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

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

# Raising an Army of Advocates: Part 2

***By Evan Farrar, Crisis Counselor***

In the September-October 2012 issue of *The Gathered View*, after attending the Institute of Special Education Advocacy (ISEA) in Williamsburg, Virginia, I wrote:

My hope is that PWSA (USA) will join this effort by raising our own army of PWS parent advocates who are equipped with the knowledge and strategies they need to support the children they love. So that someday soon a free and appropriate public education, still only a promise for too many, will at last be a reality for students with PWS in every school across the United States.

On March 7-9, 2013 this hope started to become a reality when PWSA (USA) took an exciting and unprecedented first step in building a PWS Special Education Advocacy Network by sponsoring the first Wyatt Special Education Advocacy Training (WSEAT) in Sarasota. Eleven people from the PWS community gathered from places as far away as California, Oregon, Massachusetts, Kansas, and Texas to learn basic advocacy skills through a day-long presentation on special education advocacy by Wrights Law Trainer, Patricia Howey (www.wrightslaw.com). This was followed by an additional half-day training conducted by PWSA (USA) educational experts Mary K. Ziccardi, B.J. Goff, and Michelle Holbrook. The topics ranged from basic advocacy skills, working to build a partnership with school professionals, the effective demeanor of an advocate, how to address PWS-specific IEP issues, behavioral management, and basic special education law. Participants, who included parents and professionals working in the PWS community, were selected through a competitive application process and agreed to return home to teach basic special education advocacy skills to parents in their local PWS communities.

During the two-day training, participants made new friends, learned important information to share with parents in their home communities, got to know leading special education advocates, shared their experience and expertise with each other, and engaged in wide ranging discussions with trainers and participants about the challenges and opportunities for students with PWS. It was inspiring. And



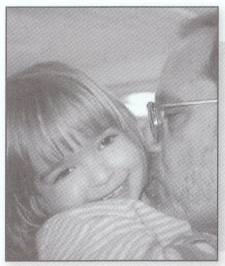
*Evan Farrar and David Wyatt*

participants agreed, giving the first WSEAT a 96% approval rating and unanimously recommending PWSA (USA) sponsor frequent WSEAT trainings in the future.

And we agree! We can't stop now. For the investment and commitment of the first WSEAT to really pay off, the follow up is vital. Our goal is to nurture and support this first class of Wyatt Advocates and then – with their help – keep building a dynamic special education network within the PWS community. We know this will help us better support students with PWS and the school professionals who work with them. If you would like to join and support the WSEAT movement, please contact me at cic3@pwsausa.org Together, one by one, school by school, community by community, and state by state we can make the hope for an army of PWS special education advocates a reality. ■

*"For Everything that has been – Thanks.*
*For Everything that will be – Yes."*
*- Dag Hammarskjold*

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*Manny kissing Isabelle*

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*Back row standing (left to right): Patricia Howey (Wrights Law Speaker), Evan Farrar (pwsa staff), Nina Roberto, Kate Beaver (pwsa staff), BJ Goff (speaker), Heather Molzer, Jennifer Arcaya, Kathryn Crawford, Roger Goatcher, Ray Valles, Michelle Holbrook (speaker), Janalee Heinemann (pwsa staff)*
*Front row sitting (left to right): Clari Bocanegra, Tammie Penta, David Wyatt (Guest of honor), Mary K. Ziccardi (speaker), Jennifer Bolander, Patsy White*
*Not pictured: Jarod Wells*



## David Wyatt PWSA (USA) Crisis Counselor Emeritus

For those who've been around PWSA (USA) – and especially involved in any way with its family support and crisis services over the years – David Wyatt is a much beloved and inspiring figure. Beginning in 2000, at the request of then Executive Director Janalee Heinemann, David began working as the first "official" PWSA (USA) Crisis Intervention Counselor. He was well suited for the task, bringing 37 years of professional counseling experience and education to his new counseling role with the PWS community. In addition to his many professional gifts, David brought to our association his humble, gentle, and calming spirit that personified the best a counselor can offer to a person or family in crisis. To this day, David's hard work and spirit of person-centered creativity and collaboration are the foundation of PWSA (USA)'s unique and very effective crisis intervention program. And so it was with great respect, gratitude, and thanksgiving that we named our first special education advocacy training after David who long ago – without the support we benefit from today – worked quietly and effectively with parents, teachers and schools across the country to help students with PWS claim their right to an appropriate and effective learning environment.

### What participants are saying about the first WSEAT:

- "The WSEAT is a positive and empowering step by PWSA (USA) to help parents provide a safe and productive school environment for their kids. It is a great opportunity to help parents in my state."
- "Having a training with a group of people with the same plans and wants for their children as I do, along with learning and expanding my IEP preparedness, will prove invaluable to my child's development. We all share a bond and have someone to help us with any questions we might have."
- "The WSEAT empowers trainees to empower parents."
- "The WSEAT is an information-packed, relevant, and helpful training on nearly every IEP issue facing families."
- "We are our child's best advocate. When we understand the law and the system, our experience can be rewarding. Thank you for the opportunity. I will be forever grateful."
- "Wow! This training took the meaning of advocacy to a whole other level. Great conference and what a great treat to get to see David Wyatt. He was such a great inspiration to me early on in my journey with PWS and with the national organization that led me to taking a leadership role in my own state."
- "The WSEAT was great opportunity to learn about PWS specific needs within the school environment." ■

# 2013 PWSA (USA) National Conference All-Stars – November 7-9, 2013



*Dale and Dottie Cooper*
*Interim Co-Executive Directors*

This is an exciting year for our entire national and chapter organization. PWSA (USA) is intensifying support to strengthen chapters by providing tools and resources to assist chapters with all areas of operations and helping chapters increase their fundraising and visibility. PWSA (USA) supports families and professionals through programs such as the new Wyatt Special Education Advocacy Training initiative (WSEAT), counseling, medical information, new parent programs, publications, and research.

All of our efforts culminate this year with the 2013 National Conference in Orlando, November 7-9. Michelle Torbert and Jackie Mallow, our conference co-chairs, have been busily at work leading teams and coordinating programs for the multifaceted event.

On November 7, PWSA (USA) will be hosting 3 simultaneous conferences, filled with "**All-Stars**" and dedicated to professional growth, as follows:

- 27th Annual Scientific Day for PWS-related research professionals presenting to each other. Parents and other professionals are welcome to attend and observe; however, findings will be presented to families in the General Conference.
- Professional Providers Day for professional caregivers providing supported living and/or employment services for persons with PWS.
- Chapter Leaders Day for the president and/or executive director of each chapter organization.
- Welcome Reception – A great opportunity for camaraderie for all families and professionals attending the conference.

On November 8 and 9 is the General Conference. You will not want to miss these two full days of presentations, information, workshops, and interventions in each of three tracks that support the needs and interests of parents and caregivers of children and adults with PWS ages 0-5, 6-19, & 20 and up. We have assembled an "**All-Star**" roster of professionals who will present the latest in research and support programs, such as education advocacy, behavioral, medical, and therapeutic interventions, in addition to legal, financial, advocacy, supported living, and family considerations.

Simultaneously, there will be separate sessions to care for and entertain our true "**All-Stars**" – our loved ones with PWS and their siblings. For young children, there will be a YIP (Youth & Infant Program) and for older children and adults we have the YAP (Youth & Adult Program). A special session for siblings will address the needs and celebrate the accomplishments of this most important part of the family structure. You will be so impressed with all the special care and programs designed for these groups.

Don't forget the grand GALA and dance on the evening of November 8. This is a remarkable opportunity for our "**All-Star**" families and professionals to come together in celebration of the great strides we have collectively made over the years. It is another wonderful opportunity for networking and absorbing the energy we give to each other.

May is Prader-Willi Syndrome Awareness Month. ***On the Move*** is a combination of fundraising and awareness campaigns that help our organization tell its story while generating critical funds to support programs and services. Chapters keep 70% of the net profits from ***On the Move*** events, and these funds can be used to help send families to the national conference or support other local services needed by those affected by PWS. This is a great opportunity for families to help each other attend the national conference. Please contact Ben Karp at bkarp@pwsausa.org for assistance with an event or virtual fundraising.

Make your plans now to attend and get "***On the Move***" with fundraising to support sending families to conference. Come one – come all. Grandparents and extended family are welcome, too!

Registration opens in June. Can't wait to see you all in November!

**CHUCKLE CORNER**

For our son's 40th birthday last weekend, the supportive living staff (at our son's request) took him to an "exotic" dance club. Afterwards he told us that one dancer kept coming up to him and asking for money or a credit card. He finally told her that he did not have any money, and besides, even if he did, he would not give her any unless she learned to be more respectful of other people!

*~Anonymous*

**Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School student-sponsored "Spirit Week" Fundraiser in Greenville, South Carolina.**

# Gastroparesis: The Newest Threat

*by Lisa Graziano, M.A., PWCF Executive Director*
*Janalee Heinemann, M.S., PWSA (USA) Director of Medical Affairs*
*Ann Scheimann, M.D., M.B.A., Gastroenterologist and PWS Specialist*

If you're a member of the Prader-Willi California Foundation and the national Prader-Willi Syndrome Association (USA), then you have read about or discussed at a meeting of some sort this thing called gastroparesis. There have been articles about the fact that it exists, alerts about it (*Medical Alert: Gastrointestinal Issues in Individuals with PWS* ), and now a peek at the likely incidence rate. What we haven't yet received enough information about is how do we know if our child/adult has it and what can we *do* about it. This is the focus of this article.

Please know that this will likely be a difficult read for those of us who care for and love someone with PWS. Knowledge is power, however, and so if the information contained within this article helps inform care providers enough that they can keep someone with PWS safer, then the read is worth it.

In 1999 *The Gathered View* included an article about the discovery by PWS specialist Rob Wharton, M.D., of what he termed Acute Idiopathic Gastric Dilation. What Dr. Wharton saw in his patient was that for some unknown (idiopathic) reason the stomach (gastric) was quickly (acute) pushed out (distended), causing the stomach tissues to die. If not immediately treated with surgery, this condition may lead to death.

Over the following years, particularly with closer examination by PWS/GI specialist Ann Scheimann, M.D., it has become clearer that a great number of other people with PWS have a stomach that empties too slowly. In fact, Dr. Scheimann now believes **it is highly probable that *a significant number of* people with PWS have some degree of a slow emptying stomach**. The medical name of this disorder is gastroparesis: the muscles in the wall of the stomach work poorly and prevent the stomach from emptying properly. As a result, food stays in the stomach longer than it should. Over time, the volume of accumulated food in the stomach can cause the stomach to become full. Like a balloon that has too much air, the stomach of someone with PWS that contains too much food can respond in one of two ways: it will rupture or the food will push so hard against the stomach lining that it "compresses and weakens" the cells in the stomach. Both of these conditions cause massive internal infection and can quickly lead to death.

Other important factors to consider are that some medications such as narcotic pain relievers and anticholinergic medications (group of bronchodilators) can also cause the stomach to empty too slowly (as well as cause dry mouth symptoms). Abnormally high blood glucose (sugar) levels or undetected hypothyroidism can also slow stomach emptying; therefore, it is important to control blood glucose levels and screen periodically for hypothyroidism.

The symptoms of a slow emptying stomach are primarily nausea, vomiting, abdominal fullness after eating, and/or pain. But for persons with PWS who often have a blunted pain threshold and an absent vomit reflex, symptoms of gastroparesis or Acute Idiopathic Gastric Dilation can be extremely difficult to detect.

At the same time the stomach empties too slowly, the bowel intestinal tract seems to empty too slowly. This means that digested food that the body turns into waste product and must eliminate from the body as feces/stool is not entirely eliminated, leaving too much stool in the intestinal tract.

Many parents and care providers believe that because their child or adult has a bowel movement every day, this means they don't have a slow emptying bowel. This is not necessarily true. Even with a regular daily bowel movement, the intestinal tract may not empty appropriately. As the colon becomes more backed up with retained stool, the ability to evacuate stool is less effective. Over a long period of time, continuous, constant hard pushing has resulted in some people with PWS experiencing rectal prolapse. (The feeling of constant fullness and pressure on the anus or itching of the skin from irritation from bile acids present in the stool can contribute to reasons that some people with PWS insert their fingers into their anus or pick at it.)

As the colon becomes more impacted with retained stool, emptying of the stomach commonly slows down. This means that the risks of gastric rupture or dilation are dangerously elevated.

## How to Detect Gastroparesis and Slow Emptying Bowel

How do we know if the individual with PWS we're caring for has gastroparesis or a slow emptying bowel? What are the signs? What are the symptoms? What do we look for? The answers are, unfortunately, that there probably aren't many easily recognizable signs or symptoms.

Because the abdominal core muscles are generally weaker in persons with PWS, the stomach can often appear to be more rounded. If food is not emptied quickly enough, the stomach can look rounded (distended) and feel "too firm" to the touch. On the other hand, for those who are taking growth hormone medication and are therefore leaner, the stomach can already feel "firm" to the touch.

The definitive test to identify delayed stomach emptying is the Gastric Emptying Study which measures the amount of time it takes for food to empty from the stomach and enter the small intestine. The test is done in the nuclear medicine section of a hospital. The patient fasts overnight and eats a breakfast that contains a tiny amount of radioactive material. The patient then lies flat and still on an exam table under a large "arm" that measures the amount of food particles that evaporate from the stomach over a period of time; generally four hours is the appropriate amount of time for the emptying study following a mixed meal of liquid and solids. There are

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**Gastroparesis,** *continued from page 4*

no side effects from a gastric emptying study; the radioactive material is not absorbed into the body and is eliminated in the stool. The test can be difficult for kids under the age of 10 to complete because it is critical that the person lie perfectly still throughout the duration of the test. It is important to make certain that other factors such as constipation and/or thyroid disease are well controlled prior to completion of the test.

### Treatment Strategies

1. As with all treatment of PWS symptoms, the first approach is to always provide Food Security: a) a healthy, low-calorie, low carbohydrate diet; b) meals and snacks served at structured times/sequences throughout the day; and c) all access to food restricted.
2. Request from PWSA (USA) information about GI issues in persons with PWS.
3. If there are GI concerns present, consider consultation with either a pediatric or adult gastroenterologist, dependent upon age. Provide the physician with your GI issues documents.
4. Discuss the pros and cons of a Gastric Emptying Study.
5. Discuss the use of medications such as metoclopramide (Reglan) and erythromycin to improve stomach emptying.
6. Discuss an assessment for stool buildup (e.g., palpitation, x-ray). The Bristol Stool Chart can be used to screen/track progress with management of constipation. Normal stools should be Bristol Class 4 *(See Table in middle column).*
7. Discuss the use of over-the-counter medications such as Miralax to improve stool elimination and over-the-counter probiotics to help regulate the balance of helpful organisms (microflora) in the intestines.
8. If there are challenging issues for your primary GI specialist physician, suggest the GI specialist contact a PWS GI specialist by contacting PWSA (USA).

### Bristol Stool Chart

| | | |
|---|---|---|
| Type 1 |  | Separate hard lumps, like nuts (hard to pass) |
| Type 2 |  | Sausage-shaped but lumpy |
| Type 3 |  | Like a sausage but with cracks on the surface |
| Type 4 |  | Like a sausage or snake, smooth and soft |
| Type 5 |  | Soft blobs with clear-cut edges |
| Type 6 |  | Fluffy pieces with ragged edges, a mushy stool |
| Type 7 |  | Watery, no solid pieces. **Entirely Liquid** |

We continue to learn more about the gastrointestinal and bowel emptying issues of PWS; as we do, we will inform you. ■

**Note: A prior eating binge has typically preceded most incidents of stomach necrosis and death, and there are no known incidents of this happening in a child under the age of 16.**

# Delayed Stomach Emptying in PWS

I have completed the final control for the patient's gastric emptying portion of the PWS study. Gastric emptying was delayed for nearly all the Prader-Willi subjects and was normal for all the obese matched-control subjects. We will be analyzing the PWS subjects to review the impact of the type of diet upon gastric emptying, the time/strength of gastric muscle contractions over the meal duration, in addition to review of the gastro intestinal (GI) peptides collected during the course of the meal.

As gastric emptying appears significantly delayed in nearly all patients with Prader-Willi syndrome, I would suggest for now controlling other factors, such as constipation, which are well documented to slow gastric emptying due to downstream effects.

*Ann O. Scheimann, M.D., M.B.A. Associate Professor of Pediatrics, Division of Pediatric Gastroenterology and Nutrition, Johns Hopkins Hospital, PWSA (USA) Clinical Advisory Board member*

**Note: the above is an important result of a grant sponsored by PWSA (USA) that is still in process.** I asked Dr. Scheimann for permission to make this initial report due to the significance to our PWS population. The following are more details on the grant that should be completed in time for them to report the outcome at our conference in November.

*~ Janalee Heinemann*

### Impact of Dietary Content upon Gastrointestinal Motility in Individuals with Prader-Willi Syndrome

*William J. Klish, M.D., Baylor College of Medicine, Division of Pediatric Gastroenterology & Nutrition & Ann Scheimann, M.D., M.B.A.*

Meals that contain large amounts of carbohydrates and can quickly raise blood sugar levels are known to increase appetite. On the other hand, meals that contain large amounts of fats are known to slow down how quickly the stomach empties into the intestine. This slows the breakdown of carbohydrates and absorption of sugars and keeps blood sugar levels relatively lower. In PWS, this delayed gastric emptying may relate to gastroparesis, in which the stomach stretches with food that accumulates because of ineffective stomach contractions (when severe, this can lead to stomach rupture).

Dr. Klish's team, headed by Dr. Ann O. Scheimann, is studying how quickly meals with varying fat and carbohydrate content exit the stomachs of people with PWS, the gut hormone responses to meal content and the relationship of the type of meal to how full that person feels after

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*Nick*

# PWSA (USA) ~ Serving New Parents Every Day!

***By Janalee Heinemann, M.S.W., PWSA (USA) Director of Research & Medical Affairs***

As most of you know, since 2001 PWSA (USA) has provided free of charge to new parents of a child with Prader-Willi syndrome an extensive **PACKAGE OF HOPE.** That packet includes booklets such as Nutritional Care For Infants and Toddlers; Growth Hormone; Therapeutic Interventions For The Child With PWS; A Child With PWS - Birth to 3; Medical Alerts; Positive, Hopeful Stories from Young Parents; etc. They also receive a free year of membership and are offered a parent mentor through this program.

Because so many children are diagnosed in the early infancy stages, we are concerned that new parents may get overwhelmed with information. So we have been working on a ***new project*** which is a publication called **THE FIRST 100 DAYS**, modeled after a publication created by Autism Speaks. We have the permission of this organization to use their model, and ***seven wonderful medical professional couples who are parents of a child with PWS from ages infancy to three are working with me on different sections of the publication.*** We have exciting plans for putting this online, putting it on a thumb drive for every new parent, distributing across the nation to NICU's, etc. There will even be a section called "What You Need To Know When Your Baby Is In the NICU". Of course, we will continue to distribute the important educational materials in our "Package of Hope" but may do more staging of the timing of distribution.

I want to thank everyone for your support of funding and services that makes such PWSA (USA) projects possible. We are still "Hungry For A Cure" but fulfilled in knowing that every single day we make a difference in the lives of so many families, as exemplified in an email I just received: *I want to thank you for all your support, advice, and help with Suzie…I never imagined that things could ever turn out so well. You were such a big help to us and I will always be grateful for that.* ■

# 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 2013-2016 Board of Directors and volunteers for Committee service. Please contact us if you or someone you know possesses the qualities necessary to be an effective member of the Board of Directors.**

- 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.
- 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, assume shared responsibility for generating resources to meet Association goals, and open doors in the community.
- Develop skills you might not already possess such as understanding financial statements, cultivating donors, soliciting funds, and cultivating board members and 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.
- Have input into decisions and policy-making that affects persons with PWS.
- Increase your knowledge about PWS and its treatment and management strategies.
- Increase your exposure to professionals who work with individuals with PWS.

To nominate yourself or someone else, please contact the Leadership Development Committee Co-Chair Lisa Graziano via the PWSA (USA) office at 800-926-4797 or 941-312-0400 or pwsausa@pwsausa.org or by fax to 941-312-0142. The deadline for nominations is Friday, June 14, 2013. ■

**Gastroparesis,** *continued from page 5*

eating. In addition, blood tests before and after each meal will help check the relationship of ghrelin and other gastrointestinal peptides to stomach emptying. This grant will further our understanding of the signals that make a person with PWS feel hungry or full and may alert parents and medical providers to a dietary component to gastroparesis, and potentially, to gastric perforation. ■



# Battle Fatigue II

*By Lisa Peters*

## Sanity Saving List

Battle Fatigue I *appeared in the March-April issue of* The Gathered View, *Lisa Peters' description of being a mother of a child with PWS. Here is Battle Fatigue II, Lisa's "Sanity Saving List", which she says is "an ever-changing record of helpful tools that help to preserve my emotional strength."*

**1) Hire a Babysitter:**

Important to finding some alone time for myself, a time to do the things that I enjoy, alone and uninterrupted. (Time hiding locked in the bathroom does not count.)

**2) Alone Time with Hubby:**

An important time to reconnect with my husband and remember what brought us together in the first place.

**3) Let Housework Slide or Hire a Helper:**

The pressure and time involved in keeping a clean house is a thief of time and can interrupt those precious few moments needed for rest and relaxation.

**4) Cancel Appointments:**

Nicholas visits with so many specialists that I could literally spend all of our time just seeing them. When times get tough, I try to take an entire month off from any specialists and non-emergency visits.

**5) Listen to Music:**

A new one that I have discovered. Locking myself in my bedroom with the door closed and an iPod filled with my favorite music has done wonders for calming my spirit.

**6) Meditate:**

Another new one for me. I have found that purchasing a few good meditation CDs is a helpful tool. It took a while to find the right CDs that resonated with me. Meditation is a lot like homework--difficult at first to make it a routine, but when I did, I noticed an improvement in my mood.

**7) Nature Walks:**

I learned this one from my son, Weston. Long walks outside amidst Mother Nature is another winner for relieving tension.

**8) Talking:**

I find it very cathartic to talk with others about how I am feeling. It is when I repress my thoughts and feelings that I notice a darker side to my disposition. However, there is a huge warning here. I must be very selective in my choice with whom to speak, for some individuals are not instinctively designed to handle such a heavy load; speaking with these individuals can actually make my pain worse. I try to speak with only those who are thoughtful and willing to listen with a sense of kindness, compassion and void of any judgement.

**9) Therapist:**

Early intervention services in our state included the services of a family therapist. I am continuing with this incredibly helpful intervention.

**10) Mini Vacations:**

I try to plan several mini family vacations throughout the year. Looking forward to time away from the rat race has worked wonders for us all, especially Nicholas who loves new adventures. A few days away works wonders in creating a restful diversion.

**11) Write, Write, Write:**

Even if I do not share these thoughts with others, the process of getting it out on paper (or computer screen) has been particularly cleansing to me.

**12) Sleep, Rest and Relaxation:**

During times of increased stress, I try to sleep more. If I can't sleep, I try to just rest and listen to music.

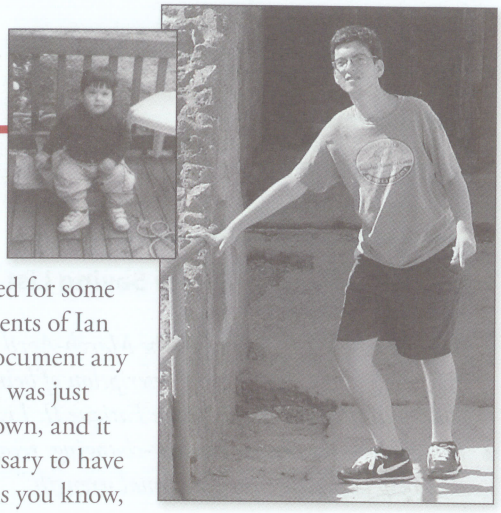
**13) Special Needs Groups and Individuals:**

No one understands me better than those who share my struggles. Reaching out to these groups or individuals can provide some interesting and effective solutions.

**14) Positive Reflection:**

This, to me, is the most important. With every stressful event that has ever occurred while raising Nicholas, if I dig deep enough, I can always find an important lesson. So, when my mind wanders back to disturbing events of the past, I force my brain to explore a positive aspect that occurred because of that experience. I do not repress the event, since I believe it is important for the mind to rewind the experience and reflect upon it.

Implementing these strategies is painful. Maintaining them...even worse, feeling like a type of special needs homework, a dreaded but necessary evil. But by calming my spirit and accepting my child and his diagnosis, I am in a way helping myself to live a happier and more fulfilling life. Ironically, however, of all my life-saving strategies, it is my son's soothing sage-like spirit that effortlessly balances my warrior woman energy. It is interesting to me that when I physically tire from the heavy load of caring for him, it is he who comforts me most, and I wonder if perhaps this is no accident. ■



*Ian: before and after photos*

# Our Journey to Approval for GHT

***By Andrea Glass***

Growth Hormone Therapy (GHT) has always amazed me with the positive results for people with PWS. My son Ian, now 17, was diagnosed with PWS when he was two. Although he was born in a top Boston hospital and followed by the head of their neurology department, his diagnosis went unsolved for two years. I remember being very angry about the fact that he was 40 pounds at two (despite a healthy diet), still not walking and had already missed out on two years of GHT. It still took one more year before the insurance company would approve GHT, although there was quite a bit of scientific evidence regarding the benefits. Every time our insurance company would change (through employment) we would have another fight on our hands regarding the benefits to Ian. Denials and appeals were frequent. Finally, when GHT was FDA approved for children with PWS, the approval process was a little quicker.

When he was 16, our current insurance provider decided that Ian had stopped growing and began a new round of denials for GHT. He had achieved a height of 5'8", weighed in at 140 pounds. His height has been impacted by a spinal fusion at age 12. I am convinced the fusion may not have been necessary had he not spent the first three years of his life with extremely low muscle tone and no GHT. Given the dramatic results of GHT, I was very concerned about his not having Adult GHT. I did not want him to have such extreme low muscle tone again. I believed this would impact his overall health, energy expenditure, hunger, ability to stay thin through exercise, and his overall fat/muscle mass ratio.

Although many studies were becoming available regarding the benefits of Adult GHT to the PWS population, we lost our fight with the insurance company on appeal because his Growth Hormone Stimulation Test showed a low normal adult range at 260 ng/ml (226-903 is normal). I went to his physicians and asked for some physical measurements of Ian so that we could document any changes. (Maybe I was just afraid of the unknown, and it would not be necessary to have Adult GHT. But, as you know, parents of children with PWS are not exactly passive. )

To measure changes in body composition, we had a DXA scan at the time of initial discontinuation of GHT and another one year later. The results after one year are as follows: weight increase of 9 pounds, height increase nominal, total body fat increase of 4.9%. There were also anecdotal changes, such as the reports from school of more sleepiness in the classroom, decreased strength as measured in the gym, decreased stamina for walking distances, and an increase of noticeable fat around his legs and buttocks.

One year later his physician applied for GHT again and based her argument on the DXA facts and the literature mentioned below. I am pleased to report that the insurance company agreed that Ian would benefit from Adult GHT, and we began treatment two weeks ago. Many children that have had the benefits of GHT throughout their lives are now aging out of the FDA approved protocol and facing insurance denials. I thought I would share this approach with others that may find it useful. ■

*For studies that show the positive impact of GHT on adults treated with GHT see: Hoybye and Thoren, Treat Endocrinol 2004, 3 (3): 153-160; Sode-Carlsen, et al. J. Clin Endocrinol Metab, November 2010, 95(11):4943-4950; Sode-Carlsen, et al. Growth Hormone & IGF Research 21 (2011) 185-190).*

## Medical and Research History

In the past 20 years, there have been many breakthroughs for PWS, most of it done by PWSA (USA) Advisory Board members. In addition, stimulated directly from involvement of scientists engaged in PWS research, interested parties and organizations, conferences are now being held to bring together international experts to address hyperphagia, an important clinical finding in PWS. Thus, the scope and arena to address problems seen in PWS is expanding by adding new investigators from other research fields such as eating behavior, obesity and treatment, and hyperphagia. ■

**1991** The DNA methylation analysis technique used for PWS diagnosis was first introduced by Dr. Dan Driscoll and colleagues.

**1991** Dr. Moris Angulo reported on GH deficiency in PWS; Dr. Philip Lee in 1993 published on the effects of GH treatment on children with PWS.

**1992** The first mouse model was developed with maternal UPD; in 1998, the first mouse model with the imprinting defect; and in 1999, the first mouse model with a deletion.

**2000** IQ differences were reported in PWS in those with maternal UPD versus the 15q11-q13 deletion.

**2000** FDA approves use of growth hormone in children.

**2002** Elevated Ghrelin levels shown in PWS and how it may contribute to obesity.

**By 2004** The NIH had supported $10 million in research funds affecting PWS.

**2004** More behavioral differences were reported by Dr. Merlin Butler and colleagues in PWS having the larger type I deletion than those with the smaller type II deletion.

**2007** The first gene expression studies were reported in humans with PWS and in a mouse model for PWS by Dr. Butler and colleagues.

**2008** An abstract showed a relationship between low leptin levels, appetite dysregulation and sleep latency.

# Sins of the Mother

A few years ago my son Victor who has PWS, my daughter and I went to church. At that time I was an investigative sergeant and subject to call out. Right before communion I received a text to call work. I told the kids to go ahead and go up for communion, which by the way is ALWAYS the highlight of church for Victor as he gets a piece of bread. After dealing with the phone call, I came back into church to find that Victor had a soggy piece of bread in his hand, saying he got it for me and that I needed to eat it right away to keep the devil away.

During this time my daughter was sitting annoyed with Victor. Immediately after church got out, Raquel told me that when they went up to get communion Victor got his bread and then told the Pastor, "I need a piece of bread for my mom." The Pastor, knowing about PWS, told him that he would get it to me later. Victor then, in a very loud voice that commanded everyone's attention, said, "You don't understand, MY MOM NEEDS IT FOR HER SINS!!!!"

Of course, there was laughter throughout church, and the Pastor told me as we were leaving for the day that it took everything he had not to bust up laughing and asked if I needed two blessings for the week due to my sins. I still laugh at this story when people come up and tell me what happened. Oh, the life of a parent with a child of PWS.

*~Tammie Penta, Arizona*



# A Long Walk

Larry Gardner, age 44, is shown here at his annual five-mile walk to benefit the Animal Humane Society. He has made this walk with Buddy, the family dog, for 11 years. In the beginning, he raised under $2,000. Last year he raised an amazing $7,000 for the animals! He goes door to door soliciting people to sponsor his walk, as well as calling friends and relatives. Larry also volunteers on a weekly basis at the animal shelter where he takes dogs for a walk.

He was the first volunteer who has a disability whom the shelter accepted. Joel, his personal trainer, has been his partner at the Animal Humane Society since the beginning. As Larry says, "I love animals and want to help them".

Larry is the son of Joan and Jim Gardner, who chaired the International Conference in 2001, and Jim has served on the PWSA (USA) Board of Directors. Joan is the PWSA (USA) parent delegate to IPWSO. ■

# ¡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! ■

*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*

**2010** A clinical trial was developed and completed using oxytocin to reduce stress and anxiety in adults with PWS.

**2010** Functional brain imaging showed people with PWS had a positive response to food even after eating a standardized meal.

**2011** As an example of just one year, PWSA (USA) spent $526,000 on research, and our Scientific and Clinical Advisory Boards donated over $309,000 worth of services.

**2011** A clinical trial in Los Angeles was established for treatment with Exenatide for overweight adolescents with PWS.

**2011** The Second Edition of the Growth Hormone Booklet completed, Birth to Three booklet revised and completed, and an extensive Physical Therapy booklet completed.

**2012** A sleep study in PWS subjects showed a shorter sleep latency and more nighttime wakefulness.

**2012** The genetic discovery of snoRNAs implicated as the cause of several features seen in PWS

**2013**...Maybe a Breakthrough...

# Health Concerns for the Camper with Prader-Willi Syndrome

*By Barb Dorn, R.N.*

**The camper with Prader-Willi syndrome (PWS) may experience some unique health issues. It is important for camp staff to be aware of these to ensure that the camper has a safe, healthy camp experience. A summary of common health concerns and some strategies are summarized below.**

## Altered Pain Response – Decreased Pain Sensitivity, High Pain Threshold

- Pain may be diminished or absent even in severe injuries
- Fatigue or irritability may be a sign of illness
- Increased bruising and swelling is common
- Complaints of pain should be assessed

### Strategies

All injuries need to be assessed by an adult – even when injuries do not appear to be severe.

Report all injuries or changes in behavior to the parent or caregiver.

Camper may require examination by a health care provider to rule out fracture or other health problem.

Apply ice and elevate injuries as needed.

## Severe Stomach Illness – Lack of Vomiting

- Severe stomach illness has been noted in persons w/ PWS who have had a binge eating episode
- Symptoms: abdominal bloating, vomiting, pain may or may not be present, general feeling of not feeling well
- It is rare for a person with PWS to vomit

### Strategies

If symptoms of stomach illness are present, notify parent.

Camper should be urgently evaluated by a health care professional.

Any incidence of vomiting should be reported to the parent.

Encourage the camper to share honestly if they have had a binge episode. If confirmed, he/she should not be punished.

## Increased Food Drive/Low Metabolism

- Because of an abnormality in the hypothalamus, campers with PWS do not register the feeling of fullness and have varying degrees of food seeking
- Many will sneak and/or steal food – often putting them at great risk for choking and gastric illness (see below)
- Require calorie restricted diet with supervision around all food.

### Strategies

Receive/follow prescription from health care professional for calorie restricted diet.

Supervise around all food sources. Keep food out of sight.

Do not use food as a reward or in camp activities.

It may be necessary to empty garbage cans that contain discarded food.

Staff should be trained in the Heimlich maneuver.

Camp staff should serve food to assist with portion control.

## Scoliosis and Other Spine Problems

- Common to see scoliosis and other spine deformities in persons w/PWS
- Many require bracing

### Strategies

Support and assist if brace is needed.

Adaptive measures may be needed for some physical activities.

Encourage good posture.

## Altered Temperature Regulation

- Common to see unexplained high and low body temperatures
- Little or no fever may be present with illness
- Often experience low tolerance to high outside temperatures.

### Strategies

Make sure the camper does not overheat.

If extreme redness of the face and sweating is noted, remove to cool area; encourage cool water and/or cooling measures.

If illness is suspected, notify parent. Fever may not be present.

## Behavior – Emotional Problems

- Persons with PWS have problems regulating their emotions
- Most do not handle change well
- Some exhibit obsessive-compulsive tendencies
- Exaggerated emotional responses and extreme anger may be seen
- Some take medications to assist with mood stabilization

### Strategies

Minimize changes. When they do occur – foreshadow and prepare if possible.

Many benefit from a schedule put into writing.

Encourage ways to appropriately share feelings and emotions. Practice and reinforce these strategies frequently.

State behavior you want to see. Avoid using word "don't".

Administer medications as ordered.

## Skin Picking and Sun Sensitivity

- Common problematic behavior seen in persons w/ PWS of all ages. Open sores common
- May pick at various openings of body
- Sensitive to sun

### Strategies

Provide diversion activities – keep hands busy. Apply lotion.

Incentive program often needed to keep wounds covered.

Encourage/teach self care of wound.

Apply mosquito repellant routinely. Have camper wear long sleeves and pants for hiking or walks in the woods.

Monitor frequent trips to bathroom. Time limits and supervision in bathroom may be needed.

Apply sunscreen; encourage wearing hat & sunglasses.

## Daytime Sleepiness

- Common to see daytime sleepiness
- May be related to sleep apnea or weak chest muscle resulting in poor air exchange

### Strategies

Get camper up and moving.

Some may require a rest time.

Some use Continuous Positive Airway Pressure (CPAP) mask/machine at night.

## Dental Problems – Dry Mouth

- Common problems: thick, sticky saliva, teeth grinding, rumination, cavities
- Most have aversion to water

### Strategies

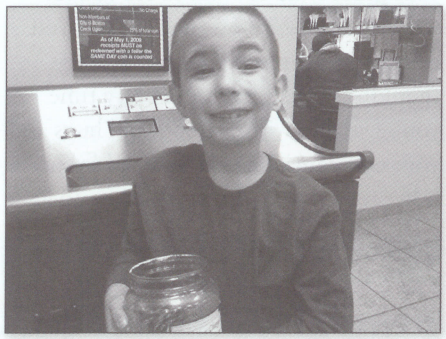
Make sure camper brushes and cares for teeth.

Encourage water. Most prefer flavored water – best if non-carbonated.

Assure compliance with use and care of bite guard if camper has one.



# Fundraising Letters from our friends across the country!



Hello,

I am mailing a check in the amount of $333.16, raised through the **"Spare Your Change for Prader-Willi Research"** campaign. My wife Karen and I have five wonderful boys, and our youngest, Gavin (pictured above), is seven with PWS. We wanted to thank the people that donated from the Boston Police Detectives Office at District 4, the Clerks Office of the Boston Municipal Court and Gavin's Papa Jack for donating their spare change over the last two months. [Here is] Gavin with his change jar at the bank after putting it into the machine. We can't thank you enough for all that you do for Gavin and all the other children and adults with PWS.

Thank You
Brian & Karen Gill ■

Dear Prader-Willi Syndrome Association (USA),

Last summer I became aware of Prader-Willi syndrome because of a little girl named Chloe Thur, niece of a family friend, and a fundraiser run by her mother, Monica Murphy. When I learned what this condition was, how it was caused, and saw her adorable picture, I was determined to do something. To raise awareness I did some research so I could explain and discuss PWS and started wearing a **"Still Hungry for a Cure"** bracelet. I wanted to do more.

I am a college professor so when classes began in August, I challenged my co-workers in the Math and Physics Department to a competition for the month of November. **A mustache-growing competition** (a clean shaven face on November 1st and grow only a mustache for the month) where we would sell tickets for votes and the individual with the most votes at the end of November would be considered the winner. The prize: the funds raised are donated to the charity of the winner's choosing. I was shocked and elated when the final count was six members, some of whom I have never seen clean shaven.

In our first department meeting following November, we tallied up the votes to see which professor was the winner. Ticket sales totaled $353.00, and it was me, Mark D'Arcy, the charity donation winner. I am happy that I was given an opportunity to not only inform others of this genetic disorder but that I was able to beat out the competition so that we could give this general donation in honor of Chloe. Please accept this donation on behalf of the Alfred State College Mathematics and Physics Department in her honor.

Thank you for the work your organization is doing to raise awareness and fight for a cure.

Sincerely,
The Alfred State College Math and Physics Department
Mr. Mark D'Arcy
Assistant Professor of Mathematics
Alfred, New York ■

## The Running of the Bears 5K

On Saturday, March 23, the first annual **Running of the Bears 5K** was held at Vestal High School in Vestal, New York, to benefit PWSA (USA). The race was organized by students from the school's Varsity Club.

The students chose to donate the proceeds from the race to PWSA (USA) after meeting Cami, the young granddaughter of a teacher from our school, who was recently diagnosed with PWS. Cami won all of our hearts with her winning smile and curious disposition. Cami's grandmother was able to teach us about PWS and the difficulties facing Cami as she grows up.

March weather in New York is unpredictable and race day turned out to be a bit chilly, windy and even a little snowy, but the inaugural race still drew 299 participants including over 100 students. Runners and walkers took off from the front of the high school, covered the 3.1 mile course and returned to a rocking party featuring student musicians, refreshments and prizes. Many local businesses contributed to help cover the costs of the party as well as commemorative "Running of the Bears" race t-shirts.

On race day, we were joined by two more local children with PWS along with their families. Cami, Ellie and Tommy rocked out to the band, danced with our students and hung out with the Bears' mascots after the race.

The event was a great success in many ways. We raised over $7,000 for PWSA (USA); we all had a really great time; and the students and staff who organized this race learned so much about the rewards of community service and how much you get back when you give.

We're all looking forward to next year's 2nd annual Running of the Bears!

Sincerely,
Sue Darpino, Race Director ■

# The Grandparent Caper

## IT'S NOT JUST THE CALORIES

*by Patrice Carroll*
*Manager of PWS Services, Latham Centers*

How do you explain to family members (grandparents in particular) about your child's diet? How many of you have heard the following- "*It's only one cookie*", "*It's a special day*", "*He's thin*", "*You don't need to worry about his diet anymore*", "*You're being too strict*", "*Just this once.*"

Grandparents want to spoil their grandchildren, and in many cases that includes food. Not giving their grandchild special treats goes against their nature, especially when that child is saying that they're hungry. Will one extra piece of cake ruin their diet and make them gain 5 pounds? Probably not, but it's not just about the calories.

We have an obligation to create an environment for our kids where they can thrive and that includes managing their expectations regarding food. When our kids know what they are going to eat, how much and when, they can relax, they can focus on the rest of their lives. When extra unexpected food is introduced, they feel anxious, stressed and out of control.



*Ellie with Grandma*

Giving a child or adult with PWS more than what they were told that they would get creates anxiety, and anxiety leads to unwanted behaviors.

You are no longer grandma or grandpa, you are a food source because you created an expectation. You want your grandchild to want to see you for your love and comfort, not because you might slip them some treats that they shouldn't have. Spoil them every time you see them, with presents and hugs and your company, not with food. If for no other reason than the more secure their minds are about what they are going to eat, the better behaved they will be.



*Jacob with Mimi*



*Kiss for Grandmother*

"*Just this once*" hurts them. It makes them feel unsafe and anxious, and that is the last thing that you want your grandchild to feel about you. And if you think that this isn't fair, you're right. It's not fair that they can't have what the other kids have and that we have to be so careful about what we give them, but it is our reality and sticking to it will make your grandchild and your whole family better for it. ■

## Counselors Corner

# School Portfolio

***By Kate Beaver, Family Support Counselor***

The PWSA (USA) family support group has developed a wonderful School Portfolio packet for parents and teachers. In this packet there are articles, a school DVD and evaluations to help the teacher understand PWS and how important the environment is for our children. It also contains end of the year evaluations that will help the next teacher understand what worked well for that child in the classroom. The evaluation for the parent is also helpful for the next teacher.

We encourage our parents to pass this school portfolio along to the teacher before the school year starts so that they can have information about the child with PWS and have time to consider the environment before the child arrives. To order a School Portfolio Packet, please contact PWSA (USA) at (800) 926-4797. ■

# New Beginnings for an Old Friend

*By Lota Mitchell, Editor,* The Gathered View



*left to right: Kate, Andy, Ken, Shawn and Conor*

For **Ken Smith**, there have actually been three new beginnings, each one taking his life in a whole new direction.

The first one came after he graduated from the University of Pittsburgh, majoring in microbiology and biochemistry. While he was in school, he had a job one summer at The Rehabilitation Institute (later to become The Children's Institute). After graduation in 1985, he returned fulltime, having discovered he preferred people to laboratory.

After 2 ½ years doing direct care with different types of patients, the next new beginning came, the beginning of his longtime connection to PWS. The Prader-Willi syndrome program at the Institute, initiated with seven patients in 1982, was growing larger every year. He became the assistant program coordinator, responsible for admissions and working with Bea Maier, who developed the program, Gwen Moore, who was Unit Manager, and Dr. Jeanne Hanchett, the pediatrician. What a dynamic team—one that many in the PWS community will remember fondly!

The natural next step was to become involved with Prader-Willi Syndrome Association (USA). He was nominated for the Board of Directors and attended his first board meeting at the Seattle national conference in 1995. This was the first of many since he has served on the board for 18 years, except for stepping off for two one-year terms as required by the PWSA (USA) bylaws after three three-year terms. He has served as board chair or board co-chair, been a member of the crisis team, and is active with the PWS Advisory Board.

Now, after 27 years Ken is no longer with The Children's Institute, so he is at the third new beginning. Not surprising, it includes his commitment to PWS. The two main areas in which he hopes to focus are:

- Working as administrative program manager with the Health Bridge Children's Hospital in Houston, Texas, helping them to set up a treatment program for children and adolescents with PWS. He is traveling every other week to Texas and is working to get a consulting role with two or three other potential treatment centers, so that in time there may be dedicated units for PWS in other parts of the country.
- If funding becomes available, the goal would be that he would be a consultant with the PWSA (USA)'s family support team on a project with the goal of preventing the need for hospitalization, addressing issues before the person gets into crisis.

Ken is also chipping away slowly, as time allows, at earning a Master's degree in Hospital Administration. He has received many supportive emails which were very gratifying for him, and he expresses thanks for all of them. We, in turn, can thank Ken for his many years of volunteer and professional dedication to PWS and look forward to many more. ■

# Contributions

**Thank you for Contributions in February and March 2013.** We try to be accurate in recognizing contributions above $25, and apologize for any errors or omissions. If you notice an error, please tell us.

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...continued on page 14

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...continued

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

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## Gastroparesis: The Newest Threat

*The most likely answer to how we treat the potential for gastropareisis and slow emptying bowel is to presume they exist and treat them as if they exist.*

*See article on page 4*

## Call for Nominations

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

*See article on page 6*

## PWSA (USA) NATIONAL CONFERENCE

**November 7-9, 2013**

PWSA USA ALL-STARS 2013

**Walt Disney World**
**Buena Vista Palace Hotel and Spa**
https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=759035&hotelID=6579

**Orlando, Florida**

**Early Bird Registration:**
**Before July 1, SAVE $25 off your registration fee!**
***Registration opens in June***
**Registrations limited for YAP (84) and YIP (60)**
***Note: The national web site is about to undergo complete redesign. During transition, estimated to be the next 2-3 months, there will be minimal updates to the existing site.***
*Conference will have its own site, and it will be published soon.*