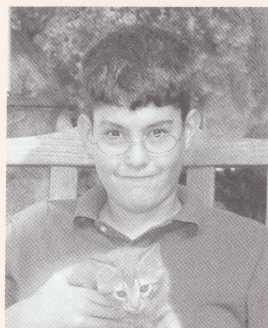




September-October 2006
Volume 31, Number 5
Our 31st Year of Publication

The *Gathered View*

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



Micah Brooks, Texas

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Greeting Old Friends, Making New Ones and Learning A Whole Lot Attendees Wild About 2006 Conference

An enthusiastic crowd of more than 800 people from eight countries came to our national conference. This year's theme: *Wild About You!*

Prader-Willi Alliance of New York, Inc, a chapter of PWSA (USA), combined efforts by hosting and including their 16th Annual State conference with PWSA (USA)'s 28th Annual National Prader-Willi conference.

Attendees gathered at Grand Island, New York, to learn more about the syndrome, share experiences and hear what is new in research. Since the location is very close to Canada, 27 people crossed the border to attend from that country. New York had 209 attending from across the state, many traveling from the New York City area, which is 8 hours from Grand Island.

Chaired by Dr. Moris Angulo of the PWSA (USA) Clinical Advisory Board, the Scientific Conference had 111 attendees, with presentations from early morning to late afternoon. Dr. Angulo was assisted by PWSA (USA) Vice President Kerry Headley. Jackie Mallow and Mary K. Ziccardi co-chaired the Providers Conference, which had 118 attendees. The Youth and Infant Program (YIP) had 110 children from infants to age 9. YIP was chaired by Jeannie Dickinson and Michelle Torbert, with medical coordination by Prentice Lantzer.

The general conference attracted over 500 people for the two-day event. Volunteers Nina Roberto, Ann Baird, Henry Singer and Harry Persanis chaired the program portion of the conference. Linda LeTendre was the registration chair to assure that the process went as smoothly as possible; Community

Development Director Jodi O'Sullivan worked with the sponsors and exhibitors; and PWSA (USA) President Carolyn Loker was in charge of food and rooming coordination. With large, unexpected attendance and overflow to a second hotel, this became a complicated process! We do not have space



here to adequately thank all the many volunteers and staff whose dedicated assistance made these events successful – but please know that we are forever grateful.

For more on Conference see page 5

Many thanks to our major sponsors: Pfizer, People, Inc., Eastern Hills Sunrise Rotary Club, & Parent Network of Western New York, who made the 2006 conference affordable and successful

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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA) unless so stated. 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:

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

Our Mission: Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted by Prader-Willi syndrome and related conditions.

Members Only: Check our website www.pwsausa.org for downloadable publications, current news, current research and much, much more limited to members only!

User Name: pwsamember Password this issue: bears06

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

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

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Four Elected to PWSA (USA) Board of Directors

PWSA (USA) members returned current directors Mark Ryan and Mary K. Ziccardi to the Board and elected Dr. Linda Gourash and Jackie Stoner Mallow as new directors.

Dr. Linda Gourash of Pittsburgh, Pennsylvania, works with partner Dr. Jan Forster at the Pittsburgh Partnership, consultants and specialists in PWS. She is also in private practice and serves on our Clinical Advisory Board.

Jackie Stoner Mallow of Oconomowoc, Wisconsin, is admissions/consultative services director for Prader-Willi Homes of Oconomowoc and serves on the board of PWSA-Wisconsin.

Mark Ryan of Newhall, California, is president of Ryan Sales International. He and wife Linda are active with the

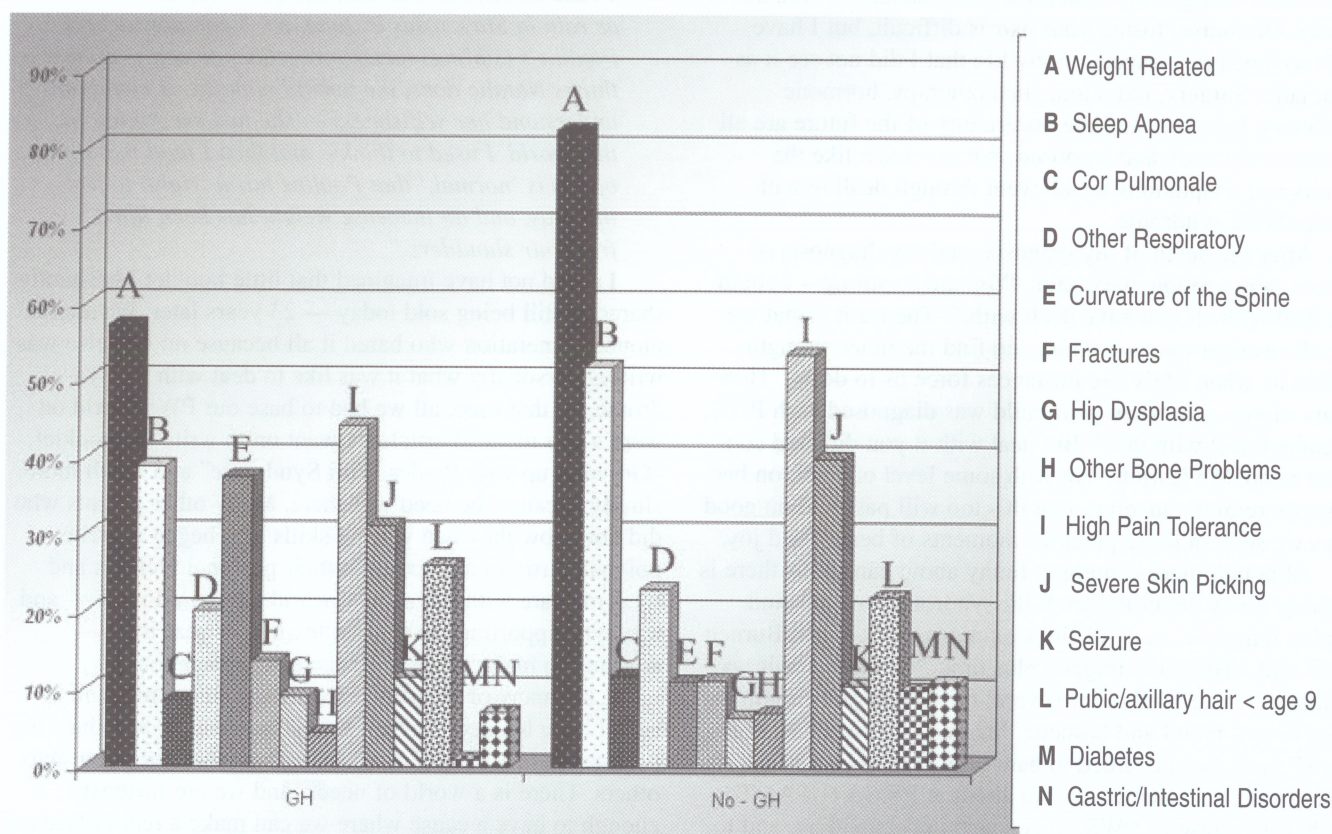
Prader-Willi California Foundation, where she is a board member. They have three children, Crystal, 26, Daniele, 23, and Trevor, 16, who has PWS.

Mary K. Ziccardi of Cleveland, Ohio, is an administrator in the northern region of REM Ohio, Inc. She has worked with both children and adults with PWS for more than 12 years and is coordinator of our Adults With PWS Advisory Board.

Jim Kane, a former officer and Board member, was among the highest vote-getters, but declined a Board seat to allow another of the highly qualified candidates to serve. Jim will continue serving as chair of the PWS Research Advocacy Committee.

PWSA (USA) Database Survey Yields **Wealth of Info**

Characteristics of PWS Individuals Ages 6-18 With and without GH Treatment



Above is some information from the results of the medical survey of 1,452 people with PWS which was presented by Barb McManus, Janalee Heinemann and Dr. Moris Angulo at the PWSA (USA) Scientific Conference. The graph shows a comparison of certain categories of UPD and Deletion with the largest variance as well as a comparison of with/without Growth Hormone in ages 6 to 18 years. It shows many of the advantages of GH in this age group.

We thank respondents for helping us collect this very valuable information. Another survey will be distributed

soon with questions not asked in the first one. Update your personal information by going to www.pwsausa.org/population and following the link at the bottom of the page.

To view the survey or make changes, you must have your entry ID number and birthdates of the person with PWS.

If you did not complete the first survey, you may also do that on this page. If you do not have computer access, call PWSA (USA) at 800-926-4797 to get a survey form.



photo by Eric Hilton

Executive Director's View

Baring It All

Janalee Heinemann

We are the pioneer generation who bared it all because no one else was writing what it was like to deal with the syndrome.... other parents began to write poignant articles We bared it all — and through supporting each other, learned to bear it all — working to make it better for the next generation.

For years you have seen pictures of me with my long blond hair. Shortly after the last *Gathered View* went to press, it was decided that I should add chemotherapy to my treatment regime for breast cancer. The chemotherapy treatments changed my look rather dramatically within a few weeks. Of course, losing your hair is difficult, but I have seen so much real tragedy in my life that I did not see it as traumatic. Surgery, radiation, chemotherapy, hormone inhibitors, hair loss, and the uncertainty of the future are all insults to the body and emotions, but are much like the insults and adaptations we all went through dealing with Prader-Willi syndrome.

After the death of my grandson and my diagnosis of cancer, some people have said, "You are so strong — I could not deal with all you have dealt with." The truth is that we are all stronger than we think, and find the inner strength within us when life's circumstances force us to do so. How many of you said when your child was diagnosed with PWS, "I cannot deal with this!" But deal with it you did, and continue to do. We learn to live with some level of grief; on bad days we remind ourselves that this too will pass and on good days we soak in those precious moments of beauty and joy.

Although there is nothing funny about cancer, as there is nothing funny about Prader-Willi syndrome, we can find coping humor in many of life's circumstances. Carol Burnett once said, "Humor is tragedy plus time." When my hair was falling out, I decided to try several new looks and bought wigs in red, blond and brunette. We have had fun with the "new" me's, but I decided to bare it all here because that is more fitting for what we are all about at PWSA (USA). To further the cause of PWS, to enhance understanding, and to give emotional support for many, many years, we have "bared it all" to each other and to the world at large.

Before PWS, I never had schooling in writing or even a burning desire to write. Then for a social work class I was taking in 1982, my daughter Sarah and I wrote a little sibling booklet on the syndrome, "Sometimes I'm Mad... Sometimes I'm Glad." At that time, I did not have enough confidence to think my book would be of importance to anyone but me. At my second national conference I showed it to Lota Mitchell, who convinced me to let PWSA (USA) publish it.

Recently I found a letter from 1983 that I received from Marge Wett, our first executive director, quoting a letter she had received:

"At the risk of sounding profusely thankful, please do tell Janalee that her book was as welcome as rain in May, roses in June, etc. I can now accept Pauline's (sibling) adverse reactions to some of the things Natalie does, the unkind remarks. I could not understand her selfishness — 'she has everything in this world' I used to think — and then I read that all of this is 'normal,' that Pauline has a 'right' to feel this way, and an immense weight has been lifted from our shoulders."

I could not have imagined that little booklet I hesitantly shared is still being sold today — 23 years later. We are the pioneer generation who bared it all because no one else was writing personally what it was like to deal with the syndrome. At that time, all we had to base our PWS world on were a few medical articles. I went on to write the booklet, "Growing up with Prader-Willi Syndrome" and much more, simply because the need was there. Many other parents who did not know they had writing skills also began to write poignant articles and exposed their personal feelings and lives to share with our special world. We bared it all — and through supporting each other, learned to bear it all — working to make it better for the next generation.

Like many of you, my tears are silent, but my pain is real. I have learned over the years that the way to reduce my personal pain is to take the focus off myself and put it onto others. There is a world of needs, and we are fortunate enough to have a cause where we can make a real difference. As awareness grows, our population grows, and our expectations grow.

I am stretching out my hand to you as Lota did to me to say, "We need you." Whether it is to "bare it all" in telling your story for articles, fundraising or awareness, together we have strength that can make a world of difference for our children with Prader-Willi syndrome. As my favorite philosopher, Kahlil Gibran, once wrote:

*Keep away from the wisdom that does not cry,
the philosophy that does not laugh,
and the greatness that does not bow before children.*

2006 National Conference THANKS & PRAISE

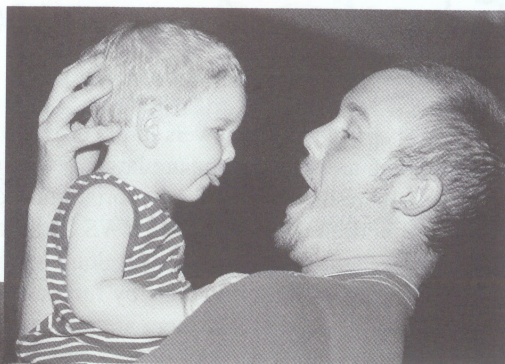
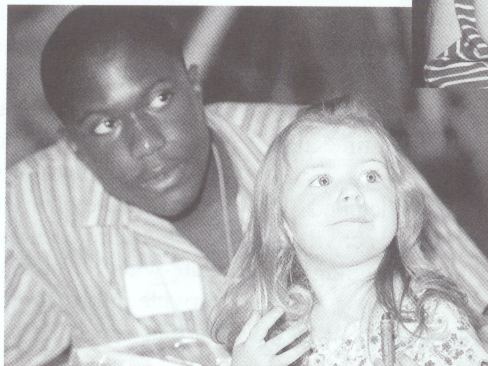
Many many thanks for your friendship and collaboration. Very compliment for wonderful organisation of the meeting in Buffalo. Anna e Giuseppe Baschiroto Italy

THANK YOU! to everyone who was part of organizing the National Convention... we are so glad we attended. It was great to be in a group where you didn't get asked, "She has *what?*" Beverly Folmer, wife of Jim, mom to Emily, 4 years old (PWS UPD) and Katelyn, also 4

Thank you. I heard wonderful things about your program from our reps who were there. It sounds like you had a very successful meeting and we were glad to be a part of it. Tom Wright, Pfizer

My children loved it. It's good to see such young kids doing so well because of GH.... I wanted to comment on how much work Jeannie Dickinson & Barb McManus put into this... & everyone else involved in putting the conference together.

Sue Cornell, mother of Chrissy, 10, who has PWS



The conference was worth everything it took to get there. My husband and I learned many nuggets that will make such a difference We made many

significant contacts with medical professionals who were helpful and freely agreed to consult with our doctors here at home.... We came away with loads of information, lots of encouragement, and



a circle of support... Thanks, National!

Lisa Thornton

Conference - continued from page 1

Awards were presented to: Barb McManus for the tremendous amount of work she did in chairing this year's conference; David Wyatt for his years of dedication to the PWS Crisis Program; Clint Hurdle for his outstanding work as PWS spokesperson; and to Anna and Guiseppe Baschiroto from Italy for their dedication to our international organization, IPWSO. Giorgio Fornasier, IPWSO's Program Director, PWS parent, and international opera singer, sang and provided music for the Gala Dinner and the closing ceremonies.

We hope you plan to join us at the 2007 PWSA (USA) National Conference in Texas!

PWSA (USA) Hosts PWS & Autism E-mail Support Group

By Ivy Boyle, M.D.

I want to invite you all to join me in a new group for parents of children with PWS and autism (or autistic tendencies). I am a parent of a 19-year-old, Alex, who has PWS. He is different from most kids with PWS I've met. He's tall, mild mannered, very accommodating, and VERY autistic. He has PWS, though, and uniparental disomy.

It is my feeling that we parents of those with a dual diagnosis of PWS and autism (or those with autistic tendencies) face unique challenges. For example, if your child is not particularly verbal, you may have to learn to communicate in different ways, and he may not be able to tell you what is bothering him. On the other hand, constant arguing, a common PWS problem, will not be your problem. I have a special interest in these kids, both because of Alex

and because of my work. I'm a child and adolescent psychiatrist with a special interest in treating autistic children and adolescents.

I am hoping to start a dialogue here with other parents who face challenges with these kids. We can talk about all sorts of concerns — how to get help, what symptoms our kids have, whether they are truly autistic, or only autistic-like, etc. I'm hoping that any of you who share these concerns, or whose children have a confusing mix of symptoms, will write. I hope we will learn from each other.

To join this new e-group, send an e-mail message to pws-autism-subscribe@yahoogroups.com or go to <http://health.groups.yahoo.com/group/pws-autism/>

Dr. Boyle is a member of the PWSA (USA) Clinical Advisory Board.

Education, Awareness and Lots of Fun

By Lota Mitchell, Associate Editor

Our chapters are like jewels in the crown of PWSA (USA). Some are small, some are large, but all sparkle brightly. All are involved in the important task of making life better for children and adults with PWS and those who love and care for them. Sometimes that is done by providing information. Sometimes it is done by fundraising — golfing and walking are popular, but there are also some very innovative and unique ways of raising money. And sometimes it's done simply by having FUN. The real win-win is when you can raise money and have a great time all at once!

Previous issues of *The Gathered View* have detailed many of the chapters' fund-raising and awareness activities. Here's just a brief sampling of what else has been going on.

Many, many thanks to the Prader-Willi Alliance of **New York** which under the direction of Barb McManus and the conference committee planned, scheduled, organized and arranged the 2006 National Conference at Grand Island. It was a joint conference of both the 28th Annual PWSA(USA) and the 16th Annual Prader-Willi of New York Alliance. A huge job well done! On a lesser note, the Alliance with help from Catholic Charities held its first annual walk-a-thon, with close to 100 people with their children and dogs.

This is the first year that **Minnesota** has published a newsletter. They report proudly that they "have worked with the group from Oakwood PW, Inc. to set up a financial assistance program for people with PWS using the interest on the funds they have invested from the sale of a group home. We are very hopeful that this will help a lot of people with expenses they couldn't cover otherwise." [Ed. Note: *Oakwood was one of the first group homes in the USA.*]

Along with their annual Walk-Along, **Arizona** held a lunch and prize give away, with over 60 people attending. Several of the children with PWS had a "buddy" to walk with from a local school. The chapter also sponsored a bowling party for 25 people with PWS. Everyone got to bowl and have a drink and popcorn afterwards.

Michigan is justly proud that it raised enough money through several fundraisers, including a Fall Bass Fishing Tournament, to send individuals to the Ohio PWS camp, families to national conference, and fund Valentine's parties for two group homes.

Missouri, too, through its PWS Walk-A-Thon plus tennis and golf tournament fundraisers, was able to fund a specialized summer camp at Wonderland Camp, help send families in need to the national conference, and assist with appliance replacement for some PWS supportive group homes. They also have a summer swim party, just for kicks.

The **Prader-Willi California Foundation** is as active as it is big. It sponsored a great general education meeting featuring experts Drs. Linda Gourash and Jan Forster, and also a Parent Training Program and a Teacher Training Program featuring M.K. Ziccardi. PWCF is providing more public awareness/education programs and is beginning to generate more media attention; implemented a new Medical Emergency Number for after-business hours response; produced educational packets for all residential and vocational service providers; and implemented a new Yahoo group specifically for residential and vocational providers and state provider case workers to communicate more quickly with each other to share PWS info, etc. A massive state-wide Physician Education Project is under way to provide information on PWS to over 4,000 physicians of various specialties.

Texas is busy establishing its state chapter. Having the national conference there next year should be a big boost.

Pennsylvania had a March Mini-Conference and several fund-raisers, plus a Pig Roast and concert to benefit Rett syndrome, autism, and PWS. In July 39 members attended the Pittsburgh Pirates/Colorado Rockies baseball game. All wore bright "safety orange" T-shirts with a big PWSA (USA) logo on the front circled by the words **Prader-Willi Syndrome Association of Pennsylvania**. The back read **Help Unlock the Mystery** — which generated questions from more than one onlooker. President Deb Fabio notes that "We haven't had rap groups for sibs at chapter meetings [yet]. However, we've done 'turkey bowling' with frozen turkeys!" Hmmm. That should pique your interest!

Primarily a fund-raising organization, **PW Families of Ohio** enjoyed a Night at the Races, and a reverse raffle. Three thousand dollars went to support IPWSO, another \$6,000 for conference grants, and another circa \$6,000 for conference grants for Ohio families.

Indiana is getting its chapter together and struggling with small numbers. Particularly enjoyable so far has been just getting together and learning to reach out to each other. Isn't that what it's all about?

The Annual Hobby Day held by **Wisconsin** in April is a unique event, used to help those with PWS and siblings learn new hobbies — as well as just have fun! Ninety-three people with PWS attended, with a lot of assistance from the 73 parents, staff, caregivers and volunteers also on hand. A dance in the afternoon gave parents and family members an opportunity to meet separately to network and discuss some of the challenges they were experiencing. The chapter plans an October training titled "A Health Update on Prader-Willi Syndrome" with a variety of health care professionals

Chapters continued on next page

Utah's "Walk for Prader-Willi Syndrome" in May exceeded all expectations. They expected 300 people and 800 showed up. They educated thousands of people about PWS thanks to public service announcements and media coverage. Best of all, instead of their "long shot" goal to raise \$10,000, Utah raised more than \$24,000!

speaking on health concerns of children and adults with PWS.

Ohio meets regularly with the E.D. for Ohio MRDD and is summarizing a survey on PWS clients served that was sent by the state to all of the counties with the purpose of trying to define the current and future needs for adult housing. Ohio-specific in-service presentations have been made to several groups, such as school support staff and county MRDD. This year's Festival, with a theme of nutrition, included information for parents and providers, and activities like swimming, crafts and carnival-style games for the "kids" of all ages. Fall and Summer Camps bring campers with PWS from several states. The upcoming one October 13 to 15 anticipates about 50 campers. For more information contact Sandy Guisti, juicete@aol.com. The Fall Mini-Conference Sept. 30 features Luc Lecavelier, Ph.D. from the University of North Carolina Prader-Willi Syndrome Clinic, speaking on behavior, and Ken Ritchey, E.D. from MRDD of Ohio, on resources.

In addition to the January Health Expo awareness effort, plus a two-day state conference, **Utah** had a Grizzly Hockey Night with a suite at the hockey game. The mascot came up and met the kids and handed out towels. The kids got to go out on the ice and high-five the players as they skated onto the ice — all through the mouth of a giant grizzly bear spewing fog! The announcer briefly described PWS to the audience. An annual swim party in August was held for all the families in Utah.

During Awareness Week **Colorado** held its first annual Kentucky Derby fundraiser at the home of Jeff and Kari Porter, with over 150 adults and 75 children attending — all wearing their brand-new PWSA "Still Hungry for a Cure" T-shirts. During that same week the Colorado Rockies set up a booth at Coors Field where the chapter could hand out brochures and sell items to raise money for PWSA. They got coverage by both the local CBS and NBC stations.



Iowa has new co-presidents, Edie and David Bogaczyk. For awareness week, their Board sponsored a statewide, day-long conference for providers, educators, caretakers and individuals with PWS with 100 people attending. Next they plan to do a family conference focused more on social and support networking activities, as well as a summer picnic and speaker programs.

Florida plans its Fall Conference Oct. 13 and 14 in Gainesville, with an attorney as guest speaker who specializes in wills and trust.

This is by no means all of our chapters or all of their activities. But if you, the reader, are not in one, you can see how much fun and information there is to be had by being a member. So seek out the chapter in your state and join — or start a new one if there isn't any.

Angel Flight Adds Rare Diseases

Angel Flight Service has been extended to include all medical and research facilities in the Rare Diseases Clinical Research Network so that no patient is denied medical access to ongoing research projects due to lack of air transportation.

Angel Flights have helped some of our families get to The Children's Institute in Pittsburgh. However, there are several exclusionary conditions, including total weight, length of flight, etc.

Families who need this service should contact the PWSA (USA) national office for more information at 1-800-926-4797.



Highlights from Scientific Day, July 19, 2006 Presented at the 28th Annual PWSA (USA) National Conference

Following are highlights from some of the abstracts presented that we believe are of greatest interest to parents and care providers. For details of each study and to review all the abstracts, members can go to our Members Only section of the web, or order abstracts through the PWSA (USA) office. Part 1 of 2

Expression of Four Genes between Chromosome 15 Breakpoints (BP1 and BP2) and Behavioral Outcomes in Prader-Willi Syndrome

Merlin G. Butler, Douglas C. Bittel, Nataliya Kibiryeva

Children's Mercy Hospitals and Clinics and University of Missouri-Kansas City School of Medicine, Kansas City, MO

Prader-Willi syndrome (PWS) is a neurodevelopmental disorder resulting from lack of expression of paternal genes from the chromosome 15q11-q13 region. A *de novo* paternally derived deletion is seen in about 70% of PWS subjects and classified as having either a large Type I (TI) deletion involving chromosome 15q breakpoints BP1 and BP3 or a smaller Type II (TII) deletion involving breakpoints BP2 and BP3.

Clinical differences have been reported between those with the typical 15q11-q13 deletion (unclassified) and maternal disomy 15 in verbal IQ, visual memory and maladaptive behavior. In addition, PWS individuals with the TI deletion reportedly have more behavioral and psychological problems than PWS individuals with the TII deletion.

Hence, we examined the relationship between expression patterns of four genes (*NIPA1*, *NIPA2*, *CYFIP1*, *GCP5*) located between the two proximal 15q breakpoints (BP1 and BP2) and behavioral, psychological and cognitive assessments previously reported to be different in individuals

with PWS having TI or TII deletions. The four genes are deleted in those with PWS having a TI deletion but not in those with a TII deletion. Thus, they become candidate genes for contributing to reported phenotypic differences between the two typical deletion subtypes.

Statistical analysis using the coefficient of determination suggested that expression of the four individual genes accounted for as much as 75% of the variation seen in several behavioral and academic assessments. The joint impact of the four genes explained from 24% to 99% of the assessment scores obtained from our subjects with PWS.

We also demonstrated significant correlations between phenotypic outcomes and gene expression of the four genes located between BP1 and BP2. Because behavior and cognition are difficult to quantify, it is obvious that the expression of the four genes between BP1 and BP2 cannot explain all the behavioral and psychological differences observed in our PWS subjects. However, the gene expression values explained more of the variability than the deletion subtype alone. This is in keeping with the fact that haploinsufficiency reduces expression of the four genes in subjects with TI deletions.

Our data further suggested that the four genes influence neurodevelopment and function in PWS with the greatest contribution identified for *NIPA2* as well as through direct interaction with other genes yet to be identified.

Psychopathology and 5HT Levels in Prader-Willi Syndrome

Elizabeth Roof, Elisabeth Dykens, Elizabeth Pantino, Ray Johnson
Vanderbilt Kennedy Center, Nashville, TN

Introduction: PWS has a behavioral phenotype that includes severe tantrums, outbursts and stubbornness, as well as many obsessive-compulsive features. We and other groups have hypothesized that many of the behaviors associated with PWS may be due to aberrant or low levels of serotonin.

SSRIs, which increase serotonin at the synaptic level, are often used in PWS populations (with variable success) to help mediate these behavior problems. The current study looks at the plasma levels of 5HT, a precursor to serotonin, in those with PWS and whether 5HT levels are related to several measures of adaptive and maladaptive behavior.

Results: Participants with PWS had plasma 5HT levels that were similar to the general population, and levels of 5HT decreased with age. Higher levels of 5HT were seen in younger participants; older persons the lowest levels. As expected, those participants with PWS who were currently using SSRI medications had lower levels of 5HT than those with PWS who were not taking SSRIs. 5HT levels did not significantly vary across gender, genetic subtypes (paternal deletion vs. maternal uniparental disomy) nor was 5HT consistently associated with compulsive or other behavior problems.

Discussion: Behavior problems are hallmark features of PWS, and often the logical symptom targets of SSRI trials. Differences in 5HT levels in those with PWS may explain some of the variable response to SSRI medication, although maladaptive behaviors and treatment responses are likely determined by multiple risk and protective factors. Discussion also includes possible associations between 5HT and more subtle features such as arousal or alertness, and issues related to 5HT supplementation in those with PWS. This research was supported by the NICHD P30HD15052 and RO1HD03568.

[Executive Director Janalee Heinemann took note of the following during the presentation: Mutations in the TPH2 enzyme are associated with a lot of the problems in PWS. Of the PWS group, 34% had the mutation – much higher than the control group. This could help explain variability in psychopathology and drug response. Behavior problems appear strongest in the 20-30 age range. Those with UPD

Prevalence in Grand Island, New York

exhibit less skin picking, more autism and psychosis. Seventy percent were on SSRIs. Dr. Dykens wants to study the positive effects on families and build on strengths.

Note: This study is sponsored by PWSA (USA).

Gastrointestinal Complications Associated with Death in PWS

David A. Stevenson, Janalee Heinemann, Moris Angulo, Merlin G. Butler, Jim Loker, Norma Rupe, Patrick Kendell, Carol Clericuzio, Ann Scheimann

University of Utah, SLC, UT, PWSA (USA), Sarasota, FL, Winthrop University, Mineola, NY, Children's Mercy Hospital and Univ. of Missouri, Kansas City, MO, Bronson Methodist Hosp., Kalamazoo, MI, University of New Mexico, Albuquerque, NM, Baylor College of Medicine and Johns Hopkins Hospital, Baltimore, MD¹²³⁴⁵⁶⁷

Background: PWS is the most common known syndromic cause of life threatening obesity, yet few studies have examined the causes of death in PWS. Early mortality and unexpected sudden deaths have been documented in PWS, but choking has not been previously reported as a cause of death.

Objective: The objective was to examine the contribution of choking and gastrointestinal complications leading to mortality in PWS.

Methods: In 1999, a brief survey was made available from PWSA (USA) bereavement program, which documented demographic data and causes of death. Families were then asked to fill out a detailed questionnaire and release medical records.

Results: Demographic information was available on 178 individuals with PWS who were deceased, and cause of death was available on 152 individuals. Updated questionnaires were completed by 50 families of which 39% reported history of choking. Choking was listed as the cause of death in 12/152 (7.9%). Of those who died of choking the average age at death was 24 years (range 3-52y; median 22.5y),

and only 2 individuals were less than 8 years. Clinical information was available for study, including food records and feeding activities around the time of death. Stomach rupture/necrosis was reported as cause of death in 4/152. Two additional patients reportedly died after episodes of suspected gastric bleeding. Of those who died due to choking 11/12 were male, and all individuals with stomach rupture or gastric bleeding were male.

Conclusions: Choking is most common in the general population between 1 and 4 years, but in our cohort the average age of death from choking was 24 years, suggesting that risks associated with choking are different in the PWS population compared with the general. Potential causes of increased choking in PWS include poor oral/motor coordination, poor gag reflex, hypotonia, hyperphagia, decreased mastication and voracious feeding habits. Implementation of preventive measures including the Heimlich maneuver training for care providers, supervised meals, better food preparation and diet modification to avoid high risk choking items may decrease mortality.

Note: This study is sponsored by PWSA (USA).

Post-operative Pulmonary Edema in Two Children with PWS

Ferdinand Coste, Jon E. Roberts, Lyn Quintos-Alagheband, Mary Cataletto, Moris Angulo

Winthrop University Hospital, SUNY Stony Brook School of Medicine, NY

Introduction: Hypotonia in PWS, along with a fundamentally abnormal response to hypercapnea [abnormally large amount of CO₂ in the blood] and hypoxia [below normal levels of oxygen], predisposes these children to alveolar hypoventilation during sleep secondary to both obstructive and central apnea. Delayed recovery and other complications post-anesthesia have been reported in individuals with PWS. We report two children with

PWS with pulmonary edema occurring during the first 24 hours post anesthesia.

Case 1: A 2-year-old, non-obese (BMI=19, +1.5 SD) male, oxygen-dependent since birth due to respiratory failure associated with congenital tracheomalacia and on growth hormone (GH) for the previous 9 months, underwent elective tonsillectomy and adenoidectomy. By 8 hours post-op he was wheezing with significant intercostal retractions and increased secretions. He rapidly progressed into severe respiratory distress unresponsive to oxygen, racemic epinephrine, albuterol and intravenous corticosteroids. He was subsequently intubated. Chest X-ray (CXR) at that time showed signs consistent with pulmonary vascular congestion. Significant improvement in blood gases and CXR were noted after administration of dexamethasone and furosemide, with complete recovery 48 hours post-op.

Case 2: A 3-year-old, non-obese (BMI=24, +1.7 SD), non-GH treated male underwent elective bilateral orchiopexy for undescended testicles. He was given general anesthesia and oxygen via face mask and was reportedly breathing spontaneously throughout the procedure. Within 30 minutes after this uncomplicated surgery he was found to have facial cyanosis, tachypnea, and stridor with progressive respiratory distress. Blood gas was within normal limits and CXR demonstrated mild cardiomegaly and signs consistent with pulmonary vascular congestion. The patient responded rapidly to furosemide and complete recovery was noted within 12 hours post-op.

Discussion: Infants and children with PWS are at increased risk for the development of respiratory complications following general anesthesia and sedation from a variety of reasons, including abnormal respiratory control

Abstracts continued on page 14

MEDICAL ALERT for Inpatient Providers for PWS

PLEASE READ THE FOLLOWING IMPORTANT HEALTH INFORMATION FROM PWSA (USA).

You are caring for a person who has Prader-Willi syndrome (PWS). Persons with PWS have some unique health needs that require close attention. The following are just some of these more critical concerns that you, as his/her health care provider need to monitor and keep in mind. NOTE: The health issues and dietary needs of an infant with PWS are very different. For more information, visit our website at www.pwsausa.org or call toll free: 1-800-926-4797.

COGNITIVE LIMITATIONS: Approximately 90% of persons with PWS have cognitive limitations. Many have guardians who assist with medical decisions. Use simple, understandable language to educate and obtain informed consent.

HYPERPHAGIA: Because of an abnormality in the hypothalamus, persons with PWS have an insatiable appetite – the feeling of fullness never reaches their brain. Many will go to extreme measures to obtain food – begging, crying, stealing and gorging. Because of hormone deficiencies, they can gain weight on half the calories of others their age. All must be on a calorie-restricted diet. **ALL FOOD SOURCES MUST BE MONITORED AND CONTROLLED. PERSONS WITH PWS HAVE HAD BINGE-EATING EPISODES THAT RESULTED IN STOMACH RUPTURE. This has occurred while in a hospital setting.**

- Place patient on a calorie-restricted diet. Have a nutritional consultation. Providing small, more frequent meals 5-6 times a day is often helpful.
- If possible, the patient with PWS should be in a private room. He/she may steal food from a roommate. Ask the roommate to remove visible food items.
- Make sure there is constant monitoring of carts delivering food to patients. A person with PWS can quickly take a tray while staff is not looking or delivering a tray.
- Promptly remove collected food trays. Watch for food that may be left out. A person with PWS will eat from any plates where food is remaining.
- Limit access to the nursing unit kitchen. Keep a supply of diet Jell-O, diet soda and other low-calorie food items if additional food may be needed for those with PWS.
- Limit the quantity of fluids consumed. A person with PWS can and will drink enormous amounts of diet soda, diet Kool Aid, etc. and suffer from water intoxication. Most do not drink or care for water.
- Make one staff person responsible for giving this patient ALL food. They are clever at getting different people to get them food. Keep lines of communication open with family members, care providers and visitors to keep informed of food the person has already consumed.
- Check weight daily. Believe what you see and tighten your vigilance!
- If the patient goes off the unit, he/she must have 1:1 supervision. Those with PWS can often get money to access vending machines, gift shops and cafeterias.
- Keep break room doors closed – especially if food is present.

SEVERE GASTRIC DISTENTION WITH ISCHEMIA:

This is a life-threatening situation that may also result in rupturing of the stomach. A person with PWS may present with abdominal distention, pain and/or vomiting but may only complain of mild abdominal discomfort. Because of altered pain response and the rarity of vomiting seen in these individuals, the presence of pain and/or vomiting must be evaluated closely. This gastric inflammation with necrosis has most often been seen in those who have had a recent binge episode and whose weight is under control. Many also have gastroparesis, which can become dangerous if overeating occurs.

ADVERSE REACTIONS TO ANESTHESIA AND SOME MEDICATIONS:

People with PWS have unusual reactions to standard doses of medications and anesthetic agents. Use extreme caution in giving medication that may cause sedation. Prolonged, exaggerated responses including respiratory arrest have been reported. Psychotropic medications must always be started at very low doses. Medications that have anti-diuretic effects may cause water intoxication.

- Monitor postoperative patients very closely. You may want to keep a pulse oximetry monitor in place for 24 hours.
- Be very conservative in administering pain medications.
- Closely monitor all liquids the patient is getting – both intravenously and orally.

ALTERED PAIN RESPONSE: Persons with PWS have a very high pain threshold which may mask injury, infection and illness. Do not use pain as a primary means of diagnosis. Some may not complain of pain until the infection or injury has become very severe. Use extreme caution when prescribing and administering pain or other narcotic medications.

RESPIRATORY CONCERNS: Those with PWS are often at risk for respiratory difficulties. Sleep apnea is common. Hypotonia, especially in the trunk area, put them at high risk for developing pneumonia and atelectasis. Obese patients who have been chronically hypoxic may not tolerate fully corrective use of oxygen and are likely to start retaining CO₂.

LACK OF VOMITING: Vomiting rarely occurs in persons with PWS. If it occurs, severe gastric illness must be ruled out. In cases of poisoning and ingestion of spoiled or contaminated food, emetics are often ineffective. Toxicity can occur if repeated doses of emetics are attempted.

BODY TEMPERATURE ABNORMALITIES: Because of hypothalamic malfunction, idiopathic hypo- and hyperthermia have been reported. Hyperthermia may occur during

**See our Website: www.pwsausa.org
or Call Toll free: 1-800-926-4797**

Medical Alert continued on page 14



President's View

A Whole New World

Carolyn Loker

In the May-June edition of *The Gathered View*, I wrote "When Life Hands You a Lemon, Peel it." I talked about my discovery that Anna knew she had Prader-Willi syndrome and how she talked about her special differences.

This discovery has opened a whole new world for us. It has allowed Anna to set herself free and let her feelings be known. She now has the opportunity to talk to her family about why Prader-Willi syndrome makes life difficult for her. And from this, we have had a number of meaningful moments.

In the weeks that have followed since our open discussion about the syndrome, Anna has asked many questions and made several statements. For example, she decided not to go to the grocery store, saying, "Mommy, it's just too hard for me because of all the food and it makes me anxious."

Anna has opened up to tell us how difficult it is when others eat in her presence. One day, shortly after Anna had eaten her lunch, a family member wanted a piece of pizza and was heading to the microwave. Anna said, "When I smell the pizza it will make me hungry!"

Her statement led us to consider options that would resolve the situation. "Would you be OK going upstairs in

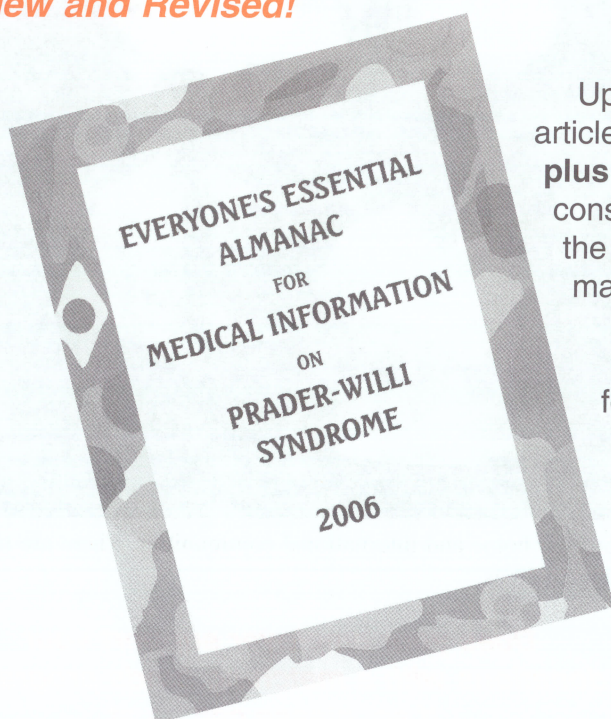
Mommy and Daddy's room to watch TV?" I asked. Anna said yes and off she went. She knew we had heard her concern and addressed it. There could have been other solutions, but this was a good one for this day.

One day Anna asked a question that hit us very hard. "When you and Daddy die, who will take care of me?" We assured Anna that she is part of a family who will always step in to help her. In her heart Anna knows that someone will always have to be with her to be her comforter and guide, but she needed reassurance, and we were able to provide that in another meaningful moment.

My message to you: Oftentimes we forget that our children do understand far more than we realize. They keep their feelings deep inside; they may be unable to set them free because of lack of speech or not knowing how to talk about them.

I feel so blessed in this stage of Anna's life that she can talk about her feelings and her special differences, and I vow to her and to all of our special children that I will do whatever it takes to make a difference in her life and in theirs. Hugs.

New and Revised!



Updated in 2006, this helpful reference contains articles published in *The Gathered View* **plus**

consensus statements and articles by members of the PWSA (USA) medical boards regarding the many medical issues sometimes related to PWS.

Cost for members is \$10 plus shipping; for non-members, \$15 plus shipping.

To order, contact the National Office at 1-800-926-4797 (toll-free in USA and Canada); Fax to 941-312-0142; or e-mail to national@pwsausa.org

Fundraising

We Recognize Your Support for PWS

By Stephen Leightman, Fund Development Committee Chair

Our association has always been dependent on the generosity of our families, members and supporters. Our growth has been characterized by increased activity in research, crisis intervention, parent and grandparent mentoring, educational programs and publications and a host of other services.

The past years have presented both opportunities and challenges as we strive to improve the lives of people with PWS and seek answers to the many questions PWS poses.

Without the financial support of our constituents, we could not offer the services we now provide, and without that financial

support continuing to grow, our future would be in doubt.

Over the past 18 months, through the work of staff and volunteers and through contributions of hundreds of people, PWSA (USA) has experienced a much needed boost in revenue. To maintain our momentum, we recently formed a Development Committee sub-committee devoted to seeking support from major donors. If anyone is interested in helping

with our efforts, please call PWSA (USA) at 800-926-4797 and ask to be put in touch with me.

Our officers, staff and everyone on the Board of Directors are deeply grateful for everything done on behalf of PWSA (USA). Often, in the rush of daily activity, we forget to properly thank everyone who has been so instrumental in our growth. To honor those who are so important to us, we have established three categories to recognize the effort and generosity of our supporters.

Annual Grassroots Fundraising

Diamond	\$50,000
Gold	\$20,000
Silver	\$10,000
Bronze	\$ 5,000
Major Donor	\$1,000
Contributor	\$500
Supporter	less than \$100

Lifetime Donors

\$100,000
\$ 50,000
\$ 20,000
\$ 10,000

Annual Donors

\$10,000
\$5,000
\$2,500
\$1,000
\$500
\$100

In addition to appearing in the Annual Report, we also have plaques recognizing contribution levels on permanent display at the

PWSA (USA) office. Thank you to everyone who has been behind us in the past. Please remember we need you even more now to ensure the future of PWSA (USA). Together we can make a difference.

PWSA (USA) Board Member Stephen Leightman is the grandfather of Josilyn Levine, 4, who has PWS.

Rotary Donates \$10,000

In June, the Eastern Hills Sunrise Rotary Club donated \$10,000 to PWSA (USA). The Club raised the money at its Monte Carlo event and Golf Tournament. Rotary Club president Scott Bylewski (second from left) presents the check to Barbara McManus (center), chair for the 28th National PWSA (USA) conference and the 16th Annual Prader Willi Alliance of New York, Inc. conference, and Jeannie Dickinson (third from right), Conference youth program director. The Eastern Hills Sunrise Rotary Club is part of Rotary International, a service organization of 1.2 million business and professional men and women who, as volunteers, address needs of their home and international communities. There are more than 32,000 Rotary Clubs in more than 200 countries and geographical areas.



Donations to PWSA (USA) for Research

Dec 1, 2005 - July 31, 2006: **\$192,527.20**

Dec 1, 2004 - July 31, 2005: **\$106,903.99**

Does your employer support your donations with a matching funds program?
If so, please call us at
1-800-926-4797

Ken and Pam Sims On Life With Lisa, Who Has PWS

Ken's View:

I'm sure that I wouldn't have had the slightest idea what Prader-Willi syndrome was if someone would have asked me over 10 years ago. Of course, I was only a young child back then, but I would guess that many adults even now wouldn't recognize the name of this condition. However, Prader-Willi syndrome has without a doubt affected my life in a great myriad of different ways.

My younger sister Lisa was born with Prader-Willi syndrome in 1990 when I was not even 5 years old. Since then, my life has been somewhat of a roller coaster ride of highs and lows as I have grown up in the same house as her.

Now I am in college, so I don't get the pleasure of interacting with my sister every day, but she has definitely left her impression on my life through all of the memories she has provided.

My sister Lisa is one of the most dynamic people I know. She has a heart of gold and she is usually very cheerful. She is extremely curious and always has some type of question on her mind. Of course, this can get a little overwhelming at times, but I'm glad she loves to learn.

She tries her hardest to accomplish everything on her "Things to Do List" which usually grows faster than it declines. She loves to do puzzles, but after a while she gets a little too addicted to them. She also loves to play video games with either my older sister Pam or with me. She loves to swim and to go for walks. However, I think among her favorite things are hugs. This list shows how much she resembles a typical American teenager.

She also has her rough moments, though, when she will become stuck on one particular subject or another. This reoccurring event has helped me to develop my patience over the years, even though there are times when my patience runs low very quickly.

But overall, Lisa has been a blessing to my family and me. I have become very thankful for all of my own blessings and for all of Lisa's unique talents and idiosyncrasies over the years. She has helped me to truly appreciate life by making it much more challenging and thus rewarding.

Even though I have experienced many difficult times with my younger sister, I have been grateful for the time shared with her. She has taught me more than I will probably ever truly realize. I have developed to a degree into the individual I am today because of her.

Just knowing her and observing her and learning more and more about PWS have inspired me to studying bioengineering. Perhaps one day I will find myself studying the genes causing PWS. Until then I will stick to my big brother role and continue providing Lisa with an occasional bear hug!



Lisa, who has PWS, with brother Ken and sister Pam

Pam's View:

My younger sister Lisa has Prader-Willi syndrome. I will be honest; it hasn't been an easy road to travel. I remember when she was a baby I didn't like to play with her because she was different. As she grew older, she was always making a scene and I was embarrassed by her. The repeating, hundreds of questions and constant picking was something that easily frustrated the whole family.

It wasn't until we finally learned that she had PWS and started to learn about it that I really began to enjoy being around her. I left for nursing school a few years ago, and I realized that we are incredibly close. She has a charm about her, and she is so smart. I am the protective big sister now. I know I wouldn't be the same if she wasn't around.

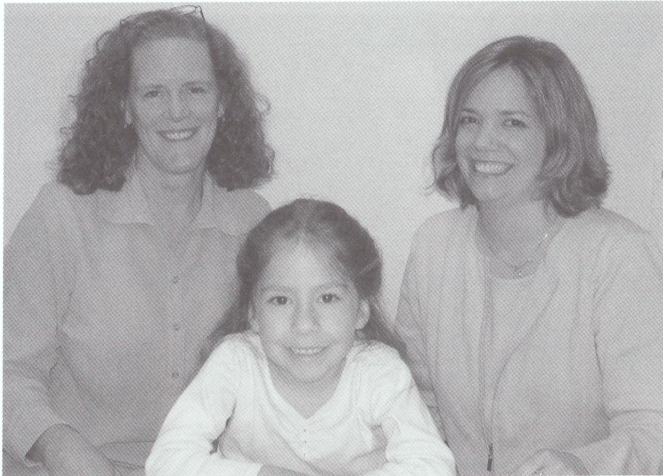
I love when she comes to visit because she always has the whole weekend planned with just what she wants to do. She has an amazing sense of humor and can certainly hold her own with talking with our brother. She isn't always the easiest person to live with, and sometimes it's just hard to be around her. But I wouldn't change a thing about her because that's what makes her so special, what makes her our 'Leebugs'!

Pam is 23, Ken is 20 and Lisa is 15. They are from Canal Fulton, Ohio.

About the PWSA Sibling Booklet

Good news! Work on the sibling booklet is progressing nicely, and it should be available in October.

Rebecca Brings Their Daily Ray of Sunshine



Speech Pathologists Susan Landess-Towne and Nancy O'Connor with Rebecca, who has PWS.

As speech language pathologists in a language-based, integrated pre-kindergarten program, we meet many wonderful and special children. None is more special to us than Rebecca Baird, a 4-year-old with Prader-Willi syndrome. But more importantly, she is often our daily ray of sunshine. On days when schedules, conflicts and workload sometimes are pressing, we delight in the presence of Rebecca and her pixie personality. She is always ready to work hard but is also fast to make those around her smile. Rebecca has grown a lot in the past year, mostly due to her own hard work and strong desire to learn new things. She is truly a star.

Kids are always thanking us for what we do in school and we just wanted to thank one of our favorite kids for making our world a greater place. Please accept our contribution to the Prader-Willi Syndrome Association as thanks for all you do.

*Susan Landess-Towne and Nancy O'Connor
Clinton Public Schools, Clinton, Massachusetts*

Scientific Day Abstracts - continued from page 9

response to hypercarbia, craniofacial configuration, obesity and hypotonia. These two cases presented illustrate that this risk is not limited to airway procedures or to children on growth hormone. Awareness and anticipation of respiratory complications in this patient population suggest that preoperative screening for sleep related breathing disorders, postoperative observation in a monitored inpatient unit and availability of respiratory support are important factors in maximizing the perioperative care to patients with PWS.

Part 2 of the Abstracts will be published in the November/December issue of The Gathered View.

Medical Alert - continued from page 10

minor illness and in procedures requiring anesthesia. Fever may be absent in cases of severe infection.

SKIN LESIONS – PICKING: It is common to see open sores caused by skin picking. Bruising is also seen. Appearance of such wounds and bruises may wrongly lead to suspicion of abuse. Persons hospitalized for cellulitis and/or wound infections require close monitoring and supervision. Extra measures to cover incisions, IV sites and/or wounds should be used. Steps to keep hands occupied are often helpful.

If you have any questions or concerns, please contact PWSA (USA). We have physicians and other health care professionals who are willing to provide consultative services. This service is professional to professional only. Phone numbers of professionals cannot be shared with family members or care provider staff. Call toll free: 1-800-926-4797 for this service to be arranged.

**PWSA (USA) • 5700 Midnight Pass Rd. Suite 6
Sarasota, FL 34242 • www.pwsausa.org**



Two biker dudes

Corbin Soo of Hawaii, 3, who has PWS, has been involved with his dad Clinton's fitness regimen since he was very young. "Our son is a marvelous inspiration to me who has undoubtedly given me a new perspective on life," writes Corbin's dad Clinton, who believes that Corbin's exposure to athletics to be a positive influence on his son's health and fitness.

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Lennae & Wade Elkington

Leigh E. Campbell

Juanita Campbell

Burton J. Fiske

Mike & Lauri Fabrizio

Kenneth & Mich Fiske

Norma Beightel

Jerry & Carol Exline

Traci Fisher

Marge & Walt Foran

A.J. Monastra

Michael Pratt

Rick & Janet Carlson

Dana Kline

Burton Fiske

Brucie Stevenson

Agostino & Carolyn Monastra

Cheryl & Steve Rittel

Burton & Karen Bauer

Barbara Jo White

Wendy Alton

Walter & Lola Fair

Katie Utter

Steven Rouse

Randal & Carol Landen

Montie & Jan Deer

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Renata & Lino Queirolo

Matt Gardner

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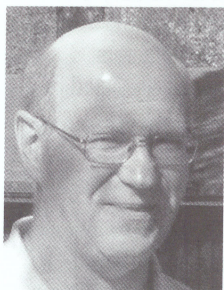
Rose Weeks

Ray Wells

Curt & Marion Shacklett

Richard Wett

Gemini Incorporated

Contributions In Memory Of**We Remember...****Christian Aashamar**

IPWSO Secretary Christian Aashamar died suddenly August 7 at age 57. Christian suffered a heart attack while vacationing at his cabin in the forest, his "favorite place in the whole world." He was rushed to the operating room, but did not survive the surgery.

Christian's death is a huge loss for Frambu Center for Rare Disorders in

Norway, for Norwegian Scouting (in which he was very active), and for IPWSO.

Although Christian worked with many disabilities, PWS was his specialty. An exceptional professional who really understood the PWS population, Christian did everything in his power to raise the quality of life for people with this complicated syndrome. In Norway, he knew and worked with

just about every person with PWS, their families, schools and workshops.

As IPWSO secretary, he was devoted to the organization and gave generously of his time and efforts. Nothing was ever too mundane or too much work for Christian and he kindheartedly devoted many hours into our new board manual and other documents. If there were any obstacles, Christian could always help us find viable practical solutions.

In 2003, the Queen of Sweden presented Christian with the highest award in recognition of his extraordinary knowledge and dedication to children with rare disorders and their families.

Christian will be missed professionally and personally by all who knew him. He leaves a big hole in the heart of IPWSO.

— Pam Eisen, IPWSO President

Contributions

Thank you for Contributions through July 2006

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

Major Benefactors (\$500 and more)

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Mike Kuna
Sylvain Gauthier
Noah Joseph Lauer
Gregory Wardle
The Maczko Family
Scott Gottlieb
Joe & Bonnie Mazzeo's 25th Anniversary
Timothy Wentworth
Julia Katherine McLean
Nick Makris
Lauren Poe
Tiffany & Adam Poe

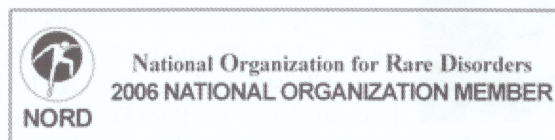
Lorrie Prettyman
Thomas Prettyman
Aubrey Scheer
George & Sara Karpach
Sherwood's 80th birthday
Patricia Davidson
Georgie Varndell
Suzanne Ryan
Avery Waldrop
Meredyth Bryant
Gerald & Christine Waldrop
Bob Pectelidis
Meredyth Bryant
Jacob Walker
Ray & Linda Straub
Scott & Laura Spanfeller
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In Honor Of

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Delfin & Sylvia Beltran	Mary Clark - 75th Birthday
Robert & Alexandra Klas	Anna Campbell
Jack Bevacqua	Vince & Florence Connelly's wedding
Antoinette Bevacqua	Howard Pearl & Jeanne Witherspoon
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John & Jane Coleman	Joseph A DiFilippo
William & Donna Jallick	Dr. & Mrs. P.B. Echols, Jr. 50th Anniversary
	Lota & Dave Mitchell
	Emily Folmer
	Maria Rafalski



Prader-Willi syndrome (PWS) is a birth defect first identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions.

