

THE GATHERED VIEW
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Federal Way, Washington 98003

Newsletter of PRADER-WILLI SYNDROME PARENTS AND FRIENDS

Post Office Box 124
Harvard, Massachusetts 01451
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VOLUME II

January, 1976

Number 1

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 the rarity of the affliction, 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 need to benefit by others' experience.

A one-year membership may be obtained by sending \$5.00 along with your name, address, and telephone number to PRADER-WILLI SYNDROME PARENTS AND FRIENDS, Box 124, Harvard, Massachusetts 01451.

HOW TO HELP THE EDITOR

Editing THE GATHERED VIEW is a volunteer job which must be sandwiched in between the time required for a part-time job, the care of a home and family, and community responsibilities. Your help is needed. Here are some things you can do:

Do send in material for THE GATHERED VIEW. Since we have only about fifty members, an occasional contribution is needed from each to provide the needed material for each issue. Material is needed for all columns.

Write material for different columns on separate sheets of paper, and label each sheet. If you are sending material you do NOT want published, please indicate so.

Understand that material may be changed to fit requirements for space and editorial policy. Also understand that it takes time for material to get into the paper, and that some material may not be used for various reasons.

If possible, write your material just as you want it published. However, if you feel that you do not have writing ability, send your ideas anyway and sooner or later someone will find the time to write them up into articles.

Do send your suggestions for improvement. The editor has had no journalism training and advice is welcome.

The editor does not have time to individually answer the letters received, so she says, "Thank you, and please write again."

PRADER-WILLI SYNDROME PARENTS AND FRIENDS IS INTERNATIONAL

PRADER-WILLI SYNDROME PARENTS AND FRIENDS now has an international membership. Among our new members we welcome two from England and one from Australia. Our two English members live in the same county and have already become acquainted. Total membership is now fifty-one.

IN APPRECIATION

THE GATHERED VIEW is typed in preparation for publication by Mrs. Lyn Willow Ekern of Kent, Washington, who performs this work as a contribution. It is an exacting task, as the material must go to the printer as camera-ready copy. The printer has commented frequently on the high quality of Mrs. Ekern's work. Our thanks to her for the fine service she performs.

MESSAGE FROM THE DIRECTOR

It is now a full year since we conceived the idea of forming an organization that would work toward improving the future of those affected by Prader-Willi syndrome. It was not until May, however, that we officially began gathering members together into a formal organization. In the seven months that followed we have been joined by over fifty members, some from as far away as Australia. We have members in England and Puerto Rico and expect that soon we will be represented in all fifty of the U.S. states. Each week we receive two to three new members. By May when it will be a year since we became formally organized we should have over a hundred parents and friends with a common interest in improving the future for those with the syndrome. With our membership, therefore, well established we should be confident that we can work together toward some fruitful accomplishments.

Although our membership is established and growing, we have hardly begun to form our organizational plans. Our prime goal in the beginning was to seek out those with our common concern and establish a vehicle for communication. We have now accomplished this through our growing membership and publication of THE GATHERED VIEW. We must now define our organization and develop plans for more positive action. The defining of our organization is essential at this point since it is required by the Internal Revenue Service in order to establish an exempt status as a non-profit organization. We need your help to do this.

With members scattered throughout the world and very few in our own local area in Massachusetts, it will not be an easy task to define and solidify a formal organization. We must do it, however, and I am therefore appealing to those of you who are able and willing to advise me of your interest in being a part of the working arm of the organization.

The following must be established to define the Articles of Organization and meet the requirements of the tax exempt non-profit status:

Name (We could change it now, if we so desire.)

Place

Purpose

Officers (Appointment? Election? Power?)

Finance

By-laws

Amendment of by-laws and Article of Organization

Regarding our purpose, I propose for consideration the following elements:

Educational

The gathering and distribution of member knowledge and experience.

The solicitation of professional knowledge and advice.

Educational material to include the following subjects:

Diet

Parental guidance

Physical, educational, and psychological improvement programs

Adult employment opportunities

Professional assistance

Charitable

Medical research

Educational improvement programs

Establishment of adult living and occupational facilities

Although it is my hope that we can reserve the space in THE GATHERED VIEW for more interesting and enlightening subjects than the business aspects of the organization, during our formative stages it is essential that your aid be solicited in developing an organization that we mutually agree will be most beneficial. Please let us hear from you regarding any specific suggestions you have related to the operation of the organization.

May 1976 bring all of us greater health, happiness, and enlightenment!

THE GATHERED EXCHANGE

Popsicles

Make popsicles by mixing artificially sweetened, powdered drink with half the amount of water and freezing in an ice cube tray or popsicle molds. Calories are negligible.

THE GATHERED EXCHANGE, Continued

How to stop a habit?

Our child has developed a habit of scratching at any insect bite or abrasion until the blood flows. We have tried everything from bandaging her arms, putting gloves on to putting plastic skin over the sores, but as we clear up one she starts to pick at another. We feel it is a certain feeling of frustration because she feels she can't keep up with other children. I would be interested to find out if any of the other children have developed this habit, and if so, how do parents cope with it?

Judith Gelb, Sydney, Australia

One reply:

Our son, age nine, also has the habit of picking, especially his lips, nose, and the inside of his thighs, which chap from rubbing as he walks. We have felt that perhaps his skin was dry due to his low-fat diet. I treat the area with baby oil or ointment. We also tell him that it's his skin and he can pick it if he wants to, but that it's very unpleasant to look at and we don't like it.

Shirley Neason

THE PROFESSIONAL VIEWAn Experience with Children with Prader-Willi Syndrome by Peggy Pipes

Ms. Pipes became interested in children with Prader-Willi syndrome when she was requested to provide nutritional guidance toward prevention of anticipated obesity of an 18-month old male who was diagnosed as having Prader-Willi syndrome. In spite of the guidance that was provided for the mother, the child gained at an excessive rate, and by 28 months was obese. His mother was considered to be a good informant. The information she provided on the food and amounts of food the child ate was considered valid and it was ascertained that this child ate no more calories than those reported for other children of his same age and height. His mother reported that the child was not stealing food, that she had recorded all the food that the child ate and that she felt sure that he was consuming no more food than the children of her friends who were the same age. It seemed then important to determine exactly how many calories this child could consume and maintain his weight. A program was designed to collect data on how much the child ate and to find out if, indeed he could lose weight on a calorie controlled diet. The child and his family moved into a residential facility which provided an opportunity for both family and the nutritionist to participate in the collection of data by weighing and recording precisely what the child consumed and calculating his caloric intake to estimate the caloric expenditure of the child. The child did lose weight although severe reduction of calories below that anticipated for other children his age was necessary and data indicated that he would have to consume fewer calories than other children his age if he were to maintain his weight in proportion to his height. The child's mother continued to collect data on the child's food intake at home for the following ninety days. The hypothesis was validated that the youngster would have to consume fewer calories than other children his age if he were to maintain his weight in growth channel.

Soon a second child with Prader-Willi syndrome was referred to the Clinical Training Unit and the mother was asked to collect the data at the home and indeed was able to do so, weighing and recording all the food taken and estimating any that was stolen. The second child also lost some weight and was able to maintain his weight in channel.

As the story of success of weight control in these children was known, other pediatricians referred children for help with management of the diet. The more children seen the more convinced she became not only that a reduction in caloric intake below that of others their height and weight and age was important, but stringent control of the environment to make food unavailable for stealing was absolutely necessary.

Ms. Pipes has indeed been impressed with the commitment of the families in working with their children to control obesity. The parents have been willing not only to modify food provided and prepared for their children and to control the total food environment, but to provide data which will be useful for future cases of children with Prader-Willi syndrome.

A VIEW OF WHO'S WHO

This month we introduce Peggy Pipes, Assistant Chief of the Nutrition Section of the Child Development and Mental Retardation Center of the University of Washington.

Peggy Pipes was born in Texas and received her B.S. at Texas Technological College. She interned as dietician at Columbia Presbyterian Medical Center and received her M.A. from Columbia University. After serving as dietician in Texas and Illinois, she attended the University of Michigan School of Public Health to earn her M.P.H. After instructing in public health nutrition at the University of Michigan for a year, she came to the University of Washington in 1968. Her many honors and professional contributions include a current term as President of the Washington State Dietetic Association.

Her publications include: "Feeding the Down's Syndrome Child," Sharing our Caring, April-May, 1971; "Weight Control of Children with Prader-Willi Syndrome," Journal of the American Dietetic Association, May, 1973; "Food and the Child with Prader-Willi Syndrome," submitted to the American Journal of Disabled Children.

THE BOOK VIEW

Child Learning Through Child Play, by Ira J. Gordon, Barry Guinagh, and R. Emile Jester, New York, St. Martin's Press, c1972.

Often I run across a book that makes me say, "How I wish I had had this book when my child was small." Such a book is Child Learning Through Child Play, a book of learning activities for two and three-year olds. This book clearly and precisely tells a parent how to play games with his child in such a way that will develop the child's small muscle skills, large muscle skills, coordination, language, imagination, creativity, problem solving ability, pattern recognition, and other skills. The games call for materials usually found around the home or easily and inexpensively purchased or made. According to the book's introduction there is a companion volume, Baby Learning Through Baby Play for the first two years of life and a book planned for four and five-year olds, which probably is in print by now. Naturally, if your child has not been developing at the normal rate for his age, you would use the book that coincides with his developmental progress rather than his chronological age.

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