



# The *Gathered View*

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



Parker Cheney, Florida

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## Bears Team Up with Illinois Chapter for PWS

Everyone was a winner when the Illinois Chapter held a Punt, Pass and Kick Competition with the 2005 NFC North Champion Chicago Bears at their indoor training field in Lake Forest, Illinois. The very successful event brought together PWS families, friends and some wonderful Chicago Bears players. Interaction between the players and the competitors brought smiles, laughter, high fives, cheers, hugs and some tears of joy.

"I had a great time working with the Chicago Bears and it was TONS of fun," wrote Alex Larson of his experience. Alex, 13½, who has PWS, reported about the day in the PWS Illinois Chapter newsletter.

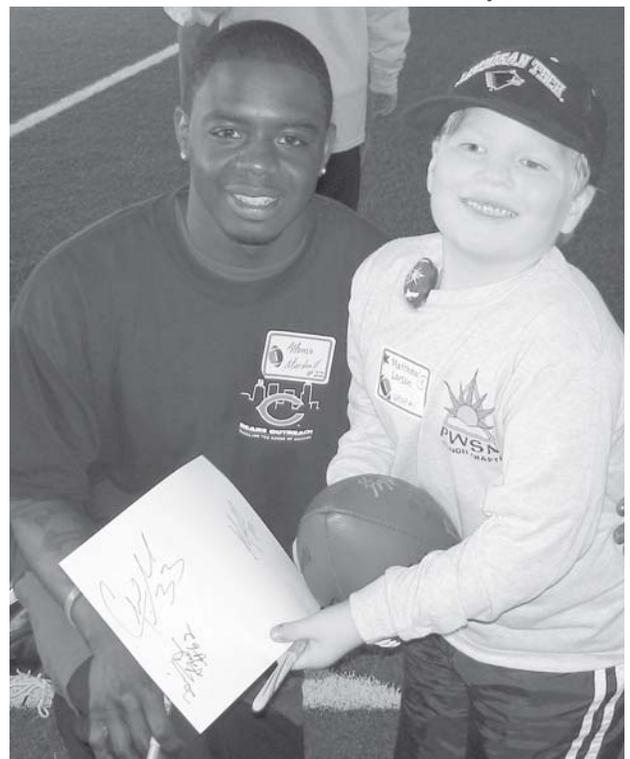
Organizing the event were Michelene and Mike Bajakian (brother-in-law and sister of Conor Heybach, 25, with PWS), with the enthusiastic support of Chapter President Ron Bruns and the rest of the Illinois chapter board of directors, including Sara & Todd Oetjen, Todd's father Larry Oetjen (who donated his band's services), Angela Krambeer, Sue Greco, Fred and Gerry Batliner and the Heybach family. Carolyn Guip and Jessica Kies of the Bears' Community Relations department were fantastic with all of their help.

Bears Coach Mike Bajakian directed seven Bears players as they coached 30 people with PWS in the intricacies of the quarterback, defensive back and offensive line positions. After the coaching session, all participated in a punt, pass and kick competition. Each received a medal and a Bears hat awarded by a Bears player at a day's end ceremony. Bears players signed autographs and chatted with the competitors and their families.

PWS Cowboy Wild Willy himself flew in from Texas, and as usual he was a great success. "A lot of kids got together and sang 'My Name's Not Willy' with Wild Willy before we left," wrote Alex.

Carolyn Loker and Jodi O'Sullivan from the national office and Dr. Jim Loker of the PWSA (USA) Clinical Advisory Board were also on hand. PWSA (USA) President Carolyn Loker called it "a very heartwarming

Photo by Mike Larson



Bears Defensive Back Alonzo Marshall with Matthew Larsen, 6, who has PWS

event for both the kids with PWS and the Chicago Bears. It was just a moment in time when our kids didn't have to think about their hunger because they were having TOO much fun!"

*Bears continued on page 13*

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**Our Mission:** Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted by Prader-Willi syndrome and related conditions.

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Deadlines to submit items for upcoming issues of *The Gathered View*

Jan/Feb: Dec 1; Mar/Apr: Feb 1; May/Jun: Apr 1;

Jul/Aug: Jun 1; Sep/Oct: Aug 1; Nov/Dec: Oct 1

# Have You Made Your Summer Vacation Plans? Get Ready to **GO WILD** for Conference!

**By Kerry Headley, Vice President, PWSA (USA)**

The 28<sup>th</sup> Annual PWSA (USA) National Conference is fast-approaching and we have an impressive line-up of speakers and presentations. This year's conference is being held on Grand Island, New York at the **Holiday Inn Grand Island**, an awesome location just minutes away from Niagara Falls.

The Conference includes the **Scientific, Professional Provider** and **Chapter President/Affiliate** Days on July 19, followed by the **General Conference** and **YIP** (Youth and Infant Programs) Programs on July 20 and 21.

The General Conference includes several sessions of interest to all attendees, as well as breakout session tracks organized into topics specifically geared toward the issues and achievements of Adult, Youth (school age), and Children from age 0–5. In addition to a review of highlights from Scientific Day, a few of the topics to be presented include:



♥ **On Track for Success: The PWS Express** (Janice Forster, M.D.)

This talk reviews learning disabilities in PWS, the importance of the daily schedule, and the debut of "TRAIN," a **Tool for Reducing Anxiety, Insecurity and Noncompliance**.

♥ **Laughter after Tears: Building a Strong Family** (Janalee Heinemann, MSW and Lisa Graziano, M.A., MFT) Coping mechanisms to create a strong, supportive and healthy marriage and family.

♥ **Relatives and Schools: Getting Them To Get It** (Linda Gourash, M.D.) Tips about how to communicate your child's needs to those who most need to know.

## Wild About You!

♥ **Pulmonary and Sleep Issues - The Breathing Safari** (Mary Cataletto, M.D.)

Journey into the growth and development of infants and young children with PWS as they relate to breathing. Explore the wonders of sleep and learn about some of the medical adventures you may encounter.

♥ **The Ins and Outs of Residential Services** (BJ Goff, Ed.D., Mary K. Ziccardi, Jackie Mallow)

Parents of young adults with PWS struggle with the decision to pursue residential placement for their child. This workshop was developed to help parents explore the options and obstacles to finding a satisfactory placement. It will touch on many shared parent and provider concerns, such as staff qualifications, turnover and training, communication, collaboration and more.

♥ **Understanding Childhood Apraxia and Speech** (Don Robin, Ph.D.)

Discussion of the signs and symptoms, impact on social and academic development, parent involvement and treatment.

♥ **Prader-Willi Syndrome: from the Orthopaedist's Viewpoint** (Harold Van Bosse, M.D.)

Discussion of the orthopaedist's role in children with PWS. Includes scoliosis, hip dysplasia, osteoporosis, other deformities, and developmental delays.

The conference will also include a Gala Banquet dinner, Silent Auction, music, dancing and a whole lot more! Don't be left out! **Log on** to the PWSA (USA) web site ([www.pwsausa.org](http://www.pwsausa.org)) and **download** your forms, **register online** or **call** 800-926-4797 and ask for forms to be mailed to you. The Registration deadline is June 30, 2006. A \$25 per person late fee applies **AFTER** June 30, 2006. No YIP Registrations will be accepted after July 8, 2006. **No registrations will be accepted after July 10.**

**Get the latest info at [www.pwsausa.org](http://www.pwsausa.org) - Register today!**



# When Life Hands You a Lemon, Peel It

Carolyn Loker

Two years ago I asked Janalee Heinemann about the appropriate time to talk with Anna about having Prader-Willi syndrome. Janalee told me Anna will start asking questions, and that will be the time to tell her.

I worried whether she was emotionally and/or cognitively able to handle the diagnosis or if it would just confuse her. No questions had yet come from Anna as I anxiously wondered how she was going to respond to the conversation I was asked to give to her Girl Scout friends about diversity.

Sitting in a circle with Anna's little Girl Scout friends, Anna being the only one with different abilities, I handed each of the five girls a lemon and asked them to study and get to know their lemons.

After a few minutes each girl put her lemon back in the basket. Then the girls were asked to pick their own lemon. Amazingly, each one picked out her exact lemon.

Going around the circle, each girl explained why she knew it was her lemon. "Mine is perfect," said one girl. "Mine is bigger," another one said. "My lemon has dents and bruises," stated another, and without hesitation, Anna excitedly told her friends about her lemon.

This led to talk with the girls about how lemons are like people, different sizes, different shades of color and some with "dents and bruises." The lemons were peeled and put back into the basket. I then asked the girls to pick out their lemons again. They looked up with curiosity and shouted, "But they're all the same!" This gave me the opportunity to tell them that people are much like their peeled lemons, pretty much the same on the inside.

I had the girls pair up and talk about what is different about each other. Each one talked about the difference between the color of their hair or eyes. Then it came time for

**This gave me the opportunity to tell them that people are much like their peeled lemons, pretty much the same on the inside.**

the little girl who was paired with Anna. She said, "Anna has blond hair and blue eyes and bigger feet than mine." That second I realized she didn't say anything about Anna's apparent back brace or her slower speech. She truly saw Anna for who she is on the inside.



Anna, second from left, with a few of her friends

We started talking about medical problems that people may have, such as blindness or hearing loss, when one girl spoke up to say she has allergies and an epi-pen at school. Another little girl was anxious to finally be able to tell her friends that she was recently diagnosed with seizures.

As our circle of friends started to become closer, Anna began speaking with such ease, as if she had been rehearsing this in her mind over and over: "I wear a brace because it helps me stand straight and tall, I get a shot

every night because it will make me grow as tall as mom, I am sad when my sisters eat in front of me because I am hungry all the time, even after I eat a full dinner!"

Holding back my tears I asked Anna, "What is the name of what you have?" Although she struggled trying to pronounce the words Prader-Willi syndrome, I knew what she was trying to say.

Anna moved beside me, closing the circle even tighter, snuggling next to my side, not speaking a word. It was as if she was trying to say without words, "Mom, that was hard and I need a big hug now." Wiping away my tears, I held her tight and understood the gift that Anna gave her friends that day, especially her mom.

Hugs to all.

## Sibling View

# I Wonder Why Angels Don't Always Appear Angelic

By Jonathan Gardner

The Gardner brothers: David, left, who has PWS, and Jonathan, right

Have you ever had an annoying brother? I have two brothers and they are both older than I am. However, one is brilliant and the other one isn't so smart. The latter one's name is David and he is 15 years old. He has Prader-Willi syndrome, which occurs when there is a deletion on the 15<sup>th</sup> chromosome, and it causes lots of problems mentally, emotionally, socially, and physically. He often makes me mad, frustrated, sad, and even embarrassed.

One symptom is that he has enormous appetite because his brain doesn't get a signal that his stomach is full no matter how much he eats. He eats endlessly and uncontrollably. He would even eat himself to death. Once, he ate about eight big bags of gummy bears at one sitting while the baby sitter was watching him. We have to watch him every moment he is around us and we had to get an alarm system just to monitor him at night or he would empty our pantry and refrigerator while we slept. He thinks he is always hungry and wants to eat all the time. He thinks about food, talks about food, and dreams about food. He seeks for food involuntarily, just as we need air to breathe. I get frustrated when he has eaten lots of my goodies I have tried to save.

Along with that he has obsessive-compulsive disorder, "OCD," which means that his mind and thoughts get stuck on one idea and can't get out of it easily. For instance, he wears only certain clothes and eats only certain foods at certain times. For example, he only wears Hanes underwear and eats only cold cereal for breakfast. Once when we went to Disneyland, my mom forgot to bring his exact underwear. He tried to take his clothes off at the park and I was so embarrassed. I wished to run away from him.

David always wants to know what time it is, where we are going, when we will get to wherever we are going, and when something will end. He loves fixed schedules and has very little flexibility. He drives me up the wall sometimes. Once, my grandfather took me and David to Idaho. David asked him almost every 10 seconds when we will be at my aunt's house. It's like a broken record player. The repetitive question drove my grandpa insane. He had to stop often to get away from that.

David counts the time with his stopwatch at the doctor's office, and then he tells the doctor how long it took for him to come into the room to check on him. Oh, how I dislike going to doctor's office with him. When he was in summer camp he received the "Father Time" award.

He isn't very flexible or cooperative. In other words he is extremely stubborn. Everything has to be HIS way. If he wants to watch a certain program on TV or play a game, he gets it no matter what. I always have to yield and watch his silly choice. That is not fair at all! There is no negotiation at all.

However, he has many other wonderful qualities. He is super good with animals. It's like he has a natural instinct to communicate with them. Extremely shy cats come to him to play and allow him to pet them, which always surprises their



owners. My grandparents have a finicky gray African parrot named Ivan. Ivan is not friendly with kids and pecks their fingers. But Ivan lets David pet him, play with him and even stands on his arm. I was jealous since I couldn't do that with Ivan. Not only that, but when we went to scout camp, he was the only one who got to ride the horses without falling off. While the stubborn horses were mistreating us, David enjoyed showing everyone else how to handle them. He may be lonely and has few friends, but he has a lot of animal friends because animals love him.

David also has a big heart and is kind. He gives you great bear hugs with love. When I am sad, he is the first one to put his arms around me. His hugs melt my frustrations and sadness away. One time David got lost for a long time. We searched for him several hours and he made us so worried. By the time we found him we all were sick to our stomachs and were drained emotionally. That night, David, noticing the unusual quietness, put his arms around my Dad with great concern and asked, "Dad, what wong? Huh? Something wong?" My Dad hugged him and we all cried. I saw a glimpse of his innocent mind.

My brother David sometimes makes me mad and sad, and I don't understand the silly things he does, but he is a wonderful human being. Despite disabilities, I love him very much. He has a genuine interest and sincere love for all of us. His humor makes me laugh, his smile is infectious, and his mind is pure and above all of us. He can be like my personal angel. Many nights before I sleep, I ask why I am blessed to have David as my brother. I wonder why angels don't always appear angelic.

*Jonathan, 13, and David, 15, live with their parents YuneJa and Duff Gardner in Orem, Utah.*

# Breast Enlargement in PWS Males

By Phillip D.K. Lee, M.D.

Part 2 of 2 parts

## Treatment

The vast majority of cases of non-PWS adolescent gynecomastia resolve without treatment, usually before the end of puberty (18-21 years old). Therefore, treatment might be considered medically unnecessary in most cases. However, psychosocial concerns, real or perceived, can be significant, even in medically minor cases. In addition, the breasts can be quite tender, making it difficult to wear tight-fitting T-shirts or athletic clothing.

In the usual case, a physician may offer supportive counseling, emphasizing that this condition is normal and self-limited. Non-prescription breast creams, typically used by women during breastfeeding, and avoidance of tight clothing may also be recommended. If these efforts are judged to be inadequate by an experienced physician, medications may be recommended to reduce production or effect of estrogens. However, it should be noted that the effectiveness of these medications in changing the natural course of adolescent gynecomastia has not been definitively proven.

Surgical therapy involves removal of the underlying mammary glands on both sides. This procedure is called mastectomy and is essentially the same procedure performed for female breast reduction or breast cancer. In my opinion, mastectomy should only be considered in cases where the breast has developed clearly female dimensions and particularly if there are progressive female-like nipple and areola changes. Surgery should be planned only in careful consultation with an experienced physician. Although complete mastectomy is a definitive procedure (new mammary tissue does not appear), surgery is not without risk and significant scarring may occur depending on the procedure used. Additional information regarding surgical treatment of gynecomastia can be found at [www.plasticsurgery.org/public\\_education/procedures/Gynecomastia.cfm](http://www.plasticsurgery.org/public_education/procedures/Gynecomastia.cfm). Male breast reduction is often not covered by third-party insurers unless a medical indication is identified.

In cases where there is significant lipomastia, weight control is absolutely essential. There are no medical therapies that will specifically reduce breast fat. Although surgery can specifically remove breast fat, this can result in a cosmetically unappealing result if the remainder of the body is still obese. In addition, unlike mammary tissue, fat can re-grow. If weight control is achieved and maintained, removal of breast fat can improve overall appearance. However, such therapy should only be considered in consultation with an experienced physician, as discussed above.

## Special Considerations in PWS

Although adolescent males with PWS do not achieve normal peak levels of testosterone, true gynecomastia (mammary tissue enlargement) is fairly common. As with non-PWS gynecomastia, the mammary tissue enlargement itself usually does not progress to a significant degree and nipple/areola changes are uncommon.

Testosterone therapy, as well as other commonly used medications in PWS (for instance, some types of psychotropic and anti-hypertensive medications) may increase the risk for gynecomastia. It has been suggested that growth hormone therapy can be associated with gynecomastia in non-PWS patients; however, a cause and effect relationship between growth hormone and gynecomastia has not been demonstrated in either non-PWS or PWS patients.

Lipomastia is very common in adolescent and adult men with PWS and can lead to very prominent breast enlargement, particularly if there is accompanying gynecomastia. If weight gain is uncontrolled, this can lead to pendulous, female-appearing breasts. As with non-PWS men, weight control is an essential first step in treating this condition.

## Three Issues to Consider

Although there may be an instinctive desire to remove abnormal-appearing, pendulous male breasts, a decision to pursue surgical therapy of breast enlargement in PWS, whether due to gynecomastia, lipomastia or both, must be very carefully considered in consultation with an experienced physician. The following three questions should have clearly positive answers before a decision is made to proceed with surgery:

1. Is treatment going to be beneficial to the affected person? In my experience, some males with PWS may be completely unconcerned with their breast enlargement, while others adamantly favor surgery. Much depends on the individual's social environment and caretaker perceptions.
2. Has weight control been achieved? Remember that breast fat may re-grow.
3. Is the benefit relatively greater than the risk? Surgery is usually performed under general anesthesia, which can be a risky option for individuals with PWS, particularly for those with preceding breathing and respiratory problems.

## Summary

Male breast enlargement is a relatively common condition in both PWS and non-PWS populations. Most cases of true gynecomastia in adolescents are due to natural, self-limited natural processes. Lipomastia, rather than gynecomastia, can be a primary factor in overweight individuals. Surgical treatment of significant, persistent male breast enlargement may be indicated based on the potential for significant adverse psychosocial effects. However, weight control is an absolute requirement before consideration of this option. In addition, cases in individuals with PWS need to be carefully and objectively considered before proceeding with surgical therapy.

*Dr. Lee serves on the PWSA (USA) Scientific Advisory Board. Part 1 of this article appeared in the March-April issue of The Gathered View.*

By Janalee Heinemann, Executive Director PWSA (USA)

The March 2006 ACMG meeting had a triple purpose for me. PWSA (USA) had an awareness booth (*made possible by a generous grant from the Gerald & Dorothy R. Friedman New York Foundation*), I was chosen as one of 10 delegates of rare disorders to be hosted by the Genetic Alliance, and to attend the meeting of the National Institutes of Health (NIH) rare disorder collaborative grant. The Genetic Alliance effectively integrated these delegates into the conference. Besides attending the entire conference, we had breakfast and lunch meetings with top geneticists to discuss the day's sessions.

I realized again that in the world of rare disorders (known as "orphan diseases"), PWSA (USA) is held in high regard for how developed we are as a non-profit. This is due to many factors, including being so well known with researchers and specialists and our abundant educational materials and programs. Although families often ask why more doctors and the public don't know about PWS, we should remember that *there are 7,000 to 8,000 syndromes*. So we can't expect every physician to have great knowledge about any one. Thus we often remind our PWS families that they must be the experts. Meeting with the other rare disorder advocates (bless them) reminded me of where we were 25 years ago: one brochure, a handful of active members, and before us, a very formidable mountain to climb. Often I only see the climb in front of us and do not take the time to appreciate how far we have come.

**Seizures and PWS** was an intriguing poster presentation from the Chapel Hill, North Carolina group. In this retrospective study of 45 patients with deletion, 10 with UPD and 1 with imprinting defect, there was a much higher incident of seizures in the deletion group. All 10 with recurring seizures had the deletion. Six other children had possible seizures, putting the seizure group at a possible 18% — much higher than reported in the literature in general or in our large medical database. We have a report of 6% in the 0-5 age group, 9% in the 6-18 age group, and 13% in the 18-and-above age group.

I contacted Barb McManus, who immediately reviewed our database to compare the type of PWS with those who had reported seizures. Out of 1,450 entered, 150 reported seizures. Comparison was very interesting. Although not to the extent of the Chapel Hill study, our database did support their findings that more with deletion reported seizures (11½% reported seizures, or 70 out of 609) than UPD (5½%, or 16 out of 292). But also, those with a translocation had 28% (7 out of 25), where those with imprinting had only 3% (1 out of 30). We did not include those with unknown type of PWS (460) or those who are PWS-like (31).

**"Opportunities and Impediments in National Collaborative Studies for Rare Genetic Diseases"** This session was led by Michael Watson, Ph.D., executive director of ACMG. Dr. Watson and I go way back to when we both worked at St. Louis Children's Hospital, part of the Washington University Medical complex in St. Louis. We both worked

with the national and international collaborative oncology groups for children, POG, COG, and CCG. In COG alone, 5,000 pediatric oncologists participated from 240 medical centers, with 85-95% of the children with cancer (40,000) enrolled in clinical trials. From this kind of collaboration, some childhood cancers have dramatically improved survival rates. For example, since 1964, Wilm's tumor studies have shown survival rates increasing from 20% to 90%.

I have thought about the question Dr. Watson pondered in his presentation: "*Why can't there be the same type of collaboration with rare disorder groups and the geneticists studying these disorders?*"

Currently, in dealing with rare disorders, NIH is primarily paying for individual grants (the NIH grant that we are a part of is the exception), so to disperse funding as a large coalition of institutions will be a major reorganization. Another challenge will be that with rare disorders, there is a much wider range of patients than in oncology.

Lessons learned from the oncology groups include:

- Competition between researchers and/or institutions can be a major impediment. They need to be willing to give up their autonomy — difficult in the university arena of publish or perish. More difficult yet is when a company is involved and there are patent issues.
- There is a tendency to base research questions on what is more likely to be funded than on what is really needed.
- The Old Guard tends to dominate, making it difficult for new researchers to get into the main arenas or to be heard.

In spite of this, there is great potential in collaboration with rare disorders.

- Collaboration between or within disciplines in different academic settings enriches ideas. There is power in collective intelligence.
- Pooling of patients improves the statistical power of data. It allows for establishing a tissue repository for current and future studies, helps establish standardization of data, and allows for intense collaborative meetings. In addition, it necessitates closer communication between NIH and the research groups, and becomes a venue for advocacy and public awareness.

**Challenges of Orphan Drug Development** was another interesting presentation by Dr. Ed Kay of Genezyme Corp. There has been a decline in filing for applications for orphan drugs. Some of the reasons include:

- Length of time to get approval increased from 4.7 years of research in 1989 to 7.8 years in 2002.
- If the population with the rare disorder is less than 200,000, the research and development costs often cannot be recovered in the 7 years the development drug company has exclusivity in advertising for that product — thus a need for "ultra orphan" status.

*Genetics continued on page 10*

# Growth Hormone for Adults with Prader-Willi Syndrome

By Barbara Y. Whitman, Ph.D.

Even before all the studies have been completed, the benefits fully examined, and the impact of possible side effects evaluated, growth hormone (GH) replacement therapy has rapidly become standard of care for infants and children with Prader-Willi syndrome (PWS). GH was first approved by the FDA for use in children with PWS in the year 2000. For treated children, the *apparent* benefits are dramatic and non-trivial; in addition to increased height there is a normalization of cranial proportions and facial features, normalization of hand and foot proportions, and for most, a slim body. With early treatment, most no longer stand out from other children as “different”, nor are they readily identifiable as having PWS.

GH replacement for those whose short stature results from congenital, traumatic or surgical endocrine system failures is relatively recent. First utilized in the late 1950s, availability was exceedingly limited, as manufacture required human pituitary glands available only at autopsy. Biosynthetic growth hormone replacements were rushed to market when an excess of those treated with cadaver-derived hormone contracted Creutzfeld-Jacob disease, a fatal neurodegenerative disorder whose causal mechanisms have only recently been specified. Since the range and depth of studies usually required prior to FDA approval of a drug were incomplete when the use of biosynthetic agents became imperative, a compromise system of surveillance was set up to monitor safety and efficacy — the model currently utilized for many new drug releases.

Short stature has always been considered a characteristic of PWS. Studies indicate that despite normal length and weight at birth, the growth rate in children decelerates over time, so that the average final adult height is approximately two standard deviations below the mean for a non-affected population. That GH deficiencies were the probable basis for the short stature was documented as early as 1971, and subsequent evidence demonstrated the impact of GH on linear growth. In the late 1990s well designed, controlled scientific studies documented that GH therapy resulted in a significantly improved rate of linear growth when compared to those not receiving treatment.

More important, however, was the concomitant improvement in body composition (increased lean, i.e., muscle, mass, increased bone mineral density, and for many, a reduction in the amount of fat tissue); improved metabolism (higher resting energy expenditure, improved respiratory parameters); and increased energy and strength. Self-esteem, behavior, and attention were improved. As the children in those original studies are now reaching adulthood, unpublished data indicate that final adult heights for individuals treated with GH as children are significantly taller than those not treated.

Unlike most long-term treatments for other chronic conditions, the side effects and safety concerns for GH therapy appear minimal to almost non-existent, *in the absence of pre-existing morbid obesity and respiratory compromise*. Most clinicians and researchers view the improved body

composition and metabolism as far more valuable even than that of increased height.

As a member of one of the first U.S. teams researching GH intervention therapy for youngsters with PWS, I recall seeing the dramatically positive body changes evident at even the first six months’ follow-up visit following initiation of GH treatment. I remarked to my colleague on the project, Dr. Susan Myers, “We have to do an adult study to see if we get the same positive body composition effects.”

## Growth Hormone Treatment for Adults

With the advent of puberty, the window of opportunity closes for increasing height through GH intervention due to a “capping” of skeletal growth potential. Further, GH levels normally decline with age in all populations. Entering adulthood already GH deficient presents significant health risks, including osteoporosis, increased body fat, decreased muscle mass, increased risks for heart and vascular disease, fatigue, social isolation and psychological depression. Thus in 1995 the FDA approved GH replacement therapy for those with either childhood or adult-onset GH deficiency. An area of research currently is the use of GH in a geriatric population, often with stunning results.

Recent studies indicate that adults with PWS continue to have the same GH deficiency that was present in childhood, with the same health risks attendant to non-PWS, GH-deficient adults. Most adults with PWS also are deficient in sex-steroid/sex hormone production, which further increases the health risks associated with GH deficiency. Thus, in addition to a possible improved body composition, the potential for improved long-term health strongly suggested the need to study GH therapy for adults with PWS.

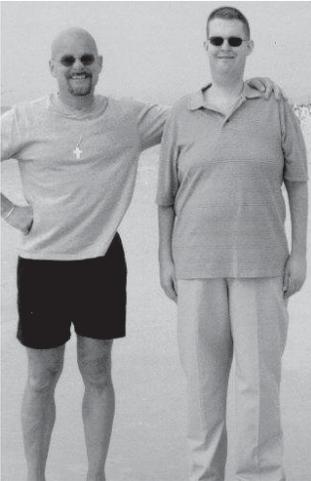
Dr. Myers and I ultimately joined with several other teams of researchers to conduct a study of GH for 40 adults with PWS, ranging from age from 19 to mid to late 40s. That study and another conducted in Sweden are now completed and results are being published. So what can we understand from these studies at this point?

Significant improvement in body composition is observed in adults with PWS, both males and females, treated with GH replacement therapy. These include increased muscle mass, and for many, a reduction in fat tissue. There also appears to a small positive impact on bone mineral density; however, these effects are not as dramatic as those noted in children, probably because bone metabolism does not change as rapidly in adults as it does in children. Loss of fat tissue is particularly apparent in the trunk area, many show a waist and hip body form for the first time. Improvement in energy and strength as demonstrated in such measures as broad jumps, running, and arm curls showed improvement after only one month of treatment. Both attention and cognition showed improvement as well.

Unlike children, however, GH treatment for adults is not without some risk. Increased fluid retention, particularly in

*continued on next page*

## Before and After GH Therapy



Top: Al Heinemann with son Matt, who has PWS, just prior to adult GH therapy. Bottom: Al and Matt in 2005 after a year on adult GH.



the feet and ankles, can initially occur and for some is sufficiently problematic to require discontinuing treatment. For some there may be a negative impact on glucose tolerance, leading to Type II diabetes. For some, the impact on scoliosis must be considered. Thus the risk/benefit ratio must be considered.

### Obtaining GH Treatment for Adults

If a caregiver is considering this treatment for his/her adult with PWS, what is involved? Since GH replacement therapy for adults with PWS does not yet have full FDA approval, formal demonstration of GH deficiency through provocative GH stimulation testing is required, even for those who have been on GH for a number of years during childhood. This timed procedure requires injecting a GH stimulating agent while fasting and measuring the peak level of GH secreted into circulating blood at specific points over a specified period of time. However, these procedures are neither straightforward nor simple. There is disagreement on what constitutes deficiency. Depending on the decision-making criteria employed, GH

deficiency is defined as peak stimulated GH levels of less than 3–7 ng/ml. While a number of provocative agents are available, peak stimulated levels may differ depending on the agent used, resulting in a requirement for two or more tests. Further complicating the variability related to stimulating agents, variability can exist between analyzing laboratories. Thus, even true GH deficiency can be masked by both the provocative agent used or the analyzing lab employed, resulting in a denial of treatment. In addition, these tests are not without risk, so tolerating two such tests constitutes a major medical procedure. What happens when one test indicates decreased GH levels, while the other is borderline or above the cutoff?

Once GH deficiency is documented, your physician may want to obtain a number of medical tests both prior to initiating therapy and again at least annually as part of therapeutic monitoring. These include an x-ray for scoliosis, a DEXA scan for bone mineral density and body composition, a sleep test to rule out life-threatening (but treatable) apnea, and multiple blood tests, including a fasting lipid panel, fasting glucose, IGF-1, hemoglobin A1c, general chemistry profile with liver enzymes, and thyroid function tests.

### Is It Worth It?

So one may ask, Is it worth it? One adult, in her mid-40s when her therapy was started, had shown enormous improvement on a number of physical measures. After 2 years of treatment, she was in danger of losing funding for her medication. She called her insurance company and said, “You can’t take away my hormone — my brain is not confused any more!” Her hormone was continued. However, even with appropriate testing and documentation of GH deficiency in adults with and without PWS, obtaining coverage for GH therapy can be difficult in the United States.

*Dr. Whitman serves on the PWSA (USA) Scientific Advisory Board. A version of this article including footnotes and list of references is available upon request from our PWSA (USA) national office and in the Members Only section of our website, [www.pwsausa.org](http://www.pwsausa.org).*

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## NEW: PWSA (USA) Current Research Summaries Available PLUS Updated Research Web Page

PWSA (USA) has exciting research news to share with all of our friends and families. Dr. Jamie Bassel, father of a sweet little boy, Zakary, has generously agreed to summarize in lay terms current research journal articles on PWS as they become available on our website at <http://www.pwsausa.org/research/index.htm>.

The research webpage also contains:

- ♥ A thermometer, updated frequently with the amount raised for research funds during the current year.
- ♥ A link to *Research Today* — a free monthly online journal that summarizes the latest research about PWS
- ♥ A link to “How to use” Pub Med — to find any abstract that has been developed into a journal article.

Research is a very important component of PWSA (USA)’s goals. In 2005, \$205,000 was raised for research. We know with your help we can raise the level much higher, especially considering what has already been collected this year.

It’s exciting to see that many, many of you realize that PWSA (USA) is known not only for the support and education that it provides, but also for our quality research grant awards. And we’re also proud that many of the top experts in the field of PWS serve on our outstanding scientific and clinical advisory boards. These are exciting times and PWSA (USA) is glad you’re part of them! Thank you!

— *Carolyn Loker, President, PWSA (USA)*

## Chapter View

# Busy Chapters Promote Awareness and Plan For Fun

By Lota Mitchell, Associate Editor

♥ Lisa Thornton, new president of the **Utah** chapter, learned in early January through a connection her brother had with a media person that the chapter could have a prominent booth at a Health Expo occurring just two days later. With the help of our Community Development Director Jodi O'Sullivan, she pulled it together!

More than 500 people stopped to talk about PWS and took literature; many signed up to participate in the Chapter's May Walk. Lisa even met the governor's wife, who agreed to help. Lisa says, "One unexpected benefit was that we felt so buoyed up by the experience. Many people would stop, listen to what we had to say, and then tell us what heroes we are and what a good job we are doing. I'm not sure it is true, but we felt like we were flying rather than dragging after 8 hours on our feet explaining a not-so-pleasant syndrome to people.

"I wrote a long letter to the sponsoring corporation's rep who helped so much, outlining the success of the expo and how much it meant to all of us, and sent a basket of fruit, chocolates, etc. My brother called and said the rep came into his office all choked up. She said that our group could have whatever we needed, that our cause is now their cause, and that the company would be with us all the way for the Walk in May!" A commercial to promote the Walk featured Utah's First Lady Mary Kay Huntsman, Lisa Thornton and Debbie Bingham of corporate sponsor Phone Directories Co.

♥ **New Jersey** plans its Spring Meeting May 20. A waiting list is being developed for a new residential facility with a special program for individuals with PWS, and an opening hoped for in a little over a year.

♥ Camp time! In addition to Sophie's Walk on June 4 at Fairview Park, **PWSA of Ohio** will have summer camp again for folks with PWS that is totally adapted to their needs. Children and adults with PWS, age 8 and up, can attend from Sunday, July 2 to Friday July 7, 2006, at Recreation Unlimited in Ashley, Ohio. R.U. will provide all activities, lodging, meals and snacks, counselors and program leaders. Cost is \$675 plus \$25 nonrefundable registration fee. Registrations will be taken on a first-come, first-served basis.

Contact Sandy PWSA of Ohio camp Coordinator, 614-876-1732, [juicete@aol.com](mailto:juicete@aol.com), for more information or registration form. Sandy reports that last year all campers maintained or lost weight during this week....and they had a great time doing it!

♥ **PWSA of WI** held its annual Hobby, Social & Training Day April 1. The all-day event is organized so that siblings, children and adults with PWS have an opportunity to actively learn about new hobbies and/or items of interest, e.g., woodwork craft, beaded necklaces, painted sun catchers.

♥ Mary Patterson, long active in the state association, is the new president of **PWSA of NC**. She has a son Ted, 15, who has PWS.

♥ No sooner had **Pennsylvania** finished holding its mini-conference in March than they were busy planning for the annual golf outing May 22.

♥ More than 65 people participated in the annual retreat held by **PWSA of Georgia** — campfire with guitar and stories, financial planning information, healthy foods, games, activities and prizes.

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## Genetics - continued from page 7

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- The tax credit in the USA is not a large enough incentive versus other countries. The NIH budget has been cut dramatically; thus the reality of more funding in this area is slim.

- To prove the drug's effectiveness, does it need to reverse the disease or is it enough just to stop progression? In trial design, placebo use is often difficult. For example, with growth hormone, who would agree to be in a study trial when there is only a 50-50 chance the child would be getting a placebo?

- With very rare disorders it is harder to show statistical significance, so the drug can die in regulatory limbo. With rare disorders where is the end point? It is not like cancer, where a child is considered "cured." Again, a good example is growth hormone for PWS. At what point, if ever, do you take a child off?

- When do you intervene — when a person is asymptomatic, or wait until they are symptomatic?

- There are often small numbers of patients at any one site, so recruitment and travel expense to a treatment center remain an issue.

On the NIH grant, I've learned to appreciate that all of the researchers involved must not only agree on what should go into the natural history forms and protocols, they must jump through many hoops (HIPPA regulations, IRB approvals from each institute, NIH requirements, requirements of the Data Technology Coordinating Center). Currently, the coordinator of the PWS section is Dr. Dan Driscoll, working with Dr. Merlin Butler and Dr. Suzanne Cassidy. All three are active members of our PWSA (USA) boards. Probably one more center will be added initially to work on PWS, and others will join once things are running smoothly. Although progress has been slower than all the investigators would like, it has been steady, and this grant is breaking ground for future collaborative grants on rare disorders.

There was much discussion on newborn genetics testing now available. This and the many other new alternatives for treatment will cause the financial cost of our health care system to explode. We now have more treatments available than money to fund them. A provocative question kept arising: *Can we as a society afford to pay for everything we know how to produce in medical care?*

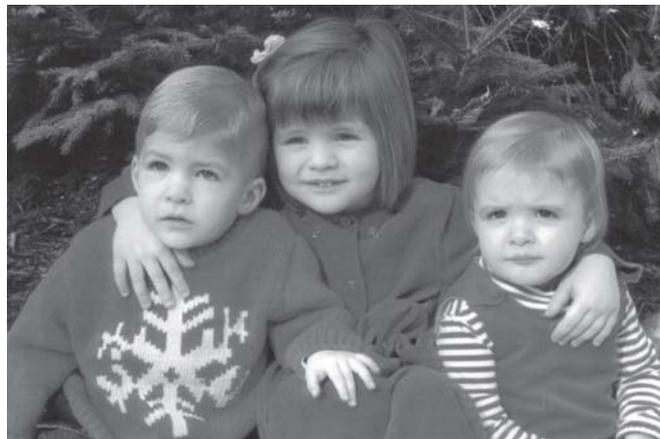
## Fundraising From the Home Front

# How Do You Spell Bingo? J A C O B!

In honor of **Jacob Perrault**, who has PWS, his parents Anita and Kyle Perrault and aunt and uncle Kate and Pete Buchbinder created a December family event. They netted \$1,700 for PWS Research from their first **JACOB Bingo Fundraiser**.

Seventy family members attended, all donating something for the party, from refreshments to game cards and pencils. They began the evening with pizza, drinks and veggies, then played 14 rounds of Bingo for the family's 14 nieces/nephews, who gave up exchanging Christmas gifts so they could donate prizes for the winners. The Bingo cards spelled out Jacob, so winners had to yell "Jacob Bingo."

"We spoke a few minutes to the audience about Jacob's milestones and accomplishments, followed by some of the challenges that adults and children with PWS like Jacob struggle with. We had the pamphlets to provide further education and awareness for those who are seeking to better understand PWS. It was an unbelievably emotional night as we were surrounded by such a wonderful and loving family,"



Jacob Perrault, who has PWS (left) with his big sister and twin sister

writes Anita. "We never thought we were going to make such a significant contribution on our first attempt."

**There is one thing stronger than all the armies of the world, and that is an idea whose time has come. ~ Voltaire**

### A Very Furry Fundraiser

Jennifer Dean arranged a "**Build-A-Bear Furry Fundraiser**" weekend in February with her local Build-A-Bear Workshop in San Antonio, Texas. A percentage of sales was donated to PWSA (USA). She organized it, handed out flyers and information about PWS, and with her 1-year-old son **Tanner**, who has PWS, greeted customers for each day of the fundraiser, which netted \$1,415.

"The fundraiser was wonderful. The line was continuously out the door. I was able to speak with each person about PWS and the response was so great. There were even three different people who knew someone with PWS. There were also a few who had worked with people with PWS," writes Jennifer. "I feel the opportunity to give 600-plus people a thank you note with info all about PWS was worth it."

Next, Jennifer got involved with the Six Flags Fiesta Texas Fundraiser ending in March. PWSA (USA) was selected as one of several groups benefiting from the sale of admission tickets to the theme park. Each ticket sold earned \$5 for PWS, for a total of \$215.

### Raising Money by Dressing Down

Anita Struebel, grandmother to **Madison Smith**, 2, who has PWS, organized a **Dress Down Day** at work in March. Anita hung a flyer with a short explanation of PWS, along with a photo of her granddaughter Madison. The effort netted \$1,555 for PWSA (USA) research by the employees of Independent Health Association in Buffalo, New York, the highest amount ever collected for a Dress Down Day charity. The amount also included checks from Anita's family and friends. "I am very proud of my co-workers who stepped forward and gave from their hearts," writes Anita.

### Saying I DO for PWSA

**Florence Larsen** and **Vince Connelly** will soon celebrate their six-month anniversary. When they were married in November, they decided to do something different. "We have a wonderful niece, **Lea Capraro**, age 10, who has PWS. She's the heart of our whole family," Florence said. So she and Vince decided that instead of wedding gifts, they'd request donations to PWSA (USA). Their request netted \$5,318! The wedding rule was: no gifts, but if you don't understand no, then donate to PWSA (USA).

"I was aware of PWSA because of Tina and Bill [Capraro, Lea's parents]," said Florence. "Bill and Tina told me how this organization was run... I wanted to do something that makes a difference in someone else's life. There are so many good causes... look in your heart to find the one you feel good about. This one was ours."

### Avon Online Fundraiser Through May 31

Holly DeRidder is holding an online fundraiser, which continues through May 31, 2006, when 100% of proceeds from ALL Avon orders online at [www.youravon.com/hollyderidder](http://www.youravon.com/hollyderidder) will be donated to PWSA (USA). Please ask friends, family, coworkers and anyone else to consider making a purchase to make this opportunity a huge success. There is something for everyone. For questions, please contact Holly at [hollybaer@moomail.net](mailto:hollybaer@moomail.net)

— **Jodi O'Sullivan**, *Community Development Director*  
and **Jane Phelan**, *Editor*

**Look for Highlights from PWSA (USA) Awareness Week in the next issue of The Gathered View.**

**Now Available** from PWSA (USA)

## Management of Prader-Willi Syndrome, 3rd Edition

The new third edition of PWSA (USA)'s book *Management of Prader-Willi Syndrome* is the most comprehensive reference in the world on the diagnosis and care of individuals with PWS.

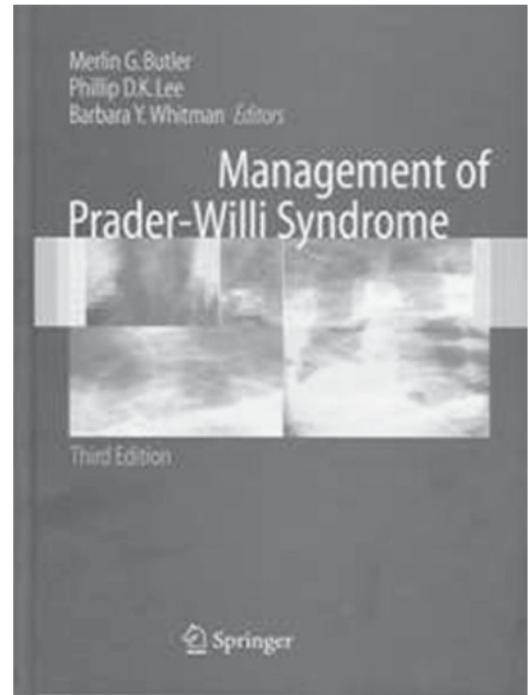
Louise Greenswag and Randell Alexander, editors of both prior editions of the textbook, call the new third edition "edited and written by the very best in the field and updated with the latest research... the single best resource of information and support for the next several years."

Part I, Diagnosis and Genetics, was edited by Merlin G. Butler, MD, PhD, William R. Brown/Missouri Chair in Medical Genetics; Chief, Section of Medical Genetics and Molecular Medicine, Children's Mercy Hospitals and Clinics; and Professor of Pediatrics, University of Missouri-Kansas City School of Medicine, Kansas City, Missouri.

Part II, Medical Physiology and Treatment, was edited by Phillip D.K. Lee, MD, Chief Scientific Officer, Immunodiagnostic Systems Ltd., Boldon, Tyne & Wear, United Kingdom; formerly Professor of Pediatrics, Division of Pediatric Endocrinology, David Geffen School of Medicine, University of California, Los Angeles.

Part III, Multidisciplinary Management, was edited by Barbara Y. Whitman, PhD, Professor of Pediatrics, Saint Louis University School of Medicine, Cardinal Glennon Children's Hospital, St. Louis, Missouri.

Price for PWSA members is \$50 plus shipping; non-members, \$75 plus shipping. To order, contact the National Office, 1-800-926-4797 (toll-free in USA and Canada); fax to 941-312-0142 or e-mail to national @pwsausa.org



## What's **NEW** at PWSA (USA) National Office

*By Janalee Heinemann, Executive Director*

First I want to thank everyone who sent me cards, love and prayers during my treatment. I wish I could thank each of you personally. For those of you who did not know, I was diagnosed with breast cancer in December, had a lumpectomy, then 36 rounds of radiation therapy. My prognosis is good and now I take a hormone inhibitor medication (and a few other drugs) for the next 5 years to help keep the cancer in remission. I had surgery on a Friday and was back at work the next Tuesday. During radiation, I had treatment in the morning and then went to work from noon to 7 or 8 p.m., so perhaps you did not even know I was gone!

A special thanks to PWSA (USA) President Carolyn Loker for taking morning medical emergency calls, and the board and staff for their support during this time. The Rev. Bernice King once said that "You cannot direct the wind, but you can adjust the sails." I have "adjusted my sails" one more time.

Second, we welcome our new part-time crisis counselor **Kate Beaver** from Madison, Wisconsin to our staff. She is assisting David Wyatt with the many crises and advocacy for services needed. David is thrilled and relieved to have Kate on board! It is a big world of needs out there. Kate has a 19-year-old daughter with PWS, has a master's degree in social work, and worked for 10 years with phone crisis counseling in another field. Her husband is an ER physician. She is part of our virtual office crew.

We also welcome **Barb McManus** to our staff. We have had more and more of a need for an office information technology specialist to maintain our membership database and office systems. Barb was a perfect fit for this job. As an active member of the PWSA (USA) Board of Directors and PWS grandmother, Barb volunteered her time to our organization in numerous ways over the years. She has maintained the membership database updates, assisted us with computer issues, and maintained our website for the last 6 years. Now that we have hired Barb part time, we have added office technology and database management to her many responsibilities. Barb recently retired from her full-time position as a programmer/analyst at the Multidisciplinary Center for Earthquake Engineering Research in Buffalo, New York. She resigned her position as a board member on January 31, 2006 to avoid conflict-of-interest issues.

But Barb will continue to chair the 2006 PWSA (USA) conference in New York this summer as a volunteer. So Barb has retired from her full-time position to work longer hours for us at half the salary she had been making. Bless Barb for her passionate commitment to our children!



# PWSA (USA) Board Appoints Kerry Headley Vice President

A resident of Columbus, Ohio, Kerry is the mother of a 7-year-old little boy, J.R., who was diagnosed very shortly after birth with Prader-Willi syndrome, Uniparental Disomy subtype. As she tells him often, J.R. is her only, but favorite, child.

Her goal since learning J.R.'s diagnosis has been to get involved, stay involved, and dedicate whatever free time she has to the Prader-Willi Syndrome Association. She's a past board member of PWSA of Ohio and a current officer in Prader-Willi Families of Ohio. She has served as PWSA (USA)'s National Conference Project Manager and Scientific Oversight Chair for the past 2 years. "Being involved in the National Conference has been such an incredible privilege for me. The conference group that I've worked with is the most talented group I've worked with in my career. The way this group gets things done while considering the human beings that make up the organization is what attracted me to want to further my involvement," she said.

Kerry works full-time as an educational strategy consultant with a firm based out of Covington, Kentucky. If you ask her what she does she'll say, "It's not a simple answer, I wish I was a nurse or a pilot. A one-word answer that everyone understands what you do." An abbreviated version of her job description is that she designs educational solutions, such as e-learning courses and leadership

PWSA (USA)  
Vice President  
Kerry Headley  
with son J.R.,  
who has PWS



seminars, for large corporations. Her job allows her the freedom to work out of her home and maintain access to great technology and resources while still being involved at every level in J.R.'s care and schooling.

"I am so honored to hold this position as national vice president. There is so much we can do together as a team and I can't think of a better team to be part of. I'm very anxious to get started!"

**Have you sponsored  
a Lose-A-Thon Participant yet?  
Support someone with a donation.  
There's still time.**

**Go to [www.pwsausa.org](http://www.pwsausa.org) and click on Lose-A-Thon**

## **Bears** - continued from page 1

The players included quarterback Rex Grossman, who passed his way into the hearts of 38 people, offensive linemen Roberto Garza and Lennie Friedman, who took some tough hits from the competitors, defensive backs Charles "Peanut" Tillman, Brandon McGowan and Alfonso Marshall, who demonstrated the art of making the game-saving interception, and wide receiver Mark Bradley, who received hundreds of perfectly thrown passes from competitors.

The focus was football and fun, with none of the "meltdowns" that can occur at gatherings like this. Michelene attributed this to excellent organization and supervision and the fact that no food or beverages other than water were allowed in the facility.

A silent auction of autographed items donated by the Bears was also very successful. Several local and national news organizations covered the event, including Comcast Sports Net, which ran a feature on Rex Grossman, Roberto Garza and Alex's brother Matt Larson, 5, who also has PWS.

Overall the event was one very good time. If you live in the Illinois area and would like to be on the invitation list for next year's event, join the Illinois Chapter by e-mailing Ron Bruns at [brbruns10@earthlink.net](mailto:brbruns10@earthlink.net) with your name, mailing address and phone number. If you would like advice on holding a similar event, send an e-mail to [JHeybach@sbcglobal.net](mailto:JHeybach@sbcglobal.net).



Wild Willy with his littlest Deputy, Brandon Greco, 22 mos., with PWS(top) , and (bottom) Alex Larson, 13½, with PWS, gets his T-shirt autographed by Bears Defensive Back Charles Tillman



## View From the Home Front

### Grateful for PWSA (USA) Support

My son Nolan Anders, age 2½, has PWS by deletion. Last July, Nolan and I attended our first ever PWSA National conference, thanks to funding from PWSA and PWSA-WI.

I want to thank you and the staff not only for helping us attend the conference, but for all of the wonderful work you all have done to help families like ours not only cope with PWS but have HOPE for our children's future. I learned a great deal at the conference, made some wonderful friends, and took away valuable information I've shared with others who could not attend.

I hope to give a little back to the National office by helping out in any way I can. I have submitted an online volunteer form and look forward to hearing whether some of my skills can be of service to PWSA (USA).

Although I am sad that Nolan's condition will be a lifelong struggle, I am grateful that Prader-Willi syndrome has such a strong advocacy group to help educate and support those of us who deal with this syndrome every day. I feel that it is partly because of the education and support I have received from PWSA (USA), parent mentors, education materials and newsletters, the National website, and the Yahoo support groups that Nolan is doing so well.

Nolan started walking independently at Christmas, and it was the best gift we

could ever receive. We are so proud of him! We do our best to accept the things about PWS we cannot change, but our greatest goal is to do all we can to help Nolan live to his fullest potential in life.

I also manage the website for PWSA-WI, and update it on a regular basis. It is a nice complement to our already strong state chapter! <http://www.pwsausa.org/wi/>

I hope to get the opportunity to meet everyone at the conference in July. Nolan and I are looking forward to another fun and motivating event.

*Jennifer Kryzak, Cedarburg, Wisconsin*



Nolan Anders, 2½, has PWS



#### Happy Birthday, Greg!

*Greg Cortellini, with his mother Sue, celebrated his 50th birthday in December 2005. Greg's diagnosis was confirmed at age 6 by Dr. Prader when he visited the Jacobi Hospital in New York. Since he has been living at the Anclote Group Home for Prader-Willi Adults in Tarpon Springs, Florida, Greg has gone from 260 lbs down to 150 lbs, said Eugene Galloway, house manager. Greg works daily at the sheltered workshop operated by UPARC (Upper Pinellas Association of Retarded Citizens) in Clearwater.*

#### PWSA (USA) and Rare Disorders Groups

PWSA (USA) has been a member of several rare disorders groups for many years, including the National Organization for Rare Disorders (NORD). NORD is a federation of voluntary health organizations and individuals with rare "orphan" diseases. NORD has a responsibility to ensure that all member organizations observe ethical standards and have responsible governance in order to maintain the public's trust in charitable institutions.

To qualify for NORD membership, a non-profit voluntary health organization must be national in scope and meet a number of stringent requirements that include supplying 501 (c)3, annual report and audit documentation, an elected board of directors that reflects its national scope, along with a list of medical and scientific advisors.

## View From the Home Front

### What a Lucky Dog!

My daughter Molly, who has PWS, and I were at that the grocery store recently. As we shopped, she was using her signs to remind me of some of the things that we were there for.

She insisted that Daddy needed “flowers please,” which I was happy to buy. She was so excited throughout the store, telling me about the flowers.

By mid-way through our trip she began using her sign for “eat” and began crying and crying to me, like I had never seen her cry before. I was upset, she had eaten a snack just before we came and wasn’t really due to eat anything for a while. But she continued crying. I was a bit surprised that this symptom would come on so strong, so suddenly.

We both cried all the way home. When we got home, she was still using her sign for “eat” and crying. (I had stopped!)

We walked into the kitchen and our dog Einstein came to greet us. Without thinking, I said, “Oh Molly, we forgot to get puppy his food.”

She stopped dead in her tracks. “YEAH,” she said, and began using her sign for eat again, combined with her sign for the dog, which is a “hu, hu, hu,” sound, like a dog



Molly, 3, with PWS, makes sure her dog Einstein gets his food

panting. She had been trying to tell me I forgot the dog food!

I somehow was mixing up her signs for the flowers (which is sniffing, like you would smell a flower) with the sign for dog. We were both so relieved. By the time we got home and put things away, it was way past her lunch time,

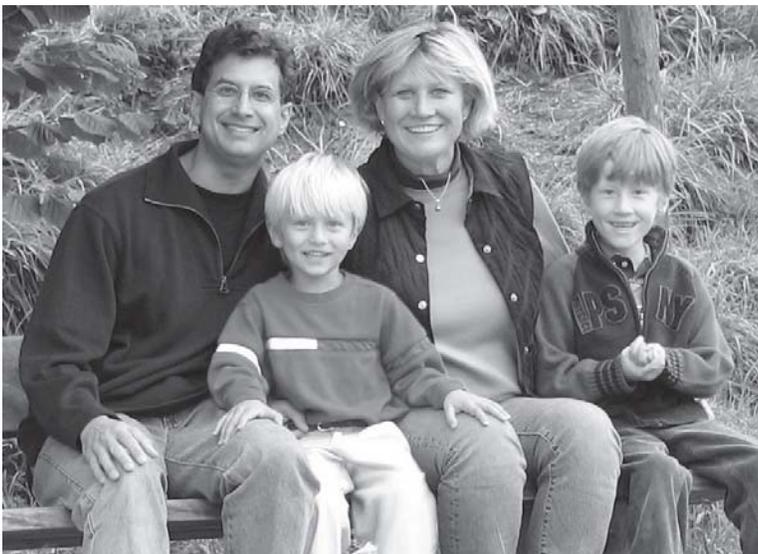
but she insisted we go back to the store for the dog’s food before she had her lunch.

So Molly’s Dad put his flowers in water and took her back to the store. I cried again, but this time it was a mixture of relief (at least for the moment) and sadness that her speech is such a barrier to her communicating with us.

**Mary Speiser, South Amboy, New Jersey**

## Involve Family and Friends in PWSA (USA)

Our visit to California for Christmas went so well. The interesting thing is that I really didn’t think my family understood Alex. We had been hesitant to go out there because of this (they instead come to our house where things are set up to meet his needs). Well, we just decided to go for it. My sister-in-law called ahead to ask about dietary concerns. We discussed hiding all of the candy, not placing candy canes on the tree, explaining to her kids why and how they can help. They made a real effort.



The Agarwal Family (L-R): Dr. David, Samuel, Janice and Alex, who has PWS

My family has been receiving the GV for several years now, and they altered their eating and snacks during our stay. They had all read the issue of GV which discussed how even though our kids are thin, we still have to be vigilant. So they were watching out for Alex and “caught” him several times trying to sneak food. The nice part is that every time he was caught he would smile, walk away, realizing that he couldn’t get away with things. The more we caught him the better he got and the easier it became for my family to realize that they really were doing a great job.

At the end my brother stated that he is becoming the cutest kid. Now I would go back for a visit in a heart beat.

I encourage every family to make their family members and close friends members of PWSA (USA). The more information they have, the better.

**Janice Agarwal, Zionsville, Indiana**

*Janice is a member of the PWSA (USA) Board of Directors.*

*Note: Auxiliary memberships are available for \$15 a year for friends, family members, professionals working with your child, anyone that you want to have a better understanding of PWS and how to handle it. Memberships entitle folks to receive The Gathered View with its wealth of information. Just call the national office to arrange for them.*



To date: \$102,344

# Angel Fund

Goal: \$150,000 - We Can Do It!

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## Fundraising For Research

# Our Valentine Research Campaign Was A **HUGE** Success

It's exciting to report that as of mid-April the 2006 Valentine Research Campaign (VRC) has raised \$80,702 from 923 donors. Thanks to 44 special valentines, their families, and donors, this is the largest amount ever donated in the four years of the VRC: the highest amount until now in any one year was \$38,000.

PWSA (USA) is thrilled to report that in the first 3½ months of this year, a total of \$93,288 has been raised for research, including the VRC. What a difference this will make when PWSA (USA) funds our next round of research grants at the end of 2006. Thank you for making this possible!

— *Carolyn Loker, President, PWSA (USA)*

### Our Valentine Sweethearts



Lindsay & Erin Anderson  
Aimee Atwood  
Rebecca Baird  
Sophia Bolander  
Isabella Burnham  
Joshua David Carter  
Laura Cassady  
Clara Ciuriuc  
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Abby Jean Heathman

Morgan Heffner  
Hannah Herne  
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Ben Hopkins  
Jakayla Howard  
Casey Howell  
Kate Kane  
Jake Klauber  
David, Ben & Caroline Knopf  
Dylan Krambeer  
Autumn Leigh Letzo

Anna Loker  
Faith Morse  
Callasandra May O'Connor  
Jake Pawulak  
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*Recent notes from our members:*

### *What PWSA (USA) Has Done For You Lately*

• “Words can not express how helpful you and the PWS organization were. You could tell you all cared about us and that truly is appreciated because we felt total trust with you. We were able to call you and know you were giving us correct advice.”

• A **mother from SC** called to thank **David Wyatt** for the crisis letter, saying it was a very big help, and that David continues to help her. “I do not know what I would have done without all of you,” she added.

• From **Bronnie Maurer**: “You have no idea the impact Tad’s (YAP director) program had on **Andy**. He talks about it all the time.” Andy will now say, ‘I am a brand new me!’ and ‘I have to be a role model.’ ”

• From **Lisa Thornton**: “I wanted to thank [Director of Development **Jodi O’Sullivan**] for all her help with pulling together this health expo in such a short amount of time. She is just the kind of person we need helping us at the national level...smart, eloquent, and knows how to get things done. ... The experience and your support has helped our little group get off the ground. “It will be up to us to fly now!”

• From **Melanie Ledgerwood**: “Thanks so much for your response and the forwarded information. I definitely see my **Lauren** as an individual who is at risk for this dangerous (GI) problem. She is slim (about 125), lives under constant diet supervision. When she comes home, we do allow her to eat differently. Most importantly, she does suffer from chronic gastric issues. Thank you from the bottom of my heart for all you have done and continue to do for Lauren and others affected by PWS.”

• From **Jennifer Bolander**: First, I want to thank all of you in the national office for all of your hard work. My daughter **Sophie** (PWS) just turned 2 on Jan. 20... and please know that the past 2 years would have been so much more difficult had we not had the support and understanding you provide through your amazing efforts. Please know that ALL of you are so very much appreciated.

• From **Carol Norman and Family**: “... A lot to thank you for. Being there when we’re in trouble is the greatest of all. I cannot thank you enough for flying us to [Children’s Institute in Pittsburgh] and home. What a wonderful blessing and what a wonderful bunch of people you are.”

# Contributions

## Thank you for Contributions through March 2006

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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Prader-Willi syndrome (PWS) is a birth defect first 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. The 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.

