

# THE GATHERED VIEW

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Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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## THE HEADQUARTERS VIEW

Parents need no longer say they are alone in their attempts to understand and cope with Prader-Willi syndrome. Although that view was true a couple of years ago, today the vehicle exists to communicate with others who have a similar challenge in life. We now have a state-by-state listing of all our members and want to encourage you to take advantage of it. Two heads have got to be better than one, and with a dozen or so working together, the rewards will probably surpass your expectations. You owe it to yourselves to give it a try.

There are now a number of members in various parts of the country working to establish local groups that can provide a better means of more intimately sharing the experiences of dealing with the syndrome. There are well-established groups in Washington State and California, and this month we are taking the first step toward the formation of a parents group in Minnesota.

We have had many requests for advice on how to go about establishing such a group, but have not yet been able to put together a set of ground rules. It may be better if we don't. That way we won't prejudice the initiative and innovativeness of other capable members. It really should be simple, however, to get started. Without knowing where you're going until you meet, you will find that there will be a natural flowing together of ideas, plans, goals, and just simply mutual interest. What is really needed, however, to get a group started is one person with initiative to contact one other person and say, "Let's go."

In order to assist you in such an endeavor, we will provide a state membership listing to anyone who requests it. We currently have the following breakdown of members.

<u>State</u>	<u>No. of Members</u>	<u>State</u>	<u>No. of Members</u>
Arizona	5	Idaho	3
California	37	Illinois	12
Colorado	7	Indiana	3
Connecticut	5	Iowa	8
Delaware	2	Kentucky	2
Florida	4	Louisiana	1
Georgia	4	Maryland	9
Hawaii	1	Massachusetts	13

Continued on Page Two



THE HEADQUARTERS VIEW, Continued

<u>State</u>	<u>No. of Members</u>	<u>State</u>	<u>No. of Members</u>
Michigan	7	Ohio	7
Minnesota	18	Oklahoma	1
Mississippi	1	Oregon	8
Missouri	4	Pennsylvania	9
Montana	3	Rhode Island	1
Nebraska	1	South Carolina	1
North Carolina	2	Texas	6
North Dakota	2	Virginia	3
New Hampshire	1	Washington	18
New Jersey	11	Wisconsin	12
New York	11	Wyoming	3
<u>Others</u>	<u>No. of Members</u>		
Puerto Rico	1		
Canada	7		
England	3		
Australia	2		
Norway	1		
Germany	1		
Kuwait	1		
Total Membership	262		

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We have had a number of new members join us recently. We try to send out as much initial written information as is practical for new members, but may have neglected to do so in some cases. If anyone has not received a free copy of R. Amren's report, PRADER-WILLI SYNDROME - A BROTHER'S VIEW, please contact us. We also have some remaining back issues of THE GATHERED VIEW, and will gladly provide them upon request.

There have been many requests for additional copies of the Amren booklet. Unfortunately, each booklet costs about a dollar to print and mail; thus we would appreciate any donations to cover these costs when requesting more copies. We are now a fully tax-exempt organization; therefore, all amounts forwarded to the organization over and above the established dues are tax deductible.

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Keep up the good work, California and Washington!

*Gene Datseling*

GATHERED NEWS

In March Health, Education, and Welfare Secretary Califano announced a major HEW reorganization which resulted in the combination of thirteen programs for handicapped individuals through six separate offices into one single ADMINISTRATION FOR HANDICAPPED INDIVIDUALS. The new Administration will have responsibility for all Office of Human Development services targeted toward handicapped persons.



HEY! THAT'S GREAT!

This beautiful young lady is Cathy May Hamilton, who will be seven years old in January. In the first picture Cathy was four years old. In the second picture, she was five and weighed 131 pounds. Two months later, in November, 1976, Cathy had gastric bypass surgery. The third picture was taken several months after the surgery, after she had lost seventy-five pounds. Her parents think it is especially great that now, with her burdensome weight gone, Cathy can run and play as never before.

THE MEDIA VIEW (formerly The Book View)

It turns out so often that this column reviews items other than books, that I decided the name BOOK VIEW no longer fits. Since the term "Media Center" is now being sometimes used to replace the word "library", the title MEDIA VIEW seemed appropriate.

With gift-giving time approaching, you might give some thought to good recordings. There are a number of outstanding recordings on the market that will get the child involved with the music he hears. Here are some of them.

Hap Palmer is the creator of a series of recordings known as "Learning Basic Skills Through Music." These are used widely in preschools and kindergartens, but are also suitable for home use. Through the use of music they involve the child in learning such things as colors, letters, numbers, body parts, and clothing. They also teach about nature as the child pretends to be an elephant or a bird. For more information write Educational Activities, Inc., Freeport, N.Y. 11520.

Young People's Records publishes a series of recordings that provide the child with rhythm experience, dramatic play, stories with musical background, and an introduction to classical music. Among the titles are "Nothing to Do", "Daddy Comes Home", and "The Carrot Seed". For information write Children's Record Guild, 100 Sixth Ave., New York, N.Y. In Canada write 1184 Castlefield, Ave., Toronto, Ont.

In my estimation the most valuable program for children on television is Misterogers Neighborhood. Mr. Rogers does an outstanding job of helping the young child develop good feelings of self-esteem and self-concept. Many of the songs used on the programs have been recorded by Small World Enterprises, Inc., 1 Palmer Square, Princeton, N.J. 08540, and are available in record shops.



A VIEW OF WHO'S WHO

This month we have two letters--one from the mother of a very young child, one from the mother of an older young man.

From Iowa:

Our Prader-Willi boy was born January 11, 1976, and was diagnosed at eleven months.

I don't quite know how to put this, but so far I have things in their proper perspective--just trying to learn as much as I possibly can. We farm and have three other active children, fourteen, twelve, and five. I'm even taking a crash course in nutrition.

From Connecticut:

About seven years ago my son was diagnosed as Prader-Willi at the Children's Hospital Medical Center in Boston.

My son has a lot of the symptoms, such as picking his skin (which he rarely does now) and picking paper, string, etc. He is sixteen, weighs 110, height 4' 7", and I might add a handsome boy with good features.

However, there is so much emphasis on overeating with these children. Paul never had this problem, always eating whatever was served. Often I would ask him if he wanted seconds, but he never would ask for more.

My husband is of Swedish and Danish extraction and we both have fair complexion with blond hair, as is my son. It was my first pregnancy, at thirty-eight years of age, and my only child.

THE GATHERED EXCHANGED

A mother responds to the person concerned about her son's feet turning out:  
We took our daughter to Dr. Bryant J. Cratty, a specialist on the needs of the handicapped, and his suggestions were as follows:  
Take a 2x8 six-foot long plank and put a border down the middle of it, a narrow board, several inches high and have your child walk up and down it for a period of time each day. We felt it helped quite a bit.

A mother's thoughts concerning a group home:  
If my daughter were to enter a group home, I would hope for the following:  
A good work-living setup where she could feel as independent as possible. Be allowed to have company and go with the parents on vacations as often as possible. And of course those in charge must be completely aware of the condition and its effects, so the party would never be punished for something they cannot help, as I feel my daughter has. They should do their share of the work as they are capable and have recreation as do normal people.

A good activity to involve a child in:  
Encourage him to grow his own plant. Help him take a cutting off one of your plants, or if you have none, the plant of a friend. Help him put the cutting in a glass of water, then watch with him until it puts out some good roots. Discuss with the child the function the roots perform for the plant. When the roots have grown sufficiently, give him a pot and dirt for planting it. Have him place it in a sufficiently lighted area and teach him to water it properly. A plastic squeeze bottle makes a good watering "can" for a young child. (You keep an eye on between waterings just in case the plant is in danger of too little or too late.) A little plant food once a month will also help it grow. Easy plants to grow in this manner are pick-a-back, philodendron, ivy, spider plant, purple velvet, and coleus.

Continued on Page Five



TOYS FOR THE YOUNG CHILD, An Article in Four Parts

by Shirley Neason

In twenty-one years experience as a mother, plus two years as a preschool teacher, I have learned much about children's toys that I wish I had known twenty-one years ago.

Play is the most important activity in a child's life. It is the preschooler's school where he learns to use his body, understand the world about him, develop relationships to other people, get acquainted with himself, relate himself to his environment, and develop skills he will use throughout life.

Some basic principles for the use of toys include the following.

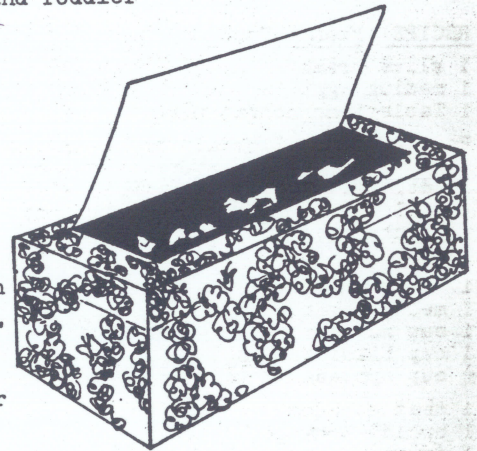
1. The four basic kinds of play are physical, manipulative, social, and imaginative.
2. Toys should be suited to the child's developmental level. The child with Prader-Willi syndrome may not be at the same level as other children his age.
3. Toys should be safe.
4. It is better to buy a few toys of good quality than many cheap toys. However, low price does not always mean "cheap". Some excellent toys are free, as this article will later point out.
5. The child should have a place of his own to store toys, and it should be arranged so he can easily put them away himself. Shelves are better for this than a box, as shelves allow the child to sort his toys as he puts them away, developing pre-mathematical concepts of number, shape, size, and sets.
6. The best toys to buy are those that will give the child enough of a challenge that he will have to put forth some effort to master them, but are not so difficult that they frustrate him or lead to misuse.
7. Child guidance experts advise that parents provide a minimum of guidance, letting the child discover things for himself. However, I found that my Prader-Willi child needed much more help in learning to use toys and in finding new ways to play than my other children did.

NEXT INSTALLMENT: Toys for the Infant and Toddler

THE GATHERED EXCHANGE, Continued

Here is a game that will be fun for your child and at the same time help develop his awareness and verbal ability:

Make a feel box. Use a shoe box with its lid. Cover the box with decorative paper, if desired. Cut around three sides of a square hole in the lid. Place one or more familiar objects inside the box, and ask the child to reach in and feel an object, then tell you what it is. If his fingers can't "tell" what it is, have him pull out the article and see if his eyes can "tell" what it is. As he becomes more familiar with the game, you can add real "mystery" items of things he may not be so familiar with.





MENUS FOR A MEASURED DIET

At Double R R Ranch this past summer, meals were carefully planned under the supervision of a nutritionist to provide a precise calorie count and adequate daily nutrition. Care was also taken to use foods that would provide a lot of bulk for the number of calories so the campers would feel they were getting sufficient food. At the end of the summer the counselors sent THE GATHERED VIEW a copy of the twenty-one day cycle of menus, along with recipes. Beginning this month, a menu will be published each issue, depending on space available. Calorie count is listed after each food. Recipes are for a single serving.

## 800-Calorie-Per-Day Menu:

Breakfast

1 slice French toast	150
$\frac{1}{4}$ cup strawberries	13.75
8 ounces nonfat milk	80

Lunch

$\frac{1}{2}$ medium deviled egg (make with mustard only)	36
1 ounce pressed meat	40
$\frac{1}{4}$ head lettuce	18
2 radishes	5
1 stalk celery	15
8 ounces nonfat milk	80
2 medium plums	33

Dinner

## Spanish Rice:

2 ounces ground beef (lean)	101
$\frac{1}{2}$ cup cooked instant rice	93
$1\frac{1}{2}$ teaspoons green onion	0

$\frac{1}{4}$ cup cooked carrots	11.25
$\frac{1}{4}$ cup cucumber	8
8 ounces nonfat milk	80
$\frac{1}{2}$ cup strawberries	27.5

RECIPE: French Toast

1 slice bread	70
1 medium egg	72
1 Tablespoon nonfat milk	5

Beat egg and milk; dip bread in and allow to soak up mixture. Bake on griddle with no fat (or spray with noncaloric vegetable coating). Top with choice of fruit.

## Toppings:

1 cup strawberries	55
1 medium peach	58
1 cup raspberries	70
1 cup blackberries	84
$\frac{1}{2}$ cup applesauce (dietetic)	50

1 meat exchange	
1 bread exchange	
1 fruit exchange	

For 1,000 calories add:

Snack

1 ounce cheddar cheese	104
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Lunch

$\frac{1}{2}$ medium deviled egg	36
1 ounce pressed meat	40

For 1200 calories add all of the above plus:

Dinner

2 ounces lean ground beef	101
1 slice of bread with $\frac{1}{2}$ teaspoon margarine	100

RECIPE: Spanish Rice

2 ounces extra lean ground beef	101
$\frac{1}{2}$ cup tomato juice	24
1 teaspoon green onion	0
$\frac{1}{2}$ cup instant rice	

Salt, pepper, hot pepper sauce

Cook ground beef and drain off excess fat. Cook instant rice, add beef, onion, and tomato juice. Heat thoroughly and season to taste.

Total calories: 218

2 meat exchanges	
1 vegetable exchange	
1 bread exchange	





THE PROFESSIONAL VIEW

For this month's column I interviewed Peggy Pipes, M.P.H., Nutritionist at the Child Development and Mental Retardation Center of the University of Washington, to get answers to some questions I had.

**QUESTION:** Most of the mothers I know who have children with Prader-Willi syndrome give their children some sugar and artificially sweetened products. Would there be any advantage for mothers of young children to leave sugar and sweeteners completely out of their children's diets as soon as they learned they had Prader-Willi syndrome?

**REPLY:** I think it would be to their advantage to leave out sugar and artificial sweetener. It would be beneficial to never allow the child to get a sweet tooth in the first place. The child is on such a limited diet that every thing he puts into his mouth should provide as many of his nutritional needs as possible.

**QUESTION:** I was concerned about the report I heard of the young man with Prader-Willi syndrome who would break into a restaurant and steal food after he had had a few drinks. What attitude toward alcohol as a beverage do you think should be encouraged in people with Prader-Willi syndrome?

**REPLY:** It is my personal opinion that alcohol is too much for the person with Prader-Willi syndrome to deal with. There are three reasons for this.

1. Alcohol is very high in calories.
2. The first effect alcohol has on a person is to break down inhibition. Since it takes a great amount of will power for a person with Prader-Willi syndrome to keep to his diet, that would be the first control to go.
3. Because of the tendency of most people with Prader-Willi syndrome to gorge themselves, an alcohol binge similar to the food binges some have experienced could be very harmful, even fatal.

**PEGGY PIPES:** Now that I have answered your questions, I would like to ask your readers some questions. I am trying to compile some data on food behavior of children with Prader-Willi syndrome. If parents would send answers to these two questions, it would be most helpful.

Question #1: What prompts your child to steal food?

Question #2: Is there any food that influences your child's behavior either for better or for worse?

GATHERED NEWS

"Prevention--Integration: Priorities for the 80's" will be the theme of the 14th World Congress of Rehabilitation International to be held in Winnipeg, Canada, June 23-27, 1980. The Congress will include workshops, discussions, and a special event to conclude the Decade of Rehabilitation and to launch the International Year for Disabled Persons proclaimed by the United Nations General Assembly for 1981. For further information write Rehabilitation International, 432 Park Avenue South, New York, New York 10016.



GATHERED REPORTS

Sacramento, California

We had a parent meeting in Sacramento in July. There are not twenty-one families with Prader-Willi children.

At the meeting Andrea Netten (nutritionist at Alta California Regional Medical Center) discussed the article in Good Housekeeping. She has received a lot of letters from people who feel their kids might have Prader-Willi and want information. The speaker was Sam Beltran, who attended the Washington meeting of the Board of Directors of Prader-Willi Syndrome Association in May. He gave a report on the meeting.

The children came to the meeting with their parents and were weighed and measured by Alta's pediatrician.

Reported by Judy Schultz

SUBSCRIPTION INFORMATION

THE GATHERED VIEW is the official newsletter of PRADER-WILLI SYNDROME ASSOCIATION, a nonprofit corporation. A subscription is included as one of the benefits of membership in the Association, and is the only basis on which subscriptions are offered. Memberships are currently \$6.00 per year for residents of the United States, Canada, and Mexico, \$7.00 for all others. Effective January 1, 1978, membership dues will be \$10.00 for domestic membership, and \$13.00 for overseas membership. To obtain membership, write to PRADER-WILLI SYNDROME ASSOCIATION, Box 392, Long Lake, Minnesota 55356. Send editorial material to THE GATHERED VIEW, 147 South 294th Street, Federal Way, Washington 98003.

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