

# THE GATHERED VIEW

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Shirley Neason, Editor

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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## MESSAGE FROM THE PRESIDENT

Diets, behavioral modification programs, physical therapy, exercise programs, recreation programs, speech therapy, special education programs, sex education, group homes, camps, employment, special treatment centers, helpful surgery, helpful medication are just some of the many topics about which we would all like to be better informed. In the new year with our membership approaching 300, I am hopeful that each of us will not only become better informed but that we will be able to share our information more freely. One of the ways this will happen is through the local groups that are finally being established.

The local meetings are great satisfaction to those who are able to attend and communicate personal experiences. I think, however, that they can achieve something greater than the personal comfort that comes from communicating with others who have had to cope with the syndrome. I am suggesting that there be more concentration on some of the specific topics mentioned above so that the information and ideas stored in everyone's memory can be brought out and collected in an organized manner. Of key importance then is that each local group have a reporter who will document the essential elements of these discussions so that the material can be forwarded to the editor of THE GATHERED VIEW for publication and benefit of all members.

A number of years ago, a large corporation initiated a formal technique for brain storming. One of the important facets of this technique is called "hitchhiking." When one member of a brain storming session throws out an idea or thought any other person may pick it up and "hitchhike" on it with his/her own contribution. A rule associated with brain storming is that no one may criticize, laugh at, or otherwise attempt to degrade any idea, no matter how ridiculous it may appear on the surface. Wild ideas are, in fact, to be encouraged. One person's wild idea often develops into a sensible suggestion after a number of "hitchhikes" have been applied to it.

I am not in any way suggesting that formal brain storming be promoted within any of the local groups. I am, however, implying that someone's information, idea, brain storm, or plan that is vocalized on the East Coast can be "hitchhiked" on in the Midwest or West Coast, or wherever, and can grow to something greater than could be expected at the local level.

Continued on Page Two



MESSAGE FROM THE PRESIDENT, Continued

We need to plant a lot more seeds for thought that may eventually grow into solid plans that will benefit all of our Prader-Willi people. Let us hope that 1978 will bring us all closer together in our attempts to provide a better world for those affected by and those coping with the syndrome.

*GARY STORLING*

MENUS FOR A MEASURED DIET

Each menu and each recipe is for one serving. Calorie count is listed after each food.

800-calorie-per-day Menu

## Breakfast:

1 medium egg	72
1 small orange	45
8 ounces nonfat milk	80

## Lunch:

3/4 hot dog	139
1/2 cup sauerkraut	42
1 stalk celery	15
3 slices tomato	10
1/2 sliced cucumber	8
1/4 small cantaloupe	39.8

## Dinner:

## Cheese fondue:

1 medium egg	72
1 cup nonfat milk	80
1 slice cubed bread	70
1 ounce cheddar cheese	104
1 cup cauliflower	28
1/2 cup cooked carrots	22.5
1/2 cup diet gelatin dessert	8

RECIPE: Cheese Fondue

1 medium egg	72
1 cup nonfat milk	80
1 slice bread, cubed	70
1 ounce cheddar cheese	104
Salt, pepper, parsley, onion to taste	0

Beat egg, add milk, bread, cheese, and seasonings. Bake in moderate oven (350°) until firm in center, about 20 to 30 minutes. Makes one serving.

For 1,000 calories add:

## For breakfast:

1 slice toast with 1/2 teaspoon margarine 100

## For lunch:

8 ounces nonfat milk 80

For 1200 calories add:

All of the above, plus:

## For lunch:

1 hot dog 139

## For dinner:

1/2 ounce cheddar cheese 52



Total calories in one serving of cheese fondue: 326

2 meat exchanges  
1 milk exchange  
1 bread exchange

If desired, substitute one of the following instead of cheese:

1 ounce chicken (55)	Total calories 277
1/4 cup tuna fish (78.8)	Total calories 301



HEY! THAT'S GREAT!

This is the latest picture of Cathy Hamilton, whom we wrote about in this column in the last issue. We did, however, make a mistake that time. Cathy lost not seventy-five pounds, as we reported, but lost fifty-seven pounds. She now weighs seventy-three pounds, great for a girl just 48 and 3/4 inches tall.

Cathy's mother, in her latest letter, writes, "We had Cathy to the Childrens Hospital in Halifax the second week in November. All the specialists were amazed and thrilled at her progress for the year since her surgery. They did numerous tests on her, and all were just fine. She is still on 700 calories per day and has approximately ten more pounds to lose to be at the normal weight for her age and height."

Cathy goes to school each day, and is doing well, but in our school system here we have no classes for children who need that little extra attention, but her teachers understand her condition and try to help in every way they can. We are more than pleased with her work and praise her lots when work is neat. When it isn't we just tell her we're proud of her, but when she takes her time it is much neater. This does encourage her for the next few days to do it neater for us. She still has terribly stubborn temper tantrums, but I try to get her into bed until it's over, and most times I lay down beside her and hold her in my arms. For some reason this has helped, perhaps because she needs reassurance at this time. She is so full of love and seems to thrive on it herself."

(Isn't it great that Cathy has such a great family to give her so much love and understanding?--Ed.)

When the newsletter runs short of room, it is always the item about the editor's own son that gets bumped. This news is a little outdated, but we still think Danny did great. Last spring he won the spelling bee at his school, and got to go to district spelling bee, where he was eliminated fourteenth among twenty-seven competitors. At the time he was ten and in a regular fourth grade, so he was competing with normal children in grades one through six.

Danny is just under fifty-three inches tall, and weighs about seventy pounds, just right for him. We weigh him every week, and adjust his calorie intake according to his weight. This keeps his weight in line and doesn't let it creep up to a point where it would require a stringent diet to get it down to the desired level.

GATHERED NEWS

The first World Congress on Future Special Education will be held at the University of Stirling, Scotland, June 25-July 1, 1978. It will be sponsored by the Council for Exceptional Children. The Congress will feature speakers, panel discussions, small seminar groups, and visits to educational facilities. For further information write CEC World Congress, 1920 Association Drive, Reston, VA 22091.



A VIEW OF WHO'S WHO

More and more interest has been expressed lately in knowing more about older people with Prader-Willi syndrome. This month our WHO'S WHO column features a letter from the mother of an adult woman with the syndrome.

Our daughter, born December 29, 1953, was full-term, our fifth living child and my ninth pregnancy. The other four were all third month miscarriages.

At birth she had total absence of muscle tone, was unable to swallow her own saliva. She was kept alive by suction withdrawal of fluid and oxygen. After two months in the hospital under constant nursing care, we brought her home against medical recommendation that she be placed in an institution, since she "could die at any minute." After her third week in the hospital, feeding with a cross cut nipple had been tried successfully.

The original diagnosis was anyotonia congenitalis--Prader-Willi was unknown in 1953. Neither medication nor therapy was prescribed by prominent physicians (now deceased.)

She was first able to sit, momentarily, without support when she was past ten months old. Her first halting steps, along furniture, came at twenty-six months. Gradual improvement followed, aided by the stimulation of having four older siblings, three of whom are brothers. I forgot to mention that Kari uttered her first cry when she was past four months, and one lung was not expanded at birth and the other only partially.

From four years of age until six, she was in nursery schools with average children. She related very well to other children and to adults. She was an outgoing, smiling child, beautiful though chubby. Her prettiness and tiny hands and feet made her look like "a big doll", as expressed by many.

Late in her fifth year she was diagnosed as Prader-Willi.

Since no "special ed" classes were then available, she entered regular first grade, repeated it, and after one year in second grade, a special class became available. Later she was fortunate enough to be accepted in St. Michael's Spécial School, where she continued in the educable division until she graduated at age 20½.

She then gained admission to a very good private sheltered workshop for girls which specializes in sewing training and production. The girls are trained to work to their individual capability. Many are adept; others less so.

Kari exhibits many of the Prader-Willi traits mentioned in the newsletter, particularly obesity (she weighs 180 and is about 4' 10" tall.) Since she was about seventeen, she has become obsessed with her health situation--she has numerous complaints, and seems to derive satisfaction from attention by doctors. She has never menstruated. Periodic visits to gynecologists, gland experts, etc., all seem fruitless, except for her obesity, which we have battled for many years. At one time low-dosage amphetamines were tried off and on with some benefit, but she became too nervous, and we feared long-term usage.

She has lived for the past two years during the week at a group home, but is home during the weekends and holicays. Often she resists returning to the group home and workshop. Since we are in our mid-sixties, we hoped this arrangement would make easier adjustment to life without parents. Her retardation is moderate, but her maturity level is not sufficient to permit independent living; perhaps we have been overprotective, and thereby hindered her development.

Continued on Page Five.



THE MEDIA VIEW

Do you have difficulty finding good books for your children? You might be able to find what you want through The Children's Book Shop, a mail-order source. The Book Shop is owned by Miriam Bourne, a mother and former school teacher, and author of ten books for children. She opened her shop because she wanted parents to be able to buy the same quality books for their homes as libraries were able to buy for their shelves. Her catalog of 130 books are all recommended by the American Library Association, and most of them have won prizes. To receive a catalog, and be on the mailing list, send your name, address, and fifty cents to The Children's Book Shop, Riverside and 81st Street (#6401), Cabin John, Maryland 20731.

GATHERED REPORTS

Seattle, Washington

Seattle area parents are planning two meetings in connection with the next clinic date.

On Tuesday, January 31, at 6:00 p.m., a potluck dinner will be held at the home of Dick and Barbara Simmons, 101 Lee Street, on Queen Anne Hill, in Seattle. Those attending are asked to bring their children with Prader-Willi syndrome, and to bring a main dish, vegetable, or fruit suitable for a low calorie diet. Also bring your recipe to share. The subject for discussion will be group homes and we will have as a guest the director of a group home in Canada that operates on a unique concept. If you plan to attend this meeting, please write or call Barbara Simmons (206) 284-9034 or Shirley Neason (206) 941-2728, so we can know how many to plan for.

Then on Wednesday, February 1, at 10:00 a.m., there will be a seminar for parents at the Child Development and Mental Retardation Center of the University of Washington. Judi LeConte, social worker on the CDMRC staff will direct the seminar on the subject of "Educational Advocacy: A Review of House Bill 90."

A VIEW OF WHO'S WHO, Continued

Most of the time she is loving and outgoing, but once her will is thwarted or she embarks on a tantrum, there's no "cooling it" until she becomes almost hysterical, screams, cries, resists every effort to reason, so we have to just let her scene subside and ignore her until she gets a handle on it. It is almost impossible to get her to see or admit that she is wrong or ever at fault. She insists she "hasn't done anything"--it's almost always "someone else's fault" (usually Mother's). Also she is a compulsive talker.

I have gone into much detail in the hope that other Prader-Willi parents will be on guard against these developments. We are of the opinion that perhaps earlier group home and workshop experience might have provided better opportunities to learn to live with her peers and others. We love her dearly and are much concerned for her welfare and happiness.



IT WILL SOON BE HERE

The handbook for parents should be available soon. You may begin sending pre-publication orders for the book. Cost of printing and mailing the booklets is estimated to be about \$2.00 each. Approximately half of this amount has been donated by members of PRADER-WILLI SYNDROME ASSOCIATION. A donation to cover the remaining cost of the books you order is requested to keep the ASSOCIATION's bank balance in the black.

THE GATHERED EXCHANGE

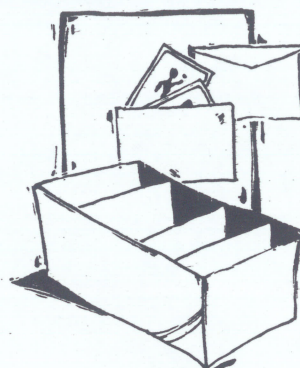
Here's a travel suggestion:

Begin now to make a list of things you need to take the next time you travel with your Prader-Willi child. Each time you travel with him/her, add things to the list you wish you had with you, and delete the things you do not find useful. Keep the list inside a suitcase, or some other place you keep travel items; then you will have it handy when you start to pack for the next trip.

Keeping photographs organized:

We thought we would remember forever the age at which our child passed those childhood milestones. Therefore, we didn't label the photographs we took. Now we often find ourselves wondering, "Just how old was he when he began to hold his head up without wobbling?"

Here's a way to keep those photos organized. Make a file box by using a shoe box and dividers. When you get an envelope of snapshots, mark the date and subjects on the envelope, then file according to year. Then some day when you want to go back and make an album, or just look them over, you will know exactly when each was taken.



Another remedy for feet turning out:

Our child had a terrible problem with this and a specialist ordered her shoes screwed onto a piece of plywood, as she was unable to walk for so long. She wore them like that even while she slept. This did help lots as when she did walk, they were pretty near straight.

E.H.

GATHERED NEWS

Fifty-five centers across the country are coordinated by the North American Riding for the Handicapped Association (NARHA). Programs vary from place to place, but each participant follows an exercise regimen prescribed by a physical therapist and approved by a physician. Trained instructors provide supervision and riders progress at their own pace. Participants are not charged, but donations are accepted. If you would like to locate a center in your area or if you're a horse person interested in starting one, write Leonard Warner, NARHA, Box 100, Department WD, Ashburn, Virginia 22001.



TOYS FOR THE YOUNG CHILD, Part Two

by Shirley Neason

Here are some suggestions for specific toys.

A good first choice for the new baby is a record player with clear sound reproduction. Select good quality recordings of sleepytime music, bright, happy music for wakeful times, and simple classical music. Other "sound" toys a young baby enjoys are a ticking clock and music boxes.

A brightly colored object placed on the side of the crib will catch Baby's attention, and mobiles, preferably more than one to alternate for variety, will provide form and movement. Provide a crib gym or similar toy to create noise when he hits it.

As soon as Baby can grasp with his hand, he is ready for squeeze toys and a safety mirror. A crib aquarium, a heavy plastic bag that can hold one or two small fish and be sealed to prevent spilling, is a delightful toy.

When Baby begins sitting up he likes cuddly toys. A texture ball is good --a stuffed ball made of different textured fabrics sewn together. At this point the child is usually ready to put things in containers, so he can have a cup and something to put in it (like a clothespin or spoon.)

At this age, or younger, if the child is physically delayed but aware of sound, introduce him to books. Choose sturdy books with one clear picture and no more than four or five words to a page. Books with animals are especially good as they encourage the child to imitate the animal sounds.

When he reaches the crawling state, give the baby balls and other toys he can push or pull. By now he is also ready for a "busy box" of buttons to push, levers to move, etc. A simple shape sorter can also be introduced, along with a simple music toy such as xylophone or drum.

Riding toys should be introduced after the child starts to walk.

Next: Toys for the Preschooler.

REHABILITATION INTERNATIONAL QUESTIONNAIRE

Rehabilitation International is carrying out a survey on the participation of disabled people in the rehabilitation process. This questionnaire is to be answered only by the disabled person himself. If you would like to respond, write your replies on a sheet of paper, sign your name and address, state what organization, if any, you belong to, and describe your disability. Also state whether or not you give permission for printing the comments you make. Mail your replies to Rehabilitation International, 432 Park Ave. So., New York, N.Y. 10016.

The Questions:

1. What do you regard as the most important issue or problem faced by disabled people today?
2. What is your position on the need for a separate organization of disabled people?
3. What do you think will be the most important issue or problem faced by disabled people during the 1980s?
4. What long range actions do you propose?



THE PROFESSIONAL VIEWOpen House at WISER Acres

On October 1, Margo Thornley opened the first group home for adolescents and adults with Prader-Willi syndrome. Called WISER Acres (WISER is an acronym for Western Institute of Specialized Education and Recreation), the home has eight residents. All who can come are invited to an open house at WISER Acres on Wednesday, February 1, from one to three in the afternoon. Take Exit 24 off I-405, turn west, and look for the WISER sign on your right in just about one block. The address is 19025 Ross Road, telephone 485-5529.

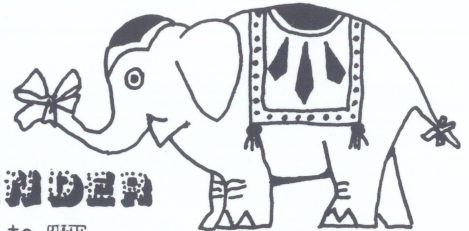
Mrs. Thornley Available as Consultant

Margo Thornley's considerable training and experience in educating the handicapped can be of value to parents' groups that are interested in developing their own camp, group home, and/or educational programs. She is available as a consultant and can be contacted by writing P. O. Box 578, Bothell, Washington 98011, or telephoning (206) 364-5545.

MEMBERSHIP DUES ARE NOW \$10.00

As of January 1, 1978, membership dues in PRADER-WILLI SYNDROME ASSOCIATION are \$10.00 for the United State, Canada, and Mexico, and \$13.00 for overseas members. Send your dues to PRADER-WILLI SYNDROME ASSOCIATION, Box 392, Long Lake, Minnesota 55356. A subscription to THE GATHERED VIEW will be sent automatically as part of your membership benefits.

Letters to the Editor should be addressed to THE GATHERED VIEW, 147 South 294th Place, Federal Way, WA 98003.



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