

THE GATHERED VIEW

Shirley Neason, Editor

26931 S.E. 403rd

Enumclaw, Washington 98022

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

Gene Deterling, President

VOLUME V

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Number 1

PRESIDENT'S MESSAGE

Over the past several years since we began as an organization, it has been encouraging to note the marked transition in the type of mail we receive. In the beginning, it was largely from desperate parents who had almost given up hope in coping with their Prader-Willi child on their own. We still receive correspondence of that nature, but it is now more in the minority and mostly from parents (and others who care) who have just heard about us. For the most part, our members who correspond with us are speaking in a much more positive tone. It is certainly not that there have been major accomplishments in treatment, behavioral modification, diet, education, facilities, and general support (although there has been much progress), but rather there is a greater awareness that now something is being done. The sharing experiences, the feeling of no longer being alone, and the working toward a common goal have given many a new feeling of hope. We're convinced that many of these hopes can someday be satisfied.

To those who are still discouraged by the lack of progress they have seen in dealing with their own situation, we want to urge you not to give up hope. For one thing, it is important to understand that there are degrees of the Prader-Willi syndrome just as there are degrees of intelligence, physical ability, hunger, metabolism, ambition, etc., in all of us. Some of us are more fortunate than others in having a child who responds more easily than some other Prader-Willi people to dietary measures and behavioral modification. It certainly is true that not all people get an equal start in life, and there are many Prader-Willi people who have additional handicaps which other Prader-Willi people don't have. Regardless, eventually we will learn how to treat them all, and even though there will always be inequities, we can still look forward to improvement in all Prader-Willi people's futures.

This year we expect we will see greater progress than in all the past years put together. This year the first national conference ever held on Prader-Willi syndrome will take place in the State of Washington on June 13th through 15th. This workshop of forty of the leading experts in the U.S. will provide a vehicle of information exchange that may be the nucleus of heretofore unplanned research and beneficial programs for Prader-Willi citizens. Then on June 29th and 30th in Minneapolis our own Prader-Willi syndrome Association will conduct its first combined annual meeting and general conference. Our plans for this meeting are beginning to gel, and in addition to a number of other top professionals in the U.S., we still have high hopes of having Dr. Prader speak at this meeting.

PRESIDENT'S MESSAGE, Continued

It is of utmost importance to us, however, to know before the end of March approximately how many attendees we will have at our Minneapolis meeting. We do not know at this point whether to expect 100 or 300 in attendance. It could even be only 50, but it might be greater than 300. So we must reserve a conference facility, and we must know the number of attendees for whom we must plan. At the current moment, we are considering a theater-type arrangement at the Marquette Hotel in downtown Minneapolis. Since we have not yet been able to procure the necessary funds to support this activity, we will probably be obliged to charge a fee of about \$10 per person for members and something greater than that for non-members. We appeal to all of you who are interested to fill out the form on the next page and mail it to us prior to the end of March. It is not binding, but it will enable us to develop our plans to meet the needs of all the attendees. We may not be able to accommodate you without this advance information.

In addition to these conferences, we believe we will make considerable progress this year in getting dedicated residential facilities established throughout the country. We will keep you posted on our progress in future issues, but for now you may be interested in reading the following announcement that we were pleased to have had published in the November issue of LINKS, a publication of The National Association of Private Residential Facilities for the Mentally Retarded. Already we have received some encouraging responses.

PRADER-WILLI SYNDROME ASSOCIATION SEEKS HELP IN DEVELOPING A NEW FACILITY

"The Prader-Willi Syndrome Association is appealing for assistance in establishing a residential facility for Prader-Willi youths and adults. The August issue of the NAPRFMR Newsletter described the syndrome. There is currently only one facility in the U.S. dedicated to persons with this syndrome. This facility is over-subscribed. There are a number of individuals in other parts of the country in desperate need of a residential facility. It is important that this be a dedicated facility because of the nature of the syndrome. There are very specific dietary requirements and behavior patterns with which to deal. The individuals seem to enjoy each other's company, and most suffer only from mild retardation.

"What is currently needed is a facility in the Midwest. The Prader-Willi Syndrome Association is now trying to establish one in the Minnesota area. We would like to hear from anyone who would be willing to establish such a facility, work toward the establishment of one, or simply work as an advisor. Some funding is currently available. Interested parties should contact Gene Deterling, P.O. Box 392, Long Lake, MN 55356."

PRADER-WILLI SYNDROME ANNUAL MEETING AND GENERAL CONFERENCE

On Friday and Saturday, June 29 and 30, 1979, in Minneapolis, Minnesota, the Prader-Willi Syndrome Association plans to hold its first annual meeting and general conference open to the public. The meeting will begin Friday morning at 8:30 a.m. with the Board of Directors annual business meeting open to all. Beginning at 1:00 p.m. the general conference will begin with noted speakers from all over the United States and, hopefully, from Europe. A part of the conference may be in workshop format, and a session will be planned where all attendees' questions can be addressed. The conference is planned to continue on Saturday, beginning at 9:00 a.m., and run to 5:00 p.m. that day.

PRADER-WILLI SYNDROME ANNUAL MEETING AND GENERAL CONFERENCE, Continued

Additional activities may be planned for children, and perhaps an evening reception for adults can be arranged.

A formal agenda and preregistration form will be mailed out in April. In the meantime, however, it is imperative that persons contemplating attending fill out the form below and mail it to Prader-Willi Syndrome Association, P.O. Box 392, Long Lake, MN 55356, not later than the end of March.

I (we) plan to attend the Prader-Willi Syndrome Association Conference in Minneapolis on June 29 and 30, 1979. It is understood that completion of this form is not confirmation of attendance.

Name (s) _____

Address _____

City/State _____ Zip _____

Number of children attending: Boys _____ Ages _____

Girls _____ Ages _____

(Circle age of Prader-Willi child if applicable.)

We will require a sitting service for our child(ren). _____

Planned accommodations: Yes _____ No _____

Price Range: \$25-35 per night _____ \$30-35 per night _____

\$35-40 per night _____ \$40-45 per night _____

\$45-50 per night _____

Type of Accommodations: Hotel _____ Motel _____ Camping* _____

Location: Downtown Minneapolis _____ Suburbs _____

*Camping in suburbs only. Information will be mailed.

I will plan my own accommodations _____

I (we) would be interested in attending an evening reception on Friday evening. (This will be an additional expense) _____

THE GATHERED EXCHANGEGrowth

"At what age does growth usually stop"? Texas

Diet

"M. was diagnosed at age three. At the time he was 38 $\frac{1}{2}$ inches tall and weighed sixty pounds. The nutritionist put him on a diet of 600 calories, eliminating starches, fats, and sugar in varying degrees. At the end of a year he was forty inches tall and weighed forty-one pounds. We are thrilled and he is much more mobile and agile. At school he is catching up to the other kids in activity because of his smaller size and his stomach no longer gets in the way". Massachusetts

Adults with Prader-Willi Syndrome

"My son is twenty-three, about one hundred pounds overweight, picks at sores, has had surgery for undescended testicles, is getting hormone shots as one testicle was removed. His retardation is mild, but emotional problems cause us much despair. He is about to lose his job because of his temper. The Department of Rehabilitation worked with him over a year, finally getting him employment by a government funded business. CETA funds have been withdrawn and they tell me he will not be kept on because of his emotional outbursts. He was doing good work. We don't know where he can go from here". Arizona

Eating away from Home

"I would like to share my solution to the problem of eating out. We have eaten in restaurants frequently and have had a few problems with my 5 $\frac{1}{2}$ year old PWS daughter. We simply tell the waitress the young lady is on a "special diet" and then ask for a modified serving of something that is offered on the regular menu. (Most dishes on children's menus tend to be starchy.) Explanations about calories or the syndrome have not been needed. Usually I order a portion of "plain" meat (without sauce or gravy) and a small portion of green vegetable, omitting starchy foods. I allow her to choose a $\frac{1}{2}$ serving of dessert so she doesn't feel left out while the others have dessert. We avoid "fast food" restaurants as the food is known to be high in calories. Some preliminary warnings also help, such as "You know you cannot have any bread or rolls when we have dinner at the restaurant." Altogether dining out has been pleasant". Connecticut

Food Access Management

"Someone wrote asking about people who don't have the food stealing problem. It is rare that M. ever helps himself to food. We always have food in the house that is not on his diet because we also have a two-year-old who seems to take on enough food for three kids since he is as active as five. It is strange to have two such totally different children, but both are great. We allow M. his own choices as to lunch, supper, etc., and always have several varieties of allowed cereals he can choose from. He is allowed access to the refrigerator after receiving permission from myself or his father; also he must say why he needs to go in the refrigerator and what he wants before he takes it, since we don't allow a shopping around of the refrigerator's contents. It sounds complicated, but works very well. The same rules apply to our two-year-old. We find M. does not feel different since he does what other kids do at home". Massachusetts

THE GATHERED EXCHANGE, ContinuedBehavior Management

"I have found that money (a penny or nickel) is a handy reward for good behavior, rather than food or candy. My child is quite a saver and I allow her to buy books or toys occasionally. Hopefully, this will substitute for the candy children like to buy with pocket money." Connecticut

Speech Development

"Our son ($4\frac{1}{2}$) was not delayed in speech. He said a few words at seven months and short sentences between one and a half and two. He spoke so fast there was difficulty understanding him. He also substituted "w" for "l" or "r". Massachusetts has Chapter 766 + Title 1 laws that make the public school systems available to three and four year olds if there is a need for help in a child's development. M. was evaluated and they suggested speech therapy. The Special Needs director enrolled him in a nursery school. School is in session five days a week for $2\frac{1}{2}$ hours. There is a maximum of twelve children in a class with a full time teacher, a speech therapist, and an aide. It is a typical nursery school, wonderfully equipped. Snacks are sent by parents and supervised by the teachers. M. has learned to tell other children they should share everything but food, and it works out great. He speaks very well now and has only been in school three months. The presence of other kids his age has encouraged him to attempt things he thought he couldn't do or were too difficult. He is independent and refuses to have things done for him. He will be entering kindergarten in the fall as his intelligence is normal and the teachers say he is smart and comprehends well." Massachusetts

Temper Tantrums

"The most difficult problem we face is a noted increase in stubbornness and temper tantrums with our $9\frac{1}{2}$ year-old. This has led to increasing tensions among her older siblings. They resent her constant interference with their affairs and at times resent her. We have found it increasingly difficult to deal with. I would appreciate any information from others who have also experienced this situation within their family". Maine

Sibling Relationships

"In response to the above problem, here is one thing we did. We purchased outside type door knobs for our older children's bedrooms--the kind with the key in the knob. That kept the older children's belongings safe from the younger child and also gave them a place to retreat when they were unable to cope with the younger child's behavior. We kept a spare key to each room hidden in the house so that parents could have access to the rooms for cleaning, putting away clothing, and in case of emergency." The Editor

Bowel Control

"I was the one who wrote concerning the bowel control problem. I had taken my son to doctors with no answer, so I took him to another clinic. This doctor took an X-ray which showed massive blockage in the colon. We started him on castor oil every night for a week to start this moving out. During the week while he's in school we give him mineral oil, and on weekends castor oil again. He said it would take at least two months to clean out and shrink the colon back to normal size. We never suspected constipation because of the frequency and looseness of movements. When he began getting relief in about three days, we had no more problems with control, even with the looseness caused by the castor oil. His disposition even improved as he felt better. The doctor said this condition is not uncommon at this age, even in normal children". Texas

THE GATHERED EXCHANGE, ContinuedDiet

"Our son (an adult) at his heaviest weighed 249 pounds. In September, 1977, we began the Liquid Protein and supplement diet prescribed by Dr. Bray at Harbor General Hospital, Torrance. At that date he weighed 225 pounds. Due to the adverse publicity about Liquid Protein, Dr. Bray discontinued its use in December, 1977. Our son was then 186 pounds. We still continue the the supplements to his diet. From December, 1977, to the present he has reached a plateau of 166/170 pounds. His lowest weight (163) was recorded in July, 1978. Only by a stricter regimen could we hope to reduce him below 166.

Sizewise he wore 50" waist slacks at 249 pounds, and they were tight on him. At his present weight he could just about get by with 38" except for the buttocks. Out our way in the P-W circle, he is considered a "model" and we personally know of no other case where such weight reduction has been accomplished". California

Recipe: Eggs in the NestIngredients:

1 Cup chopped celery
1 Tablespoon chopped onion
 $\frac{1}{2}$ Teaspoon salt
1 egg
1 meat exchange
As desired vegetable exchange

Method:

Boil celery and onion in salted water. Drain. Place vegetables in a custard cup, making a hollow in the middle. Break an egg into the hollow. Bake at 350 for 20 minutes, or until egg is desired doneness. For an Easter breakfast treat, add food coloring to the vegetables.

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This introduces a new column, but I haven't thought of a name for it. In the November-December issue, Mr. Deterling asked people who have Prader-Willi syndrome to write. This column is for their letters. I have tried to think of a name which would use either the word "gathered" or the word "view", as most of our other columns do, but haven't thought of one that satisfies me. If you have an idea for the title, please send it in.

Our first letter is from California:

"I went to the workshop last year. I went to Michigan for the summer and when I got back I was supposed to go back. Because of Prop. 13 they are not taking any more clients back to the workshop. Last year they had a Friendship Club meeting at the park where people would play games and records and have crafts once a week. Because of Prop. 13 they don't have that either. I hope someday there will be an independent type of living with a connected workshop for Prader-Willi people. All the activities have been cut out in Simi. I would like a pen pal very much. A girl around 26".

Beth Carlyon, Age 26
3706 Flood Street
Simi Valley, CA 93065

Here is a postscript by Beth's mother:

"Beth and I manage to keep occupied. We have two cats and two dogs; we walk the dogs every day. We watch Beth's diet, but she weighs 225. Her father is a teacher so is very busy. We keep a roomer which gives us spending money and helps create independence, but it is not the same as when she proudly gets to do something of her own. She rides a large three wheeler trike very well and we go biking together".

Eva Carlyon

GATHERED REPORTS

From "THE OPEN DOOR", Newsletter of the Prader-Willi Association of Australia:

We have got a little bigger. Six pages this month instead of four.

Dr. Arabella Smith is trying new techniques in chromosome testing for P.W.S. cases, and is looking for more patients to be tested at her laboratory in Sydney.

Our aim for November and December is to contact every radio station around Australia, hoping to find even more P.W.S. cases.

Our founder, Mrs. Simpson, has been asked to speak to the Cumberland College of Health and Sciences to give a 30-minute lecture on Prader-Willi syndrome. In October she spoke to SWOP, a group of businessmen and women who raise funds for charitable organizations.

Dr. Arabella Smith was the guest speaker at the December meeting of the Association. In January the speaker will be Mr. John Lysle, morning host for a radio women's show and an expert on catering. He will give advice on low-calorie meals.

We have applied for a grant to enable our chairman to visit America and make contact with the Prader-Willi Association there and to inspect group homes and holiday camps.

British Columbia

On November 30 a group of parents of people with Prader-Willi syndrome met at the L'Arche residence in Burnaby, B.C., a suburb of Vancouver. L'Arche is a community of adults, some of whom are mentally handicapped. The meeting was called and led by Judith Leckie, director of L'Arche of Greater Vancouver. There was a person with Prader-Willi syndrome in the L'Arche residence, but the other residents could not cope with her problems, and she is now in another residence. However, L'Arche still feels a responsibility toward her, and, consequently, toward others with Prader-Willi syndrome.

Twenty-one were present at the meeting, sixteen of whom were parents. In addition to the parents and L'Arche residents, two representatives of the Community Living Board, David J. MacCoy and Leslie McAneeley, attended. Community Living Board is a non-profit society currently under government contract to find alternate living arrangements for specified persons now living in institutions. Shirley Neason, Editor of THE GATHERED VIEW, also attended the meeting.

After introductory remarks, the meeting was opened for parents to express concerns and problems. This produced a lively discussion, as few of the parents had ever before met other parents of children with Prader-Willi syndrome. All were anxious to learn what problems others had experienced, and were relieved to find that the problems seem to be common to the syndrome and are not the result of faulty parenting.

All agreed that the most critical need at present is providing living arrangements for adults with Prader-Willi syndrome. Several were parents of adults and felt their need was urgent. They set another meeting for January 9. Mr. MacCoy and Ms. McAneeley stated that the Community Living Board would continue to explore alternatives and work with the parents to try to meet this need.

Reported by Shirley Neason

THE PROFESSIONAL VIEW

From the Child Development and Mental Retardation Center of the University of Washington:

We have just received word from the U.S. Department of Health, Education, and Welfare that we have been awarded a grant to hold a national conference on Prader-Willi syndrome. We would like to inform the readers of THE GATHERED VIEW that the conference will be held at the University of Washington's Lake Wilderness Conference Center on June 13-15, 1979, with funding for the conference and subsequent publication of proceedings provided by a Maternal and Child Health Training Grant from the Department of HEW. The format of the conference will be a workshop with forty invited participants (this is the maximum number that can be accommodated at Lake Wilderness.) We hope to have some closed sessions for exchange of information among the invited researchers. However, there will be open sessions which anyone will be welcome to attend. We will be issuing a call for papers shortly to the professional community and those accepted will receive free room and board while in Seattle. Whereas preference will be given to papers submitted which have research data, we will consider any papers on the subject of Prader-Willi syndrome for inclusion in the program. A copy of the call for papers can be received by writing Stephen I. Sulzbacher, Ph.D. CDMRC, WJ-10, University of Washington, Seattle, Washington 98195. In addition, persons interested in attending, but not presenting a paper, may write us stating their reasons for wanting to attend. Those invited will also receive free room and board at the conference.

It is our hope to bring together all the people actively working with Prader-Willi syndrome children in North America for this conference. Furthermore, it is hoped that the publication of the proceedings, either as a monograph supplement to a recognized journal or as a separate volume published by a national medical publisher, will focus increased attention to the solution of problems faced by Prader-Willi children. We also believe that recognition of the importance of research with Prader-Willi syndrome by the federal government in awarding us this grant is in itself a significant step forward.

Stephen I. Sulzbacher, Ph.D.
Vanja A. Holm, M.D.
Peggy Pipes, R.D., M.P.H.

A Letter to the Editor:

I received my September-October issue of THE GATHERED VIEW, and there are several responses that I feel I must make and ask that they be included in the next publication.

1) WISER ACRES is exclusively for adolescents and young adults with Prader-Willi syndrome.

2) It was never my intention to publish a booklet of menus. On your request I had my printer design a booklet that I thought you wanted as a format for your menus.

3) If, in the future you contact WISER ACRES or Double R R Ranch for information for the newsletter, please check with me for verification of the facts. For example, Scott Cameron is not a special education teacher, he is an aide in special education. In addition, I would not have approved of Scott's saying he "hoped someone would donate money for a swimming pool."

4) To state that WISER ACRES is "running as smoothly as one could expect a group home to run" is to imply that group homes usually do not run smooth. The staff and residents of WISER ACRES have had a tremendous year of growth and development. Everyone has benefited and the staff did a great job with a difficult group of eight distinct, yet common personalities. Camelot, my children's home for the retarded has run smoothly for eight years.

THE PROFESSIONAL VIEW, Continued

Despite the turmoil and upheaval of the month of October, the residents have done remarkably well. Maybe there is a lesson for all to learn--including the residents--that nothing in life is constant, that every step backwards is three steps forward, that having faith and belief strengthens a person and provides a determination to hurdle all obstacles.

Sincerely,
Margo Thornley

The editor's response:

My apologies to Mrs. Thornley and to our readers for the inaccuracies that appeared in the articles.

The matter of the menus was obviously a misunderstanding. Apparently Mrs. Thornley and I were not talking about the same subject when we conversed about the matter. Consequently, THE GATHERED VIEW will continue to publish the Double R R menus in the Menus column when there is room for it.

The statement about a "smooth-running group home" was not intended to be critical. As I visited WISER ACRES, I got the impression of a home where the residences were active and busy in activities in the home and community, and therefore there was much excitement and many comings and goings. My definition of a totally "smooth-running" operation would be one in which there is a regimented routine that is never interrupted to allow for the special occasions that make life interesting and fun.

In addition, of course, I did report on some of the problems and frustrations. I realize that it is not Mrs. Thornley's style to discuss problems. She is an energetic person who acts rather than talks, and feels that talking about problems is "negativism" which can defeat one's purpose. However, I feel that one of the purposes of THE GATHERED VIEW should be to exchange knowledge of problems as well as successes. As we become more aware of problems, we can better prepare ourselves to solve them when they present themselves to another group working toward the same goal.

HEY! THAT'S GREAT!

This is GERALD ABBE, nine years old. He was first diagnosed at age seven and a half. His parents had already started restraining his eating before diagnosis, so he had a head start on his diet. He hasn't lost any weight since he was diagnosed, but he has stayed at the same weight while growing taller. His parents are very proud of him and so are we! His mother says that he may not be a proficient correspondent, but he really would enjoy having a pen pal his age. Here is his address:

GERALD ABBE
Rt 6 Box 852
Waco, Texas 76706

THE MEDIA VIEW

Additional Chapter for Handbook:

Some have written expressing a need for an additional chapter in the handbook on adults with Prader-Willi syndrome. At the time the handbook was written we were aware that there was a gap in this area. However, none of the parents involved in producing it were parents of adults, and no one we knew had access to such information. Since that time, some information has been received which has given an indication of at least some of the problems, if not any solutions.

In the six months since the handbook was offered for sale, approximately 370 of the 500 printed have been distributed. Although requests have slowed considerably, it appears that the handbook will have to be reprinted within a year or two. It would not substantially increase the cost of printing to add another chapter, so we can start work on one about adults. If you have any information to contribute, please send it. We want such information as:

- What problems are faced by adults with Prader-Willi syndrome?
- Where do they live? (With parents? In a group home? A larger institution?)
- How are they doing with their weight?
- How are their financial needs met? Are they earning any money themselves?
- In what areas have they been successful? Unsuccessful?
- How well do they function socially? How do they get along with others?
- What medical problems do they have? How do they respond to treatment?
- How happy do they seem to be?
- What kind of relationship does their family maintain with them?
- What educational level did they reach? Are they utilizing their education?
- What do they do for recreation?
- What would they consider ideal living arrangements?
- What would parents like to have provided in the way of living arrangements?
- How tall are they? At what age did they attain full height?
- Any other information you think might be useful.

Index of THE GATHERED VIEW

The editor has nearly completed an index of THE GATHERED VIEW issues from July, 1975 to November-December, 1978. It will soon be ready for reproducing. If you would like a copy, send a self-addressed stamped envelope.

The indexing was extremely difficult because many articles contained information on a variety of subjects. For this reason, our index could probably never be considered really complete. If after receiving your index, you find yourself looking for a subject heading and it isn't there, or if there is a piece of information you have seen but can't find it listed, let us know. We can add it to future indexes.

EDITORIAL

There previously have been no editorials in THE GATHERED VIEW because the Message from the President takes the place of one. However, I find that I have some things I want to say to our readers.

First, I would like your help in writing an article on the needs and feelings of parents of people with Prader-Willi syndrome. I know that we parents do have special needs. Some we have in common with parents of children with other kinds of handicaps and some are unique to Prader-Willi syndrome. Once I develop the

EDITORIAL, Continued

article, I will try to get the opportunity to share it with professionals so they can understand these needs. I would like readers who are parents of children or adults with Prader-Willi syndrome to write and tell what your needs are that result directly from being a Prader-Willi parent, especially as they relate to professionals you deal with. For example, a mother once told me that she has been told, "There is nothing wrong with your child. You are a poor parent." Obviously neither the syndrome nor the parent's need was understood. In addition to telling your needs, also tell how others have helped or failed to help you.

Second, I want to talk about the term, "food-stealing." When a person with Prader-Willi syndrome opens the refrigerator and eats all the ice cream available, we have referred to this as "stealing." However, the word "stealing" has a moral connotation which I believe causes a problem for children. There is no moral issue involved in so-called "food-stealing." The person has a compulsion he can't overcome and right and wrong have nothing to do with it. It would be stealing only if he took the food from a store or someone else's home. Current terminology blurs the distinction. I propose we try to think of a new term to use when referring to a person's taking unauthorized food from a storage place in his residence or school. I have been thinking about it for some time, but haven't been able to come up with a suitable term. In this issue I used the topic heading, "food access management." However, this refers only to the parent's approach to controlling the access to food, and does not define the actual taking of food. Hopefully, someone can come up with a better term than "stealing." If you have an idea, send it to us. When we find a new term, we can then work to eliminate the word "food-stealing" from the Prader-Willi vocabulary.

A VIEW OF WHO'S WHO

From Maryland:

"We are parents of an $8\frac{1}{2}$ year-old girl who was diagnosed as having Prader-Willi syndrome in January, 1976, after $6\frac{1}{2}$ years of misdiagnoses by neurologists at three major medical centers. She was finally correctly diagnosed after we read the Newsweek article, recognized the symptoms immediately, and turned to Johns Hopkins Endocrinology instead of neurology.

The years of frustration of not knowing what to expect and what to do for our little girl have been a uniquely horrifying experience for all of us. I am a Registered Occupational Therapist and for $6\frac{1}{2}$ years I kept insisting there was something also metabolically at fault, although she was consistently diagnosed as brain-damaged from anoxia at birth. At present she is being followed at Johns Hopkins Endocrinology Department.

She attends a school class for physically disabled but intellectually normal children and is doing beautifully. Her motor control has improved so she can write her numbers and letters. She can read, and loves it. Her intellectual functions have always been far ahead of her motor control. School problems would be described as those of a learning disability, and I see a lot of the emotional overlay and frustration that accompanies this "diagnostic entity", having trained and worked in "Learning Disabilities" as an O.T.

She has neighborhood friends and is quite social, although food and controlling her emotions have always been a problem. But she seems to be internalizing a lot of self-control as she grows older, and we are very proud of her.

A VIEW OF WHO'S WHO, Continued

Thank goodness we feel we intuitively did the right things for her in the first 6½ years, for without guidance and the proper diagnosis, we could have done her a terrible injustice as far as the food compulsion was concerned.

She now has a little brother whom she adores, although she can't understand why he doesn't enjoy eating as much as she does"!

* * * * *

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. Editorial material may be sent to THE GATHERED VIEW, 26931 S.E. 403rd, Enumclaw, WA 98022.

The following materials are among those available from the ASSOCIATION:

"Prader-Willi Syndrome--A Handbook for Parents," Price \$2.00 for first copy to members, \$3.50 for subsequent copies and to nonmembers.

"Bibliography on Prader-Willi Syndrome". Free.

* * * * *

PRADER-WILLI SYNDROME ASSOCIATION

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