

## THE GATHERED VIEW

### NEWSLETTER OF PRADER-WILLI PARENTS AND FRIENDS

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#### SOMETHING NEW!

This is the first issue of THE GATHERED VIEW, a newsletter dedicated to providing a means of exchanging ideas and information among parents and others who must deal with the problems of people who have Prader-Willi syndrome. THE GATHERED VIEW was chosen as the name because its purpose is to gather ideas from many sources, including parents, teachers, medical people, and other professionals in the many related disciplines that make their contribution to the growth and development of handicapped people. Submissions are solicited from any and all who believe they have ideas to contribute. Payment will be the knowledge that you have helped another. Send your ideas and articles to THE GATHERED VIEW at the editorial address listed above.

At the beginning we are relying on membership dues to pay the expenses of publishing the newsletter. Eventually we may obtain funding from another source. We want to send THE GATHERED VIEW to all who might be able to use the information in it to help a person with Prader-Willi syndrome, regardless of whether or not the reader pays dues.

#### YOUR MEMBERSHIP IS NEEDED

PRADER-WILLI SYNDROME PARENTS AND FRIENDS is the name of the organization that has been formed for the benefit of the parents of children with this rare syndrome and friends who are willing to work for the betterment of the individuals affected. The organization was conceived by Gene and Fausta Deterling of Harvard, Mass. Since the syndrome is so rare, it is difficult for parents to be in contact with one another for encouragement and exchange of information. The Deterlings felt that a nationwide organization would help meet this need.

Membership, including the cost of the newsletter, is \$5.00 annually. To join, send your name, address, phone number, and a check for \$5.00 to PRADER-WILLI SYNDROME PARENTS AND FRIENDS, Box 124, Harvard, Massachusetts 04151.

#### BOOKLET BY AND FOR PARENTS PLANNED

In the Seattle area, a group of parents of children with Prader-Willi syndrome has been considering the idea of writing a booklet which would be of help to other parents. As yet, definite goals have not been formulated concerning what the booklet should contain. The parents would like to hear your ideas. If you were a parent receiving such a booklet, what help would you expect to receive from it? What attitudes would you want the readers to develop as a result of their reading? What knowledge should they gain? What skills should they develop? Write down your answers to these questions and mail them to THE GATHERED VIEW.

#### THE BOOK VIEW

What book has been a help to you in working with your child? Write to us about it. We'll include your review of the book in THE BOOK VIEW column.

On impulse one day I picked up a paperback, The Complete Book of Low Calorie Cooking by Leonard Louis Levinson (New York, Pyramid Books, c1964, 1966.) It proved to be a useful book. Daniel, my eight-year-old with Prader-Willi syndrome, is especially delighted with the chapter entitled, "The Egg and You," which presents 365 ways to cook an egg. He intends to try all 365. In addition to the usual recipes, there are useful chapters on preserving fruits, pickles, and condiments, on making your own recipes, and on appliances to aid you in your special cooking. Food exchange values are not given in the recipes, but there is a food composition table at the end of the book in addition to calories-per-serving listed with each recipe.

Book Review by Shirley Neason



### THE GATHERED EXCHANGE

This will be a regular exchange column. You may send in questions you want answered, problems you haven't been able to solve, or information or ideas you think might benefit parents and other readers.

For a starting question, here is one we all need the answer to: How do you prevent the child with Prader-Willi syndrome from getting food he's not supposed to have?

For our first idea, here is a program of exercises to improve gait and coordination, submitted by Gene and Fausta Deterling. It was developed by a physical therapist for their four-year-old.

1. Tug of War Game. The child holds one end of a four to five-foot long rope. The adult holds the other end and tries to disrupt the child's balance without actually making him fall.
2. Walk backwards. Flat-footed, on toes, on heels, then very quickly.
3. Walk-Run. Have the child walk, then run, following the adult's commands.
4. Kick-ball. Start with a large ball and work down to a tennis-size ball.
5. Stand on toes, walk on toes, run on toes.
6. Jump on both feet.
7. Stand on one foot. Time the child and work toward a goal of ten seconds. Then have the child do it with his eyes closed.
8. Play throw and catch with balls. Start with a large ball and work toward a tennis size ball.
9. Skip and gallop.
10. Balance beam. Have the child walk, then turn and walk back.
11. March to music. Have the child use a high stepping gait.
12. Have the child stand in front of a large mirror to do exercises. This helps improve body awareness and judgment of body in space.
13. Equilibrium board. This will help improve balance. Disturb the child's balance while he is in the following positions on the board: back-lying, stomach-lying, Indian sitting, on all fours, and kneeling.
14. Have the child stand tall and tell him not to let you push him over. Gently disturb his balance to each side, forward and backward.
15. An obstacle course can include any of the preceding activities. Also include activities which make him crawl through, over, and under objects. Belly-crawling and all-four crawling should be included.
16. Row the boat. Sit facing each other, holding hands, and rock forward and backward.
17. Follow the leader. Try crawling, obstacle course, running, etc.

Parents, it seems, aren't the only ones interested in helping. This letter was received from Dee Lempe of Puyallup, Washington:

Dear Prader-Willi Syndrome (Parents and Friends,)

Please take time to read this letter...I have been interested in Prader-Willi syndrome for a long time. My little brother has this syndrome. He is getting help for it now, but I would like to help, too. I love my baby brother, and I want him to get as much help as I can give him. I'm only 16; my brother is 11. Maybe age doesn't make any difference, but I want to help my brother and other kids like him. Please help me to help them. I really care. Thank you,

Dee Lempe

### A LOW CALORIE SNACK SUGGESTION

Lemonade: 2 packets granulated sugar substitute  
2 tablespoons fresh or reconstituted lemon juice  
1 cup water  
ice  
lemon slice  
Mix first three ingredients and serve over ice in large glass.  
Make a slit in lemon slice and hang it on glass. Makes one serving. EXCHANGE: Free



#### A VIEW OF WHO'S WHO

In this feature, we want to introduce families who have children with Prader-Willi syndrome, professionals who are working to help them, and others who are involved in any way. This first issue introduces Gene Deterling, organizer of PRADER-WILLI PARENTS AND FRIENDS. Here is what he wrote:

Since we first discovered our son had Prader-Willi syndrome we have been eager to learn everything we can about it in order to make his life a happy one. We soon found that there was very little information available and felt there must be numerous other parents with similar circumstances and desires as ours. We, therefore, decided to form an organization that could serve to act as a vehicle for communication and work toward the betterment of those with this syndrome. We had heard about the success of a program conducted by a nutritionist, Peggy Pipes, at the University of Washington and contacted her about our plans. She encouraged us to follow through with this effort and gave us the name of Mr. and Mrs. Neason in Washington whom she felt would be willing to work with us on this program. Mrs. Neason agreed to produce and publish our newsletter and, thanks to them, we think we're going to have a successful organization.

We thought others might be interested in our own child since we are certainly interested in hearing about other families. We are, therefore, including the following personal information about him.

Our son, Curtis, was four years old last May, and he is still the joy of our life. Considering what our expectations were for him at this age, we are delighted with his progress. He has been attending a special school since last fall, and we have high hopes that he will be able to attend a regular school, perhaps a year behind his age group. We think he is a beautiful child, and his present teacher describes him as an "adorable and lovable little guy." Curtis has an older brother 12 years old and a sister 14 years old, both completely normal children. His weight is now under control, thanks to his nutritionist, Rosanne Howard, at Children's Hospital Medical Center in Boston and the major achievements of Peggy Pipes at the University of Washington. A year and a half ago he weighed 47 pounds and now only tips the scale at 42 pounds. He is still a bit uncoordinated but is improving and is just starting to ride a tricycle.

Curtis was about a 10-month baby and was born with some conditions that our obstetrician considered abnormal, but he was unable to predict what their consequences would be. These were that his was a breach birth, he was very tiny and weak and lacked muscle tone. Curtis had crossed eyes, non-descended testes, and some very minor finger-joint restrictions. Although he rapidly gained weight, he was unable to hold his head up by himself until he was ten months old.

We were fortunate in finding a neurologist at Children's Hospital Medical Center who diagnosed Curtis' syndrome at six months of age. Dr. Bresnan predicted very well what his progress would be. Curtis began walking at two years old, just as the doctor said he would, and has followed the syndrome pattern closely.

Curtis recently underwent an eye operation to correct the crossed eyes condition, and we're delighted with results. Other than the constant effort we have to make to control his weight, our biggest problem now is getting him toilet trained. We're making some progress, but it is very slow, which we suspect is partially due to his lack of muscle control.

This brief synopsis of our son is the kind of view we hope to receive from other parents. We are eager to know the patterns of other children. We will happily share our knowledge on this subject with anyone who wishes to write to us at Park Lane, Harvard, Mass. 01451.

#### THE PROFESSIONAL VIEW

THE PROFESSIONAL VIEW is the column to which you can send questions you would like to have answered by a professional. The question will be presented to one of the staff at the Child Development and Mental Retardation Center at the University of Washington Hospital in Seattle. There was not time to present a question and get a reply before this first issue was prepared, but send your questions and we'll try to get replies for a later issue.

