

THE GATHERED VIEW

Shirley Neason, Editor

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

Gene Deterling, Director
Box 392
Long Lake, Minnesota 55356

VOLUME IV

March, 1978

Number 2

PRESIDENT'S MESSAGE

I am very happy to report that the pace of activity related to the establishment of facilities for adult Prader-Willi citizens is picking up markedly. I am normally cautious about my optimism related to this activity, but from what I see at this point, I have reason to be excited about the progress. The interest in working toward the development of group homes, camps, and employment facilities has zoomed during the past several months. We are now in correspondence with groups from all over the country who are enthusiastically organizing their local association members to work toward these goals. From what we have been able to detect, the willingness of our members to participate in these efforts is highly encouraging. I am convinced that this spirit of cooperation is going to produce benefits for our Prader-Willi people far beyond what we could have imagined only a year ago.

While we have adequate reason for encouragement in this effort, we must expect it will be a struggle and there will be some occasional setbacks. WISER Acres, the group home for adolescents and adults with Prader-Willi Syndrome established in the Seattle area by Margo Thornley, is currently undergoing a struggle to stay in operation. While the rest of us have been talking and planning, Margo has charged ahead like only a woman of her calibre can do and has already managed to set a facility in operation. Whereas this facility is receiving State aid, the amount of funding is not adequate to support the unique needs of our syndrome. Monthly food costs are running considerably higher than in similar facilities for the developmentally disabled because of the special diets. Of prime concern, however, is an edict from the fire marshal. Although the home complies with the codes for a vocational training center, it does not meet the requirements for a residential facility. The home is now required to install a fire alarm system, approximately \$3,800, and ten solid core fire doors, approximately \$1,250, for a total of \$5,050. There are no funds in the State for remodeling or start-up so the burden falls on the persons responsible for developing the group home. I am hoping that by making our Association aware of this problem, some of us who have the means will be able to provide that extra financial assistance to keep this first-of-a-kind facility alive. We must find a way.

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PRESIDENT'S MESSAGE, Continued

Any contributions can be sent either directly to WISER Acres addressed to Margo L. Thornley, Executive Director, WISER Institute, P.O. Box 578, Bothell, Washington 98011 or to our home office in Minnesota designating that the contribution is for WISER Acres. All contributions are tax deductible.

In the meantime, those of you on the East Coast who are willing to participate in a group effort to provide a facility or facilities there, should contact Mrs. Leon Williams, 13 Highland Place, Atlantic Highlands, N.J. 07716 (201) 291-0442. Mrs. Williams has indicated her intent to organize such an effort, and with an abundance of assistance, something great is bound to result.

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FINANCIAL REPORT

Prader-Willi Syndrome Association
Receipts/Expense Account - December 31, 1977

Receipts

New Member Dues	\$ 724.76
Membership renewals	867.00
Donations	<u>1,370.00</u>
	\$2,961.76

Expenses

Printing (Includes \$287.51 for THE GATHERED VIEW)	\$ 565.86
Prader-Willi Syndrome Publication (R. Amren booklet)	538.72
Postage	464.79
Legal Fees	199.00
Down payment on publication of handbook for parents	150.00
Office supplies	137.79
Office equipment	135.31
Address labels	72.98
Bank service charge	36.33
Office equipment maintenance	29.73
Telephone	19.33
Foreign currency devaluation	<u>1.02</u>
	\$2,350.86

Net Gain/Loss for Year	\$ 610.90
Cash on Hand December 31, 1977	\$1,319.67
Cash on Hand December 31, 1976	<u>\$ 708.77*</u>
	\$ 610.90

*Includes \$398.35 in THE GATHERED VIEW account reported separately last year.

Although we completed the year with what appears to be a better ending than last year, the figures are somewhat misleading. In the first week of

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THE PRESIDENT'S MESSAGE, Continued

1978, our cash-on-hand at the home office was reduced to only \$46 because of the application of \$500 toward the publication of the forthcoming parents handbook. The remainder of the cash-on-hand was held in reserve in THE GATHERED VIEW account for publication of the newsletter. Regardless, we are confident that with the increased dues and the continued generosity of our membership, we will be able to provide a stronger organization in 1978.

Once again, for our new members, we have some extra copies of most of our newsletter back issues and will make them available to you at your request.

Gave Daterling

MENUS FOR A MEASURED DIET

Calorie count is listed after each food. Recipe is for a single serving.

800-calories-per-day Menu

Breakfast

1 medium egg	72
3/4 cup tomato juice	36.5
8 ounces nonfat milk	80

Lunch

1/4 cup cottage cheese	48
small tomato	10
cup cucumber	8
cup spinach	20.5
cup strawberries	27.5
8 ounces nonfat milk	80

Dinner

Tuna Puff:

4 ounces waterpack tuna	157.5
1/8 cup nonfat milk	0
1/4 cup mushrooms	6.2
1/8 cup green pepper	0
1 medium egg	72
1 slice bread	70
1/4 cup cooked carrots	22.5
cup green beans	15
7/8 cup nonfat milk	80
1/2 cup diet gelatin	8
1/2 small apple	30.5

For 1,000 calories, add:

Breakfast: One slice toast with
1/2 teaspoon margarine 100

Lunch: 4 ounces nonfat milk 40
1/4 cup cottage cheese 48

For 1,200 calories, add all of
the above, plus:

Lunch: One ounce cheese 104

Dinner: Eight ounces nonfat
milk, 80.

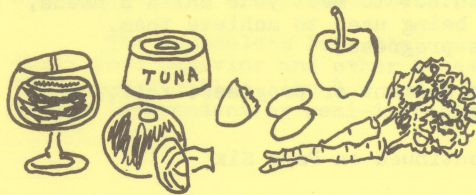
RECIPE: Tuna Puff

4 ounces (112 grams) tuna	157.5
1/8 cup nonfat milk	10
1/4 cup mushrooms	6.2
1/8 cup green pepper	0
1 medium egg, separated	72
Salt and pepper.	

Combine tuna, nonfat milk, mushrooms, and green pepper in shallow baking dish. Season with salt and pepper and heat in moderate oven (375°). Meanwhile, beat egg whites until stiff. Beat egg yolks. Fold egg whites into yolks a little at a time. Pour over hot fish and return to oven for twenty minutes or until top is brown and puffy.

Recipe from Peggy Pipes, M.P.H.

Total Calories: 245.7
2 Meat Exchanges



GETTING THE EDUCATION YOUR CHILD NEEDS

This is the time of year to plan educational placement for your child for next fall. The suggestions in this article are based on material published by the State Superintendent of Public Instruction of the State of Washington.

If your child is already in school, and is in a good program, no doubt all you need to do is check with his teacher about next year's plans for him. And you should check. Education is the school's responsibility, but parents have a responsibility to make sure the child is receiving the best the school has to offer.

If your child is not yet in school, call your school district office to find out what programs are offered to children with handicapping conditions, and how to enroll your child. Do this even if your child is still under two. Some districts have programs for preschoolers and even infants.

If your child is already in school, but you think he needs a different program than the one he is in, ask his teacher for an appointment with the special education director, or whatever person your district has assigned responsibility for special programs.

When you go for a conference, take the following with you:

The child's birth certificate. (Not needed if the school already
The child's immunization record. has a record of these on file.)
Names and addresses of clinics and other agencies that have seen the child.
A written description of special medical or handicapping conditions.

After an evaluation of his physical, scholastic, and social needs, your child will be placed in a program. Some of the options available may include:

A regular classroom with special attention by the teacher.
A regular classroom with support services (psychologist, speech therapist, physical therapist, etc.)
A regular classroom with a resource room where the child spends part of the day.
Any combination of the first three.
A self-contained special education class.
A self-contained special education class with some time spent in regular programs.
Home tutoring.
Contractual services, in which the district contracts with another district or a private school to provide services.

An appropriate educational program for your child takes into consideration his individual needs, limitations, and goals. Districts differ in the extent to which they take into consideration what the parent thinks are his child's needs. Nevertheless you need to know and evaluate his educational progress. Some steps you can take are the following:

Visit the classroom to observe and talk with the teacher.
Look at a schedule of your child's activities.
Ask the teacher what objectives have been set to meet your child's needs, and what methods and materials are being used to achieve them.
Read the written reports of your child's progress.

If you are not happy with your child's placement or progress, follow the chain of command in trying to bring about change.

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WISER ACRES OPEN HOUSE

WISER Acres, the first group home exclusively for adolescents and dependent young adults with Prader-Willi syndrome, held an open house on February 1. I attended the open house, and here are some things I learned from the visit.

WISER Acres is housed in a roomy, pleasant, ranch-type dwelling with three and a half acres of lawn and woods, with a swimming pool in the back yard. The home-like atmosphere is enhanced by pets--a dog, cat, fish, and a goat named Willi. The fish aquarium met with an accident during a temper tantrum, but the fish were rescued and await their new aquarium in a small fishbowl.

The eight residents sleep two or three to a bedroom on the main floor. A large basement is devoted to recreation and general activity. The only part of the building off limits to residents is the kitchen (naturally!), which is kept locked except during meal preparation and cleanup.

Although the home has only been in operation since October 1, all overweight residents have lost weight, and the others have maintained theirs. The "champion" went from 450 to 385 pounds. There has been no food stealing.

The staff consisted of four people at the time of the open house. Rose Jones, who was nutrition technician at Double R R Ranch the past summer, serves in that capacity at WISER Acres, and is also house manager. The counselors were Virginia Wright, who was counselor at Double R R, Marlene Bowles, and George Ruth.

All residents are away during the day in school or work training at WISER Institute. Those who attend WISER Institute study about calories daily and prepare their own lunches.

Evenings each resident has chores to do. After chores and the evening meal, residents can engage in recreation; favorites are games, models, jig-saw puzzles, TV, and playing with the animals. At least weekly a group discussion is held to discuss plans and problems.

Monday everybody goes bowling; Friday is swim day. Other special activities depend on goal achievement. Each resident receives a star for each day he remains on good behavior, does his chores, achieves the desired goals in school, and sticks to his diet. At the end of the week-those who have earned sufficient stars get to go on an excursion, such as to the movies. Those who earn their monthly quota of stars get to eat in a restaurant, no calories counted, although counselors do advise which foods to choose to keep weight down.

For exercise residents jog or hike in the woods surrounding their home.

Next to weight the most common problem seems to be temper tantrums. The counselors have been charting temper tantrums to learn what things influence them. The hallway of the residence has been declared "temper-tantrum city", and residents are asked to go there during tantrums. If a resident refuses to go, he is required to lie on the floor until his tantrum is over. The counselors have had good success in reducing the number of tantrums. One resident, who was averaging three a day when he arrived, now has had none for a month.

The counselors hope that as the residents become more self-controlled in their food behavior and other behaviors, they can get involved in the community through activities like 4-H and Scouting. The eventual goal is for residents to become independent or semi-independent in the community.

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THE PROFESSIONAL VIEW

This month we welcome a new writer to THE PROFESSIONAL VIEW column. Nancy Couhig, M.S., R.D., is a nutritionist on the staff of the Child Development and Mental Retardation Center of the University of Washington. She was asked the question: Are saccharin and foods containing saccharin safe to give to our children? Here is her response:

As with any food or additive to food, you must weigh the problems and benefits. Research has shown that saccharin causes bladder cancer in test animals. This means its use may increase your chances of cancer. The increase is only very, very slight if you consume two to three cans of diet pop each day.

This evidence must be weighed against the benefits derived from saccharin. It adds no calories to food yet allows you to enjoy sweet foods such as diet pop. For people trying to control their weight, this can be a problem.

This research must also be compared to the problem associated with obesity. The problems associated with obesity certainly makes the risk associated with the use of saccharin very small.

The use of saccharin and products containing saccharin has no "yes" or "no" answer. At this time using the products seems to bring only very slight increased risk of cancer. The risk of producing bladder cancer with the use of saccharin is much lower than the risk of lung cancer from smoking.

GETTING THE EDUCATION YOUR CHILD NEEDS, Continued

Talk to the child's teacher first. Write down your concerns before the conference so you can explain them clearly.
If you are still not satisfied, request a meeting with the district administrator of special education.
If you are unable to reach a satisfactory agreement at that point, see your district superintendent of schools.
If you still have not achieved satisfaction, go to the school district board of directors.
Your final appeal within the educational system is to the state superintendent of schools.
If all else fails, legal advice may be needed.

WISER ACRES OPEN HOUSE, Continued

One serious problem of the home is finances. The residents are state-funded, but the state does not allow extra for the higher cost of food for a low-calorie diet, nor for improvements on the building required by the state.

The staff say their job is difficult at times, but difficulties are forgotten when the young people give tokens of affection and take pride in their home.
Reported by Shirley Neason

ANNUAL BOARD OF DIRECTORS MEETING

The PRADER-WILLI SYNDROME ASSOCIATION Board of Directors' annual meeting will be held in the May/June time frame, but at this time neither exact date nor place has been established. Final details of the meeting will be provided in the May issue of the newsletter.

GATHERED REPORTSSacramento, California

Sacramento area parents met February 2 at Alta California Regional Medical Center. Carl Paternite, Ph.D., was the speaker. He showed a film on behavior, then in a talk encouraged parents to praise rather than punish their children.

Dr. Paternite also suggested that it would be good to start periodical testing of the children, twice a year the first year, then once a year thereafter. Dr. Paternite and Art Grix, M.D., of the Alta Center would be in charge of the testing. Plans were made to contact the University of Washington for ideas.

Reported by Judy Schultz

Seattle, Washington

A potluck supper was held January 31 at the home of Dick and Barbara Simmons. The purpose was to exchange ideas with a group of people who had come from Vancouver, British Columbia, to learn more about Prader-Willi syndrome. The group represented L'Arche, an international organization of Christian residential communities for the handicapped. These communities are unique in that normal people join the community on an equal basis with the handicapped residents, then all work together to solve the problems of everyday living. The Vancouver L'Arche community had had a resident with Prader-Willi syndrome, but she had to leave because her problems were more than the group could handle. However, once a person joins a L'Arche group, the commitment of the group to that person is permanent, so they were committed to helping the young women, even though she no longer lives with them. Both the Seattle group and the Vancouver group felt they had profited by the contact between the two groups.

On February 1, the regular clinic date, the parents met the new social worker for the Child Development and Mental Retardation Clinic, Judy LeConte. Judy talked about the laws of the state of Washington regarding education for the handicapped, and gave each parent literature put out by the state Superintendent of Schools. See elsewhere in this issue for an article based on the literature.

On March 1, another clinic day, parents met again. Jeff Snow, M.A., clinic psychologist, met with them for a discussion on which problems seemed to most concern the parents. Temper tantrums won the vote as the most vexing problem, so this will be the discussion topic for the next meeting on April 5.

THE MEDIA VIEW

Orders have begun to come in for the new booklet, "Prader-Willi Syndrome-- A Handbook for Parents." I now have the final proofs, and once they are completed, it will be a short task to print up the booklets. The first orders should go out in April. All who order booklets are asked to send a minimum of \$1.00 donation per book to cover the cost of printing and mailing. Send orders to THE GATHERED VIEW, 147 South 294th Place, Federal Way, Washington 98003.

 * 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, Minnesota 55356. *
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DOUBLE R R RANCH NEWS

Double R R Ranch is again offering a summer recreational and respite program for children and teenagers with Prader-Willi syndrome. The program will be in session from June 11 until August 27, 1978.

Double R R Ranch offers a dietary program designed to reduce weight in overweight children and maintain the weight of those already at the desired level. It also includes training to help ranchers understand and accept dietary limits.

The ranch is located on an idyllic five-acre setting. Trails and woods offer a variety of experiences on the ranch itself, and off-site experiences include camping, beach exploring, ferry boat trips, and excursions to zoos, museums, and other features of local interest. Exercise activities are planned to be fun as well as exercise.

George Ruth, who has been a counselor at WISER Acres, will be the program manager. The entire staff will be trained in the dietetic and emotional needs of campers with Prader-Willi syndrome.

Staff members from the Ranch will meet campers at their plane, bus, train, or ferry and provide transportation from there to the ranch.

More news is that Double R R Ranch now has a residential component, which is accepting residents on a full-time, year-round basis.

For information about either the summer program, or the residential component, write Margo Thornley, Director, Double R R Ranch, P.O. Box 578, Bothell, Washington 98011, or telephone (206) 364-5545.

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