



The *Gathered View*

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

July-August 2007
Volume 32, Number 4
Our 32nd Year of Publication



Dusty Gamble, Pennsylvania
see page 11

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Donations for Research

As of 5/31/07:
\$119,682

The Challenge of Change

Hi! As you can tell from the picture, I'm not Janalee Heinemann — but I am one of her biggest fans. Together with thousands of parents and professionals over the years, Janalee has helped build PWSA (USA) into a strong, compassionate and effective group to share information, increase awareness, fund

research and provide support to families dealing with PWS.



PWSA (USA)'s new
Executive Director
Craig Polhemus

Last December, Janalee announced her decision to shift more of her energies to medical and research

issues. As I write this, Janalee is in Romania at the International Prader-Willi Syndrome Organization (IPWSO) triennial conference in her new role as our director of research and medical affairs. Like many of you, I can't wait to hear the details of that conference from Janalee, our parent delegate Susan Hensch, and other attendees, including IPWSO President Pam Eisen.

How do you feel about change?

I suspect you know better than I do how disruptive and disturbing dealing with change can be. This is true for all of us, to one degree or another. And this is a time of major change for PWSA (USA).

In addition to a new executive director, we will soon have a new logo, a new address in Sarasota, and a new communications and development program. These changes offer new opportunities to pursue our goals of supporting families, funding research,

Craig Polhemus continued on page 13

How We Picked Craig

By Carol Hearn and Ken Smith, PWSA (USA) Board Co-Chairs

After Janalee Heinemann announced in December that she would be transitioning to a new, reduced-hours position as director of research and medical affairs, Board Member John Heybach directed a search process that started with more than 400 resumes solicited through various executive search websites.

Working through both a screening and a selection committee, eight candidates were interviewed in Tampa, Florida. Then the three top candidates were interviewed again, in Sarasota. The committee's choice, Craig Polhemus, then met with the Board at our May meeting in Dallas, and the Board appointed him executive director.

Thankfully, we have found an exceptional candidate. Craig is everything we could have hoped for and more. Not only does he have out-

standing credentials and a wealth of experience in government, for-profit and not-for-profit corporations — he also has a heart of gold.

A graduate of Princeton and of Georgetown law school, Craig has spent most of his career serving families, including those with members suffering from alcoholism, drug abuse, dementia or other impairments. He has been executive director of the American Accounting Association, staff director and counsel of the U.S. Senate Subcommittee on Alcoholism and Drug Abuse, and general counsel, deputy director, and CFO of the New York State Office for the Aging.

We know you will join us in giving Janalee a resounding thank you for her nine outstanding years as executive director and in giving Craig a warm welcome to PWSA (USA).

Prader-Willi Syndrome Association (USA)

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The Gathered View (ISSN 1077-9965) is published bimonthly by PWSA (USA) as a membership benefit. Annual U.S. membership: \$30 Individual; \$35 Family; \$40 Agencies/Professionals. Membership dues outside the U.S. are \$40 Individual, \$45 Family and \$50 Agencies/Professionals (U.S. dollars). We never deny parents membership for any reason.

Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA) unless so stated. 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:

December 1; February 1; April 1; June 1;
August 1; October 1

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.

Members Only: Check our website www.pwsausa.org for downloadable publications, current news, current research and much, much more limited to members only!

User Name: **pwsamember** **Password this issue:** **texas07**

Note: If you have difficulty logging in to the site, you may be using a browser that prevents you from entering authenticated websites. Try minimizing your program (e.g. AOL) and clicking on Internet Explorer or Netscape. Then type in the URL: <http://www.pwsausa.org/memberonly.htm>

E-mail Support Groups: We sponsor eight e-mail groups to share information. You'll find them listed in this issue and on the web at <http://www.pwsausa.org/support>

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President's View

Visions, Dreams... And Changes

Carolyn Loker

**Vision without action is merely a dream.
Action without vision just passes the time.
Vision with action can change the world.**

Joel Barker

We have a dream, we have a vision and now we are making changes.

PWSA (USA)'s dream is your dream... to find treatment options for our precious children, to help them be happy, safe and free from hunger, to be able to live independent lives.

PWSA (USA)'s vision is your vision... to raise awareness so that every child and family can be given a gentle touch and a positive word, to increase funding for programs and research so that each child will reap its rewards.

PWSA (USA)'s action has involved putting the best interest of our precious children first and changing from what we all have previously known as PWSA (USA) to a faster, more progressive organization to meet the increasing needs of our membership.

We have not lost our former executive director, Janalee Heinemann. She is just transitioning to the job that she loves the best, which is medical and research. Now we are introducing another dynamic executive director, Craig Polhemus, who will help to move us in a new direction. I'm sure other changes will follow suit to meet the increasing demands of our rapidly growing organization.

Why is our growth increasing so rapidly? It is thanks to everyone — the families and professionals helping the Association and also the ones needing the Association's help. Without you, PWSA (USA) wouldn't be moving into this new era.

In July, my three-year term as president will be expiring. I have tremendously enjoyed this endeavor, but have made a decision not to continue on as president. Several months ago the orthopedic surgeon informed us that Anna's scoliosis surgery will be in a year or two when most of her growth is completed. Our little Anna is not so little anymore. She is 5' 2" and will be a teenager in July. Because of her upcoming surgery, I want to spend more quality time with her and just have some fun prior to her operation. With the work load lightened, I have chosen to run for a board of director's position because I still want to be your voice. I am in constant contact with many members and consistently read e-mails from all of our e-groups. I want to help you help your child, and I believe that position is the best suited for those needs.

My decision not to continue as president came at precisely the right time because it was agreed that PWSA (USA) will no longer have a president's position. Today most non-profit organizations have either a chairman of the board or a president but not both.

As you see the new changes in our organization, please wrap your arms around them and know that PWSA (USA) is making these positive changes with your child at the very heart of them. Your encouragement, dedication and on-going support are needed by the Association and everyone who is a part of it.

As this is my last president's message, I want to thank you for letting me share my feelings and part of my family's life with you. You will always be in my thoughts and prayers. Many Hugs!

Time, Talents and Treasure — Thank You, Volunteers!

By Lota Mitchell, Associate Editor

PWSA (USA) accomplishes a lot by the efforts of a few — and the efforts of many. The few are the office staff; the many are all the wonderful volunteers who contribute their time, talents and treasure to the Prader-Willi mission. To list everyone who has helped would take the whole *Gathered View*, so here are just a few examples:

When the request came for Spanish subtitles on the DVD "Food, Behavior and Beyond" by Linda Gourash, M.D. and Jan Forster, M.D. (who both deserve thanks as volunteers themselves) — five people took on the painstaking, tedious job of listening to each of the five lectures on the DVD and writing them down, word for word. This created an English transcript from which subtitles could be translated. A big thank you on this difficult project goes to **Carol Trimble, Kate Buchanan, Julie Doherty, Emily Sprague, and Jacque Reidpiscitelli.**

Carol Trimble and **Kate Buchanan** also helped out with the typing on *The Sibling Book*, as did **Sam Coggeshall**. **Nina Roberto** co-edited *The Sibling Book* and did a superb job.

Thank You continued on page 15

Another Big Step Forward for PWS Research

By Janalee Heinemann, Director of Research & Medical Affairs

Mount Sinai Hospital in New York plans to hire a new researcher to focus on PWS in the coming year. This marks a major commitment to advancing knowledge about the syndrome.

The appointment is the result of incoming PWSA (USA) Board member Dr. Jamie Bassel and our New York Chapter collaborating with the Department of Genetics and Genomic Sciences at Mount Sinai. This department is one of the largest in the nation, with state-of-the-art equipment and 38 full-time, primary faculty and 16 secondary and adjunct faculty.

PWS Alliance of NY Chapter President Barb McManus and I met with Department Chairman Dr. Robert Desnick for a tour of the facility. Dr. Desnick, who has been with Mount Sinai 20 years, appears very committed to hiring the PWS researcher. He is also interested in collaborating with Dr. Moris Angulo, who is on our Clinical Advisory Board and follows more than 300 children and adults with PWS.

Jamie and his wife, Jacqueline Kotler-Bassel, were honored at The Genetic Disease Foundation's gala June 11. Attended by 475 people, including PWSA national and New York Chapter members, the gala brought tremendous

awareness about PWS. The program booklet featured eight pages honoring Jamie and Jacqueline and their work with Prader-Willi syndrome, and Jamie made an eloquent speech about their son, Zak, who has PWS.

I am full of enthusiasm and confidence that this is a giant step forward for Prader-Willi syndrome research. Our thanks to Jamie and his family for opening a big door for us.

Dr. Jamie Bassel and his wife Jacqueline Kotler-Bassel were honored for their work with PWS by The Genetic Disease Foundation in New York



Alström & Prader-Willi Syndromes – Our Common Bond

By Janalee Heinemann, Director of Research & Medical Affairs

I have known for some time that Alström syndrome (ALMS) is considered one of the “PWS-like” syndromes because both have a component of hyperphagia. I've met in the past with the founders and key coordinators of the international ALMS association, Jan Marshall, SAB chair, Robin Marshall, Executive Director, and Sandra Surette, Family Service Coordinator. We had even discussed with IPWSO starting an international collaborative effort with all of the genetic obesity groups, but the combination of lack of organization among most of these rare disorders, and our busy lives, left this dream on the back burner.

A few months ago, I was invited to present at the international ALMS conference in Texas on the topic of hyperphagia. Although Jan Marshall hears many stories from parents on the hunger and drive for food among the children with ALMS, she said no one had ever really addressed the issue.

After attending several sessions prior to mine, I was struck by how many other characteristics were similar and listed them in my presentation. It was gratifying to receive very positive feedback on my presentation, not only by parents who needed someone to confirm their struggles on this issue, but also by professionals who were struck by the commonalities. In fact, they said that due to my raising their awareness, they were going to discuss this further in their scientific meeting.

I came back determined to see that we somehow, somewhere, get the top PWS and ALMS researchers together to collaborate on their efforts. Although the syndromes originate from different genes, I believe there has to be some common crossover that will help us in our understanding of the problems and solutions for the hyperphagia.

Now that I have your curiosity piqued, let me explain more about the common features and differences between PWS and ALMS. Certainly, the most dramatic common characteristics are the constant hunger, the strong drive to get food, and obesity (98% with ALMS). At the ALMS conference I heard stories that you would have sworn were told at a PWS conference! Sneaking out of the house at night to get food, foraging in garbage cans, stealing money from parents to buy food, telling the neighbors and school they were not fed to get an extra meal, etc. The children and adults with ALMS also describe a constant sense of hunger. Like those with PWS, the drive to get food is variable, some with no more than a very strong interest in food and a little sneaking now and then, others whose every thought and action is motivated by food.

The major differences between the two groups are that children with ALMS usually go from light sensitivity to total blindness within the first two decades of their life and also have hearing loss that can lead to total deafness in some

Alström and PWS continued on next page

cases. Renal problems are common, as is cardiomyopathy, which can become life threatening. ALMS is inherited, and there seems to be a higher risk of having another child with ALMS. But, as most of you know, with PWS, only a rare subset has a risk of having another child with PWS. Children with ALMS do not have the hypotonia (muscle weakness) of our children.

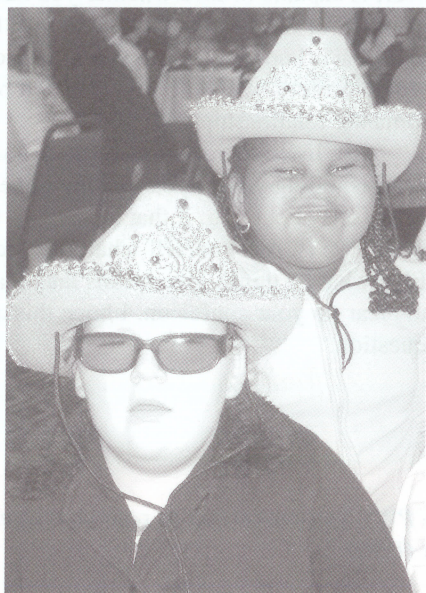
Many symptoms are “alike but...” In ALMS 98% have short stature, not at birth but becoming more prominent with age; Alström has normal insulin-like growth hormone levels. Both tend to have GI problems, but types of problems are different between the two, except that both have significant problems with constipation.

Age of onset of obesity is a little younger with ALMS (1-3 years), but typically does not become as life-threatening as with PWS.

Although both groups deal with developmental delays, children with PWS are slower achieving milestones; although both can have learning disabilities and both can have normal IQs, those with ALMS are usually very bright. Like PWS, children with ALMS often have obsessive-compulsive characteristics. Like PWS, some have autistic characteristics (more with PWS), but behavior problems in general are more dramatic with PWS. Both children and adults with PWS and ALMS are typically very loving and social.

Other common features (although the percentages of those affected are somewhat different) beyond hyperphagia are type II diabetes, scoliosis, hypogonadism, sterility, pulmonary problems, irregular menses, abnormal enamel of the teeth and other dental problems, high pain threshold, irregular thermostats regarding feeling hot or cold — and always, the hunger.

Alström syndrome is much rarer than Prader-Willi syndrome, with only 450 known in 46 countries. It has been 48 years since it was first described by Dr. Carl Henry Alström in 1959 (PWS was first diagnosed in 1956). ALMS comes from chromosome 2p where a very large, not previously known gene, *ALMS1*, is affected. Since this is an entirely different chromosome — (15 for PWS) and gene(s) than PWS — where is the crossover? I can't help but wonder if we study their differences and similarities, we may find



Two cowgirls at the 2007 international Alström conference in Texas

some pieces to the puzzle for both syndromes. PWSA (USA) Scientific Advisory Board Chair Dr. Merlin Butler stated, “We did not see a disturbance of the *ALMS1* gene in either our human or PWS mouse gene expression studies, but the *ALMS1* gene is poorly expressed in blood tissue.”

We have a lot to offer ALMS families since we have so many materials to share that would be helpful, but they also have something to offer us toward finding answers for PWS. I'm excited about the possibilities, and in my new role as director of research and medical affairs promise to pursue more collaboration between our groups and their researchers.

At this meeting, as with many groups I have attended or coordinated, I was impressed by the resiliency of the human spirit. I walked around a room full of guide dogs and white canes, and heard a mother tearfully sharing her grief over dealing with her son. He has been blind for some time, and is now having to cope with going deaf. I thought to myself, *Thank God Matt did not have Alström syndrome.*

Not long after that thought crossed my mind, an ALMS mother approached. One of her children had already died of ALMS and two others and were present with their guide dogs. She told me, “At first they insisted my oldest child had PWS, but thank God it was not that!”

I Said It, But That Doesn't Mean You Understood It

My son Matt, who has PWS, went to a Walkathon and told Dr. Barb Whitman [a member of our PWSA (USA) Scientific Advisory Board] that he had to talk to her privately. He told her, “I'm worried about my stomach.”

“Oh,” she replied, “what are you worried about?”

“I wonder if it's still there.”

“Hmm. I don't understand. Has it been hurting or have you been throwing up?” she asked him.

“No, I heard them talking about people's stomachs exploding and I wonder if mine has.”

Dr. Whitman assured Matt that it had not, nor would it unless he was sneaking a lot of extra food. (She felt compelled to get a plug in for not doing that.) So, she advised, unless he was sneaking extra and overeating, Matt didn't have to worry.

Her later comment to me was, “And there in a nutshell is the language processing issue!”

Although we can see the humor in Matt's concern, we need to remember that our children of all ages (Matt is 34) and all IQ's (Matt's is low normal) do not always process statements as we mean them.

— Janalee Heinemann

Ask The PWS Advisory Board

Can Adults with PWS Experience Love?

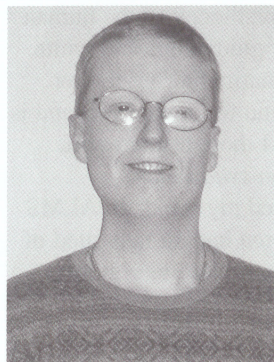
Dear PWS Advisory Board,

My boyfriend "Ellis" (not his actual name) has PWS. I'm kind of trying to figure things out.

Ellis's dad told me that he would not feel romance because of his hormone deficiency and could not feel the same love I have for him; therefore he could not return it.

Ellis said he loves me as a friend, as a girlfriend, and enough to be engaged to me. His father also said that he would not want to hold hands and he would not like to kiss me and if he did kiss me, it would be like kissing one of his sisters. Ellis has told me he would like to kiss me on the lips. I don't think he kisses his sisters on the lips. One day he held my hand for about an hour, sometimes squeezing it. He said it made him feel warm inside. I guess he liked it.

In my opinion, if he was more romantic than he is, I'd cry. Ellis has a desire to get a job... [and] his own place. I've told him these things are possible through case management. Ellis is a 20-year-old white male. I'm a 25-year-old female with learning disabilities.



Our Adults with PWS Advisory Board member Conor Heybach responds.

I will be happy to answer your question based on my own experience. I am a 26 year old man with PWS and have had experience with relationships. I am capable of romantically loving a girl outside of my family. I believe that individuals with PWS are capable of experiencing love and romance. Ellis might be at a time in his life where he might be scared of

getting close to you because every man thinks about romantic love and women often. We individuals are capable of loving someone and having a romantic relationship with the opposite sex as long as his/her family feels this is the right person for you.

I think you should trust Ellis's heart, because every ones heart is capable of love whether you have PWS, or any other disorder, or disabilities. Just because Ellis is a young man with PWS, knowing that he has a hormone deficiency, he will definitely be able to love you and be able to have a romantic relationship with you.

Also listen to your own heart and see what your own heart is telling you. If you feel the same way about Ellis as Ellis feels about you; if that is not love then I don't know what love is. Ask yourself what love means, and then ask Ellis what he thinks love means then maybe you will be able to clear up your confusion. I hope this answers your question.

Sincerely,
Conor Heybach

If you are a person with PWS, or you have a child with PWS, you are invited to send your questions to:

*Prader-Willi Syndrome Advisory Board, c/o PWSA (USA)
5700 Midnight Pass Road, Sarasota, FL 34242*

*If it is too difficult for you to submit your question by writing, you can call and tell us your question at
1-800-926-4797 Monday-Friday from 9:00 a.m. and 6:00 p.m. Eastern time. We will keep your name confidential.*

Soon The Gathered View Can Arrive In Your Inbox

Beginning soon, you can opt to receive *The Gathered View* electronically right to your e-mail address, or you can continue to have the newsletter sent by mail as always.

By e-mail you will receive the most recent copy of our PWSA (USA) newsletter before others receive it by mail. *The Gathered View* is only available to members.

In our next issue, we'll have more news about how you can sign up for electronic delivery of your newsletter. Then your copy of *The Gathered View* will be just a click away!

Log on to These PWSA (USA) eSupport Groups

Go to www.pwsausa.org/support and click on the group that interests you.

- Autism – Parents/providers of dual-diagnosed PWS and autism
- 0-5 – Parents/providers of infant and preschool children
- 6-12 – Parents/providers of school-age children
- Teens – Parents/providers of teens and young adults
- Military – Parents and providers in the military
- PWS – For people with PWS
- Spanish – For Spanish-speaking parents/providers
- Siblings – For siblings of those with the syndrome

Medical News

Does Sleep Apnea Affect Cognition?

From the Alliance Re Sleep Apnea

The following abstract illustrates why it is important to check everyone with PWS for sleep apnea.

Obstructive sleep apnea syndrome in Prader-Willi syndrome: an unrecognized and untreated cause of cognitive and behavioral deficits? Camfferman D.,

Lushington K., O'Donoghue F., Doug McEvoy R.; Adelaide Institute for Sleep Health, Repatriation General Hospital, Daw Park, Adelaide, South Australia, Australia.

Prader-Willi syndrome (PWS) is a rare genetic disorder characterized by a range of physical, psychological, and physiological abnormalities. It is also distinguished by the high prevalence of obstructive sleep apnea syndrome (OSAS), i.e., repetitive upper airway collapse during sleep resulting in hypoxia and sleep fragmentation. In non-PWS populations, OSAS is associated with a range of neurocognitive and psychosocial deficits. Importantly, these deficits are at least partly reversible following treatment. Given the findings in non-PWS populations, it is possible that OSAS may contribute to neurocognitive and psychosocial deficits in PWS. The present review examines this possibility. While acknowledging a primary contribution from the primary genetic abnormality to central neural dysfunction in PWS, we conclude that OSAS may be an important secondary contributing factor to reduced neurocognitive and psychosocial performance. Treatment of OSAS may have potential benefits in improving neurocognitive performance and behavior in PWS, but this awaits confirmatory investigation.

PMID: 17109239 [PubMed - in process]

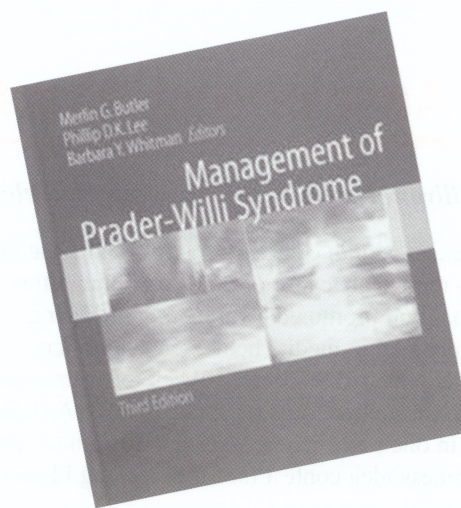
Medical Alert

Hand Sanitizer Has High Alcohol Content

Reports of children becoming intoxicated from hand sanitizers are circulating in the media, so we contacted a reliable source for facts. According to the U.S. Poison Control Center, hand sanitizers can contain more than 60% alcohol and can increase the blood alcohol level in children. A child can become intoxicated, and blood sugar levels can be lowered in young children.

Many of these sanitizers have tempting fragrances such as cinnamon, and there have been reports of children licking after a sanitizer is applied.

Concerned parents should wash off the affected site, give the child some juice and call the National Poison Control hotline, 1-800-222-1222.



Praise for Our PWS Management Book

PWSA (USA)'s book *Management of Prader-Willi Syndrome* is receiving praise from professionals. A psychiatrist sent this e-mail: "I am reading the management book like a novel! I'm one third through... it is a marvelous text! Congrats to the editors for birthing such a beautiful baby!"

The new third edition was edited by Merlin G. Butler, Phillip D. K. Lee, and Barbara Y. Whitman, with chapters contributed by 32 experts in the care of those with PWS. Louise Greenswag and Randell Alexander, editors of both prior editions of the textbook, call the third edition "edited and written by the very best in the field and updated with the latest research."

Rare is the person who will read this like a novel, but it is an excellent resource on many topics related to PWS. Price for PWSA (USA) members is \$50 plus shipping; non-member price is \$75 plus shipping.

To order, call PWSA (USA), 1-800-926-4797 (toll-free in USA and Canada); fax to 941-312-0142 or e-mail to: national@pwsausa.org.

**Effective September 1, 2007,
PWSA (USA)
will have a new address:
8588 Potter Park Drive
Suite 500
Sarasota, FL 84238**

**If you visit Sarasota, we hope you
will stop by and say hello.**

PWS Awareness Month 2007: Raising Knowledge, Br

By Jodi O'Sullivan, Director of Community Development

PWS Awareness Month of May has come and gone but PWS awareness remains because of you! In communities around the nation, you promoted awareness with flyers, contacted and appeared in media, held events and more.

This year we extended Awareness Week to Awareness Month, added an awareness tools page on the PWSA (USA) web site listing in one place items to further awareness, and created an awareness idea contest (see the winning ideas on page 10).

We thank everyone who shared their stories with PWSA (USA) and took action to make a difference for our loved ones who have PWS. Following are just some of those efforts, including those of Awareness Committee members.

Clint Hurdle, manager of the Colorado Rockies baseball team and **father of Madison, 5**, again served as **National Celebrity Spokesperson**. With a public service announcement generously donated by the Rockies and awareness efforts at Coors Field, thousands of people learned about PWS.

Utah Chapter President Lisa Thornton wrote that along with a **Party at the Park** walk event on April 28th attended by more than 900 people, a TV commercial ran 80 times in the three weeks before the event, telling what PWS is. They found new families and educated thousands.

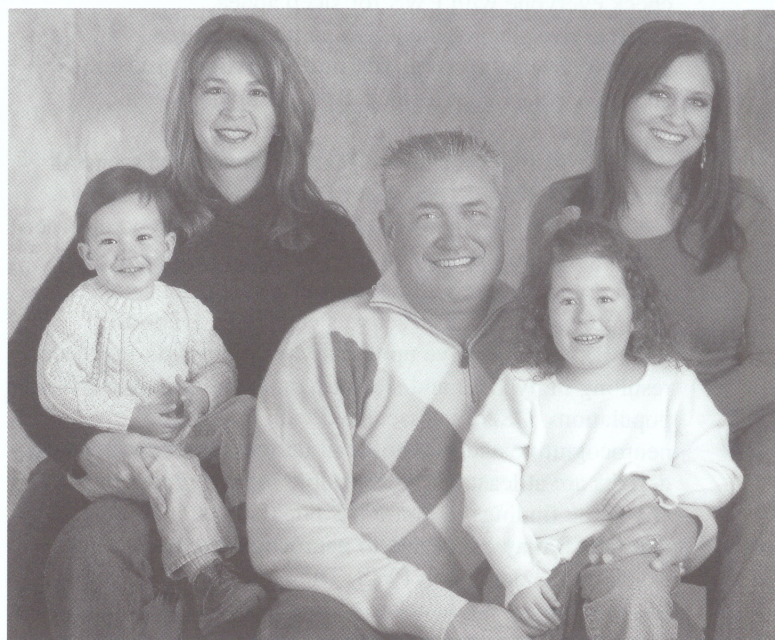
Diane Seely from Ohio, parent to **Reagan, 4**, created a **flyer** with Reagan's picture and **distributed it at his school**. When the head nurse for all the schools in their city received a copy, she asked Diane's permission to hang the flyer in all the teachers' lounges in all the schools. Wrote Diane, "She thanked me for sending it to her! She also said that Reagan's picture makes her day! Of course, this totally makes *my* day!" Diane's flyer was included on the tools page and other parents around the country notified PWSA (USA) they had modified it for their own use, handing it out to "everyone and anyone."

Barb Dorn, mother of **Tony, 22**, along with **Melissa Sirovina** and daughter **Kayla, 12½**, were interviewed in **Milwaukee, Wisconsin about PWS** on TMJ 4's "The Morning Blend Show." "Considering you never really know how long you have or what questions they will ask – it went well," Barb wrote.

Also in **Wisconsin**, **Betsy VanHeesch**, parent to **Carley, 3½**, was asked to **share Carley's story** during the **Miracle Marathon for Children's Hospital** on www.wklh.com. Prior to the interview, she wrote "Over the years, the Marathon has raised millions of dollars for Children's Health System for continued research, technology and health care for our kids. The program is based solely on stories and experiences shared by families. It can be a pretty moving experience, so I will try to keep it together!"

Sarah Garrett is one of our Awareness Contest winners. She's mom to **Corbin, 9 months**, from **Virginia**, and belongs to Iota Epsilon of Beta Sigma Phi. This year

PWS Awareness 2007 Celebrity Spokesman Clint Hurdle and his family (L- Christian, 2½, Karla, Clint, Madison, 5, who has PWS, and Ashley, Photo: Expressions by Sandy F



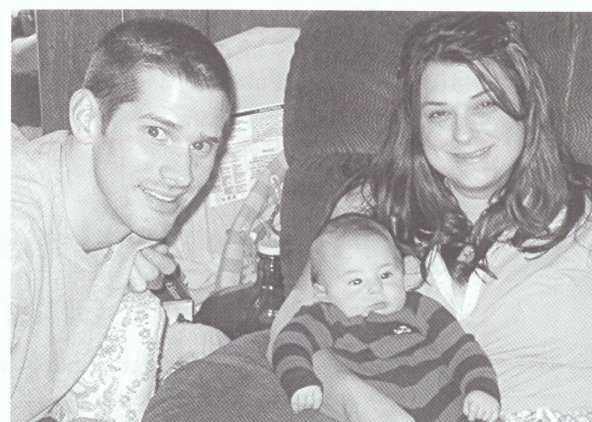
they held the "Little Miss Portsmouth Pageant" in honor of Corbin and to raise PWS awareness. The Garrett family also walked in the March of Dimes

WalkAmerica in honor of Corbin and in memory of Corbin's older brother, Luke.

Sarah wrote, "(The) dedication to Corbin brought much recognition to PWS! I was wondering if people would

even read [it], but throughout the pageant people asked us about Corbin (he was there) and I passed out the bracelets that I had, and brochures." The March of Dimes representative created an ad for the Garrett family, too. Sarah is so pumped from these efforts that she is hoping to plan a future PWS fundraiser with friends.

Among many activities, **Cindy Galyean** planned a **bowling fundraiser in honor of her niece with PWS, Alexis Stephens, 3, in North Carolina**. *The Herald* ran a two-page spread about the event and PWS: "Striking Up Awareness: 'Bowling for Alexis' to spread the word



Carl and Sarah Garrett with son Corbin

ing Hope

out PWS, raise funds for research.” It included a sidebar story, “Questions and answers about PWS,” and three pictures of adorable Alexis. Cindy wrote, “We were a little taken back when we saw what a great story Jamie had written in honor of Alexis.” Cindy already has plans for another awareness and fundraising event on September 1 at the Lee County Mud Motor Sports Complex! Cindy and Patty Hoover, Alexis’ mom, also gave a school board presentation about PWS which awarded a college course credit to those at the program. And in early June, they manned a PWS booth at their state’s largest health fair in Raleigh, the NBC17 Health & Fitness Festival, which drew about 35,000 people attended.

An article titled “Students Learn the Joy of Giving Back” appeared in *The Queens Courier* in New York about how students raised over \$500 to fulfill the wish of **Sonny Roberto, 5**, for toys through the **Make-A-Wish Foundation**. The article explained PWS and pictured Sonny with a big smile surrounded by the many children who supported him. “They cared because they got to know him through their teachers,” the article noted. Wrote mom, Nina, “This beautiful article (was) about children at a local school learning about PWS and wanting to make a difference in my son’s life.”

In **Ohio**, *The Lancaster Eagle-Gazette* ran a story, “Car show to raise awareness about eating disorder,” featuring **Julianna**

Romine, 2½. Parents Dawn and Tom coordinated the event to raise money for PWS awareness in their county and PWSA (USA) through Julianna’s Wish. In addition to the free car show were performances by local bands, a silent auction, and vendors who donated portions of their sales. Dawn wrote to the volunteers, “I would like to thank all of you for helping us no matter how little or how much that you did. You all helped! And there are no words to express our thanks!” Next year’s event is already scheduled for May 17.

Very Special Thanks To Our PWS Awareness Month Volunteer Committee!

Co-Chairs: **Carroll Beeson** (parent to Aspyr, 2, PWS, Nevada) and **Lisa Varndell** (parent to Georgie, 2, PWS, Maryland). **Committee:** **Cindy Galyean** (aunt to Alexis Stephens, 3, PWS, North Carolina); **Nina Roberto** (parent to Sonny, 5, PWS, New York); **Dawn Romine** (parent to Julianna, 2, PWS, Ohio); **Shelly Zurowski** (parent to Alexandria, 4, PWS, Nevada)



Girls Go To Bat For PWS

Cindy Galyean, aunt of Alexis Stephens, who has PWS, sent these fabulous orange furry hats to Nevada to help with PWS awareness. The 14 & under softball team (team color is orange this season!) includes the sibling of a child who has PWS. The girls wore the hats for a team picture and throughout the day at their softball tournament. When people would ask about the orange hats, the girls would educate them about PWS!

More Awareness Activities on page 10

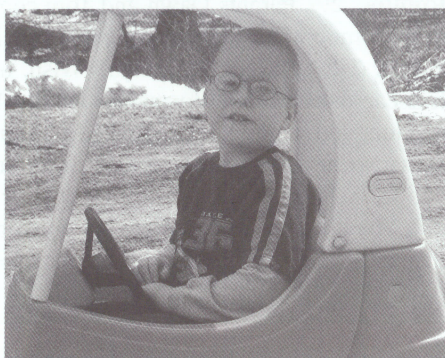
PWS Awareness Month Contest 2007

Searching For Awareness Ideas, We Found **WINNERS!**

Lisa Holbrook, Boothbay, Maine

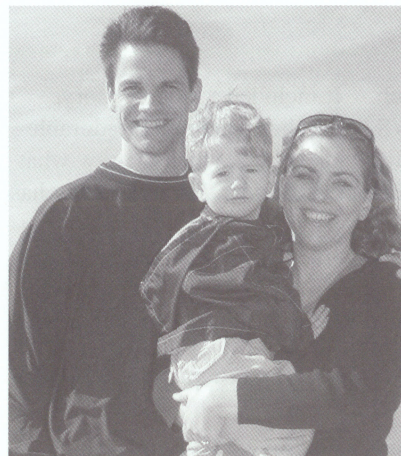
Mom to Cameron, 4, with PWS, Lisa suggests creating small pads of paper using the PWSA (USA) logo and contact information to spread awareness quickly. [Note: get permission from PWSA (USA) to use the logo.] She writes, "How many times do you write a note to send to school with your kids or give to a coworker or friend?... that is spreading awareness." She thinks pens are good, too.

Cameron makes friends everywhere he goes! In 2nd year preschool, his favorite things are trains, buses, monkeys and his car.



Jessica Howard, Falls Church, Virginia

Tom and Jessica with son Riden, 2. Riden's fascinated with trucks, reading books and playing chase.



Jessica suggests working with a retail chain to offer customers the opportunity to "round up" their bill

to the nearest dollar to donate to PWSA (USA). A grocery store chain in the Washington, D.C., area hopes to raise \$300,000 for another non-profit organization in this way.

Mike Larson, Appleton, Wisconsin

Mike, dad to Alex and Matt, both with PWS, suggests a Wine Tasting Benefit that creates awareness and incorporates fundraising. Invite friends, co-workers, neighbors, other professionals. "Make it clear it is a benefit event. There will be appetizers as well as wine. Doing this in conjunction with a local wine store will 1) have an expert to explain the wines and to supply the wine for sampling and perhaps donate some or all of the wine for tasting... and 2) the local wine store can have wines for purchase if guests like any of the wines tasted," he explains. "Sell a hand painted decorative glass for \$25 for use at the tasting.... literature on PWS can be given out or a display on PWS can explain how the funds from the benefit will be used. Our local wine store has an area set up for tastings and has accommodations for up to 70 people."

Pictured at right are Alex, 14, who's working on his Eagle Scout rank; and Matthew, 6, who began Tiger Cub Scouts this year. Both boys like to play baseball and fish at the family's cottage.



Sherie Bombardier, Webster, Massachusetts

Sherie, mom to Janelle, 11, with PWS, suggests bumper stickers or car magnets.

Janelle is in a public school inclusion class-room, the only child in the district currently with the syndrome.

Sherie spends each new school year

Janelle, right, with little sister Shannon



"educating the educators" about PWS. She writes, "People make the mistake of thinking that they are experts with Special Education students despite my warning that kids with PWS are unique. I guess that is why I have a special interest in increasing awareness of PWS. I am frustrated by viewing or hearing about 'sensationalized' stories about PWS on the television."

**Thanks to everyone who helped make
PWS Awareness Month 2007
a huge success.
We couldn't do it without YOU!**

Being The Louder Voice

By Sandra Gamble

Tingles would emerge from within the deep layers of my son's skin and his arms would itch. Dusty would tell me, "That bad voice is telling me to scratch again."

"Just ignore it," I would tell him, "you be the louder voice."

That inner voice can be a powerful guide, but when the voice is influenced by PWS it can tell us to do things we would never do otherwise. My view on my son's PWS and (in his case) atypical spectrum of characteristics has always been that, syndrome or not, we all have something to overcome at some point in life and medication is not always the answer. Sometimes, just being educated and having pure will is all it takes to deal with the problem at hand.

My son, now 13, has often and understandably complained to me over the years about what he has to deal with. My words of experience have always been the same. "True, you were dealt some tough problems. But you were also given strengths to deal with them. There is always a balance. It is your life; either you choose to use your strengths or you ignore them."

That was easier said than done when he was a mere toddler. Blood-stained sheets were not uncommon back then, nor was waking up to find him carefully picking layers of skin or gouging out old scabs with his fingernails. From his wrists to his elbows were streaks of scars and opened sores.

It took all my energy to keep them from getting infected and all my patience not to take it out on my son. At times I lost both battles. I took him to preschool with his arms wrapped in gauze and taped so he could not wedge his fingers between the folds. He hated the stares in the supermarket, and I longed for the winter months when long sleeves would help hide his bandaged arms.

I sought help from the family doctor that led me to a psychiatrist who was the father of a child with PWS. The doctor in turn gave Dusty Zoloft, but he soon became angry and then depressed. Then the doctor wanted to try Prozac, and despite my inner voice telling me it was a mistake, I gave my consent. That same year I took him to a PWS specialist, where I stressed my concern for using these kinds of medications but had no better alternative at the time. My son's dose was slowly increased, and though his picking seemed a bit better, it still remained an issue.

Eventually, his second grade teacher called, saying that he was becoming violent and throwing pencils and other objects from her desk around the classroom. He threatened his teacher and me and said he wanted to die. I called the psychiatrist and told him I had had enough — no more medications.

A colleague of the psychiatrist said she had an idea of what might help him. She told Dusty that whenever he felt like he wanted to pick he should count to 10. I thought,

you're kidding right? Apparently, my son was thinking the same thing because he looked over at me, raised an eyebrow and shook his head. I didn't have to tell her that was a dumb idea because Dusty, who is not a shy child, told her for me.

So I decided to practice what I preached and help him handle the problem. I had many conversations about what went on in his mind before he made the decision to shed blood. I broke down his decision-making process and kept asking him why. He kept blaming his brain. But I asked him, "You make the final decision, right? Then you are the one in

Now if this were a movie, the credits would be rolling by, but we realists know it is not that easy. His determination to succeed was greater than his need to pick, so over time the gauze came off and stayed off.

control." Slowly he began to understand that he could change what he did if he wanted to badly enough.

I worked with his teachers who gave him squishy toys to hold in class when they noticed him going for his arm. As a team we tried to retrain his mind with distractions and over time it helped. But it wasn't until he saw his school photo that he decided to help himself.

He stared at the photo of himself layered in gauze and began to cry. He looked at me with an angry expression but eyes full of determination. "It's not going to beat me, mom; I'm going to be the louder voice."

Now if this were a movie, the credits would be rolling by, but we realists know it is not that easy. Dusty struggled for a while, but his determination to succeed was greater than his need to pick, and so over time the gauze came off and stayed off.

These days he may occasionally pick at a hangnail or two, but he knows when he is feeling mischievous and comes to me for help. A teacher's aide in his class rubs lotion on his arm if he feels itchy and that helps. A few times a month he tells me, "Mom, I feel like I need to pick. Can you give me something to do (or hold, if he is watching TV)?"

He has come a long way, but the struggle still exists.... the end of the school year is always a big time. I think it has a lot to do with the change in routine and not having that nice structure to the day. He's older, though, and with age comes wisdom so he is getting much better overall. Now it is a pretty rare occurrence. He has girls that he wants to impress now — a big motivation and distraction.

In my opinion, all most of us need to do is to refocus on our strengths and be the louder voice.

Sandra and her son Dusty live in East Greenville, Pennsylvania.

[Editor's Note: In a future issue of The Gathered View, we'll revisit this important and troublesome topic, looking at other information and advice that has been gathered over the years.]

The Story of Annie's Gifts

My name is Dianne Arnoudse. I have Prader-Willi syndrome. I am proud to say I have my own small business!

I heard about the Micro-Enterprise program when I attended the original Income Links ME presentation in August of 2005. I was excited to learn that I might be able to start and operate my own small business.

Other programs didn't seem to fulfill my needs and I was often unable to succeed in the so-called normal work force. With my participation in the Hope Network Micro-Enterprise program and with the assistance of my Micro-Enterprise Facilitator, I was able to achieve my dream of having my own hand-crafted gifts business.

I named my business Annie's Gifts as a tribute to my dear Father and the nickname he gave to me. Annie's Gifts provides high quality sewn, embroidered, or knitted gifts and crafts at good prices. I sell and market my goods at many craft shows, through network-ing with others and with my eye-catching brochures.

I love being my own boss and I can fire, and re-hire, myself as much as I want! Of course I am in it to stay busy all the time. I feel satisfied and successful! I am no longer an unemployable woman with no prospects, but rather

a productive citizen contributing in a positive way to my community.

At my crafts shows I am in my element! I get fired up and come alive! I enjoy meeting customers and socializing with them at these many events. When I started selling at shows I used to get nervous and anxious. Not any more! I

Dianne Arnoudse, who has PWS, manages her own hand-crafted gifts business



believe it has built up self-esteem and placed me in the drivers seat of my life.

I am grateful to Income Links, Network 180, Hope Network and my ME Facilitator for the training and the support they have given to me as I have worked hard

to make my business what it is today.

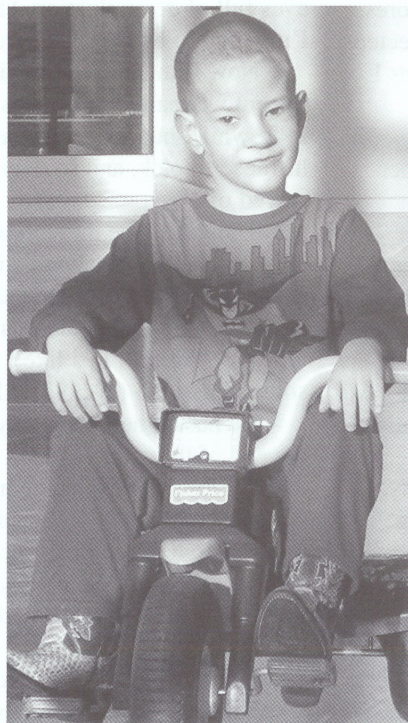
I am looking forward to my future. I do this all with hope, humor and a 2-liter of diet cola!

Dianne, 56, lives in Grand Rapids, Michigan..

Taking A Ride With Luke Ranieri

Luke, 4½, has PWS. This summer he's getting ready for kindergarten. He is going to take a whole summer of learning to read so he will be as ready as ready can be.

He and his family are also doing a lot of fun things, too, such as water skiing (a program designed for people with physical disabilities adapted to their abilities). "I want to thank you so much for all your help with my son Luke.... You help me help him reach his goals every day," writes his mother, Lisa Ranieri. "It's with your help that Luke gets to be there and do and I appreciate this more than words can say."



Luke lives in Hoover, Alabama with his mother and siblings William, age 2½, and Mallory Lynn, 15 months.

Keep PWSA (USA) Medical Alert Books Handy

I wanted to relate my experience about how helpful the Medical Alert books are. We had to take Grace to the ER because she fell [and] had a very bad goose egg on her head and was screaming.

I immediately told them about her PWS. I had the Medical Alert book in my glove box and brought it with me. They took it and read it from cover to cover. With a head injury one of the first signs they look for is vomiting. After reading in the Med Alert book that most [kids with] PWS do not vomit, they decided to do a CAT scan right away instead of just observing her for a few hours.

Everything turned out fine, but it was such a relief to be able to hand them all of the info they needed on PWS. It made the ER visit easier.

I would urge you to buy a few. I keep one in the glove box, one with her medical notebook, one on file with her pediatrician and one with my parents who watch her often. You really just never know when you might need it.

April Kercheville, of Royal Palm Beach, Florida, is mom to Paige, 5, Jenna, 3, and Grace, 18 mos. (PWS/UPD).

Lindsay Enjoys Life to the Fullest

Hi, my name is Lindsay Butler. I was 24 years old on July 1, 2007. I have Prader-Willi Syndrome. I am missing part of a chromosome, have low muscle tone, skin picking, and problems controlling my weight. I have to watch what I eat and exercise to keep the weight off.

I am currently living at home in New Jersey with both of my parents. I have an older sister named Stephanie, who doesn't have PWS. She is engaged and getting married in September. I have another sister, Meghan, who is 20, and she has PWS too. It is rare to have two of us with PWS. We share a room together. I also have a brother, Matthew, who is 12, and he doesn't have PWS.

I go to Faith Baptist Church and help out in the nursery and Junior Church. I help do babysitting for the Ladies Bible Study once a week. I am also involved with the Singles Ministry, and we go different places and do many activities.

I am active in Special Olympics in swimming. I swim the 50M freestyle, 50M backstroke, and am part of a relay team. I have won many medals for my swimming. I also play baseball with the Challenger League in my town. My dad and mom coach the team. We play against other teams for fun.

I have traveled with Guided Tours, which is a lot of fun. I recently went on my first cruise with them. We went to

Lindsay Butler with grandparents John and Mary Butler



Nassau, Bahamas, and to Disney World. It was really great to meet other people and see places. They said I did really great watching what I ate while I was on the cruise.

Lindsay continued on page 15

Craig Polhemus - continued from page 1

disseminating information and linking our members to others facing similar challenges. From my 20 years in public policy positions, I also expect PWSA (USA) and its chapters to take a more active role to influence federal and state policies about insurance coverage, Medicaid and many other issues.

My first public service job, immediately after college, was as an economist at the U.S. Bureau of Labor Statistics, where I wrote a monthly column on U.S. Supreme Court decisions and legal issues affecting health insurance, pensions and the workforce while I attended law school at night.

Upon graduation, I became legislative counsel to U.S. Senator Don Riegle of Michigan, drafting amendments and advising on votes affecting health, disability, tax, employment and public benefits issues. I next served as staff director and counsel of the U.S. Senate Subcommittee on Alcoholism and Drug Abuse.

In 1980, I moved back to Albany, New York, where I spent 15 years at the New York State Office for the Aging, beginning as general counsel and ending up as deputy director and CFO for a \$300 million, statewide services-delivery network for frail elderly. I directed a legal services program, managed major program growth as well as severe administrative cutbacks, and promoted a family-focused policy that included Caregiver Resource Centers, informal caregiver training, respite and local support for families caring for their impaired elderly relatives at home. I think much of this will be relevant to PWSA (USA), though you face special challenges in so many different areas.

In 1995, I was recruited to become executive director of a national 501(c)(3) organization, the American Accounting Association. The AAA published numerous newsletters and journals, held conferences and began new electronic communications policies, including a website with weekly highlights, optional e-mail newsletters and programs to help members face their most critical problems. Again, I think this will be useful experience as we tackle our ambitious goals for PWSA (USA).

I missed the special rewards of not-for-profit work since 2002, when I entered the private sector, working in financial services and international software sales. So when the search committee invited me for a final interview by the Board, I was thrilled to accept. The chance to work with a dedicated group of volunteers, professionals and families for so noble a cause was simply irresistible. I am ambitious for the organization, hoping we can enhance research, make early diagnosis universal, offer needed support and crisis counseling, influence public policy, and in many other ways serve families facing the stresses and struggles of dealing with PWS.

So how do I feel about change?

I am optimistic, because I know the power of a united community of dedicated parents, other relatives and friends, professionals and those who will share our goals when we reach, explain and inspire them to positive action for people with Prader-Willi syndrome. I am delighted to have the chance to help, and I thank you for welcoming me into the PWSA (USA) family.

We Remember...

Every person has something special to offer this world — and we, along with their families, want to share who they were and what they meant to the people who loved them.

Cohan Boyd



Cohan Alexander Boyd of Australia passed away in May, just days before his first birthday. He is survived by his mother Donna, father Alex and sister Tara.

Cohan died in the hospital after developing a high fever, his mother Donna reported. "The doctor since advised that Cohan had a very weak immune system and had developed a

bacterial blood infection which started shutting down his major organs," she noted. "Cohan then went unconscious and fell away, he suffered no pain as he went in his sleep.

"Even though the last year of my life has been hard, Cohan and all of you have taught me so very much, one was I found an inner fight that I never realised I had.... I want you all to know that I have appreciated every one of you 100% and I loved my son that much that I would have done anything not only to change the outcome of his diagnosis but the diagnosis of all of your children.

"Anyway this isn't goodbye, I just all wanted you to know what a special little boy I was blessed with for a short time and also that I have appreciated all your love and kindness from total strangers all over the world over the past 12 months.

"I will NEVER give up on supporting finding a cure for PWS.... Love and thoughts are and will always be with each and every parent of a child with PWS."

Kathryn Klindworth

Beloved daughter of Lois Klindworth, Kathy died of complications from pneumonia and PWS at age 41. "Childhood — actually, most of Kathy's life — was tumultuous," her mother wrote recently. There were many infections and hospitalizations, and several surgeries, but she never complained.

Kathy had a beautiful singing voice and loved to perform, her mother wrote. "She couldn't read, so she had to commit everything to memory. When she was in her 20s, and at her best mentally and physically, a choir director friend taught her many songs and hymns." Her mother has many of



Kathleen Hollrah



Kathy Hollrah died at age 31 of aspiration pneumonia complications. She was the beloved daughter of Regina Hollrah and the late Roland Hollrah of St. Charles, Missouri, sister of Carrie Gross and dear friend to housemates Terry Hopper and Jennifer Floretta, whom she regarded as part of her family.

Kathy was 2002 Volunteer of the Year at the St. Charles County YMCA, worked for the Boone Center Workshop for 5 years and was a volunteer reading to young children at a local daycare. She and her mother were a part of the "Deadly Hunger" video still used by PWSA that was made from a four-part series by a St. Louis news station 15 years ago.

Kathy was tenacious and determined. Her life focused on meeting goals and striving to reach beyond her abilities to do more, her mother noted in a loving tribute.

Regina and I go back a long way. She helped us fight to open the first supportive living homes. Recently she wrote: "I want you to know how much I appreciated your help in the beginning getting Kathy admitted to Children's for a diagnosis of PWS. I will always remember — you made it all happen for her." She added, "While Kathy died at 31, she might as well have been 60 or older — that's how full her life was."

The family has requested that memorials be made to PWSA (USA).

— *Janalee Heinemann*

those recordings, which are "among my most precious possessions," she added.

"Kathy never rode a bicycle, drove a car, got married, became a mom, shopped by herself or made many of her life's decisions," her mother wrote, but she "went to dances, sang before groups, took bus and plane trips, went camping, had a job and earned a paycheck." When Kathy moved into her first group home, her "own place," she called it, friends and family held an apartment shower for her, and she loved sharing her gifts with her new apartment mates.

Being the mother of a child with developmental disabilities was often uncomfortable, wrote her mother. "These were experiences I would not have freely chosen, but I would never have wanted to miss. Kathy truly was a gift of God and I am blessed to have been her mom."

Our PWSA (USA) Bereavement Program is coordinated by Norma and Bill Rupe. We offer free bereavement materials for our members, along with envelopes for memorial donations. For more information please contact PWSA (USA).



National Organization for Rare Disorders
2006 NATIONAL ORGANIZATION MEMBER



Thank You - continued from page 3

Several people have translated brochures, handouts, and other materials into Spanish: **Mercedes Rivera, Maria Knox, Veronica Baez, Kilma Carillo, Raquel Lopez, Mercedes Gonzalez, and Nina Roberto.**

Amy McDougall, Kate Buchanan, and Lisa Peters now are proofreaders for *The Gathered View*; Amy and Lisa have written articles for the GV.

Here are some examples of people who aren't recognized on the fund-raising page, but deserve thanks for their support of PWSA (USA) with their "treasure."

Our Administrative Specialist **Norma Rupe** donated \$1,000 for conference grants. The **Storr Family Foundation** (grandparents) donated \$10,000 again for research. **Samuel and Patrice Scheck** of Garden Grove, California, have given \$25 to \$40 twice a month since 2000. **Mary and Robert Hill** of Summit, New Jersey, just gave \$465 to sponsor 13 family memberships. The **PWS Homes of Oconomowoc**, Wisconsin, pays for 16 of their employees to be PWSA (USA) members at \$480 — thank you, **Jackie Mallow**, admissions/consultative services director there and also a PWSA (USA) board member.

We should thank also our board members, officers, Scientific Advisory and Clinical Advisory Boards, all of whom are volunteers, and the volunteers who put together the annual national conference in Dallas, Texas, and chapter presidents and officers, and all those who are doing fund-raising, and, and, and.... That list could go on and on and on. It underlines that every one of us is PWSA (USA), and PWSA (USA) is us.

Note: Lota Mitchell is also a volunteer, as co-editor of The Sibling Book and associate editor of The Gathered View.

Lindsay - continued from page 13

I have had a part time job at Lakeview Childcare Center for 5 years. It is a daycare facility near our home. I went to vocational school to learn about working in a daycare. During my time in school, I found this job. I took my resume and went in for an interview. The director hired me right then. I work in the infant room with babies until they can walk. I clean the kitchen, take out the trash, put cots out for naps, clean toys, and put them away. We take the children outside to play sometimes. I get to read to them, and play on the floor with them. I have to remember to wash my hands all day long. I like my job because the babies smile and like to play with me. I like my boss because she treats everyone equally.

At home, I also have chores to do. I set the table for dinner, feed the dog, and do laundry. I like working. I like to be active.

My grandma and grandpa live in Sarasota during the winter. Grandpa has volunteered at PWS National headquarters for 10 years. He does many jobs for them and I am proud of him for helping out. I am thankful that I have lots of people around me that love me and care for me.

Our thanks to John Butler, who volunteers 1-2 days a week during the months he and his wife spend in Sarasota.

Contributions in Memory Of

Anne Borges

Kristine Martineau

Sean Brown

Patti & Joe Fenster

Grovene Burton

John & Mary Ann Danese

Alice Cawley

Mary M. Cole

Kaye Pittman Connell

Maureen & Garry Fiske

Dr. Becky Cox

Elisabeth Dykens, Ph.D.

Charles Fritz

Tom & Sue Roberts

Claire Gallagher

Bob & Barbara Gallagher

Jeremy Girard

Joyce Mullane

Clyde Mays

Gayla Fitzpatrick

Lee Ann & Roger Souders

Mary McManus

B. Adamczak

Josephine Bellanti

John & Mary Ann Bellanti

Carol & Dave Goettlicher

David & Janet Miettlicki

Ruth O'Brien

Dean C. Noll

Mary Noll

Fred Pearsall

Lane Animal Hospital, Inc.

Chelsea State Bank

Doug & Sheila Barker

Norman & Gail Bauer

Donald & Leila Bauer

Mary & Bob Bauer

Henry & Molly Bazydlo

Marlene & Carl Bihlmeyer, Jr.

Marcyenne & Richard Bollinger

Walter & Sandra Brown

William & Susan Callaway

Betty Ellis

Jeffrey & Lois Emmert

Peter & Priscilla Flintoft

Charley & Barb Fredette

Charles & Carol Ghent

John & Madelyn Keusch

Fred Pearsall (cont'd)

Duane & Winona Landwehr

Leslie & Marsha Lentz

Barbara & Robert Merkel

George & Nancy Merkel

Nellie Robbins

Edward & Lois Schmidt

Don & Cheryl Schoenberg

John & Ramona Skittenhelm

Homer & Barbara St. John

Greg & Gail Stephens

Looman & Judith Stingo

Russell & Lora Tedder

Steven & Deborah Wireman

Adam Romagnoli

Janalee & Allen Heinemann

Tom Ryan

Alice Magnussen

Kate Updyke

Erin Schavey

RJ & Sylvia Julian

Donald Snowden

Lynn & Ed Plazewski

Pauline Strickland

Agnes & Thomas Hughes

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