



The

Gathered View

February 1995
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National Newsletter of the Prader-Willi Syndrome Association (USA)

NIH Grants \$2.34 Million for PWS Research

After a three-year effort to win federal funding, a team of researchers from Vanderbilt University in Nashville has been awarded a major grant of \$2.34 million from the National Institute of Child Health and Human Development (part of the National Institutes of Health) to study PWS over the next five years. Describing their project as "the first comprehensive study" of PWS, the Vanderbilt scientists hope "to discover the steps along the genetic pathway so we can devise a way to prevent Prader-Willi syndrome or more effectively treat people with this condition."

Co-directors of the project, which was funded effective February 1, are Merlin Butler, M.D., Ph.D., who heads the Regional Genetics Program in Vanderbilt's Department of Pediatrics, and Travis Thompson, Ph.D., a professor of psychology and director of Vanderbilt's John F. Kennedy Center for Research on Human Development. (Dr. Butler's description of the proposed research appeared on the front page of the May-June 1993 *Gathered View*.)

The study, "Prader-Willi Syndrome: Genetics and Behavior," will examine 50 individuals with PWS, age 12 and older, and 50 "control" individuals who do not have PWS but who have other eating disorders and match

the subjects with Prader-Willi in age, cognitive level, and percent of ideal body weight. In addition to thorough genetic analysis, the study will examine food motivation, metabolism, and learning difficulties related to visual perception and presence of food. A component of the study will be to observe behavior and behavior problems in the home environment.

Proposed studies of neurochemistry and early development were not covered by the NIH grant, but Dr. Thompson tells PWSA they will seek other funding for these studies.

The research team includes 14 Vanderbilt specialists from 10 different disciplines and six outside investigators, including David Ledbetter, Ph.D., a molecular geneticist at NIH and member of PWSA's Scientific Advisory Board.

Scientific Advisory Board Chair Suzanne Cassidy, M.D., comments: "I am absolutely delighted that Drs. Butler and Thompson and their colleagues were able to obtain such a large amount to study PWS! Dr. Butler has a long history of many important contributions to the management and genetics of PWS, and I am confident that the members of PWSA will benefit from this research."

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Awareness Week

May 2 is D.C. Day

by Don Goranson
Vice President, PWSA (USA)

President and Mrs. Bill Clinton, Vice President and Mrs. Al Gore, and every member of the United States Congress, both the Senate and House, will be informed about Prader-Willi syndrome on Tuesday, May 2, as part of the first-ever National Prader-Willi Syndrome Awareness Week. Awareness Day is targeted for April 29, with the period of observance scheduled to run from April 29 through May 6.

May 2 has been selected as National PWS Awareness Week's "Washington Activities Day." Plans for getting information into the hands of the nation's top elected officials were formalized on February 2 during a meeting at the Capitol Hill Club in Washington, hosted by D.C. political insider Leonard Hacker, who is the grandfather of a 5-year-old boy with Prader-Willi syndrome. The meeting was attended by PWSA (USA) Executive Director Russ Myler, Board Chair Jim Kane, Vice President Don Goranson, and D.C.-area chapter president Linda Keder.

Can You Help?

Volunteers are needed for personal delivery of PWS information to every U.S. representative's office. It would be "most effective" to have families bring their Prader-Willi son or daughter, according to Mr. Hacker. Anyone who can arrange to be in Washington on May 2 is urged to contact our national office in St. Louis.

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Out of the Office

by Russ Myler, Executive Director

Happy New Year 1995!

This year begins our 20th as an association. Usually this kind of anniversary prompts a re-counting of all the accomplishments over the years, and for this association these accomplishments are impressive. However, now is not the time to reminisce; we need to look forward.

As I write this, the new Congress is beginning its work in implementing the "Contract With America" that promises to shrink government and return many functions to state government and the private sector. Regardless of political persuasion, each of us needs to be aware that we face the probability of major changes in the delivery and availability of services many in the Association utilize now or will need in the future. Congress will be looking at every component of the human service system for a return to state or private sources. We can be assured that federal funds, which have been steadily decreasing for the past 15 years, will become even more scarce.

The Association must be actively involved in the events in Washington D.C. We must advocate for those we serve. We must assure the services we fought so hard to get established remain, and we need to assure that government policy establishes an atmosphere conducive to continued development of services so desperately needed. PWSA (USA) must increase its efforts in impacting governmental policies.

We will continue to work "inside the Beltway" through our memberships in NORD (National Organization for Rare Disorders), the Alliance of Genetic Support Groups, and VOR (Voice of The Retarded) and will develop coalitions with other groups as necessary. In addition, we are establishing our own presence "on the Hill" through the volunteer efforts of a truly remarkable man, Leonard Hacker. You saw the beginnings of this effort on the cover of the last *Gathered View* (the Senate tribute to PWSA). By the end of Awareness Week many more folks in the nation's capital will know who we are.

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.

President's Message

by Jerry Park, PWSA President, Oklahoma City

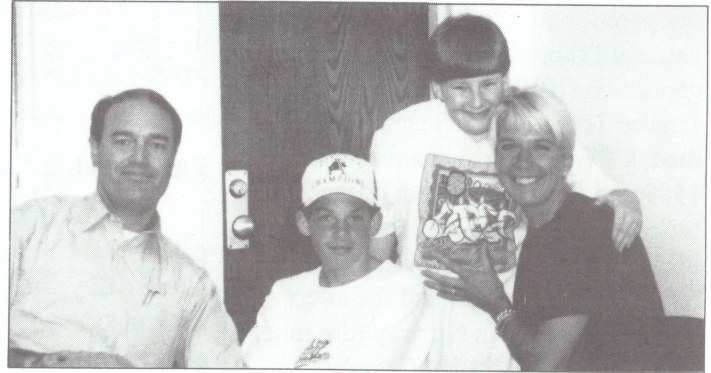
Greetings from the Midwest!

Each year after the annual PWSA (USA) conference, we leave with renewed confidence that weight and behavior can be managed for our children, siblings, relatives, and friends who were born with PWS. Our determination is once again sparked to continue to work towards educating people about the syndrome.

The assurance that a diagnosis is coming much earlier has been illustrated by the growing number of families we see at the conference, especially those with young children, and as we grow in number so do the emotional support and friendships that are the cornerstone of our organization. For three days out of each year we surround ourselves with people who have "walked in our shoes."

My decision to accept the role of president for PWSA (USA) represents a three-year commitment to this organization and the syndrome that has become such a large part of our lives. I have been on the sidelines as my wife, Penny, committed herself to PWSA with six years on the board. Penny, Janalee as president, and the former board members added a new dimension of enthusiasm and reform that propelled PWSA to a new level. Jim Kane, I, and the current board members and officers are committed to continuing a healthy, solid, and long-term growth for PWSA (USA).

1995 stands to be an exciting year for our organization as we undertake our biggest venture yet—National Prader-



Jerry and Penny Park, with sons Ross and Whit

Willi Syndrome Awareness Day, April 29. This is our opportunity for a national forum to bring Prader-Willi syndrome to the forefront through our chapters and membership. It is our opportunity to begin a better life for our PWS people, through public awareness and, most importantly, public funding.

Awareness Day 1995, being our first, may have humble beginnings, but the long-term ramifications could secure research grants, legislative recognition, and broader public support that otherwise would take years. I know you will begin *now* to plan for a successful Awareness Day. It needs to be part of all of us.

Let's begin with a renewed spirit for Awareness Day that will carry into the Seattle conference.

Washington Activities Day

(continued from page 1)

It is planned that each member of Congress will be informed in advance to expect information about Prader-Willi syndrome on May 2. Members also will be told at this time that their support is being solicited for an expected June Congressional vote on the official designation of a National Prader-Willi Syndrome Awareness Day. Our members will distribute PWSA brochures to Congressional offices on May 2 and pose for a group photo on the steps of the Capitol.

In addition, President and Mrs. Clinton and Vice President and Mrs. Gore will receive letters from PWSA on that day containing the signatures of hundreds of our members. We are attempting to arrange in-person pre-

sentations at both the White House and Vice Presidential mansion. These letters will be nonpartisan and will alert our first families as to our efforts to heighten awareness about Prader-Willi syndrome, its management difficulties, and the cost to society when there is no diagnosis.

This is a last call for chapters who would like to have member signatures included with the letters going to the President and Vice President. All you need to do is circulate a signature sheet (providing signature and complete address for each signer) and mail the list to our national office in St. Louis no later than April 1.

Each of the 32 chapters of PWSA (USA) has been asked to sponsor an event or special project during Awareness Week. Chapter presidents recently were sent final

price lists for Awareness Day merchandise, including T-shirts, ball caps, refrigerator magnets, and key chains. An additional fund-raising opportunity is now available for chapters—prepaid long-distance calling cards from Cable & Wireless, Inc., complete with our new PWSA (USA) logo. These are ideal to give to students who are away at school, to keep in the car, or to use while vacationing to avoid hotel telephone charges. The calling cards, valued at \$10 and \$20, will be available at a discount to chapters in March.

The excitement is building as chapters across the nation finalize their Awareness Day plans. We're in this together. Awareness is a goal that we share as individuals and as members of PWSA (USA) and its individual chapters. We believe that 100-percent participation is achievable. Let's go for it!

Organization News

Mildred Lacy has been appointed by PWSA's board of directors to be our parent representative to the International Prader-Willi Syndrome Organisation (IPWSO), succeeding Janalee Tomaseski-Heinemann. Mildred, a PWSA board member since 1989 and former president of the Kentucky Chapter, has an adult son, Ricky, with PWS. As parent representative, Mildred will attend the international conference in Norway this June, along with Dr. Suzanne Cassidy, PWSA's professional representative to the IPWSO.

*

A proposal by the California Foundation for formal affiliation with PWSA (USA) was considered and approved by the board of directors at its January meeting in St. Louis.

*

A PWSA research grant to partially fund a project on "Central Autonomic Function Control in Prader-Willi Syndrome" is awarded to Dr. Francis DiMario at the University of Connecticut, following board approval in January.

*

A task force is being organized to develop plans for computer databases of PWS-related information and on-line availability of information and services for our members and other interested persons. Any PWSA member who has expertise or contacts in this area is urged to call the national office and volunteer to help.

*

PWSA committees are being reviewed and restructured, making this an excellent time to get involved in the work of the national office as a new committee member. Anyone with experience in public relations, government relations, publications, fund raising or grant writing is especially urged to call the national office in St. Louis to volunteer now. (1-800-926-4797)

Vanderbilt PWS Study

(continued from page 1)

Drs. Butler and Thompson plan to describe this exciting research in more detail in a presentation to PWSA members at the national conference in Seattle this July. They also promise to give us updates on the project at succeeding PWSA conferences, but Dr. Thompson cautions that they don't expect to have any definitive results for three or four years.

Participants Needed

The researchers at Vanderbilt are seeking 50 people with PWS to participate in this comprehensive study during the next five years. Participants must be at least 12 years of age. The study proposes a group of 20 subjects in the 12-17 age range and 30 over the age of 17, including 30 males and 20 females altogether. Participants must be willing to undergo a battery of tests, including blood tests, x-rays, physical exams and measurements, eye exams, and psychological tests. A subgroup of participants will be asked to take part in an exercise study and a pilot medication study. The home study component includes observations of how the subjects spend free time and the relationship of behavior difficulties to food issues.

Results of all assessments will be shared with the individual with PWS, their parents, and their family's doctor, teachers, or other professionals involved in their care and education to help them develop health management and educational strategies.

The cost of transportation, lodging, and meals for participants and their parents will be covered by the project, and compensation for inconvenience will be provided. Study subjects should be located within reasonable driving distance of Vanderbilt Medical Center. Families in Tennessee and surrounding states are urged to contact Vanderbilt for more information.

Inquiries about the study should be directed to:

Sandra Roarke, R.D., L.D.N.

Project Coordinator

John F. Kennedy Center for Research
on Human Development

Box 40 Peabody

Vanderbilt University

Nashville, TN 37203

Tel.: (615) 343-7813; Fax: (615) 322-8236

National PWS Awareness Day—April 29, 1995

"A New Horizon for Prader-Willi Syndrome"

Be a part of it—Call your chapter—Find out how you can help

The search continues ... for a national spokesperson for PWS and PWSA to carry us beyond Awareness Day and continue to spread the word. We need your help!

Do you have a relative, friend, or business contact who's known to the general public? Someone in the entertainment industry or sports world would be ideal! If you know of a candidate who might be willing to make a commitment to help PWSA and the cause of Prader-Willi syndrome, please call the national PWSA office and let us know ...

'Obese' Gene News Reports Overstated ... (but will lead to better understanding of obesity in general)

by Robert D. Nicholls, D.Phil., and Suzanne B. Cassidy, M.D.

Department of Genetics and Center for Human Genetics

Case Western Reserve University and University Hospitals of Cleveland

Many of you have seen recent news reports on the isolation of the mouse "obese" gene and beginning studies on the same gene from humans. These news reports have stated that this is *the* obesity gene, and that this could lead to treatment of human obesity. Not surprisingly, many parents of individuals with PWS have asked: "What does this mean for my child?" and "Is this 'obese' gene related to the hyperphagia (overeating) that occurs in PWS?"

The immediate answers to these two questions are likely to be "nothing" and "no," as unfortunately the news reports have been wrong in a number of claims. The name of the gene may have contributed to misunderstanding and led to the excessive claims in the press. Geneticists usually name a gene according to its function (it is estimated that there are 50,000 or more genes, with each gene providing "instructions" by which each cell is built and functions in an organism). The effect of mutation (an error in a gene that prevents its normal function) at the gene in question was to cause obesity, and geneticists named the gene "obese," or *ob* for short. In fact, mutation of other genes in the mouse and humans can result in obesity, and many other obesity genes are probably unidentified. But each gene needs a different name, so there is only one *obese* (*ob*) gene by name. The gene or genes that lead to PWS are one of these "other" obesity-causing genes.

The related processes of appetite control and weight control are complex physiological processes that require many factors for accurate and careful regulation. Appetite and weight control have a large genetic component, but are also affected by environmental factors (such as availability of food and the social aspects of eating) and psychological factors. It is not surprising that such complex biological processes have multiple physiological and biochemical reg-

ulators. The initial studies on the *obese* gene (from mouse) suggest that in the normal situation it provides a factor (hormone) secreted from fat cells that tells the body what it should weigh. In other words, it may be a messenger from fat cells to the brain to allow the brain to control food consumption and hence control the level of energy stored in fat (adipose) tissue. Obesity is an excess of energy stored as fat. Loss of function of the *obese* gene results in loss of this messenger, so the brain of the animal does not know that

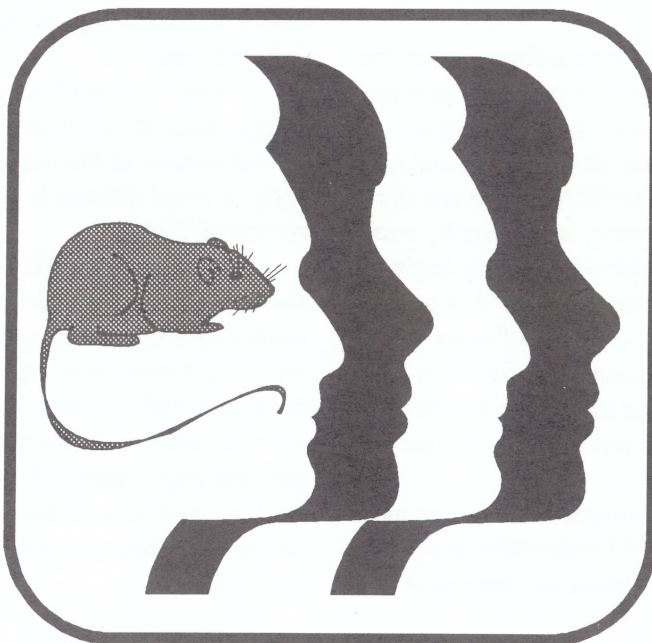
sufficient energy is stored as fat. It keeps eating and develops obesity.

We know that the gene causing obesity in PWS (and the corresponding gene in the mouse) and the *obese* gene are different. At the beginning of this commentary, we mentioned that the answer was no to whether the new findings would mean anything to PWS, in the immediate sense. However, isolation of the mouse *obese* gene will further our general understanding of weight and appetite control. In the next few years those of us studying PWS will understand which gene(s) lead to hyperphagia

and obesity in PWS. The more complete our understanding of weight and appetite control, the better prepared we will be to design effective therapeutic (treatment) methods to aid control of the hyperphagia in PWS. Thus, the current news findings will perhaps help us one day, but indirectly.

Identification of the hyperphagia and obesity gene specific to PWS in the next few years will be a huge step, but much hard work will remain to be done to develop therapeutic approaches. However, the promise of the new molecular approach to medicine is that such goals are possible.

Editor's note: Both Drs. Nicholls and Cassidy serve on PWSA's Scientific Advisory Board.



Ask the Professionals



The parent of a 9-year-old boy with PWS recently called the national office requesting information about "secondary puberty" and whether testosterone should be used to bring it on. The caller was frustrated that PWSA had no policy on this; Dr. Cassidy was asked to comment.



I have never heard of the term "secondary puberty" and don't know to what this refers. There are several pieces of information that relate to puberty and treatment of puberty in Prader-Willi syndrome. First, most people (males and females) go into puberty rather late, even though they may start out developing pubic and axillary hair earlier than the average individual. The onset of the rest of puberty is usually late and incomplete and may be disordered in that the various features of secondary sex characteristics develop out of the usual order.

by Suzanne
Cassidy, M.D.,
Professor of
Genetics and
Pediatrics, Case
Western Reserve
University, and
Chair of the
PWSA Scientific
Advisory Board

There is little information in the literature about treating males with testosterone. I personally do treat most males with testosterone beginning at about age 12 or 13. I use a very low dose to start, and gradually increase, depending upon the effects gained and the patient's own secretion of testosterone, which can be measured by testosterone levels in the blood. I usually begin treating at 25 mg IM of Depo-Testosterone by shot once a month and gradually work up over a period of years to 150 mg a month. This is less than the usual dose for males who don't go into their own puberty, but the reason for this is that most males with Prader-Willi syndrome do secrete some of their own testosterone.

The reason that this topic is controversial relates to behavior problems characteristic of Prader-Willi syndrome, typical in both males and females. However, the use of

testosterone in people who don't have PWS is associated with an increase in behavioral problems. Most of the patients I have started on testosterone have eventually been taken off it by other caregivers because it was felt that the testosterone contributes to aggressive behavior. Personally, I believe that this is a rare occurrence, but one must balance the reason for treating in the first place against the potential behavior consequences. Specifically, it is important to treat in order to develop masculine characteristics such as beard growth, body hair, enlarged genitals, and a more masculine physique (perhaps this is what the caller termed "secondary puberty"). Once these have developed, the major benefit is in increasing the development of muscle. I believe that this is a great benefit, and an additional benefit would be possibly guarding against low bone density (osteoporosis).

I must caution about using testosterone at too young an age, since it results in a growth spurt and closure of the growth centers of the bone. For this reason, if it is started early, it could ultimately lead to even shorter stature than is typical of PWS.

One reason that PWSA doesn't have a policy on this is that it is a controversial topic and there have been no good studies to document long-term benefit. In a nutshell, there are some doctors who replace the deficient testosterone in boys with PWS in order to help bring on secondary sex characteristics and others who are concerned about the behavioral implications of its use. There is little literature on the topic and no well done scientific studies. Families are advised to consult an endocrinologist for more information on this issue.

Attention, Professionals—

Research Grants Available

Funding for research on Prader-Willi syndrome, particularly for pilot or start-up projects, is available from the PWSA (USA) Research Fund. Grant requests are reviewed by the Scientific Advisory Board and voted on by PWSA's board of directors, based on the recommendations of the SAB. For more information, contact the Executive Director, PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797 or 314-962-7644. Fax 314-962-7869.

Attention, PWSA Members—

Nominations for Board of Directors

For the July 1995 elections, the Nominating Committee requests that the names of members interested in, or recommended for, a seat on the PWSA (USA) board of directors be submitted to the committee no later than April 28, 1995. Recommendations for nominees should include a brief description of the member's qualifications to serve on the board. Send or fax recommendations to the attention of the Nominating Committee Chair, c/o PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326, fax 314-962-7869.

National Conference

Keep Hope Alive in '95

—News from Conference Chair, Steve Lundh

Preparations are in full swing for this year's PWSA National Conference here in Seattle, July 20-22. We want to let you know about a few things that will be offered to attendees this year.

For so many of us, the annual conference tends to be our only vacation of the year, yet, besides our flight over the city and the ride to and from the airport, we really don't get to see the sights. Because of the difficulty of scheduling sightseeing during the conference, we are setting up a bus tour on Wednesday, July 19, which is open to everyone.

In addition, at last year's conference a number of people mentioned to me that since they were going to be coming to the Northwest, they might like to take an Alaskan cruise after the conference. I have spoken to Sea n Air Travel, which is this year's official conference travel agency, and they have put together a package that sounds fantastic. **For information or to make reservations for your flight to the conference or the Alaskan cruise, please call Sea n Air Travel at 1-800-848-6444 and ask for either Susie or Kari.** Be sure to let them know that you are going to be coming to the conference so that you may receive the special conference rates.

The Youth and Adult Activity Program (YAAP) will be divided into new age categories this year to accommodate the many adults with PWS who will attend. As in the past, we will provide child care for the 0 to 5 toddler group, but those 6 and older will be split into two groups so that we can offer a better variety of age-appropriate activities. The age cutoff is still to be determined, but outings are being chosen that will appeal to all age groups.

Be sure to contact Sea n Air Travel as soon as possible to make your travel arrangements, and please feel free to contact me with any questions or comments you might have about the conference.

(Steve Lundh can be reached at 206-284-5893 days, 206-285-7679 eves, or by fax at 206-284-5260.)

Conference Grants Available

PWSA (USA) offers grants to families who want to attend the national conference but cannot afford the expense.

To apply, send PWSA a letter that includes: 1) the size of your family and age(s) of your child(ren); 2) an indication of your income and expenses; 3) a brief summary of difficulties your family is experiencing in dealing with PWS; 4) whether your family would need all conference expenses paid or only some expenses (e.g., just transportation or lodging); and 5) whether anyone in your family has attended a previous PWSA national conference.

Letters will be reviewed by the conference grants committee. Letters requesting conference grants must be received at the national office of PWSA by April 28.

Scientific Day Information

PWSA has mailed information and the annual call for papers concerning the 10th Annual Scientific Day, July 19, 1995. The Scientific Day is devoted to the presentation of new research results on Prader-Willi syndrome and is open to all interested professionals.

If you know of any professionals who should be added to the mailing list for Scientific Day information, please call the national PWSA office.

17th Annual PWSA (USA) National Conference July 20-22, 1995

Double Tree Suites Hotel, Seattle, Washington
1-800-222-8733

Pre-Conference Day—Wednesday, July 19

- 10th Annual Scientific Day on Prader-Willi Syndrome
- Residential Providers' Workshop
- Chapter Presidents' Meeting
- Conference Registration Opens

Conference registration packets will be mailed very soon to PWSA (USA) members. Nonmembers may request packets by writing or calling the PWSA national office, 800-926-4797 or 314-962-7644.

Greeting the New Year ... and the Challenges It Will Bring

by
Lota Mitchell,
M.S.W.

1994 with all of its ups and downs is behind us, and we are now well into 1995 with its yet unknown changes, trials, and—yes—joys. For parents or caretakers of a child or an adult with PWS, every day can be a challenge! How we manage those 1995 changes and challenges can have a profound effect on our mental and even physical well-being. So we won't be up the proverbial creek without a paddle, here are a few to keep us going:

1. Mourn What's Gone

Any change, even if it's desirable, involves the loss of *What Was*. Coping successfully involves mourning that loss and accepting the reality of *What Is*. From the loss of the expected normal child when parents receive the diagnosis of PWS to the entering into a residential setting of an adult child with PWS—anything that upsets old familiar patterns and means that things will never be quite the same again must be grieved in order to adapt to the new situation.

2. Adjust Paradigms

Paradigms—our basic beliefs about *What Should Be*, even *What Must Be*, which guide and influence our thought processes—sometimes get us stuck in the transition between *What Was* and *What Is*. Extremely powerful and enduring, they help us to screen and process information quickly. They also prevent us from seeing new opportunities or alternatives. We all know that PWS isn't *What Should Be*, so we must keep our paradigms flexible in order to be willing to explore different ways of doing things and to stay open to new ideas.

3. Maintain a Positive Attitude

Third-century philosopher Marcus Aurelius observed: "If you are pained by an external thing, it is not the thing that disturbs you, but your own judgment about it. And it is in your power to wipe out this judgment now." Hans Selye, twentieth-century physician who originated the concept of stress, echoed: "Stress is not reality; it is how we react to reality. It is a perception that we have about a situation we are in." (Parents of a child with PWS in the midst of a temper tantrum in the supermarket might take exception to those views!) Expecting the best doesn't promise success in coping with whatever faces us, but it certainly raises the odds in our favor.



As 1995 rings in, here's some food for thought served up in a bit of terse verse by co-editor Lota Mitchell.

The Tale of Two Toads

Beside an open can of milk
Two happy toads were hopping.
They leaped too high and came to grief
Into the milk can plopping!

Inside the can they found themselves
With no escape in sight.
They kicked and splashed, but all in vain.
Theirs was a desperate plight.

The farmer came and closed the lid—
He didn't see them there—
The toads in milky darkness trapped
Had good cause to despair.

Said Marchbank to his friend Germaine,
"Oh, what's the use of trying?
We can't escape this dreadful place.
There's nothing left but dying!"

With these sad words he quit the fight
And sank to the bottom to drown.
The other toad kicked bravely on
Though no hope could be found.

Next day the farmer early came
With many a grunt and mutter.
He lifted the lid and saw—Germaine
Afloat on a cake of butter!

4. Monitor Self-Talk

Each of us carries on a constant internal monologue. Most of the time, the "automatic thoughts" are negative evaluators, telling us how awful things are, how poorly we are doing, and how stupid we are. Monitoring our negative self-talk and making rational responses to the "downers" can help us to feel better and maybe make the difference between sinking and swimming. Instead of blaming ourselves, we need to recognize that we do the best we can in the moment we're in with the skills and knowledge we have.

5. Take Care of Yourself

Nutritious diet, enough rest, good exercise, cultivation of the ability to relax, not smoking, drinking in moderation, all contribute to a healthier person better able to meet the demands that day-to-day life with PWS inevitably bring.

6. Decide on a Course of Action

Research indicates that the more powerless one feels in a situation, the more stress one will experience. Taking a step to gain even a tiny bit of control over situation or self helps decrease stress. An appropriate action plan might be to initiate vigorous steps, or to take a wait-and-see stance, or to put oneself on a relaxation program.

7. Seek Support

Sometimes it seems that the very foundations upon which we have built our lives are wobbling. At that point we need others to rely on, to talk to, even though we may feel more like withdrawing. Like the song says, we are people who need people. If we can share our grief and pain, it becomes more bear-

able. Our chapters, support groups, and national PWSA are all resources when we need an encouraging word, understanding, or just a listening ear.

8. Be Open to Personal Growth Opportunities

Finally, we can consider how the challenges of PWS might benefit us and/or how we can grow from it. Making new friends, widening our horizons of understanding of people with disabilities, developing or enhancing skills through volunteer experiences (chapters, support groups, and the national association need you!), even going into a profession where one can help others are a few examples.

An Open Letter to Parents of Younger Children

I am writing to share some of the successes (and failures) of our 5½-year-old daughter, Amanda, with Prader-Willi syndrome. I hope other parents of young children can benefit from some of our successes and perhaps provide new ideas to help with our current challenges.

Amanda was diagnosed with PWS at a few weeks of age with the typical symptoms of hypotonia and inability to feed. By about 6 months of age she had mastered feeding and began to gain weight. We put her on a diet, measuring every calorie she ate and adjusting the amount of calories as she grew. She currently has a diet which totals about 800 calories per day (she weighs 32 lbs. and is 37½ inches tall). For breakfast, Amanda has cereal, milk, diet toast, and fruit. For lunch and dinner she has a choice of a 70-calorie protein course and a choice of vegetables and fruit. In the afternoon she has a 50-calorie snack of rice cakes or diet jello. She drinks only diet drinks other than milk for breakfast. While I know I am being quite detailed, this simple diet has worked wonderfully for Amanda. She knows exactly how much food she will be served and is still able to make some of her own choices. She has never known any other diet and does not ask for additional food or between-meal snacks. (I do not mean to imply that if food were left out she would not eat it—all our food is locked.)

Amanda is in a regular kindergarten program at our local elementary school. She has a full-time aide who assists her with her meals and supervises her at all times. Her speech is at about a 3½-year old level and her physical skills are at about 2½ years. She seems quite bright in certain areas—she knows the alphabet, can read several words, spells her name, and sounds out certain words. Her math skills are much weaker. Because she is so physically slow she is unable to write beyond about a 2-year-old level, even though she can verbally spell her name. We recently purchased Amanda a label maker for her to take to school. The label maker is quite small, approximately 5" x 12", and has a computer keyboard. Amanda can type out her name or other words, print them out on labels, and attach them to her school work. We have also insisted that for class coloring projects Amanda be permitted to cut out magazine pictures and glue them on, rather than just have "scribbles" as her work. She enjoys school very much and the other kids treat her as if she were just younger.

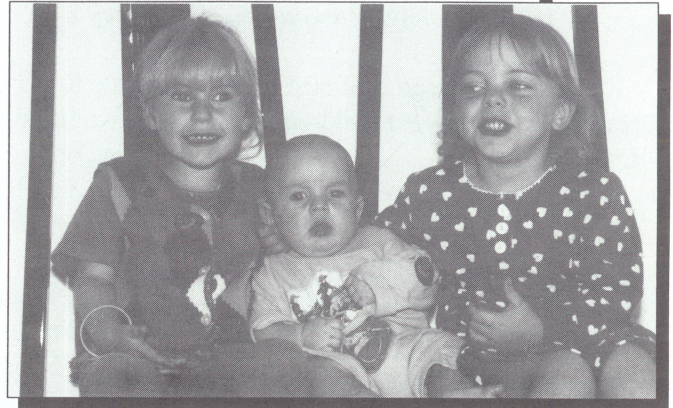
Some of our bigger challenges include:

- Constant, repetitive questioning that does not stop when replied to
- Hair pulling and hair eating
- Teeth grinding to the point that her teeth are very short
- She is very small and we are considering growth hormones but the idea of giving her a daily injection is making us hold off—has anyone experienced this?

Any ideas to assist with these problems would be appreciated. Amanda is a wonderful child and we are fortunate that she has no tantrums, a pleasant personality, is nice to her siblings, and is generally pleasant to be around.

Thanks for sending any ideas that you have. We hope to meet many new families at our sixth conference in Seattle in July.

Amy Wissmann
25724 West Simpson Place
Calabasas, CA 91302



Amanda, left, with brother Alex, 4 months, and sister Nicole, 3½.

Editor's note: If you have a response for Amy that would be helpful to other parents as well, please send a copy to the PWSA national office so that we can publish it in a future *Gathered View*.

Take Me Out to the Ball Game

by Judy Livny, Manalapan, New Jersey



Baseball season is almost here. Have you signed your children up for Little League?

You might answer, "There is no way my child could participate and compete with the other children." Well, there is a way. It is called Challenger Little League. This baseball league is specifically for children between the ages of 6 and 18 who are mentally or physically challenged.

Little League's Challenger division was developed to give every child, regardless of limitations, the opportunity to participate in an organized sport. It began in 1989, and by 1994 there were 825 leagues with over 25,000 participants.

The level of play is based upon the level of the children participating. The most inexperienced play Tee ball. More advanced players would play coach pitch or player pitch.

Although the children have uniforms and the same equipment and fields as regular Little League, the rules of the game are different. The main goal is to give everyone a

chance to play, hence the two basic rules: the batting order for each game consists of the entire team roster, and each child plays half of every game defensively.

The league that my daughter participated in last spring met for two hours on Sunday afternoons. The first hour was for practice. Each child had a teenage or adult "buddy" who helped them improve or develop their skills in throwing, catching, and batting the ball. The second hour was devoted to playing a game. Every child got their turn at bat and their chance to make a home run. Only then was it the other team's turn to come to bat and the first team's to take their place in the field.

At first the children had no conception of where to go after hitting the ball or what to do with a ball they caught in the field. But by the third or fourth game, they began to understand what they were supposed to do, and their games took on a semblance of a baseball game.

At the end of the season there was an awards ceremony, and every child proudly took home a trophy with their name engraved on it.

The benefits of this program are many. The children have an opportunity to participate in an organized sport with uniforms and equipment just like their unchallenged friends and siblings. They get some good exercise (especially important for people with Prader-Willi syndrome). They learn the skills of the game and discipline of teamwork. It is also an opportunity to socialize with other children and for the parents to meet other parents of special needs children. Another benefit, often overlooked, is to

the "buddies." These people get to know and respect a part of the population with which they might otherwise never come in contact.

There are other Challenger sports available throughout the United States, but they are not as centrally organized. In the fall, my daughter participated in a Challenger soccer league which had all the benefits of the Little League. Contact your local schools and recreation departments to find out about other Challenger sports in your area.

For more information on finding a Challenger Little League division in your area or establishing one, contact Jim Ferguson, Director of Challenger Division, Little League Baseball Headquarters, P.O. Box 34485, Williamsport, PA 17701, Tel.: (717) 326-1921.

And remember, in this league, after three strikes you are NOT out.

Editor's note: Judy Livny is the mother of Yael, who has PWS, and tells us: "Yael is doing great in school. She's in a special ed class of nine students with a teacher and aide. She gets speech twice a week, OT twice a week and adapted PE once a week. Outside of school, she goes to a gym class, a special recreation camp on Saturdays, and Sunday school. ... Yael's reading is incredible, at about second grade level (which is the grade she's in), and she's very motivated. All in all, she's a pleasure." Judy is coordinating Awareness Day activities for her New Jersey Chapter and has already helped spread the word about PWS through two newspaper articles featuring Yael, including one on her Challenger soccer team.



Yael Livny, 7, in her Little League uniform.

Options in Scouting

(The following letter was sent to the national office.)

My name is Robert W. Royer, and I am an Assistant Scoutmaster of Troop 204, Indianhead Council, Chief Black Dog District.

I am trying to get boys with disabilities to join the Cub Packs and Boy Scout Troops in their areas.

I strongly feel that a boy with a disability can get as much out of scouting as any other boy can. They can gain companionship, self assurance, and self esteem, as well as just have fun. They can advance as far as they want to by having the scout leader confer with the Council Advancement Chairman to work out reasonable accommodations, without watering down the program. In advancing to Eagle, he must complete as many of the merit badges as his ability permits; afterwards he can apply for alternate merit badges by completing the Application for Alternative Eagle Award Merit Badges. The alternative merit badge chosen must be as demanding on the scout with the disability as the required one would be on the nondisabled scout. The application must be approved by the Council Advancement Committee. Each case would have to be handled individually as each instance would be different.

I would like you to put an article in your organization's newsletter and advise parents of the availability of the Cub Scout program for boys between the ages of 7 and 10 years old and the Boy Scout program for boys 11 through 18 years.

Robert W. Royer
7833 Glenda Ct.
Apple Valley, MN 55124
Tel.: (612) 431-6691

Editor's note: Mr. Royer pledges to be there personally to assist boys in his local area to become integrated into a pack or troop and to help scout leaders working with a disabled boy. Others outside his area may want to contact him for ideas and guidance.

Ask the Parents

'SI' for Skin-Picking

This letter is in response to requests for solutions to the problem of skin picking by persons with PWS.

My daughter, Karie, started picking about age 2. This behavior continued and worsened over the years, regardless of professional guidance by a psychologist who recommended various behavior management plans, including ignoring and positive reinforcement and redirecting.

My curiosity about neurological disorders led me to the discovery of interesting similarities with autistic self-abusive behaviors. When Karie was about 12, I began sensory stimulation which merely involved a vigorous body massage each evening at bedtime, briskly rubbing her arms, legs, back, and head. She really enjoyed the extra touching, and before long, the skin picking gradually disappeared, except for minor incidents. By the time she was 13, skin picking was no longer a problem.

At age 15, Karie moved into a group home, and before long the skin picking became a problem again and was worse than ever by age 17. I was unsuccessful in getting the group home staff to provide backrubs on a regular basis. Then I learned about "sensory integration therapy," known as "SI" in the therapy community. After getting an evaluation by an occupational therapist and a prescription for daily skin massage with a special brush, Karie is once again free of skin picking.

This therapy is best carried out under the guidance of an occupational therapist, but in the meantime, parents can provide some extra sensory stimulation. This is not only beneficial to the child but very enjoyable, too. It can be a daily ritual that provides positive interaction between parent and child.

I hope this information is helpful to other families.

Teresa Kellerman
Tucson, Arizona

(*Editor's note:* See box below for more information.)

About Sensory Integration ...

Sensory Integration (SI) theory, developed more than 30 years ago by occupational therapist A. Jean Ayres, holds that in some children the brain does not properly interpret information taken in by the senses—specifically, the senses of touch, movement, and body position. With respect to touch (tactile sense), children with underlying sensory processing problems may either be overly sensitive to touch or so insensitive that they don't feel pain. When the sense

of movement (vestibular sense) is not functioning well, the child may have coordination and balance problems. The sense of body position (proprioception) is necessary for controlled body movements and manipulation of objects.

To treat sensory integration problems, occupational therapists may use a range of techniques to stimulate the senses. Although a child with PWS may not fit the classic profile of the child with "sensory integrative dysfunction," SI therapy techniques may be helpful in improving motor skills and tactile processing,

such as the example above of brushing the skin to reduce skin-picking. While use of SI therapy has grown, many in the medical community remain skeptical.

For more information, consult an occupational therapist who is familiar with SI therapy techniques or contact Sensory Integration International, 1402 Cravens Ave., Torrance, CA 90501, Tel.: (213) 533-8338.

You might also wish to read Dr. Jean Ayres' book: *Sensory Integration and the Child*, 1979, Los Angeles: Western Psychological Services.

From the Home Front

'A Great Newsletter'

I just received my October issue of *The Gathered View*, and I wanted to write to say thank you for having such a great newsletter about PWS. I look forward to each and every issue. It's so nice to know that my husband and I are not alone. We have an eight-month-old son who was diagnosed with Prader-Willi syndrome at 10 days of life. We thank God for the great doctors who knew something was wrong and found out what it was so fast.

Tyler is the light of our life. He is the happiest baby, and people are constantly commenting on what a great baby he is. We treasure every moment of every day with Tyler because we know the road ahead will be a rough one.

We know not every person with PWS is the same, but your newsletter gives us some insight on what to expect, and for that we thank you.

*Dena and Thomas Thornhill
Pineville, Louisiana*



In Need of Some Mail

Recently, our 9-year-old son Tony with Prader-Willi syndrome suffered a very rare complication as a result of taking a prescribed medication. This complication had no relationship to his Prader-Willi syndrome. It was, however, a life-threatening situation which caused him to lose 75 percent of his skin, including tissue in his mouth, throat, and eyes and all of his fingernails. He was hospitalized for 27 days and spent 21 of these days on a ventilator. Tony was discharged on January 6, and we are now in the rehabilitation aspect of his illness. As you can imagine, his muscles are very weak but he continues to grow stronger every day. He receives homebound instruction for his academics as well as occupational and physical therapy. Tony loves mail. Opening envelopes helps strengthen his fingers as well as lifts his spirits. If anyone would like to send Tony a "get well" wish, feel free to send a note or card to: Tony Dorn, 305 Amanda Way, Verona, WI 53593.

*Barb Dorn
Verona, Wisconsin*

Sweet Memories ...

My granddaughter, Allison Mahan, is a 6-year-old with Prader-Willi syndrome.

We had an experience during Christmas week that is so Prader-Willi, I have to share it:

One of Allison's friends from school came to spend the afternoon with her. They played Connect-Four, put puzzles

together, watched a video, jumped rope, recorded and played back messages and conversations on Allison's tape player, and did many things.

That evening, after the friend was gone, Allison decided to record the events of the day and onto the tape said, "I had a cracker for Amy and me and a juice for Amy and me and then I had another cracker for Amy and me but no more juice ... and ... The End."

We will save that tape forever!

Happy New Year to all the wonderful Prader-Willi parents.

*Mary J. Culver
Garden Grove, California*

Life After PWS: A Sibling's View

Julia Scalia, of San Jose, California, writes: In February 1987, my 6-year-old daughter with PWS died from a virus that hit her pancreas. My son was 8½ at the time. It has taken him a long time, even though we took him to counseling, to finally be able to openly express his feelings about her death. He wrote a folk song for his honors English class about her death that I would like to share. He has grown up to be a very sensitive, caring, giving, and loving person. I feel that although it is hard for siblings to grow up in a family with special needs, especially PWS, they learn a very special lesson about life that other children don't.

ONE MORE CHANCE ...

Please give me one more chance,
One more chance to say goodbye.

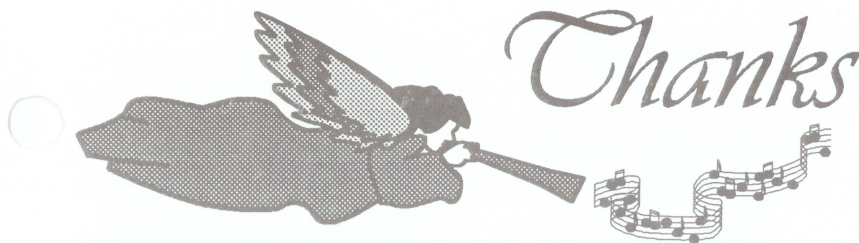
I know you didn't mean to,
I know it wasn't your fault.
I know I can't change things,
And I can taste my tears of salt.

Before your life was taken
From me and all your friends,
You were my younger sibling
And we fought to the bitter end.
Please give me one more chance,
One more chance to say goodbye.

As your death grows distant
And all those years that passed,

It's been very hard to cope
With this loss that will forever last.
I never thought this would happen,
I never thought you would die.
Please give me one more chance,
One more chance to say goodbye.

*John Scalia
Age 16, June 1994*



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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.

