



# The *Gathered View*

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

## *PWSA (USA) Conference 2005*

### **Celebrating 'A Brand New Me'**

*By Janalee Heinemann, Executive Director*

In the final, all-consuming days of conference planning, I was reminded of a comment from Jim Kane who has been with PWSA (USA) through many conferences: "I do not know of any other charitable organization in the WORLD that puts on a more complex conference!"

Working with the volunteer committee chairs of the various programs — Scientific, Providers, Adults, School age, 0-5, Chapter Presidents Day, YIP (Youth & infant program) and YAP (Youth & adult program) — plus volunteers coordinating the registration, volunteers, medical staffing, audio visual, special events, food & snacks, rooming, international, grant families, conference office, printed materials, publications, logo items, decorations, exhibitors, etc. — I am convinced of the truth of this statement.

The most complex has always been YAP. Having 145 youth and adults with PWS and their siblings attend — many with medical issues and most with insatiable appetites — creates quite a challenge! Another 49 infants and children ages 3 months to 5 years were well cared for in the YIP, thanks to Michelle Torbert and her team of volunteers.

My older son, Tad Tomaseski, who is a youth minister, directed the 2003 YAP program. Seeing what a challenge we had then getting enough well-trained volunteers, Tad vowed to bring his own youth group from Texas to assure

not only the appropriate number of volunteers for this year's conference, but the appropriate attitude and commitment. Thanks to the fund-raising Tad's Xcel team did all year, plus money donated in memory of our grandson



*Photo by Eric Hilton*  
Conference-goers dance to the Hometown News singing "A Brand New Me"

Adam, Tad was able to bring a group of 47 teens and adults to run YAP.

Beyond our historical goals of safety and fun for the attendees, Tad's goals for this year were to focus on raising the self-esteem of our children and adults (including siblings) and create a program that would reduce the potential for behavior melt-downs. We can report that for the first time in YAP history, there were no major behavior episodes in the entire two days! Laura Orozco from REM in Ohio, one of the YAP assistant directors responsible for behavior management, was happy to report that the behavior specialists

*Conference continued on page 12*



*Photos by Eric Hilton*

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

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## President's View

# With Hope In Our Hearts

**Carolyn Loker**

How does one attend a PWSA (USA) conference and not walk away with a renewed sense of hope? That is a PWSA (USA) goal and our wish for you. I saw our children and adults with excitement on their faces and light in their eyes. I saw parents sharing and grandparents telling their stories to each other. The Chapter Presidents Day brought new enthusiasm to our chapter representatives, and I was in awe hearing what they have accomplished within their region and their support of PWSA (USA).

One of PWSA (USA)'s goals for conference is to provide education — about better treatment options, schooling, behavior techniques, SSI and trusts, just to name a few. It is also our goal to provide a place where expert scientists in the field of Prader-Willi syndrome can come together and present the latest in research, as well as collaborate in hopes of finding answers to make the lives of our children and adults better. It's where we can have our top-notch PWSA (USA) scientific teams — the Scientific Advisory Board and the Clinical Advisory Board — come together to speak to parents about issues that are of concern to them.

Lisa Varndell of Grantsville, Maryland, mom to Georgie, age 13 months, who has PWS, summed it up best:

*"My husband [George] and I were thrilled that we went to the conference. It was encouraging to see the little ones doing so well. I would encourage each of you to attend.... It was not doom and gloom. It was uplifting and I felt empowered. I got reassurance that we were on the right track with Georgie's therapies and I got information about how to continue to improve them. Lots of ideas!"*

*"I didn't think my husband would get as much out of it, but he did. It was a good opportunity for him to forget about work and focus on what needs to be done or continuing being done to help Georgie progress. He really opened up to everything and I was really surprised that on the way home he asked when the next conference was and that we would definitely be going."*

*"What a wonderful conference. What great information and positive people. I came away feeling invigorated and enthusiastic. I ordered the new videos and more books to learn more. I can't thank the people at the national office enough. They were all terrific."*

*"Our kids were in the YIP/YAP programs. My daughter, Addi, age 10... loved the YAP program — of course it didn't hurt that Janalee's son, Tad, who was in charge of the program, is wonderfully kind and handsome. He was so positive with all the kids. All the young volunteers were so positive and upbeat too. It was a great experience for her to meet older kids and adults with PWS and other siblings. Really great program."*

Georgie Varndell, age 13 months, who has PWS, with his Occupational Therapist Brandy Folk at our national conference



*"Georgie was in the YIP program. Great too! I knew the first evening when we took him in for registration that he'd be fine. The Moms could hardly get out from behind the table fast enough to pick him up and play! They took care of him as if he was their own. It was comforting to know that he was happy and well-cared for. I could relax and pay attention to the speakers without worrying about him. I can't thank all these volunteers enough. When we got home, I called to order the videos and talked to Diane Spencer at the national office. After telling her how much I'd enjoyed the conference, I told her that Georgie was in the YIP program. She then told me that she'd fed Georgie his lunch on Friday at the conference! So now, even though she may not remember me every time I call — she remembers Georgie!"*

*"So try to arrange to go to the next conference. You'll be glad that you did!"*

Just seeing the smiles and hearing the laughter of our precious children and wonderful adults, not just those with PWS but moms, dads, siblings, grandparents, extended family members, providers and volunteers, gave me a renewed sense of hope, and I sincerely thank you for that.

Hugs!

P.S. The 2006 national conference will be July 19-21 at the Holiday Inn, Grand Island, New York. Hope to see you there!

**My husband and I were thrilled that we went to conference. It was encouraging to see the little ones doing so well.... It was not doom and gloom. It was uplifting and I felt empowered.**

**- Lisa Varndell**

## Chapter View

# Busy Chapters Balance Education, Fund-raising and Fun

**New Jersey** held an annual golf outing in July, their major fund-raiser. Last year they raised over \$4,400.

**Wisconsin**, too, has a golf benefit scheduled for September, their primary fund-raiser each year, plus a fund-raiser planned with a Milwaukee Brewer's game. **Minnesota** had a golf tournament fund-raiser in August, followed by their annual picnic, and in September a "Fall Retreat/Mini-Conference" with featured speaker Dr. Janice Forster.

**Pennsylvania** had a golf outing in May (isn't it wonderful that so many people like to play golf!), and a last-minute benefit concert in June featuring the Hometown News (who played at the national PWSA conference); these talented and generous musicians were in the area on their way to another gig.

Not only is the **Prader-Willi Florida Association** planning for a two-day Fall Meeting in November at Westgate River Ranch, but their June newsletter warned "Hurricane Season Are You Prepared?"

**Prader-Willi Families of Ohio** planned another golf outing in August, and on September 9, a "Night at the Races" fund-raiser in Youngstown. They expect around 200 people.

Sandy Giusti of **PWSA of Ohio** reports "We had a very successful 5-day summer camp in June... PW only... first time tried for that length. Recreation Unlimited's staff really enjoyed our 'kids' and the campers had a great time fishing, climbing trees and the 50-foot tower, playing softball, canoeing, boating... and on.... We are now planning for and

taking registrations for our fall weekend, October 14 to 16." Call Sandy for information, 614-876-1732. In addition, the chapter had a festival in April, a benefit barbeque in August, a "Families Getting Together" day in September, and on October 1, a mini-conference with Dr. Shawn McCandless speaking. All this plus several "in-services" (school and housing staff trainings), and a meeting with the director of Ohio MR/DD to discuss PWS issues.

**Prader-Willi California Foundation (PWCF)** hosted two walks, north and south, to commemorate national PWS Awareness in May. More than 500 people attended this year's Walks, which raised over \$50,000. Held at a park, a non-strenuous Walk path is created, with signs posted along the way providing information about PWS. Afterwards, families share a picnic lunch while kids of all ages enjoy dancing to a live band or DJ, exercise-related games, arts and crafts, a raffle, and an educational booth of helpful material.

PWCF's annual general education meeting takes place November 5th. Entitled "Behavioral and Psychiatric Aspects of PWS," featured speakers will be Linda Gourash, M.D., and Janice Forster, M.D. For information, visit [www.pwcf.org](http://www.pwcf.org) or contact PWCF at 310-316-3339 or 800-400-9994 (in CA) or via email at [PWCF1@aol.com](mailto:PWCF1@aol.com).

**PWS Missouri** had its Annual O'Leary's Charity Golf Tournament in May, its first PWS Walk-A-Thon in June, and anticipates the Tim O'Leary Charity Tennis Party in September. — *Lota Mitchell, Associate Editor*

## International View

# We're Dancing the Tango Through our PWS World

The intensity and excitement of the 4th Latin American Congress in Buenos Aires, Argentina last spring was extraordinary. More than 100 physicians, including many endocrinologists and pediatricians, attended this joint medical and parent congress at the Garrahan Children's Hospital. With PWS associations from Argentina, Brazil, Chile, Columbia, Paraguay, Uruguay and Peru attending, the 300-seat lecture hall completely filled. IPWSO provided international keynote speakers, including several members from PWSA (USA): Dr. Moris Angulo, pediatric endocrinologist and Latin American Medical Advisor to IPWSO; Dr. Linda Gourash, developmental pediatrician; Dr. Janice Forster, pediatric and adolescent neuro-psychiatrist; and me.

As a treat for international speakers, PWSA Argentina arranged for tango lessons and an excursion to an authentic tango parlor. Laughing our way through the evening, our insecurity was evident. As we "gracefully?" whirled on the dance floor, counting our steps and trying to blend in among the accomplished dancers, I realized that managing PWS is very much like a dance. It takes two to tango, parents and professionals working as a team, to provide a safe and secure environment. When everything is in place, there is no doubt about the next step; the tango is splendid and graceful.

Drs. Gourash and Forster provided information about everyday management of children with PWS. Families and physicians discovered that methods provided by these experienced doctors could easily be adapted to their culture. Consequently, there has been great demand for the IPWSO/PWSA (USA) Behavior Management DVD based on this team's intensive work with PWS families.

IPWSO Secretary Dr. Christian Aashamar discussed educational issues. His 20 years' experience with PWS at Frambu (Norway) Educational Center for Rare Disorders and expertise on PWS "education for life" is unsurpassed.

Enthusiasm from the audience is still reverberating, with many passionate messages of appreciation from our Latin American friends. Thanks to the work of PWSA (Argentina), Elli Korth (Congress chair, president of PWSA Argentina, and IPWSO vice president), and Dr. Torrado (coordinator, PWS Multi-Disciplinary Team, Garrahan Hospital), this exemplary Congress represents an inspiration for future PWS regional meetings.

Working together throughout the world, we are dancing a beautiful Tango!

— *Pam Eisen, IPWSO President*

# Developing a Successful IEP For Your Child

The following web sites are valuable resources for parents of children with developmental challenges, providing a wealth of information about special education.

Partners in Education, an Internet site developed in 2004 by the Minnesota Governor's Council on Developmental Disabilities, informs parents about creating a successful individualized education program (IEP) for their school children with learning challenges.

The web site, [www.partnersinpolicymaking.com/educational](http://www.partnersinpolicymaking.com/educational), includes a self-study course to assist parents of children with developmental disabilities navigate the special education system and thus help their children make the most of their potential.

It describes the elements of an IEP and explains key laws governing special education (including how to access your state's statutes), as well as the role parents play in IEP development and implementation.

The site also discusses ways parents can advocate for their children to provide a positive educational experience, and explains parental rights in due process if they believe their child's rights have not been met.

Developed to give parents the practical skills they need to create an inclusive, quality education for their children, the tutorial includes a glossary of terms, syllabus of materials used to create the tutorial, and real-life stories by parents of children with disabilities.

## How to Disagree with the IEP Team

If, when you go to the IEP meeting for your child, you disagree with items on the IEP — or think items not included should be on it — the following plan of action is suggested on [wrightslaw.com](http://wrightslaw.com).

Advise the IEP team that you don't think the IEP is appropriate, that it does not provide your child with enough help or the right kind of help. Use facts to support your position (i.e., facts from an evaluation of your child from a private sector evaluator, graphs of your child's test scores). Be polite but firm.

When the team asks you to sign consent to the IEP, use a ball point pen and put the IEP on a hard table top. Write this statement on the IEP: "I consent to this IEP being implemented but I object to it for the reasons stated during the meeting." Sign your name.

You are a member of the team and a participant in the IEP process. The law requires you to make your objections clear, and the IEP is the best document to use for doing that.

Stay calm. Take your copy of the IEP, stand and say "Thank you. I guess this meeting is over." Extend your hand to shake theirs. Pick up your tape recorder and leave.

The IEP team has a problem. You have advised them in writing that their proposed program is not appropriate for your child. You also consented to their implementing the program, so they should implement it.

*About wrightslaw.com:* Pete Wright is an attorney who represents children with special needs. Pam Wright is a psychotherapist with training in psychology and clinical social work. She manages several special education websites, including [Wrightslaw](http://Wrightslaw), [Fetaweb](http://Fetaweb), [Yellow Pages for Kids with Disabilities](http://Yellow Pages for Kids with Disabilities), and [Wrightslaw: No Child Left Behind](http://Wrightslaw: No Child Left Behind). She is the managing editor of [The Special Ed Advocate](http://The Special Ed Advocate), an electronic newsletter published weekly.

## Nutrition in Schools: What's the Law?

### Comments by Barb Dorn

Students need proper nutrition to learn and benefit from all aspects of their education. In many cases, assistance by the school's nutritional services is required in order to do this. Lack of support from the school could contribute to the obesity of PWS and its negative health effects.

To be eligible for modified meals, a student must present a statement from a physician, which includes the following:

- A description of the child's disability (PWS), including the need for dietary restrictions to prevent morbid obesity and the calorie amount that is needed for each meal. (In some cases, students may be receiving breakfast as well as lunch in the school setting.) 7 CFR Section 210.10(i)(1) and 220.8(f).
- This must be documented in the IEP.

The student could also receive low calorie snacks if other students are provided with a snack by the school. Usually students bring their own, but may receive milk. The doctor's prescription should indicate that as well (non-fat vs. low fat).

If parents are meeting resistance, they may want to share or compromise with this request. Parents can do this by agreeing to send the snack and asking the school to provide the meals. (Parents may need reminders not to send snacks

with the student but to bring the snack directly to the teacher. I used to bring in a snack supply for one to two weeks at one time). The law does not discriminate by limiting this service to only diabetics or any other condition that warrants special dietary considerations.

United States Department of Agriculture (USDA) reimburses schools for every meal served. Under their Section 504 and Child Nutrition Regulations, schools participating in federal meal programs are required to make reasonable effort to provide *at no extra charge*, special meals to students whose diets are restricted due to their disabilities [7 CFR Section 15.b26(d)(1)]. Examples of "reasonable" might include the purchase of light bread, light or fresh fruit (instead of fruit packed in heavy syrup), substituting a non-starchy vegetable for a starchy one, and other easy adjustments. Typically, this is not a major issue.

*Barb Dorn is an RN at the University of Wisconsin Hospital and Clinics, past president of PWSA (USA) and past president and program director PWSA of Wisconsin, Inc. She lives in Verona, Wisconsin with husband Don and sons Tyler and Tony, who has PWS.*

## Diabetes Type 2, Growth Hormone and PWS

Data indicate a higher incidence of Type 2 diabetes among those with Prader-Willi syndrome. Following questions about the relationship between Type 2 diabetes and growth hormone, PWSA (USA) asked physicians to comment. Dr. Phillip Lee serves on the PWSA (USA) Scientific Advisory Board and Dr. Moris Angulo, on our Clinical Advisory Board.

Growth hormone (GH) does not cause T2DM (Type 2 Diabetes Mellitus), but it can make it worse. This is because GH makes the body less sensitive to insulin, and insulin insensitivity (due to increased body fat) is the main problem in T2DM. For my patients with T2DM, I always make sure that the T2DM and body fat are well controlled, then the GH should be started at a relatively low dose and subsequently increased.

As a side comment, a person age 17 or older has probably finished growing. Therefore, he/she should be on an "adult dosing," which is usually a much lower dose than 2.5 mg.

Finally, using insulin to treat T2DM is rarely a good idea unless there is evidence of insulin deficiency (i.e., ketosis). Insulin increases body fat.

**Phillip Lee, MD**

GH can increase somehow the insulin resistance and it resolves after discontinuing GH therapy. More than anything else the cause of type 2 diabetes mellitus is secondary to genetic predisposition and excessive adiposity [body fat]. The actual incidence of this type diabetes could be as high as 25% in adolescent and adult without GH therapy.

**Moris Angulo, MD**

Glucose/insulin problems, including type 2 diabetes, are an inherent part of the PWS condition. My take is that [this person] may have some degree of insulin resistance — and likely even impaired glucose tolerance (a pre-diabetic condition) before going on the Genotropin for the second time (the blood sugar of 120 suggests that he was already having some degree of a problem). This "pre-diabetes" may have been aggravated by the GH treatment, but it is also possible that he was developing diabetes independent of the GH. Diabetes certainly does not occur in all the kids with PWS, and most kids with PWS who get diabetes have never gotten GH, so the connection is not perfectly clear.

Now with that said, the diabetes needs to be managed with the impact of the GH treatment — that is, the GH may make him require more insulin or oral medication, and if stopping the GH, it may require a lowering of the dose of the diabetes medication. Having diabetes in general (but also specifically in PWS) does NOT mean that a person cannot continue to receive GH treatment — he can continue. That is a decision that the family and the pediatric endocrinologist should make together.

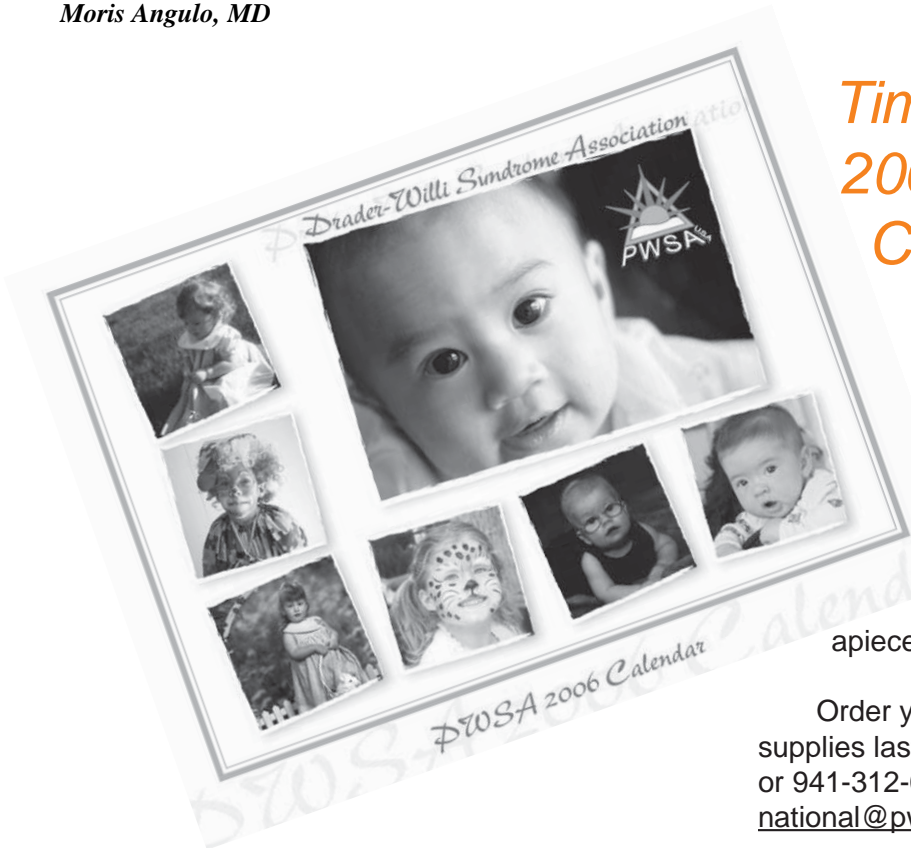
**Michael P. Wajnrajch, MD, Medical Director, US Endocrine Care, Pfizer Global Pharmaceuticals**

## Time to Order Your 2006 PWSA (USA) Calendars

Each month features color photos of lots and lots of our kids! They make great holiday gifts, or use them for fund-raisers.

Cost is \$15.00 each and includes shipping. Buy a box of 65 calendars and they cost only \$10 apiece, no shipping charges either!

Order your 2006 calendars NOW while supplies last. Call PWSA (USA) at 800-926-4797 or 941-312-0400; fax to 941-312-0142 or e-mail [national@pwsausa.org](mailto:national@pwsausa.org).



## Incidence of Choking in Those With PWS

I feel it of great importance to share this with you. Sonny choked today while he was eating breakfast (he's fine). I was able to scoop the food out of his throat, thank God.

I feel it's important to share this because if I hadn't gone to the New York conference this past May, I wouldn't have known that our children have no gag reflex and are more prone to choking.

I was bringing Sonny his juice and saw him flapping his arms, his face was red and he began grabbing at his mouth. I began reaching in with my finger and felt the waffle and was able to get it out. I was shaken all day and think that if I hadn't gone to the conference, today wouldn't have been a very happy day.

Thank you Janalee for teaching me and thank you Harry [Persanis, Prader-Willi Alliance of New York] for sending me to the conference. Big hugs to the both of you.

*Nina Roberto, Richmond Hill, New York*

*Over the last few years, we have had 12 children and adults with PWS choke to death, and many reports of other choking episodes such as the one that follows, which is why it is important for parents and caregivers to know the Heimlich Maneuver. Instructions are on our web site:*

*[www.pwsausa.org/syndrome](http://www.pwsausa.org/syndrome) under "Medical Concerns."*

*— Janalee Heinemann, Executive Director*

On the right is Sonny Roberto, 3, who has PWS, with siblings Niyani, 12; and Lennon (left), 26 months



## Preparing for a death in the family

My daughter Shawn, age 32, who has PWS, was extremely close to my late mother, Ida Moreau. I'd like to tell you about their last weeks together before Mother passed away in October, 2004.

Knowing that her time was near, in the summer of 2004 Mother had a private conversation with Shawn very early one morning about how weak she was getting and that she would likely pass on.

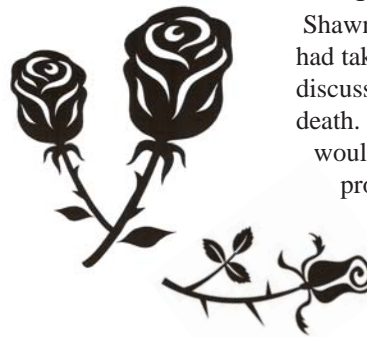
Mother wanted Shawn to be prepared for her death. The two even discussed Mother's funeral. Mother was from Texas, and they had talked about "The Yellow Rose of Texas" song. Shawn said that she would place a yellow rose in the coffin, as well as a red rose for Mother to bring to Grandpa, who had passed away 14 years ago, and a blue rose bud for the baby boy Mother had lost shortly after his birth, before I came along.

Shawn remembered the details of that conversation, and, as a result, had input into the funeral arrangements. She followed through with her commitments, and seemed very comforted to know that she was fulfilling her grandma's wishes.

Shawn was also able to tell Mother during this conversation that whenever she did pass away, Shawn would be OK — that she had her mom and dad, and Grandma should not worry about Shawn being taken care of.

Mother even gave Shawn a job to do at the funeral: take care of me. Shawn knew what her job was — she stayed very

close to me the whole time — and that seemed to help her to focus and not be overcome with sorrow. It was incredible how maturely Shawn was able to deal with it all.



I did not even know that Shawn and Mother's conversation had taken place until Shawn discussed it with me after Mother's death. Had Mother asked me, I would probably have tried to protect Shawn from getting upset by recommending that they not have such a conversation.

But thinking back, I understand how wise my mother was to prepare Shawn in this way. I'm sure now that it also gave my mother much comfort to know that Shawn was able to deal with her death and talk about it, and that Shawn would be "OK."

I'm certainly no expert, but this experience makes me think that perhaps a helpful way to deal with an impending death is to be pro-active. Have a conversation that prepares the person with PWS for both the funeral and her or his own life after the death of a loved one.

*Dottie Cooper lives with husband Dale and daughter Shawn in Alpharetta, Georgia.*



### **Cognitive and Behavioral Findings in PWS and Early-Onset Morbid Obesity**

Jennifer Miller<sup>1</sup>, John Kranzler<sup>2</sup>, Ann Hatfield<sup>1</sup>, O. Thomas Mueller<sup>3</sup>, Douglas W. Theriaque<sup>4</sup>, Anthony P. Goldstone<sup>1</sup>, Jonathan J. Shuster<sup>4,5</sup>, Daniel J. Driscoll<sup>1,6</sup>. 1 Dept. of Pediatrics, Univ. of Florida, College of Medicine, Gainesville; 2 Dept. of Educational Psychology, Univ. of Florida, Gainesville; 3 All Children's Hospital, St. Petersburg, FL; 4 General Clinical Research Center, Univ. of Florida, Gainesville; 5 Dept. of Statistics, Univ. of Florida, Gainesville; 6 Center for Mammalian Genetics, Univ. of Florida, College of Medicine, Gainesville

PWS is an excellent model to assess the causes and effects of early-onset morbid obesity (EMO), since it has a characteristic age of onset of obesity in addition to a well-described learning difficulties and behavioral problems. The early-onset morbid obesity is the most significant health problem and the primary cause of morbidity and mortality in those with PWS. We performed comprehensive cognitive, achievement, and behavioral evaluation on 3 groups (PWS, EMO, and controls) to determine if children with early-onset morbid obesity had cognitive and behavioral problems associated solely with obesity.

Significant negative behaviors and poor adaptive skills were found in the EMO group. Those in the EMO group have significantly lower cognitive function and more behavioral problems than controls with no history of childhood obesity. Therefore, childhood obesity alone may result in compromise of cognitive ability and achievement, adding to public health concern surrounding the epidemic of obesity in childhood.

### **PWSA (USA) Database Collection Uncover Areas of Needed Research**

*Janalee Heinemann, Barbara McManus, PWSA (USA), Sarasota, FL*

PWSA (USA) conducted a solicitation-based survey to update their database with those with the syndrome. As of April 2005, information was collected on 1,141 individuals.

Thirty-percent of respondents had children under age 5 years. However, the initial statistical information stated in this abstract included all who responded regardless of age. In addition, 31% of those responded did not have an official diagnosis, or more typically did not know the clinical diagnosis/description of their child. Forty-one percent were reported with the 15q deletion, 21% with maternal disomy 15 (UPD), 2% with imprinting defects, 2% were PWS-like and 2% with chromosome 15 translocations. At birth, three sets of identical twins (both with PWS) and 19 sets of fraternal twins (one with PWS) were reported. Other birth-related data were: 52% used tube feeding, 27% had emergency C-section, 25% were breech, 22% were premature, and 3% reported the use of assisted reproductive techniques. Data listed under the heading major medical concerns (current or in the past) were: 64% weight-related (obesity), 45% high pain tolerance, 39% sleep

apnea, 34% curvature of the spine, 33% severe skin picking, 19% other respiratory complications, 15% pubic or axillary hair before age 8 years, 14% fractures, 13% autistic behavior, 11% gastric/intestinal disorders, 10% seizures, 10% osteoporosis, 9% aspiration, 9% diabetes, 9% hypothyroidism, 8% heart problems, 7% hip dysplasia, 7% other bone problems, 4% gall bladder disease, and 1% mitochondrial disorder. Regarding hormone therapy, 54% at some time had received or are receiving growth hormone and 16% have received other types of hormone replacement therapy.

The collection of clinical information will be ongoing. Many of the medical concerns are age-related, thus information presented will be broken into age categories. PWSA (USA) does not claim this information to be collected for scientific purposes, but hopes the scientific community will find the information useful in future research studies and for management of PWS.

### **Assessment of Energy Expenditure in PWS: Comparison with Obese Subjects**

*Merlin G. Butler<sup>1</sup>, Douglas C. Bittell<sup>1</sup>, Zohreh Talebizadeh<sup>1</sup>, Joseph E. Donnelly<sup>2</sup>, Travis Thompson<sup>3</sup>. 1Section of Medical Genetics & Molecular Medicine, Children's Mercy Hospitals & Clinics and Univ. of Missouri-Kansas City School of Medicine, Kansas City, MO 2Center for Physical Activity & Weight Management, Univ. of Kansas, Lawrence, KS; 3 Minnesota Autism Center, Minneapolis MN*

Obesity associated with PWS is the result of a chronic imbalance between energy intake and energy expenditure (EE) due to hyperphagia, decreased physical activity, reduced metabolic rate and an inability to vomit. EE is affected by body composition as well as exercise. PWS subjects have a lower fat free mass compared with controls which may contribute to reduced basal level energy expenditure. To determine the relationship among body composition data, activity levels and metabolic rates, dual energy X-ray absorptiometry (DEXA) and a whole room respiration chamber were used to measure body composition, total EE, resting EE and physical activity during an 8-hour monitoring period.

PWS subjects had significantly decreased total EE by 18% compared to obese comparison subjects. Similarly, resting EE was significantly reduced by 17% in the PWS subjects relative to the comparison subjects. Total mechanical work performed during the 8-hour monitoring period was significantly reduced by 35% in the PWS group. Energy cost of physical activity is related to duration, intensity and type of activity and metabolic efficiency of the individual. After adjusting group differences in lean body mass by analysis of covariance, total EE and resting EE were no longer different between the two groups. Our data indicate that there is a significant reduction of energy expenditure in subjects with PWS resulting from reduced activity but also from lower energy utilization due to reduced lean body mass.



# Scientific Day 2005 Florida Conference

## **Growth Hormone Effects in Infants and Toddlers with PWS: Does Early Intervention Make a Difference?**

Barbara Y. Whitman<sup>1</sup>, Susan E. Myers<sup>1</sup>, Aaron Carrel<sup>2</sup>, Dave Allen<sup>2</sup>. <sup>1</sup> Dept. of Pediatrics, St. Louis Univ., St. Louis, MO  
<sup>2</sup> Univ. of Wisconsin, Madison

Abnormal body composition and growth hormone deficiency are well documented aspects of PWS. The authors and others have documented the beneficial effects of growth hormone replacement therapy (GHRT) on anthropometrics (including linear growth, head size, foot/hand length), body composition (including percent body fat/lean body mass), bone density, physical performance (including muscle strength and pulmonary function), and mood and behavior (including improved mood, attention, cooperativeness and sociability) in those with PWS between ages 4 and 21 years.

Obesity in PWS has its onset in the toddler years at a mean age of 2 years. Long before obesity develops, however, body composition abnormalities are evident. Body fat determined by skin-fold measurements is elevated even in underweight infants with PWS and an accompanying reduced lean body mass contributes to the infantile hypotonia. The majority of infants have a normal birth length, however, there is a gradual deceleration of linear growth during childhood with short stature observed in the majority by 12 years. We have sought to study infants during this critical period, evaluating the benefits of GHRT on these early body composition and developmental abnormalities.

In this presentation we will compare growth, body composition and developmental parameters in children age 4 to 5 treated with growth hormone (Genotropin, 1-1.5 mg/m<sup>2</sup>/d) for 24-36 months with baseline measurements of previously studied children initiating treatment at ages 4 to 6 ½ years. Preliminary comparison data indicate that children treated since infancy have improved linear growth associated with higher IGF-1 values, normal lean body mass, and significantly less absolute and age-adjusted body fat as measured by DEXA scans. Parental reports revealed significantly earlier emergence of language (15 vs 20 mos.), and a tendency toward earlier independent walking. Differential gender effects are observed for several parameters. These preliminary data suggest that early GHRT offers multiple benefits for infants and toddlers with PWS.

<sup>3</sup> *Study of Growth Hormone Intervention for Infants and Toddlers with PWS partially supported by Pharmacia/Pfizer*

<sup>4</sup> *Study of Growth Hormone Intervention for Young Children and Adolescents with PWS partially supported by Genentech*

## **The Use of Psychotropic Medications in PWS**

Elizabeth Roof, Richard Shelton, Grant Wilkinson, Richard Kim, Elisabeth Dykens. Vanderbilt Kennedy Ctr., Vanderbilt Univ. Nashville, TN

Many individuals with PWS struggle with maladaptive and psychiatric symptoms that overshadow their strengths and impede their optimal functioning (Dykens, 2002). A few open trial case reports and many anecdotal accounts suggest that some people with PWS respond well to selective serotonin reuptake inhibitors (SSRIs) such as Prozac or Zoloft. These individuals may show improvements in compulsions, skin picking or severity of tantrums. More importantly, many individuals do not show such positive responses. Other medications such as mood stabilizers and atypical antipsychotics have been tried in the PWS population with sporadic success.

Recent advances in pharmacogenetics have yet to be applied to people with mental retardation. Pharmacogenetics seeks to link genetic differences in drug metabolism with variability in drug response. In the long term, pharmacogenetics aims to develop individualized drug therapies based on a person's genetic profile (Mancama & Erwin, 2003). Pharmacogenetic studies are particularly well-justified in a population such as PWS, as persons often have a predictable set of symptoms, such as irritability and compulsions, that have a variable response rate to medications such as SSRI's and antipsychotics.

**Methods:** This pilot study examines 25 subjects with PWS, ages 8-59 years, who have been previously treated or are currently being treated with psychotropic medications for behavioral or psychiatric symptoms.

**Results:** Although preliminary, subjects with PWS showed differences in 2 different SNP's (2D6 and 2C19) in terms of drug metabolism. A full 33% of the PWS sample showed abnormalities in 2C19 SNP'S demonstrating either a 50% loss of function or poor metabolizer status. No participant was characterized as an ultra rapid metabolizer. Implications will be discussed for variability in CYP 450 analysis and other factors that may relate to drug metabolism, such as age, gender and genetic subtype.

*This research was supported in part by the Prader-Willi Syndrome Association (USA), the Vanderbilt General Clinical Research Center, and NICHD R0135681 and P30HD15052.*

*Abstracts from the Scientific Conference are available in the Members Only section on the PWSA (USA) website, [www.pwsausa.org](http://www.pwsausa.org).*

# Children Thrive On Routine and Structure

By Lisa Graziano

I believe that all children thrive on routine and structure, and especially children with any kind of disability. Knowing what to expect helps to reduce anxiety. While we always respond to an immediate need, we have always held close to routines for feeding (in infancy), naps, meals and snacks (in childhood), cleaning up toys after playing, setting and clearing the table, manners, getting dressed in the morning, getting ready for bed, etc. These routines then become incorporated into a way of living.

While many families experience “The Terrible Twos,” we did not. We instead experienced “The Horrible Threes!” Fortunately, I had a couple of girlfriends with typically developing kids who also sailed through their 2’s only to hit the full-on tantrum wall at age 3. This was important for me so that I knew my child’s behavior was not solely attributed to the behavioral symptoms associated with the syndrome.

## Expressing age-appropriate independence

Tantrum behavior is normal childhood behavior — it is the child’s expression of independence and control. It is the parent’s job to teach the child *how* to be age-appropriately independent in socially acceptable ways. Teaching kids limits reduces their overall anxiety and ultimately improves behavior.

I believe that most kids and adults with PWS have much greater difficulty managing their emotions, especially anything that is or even appears to be frustrating. I believe that their tenuous hold on their emotions is caused by their underlying biochemistry, and because of the biochemistry, they are more prone to emotional or behavioral problems when they perceive *any* frustration. I believe the emotional system takes over and completely supersedes the cognitive-thinking system. Therefore, I believe our job as parents is to help our children, from as early as possible, fight against their underlying biochemistry to stay in the cognitive-thinking mode, helping them learn to gain better control over their emotions and behave more appropriately.

Tantrums in early childhood are not only unavoidable, they are opportunities to teach appropriate social behavior and life lessons. If given the choice, no one *really* wants to share toys! Generally speaking, expecting kids under age 2 to share is probably unrealistic. After age 2 as they are learning to share, it is helpful to matter-of-factly state what behavior is expected. “It’s now time to share your toy with your friend for a minute; then she will give it back and share with you. If you are not able to share, you will not be able to play with this toy now.”

If/when the child goes into tantrum behavior, the parent can respond by calmly empathizing with the child, “You want to play with that toy. You don’t want to share. Sharing is very hard.” Then continue with a calm, firm voice, “And it is now time to share.”

If the child is not able to share — and she probably will not be — calmly follow through and let the child know she has lost the privilege to play with the toy now.

When Cameron was first learning to share, I would simply hold him on my lap as he cried, maybe leave the room where we’d been playing in order to reduce the visual reminder of his loss, and softly say a couple of times, “I know you are sad and mad.” After he calmed down, we would continue on as if nothing happened. The next time we attempted to practice sharing, I would respond with *huge* praise at the first *hint* toward sharing behavior.

## The feeling state versus the cognitive state

Once a child is overcome by emotion and is in the middle of a tantrum, it is pretty much impossible to get the child out of it — the tantrum must simply be waited out until the child has moved from the feeling state back into the cognitive state. During this feeling state, my experience is that children do not have the *ability* to think clearly; they are completely immersed in the feeling state. Later on, the whole trick is to *avoid* the tantrum or meltdown from the beginning.

Giving verbal information to the child as to what to expect next can be helpful, as well as giving the child extra time to process that information and come to accept it or, at a

## If a child feels understood, this can help her feel calmer and better able to stay in the thinking mode.

later age, to negotiate it. Watch the child for cues as to any anxiety and respond immediately.

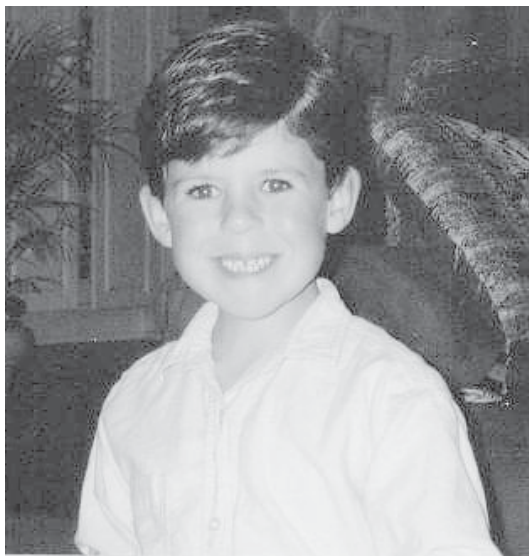
For example, in the store before returning to the car, tell the child “Ooops, Daddy forgot something in the car [pause and look for anxiety]. He needs to go to the car and get it. We will wait here until he comes back. I think we can sing ‘Twinkle, Twinkle Little Star’ three times before he comes back.” [long pause] At the first sign of anxiety (facial change, etc.) or protest, calmly empathize with and reassure the child: “I can see that you are sad or scared. [pause] You don’t want Daddy to leave.” [pause]

If the child feels understood, this can help her feel calmer and better able to stay in the thinking mode. She is now more likely to hear what is being said. Reinforcing calm behavior might sound something like, “After he goes to the car, we will be so proud of you for staying calm that you will be able to pick out a book from the store!” Placing everything in the positive can help reduce the illusion of frustration.

Having a meltdown over having to wear a bike helmet may have a lot to do with sensory integration issues. Taking the helmet off while you give her the words her screams are saying might help: “I don’t want to wear the helmet. It tickles my head.” Working with an OT (occupational therapist) who is experienced in sensory integration therapy can help. We

*Continued on next page*

Cameron Graziano, age 6, who has PWS, is learning how to successfully manage his behavior



had to stop therapeutic horseback riding for a period of time because Cameron couldn't tolerate the helmet. After working through the sensory issues, he no longer melts down over the need to wear his helmet.

### The parent's job: staying calm

If the child does tantrum — and he probably will until he's somewhat older, has learned that tantrum behavior does not get him what he wants, and has practiced staying calm and getting more of what he wants *because* he remained calm — the parent's job is to *always* stay calm (a very difficult task in the middle of a store when feeling embarrassed!) and NEVER give in to the tantrum behavior.

If a parent gives the child what the child is tantruming for, the child quickly learns that the tantrum technique works, and he will only increase the tantrum behavior next time. *It is extremely difficult to change tantrum manipulating behavior once it is established.*

Neither my husband nor I have ever spanked or hit as a form of discipline. I don't believe it is an appropriate form of discipline for children in general, and particularly not helpful with children with PWS. Instead, we use clear expectations, natural and contrived consequences, praise, positive reinforcers, withdrawal of privileges and infrequently (maybe in response to yelling or pushing), a time-out in the bedroom until he gains control over his body.

We do not use time-outs as a form of punishment nor as a means for him to think about the error of his ways. We use time-outs only as an opportunity to remove him from the situation so that he can better calm himself and gain control over his body.

### Teaching the consequences of behavior

We use consequences to teach him what will happen if he does a particular behavior. For example, "Don't throw your toy, Cameron. If you throw the toy, you will not be able to play with it for 10 minutes." Or, "Please put on your jacket. If you don't wear a jacket, you will be cold." In both cases, he will experience the consequences of his choice of behaviors and I remind him of his original choices. "I told you if you threw the toy you would lose it. You chose to

throw the toy, now you will lose playing with it for 10 minutes."

I don't believe it is helpful to try to "make" a child stop crying, but it is helpful, depending upon the situation (for instance, if the tears are being used as an attempt to manipulate), to tell the child if she is going to cry, she needs to do it in the privacy of her bedroom.

I believe the above behavior modification and management techniques can be successful regardless of the child's mental acuity.

I absolutely love and highly recommend the book, *The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children*, written by Ross W. Greene, Ph.D. This book teaches parents how to help our kids to better manage their feelings and behavior.

At age 6, Cameron does an excellent job remaining calmer when he perceives a frustration coming his way. He works hard to keep his voice calm and not cry as he tries to work things out. He knows all negotiation stops the moment he chooses to yell (or any other unacceptable behavior), and now he *rarely* loses control of his body to this point. Fatigue or anxiety make staying in control more difficult, but even under these circumstances he more often than not does a good enough job managing his behavior. We are fortunate to have been able to reach this place in his development. We hope he will continue to do a good job (and even better!) managing his emotions and behavior, and we will continue to work hard to support his current good progress.

*Lisa Graziano, mom to Cameron, age 6, and her husband TJ live in Redondo Beach, California. A family therapist in private practice, Lisa is also a member of the PWSA(USA) Board of Directors.*

## The Chuckle Corner

### Where Do They Want To Go Today?

For the silent auction at this year's PWSA (USA) Conference, Anna and her mom were assembling an Amish basket containing little boy and girl dolls.

Anna, gazing at the dolls adoringly and getting ready to place them in the basket, looked up at her mother. "Mom, I'm thinking these dolls would rather stay here with me at my house!"



**Carolyn Loker, Kalamazoo, Michigan**

P.S. The dolls did go to conference!

*Do you have a joke or funny story to share? Please send it to the PWSA(USA) office. Be sure to include your name, telephone and address in case we have questions.*



never have we had such a unified and talented team as this year. There are so many I want to give a special thanks to that I do not dare start. We have listed key chair people, but know that our utmost gratitude goes to ALL who assisted in the 2005 PWSA (USA) conference.

We had tremendous people helping — from Carolyn Loker, who added the large responsibility of co-chairing the conference with me to her many other volunteer roles as PWSA (USA) president and New Parent Mentoring coordinator, to Barb McManus, who is busy as our



spent their entire time with problem prevention rather than intervention. Our gratitude goes to REM in Ohio and ARC in Florida for again providing their staff for this role.

The gala closing demonstrated that we met those goals, as the group and their counselors danced and sang to the Hometown News song, *A Brand New Me*, and Xcel's rap song, *My Name's Not Willy!*

We have heard accolades about conference and many heartwarming stories from YAP. I think the following sums up the feedback. A mother reported her daughter's remark about YAP: "This is the first time I have been happy in over 2 years. They made me feel like it was OK to be me."

A father whose son is on our PWS Advisory Board wrote: "My son said YAP was great: 'I felt like I was part of something really important. We all felt like we were on top. Dad, I can't tell you how good it felt to be up on that stage.'" His dad went on to say, "Our kids rarely come out on top of anything, but they did at YAP. I think also that the goal and tone of YAP, in the face of the reality of PWS, showed us all what we are trying to achieve."

Another dad said after the program ended that his one son (a sibling) told his dad that he was always angry and feeling left out before YAP, but being there helped him realize the important role he could play in his brother's life, and that he counted, too.

This year's team of volunteers and staff were absolutely outstanding to work with — each with special skills in their area, cheerfully and willingly pitching in to do all it takes to make a successful conference. We have had many, many good people work on our conferences over the last 27 years, but

web site and medical database coordinator, yet took on the huge job of conference registration.

Especially touching was the volunteer assistance of the entire Girard family, who just months ago lost their son Jeremy, who had PWS.

I have written that "it takes a village" to raise a child with PWS. For our conference, it took a dedicated village within the village, with a huge heart and a lot of talent to make it successful — and successful it was!

### 2005 Conference Committee Coordinators

*Thanks to all our hard-working volunteers & staff*

Paul & Pam Alterman	Pete Girard	Lota E. Mitchell
David Agarwal, MD	Kay Goldberger	Debbie O'Neal
Janice Agarwal	Lisa Graziano	Laura Orozco
LeeRoy Ayala	Roda Guenther	Jodi O'Sullivan
JoAnne Barron	Kerry Headley	Norma Rupe
Dr. Merlin G. Butler	Janalee Heinemann	Mark Ryan
Sybil Cohen	Michelle Holbrook	Ken Smith
Dottie Cooper	Susan Jesaitis	Derek Snitker
Ann Coyne	Wauneta Lehman	Diane Spencer
Steve Dudrow	Michelle Leightman	Tad Tomaseski
Annie Durell	Carolyn Loker	Michelle Torbert
Pam Eisen	Jim Loker, MD	David Wyatt
Joan Gardner	Barb McManus	Mary K. Ziccardi

## Sibling View

# My Brother's PWS Is Part of Who I Am

*Maria Kesopoulou, Thessaloniki, Greece, writes:* I am 27, two years older than Paul. I have both good and bad memories from my childhood regarding PWS, but the way PWS affected me as a personality can only be considered good.

What was bad was the lack of information about the syndrome back then, and due to that, my parents didn't have the ability to explain to us (me and my other brother) what was happening and what was wrong. As a result, I spent all of my childhood worrying about things I didn't have to worry about and feeling guilty about what my brother and my parents were going through (and the guilt is still here).

I wanted to fit in with the other children my age, but I couldn't because kids, as you all know, can be very cruel and I couldn't explain my brother's situation or I was just mad at them for making fun of him or feeling sorry for him/me/us.

I had decided that only those who could accept and love my brother as a person would be the ones that would receive my love and acceptance in return. The same rule applied in my love life as well, and a few years back I ended a 4 year-old relationship (when I understood that my boyfriend would never accept my brother and felt embarrassed whenever we went out with him) and about a year after, another guy I dated stopped calling when I talked to him about Paul.

There is a part of me that wishes that whoever I date didn't have to date the whole package and that the fear of him failing the test didn't exist, but the other part believes that whoever fails is not the good and kind person that most, if not all, women want to find, and I have criteria to find that out!

## View From the Home Front

# In Our Family, We Just Have Faith

My name is Kristi and my husband John and I have five children. Jade is 13, Jersi, 11, Gage, 9, Jasz, 5, and Justice Faith, 14 months.

Justice was diagnosed with PWS about 2 weeks after birth. She was in the NICU for 5 days where they did the FISH test which came back normal.

A week or so later after some further blood tests we found out that she has UPD. I did as much research as possible in books (which are hard to find) and on the web. All the things I found out made my sadness even greater.

I was given the number to PWSA (USA) by many doctors and family members, but I refused to call. I wanted to prove what Justice could do before I was told what she couldn't do or wouldn't do.

We took her home on Christmas day. A few days later I decided she no longer needed her NG tube. I don't recommend this to anyone. I removed the tube and from then on she drank from a bottle. It was a lot of work, but I know for her it was the right thing.

Well, 14 months later and I finally had the courage to call PWSA (USA). I now wish that I had called right away. There

## Surveys and Commentary Sought for Sibling Booklet

*Regardless of where they live, those who have a sibling with PWS have a lot of feelings about their experience. We are planning a booklet for siblings made up of your writings and the sibling survey information.*

*Please e-mail a contribution for the Sibling View to [ssurvey@pwsausa.org](mailto:ssurvey@pwsausa.org) or mail it to the national office. You can ask from a copy of the survey from the national office or do it online at [www.pwsausa.org/sibling.asp](http://www.pwsausa.org/sibling.asp). **Deadline has been extended to December 31, 2005.***

*The online completed surveys are starting to come in! Please do one yourself!*

*— Lota Mitchell, Associate Editor*

Now I have a wonderful relationship with a guy my age and I'm putting his parents through the test... I don't want them to think that their son will not have a happy life because of me caring for my brother so much, or fear that their grandchildren may have PWS....

I feel that I wasted the one and only part of my life that could be PWSless... No regrets, however... I'm not sure how one parent can manage to have a carefree sibling during childhood and to have that same sibling feel and care about the PWS sibling's needs as an adult.

were so many days that I needed and still need support. The grief and pain that you experience can not be shared with anyone except someone who has also felt that pain.

No one can imagine how those few words "There is something wrong with your baby" can so dramatically change your life.

My three other girls all have J's for their first names and M's for their middle names. Justice was also going to follow suit. After the incredibly difficult labor, we changed her name to Justice Faith. "JUST HAVE FAITH."

This is what we have been living on for the past 14 months. Justice has been a bit of a miracle baby. All of her doctors, including her geneticist, marvel at what she has accomplished. Her OTs and PTs can't believe the leaps and bounds she has made. I apologize for rambling on. I have had a lot of this cooped up for 14 months. I apologize to any of you who got stuck reading this. I am thankful for all of you. I wish I would have contacted you sooner.

*Kristi and John Rickenbach and their family live in Findly, Minnesota.*

# 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.

## Kimberly Ann Fuja



Kim Fuja died June 14, 2005 at age 22 from complications of PWS. She lived with her parents, Phyllis and Raymond Fuja, in Farragut, Tennessee.

A graduate of Neuqua Valley High School in Naperville, Illinois, Kim wanted to become a special education teacher. Active in her church, Kim had strong faith that

God would help her overcome her struggles with depression and uncontrollable hunger.

Kim's article, "Faith Gets Me Through," was published in the PWSA booklet, "Prader-Willi Syndrome Is What I Have, Not Who I Am!" In it, she stated, "God found a way to let me know that He created me for a reason and that I am perfect the way I am."

Kim noted that she found positive aspects to PWS. "Because of my disability... I have learned that it is really important to look deep inside a person to see who they are, instead of judging them by only what you physically see."

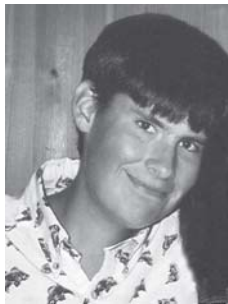
## Dustin J. Glover

Dustin Glover, age 21, who had PWS, died May 27, 2005 in Gainesville, Florida from injuries suffered after he was struck by an automobile.

He will be missed dearly by his parents, Richard A. Glover and Jennifer Jennings-Glover, and brothers Graham and Jackson of Tallahassee, Florida.

A graduate of A. Quinn Jones School in Gainesville, Dustin was known for his caring ways and devotion to animals, fishing and gardening. At the time of his death, he lived in Gainesville, where he volunteered his time and talents to both the Humane Society and the Botanical Gardens there.

His father Richard said Dustin and his mother recently spent several days at Gainesville's Shands Hospital in an experimental testing program designed to learn more about PWS, with the hope of helping others. "Dustin was happy at the time he left this world and we are confident that he is finally free of the chains that held him back and controlled his life on this earth," his father said, adding, "He will always be in our hearts."



## Cameron MacArthur

Cameron died on January 1, 2005 at age 38 from congestive heart failure. His mother June wrote that when he was first born, no one expected Cameron to hear or see or walk or talk, but he did. He had bright blue eyes and a beautiful smile, and by age 2 he was doing all those things and more. At age 12 Cameron was gaining weight and was diagnosed with type II diabetes. But it was not until the year 2000 that Cameron was diagnosed with Prader-Willi syndrome at age 33! June went on the Internet and discovered the PWSA (USA) website, where she found the support and information needed for all of Cameron's doctors. "Knowing that he had this syndrome really answered a lot of questions we had about Cameron," she said.

June offered the following remembrances of Cameron. "He loved watching old movies and "I Love Lucy" TV shows and had the best sense of direction of anyone in the family. He always remembered directions and knew how to go everywhere in the community. He was also very loving: if someone mentioned a headache, Cameron offered an instant prayer to heal "her broke head" — he was the ultimate Christian and preacher. His love was unconditional and all our family got the benefit of his love."



## Linda Beltran

On July 4, 2005, Linda Thompson Beltran, wife of Dr. Delfin "Sam" Beltran for 35 years, died after a long illness of pulmonary failure. Trained as a nurse, Linda was an expert at smocking, antique embroidery and dress making for children and grandchildren.

An anesthesiologist now retired, Sam served faithfully as the first Board Chairman of PWSA for 5 years and then as president of PWSA for another 5 years. Sarah, age 33, one of their two daughters, has PWS.

The family designated that all memorial gifts are to go to PWSA (USA). Sam's many friends in his PWS "family" who may want to express their sympathy can write to him at P.O. Box 785, Andover, KS 67002, or e-mail him at [djbltrn797@sbcglobal.net](mailto:djbltrn797@sbcglobal.net).

The PWSA (USA) Bereavement Program is coordinated by Volunteer Norma Rupe. We offer free bereavement support materials for our members, along with envelopes for memorial donations. For more information about these and other materials, please contact the PWSA (USA) National Office.



### Muskingum honors Mitchell

Lota Mitchell, shown with her daughter Julie, who has PWS, accepts the Distinguished Service Award presented by Muskingum College in New Concord, Ohio. The awards are conferred "sparingly and thoughtfully only upon those who have achieved distinction in a field involving full use of an individual's creative powers, both intellectually and aesthetically, keeping foremost in mind in all cases that the recipient's accomplishments should clearly reflect significant service to mankind, so that the conferring of such an award will always accentuate and extend the values associated with Muskingum College."

The college's highest alumnae honor recognized Lota's work on behalf of PWS, both as a leader of PWSA (USA) and in promoting understanding and awareness of the syndrome. A Muskingum graduate, Lota spent 20 years as a licensed social worker, counselor and community volunteer, and was instrumental in initiating the PWS program at the Children's Institute in Pittsburgh, Pa.

## New From PWSA (USA)

### No. 967 — *Work Out DVD*

"Working Out Big Willy Style" is a safe and effective workout with Tad Tomaseski and Patrick Taylor of Texas, who has PWS, to *My Name's Not Willy!* and other great motivating music. Cost of this entertaining and instructional DVD is \$15 plus shipping, available through the PWSA (USA) national office.

### No. 241 — *"Food Behavior & Beyond" DVD*

Developmental Pediatrician Linda Gourash, MD and Neuropsychiatrist Janice Foster, MD present strategies for dealing with behavior and management of PWS. The 2½ hour presentation is in five sections; topics include nutrition, weight management, medications and coping skills. Cost is \$25 plus shipping, available through the PWSA (USA) national office.



## Contributions In Memory Of

### Stephen Dam

Ole & Kristin Dam

### Renee Davis

Melvin & Schelley Childress

### Edith Falk

James & Linda Carraher

### Gertrude Firger

Eleanor & Richard Weiner

F. John & Catherine Kratz

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Donald & Linda Gehris

### Kimberly Ann Fuja

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### Dustin Glover

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Frances Carter

Frank & Marion Vaughn

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Jennifer Jennings-Glover

John Boatright II

John & Dabney Maloney

John & Karen Pratt

Kenneth & Susan McLeod

Kevin & Doris Carlin

Lavon & Patricia Tadlock

### Dustin Glover (cont'd)

Lois & Mary Staff

Margaret Jennings

Paul & Sally Bradshaw

Randall & Rebecca Armstrong

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Seven Hills Dental Laboratory, Inc.

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NRC Industries, Inc.

Live Oak Diagnostic

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### Andrew Hill

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William Fey

### Barbara Miller LaFebvre

Lota & Dave Mitchell

### Paul Leonard

Donald & Sandra Hartley

Randy Cochran

Patrick DiPaolo

### Jack Levine

Michele & Stephen Leightman

### Patricia McCall

Bill & Jean McCall

Sandra Moulton

### Lawton Miller

Laura's Boutique

### Elva Moratto

Jacquelyn Brokaw

### Patricia L. Rupe

William & Norma Rupe

### Anthony "Tony" Tomasilli

Sharon & Dennis Christman

## Craig wants a Pen Pal

Craig is a young male adult with PWS who would like a pen pal. His address is

Craig MacDonald  
20149 6th Place NE  
Shoreline, WA 98155

# Contributions

Thank you for Contributions through July 2005

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

## With Much Appreciation

We are deeply grateful to our individual, corporate and foundation sponsors whose contributions enable us to serve, comfort and support all of our families.

### Major Benefactors (\$500 and more)

David & Janice Agarwal	William & Norma Rupe
Cinda & Curt Ball	Walt & Terri Weiss
John & Alice Basso	PWSA of Ohio
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## A Note To Our Readers

Included with this issue of *The Gathered View* is our PWSA (USA) Annual Report for the Year 2004. We compiled totals of finances, services provided, and donations received for our annual audit.

Our auditor provided services at a reduced rate in exchange for our willingness to wait for completion of the work. We apologize for the resulting publication delay, and hope it did not inconvenience anyone. Our 2004 annual report only lists the names of major donors who contributed to PWSA (USA) during 2004, but we will change this practice in future annual reports.

**Because of space limitations, issues of *The Gathered View* will henceforth list only Major Benefactors and contributions in Memory Of and In Honor Of.** All other donations, including those to the Angel Fund and Valentine Research Fund, will be listed in our Annual Report for the Year 2005. This will leave more space for needed medical information and articles.

As always, we acknowledge with sincere appreciation the generosity of those who help support our mission to enhance the lives of everyone impacted with Prader-Willi syndrome.

### In Honor Of

Aimee Atwood	John (Jake) Pawulak	Sean Patrick Healy	Allison Hanna
Stephen King	Susan & Garry Neal	Jeannine Darcy	Carol & Glenn Hanna
Anna Guthrie	Kyle Galloway	Payton Click's 3rd Birthday	Ashlyn Ricardo & Janet Berg
J. David & Michelle Williams	Brandon Tidwell	Scott & Melissa Whitley	David & Deborah Glass
Marcus & Sharon Bantel	Leslie Torbert	Alan & Arlene Feeley	First Colony Development Co. Inc.
Tommy & Emily Joy Chandler	Delores Ward	Karyn & Colin Jones	Edaville USA
James & Robyn Burdette	Merv & Judy Waldman	Bill & Marolyn Halverson	New England Home
John & Jamie Calabrese	Michelle & Tommy Torbert	Edward & Kristi Zammit	Walter & Marianna Moseley
<b>Erika Breneisen</b>	<b>Luke Needel</b>	Paul Richardson	Wayne & Lynn Maurice
Jere & Isa Breneisen	Richard & Ruth Aronson	Jewel Allen	Donald & Dorothy Smythe
<b>Hailey Postal's 2nd Birthday</b>	<b>Sonny Roberto</b>	Robert & Catherine Rohloff	<b>Danielle White</b>
Kimberly & Evan Postal	Michael Roberto	Gerald & Nita Merritt	Anne O. Urquhart Miller
Dr. James & Darcy MacGaffey	<b>Sophie Bolander</b>	Bryan Denham	<b>Eliot Slifcak's 1st Birthday</b>
Larry & Darlene Preston	Marianne Karras	John & Michael Miller	Joseph & Mary Ellen Matts
Cynthia Ferrante	<b>Tim O'Leary</b>	John & Karen Conroy	<b>Grace Larmer-DiFilippo</b>
Allegra Korman	Lynne Croshier	Mallory Bowie	Joseph A DiFilippo
Sandra Gephart	<b>Madison Riley Hurdle</b>	Mr. & Mrs. Robert Legendre	<b>Kerrigan Mehner</b>
<b>Jack &amp; Isabella Burnham</b>	Jerry Rubin	<b>Alessandra Reinhardt</b>	Suzanne Schreiner
Alan & Trisha Keene	<b>Roxy Peterson</b>	Caryn & Steven Schreiner	
	Edith Lipinski		

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.

