



The *Gathered View*

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

21st Annual Conference Our Biggest Ever!

*Over 1,000 people attended the Prader-Willi Syndrome Association (USA)'s
21st Annual National Conference, July 7-10, 1999, in San Diego, California.*

Multi-Cultural Action Coalition Formed

During the 1999 San Diego 21st annual conference, a special meeting was held to address the issues related to minority populations with PWS, and how PWSA (USA) can best meet their needs. An ad hoc coalition was formed, and the following areas of focus were outlined for the coming year:

1. Outreach to the medical community emphasizing the under-diagnosis of children of African-American ancestry who have PWS, due to the lack of knowledge of the broader variances in physical differences. (They may have less typical facial appearance, taller stature, and larger hands and feet than Caucasians with PWS.)
2. Translation/development of more information available on PWS in Spanish.
3. Fund-raising for future conference grants specifically to enable minority families to attend.

If any PWSA member is interested in becoming involved with this new coalition, please send your name, address, and special interest to the national office (to my attention).

—Janalee Heinemann

Thanks to all of you who attended the

21st Annual PWSA National Conference in San Diego. Your presence made the conference a success by almost any measure. And a special thanks to those parents and service providers who responded to our call for volunteers for the Friday Youth and Adult Activities Program field trip. You gave up a day of conference presentations to assure that our kids would have an adequate number of counselors for a safe trip ... we really appreciate you all.

More than 1,000 people registered for this year's conference (1,024, to be exact) ... and this does not include a number of community volunteers who supported the conference. On Wednesday, July 7, we had 54 registered for the Scientific Conference and 147 for the Residential and Community Service Providers Conference.

On Thursday, over 575 people were present at the opening ceremonies of the parent and professional conference, which the U.S. Navy Band got off to a rousing start. Of those pre-



sent it was estimated—based on a show of hands—that over 50 percent were attending a PWSA (USA) national conference for the first time. Over 200 of the registered parents and professionals were from California.

The Youth and Adult Activities Program (YAAP) had 300 participants (205 with Prader-Willi syndrome, and 95 siblings) and more than 100 volunteer counselors. Linda Ryan led this program in cooperation with Josh's Friends (John and Debbie Stallings and their assistant directors) for the children over age 6 and the adults, and with the services of KiddieCorp for the children 5 years and younger.

The distribution of YAAP partici-

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San Diego Conference—continued from page 1

pants by age is exhibiting an encouraging trend. The number of young children participating in the program continues to grow with each conference, as children are diagnosed at an earlier age. This year the percentage of YAAP participants under 12 years is nearing the percentage over 12 years of age. It must be that PWSA-USA's awareness and educational efforts are making a difference, and the increased availability of information about PWS on the Internet has certainly helped. The distribution of YAAP participants by age is shown below:

- 62 children from 1½ months through 5 years (32 with PWS and 30 siblings)
- 77 children age 6 through 11 years (37 with PWS and 40 siblings)
- 55 adolescents, 12 through 17 years (30 with PWS and 25 siblings)
- 106 adults with PWS, 18 years and older

There are too many stories to tell and too many people to thank for the space available in this issue of *The Gathered View*. Look for more conference news, photos, and acknowledgements in our next issue. Meanwhile, kudos to the many people who contributed their time, their talent, and their dollars to make this 21st Annual National PWSA Conference a success!

—Frank and Fran Moss, 1999 Conference Co-Chairs

Conference Media Coverage Spanned the Coasts

Media coverage during the national conference reached a much greater audience than originally anticipated. Martha Brownley of the CBS affiliate in San Diego created a segment that not only aired in the San Diego market, it was also broadcast on the news satellite and carried by news stations across the country. Unfortunately we have no way of knowing how many or which stations carried the story.

Many thanks to Paul, Amy, and Amanda Wissmann and Dr. Jeanne Hanchett for their willingness to share! Amanda's grandmother was able to see the story in New York!

We're still anticipating a story from the *San Diego Union Tribune*. Cheryl Clark of the *Union Tribune* spoke with many of you and is eager to help create more awareness about PWS.

Thank you to everyone who opened their hearts and lives to these reporters. We'll keep you posted on future opportunities.

—Pam Tobler, PWSA Board Member

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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). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

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Taking the Volunteer Spirit Back Home

by Barb Dorn, PWSA (USA) President

I am writing this message after returning from another successful conference. I can't begin to thank *all* the volunteers, parents, officers, board members, and families from the Prader-Willi California Foundation and PWSA (USA) for everything they did to make this conference a truly memorable event. I also want to thank Norma and Brenda for all the hard work and time that they contributed at the conference. I am always amazed at and admire those persons who give so much to "our kids" even though they are not relatives to those who have PWS. I am also awestruck to see volunteers and professionals give so much of their time and energy toward supporting, educating, and advocating for persons with PWS. Once again, THANKS to everyone.

I came away from this conference with the belief that no matter where we live, no matter how much money we have, and no matter what our race or skin color—as people who support and care for persons who have PWS, we all face the same issues and challenges. In every session and meeting I attended (and I attended a lot of meetings), I heard people share common concerns. We may not have gotten all of our problems solved, but there is comfort in knowing we are not alone.

On Wednesday, I spent the day with 21 chapter presidents and representatives from across the United States. We shared our frustrations in trying to get members involved. How do we get more parents of younger children involved? How do we get more parents of older children involved? What can we do to educate more professionals? We soon realized that we did not have all the answers and that we all face the same concerns.

If you are not involved in your local chapter, please become involved. The key to being able to support and make a difference for people with PWS has to be at the local level. PWSA (USA) can only do so much (and they sure do a heck of a lot!). But they can't get people connected

to resources in their area without your help and support. Just showing up for events and meetings shows that you care.

Another meeting I attended was the Publications Committee meeting. We had about 12 people taking on 14 more projects for 1999-2000. Our goal once again is to improve and expand on the resources that we provide to our members.

"... The key to being able to support and make a difference for people with PWS has to be at the local level. ...

"... For those who did attend [the San Diego conference], be the messenger of what you have learned. Share, educate and support."

If anyone has an interest and/or talent in writing or editing, please contact our national office so that they can put you in touch with Lota Mitchell, our chairperson for this committee. Once again, without the dedication of these volunteers, we would not be able to share this much-needed information with others.

Hard work is now underway for both our 2000 and 2001 conferences. So much time, energy, and commitment goes into these meetings. I remember attending my first conference. It was in Chicago. After I left it, I came back and started working on putting together a chapter for the State of Wisconsin. *You can make a difference.* Allow this conference to energize you.

We realize that not everyone can attend our conferences. This year, PWSA (USA) was able to assist 24 families in attending. For those who did attend, be the messenger of what you have learned. Share, educate and support. You can be a catalyst for making a difference.

Once again, thanks to all who put forth so much hard work so that we can learn to keep taking steps forward to improve the lives of persons with PWS.

Until next time ... Take care!

Grandparents Needed for Book Project

We are currently seeking grandparents of children with PWS who might be able and willing to help us develop a booklet for other grandparents.

What does the grandparent of a child with PWS need to know? How can they offer support to their son or daughter whose child is affected? How can they cope with their own feelings about their grandchild's condition? Those who volunteer to help will receive a survey to complete that will help us answer these and other questions.

If any grandparent is interested in participating, please send your name and address, and also the name and age of your grandchild with PWS, to: PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242.

Forever After

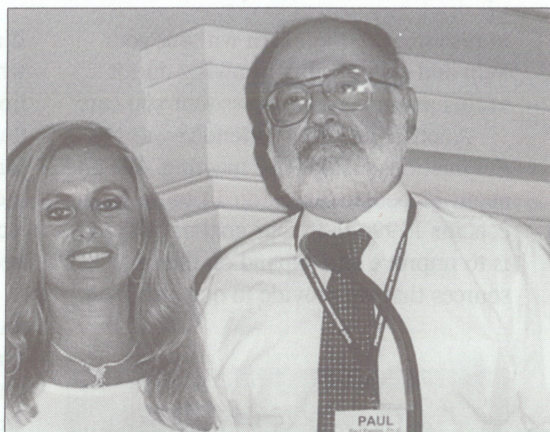
by Janalee Heinemann

Recently, my 3-year-old granddaughter, Taina, patted my face and said, "Are you getting really old Grandma?" When I said, "Yes, Taina, I am getting really old." She got a blanket and wrapped it around my shoulders and said, "Don't worry, Grandma, I will take care of you." Now, since I am a grandma who still rollerblades, snorkels, and kayaks, I found that real cute — but I reflect back to my own grandparents and realize the day will probably come when I will count on family to sustain me.

As I mentioned at the national conference in San Diego, I have come to appreciate more and more how important the national office is, and I realize that PWSA (USA) must live far beyond all of us. Accepting this reality, I realize that as the executive director, I must worry, not only about our needs in the next few years, but about the future of the association. Due to this awareness, and because of my deep love for bereaved families, I was especially touched during conference week by the examples of four families devoted — not only to their own child with PWS — but to sustaining PWSA (USA) and children with the syndrome now and "forever after."

At the conference, **Paul Paolini**, president of the Prader-Willi California Foundation (PWCF), donated \$40,000 to kick off our PWSA (USA) endowment fund. This money was given in honor of his son, **Michael**, who had PWS and died at age 19, and his deceased wife, **Claudia**. Paul credits Claudia with being a driving force in establishing the PWCF.

As Paul has told me, he is not a rich man, but he wanted somehow to create something positive out of his tragedy and to do the best he could to help all people with PWS in perpetuity—or "forever after." The yearly interest from Paul's do-



Paul Paolini (with Janalee) was recognized at the conference banquet for launching PWSA's new endowment fund.

nation will go into the **Paolini Crisis Intervention and Prevention Trust**.

I was honored that Paul shared his son Michael's eulogy (given by a close friend, Steven Dahms) with me. In the eulogy, Steven quoted Gilda Radner, who said, "I wanted a perfect ending, but I've learned the hard way that some poems don't rhyme and some stories do not have a clear beginning, middle, and end. Life is *not* about knowing, but about having to change, about taking risks, about taking the moment, and about making the best of it without knowing what is going to happen next."

Steven went on to say, "Life is all about managing and what you accomplish with what you have. The difficulties placed in Michael's path were substantial, disheartening to the best of us, but due to his courage, fortitude, love, profound joy and a loving, dedicated, intensely knit, and committed family, he overcame them in inspiring fashion, and thereby added to the sum of our human joy, and for this he must be lauded by the angels."

Also while at conference, I received a call about the death of one of my oldest friends with PWS, **Phil Miller** from Missouri. Phil died at the age of 56. At the conference each year, Phil would remind me to save a dance for him. During "our dance," I could count on Phil telling me in detail what they had to eat at the YAAP banquet. **Phil's father, Charlie Miller, is the founder of Camp Wonderland, located in the Ozarks in Missouri.** Charlie had a dream many years ago to build an accessible camp for individuals with physical challenges, so he donated the land and raised money for the de-

velopment of Camp Wonderland — the camp that today has a specialized PWS program one week each summer. Many individuals with the syndrome from all over the United States attend every year.

Just before I left for conference, I received a call from **Carole Smith of Cincinnati, Ohio**, mother of **Skyler Smith**, who had PWS and died at 15 months of age. Carole wrote, "Our beautiful blue-eyed baby boy is no longer with us, but his memory can go on by way of helping other children." She donated money to initiate the "**Skyler Smith Me-**



Skyler Patrick-Pacotti Smith at 15 months of age.



Left: Janalee and Phil Miller enjoying their annual dance at an earlier PWSA conference.

Right: Stuart Pike, celebrating life with two thumbs up.



morial Scholarship Fund," which will go towards supporting the education of young people with PWS.

The first morning I was back from conference, I received a call from Esther "Liz" Pike of Sonora, California, whose 33-year-old son, Stuart, had just died 45 minutes before she called. In spite of her great grief, she had the fortitude to call me to say she wanted to help all children with PWS by donating to the **Brain and Tissue Bank**. Liz has been a long-time member and remembered reading that brain tissue should be donated within hours to be most helpful in research on PWS. Because she called so soon, I contacted several physicians who serve on our advisory boards, and arranged with the medical examiner to have the donation go directly to the University of Florida Brain Bank, where the neuropathologist, Dr. Eskin, personally arranged to preserve the most needed tissue for PWS research.

I know that for many of our parents it is hard to read about children who die, but there is only one greater tragedy than to lose your child—and it is to have people act as if your child never existed and have your child's death be in vain. These four special families that touched me so deeply this week have reached beyond their own pain to touch all of our

lives because they care so deeply about *all* children with Prader-Willi syndrome. In spite of their grief, each family in their own way has found a way to care about all children with PWS "forever after."

Our heartfelt thank-you goes to these parents. May all of our Prader-Willi "angels" watch over their special children.

Death of 7-Year-Old Chicago Girl Elicits Calls

I want to thank our parents in the Midwest who alerted us to the death of a little 7-year-old girl in Chicago. She died of obesity-related causes, and her mother was charged with neglect for not monitoring her eating habits. The other children were taken out of the home. On the day that little Emilia Santana died, her mother gave birth to a child that was taken from her immediately. Several of our PWSA families who heard about it through the news reports called to say it sounded like this child had Prader-Willi syndrome.

To avoid another Christina Corrigan case, I immediately had contact with the two social service agencies involved, the medical examiner, our board physicians, and the detective involved. All were cooperative except the detective, who stated after a half-hour phone conversation in which I explained the syndrome, "It sounds to me like (PWS is) something a defense attorney made up."

Methylation analysis testing (a definitive DNA test for PWS) was done on the child through Dr. David Ledbetter's lab at the University of Chicago. The tests came back negative. However, in my last conversation with one of the social service agencies, the staffer said that after reading all of the information we sent, he still feels that Emilia had PWS.

From what I've told, pending charges were dropped against the mother, and there has been a positive outcome of the case. I want to thank our ever-vigilant families who cared enough to call.

—Janalee

ENDO '99

PWSA (USA) sponsored an awareness booth at the Endocrine Society's 81st Annual Meeting in San Diego, California, in June. There were over 6,000 in attendance, which gave us four days of non-stop contact with endocrinologists from all over the world. Forty percent of the physicians attending were from other nations. It was exciting to "spread the word" to so many physicians all at once. The most frequently asked question was regarding the use of growth hormone in people with PWS.

While at the endocrinology meeting, I had the opportunity to meet with representatives from Genentech and Eli Lilly (two U.S. companies that manufacture synthetic growth hormone). Jon Taylor of Genentech presented us with a very generous \$10,000 check toward our 1999 national conference expenses. We are hoping to establish relationships with all of the major pharmaceutical companies.

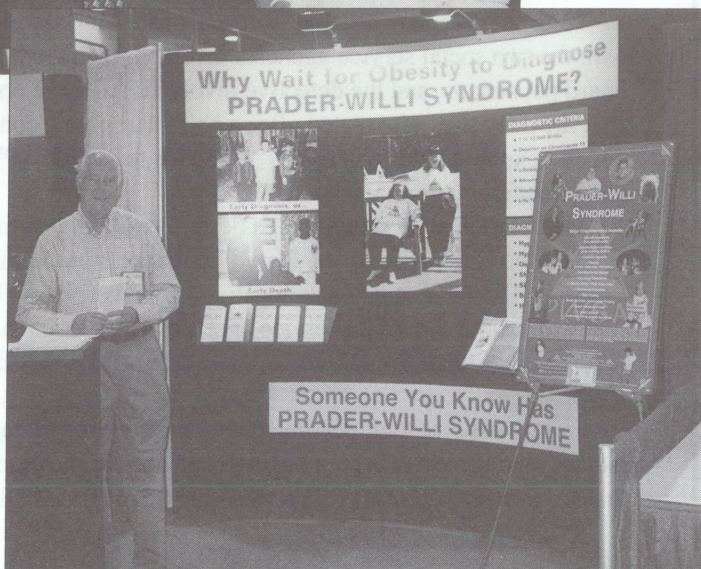
A special thanks goes to Bud Bush, one of our California members, who allowed us to store over 60 boxes of materials at his home and then personally hauled them all to both the Endo '99 exhibit and the national conference. Bud also worked the booth with me, as did Fran and Frank Moss and Marilyn Bintz. Also, thanks go to the PWSA Georgia chapter for loaning us their very professional and eye-catching display.

—Janalee



Above: Jon Taylor of Genentech presents to Janalee Heinemann (left) and Fran Moss a \$10,000 contribution check toward PWSA's San Diego conference expenses.

Right: Bud Bush greets visitors to the PWSA (USA) booth at the Endocrine Society's annual meeting in June in San Diego. The booth is on loan from our Georgia chapter.



PWSA Video Wins a 'Telly' Award

Although the annual "Telly" awards may not prompt that ring of familiarity of an "Oscar" or "Emmy," the highly respected Telly competition has named the PWSA (USA) video "Searching for Solutions" a 1999 "Finalist."

Notification of this honor came in June following the 20th Annual Telly Awards, a national competition recognizing "outstanding non-network television commercials and programs and non-broadcast videos and film production." More than 11,000 entries were judged in the 1999 competition.

According to the Telly Awards Fact Sheet, 7 to 10 percent of the entrants are designated "winners," and another 14 to 18 percent earn "finalist" honors. "When you consider that entrants submit only their very best work, earning Telly recognition is a significant creative achievement," the document states. "... The judges look at each piece as a whole and reward outstanding quality." The category in which "Searching for Solutions" was judged (videos and films) draws the company of some of the biggest and most prestigious, including client firms such as Sony Pictures, Warner Bros., 20th Century Fox, Universal Pictures, and The Discovery Channel.

"Searching for Solutions" was released by PWSA (USA) in the summer of 1998 and had its official debut during the annual national conference held in Columbus, Ohio. The video, which is designed for general audiences, features the stories of PWSA member families and the scientific, medical,

behavioral, and life skills commentaries of respected professionals. The 18-minute tape was produced by Kevin Chippendale and his staff from Graft, Inc., based in Orlando, Florida. The project was funded in full by PWSA (USA) benefactors and was supervised by Board Member Don Goranson of Connecticut and Louise Green-swag, R.N., Ph.D., of Iowa.

"Searching for Solutions" is available for sale in both U.S. and European (PAL) formats through PWSA (USA). The price is \$20 for members, \$25 for nonmembers, plus \$4 shipping to U.S. and Canada (\$10 shipping for International orders).

—Don Goranson

'99 Conference Videos

The Prader-Willi California Foundation received a \$20,000 grant from the San Diego Regional Center and the California Department of Developmental Services for the purpose of videotaping the sessions at the national Prader-Willi Syndrome Association conference in San Diego.

The regional centers in California are state-funded, private nonprofit organizations which contract annually with the California Department of Developmental Services to provide services to persons with developmental disabilities in California.

Taping done at the conference will be edited to prepare educational videos on Prader-Willi syndrome for use not only by the 21 regional centers in California but also by PWSA (USA) in an effort to increase the awareness of the syndrome and to identify services needed by persons with PWS.

—Bud Bush

Editor's note: Watch The Gathered View for a future announcement of the availability of conference videos.

PWSA Business News

Slate of Four Elected to Board

At the annual PWSA membership meeting, held on Friday morning, July 9, at the San Diego conference, Jim Kane (chair of the Leadership Development Committee) presented the slate of four nominees for four open positions on the board: **Dottie Cooper, Pauline Haller, Carolyn Loker, and Pam Tobler**. Each nominee made a statement, and the floor was then opened for other nominations. With no additional candidates proposed either from the floor or by proxy, PWSA members present voted to approve the slate. Congratulations to our new board members!

PWSA President Barb Dorn expressed the Association's thanks to the four directors who left the board after the July election: **Paul Alterman**, who will continue to handle our specialty PWSA merchandise for conference sales; **Jim Kane**, who continues as PWSA Treasurer; **Fran Moss**; and **Pauline Parent**. Barb also announced that the directors had reelected **Ken Smith** to serve another year as board chair.

Clinical Advisory Board Approved

Board Member **Dan Driscoll, M.D.**, announced at the general membership meeting that the proposal for a new advisory body had been approved by the board of directors and that this group will be called the Clinical Advisory Board. Although the membership of this board has not been finalized, the CAB held an initial meeting during conference week and chose Drs. Driscoll and **Rob Wharton** to serve as its first co-chairs. While the Scientific Advisory Board will continue to review research proposals for grant requests and access to PWSA families, the new clinical board will advise the association on aspects of treatment, develop guidelines, write articles, and so forth. (More on this new board in the next newsletter.)

Finances and Donations

Treasurer Jim Kane gave the annual financial report, summarized in the two tables below. Janalee reported that the Prader-Willi California Foundation raised \$64,000 in corporate grants to support the San Diego conference, and announced the launching of two new funds by member donors—the Paolini Crisis Intervention and Prevention Trust and the Skyler Smith Memorial Scholarship Fund (see p. 4.) Paul Alterman announced that the 1998-99 Angel Fund exceeded its ambitious goal, raising \$80,000. **Mike Larson** succeeds Paul as fundraising committee chair.

PWSA (USA) CONDENSED BALANCE SHEET AS OF 12/31/98

ASSETS

Cash and Investments	\$257,098
Deposits	2,967
Inventory	16,040
Equipment (net of depreciation)	2,386
TOTAL ASSETS	278,491

LIABILITIES

Payroll Taxes	\$ 1,875
TOTAL LIABILITIES	1,875

FUND BALANCES

General Fund	\$235,326
Research Fund	41,290
TOTAL FUND BALANCE	\$278,491

PWSA (USA) CONDENSED INCOME STATEMENT FOR THE YEAR ENDED 12/31/98

INCOME

Revenue	\$132,939
Public Support	172,839
TOTAL INCOME	305,778

EXPENSE

Program Services	\$259,286
Management & General	47,283
Fundraising	8,260
Research	11,845
TOTAL EXPENSE	314,829

SURPLUS (DEFICIT) (\$ 9,051)

Growth Hormone Treatment a Major Focus of 1999 PWSA Conference, Scientific Meeting

by Linda Keder, Editor, *The Gathered View*

For the second year in a row, the subject of growth hormone therapy for individuals with PWS was a major focus of the PWSA national conference. In addition to a full-day symposium on growth hormone for professionals on July 7, coordinated by **Dr. Phillip D.K. Lee** of the PWSA Scientific Advisory Board, a luncheon meeting was provided for parents the next day, featuring many of the speakers from the scientific session, and a general session on July 10 provided additional summaries and an open question period. Reports from three different ongoing studies of growth hormone therapy in children with PWS showed continued benefits in a number of areas tested—notably, increased height, improved body composition, and improved motor ability/activity—while other speakers addressed issues related to GH treatment for adults and possible negative effects of GH.

Funding for the scientific meeting and the parent luncheon was provided by two manufacturers of growth hormone: **Pharmacia & Upjohn** contributed \$15,000 toward the travel expenses of three speakers (Drs. Eiholzer, Ellis, and Mogul), and a portion of **Genentech's** \$10,000 conference contribution (see p. 6) was used to provide the family luncheon.

Growth hormone therapy, administered in the form of regular injections, has been tried with a growing number of individuals with PWS since the synthetic form of GH became widely available in 1985. However, it is only in the past one to two years that “controlled” studies have been published, comparing the effects of GH in individuals with PWS with characteristics of a similar group of individuals not receiving treatment.

Research Updates

Reports from major studies were presented by **Dr. Aaron Carrel**, a pediatric

endocrinologist at the University of Wisconsin-Madison, and **Dr. Urs Eiholzer**, director of the Foundation for Growth, Puberty and Adolescence in Zurich, Switzerland. Dr. Carrel is one of the principal investigators in the PWS GH study that is being conducted jointly by the University of Wisconsin and St. Louis University—the first major controlled study on this subject in the United States. (**Dr. Barbara Whitman**, a principal investigator at the St. Louis site, presented her initial findings on behavioral effects of GH treatment at a separate conference symposium on behavior.) Dr. Eiholzer, who has studied and published with Dr. Andrea Prader, after whom the Prader-Willi syndrome is named, follows some 40 children and adults with PWS and has collected three and half years of data on growth hormone effects in children with PWS, some starting at a very young age.

United States

Dr. Carrel reported that all 54 children in the Wisconsin-St. Louis study tested low for GH in response to a clonidine stimulation test, and all had low levels of IGF-I. Prior to treatment, the body fat of the participants ranged from 40 percent to 63 percent of their body mass, compared with 10 percent to 22 percent in a similar group of children without PWS, and all had lower than average energy expenditure. The results of one year of GH treatment in this study, published in *The Journal of Pediatrics* (February 1999, 134:215-21), included significantly increased growth rate, reduced fat mass, increased lean body (muscle) mass, and a “trend” toward increased energy expenditure. Of great importance to families, the study noted, were measurable improvements in the children’s muscle strength and coordination, which parents had seen reflected in the acquisition of new gross motor skills and improved function in day-to-day activities. Dr. Carrel reported

at the conference that the participants who have now been on GH for a full two years have maintained the benefits they gained in the first year and have registered additional increases in bone mineral density (BMD), which is commonly deficient in PWS. The next phase of the study, he explained, will compare results of three GH daily dosage levels—0.3 mg, 1.0 mg (the same as the first-year treatment level), and 1.5 mg per meter² of body surface area.

Switzerland

Dr. Eiholzer and colleagues in Switzerland had published a report in 1998 (*European Journal of Pediatrics* 157:368-377) on one year of GH treatment in 12 children with PWS, documenting dramatic changes in height, growth rate, and muscle mass, and improvements in motor abilities. At the PWSA conference, Dr. Eiholzer updated that report with data on 23 children now treated for an average of three and a half years. Results were compared for three treatment groups: (1) 10 young underweight children, ages 0.3 to 4.1; (2) 8 prepubertal overweight children, ages 3.7 to 9.5; and (3) 5 “pubertal” overweight children, ages 9.0 to 14.6. In all three groups, GH treatment resulted in a decrease in fat mass, a result typically found in treating growth hormone deficiency. The first and second groups had opposite results, however, in weight and weight for height: the young underweight group gained weight (because the gain in muscle mass outweighed the loss of fat), and the overweight prepubertal children lost weight (because the decline in fat mass outweighed the gain in muscle and bone mass). Also, the youngest group did not have a significant gain in height velocity in the first year, whereas the children in the middle age group did.

Over three years of treatment, all the children in the first two groups reached

normal height, weight, and hand length, and their final height prognosis approached their parents' target height. In both groups also, fat mass was reduced and muscle mass increased, but neither change reached what were calculated to be "normal" levels for peers without PWS. The improvements in body composition did, however, result in improved physical performance. Dr. Eiholzer noted that the GH-treated infants took their first step at an average of 20 months, compared with a predicted 28-to-32 months in the literature on PWS, but that the GH treatment did not appear to accelerate other (non-motor) areas of early development. In the third group—the older children who had some early pubertal signs such as pubic hair and early breast development—the results of GH treatment were similar to the younger overweight children, but the effects were not nearly as dramatic.

Sweden

Drs. Ann Christin Lindgren and Martin Ritzén of Sweden submitted an abstract for the PWSA scientific symposium, although they were unable to attend in person. This research group has now followed 18 prepubertal children (ages 3 to 12) with PWS during five years of a GH treatment study. One-year results on 29 children were published in 1998 (*Acta Paediatrica* 87: 28-31), reporting an "amazing response to GH treatment, with increased growth and decreased fat mass, surpassing the effects of GH treatment of children with isolated growth hormone deficiency ..." The researchers' 1999 report indicates that the increased height percentile, achieved in the first year of GH treatment, was maintained during continued treatment with GH. When treatment was stopped for six months, as part of the research plan, Body Mass Index (BMI, which is a person's weight in kilograms, divided by height in meters squared) measurements rose, suggesting an adverse change in body composition. When GH treatment was resumed, BMI scores dropped to a lower rate again and stabilized. The Swedish team noted that two children in the study had developed Type 2 diabetes following a period of rapid weight gain, but that the problem resolved when GH treatment was withdrawn.

"Our daughter is age 14 and has been on GH for 3 years in the study at the Univ. of Wis., Madison. She has gained some height, [but] most importantly has had large gains in muscle tone and endurance. She no longer falls asleep at the "drop of a hat." She is more alert and has more energy and strength to do more in school and socially. She plays the baritone in the school band. All her grades in school have improved and her behavior is better now since she is not as tired. She has more patience and is willing to listen and discuss things. GH has greatly improved her life!"

—Parent comment submitted for final question/answer session at the 1999 PWSA conference.

Other Considerations

Two other speakers who presented at both the scientific meeting and the family luncheon on growth hormone were **Drs. Kenneth Ellis** of Baylor College of Medicine and **Harriette Mogul** of New York Medical College, specialists in the fields of body composition and adult endocrinology, respectively.

Body Composition Studies

Dr. Ellis, who is director of the Body Composition Laboratory at the USDA/ARS Children's Nutrition Research Center in Houston, reviewed the various methods for assessing body composition, an important aspect of GH studies in PWS. He predicted that the DEXA scan "will become the gold standard" for the next millenium. The DEXA scan assesses fat, bone, and lean body mass noninvasively, at low risk to the patient, and is FDA-approved for all ages. Differences between DEXA machines produced by different manufacturers, however, makes it important to use the same machine for all follow-up tests for most accurate results. Dr. Ellis notes that BMI alone does not indicate a person's percent body fat—there are too many variations, including ethnic and age patterns, and there is no assurance that people with a normal BMI have normal fat mass.

GH Treatment of Adults

Dr. Mogul, who is chief of the Section of Osteoporosis and Obesity Research at her institution, has proposed a research study on GH in adults with PWS and reports that there's been "an explosion in the literature" on GH in adults in general, since the Food and Drug Ad-

ministration approved its use for adults with GH deficiency (GHD). GHD in adults, she reports, is associated with lower bone mineral density (BMD) and increased risk of osteoporotic fractures, increased fat mass and truncal obesity, and higher incidence of Type 2 diabetes and cardiovascular events.

Individuals who've been on GH treatment as children should be retested for deficiency as adults, following six months without treatment, Dr. Mogul advises, noting that about 40 percent of GH-deficient children don't need GH as adults. Pre-treatment screenings for adults should include a DEXA scan (for bone mineral density), a glucose tolerance test with insulin level, lipid profile, GH stimulation test (IGFBP-3 and IGFBP-1), appropriate cancer screening (because GH could accelerate the growth of an existing tumor), and possibly body composition studies, says Dr. Mogul. She notes that BMD is affected not only by GH but also by estrogen and testosterone, which may also need replacing in individuals with PWS.

Parental Decision-making

Dr. Jeanne Hanchett, a pediatrician at The Children's Institute's PWS Program in Pittsburgh and a member of the PWSA Scientific Advisory Board, gave a report at both the scientific symposium and the general conference regarding parent views on GH therapy. Out of nearly 500 children and adults who have been patients at the Institute, Dr. Hanchett identified 20 (7 females and 13 males, ages 8 to 26), who either were on growth hormone at the time of admission or had received GH treatment at some

(Continued on page 10)

Growth Hormone—continued from page 9

time prior. In reviewing their histories, Dr. Hanchett found that parents "were pleased with growth hormone if the child did not develop significant scoliosis and if [GH] did not interfere with their ability to handle their child during behavioral upsets." Five of the 20 children, she noted, had been taken off GH "prematurely" because of parent concerns about behavior management, and three had treatment stopped because of scoliosis concerns. Four ceased GH treatment for other reasons—three for lack of growth and one for excessive growth.

At a conference session entitled "Ask the Experts," **Dr. Robert Wharton**, a pediatrician and medical ethicist who is co-chair of PWSA's new Clinical Advisory Board, addressed the issue of decision-making about GH treatment. He argued that, although the decision rightfully belongs to parents, it would be unethical to deny children GH treatment and its now-documented health benefits in order to limit their size and strength for easier behavior management.

The Future

The July 7 symposium on growth hormone was organized by Dr. Phillip D.K. Lee, Director of Pediatric Endocrinology and Metabolism at Children's Hospital of Orange County, Calif., and a member of PWSA's Scientific Advisory Board. Dr. Lee published one of the earliest articles on growth hormone treatment in PWS (1987) and authored PWSA's policy statement on growth hormone, which was approved by the board of directors in 1996 and is currently under review for possible revisions. Stating that GH has "no major safety or efficacy issues," Dr. Lee proposed that a consensus statement be drafted to document that children and adults with PWS are likely to be deficient in growth hormone and that they should be evaluated and treated in the same way as any other group at risk for GHD. This proposed



Penny Park offers a parent viewpoint on GH treatment, after presentations by Drs. Jeanne Hanchett and Phillip Lee, right.

statement, which might aid families in obtaining testing for GH deficiency and, when appropriate, insurance coverage of GH treatment for their children with PWS, was referred to PWSA's scientific and medical advisors.

Many families are anxiously awaiting further research and guidance on how early they should consider GH treatment for their children, what kind of deficiency testing should be done, what screenings and monitoring should be done to prevent negative effects, what dosages should be used, and whether their adult children would benefit from GH therapy. Some have had great difficulty either persuading their doctor to consider GH treatment or their health care/insurance plan to cover its high cost (about \$20,000 to \$40,000 a year).

In her keynote address, Scientific Advisory Board Chair **Dr. Suzanne Cassidy** predicted that GH treatment may eventually become the "standard of care" for children and adults with PWS. She urged families to participate in research projects, because it is through well-designed studies that the unresolved questions about growth hormone will ultimately be answered.

It was clear from this year's conference that there is a growing body of evidence concerning the physical effects and health benefits of GH treatment in children with PWS. It was also apparent that GH treatment is an individual decision that parents have struggled with in the past and will continue to face as their children age and change. ▲

International View

Following in edited version is a report from the May 1999 newsletter of the International PWS Organisation (IPWSO). The author is Peter Davies of Australia, associate professor at the School of Human Movement Studies, Queensland University of Technology.

"The 27th International Symposium, Growth Hormone and Growth Factors in Endocrinology and Metabolism was held in Nice (France), April 16-17, 1999. ... The symposium organizers, Pharmacia and Upjohn, decided this year, for the first time, to include a session lasting two hours relating to growth hormone treatment in Prader-Willi syndrome. There were six speakers of which I was one, the others coming from Sweden and the USA. Three of the speakers reported the results of trials of growth hormone in children with Prader-Willi syndrome, and the findings were remarkably similar. The basic results were that when given a daily injection of growth hormone the children increased their rate of growth in height, but more importantly, I believe, showed beneficial changes in body composition. In effect, the children increased the amount of muscle and reduced the amount of fat. One study also measured muscle strength which showed a dramatic increase when receiving growth hormone injections.

"One aspect of the symposium was particularly interesting in my view. A few years ago, the discussion and debate would have been 'Is it worthwhile giving children with Prader-Willi syndrome growth hormone?' and 'Does it really do any good?' At this meeting the discussion/debate centered around questions like 'At what age should we start treatment?' and 'What dose should we use?'"

(*Wavelength*, Vol. 8, Issue 1)

The scientific abstracts presented in San Diego are available in booklet form from the PWSA office for \$10, plus \$4 shipping to U.S. and Canada (\$10 overseas shipping). Call 800-926-4797.

Many New Tools Available for Education & Training

The past year was a busy one for the Publications Committee. Thanks to dedicated committee members Linda Keder, Mike Larson, Suzanne Ceppos, Barb Dorn, Bob Hartnett, Rachel Tugon, Carolyn and Jim Loker, Scott Ditzman, and Hope Mays, among others, many new or revised and updated publications were produced over the year. Consider:

- *Medical Alert* brochure: revised and updated
- *Health and Medical Issues*: new collection
- *Birth to Three* booklet: revised and expanded
- *Handbook for Parents*: revised and expanded
- *Supporting the Student with PWS*: new audiotope package
- *The Early Years*: new collection
- *Health Care Guidelines*: new
- *PWSA poster*: new
- *Understanding PWS*, a training video for group home providers: new (by PWSA of Minnesota)

Many more projects are planned for the year ahead, including booklets for parents and for grandparents (see p. 3) and publications on infant nutrition, growth hormone, and residential staff training. Pam Tobler, a new board member, will join me as co-chair of this committee. Although we now have a large, productive committee, we welcome suggestions and additional help from any member who would like to become involved.

—Lota Mitchell, Chair, Publications Committee

Seeking Participants for a Study of Contact with the Legal System

by Barbara Whitman, Ph.D.

Over the years, I have been asked to intervene on behalf of a person with Prader-Willi syndrome who has "run afoul of the law." Additionally, I have heard other anecdotal reports of persons in legal trouble—or families contacted by the law for legal concerns.

I am conducting a study to determine the variety of reasons for which persons with Prader-Willi syndrome have had legal difficulties and how these issues were handled legally. This includes those of school age for whom the Safe Schools Act has been misapplied. A portion of this study will focus on families accused of abuse or neglect on the basis of Prader-Willi symptoms.

If you are willing to be contacted and interviewed, please notify Dr. Barbara Whitman at St. Louis University by telephone, 314-577-5609 (work), or by e-mail: WhitmanB@SLU.EDU.

In Search Of ...

Pakistani, Turkish Family

We have heard from a family in the United States with a Pakistani and Turkish background who are interested in contacting any other family with a similar background. Please contact the national PWSA office, if you fit this description or know someone who does. Telephone: 1-800-926-4797. E-mail: PWSAUSA@aol.com.

Translators

We are in need of people to translate PWSA materials into Spanish and other languages. If you have skill in this area or know someone who does, please contact the PWSA (USA) office. Telephone: 1-800-926-4797; E-mail: PWSAUSA@aol.com.

Single Parents

One of PWSA's new projects will be a collection on coping with being the parent of a child or adult with PWS. We want to break new ground with a section for single parents. Barbara Whitman, Ph.D., a behavior specialist, will be in charge of that section and would like to contact as many single parents as she can.

If you are a single parent and would be willing to participate in this project, please contact Dr. Whitman by telephone (314-577-5609, days) or e-mail (WhitmanB@SLU.EDU), giving your name, address, and phone number.

Prader-Willi Syndrome Center To Open in Baltimore, Md.

The University of Maryland Children's Medical Center in Baltimore announces the opening in September of a multidisciplinary center to serve the needs of children and adults with PWS. The new center will be operated in the Division of Pediatric Endocrinology under the direction of Debra Counts, M.D. Patient services will include genetics and genetic counseling, medical nutrition therapy, exercise physiology, endocrinology, and chronic disease coping, with referrals as need to orthopedics, ophthalmology, and psychiatry. Research on growth hormone in PWS also is planned.

For more information, contact the Prader-Willi Syndrome Center at 410-328-3410.

The ADA and Child Care Providers

Frequently Asked Questions

by Jacquie Brennan

Brennan & Associates – Attorneys At Law, Houston, Texas

Q *My daughter has Prader-Willi Syndrome and the day care center in my neighborhood said they can't accept her into their program because it's too much trouble. Can they do that?*

No, they cannot. The Americans with Disabilities Act (ADA), which prohibits discrimination against individuals with disabilities, specifically mentions day care centers in its list of public accommodations that are covered under Title III.

Q *What kind of discrimination by day care centers is prohibited?*

Day care centers cannot legally deny a child with a disability the opportunity to participate in, or benefit from, their programs. They must provide an opportunity to participate that is the same as it is for children without disabilities.

Q *The day care center told me that their liability insurance carrier told them that they cannot have children with disabilities on the premises. Is that a lawful reason for not admitting my child?*

No. The ADA prohibits any child care provider from refusing to serve a child with a disability just because of insurance coverage or rates.



Q *The day care center said that they would let my 4-year-old son with PWS attend their center, but they have a policy that all children must be toilet trained by the age of 3. Because of his mental retardation, he is not toilet trained yet. They say they can't change their policy. Is that fair?*

No. It is not fair and it is against the law. The ADA requires public accommodations, such as day care centers, to make reasonable modifications in their policies, practices, or procedures when necessary to avoid discrimination based on disability unless the modifications would fundamentally alter the nature of the program. In this case, the toilet training policy can be easily waived without changing the nature of their program.

Q *My child uses a wheelchair for mobility. We want to enroll him in an after-school program at a day care center near our school, but there is no ramp so that he can get inside the center. I asked the center about it and they said it would be too expensive to do that. Do they have to put in a ramp if I request it?*

Yes. In fact, they are supposed to put in a ramp whether or not anyone requests it. All places of public accommodation, including day care centers, must be accessible to individuals who use wheelchairs. The ADA provides very specific guidelines and requirements for ramps, parking spaces, doorways, and bathrooms.

Q *My child has PWS. I work a job that involves shift work, so I can't use a traditional day care center. I have been looking for individuals who keep children in their homes as an alternative to a day care center, but some of the people I've talked to have said that they are not equipped to handle a child who has a disability. I know that big day care centers have to accept children with disabilities, but does the same law apply to individuals who keep kids in their homes?*

Yes. Private residences in general are not covered by the ADA. However, when a public accommodation, such as child care, is operated out of the home, then the home is a covered entity and must follow the ADA. No child care provider, whether in their own home, a small center, or part of a large chain of centers, may deny services to a child because of a disability. Regulations issued by the Department of Justice require that all child care facilities, including those in private homes, be accessible to children with disabilities. In homes, the part of the home used to provide child care, as well as the path of travel and the entry, must be accessible, but the part of the home that is used exclusively as a residence is not covered under the ADA.

Q *As a parent of a child with Prader-Willi Syndrome, do I have a right to expect that a child care provider will respect my wishes regarding snacks for my child or not using food as a method of discipline?*

Yes, you do. Explain to your child care provider that your child has PWS and explain what that involves and why the issue of food is so important. If they

have a policy about a child not getting a snack if s/he misbehaves, then they must modify that policy for your child with a disability. If they reward good behavior with extra food or “better” food, instruct them not to do that with your child. Be sure to follow up on your instructions, particularly when new staff members are hired.

Q What should I do if my child has been discriminated against by a child care provider?

First, talk to the child care provider about your concerns. Sometimes good communications between the parent and the provider can solve the problem. If that doesn't work, you may want to consult an attorney who practices in the area of disability law so that the attorney can contact the provider to make the provider aware of the law in this area and see if an agreement can be reached. If that fails, you may contact the Office on the Americans with Disabilities Act, Civil Rights Division of the U.S. Department of Justice, or you may file suit in federal court.

LEGAL QUESTIONS?

Jacquie Brennan, who contributed these articles on child care (left) and food issues in the school (right), has volunteered to address other parent concerns in future issues of *The Gathered View*.

Jacquie enlarged her own family by adopting a little boy, who it turned out, has PWS. The experience led her to adopt four other children with disabilities and to earn a law degree, specializing in disability and school law.

You can reach Jacquie by phone at 713-522-1211, or by e-mail at: Law-Brennan@aol.com.

She also has a Web page:
www.LawBrennan.com

Food Fights At School!

Addressing Food Issues at School for Students with PWS

by Jacquie Brennan
Brennan & Associates – Attorneys At Law, Houston, Texas

- 1** If you have not yet told the school district the basic facts about Prader-Willi syndrome, do it now. The more educated school personnel are about PWS, the more help they can provide to your child.
- 2** Get brochures and booklets about PWS and education issues from PWSA and give them to every person who has contact with your child at school—from the regular education teacher to the principal to the special education teacher to aides to the music teacher to the cafeteria worker to the gym teacher to the janitor. Everyone should be informed. Obviously, a simple brochure or a one-page FAQ (Frequently Asked Questions) sheet you put together is plenty for most people to know, but teachers will probably need more information. Once you have educated the major players in your child's educational environment, it's time to seriously address food issues.
- 3** Address food issues at the IEP (Individualized Education Plan) meeting with all team members present.
- 4** Tell the team that your child should never be given food as a reward (it might surprise you to know how often this happens in many classrooms).
- 5** Tell the team that your child should never be punished by deprivation of food. Sometimes if students misbehave, they are not allowed the same snack as everybody else. Usually, this means they get a healthier snack, but it's still treated as a punishment.
- 6** Discuss a behavior management plan in the event that your child steals food. Food stealing/hoarding is a manifestation of PWS and should not necessarily be subject to the typical disciplinary rules.
- 7** School meal programs—both breakfast and lunch programs—are administered at the federal level by the U.S. Dept. of Agriculture (USDA). USDA reimburses schools for every meal served to students. Schools are required to make a reasonable effort to provide special meals to students whose diets are restricted due to their disabilities. 7 CFR § 15b.26(d)(1). These meals are provided at no extra charge. You pay the same price that is charged for the typical meal served.
To be eligible for the modified meals (these can be low calorie, low fat, or smaller portions, or any combination), a student must have a letter from a physician that includes a brief description of PWS, the need for dietary restrictions to prevent morbid obesity, what kind of meal modification you want, the caloric content you desire, and foods that are or are not acceptable. You can write the letter and just have your doctor sign it. Put this modification in the IEP.
- 8** Monitor!

Four mothers speak out: The power of thought ...

One and a Half

by Nancy Finegold, Flushing, New York

One of the hardest challenges facing any parent of a child with a disability is having the strength and the insight to view them as a whole person, a complete human being. For myself, this is a concept that I knowingly struggle with every day. In a strange, almost unexplainable way, the fact that my daughter isn't as active as most other babies, doesn't cry like they do, doesn't reach milestones at the same pace, and doesn't demand as much attention diminishes her worthiness in my eyes. I know this sounds like a terrible thing to have to admit, but if I'm really honest with myself, and really dig down deep within myself, I know that it is true. This is most likely true for the majority of "normal" people's view of the disabled world in general. When we see people with a disability, no matter what form that disability takes, we feel that they are missing some essential part of themselves that should have been rightfully theirs. We feel sorry for them, and this pity makes us uncomfortable. This results in a strong tendency to want to avoid disabled people, to not want to have to deal with them. When our own children evoke these kind of feelings, we feel guilty and ashamed, but the feelings are still real.

I became most aware of this shortcoming in myself a few weeks ago when someone at work, whom I hardly know and doesn't really know me, asked if I had any children, I casually replied "yes, I have two." As the words left my mouth I felt that I wasn't being totally honest with this woman. I had to fight back the urge to explain further. I wanted to say "I've given birth to two babies, but due to unfortunate circumstances, I really only have one and a half." Of course I kept this last part to myself, but it was there, hovering over me like a dark cloud, and I believed it sadly and strongly to be true. On some level, in my eyes, she is less than whole because she isn't what I expected her to be, what she should've

been. I realize that this feeling is at the root of many strong and difficult emotions that I have towards Dina. I feel that she is somehow not as important as my son, who is a healthy and rambunctious 3-year-old. I feel that she does not need or deserve as much attention, time and love as he does. The money I spend on her baby-sitter, doctor bills, and daily care is somehow on some level not as well-spent as the money I spend on my son. The time I spend with Dina playing with her, reading to her, and just trying to love her somehow seems to require more energy. There is always this little voice in the background asking, "What if I'm wasting my time?" I try to keep these feelings below the surface, to block them out and not recognize them. But these subtle and painful feelings do surface at times, and their existence shocks and angers me. This is how I feel about my own flesh and blood! What kind of mother am I?! A mother is supposed to love her children no matter what, unconditionally. The road that lies ahead of me is long. It will no doubt be a lifetime struggle to see my daughter as whole and perfect just the



Dina Finegold at age 10 months.

way she is. I need to believe in my heart that with all of her imperfections, she is just the way she was meant to be. She is her own individual person, beautiful, special, and worthy. Worthy of mine and everyone else's money, time, love, and respect. There are times when I look at her and for a brief moment I really believe all this to be true. I really know that she is her own beautiful talented little person, and that my life is so much more full and enriched with her in the world, despite the pain and challenges, and that I really do have two whole children. Those moments feel so good!

Hope Mays, executive director of PWSA's Georgia Chapter, recently attended and reported on a caregivers' conference called "Meaningful Days," which focused on enhancing the lives of adults with disabilities. She writes:

"More than one speaker talked about relationships and their importance to meaningful days and lives. ... I couldn't help but think about how as a parent I sometimes get caught up with the *business* of Clyde rather than the *essence* of Clyde. I try so hard to get his OT, PT, SLT, IEP and ETC organized that I forget to help him develop relationships. The speakers reminded us to get to know the person—yes, even our own children—by *listening*, with the ears, with the eyes, with the heart. Learn the person's likes and dislikes, find ways to incorporate those things into daily life, school, work, and relationships. ... For me, seeing beyond my son's syndrome took a number of years and has required a lot of growth on my part. I've had to research and learn about quality of life issues for people with disabilities. I've had to open my mind and think 'outside of the box.'" (Excerpted from The Georgia View)

—and of words ...

What's in a Name?

by Rachel Tugon, Louisville, Kentucky

Words are perhaps the most powerful tools used in the development of our self-image. Interestingly enough, most of those words come from other people. Words, both positive and negative, live in our memories and work together to paint the picture that we see of ourselves. To underestimate their importance is a mistake.

If we think of the words that are used to describe certain groups of people, we know that groupings are often made along ethnic and religious lines. We struggle when we try to decide any one thing all Americans or Chinese or Brazilians *are* or *believe*. It is equally difficult to define Christianity or Buddhism and make generalizations as to what these belief systems mean to individuals. Making broad generalizations and attempting to label people because of a single characteristic often leads to painful misunderstandings.

Prader-Willi syndrome is a genetic birth defect that brings with it a variety of issues. **It is something that some individuals have, not something that they are.** When we refer to our children or loved ones as Prader-Willis or PWS, we are defining them and limiting them in our own minds and theirs. By our choice of words, we are saying that all they are is Prader-Willi syndrome. Given, PWS is an important part of their lives, and many of the symptoms are present in a significant percentage of the population, but each person with PWS is a distinct individual with strengths and challenges all his or her own. We do a great disservice to those we love so deeply when we categorize them according to their disability rather than according to their abilities.

We do this unintentionally, usually as a time-saver when we are speaking to others about PWS. But we don't need to do it at all. Saving time cannot be as important as the negative effect our choice

of words could have on those we love so much. Take the time to talk about your "child with PWS" or your "daughter/son with Prader-Willi syndrome." Not taking the time to watch our words serves as reinforcement to the person with PWS that we believe that they are controlled by the traditional limits of PWS. Taking that time will contribute to everyone's understanding that although PWS is a part of his or her life, it is not all.

Yes, my daughter has Prader-Willi syndrome, but that is not all she has. She has the ability to reach out to strangers in a way I never could. She has beautiful eyes that light my path through the darkest days. She has hugs that bind our

hearts and give me strength to do whatever needs to be done. And she has a future and a life that will be influenced by, but not defined by PWS. I want to know that the words I have chosen to use, the words she will remember, have been chosen carefully, will build her up, strengthen and nurture her as she paints this picture of herself. For all she has given me, I can do no less for her.

Editor's note: Rachel Tugon is the mother of Erin, age 3, who has been featured in The Gathered View and in PWSA's Angel Fund campaign for 1998-99. Rachel serves on PWSA's Publications Committee.

Remember To Put the Person First

by Pat LaBella, Wisconsin Chapter President

The other day I ran into a mother and her small child at a ball game. The little girl had really white hair and pink eyes. It crossed my mind that this young mother might be feeling alone and isolated while dealing with her child's "differences." Thinking I could be of some support to the woman, I tried to establish some common ground. I said, "I have a daughter with a disability. I know how difficult it can be sometimes. Is your daughter an albino?" The woman was obviously frustrated but she patiently responded, "No, she's not an albino. She's a little girl who has a condition called albinism." I got the point. I apologized for my ignorance and thanked her for reminding me of what I already knew. The person is more important than the disability.

Hopefully, others can also learn from my mistake. Let's remember to put the person first when describing Prader-Willi syndrome or any other disability. I'm not a Prader-Willi mom." I don't have Prader-Willi. I am a mom with a child with Prader-Willi syndrome. We aren't "the Prader-Willi family." My daughter is not a "Prader" or a Prader-Willi." She is a person first and she happens to have a disability called Prader-Willi syndrome. One of my goals is to retrain myself to remember the uniqueness of each person and to be more person-sensitive and person-centered when I speak. How about you?

(Reprinted from The Wisconsin Connection, newsletter of PWSA of Wisconsin.)

May and June Donations

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Angel (\$100-\$249)

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Woodland Baptist Church (*In honor of Erin Tugon*)
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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.

