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

The Gathered View

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

I'm No Expert

By Lisa Peters

I am not an expert at anything.

I am not a fine-tuned athlete with golden trophies lined on a shelf in my living room. Music and art are like foreign languages to me. I am not a banker, a lawyer or a CEO. I have trouble just balancing my checkbook. So when my son Nicholas was born with Prader-Willi syndrome, I found myself completely unprepared for the job.

Physicians from Children's Hospital handed me my tiny infant amidst a flurry of complex medical terms. Words like hyperphagia, hypotonia and cryptorchidism were thrown at me like icy snowballs hurled from some anonymous attacker. Geneticists and endocrinologists surrounded my bedside like nervous advisors briefing the President on the latest global crisis. Critical medical decisions were now presented to me for immediate answer. Did I want my son to have a tube placed in his nose or stomach? Do I want to consider giving my child growth hormone injections? Here is your list of upcoming doctor appointments.

My role in life was now clearly defined, and my son's precious life depended on it.

My easygoing life was officially over. Treading water was no longer an option. A clear life's purpose with devastating consequences had been thrust upon me. It was almost as if since I had not bothered to define who I was, God, sensing my indecision, decided to do it for me. And while I wasn't wearing red spandex tights and leaping tall buildings in a single bound, I suddenly realized that like it or not I had become a superhero.

Suddenly, I could relate to the hardships of the likes of Clark Kent, Peter Parker and Bruce Wayne. These colorful cartoon caricatures now held the key to my success as a parent of a child with special needs. Like them, my identity as a superhero was cleverly concealed under the disguise of a mild-mannered, stay-at-home mom. As a fledgling caped crusader my new responsibilities of fighting and advocating for my son felt uncomfortable, awkward, even overwhelming. I was reluctant to utilize these powerful abilities and fine-tune them into the superhero skills needed for defeating the most fearsome of foes. And although the future of the world did not rest in my hands, the quality of life for my child most certainly did.

Nicholas at one month who transformed his mom into a superhero..

My superpowers are even more impressive than slinging a few spiderwebs or running faster than a train.

I can thread a feeding tube faster than a speeding bullet.

I understand acronyms like IEP, AFO's, GH, UPD, CoQ10, ABA, IGF-1, BP-3, FISH and MEM.

I can recall all 11 names and phone numbers of all 11 specialists we see at Children's Hospital.

I am able to comprehend complex medical terms in a single doctor's visit.

I am able to negotiate the harrowing halls of the parking garage at Children's Hospital in Boston.

Wielding my magic PWS Medical Alert booklet, I have singlehandedly educated countless ER doctors, dentists, anesthesiologists, primary care physicians and nurse practitioners on all the medical complexities of PWS.

I can calculate the number of calories in a lunchtime meal faster than you can say "pass the butter please".

I can divert a full-blown temper tantrum just by singing a song or asking a question.

I wear an invisible force field perfectly designed to repel thoughtless comments and ignorant remarks, like "I think

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Shawn

In this Issue

Volume 35, Number 6 ~ November-December 2010 ~ Our 35th Year of Publication

The following is a summary of a presentation made by Ann Scheimann, M.D., M.B.A., who is an expert on PWS and national consultant on PWS gastro (GI) issues. It is reprinted by permission from the PWCF News.

A Comprehensive Overview Of GI Issues in Prader-Willi Syndrome

By Ann Scheimann, M.D., M.B.A., Johns Hopkins School of Medicine, Baltimore, MD

The prevalence of GI issues in persons with PWS of all ages is quite high. In addition to early feeding difficulties, reflux and aspiration symptoms are frequent problems in infancy. Problems with digestion affect approximately 35% of adults; constipation and diarrhea problems occur in 20-35%. Gastroesophageal reflux disease, GERD, is common.

Dr. Scheimann outlined suggestions to treat GERD in infants: use thickened feedings, avoid overfeeding, use more prone positioning, and eliminate all exposure to tobacco smoke. For older children and adults she recommended: avoid lying down after eating a meal, elevate the head of the bed, lose weight, avoid all tobacco, and avoid foods and medications that may cause reflux. Fundoplication is a surgical option when lifestyle changes and medications aren't enough.

Oral problems are common, including small mouths causing teeth crowding and enamel erosion. Salivary flow is generally far less than normal [dry mouth products such as Biotene can be helpful]. Factors predisposing someone to choking, a serious and not uncommon occurrence in persons with PWS, include hyperphagia (high drive for food), thick saliva, weak pharyngeal muscles, and reflux. Dr. Scheimann advised all care providers to learn the Heimlich maneuver, treat reflux and gastritis symptoms, encourage chewing during meals, and, of course, supervise persons with PWS at all times.

Risk factors for developing gallstones, also not uncommon, include obesity, low fiber/high fat diet, and diabetes mellitus. 70-80% of normal adults in one study had no biliary symptoms when their gallstones were detected- the majority of healthy adults did not require treatment for gallstones unless symptoms arose such as right-sided abdominal pain or pain after meals.

Constipation and encopresis (involuntary fecal soiling) are common problems. Factors that add to constipating conditions include developmental factors (cognition, genetics, fluid intake, etc.) and altered anatomy (low muscle tone, malrotation, etc.). Rectal ulcers can occur when there is chronic constipation. General guidelines to treat constipation in infancy include the careful use of glycerin suppositories or softening agents such as Karo syrup and the increase of fiber intake when solids are introduced. She cautioned against using enemas, suppositories and finger dilations unless recommended by the physician. For the school-age child and adult, her suggestions included a fiber-rich diet plus water and the continuous use of medications, such as Miralax, with appropriate amounts of fluid on a daily basis rather than intermittent dosing.

Gastric motility (the rate at which the stomach empties) and an impaired vomit reflex (controlled by the central nervous system) contribute to serious stomach expansion and stomach rupture problems that can cause death. Warning signs and immediate hospitalization or ER evaluation for potential gastric rupture or gastric necrosis included a binge eating episode followed by abdominal discomfort, recent history of gastritis or ulcer.

While a variety of bariatric surgery techniques have been attempted in persons with PWS, the long-term results have been very poor. Research continues to explore viable treatment options, but bariatric surgery is not currently one of them. ■

New Clue for Understanding the Hunger of Prader-Willi Syndrome: Research Volunteers are Needed for Further Studies

In the July 2010 issue of *The Journal of Clinical Endocrinology & Metabolism*, Dr. Joan C. Han, a pediatric endocrinologist at the National Institutes of Health (NIH), and her colleagues reported the results of a small pilot study of 13 patients with PWS. They observed that patients with PWS appear to have lower blood concentrations of brain-derived neurotrophic factor (BDNF). BDNF is a protein that is believed to play an important role in controlling appetite and may provide some answers to understanding the insatiable hunger of PWS and other conditions associated with hyperphagia.

Dr. Han and her colleagues recently received a grant from the PWSA (USA) to conduct further studies on BDNF, and they are seeking patients with PWS (ages 0-18 years old) for this research. Participation involves providing medical information and a blood sample. For more information, please contact Dr. Han at (301) 435-7820 or hanjo@mail.nih.gov. ■

Shining a Light Around the World

By Janalee Heinemann, MSW
Director of Research & Medical Affairs, PWSA (USA)
Vice President, IPWSO

American Diabetes 70th Scientific Conference: Thanks to funding from the Gerald J. and Dorothy R. Friedman, New York Foundation, PWSA (USA) had for the first time an awareness booth at this meeting in Orlando. Attending were 17,000 endocrinologists. Although it was an American conference, a significant number of attendees who stopped by our booth for information were from India (Type 2 diabetes significantly increased since they have taken on more of a western diet), China, Brazil, and Indonesia. Over 300 attendees requested information on PWS.

Prague, Czech Republic ESPE Conference: I worked with our international Executive Director of IPWSO, Giorgio Fornasier, on a collaborative awareness booth for the conference. IPWSO was able to obtain the funding from Pfizer International, and we have the educational materials. Over 3,000 endocrinologists were at this conference from 91 countries. It is amazing to see how knowledge of PWS is spreading. Some of the physicians who came by our booth were from South Korea, Bangladesh, Ukraine, Estonia, Iran, Saudi Arabia, Egypt, Palestine, Morocco, Tunisia, Algeria, Liberia, Malaysia, Kenya, and Singapore. It is a real "high' when someone stops by and is so eager to get our educational materials—and wonderful to know how much that simple act can help so many people. The country most represented in stopping for PWS educational materials was China, which is amazing since it was only four years ago that through IPWSO we helped put on the first conference on PWS in their country. It is also a sign of their economic growth that so many from China attended this meeting. There were many from European countries and a surprising number from South American countries, but very few from the USA. That is unusual for this conference and may be a sign of the budget cuts in the USA with most universities and hospitals

Janalee Heinemann and Giorgio Fornasier

Czech Republic Parents PWS meeting: Because Giorgio and I were there for the Prague ESPE conference, the Czech Republic PWS group organized a two-day meeting for their families. The parent delegate for Slovakia, Maria Benedekova, and her family spent all night on the train to get there. It was wonderful meeting the families and children. They had a good physician translator, and the parents had many questions. The younger children are all very slim and on growth hormone, in sharp contrast to most of the older children/adults who did not have that option. I did three presentations and Giorgio did two. The professional delegate, Pavel Birčák, said afterwards that he was very pleased because the parents were leaving with a good feeling where sometimes if they have a doctor speak, they leave very "down".

Yerevan, Armenia: I went on alone to Armenia to help Prof. Albert Matevosyan coordinate the historic first conference on PWS in their nation. This took place in the framework of the First International South Caucasian Conference on Rare Disease and Orphan Drugs, dedicated to the 90th anniversary of Yerevan State Medical University. I want to give special thanks to all of those involved in the PWS segment for financially supporting their own expenses. Besides me presenting from the USA were Dr. Barb Whitman from St. Louis University in Missouri and Dr. Mary Cataletto from Winthrop University Hospital in New York. Joan (our IPWSO delegate for PWSA) and Jim Gardner also attended and helped coordinate the conference, The PWS section of the conference was dedicated to the memory of our dear past IPWSO president and PWSA (USA) delegate, Pam Eisen.

It is a wonderful feeling to light one candle – knowing that the candle you lit will light ten others – and that ten others will light 100… and though you may never see the culmination of the glow, the awareness you spread shines around the world. ■

Executive Director View

Evan Farrar

Since becoming Executive Director of PWSA (USA), I've had an opportunity to visit chapter meetings in Oklahoma and Florida. Both were vivid reminders of how much important and essential work is happening in our partner chapters and affiliates across the country. I look forward in the months and years ahead – in chapter meetings and other settings - to visiting other members of the PWS community to learn what successes and challenges in local and state communities can inform our work on the national level because nothing is more important than having a strong and collaborative relationship across the PWS community. The stronger we are in our ability to work together, the stronger we will be in providing support and hope to people and families living with PWS.

In September, shortly after being named Executive Director, I attended the PWSA (USA) Board of Directors meeting in Washington, D.C. As a way of introducing myself to readers of the Gathered View, I would like to share some of my remarks to the Board so you have a better sense of my approach to serving as PWSA (USA)'s Executive Director and some of my initial priorities.

Dear Board Members:

I want to talk with you for a few minutes this morning about my approach to the job of Executive Director and my vision for what's ahead. I want to begin with my vision. I envision a PWSA (USA) in the future that builds on the great strengths of our past and present. I envision an organization that is mission focused and mission driven. And yes, I envision a PWSA (USA) with more financial resources, more programs, more research, more family, medical and crisis support, and more advocacy to support people living with PWS across the country – and even the world.

I want your involvement, ideas and support. I want everyone around this table – every person on the Board – to know what we are doing and why. And I want us all to feel invested in how we are living out our mission. Because I need you engaged. And I need us unified and working together.

Some of you don't know me very well yet. But those of you who've had a chance to work with me closely know that I love collaboration, communication, and being part of a team. None of those characteristics are going to change now that I am Executive Director. We have too much work to do not to share it.

And while I want us to move as swiftly as we can to reach our goals, I also want to ask for your patience as well. We have a new team in place. And we need some time to get to know each other and establish our priorities so that we can help you as a Board with our best ideas, recommendations, and strategies in the years ahead.

But my first and most important goal is already being accomplished as I keenly look for those areas in our organization that need my attention as Executive Director. So far, these are the areas I've identified:

Fundraising. *We need an Executive Director who isn't going to delegate fundraising but is going to be an active, interested, and dedicated participant in the process*

Awareness. *We need an Executive Director who is visible and active in spreading PWS and PWSA awareness.*

Chapter Relations. *The Executive Director has a critical role in maintaining and strengthening chapter relations, and that is a very important priority for me.*

Advocacy. *The Executive Director must be the point person for advocacy at PWSA. Whether it is resisting deep Medicaid cuts that impact our families or resuming the push for adding PWS to Social Security's qualified list of impairments – we can't afford to have an Executive Director sitting on the sideline while these important issues are being debated across the country.*

Communication. *Whether we are talking about how to use social media, generating press releases, how we use* The Gathered View*, establishing new forms of communication, responding to press inquiries – we need a comprehensive communication strategy that allows us to work effectively and cohesively in communicating our message not just to our membership but beyond as well.*

Strategic review of our programs. *All of our programs are strong. But all have more potential. As Executive Director I want to facilitate a conversation with key staff, board members, stakeholders, and consumers to evaluate what we are doing and to propose new directions as well as establishing clear objectives and benchmarks so that we can clearly measure how we are doing on a year to year basis.*

continued on next page

Executive Director, *continued from page 4*

You may have other priorities to add to this list and, if so, I want to hear them. But here is the good news. I don't feel overwhelmed. I look around and I see a room full of partners in this work. No challenge I've discussed – or that we will discuss today or tomorrow – is too great for us if we meet it together.

One of the most gratifying responses to my decision to become Executive Director came from the many parents and families I got to know through the PWSA (USA) Crisis Intervention Program who wrote e-mails or Facebook messages to thank me for taking on the job of Executive Director. I think they were happy about this news because they know that their story goes with me into this new job. Their experience in some way will profoundly inform how I act and listen in this job.

And, in the same way when they called in crisis they hoped I would come through for them, they are hoping the same now. In other words, they are counting on me. They are counting on us. It really is an awesome and humbling responsibility. And it is because of those we serve that failure for us is not an option. So let's get to work. It is a new day for PWSA (USA).

And I thank you for the privilege of serving as Executive Director.

Evan Farrar

Did you Know?

Four new grants were approved by PWSA (USA) in 2010 that specifically target the hyperphagia (uncontrollable drive to eat) which is the most life-limiting aspect of the syndrome.

Joint Strategy Session:

The Boards and Senior Staffs of PWSA (USA) and FPWR Meet to Benefit PWS

The Foundation for Prader-Willi Research and the Prader-Willi Syndrome Association (USA) held a joint meeting of both boards and senior staffs on September 11th, 2010, in Bethesda, Maryland. The meeting was chaired by Alice Viroslav of FPWR and John Heybach of PWSA (USA). The purpose of this all-day strategy meeting was threefold: to get to know each other personally; to jointly identify and prioritize current and future challenges facing individuals with PWS, their families and caregivers; and to determine some specific next steps where the two organizations can work together to begin to meet these challenges.

Based on feedback from the participants, the day was a great success. During the large group and breakout sessions and over lunch both groups got to know each other personally, some for the first time and others to expand their working relationships and friendships.

During the general group sessions a large number of key current and future challenges were identified that the PWS community in general needs to address in order to continue to improve the quality of the lives of individuals with PWS, their families and caregivers. Key questions such as "How do we translate medical challenges into research programs?", "How do we turn research findings into practical treatments?", "How can we work together to further our advocacy efforts in all areas at the national, state and local levels?", "How do we share information more efficiently?", "How can we fundraise more effectively?", and many others were identified and discussed by the group.

A number of smaller working groups, composed of members of both organizations, were formed with the task of addressing some specific next steps such as (1) planning joint fundraising efforts, (2) creating a joint strategic plan for research priorities based on the results of the PWS Research Strategy Workshop held at the National Institutes of Health in November 2009, (3) begin working toward creating a joint database of medical information and a bio-repository for PWS research, and (4) begin to coordinate and prioritize advocacy activities.

A FPWR/PWSA (USA) Steering Committee was formed to help guide this joint cooperative process as it evolves. The members of this steering committee are Alice Viroslav, M.D., John Heybach, Ph.D., Theresa Strong, Ph.D., Mary Kay Ziccardi, Ken Smith and Lauren Roth, Ph.D. ■

David Crump, Development Coordinator

Creating Value

In her book, *The Soul of Money*, Lynne Twist suggests that money is like water. When it is blocked or held too long, it tends to grow stagnant, even toxic. But when we allow it to flow, it can purify, cleanse, create growth, and nourish. By creating channels for it to flow through our lives, guided by our noblest commitments, **money can become a current, a conduit for expressing our closest held intentions and deepest values.**

One way to direct this flow is by designating the persons and causes we want our estate to benefit. PWSA (USA) was the recipient of this kind of decision recently, from a grandfather who specified our association as a beneficiary in his will. Life insurance policies are another tool that can be used to designate a gift to an organization whose work we want to be a part of.

For more information on ways you can help support the work of PWSA (USA), please contact David Crump at 941-312-0400 or dcrump@pwsausa.org.

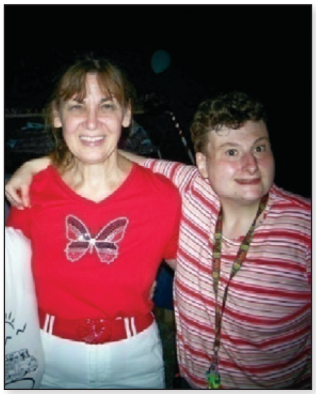
The 7th Annual Golf Fore Prader-Willi Syndrome Association Charity Tournament in honor of **Madison Hurdle**, organized by **Karla and Clint Hurdle,** was a tremendous success again this year. Taking place early in July, the event raised over $115,000 in support for PWSA (USA) and the PWSA of Colorado Group Home.

The 6th Annual Clyde's Run was held July 17 in Mountain Park, Georgia. This 5k run and 1 mile walk commemorate the life of **Clyde May,** one of the town's favorite sons who died in 2004 of complications from PWS. This year's event raised over $3,000 for PWSA (USA) in addition to supporting the work of the Georgia Association for Prader-Willi Syndrome, Inc.

The 2nd Annual PWS Bowling Fundraiser, hosted by **Fran Baehr** in East Islip, New York, took place the end of August and raised just over $2,000. "It takes a lot of work," Fran commented, "but it is all worth it, to help our kids." Besides bowling, attendees were able to participate in a Chinese Auction and enjoy food and live music.

On September 18, **the Benoit Bash** was held in honor of **Brooke Detiege.** According to her mom, **Nicki,** "Brooke is a girl that does not let anything stop her! Diagnosed with PWS a week after birth, she is now in the third grade and is involved in Girl Scouts, horseback riding, and swimming – among other activities. She is very friendly and loving, and leaves a lasting impression on each person she meets!" Bash attendees competed in a bean bag tournament, participated in a 50-50 drawing, and were entertained by the music of four different live bands. The event raised $1,250 in Brooke's honor!

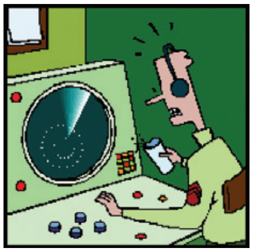
The 2nd Annual Prader Palooza Concert in Missouri brought together, among others, **eight young adults with PWS** with their support staff for a fun September afternoon in the sun. Eighteen musicians representing five different music groups provided entertainment, and the event raised nearly $2,000. Thank you to **Brigid Amoroso, her brother Tim,** and others who helped organize and make this event a success.



Brigid and daughter, Angie

The 2nd Annual Putt for PWS was held on September 19 in Arlington, VA to support **Charlie Deleage, Matthew Berl, Noël Bensaid, Ginny McMahon, Jackson Elder, and Riden Howard,** all of whom have PWS. Through the work of an active planning team, support from several sponsors, a raffle, the Putt Tournament, and many generous donations, the event shot past its goal of $7,000 to raise over $11,000. "We always end up with more than we thought," says Dominique Deleage, event organizer and Charlie's father. "People around us are SO generous and SO caring!"

Make sure we are on your Radar Screen!



National Awareness and Fundraising Campaign in May 2011PWSA (USA) will be rolling out a campaign to take place in May 2011. The campaign is being designed to benefit local chapters and groups as well as to support work at the national level. Look for more details in coming weeks. For more information contact David Crump at 941-312-0400 or at dcrump@pwsausa.org ■

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School in Greenville, South Carolina.

In the Trenches Vol. 1

by Jessica Patay

Twenty-nine questions in 10 minutes. It was a typical ride home from an afternoon activity. The car seems to have this effect on children I've been told, but especially on Ryan, my 6-year-old with PWS. He is my "high-need-to-know-kid" and is always shooting off questions. A sampling of Ryan's questions on this particular ride home:

- Are the clouds out?
- Do the clouds go away when the sun comes out?
- Do the clouds make it cold?
- Are the clouds in the morning?
- Will it be sunny on Monday?
- Why does the sun come out?

Lately Ryan has been obsessed with the weather. I have had to say to him over and over that "We don't discuss the weather anymore," or "I am not in charge of the weather." I have realized that no matter how many times I answer these questions, they do not go away and his anxiety is not appeased.

Ryan is a prolific question-asker. It is a strength. Curiosity is a good thing. (I keep telling myself that.) His questions, most often though, are fueled by his anxiety and inability to process the world's information around him. He often sees the world in still photographs instead of an ongoing video. His challenges processing information are exacerbated by his impaired short-term memory. Because, of course, he's asked these questions yesterday, a week ago, a month ago, or even just two minutes ago.

As a mother, I am a teacher to my three children, a teacher of new sounds, words, ideas, concepts, beliefs, values and morals. I enjoy this part of parenting. As a mother, I am called to nurture my children, a role I relish. As a mother, I am called to soothe my children's fears, to settle an anxious thought with answers, with comfort, with love and tenderness. However, how do I do this when I have a child who is *always* asking questions, over and over and over, a bottomless well of them? My child, and probably your children, are **always** asking questions until our patience tank is screaming EMPTY in angry red!

Sometimes we keep answering questions. Sometimes we empathize and clarify what it is at the heart of it. Sometimes we answer a few and then disengage. Sometimes we lose our calm resolve and say a little too loudly, "No more questions!" We hope that these tactics work. And sometimes they do. For a few hours or a few minutes.

What helps me in moments like these, when I want to pull out my fingernails one by one after Ryan has asked Question #873 that day, is to take a deep breath and say to myself, "It's not his fault. He is not TRYING to drive me crazy. He can't help it. He can't! Ryan loves me. I love Ryan, and I love all his parts that don't work quite right." I take another deep breath.

An "aha" moment came to me today. I have questions too. Lots of them, and all of the time, just like Ryan. Except mine are inside my head and heart.

And as a parent of a child with PWS, you do, too. The questions are there, dangling over us, sometimes like twinkling lights or a rain cloud, depending on the day or season of our special journeys.

My big ones go like this:

Ryan and Jessica

- Will Ryan ever learn to read and write (legibly)?
- When will the food-seeking and stealing behavior begin? Or will it not be as prominent an issue for him?
- What will he be like when he is a teenager? An adult?
- How will others treat him when he is older?
- Will Ryan have any true friends in life?
- Will I lose him prematurely?
- Why was Ryan given to our family? (I ask WHY again…)

I have my own anxiety and angst in living with PWS, as I am sure every parent or caregiver does. Just like Ryan, I have a million questions. *However, I have a choice.* I can stay stuck in my questions and be paralyzed by fear. Or I can tell myself, "I'm all done with these questions today." I can take a deep breath, pray, meditate, smile and remind myself that Ryan was given to me. He's a gift. He is full of goodness and unparalleled gratitude and affection. He is full of priceless treasures and life lessons for me and for our family. And most likely, he will always be full of questions. ■

Jessica Patay and Ryan live in Palos Verdes, California. She plans to write more "volumes" of "In the Trenches".

PWSA (USA)'s 9th Annual Valentine's Day Campaign begins January 1.

PWSA (USA) has designed a letter for the campaign for you to send out to your family and friends; it will include a picture of your child.

Here are a couple quotes from the letter: "Our four grants in 2010 specifically target the hyperphagia (uncontrollable drive to eat) which is the most life-limiting aspect of the syndrome. Now, we need your urgent help in raising another $50,000 to fund a very exciting research project that has just been presented to our research committee. This project has real potential for providing therapeutic relief from the hunger…With your help, we will alleviate the hunger and other symptoms in our children's lifetime (or -- continue to fight for a cure until our last breath)."

This is an easy and effective way that you can raise funds for research. For more details, go to www.pwsausa.org/valentine/ or contact Dorothy M. Sass at (941) 487-6728 or dsass@pwsausa.org ■

PWSA (USA) participates in the Combined Federal Campaign, and YOU can help!

Designation Code 10088

It is that time of year again when the Combined Federal Campaign (CFC) is in full swing! This is an annual fundraising effort that gives federal employees the opportunity to donate to their favorite nonprofit organizations.

All of us in the PWS community are passionate about enhancing the quality of life of our children and our families. Participating and/or encouraging our family and friends to participate in the Combined Federal Campaign is just one more way to support the research, education, advocacy and support provided through PWSA (USA). If you are a federal employee or have family members or friends who are federal employees, please ask them to consider a donation to PWSA (USA). Our CFC designation code is **10088**.

Thank you! ■

PWSA (USA) Conference 2011

Plan Ahead!

The planning committee for our upcoming conference to be held November 11-13, 2011, in Orlando, Florida is hard at work!

The site of the conference will be the Buena Vista Palace Hotel, located on Walt Disney World property across the street from the Downtown Disney Marketplace. The hotel sits on 27 beautifully landscaped acres just 20 minutes from the Orlando International Airport. For a photo tour of the hotel, please visit www.buenavistapalace.com.

The Scientific and Providers Conferences will be held on November 11th, followed by two days of stimulating speakers and informative sessions for our families that includes exciting, fun-filled YIP and YAP Programs. Save the date and mark your calendars now!

Watch the PWSA (USA) web site and The Gathered View for further details as they develop. Making reservations under the PWSA (USA) conference group rate will be provided soon. Please make your reservations under the group name after this information is given. ■

YAHOO! PWS is Connected!

As of September 1, PWSA (USA) had the following in Yahoo! e-mail Groups:

0-5	806
6-12	504
TEENS	204
18-up	60
CLE	219
Grandparents	55
Providers	120
Spanish	7
Siblings	107
With PWS	39

Other lists include Military, Autism, etc.

Without duplication of e-mail addresses we are supporting 1,481 through Yahoo! Groups. ■

Cindy, the Voice with a Smile

By Denise Servais

You may not recognize the name, but if you have ever called PWSA, there is a good chance you may have talked to Cindy Beles. Cindy is the Triage Advocate for PWSA, spending most of her time as the main person answering phone calls that come into the organization--phone calls that come from people all over the world.

After taking the initial phone call and getting some basic information, Cindy transfers the call to the most appropriate person, such as a crisis counselor.

If it is a call from a family with a new diagnosis, Cindy will spend time talking with them, listening to their concerns, answering questions and determining what needs they may have. She then puts their name into a database and sends out the Package of Hope.

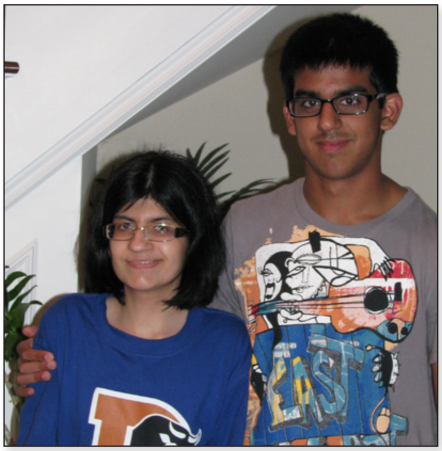
In addition to the Package of Hope, she sends out information to grandparents. She also sends out DVDs and medical packets to pediatricians, who are especially grateful for the information. She signs up newly diagnosed families with one year of free membership to the organization. In addition, she does all of the ordering for any requests for PWSA products.

Cindy has been with PWSA for six years. She says what she likes best about her job is working with families. "I'm a mom of five sons. One is handicapped. I have compassion and understand the concerns of our parents… I was drawn to a place where I could help people and make a difference. I have a lot of job gratification."

When she is not taking phone calls, Cindy enjoys spending time with her family in Sarasota, where she resides. She has two grandchildren and enjoys swimming and going to the beach.

Thank you, Cindy, for your good work! ■

Sibling View



My name is Shariq Iqbal [from Pittsburgh, Pennsylvania], and I am the 17-year-old brother of Mishal Iqbal, who has PWS. I thought it would be beneficial for the community to read an article from the perspective of a younger sibling so I wrote this essay.

Growing up as the Younger Sibling of a PWS Child

When I was a child, I looked up to my sister like all younger brothers would. It barely even occurred to me that there was something different about her. We played games, shared toys, and did everything else that young siblings would do together. For all I knew, she was completely normal. There was no specific moment that I found out she has PWS. It was more of a gradual process. As I grew older, I began to notice the things that were different about her. She had an abnormal amount of tantrums, she was small for her age, and she had a near constant preoccupation with food, but I still loved her. When my parents told me she had PWS, it did not take me by surprise, and my opinion of her never changed. She was and always will be my loving sister.

Since my sister matured at a much slower rate than normal, she and I were able to bond as young children. Even though she is four years older than me, we communicated at the same level. It was wonderful to have a sister that enjoyed spending time with me and was essentially the same age as me.

As I became older, my older sister slowly became my little sister. While she remains an avid fan of "The Disney Channel," I have outgrown such forms of entertainment. Whenever my parents go out, they tell me to watch "the kids" (A.K.A. my sister and my little brother), and I make sure that she does not overeat or steal food while my parents are away. I watch over her just as an older brother would, despite her being older than me.

PWS changes the lives of parents, but I have not known any other life. This syndrome has been a part of my life since the day I was born, and I have learned many things from it. My sister has inspired me with her amazing self-control and resilience. Despite all of the factors working against her, she has managed to maintain a healthy weight her entire life. She has gone through scoliosis, dislocating patellae, and daily growth hormone injections with few complaints.

She recently had surgery for one of her dislocating patellae and experienced multiple complications. She had the initial surgery, surgery to clean an infection, then IV antibiotics to kill the rest of the infection, surgery to repair

continued on page 11

From the Home Front

Rob Lutz, Philadephia, Pennsylvania, former board member and father of Isabel, age 10, reports:

I want to let you know about two PWS things we've stumbled across:

The first is a keyless lock that is activated by fingerprints. For anyone with a locked pantry or the like it could be a valuable tool that is error proof. See the site below.

http://www.gokeyless.com/category.php?id=149&main=3&parent=149&gclid=CNykqcHQiqMCFdID5QodlxrefA

The second is an "adult" tricycle. Isabel doesn't seem to have the balance to do a two-wheel bike, and training wheels are both "childish" and not able to support her well enough. So, we got the bike below and she is enjoying it since it is clearly an "adult" bike but makes her feel stable.

http://www.amazon.com/Westport-42078-Adult-Folding-Tricycle/dp/B000Z89JFO/ref=sr_1_1?ie=UTF8&s=sporting-goods&qid=1280196913&sr=8-1 ■

Tracey Lombardi, Ocean, New Jersey, says

[I] use these for Cole, almost 4, and they are fantastic... keeps him so cool, he has hard time in heat.

www.chilltowels.com ■

Skye Walker recommends: www.waldenfarms.com

They make gluten-free and calorie-free products that are incredibly tasty. I was skeptical at first, but I have lost 40 pounds after being sick from hormone therapies which made me gain weight. And Trevor, 8, is losing, too. I thought other PWS families might be interested in their products. ■

From England

My daughter Taylor is 16, and we have just completed the London 10K run for PWS UK. Taylor is a great example of what can be achieved with positive conditioning towards food, nutrition and fitness. She has walked 25 miles on three occasions for her school, [done] three 5K fun runs and is a regular participant in fitness classes at our health and fitness centre ... Just wanted to share this story with you ... we have a great story to tell, and young families should be encouraged to use the "predictability " of this condition to their advantage.

~Frank Phillips ■

A Big Thank You to PWSA (USA)!

I just want to thank you for running the article "The Make-A-Wish Foundation granted Reagan's wish to meet Rascal Flatts!" What a wonderful article! By the end of it, I was crying, too, just like Reagan's mom... tears of joy and happiness. This little boy looks and sounds (from the article) so adorable and sweet. I'm overjoyed. God blessed him and their family in such an awesome way!!

Also, want to thank you for the very informative "Scoliosis" article. I'm going online soon to download the entire article and mail it to our daughter's orthopedic doctor.

And last, congratulations to Mr. Evan Farrar! He sounds truly wonderful and fit for the position. Our family wishes him the very best.

We thank everyone from PWSA (USA) for all you do. Stay strong! God bless.

Suzy Brice and family
Coral Springs, FL

I'm No Expert, *continued from page 1*

I have PWS", "It could be worse" or "Just a snack won't hurt".

I have a monthly schedule of appointments that rivals the Secretary of State.

I spend more time speaking to teachers, therapists, physicians and psychiatrists than I do speaking with my own family members.

I can design an IEP that reads like an owner's manual.

I can activate my superhero laptop, and like the bat phone to the commissioner's office, I can instantly connect with fellow superheroes from around the world who share the same evil archenemy as me.

Like the lone superhero misunderstood by the world, I, too, feel a sense of loneliness that comes from living a life few can understand. I, too, feel unappreciated for the mentally and physically exhausting role I play in saving a life.

When my son Nicholas was first diagnosed with PWS, I wondered how the world would change his life. What I never realized was just how much his diagnosis would change mine. And while I don't have shiny blue-black hair and ride in the Batmobile, I have come to realize that like my superhero comrades, perhaps by embracing my new persona and using it to spread awareness and hope, the world will become a better place for our children. ■

Chapter View

By Barb McManus,
Director of Family Support

A chapter provides a local resource that is hard to match on the national level. The chapter works with our organization to provide help for individuals with parent mentoring for newly diagnosed, advocacy and awareness. We share the same goals and support the same concerns. The key to help families is communication!

We have set up e-mail Yahoo! Groups for parents of infants and toddlers, school age, teens and over age 18, siblings, PWS & autism, grandparents, military and for those who have the syndrome to share their concerns.

These e-group lists we support have one problem. They cannot help with issues that are state specific. Concerns such as placement, eligibility, benefits, services, laws and regulations are best addressed on state- based communications. We have now set up e-groups for almost every state in the USA! If you are not a member of one of these state-based groups, please sign up at www.pwsausa.org/links/chapter.htm If your state is not listed on this page and you would like to help get a list going in your state, e-mail Barbara McManus at bmcmanus@pwsausa.org. ■

Chapter news

Each week on Friday, we will be sending an e-bulletin to all who have signed up to receive it. If you have not signed up yet, please visit www.pwsausa.org and add your e-mail to our list on the box below the pictures. ■

Prader-Willi **California** Foundation Conference addressed BEHAVIOR!! On November 6, all day at the Hilton San Jose. Titled "The Behavior Toolbox", PWS Experts Linda Gourash, M.D. and Janice Forster, M.D., were the presenters. ■

The PWSA of **Iowa** has been working with Prairie View Management to establish residential placement for PWS. Prairie View Management, Inc. has developed a program to specifically address the needs of persons with Prader-Willi syndrome, and other food-related conditions which require management of access to food. The program is focused on fitness, proper nutrition and positive behavior supports centered on keeping clients active, involved and responsible for their daily lives. For more information contact Sylvia Mork at sylvia_pvmi@netins.net ■

Prader-Willi Syndrome Association of **Michigan** planned its November Family Gathering for November 13, with a presentation on Special Needs Trusts by Patricia E. Kefalas Dudek, followed by a family sharing time, lunch, and candle pickup. For more information visit http://www.pwsami.org/ or call (734) 998-3507. ■

The Prader-Willi Alliance of **New York**, Inc. is planning the 21st Annual Conference in Albany, New York, scheduled for April 28-30, 2011. Requests for Proposal (RFP) are being accepted for presentations at this conference. For more information go to www.prader-willi.org. ■

PWSA-**New England** hosted the Second Annual PWS Walkathon in June, 2010. The walkathon was spearheaded by Cindy and Jarrod Wells, parents of Madeline, age 2. Family and friends came together to financially support this cause which resulted in a very profitable event. PWSA-NE is also trying to make a difference in the adult eligibility laws that currently prevent PWS individuals from receiving services once they are 18 if their IQ is over 70. Their goal is to change the wording in the existing law, so that a diagnosis of PWS would automatically qualify an individual for adult DDS services. ■

The Prader-Willi Syndrome Association of **Pennsylvania** chapter met November 13 at The Children's Institute in Pittsburgh. The meeting included lunch, childcare, and election of officers and board members. Chapter contact: Debbie Fabio, President, 724-779-4415 or debpwsapa@yahoo.com ■

PWSA of **Tennessee** has a new website at http://www.pws-tn.org/ ■

PWSA of **Florida** held their annual conference in Orlando, Florida, on October 15-17, 2010 at the Regal Sun Resort. Speakers were Dr. Jennifer Miller, University of Florida, Dr. Greg Cherpes, The Children's Institute in Pittsburgh, Evan Farrar and Barbara McManus, PWSA (USA). ■

Sibling, *continued from page 9*

nerve damage that occurred due to the first procedure, and most recently surgery to regain flexibility in her knee that had been lost after the first operation. After all this we found out that the initial surgery did not work and her patella is still in a dislocated position. She endured all of this without a single tear. My family has learned a lot from her. How can we complain about little things when a member of our family has been through so much?

I cannot say that growing up with a sister that has PWS was easy, but I can say that I would not have had it any other way. From my childhood to my current high school years, my sister has always been there with her smile that never fades. That smile has been the light that guided me my whole life, and I could never thank her enough for all that she has brought to my life. ■

[Thank you, Shariq. Siblings of any age are encouraged to write about their experiences and submit them to The Gathered View.*]*

Great Ideas for the Holidays!

From our 0-5 e-mail group comes a list of 45 non-food related activities and ideas for the holidays.

1. Participate in or host a Turkey Trot
2. Christmas Lights Appreciation Walk 
3. Design luminarias to decorate your walkway
4. Go on a hike 
5. Pull out or make CDs of Christmas songs to sing and dance to
6. Put on a "Family Dance" with a special family music album
7. Put together puzzles
8. Take gifts to neighbors
9. Sing carols at elderly homes
10. Make a family scrapbook of memories from past holidays/ family events
11. Create scrapbook pages for photos you will take during the holidays
12. Play a pick-up game of softball, waffle ball, hockey, kickball--you get the point!
13. Play board games (You can even have a tournament if you like competition!)
14.  Decorate ornaments
15. Host an ornament-making party
16. Go caroling!
17.  Make homemade holiday cards
18. Collect leaves to make leaf-rubbing cards
19. Watch holiday movies
20. Share your favorite Christmas memories
21. Read Christmas books such as "T'was the Night Before Christmas"
22. Create a Family Tree - make a holiday tree with homemade ornaments using family pictures
23. Go for a hike to try to find wild turkeys
24. Scavenger hunts foraging for greens and such for decorations.
25. Write your own Christmas story; make a book.
26.  Fill a count-down calendar with good thoughts for the day. Every day open a good thought. A good opportunity for positive reinforcement for good behaviors
27. Make puzzles out of old Christmas cards, Christmas pictures, etc. (Put velcro on the back for extra OT work pulling and putting them together)
28. Create pine cone gifts by rolling them in lard or sunflower butter and birdseed; wrap and give as gifts.
29. Every year the children each choose a new Christmas book... and when our tree is set up, we take the box of Christmas books out and pile them around the base of the Christmas tree. The children are thrilled by the 'newness' of reading material and gravitate to the books often. 
30. We go to the fabric store each year and sew new Christmas pajamas and matching stockings. (We donate the ones from the previous year to the Salvation Army).
31. Skating rink in the back yard (turn on the hose when it is cold enough to freeze)
32. Tobogganing 
33. Walks all bundled up, in the evenings after dinner, whenever there is snow falling.
34. Go to the neighborhood rink for a make-shift hockey game.
35. Build a snow family
36. In the snow banks created from the snowplows, we love to dig a snow fort.
37. Snow ball battle with the neighbors (their fort is always right across the street from ours)
38. Make homemade Christmas wreaths
39.  Take small gifts, stockings etc., to a local children's hospital

40. Take small gifts, stockings, etc., to a local NICU

41. Pull out old family pictures or videos

42. Visit local attractions (amusement parks, museums, etc.)

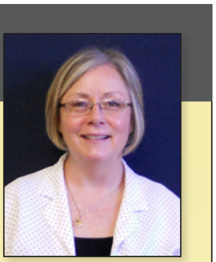
43. Make collages from old Christmas cards

44. Ring bells for Salvation Army

45.  Host a New Years hat-making party

Best wishes to all the members of the Prader-Willi syndrome family, near and far, for a Merry Christmas, a Happy Hanukkah, Happy 2011, and a safe holiday filled with the joy of family and friends

Counselors Corner



Kate Beaver

Giving Hope

For the past three years Kate Beaver (the Alterman Crisis Counselor) and Evan Farrar have served as PWSA (USA)'s Crisis Intervention Counselors. With Evan's appointment to the position of Executive Director, PWSA is very fortunate to have Kate taking on additional hours of coverage to keep our crisis program going strong as we search for Evan's replacement. We thought this would be a good opportunity for you to learn a little more about Kate.

Prior to joining PWSA, Kate, who has a Master's in Social Work, worked in a substance abuse program. But when a PWSA (USA) Crisis Intervention Counselor position opened, she applied because it gave her a unique opportunity to bring her professional skills to the service of a community she cares deeply about: families and children living with PWS. This community she is part of, as the parent of a daughter, Hana, who was born with PWS.

Kate explains, "I felt I had a great deal of experience working as a professional helping people to solve problems as a social worker. And a great deal of first-hand knowledge of PWS and the challenges parents face raising children with the syndrome. So working as a PWSA Crisis Intervention Counselor allowed me to bring together these two very important experiences in my life for the benefit of others living with PWS." She adds, "The best part of this job is I get to help people every day. I have a chance, at the very least, to give them hope in the midst of a crisis."

The most challenging part of the job, Kate says, is the increasing number of complex crisis cases she works on as a Crisis Intervention Counselor. "And the number is constantly growing," she reports, "because there are lots of families struggling in our PWS community, especially during these difficult economic times--which is why having a crisis intervention counseling program is so important."

Having a qualified professional like Kate – who understands the syndrome – available to work with our families is one of the most important support services PWSA (USA) provides. We are thankful as we continue our search for an additional Crisis Intervention Counselor that Kate continues to provide the quality crisis intervention counseling our families need and deserve.

See you next time in the Counselors Corner! ■

Contributions

Thank you for Contributions in August and September 2010 We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

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New PWSA (USA) e-Bulletin

Beginning early in 2011, PWSA will launch its new, weekly e-Bulletin, with announcements and other time-sensitive information of interest to all of us in the PWS Community. To sign up go to www.pwsausa.org/

Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers.
PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to **www.pwsausa.org/donate**

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

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

The Gathered View (ISSN 1077-9965)
Editor, Lota Mitchell
GV Designer, Sara Dwyer

Published bimonthly by PWSA (USA) as a membership benefit. Annual U.S. membership: $50 (individual, family, or agency/professional). Annual membership outside the U.S.: $60 (individual, family, or agency/professional). We never deny parents membership for any reason.

Medical information published in *The Gathered View* is not a substitute for individual care by a licensed medical professional.

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

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