

PRESIDENT'S MESSAGE

By now you should all have received a separate notice announcing our second national conference on Prader-Willi syndrome. Because of the importance of this event and the short period of time until the June conference, we felt we could not wait until the issuance of this newsletter to announce it. Although we had originally planned to hold the conference during the last week of June, we were forced to reschedule it for the third week of June in order to avoid the increased hotel summer rates which will go into effect a week earlier this year.

The East Coast, as a site for this year's meeting, has actually been in our plans for two years. Although we didn't know for sure that we would be able to hold a national conference in 1981, we felt it was important to at least conduct our annual business meeting on the East Coast in order to allow as many as possible of our Eastern members to participate. We have held our previous meetings in Seattle, San Francisco, and Minneapolis. This year's site in Hyannis, Massachusetts, on Cape Cod, has a lot to offer, both from a convention standpoint and pleasure standpoint. We're sure that a number of you will want to take advantage of this conference by combining it with some vacation on beautiful Cape Cod.

The formal announcement and agenda for the conference will be mailed out in April and will include a hotel pre-registration card which the hotel will need to receive by June 1st in order to guarantee the reservation. We will also advise you at that time about the other details of the conference, particularly the children's program.

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Our committees are very slowly beginning to take shape, but we are still shy five chairpersons and many volunteers to work on the committees. The establishment of seven committees to work on various programs related to Prader-Willi syndrome was proposed and approved at last year's board meeting, and we are still struggling to get them "off the ground." I am happy to announce, however, the appointment of two committee chairpersons for two of these committees. They are as follows:

Continued

PRESIDENT'S MESSAGE, ContinuedResidential Facilities

Mrs. Lois Olson
3771 Dennis Lane
White Bear Lake, MN 55110

Clinic Services

Dr. Betty Schultze
12935 Mason Manor Drive
Creve Coeur, MO 63141

Each of these individuals will be searching for volunteers to be part of their committees. They can't do it themselves. They need your help.

By far the most difficult problem associated with the operation of these committees (and our central organization for that matter) is the scattered membership. Although the lack of proximity is a major challenge, the fact that we have established a successful international association facing the same challenge is proof that it can be done. The second significant challenge is that of defining the charter and specific goals of each committee. There is very little directions being provided and maximum flexibility being allowed by our central office. We believe that with maximum freedom for ingenuity, the committees will develop constructive, innovative programs that will eventually be beneficial to all of our membership. We will need to be patient, however, as it will take some time for the committees just to get organized. Nevertheless, we're hoping that we will at least have some progress reports presented by the committee heads at our annual meeting this summer.

The remaining committees still lacking a chairperson are Vocational Training and Placement, Fund Raising, Respite Care, Recreation (Including Camps), and Promotion of Research. They simply will never be operational until someone steps forth to lead them. Please don't hesitate. We need you now.

Continued on Page Three

GATHERED REPORTSWashington: Seattle

Prader-Willi Association Northwest met on March 13. By common consent, Bert Holmes was appointed director and Shirley Neason secretary. Michael Soltman, director of Camp Orkila, a YMCA camp, was the speaker. He stated that he was willing to mainstream children with Prader-Willi syndrome into a one-week camp for 8-12-year-olds (older P-W children would be accepted if it were deemed that they fit developmentally into this group.) Campers would be carefully screened for suitability, and would be housed at the ratio of two P-W children in a cabin with six normal children and one leader (a trained adult). Cost of the camp is \$88. Only P-W children who have been through the clinic at the Child Development and Mental Retardation Center of the University of Washington will be considered.

After Mr. Soltman's talk, it was reported that Gold Creek, a camp owned by King County (Seattle area), has been made available to the group for the last three weeks in August. It was agreed that we should pursue the organization of a camp for Prader-Willi youngsters at this location, and an interview committee was appointed to secure a director. It was estimated that the total cost of operating the camp would be \$125 per week per camper. Bert Holmes indicated that he would begin immediately to search for sources of funding.

Further information on either camp may be obtained by writing THE GATHERED VIEW.

Reported by Shirley Neason

PRESIDENT'S MESSAGE, Continued

The following is our 1979 financial report. As in all our previous years, we have managed to squeeze out a meagre gain. As you can see, however, by the \$2679.80 cash on hand, we are still operating on the thin edge. It's only through the generosity of your donations that we are managing to "keep our heads above water." It should be obvious we must rely on your continuing support.

Financial Report - December 31, 1979

PRADER-WILLI SYNDROME ASSOCIATION

Receipts

Membership dues	\$3785.44
Donations	2857.95
Handbook Sales	433.60
National Conference	3167.42
Savings Account Interest	121.40
	<u>\$10,365.81</u>

Expenses

Salaries	\$3000.00
National Conference	3342.52
Printing	1725.59
Postage	516.82
Computer Service	368.41
Fund-Raising Seminar	370.00
Office Supplies	260.69
Secretarial Service	207.00
Unemployment Insurance	40.10
Currency Devaluation	21.36
Telephone	10.50
Miscellaneous	149.33
	<u>\$10,012.32</u>

Net Gain/(Loss) for year	\$353.49
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Cash on Hand, December 31, 1979	\$2679.80
Cash on Hand, December 31, 1978	\$2326.31
Net Increase/(Decrease) in Cash on Hand	\$353.49

GATHERED REPORTSCommittee On Clinic Services

The Committee On Clinic Services has started to function. I hesitated to begin until I had some confirmation about committee memberships, but I have started or else there would be little done by June. Two St. Louis members are helping me. I have been writing letters (71 at present) and have begun to receive information. Our next step is that of organizing it, but I think we have that worked out.

Reported by Betty Robb Schultze

THE FUND-RAISING VIEW

by Marge A. Wett

FIRST THE GOOD NEWS AND THEN THE BAD...

Although we are still receiving donations to our membership fund drive, I thought you might like a report of the results. The good news: we have received over \$1900.00. Then the bad news: it came from only 51 members.

Maybe I expected too much, but I feel our pleas for help and funding have had disappointing results. Everyone is busy, inflation has hit, but the Prader-Willi organization needs YOU and your support.

We greatly appreciate all of you who did generously respond to our plea, and of course all of you who have contributed in the past.

One result of your gifts is the printing and mailing of our updated literature, which should be out around the end of March.

Let's hope for more good news!

ANY I.B.M.ERS?...

It was suggested by one of our members that employees of I.B.M. can apply for a \$1,000.00 grant for handicapped children. This is available to employees only. If any member is an employee of I.B.M., please write to me.

A LETTER FROM CANADA...

Enclosed is a cheque for \$10 as a donation re your request for help. It is signed by me, but is a donation from my three-and-a-half-year-old Prader-Willi son, David.

Since P.W. knows no territorial boundaries and affects children everywhere, this money is given with a plea for our Canadian Prader-Willi children (undiagnosed). There are too many medical doctors who do not know of P.W. syndrome. I have introduced P.W. to far too many in our travels and for a P.W. parent that is frightening. Please include Canada as a part of your "drive to educate."

Perhaps you can make a special request to your Canadian members in the next GATHERED VIEW to support the additional cost for educating our medical doctors.

Please keep up the good work. THE GATHERED VIEW is very important to parents. It is our bridge off of a remote island in an often cold sea.

GATHERED NEWSResidential Services

Role of parents and relatives in alternative living programs is explored in a 3-part series of articles carried in Alternative Living Programs, a project newsletter of the Indiana State Developmental Disabilities Council, Grant Blackford Developmental Center, 2724 S. Carey St., Marion, IN 46952.

P.C.M.R. Newsbreak

HEY! THAT'S GREAT!



This is Darren, age 11. Darren's weight is just right for his age and height, and he is proud of it. Last summer he was on the local swim team. He can only swim one length, but he earned ribbons at nearly every meet because there weren't that many others who were out there working for the ribbons. Congratulations, Darren!

Darren also takes organ lessons and got a trophy at his last recital.

Darren's mother writes, "He is sheer joy to our whole family and gives so much of himself, and this is what makes it all worthwhile. We have gone through frustrating and depressing times and even felt like we wished we could escape from it, but we have a deep trust in God and know that He has Darren in the palm of His hand. He cares about Darren's future, and guess what—Darren will be a success!"

"SPECIAL LITTLE GIRL"

There's a special girl in our house;
She is our pride and joy—

Our fifth baby, all dimples and curls.
The family complete—two boys, three girls.

She brought with her from heaven above
The real true meaning of family love.

She did not develop as most children do;
From six months to a year she hardly grew.

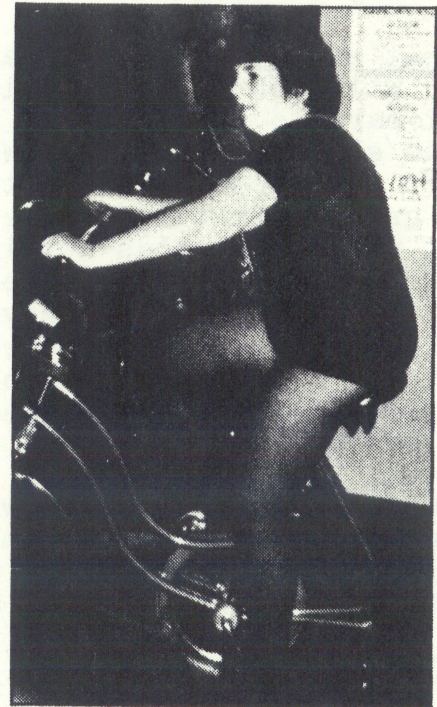
A reason for this they could not find;
Bewilderment and wonder remained in our mind.

"Time will tell," the doctors would say.
Obvious improvement day by day.

Over the years, as progress was made,
Her inabilities were beginning to fade.

After twelve long years, the answer not known,
The search did end—it's Prader-Willi syndrome.

From the sea of hopelessness there cast this lovely pearl.
'Twas the hand of God that sent us our "Special Little Girl".



Danielle Ledoux
Age 14

By Cellie Ledoux 3/21/79

THE MEDIA VIEW

Dear Abby,

"Dear Abby" recently published a letter from a mother of an overweight boy ^{who} ~~that~~ ate "everything". Her advice, of course, was to talk to a doctor. This prompted me to start a campaign to flood Abby with letters that this child may be a Prader-Willi syndrome child, and ~~her~~ ^{his} doctor may not know it.

Whether others did the same thing, or our local campaign was successful, I don't know, but I do know we received a call from one of Abby's staff and then a personal note from Abby herself. She is going to write something in her column about Prader-Willi.

Naturally, we will be flooded with letters from non-Prader-Willi people, but hopefully we will reach hundreds of people who are searching for help. As my husband (Richard Wett, M.D.) said, "More doctors read Abby than medical journals."

The opportunity for this publicity is tremendous. Thought you'd all like to share my joy.

Marge A. Wett

Let's Play to Grow.

Let's Play to Grow is a kit with a parent's manual, eleven guides to doing things with your special child, a chart to record the child's activities, and a post card to send in when he completes the chart. In return for the post card he/she gets, free, a "Winner's" patch and another chart to fill out to send in for another free patch. The kit is designed to be used in the family or in group activities. The guides show how to develop the child's skills bit by bit until he builds ability and confidence. Included are guides to infant stimulation, creative movement, creative activities, large motor skills, outdoor fun, water fun, and several types of ball games.

The philosophy explained in the parent's manual: "The special child is a blessing. It is our work to celebrate his life, his spirit, his right to grow, to be who he is. These pages will tell us with simplicity and joy how we might begin."

Let's Play to Grow is well worth the cost and is appropriate for children, teenagers, and probably even adults with Prader-Willi syndrome. To order, send \$2.50 to Let's Play To Grow, Joseph P. Kennedy, Jr., Foundation, 1701 K Street, N.W. Washington, D. C.

Reviewed by Shirley Neason

Woman's Day

The March, 1980, issue of Woman's Day contains a "Collector's Cookbook" entitled "Trimming the Calories From Favorite Recipes. In addition to recipes, the insert contains many helpful hints on how to trim calories from every type of dish, and how many calories you'll save by following their hints. The stated purpose of this tear-out booklet is to make the techniques and substitutions suggested as routine as cooking without them once was. I tried the "Poached Fish Creole" and my family really liked it--a big plus, as I have found few low-calorie fish recipes they like. (I don't cook separately for my Prader-Willi child; we all "eat slim", and just eat larger quantities if we need more calories.)

Reviewed by Shirley Neason

A VIEW OF WHO'S WHO

This is the story of a one-year-old (at the time her mother wrote), herein called L.

L was born breech August 17, 1977, weighing six pounds, one ounce. She was my second child and I'd been told every pregnancy is different, so didn't think anything was out of the ordinary until toward the end of the pregnancy, when I began to get very nervous and fearful. I had felt little or no fetal movement, and just felt this baby had something wrong with it.

Although L had a sucking problem and was losing weight, I was reassured by both my obstetrician and pediatrician that she was normal for a newborn. We brought L home. One week passed, and I could see her weight loss. I was nursing her and knew she had no suction.

Then it all began. We took her to the pediatrician and he put her in Children's Hospital. She was so close to death by the time they started tube feedings that my husband and I never thought she'd pull through. She had every kind of test and in five days we had a hospital bill of over \$4000 and no diagnosis. They concluded there was some insult to the brain, although all brain tests came out normal, as did all other tests.

L was floppy, slept constantly, and never cried. We tube fed her every three hours for two and a half months. She finally started responding to us and her surroundings. When she was three months old we saw the geneticist the second time. My husband mentioned that L had extremely small feet. Something clicked in the doctor's mind and he got out a textbook. The page he showed us was on Prader-Willi syndrome.

We had our diagnosis. Now what? The doctor offered no help as far as clinics or other parents, although he had two other Prader-Willi children in his practice. He told us all that really needed to be done was a little mental stimulation at age two, and when the hunger started, diet pills. We went home thinking it wasn't so terrible if that's all there is to it. But the more I thought about it, the more I was convinced that there was a lot more.

I obtained some research^{MATERIAL} from the University of Minnesota that Dr. Hans Zellweger had done and was convinced my only hope to help L was to get her to this doctor. He practices in Iowa City, where my husband had attended college. I had an old Iowa City phone book, and looked up Dr. Zellweger's number, praying he'd still be there. I reached him and set up an appointment for February 1, which turned out to be the day of the blizzard of the year. Dr. Zellweger was so helpful; he covered all aspects of the syndrome and put L on a strict diet along with a behavior modification program. He also recommended therapy and the Infant Stimulation program at Myers Rehabilitation Center in Omaha.

L is presently enrolled at Myers and has been in Infant Stimulation classes since she was seven months old. She sees Dr. Zellweger every four to six months. She is doing very well. She has stopped tube feedings and started to hold her own bottle. She weighed 13 pounds, 12 ounces at one year.

L is very special to us. She's a darling little redhead and so good, so easy to enjoy and love. I know we have a long road ahead, and we need all the support we can get. I'm determined to devote everything I have in me to make her life happy and healthy.

10 GUIDELINES FOR LIVING WITH A PRADER-WILLI CHILD

1. Accept your child's limitations. Be tolerant and patient.
2. Provide opportunities for the development of muscle tone--long walks, for instance.
3. Keep home life organized. Keep mealtimes, chores, and bedtime as consistent as possible. Household routines help him accept order.
4. Avoid fatigue. Exhaustion can break down the child's self-control.
5. Avoid gatherings where the child's behavior would be inappropriate and embarrassing.
6. Maintain firm discipline through a few simple, clear, important rules--with others added only as needed. Avoid unnecessary rules and constant "Don't do that."
7. Enforce discipline by sending the child to a quiet room.
8. Build up his ability to retain information in his memory. Read to him, color with him, play games of gradually increasing difficulty. Matching pictures is an excellent way to train his memory. Don't have so many toys around that they distract him.
9. Protect the child against overreaction by neighbors. He must always feel accepted by his family.
10. Get away from time to time by having a babysitter in, taking turns between parents, and by sharing the responsibility for the child's care.

Adapted from "10 Guidelines for Living with a Hyperactive Child"
from Pediatrics.

THE PROFESSIONAL VIEW

Recipes by Nancy Couhig, R.D., Nutritionist at the Child Development and Mental Retardation Center of the University of Washington.

TUNA BURGERS

$\frac{1}{2}$ cup water pack tuna
(or well-rinsed oil pack)
Crust of one slice of bread
Dash parmesan cheese
Dash pepper.
1 teaspoon parsley flakes
1 egg.

Mix ingredients well. Form into three patties. Broil under slow broiler about 6-8 inches from broiler, or bake in a pan sprayed with no-calorie vegetable coating.

Calories per serving: 72
Calories per serving with bun: 161.

PORK-FRUIT CABBAGE DINNER

4 pork chops (about $1\frac{1}{2}$ lb.)
1 teaspoon salt
1 teaspoon pepper
2 lbs. cabbage, shredded
(about 2 cups raw)
2 medium apples, peeled, cored,
and sliced
4 medium pitted prunes
2 beef bouillon cubes
1 cup water

Trim fat from pork chops. Spray large skillet with nonstick coating. Brown chops. Add remaining ingredients. Cover tightly and simmer 20-25 minutes or until tender. Garnish with parsley. Four servings.

Calories per recipe: 1242
Calories per serving: 310

MENUS FOR A MEASURED DIET

800-Calories Per Day Menu

Breakfast:

1 medium egg	72
$\frac{1}{2}$ cup strawberries	27.5
8 ounces nonfat milk	80

Lunch:

2 ounces roast beef	103
1 cup string beans	31
1 small tomato	20
8 ounces nonfat milk	80
2 medium plums	33

Dinner:

Shrimp Creole:

2 ounces boiled shrimp	128
$\frac{1}{2}$ cup stewed tomato	31.6
$\frac{1}{4}$ cup cooked carrots	12
1 Tablespoon mushrooms	0
1 Tablespoon onion	0
$\frac{1}{2}$ cup cooked rice	93
$\frac{1}{4}$ cup cooked celery	21
1 cup broccoli	40
$\frac{1}{2}$ cup diet gelatin	8
1 small peach	38

For 1000 calories, add:

Breakfast:

1 slice toast with 1 tsp margarine	100
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Lunch:

1 ounce cheddar cheese	104
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For 1200 calories, add all of the above, plus:

Dinner:

1 ounce shrimp	64
8 ounces nonfat milk	80

Recipe: Shrimp Creole

Combine shrimp, tomatoes, carrots, onion, mushrooms and simmer for 15 min. Serve over rice.

INFORMATION FOR COMMITTEE CHAIRMEN

A good source of information for our seven committees is the regular bulletin sent out by the President's Committee on Mental Retardation. The P.C.M.R. Newsbreak gathers news from around the the country about what is going on in the fields of residential living, education, vocational training, etc., all areas covered by our committees. The committee chairman can write and ask to be placed on the mailing list. The address: President's Committee on Mental Retardation, Department of Health, Education, and Welfare, Washington, D.C. 20201.

THE GATHERED EXCHANGE

Residences

Concerning group homes, I am not able to financially afford transportation to areas that might develop these homes, so I can't be interested. The need is certainly great, but I could never place my child where I would be so limited in contact for so long a time. I'm sure the contact with others with similar problems and the social acceptance she would receive would help in many ways.

Mississippi Member

THE GATHERED EXCHANGE, ContinuedBreathing Problems

Would like to add what happened to my son with the problem of sleep. The term they called his problem was obstructive sleep atnea. It was lack of oxygen caused by a blockage in his upper throat. He now has a tracheostomy and has oxygen at night. He seldom sleeps daytimes now, even though the trach is plugged daytimes, so he can talk. Nights he used to wake up several times. The doctor said this was because when he couldn't get enough oxygen, he would wake up and sit up and the oxygen would start flowing again. I would say to anyone who has a child with this problem: have the doctor check it out before they get as bad as my son. There may be other ways it can be corrected if caught in time.

New York Member

Diet

A low-calorie product is Thinny-Thin Dietary Frozen Dessert. It has only 18.5 calories per fluid ounce and contains no saccharin or artificial sweeteners. Available in five flavors: vanilla, chocolate, coffee, strawberry, and mint, it is distributed by Carvel's Ice Cream. They also have Thinny-Thin Cakes, which they will decorate for birthdays and other occasions.

Minnesota Member

Health Problems

I wanted to tell about our experience in August. Our PWS daughter had complained of stomach ache several times over the summer and even more during the weeks of swimming lessons. She continued to go and participate, but her interest in eating grew less; she spent most of her time "resting." This went on about two days. Her appetite grew worse, and I was sure she must be really sick. I took her to the emergency room on Sunday, August 26. With the help of the material I have from the PWSA, I convinced the doctor she really was sick. (She did not appear sick.) She entered the hospital and after two days of testing, they operated for gall stones. Much to the surgeon's surprise, she was having an acute attack when he got in. It was diagnosed as chronic and acute gall bladder disease and gall stones. She was back home in three days and able to eat anything. She even went swimming in ten days. I would never have believed her ability to endure pain if I had not experienced this with her. If I had not read the account of the child who died from ruptured appendix (THE GATHERED VIEW, May, 1978), I would never have been aware of her possible acute situation so I could take her for medical help. This article was also the factor that caused the doctor to act immediately.

Mississippi Member

Education

Our son is ten years old, in fourth grade in public school, maintaining his weight on 1000 calories per day. He has sensory integration therapy and benefits from lots of exercise and recreation.

California Member

Recreation

I'd like to recommend to parents with young P-W children to start them swimming as young as possible. D can't play sports like baseball, football, etc., because of poor muscle tone, and even has problems with simple skills like hopping and jumping, but in the water he can bounce, jump, and swim with the best of them. We've been working with him in the water since he was a baby.

Illinois Member

THE GATHERED EXCHANGE, ContinuedTreatment and Medication

I would like to send information from my daughter's medical records to other doctors who are doing research on Prader-Willi syndrome, but I don't know to whom I should send them. Her treatment with hormones and cortisone seems to be helping so much that I would like to share it with someone. I have received only one questionnaire concerning her in the time I have belonged to the Association, and this was before the convention. Being so isolated from other cases and dealing with doctors who are not necessarily interested in what has been found by those with more experience in this field leaves me confused and uncertain as to how to handle this.

(Editor's note: Any professional who would like this information, please write to THE GATHERED VIEW, and we will forward your request to this member.)

Temper Tantrums

We have found my son's temper tantrums to be caused from sugar. I can tell now if he has had anything with sugar because he becomes a totally different personality. I do wish they could find something to counteract the sugar rather than just wait for it to get out of their system. Within a day it is usually gone, but we can have a few bad hours before a new day. I will be happy to hear from others with similar problems.

New York Member

o The Mother of K (A View of Who's Who, January-February, 1980)

Thank you for sharing yourself with us. Everything you described, all of us with P-W children have gone through or will to one degree or another. I felt alone so long (my daughter is 28). I was drinking a little too much, although taking care of my family. I studied the Rosicrucian philosophy, which was a help, then I took a course in psychic Phenomenon from Mr. Bam Price. He has a T.M. weekend, in collaboration with Edgar Mitchell, who wrote the book, Psychic Phenomenon. Revelation is what it is progressing to do for me. I also took a class from Dr. Milan Ryzl of U.S.C. He will be travelling the U.S. soon teaching Reincarnation and Karma. Some may feel it could be straying from Religion per say, but I feel closer to God and Christ, and through training and meditation hope to proceed from there. If we all gathered in a circle and put our troubles in the middle, it is likely we would choose our own. I have a friend with seven children, four of whom are severely retarded; her husband died recently, and she has a smile on her face and hugs for her children. Another lost a retarded boy of her own, then adopted a boy who later turned out to be severely retarded. She loves him and smiles thru it all. I had to learn to enjoy life in spite of the problems. I haven't got it made, but what a joy working on it. I hope this note is a help. My most difficult time was when my daughter was the age of yours. I tried to help her find other goals than the "Social Norm," which is changing so fast, who knows what it is?

Mother of B

Annual Conference

I would like to thank all who worked so long and faithfully to make the Minnesota convention possible. It meant so much to me and I'm sure to everyone there. I am looking forward to attending at Hyannis, if I possibly can, and to bringing my PW child with me.

Mississippi Member

THE GATHERED EXCHANGE, Continued

Recipe: Parfait

- 2 ounces orange juice
- 5 ounces plain nonfat yogurt
- 1 teaspoon gelatin
- 1 egg
- Artificial sweetener to taste

Method: Dissolve gelatin in orange juice over medium heat. Cool and add yogurt. Chill until partially set, then whip the white of the egg and fold into the yogurt mixture along with the sweetener. Chill until set.
Australia Member, Reprinted from The Open Door.

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, 5515 Malibu Drive, Edina, MN 55436.

A booklet entitled "Prader-Willi Syndrome--A Handbook for Parents" is available. The cost is \$2.00 for the first copy to members, \$3.50 for nonmembers and subsequent copies to members. Order the handbook from THE GATHERED VIEW, 26931 S. E. 403rd, Enumclaw, WA 98022.
