

# THE GATHERED VIEW

Published Bi-Monthly

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Newsletter of PRADER-WILLI SYNDROME ASSOCIATION  
Formerly PRADER-WILLI SYNDROME PARENTS AND FRIENDS  
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Box 392  
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Membership Dues: \$6.00 per year  
Overseas Membership: \$7.00 per year

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## MESSAGE FROM THE PRESIDENT

I am pleased to report that our organization held its first annual meeting on May 27th in Seattle. In my estimation it was a major accomplishment and a very important step in laying the groundwork for an effective lasting organization. It was an accomplishment because there is great difficulty with our type of organization where the membership is widely scattered, in pulling together the right people at an agreed upon time and at a suitable meeting place.

The significant results of the meeting were:

1. A formal set of bylaws was adopted. A copy will be sent to all members soon.
2. The name of the organization has been changed to Prader-Willi Syndrome Association. Our letterhead and all other printed material will be changed to the new name but will for a year or so include the words "Formerly Prader-Willi Syndrome Parents and Friends."
3. A Board of Directors was formalized and a Chairman of the Board elected.
4. The Articles of Incorporation were approved. As soon as the paperwork is processed, we will be an official non-profit corporation.
5. The officers of the corporation were elected.
6. A dues increase was unanimously voted. This is not a happy note, but it was necessary to keep us solvent and allow the organization to purchase some assets. (The organization presently does not even own a typewriter.) The new dues will be \$10 for a domestic membership, including Canada and Mexico, and \$13 for overseas membership. We have not yet determined the effective date.

Delfin Beltran, M.D., has been elected Chairman of the Board. The additional nine members of the Board of Directors are: Eugene Deterling, Fausta Deterling, Bryan Hall, M.D., Vanja Holm, M.D., Shirley Neason, Andrea Netten, R.D., Peppy Pipes, M.P.H., Judy Schultz, and Stephen Sulzbacher, Ph.D.

MESSAGE FROM THE PRESIDENT, Continued

The elected officers are: President - Gene Deterling, Vice-President - Andrea Netten, Treasurer - Gene Deterling, Secretary - Fausta Deterling.

Although not an elected position, the Board agreed special recognition is due Shirley Neason as Editor of THE GATHERED VIEW. (What would we do without her!) Shirley's name will appear on all our official documents.

It was most gratifying to hear more about the fine work Dr. Holm, Peggy Pipes, and Dr. Sulzbacher, along with the rest of CDMRC, are doing in support of Prader-Willi syndrome. I am convinced that more will be learned about the syndrome in the next two years than has been learned in the past twenty.

It was also a special pleasure meeting Margo Thornley, a very dynamic, capable woman, who has recently opened a summer camp exclusively for Prader-Willi people. We visited the camp and another facility, the W.I.S.E.R. Institute, nearby which Mrs. Thornley founded. One could not go away from visiting these facilities without being markedly impressed by Mrs. Thornley's accomplishments.

I am also happy to report that the first formal publication devoted exclusively to Prader-Willi syndrome is now at the printers. The publication is a report written by one of our members, Robert Amren, whose adult brother has Prader-Willi syndrome. Although it was written while he was a student at Southern Pacific College and does not pretend to be authoritative, it is a thorough study of the subject of the syndrome and presents an intimate view of the feelings of a Prader-Willi adult.

We are fortunate in having Mr. Amren contribute this work to our organization and are most thankful to Mr. and Mrs. Kenneth J. Kelley for having contributed the necessary funds for its publication. We will be forwarding a copy to each of you sometime in July.

The good things all seem to come at once. We are delighted to hear that Shirley Neason's book is also about ready to go to press. This is a comprehensive work that will be welcomed by all who must cope with the syndrome. The cost to publish this book currently exceeds the funds available, but it now appears that some of our generous members will make it all possible.

*Gene Deterling*

CORRESPONDENTS NEEDED

As the result of publicity in recent months, the Child Development and Mental Retardation Center of the University of Washington has been getting inquiries about Prader-Willi syndrome from all over the nation. They cannot effectively handle the volume of mail they have been getting and still fulfill their other responsibilities. The staff at the Center wonders if there are members of PRADER-WILLI SYNDROME ASSOCIATION in various parts of the country who would be willing to answer inquiries from parents in their area. If you are interested in performing this needed service, write THE GATHERED VIEW, and we will forward your reply to CDMRC.

HEY! THAT'S GREAT!

Parents, here's your chance to pat your child on the back (along with taking a bow yourself for the help you've given him/her.) The purpose of this new column is to give recognition to achievements by persons with Prader-Willi syndrome. Please send reports about what your child, or another person with the syndrome, is doing that you think is worthy of recognition. First names only will be used, unless otherwise requested. We will also use pictures in this column. Pictures can be sent for use by themselves, and do not necessarily have to be accompanied by a report of achievement. However, please send the release form below with the picture. (Make a copy on a separate piece of paper if you do not want to cut up your GATHERED VIEW.) If you have previously sent a picture, and would like to have it published, send the release form with a note explaining that we already have the picture.

#### RELEASE FORM

I give permission for the accompanying picture of \_\_\_\_\_  
 to be printed in THE GATHERED VIEW. Age (optional) \_\_\_\_\_ (Name of person pictured)  
 Name of person as you want it to appear in print \_\_\_\_\_  
 SIGNED \_\_\_\_\_ RELATIONSHIP \_\_\_\_\_

#### FILE OF DIAGNOSTICIANS

Dr. Vanja Holm, director of the Prader-Willi clinic at the Child Development and Mental Retardation Center of the University of Washington, is building a file of names of physicians who have successfully diagnosed Prader-Willi syndrome. If you have the name and address of a physician who has successfully diagnosed the syndrome, please send it to THE GATHERED VIEW, and we will forward it to Dr. Holm.

#### GATHERED REPORTS

##### Sacramento, California

On July 7, Sacramento area parents met at Alta California Regional Center. Andrea Netten, Alta California nutritionist, and Dr. Delfin Beltran, Chairman of the Board of PRADER-WILLI SYNDROME ASSOCIATION, gave a report to the parents on the PRADER-WILLI SYNDROME ASSOCIATION Board of Directors meeting in Seattle on May 27.

Reported by Andrea E. Netten

##### Seattle, Washington

Seattle area parents have had two recent meetings. An evening meeting was held on May 26 so that parents could meet members of the Board of Directors who were in Seattle for the Board meeting the following day. July 6 was clinic day at the Child Development and Mental Retardation Center, and attending parents met with Margo Thornley for a report on the current status of Double R & R Ranch. They also heard a report from Alice Lobenstein, nurse-coordinator for the Prader-Willi clinic, about her plans to conduct group therapy sessions at the ranch. In addition, Margo Thornley reported that she has had an offer of new facilities for W.I.S.E.R., which would permit the conversion of the present facilities into a group home. As a result, she has applied to the state for a license to operate a group home for children with Prader-Willi syndrome.

Reported by Sue Iverson

DOUBLE R & R RANCH

Double R & R Ranch is experiencing a Remarkable & Rewarding beginning. Designed by its director, Margo Thornley, to expressly meet the needs of youngsters with Prader-Willi syndrome, the ranch is offering a full summer of camping experience in a rustic setting. Ranchers are housed in the homelike setting of a modern ranch-style dwelling.

The diet has been especially planned to meet the nutritional needs of the ranchers, and at the same time help reduce their weight, if necessary. Menus have been planned under the supervision of a nutritionist for a twenty-one day cycle to provide variety. Each rancher's food is measured to meet individual caloric requirements and plates are arranged so food appears attractive and plentiful.

Monday is "weigh-in" day. The children are transported to the Child Development and Mental Retardation Center to be weighed on professional scales. So far all ranchers have lost weight.

A unique arrangement provides food security without completely closing off the kitchen. A screen has been installed across the kitchen opening, with a door in the center. When no one is on duty in the kitchen, the door is locked.

During their first week of residence, Ranchers go to the Western Institute of Specialized Education and Recreation (W.I.S.E.R.) for evaluation so that individual needs can be taken into consideration in carrying out the program.

Activities include swimming, field trips, games, and other recreational activities. A special feature is a marked pathway for developing stamina. The pathway and other recreational activities were developed by a physical therapist.

Average number of ranchers registered is four, and six are the most registered for any one week. There are still openings, so if you are interested, write to Margo Thornley, Director, Double R & R Ranch, P. O. Box 578, Bothell, WA 98011, or telephone (206) 485-5529.

THE BOOK VIEW

The article that Gene Deterling wrote for the THE EXCEPTIONAL PARENT was published in the June issue. I do not have a copy available, so cannot comment on the article. If you would like to subscribe to this magazine, or send for a single copy of the June issue, their address is THE EXCEPTIONAL PARENT, P. O. Box 641, Penacook, N.H. 03301. The cost of a one-year subscription is \$10.00.

An unexpected result of the article came in the form of a visit from a mother of a child with Cornelia deLange's syndrome. It seems that this mother, who lives in Seattle, has been wanting to begin a newsletter for parents of children with the deLange syndrome. When she read the article, she was glad to find that THE GATHERED VIEW was published nearby, and made arrangements to come see our operation so she could get some ideas. She expects to begin publishing within the next month. An ironic note is that deLange's, which is even more rare than Prader-Willi syndrome, has many symptoms that are the opposite of Prader-Willi. Children with deLange's refuse to eat. The mother reported that every meal involves a battle with her twelve year old to get a minimal amount of food into her. Naturally, the children are underweight. In addition they are hypertonic (with muscle tone so tight the muscles are stiff) and hyperactive.

It is rewarding to know that our work as an association is contributing even to those beyond our own group.

THE GATHERED EXCHANGE, Continued

necessary to accomplish the desired objectives, then trim their immediate goals, if necessary, to what can be realistically expected. An analysis of the goals then ought to tell them how much organization is needed to carry on, and how much money, if any, they need to raise. The Seattle group is very informal and has almost no organization. Much of the leadership is provided by the Child Development and Mental Retardation Center. The nurse who coordinates the Prader-Willi clinic arranges for publicity and a meeting room, and obtains speakers for the group from among the staff at the Center. One of the functions of the group is to offer encouragement and information to parents who come in from out of town. For this reason, most of our meetings are on clinic day. I encourage representatives of other parent groups to write to THE GATHERED VIEW to share with others how your group is organized and what its objectives are.

GATHERED NEWS

The Jean Riley Publishing Company was recently established to maintain and operate facilities for the printing, publishing, and distribution of written or transcribed material contributed by disabled individuals. An autobiographical sketch must be submitted in advance of manuscripts, indicating the nature of the disability. The corporation will publish fiction, nonfiction, poetry, and artistic endeavors. The address is Jean Riley Publishing Company, 415 N. East Street, Arlington, Texas 76011.

from the COPH Bulletin  
(Congress of Organizations of the  
Physically Handicapped)

Highline Community College, located in a suburb of Seattle, Washington, is offering a two-credit course for parents of handicapped preschoolers. The course is designed to assist the parents in recognizing their position as principal teachers of the handicapped child and to acquire skills to train the child. Also covered will be training on how to minimize the negative impact on the family from the demands of the handicapped child. The children will attend preschool classes in the college's Early Childhood Lab while their parents attend class. Part of the class time will be spent by the parents working with their own children in the lab.

from the Federal Way, WA, News

Sheltered Village in Lake Geneva, Wisconsin, was started as a home for the physically handicapped and the mentally handicapped to live together.

from the COPH Bulletin

A VIEW OF WHO'S WHO

The names of our Board of Directors were introduced in the MESSAGE FROM THE PRESIDENT. The WHO'S WHO column introduces them to you in further detail.

BRYAN D. HALL, M.D., is Assistant Professor of Pediatrics and Associate Director of Birth Defects Center at the University of California in San Francisco. He was born in Kentucky, is married, and has three children. He received his college training and M.D. at the University of Louisville and did resident work in England and Louisville Children's Hospital. From 1970 until 1972 he was a Senior Fellow with Dr. David W. Smith at the University of Washington School of Medicine and he

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THE GATHERED EXCHANGE, Continued

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## A VIEW OF WHO'S WHO, Continued

and Dr. Smith co-authored an article on Prader-Willi syndrome for the Journal of Pediatrics. He currently has twenty patients with the syndrome.

JUDY SCHULTZ is the mother of a five-year-old son with Prader-Willi syndrome. She also has two younger children. The youngest was born June 7, and his impending birth prevented her from attending the Board meeting. Judy has been working with her five-year-old since birth. He was in an infant project until he was three, and is now in one of Sacramento's best integrated preschools. She is active in the Sacramento, California, Prader-Willi parent group, and is the reporter to THE GATHERED VIEW for that group.

STEPHEN SULZBACHER, Ph. D., works in the field of psychology and special education at the Child Development and Mental Retardation Center of the University of Washington. He received his Bachelor's from Penn State and did graduate work at Hollins College, Virginia, and the University of Kansas. He received his Ph. D. from the University of Washington. He became interested in Prader-Willi syndrome because he felt that children with this syndrome constituted a group he could do something for. Dr. Sulzbacher was married in December, 1976. His wife is a research analyst working on the fetal alcohol syndrome.

GENE DETERLING, President of PRADER-WILLI SYNDROME ASSOCIATION, is the founder, along with his wife, of the organization. He is employed as a member of the corporate staff at Honeywell Information Systems in Minneapolis in the position of Product Director for computer peripheral equipment. He is a graduate of St. John University with a degree in physics and has done graduate work at several large universities. He previously founded another non-profit organization, but this is the first for the handicapped. He has a boy with Prader-Willi syndrome, age six, and also has a fourteen-year-old son, and a sixteen-year-old daughter.

FAUSTA DETERLING, Secretary of PRADER-WILLI SYNDROME ASSOCIATION, is a native of Massachusetts. She attended Radcliffe College, the Museum of Fine Arts School in Boston, and the Katherine Gibbs School, also in Boston. She has done volunteer work with handicapped children and expects to be doing more volunteer work with the learning disabled in the local school system.

(For a further introduction to the Deterlings, see the July, 1975, issue.)

PEGGY PIPES, R.D., M.P.H., is chief of the Nutrition Section of the Clinical Training Unit of the Child Development and Mental Retardation Center of the University of Washington, and Lecturer in Home Economics. Peggy was born in Texas and received her B.S. at Texas Technological College. She interned at Columbia Presbyterian Medical Center and received her M.S. from Columbia University and her M.P.H. at the University of Michigan. She came to Seattle in 1968, and in 1970 began her experimental program to try to bring about weight loss in children with Prader-Willi syndrome. She has published two articles on the syndrome. Her most recent publication is a book, Nutrition in Infancy and Childhood, which she dedicated to parents of children with Prader-Willi syndrome.

(For a further introduction to Peggy Pipes, see the January, 1976, issue.)

ANDREA E. NETTEN, R.D., Vice-President of PRADER-WILLI SYNDROME ASSOCIATION, has been Nutrition Consultant at Alta California Regional Center for the Developmentally Disabled in Sacramento since 1974. She graduated from the University of Rhode Island, and completed her dietetic internship in 1968 at the New York Hospital Cornell Medical Center in New York City. Then she was pediatric dietitian at Boston Floating Hospital (Tufts-New England Medical Center.) She returned to graduate school at the University of Washington in 1973 and expects to receive her M.S. in nutrition this fall. She became interested in Prader-Willi Syndrome while in graduate school. At Alta she has sponsored a parents' group for a year and a half.

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It now consists of eighteen families with children ranging from three to eighteen, with the majority of them being under seven.

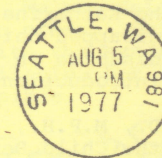
SHIRLEY NEASON is a native of Pennsylvania and attended Roberts Wesleyan College in Rochester, N.Y. She taught high school English for two years and more recently taught preschool for two years. She has a twenty-year-old son, an eighteen-year-old daughter, and a ten-year-old son. The ten-year-old has Prader-Willi syndrome. Her husband is a manager for Boeing Computer Services.

DELFIN J. BELTRAN, M.D., is a cardio-vascular anesthesiologist, practicing in Portola Valley, California. He was formerly on the staff at Stanford Medical School. He has a five-year-old daughter with Prader-Willi syndrome.

VANJA HOLM, M.D., is Assistant Professor of Pediatrics at the University of Washington School of Medicine. She was born in Kiruna, Sweden, north of the Arctic Circle, and got her medical degree from Karolinska Institute in Stockholm. While in Stockholm, she met and married an American studying economics there, and returned with him to his native Seattle, where they recently celebrated their silver wedding anniversary. They have a son and a daughter, both in college. Dr. Holm received the remainder of her medical training at the University of Washington. She practiced general pediatrics with Group Health Cooperative and has worked as a school physician, among other professional experiences.

(More about Dr. Holm's work in the next issue.)

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