



The *Gathered View*

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

Why Awareness Day???

by Jim Kane, Chair, PWSA (USA) Board of Directors

As we approach the first PWS Awareness Day, we are constantly asked by friends and family: "Why is *awareness* of PWS so important?" "Why is it important to have a national association for PWS?"

Many of the answers lie in the special supplement to this edition of *The Gathered View*. Tracing the history of the syndrome from its original identification through to the current work on its genetic causes and to advances made in management of the syndrome clearly demonstrates the result of better awareness of the syndrome in the professional community. A broader based knowledge or awareness of PWS has resulted in improvements in diagnosis and treatment—which, in turn, has improved the lives of our families and particularly our family members with PWS. Continued support for research and improvements in health care, educational and residential services are predicated on a broader awareness of the scope of PWS and its extraordinary human and societal costs.

An equally important result of a greater awareness of PWS is the understanding and compassion that our families can and do receive from a

greater public awareness of PWS. Many times over the past 13 years we have had occasion to discuss our child with friends or relatives, only to have them express a sense of relief when the "problem" is explained, with a real diagnosis. Those conversations are usually followed by a kinder and gentler approach to Kate. The quality of our child's life depends not just on our direct interaction but on the multitude of personal relationships she develops outside our family. One of our greatest responsibilities as parents is preparing the world for her, as well as preparing her for the world.

Whether we are spreading awareness to our child's teacher, doctor, or neighbor or telling the Prader-Willi story to a newspaper reporter, the national Association is our biggest supporter. PWSA provides us the information, access to experts, links with other families, and simply the hope to push on. Awareness is an ongoing focus of the national office. Through the annual conference, publications, research promotion, public relations efforts, and 800 telephone line, PWSA (USA) exists to increase education and awareness.

This first Awareness Day campaign enables PWSA to extend its reach through the work of chapters and individual members. It is a rallying point to build on for PWSA's future. For the first time, our message is being heard all across the country.

The individual efforts of each of you made this Awareness Day outreach possible. The national Association, on behalf of every person diagnosed with PWS and those who will be diagnosed in the future, extends its heartfelt thanks.

*See You
in
Seattle!*

**PWSA (USA)
National Conference
July 20-22
Seattle, Washington**

Call the national PWSA office for information or additional registration forms: 1-800-926-4797

inside

Vocational prospects changing.....	3
Research on behavior, family stress.....	4
Nutrition notes.....	5
Parent letters	6

Special Supplement:

"A New Horizon for Prader-Willi Syndrome"

An Awareness Day Progress Report

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Out of the Office

by Russ Myler, Executive Director

In 1993, the national office had 2,814 incoming calls; in 1994, 5,561; and in the first two months of 1995, 1,061. I mention these figures because this article is about victories.

The phone victory comes from a Board goal to increase contact with members, chapters, professionals, and the general public (more than one-third of our calls are from people never before in touch with us).

The almost 400 persons donating to the Angel Fund Program represent another victory. The growing success of this program makes possible the continued expansion of services by the Association. All of you Angels should feel good about your victory.

Members of the Georgia Chapter were, and now members of the Northwest Chapter will be, responsible for the continuing tradition of an ever larger national conference that presents the best information available to families, parents, and professionals. The New York Alliance and New England Chapters continue their highly successful regional conference, while Florida, Wisconsin, Ohio, and New Mexico also held local conferences this year.

The Connecticut Chapter secured legislation opening the doors to service for many persons with the syndrome who had been denied services before. The Wisconsin Chapter gained formal recognition of PWS as a developmental disability in that state, also making service available to more persons with the syndrome. More of us, working together, are experiencing victories across the country.

Drs. Travis Thompson and Merlin Butler succeeded in securing funds for extensive research into the syndrome, a victory for us all. A U.S. Senator and a Congressman intervened with their state's bureaucracy to open the doors of the Rehab Institute to a person with the syndrome. Maureen's work with a school counselor aided a parent in her work with her child's IEP. The Association flew a person to Pittsburgh for treatment at the Rehab Institute. All across the country we are turning past frustrations into present victories.

I hope each of you will take a moment to write us and tell of your victories, large and small. An occasional *Gathered View* article on our ongoing victories will do us all good.

The Gathered View (ISSN 1077-9965) is published bimonthly by the Prader-Willi Syndrome Association (USA) as a benefit of membership. Annual membership dues are: \$21 Individual, \$26 Family, and \$31 Agencies/Professionals (U.S. Funds). Additional copies or reprints of specific articles can be purchased by members for a nominal charge.

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.

Editors: Linda Keder, Silver Spring, MD

Lota Mitchell, M.S.W., Pittsburgh, PA

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.

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.

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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.

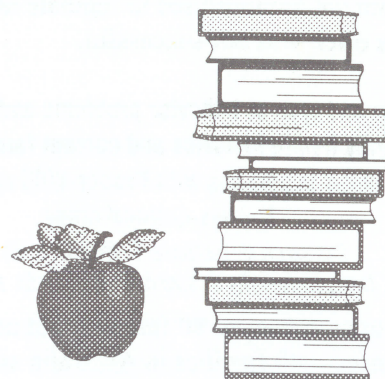
At those hearings, the lawmakers expressed general support for IDEA but voiced concerns about discipline problems, the high costs of litigation and the overly contentious nature of due process hearings, and a backlash against special education, according to *CEC Today*, the member newsletter of the Council 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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Don't forget food safety! Refrigerate or use chilled thermal containers for dairy and meat products.

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:

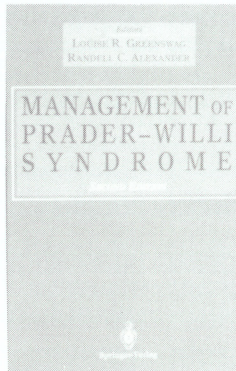
- 1 Starch (about 80 calories)*
- 1 Meat (55 to 100 calories)*
- ½ Milk (about 45 calories)*
- 1 Fruit (about 60 calories)*

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.

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

We have another response to Milton Trachtenberg's letter about "Life After PWS," this one from Judy Crump, of Dexter, Missouri. We thank her for sharing.

We are pleased to have the opportunity to share our experience of "Life after PWS" with an association that helped to provide the support we needed during our search for answers to this dreadful syndrome.

Scott was born July 2, 1960, and died July 21, 1980, at the age of 20. He was a beautiful, loving child who taught us many valuable lessons concerning humanity. Scott's health problems required great energies; thus we were challenged emotionally, spiritually, and physically.

After Scott's death, a huge void was experienced within the family, and it was necessary for major adjustments to occur. Scott's siblings, Lisa and Lori—16 and 14, respectively—were in the stage of growth and development that allowed them peer support and acceptance of change. My daughters' personality attributes associated with the expressions of compassion and appreciation of the unique characteristics of their fellow man were, I believe, affected by their special relationship with their brother Scott.

Gary, Scott's father, increased his energies into his farm-related business. It seemed that he and our daughters

were able to acquire a life balance of normality more rapidly than I, the primary caregiver.

While struggling with my grief, I began to reflect upon the individuals and institutions in the helping fields that had provided the environment for me to gain the needed strength, courage, and faith during those turbulent years. I have experienced life's contradictions, as well as its impetus for personal change and growth. These challenges have caused me to better appreciate and understand the need for each individual to develop their unique gifts and talents to the utmost. Consequently, I returned to college to earn my Master's in counseling. Today I am a licensed social worker and counselor, functioning as Church Counselor with an emphasis on Family Ministry Support Programs.

Scott's life provided valuable lessons, and hopefully because of this experience, someday my life will help make a significant difference in others, too. Perhaps the memorial plaque placed in the sheltered workshop where Scott was employed will express Scott's generous, unique qualities: *"In Memory of Scott Crump, who was a willing worker who freely gave his smiles to the world."*

May those who have experienced similar losses regain the needed strengths to use their life experience to enrich others, thus enabling acceptance of such a tribulation.

From the Home Front



We've heard good news and words of encouragement from members lately. Here's a sampling:

'A Big Thank You From Tony Dorn!'

"Thanks so much for running the article about Tony in the last issue of *The Gathered View*. Tony has received at least 50 cards and letters from people all over the United States. He has been thrilled to tears, and it made having PWS 'kind of special.' Tony is doing much better now. ... His hand muscles and general endurance have improved ... but he is still having trouble with his eyes. Every day keeps getting better. We really appreciate all the get well wishes."

—Don, Barb, Tony, and Tyler Dorn, Verona, Wis.

"Thanks for your recent help with me on Dusty's SSI claim. He has been approved! Keep up the GOOD work."

—Susan Jacobs, Jacksonville, Fla.

"Hopefully, as PWS becomes more widely known, others will contribute and help PWSA along in the great things it is doing for our children. I really enjoy *The Gathered View* and the information I have obtained from you."

—Cindy Kelley, Monroe, La.

A free source of information on ...

SSI and SSDI Benefits

The *Benefits Resource Network*, operated by Kennedy Krieger Community Resources in Baltimore, Md., advises persons with disabilities and their family members on Social Security benefits (Supplemental Security Income and Social Security Disability Income) and on Social Security Administration work incentives.

The Benefits Resource Network

1-800-677-9675

(410) 327-7122 in the Baltimore Metro area
9:00 a.m. to 5:00 p.m. (EST), Monday-Friday

Prader-Willi Syndrome—Home, School and Community

by Terrance James and Roy Brown, based on research in Canada, was noted in the December *Gathered View*. We've just learned that the book is available at a much lower price—\$32.50 US, including shipping and handling—from: **PWSA Alberta, 620 Hunterston Cres. N.W., Alberta, T2K 4N2., Canada.** Our thanks to Margaret and Geoff Willott of Calgary for alerting us to this source!

The Sibling View

Happy Birthday, Dinah!

Gil Stafford, from Grand Canyon University Department of Intercollegiate Athletics in Phoenix, Arizona, sent the following tribute to his sister with PWS.

Dinah will be 40 on January 24, and as her older and only brother I would like to thank Dr. Suzanne Cassidy for her genuine love, concern, and treatment of Dinah and her reassurance and honesty with my parents. It wasn't until just a few years ago that we learned of the Prader-Willi syndrome and that this was Dinah's malady. I guess in some sense it is nice to know that there is a "reason" that Dinah is "special."

Actually, I've always known Dinah is special and I didn't need a reason. She's my sister, and I love her with all my heart. Someone asked me recently if I could change Dinah and make her "normal," would I? I'm sure I would, for her sake and for my parents. But I know that if Dinah were not the way she is now, I wouldn't be the way I am now. She has taught me how to live.

I remember on more than one occasion giving a few boys bloody noses for their making rude comments about my sister. I never worried about what they said or that I would lose friends. I just saw it as something I had to do, to protect my sister. As I look back, those experiences made me just a little tougher, and in the long run, probably more tolerant of others because I learned I couldn't give the whole world a bloody nose.

Just as my family would always come to watch the games I played in, we would all go together to watch the programs where Dinah was involved. I learned to see life through the eyes of my sister and her friends. She taught me to take life for what it really is, something we can't take too seriously. When I would want to cry, Dinah would show me how to laugh at myself. She taught me that a good sense of humor is paramount in being able to see the truth of life. Dinah has shown me how to look at the basal value of life. She loves unconditionally. She loves through pure eyes. She's honest—as honest as she can be at all times. I see that what's expected out of us in life is just that, the best we can be, nothing more.

That, I would say, would be my only advice to parents and siblings of a person with PWS. Don't expect anything from your child, your brother or sister, your parents, or yourself that is not able to be given. Give all you can and then live with the fact that that's all there is to give. As Dinah does, just love.

To Dinah I say thank you, I love you, and Happy Birthday. If I could change you, I probably would, but I can't say that I would be better off.

Sincere Thanks to our contributors

(Donations received in February and March)

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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.

