

# THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT

Edie Marie, Editor  
5515 Malibu Drive  
Edina, MN 55436

VOLUME IX

JANUARY-FEBRUARY, 1983

NUMBER 1

## PRESIDENT'S MESSAGE

At one time or another most of us have had the experience of enduring some form of difficulty that ends and leaves us with a sense of satisfaction. This past Christmas week the forces of weather entered California and proceeded to cause hardships to many as the storms moved across the country. As I am writing this, a single storm center has caused floods from the rains, downed lines of power and communication from the winds, and paralyzed transportation from snow-blocked roads, railroads and runways. Lives have been lost and where saved sometimes significantly altered. When the storms are gone and the sun comes out, we pick up the pieces and go on to our normal lives. The sense of satisfaction usually comes from our personal pride in having survived adversity. If that satisfaction is not there, its absence usually means that we don't believe that we performed up to our personal standard.

When we consider a human life, the question that very often becomes the core of the challenge is where is there normal in this life. The question so often posed is, what is normal? Somewhere back in my medical education, I was given the flip answer that normal is the absence of abnormal. With a little inspection, the flip answer may not be so absurd after all. The ability to identify the abnormal may be superficially easy, an automobile with three wheels is definitely abnormal. At least today it is abnormal. Conservation-conscious car buffs might disagree, and enter into a long dissertation into the advantages of the three-wheeled vehicle, making reference to inherent characteristics of stability, ease of design, reduced friction and drag, and so forth. They would then go on to tell us about the great future for this abnormal type of design, or, translated, they would point out that in the face of current needs to conserve energy, the unusual might well become the common, and cease to be the abnormal.

Genetic disorders are not like snowstorms or floods or tragic winds. They do not pass with time and return to normal. Genetic disorders are like three-wheeled cars. As we understand and become educated in the nature of the difference, as we become familiar with the abnormality, as we learn to see the normal part of the different person who suffers that difference, it becomes possible to live with a more normal relationship to that person.



PRESIDENT'S MESSAGE (Cont.)

Without a growing familiarity with the unfamiliar, we will remain less effective in our efforts to be of service or to care for, or teach, or love, the different person. I recently had a discussion with a close friend who numbers among her many talents a deep interest in animals and their relationships to man as pet, or friend, or associate, in achieving a task. The discussion arose from a question about prejudices and the relationship to fears of the unknown or even threats from the unknown. The essence of that discussion was the apparent inherited trait of animals to distrust and fear the unknown animal that enters its awareness, and the consequent defensive posture assumed by the animal when confronted with the unknown. It would seem that prejudice exists as an inherent trait. The manner in which we react when we sense ourselves responding with this defensive posture to a different person might well reflect our abilities to provide for the needs of the handicapped.

This may all be too deep, and we may not wish to dwell for any great length of time on self-examination, but from time to time, parents and professionals dealing with different persons need to come out of the storm, check our prejudices, lick our wounds, and try to develop an individual perspective to the situation. Living with guilt for presumed failures does little to assist us in helping those who need our help.

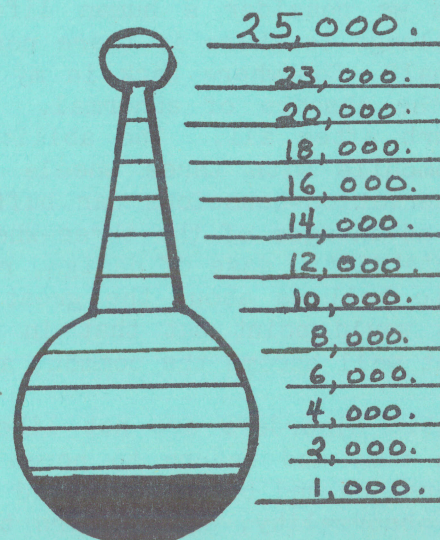
*Delfin J. Beltran, M.D.*

RESEARCH FUND

With the additions of seven members that contributed to the Research Fund directly in December, as well as the seven members that donated memorials this past month, our Fund has now reached the total of \$1,719.00.

A portion of the direct contribution was from the employees of one of our members that made this contribution as a Christmas gift in his name. Another \$100.00 contribution was with a matching fund so we will be receiving another \$100.00 from this member's company.

We greatly appreciate the interest of the members that feel a Research Fund should be established.





SAN DIEGO TO HOST 5TH ANNUAL NATIONAL CONFERENCE  
JUNE 1983

"Prader Willi Syndrome Today - How far have we come....How far can we go?" is the theme for the 5th Annual National Conference of the Prader Willi Syndrome Association to be held in San Diego, California, on June 16, 17, and 18, 1983, hosted by the Prader Willi California Foundation. Harvey Bush and Betty Shadell and their committee have been hard at work on arrangements for months. Hotel and conference space have been secured at the lovely Bahia Hotel at a very reasonable rate.

Families, professionals and people with Prader Willi syndrome can look forward to participating in a myriad of workshops, presentations and panels to bring themselves up to date on the latest information on PWS. Fields to be covered include:

EDUCATION: from pre-school to vocational  
LIVING ARRANGEMENTS: from home to group homes and beyond  
BEHAVIOR MODIFICATION FOR PARENTS  
ADVOCACY: how to get what each person needs  
MEDICAL UPDATE: weight control, obesity, psychiatry, genetics

For the people with Prader Willi syndrome who will be attending there will be workshops and classes on meal planning, video game techniques, jobs (how to get them, how to keep them), and beauty planning (including a fashion show and hair styles for both men and women), as well as many social and recreational opportunities.

Anyone interested in participating in the presentations - and that includes parents, professionals or people with PWS - still has time to contact Laurie Stokely, who is coordinating the program:

Laurie Stokely, Director  
Developmental Services Division  
Straight Talk Clinic, Inc.  
5712 Camp Street  
Cypress, CA 90630  
(714) 828-2000

Deadline for submission of presentation is March 1, 1983.



In Memory....

Our sincere sympathy goes out to the Tom and Francis McAndrew family for the loss of their 21-year-old daughter Laurie, in an auto accident in October. Because of their son, Stevie, who is 12, the family named the PWSA as recipient of their memorial funds and we received a check for \$732 from the good people of Kahoka, MO. In adding this check to our research fund, we hope this tragic loss will aid all families that include PW children. This is a picture of Stevie that the family shared with us.

Memorial funds are placed in our Research Fund. The family receives a notification that a memorial donation has been made in their name.

ORPHAN DRUGS

Many of you have probably read paper articles lately about "orphan drugs". PWSA has been involved with writing letters urging support of the bill recently passed by Congress. At the present time, we are not aware of any drug that could help our children being held up because of the quantity involved, but this could be a very pressing problem for us.

The bill recently passed by Congress would encourage drug companies to undertake research and marketing for drugs needed in small quantities by providing a 73% tax writeoff for the cost of developing them. It would also include a \$12 million federal grant. At the time of this publication, the bill awaits Reagan's signature.

Research and marketing of drugs that will treat a syndrome such as PWS are costly. Drugs can cut costs for the federal government by changing the needs of the patients. Certainly this is the case for our syndrome. Let's all hope that help will be forthcoming.

HANDBOOK TRANSLATIONS AVAILABLE

Beginning with the new year, the PWSA office will have a couple of foreign language versions of our handbook available for our membership. In addition to our regular English version, we now have Spanish and French translations of a synopsis of the handbook. For a copy of the translations, write the PWSA at the national address.

A NJ PARENT WRITES:

"Our daughter is doing really well in a Lean-Teen group at our local hospital. She's the only PW - most of the group just overweight. She is counting calories (1200) and using an exchange system--AND self-monitoring. We are incredulous. It's the structure, weighing and counting that satisfies her needs, I think. She has lost 15 pounds in 10 months--but really did it herself. School is good too!"



PUBLICITY

As we all know, publicity is essential in our efforts to help parents, educators, and medical people learn about PWS. BUT, publicity can be non-productive if it creates myths, misconceptions, and incorrect information. We have gone through articles that have appeared in newspapers and have made comments on some of the statements that have been made. Some contain information incorrectly supplied, but most are probably misquotes and/or misinterpretations of information shared.

"bizarre eating disorder": The dictionary uses "odd in manner, grotesque, queer, eccentric and whimsically strange" as adjectives for the word bizarre. Usually this is a word coined by journalists, we hope it is not used by parents.

"persons sometimes weighing 400 or 500 pounds", "I believe many heavy circus people in the past had the syndrome": We feel these ideas are dangerous because most young people with this syndrome cannot be allowed to reach over 350 pounds without developing irreversible damage which causes an early death.

"a person suffering from this disease rarely lives to be 13 years old": We prefer "syndrome" or "birth defect" as more descriptive than "disease". Children rarely die of PWS at a young age unless they are allowed to reach the morbid obesity stage.

"a disorder rarely diagnosed until the child is at least 12 years old": Late diagnoses were certainly the norm in the past, but earlier diagnoses are now occurring as knowledge increases. With the high-resolution chromosome test, birth diagnosis can be made, although this test does not run 100% as yet.

"experts say 5,000 Americans have this malady": PWSA has a list of over 2,000 people but know this list is far from complete with just the diagnosed cases, and feel it is impossible to estimate how many undiagnosed cases there are.

"I know of children who drank motor oil and liquid soap": Certainly this is possible, but for the most part children with PWS do not consume inedible food items.

"girls do not develop breasts": Although sexual development stops before completion, girls with PWS do have some sexual development such as body hair and breast development.

"researchers seem certain a victim's I.Q. increases as weight decreases": Dr. Holm's study showed an increase in I.Q. with those children that did not become obese, but unfortunately a raise in I.Q. was not noted in those that lost weight.

"the disease is not inherited nor is it the results of brain damage or pre-natal injury, but rather is a neurological disorder. Current theory holds that it is probably genetic in origin". Only through continued research can we make statements such as those quoted because we do not have proof of the cause of PWS. Suppositions can certainly be presented because of the symptoms that are present. Our current theory is that the syndrome is a result of damage occurring to the hypothalamic region of the brain during the development of the fetus. Stating the syndrome is the result of fetal damage resulting in a birth defect, with an unknown cause, is the most accurate description that we can give.

"I have to discipline her if she's going to learn control (sneaking food), I'm hoping that if control comes at an early age, it will be a little easier going later on": Young people with this syndrome do not learn control. Unfortunately, the desire for food is a life-long problem. Certainly discipline is just as important for young people with this syndrome as it is for any child, but it is unrealistic to feel you will teach food control.



## PUBLICITY (cont.)

"we see similarity between anexoria-nervosa and PWS, they gorge themselves and then induce vomiting": Gorging and vomiting is definitely a symptom of anexoria but we know of no people with PWS that induce vomiting. Vomiting is unusual in PWS at any time.

"more cases reported in males than in females": Untrue, it is an easier diagnosis to make in males because of the more visible genitalia but numbers seem fairly close to both sexes.

"vitamins, special foods, treatments with cellular injections, can control the PWS condition" (no white flour, sugar, food coloring, preservatives, small amounts of vegetables and grain, diet high in protein, low in carbohydrates, salt and fat): Naturally people disagree about the proper treatment and diet for these young people. Most experts do not recommend special diets and mega-vitamin treatment. Cellular injections is not an accepted treatment in the U.S. There certainly are no studies to back up that statement that anything "controls" the PWS condition. Success has been found by many with limiting caloric intake, and complete food control is necessary, but sticking with a nutritionally well-balanced diet is recommended. High protein, low carbohydrate diets used over a period of time can be injurious to health and do not provide good nutrition for growth and development (especially of the brain).

PARENTELE

The Parent Network, Inc., with which some of our membership are probably very familiar, has changed its name to Parentele. Parentele, for those of us who are not familiar with it, is a national coalition that was conceived, and is organized and operated by parents and friends of those with special needs. It is designed to provide a linkage between parent groups across the country and to facilitate the sharing of current information. The organization publishes a newsletter, The Crisscross, which contains a wealth of information of interest to anyone involved with a special child or adult. They have been very supportive of the PWSA in many issues of this newsletter. Anyone who may wish for further information about this organization can contact them at their national address:

Parentele  
1301 East 38th Street  
Indianapolis, IN 46205  
(317) 926-4142

P.S. (They are a volunteer organization and can always use extra help if any of our membership would like to offer them a hand!)

MESSAGE FROM ABROAD

This is a nice letter that PWSA received from one of our foreign members; we felt it was worth sharing with the membership.

"I much appreciate the newsletters and though my daughter is the only known sufferer of the syndrome, (in their country), I believe there are growing numbers in the U.K. I do feel that the group homes that are being provided in America and the U.K. are the most positive help to the sufferers, as there are so many temptations in life, and for anyone who has ever tried to diet, they will surely understand how impossible it is for the PW people.

Publicity is all important, too, and the more society can be enlightened the more help and understanding PW sufferers will receive. Carry on the good work and be assured of my continued membership at all times. 'Thank you' all for your efforts and support."



SOUTHERN NEW ENGLAND CHAPTER

On Nov. 17, the Southern New England chapter of the PWSA met at the Newington Children's Hospital in CT. Among other things, the group heard a presentation by Robert Gorman, from MARCH, Inc., who has offered the services of his organization in helping the chapter open a group home for PWS people. The chapter was quite pleased by the offer and hopes to begin finalizing their arrangements soon. Another group home for PW people would be one of the best assets right now for the PWSA! The chapter's next meeting will be Wed., Jan. 19, at Newington.

OUR SEVENTH CHAPTER

A hearty welcome to the Colorado Prader-Willi Association, our newest PWSA chapter! This chapter is in full swing in the Denver area and plans to hold their meetings whenever possible on Saturday afternoons so that families from other Colorado areas can attend.

PWS NEEDS SURVEY

The Wiser Institute and Camelot Society conducted a survey in Seattle, WA to determine the special needs of PWS people in their area. Some of the results may be of interest to the membership. The results were based on 126 of the 156 questionnaires that were sent to PW families. In these responses, the age of the PW people ranged from 3 to 38; their I.Q.'s fell into four categories: 29-50 (13 people fit in this range), 51-67 (20), 68-80 (34), and 81-100 (15), 44 respondents were not aware of their child's I.Q. 107 of the families questioned answered that their child was enrolled in the public school system, with 35 being in private schools; the majority of these students were in special education. Where employment was concerned, 32 of the PW people employed worked in a Sheltered Workshop, 1 held a position in competitive employment under a father's supervision, and 1 worked on a volunteer basis. The needs given the most priority by the parents of PW people were: Group home (62), Respite care (32), Behavior control (84), and Diet control (132).

FLORIDA SUCCESS STORY

A Parent from FL sends us this good news about his daughter: "The item from Dr. Terry Page of the JFK Institute in Baltimore in the last GV prompts this note. My daughter was probably their first PWS patient in Dr. Page's program and her progress has been fantastic. She weighed 257 (lbs.) in Dec. 1980 and now she is down to 175 and still losing at the rate of 4 pounds per month.

I would urge everyone to request and submit the survey questionnaire to Dr. Page so he will get a good reading on the need for his program. After years of trying all other kinds of weight control, the program developed by Dr. Page has worked wonders for my daughter. We want to share the good news."

PWSA is happy to pass on good news. Keep on sharing your successes with us!



NUTRITION AND OUR BASIC NEEDS

This is part one of a three-part article about nutrition and the daily diet. What each person eats every day is important not only to our PW people, who must follow their special diets in order to combat obesity, but it is also important to the health and well-being of everyone who eats. This article, therefore, will include basic nutritional information and suggestions about the diet that should be followed by PW people, their family members and friends.

Nutrition is the study of the food we eat and how our bodies use that food; it has a special significance for all health-conscious individuals. The consequences of serious malnutrition affect not only children, who when deprived of a proper diet do not grow, learn well, or develop important social skills and affective responses, but also cause adults to be poor workers and citizens.

There are forty nutrients known to be essential to maintaining good health, (including at least 18 minerals and 13 vitamins). Rather than dealing with each of the forty individually, however, it is easier to divide them into six basic classes: water, proteins, fats, carbohydrates, vitamins, and minerals. Often, nutritionists add another category to this list: fiber.

Each of these classes of nutrients provides several essential functions in our bodies, as illustrated in the chart below.

<u>NUTRIENT</u>	<u>FUNCTIONS</u>	<u>MAIN FOOD SOURCES</u>
Protein	Builds, repairs tissue Regulates body processes Supplies energy	Meat, fish, poultry, dried beans, peas, seeds, nuts, milk, cheese, eggs, cereal grains
Fat	Provides essential fatty acid, linoleic acid Promotes absorption of fat-soluble vitamins A, D, E, K Supplies energy	Fats and oils, nuts, meat, fish, poultry, dairy products, some seeds
Carbohydrates	Supply energy Spare protein Aid in burning of fat	Grain products, fruits, some vegetables, milk
Vitamins	Regulate body processes, including the release of energy from food.	All foods except sugar, alcohol, and highly refined fats and oils
Minerals	Regulate body processes Maintain body tissues	All foods except sugar, alcohol, and highly refined fats and oils
Water	Transports nutrients Regulates body temperature. Participates in chemical reactions Removes waste material	Water, tea, coffee, and other beverages; almost all foods have some water
Fiber	Indigestible and cannot participate in biological functions within the body Important to digestion and excretion	Whole grain cereals, breads, vegetables, fruit



## NUTRITION AND OUR BASIC NEEDS (Cont.)

The US has been using a system in which foods are classified into four groups, commonly known as the "Basic Four". These four groups are 1) Vegetables and Fruits, 2) Breads and Cereals, 3) Milk and Cheese, and 4) Meats, Fish, Poultry, and Beans. (Fats and Sweets are put into a separate group.) The Basic Four generally does well in guaranteeing adequate amounts of protein, niacin, thiamine, riboflavin, vitamins A&C, iron, calcium, and the minimum amount of carbohydrates in the diet, but using only this method of planning a diet requires a thorough knowledge of food composition. Relying haphazardly on the Basic Four to meet nutritional needs can be risky, particularly for a PW child that has calorie restrictions.

Another basic guideline for governing the diet was released by the government in 1980. This was the Seven Dietary Guidelines: 1) Eat a variety of foods, 2) Maintain an ideal weight, 3) Avoid too much fat, saturated fat, and cholesterol, 4) Eat foods with adequate starch and fiber, 5) Avoid too much sugar, 6) Avoid too much sodium, 7) If you drink alcohol, do so in moderation. (Actually, alcohol should not be given to young people with PWS, among other things, alcohol can be stimulating to the appetite.)

Some other suggestions which may help people follow these guidelines include: once a week have liver instead of chicken or beef; it adds vitamins and minerals. Substitute whole grain cereals for refined ones (oatmeal instead of sugared cold cereals.) Include larger and more frequent servings of dark green and leafy vegetables, (lettuce, greens, kale, collards). Fish, dry beans, nuts provide minerals and polyunsaturated fats. Sweet desserts containing milk (puddings, ice cream, pastries) or fruits have some nutritional advantages over those that are mainly whipped cream or sugar.

PW MINNESOTA CHAPTER

The PWA of MN held its last bi-monthly meeting in Nov. Among other business, the chapter decided to hold another large garage sale next Spring to raise funds. The group also decided to use their \$300.00 donation from Edina High School to make a video tape presentation using young people with PWS. Members were asked to look into locating equipment or professionals to help produce the tape for a smaller fee.

The chapter's next meeting will be on Jan. 21 at the Gillette Children's Hospital in St. Paul. This meeting will be a special tour of the area of the hospital that will be used for a PW clinic. It will also include an explanation about the clinic by Dr. Richard Nelson. Parents interested in attending are asked to meet at 7:30 pm at the Gillette Hospital.



## MATERIALS AVAILABLE THROUGH PWSA

- HANDBOOK, "PRADER-WILLI SYNDROME - A HANDBOOK FOR PARENTS" by Shirley Neason.  
\$2.50 membership cost; \$3.50 non-members  
\$2.00 per copy bulk quantity to chapters
- OVERVIEW, "AN OVERVIEW OF THE PRADER-WILLI SYNDROME" by Lota Mitchell, M.S.W.  
Recommended for parents and professionals.  
\$2.50 membership cost; \$3.00 non-members  
\$2.00 per copy bulk quantity to chapters
- PWS BOOK, "PRADER-WILLI SYNDROME" edited by Vanja Holm, M.D., Stephen Sulzbacher, Ph.D., Peggy Pipes, M.P.H.  
A collection of papers presented at a medical conference.  
Recommended for parents and professionals.  
\$24.50 U.S. Funds; \$31.50 Overseas Airmail and Canadian checks.
- DIRECTORY, "DIRECTORY FOR CLINIC SERVICES" Compiled by PWSA Clinic Services Committee.  
\$2.50 per copy; \$2.00 bulk to chapters
- CONFERENCE PAPERS, "1979 NATIONAL CONFERENCE PAPERS"  
Conference Introductions, Gene Deterling; Prader-Willi Syndrome, Hans Zellweger, M.D.; Synopsis of Speech & Language Testing, 1 Child, Betty R. Schultze, Ed. D.; Study of 8 PWS people in a residential home, Margo Thornley; Adults with PWS, Shirley Neason; Diagnostic & Counseling Dilemmas, Bryan Hall, M.D.; Residential School Program for 2 PWS pre-teens, Eleanor Watson, R.D.; Questions at close.  
\$5.00 per set
- CONFERENCE PAPERS, "1980 NATIONAL CONFERENCE PAPERS"  
Conference Introductions, Gene Deterling; Care study of larger group of PWS children, Andree Walczak, M.D.; Abstract of Sucrose Behavior Study, Peggy Otto; Due Process in Education report, Betty Schultze, Ed.D.; Behavior Change Contract Ideas; Features (Less Frequent?) of PWS, Bryan Hall, M.D.; Treatment of Undescended Testes, Stacy Roback, M.D.; Questions at close.  
\$5.00 per set
- MEETING PAPERS, "1982 MEETINGS"  
Includes four presentations from 1982 National Conference and one of the Midwest Regional meetings.  
Parents and Professionals Interaction Panel, Dale Herrick; Medical Research in PW-Update, James Hanson, M.D.; General Concepts of Nutrition, Alfred Meyer, nutritionist; Discussion of Workshops, and a list of Questions to Ponder for parents, Orv Karan, Ph.D.  
\$1.00 per set
- INFORMATION SHEETS, published by PWSA  
Synopsis, PWS and Association. Common Sense Approach to Dietary Management of the PW person; Speech Pathology, Occupational and Physical Therapies.  
\$1.00 per set
- CHILDREN'S BOOK, "SOMETIMES I'M MAD, SOMETIMES I'M GLAD...ON BEING A PRADER-WILLI FAMILY." by Janalee. Written to promote discussions on dealing with having a brother/sister with PWS. \$2.50 per copy. \$2.00 bulk quantities to chapters.

Place order by sending check to: Prader-Willi Syndrome Association  
5515 Malibu Drive  
Edina, MN 55436



KENTUCKY MEETING

The PW KY Association met last month at the U of KY Medical Center. Their meeting included presentations by professionals Dr. Neville Pohl and Shelly Stanley. These presentations focused on diet and behavior management, and physical activity and weight control. During the discussion, someone suggested the use of a portable inexpensive alarm system to be attached to the door of a PW person's bedroom at night. The alarm would alert the parent when the person leaves the room during the night. Possibly this could work for people unable to lock their kitchens. The chapter's next meeting is scheduled for March 5 at the Metro Industrial Services in Lexington. The agenda will include a tour of that facility.

ANNOUNCING THE \$2.00/TICKET RAFFLE WILL BE HELD....

The National PWSA office would like to announce that, even though we have not received the hopeful goal of orders for 4,000 tickets, we do have enough ticket orders to pay for the printing, mailing, and prize money with enough profit to help support the 1983 Conference, therefore we have decided to hold our fund-raising raffle. We did not have enough support to consider the \$10./ticket raffle. Tickets will be sold for \$2./ticket and the drawing prize will be \$1,000.00. We hope to hear from more members who may wish to order the \$2.00 tickets, whether for themselves or for selling to others.

We realize that there are probably some members who would like to support our efforts to raise money for our 1983 conference, but who may not be able to sell raffle tickets. If such is the case, a small donation made to the PWSA Conference Fund would be a generous way of showing your support.

The California Foundation has made a \$1,000.00 donation to be used for the conference. We would like to thank them and encourage any other chapter or group who has the available funds to make a contribution. Every little amount donated will help make this conference the best that we've ever had!

All tickets ordered now, and in our previous poll, will be printed after we receive our license for their sale, and should be in the mail by the end of January.

-----  
NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

Please fill my order for \_\_\_\_\_ tickets to be used for my personal use or sold to others for \$2.00 per ticket. It is my understanding that these tickets are for a \$1,000.00 prize raffle being held to raise money to help support the 1983 Annual Conference.

Please return this order to: PWSA, 5515 MALIBU DRIVE, EDINA, MN 55436



A WORKING PERSON'S CALORIE CHARTACTIVITY--CALORIES\_CONSUMED

Beating around the bush; 75  
Climbing the walls; 150  
Passing the buck; 25  
Dragging your heels; 100  
Pushing you luck; 250  
Making mountains out of molehills; 500

Jumping to conclusions; 100  
Swallowing your pride; 50  
Throwing your weight around; 50-300  
Bending over backwards; 75  
Running around in circles; 350  
Climbing the ladder of success; 750

TRI-STATE AREA GROUP

This group, consisting of members from PA, OH, and WV, recently elected new officers. They are: President: Pam Vogt, OH; Vice President: Pat Testa, OH; R. Secretary: Lynda Elam, OH; C. Secretary: Kathy McGall, PA; and Treasurer: Tom Giusti, OH. The group's last meeting featured Dr. Ruth Owen as a speaker. The next meeting is scheduled for next Spring at the Rehabilitation Institute.

\*\*\*\*\*  
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