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Newsletter of PRADER WILLI SYNDROME PARENTS AND FRIENDS

Box 252
Long Lake, Minnesota 55356
Gene Deterling, Director

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PRADER WILLI SYNDROME PARENTS AND FRIENDS

Prader-Willi syndrome is a rare birth defect that results in initial hypotonia (lack of muscle tone) and later a compulsive tendency toward obesity, as well as other complications. Because of its rarity, there is much to be learned about its treatment and perhaps eventual prevention. The non-profit organization, PRADER-WILLI SYNDROME PARENTS AND FRIENDS, has been formed to provide a vehicle of communication for persons who have had experience with the syndrome and those who can benefit by others' experience.

A one-year membership, which includes a subscription to THE GATHERED VIEW, may be obtained by sending \$6.00 with your name, address, and telephone number to PRADER WILLI SYNDROME PARENTS AND FRIENDS, Box 252, Long Lake, Minnesota 55356.

MESSAGE FROM THE DIRECTOR

We are still in the recovery stage of our recent relocation from Massachusetts to Minnesota. Stability is in sight, however, and we are about to begin answering our backlog of special requests.

We haven't had the opportunity to individually thank those of you who have sent donations along with your membership renewals. Every dollar, however, is well appreciated, and you may rest assured that we will apply these funds to the maximum benefit of all our Prader-Willi citizens.

Progress is being made on Shirley Neason's book on the Prader-Willi person presently entitled A VERY SPECIAL PERSON. Our organization is working on obtaining the additional funding to assist in financing the publication.

We have another document on Prader-Willi syndrome prepared by one of our members for the Psychology Department at Pacific Christian College in California. The author has a brother with the syndrome and has been able to assemble a concise study while at the same time including a penetrating sentiment for those affected. It is a touching, well-prepared document that could only be written by someone who cares. We believe this information would be of value to all our members and plan to make it available to everyone before the end of the year.

Our organization has now grown to 165 members and represents a solid base from which an abundance of benefits can develop.

Eugene Deterling

APOLOGIES TO PEGGY

A typographical error was allowed to slip by in the last issue, resulting in a misprint in the spelling of the name of Peggy Pipes, nutritionist at the Child Development and Mental Retardation Center of the University of Washington. Although she is a lady with a great deal of pep, her name is Peggy, not Peppy! Apologies to you, Peggy!

POSSIBILITY OF SPECIAL CAMP

There is a possibility that next summer a camp experience can be provided that is expressly designed to meet the needs of children with Prader-Willi syndrome. The idea was advanced by Margo Thornley, M.Ed. Mrs. Thornley is the director of the Western Institute of Specialized Education and Recreation in Bothell, Washington, a suburb of Seattle. W.I.S.E.R. is a day training facility for the handicapped which specializes in vocational training with emphasis on developing recreational skills. Their philosophy is that many of the physical skills developed in recreational activities are the same skills needed in vocational work.

The facilities owned by W.I.S.E.R. are readily adaptable to a residential camp use. Mrs. Thornley had read about the problems of children with Prader-Willi Syndrome and was impressed with the possibility of a camp where the children could have their food intake monitored and at the same time be engaged in activities that would develop their muscle tone, stamina, and physical coordination.

It is not known yet whether funding can be obtained for the camp, or if parents would have to bear the cost themselves. Mrs. Thornley is working on this and other details of the camp program.

Mrs. Thornley's idea received an enthusiastic reception from Seattle area parents, who favored the idea even if they had to pay for it themselves. The camp would, of course, be open to all children with Prader-Willi syndrome whose parents could provide transportation to the camp.

Mrs. Thornley is highly qualified in her field, having worked with children and adults with all degrees of handicaps in both residential and day facilities. She is the author of the book, Every Child Can Learn...Something, and has had a number of articles published in professional journals dealing with mental retardation.

SOUTHERN CALIFORNIA PARENTS ORGANIZE

A group of parents with children who have Prader-Willi syndrome is being formed at Harbor General Hospital. Any parents in the Southern California area interested in further information should write to Dr. George A. Bray, 1000 West Carson Street, Torrance, California 90509.

THE PROFESSIONAL VIEW

Here is an idea from Paula Schmidt, O.T.R., therapist at the Child Development and Mental Retardation Center of the University of Washington.

Since scratching and picking at bites and sores seems to be a concern of many parents, here is a tip that may help cut down itching. Have your child use a bath brush or loofah sponge for his bath, and scrub himself briskly with it. If you do not have either of these, a brisk rubbing with a rough washcloth will also help. This increases circulation, which in turn helps cut down itching. When a child has a bite or sore that itches, encourage him to rub with the palm of his hand, rather than scratch with his fingernails. Also encourage him to rub around the sore rather than directly on it. A preparation you might try, which I have found quite effective for my own use on bug and mosquito bites and on rashes is Rhuli Cream.

GOOD ORAL HEALTH CAN BE FOREVER

This is the title of a booklet on dental health we offered a few months ago. If you would like a copy of this booklet, which gives diagrammed directions on the new methods of proper toothbrushing and flossing, send your request to THE GATHERED VIEW. The booklet is free and postage paid.

Our story this month was sent to us by a mother in Australia.

Karen was born 22nd June 1966, after a long labor, by Ceasarian section. She had to have oxygen at birth, as she was not breathing. She looked like a typical Prader-Willi, although at that stage nobody had heard of the syndrome here. She had blond, almost white hair, a lovely round face, but very thin arms and legs with little muscle control. She was unable to cry for almost a year. She had to be tube fed for three months as she was unable to suck. Her eyes were moving from side to side so she was looked at by an ophthalmic surgeon, who thought she is part albino and lack of pigment was one reason for the poor eyesight and lack of control.

Karen did not hold her head until she was six months old. I, as her mother, felt there was something wrong with her, although our pediatrician felt she will be all right once she will get over the trauma of her long birth. I was not satisfied with such explanations and insisted that an orthopedic surgeon have a look at Karen. He told us she had both her hips dislocated and will have to go to the hospital to be manipulated and placed in a plaster cast. Up to this state Karen was a fragile looking, beautiful baby with blond, curly hair.

The plaster was on her for six months and after that she was placed in a frame for twelve months. By the time she came out of the frame she had obviously put on a lot of weight, which we attributed to the fact that she was immobile for such a long time. The doctor told us that after a few months she will be able to crawl, but Karen had decided that crawling was not for her. She used to sit on her bottom and by jumping and moving her legs forward got to where she wanted to go. She became quite an expert at it, and very fast.

It took her a long time to walk. She was three when she started kindly and at that stage could only walk with assistance. By then she also wore glasses.

Karen could speak quite early on and seemed to understand what was going on around her, but there seemed to be something wrong, although I couldn't put my finger on just where. She continued to gain weight rapidly despite the fact that we put her on a diet. In the meantime I kept going to our doctor that there was something wrong. He kept assuring us that she will grow out of it, not to worry. She has to get over her bad eyesight and dislocated hips.

Karen started a private school at age five. It was obvious to us that she could not cope with the work there, and it was getting increasingly hard to control her behavior at home. By this time we had a very active little boy who also wanted his share of our attention. We started on the long track of finding adequate schooling for our daughter. This was made doubly difficult by the fact that nobody seemed sure what was wrong with her. We knew that she is mildly retarded, but that did not account for the difficult behavior pattern that was emerging and the constant watch over her appetite we had to make.

At six and one-half Karen was finally diagnosed as Prader-Willi, which still did not make it any easier as far as schooling went, but at least we knew what was wrong.

This year finally, Karen has been accepted at a boarding school for mildly retarded girls. It was a hard decision to send her there, but one we are very happy about now. The structured environment there seems to suit Karen a lot more than our home routine. A full time matron is on duty who is helping with Karen's diet. In six months Karen has lost twenty pounds and is quite happy with her present food allowance. She now weighs 68 pounds.

Our main concern at present is that Karen has developed a habit of scratching at insect bites or abrasions, to the point that she has to be kept under constant watch most of the time. She picks until the blood flows, which, incidentally, does not seem to hurt her. We have tried everything to try and stop this, from bandaging her arms to putting gloves on her to putting plastic skin over the sores, but as we clear up one, she starts to pick at another one. We feel that it is a feeling of frustration because she feels she can't keep up with other children. Although she loves to be with other children, she is very much an outsider with them.

It is interesting to note, however, that she gets along very well with adults. All in all, she is a very lovable child with a pleasant personality.

THE BOOK VIEW

It is important to the development of preschool children that they gain the ability to perceive colors, shapes, sizes, and relationships. The easy and enjoyable games in the book, Thinking is Child's Play, are based on the theories of the Swiss psychologist, Jean Piaget, who pioneered the study of how children learn in these areas.

The games involve both parent and child and make use of materials found around the home or purchased at small cost. In addition to contributing to the child's thinking process, playing the games will give parents insight into how children think and will suggest other intellectually stimulating activities to fit into daily life.

Because most children with Prader-Willi syndrome develop at a slower rate than other children, the book will be useful to the parents of elementary school age children as well as parents of preschoolers.

Thinking is Child's Play, by Evelyn Sharp. Disus Books, Published by Avon Books, 959 Eighth Ave., New York, N.Y. 10019, c1969. Paperback.

LETTERS FROM READERS

Dear Dr. Deterling:

I have enclosed herewith my check in the amount of six dollars. It is with pleasure that I hereby renew my membership.

I cannot stress enough the importance of our organization. It is so important that periodic articles are published regarding Prader-Willi so that we may locate and aid as many persons afflicted with this syndrome as possible.

If it were not for a small article which I read in a local paper relating the work being done in Seattle by Dr. Holm and Ms. Pipes, my daughter would still be hopelessly obese, and we would still be at a loss as to where to turn.

Upon reading the article I wrote to Dr. Holm, and she referred me to Mrs. Roseanne Howard at Children's Hospital. Our daughter has lost 19 pounds in a year through her devoted efforts and guidance. Mrs. Howard also referred me to you. I look forward to the monthly newsletters. I feel they are not only a service of comfort and reinforcement, but also that we are no longer alone, and also, there is someone who understands.

Thank you so much for your continued efforts. We deeply appreciate your concern. P.H.

Dear Mrs. Neason:

The Post Office tells us our newsletter is being delayed because of an error. . . The correct number is . . . Your newsletter is our only contact we have with others who have the P-W problem, and we appreciate it. D.K.

(We use only the initials of contributors unless we are given specific permission to use the person's name.)

SYMPOSIUM ON PARENTING TO BE PRESENTED

A symposium, THE ART AND SCIENCE OF PARENTING THE DISABLED CHILD, will be presented November 20 and 21 at the University of California, San Francisco. This symposium is designed for families of developmentally delayed or disabled children, and for those who provide health and education services to these infants and their families. The focus will be on the value of the parent as a constructive force in the care of the child as early in life as possible.

For further details and registration, please write to Sara Fisher, Program Assistant, Continuing Education in Nursing, Room N631X, University of California, San Francisco, California 94143.

THE GATHERED EXCHANGE

Low-Calorie Teriyaki Sauce:

1/4 cup soy sauce
1/4 teaspoon dry mustard
1/4 teaspoon ginger
1/4 teaspoon garlic powder

Mix ingredients together. Pour over chicken or fish to marinate, then bake the chicken or fish in the oven according to time and temperature recommended for that product.

Send your recipes:

Does anyone have any other good recipes for cooking chicken or fish in low-calorie ways? These are two good low-calorie protein sources, but I have difficulty finding a variety of ways to cook them that we really like.

Shirley Neason

Low-Calorie Peach or Strawberry Ice Cream:

4 oz. evaporated skim milk
8 frozen strawberries or one sliced frozen peach
3 envelopes (6 teaspoons) powdered sugar substitute
Food coloring (if desired)

Freeze the milk in a paper cup (it should be in a solid frozen state). Ten to fifteen minutes before making ice cream, remove milk and fruit from the freezer and allow to stand at room temperature. Peel paper cup off milk and cut milk and fruit into chunks. With mixer on low speed, mix until smooth. Change mixer to higher speed and mix until desired consistency. Place in freezer ten minutes before eating, if desired. This is a generous portion and delicious. You can freeze several portions ahead of time and keep them frozen until ready to use.

Janice Dixon

Slow-crockery Cooking:

I bought a slow-crockery cooker, and I'm please with its use in preparing foods for my child's diet. A slow-crockery cooker is an electrical appliance designed to cook foods at lower temperatures and for longer periods of time than the use of an oven permits. The heating coils are distributed throughout the bottom and sides of the cooker for even distribution of heat. There are two settings on my cooker. "High" cooks the food in about three times as much time as a similar dish would require on the range. "Low" requires about double the length of time as "high." The first advantage I discovered is that less fat is required in most recipes. Because the long cooking blends flavors together, fat is not needed for flavor. Meats can be browned and the fat drained off before adding to the cooker. I used to hate throwing out the fat, knowing I was throwing away good broth with it. Now I put the fat in the refrigerator when I start the cooker, and it is congealed before the food is done. I simply lift off the fat and pour the broth into the cooker. Another advantage is that food can be prepared while I'm cleaning up from breakfast, when I have to be in the kitchen anyway. Then I cover the pot, put the food away and lock it, and I don't have to get any more food out until a short time before the meal is served. If a child should try to help himself from the cooker, it could be easily plugged into any electrical outlet in any room in the house that can be locked.

Shirley Neason

Dietetic Syrup:

12 oz. can Shasta diet creme
soda
1 tablespoon cornstarch
1/4 teaspoon vanilla
1/4 teaspoon mapleine
2 drops yellow food coloring
1 drop red food coloring

Mix cornstarch with diet soda. Cook, stirring constantly, until liquid boils and thickens slightly. Cool. Add vanilla, mapleine, and food coloring. Calories negligible. Use as desired.

THE GATHERED EXCHANGE, Continued

More about picking at sores:

I read in the January newsletter of the child who picks and scratches bites and abrasions till they bleed. I also tried bandages and bandaids, etc. One day I said to him, "If you pick that, you'd better stay home from school tomorrow so it can heal up, as I don't want you to pick up an infection and get a sore arm." It worked like a miracle as he loves school. I have to keep reminding him, but it works every time, and he thinks I am worrying that he will pick up an infection, rather than just nagging him about it. I am not certain why he picks, but he doesn't show any signs of being frustrated at all.

Mother of a 7-year old

A do-it-yourself Halloween mask for children:

Give your child the following supplies: a paper bag the right size to fit his head, several newspapers, and thick wheat paste. Give him/her the following instructions: Stuff the bag full of crumpled newspaper. Cut several sheets of newspaper into 2" by 8" strips. Dip the strips into the paste. Paste the strips on the bag, smoothing down each one with your fingers. Set the bag aside to dry for several days until it is hard. Remove the crumpled newspaper. Have someone mark the proper places for the eyes and mouth and cut them out. Paint the mask to represent what you want to pretend to be on Halloween.

Coleslaw Dressing:

$\frac{1}{2}$ teaspoon salt
 $\frac{1}{2}$ teaspoon prepared mustard
 $\frac{1}{8}$ teaspoon pepper
 $\frac{1}{4}$ teaspoon garlic salt
3 tablespoons granulated
sugar substitute
 $\frac{1}{2}$ cup evaporated skim milk
2 tablespoons cider vinegar

Mix together dry ingredients and mustard.
Gradually stir in evaporated skim milk.
Slowly add vinegar, stirring constantly.
Chill.
 $\frac{1}{4}$ cup = 1 fat exchange
11 calories per tablespoonful

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