

The *Gathered View*

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

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

Kate's Best Friends

by *Dianne Rogers Hamilton*

The first pet our daughter Kate, 8, who has PWS, remembers was Clancy, a big black Labrador retriever. Clancy lived to eat. We had to keep his food well secured, or he would gorge until he was sick. Kate had great empathy for Clancy and understood his love of food. Witnessing how sick Clancy would get after overeating made it very easy for Kate to understand why she is on a controlled diet. She knew she didn't want to get sick like Clancy.

Having Clancy allowed Kate and me to participate in one mother-daughter activity I never thought we'd do: baking. Kate understands the difference between 'people' food and 'dog' food. (*Dog food is **stinky!***) We found an easy recipe for homemade dog treats, which Clancy loved. We found a bone shaped cookie cutter and made 'dog bones' for all our doggy friends. Kate has a great sense of pride in being able to give a gift she has made.

My husband Gary and I decided we needed a dog more protective than Clancy, who was aging. We worried about allowing Kate, an only child, to play outside alone. After much research, we took Holly, a Shiloh shepherd, home in December 2006. We encouraged Kate and Holly to spend a lot of time together and made sure Kate was involved in Holly's care. Kate and Holly have an amazing relationship, and having Holly in our life has impacted us in ways we didn't expect.

Like all children, Kate sometimes has temper tantrums. On an off day, she can be overly sensitive and easily upset. One day, Kate began crying in a fit of temper. Holly started howling, long and mournfully. Kate and I started laughing, the howling



Kate

stopped, and the temper tantrum was over. The situation was completely diffused, and Kate was once again a happy child. We've witnessed this many

times. It doesn't matter if Kate is angry or injured--Kate cries, Holly howls, everyone laughs and gets to enjoy the rest of the day. For this alone, we consider Holly to be worth her weight in gold.

Holly is never far from Kate. If Kate is outside, Holly is outside. Holly simply will not allow Kate to go out on her own. Any fears we had about Kate playing outside alone are gone.

Kate is high functioning, but she thinks rather concretely and cannot understand abstract concepts. When Holly went into heat before we had her spayed, Kate started asking questions, and I realized I had the perfect teaching opportunity. I explained that Holly's body was telling her that she was almost ready to have puppies. Kate asked more questions until her curiosity was sated. I won't broach the subject of human menstruation with Kate until I have to, but I know our experience with Holly will make it far more understandable.

Living close to Holly's breeder, Jan, has given us

Kate's... continued on page 9

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Holly

In this Issue

Joint Statement with FPWR.....	6
Spanking Doesn't Work.....	8
Understanding FDA Approval for GH.....	4
Loving Hearts - Alert!	11

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USA
**PRADER-WILLI
SYNDROME
ASSOCIATION** *Still hungry
for a cure.*

8588 Potter Park Drive, Suite 500
Sarasota, Florida 34238
800-926-4797 ~ 941-312-0400
Fax 941-312-0142
info@pwsausa.org
www.pwsausa.org

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We sponsor nine groups to share information.
Go to: www.pwsausa.org/support

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Deadlines to submit items to *The Gathered View* are: Dec. 1; Feb. 1; Apr. 1; Aug. 1; Oct. 1

Executive Director's View Trust and Cooperation

Photo by Eric Hilton



Craig Polhemus

On October 7, 2008, *USA Today* ran a full-page ad from the Better Business Bureau (BBB) headlined "Start With Trust". The ad listed PWSA (USA) among about 225 charities (less than a quarter of all charities reviewed) that earned the Better Business Charity Seal by meeting 20 rigorous *BBB Wise Giving Alliance* standards. We are proud that PWSA (USA) is recognized as a responsible, well-run charity – and this Better Business Bureau recognition means you can feel confident in recommending PWSA (USA) to friends and family members who want to be sure they contribute to a charity they can trust.

Both PWSA (USA) and the Foundation for Prader-Willi Research (FPWR) urged members and friends to vote for a proposal from Jessica Howard, mother of 3-year-old Riden, who has PWS, to "Fight Obesity With a Cure for PWS" through the American Express Members Project. This proposal came in 16th among 1190 proposals – an astonishing outcome for a rare disease community! Although we were not selected to advance to the next stage of competition, this effort continues to raise awareness and contributions.

For instance, a new article in About.com's *Special Needs Children* department, "Celebrating Top Members Project Vote-Getters – Spotlight on Prader-Willi Syndrome" by Terri Mauro, summarizes some exciting research possibilities (www.specialchildren.about.com/b/2008/10/08/celebrating-

[top-members-project-vote-getters-spotlight-on-prader-willi-syndrome.htm](http://www.pwsausa.org/newlook/give.htm)). The article includes links for viewers to offer to help (www.pwsausa.org/newlook/give.htm) or to make instant, secure donations (www.pwsausa.org/support/donations.asp).

Among the exciting research possibilities I cited in that article: Current research indicates in a test setting that if people with PWS eat an extremely large meal early in the day, this causes a clearly measurable reduction in hunger later on. If we can determine which hormones are causing the reduction in hunger from the large meal, **we hope these hormones can be combined into a 'cocktail' that could be used to cause the same reduction in hunger without the excessive caloric intake.**

This and other exciting research was discussed at two conferences I attended recently: The Florida chapter fall meeting, and the FPWR annual conference held near Washington, DC. On "Hike the Hill" day, September 8, 2008, we all met with our Representatives and Senators or their staff to promote awareness and ask their support for H. Res. 1386, calling for increased research funding and federal recognition of the annual PWS Awareness Month.

As we near year's end, I hope you will remember us as a *BBB Wise Giving Alliance* charity and urge your friends to do the same. If you know of anyone who should receive an Angel Drive card, please call me at 800-926-4797 or email cpolhemus@pwsausa.org with their names and addresses. Together, we are strong and can accomplish miracles for our children.

Working Together to Advance Research

The Foundation for Prader-Willi Research and the Prader-Willi Syndrome Association (USA) are exploring ways to work together to advance research into the causes of, treatments for, and eventual cure of Prader-Willi syndrome. The two organizations are currently working to:

- support H. Res. 1386, declaring a National Awareness Month for PWS and emphasizing the need for increased financial support for PWS research;
- monitor pending legislation regarding availability of growth hormone for persons with PWS.

We look forward to future discussions and opportunities for collaboration between these two outstanding organizations as we all work to eliminate the challenges of Prader-Willi syndrome.



from left to right Craig Polhemus, Tommy Maczko, 3, who has PWS, and Hetaf Al-Kraydi, Executive Director of FPWR.

Medical View – Ask The Professionals

Understanding FDA Approval on Growth Hormone Therapy & PWS

Janalee Heinemann, MSW

PWSA (USA) Director of Research & Medical Affairs

Question:

I thought the FDA approved growth hormone therapy (GHT) for children with PWS, so why are there still some problems with getting approval for GHT for PWS?

Answer:

I asked FDA director of Office of Orphan Products, Dr. Timothy Cote, about the growth hormone (GH) approval issue, "Since basically all GH is alike, why could the indication that Pfizer got for Genotropin not transfer over to other GH products?" I explained that even though Pharmacia's (bought out by Pfizer) seven-year exclusivity for advertising GH for PWS is up, other GH companies do not want to go through the expense of doing their own research for GH with PWS, and insurance is using the fact they do not have the indication as an excuse for denial in some cases.

Dr. Cote said it is a regulatory issue. There are no generic biologics. It is not like generic drugs. Every biologic is considered to be different, each has to be individually licensed, and because they are so complex, biologics are not really all the same. Dr. Cote said the day may come when there are some generic biologics, but not now.

Dr. Cote's recommendation is to get the word out that Genotropin is the product licensed for PWS. I told him we try not to promote one product over

another, but we agreed that in this case, if it makes approval easier, physicians and parents should be informed of this. He said that after all, Pharmacia/Pfizer put the money into the research so perhaps it is appropriate they get the PWS business.

Further information I have learned on this complex issue:

Only Pfizer has sought and obtained regulatory approval for GH treatment of PWS in the US, Europe and elsewhere, even if other companies (such as Genentech) have funded studies of GH treatment of PWS. Because of this, only Pfizer is approved to market their GH product for use in PWS (in other words, only Pfizer can advertise for this use). Any other company promoting use of GH for treatment with PWS would be subject to legal penalties for promotion of off-label use.

There are several "traditional" GH products marketed in the U.S., e.g., by Pfizer, Genentech, EMD Serono, Lilly and Novo. Although the active ingredient, recombinant DNA-derived human GH (somatropin), is considered to be identical between manufacturers, there are differences between the actual preparations (e.g., manufacturing procedures, buffers, degradation profiles, other ingredients, etc.) which can create different safety concerns, and these safety concerns can differ for different groups of patients. Therefore the

FDA feels each product needs to be separately tested in each type of disorder before it can receive marketing approval for that specific disorder. Because this type of testing can cost a lot of money and take several years, each company has to carefully decide which diseases it will pursue for a particular drug. The relatively small number of PWS patients (limited market potential) decreases the economic feasibility of testing multiple GH products for treatment of PWS. Therefore it may be unlikely that other companies will conduct a PWS marketing approval study for their GH product unless they can foresee a marketing advantage over the Pfizer product.

It is important to realize, though, that the FDA does not directly regulate physician practice. Physicians have a right to prescribe approved medications for off-label use (uses other than the one that is approved) in the course of *usual medical practice*. Within the US, the standards for usual medical practice are regulated by the medical boards in each state, not by the FDA. Typical standards for usual medical practice in relation to drug prescribing include a proper medical examination and diagnosis, a treatment plan, follow up visits and ensuring appropriate use of the medication.

Within the realm of usual medical practice, physicians may prescribe a drug that has the same active ingredient. For instance, because Genotropin and Humatrope have the same active ingredient (somatropin), a physician may prescribe

Medical View continued on page 5

Visit our newly improved web site for more pictures, regular updates and more...
www.pwsausa.org

Understanding FDA Approval, *continued from page 4*

Humatrope (Lilly's product) for treatment of PWS, even though Lilly does not have marketing approval for the use of Humatrope in PWS and Lilly is prohibited from promoting the use of Humatrope in PWS. In fact, even if no somatropin brands were approved for use in PWS, a physician could prescribe an otherwise-approved somatropin preparation for treatment of a patient with PWS within usual medical practice. For instance, before Pfizer received marketing approval for GH use in PWS, many prescriptions for GH use in PWS were off-label.

Even with a physician prescription, however, obtaining reimbursement for off-label use of a drug or an equivalent alternative to an approved drug

can be extremely difficult. In the U.S., some third-party payers disallow reimbursement for off-label prescriptions or non-formulary drugs, to control costs and prevent inappropriate off-label medication use. It should also be noted that a formulary drug may not be consistent with the approved label. For instance, a third-party payer may have Brand X as the only GH in their formulary even though Brand X may not be approved for all types of uses (the FDA does not regulate formulary listings). Reimbursement decisions can usually be appealed, often successfully, although the process can be difficult depending on the situation. Call the PWSA (USA) Crisis Intervention Program if you need help with an appeal.

Summary Points:

- The FDA is responsible for determining the safety of each

drug before granting marketing approval.

- The FDA does not regulate physician prescribing practices.
- Physicians have the right to prescribe approved medications for off-label uses within usual medical practice.
- Reimbursement agencies may disallow prescriptions for off-label uses of drugs, or require use of alternate drugs that have the same active ingredient. Such decisions can usually be appealed.

At PWSA (USA) we continue to fight for the right for our children to have access to this life-altering and potentially life-saving drug. I will keep you updated on the issues and our progress. Knowledge is power – and our PWS family is indeed a powerful force! ■

A World of Difference – Spreading PWS Awareness To The Medical Community in 2008

By Janalee Heinemann, Director of Research & Medical Affairs

PENS (Pediatric Endocrinology Nursing Society)

– April, Cincinnati, Ohio

In addition to our PWSA (USA) awareness booth at this national conference, I teamed up with an endocrinology nurse practitioner, Kathy Clark, for a very well received 1½ hour presentation on PWS to all the conference attendees. I think all 250 attending came to the booth to get our extensive packets on PWS. Our video-taped presentation will be used for educational purposes.

(funded by CIBC-Children's Miracle Network)

ENDO 2008 (The Endocrine Society) – June, San Francisco, California

Of the 9,000 attending, over 7,400 were physicians and researchers. Besides hundreds of educational materials, we gave out approximately 300 full folders/packets we created on growth hormone and other medical issues, and another 75 folders we created with materials specifically for researchers. Many international endocrinologists attending were very interested in our materials. We

were able to include information on our international organization, International Prader-Willi Syndrome Organisation (IPWSO).

I met with several drug companies and talked to the new Director of Communications of The Obesity Society. We worked on the concept of a special section on genetic causes of obesity in one of their magazine editions and also having a speaker on PWS for their next conference

(funded by the Gerald J. & Dorothy R. Friedman Foundation In honor of Sophie Grace Coggeshall)

ESPE (European Society for Paediatric Endocrinology) –

September, Istanbul, Turkey

As IPWSO's consultant on research and medical affairs, I worked this conference with Giorgio Fornasier from Italy because our dear international president, Pam Eisen, was too ill to attend. I had sent Giorgio 11 articles for extra handouts to add to the medical packets which contain materials we

A World of Difference, continued on page 6

Medical View

A World of Difference

– continued from page 5

have shared in the past. There were two presentations on PWS at the meeting by Dr. Maité Tauber from France and nine poster presentations on the syndrome. This was the most that PWS has ever been represented at this meeting attended by endocrinologists from all over the world.

IPWSO now has 78 country members. At ESPE, we established good contacts with professional delegates in 5 new countries that will become members of IPWSO soon: Iran, United Arab Emirates, Libya, Lithuania and Uzbekistan. All appreciated IPWSO's offer to do free DNA methylation tests in Italy and will send blood samples of all clinical diagnosed patients they have. We met 3 doctors from Dubai and Abu Dhabi wishing to be representatives for IPWSO. Many doctors from China, Colombia and Mexico asked for information and how to send blood samples for tests in Italy. Giorgio was able to get a new professional delegate in

Slovenia. Many doctors offered to translate the Medical Alert in their language. We established a good contact with a Greek doctor from Thessaloniki and had contact with many doctors in Cyprus where IPWSO is not represented yet.

We were pleased that many doctors also came to our booth from well organized countries such as UK, Denmark, Sweden, USA, France, Germany and Holland, and collected our educational material and had medical questions. I even learned about a new PWS clinic starting in the USA that we were not aware of!

(funded by IPWSO)

NSCG (National Society of Genetic Counselors) – October, Los Angeles, CA

As I write, we are preparing materials for this conference. Because we try to diversify the medical communities where we have a booth each year, I choose educational materials most appropriate for that particular group. Initially, genetic counselors often have the most contact with our families, so it is imperative to give them the needed information.

(funded by CIBC-Children's Miracle Network)

These awareness booths are always hard work, but they also energize me when I see how much awareness and PR we can do on Prader-Willi syndrome at the events. Typically, the few other nonprofit booths (at ESPE we were the only charitable organization represented) have very little traffic compared to us. At each event, our booth was consistently busy. It is exciting to see the interest in PWS and imperative that we continue to educate the medical community. A big thank you goes to the sponsors that make this possible.

Sometimes we do not comprehend the realities in another country and how precious the educational materials are that we distribute on PWS. When I told Dr. Lindita Grimci, who is an endocrinologist at a university hospital center in Albania, that I could email more information to her, she told me there were no computers in her hospital. ■

Research View

Another Way to Impact on Research – Brain & Tissue Donations

“Tissue donation offers new hope and life to future generations.”

The National Institute of Child Health and Human Development (NICHD) Brain & Tissue Bank has a pre-registration program and will send you written information. We hope you never need it, and we understand that it is not something you even want to think about. But please keep the following information available or go to the Medical Alert section of our web site at www.pwsausa.org. Remember -- with brain tissue, hours can make a difference.

NICHD Brain and Tissue Bank for Developmental Disorders *(covers entire USA, Canada, and internationally when possible)*

University of Maryland
655 West Baltimore Street, BRB 13-013
Baltimore, MD 21201

Project Coordinator Melissa Davis
1-800-847-1539 or 410-706-1755

Fax: 410-706-2128

E-mail: btbumab@maryland.edu

Family Website: www.btbankfamily.org

Researchers Website: www.btbank.org



PWSA (USA) is included in the Combined Federal Campaign. If you work for the Federal government and its agencies, use CFC ID No. 10088 to designate PWSA (USA) to receive donations. Questions? Call PWSA (USA) at 1-800-926-4797.



Central Adrenal Insufficiency in Individuals with Prader-Willi Syndrome

By Jennifer L Miller, M.D., Pediatric Endocrinology, University of Florida, PWSA (USA) Clinical Advisory Board

A recent article in the Journal of Clinical Endocrinology and Metabolism by de Lind van Wijngaarden et al indicated that there may be a high frequency of central adrenal insufficiency (CAI) in individuals with Prader-Willi syndrome. Morning salivary cortisol levels and cortisol profiles were normal in all the children studied, leading the authors of the study to conclude that CAI in individuals with PWS only becomes apparent during stress. Therefore, the presence or absence of CAI cannot be determined by measuring an 8 AM cortisol level – the individual must be tested while stressed (e.g. with febrile illness) or using a stimulation test.

Given this information, we (at the University of Florida) recommend that all individuals with PWS should be screened for the presence of CAI. The two ways to test for CAI are (1) to measure a cortisol and ACTH level while the child is sick or (2) to perform a stimulation test which will evaluate the hypothalamic-pituitary-adrenal axis. Because some children with PWS do not have fevers when ill, it can be difficult for parents and physicians to know when the child is sick enough to put the body under significant stress to accurately assess the presence of CAI. Thus, a stimulation test may be the best way to detect adrenal insufficiency. The metyrapone stimulation test was used in the

above-mentioned research study, but this test is not usually done in the United States. A low-dose ACTH stimulation test (1 mcg ACTH) has ~ 95% sensitivity for diagnosing impaired adrenal function, but may miss mild CAI. A glucagon stimulation test has equal sensitivity for diagnosing CAI but may pick up more subtle abnormalities of the hypothalamic-pituitary-adrenal axis, and an insulin-tolerance test is the gold standard for evaluating for the presence of CAI.

Please present this information to your endocrinologist and discuss testing for CAI with him/her. It is important to discuss the fact that the presence or absence of CAI in an individual with PWS cannot be determined by measuring an 8 AM cortisol level – the individual must be tested under a stressful condition (e.g. illness) or using a stimulation test.

If your child does have adrenal insufficiency, your endocrinologist will determine the best course of treatment. In general, your child can most likely be treated with stress-dose steroids (hydrocortisone) during times of illness. You will be given a Solu-cortef emergency kit, which is an injection to be used if your child is vomiting or unconscious. If you have to use the emergency injection, your child needs to go to the Emergency Room immediately for further evaluation. ■

Get Ready!

Riddle: When do you have to lose in order to win?

Answer: When participating in the 2009 PWSA (USA) Lose-A-Thon

Our fourth annual Lose-A-Thon will begin January 1 and will go through PWS Awareness Month of May, ending May 31, 2009. That's five whole months to get into a healthy life style however you choose to do it. Now here's the exciting part—while you are losing weight, you are also fundraising for PWSA (USA) and joining with others across the country to do the same. A bonus is becoming a role model for a person who has PWS.

What you get out of it besides feeling good because of better health and supporting PWSA (USA):

- Additional warm fuzzies if you do it in honor/memory of someone with PWS.

- Camaraderie/Support on a special email group for Lose-A-Thon participants.
- Expert input—a licensed fitness coach and nutritionist to answer your 'burning calories' questions and provide monthly articles.
- Recognition and prizes.

Other ideas to make it rewarding:

- Sign up on your own or recruit a team from your office, school, or club.
- Partner with a person with PWS (send each other encouraging notes to keep the motivation high).
- Share low calorie recipes or resources with others.

Register at <http://www.pwsausa.org/fundraising/lose-a-thon/> No computer? Call Diane at 1-800-926-4797. ■

Spanking Doesn't Work!

by Lisa Graziano, M.A., MFT

Discipline is, in fact, a form of education. As parents, our job is to teach our children the safe and proper thing to do in any given situation--right from wrong, safety from danger, and respect for neighbor. How we teach depends a lot on how we grew up. If our parents believed "spare the rod, spoil the child," odds are that we are more likely to use hitting to discipline. Why? *Children imitate what they see their parents do.* It is difficult to teach your child not to hit others when they are hit by you! When disciplining the child with PWS, the rule is **Do Not Hit.**

Whether or not we believe in spanking, swatting or hitting a child's bottom or any other body part, *it is ineffective, counterproductive and potentially dangerous to do so with a child with Prader-Willi syndrome.*

It Can Be Dangerous

Developmental pediatrician and PWS expert Linda M. Gourash, of the *Pittsburgh Partnership, Specialists in Prader-Willi Syndrome*, says, "With a high pain threshold and small muscles in the bum, the risk of real injury could arise before any learning takes place. Even if it seems to 'work' in the short run, the cost will be horrendous in overall increase in tension and anxiety, the major contributors to PWS behavior problems. Our overwhelming experience is that people with PWS do not learn from negative consequences" and that "yelling and scolding [are also] very counterproductive strategies." She recommends, "Speak calmly and firmly, not sternly."

Janalee Heinemann, PWSA (USA) Director of Research and

Medical Affairs, warns,

"Spanking will usually *not* calm the child with PWS down but [instead will] accelerate their acting out behaviors. The parent is then at risk for losing control of his or her own emotions and going beyond the limits of spanking to become truly physically abusive. Because children with PWS often bruise more easily than typical children, a spanking may leave bruises, thus leaving the parent vulnerable for being reported for child abuse -- and any marks left on a child (or disabled adult) can legally be considered abuse."

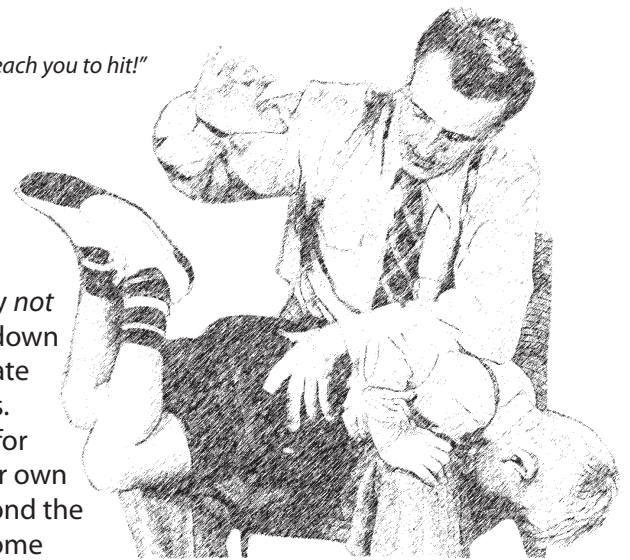
It is Counterproductive

Most people with PWS are very concrete, black-and-white thinkers. They rely on hard and fast rules and tend to feel very anxious with the "gray" areas. Knowing the rules and following them reduces anxiety--leading to better overall behavior. PWS expert Mary K. Ziccardi, Administrator of REM Ohio, Inc., adds, "To learn from consequences, a person needs insight and the ability to problem solve, use memory, logic, and sequential thinking, [and] be able to compare and discriminate information. We know that PWS compromises or impairs most of these needed skills."

PWSA (USA) Crisis Counselor Evan Farrar notes, "The perseverative quality of people with PWS predisposes them to react stubbornly to negative consequences. In the most severe cases, the person may shut down completely in response to a negative consequence."

Ziccardi and Farrar agree that

"I'll teach you to hit!"



punishment does not teach a new skill and may even increase the likelihood of the undesirable behavior because negative attention is better than no attention.

The Better Way

To teach a child with PWS not to hit--and it is *critical to do so*--then you must teach the child that hitting is *never* okay. Children and adults with PWS may not be able to differentiate when it is okay or not okay to hit. For them, it's either okay or it's not okay to hit. Swatting, spanking, etc., are all forms of hitting and are *never* okay to be used on a child with PWS.

Children with PWS need to be taught *directly* what you want them to learn. Hitting the child's hand will *not* teach him that touching a flame will burn. Hitting his hand *will* teach him that hitting is okay. Instead, physically move his hand away from the flame, and teach him with words that the flame will burn.

People with PWS are very prone to feeling overwhelming amounts of frustration and anxiety. Unfortunately, they are more prone to acting out their anxiety and frustration physically than typically developing kids and even other kids with

Spanking continued on next page

Spanking, continued from page 8

developmental disabilities. Dr. Gourash advises, "Food Security, daily schedule, incentive plans, meeting sensory needs and low expressed emotion appear to be the key components of PWS behavior management."

Jan Forster, a developmental neuropsychiatrist and the other half of the *Pittsburgh Partnership*, says, "Learning in PWS is best accomplished through positive reinforcement. This means catching your child doing something *good* in a situation and telling them that they have done a good job. This is much more effective than punishing them

Kate's... continued from p. 1

the opportunity to visit whenever Jan has a litter of puppies. On one visit we met a lovely little puppy that Kate had fun playing with. Soon after, Jan learned it had been born with a major medical issue and chose to have it euthanized. Kate asked many questions about the puppy and its death. I explained that the puppy was sick, Jan didn't want the puppy to suffer, and the vet gave the puppy 'medicine' to make it die. We talked about it for weeks.

This past January, Clancy, then 13, became very ill. The adults knew that he wasn't going to get better. Kate was very worried and asked me to take him to the vet. I suggested that Clancy might not be able to get better. Kate thought for a moment and then said, "If Clancy can't get better, maybe we should give him the die medicine." I said, "Die medicine?" Kate answered, "You know, the medicine that will make him die." I quickly asked, "Who told you about that?" Kate responded

for a *bad* behavior. The next time they are in that situation they are far more likely to do the behavior that received the praise."

Dr. Forster and Dr. Gourash feel that "low expressed emotion is one of the most useful tools in behavior management. Persons with PWS have difficulty processing two things at once. So if you use an angry (stern) tone with them while you are saying something meaningful, they will process only the anger, not the content! If you hit them when they do something undesirable, they will attend only to the hitting, not the *reason* why. So when a child does something wrong, the best way to react is

rather disdainfully, saying "Jan's puppy" like I had lost my mind. I was stunned! Kate, an eight-year-old with special needs, decided her dog was suffering and would be better off being euthanized.

We sat with Clancy before the vet came in, while Kate asked all sorts of questions about what was going to happen. We talked about what doggy heaven would be like. Kate decided there would be doggy restaurants and Clancy would be able to eat as much as he wanted without getting sick. This was fitting, considering that Clancy would typically eat anything within his reach. The vet was absolutely wonderful with Kate, and Clancy's final moments were very peaceful. Kate sat stoically watching while I sobbed.

Afterwards, Kate had more questions, many of which related to human death. Watching Clancy had given her a far greater understanding of death.

We now have our second Shiloh, a puppy named Maximus. Holly isn't yet two. I can't imagine what these dogs will teach us in

with neutral voice while you tell them the *appropriate* thing to do and, if necessary, move them to a safer place. Low attention to outrageous behavior is especially important because some children with PWS seem to thrive on their ability to create a stir."

Teaching our kids from a very, very early age that hitting is *never* okay at the same time we teach them *how* to manage their impulses and frustrations will serve them well throughout their lifetime—and ours. ■

[Ed. Note: Watch for an article in a future issue of the GV about management of parental stress, an essential component of discipline.]

the future, but I am certain they will help us find what we need to help Kate.

A *post-note*... After reading this, you might think it would be beneficial to get a dog. Our experience has been successful in part because we researched dog breeds and had frank discussions with a number of breeders about our needs as a family and the needs of particular dog breeds. Responsible breeders like to ensure their puppies have a successful placement in a home and will ask about your lifestyle and expectations of a dog. Also, our Shiloh breeder has her puppies' temperaments tested, using the Volhard Puppy Aptitude Test, before she decides in which home each puppy will be placed. ■

~ Dianne Rogers Hamilton,
Prince Edward Island,
Canada

Fundraising

Fun and Funds: Events to Remember!

Contentment comes when you know you've done something good for someone else, and you're not expecting anything in return. ~Bill Grosz

Dawn and Tom Romine, Ohio parents of Julianna, 2, have held two **Julianna's Wish Annual Car Shows** with cars to see, people to meet, and bands to hear. The first, in May 2007, raised \$200 for PWSA (USA), and a third is planned for 2009.

The **37th Annual Florida State Winnie Gators Rally "Fiesta del Sol"** drew a crowd of more than 300 motor homes and nearly 600 people representing 23 states in March 2008. This year and next, the Winnie Gators have generously chosen to support PWSA (USA) through the donations they receive at the event. At the 2008 Rally, The Winnie Gators raised \$1,433; an additional gift of \$1,500 from Gordon and Pat Crosby of the Crosby Foundation was also donated to total \$2,933 for PWSA (USA). Thanks to **Beverly Delemos**, mom to **Abby**, 18, who has PWS, and her family for bringing awareness of PWS to the Winnie Gators and for their support this year!

A treasure chest of knowledge and a PWS pirate-themed booth were at the **Newport Seafood and Wine Festival** in Oregon, one of the biggest events of its kind in the USA with more than 15,000 people attending. Thanks to **Friends for PWS**, attendees at the festival learned a great deal about PWS and beautiful **Sequoia Chavez**, 17 months old with PWS and daughter of **Kelly and Christopher Chavez**. Friends for PWS generously donated \$700 to PWSA (USA).

Several restaurants participated in Awareness and Fundraising during the month of May (PWS Awareness Month). **The Melting Pot A Fondue Restaurant**, in Littleton and Louisville, Colorado area, dedicated a portion of the proceeds from a specially advertised menu item, raising \$3,600 for PWSA (USA). The request to dedicate the proceeds was made by Alan Roach, a local radio talk show host. Thank you, **Alan Roach** and **The Melting Pot!**

A grandmother and parents of twin girls with PWS in NJ offered to put brochures about PWS and a *change jar* for donations at their two **IHOP** locations in Clifton, NJ, resulting in a \$1,000 donation. Thank you, **Maureen and Chip O'Neil** and your family for your dedication.

Cindy Galyean, auntie to **Alexis**, 4, runs from one PWSA (USA) event to the next. She is frequently involved providing awareness at events such as local health fairs in her home state of North Carolina. In

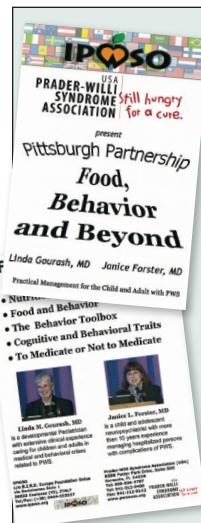
May, Cindy and the **Kendall Lanes** hosted the **2nd Annual Alexis Bowling Night** which raised \$1,546 for PWSA (USA), a portion of which will be used for research.

Pamela Santos and her family from Cambridge, MA hosted a dinner and silent auction for 150 people in May called **Jenna's Hope for a Cure**. They donated \$835 to PWSA (USA) for "most critical need." The family prepared everything that was served at the event and said they had so much fun doing this event, they're going to do it again next year!

Special Education Math teacher **Evan Postal**, father of **Hailey Postal, 5**, who has PWS, organized the **Westlake High School Comedy Sportz Prader-Willi Syndrome Charity Event** on May 30, 2008. Pamphlets, team members sporting PWSA (USA) wristbands, and an audio visual presentation before intermission describing PWS all generated great awareness. One hundred and forty people learned about PWS and got to meet Hailey. The event raised \$800 to support PWSA (USA) and Prader-Willi California Foundation. A repeat performance is in the works for next year. ■

You can check out upcoming events in your area on the PWSA (USA) events page at:

www.pwsausa.org/fundraising/events/



"Food, Behavior and Beyond – Practical Management for the Child and Adult with PWS"

Linda Gourash, M.D., developmental pediatrician, and Janice L. Forster, M.D., child and adolescent neuropsychiatrist

Information-packed 2005 DVD on nutrition, food and behavior, cognitive and behavior traits, and medications.

- 5 segments
 - 2 ½ hours
 - \$25 for members
 - \$30 for nonmembers
- Available now with Spanish subtitles!**



Loving Hearts -Alert!

by *Diane Spencer*

For those of you who have a heart for raising funds for PWS research, opportunity

is coming soon! The 2009 7th Annual Valentine Research Fund Campaign is open to any and all who are looking for an easy, loving way to raise research dollars. Use our sample letter or draft your own requesting donations in honor or memory of your Valentine who has PWS to send to family, friends, and business associates. Hand them out to strangers or post them wherever they are allowed.

It's easy. Start by selecting the format below that is comfortable for you.

1. Do-it-yourself version – a Valentine letter will be available online by January 1 at www.pwsausa.org/Valentine for you to download and insert a picture of your special Valentine who has PWS. Or create your own. Once ready, just mail or e-mail the letter to those on your list.

2. You do some of the work – mail or e-mail* a picture of your special Valentine along with a letter that you want us to print. We'll put it together and mail the letters back to you to send out (tell us how many letters). Or we'll e-mail it back to you so you can print and send and/or e-mail it. Please tell us if you want us to print and mail or e-mail the letter back to you and provide the address to where it should be sent.

3. We do it all – mail or e-mail* a picture of your special Valentine. We'll use the sample letter and

put it together. We'll then send it back to you to send out by mail or e-mail. Please tell us if you want us to print and mail (include quantity needed) or e-mail the letter back to you and provide the address to where it should be sent.

See the web site for further instructions in late December. This will include how to set up a corresponding Firstgiving page where your donors have the option to make an online donation. Get ready for an outpouring of love!

**Mail to: PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238, ATTN: Diane Spencer, Vday 2009*

E-mail to: Diane Spencer, dspencer@pwsausa.org and put in subject line, "Vday 2009, (your first name initial and last name)"

Deadline to receive requests for letters is Jan. 16th.

A few examples of some of the new research we are funding:

- new diagnostic testing that will give us more information on subsets of PWS.
- a drug study that has the most promise of helping with the appetite.
- a study that looks at the relationship between PWS and autism.
- a study that should define more clearly the GI risk factors for PWS and how to prevent them.
- Sponsorship of a collaborative scientific conference where we will bring together the top researchers with the various disorders who are dealing with the insatiable appetite in an attempt to put together pieces of the puzzle on the unrelenting hunger. ■



Counselors Corner

by *David Wyatt, Alterman Crisis Intervention Counselor emeritus*

Parents of children with PWS are often faced with difficult and painful decisions. The nature of the developmental disabilities often present challenging decisions about school (e.g., mainstream and/or Special Ed.), special settings where their needs may be more adequately addressed (e.g., placement in The Children's Institute in Pittsburgh

for weight and behavior issues), employment opportunities, or perhaps finding a supportive living home for placement when they need such a setting. The focus is on doing the best thing for their child. The PWSA (USA) Crisis Intervention Counselors are available to help focus on what "the best thing" might be. Parents need to be knowledgeable about what services are available for their child and how to be pleasantly assertive in obtaining these services. We can help

through personal support, providing educational materials, helping find resources, writing letters of support and putting parents in touch with each other. MOST important is helping the parents not to think or feel of themselves as "failing in parenting." ■

Production, printing and mailing of this newsletter was underwritten by a generous grant from CIBC World Markets Corp./ Miracle Day USA.

A Tax Efficient Way to Help PWSA (USA)

By Steve Leightman, Chair, Finance Committee

PWSA (USA) touches our lives in many ways:

- Counseling, connecting and informing families
- Serving as a resource for our schools
- Providing valuable clinical information to our doctors
- Sponsoring important research studies
- Helping resolve a dispute with our insurance company

In my case, PWSA (USA) entered our family's life when my granddaughter Josilyn was diagnosed at the age of three weeks. We were devastated, filled with questions and despair with seemingly nowhere to turn. Then we called Sarasota and discovered a wonderful new organization. The information and support we received and continue to draw upon have made an enormous difference to us and to Josilyn. She is now 6 1/2 in a regular first grade class and one of the sweetest children on earth. The debt I owe to PWSA (USA) can never be repaid.

Many of us have had similar experiences and would like an efficient way to "give back." Especially in these difficult

economic times, PWSA (USA) needs your help more than ever if we are to continue to provide the quality and scope of our programs, literature, research and counseling.

Most of our contributions come from cash gifts for which we are very grateful. There may be other ways to help that offer multiple advantages both to our Association and to the donor. In spite of the current huge economic downturn, some of us own appreciated stock which may "over-concentrate" a portfolio, potentially increasing risk in what has proved to be a challenging equity environment or creating a problematic capital gain if sold. The result – an unhealthy investment "stalemate".

You can enjoy a double advantage when you donate appreciated stock.

- You can avoid capital gains taxes that otherwise would have been incurred on the potential profit upon disposition of the property,
- and you also receive a tax deduction (subject to income limitations) for the full market value of the gift on the date it

is given to PWSA (USA).

FOR EXAMPLE: Suppose you donate a stock worth \$25,000 to PWSA (USA). The stock may have cost only \$12,000 when it was purchased four years ago. By donating the stock to the Association, you avoid the \$13,000 capital gain and receive a potential income tax deduction of \$25,000.

Of course, any tax consequences of a gift should be discussed with your tax professional who is familiar with your personal financial situation.

Donating a stock to PWSA (USA) rather than cash is an easy process. Simply call our office at 800-926-4797, and we will provide the information you need, either to send the stock certificates to us or have them transferred to the Association's brokerage account.

This is just one method of giving that not only helps PWSA (USA) but can help you as well. For more information, please call our office, and we will be happy to work with you and your financial professional to customize a gifting program that optimizes the benefits to PWSA (USA) and to you. ■

Web Notes

Janalee Heinemann's Article for NORD Newsletter

The year 2008 marks the 25th anniversaries of the Orphan Drug Act and the National Organization for Rare Disorders (NORD), of which PWSA (USA) is a member. NORD invited Janalee Heinemann, our Director of Research & Medical Affairs, to write about

PWSA (USA)'s experiences with an orphan drug.

Her guest column, published in the summer/fall edition of the NORD Orphan Disease Update and entitled "A Prader-Willi Syndrome Tribute to the Orphan Drug Act", discussed the use of growth hormone therapy and how it is improving the lives of children with PWS.

The article can be accessed by going to www.pwsausa.org and clicking on the Media Room

button. Or call the national office to have a copy sent out. ■

Resources for Teachers

Parents, if you are looking for information for your child's teacher, there is a treasure trove to be found on the www.pwsausa.org web site. Just click on the Be Informed button on the top of the home page and then on For Educators. ■

From the Home Front Christmas Reflections

Each major holiday, birthday or milestone, I can't help but reflect on where we were and where we are now. Christmas gets me thinking and feeling. Mostly I am so thankful. But as Luke's mom, each Christmas is filled with so much emotion, from fear and sadness to joy and pride. Over the years, Christmas revolved around extensive planning to accommodate Prader Willi syndrome, but this year, Luke's 6th, is our first year we have come to the point in healing where we will watch him for his safety, of course, but can focus on the joy of family and the splendor of the holiday.



Luke

When Luke was 3, I was astonished at all the free time I got at the holiday by not overcooking and being stuck with leftovers. It was also a year where he reached plenty of milestones. As the hypotonia was leaving, I began to know more about my child. I felt like the hypotonia masks so much of the child's thoughts, abilities, and means of expression. But still we were terrified of this stranger Prader-Willi. We watched him meticulously for behaviors and never let him out of our sight, not even for a minute so others at Christmas wouldn't ever have to see what we feared. It was all unknown. And all that energy was

a waste. He was just a little boy - a toddler.

At 5 years of age, I reflected again. I shared my feelings with the parents on the 0-5 board with whom I spent every day online.

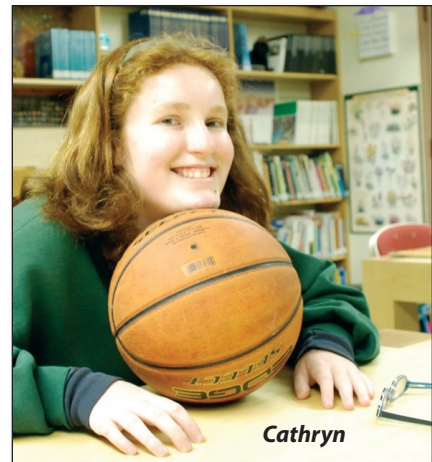
"...I wrote a note on this board when he was 3. I just re-read it. It's amazing, but over these 2 years I've forgotten a lot of the challenges we've had. I've forgotten all the things that became missing when I imagined our life with PWS. All that seemed to have been taken was replaced in abundance.

"Instead, it's been a life of many challenges, but challenges we could accomplish. And mostly, it's still nothing like we were initially told. I for a long time could not understand what the other mothers meant about the joy of having a special child. I now am beginning to understand.

"I've spent a lot of time watching him and his peers, and I've realized no one is ready all the time and none of the 'other' children are perfect. Their parents are always on pins and needles about something, too. I realized all these moms are just as vulnerable as I am when it comes to their children."

At this Christmas holiday, my son is 6. We celebrate many joys and are proud of many 'ordinary' accomplishments. I absolutely relished the day he did homework, a dinosaur poster project. Even better was getting to put the rubber bands on it and send him to school just like any other child. I know chapters are written about behavior, hyperphagia and the like, and our family certainly can relate to those, but little is written about the 'ordinary' accomplishments and simple joys that make us special parents. ■

~Robert and Lisa Ranieri
Hoover, Alabama
Mom to Luke 6,
William 4,
Mallory Lynn 2



Cathryn

Photo provided by Intermountain Catholic

A Very Special Girl

Our daughter Cathryn is an eighth grader at Our Lady of Lourdes Catholic School. She was elected as the Student Body President for the 2008-2009 school year. No other students wanted to run against her. They said "they wanted Cathryn to win." Since she's gone to this school that has been the prevailing attitude of her classmates--one of acceptance and love. Are we ever lucky!!

She has been mainstreamed in school for her entire schooling. Thus far it has worked out really well. She is on a somewhat altered curriculum, but goes to all the core classes with an aid who has effectively been able to bring the material down to her level. Cathryn continues to surprise us in everything she does. She always rises to the occasion, and performs like a champ.

One of Cathryn's passions is basketball. She fully supports our local professional team "the Jazz" and goes to all the Judge Memorial High School games. She is their number one fan. She also gets off the side lines by playing on her own Special Olympics team "the Dyno-stars". They won their last game, with Cathryn being the high scorer and making the game-

Special Girl, continued on page 14

From the Home Front,
continued from page 13

winning shot. She also kept a close watch on the score keeper. She noticed that he had not given them one of their baskets and didn't hesitate to let him know, thus making the game a winner for her team instead of a tie.

We have really concentrated on getting Cathryn tons of exercise. She has been exercising at a local gym doing some boxing, as well as some weight lifting. It amazes us how hard she works. At the end of her workout, she is so jazzed and much more engaged

psychologically. We feel it has helped tremendously with any behavioral issues we may face.

Of course, the Prader-Willi demon rears its ugly head from time to time. At these moments she needs reassurance she is not being placed on "Santa or the Easter Bunny's bad list." As soon as we reassure her, she moves along nicely. Just know that our dreams for Cathryn are no less than for our other children...just a bit different. We know we won't be disappointed, whatever the future looks like. ■

~Caryn and Richard Hunt
Salt Lake City, Utah



Caught in the act!
Ruchama Broyde, age 4

First you sneak-- and then you snooze!
~ Yisroel and Chana Broyde
Lakewood, NJ

Correction:
The correct e-mail address for Christopher's (Drums) Workshop is: pattiehuffkelly@yahoo.com

We Remember



Page Nicole Bintz

June 12, 1971 - July 23, 2008

Page is survived by her parents John and Marilyn, brother Dana, sister-in-law Shawna, nieces Vanessa and Sarah, and her uncle David.

Friends have reminded us of incidents they remember about her. We would like to share two of them.

Page loved "Trick or Treat" (no surprise) and, when she was seven, remembered three neighbors who had not been home that evening. At Christmas she realized people had a lot of goodies around. So on the afternoon of Christmas Eve she returned to those neighbors, explaining that she had been there for trick or treat and they had not been home. Would they perhaps have something now? Did they ever. She came home with plates full of treats.

As an adult she was able to realize her dream of supported living in her own house. We were

to visit to see her new place. She decided to have a BBQ/picnic to introduce us to her friends. Informed that about twenty people were coming, would we mind stopping at the store for something. We asked what she needed. Her reply, "Could you get two cases of diet soda, a bag of charcoal, paper plates, the hot dogs, hot dog buns, ketchup and mustard. I've got all the rest."

For all the problems, struggles, joy and laughter, Page was much loved and we will miss her. ■

~Marilyn Bintz

"May you all have a safe and happy holiday, experience the blessings of the season, and look forward to the new year with hope for more advances in the care and treatment of Prader-Willi syndrome."

Contributions

Thank you for Contributions in August and September 2008

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

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In Honor of (Honoree in bold)

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continued on back page

In Honor of (Honoree in bold)

Ashley Fender's 8th Birthday Katherine Radaz Wayne and Karen Wendel Jacob Fiske's 3rd Birthday Walter and Marge Foran Brennen Fletcher Mary Jo Breslin Mary Breslin Renee and Richard Fletcher Joseph and Elizabeth Keating Tony and Pam Keating John and Maureen Yates Ryan Fochs Harlan and Melba Hamlin Brooke Fuller Scott DeWitt Jim and Sue Fuller Molly Fuller Ralph Garlick James Harding Susan and Brad Laffrey David and Betty McHugh Michael Murphy Jerry Timmer, Jr. Brooke Gabaldon Frank and Julie Scott Joan and Jim Gardner Mary Ann Lockhart Corbin Garrett Joan and Tom Garrett Ruaidhri (Rory) Gillespie Penny and Sean Gillespie Sienna Grace Godfrey Lois Bascom Charlie Graham Shelly and Eric Graham Josie Faye Grandsard Anita and Robert Ashe Chase Grey Robin and Ken Grey Kirsten Guinn Carol Michels Mark Haley Dick and Peggy Haley Samantha Harris Becky Schulte Owen Hartman Jacqueline Herbert Shonetta Hayes Gloria Means	J R Headley James Headley Sean Patrick Healy Kathleen Healy Hannah Herne John Burke Conor Heybach Howard Emmer and Rene Heybach Paula Heybach Henry and Janet Underwood Lexi Higgins Ron and Mary Lee Higgins Oscar Hill Jennifer Hill David Homer John Homer Collin Hughes Angela and Mark Hughes William Ronald Hughes II Bill and Margie Hughes Abel and Barbara Parsons Cathryn Hunt Caryn and Richard Hunt Madison Hurdle's 6th Birthday Joe and Sue Iversen Peter Ingalls Mary Ingalls Barbara Wentworth Nancy Janes Jean Janes Julien Swiger Jernigan Maurice Boyd and Irene Jernigan Payton Click Jones Jewel Allen Bartrum Trail Senior Mens Golf Association H W Bedingfield, Jr. Peggy and Bud Carter C E and Deborah Carter Forest Hills Mens Senior Golf Geotechnical & Environmental Consultants Inc. William and Isabell Heberger Angela Hillesland Judy Huff Lansing Lee, Jr. W B Mullins	Kathy and Robert Riley Jim and Mary Ellen Riviello Gladys Simpson Carol and Jerry Williams Thomas Keating's Retirement Dennis Murphy Lauren Khourie Pat Bacon-Brandt Matthew Killian Lynne LaMar Emma Kimmel David and Nancy Kimmel Jaycie Kinn Jennifer and Joseph Kinn Ben Knopf Richard and Lisa Menti Lia Kreacic Florence and Tony Kreacic Daniel Kresch Catherine Courtney Talia Lazar Bonnie and Steve Lazar Danielle Ledoux's 43rd Birthday Raoul and Claire Ledoux Ben and Janis Leightman's Anniversary Steve and Michele Leightman Raymond and Ida Leightman's Anniversary Ben and Janis Leightman Steve Leightman's Birthday Raymond and Ida Leightman Josi Levine Jane Schiff Rachel Levy Diane and Lawrence Hoefler Jack Lindsey Thompson Baptist Church Jackson Lowe Stephen and Connie Lowe Thomas Jersey Maczko Cathryn and John Maczko Ramon Madrid, Jr. Kelly and Patrick Gibbs Allison Mahan Libby and Rob Fuller Max Manning	Anne Manning Michael Marchitelli Michael and Lin Marchitelli Karin Marcovici Victor and Vivian Marcovici Evan Matesevac's 2nd Birthday Norm and Charlotte Karin Danielle Magness Aaron McCleary's 9th Birthday Patrice McCleary Duncan McRae Thomas and Patricia McRae Brian Melchin Joseph Melchin Christopher Mesropian Claudine Roman Luke Mukoda Robert and Darlene Mukoda Steven C. Neiger Susan Roubal Ewald & Vivian Neitzel's 50th Anniversary Martha and Gary Girdaukas Eileen Noble, RN Susan Ferraro Lily O'Leary Rene and Irene Mailloux Nancy O'Leary Nicholas Paige Kathleen and Ralph Paige Michael Pajon Mayra Rubio Caroline Parcell Lloyd and Alice Parcell John "Jake" Pawulak Susan and Garry Neal Quarterdeck Restaurant David Dempsey Lilah Penaflo's 1st Birthday Angelique and Fred Penaflo Christine Persanis Harry and Muriel Persanis Brooke Pfeiffer Donald Armento MD Lauren Pfeiffer John Halter Mel and Chris Pfeiffer PWSA (USA) Staff	Gary and Carolyn Weakly Teresa A. 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Watson Ralph and Margaret Shirkey Cynthia Watson Ruth Watson Garrett Weaver Bill and Claudette Slaughter Dominic Wenzel Sue Genthner Ashley Willis Bill and Jude Johnston Michael and Muriel Tate Truman Willoughby Jean and Chuck Willoughby Alden Young's 1st Birthday Kathleen Downs Joseph Young Jeannette and Thomas Young Regina and Sheila Dardis Janet Torreso Lorraine Young Sean Michael Youngkin Duane and Caroline Coykendall
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Prader-Willi syndrome (PWS) is a birth defect 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. 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.



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USA
PRADER-WILLI SYNDROME ASSOCIATION
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