



The *Gathered View*

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

**PWSA (USA) Awareness
Week is April 30-May 6**



Opal Fritchley, Canada

In this issue

3 CoQ10 update by our
Clinical Advisory Board

Participants wanted for
PWSA (USA)
Research Grant

4 Paying It Forward

5 Highlights from our
January Board of
Directors Meeting

6 Breast Enlargement in
Males with PWS

8 Latest on our 28th
National Conference

9 2006 Nominees to our
Board and Vote Proxy

11 View From the
Home Front

14 We Remember

What PWSA (USA) Has Done For You Lately

Supported Quality Research About PWS

- In 2005, PWSA (USA) approved **funding \$250,754 for research grants**. Our Scientific Advisory Board will review the next round of grant applications and our Grants Committee will make the 2006 awards.
- **PWSA (USA) grantee Dr. David Stevenson** from the University of Utah has been selected to make a **presentation at** a major medical meeting, **the 2006 Pediatric Academic Societies' Annual Meeting** in San Francisco, California, April 29-May 2. Dr. Steven's subject is "Deaths Due to Choking in Prader-Willi Syndrome," **which comes from the ongoing Study of Deaths Grant funded by PWSA (USA)**. His presentation will bring significant awareness of PWS.

Educated People Around the World

- The PWSA (USA) web site averages **2,908 visits a day from 155 countries**.
- Offered **parent mentoring and free educational materials for 129 families** of infants and toddlers in 2005.
- In 2005 **mailed 63,672 educational materials on PWS** plus **18,000 copies** of our **educational newsletter** and **1,400 free Medical Alert booklets**.

Helped Families in Crisis

- Provided **free support for 483 crises** situations in 2005.

Published Information from Qualified Professionals

- The new DVD "Food, Behavior and Beyond" by Drs. Gourash and Forster made an impact.

Praise from a professional —

I have found the DVD very useful. I use a portion of it for staff training and have built an entire behavior support plan around the general principles.... It is a "must have" for parents of children with PWS and anyone working with those with PWS. With the help of your organization and Ms. [Mary K.] Ziccardi's generous assist-ance, we seem to be creating our own little success story here. Thanks for all of your support.

*Garner Farrier, M.S., Associate
Psychologist, Corpus Christi State School*

One family's story —

I was at my wit's end with Tyler [age 10, who has PWS]. He was so sneaky and had a lot of behavior problems, plus the constant



Like Whit Park and Abbot Philson, PWSA (USA) keeps the Research target in sight: We're Hungry For A Cure!

asking for food. I purchased the DVD from the PWSA (USA) web site. We have tried to be consistent and prevention, prevention, prevention, but the older he gets the more complex the issues become. After watching the video, I took so much away from it. So many things became clear.

I made up a menu with the suggestions from the video, which gave him tons more food. He also love dressings & dips, so I put some low-calorie dressing in one small dip bowl, diet jelly for his bread in another bowl,

Tyler continued on page 11

Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Road, Suite 6 • Sarasota, Florida 34242
1-800-926-4797 9 a.m. to 7 p.m. Eastern Time
Local telephone: 941-312-0400 • Fax 941-312-0142
e-mail: national@pwsausa.org • web site: www.pwsausa.org

OFFICERS

President, **Carolyn Loker**, Kalamazoo, MI
Vice-President, **Ken Smith**, Pittsburgh, PA
Secretary, **Julie Doherty**, Tallahassee, FL
Treasurer, **Karen Goldberger**, Davenport, IA

STAFF & VOLUNTEERS

Janalee Heinemann, Executive Director
Diane Spencer, Support Coordinator
David Wyatt, Alterman Crisis Counselor
Kate Beaver, Crisis Counselor
Sharon Middleton, Business Manager
Ann Coyne, Financial Manager
Barbara McManus, Office Technology
Cindy Beles, Triage Advocate
Norma Rupe, Bereavement Coordinator
Carolyn Loker, Young Parent Mentoring
Vicki Knopf, Parent Mentoring II
Jodi O'Sullivan, Community Development

NEWSLETTER

Jane Phelan, Editor

Lota Mitchell, Associate Editor

The Gathered View (ISSN 1077-9965) is published bimonthly by the Prader-Willi Syndrome Association (USA) as a benefit of membership. Annual U.S. membership dues are: \$30 Individual; \$35 Family; \$40 Agencies/Professionals. Membership dues outside the United States are \$40 Individual, \$45 Family and \$50 Agencies/Professionals (US Funds). 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* should not be considered a substitute for individualized care by a licensed medical professional.

Adults with PWS Advisory Board

Shawn Cooper, Georgia
Brooke Fuller, Michigan
Conor Heybach, Illinois
Kate Kane, Maryland
Andy Maurer, South Carolina
Margaret Miller, Pennsylvania
Mike Nacht, Ohio
Abbott Philson, Maine



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

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: tiger06

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>

PWSA (USA) Board of Directors

| | |
|-----------------------------------------------|------------------------------------|
| <i>Co-chair</i> - Carol Hearn, Plymouth, MN | John Heybach, Chicago, IL |
| <i>Co-chair</i> - Ken Smith, Pittsburgh, PA | Stephen Leightman, Cherry Hill, NJ |
| Janice Agarwal, Zionsville, IN | Robert Lutz, Bryn Mawr, PA |
| William Capraro, Oak Brook, IL | Mark Ryan, Newhall, CA |
| Daniel Driscoll, Ph.D., M.D., Gainesville, FL | Mary K. Ziccardi, Cleveland, OH |
| Lisa Graziano, Redondo Beach, CA | |

Scientific Advisory Board

Chair - Merlin G. Butler, M.D., Ph.D., Children's Mercy Hospital, Kansas City, MO
Chair Emeritus - Vanja Holm, M.D., University of Washington, Seattle, WA
Suzanne B. Cassidy, M.D., U.C.I. Medical Center, Orange, CA
Joe Donnelly, Ed.D., University of Kansas, Lawrence, KS
Elisabeth M. Dykens, Ph.D., Vanderbilt University, Nashville, TN
David Ledbetter, Ph.D., Emory University School of Medicine, Atlanta, GA
Phillip D.K. Lee, M.D., Immunodiagnostic Systems Ltd., Boldon, UK
Harriette Mogul, M.D., M.P.H., New York Medical College, Valhalla, NY
Sue Myers, M.D., St. Louis University, St. Louis, MO
Robert Nicholls, D. Phil., Children's Hospital of Pittsburgh, Pittsburgh, PA
Ann Scheimann, M.D., Johns Hopkins University, Baltimore, MD
Rachel Wevrick, Ph.D., University of Alberta, Edmonton, Alberta, CN
Barbara Y. Whitman, Ph.D., St. Louis University, St. Louis, MO

Clinical Advisory Board

Chair - Daniel J. Driscoll, Ph.D., M.D., Univ. of Florida Health Science Center, Gainesville, FL
Moris Angulo, M.D., Winthrop University Hospital, Mineola, NY
Ivy Boyle, M.D., Bellefaire JCB, Cleveland, OH
Janice Forster, M.D., Pittsburgh Partnership, Pittsburgh, PA
Linda Gourash, M.D., Pittsburgh Partnership, Pittsburgh, PA
Louise Greenswag, R.N., Ph.D., Center for Disabilities and Development, University of Iowa, IA
Bryan Hainline, M.D., Ph.D., Riley Children's Hospital, Indiana University School of Medicine, IN
Jeanne Hanchett, M.D., The Children's Institute, Pittsburgh, PA
Jim Loker, M.D., Bronson Methodist Hospital, Kalamazoo, MI
Barbara Y. Whitman, Ph.D., St. Louis University, MO
Liaison Members:
Suzanne Cassidy, M.D., Scientific Advisory Board, U.C.I. Medical Center, Orange, CA
Janalee Heinemann, M.S.W., Executive Director, PWSA (USA), Sarasota, FL
Carolyn Loker, President, PWSA (USA)
Ken Smith, The Children's Institute, Pittsburgh, PA

Deadlines to submit items for upcoming issues of *The Gathered View*
Jan/Feb: Dec 1; Mar/Apr: Feb 1; May/Jun: Apr 1;
Jul/Aug: Jun 1; Sep/Oct: Aug 1; Nov/Dec: Oct 1

Ask the Professionals

Coenzyme Q10 (CoQ10) & Prader-Willi Syndrome

The PWSA (USA) Clinical Advisory Board offers the following up-to-date information concerning the use of Coenzyme Q10.

Coenzyme Q10 (or “CoQ10”) is a naturally occurring vitamin-like substance in the body. CoQ10 is essential in energy production in all living cells, especially in the muscle. If deficient in CoQ10, an individual may feel less energetic, have reduced muscle function and have a decreased metabolic rate. CoQ10 also acts as an antioxidant in the blood and all cell membranes.

- Individuals with PWS may have decreased levels of CoQ10. A blood test can determine if an individual’s CoQ10 level in the blood is lower than normal. A muscle biopsy would be the best way to determine cellular CoQ10 level, but at this point we do not feel muscle biopsies are warranted.

- When CoQ10 levels are low, supplementing with CoQ10 may help increase energy level, muscle function and metabolism. Some parents also see an increase in activity and attentiveness after supplementing their PWS child with CoQ10. However, while some parents feel that their child demonstrates improvements with CoQ10, others feel that it has no effect. Also, parents should be clear that CoQ10 supplementation is not a substitute for growth hormone treatment which has clearly been shown to have multiple benefits for individuals with PWS.

- The information we have on the effectiveness of CoQ10 is all “anecdotal” data (i.e., from parents commenting on their personal experiences with their child). There have not been any controlled scientific research studies about the

effects of CoQ10 in individuals with PWS. At this time, there are no KNOWN adverse side effects of taking CoQ10 if taken in an appropriate dose.

- The recommended starting supplemental dose of CoQ10 varies according to different groups. It is anywhere from 1-30 mg per kg per day for infants, and *no more than 180–200 mg* per day for older children. We have typically found that 60–100 mg per day in the older children and adults is sufficient to raise the blood level to the normal range in those individuals who were initially found to have low levels. If families are contemplating supplementation with CoQ10, we would recommend testing a blood level before and after starting CoQ10.

- Dissolved CoQ10 in softgel capsules (which contain vitamin E and other lipids to help the body absorb the CoQ10) are better absorbed than dry powder CoQ10 tablets or capsules. The CoQ10 softgels typically come in 60- or 100-mg doses. Therefore, 1-3 capsules per day will need to be taken by older children and adults.

CoQ10 can be purchased over-the-counter at most pharmacies OR can be purchased directly through various medical suppliers. There is also a liquid preparation available for children who cannot swallow pills. PWSA (USA) can provide direct contact information for those families having difficulty finding a source for the liquid preparation.

Revised Feb. 16, 2006 by the CAB for The Gathered View

PWSA (USA) Research Grant Participants Needed

The Use of Psychotropic Medications in Prader-Willi Syndrome

By Elizabeth Roof and Elisabeth Dykens, Vanderbilt University, Tennessee

Why is there such variability in how people with the same syndrome respond to the same medication? A new way to answer this question comes from the field of pharmacogenetics — or how genetic differences in drug metabolism lead to different responses to medication.

This pilot study examines how people with PWS break down and use various medications often prescribed to treat behavior problems. Many people with PWS have a predictable set of symptoms such as irritability, behavioral rigidity and compulsions. When these problems intensify or do not respond to behavioral interventions, physicians often prescribe a medication from a group called SSRIs (e.g., Prozac, Paxil). These medications are initially metabolized in our bodies by the liver, primarily by a family of liver enzymes collectively called CYP450. People may be characterized as poor, extensive or ultra-rapid metabolizers of medications based on how quickly and fully their individual CYP450 enzymes metabolize various medications.

We are identifying whether people with PWS show unusual CYP450 profiles, and whether they differ from others in how they metabolize psychotropic medicines. We will also assess if there are differences in CYP450 enzymes across such variables as genetic subtypes of PWS, or gender.

We are still recruiting 175 people with PWS aged 8 through adult and will relate their CYP450 enzyme status (which we can identify from saliva samples) to their psychotropic treatment response based on questionnaires filled out by primary caregivers. To date we have saliva samples for approximately 70 participants. Our preliminary findings are promising: they show unusual alterations in at least one of the enzymes in the CYP450 family. We plan to give individual feedback about the CYP450 to all families who participate.

We will also generate a summary report about medication use, dosages and responses for the PWS sample as a whole. As the first study to apply pharmacogenetic approaches to those with developmental disabilities, the study will help physicians and families avoid the behavioral and medical risks of failed drug trials and of adverse events, as well as optimize treatment outcomes. For more information call Elizabeth Roof, Research Coordinator at 615-343-3330, or e-mail to Elizabeth.roof@vanderbilt.edu



Paying It Forward

Janalee Heinemann

Remember the touching movie, *Pay It Forward*, starring a little boy, Haley Joel Osment? In it, he takes on a teacher's assignment to change the world by starting a movement to do something very special for three people, then asking each person in return not to pay it back – but pay it forward — and do something special for three other people. These generous acts could then multiply to truly change the world. In reflecting on the movie, I realized it is not unlike the PWSA (USA) "movement." Our association has been built on the philosophy of paying it forward.

Twenty-five years ago after going to our first national conference and getting the education and personal support to turn our lives around and get our son Matt's weight under control, my husband Al and I decided to "pay it forward" and start the Missouri state association so others could get the support we received. Hundreds of other parents, grandparents, relatives and friends have also joined our movement over the years.

Some learn the concept of paying it forward long before they have a child born with the syndrome, so it comes naturally. An example is our board chair Carol Hearn. Her younger sister Kay Halverson, who was gifted in many ways, had a severe stroke at age 17. She remained without any voluntary movement for the next 34 years, except for being able to relay messages by a (sometimes unreliable) squeeze of the hand. She could think and feel, but could not move or speak. Kay just died in January, but during those 34 years until her death, more than a thousand volunteers helped Carol's family with Kay's 24 hour-a-day care. Thus, when Carol's son David was born with PWS, although she is a busy attorney and mom, Carol naturally chose to "pay it forward" and do what she could do to help other families dealing with Prader-Willi syndrome.

For others, the concept of paying it forward comes after they get beyond the initial grief of the diagnosis and realize that they are fortunate that their child (or grandchild or niece or nephew) was born now, and not years ago before PWSA (USA) was founded. As one young mother recently wrote, "I just want to thank you and the staff not only for helping us attend the conference, but for all of the wonderful work you all have done to help families like ours not only cope with PWS but have HOPE for our children's future." It is thanks to several of these families that our organization ended up in the "black" for 2005. Some braved doing a fundraiser for the first time, some made personal donations, and some did unique solicitations to obtain contributions from family and friends. All did it from their hearts.

One of the most touching donations we received was from a mom in New York whom we have helped out over the years through her child's crises, with a conference grant, etc. She said that PWSA (USA) had done so much for her that she would sometimes lie awake at night wondering how she could help us to help others. This mother is divorced, has relapsed with cancer, and has little money. But she decided that she could donate two diamond rings for our silent auction at conference: one was her engagement ring and one was given to her by her father. I let her know how touched I was, but I thought she should sell them to get money for herself. But she could not be dissuaded. She had found a way to "pay it forward."

Last night on the car radio, I accidentally tuned to a talk radio program. A caller was telling of her dismay because at a fancy dinner party she was giving, someone had the audacity (in her mind) to ask if she had any white wine after she had spent hours planning the dinner and carefully selecting the wine to be served. I felt sorry for her, but not for the reason she wanted sympathy. I felt sorry for her because her life was so caught up in frivolous details and devoid of real issues that she will probably never get to know the beautiful people in our lives who have learned what is really important: the smile of a baby, the hug of a child, the first steps of a child who had to work extra hard to make that milestone, the joy of an older child after losing 50 pounds, the understanding and warmth of a true friend, or the gift of a parent you may never meet who paid it forward.

Our association has been built on the philosophy of paying it forward.

Members Only on the PWSA Website

Be sure you get into the habit of visiting the **Members Only** section of www.pwsausa.org, which will become increasingly important.

Many new items are now in this area, and more will continue to be added, including research abstracts from our scientific meetings, downloadable handouts, a Care Notebook, and more.

You must be a member of PWSA (USA) to enter that section of the web site. Password and Usernames are in *The Gathered View* on page 2 and are changed periodically.





Highlights From Our January Board Meeting

Carol Hearn

The PWSA (USA) Board of Directors, together with the officers and various staff and committee members, met for 2½ days of board and committee meetings in late January 2006. Although the work of this dedicated board continues year-round, the two in-person board meetings held each year (in January and another following conference in the summer) provide a vital opportunity for everybody involved to exchange ideas and organize efforts for the coming months. Highlights of this January’s meetings include the following:

- **Strategic Planning** – We’re nearing the end of our current 5-year strategic plan, and have many exciting challenges ahead. A strategic planning committee of the board is organizing the effort to set our course for the next 5 years.

- **Finance** – By keeping expenses in line and intensifying fundraising efforts, PWSA (USA) managed in 2005 to turn a projected \$20,000 deficit into a surplus of approximately \$28,000 (based on preliminary, unaudited numbers). That is great news, but we cannot rest on our laurels – we have much to accomplish in the coming year and beyond, and virtually all of it will require money.

- **Fund Development** – Under the fine leadership of Community Development Director Jodi O’Sullivan, and with the help of individual volunteers too numerous to mention, our grassroots efforts are producing encouraging results for both fundraising and awareness. We need to continue those efforts in order to sustain, in the short term, our current funding levels for research, crisis intervention, mentoring and the other programs we currently provide. For the long term, however, we must redouble our efforts to finance our endowment fund and attract substantial donations from larger donors such as foundations, corporations and government sources.

- **Research**

The board confirmed funding (which had been tentatively approved via e-mail vote in late 2005) for two important new research projects:

Gastrointestinal Motility (Drs. Kish and Scheimann): This 2-year grant (totaling \$104,758) is designed to study the impact of dietary content upon gastrointestinal motility in PWS. This research will further our understanding of the signals that make a person with PWS feel hungry or full and may alert parents and medical providers to a dietary component to gastroparesis, and potentially, to gastric perforation.

Necdin (Dr. Reyes, et al.): This 2-year grant (totaling \$98,496) is designed to study how necdin (one of the proteins made by chromosome 15 genes) is expressed in brain cells and if expression relates to appetite. Researchers suspect a necdin deficiency may cause the insatiable hunger associated with PWS.

To ensure that we continue to receive high-caliber grant proposals like these, we must commit ourselves to a regular cycle of awarding grants. To support that commitment, we must intensify our efforts to raise funds for research.

- **Crisis Intervention** – PWSA (USA)’s crisis intervention program provides help to families experiencing a variety

This is an exciting time.... We are already doing many things right, but we could be doing so much more if only we had the resources.

of PWS-related crises, including medical, legal and behavioral issues. The program includes an educational consulting team that has had great success in turning difficult school situations into supportive environments. The board is creating a legal resources team to help families access appropriate resources when confronted with legal crises related to PWS. Janalee Heinemann, assisted by Carolyn Loker, handles most medical crises with the help of countless physicians, scientists and other medical personnel who donate hundreds of hours of services each year. David Wyatt, our crisis intervention counselor, has been trying to retire for several years. We may actually let him do it this year, as we have hired one new part-time crisis intervention counselor and hope to hire another in mid-2006.

- **Parent Mentoring** – This program of 65 parent mentors in the U.S. and Canada continues to serve a crucial role in providing vital information and a warm welcome to families of newly-diagnosed individuals. Approximately 129 families received mentoring services during 2005.

- **Publications** – This committee handles a variety of tasks, including creating and publishing *The Gathered View*, managing the website, updating current PWSA publications, and developing or acquiring new publications, educational materials and other items that may be of help to PWSA (USA) members. This year, the new DVD “Food, Behavior and Beyond” (featuring presentations by Drs. Gourash and Forster) has been particularly well-received

Board Highlights continued on page 10

Breast Enlargement in PWS Males

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

Part 1 of 2 parts

Breast enlargement is one of the most common medical complaints in adolescent and adult men with PWS. However, there is a surprising lack of data concerning the occurrence, diagnosis and treatment of this condition.

One reason for the lack of PWS-specific information may be that breast enlargement is also extremely common in non-PWS males. As far as we know, there are no major medical differences between breast enlargement in PWS versus non-PWS males. However, there may be special considerations in PWS as described below.

Normal Breast Development

Both males and females are born with the same breast tissue, identified externally by paired nipples, each surrounded by a dark circular area called the areola. Undeveloped milk glands and ducts, called mammary glands, are located under each nipple/areola. Both male and female newborn infants can have a mild protrusion of these areas, sometimes with a small amount of milk production, due to maternal/fetal hormone changes prior to birth. However, during usual infancy and childhood, there is no additional hormone stimulation and the breasts do not protrude significantly from the chest wall.

During normal puberty, females produce increasing amounts of estrogens from the ovaries. These cause the mammary gland tissue to enlarge, causing protrusion of the breasts from the chest wall. In addition, the nipples and areolae enlarge, become darker, and protrude from the rest of the breast tissue. Although female breast development primarily occurs during adolescence, additional enlargement may occur during pregnancy and breastfeeding.

In males, the main puberty hormone is testosterone, produced by the testes. Testosterone levels increase rapidly during puberty to extremely high levels, causing the physical signs of male puberty, including genital enlargement and facial hair growth. Testosterone itself also prevents breast enlargement. However, some of the testosterone can be chemically converted into estrogens in the body.

Although the estrogen levels are still much lower than in females, it is thought that the proportion of estrogen to testosterone activity during puberty can increase and cause the mammary glands to enlarge. This causes some degree of breast enlargement in more than 60% of adolescent boys.

Breast enlargement due to stimulation of mammary gland growth is called gynecomastia. The word "gynecomastia" refers only to breast enlargement in males, not females. "Adolescent gynecomastia" refers to gynecomastia in adolescent males.

Unlike breast development in adolescent females, most cases of gynecomastia are not accompanied by significant enlargement of the nipples or areolae. In addition, the protrusion is usually limited to a small, firm coin-like disk

under each nipple or small, barely noticeable mounds. Occasionally, a small amount of clear or milky discharge from the nipple occurs. Although most cases of gynecomastia involve both breasts, a significant number of adolescent boys can have unilateral (one-sided) involvement.

After puberty, the hormone balance shifts and adolescent gynecomastia usually disappears, although enlargement of the mammary glands may persist in some cases. It is estimated that 30% of more of normal adult men have gynecomastia, either as a continuation from adolescent life or as a new occurrence.

Other General Considerations

Gynecomastia has been associated with:

- Use of several types of medications and dietary supplements.
- Medical conditions, such as hypo or hyperthyroidism.
- Estrogen-producing tumors, including testicular tumors. These cases are very uncommon and are not reported to be increased in PWS.
- Chromosome abnormalities involving the X-chromosome, such as Klinefelter Syndrome.

Therefore, although the vast majority of cases of adolescent gynecomastia are due to normal physiology, a routine physician evaluation is not unreasonable, particularly if the female-like changes occur in the nipples and areolae or if the breast protrusion is progressive to the point where a training bra might be considered for a girl.

The presence of persistent mammary gland tissue can lead to an increased risk for breast cancer. However, male breast cancer is uncommon in the general population despite the common nature of gynecomastia, and no cases have been reported in PWS. Nonetheless, individuals with gynecomastia should have regular breast examinations.

Male breast enlargement is not always due to mammary gland enlargement. The breasts also contain a significant amount of fatty tissue. In obese individuals, this fatty tissue usually increases along with the rest of the body fat, causing the breasts to protrude. It is often said that adolescent gynecomastia occurs more commonly in obese boys. However, this impression is probably due primarily to the presence of excessive fatty tissue. This condition is sometimes called pseudogynecomastia or lipomastia. In addition, fat tissue can cause increased conversion of testosterone to estrogen, resulting in accentuation of true adolescent mammary gland enlargement, or gynecomastia.

Dr. Lee serves on the PWSA (USA) Scientific Advisory Board. Part 2 of this article will appear in the May-June issue of The Gathered View.

PWSA (USA) Seeks Member As Parent Delegate to IPWSO

The International Prader-Willi Syndrome Organization (IPWSO) provides education, advocacy, and support services to member associations who work to improve the quality of life for people with PWS and their families around the world.

PWSA's Parent Delegate is a representative of PWSA (USA) and the liaison between PWSA and IPWSO. The delegate attends the IPWSO International Conference held every three years. The delegate makes international materials available to PWSA members, including the IPWSO website; organizes and facilitates the international component at PWSA (USA)'s conference; prepares a summary of international activities for PWSA (USA)'s Board of Directors and for publication, and in person twice a year at PWSA (USA)'s Board meetings; and assists the IPWSO president as needed.

The term is from 2006 through 2009. Some travel costs to attend the international conference and the PWSA (USA) board meetings are reimbursed. There will likely be some

non-reimbursable costs; additional information about these costs is available upon request.

The parent delegate must be a member of PWSA (USA), have an understanding of different cultural realities, possess good people skills, be interested in raising funds that support international programs, have sufficient time and energy, be proficient with the Internet and e-mail, and have a heart for PWS families in emerging countries.

If you have the desire and possess the qualities necessary, contact the Leadership Development Committee and provide a brief description of your qualifications no later than June 30, 2006. Please mail your information to: PWSA (USA), Attention: Leadership Development Committee Chair, 5700 Midnight Pass Road, Suite 6, Sarasota, FL 34242; or e-mail to: pwsausa@pwsausa.org

If you have questions, please contact Leadership Development Committee Chair Lisa Graziano by e-mail to tlcgraz@aol.com

PWSA (USA) Announces Two New E-mail Support Programs

We are proud to announce the initiation of two more e-mail support programs: The **PWS Extreme** e-mail support program (David Wyatt/ Kate Beaver co-moderators) is for parents/caregivers of individuals with PWS over age 6 who have extreme issues with weight and behavior. Participants in this e-Support Group share information and parenting strategies and discuss issues. Topics are extreme situations that will not be posted in the other support groups. A PWSA (USA) crisis counselor will monitor this list.

The **Military Families** e-mail support program (Carol Craig/Carolyn Loker co-moderators) is for parents/caregivers/extended family members of individuals with PWS. Participants in this e-Support Group share information and parenting strategies with an emphasis on issues which are unique to those who serve or have served in the active or reserve military and national guard. The Military Group provides an opportunity to connect people who wish to share their experience and expertise gained while raising an Exceptional Family Member (EFM) diagnosed with PWS.

These new PWS e-mail support and information programs are added to our existing groups, which are:

- Families of children with PWS birth to 5 (Lisa Graziano/Carolyn Loker co-moderators)
- Families of children with PWS 6 to 12 (Tanya Selden/Sybil Cohen co-moderators)
- Families of teenagers with PWS (Jeannie Dickinson/Joan Mitchell co-moderators)
- Siblings of individuals with PWS (Ali Gilbert)
- Individuals with PWS (Jeannie Dickinson/Barb McManus co-moderators)

The programs are sponsored by Prader-Willi Syndrome Association (USA) to provide information and support to parents and providers of people with PWS. Contact the support groups at <http://www.pwsausa.org/support/>

A big thanks to the volunteer moderators of these crucial e-mail support programs. Please consider joining us!

— Carolyn Loker, President

The Role of CoQ10, Growth Hormone and PWS

In the last Gathered View, I promised to give a report on a study in Taiwan on CoQ10 and Growth Hormone (GH) therapy. Dr Jia-Woei Hou, from the Medical Genetics and Metabolism Department at Chang Gung Memorial Hospital, reported on a study using three groups of subjects with PWS for a total of 30: 1) eight on CoQ10 alone; 2) 12 on CoQ10 and GH; and 3) a control group of 10 with PWS on neither CoQ10 or GH. The PWS patients on GH alone were not included in this study, but will be in follow up studies.

They performed anthropometric measurements, xray absorptiometry, strength and agility tests. The results indicated that the children did significantly better when they were on a combination of both GH and CoQ10. It was said to normalize lipid levels, improve body composition and strength and

agility measures. They also stated it improved the feeding behavior. Dr. Hou concluded that the combination of both CoQ10 and GHT gives more benefits than CoQ10 alone.

General response to this study from our researchers was whether any of the clinical benefits are due to CoQ10 alone. Additional questions include: are there any age related differences (infants, children, etc.), length of treatment and dosage. The clinical changes reported are also seen following GH therapy, so no real conclusions can be made. A study is needed that will assess the potential added benefit due to CoQ10 in group 2 by using a comparison group that received GH therapy but did not receive CoQ10.

— Janalee Heinemann, Executive Director

Making your summer travel plans? Don't forget to include the 28th Annual PWSA (USA) Conference!

The 28th Annual National PWSA (USA) conference, combined with the 16th Annual Prader Willi Alliance of New York, Inc. conference, is fast-approaching and we're expecting a great turnout! The conference will be held on Grand Island, New York at the Holiday Inn of Grand Island. Grand Island is just minutes away from Niagara Falls, one of the Seven Wonders of the World.

The Conference includes a Scientific, Provider and Chapter President/Affiliate Day on July 19 followed by the General Conference on July 20 and 21. The annual Gala Banquet will be held on Thursday evening, July 20.

We will be offering a structured childcare/YIP program for children ages 9 and under. We have lots of FUN activities planned for the YIP program this year and featuring appearances by:

- ♣ The Buffalo Mobile Zoo "Sensory Safari"
- ♣ "Beats Me", a drum and percussion ensemble, and
- ♣ Kids on the Block, a disability awareness program that educates children about people with disabilities and acceptance of differences through the use of puppet theater



Wild About You!

There will **not** be childcare or structured programming for children 10 and older. All children are welcome to attend with parental supervision.

The General Conference includes several sessions of interest to all attendees, as well as breakout session tracks organized into topics specifically geared toward the issues and achievements of Adult, Youth (school age), and Children from age 0–5. Look to the next issue of *The Gathered View* for more details on the track topics.

Conference registration will be available April 1 on the PWSA (USA) website. PWSA (USA) has secured a block of rooms at the Holiday Inn of Grand Island at the discounted rate of \$99 a night for up to four in a room. Hotel reservations can be made at any time through Globetrotter Travel by phone at 1-800-322-7032 (press 2), e-mail pwsa-usa@globetrottermgmt.com, or online at www.globetrottermgmt.com/pwsa-usa.

Don't miss an opportunity to meet new friends, renew friendships and learn about new research!

Make Your Voice Heard During PWS Awareness Week

By Jodi O'Sullivan, Director of Community Development

PWS Awareness Week is the first week in May every year. This year, the dates are April 29 – May 6, 2006. PWS Awareness Week is a public education initiative begun by PWSA (USA) to increase awareness of PWS and save lives. This is a unique opportunity for all of us from coast to coast to stand together with one voice during a specified time of the year to be heard. YOU can be a voice for PWS. YOU can make a difference, and we need YOUR help!

There are many ways you can have an impact. A talented and earnest group of volunteers on the PWSA (USA) Awareness Committee has developed an entire section on the

PWSA (USA) web site with ideas, tools and useful information for promoting awareness. This includes ways to participate by educational efforts, fundraising, advocacy and media attention. Please visit <http://www.pwsausa.org/AwarenessWeek/index.htm> to see all that is available for you to do in your own community. Be sure to share your success with our office!

Special thanks and praise go to the Awareness Committee members who worked so hard to bring this to you: Julie Ayotte, Carroll Beeson, Debbie Lange, Carolyn Loker, Barb McManus, Nina Roberto and Lisa Vardell.

2006 Nominees to the PWSA (USA) Board

There are four openings on the Board of Directors. The nominees are:

Christine Bevacqua, PT — Tinton Falls, New Jersey



Christine is the aunt of 3-year-old Jack Bevacqua, who has PWS. A licensed physical therapist, she has been practicing for more than 11 years. After Jack was born and diagnosed at one month of life, Christine wanted to learn more about PWS and find a way to spread awareness. In 2004 and again in 2005 she ran a benefit dinner dance to raise money for PWSA (USA) and the New Jersey chapter. Planning the first dance in only six weeks and with the help of family and friends, she was able to raise \$12,000. In 2005 she raised \$15,100 and began a yearly tradition. She is very passionate about this cause and believes she will be a useful addition to the Board. She has a daughter Kayla, 6, and a son Justin, 2.

Linda Gourash, M.D. — Pittsburgh, Pennsylvania



Dr. Linda Gourash is a developmental pediatrician. She received her medical degree from Georgetown University, completed her pediatric training at the Children's Hospital of Pittsburgh in 1980, and served on the full-time faculty of the University of Pittsburgh School of Medicine until 1991, primarily working with developmentally handicapped children hospitalized with severe

behavior disorders. As admitting physician and treatment team leader of the PWS program of the Children's Institute of Pittsburgh, Dr. Gourash worked for more than 5 years almost exclusively with children and adults with PWS and related disorders. Currently she serves on the PWSA (USA) Clinical Advisory Board and is a conference speaker for PWSA and IPWSO. In 2005 she and Dr. Janice Forster formed the Pittsburgh Partnership, Specialists in PWS, an independent consulting firm. She also has a private practice in developmental pediatrics in Pittsburgh, where she lives with her husband, Bill, a nurse practitioner, and her two teenage daughters, Theresa and Cassie, regulars in the volunteer corps for YIP and YAP.

Jackie Stoner Mallow — Oconomowoc, Wisconsin



Jackie has worked since 1985 in a residential setting with children and adults who have been dually diagnosed. She has worked exclusively with individuals with PWS since 1996, providing educational training, support, guidance and consultation nationwide. She is Admissions/Consultative Services Director for Prader-Willi Homes of

Oconomowoc, and on the board of directors for PWSA-Wisconsin since 1997. For more than 9 years she has been a presenter at the national and international level for PWSA (USA) and IPWSO.

Born and raised in the Oconomowoc, Wisconsin area she enjoys the outdoors, a good book, and her family and friends. Her husband Bruce and children Nick and Samantha are the loves of her life, and her profession is her passion.

James G. Kane — Baltimore, Maryland



Jim is a real estate professional with a B.S. from the University of Notre Dame and an M.B.A. from Babson College. A former PWSA (USA) officer and board member, in recent years Jim has focused on research as chair of the PWS Research Advocacy Committee. This group brings researchers from various specialties to focus on collaborating on aspects of PWS such as

hyperphagia, and then locating funding sources. He and his wife Kit, a former special education teacher, have been married for 29 years and have two children, Kate, 24, who has PWS, and Molly, 20, a sophomore at Boston College. Jim writes, "Since my daughter Kate was diagnosed at the age of 5, Kit and I have involved ourselves in many of the activities of PWSA (USA). The incredible demand for knowledge about PWS and the never-waning need for assistance for families affected by PWS have sparked my renewed interest to get back involved in a significant way."

Mark Ryan — Newhall, California



Mark Ryan is President and owner of Ryan Sales International (RSI), a worldwide aerospace marketing company. Mark spent 4 years in the Air Force, earning his pilot license in 1975. He and his wife Linda (board member of California PWCF) reside in Southern California and have three children: Crystal (26), Danielle (23) and Trevor (16), who was diagnosed with PWS at age 5. Mark has been on the board for the past 3

years and chair of the calendar committee. Mark wants to bring new ideas to the board from a business entrepreneurial view and marketing perspective. His hobbies include motorcycle riding, boating, computers and golf.

Mary K. Ziccardi — Cleveland, Ohio



Mary K. is an Administrator in the northern region of REM Ohio, Inc., a residential agency supporting more than 200 people with mental retardation and developmental disabilities, where she has been employed for 18 years. Mary K. has worked with both children and adults with PWS for more than 12 years. She created and developed the very first PWS-specific residential home

in Ohio in 1994, followed by four additional programs, to date. Mary K. has provided PWS-based training and consulting to dozens of individuals, families, residential and vocational providers and schools. She authored the residential chapter of *The Management of Prader-Willi Syndrome*, 3rd edition. She is completing her second term on PWSA (USA)'s Board of Directors, where she has chaired the Crisis Committee, and has been instrumental in many years of Provider's Day Conference and YAAP activities. Mary K also is the coordinator of our Adults with PWS Advisory Board.

Prader-Willi Syndrome Association (USA) 2006 Official Proxy
Must be received at PWSA (USA) office by June 30, 2006

I hereby appoint _____ of _____
(print name of your designated proxy voter) (state of residence)

vote as my proxy at the PWSA (USA) Annual Membership Meeting in Grand Island, New York July 2006.

Instructions to proxy voter:

Please cast my vote as you see fit **OR**

I am a member in good standing of PWSA (USA)

Name _____
(please print)

Signature _____

Date _____

Please cast my vote for the Board of Directors candidates I have marked below:
(VOTE FOR 4)

- Christine Bevacqua
- Linda Gourash
- Jim Kane
- Jacki Stoner Mallow
- Mark Ryan
- Mary K. Ziccardi

(This space provided for a write-in candidate)

ALL VOTERS Must Check One of the following:

- I have an Individual Membership
- We have a Family Membership, which has two votes, and are both voting for the same candidates.
- We have a Family Membership, which has two votes, and are each voting for separate candidates. (If you are voting separately, please use separate copies of this proxy.)

Board Highlights - continued from page 5

by both parents and residential care providers, as have the workout video and a number of materials for educators.

- **Web site** – Thanks to our tireless webmaster, Barb McManus, the PWSA (USA) web site is improving every day, delivering vital information about PWS to thousands of users throughout the world. Although the majority of users are from the U.S., Canada and the U.K, the site was accessed by users in 155 countries during 2005.

- **PWSA Logo**

From time to time over the years, various people have suggested that a new logo might help PWSA (USA) communicate more effectively to the general public what Prader-Willi syndrome is, what the organization's mission is and/or why help is needed so urgently. At our July 2005 board meeting, there was a proposal that PWSA (USA) should consider adopting a new logo.

The board created a logo team to look into the proposal and help the board assess whether it should adopt a new logo, and, if so, how it should go about the process and what the options might be. In December and January, the logo team developed and sent out via e-mail a short survey designed to elicit information about PWSA (USA)'s current logo and various features of a proposed logo. The team is

now developing some additional logo concepts and will be seeking input on those in the near future. Updates on the logo process will be posted on the Members Only section of the web site.

Based on the comments we received in connection with the survey and via various email message boards, it is clear that PWSA (USA) members are passionate about this organization and want to make sure that whatever branding is used accurately reflects their view of the organization's mission. Obviously, the ultimate decision cannot be made by a committee of thousands, but we are doing our best to devise a decision-making process that allows for meaningful input by all stakeholders without being so cumbersome that it grinds to a halt. We trust that the end result will be a logo that we can all identify with and that will position our organization well to meet the many challenges that lie ahead.

This is an exciting time for PWSA (USA). We are already doing many things right, but there is so much more we could be doing if only we had the manpower and financial resources. If every PWSA (USA) member recommitted himself or herself to the task of strengthening and supporting this organization, just imagine what we could accomplish together.

View From the Home Front

An Unexpected Holiday Gift

For the six short years that I have had the joy of having Ciera with me, I have learned and anticipated so much about the extreme hunger issues. For the past several years I have waited for these issues to hit our household.

When we got the diagnosis at six weeks old, I read everything that I possibly could. As I am sure that most parents do, I cried for days, but the one thing that stuck in mind was “Behavior Modification.” We have tried to teach Ciera, as every parent does, that you do not take food without asking, and for some reason it has gotten through to Ciera.

Anyway, here is my little bit of unexpected holiday cheer. One Sunday afternoon, my son, my mom and I were sitting out on the front porch and Ciera had been inside the house playing. She poked her head out the door and said, “Mama, mere please.” So I get up and go in, and she said, “No no mad please.” Of course I’m thinking the worst.



Ciera, 6, who has PWS

My mom and my son had been making a holiday cake and candies, and they were all left sitting out to cool. I asked Ciera to show me what she’d done, and she took me over to the water cooler where she was getting water in a cup, missed the cup and made a mess on the floor. So I showed her where the towels were and how to clean it up, and everything was fine.

Well then she noticed the cake. So there she was, standing right in front of the two cooling layers asking me what it was. I told her that Momo and Bubba were making a holiday cake and they were not done with it yet and it needed to cool and be decorated. I told her not to touch it and I was going back outside.

So I left her standing there and walked out. I stayed gone about 10 minutes. I walked back in and she wasn’t standing there. She was sitting on the kitchen floor playing with her etch-a-sketch and she had not touched the cake or any of the other candies.

I was so proud of her, but I didn’t want to draw that much attention to what she hadn’t done. So I just quietly walked back outside and enjoyed her moment of accomplishment.

Becky B. Lee, Ozona, Texas

Looking For The PWS ‘Thing’

I’m a new member to PWSA but not new to Prader-Willi syndrome. This is my son Aubrey and my daughter Zoe. We were blessed with him when he was 4.5 months old and were his foster parents for 5 years and in January of last year we were given guardianship. He has blessed our whole family beyond words. He and his sister are the best of friends. We were so proud of him this summer as he almost instantly learned how to swim; it amazed us. He’s a fish.

Over the years we have tried to describe what PWS is to him and he has a bit of an idea. He knows that is the reason he is always hungry and the reason he gets growth hormone shots. When we received our first newsletter I told him it was some very special mail as it talked about PWS and had pictures of others with PWS.

Well he went looking for “Prader-willi syndrome” in the envelope and in the newsletter sort of like it was a “thing” that would unlock the mystery to him. In the end when he discovered there wasn’t a “thing” in there he went hysterical. Which is just like him, as he has the best sense of humor of anyone I’ve ever met. Hopefully this will help him throughout his life.

Aubrey, who has PWS, with his sister Zoe



Chris and Joy Capps live in Hendersonville, North Carolina

Tyler - continued from page 1

and a tiny amount of BBQ sauce in another. He could put his jelly on his bread and dressing on the salad, it was a huge hit. He finished dinner last. He looked at that menu all weekend and I was asked only one time about food. I also made an incentive “special treat” list. This was so exciting to him to actually pick what-ever HE wanted. I put several very little- or low-calorie treats on the list. He carried that list with him. We told him he could have one treat at lunch if the morning was a success, and one at bedtime. He stopped

obsessing about other things and focused on his menu and list. He told me that he was so proud of himself because he did not steal anything because he had to be good for that treat and had thought about it all day. I also told him all day how proud I was, he even asked to help us work! We had the most wonderful weekend with him. His father and I are soooooo proud of him. We did a few other things suggested in the video. I wish I had this DVD 2 years ago. PWSA, thank you so much.

Julie Jarvis, Atascadero, California

View From the Home Front

Campers Enjoy the Great Outdoors

PWSA of Ohio sponsored its fourth weekend camp in October 2005 with 47 registered campers from six states. The participants fished, climbed trees, enjoyed trick-or-treat, danced and made many friends. All campers received a T-shirt due to the generosity of Geri Merida, a long-time PWSA of Ohio member, who donated the cost.

The camp has allowed opportunities for the social and emotional growth of those attending. They are able to participate in activities available to most others that they are typically denied in a safe environment without losing any of the essence of the experience. Their physical, social and emotional well-being are nurtured in a positively-reinforced atmosphere that encourages them to experience all that they *can do* without their being aware of the constant restrictions with which they live on a daily basis.

Our camps allow not only the campers to rejuvenate their sense of individuality as well as encourage their growth socially, but also allow the care-givers and parents to experience a break from the 24/7 commitment of care-taking. So, all parties are more refreshed to continue and appreciate each other. The success of this camp has also encouraged Recreation Unlimited to offer a five-day summer camp for children and adults with PWS. This is something that they were originally very reluctant to do. The best measure of camp success is the smiles of the campers and the enthusiasm they express when talking about camp. — Sandy Giusti

Sandy lives in Columbus, Ohio with her husband Tom. Her daughter Angela, 36, has PWS.



Heather Bishop, who has PWS, loved her T-shirt from the PWSA of Ohio camp



PWSA (USA) Gains a Lot From Lose-A-Thon

Let's hear a cheer for our current Lose-A-Thon participants! They have accepted the challenge to lose weight for a healthy life, to be role models for their loved ones who have PWS, and to support PWSA (USA). They are an inspiration to all of us.

Check back in the coming months on our Web site to see their progress. If someone you know is participating, be sure to offer him/her words of encouragement and praise — and make a financial donation to PWSA (USA) to really keep him/her motivated. (You can make it online!) At the end of February the Lose-A-Thon participants had already brought in more than \$6,500 toward the \$30,000 goal.

We applaud their efforts and stand behind each of them through this endeavor. Keep it up!

It's not too late if you are still thinking of participating. Just go to our web site www.pwsausa.org to register, use the sample letter and donation form already created for you, and get started. If you do not have access to the computer or the Internet, call our office at 800-926-4797 for these items. The program wraps up in May 2006, so take the plunge now and go for it. Best of luck!

4th Annual Texas Prader-Willi Day Camp

Texas Children's Hospital sponsored 44 guests at the Camp For All facilities in Brenham, Texas. Fourteen children with PWS and their siblings and parents attended. The weather was perfect for the outdoor activities which included horseback riding, canoeing, fishing, archery, and hands-on fun with the creepy crawlers and the farm barn. Attendees included at the camp included PWSA (USA) Scientific Advisory Board member Ann Scheimann, M.D.; Betsy Haylsett, R.N. and Norma Terrazas, R.D. Plans are already under way for an even bigger and better 2006 camp for all eligible patients at Texas Children's Hospital Prader-Willi Clinic.

The Chuckle Corner

The Totally No Fat Lifestyle

In my son's own special way, understanding the special diet he is on, one morning while I was getting him ready for school, after putting on his deodorant, Evan said, "Smell good..." Then he picked up the deodorant, turned it around and said, "Momma, see NO FAT!"



Bonnie Thomas, Hudson, New York

Fundraising From the Home Front

Our Families Share Their Awareness and Fundraising Projects

They've done it again! The **2nd Annual Jack Martin Bevacqua Dinner Dance** netted more than \$13,500 in Jack's name with most funds apportioned to support PWSA (USA)-funded research. Another \$1,600 went to the New Jersey chapter. Jack, now 3, has PWS.

Christine Bevacqua was inspired to start this fundraiser for her nephew last year when she and Christie (Jack's mom) attended a fundraiser for CF held at a local hall. "I am a sucker for a challenge and decided I could do that," said Christine.

She said the highlight both years was realizing how much was raised. "The best part of planning is always learning how many people and businesses are so very generous and willing to help," she reported. She asked a talented artist friend to donate a piece of his work for the silent auction, and it brought in the highest single donation. In planning for next year (yes, this will be an annual event!) Christine said she'll start earlier asking for auction and raffle donations to raise more money and generate more publicity.

Christine reports that Jack is in a special needs pre-school this year having the time of his life.

Nobody made a greater mistake than he who did nothing because he could do only a little. ~ Edmund Burke



Jack Bevacqua, who has PWS, was the little man of the hour at the fundraiser organized by his Aunt Christine

Our Marathon Runners

Marc Shapiro raised more than \$1,300 when he ran the **Chicago Marathon in honor of his brother Daniel**, 23,

who has PWS. "My brother Daniel has accomplished so much despite his syndrome and I wanted to bring attention to an organization that often is not recognized," he said. Besides actually finishing the marathon, Marc said he was "touched that the community surrounding Daniel is so strong and supportive. I received so many notes of encouragement, both about running the race and raising money, from my friends and family."

Marc advised it pays to stay organized: "keep a list of everyone who's donated and make sure to send thank you cards."

Ryan O'Sullivan netted more than \$7,000

in the **Columbus, Ohio Marathon**. It was his third marathon for PWSA (USA) **in honor of Josilyn Faith Levine**, 3, who has PWS. "I would do anything to help my niece Josilyn," said Ryan. "At about mile 24. . .my legs started cramping up and almost felt like stopping. I just thought about the struggles that Josilyn goes through on a daily basis. . . I just kept hearing Josi yelling 'Rah-Rah' (her name for me) echoing through my mind, cheering me on. It kept me going."



Marc Shapiro running the Chicago Marathon in honor of his brother Daniel, who has PWS

Karen Hamlin-Fochs, parent to **Ryan**, 3 with PWS, is a buyer for Ross Dress for Less. The company had accumulated quite a few framed art and mirror samples for their stores, and sold them below cost to their employees in the New York buying office. They donated the profits, \$1,600, to PWSA (USA). In the post to employees about the Employee Sample Sale, a link to the PWSA (USA) web site was included. "I don't know how many people checked it out, but if it raised some awareness then I'm glad," Karen said.

Tupperware saleswoman Yolanda Ornelas made an additional \$168.62 donation on behalf of **Danielle Culley**, who held an on-line Tupperware party. Yolanda continues to donate 100% of profits from on-line sales to PWSA (USA). To learn more, call Yolanda at 347-203-4546 or visit www.my.tupperware.com/yornelas

Bobbi Martello and her team of volunteers held the **1st Annual Madison Hurdle Softball Tournament** in Florida in November, raising over \$3,500 for PWSA (USA). "When my niece was diagnosed with PWS it really made me start to think, and instead of asking 'Why?' I thought of asking, 'How can we help?'" she said. "It was my father-in-law's idea to do the softball tournament and my husband and I took it and ran," she said. One of Bobbi's tips for planning a fundraiser is to "make sure all your volunteers are in 110%. It makes for such a positive atmosphere." Bobbi and her husband plan to make this an annual event.

Dawn Atwood, parent to 2-year-old **Aimee**, who has PWS, generated PWSA (USA) donations totaling over \$2,000 when she sold two Stephen King books on eBay and chose to donate 100% of the proceeds to PWSA (USA). One book was a collector's item — a signed, limited edition of *The Girl Who Loved Tom Gordon*. Thanks, Dawn, for being the first person to donate to PWSA (USA) via eBay!

Visit <http://givingworks.ebay.com/sell/> to learn how you can do this, too, through eBay's non-profit arm, Giving Works powered by MissionFish. Prader-Willi Syndrome Association (USA) is a registered MissionFish charity, and our number is 6661. — **Jodi O'Sullivan and Jane Phelan**

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.



Colleen M. Doherty

Colleen's family wishes to share these memories: Colleen was our baby sister for 39 years; she was on the bottom of the totem pole and yet the first to leave us. Besides having Prader-Willi, she was like any other little sister. She just wanted to be with her family, sit around and talk, and have a cup of coffee.

The holidays were very special for her because she knew she was coming home to visit her family and catch up on all the changes in our lives since her last visit. There are too many special moments to list, and there's not enough paper in the world to put them on.

Colleen lived at Gatehouse where she met and fell in love with a young man; his name is Toby. She would talk about her first kiss, what he gave her for Christmas, her birthday and Valentine's Day. She was a typical girl, giddy over a guy, smiles from ear to ear when she talked of him. They went everywhere together, group parties and dances. Oh, how she loved to dance, especially the slow ones, so they could hold each other tight.

Colleen was a big part of our lives and always will be. Her purpose in life was to make people happy; that's all she wanted. She loved life more than you could imagine; now she's in her new home where pain and sorrow don't exist. She passed her legacy on to all of us: to make the world aware of of this dreadfully terrible sickness. Her first wish in life was for someone to find a cure for Prader-Willi.

Colleen left us on December 27, 2005 at 3:30 p.m. At 3:31 p.m., a baby was born. Colleen left through one door and opened another door for a new life. As she walked on the streets of gold, she realized that she was free of Prader-Willi.



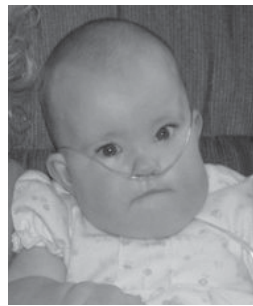
Joanna Katsikas

Nicholas and Thalia Katsikas of Athens, Greece sent the following letter recently:

We would like to donate \$1,000 to Prader Willi Syndrome Association in the memory of our loving daughter Joanna, 20, who passed away in December 2003.

We wish that this donation will assist the people involved scientifically and emotionally with Prader Willi Syndrome Association that helped us a lot during Joanna's life.

We would also like to congratulate your Association for the effort and wish you all happy New Year full of happiness and joy.



Erin Schavey

Erin's parents Sue and Harlan share the following: Erin came into this world so early and so small, weighing only 1lb. 14 oz. This small baby, who weighed so little and had weak muscles, had the strongest spirit of anyone we have ever known. She forever changed not only our lives, but so many others as

well. Erin had a complicated medical history and died December 8, 2005 due to problems with her electrolytes (a high potassium level) at the age of 14 months.

After Erin spent 16 weeks in the NICU, we were excited with the small gains she made each day. She seemed so fragile, but her inner strength and resilience brought out a strength in us that we didn't even know we had.

Erin knew how to be happy with the simple pleasures in life. By watching Erin, we learned how to slow down some and enjoy them with her. All Erin's sister Lauren had to do was enter the room and lay beside her in the crib or on the floor and Erin would turn toward her and her eyes would light up. Erin taught Lauren a level of love and compassion that some people never achieve as adults.

Even though her life was so short, she overcame so much and fulfilled monumental tasks. Not only did she help us teach doctors, nurses, and other medical staff about PWS, she helped us meet people that we would never have had the opportunity to have known. We feel that she was also sent here to help change a major health organization's policy on specialized medications. We had been battling our insurance company regarding their policies on the use of growth hormones. Only hours prior to Erin's death, we learned that the company had decided to look at children with special medical issues based on the individual's condition rather than a generic criteria list. Erin made them realize that one size does not fit all. We feel that it was truly her task here on Earth to change the policy so that it would make it easier for other children in her situation to be able to receive the type of care and treatment they needed and deserved.

Who ever thought that such a small child could have such a huge impact, not only on those who knew her, but on so many others that we may never know. We miss Erin each day but her love will forever remain in our hearts.

Editor's Note: Families got to know little Erin and her family via the 0-5 email group. Forty families donated in her memory. Their letter to her family included the following:

"At this time of your loss we want to reach out to tell you we grieve with you, cry with you, and most of all pray with you....We cannot do anything to take away the pain...the only thing we knew to do was to donate money to PWSA (USA) so that because of [Erin], others may be helped."

Contributions In Memory Of

| | | | |
|-----------------------------------------------|---------------------------------------------------------|---------------------------------------------------------------------|---------------------------------------------------------|
| Andrew Rico Laura Searcy | Eileen Eggers Prader-Willi Association of MN | Erin Margaret Schavey (cont'd) Jeffrey & Michelle Wallace | Karen Ward (cont'd) Carrie Kuehne |
| Ardith Woolley John & Wendy Van Elk | Erin Margaret Schavey Stephanie & Marc Arnold | Andrea & Bob Warren | John & Alma Martin |
| Bob Olson John & Marilyn Bintz | Tim & Dawn Atwood | Evelyn Krebsbach Duane & Mary Jane Breitling | Laura Masse |
| Byron Cutler Larry Stuart | Paul & Robin Barrett | Joanne Geist | Peter & Linda Miller |
| Colleen Doherty Paul & Carla Alfani | Carroll Beeson | Barbara Herrick | Craig & Louzetta Naylor |
| Richard & Noreen Allen | Theresa & James Bender | Joan Krebsbach | Esther Nelson |
| Stacy Broutman | Christie & Kevin Bevacqua | David Laske | James & Vicki Nelson |
| Kelly Butterfield | Jennifer & Brad Bolander | Ardell & Audrey Olson | Arthur & Cheryl Owens |
| Dawn & Richard Castillo | Jennifer & Chad Buchanan | Marion Potter | William & Mary Kay Payne |
| Dennis & Joann Doherty | Paul & Doreen Busfield | Delores Scheel | Fred & Barbara Pilgrim |
| Thomas & Cynthia Heimbuch | Scott & Bethany Cheney | George Stewart Calvin & Kathy Cassady | Richard & Katheryn Prosser |
| Chelsea Hoff | Matt & Jennifer Dean | Glenn Davidson Don Oliver & Diane Spencer | Dianna Rio |
| Cynthia Malone | Beverly & James Folmer | Janet Wallace Moore Roy & Selma Veal | Jan & Trina Stout |
| Michael & Linda Mayer | Louie & Cathy Gorena | Jeremy Girard Peter & Gayle Girard | Joe Trauerman |
| Lizabeth Moser-Sadzewicz | Lisa & TJ Graziano | Chris Hegman & Thomas Schellenberg | Selmer & Mary Ellen Uhr |
| Ronald & Mary Ann Sellers | Lori & Michael Guthrie | Daniel & Taylor Wood | ITT Industries |
| Ray Zimmerman | Lisa & Mike Holbrook | Colleen Girard | Kay Halverson (Carol Hearn's sister) |
| Mr. & Mrs. R. Miller | Thomas & Jessica Howard | Joanna Katsikas Nicholas & Thalia Katsikas | Frank & Jane Duffy |
| Mr. & Mrs. P. Ponczuk | Renea Johnson | Kalman Yosef Plotke Rick & Carol Plotke | Christopher Mahler |
| Cindy Malone / Nancy Smith | Angela & Christopher Krambeer | Karen Ward Carl & Evelyn Anderson, Jr. | George & Ruth Paulson |
| Gloria Keane | Walter & Jennifer Kryzak | Jack & Betty Austin | William & Kim Rothermel, Jr. |
| Leroy Darragh | Kay Larson-Blair | Cynthia Barlow | Leigh E. Campbell Juanita Campbell |
| Chuck & Nancy Kirby | Eric Macks & Suzette LaVigne | Donna Branham | Linda Beltran John & Marilyn Bintz |
| Sue & Steve Malone | Kevin & Hope Liddiard | Shirley Bristow | Larry & Carolyn Thompson |
| David Rodriguez Family | Jennifer & Dennis Lindsey | Annette Chastain | Maurine S. Tomlinson Hugh & Susan Dykens, Jr. |
| Patricia Strauradakas | Jim & Carolyn Loker | Richard & Vicki Duke | Robert Wolfe Debbie & Michael Fabio |
| Mr. & Mrs. M. Stahl & Sons | Cathryn & John Maczko | Jo & Sidney Dunn | Stewart MacCarter Timothy Wentworth |
| Pris & Mike Koza | Aris & Gibson McMahon | Mary Virginia Fearnside | Andrew Carol Morrison |
| Paul & Nancy Hoff | Kristen & Timothy O'Connor | James Fuller & Mary Frary | Dustin Glover Arlene & Angie Padilla |
| Michael Hoff & Family | Sara & Todd Oetjens | Paula Green | Edmund M. Funai Maryann Lucchese |
| Mr. & Mrs. M. Shipp | Joyce & Brian Opp | J. Dale & Charlotte Hewett | Kenneth Ayotte Ronald & Eileen Ayotte |
| Gerald Hanyzewski | Lisa & Jeffrey Peters | Henry & Helen Hirschman | Ricky Henderson Marjorie Henderson |
| Richard Carrillo | Jeff & Katrina Sanders | Donald Holmes, P.A. | |
| Mr. & Mrs. D. Mull | Pamela & Emanuel Santos | | |
| Wolf Lake Rod & Gun Club | Sue & Harlan Schavey | | |
| GI Nurses / MOB 3 rd Floor | Diane & Robert Seeley | | |
| Dr. Jack Gordon Karen Lynn Whyte | Denise & Jeffrey Servais | | |
| | Clinton & Mary Speiser | | |
| | Neal & Angela Spradlin | | |
| | Lisa & Sid Thornton | | |
| | Will & Deanna Troxel | | |

We Remember - *continued from page 14*

Garold M. Butler

Dr. Merlin G. Butler's father, Garold M. Butler, died in January, 2006 at the age of 84. Dr. Butler said his father was "a very strong and stoic person. He survived D-day at Utah Beach in Normandy, France and several months as a POW in Germany, but chronic renal failure and worsening health was too much."

Condolences to Dr. Butler should be mailed to the following address: Merlin G. Butler, M.D., Ph.D., F.F.A.C.M.G., Section of Medical Genetics and Molecular Medicine, University of Missouri-Kansas City School of Medicine, Children's Mercy Hospitals and Clinics, 2401 Gillham Rd. Kansas City, MO. 64108.

Helene Bletterman

Dr. Suzanne Cassidy writes that her mother, Helene Bletterman, passed away peacefully on Sunday, January 29, 2006. She was 87.

Any donations in memory of Dr. Cassidy's mother could go to support the interdepartmental macromolecular laboratory that her late father funded at Hebrew University in Jerusalem. Donations should be made to American Friends of Hebrew University (AFHU) and indicate in the "for" line that it is for the Helen and Maurice Bletterman Laboratory. Mail to: AFHU, 9911 West Pico Boulevard, Suite 1520, Los Angeles, CA 90035.

PWSA(USA) gratefully acknowledges the printing and mailing of our newsletter is made possible by a generous grant from the Gerald & Dorothy R Friedman New York Foundation

Contributions

Thank you for Contributions through January 2006

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

Major Benefactors (\$500 and more)

Anthony Abbott
David & Janice Agarwal
Richard & Jolayne Alger
George & Shannon Baughman
Delfin J. Beltran, M.D.
Agnes Bennett
Mark & Joy Bitzer
William & Tina Capraro, Jr.
Patricia O'Keefe Carey
Robert & Barbara Christenson
Mitchell & Francine Cohen
Johanna Costello
Mary Culver
Peter & Kathy Devlin
John & Joan Dickinson
Eric & Jennifer Dorre
Steve & Gwen Dudrow
Irene Eisenbise
PWSA of Ohio
Kate Freeman
James E & Suzanne L Fuller
Joan & Jim Gardner
Peter & Gayle Girard
Mark Greenberg & Robin Fleischmann
Kathleen & Jonathan Grussing
Daniel & Nancy Gulling
Jay & Susan Henoch
John & Sue Heybach
Thomas & Jessica Howard
Louise & Clinton Hurdle
Clint & Karla Hurdle
Jennifer Jennings-Glover
Nicholas & Thalia Katsikas
David & Linda Kaugher
Jill Keenom
John & Bonnie Kraft
Mercedes Lat
Robert & Wauneta Lehman
Richard Lewis
Judy Livny
Charles Lockwood, MD
Robert Lorenzini
Jean & Douglas Lowe
Steven & Susan Lundh
Robert & Debra Lutz
Richard & Patricia Lutz
Sue & Paul Mahler
Robert Mann
Barbara & Michael McManus
Lota & Dave Mitchell
Michael & Donna Pappagallo
Daniel & Sara Jane Pate
John & Carolyn Rodman
Sue & Harlan Schavey

Robin & Ellery Sedgwick
Curt & Marion Shacklett
William Stege
Peter & Alice Tenbeau
Michelle & Tommy Torbert
Cheryl Travelstead
James Trentacosta
James D & Wava Van Becelaere
Lois & Steve Willett
Francis H. Williams
Howard & Genevieve Willis
Paul & Amy Wissmann
Allan & Frannie Zalesky
Brookline Lodge of Elks No. 886
Great Lakes Capital Fund
Long Island Super Sport Team
Sam P. Alterman Family Foundation
Akin & Porter Produce, Inc.
Wal-Mart Foundation
Fieldstone Foundation
United Way
PWSA of Iowa
Trimont Engineering Co.
Golf Etc. College Station
PWSA of Michigan

In Honor Of

Ashley Willis
Howard & Genevieve Willis
Evan Victor Macks
Lisa L. Zeiter
Finley Harris Woods
Elsa Woods
Hannah Viroslav
Robert Mann
Jake Pawulak
Andrew & Faye Jeannett
Lilli Griffith
Carol Morrison
Alison Smith
Matthew Probasco
Ben Leightman
Nancy Belotto
Brayden Crosson
Nancy & Joe Crosson
Caleb Ennis
Diane Keeler
Stanley & Phyllis Tetlow
Eldridge & Delores Waugh
Camden Marshburn
Hal & Robin Thorne Thorne
Dr. & Mrs. Marvin Stephens
Karen & Rick Barrett
Dylan Krambeer
Angela & Christopher Krambeer

In Honor Of

Elizabeth Frawley's Nieces & Nephews
Elizabeth Wright Frawley
Emily Weingart
Irene Eisenbise
William & Terri McCauley
Roger & Kay Rankin
Ruth Wolfe
Florence Larsen/ Vince Connelly
Thomas Cahill, Ph.D., PC
Barbara A. Crays
Ronald & Katherine James
Elizabeth Lassar
Jeremy & Wendy Margolis
Royal & Mary Lynn Martin
Hugh McCombs
Scott Mendeloff
Ira & Andrea Raphaelson
David Reidy
Susan Lichtenstein & John Rokacz
Ellyn Stone
Ron & Catherine Taisch
Alice & Herbert Zarov
Ginny McMahon
Daniel & Sara Jane Pate
Grandma & Grandpa McCabe
Jason McCabe
Hudson Slocum
Kolby Slocum
Isabel Lutz
Andrew Braun
Jack Bevacqua
Paul & Diane Anderson
Jacob G. Walker
Tracy Walker
Jim Kane Family
Donese Brittingham
Jodi O'Sullivan
Kelly & Kevin Delongchamp
Joslyn Ecker
Howard & Charlotte Arthur, Jr.
Justin Vitro
Billy & Shannon Vitro
Lauren Pfeiffer
Angel & Max Dawson
Lota Mitchell
Steve & Gwen Dudrow
George & Margaret Smith
Louise Greenswag
Norma Brecher
Lucy Lutrell
Golf Etc. College Station
Madison Hurdle
Miles For Miracles
Malea Bonk
Donna Griffo-Johnson
Marcia Dunn
Steve & Gwen Dudrow
Mr. & Mrs. Don Warren
Karen & Rick Barrett
Mr. & Mrs. John Hruska & Sam Paul & Betty Kramer
Mrs. W.J. Hruska & Family
Paul & Betty Kramer
Oliver Barrett
Prudy & Tom Nelson
Riley Donovan
Ginny Ryan
Ruaidhri Gillespie
Jennifer Murray
Sara Oliver Henry
Ozmer Henry Jr.
Sonny Roberto
Sharon Cohen
Stephen & Becky Olson
Sleepy Hollow Hills, L.L.C.
Talon Garofalo
Sharon Pohn
The Black Family
Melissa Anderson
The Dracup and Fuller Wedding
Drac & Patricia Mitchell
PWSA Office Staff
Jodi & Ryan O'Sullivan
Thomas Riden Howard, Jr.
Thomas & Jessica Howard
Troy Toby
Kentuckiana Yacht Sales
William Stege
Kate Freeman
Zachary Greenburg
Patricia O'Keefe Carey
John Ross Comes
John & Susan Comes
Christopher & Lisa Comes
John Trimble
Joyce Hogan
Lincoln Cash Saltzman
Debbie & David Levy
Mr. & Mrs. Robert Gallicchio
Christie & Kevin Bevacqua
Mr. & Mrs. William Jallick
Christie & Kevin Bevacqua
Mr. and Mrs. Tom Barber
Karen & Rick Barrett
Richard Bonk Birthday
Donna & Keith Johnson
Sheridan York
John & Joan Stoner
Janalee Heinemann/PWSA (USA)
Jay & Susan Henoch
Due to space limits, listed are donations In Memory Of, In Honor Of and Major Benefactors. All donations are listed in the Annual Report. A report on our 2006 Angel Fund campaign and donors will be published in the May-June edition of *The Gathered View*.

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

