

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

The New England Journal of Medicine is a well recognized and reliable source of information for physicians and people interested in medically related matters. The report of Dr. Ledbetter's group at Baylor that suggested a causal relationship between chromosome 15 abnormalities and PWS was a milestone of importance to us that was reported in the N.E.J.M. The daily newspapers, television and magazines are constantly bombarding the public with medical discoveries, popular cures, solutions to all sorts of bodily ailments and warnings against the toxicity, cancer causing effects, as well as downright deadly effects, of everything from the food we love to eat, to the smoke we hate to breathe.

The answer to almost every major problem that the aware generation has dredged up, turned over (in our minds), exposed (to the light of scrutiny), revealed (for all to see) and disected (to the finest minutia) has been the education of the average man (on the street). If only the message of truth and the application of common sense were brought to and applied by the public, we could survive the onslaught of the special interest, the greed of big business, the bungling of the bureaucrat and false ways of the extremes. I still am looking to find where the truth lies but I did find out what common sense is — it is the viewpoint of the speaker.

A current issue of the N.E.J.M. describes a specific neurologic injury consisting of sensory nerve damage as a result of Vitamin B6, pyrodoxine megavitaminosis (the use of massive doses of vitamins far in excess of the known useful dose). Megavitamin therapy has been popular in the media and among the hopeful in the past several years for the treatment of all sorts of ills for which traditional medicine has yet to find a satisfactory solution, cure or alleviation. The common cold has caused the massive consumption of Vitamin C. In this article, Vitamin B6 had been used to treat menstrual periodic edema in doses up to 3000 times the recommended daily allowance. It is interesting that the paper points out that lesser doses of B6 are effective in the treatment of certain types of toxic neurophathy and further that it is one of the water soluble (as opposed to the fat soluable vitamins A & D) vitamins that supposedly is promptly excreted in the urine when the dose taken is greater than the needs of the body, consequently considered previously as safe and non-toxic.

A frequent effect of unexplained maladies, diseases without known cures, and genetic disorders with consequences unacceptable to those involved is the "I'll try anything that might work" approach to the resolution of the problem. This is usually fortified by the "If it doesn't work, what have I lost?" theory. The affected person in desperation and fear rationalizes their antiestablishment attitude, "Those dumb doctors don't know what caused it and sure as heck don't know how to help me (in a manner acceptable to me) so why shouldn't I try Brand X". Because the PWSA recognized the

PRESIDENT'S MESSAGE (CONT.)

Probability that affected persons and their families may be besieged with this type of problem, the scientific advisory committee has been established. The committee is chaired by Dr. Bryan Hall and has been charged with the responsibility of applying the scientific method to information related to PWS. It is important to understand that the scientific method is not a guarantee of absolute truth but it is the most successful technique of picturing a problem, gathering related information, theorizing possible causes and effects and testing for the truth of the matter. The multiple problems faced by PW persons exposes them to superstition, ignorance, do-gooding, fraud, and charlatans. People with a problem hardly need the aggrivation of the additional problems that can be created by that group. As demonstrated in the article cited above from the N.E.J.M., even supposedly benign "popular cures" can prove to be damaging besides not being beneficial.

In addition to the evaluation of existing concepts, the committee has the responsibility to evaluate proposals for research projects involving PW persons, when asked to do so. The committee has reviewed and accepted the first research project that will be funded by the PWSA. A description of this project is found in this issue.

Delfin J. Beltran, M. D. President

A MOTHER'S SUGGESTIONS FOR FEEDING A PERSON WITH PW

"Before starting the list, I must mention that the most helpful thing has been knowing what the problem is and that the eating is not really lack of discipline, but an illness. It helps us have patience. Like (many), I thank God that we met a doctor who knew about PW.

We have used Ayds to help my son get past the 'hungries' before breakfast and supper. Our approach to his diet is as much as possible to avoid his resentment and feeling deprived, yet still keep the calories down.

When we have pancakes (only occasionally), we take the batter for one pancake and mix it gently into two well-beaten egg whites. That makes it into three pancakes, so he feels he has the same as everyone else.

Once a week, we go downtown and he is allowed an ice cream cone. He looks forward to it all week, and watches his own diet, breakfast and lunch, on Saturday, because of it. 'I can't have any toast today because it's ice cream day.' The rest of the time, we make sure he has a lot of vegetables at all meals except breakfast, and sometimes even then. He loves canned green beans, cold, in a bowl, and sometimes has that for breakfast with a few small round Melba Toast (8-10 calories each) so he has maybe 4 to 5.

A favorite trick is if we are going to be a little late for supper and want to have gravy, etc. and don't want him to feel left out, he is given a choice of an early supper (say, lots of vegetables with cheese grated over them) without having to wait, or having what we have an hour later. Normally he chooses the 'right now' meal, which has only a portion of the calories, of course. We've started making him 'jam' with juice, no sugar, and a pectin substitute called 'Slim-set."

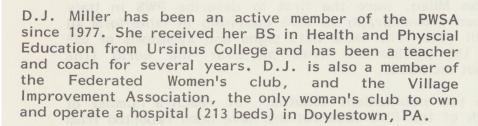
(We appreciate parents sharing good tips like these with the membership. It is sometimes hard for us to remember that our children's tastes are different than ours and some low calorie foods are treats for them.)

WELCOME NEW BOARD MEMBERS!

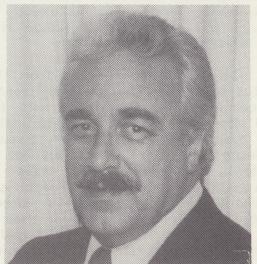
The PWSA would like to extend an official welcome to our two newest board members, Lee Forthman from IN and Doris Jane H. Miller from PA. To tell you a little bit more about them:

Lee Forthman has been a member of the PWSA since 1976. After graduating from the U. of Baltimore with a degree in Business Administration, he began his career in the trucking industry. He currently manages two Mack Trucks dealerships in the state of Indiana.

For the past two years, Lee has served as President of the PW Midwest Association which encompassed a six-state area, and he was recently elected as President of the newly organized PWSA of IN. Lee and his wife, Janice, live in Indianapolis with their 14-year-old PW son, Steven, and daughters Jane, 20, and Cheryl, 10.



D.J. cofounded the PW Midlantic Association in September of 1980. She is an active member of this regional group composed of members from PA, NJ, NY, DE, and MD. D.J. and her husband, Robert, have four daughters; Margaret, their PW child, is the youngest.





PARENTAL DATA NEEDED

Dr. Bryan Hall would like the parents of PW persons to send him their names along with the birth dates of the father, mother, and their PW child. Those members who have had formal evaluations by Dr. Hall while he was in WA, CA, or KY do not need to send any information. Also, those who gave Dr. Hall their names and ages at the 1983 San Diego conference do not need to send anything. This data will be used by Dr. Hall to study the relationship, if any, between paternal and/or maternal age and the occurrence of PWS. Please send the information to:

Dr. Bryan Hall Dept. of Pediatrics University of Kentucky 800 Rose St. Lexington, KY 40536

PRADER-WILLI SYNDROME ABROAD

Two excellent publications on PWS from other countries, one from Italy and the other from Japan, have appeared recently, and a short review of them might be of interest to the readers of the GV.

The Japanese Pediatric Society organized a symposium on PWS on May 15, 1981, in Tokushima, Japan. That is exactly 25 years after PWS was first described in 1956. Dr. Prader was the guest of honor at that meeting and presented a splendid overview of our present knowledge of PWS.

Dr. Onishi and co-workers from the Osaka U Medical School talked about the current status of PWS in Japan. They sent inquiries to 1,053 of the larger Japanese hospitals concerning their experience with the syndrome. The 499 (43.3%) of them that replied had observed 137 children and adolescents with PWS between 1975 and 1979. The other 654 hospitals did not answer. Assuming equal distribution throughout Japan, one could estimate that there are about 300 recognized cases of PWS in Japan (pop. about 120 million). Non-recognized cases are probably much more frequent, notably, non-recognized girls. Dr. Prader and others believe that the frequency of PWS in girls is about the same as in boys, although the usual ratio of girls to boys is indicated as 4:10. The clinical findings of their cases coincide with our experiences here in the US. Let me mention here that 8% of their cases, where an IQ test was performed, had an IQ within the normal range, which again coincides with our experience.

R. Mancini and his co-workers, from Milan, were the first to describe PWS in Italy (1968). 14 years later, they published a monograph on PWS compiling in table form all cases reported in the literature until 1981. The table lists signs and symptoms of 665 cases which they collected from 193 publications from all over the world (the above-mentioned Japanese cases are not included).

Thus, if we put the data of these two publications together, we reach a number of nearly 1,000 cases of PWS. The bulk of the PWS observations have been reported from the US and Canada, yet Mancini and co-workers also mentioned cases from almost all the European countries (except Rumania, Portugal, and Norway), Israel, Australia, Mexico, and Uruguay. No cases are listed from other South American states or from Africa and Asia (except the cases from Israel and India). This, however, does not mean that PWS does not exist in these countries, yet, more urgent problems may exist in these developing countries, such as acute infections or undernutrition. Poor infant feeding exists in many of these countries and could explain why PWS is not observed there with the same frequency as we see it in our country.

That brings me to some new experience in the PWS which was mentioned by Dr. Prader in his speech in Japan. He mentioned how difficult it is to feed PWS babies in the first, or hypotonic phase, of their condition. Then he continued, "When in subsequent months or years, the PWS child starts to eat better, the parents are happy and even overjoyed. After months of frustration, they give the child as much as he wants and praise him for his good eating habits that have suddenly appeared. The more the baby eats, the happier the mother is and the more praise the baby gets. This causes an almost vicious circle, like a Pavlovian reflex, which in part may be responsible for the obesity developing in subsequent years." Dr. Prader concludes that this is presently a mere theory, but there may be some truth in it.

PWS ABROAD (cont.)

I have seen a few children whose diagnosis was made in infancy (during the hypotonic phase). We put them on a rigorously controlled caloric intake. So far, these children—although they show some evidence of persistent hunger—have done well as far as body weight is concerned. They are now 3 and 4 years old and do not show any evidence of obesity. However, it is too early to make a definitive statement about the efficacy of this treatment, since more than 10% of the PWS children, according to Mancini's monograph, develop obesity after the 4th year of life. Nevertheless, the new treatment is worth being tried. This, however, implies that an early diagnosis is needed, and reaching that goal should be a challenge for doctors interested in PWS, as well as the local PWS associations.

Of course, this may not solve the whole problem of PWS. We still have the picking of sores and the emotional outbursts that occur, notably in their second decade, and which are very often a trying experience for the family.

References: "Record of a Symposium on PWS," held in Tokushima, Japan on May 15, 1981, Acta Pediatrica Japania, Vol. 23, December 1981.

Mancini, R. et,al., "The PWS," Acta Medica Auxologica, Vol.14, Suppl.

1982, Editor: Capelli; Bologna, Italy.

Hans Zellweger, M.D. Professor Emeritus of Pediatrics University of Iowa

(Ed. note: The GV would like to thank Dr. Zellweger again for his interesting, insightful contribution. If we add the above figures to our listing of persons with PWS, we arrive at over 1300 and know there are many more U.S. cases undiagnosed. We also have members from Norway, South Africa and Argentina.

To the other professional: Why not take a moment and write down some of your recent observations about PWS? The GV is very happy to publish all relevant material that we receive, and we especially welcome contributions from our professional members currently studying and working with people with PWS.)

NATIONAL MEMBERSHIP MONTH - AUGUST

The GV is sorry to report that our national membership month suggestion was not overwhelmingly received by the membership. We would like to thank the Texas group for their membership drive, (which was started before we suggested a membership month), and the California conference committee for their efforts in getting new members to join.

The actual response to the last issue's comments about the benefits of an increase in membership was not good. We did have some dedicated members who recruited more people to the association, and we thank them, but we are sorry that we can't report the outstanding response that we had hoped for. Of course, it is not too late! Every new member we get helps us grow and reach our goals.

CHAPTER UPDATE

PWSA now has nine official chapters across the country, and the GV would like to bring the membership up to date about what they are doing.

SOUTHERN NEW ENGLAND PWS: Our first chapter meets in CT. They have two important on-going projects. One is the opening of a PW group home with the help of MARCH, INC. At the last report, possible sites had been looked at for the home, and definite progress had been made towards opening. This group is also involved with a very successful PW clinic at the U of CT run by Dr. Suzanne Cassidy and Carrie Mukaida, R.D., active members in the chapter.

PW GREATER NEW YORK: This active chapter has been striving to gain school programs and facilities badly needed in New York state. New York currently has very few placement situations appropriate for PW people, so the group has made that goal their primary concern. Rita Welch, President, has been unbelieveable in her efforts to contact state officials, and has hopes that a meeting now scheduled for October may be "beginning" for the state to fill these needs.

PW KENTUCKY: This newly incorporated chapter held its last meeting the beginning of August. Included in the agenda of that meeting were plans to raise funds by setting up a booth with donated craft and flea market items at a local fair. The group has also been invited to give a presentation at a conference in Louisville where they hope to inform educators about PWS.

PWS MISSOURI: The MO Chapter keeps us informed about their activities through their own chapter newsletter. Their concerns have included making PWS known throughout the state in order to contact and support more PW parents. Just recently, the Knights of Columbus Developmental Ctr. from Cardinal Glennon Memorial Hospital agreed to become MO's central resource center and specialists on PWS. The chapter is also going to be hosting the next meeting of the PW Midwest Association in October.

PW MIDLANTIC: Meeting in Eastern PA and surrounding areas, this chapter gets together twice a year. At their spring meeting, the group held a successful 50-50 raffle to raise funds for the Research Fund; they collected \$854. The speakers at that meeting included a psychologist who gave parents tips about dealing with PW children in a family setting. Dr. Terry Page also discussed his work at JFK Institute.

PWA OF MINNESOTA: A new PW workshop and clinic are among this chapter's recent accomplishments. Mostly through the efforts of Peggy Anderson, the PW Alternatives Workshop opened about a month ago. A PW clinic at Gillette Hospital in St. Paul is also now running, with clinic days twice a month. Recently, the chapter held its largest annual picnic and camp -out with 11 residents from Oakwood, the Oakwood staff, and PW families and friends spending a camping weekend together.

PW COLORADO: This chapter is a small, close-knit group of families meeting near Denver. Their recent projects have included spreading information around their state by drafting letters to professionals about PWS and publishing stories about PW people and their families in various newspapers and magazines. The group is also interested in fund-raising.

PWA OF NEW ENGLAND: Meeting in MA, this group recently became a chapter of PWSA. They have been working closely with other groups in their area.

PW TRI-STATE: Our newest chapter, this Eastern group has been working closely with the Rehabilitation Institue of Pittsburgh. They arranged for a summer camp for PW people to be held there, which is now in its 2nd year. The chapter has future plans for opening a suitable group home.

GATHERED VIEW CLARIFICATION

An article which appeared in the last issue of the GV, "Accuracy is Very Important," included a quotation from Dr. James Mascarello which he would like us to clarify. Dr. Mascarello stated in his presentation that he saw a paper that described the syndrome as being caused by a deletion in chromosome 15 and he disagreed with that statement. By saying that, he did not necessarily mean that deletions in chromosome 15 could not cause PWS, but that it might also have other causes.

In Dr. Mascarello's opinion, every case of PWS is caused by some defect, even if it is an undetected one, in chromosome 15. But he would like to point out that not all chromosome defects are deletions. He feels that to oversimplify and state that a deletion causes the syndrome would be a major disservice to those PWS patients in whom no deletion was found.

UPDATE ON MICHAEL REESE CLINIC

Dr. Andree Walczak, a long-time supporter of PWSA, was unable to make our conference because of illness, but she sends us the following report about the PW clinic at Michael Reese Hospital in IL.

"Our clinic is now 7 years old and quite alive. Many children have been attending since the beginning and have become very good friends. The parents have also formed close bonds and have helped each other during the many crises that one encounters with a PW child.

The children are getting ready for their yearly 3-week summer camp in June. This year we will have press coverage of the camp which will give some publicity to the syndrome and perhaps help to get funding for a PW home, as the future of our children is an ever-pressing and anxiety-producing issue with all our parents.

We have been participating in two good researches. One at Indiana U on chromosomes (Dr. Butler), and the other on energy expenditure at the U of Chicago (Dr. Schoeller)."

ANNUAL TASH CONFERENCE

"Interdependence: The Next Decade," is the title of the 10th annual conference of TASH (The Association for the Severely Handicapped). The conference will be held Nov. 3-5 at Cathedral Hill Hotel in San Francisco, CA. For more information about the program contact: Hiroko Roe, Conference Coordinator, TASH, 7010 Roosevelt Way, N.E., Seattle, WA 98115. Or call: (206) 523-8446.

ANNUAL CONFERENCE TIME AGAIN????

It seems we just arrived back from the last conference, and we are already talking about next year. For those that are required to plan ahead, the 1984 6th ANNUAL NATIONAL CONFERENCE will be held in Minneapolis June 14, 15 and 16th. The conference committe is being formed and will soon be hard at work planning another great conference.

KIDS ON THE BLOCK

"Kids on the Block" are specially designed handicapped puppets made to represent various disabilities in order to increase public awareness of certain handicapping conditions. The Greater Enfield ARC of CT has approached the manufacturer of these puppets with the idea of creating a puppet with PWS. The response they got was that the creator of the puppets must receive many requests for such a puppet before they would consider making it. Greater Enfield feels that if enough of our members wrote, the puppet would be given serious consideration.

Such a puppet would be extremely helpful in meeting our goal of making PWS known. Help Great Enfield get the attention of the "Kids on the Block" by writing to ask them to make a PWS puppet! You can write to:

Barbara Aiello Kids on the Block, Inc. 1712 Eye St. N.W., Suite 1008 Washington, D.C. 20006

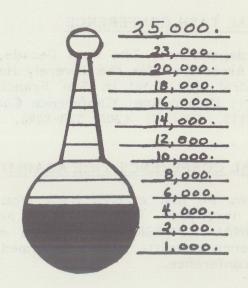
HELPING PW'S IN MASSACHUSETTS

The newsletter of Residential Rehabilitation Centers reported a program, developed on a mentor/ staff apartment model, will be designed to address the specific needs of two young adults with PWS. "Two residents of the Gilbough Center program have recently been integrated into community based programs, according to Nancy Drwal, Center coordinator... The fact that two of our clients have developed to a point where they are now able to be integrated into community programs has exceeded our initial expectations."

RESEARCH FUND

July and August donations enabled our fund to grow by \$1145.43, bringing our total to \$5177.43. This growth is contributed to direct donations from the United Way of Hutchinson, MN (obtained by the Aul family), Zonta International, (obtained by the Rasmussens of Austin, MN), and members Bush, Breneisen and Neason. Memorial contributions were received from member Mitchell, and non-members Stone and Hoffert.

A BIG THANK YOU for members who support us in our efforts with this fund as well as those members who enable us to complete other projects with contributing dues donations.



FROM A SOMETIMES I'M MAD, SOMETIMES I'M GLAD CANADIAN MOM

"I recently visited the PWSA office in Edina, and I want to take a minute to tell you, who maybe like me, wondered where and what the PW office looked like. It is a one-room office in Marge's home that is filled with 'have done' and 'to do' work regarding the PWSA. I was amazed at the volume of paperwork that it takes to put together the GV. Each of us certainly benefits from the efforts and time that Marge and Edie put into running the office.

Regarding the letter to R. Simmons: my PW daughter is busy right now writing to Richard. I think it would be great if more persons with PW did the same, along with a

letter from Mom or Dad.

I would also like to comment on the ostracizing and tantalizing (teasing) that my daughter has to put up with in everyday living. Before I comment, I want to mention that my daughter's weight is under control and she works hard planning and counting her calorie intake every day. She is also aware of the importance of 'nutritious' vs. 'junk' calories. Needless to say, her school lunches don't resemble those of other kids, and this we've talked about and she's accepted. But then along come four kids who literally pass a cookie, candy, cake, etc. under her nose and say, 'too bad you can't have this, boy, is it ever good.'

Another hurting incident she experienced just recently was at a family gathering. (An obese) relative was giving candy to the kids, and as she gave it to each, she would shake her finger and say, 'don't eat it until after or I won't give it to you.' My daughter was extremely hurt and remarked that it was because of her that the kids

were told not to eat their candy.

How do you make people understand that people with PWS have feelings too? Maybe, a big sign pinned to her back saying, 'Please remember that I have feelings, too!!' You know, a lot of the time, I feel that I can cope with PWS fairly well, but it's family and society that I can't cope with!"

GROWTH HORMONES

Dr. Beltran's daughter is currently involved in a study of synthetic growth hormones. We thought the membership might be interested in her progress. Dr. Beltran writes: "Dr. Hintz originally told me he wouldn't use growth hormones on PWS. His associate...did the work-up on (my daughter) and decided to go ahead with her. Her one year growth was 4 inches, with another inch on the first three months exam in the second year."

Also on the topic of growth hormones: Dr. Vanja Holm of the U of WA reported at the conference about her studies involving the use of the hormone Anavar with six PW boys. She reports that three of the boys have shown little to no effect from the drug, while the other three, two of whom just started taking the hormone a year ago, have reacted favorably to it so far. It is a little too early to give any definite report, but her early results seem to indicate some improvement in growth in PW boys that were previously growing below the 50th percentile on the growth charts that Dr. Holm developed for children with PWS. Dr. Holm also mentioned that she would not recommend trying Anavar with girls, because of the unfavorable masculinization that it may cause.

A LOOK BACK--PART FOUR

For those who missed parts 1-3 of this series, "A Look Back" is a special review of the growth and development of the PWSA from its roots in 1975 to the present. Part three followed the organization through its incorporation in 1977 as the official international, non-profit organization.

This part of the series will take us through 1978, and up to 1979, an important period of time for the PWSA, because it marked the beginning of our annual conference. The first general meeting and conference was held in Minneapolis in June, 1979. But first, a little about the year that led up to that meeting.

In 1978, PWSA had a membership of about 300. And, as member's children grew older, concern about the older PW person increased. The first plans for PW group homes were developed, and much of the GV articles of that time discussed WISER acres, a group home in Seattle. Other concerns also arose, centered especially around PW behaviors and diet, evidenced by the following excerpts from two articles:

". . . One way to eliminate some barriers to behavior change is to hold a family meeting to discuss problems and find workable solutions...go over the following questions to clarify your definition of the problem, how to change it, and who will be involved.

I. The Behavior

a. What is it? Be Specific! (i.e. 'He looks at me funny' is not specific, 'He stares at me for 5 minutes or more' is specific.)

b. How many times does it happen in a given day and for how long?

c. Is it public or private?

- d. Who is present when it occurs?
- e. Who does it bother most? Least?

II. Solutions

a. How many ways can you think of to change the behavior?

b. For each way you can think of, answer the following:

i. Who in the family has to be involved in the program to make it effective?

ii. How much time will it take from each person? For how long?

iii. Who will get 'less done' from those family members involved in the program? How much less?"

"A teacher...formed the club for students...who were overweight. The club has its own T-shirts, and the children are very proud of themselves, showing a vast improvement in self-image.

Each day at lunch time, the kids, with their sponsor, go to the school kitchen and prepare their own lunch. They have made up a scrapbook showing the caloric values of different foods. Menus are planned a week in advance and sent home so parents can work them into their menu plans...Club members are permitted to compare their lunches with the regular lunches and see that, although the calorie value of their food is much lower, they are actually getting a larger volume of food. They now feel special, rather than different."

A LOOK BACK (Cont.)

Much of the articles in the 1979 GV's discussed, understandably, the annual conference, which turned out to be a smashing success. 165 people attended the meeting, and according to the Sept-Oct issue, many described the conference in "glowing terms," lighting the way for the 2nd annual conference. Needless to say, the GV issues in 1979 also included articles about other subjects, but those will have to keep until part 5 of "A Look Back."

CONCERN ABOUT ASPARTAME

Some of you may have seen recent newspaper articles regarding a letter published in the New England Journal of Medicine regarding one doctor's opinion of aspartame, the new artificial sweetener. This doctor was theorizing possible problems based only on animal studies.

We feel the drug has been highly researched, and approval by the Food & Drug Administration certainly carries a great deal of weight. Naturally, as in any product, if any side effects are noted, such as the dizziness and behavior changes mentioned, discontinuing usage would be recommended.

RESEARCH GRANT AWARDED

A research grant has been awarded by PWSA. This \$4,000. grant will be used as a 6 month pilot project to study behavioral problems associated with PWS individuals living in a group home.

A steering committee was formed including two psychologists, an administrative consultant, two directors of PWS facilities, director of PWSA, an Oakwood Board member and staff (when available) of Oakwood Residence. The main objective of the research project will be to develop preventive technics to reduce maladaptive behavior. The pilot project will be sharing findings throughout the year in the GV.

It is estimated the complete study will take 2-3 years, and hopefully knowledge gained will be of benefit to all families with need of this type of help.

UPCOMING MEETINGS

PW MIDLANTIC

The fall meeting of this group will be held October 1st at The Woods School in Langhorne, PA. A Wood's psychologist will conduct two panels and three medical staff from Thomas Jefferson Medical College will also conduct a panel. The Youth Program will be incorporated into the Saturday program. Contact D.J. Miller, 238 E. Court St., Doylestown, PA 18901 - phone (215) 348-4820.

UPCOMING MEETINGS (Cont.)

PWA-MN

September 23rd is the date for the next regular meeting of this chapter. (Meetings are held the 4th Fri. eve. every other month during the school year.) The location for this meeting will be at the new PW workshop; Alternatives Work Activity Center, 400 Stinson Blvd., Minneapolis.

PW MIDWEST

The next PW Midwest Assoc. meeting will take place Oct. 8th at the UCP Assoc. Canterbury Ctr. in St. Louis, MO. The meeting will include four presentations in addition to a business meeting and informal sharing time. Contact Al or Janalee Heinemann for reservations as soon as possible.

OH-PA-WV

The next Tri-State Chapter meeting will take place October 22nd at Deepwood Ctr. in Mentor, OH. The chapter is working toward more recognition by the medical and educational communities, and there will be talks by doctors, teachers, and parents. A children's program will be included. Contact Peg Ott, 30021 Regent, Wickliffe, OH - phone (216) 944-4271, for more information and luncheon reservations.

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 Canada and overseas members. Send dues and change of address notices to: PWSA, 5515 Malibu Drive, Edina, MN 55436.

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