

# THE GATHERED VIEW

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Enumclaw, Washington 98022

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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Gene Deterling, President

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## PRESIDENT'S MESSAGE

Since we are just going to press about the time of our National Conference in Minneapolis, we are unable to provide you with any of the highlights or results of the conference. We are assured, however, that we will have between 160 and 180 members, professionals and other interested parties in attendance. This is in addition to the 30 to 40 children, many of whom are Prader-Willi, who will participate in the children's program which will be provided concurrently with the conference sessions. Although we are approaching this conference with some natural apprehensions about such a first-of-a-kind venture, we are confident that overall the attendees will leave with a warm feeling and a conviction that we have truly made a very important start in pulling together the professionals and parents into a forum which is going to lead to better communication about the syndrome and the promotion of future research to help treat it. In our next newsletter, we will provide you with the results and some of the significant details.

The Seattle Conference sponsored by CDMRC at the University of Washington in mid-June was, in my estimation, an encouraging success. Having been privileged to be a keynote speaker and participant at the event, I had the opportunity to hear a number of fascinating technical presentations on a variety of subjects related to our syndrome. Although there was no information presented that would lead one to believe there was a major "break-through" near at hand (and of course I didn't expect any), I left the meeting feeling that we now do have reason to believe that an era of discovery lies ahead as the medical profession becomes more and more alert to our needs. Most of the papers from the conference will be published as part of the proceedings by the University of Washington and will be available in about six months. We will advise you about how to order these as soon as we have the information.

It has been a very, very busy month for all of us who have been involved with these two conferences, but I am sure we will be able to look back on this month of June as the greatest month of progress for Prader-Willi people since the syndrome was first described 23 years ago.

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SCOLIOSIS PREVALENT IN PATIENTS WITH PRADER-WILLI SYNDROME

Scoliosis, or curvature of the spine, is much more prevalent in patients with Prader-Willi syndrome than was previously realized. In recent months, Edwin L. Laurnen, M.D., Clinical Associate Professor of Orthopedic Surgery at the University of Washington has screened thirty patients with Prader-Willi syndrome, and found that 87% of them had structural scoliosis greater than 10%. He found scoliosis even in preschool children and infants with the syndrome.

When scoliosis is discovered in a patient, it is necessary to follow the patient regularly to see if the curve is increasing. If the degree of curve reaches 20%, bracing is necessary. If the degree of curve reaches 45%, or if the curve continues to increase after skeletal maturity is reached, surgery becomes necessary. Failure to treat scoliosis may lead to arthritis of the spine, and a severe curve left untreated can crowd internal organs, leading to respiratory difficulties and other organ malfunctions.

Exercise will not prevent or correct a curve, reported Dr. Laurnen, but exercises are useful for strengthening back muscles that have weakened due to wearing a brace.

Scoliosis can be detected at home if the child is not obese. However, if obesity is present, the fat usually hides the curve and scoliosis can be detected only by x-ray.

Page 35 of the booklet, "Prader-Willi Syndrome--A Handbook for Parents," gives brief instructions on checking for scoliosis at home. A more detailed, illustrated booklet is available by writing to The Scoliosis Association, Inc., One Penn Plaza, New York, N.Y. 10001. They also have available an article for teens on wearing braces. The Scoliosis Association also publishes a quarterly newsletter, "Backtalk" to keep parents up-to-date on questions pertaining to scoliosis. Anyone interested can join the Scoliosis Association for a \$5.00 annual membership fee.

FIRE DAMAGES BELONGINGS AT DOUBLE R R RANCH

A fire at Double R R Ranch on June 20 damaged some of the belongings of campers and staff. The building was quickly evacuated and there were no injuries. Campers were moved to Bedford Group Home for the first night, then to a motel until another site could be found for housing.

THE MEDIA VIEW

Books for children about physical and mental disabilities: (Reprinted from the Washington State Association of Group Homes Newsletter)

LIKE ME, by Alan Brighton (for younger children)  
MY BROTHER STEVEN IS RETARDED, by Harriet Sobol (nonfiction)  
ME, TOO, by Vera Cleaver (Older readers)  
DON'T TAKE TEDDY, by Judy Long (Older readers)  
VOLUNTEER SPRING, by Judy Long (Older readers)



HEY! THAT'S GREAT!

This column is primarily to recognize special achievements of people with Prader-Willi syndrome. However, their parents do great things, also, and from time to time we want to recognize them.

Betty Hourihan of Milton, Massachusetts, is the mother of an 18-year-old daughter who has Prader-Willi syndrome. Mrs. Hourihan founded an organization called VIA (Volunteer Information Agency). VIA is an information and referral center to help parents of children with special needs. Its secondary function is to act as liaison between facilities needing volunteers and people interested in doing volunteer work. VIA, located in Quincy, Mass., is staffed by trained volunteers whose training is periodically updated in workshops. VIA opened in 1972, and since then has helped hundreds of families. In addition to referral services, volunteers listen sympathetically to the parents' problems and lend appropriate parental guidelines from the VIA library.

In dealing with families, Mrs. Hourihan became aware of the emotional fall-out of the special child on the entire family. To meet a need in this area, she wrote a pamphlet titled, "There is Something Special About You." This pamphlet explains to brothers and sisters why the child with special needs creates special problems, what the sibling can do to cope with them, and how the experience can make the brother or sister gain something from living with the special child that will make him a special person.

VIA's newest endeavor is forming After School Teen Clubs, joining adolescent special needs children with high schoolers to provide friendship and recreation. VIA also sponsors a swim program for children with special needs.

Mrs. Hourihan is still the volunteer director of VIA.



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This is Rebecca Simpson, age 6, of Campbelltown, N.S.W., Australia, with her "friend." Rebecca and her parents have done a good job of keeping her weight down, and her weight at the time the picture was taken was forty-five pounds. Rebecca's mother will be attending the National Conference of the Prader-Willi Syndrome Association in Minneapolis on June 29-30, then will remain in the United States for a few days to observe camping programs and group homes for people with Prader-Willi syndrome.

\* \* \* \*

Congratulations to Russell Iverson of Kent, Washington. He recently participated in the Swimming Special Olympics. He brought home a gold medal and first place ribbon for the 25-yard free style and a third and fourth place ribbon for the 25-yard back stroke. Well done, Russ!





THE GATHERED EXCHANGEResources

It is said that one of the characteristics of Prader-Willi syndrome is a personality change with temper tantrums and stubbornness typical. For the period of the last two years our son has been experiencing aggressive behavior and tantrums. It was recommended to us by our psychologist to place him in a resident setting. Since we were against such a decision, our doctor has started a program as an alternative where behavior therapists have been working with us in our home to correct A's aggressive behavior and tantrums. We feel very fortunate to have such a program available to us and for the past several months have been working quite extensively on a very sophisticated behavior modification program. We have experienced a great deal of improvement in A. For example, before the program he was unable to ride to school on the bus with other children, as he would strike the children and driver if he became upset. This year he has returned to the bus and is doing nicely with few behavior problems.

New Jersey Member

Temper Tantrums

We are unable to completely extinguish our son's temper tantrums and are at a loss to explain why. It would be most helpful if others could inform us of their progress in dealing with this type of behavior. Also we are curious if professionals feel there is something within the syndrome which might be causing the emotional disturbance of Prader-Willi children. We are very concerned about our son's development and would appreciate any help we can get.

New Jersey

Exercise

Walking has been my daughter's main exercise. (She can't run yet.) We have reached a distance of  $1\frac{1}{2}$  miles and, although the results are not as good as with jogging, walking does help with the weight control and also has increased her strength.

Connecticut Member

Education

If you are looking for an advocate to accompany you to a school meeting on your child's Individualized Education Program, or just want to talk to someone who has some know-how, it will help to contact a parent group in your community. You can get the names of organizations whose members can help from the following address: Parents Campaign for Handicapped Children and Youth, Box 1492, Washington, D.C. 20013.

Eating Out

When we are out and need to eat at a fast food restaurant, we order a small hamburger (257 calories) and a glass of diet soda pop for our P-W child. We bring with us a package of Apple Snacks (50 calories), and that makes a sufficient meal for these occasional situations.

Washington Member

Menus

What are some convenience foods that are low in calories and can be prepared when I am in a hurry?

Washington Member



THE GATHERED EXCHANGE, ContinuedResidences

I am the administrator for a group home. We have one home, but intend to expand. The transitional group home, which has been operating for about a year and a half, is occupied by eight mildly retarded adults who may be able to benefit from the guiding, teaching, and type of living arrangement necessary for them to develop daily living skills and move on to more independent living. It's really living. It's really exciting to be part of their growing experiences. We continually readjust programs to meet individual needs and different levels of functioning. Another group of parents from this area are developing a facility in their community. They have obtained HUD funding, and will begin building in April. One of their members is an expert on writing grants for HUD funding and would be an excellent resource for anyone interested in seeking Federal monies. My primary function is parenting, which cannot be done half-heartedly, as my sixth child (fifth son) has Prader-Willi syndrome. One of the reasons for choosing this type of employment was to gain skills and knowledge necessary to eventually develop a Group Home in our area for Prader-Willi children or adults. (We do not have a diagnosed adult population at present in our area.)

Wisconsin Member

Metabolism

One thing I would find helpful would be any information on the pathophysiology. I feel it might help us understand some of the behavior better. I have a background in nursing and my husband in pharmacy, so that makes us want to delve further into understanding the symptoms (i.e., behavior) to see if they relate to the metabolic process. Perhaps there is a connection between sugar levels, insulin secretion, and temper outbursts.

Ontario Member

Speech Development

I want to ask about speech development in children with Prader-Willi syndrome. My daughter's speech development seems to be significantly behind her overall mental development. She seems so alert and normal in many ways, but her speech is very inarticulate. I wondered if it is usual for their speech to be more delayed than other areas, and if this could have anything to do with the poor muscle tone.

Tennessee Member

Diet

Campbell's recently published an ad listing the calorie contents of sixteen of their soups which are 90 calories or less per 10-ounce servings.

|                                |  |
|--------------------------------|--|
| Beef Broth--30 calories        | Consomme--45 calories                  |
| Beef Noodle--90 calories       | Golden Vegetable NoodleOs--90 calories |
| Beefy Mushroom--90 calories    | Old Fashioned Vegetable--90 calories   |
| Chicken & Stars--80 calories   | Onion--80 calories                     |
| Chicken Gumbo--70 calories     | Turkey Noodle--80 calories             |
| Chicken NoodleOs--90 calories  | Turkey Vegetable--90 calories          |
| Chicken Vegetable--90 calories | Vegetarian Vegetable--90 calories      |
| Chicken with Rice--80 calories | Chicken Broth--50 calories             |



A HOME WEIGHT CONTROL PROGRAM

by Shirley Neason

Two years ago we started a weight control program for our son, Danny, now twelve, that seems to be working fairly well. I decided to pass the idea on in the event that it might be adaptable to the needs of others with Prader-Willi.

The most important benefit of the program is that Danny has become very much aware of his dietary needs, both from a nutritional and weight control aspect. He also has learned to measure his own food portions.

A key aspect is the use of scales. He can't argue with scales as he might with his parents. No matter how vehemently he may insist he hasn't overeaten or misappropriated food, if the weight is up, the food intake goes down. We purchased balance beam scales (from Sears) for accuracy to a quarter pound.

All the facets of the program are written on a chart and posted in the kitchen so everything is perfectly clear to both Danny and anyone who might be preparing his food. Some things have been changed as a result of trial and error, and each change is posted.

The first thing on the chart is the schedule of the food intake level. He was at an acceptable weight when we began, so his weight at that time was the starting point. At the optimum weight level, he gets the maximum number of exchanges allowable, plus 100 calories extra of any food he desires. The food is left unlocked. For each pound of weight gained above that level, he receives one less privilege. One interesting occurrence was that at the one time when he reached the privilege level of having the food unlocked, he was able to go for several days without getting into food. However, as soon as his weight was up to the point that he lost that privilege, he began taking food again whenever the opportunity arose. As a result of this experience, I plan to gradually increase the weight level at which the food is left unlocked, as I believe he can eventually handle that responsibility if it is not dropped on him too abruptly. He has rarely dropped below the 1000-calories-per-day level.

For an overweight child, I would suggest setting the privilege level at a weight attainable in a rather short time, and using something other than an increased calorie level as an earned privilege, depending on what the nutritionist advises for that particular child.

This is the way Danny's privilege "contract" looks at present. The nutritionist advises us when to raise weight levels.

| <u>PRIVILEGE LEVEL</u>     | <u>WEIGHT</u> | <u>RULES</u>  |
|----------------------------|---------------|---|
| 100 calories extra.....    | 73 lb.        | Weights are based on Monday night weight just before bedtime. In addition, a weighing must be made any night it is suspected that food has disappeared, and any night that food has been unlocked during that day. At Danny's choice, he may weigh any night he wants to try to qualify for a higher privilege. In order to qualify for an increase in privilege, all allowable foods for the day must have been eaten. An increase in privilege is limited to one level per day. |
| Measure his own food.....  | 74 lb.        |   |
| Food left unlocked.....    | 75 lb.        |   |
| 1800 calorie diet.....     | 76 lb.        |   |
| 1600 calorie diet.....     | 77 lb.        |   |
| 1400 calorie diet.....     | 78 lb.        |   |
| 1200 calorie diet.....     | 79 lb.        |   |
| 1000 calorie diet.....     | 80 lb.        |   |
| 800 calorie diet.....      | 81 lb.        |   |
| 600 calorie diet.....      | 82 lb.        |   |
| 2 milk exchanges only..... | 83 lb.        |   |



A HOME WEIGHT CONTROL PROGRAM, Continued

When it is confirmed that unauthorized food has been taken and consumed, an additional penalty is imposed, and Danny is not permitted to have food at any special function (parties, birthdays, etc.) for two weeks.

Here are the exchange lists for the different calorie levels (they are not exact, but are sufficiently accurate to be effective.) We attempt to prepare all foods by the method which will cut calories to the minimum. On the actual chart, I list all the exchanges for each calorie level to keep it positive and to prevent confusion. I list it here according to what I eliminate at each level in order to save space.

1800 Calories

4 milk exchanges  
4 vegetable exchanges  
3 fruit exchanges  
5 bread exchanges  
7 meat exchanges  
1 fat exchange  
1 sweet dessert  
(200 calorie limits)

1600 Calories: Eliminate 1 meat exchange, 1 bread.

1400 Calories: Eliminate further the sweet dessert.

1200 Calories: Eliminate further 1 milk exchange,  
1 bread exchange, and the fat exchange.

1000 Calories: Eliminate further 1 milk exchange,  
1 fruit exchange, and 1 bread exchange;  
add 1 vegetable exchange.

800 Calories: Eliminate further 1 bread exchange  
and 1 meat exchange.

600 Calories: Eliminate further 1 fruit exchange,  
1 bread exchange, and 1 meat exchange.

I want to emphasize that the details of this plan were devised for one individual, and while the idea may be adapted for another child, the details should be worked out with that child's nutritionist or physician with his individual needs in mind.

The key to success in this program, we feel, is the use of the scales as the monitor, and consistency in following the program precisely. Any deviation or laxity from the written contract disrupts the child's ability to handle the controls. Consistency allows him to not only follow the program himself, but to accept restrictions when they are necessary.

THE PROFESSIONAL VIEW

Here is a question sent in by a reader, with a response by a nutritionist at the Child Development and Mental Retardation Center at the University of Washington.

QUESTION: Would it be possible for a knowledgeable nutritionist like Peggy Pipes to develop a weight loss program for people with Prader-Willi syndrome?

RESPONSE BY PEGGY PIPES, M.P.H., R.D.: I suppose you are referring to a program that could be reproduced and sent to anyone who asked for it. This is not possible, because the caloric needs of individuals differ greatly. Parents of children with Prader-Willi syndrome need to find a nutritionist who can help them establish a reasonable level of calorie intake for their individual child. If you can't find such a person, write to me and I will refer you to someone in your area.



NATIONAL PRADER-WILLI SYNDROME WORKSHOP

"Marvelous." "I learned so much."

These were the comments of parents who attended as guests the National Prader-Willi Syndrome Workshop at Lake Wilderness Conference Center in Maple Valley, Washington on June 13-15, 1979. The workshop was sponsored by the child Development and Mental Retardation Center of the University of Washington.

The stated goal of the workshop was to put together a set of management suggestions to handle Prader-Willi syndrome in regard to medical, nutritional, behavioral, and living aspects. Other goals were to come to agreement on the suggestions, to make the suggestions publishable, and to suggest subjects for further research.

Keynote speakers were Gerald LaVeck, M.D., who spoke on federal programs for the developmentally disabled which apply to Prader-Willi syndrome, and Gene Deterling, founder and president of the Prader-Willi Syndrome Association, who brought the parents' point of view.

Papers presented involved the medical and nutritional aspects, behavioral aspects, diagnosis, and social aspects of Prader-Willi syndrome. In addition to the University of Washington, there were speakers from the University of Iowa, Mayo Clinic, Camarillo State Hospital (California), University of Illinois, University of British Columbia, WISER Institute (Seattle) and Rainier School (Buckley, Washington.)

The results of the workshop will be published in a book by the University Park Press, Baltimore. An announcement will be published in THE GATHERED VIEW when it is available for purchase.

THE GATHERED EXCHANGERecreation and Play

Don't put it off! Your child is growing older every day, and you need to go ahead with those parent-child activities you were going to do. If you haven't thought of one, how about buying a book on birds, butterflies, insects, or other natural source of wonder? Add a pair of field glasses and begin going for daily walks to see how many species you can identify. Or look for mosses, tree bark, leaves, shells, or whatever to make a collection. Find out what places there are of interest nearby, and take your child on an excursion with a brother, sister, or friend. A picnic lunch will add even more fun--one way to add food to the occasion without adding calories to the day.

Behavior Modification

Many nutritionists are teaching behavior modification as a means of weight control. Here are suggestions frequently made. I don't know if they will work for Prader-Willi syndrome, but it's worth a try.

Eat only at the table, never while reading or watching TV.

Eat only at certain prescribed times.

Provide raw vegetables for snacks.

Eat slowly. Swallow each mouthful before taking another bite. Lay down the knife and fork between each bite. Eat everything with a knife and fork.

Use a smaller plate to make the food look like more.



MENUS FOR A MEASURED DIET

## 800-Calories-Per-Day Menu

## Breakfast:

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

## Lunch:

|                            |    |
|----------------------------|----|
| 2 ounces pressed meat      | 80 |
| 1 cup zucchini             | 22 |
| $\frac{1}{2}$ cup cucumber | 8  |
| $\frac{1}{4}$ head lettuce | 18 |
| 8 ounces nonfat milk       | 80 |
| 2 medium plums             | 33 |

## Dinner:

## Cheese omelet:

|                               |      |
|-------------------------------|------|
| 1 medium egg                  | 72   |
| $\frac{1}{2}$ cup rice        | 93   |
| 1 ounce cheddar cheese        | 104  |
| $\frac{1}{3}$ cup mushrooms   | 8.3  |
| $\frac{1}{3}$ cup broccoli    | 13.3 |
| $\frac{1}{2}$ cup nonfat milk | 40   |
| 1 cup watermelon              | 42   |

## For 1000 Calories, add:

## Breakfast:

|                                     |     |
|-------------------------------------|-----|
| 1 slice toast with 1 tsp. margarine | 100 |
|-------------------------------------|-----|

## Lunch:

|                          |    |
|--------------------------|----|
| 1 ounce cheese           | 52 |
| $\frac{1}{2}$ medium egg | 36 |

For 1200 calories, add all of the above,  
plus:

## Lunch:

|                |     |
|----------------|-----|
| 1 ounce cheese | 104 |
| 1 medium egg   | 72  |

## Dinner:

|                               |    |
|-------------------------------|----|
| $\frac{1}{2}$ cup nonfat milk | 40 |
|-------------------------------|----|

GATHERED NEWS

In May a tragic accident occurred in Crystal Lake, Illinois. A thirteen-year-old boy with Prader-Willi syndrome was alone at home during the day while his mother worked. For his own safety, the mother had chained him to his bed. However, the home caught fire and the boy died in the fire. A report of the Children and Family Services Department of Illinois had been issued earlier the same day stating that the Department was planning action to help the family.

Reported in the Milwaukee Journal

H. J. Heinz has purchased Weight Watchers International. Heinz is using the acquisition to lay the groundwork for a nationwide chain of Weight Watchers-restaurants, health resorts, and weight loss camps. Heinz also plans to expand the line of Weight Watchers foods offered in grocery stores.

Reported in Business Week

On July 1 new regulations for the labeling of diet foods go into effect. Foods labeled "low-calorie" cannot contain more than 40 calories per serving. "Reduced-calorie foods" must contain at least one-third fewer calories than the food for which they substitute and the label must show a comparison with the regular food. Foods naturally low in calories may not carry the term "low-calorie" before the name of the food, but may contain a phrase such as "celery, a low-calorie food." Any food that is labeled sugar-free, sugarless, or no-sugar must bear a statement such as "not a reduced calorie food" or "not for weight control" if it does not meet the nutritional and labeling requirements for low calorie and reduced calorie foods. All foods claiming to be low in calories or reduced in calories must carry nutrition information.



EDITORIAL

I feel a little frustrated with this issue of the newsletter because there are so many exciting things going on, yet I can't give full reports on them due to time limitations.

I attended the National Prader-Willi Syndrome Workshop at Lake Wilderness. I am confident that it has improved the outlook for the future of our children, but the practical application of what was learned there will take some time to be assimilated and communicated.

I am even more excited about the National Conference in Minneapolis, but this issue of the newsletter will go to press before the meeting. I am especially looking forward to meeting more parents, many of whose names I know, but whom I can now meet face to face. Even more, I am confident that this meeting will bring parents together in a way that will unite us to accomplish many more things than we have previously dreamed of in our four years existence as an organization.

A VIEW OF WHO'S WHO

This is the story of a three-and-a-half-year-old boy, herein called B.

We are the parents of B., age 3½, diagnosed Prader-Willi at three months. Our first and main concern was keeping him alive due to inability to swallow and many bouts with colds and pneumonia.

We were glad B was diagnosed early so we could start him out on a good diet of high protein and low carbohydrate and sugar. This has not been a problem yet; he understands discipline and cannot get to a food source. His weight is good at thirty-two pounds for a height of thirty-five inches.

Behaviorally B is a happy, well-adjusted child with a normal temper. He started receiving the Infant Development lessons at home at two years and is now going out to school four mornings a week. Learning comes fairly easy if it is taught individually. B understands everything, but is just beginning to say a few words. He has severe hypotonia (muscle weakness) and has managed to crawl with effort, cruises around furniture and takes three or four steps along. He is beginning to potty train and has good control.

There seems to be some breathing difficulty when sleeping characterized by the strides which he's had since birth. His shirt is always soaked with perspiration when he wakes.

B is such a joy to have and love. We know our lives have been enriched through caring for him. When his life seemed to be in the balance, we reminded ourselves that God who gave him to us loves him even more. We want to be a help to others who may have some of our concerns and welcome any correspondence.

One thing we have learned: we must look out for our child's welfare, do all we can to promote their education, get involved, and know what is going on. We have an active parent group in our Early Childhood Training Program, where eleven children are enrolled. We Moms volunteer and help the teacher and aide daily. Our children receive occupational therapy, physical therapy, and speech therapy, but we continually contend for it or we would not have it.



GATHERED REPORTSCalifornia: Los Angeles

Our second meeting of Prader-Willi parents was held April 18 with over 25 attending. Lloyd Robinson, attorney, explained the workings of a non-profit corporation. John Davies from the Dept. of Developmental Services explained how a Prader-Willi organization would be able to obtain funds from the state.

Bob Scott, a member of our group, distributed a parent information questionnaire and a proposed organizational chart. We voted to call our group "The Prader-Willi California Foundation." The initiation fee will be \$25.00 per couple. Mr. Robinson has been requested to immediately draw up papers for our non-profit corporation.

We expect to file for funds from the state in the next two months. Ideally we would like to start two group homes: one for people under 21 and one for people over 21. Both schools must be associated with either academic or vocational schools.

Dr. Kathleen Wishner is planning to visit the University of Washington Prader-Willi research group in April. One of our members plans to enroll her son at the Double R R Ranch in Bothell, Washington, in May, and another will travel to Seattle in June to enroll his son in camp.

Reported by Cal Menzer

NANCY'S RECIPES

BY Nancy Couhig, R.D., Nutritionist

Hamburger Pie

¼ pound lean hamburger  
1 cup chopped onion  
¼ cup tomato sauce  
1 medium egg  
¾ cup skim milk  
½ cup biscuit mix  
1 teaspoon salt  
1/8 teaspoon pepper  
1/8 teaspoon garlic powder

Brown meat. Drain fat. Add onions, tomato sauce, and seasonings. Cook until soft. Press in the bottom of a 10" pie pan. Place eggs, milk, and biscuit mix in blender. Blend until smooth. Pour over meat mixture. Bake in 350° oven for 30 minutes, or until mixture is set and knife inserted in center is clean. Top with shredded lettuce and Taco sauce for Hamburger Pie Ole. Nutrients for ¼ pie: 280 calories, 16.9 grams protein; 17.7 grams carbohydrate.

Rhubarb-Strawberry Dessert

1½ cups diced rhubarb  
1½ cups strawberries  
½ cup + 3 tablespoons powdered sugar substitute  
Dash of salt  
1 cup skim milk  
1 tablespoon lemon juice  
½ teaspoon vanilla  
2 egg whites

In covered saucepan simmer rhubarb, strawberries, and ½ cup artificial sweetener and salt until tender. Cool. Stir in milk, lemon juice, and vanilla. Pour into 2 freezer trays; freeze until almost firm. While the mixture is freezing, beat egg whites. Gradually add remaining 3 tablespoons artificial sweetener. Beat until stiff peaks form. Set aside.

Beat fruit mixture until fluffy. Fold in egg white mixture. Return to freezer trays and freeze until firm.

Yield: 8 servings.

Calories per serving: 27.



THE GATHERED EXCHANGE, ContinuedEducation

Suggestions for helping your child learn better and faster:

Listen to your child--really listen. Listen until you understand exactly where he is having a problem with what he is trying to learn.

Give help, not answers--hints, similar examples, where to find answers.

Reinforce what he has done right through praise.

Forget how you learned it; he may learn in a different way.

Give him ways to use what he learns: writing thank you letters, keeping track of his calories, reading maps on trips, etc.

Make sure he does his work. He is easily distractable; turn off the TV, radio, and conversation; give him a private place to do his homework.

Keep calm. If you get upset, it will discourage the child from coming to you with his learning problems.

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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.

A booklet, "Prader-Willi Syndrome--A Handbook for Parents" may be ordered from THE GATHERED VIEW, 26931 S. E. 403rd, Enumclaw, Washington 98022. The price is \$2.00 for the first copy to members; \$3.50 for subsequent copies and for copies to non members.

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