

# The *Gathered View*

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

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

## Hurdle and the Rockies are PWSA (USA) Champions

*By Jodi O'Sullivan, Director of Development & Communications*

By now you've all heard the name Clint Hurdle. Manager of the Colorado Rockies major league baseball team and father of three, Clint has not kept the plight of his daughter Madison, age 5, who has PWS, a secret.

In fact, just the opposite. Clint and wife Karla have given their time to make the world aware of PWS and raise funds for PWSA (USA). All while the Colorado Rockies played their hearts out to win the National League Championship.

While Clint and the Rockies were making headlines as the underdogs who made it all the way to the 2007 World Series, the Hurdles were also closing out their annual golf event to benefit PWSA (USA).

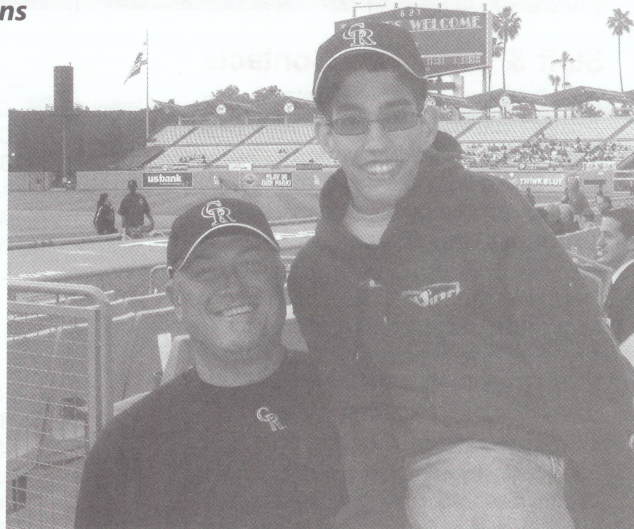
This year, they've netted close to \$90,000! Clint and Karla even called PWSA (USA) during the NL playoffs to confirm that the funds they sent had been received. No one expected to hear from them, but they made the extra effort. And just before the World Series began, Karla called again to arrange a World Series fundraiser sponsored by the pediatric practice where Madison is a patient. Another astonishing gesture.

**See Page 7 for Tips to  
Head Off Holiday Mishaps**

Clint often mentions that he's the national spokesman for PWS, a public education project he took on two years ago for PWSA (USA). He has gone far beyond what was expected of him. At his request, the Rockies donated time and talent to create the public service announcement now on the PWSA (USA) web site and now also on YouTube. YouTube awarded us an "Honor" based on having the 36th most popular sports video on their service in one day.

Clint accomplished for PWS what no one was able to do before despite best efforts — get PWS in the news on a large scale, with accurate information about the syndrome, and turn the perception of PWS from negative to positive.

During baseball season, Clint went to meet-and-greets at state chapter events for both away and home games, and arranged for PWSA to have an awareness booth at Coors Field, the Rockies' home stadium. Colorado chapter members dutifully manned the booth, keeping PWS in the minds of baseball spectators. Between the media and PWSA at the stadium, it's probably safe to assume that PWS is now a household term in Denver, if not the state of Colorado.



Clint Hurdle at the ball park with Trevor Ryan, who has PWS.

And what do Clint and Karla ask in return? Nothing. This remarkable couple, who have raised hundreds of thousands of dollars for PWSA (USA), given PWS a new life in the

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# PRADER-WILLI SYNDROME ASSOCIATION

Still hungry  
for a cure.

8588 Potter Park Drive, Suite 500  
Sarasota, Florida 34238  
800-926-4797 \* 941-312-0400  
Fax 941-312-0142  
[info@pwsausa.org](mailto:info@pwsausa.org)  
[www.pwsausa.org](http://www.pwsausa.org)

**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 impacted by Prader-Willi syndrome.

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Cindy Beles, Triage Advocate  
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Rachel Elder, Community Development  
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**Members Only:** See our website [www.pwsausa.org](http://www.pwsausa.org) for downloadable publications, current news, current research and more limited to members only.

**User Name:** [pwsamember](http://www.pwsausa.org) **Password:** [together07](http://www.pwsausa.org)  
Note: If you have difficulty logging in, please contact [info@pwsausa.org](mailto:info@pwsausa.org).

## E-mail Support Groups:

We sponsor nine groups to share information.  
Go to: [www.pwsausa.org/support](http://www.pwsausa.org/support)

## The Gathered View (ISSN 1077-9965)

Jane Phelan, Editor  
Lota Mitchell, Associate Editor

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

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



Craig Polhemus

## PWSA (USA) and You

What does PWSA (USA) mean to you?

You can probably answer quickly if you've ever called on us for medical information, or during a crisis, or for educational materials or family support.

But sometimes what we do here at PWSA (USA) might not be so evident in your daily life.

- Fostering PWS research is one of our most important roles. Results are not often immediate, but over the years we've made significant progress regarding diagnosis and treatment of PWS. Research continues to improve our children's lives tomorrow.
- Our Scientific and Clinical Advisory Boards of *volunteers* are some of the world's experts on PWS, who generously make themselves available to consult on PWS issues. They help our children today.
- We established and maintain the largest-ever database of those with PWS, including medical information now mined by PWS experts around the world.
- We manage an extensive Web site that received 900,000 visits in 2006 alone. The Web site is the world's single largest collection of information about PWS.
- We promote PWS awareness and provide an accurate explanation of PWS to the public.
- We coordinate with the International Prader-Willi Syndrome Organization to significantly advance diagnosis and treatment of PWS worldwide.

Have you ever considered how much you mean to PWSA (USA)?

I have. We *are* a working partnership, after all.

You are the backbone of PWSA (USA), and we could not operate our programs through the national office without your time, your voice and your financial generosity. Together, we give help and hope to all families living with PWS.

Soon you'll receive information about our annual PWS Angel Fund, which provides essential support that allows PWSA (USA) to operate and save lives. As you make your plans for giving this year and beyond, please support your partnership with PWSA (USA) and ask family and others to help also. Support opportunities include:

- Donations of cash, stock, bonds, property
- Estate planning bequests through wills, life insurance policies, trusts

- Corporate and foundation grants and matching funds programs

- Coordinating a fundraising event

- Membership — not only yours, but also grandparents, aunts, uncles, cousins and care providers.

We're happy to assist in arranging any of these donation options, all of which have tax benefits for you, too.

We currently operate on just over \$1.75 million a year. Be assured that your contributions are never taken for granted. We're very proud of PWSA (USA)'s excellent reputation among charity watchdog groups. Because of our efficient financial management, we've earned highest ratings from the Better Business Bureau's Wise Giving Alliance Standards for Charity Accountability (give.org), the Combined Federal Campaign, and Charity Navigator.

A new Board member once said, "I am just blown away by all you do on what little you have. I had no idea."

Hundreds of new PWS cases arise every year. That means hundreds of families who need our help. We know you won't let anything stop you when it comes to your loved one with PWS, and neither will we at PWSA (USA).

Because we're in this together. Mahatma Gandhi said: "Be the change you want to see in the world." Together, we can be agents of change for PWS families everywhere. ~

### How PWSA (USA) Gives Help and Hope

**Crisis intervention** for medical emergencies \* life-threatening weight \* aggressive behavior

**Family support** for non-crisis needs such as information \* referral \* assistance

**Medical Information** such as growth hormone updates \* diet management \* anesthesia precautions \* respiratory concerns

**Educational materials** including age-appropriate pamphlets & books for doctors, teachers, care providers \* DVDs \* *The Gathered View*

**Advocacy Assistance** for individual cases about insurance \* IEPs \* Social Security & Medicare \* legal issues

**Public Policy Advocacy** on SSI \* Medicaid \* group homes

**Support** such as PWS Package of Hope \* parent and grandparent mentoring \* online support groups \* state chapters \* national conference

## Updates on PWSA (USA) Research

By Janalee Heinemann, Director of Research & Medical Affairs

We have recently received updates on some of the research PWSA (USA) is sponsoring, so I want to share this information with you. Remember that we need *your* support to keep research moving forward!

### Sex Hormones/Sexuality

Drs. Varda Gross-Tsur and Harry Hirsch of Israel are studying gonadal function in PWS and sexual behavior. To date, they have obtained blood samples from 79 children and adults with PWS, and are doing ultrasounds of the ovaries and uterus, etc. It is already clear to them that our PWS population represents a wide spectrum of reproductive hormone function and that sexuality is a very important issue.

**What this means to us:** We now know of at least three documented cases worldwide of women with PWS giving birth (two mothers with deletion had children with Angelman syndrome. One mother with

UPD has a child who appears to be typically developing. ) We can no longer say all are sterile, but this study will help us understand the range of reproductive hormones. It will also define further (as we have written in the PWS management book) the sexual and relationship needs of those with PWS.

### Psychotropic Medications

Although there have been significant advances in — and application of — psychotropic medication with PWS, reactions to these medications are dramatically variable. Dr. Elisabeth Dykens, Elizabeth Roof and colleagues are working to understand reasons for such variability in the response to psychotropic medications. They predict it may be related to genes involved in drug metabolism. For example, poor metabolizers may have negative side effects if given too high dosages. Their study identifies the CYP450 enzyme status in those with PWS.

**What this means to us:** With this study, we should be able to identify more accurately what drugs work better and in what dosage for PWS.

### Genetics

Dr. Merlin Butler is working on the expression of four genes between chromosome 15 breakpoints BP1 and BP2 in PWS and the impact on cognition and behavior. Preliminary analysis of the data indicates more expression of each gene when two alleles (alternative forms of a gene) are present, but a significant amount of variation in expression from individual to individual regardless of the copy number. New technology allows identification of different size deletions within the type I and type II deletion subgroups, which may help explain further the differences in expression.

**What this means to us:** More sophisticated and accurate testing is becoming available which will help define the genetic reasons for the differences in behavior and cognition within PWS.

### Donations for Research 2007

**As of 9/30: \$131,070**

has been donated to PWSA (USA).

To view our latest PWS research news go to [www.pwsausa.org](http://www.pwsausa.org)

### Gastric Rupture and Necrosis Deaths in PWS

PWSA (USA) recently funded a study of causes of death in people with PWS. Over several years, we recognized that 3% of reported individuals had died due to rupture and necrosis of the stomach.

In addition, four other people were suspected to have gastric rupture. After reviewing the history surrounding those with gastric rupture and necrosis, vomiting and abdominal pain were often reported, which was rarely reported in other PWS deaths.

The reports prompted the committee working on this project to suggest that physicians consider an emergent evaluation for gastric rupture and necrosis in people with PWS who present with vomiting and abdominal pain.

Those with bingeing and recent weight loss may be at more risk for gastric rupture and necrosis, but further investigations are needed. Still, close supervision is recommended when people with PWS are in situations with large quantities of food in new environments (holiday events or birthday parties) so as to avoid bingeing episodes.

Details of this study are in the Journal of Pediatric Gastroenterology and Nutrition, "Gastric rupture and necrosis in Prader-Willi syndrome" (Stevenson DA, Heinemann J, Angulo M, Butler MG, Loker J, Rupe N, Kendell P, Cassidy SB, Scheimann A. : J Pediatr Gastroenterol Nutr 2007; 45:272-4).

— Janalee Heinemann

# Research Funding Avenues Lead To NIH and ORD

By Janalee Heinemann, Director of Research & Medical Affairs

Recently I attended some important meetings in Maryland under the auspices of the National Institutes of Health's Office of Rare Diseases (ORD). One of the meetings was of the Coalition of Patient Advocacy Groups (CPAG), of which I am co-chair.

The Conference on Clinical Research for Rare Diseases meeting was primarily for young researchers, and PWSA (USA) provided \$2,500 in support of grants for attendees. The conference was hosted by the Rare Diseases Clinical Research Network and was primarily supported by the ORD and the National Center for Research Resources. PWSA (USA), one of nine rare disorder groups to also provide financial support, was thanked both verbally and in print.

So, besides education, our donation brought a lot of awareness and good PR. We have to remember that we are competing and collaborating with more than 7,000 rare diseases for awareness and funding. These meetings gave visibility and focus to *our* rare disease and promoted strongly that researchers collaborate with advocacy groups.

## Focus on PWS

The Rare Diseases Clinical Research Network Steering Committee is the steering committee for the major NIH rare disease research grant in which we are participants. There are 10 consortia, one of which focuses on Angelman, PW and Rhatt syndromes. Our Dr. Dan Driscoll chairs the PWS section of this grant. Also under the PWS section are Children's Mercy Hospital, Kansas City (Dr. Merlin Butler); University of California at Irvine; and Vanderbilt University, Tennessee (Dr. Elisabeth Dykens). I was asked to report on the CPAG meeting to the Steering Committee.

I can't emphasize enough the importance of our participation in these meetings. Most important, besides advocacy for our personal interest with the grant, was to promote researchers' involvement with patient advocacy groups in several arenas.

Most of the Office of Rare Diseases attendees spoke the next day at the Conference on Clinical Research. They gave a strong, clear and consistent message to all the researchers attending that they should be contacting the patient advocacy groups for whatever disease/disorder they are studying. I was asked to address this with the group.

**We have to remember that we are competing and collaborating with more than 7,000 rare diseases for awareness and funding.**

## A 'Think Tank' meeting about the hunger drive

During these three days, I began to envision a plan for a 1-2 day scientific "think tank" meeting with some of the rare disorders that have the insatiable appetite component. Thanks to Dr. Jennifer Miller, I met researcher Joan Han, who works with WAGR syndrome, a complex of congenital developmental abnormalities. They have only recently realized the extent to which many of their children have the insatiable hunger drive. Similar to when I spoke to the

Alström Association, no one has ever really dealt with this problem, so she was delighted that I could give her information to share

with families. Add researchers from Bardet-Biedl syndrome and one or two more rare disorders with this phenotype, and I believe such a meeting might lead to new insights for future research.

## FDA approval for growth hormone

I also met with Dr. Tan Nguyen of the Office of Orphan Products Development at the FDA, who was on the committee that approved indication for PWS and growth hormone (GH). He was concerned about the reported GH deaths. When I explained the background and how well our children with PWS are doing on growth hormone, he was relieved and delighted. I shared many pictures of children doing well, and he will use some for his future presentations. Tan said that the committee agonizes over these decisions, but seldom gets feedback. He had some recommendations which I hope will pave the way for future FDA approvals for Prader-Willi syndrome. ~

## A Special Opportunity To Give This Year

This year, if you are at least 70½ you can make a charitable rollover gift from your IRA to PWSA (USA). In the past ten months, Americans have rolled over more than \$69 million to charities of their choice, but this opportunity will end this year unless Congress renews it at the last minute.

Under the current provision (set to expire December 31, 2007), a donor who has reached the age of 70½ is allowed to exclude from his or her income any IRA funds up to \$100,000 that are withdrawn and transferred to a charity like PWSA (USA). For more information, contact PWSA (USA) at 800-926-4797 or [info@pwsausa.org](mailto:info@pwsausa.org). ~

## Deep Brain Stimulation

*I posed a question to Dr. Tony Goldstone, one of the renowned PWS researchers in the United Kingdom, who has special expertise in the hunger drive. Dr. Dan Driscoll, chair of our PWSA (USA) Clinical Advisory Board, frequently collaborates with Dr. Goldstone, who attends our scientific meetings. — Janalee Heinemann, Director of Research & Medical Affairs*

### Question:

I've been reading about deep brain stimulation to turn off the area of the brain that makes you hungry. Is this possibly a cure for our kids' constant hunger problems? People are doing it for behavior, headaches and pain (targeting a slightly different area of the hypothalamus), but no one has done it for hunger. A center in Italy has approval and agreement to do this with a patient at a cost of \$38,000.

### Dr. Goldstone's Response:

We have in fact had similar discussions with [Dr. Driscoll] in Florida about deep brain stimulation (DBS) for obesity and hyperphagia in PWS.

DBS is an exciting possibility for the treatment of hyperphagia, but after discussions amongst myself and Dr. Dan Driscoll, with advice from Dr. Dick Swaab (international expert from the Netherlands on the PWS brain) and Dr. Stephen Bloom (international expert from the UK on the metabolic system), our conclusion is that at present we could not support its use in PWS with currently available knowledge. At present, environmental control remains of primary importance. This conclusion is based on the following thoughts.

#### \* Safety

While it is appreciated that DBS is increasingly used for a variety of conditions (e.g. Parkinson's, cluster headache) with an apparently satisfactory safety profile as far as general neurosurgical complications, the areas of brain involved are different from those that might be targeted in PWS. While the posterior hypothalamus has been targeted in cluster headache, this is away from some of the more important areas in hormone and autonomic nervous system control that are near appetite centers.

#### \* Target

We do not know which area of the hypothalamus to target in PWS with DBS. While the paraventricular nucleus might be one (low oxytocin cell number), the area has lots of other functions. The ventromedial hypothalamus (VMH) has been targeted in animal

studies involving both lesions and electrical stimulation, though results in primates were to our mind not conclusive. Furthermore, the human VMH is very different from mouse and rat VMH. As we do more functional neuroimaging studies in PWS, we may find areas outside the hypothalamus that might be potential targets for DBS, e.g. in reward pathways.

#### \* Consent

The ability of people with PWS to give informed consent for such an invasive procedure is an issue. We are concerned that approval for DBS in PWS may be given by internal review boards and ethics committees without sufficient understanding of the complexities of PWS.

### Definitions To Know

**hyperphagia:** consuming more than normal quantity of food

**low oxytocin cell number:** the number of nerve cells which contain the chemical oxytocin are low

**reward pathways:** the parts of the brain which are involved in how we react to rewarding and pleasurable situations and drugs

#### \* Side effects

The psychological and psychiatric manifestations of PWS mean that there may be an increased risk of behavioral side effect from DBS (though this will depend on brain area targeted). This may also apply to endocrine and other side effects due to the multi-system nature of PWS phenotype. Monitoring for side effects in systems which are already affected may also be difficult.

#### \* PWS versus non-PWS

Our feeling was that DBS should be tried first on non-PWS subjects with severe obesity (e.g. severe enough to warrant bariatric surgery, but this avenue [is] not being taken for some reason). This would at least validate safety in a subject who can give informed consent and in whom monitoring of behavioral and other side effects could be made before proceeding. Demonstration of effectiveness may be less of an issue in non-PWS study.

The risk of hormonal and autonomic side effects (e.g. changes in levels of stress hormones such as cortisol, heart rate and rhythm, and blood pressure) means that any hypothalamic DBS studies in non-PWS subjects, let alone PWS, need to be done very carefully with excellent monitoring, which would need involvement of endocrinologists, psychiatrists and physicians in addition to neurosurgeons. ~

## While Visions of Sugar Plums Dance in Their Heads

**By Janalee Heinemann, Director of Research & Medical Affairs**

It's OK to have visions of sugar plums dance in the dreams of your child with Prader-Willi syndrome — but how do you keep them out of their mouths? With food so plentiful during the holidays, it's important to plan ahead to prevent problems.

### **At holiday time...**

If you will be with relatives, carefully plan ahead and communicate the importance of food control with all involved. Make sure all attending know "the rules of engagement" and agree to cooperate.

It's OK to request that Grandma and other relatives tuck away tempting items during your visit and discreetly check with you prior to offering your child a treat.

- \* If your child is old enough, rehearse "the rules" before that day and come to a mutual agreement on what your child will be allowed to eat. You can barter: "Do you want a little extra turkey and dressing, or do you want a piece of pie as your special treat?"

- \* Make sure you know what everyone is bringing, so there are no surprises about what the choices will be.

- \* See that someone at all times is clearly in charge of your child with PWS. In fairness to Mom, you should switch off, each taking an hour, and clearly defining when you are changing guards. As Dr. Linda Gourash states, *"When everyone is in charge, no one is in charge."*

- \* Grandpa and grandma or aunt and uncle may want to bring a special gift toy to compensate for the food they have to deny your child.

- \* Review with the hostess or your family how to contain the accessibility of food. See to it that where your child is sitting there will not be bowls of food, rolls or condiments nearby. (Many people do not consider how many calories our children can consume with the extras: sugar, butter, catsup, etc.)

- \* After eating, when people are just visiting, see to it that if all the food cannot be put away, someone is responsible for guarding it.

Your child must have the security of knowing you will be strong in your commitment to keep him/her protected from food. Giving in, even once, means several battles ahead. Never forget that consistency is the key.

### **Review your family situation**

Of course, each family must judge their own situation based on their child's food drive and their

own regulations on treats. Some families are raising their children to never have any sweets — no exceptions. Others (like ours) just go by calories and the weight of the child, trying to keep the diet lower in quantity yet similar to others in variety. Often, the most important thing is to prevent food sneaking or food demands.

There is a large variance in the food drive of children with PWS. Some will ask or beg for more food, but make no significant attempts to sneak food. On the other hand, some will go to great extremes to get food and are incredibly clever at doing so.

### **It's your holiday too**

Take special time away from your children. Tell your relatives what you would like for a gift is a day, night or weekend away from your children. Then you can come back refreshed to help make it a happy holiday for all. ~

### **Holiday Alert**

A couple of holiday seasons ago, three of our teens and adults with PWS (and a fourth unconfirmed) had unexpected deaths due to food-binging episodes that led to necrosis of the stomach wall and a perforation (tear) in the stomach.

In three of the four deaths, the person with PWS was slim, so there was no great concern about weight gain. Since then, we have been putting out alerts during the holiday season.

In this last year, two more deaths occurred in a similar way. Keep in mind that because a person with PWS is slim, it does not mean he or she has total food control. Add too many temptations, lack of feeling full, high pain threshold and a weak vomiting reflex — and you have the potential of filling the stomach dangerously full.

Because there are many food-binging episodes of our children and adults with PWS, most without such disastrous results, we think there are probably other factors that play into this life-threatening situation that have not been identified to date. Please make sure to provide the safety and security that your child deserves.

## Information for Medical Professionals

# Giving Difficult News to a Family

By Janalee Heinemann, Director of Research & Medical Affairs

***You can give good news anywhere, but when you are giving parents information that will be difficult for them to hear, remember that what you tell them, where you tell them, and how you tell them will remain with them the rest of their lives.***

A tearful mother called just after her firstborn was diagnosed with PWS. After a geneticist told her about PWS and gave her a brochure from the 1970s, she said, "I thought I should just go home and kill myself."

A young father told me that immediately after getting the diagnosis, he went on the Web. After reading medical information written by researchers and about the 350-pound girl with PWS who ate from garbage cans, within two hours he went to the hospital because he thought he was having a heart attack.

Another father told me that after getting the diagnosis and prognosis by a physician, he thought he should take his baby and drive off a cliff.

So please, medical professionals, take some time when you deliver your diagnosis.

Take the time to set up a private setting, see that the parents are not greatly outnumbered by staff, and allow them their grief — and their hope. Give them permission to be upset by using a sympathetic comment such as, "I appreciate how frightening it is to hear this news."

Don't give them too much information immediately after telling them the diagnosis because they are not hearing it. Their minds froze on "Your child has Prader-Willi syndrome."

On the other hand, don't wait too long. If possible, give them time to regroup, and plan to come back within an hour or two to answer their questions. Waiting another day to answer the questions that will arise seems unbearable to these parents.

Take the time to find out what resources are available and where the family can turn for appropriate support. Often I find that a physician gave the family an outdated brochure or printed some dismal research from the Internet. It is important with rare disorders to know your facts or you may be traumatizing a family more than necessary. For example, it is typical for a geneticist to tell a parent that their child with PWS will be "retarded," when in fact that is not necessarily true. All children with PWS have learning disabilities, but all are not retarded.

However, don't be unrealistically cheerful. Be kindly honest. These parents deserve the truths they need to know *at that time*. Some of the reality can wait until they have adjusted and been connected with the appropriate support organization.

Giving parents realistic, honest answers without destroying all hope is a constant challenge for both our association and you as a physician. We continually weigh what we put in our newsletter. We search for a balance between that which will give hope to parents of the young

child, yet be honest and a venue for education and support for all families.

If the potential reality of the future is not tempered by hope and encouragement, parents will run from the truth and the support organization. The consequence? They don't call us until years later when lives are out of control and they are desperate for assistance. On the other hand, if we allow them to remain in denial, too many important years are lost when we could have made a difference.

Consider also the educational and emotional level of the family when you plan your discussion. When I was diagnosed with breast cancer, the nurse gave me a booklet and said, "Don't read beyond the tab." That did give me a laugh for the day! She knew I've been in the medical field for years. Why would she think I would *not* read beyond that tab? That's why at PWSA (USA) we give parents reading materials appropriate for the age of their children. We cannot stop parents of an infant from reading about the older child, but we try not to throw those materials in their faces.

The best balance is to tell the family that early education and control are essential to their child's outcome — and that they can do it! It's often too much for new parents to make that first call to our office. So get their permission to share their name with us. One mother said it took two months to get the courage to call; then she hung up before anyone answered.

We give parents hope through our personal stories and by connecting them with our New Parent Mentoring Program. Recently, the extended family of a child diagnosed at just days old had me on speaker phone in the hospital room where they had gathered.

After I had answered questions, just before I hung up, I said, as I often do, "Oh, by the way, I have a 34-year-old son with Prader-Willi syndrome and he is tall, slim and happy." I could hear people in that room cheering.

"You do not know how much that meant to us," said the grandmother.

I had almost not added those important words. But for that family, those words were their lifeline of hope.

You, as medical professionals, are a family's lifeline of hope — and truth. Please remember when you walk into the room that if you handle the situation appropriately, your knowledge and compassion will remain with that family for the rest of their lives.

It is an awesome responsibility, but also a wonderful opportunity to make a significant difference at a crucial time in a family's life. ~

# Sleep Problems in PWS

By Janice Forster, M.D.

Sleep problems occur frequently among individuals with PWS. The most common problem is *excessive daytime sleepiness* (EDS). Sometimes EDS is related to *sleep apnea* that disrupts the quality and efficiency of sleep.

Obstructive sleep apnea is associated with increasing body mass index (BMI). Central sleep apnea occurs independent of BMI. Many of our individuals with PWS experience oxygen desaturations as a result of these apneas, but some of this hypoxemia can occur independent of apnea or hypopnea.

It is common for those with PWS to receive sleep studies to investigate the occurrence of apnea or oxygen desaturation. Sleep apnea can interrupt the continuity of sleep, and these disruptions result in a decrease in both the quality and quantity of sleep. Excessive daytime sleepiness can result from this decrease in sleep efficiency.

Typical individuals experience many cycles of REM (rapid eye movement) sleep and NREM (non-rapid eye movement sleep) through the night. Each sleep cycle lasts 90-120 minutes. At the onset of sleep, NREM sleep dominates the cycle; as the night progresses, REM sleep (dream sleep) dominates the cycle. Coordination of these sleep cycles is controlled in the hypothalamus. If a typical person sleeps only 4 hours but usually requires 8 hours, the requirements for NREM sleep are satisfied, but he/she needs to make up the loss of REM sleep. The sleepiness experienced the next day is associated with the intrusion of REM sleep into their wakefulness; this is taken away by a planned nap or possibly experienced as an involuntary "cat nap."

Due to hypothalamic dysfunction, people with PWS have intrinsic abnormalities of sleep/wake cycles. They have more sleep cycles per night and more REM periods, but the overall amount of REM sleep is decreased. Further, their sleep efficiency may be compromised by the occurrence of apneas, increasing their "sleep debt" daily. Because excessive daytime sleepiness has been correlated with the intrusion of REM sleep into wakefulness, people with PWS may appear to have narcolepsy-like symptoms.

Narcolepsy is a sleep disorder originally described as sleep attacks, an irresistible urge to sleep. However, the majority of those with the condition display EDS. Narcolepsy is a disorder affecting the cycles of sleep resulting in sleep fragmentation and the intrusion of REM sleep into wakefulness.

In fact, the associated symptoms of narcolepsy are related to this phenomenon: *cataplexy* (the sudden loss of muscle control in response to strong emotions); *hypnagogic hallucinations* (vivid dreams at sleep onset); *hypnopompic hallucinations* (vivid dreams just before awakening); and *sleep paralysis* (inability to move voluntary muscles during the transition between wakefulness and sleep).

REM sleep is associated with a loss of voluntary motor control that prevents the acting out of dreams. Sleep

paralysis and cataplexy are the manifestation of this loss of voluntary motor control intruding into wakefulness.

Narcolepsy occurs with or without cataplexy, and occasionally, cataplexy occurs without narcolepsy. (For example, because antidepressants suppress REM sleep, their discontinuation has been noted to cause REM rebound and the precipitation of attacks of cataplexy.)

Narcolepsy is diagnosed by clinical findings and by the results of the Multiple Sleep Latency Test (MSLT). In contrast to nighttime sleep studies that most people with PWS receive, the MSLT is performed 4-5 times through the day in the sleep lab at 2-hour intervals, measuring the onset of sleep and REM periods during naps.

In narcolepsy the time that it takes to fall asleep is very short, and the time that it takes to experience a REM period is similarly shortened. A hereditary form of narcolepsy has been described, but narcolepsy also occurs as a result of central nervous system dysfunction when the function of the hypothalamus is impaired. Some with PWS have also been diagnosed with narcolepsy. Because most with PWS who have EDS receive nighttime sleep studies to look for sleep apneas, the findings associated with the daytime MSLT have not been systematically explored. Further, it is possible that the narcolepsy-like symptoms in PWS are the result of sleep deprivation due to sleep apnea or disruption by other intrinsic factors.

The treatments for excessive daytime sleepiness and narcolepsy are similar. The first intervention is to improve sleep hygiene by shaping behavior to assure the appropriate amount of sleep and to supplement this with planned naps, if necessary. The second intervention is to treat the source of sleep disruption; CPAP or BIPAP are needed for obstructive sleep apnea or intermittent hypoxemia. Then the daytime use of stimulant medication (either methylphenidate or dextroamphetamine derivatives) and/or modafinil (Provigil) is recommended.

In select situations with careful monitoring, both stimulants and modafinil may be administered more than once per day if needed, but not too close to bedtime as they might interfere with sleep onset. Modafinil is approved for treatment of narcolepsy and excessive daytime sleepiness, but a copy of the sleep study may be required to authorize its use for EDS.

Many people who have EDS for any reason have difficulty with attention span and memory. Therefore, improving sleep efficiency and using stimulant medication to treat residual symptoms will improve level of function. Of all of the narcolepsy symptoms, cataplexy is the most difficult to treat and may require consultation with a neuropsychiatric sleep specialist.

Psychiatrist Janice Forster of the Pittsburgh Partnership, Pittsburgh, Pennsylvania, serves on the PWSA (USA) Clinical Advisory Board. ~

## PWSA (USA) Names Care Provider Advisory Board



(L-R): Mary K Ziccardi, Rem Ohio Inc.; David Wyatt, PWSA (USA), FL; Patrice Carroll, Advocates Inc., MA; Chair Jackie Mallow, Prader-Willi Homes of Oconomowoc, WI; Steve Drago, ARC-Alachua Co., FL; Jeff Covington, Catholic Charities Disabilities Services, NY. Not shown, BJ Goff, PWS consultant, Springfield, MA.

The PWSA (USA) Care Provider Advisory Board held its first meeting at the PWSA (USA) National Conference in Dallas last August. Its mission is to support the PWSA (USA) mission and vision statements by providing (for Care Providers) a collegial atmosphere that will bridge relationships and promote education and understanding of current and future needs.

Initial focus includes liaison for crisis support, relationship and network building, and professionalism

through teaching and training advocacy. The first project will be to update the PWSA (USA) database on facilities that provide care for those with PWS.

The Care Provider Advisory Board will develop a "standard of care" that should be in place to establish a safe and therapeutic living environment for those with PWS. A mentor program will offer providers a support system to develop and sustain this standard of care. ~

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## Dealing with a Dual Diagnosis of PWS & Autism

**By Ivy R. Boyle, M.D.**

When my son Alex was born 20 years ago, something was clearly wrong. By the time he was a year old, I had narrowed it down to PWS. It took another year for the pediatricians and neurologists to agree. In those days, understanding of the syndrome was much more primitive, and I was told he "couldn't have Prader-Willi syndrome because he isn't fat."

By the time Alex was 4, he had been tested (UPD) and my husband and I had read everything we could about PWS. We considered ourselves experts. I, as a child and adolescent psychiatrist, was surprised, though, by how much PWS looked like autism. That year we attended our first national PWS meeting, in Chicago, and I was surprised again. Alex looked autistic, but the other children did not! This was the beginning of our journey with a dual-diagnosis child.

We continued to go to meetings, but Alex looked and acted entirely different from his age cohort. He was thin, less obsessed with food than most, and, in some ways, easier. He didn't steal food, lie, or attempt to manipulate or charm others. However, he could not play with toys (his beads, which he holds and rubs, remain his favored item), had absolutely no attention span, and was very hyperactive. His speech consisted of short phrases, and he never learned to say "I". His favorite phrase is still "you want a cookie."

I stopped going to groups where parents shared advice on managing behaviors I never encountered. Often, though, a parent would come to me and say,

"My child is just like yours. I don't bring her because she would not fit in here."

I often say that when a child has PWS and autism, autism wins. However Alex certainly has PWS, does not know when he is full, and often asks for more food. I believe that PWS is the core problem, and that for some children autism is the adjunct diagnosis.

Currently, autistic-like behaviors are being recognized in children with PWS who do not look classically autistic. Then there is the group like Alex, who would be recognized as autistic in any community. This group, I suspect, is larger than we previously understood. Those in this group may also have some features which make them different from other autistic children. Alex remains unusually sweet and friendly compared to the children he attends school with. He is also very intrusive, wanting my attention constantly, unlike autistic children who withdraw from others.

There is now a support group at <http://health.groups.yahoo.com/group/pws-autism/> for families of children with dual diagnoses. If your child has these issues, I hope you will join our group and share. If you are already in this group, please watch for and fill out questionnaires that are occasionally suggested at this site. We are hoping to characterize these children and adults more accurately, and to provide services to this group of PWS families as well.

*Dr. Ivy R. Boyle is a member of the PWSA (USA) Clinical Advisory Board. ~*

# IPWSO Conference: A Worldwide Effort To Confront PWS

By Susan Henoch, PWSA (USA)'s IPWSO Parent Delegate

One in 15,000 is the estimated statistical number of PWS births. It often feels like a lonely statistic, but when parents, professional care providers and scientists met this summer for the Sixth International Prader-Willi Syndrome Organization (IPWSO) Conference, we immediately coalesced into an extended family.

Representatives of PWS associations from 44 countries came to Cluj, Romania, for three days to search for information and meet informally for support and encouragement. We focused on one issue: improving the lives of people living with PWS.

I was honored to attend as the new parent delegate from the United States, which allowed me to engage in lively conversation with scientists about their latest findings, with providers about new program components and with parents about everyday life.

It was especially heartening to exchange information with those from countries just beginning to recognize PWS. An IPSWO grant allowed representatives from 14 Eastern European countries, who otherwise could not have attended, to participate and return home to organize national PWS associations.

This was the first conference held in Eastern Europe. Romanian PWSA President Dorica Dan and her colleagues, assisted by IPWSO President Pam Eisen, Past President Giorgio Fornasier, and U.S. Peace Corps volunteers, worked tirelessly to provide an atmosphere of professionalism with Romanian spirit. Between sessions and during meals, we met informally, one of the most valuable aspects of the Conference.

Since this was my first IPWSO conference, I attended as many sessions as I could to learn about the latest medical research and creative ideas for caretaking. My daughter Sophie, after nearly 19 years at home, is a resident of the Prader-Willi Homes of Oconomowoc, Wisconsin, a program wonderfully responsive to new ideas.

The primary message from the scientific sessions was that although there is no cure yet for PWS, effective treatments for specific symptoms are gaining widespread use. More subtle avenues of research, particularly in genetics, are under investigation, now that there's a fuller understanding of the basic outlines of PWS.

Scientists are already recommending that home and group programs implement changes that

contribute to less stressful day-to-day environments. One scientist calls this the "whole person" approach, promoting an individual's strengths rather than dwelling on maladaptive behaviors.

Certain interventions can enhance well-being, such as recognizing the nurturing behavior of many with PWS by making sure they have pets with whom to bond and care for, establishing friendships and providing meaningful work. Activities that increase a sense of "flow," during which the sense of time and self disappear into the focus and enjoyment of the

**For more details about IPWSO's Romania Conference, click on the following link:**  
[www.pwsausa.org/romania.htm](http://www.pwsausa.org/romania.htm)

activity itself, lessen depression and increase the overall sense of health.

In the Professional Care Provider sessions, residential directors described their programs, details of which differed surprisingly from country to country, depending on philosophy, cultural norms and values, moral beliefs, and most importantly, funding. All agreed, however, that to be successful, a program must provide ongoing staff training and development. They want to establish international standards of excellence in care, so in June 2008, the first Providers Conference will be held in Germany to deal with these issues.

Several countries offered inspiring examples of good care. Everyone took home ideas to discuss and perhaps incorporate into their own programs.

It's exciting to be part of the worldwide effort to confront PWS. IPWSO now has 79 member countries, and more are joining — Uganda and Jordan officially joined during the Conference!

In addition to supporting new PWS associations and helping organize regional conferences, IPWSO currently provides free diagnoses for many who can't afford them and is implementing a diagnostic certification program in Italy for emerging countries.

The next IPWSO Conference will take place in 2010 in Taiwan. ~



National Organization for Rare Disorders  
2006 NATIONAL ORGANIZATION MEMBER



## The Therapy of Love

**By Giorgio Fornasier, Limana, Italy**

My son Daniele was born 31 years ago and we were lucky that the pediatrician who saw him first knew about PWS and made a clinical diagnosis when he was 8 months old.

After he finished his studies, he worked successfully for over 11 years and was happy to live a life that looked normal to him. Two years ago, something changed dramatically and we think someone at work offended him, saying he was a disabled boy without a future. He probably opened his eyes on a different reality and realized most of his schoolmates were driving a car, had their own apartment and were married with children. He had nothing instead and no hope or expectations to have it in the future!

He fell into a depression, left his job and kept crying. He tried to find a way out and thought life was easier in South America where we went together and where some "friends" told him he could get as many girls as he wanted and he could get an easy life. He started speaking Spanish and changed his name with a Spanish one and got angry with anybody calling him Daniele. He also tried to get an air ticket to go to Paraguay and drove us a bit crazy.

Facing this crisis, we felt lost and desperate and took him to a specialized hospital in Milano. For the first time in his life, he had to take psychotropic drugs to overcome his paranoid obsession and after a few months, he forgot about his Spanish identity and was Daniele again. But he was no more the cheerful and caring boy we knew and we had to accept this change and a new reality.

To worsen the situation, 10 months ago his brother Redi, who is only 1 year older, became father of a beautiful boy whose name is Alessio. You can imagine how happy we were, but Daniele wasn't, and strongly refused to be called as uncle.

Psychologists at the hospital said he was jealous, but this was not the case. Our children with PWS are not stupid, they have a simple but clear and precise logic that we "normal" people often do not realize. To recognize Alessio as his nephew was the same as admitting his defeat and to be different with no hope to be a father himself too.

I took Daniele with me to Brazil last February to offer my wife a period of relief, as I was leading a group of 40 tourists to visit the south of this country where a large population of Italian origin lives. At the end of our program we visited Bairro da Juventude, an institute run by an Italian Priest, Father Vincenzo

Lumetta, who cares for over 1,500 children of the poor and degraded outskirts of a town in Santa Caterina state. These

are children who have not enough to eat or have not enough clothes and often suffer violence. Children who can have a future only in this house where they can find love, food, clean clothes and especially a good education, so they can get a job when they finish school.

As I am personally involved in helping this mission to support these children with sponsoring of Italian families that we call "distance adoption," I lead tours there, as many adopt children and provide the money for them to be followed and continue studies.

I was busy with my group and did not realize that Daniele chose a boy and a girl, took a form and filled it to become their "father." While I was with Father Vincenzo and had made my annual donation to the Institute, the door opened and Daniele came in holding a boy and a girl by hand. He was excited. He first looked at me and then said: "Father Vincenzo, I adopted these two children!"

Father Vincenzo, who knew of Daniele's crisis, smiled and said: "They are yours! Your father just paid one year fee for both."

I will never forget the gratitude and happiness in my son's eyes. He gave me a long, strong hug and then introduced me to my new grandchildren, João Pedro and Ana Alice. Daniele then phoned my wife first and said: "Mom, I made you Grandma twice!" Then he phoned his brother and proudly said: "Now you're uncle too!"

Then he said the key magic words that made me cry and understand the nightmare was over: "How is my nephew Alessio?"

A few days later I brought a new Daniele back home, the happy smiling boy we knew, more mature and more careful now. He was the responsible father of João Pedro and Ana Alice. Our son Daniele is now a

*Therapy continued on the next page*

Daniele Fornasier (right)  
with João Pedro



## To Procreate or not, that is the question.

**By Diane Seely**

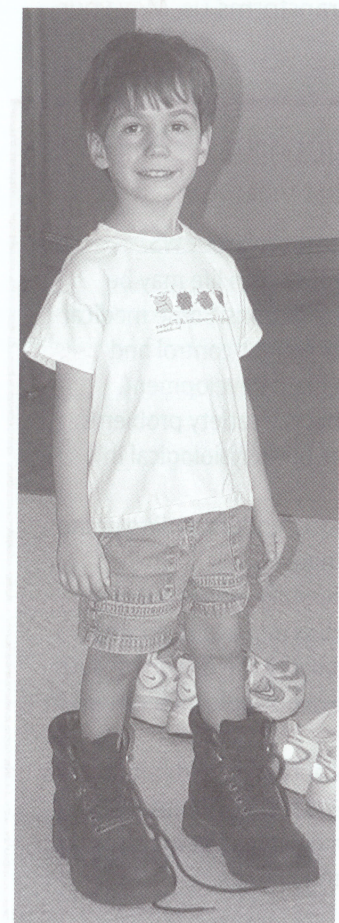
I was 42 when my little guy was born, on my second marriage and already had four beautiful, healthy children: a son and three sweet little girls.

I met my second husband when I was 38. One of the first things that I warned him about was that I had no desire to have another child. He's eight years

younger than I, and had no previous children. We had many deep conversations on this subject.

Fast forward to Sept. 11, 2001. I watched along with the rest of the world in horror as the Twin Towers were destroyed. I was shocked into disbelief that this world could be filled with such hatred. I could not stop thinking about all of the children and mothers left alone without a husband/father. I realized that if something would happen to my husband, God forbid, I would have no connection, no blood left between us.

I wanted the gift of a child. I could already see in my mind's eye what he would look like: bright blue eyes and golden blonde hair. It never crossed my mind that this child would be anything but perfect.



For Reagan Seely, who has PWS, Daddy's shoes are perfect

My youngest daughter was 9 years old then. I had to remind myself often what this would mean. No more sleeping in (or sleeping through the night, for that matter) for the next few years. No more long romantic weekends at Bed & Breakfasts. Or going out to nice restaurants, or movies, or shopping all day. History. I tried to warn my husband. Poor guy, he had no idea what he was in for.

Four years later. I'm older, I get tired easier, it's harder to keep up, but I know when to stop pushing myself and be still and enjoy the moment. I still sleep in occasionally (I'll take 8:00 over 6:30 any day),

although these days the first thing I see when I open my eyes is this handsome, sweet boy with a head full of thick, dark hair, long lashes and daddy's cute little nose.

Having another child? Well, for me it's everything that I imagined it would be. More challenging? Yes, because of PWS, but oh so much sweeter with each small victory.

When we first made our decision, I believed that there could be a perfect marriage, a perfect blending of families, a perfect child born from our love. But what I have learned is that there is no perfect marriage or perfect family without a whole lot of compromise.

There is, I believe, a perfect love. I have hope and faith that this perfect love will prevail in times of a turbulent relationship. And that blending a family is like a cake recipe: you can add to it or cut it in half. Either way, it bakes the same.

The perfect child is in every child that is given to us. You will see it with your heart and not your eyes.

*Diane and Rob Seely are the parents of Reagan, 4½, who has PWS, and Justin, Kristin, Caitlin and Alisyn. They live in Plain City, Ohio. ~*

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### Therapy - continued from page 12

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wonderful uncle to Alessio. He went back to work as a volunteer guard at the local Municipality. He talks about his children and proudly shows their pictures, as all "normal" parents do. He writes to them quite often and they answer to him and have exchange of drawings they make.

Once again our son with PWS is surprising us. He did not know the causes, but he realized he could not have biological children, so he found the way to get his own family anyway. His life has changed completely and he is taking care to save or earn money he needs to pay the annual fees.

We plan a trip to Brazil with Daniele to see how our grandchildren are doing, and this is really the best therapy we can offer our child and ourselves too... a therapy of love.

*Giorgio Fornasier is past president and current director of programs for IPWSO, the international organization for PWS. For information about Father Vincenzo's program, contact Giorgio at [g.fornas@alice.it](mailto:g.fornas@alice.it). ~*

# Our Valentine Research Fund Campaign — Don't Miss A Heartbeat!

By Rachel Elder, Community Development

It's time to get pumped for PWSA (USA)'s 6<sup>th</sup> Annual Valentine Research Fund Campaign. It's a *lovely* time to be involved and you'll *love* how easy it is to send letters to help raise funds for our *loved* ones with PWS.

A critical component of PWSA (USA) is supporting research. Last year we raised \$58,656 through our Valentine Research Fund Campaign. This year, we set our sights high, believing that with the power of love, we can attain more. We hope you'll help lift us up higher to reach \$100,000 to find new treatments and ultimately a cure.

Thanks to the many families who put their hearts into this effort in the past, research funded by PWSA (USA) has expanded understanding of PWS and furthered collaboration with other organizations.

We can do more! You can help fund projects waiting in the wings by participating in this year's Valentine Research Fund Campaign.

Here's how it works:

A valentine letter will be available online in January at [www.pwsausa.org](http://www.pwsausa.org) for you to download and insert a picture if you wish to do this yourself.

Or you can mail in your special Valentine picture, along with the number of ready-made letters you want us to print, to: PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238, Attention Sharon.

Or e-mail Sharon at [smiddleton@pwsausa.org](mailto:smiddleton@pwsausa.org) with a scanned picture and number of letters you wish to send, along with your mailing contact information.

**The deadline to send in your special Valentine picture is January 25, 2008.** Please call Sharon at 800-926-4797 with any questions. We'll send the letter back to you ready to sign and address.

A personal donation page on the PWSA (USA) website will be created for each family who joins, including a picture of your Valentine. Call Sharon if you would like a flyer including your special Valentine's picture for your workplace bulletin board.

To make a single donation specifically for research, do so online at [www.pwsausa.org/donate](http://www.pwsausa.org/donate) or mail a contribution to the PWSA (USA) address above.

Remember, it's *love* that transforms us. *May your life be filled with love.* ~

## Research funded by PWSA (USA) has expanded understanding of PWS. What that means to us:

- ♥ We have more accurate testing for PWS.
- ♥ We know weight control early in life may be necessary for more than medical reasons. Some medical professionals theorize that early weight control and growth hormone may improve brain development.
- ♥ We have more proof that the satiety problems with PWS are not psychological, but physiological in nature.
- ♥ We are acquiring a greater understanding of the connection between PWS and autism.
- ♥ We should be able to identify more accurately what drugs work better — and, as important, in what dosage for PWS — through studying the reason for such variability in the response to psychotropic medications in our population.
- ♥ We are supporting collaboration with researchers who focus on other syndromes dealing with insatiable appetite to find possible common links that may lead to treatment options to combat the hunger.

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## Valentine Research Fund \* Mail to: PWSA (USA), 8588 Potter Park Dr., Suite 500, Sarasota, FL 34238

The Valentine Research Fund is our only fund appeal dedicated solely to research projects. It is separate from our annual Angel Fund Drive, which also supports essential PWSA (USA) operations and programs.

My Valentine is \_\_\_\_\_ My name is \_\_\_\_\_

My Address \_\_\_\_\_ City \_\_\_\_\_ St \_\_\_\_\_ Zip \_\_\_\_\_

Telephone # \_\_\_\_\_ Donation \$ \_\_\_\_\_ By Check \_\_\_\_\_ By Credit Card \_\_\_\_\_

Credit Card # \_\_\_\_\_ (Mastercard, Visa & Discover accepted) Exp Date \_\_\_\_\_

Name on Card \_\_\_\_\_ Your Signature \_\_\_\_\_

Please make checks payable to PWSA (USA).

Or donate online at [www.pwsausa.org](http://www.pwsausa.org). Click on "Valentine Research Donation." Many Thanks!



*Nate  
Bennett  
joins us in  
wishing you  
the  
happiest of  
holidays!*

## **Champs** - continued from page 1

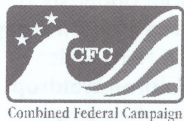
public eye, enlisted the support of the Colorado Rockies organization for PWS, and taken time to meet other families affected by PWS, in their quiet way go about their lives as we all do, earning a paycheck and raising their children the best way they know how.

To them, what they do for PWS, and thus for all of us, is all in a day's work. We all know better, though. We know the effort it takes to repeat the story of PWS and how it affects your child and family and to explain in simple terms a syndrome that baffles even medical professionals.

We can imagine the strength it takes for Clint and Karla to put their child in the limelight in hopes that something good will come of it while seeking not pity, but respect and dignity, for Madison and for all others who have PWS.

Clint and his team have set an example and sent a powerful message. Don't give up on the underdog, whether it's a baseball team or a person who has PWS. No one could predict who would win the World Series this year. Most likely everyone in the PWS community was rooting for the Rockies, even those who don't usually follow baseball. We suspect that even staunch Red Sox fans affected by PWS may have been also cheering on Clint and the Rockies.

One thing is for certain, though. Clint and the Colorado Rockies remain our PWSA Champions. ~



PWSA (USA) is included in the Combined Federal Campaign. If you work for the Federal government and its agencies, use

**CFC ID No. 10088**

to designate PWSA (USA) to receive donations. Questions? Call PWSA (USA) at 1-800-926-4797

**PWSA(USA) gratefully acknowledges the production, printing and mailing of our newsletter is made possible by a generous grant from CIBC World Markets Corp. Miracle Day USA., helping children around the world**

## **Lose-A-Thon Begins Jan. 1 With New Features**

"It's such a great idea, I'm going to do it." That's what Executive Director Craig Polhemus said about our PWSA (USA) Lose-A-Thon 2008.

Our third annual Lose-A-Thon will begin January 1 and run through PWS Awareness Month in May. Tip the scales for PWSA (USA) by joining Craig to get in shape, feel great and support our worthy cause.

We have great new features this year too! We've recruited fitness and nutrition experts to help you drop those pounds, and created an online support community with a new Lose-A-Thon Yahoo Group.

Our nutrition expert Norma Terrazas is a registered dietician at Texas Children's Hospital in Houston and serves on the PWSA (USA) Clinical Advisory Board.

Nationally certified fitness trainer Al Heinemann owns Personalized Fitness and Massage Center in Sarasota, Florida. You know him as the husband of Janalee and father of 34-year-old Matt, who has PWS. Al is also founder of the PWSA Missouri chapter and a long-time volunteer.

Our health gurus will provide monthly well-being articles, tips and ideas on our web site. Lose-A-Thon participants can also "Ask the Expert" their toughest questions.

We hope that encouragement, knowledge and support from the experts and each other give anyone thinking of joining the Lose-A-Thon an extra incentive beyond helping loved ones who have PWS.

Now that we've got your attention, here's how it works. You choose your own method to lose weight. Then send your own letter (or one PWSA (USA) has already drafted for you) to your closest family and friends, telling them of your plans and asking them to sponsor you.

No sweat! Sign up at [www.pwsausa.org](http://www.pwsausa.org), follow the instructions and commit to lose a certain percentage of body fat or number of pounds. Those who reach their goal and raise \$1,000 will be this year's "Incredible Losers."

"Really, it's about living a healthy life and setting an example," said Craig, adding, "This is the perfect year to join, with all the new features to help participants in this effort."

Let's get going! ~

**Get the most recent copy of our PWSA (USA) newsletter before others receive it by mail. The Gathered View is available only to members. To get your electronic Gathered View, go to [www.pwsausa.org/emailGV.htm](http://www.pwsausa.org/emailGV.htm)**

# Contributions

**Thank you for Contributions through September 2007**

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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Lori & Darrin Kerbs  
Joesolyn Calderon Kidd  
Partners in Pediatrics  
Sarasota Bay Club  
Donovan Nichols  
Martin Niehaus  
David Paoli  
Michael Peebles  
Mike & Amy Pfeiffer  
Craig & Susan Polhemus  
Jeff & Carolyn Porter  
Sam & Barbara Rubinson  
Brad Schultz  
Carol and Hans Storr  
Keys Tinney  
Jason & Christine Waldrop  
Dan & Joanne Walker  
Francis Warzecha

**Ally Marie Arant**  
Mary Claire Blackshaw  
Michael & Lisa Matesevac  
Dorrie & Luke McSorley  
Mary Beth Ritthaler  
**Hannah Behnken**  
Ann & Jay Behnken  
**Malea Bonk**  
Rich & Malea Bonk  
**Aaron Burnhardt & Ross Millhiser, IV**  
Carol & Hans Storr  
**Chrissy Burton**  
Clayton & Sue Burton  
**Ryan Casey**  
Ray & Sharon Casey  
**Antonio Cital**  
James & Margie Sappington  
**Austin Derrick**  
Raymond & Tana Derrick  
**Jessika Dickinson**  
Matt & Becky Reardon  
**Ashley Fender**  
Wayne & Karen Wendel

**Jacob Fiske**  
Wilma Fiske  
**Angie Giusti**  
Tom & Sandy Giusti  
**Shonetta Hayes' Birthday**  
Gloria Ann & Milton Means  
**J. R. Headley**  
Robert & Daylene Wood  
**Clint Hurdle**  
Mesch Commercial  
**Madison Hurdle**  
Ann Adams  
Joe & Sue Iversen  
**Jaycie Kinn**  
Jennifer & Joseph Kinn  
**Janis & Ben Leightman's 63rd Anniversary**  
Stephen & Michele Leightman  
Anna Leightman  
**Steve Leightman**  
Ida Leightman  
**Peder Lundh**  
Steve & Susan Lundh  
**Evan Matesevac's 1st Birthday**  
Catherine Fairlamb  
Norm & Charlotte Karin  
Susan Matesevac  
**Lota Mitchell**  
Lois Beatty  
**Steven C. Neiger**  
Susan Roubal  
**Lily O'Leary**  
Rene & Irene Mailloux  
**Aiden Painter**  
Rebecca Dunn  
**Lily Schactman's 3rd Birthday**  
Talya Bloom  
Marcey Dolgoff  
Elizabeth Martin  
Ben & Raina Nadler  
Janet Stromberg  
**Ridley Grace Underwood**  
Carla Rowley  
Lisa & Tom Underwood  
**Roy Valeo 70th Birthday**  
Bonnie & Herb Heller  
**Avery Lauren Waldrop**  
Jennifer & Ben Jones

## Contributions in Memory Of

**Alan "Ben" Anderson**  
JJ & Leslie Anderson  
**Deborah Barkeley**  
Norman & Cynthia Barkeley  
**Regina Brady**  
Marcia & Michael DiMauro  
John Kelley  
**Jonathan Ross Davis**  
Dennie & George Lindsey  
**Walter Clayton Evans**  
Chad & Betsy Lindsey  
**Daniel Fabio**  
Barbara Wolf  
**William Hancock, Sr.**  
Robert & Cathleen Dowe  
Robert & Faith Duncan  
George & Sheri Morgan  
Anne Webb  
**Deborah Kubichek**  
Michael & Shirley Gunning  
**Dick Lockhart**  
Mary Ann Lockhart

**Charles "Clyde" Mays**  
Nannette & Jeffrey Johnson  
**Rabbi Judah Nadich**  
Eleanor & Richard Weiner  
**Veronica Palys**  
Edwin & Theodora Sojka  
Phyllis Uzendowski  
**Tresa Taber**  
Donna Sparre & Robert Dahlin  
**Jeffrey Teichman**  
Samuel Handwerger  
Martin & Marla Teichman  
**Lynn & Al Till & Father Herb**  
Jean Till  
**Oscar Franklin "Jack" Underwood III**  
John & Jo Price  
Rebecca Sparkman  
**Elaine Valenti**  
Virginia Sheeran  
**Bill Walker**  
Gretchen Hannefield

**Nicolas Krebsbach**  
Wallace & Violet Beaton  
Perry & Carol Beaton  
Kevin Bjorlie  
Duane & Mary Jane Breitling  
Lew Brown  
Janet Buchberger  
Elaine Dobrinz  
Larry & Uneva Dobrinz  
Timothy Fritz  
Joanne Geist  
Judith Hatchett  
Barbara Herrick  
Gordon & Aileen Jones  
Joy Kahl  
Gothard & Marilyn Knutson  
Joan Krebsbach  
David & Luella Laske  
Jennifer Neumiller  
Catherine Reiliender  
Una Rydeen  
Ardis Hoven & Ronald Sanders  
Margaret Young

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](http://www.pwsausa.org/donate)

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