

# THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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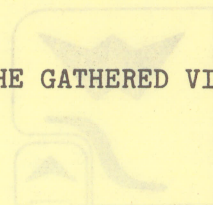
NUMBER 5

## PRESIDENT'S MESSAGE

Recently, my day started with a telephone call from a teacher concerned about a new pupil scheduled to enter her class this Fall. Her concern occurred when she was told that one of her special students had been diagnosed as having Prader-Willi Syndrome. This teacher wanted to know what PWS was and how could she prepare herself to be a better teacher. That kind of concern creates a warmth in one's soul. Unfortunately, the conversation revealed a flip-side to the situation. This child came from a broken home, and lived with a parent that chooses not to recognize the importance of being involved in the multifaceted nature of the child's problem. The teacher indicated an unwillingness of the parent to become involved in dietary management, concern for social development skill, educational planning (IEP), and even less concern about the more subtle needs of this Prader-Willi person.

This event recalled to me one of the most joyous events I have experienced in attending the annual Prader-Willi conferences. This particular event occurred at the first conference in Minneapolis during the evening banquet. I was sitting next to a Prader-Willi mother from the Midwest. We swapped tales for several minutes, as parents do at these meetings. After relating several similarities, this wonderful mother told me that she raised her Prader-Willi child without the benefit of a diagnosis (the opposite of my story). Then she dropped the bomb. Her child was living on his own in a special apartment for the handicapped, he was earning a supporting wage at a vocational center, he was even buying and preparing his own diet with his apartment mate. I couldn't believe it. This was the first time that I had heard of a Prader-Willi person growing to that level of independence. It was achieved by a parent capable of recognizing her child's needs and expending the talent and energy necessary to daily meet those needs, whether dietary, social, physical, or educational.

These two opposite examples point out the great variation that exists in how individuals meet their daily challenge and responsibilities of being a Prader-Willi parent. This can be a delicate and painful, as well as rewarding, role. Each of us has a different capability to recognize our Prader-Willi person's needs as they exist in daily life. We differ, too, in how we relate those needs to our own, and not infrequently this area of conflict is the source of instabilities in the family relationships. This whole topic is vastly complex, and individual answers are not easily obtained. Some of the techniques of seeking help were discussed at the sessions held during this year's meeting in Kansas City. One of the most impressive things to come out of any of our meetings to date was accomplished during this conference.



## President's Message (Cont.)

Dr. John Rustemeyer is a practicing clinical psychologist, educator, and administrator from St. Louis. His interests include the learning disabled child and family therapy. John and six Prader-Willi parent couples conducted a video-taped discussion that lasted about one hour. This video tape provides an invaluable insight into the character of the problems of being a Prader-Willi parent, and how these couples have approached solutions. The tape has been copied and is available from the national office on a rental basis for a nominal fee. Those of you who had the opportunity to view the tape at the conference will want to see it again, and for those not as fortunate it is well worth the cost to arrange a showing at a local meeting. It is not "E.T.", but for those of us who are involved with Prader-Willi persons it is almost as impelling.

*Delfin J. Beltran, M.D.*

VIDEO TAPES AVAILABLE

At the 4th Annual PWSA Conference, Dr. Betty Schultze made arrangements for Dr. John Rustemeyer, Psychologist, to interview several parents regarding coping with this syndrome. This video tape is now available for borrowing. We have copies both in the VHS and Betamax so they can be shown on either of these two systems. Please specify which you need when ordering.

Due to the cost of producing the tapes, we have set a rental price of \$20.00 for members and chapters, and a price of \$50.00 for outside sources that may care to rent a copy. This cost is set to offset the production cost, postage and insurance for mailing, as well as replacement when necessary. Tapes can only be shown a limited number of times before the quality diminishes.

Dr. Beltran also spent a couple of studio hours improving the quality of the tape and donated that cost of studio rental and his time, for which we are very appreciative.

If you are interested in borrowing a copy of this tape, please contact the national office.

WELCOME TO OUR FIRST OFFICIAL CHAPTER

PWSA welcomes the Southern New England Prader-Willi Syndrome Parent Support Group as the first official chapter of our organization. At their July 21st meeting, a decision was made to complete the process of applying for chapter status. A discussion will be held at the next meeting about changing their name to the form suggested by PWSA, and reports will be given on their PW Clinic and group home organization.

The next meeting is scheduled for September 15th at Newington Children's Hospital.

## INTRODUCING....

The GV would like to introduce its readers to one of the two new board members who were elected during the general meeting last June.

Dorothy Thompson

Dorothy is presently employed by Contemporary Health Services as a consultant in Facility Development and Quality Assurance. She is a certified QMRP, and holds a MA in Personnel and Guidance from the U. of Michigan. She has also studied Psychology and Special Education at the U. of Minnesota, San Francisco State College, the College of St. Thomas, Perkins Institute for the Blind in Waterloo, MA, and in programs for the deaf-blind in the Netherlands and England, and programs for the Retarded in So. America. She has represented the Midwest at the NATO Year of the Child Conference in Puerto Rico. Her previous employment includes the Director of Education and Residential Services at the MN School for the Blind in Fairbault, MN where she instituted the only school for the deaf-blind in the Midwest. She also spent eight years as the Director of Clara Doerr and Lidley Hall, a residence for mildly retarded young adults in Minneapolis where she took part in some of the first PW research programs. This work led to a continuing interest in PW people and her key role with the PW MN group in establishing Oakwood Residence, the largest group home for PW people in the U.S.



THINK AHEAD...

Betty Shadell, Chairperson for the 5th ANNUAL PRADER-WILLI CONFERENCE, has made arrangements for the conference to be held on the 3rd weekend in June, (June 16-17-18), at the Bahia Conference Center in Mission Bay, California.

Plan now to reserve these dates.

SPECIAL THANKS

A special thanks to Richard Mast, owner of Wilcox Paper Company, who recently supplied us with several cartons of copy paper. We have now purchased our own copy machine and will be doing a lot of our own printing.

NOTES FROM THE MIDWEST REGIONAL MEETING IN OCONOMOWOC

Dave Johnson, Director of Oconomowoc Developmental Training Center, gave a presentation regarding their facilities. At the present time, their 60-bed facility includes 6 young people with PWS, ages 4-17. Mr. Johnson feels their facility is an ideal setting for serving PWS residents. ODTTC is a residential care facility with a school, on-grounds workshop facility, and contracts for any needed therapies.

Other speakers included some therapists from SOMED (Social Occupational Medical Educational Delivery of Service) a private company that serves ODTTC. One therapist stated there is really no profile for communicative disorders in PW children. That means that when a child is diagnosed a PW we can't just assume that they're going to have specific speech and language problems. However, she did find that there were some characteristics that were similar and these are disordered syntax, sentence order, motor planning, and poor imitative development.

Another therapist talked about language and articulation. He found a higher than normal pitch in the voice of a male PW. Normally during the time of the puberty growth spurt, the larynx enlarges, and it enlarges more in the male than the female. This causes the voice to drop. When the puberty growth spurt does not take place, the pitch remains higher. Another suggestion was made that it would be a good idea to inform your dentist or orthodontist about this lack of puberty growth since it might have some effect on when dental treatment is done.

Another characteristic is that with obesity you find very shallow breathing, and we have to be cautious about hyperventilation. Because of the shallow breathing, we might expect a very soft voice and short phrasing. The child hasn't developed the lung capacity, and of course the weight itself prevents a large intake of air.

Orv Karan, a Psychologist from Madison, gave a presentation with a great deal of information about Sheltered Workshops and Day and Work Activity Centers. Sheltered Workshops concentrate on work, and try to train their employees for competitive employment outside of a sheltered environment. Day and Work Activity Centers include work and therapies for those placed there, and even though they try to parallel competitive employment, most of their employees are not expected to be moved into outside jobs. Dr. Karan gave statistics on the number of people served by these facilities, how many advance, and what the pay scale is. He left it to the people to decide whether there is a need for change in this area of placement, and there wasn't much doubt that things should be improved.

Dr. Karan also shared the following list of "Questions to Ponder" and "General Considerations."

QUESTIONS TO PONDER

WHOSE STANDARDS ARE BEING USED TO DETERMINE THAT A PERSON'S BEHAVIOR SHOULD BE CHANGED?

ARE THE OBJECTIVES OF THOSE DEVELOPING A CHANGE PROGRAM REALISTIC AND/OR REASONABLE?

IS THE CHANGE PROGRAM REACTIONARY, RETALIATORY, OR THERAPEUTIC?

IS IT REALISTIC AND/OR APPROPRIATE TO EXPECT A CERTAIN LEVEL OF BEHAVIOR IN ONE SETTING WHEN OTHER SETTINGS DO NOT HAVE THESE SAME EXPECTATIONS?

Notes from Midwest Regional Meeting (cont.)

Dr. Karan's Questions to Ponder Cont.

IS IT POSSIBLE TO OBTAIN THE COOPERATION OF AT LEAST SOME OF THE PEOPLE IN THE PERSON'S NATURAL ENVIRONMENT WHO WILL SUPPORT THE PROGRAM GOALS?

WHO IS MAKING THE DECISIONS ABOUT A PERSON'S BEHAVIOR CHANGE PROGRAM AND ON WHAT BASIS?

IF A PERSON IS NOT IMPROVING WHAT RESOURCES ARE AVAILABLE TO ASSIST?

IS A BEHAVIOR CHANGE PROGRAM THAT IS DEVELOPED DURING A CRISIS IN EVERYONE'S BEST INTEREST?

ARE OUTSIDE CONSULTANTS KNOWLEDGEABLE OF AND FAMILIAR WITH THE PERSON'S DAILY ACTIVITIES AND IMMEDIATE AND EVENING ENVIRONMENTS?

THE STAFFING: WHAT IS THE PURPOSE OF THE MEETING AND ARE THERE ANY HIDDEN AGENDAS?

WHO IS INVOLVED AND HOW MUCH DO THEY REALLY KNOW ABOUT THE PERSON'S ACTUAL BEHAVIOR?

ARE THE PERCEPTIONS BASED ON SUBJECTIVE IMPRESSIONS OR OBJECTIVE DATA?

TO WHAT EXTENT IS THE PERSON'S INAPPROPRIATE BEHAVIOR A FUNCTION OF THE SETTING'S INAPPROPRIATENESS?

WHY SHOULD THE PERSON BE LEARNING WHAT SHE/HE IS BEING TAUGHT?--WHAT IS ITS RELATIONSHIP TO THE BROADER COMMUNITY OF VOCATIONAL AND RESIDENTIAL OPTIONS?

DOES THE PERSON VALUE HIS/HER PLACEMENT IN A PARTICULAR SETTING? DO THE SIGNIFICANT PEOPLE IN THE PERSON'S LIFE VALUE THE SETTING?

HAVE PARENTS AND/OR OTHERS OF SIGNIFICANCE BEEN ACTIVE PARTICIPANTS IN DECISION MAKING?

HOW MUCH DO PARENTS AND OTHERS OF SIGNIFICANCE REALLY KNOW ABOUT THE OPTIONS THAT EXIST AND HOW SUPPORTIVE ARE THEY OF THE OPTIONS?

ARE THERE APPROPRIATE MOTIVATIONAL INCENTIVES AVAILABLE AND DO THEY WORK?

ARE THERE GOOD WORKING RELATIONSHIPS AMONG ALL THE PARTIES/AGENCIES INVOLVED WITH THE PERSON?

GENERAL CONSIDERATIONS:

ALTHOUGH DRUGS MAY REDUCE OR CONTROL AGGRESSION SUCH AN APPROACH DOES NOT TEACH SUITABLE SKILLS FOR SOCIAL ADAPTATION.

PUNISHMENT DOES NOT TEACH A PERSON WHAT SHE/HE SHOULD DO, ONLY WHAT SHE/HE SHOULD NOT DO.

RATHER THAN FOCUSING ON CONSEQUATING INAPPROPRIATE BEHAVIORS AFTER THEY OCCUR, FIRST FOCUS ON REPLACING THESE BEHAVIORS WITH MORE APPROPRIATE ONES. FOCUS ON SUCCESSFUL BEHAVIOR.

Notes from Midwest Regional Meeting (cont.)

## Dr. Karan's Questions to Ponder Cont.

THE PRESENCE OF ADDITIONAL ABNORMALITIES ASSOCIATED WITH MENTAL RETARDATION SERVE TO INCREASE THE GENERAL INADEQUACY OF THE INDIVIDUAL WHICH IN TURN INCREASES THE FREQUENCY OF NEGATIVE EMOTIONAL EXPERIENCES.

MAINTAIN A POSITIVE INTERACTION AS MUCH AS POSSIBLE.

FORCING CONFRONTATIONS IS DANGEROUS AND GENERALLY RESULTS IN AN EROSION OF POSITIVE RELATIONSHIPS.

DEFUSE POTENTIALLY DISRUPTIVE EPISODES RATHER THAN CONFRONTING THEM, E.G., AVOID CONFRONTATIONS, DISTRACTIONS, ETC.

TRY NOT TO USE YOUR GUT AS YOUR GUIDE. JUST BECAUSE IT FEELS RIGHT TO YOU DOES NOT MEAN IT IS THE BEST WAY TO ENCOURAGE APPROPRIATE BEHAVIOR.

MAKE SURE YOUR EXPECTATIONS ARE REASONABLE AND ALLOW FOR FLEXIBILITY. MAY NEED TO MANIPULATE ENVIRONMENT OR YOUR EXPECTATION TO GIVE SUCCESS EXPERIENCES.

SHARE THE EMOTIONAL INTENSITY AMONG PEOPLE. SHARE IN PROBLEM SOLVING.

BE AWARE WHEN YOUR EMOTIONAL BUTTONS ARE BEING PUSHED BECAUSE IF YOU "BLOW YOUR COOL" THE SITUATION COULD INTENSIFY TO AN EXTREME DEGREE.

TRY NOT TO HOLD A GRUDGE--WHEN THE PROBLEM IS OVER, LET IT BE OVER AND TRY TO RETURN TO THE POSITIVE RATHER THAN STICKING WITH THE NEGATIVE.

Complete copies of the transcripts of all the above mentioned presentations, along with a short presentation on general nutrition, can be ordered from the National Office.

NEW PAPERS AVAILABLE:

We have a copy of one panel member's presentation, and notes from Dr. Hanson presentation from the conference that was just held in June. We also have summaries from several presentations made at the last Midwest Regional Meeting. (More detailed information in this issue.) This is a listing:

## 4th Annual Conference:

Dale Herrick, Jackson Cty. Direction Service Center

1 page presentation from Parents & Professionals Interaction Panel

James Hanson, M.D. "Medical Research in PW - Update."

1 page summary of presentation.

## Midwest Regional Meeting at Oconomowoc Developmental Training Center:

Alfred Meyer, Nutritionist

1 page summary of general concepts of nutrition

Orv Karan, Ph.D., Psychologist

2 page synopsis of presentation including discussion of sheltered workshops, questions to ponder and general considerations for parents.

If any member would like a set, please send \$1.00 to cover expenses or a self-addressed envelope with 37¢ postage for mailing.

Here are some suggestions from these two meeting presentations:

Dale Herrick - Parents are advocates-- keep a file or notebook, add every piece of information, all conversations, times, dates--ALL to carry with you. Every two years update your social history (medical history) on your child. When meeting a person, send it ahead for them to look at. Practice listening (communication has to be both ways). Take notes. Keep an overview and handbook in your file--share this with those you meet with. Investigate, seek out what are the best places.

Paul Kinder - Recommended contacting State Agencies for help in education, therapies, etc. For best results in getting help follow the chain of command, start with the principal and work up from there.

Fred Schultz - Train your physician--for a better working relationship with him, don't put him on the defensive.

Vanja Holm - Tell your teachers and educators that the problems are severe with these young people. Be informative on all aspects.

SOMED - There is no speech profile on PWS, the children are not processing what is heard, sometimes because the auditory goes too fast. Present material in more than just auditory form - sensory holds longer.

Due to the purchase of a copy machine, we are now able to offer conference papers from the years 1979 and 1980 at \$5.00 per set rather than the \$10.00 we previously had to charge. We are sorry but we still have not been able to obtain a copy of the 1981 conference papers from Florida Atlantic University.

#### PARENTS BEWARE

The following is a letter recently received from a concerned member:

"I would like to inform the membership of a recent disappointing experience so that they may benefit when choosing a summer camp for a PW child.

As parents of a PW child, we were delighted to receive information last Spring that a camp for PW clients would be opening this Summer in our region.

The camp described in the letter sounded delightful, and the listed activities and excursions would be a delightful experience for our child. The cost was extremely high.

But what a disappointment! The camp was on the large campsite that was so beautifully described, but the cabins relegated to the PW children were isolated from the main camp and were extremely dilapidated.

Some of the window screens were torn, which would have permitted mosquitoes and other insects easy access to the campers. The bathroom facilities were old and safety hazards were evident. The shower stalls were located in a distant building. They were dirty and the drain was plugged with an accumulation of water. An adjacent building was used for food storage and preparation. The screens on this building were also torn and the preparation table was makeshift particle board, posing a health hazard.

It was disappointing enough to find such intolerable conditions--but the real frustration was the unconscionable insult to our PW children."

(Editors note: Parents, please beware. Be sure to personally thoroughly check out any camp, group home, institution, residential school, etc. before enrolling your child. This means visiting the facilities, talking to the staff, and, if possible, asking those who have used the facility in the past about their experiences and recommendations. Please also keep in mind that although from time to time the GV will print announcements about summer camps and group homes, these are not to be taken as recommendations for the facilities, so investigate all such residential programs carefully!)

#### RAISING THE QUESTION OF IQ'S

A New Jersey member recently asked in a letter whether it was true that some PW people are not retarded and whether any of our membership parents have children who are not in the below normal IQ range. The answers to both questions are yes; it is true that all PW people do not necessarily test out in the retarded range of the IQ scale. As a matter of fact, there are PW people with normal intelligence, mental retardation being a very common, although not a necessary characteristic of the syndrome. The national association knows of several PW individuals whose IQ's are above the 80's, and reports that about 5% of the people questioned responded that their child was not retarded. This figure seems to run true to the figures reported by the medical profession.

This fact does often present problems for parents when they are attempting to enroll their children in special schools or residential placements that have mental retardation funding, but it does not mean that they should abandon the attempt. Many higher IQ PW's still need the special attention that such placements can give them, and it should not be assumed that all children can function on the same level as their IQ. There have been many cases when people with PW and high IQ levels have been placed in special schools and group homes because parents or professionals have been able to prove that some PW's functioning level needs do not necessarily correspond with their tested IQ.

#### CONFERENCE EXPENSES

Comments have been made questioning the amount of registration, dinner and youth activity fees that are charged for attending the conference. As was noted in the last issue, we would like the fees as low as possible in order that as many members as possible are able to attend. It is a tremendously hard task to budget costs with so many unknowns. Eleanor Watson tackled this hard task and did a terrific job. If we paid all expenses and pay for those making the arrangements, our fees would be a great deal higher.

We hope you will look over these figures and feel free to make comments if you would like.

## Conferences Expenses (cont.)

## PWSA FOURTH ANNUAL MEETING, JUNE, 1982

## SUMMARY OF INCOME AND EXPENSES:

## INCOME:

Adult registrations. . . . .	\$ 2863.00	
5 @ \$17.50 = \$135. 124 @ \$22. = \$2728.		
Dinner registrations. . . . .	\$ 1785.00	
102 @ \$17.50 = \$1785.		
Youth Activity Fee. . . . .	\$ 918.25	
2 @ \$10. 2 @ \$28.25 58 @ \$15.		
Coffee Kitty Donations. . . . .	\$ 83.77	
		\$5650.02

## EXPENSES:

Refunds. . . . .	\$ 268.00	
Reservations cancelled and one bad check		
Youth Activity Program . . . . .	\$ 1480.10	
Buses \$135. Food \$1065.86. Programs \$279.24.		
Planning, Mailings, and Supplies . . . . .	\$ 912.14	
Phone \$243.64. Postage \$198.32. Typist \$110.		
Printing & Supplies \$360.18		
Adult Meal Expenses. . . . .	\$ 1768.30	
Banquet 1212.91, Receptions 174.24, Coffee 381.15		
Program Expenses . . . . .	\$ 1489.55	
Video Taping \$125.40		\$5918.09
Reimbursement of speakers expenses:		
Burke 99.30 Hotel and gas		
Hanson 50.33 Hotel		
Kean 55.12 Hotel		
Rustemeyer 156.16 Hotel and gas		
Schultz 50.00 Hotel		
Mitchell 75.00 Hotel		
Schultze 200.00 (Token payment toward planning		
Watson 200.00 and actual conference expenses)		
Wett 478.24 Hotel 392.80, Gas 85.44		
		(\$ 268.07)

Since we came out with a deficit of \$268.07 for the conference, it was decided to use part of a \$600.00 donation that we received from Edina High School to cover this expense. We felt using some of this donation to treat the youth activity registrants to a night at the movies was a good use of their donation.

FINDING VOCATIONAL INFORMATION

Following the conference, Jennifer Holvoet, Ph.D., University of Kansas, Department of Special Education, shared a few names with us that are sources of vocational information:

Marc Gold and Associates  
108 W. Oregon Street  
Urbana, IL 61801

Training and placing moderately retarded or multiply-handicapped in high technology industrial jobs. They have some job placements in Texas also.

Experience-Based Career Education Together  
Salt Lake City School District  
Pupil Services, 440 E. 1st So.  
Salt Lake City, UT 84111

Curriculum directed by Ms. Rickie McCandless, provides high school age handicapped children direct experience in a variety of employment settings. Other states may wish to use this program idea in their state.

William B. Carrell  
Multiple Careers Management Center  
4528 Rusk Avenue  
Dallas, TX 75204

Project focusing on the development of an occupational training program geared toward competitive employment for high school students with mild to moderate retardation.

Cooperative Vocational Educational Project  
Educational Service Unit #9  
1117 E. South Street  
P.O. Box 2047  
Hastings, NE 68901

Project directed by Ms. Polly Feis, provides vocational opportunities for handicapped secondary students who live in rural areas.

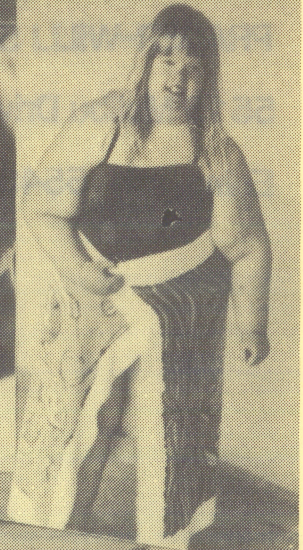
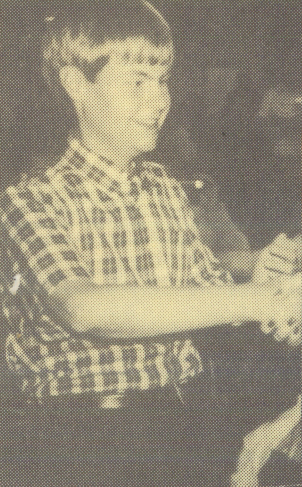
We thank Dr. Holvoet for sharing this information with us.

PW'S IN THE NEWS

One of our Oregon members recently shared an article with us that had appeared in their local paper regarding their daughter with PWS. The national office appreciates receiving these articles and has started a scrapbook to share with others.

The member wrote that since the article appeared they have had a lot more support from family and friends. Educating everyone about the syndrome does help. Marge Wett made the suggestion at a couple of recent area meetings that parents can help by offering to share their experiences with the media. She did caution, however, that you should consider the intentions of the paper that does the interview; are they really interested in sincere reporting, or are they trying to dramatize a situation in order to "sell more papers"?

If any of you are contacted, or if you contact your local paper with a story about your family, please feel free to give the name and phone number of the national office; they would be happy to give the reported more details regarding the medical aspects of the syndrome.



COLORADO MEMBERS

Attention Colorado members! A new PWS support group is now meeting in the Denver area. This group's second meeting was held on Sept. 8, and they have decided to make education and awareness of PWS in Colorado their primary goals. This group is eager to increase their membership and invites anyone involved with PWS in Colorado to attend their meetings. Interested parties may contact Florence Gunnison, 7005 W. 33rd Ave., Wheat Ridge, CO 80033 for more information.

UPCOMING MEETING DATES

SEPT. 15 - SO NEW ENGLAND PWS PARENT SUPPORT GROUP - Newington Children's Hosp., CT.  
 SEPT. 17 - PW MINNESOTA ASSOC. - Honeywell Bldg. Minneapolis, MN  
 SEPT. 25 - PW MIDDLE ATLANTIC ASSOC. - Host Farm Resort, Lancaster, PA  
 OCT. 16 - PW MIDWEST REGIONAL GROUP - Child Development Center, Riley Hosp., IN

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 THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$15.00 per year for U.S. members; \$20.00 per year for Canadian and overseas members. Send dues and change of address notices to: PWSA, 5515 Malibu Drive, Edina, MN 55436.  
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