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

The response has certainly not been overwhelming yet, but a few letters are dribbling in from parents and guardians who are indicating in writing their desire to place their Prader-Willi child or client patient in a dedicated residential setting in the Minneapolis area or any other location in the United States. A dedicated residential facility does not yet exist in Minnesota but, as mentioned in the previous edition of THE GATHERED VIEW, we have been working with several professional group home managers in the Minneapolis area who have indicated a willingness to open a Prader-Willi home provided there is assurance that such a facility would be fully occupied. We need at least twenty-five letters indicating an interest and probable intention to place Prader-Willi persons in such a facility before a home of this nature could be opened.

The debate, however, still goes on as to whether a dedicated facility is the best solution. There are good arguments for both a dedicated facility and a mixed group facility. We would like to hear from our membership about your views on the subject. Those for a dedicated home believe it would have the advantage of providing an environment in which all the residents could be treated relatively equally. The residents would perhaps have more in common with each other and would not be tempted by uncontrolled diets of other non-Prader-Willi residents. It would also provide a nucleus of Prader-Willi people who could be controlled and studied in order to develop recommendations for continuing education, employment, recreation, and general future living limitations. Those who favor a mixed group environment argue that Prader-Willi people must live in the world with all types of people and can more readily accommodate the challenges of the outside world when they also reside in an atmosphere of mixed personalities and physical makeup. The mixed group home will also always have the advantage of being more available throughout the country and world.

Regardless, progress continues, but slowly, toward the development of dedicated group homes and a better understanding of behavioral management in the mixed group homes.

Continued
PRESIDENT'S MESSAGE, Continued

Those of you who were at the National Conference this past June will recall that at our Board of Directors meeting a motion was made and approved that seven committees be established throughout the country to work in conjunction with our national organization on seven major areas. The committees will study and direct their activities towards the following subjects: fund raising, clinic services, group homes, respite care, recreation (including camps), vocational training and placement, and promotion of research. In order to implement this motion, we are in need of persons from our membership who are willing to head up or serve on these committees. We have a few volunteers already, but are searching for many more. The committees will develop reports to be presented to the general membership at our annual meetings and during the year in THE GATHERED VIEW. Many of you have indicated a willingness to help the Prader-Willi Syndrome Association in any way possible. This is a way. We need your help. Please volunteer your assistance by sending us a letter here at our home office in Minnesota.

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Regarding basic research, we hope soon to be able to inform you of a new proposed research program directed toward diet control in Prader-Willi people. The research program will be conducted in the Midwest by a recognized authority on Prader-Willi dietary management, providing that a research grant request is funded. The research program will study the relationship between adipose tissue function and food intake in human beings. The program will be directed toward Prader-Willi persons but will make comparisons with normal subjects.

We have cooperated with the researcher on the grant proposal and hope this will be one more step toward unlocking the secret of the food problem in our syndrome.

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In our future issues of THE GATHERED VIEW we will advise you of our plans for next year's National Conference. We do not yet have anything substantive to report, but we are working on tentative dates for the three-day conference of June 27, 28, and 29, and a location of Hyannis, MA. We suggest you reserve these dates for a combination informative session on Prader-Willi Syndrome and a pleasant gathering with other Prader-Willi parents and guardians.

GATHERED REPORTS

Minnesota: Minneapolis

The photo at right was taken in September at a family picnic held by the Minnesota parents at a state park near Minneapolis. This is the third such outing, and it has given the Prader-Willi children a chance to meet and become better acquainted, as well as giving an opportunity for siblings to observe how other families interact with their Prader-Willi member.

Reported by Gene Deterling
A group for brothers and sisters of children with Prader-Willi syndrome is being led by Judi Leconte and Nancy Couhig of the Child Development and Mental Retardation Center. This initial group is focusing on information about Prader-Willi syndrome, introduction to the clinic and staff, and provides time for discussion of daily problems faced by brothers and sisters in regard to diet and behavior. Session 1 covered introductions and explanation of the aspects of Prader-Willi syndrome (physical characteristics, mental retardation, nutrition). Session 2 covered normal development and the differences between the brother/sister and a Prader-Willi person. Session 3 focused on feelings about brother or sister and ways one can handle these feelings. Session 4 will involve touring the Prader-Willi clinic and meeting the staff. The sessions are planned for Saturdays, October 13, 20, and 27, and Wednesday, November 7.

On October 3, parents met at the Child Development and Mental Retardation Center for a meeting to plan a camp program for next summer. The speaker was Judith Liddell, camp director for the King County Association for Retarder Citizens. She recommended that the procedure for establishing a camp be carried out in the following order:

1. Determine the objectives for the camp. (Deadline October 31).
2. Arrive for a location.
3. Determine costs.
   a. Space  b. Food  c. Staff  d. Other
4. Develop a budget
5. Obtain IRS tax-exempt status
6. Investigate funding possibilities
   a) County case services  b) Home aid respite care  c) Corporations
7. Anticipate all the problems that could possibly arise, plan prevention for such, and obtain adequate insurance.
8. Develop program.
9. Hire a director. (Deadline February).

Judy also suggested that different members of the group be assigned to follow up on each of these steps so that each person need gain expertise in only one aspect of the camping program.

Another parent meeting was held October 25 to determine the objectives for the camp. See separate article for results of this meeting.

The next meeting will be held at the home of Sue and Tom Iverson in Kent on Thursday, December 6 at 7:00 p.m. For further information, contact Shirley Neason at (206) 825-6301. All parents in the area are urged to attend.

Reported by Shirley Neason.

California: Los Angeles

With the assistance of the Dubnoff Center the Prader-Willi California Foundation has submitted an Idea Statement and Request for Funds to the State in order to establish a residence goal.

We should be informed of the results of the original submission within two weeks, at which time we will be required to formalize a more complete budget and grant proposal.

If our request is approved, funds will be made available from the State in July, 1980. In the meantime, we are still at work!

Reported by Robert F. Scott, Jr., President PWCF
GATHERED REPORTS, Continued

California: Sacramento

A parents group meeting was held September 9, 1979, at the Alta California Regional Center in Sacramento. The program included a report from psychologist Jeff Miller, who attended the meetings in Los Angeles regarding the establishment of a residential home designed especially to meet the needs of individuals with Prader-Willi syndrome. Andrea Netten Sechrist, Alta's nutritionist, reported on the Prader-Willi meeting held by CDMRC in Seattle. Dr. Sam Beltran and Marilyn Bintz, who are both parents, enthusiastically discussed the Minneapolis Prader-Willi meeting. Dr. Beltran shared the Board of Directors minutes with the group and urged the group to become as involved as possible in support of the association, and to consider volunteering to work with one of the committees. He also discussed the importance of being a strong advocate for one's child in securing appropriate educational programs. Both parents who attended the Minneapolis meeting commented on how impressed they were with the devotion of the parents from around the country working with their Prader-Willi children.

Reported by Andrea Netten Sechrist, R.D., M.S.

A VIEW OF WHO'S WHO

At the annual meeting in Minneapolis in June, a new vice-president was elected, Mrs. Marge Wett of Edina, Minnesota. At the same meeting it was voted to open the new salaried position of fund-raising chairperson. Mrs. Wett was elected to fill this position also. Here is an introduction to Marge Wett.

She attended colleges in Wisconsin and Minnesota.

She has been married twenty-five years and has seven children. One of her sons has just graduated from college, a son and daughter are in college, a son is in the Air Force and also going to college. She has a daughter in senior high school, a daughter in junior high, and the youngest is in elementary school. Her junior-high daughter, Lisa, has the Prader-Willi syndrome.

The Wett family likes to ski and travel together and have recently taken on the project of remodeling an old farmhouse they bought.

Marge has been a "professional volunteer" for about twenty years. She has worked chiefly in the areas of hospitals, schools, churches, and new neighbor groups. She has held several offices, the last two being Ways and Means Chairman for one of the local schools and President for a group named "Edina's Special Children's Group."

When she can't find anything else to do, she runs a business, "Mardi's Studio", where she welds and makes metal sculpture.
A VIEW OF WHO'S WHO

This is the story of an 18-year-old with Prader-Willi syndrome, herein called L.

I read the article in Home Life and for the first time in our daughter's eighteen years, I heard of someone like her. With the help of the article, our endocrinologist was able to make a diagnosis that made her surgery for scoliosis much safer. He started treatment to replace hormones not present because of the inactive pituitary glands. She had the surgery in August (1978) and came out of her cast last week (March, 1979). There is a possibility that the bones did not fuse as evidenced by pain and curve increase.

L is the youngest of five children, the only one at home now. She has had much love and attention; we have always tried to treat her as nearly like the other children as possible. She sat alone at one year, walked and talked at two. She could carry a tune before she could talk. She had eye surgery twice between her second and fourth birthdays. Her eyes do not fuse, but she has good vision in each eye although she is nearsighted. Her teeth were badly decayed, and we had to place her in the hospital, while still a baby, for them to be repaired. She held food in her mouth for long periods of time which probably caused this.

Toilet training was no problem. She has always tried to achieve and has an unbelievable ability to stay with work or play through hours and days. She can entertain herself and is working on or planning something new all the time. She no longer tries to achieve the more difficult accomplishments but works at a lower level where she doesn't have to think so hard. She has trouble counting money and telling time, but she can add, subtract, multiply, and divide. She reads well, but must read aloud to comprehend. She has had excellent teachers and went to public school in L.D. or E.R. classes until high school. She is now in a special private school and is in the eleventh grade.

L has always had a weight problem, but she has worked hard at controlling her weight on several occasions. She began the diabetic diet before her surgery and has lost from 159 to 124 pounds during the last eight months. She looks so good and has such high hopes that keeping her on the diet is not difficult. I am not as optimistic at this point as she is. She is taking Cortisone, Premaring, and Provera which is causing her to mature physically.

She is prone to prefabricate when the truth would be better, especially with her peers (whatever age that might be!). She is very jealous of praise and must be constantly reassured in whatever she does.

She had been helping in the church nursery until recently when we learned that she would not listen to nor obey those in charge, so she has had to give this up. She could do many things if she were not so headstrong and unable or unwilling to listen to reason. You cannot reason with her once her mind is set. She is also very inconsistent in her emotional reactions.

I am a home economics teacher, and I'm sure that our experience with the older children and my training in nutrition have helped us to instinctively support L in some of the eating and social problems although we knew nothing about the syndrome during her early years. This certainly doesn't mean that we feel equipped to handle the problems that we see before us. In fact, with all her attributes, I cannot imagine L able to be independent or stable enough to be employed in intellectually oriented jobs, and she hasn't the strength or stamina for physical work.
REPORT FROM THE FUND RAISING CHAIRMAN

In June I attended a three-day conference in Chicago on Fund Raising. The reason I attended this conference for the Prader-Willi Syndrome Association is to obtain some necessary background to get our organization "off the ground", so to speak, in attempting to get some funding. I believe we have been an organization long enough now and are established enough that we should be thinking ahead to the time when we can open an office and have at least one secretary to handle some of the necessary paperwork that goes along with a national organization. As many of you know, for years Gene and Fausta Deterling have been doing this job, and it really is a full-time job.

There are foundations and people that are willing to donate money to "good causes", but the "good causes" far outnumber the amount of money available. Funding is not going to be an easy job. Very few of these foundations that do give larger sums of money are very eager to give money to organizations unless they are convinced that the Directors and the membership have given their "all" and are really backing their own organization. Giving their "all" includes time and money as well as a show of genuine effort.

What have we done as an organization and as individuals?

What fund raising has any of the various parts of the country done that was contributed to the running of the National organization?

If I am going to be successful as a Fund Raiser for the National Organization, I need a Board of Directors, and a full membership that is doing their part.

In the very near future we are going to get together an approach to work on. Let me hear from some of you what part you are going to play in making our goal successful.

Marge A. Wett, Fund Raising Chairman, Prader-Willi Syndrome Ass.

P.S. We received one generous donation for the Prader-Willi Syndrome Association. One member decided to give us their "United Way" donation for this year. What a terrific boost for our needy treasury if a few more people decided to do that now and then.

HEY! THAT'S GREAT!

This is Illya, age 14, in the ninth grade. He is in a Special Education class going at his own pace. He is very mannerly, happy, and well-liked by young and old people. He is on a diet, and is getting adjusted to it very well. He never makes a fuss if he can't do something or have something that he shouldn't. He understands very well and is dearly loved by his family.
MENUS FOR A MEASURED DIET

A HOLIDAY DINNER

Orange-Creme Cocktail
Diet Vegetable Dip
Raw Vegetables
Turkey
Special Dressing

Diet Vegetable Dip
1 8-ounce bottle low calorie bleu cheese dressing
2 ounces bleu cheese
½ cup nonfat milk

Blend ingredients and serve with raw vegetables, such as celery, carrots, radishes, cucumbers, cauliflower, green pepper.
2 tablespoons = 1 serving

Special Dressing
½ cup chopped onion
1/3 cup diced celery
2 tablespoons chopped parsley
½ teaspoon poultry seasoning
1/3 cup chopped mushrooms
3 tablespoons chicken or turkey broth
1 ounce cubed bread

Combine ingredients and bake in small pan in 350° oven 45 min.

Low-Calorie Cranberry Sauce
Broccoli with Low-Cal Hollandaise Sauce
Bread
Orange Spread (for bread)
Fresh Fruit
Skim Milk

Orange-Creme Cocktail
2 tablespoons orange juice concentrate
½ cup diet creme soda
½ teaspoon lime juice

Low-cal Hollandaise Sauce
1 cup low-fat cottage cheese
3 tablespoons lemon juice
2 egg yolks
½ teaspoon prepared mustard
½ teaspoon seasoned salt
½ teaspoon salt.

Blend ingredients in blender until smooth
½ cup = 1 serving.

Orange Spread
6 ounces Ricotta cheese
2 teaspoons orange juice concentrate
1 teaspoon vanilla
2 packets powdered artificial sweetener
3 drops yellow food coloring
1 drop red food coloring.

Stir until well blended.
1 teaspoon = 1 serving.

THE MEDIA VIEW

Parents Handbook
The booklet, "Prader-Willi Syndrome--A Handbook for Parents", is available once again. Because of the demand, a reprinting was done without waiting for revisions to be made. Revisions will come at a later date. The price is still the same: $2.00 for the first copy to members; $3.50 for non-members and for subsequent copies to members.

Legislation
If you would like a copy of the latest edition of the publication, "A Summary of Selected Legislation Relating to the Handicapped," free copies can be ordered from:
Office for Handicapped Individuals
Clearinghouse on the Handicapped, Room 338.D
Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
STUDENTS' LIVES CHANGED AFTER EXCESS WEIGHT LOSS

(This information has been provided through the cooperation and permission of the parents and students involved in hopes that it may benefit others with Prader-Willi syndrome).

Reprinted from Lakemary News, newsletter of Lakemary Center, 100 Lakemary Drive, Paola, Kansas 66071.

by Gene Kean

Joy Courtwright, 16, of Kansas City has lost 120 pounds, more than half her weight of 238 pounds two years ago. Now at 118 pounds and nearing her goal of 105 pounds, she is a very happy girl. Saying that her life has changed is almost an understatement.

Another student, Cecilia Budke, 8, of Hays, Kansas, now 74 pounds, has lost over 57 pounds, which doctors say saved her life. She, too, can now run, play, tie shoes, wear ready made clothes, and participate with other students in activities.

When Cecilia was enrolled at Lakemary Center at 7, she was 121 pounds and had been 131 pounds when admitted to a hospital in congestive heart failure from overweight. Recommendation was made by physicians for her to be placed in a more controlled situation than was possible at home to diminish the excess obesity with a secondary problem of cardiac decompensation.

Both Joy and Cecilia have Prader-Willi syndrome, but for now have won new lives by their own determination and those dedicated to help them.

Both girls are currently on a 1,000 calorie diet eating in the dining room with other students. They are also on a regular program of exercise.

The older girl had been placed on a 1,250 calorie diet when she arrived at Lakemary June, 1977, at fourteen, weighing 238 pounds and 57 inches tall. She had begun gaining large amounts of weight at the age of two. At ten an ileal bypass surgery was done as a "last resort" in the struggle to curb weight gain. However, following surgery, the weight gain continued.

She lost 12½ pounds the first month at Lakemary. She was ecstatic and kept joyfully repeating, "I can't believe this!" Weight loss continued to average two pounds a week for eight months. After a two-month "plateau" the consultant dietitian and medical staff agreed to change the diet to 1,000 calories daily. Weight loss then continued at about 5 to 6 pounds per month. Just before her 16th birthday (September, 1978), Joy was given an all school "recognition party" with parents in attendance to celebrate the accomplishment of 100 pounds of weight loss.

The girls' trays are prepared separately with measured portions of the regular menus and substitutions such as a vegetable rather than French fries, and Continued
fruit for dessert rather than cake or cookies. They receive a well-balanced meal and no vitamin supplements have been used, according to Lakemary Nurse Joyce Wassmer and Eleanor Watson, consulting dietitian.

"We subscribe to the theory that absence of refined sugars in the diet may help to control hunger," said Joyce Wassmer. "Some research has indicated that Prader-Willi children may be borderline diabetic.

On picnics and outings, child care and resident staff see that low-calorie snacks, diet pop, etc., are provided for eight students who are in a weight loss group.

"Changing eating habits as learned in a structured setting is difficult to maintain in the home situation," said Nurse Wassman. Home visits often are in conjunction with holidays and special occasions requiring extra diligence on the part of parents to maintain diets while the children are home. These two girls' diets have been successful because of the fine cooperation the parents have given to the program.

Sugar, ice cream, cake, other sweet desserts, and access to food must be eliminated during home visits, with no exceptions because of holidays. Joy's mother served watermelon instead of cake and ice cream when she was home for her birthday weekend.

All parents concerned and the social agencies are now very positive about the results being obtained. One parent commented how thankful they are to have made the decision for out of home placement at Lakemary. They have a friend with a Prader-Willi syndrome child who decided to have their child remain at home. She is now at 350 pounds, has passed her 18th birthday, making many residential facilities for children unavailable to her.

Other concerns had been lack of good peer relationships in their own home communities and schools. At Lakemary the girls have many friends and, in some instances, have become leaders in their classroom or residential groups. "With parental goal of return to home living, we see close contact and cooperative planning of individual programs for training as essential," said Mrs. Wassmer.

Positive reinforcement in the form of praise and encouragement is the primary form of behavioral management. The girls get to carry a note indicating the amount of weekly weight loss to share with staff and friends who praise them. Calling home is another earned privilege.

THE GATHERED EXCHANGE

Services

It is with much anguish that I am writing concerning an article which appeared in the Chicago Sun-Times concerning a thirteen-year-old boy who died from smoke inhalation in Crystal Lake, Illinois. As the article states, the young boy suffered from Prader-Willi syndrome and was chained by his mother to his bed when she had to leave him alone. Because he was chained to the bed, he was unable to escape the toxic fumes which eventually caused his demise. I'm bringing this to your attention to demonstrate the serious tragedies which can result because of inadequate treatment of Prader-Willi patients.

Illinois Member
Motor Development

Are there children with the syndrome who cannot walk long distances? My son is 14 and still has to go to school by car. He has had three treatments for duodenal ulcer.

Canadian Member

Services

Iowans who are concerned about their genetic risk have available a Regional Genetic Consultation Service. Hans Zellweger, M.D., a world-recognized expert on Prader-Willi Syndrome, is clinical director of the Service. The counseling involves diagnosis, interpretation of risks, supportive counseling, and follow-up counseling. For further information, contact the Regional Genetic Consultation Service, Division of Medical Genetics, The University of Iowa Hospitals and Clinics, Iowa City, Iowa 52242. Telephone (319) 356-2674.

Scoliosis

This test only takes a minute. Have your child dressed in briefs or shorts. Ask him/her to bend forward and hang arms in front. When scoliosis is present, the most obvious sign will be a "rib hump" on the back. Next have child stand up straight with hands at sides. Look at the back, and answer these questions for yourself:

- Is one shoulder higher than the other?
- Is one shoulder blade more prominent than the other?
- Is the greater distance between arm and body on one side than the other?
- Is one hip higher or more prominent than the other?
- Is the head out of line with the base of the spine?

If your answer to any of these questions is "yes", you should have the child checked for scoliosis by your physician.

(Note: if your child is extremely obese, this home test is not sufficient. X-rays are required to determine the presence of scoliosis).

SEATTLE AREA CAMP PLANNED

Seattle area parents met on October 25 and made the following plans for a parent-sponsored summer residential camp. Plans are subject to change depending on available facilities, funding, and response.

The camp will operate for nine weeks, from June 15 to August 17. It will be planned for youngsters between the ages of eight and eighteen who have Prader-Willi syndrome. The camp will be planned in three-week cycles, with the program to be generally repeated each three weeks for six campers at a time. Staff would consist of a director, two counselors, and a housekeeper/cook who would rotate time on duty with six days on and two days off.

Goals of the camp are to provide respite for parents, and training for the campers in social and physical skills through diet management, diet education, recreation, development of recreational skills, occupational therapy through crafts, development of conversational skills, and improvement of self-image.

Parents outside the Seattle area who would be interested in sending your Prader-Willi child to this camp, please write Shirley Neason, 26931 S.E. 403rd, Enumclaw, WA 98022. Let us know when you would want your child to attend, for how long, and how much you feel you could pay. Further suggestions are welcome.
THE PROFESSIONAL VIEW

We are a group home serving 34 developmentally disabled individuals. We have four individuals with the Prader-Willi syndrome and have enjoyed pretty good success in helping them control their weight problems.

The oldest individual, a male 15 years old, has been with us for four years. He weighed 89 pounds when he moved in, lost weight and then went up to 104 pounds. Since that time, however, he has lost weight and gained height. As of 10-2-79, he weighs 72 pounds and is 4' 8½" tall. He looks thin, but healthy.

Our other three Prader-Willi syndrome clients are females. One has been with us for a month and has lost three pounds in that time. Her mother was very impressed when they had their first visit, commenting not only about the weight loss, but also about manners and behavior being improved.

Our youngest Prader-Willi female, age six, moved in with us July 1, 1979. She is obviously the most overweight of the four. She weighed 65 pounds on July 1 and as of October 2 she weighed 55 pounds. She is much more active, agile, and talkative. She still has a lot of extra weight to lose as she is short.

The fourth child, a female eight years, ten month old, has lost five pounds in the year and four months she has lived with us. She weighs 50 pounds and is 3' 9" tall. This gal is most persistent in her efforts to steal, sneak, or pilfer food. The biggest problem is when she visits home, when she has gained three or four pounds in a week's time.

Along with looking better in their clothes, posture, and overall appearance, there seems to be less temper tantrums, stealing, complacency, etc. Overall the four individuals are more agile, involved in everyday activities, handle stress better, and have more congenial and pleasant personalities.

If we tried to pinpoint our success to any two major factors, I'd say first is a good diet program, directed by Sara Rasmussen. Not only do the Prader-Willi residents get a limited number of calories per day, but the food is tasty, attractive, and similar to what the other thirty in the home receive.

The second factor is activity. We keep individuals involved and offer a variety of events on a daily basis to keep interest up. This keeps individuals involved and hopefully their minds off food, and it also helps burn up those unneeded calories and excess fat.

I don't want to dismiss any of the common problems that we also have to contend with daily. Believe me, it can be an uphill run (I'm a runner) for the most part. It is satisfying to see individuals improve in their self-awareness and self-image when they lose weight. The male individual looks forward to getting weighed and is very proud of his "skinny appearance."

We would be happy to show interested individuals with Prader-Willi syndrome and their parents our facility, should they be in our area. We're about 100 miles north of Sacramento in the pines and oaks of the Sierra Nevada foothills.

Kent E. Rasmussen, Administrator
Sunny Acres Homes
810 College Hill Drive
Paradise, California 95969
GATHERED NEWS

Resources
An early stimulation program for handicapped infants under three offers in-home infant stimulation services in rural North Dakota. Two occupational therapists provide direct services in nine counties to assure maximum possible development of preschool disabled children. Information: Judith Herzog, South Central Mental Health & Retardation Center, Box 334, Jamestown, ND 58401.
P.C.M.R. Newsbreak, August, 1979

Resources
Parents needing information, training, and support in using PL 94-142 (Education For All Handicapped Children Act) to their children's advantage in the Atlanta area can call on the Advocacy Exchange Network for help: Region III Advocacy Coordinator, 1375 Peachtree St. N.E. (Rm. 766) Atlanta, GA 30309.
P.C.M.R. Newsbreak, August, 1979

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