

THE GATHERED VIEW

Shirley Neason, Editor
26931 S.E. 403rd
Enumclaw, Washington 98022

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

Gene Deterling, President

VOLUME V

September-October, 1979

Number 5

PRESIDENT'S MESSAGE

An unqualified success! That was the ultimate compliment we modestly applied to our very own National Conference held in Minneapolis on June 29th and 30th. Perhaps that's a slight exaggeration, but you would hardly know it from reading the conference evaluation sheets filled out by most. Many of the 165 attendees responded in glowing terms, indicating they would attend another conference and hoping that it would be an annual occurrence. "It was a two-day high for me," responded one person. Letters received after the conference have been even more positive. As one California member wrote, "I really feel the meeting was much more like a reunion. I went not knowing anyone, worried that I would not meet anyone, joined the group that closed the bar each night, opened the coffee shop each morning, stayed one day longer than I had planned, arrived home exhausted, but very happy I had gone. I hope there will be another meeting next year..."

There were some recommendations made that we intend to consider for future conferences. In summary they were that there be more time allotted for round-table discussions with professionals as well as parents; presentations by parents about how they have overcome the various difficulties associated with the syndrome; professionals use less technical jargon; there be more information about group homes; there be more information about educational requirements and experiences with Prader-Willi people.

It's unfortunate that not everyone could attend, but we will do our best to make as much of the conference material as possible available to you. We attempted to record the presentations, but because of technical difficulties, we could not recover every word. We are now in the process of transcribing the sessions. We will advise you as soon as we have the information available.

The Board of Directors meeting, held on the first morning of the conference, was well attended, and the Board was pleased to hear for the first time from the membership at large. The full minutes of this meeting will be published in a later issue. The highlights were: Two new Board members were elected: Mrs. Jean Janes from Minneapolis and Mrs. Cellie Ledoux from Enfield, CT. Stephen Sulzbacher was re-elected to a new three-year term. The current president and secretary indicated their intention to resign as officers in favor of bringing in "new blood" within

PRESIDENT'S MESSAGE, Continued

the next year. A new vice-president was elected, Mrs. Marge Wett of Edina, MN. A proposal was voted on and passed that will create seven committees scattered throughout the country to work on various aspects of assistance to Prader-Willi people. The financial situation of the Association was shown to be below plan, but not in imminent jeopardy. A new salaried position (token salary for the time being) for a fund-raising chairperson was proposed and accepted.

You will be reading more about all of these aspects of the conference and board meeting in the ensuing months.

As you should be well aware by now, we have a number of groups working throughout the country to establish residential facilities for Prader-Willi people. I strongly believe that within the next two years, we will have four such facilities in addition to Margo Thornley's homes in the Seattle area. One of the critical items for the establishment of such facilities is the generation of a list of potential residents. We have been working with several group home managers in the Minneapolis area who have indicated a willingness to open a Prader-Willi home provided there is assurance that such a facility would be fully occupied. In order to provide this assurance, I am requesting all of you who would be interested in placing your Prader-Willi person in an appropriate home to write to us here in Long Lake immediately stating the age and sex of the person and when he/she would be ready to become a resident. This request applies to all areas since we will then catalog the Prader-Willi people by areas and advise all the other local groups working on such facilities about the potential residents. We are at a stage where we can make some rapid progress if we can accumulate a sizeable list.

My second request is for as many photos, slides, and articles of significance as possible about Prader-Willi people you know. For too long now, we have neglected to receive the necessary publicity about our organization and the syndrome in general. We are now prepared to put together a formal brochure that can be used to convince the unknowing about the needs of our Prader-Willi people. We also need this visual material to prepare presentations for our fund-raising activities. We will also prepare a slide presentation that we can use when we have the opportunity to meet with the press, the news media, and potential suppliers of funds.

The type of material that would be most effective would be extreme cases or before-and-after photos. We do not, however, wish to limit ourselves to these. In order for us to use the information, we will need your written consent.

We hope to hear from many of the professional people who have shown some impressive slides at the conferences held in Minneapolis and Seattle. We will return all material, if requested, and will gladly duplicate any slides or other material at our expense.

Please help. This is a most important program. Send all material to us here at P.O. Box 392, Long Lake, MN, 55356.

A VIEW OF WHO'S WHO



One of the new board members elected at the National Conference was Mrs. Claire Ledoux, known to her family and friends as "Cellie."

Mrs. Ledoux is the financial administrator for the Greater Enfield Association for Retarded and Handicapped Citizens, Inc., of Enfield, Connecticut. She joined GEARHC in 1966 and was elected to the Board of Directors as treasurer in 1967. She worked as a volunteer and board member until 1974, at which time she became a staff member as bookkeeper/secretary.

Mrs. Ledoux and her husband, Ralph, are the parents of five children, ranging in age from fourteen to twenty-four. Their fourteen-year-old daughter, Danielle, has Prader-Willi syndrome. Danielle was diagnosed in 1977, and the parents

became members of the Prader-Willi Syndrome Association in 1978.

Mrs. Ledoux states that the continued growth and success in the operation of the Prader-Willi Syndrome Association will be her prime concern as a board member. As the East Coast representative, she will be available to promote and assist in gathering information about Prader-Willi syndrome.

Mrs. Jean Janes

Our other new board member is Jean Janes of St. Paul, Minnesota. Mrs. Janes graduated from the University of Minnesota School of Social Work, and has been associated with one or more social agencies since graduation. She was employed with Family Service of St. Paul, a private, non-sectarian casework agency. Since her retirement three years ago, she has served on the Board of Directors of Family Service, as well as the Board of Directors of the St. Paul Medical Center Volunteer Services. She is also currently an Elder in her church, where she chairs the Ministry to the Community Committee. She says her favorite hobby, next to gardening, is doing volunteer work!

Mr. and Mrs. Janes are the parents of two daughters, and have one grand-daughter. Their twenty-four old daughter, Nancy, was diagnosed as having Prader-Willi syndrome at the age of five years, and has been seen regularly since at the Mayo Clinic in Rochester Minnesota.

The interest of Mr. and Mrs. Janes in trying to learn more about the possible cause, treatment, and concern for their situation and all others is obviously of long standing, and Mrs. Janes pledges to see that the work and accomplishments of the Prader-Willi Syndrome Association are carried on.

GATHERED NEWS

Shake 'n' Bake Barbecue Chicken Coating is 50.9% sugar--more than 5 times the percentage of sugar found in Coca-Cola.

Consumer Reports

GATHERED REPORTSCalifornia: Los Angeles

The Prader-Willi California Foundation held its second meeting at Harbour General Hospital in Torrance. Approximately 80 people attended, some from as far away as Tucson, Arizona.

Dr. Jeff Miller, Psychologist from Alta Regional Center in Sacramento, spoke on his experiences of 15-20 P.W. people in the area around Sacramento for the past four years.

Dr. George Bray has now returned permanently to Harbour General Hospital. He announced the great news that starting in October, Dr. Brazell will join him in opening a clinic at Harbour General for Prader-Willi people.

Carl Martens told about the national meeting in Minneapolis, and Marsha Udes told of her experiences for three days in the Prader-Willi group homes in Seattle.

John Davies of the Dept. of Developmental Services, State of Calif., told of the work done so far toward starting a P.W. group home in California.

Gil Frietag of Dubnoff Center told about their school and group homes. They are investigating the possibility of assisting our organization in opening a P.W. group home.

Bob Scott read the by-laws of California Prader-Willi Foundation, which were approved, and our non-profit corporation is now in existence.

Reported by Cal Menzer

Missouri: St. Louis

An organizational meeting to establish a Missouri group of the Prader-Willi Syndrome Association was held at CEMREL, Inc., in St. Louis on June 16, 1979. Another meeting will be held in the fall. This meeting will further explore the desire of parents and professionals in Missouri to work within an organizational framework to help in identifying children with this syndrome, as well as securing proper medical, dietary, and educational services for Prader-Willi children and adults. Anyone interested in such an organization should contact Betty R. Schultze, Ed. D., 12935 Mason Manor Drive, Creve Coeur, Missouri 63141.

Australia

The Prader-Willi Association (Australia) was represented at the Prader-Willi Conference in Minneapolis by three members, Pearl Simpson and George and Judy Gelb. Following the conference, Mrs. Simpson then traveled to Seattle to observe the group homes there.

The Prader-Willi Association was able to assist an American couple who were living in Sydney with their young adult Prader-Willi son and were unaware of any facilities within the U.S. to which they were returning. Thanks to the Australian Association, they were put in contact with a group in the U.S.

Weight Watchers has opened a motel in Leura, New South Wales. There families can vacation without having to worry about the diet of any individuals needing special care to keep their weight down.

from THE OPEN DOOR

GATHERED REPORTS, ContinuedNew York: Cortland

While on vacation this summer, your editor attended a meeting of Seven Valley Shepherds, Inc., in Cortland, N.Y. Because this is not a heavily populated area, there is not a large population of people with Prader-Willi syndrome. Therefore, Mrs. Ruby Stephens, who has a 27-year-old son with the syndrome, organized the Seven Valley Shepherds in conjunction with parents of young people with other developmental disabilities who had need for facilities somewhat different from those usually provided for the handicapped.

Seven Valley Shepherds at present has a ceramic shop where the young handicapped adults make and sell ceramic objects. Their goal now is to obtain property where a group home can be operated in conjunction with work opportunities. At the meeting it was reported that a piece of property for sale had been located, but the next problem is to raise sufficient funds for purchase.

THE INSIDE VIEW

Jon Cardarella's mother (with Jon's permission) sent the following letter which Jon had written to his teacher. Jon had been taping a TV talk by John Powell, when he realized that parts of the talk contained some things he wanted to say to his teacher, Mrs. Bilmore. Jon played the tape back over and over to take out the parts he wanted to say.

"God not fooled. You know the most important thing you can tell a child that he may take charge of his life and he can do something about it.

"It isn't what you said, but what he hears you say.

"You are a fine person. You have a good mind. You are capable of making decisions. Sometimes you have to change the vision of yourself.

"I am going to say a prayer of gratitude for you. I am making a decision to believe in myself right now. Now I am worthwhile.

"Life is love. Can you believe that.

"You know that life is questioning you every day. We need someone to stand with us. It is hard to stand alone."



Dear Editor of the Gathered View:

My name is Spencer Fransen. I have the Prader-Willi syndrome. I'm 13½. I'm going into 7th grade this fall. I would like to have a pen pal who also has PWS. I live in Dakota, Ill., with my mother and my two sisters. I'm the oldest in our family and I'm the first one to get up each morning because I have a paper route. I have a pet cat named Kizzie. She goes with me on the paper route. I like to play baseball and read books and do puzzles. Also I like to help my mother in the garden. I like to pick my corn. I planted eleven rows of corn this year.

I'm looking forward to Camp Success. I have gone there for seven years. I really like it. Last year I won the best male camper trophy.

Spencer Fransen
Box 11
Dakota, IL 61018

THE MEDIA VIEWHandbook for Parents

The booklet published by the Prader-Willi Syndrome Association, "Prader-Willi Syndrome: A Handbook for Parents," is sold out, so please do not send any more orders for the booklet. As soon as the booklet is reprinted, we will let you know.

In reprinting the booklet, we hope to add a chapter on "Adults With Prader-Willi Syndrome." If there are any suggestions, additions, or corrections you would like to see in the booklet, please let us know immediately. We want to make the booklet available again as soon as possible.

There is Something Special About You

Because of the emotional fallout that affects the entire family which has a special child, Betty Hourihan of Milton, Massachusetts, wrote a pamphlet entitled "There is Something Special About You", which is directed toward the brothers and sisters of special children. The pamphlet is used in counseling sessions at VIA, an organization which Mrs. Hourihan founded to help families who need help with their special children.

Mrs. Hourihan, who is the mother of a Prader-Willi child, was kind enough to send us several copies of her pamphlet. If you would like a copy to share with the children in your family, send a request, along with a business-size, stamped, self-addressed envelope to Shirley Neason. Editor, THE GATHERED VIEW, 26931 S. E. 403rd, Enumclaw, Washington 98022.

FIRES PLAGUE CAMP

A series of seven fires disrupted the summer camp program of Double R R Ranch, a camp for youngsters with Prader-Willi syndrome. The first two fires, occurring only an hour apart, were in a house rented for the camp on Whidbey Island, Washington. The residents were then removed to an apartment in Olympia, Washington. There five more fires occurred. The fire marshal determined that all of the fires were deliberately set. After the fifth fire in Olympia, the campers were moved to the Brookhaven Group Home for people with Prader-Willi syndrome. At this time, parents were contacted to take their children home as it could not be determined which of the campers was responsible for the fires.

During the stay at Brookhaven, another fire completely destroyed that home. This time the fire marshal was able to determine who started the fire. However, the ten-year-old who started it could not have been responsible for the seven fires, as he had not yet arrived at the time they were set. It still remains undetermined who set those fires. All of the Double R R campers have subsequently gone home, and Brookhaven residents have been re-established in a new building.

When contacted concerning the fires, Margo Thornley, director of Double R R Ranch and Brookhaven, pointed out that parents need to be alert to this danger. Children with Prader-Willi syndrome and similar disabilities have the same fascination to experiment as other children, but lack perception and the ability to respond to emergencies. As a result, they are more likely to repeat the experimentation and to allow the situation to grow to dangerous proportions. Therefore, it is wise to keep combustion supplies well out of access.

THE PROFESSIONAL VIEW

For the most part we have not reported the content of the two conferences on Prader-Willi syndrome that were held the past summer, since this will be made available at a later date.

However, Dr. Betty Robb Schultze included in her presentation a summary of the needs in the preschool education of children with Prader-Willi syndrome. The recommendations she made were concise and direct and we pass them on to you.

The following recommendations were made:

1. Professionals from the various fields which are involved in the screening and evaluation of pre-school-aged children should become aware of the Prader-Willi syndrome. This would help in the early identification of these children so appropriate medical and educational management can be established.
2. Programs of early childhood special education which stress a noncategorical approach to intervention should be made available to children with Prader-Willi by the time they are at least three years of age. Prior to the age of three, infant-parent programs should be provided to give assistance and support to the parents and children during the critical early years of infancy.
3. Information regarding this syndrome should be made available in the professional literature of fields such as special education and speech and language pathology. The range in the functional behaviors of Prader-Willi children and methods of intervention should be presented.
4. Efforts to inform the medical profession of the benefits of early intervention for children with the Prader-Willi syndrome should be initiated and its cooperation elicited in referring parents and children for assistance during the early formative years.
5. Research should be initiated to reveal if there is a distinct pattern of psycholinguistic abilities characteristic of children with Prader-Willi syndrome. If differences between channels do exist, for example, lower verbal-auditory skills than visual-motor skills, it presents implications for intervention techniques when programming for children with this syndrome.

PROPOSAL TO CREATE COMMITTEES

At the Board of Directors meeting in Minneapolis, a proposal was adopted to form seven committees that would search for ideas and services in seven areas of need and share the information gathered with the membership at large. Before these committees can be formed, the president will need to know who among our members has an interest in a specific area. If you would be willing to serve on a committee, particularly as chairman, which is the first need, please let Mr. Deterling know. The seven committees are as follows:

- | | |
|--------------------|--------------------------------------|
| 1. Fund raising | 5. Recreation (including camps) |
| 2. Clinic services | 6. Vocational training and placement |
| 3. Group homes | 7. Research |
| 4. Respite care | |

THE GATHERED EXCHANGETopics for Exchange

I would like to see a list of topics to which parents could respond, and then one topic covered thoroughly in one issue. I guess I believe that someone out there is doing much better than I, and I want them to share. I think behaviorally our children are much more alike than many of us suspected. The answers to some of the questions may not suggest a cure or lead to any significant research, but I feel discussion of them will be helpful to parents. Examples of questions I have are:

Do other children like to take long showers and sleep in the shower?

Do other children absolutely refuse to drink water?

Is a peculiar strong body or urine odor occasionally present?

California Member

Topics for Exchange: Editor's Response

The above suggestion of devoting one issue of THE GATHERED VIEW to a single subject could be carried out only if the required amount of material to fill an issue were to come in. If other readers think this is a good idea, only the readers can make it work. To find what topics others are interested in, simply look through back issues to see what topics have been discussed. Add any others you are interested in, then send in your questions, your ideas, and your answers. The items can then be sorted by topic to be used in future issues as material on a given topic is accumulated.

Behavior Management

The item on role-playing was very welcome. No professional had asked me about this, and I did not realize it might be a problem that went with the syndrome. There have been times I have been frightened, because I was not sure my child could separate fact from fantasy. I think this area needs more discussion.

California Member

Temper Tantrums

We are having a problem with our daughter who will be 18. She used to be very sweet and easy to care for, but lately when she gets upset she really gets angry and stomps around, hits herself, slapping herself on her arms and legs. So far I've found trying to sympathize with her helps better than punishment. She doesn't talk except for a few words, so it is hard to know what causes her to be upset. At one time I was able to get her to lose weight, but in the last years she fights a diet, and it is almost impossible to put up with the trouble she causes if she doesn't get a bit of everything the rest of the family eats.

Wisconsin Member

Eating Out

Tupperware markets a lunchbox that is very useful for low calorie lunches away from home. The outfit consists of a larger plastic container that has a sandwich size plastic carton, another oblong carton for salads, fruits, etc., a $\frac{1}{2}$ -round carton for cottage cheese, desserts, etc., and a $\frac{3}{4}$ cup sealed plastic glass for beverages. The smaller cartons fit neatly into the larger container with just enough room to tuck in a napkin and a plastic spoon and fork.

Washington Member

THE GATHERED EXCHANGE, ContinuedBladder Control

My daughter, at 18, has finally reached the point she no longer wets the bed frequently. I get her up once during the night to go to the bathroom.

Wisconsin Member

Sleep

My daughter is slightly overweight, was once excessively overweight, but I do not feel obesity-hypoventilation syndrome is her problem. It seems much more that when she is tired, she goes to sleep then and there regardless of what she is doing. Many an evening she puts her head on her dinner plate and falls asleep. She seems unable to stay awake on a car ride longer than five minutes. This is not something I am particularly concerned about (sometimes I wish I could fall asleep at the table and not have to clear), but it is an area about which I would like to see more parent discussion.

California Member

Recreation and Play

A sand box is excellent for a young child. Use an old tire, a small plastic wading pool, or four 1" x 10" x 8' boards nailed together. Fill with clean sand. Use a large piece of heavy plastic held down with four bricks to cover it when not in use. Use unbreakable items from the kitchen or toy box for sand toys, such as: plastic measuring spoons, wooden spoons, plastic pitcher, strainer, old coffee pot, flour sifter, rolling pin, small dolls, toy cars, eggbeater, margarine containers, cookie cutters, muffin tin, egg cartons, plastic shovel, plastic blocks. Add water occasionally for a different type of play. The value of sand play is realized in measuring, pouring, rolling, "baking", sifting, imagining, patting, piling, etc.

Recreation and Play

Many children with Prader-Willi get difficult while a meal is prepared. This suggestion might help to keep the child occupied. Gather a few shoe boxes, and place an activity in each box that will keep the child occupied. His first project might be to cover the boxes with attractive paper. One box can contain paper, pencil, and envelopes for letter writing. Another might contain play dough and utensils for molding it. Another might be a collage box containing old magazines, scraps of construction paper, yarn, and other materials. Provide paste and something to paste the scraps on, such as the plastic foam trays meat comes in. Other suggestions: paper plates to draw on or make collages on, shoelaces with spools to string on them, and junk mail. To make homemade paste: mix a thin paste of flour and water in a pan, then cook until thick. Keep refrigerated.

To make homemade play dough: Combine 1 cup flour, 1 cup water, $\frac{1}{2}$ cup salt, 2 teaspoons cream of tartar, 1 tablespoon cooking oil, and food coloring in a heavy aluminum pan. Bring to a boil and cook until the mixture pulls away from the pan. When cool, knead until pliable. Store in tightly-covered container or plastic bag. Keeps weeks without refrigeration.

Resources

Parents should contact their local County Developmental Disability Boards and register their children for services. This will bring Prader-Willi syndrome to the attention of the board and point up the need for services, making funds more readily available.

Wisconsin Member

THE GATHERED EXCHANGE, ContinuedDiet

My PWS daughter does not share some of my food hang-ups, and I find I must be careful not to teach them to her. She does not get tired of eating foods frequently; she does not feel some foods need to be eaten hot, or that the size of the servings determine if it is a good meal. She would call a sandwich and milk a poor meal compared to $\frac{1}{2}$ cup cottage cheese, $\frac{1}{2}$ cup A vegetable, 3 fresh mushrooms, an apple, and skim milk, because she got more things for the second meal. The number of items served is her criterion for an adequate meal. Her school lunches consist of a protein food such as lowfat cottage cheese, cooked egg, plain tuna, etc., an A vegetable (frequently left over from the night before), fruit, either a free food or a small amount of something raw from the A vegetable list, and skim milk. I avoid all bread products. I also feel the longer she spend eating the meal, the more satisfied she is; therefore apples are better than applesauce, etc.

California Member

Family Life

Are you recording those important moments with your child so you will remember them? All children have cute sayings. I well remember the first word my Prader-Willi child said--it naturally had to do with food--it was "juice." However, many of the other things he did are forgotten. Often we mothers think we will never forget what our child did and when, but time has a way of dimming memories. Keep a file or notebook to record these important things. Include artwork and other "treasures" the child has created. Be sure to date each entry.

Picking

I wish to share information regarding the "picking" problem, and the methods which are currently working with our PWS child. She has had fairly extensive sensory integration therapy using the A. Jean Ayers, Ph. D., Method. I will not go into this therapy nor evaluate whether it was worth all the money, time, and effort; except the technique for increasing skin sensation. Children with sensory integration deficits are insensitive to heat, cold, and pain. The technique is to vigorously rub the skin (except the genital area) with a rough washcloth for several minutes several times each day. It may be necessary to start gently and increase the vigor as the child tolerates it. If this method works, you should notice increased crying with small cuts, scrapes, and bruises, but decreased picking as it now causes pain. Some parents may not like the trade off. Even though her therapy was discontinued a year and a half ago, our daughter asks for her "rub" almost every night. As for cuts and scratches, I got tired of always having to clean them up, so I taught her to do a very thorough scrubbing with soap and water, rinse, dry, and apply a disinfectant. Later when we catch her picking at it, we tell her she has gotten germs in it and she will now have to clean it all over again. This more constructive occupation with the wound has kept her from picking it open. For bug bites, we give her 100 mg of vitamin B1 daily. Bug bites have been totally eliminated. I had felt that bugs which bite no one else bit my daughter.

California Member

THE RIGHT TO AN APPROPRIATE EDUCATION

The Education for All Handicapped Children Act (Public Law 94-142) requires states to provide a free, appropriate education for every handicapped child. It also involves the parents much more in their child's education than previously. Here are some do's and don'ts for parents in planning a child's education.

Contacting the School

DO...get in touch with your local superintendent if your child is not in school or not getting an appropriate education.

DO...find out about preschool services for handicapped children. Call your district superintendent or the principal of the local school.

DO...make every effort to work with your child's classroom teacher if the child is in school but having problems. You and the teacher may be able together to make discoveries that will help the child.

DO...Remember that you can ask for a re-evaluation if your child is already in a special education program and the program is not meeting his needs.

DO...put your request for an evaluation in writing to the principal or superintendent. Keep copies of correspondence. If vital information is discussed on the phone, write a letter confirming it.

Due Process. You must receive written notice from your school system asking your permission to test your child, even if you requested the evaluation. You must also get a notice in writing if the school turns down your request, explaining why. If you wish to protest the school's decision, you can request a due process hearing.

DO...keep a file on your child's education. It should include diagnostic test results, other professional reports, notations of your own or the teacher's attempts to solve problems, reports from teachers, copies of letters to and from school officials, copies of state and federal laws and procedures, and any other relevant information.

Testing and Evaluation

DO...be sure the evaluation of your child is complete, that it does not consist of only a single test, but tells how your child is doing in all areas of intellectual, physical, and emotional development.

DO...get your child a complete physical examination and correct any physical problems.

DO...remember that pinpointing a child's problems does not tell about what he can do.

DO...tell the school evaluation team your own observations of your child's behavior, strengths, and weaknesses.

DO...ask what tests will be given your child and why. Inform yourself as fully as possible what these tests are expected to do before giving your consent to have your child tested.

DO...be sure that the testing takes into consideration the child's handicaps and cultural background so that the picture of his ability is a true one.

DO...insist that the results of testing and evaluation be explained to you in clear, jargon-free terms and that you have copies for your file.

Due Process. If you do not feel that the school's evaluation is fair or accurate, you may get an independent evaluation from other professionals. However if the school asks for a due process hearing, and the ruling is in the school's favor, you will have to pay for the evaluation yourself.

If you feel that the school's decision about where to place your child as a result of testing and evaluation is wrong, you can request a due process hearing.

Continued

THE RIGHT TO AN APPROPRIATE EDUCATION, ContinuedAttending IEP Meetings

DO...attend all meetings held to plan or check into your child's individualized education program (IEP). Schools are expected to arrange the meetings at times when one or both parents may attend.

DO...prepare for the meeting that will design your child's program. Have your file with needed information readily available. Make sure the school's records are accurate and up-to-date.

DO...bring along a helper to the IEP meeting if it will make you feel more secure. A trained advocate or another parent can help.

DO...be as clear as possible in your own mind about what you think your child is ready to learn. Make a checklist of key items.

DO...be able to back up your requests for special help with diagnostic reports, observations, etc. If you wish, you may have a professional who has worked with your child accompany you.

DO...remember that diagnostic tests are not infallible. Make sure the others at the conference remember you're talking about a real child, not just scores on tests.

DO...think twice about placing your child in a classroom that has a label.

DO...try to understand mainstreaming. If the child can hold his own in the regular classroom with aid and understanding, he should be given the chance. If he needs a separate classroom, he should still join his peers in some activities.

DO...remember that you are an equal-status member of the team. Meetings about a child's school needs should not be confrontations, but an honest examination of alternatives.

From CLOSER LOOK (To Be Continued)

PRADER-WILLI SYNDROME ASSOCIATION**Box 392****Long Lake, Minnesota 55356****Non-Profit Org.****U.S. Postage****PAID****Permit No. 31****Long Lake, MN****010000012****MR/MRS WEBSTER C LEYSHON****10414 HUNTLEY AVENUE****SILVER SPRING MD 20902**