

PRESIDENT'S MESSAGE

The word is out. It's time to plan. Kansas City is the site for the FOURTH Annual Meeting of the Prader-Willi Syndrome Association. Complete details are presented inside. I just wanted to take advantage of the fact that this message is the first thing you see upon opening the Gathered View. Let me encourage all of you who read this to give serious consideration to attending this meeting. Many of us must attend meetings related to our work and one more meeting seems a chore. The Prader-Willi meeting is different. As a dyed-in-the-wool meeting hater, I have found it a privilege to attend the previous three national meetings. They are put on as the product of love, the same effort that went into founding and nurturing this organization, continues to produce the annual meeting. This year Betty Schultze of St. Louis, who put together the Directory for Clinical Services, has teamed with Eleanor Watson of Kansas City to carry the burden of planning the program and making the arrangements for our meeting. Marge Wett will assist with the facilities of the Association office in Minnesota.

This meeting is important because it provides the opportunity for us to meet other PW people and to learn from each other. The program is designed to give you information on practical food management and planning, how to work with the people who help you, understanding the problems of living with PWS and involvement with vocational training and group homes. These are topics of importance and interest to PW people. They will be presented by persons who have worked with the problems, but most importantly they will be there to guide you on how to work through the daily problems that are faced in helping PW persons achieve their maximum potential.

Half of one day will be devoted to the annual meeting of the Board of Directors of the PWSA. This is the only business meeting of the Association each year. It gives the membership the opportunity to be involved in the decisions that affect their organization. The key to success in this or any organization is the interest shown by its members in handling the responsibilities of membership. It is gratifying to see the growing interest of people to form local groups in the support of the goals of this Association. It is important for these groups to determine leaders that can represent those at the local level who are unable to attend the national meetings. Only through your voice at the national meetings can the individual desires and feelings of the members be made known. Since local groups are in the formative stage, it is vital that input to the Board be made at this meeting by the groups to ensure that locals can determine the proper support to them from the national organization. Similarly local groups should be prepared to nominate and support candidates that they recognize as leaders and proponents of their views to provide active input to the Board decisions. There will be an election for three openings on the Board of Directors.



President's Message, cont.

As time passes and the organization grows, it will be necessary to find additional leadership to share the increasing responsibilities of the Association. The by-laws make provisions for paid positions of responsibility and growing demands bring the need for such persons closer to reality. These are matters of concern that will require discussions and decision at this meeting. All PWSA members are welcome at the meeting of the Board and their viewpoints will be solicited during the deliberations. The election of three Directors to the Board will be accomplished during the meeting. Plan now to attend your meeting of the PWSA in Kansas City, June 24, 25, and 26.

Delfin J. Beltran, M.D.  
President

FORMATION OF TWO NEW GROUPS

I would like to announce the formation of the parent's and children's support group for the St. Louis, MO area. As a group of 5 families that have been meeting monthly since last October, we are attempting to share information and provide emotional support not only for the parents and children, but also for the siblings of the PW children. We are excited about the possibilities of meeting other families at the national conference, which we were happy to find out will be in relatively close Kansas City. If there are other families in our area that are interested in the group, please feel free to contact me for information.

Allen Heinemann  
12177 Oakwilde Court  
Maryland Heights, MO 63043

The following people would like to be contacted by people in the State of Texas that have PWS children. We are attempting to organize a PWSA on the State level.

Elizabeth Briggs  
2914 Hunters Glen  
Missouri City, TX 77459  
(713) 723-6776, 437-1286

Lin Marchitelli  
9010 Troulon  
Houston, TX 77036  
(713) 772-4559

Peggy Westbrook  
3026 Green Tee Drive  
Pearland, TX 77581  
(713) 485-9811

NEWS FROM GILBOUGH CENTER

The Gilbough Center has expanded their dedicated PW home from three to six residents. They are pleased with everyone's progress and report a good steady weight loss.

Another development is their affiliation with the Tufts-New England Medical Center in Boston. Dr. Francesca LaVecchio has opened a PW Clinic at the medical center. In addition to providing comprehensive medical services, this clinic is also initiating endocrine studies. Dr. LaVecchio has agreed to conduct a weekend workshop for parents on April 30th and May 1st, "Coping with PW - A Workshop for Parents".

Gilbough is also working on opening supervised apartments that will service PW young people. Referrals from in-state and out-of-state are now being accepted. These units are opening in June or July.

Gilbough is also seeking feasibility of developing a summer camp. If you would like further information on any of the above activities, please contact:

A two-week camp has been arranged. Details from Nancy.

Nancy M. Drwal, Program Coordinator  
Gilbough Center  
Route 6A, P.O. Box G  
Brewster, MA 02631



ANNOUNCEMENT OF 4TH ANNUAL NATIONAL CONFERENCE AND BUSINESS MEETINGJUNE 24-25-26, Glenwood Manor, Overland Park, Kansas

The 4th Annual National Conference and Business meeting of the PWSA will be held on June 24-25-26, 1982 in Overland Park, KS at the Glenwood Manor. Overland Park is in the Greater Kansas City Area, accessible by major highways. There is hourly, direct bus service to and from Kansas City International Airport to Glenwood Manor for \$10.00.

Accommodations at Glenwood Manor, and adjoining complex, are attractive and offer many services. There are 270 rooms, located on 120 acres which include a 15 acre-fishing lake with beach and boating, a swimming pool, tennis courts, children's playground, two restaurants, two theatres, shops and laundry facilities. Additional facilities adjacent to the Glenwood Manor complex include a Putt-Putt golf course, several shopping centers and restaurants. The Conference, Business Meeting and Association Dinner will be held on the premises of Glenwood Manor in the exhibition, meeting and dining facilities for Conventions and Conferences. These facilities are attractive, self-contained units which will add to your conference enjoyment. You will walk to and from your rooms to the Conference and be able to meet and visit with others in attendance.

The Activity Program for Prader-Willi People and other siblings is tentatively planned to include a trip to the Kansas City Zoo, a Lakeside Party at Glenwood Lake, a bus trip to Lakemary Center for activities and lunch, a movie, a picnic, sports activities, a pool party and an Action Shop on nutrition and dieting. Three lunches, one dinner, the movie and transportation are included in the Activity Program fee. The fee for each participant will be no higher than \$15.00. Efforts will be made to lower this cost as much as possible.

The tentative Program Agenda will focus primarily on the expressed concerns of parents and will emphasize: (1) Management of nutrition and dietetic aspects of PWS, (2) Adjustment and coping for families of and individuals with PWS, and (3) Requisites for parents in planning and securing appropriate educational programs for their children. There is one medical presentation planned. Personnel to implement the program will be secured from the Kansas City District Dietetic Association, the Mental Health Association of St. Louis, Area Institutions for Higher Education, Area Local Education Agencies, Area Physicians, and State Level Consultants in Special Education. The format for the conference will consist of Panel Discussions, Individual Presentations, Action Shops and Video Tapes. All of these will be built around a discussion format following initial information given by the presentator (s).

Preceding, or following the PWSA Conference, there are an endless variety of things to do in Kansas City if you would like to turn this event into your family vacation. The Kansas City Royals, the Starlight Theatre, the Nelson Art Gallery, World's of Fun, the Harry S. Truman Library and Museum and the Crown Center are attractions you can build into your visit to the Kansas City area.

Betty R. Schultze, Ed.D., St. Louis, MO is serving as Local Program Chairperson and Eleanor P. Watson, R.D., Paola, KS is serving as Local Arrangements Chairperson for the Conference. Plan to include the PWSA Conference in your summer plans.. The Program and Registration Form will be mailed to members of the Association by the middle of April.



Prader-Willi Syndrome AssociationFinancial ReportDecember 31, 1981Receipts

Membership dues	\$7009.46	
Donations (Includes \$1000 from March of Dimes)	4078.22	
* Material Sales	8557.16	
National Conference	3791.00	
Interest	<u>731.53</u>	\$24,167.37

Expenses

Salaries	0.00	
PWS Book	6106.80	
National Conference	4224.13	
Printing	2853.41	
Postage	2046.22	
Travel	1424.55	
Clinic Services Directory	662.90	
Office Equipment	460.37	
Secretarial Service	422.75	
Computer Service	413.74	
Office Supplies	358.06	
Other Outside Services	263.50	
Currency Devaluation	156.76	
Telephone	101.39	
National Committees	93.13	
National Chapters	38.22	
Miscellaneous	<u>10.00</u>	\$19,635.93

Net Increase

\$4,531.44

\* Handbook, Conference Papers, PWS Book, PWS Overview, Clinic Services Directory, and Membership lists.

We closed out 1981 in better financial condition than projected when our 1981 budget was set in mid 1980 but not as good as anticipated when re-estimated last June. We ended last year with an increase in cash reserves of \$4,531.44, graced by the fact that we did not pay any salaries. If the \$7,500 budgeted salaries had been paid, we would of course have suffered a loss for the year. Our overall revenue was greater than budgeted (\$24,167.37 versus \$18,200), primarily due to sales of publication material, but our expenses, likewise, were over budget (\$19,636.93 versus \$17,975) due to increased printing costs and other unanticipated expenses.

In summary, our conservative planning and avoidance of salary payments has kept us in the black. It should, however, be obvious we have a long way to go before we can consider ourselves a viable organization not dependent on volunteer help which now is a full-time commitment.

Eugene C. Deterling, Treasurer



TRI-STATE GROUP

The Tri-State Conference for Ohio, West Virginia, and Pennsylvania will be held on Saturday, May 15th, at the Airport Holiday Inn, Pittsburgh, from 9:30 - 4:00. Parents, professionals, PW people and siblings are welcome.

Pauline Middleton Allis, family therapist, will lead us in exploring the problems that the various family members encounter and, most important, how to cope. For information:

Lota Mitchell  
844 Foxland Drive  
Pittsburgh, PA 15243  
(412) 561-3026 evenings

Patti Smith  
5920 Elwood Street  
Pittsburgh, PA 15232  
(412) 661-4645 evenings

MIDDLE ATLANTIC ASSOCIATION (PA, NJ, MD, DE, NY)

Our fourth group meeting will be held at the Holiday Inn, Intersection Route 17 South and 3 Lyndhurst, NJ, on Saturday, April 17th, from 10:00 - 4:30.

Marge (our Executive Director) and Dick (our Board Chairman) Wett will be part of our program. The National Association is coming to meet YOU. The establishment of a group home will be the main topic of this meeting. The PW young people's activity will be scheduled according to the weather.

Newly elected officers for this group are:

Pres: Doris Jane Miller, Doylestown, PA	VP: Lorraine Diamond, Cherry Hill, NJ
Secy: Isa Breneisen, E. Petersburg, PA	Treas: Lougene Burleigh, Bethesda, MD
Program Co-Chairpersons: Ellen Gootzit, Baltimore, MD & Volene Howe, Rochester, NY.	

OTHER PWSA GROUPS

While attending a medical meeting in the San Diego area in January, Dick Wett and Marge were able to spend one evening with some parents from this area. Fran Butler, Executive Director of Friends of Handicapped Children, was able to attend the meetings and had the opportunity to question the Wetts about the opening of the PW home in Minnesota. Ms. Butler will be directing the opening of a home for PW's in June of this year in the San Diego area. Some time was also spent discussing the formation of chapters.

The Wetts will also be traveling to San Francisco in March. During this trip they plan on spending one day visiting the Alta Regional Center in Sacramento and meeting with a group of parents from this area. In April they will be attending the Middle Atlantic meeting.

SKIN PICKING PROBLEM

One of our Canadian members writes that she would appreciate some help in dealing with the skin picking problem with her 5 year old daughter. She writes that the problem has been going on for 3 years, particularly during the night, and that she picks her nose, lips, arms and hands to the point of bleeding.

These are the things that have been tried unsuccessfully to overcome this problem: wearing a sleep shirt with sleeves tied shut and closed in the back; every sore remedy on the market; cutting the nails short; a relaxant type of drug for sleeping; vaseline; lotion and bribery.

Perhaps some parent or professional might have some new innovative ideas that they could share with this very frustrated parent.



A CO PARENT WRITES:

"The one thing that bothers me the most is why some parents won't even try to work with their PW's weight problem. We heard so many of these sorts of comments and yet I feel it is the most important aspect of the syndrome! Is there a chance of getting a good speaker on diet control and exercises at the next conference? Our son's therapist is convinced that walking (brisk) will help him a lot and wants us to have a 3 mile goal in mind! I've started and am keeping records just to see if the results are there. She has had terrific results with Down's Syndrome! So with a goal in mind, we've started out just a block at a time and hopefully by the end of the year we'll be close to our goal and see some positive results! We'll let you know!"

INFORMATION FROM JANUARY TASH NEWSLETTER

Programs for the Handicapped, available free of charge, contact:

Programs for the Handicapped  
Department of Education  
Office of Special Education and Rehabilitative Services  
Office of Information and Resources for the Handicapped  
Washington, DC 20202

Food and Nutrition Information Center (FNIC), source of information and will respond to reference questions:

FNIC  
National Agricultural Library  
Room 304  
Beltsville, MD 20705

Association for Children and Adults with Learning Disabilities (ACALD) has approximately 15 publications on the relationship between learning disabilities and nutrition. A list is available through:

ACALD  
4156 Library Road  
Pittsburgh, PA 15234 (412) 341-1515

The State Fire Marshall's Office in Ohio have responded to the need of safety of residents in group homes and has developed a training package for residents and staff. The package consists of a slide/tape program, copy of the script, and a leader's guide. The package is available for \$30.00 from:

Sherry Kovach, Fire Safety Educator  
State of Ohio, Department of Commerce  
Division of State Fire Marshall  
8895 East Main Street  
Reynoldsburg, OH 43068 (614) 864-5510

AN ENGLISH MEMBER WRITES:

".....I enjoy reading the 'Gathered View' very much and find it very helpful. We now have an Association here in England, but we are always very interested to hear what is happening in the U.S."

We hope our English members will continue to share what they are doing also.



## A NUTRITIONIST WRITES

"I have just read your January-February issue of The Gathered View. There is a lot of good information in this issue. As a nutritionist that has worked with PW children and their families, I'm pleased you exist.

One item I took exception to was 'Milk Substitute', page 4. Meadow Fresh is not a substitute for milk. It is an imitation, milk like product. It is mostly made from whey, sugars, salt and coconut oil. It is not nutritionally equal to nor better than milk.

Labeling issues, misleading information, and inconsistent quality as far as content are some of the serious legal issues faced by Meadow Fresh Farms, Inc."

Editor's note: The above is part of a letter that we received from the director of nutrition services with the Texas Department of Health. She also included some test results from the University of Iowa and the State Health Department of Utah.

As most of you know, it is the purpose of our newsletter to share information with you that we obtain from many different sources. It is never our intention to endorse or recommend any of the things we share with you; we have not read each book or pamphlet that we review, we have not tried each recipe that we print, nor verified the nutritional value if given. It would be very difficult for us to do this. Since we have found this product to be controversial, we do recommend that anyone planning on using it to first check with their doctor or nutritionist and obtain their opinion. We would be happy to share the information we have on the product with anyone requesting it.

## GREATER NEW YORK AREA GROUP

The last issue of the GV mentioned a hospital that has established a PW clinic. The full name and address of this clinic is:

Nassau County Medical Center  
Genetics Department  
2201 Hempstead Turnpike  
East Meadow, NY 11554

New York State people seeking a  
PW residence, please contact:  
Rita Welch, 6-12 160 St., Beech-  
hurst, 11357.

## GOVERNOR'S COUNCIL

Our Executive Director, Marge Wett, has just received an appointment to the "Governor's Planning Council on Development Disabilities", for the State of Minnesota. This council operates in addition to another state council and has federal affiliation as well as state. Over 60 applications were reviewed for the 14 positions that were filled, so we are fortunate to have a representative to our organization appointed.

Hopefully some direct benefits for PWSA can be achieved by this membership.

## CROCK POT HAMBERGER SOUP

3 beef bouillon cubes	3 stalks celery, chop'd	1 (10 oz.) frozen mixed vegetables
3 cups boiling water	3 carrots, cut in chunks	1 tsp. pepper
1 lb. ground beef	2 med. potatoes, peel'd cubed	salt if desired
2 sm. onions, chop'd	1 (16 oz.) can tomato wedges	

Dissolve bouillon cubes in water. Brown ground beef and drain. Place bouillon, beef and all of the vegetables in electric slow cooker. Cover, cook, low heat 8-10 hours. Seasoning may be added. Serves 6

This can be cooked in the conventional way: Follow directions above except cook in soup kettle until vegetables are tender, about 1 hour. 224 calories per serving.



A DE MEMBER WRITES

"....We may not have some of the things other states have but we do have a super hospital, the doctors and staff at A.I. duPont Institute, and a Vocational Rehabilitation Counselor that has worked closely with our daughter and supported us throughout the years. When I applied for the SSI, I used the names as references and also gave them a copy of Wett's newspaper article re PW.

Currently our daughter is in an Easter Seal Program that has all the promise of a good program for a PW. Perhaps this may be a source for others to pursue. When she began this program, I gave them a copy of the Overview. Again I feel distributing these articles to these agencies can educate and give more understanding re the syndrome, and in turn give us more support. Praise to you for the excellent book, Prader-Willi Syndrome!"

(Editor's note: Most states do not have a lot of things but our membership is changing this picture and we are very happy to share these successes with all of the membership. The praise for the PWS book goes to Dr. Holm and the CDMRC Clinic in Seattle for the meeting that made the collection of these medical papers possible.)

SUGGESTIONS FROM THE EDUCATION COMMITTEE:

One out of every 10,000 people may have heard of Prader-Willi. My aim for the Education Committee is to make this 100 people out of every 10,000 familiar with Prader-Willi.

Early diagnosis is the single most important advantage a Prader-Willi person can have. If PWS becomes a household word, the victims of it will have a better chance for success.

If you go to the special education department of your school system with a Prader-Willi child--and they've heard of PWS it will be next to impossible to convince them that:

- 1) mainstreaming is unsuitable for most PW children.
- 2) the PW child has unbelievable social habits.
- 3) the PW child may indeed eat himself to death.

If, however, the special education department is familiar with PWS, everything is simplified.

Your PW child at 18 years should make application for SSI--disability benefits. If your local Supplemental Security Income Office has never heard the word "Prader-Willi", you may have an uphill battle trying to prove eligibility. If, however, the social security people are familiar with PWS--all that's left is paperwork.

\*\*\*Finally what can YOU do to make 100 out of every 10,000 people aware of Prader-Willi?

Make a photocopy of the synopsis of PWS and send it to: (copy included this issue)

- 1) Your school district - special education department.
- 2) Check your phone book for county agencies and medical groups suitable for receipt of this article. Send to several of them.
- 3) Local workshops for disabled.
- 4) Local Newspaper - feature articles concerning PW (perhaps your own child if you are comfortable with this) include item on any area meetings for PW.

The Education Committee would appreciate hearing from you as to success or failure. Thank you!

D. J. Miller, Chairperson  
238 East Court Street  
Doylestown, PA 18901



### Prader-Willi Syndrome

A syndrome is a group of signs and symptoms that occurs together and characterize a disease or disorder. This syndrome was described in 1956 by doctors A. Prader, A. Labhart, and H. Willi, and is sometimes referred to as Prader-Labhart-Willi syndrome. It is considered an uncommon condition resulting from a birth defect. The pattern of characteristics associated with PWS is remarkably consistent among those affected by it. PWS is believed to be among the five most common syndromes seen in most birth defects clinics.

The syndrome generally occurs sporadically, doctors have stated there is not a high risk that parents with an afflicted child will have another child with the same condition. Cases of more than one per family have been reported in the past and investigated with a lack of a proven diagnosis found to always be the case. Recently a family of four children has been found and all display the typical characteristics of this syndrome although none have the chromosome #15 deletion. Further investigation is taking place.

### Characteristics

Features considered essential for a diagnosis of PWS include hypotonia, feeding problems, mild dysmorphism and delayed motor development in infancy. Childhood features include some degree of hyperphagia, intellectual impairment/school problems and abnormal pubertal development. The significant manifestations of PWS are hypotonia (lack of muscle tone, size and strength), hypogonadism (underdeveloped or small genitals, lack of complete sexual development), adult short stature, and central nervous system performance dysfunction (some degree of mental retardation in 90% of the cases, insatiable appetite that leads to obesity, if food is not controlled).

Obesity generally becomes prominent before 5 years of age, if food intake is not controlled, with the central body, lower trunk and buttocks more involved than the rest of the body. The average age of onset is 2.9 years of age. The average adult height is about 60", with some exceptions as great as 69" and as low as 42". Hypotonia is most evident during infancy with general improvement thereafter. Hypotonia consists of the lack of ability to control the head and limbs, a weak cry, and poor sucking ability. The ability to hold the head erect generally occurs late in the first year. Sitting occurs around 11 months, walking at about 24 months, and talking in short sentences at 3½ years. There are records, however, of infants with this syndrome sitting at 4 months, walking at 14 months, and talking under the age of 2. Sexual development may begin at a young age but stops before reaching the normal adult level. Hypogonadism is most evident among males because of their anatomy, with a small penis and frequently undescended testes. In the female, a small clitoris and hypospadias are more difficult to detect.

Central Nervous System Performance Dysfunction can be characterized by varying degrees of I.Q. overall. I.Q., usually in the 70's range, can fall below 40 and be above 100 in some cases. Persons with PWS have a good performance in some areas and are lacking in others. For example, a person with this syndrome is usually a good reader but very poor in math. Abstract thinking seems to be a consistent problem area. Generally these young people do not function at their overall I.Q. level. They also lack balance, large muscle strength, endurance, and good coordination. An example, people excel in puzzle-making and other activities using small muscles, but find athletic activities and other functions requiring good coordination and muscle strength very difficult.

Other characteristics are small hands and feet, which may be puffy in appearance, and a harder-to-detect narrow bifrontal forehead diameter. Somnolence (excessive sleepiness) is not usually mentioned in the medical literature but is frequently reported by parents even in children that are not obese. Sleep apnea has also been studied recently. Scratching and picking at sores or insect bites is common. Strabismus and myopia (wandering eye and near-sightedness) are also common. Some individuals develop diabetes, heart problems and scoliosis. These symptoms seem to be appearing less as the weight of the person with PWS is



more controlled. Children are generally affectionate and happy in their early years, but subtle changes often occur after about 5 years of age, with personality problems developing in late adolescence. Temper tantrums and stubbornness are typical, and may be part of the CNS dysfunction.

Of all the characteristics, controlling food intake and behavior are by far the most difficult characteristics with which to deal. The fact that people with this syndrome require considerably fewer calories than the average person to gain weight does not help. Only through the application of extreme dietary measures and family or residence guidance, can obesity be controlled. The desire to eat is believed to be a dysfunction of the central nervous system, as is behavioral problems.

### Treatment

Research is an ongoing practice but at the present time there is no known cure for this syndrome. High-resolution prometaphase analysis is recommended because a chromosome #15 interstitial deletion has been found in approximately 50% of patients tested, and can be used to prove a suspected PWS diagnosis. PWS is a complex syndrome with multiple medical, educational, and behavioral features, therefore necessitates management of the various problems by a multi-disciplinary team of experts. Fortunately, more and more PWS clinics are being developed throughout the country. Even though the characteristics of this syndrome can be minimized, they continue to be a life-long problem and independent living is rarely achieved by someone with PWS.

### Prader-Willi Syndrome Association

PWSA was formed in early 1975 in order to provide a vehicle of communication for parents, professionals, and other interested citizens. It is an organization dedicated to the sharing of experiences in how to cope with this syndrome. It is the belief of the founders of this non-profit organization that only by working together will we be able to solve the many attendant problems associated with PWS.

A bi-monthly newsletter entitled "THE GATHERED VIEW" is the primary communications media for the organization. Members are asked to contribute knowledge and experiences for publication. All available contributed professional advice is also included. National annual meetings are conducted for parents and professionals with a youth activity program running concurrently with the adult meeting.

Membership in the U.S., including the subscription to the newsletter, is \$15.00 annually. Memberships outside of the U.S. are \$20.00 annually. Parents, friends, professionals, and interested citizens are urged to subscribe to this organization. Lay and professional literature is available at minimal cost. To obtain an application form, please contact PWSA or mail your name, address and phone number along with a dues check to:

Prader-Willi Syndrome Association  
5515 Malibu Drive  
Edina, Minnesota 55436  
(612) 933-0113

Revised: November, 1985



NEW REGIONAL GROUP FORMED

The first meeting of the Prader Willi Midwest Association was held in Bradley, Illinois. Following a discussion on affiliation with the national PWSA, it was voted unanimously that a regional chapter be formed under the above name. The following people resumed their terms as officers:

President: Lee Forthman  
Vice President: Jerry Siegan  
Secretary: Dianne Walsh  
Treasurer: Robert Hiatt

Goals for the organization were discussed and three committees including thirty of the members present were formed. They are: Residential Development, Education, and Family Stress & Counseling. Future plans for other committees were also discussed.

After agreeing on meeting four times a year, the next meeting was scheduled for March 13th in Peoria, IL. For information regarding this group, please contact:

Lee or Janice Forthman  
2047 Bechtel Road  
Indianapolis, IN 46260

The first meeting was well attended and included people from the states of Indiana, Illinois, Wisconsin, Michigan and Missouri.

SWEDISH MEMBER

We thank one of the Swedish members for writing and sharing information and a picture of her son Johannes. She writes that her son was diagnosed at 3 and is now 15 and she has never met another family with a Prader-Willi child therefore greatly appreciates the information she has obtained through the GV and the book by Drs. Holm, Sulzbacher and Pipes.

She also writes in spite of the usual problems, the family thinks Johannes is a wonderful person. He goes to a regular school and is working with young people two years younger and with help is keeping up. Johannes has an older brother and adopted twin sisters.

We appreciate being able to share information about our members.





AN NE MEMBER WRITES:

"Enclosed please find my check for \$30.00 to pay for our 1982 membership. Enjoying very much the GV. Only wish it was monthly.

Our daughter started kindergarten this fall and except for a very definite communication barriers seems to be handling it very well. We live in a small school district and we're finding all of the school personnel from her teacher right up through the principal and superintendant, very helpful and supportive. One thing I was very impressed with was the fact that when I said I didn't want her to have milk and graham crackers every day for snacks, they began scheduling her snack according to whatever was on the school lunch menu for the day. If the menu included a relish tray, they give her a carrot or celery stick. If it includes fruit, they give her a piece of fruit and they give her 2% milk instead of whole milk. Our daughter and the other children have accepted the differences very well.

We haven't seen any tremendous weight loss yet but I'm encouraged that since the conference last June we've been able to maintain her weight and we aren't seeing the gains we were seeing before. The speech is coming, very slowly, but coming. She's using her deaf sign less and less all the time.

Look forward to the trip to K.C. Our entire family will attend the Conference this year."

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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 \$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: PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436.  
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