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# The *Gathered View*

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



Cohan Boyd, Australia

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**Donations for Research**  
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**\$212,392**

## Going Through A Change of View

By Diane Seely

In my previous life... I believed that children with special needs only belonged to other parents and that it could never happen to me. God knows I just wasn't cut out for that. After all, I am the mother of four healthy children. I looked at parents with pity as they pushed a wheelchair through the mall and breathed a huge sigh of relief that it's someone else.

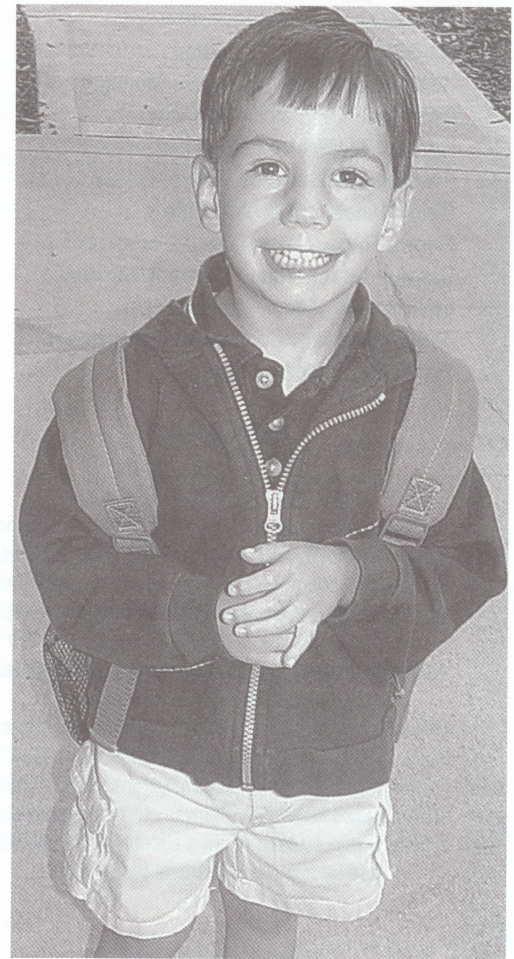
Now as I lovingly watch my sweet boy sleeping in my arms, after 3 years I have finally begun to accept that I am now that parent and this child is not someone else's.

Those first years were a blur of sadness and shock at what we had been handed as we struggled to find any hope for the future. This devastating news has not only changed my life, it's changed who I am. I see things differently now. When I see a mother with her child in a wheelchair in the mall, struggling to get through the too narrow aisles, I feel like I know her already. I've felt the stinging pain in hearing those words that echo in my head, "There's something wrong with your baby."

As I turn 46 this year, I am humbly wiser now. My reality is that my fifth child has Prader-Willi syndrome. At his diagnosis at a mere 4 weeks old weighing only 4 lbs., we were told of his destiny. A life full of developmental delays, a metabolic disorder, we were told. At first he will struggle to eat, then as he got better it would level out for a short period, then it will reverse and he will eat to the extent of possibly gorging himself. He will never feel full; his diet will need to be closely monitored. We may have to resort to locking our cabinets and our refrigerator to keep him from eating himself to death.

The irony in this is the motto I have tried to impose on my growing children: eat to live, not live to eat. We already had ground rules about snacks and soda in our house. But counting calories? I never dieted in my life. I

Reagan Seely, who has PWS, is ready for his first day of pre-school



ate when I wanted and never gained a pound! I had a strong sense of blame for those who were overweight and a belief that it was mostly just laziness or lack of self-control on their part.

Today when I see an overweight person, I no longer see he/she is *fat* and look away in disgust. I look into his/her eyes and see that there is a soul that longs to be recognized and a heart that is worthy of love.

*Reagan continued on page 13*



# 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](mailto:national@pwsausa.org) • web site: [www.pwsausa.org](http://www.pwsausa.org)

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*The Gathered View* are:

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

**Our Mission:** PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those impacted by Prader-Willi syndrome.

**Members Only:** Check our website [www.pwsausa.org](http://www.pwsausa.org) for downloadable publications, current news, current research and much, much more limited to members only!

User Name: pwsamember Password this issue: texas07

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

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

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## Great Results Come From Working Together

**Carolyn Loker**

*I'm so pleased to report that we have a new educational DVD available, Understanding the Student with PWS: Strategies for Success. I'm even more pleased to let Michelle Donaldson tell you how this valuable tool came about because so many people were willing to work together.*

My son with PWS is 16 and we are in our 11th year of school. We've had some wonderful teachers, aides and administrators and, of course, plenty of folks who just couldn't "get" PWS. We've also had repeated suspensions, and two legal battles with our school district. I know that our situation is, sadly, far from unique.

I have delivered numerous copies of the "Pupils Wanting Success" packet by Barb Dorn and BJ Goff, highlighting the parts that are particularly relevant to our situation. And while it's been as useful as the willingness of school staff to read, retain and apply the information, I realized we needed more to prevent repeated recurrences of incidents that were preventable if the adults involved were truly educated about PWS. I desperately wished for a DVD to educate school staff about PWS specific school issues.

When I joined the Prader-Willi California Foundation Board of Directors (PWCF), our Executive Director Lisa Graziano encouraged me to work on creating just such a DVD. I knew a DVD producer, Ruby Gold from Saving Time Productions, who was willing to work with me on this project. Later we learned there was a parent in Massachusetts, Bob Bernstein, with a plan to raise funds for such a project (read about his event on page 11), and a committee from PWSA (USA) who were also exploring creating a school DVD. So we joined forces and finances to make the DVD a reality.

Mary Kay Ziccardi, a PWS school expert who also serves on the PWSA (USA) Board of Directors, came to California for a school consultation and graciously spent her free time being interviewed for the educational DVD. With our PWS expert interview completed, we found teachers and kids who were willing to participate and demonstrate management strategies.

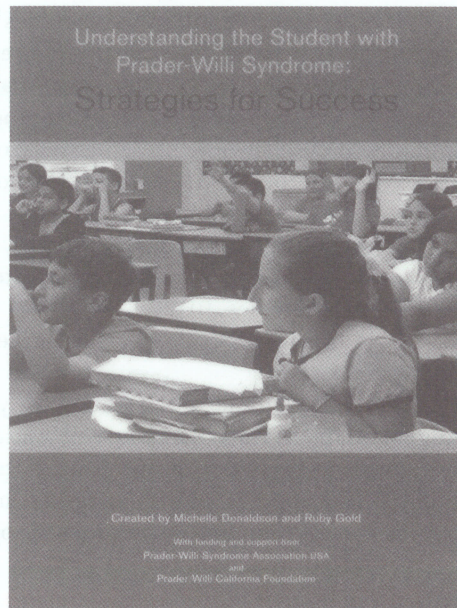
PWSA (USA) and PWCF are proud to make this new DVD available. We hope that families can require DVD viewing for school staff in their IEP's; we made it short enough (about 40 minutes) to be viewed during a lunch or prep period by a number of school staff, while still addressing many of the major issues involved in teaching a student with PWS.

Obviously, 40 minutes of viewing time cannot tell staff all they need to know about the many facets and differing

abilities of students with PWS, but it can provide a good basis for educators and families to strategize solutions for their particular student's needs. By presenting some of the more difficult issues, such as lying, confabulation and tantrums, we hope

to move the discussion beyond "that parent is making excuses for his/her child" to "that is a manifestation of that child's disability – how can we better manage the environment to reduce or eliminate that behavior?"

This collaborative effort among numerous people and two organizations provides another example of the great things we can accomplish working together to support our children with PWS.



### A Parent Praises Our New DVD

Anita Perrault, whose son Jacob has PWS, received the new school DVD just as she was preparing for a meeting at Jacob's school in early December. She showed the entire video using the lower grade track to teachers, therapists and others. She paused the video at times to talk about how something just covered related to Jacob.

Anita noticed that one of his teachers had a "light bulb" moment when she understood how careful she would have to be in setting routines for a student with PWS and communicating if they were to change. The DVD offered options of what may be a helpful approach in transitioning from one activity to the next.

"I am very grateful to have been given this DVD," said Anita, "and a very special thank you to Cindy (Beles) from National who overnighted it to me so I was able to share it with the group."



## 2007 PWSA (USA) National Conference

# What's Happening in Texas This summer? A Whole Lot!

The 29<sup>th</sup> Annual PWSA (USA) National Conference is fast approaching and we have an incredible line-up of speakers and presentations. The Conference will be held **August 1-3** at **The Hotel InterContinental Dallas** in Addison, Texas.

This year's Conference includes the **Scientific, Professional Provider** and **Chapter President/Affiliate Days** on August 1, followed by the **General Conference** and **YAP** (Youth and Adult Program)/ **YIP** (Youth and Infant Programs) Programs on August 2 and 3.

A graphic featuring a silhouette of a person riding a horse, with a speech bubble above them containing the text "Blazing New Trails". The background shows a silhouette of a mountain range.

## Blazing New Trails

The General Conference includes several sessions of interest to all attendees, as well as breakout sessions organized into topics specifically geared toward the issues and achievements of Adults, Youth (school age), and Children from age 0 – 5 who have Prader-Willi syndrome. We are featuring a general session panel comprised of doctors from the fields of endocrinology, genetics, speech pathology, behavior experts and gastroenterology, along with an overview presentation from the Scientific Day to recap the exciting research going on in the world of PWS. The breakout sessions include speakers on:

- Speech Apraxia/Dyspraxia
- Behavior Modification Strategies
- Genetics 101
- School Strategies for Success
- Crisis Intervention
- My Child is 21, what's next?
- Legal Rights under ADA, IDEA, and Guardianships
- Strengthening Family Relationships

We will continue the tradition of years past with a General Membership Meeting during the lunch hour on August 2 and a Gala Banquet celebration on Thursday evening. This year the Gala Banquet will be divided into two separate events: a dinner for adults and children under 5 for a chance to socialize and unwind; and a "night at the prom" dinner with dancing and music for our YAP participants. We will once again hold a Silent Auction as well as lots of fun and inspirational programming for our YAP participants.

**Don't be left out! Registration will be available on [www.pwsausa.org](http://www.pwsausa.org) beginning April 1, 2007.**

## Plan NOW for 2007 Conference Grant Requests

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

- State Developmental Disability Council – 1-800-695-0285
- NICHCY or check their web site [www.nichcy.org](http://www.nichcy.org)
- Your local church or temple, or your state PWS Chapter
- The ARC (disability related funding)
- Parent-to-Parent (disability related funding)

And then...PWSA(USA) Grants. Please use these criteria to prepare your grant request to PWSA (USA): Names of family members to attend (maximum 4 people, please); children's ages; address, e-mail, and phone numbers. Reason you want to attend, what you hope to achieve and how you'll share information. Explain special financial and/or emotional needs of your family. Specify dollar amount needed and its purpose, i.e. registration, lodging, travel, etc.

How much can you put toward the cost? What grants have you received before (national or local conferences)?

**All grant recipients will be required to be or become members of PWSA (USA). If the membership cost is a problem, a Scholarship membership can be requested.** Grant funds apply *only* to those registered for the conference programs. Grant funds may not be used for extra nights' lodging, food, etc.

So that we can assist more families, grants may not always include air fare. All reservations will be made through our travel group. **Submission deadline is April 30, 2007 for PWSA (USA) grant applications.**

- E-mail grant requests to: [national@pwsausa.org](mailto:national@pwsausa.org)
- Fax to: 941-312-0142
- Mail to: Prader-Willi Syndrome Association (USA)  
5700 Midnight Pass Rd. Ste. 6  
Sarasota, FL 34242  
Attn: Grant Committee

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# The Children's Institute: A Success Story for PWS Families

By Lota Mitchell, Associate Editor

"Welcome!" said Lucy Krut, R.N., Patient Care Coordinator at The Children's Institute (TCI) when I visited the Prader-Willi program and its newly remodeled unit.

TCI began in 1902 as the Memorial Home for Crippled Children, becoming a leader in pediatric rehabilitation techniques. In 1981 it became The Rehabilitation Institute of Pittsburgh, reflecting its increased scope in treating both children and adults with disabilities.

That year also saw the first program for children with PWS, ages 8 to 12, expanding the following year to encompass the teen years. Soon individuals with PWS of all ages were included, and patients from all over the country and beyond were admitted. In 1998 the renamed Children's Institute returned to its roots of serving only children with disabilities but retained its program for PWS for all ages.

A shining example is PWS program graduate Alex Ashe, age 18. When this young man from Chicago entered TCI in November 2005, his vital statistics were: 5'1", weight 322 lbs., 2X top, 44" waist. There he learned the importance of diet and exercise. When he left eight weeks later weighing 197.7 lbs., his family diligently kept up the structure and diet at home.

Proud mom Anita Ashe reports his November 2006 vital statistics: weight 133 lbs., man's small or medium top, 32" jeans. "He continues to exercise daily, walks every day for 30 min. and works out at a local health club about 3-4 days a week to build muscle and endurance (stair master, treadmill and upper body machines) and swims! He no longer eats between meals ever, and has about 800-1000 calories a day! I have become a creative meal planner and he very rarely says that he's hungry. The Institute taught us how to do it! We are consistent — Alex looks wonderful, feels good, and is very proud of his discipline and compliance — he knows the rules and when offered a "treat" from someone who doesn't know about his new life — he will politely refuse!"

Unit psychiatrist Dr. Gregory Cherpes, certified for both adult and pediatrics, has spent his entire career with developmental disabilities. His goals are to help people "find their human dignity," dispel stigma and the sense of internal fault. His medication philosophy is "small doses, small changes" to target symptoms.

Dr. Cindy Smith, attending physician for the program, is certified in pediatrics, physical medicine and rehabilitation. She believes it's necessary for her patients to "change completely their whole mind set. They need to know that they can be thin and happy, they need routine, and they need the anxiety about food taken out."

An important team member is Patient Care Manager Ken Smith, who assists in getting patients in and coordinates parent education. Ken, who is also co-chair of the PWSA (USA) Board of Directors, has been with the program 21 years, working first with Bea Maier, its originator.

Lucy is one of two full-time R.N.s in the direct care staff, along with two part-time R.N.s and 14 health care workers, many of whom have been there 10 years or more.

Alex Ashe, below, who has PWS, once weighed over 300 pounds (inset). He slimmed down and now keeps his weight under control.

Other support staff include psychology, dietary, speech, PT, OT, and recreational therapy. Teachers work with younger patients in conjunction with their original schools.

Patients had just moved into the new, truly impressive state-of-the-art unit two weeks earlier. Instead of the four-to-a-room of the past, rooms are either private or semi-private. Two rec rooms provide ample areas for relaxation and socialization, complete with TV, puzzles and computer. On Sundays patients are treated to a movie and popcorn. Breakfast is served right on the unit. A step-in whirlpool with a door can accommodate the largest patient. The all-new beds include two huge bariatric ones that can fold into chairs and assist the severely obese to get up.

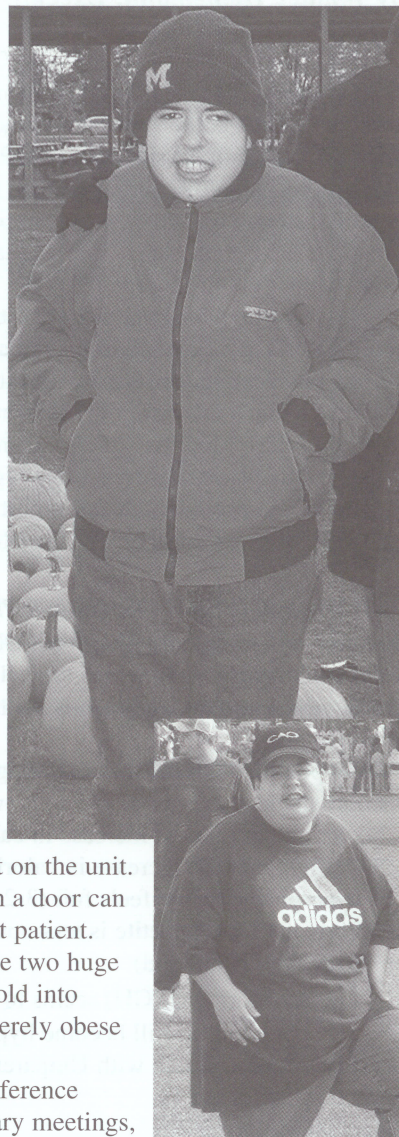
There's a small conference room for multidisciplinary meetings, and a quiet room with a see-through window if a person is a danger to self. Only five times was this needed in 2005.

The unit is designed for 12 patients. Each has an integrated treatment plan. Average stay is 45 days, with a range of 30-90. Typical diet is 600 calories a day, although some receive more. Exercise is an essential component.

Discharge planning is crucial. Parents receive education at admission, at midway, to meet with dietician and psychologist — and get homework — and at discharge. Dr. Smith noted that insurance companies support parent education because their money is spent in vain if necessary supports are not put into place when the individual goes home.

Alex's mom says, "We never could have accomplished all of the necessary changes at home without the Institute in Pittsburgh."

What a success story — and Alex is only one of many children and adults with PWS who have received life-saving help at the Institute in a program unlike any other in the world.





# Worldwide Experts Meet On PWS In Toulouse, France

By Janalee Heinemann, Executive Director

Prior to this two-day meeting in October, Dr. Linda Gourash, Pam Eisen and I visited the main PWS clinic in the hospital of Dr. Maïthé Tauber in France and met with its impressive staff of 18 specialists on PWS. This clinic, started in 2004, has a multidisciplinary team including a dentist, digestive surgeon, neurologist, orthopedist, a gynecologist for adults, speech therapist and language center, psychologist, endocrinologist, geneticist, etc. They follow 105 patients, of whom 75 are children. A transition team coordinates adult care and trains the adult specialists.

At the meeting, I was privileged to be the first speaker. There was much interest in the information I presented (thanks to Barb McManus' help) from our medical and study of death data bases. Here are some highlights of key interest to parents and providers. A full report can be found on the web site, [www.pwsausa.org](http://www.pwsausa.org), in the Members Only section.

• **D Driscoll (USA) – Nutritional Phases** – more complex than in two traditionally described. Obesity usually comes before the hyperphagia, which typically comes later than classically described, and then is further exacerbated by the hyperphagia.

- 1a) hypotonia with difficulty feeding (0-6 months)
- 1b) no difficulty feeding, growing on curve (3-24 months)
- 2a) weight up without increase in calories (1.5-3yrs)
- 2b) weight up with increase in calories (2-12 years)
- 3) hyperphagic, never feels full (3-21 yrs +)
- 4) Previous 3 but appetite is less now (adulthood; most likely later adulthood)

Growth Hormone (GH) seems to delay the onset of Phase 2, but children still become hyperphagic. GH may decrease ghrelin. Those with Uniparental Disomy usually have a milder phase 1a.

• **B Rogé (France) – Is There A Relationship Between Autism And PWS?** – Autism spectrum disorder is seen in 25.3% of children with PWS. Those with PWS are more into collecting and storing objects. Those with autism are more into lining up objects. UPD at greater risk for autism symptomatology. IQ makes no difference. Still seeing a high rate of psychotic disorders in UPD, more non-psychotic depression in deletion.

• **T Nagai (Japan) – Overview Of Spontaneous Death Report In Japan** – Deaths of 17 Japanese patients with PWS reported. One was on GH. Ten died under age 5 from rotavirus and respiratory – primarily aspiration. Four deaths of those over age 20 obesity and diabetes related. Two were reported with cardiomyopathy, and two died in bathtubs.

• **A Hokken-Koelga (Netherlands) – Does GH Improve Cognitive & Social Development?** – Studied the effect of GH on psychomotor development in 43 Dutch infants, aged

6 months to 3 years. Had a control group. Motor development improved, and mental development tended to improve with GH. The earlier the start, the more the improvement. They think ideal age to start GH is 6 months.

• **M Ritzen (Sweden) – Breathing And Sleeping Abnormalities** – GH improves ventilatory response and increases respiratory muscles. All children with PWS have sleep related apnea disorder. Obstructive apnea is obesity related. He feels respiratory risk is the issue – not GH. He recommends hospitalization during illness.

• **B Schlüter (Denmark) – Sleep Disorders: Diagnostic And Treatment, A Practical Approach** – The circadian rhythm of sleep and wakefulness is disturbed by the hypothalamic dysfunction. There is an abnormal sleep architecture. Polysomnography is strongly recommended prior to and after starting GH treatment.

• **J Miller (USA) – Is There Any Relationship With IGF-1 Levels?** – All those with PWS have some sleep disturbed breathing. Airway infections worsen it. Obstructive apnea may worsen with GH due to possible hypertrophy of tonsils and adenoids. IGF-1 levels need to be monitored. GH can increase head size. In older kids, it can create acromegaly (overgrowth of the face) & elongation of hands. Should we be using monitors as a precaution during respiratory illness? Should we be using melatonin to improve sleep cycle?

• **D Festen (The Netherlands) – Prevalence Of Breathing Disorders In Children With PWS** – She agreed most with PWS have apnea, mostly central apnea. Obstructive apnea observed in 50% of obese children with PWS. Sleep-related breathing disorders were not aggravated by GH treatment and central apnea may even be reduced. Obstructive apnea may increase during upper respiratory tract infections. (This data excluded those with upper respiratory infections or tonsillectomies, which could affect the conclusion.)

• **M Butler (USA) – Does The Genotype Influence Our Care?** – Type 1 (larger deletion) is 40% and Type 2 (smaller) is 60%. Type 1 performed more poorly in academic achievements, had more behavioral and psychological problems than Type II. Four genes are absent in Type I.

• **F Muscatelli (France) – Necdin not expressed in PWS.** Necdin deficient mice mimic PWS in poor growth, high pain threshold, skin scratching, better spatial skills, central respiratory problems.

*France continued on page 7*

Find the full report of the 2<sup>nd</sup> Expert Meeting on PWS at [www.congrex.com/pws2006](http://www.congrex.com/pws2006)



- **B Horsthemke (Germany) – Imprinting Defects** – account for approximately 1% of patients with PWS. Imprinting Center (IC) deletions represent only 15% of this type of defects and have a recurrence risk as high as 50%. They have a rapid screening method that distinguishes different deletion types and detects small rearrangements.

- **J Miller (USA) – Studied 20 with PWS, 18 EMOs (early morbid obesity) and 21 sibs.** Did brain scans. There were pituitary gland abnormalities in both PWS and EMO. They defined brain differences. Suspect that GH will improve brain development. It made a difference in myelin development.

- **A Carrel (USA) – Effects of GH Treatment** – Improvements can be seen in growth rate, metabolic profile, body composition (lean muscle mass and body fat), physical function, agility and neurodevelopment. If taken off GH, children's body fat went up. With GH, significant increase in calories tolerated, pulmonary strength statistically improved. In infants, mobility and stability significantly increased. More benefit if started earlier. Response to GH is greatest in the first 12 months. Improves, but does not bring them up to "normal."

- **A. Goldstone (UK) – PWS And Peripheral Satiety Signals** – Various peripheral signals (of which ghrelin is one) act to control appetite.

Interaction of peripheral signals, the autonomic nervous system and higher brain centres link the homeostatic state, response to food stimuli and food intake.

Delayed meal termination and impaired satiation, as well as earlier meal initiation and return of hunger, occur in PWS patients, despite delayed gastric emptying.

No defects of leptin, gastrin, obestatin, somatostatin, glucagon, cholecystokinin, gastric inhibitory peptide, peptide YY or glucagons-like peptide-1 contribute to hyperphagia. Elevated ghrelin, pancreatic polypeptide deficiency and, perhaps, hyperinsulinaemia may contribute to hyperphagia.

Functional MRI and positron emission tomography show abnormal corticolimbic activity after oral glucose or eating a meal, suggesting increased reward, emotional and motivational responses in PWS patients.

- **F Accadbled & T Odent (France) Scoliosis: Epidemiology and Management** – 139 patients. Prevalence of scoliosis is 40-50% without gender difference – 0-5 15%, 5-10 22%, 10 + 63%. AIS (acute idiopathic scoliosis) more in girls. Obesity worsens scoliosis. They use a rigid brace in young children. Difficulty in molding – lack of compliance, weight fluctuation. Surgery complications – obesity, diabetes, self mutilation, osteoporosis, compromised respiratory function. 30% have major complications from surgery. Halo traction not recommended.

France continued on page 8

## PWSA (USA) Presentation in France From Our Database Study

# What Can We Learn From Parents and Associations?

By Janalee Heinemann, MSW, PWSA (USA) Executive  
Director and Barb McManus, PWSA (USA) Data  
Collections Coordinator

### Objective

To highlight key areas of interest gleaned from the quantitative medical (1,471) and death (178) databases of the extensive membership organization in the USA that was founded by Prader-Willi syndrome parents.

### Design

Surveys were made available through PWSA (USA) which documented demographic data. Medical surveys completed by families were categorized by ages 0-5, 6-18, 19-34, 35 and up to compare medical issues at various ages. Also compared was UPD vs. deletion and those with PWS on growth hormone vs. persons not on growth hormone.

In the mortality study, PWSA (USA) has basic information of 178 deaths. Cause of death is recorded on 152, and more extensive questionnaires, medical records and/or autopsies have been obtained on 55 children and adults with PWS. Questionnaires and medical records are reviewed by a medical team.

### Medical database result samples

Significant variances by age: weight-related 0-5 (37%), 6-18 (62%), 19-34 (79%), 35 & up (87%) [Those with a BMI in the obese range had a much higher percentage of morbidly obese in the 19-34 age range (112 of 205) than those in the 35 & up (23 of 145)]; diabetes 0-5 (0%), 6-18 (10%), 19-34 (18%), 35 & up (26%); high pain tolerance 0-5 (18%), 6-18 (46%), 19-34 (64%), 35 & up (63%).

Significant variances of UPD Vs. deletion in the 6-18 age group: weight-related UPD (51%), deletion (64%); sleep apnea UPD (30%), deletion (45%); severe skin picking UPD (21%), deletion (38%); autistic behavior UPD (21%), deletion (15%).

Significant variances of growth hormone vs. no growth hormone in the 6-18 age group: weight related GH (57%), no-GH (82%); sleep apnea GH (39%), no-GH (52%); diabetes GH (1%), no-GH (10%); severe skin picking GH (31%), no-GH (40%); hypothyroidism GH (11%), no-GH (3%).

### Mortality study

As expected, most deaths were obesity-related. Two unique causes of death bring special alerts: gastric rupture and necrosis, and choking in the older person with PWS

### Conclusion

Large parent-based organizations may have easier access to information on rare disorders. Professional partnering with PWSA (USA) has enhanced the knowledge of medical professionals and scientists and given them more insight on areas needing qualitative research.

✓ Make sure you are counted! Participate in  
our PWSA (USA) study by going to  
[www.pwsausa.org/population](http://www.pwsausa.org/population)



## Poisoning in People with Prader-Willi Syndrome

*The following report from a mother in New Jersey is a reminder to parents and caregivers of the increased prevalence of poisoning in people with PWS. Studies have shown that those with a history of eating unusual objects were found to have a 5.7-fold increased risk of poisoning over those with PWS without such a history. A history of extreme behaviors was also seen to have a relationship to poisoning. Primary care providers and poison control centers also need to be aware of this association, as well as the implications of PWS for diagnosing and treating ingestions.*

— **Janalee Heinemann**

"Last night I spent the night in the hospital with my daughter. She came stumbling down our hallway at 4:45 p.m. At first, I thought she was joking around. Five minutes later she collapsed. By the time we got her to the hospital at 5:15, she was unconscious. She was tested for all kinds of things that she may have ingested and we found out that her blood alcohol level was .181. After 2 hours of trying to figure out what she either ate, drank or was given, we realized that she drank tequila, at least six ounces of it, all at once.

"This was truly a wake-up call for us that we have to be 100% diligent with regard to locking up things like liquor and medicine in addition to food. I simply forgot to put it away properly and even though it was not out in the open, she found it and seized the moment, totally unaware of what she was drinking. It was so frightening until we realized what had happened and that she would come out of it. It could have been a lot worse...she could have fallen down stairs in her drunken state or ingested something more threatening.

"If there is any good to come from this, it is the fact that I can alert other parents to be aware and prepared. My daughter is fine now. The other part to this is that she showed no pain with regard to any sort of hangover/headache and she didn't vomit, even after consuming several ounces of the tequila — it doesn't get any more "PWS" than that!

"The funny thing is that she won't eat a tomato because 'they taste nasty.' I wonder how she would describe the taste of several shots of straight tequila without any lime or salt!"

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### France - continued from page 7

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• **G Grugni (Italy) – Sex Steroid Replacement and Bone Health** – Skeletal development involves a number of systemic hormones (e.g. gonadal steroids, estrogen, androgen receptors). 37% of skeletal mass is accrued during pubertal stage. PWS is unusual in having low bone density in spite of obesity. Starting in adolescents, those with PWS should have a DEXA scan every 1-2 years. Recommended estrogen to be given if low E2 levels and/or when bone mineral density (BMD) becomes low normal. For males, low dose testosterone starting early adolescents with patches or gel preparations in select cases. BMD did not change significantly with GH treatment. Need calcium supplements with vitamin D and low-impact aerobic activity. Biphosphonate recommended in severe cases.

• **D Thuilleaux & A Vogels (France) – Presentation and Treatment Of Psychiatric Disorders** – Rapid cycling of depressive episodes and delusional episodes. When they cycle, can go from phases of hyperactivity to phases of hypoactivity. Psychosis – deletion 16% and in UPD 71% in those older than 13 years. Stressors that can precipitate a psychotic episode are: loss, separation, strict dieting. Behavior pattern during childhood of those most likely to have a psychotic episode is that all were active and extroverted. Alarm signs are: refusal of food, hallucinations, disturbed sleep cycles. Use meds in low dose and work on stress reduction.

Typical behaviors – fixation, magical belief, lies, lack of inhibition, acute feeling of injustice, hyper-sensitive to the judgment of others. More Pervasive Development Disorders than classic OCD. Difficulty in introspection. Full autonomy is not realistic.

• **BP Hauffa (Denmark) – Is Ghrelin Involved In The PWS Phenotype?** – Ghrelin may be one player amongst a number of neuroendocrine factors that contribute to hyperphagia and obesity in PWS. Ghrelin is the only known orexigenic (substance that increases or stimulates the appetite) hormone. Plasma ghrelin levels increase before meals to stimulate hunger, and decline after food; are inversely related to BMI, body fat and insulin; decrease with age.

Somatostatin acutely decreases plasma ghrelin, but does not decrease appetite.

Inconsistent results have been obtained with GH treatment in PWS. In some studies, no effect has been found, but in the speaker's own study, plasma total ghrelin (but not the active acylated ghrelin) was significantly decreased by GH treatment.

In the future, blocking the action of ghrelin may help to clarify the physiological role of ghrelin.

• **D Swaab (Denmark) — What Is Wrong With The Hypothalamus?** – Hypothalamic dysfunction can explain many of the symptoms of PWS. The paraventricular nucleus (PVN) is a center for autonomic hormonal and appetite regulation. In PWS patients the volume of the PVN and the total number of PVN cells are decreased; the number of oxytocin neurons in the PVN is decreased.

No abnormalities in neuropeptide Y, agouti-related protein, pro-opiomelanocortin, gonadotrophin-releasing hormone, melanin-concentrating hormone receptor 1, ghrelin receptor or orexin have been found that could explain the phenotype of PWS.

Preliminary studies found Alzheimer's-like neurofibrillary tangles in the hypothalamus of older patients with PWS.





# PWSA (USA)

## Prader-Willi Syndrome Association (USA)

### Allegations of Abuse and/or Neglect in the Person with Prader-Willi Syndrome

Prepared by Barb Dorn R.N., B.S.N., and Kate Beaver, M.S.W., Crisis Intervention Counselors, PWSA (USA)

Because of some intrinsic features of the syndrome, parents and care providers for persons with Prader-Willi syndrome (PWS) are at increased risk for accusations of child abuse. The safety and well-being of a child or adult with PWS is always the number one priority and concern. While all reports or suspicions of abuse or neglect should be evaluated by a human service professional, it is important for the investigating professional to be informed regarding signs and behaviors seen in many persons with PWS. We provide the following information to assist the professional during the investigative process.

**Sores – Skin Picking** – It is common to see open sores across many parts of the body on a person with PWS. These sores typically result

because of a serious skin-picking habit coupled with a decreased sense of the pain that in unaffected individuals would lead to cessation of the picking. Many persons with this disorder will pick at insect bites, pimples and other skin lesions. You may see finger nails that

are bitten very short and cuticles that may be scabbed or scarred. It is common for many to pick at various openings of their body – nose, rectum and vagina. In some cases, affected individuals will pick at areas of their skin for no apparent reason. These sores can be mistaken for cigarette burns. Many parents and care-givers have been accused of abuse. However, after a thorough investigation, most are found to be innocent.



**Food Safety – Locks, Alarms and Food Restriction** – The hypothalamus in the brain of persons with PWS does not function properly. The appetite control center is located in this area. When people with PWS eat, the message of fullness never reaches their brain. They are always hungry and driven to find food. These individuals require structure around food in order to keep them healthy. Most persons with this disability require environmental supports to prevent access to food so they will not rupture their stomach or eat themselves to death. Parents and caregivers must use locks and/or alarms to keep them safe. In addition, persons with PWS can gain weight very easily and they require a very low-calorie diet. Even though these measures seem extreme, food-seeking behaviors in many of these individuals are so strong that these environmental supports can be life-saving.

#### **Statements of Abuse or Neglect by the Person with PWS**

– Many people with PWS will go to extreme measures to try and get food. Some have falsely accused their parents and caregivers of hurting them or denying them food, in hopes that this will get them more food. We often do not know

exactly why they make these allegations. Many are angry living with this disorder and may target frustration and anger at those who love and care for them.

**Bruising** – Persons with PWS bruise easily. The exact cause for this is unclear. Common blood tests to measure the body's ability to clot are typically normal. It is not uncommon to see a great deal of swelling in addition to numerous, sometimes large bruises after a minor bump or injury. In most instances, careful examination will reveal that the pattern of bruising is clearly unlike that found in typical cases of child abuse and should not be mistaken as such.



**For more information, please visit our website, [www.pwsausa.org](http://www.pwsausa.org), or contact PWSA (USA) 1-800-926-4797**

We all want children and adults with PWS to be safe. We also want those who may be accused of possible abuse or neglect to be given a thorough and fair chance to receive an evaluation by a professional who has a clear understanding of PWS.



## Fun and Games Yield Funds for PWS

*By Jodi O'Sullivan, Director of Community Development and Jane Phelan, Editor*

**Kevin Mullen, Darrin Kerbs and Clint and Karla Hurdle** think BIG. After raising \$57,000 at a golf tournament for PWSA (USA) in 2005, Kevin said, "I can only imagine what we will do with more time to plan this next year." In 2006, he, Darrin, Clint and Karla coordinated the **3rd Annual Golf Fore PWSA (USA) in Honor of Madison Hurdle** and netted \$72,202. That's some great planning! Kevin and Darrin are friends of **Clint and Karla** of Colorado, the parents of 4-year-old Madison, who has PWS. "I think it was an outstanding event," Kevin reported. We think everybody should have friends like Kevin and Darrin.

Clint, manager of the Colorado Rockies baseball team, served as spokesman for 2006 PWS Awareness Week. He and Karla have recruited friends and family for PWS, raising thousands of dollars at sports tournaments and more.

**Michele and Stephen Leightman** of New Jersey co-chaired "A Night To Remember — An Evening of Music and Comedy" at the Arden Theatre in Philadelphia, Pennsylvania in October. They're grandparents of Josilyn Levine, age 4, with PWS. Steve is on the PWSA (USA) Board of Directors.

A Host Committee of PWS families from the New Jersey and Eastern Pennsylvania area helped with the event planning and the guest lists. Members were: **Michael Burns & Sybil Cohen, parents of Rose, 10; Bear & L.A. Leis, parents of Amber, 12; Robert & Debra Lutz, parents of Isabel, 7; Dave & Anina Pfeiffer, parents of Brooke, 7; Mitchell & Staci Sklar, parents of Adam, 10; Suzanne Tate, parent of Ashley Willis, 4; Lynne Zarrin, grandparent of Isabel Lutz, age 7.**

This very successful event netted over \$34,000 in funds for PWSA (USA). The group plans to do it again, including more families who volunteered to help with the next event.

Sports events continue to be successful fundraisers. **Patrick Meakim** of Pennsylvania, **parent to Bridget, 10, who has PWS**, organized the **3rd Annual Cal-Chip Electronics Charity Golf Tournament** in September. The event went well, Pat reported, netting \$8,050 to support PWSA (USA)'s efforts for PWS. And how's this for uniting: Steve and Michele Leightman attended the tournament awards dinner, where Steve gave a presentation to guests about PWS and PWSA (USA).

The **Neighborhood Sports Grill 2nd Annual Charity Golf Tournament** in Florida netted \$1,200 for PWS. It was a fun day of golf in a four-person scramble format and included contests, raffles and a live auction.

**Jamie and Jackie Bassel, parents of Zachary, 2, with PWS**, worked with friend Shawn Ellen who enticed owners of the Neighborhood Sports Grill to designate PWSA (USA) as one of the event charities. The **Levine family** of Florida (including **Josilyn, 4, with PWS**) was on hand to represent PWSA (USA) and create additional awareness of PWS.

**Start by doing what's necessary;  
then do what's possible; and  
suddenly you are doing the impossible.**

*~ St. Francis of Assisi*

Taking their theme from football, **Bob Bernstein, Mike Smith and the PWS New England Chapter** teamed up for their fundraiser, **First & Goal**, and scored, netting \$36,285 from their first effort. The evening that included dinner, dancing, silent auction and entertainment by musician John Eddie and comedian Artie Lange at Gillette Stadium in Massachusetts. The funds supported production and distribu-

tion of the new education DVD, "Understanding the Student with Prader-Willi Syndrome—Strategies for Success," to educate teachers on ways to work with children who have

PWS. See more about this DVD on page 3.

Bob is parent to **Brandon, 10**, of Massachusetts, **who has PWS**, and Mike is a friend. They enlisted help from Sherie Bombardier, co-president of the PWS New England Chapter. Bob was inspired to raise money for the DVD because of his own poor experiences. "The true highlight of the evening was seeing 250 people at the actual event watching and reacting to the overview of the video that we were able to show that night," Bob wrote, adding, "It was one of the most gratifying events of my life. To see the actual finished production made everything seem so worth while!"

Rolling a different kind of ball, the **Tuskegee Airmen Motorcycle Club of Virginia** netted \$625 in strikes for PWSA (USA) at their **Prader-Willi Bowling Fundraiser** in October in Virginia. It was a first effort, reports **Sharon Mayo, parent to Johnae, 9½, who has PWS**. Nine of the Tuskegee Airmen club members volunteered to bowl in the event. Also on hand were **Cindy Galvean** from North Carolina, **aunt to Alexis, 10, with PWS**, who set up a table with special PWS tee-shirts she had made. **Lori Guthrie** of Virginia, **parent of Anna, 6, who has PWS**, helped secure media coverage. "I was very touched that Cindy and her family were so supportive and she told me if I needed any help in the future to let her know," reports Sharon, who has plans for a bigger bowling event next year.

And here's a different kind of fundraiser. **Pamela Claudio** of Welcome Home Care, along with **Kara and Adam Chymbor, parents to Evan, 3, with PWS**, all of Connecticut organized a **Health & Fun Field Day Fundraiser in honor of Evan Chymbor**, sponsored by Welcome Home Care. The fall event, attended by other local parents and families of children with PWS, had food, games, wrist-a-bouts, health information and a raffle of more than 50 items. It netted \$5,515 for PWSA (USA). "As Evan's parents, it was wonderful to see all the support we were able to gather in his name," writes Kara. "The Mayor of Meriden kicked off the event, presenting a citation to Evan. In Meriden, that day was officially 'Prader-Willi Syndrome Association Day in Honor of Evan Chymbor.' Evan was so proud during the presentation, you would think he was the mayor."



## A New Life for Laura

*By Louis Schutz*

Born three weeks late with “failure to thrive,” Laura was immediately whisked away by nurses. It was hours before I was able to hold her. An ominous beginning to what would become a lifelong struggle. Weak muscled (hypotonic), not wanting or able to eat for 5 months, our beautiful blond-haired daughter was not doing well. Scoffed at by doctors, we knew something was wrong and vigorously pursued further testing and treatments.

Physical, occupational and speech therapy were the daily routine. It would take 3 long, torturous years and multiple failed medical tests to give us the proper diagnosis of Prader-Willi syndrome.

Laura, now 19, has been a rare combination of frustration and elation. With an I.Q. of around 60 she is often brilliant in ways “normal” people are not: enjoying a horror movie and then watching Barney. She is a simply brilliant fisherman who can cast and fish for hours, most of the time out-fishing everyone in the boat. She baits her own hook, casts and releases the fish by herself.

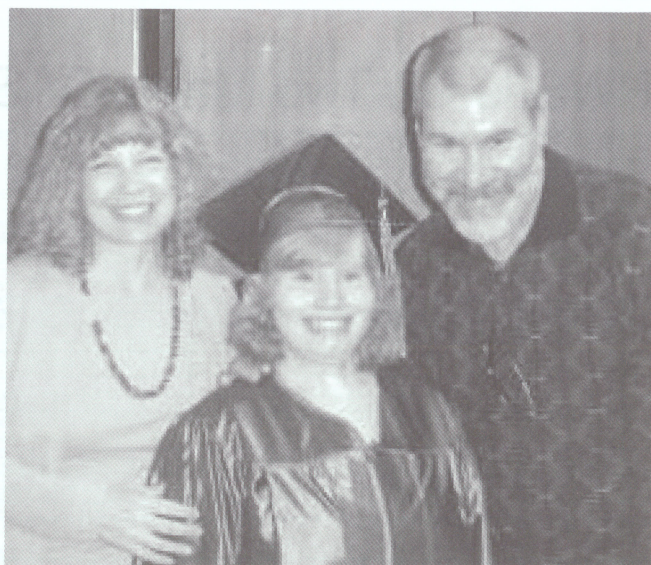
Loving and friendly to all she meets — I have lost count of the parents who have approached and thanked me for her kind attention bestowed upon their disabled child at different events. A person in a wheelchair is soon her new best buddy. Few are left untouched by her charming, loving ways. Everyone is Laura’s friend, greeted with hugs and a genuine warmth. Sincere questions are asked about their pets, children and current events in their lives. She remembers everything about each person. She knows every dog in the neighborhood by name, and they seem to know her, too.

A few years back when discussing her disabilities she looked me in the eye and floored me by saying, “Dad, I do not have disabilities, I have special-abilities,” something I have often witnessed as she has grown. After all, how many people return a year later to Disneyworld and are greeted by name by employees who remember her? Her warm smile, positive attitude and love have that effect on so many people she has met.

Her birth has had a profound effect on my life and those around her. Past care providers and teachers still call and talk with her, often marveling at her growth and mature phone banter.

At 8 years old we faced the dilemma of placing Laura in a group home. She was losing out in school, her friends and quality of life were disappearing. Her behaviors were getting worse and we felt as if we were losing control of her life and ours. Left with us only, we felt she had a dwindling, less enriching future. Without doubt the most difficult and painful decision we had ever made concerning her future was now before us. After all, do you place her at 8 or 18, or perhaps you keep her at home. Sacrificing our lives for her was an option, but we were not sure it was really in her best long-term interest or ours.

Then we read in a PWS newsletter about the parents who had kept their child at home, tragically dying in a car



Laura Schutz, who has PWS, with her parents, Judy and Louis Schutz

crash and leaving their now adult son without any safety net. We made our decision to place her, in what turned out to be a year-long struggle of government bureaucracy and frustration.

I began phoning various agencies for information and actually lost my voice after hundreds of phone calls with no results. Not one of those people offered me any hope or real help. Finally at a national conference we discovered a wonderful facility that specialized in long-term care of clients with PWS in Wisconsin. We lived outside Chicago, with not one appropriate placement facility for her in Illinois at that time. When told she had PWS, all the facilities said they could not handle her. This was a rude awakening, since she had been living at home with us and we had been taking care of her for her whole life.

Placing her a hour and half away in a specialized facility in Wisconsin was gut wrenching. When we all inspected the facility, Laura immediately made new friends and was positive about the experience.

After her two-week trial stay, I picked her up and spent the day with her off grounds, per the staff’s suggestion. When it was time to return her, I pulled up to the front doors dreading this moment. Laura ran out of the car to be with her new friends. When I called out to her for a hug or a kiss goodbye, she waved to me over her shoulder as she ran in to play, never once glancing back.

Recently I volunteered to help chaperone 35 kids from her school, each with different disabilities, on a two-day field trip. It was one of the best two days of my life. These kids were all well behaved, and they had a ball. Watching the movie ELF at 8:00 p.m. on the way home when the main character was singing “Santa Claus is Coming to Town,” Laura began singing the song and slowly so did all her friends on the bus, a truly magical moment.

Now living in a specialized group home for adults with PWS, Laura has a boyfriend, continuing education and a future with sheltered job placements and friends. Her own

*Laura continued on page 13*



## PWS Is On Two Major TV Shows In One Evening!



### Inside Edition

Teenager Kayla Dennette-Olson of Prosser, Washington (shown at left with camera crew), who has PWS, was featured on Inside Edition along with her grandmother, Pat, and Executive Director Janalee Heinemann. The title was "Can't Stop Eating" and Kayla was featured as "a brave teenager facing a unique dilemma."

### 20/20

A 20/20 segment showed former childhood stars and what they are doing now. Mayim Bialik, who played a young Bette Midler in the 1990s movie "Beaches" and was "Blossom" in one of the highest ranking shows on TV, was featured — as was her current research with PWS. Mayim, now completing her thesis on PWS, is becoming a neuroscientist. She is working with Dr. Elisabeth Dykens, who is a member of the PWSA (USA) Scientific Advisory Board.

## PWSA (USA) Gets A 4-Star Rating

PWSA (USA) received the following from Charity Navigator: "We are proud to announce the Prader-Willi Syndrome Association (USA) has earned a 4-star rating for its ability to efficiently manage and grow its finances. Less than a quarter of the charities we evaluate have received our highest rating, indicating PWSA (USA) outperforms the majority of nonprofits in America in respect to fiscal responsibility. This 'exceptional' designation from Charity Navigator differentiates PWSA (USA) from its peers and demonstrates to the public it is worthy of their trust."

## PWSA (USA) Included in CIBC World Markets Miracle Day

Thanks to Mark Greenberg and his fellow employees at AIM Advisors, Inc. (Denver), PWSA (USA) was nominated and approved as a Miracle Day charity when CIBC World Markets Corp. held its annual Miracle Day campaign on December 6, 2006. Miracle Day is an effort to raise awareness for children who are underserved, at-risk or in need. We are very grateful that due to this grant funding, we have been able to fund the programming for the PWS Educational Crisis Counselor.

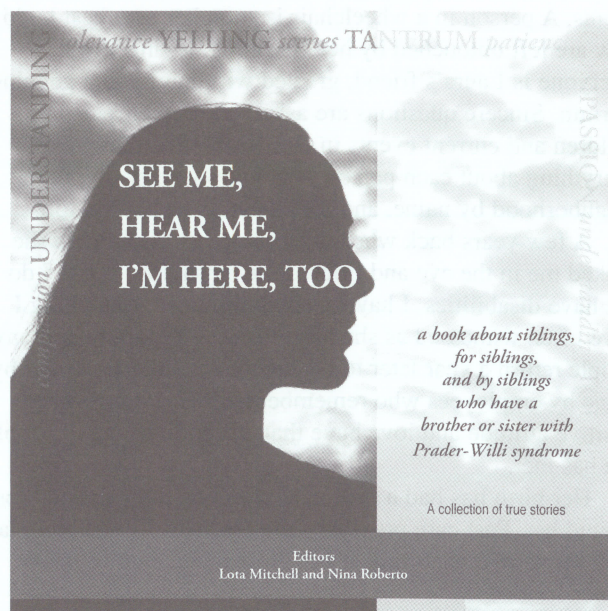
## Judge Angiolillo Promoted to State Court

Congratulations to Judge Daniel D. Angiolillo of West Harrison, New York, who has been appointed by Governor George Pataki to serve in the Appellate Division of the Second Department.

Judge Angiolillo, whose daughter Danielle, 21, has PWS, is a past president of the PWS New York Chapter. "I'm thrilled, I'm humbled, honored and thankful," said the judge of his appointment.



## New PWSA (USA) Sibling Booklet Is Now Available



*See Me, Hear Me, I'm Here, Too* is an honest, poignant, and sometimes humorous recollection from the siblings of those who have PWS. Edited by Lota Mitchell and Nina Roberto, the booklet includes an array of the unforgettable memories and emotions that have been etched in the hearts of these siblings, along with tips for parents.

To order the new Sibling Booklet, contact PWSA (USA) at 1-800-926-4797



## Reagan - continued from page 1

Our son learned to walk at 14 months; he does talk, although he is difficult to understand; he loves music and can sing his ABC's; he plays make-believe like all other toddlers. There are differences... some too mild for most to see and others more obvious. As we approach the second phase of this bizarre syndrome there are so many unknowns yet. Will the developmental gap widen as he grows? How will we handle a life that is a constant fight with hunger? Will he need to live in a group home?

If God indeed chose us to be parents to this precious little boy, then neither irony nor fate has anything to do with it. I do believe that He gave us an enormous responsibility, but on this path in which He leads us I believe He will protect us along the journey.

We are fortunate for an early diagnosis, along with the handful of specialists and daily therapies. The biggest factor in our success has been the growth hormone therapy, a daily injection that he will need for the rest of his life. We are forever grateful for the pioneers that brought us to this point. However, without funding for research to find medications to control the hunger, there is no chance for the opportunities that my other kids have.

Many ask if he will outgrow this condition. The answer is no, Reagan will always have it. The question is, will he eat to live or live to eat?

*Diane and Rob Seely are the parents of Reagan, 3½, who has PWS, and the rest of the "n" crowd: Justin, 20; Kristin, 17; Caitlin, 15; and Alisyn, 13. They live in Plain City, Ohio.*

## Laura - continued from page 12

life with a future. I have never again looked at anyone with a disability in the same light. I have realized that nearly every disabled person I have met wants what most of us do... They want to fit in, they want love, a purpose in life and respect.

I now realize that as a society we should not be judged by how those with wealth and power or fame are treated but how we care for those who cannot care for themselves. We need to do more.

*Louis and his wife Judy live in Skokie, Illinois.*

**Executive Director's note:** *Although it is very unusual for a child this young to need placement, we must remember that there is a broad spectrum within the syndrome regarding behavior, food foraging, IQ, muscle tone, etc. It is also important to note that finding funding and the right type of placement for a child under age 18 is very challenging because there are very few placement settings who take out-of-state or under age 18. Funding usually comes from either a Medicaid Waiver or state agencies. Eligibility is based on a crisis priority system and parent's income is often too high to qualify for aid. Over age 18, income is based on the income of the person with the syndrome, not the parent.*

— Janalee Heinemann

## The Chuckle Corner

### Looking For Bill

Our daughter Molly, who has PWS and speech apraxia, is just beginning to talk, and it is just wonderful to finally get to know what she is thinking about.



Recently we were in a restaurant. Molly, age 3½, was getting tired and wanted to leave. I told her that we would go after the bill came.

She looked across the dining room and pointed at a man. "Is that him? I think it is him." (She was looking for an actual Bill).

We started to laugh. We are still getting used to her having things to say and didn't expect this!

*Mary Speiser, South Amboy, New Jersey*

## Romania To Host IPWSO Conference in June 2007

The Romania Prader-Willi Syndrome Association (RPWSA) will host the sixth International PWS Workshop and Conference, 21 June - 24 June 2007. Celebrating our past fifty years of progress since identification of PWS and starting the next half century on the cusp of exciting new research, this meeting marks an historical and very important moment for the International Prader-Willi Syndrome Organization (IPWSO).

On behalf of the IPWSO Board, I congratulate Dorica Dan, (President RPWSA and IPWSO Parent Delegate) and members of the RPWSA for their courage and enthusiasm in taking on this exciting project.

Organizing an international conference and initiating new projects for patients with PWS is a great challenge for RPWSA and the Romanian medical department. Our goal is that the conference will attract more scientists from multiple disciplines such as rehabilitation, social work, occupational and physical therapy, psychiatry, speech therapy and also professionals from the neighboring countries.

Our international forum for scientists, parent workshops, and General Assembly will provide an atmosphere for learning, connecting, sharing, and planning. Imagine the possibilities!

After fifty years of progress in PWS, we consider that it is time to reconsider the capacities and possibilities that our children have. We have chosen the theme of the conference to be "Concentrate on the Positive Aspects of PWS," as we really believe that our children have a lot to offer: love, joy and sharing skills.

— Pam Eisen, IPWSO President



# 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.

## We Remember Those With PWS Who Died in 2006

**Paul Battersby**  
7/8/72 – 5/25/06  
Son of Marilyn Battersby, OR

**Ryan Bourdon**  
5/9/82 – 11/1/06  
Son of Kathy Bourdon, MI

**Sean Brown**  
1/3/93 – 2/26/06  
Son of Rose Marie Brown, NY

**Scott Crocker**  
5/10/77 – 3/30/06  
Son of Ann Crocker, CA

**Cindy Fankhauser**  
7/3/59 – 12/7/06  
Daughter of Joanne Fankhauser, WA

**Gloria Flibotte**  
3/18/50 – 9/14/06  
Ward of Betty Dew, MA

**Laura Harsh**  
10/15/67 – 1/3/06  
Daughter of Joe & Trudy Harsh, VA

**Candace Hungerford**  
8/28/60 – 2/25/06  
Daughter of Ken & Marilyn Hungerford, OK

**April Kennedy**  
9/26/66 – 3/27/06  
Daughter of Patsy & Jeffry Kennedy, IL

**Stein Erik Lovsland**  
11/10/65 – 5/10/06  
Son of Signe Holte Lovsland, Norway

**Matthew McEttrick**  
3/12/74 – 2/2/06  
Son of Joe & Noel McEttrick, MA

**Ramona Perry**  
3/30/05 – 1/24/06  
Daughter of Nicole Perry, IL

**Tracey Pickett**  
4/13/81 – 1/28/06  
Daughter of Sharon Myers, MD

**Kay Richards**  
1/6/57 – 6/4/06  
Daughter of Marjory Richards, MT

**Christopher Timmons**  
4/2/86 – 4/6/06  
Grandson of Angie Clark, CA

**Pollyanna Spurlock**  
5/24/79 – 10/9/06  
Daughter of Pat & Nancy Spurlock, AZ

**Jennifer Watson**  
6/21/74 – 6/24/06  
Daughter of Jerry Watson, UT

**Michael Weeks**  
1/17/47 – 5/25/06  
Son of Rose Weeks, MA

**Janet Weichbrodt**  
3/27/46 – 2/6/06  
Sister of Arlene Rose, IL

**Brenda Yaniak**  
11/18/56 – 7/2/06  
Daughter of Rosemary Sofield, FL

### Paul Alterman



It is with great sadness that I report the death of our long-time past board member, major donor and friend Paul Alterman of Atlanta Georgia. Paul, who was 57 years old, died from kidney cancer. He was the proud father of John, Katie, Andy (PWS), Michael and Amy.

Paul also had two grandchildren and was looking forward to the third. His wife Pam and I raised our stepsons with PWS during the same era.

Thanks to Paul, a very important grant has made a world of difference in the lives of our families in crises. Since 2001, the **Alterman Family Foundations** have supported a part-time crisis counselor position. Many of you know what a crucial difference this support has made for our families. Paul had a strong commitment to this special program, and his children and Pam were all involved with volunteering for our national conferences. Our prayers go out to this wonderful family. To send a card or note, Pam's address is 1293 Waterford Green Trail, Marietta, GA 30068.

— *Janalee Heinemann*

### Bobby Miller

Bobby Miller, of Doylestown, Pennsylvania, died Oct. 25, 2006, after battling cancer of liver and lung for almost 3 years.

He and his wife D.J. were two of the earliest members of PWSA (USA) and attended 21 national conferences, stopping only in the past few years because of health problems. Their daughter Margaret, 42, has PWS.

D.J., a tireless worker for PWS, has been a member of the PWSA (USA) Board of Directors, founded the Mid-Atlantic chapter which later divided into state chapters, and chaired the 1992 national conference in Philadelphia.

Bronnie Maurer described Bobby's funeral as exactly what he would have wanted it to be. He had an honor guard from the fire department during calling hours and, as a World War II veteran, had a navy honor guard during the burial. Jerry Breneisen played "Taps."

Our sympathy goes to D.J. and Bobby's family. To send a card or note of sympathy, D.J.'s address is 238 E. Court Street, Doylestown, PA 18901.

— *Lota Mitchell*



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Call PWSA (USA) at  
1-800-926-4797



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