

# THE GATHERED VIEW

GATHERED VIEW EDITOR

5515 Malibu Drive  
Edina, MN 55436

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT

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## PRESIDENT'S MESSAGE

If you have read only one of my previous letters you will know that my main line of thought is communication, two minds transferring thoughts. Just this evening a television commentator transferred an interesting thought with this quote, "Conversation is the exchange of knowledge, argument is the exchange of ignorance." During the past week I have been privileged to have many stimulating conversations with people who have an interest that is similar to readers of this newsletter, and many who had knowledge much greater than mine in the area of our concern. In response to a suggestion from Dave Ledbetter, (Dave did the work leading to the definition of the relationship of chromosome 15 and PWS) I attended the annual meeting of the American Society of Human Genetics held in Dallas, Texas, October 28-31. My purpose in attending was to have an informational booth that would provide information about the PWSA, our purpose and goals as well as our existence. This information was aimed at the specialists who attend this meeting as they are the physicians, scientists and counselors who are at the forefront of knowledge about genetic problems like PWS and provide this knowledge to the persons afflicted and their families through the various dysmorphology and genetic counseling centers. These are the people most likely to be in contact with persons at the time of diagnosing Prader-Willi Syndrome.

Meetings can be a challenge from many aspects. The first in this case was preparing a demonstration booth, a task totally foreign to me. The space was provided without charge by the Society, but to attract visitors the booth needs decoration and furniture, as well as informational posters and handouts and examples of our work. The booth decorations are rented from a company that set up the fifteen displays and sixty scientific poster boards and I arranged the materials and furniture in the ten by twelve space that was to be my conversational home for two days. The first people I met were the technical sales representatives for the \$85,000.00 microscope that geneticists use to see if our children have an abnormality of their chromosome 15. I was flanked on the other side of my booth by the computer specialist responsible for the national computer network (Birth Defects Information System) that is funded by the March of Dimes and provides clinicians with a means of comparing the findings of their patients with the over 1000 known genetic disorders as well as a file of patients for whom a specific diagnosis cannot yet be made (this is the largest group in the file).

Over the two days that the booth was open I had direct conversational contact with about fifteen percent of the nine hundred and fifty persons in attendance. Several physicians that I had previously talked to on the telephone or written letters to were there and I had the pleasure of connecting a name to a face. People such as Dr. McKusick of Johns Hopkins, whose encyclopedic work is a standard reference of the clinical geneticist, stopped and recognized the work of the PWSA. I had the pleasure of talking to old friends such as Bryan Hall and Jurgen Herrmann who have supported our organization from its beginnings. The nature and purpose of the PWSA were discussed with persons from Egypt to



PRESIDENTS MESSAGE, Continued

the Philipines. Many persons stopped to compliment our organization for work accomplished that they were familiar with (tasks usually performed by Marge Wett's office). The quality and content of THE GATHERED VIEW was repeatedly complimented and one counselor said it was the best newsletter published by the more than fifty parents organizations like ours. For those who were unaware of our group there were handout sheets, clinic registrations forms to be added to the Clinic Services Directory, order forms for the Handbook and Overview and Dr. Holm's textbook and membership applications. Hopefully, the home office will be deluged with responses.

From the scientific standpoint, this anesthesiologist was definitely wading in unfamiliar waters. As long as the topics were clinically oriented, I was able to keep afloat but when they started kicking around the terminology of the cytogenetics laboratories, showing slides of squiggly chromosomes or statistical charts and graphs whose labels were foreign, I drowned. The crown to my realization of ignorance occurred on the last morning when the newly developing research techniques of biochemical and molecular genetics were discussed. I hoped that they would start shouting, then perhaps the vocal utterances that were sailing past with the speed of light would become familiar.

The net effect of the trip was, I think, worthwhile. We have made some people newly aware of our association and hopefully we will have made contacts that will be beneficial to our Prader-Willi persons and their supporting family. There is a growing interest in this organization and although it can be called a parent's organization we have had excellent professional participation and the welcome extended to the professionals I have had the privilege of meeting, at this program, was sincere. Through their efforts we may be able to help new members of our community provide a better life for additional PW persons.

DR. BELTRAN ALSO WRITES

There has been a recent addition to my home. Through a set of unusual events and good fortune my home now has two new Atari computers. Because of my interest in the role of computers in education and science, Ted M. Kahn, Ph.D., Executive Director, Institute for Educational Action Research, Atari Incorporated, Sunnyvale, CA, has granted to me an Atari 400 and an Atari 800 with additional hardware for the purpose of developing programs applicable to the educational and other needs of Prader-Willi persons. This is a powerful, advanced home computer system with exceptional color graphics and sound capabilities that is well suited to educational programs. Besides learning programs, I plan to develop a data base file of persons with PWS that will permit the collection of important data for research without infringing on the privacy of the individuals or their families. This will be done in a manner that will make the screened data compatible with Birth Defects Information System sponsored by the March of Dimes and noted in my President's letter. I plan to have my computer connected to one of the national networks such as the Source or Compuserve in the near future and would like to hear from any other persons associated with the PWSA that will be similarly on line or have any interest at all in the possible role of computers in these areas.

CONSENT FORMS

We have received 66 additional consent forms from our membership. (This brings our total to 283). We sincerely thank the members that did take the time to return this form but again we are disappointed that we have several hundred that did not respond. IT IS NOT TOO LATE! All we need is the name and birth date of your child and a statement of consent or non-consent, to add this to our listing.



A CANADIAN PARENT WRITES:

"I look forward to The Gathered View and find it very informative. Since learning that my daughter had PWS two years ago, our life has changed greatly. \_\_\_\_\_ lives in a community home with two other clients that are not PWS. It was very difficult at first for the staff to understand the eating and behavior habits and \_\_\_\_\_ reached a weight of 263 pounds, she is 4' 8" high. She could hardly walk. With the help of our local association and The Gathered View, the children's hospital, she has been on a 1000 calorie a day diet with 24 hour supervision for 13 months and now weighs 165 pounds. She will sneak food sometimes at the workshop but they are also very helpful...with the loss of weight for the first time in several years she really feels good about herself and is becoming a much happier and cheerful person."

PRADER-WILLI SYNDROME PARENTS ASSOCIATION

One of the British T.V. channels, B.B.C. 1., recently featured Prader-Willi Syndrome on one of its medical programs. As a result of this, we have so far received 32 letters from parents, speech therapists, health visitors and hospitals. Sixteen of these were from parents of diagnosed P.W. children, who had had no previous contact with any other P.W. family.

This brings the total number of diagnosed cases known to us in the British Isles up to 51. This has been a very encouraging response and we are now going to try to interest other T.V. channels, Radio Stations, magazines, etc. in featuring Prader-Willi Syndrome.

Mrs. Janet Williams, Secretary  
Prader-Willi Syndrome Parents Association  
30 Follett Drive, Abbots Langley, Herts WD5 0LP

One of the members of the British PWSP Association has asked if anyone has tried hypnotherapy in relation to the cutting down of sugar, or food intake, for P.W. people. If anyone has any information or views on this subject they can write to the National Office or directly to Janet at the above address.

TERRIFIC

One of our Minnesota members approached their local United Way and asked to be included in the 1981-82 budget. The budget meeting was held and the United Way of the Hutchinson Area allocated a budget of \$400.00 for the Prader-Willi Syndrome Association.

Sometimes it's just there for the asking, have you asked lately?

We sincerely thank the Aul family for their efforts on our behalf.

UPDATE ON NEXT YEAR'S CONFERENCE

We have received 120 votes from our membership stating their preference in location for our Fourth Annual Prader-Willi Conference. Dr. Beltran has appointed a "site selection committee" comprised of representatives from the previous three conferences and as soon as they receive bids from the locations containing program suggestions etc., this committee will evaluate these bids, and your votes, and make the selection for next summer. We hope this decision will be able to be made in the next month or so.

WE'RE ALL EDUCATORS

D. J. Miller, Chairman of our Education Committee, called on all of us to be educators at our last conference in June. We are the people that can be effective in making this syndrome a known entity rather than an unknown.



WE'RE ALL EDUCATORS, Continued

One of our Canadian members wrote: "I think it might be beneficial to put in the next GV the idea of calling local services that work with handicapped children and talking with them about Prader-Willi. I found that everyone I talked with was really interested and wanted to know more. None of them had previously heard of Prader-Willi."

This member sent us the names and addresses of four organizations, along with a donation, and asked us to send them information.

The National Office would be very happy to share our information sheets with any names sent. Some groups are having fund drives and mailing our handbooks and overviews to all local libraries and medical schools.

We have people ask, "What can we do at this distance?" This is one suggestion, be an educator, be a promoter, help people to recognize this syndrome exists.

The National office received a letter recently from a pediatrician. "Thank you for filling my order for five Prader-Willi Association handbooks and the other information. I am sure that my patients will benefit greatly from this. I enclose a money order to cover the costs." Hopefully, this type of letter will replace the parents request for a handbook to share with their doctor because "he doesn't know anything about this syndrome."

RESIDENTIAL CARE

A recent ad prompted the National Office to contact an institute in the State of Wisconsin regarding placement of our children. This is the information that was obtained from them:

"It is our opinion that, on an individual basis, children ages 2-18 years diagnosed as having PWS could be considered for enrollment at Chileda. Chileda is located on a Medical Center Campus, and has four homes which are highly staffed at all hours which would negate the need for unsightly locks on refrigerators, cabinets, etc. The accompanying myriad of problems are not different from many of the children already experiencing Chileda."

1981 Average Monthly Costs:

Educational Costs	702.93
Room and Board	761.11
Mgmt. & General	510.32
Residential Staff	1093.76
Recreation	49.56
Social Services	<u>114.94</u>

Chileda Habilitation Institute

1020 Mississippi Street  
P. O. Box 2799  
La Crosse, WI 54601  
(608) 782-6480

Total \$3,232.62

We do have further information that we would be happy to share with you, or you could contact Chileda directly. We cannot recommend this institute as we do not have sufficient information to do so, it would be your obligation to investigate if you are interested. We do know that they do have some openings and that they do accept out-of-state placement. We have no idea how difficult funding would be to obtain.

A DISSENTING OPINION ON MAINSTREAMING

Does mainstreaming handicapped children in regular classrooms enhance their social and intellectual development?

Unfortunately, says a New York City educator, in many cases the goals of the Education of All Handicapped Children Act have not been met "because many handicapped children have been placed in classroom situations they could not handle."



A DISSENTING OPINION ON MAINSTREAMING, Continued

This is the view of Ronnie Gordon, associate professor of rehabilitation medicine and director of pre-school and infant-developmental programs at New York University Medical Center.

"At best," she says, "mainstreaming has somewhat increased the social interaction of handicapped and normal children. But at worst, it has kept the handicapped from developing their intellectual capabilities because it has deprived them of the individual attention they need."

Her findings were sharply challenged by Jerry C. Gross, architect of the New York City Board of Education program under which the number of mainstreamed children in city schools has risen from several hundred to 7,000 in the last two years. Said Gross: "There have been no studies that show that handicapped children enrolled in special education classes do any better than children enrolled in mainstream classes. One reason they don't is that special education classes deprive handicapped children of normal peers from whom they can learn ways of behaving."

Gross conceded that special classes are still required for severely handicapped students "who cannot keep up with normal youngsters." But he added that "from my observations, mildly handicapped children enrolled in mainstream classes develop more skills than do the mildly handicapped enrolled in special education classes." Other studies have shown that mainstreaming can have a positive effect on the social acceptance of handicapped children.

One of the first studies of mainstreaming was done in 1975 by Suzan Wynne, coordinator of Washington, DC Advocates for Handicapped Children. She said, "We suggested in our report that mainstreaming go ahead, but with a full complement of support services. Unfortunately, too many handicapped children are plunked in regular classes without getting more than an hour or two of the special instruction needed."

In the NYU study, Prof. Gordon followed the progress of 50 pre-school handicapped and normal children for two years after they had been placed in five educational programs in New York City. Prof. Gordon found that one of the often-stated goals of mainstreaming — increased socializing by handicapped children — did not occur. She reported that handicapped children in both the segregated and mainstreaming classes interacted less with their peers than did non-handicapped children. Moreover, the handicapped children in mainstream classes interacted more often with the teachers and materials than with their peers. "Most of the social interaction remained at a primitive level," said Prof. Gordon, because the handicapped are less mature and have had fewer experiences than normal children of the same age." She said, for example, that a handicapped child's way of relating to the normal child was often inappropriate.

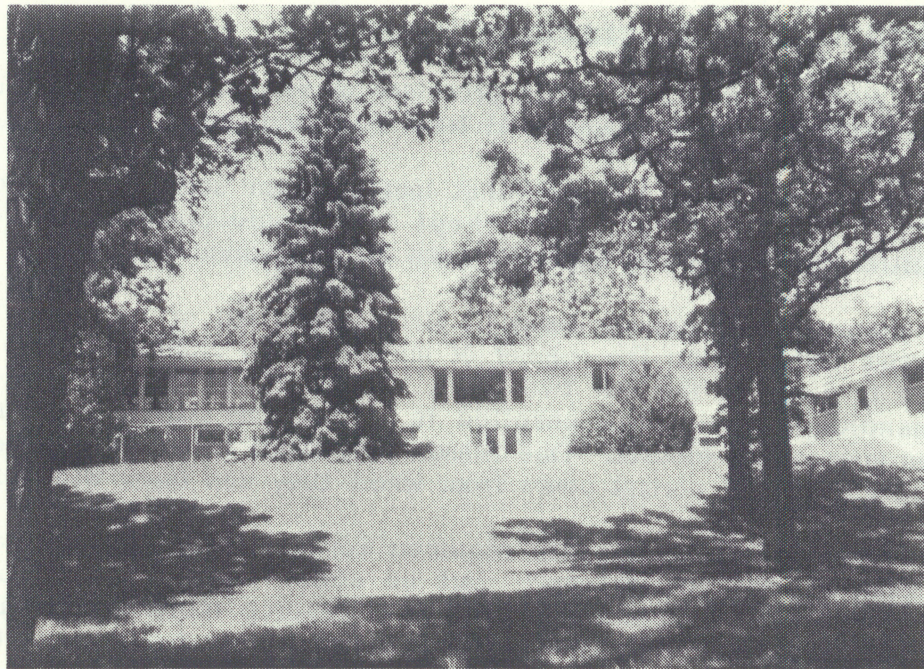
The research also questioned the assumption that mainstreaming would enhance the intellectual development of the handicapped youngsters because it gave them an opportunity to observe normal children working with puzzles, games, and other materials and to acquire such learning skills on their own. The NYU report found instead that although mainstreaming children interacted more with materials than did those in specialized settings, they were less likely to complete tasks involving these materials or to use them in imaginative ways than were the handicapped in specialized classes.

"The only group of children in our pilot study who didn't make gains in intellectual development were the handicapped who were mainstreamed," Prof. Gordon said.

Those in mainstreamed classes, she said, "tended to hold materials but not use them to carry out tasks only if the teachers had specifically directed the children's action step by step."

excerpts from July/August, 1981 issue of UP FRONT





#### OAKWOOD RESIDENCE OPENS FOR 15 PRADER-WILLI PERSONS IN MINNESOTA

"I thought this was going to be a diet place." "Wow, look at all the food!" These were comments heard at the first dinner served at Oakwood Residence in Minnetonka, Minnesota.

Oakwood opened its doors September 1 with 14 Prader-Willi persons age 15 to 28 moving into its spacious rooms. In the month since Oakwood opened, the fourteen residents have lost a total of 103 pounds - and lost it without feeling they were deprived. This has been accomplished with a basic 1000 calorie diet (modified for those who need more or less calories), an extensive exercise program, and, of course, a locked food supply. The diet has been designed by a Registered Dietician and is prepared by our chef and monitored by our R.N. Included in the menu are a great variety of foods, many fruits and vegetables, two beverages each meal and a bedtime snack. Exercise is fun at Oakwood with several visits to the local YMCA each week for swimming, walks in the area and exercise sessions with staff.

At the Open House on October 11, we had TV coverage by a local station, with the residents playing star roles. The residents proudly showed the 100 visitors through the home, gaining many compliments on the warm, homey atmosphere. (Residents have decorated their bedrooms individually, and keep their own rooms clean and tidy).

The residents of Oakwood go to a variety of day programs, the younger members attend the local high schools, two residents are in Day Activity Programs, some are in work training programs and some are in Sheltered Workshops. The program is staffed by 14 part and full time employees headed by our Director, Sue Donahoe, who oversees the day-to-day activities. Our 15th resident has now joined the group, so we are filled in capacity.

We want to express our deep gratitude to Dorothy Thompson and Jon Thompson. We have been very fortunate to have their leadership and expertise in developing Oakwood. Without their help, Oakwood would not be here!

In future issues of The Gathered View, we will be having updates from the Oakwood staff, and within a few months we hope to be able to share some of the programs which are helping our PWS young people live so much happier and healthier lives.

Editor's Note: Dorothy Thompson is available as a consultant and may be contacted at 5505 12th Avenue South, Minneapolis, MN 55417.



## ONE DAY AT A TIME

Frequently our newsletter contains articles about problems facing parents with older children. This is understandable because they are the parents that are now seeking answers. The parents of the younger children do not have the same problems. Dr. Robert Cooke, a pediatrician from a medical college in Pennsylvania, wrote some thoughts on dealing with the special needs children that we would like to share with you.

In dealing with special-needs children, I believe the emphasis should be placed in terms of the day-to-day life of these children rather than the long range prospects. What is going to happen tomorrow, what about next week? Parents should be counseled not to worry about what is going to happen next year or in the years after. Their planning won't accomplish anything. What's the point of worrying whether this child might get to high school when he's now a pre-schooler? There are a lot of steps in between, where time and circumstances and community can change and play roles in what may happen to this particular child. And thinking that this child may end up in an institution with no one to care for him, only yields depression. There is no way for a parent to know what the future will mean for their child.

The emphasis should be on short-range planning. What can we do to make things better for our children next week or next month?

We overemphasize accomplishment in our children, and worry too much about what they are going to become. Parenting of both normal and abnormal children goes too much in the direction of the end product.

Parents of young people with this syndrome are concerned with the future of their children, particularly now when so very few facilities are available to help and serve their children. But the picture is changing, things are looking brighter!

One-day-at-a-time is not always the easiest, but it can be the most practical.

A recent ad for United Technologies Electronics Group in the Wall Street Journal seems appropriate with this thinking:

"Think how microelectronics could change the flowerpot, and along with it, the whole relationship between the flower and you. No more guilt feelings for not having watered your plants. Tomorrow, little sensors could start a built-in-sprinkler system.

No more missing the few hours of the year when your Queen of the Night blossoms. Tomorrow's flowerpot could predict the exact time. No more lonely flowers when you take long vacations. Tomorrow's microelectronics could simulate your presence by generating all the little personal vibrations that make you so dear to your green friends.

Microelectronics will touch and change nearly every object in the world over the next fifteen years, from the biggest to the smallest, from the most likely to the most unlikely. Whatever can be invented will be invented; such as the nature of the human brain."

## A LOOK BACK

"SOMETHING NEW. This is the first issued of THE GATHERED VIEW, a newsletter dedicated to providing a means of exchanging ideas and information among parents and others who must deal with the problems of people who have PWS.



A LOOK BACK, Continued

THE GATHERED VIEW was chosen as the name because its purpose is to gather ideas from many sources, including parents, teachers, medical people, and other professionals in the many related disciplines that make their contributions to the growth and development of handicapped people. Submissions are solicited from any and all who believe they have ideas to contribute. Payment will be the knowledge that you have helped another. Send your ideas and articles to THE GATHERED VIEW at the editorial address listed above."

The above paragraph appeared as the lead off article in the first issue of this newsletter in July, 1975. It is interesting that the only part we would have to change to place the same paragraph again would be the fact that this is not the first issue of THE GATHERED VIEW, but it is the 40th issue.

Thanks to a Dr. Michael Bresnan at Boston Children's Hospital, and a dietician Roseann Howard, the son of Mr. and Mrs. Gene Deterling was diagnosed at the age of six months. Gene and Fausta wanted to learn everything that they could in order to make their son's life a happy one but soon found that there was very little information available and felt there must be numerous other parents with similar circumstances and desires as theirs. Roseann Howard knew of a nutritionist, Peggy Pipes, at the University of Washington and she gave this name to the Deterlings. Peggy encouraged their idea to start an organization for parents and gave them the names of Mr. and Mrs. T. G. Neason in Washington. It was because of the efforts of these two couples that the Prader-Willi Syndrome Association was founded.

A list of eight parents and professionals comprised the beginning. With a little publicity, the number grew to 18 the next month and one year later reached the 100 mark. All but seven of these first 100 members are still maintaining an active membership in our organization.

The parents in Seattle started meeting as a group because of the PW clinic at CDMRC. Parent groups were also organized at Alta Regional Center in California, Michael Reese Hospital in Chicago, in Minnesota and gradually other areas.

With a lot of correspondence, Gene managed to form a board and the Prader-Willi Syndrome Association became formalized in May of 1977.

The comment heard most frequently was, "I've been waiting years for an organization." Again, it really isn't that different today. Parents and professionals are happy to learn of the existence of a group. We have just registered our 932nd member, and presently have an active membership of 724. We are still growing, we are still struggling in some of the same areas, but we have accomplished a great deal and certainly hope to continue to do so.

We will continue to share some of the history of our group in the forthcoming issues of the GV.

FROM AN OK PARENT

Dear Parents or Guardians:

Would you like to have your PW child experience a week of camp life in a parent-child special session and/or a session in which there would be food control. The place is New Life Ranch, a recreation center in the Ozarks of Northeast Oklahoma, also near Siloam Springs, AR. If you would be interested for June or July, 1982, drop me a note with your name, child's age and any special remarks.

Mrs. Marion Shacklett, 6715 South Quincy, Tulsa, OK 74136



SSI AND SSI-DCP

We have asked parents for information on their personal experiences with funding through the Social Security department and investigated this as much as possible as we were seeking to find if the national PWSA could be of some help to parents in this area.

The following information was obtained by the national office:

SSI

States do follow Federal guidelines with very few exceptions. To approve, they check with a listing, to see if the person is disabled or included on their listing. If the person is unable to work, is blind, has missing limbs, etc. or if their body is deteriorating, it is much easier to prove this disability.

Naturally, Prader-Willi is not on this listing and probably could not be placed on it as a physical disability except in the cases of morbid obesity. Therefore, each case has to be determined on a case by case judgement. Regions do differ, job availability varies. The decision has to be made by the information that is given to them. A Wisconsin parent wrote, it is vital to give them whatever information you can. Be sure to include that your child is mentally retarded, if this is the case. Be sure to include education, vocational experiences, particularly if they have been fired from Opportunity Workshops etc. One man stated a lot of denials are made because the parents did not supply enough information.

One office told me approximately 44% of claims go through on the initial request. If they do not, an appeal usually qualifies about 11% more. If you still have not been approved, you may go before a judge and another 50% are then approved. So it helps to be persistent. If this percentage carried through it would mean about 78 out of 100 are approved.

Judgement is made more on the effect the disability has on the person than the cause of the disability.

SSI-DCP

Congress passed Public Law 94-566 in late 1976 to amend Title XVI of the Social Security Act to provide a state formula grant program to be known as Supplemental Security Income - Disabled Children's Program (SSI-DCP). Recognizing that children with chronic illness and handicapping conditions require more or less continuous care and services over extended periods the individuals involved in the development and passage of the legislation sought to create a program that by design required planning and care for the child's total needs. Educational programming was to be considered along with treatment of a child's physical disability. Any services provided were to be adapted to incorporate changes occurring in a child's growth and development. The legislation stressed the importance of an integrated and comprehensive approach to providing services by mandating interagency coordination.

The SSI-DCP serves children up to age 16 who are eligible for SSI benefits from the Social Security Administration. The child and parents must have a low or moderate income with limited resources. Once a child is determined eligible they are referred to the DCP directly from the Social Security Administration. Assessments are done to evaluate the child's needs. In the State of Minnesota they are serving 1300 children at present, and 50% of these children no longer reside in their natural homes.

A Wisconsin parent wrote: "In response to the question of SSI for Prader-Willi Children, our son, aged 11, has qualified here in Wisconsin but not without a battle. Our first application was turned down after three months of waiting. You need an attorney who



SSI-DCP, Continued

will document all of your child's medical records, school records, etc. If your application was turned down - appeal it as soon as possible even if the appeal time, 90 days or whatever have passed.

Our son's case was appealed 1-1/2 years after the first application was denied. All medical history, school records, should be sent along with a statement signed by parents and attorney, explaining every problem, every disability, and every special need etc., your child has. This should be explained in complete detail, what he can not do for himself should also be included.

Our son was then sent by Social Security to a doctor miles away to be examined, who did not know him or his history. I feel this doctor's report was the deciding factor in our case."

It is our opinion that even though this qualifying is done by a federal agency, it is an individualized decision and each case is considered on the information that you, as a parent, supply and the national office can not hope to make this procedure any easier. We have heard from several parents now that they have qualified but it has been with a great deal of effort. All of the parents we have heard from have had older children except the case of the 11 year old mentioned above. We have heard from other parents that are still trying. If we receive any further information, we will share it with you.

GOOD NEWS - BAD NEWS

We are happy to share good news whenever we can but feel it is fair to sometimes share bad news also. Parents all over the country are badly in need of a proper placement for their children and the places just do not exist. One mother wrote us: "I feel that I must get my son out of the place where he is at present. They have refused to reduce his medication. His eyes roll back in his head as well as many other symptoms — especially asleep most of the time. I can't understand why the government will pay almost \$1000 to a Residence-Workshop placement for my son but will not allow one cent for his care in his own home. I feel so badly about this as I do not think he is receiving the care, love and concern which he needs, nor the diet supervision which we all know is so vital." This mother wants to care for her own son but cannot afford to quit work to do so. Her son has had several placements where their answer to behavior problems is the use of tranquilizers, and where they admit food control is not possible.

Another mother that has been fighting for a proper placement of her son for several years writes: "My son is now in a nursing home on the recommendation of a clinic doctor, who found he was severely anemic (requiring 3 blood transfusions) and suffering from congestive heart failure. The doctor says his heart and lung involvement is irreversible, so he estimates 'more than a year but less than five' of life."

The Minnesota parents group worked unbelievably for almost two years to open a proper residence for young people with this syndrome. A woman in New Jersey has recently opened a home and is getting no cooperation from the state whatsoever.

Through parent education and publicity, whenever it can be obtained, the PWSA is working to do whatever we can to alleviate situations such as these. With strength and "people power" more and more parent groups are forming, and hopefully, more and more facilities will become available.

We understand about 35 people (parents, professionals and interested persons) attended a meeting in Massachusetts in September. The Middle Atlantic Group (PA, NJ, MD, DE, NY) held their 3rd get together in Horsham, PA on September 26th. Nina L. Steg, M.D., Chief of Pediatrics, Alfred I. duPont Institute of Wilmington, DE was the speaker. October 17th was the date for the Tri-State Area meeting in Western Pennsylvania and also the date of the Midwest Regional meeting in Illinois.



Letters have been sent out to parents and organizations in Connecticut and they hope to have held their first meeting November 18th. They have been working with Dr. Suzanne Cassidy who comes from the University of Washington in Seattle and studied under Dr. Vanja Holm. She is now on the faculty at the University of Connecticut Health Center.

We hope these groups will continue to share news of their meetings and the knowledge gained with others in areas where meetings have not begun.

#### LOWER MAINLAND PRADER-WILLI SYNDROME ASSOCIATION

"Lower Mainland" is the designation for a group of municipalities and cities in and around Vancouver, B.C. Canada and the above has been the new name chosen for a group of parents that have been meeting since November, 1978.

Their first goal was to try and find some way to educate the general public and interested professionals about the PWS. In the near future they hope to have a presentation made by Dr. David Suzuki, a well known geneticist in Canada, on the CBC network.

Their long range goal is to get a group home, with trained staff, for PW persons that could also be used as a relief center for parents with young PW children. Because of the lack of success with present placement of PW young people, this group hopes to have a very structured and well staffed home and realizes the enormous amount of work that they have ahead of them.

Through the efforts of a senior citizen group, they have published a pamphlet about the syndrome. This fall they are planning on distributing it to all school districts throughout the Province of British Columbia, as well as the public health offices, in the hopes that it will answer some questions for parents of PW children.

If anyone in the B.C. area would care to contact this group, you may contact either of these people:

Isobel J. Fairweather, Chairperson  
L.M.P.W.S.A.  
809 Prospect Street  
Coquitlam, B.C., Canada V3J 6E8

Mrs. Gill Leakey  
L.M.P.W.S.A.  
69 East 46th Avenue  
Vancouver, B.C., Canada V5W 1Z2

#### EXCERPTS FROM A PARENT MEMBER

I would like to tell you about our PW daughter that has spent over 15 years in an institution. It was surely one of the hardest decisions my husband and I ever had to make but with other children to consider we felt we had no choice. She was causing terrible disruptions in our home life and it was coming to the point that life really wasn't worth living. She was a delightful young child but from about the age of 11 on her behavior changed drastically, and even though she appears fairly bright and not really that retarded, problems at home and school seemed almost insurmountable. Our whole family attended therapy sessions with a psychiatrist....there were no answers or help for all of our questions and problems.

As far as the institution is concerned, over the years we had some problems...but with the growing knowledge of the syndrome and the fact that there are now other PW children there, things have sorted themselves out. Our daughter's behavior has improved immensely. She attends a sheltered workshop daily...(She mentioned food was not completely controlled in her traveling and living arrangements). Our daughter is one of those people who really doesn't bother about eating too much unless the food is out for her to see, so although she's gained a bit too much over the summer, her weight certainly has never been out of control.

As I said before, I don't agree that institutions are the place for PW people, but an awful lot depends on the institution. I feel very sorry for parents who, though they may have adequate institutions in their areas, are unable to bring themselves to part with their children. They go



through what I call "living hell" in order to avoid the stigma of an institution. The new concept of having handicapped people live in the community is a grand idea, but until we have something better than what we have at present to offer PW people, I feel the whole family has to be considered and not just one person.

#### PRADER-WILLI MIDWEST REGION ASSOCIATION

On October 17th, parents from a six state region attended a meeting and formed the Prader-Willi Midwest Regional Association. Officers were elected and committees were formed to work on various projects. One member wrote us that they are very excited about the prospects for this regional group and hope to be an active and integral part of the National Association.

The National PWSA is in the process of developing guidelines to be used by member groups. We hope to be able to submit these to chapters for their approval and suggestions by the end of the year, and have them finalized shortly after the beginning of next year. These forms will be submitted to the following groups: P-W Northwest Association, Washington; P-W Association of Minnesota; P-W CA Foundation; San Diego Area Group; PWSA-Australia; PWA of Canada; PWS Parents Association of England; Middle Atlantic States in Pennsylvania; the Boston MA group; the Tri-State Area group in Western Pennsylvania; Lower Mainlands PWSA of Canada and the above Midwest Region group meeting in Illinois. If your group is not mentioned, please advise us of the name and address of your contact person in order that you may receive this information.

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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 U.S. members; \$15.00 per year for Canada, Mexico and overseas members. Send dues and change of address notices to PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436.  
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