



The *Gathered View*

January-February 2003
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National Newsletter of the Prader-Willi Syndrome Association (USA)

We Remember

Rob Wharton, Angel of Hope

By Carolyn Loker

Pediatrician Robert H. Wharton, M.D., co-chair of the PWSA (USA) Clinical Advisory Board, died November 27, 2002 after a valiant struggle against cancer. A pediatrician, Dr.

Wharton was associated with Spaulding Rehabilitation Hospital in Boston, Massachusetts. He is survived by his wife Karen and three grown children. Rob and Karen were the first to provide many young parents real hope for their children with PWS.

Together, they also made significant contributions to our literature on PWS.



Rob Wharton and his wife Karen

A letter to Rob

How can I put in words a lifetime of giving? Your dedication and love for our children and families cannot be captured by pen and paper. I remember the first National conference my family attended when our little Anna was nearly 2 years old, 5 months after receiving her diagnosis. For the first time I felt a glimmer of hope, which came from you and your wonderful wife Karen. Both of you were presenting a session with parents of young children. It became clear from your presentation about early intervention, teaching emotional and social appropriateness, (floor time) playing and interacting with our children, becoming our child's advocate and the use of growth hormone at an early age that there is hope for a better future.

After returning home from the conference, Jim and I immediately started our search for treatment with growth hormone for Anna, which was accomplished nine months later.

Rob, it is because of you that Anna and many other children and families who have been touched by you are exceeding unexpected limits. Our new generation of parents is much stronger because you helped map out the different path we travel.

Two and a half years ago we received the devastating news of your affliction with cancer. You were determined to fight this ugly disease, but the bad news kept coming. You always held a

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Cami Brannan, Dedicated Scientist

University of Florida geneticist Camilynn Irene Brannan, Ph.D., who achieved national recognition in fundamental genetics research, died October 15, 2002 following a battle with pancreatic cancer. She was 39 years old.



Cami Brannan

Cami made tremendous contributions toward understanding Prader-Willi and Angelman syndromes, and even proposed a seminal model of gene regulation for this region. She developed the first mouse model for Prader-Willi syndrome by creating a mouse that harbored an imprinting center mutation. This mouse model is now being used in several labs, which will lead to a better understanding of Prader-Willi syndrome, and hopefully one day help lead to rational treatments. Cami also made important contributions in the field of juvenile leukemia. She established a neurofibromatosis type 1 (NF1) knockout mouse, which she

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The Gathered View welcomes articles, letters, personal stories and photographs and news of interest to those concerned with Prader-Willi syndrome.

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA) in Sarasota, Florida.



PWSA 2003 Annual Conference July 2-5

Fulfilling The Dream: Joining Together to Secure Brighter Horizons
Join us at the Sheraton World Resort in Orlando, Florida

Begin **NOW** to plan for grant requests

Suggestions: Start to look at alternative, local grant sources. Have your request in writing, be prepared before you call. Do not wait, many funds get used up early in the year.

- State Developmental Disability Council – Check NICHCY at 1-800-695-0285 or www.nichcy.org to find your state contact
- Check with your local PWSA chapter for grant funding
- Make-A-Wish Foundation (Especially since the conference will be held in every child's favorite place, Orlando (1-800-676-9474). It is important to point out in your request that PWS is a life-threatening disorder.
- If you have a relationship with a local church, check for funding
- The Arc (disability related funding)
- Parent-to-Parent (disability related funding)
- And then...PWSA (USA) Grants

**Check Our Web Site for
the latest Conference Information**
www.pwsausa.org.

Making conference grant requests from PWSA

Please use the following criteria when requesting a grant.

- Reason for wanting to go to the conference, benefits you and your family hope to achieve, what do you wish to learn.
- Explain the financial and emotional needs of your family
- Names of family members you hope will attend (maximum of 4 people)
- Require funding for what purpose: registration, lodging, travel, etc.
- How much can you afford to put toward the conference cost?
- Have you received grants in the past for PWSA (USA) or for local state conferences?

All grant recipients will be required to be or become members of PWSA (USA). If the membership cost is a problem, a Scholarship Membership can be requested. So that we can assist more families, grants may not always include air fare.

All reservations will be made through our travel group. Submission Deadline is April 21, 2003. Grant requests may be e-mailed to national@pwsausa.org or mailed to: Prader-Willi Syndrome Assoc. 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242, Attn: Grant Committee.

PWS Study Confirms Ghrelin Role in Appetite

Ed. Note: We recently received the following note and article from Dr. Angelo DelParigi.

"As perhaps you already saw in a previous e-mail, a contribution from our group on the possible pathogenetic role of ghrelin in PWS' hunger has been published. This confirms (with more metabolic information and genetic control for PWS diagnosis) data already published (while our manuscript was under submission) by Cummings et al. (Nat Med 2002). I have an important debt with PWSA and all PWS subjects and their families, so want to thank them and to share our results."

High Circulating Ghrelin: A Potential Cause for Hyperphagia and Obesity in Prader-Willi Syndrome
Angelo DelParigi, Matthias Tschöp, Mark L. Heiman, Arline D. Salbe, Barbora Vozarova, Susan M. Sell, Joy C. Bunt and P. Antonio Tataranni (*Journal of Clinical Endocrinology and Metabolism*, December 2002)

PWS is the most common genetic form of obesity (1:15,000 live births). It is characterized by hyperphagia, whose cause remains unknown.

We assessed that fasting circulating ghrelin, a hormone mainly secreted by the stomach and stimulating food intake, were 3-fold higher in seven adult individuals with PWS than in healthy controls.

Similar findings have been already published (while our manuscript was submitted) by D.E. Cummings and colleagues in a separate group of 18 PWS subjects (*Nature Medicine* 2002)

and are consistent with the hypothesis that ghrelin is a physiological regulator of appetite in humans. We think that the higher plasma concentration of ghrelin observed in individuals with PWS may be responsible, at least in part, for the hyperphagia and obesity of the syndrome. Intervention studies using blockers of ghrelin action or secretion would be needed to test this hypothesis.

10th Adult Sought for Feeding Study

We are still looking to recruit a 10th adult subject to be included in the above feeding study. The following are the inclusion/exclusion criteria of the study:
Age: 18 years old or over; body weight less than 350 lb.; IQ score of at least 65 in one of the 3 scales; genetic confirmation of the diagnosis; no diseases (aside from PWS); no chronic medications, including but not limited to Prozac, Clonopin, Tegretol, Zyprexa, and/or Growth Hormone; no PET scan during the past year or any radiation exposure (such as X-rays) for clinical or research purposes in the past 6 months; available to come to the Clinical Research Unit at Phoenix Indian Medical Center (PIMC) in Phoenix, Arizona for a complete evaluation, together with his/her caregiver and/or family member.

The study requires a four-day hospital stay. NIH covers travel expenses for volunteer and caregiver and will provide a reimbursement for time and participation of \$625.

For further information, call 602-200-5327.

How Children Develop Balance Reactions

By Janice Agarwal, P.T.

Background

Children want to explore their environment, by rolling, crawling, or walking. In order for this to occur, children need to constantly react to surroundings using a complex neurological and musculoskeletal system to restore or maintain body equilibrium with respect to gravity, the terrain, and other body parts. Equilibrium reactions are what our body does to keep from falling. Protective reactions are what we do to protect ourselves if we do fall.

As children progress from movement while lying on their bellies (in prone) or while lying on their backs (in supine) to movements needed to walk, they develop reactions to facilitate safe interactions with their environment. "Righting reactions" allow a child to orient his head in three-dimensional space so that his eyes and mouth are in a vertical plane (looking forward) regardless of the position of his body. A child lying on his belly lifts his head up to look forward. Righting reactions also help to restore a body's alignment to neutral when segments of the body have been rotated. As righting reactions develop in a particular position, a child uses them to develop "protective reactions."

Protective reactions are generally extension (reaching out) movements of the arms and legs in the same direction as the force affecting the child. If a child is pushed forward, he should reach forward with his shoulders and arms and bend his wrists backwards as he tries to break his fall. Depending on the position of the child, this reaction can involve extension of one or both arms or legs. The limb that is reaching out needs to be able to bear weight and "protect" the body as it falls.

As protective reactions develop in each position (prone, supine, upright) or movement pattern (crawling, walking, running), "equilibrium reactions" emerge. Equilibrium reactions work to counteract external forces and restore a child's balance and center of gravity. They help a child compensate for changes in position and help return the child to the position from which something forced them away, i.e. back to a stable base of support. We generally use the muscles of our trunk and extremities (arms and legs) to maintain our equilibrium.

As part of a normal developmental sequence, children use righting reactions to facilitate head control, the ability to lift one's head up and maintain "looking up" position. As they begin to sit, they learn to use gross extremity movements and protective reactions to keep themselves from falling over, then subtle trunk and extremity muscle movements and equilibrium reactions to maintain a seated position. A mature equilibrium response in one position is felt to be necessary before a child can attain the next developmental motor milestone. A child must have mature equilibrium reactions while sitting before being able to optimally learn how to crawl or walk.

When one considers this developmental sequence, the importance of having appropriate reactions in all basic positions becomes obvious. This explains why therapists invest so much time developing and facilitating what appear to be simple

postures and movements. "Postural reactions" (righting, protective, and equilibrium reactions) must be integrated into all areas of motor development. Methods of facilitating postural reactions are limited only by a therapist's or parent's imagination. By being creative, we can make a child want to participate in any activity.

What to do

It's best to start with an activity in which a child is likely to have some success. Use positive verbal reinforcement of specific achievements as praise. Most children know when they have worked hard to achieve a desired response and you will learn that unearned rewards will not facilitate future cooperation or participation, so use praise judiciously.

It's also important to provide many different kinds of stimuli to encourage a reaction and develop variation in the type and quality of the reaction. If a child has just learned to stand, it's best to work on postural and equilibrium reactions of the sitting position to create a solid foundation of reactions before moving on to work on the next milestone. As examples, you can work on postural reactions with blindfolds on, with different speeds of stimuli or unexpected diagonal movements, or challenge a sitting child to reach for a toy at the outer limits of his postural stability. Making certain that basic reactions are fully functional under such varying conditions is more appropriate than just pushing the child who is sitting to only develop protective extension.

The ultimate goal of our facilitating postural reactions is to have the child develop reflexive (automatic) reactions. Maintaining stability and responding to environmental stimuli requires that muscle movements be performed at speeds faster than voluntary and purposeful movements. Therapists initially try to teach a child to become aware of how a certain movement feels. Conscious awareness of how a postural reaction or

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Maria Vucci, 2½, who has PWS, here with her mother Anne, develops balance reactions through a variety of activities.

Activities for Reactions

Up & Down

- Sitting and bouncing on a therapy ball or inflatable mattress
- Jumping on a trampoline or couch cushions on the floor
- Jumping like an animal or off a small stair or stool
- Jumping (just for fun to music) on packing bubbles, bubbles on a wet grass
- Marching to music
- Jumping onto an inflatable mattress
- Jumping into a pool

Front & Back

- Swinging on a swing, platform, or inner tube
- Rocking on a rocking horse or in a rocking chair
- Sitting on the floor with a partner, facing each other, feet touching, holding hands, and rocking back and forth
- Sliding down a slide
- Walking on tiptoes
- Wheelbarrow walking
- Lying over therapy ball on tummy or on back
- Lying upside down over a bean ball, ball, or sofa
- Climbing up and over cushions

Circles

- Sitting on a Sit n' Spin or sitting in a laundry basket and sliding in circles
- Standing and twirling
- Spinning on a swing (could be an truck/tractor inner tube or tire swing)
- Doing somersaults (being careful to guide and protect the head and neck)
- Rolling in a large cardboard box or barrel
- Spinning on an office chair
- Sliding down a circular slide at a playground
- Pillow fights
- Swinging a child (holding under his/her arms while turning in circles)

Games

- Simon Says
- Mother May I
- Red Light - Green Light
- Flashlight Tag
- Hide & Seek
- Hopscotch
- Tag
- Blindman's walk (lead a blindfolded child by the hand to touch and try to identify different objects)
- Catch (first roll the ball toward your child, then roll it to his right or left, then bounce it to him, then stand and catch, etc.). Work with different textures and sizes of balls. Roll and throw a beach ball with a clear panel, filled with a little water and bubble bath.
- Leap frog

Balance - *continued from page 4*

specific muscle group activity feels then transitions into mature postural reactions that become automatic, do not require conscious control, and are well coordinated.

Facilitation of protective reactions can be difficult. Most children are fearful of rapid movements or of being pushed, especially when they realize that there is a chance they may fall and be hurt. Other children find such movements a wonderful game and trustingly allow themselves to be pushed over despite not having equilibrium or protective responses. Working around these problems can be a challenge. In addition to gently pushing or pulling a child out of his center of gravity, you can place a toy just out of his reach or lift his leg to change his base of support. Both activities force him out of balance and challenge him to protect himself as he reaches for the toy. As you encourage protective reactions, you also encourage equilibrium reactions. If a child doesn't use a protective reaction to keep from falling over, he has learned to use an equilibrium reaction!

Protective and equilibrium reactions evoked on a child's stable base of support should be facilitated under a wide variety of conditions. This emphasizes development of reactions while a child sits and stands. Reactions can also be evoked when a child has an unstable base of support. This emphasizes development of reactions while a child crawls and walks, or while a child is learning to transition from one type of movement to another (going from crawling to sitting or first pulling up from a crawl to a stand).

A variety of therapeutic and household equipment can be used to elicit equilibrium reactions on an unstable base of support. Often, this type of activity is the most fun. Roll on a gymnastics ball, walk on an inflatable mattress, swing on a platform or in an inflated truck or tractor inner tube (instead of an infant bucket), or use a rocking horse or rocking. These are examples of playthings that are wonderful for the child and versatile for both parents and therapists. As always, however, care not to go beyond the capabilities of the child must be taken with any equipment or activity.

Janice M. Agarwal is a physical therapist specializing in the needs of young children. Her son Alexander, age 3, has PWS. Janice is also newly elected to the PWSA (USA) Board of Directors and volunteers in the Parent Mentoring Program.

Praise for PWSA (USA)

Here are some recent comments from our members...

- "I just had to write to say how informative your web site is. We are in the process of adopting a little boy with PWS and not having heard of it previously looked it up on the web. It has opened our eyes to this awful chromosome disorder and how parents cope. Extremely interesting. Thanks."

- "PWSA (USA) is definitely the gold standard for the rest of the PWS world. I think every other country's organization wishes theirs was as good as ours. People that think otherwise should check it out and find out for themselves. Keep up the great work!"

Finding A Successful Employment Setting

By Janalee Heinemann, Executive Director

Our PWSA (USA) founding father Gene Deterling wrote: "At one of our Minnesota group meetings this past year we discussed what we thought were the main issues we should be addressing in the upcoming years. One of them, which I sponsored, was the need for an aggressive vocational/employment program for our young adults with PWS.... Although I know there are some individuals who have been very fortunate in finding good employment opportunities, many are either working in very menial jobs or not working at all. The problem is not in finding a day program, but that they do not offer sufficiently challenging or satisfying work opportunities."

On a personal level, we are currently dealing with our son Matt's significant weight gain due to poor food control in his sheltered workshop environment. Although Matt is intellectually high enough functioning to do competitive employment, he has had to quit a couple of jobs due to weight gain and now is even in trouble in the supportive employment setting. Matt is very open about the problem and acknowledges he has access to food in the following ways:

- 1) During his many trips to the restroom, he stops by lockers that he knows co-employees don't lock.
- 2) He borrows money from other employees who are lower functioning and buys food at the vending machines.
- 3) He has too many opportunities to acquire food during the lunch break.

I won't detail how we are attempting to deal with the situation, but when the supervisor said she could not provide supervision during restroom breaks and lunch, I asked if such services were provided for anyone in a wheelchair. When she said yes, I asked, "What is the difference between Matt's need for support due to his disability and theirs? Matt can't control his food seeking any more than they can control their inability to walk."

PWSA (USA) NEEDS YOUR HELP! We want learn what works and doesn't work for your young people with PWS in an employment setting. If you know about the employment experience of a person with PWS, please fill out the survey below and tell us what has worked and what has not so we can share this information with others.

PWS EMPLOYMENT SURVEY (Please use an extra sheet of paper if needed.)

1. Is the person with PWS in a sheltered workshop setting? Has it been successful? For how long?
2. What type of work does this person(s) do in the setting? Is this a satisfying job for the person?
3. Is the person with PWS in competitive employment (or other such as volunteer work)? Define.
4. What are the job skill strengths/skills of the person(s)
5. If employment is successful, what has made the difference to enable it to be successful?
6. If employment is (or has been) unsuccessful, what has contributed to its lack of success?
7. What are the food controls in the setting?
8. Your relationship to the person(s)?
9. Age and sex of the person(s)?
10. Can we contact you to ask further questions if necessary? If yes, please put contact information below.
11. Do we have your permission to quote you in future publications on this topic? Would you prefer it to be:
____ Anonymous? ____ Or can we use your name? (Choose one.)



You Don't Know What You've Got...

By Lota Mitchell, PWSA (USA) President

Among the many memories of 2002 are our Thanksgiving holiday weekend at the Virginia farm and the week thereafter.

A 19-pound turkey, roasted in the wood stove by my son Doug, and a 16-pound ham plus yummy side dishes, pies and cookies, fed a couple dozen adults and children, plus four babies. Julie didn't join us because there is too much food for too long with zero food security. She understands, but misses seeing her "dozens of cousins."

On Monday Dave and I headed to North Carolina to babysit grandchildren Colleen, 6, and Joe, 17 months. Doug and wife Shannon left amid storm warnings Wednesday for a combination business/pleasure trip to his company's headquarters in Wisconsin.

One to 2 inches of snow predicted — that barely slows traffic in Pittsburgh where I'm from. Power outage? We have them occasionally, but they last from minutes to just a few hours. I didn't take the storm warnings too seriously. Big mistake! At 3:30 a.m. Thursday with dings and pops the power went off for the next three days and nights, leaving us without heat, light and water. Doug lives in the country outside Chapel Hill with well water pumped by electricity.

Suddenly the "essentials" I was used to were gone.

The gas fireplace kept the living/dining/kitchen great room, well, not exactly warm but bearable if we layered on our heaviest clothes. The well-insulated refrigerator held a good supply of milk, juices, fruit and cheese. There was plenty of peanut butter and bread, so with cereal for breakfast and sandwiches for lunches we certainly wouldn't starve. However, cold dinner, repeating lunch, was the pits. Oh for a steaming bowl of soup or mug of hot tea!

Our greatest need was water, and here a guardian angel, wearing a sweatshirt, saved us. Gary, a friend of Doug, who lived 10 minutes away, had needed 2 ½ hours, a 4X4, and a chain saw to get to our place to check on Doug's Black Angus cattle. Gary had to climb over fences and walk through ice-crusted pastures to get to the house because wires, weighted down by ice, were drooping too low across the access lane to drive a vehicle under them.

He came back several hours later with all he could find — a 12-pack of bottled water, which I carefully rationed out. Forget washing hands and face. Ice cold water, slowly melted from icicles and crusted snow, served with a bit of detergent to wash a few dishes. Dave brought buckets of water up from the swimming pool to flush the toilet. One phone was working upstairs; the other portables needed electricity.

By next afternoon melting allowed the drooping wires to rise enough for a car to pass, so we drove past multitudes of broken branches and trees to Siler City to replenish supplies.

Next morning we went back for breakfast at McDonald's. There we saw a long convoy of power trucks from Mt. Airy, N.C., a couple hours distant, coming to assist — people helping people.

Darkness fell quickly in the evenings. Dave did crossword puzzles by candlelight. Colleen and I drew pictures and colored. We went to bed early, usually in our grubby clothes, and slept instantly.

Saturday evening Doug and Shannon arrived back at their candlelit home, looking slightly stunned. Even though they had called us a couple times each day, reality was shocking. Shannon said it looked like a war zone. Again, early to bed, but what joy at 4:00 a.m. when we heard pops, squawks and the lights came on! I couldn't help thinking of the men outside at

After I finished writing this, it occurred to me that there is a rough parallel with PWSA(USA). The Association is like our power company. If it would have an outage because of lack of funds, then the lines that fan out to us the membership could no longer deliver the power we need (e.g., current information, written materials, Parent Mentoring, conferences, Crisis Intervention). Keep the financial support and volunteer help flowing to keep the power surging!

that moment, in subfreezing temperatures and total darkness, working selflessly to give us power.

Back home, I still marvel occasionally at the wonder of faucets that produce water, toilets that flush, hot showers and hot tea, lights that turn on, clean clothes, and my warm house. All luxuries that we see as necessities and take for granted, yet much of the world's population doesn't have them.

I am again reminded of the words of our conference 2002 keynote speaker, Jason, that wonderful young man who has been quadriplegic since his teens from a diving accident: "You can't be depressed and grateful at the same time." How very much we have to be grateful for! Even as we grieve for our beautiful babies diagnosed with PWS, cope with temper tantrums and food-seeking of our children, worry about their health when pounds pile on, and nurse our own often heavy hearts, we mustn't lose a sense of deep gratitude for those we love and all we have. Peace.

Our Common Language

By Pam Eisen, PWSA (USA) IPWSO Delegate

In April 2001 Janalee Heinemann and I had the pleasure of meeting Carlos Molinet and Dr. Fanny Cortés at the IPWSO Exceptional Meeting, held at the Baschiroto Institute for Rare Disease (B.I.R.D.) in Italy. As part of this great international family, we instantly became friends, sharing, laughing, and even crying together when, at the closing, we sang our theme song, "Fly High."

Eager to know more about PWSA-USA, our publications and our experience of 26 years, Carlos seemed especially intent on applying all that he could learn to the reality of the Chilean organization. He conveyed the significance of support from a national organization with a longer history and therefore more knowledge. He wanted Janalee and me to join American doctors Suzanne Cassidy and Moris Angulo in attending the 2nd Latin American Conference in October 2002 in Santiago, Chile.

Not knowing what to expect, Janalee and I dubbed this trip our "Latin American Adventure." Never could we imagine such a wonderful experience and the impact of meeting these warm, generous, vibrant loving people.

Carlos greeted us at the airport with muchos abrazos y besos (many hugs and kisses) and communicated in his limited English that, because of our common goal and the love we have in our hearts, language would not be a barrier — and this was certainly true!

While Janalee and I marveled at the sight of the dramatic Andes rising up on the edge of the city, Carlos informed us of the vigorous conference schedule. He told us that the force of our international network was already under way. After

dropping us off at the airport, he would join

IPWSO-President Giorgio Fornasier on a radio broadcast featuring the Latin American Congress, PWS awareness and the significance of an early diagnosis.

From our first moments in Chile we sensed that our adventure would be extraordinary. Working in close cooperation on an international level, sharing educational material, knowledge and experience would provide new possibilities for increased numbers of children to have an early diagnosis, for the expansion of multi-disciplinary services, and for expanded family support.

Under the direction of Dr. Fanny Cortés, a very impressive array of expert speakers kept the attention of conference participants. Using local professionals and resources while also reaching out to other professionals throughout the world maximized the limited time of three days.

Welcoming us with the warmest and most generous hospitality, the families' constant heartfelt outpouring of affection and appreciation for this exchange and unity of information was poignant. Parents were reluctant to take breaks, attempting to get as much information as possible. One evening a group of parents asked if it would be OK to take their children home, feed them dinner and then join us at the hotel.

At 10:00 in the evening parents showed up, eager to join us in continued discussion.

Throughout the conference, Dr. Cortés seemed to be everywhere, calmly smiling and pitching right in to see that all went smoothly. Janalee and I had the privilege of meeting many of her patients and their families. Because these wonderful people touched and enriched our lives, we would like to introduce you to just a few so you can also experience the wonder and power of reaching out to each other throughout the world:

Sarah and her husband came from the far north of Chile by bus, an 11-hour trip. They sold their house to cover medical expenses and the care of their child.

They make this journey to Santiago every month so that Dr. Cortés can follow their child's development. Family and friends have lovingly given support, contributing time and money.

The founder and director of a special needs



Janalee Heinemann, Fefe Portugal and Pam Eisen

We all speak the common language of parents striving for a better life for our children.

school in Santiago, *Amalia* is the mother of a beautiful 19-year-old daughter with PWS. In precise English, she offered to interpret for me so I could meet some of the families. I was especially moved when she gave me a copy of her school's brochure and explained the logo — a black flower with one orange petal. *Amalia* explained that just as our children with PWS are different, so is this one petal. "But," she expressed, "this petal is needed to complete the flower beautifully."

Marella, a precious 7-year-old with large dark eyes, saw me enter the room where the youth program was being held and immediately ran across the room and lifted her arms for me to pick her up. Throughout that day she followed me, sitting on my lap, sharing her snack with me and supplying a plethora of hugs and kisses. Language did not seem to be a problem as she spoke to Janalee and me in Spanish, conveying her trust and affection. At the close of this Congress, as we joined in the dancing and hugged our new friends, we realized that we all speak the common language of parents striving for a better life for our children.

Be sure to check the website for *Asociación Nacional Síndrome de Prader-Willi (Chile)* <http://www.prader-willi.cl>

A Chance to Live

By Janalee Heinemann, Executive Director, PWSA (USA)

With a smile beneath the tears, the mother who is also physician hugged us in thanks and said, "For the first time I feel my child has a chance to live." Her 7-year-old son, Ricardo, and the teenage boy with Prader-Willi syndrome, Erico, both wrote down their phone numbers, and through an interpreter, asked us to call them the next day.

With the help of our host, Helena, thankfully we did call the next morning, because both sets of parents said the boys had been sitting by the phone awaiting our call.

This is just one of the stories that puts a face to the names of thousands of children around world with PWS who need our support. Their story could have been our story 20 years ago. Their need is no different than our children's needs — to be loved, to have friends — to live.

During our trip to Brazil after Chile (see Pam Eisen's story), Pam and I felt we were able to help make significant progress in the start-up of the national PWS organization in

Doors opened wide for us and we felt reassured that Helena had the right combination of compassion, knowledge of the syndrome, political skills and resolve to keep her foot in the door to see that her dream of a national organization becomes a reality.

Helena said she feels that by the time they have things together enough to help the children with PWS in Brazil, it will be too late for her daughter. Fefê already suffers from obesity-related problems and is on oxygen. Why does Helena sacrifice so much of her own life and money to do what she does in spite of the fact it may not save the life of her own child? Because like many of us, she feels that all children with Prader-Willi syndrome count and deserve a chance at life.

The faces may have different colors and be in different nations, but the story remains the same. It takes just one child in need and one parent determined to break down or scale brick walls to make a difference. And it takes the same parent

takes just one child in need and one parent determined to make a difference.

realizing that this is not just about MY child, but about ALL children. Bless the



Janalee and Pam with families they met in Brazil

Brazil, thanks to the fortitude and charm of one mother (Don't these stories usually start with one determined mother or father?), Helena Portugal, of Brazil.

Helena is a single parent of a teen with PWS, Fefê. Helena barely survives on her nursing salary — yet she took off a week of work to coordinate appointments and be our translator for the many meetings she had arranged at hospitals, universities, attorneys' offices and television shows.

It was also thanks to one Guardian Angel (Isn't there usually one "special stranger" in these stories?), Ubaldo Barrak, the CEO of the first Brazil Goodwill, who I met in Sarasota though a mutual friend. Ubaldo has been a lifesaver to Helena in many ways, has assisted us in our "adventures" in Brazil — and rescued us more than once!

We appeared on two Military Police TV shows in Sao Paulo (one show was national), met with top physicians at several universities and hospitals, taught a university class, met with families in Rio de Janeiro, and met with two attorneys. Alfredo Labriola, the Goodwill attorney and friend of Ubaldo's, offered to donate his services to do the non-profit-status legal work.

Henelas and Giorgios of the world who have a greater world vision — and have encouraged us to be a part of the solution.

A note From IPWSO's President Giorgio Fornasier of Italy

Dear friends,

Here is just a sample of what we're doing and the close solidarity we created after our meeting in April. It is incredible how a few words can change desperation into relief and hope. For those who do not understand Spanish, Palmira from Ecuador wrote:

"Hello Prader Willi world !!! You cannot imagine the emotion I got. It happened I could not even stop crying, realising I am no more alone. THANK YOU A THOUSAND TIMES, THANK YOU to everybody to be so available, to guide me and offer your support. From now on I know whom to refer to when I need to share because I know I have very good friends around. I discusses with my husband Byron to make a methylation test on our daughter Juanja urgently, which is not available here in Ecuador and nobody knows about. I will send you a picture soon so you know my angel here in this human world ... my daughter Juanja.

Thank you and greetings"
Palmira Cevallos

Have a nice and serene week end as I will do.
Love you as always,
Giorgio

The Many Angels Who Support Us

By Maureen Wheat, Director of Development

In the tragic aftermath of September 11 and during the slumping US economy, many charitable organizations are experiencing a challenge sustaining current levels of donations and raising new revenues.

According to general statistics in the non-profit world, while overall giving this year is growing at one half of one percent, this represents a marked decline from last year's surge of 6 percent. Gifts from corporations fell an estimated 12 percent and will continue to decline from the previous booms of the mid to late 90s. Overall, individual giving continues to be steady with small growth anticipated.

The good news in this for our organization is that our generous donors continue to support PWSA (USA), and fund-raising opportunities for individuals and chapters have materialized in amazing and heartfelt ways.

Combined Federal Campaign

Bill Vucci, devoted father to daughter Maria, who is diagnosed with PWS, has invested his time and resources working on behalf of PWSA (USA). A federal employee, Bill has helped with the Angel Fund, and more recently has taken on the leadership role as Combined Federal Campaign (CFC) Team Captain. As a spokesperson for the CFC, Bill has made a video asking his fellow employees to consider "helping one of their own" with contributions to PWSA (USA) in Maria's name. Bill recently told me that he has "picked up a cross and banner to tell the world about PWS."

Chapter golf tournament

Mary Lynn Larson, program director for the Wisconsin chapter of PWSA, helps to organize an annual charity golf tournament on behalf of her chapter. Members of the chapter solicit "Hole Sponsors," who in turn have their names designated at one of the 18 holes. In asking local businesses for donations that could be used as door prizes, Mary Lynn tells us, "We have had many prizes donated, and we have actually set some aside (with donors' permission), hoping for a time we could sponsor a raffle to perhaps draw in more money." Mary Lynn credits much of the energy and success of chapter fund-raising to the chapter's Past President Barb Dorn, who has generously shared her knowledge of fund raising with all who are interested.

Partnering with local business

Bill and Tina Capraro, loving parents of daughter Lea, who is diagnosed with PWS, along with members of PWSA (USA), raised more than \$50,000 for PWSA (USA). Never having hosted a fund raiser, but feeling compelled to make a difference, the Capraros teamed up with a local business in Chicago, Walter E. Smithe Custom Furniture Store, which provided the space, donations from sales and generosity of spirit to help the Capraros host a gala evening of cocktails, hors d'oeuvres and

entertainment. This blessed partnership not only raised vital resources for PWSA (USA), but also helped to tell the world about PWS.

Building the PWSA (USA) donor base

Mary Cassady, Amy Gardner, Betsy Ford, Mary Hill and members of the New Jersey Chapter, Stephen Lightman, Catherine Whitney and Angela Hughes, all helped with our Angel Fund mailing by sending solicitations to family and friends who may not know about PWS. This not only helped to introduce people to the syndrome but also helped the national organization build its donor base.

Obtaining a PWSA (USA) fund-raising packet

In response to all of the members and chapters who have expressed an interest in getting involved in sustaining and growing PWSA (USA) by raising donations for the national office, we have created a fund-raising packet, *Securing the Hopes & Dreams for People Impacted by PWS*. It is our fervent hope that all members call or e-mail PWSA (USA) for a packet. Once you have received the packet, please read it from cover to cover. We hope it will not only inspire ideas, but also give you vital information in making your journey through fund raising easier. Also, please pay special attention to the legalities involved with fundraising on behalf of PWSA (USA).

Everything I have shared with you is just a sampling of how individuals and chapters are helping to raise much needed contributions for PWSA (USA). Every story stands as a testament to how each one of us can make a difference in the fight to find answers and a cure for PWS. All of these people and the hundreds of you who donate your time and money to PWSA (USA) are truly the angels who walk among us!

Finally, a special thank you to all who work on behalf of PWSA (USA). Your commitment to the national office is not only appreciated, but helps secure the vital link between people in crisis and the services that provide hope and dignity for those impacted by PWS. As a Native American proverb reminds us, "We are eager to share our gifts in the name of Love."

Note: Specific references concerning non-profit contributions are available upon request.

Your Gifts Benefit Those with PWS

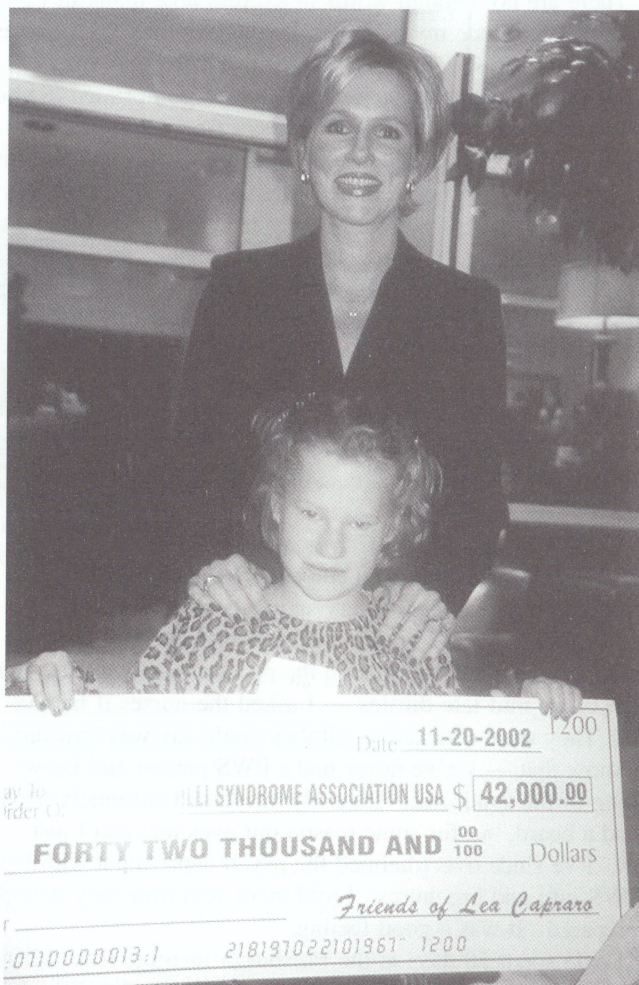
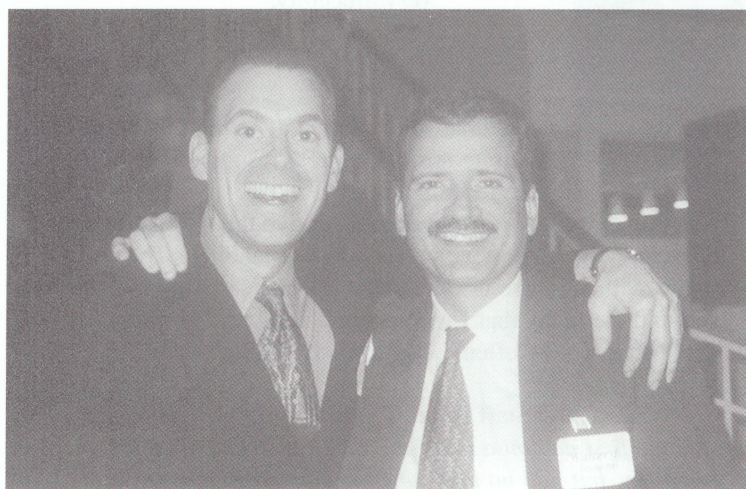
PWSA (USA) recently received the following letter of thanks.

"The PWS materials arrived yesterday. I have read them all and listened to the tape. They are very helpful, perhaps the tape the most, as it best integrates the information. What was most helpful were the medical and behavioral components. With many thanks for your kindness and help."

Extraordinary People — Extraordinary Music

The Walter E. Smithe Furniture Store Fund-raiser in Honor of Lea Capraro

Thanks to a long friendship with Walter Smithe, Tina and Bill Capraro had the opportunity to host the gala grand opening of the new Walter E. Smithe store in Oak Brook, Illinois. One hundred percent of the proceeds went to PWSA (USA). Even more extraordinary is that the Smithe family covered all of the cost, and even donated 5 percent of all sales for the evening to PWSA (USA). Underwriters included August Associates, Cimco Communications and Source 4. A total of \$55,000 was raised at this event — the largest fund-raiser ever hosted by a PWS family in the 27-year history of PWSA (USA)!



Bill Capraro and Walter E. Smithe (top left); Tina Capraro with her daughter Lea, 7, who has PWS (top right), at the Walter E. Smithe Furniture Store fund-raiser in honor of Lea for the benefit of PWSA (USA).



Photo by Eric Michael Hilton

Classical Guitar, Sarasota Style

The nationally renowned guitarist, Esteban (left), along with his daughter Theresa on the violin and percussionist Scott, donated their talents to a very special evening of wine, food and music for the soul at Michael's Wine Cellar in Sarasota. This fund-raising event for PWSA (USA) was hosted by the national staff and included a silent art auction. Esteban's extraordinary talent and passion produced an evening of music that enraptured the hearts of all who attended.

Classical guitarist Esteban (at left) playing at a Sarasota, Florida fund-raiser for PWSA (USA).

I Will Survive This — I Know Now I Have Support

Dear Friends at PWSA (USA),

There are not enough words to express how thankful I am for your help. Since my daughter, Lexie, was born six years ago our lives have drastically been changed. I often read my favorite poem "Welcome to Holland" which you printed in your newsletter 5-6 years ago. It was the very first newsletter I received and Lexie was about 9 months old. I remember sitting on my porch crying, not because I was sad, but because it was the first thing that truly described my feelings. As the poem states, "You now have to buy new guide books and meet people you would normally never have met — Holland's not a bad place — Holland has tulips, Holland has windmills." Of course, I'm sure I got some of my quotes wrong — the general message moved me very much. Please consider reprinting it — many new parents may be touched as much as I was.

When I lived in North Carolina and was chapter president, it was so therapeutic for me. Then my divorce happened very suddenly and I came back home to Richmond, Virginia. I've only met one family here. I worked in a hospital and was on the psych floor. One day I saw a man in his mid-late thirties — I asked the nurses if he had PWS. They were shocked — all they could say was how did you know that — we've never had a PWS patient and knew nothing of the syndrome. Honestly, he wasn't extremely obese, he had a beard, but for some reason our eyes met and I just knew. I've since overwhelmed the psych department with loads of PWS info and brochures. I told them next time they would be prepared. It was a good feeling.

Lexie spent 58 days at the Pittsburgh Institute from 12/01-2/02 (thru all the holidays). It was very, very hard to have her away — at first I felt relieved, then guilty for feeling that way. But I soon realized it wasn't forever, and ultimately it would help her. They are amazing! The other PWS patients were all adults and took to Lexie right away. During my visits I saw how fortunate we were — Lexie is only 6 and having that advantage of knowing since birth is a gift. During her stay I was told that Lexie also has brain damage to her right frontal lobe (the injury occurred at birth — forceps!) While in NICU, we were told she had a bleed on the brain but it was "normal" with such a traumatic birth and not to worry.

Well, 6 years later the statutes of limitations have passed in NC and legally I can't do a thing. It explains why she is still non-verbal and her tantrums are at least 16-20/day, some lasting as long as 1 hour. Due to the injury she is "clinically" autistic. She certainly has *many* O.C.D. tendencies. Her brother is 9 and is an amazing child; what he puts up with daily and tolerates is amazing. He's very special and I feel he will be a stronger person for it.

After losing three jobs in a row, my self-confidence plummeted as well as my finances. When I called Diane a few days ago I was at my wits end and felt hopeless. Her kind words and support helped me so much. For the first time in

months I slept thru the night. You *all* do amazing things! And just knowing someone understands my life is incredible. Your generous financial help means so much to me, I cannot thank you enough. I know now I'm not alone, even if it's just a supportive ear on the other end of the phone. God bless you *all* and THANK YOU!

I've attended two national conferences (Orlando & Pittsburgh) and hope to go again soon. So don't be surprised if a red-headed woman from Virginia walks up and gives you a big hug — it will be me! Thank you again.

Very Sincerely,
Patricia Spittler, Richmond, Virginia



*Lexie, 6, who has PWS,
with her brother Josh, 9.*

P.S. Also Ken Smith & Becky Gloninger are incredible (the entire staff at the Pittsburgh Institute are) It's a great resource if families are able to utilize it.

I know I will survive this — I know now I have support. I know now I have understanding. Those three things will and have made a major difference in my life. My son told me today that I was smiling. He said, "Mommy, you don't do that very often." My tears then were of joy!

PWSA (USA) Staff Note: *I talked with Patricia 9/17/02— it was the first day on a new job. She had been called for an interview, but had no idea how the company came by her resume. They hired her the next day. Her hours are during the times when the children are in school and she does not have to do any holidays or weekends, so the day care problem is solved. She was ecstatic.*

— Diane Spencer, PWSA (USA) Support Coordinator

The Chuckle Corner

In his four short years of life, Cameron has already visited his fair share of hotels — four PWSA conference hotel visits, four family vacation hotel visits, and currently we're staying in yet another hotel while our house receives repairs. Cameron delights in his ability to find the correct room number and then unlock the door.

We hadn't realized just how much of an impact all these hotel stays have had on him until recently when he asked where Jesus lives. A bit perplexed, I answered that Jesus lives in Heaven.

Without missing a beat he asked, "And what number's on Heaven's door?"

Liza Graziano, Redondo Beach, California



Please send your joke or funny story to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions.

Jerad and Ronaele — And Their Forever Friendship

It began on July 16, 1993 in Scottsdale, Arizona. It was to be our first PWSA (USA) Conference.

Before we left our Oregon home, our daughter Ronaele, then 13 (and now 22 years old) told us very adamantly that she **WOULD** find a boyfriend. She did. But that's another story.

It was the second day of the conference when she told us she had found her man. She brought him to our table to introduce him to us. He was formal, quite handsome and very polite. His name was Jerad.

Jerad told Ronnie he was 13. Later in a conversation Jerad's mother Marcia was very surprised to learn that her 16-year-old son was now only 13. Jerad later revealed to Ronnie that he thought if he told her his real age, she would think he was too old for her.

Thus was the beginning of a long and eventful relationship!

Since their meeting in 1993, Jerad and Ronnie have spent the summer months together in our Central Oregon home.

Jerad travels to Oregon by plane from his home in Phoenix, Arizona. Ronnie has also visited Jerad at his home, and just last year our entire family of four traveled to Phoenix to be with Jerad and his family for a month.

Highlights of their summer activities include fishing, camping, hiking, biking, (three-wheeled bikes named Rudy and Ruby) and swimming at the river.

Time at home is spent doing the usual: watching movies, doing puzzle books and playing with Ronnie's 8-year-old brother Samson. They also are quite occupied by their 111 imaginary kids (and they remember the names of each and every one!)

Jerad and Ronnie both **ADORE** stuffed animals, and each of them has quite a collection. They both are quite proud to be American, and show their patriotism by sporting their "American" t-shirts and flag every chance they get.

Like all other people with PWS, Ronnie and Jerad must follow a strict regimen of diet (Mom's job) and exercise (Dad's job) in order to maintain healthy bodies. They use variations of the diabetic exchange, with a caloric intake of approximately 900-1000 calories each day. They are under constant supervision in order to prevent sneaking food.

Along with their diet is their walking program. Ronnie and Jerad walk three to four times each week for approximately 2-4 miles each walk.

We are blessed with nice weather and a lot of beautiful places in which to walk. They have names for each of their walks, such as "Jerad's trail" and "Big Tree." Their favorite is



Ronnie and Jared at the summit of one of their favorite trails.

"Lava Butte," one of the many small volcanoes in the area. It is approximately a 3½ mile climb with a 500-foot elevation gain!

We are very proud of Ronnie and Jerad for their efforts because we all know it's not always easy to be motivated to exercise.

Being together has helped Ronnie and Jerad to motivate each other when one doesn't feel like walking, or the other feels like "sneaking." Couldn't we all use that kind of loving support?

It's been more than 9 years since Ronnie and Jerad met, and when they are apart they continue their relationship through phone calls, e-mails, letters, cards and gifts. They hope to marry each other some day.

We feel fortunate that Jerad's wonderful family has allowed us to be a part of his life. We are so thankful God brought Jerad and Ronnie and our families together. We've learned from each other and shared much laughter and tears.

Sam & Christie Loomis live with their daughter Ronaele in LaPine, Oregon.

Shop the PWSA(USA) Web Mall

Shop from 140 Internet merchants who pay commissions up to 14 percent to PWSA(USA) on every sale. Merchants include Amazon, Borders.com, Disney, ESPN, L.L. Bean, Lands End, Hallmark, CDNOW and FTD.

Find the mall at www.pwsausa.org.

All shopping is fully secured, and the mall offers full privacy protection.

Rob - continued from page 1

place in my heart because I felt a sense of peace that as long as you were with us, my little Anna would be the best she can be. I always had so much hope because you were always there to help guide me. Now I guess I'll have to put on my boots, travel through rough waters, and pray that you'll continue to be Anna's guardian angel.

We were so delighted to see you at the 2001 International PWS conference, where you shyly accepted an award entitled "Our Angel of Hope" and received a standing ovation from the families and your colleagues who respected you.

Six months passed and more distressing news came. We were informed your precious life was about to end. You wanted your friends and family gathered together to "celebrate your Life." It is such a blessing to be a part of that — to experience the renewal of your wedding vows with your wife Karen, to meet your wonderful children, to cry with you, laugh with you, hug you and tell you what a difference you have made to all of our children and families. When Janalee, Dr. Rob Nichols, Jim and I were at your celebration it became apparent that you wanted this for us, too. You wanted us to be embraced by friends to gain the strength needed. I realized this when you gave out

hats with two circles entwined on the front saying, "circle of strength" and on the back stitched with your initials and the day of your life's celebration.

We then received exciting news you were on an experimental drug and things were turning around. You were even planning on speaking at the 2003 National conference. But the drug stopped working, and your health declined rapidly. The day before Thanksgiving we received the heartbreaking news that your precious life ended in the arms of Karen, your soul mate, surrounded by your children, family and friends.

Rob, speaking from the hearts of all our children, families and colleagues, you will always be remembered for your love for life, your dedication and compassion. In my heart, I know that you are not only Anna's guardian angel, you are the guardian angel of the many children you touched.

C.S. Lewis once wrote: Grief and pain are the price we humans have to pay for the love and total commitment we have for another person." The more we love, the more we hurt when we lose the object of our love. But if we are honest with ourselves, would we have it any other way?

Sadly missing you,
Carolyn Loker

Cami - continued from page 1

used to identify two cooperating genes that are involved in progression to acute juvenile myeloid leukemia. Cami earned her Ph.D. in Biological Sciences at Princeton University and completed a postdoctoral fellowship in the mammalian genetics laboratory of the National Cancer Institute in Frederick, Maryland before joining the faculty in the Department of Molecular Genetics and Microbiology at the University of Florida (UF) in 1995. Cami was an Associate Professor and one of the most successful scientists in the College of Medicine at UF. She was the recipient of three prestigious grants from the National Institutes of Health (NIH) and another from the U.S. Department of Defense. Cami was the author or co-author of 39 articles published in scholarly journals and co-author of two textbook chapters. She also served as a grant reviewer for the Wellcome Trust, the U.S. Department of Defense, and the NIH.

At UF, Cami was a highly respected teacher to graduate students and medical students, and a caring and insightful mentor to graduate students and post-doctoral fellows in her laboratory. She was a wonderful person and one of the most successful faculty members in the College of Medicine. Despite her young age she had already made a major mark in the international scientific community. During her tenure at UF, she assembled a first-rate group of researchers in her laboratory who will continue her scientific legacy.

Cami is survived by her husband Jim Resnick and her son Sam. Her colleagues have established a fund in her name to support graduate student fellowships and awards, and a lecture-ship in genetics. Contributions to the Camilynn Brannan Memorial Fund can be made to: University of Florida Foundation, Attention: Linda C. Luecking, University of Florida HSC Development, Box 103560, Gainesville, FL 32610.

Doctor Seeks PWS Group for China

A geneticist and pediatrician from China who is presently studying and working at the University of Pennsylvania, wrote the following:

"I was so excited when I got to know from Dr. Nicholls that your organisation is a non-profit international organization dedicated to serve the PWS patients and their families as well as doctors who are interested in this disorder. However I feel very pity that our country is not a member of this great organization, because we don't have a national PWS association.

"As you know, China is the most populated country in the world and it is supposed to have the largest number of PWS patients/families in the world too. However most of PWS patients in our country are not correctly diagnosed because lack of good diagnostic techniques and very few doctors have been trained in this field.... Our PWS patients need to be appropriately diagnosed, they and their families need to be well guided in their struggle against the disorder and our doctors need to be trained for better service to PWS patients. I think that IPWSO can help us to achieve our goal. So I talked to some of my colleagues and we plan to establish a Chinese PWS Association.... I'd like to act as a professional (IPWSO) delegate... for establishment of Chinese PWS Association."

IPWSO President Giorgio Fornasier has tried to enter China in the past, but could not get through for political reasons.

"With China as a member of our organization, PWSA (USA)'s educational packets, translated in different languages including Chinese, can be very useful and save lives. Thank God, we have now a qualified contact to enter this huge reality," Giorgio responded. "I wrote (this doctor) already, welcoming her... I hope we can encourage her in her mission."

Angel Fund Contributions

October-November 2002

Gabriel (\$1,000 or more)

The Dolese Foundation
Kathy & Ken Boehl
William A. & Tina Capraro,
Jr.
Sharon & Karl Cressman
James E & Suzanne L Fuller
R. B. Galloway
Gregory & Sandra Olson
Torbert Produce, Inc.

Heavenly Angel (\$500-\$999)

Mary & Bob Hill (*in honor of Oscar Hill*)
Robert F. Lebow
Shirley Mills (*in memory of Tom Mills*)
Terry & Debbie Mleczewski
Bruce & Bebe Whyte

Arch Angel (\$250-\$499)

Norman A. Barkeley
Robert & Barbara Christenson
Joseph A DiFilippo (*in honor of Grace Larmer DiFilippo*)
Jim and Joan Gardner
R. B. Gilpatrick (*in memory of Col. Marshall W. Baker*)
William V & Janet Judy
Elizabeth Kenney
Jodi & Ross Laufgraben
Arthur & Barbara Louv
Steven & Susan Lundh
Rick & Susan Moccia
Robert Muirhead
George Mullen
Sal Nicrone
Anina & David Pfeiffer
Larry & Jan Rosenfield
John & Debbie Stallings
William Stege

Angel (\$100-\$249)

WEBCO Graphics
Israels Design For Living
Service Excellence Group
Melinda Wyatt, Inc.
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Versa Handling Company
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Roger & Beth Barnett
Delfin J. Beltran, M.D.
William & Elizabeth Bennett
Robert & Fern Bitzer
Catherine Bouton
Mary & Holger Bracht
Mindi & Richard Bressler
Wanda Buccheri
Jullie Burnett
Merlin & Ranae Butler
Bill and Judy Castle
Frank & Carol Cava
Mae Chandler (*in memory of Grace Chandler*)
Hymen & Ruth Chausow
Kevin Chippendale
Mary & Ken Conry
Joyce & Michael Cooley (*in honor of Jean & Maurice Vermeulen's 50th Anniversary*)
John Cooper
Patsy & Steve Coppock
Duane & Caroline Coykendall
Gail & Donald Daum
James & Christa Davis
Douglas & Barbara Dsida
Annie Durell
Hugh and Susan Dykens, Jr.
Pamela & Robert Eaton
Lee Englund
Gladys Faherty
Jason & Nancy Finegold
Mr. & Mrs. William Fisher
Peter Fleischmann
Barry & Sara Formslag
Angela Francavilla
Rob Fuller
Robert Funk
Norman Gerou
Stephen & Sandra Ginn
Martha & Gary Girdaukas
Goldschmidt & Associates
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Jim & Joni Gorman
Louise Greenswag
Richard A. Hadsall
Dick & Peggy Haley
Lee & Jack Hancock
Melvin & Jane Handwerker
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Angela & Mark Hughes (*in honor of Collin Hughes*)
Guy & Lori Hurley
Adam Inselbuch
Karen & Timothy Jobe
Robert & Alice Jones
Lois Jean Kane

Angel (\$100-\$249)

David & Tammy Kenney (*in honor of Julia Kenney*)
Barbara & William Kerrigan
William Klein, Sr.
Jeanne W. Krautwurst
Mercedes A. Lat
Nelson & Hope Leonard
Marcia Levine
Renee & Ira Levine (*in honor of Josilyn Levine*)
Victor & Linda Lewin
Mark F. Lewis
Sharon Lewis
Stephanie Lutz Bittle
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Ralph Magalee
Raymond & Anita Marchant, Jr.
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Bernice & James McKean
Joseph McManus
Gloria Ann & Milton Means
Richard & Carol Medina
John & Karen Meslow
Kathryn & Glenn Moffett
Bob & Cathy Mook (*in honor of Crosby Mook*)
Reinard P. Nanzig
Anila Nijhawan
Bernard & Millie O'Connor
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Jerri Pate
Arvind F. Patel
Cindy Pennington
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Thomas & Allison Pierson
John Powers
Kenneth & Ruth Prettyman
Katherine D. Radaz (*in honor of Ashley Fender*)
J. Harold & Diane A. Ranck, Jr.
Kathleen & Thomas Reilly
Jack Roe
Dennis & Sharon Saacks
Cynthia Sajid
Lyle & Rita Schertz
Fred & Kathleen Schloessinger
William G. Seal
Gary & Sharon Seedorf (*in honor of Hannah Behnken*)
Carole & Joseph Smith (*in memory of Skylar Smith*)
Early & Jackie Spiars
Bernard Starr
Robert & Marjorie Stickler
Sandra Strazzulla

Angel (\$100-\$249)

John & Carol Talanian
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