

# THE GATHERED VIEW

*for the younger set*

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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## PRESIDENT'S MESSAGE

This issue of the GATHERED VIEW will go out to over 1300 members of the Prader-Willi Syndrome Association. I checked back through the old copies of the newsletter to look at the growth of this organization since its inception in the summer of 1975. Volume 1, Number 2, of the GATHERED VIEW was published for twenty-six members paying dues of five dollars. By the time that the first PWSA Conference was held in June, 1979, membership was near 400 and dues had risen to ten dollars. Another three years saw membership almost double to over seven hundred and dues rise to fifteen dollars. The PWSA is now starting its twelfth year of service to a membership that has again almost doubled. It was not without great concern and deliberation that your Board of Directors reviewed the budget for 1987 and concluded that it would be necessary to raise the dues to cover the expenses.

Is there an alternative to a dues increase? There may be the next time the question comes up. That quite simply put is more members. As the figures cited above show, the membership already shows healthy growth in response to increased awareness of PWS. The initial goal to increase awareness of the syndrome, among the public and professionals, seems to be increasingly effective. The incidence of this syndrome is estimated at about one in ten thousand live births (3,749,000 in 1984). Thus, there are about 400 new families, plus a like number of various professionals, each year who can benefit as you have done in the past from knowing about the PWSA. Now look once again at the numbers. If each of us, as members, were successful in contacting others to the degree that all new persons with PW were known, we would have a membership approaching ten thousand concerned parents and their professionals.

Why has this push for membership come up at this time? The activities of your Board of Directors and the Executive Director as summarized in this recent past meeting of the board and the conference in Sacramento are the clues. First, is the successful Scientific Session at the June meeting. This means that your organization may well become the recognized focus for professional activities related to PWS. Next year's conference will have a larger university affiliated day devoted to PWS. Second, the PWS Crisis Center may well become a bricks and mortar reality in the next year. The third, and major reason, is related to a realistic evaluation of where we are in the form of a central office and what it takes to carry out that responsibility.

Marge Wett carries the burden of the office by donating sixty hour weeks. She is assisted for twenty-four hours a week by Judy Goff. Your Board, at its December meeting, analyzed the jobs being done by this pair and were appalled at the conclusion that hiring an equivalent amount of help would probably cost in excess of sixty thousand dollars a year. Compare that with the only source of revenue



available, dues. Thanks to the generosity of several members making payments of one hundred dollars a year as patron members and many making payments of thirty dollars as contributing members, we have dues revenue of nearly twenty thousand dollars or one-third of the amount necessary to carry out our responsibilities realistically.

The bottom line to this issue's letter is a dedicated, concerted membership drive by every person that knows about the PWSA. Each and every person that comes in contact with your life as a PWS family member, each physician, special education teacher, vocational person, speech therapist, social worker, occupational therapist or whatever capacity, needs to be solicited as a member of this Association. As you have heard me say many times, each of you as a family member is the PWS expert with the knowledge and power to help someone else know more about the problems of PW persons and their support group. Failure of each of us to carry out this task could mean the loss of the ability of this Association to survive economically. Love creates survival with a gift, economics is created when we need to ask.

*Delfin J. Beltran, MD*

President

(To make it easier to solicit some new members, we have included a membership application on page 11 so this can be easily removed and used.)

#### PWSA HONORS RITA WELCH

In recognition of the efforts of Rita, President Sam Beltran, Board Member Dorothy Thompson and Executive Director Marge Wett, traveled to NY in November as part of their program and to present Rita with well-deserved recognition. While presenting Rita with a plaque, Marge said, "I'm privileged today to be here as a representative of the national PWSA. I'm glad to be the one to honor Rita as President of the NY PWA and recognize her contributions to your chapter and to the national organization.

Any attempt to list what Rita has contributed to the PW cause would keep me up here all day. If I tried to list what Rita has accomplished, that list would be sorely incomplete. No one could possibly know all of the ways in which Rita has served the NY association, people with PW, and the national association. Rita has contributed far and above what could be expected of any person. A member of another state chapter was elected president and resigned after serving 6 months. She stated no one person was capable of doing what was expected of her--no one

could give that level of output--no one could take that frustration. Luckily for NY, Rita has demonstrated she is a person who can. She not only has been capable of doing what was expected but has done far more than could even be anticipated.

As Executive Director of PWSA, I am very proud to point to NY as a model for other chapters. We all know no one person can be a chapter. A chapter is a group of people--but in order to be a successful group, the necessary leadership must be present. We recognize Rita as that necessary leader--we would like to thank her for all she has given. We would like to thank her for all of the people she has affected, people who cannot thank her themselves. We would like to thank Rita and the entire NY chapter and state we are proud to have all of you as members of the national PWSA.

Rita, we would like to present you with this plaque in special recognition for all you have done for all of us."



A NEW YEAR WITH GREAT PROMISE

Has your mailbox been stuffed with requests for donations? As the year draws to a close, many organizations do fund raising. It's the season of good will, it's the end of the year, and it is decision time as to who deserves your support.

"Who should we donate to?" "Who deserves our support?" "Who needs us most?" We hope that all of you can answer PWSA to those questions. We hope you feel the PWSA accomplishments warrant your support. We hope all of you understand your support is necessary because we have very few other sources available to us. Even though we have a great bunch of volunteers, most of the projects that come about--projects to benefit our members--are based on our financial ability. This is a fact of life.

Recently envelopes were mailed to each member, along with applications for the Crisis Intervention and Transitional Center. Three funds need your support:

Crisis Intervention & Transitional Center

(\$50,000 is needed for the building and funds are needed to support admissions unable to obtain funding.)

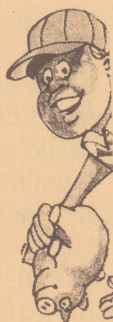
Research Fund

(Small needs grants, seed-money for larger studies, projects directly relating to PWS)

Operating Funds

(Dues cannot support our operating budget. Even though dues have been raised, we still need the help of members capable of paying higher dues to continue to use the contributing and patron dues amounts.)

One of our members recently asked us about united funds. Some funds honor requests that donations be shared with PWSA, some do not. The problem is that they do not inform you, they just ignore your request. Also, a certain portion of the contribution is used to operate the fund. United funds also do not inform an organization where the donation comes from so we have no way to know where the donation has come from. We would like to suggest that a smaller amount could be contributed to your local united fund and then make your PWSA donation direct.



A few members have informed those who have contacted them that this year all of their donations will be going to PWSA and have started making monthly contributions. One member said some people even ask what is PWS and then they have the opportunity to educate a new person.

Last year we asked for names and addresses of friends and relatives that we could contact directly in order to meet the matching McDonald's grant. Many names were shared with us and we topped the \$25,000 needed in a few months. We plan on contacting these people again this year. If new members would like to share names and complete addresses for this purpose, we could build this listing and achieve a higher goal.

We have been pleased by what has been accomplished in the past and look forward to greater promise in 1987. We still have grave needs that have not been met, we must continue to do our best to better the lives of all of our children and families.

We need support from all of you to make 1987 the best year PWSA has ever had.

SOME PEOPLE ASK

What is genetics? Genetics is the study of heredity or the way conditions or traits are passed down in families. Genetic material determines many things about us--hair color, bone structure, etc. When there is too much, too little, or altered genetic material, the individual has a genetic disorder. This genetic disorder can have a mild effect, such as color blindness, or can be so severe as to cause early death.

What is genetic counseling? Genetic counseling helps an individual, parent, or a couple understand a genetic problem in their family and the risks for it recurring. A diagnosis of the genetic disorder must be made by a trained geneticist. A physical examination, family history, medical history and special laboratory tests are used to make the diagnosis. The diagnosis may cause stress for the family. Genetic counseling is more than giving the facts, it is giving emotional support, assisting families in making plans and providing referrals to other programs. (Arkansas Genetics Program brochure)

Whether PWS is a genetic disorder or not, our families can benefit from genetic counseling. Psychosocial (emotional) support is needed in dealing with stress and feelings.



SUMMARY OF 1986 BOARD MEETINGS:

June meeting. Items of interest discussed:

Election or review of PWSA officers. Action: Review each December. Officers would not have vote at board meetings.

Scientific portion of conference. Action: Motion: Scientific session will be annual and held day prior to general meeting.

What constitutes a membership, a quorum, proxy votes, open meeting at conference. Action: Membership was cleared by new dues structure. Individual member will have one vote, family membership-two votes, agency/professional-one vote. A quorum was established in bylaws and would include members in attendance at general meeting and proxy votes. Open meeting will no longer be a board meeting but a general meeting which will include reports, opportunity for members to ask questions, voice opinions, request action by board. This meeting will be conducted by the PWSA President. More control will be used over ballots.

Affiliation of National PWSA and the California Foundation was discussed. An offer by PWSA for new category of affiliation was voted down by the California board.

A request that PWSA establish a non-smoking policy for group homes and three new members be added to Scientific Advisory Committee was discussed. Action: Board decision group homes should establish their own policy and there were no openings on Scientific Advisory Committee at present time and expansion would not be advisable. Motion: that the Executive Director recognize the tremendous efforts and accomplishments of the NY Chapter through the presentation of an award.

Incumbants were re-elected to board and vacancy was filled by Janalee Heinemann of Missouri.

Motion: The 1987 National Conference dates June 17-20 in Houston, Texas. (Note, 1988 conference will be in Louisville, KY June 22-25.)

Motion: Bylaws were revised and will be submitted to IRS as required.

Motion: Summary of minutes will be submitted to chapters and in GV, with latest Treasurer's report included. It was also suggested that agenda at conference include Treasurer's report.

Motion: Salary of \$1,000./month be paid to Executive Director for July-December, 1986 from Salary/Reinbursement budget and that a more complete structure be studied and presented at December meeting.

Motion: Harvey (Bud) Bush be appointed Vice-President.

Motion: Fausta Deterling be appointed as Secretary.

December meeting. Items of interest discussed:

Recommendation that National PWSA and all interested chapters become representatives of media marketing firm for Sprint long distance services as a fund raiser was rejected by board as not being a suitable project for PWSA.

President urged a definite effort to enlarge membership citing that dues were insufficient for operation. Additional suggestion was to contact dropped members. President also commented on efforts to open crisis center.

It was suggested that friends and relatives from our last January fund raising efforts be contacted again this coming year, and that entire membership receive a donation envelope.

Review of handling of finances and investing. Amended motion: A standing investment committee of three be charged with responsibility of investing and developing policy. Committee later appointed (Roy Smith as treasurer, Bud Bush as Vice President, and Ted Briggs as board volunteer) will submit quarterly reports, board meeting reports, and be subject to board review. Policy intention will be income while protecting original capital and follow general outline of 50% invested in Government insured securities, 25% in A+ investments, 15% in B+ or higher and a 10% discretionary fund. Amended motion: Handling of finances will be changed to include two separate bank accounts with additional signatures required on disbursements other than general operating.



SUMMARY OF BOARD MINUTES (cont)

Update on progress of book sponsored by Research Fund Grant, edited by Louise Greenswag. After final chapters are received the decision will be made to either print or have the book published.

Proposal was submitted by Laura Baker School to open a crisis center for PWSA. Motion: Letter of Intent will be issued before end of 1986 to open negotiations for establishment of PWSA Crisis Intervention and Transitional Center for people with PWS, along with possibility of future expansion.

Should PWSA review or certify PWS group homes? Decision, continue to assist but not certify.

Computerization of Questionnaire data has hit a snag and is not completed at this time.

Reported that investigation of suitable salary structure was discontinued because membership dues income is not sufficient to pay reasonable salaries of \$28,000 to \$32,000 for Executive Director and \$15,000 for secretary. Action: Dues increase as first step to address this issue. Three categories of membership: Individual \$20., Family \$25., Agency/Professional \$30. (U.S.Funds). Later action included continuing \$1,000./month salary for Executive Director.

Improvement of GV was discussed. New first page heading is being developed.

Budget approved:

RECEIPTS

Membership Dues	\$29,000.
Contributions (operating)	15,000.
Material Sales	10,000.
Interest earned	5,000.
Conference	24,000.

Total \$83,000.

EXPENSES

Salaries	\$24,000.
Rent	6,000.
Travel Reimbursements	8,000.
Operating	14,000.
Conference	24,000.
Capital Equipment	2,000.
Material sales	5,000.

\$83,000.

Review of officers by board, re-elected Delfin Beltran, M.D. as President, Harvey Bush, as Vice-President, Fausta Deterling as Secretary, and Roy Smith as Treasurer. Lota Mitchell of Pittsburgh, PA was elected as chairperson for the board.

The Executive Director mentioned the possibility of a large donation being made to the present NDC fund. (It was later found this would not materialize.)

1986 RECEIPTS AND EXPENSES:RECEIPTS

Membership dues	\$22,081.
Total Contributions	95,223.
Material Sales	9,623.
Interest	11,700.
Conference	22,688.

Total \$161,315.

EXPENSES

Salaries/Travel Reimbursements	\$18,394.
Contributions/Grants	4,000.
Direct Publishing	2,442.
Operating	13,603.
Conference	21,106.
Capital Equipment	845.

\$60,490.

(Operating receipts were \$31,704. for the year, operating expenses were \$35,284. showing an actual loss of \$3580. for 1986)

Break Down of present balances in various funds:

<u>NDC</u>	\$155,297.	(If negotiations are completed, we will need \$200,000 for Crisis Center (CIT).)
<u>CONFERENCE</u>	4,075.	(Accumulated total over 7 conferences.)
<u>RESEARCH</u>	10,488.	
<u>GENERAL OPERAT'G</u>	51,383.	(This fund has built up over years because no salaries or rent has been paid prior to 1986.)



CHAPTERS

The PWSA-Connecticut Chapter, Inc. meets at the Newington Children's Hospital. The peer group will meet every month along with parents and friends. Upcoming dates are: Jan. 21; Feb. 18; Mar. 18; Apr. 15; May 20; Jun. 24; Jul. 15; Aug. 19; Sep. 16; Oct. 21; Nov. 18; Dec. 16.

Posters are still available, minimum order 10, at \$1.00/ea. plus postage. Contact Suellen Inwood, 335 Davis Rd., Fairfield, CT 06430.

Have you shared your camping experiences with Janalee Heinemann? (Sept-Oct, GV). Janalee's address is 12198 Sage Meadow La., Maryland Heights, MO 63043.

Ground has been broken for the Missouri-Kansas City area PW home. The plans look great. Congratulations for all of their efforts to make this home a reality.

Directory Update (Nov-Dec GV). Help the Kentucky chapter in their efforts to update our professional directory. If you are the designated contact person we hope you are working on your addition. Individuals may also supply names and addresses either to KY or PWSA.

The PWS Southeastern Association announces "The South will rise again". The group is following their successful July conference with a workshop scheduled for Feb. 21-22. The Saturday schedule will include sessions on education, transition, exercise, diet and behavior. Evening activities are planned and Sunday morning will include on workshop on group homes. Many activities are planned for the children.

The University Inn will offer a room for up to 4 for \$31., as continued evidence of support from the Sparks Center. Cost is \$15./adult, \$25./child. Children's rate includes 5 meals, craft supplies, and supervised activities. To receive a registration packet call Melody Walton, (904)654-1425 or write: PWS February Blast, 118 Palmetto St., Destin, FL 32541.

CONGRATULATIONS

...to our board member, Lota Mitchell of Pittsburgh, PA on her new position as Chairperson of the Board of Directors for PWSA.

Lota is a long-time active member of our group, and serves as a parent as well as a professional in her contributions. Lota has a Master's Degree in Social Work and is the mother of a 17-year old daughter with PWS. She has served on the PWSA board since 1980, and has been active at a national level as well as with an area chapter.

We are very fortunate to have Lota serve in this position.

NEW PUBLICATION

In appreciation for the research assistance from PWSA, Eileen Raab donated a completed monograph that she had written as an assignment.

"Understanding Prader-Willi Syndrome: A Literature Review for Educators and Families", was intended as a review of the presently available materials on the syndrome and particularly aimed for use by special education teachers. In addition to the review of literature, the monograph includes a ten-page section suitable for use on an overhead projector.

This paper is now available through the national office at the price of \$3.75/copy.

**Mark your new calendars today!!! June 18-19-20 in Houston.**

**1987 PWSA 9th Annual National Conference**







Some dietary hints do not add up to much at one time, but accumulated may make a difference. Try some of these:

Serve your person with PW his meals on a smaller plate--it makes it look like more. Serving three ounces of meat and doubling the vegies makes about a 300 calories difference.

Encourage putting utensils down between bites. Use a teaspoon for soups, cereals to make it last longer. Some people use timers to make sure meal takes longer.

Sweeten your own yogurt with fresh fruits or 1 tsp. of preserves, instead of buying fruit yogurts.

If you use a lot of sauces and your children feel left out, use pureed vegetables for their sauce.

Substitute yogurt for sour cream.

Graham cracker crusts are lower in calories for pies or serve a pie without the bottom or top crust.

Bran muffin are more filling and more nourishing than doughnuts, and high fiber.

Saute vegies in bouillon or stock instead of oil. Save stock for later use by freezing in ice cube trays.

Steaming, boiling or microwaving, of course are less calories than frying.

Marinate or baste with lemon or lime juice, tomato juice, wine, broth or bouillon rather than fat.

Stuff fish and poultry with vegies.

Use a thin smear of jam for pancakes or french toast rather than syrup.

Know what you are buying!

"Low Calorie" Use of this label means less than 40 calories per serving and no more than 40 calories per 3½ ozs.

"Reduced Calories" This food must be at least 1/3 lower in calorie count than comparable food not reduced. Reduced-calorie food cannot be nutritionally inferior to its modified counterpart.

"Sugar Free" Foods bearing this label are not necessarily low in calories. Instead it means artificial sweeteners are used.

"Artificially Sweetened" Chemical sweeteners such as saccharin or aspartame.

"Light foods" Lights or lites mean things other than calories frequently. Check calorie content to know. One "light" corn chip is 10 calories less per serving--not much saving.

A few books that may be helpful.

"Dietician's Food Favorites" Cahners Publishing, 1985 \$25. Over 500 recipes tested by the American Dietetic Assoc.

"The New American Diet" by Sonja L. Connor, MS, RD and William Conner, MD. Simon and Schuster 1986 \$18.95. Recipes analyzed for calories, fat, sodium and carbohydrate.

"The Complete Fish Cookbook: 500 ways to cook fish" Dan & Inez Morris, MacMillan Publishing, 1986, \$22.50.

"Uncommon Fruits and Vegetables: A Commonsense Guide" Elizabeth Schneider, Harper & Row Publishers, 1986, \$25.

"Parent's Guide to Nutrition: Healthy Eating from Birth Through Adolescence" Susan Baker, MD and Roberts Henry, RD, Addison-Wesley Publishers, 1986, \$16.95.

With the purchase of food, the buyer must beware just as in any other shopping. Marketing tricks are used with food products, for example the use of some words like harvest, farm, land, valley life, or country are used on packages to convey wholesomeness. These terms mean nothing when it comes to nutrition. Color is also used, white conveying purity, reds and brown associated with richness etc.

Another advertising ploy is to boast about the lack of certain ingredients with phrases such as "no preservatives", "no sugar added", or "no artificial flavors". Some foods such as orange juice or raisins do not need preservatives, some food are naturally sweetened, and no artificial flavors does not mean no other artificial additives are included.

Many labels are confusing or do not include all of the information that you are seeking. Do not fall for the label that looks "healthful" by its coloring, letter styling or bold claims, but learn more about foods through reliable sources.

#### A SISTER SHARES:

On December 11th, my brother, Joel, lost his life choking on a piece of bread he had sneaked out of the lunchroom at school. His teacher, one of the most dedicated people ever to work with him, found him too late. The following is a eulogy delivered at Joel's funeral - it was a packed house - not only relatives and present friends and teachers, but even those wonderful individuals who had worked with Joel as a child and still remembered the intimacy and love he generated:

"My brother, Joel, was an "exceptional" person--not because he was handicapped, but in his own right as a human being. In his unique way, Joel was very special to many people. I think we can all agree that he had a positive impact on each of us.

Joel touched the lives of all those who came in contact with him. He loved people and valued their friendship. Joel's sense of humor and engaging charm endeared him to those who were lucky enough to be a part of his life. His personality could be likened to a welcoming committee--he invited people warmly into his life. Joel just had this talent for making people feel good.

In speaking to many of you this weekend, there were endless "Joel stories" that I was

privileged to have shared with me. My brother faced life with an innocence and a refreshing honesty that made each and every person that he connected with feel very special--as though he and they had their own exclusive rapport.

Joel, unknowingly, in his lifetime gave so much and only asked to be liked in return--his only motive was to be your friend and to be accepted. We are a lucky group of people--our lives are far richer because we were fortunate enough to really know my brother.

And last, my parents--whose lives he touched the most. His anchors in life. My parents devoted 34 years--hard years--to putting quality and love into Joel's limited world. And, they succeeded 100% in developing Joel to his highest potential. And their endless efforts are in no way wasted or unrewarded--for my parents received the most from my brother and in a sense--they are the luckiest people in this room. He loved them deeply; and as all of us who know Joel can attest to, he showed his love and appreciation constantly.

I don't think there are enough words to eulogize my brother, Joel. I think the real tribute will stand the test of time--I believe that whenever any of us call upon our memories of my brother, there will be a tear in our eyes, a smile on our lips, and above all, the love in our hearts that Joel lived daily.

Thank you for everything, Joel. We all love you!!

#### A MEMBER WRITES:

I feel it would be very beneficial for many of our children to get some therapy through the Muscular Dystrophy Association (MDA). MDA lists benign congenital hypotonia as one of the neuro-muscular diseases they service. My son was diagnosed as having this condition in infancy. Later, however, they would not do an evaluation on his muscles. A physical therapist later told us his hand muscles were so low functioning that they were "off the charts". She recommended various ways of exercising the hands and felt that their performance could be substantially improved.

Another member mentioned her daughter had a low rating upon testing for a sheltered workshop job because of her inability to staple with one hand. This may be something members with younger children may want to check into.



CONTRIBUTIONS

As we wrap up 1986 we must reflect on all that has been contributed to this organization (YOUR organization) this past year. Contributions do not all come in money contributed, but in the many hours also donated by caring members of this group. The hours spent by the national office staff, the Executive Director and her secretary, both of whom are now paid staff members but underpaid by the amount of time and devotion that is given. The former Board Chairman who has donated a room in his home for the past seven years and just added a \$12,000 addition so the expanding office could keep functioning, as well as his donations serving as chairman. The founders of this organization who still continue to be as involved as they were in 1975. The officers and other members of the board who donate their time all during the years as well as at the two annual board meetings and receive no reimbursement for their expenses. The officers and active members of all of the individual chapters who spend countless hours organizing meetings for their area as well as assistance for their members.

We have deliberately not named names because we know we would miss some very special people but you all know who you are--and we are sending a very special end-of-the-year thank you to all of you.

The past couple of months we had some special people who belong in our Special Box

\*\*\*\*\*  
 \*  
 \* Rochester group  
 \* Bill Stege  
 \* Nichols family  
 \* Stew & Bronnie Maurer  
 \* Eileen Raab  
 \* Abell family  
 \*\*\*\*\*

\* The Rochester group organized the sale of gift wrapping paper, sold by their children and made a generous donation to the Research Fund.

\* Bill Stege, who copies our slide presentation onto video tape at no charge so we can offer it to our members at a low cost.

Memorial donations made by relatives and friends of the Sara Abell family.

The Nichols family who sent a very generous memorial contribution to honor their granddaughter.

We'd also like to say a special thanks to five individuals who closed the year with a very generous \$1000. donation.

Stew & Bronnie Maurer who continue their support by hosting the mid-term board meeting and making the costs lower to board members.

Eileen Raab who donated her recent monograph to our organization so this could be shared with our members.

We also have chapters that make yearly contributions like the Kentucky chapter and the Michigan chapter who have encouraged their members support. We have many members who make monthly donations and we can't possibly name them all but their support is very important. We also thank families that direct their memorial contributions to PWSA.

During the months of November and December the following people supported two funds:  
 Research Donors: Rochester kids, Nashville Comm.Church, Van Zomeren, Mook (Leonard), Staples, Capital Area United Fund, So Nevada CFC, Braun, two other United Ways, Maurer(2) (Colony Square Hotel) and DeHaan.

NDC Donors: Kier (Botich), Mitchell (Echols), Levikoff (Charny)(Antell)(Harmelin)(Black), Dixon (2), Sunde (Havnen), Klein (Morlock)(Klein)(Scanlon), Beltran(2), Boyd (3), Noll, Abell (Delaney)(Ritter)(Spalding)(GA R.Ctr.), Kappler (Nichols 2)(Rocky Mt), Dam (Digital), Nanzig, Wolcott, Miller (Creswick)(Yardschuk), Means, Eager, Castle, Phillips, Breneisen, Englemann (Hajofsky)(Deyling)(Novak), LaBella (Zuege), Gordon (Winthner)(Pieri)(Wilson) (Parker)(Reider)(Savar)(Weinburg)(Solitrin)(Parola), Wagstrom (Vi kingland Kiwanis), PWSA KY, Lat, Notbohm, Ackerson (Wortley), Veziroglu, Mays, Cortellini (Castiglia), Robbins, Novak (Kokoszka), Fuller (Johnson Pump), Goff, Wett, Englemann (Koch).



## EDUCATION

Learning and fitting into the educational system is one of the problems that parents of children with PWS face. PW parents are informed that about 95% of young people with this syndrome have some degree of mental retardation (MR), usually mild or moderate. Educational problems are more likely to fall in the range of learning disabilities (LD) rather than MR. Our children can have very "spiked" testing, they can fall several grades below in some subjects and yet grades above in others. In teaching, we have found that there can be very definite "input" problems. Teaching, for example, by showing a flash card with a picture and the word printed below and saying the word at the same time is using three inputs--the picture, the printed word, and the verbal. This type of teaching requires more of a one-to-one type of structure which seems to best serve the need. Many refer to this as a teaching pattern for LD problems rather than MR.

All too often too much time is spent on emphasis on the weaknesses rather than the strengths. People with older children faced teachers who had never heard of this syndrome, some parents are now facing teachers who have heard of the condition and are immediately placing the child in a slot that might not be a good fit. Each child is unique, they have particular strengths as well as weaknesses, and the educational plan for your child must be developed for him/her.

LD is more than a difficulty in academic achievement or lack of motivation, it affects the child's ability to take in information. The impaired ability can be in speech, thinking, judgment, reasoning, and organization.

Here are some educational terms you may encounter:

**Developmental Lag:** significant departure in milestones (speech, walking etc.)

**Motor Execution Skills:** poor gross or fine motor coordination. Handwriting, hand-eye skills, cutting, etc.

**Receptive Language Skills:** delayed reading readiness, difficulty absorbing new information, poor spelling, math skills, difficulty in understanding spoken commands.

**Expressive Language Skills:** speech production, poor articulation, difficulty in developing speech patterns.

**Concept Formation:** Verbal abstract reasoning (how are things alike-different)

**Memory Functioning:** forgetful, absent-minded easily confused, poor long-term as well as immediate.

**Activity Level:** poor attention span, constant moving.

**Noise Sensitivity:** easily startled, bothered by "outside" noises.

We can't emphasize working with the strengths as well as the weaknesses. Many therapy groups of older children with PWS refer to the poor self-image. Work on developing some skills outside of the academic fields to help instill confidence in ability.

Help him/her organize to eliminate some frustrations. Set reasonable time limits on assigned tasks. Also remember praise goes a long way with our children.

Give instructions verbally and visually. Don't overload schedules, a worn-out child is not going to be an agreeable one.

Don't be pushed by educators with the statement other children with the same IQ can accomplish more, therefore, your child should be in this particular setting or class. Always being "at the bottom" of the pile can lower self-esteem.

Work on coordination, hand-eye dexterity, by adding games to normal daily routines.

PWSA is always happy to share the fact sheet for educators developed by educator Marsha Lupi. We also have an educational packet (ordered separately \$3) or with the complete conference papers \$8) U.S.

Some parents that are told an early diagnosis is an advantage ask how--education can be one example.

### FUND BALANCES:

#### NDC FUND

**\$155,297.**

During 1986 \$90,010.68 was contributed to this fund.

#### RESEARCH FUND

**\$10,488.**

During 1986 \$2,436.44 was contributed to this fund. 80% (1949.15) remains in this fund and 20% (487.29) goes in operating. One \$4000. grant was awarded this year from this fund.

Total contributions for the year were:

**\$95,223.00**

(which does not include contributing and patron dues)

We are very proud of our members support



CIRCLE OF FRIENDS LETTERS

"It amazes our family how much your son and our daughter resemble each other--they look more like siblings than my own children." This amazed a lot of other people too when we first started having conferences but then we have those with all of the symptoms that look completely different too.

"Our nutritionist hasn't put any major restrictions on our son's diet. She thinks our lives should be as normal as possible--of course we avoid junk." Establishing good eating habits when young is very important. We believe this is more important than worrying about "differences" or too many restrictions when weight isn't a problem yet.

"I used to dwell on too much literature and PW material. The first year after diagnosis we crammed all the information we could down our throats and some of it is so negative. I think we need to educate ourselves but not bury ourselves in the syndrome." We agree, but we wish we had a way to teach all of the necessary facts and symptoms without it being depressing. This mother went on to write: "I've put (my son) in God's hands, God knows what He's doing. I don't want to try to figure out what the future holds for my son. God is in control, He loves me and my son too." As an organization, we feel we must stay away from religious issues because we have members with many different beliefs and we need to be able to serve all, but we feel putting your child's future in the "hands of God" can be a very dangerous medical attitude.

One mother asks of the importance of having a "PW specialist and nutritionist". PWSA frequently gets calls asking about specialists and the importance of seeing them. Our answer is that it is frequently the case of the parents having to teach the primary care physician about the syndrome so he can serve in that capacity. Traveling many miles to see a "specialist" for normal care can be very burdensome for a family and very unnecessary. When specific problems arise, then this can be a different situation. We do feel a nutritionist or dietician can be very helpful and start a suitable pattern for good nutrition for your child.

One parent suggested that PW should stand for "Precious Wonder". Great attitude.

"Sometimes I think, 'Oh how nice it would be to relax and not always be a mean monster Mom, let my daughter do whatever, eat whatever, no exercises, no school work, but I love her too much to let my guard down.' Somehow she doesn't hold grudges." We frequently talk about the children not having the problems, that the parents have them. We believe this is true. We look at ourselves as monsters because of what we reinforce and it doesn't bother the children at all, all of this just becomes normal routine. One older child was quoted in a news article that she had a weight problem but it was her problem not her family. I think this points out their feelings.

Another mother shared that she keeps a loose-leaf notebook. "I have found having my loose-leaf has been a neat tool in explaining the condition, documenting new information, photos, addresses, everything having to do with PWS. Anytime I go to a new doctor I bring this notebook and let them thumb through it and take any copies they would like, never leaving it anywhere though because it is too important."

"I wrote and obtained the names and addresses of other PW families in my area. I was shocked to find another PW family just 10 miles away. I wrote and we now visit from time to time. Her daughter is older but when we go over my daughter goes to her room and they stay there for hours, making things and watching TV."

Another mother wrote that she had a very hard time accepting that her baby was mentally retarded even though she knew her baby was different. "It took me a long time to accept the fact that I had a very special little girl, that she was given to me to love and help. ....After I accepted that fact and realized that she is a very special gift to me, it helped me a lot. I could dwell on all the bad things that has happened and that will happen, but I don't. I live day by day. I enjoy the happy times and I will remember them always."

Circle of Friends letters are one way to share. The GV is another way to share. We hope our members will continue to share their joys and solutions as well as problems in order that all of our members can benefit.



## PRADER-WILLI SYNDROME ASSOCIATION

## MEMBERSHIP APPLICATION

NAME _____	PHONE _____	DATE _____
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ADDRESS \_\_\_\_\_

ZIP

REASON FOR JOINING:

Parent \_\_\_\_\_ Educator \_\_\_\_\_ Medical \_\_\_\_\_ Organization \_\_\_\_\_ Other \_\_\_\_\_

Where did you learn about our organization?

**MEMBERSHIP DUES:**      \$20.00 Individual Membership;    \$25. Family      Annual fees,  
                               \$30.00 Agency or Professional                          U.S. Funds

MAILING ADDRESS: **PRADER-WILLI SYNDROME ASSOCIATION**

## 5515 Malibu Drive

Edina, MN 55436

If you are a parent of a Prader-Willi child or adult, would you furnish us with their name and birthdate? Naturally, sharing this information with us is not required for membership, please complete only if you choose to do so.

Name	Birthdate
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We have two listings of people with this syndrome. One is a National Listing that will be available for research statistics, etc. It will never be given to anyone indiscriminately, but will be shared with other members that have given us their child's name, if requested. The second listing is entitled a non-consent list. This listing was compiled in order that we have a record of all known cases of the syndrome. This will never be shared with anyone. Could we add your child's name to one of these lists?

National Listing\_\_\_\_\_ Non-Consent List\_\_\_\_\_

We also publish a Clinic Services Directory that lists physicians and facilities acquainted with Prader-Willi Syndrome, which we share with others seeking this information. Do you have anyone that works with your person with this syndrome that could be added to our list? (Please give us complete names and addresses.)

We thank you sincerely for your assistance.



## TOP PRICES FOR PRE-1950 FOUNTAIN PENS

WATERMANS-PARKER-SHEAFFER-EVERSHARP  
SWAN-CONKLIN-HOLLAND-LAUGHLIN  
LE BOEUF-WAHL-WIRT-WEBSTER  
OTHERS

Undamaged in Good Condition with 14K. Points

Send Description-Price-Phone No. to:

*Classic Fountain Pens*

BOX 1782 • FORT PIERCE, FLORIDA 33454

The member who collects these pens has offered PWSA a donation for any pens obtained because of our mentioning them. We do not intend to become a newsletter full of ads but if we have the space we can insert items of this type if we feel they will benefit our members.

Rural is:

- When school board meetings are moved to Saturday night because they are the biggest event in town.
- When it says, "Welcome to Ft. Thomas" on both sides of the sign.
- When across town and across the street are the same thing.
- When fast food is opening a can of baked beans.
- When the graveyard shift at the Stop and Go knows that you like Oreos, Sprite, and Glamour magazine.
- When high school attendance policy includes days off for hunting.
- When you have to leave town to talk to someone who is not a relative.
- When the only policeman has a two-way radio and tries to talk to himself.
- Going out to eat means eating outdoors.
- Where you are offered a job along with a place to live.
- When you take your kids to the city and they try to get gum out of a parking meter.

Our favorite remains:

When someone asks how you are and really listens when you tell them.

Stolen from ACRES

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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./year Individual, \$25./year Family, and \$30./year for Agencies/Professionals. (U.S.Funds) Send dues and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.  
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PRADER-WILLI SYNDROME ASSOCIATION  
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EDINA, MINNESOTA 55436  
U.S.A.

*First Class Mail*