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

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

Blazing New Trails at our 2007 National Conference

"Blazing New Trails," the 2007 PWSA National Conference, attracted more than 700 parents, grandparents, providers and researchers to Dallas this summer.

Thursday, August 1, was simultaneously Scientific Day, Providers Day and Chapter Presidents Day.

Research presentations were summarized for General Conference attendees on August 3, the final day of the conference, by Drs. Merlin Butler and Ann Scheimann. Those summaries are available in the Members Only section on our web site, www.pwsausa.org.

Some 144 participants in the Youth and Adult Program (YAP) learned a new rap song, "I Ain't Trippin'," as part of an exciting program that featured the return of Wild Willy and the introduction of Silly Lilly. Tad Tomaseski, assisted by Leeroy Ayala and Derek Snitker, directed more than 80 volunteers from Celebration Covenant Church of Frisco, Texas, to make YAP the in place to be in Dallas.

The Youth and Infant Program (YIP) directed by Michelle Holbrook attracted 43 children age 5 and under and was well received by parents.



Janalee and Al Heinemann were the keynote speakers at Thursday's opening ceremonies. Beginning with the discovery of PWS in 1956, the creation of PWSA (USA) in 1975, and the first PWSA (USA) national conference in 1979, Janalee and Al integrated their historical account of PWSA with the life of their family. After Janalee and Al attended their first PWSA conference in 1981, "We came home and locked the refrigerator," Janalee recalled. Their son Matt thanked them, saying, "My hand go into the refrigerator and I can't stop it!"

Al proposed to Janalee on their way home from the 1982 PWSA (USA) national conference in Kansas City, Missouri.

The keynote speech brought us to 2007, when Janalee

Conference continued on page 8

PWSA (USA) Adopts A New Logo and New Look

The Board's adoption of a new logo is part of a larger plan to develop a cohesive image or "brand" for PWSA (USA) in the mind of the public.

New materials in various media — from our web site to press releases and *The Gathered View* — will use the same logo and general style to help people remember PWSA and its mission. Our new Gathered View is a work in progress; watch for more improvements in coming issues.

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PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

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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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Members Only: See our website www.pwsausa.org for downloadable publications, current news, current research and more limited to members only!
User Name: pwsamember Password: together07
Note: If you have difficulty logging in to the site, your browser may be preventing you from entering authenticated websites. Try minimizing your program (e.g. AOL) and clicking on Internet Explorer or Netscape. Then type in the URL: http://www.pwsausa.org/memberonly.htm

E-mail Support Groups:
We sponsor nine groups to share information. Go to: www.pwsausa.org/support

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Medical information published in *The Gathered View* is not a substitute for individual care by a licensed medical professional.

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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



Photo by Eric Hilton

Craig Polhemus

The World We Dream Of

Join me in imagining a world where:

* Every newborn with PWS is diagnosed within the first 3 months of life.
* All parents have the information they need about PWS and how it may affect their child.
* All medical, educational and law enforcement personnel understand the special challenges faced by those with PWS.
* All families can easily access testing, intervention, supportive, crisis and vocational services for their child.

In imagining such a world, you have replicated part of PWSA's strategic planning process. During 2006 and early 2007, your Board of Directors defined the world we want to live in, set forth critical actions to help create that world and took steps to begin bringing it to life.

When I became executive director this June, the Board presented me with this visionary strategic plan to guide me and the entire organization. What a wonderful tool to be handed as I began my new job! It's both a road-map and a picture of our destination.

The process began with agreement on our mission: Promoting and funding research, providing education, and offering support to enhance the quality of life of those affected by PWS.

In research, our desired world includes:

* Research that identifies the causes, symptoms and effective therapies for PWS.
* Improvements in health, quality of life and life expectancy.
* PWSA having the needed financial resources, influence with the National Institutes of Health and other funders and both the capability and the determination to lead the world in understanding and curing or alleviating PWS.

The PWSA Strategic Plan for 2007-2012 covers seven focus areas: Awareness & Education, Advocacy, Crisis Management, State and Local Support, Research, Fundraising and Administration & Structure.

Parallel to the strategic plan is a development and communications plan to help raise funds to meet our financial goals for the next few years. Much of the initial implementation of this plan is being funded by generous donations from Jason and Christine Waldrop of South Riding, Virginia.

On an organizational level, we envision a country where:

* Every family affected by PWS has access to a strong PWSA chapter or affiliate supported by and supportive of PWSA (USA).
* PWSA (USA) and its state chapters and affiliates are recognized and respected by legislators, medical professionals, researchers, educators, law enforcement and the public as the unified voice of the PWS community.
* PWSA has sufficient financial, technological and human resources to fulfill its mission as long as there are people who suffer from PWS.

Why did the Board develop a new strategic plan? Because Board members recognized that PWSA (USA) has grown dramatically over the past 30 years— and that our growth is accelerating. To ensure that our effectiveness keeps pace with our size, we must plan and prioritize our activities. The strategic plan provides an assessment tool to both guide and evaluate our actions.

Advocacy is subdivided into policy and lifestyle (individual) advocacy. Our goals include a world where:

* Medicare, SSI and Medicaid are available to all who need them.
* Appropriate placement options including specialized homes with well-trained and supportive staff are available in every state.
* Insurance covers both existing and evolving medical treatments.
* Appropriate psychological support and crisis care services are universally available.

Board member John Heybach chairs the Strategic Planning Committee that developed the

Strategic Planning continued on page 12

Presented at the 29th Annual PWSA (USA) National Conference

Behavioral and Cognitive Differences between the Genetic Subtypes of PWS

Supported in part by a PWSA (USA) research grant.

Jennifer R. Zarcone, D. Napolitano, C. Peterson, J. Guadagnino, D.C. Bittel, Merlin G. Butler, T.I. Thompson*

Clear behavioral phenotypes are associated with each genetic subtype of PWS. By delineating behavioral phenotypes associated with each subtype, preventive strategies and more successful psychiatric, psychological and behavioral treatments can be used. These data indicate the behavioral phenotype across three genetic subtypes may fall on a spectrum with some overlap in compulsivity, cognitive skills and adaptive behavior.

Results support previous findings that those with UPD tend to have better verbal skills and adaptive behavior scores; those with Type II tend to have better broad independence and social communication scores and motor skills than both UPD and Type I participants. Those with a deletion are more likely to have self-injury (skin picking), steal and hoard, and are more withdrawn, although they have better visual motor skills.

There were no differences in level of aggression or activity between subtypes. Additional analyses indicate that those with Type I deletion have more hand-washing/bathing/grooming compulsions than the other two groups. Those with Type II deletions had more academic compulsions such as rereading, erasing and repeatedly counting numbers/objects. There were no significant differences among the three groups on numbers or global severity of compulsive behavior.

Methylation-Specific Multiplex Ligation-Dependent Probe Amplification (MS-MLPA) in PWS

*Soo-Jeong Kim, Jennifer Miller,** K. A. Schwenk, C. L. Hollywood, P. J. Kuipers and Daniel J. Driscoll***

Methylation-Specific Multiplex Ligation-dependent Probe Amplification (MS-MLPA) from MRC-Holland is a new technique that can detect the copy number and DNA methylation status of genes. MS-MLPA was able to provide significantly more information regarding the extent of deletion in PWS subjects than the standard clinical Fluorescent *In Situ* Hybridization (FISH) technique. While microarray-based comparative genomic hybridization (CGH) generates more detailed information about extent of the deletion, the high cost of this technique limits its feasibility in this context. Compared to array CGH, researchers found MS-MLPA labor and cost effective. It also provides information regarding DNA methylation status and correctly identified the PWS, AS and control subjects. Among 63 deletion patients studied with PWS, 36% were found to be Type I, 52% Type II and 11% were "unique" deletions (neither Type 1 or II). This unique class will be particularly valuable in future genotype-phenotype correlations.

High Resolution Array Comparative Genomic Hybridization (aCGH) in Individuals with PWS and Typical 15q11-q13 Deletions

Merlin G. Butler, N. Kibiryeva, W. Fischer, D. C. Bittel*

A paternal 15q11-q13 deletion is found in about 70% of PWS subjects and the remaining cases have uniparental maternal disomy 15, imprinting defects or translocations. The proximal deletion breakpoint in the 15q11-q13 region occurs at one of two sites located within either of two large duplicons allowing for identification of two typical deletion subgroups.

Using newer technology with high resolution oligonucleotide aCGH analysis, researchers examined the position of the chromosome 15 breakpoints. Additional studies are required to further characterize these regions of copy number variation among PWS and control subjects. Thus, use of high resolution oligonucleotide microarrays will allow for more detailed genomic data and more precise location and assignment of breakpoints (therefore potential gene involvement) as well as more detailed genotype – phenotype correlations.

Brain Size and Cerebellar Volume in Individuals with PWS: What Factors may Influence Brain Development and IQ

*Jennifer L. Miller,** K. Schwenk, M. Long, S. Towler, Daniel J. Driscoll,** C. Leonard*

Both total brain volume and the cerebellum have been found to correlate with cognition. In a previous study the authors noted that individuals with PWS and those with early-onset morbid obesity (EMO) of unknown etiology had lower cognitive function than their normal-weight siblings.

Researchers measured total brain volume and total cerebellar volume and found that the total brain volumes were similar in all groups, but the cerebellum and cerebellar/cerebral volume ratio was smaller in both those with EMO and PWS compared to controls. There was no difference in cerebellum/cerebral volume ratio between those with PWS and those with EMO, or between the two major sub-types of PWS (deletion vs. maternal uniparental disomy).

Decreased cerebellar/cerebral volume ratio in both EMO and PWS, along with findings of decreased cognitive scores in both of these groups compared to controls, further suggests that the cerebellum plays a role in overall cognitive functioning. Also, since the only commonality between those with PWS and those with EMO is development of obesity early in life, our findings suggest that early-onset childhood obesity may result in decrease of cerebellar volume with concommitent decrease in cognitive function.

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

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

*Barbara Y. Whitman,** S. Myers, A. Carrel, David Allen*

Infants with PWS display decreased muscle mass, hypotonia and abnormally increased fat tissue as documented by DEXA scan prior to evidence of excess weight or hyperphagia. Growth hormone (GH) administration to older children with PWS improves, but does not normalize, body composition, energy expenditure, and strength/agility. Researchers investigated whether GH therapy of infants with PWS can improve hypotonia and prevent deterioration in body composition, and whether GH dose impacts changes in these areas.

Children treated since infancy had significantly improved standard height scores and better BMIs; body composition by DEXA showed the early treated groups had significantly less total fat tissue.The early treated group talked significantly earlier (14.5 vs. 21.5 mo.).

This comparison of a group of infants receiving GH replacement therapy from early on to an untreated group of approximately the same age suggests the impact of early GH hormone therapy has a broad-ranging impact beyond simply increased height. The positive changes are intriguing and will require long term follow-up to assess both the stability and ultimate meaning of these findings.

Sleep Characteristics in Infants with PWS

*Gila Hertz, M. Cateleto, Moris Angulo***

The temporal course of sleep disturbance in PWS is not well understood. This study characterized sleep architecture and breathing patterns in infants with PWS less than 3 years old to identify developmental sleep trends that possibly precede later abnormalities.

There was no difference in sleep architecture between infants with PWS and infants with mild sleep disordered breathing. Infants with PWS under 3 years old may present with mild sleep-disordered breathing (SDB) even before obesity develops. Like non-PWS infants with mild SDB, their sleep is lighter and REM sleep is reduced as compared to normal controls. Infants with PWS show a trend to decreased REM latency, a sleep feature characteristic in sleep of adults with PWS. Some sleep abnormalities previously observed in older children with PWS may already present in a much younger age in this population. Additional studies are needed to solidify these findings and to compare their sleep to normal age-matched controls.

** Merlin G. Butler, M.D., Ph.D.; Elisabeth M. Dykens, Ph.D. and Barbara Y. Whitman, Ph.D. serve on the PWSA (USA) Scientific Advisory Board.*

*** Daniel J. Driscoll, Ph.D., M.D.; Moris Angulo, M.D.; Jennifer Miller, M.D. and Barbara Y. Whitman, Ph.D. serve on the PWSA (USA) Clinical Advisory Board.*

Special Anesthesia Concerns for Patients with PWS: Winthrop Univ. Hosp. Ctr. Experience

*Jon Roberts, M. Cataletto, M. L. Quintos-Alagheband, F. Coste, Moris Angulo***

PWS features include muscular hypotonia, central nervous system abnormalities, obesity, hypogonadism and skeletal abnormalities. Decreased pulmonary reserve secondary to chest wall deformity (i.e., scoliosis), hypotonia and obesity may complicate ventilatory management during and following anesthesia. Other characteristics, such as abnormal response to hypercapnia and hypoxia, narrowed oropharyngeal space, hypoplastic dental enamel, thick secretions, prolonged/exaggerated response to sedatives, and increased risk of gastric aspiration, can lead to potential difficulties in airway management. Familiarity with these issues can facilitate the anesthesia experience and prevent the number and severity of postoperative complications.

Children with PWS may be at increased risk for post-operative complications, most occurring within 24 hours after surgery. The data presented stress importance of preoperative assessment, airway management and postoperative monitoring. Staff should be knowledgeable of anatomical and pathophysiological features unique to PWS. Close monitoring for at least 24 hours post-operatively may be warranted.

Psychotropic Medications in PWS

Supported in part by a PWSA (USA) research grant.

*Elizabeth Roof, R. Kossler, R. Johnson, E. Dykens**

This pilot study applies advances in pharmacogenetics to shed new light on the variable responses to psychotropic medications often seen in PWS by type, combination and efficacy.

Such studies are well-justified in PWS, as persons typically have a predictable set of symptoms (irritability, compulsions) often treated with SSRIs. Some respond well to these agents and others quite poorly; variability may relate to genes involved in drug metabolism. Genetic polymorphisms in the first phase of metabolism of SSRIs are well-characterized, and involve a family of CYP450 enzymes. This study identifies CYP450 enzyme status in those with PWS, classifies them as poor, intermediate, rapid, or ultra rapid drug metabolizers, and relates these classifications to reported drug responses. (Note: No one with PWS in this sample was an ultra rapid metabolizer (UM). Typically those with UM metabolize medicines so quickly that obtaining therapeutic medicine levels is very difficult. Poor metabolizers could have many side effects if given too high a dose which was found to be more common in PWS.)

Findings have implications for research and intervention. We believe PWS is the first developmental disorder in which CYP450 status was examined, leading the way for other disabilities. Doctors who know the CYP450 status of PWS patients can adjust dosages of SSRI or other medications to optimize outcomes.

PWSA (USA) Research Grant Results

Effect of a Long-Acting Somatostatin Analogue on Ghrelin, Food-Seeking Behavior and Weight in Subjects with PWS

By Janalee Heinemann, Director of Research & Medical Affairs

Researchers at British Columbia's Children's Hospital (Vancouver, Canada) investigated whether inhibition of ghrelin by a long-acting analogue of somatostatin (Sandostatin LAR®, Novartis Canada) could represent a safe and efficient approach to decrease appetite and weight gain in children and adolescents with PWS.

We know that concentrations of ghrelin, a hormone that stimulates appetite, are high in subjects with PWS. Somatostatin is a hormone made by the human body that has many actions. Synthetic analogues have been developed and are known to decrease ghrelin concentrations in both in subjects with and those without PWS.

The study involved two 4-month periods separated by a 6-month "washout period." All subjects received, in random order, placebo and somatostatin. The study was blind and placebo-controlled, meaning neither the subject (or his/her family) nor the investigator knew when placebo or somatostatin analogue was injected. The reason for such a long washout period between the two study times is that the duration of action of the long-acting analogue of somatostatin is several weeks.

Preliminary results were presented by Dr. K. De Waele at the 2006 PWSA national conference. Final results were presented in June 2007 at the European Society for Pediatric Endocrinology meeting and the abstract officially published in "Hormone Research." Drs. Jean-Pierre Chanoine and Kathleen De Waele are presently writing an article to be submitted for publication in a peer-reviewed journal this fall.

The results are very clear. The somatostatin analog Octreotide does markedly decrease not only total, but, more interestingly, active ghrelin concentrations by 50-70%. Unfortunately, this did not result in a weight decrease over 4 months compared to the control group.

Researchers also studied appetite and behavior through validated questionnaires but could not find consistent effects of the treatment. Somatostatin analogues were associated with side effects (gallbladder sludge or stones) in 50% of subjects.

So, prolonged decrease in ghrelin occurs, but in this study, it did not result in weight or appetite changes.

Heinemann Co-Chairs Coalition of Patient Advocacy Groups



Photo by Eric Hilton

Janalee Heinemann

In her new role as our director of research and medical affairs, Janalee Heinemann has been elected co-chair of the Coalition of Patient Advocacy Groups (CPAG) for the National Institutes of Health's Rare Diseases Clinical Research Network.

The CPAG represents more than 30 patient advocacy groups, and Janalee will be helping to ensure that their voices are heard.

The Rare Diseases Clinical Research Network grew out of the Rare Disease Act of 2002, which directed NIH to support "regional centers of excellence for clinical research into, training in, and demonstration of diagnostic, prevention, control, and treatment methods for rare diseases."

Donations for Research 2007
As of 7/31: $128,325
has been donated to PWSA (USA) for PWS Research
To view our latest research news and abstracts from the IPWSO Conference (our international organization) in Romania, go to Members Only at www.pwsausa.org

Chapter View

Chapter Presidents Have Their Day

By Craig Polhemus, Executive Director

As your incoming executive director, I was eager to attend a meeting with representatives of approximately 20 PWSA (USA) chapters and affiliates on Wednesday, August 1, to discuss new developments and share information about your local projects. They made dozens of suggestions for increasing member involvement, fundraising, communications and parent support.

Our meeting also included some of PWSA (USA)'s Board of Directors and staff. PWSA (USA) Co-Chair Carol Hearn described some changes in the organization's structure, including discontinuation of the national president and vice president positions. She explained that most non-profit organizations do not have both board chairs and a president. Outgoing PWSA (USA) President Carolyn Loker, returning to the Board of Directors, thanked the chapter presidents for their help and support over the years.

Finance Committee Chair and Strategic Planning Committee Member Steve Leightman described the development of the new Strategic Plan and Strategic Development and Communications Plan, including the branding initiative and new logo.

I used the two plans' priorities to frame my discussion of goals for the future. I told the group that because I had no prior expertise in PWS, I have a special need for consultation and teamwork. "I am not coming in with all the answers, but I am committed to our mutual success," I said, adding, "My actions will be guided by the PWSA (USA) Board, by the strategic plan, and by 135 job goals I am tracking with the Executive Director Transition Team."

PWSA (USA) crisis team members also spoke. Alterman Crisis Counselor David Wyatt is retiring from his paid position in October, but will continue to volunteer. Crisis Counselor Kate Beaver is continuing in her role, and team member Evan Farrar began work the week before the conference. Barb Dorn resigned from her crisis counselor position to focus on Wisconsin issues and the 2008 National Conference.

Dr. Jim Loker of our Clinical Advisory Board and Research and Medical Affairs Director Janalee Heinemann gave an update on the latest PWS research, including projects funded by PWSA (USA) grants.

PWSA (USA) Parent Delegate to IPWSO (International Prader-Willi Syndrome Organization) Susan Henoch and IPWSO President Pam Eisen reported on the 2007 conference in Romania.

Chapter presidents each summarized developments in their regions. Suggestions for improvement included providing material to be used in chapter newsletters, increased advocacy, making chapters more visible on the PWSA (USA) web site, revisions to chapter filing requirements, supplying chapter letterhead incorporating the new logo, and providing templates for brochures, annual reports, and fundraising projects. The group agreed to participate in planning next year's Presidents Day.

Open communication is vital to a healthy organization, and this was a good meeting. Chapters are the local contact for our members, and we have no higher priorities than serving our membership. So it is important for all of us to communicate when there are issues, problems, or, most importantly, ways that we can help.

Waldrop Family Aids Development

Contributions from the family of 2-year-old Avery Waldrop, who has PWS, are having a major impact on PWSA (USA)'s development and communications programs. Avery's parents, Jason and Christine Waldrop, have pledged $217,500 to support creation and implementation of the PWSA (USA) Development and Communications Plan for 2007-2010.

In addition, CWPS (Connected WorkPlace Solutions), Inc., owned by Jason and his parents Gerald and Christine Waldrop, is donating a state-of-the-art telephone system for the move to our new office, 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238.

stepped down as executive director to assume a reduced-hours role as PWSA (USA)'s director of research and medical affairs. She and PWSA (USA) received special awards from the International Prader-Willi Syndrome Organization (IPWSO), presented by IPWSO President Pam Eisen, for their long-term support of IPWSO's mission to educate the world about PWS.

At Thursday's Annual Membership Meeting and lunch, Finance Committee Chair and Strategic Planning Committee Member Steve Leightman presented the association's new strategic plan (read more on page 3) and described a branding initiative including our new logo.

"This is my first chance to talk to a roomful of heroes," new Executive Director Craig Polhemus then told attendees. "Every one of you, whether provider or scientist, but especially parents and other relatives, is a true hero. You devote your time, your energies and your love to help improve the lives of those with PWS."

Thursday evening featured the general Gala, the YAP Gala and a silent auction.

Friday's agenda featured more breakout sessions on topics such as legal rights in public schools, understanding PWS behavior, options for crisis and building a strong family. The conference ended with closing ceremonies featuring an inspirational talk by YAP Director Tad Tomaseski and a special appearance by Wild Willy and Silly Lilly.

For more Conference photos and evaluation forms, go to our web site at www.pwsausa.org

- "The kids all couldn't stop talking about how much fun they had at the YAP program. They met a lot of new friends and enjoyed it all."

- "Being at the conference was a wonderful way for us to interact with other families that know what we are going through. Since our daughter was diagnosed 5 weeks ago, we have been reading nonstop about PWS but the conference really allowed us to put a lot of things and decisions into perspective."





Praise from Conference Attendees

- "Thank you to all the organizers and volunteers who made this conference such an informative, well-organized and valuable experience for our family."

- "I was extremely impressed with YIP. This was our first time at a PWS conference and both our 4-year-old (PWS) and 2-year-old daughters were in the program.... We were very grateful to have such competent child-care, and knowing that we did allowed us to really take full advantage of the conference."



IDEA ALERT

For Parents/Guardians of Children with PWS

IDEA, the Individuals with Disabilities Education Act, specifies how school systems must accommodate the special needs of children with disabilities in their districts.

Check the Report Card

State IDEA report cards show how states are complying with Parts B and C by four categories:

- Meets requirements of IDEA
- Needs assistance in implementing requirements of IDEA
- Needs intervention in implementing requirements of IDEA
- Needs substantial intervention in implementing requirements of IDEA

Access this at http://www.ed.gov/policy/speced/guid/idea/monitor/factsheet/html

Part B Determination

The IDEA Part B Sections 611 and 619 formula grant programs assist states in providing a free, appropriate public education in the least restrictive environment for children with disabilities ages 3 through 21.

All states are to have in place a plan evaluating their implementation of Part B and describing how they will improve it. This report is to be public and and available through various media. Only nine states meet the requirements of Part B.

Part C Determination

Part C is similar to Part B except that it assists states in providing early intervention services for infants and toddlers (from birth through age 2) and their families. This report is also public and requires annual reporting. Only 16 states meet the requirements of Part C.

Contact your legislative representatives

If you have a PWS chapter in your state, you may want to bring this important information before your group. You might want to prepare a plan and begin talking to your local and state office holders.

If you live in a state that has no organized PWS group and are interested in working to contact your legislative officials, e-mail your contact information to: national@pwsausa.org.

High Court Rules on Special Ed

A Supreme Court decision in May gives parents of children with disabilities the right to go to court without a lawyer to challenge their public school district's individualized plan for their child's education.

The decision (Winkelman v. Parma City School District, No. 05-983) involved interpretation of the IDEA, the Federal law that gives all children the right to a "free appropriate public education" regardless of disability.

Parents who have tried to handle their own cases have sometimes been accused of violating state statutes against the unauthorized practice of law.

The Supreme Court's ruling will, as a result, change the status quo in many states. For more information on this decision, go to www.wrightslaw.com/law/art/winkleman.pwanalysis.htm

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

We Want to Hear From YOU!

We love people stories! Do you have experiences to share with other PWS families? Tell us about the good times (and the not so good ones, too), your challenges and how you're dealing with them, and, of course, send your funny stories for our Chuckle Corner. Send them by snail mail to PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238 or e-mail us at gatheredview@pwsausa.org.

Grandparent View

Emily Brings Joy To My Heart

By Jacque Reid-Piscitelli

My granddaughter Emily brings joy to my heart and to everyone around her. She has also given new meaning to the word *hope* — a kind of hope we can all work together toward achieving — hope for the future.



Jacque with granddaughter Emily, who has PWS

We weren't always hopeful, however. I remember those days before her birth when we worried about the baby not moving much and were anxious through all the ultra-sounds to check her heart, lungs and well-being. Finally, it was time for her to be born, and there was great joy when we first saw how perfect Emily was. Wonder of all wonders, she had hair — the first one born in our family with hair — a full head of it. But she was so floppy; she wasn't interested in eating; it seemed she just wanted to sleep. Worst of all was waiting for results of all the tests she had so patiently endured — waiting to see if there would be a diagnosis. When it finally came, we were devastated — but there was strength to be had in finally knowing.

Emily is now 17 months old. She is much like any other child her age — just somewhat delayed. She is crawling while yearning to walk, learning to sign and beginning to talk. She understands what is said to her and readily follows directions.

If anything Emily has brought our family closer together. It is amazing to watch Emily's mom (my daughter Reagin) work with her, play with her, coach her, and most of all love her. Emily's "Aunnie" (my daughter Aimee) has been a source of strength and has given of herself endlessly/tirelessly. How wonderful to watch Emily play with and be loved by her big sister Erin and her cousin Kayla. Emily is LOVE. Her face lights up and she races to give everyone hugs and to be held and to cuddle.

She has been such a beautiful sweet baby through all of the worst of times and remains so in the best of times. She has taught us to hope for a brighter future — however, not just to sit and hope but to work to make that hope a reality.

PWS Grandparents Can Play A Special Role

By Lota Mitchell, Associate Editor

In most families grandparents play a very special role, sometimes an essential role. Many of us have treasured memories about times spent with a beloved grandpa or grandma. In the PWSA family, grandparents are very important, too, and many are very active.

Some examples: **Barb McManus, grandmother to Jessika**, is our webmaster and information technology guru. Retired from a professional computer position, Barb awes everyone with her knowledge. **Steve Leightman, grandfather to Josilyn**, is on the Board and is spearheading the PWSA (USA) development program. **Kay Goldberger, CPA and grandmom of Callaghan and Reilly**, is treasurer of PWSA (USA).

This year at the national conference in Dallas, grandparents met together for a workshop facilitated by **Michele Leightman, grandmother to Josilyn** and a coordinator of the Grandparent Mentor Program. More than a dozen grandparents attended, coming from New York, New Jersey, Pennsylvania, Georgia, Oklahoma, Michigan and Texas.

They shared experiences of having a grandchild with PWS and discussed ways grandparents

Grandparents continued on next page

Grandmother joins Team Noelle for Fall Fundraiser Run

By Amy McDougal

Many of us are fortunate to have supportive families and we count ourselves among this number. We've been particularly blessed to have my mother, Lynda Wells, do daycare for Noelle (age 5, with PWS) and her brother Logan (age 3). She has also done research, participated in speech and physical therapy sessions, monitored Noelle's diet, and even worked with Noelle on a preschool curriculum, all while ensuring that my husband and I are kept up to date on day-to-day growth we miss while we were at work.

When I suggested our family to get involved in awareness and fundraising, my mom was the first to sign on. Enthusiastic PWS grandmother that she is, Mom will join me and my sisters, Erin Hicks and Stephanie Whitacre, in running a marathon in Hartford, Connecticut this fall. We'll each run a 6.5- to 7.5-mile leg. To promote PWS awareness and raise funds, I created a website detailing our plans for this endeavor, www.firstgiving.com/TeamNoellePWS.

While our family was initially frightened and overwhelmed by Noelle's diagnosis and what the future might hold, Mom says having Noelle has been a huge blessing. She spoke for us all when she said she wants to encourage other families dealing with PWS (or any other disability) to hang in there and persevere. There are tough times, but the rewards are enormous!



Team Noelle (clockwise from top right) includes Grandmother Lynda, daughters Amy, (mother of Noelle, 5, who has PWS), Stephanie and Erin.

Grandparents - *continued from page 10*

can help their families as well as issues affecting grandparents who provide ongoing childcare or are raising a grandchild. They weighed the benefits and difficulties of living near or far from the grandchild and his or her family, and talked about relationships between maternal/paternal grandparents — and even about the loss of a grandchild with PWS.

They explored ways PWS grandparents can communicate and exchange helpful information, such as the grandparent link on www.pwsausa.org along with areas of interest they'd like to see included, a Yahoo chat group for grandparents which would include biologically unrelated people having close relationships with the child www.pwsausa.org/egroups/grandparent.htm, and a Grandparent Directory. **Maureen O'Neal** and Michele Leightman are to be moderators for the Yahoo e-mail group.

Another topic was how grandparents can get involved, such as becoming members of national and state chapters, thus helping to increase membership (numbers are often vital in seeking services), and helping with education, awareness and fund-raising. They encourage asking parents for grandparent contact information and letting parents know about the grandparent mentor program and link at the web site.

More and more we recognize that grandparents are vital resources for their families and the family of PWS.

The 2006 Annual Report of PWSA (USA) is available on our web site at www.pwsausa.org or may be requested by calling our national office at 800-926-4797

View From the Home Front

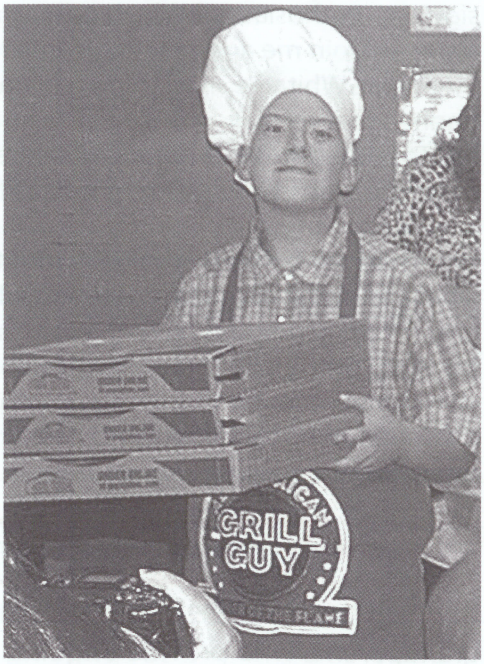


Dancing with Josie

My granddaughter Josilyn Levine, almost 5, who has PWS, had dress rehearsal for her spring ballet recital, the second year she has performed. She was in blue velvet and tulle. She knew all of her steps. Her hair was up in a ballet dancer's bun. She looked beautiful. She danced with grace. She danced to "What a Wonderful World " sung by Louis Armstrong.

She danced and I cried. I cried with pride in her performance. I cried for all of the effort that I know her parents have put into to get her to this point. I cried because it is not yet a wonderful world. It is a better world, and with all of our love and effort, we will make it a wonderful world. *— Ronnie Levine, Cherry Hill, New Jersey*

Pizza Guy Delivers



My son Aaron Carvajal, age 9, was in a school play and played the pizza delivery man. The pizza boxes were empty, of course. His line was, "Who wants hot, fresh, pepperoni pizza?"

When it was his time, he walked up so proud and then looked at his teacher and asked if it was his turn to talk. Then he said his line so nice and clear I cried! It's hard to remember that little boy who barely walked at age 3 and 6 years ago only being able to say Ma La and Da.

Aaron has come such a long way. He now brings much more laughter and joy than tears. *— Susan Fisher, San Antonio, Texas*

Strategic Planning - *continued from page 3*

plan. Because John was unable to attend the National Conference this August, Strategic Planning Committee member and Finance Committee Chair Steve Leightman presented it at both the Chapter Presidents session and the Annual Membership Meeting and luncheon. A presentation of the guiding principles in all seven areas can be found at www.pwsausa.org/strategicplan.

The Strategic Plan is not a static document. It will be updated every 6 months to reflect changes in opportunities and accomplishments. To make sure that our efforts reflect our members' goals, will you please take the time to review the plan's guiding principles and let me know at exdir@pwsausa.org where they fall short of the world you dream of?

We won't bring that world fully into existence within a few months or even a few years. But sharing our dreams and using them to guide our actions is the best way to begin creating the world we dream of.

Universal diagnosis, widespread awareness, revolutionary research results, adequate financial resources – our dreams describe a world quite different from the one we face today. The strategic planning process is more than a dream, however. It is a tool to help us bring our dreams into reality.

Andrew Wants To Be in Radio

My name is Andrew Fiedler, I am 19 and I have a disability. My disability is called Prader-Willi syndrome.

When I was 1½ years old I broke my mom and dad's stereo because I was fooling around with it.



I was playing with the stereo because I liked music and I was fascinated by pushing buttons on the stereo. I was 2 years old when I got my first childrens stereo.

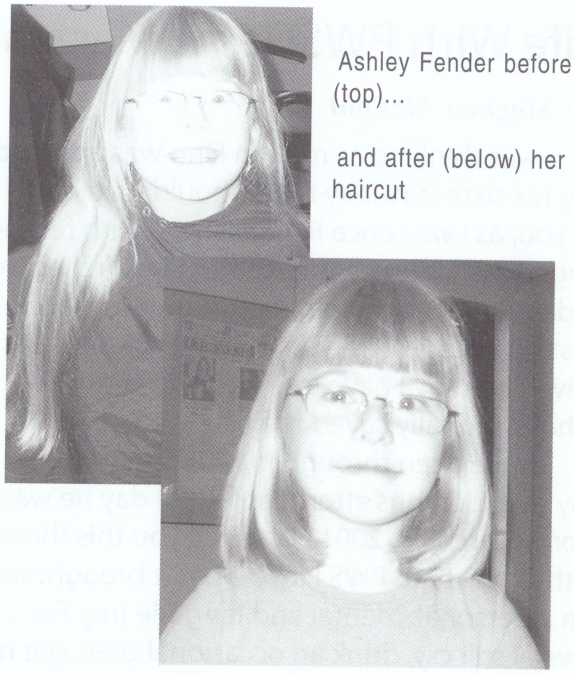
Since then I took piano lessons and drum lessons. I went to Cook Middle School and I was in the marching band for 2 years.

When I was in High School I was the DJ at Chops Teen Center for two years. I was part of the Youth Radio Program at a Radio Station in Rohnert Park called KRCB. I really like listening to music so I decided to become an usher at the Wells Fargo Center so I can see concerts for free and help people to their seats. I'm in a program called SCOE and I work at Costco in Santa Rosa. I really do not like the SCOE Program and I feel it's really boring.

At Costco I do pizza boxes and also put boxes in carts. I really want to try something new and something that I like.

I want to go to a school called Riverview in Cape Cod, Mass. The school is for developmentally disabled people. I visited the school for three days and I already got accepted. If I go to Riverview I would learn how to be more independent, take academic classes. I would also learn how to live in a dorm with a couple guys and get along with them and work out conflicts. Also what's really cool is I could get a radio internship through the Community College connected to the Riverview School. I would like to work at a radio station. I really want to go off and learn all of this. Right now I'm learning how to set up my own radio station online on the Internet.

Andrew Fiedler lives in Santa Rosa, California



Ashley Fender before (top)...

and after (below) her haircut

Long Locks Lopped for Love

Six-year-old Ashley Fender of St. Charles, Illinois, who has PWS, donated her long, beautiful hair to Locks of Love last year so she could help people who have lost their hair.

Her grandma reports that Ashley's hair is growing long again, and she is happy and proud to help others, just as they are helping Ashley.

Update on Angel Flights

Angel flights are now available for families participating in PWS research projects. The contact person is Marita Eddy at 301-451-9646.

The flight distance is normally 300-1,000 miles, but if the distance is farther, they still may be able to help. They have some resources for commercial flights, primarily through donated frequent flier miles.

Both parents can travel. Total weight is a factor because the planes are small.

An appointment must be set before Angel Flights can work with the family.

Thanks and Praise for PWSA

I really appreciate all those who helped me get Buster (17, with PWS) into The Children's Institute, and all those at National who helped me through my recent crisis. You have been a Godsend.

Life With PWS: It's A Marathon, Not A Sprint

By Meghan McCool

I was thinking as my son Finn was approaching his sixth birthday that I should give back to all of you, as I was once in your shoes with feelings of anger, guilt, depression, bargaining. I relied on older parents to help me through the maze of the first two years of his life and as these six years have flown by I have lost touch with the people who essentially saved me.

I have been through marital counseling and my own demons after that fateful day he was born, March 17, 2001. I can tell you this though — although I hate PWS I love what it brought to me on a personal, mental and tangible (my Finn) level. I still cry, drink an occasional beer, get mad for no reason, but life goes on and does not stop. I tried to assuage my grief over Finn by having more kids (three!) and although now I have a large beautiful family, Finn still has PWS. I did some strange things to try to alleviate my pain.

My son Finn has deletion. He does not have blond hair or blue eyes. He does not have eye or ear problems and we have been blessed that he does not have major medical problems yet. He does not food seek, he is on GH and other supplements. He does not ask for snacks, or extra food.

He has been riding his two-wheeler (no training wheels) since he was 4. My husband spent hours chasing after him and there were many bruises. He plays soccer twice per week and he is slower than his peers. He goes to gymnastics and he is the most uncoordinated in the group but we see it as necessary — it does sometimes get hard to see him not be as fast or agile as his peers but that is all part of the process. He must learn that exercise is to be enjoyed and every day a part of his life.

We home-school him because he has a speech delay (defined as one year behind typically developing peers). Speech has always been a struggle but we do what we can. Once he is able to really communicate well, I would feel comfortable putting him in school. Because he has splintered skills we can progress at the pace he needs to. He is on a first-grade curriculum now! He adds double digits, reads the Dr. Seuss books and the Level 2 DK readers, spells well and uses his writing journal every day. We spend 3-4 hrs. per day at "school," and he goes to kindergarten two times per week.

What is challenging in our lives:

- He is not as aggressive or outgoing as his peers. There is a shyness about him and we need to encourage him to play sometimes.
- He tends to give up easily when he feels he cannot do something, so we have made ourselves a mix of cheerleader and tough love.
- We have no meltdowns, but I think it is because we got information from [PWSA(USA)] and books and starting when he was 2 we followed the plan.
- We followed all the advice about food and restrictions. There are no sweets or junk food in our lives. It is not restrictive but rather a family lifestyle choice that we would rather fill our bellies with healthy stuff than waste a precious calorie.
- His teeth are BAD. We have no juice (flavored water is great), but we cannot seem to beat the enamel issues. We try hard, though!
- His speech is behind, so we have horns, straws, etc. everywhere. But this is a marathon, not a sprint.

So to all of you who are new or who sometimes want to give up — I have been there and I know the range of emotions that sometimes drown you. My good friends' daughter, born at the same time as Finn, was diagnosed with aggressive leukemia and may not survive the year.

Everyone you meet is fighting a battle, and although you may be jealous or wistful when you go to a playground or school, you must remember that just as you are wishing you could take this disease away, there may be someone looking at your angel and thinking, *I wish my baby had those pretty eyes. I wish my baby could walk. I wish my baby could talk.* You just never know.

Some days all I can say about Finn is "Thank you for giving me a hug today," because he was a typical 5-year-old that day. I wish you all peace and love on your journey.

The McCool family lives in San Diego, California.

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.

Debbie Kubichek



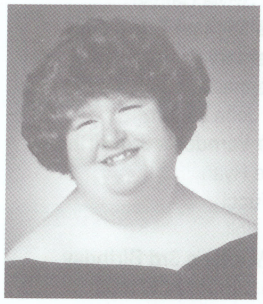
Debbie, 46, daughter of Judith and Luis Kubichek of Windsor, California, died peacefully on June 21, 2007.

Her mother Judith wrote that Debbie enjoyed "the fun things in life like parties.... and loved working and earning her own money." Debbie won a first prize in swimming and was so proud to be on the podium at the Special Olympics.

Debbie is also survived by her brother Andy, sister-in-law Patricia and niece Shayna.

The family asks that memorial contributions be made to PWSA(USA), which "kept us going in very difficult times," wrote Judith.

Laura Mitchell



Laura, 30, daughter of Wanda Mitchell of Vernon, Alabama, was living at home when she died in February, 2007.

Laura attended ARC and had a few jobs. She loved to get a little money for her work, her mother wrote.

She also loved going to church. "She had a smile for everyone, and she loved for people to visit her. She is missed by family and friends." A poem written by family friend noted "her memory will be treasured in all our hearts forever."

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).

Gathered View now available electronically

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

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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. The Prader-Willi Syndrome Association(USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA(USA) is supported solely by memberships and tax-deductible contributions.

USA
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Still hungry for a cure.