

# THE GATHERED VIEW

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Shirley Neason, Editor  
26931 S.E. 403rd  
Enumclaw, Washington 98022

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

Gene Deterling, President

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## PRESIDENT'S MESSAGE

Those of you who were early members of our organization recall that it was originally called "Prader-Willi Syndrome Parents and Friends." It was named that because, in our naivete, we believed that only parents, professionals and other adults like ourselves could help Prader-Willi people. We have learned a little, however, now that we are in the adolescent phase of our organization, and we're now convinced that we have failed to call upon a most valuable source of assistance - other Prader-Willi people.

How else can we really learn how Prader-Willi people feel, what they really think they want, what they think they can do, what they think they can't do, and what they want us to do for them? We need to listen a lot more to the people we are trying to help so that we can truly try to understand the emotional, psychological and other motivational factors that influence their daily lives. As parents, we certainly believe we know our own children, but as persons who have lived "normal" lives, we too quickly formulate our own set of criteria by which we believe a Prader-Willi person should think, fear, love, hate, work, worry, and aspire to in life. I think it is time to become enlightened by those who do the thinking, etc., in their own lives. Most importantly, however, it is not only we parents, professionals and other adults like us who need to be enlightened; it is also the Prader-Willi people themselves. Our goal in this Association is to be a vehicle of communication, and beginning now, we hope to extend our communication to and between the Prader-Willi people.

We don't know how many of our readers are Prader-Willi people, but we know for certain that some of them are. We, therefore, want to encourage all of you who are, to write to us and tell us anything you want to say about yourselves or anything you want to discuss. We won't promise to publish everything, and we definitely won't publish your name without your permission, but we do promise to publish as much information as we feel is of value to you and your friends. If you think you would like a Prader-Willi pen pal with whom you can communicate, just let us know, and we will do our best to arrange that.

Please direct your correspondence to our home office at P. O. Box 392,  
Long Lake, MN. 55356.



**PRESIDENT'S MESSAGE (continued)**

We can take our hat off to the Australians. In the past several months we have seen a display of determination that we wish we could emulate. Some of our Australian members and some who are not have decided to form a local organization (and I use the word "local" loosely) in Australia. We are pleased to have been kept informed about their progress, and wish them the greatest success in their endeavor. Already they have begun publishing their newsletter, have been interviewed on the radio, have a potential TV interview in the works, have conducted a fund-raising campaign, and have too many other activities in the planning stages to mention in this writing. If you live in Australia or want to move there, be sure and contact Mrs. Pearl Simpson, 10 Hume St., Campbelltown 2560, N. S. W., Australia.

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We have already heard from a number of people who plan to travel over a thousand miles to attend our Annual Meeting and workshop in Minneapolis next June 29th and 30th. We haven't worked out all of the details yet because we have not yet received the funding that we hope to obtain and that is essential for the success of this meeting. Please keep the date in mind, though, and we will advise you about all the details as soon as we have them semi-solidified.

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In our September newsletter we indicated that we thought it would be a good idea to have some hand-out cards printed which could be shown to the waiter or waitress in restaurants and other eating places to alert them to the fact that our child does not need all of the extra calories that are so often served even with a child's meal. In response to that note, we were grateful to receive a set of printed cards as a gift from Brett Arnold the son of Mr. & Mrs. F. W. Arnold, in Hoosick Falls, N. Y. We have stapled one of these to each newsletter and hope you will find it helpful. These cards can be laminated for re-use.

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**THE GATHERED EXCHANGE**Adult Problems

As a young child, K. could not have been sweeter, more lovable. She is still so, under most circumstances, but we find as she has grown older (she is now twenty-five), her personality appears to change radically. She borders on hysteria if any fault or blame is ascribed to her. She doesn't get along well with her peers and tends to be something of a "loner." Weight control is also more difficult than when she was younger, although she does try to cooperate most of the time. However, "snitching" occurs now and then. We are worried about her future, as her father and I are past sixty-five. What knowledge exists about changing personality traits as the Prader-Willi individual grows older?

From Louisiana

RECIPE: Sour Cream

Combine in blender 1 cup cottage cheese and 2 tablespoons buttermilk. Blend on high until smooth. Dry onion soup mix may be added without significantly changing food value.



## THE GATHERED EXCHANGE (continued)

### Picking and Scratching

I've noticed a lot of reference to the children "picking." Our son had, until two weeks ago, a cluster of mosquito bites on each arm from last summer. He kept them open and sore all winter into this summer. I tried Aloe Vera ointment from the health food store (or perhaps you have your own plant.) I kept the ointment on and covered and we actually saw an improvement in two days. It was healed within a week! He still picks, but the speed of healing seems to get ahead of him. If other parents are as discouraged as we were, it's worth a try. It's also a wonder on burns. I'm told a few drugstores have an "Aloe Relief", which is probably the same thing.

From Montana

### Abnormal Saliva

A member wishes to know whether sugar causes a white foamy ring to appear around the mouth. She wonders if this could be caused by abnormal saliva.

### Picking and Scratching

I was happy to read about Kennilog. It helped our son's picking and scratching also. Thanks!!

From Massachusetts

### Recreation and Play

The story of "Rudolph the Red-Nosed Reindeer" is an excellent story for our children to view during its annual television holiday showing. This story of the little reindeer who is ridiculed for his difference, then finds a way to make an asset of his difference should be an inspiration to all who have to overcome odds to be accepted by others.

### Bullying

If your child is picked on by others, here are some suggestions:  
Listen sympathetically to your child, but don't censure the offending child.  
Try to deal with the problem unemotionally.  
Do all you can to help the child overcome the traits that make him/her the object of ridicule. Also try to have his/her dress, hairstyle, etc., in keeping with what others his/her age have.  
Build up his/her self-confidence by reinforcing a positive image and encouraging him/her to develop some special skills.  
Encourage friendship with at least one other child.

Gesell Institute

### Recipe: Calorie-Free "Snow Cones"

Boil down a favorite flavor of diet pop to half volume. Crush ice in blender to make one cup of crushed ice. Add  $\frac{1}{2}$  cup water to ice in blender. Run blender until ice looks like snow crystals. Drain and place in dish or cup. Pour two tablespoons of the "syrup" over the "snow".

### Handbook Correction

In the handbook, "Prader-Willi Syndrome--A Handbook for Parents," on page 36, where it says, "Be sure his physician...regularly tests his urine for sugar," it should say, "Be sure your physician regularly tests his blood sugar." The blood sugar test is more exact than the urine test in the evaluation of diabetes.

Adolfo P'erez Comas, M.D., Ph.D.



## THE PROFESSIONAL VIEW

The following was received in response to the parent who asked for suggestions to solve the problem of bowel control in an older child. Nurse Steinmann sent us her entire program; however, it was too long to be printed in its entirety in THE GATHERED VIEW. A self-addressed, stamped envelope with your request would be appreciated. (Note to the parent sending the original request: I cannot find your address in my files. If you will write again, I will send you a copy of Nurse Steinmann's program.)  
Dear Editor:

In the September, 1978, issue of GATHERED VIEW, there is a request from a reader for information about a bowel control program. Enclosed is a Bowel Control protocol and a copy of a bowel program outline that was successfully used with a nine-year-old moderately retarded male client in our clinic.

I was somewhat hesitant to send the protocol since I felt the reader could benefit from someone with a professional background--nursing, social work, or behavioral disabilities--to assist in setting up an individualized program to meet the child's needs. I would be willing to correspond with the reader if such a person is unavailable.

Mary J. Steinmann, R.N., M.S., Clin. Nurse Spec.  
Waisman Center, University of Wisconsin

## BEHAVIORAL TREATMENT OF PRADER-WILLI SYNDROME

by Barringer D. Marshall, Jr., M.D.  
Supervisor, Clinical Research Unit, Camarillo State Hospital

The staff of the Clinical Research Unit (CRU), Unit 45, at Camarillo State Hospital have developed an effective weight reduction program for young adult Prader-Willi (PW) residents. The program utilizes the standard hospital meal and the PW residents are taught to divide this meal into two parts, choosing and consuming no more than half of any portion. Initially (1) the staff divide and choose portions, then in successive phases the residents learn to (2) divide, choose, and consume one portion at a time, (3) divide and choose one portion at a time, but consume the meal only after all portions have been divided, and (4) divide the entire meal at one time and then consume it. Thirty seconds are allowed to divide portions. The entire program is monitored by the staff. The diet (desserts are excluded) provides approximately 1000 calories per day.

For taking too much time, or choosing the larger of the divided portions, the portion is forfeited except in phase 4, in which case the entire meal is relinquished. Ingestion of unapproved foods between meals results in loss of the next meal. No more than two meals may be missed consecutively. Residents are weighed weekly and ground privileges are contingent upon a one pound weight loss and no more than two violations of the meal program for the preceding week. The program, though apparently harsh, is necessary and potentially life saving for PW residents. Moderately severe respiratory distress, particularly severe after minimal exercise, has been a problem for all PW residents seen on the CRU. One had a history of congestive heart failure related to obesity and one had a diabetic glucose tolerance curve. The program is approved by the hospital Human Rights Committee on an individual basis only with the consent of the resident or the resident's parent, guardian or conservator.

Continued on Page Five



## BEHAVIORAL TREATMENT (continued)

PW residents also participate in an exercise program consisting of daily walks, extended to tolerance, and stretching exercises and calisthenics three times a week. They are trained to request positive social reinforcement for weight loss and to discriminate among high, medium, and low calorie foods. Urinary acetone determinations are performed weekly to screen for metabolic acidosis. Other aspects of the PW program, not necessarily related to weight reduction, include room cleanup and task performance in the CRU credit economy, grooming, bathing, table manners and efforts to reduce tantrums and self-abuse, usually skin-picking and gouging. Educational sessions have been held for the families with an effort to have the CRU program continued in the home during visits and after discharge.

The CRU now has had experience treating four PW residents, L.N., a male, 56 inches tall, lost from 180 lbs. to 100 lbs.; B.H., a female, 56 inches tall, lost from 170 lbs. to 90 lbs.; G.S., a male, 58 inches tall, lost from 234 lbs. to 96 lbs. Rate of weight loss varied among the four residents, but after 48 months of accumulated treatment has averaged  $7\frac{1}{2}$  lbs. per month. Duration of treatment may be from one to two years.

The greatest remaining problem is generalization of treatment. PW residents have generally made an excellent adjustment to the treatment program and have tolerated dietary restriction with little difficulty. Attempts to fade staff monitoring have been only partially successful, and it is likely that some degree of supervision will be required following discharge. The dietary program is highly exportable and potentially can be administered in the resident's home or in a Board and Care home. There appears to be a great need for a community based facility in California where PW residents may be referred for residence and maintenance of treatment effects.

Referrals are accepted from throughout California. Inquiries should be referred to Mr. Dennis O'Bosky, M.S.W., Unit 45, Clinical Research Unit, Box "A", Camarillo, California 93010; telephone (805) 484-3661, Extension 2241 or 2345.

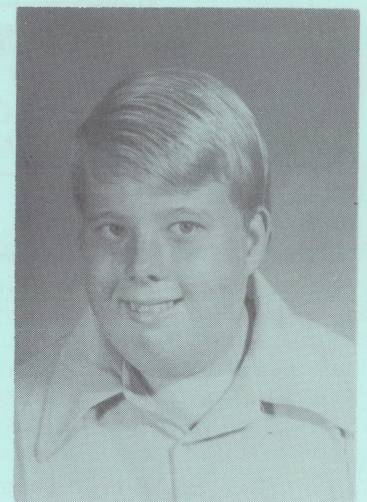
HEY! THAT'S GREAT!



Randy at two.

The recent article in Home Life was seen by a parent of a young person with Prader-Willi syndrome who had not previously known of the existence of our organization. Now we have a new member, and these are pictures of her son, Randy. Randy is 17, and has been on a research program at Mayo Clinic since he was 3. He has been on a ketogenic diet since 1972. His parents still keep the food locked up, but Randy is very understanding and even reminds them to lock it up at bedtime.

Randy is in special education and has learned to read and write, which his parents think is great, as they had been told he would never "have any mentality."



Randy at fifteen.



## GATHERED NEWS

### People First

In the Northwest people labeled as retarded have formed their own advocacy organization, People First. President Terry Hooton states that, "Our handicaps are secondary. When it comes to every day living, we want to be respected as an individual, not looked at as a disability."

A film recording the story of the first convention of People First has been made and is being distributed by Stanfield House, P.O. Box 3208, Santa Monica, CA 90403. It rents for \$35.00 and sells for \$300.00.

If there is a group of people in your area who would like to become more independent and speak for themselves, you can start a People First chapter. For more information, contact People First, P.O. Box 164, Puyallup, WA 98371.

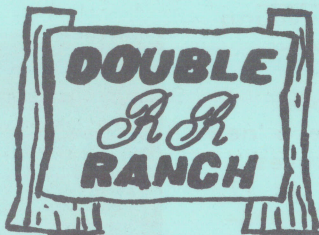
### To Live as Equals

The potential of the mentally retarded is the topic of a film entitled, "To Live As Equals." Narrated by singer Jerome Hines, father of a mentally retarded son, depicts such scenes as a jazz band, an infant stimulation program, and a retarded couple raising a normal child. Persons interested in showing the film may contact Lodon Films, 52 Undercliff Terrace South, West Orange, NJ 07052.

### Importance of Jobs

A recent three-year study at the University of Michigan shows that jobs are as important to the mentally retarded as they are to everyone else. The study shows that even severely retarded persons can perform productive and complex work. The program taught clients to drive tractors, operate pneumatic screwdrivers, and assemble 26-piece flush valve units. Parents of the clients involved were not only amazed at their accomplishments, but noted positive personality changes also.

## DOUBLE R R RANCH



Another camping season has come and gone at Double R R Ranch, and it has been a year of excitement and frustration.

As reported in July, Double R R Ranch acquired a new facility this year, a six and a half acre camp with cabins. The deal was not closed until mid-June, so that left little time to get the cabins, which were many years old and run down, in condition to house campers. The early campers were housed at the Double R

R Residential Component, while the cabins were being prepared for the larger influx of campers expected in August. As those who have had experience with this kind of work can understand, things did not go on schedule, and only two cabins were ready by August. However, since the cabin site offered the advantages of increased acreage and a more "camplike" atmosphere, the group was moved to the new site. A leak in a cabin roof a few days later put an end to that experiment, and the campers were transferred back to the residential unit which at that time did not have any permanent residents.

However, these problems did not mean much to the campers. They were having an exciting time. They went on several field trips and saw some unusual sights. During "Seafair," Seattle's annual festival, they got to go to the hydroplane pits to see the drivers working on their boats in preparation for the races. On a trip over the Cascade



## DOUBLE R R RANCH (continued)

Mountains they saw a real forest fire, and got to visit a large waterfall.

For next year, reports director Margo Thornley, there are plans to build a new dormitory and kitchen-dining room facility for the camp. The present cabins will be converted to activity centers.



One of the highlights of the reporter's annual visit to Double R R Ranch is picture-taking. The campers always demand that all their pictures appear in the newsletter. The above pictures are the response to that demand. These were the eight campers in residence on the day I visited, engaged in their favorite activity--lunch.

## GIFT-WRAPPING IDEA

Your child's finger paintings make good gift wrapping paper for special people like brothers, sisters, and grandparents.

## A VIEW OF WHO'S WHO

Introducing the newest member of the Board of Directors of PRADER-WILLI SYNDROME ASSOCIATION.

Richard J. Wett, M.D., a graduate of Marquette University School of Medicine, has been in the practice of anesthesiology in Minneapolis since 1962. He and his wife, Marge, have seven children ages twenty-three to ten years, including their Prader-Willi child, Lisa, aged thirteen.

Dr. Wett was born in Woodstock, Illinois, where he attended St. Mary's School prior to attending Marquette University. He and his family currently live in Edina, Minnesota.

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From a mother in Texas:

Caroline is 5½ now. The surgery that Dr. Dean MacEwen did on her at the duPont Institute in Wilmington, Delaware (see THE GATHERED EXCHANGE in the May, 1977, issue of THE GATHERED VIEW) was successful in keeping her hip in joint, and she has been walking for over a year now. She is not too sturdy on her feet yet, but is improving every day.

Someone asked about speech therapy. I have been taking her several times a week to the local university. She also has speech therapy at school (she is in the early childhood program). The quality of her speech is poor (too nasal), and she is about a year



## From a mother in Texas, Continued

behind in sentence structure. My "gut" feeling is that she knows a lot, learns readily, but for some reason has trouble spelling it back to us in a form easily understood. She recognizes all the letters of the alphabet, counts to ten easily, and we have had great success with the Tommy stories by Zedler--a process where a card with a picture that incorporates a letter in different color is shown the child. He traces the letter with his finger while a story is told that leads up to the proper sound the letter makes. We were really impressed with how quickly Caroline caught on and remembered. This should be a good start on reading readiness. Also, I can use it to help when she uses letter substitution; e.g. Uncle Wick instead of Uncle Vick. We have discovered that she is definitely a visual learner rather than an oral one. This may be inherited, as I certainly am.

Our main concern at the moment is that she has been 39½" for two years now; still weighs around forty-one pounds. She's pretty good about food. We went through a spell of her climbing up and getting into the breadbox, taking the bread back to her room, and squirreling it away under the bed. I've tried to be the same with her as I was with my other children when they were young. So she was spanked for this, but talked with also and it was emphasized that any time she felt hungry and had to eat to please come to me and we would find something for her to eat, which I do. She loves dill pickles, cantaloupe, etc., so we're pretty free with them.

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## Story of a 7-year-old from California:

C. was born May 23, 1971. I was forty, and so surprised when difficulty was experienced at birth, as my other two were quite easy. His breathing was getting weak, so they tried inducing, thereby depriving him of oxygen several times (a special machine monitored the contractions and his breathing, which indicated to them when oxygen was cut off.) He finally was taken by "C" Section. He was three weeks overdue, and, although the staff knew something was wrong, they led us to believe everything was O.K. Two days later the pediatrician broke the news. I had suspected throughout the pregnancy something was wrong, as the movement was very odd, so I didn't even break down.

He was very floppy--the only thing that moved was his eyes--and was tube fed. We brought him home when he was three weeks old (in spite of being told to admit him to an institution.) I tub-fed him every four hours around the clock. After a few weeks, I'd put a nipple in his mouth, working it in and out, tube-fed him, then put the nipple in again. In several weeks time, he got the idea, and we had a celebration when he drank one once in one hour's time. Soon he could drink the whole thing in a reasonable amount of time, and he certainly enjoyed the baby food when it was introduced into his diet.

He was diagnosed as cerebral palsy at three months and started to receive physical therapy. At eighteen months he attended a nursery school in connection with the Tichenor Clinic in Long Beach. They taught him to feed himself. Although he showed no weight problem at this time, we were advised to restrict his diet as his muscles were very weak; he had orthopedic problems; and if he ever was going to sit up, etc., he couldn't be heavy. He sat up at age three. Also on his third birthday he was enrolled in a public school in Fountain Valley, one of the first in the area to start working with handicapped children in a school that was basically for typical children. His advancement has been fantastic. He gets his physical, occupational, and speech therapy there in addition to the academic studies. He now can count to twenty, knows the alphabet, and the sounds, and they're starting beginning reading books. (He loves books, and will spend hours paging through them making up stories.)



## A VIEW OF WHO'S WHO (Continued)

Due to his orthopedic problems he has only been walking since the beginning of this year. He had surgery for a dislocated hip when he was four and surgery again when he was  $5\frac{1}{2}$  for an extremely turned in foot. We hated to see him have these surgeries, but we realize now that they may have been blessings in disguise, as he hasn't been able to get into the cupboard or refrigerator, or get food from other sources.

He was diagnosed Prader-Willi by Dr. Dumars of UCI in early 1976 when an observant social worker from Regional Center asked to get copies of all his records. Unknown to us, a doctor had indicated "possible Prader-Willi" as early as two years of age; Dr. Dumars verified this suspicion. He has so many of the characteristics: undescended testes, high pain tolerance, small hands and feet, speech problems (stutters occasionally and has a very high arch), although he is very verbal to the point of being very annoying at times by repeating the same thing over and over, short stature (43") and overweight for his height (50 lbs.), has worn glasses for about nine months and has one eye patched for amblyopia, and his saliva is foamy at times. He is happy most of the time, very friendly, and well-liked by his classmates, teachers, and therapists.

Present problems: (1) Since he turned seven, there are more frequent temper tantrums, not necessarily food related, but due to communication misunderstandings. At home we isolate him in his room, but in public it gets a little embarrassing at times. (2) We still have to diaper him at night and we haven't found an effective way of breaking this habit--maybe some other parents have suggestions. (3) Finding pants to fit such a short, fat boy. I'm beginning to get a complex about all the merchandise that I have to return to the stores.

My other children were eleven and thirteen when C. was born, and it had some negative effects on our older son who went through stormy teen-age years when my husband and I were trying to help C. through his surgeries, etc. On the other hand, our daughter had a more positive outcome. This fall she enters UCI with a scholarship to go into the field of child psychology, hopefully working with handicapped children.

P.S. I might add: C.'s birth weight was six pounds, fifteen ounces, in spite of being overdue. The other children were eight pounds, nine ounces and ten pounds, nine ounces. The ironic thing is that this third birth had a different doctor who kept me on a very strict diet and even gave me diet pills which seemed to make the baby draw together very tightly into a ball.

## GATHERED REPORTS

### Sussex, England

Here in England eight of us who are mothers of Prader-Willi children have started a correspondence magazine. We each write a letter and enclose it in a folder, and it circulates round all our families. When we receive it we take out our old letter and write a new one to put in. I enclose THE GATHERED VIEW for those who don't receive it, and I will also circulate the handbook when I get it. Then if the others want a copy they can send for one.

Reported by Helen Perrin

### Campbelltown, N. S. W., Australia

The Prader-Willi Association of Australia is really off to a flying start. Here are some of their activities as gleaned from a copy of their newsletter, THE OPEN DOOR:

They are busy raising funds through sales and raffles and through donations from businesses.

They are promoting the sale of the handbook recently published by our Association.



Campbelltown, N. S. W., Australia (continued)

A mother of a fifteen-month-old with Prader-Willi syndrome wrote that she is introducing no sweetening agents at all into her daughter's diet, and the baby is developing a taste for yogurt mixed with fruit.

TV and radio interviews, combined with publicity to the various hospitals and medical centers have made their existence known throughout the country.

The editor of the newsletter does not herself have a child with Prader-Willi syndrome. (I know her help is truly appreciated by the parents!--Ed.)

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We also received a copy of the minutes of the last meeting of the Prader-Willi Association of Australia, and here are some highlights from it:

A kindergarten teacher in Western Australia, who had taught a child with Prader-Willi syndrome, has applied for a scholarship to enable her to visit America to study the syndrome there.

Dr. Arabella Smith, who is in charge of the chromosome laboratory at Ryde Psychiatric Hospital is studying and working on new techniques available on the syndrome. Dr. M. Silink of the Royal Alexander Hospital for children in Sydney also offered help to the Association in providing more information to parents.

A fifteen year old boy with Prader-Willi syndrome died in Brisbane after surgery to try to help with his weight.

The total number of diagnosed cases that have reached the attention of the Association numbers fifteen, with letters from twenty parents whose children are undiagnosed, but show all the symptoms of Prader-Willi syndrome.

Seattle, Washington

At the last regular meeting of mothers on clinic day, October 4, it was decided that there is need for the parents of this area to organize it into a legal nonprofit corporation. The residential unit of Double R R Ranch was forced to close on October 1, because of lack of funds. Residents are living temporarily at WISER ACRES, but there was great need to get Double R R back in operation. Consequently, on October 10th, parents met with attorney Bill Dussault, who specializes in handling legal matters concerning the handicapped. After listening to his comments on what is required to begin and maintain the operation of a group home, the parents voted to organize as a nonprofit corporation and to ask Mr. Dussault to take care of the necessary legal papers.

The group did not feel that they would be able to get immediately involved in the operation of a group home, because they thought that such a small group of people would not have enough resources in time and money to do it effectively. However, they did feel that incorporation would get them in a state of readiness in case the way did open for them to sponsor a group home or camp.



## THE MEDIA VIEW

### Spanish Language Information

Many, many thanks to Dr. Adolfo P'erez Comas, director of the Medical Genetics Department and Pediatric Endocrinology Section of the Mayaguez Medical Center in Puerto Rico, who translated information on Prader-Willi syndrome into Spanish. If you would like a copy of this information, send your request to THE GATHERED VIEW. A self-addressed, stamped envelope along with your request would be appreciated.

### Books about Books

It is a puzzling task to select good books for children from among the endless numbers, both good and bad, offered on the market today. It is my opinion that the younger and less capable the child, the more care should be given to the selection of books for him to read or to be read to him. There are books to help us choose books, and here are three of them.

A Parent's Guide to Children's Reading, by Nancy Larrick, New York, Doubleday & Company, Inc., c1976.

This is an old standby that has been revised to include more recent books in its listings. Dr. Larrick has been a teacher, editor of children's books, and professor of education. She shows the parent how to become involved in helping the child develop reading skill and pleasure and choose books that will be of most value to him.

Children's Reading in the Home, by May Hill Arbuthnot, Glenview, Illinois. Scott Foresman & Company, c1969.

May Hill Arbuthnot's book more fully describes each book listed, telling something of the plot and the illustrations. One valuable feature is separate listings of books that will appeal to children who are not good readers, and also for those who read better than their peers.

Children and Books, by May Hill Arbuthnot and Zena Sutherland. Glenview, Illinois. Scott Foresman & Company, c1972.

For those who want a more thorough background in children's literature, Children & Books, designed as a college textbook, is valuable for all adults who are interested in bringing children and books together. This book goes into more detail concerning the history of children's books, the lives of authors and illustrators, and the selection of books according to children's needs.

Reviewed by Shirley Neason

## CHANGE OF ADDRESS

Please note that THE GATHERED VIEW has a new address. The editor moved recently, and, since THE GATHERED VIEW is published in her home, it has the same as hers. The new address is 26931 S. E. 403rd, Enumclaw, WA 98022. To avoid delays, please include the editor's name, Mrs. Shirley Neason, with the address on the envelope.



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 material is available free by writing to the Minnesota address:

- Bibliography on Prader-Willi syndrome
- Prader-Willi Syndrome-An Underdiagnosed Malady
- Synopsis of Prader-Willi Syndrome and the Association
- State Listings of Prader-Willi Syndrome Association Members
- Summary of Observations on Children with the Syndrome (University of Washington)

The following are available from THE GATHERED VIEW at the Washington address:

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

- "Informacion y Sugerencias para los Padres," a synopsis for Spanish-speaking parents. Free.

When ordering free material, please enclose a self-addressed, stamped envelope.

## PRADER-WILLI SYNDROME ASSOCIATION

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