

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 2

PRESIDENT'S MESSAGE

There remains ahead a great deal of activity to finalize our agenda for our annual meeting on June 29th and 30th. We have not yet heard from all of the people whom we have requested to present papers; however, we expect to have some key speakers such as Vanja Holm, M.D., and others from the University of Washington, Margo Thornley from WISER Acres & Double R R Ranch, Bryan Hall, M.D. from the University of California, H. Zellweger and J.W. Hanson, M.D. from the University of Iowa, A.B. Hayles, M.D. from Mayo Clinic as well as a number of others who will address the fields of dietary management, behavioral modification, education, and residential treatment. The response from our membership has been very encouraging so far with over 75 members already indicating they plan to attend this conference.

Our plans are essentially unchanged for the meeting with the exception that we have now decided to hold it at the Leamington Hotel in downtown Minneapolis rather than the Marquette Inn in order to allow ourselves greater flexibility for increased attendance. We will be sending announcement and pre-registration forms out in April and hope to attract a number of professionals and other interested persons to this first-ever open conference on the subject of Prader-Willi syndrome.

The Minnesota group which will be hosting the conference has been meeting regularly to organize the details. One of the more difficult tasks ahead is to work out a program for the children and young adults (including Prader-Willi people) who will accompany their parents to Minneapolis. A formidable task though it is, we are confident that, with the understanding and cooperation of the visiting parents, we should be able to make this a pleasant and memorable event for all.

If you haven't already given serious consideration to attending this meeting, please do so and let us know as soon as possible so you can be assured of accommodations. If any of you would be interested in presenting a paper or sponsoring any appropriate activity at this conference, you would be welcome to submit an abstract. Just contact us here at our home office as soon as possible, and we will advise you whether we can fit it into the program. Although we expect to announce our planned agenda in April, we will remain flexible as late as possible. Since this is our first attempt at such a conference, we know that even the best laid plans will have to leave room for better ideas the closer we get to June 29th.

THE PRESIDENT'S MESSAGE, Continued

A number of our members are concerning themselves with the problem of establishing group homes in various parts of the country. Programs like this take a long time, so we can't expect immediate results. In California, for example, a parents group held a meeting on March 18th for the express purpose of discussing the establishment of a group home. A number of noted authorities on Prader-Willi syndrome and residential facilities were invited to speak at this meeting. We did not have the results of the meeting at the time of our publication, but those who would like further information may contact Cal Menzer, 11750 Sunset Blvd. #124, Los Angeles, CA 90049.

The following is our financial report for 1978. Although it appears we have a favorable financial position, in actuality we are continually concerned about our survival. As should be obvious from the report, if it were not for the donations received in 1978, we would be operating at a loss. We are dependent upon the continued generosity of our membership in order to perpetuate and expand our organization.

FINANCIAL REPORT

Prader-Willi Syndrome Association
Receipts / Expense Statement - December 31, 1978

Receipts

Membership Dues	\$2,923.35
Donations - Miscellaneous	2,559.00
Donations - Handbook	934.84
Savings Account Interest	<u>21.37</u>
	\$6,438.56

Expenses

Salaries (Secretary and Editor)	\$1,500.00
Handbook Publication	1,053.67
Donation (to WISER Acres)*	1,000.00
Publishing & Printing (Newsletter plus General Printing)	680.03
Postage	460.41
Office Equipment & Supplies	199.60
Computer Service (Including Address Labels)	196.60
Office Equipment Maintenance	134.80
Miscellaneous	74.10
Telephone	67.40
Outside Services	51.00
Currency Devaluation	<u>14.31</u>
	\$5,431.92

Net Gain / (Loss) for Year	\$1,006.64
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*Private Contribution Designated for WISER Acres

Cash on Hand December 31, 1978	\$2,326.31
Cash on Hand December 31, 1977	<u>\$1,319.67</u>
Net Increase / (Decrease) in Cash on Hand	\$1,006.64

GATHERED REPORTS

Australia

THE OPEN DOOR, Newsletter of the Prader-Willi Association of Australia, has a new editor. Wendy Birkin, the former editor, was no longer able to serve, and was succeeded by Marie E. Penny. The newsletter is published in Campbelltown, N.S.W.

The Prader-Willi Association of Australia has now obtained official recognition as a Registered Charity.

Dr. C. Clarke, a psychologist at the University of New South Wales wishes to carry out some behaviour modification programmes within the family situation.
from THE OPEN DOOR

Seattle, Washington

For the next four months, parent meetings will be held on Prader-Willi Clinic day at the Child Development and Mental Retardation Center of the University of Washington. These meetings, which will focus on exercise and progressive relaxation, will be led by Judi Leconte, M.S.W., and Paula Carman, M.O.T., O.T.R. The March and April meetings will deal with exercises. Both meetings will be basically the same, as a different group of parents is expected at each meeting. Likewise, the June meeting will be pretty much a repeat of the May meeting, which will deal with progressive relaxation. Parents planning to attend any of these meetings are asked to wear casual, comfortable clothing, as the parents will learn by doing in order to teach their children. In addition, it is hoped the parent will find the exercises and relaxation fun and profitable for themselves.

In addition to this planned program, there will be food ideas available and there will also be time for parents to exchange ideas.

The meetings are planned for 10:00 a.m. on the first Wednesday of each month. Parents whose children do not have appointments on those days may come just for the parents meeting if they wish.

GROUP HOMES HAVE NEW GOVERNING BODY

Camelot-Carlton Center for Exceptional Children, pioneers in establishing group homes for the mentally retarded, will become the governing body of WISER Acres and Double R R Ranch Residence as of April 1, reports Margo Thornley.

Mrs. Thornley, founder of Camelot-Carlton and its executive director for the ten years of its existence, felt that having a long-established umbrella nonprofit corporation as the governing body would be of primary benefit to youngsters and adults with Prader-Willi syndrome.

The Board of Directors has launched a building program and plans to build or rehabilitate three homes by 1981 and establish a treatment center. WISER Institute will provide vocational training for persons with Prader-Willi.

DOUBLE R R RANCH CAMPING PROGRAM

The Double R R Ranch camp unit will offer a summer camping program for young people with Prader-Willi syndrome from June 10 until August 25. Information and registration forms may be obtained by writing Margo Thornley, Director, Double R R Ranch, P. O. Box 578, Bothell, WA 98011.

A VIEW OF WHO'S WHO

Here is the story provided by one of our members of a young man (herein called N) with Prader-Willi syndrome.

"My son was born in 1951--listless, weak muscle tone, couldn't swallow--he was in the hospital seven weeks and fed with a tube. When he came home I force fed him for two months until he was able to suck the bottle himself.

At eighteen months we took him to the University of Minnesota. He spent three weeks in an intensive examination. A dentist recognized the appearance of N as something he encountered in the east. He contacted a hospital there and came up with the Prader-Willi diagnosis. The only advice at that time was not to put him on too strict a diet because he would become like an animal--sneak food and eat anything he could get, even garbage!

N attended private school for three years. At seven he attended the local special ed class. This class was started through the efforts of the local Association for Retarded Citizens. He made some progress in reading and writing. Now he reads the newspaper, writes beautifully, and can handle money.

At nineteen he entered the Vocational Training Center (another spinoff of the local ARC), in the sheltered workshop. They have an excellent staff, who struggled with N's stubbornness, slowness, temper tantrums, etc., not knowing exactly what his problem was. I have given them the information gained from the Prader-Willi Association, and they have been delighted to have something to work with. In December, 1976, N weighed 300 pounds. His counselor began weighing him twice a week and his doctor started him on an 800-calorie diet. He lost very slowly and not until I cut the calories to 750 did he show much weight loss. He was told at the center that if he gained over five pounds in one week he would be fired until he lost the pounds. He was fired three times. He is not allowed to shop by himself or carry any money with him. Up to this point he had shopped by himself, and, of course, ATE while shopping! He now weighs 250 pounds, has matured a good deal, and does a good job of regulating his own meals as far as calories go--knows what he can exchange for what, etc. However, he still needs to be watched as a handy open jar of peanut butter, cheese, sweets, etc., is too much for him to resist and he will still sneak food when the opportunity arises.

N and our family have come a long way since 1952, but only since I joined the Prader-Willi Association have we truly realized the battle N has been fighting, and the reasons for his temper tantrums, etc. Had we had this information when he was younger, we could have avoided many of his emotional problems, and would not have let him gain 300 pounds. Also we would have spent more time on his physical condition (demanded more exercise, saw to it that he walked more, etc.) instead of concentrating on his academic ability.

The Association for Retarded Citizens has been a great help to us, although they had no information about Prader-Willi syndrome until recently. It would be a good place for parents to start if there is no Prader-Willi group near them. It would be one way to educate people about Prader-Willi Syndrome."

A VIEW OF WHO'S WHO, Continued

During our first year of publication, the WHO'S WHO column featured the story of Christopher, who lives in England. His mother later sent an update, and here is a further update, along with a picture. Christopher was born in February, 1967.

"Last December (1977), Christopher was taken ill with what at first appeared to be a badly infected throat. He was also delirious. Doctor prescribed penicillin and said he should improve with that. Instead he got much worse. He didn't know us for three days.

Doctor came again and didn't know what was wrong. His temperature dropped and he just sat huddled in a chair. He wouldn't look at us or talk to us. I had to feed him, as his hands were shaking so badly he couldn't hold a spoon.

This had gone on for a month when he was admitted to a hospital for tests: blood tests, brain scan, x-rays, which didn't show anything. He then had an EmiScan which also didn't show anything. He was then put on Artone and later Sinemet which gradually stopped the shaking and rigidity in his muscles. He had trouble swallowing, and I had to liquidize his food for some time.

Slowly he became more himself, the happy child he was. In June we tried to reduce drugs, but he slowly went back into his shell. We increased the drugs and he became more himself. We were told later that the illness he had left a form of Parkinson's Disease. He began to get much better.

One night near the beginning of October, he seemed perfectly all right when he went to bed. He woke about 10 p.m., gasping for breath. We called the doctor. He was quite baffled once again. He seems to think that Chris must incubate things, and it just doesn't show until it is critical.

He gave him various medicines. Chris slept all night and his breathing was perfectly all right next day. He seems quieter again now, but he never was back to his bubbly self. He always enjoyed being taken out, and the more people we had in the house the better he liked it. Now he doesn't seem to care what is going on around him.

I am sending a photograph of Chris which was taken a little while before his last illness, a school photograph. I was quite surprised when I saw it. He looked just like he used to.

My husband and I would like to thank all the people who make THE GATHERED VIEW such a success. Our doctor is always interested to read anything which might help medically. We have a wonderful doctor who always has time to listen to our troubles and was a tower of strength to me during Chris's long illness.

A year ago Chris got a new headmaster at school. He has changed the school entirely, and the children are taken all over the place on various visits. Christopher has just been to Blackpool (a seaside) for three days with a group of children, and it was a great success."

THE PROFESSIONAL VIEW

Here are a couple of questions sent in by readers, with answers by Vanja Holm, M.D., of the Child Development and Mental Retardation Center of the University of Washington.

QUESTION: Do you have advice on growth hormones for pre-adolescents or adolescents with Prader-Willi syndrome?

DR. HOLM: Growth hormones have not been found to be deficient in adolescents with Prader-Willi syndrome; therefore, we would not expect growth hormone therapy to be helpful.

QUESTION: Would you recommend surgery for undescended testicles in pre-adolescent children?

DR. HOLM: I would recommend having the surgery if your physician advises it. Undescended testes are more susceptible to malignancy.

PAPER ON PRADER-WILLI SYNDROME TO BE READ AT CONVENTION

A paper will be presented at the Annual Convention of the American Association on Mental Deficiency in Miami Beach on May 29, 1979 at 4:35 p.m. on two Prader-Willi syndrome children who have been treated at Lakemary Center, Paola, Kansas. The paper will be presented by Dr. Gene Baska, Consultant Pediatric Neurologist at Lakemary Center, who is Chief, Section of Neurology, Children's Mercy Hospital, and Professor of Pediatric Neurology, University of Missouri Medical School, Kansas City, Missouri.

The paper will be co-authored by Joyce Wassmer, R.N., and John M. Throne, Ph.D. The title of the paper will be: "A Successful Weight Reduction Program for Two Mentally Retarded Children with Prader-Willi Syndrome."

John M. Throne, Ph.D., Executive Director
Lakemary Center

HEY! THAT'S GREAT!

Kathy Olson lives in an adult group home in St. Louis Park, Minnesota. As part of the program, she spends time at the YMCA pool. During the fall of 1977 someone noticed Kathy's swimming ability and encouraged her to enter the Special Olympics. She started really working on her strength and strokes to improve her skills. One of the Y instructors and a couple of other young men who were interested coached her. One day her mother observed her swimming sixteen lengths of the pool. The regional meet was held in February, and Kathy won first place in the 50-yard backstroke dash. Then about a month later she competed in the state meet and came in first again! What a thrill this was for her. Prize winners were awarded gold, silver, and bronze medals much as regular Olympic winners are. The medal is about three inches in diameter and on a lovely purple ribbon. She was so proud of it, she was reported to have worn it day and night for three or four days. On her next appointment to the University Medical Center she wore it to show her doctor. She is now working to be ready for the next Olympics, and reports she has built up her sit-ups to the point that she won a bet with her advisor by doing one hundred sit-ups without stopping.

HEY! THAT'S GREAT! Continued

This is a picture of Judith Kimberly Ipsen. She goes by "Kim" and is sixteen years old. She attends Arin Education Center in the town of Indiana, Pennsylvania. She knows her alphabet well and can read some. She loves to color and write letters. She likes to copy words and poems, but writes letters herself. She puts puzzles together very well and likes to play with dolls or any paper work.

She would love to have a penpal. Write to:

Kim Ipsen
Box 357
Rochester Mills, PA 15771

MENUS FOR A MEASURED DIET

800-Calories-Per-Day Menu:

Breakfast:

1 ounce bran cereal	70
$\frac{1}{4}$ small cantaloupe	39.8
8 ounces nonfat milk	80

Lunch:

2 ounces tuna	60
Lettuce leaf	5
1 ounce cheddar cheese	104
$\frac{1}{2}$ cup asparagus	14.5
$\frac{1}{2}$ cup cucumber	8
2 medium plums	33
8 ounces nonfat milk	80

Dinner:

2-ounce hamburger patty	101
1 small potato	88
Salad:	
$\frac{1}{4}$ head lettuce	18
$\frac{1}{2}$ cup cucumber	8
$\frac{1}{2}$ small tomato	10
$\frac{1}{2}$ cup Brussels sprouts	28
$\frac{1}{2}$ cup diet gelatin	8
1 small apple	61

For 1000 calories, add:

Breakfast:

1 slice toast with $\frac{1}{2}$ 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:

2 ounces hamburger	101
8 ounces nonfat milk	80

GATHERED NEWS

All a counselor needs to know about PS-142 (Education for all Handicapped Children Act) is in the August 10 issue of the American Personnel and Guidance Association GUIDEPOST. Copies 75¢ for members, \$1 for nonmembers from APGA, 1607 New Hampshire Ave., N.W., Washington, D.C. 20009

from P.C.M.R. Newsbreak

THE GATHERED EXCHANGEResidences

"My daughter lives at an adult group home which is not for Prader-Willi people only, but for people with serious health problems--seizures, diabetes, etc. She is the only Prader-Willi resident. It took a while for the staff to get to understand all her problems and the food drive, but the staff is great, and they have really persevered so things are going very well. All the residents are somewhat retarded, but most go to a sheltered workshop or the day exercise program at the other facility the group owns. K goes to the Y and uses their exercise equipment. She had made friends with ladies who belong to the Y and was invited on some of their outings, which has enriched her socially. In addition to a fine daytime program, the activities planned at the unit where she lives include movies, concerts, trips to the library, the state fair this summer, bowling on their own league, etc. She cares for her share of her room, does her own laundry, etc. Because many of the residents need special diets, she does not feel she's the only one denied food and has accepted her 1000 calories diet better than we expected. The kitchen is locked when not in use, and no food is allowed in rooms. Because her day program is under the same management, the food controls can be carried out during the day as well as when she's "home". With this good planning and her cooperation, she has lost 75 pounds in the time she's been there and has not had a lot of stress over it. Her temper tantrums are way down. There are quarterly reviews of each resident's progress--staff, parents, caseworker, and resident sit down together and discuss problems and improvements. Actual contracts are written and signed by her and the staff to obtain any behavior improvements--keep her room tidier, brush her teeth, stay on her diet, correct temper tantrums, etc. The contract states her goal and the consequences if she breaks her contract. If she goes off her diet contract--steals food, for example--her TV is removed for one week and she is not allowed to go on any outside activity at which food is served for one month. Needless to say, she doesn't want to give up either of those so the food stealing has been curbed considerably. They also set goals for her with special rewards--for instance, promise her a special treat (dinner out or a movie) with one of the staff if she loses a certain amount of weight. They always follow through with the promise so she knows she trusts them and works for the reward. They have used food rewards in this way and it seems to really be the best reward, but is not used frequently, only for a really special achievement. I was amazed to note the similarities of the P-W home in Washington and the provisions for her care here. It appears that with the right kind of staff and planning, P-W people can be worked into other residential facilities until such time as there are dedicated P-W homes for them."

Minnesota Member

Behavior Management

"We are concerned over R's love of playing role-playing games. Initially I encouraged her games as I thought it was good imaginative play. I now feel, though, she tries to insist on playing the games long after what I consider a normal time. Any advice would be appreciated."

Australia Member

THE GATHERED EXCHANGE, ContinuedEducation

"R has for the past eighteen months been attending preschool for normal children. Her temper tantrums have gradually decreased; her teacher says she mixes well with other children. As a family we have begun to explain to her about her condition, and she appears to understand and grasp the situation very well. We are having great difficulty regarding her education for next year. At the moment this matter is being dealt with by the Minister of Education. We have been told that the ordinary schools will not take responsibility for her eating habits. We have been offered a place for her at a school for crippled children, but do not feel this would be suitable for her. Any advice from other parents would be appreciated."

Australia Member

Food Access Management

Here are some of the suggestions for words to substitute for "food-stealing." Which is your favorite? Do you have a better one to suggest?

Indulging	Binge-ing	Lift
Appropriate	Smuggle	Stickyfingered
Misappropriate	Take	Unauthorized requisition

Personality Traits

"I feel children who suffer from the Prader-Willi syndrome not only suffer from a lack of being able to switch off their brains where food is concerned, but also have the same problem re work, games, hobbies, etc. Of course, I only have experience with two Prader-Willi children, who are identical regarding this."

Australia Member

Recipe: Eggs in the Nest

"I tried eggs in a nest, but substituted cabbage for the celery. I enjoyed the dish. (This was from a person who does not have to be on a strict diet, as Prader-Willi people do, so it indicates the dish could be enjoyed by the entire family.)"

Washington Member

Eating Out

"Many parents have written about the calorie problems involved due to the many birthday celebrations in schools. I am pleased by the way my son's school handles birthday celebrations. They did not institute this practice due to my son's diet, but rather had established this policy because they felt that frequent servings of sugary foods are not good for children and also because their celebration makes the birthday child more the center of attention which they feel is good for the child's self-esteem. Their practice is to provide a cupcake or a doughnut for the birthday child only, and not for all the children. The "goodie" is centered with a candle and the birthday child is called to the front of the room. He holds his lighted "birthday cake" while the class sings "Happy Birthday." He then blows out the candle and takes his cake to his desk to eat at his leisure. When it is my child's birthday, I provide a small square of angel food cake, which gives him the same birthday experience as the other children, but does not overload him with calories."

Washington Member

Food Preparation

When cooking rice, use one teaspoon of lemon juice per cup of rice in place of the butter. Good taste with fewer calories.

BUILDING A BRIDGE TO THE FUTURE

By Elain Unger

"In the November-December newsletter, parents from Louisiana refer to the radical changes that occur as the child grows to adolescence and beyond, and the problems of coping as parents, too, grow older and needs change. The question is raised: what knowledge exists concerning this complex, inescapable reality? What methods and solutions are presently available? What is being done to find new ways to meet this problem? For many of us this is of immediate and critical concern, and we dare not hesitate in confronting the challenge.

In Seattle a mothers' meeting which discussed group homes apparently did not feel immediately concerned, most likely due to the fact that younger children are more easily managed, but they did indicate an awareness of the need to be in a "state of readiness" for the future.

At present WISER Acres and Double R R Ranch located in Bothell, Washington (near Seattle), are the only two group homes exclusively for those with Prader-Willi syndrome existing in the entire United States! They are the solid creation of a most unusual, informed, dedicated educator--Margo Thornley. Visiting these beautiful homes, one can see the reality and security of a new way of life and hope and friendship already achieved. Nowhere else in this country is there such a comprehensive approach to the living, training, food management, overall health care, and research needed for our sons and daughters. As the widowed parent of a young man of twenty with Prader-Willi syndrome, I can personally attest to the remarkable efficacy of Margo Thornley's unique and salutary approach to the present and future well-being of the residents in the group homes she directs.

During the twenty years of my son's life he received the finest medical treatment available in New York City and its environs. Everything else to enhance his development came from his family and random programs--none of the latter precisely geared to his specific needs. Most parents and siblings face the ultimate dilemma of either living in a constricted, frustrating situation, or placement of the person they love in inappropriate programs or institutions out of desperation. This need not be!

Through THE GATHERED VIEW, I learned of Margo Thornley's work, and after much investigation brought my son to the home and school in Seattle. In the five months he has been at Double R R he has lost forty pounds, has received the finest in intelligent, responsible, supervised care and living conditions with his peers. He has matured in all areas and has received vocational training and evaluation at WISER Institute. Of paramount importance, he has had the most advanced medical treatment for his condition at the University of Washington Hospital Prader-Willi clinic under the supervision of Dr. Robert Schwartz.

While he was home during this recent winter holiday, my son and I visited the hospital team which attended him (a large sophisticated New York facility.) The medical specialists were in awe at his improved state of health. In the director's own words: "This is a miracle on earth."

To all parents whose children are growing up Prader-Willi, who want for them to live their potential, who seek peace of mind, I can truly say we now have a way. The future is brighter, and Margo Thornley is building the bridge to cross into it. Her efforts deserve the solid support of all those interested in and affected by Prader-Willi syndrome."

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This time we did not receive a letter from anyone with Prader-Willi syndrome for our column. We would like to receive more letters to print. If you are a parent or houseparent, please encourage the young person in your care to write to us.

We did, however, receive some suggestions for a title for the column. Which one do you like best? Or do you have another name you prefer? Let us know. Suggestions are:

"Personal Viewpoint"

"The Inside View"

"Inner View"

The person who suggested "The Inside View" wrote: "I think it would really be enlightening and interesting to hear from PWS children, especially to see how they feel "inside" themselves about their problem. What better way can we get to know about them and their feelings and frustrations? I am looking forward to this column."

THE MEDIA VIEW

Following are some books on topics which may be of interest to you. I have not read the books myself, so cannot make any recommendations on how useful the books might be. If any of our readers have read a book lately that was useful to you, please pass the word along by sending a review of it to THE GATHERED VIEW. Likewise, if you have read a book which you feel might disappoint our readers if they were to buy it, tell us about it also. We all want to spend our money wisely, and this is one way to help one another.

About Jobs and Mentally Retarded People, The President's Committee on Employment of the Handicapped/National Association for Retarded Children, 1974 Available from The President's Committee on Employment of the Handicapped, Washington, D.C. 20210.

New Horizons: The Retarded Citizen in Quest of a Home, Cherington and Dwybad, eds., 1974. President's Committee on Mental Retardation, Washington, D.C. 20201.

International Directory of Genetic Services, Lynch, Guirgis, et al, 1977 The Professional Education Department, The National Foundation-March of Dimes, 1275 Mamaroneck Ave., White Plains, NY 10105.

Access Amtrak. A Guide to Amtrak Services for Elderly and Handicapped Travelers, 1977, National Railroad Passenger Corporation, 955 L'Enfant Plaza, S.W., Washington, D.C. 20024.

Heartaches and Handicaps: An Irreverent Survival Manual for Parents, 1976. Stigen, G., Palo Alto, California. Science and Behavior Books, Inc.

The Fullest Life: Innovation in Recreational Programming for Mentally Retarded Citizens, 1976, National Association for Retarded Citizens, 2709 Avenue E East, P.O. Box 6109, Arlington, TX 76011.

EDITORIAL

In the last issue requests were made for input for two articles that are being prepared: one on "Adults With Prader-Willi Syndrome", and one on "Needs of Parents Whose Children Have Prader-Willi Syndrome." So far I have received very little input on these topics. I would like to have these articles completed in time for our Annual Meeting in June, so I urge you to send any information, opinions, or ideas you may have on these subjects.

Incidentally, in the article on "Needs of Parents", the word "children" does not refer to an age but a relationship. Those who are parents of adult sons and daughters with the syndrome have special needs also, and their input will be valuable for that article as well as the one on adults.

* * * *

It would be nice to have some pictures of the Annual Meeting to print in THE GATHERED VIEW. However, your editor is not a good photographer. If you plan to attend the meeting in Minneapolis, and are a good amateur or professional photographer, and would be willing to take and donate photos to the newsletter, please let me know. You can write in advance, or contact me at the meeting.

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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.

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