

THE GATHERED VIEW

Shirley Neason, Editor

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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Box 392
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VOLUME III

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THE HEADQUARTERS VIEW

A little publicity goes a long way. A lot of publicity can go too far. At least that is what's been happening to us. Too far is when you receive 300 letters a week asking for information; and when you have a backlog of 700 unanswered letters, that's called too much.

Well, it is nice to be recognized, but it would have been nicer not to have it happen so suddenly. The two recent articles in national periodicals is what did it, of course. The May issue of GOOD HOUSEKEEPING with the article entitled "The Eating Disease" didn't hurt a bit, but the followup "Letters to the Editor" in the August issue generated a downpour of responses to the notation about our organization being a clearinghouse for information on Prader-Willi syndrome. Unfortunately, most of the letters came from people who didn't bother to read the original article and only saw the reference to "The Eating Disease." Ninety-five per cent of the inquiries came from those who have some sort of "Eating Disease," but nothing related to the syndrome. Incidentally, we did not see an advance copy of the article before it was published, so could not make any suggestions for clarification.

And then the article in the July issue of THE EXCEPTIONAL PARENT helped to keep our post office box loaded. This magazine, however, has a readership more focused on the handicapped so most of the resultant inquiries were from those whom we may be able to help.

Nevertheless, we will answer all our correspondence--maybe by Christmas--and then get back on track to some of our earlier planned goals. Needless to say, if you've written to us recently about a special request and you haven't received a prompt answer, it isn't that we've quit trying.

As announced in our July GATHERED VIEW, the Board of Directors has decided that it is necessary to increase our dues to \$10 for domestic membership and \$13 for overseas membership. Unfortunately, (or fortunately, depending upon the way you look at it) it takes time to do that since all of our announcements and membership remainders have to be changed and new ones printed. On top of that, the article in THE EXCEPTIONAL PARENT was written last November but not published until July, and that listed our old dues structure. Thus, we have delayed the increase, but will definitely put it into effect on January 1, 1978.

We have accomplished two major steps in our organizational program. We

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THE HEADQUARTERS VIEW, Continued

are now an official non-profit corporation, and we have filed all of the necessary paperwork with the IRS for a tax-exempt status. Although we have not yet received a reply yet from the IRS, the tax exempt status should be retro-active to July, 1975, so any previous donations may still be considered tax deductible.

In our future issues, we hope to devote more of our space to the adult Prader-Willi citizen. You can all help by forwarding to our editor information on this subject; particularly about adult facilities, programs, workshops, occupations, etc. At some point, we will be able to supply a list of each of these facilities to our many members who request them.

There is still so much we can do.

Gwen Deterling

NEW GROUP HOME TO OPEN

On October 1, a group home for young people with Prader-Willi syndrome will open in Bothell, Washington. As far as is known, this is the first of its kind. Margo Thornley, director of Double R R Ranch, will direct the group home, which will have the same dietary control as the Ranch. Eight people have so far applied for residency. Ginny Wright and Rose Mary Jones will put their experience as counselors at Double R R Ranch to good use as they join the home's staff. Shirley Neason, editor of THE GATHERED VIEW, has been appointed to the home's advisory board.

In addition to the home, a class providing vocational and academic training for day students with Prader-Willi syndrome will be provided at Western Institute of Specialized Education and Recreation, also in Bothell.

Double R R Ranch will also continue to be available for full-time, week-end or weekly residents. The minimum age for admission is six.

Applications for any of these services will be considered regardless of place of residence of the parents. For information contact Margo Thornley, P. O. Box 578, Bothell, WA 98011 or telephone (206) 485-5529.

THE BOOK VIEW

By now you should have received your copy of the booklet, "Prader-Willi Syndrome--A Brother's View" by Robert Amren, published by the Prader-Willi Syndrome Association. One copy of the booklet was sent free to each member of the Association.

While the book contains many facts about the syndrome, it is essentially a personal story of the thoughts and feelings of a person with Prader-Willi syndrome and his family. As such, it will be read with interest by all who have a loved one with the syndrome and by those who work with them. I personally, would like to express my appreciation to Robert Amren for sharing his experience with us and to Mr. and Mrs. Kenneth J. Kelley for making the booklet's publication financially possible.

THE GATHERED EXCHANGE

Please send your questions, ideas, recipes, and comments to be included in THE GATHERED EXCHANGE.

Here is a Canadian mother's response to the question about the gastric bypass:
In November 1976 our little girl had a type of gastric bypass for Prader-Willi syndrome. This was the only hope for her; she was fast becoming a bed patient. At six years she weighed 131 pounds. Since her operation she has lost 56 pounds over a period of eight months. It was our answer to prayer and a miracle. She can run and play once more, and that terrible craving for food all the time has changed as she no longer has the tummy to hold it. This gave us back a new girl and new hope. I do agree that it is a very serious operation and it does have other things to take care of after, like vitamin supplement, along with regular blood tests, etc. We were told here in Canada that our daughter was the first to have surgery for this condition. Each day we are thankful we gave our consent to have it done. It was a long, hard ordeal, but worth it to see her run and play once more.

Here is a question that has been on my mind lately:
I have heard from a few parents who say their child does not steal food. I would like to hear from these and other parents who do not seem to have as severe a problem as some of us in this respect. Do you think your child just naturally does not crave food as badly as the others or is it the result of training? If you think it is the result of training, could you tell us specifically how you went about training him/her?

Another question from the editor:
Since our Seattle group home is the first experience with a group home expressly for residents with Prader-Willi syndrome, I would like to hear from parents of young people concerning what they would expect a group home to do for their children. I do not necessarily just want to hear from parents who are considering placing their children in a group home; I would like to hear from any parent who has thoughts about the kind of services that ought to be offered.

Information concerning Boy Scouting:
It is a national policy of the Boy Scouts of America in each of its three programs--Cub Scouting, Boy Scouting, and Exploring--to waive the upper-age requirements for boys who are retarded. In actual practice, the boy does not have to be actually academically retarded--we have obtained this waiver for our son who fits socially better with a younger group, but is not retarded in his academic progress in school.

Another question:
My son's feet toe out when he walks. In visits to the clinic, I notice that this problem seems to be common among the children with Prader-Willi syndrome. Does anyone know of exercise or other measures that can be taken to correct it?

Do you know the facts about diet "candy?"
Diet "candy" should not be included in the range of treats offered to people with Prader-Willi syndrome. This "candy" is sugar-free, but not low enough in calories to be used as an "extra." If you feel you must give your child an occasional piece of candy, try a miniature marshmallow (two calories), a jelly bean (ten calories), a small gumdrop (six calories), or a candy "corn" (six calories).

You can make jams and jellies without sugar:
Use Slim Set pectin, manufactured by MCP Foods, Inc.

A DAY AT DOUBLE R R RANCH

by Shirley Neason

The first summer's operation of Double R R Ranch, a camp for young people with Prader-Willi syndrome, is history and soon reports from the counselors will be going to parents of the children involved.

For the parent's point of view, I spent a full day observing at the ranch.

A group discussion was in progress when I arrived at 2:00 p.m. on a Tuesday. The counselor had been asking the six ranchers, who ranged in age from seven to sixteen, to talk about what made them angry and how they could handle their angry feelings. Then the discussion shifted to food as the counselors attempted to find out how aware the ranchers were of what and how much they should eat. Each was given a different copy of a popular household magazine and asked to



Off for a hike with counselor Ginny.



Meal time--the most important time of the day.

turn to the first picture of food. One by one they named the pictured food, what ingredients it was likely to contain, whether or not it was a good food for them to eat, and why, and how much of it would be an allowable serving. Most responses were quite accurate.

At three-thirty the group went swimming. This summer was uncharacteristically hot for the Pacific Northwest, so swimming played a larger part in the program than it might during a more normal summer. The counselors encouraged physical activity by getting the swimmers involved in water tag and water volley ball. Transportation to and from the pool was provided by Eddie, a friend of the counselors who volunteered his services to the ranch.

Upon returning from swimming the young people had free time while counselors Ginny Wright and Rose Mary Jones prepared the evening meal. As the counselors worked, they talked about their experiences.

"We have had no food problems. The kids understand clearly that there is no food anywhere except in the kitchen and it is kept locked between meals.

"We take the children's pictures and post their weights when they arrive, and again when they leave.

"We try to give them some food experiences other than just eating. When we went overnight camping, they got to cook their own hot dogs and stir their own bouillon."



At the pool. That's Margo Thornley in the swim cap; my son, Dan, in the inner tube.

Then supper was served: plates heaped high with food, yet so low in calories they fit easily into an 800-calorie-a-day diet. Each child's calorie limit had been established by a nutritionist. Some received 800 calories, some 1000, and some 1200 per day. Those allowed more than 800 received their extra calories in bread servings. This meal consisted of green pepper stuffed with cottage cheese, corn, peas, non-fat milk, diet gelatin, and fresh plums.

After supper it was time for a daily ritual: racing a counselor to the mailbox about a quarter mile away to pick up the daily paper. Games like this are included in the daily routine to work more exercise into the program.

While they were gone the other counselor washed dishes. She talked about the program.

"This summer has been played by ear. We are learning from the kids. We are trying to present them with a variety of learning situations and unusual experiences. Here at camp, diet and exercise are the same as at home. We try to make all other experiences different. Field trips and overnight campouts provide a change of scenery. Some occasional activities we have had are art lessons, ukelele lessons, and horseback riding.

We try to match the children's moods. Sometimes they want the counselors to be one of them; sometimes they are homesick and want a "family" atmosphere. We observe the children to learn their favorite activities, then encourage them in those while trying to discover ways to add more physical and learning activities."

Soon it was time to begin getting ready for bed. The TV was turned on to entertain the ranchers as they waited their turn at one of the two bathrooms. However, they seemed more interested in talking. There seemed to be an intense comradeship among them, as though they could be completely open knowing that each understood the others' problems and shortcomings.

At 9:00 p.m. campers were tucked in for the night, and Rose and Ginny began their paper work. Records were kept of each child's daily weight, his food intake, food rejection, and any unusual behavior. As the counselors worked they talked some more.

"These kids are so unique and so neat; they are a society all their own. It's one of the greatest experiences of our lives.

"The Seattle area campers, who already knew one



Counselor Rose gives friendly advice.



A phone call from home.

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A DAY AT DOUBLE R R RANCH, Continued

another from meeting at the clinic and being in summer school together, adapted readily to the camp program. Children who had never before met a child with their problems seemed overwhelmed at first.

As the records were being completed, nutritionist Mary Lou Beck dropped in to check on the food situation. She found one day's menu that was a little unbalanced and recommended a change. She also suggested that less bouillon be served on camping trips because of its high sodium content. Otherwise, she was pleased with the nutritional program.

Finally the day's work was ended, and Ginny and Rose were able to call their time their own. They commented, "This is almost a twenty-four-hour-day job, but when we need an evening out or a day off, Pete and Linda Pierson, the caretakers, take over for us."

The next day's activities began at eight. Every rancher was weighed, amid much discussion and bragging about weight loss. Then they took their daily baths, made their beds, and took care of other chores. That done, they watched TV or played quiet games while the counselors cooked breakfast and did the laundry.

Breakfast consisted of "fried" (without fat) egg (72 calories), $\frac{1}{2}$ cantaloupe (40 calories), and eight ounces non-fat milk (80 calories.) In addition, one slice of toast with $\frac{1}{2}$ teaspoon margarine went to those on a 1000 calorie or higher diet.

Breakfast was over at 9:30. The counselors reported they were running late since one child had been allowed to sleep later than usual because she had seemed tired the night before.

At ten the group went for a hike. It was slower than usual, as the newest camper was quite overweight and could not walk fast. After the long walk up the driveway, the group divided into buddy teams to walk along the highway. Campers offered encouragement to one another to keep on the side of the road, and to keep up with the group. The counselor pointed out familiar animals and new ones. The heavier campers perspired freely as the day grew warmer. The hike ended with a race back to the house, with the winner receiving a double portion of the morning's treat: sugar-free gum.

The next few minutes were free. The late sleeper made her bed; another camper did medically prescribed exercises; two fed the pet snake; others played on the playground equipment.

At 11:00 group discussion took place around a glass of Kool-aid. The question was, "Why do you like this group?" Answers came rapidly.

"Nobody calls me names."

"People do things here."

"I have friends here."

"Everybody understands each other."

"Nobody picks on you."

The conversation wandered to food. The counselor brought it back.

"How do you feel when someone calls you names?" she asked.

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A DAY AT DOUBLE R R RANCH, Continued

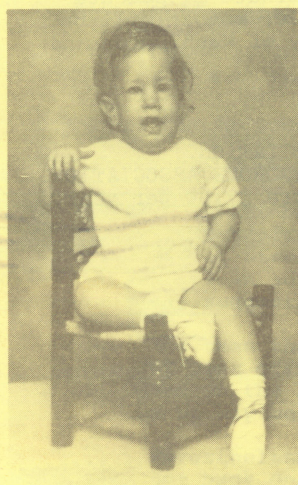
The discussion eventually led to TV, revealing that many of the ranchers did not distinguish clearly between reality and fantasy. During the discussion the counselor helped the children clear up their misconceptions while at the same time learning to take turns and to stick to the subject.

Lunch time arrived--tomato, cucumber, green beans, cottage cheese, milk, and Kool-aid--a good meal for a hot day. Mealtime conversation turned to the article that would result from my visit there. They asked me to promise that all their names would appear in the article.

So as I prepared to leave, Double R R Ranchers David, Danny, Russ, Tim, Todd and Terry were planning a trip to the zoo.

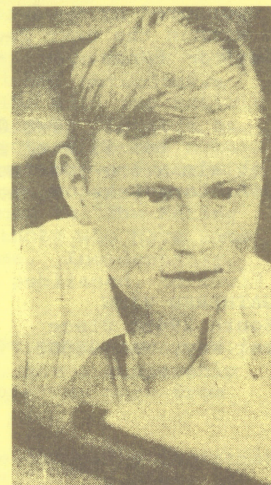
HEY! THAT'S GREAT!

The purpose of this column is to give recognition to achievements by persons with Prader-Willi syndrome. Please send reports about what your child, or another person with the syndrome, is doing that you think is worthy of recognition. You may include a picture of the person along with a release giving permission to print the picture. Be sure to state whether or not the person's name is to be used, and, if so, exactly how you want it to appear.



This young man's mother writes, "At this early age (fourteen months) we thought it quite an accomplishment to sit on a chair. The terrible head lag is very fresh in our minds."

This is Peter Schreffler, age 20, who recently got his first job as a file clerk. He is working under a CETA-funded program called Training Through Placement for retarded young people. Peter's co-workers report that his pleasant attitude has made a hit at City Hall, his place of employment, and that his ability should eventually earn him placement in private industry.

ABOUT THE PARENTS' HANDBOOK

The parents' handbook is now at the printer. To save money, I will do the proofing myself. Never having had experience in this, I do not know how long it will take. Hopefully, the book will be ready by the end of the year.

THE PROFESSIONAL VIEW

This month's PROFESSIONAL VIEW comes from Vanja Holm, M.D., who tells of her work and her feelings about how to approach the treatment of Prader-Willi syndrome.

THE HEADQUARTERS VIEW, Continued

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THE PROFESSIONAL VIEW, continued

For the past 12 years I have been devoting my professional time exclusively to the care of handicapped children, spending most of my time at the Child Development and Mental Retardation Center, which is one of several interdisciplinary University (of Washington) Affiliated Facilities charged with training of different kinds of professional students in the care of children with development disabilities. The Prader-Willi Clinic is but one of several clinics for handicapped children in our facility; my own special interest, in addition to the Prader-Willi syndrome children, includes early recognition and treatment of cerebral palsy, management of young children with Down's syndrome, PKU, and others.

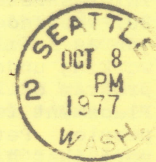
My main theme is that if we are going to improve the lot for handicapped children, their disabilities have to be recognized early so that appropriate management can be instituted. In this respect, I am hoping that we can educate physicians to suspect the Prader-Willi syndrome before the gross obesity becomes such a management problem. I like to emphasize that the appropriate treatment of this syndrome is an interdisciplinary affair. There are so many nutritional, behavioral, educational, social, as well as medical aspects to this problem that it can only be alleviated if people with a variety of expertise work together.

PRADER-WILLI SYNDROME TO BE FEATURED ON TV

Prader-Willi syndrome will be the subject of a three-minute TV science spot sponsored by Newsweek. Times and stations are not available, but it will be shown within the next few weeks. It was filmed at the University of Washington and Double R R Ranch.

A subscription to THE GATHERED VIEW is included as one of the benefits of membership in PRADER-WILLI SYNDROME ASSOCIATION. To obtain a one-year membership, send \$6.00 to PRADER-WILLI SYNDROME ASSOCIATION, Box 392, Long Lake, Minnesota 55356. Overseas membership dues are \$7.00 per year.

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