.

Conclusions: The well-documented high death rate from choking and pulmonary infection in children and adults with PWS cannot be solely attributed to eating behaviors. The combination of rapid eating and dysphagia greatly increases the risk of aspiration and asphyxiation in persons with PWS. Food impaction within the esophagus and/or unexpected regurgitation can also result in airway occlusion and/or aspiration. ■

Study of Mortality in Prader-Willi Syndrome

PWSA (USA) Study of Death Committee: David Stevenson[1], Ann Scheimann[2], Merlin Butler[3], Moris Angulo[4], June-Anne Gold[5], Janalee Heinemann[6], Carolyn Loker[6], James Loker[7]

[1]Department of Pediatrics, Stanford University, Los Angeles, CA; [2]Johns Hopkins University, Baylor Medical Center, Baltimore, MD, Houston, TX; [3]Departments of Psychiatry & Behavioral Sciences and Pediatrics, University of Kansas Medical Center, Kansas City, KS; [4]Department of Pediatrics, Winthrop University Hospital, Mineola, NY; [5]Department of Pediatrics, Loma Linda University, Los Angeles, CA; [6]Prader-Willi Syndrome Association (USA), Sarasota, FL; [7]Department of Pediatrics, Bronson Hospital, Western Michigan University, Kalamazoo, MI

Introduction/Background: Studies have shown that individuals with Prader-Willi syndrome (PWS) are at increased risk for premature obesity-related death and these usually involve small numbers of individuals. Since 1973, PWSA (USA) has kept a database on causes of death in Prader-Willi syndrome. In 2011, Dr. David Stevenson presented a paper on the results of a detailed questionnaire on 27 individuals with Prader-Willi syndrome utilizing this database. The database is part of the bereavement program at PWSA (USA). There are now over 480 individuals in the database making it the largest collection examining the causes of death in PWS.

Conclusions: Disadvantages of this study include relying on parental understanding of the cause of death. Autopsies were obtained in less than 10% of cases. However, significant insight from this study has led to new practices in management including risk of gastric rupture, choking and pulmonary embolism. Further investigation is needed in these areas to decrease the risk in the PWS population. ■

Contributing Factors of Mortality in Prader-Willi Syndrome

June-Anne Gold[1,2], Jennifer Nicole Wallace[1,3], Kathryn Osann[1], Barbara McManus[4], Virginia Kimonis[1], Ann Scheimann[5], Moris Angulo[6], Dan Driscoll[7], Merlin Butler[8], Janalee Heinemann[4], Carolyn Loker[4], Jim Loker[9], David Stevenson[3]

[1]University of California, Irvine, Irvine, CA; [2]University of Loma Linda, Loma Linda, CA; [3]Stanford University, San Francisco, CA; [4]Prader-Willi Syndrome Association (USA), Sarasota, FL; [5]Johns Hopkins School of Medicine, Baltimore, MD; [6]Winthrop University Hospital, Mineola, NY; [7]University of Florida School of Medicine, Gainesville, FL; [8]University of Kansas Medical Center, Kansas City, KS; [9]Bronson Hospital, Western Michigan University, Kalamazoo, MI

Introduction/Background: The purpose of this study was to identify the average age and causes of death among a group of patients from the Prader-Willi Syndrome Association (USA). In addition, this study tested the main hypothesis that genetic subtype, BMI, age of diagnosis, clinical symptoms, and growth hormone treatment differ among deceased individuals with PWS and living individuals with PWS. This study also analyzed the total cohort of individuals with PWS for differences in clinical symptoms based on genetic subtype, growth hormone use, and gender.

Results/Discussion: The most frequent causes of death fell into the categories of cardio-respiratory, infection, accident, gastrointestinal problems, and kidney failure. Deceased individuals with PWS had lower rates of growth hormone use as well as higher rates of specific clinical features, including BMI, heart problems, respiratory complications, sleep apnea, weight concerns, diabetes, osteoporosis, high pain tolerance, and skin picking behaviors, when compared to living individuals with PWS. These factors may contribute to increased mortality in patients with PWS, though further investigation and discussion is needed. The majority of deaths were both unexpected (77.9%) and sudden (72.1%). In addition, few affected individuals had new complaints (26.5%) or behavioral changes (22.1) prior to their death.

Conclusions: As a result, families and caretakers should have a low threshold for bringing their affected individual to medical attention when there is a concern. It is important that families are educated on the factors surrounding mortality as well as the high pain tolerance within the PWS population. This study also documented differences in PWS phenotype by genetic subtype, use of growth hormone treatment, and gender. The results add to the evidence that growth hormone treatment is beneficial for patients with PWS and that clinical differences may exist between the deletion and UPD subgroups of PWS. ■

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/

PWSA (USA) Supports Two New Important Studies

A study on the role of PWS male caregivers has been approved by PWSA (USA)

Did you know there is a dearth of knowledge relevant to the effectiveness of PWSA (USA) materials, for specifically supporting male caregivers? Did you know male perceptions and attitudes regarding caregiving for children and adults with chronic illnesses and developmental disorders are rarely investigated?

As announced on page one (in the Executive Director View), this grant has been awarded on the role of PWS male caregivers. Thanks to this study, to be led by Dr. Caldwell, an investigation into the coping and parenting of male caregivers of children and adults with Prader-Willi syndrome has been awarded.

This gives PWSA (USA) the opportunity to ultimately lead in this area and create value for our organization, while offering a set of support tools specific to addressing questions like these:

- What are the perceptions of male caregivers regarding PWSA (USA) support materials?
- What are supporting needs of male caregivers, and are they different than female caregivers?
- How might PWSA (USA) meet the differential needs, if any, of male caregivers?
- Develop a set of programmatic recommendations for PWSA (USA) National and State Chapters.
- Submit a manuscript for publication that will increase the awareness of PWSA (USA) in the research and family medicine community.

PWS fathers, caregivers, and role models: your participation will generate robust data, which will benefit the entire PWS community. Thank you in advance for your pledge of supporting feedback. ■

Understanding the Risks of Deep Vein Thrombosis (DVTs) and Pulmonary Embolisms (PEs) in PWS

There are now over 480 individual PWS deaths in the PWSA (USA) database, making it the largest collection in the world looking at the causes of death in PWS. Approximately 7% of the individuals with a reported cause of death died from pulmonary embolism (PE). This has not been reported as a risk factor in Prader-Willi syndrome in prior studies on mortality.

As an organization, thanks to the diligent file reviews by Dr. Jim and Carolyn Loker, we have only recently become aware of the risk of deaths from PEs in Prader-Willi syndrome. PEs are caused by a blocked artery in the lungs. The most common cause of such a blockage is a blood clot that forms in a deep vein in the leg: a deep vein thrombosis (DVT). We need to have a better understanding of these significant risk factors. PWSA (USA) will be doing an extensive survey among our membership and supporting a statistical review study. ■

We will be counting on you!
Help us by filling out surveys in the near future.
We can only save and transform lives with your help!

Janalee Heinemann, M.S.W.
Coordinator of Research & International Affairs, PWSA (USA)

Organization News

Welcome New SAB Members

Please join us in welcoming two new members to the Scientific Advisory Board (SAB) for PWSA (USA).

Ann Manzardo received her Ph.D. in Pharmacology from the University of California, Irvine with an additional graduate degree in Clinical Research Science from University of Kansas Medical Center where she is an Associate Professor of Psychiatry and Behavioral Sciences. She has been involved with many aspects of research in Dr. Merlin Butler's laboratory for several years. Her background in statistics has been useful in the study of DNA methylation, genetic variation and expression in PWS and the characterization of various neuroendocrine and immunological disturbances in PWS. She has most recently presented the results of the transcranial direct current stimulation study at the 2015 PWSA Scientific Day Conference.

Stefan Stamm, Ph.D., is a Professor of Molecular and Cell Biochemistry at the University of Kentucky and trained in molecular biology. His main area of research and focus involves RNA splicing and sequencing and factors contributing to gene regulation. His interest in gene expression and chromatin biology over the past 10 years has led to studies in Prader-Willi syndrome whereby his skills have been utilized in examining non-coding RNA and processing of gene splicing events related to Prader-Willi syndrome. He has published several important reports on mechanisms that control gene splicing and our understanding of the outcome of the disturbed genes in chromosome 15 contributing to this syndrome. ■

True happiness is to enjoy the present, without anxious dependence upon the future, not to amuse ourselves with either hopes or fears but to rest satisfied with what we have, which is sufficient, for he that is so wants nothing. The greatest blessings of mankind are within us and within our reach. A wise man is content with his lot, whatever it may be, without wishing for what he has not.
~ Lucius Annaeus Seneca

Contributed by Clint Hurdle

Moris in Mexico

By Janalee Heinemann, M.S.W.
Coordinator of Research & International Affairs, PWSA (USA)

Editor's Note: Moris Angulo, M.D., a member of the PWSA (USA) Clinical Advisory Board, reported in a letter to Janalee Heinemann about his "very successful" trip to Mexico in November 2015.



Janalee,

I started in the state of Puebla about 2.5 hours from Mexico City where I had the opportunity to see a family that lost their infant at 9 months after severe septicemia. It was difficult to counsel them because of the guilt they had about having and losing their little angel with PWS.

The next day on Nov 20th, I returned to Mexico City to lecture at the biggest hospital, "Hospital General de Mexico" to a wide range of specialists including, endocrinologists, geneticists, pediatricians, psychiatrists, nutritionists and other health caretakers. My talk was well accepted with many questions during and after but most impressive was their interest in diagnosis and management of PWS!!! Some of the participants wanted to have a rotation at my hospital's division; thus I have to check with my director about the possibility of it.

This is the first time the founders of the "Maria José PWS Foundation" extended their awareness from their city of Pachuca, Hidalgo to the capital of the country, Mexico City.

The following day we traveled to Pachuca to meet families and their children with PWS. At the first International PWS in Pachuca in 2005, we had only 3-5 local families. On March 2009 the daughter of one family, Maria José, died at age eight after "gastric rupture" with history of gastroparesis. The departure of their little angel to heaven inspired Josefina and Beto to work harder to help families not only in their town but also all over Mexico. During this International Symposium, we had families from 15 states and one from Ecuador, South America!!!! I had the opportunity to diagnose two sisters with Bardet-Biedl and one boy with Kabuki syndrome without right testing previously diagnosed with PWS.

Lunch after the meeting was exceptional with more than 180 participants including children and adults with PWS.



I really thank the PWSA (USA) as well as IPWSO for helping parents and professionals with awareness, management and wide range of concerns of this multisystemic condition.

I do not know for how long but I am still following your inspiration to work for these lovely kids and their families.

Love,

Moris





Hip Hip Hooray!

Many congratulations to Tony Holland, who has been honored in the Queen's Birthday Honours List. Professor Anthony John Holland, Cambridgeshire, becomes a CBE (Commander of the Order of the British Empire) for services to psychiatry. Tony is chair of the IPWSO Clinical & Scientific Advisory board, and Professor of the Psychiatry of Learning Disabilities, University of Cambridge. Here is the link to view the list: http://bit.ly/1QZKvzC

Very well-deserved, so proud for you, Tony!

Oxytocin Phase 2 Study Research Campaign Extended to March 31

Over $525,000 has been raised by our families, businesses, and chapters during the first six months of the campaign to fund this potentially life-changing research study.

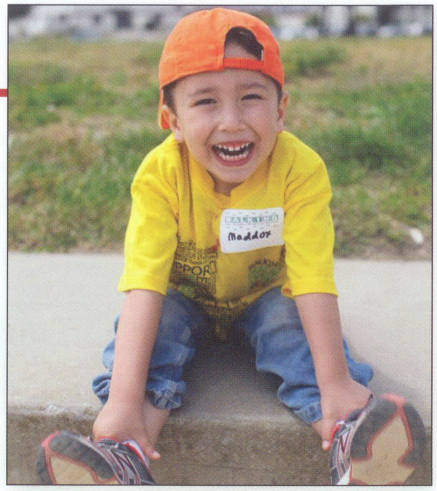
Top 10 quotes from parents whose children participated in the Oxytocin Trial

You've heard from medical researchers around the world, as well as the Prader-Willi Syndrome Association (USA) about the extraordinary benefits of Oxytocin therapy for people with Prader-Willi syndrome.

Now hear it straight from the parents. Parents whose children participated in the Phase 1 Oxytocin study conducted in 2015 noted the following improved quality of life benefits. These testimonials truly emphasize why Drs. Miller and Driscoll, along with PWSA (USA) are fast-tracking the Phase 2 Study:

- *"Oxytocin unlocked my daughter's brain."*
- *"With Oxytocin, the repetitive questions stopped."*
- *"The anxiety and worry were gone while she was taking Oxytocin."*
- *"My child was suddenly present, and her eye contact was better."*
- *"This medicine has changed the way I interact with my child."*
- *"His social interactions improved dramatically."*
- *"For the first time in as long as I can remember, she skipped her morning snack."*
- *"She skipped her morning snack EVERY DAY that she received the medicine."*
- *"At a barbeque, my child chose to play with other kids instead of eat."*
- *"What would usually take 3 or 4 requests were now done promptly."*

Consider supporting to this study by contributing through PWSA (USA). You may mail donations to the PWSA (USA) office or go online and contribute at: https://www.firstgiving.com/pwsausa/oxytocin-study



Angel Drive

The 2015 Angel Drive was a whopping success. Nearly 700 donors contributed over $160,000 to the year-end Angel Drive in November and December, surpassing the prior year by nearly $65,000, an increase of over 67%. Thanks to all the supporters that made donations to this campaign. Special recognition goes to a small circle of major donors who provided funding to match donations to the Angel Drive. Funds raised from this campaign will ensure that our research, family, crisis, medical, school and educational support will continue in 2016. We anticipate over 2,000 calls from PWS families in 2016 seeking help from PWSA (USA); we could not serve them without loyal and generous supporters like you. ■

With deep appreciation and gratitude

On behalf of the children and families we serve, the Association wishes to extend sincere thanks to our 2015 Circus of Hope Conference Sponsors. Your support made this conference a very successful experience for our attendees, for which we are very grateful.

Big Top Sponsor: Casting for A Cause

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Rhythm Pharmaceuticals • ARC of Alachua County, Gainesville, FL • HealthBridge Children's Hospital

Additional Sponsorships provided by the following Chapters

Alaska • Arizona • Georgia • Idaho • New York • Texas • Wisconsin

Here are a few photos taken at the 2015 PWSA (USA) national conference, along with attendee feedback received.





Seeing and talking with old acquaintances; getting new, important info & clarification of some issues; it's wonderful the PWSA (USA) has input and representation of top-notch medical & scientific folks.







This was my second conference and I intend on returning every time it is offered.

A lot of practical strategies to apply, better understanding of PWS, a great forum to feel "at home and understood"

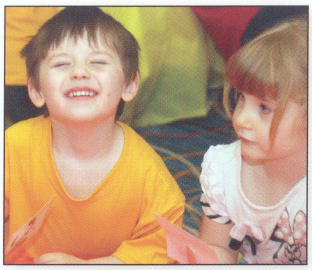


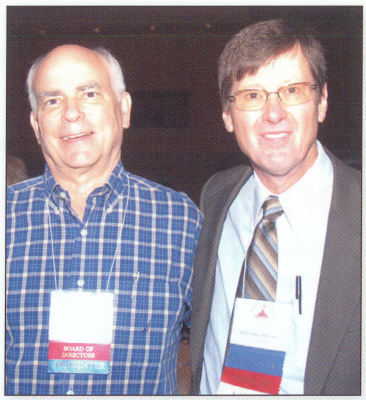


Wonderful to be with Prader-Willi community – so promising, encouraging, heartwarming and informative!



A wonderful conference with exciting scientific updates. Keep up the good work. We look forward to attending the next conference.















Look forward to future conferences – this was my first time.

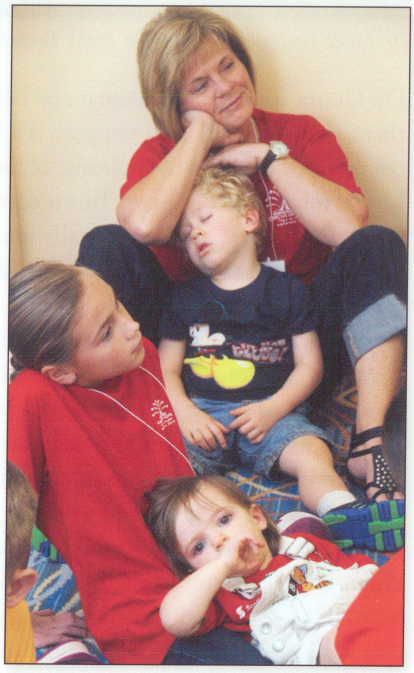
I'm so thankful for all the effort of PWSA (USA) for putting the hard work in to help us parents make our children's lives successful and manageable.
As the kids get older, I think it is even more important to be there for other parents. The learning is definitely a two-way process. Love it – Never Quit…EVER



Updates on research, techniques and tips to use at home, one-on-one with Evan



Networking (realization that I'm not ALONE) new information on meds and behavior tactics



Overall, the conference exceeded expectations! Great job! I appreciate all of the work to put it on.

I was thrilled that my daughter and I could network with other families in the same boat. Also, it was awesome to meet all the dedicated people involved in PWSA (USA) and to be able to hear them speak and to speak to them, individual questions, and receive excellent information.

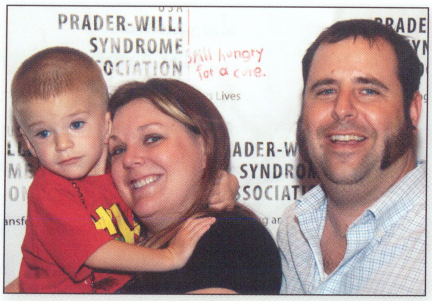






Being able to network with people I've known online for the past four years or so but haven't been able to put a face with. Being around other people that know what it's like to have a child with PWS. I was grateful to be able to attend due to being sponsored; and by this happening, my mom was able to come as a grandparent first-time attendee. I learned very valuable tools to take back to school for her IEP and different ways to handle her tantrums/ behaviors.













The Gathered View *was very fortunate to have talented writers at this year's conference. This month, we're featuring a wonderful report on Dr. Gourash's presentation by Denise Servais and a review of Elizabeth Roof's session by Andrea Glass, on the facing page 11.*

Dr. Linda Gourash - PWS Behavior Management Skills 101

By Denise Servais, mother to Maya

If there is one thing that my husband and I have had trouble agreeing on, it's how to manage our 11-year-old daughter's challenging behaviors. So anytime I get a chance to hear an expert speak on this subject, I'm there. At the Prader-Willi Syndrome Association (USA) conference this past November, I attended Dr. Linda Gourash's presentation entitled "PWS Behavior Management Skills 101." Dr. Gourash is a developmental pediatrician and an expert on behavior with people with PWS.



Maya age 11

Even though I have heard Dr. Gourash speak many times about behavior, I always learn something new. Her engaging presentations are clear and her explanations easy to understand. However, in spite of what may seem like an easy plan to follow, managing expectations and our own reactions to challenging behaviors can be anything but easy, as Dr. Gourash acknowledges. She recommended practicing and using three skills that will be the most valuable when dealing with a child who is demonstrating undesirable behaviors: *Low Attention, Low Expressed Emotion and Not Arguing.* She suggested these skills are especially effective when used in conjunction with a system of incentives and consequences in place for behavior. These three valuable skills are summarized below from her handout.

Low Attention- Dr. Gourash explained that low attention is critical when dealing with a child who is demonstrating undesirable behaviors, no matter what level of functioning in the child. Low attention can be a main tool in extinguishing a behavior and assures that you are not inadvertently reinforcing an undesirable behavior. When using low attention, it may appear to the child that he is being ignored. The parent is using as few words as possible and avoiding eye contact if possible. By using low attention, the child is learning that his misbehavior is ineffective.



Dr. Linda Gourash, left, with Dr. Janice Forster

Dr. Gourash points out these many behaviors extinguish themselves when they do not get a response. This may appear counterintuitive, but the opposite of low attention would be reacting to the behavior. This is counterproductive, Dr. Gourash believes, and can actually make the child even more out of control, while teaching the child behaviors you do not want him to imitate.

Low Expressed Emotion- This means using a neutral, matter of fact tone. Low expressed emotion means sounding bored even when the child's behavior appears to be provocative. Volume should be as soft as possible and still be heard. Using low expressed emotion helps in reducing outbursts and encourages the child to calm down. It means saying as little as possible, but having a few well-chosen words to say to the child. Use these words to tell the child what you want him to do, instead of saying what the child is doing at that moment. Dr. Gourash suggests repeating these words to the child without changing tone. Having an emotional tone or saying too much is difficult for an upset child to process, she cautions.

Dr. Gourash points out these many behaviors extinguish themselves when they do not get a response.

Not Arguing- Even though it is so tempting to argue, Dr. Gourash notes that when you argue with your child, you are legitimizing your child's arguments, even if you think you are not.

It doesn't matter what the reason is for your child's difficult behaviors - be that due to PWS, puberty, or something else; Dr. Gourash recommends using the same skills. She emphasizes that using these skills will actually put the parent in control and not the child.

To learn more about managing behaviors associated with PWS, Dr. Gourash, along with Dr. Janice Forster, developed a DVD available for purchase from PWSA (USA), entitled "Food, Behavior, and Beyond." To order this DVD go to: http://www.pwsausa.org/product/food-behavior-beyond-practical-management-for-the-child-adult-with-pws-dvd/ ■

Adulthood 101

A seminar by Elizabeth Roof, M.A., Senior Research Specialist, Prader-Willi Syndrome and Williams Syndrome Research Projects at Vanderbilt Kennedy Center

As reviewed by Andrea Glass

As always, hearing Elizabeth Roof speak with her very comprehensive knowledge of Prader-Willi syndrome (PWS) is an enjoyable, learning experience. Her research grants (looking at compulsivity in PWS and behavioral phenotype trajectories in PWS) have included over 245 people ages 4 to 66 years with PWS, for a total of 645 visits, from the U.S. and Canada. Elizabeth Roof has gathered an impressive amount of data and has firsthand seen many of the issues we see with our children.

Her findings: Of those 245 individuals with PWS (mean age: 16.5), 51.6% were female/48.4% male, 145 deletion, 88 UPD, and 7 had an imprinting defect. Her report reflects on life expectancy (can be normal), the level of independence (some supports will be required), behavior (may get better with age), hyperphagia (only a few get better with age). In this fairly large sample, average IQ was 65-70 (range was 40-125). Due to food-seeking and maladaptive behaviors, these individuals require a higher level of care than predicted by IQ.

The busier our children with PWS stay, the healthier they are mentally.

On a personal level, Adulthood 101 has me on the edge of my chair. My son is 20 and we are there. Dealing with PWS for the past 20 years has been difficult at times, and seeing changes in my child at this stage of life are somewhat unsettling. This seminar addressed the prevalence of autism spectrum disorder (ASD) in PWS, attention deficit hyperactivity disorder (ADHD), obsessive/compulsive disorder, anxiety, depression and psychosis. 39% of boys met the criteria for ADHD, but typically without the 'H' – hyperactivity – component. 27.5% had motor and vocal tics, such as repeating words, sounds and phrases.

More from Elizabeth Roof's seminar: Although it has been written that psychosis is more prevalent in those with UPD (80-90%), that doesn't rule out that an individual with deletion can become psychotic. It is difficult to separate the display of compulsive thoughts (such as a young woman thinking/believing she is pregnant), and actual psychosis. Medications may help with these compulsive thoughts. When a person is truly psychotic, they typically can't function to "*their* normal" anymore. The individual does not sleep, eat normally, will appear disheveled, and the delusions get bigger and more severe. This is typically a temporary state and may be treated with medications for a short term, and needs to be caught early. Interviews with this sample show that after a short treatment period, the individual often returns to baseline after treatment. In this study there were only 21 people with the diagnosis of psychosis. The typical age onset is late teens to early 20s and is typically precipitated by stress (loss of boy or girlfriend, diet, school changes and other transitions).

Anxiety also is quite prevalent in PWS, but can appear different in this population. When environmental changes aren't enough, medications can be very effective. However, there can be odd side affects that are more common with UPD and Imprint Mutations. Interestingly, this study shows that very few individuals with PWS have depression (only about 8%). They are typically higher-functioning females with limited social connections. Again, it appears differently in PWS and is typically displayed as irritability, being easily annoyed, not motivated, a displaced aggression, sleep changes, and repetitive behavior.

Personally, a very important take-away for me was Elizabeth's insight that: the busier our children with PWS stay, the healthier they are mentally. It is unhealthy for the child with PWS to spend much time alone, where compulsive thoughts take over. Regularly scheduled activities and respite are useful tools. School, family activities, volunteer opportunities, etc., make a huge difference on risk factors for psychiatric issues. Support in adulthood is determined more by adaptive behavior skills than cognitive ability. Adults with PWS need lifelong help (assistance) for money and food access, job/volunteer placements, residential services, religious/spiritual life, friendships and social opportunities, and exercise and leisure. Families need to plan for the future!

A favorite slide from Elizabeth Roof's *Adulthood 101* is below and resonated with me; I hope it does for you too.

You are not alone!!

- You have to take care of your needs - both physical and mental.
- You have to let go a little bit.
- You have to trust others.
- You have to trust yourself to do what is best.
- Oh, and you will have to fight like Hell to get services.

(Note: If you are seeing any symptoms of compulsive thinking, anxiety, or psychosis, alert your child's medical provider right away. Psychotropic medications can be an important and effective intervention to diminish and prevent psychiatric illness. However, because every person with PWS is different, it is important to have a medical professional evaluate your child to determine which treatment options are most appropriate. You can view the YouTube link for Elizabeth Roof's video on mental health issues at https://www.youtube.com/watch?v=ls8aHNOTDY0&feature=youtu.be ■

Our Chapter Leaders

By Crystal L. Boser, Chapter Relations Co-Chairperson, PWSA (USA), President, PWSA-WI, Inc.

This past November, Chapter Leaders converged on Florida for the Chapter Leaders meeting at the 2015 PWSA (USA) national conference.

The Chapter Leaders meeting is important for chapter leaders to attend for a variety of different reasons.

1. This meeting gives everyone an opportunity to hear about what PWSA (USA) has been doing throughout the year and learn about what they have planned for the upcoming year. For example, at our November meeting we learned about the history of PWSA (USA) , the **number** of crisis/medical calls the PWSA (USA) office had taken throughout the year, the **number** of new diagnoses received at the office, and about the **Adults with PWS Advisory Board**. We also learned about **various research projects** PWSA (USA) is supporting, the **Studies of Death** being conducted, the **new transition resource** PWSA (USA) recently published, the new PWSA (USA) **website** that went live right before conference, the updated **parent mentor program** and how PWSA (USA) can help chapters with regard to fundraising with support and training tools.

2. The Chapter Leaders Meeting gives the Chapter Relations Committee (CRC) the opportunity to share new information with regard to chapter operations and what they are doing to help expand the PWS community. For example, during this past Chapter Leaders Meeting, the CRC shared the new **Chapter Formation** manual as well as the new **Chapter Operations** manual. In addition, the CRC was able to share information about newly formed chapters, such as **New Mexico, Louisiana, and New Hampshire.**



3. Lastly, the Chapter Leaders Meeting gives chapter leaders an opportunity to share information about what they are doing in their respective chapters. Chapter Leaders are at their best when collaborating: sharing best practices of what has worked in their states, what has not worked, and brainstorming new ideas that can be done in the PWS community. In addition, leaders of more established chapters are able to share how the chapters got started and how they have continued to grow. Simply stated, the Chapter Leaders Meeting is **the one time** during the year when Chapter Leaders can get together in person and talk about how to accomplish similar goals and share information to help better the PWS communities throughout the U.S.!





2016 Chapter Leader goals vary by chapter. Some newly formed chapters are focusing on forming official boards, hosting board meetings and holding awareness/fundraising events. Other more established chapters are focusing on bringing in speakers to their areas. These events are designed to present to physicians/families, to educate, expand fundraising/awareness efforts and aid in establishing group homes.

One main goal many of the chapters have is **changing legislation to include PWS in every state statute**. The chapters will be working together and with PWSA (USA) to accomplish this significant priority, as it is a HUGE undertaking.

Goals for the CRC are to continue to find chapter leaders for all 50 states, continue to support current chapter leaders any way we can, and continue to act as a liaison between PWSA (USA) and each of the chapters. Plans to host another Chapter Leaders Meeting in later summer of 2016 are in the works; details should be released within the next few months.

Visit: http://www.pwsausa.org/find-a-chapter/ to locate a chapter in your area. If your area needs information on beginning a chapter, please contact Leanne Gilliland, Development Specialist, lgilliland@pwsausa.org or 941-487-6743, or Crystal Boser, Chapter Relations Co-Chairperson, at crystal.boser@aol.com or 414-403-1935.

Let's connect and make 2016 a great year for Chapters! ■

Welcome to the family!

We would like to welcome the Prader-Willi Syndrome Association of Montana as an official chapter of the Prader-Willi Syndrome Association (USA). Together, anything is possible! ■

Chapter events through May include:

January 23 Northern CA- Support Group
January 30 WI- Fifth Annual **Snowflake Ball**
February 7 CA- LA County Support Group
April 4 IN- Pirates game in Indianapolis
April 4 IN- Bowling fundraiser
April 24 Southern CA Walk
April 29 WI- Dr. Ann Scheimann - two presentations
April 30 Northern CA- Support Group
May 7 WI- Annual ***On The Move*** Walk-a-thon
May 13-14 NY- State conference in Albany
May 14 IN- ***On The Move*** 5K
May 16 NY- **Golf for PWS** in Mt. Sinai
May 20 MN- **Golf Scramble**
May 21 MA- Seventh Annual **Hunter Lens Golf Tournament**

My Normal

By Kathryn Lucero

When I was pregnant I would dream about what it would be like to hold my son and look into his eyes. I would dream about holding and comforting him when he would cry and I would think about how I would manage sleepless nights. I would daydream about my son and what he would be like when he got older. Maybe he would be a soccer player and also play an instrument, maybe he would be an artist with the love of the outdoors. These are all normal things to think about, right? Normal.

When my son was born and diagnosed, many of the things that I thought were normal were not normal at all. My normal was holding my son as he slept for hours. I only looked at his big beautiful eyes when he was upset when the NICU nurses would touch him with their cold hands, and my sleepless nights were due to me being worried, stressed and pumping. When he came home, I continued to think about all the normal things that my son would be doing, such as his first smile, holding my fingers when sleeping, holding his bottle, sitting up and, of course, the list goes on. The amazing thing is, he DID all of these things, these very normal typical things my son did do, he just did them in his own time. This was my normal.

I now have a toddler that is active and on the move. At this time he is not walking, but he has figured out his own way to get from one place to another, be it crawling, cruising furniture or even riding on a toy fire truck. He has his own jargon and the best facial expressions. I still think about him playing soccer, participating in Karate and even playing an instrument; this is my normal. At the 2015 PWSA (USA) Conference I met many wonderful people and families that have truly made an impact on my life. I went to this conference and felt a sense of belonging and what normal truly is.



My normal is all I know. When my friends talk about their unruly toddlers and their stresses about bedtime routines, I think to myself: I have no idea what that is like and I am really okay with that. I may not know what the future holds or how he will get from point A to point B. I don't know what those points are, but my son will reach those milestones in his own time; this is my normal. ■

A New Partnership

By Bonnie L. Shelley, Ph.D., Coordinator of Medical Affairs

I am so pleased and privileged to announce the new partnership between PWSA (USA) and Shriners Hospitals for Children. This relationship is exciting and, indeed, hopeful.

During the 2015 PWSA (USA) National Conference I was fortunate to be introduced to Ms. Cheryl Stauss, former First Lady of Shriners International. Cheryl served as First Lady of Shriners International from 2014-2015 as her husband, Dale, served in the highest leadership position with Shriners International, Imperial Potentate. Cheryl's work is so very significant for children in need of medical care and especially significant for children with Prader-Willi syndrome (PWS) and their families.

During her tenure, Cheryl began the fundraising program, *The Journey of Hope*. This program promoted awareness of the high rate of scoliosis in children with PWS. Cheryl is no stranger to Prader-Willi syndrome as her young grandson, Ben, has PWS. Cheryl's awareness that 40% diagnosed with PWS also develop scoliosis, many during infancy, as well as her awareness that many families cannot access medical services due to financial constraints became the impetus for *The Journey of Hope.*

With this partnership, PWSA (USA) and Shriners Hospitals for Children want PWS families to know of the valuable resources provided by Shriners Hospitals for Children throughout the nation. There are 22 hospital locations, and most have orthopaedic specialists. In addition, Shriners International will provide transportation for families traveling from home to the Shriners Hospitals for Children of their choice.

In the world of Prader-Willi syndrome, we take solace in knowing that Dr. Harold van Bosse, Shriners Hospital, Philadelphia, is not only an orthopaedic specialist, he is also a specialist in PWS. His kindness, compassion and expertise is renown to families in the PWS community and also to those of us who work and serve those living with PWS.

I encourage you to view the following links in order listed:

To learn more about *The Journey of Hope,* narrated by Cheryl Stauss, and Shriners Hospitals for Children, visit https://www.youtube.com/watch?v=YrktmYzGZYk.

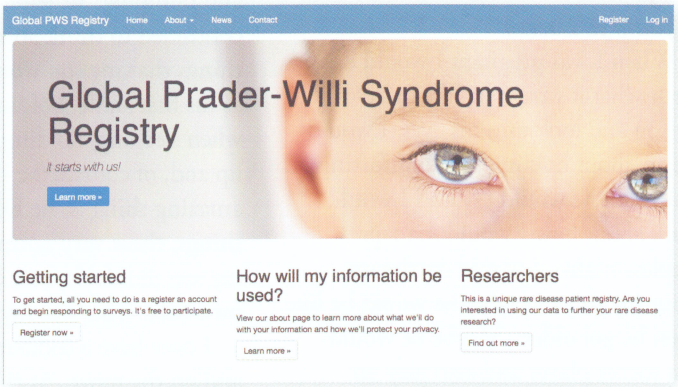
To learn how to refer your loved one for care at one of the 22 Shriners Hospitals for Children, please visit http://www.shrinershospitalsforchildren.org/refer-a-patient.

To learn how Shriners International will provide transportation assistance to our families traveling from home to the Shriners Hospitals for Children of their choice, please visit http://www.shrinersinternational.org/en/Locations

God bless each of you and Shriners Hospitals for Children as we applaud Cheryl's *Journey of Hope* and the hope it brings to our children with PWS and scoliosis. ■

Every Person Matters

Register Now Global Prader-Willi Syndrome Registry



Advance PWS research faster than ever by providing researchers with comprehensive, accurate, and research-ready data that is easily accessible. The Global PWS Registry is a secure database compliant with U.S. Health Information privacy laws, and FDA regulations that will: **Document** the full range of PWS characteristics – across the lifespan, **Expedite** completion of clinical trials, **Drive** unmet research and treatments, **Guide** standards of care and **Improve** the lives of those affected by PWS.

To achieve these goals, and create the most robust PWS registry possible, every person with PWS should be included in the registry. Through a series of electronic surveys, the registry collects information on a wide range of topics including developmental history, medical complications, and quality of life issues. So whether your loved one with PWS is 2, 15 or 52 we need your help in making sure they are included to provide a complete picture of the PWS community. This is a great way people with PWS – of all ages – can help advance research, develop new treatments and improve the quality of life of the entire PWS community. It is also a powerful reminder that every person with PWS matters – and so does their unique life experience. So 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**

e-News...

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

CHUCKLE CORNER

A "Hair Club for Men" introductory package came in the mail today for my daughter, Janelle, age 20. Two weeks ago she signed up for an adoption agency to put her baby up for adoption. Last week she tried to order $15 worth of gummy bears from a candy warehouse. Oh, how I *love* the Internet!

~Sherie Bombardier, Massachusetts

Want to Share YOUR Story?

PWSA (USA) is accepting stories and pictures of your child/adult with PWS for use in the "From the Home Front". Individuals of all ages, both genders, and all ethnic backgrounds are welcomed.

We have professional writers available to interview you and assist in crafting your story. For consideration or questions, contact us at pwsaeditor@pwsausa.org. We'd love to hear from you!

Photos should be a MINIMUM of 1000 pixels high OR wide, in a JPG format. Please email your stories and photos to pwsaeditor@pwsausa.org. We can't wait to hear from you!

ATTENTION Federal Employees

If you work for the Federal government, the Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all." **PWSA (USA) CFC ID # is 10088**

CFC® Combined Federal Campaign

For more information about the CFC program and how it works, go to their Web site at: https://www.opm.gov/combined-federal-campaign/ or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee.

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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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E-mail Support Groups: We sponsor nine groups to share information. Go to: www.pwsausa.org/egroups

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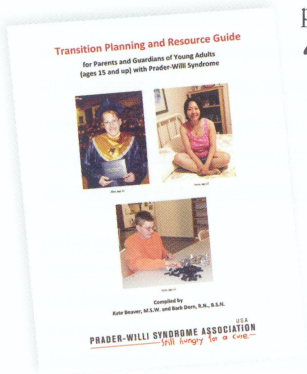
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New Publication!

Transitioning into the adult world can be frustrating, intimidating, and overwhelming for both PWS youths and their families. That's why it's important for parents and their children to begin transition planning when children reach 14–16 years of age. PWSA (USA) is now offering an updated publication, the ***Transition Planning and Resource Guide,*** developed especially for parents and guardians of young adults with PWS. This 104-page booklet help you answer questions about a wide range of topics, including but not limited to: **Vocational evaluation and transition from school to work for the student with PWS, Residential living options/considerations and services, Transportation issues, Important legal and financial issues, Personal health education, Transitioning to the adult health care system, Educating health care professionals,** and **Health insurance coverage.**



A **Transition Planning Timeline** is one of the forms also included to ensure that you consider all of the aspects involved in the transition planning process. To purchase for $25.00, visit: http://bit.ly/1RRb3H6 or email: sales@pwsausa.org. ■

¡HOLA!

By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.

¡Hola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que nececitan informacion y ayuda. Les quiero directar a www.pwsausa.org donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

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