

# THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

**DELFIN J. BELTRAN, M.D., PRESIDENT**

Gail Anderson, Editor  
5515 Malibu Drive  
Edina, MN 55436

VOLUME X

MARCH - APRIL, 1984

NUMBER 1

## PRESIDENT'S MESSAGE

As an emigrant to the San Francisco peninsula after living in Wisconsin for 40 years, I continue to sense that certain things here are minor miracles. Last Saturday evening, Linda and I were headed up the bayshore freeway. Every time we sweep around the four-lane curve at San Francisco General Hospital to see Bagdad by the Bay, we have this sense of wonderment at living so close to this bedazzling panorama that springs up before us. We were headed for another event that almost numbed our senses. As long as I can remember having a feeling for music, the name Yehudi Menuhin has meant violin virtuosity. To see and hear him for the first time created a unique and thrilling experience. The remainder of the program involved 100 instrumental musicians and a chorus of 125. Eight musicians comprised the percussion section. The range and effect varied from soft vocal murmurs to thundering blends of instruments and choir that could be felt almost as clearly as it was heard.

Many of you, who have attended the National PWSA Conferences in the past, have expressed a sense of wonderment at the experience. Those of us, who have had the opportunity of attending several of the meetings, look forward to the experience as a shot in the arm to cap the year and prepare us for the year to come. This year's conference will not only mark the annual cycle, but will be the start of our second five-year cycle. On June 21, 22 and 23, the PWSA Sixth Annual Conference will return to its place of birth—Minneapolis. It must be a sign of advancing age, but it is nearly inconceivable to me that the first PWSA conference, planned with such eager hope, could have cycled that far back into our history.

How many times have we voiced the name "Prader" since the first time someone said, "I believe your child has Prader-Willi Syndrome."? Our first response was undoubtedly, "Prader what?". For a long time we were afraid to say it, it might only have slipped out of our mouths in a half whisper, and when our family or friends asked, "What is Prader—what did you call it?", we threw up our hands in a hopeless gesture of ignorance, frustration and desperation. Would you like to have the opportunity to transform that name into reality? Andrea Prader, M.D. is a professor of pediatrics in Zurich, Switzerland. His studies resulted in the first report defining the syndrome that now bears his name. Dr. Prader will make the trip to the Minneapolis conference to be our honored guest.



President's message continued:

The program of this year's conference has been beautifully orchestrated by the sponsoring Minnesota chapter of the PWSA. Researchers, sponsored by a grant created from PWSA member donations, will report on the progress of their studies. This is the first effort by our organization to become involved as a sponsor into the area of research. There will be an unusual opportunity to develop a working knowledge of the role of residential facilities in fulfilling the needs of people with PW. Many professionals will give insight into their special talents, based on their work with our children. You as a parent or professional will have the opportunity to be with and enjoy the companionship that seems unique to those involved in Prader-Willi Syndrome. You can become involved in an experience of hearing and feeling that will support your responsibility of Prader-Willi Syndrome concern. Join us. Minneapolis, June 21-23, 1984.

*Delfin J. Beltran, M.D.*

NOTE: Efforts are being made to have this year's meeting accredited, which, we hope, will encourage more professionals to attend.

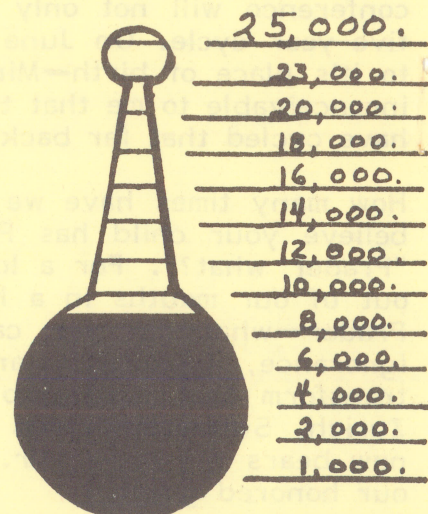
### RESEARCH FUND

We wish to thank the members that responded to our call for support to this worthwhile project of our organization.

A special thanks to members Schultze, Rae, Braunreiter, PWSA-Australian Victoria Branch, Sunde and Krebsbach for sizeable donations. And to the rest of the members whose memorial donations and direct donations help our fund total grow. January and February donations included: Cash, Gordon, C.I.S., Robertson, Jornov, Fick, Ingalls, Alexander, Rinald, Greenswag, Drake, Stone, Parent, Nanzig, Eager, Robbins, Daly, Masterton, Lobenberg & McDonald.

These two months donations totaled \$2176.30, bringing our new fund total to \$9168.90.

We also thank members who continue to show their support in contributing higher dues fees.





SUMMER CAMP

Two summer sessions will again be offered by the Rehabilitation Institute of Pittsburgh. The program, designed especially for children with PW, is very expensive but qualifies for health insurance coverage. Children and adolescents will swim and hike. They will also participate in games and crafts focusing on physical fitness, social skills, communications, nutritional awareness and weight control. Students over 16 may participate in some prevocational activities.

The sessions, which run from June 25 to July 30 for young people and from July 30 to August 24 for older participants, include parent training. Spaces are limited, so contact the Institute soon by writing to: Bea Maier, Ph.D., The Rehabilitation Institute of Pittsburgh, 6301 Northumberland Street, Pittsburgh, PA 15217.

SLIDE PRESENTATION NOW AVAILABLE FOR MEMBERS USE

PWSA has completed work with a professional production company on a 15-minute audio/visual slide presentation now available for member use. This presentation can be used for education as well as for fund raising. We feel it is an excellent way to inform others about PWS.

Members wishing to use the presentation, may borrow it for the cost of postage. A slide projector, screen and a tape recorder are needed to show. Duplicate slides and tape can also be ordered for anyone wishing to purchase their own copy, and this is available for \$75.00. Please let the national office know if you are interested in using this material.

HAVE YOU ORDERED YOUR TICKETS?

Orders for tickets have been coming in very slowly this year. We have received enough orders for tickets to proceed with this money raiser, but we do not have enough orders now to raise any funds. The first 700 tickets cover the cost of the prizes and expenses incurred, we now need a few thousand tickets ordered to use for conference expenses.

We hope you will use the order form below, we do need the support of all of our members for this to be successful. Not everyone approves of raffles and wishes to sell tickets, but it is a way to keep our conference registration prices lower. If you are not a seller, why not purchase a few tickets, and if you win, donate the money to the research fund. That way you are supporting two efforts of your association.

First prize is \$1,000. Second prize is His and Hers Seiko Watches, and third prize is a Panasonic Radio/Cassette Recorder.

TICKET ORDER FORM:

Please send \_\_\_\_\_ tickets which will be bought or sold for \$2. per ticket. (Payment may accompany the order or be submitted after tickets are sold.)

\_\_\_\_\_ Tickets are for me, check enclosed, save me work, just mail the tickets and keep the stubs.

Orders will be filled in March, stubs must be returned before the end of May.

NAME \_\_\_\_\_ ADDRESS \_\_\_\_\_



DR. PRADER TO ATTEND CONFERENCE

The Minnesota Conference Committee is happy to announce that Dr. Andrea Prader of Switzerland has accepted our invitation to attend the conference this June. We are also pleased that Dr. Hans Zellweger of Iowa has also accepted our invitation. The two doctors will be honored at the banquet for their early work in the identification of the symptoms that were consequently named Prader-Willi syndrome.

The committee has formulated the meeting agenda and the youth activity program and will have the necessary pre-registration materials in the mail shortly. The meeting dates are June 21, 22, 23.

At last year's meeting a bid was accepted from the Southern New England chapter to hold the 1985 conference in Connecticut. We are now accepting bids for the 1986 meeting. Now is the time to start planning if your group would like to host the 1986 meeting.

UPCOMING SEMINAR

The Tri-State Chapter (W.PA., OH, & W.V.) will have a seminar on March 31st at the Rehabilitation Institute of Pittsburgh. Discussions will include diet counseling, the right to education, hints on successful IEP meetings and the pros and cons of hormone therapy.

ASSISTANCE WITH MEDICAL BILLS

One member responding to our request for assistance with PWS medical bills offered several good suggestions: She urged parents to contact groups such as the March of Dimes, Easter Seals, Lions, Elks, or Knights of Columbus. Some groups occasionally "adopt" a handicapped child and pay medical expenses.

The way that a physician or dentist writes up recommended treatment can also influence whether medical insurance will cover the cost. The member said it would benefit parents to discuss the situation with the person taking care of their child.

Parents also may be able to obtain medical care through the National Institute of Health in Bethesda, MD. The Institute treats patients without cost, even covering transportation in some cases. They cannot accept all patients who apply. Becoming a research subject has drawbacks, the major one being the travel time from home to the center. It also has bonuses, it is an unusual opportunity to receive a form of medical care which many consider the best type. Because the entire hospital is an ongoing research project, a special camaraderie exists between patients and staff.

This member also saved money by using "bread and board" guest houses while traveling to a clinic for her child. A list of these places was supplied by the clinic she visited. We would be happy to add a list of accommodations to our directory if members will share their personal lists of facilities near clinics they use.

We thank this member for sharing her ideas with the membership.

CAMP KEYSTONE

The GV received advertising from Camp Keystone in the Pocono Mountains. The camp is accredited by the American Camping Association and serves the mentally retarded. They have "80 acres with super accommodations, a lively sports program and a special feature involving the cultural and performing arts...". The camp includes medical diagnostic services and a well trained staff. For more information write to:

Eugene M. Langan, Jr. Keystone City Residence Inc.  
406 N. Washington Ave. Scranton, PA 18503



LETTERS FROM MEMBERS:

An Arkansas member praised the conferences and wrote: "We're looking forward to the Minneapolis conference in June. The conference in San Diego seemed to be a turning point in our son's life. His attitude toward his disability seems so much better, and I feel better. I certainly don't feel so alone with this...."

Another parent from New York wrote, "Since I cannot go out to work I do couponing and refunding and use the money to pay my dues and attend some of the national and local conferences." She called herself the nutritionist, psychologist and spokesperson for her daughter. The newsletter, she wrote, helps her by providing recipes, diet tips and input from parents for dealing with behavior problems. She has also been aided by the national publications. Her daughter increased her order for raffle tickets to 30 this year as she "appreciates all that the people are doing for PWSA."

A very inspirational letter was received from a Washington parent. She has three young children, the youngest having PWS. She was informed on the same weekend that her youngest child had possible brain damage, and that she, the mother, had cancer. She wrote, "Our world fell apart in one weekend. I don't need to tell you the feelings one goes through when something is wrong with your child. I went through one year of a clinical depression where I did not smile or laugh once. We didn't know if I was going to live or die or if our daughter was going to live or die.....Things had to change so I put my trust in the Lord and decided we would do something positive with this experience instead of being bitter and unhappy...We enjoy our daughter so much. We wish she was not PW but we wouldn't trade her for the world. We feel very lucky to have her. She has taught us so much. ... She attends preschool and loves it. She loves people and of course food! She will share her food with me though but it's hard when I can't give it to her in return. Her sister and brother watch out for her and everyone who knows her loves her...." Her letter closed with asking what she could do for PWSA.

We appreciate being able to share letters with our members. "Sharing and Caring" is a great motto for our organization.

PUBLICATIONS OF INTEREST

The AFT Teacher's Network for the Education of the Handicapped has the following publications available:

- #435 PL 94-142 GUIDE TO UNDERSTANDING THE EDUCATION FOR ALL  
HANDICAPPED CHILDREN ACT by Rauth. Single copy free; \$5.00 for 100
- #436 PL 94-142 PRESERVING BOTH CHILDREN'S AND TEACHER'S RIGHTS by  
RAUTH. Single copy free; \$5.00 for 100
- #593 MAINSTREAMING: A RIVER TO NOWHERE OR A PROMISING CURRENT? by  
Rauth. Single copy 25¢; \$20.00 for 100
- #438 WHAT ARE LEARNING DISABILITIES by AFT Teachers' Network  
Single copy 50¢; \$45.00 for 100
- #446 THE SLOW LEARNER AND RETARDED CHILD IN THE REGULAR CLASS by  
AFT Teachers' Network. Single copy 50¢; \$45.00 for 100
- #470 MAINSTREAMING: FROM INTENT TO IMPLEMENTATION by AFT Teachers'  
Network. Single copy 65¢; \$60.00 for 100

Mail orders and check to: Order Department, American Federation of Teachers,  
11 Dupont Circle, N.W., Washington, DC 20036



SYMPATHY AND SUPPORT

PWSA extends its sympathy to the family of Rona Lennhoff. Rona was struck by a car and killed in January. The Lennhoffs, from Oceanside, NY, have been members of PWSA for several years. We all share the grief this family has caused by this tragedy.

Another aspect of this tragedy is that the parents were in the process of trying to obtain a proper placement for their daughter. Had the State of New York responded to this need, this accident need not have taken place.

Many of you are aware of the tremendous amount of effort the New York chapter has expended to get services in the State of New York for persons with PWS. Rita Welch, president of this chapter has done everything humanly possible to get the needs of these young people met. Rita needs all of the people in the state to write to her about poor or lack of placement for their children, incorrect school placement or unavailable facilities. Numbers carry a tremendous amount of weight when you are dealing with those capable of supplying services. All Members in the state should sit down today and write to Rita. Her address is: 6-12 160 St., Beechhurst, NY 11357.

We also send our greetings to Wendy, who is currently recovering from chemotherapy for leukemia. Wendy is one of our faithful workers, helping get the GV in the mail. She is a resident of Oakwood and would appreciate a card from other young people with PW. Her address is:

Wendy Virnig, Oakwood Residence, 13403 McGinty Rd., Minnetonka, MN 55343

*A Day's Work...*



## EATING DISORDERS PROGRAM

At the request of the PWA of Minnesota, a special workshop opened in July to serve people who were demitted from other programs for low productivity, interfering behavior problems, stealing and uncontrollable weight gain. The program is more restrictive than the environments associated with competitive employment, sheltered workshops and developmental achievement centers. It is less restrictive than state hospitals and correctional institutions. The goal of the program is to allow those who are able to graduate to less restrictive environments and to keep others from slipping into more restrictive settings. The program has two areas of concentration, group therapy and work adjustment.

According to Director Omar Othman, who submitted these facts to the GV, the program has already been successful in reducing behavioral problems, maintaining or reducing weight and providing meaningful therapy and work sessions. The psychological problems of the participants vary from sociopathic to low self-esteem, dependence and inappropriate manipulation of the environment.

About 40% of the participant's time is spent in work, which programmers believe enhances a positive self-image and develops social, communication and work skills necessary for the individual's transition into a less structured community work setting. Work segments emphasize quality of workmanship in order to instill an internal feeling of pride. The other parts of the program consist of:

**ROLE PLAYING:** This group presents, in concrete terms, appropriate methods to resolve interpersonal conflicts. The format is determined by a board game in which players are presented a conflict and are required to act out the problem and an appropriate method of resolving it.

**STRESS HANDLING:** This group provides instruction in appropriate display of anger, frustration, confusion and impulsiveness.

**PROBLEM SOLVING:** Participants in the problem solving program tend toward egocentricity and often fail to see that others share many of their problems. Their methods of conflict resolution, therefore, tend to be exclusivity at another's expense or devious in effect. Participants are encouraged to make decisions regarding the choice of a problem, the preventive measures and possible solutions.

**COMMUNITY ORIENTATION:** This group combines human rights and responsibilities, vulnerable adults, governmental structure and community infrastructure discussions in order to present a global view of the participants' impact on society and vice-versa. The group discusses principals of least restrictive alternatives and what is expected of individuals to advance within the established system.

**FOOD:** Participants in the food program, if given a choice, would chose a very poor diet. Nutrition groups discuss food groups, substituting within a group and menu planning. For participants with necessary control, there is shopping, food preparation and supervised cooking instruction. Participants also discuss lowering anxiety and raising self-control in the presence of food.

**EXERCISE:** This group attacks problems of poor muscle tone and cardio-vascular condition. Participants do aerobic dance to tapes with graduated levels of difficulty. They lift weights and are given homework assignments, for which they receive rewards.

The program has only been in operation for seven months and hopefully will develop to fill a void presently existing for our children. In the future we hope this especially designed program will be able to furnish information to help other programs that are willing to adopt changes to retain young adults with PWS in their programs or more workshops such as this one can be opened in other areas of the country. We will continue to share information on this program as it continues to operate.



## BEHAVIOR STUDY UPDATE

Last Fall, the National PWSA board awarded a \$4,000 grant for research into diminishing maladaptive behaviors. Fifteen residents, with PW, at Oakwood are being studied. The project has eight major goals. 1- To work from a positive reinforcement frame and to give the residents a reward for not engaging in specific negative behaviors. 2- To have a system set up that was easy for residents to understand and staff to carry out. 3- To have a group contingency set up to give extra rewards when all the residents behaved appropriately. 4- To give the residents a wide selection of rewards. 5- To have a system easy to modify to individual resident needs. 6- A program that could be used at home by parents. 7- If the program was successful at Oakwood, a similar approach could be used by parents whose children still live at home. 8- A system that is inexpensive and easy to maintain.

Two display cases were built to simplify recording, reinforcement and counting of resident achievements. One cabinet holds a stick for each resident onto which beads can be slid from the top and displayed through a plexiglass window in the front. The second cabinet is for displaying the items which may be exchanged for the beads each week. Beads are awarded three times daily for not engaging in a specified behavior. Each week a goal is established which, when reached, earns the resident a prize. The resident with the most beads gets first choice of the prizes. Other residents choose prizes in order of the beads they earned. Prizes are picked with the residents in mind, all items are worth around \$1 or are special privileges (go fishing, staff time, staff will clean their room or do their laundry, go to a staff's house, help wash a dog, beautician session, etc.). If all residents achieve their weekly goals, the group gets its choice of a current movie on VCR tape.

After a month of baselining the behaviors, the program began by targeting on physical aggression. This behavior was picked because it occurs with low frequency so the residents would easily receive rewards and learn the system. The goal for prizes began at 15 beads out of a possible 21 and has now risen to 20.

New behaviors will be introduced into the program soon. So far both residents and staff are enthusiastic about the project. Parents become involved when residents visit home. Parents fill out the recording sheets and return them with the resident. At the group home, the resident exchanges points on the sheet for beads. The project will run through May, so results will be available at the National PW Conference.

Oakwood has received donations for the display case such as jewelry and various toiletries. Anyone who would like to donate small, new items suitable for the Oakwood group or would like more information on the behavior project contact:

Bob Carlson, Director  
Oakwood Residence, Inc.  
13403 E. McGinty Road  
Minnetonka, MN 55343  
Phone #(612) 938-8130

## SUNBURN ADVICE

Richard King, M.D., genetics department of the University of Minnesota, is currently doing research on pigmentation with the child with PW. He made a very helpful suggestion which we would like to pass on to parents of our fair-skinned children. For two weeks prior to a vacation, apply sun block containing the highest possible PABA content. It should be applied to all exposed skin twice a day. It will build up a complete sun block so your child may swim or play in the sun without burning. As a full summer protection, twice a day treatment would need to be continued throughout the summer. Coppertone 15 is one of those containing the highest amount of PABA.



Dear Pen Pal,

I would like you to be my friend.

I live up in the mountains. I like my snowmobile and my family and pets. I have Rosie, my dog, and Bootsie my puppy dog. I have 3 ducks and chickens and a cow and Piegons, and horses, sheep, a turtle, and rabbits. I like school. I like science, English, social studies, weather, reading about Golly, Pity, Cass, Oswald, Cuddles, and Polo. I have nice beautiful teachers. I am 12 and am very nice. I am lonely and would like to be a pen pal. I am sometimes sad because I have nobody to play with. My name is Tim Andersen.

Tim is 12 years old and lives in Montana as he wrote in his letter. He would prefer to have a boy pen pal and his age, if possible. If you write a letter to Tim, send it to us and we will forward it to him. If you would like to add your name to our list of pen pals, just send us your name and address and we will share your name with others who want to be pen pals too.

PWSA PEN PALS  
5515 Malibu Drive  
Edina, MN 55436



WHAT'S NEW WITH GROWTH HORMONES?

Parents of children with PW have been very interested in the recent publicity regarding genetics. Some doctors, well acquainted with the syndrome, have been using hormones on a limited number of patients. In the past two years genetic engineering has expanded, moving from test tubes to patients. Parents are hopeful that increased height will help their children's appearance and ability to carry more weight.

The growth hormone currently being tested is expected to be licensed and mass-marketed soon. Formerly the hormone, given to patients with growth impairments, was removed from the pituitary glands of cadavers. Fifty glands and \$5,000 would only supply a child for one year. Consequently, only 1,500 of the estimated 50,000 in need received the drug. Doctor reports on some of the other children being treated have been good but we do not have enough information on those with PW to report their successes. One of the problems with treatment for children with this syndrome has been their resistance to the necessary injections.

The drug can replace faulty genes that are suppose to signal hormones for growth to begin working and spur healthy genes into asking the body for more growth hormones. Some doctors recommend only short-term use of the drug to patients who have minor growth problems not related to hormone deficiencies. Since the drug is still being tested, some questions have not been answered. Also, while the drug may be more available, the cost won't drop until other uses raise demand. Health insurances will cover part of the cost, according to the producers at Genetech, Inc.

Genetech recently announced 14 new products developed through a technique called gene-splicing. The technique can also be used to produce hormones aiding metabolism dysfunction and sexual development. Gene-splicing begins by isolating a human gene that tells the body to produce a particular hormone. That gene is spliced with bacteria using enzymes to produce the reaction. It is put into a nutrient pool where the bacteria carrying the gene grow. The material is then converted into injectable form. Since bacteria grow rapidly, large quantities can be produced. The only limitation is being able to locate and isolate the particular gene needed for the specific problem. A human-insulin made by gene-splicing is now being marketed. Further research is aimed at producing drugs for other purposes.

GLOSSARY OF TERMS:

GENES: The basic units of heredity. Genes not only determine eye color but every biochemical function of the trillions of cells in your body. Genes do that by instructing each cell to make specific enzymes, hormones and other proteins. There are tens of thousands of genes in each human cell.

HORMONES: The body's chemical messengers. They travel from place to place in the body, controlling such things as overall growth and some sexual and metabolic functions.

CELLS: The basic building blocks of all tissue in the body. There are trillions of cells in your body, all of which contain the same inherited genetic material.

CHROMOSOMES: Threadlike length of DNA that are, in effect, long strings of genes. There are 46 chromosomes in each human cell and hundreds of genes on each.

DNA: Deoxiribonucleic acid, the chemical substance of heredity. Genes and chromsomes are made of DNA.

ENZYME: A biological catalyst that makes a specific chemical reaction take place. Genes control the functioning of cells primarily by sending out instructions for the cells to make specific enzymes.



PROXY BALLOT

In compliance with the bylaws of the PWSA, the membership is responsible for the election of the Directors of the Corporation. We realize that not all members can be present to cast their vote, therefore, the following proxy may be used by members who cannot be present at the general meeting in June. Please designate one of the names listed below (or your own selected delegate that will be attending) to represent you at this meeting. Your proxy will have the full power to act on your behalf in the election of three directors at the business meeting. You may designate your proxy to vote as you direct.

This proxy form must be received by PWSA no later than June 1, 1984.

I designate the following one person, whose name I have checked below, to represent me in any membership vote, including the election of the Directors of the Corporation.

## Board Members:

Chairman, Richard J. Wett, M.D.; MN \_\_\_\_\_

Fausta Deterling; MN \_\_\_\_\_

Vanja Holm, M.D.; WA \_\_\_\_\_

Claire Ledoux; CT \_\_\_\_\_

Shirley Neason; WA \_\_\_\_\_

Dorothy Thompson; MN \_\_\_\_\_

Gene Deterling; MN \_\_\_\_\_

Lota Mitchell, MSW; PA \_\_\_\_\_

Betty Schultze, Ed.D.; MO \_\_\_\_\_

Stewart Maurer; GA \_\_\_\_\_

D. J. Miller, PA \_\_\_\_\_

Lee Forthman; IN \_\_\_\_\_

Officers: Delfin J. Beltran, M.D.; CA \_\_\_\_\_

Roy Smith; CT \_\_\_\_\_

Director, Marge A. Wett, MN \_\_\_\_\_

Your designated representative (Name) \_\_\_\_\_

\_\_\_\_\_  
Your signature (s)  
(Ballot may be used by more than one member.)

\_\_\_\_\_  
date

Please mail to: PWSA, 5515 Malibu Drive, Edina, MN 55436



PWSA CHAPTERS

Ten parent groups in various parts of the country have become official chapters of PWSA. Several other areas are meeting regularly and in the process of becoming chapters also. The ten chapters are:

SO. NEW ENGLAND PWS PARENT SUPPORT GROUP - STATE OF CT.  
PW GREATER NEW YORK ASSOCIATION - STATE OF NEW YORK  
PW KENTUCKY ASSOCIATION - STATE OF KENTUCKY  
PWS MISSOURI - STATE OF MISSOURI  
PW MIDLANTIC ASSOCIATION - STATES INCLUDING PA,NY,NJ,DE, & MD  
PWS OF MINNESOTA - STATE OF MINNESOTA  
PW COLORADO ASSOCIATION - STATE OF COLORADO  
THE PWS OF NEW ENGLAND, INC. - STATES OF MA AND NH  
PW TRI-STATE ASSOCIATION - STATES OF OH,PA, AND W.VA.  
PWSA OF INDIANA - STATE OF INDIANA

If anyone is interested in joining one of these groups, please contact the PWSA office and we will be happy to put you in contact with any of these groups. Some upcoming meetings: S.New England, March 21 at Newington,CT; March 23 in Minneapolis; March 25 in Indianapolis; April 1 in Missouri and the spring April meeting for the Midlantic group.

\*\*\*\*\*  
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.  
\*\*\*\*\*

PRADER-WILLI SYNDROME ASSOCIATION  
5515 MALIBU DRIVE  
EDINA, MINNESOTA 55436