

The *Gathered View*

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

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

Moments That Take Your Breath Away

By Vicki Knopf

I don't know if it's the time of year or what, but I have been experiencing and remembering many "take your breath away" moments lately.

One of the more difficult parts of being a parent to a child with special needs is learning to deal with the grief. David will be 13 tomorrow. In 13 years I have come to accept PWS and what it means for him, but there are still times that it hits me out of nowhere. That feeling of sadness for what never was and never will be.

Tonight I had one of those "take your breath away" moments. It's been a long week. Dave, my husband, has been working long hours on night shift, and because he is not home at night I am not sleeping well so I am tired.

David has been wound up about his birthday all week, reminding me 2 million times a day that his birthday is Saturday. Like I could forget. The other thing he has been very excited about all week is that he has his first Middle School Dance tonight. He has had the ticket in his wallet all week and has been so excited.

He was showered, dressed, and had sprayed half a can of Axe on himself by 5:30. (Did I mention that the dance didn't start until 7p.m.?) So we waited until 6:45 to leave the house and I drove him over to the school. On the way we chatted about the dance, and he reminded

me that he was only supposed to dance with the girls... not boys.

When we got to the school, I went in to make sure that whoever was tending the snack table was familiar with David and would make sure he didn't hang out there all night. I was happy to see two familiar faces at the snack table so we chatted for a few minutes, and I reluctantly got ready to leave. I said goodbye to David as he headed into the gym.

As he walked away with two friends, he stopped, looked at me over his shoulder and said, "You can go, mom, I am OK."

That is all it took for the tears to well up. I headed to the parking lot so I could be alone in my thoughts. I got into the Suburban, turned the key, and the radio came on. I had the radio on some sappy station that had been playing Christmas Carols earlier in the day. What I heard made chills go up my spine and the tears start to flow.

When David was a newborn he would get very alert if I sang and danced with him. I would slow dance with him on my shoulder and our song was a song by an artist named Joshua Kadison. The song is titled "Beautiful in My Eyes." I used to sing it to David and wonder if he would ever dance with a girl other than I, if anyone other than I would ever think he was beautiful, if anyone other



David Knopf, a teen with PWS, recently attended his first middle school dance

than his family would ever love him. I would slow dance with him, sing and let the tears flow for my beautiful boy.

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**PRADER-WILLI
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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.

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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; Jun. 1; Aug. 1; Oct. 1

Executive Director's View

Photo by Eric Hilton



Craig Polhemus

A Victory For Our Families

Late last year, the PWS community scored a major victory in our efforts to influence public policy to better serve teenagers and adults with Prader-Willi syndrome.

With only a week's notice, almost 200 people responded to my e-mail urging them to write to the Social Security Administration (SSA) regarding the process for determining disability for SSI. Well over 10% of the 1,500 comments received by the SSA from those concerned with any disability came from our families — a truly stunning accomplishment for a rare disorder.

As a result, I was asked to testify in December before the Social Security Commissioner, SSA's chief administrative law judge, and other high-ranking officials about the difficulties our families face in establishing disability for SSI.

Except for the lowest-income families, SSI eligibility usually starts when the individual with PWS turns 18 — but most frequently the initial application is denied. The next stages are a request for reconsideration and then an actual hearing before an administrative law judge. We almost always win at that final stage, but this can take up to three years and all too many families get discouraged and do not pursue the necessary appeals. We also know of people who have died while awaiting a decision that would have provided Medicaid and needed income.

At the December hearing in Washington, the SSA Commissioner and other SSA officials learned for the first time of the factors — such as the risk of food-seeking and behavioral issues — that make most of those with PWS unable to work in traditional employment settings. The officials indicated that during 2008 there is an excellent chance that PWS will be added to a Listing of Impairments for which disability is automatically presumed. This would dramatically shorten the SSI application process.

Even before they change the Listing of Impairments, SSA is considering incorporating several behavioral questions focused on PWS in its first-level disability determination process. I provided a draft of

those questions during the hearing, and our Crisis Intervention Counselors are refining it now.

We are also developing new forms to be signed by a child's doctor and parents responding to the same types of questions. Parents should include these new forms with their child's application for SSI, no matter what stage it currently may be in the process. The forms may be found at www.pwsausa.org/ssi.htm. Because it provides Medicaid eligibility along with

Well over 10% of the 1,500 comments received by the Social Security Administration from those concerned with any disability came from PWS families — a truly stunning accomplishment for a rare disorder.

funding to help pay for group homes or other supportive living arrangements, obtaining SSI is the key financial challenge faced by parents of older teens with PWS. We are notifying parents of 17-year-old

children with PWS to plan for and begin preparing their SSI application early. As always, our Family Support and Crisis Intervention staff are available to help.

Would I have been asked to testify without the almost 200 letters on PWS? Probably not. And without that special opportunity to educate high-level SSA officials on the special needs of those with PWS, families might have continued to struggle to prove eligibility. This victory demonstrates the power of unity.

During 2008, I hope you will join us in further advocacy on insurance, government benefits, legal and health-related issues. If you know of public policy issues where we can make a difference, please tell me (cpolhemus@pwsausa.org). In unity there is strength — and we proved it by this victory for those with PWS.

Sex and the Male with PWS

By Janalee Heinemann, Director of Research & Medical Affairs

In the past, our primary concerns were to increase awareness of PWS and improve outcomes for our infants and children. Continued progress in these areas now allows us to focus on quality of life issues. Improved management, including early diagnosis, behavioral intervention and medical therapy, including the use of growth hormone, has changed the outlook for those with PWS. Many adolescents and young adults with PWS can now be more integrated within the community.

One quality of life issue that has received little attention in the past is the sexual health of adolescents and young adults with PWS. Natural sexual development is often incomplete for those with PWS. However, they often have the same sexual needs and desires for relationships as their peers. We parents and caretakers share concerns about how to address these issues and encourage healthy lifestyles while considering the social vulnerability of those with PWS.

Questions frequently arise regarding sexual preferences, dating, sexual function, contra-ception and fertility.

Un-edited examples of recent questions

- I have one question to ask you. Can people that has Prader Willie syndrome can one day can they be a Parent yes or no?
- hi merry Christmas can you send me info about gonadotropin please I really want to have kids with my girlfriend when I get married to her please i really do.
- will this disease make me sterile?
- Are there people with PWS who are homosexual?
- i was wondering what is the special kind of medicine for producing sperm. is it called genetobin something like that. well i wanted to know so i can tell doctor i wanted to get married and have my own family im one of them can produce sperm i had a normal erection and i just wanted to know what was it called so i can have then stronger. Thanks. write back soon.
- Do I need sex hormone replacement therapy? What do they do to me?
- (From a concerned mother): Do you know if our boys can function sexually at all? I mean are they able to have intercourse?

For female adolescents and adults, consensus is that estrogen replacement treatment may be necessary, although research is needed on best ways to implement treatment.

The situation is much less clear for males with PWS. Most do not finish puberty unless testosterone therapy is given. However, there is continued reluctance to administer this treatment. Without adequate testosterone, there is a high risk for development of weak bones, or osteoporosis, and other medical problems. Also, males who are inadequately virilized may suffer from significant social limitations that could seriously affect social relationships and self-esteem. While we know that although rare, it is possible for females with PWS to become pregnant, very little is known about male fertility.

Male continued on page 5

A Mother Shares Her Concern

Do I wait until puberty to have my son with PWS treated for his small penis and undescended testicles?
Moris Angulo, M.D. responds

The treatment in general of micropenis (small penis) for anyone is better when treatment is given during infancy or early childhood. Early in life males have large number of androgen receptors but they gradually decrease with age; therefore late treatment with androgen can give erection but not enlargement of the penis.

In theory, males with PWS could be treated with a combination of LH and FSH, as in another condition of hypogonadotropic hypogonadism known as Kallmann syndrome. Androgen replacement improves both libido and erectile function. Restoring fertility is theoretically possible in patients who generally respond to treatment with pulsatile GnRH or gonadotropins. This is another reason I recommend medical management with gonadotropins early for male infants with PWS with undescended testicles before surgery. Even in the case of failure to bring the testicles down to the scrotum, the testis still produces testosterone under such stimulation which could help for further enlargement of the penis.

Androgen therapy in males should begin with low dose followed by gradual increase as tolerated to avoid behavioral problems seen at the normal recommended dose for hypogonadic males.

Dr. Angulo is a PWSA (USA) Clinical Advisory Board member with dual degrees in endocrinology/genetics.

Research View

Researchers Seek Study Participants

A study to evaluate the effect of a new weight loss drug on body weight and appetite of subjects with Prader-Willi syndrome

Cannabinoid system has been known to modulate feeding behavior and appetite. Cannabinoid receptor CB1 is involved in regulation of appetite, body weight, and metabolism, and is found in the central nervous system (CNS), autonomic gastric nerve endings of the peripheral nervous system (PNS), and other key cells involved in body energy metabolism, including fat cells.

A new CB1 receptor blocking drug, rimonabant, has shown promising results in treatment of obesity and its cardiovascular complications in obese adults. Studies have shown that in addition to the inhibitory effect on food intake, rimonabant directly increases energy expenditure.

CB1 receptor has also been identified in normal cells of the anterior pituitary in the brain. Activation of

CB1 receptor can decrease growth hormone secretion from the pituitary, while blocking the CB1 by rimonabant can block this effect on growth hormone secretion.

Dr. Angulo and Dr. Motaghedi are conducting a randomized, double blind, controlled study evaluating the effect of this investigational drug on the body weight and fat content of adult patients with PWS.

The effect of this investigational drug on blood sugar, lipids, Ghrelin, Leptin and GH regulated IGF1 and IGFBP-3 will also be tested. Patients will be followed for six months. Currently, this trial is recruiting adults with PWS who are not taking growth hormone or psychotropic medications.

Please contact Dr. Roja Motaghedi at New York-Presbyterian Hospital/Weill Cornell Medical Center, 212-746-3462, for further information.

Male - continued from page 4

PWSA (USA) is actively addressing the issue of sexuality in PWS, sponsoring an extensive study in Israel led by Drs. Varda Gross-Tsur and Harry Hirsch. We will report results of that study in the near future. PWSA (USA) is also a cooperating partner in a study led by Drs. Susan Myers and Barbara Whitman in St. Louis, Missouri.

Sexual health in PWS is addressed in Chapter 21, "Advocacy Issues: Sexuality," of our *Management of PWS* textbook, which I co-authored with David Wyatt and Barbara J. Goff. Status of medical knowledge of sexual health is reviewed in the book in Chapter 5, "Medical Considerations," by Drs. Urs Eiholzer and Phillip D.K. Lee.

Both the PWSA (USA) Clinical Advisory Board and Scientific Advisory Board members volunteer their time to answer hundreds of members' medical and scientific questions. In an upcoming issue, Dr. Phillip D.K. Lee of our Scientific Advisory Board will review medical aspects of male sexual health in PWS. In future issues, we will focus on other topics related to both male and female sexuality, along with other issues related to quality of life.

I welcome your questions on these topics; please e-mail me at jheinemann@pwsausa.org.

Plan to Attend the 23rd Annual PWSA (USA) Scientific Day Conference & 30th Annual PWSA (USA) National Conference

We are seeking scientists, researchers and medical personnel who are interested in presenting abstracts of recent research studies at our Scientific Day session on **July 2, 2008** at The Wyndham Milwaukee Airport and Convention Center in Milwaukee, Wisconsin.

The PWSA (USA) Conference Scientific Day is an opportunity to network with leading researchers and hear presentations on topics such as: Genetics, Medical, Nutrition, Behavior, Social, Endocrine, and Diagnostic Criteria. Scientific Day is co-chaired this year by **Aaron Carrel, M.D.**, Associate Professor of Pediatrics, University of Wisconsin Children's Hospital, Pediatric Endocrinology, Diabetes, and Fitness and by **Merlin G. Butler, M.D., Ph.D.**, William R. Brown/Missouri Chair in Medical Genetics, Chief, Section of Medical Genetics and Molecular Medicine, Professor of Pediatrics, University of Missouri-Kansas City School of Medicine Children's Mercy Hospitals and Clinics.

A presenters' **Intent to Submit** form will be available on the PWSA(USA) web site in January and will be e-mailed to our scientific and medical personnel database, past presenters and attendees.

Send questions to Scientific Day Coordinator Kerry Headley at k.headley@pwsausa.org.



Part 2 of Highlights from PWSA (USA) 2007 Scientific Day

Energy Requirements of Infants and Young Children with PWS: With and Without Growth Hormone Therapy

Laura F. Goodwin, Joanna M. Ornoch, Karen Balko, Glenn Berall

The energy requirements of infants and young children with PWS are unknown. The study objectives were to determine energy requirements of infants/children with PWS with or without growth hormone therapy while considering the genetic subtype, and compare these energy requirements to age-matched children in the literature.

The lower metabolic need suggests that infants and young children with PWS may be overfed even prior to onset of hyperphagia if calories-per-centimeter standards developed in older patients are applied to this group of young children with PWS. The data also suggest that best practice for this population would include conducting regular basal metabolic rate testing as a standard method of energy requirement assessment. Through examination of mREE, energy requirements for proper growth, development and prevention and/or treatment of obesity or undernutrition in infancy and early childhood can be determined to better guide clinicians in prescribing appropriate calorie amounts for their patients with PWS. Further studies with larger study samples are necessary to determine the role of growth hormone therapy on energy requirements.

A Conceptual Framework for Understanding Symptoms of Autistic Disorder in the PWS Phenotype

Janice Forster,* Linda Gourash*

Autistic Disorder is diagnosed by the presence of 1) qualitative impairment in social interaction, 2) qualitative impairment in communication, 3) restricted/repetitive and stereotypic patterns of behavior, and 4) developmental delay with onset of symptoms occurring prior to age 3. In this presentation, a conceptual framework was described to understand the overlap between the autism phenotype (characteristics) and those of PWS.

Most studies examining autistic symptoms within the PWS phenotype have used DSM-IV diagnostic criteria (qualitative symptoms) for autistic disorder. Sample size has been small and the population of people with PWS has been varied for age, gender, IQ, and genotype. Some studies tried to use adaptive behavior scales to quantify the level of functioning. Overall, the use of different scales makes difficult the task of comparing results.

Although a few people with PWS undoubtedly meet criteria for Autistic Disorder by DSM-IV criteria and ADI-R, the majority reflect the *heterogeneity* of the PWS phenotype and the autistic spectrum. Defining domains of overlap and difference and combining these results with studies of first-degree relatives will inform results in the social communication and language domains. Understanding the genetic contribution to the *heterogeneity* of PWS phenotype will enhance our understanding of the genetic etiology of autistic spectrum disorders overall.

Stress, Health, and Mental Health in Mothers of Children with PWS and Other Types of Disabilities

Elisabeth Dykens,** Rebecca Kossler, Elizabeth Roof

Raising children with intellectual or developmental disabilities is consistently associated with heightened parental stress, and previous studies find that levels of stress are relatively high in parents of children with PWS. While chronic high stress is associated with a host of health and mental health concerns, these have yet to be examined in mothers of children with PWS. This study identified stress levels, coping styles, and psychiatric and health status of mothers of children with PWS, along with cortisol, a biomarker of stress. Researchers first compared these measures in mothers of children with PWS to mothers of children with Williams syndrome or autism spectrum disorder (ASD). Then they identified correlates of cortisol levels within each group. Mean ages of offspring were similar across groups (9-11 years).

The three groups were similar in depressive symptoms, psychiatric histories, life satisfaction, and positive perceptions. Nonetheless, mothers of children with PWS had a significant, two-fold increase in distress relative to remaining groups, and significantly higher mean levels of cortisol. Cortisol in the PWS group was associated with maternal anxiety, avoidant coping, and child compulsivity.

Critical Analysis of Bariatric Procedures in PWS

Ann Scheimann,** Merlin G. Butler,** Linda Gourash,* William Klish

PWS is considered the most common genetic etiology for development of obesity. Although some morbidities associated with PWS, including respiratory disturbance/hypoventilation, diabetes and stroke, are commonly seen in obesity, others, such as osteoporosis arising from diet restrictions, growth hormone deficiency and hypogonadism, and altered pain threshold/inability to vomit, pose unique issues. Reviewed were a variety of bariatric procedures that have been attempted for PWS to bring about gastric stasis, decrease gastric volume, and induce malabsorption, with poor results in PWS compared to normal obese. There is no apparent effect of bariatric surgery on hyperphagia in PWS. Therefore, the need for dietary intervention and monitoring is not eliminated. Over the long term, weight gain may recur after the patient develops compensatory dietary strategies.

Individuals with PWS and Others with Early-onset Morbid Obesity Share Similar Relative Strengths in Cognition and Achievement

Krista A. Schwenk, Jennifer Miller,* John H. Kranzler, Daniel J. Driscoll*

Testing was done to determine the extent to which individuals with PWS, early-onset morbid obesity (EMO) of unknown etiology, and their normal sibling control participants reached the attainments predicted by their IQ. In

continued on next page

addition, relative strengths and weaknesses of the three groups (PWS, EMO, and controls) were investigated.

All three groups scored higher on their overall achievement score (TIA) than their IQ, but the difference between scores was only significant for the PWS group (PWS: TIA = 67, IQ = 63; EMO: TIA = 79, IQ = 75; Control: TIA = 109, IQ = 108). Mean differences between the PWS and EMO groups were not significantly different on the Cognitive Efficiency and Phonemic Awareness clusters. The PWS and EMO groups scored significantly higher on the Verbal Ability, Thinking Ability, and Phonemic Awareness cluster scores of the WJIII-Cog than predicted by their overall IQ. Moreover, Phonemic Awareness was a particular strength for both the PWS and EMO groups.

Mean overall achievement between the PWS and EMO groups was not significantly different. In addition, both the PWS and EMO groups scored significantly higher on the Oral Language and Academic Skills cluster scores of the WJIII-TA than their TIA.

Results indicate that people with PWS and EMO share many similarities in cognitive abilities and achievement scores. Both groups scored significantly higher on the Phonemic Awareness cluster compared to their IQ and on the Oral Language cluster compared to their TIA. Results indicate that those with PWS and others with EMO have relative strengths in linguistic competency, listening ability, and comprehension.

Mood Activation as a Complication of Gonadal Steroid Therapy in PWS

Glenn B. Berall, Janice L. Forster, Linda M. Gourash**

The antidepressant effect of estrogen in neurotypical individuals is well documented, especially in the perimenopausal period. The authors note that the combination of hormone replacement therapy (HRT) and medication in the selective serotonin reuptake inhibitor (SSRI) class may be a stimulus to mood activation in PWS. Mood activation presents with mood elevation, lability, irritability, impulsivity, and/or increased goal-directed behavior. Although mood activation can be an early manifestation of Bipolar Mood Disorder, it has also been associated with the use of antidepressants and stimulant medications. Unlike Bipolar Mood Disorder that requires management with mood-stabilizing agents together with environmental interventions, mood activation is preferentially treated by withdrawing the agent producing the iatrogenic effects. The identification of the root cause for mood activation is the first step toward effective management.

Gonadal hormone replacement has been recommended in PWS for management of osteoporosis. It has also been used to further the development of secondary sexual characteristics to improve self-esteem and social assimilation. SSRI medications are often selected for the management of symptoms of anger, impulsivity, moodi-

ness and excessive/repetitive behaviors occurring among those with PWS.

A combination of estrogen and SSRI medication results in the augmentation of the antidepressant effect through serotonin function. Further, studies in rat models suggest that the results of estrogen augmentation on behavior equivalents of mood occur more quickly than the antidepressant effects of the SSRI medications.

Although the precise mechanism of mood activation in PWS and other special populations has not been clearly explained, the amplified effects of SSRI medication and gonadal steroids used in combination provide another etiological pathway for consideration. The clinician must proceed cautiously when using SSRI medication or gonadal steroid replacement therapy in people with PWS, and especially when using these agents in combination.

Loss of Magel2 in PWS: Lessons from a Mouse Model

*Rachel Wevrick,** Rebecca E. Mercer, Erin M. Kwolek, Jocelyn M. Bischof*

Researchers generated gene-targeted mice for two key PWS genes, encoding *necdin* and *Magel2*. These two proteins are part of the MAGE multi-protein family with roles in cell migration, cytoskeletal rearrangement, neurotrophin signaling, differentiation, and apoptosis.

In mice, *Magel2* is highly expressed in a circadian fashion in the suprachiasmatic nucleus of the hypothalamus, the circadian-rhythm generating center of the brain. Gene-targeted mutation of *Magel2* in mice causes altered circadian-rhythm output and reduced motor activity. The role of the hypothalamus in the coordinated regulation of appetite and body weight prompted examination of whether *Magel2* is also required for additional hypothalamic functions that are relevant to abnormal growth and metabolism in PWS. They found that *Magel2*-null mice exhibit neonatal growth retardation and excessive weight gain after weaning.

They also note signs of altered metabolism in adult mice, which recapitulate fundamental aspects of the PWS phenotype such as increased fat mass and decreased lean mass. Both male and female mice have reduced reproductive capacity that declines with age.

The researchers propose that combined loss of *necdin* and *Magel2* act in an additive or cooperative manner to cause delayed or abnormal development of the nervous system, leading to altered physiology in individuals with PWS. *Magel2*-null mice provide an opportunity to examine the physiological basis for PWS neonatal failure to thrive and post-weaning weight gain, and to understand the relationships among circadian rhythm, feeding behavior, metabolism, and fertility.

* Daniel J. Driscoll, Ph.D., M.D.; Janice Forster, M.D.; Linda Gourash, M.D.; and Jennifer Miller, M.D. serve on the PWSA (USA) Clinical Advisory Board.

** Merlin G. Butler, M.D., Ph.D.; Elisabeth Dykens, Ph.D.; Ann Scheimann, M.D.; and Rachel Wevrick, Ph.D. serve on the PWSA (USA) Scientific Advisory Board.

See all Scientific Day 2007 abstracts in the Members Only section of www.pwsausa.org

Making your Summer Travel Plans? Don't forget to include the 30th Annual PWSA (USA) Conference!



Our 2008 National PWSA (USA) Conference is fast approaching and we're expecting a great turnout! We are excited to announce that the conference will be held July 2nd thru the 4th at The Wyndham Milwaukee Airport and Convention Center in Milwaukee, Wisconsin.

The Wisconsin Chapter is hosting this year's conference and the theme is **MOO-VING FORWARD**. The chapter selected this theme to highlight Wisconsin as America's Dairy Land. "Forward," the State motto, reflects Wisconsin's continuous drive to be a national leader. We hope this will also promote the message that research and support for people with PWS is moving forward and life with PWS can be positive and fulfilling. A fun-filled, informative three days of programming are planned and the Wisconsin Chapter is rolling out the welcome mat.

The Conference includes a Scientific, Provider and Chapter /Affiliate President Day on July 2, followed by the General Conference on July 3 and 4. The General Conference has sessions of interest to all attendees, as well as breakout sessions geared toward issues of Adults, Teenagers, School Age, and Children from age 0-5.

Conference registration will begin April 1, 2008 on the PWSA (USA) website. We have secured a block of rooms at The Wyndham Milwaukee Airport and Convention Center at the discounted rate of \$98 a night for up to four in a room. Make hotel reservations at any time through Globetrotter Travel by phone at 800-322-7032 (press 2), e-mail pwsa-usa@globetrottermgmt.com, or online at www.globetrottermgmt.com/pwsa-usa.

We will be offering a fun, structured childcare/YIP program for children ages 0-5. Registration in the YIP program is limited to 50 participants, so make your reservations early and don't be left out! Wild Willy and Silly Lilly will again make a special appearance at conference and have fun activities in store for the YIP group.

Thinking about Conference but not sure you have the funds to go?

It's not too early to start looking for funds or sponsorship to attend the National Conference. Funds are available through a variety of sources including:

- Your State Developmental Disability Council (800) 695-0285
- NICHCY at www.nichcy.org
- The ARC (disability related funding)
- Parent-to-Parent (disability-related funding)
- Church or temple
- Your Prader-Willi Syndrome Association state chapter or affiliate

The following expense information will be helpful when applying for grant funds:

- 2008 Conference Registration Fee: \$175 per Adult
- 2008 Youth Programming Fee: \$50 per child (Ages 0-5 only)
- Hotel: \$98 + tax per night
- Transportation Costs (varies)

If you can verify that all other efforts to obtain funding have failed, you may be eligible for a PWSA (USA) grant. Grants will become available April 1, 2008 when registration opens. For more information and grant application guidelines, go to www.pwsausa.org/conf/grants.asp.

Join us in Wisconsin for an uplifting, informative conference that is sure to be memorable! Don't miss the opportunity to meet new friends, renew old friendships and learn about the latest research.

PWSA (USA) eSupport Groups

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

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

IPWSO Plans Conference for PWS Providers

The International Prader-Willi Syndrome Organization (IPWSO) is sponsoring an International Caretakers Conference for PWS Experts June 3-5, 2008, in Herne, Germany.

This special global event for professionals dealing every day with the care of people with PWS is planned as a dynamic working body developing global standards and guidelines of care. The end product will be a published booklet with abstracts, consensus statements on the elements of global “best practice” in caretaking of people with PWS, recommendations, and topics for future consideration. This conference may lead toward a system for certifying PWS providers in individual countries.

“In my travels I have had the privilege to see amazing models of supportive living and caretaker curriculums in many countries,” said Pam Eisen, president of IPWSO. “Although each of our member countries which have group homes, respite or rehabilitation programs approaches the care of people with PWS from different perspectives and cultures, there are many basics which apply to all. There are also many ideas to share and others to learn, which makes this conference a wonderful opportunity for all who participate.”

The price is 100 Euros a night, which includes food registration, and accommodations. More information is available at www.ipwso.org or www.pws-caretakers-conference.de.

**Donations for Research 2007
As of 11/30: \$134,900
has been donated for PWS Research**

PWSA (USA) Crisis Funding Update

Two generous families have renewed their funding for parts of the PWSA (USA) Crisis Intervention Support Program.

The Chippie Alterman Foundation has awarded \$10,000 toward the funding of our Alterman Crisis Intervention Counselor, Kate Beaver. David Wyatt, the founding Alterman Crisis Intervention Counselor, has recently retired but remains active on our two Crisis Coordinating Teams, which are chaired by our new full-time Crisis Intervention Counselor, Evan Farrar.

Steven and Lois Willett have also renewed their support for special legal and educational needs of families in crisis. Since 2002, the Willetts, whose nephew is Brian Schertz (19, with PWS), have contributed \$300,000, and scores of families have benefited from this special assistance.

However, financial support which funds After-Hours Crisis Counselor Prentice Lantzer and the pilot 24-hour, 7-day-a-week, After-Hours Emergency Medical Hotline program has expired. PWSA (USA) has extended the pilot period as we seek additional funding for this potentially life-saving program.

For more information, contact Director of Development and Communications Jodi O’Sullivan at (800) 926-4797 ext. 732 or josullivan@pwsausa.org.

PWSA (USA) is grateful to the Alterman and Willett families and to Colleen’s Angels, which supported the first year of the After-Hours Emergency Medical Hotline pilot program.

— **Craig Polhemus, Executive Director**

Do You Need Information About Summer Camps?

Hundreds of camps across the U.S. serve children and adults with disabilities in daily, weekly or extended programs. Some have experience working with people with PWS; others do not. Some camps have a limited number of slots or have special weeks for certain ages or disabilities. It’s never too early to begin the research.

For information go to www.pwsausa.org or call PWSA(USA), 800-926-4797.

Remember, parents and caregivers must research and make the final decision as to whether the camp we may suggest is the right match for your son, daughter or resident.

Sibling View

A New York Connection, Thanks to Our Siblings

By Ross Park

What started as a blind date set up by one of my good friends turned into a friendship that will last a lifetime... and we have our siblings to thank for it.

My friend Amanda and I were on a bus uptown after a movie in New York City when she started to show me pictures of her previous night out. Suddenly she stopped. "Why didn't I think of this before?" she said.

"What?" I said in return.

"I have the perfect girl for you to meet."

As Amanda showed me pictures and started to tell me more about this mystery woman, I began to get more and more interested to meet her. We had similar views, music tastes, food cravings and outgoing personalities. The next weekend we had a chance to meet briefly while out for drinks with friends.

While we were out to dinner that following week, I began to ask her about her family. She spoke of her mom and her dad, told stories about her little brother. But when she got to her older sister she paused, then began to speak words that I have repeated many times throughout my life.

She explained her sister's limitations. And a few minutes into our conversation I stopped her mid-sentence. "Was your sister born with a syndrome?"

Before she spoke anything, I already knew what the answer was... Prader-Willi syndrome. She had explained her sister the same way that I have explained my brother Whit for probably the last 20 years.

It shocked her about as much as it shocked me, and it took each of us several minutes to let this revelation settle in. We then spent the next hour and a half telling stories about growing up with siblings with PWS and enjoying the comfort that someone else understood this side of our lives. When the evening ended, I knew that no matter where this date would lead us, I would have a friend for life — all thanks to my brother Whit.

Meggie Walcott is the friend that I speak of, and her sister, Bevin (27), is a regular attendee at the Prader-Willi syndrome conferences.

My brother Whit (24) has also attended the conferences every year since he was about 8. I had the



Ross Park

pleasure of attending the conference this year in Dallas, where my mom and Meggie's mom introduced Whit and Bevin. Within 20 minutes of their banquet they were out on the dance floor together. It was great. They are new friends and continue to keep in touch.

Meggie and I still hang out in NYC... and occasionally even we get the chance to get out and dance. I guess it runs in the family.

So for other siblings out there who sometimes think that there is no one else that really understands what you are going through, just think: if two people can randomly meet in a city of 8 million people, then anything is possible. Just keep talking and remember that we are all always here to support you.

PWSA(USA) gratefully acknowledges the production, printing and mailing of our newsletter is made possible by a generous grant from CIBC World Markets Corp./ Miracle Day USA

Many Thanks From the Hurdle Family and the Colorado Rockies

Thanks to all of you at PWSA (USA) who assisted in creating a place for all the generous messages to be accumulated and then forwarded to our family.

We feel very fortunate to have been given our daughter Madison, who has PWS, and the related platform in which to bring awareness to this syndrome that has affected many of our loved ones. We do believe that things happen for a reason... We were blessed with Madison... Clint was given the opportunity to be manager for the Colorado Rockies baseball club which has been so generous with their time, energy and financial backing.

We humbly feel that we are doing what any of our other PWS families would be doing if given the same circumstances. We all need to work together in the lives of our special children.

Sincerely,

Karla, Clint, Ashley, Madison and Christian Hurdle

Fundraising

Your Grassroots Fundraisers Help Support PWSA (USA)

By Jodi O'Sullivan, Director of Development & Communications

PWSA (USA) appreciates all the volunteers who conducted grassroots fundraisers and who raised approximately \$300,000 net in 2007! Thank you!

1st Annual Dash for Prader-Willi, Matt Szapacs & Cindy (Leahy) Szapacs & Kate Madden, Pa.

2nd Annual Super Bowl Fundraiser, Steck (Denise, James, Kayleigh)/Fleming Families, N.Y.

2nd Annual Tuskegee Airmen Motorcycle Club of Va. Prader-Willi Bowling Fundraiser, Sharon Mayo, Va.

3rd Annual Madison Hurdle Softball Tournament, Bobbi Martello, Fla.

3rd Annual Jacob Bingo, Anita Perrault & Family, N.Y.

4th Annual Jack Martin Bevacqua Dinner Dance, Chris Bevacqua, N.J.

4th Annual Music for Mickey, Lisa & Patrick Phernetton, Ind.

4th Annual Prader-Willi Classic LPGA Pro-Am Event, Tennis Tournament, and a Night of Comedy In Honor of Josilyn Faith Levine and Zakary Maxwell Bassel, Levine & Bassel Families, Fla.

Annual Charity Golf Outing, Maurice Fox & Peter Kearney, N.Y.

Bears Training Camp Event, PWSA of Illinois Bowling for Alexis, Cindy Galyean, N.C.

Casual Day at St. Thomas the Apostle School In Honor of Dylan Krambeer, Chris & Angela Krambeer, Ill.

Casual Day Fundraiser In Honor of Grant Whiting, Deb Whiting, N.Y.

Co-ed Slow Pitch Softball Tournament In Honor of Anneke Kramer, Stephanie Daale, Shannon Daale & Stacy Kramer, Iowa.

Dress Down Day In Honor of Madison Smith, Anita Streubel, N.Y.

(Our list continues in the next issue of The Gathered View. We try to be accurate. Please tell us if you notice an error.)

♥ Valentine Research Fund Campaign ♥

Bring love and research hand-in-hand this Valentine's Day. It's a match made in heaven!

With the overwhelming love we have for our sweethearts with PWS, we can support research to ultimately find a cure for PWS. Become a part of or support PWSA (USA)'s 6th Annual Valentine Research Fund Campaign. Go to www.pwsausa.org/valentine to donate or learn how you can help bring your love and PWS research together in 2008.

May We Help You With Awareness Month?

PWS Awareness Month of May is just around the corner. That means it's time to start thinking about what you can do to generate PWS awareness and education in your community.

The Awareness Committee has begun work to help you and will have ideas and tools you can use to make it easy. Look for more on the web site and the next Gathered View.

May is the perfect time to hold a fundraiser! If you would like to plan one, call Jodi O'Sullivan or Rachel Elder at (800) 926-4797 to get started with ideas and support.

What would you attempt to do if you knew you could not fail?

— Anonymous

On your mark, get set... Lose-A-Thon!

Our 3rd Annual PWSA (USA) Lose-A-Thon is ready for you to join. We officially started January 1, 2008 and are waiting for you to jump in and take charge of your health.

Lose weight for a healthier life and do it to support PWSA (USA). You will inspire and directly help those you care about who are affected by PWS! Isn't that the one of the best reasons to join up?

Lose-A-Thon participants choose their own method of reaching weight goals while setting an example for others who need to do the same. Don't forget the new, valuable features this year, too. Monthly articles about nutrition and exercise provide motivating and helpful insight and Ask the Experts answers your questions along the way. We've also created a Lose-A-Thon Community Yahoo! Group where participants can support and encourage each other. All these great opportunities are available *only* to Lose-A-Thon participants!

Go to: www.pwsausa.org/fundraising/lose-a-thon to get started.

Questions? Contact Rachel Elder, community development coordinator, at relder@pwsausa.org.



View From the Home Front

Dealing With Orthopedic Issues and PWS

By Lisa Peters

I have just recently discovered some new interesting orthopedic facts related to PWS.

My son Nicholas, 5, sees a pediatric orthopedist with more than 43 years' experience treating children with PWS. During our discussion, he outlined a few other orthopedic issues to watch for in our children (in addition to the hip dysplasia and scoliosis).

Low muscle tone causes ligamentous laxity, which is a looseness of our children's ligaments. Ligaments are supposed to be tight; it is this tightness that keeps the joints restricted to normal ranges of motion. If muscle control does not compensate for ligament laxity, then joint instability may result.

It is this laxity (combined with a shallow hip joint) that makes our children more susceptible to hip problems. But there are other body areas this looseness can affect; one is the radial head in the elbow which can be susceptible to dislocation during the first 18 months of life. This condition can be treated by bracing at night to prevent hyperextension. Another problem area can be the knee cap, as once again this laxity can make the knee cap more susceptible to dislocation. A dislocated knee can make it difficult for our children to learn to stand. Dr. Seymour Zimbler of Children's Hospital in Boston explained that early

intervention typically includes checking children with low tone to see if their knees buckle or hyper-extend. If the initial problem is not secondary to poor foot placement and does not resolve with physical therapy, a knee brace is typically prescribed.

Dr. Zimbler said all children with PWS suffer from some degree of valgus feet ("flat feet") usually requiring some form of foot support. Nicholas was diagnosed with this condition and uses a plastic shoe insert (molded to the shape of his foot) in his shoes.

Valgus feet is a weakness of the foot that causes our children to compensate by using more muscles inappropriately in order to walk forward, creating an unstable gait. If not resolved at a young age, a child will have difficulty moving on to higher motor tasks such as running and jumping and maintaining good balance control. Nicholas would walk forward by swinging his legs out from his hips. Hip and knee problems can arise because of overcompensation for the weakness in the foot. By positioning the foot in a corrected position using shoe inserts, the progressive nature of the condition can be controlled. Increased foot stability eases the stress to the hips and knees and normalizes the child's stride.

Lisa Peters, Georgetown, Massachusetts

Moments - continued from page 1

There coming from the radio was the song "Beautiful in My Eyes." I was frozen, I couldn't move, I felt like the air was being pulled from my lungs, and then the tears rolled down my face. Right there in the school parking lot I realized that David would dance with a girl tonight and that he has friends who think he is beautiful inside and out.



Infant David Knopf

All the fears I had for him when he was a baby came rushing back and then melted away. It made me realize that so many of my dreams for him will come true... maybe not exactly as I had imagined, but they will come true... nothing is impossible. This kid continues to teach me and humble me.

"Life is not measured by number the breaths you take; it's measured by the number of moments that take your breath away."

Happy Birthday, David!

About The Knopf Family...

Our journey with PWS started December 1, 1994 when our son David was born — our fourth child after three healthy boys. Jacob was born 13 months later.

We had five little boys and life was good. But we both had a feeling that something, or someone, was missing. Then we learned of a baby with PWS who needed a family. So in September 1999, Ben joined our family at age 5 months. He stole our hearts and life was good... but someone was still missing.

In May 2001, I was put in contact with a family who had a baby girl with PWS. They were making adoption plans. Long story short, Caroline Grace Elise came to us at 7 weeks old. We all fell completely in love with this baby girl! She was the missing piece to our family. Seven kids, three with PWS... maybe we are saints, maybe we are crazy, maybe we're a little of both! Either way, life is good and our family is complete.

Vicki Knopf coordinates our PWSA (USA) Parent Mentoring II program. Read the Knopf blog at www.theknopfcrew.blogspot.com

View From the Home Front

Michael's First Soccer Game

Michael is 4 ½ years old and has just had his first soccer game. He absolutely loved it! Thought that he was the coolest guy on the field, wearing cleats and shin guards and a team shirt. . . .

He so enjoyed being part of the team (The Leopards), running with all the other kids, not really going after the ball but always running in the right direction.

There we all sat and watched, his Dad, Mom, Big Sister, Grandma and Auntie, with giant smiles on our faces the whole hour. You have never seen a little boy so happy to be a part of a team.

Standing there and watching him, my eyes filled up. WOW. Who would have ever thought this day would be here for my little guy. Yes, I admit it made me sad at first, because his little legs would only allow him to go so fast. But his determination to keep up was so *there*. And every time Mike would run past us you would hear him yell, "Hi Mom!"

Then seeing him high-five his team mates quickly brought my tears of sadness to very happy tears. PWS or no PWS, here is my little boy who had the best time ever and can hardly wait for this week's game.

And neither can we.

Cindy McAndrew, Tyngsboro, Massachusetts

Support for 1,000 Families

The PWSA (USA) Parent Mentor Program has reached a wonderful milestone: it has supported more than 1,000 new families. Thank you, Parent Mentors: we celebrate another win for our kids!

Chuckle Corner

My son Joshua, age 11, made me giggle the other day when he was patting his tummy and saying, "Enough of that growling, I just fed you. You have Prader-Willi and that's all there is to it. Keep it quiet in there!"

Carrie LaBarge, Spring Hill, Florida



Nice to see you

The Forsters of Pittsburgh, Pennsylvania visited our office in Sarasota, Florida. Pictured L-R: Jennifer (17), Donna (Mom), Rachel (12, who has PWS), Kimberly (14), Sarah (16), and John (Dad). "Thank you so much for letting us visit the National Office with no advance notice," writes Mrs. Donna Forster. "It was nice to see where everything comes together at the national level, and talk to some of the people involved in keeping it running smoothly."

Watched Over by Guardian Angels

All the behavior stuff seems totally unimportant when you don't have your child — doesn't it? Today was our reality check!

Ryan ran away this morning because he was upset about getting on the bus before he could put the trash cans away. I told Ryan (age 9, who has PWS) I would leave the trash cans out for him to put away when he got home. But he got angry, pushed them over and ran up the street. By the time the bus got out of my way and I caught up to where I saw him last, he was gone!

My neighbors and I looked in our neighborhood for 20 minutes, but then we realized we had to call the police: he could be in danger! After the police were involved, we searched for 2 hours before he was found 3½ miles from home on a four-lane road. Thankfully, Ryan had encountered a retired bus driver from the special school district, who called the police.

It seemed like an eternity and when it was all over, I was so relieved to see him I could barely speak! In the grand scheme of things, my husband and I said to each other, we can live with all the quirks and all the behavior problems... But we can't live without him! Thank God for all the Guardian Angels who helped today!

Kelly Becker, St. Louis, Missouri

Gathered View now available electronically

If you'd like an electronic version of our PWSA (USA) newsletter before it arrives in the mail, e-mail your request to info@pwsausa.org.

Balancing *The Gathered View* For the Home Front

By Lota Mitchell, Associate Editor

Recently Director of Research & Medical Affairs Janalee Heinemann received an e-mail, along with pictures of an adorable little boy, expressing some feelings about *The Gathered View*:

"Cole truly is an inspiration to my husband and me... Each week he's improving more and more! I want to express a concern that I have. I have been receiving the GV since Cole was first diagnosed and was happy to gain such a wealth of knowledge of the syndrome, techniques, experiments and also other parents' experiences of having a child with PWS.

"But as a new parent... I find the GV very hard to read. I am not in denial that my child has this syndrome but I feel many of the experiences and stories parents write are depressing instead of upbeat and positive. I understand parents have to grieve but as a young mother of a child with PWS who is doing so well, I want to read about all the GOOD things!"

Janalee responded to her this way: "I appreciate your feelings.... The problem is that one size does not fit all. We have also been criticized for the GV being too optimistic, and parents of children with problems no longer feel they can relate to it. It is a big world of parent personalities, ages, and variances within the syndrome that we are trying to serve. Many years ago... we even started a separate GV for parents of the young child — but then got criticized by the parents who said they did not want us to keep information from them. I wish I had a solution for this dilemma. I know one thing it did for me when Matt [our son who has PWS] was young was to be determined that that would not be Matt's future, and it wasn't. He is 34 years old, tall, slim and happy. Some of the tough stories were good motivators for us to do it different — for Matt and for all of the children with PWS."

Sometimes it is other parents who provide the balance. Here is a mother sharing her own story with another mother having a really hard time:

"I was in tears yesterday because of my son. My marriage right now is going through a rough patch because of how much time dealing with him consumes I, too, am at my breaking point. I have been fighting for him all his life and at this point I am tired.

"I have a very supportive family as well as a team that includes his behavioral specialists, weight management specialist, pediatrician, etc. The question is why isn't this enough? He is still acting up and I don't know what else to do for him. I just wanted to let you know that you are not alone."

So what do we as editors do as we try to determine the content of *The Gathered View*? We cannot ignore the wide range of needs and ages of those who will read it.

Some with children doing well may find it depressing to read about children who are not doing well and want to read about children who are doing great.

Conversely, some may find it depressing to read about children who are doing well when theirs are not and want to read that they are not alone in the problems they are having.

Perhaps the answer lies in parents choosing which articles meet their particular needs over those they don't relate to at this time in their child's life and thus don't want to read. Just as they choose what their child ren watch on television.

Janalee's last sentence to Cole's mother was, "Hang in there, keep reading, [and] keep optimistic!" That's good advice for us all.

One Day God Sent Two Angels...

I have a story to tell you about how great people can be. Most of the time we live week to week. [My husband's] boss told him about a couple with a baby with some of the same problems as our child and they wanted to talk to us about coping with everything. So we expected to talk to them about feelings, pressure and everything.

After they were in our home for about an hour, we realized something was wrong. As they talked, we found out their baby girl at 16 months passed away 3 years ago from a rare genetic problem. And the next thing that came out was, on [the anniversary of their daughter's death] they had a motorcycle [event] called Kayla's Ride and they wanted to help us out.

After losing their baby girl they wanted to help others and by helping us and our child, they are keeping their baby's spirit alive. They gave us money and said here it is, not a lot, but we hope it will help you with bills or whatever.

We hugged them, said how thankful we where and cried. This couple who didn't even know us and never had talked to us before had raised \$900.

I am still in shock and disbelief and I still cry when I talk about it. But I want to say that yes, sometimes we come into contact with mean and cruel people, but sometimes God sends these great angels to show there are still good people out there. God bless them.

Terre Haute, Indiana

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.

Barbara Michaud

Barbara, daughter of Catherine and the late Harry Michaud, was 42 when she was killed in a traffic collision on June 28, 2006. Tragically, Barbara's death occurred just days after she was awarded a certificate of achievement by The Northeast Region, Department of Mental Retardation, for exemplifying the ideals of self-determination.

"We were all so proud of Barbara," her mother Catherine wrote. "She was very optimistic about life, made friends easily and had an infectious laugh." She loved living with roommates at her group home, and attending a sheltered workshop. Barbara and her younger sister Lynne were best friends from the start.

"Norma [Rupe], thank you for the beautiful booklet that arrived in today's mail. I read every word and found peace in knowing others share my sorrow, especially during this time of the year," Catherine added.

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

Contributions in Memory Of

Sophie Bourgoult

Edwin & Theodora Sojka

Diane Chausow

Hymen & Ruth Chausow

Stephen Dam

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Combined Federal Campaign

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

PLEASE GIVE OF YOUR TIME AND TREASURE

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

To achieve our ambitious goals, we need your help. If you can, please contribute by tearing off and returning this form and sending it to: **PWSA (USA) * 8588 Potter Park Drive, Suite 500 * Sarasota, FL 34238**

___ Enclosed is a check for \$_____.

___ Please charge my credit card for a donation of \$_____.

Mastercard/Visa/Discover accepted Card no. _____ Exp. Date _____

[OPTIONAL] Please direct my contribution to: ___ Program Support ___ Research ___ Angel Fund

___ I would like to run a fundraiser in my community. Please contact me.

[OPTIONAL] Type of fundraiser envisioned _____

Name _____

Address _____ City _____

State/Prov. _____ Zip _____ Country _____ Telephone _____

e-mail _____

Contributions

Thank you for Contributions through November 2007

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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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.

PWSA(USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to www.pwsausa.org/donate

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