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

In everyone's life, in every business, in every activity in which people engage themselves, and in every struggling organization such as ours there are bound to be periods of discouragement. I am happy to report, however, that our moments of discouragement with the progress of our organization have passed, and we are now back on track with the goals we originally set out to achieve. We had a temporary lull this spring and early summer during which I was seriously concerned about the future of our (almost) five-year-old organization, the Prader-Willi Syndrome Association, when the membership growth had stagnated. Our National Conference this past summer, however, must have been the catalyst which turned everything around. Since July we have added fifty memberships, already surpassing the goal of 390 members estimated for year-end 1979 at our Board Meeting in June. With a year-end membership of 401, we are still a little below the 415 estimate made a year and a half ago at our Board Meeting in San Francisco but at least we're moving in the right direction. As a result of our June Board Meeting and some ensuing action, we are building some additional strength into our organization which should enhance our future and that of our Prader-Willi people.

We have begun the establishment of some of the national committees about which we have spoken in recent issues of THE GATHERED VIEW. We now have tentative candidates for chairpersons of the Vocational Training and Placement Committee, the Fund Raising Committee, and the Clinic Services Committee. We still must find members to head the Group Placement, Respite Care, Recreation (including camps) and Promotion of Research Committees. Hopefully by our next issue, we will be able to hear from many more of you who will serve as either chairpersons or working members of these committees.

Our organization is also in a transition stage as we move our administrative activities to a new address. At our national meeting, Fausta and I announced that we will be retiring from our positions as Secretary and President as soon as we have suitable replacements. We have taken the first step by transferring the secretarial position to Marge Wett who has now assumed the duties of Vice President/ Secretary. This is only the beginning

Continued

PRESIDENT'S MESSAGE, Continued

of some important steps which will allow Marge to take over much broader responsibilities for developing the future of the Prader-Willi Syndrome Association. I consider this a very positive move and hope you will join me in welcoming Marge to this new position.

From this point on our new headquarters address will be:

Prader-Willi Syndrome Association
5515 Malibu Drive
Edina, MN 55436

We will also retain our previous Long Lake Post Office Box for at least another year to allow our new address to be fully publicized.

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The response to our request for an updating of our listing of Facilities, Physicians and Other Practitioners familiar with Prader-Willi Syndrome has been very encouraging. Similarly, the response to our request for names of Prader-Willi people has been exceptionally good. We are now in the process of sorting out all this information and will publish formal listings as soon as possible. We will make our listings of Facilities, Physicians, and Other Practitioners available to our members. Our listing of Prader-Willi people will be forwarded to all parents and guardians who have provided this information, but we will otherwise do our best to maintain the confidentiality of the names. It is still not too late to send your replies. We will try to update these listings once a year.

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Our need for additional funds has become more critical as we struggle to expand our activities, and unless we continue to receive donations from our membership, we will be forced to curtail some of our plans. I have faith in all of you, however, and expect that you recognize that we are all in this together and you will continue to support the only international organization in the world dedicated to the betterment of the future of all Prader-Willi people. I am confident that our recent appeal mailed to our membership will not go unheeded.

Gene Derterling

THE MEDIA VIEW

The Exceptional Parent

The Exceptional Parent is a magazine for parents of handicapped children. A sample copy of a recent issue of this magazine is available from the publisher. Send $1.00 to cover postage and handling to: SAMPLE COPY, The Exceptional Parent Magazine, Suite 700, Statler Office Building, Boston, MA 02116.

Also available from the magazine are free descriptive brochures for distribution at meetings. These can be ordered in any quantity, and may be ordered from the same address.

THE FUND RAISING VIEW
A Letter From A Member:

Gene Deterling, President-Treasurer
Prader-Willi Syndrome Association

Dear Gene:

Enclosed you will find a check for two hundred dollars from the Military Order of the Purple Heart, Chapter 5.

I solicited the donation from this organization for our Association. I would like to challenge the other members of the Association to make solicitations of the various organizations, and try to match this donation.

I feel it is very important that we increase the number of outside donations to our Association, especially if we are to realize any growth and be in a position later to further any research into our children's syndrome.

Sincerely,
Joseph K. Corcoran

THE BLUE ROSE

by Wendy Birkin, former editor of The Open Door, newsletter of the Prader-Willi Association (Australia):

Why am I different to other boys and girls?
I have five fingers and toes, my hair has soft brown curls.
We are all like flowers in a garden, yet I stand out from the rest.
I move a little slower, don't seem to have much zest.
Maybe I can be a flower; I can be a blue rose.
A blue rose is beautiful; there aren't many of those.
I shall stand tall in the garden, hold my head up high.
I shall be admired, have people say, "What a beautiful rose.
I wish we had one of those, so rare and precious, a delight to behold".
As I grow, I shall stand apart, but a blue rose doesn't care.
A precious gift sent to only a few, I'm glad that God gave me to you.
For you will tend me with loving care; your love will share.
When I feel different in moments of reflection.
I know that your love will be there, your tender care.
It feels good to be different, precious, and rare.
I hope you will help me through the years,
The tempers, frustrations and terrible fears, the silent tears.
I am a Prader-Willi syndrome child, a blue rose.
It feels nice to be one of those.

GATHERED NEWS

15 planning points and 13 program maintenance principles, stated in four pages make up a valuable paper, "Alternative Living Programs," prepared by the Grant-Blackford Development Center, 2724 S. Carey St., Marion, IN 46952

P.C.M.R. Newsbreak, June, 1979

THE MEDIA VIEW, Continued

Prader-Willi Syndrome: A Handbook for Parents

We want to remind our readers that copies of the handbook for parents are once again available. The cost is $2.00 for the first copy to members and $3.50 for subsequent copies to members and copies to non-members. Order the handbook from THE GATHERED VIEW, 26931 S. E. 403rd, Enumclaw, WA 98022.

THE RIGHT TO AN APPROPRIATE EDUCATION, Continued from the September-October Issue

Study the Final IEP Before Giving Consent

Do... have a complete understanding of the IEP that is produced. A final copy should be given you in writing. It should not contain general goals, but clear cut objectives such as learning to read at first grade level. The IEP should state how much time a child is to spend in the mainstream and clearly define the services to be given. Check the IEP with people who can advise you.

DO... make sure that appropriate vocational education is in a teenager's IEP

DO... be firm about things you consider important without being so rigid the school can't get the plan off the ground. If a specific class or program has been recommended, visit it to see if it really meets your child's needs.

Due Process. Parents must give consent to placement of their child. If you feel an essential part of the program is omitted, is harmful to your child, or is inappropriate, make your objections known. If the school system is not able to provide the kind of educational program your child must have, it is responsible for financing an appropriate education in a private facility. In all controversies you must have documentation to support your view. If possible, meet with the IEP team again to present your view. If you reach a dead end, ask for a due process hearing. While controversial issues are being decided, children must be permitted to remain in their present school setting.

Follow the Program and Make Sure It's Working

DO... get to know the teacher once your child is placed. Regular conferences are important. A good relationship between you and the teacher can catch a lot of problems before they get too big to change.

DO... help teacher and other school people learn more about handicaps. Share books and articles. If possible, arrange for your child to become acquainted with the teacher before school starts. Offer to talk to other parents in the class so they can help their children accept and understand differences.

DO... make sure a formal evaluation of your child's program takes place every year--more often if necessary.

DO... listen to your child and respect what he's saying to get his reaction to schoolwork, to his teacher, and his classmates.

But Don't

DON'T... let other people plan for you. If you have reason to think the school people have met "behind the scenes" to agree on the IEP, effectively keeping you out of the act, let them know that you and the school must work together.

DON'T... settle for poor or inadequate services. If you find that the

Continued

THE RIGHT TO AN APPROPRIATE EDUCATION, Continued

resources to carry out your child's IEP don't exist, demand changes in keeping with the promise of an appropriate program.

Due Process. If the school does not provide the appropriate resources in response to your requests, you may request a due process hearing.

DON'T... let yourself feel put down at meetings held to discuss, plan, or evaluate your child's program. If professionals use language you don't understand, feel free to ask for an explanation. You can make valuable contributions by raising questions when ideas and recommendations don't seem to make sense.

DON'T... forget that, no matter how important eductional services may be, you child is a young, responsive, growing individual with the need to laugh, play, and make friends. He must have every chance possible to join the fun activities in school.

DON'T... try to do this all alone. Join with other parents of handicapped children or the PTA to learn all you can about State and Federal laws, the way your own school system works, and how to get appropriate action.

About Due Process

Throughout this guide, times are indicated when due process can be initiated. Here's a quick review of the main steps involved in due process:

1. You must receive notice in writing before the school system takes or recommends any action that may change your child's school program or if a school refuses to take action to change the child's program.
2. You have the right to give or withhold permission for your child to be tested to determine whether or not he requires special education services, evaluated by specialists to determine what his educational needs are, or placed in a specific school program.
3. You have the right to see and examine all school records related to the identification, evaluation, and placement of your child. If you find that certain records are inaccurate or misleading, you have the right to ask that they be removed from the file. Once removed, they may not be used in planning for your child's placement.
4. If you do not agree with the school's course of action at any point along the way, you have the right to request an impartial due process hearing.
5. If you fail to win your case, you have the right to appeal the results of the due process hearing to the State Department of Education; and, you can appeal to the courts if you lose your case at the State level.

Remember that due process can be exhausting. Before going this route, be sure you have tried to settle differences through every other means. If you're sure a due process hearing must be held to resolve conflicting points of view, you must prepare thoroughly. Get help from an advocacy group or a lawyer who is familiar with education law and procedures in your State.

Your rights at a hearing:

1. The hearing officer must be impartial, may not be employed by the school district involved in the education of your child.
2. You have the right to legal counsel (which may be advocate), to examine witnesses, present evidence, ask questions of school representatives, obtain a record of the hearing and all its findings.

Write directly to the superintendent of schools in your district to request a hearing. Hearings must be held not later than 45 days after requested. The State Department of Education must review appeals within 30 days.

From Closer Look, Fall, 1977
A Project of the Parents Campaign For
Handicapped Children and Youth

THE GATHERED EXCHANGE

Recipe: Texas Hash

1½ pounds lean ground beef
1 large onion, sliced
1 large green pepper, chopped
1 pound can tomatoes
1 to 2 teaspoons chili power
2 teaspoons salt
1/8 teaspoon pepper
1 pound can tomato puree

Brown mean, onions, and pepper in large skillet. Pour off fat and squeeze meat mixture in paper towels to remove further fat. Add remaining ingredients and cook about 30 minutes, or until of desired consistency. Serve over cooked rice.

40 grams hash = 1 meat exchange and 1/2 vegetable exchange
1/2 cup rice = 1 bread exchange

Washington Member.

Education

My daughter is in the first grade and is not receiving any special education. She is in the top two reading groups, but is finding it difficult to learn to write. Her principal has given her until the end of March to learn to write, or we will have to find a special class for her. I have arranged for her to have coaching lessons. If anyone has experienced similar problems, I would be most grateful to know how you overcame them.

Australia Member.

Orthopedic Development

Last year we discovered that our son had one leg shorter than the other, 3/4 inches shorter. I saw another Prader-Willi child at the school he attends, and she too had one leg shorter than the other. Is it possible this is common in the Prader-Willi children? Our son now wears shoes and sneakers with a platform sole on the shorter leg. This causes him to walk better an d perhaps helps his back since he, too, has scoliosis. Perhaps it would be worthwhile for other parents to look into this possibility for their own child.

New Jersey Member.

Orthopedic Development

Our son has one leg shorter than the other, although the difference is only ¼". In a normal child nothing would be done to correct such an insignificant difference. However, because of the tendency to scoliosis (and our son does have scoliosis), the physician advised that it be corrected. For some of his shoes, I did not have a lift added by a shoemaker, but bought a set of heel cushions, and used one in only the shoe for the shorter leg. This gave him just the amount of lift he needed.

Washington Member.

Teaching Games

1. "Connect 4" by Milton Bradley teaches motor ability, sequence, and strategy.
2. "Scan" by Parker Brothers.
3. "Very Important Numbers" by Curriculum Associates, Bridge Street, Newton, MA 02195, teaches multiplication.

From Wash. Assoc. for Children With Learning Disabilities Newsletter.

Scoliosis

Scoliosis is an abnormal lateral curvature of the spine. Almost always painless, it can go unnoticed until it becomes severe. If untreated, it can result in serious deformities of the spine and rib cage.

A VIEW OF WHO'S WHO

This is the story of a 16-year old, herein called K.

My daughter is 16. My story is much the same as other parents I have read about, but until I came across an advertisement for THE GATHERED VIEW I felt alone and frustrated. I knew of NO ONE who was familiar with the syndrome.

K was born lethargic and lifeless, with almost no sucking ability and inability to cry audibly. At first the doctors thought she was premature, but I felt certain they were wrong. She weighed four pounds, four ounces. I visited the hospital each day to feed her (it took a special way the nurses didn't seem to have), and within a month she was five pounds. I was given several diagnoses, none of which seemed reasonable. At five months she was examined by a neurosurgeon. He said she was retarded--seemed to be stunted during pregnancy, and he had no idea how well she would develop. The team put in their report that it was possibly due to a kidney infection which I had in late pregnancy, but they did not tell me this.

We moved quite a bit between Utah, New York, and Miami. Consequently, I was able to have her checked periodically at U of U Medical Research Department, Babies Hospital (Presbyterian Hospital) in New York City, and Mailman Clinic in Florida--three of the finest research clinics. Yet it was a pediatrician in Salt Lake City who was first to diagnose K's syndrome. She realized K's weight problems were unusual and did some late night studying to find the problem. I was so thrilled to finally find SOMEONE who had some idea of what was happening to K! This was in 1972. K was nine with the usual weight and other related problems. She referred me to a specialist who she felt could help me. His answer was that "many doctors" (meaning HIM) don't believe in the syndrome, and he told me to take her hiking in the mountains more often for the weight problem. I told him we would be moving to Florida soon, and he said to seek help there.

In Florida K developed serious medical problems as her weight continued to climb. The biggest problem was sleepiness. I have not read where other parents have mentioned this problem, and yet I know it is a characteristic of the "Chubby Puffer" category of PWS which fits K.

K began to take "catnaps" during school and they became more and more frequent until every time she sat down she fell asleep. It reminded me of switching off a light it was so quick. She would wake up just as quickly. I searched frantically for a doctor who could help me. The school (Special Ed) referred me tc the Mailman Clinic. I told them she had been diagnosed as Prader-Willi. They gave her the usual physical and could find nothing to cause the sleeping. Also her weight was gaining. They gave me the impression, as had other doctors, there was nothing they could do for the weight, and eventually she would die from heart problems-- her heart was already becoming enlarged. At that point I just about gave up-- I was so tired of searching, of interviews for her history, family history, etc., with always no help. One doctor wanted to put her in the hospital, but by this time I was so discouraged and tired, and he could not tell me what he was looking for or what it might cost. I had five other children by this time. I told him I would work on the problem myself the best I could.

Meanwhile we moved back to Utah and then to Pennsylvania. By the fall

Continued

A VIEW OF WHO'S WHO, Continued

of 1976, K's weight was gaining fast. She breathed noisily and preferred to sit up to sleep. No matter how often I laid her down, she would sit up again. Some doctors had told me to have her tonsils out, but none wanted to do it. Suddenly she took a definite change for the worse, rather than gradual. She fell down stairs, bumping her head. She began to sleep more than ever, but I did not feel this was due to the fall. Through another physician, I was able to get hold of a specialist at the nearest children's hospital. At first, she just wanted to make an appointment, but when I related the symptoms, and told her K was going blue and would be dead soon if someone didn't help, she realized what was going on and had me bring her in immediately. It was just in time.

This was the turning point in my life and in K's. For the first time I had found a doctor who knew what to do and how to get help. I was able to find out what was wrong and get it corrected. K was only in the hospital two weeks, yet much was accomplished. First, the doctor realized K needed oxygen in her blood and took measures to do this. I don't remember all the procedures--I don't think it was anything unusual. Why hadn't someone recognized this before? Then she got in touch with a doctor familiar with Prader-Willi. I didn't know there were any! At no time had anyone ever given me any hope or even suggestions--only that PWS was rare and practically hopeless, that children never lived past twenty because weight was uncontrollable.

Now a team of specialists was doing something for K. After consultation, they decided it was most important to take out her tonsils, even though in her condition the risk was high. They got her physical condition as stable as they could, then took them out. What a difference! Apparently, K had the problems of a narrow throat and enlarged tonsils, plus weak muscle tone. This was closing off her throat and her breathing when she lay down. They were able to bring her weight down rapidly, as she was holding a great deal of water. I have forgotten how they did this, but when I brought her home, she was put on the high protein diet, 800 calories, and on digitalis and hydrodiuril. In about five months her weight dropped from 160 to 110 pounds. Her sleepiness is caused from too much carbon-dioxide in her system. The digitalis helps her heart pump more oxygen in and clean her system out better. When she gets sleepy, I usually have her exercise and breathe deeply to get the oxygen in her system. This really helps. Her heart is now normal. She has to stay on the two medications. I notice a difference when she doesn't take them. I do not count all her calories, but she has been able to maintain her weight at 110-115 for almost two years now. My family doctor gave me the name of a doctor in Philadelphia named Dieterling who sent information for a research paper my daughter was doing on the subject of PWS. This material was enlightening, discussing the three categories of PWS, including the most rare, which is the Chubby-Puffer category.

This brings me to the present as I try to deal with the frustrations of raising a child with PWS.

K picks at sores til she has them sometimes for months or even a year. She sneaks food til I want to scream, and her innovations for getting food are endless. The one thing she definitely is is consistent--she never misses an opportunity or a crumb. She keeps one eye on me and the other on the garbage can, counter, floor. If I go outside or upstairs, she makes a beeline for the kitchen. She is so quick and cunning I have to be on constant watch. She likes to set the table, clear the table, wash dishes--anything that will give her an opportunity to be near food. She never, never misses an opportunity to sneak a scrap; it doesn't matter how much she has had to eat.

Continued

A VIEW OF WHO'S WHO, Continued

K is very cooperative about staying on her diet at mealtimes. She wants to keep her weight down, but cannot resist an opportunity to sneak extra food. I can't trust her out in the neighborhood or to go to the grocery store. Once when she thought a neighbor was not at home, she went in and got into her refrigerator.

We live in such a food-oriented world. It seems that every social is planned around food--always fattening and sweet. Christmas, Halloween, Easter, birthdays, Valentine's--all are celebrated with goodies at home, church socials, school. School is a definite problem this way. They try to cooperate, but so many activities involve food. They take field trips to restaurants and often stop at MacDonald's on other field trips. They show the children how to grocery shop, have cooking lessons, birthday treats, plus daily snacks. It is hard to make special things for K each time. She also gets tired of watching other kids each French fries, etc. It's a constant hassle.

My house is not built so I can shut off the kitchen. If my family were not so large, I think I could deal with the food problem a little easier, but I have seven children from seven to nineteen, plus a 45-year old brother living with me who is crippled and retarded and has a huge appetite, but is slim. It would take me pages to mention all the problems. (All my other children are super-slim with large appetites.)

One other major problem with K is stealing (for want of a better word). She is forever getting into her brothers and sisters rooms and things. I try to get them to lock their rooms, but our house is old and the doors do not lock easily. Also they resent the nuisance. I know she checks their rooms, and mine too, but I never catch her; I just find things in her pockets or drawers. She will take their notebooks and school papers, erase everything on them and write it over in her own writing. I give her plenty of paper, pencils, crayons, coloring books, workbooks, etc., of her own. It just seems to be a compulsion. She had to stop riding the bus because she got into the bus driver's purse for gum. At school she also takes pencils and paper.

I have tried to work with her on this, but she only gets worse. If she wants something she just watches for her opportunity, and when confronted only seems sorry she was caught. She has learned to deny and be so convincing she gets the benefit of the doubt, but I then find out she did do it. She will only admit it when she knows for certain I know she did it. I worked for a long time trying to get her to admit when she had taken something, but she has only become more proficient with denials. Often when I go someplace, I have offered her a reward if she does not get into food while I am gone. When I come home, she is very quick to tell me how good she was and didn't touch a single bit of food. Then I find out from the other kids that they couldn't keep her out of the refrigerator, and she ate some cake.

The compulsion K has for taking food or other things, even though they are small things, has made our life so frustrating I don't know how to handle it. Sometimes I feel like I can't go on because the problem is so consistent and never ending. Everyone has their own problems, but I don't personally know anyone who has this same type of problem. There is no one to share ideas with. I feel very alone. When I get my GATHERED VIEW, I find myself looking eagerly for answers, or just another parent telling of her frustration.

GATHERED REPORTS

California: Los Angeles

The Channel Two (CBS) News Team was scheduled to film a special report on Prader-Willi Syndrome at Harbor General Hospital on November 21.

In spite of short notice, members of the Prader-Willi California Foundation were very responsive in submitting letters of support for a group home to the Dubnoff Center.

Reported by Robert F. Scott, Jr., President, CPWF

Australia

A special meeting was held recently to discuss the future aims of the Association. The main topics of discussion were: (1) establishing a Prader-Willi clinic in Sydney, (2) establishing some form of temporary or permanent care for Prader-Willi sufferers.

Parents were asked to ask themselves the following questions:

(1) Are your child's total needs being met at home?
(2) If not, are they being met in another environment?
(3) Are you able to manage the day-to-day care of your child?
(4) Are you suffering emotionally as a parent of a Prader-Willi child?
(5) What future problems do you envisage?
(6) Are you reaching a crisis point?

Dr. R. Silink of the Royal Alexandria Hospital for Children in Sydney has agreed to help the Association in the establishment of a Prader-Willi clinic.

The Association has been raising money through guest speaking at various organizations such as the Women's Ministries, Assemblies of God, Quota Club, and the Old Bastards Club in Toongabbie. Money is also being raised through members holding street stalls in various communities.

From The Open Door, Newsletter of the Prader-Willi Assoc. (Australia)

NEW HOUSE MANAGER FOR BROOKHAVEN

Brookhaven, a group home for people with Prader-Willi syndrome in Seattle, Washington, has a new house manager. She is Dot Hutchins who has been there since November 1. Ms. Hutchins received her degree in Child Development and Special Education at the University of Maine. She has previously worked for the Forest Service in Maine, for a group home in Ellensburg, Washington, and in a Nellie Goodhue group home in Seattle.

HEY! THAT'S GREAT!

In October, Rebecca's school had a race day. Rebecca is in a regular school, but she entered the race anyway. Although she was the last to finish, all the children and parents cheered her on towards the finishing line. This first-grader, who finished last, became the first to teach some children a lesson in perseverance. Rebecca lives in Australia.

ORDER FORM FOR 1979 CONFERENCE MATERIAL

#1 CONFERENCE INTRODUCTIONS by Gene Deterling, President (Includes announcements and comments throughout the meeting) 4 pages, COST $2.00

#2 ABOUT THE SYNDROME OF PRADER-WILLI by Hans Zellweger, M. D., Iowa City, IA. 7 pages, COST $3.00

#3 A PROGRAM FOR A PRESCHOOL-AGED CHILD WITH PRADER-WILLI SYNDROME by Betty R. Schultze, Ed.D., St. Louis, MO. Condensed version, 5 pages, COST $2.00

#3B Complete copy of above talk by Dr. Schultze. 30 pages, COST $6.00 Contains more test data, double spaced original copy.

#4 RESULTS OF A LONGITUDINAL INTERVENTION PROGRAM FOR 8 ADOLESCENTS & ADULTS WITH PWS RESIDING IN A CONTROLLED LIVING & CALORIC ENVIRONMENT by Margo Thornley, Executive Director WISER Institute, Seattle, WA. 4 pages, COST $2.00

#5 ADULTS WITH PRADER-WILLI SYNDROME by Shirley Neason, Editor "THE GATHERED VIEW, Enumclaw, WA. 3 pages, COST $2.00

#6 DIAGNOSTIC AND COUNSELING DILEMMAS IN PRADER-WILLI SYNDROME by Bryan Hall, M. D., San Francisco, CA. 3 pages, COST $2.00

#7 A SUCCESSFUL WEIGHT REDUCTION PROGRAM FOR TWO MENTALLY RETARDED CHILDREN WITH PWS IN A RESIDENTIAL SCHOOL PROGRAM by Eleanor Watson, R.D., Paola, KA. 3 pages, COST $2.00

#8 QUESTIONS FROM THE FLOOR DURING THE CONFERENCE, AND THE ROUND TABLE DISCUSSION 12 pages, COST $3.50

#9 COMPLETE SET OF ABOVE PAPERS (EXCEPT #3B), 41 pages, COST $15.00

CIRCLE PAPER NUMBERS WANTED
TOTAL COST ENCLOSED_____ NAME_____

ADDRESS_____

_____

PLEASE SEND ORDERS TO: PRADER-WILLI SYNDROME ASSOCIATION
5515 MALIBU DRIVE
EDINA, MN 55436

CONFERENCE MATERIAL

The NATIONAL CONFERENCE ON PRADER-WILLI SYNDROME was presented by the Prader-Willi Syndrome Association in the summer of 1979, at the Hotel Leamington in Minneapolis, Minnesota. The first-ever conference, open to the public, featured some of the leading authorities in the country who presented papers on a variety of subjects related to the Prader-Willi Syndrome.

An attempt was made to tape the entire conference with the intention of making copies of these tapes available to all members. Unfortunately, the quality of the tapes did not allow us to reproduce them. It was the decision of some of the doctor presentors not to offer all of the presentations since some of the doctors' material will be coming out in book form soon. Consequently, we will be offering six of the presentors' papers. We have compiled this material to be able to offer it to you at the lowest price possible. The order form is on the reverse side of this page.

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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 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.

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