



The Gathered View

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

A New Day for PWSA

by Don Goranson
Vice President, PWSA (USA)

The enthusiasm was contagious. You could actually feel it! There was a spontaneous standing ovation, brisk sales of the new T-shirts and other items put out for sale, hundreds of our members signed a letter to President and Mrs. Clinton, and there was heightened optimism for our future.

The site was the Atlanta Marriott Northwest, as PWSA (USA) national conference attendees—nearly 700 strong—saw the unveiling of a new logo and heard of renewed efforts at building awareness on several fronts. Let's face it—our organization was ready for a jump start, a "new beginning."

The design of a new logo, general-audience brochure, and other materials was authorized by the national board of directors one year ago during the Scottsdale, Arizona, conference. We worked to develop a total package that clearly represented who we are and what we stand for. We were ready to move forward. We needed to prepare ourselves to face the challenges of growth, fund raising, and recognition, as well as higher levels of service and support for our rapidly growing constituency.

A small Connecticut design firm was enlisted to work with us. Our new look needed to be simple yet elegant, warm and futuristic, and embody a concept that conveyed hope. Most important, our new look needed to have meaning and instant recognition.

Three very different concepts were presented to the board at its mid-winter meeting in St. Louis. Members saw slides, overheads, and mock-ups of a new logo, a new brochure, letterhead, business cards, envelopes, and other materials. As a result of much discussion the board voted to pursue one of the three options, with the Atlanta conference targeted for an official unveiling. A new 8-foot banner was displayed

during the opening session of the conference so that everyone could celebrate our new look and beginning.

A full set of new materials has been developed, with each piece utilizing our

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Our new logo...

is neither simplistic nor abstract and comes with very definite symbolism. The designer wanted the spikes of the sunburst to pierce a known shape, to break through the boundaries or limitations of that shape. We chose the triangle because it symbolizes the PWS body shape, the food pyramid, the mountain to be scaled, and even the pyramid of power, with many supporting few.

The sun exudes warmth and depicts new days and also the concept of one day at a time. The spikes show breakthroughs and, therefore, hope, progress, reaching out, the future, and optimism. The colors (orange and gold in the full-color logo) are warm and cheerful.

Finally, we have used at the base of the triangle a line depicting an uneven horizon to symbolize the ups and downs of dealing with Prader-Willi syndrome. But remember this: the sun is rising, representing the uplifting thoughts of the new day, of promise and hope.

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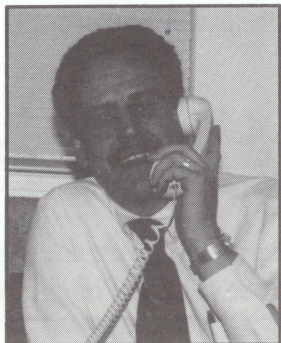
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Out of the Office

by Russ Myler, *Executive Director*

"Do more with less." I hear that phrase everywhere. It has even extended to government circles (we will see how that works out). Everyone is experiencing increased work and less time in which to do it. It seems doing more with less extends to family life as well, not only with money, but time too. Life seems to present more challenges than ever and seemingly less time to meet those challenges. It takes a real hero to go above and beyond what it takes to work and run a family. I thought about that while working with the over 100 volunteers giving a lot of their time to the national conference in Atlanta. Volunteers in and to the Association are really heroes.

We have some visible heroes: the officers and members of the board of directors. They daily give of their time and treasure to PWSA (USA). Our two editors of *The Gathered View* give hours of their day to make the newsletter a valuable resource for us. Committee chairs and members who work in every area of the Association's daily activities to produce publications, gain public recognition, make investment strategies, and focus upon treatment and research. These are some of our more public heroes.

But we have many less public heroes. Our chapter presidents and chapter board members, who work tirelessly to support the effort at the state level, who take referral phone calls from parents of newly diagnosed persons with the syndrome, who work with state governments and agencies to improve the resources available to those we serve, and who see to it that local support and education is consistently available. These people are heroes as well.

We have many unsung heroes in the country that you don't know exist. One such hero is a person in the Southwest who sends \$50 a month from his paycheck as a donation to the research fund. There are women in the Midwest and on the East Coast who hold their own fund raisers and send the proceeds to the Association. There is a person with the syndrome who makes beautiful hooked rugs and donates the proceeds from their sale to the Association. Members of the Minnesota Chapter, and now the Missouri Chapter, who have donated time in the national office. These unknown heroes, and many more like them, make this Association a great one.

To all of you who give of your time, talent, and treasure, from all of us in PWSA (USA),
THANK YOU.

Stay Tuned for New President's Message...

Our new PWSA (USA) president is Jerry Park of Oklahoma City, father of 10-year-old Whit, who has PWS, and husband of Penny Park, who served on the PWSA board of directors from 1988 to 1994. Jerry, who accepted his appointment to office at the close of our national conference in Atlanta, will introduce himself in the September-October issue of *The Gathered View*.

-- the editors

In Memoriam

David Eugene Burleigh

July 22, 1960

June 22, 1994

Post-Conference Notes and Thanks

by Dottie Cooper, President, Georgia Chapter, and 1994 Conference Coordinator

Down here in the "Sunny South" we are still basking in the glow of your warm response to the national PWSA conference held in Atlanta. We have received sooooo many warm messages from all over the country since the conference, and we're glad you still have "Georgia on Your Mind." You all were great, and I certainly hope you learned as much and had as much fun as we did. For all you "Newcomers," welcome to our "Family" of PWS supporters, families, and friends. For all you "Old Timers," it was great to get together again.

Your energy at the conference has inspired us in Georgia. Our membership is growing, new members are requesting that we have more frequent meetings, and we are continuing to build our organization. Community awareness is now great, and we have individuals coming to us to ask what they can do to help us. A "kickoff" meeting has been set to work with our wonderful LADD organization (Living Alternatives for the Developmentally Disabled) to pursue the establishment of a second Independent Living Home. Moreover, the presence of over 650 individuals associated with PWS from around the country was the catalyst for Emory University to ask us to begin work with them towards the establishment of a "treatment center" for persons with PWS at Emory University in Georgia. Thank you for helping us bring to their attention the compelling need for services.

As in conferences past, enough cannot be said for all the wonderful "heroes" who worked so hard to plan and supervise the YAAP Program (Youth and Adult Activities). No one understands better than families associated with PWS what a tremendous challenge that is. To the parent, sibling, and other individual volunteers, the wonderful LADD staff, and the Telephone Pioneers, you did an unbelievable job with that program and a wonderful service to parents and caretakers. We just can't thank you enough.

GEORGIA NATIONAL CONFERENCE "SCRAPBOOK"

The "Dream Team" is in the process of putting together a scrapbook of the Georgia conference. If any of you have pictures that you would like to share, please send them to the following address:

Georgia Association for PWS
1218 West Paces Ferry Road
Suite 104
Atlanta, Georgia 30327

*A very, very special
THANK YOU to ...
Dottie Cooper,
coordinator of the 1994
national conference.
Everyone who was
there can attest to the
fantastic job she did.*

Individuals and organizations who contributed to the 1994 National Conference:

GEORGIA PWS CONFERENCE PLANNING COMMITTEE (the Georgia "Dream Team"):

Paul and Pam Alterman, Hope Mays, Susan Suppes, Ed and Kay Thomas, Ron and Linda Drotos, Lamar and Barbara Paul, and Karen Ripley.

CORPORATE SPONSORS:

BellSouth Telecommunications; Hewitt & Hewitt; Lotus Corporation; Westinghouse Electric Corporation; Alterman Real Estate, L.T.D.; Georgia Governor's Council on Developmental Disabilities; AMOCO; and SPA Foundation.

SPECIAL CONTRIBUTORS:

Telephone Pioneers of America—Dogwood Chapter; BellSouth Facilitators; "The Variations" band; the LADD staff; and many other organizations and individual volunteers.

A special thanks for our **PROFESSIONAL DAY SPONSORS:**

Emory University— **SCIENTIFIC DAY**

Living Alternatives for the Developmentally Disabled (LADD)— **RESIDENTIAL PROVIDERS DAY**

Conference Highlights

Scientific Day

The annual PWSA Scientific Day was held the day before the national conference under the leadership of Suzanne Cassidy, M.D., chair of the PWSA (USA) Scientific Advisory Board. Seventeen studies and their findings were presented to the assembled researchers. Eight of the studies pertained to genetic research, while the remainder investigated a variety of areas. Dr. Cassidy points out that while there were no dramatic breakthroughs in the reports, the number of studies and the attendance indicate ongoing interest in the syndrome and a progression forward on a number of fronts.

Anyone interested in more information on the studies presented should contact the PWSA national office to obtain a list or purchase the published abstracts.

Residential Providers Workshop

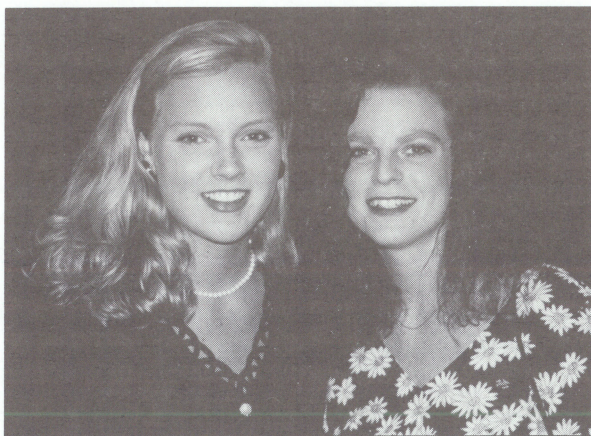
Over 50 providers of residential services representing 23 programs from 12 states participated in this workshop. Residential options that were represented included both designated and integrated group homes and supervised apartment programs. The major objectives of the workshop were to link residential providers for support and exchange of information, to encourage the creation of a network among providers with the national office as a backup resource, and to provide an opportunity for dialogue.

A brief overview described those aspects of PWS that have an impact on delivery of services. Individuals with

PWS are able to successfully adapt in a variety of residential settings, although the process of adaptation and time needed for adjustment will vary with each person. John Schrorring, director of Castlewood Home in Lexington, Kentucky, described that program. Janet Goodacres, director of vocational rehabilitation in Lexington, offered guidelines for helping persons with PWS adapt in the world of work. The staff from Community Systems, Inc., in Burke, Virginia, presented an overview of their services for three individuals with PWS.

Discussion and dialogue followed these presentations. Much time was devoted to a variety of opinions about managing dietary issues. It appears that various states and agencies use different criteria. Some behavioral management concerns were identified, and questions arose relating to guardianship. One point was abundantly clear—that different agencies use different approaches based on their philosophies and state guidelines and that no one program is better than another. There was not enough time to discuss staff development and maintenance, and it was suggested that the workshop time be extended.

—by Louise R. Greenswag, who, with David Mansell, facilitated this workshop



"YAAP leaders Stacey Northrup and Katie Alterman"



"Whit Park dances in conference T"

Grandparents are Great

It was a "first" at a national conference—a gathering of 15 grandparents of children with PWS. It turned out to be a wonderfully empathetic, understanding group. Most were familiar with PWS and were encouraging and sympathetic to a new grandfather of a three-month-old, newly diagnosed boy whom he had not yet seen. This granddad was attending the conference in order to learn all he could so he in turn could offer support and understanding to the child's parents. It seems that extended family can confront the issues associated with PWS and that the vitality of family life need not be sacrificed. The caring and compassion expressed in the dialogue among these grandparents revealed a strong desire to learn about PWS, to help their children, and to love their very special grandchildren.

—Louise Greenswag, session leader

The 1994 Honorees

PWSA's best-kept secret is revealed the night of the banquet when the person or persons to be honored for that year are presented. This year there were two special people—Bea Maier, Ph.D., from Pitts-

burgh, Pennsylvania, and Janalee Tomaseski-Heinemann, M.S.W., from St. Louis, Missouri.

Bea Maier, as senior coordinator of The Rehabilitation Institute of Pittsburgh, has overseen the entry and progress through TRI of 162 children and young people with PWS. For the past 12 years, she has been deeply committed to the research and treatment of this population. With understanding and encouragement she has provided support and guidance to their families. She has given of herself, not only professionally but personally, to individuals, to the local support group, and to the state chapter. More than one parent sees Bea as having helped to save their child's life—and perhaps their own sanity! As she approaches retirement next month, she promises to continue her involvement with PWS on a volunteer basis.

Janalee Tomaseski-Heinemann completed, at the close of the national conference, her three-year term as president of PWSA. During that time in the top office of the organization, she helped to pilot PWSA with tact and wisdom through some major transitions. She is at least as well known for her writing—humorous, down-to-earth vignettes of life with PWS in the form of son Matt, now in his 20s. As evidenced in the many letters she receives thanking her, people from all over the world have been touched in heart and mind as she reflected for them their feelings, struggles, and experiences in their own lives with PWS. She and her husband, Al, are making big changes in their lives—leaving their jobs and moving to Sarasota, Florida, for new challenges—but Janalee promises not to stop writing for us.

Election Results

Because several board seats vacated in the past due to health or other personal reasons had been filled by new, full-term

board members, and because two one-year terms expired in July, there were seven seats on the board of directors up for election this year. It was deemed necessary to have this year's and next year's elections include both two- and three-year terms in order to bring the number of positions open each year back to four, as prescribed by our bylaws. This year's ballot included four two-year terms and three three-year terms.



"Janalee gets praise from Penny Park"

Elected for two-year board terms were incumbents Stewart Maurer, Jim Kane, and Paul Alterman and new director, Penny Townsend. Elected for three-year terms were incumbents Louise Greenswag, R.N., Ph.D., and Barbara Whitman, Ph.D., and new director Don Goranson.

Congratulations to these successful candidates! And thanks for their work and devotion go to Suzanne Cassidy, M.D., and Penny Park, who have completed their terms and are leaving the board.

Board of Directors Meeting—

As usual at the national conference, meeting time for the board of directors was hard to come by because of conference events, needs of children, and outside demands. Nevertheless they were able, under the leadership of Jim Kane, who was reappointed to another one-year term as chairman, to address a number of concerns of the organization. Among

other items, the board: decided to pursue a simple, inexpensive trademarking of our new logo; approved additional funds to continue accelerated revision of PWSA brochures and other publications; considered ways to address the problem of backlog in production and distribution of orders; will pursue outside funding to develop a group home staff training video; approved a \$4,000 grant from the research fund to study the incidence of cancer in the PWS population; and elected Jerry Park the new president of PWSA for a three-year term.

The board and officers will meet again in January 1995 for a highly focused two-day meeting. If members have concerns they would like to see brought before the board, let Chairman Jim Kane know through the national office.

Conference Wares

A limited supply of high quality merchandise is available at the PWSA national office - telephone orders only - 800-926-4797. Shipping/handling included in price of item.

1994 Conference T-shirt - \$10.00, white with Georgia peach integrated into the new PWSA logo, (XL only)

PWSA Logo T-shirt - \$13.00, white with full-front, 3-color logo (XL)

PWSA Golf Shirt w/collar - \$40.00, white with 3-color, embroidered logo on left chest (XL)

PWSA baseball cap - \$18.00, blue or olive cloth cap with 3-color, embroidered logo

Logo key ring - \$2.50, with 800 phone number

Small tote bag - \$7.50, natural canvas with new PWSA logo, 13" x 13"

Water bottle - \$3.00, 10 oz. plastic bottle and drinking straw with new PWSA logo

Supplemental Security Income (SSI) Benefits:

How Do Children and Adults with PWS Qualify?

What Is SSI?

SSI is a federal program that pays monthly benefits to people with low income and limited assets who are elderly, blind, or disabled. Children under age 18 can qualify if they meet Social Security's definition of disability and if their family's income and assets fall within the eligibility limits. The SSI program is administered by the Social Security Administration (SSA) but is different from Social Security benefits, which are based on a person's prior work.

As the name implies, **Supplemental** Security Income supplements a person's income up to a certain level. This level varies from state to state and can go up every year based on cost-of-living increases. In 1994, the maximum federal benefit for children with disabilities is \$446 a month; 24 states supplement federal SSI payments with an additional amount. The actual amount paid to an individual is based on family income: the higher the income, the lower the SSI benefit.

In most states, SSI recipients also qualify for Medicaid coverage, which pays for hospital stays, doctor bills, prescription drugs, and other health costs. Depending on the state, Medicaid coverage may come automatically with SSI eligibility or may require a separate application process.

How Is Eligibility for SSI Determined?

When someone applies for SSI, the Social Security Administration reviews that person's financial records to determine whether their income and assets are low enough to qualify them as financially needy. Some forms of income and resources are not considered in this determination. In the case of a child under age 18 who lives at home or one who returns home occasionally from a residential school, the income and resources of the parents may be "deemed" (counted as being available) to the child. (See box on Financial Eligibility for more details, page 8.)

In addition to qualifying financially, the person seeking SSI benefits because of disability must meet the Social Security Administration's definition of "disabled." Documents and evidence pertaining to the disability are sent to a state office, usually called the Disability Determination Service (DDS), where a team comprised of a disability evaluation specialist and a doctor reviews the person's case to decide if he or she meets the definition of disability. The DDS may arrange for a special medical examination, if a decision cannot be made based on the information provided.

In order to qualify for SSI, an adult applicant (age 18 or older), must have a physical or mental impairment, or combination of impairments, that is expected to keep him or her from doing any "substantial" work for at least a year or is expected to result in death. (Generally, a job that pays \$500 or more a month is considered substantial.)

A child under 18 is considered "disabled" for SSI purposes if the impairment is found to be as severe as a condition that would prevent an adult from working. In making this determination, the evaluators check to see whether the child's disability is specifically named in a list of impairments contained in the Social Security regulations (PWS is not), or if the child's condition is equal to an impairment that is on the list (a case can certainly be made that PWS is equal). If disability cannot be established using the list of impairments, then the evaluators will do an "individual functional assessment" to determine whether the condition substantially reduces the child's ability to do the things and behave in the ways that children of a similar age normally do. If so, the child will be eligible for SSI. (See box on Meeting Disability Requirements for more details.)

The Zebley Case

In 1990, the Supreme Court decided (in *Zebley v. Sullivan*, known as the *Zebley* case) that the disability determination process then in use for children under 18 was illegal. As a result, members of the *Zebley* class—children whose SSI applications

were denied for medical reasons after January 1, 1980—may receive benefits back to the date of their original application, even if they are now adults. For more information, call the Zebley Implementation Project, sponsored by Community Legal Services of Philadelphia: 1-800-523-0000.

How Do You Apply for SSI?

Call or visit your local Social Security office to apply for SSI. To find your nearest office, check the government section of your phone book or call directory assistance. You can also apply by calling Social Security's toll-free number: 1-800-772-1213 between 7 a.m. and 7 p.m. weekdays. (You're advised to call early or late in the day and to avoid Mondays and the first few days of each month.)

If you think you might qualify for benefits, it's important to apply immediately. The date of your first phone call or visit to SSA to apply is the date benefits begin once the child is found eligible for SSI (if the application is filed within 60 days of that visit or call). It may take Social Security six months or more to make the eligibility decision, but benefits are paid back to the month of application.

Many documents are needed to complete an SSI application, but you do not need to have all of them in hand to begin the process. The Social Security office will tell you what you need and can provide you with publications explaining the process. Among the documents you will probably be asked to bring or send (originals are required and returned) are:

- Social Security card or number
- Birth certificate or other proof of age
- Proof of citizenship or immigration status
- Proof of income (payroll stubs or self-employed tax return, records showing amounts and sources of unearned income)
- Proof of resources (property tax bill for real estate, auto registration, bank statements and passbooks, savings bonds, stock certificates, life insurance policies, etc.)
- Medical information (information about the disability, medical and therapy reports about your child; names and addresses of doctors, hospitals, etc., that have treated your child; a copy of the Individualized Family Services Plan (IFSP) or Individualized Education Plan (IEP) if the child is receiving early intervention or special education services; and your own notes about your child's disability)

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Meeting Disability Requirements for Children Under 18

Although Prader-Willi syndrome does not appear on SSA's list of impairments, it can be argued that it is medically or functionally as serious as a listed impairment. PWS, in fact, fits in at least three of the 13 impairment categories qualifying for SSI:

* *Mental and Emotional Disorders* (specific disorders listed include mental retardation/organic mental disorders; mood disorders; anxiety disorders; somatoform, eating, and tic disorders; autistic disorder and other pervasive developmental disorders; developmental and emotional disorders of newborn and younger infants; and others);

* *Neurological* (includes motor dysfunction due to, and communication impairment associated with, neurological disorder; cerebral palsy; and others); and

* *Multiple Body Systems* (includes Down syndrome, multiple body dysfunction, catastrophic congenital abnormalities, and others).

To make the case that PWS is equal to a listed impairment and demonstrate that a child with PWS functions well below other children the same age in one or more areas, applicants should be prepared to provide:

1. Documentation of the syndrome as a recognized disorder - Supply literature about PWS and cite the classification numbers for PWS from the *Index Medicus*, the American Association on Mental Retardation (AAMR), and the *International Classification of Diseases* (the PWSA national office can help);

2. Medical certification that the child has PWS - This must be written by a medical professional and specifically identify how the syndrome limits the child's ability to function; and

3. Other documentation of the child's impairments, delays, and medi-

cal problems - In addition to copies of all formal medical and non-medical records, parents should supply their own notes about the effect of PWS on the child's physical, mental, emotional, learning, and behavioral development and overall functioning, giving specific examples and as much detail as possible. Narrative reports from friends, relatives, day care providers, social workers, education staff, medical professionals, and anyone else who knows the child can help to demonstrate that PWS interferes with the child's age-appropriate development and activities.

If a functional assessment is required, SSA will measure the child's abilities against norms for that age group in cognition, communication, motor abilities, social abilities, responsiveness to stimuli (in the first year of life), personal/behavioral patterns (after the first year), and concentration, persistence and pace in task completion (age 3 and up).

What If You're Turned Down?

SSI decisions—particularly those determining that a child is “not disabled”—might be reversed through an appeal. There are three levels of appeal available and each must be requested within 60 days of the last denial of benefits:

1. Reconsideration - A form to request reconsideration must be obtained from SSA. With this form, you can add information or reports about your child's disability. If the application is again denied, proceed to the next step.

2. Administrative Law Judge (ALJ) Hearing - This is an informal, private hearing in which new information can be presented and witnesses (doctors, teachers, friends, etc.) can testify. It's a good idea to get a lawyer or advocate to help with this level of appeal and to arrange for expert testimony from a professional experienced in PWS. (Consult the state Protection and Advocacy office about the availability of public funding to pay expert witnesses.) More than half of the denials brought to ALJ hearings are reversed.

3. Appeals Council Review - If the child is again denied benefits, a review by the Appeals Council can be requested. It's advisable to get an advocate to assist with this step.

If all three appeals fail, the parent or child has another 60 days to appeal the decision to a federal court.

For assistance with SSI applications or appeals, look for a lawyer or advocate who has experience in handling developmental disabilities services cases. Possible sources of help include:

- the local legal aid/services office,
- the state Protection and Advocacy office (every state is required by law to have this office),
- a local or state bar association's lawyer referral program, or
- the National Organization of Social Security Claimants Representatives, 1-800-431-2804.

A helpful, 18-page booklet, “SSI: New Opportunities for Children with Disabilities” (\$3 per copy) and more extensive publications on SSI are available from the Judge David L. Bazelon Center for Mental Health Law, 1101 15th St., N.W., Suite 1212, Washington, DC 20005, telephone 1-202-467-5730.

—This article was compiled by Linda Keder based on published resources and in consultation with Louise Greenswag, who has served as an expert witness on PWS at SSI hearings.

Financial Eligibility for Children Under 18

Income Limits - For an only child to be eligible for federal SSI benefits in 1994, the parents' monthly earned income can be no greater than \$2,354 (\$1,908 in a one-parent household). The limit increases by \$223 for each additional child with no disability in the family.

If parents receive unearned income (e.g., Social Security, pension, Veterans benefits, state disability or unemployment benefits), the monthly income limit is lower: \$1,154 (\$931 in a one-parent household). Again, add \$223 for each nondisabled child in the home.

A family that has both earned and unearned income might qualify if their total income falls between the earned and unearned limits for their family size.

In determining SSI eligibility, Social Security does not count some forms of income such as foster care payments, education loans, Aid to Families with Dependent Children (AFDC), welfare, food stamps, Agent Orange payments, and a portion of child support payments.

In states that supplement SSI the income limits are higher, and both federal and

state limits may increase from year to year. Applicants are advised to find out the current income limits in their state and, if denied benefits based on income, to reapply for SSI whenever the limits are changed or their income decreases.

Resources - The combination of the child's and the parents' resources (cash and possessions) may not exceed \$5,000 (\$4,000 in a one-parent household). This includes a personal allowance of \$3,000 for the parents (\$2,000 for a single parent). However, many things a family owns are not counted in the computation of resources for SSI purposes—for example: the family home and land; furniture, personal belongings, and household goods up to \$2,000 in value; one car, if needed for employment or medical treatment; life insurance policies worth up to \$1,500; wedding and engagement rings; and property needed for self-support.

A Hand for the Handbook:

*Thank you,
Kristen West!!*

The Prader-Willi Syndrome—A Handbook for Parents, by Shirley Neason, has been out of print for over a year. The good news is that it has undergone some editing, updating, and facelifting during that time and will be available again this fall.

Another piece of good news is that the computer typesetting of the handbook was done by Kristen West, 18, of Hurst, Texas, who has Prader-Willi syndrome. Her dad, Gerald West, writes:

SSI Testimonials Needed

The SSI program has come under attack in the media since the Zebley decision. Its critics charge that many families are defrauding the government and winning benefits on behalf of children who are not truly disabled.

The National Parent Network on Disabilities (NPND) wants to counter these claims—and ensure the future of the SSI program—by collecting as many stories as possible about the positive impact of SSI benefits on the families of children with disabilities.

If you have a story to help in this effort, send it as soon as possible to:

Patricia McGill Smith
Executive Director
National Parent Network
on Disabilities
1600 Prince Street, Suite 115
Alexandria, VA 22314

“At the Phoenix national conference [July 1993], I informed Tere Schaefer [then PWSA executive director] that Kristen had graduated from high school in May and had received a Macintosh computer for her graduation. I asked Tere if there was something Kristen might do for the National PW Association with her computer. Tere seemed appreciative of the inquiry and answered that the Association was planning to republish the parent handbook and that Kristen could be most helpful if she would retype the handbook and put the information on diskette. Only a PW parent could understand how excited Kristen was. Upon returning home to Texas, checking of the daily mail for something from the PW Association office was Kristen’s ultimate top priority in life (besides her pets, jigsaw puzzles, coupon cutouts, daycare projects, needle point, swimming, and helping her mom take care of the foster kids in our home).

“Sometime in mid-August or early September, Kristen received from Tere a blank diskette and a copy of the latest parent handbook with instructions as to

what was wanted. Kristen had some guidance from her Aunt Carol as to setting up some of the pages, and I assisted in proofing the pages for typing errors, but she did 99.99% of the work, and her desire to complete the project was normal PW perseverance. After work at Kindercare during the day, she worked nearly every day for two or three hours, and more on weekends, in getting the information into the computer. It took her almost two months to retype the whole booklet. She was extremely proud of herself and the resultant copy of the handbook. We were all proud of her, too.”

Every member of our Association can be proud of her, too—that a young person with the syndrome was able and willing to accomplish such a task. Although completion of the publication has been delayed for a number of reasons—staff changes, an office move, and the inevitable technical problems—everyone can be very sure that, because of Kristen, the forthcoming edition of the parent handbook will be a very, very special one.

Research Notes

Congratulations to **Dr. Rob Nicholls**, a member of the PWSA Scientific Advisory Board, who not only has been appointed associate professor in the Department of Genetics at Case Western Reserve University but also has received a substantial grant from the National Institutes of Health to investigate molecular mechanisms of genomic imprinting. Genomic imprinting is a process by which the expression of some genes is modified depending upon whether they are inherited from the mother or the father. Prader-Willi syndrome is the first human example of a disorder of genomic imprinting. Co-principal in the research with Dr. Nicholls is Dan Driscoll, M.D., Ph.D., at the University of Florida in Gainesville.

Suzanne Hart, Ph.D., whose research on the oral/dental characteristics of PWS was noted in the last issue of *The Gathered View*, has relocated. Anyone wishing to contact Dr. Hart concerning her PWS studies should note her new address: Suzanne Hart, Ph.D., Department of Pediatrics, Bowman Gray School of Medicine, Medical Center Blvd., Winston-Salem, N.C. 27157. Telephone (910) 716-4321.

Taking Charge Helps Conquer the Grief

by Ivy Boyle, M.D., parent

When I was at the Prader-Willi conference this year, I was asked how I, a psychiatrist and a parent of a child with PWS, dealt with my grief about having an impaired child. This is a very provocative question because, although Alex is only 7 years old, I don't see myself as grieving now. How did I change, then? I certainly grieved at his birth. Actually, the entire first year of Alex's life is a blur to me, probably because I saw it through a haze of tears.

Alex was born just before the explosion in PW diagnosis. We knew something was terribly wrong, but nobody could tell us what. (Later, after the discovery of uniparental disomy, when PWS became the "diagnosis of the month," more and more children were diagnosed at birth. We just missed it.) When Alex was a year old, though, I came across literature about Prader-Willi syndrome, and I was stunned. They were describing my child.

The second year of Alex's life passed in a mixture of tears and terror. First I had to convince all the other doctors in Alex's and my life that I knew what I was talking about. "Nonsense," said his father, also a doctor. "Nonsense," said the neurologist. "Nonsense," said the pediatrician. "Prader-Willi children eat too much. Alex isn't fat."

I didn't want Alex to have PWS; I didn't like what I read about it. Articles described lock on refrigerators, tantrums, family stress. This did not look too appealing. When Alex was 2, however,

the diagnosis was confirmed. To reassure me, the neurologist had finally sent me to see the two local experts in PWS. They were supposed to tell me I was neurotic. Unfortunately, they agreed with the diagnosis. Interestingly, this was also the beginning of my personal recovery.

Once we had a diagnosis, my husband and I dealt with it very much like we dealt with anything new in our lives. We researched it to death. We read everything we could find, not just about PWS, but about obesity, mental retardation, sleep disorders, brain functioning—anything we could get our hands on. Our lives got less sad and more interesting. We also had a stroke of luck. One of the experts in PWS was a warm, supportive physician, an excellent clinician, who was wonderfully informative to us, but was also fascinated with anything we had to tell her. She found PWS exciting, and this gave us hope. We stuck close to her and began a partnership.

When Alex was 2-1/2, an article was published about the rejuvenating qualities of growth hormone in normal adults who had poor muscle mass and fatigue. It got a lot of play in the popular press, as well. Poor muscles and fatigue sounded like our son, so into the physician's office we went, waving the article. "Funny you should mention it," she said, "I was going to discuss it with you. We've been wondering about growth hormone in these children." After lots of tests, and discussion of the risks and benefits of growth hormone, we decided to begin Alex on this medication. He was the first child with PWS in our area to try it.

If growth hormone had not been so successful with Alex, my story about grief might be different. It was very successful, however. Alex still had PWS, but was now, as a friend of mine put it, "like a piece of taffy that has been stretched." He was taller, thinner, stronger, and generally more functional. We had had wonderful success with the very first medication we tried! For my husband and myself, it was as if someone had said to us: "The syndrome is no longer fully in charge. You have some say, too." It was only a short step, then, to trying to work on other problems with Alex. When his tantrums began at age 4, our position was, "We can make this right." And we did, although it took awhile to get the correct dosages of medication. We simply did not give up.

Alex is now 7 years old, and he certainly has PWS. I don't grieve, however. He is tall, is not overweight, and is a sweet-natured child who never tantrums. His brothers adore him. I am currently at a stalemate with PWS, however, because there are problems that no medication has been able to touch. Alex is very low-functioning intellectually, and I certainly see no change in this in the near future. I am keeping my eyes open, however, and if anything emerges, my husband and I will be among the first to know.

If I had the chance to choose, I would choose not to have a child with PWS. I am crazy about Alex, however, and cannot imagine life without him. I guess my way of handling my sadness has been to refuse to feel helpless in the face of this problem. Because of this, I have changed as a person. I don't wait until "all the data is in," don't take the "experts" word as the final answer, and try to learn as much as I can, whether it's from the literature or from other parents. (PWSA-USA has been a great help there!) By taking charge, my husband and I have hopes that we can help create a future for Alex that we can be proud of.

Skin Picking and Other Forms of Self-Trauma in Prader-Willi Syndrome

by Jeanne Hanchett, M.D., The Rehabilitation Institute of Pittsburgh

About 80 percent of persons with PWS pick their skin. This behavior is one of the hallmarks of this syndrome and is helpful in establishing the diagnosis. In most persons this is mild and intermittent, occurring when there is a minor skin lesion such as a mosquito bite or slight abrasion. However, some have severe and persistent skin picking which goes on for years.

There has been no uniformly helpful treatment. Here at TRI we have had some success with using Play-Doh or Silly Putty to "keep the fingers busy." This works for short periods of time, i.e., a few weeks or a few months, but does not cause complete resolution of picking. It works best in persons who are aware of their skin picking, those who admit that they pick their skin and ask if there is something they can do to keep themselves from picking. We sometimes offer a choice of Play-Doh or Silly Putty and even offer a choice of colors and suggest that they keep it with them at all times, particularly in bed at night. If it is a concern that small pieces of this may drop off and stain furniture or carpeting, it can be enclosed in a small plastic bag which seals.

We have tried Periacin, Prozac, and topical skin creams, none of which has been helpful. One thing which we have found definitely not to be helpful is to tell the person that he/she should not pick or to say "stop picking your skin." In some cases this even results in more picking. The less attention the better. We do, however, suggest that hands be washed whenever we see blood on fingers or hands.

The second most common type of self-trauma in PWS is rectal picking. This is present in about 15 percent of our patients and appears to be more common in adolescents and adults. It is usually detected by rectal bleeding or evidence of fecal material under the fingernails. Again, we have found that telling a person not to do this is not helpful, but there are some other very practical ways to limit the habit. Since patients pick their rectum when they are sitting on the toilet, we limit the amount of time that a person can spend in the bathroom and, if necessary, have a staff member or family member stand at the bathroom door and enforce a time limit. We also do not allow patients to go to the bathroom any more frequently than we feel is necessary. We have some patients who attempt to go to the bathroom every few minutes, both to avoid time in therapies or activities that are unpleasant for them (such as exercise) and also to pick the rectum. Therefore, our patients here at TRI are almost never allowed to leave a therapy to go to the bathroom but instead must go between therapies and at other times.

Rectal picking is a very difficult symptom for parents to manage and a particularly distressing one, because of the social implications. We have had several cases where patients were felt to

have organic illness as the cause for rectal bleeding; these have included diagnoses of ulcerative colitis, regional enteritis, and polyps. On further investigation, none of these diagnoses has been found to be present. Therefore, at this time we feel that rectal bleeding in a person with PWS can be considered to be due to rectal picking. Sometimes it is necessary to have a gastroenterologic workup, particularly if bleeding is excessive. Colonoscopy usually shows an isolated area of bleeding and irritation, which is about one finger's length into the rectum. We have seen one particularly severe case which required intensive management, one case of moderate anemia related to bleeding, and one case of an abscess of the rectum related to picking. However, in most patients this habit has not caused serious injury.

We have seen many other kinds of self-trauma, all of which we feel are related to an overall tendency for persons with PWS to pick at themselves. We have many patients who have pulled out one or more toenails on multiple occasions. We have also had patients who pull out fingernails, teeth, hair, and eyelashes. We have had two cases of patients who rubbed an eye enough to give themselves recurrent conjunctivitis (pink eye). We have also noted extreme nail biting, clipping of nails so short that they bleed, excessive pulling of "hang nails" and self-inflicted injury with pins, needles, tacks, and earrings.

Some of these behaviors seem to be more common when the person is anxious or upset, but most of the time we are unable to ascertain why patients traumatize themselves. Although pain threshold seems to be higher in PWS, this does not account for these widespread behaviors. It may be related to problems of self-image or self-esteem since some parents report that when a person with PWS is unhappy with himself/herself, picking is more frequent. In other persons, it may be related to boredom or "time on their hands." Many times there is no clear relationship to any factor.

In summary, there is no uniformly successful way to deal with self-traumatizing behavior in PWS. Too much attention on the part of parents seems to be counter-productive. A matter-of-fact approach of keeping one's hands clean seems to work the best for skin picking. Limiting time spent in the bathroom is helpful in reducing rectal picking.

Does someone you
picking? Has any

Q:

know have difficulty with skin
particular treatment or measure
been successful in their case? Please write or call the national
office to share your experience with other families.

Dr. Hanchett is a pediatrician with The Rehabilitation Institute of Pittsburgh (TRI), and member of the PWSA (USA) Scientific Advisory Board.

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International Prader-Willi Syndrome Organisation

2nd International Conference

June 15-18, 1995

Oslo, Norway

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Obesity Management
Psychopharmacology*

*Educational Aspects
Living and Working
Training of Professionals
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IPWSO*

A New Day...

continued from page 1

new logo and colors. There are letterhead and note cards with accompanying envelopes and business cards for our office staff. Our new national brochure and press kit—both of which will be distributed next spring during our first national awareness week—are especially noteworthy.

Through the past year of work on this image enhancement project, there were three examples of significant corporate benevolence. To the following we owe a debt of gratitude:

* **GRAPHCOM**, a "mom and pop" design firm in New Britain, Conn., which contributed roughly \$2 in services for every \$1 it charged during a full one-year commitment;

* **BellSouth Telecommunications**, without whom we would not have—because we simply could not have afforded—a press kit of "Madison Avenue" quality; and

* **Sweet Printing Co.** of Glastonbury, Conn., which paid for the entire cost of shipping some 4,000 pounds of new materials to our headquarters in St. Louis.

We now have a new office, new office leadership, a new logo, national brochure, press kit, image, and colors. May we have the enthusiasm to match. Let us celebrate our new beginning.

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