

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT

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Edina, MN 55436

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GREETINGS IN THE NEW YEAR

Christmas time and the new year start people thinking about the past year. Twenty years ago, when my husband started practicing medicine in Minnesota, his partnership gave a Christmas party and thanked a handful of people for the past successful year. Recently, this same party was attended by over a hundred people and a "list" was used to thank key individuals so no one would be forgotten.

PWSA, although younger, has the same pattern. In 1975, a handful of people were responsible for this organization, now a "list" would be needed also. Allow me a few lines to thank a few people, starting with the Chairman of the Board, Richard Wett, who among other things, donates a part of his home and a part of his wife to PWSA. And then there is "Sam" Beltran, a very dedicated president, along with the other officers and members of the board, who are there when they are needed. Many key people throughout the country are also responsible for making this organization viable and growing. Many thanks are extended to all of these people and richly deserved.

Thinking over the past year, as Executive Director, I would love to say these key people and the rest of our membership have made it an outstanding year for our organization, but I am afraid I can't feel that is true. I am very pleased with what has been done but I feel we could have done more. There are many joys but also many sorrows connected with my job. The joys of working with people and accomplishing goals for our children but also the sorrows of needs not being met for many of our families. I receive phone calls from parents telling me of their desperate need of help that does not exist in their state. They have a child/young adult whose behavior or weight (usually both) are out of control and there is no help available. We have chapters that have been working for years to force their state to offer proper placement for their children and are still waiting. A few groups and chapters have managed to open a home in their state, some are in the process of doing just that, and many want to get started. But even in states where one home has been opened, there is still a need for others because the established homes can only accomodate a limited number of residents. If the national organization is going to be of more help to these people, it must receive help from its members.

A Research Fund was established 18 months ago. Approximately \$12,500. has been donated to this fund. If we subtract approximately \$5,000. of this figure from two memorial funds and \$3,200. that came from five large donations, a balance of \$4,300. was donated by our approximately 1350 members. This gives us an average of \$3.00 per person donated in an 18 month period of time. I am very aware that some of our members cannot afford any donations but is it true that the rest of us only felt this fund was worthy of a \$3.00 donation in an 18 month period of time?



NEW YEAR'S GREETINGS (cont.)

I receive letters stating, "Thank God we found you people!", "the GV is my only source of information and I would be lost without it", and "through the PWSA our state has now established a parent group that has been the answer to my prayers". Is it possible we are only meeting the needs of a few people that feel the organization is worthy of their support? Unfortunately, we are living in a time where we can't offer a worthy cause and expect someone to immediately come to our rescue with funding. How many of you are willing to pledge your support to the national organization in the coming year?

Marge A. Wett, Executive Director

UPCOMING CHAPTER MEETINGS

Southern New England Prader-Willi Syndrome Parent Support Group will be holding their next meeting on January 28th. Most of the meeting is scheduled for preparation of opening their group home.

Prader-Willi Association of Minnesota's next meeting will be held January 27th. Topics will include alternative living arrangements for people with PWS and the Oakwood video tape will also be shown.

Prader-Willi Kentucky Association will hold their next meeting in Louisville on February 4th. A speaker will explain steps to be taken to obtain grant money.

GETTING SECOND OPINIONS

Frequently all of us have heard the suggestion that "getting a second opinion" is a good idea when surgery or other suggestive treatments are mentioned. We would like to extend this suggestion also to parents when certain treatment is prescribed for their children with PW. Too often suggestions are made by well meaning people who do not understand the uniqueness of the syndrome. The National office would be very happy to accept your calls and letters, and suggest another person to contact if you do not have someone to contact for a second opinion. A good example is having a doctor suggest doing a gastric stomach stapling as a means of weight reduction, when it has been proven weight loss can be achieved with dieting, exercise, and food control. Please let us know if we can be of help.

6th ANNUAL PWS NAT'L CONFERENCE

JUNE 21, 22, 23, 1984

MINNEAPOLIS

GUARDIANSHIP

Since we had an article about guardianship in the last issue, we thought we would share information regarding two recent MN applications.

Case #1: The parents engaged a senior partner of a large law firm and applied for guardianship for their daughter who had just turned 18. The court sent an inquirer to talk with the girl and advised her of her rights to have a lawyer which she agreed to have. After visiting her and finding she had no objections to the guardianship, her lawyer recommended it also. A fifteen minute court appearance was routine and guardianship was awarded to the parents. The cost of the lawyer was not discussed prior to the procedure and the parents were surprised when the total fee was \$635.00.

Case #2: The parents engaged a lawyer who is knowledgeable about mentally and physically handicapped cases. Their daughter had also just turned 18 and objected to her parents gaining guardianship. Her lawyer also felt it was not necessary and even attacked the usage of anyone stating that this girl had Prader-Willi syndrome because this syndrome is not listed in one psychiatric source. The parents did not question what their lawyer planned to do in court, they just assumed he knew enough about the syndrome and would take care of everything that needed to be done. The girl's lawyer was better prepared, he attacked everything the mother said in regard to the needs of her daughter, had a psychiatrist appear in court, who after a five minute visit with the girl, stated she was capable of making her own decisions. After a long period of time, many postponements, the court put off a decision for a year period of time, and "compromised" with the lawyers by having the girl agree to sign a statement that she would live in the residence she now resides in, and would agree to medical treatment that was recommended. The parents were very disappointed with the lack of preparation on the part of their lawyer and even felt in the end that he was not convinced that guardianship was even necessary and took the "easy way out" by agreeing with this postponement. Since the daughter has not signed the agreement as yet, the parents have not received a bill from their lawyer as yet.

We certainly are not suggesting that due to problems or costs that guardianship should not be sought for children that do need assistance in choosing the proper residence, having help with their finances, and certainly agreeing to proper medical care, but we hoped by sharing the experiences of these two cases that better informed parents will "lawyer shop" and not make the same mistakes that were made in these two cases.

KENTUCKY CHAPTER

The PW Kentucky Association celebrated their first anniversary as an organization. The president reviewed the accomplishments of their first year and stated they were pleased with the progress that has been made.

A representative from the KY Protection and Advocacy Division gave the group information on the various forms of guardianship. The group also decided to donate their dues rebate to the National Research Fund and also donate 5% of their raised funds in the future.

During the meeting the young people made Christmas tree ornaments.

The support of this chapter is greatly appreciated. Much is gained by a good relationship that exists right now with all of the chapters and the national organization.

WARNINGS ON THE DOMAN-DELACATO TREATMENT

An actual cure for mental retardation and other developmental disabilities would be a dream come true for thousands of families. To some, it seems this dream may have come true through treatment developed by Glen Doman, a physical therapist, and Carl Delacato, a doctor of education, known as the Doman-Delacato treatment. But this method of treatment, based on "patterning" has been greatly criticized and become a very controversial method of treatment.

The Doman-Delacato treatment began at the Institutes for the Achievement of Human Potential (IAHP) in Philadelphia. It is now also offered at the National Academy for Child Development in California and has several branches throughout the western part of the U.S. This method of treatment claims to cure the developmental disability rather than treat symptoms, which is a more standard approach. Their theory is based on the assumption that nearly all mental retardation is caused by brain damage or poor neurological organization, so to help the individual one must simply "reorganize the brain". This theory is not scientifically supported and has even been found to be inconsistent with accepted information on neurological development. Further, treatment is based on the importance of establishing cerebral dominance (left or right sided-ness), and again, studies have shown this is not important in developing reading and language skills.

Inadequacy of theory does not necessarily prove a treatment to be ineffective. There are in fact hundreds of testimonials, to support the treatment, but scientific studies have not shown it to be effective. In 1960, Dr. Robert Doman, the medical spokesperson for the institutes, published a study showing it to be of value, but the study used no control groups or standard statistical procedures and used the treatment's own assessment profile to determine efficacy. In general, studies have not stood up to scientific scrutiny. More recent studies that have been more scientifically sound either show slight improvement (and this is to be debated) or no support at all.

Many groups and organizations, including the American Academy of Pediatrics have offered caution when regarding this treatment. Besides the fact that theory and treatment techniques are not supported scientifically, there are other reasons to question the Doman-Delacato treatment. First of all, the organization alleges to be a non-profit parent group; the validity of this has been questioned. The cost can be great and the only thing parents have in common is that all children are treated by the same method. Also, it claims to treat all ages while it is a part of the National Academy for Child Development--a misleading title. The NACD claims to be eclectic in its methods but only seems to advocate patterning as a treatment, and its director, Dr. R. Doman apparently is not qualified to recommend other treatment methods, as shown by material available from NACD.

Despite all the reservations discussed thus far, the greatest drawback to the Doman-Delacato treatment seems to be the tremendous stress it puts on the parents and families. The program requires treatment twelve hours a day, seven days a week. If the program is not followed to the letter, absolutely no scheduling changes allowed, the program may fail. This places a great burden on the parents for their own training, training and recruiting volunteers, the responsibility and accompanying guilt if the program fails, and stress resulting from all these pressures. And even if the program is completed as prescribed, there are no guarantees. There may also be a false sense of hope lurking in these parent's minds and with recent legislation and positive attitudes about helping the developmentally disabled, parents do not need to depend on unconventional and extreme forms of treatment.

WARNINGS (cont)

Standard methods of medical management, regular developmental assessments, education, physical-occupational-speech therapies, and parent support, are available and certainly more dependable for parents. Although new methods will and should be researched and discovered, until they can be proven effective and efficient, we must be very cautious in contemplating their use for the sake of the individual we seek to help, the parents and the families.

(Sources of information for the above article include a recently published medical paper of Dr. Vanja A. Holm, University of Washington and Exceptional Parent magazine.)

THE NECESSITY OF WILLS

Most parents are very concerned with what will happen to their children upon their death. As we, and our children grow older, needs change. Particularly in the case of young adults with development disabilities. While we are alive, we can supplement the needs of our children, even when they are receiving benefits from funding programs, but when death occurs a very different situation presents itself. The only way a parent can effectively insure a continuation of "what they want for their child" is to have a will. All of us should be aware that if our child inherits anything of value in excess of \$1500.00, they will no longer be eligible for S.S.I. and many other state or federal benefit programs. For example, if a young adult lived with his parents and inherited their estate upon their death, he/she could be placed in a nursing home or even hospital at a very high daily cost until the estate has been completely used in this manner. Unfortunately, a high cost does not even assure the proper placement. In the meantime, they will also be denied other services that may be available.

Drafting a will that will maintain your child's eligibility for basic funded programs is essential. The will must be drawn to allow the use of some portion of your estate to supplement the other benefits, without denying the person's eligibility. Options, such as trusts, family arrangements, can be explained by knowledgeable persons. (And don't forget Grandma or your unmarried brothers or sisters. Frequently, upon death, families discover a handicapped child is remembered because they felt a greater need for them to inherit an estate). Protect your child from this happening, if you feel it may be a possibility, ask the person and explain the situation.

Don't make the mistake of waiting until you are prepared to retire to take care of this very important task. In the future, PWSA may be able to offer the facilities to establish trusts for this purpose. In the meantime, you might consider PWSA worthy of also being included as a beneficiary.

BEHAVIOR WORKSHOP TO BE HELD

Louise Greenswag, R.N., M.A., of the University of Iowa will be presenting a workshop for professionals working with people with PWS.

The workshop will be held on Tuesday, January 31st from 9 to 4, at the Hopkins House, 1501 Highway 7, Minneapolis. Cost of registration will be \$15.00 per person, which includes lunch. Reservations required by January 15th; check to Oakwood Residence. For further information, contact Director Bob Carlson.

JUNIOR ACHIEVEMENT FOR SPECIAL EDUCATION STUDENTS

Junior Achievement, a long standing organization that gives high school students a feel for the business world, now involves mentally handicapped students as well. An article last month in the Minneapolis paper tells about Tonka Manufacturing, a JA company run by seven special ed students. The participants choose their own name, the product they would like to make, how much to ask for a selling price, and do the manufacturing and selling. These young people chose to have an automobile emergency light as their product. Selling is the hard part for many of the students but one parent felt the selling would help her son develop socially -- to learn how to handle himself with strangers. Two of these students are residents from the PW Oakwood Residence. Gregory, an 18 year old, said he enjoys putting the light together, "it's not easy, but kind of fun to do". Doug said he likes to make some extra money.

The seven members attend school together at a high school in Bloomington. They get together every Tuesday afternoon at the Excelsior Community Center. JA generally aims at teaching students about the capitalist system by starting and running their own company. Whether these students are learning about this or not is unclear but they are gaining training and experience to enter the job market one day -- it shows future employers they are capable of doing this type of work. Besides experience and new skills learned, participants enjoy the socialization that goes along with it. The two advisors to the company have also gained something. They realize, besides being a little bit immature, the mentally handicapped students have personalities much like regular students and that the handicapped students can gain from JA as well. One advisor stated he hopes to head the project into some kind of workshop eventually.

Tonka Manufacturing has a sales goal of 500 during a 24 week period. We are happy to share this experience of these two young men with others.

AUSTRALIAN PUBLICITY

A special newspaper titled "Reveille" from Austrailia recently published a very extensive article on PWS. The next issue included a letter to the editor which is quoted in part here: "Dear Editor, It was inspiring to read a comprehensive profile on PWS, particularly one which does not veil over the complex significant features of this disorder solely by the problems of hyperphagia and the seemingly ill-begotten notion that PWS individuals are, virtually, uniformly, and permanently, retarded....

Recently acquired data from the U.S.A. provides powerful evidence to prove that they are learning disabled rather than retarded. Also, quite despite I.Q. test performances, their abilities point to a high quality of intelligence.... We cannot know of someones special artistic skills from a standard I.Q. test.

I would strongly urge that one most significant factor disabling people with PWS is their misrepresentation of being quite severely retarded. Lack of understanding, recognition, and of opportunities to explore and exploit their natural developmental capacities usually follows, thereby fulfilling false prophecies of specialists, who admitted in the same breath, were based on hypotheses which amounted to nothing.

Shouldn't we give the individuals with this relatively new and unpredictable condition, the opportunity to show and tell what they are all about? "

A+ FOR ASPERTAME!

By now most people have heard of the new wonder sweetener called aspartame. It just came on the market this year after its accidental discovery by a Searle chemist 18 years ago! Its brand name is Nutra Sweet, which is an ingredient in familiar products, (see the idea on Nutra Sweet Koolaid which follows this article), or is found as a table-top sweetener called Equal. Two teaspoons of sugar will give you 36 calories; the same amount of sweetness in aspartame will give you four.

There is a great demand for low calorie sweeteners in the U.S. Up until now our only choice has been saccharin, and as we know this has its drawbacks (besides leaving a bitter aftertaste, it has been charged with being a carcinogen). Because of its potential for great usage, millions of people dieting, parents trying to avoid tooth decay for their children, and those on special medical diets, alternatives to saccharin have been the subject of intensive testing. After millions of dollars and 116 accepted scientific articles, the FDA has approved aspartame as a safe product.

One reason aspartame appears to be safe is that it is a natural substance. It is made up of two amino acids and digested as a protein. Both of these amino acids are already present in our food chain in much higher proportions. Prospects of its long term safety are very good. Thus, aspartame may prove to be a true blessing for those with PWS who need to watch calories as their lifetime regime.

KOOL AID

Here's an idea contributed by a member on how to stretch your food dollar: "The new product on the market by Kool-Aid, which is sweetened with aspartame is quite expensive, but I have found that the products can be mixed with much more water than the package calls for and is still very tasty, in fact more so, as I find it too sweet and too strong when mixed according to directions."

SUGARLESS COOKIES

Recipes for cookies without sugar are hard to find. Here's one from the Los Angeles Times that won 3rd prize at the American Dental Association contest in 1981.

SUGARLESS RAISIN COOKIES

½ c. butter or margarine
1 egg
2 tsp. vanilla
1 c. flour

¼ tsp. baking powder
½ to 1 c. raisins or pitted dates, chopped
1 c. shredded unsweetened coconut
1 c. chopped walnuts

Beat butter with egg and vanilla in electric mixer until smooth. Combine flour, baking powder and ¼ tsp. salt (optional). Gradually add flour mixture to butter mixture and beat until blended. Fold in raisins or dates, coconut and walnuts until blended. Form dough into 2 (1½") rolls, wrap in wax paper or foil and chill in freezer until firm enough to slice easily, about 2 hrs. (Dough can be frozen for up to a month) With a sharp knife, cut into 3/4" slices. Place on lightly greased baking sheet, bake 350° about 12 minutes or until golden brown. Cool on rack. Makes about 2 dozen.

KNOWING ONESELF

Objective, measurable, quantify: These are words often stressed in programming for the mentally handicapped person. The topic most avoided is that of mental retardation, feelings and what the person perceives themselves to be. What does this person feel about his/her mental retardation? Are not feelings and emotions part of the mentally retarded's development as well as anyone else's? Self-awareness is an area too often neglected when dealing with mentally retarded persons; persons for whom awareness of one's feelings about oneself, due to reactions and rejections by others, may be even more important than for others.

This is a painful and difficult subject. What great pains we take to avoid the word "retarded". Even in a counseling situation, mental retardation is the subject most often avoided. It may be difficult to let your child express feelings about being mentally retarded because it only reminds you of the handicap. But, by denying that the person is retarded, we only succeed in preventing the person from coming to terms with the handicap; accepting it and realizing that being smarter is not what makes a person okay. Thus, the issue must be confronted.

It may be difficult to really know if a retarded person is aware of his/her handicap. It may be difficult for the person to verbalize it for either cognitive reasons, emotional reasons, or for not having (or believing) he has anyone to talk to about it. There are ways to discern someone's inner experiences without verbalizing. Special psychological projective tests, such as the Rorschach, are available to professionals. Parents may look for certain behaviors that may indicate self-awareness. A poor self-image may be projected by either withdrawal and avoiding the public eye, or acting out.

The mentally retarded person may feel different and even disliked. They may feel failure more often than we realize (i.e. every time a sibling takes a stride and they don't!). They must learn to cope with these feelings. Learning to verbalize about them may help them to begin to feel better and freer about their limitations. We all feel better when we "get a problem off our chest", so for the mentally retarded as well.

In conclusion, all people dealing with mentally retarded persons have a responsibility not to deny the individual's self-awareness. Encouraging self-awareness will help the person to first know, and then to accept, his limitations. In the process the individual will come to know his strengths as well. It is not until the mentally retarded knows himself, that he can feel good about himself.

TELLING YOUR CHILD ABOUT HIS/HER SYNDROME

A parent from Utah wrote to PWSA asking when and how she should tell her daughter about her syndrome. This may be a problem for many parents, so we have included PWSA's response to her.

The experts say that about age eleven is the time a retarded child understands what the word retarded means and that they may have more trouble learning in school than the other kids. But, they also say not to wait until then to start talking about it because the child will hear it from others before then. An important point to stress to your child is that he or she is different than other kids, but there's nothing wrong with being different. One child may have blond hair and one may have brown hair--they are different, but that doesn't make one better than the other.

TELLING YOUR CHILD (Cont.)

Marge Wett, PWSA Executive Director, tells about an experience she had with one mother in talking with her about her child with PWS: I talked with a mother in a local clinic that had allowed her 11 yr.-old daughter to reach the weight of 130 pounds. She just could not say no to her, and when her other children had treats, she gave her daughter with PWS a treat too, and it had to be the same because she could not treat them differently. The doctors and I convinced her that she was literally killing the girl and that she had to accept this daughter was different. It has been about nine months now and the girl has lost 40 pounds and the mother said it wasn't nearly as hard to do as she imagined it would be. She is busy teaching her daughter the differences between high and low calorie foods and low calorie treats etc. I think the children's book, Prader-Willi and You, is an excellent way to teach your children about exchanges.

We must remember that even though our children are behind in development, they understand more than we give them credit for. Reading to them, starting at an early age, and particularly repeating the same material frequently, does make a difference. We recommend adding our books, Prader-Willi and You, Sometimes I'm Mad, Sometimes I'm Glad, books on disabilities (for example Judy Blume's books), to your regular reading materials for your child.

GOOD NEWS FROM THE SOUTHERN NEW ENGLAND CHAPTER

The Southern New England Chapter has been approved to open a PW group home in Connecticut! They have now proceeded with the purchase of a ranch-style home on a 5-acre site near Ellington, which will house six residents. Applications for placement are available from:

March Inc. of Manchester, P.O. Box 574 Manchester, CT 06040

Please apply as soon as possible; decisions will be made in January. Residents must be 18 yrs. or older. All parents are urged to apply whether their child is ready now or not as this will show interest and need for future needs. Their phone is (203) 646-4446.

MEMBER REQUEST

Anyone having suggestions as to how a family can cover medical expenses when income is too high to qualify for assistance, yet not high enough to afford extra costs, please contact PWSA and we will share them with our members. Specifically, suggestions for residents of Ohio would be appreciated.

LEE STREET HOUSE

A newly licensed home for six developmentally disabled adults who have PWS has been opened in Northern California. The home is a 5 bedroom house, situated on an acre of land in a small town north of Chico. At the moment they have three residents with this syndrome and have three vacancies. A local workshop is also available for the residents.

All interested California residents can contact their local regional center, or the home direct. Out-of-state placements will be accepted--rates are \$670./mo. for board and care and \$16.40/day for the workshop. For further information contact: Linda Hamilton, 25401 Lee Street, Los Molinos, CA 96055 (916) 384-1488.

SOLVING HUNGER MYSTERY

Dr. George Bray made the statement a couple of years ago in California that there are eight distinct "Varieties" of obesity but added that the type that people with PWS have would probably be one of the first to be medically treatable.

Researchers believe that endorphins are hunger's chemical messengers, and the target is probably the gland in the brain, the hypothalamus.

Dr. David Margules, from Temple University, a doctor that has spoken with some of the members of PWSA in group meetings out east, has been conducting a series of experiments and was able to show that a genetically obese strain of rats decreased their food intake significantly and lost weight when treated with injections of naloxone, a drug which blocks the effect of opiates and endorphins. This drug is also available now in oral form, naltrexone.

Other studies have also been conducted by other doctors in other locations and feel the limited studies have certainly warranted further study. Whether or not naltrexone turns out to be the much sought after diet drug that doctors have been searching for, researchers believe they are closer than ever to solving the mystery of hunger.

MIDWEST FALL CONFERENCE

On October 8th, the second annual Midwest Regional Prader-Willi Syndrome Conference was hosted in St. Louis. Many valuable sessions were held including:

- a sharing session for children with PW
- a sharing session for the siblings of children with PW
- prioritizing issues of older children with PW
- family communications
- educational aspects of PWS
- estate planning for handicapped children

Jerry Siegan, parent and attorney, was elected president for the upcoming year.

Locally, the St. Louis group now has 15 families, and corresponds with about 50 parents and professionals across the state. The newest family has a 31 year old son with PWS; he was diagnosed 15 years ago but just this fall met with another PW family for the first time!

THANK YOU AGAIN

Thanks are given again to all who have contributed Campbell soup labels for the Oakwood Residence in Minnetonka. They are greatly appreciated and are used to help purchase new equipment for the home. To help save postage, trim labels down to only the Campbell logo and the kind of soup. Or, bring them to the next PWSA conference. Betty Crocker coupons are also used. You might try asking your neighbors or church groups to save too -- it can really add up that way!

Thanks also to all of the residents at Oakwood who are continuing to colate, fold and staple the Gathered View each issue. And a special thank you to Lois Olson for supervising this project. They all do a great job!!!

PWSA DISCLAIMER

Many of our east coast members have been contacted by a newly formed non-profit organization which operates a group home, out-client service, and a program on vitamin therapy and weight loss.

We would like our membership to know that PWSA has no connection with this group, nor have they felt it necessary to share their methods in details with us in order that they be approved by our Scientific Advisory Committee.

Whenever any of our members are approached with offers, such as this, we would be very happy to be asked about them and we would then in turn share any information we have about their offers and claims.

FIRST PRIZE \$1000**RAFFLE TIME AGAIN!!**

Last year PWSA conducted an International Raffle to support the annual conference. The raffle was well supported by the membership and enabled us to keep conference registration costs down as well as complete the availability of conference papers to those who were unable to attend the actual meetings. Since 25¢ per ticket was refunded to chapters for tickets sold by their members, it also served as a money raiser for those chapters participating.

We are very happy to be able to give members a chance again to support the upcoming conference and be able to obtain some outside support for our group from friends. The ticket can also serve as a means of spreading knowledge of the syndrome, which is something we all try to achieve.

Please use the order form below to order your tickets now. Orders will be filled in March. Over 700 tickets must be ordered to cover the expense of the raffle, so we need everyone's support. If we do not get sufficient orders, the raffle will not be held. We hope you will again support us in this effort.

We will retain the \$1000.00 cash first prize and also have a 2nd and 3rd prize in merchandise. The cost will remain \$2.00 per ticket. The drawing will take place in June at the conference.

In order to make the raffle equitable, tickets can be paid for in Canadian funds (and the first prize will be paid in Canadian funds also). Overseas members may change the cost and prize in order to have an equivalent value in their country. We hope you will all support this effort.

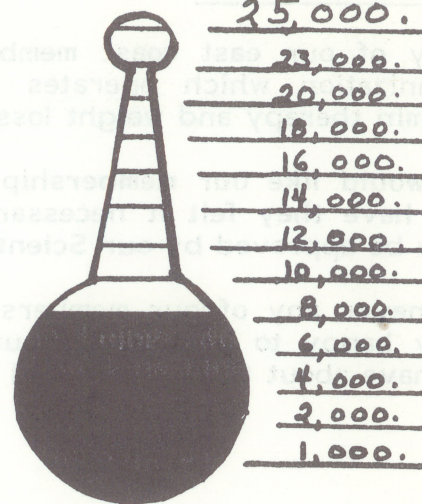
RAFFLE TICKET ORDER FORM

Please send _____ tickets which will be bought or sold for \$2.00 per ticket. (Payment may accompany the order or be submitted after tickets are sold)

Tickets will be mailed in March to you, stubs must be returned before the end of May.

NAME _____ ADDRESS _____

Memorial donations contributed another \$714.40 to our research fund for the months of November and December. Several very generous donations directly from members, a donation from a sports event in New Hampshire, a matching fund donation arranged by a California member, and a Christmas gift honoring their employer from a Georgia hotel added an additional \$739.20 to the fund. The end of the year total for the fund is now \$8467.30 (with \$2000.00 of this money already committed.)



 THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$15.00 per year for U.S. members; \$20.00 per year for Canada and Overseas members. Send dues and change of address notices to: PWSA, 5515 Malibu Drive, Edina, MN 55436.

PRADER-WILLI SYNDROME ASSOCIATION
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