

THE GATHERED VIEW

Published Bi-Monthly

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147 South 294th Place
Federal Way, Washington 98003

Newsletter of PRADER-WILLI SYNDROME PARENTS AND FRIENDS

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Box 392
Long Lake, Minnesota 55356
Membership Dues: \$6.00 per year

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MESSAGE FROM THE DIRECTOR

Once each year we are required to report to our membership on the operating profit or loss for our organization. The report shown is a consolidated report and includes the expense for THE GATHERED VIEW publication, for which there was a separate Receipts/Expense Statement in our last issue of the newsletter. As you will note below, we showed a loss of \$82.74 in 1976 which is acceptable for the size of our organization and considering that we are a non-profit organization. Of concern is our small amount of working capital (\$310.42), but we expect to be able to limp along through 1977 without any major problems, particularly since some of our 1976 home office expenses will be non-recurring this year. There is adequate reserve for THE GATHERED VIEW publication (as noted in our previous issue), although we carry it as an anticipated or accrued expense in 1976.

Our total membership at the end of 1976 including new members, renewals and anticipated renewals was 193. At the end of February, 1977, our membership totaled 208.

In future issues I hope to be able to reserve this column for more interesting noteworthy information more directly related to the syndrome.

Prader-Willi Syndrome Parents and Friends Receipts/Expense Statement - December 31, 1976

Receipts

New Member Dues	\$ 710.50
Member Renewal Dues	202.00
Donations	84.00
	<u>\$ 996.50</u>

Expenses

Forwarded for THE GATHERED VIEW Publication	\$ 507.00
Typing Service	167.15
Office Supplies	162.61
Printing Service	130.35
Postage	62.35
Bank Service	28.74
Telephone	21.04
	<u>\$1,079.24</u>

Profit/Loss for Year (\$82.74)

Bank Balance December 31, 1975	\$ 393.16
Bank Balance December 31, 1976	<u>310.42</u>

Increase/(Decrease) (\$82.74)

THE PROFESSIONAL VIEW

Last month we published a letter a parent had written to help a teacher handle classroom problems concerning her child. This month we have a memorandum for teachers developed by two educational consultants at the Child Development and Mental Retardation Center of the University of Washington.

Memorandum To Teachers of Children With Prader-Willi Syndrome

As you are aware, children with Prader-Willi syndrome need to be maintained on a fairly strict dietary regimen to maintain even moderate weight control. Families of these children who attend our clinic have received very sophisticated advice on managing nutrition and caloric intake for their children. In general, this means children bringing their own lunches rather than participating in school lunch programs. Nevertheless, the children have great difficulty in curbing their voracious appetites, and we are grateful for your assistance in keeping them from having access to other children's lunches or lunchroom garbage.

Another characteristic of many Prader-Willi syndrome children is refusal to do assigned schoolwork, threats of tantrums, and general lack of motivation. In general, we recommend social reinforcement procedures and token economies of the sort employed in many special education classrooms as being the most appropriate for these children. However, in case these procedures fail, we recommend the following two sets of procedures which have developed in cooperation with our nutritionist:

1. Using the child's lunch as a reinforcer--we suggest dividing the lunch into bite-size portions (ideally the parent would send the lunch along prepared this way). The child could then be instructed that he would get one "chunk" of his lunch after he completes each portion of his daily work. For example, he might get a bite of his sandwich after finishing three pages in his Sullivan readers, then another bite after doing four arithmetic pages, etc. You could arrange to dispense about half his lunch in this fashion and let him have the other half during standard lunchtime period. If you experience problems in the afternoon you might also hold back a small portion of the lunch for the very end of the day if he continues to behave himself. If the child does not complete the assigned work, the lunch should be thrown away and a note sent home to the parents to be extra alert for food stealing that afternoon. Obviously these children will survive quite nicely if they miss a few lunches!

2. Our nutritionist has suggested several foods which children with Prader-Willi syndrome may have in unlimited quantities. We suggest you might want to stock up on some of these to use as bonus reinforcers in conjunction with the program 1 outlined above, or you could allow the child a "normal" lunch and simply use the following foods as additional reinforcers (keeping the parents informed, of course). Small slices of celery, carrot, or dill pickles can be used as reinforcers. Our nutritionist informs us that the children may have as much of the three foods as they wish. Nevertheless, I would dispense only one thin stick at a time. These reinforcers might be particularly useful in a classroom where other candy-type reinforcers are used with other children so that the Prader-Willi child could also be reinforced with food of a type this child could tolerate. In fact, our nutritionist suggests that perhaps the entire class would benefit from these reinforcers instead of sweets. We also recommend a sweet reinforcer: jello sticks. However, these must be made with dietetic gelatin such as D-Zerta. To make jello sticks, use 1/2 to 2/3 the amount of water recommended on the package. When the product hardens it will be thicker and gummier than normal jello, but will not require refrigeration.

Another food which could be used, but not in unlimited quantities, is beef jerky, which you would probably want the parent to provide since it is considerably more expensive than the other foods listed above.

Stephen Sulzbacher, Ph. D.
Jeff Snow, M. A.

IS NORTHERN CALIFORNIA WITHIN YOUR REACH?

The Prader-Willi Parents Group that is meeting in Sacramento has been discussing the possibility of a camp program for the coming summer. The Meteor Ranch Camp in Upper Lake, California, at Clearlake has been suggested. It is about a three-hour drive northwest of Sacramento.

The camp directors have indicated that if enough Prader-Willi children are interested in attending a session, they would arrange a definite diet and exercise program geared especially to their needs.

The camp has a fully structured and supervised program with very little "free" time. Campers are with counselors at all times, and there is one counselor for every two campers. The directors have been working in camps for the handicapped for ten years. The camp emphasis is on spiritual, physical, and emotional needs.

Our seven-year-old, Katy, went to a week session last summer. She had a wonderful time and lost three pounds! Our family highly recommends the Meteor Ranch staff.

Diane Morine (Katy's Mom)

For further information contact:

Mrs. Phyllis Wilcox, Director
Meteor Ranch Camp
2255 East Highway 20
Upper Lake, CA 95485

or
Mrs. Diane Morine
Star Route 1
Clearlake Oaks, CA 95423
(707) 998-1606

GATHERED REPORTS

In response to a request for reporters from parent groups, we received a reply from Judy Schultz of Sacramento, California, saying she would be glad to keep us up-to-date on what her group is doing. We would appreciate hearing from other groups also. Judy's report is the first in a new column, GATHERED REPORTS.

Sacramento, California

I would be glad to keep you up to date on what our Sacramento group is doing. We are going to have a meeting next month (the letter was written in December, but missed the January issue) at Alta California Regional Center. We have a meeting about every third month. Our group consists of parents of eleven children, six of them living in Sacramento, and the others from Fresno, Woodland, Clearlake Park, Portola Valley, and Stockton. Andrea Nettin, nutritionist at Alta formed the group and conducts the meetings.

Judy Schultz

Seattle, Washington

I'll appoint myself reporter for the Seattle group for the time being. We have informal meetings on clinic days, when all the parents who have appointments on that day get together and exchange ideas. Formal meetings are held occasionally on clinic days, and once in a while we have a night meeting so working parents have an opportunity to attend. We usually have a speaker at the night meetings. Alice Lobenstein is the nurse-coordinator for the group, and Sue Iverson is the parent-coordinator.

On our last clinic day (March 2), Margo Thornley dropped in to tell of her plans for summer camp. There is a full report on these plans in the following article.

DOUBLE R R RANCH

A Summer Recreational and Respite Residence for Children with Prader-Willi Syndrome-
June 12, 1977 - August 28, 1977

... provides a twelve week educational and recreational program

from June through August in an idyllic setting encompassing five acres. Weekend respite is provided throughout the year. Cradled between two mountain ranges, the Olympics to the West and the Cascades to the East, and dominated by tall evergreen trees, this area has its highest appeal to those who appreciate a harmonious balance between the individual and nature. Trails and wooded areas offer a wide variety of experiences and activities.

In this setting, a specialized program to develop self-help skills, nutritional skills, communication skills, social and physical growth will be offered in a structured, controlled environment.

Daily living skills, vocational evaluation and training will be offered to develop desirable work skills and attitudes. Physical education activities to develop stamina and muscle tone will be an integral part of the program.

Recreational activities include off-site participation in community recreational facilities for bowling, skating and mini-golf. On-site recreation includes swimming, horseback riding, tennis, badminton, bocce, and team sports. Dancing, musical games, and creative drama will be utilized to develop communication and peer interaction.

Field trips to points of interest in the Puget Sound area include ferry rides to the San Juan Islands, Vancouver, B.C., Space Needle, mountains, and seashore. Winter snow activities will be available for weekend residents.

A professional staff, including a dietician, will meet the special nutritional and caloric needs of each child. Counselors will be provided at a two to one ratio.

We will meet your plane, train, bus, or ferry, and take your son or daughter to the ranch.

For more information please write to:

Margo Thornley, Director
Double R R Ranch
P. O. Box 578
Bothell, WA 98011
(206) 485-5529

THE GATHERED EXCHANGE

A Low-Calorie Easter Basket:

Supplies needed:
1 Easter basket
Easter "grass"
Large empty plastic eggs
Gifts to put in eggs
Two or three small marsh-
mallow bunnies or chicks
Six or eight jelly beans
1 pkg. neufchatel cheese
Flavorings (anise, mint, etc.)
Food coloring
Artificial sweetener
Plastic wrap or
colored cellophane
3 small balloons
1 recipe jello sticks
Small plastic eggs

Instructions:

To make "candy" eggs, soften neufchatel, divide into two or three containers, add flavoring, artificial sweetener, and food coloring as desired. Return to refrigerator until firm. Shape into egg shapes and wrap in cellophane or plastic wrap. Make jello sticks according to instructions in THE PROFESSIONAL VIEW. Mold in small plastic eggs and wrap in plastic wrap when firm. The night before Easter, prepare the basket with grass, place gifts in large eggs and add to basket. Tie the three balloons to the handle, and place where the child can find it in case he awakes before you do. Hopefully you can awake first and sneak the food items into the basket before he finds it.

IMPORTANT: Neufchatel cheese counts as a fat exchange. I can't find it listed in an exchange list, but The Brand Name Calorie Counter indicates that two tablespoons contain approximately seventy calories.

THE GATHERED EXCHANGE, Continued

A Mother's Day gift your child can make:

Materials needed:
 A tin can of the desired
 shape and size
 Self-adhesive plastic
 shelf lining
 Three identical plastic
 bottle tops
 White glue

Procedure:

Cover the tin can with the shelf covering.
 Glue the three bottle tops to the bottom
 of the can. This gift can be used for a
 vase, pencil holder, candy dish or desk
 caddy.

A tip for summer travel:

Sometimes travel on a hot day calls for a cold drink. For a refreshing
 change from diet pop, try canned diet iced tea. Before leaving on the trip,
 partially freeze the tea in your freezer. Sometimes the tea is available
 ready-chilled in service stations.

THE BOOK VIEW

Every Child Can Learn...Something, Handbook for Parents and Teachers of
 Severely Retarded Children, by Margo Thornley, illus. by Jacques Rupp, c1973,
 Bernie Straub Pub. Co., Seattle, Washington. Order from: W.I.S.E.R. Institute,
 P. O. Box 578, Bothell, WA 98011. Price: \$5.00 postage paid.

Most people with Prader-Willi syndrome are not severely retarded, but don't
 let the subtitle of this book turn you off. It is packed full of useful inform-
 ation every parent and teacher can use with young people of differing mental
 capacities in teaching self-help and academic skills.

I was especially impressed with Mrs. Thornley's philosophy that children
 should not be denied the opportunity to learn simply because they have been given
 a label, such as mildly, moderately, or severely retarded that indicates they
 can only learn certain things. She says, "The quickest way to produce below-
 normal intelligence is to deny a child the opportunity for mind, body, and spirit
 to grow through normal, stimulating contacts. Whatever we measure as 'intelli-
 gence' can be raised with appropriate educational opportunity for both 'normal'
 and exceptional children."

What is it you want a particular child to learn? To dress himself? Eat
 with a spoon? Follow directions? Write his name? Do arithmetic? The step-by-
 step teaching techniques outlined in this book are designed to help the slow-
 learner acquire these and other needed skills.

Exchange Lists for Meal Planning, c1976. American Diabetes Association,
 Inc. 1 West 48th St. (600 Fifth Avenue), New York, N.Y. 10020

This new edition of exchange lists is much more colorful and easy to use
 than the previous edition. Some lists have been revised. There is only one
 vegetable exchange list, with the higher-calorie vegetables now included in the
 bread exchange list. Meat-exchange lists have been divided into three lists of
 lean, medium-fat, and high-fat meats. This new meat listing is intended for
 those who are concerned about cholesterol, but will also be useful for those
 planning Prader-Willi diets. The books are fifty cents each. The local American
 Diabetes Association office informed me that the booklets are available from the
 national office only in quantities of ten or more, so they should be ordered from
 the local offices of the American Diabetes Association or the American Dietetic
 Association. If neither of these has an office in your area, ask your doctor
 or local health department where you can obtain one.

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A VIEW OF WHO'S WHO

This month's letter is from a mother who is interested in correspondence, so her name and address are included for those who want to write to her.

I am very interested in hearing from parents who have children age eighteen and over. What is the future for them as far as jobs, marriage, children, etc? If they do have children, would their children have this syndrome?

My daughter is now 18 1/2. I found out just a year ago she had this. I had been taking her to Stanford University Medical School in the Special Problem Clinic. At the same time I read an article in the newspaper about a study made of the syndrome at the University of Washington. I knew from that article this is what it was. Stanford University and Children's Hospital said they had seen only one other case.

For the past year now she has been living in a controlled environment. She was 336 pounds and is now 246--a super weight loss! (She spent eight days during the holidays at home--gained fourteen pounds.) Food must be locked and she only given a special diet (900 calories). She has behavior and social problems. Although her I.Q. is about 80, she has always worked very hard in school and will graduate this year. I had taken her to many doctors since birth but really never was given any help.

Will be looking forward to hearing from someone soon. If I can help someone else, I'd be glad to do so.

Helen Foley
26665 Huntwood
Hayward, CA 94544

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