



# The *Gathered View*

April 1996  
Volume XXI, Number 2

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

## Conference '96 Update

*Speakers to include national, local experts*

**J**oin us "Where the Lights Are Shining" in St. Louis, Missouri, July 18-20...

The 18th Annual National PWSA Conference planning is well under way, and it looks like this year's event will be an exciting opportunity for everyone who attends.

Featured speakers will include:

- Janalee Tomaseski-Heineman, M.S.W., parent and past national PWSA president, delivering the keynote speech;
- Lota Mitchell, M.S.W., parent, *Gathered View* co-editor, and employee assistance program counselor, speaking on stress management;
- Jerry Ford, executive director of Arc of Missouri, past state legislator, and lobbyist, speaking on legislative issues;
- Louise Greenswag, R.N., Ph.D., speaking on Supplemental Security Income (SSI) benefits and how to establish eligibility;
- Jenny Vineyard, a public relations specialist, addressing strategies for positive public relations on the syndrome;
- Curt Shacklett, attorney and parent, speaking on legal issues; and

- Rev. Dennis Brodeur, Ph.D., St. Louis University School of Medicine, speaking on bioethical issues in genetics.

Among the other speakers lined up for this year's conference are: Scientific Advisory Board Members Merlin Butler, M.D., Suzanne Cassidy, M.D., Barbara Whitman, Ph.D., and Elisabeth Dykens, Ph.D.; PWSA (USA) President Jerry Park; Patricia Wheeler, advocacy specialist with the Missouri Protection and Advocacy office; and speech pathologist Marilyn Goldwasser.


In addition to the topics mentioned, there will be sessions covering growth hormone, early diagnosis, living alternatives, educational issues, behavior management, nutrition, psychological issues, and many more.

Also this year we continue the very popular "For \_\_\_\_ Only" sessions. For mothers, fathers, siblings, grandparents, and—for the first time—single parents only.


The Residential and Community Service Providers Workshop will be held on Thursday this year, concurrent with the family conference. It was moved from its previous Wednesday schedule in response to requests to make the Scientific Day Meeting (on

Wednesday) more available to service providers.

For 17 years, our conferences have gotten better and better. 1996 will prove to be no exception. Join us in St. Louis for fun, learning, and friendship.








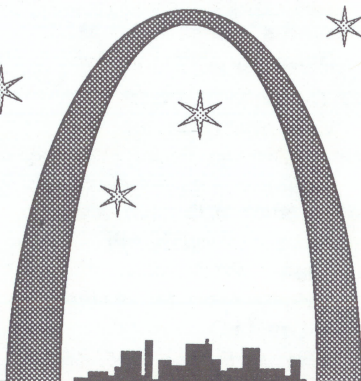
## MEET US IN ST. LOUIS



Deadline for early  
conference registration:  
**May 30**

For hotel and travel  
arrangements: Pat Mann,  
**1-800-784-7581**

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## Out of the Office ...

by Russ Myler, Executive Director



I have mentioned in past columns how much we have accomplished in our Association over the past 21 years. These accomplishments have been hard fought. We should feel proud. However, the future looks to be no easier for us and those we serve. Changes at the national level of government may result in us having to regain lost ground state by state.

If the current trend of turning control of service programs over to state-level decision makers continues, we will be faced with the task of convincing each state legislature of the need to include PWS in service provision. This will occur state by state and service by service. We must be prepared and ready for this eventuality.

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*Increase in number of members at both chapter and national levels is a vital component in developing a voice that legislators will hear.*

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To do this requires a strong national organization, adequately funded and staffed to be able to support strong chapters. Increase in number of members at both chapter and national levels is a vital component in developing a voice that legislators will hear. Like it or not, legislators are concerned with numbers. The numbers reflect the level of need, for one thing, but they also reflect the level of support the chapter and national have within the community. If there are estimates of 500 persons with the syndrome in a state, and the chapter represents 50, the legislators question the authority of the chapter to speak or make demands. Numbers count at both the local and national levels!

While the above speaks to advocacy, the other fact is that increased members means more persons will have the support of the Association and the Association resources available to them. I ask each of you to work to enlist additional members and past members to the Association. You will be doing it for all the right reasons.

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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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Communications regarding *The Gathered View* or PWSA membership should be directed to the national office of PWSA (USA), 2510 S. Brentwood Boulevard, Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797, or (314) 962-7644 in the St. Louis area. Fax (314) 962-7869. E-mail: [pwsa\\_usa@aol.com](mailto:pwsa_usa@aol.com).



# CAMPS...CAMPS...CAMPS...CAMPS...CAMPS...CAMPS

## The 'Boggy Creek Gang'— New Florida Camp with Connections

While its name may conjure up images of swamps and mosquitoes, the Boggy Creek Gang is actually a not-for-profit public corporation founded in 1989 to respond to the growing need for therapeutic camps in the southeastern United States. Besides our Florida PWSA Chapter, the Boggy Creek Gang has a few other notable connections. Its founders include actor Paul Newman and General H. Norman Schwarzkopf.

Newman became aware of the project in 1990 and generously provided seed money for the camp, becoming cofounder of the Boggy Creek Gang with Schwarzkopf and Theodore Forstmann. The organization is governed by a national board comprised of leaders from business, civic, and medical communities. This group of dedicated individuals has embarked on a \$15 million capital campaign to make the camp a reality.

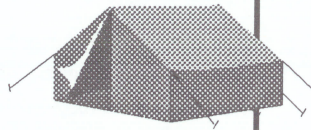
Although the camp is in its beginning stages, the first few campers were served last summer, and the Florida chapter is working with the organization to set up camp sessions for kids with PWS. Through a letter of intent, the Florida chapter has committed to providing camper and family referrals,

volunteers, funds for camper scholarships, and support with planning and program assessment for Boggy Creek campers with PWS.

The Boggy Creek Gang will provide a safe and exciting camp experience, along with medical support as needed, for children ages 7 to 17 with chronic diseases or other special needs. The Gang also plans to offer educational conferences, retreats, and family weekends to serve the needs of siblings, parents, and other family members.

The 232-acre campsite 40 minutes north of Orlando was provided by the Walt Disney Memorial Cancer Institute at Florida Hospital. At completion, there will be 16 camper cabins, a theater, medical center, dining hall, arts and craft center, and recreation center. Buildings serving the families will include group lodges and meeting facilities. The grounds will have a heated pool, nature center and little farm, horse trails, and two large lakes for canoeing and fishing.

For more information about the the Boggy Creek Gang Camp, contact Florida Chapter President Roda Guenther, 853 Monticello Ct., Cape Coral, FL 33904. Tel.: (941) 542-6406.



## PWS Week at Wonderland Camp Rocky Mount, MO

**June 23-28, 1996**

Open to children and adults  
with Prader-Willi syndrome  
Fee: \$285

To register for camp, contact  
Allen Moore at Wonderland  
Camp, (573) 392-1000

To register for transportation to  
and from the airport, or to find  
out about financial aid for  
Missouri campers, contact:  
Jan Wallis, (314) 542-1159 days  
or (314) 978-1120 evenings

Group home residents who will need  
extra supervision at camp should  
bring a staff person with them  
(attendants pay for meals only)

## Pittsburgh Rehab Summer Services

The Rehabilitation Institute of Pittsburgh (TRI) provides a year-round crisis intervention program for children and adults with PWS, focusing on motor skills, weight loss, and social adaptability in a recreational setting with highly skilled therapists. Families with school-age children often try to schedule a needed visit to "The Rehab" during school vacation. Summer stays average 28-30 days, based on the severity of the child's medical and behavioral condition. Average age during the summer is 8 to 21, but participants of all ages are accepted throughout the year.

Admissions are ongoing, and TRI attempts to group summer participants by age. Admission to TRI requires an application and consent form, a physician referral, and a funding source. TRI is a Medicaid provider for these states: MI, NJ, NY, OH, PA, and WI; and they are glad to assist families in working with their insurance company or Medicaid provider. For more information, contact Ken Smith at TRI: (412) 521-9000.

*Looking for a summer camp  
for a special child?*

*Know of a good camp or  
program you could  
recommend to others?*

*Call the national PWSA  
office—1-800-926-4797—  
and help make this the best  
summer ever for someone  
with PWS!*





## Chapter Notes

Chapters are buzzing with a variety of meetings and activities this spring, many of which will be over by the time you receive this newsletter. Especially exciting are the conferences. They popped up all over in 1995—north, south, east, and west—and more will be happening again in 1996 in many spots in the nation, some with the same sponsors, others with new ones. But every one of them adds to getting the word out about Prader-Willi syndrome, and every one of them helps people in the area get in touch with one another for information and support. Right on!

◆**Prader-Willi Florida Association** has a spring meeting with a full program of information and fun slated for May 3-5 at the Admiral Golf Resort in Lehigh, near Fort Myers. Contact: Roda Guenther, (941) 542-6406.

Florida, by the way, is hosting the 1997 PWSA (USA) national conference the week of July 16-20 in Orlando and is already hard at work making plans!

◆**PWSA of Ohio** will meet on Saturday, May 18, at Columbus Children's Hospital at 9:00 a.m. There will be two speakers: one on developing a supported living home and one on special education issues. Contact: Pat Shiley, (216) 741-6778.

◆**PWSA of Maryland & Metropolitan Washington** will hold a spring meeting on May 4, with an information fair about area recreation and activity programs and a group craft project and celebration for

the kids. Contact: Linda Keder, (301) 384-4955.

◆**PWSA-Missouri** holds a monthly support group meeting at Cardinal Glennon Children's Hospital in St. Louis. Right now they are busily working on the 1996 PWSA-USA National Conference to be held in St. Louis on July 17-20. They would welcome anyone who wishes to volunteer their time to assist on any committee. Contact: Jerri Evetts, (314) 391-7118, or Paula Kollarik, (314) 931-0920 or 1-800-222-7623, x7401.

◆**Prader-Willi Syndrome Project of New Mexico** hosted "A Conference for Families of People with Prader-Willi Syndrome" in Albuquerque on March 22-24. Contact: (505) 345-4911 in Albuquerque or 1-800-794-7970.

◆**The Prader-Willi Alliance of New York/PWSA of New England** Joint Conference in Albany is a two-day affair on April 26 and 27, with speakers on a number of important topics relating to PWS. Contact: 1-800-358-0682.

◆**PWSA of Pennsylvania's** spring meeting on Saturday, April 27, at Millersville University has a dual purpose of fundraiser for Awareness Day and a parent meeting with a guest speaker on behavioral concerns. Contact: Deb Demko, (717) 624-2977.

◆**PWSA of Wisconsin** met in Sun Prairie on March 9 and will sponsor a Spring Dance on April 20. Contact: Barb Dorn, 1-608-845-9597.

## Laura Baker School in Minnesota Announces Residential Openings, Medicaid Eligibility

Laura Baker School, a nationally known residential service provider that has served individuals with PWS for the past 10 years, has sent PWSA chapters notice that they received their ICF/MF certification on Jan. 1, which permits federal Medicaid funding for out-of-state placements. The facility currently has openings and plans a second living unit dedicated to PWS.

In addition to residential placement, Laura Baker offers Crisis and Transitional Services for people with Prader-Willi syndrome. Crisis services generally last under six months, while transition services for health, behavioral, educational, vocational and/or residential concerns may last several years but are not intended to be permanent. Short-term respite stays also may be available. For more information, contact Sandra Gerdes, Director of Admissions, Laura Baker Services for People with Prader-Willi Syndrome, 211 Oak St., P.O. Box 611, Northfield, MN 55057. Telephone: (507) 645-8866.

## 2nd Annual PWS Service Providers Conference

**June 20-22, 1996  
Bethesda, Maryland**

Prader-Willi Syndrome Professional Associates, The Prader-Willi Forum, and *Prader-Willi Perspectives* announce their second joint conference, to be held June 20-22 at the Holiday Inn Bethesda, just outside Washington, D.C.

Speakers include Dr. Suzanne Cassidy of Case Western Reserve University, Drs. Elisabeth Dykens and Robert Ho-dapp of U.C.L.A., staff of the Rehabilitation Institute of Pittsburgh, and a residential panel moderated by Pat Cormier of the Gilbough Centers.

Conference registration is \$110 each for professionals and \$85 per family (two persons), with discounts for additional registrants from an organization or family. Lunch is \$18.50 per day. For more information, contact: 1-800-358-0682.

### The Brain and Tissue Banks for Developmental Disorders

*To obtain information about tissue donation and advance registration, or to report the death or impending death of a family member with PWS:*

#### Northern United States

**1-800-847-1539**

Sally Wisniewski, B.A.  
Project Coordinator  
University of Maryland

#### Southern United States

**1-800-592-7246**

Elsa Robinson, R.N.  
Project Coordinator  
University of Miami

*For guidance on which bank to call or to speak with a PWSA scientific advisor about PWS research and the need for tissue, call:*

David Ledbetter, Ph.D., or  
Ann C.M. Smith, M.A., CGC  
National Institutes of Health  
(301) 402-2011



lieving that if they choose to participate, the siblings of these special kids receive a special gift of insight...but it's not really a gift. It has been paid for with years of learning to live and love in a situation that may often seem unfair and often be challenging. My conversation with Jerry reminded me of how important it is to be able to connect with others. I felt great pride for the work of Jerry and Penny Park and for the influence it has had on their children.

The conference was a time for us to become closer as a family. In everyday life our needs are so individual, but from the very start we had a common focus for this trip. Before we left, Lindsey got mad at Casey and said to me, "I wish Casey wasn't even going." I said, "If it wasn't for Casey, none of us would be going." "Oh yeah," said Lindsey, laughing at herself. Even with all the conference activities, there were still intimate family moments—like when Lindsey called me into the hotel bathroom, peeked her head out from behind the shower curtain, and asked, "Mom, I was just wondering...how do snakes have sex?" Where are those public television specials when you need them?

For me, the very articulate Sally Underwood [an adult with PWS who spoke at the conference] summed up the "other side" of the picture with her story. So often we find comfort as parents sharing our stories...the locks, leaving home, dependents...in trouble again. It is hard to live with...difficult to manage...we are busy, busy doing our job as parents looking out for our children. Sally's words were, "My mom can be so frustrating!" It was a reminder that there are two sides of the story. I get caught up in the side I live. The parent side. More than once at the conference I saw the other side. One of those times was at the dance. A young man was going around from person to person asking, "Do you have Prader-Willi syndrome?" When he came to my son, he asked...Casey said "yes"...and he reached into a plastic bag full of papers. He handed one of them to Casey. It had his name, address, and phone on it and one sentence: "I would like to get to know you better." His name was Michael, and he shared with me that he is 17. His dream is to go to school to become a nurse so he can help others with PWS.

Casey was asked to dance by the beautiful Katherine. It was the first time I had seen him blush. Katherine had been to the conference before. Her mother had emphasized to Katherine to dance with several friends, but Casey didn't care...he did not take his eyes off "his" date. He was "in love" and Katherine will be a part of his vocabulary for quite a while.



Casey at the dance with Katherine Baker (above) and dreaming conference dreams with sister Shanna.

It was strange to feel like we were on vacation while being surrounded by the syndrome. You'd think that would be a contradiction! There were constant "reminders" of PWS realities. As we entered the hotel after going out for dinner, I slowed down upon seeing a young woman in front of the hotel unescorted. "Where did you go?" she asked, following us back inside. I was carrying a paper bag full of extra clothes. "Out to dinner," I said. She eyed the large bag and asked, "Do you have any leftovers?" I remembered how often I tell my kids, "It doesn't hurt to ask"...and our kids with PW are never afraid to ask! Although it's embarrassing, it can be humorous, too.

After the "Fathers Only" meeting, Lonnie departed chuckling. Geoffrey Willott had raised his hand to ask a question, stood up, and said, "How do you lock up the apple tree?" What a relief to meet parents with older dependents with PW whose sense of humor had survived!

By the time the last day of conference rolled around, I might have expected the hotel staff to be irritable, but the opposite was true. They remained patient, courteous, and respectful throughout the conference—from the person bringing in the

bags to the guy in the gift shop. I asked the gift shop manager how things were going. He shared with me that the staff had been educated about the syndrome prior to the conference. He had one adult with PW come in and place a camera, a pack of gum, and two large chocolate chip cookies on the counter. The manager asked, "Are you sure you can have those?"...And that's all it took..."He

knew," so the cookies were put back without a problem. "Everyone has been so accommodating," I said. He said to me: "These four days will be something we all remember. We've been educated about something new, and I believe the impact of that will last a lifetime." It was time for my eyes to tear up. Maybe with awareness, the road won't feel so lonely.



I certainly hope we have another opportunity to experience another conference. This one did amazing things for us. It was a kind of beginning for us. The beginning of some shared understanding. Thank you! ♦

*SueAnn and Lonnie Belknap, Casey and Lindsey Cronn, and Shanna Belknap*

## Conference Registrants

You can help other families in need experience the joys of attending their first PWSA conference!

On your registration form, specify an amount you wish to contribute toward the conference scholarship fund, and add it to your total.



# Being a Dad

by Mike Larson, Wisconsin Chapter President and father of Alex

I remember the day my son was born. Driving home from the hospital late that evening, I was immersed in the miracle of life that unfolded before me that day. So many things raced through my mind that evening, but there was one driving feeling that has never diminished since that first day—the feeling that there was a great gift deep within my son. He had a potential to do just about anything in this world. There were no limitations. He would have all the advantages to fully develop his talents and make a difference in this world. I felt he had the potential to surpass any dreams I could imagine.

Seven weeks later, shortly after leaving the hospital, we received his diagnosis of Prader-Willi syndrome. I'm sure I don't need to tell the other parents of children with PWS how devastated we were. All of the dreams that I had formulated for years, ever since I was a small boy thinking of when I would be a dad, were dashed before my eyes. The following several months were to be one of the lowest periods in my life. There was a lot of self pity, concern for the immediate medical issues of caring for our son, and the unknown of what life was going to deal each one of us down the road. Grieving over the lost dreams was very painful. It still is. I'm not sure if I will ever be over the pain. But I love my son more than life itself. Through it all, I had to try to be the best dad I could be. I did not want to miss an opportunity that could benefit him.

After a while I realized that new dreams could be made. They were different than the first dreams I had made, but it was important to me that they be there. Through the past months I felt I had been broken down into the most basic of elements. At times it was difficult to see myself like I was. However, throughout this process there was one thought that never died. From that first

day, I never lost the feeling that my son would have a purpose in this life and he would make a difference in this world.

I believe that there is only one who knows what our true purpose is on this earth. I may never know what my son's or my own purpose is, but I see many things most every day that astound me about how much insight my son has for living. My son is 3 now, and I can't explain how someone who has lived for three short years can teach me what life is about. He has shown me what my life's priorities should be, what the rewards for perseverance and

personal accomplishments are, giving unconditional love, and having fun. He can warm the coldest of souls and brighten the day of all he meets. Already he has touched and altered the course of many lives. He is teaching others as he has taught me. Maybe this is his purpose; I don't know. What I do know is that he has made a difference in my life and others who know him. But still deep down I feel there are much greater lessons to come.

I still cycle through periods when I am afraid of what the future will hold for him. Most parents probably feel this. I want the best for him. And, most of all, I wish for him to have and live out dreams of his own. ♦



## On Fathers and Disability...

"There isn't much research on fathers and even less on fathers who have children with disabilities," according to the Beach Center on Families and Disability, a federally funded research and information center at the University of Kansas. In its Winter 1995 newsletter, the Beach Center reports the following discoveries about dads:

"What is known is that fathers of children with disabilities think of themselves as pretty much the same as fathers of children without disabilities. They both spend about the same amount of time caring for their children and generally take on the role of playmate rather than caregiver.

"As strong influences on the child and family unit, fathers affect their children's cognitive, personal-social, and sex-role identification development. Children who have positive relationships with their fathers tend to have higher achievement, motivation, cognitive competence, and better social skills.

"Fathers who view their children with disabilities positively also encourage mothers in their child care activities.

"Factors that influence a father's relationship with his child include the parents' employment, their personal and cultural characteristics, and the child's traits (including temperament and gender).

"Service providers should value the participation of fathers and other male family members. They should also recognize that every male in a child's life has strengths and these strengths play a major role in family functioning."

**For more information about the research**, and to get on their free mailing list, contact the Beach Center on Families and Disability, 3111 Haworth Hall, The University of Kansas, Lawrence, KS 66045-7516, Tel: 913-864-7600, E-mail: BEACH@DOLE.LSI.UKANS.EDU.

**Sources of support for dads** include: **National Fathers' Network**, The Kinderling Center, 16120 NE Eighth St., Bellevue, WA 98008, Tel: 206-747-4004 or 206-282-1069; and an Internet bulletin board called **Dadvocat**, E-mail to subscribe: DADVOCAT@UKCC.uky.ed.

*Uncommon Fathers: Reflections on Raising a Child With a Disability* (1995) is a book of essays written by fathers for fathers, available from Woodbine House (800-843-7323) for \$14.95 + \$4 shipping & handling.



## IEP Know-How

Under the federal Individuals with Disabilities Education Act (IDEA), which is still awaiting reauthorization in Congress, parents have the right to participate in developing their child's IEP, or "Individualized Education Program."

The IEP team meeting, typically held in the spring to plan for the following school year, has three purposes: to identify the student's educational needs, to write broad goals and specific objectives for the coming year, and to select the educational placement where those goals can best be met. Parents know their child best and certainly understand Prader-Willi syndrome better than most school staff they will encounter, so their participation is critical to achieving the best IEP for their child.

Being prepared is key to being an effective member of the team. In addition to being a careful observer of the child's behavior and knowledgeable about PWS, parents need to become informed about their rights under both federal and state laws and the ins and outs of their local school system. That's a tall order—but there are several reassurances for parents who are new to this: There are many resources to help you become informed; IEP meetings become less frightening with experience; and no IEP is cast in stone. In fact, there can be as many IEP meetings as necessary during a year to monitor progress or change the plan.

The National Information Center for Children and Youth with Disabilities (known as NICHCY) has helpful *free* publications on special education (See box at right.) Most of NICHCY's publications are also available on the Internet (address: [gopher.aed.org](http://gopher.aed.org)). From the AED menu, select "6—Disability Services."

Your state Parent Training and Information Center also can be a valuable source of guidance, both on education laws and on the local school system. Parents who don't know where to find the nearest parent training center can ask their PWSA chapter leaders, call NICHCY at 1-800-695-0285, call the

state education department, or consult the "1996 Resource Guide" published by *Exceptional Parent* magazine (\$9.95 + \$3 shipping, 1-800-535-1910).

In the April 1995 issue of *Exceptional Parent*, attorney and parent Barbara Ebenstein offered parents strategies for effective IEP involvement. One of her points is to "Work things out before the annual review." She explains that "The best annual review is a short meeting in which the committee gives approval to what has already been decided."

In order for it to work that way, parents need pre-meeting access to their child's assessments and proposed goals and objectives. Likewise, parents need to have made their own observations of the current and possible next placements and shared their thoughts and views on the child's needs weeks before the meeting.

Some of Ebenstein's other tips are:

- Keep written records of every dealing with the school district, including notes on phone calls and dates you sent documents.
- Get letters from doctors, therapists, etc., to document needs that have not been addressed.
- Make sure your child's classification or disability code (required in many states) is appropriate for the services and placement needed. (Although placement decisions are supposed to be based on the IEP, some are still made based on the disability.)
- Be sure school assessments accurately reflect your child's performance; if not, request an independent evaluation.
- The IEP should state who is accountable for each educational objective.

### IDEA UNDER SEIGE!

As the *GV* goes to press, Congress is turning its attention to reauthorization of this important law. Critics are trying to suspend the law or dilute its protections regarding IEP objectives, discipline of students with disabilities, and attorney's fees for parents who win court cases. Parents are urged to tell your legislators how important IDEA is to your child, and insist that it not be weakened!



## Information Resources for Special Education

### FREE BOOKLETS

Call NICHCY, 1-800-695-0285

*"Questions Often Asked About Special Education Services,"* LG1, September 1994 (7 pages)—a brief introduction for anyone new to special education.

*"Questions and Answers About the IDEA,"* ND21, September 1993 (15 pages)—an overview of the mandates and requirements of the Individuals with Disabilities Education Act.

*"Individualized Education Programs,"* LG2, March 1994 (23 pages)—a detailed explanation of the IEP process, including excerpts from the federal law.

*"Related Services for School-Aged Children with Disabilities,"* ND16, Vol. I, No. 2, 1991 (23 pages)—explains the rights to services such as speech therapy, occupational and physical therapy, school health services, counseling, transportation, etc.

*"Planning for Inclusion,"* ND24, July 1995 (31 pages)—an overview of the issues and strategies, lists of references and resources.

*"Transition Services in the IEP,"* TS8, March 1993 (27 pages)—explains the requirement that the IEP include a statement of transition services for students who are age 16 or older, and younger if appropriate.

*"Helping Students Develop Their IEPs,"* TA2, and *"A Student's Guide to the IEP,"* ST1, including audiotape and booklet—guides teachers, parents, and students in promoting student involvement in developing the IEP.

### BOOKS

There also are several current books on special education that parents and professionals will find helpful. They may be found through a library or bookstore or purchased directly from the publishers:

*Negotiating the Special Education Maze: A Guide for Parents and Teachers* (2nd ed., 1990), by Anderson, Chitwood, and Hayden, Woodbine House (1-800-843-7323), \$14.95.

*You, Your Child, and "Special" Education: A Guide to Making the System Work* (1993), by B.C. Cutler, Paul H. Brookes (1-800-638-3775), \$22.00.

*Deciphering the System; A Guide for Families of Young Child with Disabilities* (1993), by Beckman and Boyes, Brookline Books (1-800-666-BOOK), \$21.95.



# A First Conference Experience

## 'The beginning of some shared understanding'

*SueAnn Belknap from Corvallis, Oregon, whose family received a grant to attend the 1995 PWSA conference in Seattle, sent this article with the following note to the conference grant committee: "This is a heartfelt thank you for covering the cost of the hotel, our registration, and the youth program for our three children. I'm excited to share with you our family experience. It was positive beyond my expectations! It was the first family vacation we've had."*

When we entered the Doubletree Suites Hotel, my first thought was that it was the first time my children had stayed in a hotel. I imagine it put their expectations of a hotel out of proportion for any future trips we might take at a Motel 6...it was beautiful. Lonnie announced to the kids, "Now, when we go to the conference in the morning, don't leave a bunch of stuff on the beds because the hotel maids will come in to make them." Casey, my son with PWS, asked in all seriousness, "Will they tuck us in, too?" The girls laughed, but he waited patiently until I told him "no," that was still my job.

We had driven six hours from Corvallis, Oregon, in an unair-conditioned Toyota. The three kids sat squished together in the 100-degree weather for the entire trip. It was to be expected that they would be cranky and restless. As we got ready to go to the "social" get-together, they fussed and whined.

We walked into the meeting place. People were dispersed at tables, some glancing around for familiar faces; others just watched people enter. While we adults kept to ourselves for the first few minutes—I timed this on my watch—it took Casey four minutes to begin socializing. Within 10 minutes he was surrounded by four young women playing a customized version of tic-tac-toe that included some sort of hidden dragon. They were in their own world, laughing and talking.

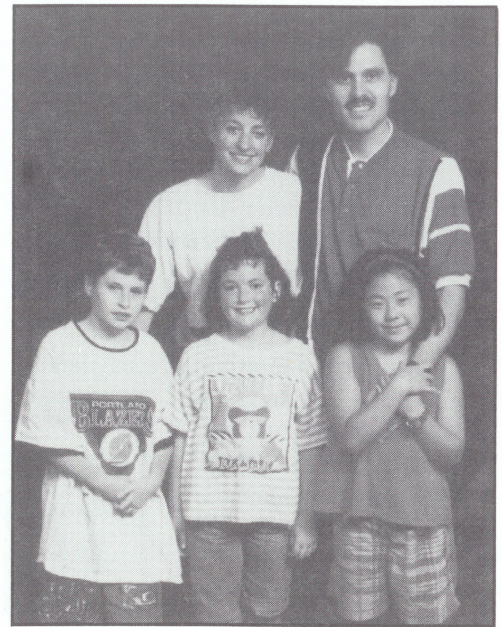
When Casey was 6, he asked me why he could not eat all the food he wanted. I said, "because you have Prader-Willi syndrome and it would hurt you." I had only known for two years that he had the syndrome and was still struggling with its limitations myself. I thought Casey would not really understand until he was 10 or

older what having PWS would mean. But, at 6 years old, Casey's eyes filled with tears and he sobbed, "I don't want Prader-Willi syndrome—take it off!" I remember telling him, "Casey, do you know there are other children like you?" His response surprised me. He said, "Where are they? I want to see them." I promised Casey that someday he would get to meet other kids just like him. Then we talked about how each person is unique. I thought about that time six years ago as I watched Casey play tic-tac-toe, all smiles, with four kids "just like him."

I knew better than to interrupt this precious time for Casey, so I glanced around at the other adults glancing back at me. A woman near me had a name tag indicating she was from Boise, Idaho. Five years ago some friends of mine in Boise sent me a newspaper article on a woman in Boise with a young daughter. She wanted to start a PW support group. I called and talked with her once. I took a chance—"Were you in the Boise newspaper five years ago?" It was her! Her name is Robbie Johnson. We ended up seeing each other throughout much of the remaining time in Seattle. She had been through many of the challenges I had faced when I was a low-income single parent.

One of the miracles of this trip took place with my daughter Lindsey. One of the main reasons I wanted our daughters there was so they could get to know some other siblings. What started out as a brief introduction between Lindsey and Kirsten [a girl her age she met at the social] developed into a special bond over the duration of our stay. They were inseparable.

I had been very concerned about Lindsey. One day last year when I picked



The Belknap family in Seattle: SueAnn and Lonnie, Casey (age 12), Lindsey (7), and Shanna (10).

her up from school, she had blurted out to another child in the hallway, "I have a retarded brother." "Why did you say that?" I asked. "Well, I do," she said. She was also struggling with the idea that she [younger than Casey] was becoming the "big sister."

Shanna lives with her mother and visits us every other weekend. She handles being with Casey really well, but when an impromptu sibling workshop formed, she had things to say! Normally, she is a bit shy, but she had no trouble talking about Casey looking in her bags for her toothpaste or treats when she comes to visit. Both girls emerged from this trip feeling closer to each other. They are also less stressed with Casey.

That same day I turned to Jerry Park, the current Association President, and said: "I came here with many concerns for the challenges my daughter will face having a brother with PWS, but I was so impressed by the young people who spoke on being siblings today—especially Ross, since he was asked at the last minute to speak. I found myself thinking that in his teens that young guy has learned what has taken me 35 years *plus* raising Casey for almost 13 years to learn...he already knows." I was confused by the hint of tears in Jerry's eyes. He responded: "We never really knew how he felt about things. Until this year he didn't talk about it much." I didn't realize that I had been talking to Jerry about his son. I left be-



## Ask the Professionals

**Q:** Has hypnosis been tried as a means of reducing the food-seeking or other behaviors, such as skin-picking, in people with PWS? If so, with what results?

*Barbara Y. Whitman, Ph.D., responds:*

**A:** I have no experience with its use for skin-picking, but I do have experience and some data regarding its use for food-related behaviors. In the early days when I worked with kids with PWS, I did indeed try several techniques such as relaxation techniques, imaging, and hypnosis for behavior difficulties and food. That was before I had come to fully understand the pattern of learning difficulties, and before we did the drug studies that lead us to certain brain pathways to be considered. None of the kids that I have worked with, nor those I know have had hypnosis tried as an intervention, have had any success or change in their eating behavior because of hypnosis. The reason, as we now know, is fairly clear: hypnosis is aimed toward the psychological unconscious as a means of changing behavior, and the food behaviors attached to PWS are physiologic in origin. Thus it would be reasonable that it wouldn't work.

I have had some success with the use of relaxation techniques as a way of dealing with both perseveration and escalating upsetness that would lead to a tantrum. Once these techniques are taught, if you can prompt the person to use them at the appropriate times, they can be quite effective. This takes an older child, adolescent, or adult usually to benefit from them. Meditation, needless to say, is not useful.

As for hypnosis for skin-picking, I would seriously doubt its usefulness, for the same reason. It appears that skin-picking occurs when the youngsters are upset or bored. I suggest looking at when the picking is occurring and making appropriate intervention. For instance, if it occurs when the person is bored, the answer is obvious. If when upset, give them something else to have

in their hands, such as a handkerchief to twist or silly putty to squeeze.



### Parent-to-Parent Tip:

To keep hands busy, provide the child with a length of "gimp" (plastic cord sold at craft stores), a Koosh ball, or other small, textured object that is age-appropriate and can be carried in a pocket as an alternative to skin-picking.

**Q:** How common are seizures in infants and young children with PWS? What is the treatment and prognosis for a young child who is having seizures?

*Suzanne B. Cassidy, M.D., responds:*

**A:** Seizures have been reported to occur in 5 percent to 10 percent of people with PWS. My experience has been that the figure is probably too high, and the incidence is more likely to be 2 percent to 5 percent. In the general population,

seizures occur in 3 percent of people, so it is unclear if there is an increase over background risk in PWS.

Like anyone, people with PWS can have seizures with fever. These are usually benign and frequently don't need treatment. In the few patients I have followed with a seizure disorder, the seizures tend to come on in the second or third decade of life, and tend to be relatively mild and easily treated. They can be convulsive seizures (called grand mal), absence seizures (called petit mal), or more uncommon types. Their treatment is the same in people with PWS as it is in the general population.

Seizures do not appear to change the prognosis or treatment of PWS.

*Vanja A. Holm, M.D., adds:*

I have encountered seizures in early childhood in PWS. In my experience they are not a common problem. Bryan Hall [M.D., former member of the Scientific Advisory Board from University of Kentucky] has suggested that seizure disorders are more common in this group than in the general population. I have no data to confirm or refute his opinion.

## Last Call for Growth Hormone Study Participants

The study of growth hormone in children with Prader-Willi syndrome, a joint project of St. Louis University and the University of Wisconsin, still has several openings for participants. Each research site can take an additional three or more children.

This may be the last opportunity for several years to enter such a study and receive growth hormone treatments at no cost. Since the enrollment period is coming to a close, all interested families are urged to contact the closest research team without delay. Contacts for the two sites are:

Missouri—Barbara Whitman, Ph.D., or Sue Myers, M.D.  
Telephone: (314) 577-5600, ext. 2443 or 3244

Wisconsin—David Allen, M.D., or Aaron Carrel, M.D.  
Telephone: (608) 263-5835



## The Lowdown on Olestra...

What are we to make of this new fat that doesn't make you fat? Will it be a godsend, a curse, or something in between for people with PWS?

In case you haven't read about it in the news, "olestra" is a man-made fat created by Procter & Gamble 25 years ago but only recently approved (Jan. 30, 1996) by the Food and Drug Administration and only for use in snack foods. Although it is a fat, its molecules are too large and tightly packed to be broken down by the intestinal enzymes and absorbed into the body. Foods cooked with olestra taste like they've been cooked with fat but have zero fat calories because the fat passes through the system.

Does this sound too good to be true? Some researchers and critics think so. The chief problem, nutritionally speaking, is that olestra takes out of the body with it some essential vitamins and nutrients that are soluble in fat, specifically vitamins A, D, E, and K, and certain carotenoids, such as beta-carotene. To prevent vitamin losses, P&G has fortified olestra with vitamins A, D, E, and K. It has not, however, added any carotenoids to olestra, since the role of carotenoids is not well understood and no minimum levels have been established. This is the issue that most concerns olestra critics such as the Center for Science in the Public Interest (CSPI), which has appealed the FDA approval. A second area of concern is that heavy use of olestra can cause gas, stomach cramps, and diarrhea in some people—but this turns out to be close to the percentage (about 2 percent) that have these reactions to existing snack foods. Products with olestra, however, will actually carry a warning label about the possible gastrointestinal problems.

Gail Overton, MSLN, a nutritionist and training coordinator for the Prader-Willi Syndrome Project of New Mexico and member of PWSA's board of directors, says she was "delighted" to see olestra heading for FDA approval. Noting that a third of all Americans are obese, Gail gives her recommendation on olestra in the Spring 1996 issue of the *PWS Project News*: "I believe food is the number-

one most abused substance in our society. I recommend the use of these 'fake' foods, including olestra, for persons with PWS. I think that, as with all things, moderation is the key; and if such a product is used wisely and not depended on solely to address the food-related issues of PWS, then we have on our hands another very appropriate product."

Bear in mind that, for now at least, olestra can be used only in snack foods such as potato chips, tortilla chips, and crackers. A 28-gram bag of potato chips made with olestra will be classified fat-free and contain 70 calories—versus 10 grams of fat and 160 calories for ordinary chips. Certainly, if someone is already eating regular versions of these products, a switch to the olestra version will cut calories and fat. Whether it's wise to add these products to the diet of someone who has not been eating such snacks and is not used to the taste and "mouth-feel" of fat is another question.

Olestra will appear under the trade name "Olean" and may show up in Pringles potato chips and other Procter & Gamble products as early as this summer. P&G also plans to market Olean to other food manufacturers. This may be just the beginning. According to a science report in *The Washington Post*, "Nabisco, Frito-Lay, Arco, Dow Chemical and other companies are working on their own designer fats, although none has been approved for use." ("Food Scientists Fake the Flavor and Feel of Fat," *Washington Post*, Jan. 11, 1995, p. H8)

### For further reading:

"Are We Ready for Fat-Free Fat?" by Michael D. Lemonick, *Time*, Jan. 8, 1996, pp. 52-61.

"Olestra, Procter's Big Gamble," by Myra Karstadt and Stephen Schmidt, *Nutrition Action Health Letter*, Vol. 23, No. 2, pp. 4-5. (CSPI, Suite 300, 1875 Connecticut Ave., N.W., Washington, DC 20009-5728, Tel: 1-800-237-4874 for subscription information)

"Olestra and Other Fat Substitutes (Revised)," background paper, free from: FDA, HFE-88, Rockville, MD 20857. (Item No. BG 95-18)

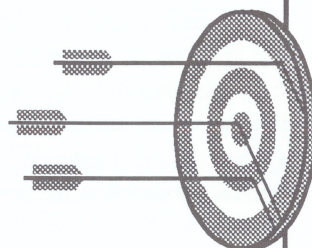
—Linda Keder

## Fat Replacement—Another Way

When you take fat out of a diet, there's no question the food seems dry and less satisfying. The answer to this problem, say authors Covert Bailey and Ronda Gates, is simple: add moisture. In their new book, *Smart Eating—Choosing Wisely, Living Lean* (Houghton Mifflin Co., 1996), Bailey and Gates offer the following ideas for making a low-fat diet more palatable:

- **Use lots of tomatoes**—chopped on potatoes and pasta, sliced on sandwiches, and cherry tomatoes in salads and on the side. "Tomatoes are a miracle food," they say.
- **Use lowfat cottage cheese** "on everything"—add a dollop to a bowl of chili or soup to enrich.
- **Gravy is great** for moistening a number of foods. While there are fat-free gravies on the market now, you can make a simple one at home with chicken or beef broth, some lowfat evaporated milk, a teaspoon of Butter Buds, a little cornstarch, herbs, and some garlic or onion powder.
- **Serve soup often** to add moisture to the diet.

*Smart Eating* espouses four "Target Principles"—Eat a diet that is: 1) Low in fat, 2) Low in sugar, 3) High in fiber, and 4) Balanced and varied. All fad diets can be measured against these four principles, the authors say. Their book offers a clever diet aid for the refrigerator door—a target divided into four equal wedges for the four major food groups, with the bull's-eye listing the "best" foods in each group and the outer rings containing foods with increasing amounts of fat and sugar and/or decreasing amounts of fiber. The advice, of course, is to "aim for the bull's-eye" as often as possible.





### It Helps to Know

*Harriet Thom of Prince Rupert, British Columbia, sent us the article below with the following note:*

"I thought other parents who have lost people with PWS might wonder about the wisdom of attending future conferences. ...I am therefore enclosing an article about my experience..."

"On a personal note, it has been a year today since we lost Trevor. We still miss him, of course. We probably always will. But life really does go on, and we are now able to enjoy many aspects which were not possible when we were dealing with PWS on a daily basis.

"There is discussion about the possibility of forming a Canadian National PWS Association. I am hoping that I will have the opportunity and continue to have the desire to be involved, and that way be able to assist in providing others with the support your organization provided when we were in need.

"Following the *Gathered View* article regarding Trevor's death, I am corresponding with three parents who are currently dealing with PWS and are seeking information about different aspects of Trevor's life. It helps to know that maybe Trevor's experiences might make some small improvement in the lives of others with PWS."

### *'Attending the conference after losing our son with PWS was the right decision for me ...'*

To attend or not to attend? Our son Trevor and I had looked forward to attending the Seattle conference (it would have been our third). We always enjoyed them. He died eight months before the conference. To go, or not to go. I waffled back and forth. I wanted to go, but at times was fearful of how I'd feel.

As the deadline for registration neared, my sister agreed to accompany me. My support system was in place. I decided to go. And for me that was the right decision.

Because of my hesitancy, I made reservations for only one of the three days. Before the end of the first day, I knew one day was not enough and stayed on. It was like going home to another family. The familiar faces. Renewing acquaintances. Sharing experiences. People who had acquired the same sense of humor (our lifeline to sanity).

Unexpectedly, I wanted to spend time with those with PWS. The conference is such a highlight for them—and they are on their best behavior. Lots of activities and the banquet in the evening provided the needed incentive for cooperation. Spending a day with two busloads of young adults with PWS was an experience I would not have missed. Their openness. Their acceptance. Their freely given affection. Their evident enjoyment of spending time with others who face the same problems. I was able to see in others the traits we had come to love in Trevor and was reminded of all the good times. I made many new friends with PW, two youngsters with whom I plan to keep in contact and hope to see again within the next year.

Our son's quality of life was significantly reduced at the end of his life due to health and restrictions necessitated by behavior problems. We miss him a lot, but I have been blessed with an early acceptance of his death. Seeing others who have similar traits, shapes, and the courage to laugh in spite of all the problems they face was an experience for which I am thankful.

For each one of us who faces the death of someone we love, the process is different. For me attendance at the conference was not only enjoyable, but an experience I would not want to have missed.

—Harriett Thom



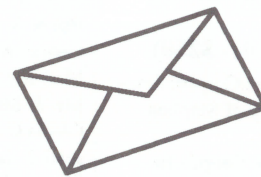
### Pen Pal Wanted

I have a 14-year-old daughter with Prader-Willi syndrome. We have no children near us with this syndrome. My daughter, Erin, would love to have a pen pal. Her address is:

Miss Erin Kilgallon  
115 Pleasant Rd.  
Norristown, PA 19401  
Tel.: (610) 275-5939

Anyone wishing to write or call, please do.

—Peggy Kilgallon



### A Warning About OTC Medications

Diana Baker of Burke, Va., called to pass along a warning to other families about the dangers of having over-the-counter medications accessible to the family member with PWS. Tums may be a good source of calcium, but they also tasted too much like candy to Diana's daughter, so she began taking more than her daily allotment. Then, she found the Tylenol ... Fortunately, Diana and her husband discovered tell-tale wrappings before their daughter did herself harm, but not before the pet cat had a seizure from eating a Tylenol capsule that was dropped on the floor. The moral of this story is simple: Many medicines look and taste too much like candy for our kids to resist. For their safety and that of their siblings—as well as the household pets—keep *all* medicines out of reach or locked away.





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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.

