The
Gathered View
PRADER-WILLI SYNDROME ASSOCIATION USA
Still hungry for a cure.
National Newsletter of the Prader-Willi Syndrome Association (USA)



40 Year Flashback

1983-1993: The Decade of Scientific Accomplishments in Prader-Willi Syndrome

By Merlin G. Butler, M.D., Ph.D.

The decade of 1983 to 1993 will be recognized as one of the pivotal decades for increasing the knowledge base and understanding of the cause and diagnosis of Prader-Willi syndrome (PWS), a rare obesity-related genetic disorder. A search of Pubmed (www.PubMed.com) revealed that 479 research articles were published on PWS during this time frame. Leading the decade was a report by Butler and Palmer in 1983 using differences in **chromosome 15 staining properties in PWS families found that the chromosome 15 donated by the father led to the chromosome 15 deletion seen in the child with PWS even though the father's chromosome 15 was normal.** Studies using high resolution chromosome analysis showed that the majority of individuals with PWS had the deletion of the 15q11-q13 region. The discovery that the chromosome 15 donated by the father led to the chromosome 15 defect in PWS began the pursuit to unravel the genetic mystery behind the cause of this syndrome.

The years between 1984 to 1990 lead to multiple investigative reports (e.g., Bray, Cassidy, Butler, Wenger, Ishikiriyama, Mattei, Eiholzer) on about 200 individuals diagnosed with PWS leading to improved description of clinical characteristics and cytogenetic findings in this rare genetic disorder. During this interval, several clinical cohorts and cytogenetic correlation studies involving the deletion versus non-deletion status were reported and less variation was found in clinical presentation and hypopigmentation noted in those with the chromosome 15q11-q13 deletion compared with those having normal appearing chromosome 15s. Different chromosome 15 rearrangements were also reported during this time and included inversions, translocations and duplications **utilizing high resolution chromosome techniques.** In 1987, several reports with important discoveries were made which led to a better understanding of the genetics, clinical phenotypic description, behavioral/psychiatric aspects and recognized emotional problems. **The first use of growth hormone** to treat the short stature in PWS was also reported by Lee, Angulo and others.

During this productive era, the recognition of **Angelman syndrome, an entirely different clinical disorder, was reported with the same appearing 15q11-q13 deletion but of maternal origin.** This observation of a separate condition with the same cytogenetic defect inspired additional research and interest in the study of rare disorders. Increased research led to the discovery of new genetic principles with the application of newly identified DNA markers from chromosome 15 and molecular genetic techniques. Rare familial cases of PWS were reported and recurrence risks proposed for genetic counseling purposes. In addition, obesity and hypogonadism, cardinal features in PWS, were further characterized along with precocious puberty and the risk for scoliosis. Reports on body composition measures, fatness patterns, nutrition and energy expenditure studies were also generated during this era including studies in infants diagnosed with PWS.

In 1989, Nicholls, Knoll, Butler and others reported studies using recently identified polymorphic DNA markers from the 15q11-q13 region in those with PWS having only normal appearing chromosomes. Their research searched for subtle deletions not detectable using cytogenetic techniques and discovered that chromosome 15 did not show submicroscopic deletions in those with normal appearing chromosomes but found that **both chromosome 15s came from the mother, coined uniparental maternal disomy 15.** This surprising observation was combined with our knowledge of the paternal origin of the chromosome 15 leading to the deletion seen in PWS and discovery of the same chromosome deletion in Angelman syndrome (AS) but from the mother. **Hence, the genetic mystery was unraveled and both PWS and AS became recognized as the first**

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Be part of something great and hold your own On The Move (OTM) event!

Be part of something great and hold your own **On The Move (OTM)** event. This year is the 40th year of PWSA (USA) helping our families through funding research, family crisis calls, awareness, advocacy and education programs. Our goal is to hold 40 OTM events during our 40th year! We are continuing to help save and transform lives and **On The Move** is a vital part of our efforts. Your involvement in OTM as an event organizer, fundraiser and participant means everything to the PWS community.

Here are a few reasons to conduct an On The Move event:

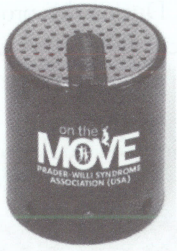
- Raises critical funds for vital research, family support, advocacy, awareness, and education
- Win great prizes!
- Includes an element of physical activity and community camaraderie
- Great way to get friends, family, neighbors, co-workers together for a fun event
- All of the funds raised will go towards helping those affected by PWS both locally and nationally
- Can be held by state chapters, individuals, and groups
- Terrific way to spread awareness and for local chapters to gain visibility
- You can raise maximum funds for minimal expense
- PWSA (USA) development team is here to help you as you move along in the process; we can provide you with the support needed to make your event great
- We can set you up a personalized webpage for you and for your participates that will allow you to collect online donations
- Our event kit and staff support provide the direction you need to organize successful event

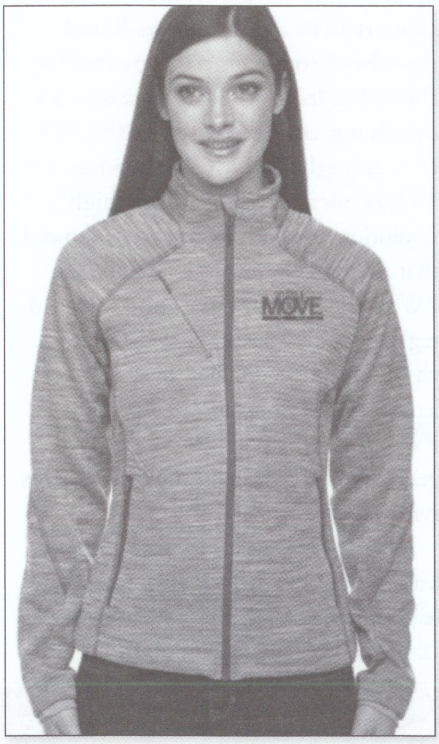














Option 1: Organizing Your Own Event

Planning your own event is a great way to be a part of ***On The Move***. A community walk is a fun event where people in your local community can come together to support PWS in a friendly atmosphere. While our priority is walk events because of their proven success, our staff can also help you with other fundraisers like, golf, bowling, and dinner/ auction events. We will create a personal webpage for you to use to solicit donations online and to spread the word through social media and emails. If you're planning to have your own event:

1. Contact PWSA (USA) to obtain the On The Move event packet which will provide all of the necessary information and resources to have a successful **OTM** fundraiser
2. Submit the OTM Event Agreement (within the event packet) to lgilliland@pwsausa.org
3. We will create a FirstGiving event page for you and list your event on our national and ***On The Move*** websites
4. You can customize your event page with pictures and personal stories (if you are not great with computers, we can do it for you!!)
5. Spread the word by sending out emails and posting to your social media networks with the easy to use tools for registration and donation



Option 2: "eWALK" Virtual Walk

For the very first time, PWSA (USA) is holding a virtual walk. If you do not have time for an event or if there is not an event in your area then this is the perfect choice for you! This option is easy for spreading awareness and raising much needed funds. Our development team at PWSA (USA) will help you throughout the whole process and create your own virtual walk fundraising website page. You can set the date to make it live and how long you want to keep the page live.

Your personalized online fundraising page will generate funds and awareness through email, social media, friends, family or even



just talking to a complete stranger in the community about PWS and your efforts. All someone will have to do is go to your page and donate to your event. It's that simple!! If you're planning your first **eWALK** **OTM** virtual walk:

1. Contact Leanne Gilliland or Donny Moore via email at lgilliland@pwsausa.org or dmoore@pwsausa.org
2. Call us at **800-926-4797** and speak directly to **Leanne** or **Donny**
3. We will create your own online giving page and help you through the process on how to personalize your event page
4. We will send you your very own **eWALK** step by step guide that will give you all the information and tips to help you along the way
5. Start sharing with your friends and family through email and social media tools

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examples of genomic imprinting in humans in which gene activity or the differential expression of the genetic information depends on the parent of origin. Hypopigmentation was also seen in those with the chromosome 15 deletion in both syndromes which supported the role of this chromosome region in pigment production. In the early 1990s, behavioral characteristics were further described and syndrome-specific growth charts developed for PWS along with the frequency of maternal disomy 15 established. **PWS became recognized as the most common known syndromic cause of marked obesity supported by metabolic, biochemical and endocrine surveys.**

Detailed molecular studies in PWS led to the discovery of **DNA methylation testing** for the diagnosis of PWS and AS reported by Driscoll, Nicholls and others in 1993. The **consensus diagnostic criteria for PWS** was also reported in the same year by Holm and others and became one of the most highly cited papers in pediatrics in the past 50 years. The development of **fluorescence in situ hybridization (FISH)** and molecular cytogenetics led to further characterization of the small deletions in the 15q11-q13 region in both PWS and AS which helped in the discovery of a number of other microdeletion syndromes, thereby advancing and expanding the field of medical genetics and syndrome identification. ■

Dr. Merlin Butler – PWS Researcher & Publisher Extraordinaire

As most of you know, Dr. Merlin Butler is a geneticist who is the Chair of our PWSA (USA) Scientific Advisory Board. What you may not know is that he has published more on Prader-Willi syndrome than anyone else in the world! Below are abstracts from some of his recent publications that have been written for us by Dr. Butler with the assistance of Dr. Ann Manzardo, a research colleague in Kansas City. In the last *Gathered View* edition, we recognized his publication of growth charts for non-growth hormone treated PWS, and he is currently (along with statistician Jaehoon Lee, Ph.D.) completing the work on a publication of growth charts for those with PWS treated with growth hormone. This work is funded by PWSA (USA) thanks to a grant from Pfizer. So, between November 2014 and February 2015, Dr. Butler has have been one of the primary authors in the publication of 9 research articles and/or book chapters on PWS (3 abstracted below) and 8 other non-PWS genetic articles. Due to space limitations, we do not have the ability in this edition to abstract another important article recently written by Dr. Butler and published in the *American Journal of Medical Genetics,* **"Increased Plasma Chemokine Levels In Children With Prader–Willi Syndrome".**

We are very proud to have such a close working relationship with Dr. Butler, and are grateful for the hundreds of hours of volunteer time he yearly donates to PWSA (USA).

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

Coding and Noncoding Expression Patterns Associated with Rare Obesity-Related Disorders: Prader–Willi and Alström syndromes

Merlin G. Butler, Kun Wang, Jan D. Marshall, Jürgen K. Naggert, Jasmine F. Rethmeyer, Sumedha S. Gunewardena and Ann M. Manzardo; Dove Press - *Advances in Genomics and Genetics Jan 2015* ***This research was partially supported by a grant from the Prader-Willi Syndrome Association (USA)***

Hyperphagia, or profound food seeking, and obesity are key features of several rare genetic obesity-related syndromes. Prader-Willi syndrome (PWS) is caused by a failure of gene expression in a critical region of chromosome 15 inherited specifically from the father and not the mother through complex genetic mechanisms. The region has a characteristic "imprint" that results in the activation of a different set of genes on the mother's versus the father's chromosomes. PWS most commonly results from a deletion or loss of the region inherited from the father, but may also result from a loss of the regulatory imprint for a variety of other reasons, including the inheritance of both chromosome 15s from the mother.

Alström syndrome (ALMS) is another rare and complex obesity-related syndrome (a subset has the significant hyperphagia similar to PWS), with very severe multiorgan disturbances resulting in loss of hearing and sight and eventually multiorgan failure leading to death. ALMS results from a simple "loss of function" mutation of a single gene (ALMS1) which is known to impact ciliary proteins – needed for the transport of biological materials in cells. Even though scientists understand the genetic causes for these illnesses, there are still many questions about how and why the specific genetic changes produce the symptoms that we observe and how we might intervene to change the disease course.

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To improve scientific understanding of biological pathways that control food intake, energy balance and obesity, we used state-of-the-art genetic technology to examine gene expression patterns in PWS, ALMS and obese adult males compared to non-obese control males. Gene expression patterns were studied by measuring the amount of gene product composed of RNA (a close cousin of DNA) that is present in living blood cells. These products include RNA from both "coding" genes (that eventually code for protein produced in the cell) and "noncoding" genes (including snoRNAs in the SNRPN region of chromosome 15) that function to regulate how much coding RNA "message" is made and converted into protein and in what form. Our examination used highly sensitive methods able to detect millions of different coding and noncoding RNA molecules and estimate their levels in living blood cells.

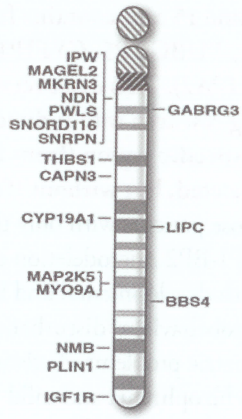
Using very stringent conditions, our study found relatively normal coding gene expression patterns in PWS and obese individuals. Levels of snoRNA from genetic material in the SNRPN region of chromosome 15 were low in PWS which is the defining feature of the disorder. This result is consistent with the role of the SNRPN region in the "processing" rather than the "production" of RNA message for a specific subset of genes with a relatively limited scope of activity. Obese males also showed reduced blood cell levels of RNA message for the metallothionein protein complex which is involved in the transport of toxins out of cells and may reflect an increased vulnerability to damage from metal toxins. In contrast, we found 231 separate genes to be elevated in ALMS compared to control male subjects. These genes impacted basic cellular functions such as cell division, gene expression mechanisms, and development. Additionally, 124 genes were found to be reduced. These genes were involved with cellular metabolism, immune responses, and cell communication. The data suggests that ALMS1 gene activity directly impacts protein synthesis for a broad range of gene products, and loss of ALMS1 profoundly changes protein levels produced in the cell, severely impacting their function. **The high number of gene and noncoding RNA disturbances seen in ALMS contrast with observations in PWS and obesity and may reflect the progressing multiorgan dysfunction associated with ALMS disease processes.** ■

Clinically Relevant Known and Candidate Genes For Obesity and Their Overlap With Human Infertility and Reproduction

Merlin G. Butler & Austen McGuire & Ann M. Manzardo, Journal of Assisted Reproduction and Genetics –2015

Partial funding support was provided by the Prader-Willi Syndrome Association (USA) through the Headley Family Scholarship

The study of genetic obesity syndromes like Prader-Willi syndrome has helped in the identification and characterization of causative genes and molecular mechanisms related to obesity and hyperphagia such as SNRPN, and the leptin/melanocortin pathways. A large number of causative genes are now known, but individually these genes only explain a small percentage of obesity seen in the general population. In addition, there is a great deal of genetic overlap with biological systems that are impacted by obesity. For example, obesity in women can alter reproductive hormone function and numerous biological processes impacting fertility and reducing the ability to conceive and sustain a pregnancy to term. **Genetic dissection of obesity and its interface with infertility will help to characterize disease mechanisms and processes and provide new targets for drug design and therapy leading to earlier diagnosis, potential treatment strategies and prevention in individuals with obesity and/or infertility, including those with Prader-Will syndrome.** Our published report provides a high resolution image of human chromosomes referred to as "ideograms" which are labeled with the location of gene symbols using the most updated list of 370 documented obesity-related genes with several overlapping with human infertility as identified through a systematic search of literature and computer web sources. The image provides a broader view of a large amount of genetic information in the field of obesity and infertility in a convenient format for the readership to



compare the location and distribution of genetic biomarkers with support by the master list of genes in alphabetical order and description in tabular form. The authors encourage the use of this current collection of clinically relevant candidate and known genes in their evaluation of patients and families to enhance clinical application and relevance.

The ideogram for chromosome 15 with the location of obesity-related genes is shown above. ■

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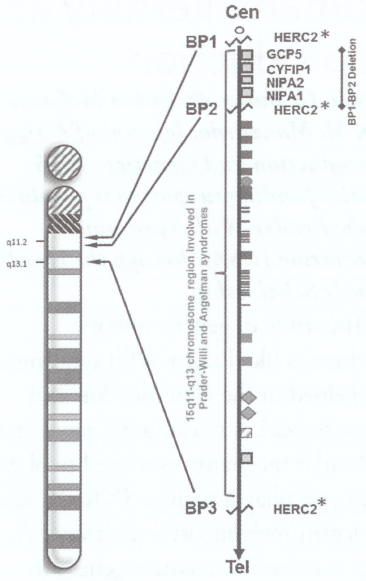
The 15q11.2 BP1–BP2 Microdeletion Syndrome: A Review

Devin M. Cox †,* and Merlin G. Butler

International Journal of Molecular Sciences – Feb. 2015

Research on Prader-Willi (PWS) and Angelman syndrome (AS) has led to discoveries about the different genetic subtypes of these disorders (type I deletion, type II deletion, uniparental disomy, imprinting center defect). This research led to evidence that those individuals with PWS or AS and having the larger type I deletion were typically more severely affected than those with the smaller type II deletion. **The extra deleted region in the type I deletion is between breakpoint 1 (BP1) and breakpoint 2 (BP2) on the proximal long arm of chromosome 15 and contains four genes (i.e., TUBGCP5, CYFIP1, NIPA1, NIPA2). This discovery led to expanding research into individuals with this specific region (from BP1 to BP2) deleted, but without PWS or AS.** Those patients with only the 15q11.2 BP1-BP2 microdeletion can present with developmental and language delay, neurobehavioral disturbances and psychiatric problems. Autism, seizures, schizophrenia and mild dysmorphic features are less commonly seen, but can be present. The 15q11.2 BP1-BP2 microdeletion, or Burnside-Butler syndrome, is now emerging as a recognized disorder. This microdeletion is seen in approximately 1% of patients presenting for chromosome microarray analysis, which is two to four times more often than seen in controls or individuals without any symptoms.

Review of clinical features from 200 individuals from the literature with this microdeletion showed developmental and speech delays in about 70% of cases; dysmorphic features in about 50%; and writing, reading and memory problems in about 60%. Verbal IQ scores of less than 75, general behavioral problems and abnormal brain imaging were seen in about 50% of cases. Other clinical features seen but not considered as common were seizures/epilepsy, autism spectrum disorder, attention deficit disorder (ADD)/attention deficit hyperactivity disorder (ADHD), schizophrenia/paranoid psychosis and motor delay. Not all individuals with this microdeletion are clinically affected, yet the collection of findings appears to share biological pathways and presumed genetic mechanisms. ■



Videos to Watch!

Earlier this year IPWSO and the Prader-Willi Syndrome Association of Ireland joined forces to make four educational films.

These have now been released and are available on our PWSA (USA) website via YouTube as follows:

New Diagnosis: by Dr. Suzanne Cassidy
http://youtu.be/cHPe-zb8vU4

Growth Hormone: by Dr. Charlotte Höybye
https://www.youtube.com/watch?v=q9i6ygajeL0&feature=youtu.be

Dietary Management: introduced by families
http://youtu.be/FTzPCsLEGuM

Behaviour and Mental Health: by Professor A. J. Holland
https://www.youtube.com/watch?v=5MfuGXRXSKY

We hope you will share these and use them for educational purposes. ■

"A new morning means
a new beginning,
a new struggle,
a new endeavor,
but with God by our side,
we can overcome
any challenges and
turn obstacles
into stepping stones."

– anonymous

contributed by Clint Hurdle

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.**

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

Annual Meeting of the PWSA (USA) Advisory Board

By Ken Smith, Executive Director, PWSA (USA)

In January six members of the PWSA (USA) Advisory Board converged on Sarasota and the national office for their annual meeting. These young adults were there to address issues and offer their unique opinions from the viewpoint of people who have PWS.

If you are not familiar with the Advisory Board, here's a little history. 2003 was an important year for PWSA (USA). The PWS community gathered for the 25th national conference, held in Orlando on the Fourth of July. Clint Hurdle, currently manager of the Pittsburgh Pirates, connected with PWSA (USA) because of the birth of his daughter, Madison, who has PWS. And the very first meeting of the PWSA (USA) Advisory Board was held at that conference where they were introduced and participated in the general membership meeting and luncheon.

David Wyatt, Ken Smith, Mary K. Ziccardi and Janalee Heinemann were their advisors. We all grieve the loss of David but are happy to have Evan Farrar as an advisor. A few of the eight adults with PWS on that first Advisory Board are still serving, and some different faces have appeared. Trevor Ryan from California is a brand new member.



left to right: Shawn Cooper, Abbott Philson, Ken Smith, Conor Heybach, Kate Kane, Mary K Ziccardi, Brooke Fuller, Lauren Lange

Mary K. wrote for the Gathered View in 2003, "Each participant shared his or her past and current residential and vocational experience, and successes and disappointments were openly and enthusiastically debated within the group. Interestingly, members said they do not wish to live or work completely independently, agreeing that they feel happier and healthier when supervision and support are consistently provided."

This year, in addition to trips to the beach and other activities, the group conducted a live Facebook chat, answering questions from people in the PWS community about a variety of issues. They also helped to develop a new handout that PWSA (USA) is creating for schools to support students with PWS.

Like the rest of the world, not everyone lives up to their potential, but seeing what these young adults have done and are doing may give a large measure of hope to parents of little ones who wonder and fear for their child's future. We offer bios of half the Advisory Board members in this issue and will follow up with the other four in the May-June *Gathered View.* Meet Trevor Ryan, Conor Heybach, Lauren Lange and Brooke Fuller:



Hello, my name is **Trevor Ryan** and I am 25 years old. I live in Newhall, California, with my mom and dad. I have two sisters, Crystal and Danielle. Since graduating from high school, I work at a company named AMS. They are a fulfillment company that processes online orders for many products such as Tom's Shoes and Paul Mitchell hair products. My job is to make boxes to ship the products and also sort inventory. Almost every day after work, I go to the gym to work out. My favorite things to do include hiking, reading, going to the gym, swimming, using my computer and spending time with my family. I am excited to start working with the Advisory Board!



Brooke Fuller lives in Grand Rapids, Michigan where she is an active member of the community. She holds an associate degree from Davenport College in Accounting. She is a board member of the ARC-Kent County and serves on the Recipients Rights Committee of Network 180/Kent County Community mental health. She holds a certificate in Peer Support mentoring from the Developmental Disabilities Council of Michigan and has participated in Self-Determination training through the Michigan ARC network. Brooke regularly speaks to service providers and classrooms about various topics related to her life. She is a thoughtful advocate for herself and others. She is an avid swimmer and Special Olympics athlete, who also enjoys walking, taking care of her three cats, and traveling.

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Lauren Lange received a very late diagnosis of PWS at age 16. Due to a traumatic birth and two episodes of asphyxiation/ resuscitation, the resulting brain damage caused physicians to overlook any other diagnosis. At age 16, already obese, Lauren received a diagnosis of Type 2 Diabetes and subsequently was referred to the Emory Genetics Clinic where she received her diagnosis of PWS. That same year, 1997, she spent three months at The Children's Institute in Pittsburgh, which was extremely helpful in educating her family about her needs.

While her school years were particularly difficult, after high school Lauren began her active volunteering career. She volunteered for many years at Children's Healthcare of Atlanta-Egleston and three years at Angel Flight in Atlanta. Today, Lauren is very healthy, active and happy. She has a personal care assistant who has been with her almost four years. Her weekly schedule is filled with many activities. She participates in equine therapy where she trains and works with miniature horses. She has a volunteer position at The Pier Organization near her home, where she works on an administrative project for UPS and Merke Pharmaceuticals; does volunteer work at The Forsyth County Humane Society Thrift Store and for her mother, who serves as Executive Director for the Georgia Association for PWS since 2004. Three times a week, she works out with a personal trainer. She also participates in Zumba classes at the gym. She lives at home with her Mom and Dad.



Conor Heybach was born in New York in 1980 and has lived in Switzerland and Chicago. Conor was diagnosed with PWS in 1995. He attended Hardey Prep elementary school and Archbishop Quigley College Prep High School in Chicago where he played on the golf team and chess team and then attended Northeastern Illinois University, where he wrote for the school paper and founded the chess club. Conor graduated from NEIU in 2009 with a Bachelors degree in Criminal Justice. Conor works as Chess Educator and Chess Club Coach and Security and Administrative Assistant at Altus Academy in Chicago. Conor lives with his parents and is a frequent visitor to the home of his sister Michelene, brother-in-law Mike Bajakian and three nieces. Conor has also worked as an election Judge for Cook County for the last 10 years. According to Conor, "It's a struggle to live with PWS, but it's a great opportunity to be on the Advisory Board with my friends in order to give advice and inspiration to the organization and to all the families who struggle with PWS." ■

Prader-Willi Syndrome Equity Coalition

Racial and ethnic diversity in rare disorders like Prader-Willi syndrome (PWS) is often hard to detect. Not because they do not exist but because communities of color and economically disadvantaged families have limited access to high quality healthcare. Disparities in health care are well documented in the United States but they do not have to exist in PWS.

PWSA (USA) is excited to announce the formation of the PWS Equity Coalition. In our first conference call, we identified some of the issues and cultural barriers:

- lack of literature defining racial and ethnic differences within the syndrome
- lack of nonwhite families' participation in clinical trials
- lack of appreciation of the impact on PWS families dealing with food management regarding their extended families and communities in the African-American and Hispanic populations
- lack of knowledge on diagnosis and treatment of PWS in medical communities dealing primarily with African-American and Hispanic populations

"Be the change you wish to see in the world!" Gandhi

We invite families, service providers, and researchers who have a particular interest and/or expertise in the area of eradicating inequities in PWS research, diagnosis, treatment, and services, to let us know if they would like to participate. Interested parties can email Leon D. Caldwell at lcaldwell@pwsausa.org with a copy to Janalee Heinemann at jheinemann@pwsausa.org. Please describe the reason for your interest and your particular issues of concern. ■

A Note to Share-

Readers: This article written by Amy McDougall was initially published on the Facebook PWS open forum. She has given us permission to publish this edited version in the Gathered View.

In the midst of a "situation" at church, where well-meaning people kept bringing in extra food, I needed to do a little writing. Thought I would share with group, with the hope that maybe someone else would be able to revise/reuse…

Rather than simply talking about what Noelle's syndrome is [PWS], I thought it might be helpful to share some insight into her world on a daily basis. Imagine the hungriest you've ever been. That gnawing feeling in your stomach, the nausea and pain that makes it difficult to focus on anything other than when you might be able to get something to eat. Now imagine that you have that horrible feeling every minute of every day.

And that feeling doesn't subside no matter how much you eat. You don't even know what it feels like to feel full, even if you consume enough to stretch your stomach to the point of rupture. Add to that an inefficient metabolism, so you could become morbidly obese on less than 1000 calories a day. There's no medication that takes away the insatiable appetite. That's life with Prader-Willi Syndrome.

This is what Noelle deals with every day. We can't get rid of the hunger and we need to keep her healthy, so the best we can do is try to combat the resulting anxiety. The only way that we can diminish her anxiety is to create structure and routines that keep her focused on anything other than the possibility of getting food. We lock our entire kitchen to keep her safe. We only eat at certain times and we carefully tailor her diet in order to keep her calories down. Staff at school do the same.



Noelle appears to be a sweet and easy going girl, but the reality is that she is expending incredible amounts of energy every moment to deal with the craving for food. Breaks in routine and unexpected exposure to food literally become overwhelming. As a parent, it breaks my heart to watch my little girl starving in a society that equates food with comfort.

So what can adults and her peers do to help? The bottom line is that the most productive way to diminish her anxiety is to limit any food in her presence to only what has been planned in advance and not change that plan. Know that Noelle greatly appreciates others' willingness to think of her needs.

I admit, I often feel that I am walking on a tightrope. I want so badly to not place demands on others and appear to place our family's need ahead of others'needs, yet Noelle is my little girl. God has created an amazing individual in her. I know that I'm not alone in wanting to provide the opportunity for her to grow into the woman God wants her to be. ■

~ Edited by Andrea Glass

Kahlil's Smile

By Leon D. Caldwell, Ph.D., father to Kahlil

Kahlil has a brilliant smile. It's contagious; you smile back when you see it. That joyful grin, though, quickly transforms into a pout when he fixates on the next meal.

We know he's not hungry. He just ate.

His brain and body tell him one thing despite the meal we served an hour ago. And our hearts experience a mix of emotions – love, frustration, guilt and exhaustion – despite the fact we know it's a spectrum disorder.

This wasn't always the case. Doctors misdiagnosed Kahlil with childhood obesity until he was six. Finally, a pediatric endocrinologist conducted a genetic test that introduced us to these words: Prader-Willi Syndrome.

First came shock, followed by denial, anger at the pediatricians and then finally acceptance. Five years later, the journey remains a struggle for us. We have to remind ourselves that PWS is a spectrum disorder with a range of features. We fight tears and frustration in the hardest moments.



Groups such as PWSA (USA) and mainstream media coverage have increased our understanding of PWS and more importantly, helped us feel a little less alone. We have resources and information on why our son has gained so much weight despite his physical activity and healthy diet. We can explain to friends the reasons why Kahlil always wants to eat and, if denied, will sneak food at a party. Digestible information to share with family and friends has been the best resource. It helps us feel a little less embarrassed and more empowered that we can articulate how to keep Kahlil smiling.

…information to share with family and friends has been the best resource. It helps us feel… more empowered that we can articulate how to keep Kahlil smiling.

We know that together, we can manage his PWS. ■



Part 2 of 2-Part Series – *continued from the January-February 2015 issue of Gathered View.*

Implementing the TRAIN (Tool for Reducing Anxiety, Insecurity and Noncompliance)

By Janice L. Forster, M.D. and Linda M. Gourash, M.D. of the Pittsburgh Partnership, Specialists in Prader-Willi Syndrome

Designing the TRAIN

Daily activity:	Time of day:	Estimated duration:	Comments:
Getting up in the morning	6 am	1 hour	Doesn't awaken with alarm; never wants to get out of bed
Getting washed and dressed	7 am	1 hour	Dawdles; needs 1:1 coaching; argues about what to wear
Breakfast	8 am	15 minutes	
Gets on the school bus	8:30 am	15 minutes	Always slow
Gets off the bus	4 pm	5 minutes	
Snack	4:05 pm	10 minutes	
Walks the dog with mom	4:15 pm	30 minutes	
Videogames	4:45 pm	1 hour	
Dinner	6 pm	30 minutes	
Homework	7 pm	1 hour	Slow; needs 1:1 coaching
Showers and gets ready for bed	8 pm	1 hour	Dawdles; uses too much water and body wash
Bedtime snack	9 pm	15 minutes	
Bedtime	9:30 pm	1 ½ hours	Never wants to go to sleep!

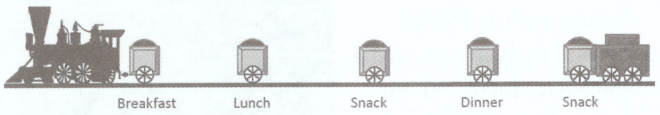
STEP 1 With a pencil and paper, write down the schedule for a typical day as it currently exists for your child with PWS, emphasizing the order of activities and an estimate of the amount of time devoted to each one. Make any comments that explain the amount of time expended for each activity, if relevant. This is an exercise. Not too many families can actually complete this schedule and keep it running consistently.

Note: If your schedule looks like this, and your child with PWS knows or refers to this schedule, you may not need the TRAIN!

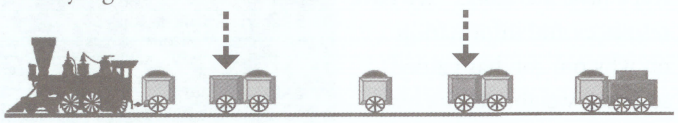
STEP 2 Create the track for the linear schedule for the day, starting with the morning (near the engine) and ending with bedtime (near the caboose). It is helpful to have "train cars" that are either stylized to represent meals and activities (for younger children) or small white eraser boards to write on for meals and activities for older persons. Some parents/carers use a velcro strip to fasten the train cars.



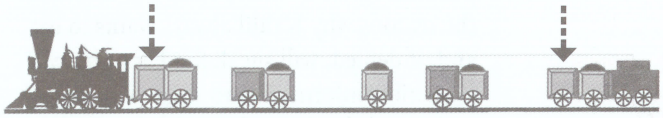
STEP 3 Place the **mealtimes and snack** on the track.



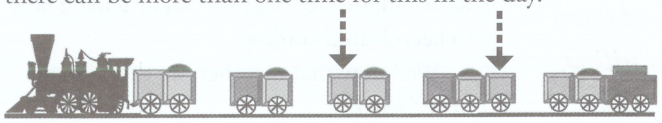
STEP 4 Add the **exercise times** on the track. Exercise is usually right before the meal or snack.



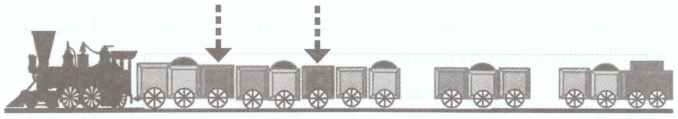
STEP 5 Place the **grooming and dressing times** on the track. Grooming is usually right before the meal or snacks.



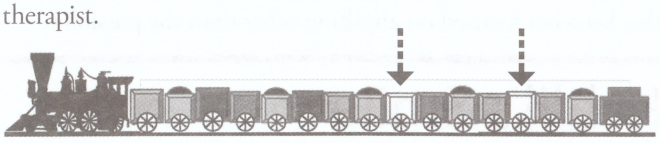
STEP 6 Place the opportunities for **leisure time** on the track; there can be more than one time for this in the day.



STEP 7 Place **non-preferred activities**, such as school work or chores (laundry), before the leisure time.



STEP 8 Place sensorimotor activities on the daily schedule. A sensory diet can be developed with the help of an occupational therapist.



Remember, it is the order of the events in the day and not the clock time of day that is critical for the running of the TRAIN. The engineer determines the activities and the order of events in a given time frame. There can be several engineers of the TRAIN across the day; for example, one engineer for the morning routine, one engineer for school or work, and one engineer for the evening routine. The person with PWS should always know who the engineer is.

Find a place in the home, school or work environment to display the TRAIN. It is important to have the schedule in a prominent place, so the person with PWS can refer to it.

Implementing the TRAIN

STEP 1 Explain the concept of the TRAIN to the person with PWS as follows, positive and upbeat: "We have an exciting new way to keep you 'on track' with your daily schedule! It's called the TRAIN. We know that you like to know what is happening in your day. So, just likea real train, all the events in the day are put on the schedule so that you can see what comes next and what you've already accomplished. This is just like the rail cars on a real train track."

STEP 2 Show the linear schedule of the TRAIN without the rail cars, and demonstrate in real time where they are in the schedule just now.
Just as you conceptualized your design of the TRAIN, you will implement the schedule for the person with PWS in the same way.

STEP 3 Show where the meals and snacks appear on the linear schedule. Practice this for one week. If you are using a white board, you can actually write in the menu for that meal.

STEP 4 Show where the exercise falls on the schedule. This should always be before a meal or a snack. Implement this for one week.

STEP 5 Show where grooming and dressing occur on the schedule.

STEP 6 Show where leisure "self-guided fun" activities fit into the schedule.

STEP 7 Show where chores and school work occur on the schedule.

STEP 8 Show where sensory stimulation and sensory motor activities fit into the daily plan.

Establishing a back-up plan:

For every preferred activity, there should be an alternative determined in advance. For example, if an outing is planned but not possible due to weather or transportation problems, a movie, game or extra leisure time can be substituted. The person with PWS should know this alternative in advance.

The Day Stops Here!

When a tantrum or shut down impedes the flow of the day, the schedule stops until the person's behavior reorganizes. When the person is ready to get back on the TRAIN and resume their day, the order of activities on the schedule should be followed exactly, but the duration of time in the activity is decreased, and the expected outcome of activities is diminished. For example, exercise time might be decreased from 1 hour to half-hour, TV time is similarly reduced, and instead of doing two loads of laundry, only one load is required. The meal time schedule may be delayed. If the tantrum or shut down lasts long enough to miss a meal, the person can still get their meal if they pull themselves together. But if hours go by and the meal cannot be saved, the person is offered a predetermined "no frills meal" with fewer components and condiments to equal the calories they lost. The objective is to catch up to the daily schedule by the next meal, if possible, and most certainly to complete the daily schedule before bedtime, because the next day should start anew.
Tantrums and shut downs should receive low attention (matter-of-fact demeanor; acting as if bored), but the safety of all should be assured. The PWS person in a shut down or tantrum should never be ignored, however. People with PWS have a poor sense of time passing. Incidents can last 5 minutes, 5 hours, or 5 days. While providing low attention and low affect, the carer is also supportive of the person in shut-down, reminding them that time is passing, and that they really want the person to get to experience their next preferred activity. The context of the event is an important consideration also. A person with PWS could be angry at one carer, but interact with another as if nothing happened. This characteristic can be used adaptively to get the person back on the TRAIN.
Explain ***The Day Stops Here!*** to the PWS person in the following way, in words that are appropriate for their developmental level:
"We know that every now and then you have a [tantrum or meltdown]."
It is important to use the words that the person knows for these behaviors.
"When you have [a behavior], it stops the TRAIN; that means, everything that is supposed to happen is postponed, ***including meals and snacks***, until you get your behavior organized. There is good news; we will hold your meal or snack for a while; but if your behavior goes on too long, we will give you a drink that has all the calories of a meal. So, together, we will do everything we can to get your behavior back on track. After your behavior gets back to normal, you can get back on the TRAIN and resume your daily schedule."

Troubleshooting

Dawdling (due to deliberate slowness, getting lost in thought, or being unable to remember what to do next) and difficulty leaving one activity to begin another (shifting) are common manifestations of the cognitive style associated with PWS. When the next activity is a rewarding one (something the person enjoys doing), the transition is usually smooth and timely.

1. If there are times in the day when the person shuts down, melts down, or the transition is rough, change the sequence of activities by scheduling a more preferred activity at the time of the meltdown to improve the flow of the day.

2. If you have optimally managed the sequence of the activities in the day, increase the density of reward by scheduling two preferred activities in a row to get over the rough transition.

3. If you have increased the density of the reinforcing activities, and there are still problems, implement an incentive plan as follows: Tell the person that you know (and demonstrate on the schedule) that they seem to have trouble at this particular time of day. Tell them that whenever they make a successful transition over the rough spot, they will earn a ticket or token. This small reward can be exchanged for bonus time for a preferred activity (e.g., screen time, collections, time with a family member or peer, etc.). ■

Remember, every child is unique and each child's train is built to suit their individual needs. Although the TRAIN is designed to decrease uncertainty across the day, some children will require behavior plans that are supervised by a professional. Help is available!

www.PittsburghPartnership.com

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
- Graphic design
- 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

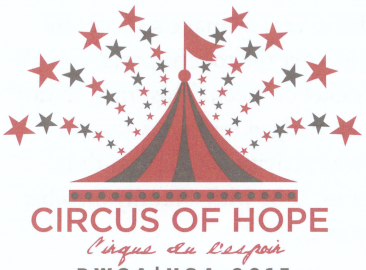
• Increasing your knowledge about PWS and its treatment and management strategies

• 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 Mary K. Ziccardi via the PWSA (USA) office at 800-926-4797 or 941-312-0400 or info@pwsausa.org or by fax to 941-312-0142. The deadline for nominations is May 15, 2015.

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 some time to help, please fill in our volunteer form at www.pwsausa.org/help/volunteer.asp. There is no deadline, as volunteers are always welcome. ■

Prader-Willi Syndrome Association (USA)
8588 Potter Park Drive, Suite 500, Sarasota, FL 34238
www.pwsausa.org



Come One, Come All, to the Greatest Show on Earth!

From November 4th - 7th PWSA (USA) will be hosting Circus of Hope – our 2015 National Conference at the Buena Vista Palace in Orlando, FL. We invite you to join us at the largest conference of this kind. Experience where Research and Support Services come together at singular event with the one common goal: to improve the lives of individuals diagnosed with PWS. The conference sets the stage with programs tailored for parents, people with PWS of all ages, siblings, and scientists, in addition to medical and professional providers, who will travel from all over the world to attend. The opportunities to network with others who understand is priceless; whether you are a professional or a family member, you will leave feeling recharged and informed. For our kiddos, they will feel a sense of community and belonging.

The conference events will include: • Scientific Day • Professional Providers Day • General Conference • Youth & Infant Program (YIP) • Youth & Adult Program (YAP) • Sibling Program • Chapter Leaders Day • Gala Events • Exhibit Hall • International PWSO Professional Providers & Caregivers Day

For more information please visit pwsausa.org or call us at 941-312-0400. We look forward to seeing you there!

The Consequences of Graduating at 18

By Kate Beaver, M.S.W., C.S.W., Crisis Intervention Counselor, PWSA (USA) and B.J. Goff, Ed.D., Goff Associates Disability Consultants; PWSA (USA) Professional Providers Advisory Board Members

One of the major questions we receive from parents is about their children graduating from high school at 18 with either a certificate or diploma or continuing an educational program until age 21 or 22 (varies by state). This is a question that each family needs to consider carefully at the start of the student's high school program, not in 11th or, worse yet, 12th grade.

Generally, the right to special education ends when the student "ages out" or when the student meets the exit criteria for high school and graduates with a regular diploma. Aging out refers to the upper age limit set by the states whereby a student may continue to receive special education services; typically 21-22. However, some states have passed laws allowing their special education students to continue receiving services until the age of 25. ***Federal law under IDEA (http://idea.ed.gov/explore/home) mandates that students be allowed to remain in school until they turn 21, as long as they do not graduate.*** States may extend the age, but they cannot make it less than what federal law stipulates. Be sure to ask YOUR school district what their age limit is for continuing education.

Here are some questions to ask your school (sooner rather than later).

- What is the age at which my child has a transition plan?
- What is the age whereby my child is no longer eligible for educational services?
- What kind of transition programs and services do you provide (or arrange to be provided) for students who remain in school beyond their senior year?
- If my child is not eligible for a general education diploma at the time of graduation, but instead continues on in an educational/vocational program through the school, can he continue to work on those unmet diploma requirements? (Or receive help toward GED?)
- What exactly does a certificate represent? Completion of IEP (Individualized Education Program) goals? Attendance?

Remember, once your child exits the school system, you are not greeted by someone from the adult system who offers you all kinds of options. Indeed, while your child may be *eligible* for various programs and services, he or she is not *entitled* to much of anything. It's all on you to seek out options, get assessments, visit programs, get on waiting lists, fill out paperwork for the adult service system and whatever else is required.

PWSA (USA) will soon have a more in-depth article on this subject. Call (800) 926-4797 for a copy. ■

ABLE Act Overview

By Kate Beaver, M.S.W., C.S.W., Crisis Intervention Counselor

The Achieving a Better Life Experience (ABLE) Act of 2013 (S. 313/H.R.647) was introduced in the 113th Congress by a bipartisan, bicameral set of Congressional Champions including Sens. Robert Casey, Jr., (D-PA) and Richard Burr (R-NC), and Reps. Ander Crenshaw (R-FL), Chris Van Hollen (D-MD), Cathy McMorris Rodgers (R-WA), and Pete Sessions (R-TX), and in the US Senate on Feb. 13, 2013. On December 3, 2014, the ABLE Act passed in the US House of Representatives (404-17). Two weeks later, on December 16, the US Senate voted to pass the ABLE Act as a part of the Tax Extenders package. On Friday, December 19, 2014, the President of the United States signed the Tax Extenders package, making the ABLE Act the law of the land.

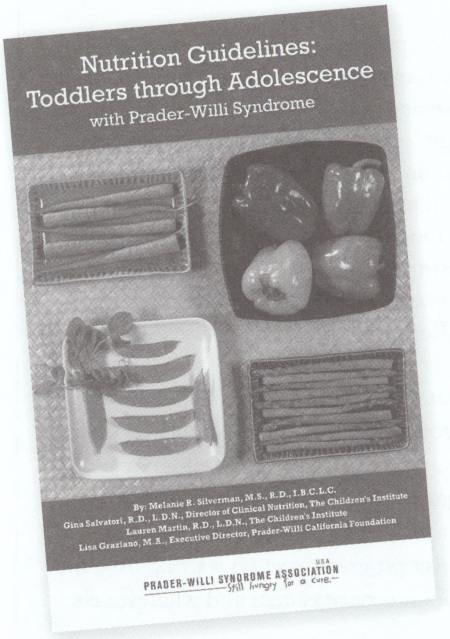
The ABLE Act amends Section 529 of the Internal Revenue Service Code of 1986 to create tax-free savings accounts for individuals with disabilities. The bill aims to ease financial strains faced by individuals with disabilities by making tax-free savings accounts available to cover qualified expenses such as education, housing, and transportation. The bill would supplement, but not supplant, benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary's employment, and other sources.

An ABLE account could fund a variety of essential expenses for individuals, including medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation. The ABLE Act provides individuals with disabilities the same types of flexible savings tools that all other Americans have through college savings accounts, health savings accounts, and individual retirement accounts. The legislation also contains Medicaid fraud protection against abuse and a Medicaid pay-back provision when the beneficiary passes away. It will eliminate barriers to work and saving by preventing dollars saved through ABLE accounts from counting against an individual's eligibility for any federal benefits program. ■

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

New Publication!

Nutrition Guidelines: Toddlers-Adolescence with PWS



Thanks to the volunteer efforts of Melanie Silverman, M.S., R.D., I.B.C.I.C, Gina Salvatori, R.D., L.D.N. (Director of Clinical Nutrition at The Children's Institute), Lauren Martin, R.D., L.D.N. (also with The Children's Institute) and Lisa Graziano, M.A., Executive Director of the Prader-Willi California Foundation, we are pleased to offer an updated nutrition booklet. These wonderful professionals donated numerous hours to revamp and update this 16 page publication, which includes sections on calorie needs, what and how to feed your child, special events, and much more. This booklet can be purchased for $7.50 by calling the office, 1-800-926-4797, or by ordering from our website, www.pwsausa.org/shop/publications.

This same team is putting the finishing touches on an updated Nutrition Guidelines: Adolescence-Adult with PWS. We anticipate that will be available for purchase in the next couple of months. ■



WE REMEMBER

On June 11, 2000, Maria José, a beautiful infant was born to Josefina and Beto, a young Mexican couple from Pachuca, Mexico.

Maria José was born with most symptoms and signs of Prader-Willi syndrome (PWS) and enrolled in an early intervention program; her diagnosis however, was confirmed by lab testing until age 2 years. She never vomited but had several episodes (#5) of abdominal distention. Her mother learned how to measure Maria José abdomen's circumference, thus she knew when to alarm and seek medical attention to the pediatric emergency room at the nearest hospital. Each time she had these abdominal distention, she received medical management with nasogastric tube to decompress her abdomen and occasionally she needed hospital admission.

During her 5th episode, she complained of mild abdominal pain without any vomiting or fever. Her mother noticed she was getting progressively worse and took her to the emergency room without any response to common procedures. Five hours after onset of clinical symptoms, she underwent surgical intervention for questionable gastro-intestinal perforation. Her surgery was successful according to Maria José's mother, unfortunately 2 hours later, she developed severe peritonitis that did not respond to broad-spectrum antibiotics and took her place in heaven at age 9 years 2 months.

Maria José was the only child and her parents aware of lack of knowledge of PWS in the community, organized with their own effort and personal expenses the first "PWS Conference" for families, nutritionists, physical therapist, pediatrician and other health care professionals on March 2005, before their daughter's fifth birthday. Maria José was the only child known to have this genetic condition in her town of Pachuca. Along with other speakers, I had the opportunity to participate in this interesting small meeting in which the audience included more health care takers than families. Children of 6 participating families had clinical but not confirmed diagnosis of PWS and they were from different towns or states in Mexico. From March 2005 till present time, Josefina and Beto have organized 4 events with increasing number of health care professionals and families. Last conference was held in Pachuca, October 9-11, 2014. This meeting was a real success not only with larger audience that included 130 health care professionals and 88 families but participation of local government authorities. For the first time Maria José's parents received a partial aid from local governmental office to house PWS families from out state. My meeting this time was not only with parents and other professionals but two members of the government who kindly listened to parents' concerns and agreed to apply at higher government level to help to "Increase the awareness of PWS at national level".

Josefina and Beto believe indeed that their little angel is watching them from heaven and by helping other families with PWS, she will be even happier! ■

Moris Angulo, M.D.

IPWSO Venezuela Parent Delegate Visits PWSA (USA) Office





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

We had a wonderful visit at our office from Alicia Borga, her husband Ernesto, and her son Carlos who has PWS. We had a translator, Fanny, who was kind enough to volunteer her time. Hearing the realities of current life in Venezuela helped us to appreciate all over again how fortunate we are in our country. Although Alicia and her husband are professional lawyers, there is very little work for them and they have to live behind high walls with guards. Their adult children and grandchildren also lived with them for safety reasons. Carlos states it is not safe for him to go out in the community. Alicia struggles with how to help the families dealing with PWS in her country because the barriers are great and the resources are few. We gave her many materials on PWS to take home with our blessing to translate all if possible. The following is a translation of an email from Alicia after the visit.

Cara Janalee,

Many thanks to everybody, Alicia. We are going to fly back to Caracas tomorrow very happy we could share our happiness with you. We wish to thank you a lot for the love we received, especially from you Janalee together with your staff, Fanny and her husband who were so kind to help us. A big hug hoping to meet again. I'll keep you posted from Caracas if I can.

Alicia

I am proud to say that PWSA (USA) has always had a generous international heart. May we always remember to extend a helping hand to people dealing with Prader-Willi syndrome around the world in less developed countries or countries that are in crises. ■

Too often we underestimate the power of the smallest act of caring, which in itself has the potential to turn a life around

~Leo Buscaglia

Sandy Guisti- A Tireless Volunteer Making a Difference

By Lota Mitchell

I first met Sandy and Tom Guisti at a support group meeting in Pittsburgh for parents about 1981 from Ohio, Pennsylvania, and West Virginia. This was before the days of email and chapters. Their daughter, Angie, will be 45 in April, and my daughter, Julie, was 45 in October.

Our tri-state group divided after a few years because of differing state laws. Sandy went on to assist in the formation of Prader-Willi Syndrome Association of Ohio in 1987, where she is presently a board member and Vice-president and Past Chairman of the board.

For the past 17 years she has planned and cooked a 5-to-6 course gourmet meal as a benefit dinner for the organization. She says, "The dinner covers two evenings, a Friday and a Saturday. We serve about 25 people plus all of the workers. We have a fun time those two days cooking, talking, laughing and eating." Over these years this event has raised close to $100,000, a portion of which has gone to support PWSA (USA). When the national Prader-Willi conference was held in Columbus, she served as co-chairman of venue arrangements.

She founded PWSA of Ohio Weekend Camp and has coordinated it for 15 camps, and she has organized many Family Festivals for the Ohio chapter, a one-day event with swimming, bingo, crafts, carnival games and one or two speakers or discussion sessions.

At present she publishes the PWSA of Ohio newsletter "The Prader-Willi Voice", maintains the organization data base and membership file, refers families affected by PWS to people and programs when they are in crisis. She prepares displays and represents PWSA of Ohio at events and is presently helping update the PWSA of Ohio Road Show, a presentation to be offered around Ohio to County Boards and agencies to raise awareness of PWS.

Yes, one dedicated person can make a difference! ■

Contributions

Thank you for contributions in December 2014 -January 2015. We try to be accurate in recognizing contributions above $25, and apologize for any errors or omissions. If you notice an error, please tell us.

Major Benefactors ($500 and more)

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

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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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Thank you Angels!

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Mark your calendars and save the date for the 2015 PWSA (USA) National Conference. The event dates are **November 4-7th** at the Buena Vista Palace in Orlando, FL. Details and more news on page 12...

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