

THE GATHERED VIEW

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

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

Gene Deterling, President

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PRESIDENT'S MESSAGE

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.

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)

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 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

½ pound lean hamburger
 1 cup chopped onion
 ½ 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, Continued

Education

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.

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.

PRADER-WILLI SYNDROME ASSOCIATION
 Box 392
 Long Lake, Minnesota 55356

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 12177 OAKWILDE CT
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