

THE GATHERED VIEW

Shirley Neason, Editor  
147 South 294th Place  
Federal Way, Washington 98003

Newsletter of PRADER-WILLI SYNDROME PARENTS AND FRIENDS

Post Office Box 124  
Harvard, Massachusetts 01451  
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 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.

GIVE IT THE RIGHT ZIP

In some of the initial publicity concerning PRADER-WILLI SYNDROME PARENTS AND FRIENDS (including the first issue of THE GATHERED VIEW, an error was made in the zip code of the address. The correct address of the organization is: PRADER-WILLI SYNDROME PARENTS AND FRIENDS, Box 124, Harvard, Massachusetts 01451. And as if that weren't enough confusion, the post office department decided to change the zip code for Federal Way, Washington, to 98003.

SEATTLE AREA PARENTS GET TOGETHER

Parents of children with Prader-Willi syndrome who live in the Seattle area have begun meeting regularly for the purpose of exchanging information and encouragement. The group, which has not adopted a name, written by-laws, or formal organizational structure, is being chaired by Sue Iverson, mother of an eight-year-old boy with Prader-Willi syndrome. Meetings are held at the Child Development and Mental Retardation Center of the University of Washington. Sue Inglis, R.N., M.N., nursing coordinator for the Prader-Willi clinic at CDMRC, serves as adviser to the group.

Meetings are held monthly. Two out of three meetings are held during the daytime so that parents can bring their children to the clinic at the same time. Every third meeting is held in the evening to allow parents to participate who are unable to attend daytime meetings. Each meeting features a talk by a professional who works with people with Prader-Willi syndrome. In addition, parents exchange information and discuss ways to help parents in other parts of the country who do not have access to services comparable to those offered by CDMRC.

The first meeting was held September 18, 1975. Dr. Richard Rolla, dentist at CDMRC, spoke to the group. The parents then made plans to act as "pen pals" to parents who have written to CDMRC concerning their difficulty in obtaining adequate services for their children.

MEMBERSHIP GROWING

Paid membership in PRADER-WILLI SYNDROME PARENTS AND FRIENDS now stands at twenty-six, with more inquiries coming in regularly. The largest number of members live in Washington state, with California second and Massachusetts third. We have one member each from Maryland, New York, Ohio, Missouri and Wisconsin.



#### SINCERE SYMPATHY

Our deepest sympathy is extended to members Webster and Martha Leyshon of Silver Spring, Maryland, on the death of their daughter, Susan Marie. Susan, who was born in 1953 with Prader-Willi syndrome, died on August 7, 1975. A memorial Celebration of Susan's life was held on August 11 at the Woodside United Methodist Church in Silver Spring.

In spite of her handicap, Susan's brief life was an active one. She graduated from high school, participated in the workshop and recreation programs of the Centers for the Handicapped, Inc., was an active Girl Scout, and was a member of the Montgomery County Association of Retarded Citizens.

Upon the death of their daughter, Mr. and Mrs. Leyshon requested that expressions of sympathy be in the form of contributions to PRADER-WILLI SYNDROME PARENTS AND FRIENDS. As a result, \$398.00 has been received to date by the organization. Other parents will long appreciate the thoughtfulness of the Leyshon family in turning the occasion of their sorrow to the benefit of the living.

#### THE BOOK VIEW

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

This month's review of Hide or Seek by Dr. James Dobson (Revell, c1974, \$4.95) was written by T. G. Neason of Federal Way, Washington.

#### HIDE OR SEEK

Our culture places excessive emphasis on two characteristics over which the individual has little or no control: beauty and intelligence. The person who is reasonably endowed with one or both of these characteristics may not be aware of the trauma that our culture inflicts on the unfortunate who falls below the norm. Accordingly, we unintentionally brutalize the emotional development of the unattractive and/or the slow learner.

The process begins in infancy and is accelerated as the child is exposed to those outside the immediate family. "Retardo" or "What a dog" are common taunts heard on the playground.

Hide or Seek by Dr. James Dobson addresses this aspect of our culture in an effective and interesting manner. Dr. Dobson provides sufficient examples to make us conscious of the negative impact our culture has on unattractive and/or unintelligent people.

Since there is little hope of making a significant improvement in our culture, Dr. Dobson provides detailed recommendations for parents to prepare their children to cope with potentially damaging situations.

As a parent of three children, I think that Hide or Seek should be required reading for all parents.

#### 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 in Seattle. A few questions have been submitted, and the professionals are working on them. Since they are very busy people, and have to work this task in among their many other duties, we have not been able to get a reply ready for this issue. Do keep the questions coming.

#### HELPFUL HINT

It is not necessary to completely deprive your dieting child of candy. A miniature marshmallow contains only two calories, a jellybean six, a small gumdrop five.



A VIEW OF WHO'S WHO

In this feature, we introduce families who have children with Prader-Willi syndrome, professionals who are working to help them, or others who are involved in some way. This issue features a letter from Mary L. Gidge of Yakima, Washington, concerning her son, Scott.

Scott was born January 7, 1960, after a normal pregnancy. He was not as active as my first son (now 17) and a daughter (now 12), both normal and healthy, but other than that, no difference.

The doctors knew immediately that something was wrong, and I was not allowed to see him for three days. He was out in an oxygen tent for a week and tube fed for three days. I went daily and learned to feed him. Still the doctors didn't know what was wrong; only that he was very weak. He weighed only five pounds and eleven ounces, very thin from the neck down, but had the face of an angel.

We brought him home after a month. He was fed with preemie nipples, as he didn't have enough strength to suck from regular nipples. He never cried until he was six months old, so I set an alarm for his feedings every two hours. He smiled and cooed like any other baby and was very happy.

He could not hold his head up until he was seven and a half months old. He had undescended testes, very small hands and feet, and blond hair that grew straight up. When we would hold him for any length of time, his legs would turn blue because of poor circulation.

When he was five months old, we took him to the University of Oregon Medical School in Portland for three days of every test possible. They could only come up with weak muscle tone, nothing else. We took him later to Children's Orthopedic Hospital in Seattle and heard the same thing. Apparently at this time no one had heard of Prader-Willi.

He did not learn to walk alone until he was two years, eight months old, but figured out his own mode of transportation. He would sit on his fanny, put his hands on his ankles, and scoot! He got everywhere! He used a walker when he was a year old.

He was potty trained at two and a half and completely dressed himself at three. We treated him as a normal child, since we didn't know what his problem was, and he responded in kind. He learned to talk at an early age and spoke beautifully until he had his tonsils out at eight. He now speaks in a nasal tone. I believe this is due to his lack of muscle tone, and he was afraid or unable to use his voice properly.

He was always a delight, always smiling, and loved everybody.

He began to get heavy after age two, and his doctor put him on diet pills, but they did not seem to help. When he was two and a half he weighed 32 pounds, when he was four, 50 pounds, and at five and a half he weighed 62 pounds. We took him to a doctor who treated obese adults with great success. He lost eight pounds, but it was a drop in the bucket compared to what he needed to lose.

He would go to neighbors, eat whatever was in sight, and was fantastic at sneaking food--so far our only major problem. He once went to a neighbor's patio--the table set, the mother inside--and ate all the cottage cheese salads. The desire to eat was uncontrollable.

He started kindergarten at five and repeated the class two years. He was slow to learn, but loved school and the children loved him. He was in a regular class, but they seemed to understand.

When he was eight he was bussed to a special education class. Math made absolutely no sense to him, but he had a fantastic memory and learned all the answers, but could not reason why. Two years later he learned to read--what a thrill! We believed he would not--at least not that early. His printing was perfect; his writing less than perfect.

When he was in his twelfth year, I had a call from his doctor who said, "Mary, I think I've found what is Scott's problem." In the Journal of Pediatrics was an article on Prader-Willi syndrome. There was a picture with this article that looked exactly like Scott. If I didn't know better, I would have sworn it was my son.

(To be continued in next issue.)



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THE GATHERED EXCHANGE

This is a regular exchange column, featuring questions you want answered, problems you need solved, answers to other parents' questions, and information or ideas you think might benefit parents and other readers.

This letter was received from Karl D. Reyer of Baton Rouge, Louisiana:

May I suggest that each issue of THE GATHERED VIEW contain a brief statement about Prader-Willi syndrome. Our daughter, Mrs. W. C. Leyshon, sent us a copy of Vol. 1, No. 1. She knows (about Prader-Willi syndrome), but we don't.

Editor's Reply:

Splendid idea, Mr. Reyer! No sooner said than done. See the first article in this issue.

Last month the question was:

How do you prevent the child with Prader-Willi syndrome from getting food he's not supposed to have?

Here is one reply we received:

We were told to put locks on our refrigerator and food cabinets. This works well at home, but what do you do about the times your child is away from home?

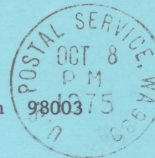
Faust Deterling, Harvard, Massachusetts

Recipe for Ice Cream on-a-stick:

Add orange juice to yogurt until it is runny. Pour into paper cups. When partially frozen, insert ice cream stick. Freeze until hard. 60 calories per 1/2 cup

Peggy Pipes, Nutritionist  
Child Development and Mental Retardation  
Center, University of Washington

THE GATHERED VIEW  
Shirley Neason, Editor  
147 South 294th Place  
Federal Way, Washington



Mr. and Mrs. Webster C. Leyshon  
10414 Huntley Avenue  
Silver Spring, Md. 20902