

The Gathered View

for the younger set

Newsletter of the Prader-Willi Syndrome Association

MAY-JUNE 1989

VOLUME IV, NUMBER 3

President's Message

With thirty-five years experience as a physician it has been possible for me to have served on any number of committees and organizations. More and more our litigious society emphasizes the need for members of such groups to become knowledgeable in the rules and by-laws that govern such activities. Consequently, groups develop increasingly complex rules of operation that hopefully will permit safe conduct throughout the life of the group or organization. The board of directors of the PWSA has recently completed appropriate revisions of the by-laws so they will be in accordance with the current thinking of the board and their belief in how the Association should function in order to carry out the mandate of its founders. Similarly, each of our chapters has a set of by-laws that provides a guide for the conduct of the affairs of the group. By-laws can only be useful if the members of the group respect their meaning and are willing to be governed by such rules and to carry out the responsibilities that are imposed on the individuals of the organization by those rules.

This past weekend I became aware of two widely disparate events that focused my attention on these two concepts. For the past twenty or so years this nation has been in an upheaval over the concept of rights as a result of the discriminatory practices regarding education and voting rights in the South. This is a complex issue and I certainly can't define the problem, the involved factors or any of the multitudinous consequences in anything as brief as this bi-monthly letter. The first problem that I noted was the election of the mayor of the City of Los Angeles. According to the news reports that I heard, Mayor Bradley won an easy victory in an election in which twenty-five percent of the eligible voters accepted their *responsibility* and cast a ballot. That means that seventy-five percent *did not accept the responsibility to carry out their rights*. This is almost unfathomable that the country's largest city, with probably the greatest conglomeration of minorities in recorded history basically doesn't care how or who runs their lives. The second occurrence was closer to home. It was Saturday morning and with a little coaching from my "honey-do" list, I packed all of the cardboard boxes and newspapers into the station wagon and headed for the collection bins that have been set out to raise money for our schools. Lo and behold there was a newspaper bin, but nothing for the cardboard. It seems my well-to-do neighbors felt it was too much trouble to follow the simple rules to deposit into the containers so marked only flattened kraft board boxes without glazed or plastic coatings. It became too expensive for the volunteer efforts of the scavenging company to correct for their laziness and sort out improperly deposited material and they quit collecting the cardboard.

My point should be obvious by now that the PWSA or any of its affiliates cannot survive to achieve their goals if we as individuals neglect to perform our share of the efforts that will make survival of the organization possible. The presence of a rule is useless without living support of the principles involved. Membership responsibility includes dues and donations, sharing knowledge and information with others through *The Gathered View*, attending meetings, responding to requests from the Executive Director, voting for directors and officers through direct participation or proxy balloting and a thousand other little bits of effort that will combine to permit our organization to carry out the goals on which we are founded. -- Delfin J. Beltran, President

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PWSA

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Conference Time is Election Time

PWSA is operated on the structure headed by a 12-person Board of Directors. These directors are elected by the general membership, at the annual conference, to serve a 3-year term. At the end of their 3-year term, board members are asked if they will be seeking another term. Those interested are requested to submit a photo, if available, and a few paragraphs of general information for our readers. Nominations for those same seats may be made at this time or when nominations are opened to the floor at the general meeting. To be a nominee, a person must be willing to attend two yearly board meetings at their own expense, and serve on committees during their term. Any nominations received prior to the printing of the ballots will appear on the ballot. Nominations made during the general meeting will be posted at the conference.

Members who are not able to attend the conference are given the opportunity to cast a proxy ballot. Proxy means you are asking someone else to represent you because you cannot be present to vote yourself. Your proxy ballot may be given to the person you have asked to represent you, or it may be mailed to the national PWSA office. If sent to PWSA, the extra votes are turned over to the person at the conference. Members present at the conference are given their ballots at the registration desk following the general meeting. As a member you are allowed one ballot as an individual paid member or one ballot as a paid organization. Family members are entitled to receive two ballots. You are entitled to cast one vote for each board vacancy (there are five seats up for election this year) but you may cast only one vote for each candidate of your choice. In other words, your five votes may not be cast for one person.

Information on the incumbents is included in this issue. The actual proxy ballot will be found on page 12.

SSI

The National Organization for Rare Disorders (NORD) has been working with the Social Security Administration (SSA) to rectify the denials of SSI to rare disorders because they are not listed in the SSA's Listing of Impairments. We find this interesting, because we had been informed that there was no such listing, every individual case had to be investigated.

At any rate, NORD is suggesting that the SSA revise their list to focus more on generic medical criteria, such as symptoms, so approval will be made on the disability.

Orphan Commission Report (From NORD ON-LINE)

The report of the National Commission of Orphan Diseases was submitted to Congress during April 1989. A few major findings include:

- Rare Disease Research (1987): Federal Government, \$1.3 billion; drug companies, \$51.6 million; foundations, \$41.6 million.
- Of the \$1.3 billion, over half was spent on approximately 200 rare forms of cancer, leaving only \$640 million for the 4,800 orphan diseases.
- Funding is harder to obtain for rare disease research.
- Lack of funds is the single greatest barrier to discovery of treatment.
- Progress is inhibited by lack of funding and lack of coordination of existing resources.
- 47% of researchers report it is difficult to find sufficient number of patients to participate in studies.
- 76% of rare disease patients report it is difficult to obtain information about research projects.
- 42% of doctors say they need, but are unable to find, printed information to give to their rare disease patients concerning their illness.
- 39% of physicians (in survey) had used an investigational drug for at least one of their patients. Of those who had never used an experimental treatment, 72% said they would not consider using them.
- From another survey: 31% took between 1 & 5 years to receive a proper diagnosis; 15% went

undiagnosed 6 or more years; 45% said their illness caused extreme financial hardship; 42% reported their disorder prevents them from working or attending school.

- A survey of 106 foundations found only 12 foundations funded rare disease research grants. These 12 foundations devoted only 1.3% of their medical research budget to rare disease grants.

- Congress has not adequately funded the FDA Orphan Products Development Program. \$12 million was authorized to be spent in 1988, but only \$7 million was appropriated, with not less than \$5 million to be spent on grants to scientists developing new treatments for rare disease. Since the Orphan Drug Act was implemented in 1983, 257 orphan products have been designated by the FDA, and 33 of those products are approved for marketing.

- The Commission concluded that rare disease research and product development are largely uncoordinated and underfunded; information is lacking and poorly disseminated; the financial burden of an orphan disease can reduce a family to poverty. In short, the needs of patients with orphan diseases are not being adequately met.

- A full copy of the report can be obtained from the National Commission on Orphan Diseases, Park Bldg., Room 1-20, 5600 Fishers Lane, Rockville, MD 20857.

New Brochures

Great progress is being made by committee members in developing a series of information brochures for PWS. Two groups, one a parent group in PA and the Midlantic Chapter, each donated \$200 to the national brochure fund rather than go to the expense of developing their own. Special consideration has gone into the development of these brochures in order that chapters may use them also. Considering our limited budget, the board allotted \$1500 to develop and print the first supply of these new brochures. Any other donations would be appreciated, and would improve the quality of the finished products.

The Gathered View is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. The opinions expressed in *The Gathered View* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of the PWSA. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$20.00 per year Individual; \$25.00 per year Family, and \$30.00 per year for Agencies/Professionals (U.S. Funds). Send dues and change of address to: PWSA, 6490 Excelsior Blvd., E-102, St. Louis Park, MN 55426. Any questions? Call us at (612) 926-1947.

Words & Initials You May Run Into

Practitioners:

- *Orthopedists* specialize in bone and joint problems
- *Neurologists* specialize in brain and nerve function
- *Neurosurgeons* are skilled in surgery of the brain and nerves
- *Physiatrists* are medical doctors who specialize in the mechanics of how the body moves and functions
- *Occupational and Physical Therapists* follow doctors' orders and plan programs to improve eye-hand-body function
- *Orthotists* are experts in braces and supports
- *Psychologists* are skilled in counseling and testing social, emotional and academic functions
- *Dieticians* are trained to evaluate and plan special diets
- *Clinical Nurses* are skilled in specialized problems
- *Speech and Language Pathologists* are skilled in helping with problems of communication
- *Education specialists* are certified teachers who can remediate learning problems
- *Social Workers* counsel children and families, make referrals for help

Medical terms:

- *Cryptorchidism* = undescended testicles
- *Delayed Milestones* = delay in walking, talking, speech, etc.
- *Diabetes Mellitus* = most common form of diabetes
- *Endocrine Glands* = pituitary, thyroid, ovaries, testes
- *Etiology* = study of causes of diseases or disorders
- *Hypogenitalism* or *Hypogonadism* = genital organs are undersized or non-existent

- *Hypotonia* = poor muscle tone; muscles are soft, weak and flabby
- *Lordosis, Kyphosis* and *Scoliosis* = forms of spinal deformities
- *Metabolic* = body's process of absorbing the nourishment from food and turning it into energy or stored fat
- *Morbid Obesity* = extreme overweight (danger of causing death)
- *Narrow Bifrontal Diameter* = narrow forehead
- *Secondary Sexual Characteristics* = body changes accompanying the onset of puberty, such as growth of underarm hair, changing of the voice, beard growth, breast development

Educational initials:

- *I.E.P.* = individual educational program or plan (contact between you and the school system as to what they will provide)
- *94-142* = Public Law numbered 94-142 which states mandated education, "The Education of All Handicapped Children Act of 1975"
- *99-457* = an amendment to P.L. 94-142 passed in 1986 which requires states to provide a free, appropriate education to all children ages 3 to 5 by school year 1991-92 and provides funds for states to serve ages birth through 2 years with handicaps
- *I.Q.* = tested level of intelligence
- *TMR & EMR* = Trainable (lower I.Q.) and Educable mentally retarded
- *Spec. Ed.* = Special Education, specifically designed instruction, usually given in a special resource room in regular schools

Early Intervention

Infants are active learners from birth. Having a handicap doesn't change this fact, however, these infants may need extra help in developing the skills needed to learn and grow. This help may come from structured early intervention programs as well as from normal, everyday interactions with parents and other family members. Parents need to become aware of the importance of their role in facilitating, guiding and supporting their baby's development. With time and understanding, parents can become their baby's best ally in interpreting needs. Also, with time and understanding, they will be able to develop the coping skills they'll need to face the day-to-day realities of the handicap.

The majority of new parents start out with little preparation or special training in meeting the unique, ongoing challenges and demands of a newborn. Even experienced parents must readjust their lives whenever another child is added to the family. Parents of handicapped children must deal not only with the normal challenges of parenthood, but with additional stresses and concerns for which they are typically not prepared.

Parents often experience a range of emotions during the hospital stay that may or may not be offset by a caring and understanding hospital staff or doctor and by the support and encouragement of family and friends.

Parents with vulnerable infants find it more difficult to put aside their fears. The stress and emotions of the first days and weeks of the baby's life will take time to fade, and anxiety about the future is very real. With PWS, parents frequently must learn complicated feeding procedures, handling of a hypotonic infant, continuous monitoring because of a fragile infant, and the possibility of the financial consequences. Finding adequate child care may be more difficult causing parents to miss out on sorely needed respite and privacy at a time when it is needed most. Single parents may feel these stresses even more intensely.

All of these concerns and pressures can cause many parents of infants with handicaps to feel isolated and singularly responsible for raising and caring for their infant. Some parents may always have difficulty coping with a handicapped child. It is important to remember that the emotional and physical demands that accompany the birth of a child with special needs should never be underestimated and outside help should be sought.

Board Incumbents

Janalee Tomaseski-Heinemann is a pediatric medical social worker at St. Louis Children's Hospital, and the parent of a 16 year old son who has Prader-Willi syndrome. Janalee and her husband Al founded the PWS MO Chapter in 1982 and are editors of their newsletter. Janalee has written several articles reprinted by our national association, wrote "Sometimes I'm Mad..." and a chapter for the new "Management of PWS" book. Janalee has been a very active board member and has contributed to several very important projects.

On a professional level, Janalee works with children with cancer and is involved with several support groups and programs. She has 5 children, 2 grandchildren. Because she and Al believe in working together on PW rather than working against each other due to PW, Janalee commented that in having her on the board, you are getting two for the price of one!



Lota Mitchell has served on the board for three terms, serving as the chairperson the past two years. She has been a very active board member, authoring one of our Overviews, spending a great deal of time and effort into completing our Manual and is presently working hard on the informational brochure package. Lota is the mother of a 19 year old daughter with PWS.

Lota has a Master's degree in Social Work and provides the Employee Assistance Program at Westinghouse Electric Corporation locations in Pittsburgh. She is interested in serving another term for PWSA.

Board member Fausta Deterling writes: "I have found it rewarding and a privilege to serve on such a dedicated board but feel that it is now time to step aside. I feel that we have so many interested people in our membership who would serve the board well. As I look at our current board, there are nine parents and three non-parent (PWS) professionals. There are six members of the board who work in the health-care field. This is a good balance, and I hope that in selecting nominees, we will be able to maintain the type of balance which will best represent the membership."

Volunteers

A few months ago two professionals, psychologist Louise Greenswag and Randy Alexander, M.D., volunteered to start a column for the newsletter titled "For Your Information," fielding any questions any of our members might have. We now have a third professional, nutritionist Maria Ferraco offering to share her knowledge of this syndrome. Members will certainly recognize Louise's name as she has donated a great deal of time in support of our organization and recently joined with Dr. Alexander in editing our latest management book on PWS. Maria has a great deal of experience to offer in the field of nutrition from her work at the Rehabilitation Institute of Pittsburgh.

We hope our members will take advantage of these generous offers and share some questions with us in order that we may start this helpful column.

Conference Registration Time is Here

If you didn't receive your conference registration packet by now either we or the postal system let you down! If interested, please let us know if you need the forms to register.

11th Annual (1st International) Prader-Willi Syndrome Association Conference

Where: Calgary, Alberta, Canada

When: July 20-22, 1989 (pre-conference July 19)

Hotel Contact: Marlborough Inn, Canada 1-800-661-1464, U.S. 1-403-248-8888

Group Travel: Outside MN 1-800-222-7907; MN 1-800-747-2252 or 881-7811. Since there are so many "specials" available, check your local sources as well as Group Travel for the best available air rate.

Any questions: PWSA 1-612-926-1947

To enter Canada, ALL will need a passport, voter's I.D. card or certified copy of birth certificate. Drivers will need proof of insurance (I.D. card).

The Rain Man in Our World of PWS

(excerpts from the MO newsletter by Janalee Heinemann)

Two days after Matt's departure from a Christmas visit, Al and I went to see Dustin Hoffman in "Rain Man," and laughed and cried in empathy. Although Dustin's character was that of a person whose mental disability was autism rather than PWS, it reminded us of the similarities more than the dissimilarities. Al felt sad for a few days after the movie and finally realized the reason was because it brought to the surface that chronic grief we all have tucked away, mourning the son that would never be.

Janalee mentioned several words: TEDIOUS is the word that looms the largest, like a big oak tree in all of our back yards. This is a word that has to be experienced rather than explained. Tediousness covers a broad realm of idiosyncrasies of many brain-damaged people.

REPETITIVENESS is one of the main branches on the tedious tree. As Raymond went over the same phrases time and time again, sometimes the same phrases flow out of Matt's mouth like a player piano stuck on the same song. STUBBORNNESS is another large branch of the tedious tree. Don't try to use logic to explain alternatives. Matt's world is black and white with no shades of gray allowed.

A NEED FOR ROUTINE can go from a minor tedious issue to a major problem during holidays or traveling. Try to convince one of our "kids" that you are going to skip an item of food that they always have at dinner, or that lunch will be at 2:00 rather than 12:00! Another common branch of the tedious tree is a SENSE OF URGENCY, where even minor issues seem very important to them. Raymond's brother (like we parents) was often perplexed and frustrated with seemingly little issues being blown out of proportion.

Another tree we all grow is the BITTERSWEET TREE. This one grows best when you don't know whether to laugh or cry. Matt longs for a driver's license at 16 -- like all other boys his age but he doesn't have the capacity to make them a reality. Raymond's LACK OF A SENSE OF HUMOR made us laugh. The subtleness of humor seldom fits into Matt's world. One of the hardest parts of the Bittersweet Tree to accept is the LACK OF BONDING. Although Matt can be as sweet as can be and will show affection more than most boys his age, he and other young people with PWS usually do not feel the pain of separation that most people do. Sometimes we laugh at the Bittersweet Tree and sometimes we cry.

At Risk Families

Guest contributors Factor and Heller (Addvantage) write: "Last October, a 51 year old man with mental retardation was shot by his 81 year old widowed mother. The mother, who was in poor health, attempted to murder her son and take her own life. Fortunately, both were found by a neighbor and survived. This tragedy occurred because the mother feared her son would not be properly taken care of after she died. Although this action was extreme, her plight reflects the concerns of many older parents caring for offspring with developmental disabilities (DD) at home. Because they have not planned for their child's future, there is often a crisis when they die or become too infirm to provide care.

To better understand why many older parents do not make permanent plans, the Institute for the Study of Developmental Disabilities (University of Illinois at Chicago) interviewed a statewide sample of 100 families caring for a disabled relative age 30 or older at home. One-third of the families resided in rural communities and 25 were black. The average ages of the DD family members and their caregivers were 38 and 63, respectively. Slightly over half the caregivers expected their disabled relative to live with another family member, usually a brother or sister, rather than enter a residential program when they could no longer provide care. Although parents had strong concerns about transferring caregiving responsibilities to their other children, any feelings of guilt were offset by negative perceptions about the quality of care in residential placements.

Several factors help explain why so few parents plan for their child's future. Most had committed themselves to keeping their offspring at home. Also, many older parents find that having their disabled child at home eases their own loneliness and provides them with a sense of purpose. Consequently, the thought of planning for this child beyond their own lifetime is quite painful. Concerns about residential placement and the guilt of burdening other relatives with their caregiving responsibilities often result in a lack of planning."

The national office works with a great number of parents seeking a suitable placement for their children and young adults with PWS. Even though developing a residential facility can be very time consuming and a great deal of work, we enjoy sharing the joy of these young people and their families when a placement is made. Many parents state, "there is no way my son or daughter will be happy in a group home," and these same parents come back a short time later relating how wonderful the placement has worked out. On the other hand, we are saddened when approached by parents in their late 60s and 70s who have older adults that they can no longer care for and finding a placement for an older person is far more difficult. We do hope our families will continue to seek what is best for their child, and that certainly can be a group home placement.

Our Monthly Thank You!

We are happy to report a total addition of \$130 to our CIT fund; \$1129.84 to our research fund; \$297.18 to our operating budget, and a special \$200 donation for brochure development. And, as always, we thank members who pay a larger amount than is required for dues.

A special thank you goes to our regular donors: Olson, Dixon, and Boyd; generous donations from non-members Leonard (for member Mook), VFW (for member Krebsbach), Liberal Club (for member DeSa), Winnebago U.F. and National Cap.UW; memorial donations for Phillips (Harbor House), and for Kappler (Melissa Haynes Memorial); and other member donations: Richarz(2), Smith, Tracy, Nanzig, Auten, Weiner, Singer, Castle, Daly, Van Zomeren, Schneider, Uzendowski, Parent, Willinsky (Kandall) and a CFC.

Dues and donations are the major source of income our group has to continue operation.

Excessive Daytime Sleepiness

by B. Helbring-Zwansenburg, M.D.
Dr. J.H. Pameijer Foundation, Rotterdam

"In 1986 we started a study in The Netherlands (with the assistance of the PWA in this country) to investigate the possibility that excessive daytime sleepiness is a characteristic symptom of PWS. We consider excessive daytime sleepiness (EDS) present if there are periods of sleepiness in the morning, in the afternoon, and in the evening. The phenomenon of EDS has not been mentioned as one of the characteristics of the (syndrome). There are, however, a few authors in literature who consider EDS as a symptom of the (syndrome). Some of them suppose the symptom occurs especially in obese patients. Our own clinical experience, however, is that EDS occurs in many patients with the syndrome, irrespective of their obesity. Consequently, the question arose, whether EDS is one of the characteristics of the PWS. To answer this question we compared a group of patients with PW in The Netherlands with a control group. To our knowledge no publications are available where patients have been compared with controls. A group of patients with the Down syndrome served as the control group.

As a method of study we developed a questionnaire, comprising questions relating to the symptoms of PWS and to the sleep patterns. Patients using medications, which might influence the sleep patterns, have been excluded from the study.

Our PW group consists of 60 persons, the Down group of 61 persons. We matched the two group to age and gender. The mean age of the PW group was 19 years, and of the Down group 19.1 years. EDS was present in 75% of the PW patients and in 11.5% of the Down patients.

We might conclude that EDS occurs more often in the PW (syndrome) than in the Down syndrome. This conclusion became more objective after making corrections in our statistical analysis for confounders like age, gender, obesity, total sleeping time and snoring (as a phenomenon of the apnea syndrome).

This finally led to the calculation of an Odd's ratio of 30.7, which means that EDS occurs about 30 times more in the PWS than in the Down

syndrome. In our opinion EDS is an indication of a disturbance of the sleep-wake cycle. Perhaps the temper tantrums we frequently observe in the patients with PW are secondary to this cycle-disturbance."

A special thanks to the Prader-Willi Vereniging, Netherlands, for sharing this paper with us.

Thoughts on Education

(from National Fragile X Foundation)

Fragile X Syndrome is an inherited abnormality of the X chromosome which causes disabilities ranging from varying degrees of learning problems to mental retardation. Some of their characteristics are similar to those found in PWS, such as language delays, behavior problems, poor eye contact, delayed motor development. These are some excerpts from an interview with Marcia L. Braden, Education Specialist:

Some children process information better when presented visually. Parents have found with PWS that presenting visually and auditorially simultaneously helps.

Utilize pictorial approach to behavior management. Visual cueing can be used to promote spontaneous methods of behavioral control which may eventually become integrated into the child's internal monitoring system.

The current "buzz term" in special education is Least Restrictive Environment. This new concept has caused repeated concern for educators, parents and special needs children while attempting to meet complex needs through different delivery systems. While it might be a good way to enhance social development, it certainly will not take the place of individualized curriculum and special education services.

The issue of class size may not be as critical as staff-to-pupil ratio.

In order to be effective as a teacher, it is critical to understand the basic behaviors associated with a syndrome; in particular strong reactions to change (need for pre-programming).

Michigan Conference

"Relatively Speaking," a conference for the entire family and professionals. August 17-19, 1989, The Peer Support Project, 300 N. Washington Square, Ste. 205, Lansing, MI 48933. (517) 487-9260.

Pictures Tell The Story

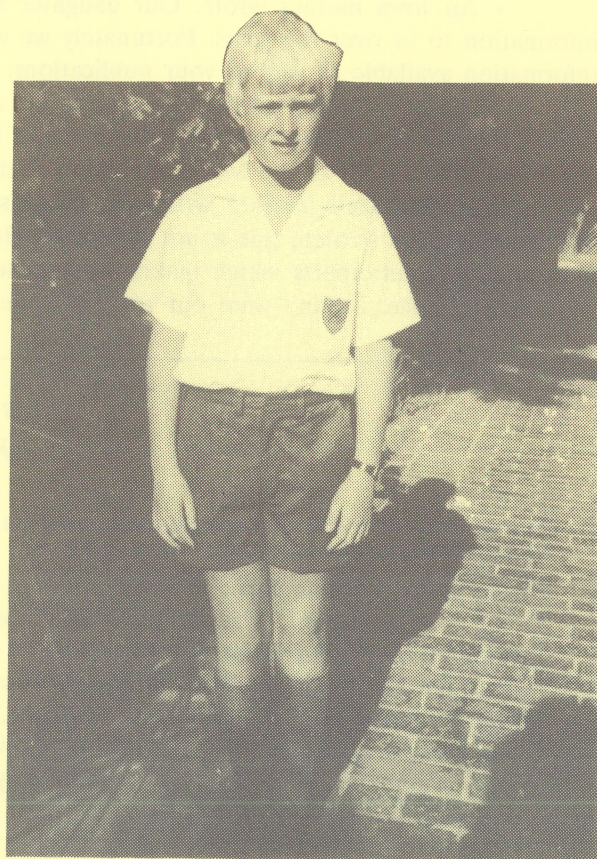


A couple of champs!

Heidi and Joe are members of the Fridley (MN) Adapted Soccer and Floor Hockey Team. Heidi has been a team member for 4 years and lettered each year in both sports. This is Joe's first year and he is doing great. The team was 2nd in the State in Soccer, and State champs in Floor Hockey. We congratulate both of these young people and thank the parents for sharing the good news!

Meet Jassim!

We thank one of our members from South Africa for sharing a photo and success story with us. Her son is doing well in the weight and behavior areas (at age 13) and states part of the motivation was their trip to a conference in 1986. She writes, "That made such a change for Jassim, from that day he accepted himself, and realized that he was different, but not the only one. It has also motivated him to keep his weight down. I enjoy getting the Gathered View and admire all the work you do. We hope to join you again at a conference, if only it wasn't so far away, we would be there every year."



A Tribute to Bradley

A Canadian family who lost their son a short time ago shared this tribute with us:

Everyone has a purpose in life, no matter how long or short that life may be. We all have a role to play, big or small, important or non-important. Brad's purpose in life was to show all who cared to learn and listen that special people, like himself, have feelings and desires, a need to love and be loved and contribute to society, to develop their individual personalities and talents, and to play their role in life to the best of their ability and most important that they have a right to all of these.

Brad's role started at birth and ended a few days ago. It was a very strenuous part, mentally, emotionally and physically.

Many positive things can be said about Brad's attitude toward life, but to put it simply, he wanted to experience all life had to offer with no regrets for having failed, as long as he had a chance to try for success.

People who knew Brad will remember him as an emotional, caring person who was not afraid to express himself to people he knew. He remembered special things about people he had met and always had good things to say about them. As one of his aunts would say, "He had a hug for everyone, that came from the heart."

In his short time on earth, Brad endured more physical hardships than any one person should have to bear. In the end it was his body that finally gave up, not his spirit.

We believe that God could see that Brad had completed his part to the best of his capabilities and called him home.

Did Brad fulfill his purpose? We believe he did!

Other Parents Share

▪ An Iowa mother wrote: Our daughter Melissa died March 22nd. The PWSA has been a great source of information to us over the years. Fortunately we were able to attend two conferences and have read and re-read any information available as well as your publications.

Despite the many problems, Melissa was a happy, loving person. She leaves us with so many memories and a real loss. We will always remember the fun and laughter she brought to all of us. It is our hope that someday PWS will be as well known as the March of Dimes, Cerebral Palsy, Heart Association, and so on.

▪ A Wisconsin mother writes, in response to the mother that advised throwing out all convenience foods and cooking from scratch, this is not necessary. Health food stores carry hot dogs, cake mixes, TV dinners, and many natural food counterparts which makes it possible to follow the eliminated sugar, artificial colors, etc. diet without the inconvenience. I didn't want our readers to be alarmed by the work involved in undertaking this diet.

Joys of a PW Parent *(Kentucky mother)*

Seeing him walk down the aisle at graduation.

Buying flowers for his senior prom date.

Flying alone -- round trip.

Going to a restaurant, ordering a strawberry daiquiri while wearing his handmade alligator sun visor hat.

Praying at church for those less fortunate.

Asking me to call on the Lord instead of checking up on him.

Seeing his pride when he tells he is an uncle.

Being able to read and write enough to survive.

When he tells me, "Mom, I ports (supports) you like you ports me."

Information Sought

As the statistics from NORD state, research information is not always available. PWSA members have been terrific in responding to our requests for information and we have just completed computerizing our extensive questionnaire study. In the next few months we may be asking you for further data and encouraging those not in the survey to add to our impressive numbers. In the meantime, we have been asked to obtain information on the following subjects:

VOCATIONAL PLACEMENT

Employer _____

Job Description _____

Is placement successful? Yes _____ No _____ If no, why? _____

Are they happy with job? Yes _____ No _____ Are you happy with their placement? Yes _____ No _____

List previous employments _____

List problems with previous jobs (were attempts made to solve problems, what previous information was shared with employers, were job coaches used, etc.)

MEDICATIONS

Is your person with PW on medications? Yes _____ No _____

<i>Drug</i>	<i>Age Prescribed</i>	<i>Dose Given</i>	<i>Length Time Used</i>	<i>Why Prescribed</i>	<i>Successful?</i>	<i>Side Effects</i>
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LONG TERM EFFECTS ON FAMILY

Has PW dieting in your home affected the other children in the family? Yes _____ No _____

What effects (anorexia, overeating, behavior problems, etc.)? List problems and age of person when occurred.

What is a proxy ballot? A proxy ballot gives you the opportunity to vote even though you cannot be present at the conference. *How do I pick my proxy?* Anyone who is going to be at the conference can act as a proxy for you. This can be a board member, an officer, or any member of PWSA. For your convenience the board and officers are listed on page two. *Why should I submit a proxy?* This is your opportunity to be an active member. If no proxies are submitted, just the members in attendance will make the decisions. *Can I tell my proxy how to vote?* Yes, you may direct him/her how you want your ballot case, or you may let them choose. *What do I do with my proxy ballot?* Give it directly to the person you choose, or mail it to PWSA and they will give it to your proxy at the meeting.

PROXY BALLOT

I would like the following person to act as my proxy in all voting transpiring during the 1989 general meeting:

Name of proxy: _____

Please vote on my behalf or follow these guidelines: _____

Date: _____

Signature(s): _____

Must be returned to PWSA before July 1, 1989. THIS IS YOUR OFFICIAL PROXY and the only legal acceptable medium to be used (reproductions in other newsletters or phone calls are not legal).

PRADER-WILLI SYNDROME ASSOCIATION

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First Class Mail