

# THE GATHERED VIEW

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Enumclaw, Washington 98022

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

Gene Deterling, President

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## PRESIDENT'S MESSAGE

June may very well be the most historical month for our syndrome since it was first described in 1956. With two of the first ever national conferences scheduled to discuss the syndrome, there will probably be more knowledge shared on the subject than in all of the past twenty-three years. We have good reason to be excited about these conferences since for the first time professional experts and parents will have the opportunity to gather together to share their knowledge of Prader-Willi Syndrome. Knowledge is one of the most priceless assets a human can possess, but it remains virtually valueless until it is shared. Along with the sharing will come dialogue and debate and re-thinking, and, hopefully, finally some convictions, conclusions and discoveries. The ultimate goal, however, is action. Knowledge, discovery, and action are the essential ingredients that we must have if we are ever to diminish the plight of those who carry the burden of the syndrome. By the end of June, we will have taken the first step, a most important step, an impressive gathering of knowledge.

The two conferences, of course, are those we have previously announced in THE GATHERED VIEW. The first is on June 13th to 15th in the Seattle area sponsored by the Child Development and Mental Retardation Center at the University of Washington, and will be primarily dedicated to the gathering of research data, but will include papers on the general aspects of the syndrome.

The second conference is our own national conference scheduled for this June 29th and 30th. By now all of you should have received an announcement and pre-registration form. If, for any reason, you did not receive this notice, please contact us here at our home office in Minnesota immediately. Although we feel we have our plans fairly well finalized, we won't be able to make a good prediction of the attendance until about a week before the conference. We have sent out 2,500 announcements so anticipate we will have in the order of 300 attendees, of which at least 100 will be parents of Prader-Willi people.

Our annual business meeting will be held in the morning of the first day, Friday, June 29th, and will be open to all of our members. Our bylaws call for the Board members to be elected by the general membership; thus you will have the opportunity to vote for the directors of your organization. Any other business matters may also be introduced by our membership at this meeting.

Continued on Page two



PRESIDENT'S MESSAGE, Continued

For those who are planning on bringing their children to this conference, the Minnesota group has been preparing plans for activities during the two days of sessions. We will advise all those partners who have informed us of their plans to attend with their children of the details in a letter that will be issued before the end of May.

We are pleased to announce that in conjunction with our conference, Jurgen Harrmann, M.D., from the Dept. of Pediatrics at the Medical College of Wisconsin in Milwaukee, will provide the services of a medical clinic at the conference hotel on Friday morning during the time of the business meeting for those parents or persons with Prader-Willi Syndrome. There will be no charge for this service. We are very grateful to Dr. Herrmann for volunteering to conduct this service and believe that the gathering of Prader-Willi families and medical experts familiar with the condition will provide a natural opportunity for such a clinic. Dr. Herrmann has also indicated that he plans to issue a general questionnaire on coping with the syndrome to all of our membership. The questionnaire will be mailed out in the near future.

All in all, it looks as though June is ready to bust out all over with opportunity. We are hoping to see many of you either in the Seattle area or in Minneapolis during the great month of June.

NATIONAL CONFERENCE ON PRADER-WILLI SYNDROME

Planning for the National Conference on Prader-Willi Syndrome sponsored by the Child Development and Natural Retardation Center of the University of Washington is in the final stages. Approximately 50 professionals from the United States and Canada will meet at the University of Washington's Lake Wilderness Conference Center from June 13 through 15 to hear and discuss papers about current research on medical, nutritional, and behavioral aspects of Prader-Willi Syndrome. The opening session of the conference will be addressed by Gene Deterling, President of the Prader-Willi Syndrome Association. Discussion groups will work out a consensus on recommendations for future directions in serving individuals with this disability. Most of the conference papers will be published in a book to be edited by Vanja Holm, Stephen Sulzbacher, and Peggy Pipes of the University of Washington.

Parents from the Seattle area who are interested in attending conference sessions on a space available basis should contact Sue Chapman at 545-1284 before June 4 for reservations.

Reported by Mike Steffes

RESPIRE CARE

Idaho has enacted a Respite Care Services Act that authorizes services for eligible individuals and provides relief to parents or guardians. For information contact Jerry Fowler, Chief, Bureau of Adult and Child Development, Department of Health and Welfare, Statehouse, Boise, ID 83720.

From P C M R Newsbreak



HEY! THAT'S GREAT!

This is Stacey, age four. She is 33 1/2 inches tall and weighs just twenty-eight pounds. Her doctor is extremely pleased and surprised that she has kept her weight down so well. She was tentatively diagnosed (later confirmed) at six months and her parents immediately began controlling her food intake. Though she seems to have no cut off point to her appetite, she has always accepted what she was given with no complaint and without asking for more. With her, food has been out of sight, out of mind. She does not have a specific diet, it is just greatly restricted on starchy food and gets almost no sugar. Her doctor and parents hope that with this good start and with proper control she need never develop a serious weight problem.

This is Laura White of Jackson, Mississippi. She is 4 1/2 feet tall and weighs 124 pounds. This is thirty-five pounds less than she weighed eight months ago. She is really doing a good job of staying on her diet.

Laura has always tried to achieve and is working on or planning a new project all the time. She is in the eleventh grade. She is a good reader and knows her arithmetic facts well.

THE INSIDE VIEW

The most popular title for our column of letters from people with Prader-Willi syndrome was THE INSIDE VIEW, so here it is. With a little coaxing I was able to get my own son to write a letter to the column. Since I imagine that many other young people with Prader-Willi Syndrome are like my son, definitely not self-starters, they will probably need a little encouragement to write to us. So please tell the Prader-Willi person in your home that THE GATHERED VIEW would dearly love to have a letter from him/her.

DEAR GATHERED VIEW,

My name is Daniel Neason. Do you know what I do? I act like a Prader-Willi. I eat food that I'm not supposed to have. Why can't I eat it? Because my weight goes up! Then what do I do? I cut down on my food situation. What happens then? My weight goes down a little bit at a time. Now what do you think will happen? I will get higher privileges on my food situation or 1800 + 100 calories.

My problems are that when I get married my wife cannot or might not produce babies. I would have to adopt babies or marry a widow with children or babies. I cannot have food with sugar in it. I can only eat a certain amount.



THE PROFESSIONAL VIEW

## OBESITY-HYPOVENTILATION SYNDROME

by

David M. Orenstein, M.D.

Assistant Professor of Pediatrics

Rainbow Babies &amp; Childrens Hospital, Cleveland, Ohio

Many people with Prader-Willi Syndrome seem to have a problem with excessive sleepiness. In our experience these patients have all been tremendously overweight. We feel that there are two factors which cause the sleepiness; namely, their obesity and a poor responsiveness to carbon dioxide (which I'll explain in a moment.) We don't think the sleepiness is directly related to the Prader-Willi syndrome.

Among any group of tremendously overweight people, a certain percentage will have excessive sleepiness. This is caused by a problem called the obesity-hypoventilation syndrome. All these patients hypoventilate, which means that they don't breathe deeply enough. Because of not breathing deeply enough they are not able to rid their bodies of carbon dioxide. As carbon dioxide levels build up, patients fall asleep. These patients don't breathe deeply enough for two reasons: one is that they have so much fat on the chest wall and in the abdomen which needs to be moved with each breath that it gets to be too much work. The second reason is that their bodies are not able to respond properly to increasing levels of carbon dioxide. Usually when carbon dioxide levels rise in a person, the body senses this and increases the rate and depth of breathing in order to eliminate carbon dioxide. Some people's bodies are not able to sense an increasing level of carbon dioxide and therefore they don't increase their breathing when carbon dioxide starts building up.

It seems that a certain percentage of all people have this poor responsiveness to carbon dioxide, but if they don't have any other breathing problems, carbon dioxide won't begin to build up in the first place, and they won't have any trouble. But if there are other breathing problems (like severe obesity or emphysema), the combination of that problem and the poor response to carbon dioxide add together to give the person high levels of carbon dioxide and increased sleepiness.

The tendency to have a low ventilatory response to carbon dioxide may run in families. Recently we've looked at seven Prader-Willi families, including two families in which the Prader-Willi child had had the obesity-hypoventilation syndrome, with excessive sleepiness, excessive carbon dioxide levels, and other serious problems that go along with this. In testing our seven Prader-Willi patients and their family members, we found that the two Prader-Willi children who had the obesity-hypoventilation syndrome had, as expected, very low responses to carbon dioxide. We also found that these children's healthy family members also showed low responses to carbon dioxide. The other Prader-Willi children, who had not had the sleepiness problem or the hypoventilation problem, had normal responses to carbon dioxide, as did most of their family members.

So it seems that with Prader-Willi syndrome, just as with people who are obese for other reasons, breathing problems, hypoventilation, and sleepiness may come from a combination of a low response to carbon dioxide, and severe obesity, and that the low ventilatory response to carbon dioxide may be determined in part by familial factors.

Continued on Page Five



OBESITY-HYPOVENTILATION SYNDROME, Continued

Being able to identify those patients with Prader-willi syndrome who may have the obesity-hypoventilation syndrome is very important because the problem can be much more severe than simply sleeping too many hours of the day. With the obesity-hypoventilation syndrome, in addition to carbon dioxide levels building up too high, oxygen levels in the body also drop too low. If the carbon dioxide levels are too high and the oxygen levels too low for too long a period of time, this can cause very serious consequences, including heart failure. For this reason excessive sleepiness in any patient who is very overweight should be taken very seriously, with attempts made to understand what has caused the sleepiness, and if it is the obesity-hypoventilation syndrome, to treat it promptly and vigorously.

## ACTIVITY SUGGESTIONS FOR PRADER-WILLI PERSONS AND THEIR PARENTS

by

Paula Carman, O.T.R., Occupational Therapist, Reg.

Many families already participate in one or more of the following activities which promote coordination, strength and endurance, and enjoyment: bike riding, horseriding, hiking, jogging, roller skating, dancing, soccer, basketball, volleyball, badminton, swimming, skiing, bowling, golf. Fun and exercise should go together and should be done with other people for maximum enjoyment. If an exercise program is more suited to your family, make it a group activity, preferably with music, and add variations to make it fun.

Some activities for strengthening trunk extensor muscles are as follows:

- 1) Lie prone on stomach, raise arms, head and legs from the surface.
  - a) Pretend to swim--alternate arms or breaststroke; kick, too!
  - b) Play catch, rolling ball back and forth with other persons who are play prone.
- 2) Prone on scooter board
  - a) Supported with board under trunk
  - b) Board under legs--more work for arms.
  - c) Relay--pick up bean bags at one side of the room and bring one at a time to the other side of the room.
- 3) Rhythm instruments in time to music while lying prone, holding head and arms up from the surface.

Activities for strengthening trunk flexor muscles are as follows (Make up your own, too):

- 1) Situps--facing a partner (legs bent at knees), come up and clap hands together, then only go back a little ways (not all the way back); this can be fun with music at a fast pace.
- 2) See-saw situps--these are less demanding than #1; hold partner's hands and alternate going back (it is not necessary to go down to floor with back and head.)
- 3) Sit and roll hips in time to music; becomes sit-walk with practice (shift weight and pull unweighted side of body forward, then alternate with the other side.)



ACTIVITY SUGGESTIONS, Continued

- 4) Dancing--"Twist", bump, just moving to the music; trunk should get some exercise rotating and bending.

Activities to promote visual motor coordinatin with a ball (8-10 inches):

- 1) Catch--with or without a bounce.
- 2) Bouncing the ball a designated number of times
- 3) Throwing the ball into the air and catching it.
- 4) Kicking the ball towards a target or through a simple maze.
- 5) Hit a suspended ball or balloon with hand or bat.

Activities for ventilating frustration, anger--all of this more effective with yelling. Decide in advance what is acceptable and go through some practice runs; then when an outburst occurs try to direct energy toward that activity.

- 1) Kick a cardboard box or tin can for as far as possible.
- 2) Kick a ball against a wall or into a field and go chase it.
- 3) Hit a pillow, punching bag, suspended rug, or couch cushion with fist or racket.
- 4) Jump up and down; go for a run.
- 5) Have a bataka duel--soft foam "swords" or "bats". (Children should be fairly evenly matched in size and skill.)

MORE PROFESSIONAL VIEW

QUESTION FROM A READER: At what age to adolescents with Prader-Willi syndrome usually stop growing?

REPLY: Around the age of twelve. People with Prader-Willi syndrome seem to fail to have a normal pre-adolescent growth spurt.

Vanja Holm, M D Pediatrician  
University of Washington

RECOMMENDATION: Children with developmental problems should be given experience in handling money at an early age, due to the fact that it takes them longer to acquire social skills than normal children. When the child is first given an allowance, it is wise for the parents to require the child to begin keeping accounts in order to gain experience in calculating his income and outgo. A savings account should be opened in early years, and when the child reaches the early teen years, he should have the experience of having his own checking account.

Stephen Sulzbacher, Ph D , Psychologist  
University of Washington



GATHERED REPORTSCalifornia: Los Angeles

Over 50 people attended the first meeting at Harbour General Hospital on March 18. Dr. Bray, authority on Prader-Willi syndrome for Southern California, a world authority on obesity, and Nutritional Director, HEW, explained the behavior and medical problems of P-W people. He pledged support and medical backup to any endeavor undertaken by the group.

Harry Schonfeld, Assistant Chief of Developmental Services in Southern California, advised concerning the licensing process for group homes, the legal aspects of a nonprofit facility, and possible funding.

Margo Thornley, Seattle, director of WISER Institute, WISER Acres Home, and Double RR Ranch, and member of the National Advisory Council on Vocational, Education, discussed behavior problems of P-W people and how they deal with them at WISER Acres and Double R R Ranch. She also discussed the need for education of P-W people and the problems encountered.

A committee was formed to plan another meeting and to look in to the development of a group home for P-W people in California with access to academic and vocational training.

Reported by Cal Menzer

Australia

Sad news from Australia: Shane Hills, eight, of Darwin, passed away Feb. 11. Shane was a Prader-Willi child who during his short life made a multitude of friends due to his special personality.

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On behalf of members of the Prader-Willi Syndrome Association, The Gathered View extends sympathy to Shane's parents, Mr. and Mrs. Ron Hills.

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Parents of a Prader-Willi daughter in South Australia report success in developing an integrated program for intellectually handicapped children in the public schools. Parents received a grant to hire a teacher to travel from school to school to support handicapped children on a one to one basis.

From THE OPEN DOOR

Onatario: Hamilton

K. Ross Parker, M.D., McMaster University, Dept. of Family Medicine, 1200 Main St. West, Hamilton, Ontario, L8S 4J9, invites inquiries from parents in Canada re the Prader-Willi syndrome. He has a group of eight families who are communicating with each other and are trying to establish a summer camp in Ontario.

California: Sacramento

Sacramento parents met at Alta regional Center on Thursday evening, April 27. The speaker was Wilma Poage, Educational Specialist. Her lecture included what to do before the school meeting (IEP--Individualized Education Program Review), during the meeting, and after the meeting. She also handed out pamphlets on the subject.

Reported by Judy Schultz



THE MEDIA VIEW

The Family Guide to Better Food and Better Health, by Ronald M. Deutsch, c1971, Meredith Corporation, 1716 Locust Street, Des Moines, Iowa 50336.

This book is one of the most outstanding books on nutrition written for the average consumer. In addition to telling us what foods are needed by our body, the author, who served on President's White House Conference on Food, Nutrition, and Health, gives a fascinating picture of what happens to food after it is consumed and absorbed into the body. The author goes on to tell us how to prepare foods in order to preserve the nutritional values with which they come to us. The book is adequately illustrated with charts to show the nutritional needs of humans at various stages of life and the nutrient content of various foods.

Best of all, this book can be obtained free during the next few months. All you have to do is save the box tops from Post Grape Nuts or Post Grape Nuts Flakes or the envelopes from single servings of Sanka Brand Decaffeinated Coffee served in restaurants. Any combination of four of these box tops or envelopes may be mailed to: Family Guide to Better Health, P.O. Box 3037, Kankakee, IL 60901, for your copy of the book.

Woman's Day

The April, 1979, issue of Woman's Day provides an entire month's supply of low-calorie menus. They are attractive, easily prepared menus for the main meal of the day, and fit easily into the Prader-Wili diet at approximately 500 calories each. Recipes are given for some of the dishes.

MENUS FOR A MEASURED DIET800-Calories-Per-Day Menu

## Breakfast:

1 medium egg	72
1/4 small cantaloupe	39.8
8 ounces nonfat milk	80

## Lunch:

1 ounce pressed meat	40
1/4 cup cottage cheese	48
1/4 head lettuce	18
1 small tomato	20
1 cup cucumber	16
1 cup broccoli	40
8 ounces nonfat milk	80
1 small orange	45

## Dinner:

2 ounces turkey	110
1 small potato	88
1/2 cup peas	57
1 cup spinach	41
1 cup watermelon	42
1/2 cup diet gelatin	8

For 1,000 Calories, add:

## Breakfast:

1 slice toast with 1/2 tsp	
margarine	100

## Lunch:

1 ounce pressed meat	40
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## Dinner:

1 ounce turkey	40
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For 1,200 Calories, add all of the above, plus:

## Lunch:

1/4 cup cottage cheese	48
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## Dinner:

1 ounce turkey	55
8 ounces nonfat milk	80
diet gelatin	8



A VIEW OF WHO'S WHO

This is the story of a nine-year old boy with Prader-Willi syndrome, herein called S.

Our son is nine and was diagnosed Prader-Willi at age three. He weighs 58 pounds and is 60 inches tall. He has a speech problem, is hypotonic, loves to work large puzzles, has a temper, is a very hard worker, has a good sense of humor, and is enrolled in a learning disabilities class in public school.

S has been on a diet for six years now with a few stealing transgressions. We have explained to him and his sisters (ten and four and a half) why he needs to be on a diet, that he'll probably always need to be on one, what foods make him gain weight, and what foods he can snack on. (Fresh, cleaned vegetables are kept for him in the refrigerator, for when he feels he needs to snack. We try to snack only mid-morning and mid-afternoon.) And we repeat this to him about once a week. On the three or four times that he has stolen large quantities of food (bread, cake, etc., inadvertently left out on the table), he has been denied desserts and snacks for several days, because "he'd already had the calories he was allowed." This seems to work well with him.

When we go to a restaurant, we automatically take away about 3/4 of the potatoes, bread, etc., take any breading off the meat and ask him to share his dessert with us. Very rarely does he complain about this, since we again remind him that we don't want him to become too fat. And it works, too because S really doesn't want S to get fat! I'm sure initially (at age three or four), he became upset with us for removing food from his plate, but we said it was either this or not going to a restaurant. Faced with these alternatives S decided we could raid his plate.

About two years ago we put S on the Feingold diet of no artificial colors or flavors, but allowed BHA and BHT. We explained it was to help him control his frequent and intense bursts of temper. After a week or so, his temper tantrums were greatly reduced. And he also recognized that he was screaming less and could even be reasoned with during a temper outburst. We kept S on this diet for six months and then slowly took him off of it to see if he could now control himself. Although he slipped back into the old patterns a couple of times during the first month, S was able to bring himself under control. I would just tell him that if he couldn't control his screaming, he would have to go back on the no artificial colors and flavors diet, because these temper tantrums were not acceptable behavior. He now still exhibits a temper (maybe twice a week), but nowhere near the three times a day frequency he once had.

We are very fortunate in being able to reason with S and in being able to put some of the responsibility for his diet on him. I don't think he ever feels full after a meal, or has ever found a food he doesn't like, or even really cares what the food tastes like. But he has come to accept his one serving of food at meals, and even his smaller portions of most foods. The battle isn't over, but his own desire not to get too fat sometimes influences his decision to stop eating. The big secret we need to know is how to make a Prader-Willi responsible and able to control his or her own diet.



THE GATHERED EXCHANGEBehavior Management

We are concerned over R's love of playing role-playing games. Initially I encouraged her games as I thought it was good imaginative play. I now feel, though, she tries to insist on playing the games long after what I consider a normal time. Any advice would be appreciated.

Australia member

Behavior Management

We also had the problem of role-playing games. I, too, encouraged the games, thinking it was good imaginative play and good for developing speech. I did not realize there could be a problem until a psychologist at the clinic noticed the role-playing and told me it could lead to problems if the child should become so immersed in it that he loses touch with reality. With the help of a psychologist's suggestions, our child was able to strike a better balance between reality and fantasy.

Here are some of his suggestions:

- 1) Do not forbid the child to play the games.
- 2) Don't allow the child to slip in and out of roles without transition. When he says "I am a bear" (or whatever), you can say something like, "I know you are really Sandi, but you are pretending to be a bear." Also encourage the child to state for himself that he is pretending. You can refuse to enter the game until he clearly states he is pretending.
- 3) Led the child to approach people as himself when first meeting them (as when he gets up in the morning, arrives at school, or a visitor comes.) After he has engaged in normal conversation, then he can ask to play a pretend game with someone.
- 4) Make it clear the child is better liked as himself than as the things he pretends to be.
- 5) If the game goes on too long, say you no longer want to pretend. If the child continues, do not respond to the pretend person, but to the real person.
- 6) Encourage participation in other activities such as crafts or other types of games.
- 7) Allow only a limited amount of watching of fantasy type programs on TV.

Washington Member

Surgery

Would it be possible to have an up-to-date report on the results of stomach stapling--evaluation by parents of those who have had it, medical opinions, expected advantages, daily food intake routine, negative side effects, etc.? What change in eating behavior and weight loss might be expected from this surgery?

Idaho Member

Sexual Development

My 18 year old daughter's teacher thinks her moods and temper tantrums may be worse near her menstrual periods. So far she only has a bit of spotting, not enough to really need a pad. It lasts about two weeks, but sometimes skips a month or two or three days before it starts again.

Wisconsin Member

Menus

I need some menus for low-calorie sack lunches.

Washington Member



## ANNUAL BUSINESS MEETING

In compliance with the bylaws of the Prader-Willi Syndrome Association, the membership is responsible for the election of the Directors of the Corporation. We realize that not all members, or even a majority, can be present at the annual business meeting which this year is scheduled for Friday, June 29th, at 9:00 A.M. at the Leamington Hotel in Minneapolis, Minnesota. We are, therefore, enclosing the following proxy ballot for those who cannot be present. Please designate one of the names listed below (or your own selected delegate) to represent you at this meeting if you are unable to attend. Your proxy will have the full power to act in your behalf for all business matters, including the election of the Directors at this business meeting.

This proxy form must be received by the Prader-Willi Syndrome Association no later than June 26, 1979.

I designate the following person whose name I have checked on the appropriate line to represent me in all of the corporation business decisions including the election of the Directors of the corporation.

Delfin J. Beltran, Board Chairman \_\_\_\_\_

Fausta Deterling, Board Member \_\_\_\_\_

Bryan D. Hall, Board Member \_\_\_\_\_

Vanja Holm, Board Member \_\_\_\_\_

Shirley Neason, Board Member \_\_\_\_\_

Peggy Pipes, Board Member \_\_\_\_\_

Andrea Netten Sechrist, Board Member \_\_\_\_\_

Judy Schultz, Board Member \_\_\_\_\_

Stephen Sulzbacher, Board Member \_\_\_\_\_

Richard J. Wett, Board Member \_\_\_\_\_

Gene Deterling, President \_\_\_\_\_

\_\_\_\_\_, Other Designate \_\_\_\_\_

\_\_\_\_\_  
Your Signature

\_\_\_\_\_  
Date

Mail to: Prader-Willi Syndrome Association, P.O. Box 392, Long Lake,  
MN. 55356







THE GATHERED EXCHANGE, ContinuedBehavior Management

In the last year there has been great improvement in my 18 year old daughter's control of her tantrums. Her school uses behavior modification and they have been teaching her to cry instead of acting out. As a baby she was uable to cry and never learned to use tears as an emotional outlet. We are encouraging her to cry and it seems to be working. She is also learning to talk about when "bad feelings are coming on her." Recently she attended her grandmother's eightieth birthday party with 100 people. She was tremendously excited but behaved perfectly. (Of course, she was off her diet for the occasion.) The next day, she felt exhausted, as we all did, but we continually explained to her the resons for her feelings and assured her that they would pass. She finally cried herself to sleep and got through the day without a tantrum. The next morning she woke me to tell me, "You were right. Today I have happy feelings!"

Massachusetts Member

Resources

Our son is eleven and doing well in school and socially. He spends a lot of time at the YMCA and swims four or five times a week. We are able now to let him go alone, which to me is quite an achievement. I did obtain funding from United Way for the YMCA to hire a Special Needs director, and do some staff training to serve the developmentally disabled. All efforts, so far, have been mainstreaming, and he has done remarkably well. He attends three afternoons a week after school and on Saturday mornings. It is difficult to find community resources for our children as they get older, so this is one of my continual pet proejects. Now we are developing plans for a middle school age program. Wanted to share this, as it may be an inspriation to others to start thinking of the YMCAs in their areas. It is a great place for exercise, and a place they can use for a life-time.

Wisconsin Member

RELATIONSHIP OF SUGAR TO BEHAVIOR TO BE STUDIED

Peggy Otto, R.D., is writing her master's thesis in nutrition on the relationship of sugar to behavior in children with Prader-Willi syndrome. Ms. Otto will be studying six children at the Child Development and Mental Retardation Center at the Unviersity of Washington. Each child will be brought to the clinic twice for testing. The child will be given a cup of beverage in lieu of breakfast. The beverage will contain nutrients to replace his breakfast, plus either a placebo or a given amount of simple sugar. The child will then be tested and observed over the succeeding four hours and changes in his responses and behavior recorded. In addition a questionnaire will be sent home for the parents to fill out regarding the child's behavior for the remainder of the day.

The plan for the thesis grew out of a similar project conducted earlier by Ms. Otto at CDMRC. It is anticipated that the protocol developed by Ms. Otto for the experiments will be available for use by other nutritionists and health professionals in clinics throughout the nation.

Ms. Otto, a native of Bremerton, Washington, received her B.S. degree at the Unviersity of Washington in 1974. She served her internship at Rhode Island Hospital in Providence, then remained in Rhode Island as dietician



RELATIONSHIP OF SUGAR AND BEHAVIOR, Continued

at St. Joseph's Hospital for four years. Her last year she was chief of clinical dietetics. She worked with pediatrics, the coronary care unit, and in WIC, a federally funded food program for infants, children, and pregnant women. She was community nutrition chairman for the Girl Scouts, working on projects with the girls, was in demand as a speaker on pediatric nutrition, and was on an American Hart Association committee.

At the University of Washington, Ms. Otto is on an 18-month fellowship to work toward her Master's degree.

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THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION, and is sent to all members. Membership dues are \$10.00 per year for the U.S., Mexico, and Canada; \$13.00 per year for overseas members. Send dues and change of address notices to PRADER-WILLI SYNDROME ASSOCIATION, Box 392, Long Lake, MN 55356.

A booklet, "Prader-Willi-Syndrome--A Handbook for Parents" may be ordered from THE GATHERED VIEW, 26931 S.E. 403rd, Enumclaw, Washington 98022. The price is \$2.00 for the first copy to members; \$3.50 for subsequent copies and for copies to nonmembers.

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