

THE GATHERED VIEW

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Enumclaw, Washington 98022

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

Gene Deterling, President

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PRESIDENT'S MESSAGE

The past two months have been big months for us as far as publicity is concerned. As many of you are aware, the "Dear Abby" addressed the subject of Prader-Willi syndrome in response to an earlier letter from a parent who had described the problems with her child as being similar to those of a Prader-Willi person. The original letter from the concerned mother did not mention the word Prader-Willi, but many of our members wrote in to "Dear Abby" and suggested that the child's condition could very well be related to Prader-Willi Syndrome. As a result of the "Dear Abby" column published in the latter part of March, we have received well over 2,000 letters. Although only a small portion of the letters were from persons truly involved with the syndrome, it was a sign that there is now a greater awareness of Prader-Willi syndrome.

In addition to the responses, we have provided information to several newspapers and a major TV program in the Chicago area. Although it is difficult at this time to summarize the results, it is safe to say that there has been a greater awareness of the syndrome in the past two months than in the past four years.

For the next two months, we will be preparing for another big event. Our national conference is scheduled for June 19, 20, and 21st on Cape Cod, and much of our effort today is being dedicated to the preparations for this conference. By now, you should have received the announcement along with the agency, and, hopefully, have already sent in your pre-registration form and have made your reservations at the Sheraton-Regal Inn. We are expecting that this year's conference will be at least as well received as last year's was. We have an additional half day in the schedule in order to allow more time for communication among families and between parents and professionals. Those of you who were fortunate enough to attend last year's conference will recall the major impact it had on your knowledge of the syndrome, and if you brought your children, the memory of that event. Although there are always some unknowns in the planning process, we feel confident at this point that the attendees will leave with the same high degree of appreciation as those of last year.

Continued

PRESIDENT'S MESSAGE, continued

I am not terribly happy to announce this, but on July 1st I will be resigning from my position as president of the Association. This should not be a surprise for those of you who have been reading THE GATHERED VIEW for the past year, since I announced my intentions a year ago at the national conference. I will have been in this position for five years since the founding of the organization and now feel it is time for "new blood" to be introduced into the organization. When my wife and I, along with Shirley Neason, founded the organization in early 1975, we did not fully realize the effort that would be involved with the future growth. The fact of the matter is that I am unable to spend the amount of time that is required, and for the sake of the future of the Association, believe that it is absolutely necessary that a new president be elected. We do not yet have a definite new candidate in mind, but expect that at the time of our Board Meeting on June 20th, we will have at least one candidate. Since this is your organization as well as mine, I hope that all will cooperate in the selection of our new president.

The next President's Message will be my last, and it will not be without some regret. Although I will no longer be acting in the position of president, I will retain my position as treasurer and will continue to devote as much available time as possible to the future of the organization. I feel confident now that it has the capacity of growing to be a self-sustaining Association with many new benefits for Prader-Willi people.

FREE CLINIC AT CONFERENCE

Douglas Macko, D.D.S., and Andrew Poole, D.D.S., have offered to conduct a free oral, facial, and dental examination clinic for Prader-Willi people during our national conference. The time for the clinic will be announced at the beginning of the conference.

GATHERED NEWSBladder Control

Wet Alert is an electronic toileting control system created by a developmental psychologist. The system combines behavior modification with an electronic device to train individuals whose mental function is 24 months or older. For price information, write Wet Control Systems, 2600 East Southern Avenue/Suite C-2, Tempe, Arizona 85282.

Residences

With plans to open 200 group homes for the developmentally disabled during the next three years, the Michigan Department of Mental Health devoted the April, 1979, issue of its newsletter, LINK, to its group homes plans, people, and progress. Information: LINK, MDMH, Lewis Cass Building, Lansing, Michigan 48926.

THE MEDIA VIEWDear Abby

We hit the publicity "jackpot" in April! As we mentioned in our March-April GV, "Dear Abby" printed a letter and our address in her column. Even though we did have several objections to what she printed, (namely, the letter stressed "sensationalism" rather than education, and she misprinted the house number of our address) we were pleased with the exposure. During the week which followed the column, we received around 2,000 letters, about 20% of which were inquiries from parents, doctors, and other related medical and educational facilities. The few desperate letters for help received from parents with diagnosed Prader-Willi children made the handling of all this mail worthwhile.

We also received several requests for more information from newspapers and two other free lance writers. The St. Paul Pioneer Press, one of these requests, already ran a very good, front-page article on the Syndrome.

(A big thanks to the Wett family, especially Edie, who was on her college break, for answering a majority of these letters.)

Reported by Marge A. Wett

A Reading List on Scoliosis

Brace Yourself and What If You Need an Operation for Scoliosis?, \$1.50.
Rainbow Youth Spine Center, 2065 Adelbert Road, Cleveland, OH 44106.

CIBA Symposium "Scoliosis", \$1.00.
CIBA Pharmaceutical Company, Medical Education Division, Summit, NJ 07901.

Early Detection of Spinal Deformity.
Drs. Bacevich and Rozen, 7770 Cooper Road, Cincinnati, OH 45242.

Scoliosis - Curvature of the Spine.
National Scoliosis Foundation, 48 Stone Road, Belmont, MA 02178.

Scoliosis Screening Program Informational Booklet
Portsmouth Orthopaedics, Inc., Mercy Medical Plaza, Suite 1, 1835 Oakland Avenue,
Portsmouth, OH 45662

Scoliosis - What's That? \$.25.

So You Have Scoliosis and When You Are Hospitalized for the Correction Of Your Spine,
\$3.00 for both.
Greater Cincinnati Spinal Deformity Center, Suite 5307, Good Samaritan Hospital,
Cincinnati, OH 45220.

Your Milwaukee Brace
Portsmouth Orthopaedics, Inc., Mercy Medical Plaza, Suite 1, 1835 Oakland Avenue,
Portsmouth, OH 45662.

A Straight Look At Spinal Curves - Article from Family Circle magazine.
National Scoliosis Foundation, 48 Stone Road, Belmont, MA 02178.

THE MEDIA VIEW, Continued

Mental Retardation: The Leading Edge. Service Programs That Work, by the President's Committee on Mental Retardation, 1979. MR78, for sale by The Superintendent of Documents, U. S. Government Printing Office, Washington, DC 20402.

This report, rather than offering recommendations, describes in detail a wide range of successful programs currently underway throughout the nation. These programs share the goal of bringing retarded citizens into a future of hope, understanding, and personal pride as productive individuals.

The nine sections of the report deal with the family, public school education, community residences, work, self-assertion, the retarded offender, mental health, prevention, and some new directions.

Reviewed by Shirley Neason

A VIEW OF WHO'S WHO

This is the story of an 18-year-old, herein called J.

Our daughter, J, is eighteen years old, and the letters other parents write are much like I would write describing her—except our daughter doesn't talk, except one or two word phrases when she really wants something, which is seldom. She is quite happy most of the time. She went through many unusual behavior spells: coloring on walls, bending spoons, throwing breakable glass, plants, etc., usually without being angry. Then she'd slap her hand and cry. At age sixteen it seemed she had temper tantrums when she would throw things. In this past year she hasn't had temper tantrums except once in a while. Maybe once in two months. She is very overweight, is about 50" tall, and weighs 250 pounds. I try to limit her calories without her realizing it because when we had her on a strict diet, her mood and temper was terrible.

She enjoys going to TMR class at school. She is very afraid to walk on snow or wet sidewalks and has had breathing difficulty, but medication helps that, and having elevated the head of her bed helps her. J can't bathe or get ready for school without help as time means nothing to her and she isn't that interested about anything.

This is the story of a one-year-old.

We have a 13-month-old daughter who was diagnosed as Prader-Willi in July. We first took her to the University of Iowa, then to the Mayo Clinic, then back to the University of Iowa to Dr. Hans Zellweger, who confirmed the diagnosis. We made a move in August with the company my husband is employed with, and she is now under the care of new doctors, but we will be making yearly trips back to the University of Iowa for checks with Dr. Zellweger. We love our daughter more than anything and will do anything we possibly can to see that she grows up with the love and best possible care we and the doctors can give her. I am trying to gather all the information on the syndrome so we can fully understand it.

GATHERED REPORTS

California

The Prader-Willi California foundation had a meeting scheduled for May 4, 1980, at Harbour General Hospital in Torrance. Dr. Bryan Hall was scheduled to summarize a research study of 30 Prader-Willi people. He was a speaker at the 1979 national Prader-Willi meeting in Minneapolis. Annette Dahlman, Executive Director of Dubnoff Center for Child Development, was to outline the plans and projections for the recently funded Prader-Willi group home due to start in 1980. Robert Scott, President of the Foundation, was to speak as well as preside over the business meeting. Dr. George Bray was scheduled to update parents on the one-day-a-month Prader-Willi clinic at Harbour General Hospital. Harvey (Bud) Bush was to report on the progress of a Prader-Willi home in the San Diego area.

The Prader-Willi California Foundation is now incorporated and moving ahead.

Reported by Cal Menzer

Washington: Seattle

The Prader-Willi Northwest Association is now incorporated in the state of Washington. Parents and other interested parties living in any of the Northwest states are invited to become members. Meetings are currently being held every two weeks to plan for the camp which will be held the last three weeks in August. Persons interested in attending the meetings may find out the date and place of the next meeting by writing or calling Judy Leconte, M.S.W., WJ-10, CDMRC, University of Washington, Seattle, WA 98195. Or call (206) 545-1283.

At this writing we have not be able to hire a director for the camp, but we are still searching.

Reported by Shirley Neason

THE GATHERED EXCHANGE

Education

I read to H before he was a year old and still average three books a day. It is very important for a child who is non-verbal, as it opens a world to him that otherwise may have been closed. Plus, and maybe more important, it gives him a tool to use to show the professionals how smart he is. So read! H is now nine years old and we are fighting the TMR label that he has.

Nebraska Member

Food Access Management

D will be eleven this May. He weighs 65 pounds and is not overweight. I can't emphasize how hard we've worked, but it's worth it. He has been a big part of it himself in working with us. We have never stressed he "can't help it". We've always stressed, "You can keep from stealing if you work at it," and this is the attitude he has developed.

Illinois Member

THE GATHERED EXCHANGE, Continued

Adults With Prader-Willi Syndrome

I would like to hear from others with PWS adults. Many programs are being started for the younger ones, but I would like to know what other parents with older children are doing.

New York Member

Recipe: Ice Cream

1 teaspoon gelatin
2 teaspoons cold water
1 teaspoon vanilla

1 cup evaporated skim milk
Artificial sweetener to taste

Method: Sprinkle the gelatin over cold water. Heat evaporated milk slowly. When hot (not boiling) place in mixing bowl. Stir gelatin and add to milk. Chill until set. When set, whip the mixture until it stands in peaks, but not dry. Add vanilla and sweetener and beat again. Return to freezer 30-40 minutes. Soften in refrigerator before serving. Makes eight servings.

Australia, Reprinted from The Open Door

Food Access Management

When our son goes outside to play, he is not allowed to go inside friends homes unless he has our permission first. This way he is not in other homes where food doesn't have to be kept away. The homes he's allowed in are ones where the parents are aware of the problem.

Illinois Member

Scoliosis

Treatment of scoliosis: for the mild curve, treatment presently includes periodic medical follow-up to observe the growth pattern of the spine. More serious curves are treated with bracing and/or casting, as well as by the above. In some cases the curve becomes so severe surgery is necessary.

Education

E is in an EMH class in school and we find it is very important to work together with the teacher. The teacher can't solve behavior problems unless we are aware of them and help at home, too. She set up a "report book" which consists of a diary. Each day she puts either a happy face or sad face, depending on the problems or lack of them. She used to write an explanation of the problems, but now he will tell about them himself. I also write notes to go back to her. He can't tear out pages because they are dated. Now he rarely gets a sad face. We are planning to throw the book away soon since he has established a pattern of good behavior. I talked to him about how he feels about himself when he is bad or good, and he discovered he likes that happy feeling.

Illinois Member

THE GATHERED EXCHANGE, ContinuedRecipe: Sugar-Free, Fat-Free Granola

2-1/2 cups rolled oats	1 teaspoon cinnamon
2 cups Grape Nuts cereal	3 apples, grated
1/2 cup rice flour	3 tablespoons frozen apple juice concentrate
1/2 cup powdered dry milk	1 teaspoon vanilla

Combine all ingredients. Place mixture on large, flat, nonstick pan. Bake at 275° for 45 minutes or until dry and crumbly. Store in air tight container. 3/4 cup = 2 bread exchanges - 1/2 fruit exchange.

Residences

We have received a letter from a woman in Sacramento, California, that runs a family home licensed for five children. She presently has two Prader-Willi young people in her home and has been working with Prader-Willi children since 1967. The Prader-Willi Association cannot recommend homes, but if anyone in this area is looking for a placement, we would be happy to forward a copy of her letter to you and you could investigate the possibility.

Sleep Irregularities

My son doesn't sleep in the shower, but if he takes a bath, he would invariably go to sleep.

New York Member

Fun Learning At Home To Reinforce Academic Skills

1. Use pipe cleaners to make letter and number figures. Available at hobby and craft store.
2. Make a blackboard by spraying the smooth side of a piece of masonite with blackboard paint. Use the rough side for tracing patterns, letters and numbers with fingers.
3. Let your child count the change in your purse or pocket.
4. Plastic letters (magnetized) can be purchased and placed on the refrigerator. Get your child to answer a question you have arranged. (I used to hide his daily can of diet pop, then arrange the letters to tell him where to find it.)
5. Bathroom newspaper: install a tablet and pencil on a string in the bathroom. Each person going in and out is to answer the note on the previous page and write a note for the next person.

From Washington Association for Children With Learning Disabilities Newsletter

Food Access Management

We have so constantly repeated to our son that he should stay out of the kitchen so he won't be tempted, that now I often hear him tell himself that.

Illinois Member

A PARENT'S SHOPPING LIST OF GAMES

<u>Game</u>	<u>Skill</u>	<u>Ages</u>
3D Tic Tac Toe	Math and Logic	6 to adult
"Quibic"		
Dominoes	Math and Grouping	5 to adult
Perfection	Eye/Hand Coordination	5 to adult
	Visual Discrimination	
Yahtzee	Math	5 to adult
Cuisinaire Rods	Math	5 to adult
Mancala	Math	7 to adult
Concentration Game	Math and Visual Memory	7 to adult
Spill and Spell Game	Spelling	8 to adult
Game of the States	Language/Memory	6 to junior high
United States Puzzle	Language/Memory	6 to junior high
Password	Language Skills	8 to adult
Multi Rollaway	Visual Motor	6 to junior high
Scan	Visual Skills	6 to junior high
Memory Game	Visual Memory	6 to junior high
World Map Puzzle	Language/Memory	6 to junior high
Etch a Sketch	Eye/Hand Coordination	6 to junior high
Space Probe	Eye/Hand Coordination	6 to high school
Label Maker	Spelling, Sight Words	6 to junior high
Barrel of Monkeys	Eye/Hand Coordination	6 to junior high
Stratego	Logic and Reasoning	7 to junior high
Scribbage	Reading and Spelling	8 to junior high
Battleship	Logic and Reasoning	7 to junior high
Chess	General	7 to high school
Mathomatic	Math	7 to junior high
Dial 'n' Spell	Spelling	7 to junior high
Monopoly	Understanding Money	All
	Reading	
Probe	Reading and Spelling	8 to high school
Scrabble	Reading and Spelling	All
Bouncing Putty	Strengthen Hand	6 to high school
(From Sporting Goods Store)		
Tinker Toys	Eye/Hand Coordination	6 to 12
Bean Bag Toss	Eye/Hand Coordination	6 to 12
Checkers	Concentration/Reasoning	6 to junior high
Pick Up Sticks	Fine Motor	6 to 12
Constructo Straws	Fine Motor	6 to 10
Funny Bones	Body Parts	6 to junior high
Puzzles	General	All
Card Games	General	All
Puppets	General	All
Puppets	General	All
Chalk and Chalk Boards	General	All
Sesame Street Records	General	All
Lite Brite	General	All
Pro-Draft	Reading and Math	8 to adult
Heads Up	Reading and Math	8 to adult
Magnifying Glass	Science	6 to adult
Gyroscope	Science	6 to adult

EDITORIAL

It was five years ago this past winter that I first received a letter from Gene and Fausta Deterling suggesting that we work together to begin an organization of parents of children with Prader-Willi syndrome. My response was that I would be willing to edit a newsletter if they would take the leadership responsibilities. Thus Prader-Willi Syndrome Association was born.

As the Prader-Willi Syndrome Association grew over the years and expanded to include professionals and others as well as parents, editing THE GATHERED VIEW became an exciting and rewarding experience. The receipt of many letters from parents who were thankful to at last learn that they were not alone in their problems let me know that the work was fulfilling a worthy purpose. Even more thrilling were the telephone calls that came—occasionally even late at night or very early in the morning—from people desperately needing information. Although I wasn't always able to meet their need, each call brought additional information as to what the needs were so we could begin to work on meeting them. Also exciting has been the many opportunities to meet other parents face-to-face and share experiences with them.

Along with the rewards there were a few frustrations. Most of the frustrations arose because of the geographical distance between Minneapolis and Seattle. There was duplication of correspondence, delays in meeting deadlines, and occasional misunderstandings because of the lack of immediate communication, and the extra cost of mailing items back and forth and making long distance telephone calls.

As a result, early this year I recommended that now that we have our headquarters firmly established in the Minneapolis area, we try to find an editor who lives in that area. Our super new secretary, Marge Wett, has been conducting a search and feels she has found someone who will be an outstanding editor. The name of the new candidate for editor will be presented at the Board of Directors Meeting on June 20th.

I will, of course, continue to be active in the Prader-Willi Syndrome Association, currently as part of the Board of Directors.

I want to say thank you to the readers of THE GATHERED VIEW. Thank you for your support and your letters of encouragement over the years. Thank you for all the stories, items, and pictures you have sent to be included in THE GATHERED VIEW. And thank you most of all for caring about people with Prader-Willi Syndrome.

The new editor will begin editorial duties with the July-August issue of THE GATHERED VIEW. I encourage you to continue your support by sending material to be included in the newsletter. The new editor will not be the parent of a person with Prader-Willi syndrome, so does not have the background of personal experience to draw on. A lot will depend on you.

I hope to see many of you in Hyannis.

HEY! THAT'S GREAT!

JoAnn Endres
Wisconsin
Age 18



Daniel Neason
Washington
Age 13



Lisa Wett
Minnesota
Age 15

MENUS FOR A MEASURED DIET**800-Calories-Per-Day Menu:****Breakfast:**

1 medium egg	72
1/2 cup strawberries	27.5
8 ounces nonfat milk	80

Lunch:

1 ounce pressed meat	40
1/4 cup cottage cheese	48
1/4 head lettuce	18
1/2 small tomato	10
1/4 cup cucumber	4
1 small peach	38

Dinner:

1 hot dog	149
1/2 cup kidney beans	109
1/4 small tomato	10
1 stalk celery	15
8 ounces nonfat milk	80
1/2 cup diet gelatin	8
2 medium plums	33

For 1000 calories, add:**Breakfast:**

1 slice toast with	
1/2 teaspoon margarine	100

Lunch:

1 ounce cheddar cheese	104
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**For 1200 calories add all of the above,
plus:**

Lunch:

1/4 cup cottage cheese	48
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Dinner:

1 hot dog	149
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ANNUAL BUSINESS MEETING

In compliance with the bylaws of the Prader-Willi Syndrome Association, the membership is responsible for the election of the Directors of the Corporation. We realize that not all members, possibly a majority, can be present at the annual business meeting which this year is scheduled for Friday, June 20th, in Hyannis, Massachusetts. We are, therefore, enclosing the following proxy ballot for those who cannot be present. Please designate one of the names listed below (or your own selected delegate) to represent you at this meeting if you are unable to attend. Your proxy will have the full power to act in your behalf for all business matters, including the election of the Directors at this business meeting.

This proxy form must be received by the Prader-Willi Syndrome Association no later than June 13, 1980.

Board Chairman, Dr. Delfin Beltran, and board members Fausta Deterling, Dr. Bryan Hall, and Peggy Pipes, board terms have expired and they will be up for re-election at this meeting.

I designate the following person whose name I have checked on the appropriate line to represent me in all of the corporation business decisions including the election of the Directors of the corporation.

Delfin J. Beltran, Board Chairman

Fausta Deterling, Board Member

Bryan D. Hall, Board Member

Vanja Holm, Board Member

Shirley Neason, Board Member

Peggy Pipes, Board Member

Stephen Sulzbacher, Board Member

Richard J. Wett, Board Member

Clarie Ledoux, Board Member

Jean T. Janes, Board Member

Gene Deterling, President

Marge A. Wett, Vice-President

_____ Other (Designate)

Your signature

Date

Please mail to: Prader Willi Syndrome Association, 5515 Malibu Drive,
Edina, Minnesota 55436, no later than June 13, 1980.

EVERYTHING TO ONE ADDRESS

Now that THE GATHERED VIEW will be edited in Minneapolis, it no longer will be necessary to use a separate address for sending items for THE GATHERED VIEW or for ordering handbooks. All future mail should go to the new address of the PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436.

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, 5515 Malibu Drive, Edina, MN 55436.

Among the materials available from the Prader-Willi Syndrome Association are:

"Prader-Willi Syndrome—A Handbook for Parents." \$2.00 for the first copy to members; \$3.50 for non-members and subsequent copies to members.

"Transcripts of the 1979 Prader-Willi Syndrome Association Conference in Minneapolis." \$15.00 for the complete set. For prices on individual papers, send for order form.

PRADER-WILLI SYNDROME ASSOCIATION

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