



# The *Gathered View*

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

## Seattle Conference Sets Attendance Records

Registration for the 19th Annual PWSA (USA) National Conference, held in Seattle, Washington, July 20-22, broke the 700 mark, setting a new record for the number of parents, children, professionals, and service providers attending our national three-day meeting to share information, experiences, and friendship. Of the estimated 740 attendees (including 50 from Canada!), some 200 were participants in the Youth and Adult Activities Program (YAAP), and half of those were adults with Prader-Willi syndrome.

The attendance was not the only outstanding feature of this year's conference. For the first time ever, the conference was opened and closed by people with the syndrome, who told first-hand of their challenges and successes.

Some highlights of the meeting were:

- Sally Underwood, a "30 something," articulate woman with PWS, who resides in a group home in the Seattle area, set an upbeat tone for the conference Thursday morning with a 15-minute personal testimony. She talked about the value of group homes, her job, her relationship with her parents, and *her engagement to be married*, which led to a humorous repartee with the audience about her fiancé.

- Bill Dussault, estates and trusts attorney extraordinaire, held the audience in rapt attention for an hour and a half—and could easily have gone another hour—stressing the whys and wherefores of future planning—specifically the importance of special needs trusts, living wills, and selection of guardians for offspring with PWS.

- There were few dry eyes when a duo from the LDS Church sang "Look Beyond," a song first sung at the Salt Lake City PWSA conference.

- The YAAP agenda included a trip to the aquarium, a ferry ride, and of course a jam-packed dance floor Friday night. It won rave reviews from participants for the creative meals. (Featured were boxed picnic lunches that included fat-free potato chips and cookies and specially created menus at the restaurant where the group stopped to dine.)

- The conference closed with Craig MacDonald, son of Northwest chapter Presidents Angus and Nancy MacDonald, telling how he had earned his Eagle Scout badge—the highest Boy Scout honor.

To the Seattle conference committee, congratulations on an outstanding job!



### Parents of school-age children—

*Have you taken the following steps to get your child off to a good start?*

- ✓ Reviewed your child's IEP to make sure it is still appropriate?  
(Children sometimes make unexpected gains in the summer months, necessitating new goals and objectives.)
- ✓ Educated your child's teacher and other school staff about PWS and how to avoid problems related to it? (See page 9 for suggested materials to give or lend to the school.)
- ✓ Checked that all support services that are in your child's IEP are in place? (Don't assume that the school got the aide, the O.T., or the special desk your child needs—call or visit the school and make sure.)
- ✓ Shown your support for the school and your willingness to work with them to help your child succeed? (Join the PTA and find some way to volunteer, establish regular two-way communication with your child's teachers, and give compliments when the staff has done a good job!)

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## Welcome, New Board Members

Newly elected to the PWSA board of directors for a three-year term are:

**James Gardner**—President of the Minnesota PWSA chapter and the parent of a young adult with PWS;

**Gail Overton**—Health and Training Coordinator of the Prader-Willi Syndrome Project of New Mexico, licensed nutritionist, and author;

**Leo Schertz**—President of the Indiana PWSA chapter and the parent of a young child with PWS; and

**Ken Smith**—Program Manager of the Chronic Illness and Developmental Disabilities Program at The Rehabilitation Institute of Pittsburgh, Pennsylvania.

**Pauline Parent**—mother of a young man with the syndrome and a board member since 1992, was reelected to the board for a one-year term.

Our thanks for their work and dedication to those who left the board in July after completing their terms: D.J. Miller, Mildred Lacy, Paul Wissman, Annette Ruiz.

Paul Wissman is also stepping down as PWSA treasurer due to his work demands, and a search has begun for a new treasurer for PWSA.

## Awareness Day Wrapup—on to '96!

Don Goranson reported that a formal response was received from the White House to our letter with 1,832 signatures sent to President and Mrs. Clinton and that the governors of six states signed proclamations for PWS Awareness Day. In all, 26 of PWSA's 32 chapters participated in the first Awareness Day campaign. In addition to increasing awareness across the nation, at least 35 new individuals with PWS were identified as well as several new providers.

Lest we breathe a sigh and sit back on our laurels, Don tells us to get ready. Awareness Day and Week 1995 was so successful that there will be an Awareness Day and Week 1996. The dates are already tentatively set for April 27 through May 4.

In preparation, Don is requesting professionally done, current photographs of our children with PWS, chapter picnics and activities, etc. PWSA will pay for it. Particularly desired are before-and-after photos of persons with the syndrome. Call the national office for more information (1-800-926-4797).

## Chapter Presidents' Goals

PWSA President Jerry Park chaired the well-attended daylong session for chapter presidents and representatives. In addition to reviewing chapter Awareness Day projects and planning for the 1996 effort, chapter officials discussed:

—the need for fast information exchange with the na-

tional office through computers (a project in the works);

—proposed development of "SWAT" teams that would be available to come into a state and represent individuals, challenge laws, or support the state chapter's legislative or community agendas;

—the need for chapters to begin tracking known cases of PWS and the types of services and funding received, in order to have reliable data on incidence and costs that are needed for effective advocacy;

—ways to recognize/reward chapters for outstanding performance and projects; and

—the possibility of holding regional chapter presidents' meetings with national officials during the year.

Some chapter representatives also expressed the desire for more regional conferences in addition to the national conference.

**“Dear PWSA Conference Committee, Thanks for the superiest greati-est wonderful beautifulliest time I have ever had.”**

*—YAAP participant, Seattle conference*

## PWSA Membership Dues Increase in August

At its July meeting, the PWSA (USA) board of directors voted to raise membership dues by \$9 in each category, effective August 1, bringing individual memberships to \$30 a year. (See box on page 2 for other category rates.)

While this is a major increase, it is the first substantial one for PWSA since January 1987, when dues rose from \$15 for all U.S. members to \$20 for individuals, \$25 for families, and \$30 for professionals and organizations. We have increased dues by only \$1 in the intervening years (in 1992); meanwhile all of our expenses have increased by much greater percentages. If we're to continue handling the volume of calls that we do on our 800 line, producing *The Gathered View*, developing other quality information services, and increasing advocacy efforts, we need new income from several sources. Unfortunately, one of them must be member dues.

Although our new dues are not out of line with many other disability organizations, we know this will be a sacrifice for some of our members, and we ask your understanding and continued support. Please be assured that no one will be denied membership in PWSA because of inability to pay dues.





## Report from the International Conference in Norway

### Mildred Lacy Is Elected IPWSO Vice-President

At the Second International Conference on Prader-Willi Syndrome, sponsored by the International Prader-Willi Syndrome Organisation (IPWSO) this past June in Oslo, Norway, Mildred Lacy, parent delegate from PWSA (USA), was elected vice-president of the international board of directors. She will serve for a term of four years.

Conference attendees included 225 participants representing 24 countries and 15 children with PWS. The opening address was given by Dr. Andrea Prader, who with his colleagues identified the syndrome 39 years ago. Dr. Suzanne Cassidy, who played a leading role in organizing the scientific portion of the first international conference and is the PWSA (USA) professional delegate, gave the overview of PWS. Other presenters from the United States included PWSA Scientific Advisory Board members Louise Greenswag, Ph.D., Barbara Whitman, Ph.D., and Robert Nicholls, D.Phil., and Elisabeth Dykens, Ph.D., of Yale University.

IPWSO was founded in Holland in May 1991 during the first International Conference and registered in Sweden in 1993 as a charity organization. There are now 19 member countries and two associate member countries. To become a member, a country must have an active membership chapter. Each member country appoints one parent delegate and one professional delegate.

Among other objectives, IPWSO provides an arena for the exchange of international scientific information about PWS through its conferences and newsletters. A newsletter for parents is edited by Linda Thornton (New Zealand), and one for professionals is edited by Dr. Ellie Smith (Australia). The President, Jean Phillips-Martinsson (Sweden) travels to other countries to encourage the development of new national associations. The Swedish government provides funding for her travels and administrative costs.

Because of the geographical spread of the board, "meetings" are held by fax. (Mildred reports receiving an average of 4-5 faxes a month.) The next international conference will be held in Spain in 1998. PWSA (USA) looks forward to hosting a future conference (perhaps 2001?) for the international PWS community.

## Residential Providers' Meeting

The annual session for residential providers was facilitated by Louise Greenswag, R.N., Ph.D. The 85 attendees represented both "integrated" (serving a variety of disabilities) and "designated" (PWS only) group homes, as well as supervised apartments and other living options.

Providers are dealing with many issues: staff development, behavior management, integrating families into the process, and the myriad of agency, community, and government rules, regulations, and guidelines. There is a movement toward smaller group homes—down from 6-10 residents to just 2-3 residents per home—and different problems come with different sizes. Also, as time goes by, weight issues become secondary to behavior issues.

Only service providers attended this session. Past experience taught that parents' agenda of expressing their dissatisfactions interfered with providers' agenda of networking with other providers for information and resources. It is hoped that a dialogue can be negotiated in the future that will be mutually productive. However, providers recognized the importance of ongoing relationships with and input from the parents of their residents. Parents, on the other hand, should actively support getting information to providers, most of whom desire growth and learning. And parents need to realize that all is not perfect, and negotiation and compromise are necessary.

## The \$20 PWSA Long-Distance Calling Cards Sold Like Hotcakes!

### \$10 cards are still available

### *Great for college students & travelers!*

Each card is coded with a prepaid amount of long-distance calling time. Call from any touch-tone phone and follow the directions on the back of the card—avoiding bills, hotel charges, aggravation, and pockets full of change.

### Every card you buy supports your Association

Call now to order:  
**1-800-926-4797**

**(Cards expire in February)**



## Research

### Scientific Day Report

*While there were no major breakthroughs reported this year, a number of interesting studies on Prader-Willi syndrome were presented at PWSA's 10th annual Scientific Day. The Gathered View will present a capsule of one or two of these in each of the next few issues.*

#### **Menstrual period in Prader-Willi syndrome females**

*Research by Jeanne M. Hanchett, M.D.  
The Rehabilitation Institute, Pittsburgh, Pa.*

Dr. Hanchett reviewed the records of 106 females, age 15 to 63, who had been seen at The Rehabilitation Institute in Pittsburgh. Forty-six patients (43 percent) had experienced the onset of menstruation, 13 (12 percent) were given hormones to induce menstruation, and 47 (44 percent) had never had a period. Of those who had never had a period, most were under 20 years of age.

Of those who had menstruated, most began before age 25. The age of onset ranged from 7½ to 38 years, with three patients having premature menarche (before age 10) and one-fifth starting periods after age 25. Most patients had scant, infrequent, irregular menses; but several had excessive bleeding. Hormone treatment administered to regulate menstrual flow in many patients often was not successful.

#### **The prevalence and type of behavior problems and the contribution of extended family health histories and current family stress to such problems in persons with Prader-Willi syndrome:**

##### **A cross-cultural study**

*Research by Barbara Y. Whitman, Ph.D.  
St. Louis University School of Medicine, St. Louis, Mo.*

Dr. Whitman surveyed 80 families that attended 1994 PWS conferences—40 families in Australia and New Zealand and 40 families in the United States—to examine behavior problems of children with PWS in the context of their families. The ages of the children with PWS ranged from preschool to 35 in both groups. The U.S. sample included some persons now in group homes, whereas most in the Australia/New Zealand group lived in their family homes.

Based on a parent-completed questionnaire, 20 in the U.S. group and 12 in the Australia/New Zealand group were identified as having behavior disorders. The most common diagnosis was *neuroses—compulsive type* (found in 18 subjects). Others had signs of *attention difficulties* (9 subjects), *mild depression* (3), *somatization disorder* (2), or *psychotic disorder* (1).

There was no apparent association in these families between a family psychiatric history and serious behavior difficulties in the person with PWS; however, it did appear that conflict between the parents—both in general and with respect to child-rearing and discipline practices—did contribute to severe behavior problems.

### New Growth Hormone Study

An initial two-year grant to study the impact of growth hormone on persons with Prader-Willi syndrome has been awarded to researchers at St. Louis University and the University of Wisconsin by The Genentech Foundation. The two-site funding will launch growth hormone research proposed by Barbara Whitman, Ph.D., and Susan Myers, M.D., of St. Louis University School of Medicine in conjunction with that proposed earlier by David Allen, M.D., Richard Pauli, M.D., Ph.D., and David Bernhardt, M.D., of the University of Wisconsin-Madison.

The researchers hope to follow 20 to 30 children and young adults at each site over an extended period of time to gather systematic data on the impact and effectiveness of growth hormone on a number of growth and behavioral parameters. Specifically, growth, weight gain, lean and fat body mass, bone density, muscle strength, pulmonary function, and behavior will be evaluated. The study has been designed so that no eligible child will be denied the hormone, although some may have the hormones delayed for purposes of comparison to those treated from the start.

#### **Participants Needed**

Participants, both male and female, must be at least 4 to 5 years of age, with the upper age limit dependent on the degree of physical maturation as assessed by a bone age x-ray. They must be willing and able to travel to the research site about every three months and to complete all testing. These include physical exams and measurements, blood tests, x-rays, breathing studies, and behavioral interviews. Results of all assessments will be shared with the individual with PWS, their parents and other appointed caregivers, their family's doctors, and other professionals involved in their care to help them develop health management strategies.

***If you want your child to receive growth hormone and think that he/she may be eligible, please contact the research team nearest you for more specific information:***

Barbara Y. Whitman, Ph.D., or Sue Myers, M.D.  
St. Louis University Department of Pediatrics  
1465 S. Grand Avenue  
St. Louis, Missouri 63104  
Telephone: (314) 577-5600, ext. 2443 or 3244  
Fax: (314) 268-6411

David Allen, M.D.  
University of Wisconsin Children's Hospital  
(608) 263-5835

(Note: Wisconsin-area parents who have already contacted Barb Dorn to indicate their interest in the research do not need to reapply; the researchers will contact those on the original list.)



## Changes Coming in the Federal Special Ed Law?

As our children head off for another year of school, Congress continues its consideration of the Individuals with Disabilities Education Act (IDEA), the federal law that establishes the framework for special education services and grants states some funding toward providing these services.

Although Part B of IDEA—the state grant program—is permanently authorized and will not expire, it could be revised or repealed by Congress. Despite major attacks by some conservative groups (at the extreme end, the Heritage Foundation called for its repeal), IDEA is likely to survive but may receive little additional funding for Part B. According to the Council for Exceptional Children, Part B funds currently supply only about \$400 per student annually, covering a mere 8 percent of states' costs (the federal government originally was to provide 40 percent).

Parts C through H of the law, which cover early intervention programs, transition services, staff development, parent training, and other special programs and services, will expire if not reauthorized this year, and funding for these programs is in jeopardy.

### House Committee Cuts Support Programs

The House Appropriations Committee passed funding recommendations for IDEA on August 3, completely eliminating funds for special education staff development, research, information clearinghouses, early childhood education support programs, and new technology. Parent training funds, which also had been eliminated in the recommendations from the Appropriations Subcommittee on Education and Labor, were restored under pressure from advocacy groups. The Committee approved only slight increases in Part B and Preschool Grant funding, and maintained current funding levels for other IDEA programs.

At initial hearings held in May before a House/Senate committee, many national advocacy groups told Congress of the need for continuation of IDEA, increases in funding, and improvements to the law. Various advocacy groups recommended:

- changes to the funding formula to give school systems greater flexibility in providing services;
- including children with disabilities in school and state assessments, with necessary accommodations, in order to make educational systems accountable for their academic progress;
- increased federal funding for teacher training to successfully include more students with disabilities in regular classrooms;
- permitting use of funds for students *at risk* of needing special education support;

- and involving parents more in educational decisions through additional funding for parent training.

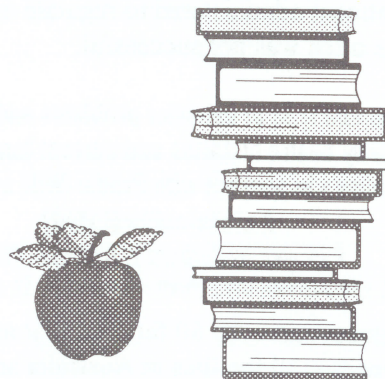
At those hearings, the lawmakers expressed general support for IDEA but voiced concerns about discipline problems, the high costs of litigation and the overly contentious nature of due process hearings, and a backlash against special education, according to *CEC Today*, the member newsletter of the Council for Exceptional Children.

### Next Steps

President Clinton has indicated that he will veto any bill that makes significant cuts in education funding. The Administration plans to introduce its own education bills in both houses of Congress.

The Senate has held hearings on IDEA and will take up the issue of program funding around the second week in September, according to sources at CEC.

Parents and other advocates for special education are urged to contact their senators now to communicate the importance of special education programs and their continued funding.



*Editor's note:* Membership in the Council for Exceptional Children is one way to stay on top of changes in special education. While primarily an organization for professional educators, CEC offers an associate membership to parents. For \$35 a year, members receive the monthly newsletter, *CEC Today*, and their choice of a bimonthly educational research journal, *Exceptional Children*, or *TEACHING Exceptional Children*, a quarterly magazine filled with tips and strategies for the classroom. Members also get discounts on publications (including CEC's *Special Education Advocacy Handbook*) and custom searches of the ERIC and Exceptional Child Education Resources databases. For membership information, write to: The Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589, or call 1-800-845-6232 (703-620-3660 in the Washington, D.C., area).

—Linda Keder



# Starting Middle School—

One family's approach to preparing a new school and staff for their daughter with PWS

When Stephanie Baker enters Mayfield Woods Middle School this month, she and everyone else will be ready, thanks to the groundwork laid by her parents, Bob and Peggy Baker of Elkridge, Maryland. If all goes according to plan, one week before school begins, the Bakers and their pediatrician will have the undivided attention of the school principal and assistant principal, their daughter's new regular and special education teachers, her key support staff (speech therapist, occupational therapist, and adapted P.E. aide), the related arts staff (art, music,

and P.E. teachers), the cafeteria workers, and even the school custodians.

First the medical doctor will present the basic information about Prader-Willi syndrome and answer school staff questions. Then Bob and Peggy—and possibly Stephanie herself—will give the staff more specific information about how PWS affects Stephanie and what the school team can do to prevent problems related to her disability. The doctor's presence provides a high level of credibility and reinforcement to their staff training, Bob explains. It's best to have a doctor who knows your child well, but, basically, any professional who knows about PWS is better than no professional when it comes to convincing schools about the needed measures, he says.

The staff training meeting is only one step in the process, however. The Bakers began last spring to prepare for Stephanie's transition to middle school by observing several times in the new school, meeting with the middle school guidance counselor and special education support staff, having the special education team leader from the middle school observe Stephanie and talk with her elementary school team, meeting with the new principal to set up the staff training meeting, and making sure Stephanie's IEP (Individualized Education Program) was appropriate for the next year. The Bakers often take a doctor with them to IEP meetings, as well, and this year they also engaged an independent educational consultant to review the IEP. The consultant helped them pare down the number of goals and make sure they were achievable and measurable.

Although all these professionals cost money, the Bakers say that it's worth it to ensure that Stephanie gets the supports she needs, especially her classroom aide, who monitors and assists her throughout the day and instructs her in basic life skills.

The Bakers have created a school information packet about PWS—including the *Management* textbook, a PWSA video, articles, booklets, and brochures—which stays at Stephanie's school for staff reference.

One final bit of strategy that the Bakers recommend is to be visibly involved in and supportive of the school. To that end, Peggy Baker regularly volunteers at her daughter's school—not necessarily in Stephanie's classroom, but often in the media center, which provides a central location from which to meet teachers and monitor school happenings. The Bakers have found that they can best advocate for their child when they know the school and its programs and can suggest ways for her to fit in.

—Linda Keder

## On Discipline and Expulsion

The question sometimes arises whether the behaviors associated with PWS can be subject to discipline or even expulsion from school if they persist in disrupting the classroom.

There is very little said in IDEA that directly relates to discipline and children with disabilities; however, Section 615 (e)(3) of the law states what is known as the "stay put" procedural safeguard, which has been applied by the courts in discipline cases. In essence, this part of the law says that a child's placement cannot be changed until the parents and the school agree to the change or, barring an agreement, a decision has been reached through legal proceedings. However, section 300.513 of the regulations governing IDEA adds the note: "While the placement may not be changed, this does not preclude the agency from using its normal procedures for dealing with children who are endangering themselves or others."





In *Honig v. Doe* (1988, 485 U.S. 305), the Supreme Court prohibited state or local school authorities from unilaterally excluding children with disabilities from the classroom for dangerous or disruptive conduct related to their disabilities while review proceedings are pending. The Court held that an expulsion or suspension of such a child for longer than 10 days constitutes a change in placement. Therefore, after the 10-day period the stay-put provision applies, and the child must be returned to her or his current placement. The child must remain in this placement during any due process proceedings unless school officials can show that "maintaining the child in his or her current placement is substantially likely to result in injury either to himself or herself, or to others." This ruling allows schools to seek court injunctions to prevent dangerous students from returning to the current placement after 10 days. The U.S. Department of Education has reinforced these provisions through policy letters and has proposed alternative discipline methods for students with disabilities—e.g., use of study carrels, timeouts, or other restrictions in privileges, to the extent they would not be inconsistent with the child's IEP.

(Source: *CEC Today*, Vol. 1, No. 3, June 1994)



## An Easy Formula for Packing a Balanced, Low-Calorie Lunch . . .

**① Start by choosing one item from each of these categories:**

			
Bread/Starch	Meat/Protein	Milk/Dairy	Fruit
Bread - 1 slice Diet bread - 2 slices English muffin - ½ Bagel - ½ large/1 mini Roll (small, plain) - 1 Pita bread (6") - ½ Rice cakes - 2 large/8 minis Lowfat crackers - about 5 Bread sticks (4" crisp) - 2 Pretzels - 8 three-ring/ 1½ pretzel rods Fat-free potato chips - 1 oz. Popcorn (air-popped, no butter) - up to 3 cups Tortilla - ½ large/1 small Graham crackers - 3 squares Animal crackers - 8 Diet pudding - ½ cup Waffle/pancake/muffin (small, lowfat) - 1	Lowfat lunchmeat (turkey, roast beef, ham, or chicken) - 1 slice Leftover cooked meat - 1 oz. Tuna or chicken salad (made with fat-free mayo or plain yogurt) - ¼ cup Cheese (lowfat or nonfat) - 1 slice or 1 oz. Cottage cheese (lowfat or nonfat) - ¼ cup Cream cheese (nonfat) - 2 tablespoons Peanut butter - 1 tablespoon Hard-boiled egg - 1 (Note: yolks are high in cholesterol and fat, so limit use.) Egg whites - Use cooked halves as containers for tuna salad, etc.	Skim milk - ½ cup (4 oz.)  Yogurt (nonfat, sugarfree) - ½ cup (4 oz.)  (Cheese and eggs are listed under Meat/ Protein)	<i>Fresh fruit:</i> 1 small apple, peach, or pear 1 large kiwi 2 small plums, figs, or tangerines 4 apricots ½ grapefruit, mango, or 9" banana 15 small grapes 12 large cherries 1 cup strawberries, raspberries, or melon (any kind) ¾ cup blueberries, blackberries, or raw pineapple Applesauce or canned fruit (in juice) - ½ cup Raisins - 2 tablespoons Dried apricots - 7 halves Fruit juice (citrus, apple, or pineapple) - ½ cup (4 oz.)

**② Then add two or more of these:**

Carrot or celery sticks Cucumber slices Pepper rings Lettuce leaf for sandwich Tomatoes Zucchini Broccoli or Cauliflower Mushrooms Radishes	Low-calorie diet dressing as a marinade for any of the vegetables at left  Mustard or ketchup Dill pickles Diet jelly/jam  Tomato or V-8 juice Diet beverages
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*Note: This chart is adapted from a 1994 PWSA conference handout. Based on the Exchange Lists published by the American Dietetic Association and the American Diabetes Association, suggested portions in the matching columns above are in most cases equal to:*

- 1 Starch (about 80 calories)*
- 1 Meat (55 to 100 calories)*
- ½ Milk (about 45 calories)*
- 1 Fruit (about 60 calories)*

*For greater precision in counting calories and exchanges, those preparing lunches are urged to read food package labels for specific serving sizes and calorie counts and to adapt quantities for each child or adult according to the prescribed diet.*

**Don't forget food safety! Refrigerate or use chilled thermal containers for dairy and meat products.**

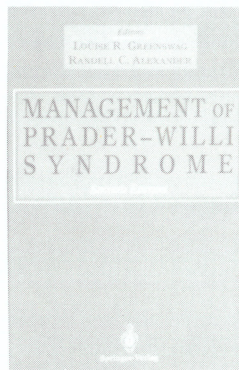


## Book Review

### Management of Prader-Willi Syndrome

Second Edition

Edited by Louise R. Greenswag and Randall Alexander,  
Springer-Verlag, 1995



Since the first edition of the textbook *Management of Prader-Willi Syndrome* was published in 1988, there have been breakthroughs in the genetics field, advances in diagnosis, and increasing use of growth hormones and psychotropic medications in the treatment of Prader-Willi syndrome. The newly released second edition, again edited

by Louise Greenswag, Ph.D., and Randall Alexander, M.D., offers an updated and expanded resource for professionals in a variety of disciplines as well as an essential tool for parents. Within its 393 pages is a wealth of information on every aspect of PWS.

In addition to covering the latest in diagnostic, medical, and genetic knowledge about PWS, the book includes chapters on education, speech and language, physical and occupational therapy, nutrition, dental care, behavioral management, residential and vocational programming, crisis intervention, family and sibling issues, and case studies. Among the 10 appendices to the book are sections on sleep disorders, growth charts for PWS, activity therapy guidelines, speech and language resources, behavior management programs, and vocational training.

While the language in some sections of the book is technical, parents will nevertheless find the answers to many questions in this volume. A glossary and reading list, as well as detailed chapter references, assist readers with technical terms and point them to sources of additional information. Parents will especially appreciate the chapter entitled "Two Families' Points of View." This is a book that should be on the reference shelf of every parent and professional who is dealing with PWS and one that parents can use to educate service providers who work with their children but who are not familiar with the syndrome.

*Management of Prader-Willi Syndrome* can be ordered from the national PWSA office for \$39.95 (PWSA member rate) or \$45 (nonmembers), plus \$3.50 for postage and handling within the U.S. (Orders from outside the U.S. will be invoiced for actual postage costs; payment in US Funds required.) Mail orders with payment to: PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326.

—Reviewed by Lota Mitchell and Linda Keder

### A Reading List for Teachers

**"Educational Considerations,"** Karen Levine and Robert H. Wharton, Chapter 11 in *Management of Prader-Willi Syndrome*, Revised Edition (1995), pp. 156-169.

**"Psychological and Behavioral Management,"** Barbara Y. Whitman and Louise R. Greenswag, Chapter 9 in *Management of Prader-Willi Syndrome*, Revised Edition (1995), pp. 125-141.

**"Speech and Language Issues,"** Debora A. Downey and Claudia L. Knutson, Chapter 10 in *Management of Prader-Willi Syndrome*, Revised Edition (1995), pp. 142-155.

**"Physical and Occupational Therapy,"** Elizabeth True Lloyd and Mary Alice Deusterhaus-Minor, Chapter 8 in *Management of Prader-Willi Syndrome*, Revised Edition (1995), pp. 115-122.

**"Education of the Child with Prader-Willi Syndrome,"** Marsha H. Lupi, Chapter 11 in *Management of Prader-Willi Syndrome* (first edition, 1988), pp. 113-123.

#### PWSA Brochures:

"What Educators Should Know About Prader-Willi Syndrome"

"Prader-Willi Syndrome: Weight & Behavior Management"

"Prader-Willi Syndrome Medical Alert: A Diagnosis and Reference Guide for Physicians and Other Health Professionals"

"Speech and Language & Prader-Willi Syndrome"

#### PWSA Audiocassette and Booklet:

"Educational Issues/PWS for Teachers"

#### Articles/Booklets published by Prader-Willi Perspectives (1-800-358-0682):

**"Psychological and Psychoeducational Testing of Young Children with Prader-Willi Syndrome: Information for Parents and Professionals,"** Karen Levine and Meg Comeau, *Prader-Willi Perspectives*, Vol. 3, No. 2, January 1995, pp. 3-7.

**"Educational Considerations for Children with Prader-Willi Syndrome and Their Families,"** Karen Levine, Robert Wharton, and Maria Fragala, *Prader-Willi Perspectives*, Vol. 1, No. 3, April 1993, pp. 3-9.

**"Children with Prader-Willi Syndrome: Information for School Staff"** (booklet by K. Levine and R. Wharton)

**"Physical Therapy Intervention for Individuals with Prader-Willi Syndrome"** (booklet by M. Fragala)





*We are pleased to hear again from Past President Janalee Tomaseski-Heinemann, as many have enjoyed her writings about her son Matt over the years. She thought people might enjoy reading about a positive experience—which is what she and Al had when Matt came to visit them in their new home in Florida.*

### ***Sadie—A Very Special Lady***

Our 22-year-old son, Matt, who is living in a supportive living home in St. Louis, just left our new home in Florida after a one-week visit. As to be expected, with a different setting, we were concerned about how he would do and the logistics of food, day supervision, etc. We were fortunate in that we were able to put most of our refrigerated food in our son Tad's condo, which is in the same complex. The rest of the food we locked in the hall closet. To further reduce the chance of problems, we invited (and paid for) Sadie, one of Matt's favorite staff people, to come with him.

Thanks to Sadie and thanks to changes in Matt, I can unequivocally say it was the best week we have spent with Matt—ever!! Not only were there no major scenes, but Matt wasn't even tedious and was loving, happy, and enthused about everything he did. Sadie had never been to Florida or the ocean, so she openly delighted in everything. Because Matt likes her so much and wanted her to have a good time, he delighted in her joy.

We often complained and heard complaints about staff members, so this visit was a good reminder of the unsung heroes out there caring for our adult children. Sadie has been with the home since it opened about two and a half years ago. She had no formal education in special needs children and no background in PWS, but she brought with her qualities you can't teach or buy. Sadie has experience with her own 12-year-old child who is autistic. Sadie has a positive and calming personality, and a loving and forgiving attitude. Sadie said she always stops to assess: "How would I want my child to be treated?" And, she said, she works hard to never carry hurt and anger over to the next day. We were able to observe at length how she could get Matt to cooperate, mainly because he wanted to please Sadie and because she would make him feel good about himself. Sadie's positive attitude on life and love of people with special needs shows in all she does.

Many of you will remember our trials of getting our St. Louis homes opened and the traumas of Matt adjusting to his new home. We held on to the two-year theory that it takes approximately two years for our young people to adjust. At first Al and I wondered if everyone could hang on

## Upcoming PWS Conferences

**September 16, 1995**

### **A Symposium on the Genetic and Developmental Considerations of Individuals with Prader-Willi Syndrome**

UCLA Sunset Village Conference Center, Los Angeles, California  
A full-day conference covering genetics and diagnosis, life sequences in PWS, behavior, nutrition and diet, endocrine issues, health and fitness. Registration fees: Professionals \$70 (\$100 after 8/30/95); Families \$40/person or \$60/couple (\$60 and \$70, respectively, after 8/30/95) Co-sponsored by the Prader-Willi California Foundation. For more information, contact Fran Moss at 805-389-3484.

**October 19–20, 1995**

### **First Annual Prader-Willi Syndrome Service Providers Conference**

Radisson Hotel Lincolnwood, Lincolnwood, Illinois (near Chicago)  
A two-day conference featuring medical and genetic aspects, psychological and behavioral aspects, and residential needs of people with PWS. Registration fee: \$60, plus \$12.50/day for lunch. For more information, contact Prader-Willi Perspectives at 1-800-358-0682

**July 18–20, 1996**

### **20th Annual PWSA (USA) National Conference**

St. Louis, Missouri

long enough for Matt to adjust, but thanks to a determined staff, he gradually began to adapt.

One of the hardest realities Matt had to face was his inability to maintain a "normal" job. With a lot of help, he was finally able to get a few jobs, but was let go each time. The last job was at Target [department store]. Matt felt he had arrived. He did well the first few weeks. Unfortunately, they discovered that the job coach, who wasn't adequately trained about PWS, had been rewarding Matt with four large candy bars a day! Also, at the first staff meeting, Matt ate the entire large box of donuts! The grand finale came when Matt was caught in the aisle with two boxes of cookies, one eaten. When told that he would have to give the other box back or be let go—you can guess what he chose. Fortunately, the same Matt who swore he would never work in a sheltered workshop is now quite content in doing so. Like most of us, in order to accept reality, Matt has had to first try out his dreams.

Matt is also learning from staff members like Sadie that it's not so much what you do, it's the attitude in which you do it that counts. At present, the loving, gently polite personality traits of Matt are shining through. For Matt and for all of our other young people in placement, we thank Sadie, a very special lady, and all of the other staff whose work and dedication go largely unnoticed. Thanks to them, we were able to fondly hug Matt (who had on his Goofy hat and was sporting a three-day beard) goodbye and honestly say we enjoyed every moment of his visit.

—Janalee Tomaseski-Heinemann



## Life After PWS

*Harriet Thom of British Columbia, Canada, sent us the following tribute to her son, Trevor, who died on Nov. 27, 1994, at age 19. Trevor's name has appeared a number of times in The Gathered View, most recently with an article he wrote after attending the PWSA conference in Arizona in 1993. In her letter to PWSA, Harriet writes: "We wish to continue as members of PWSA and would be happy to correspond with anyone to which this would be helpful."*

## IN LOVING MEMORY OF TREVOR

Cheerful, optimistic, and courageous are the words chosen to describe Trevor when writing his obituary. At 19, Trevor had accomplished the two major goals he had set for himself. He graduated from high school and moved to a semi-independent living situation. He was very proud of his accomplishments and of having his own apartment.

Providing education regarding Prader-Willi syndrome was a priority for our family. As Trevor matured, he took an increasingly important role, supported by others who would add the information he preferred not to discuss. Teachers and most others who spent time with Trevor welcomed the information.

Last year Trevor turned 19—an adult under our law. Everything changed. As he was high functioning, guardianship was not an option. While 24-hour supervision was attempted, the emphasis changed when he moved from home. Maximizing his enjoyment and minimizing stress had been high priorities; independence and adult choices became the new emphasis.

While in his hometown, choices were allowed in moderation. Then he was sent out of town to a large facility for assessment. When he complained about being hungry, he was told that as an adult he had the right to request that he no longer be on a diet! He could not resist that type of temptation, and his diet-free status was granted—neither his family nor personal physician was consulted. He died one month later.

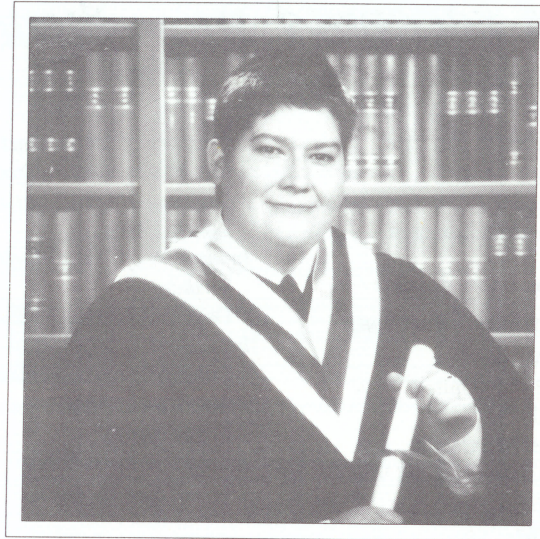
For the past 13 years, *The Gathered View* has been among the most popular mail received, and attendance at conferences was eagerly anticipated. Because we live in northern Canada, Trevor was only able to attend two conferences, but those were highlights in his life. He was eagerly awaiting his trip to Seattle. In Trevor's words, "It is always neat going to conference ... because I know that I am not alone."

Without the Association, Trevor's life would have had less quality; his family would not have had the understanding nor support which was so crucial. The information, guidance, and friendship resulting from our affiliation with PWSA was, and always will be, appreciated.

Losing a son who has Prader-Willi syndrome creates a mixture of emotions and changes for those left behind. The peace of knowing that he will never again be teased contrasts with the knowledge that

the days of jigsaw puzzles and games are over. The fear of his setting a fire which would hurt someone (and devastate him) is gone, but so are the hugs and all the times when the problems were eclipsed by the warmth of his love. The kitchen is accessible—but a void is left in the family.

I like to think of Trevor as a butterfly. For most of his life, his malfunctioning body was a cocoon, which separated him from many of the pleasures of everyday life and limited his activities. Death freed him from that cocoon and allowed his beautiful spirit to be free.



**Trevor Thom in 1994**

## Parent Requests

**A family in Puerto Rico wishes to correspond with another family in Spanish. The age of their child with PWS is unknown.**

**Any parent who is willing to initiate an exchange with this family should call the national PWSA office for more information—1-800-926-4797.**



# A Plea to Watch What We Say ...

At the close of the Seattle conference, Hope Mays—parent, executive director of the Georgia chapter, and disability advocate—asked to address the PWSA board of directors to express her concern about the language many people use in talking about individuals with Prader-Willi syndrome. She cited instances throughout the conference in which various speakers, PWSA officials, and others referred to “PWs,” “PW people,” even “Praders,” or spoke of adults with the syndrome as “kids” or “youngsters.”

Hope's point is well taken—many of us are light years behind the national disability movement in this regard. The language we choose in speaking about our child/patient/client with PWS should focus on *the person*, not the disability; and the terms we use should be appropriate to the age of the person. It takes only one more word to say “my child with PWS” instead of “my PW child.” But what a difference it can make in how we think about that child! If we are to win respect and appropriate services for people with Prader-Willi syndrome, we must first show our own respect by using the proper language. As Dr. Elisabeth Dykens, the Yale psychologist, succinctly puts it: “People are more than their syndromes.” The right language keeps us reminded of that.

*Let's get with the movement, folks!*

## Contributions received in June and July

### AWARENESS DAY Chapter Fund-sharing

Kentucky PWA  
PWSA of Maryland & Metro D.C.  
Missouri Chapter  
PWS Association of New England  
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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.

