

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 VIII

NOVEMBER-DECEMBER, 1982

NUMBER 6

PRESIDENT'S MESSAGE

When we become sick we first question what is wrong, then what can be done to stop feeling sick. A similar reaction occurs with an injury. Depending on how sick or how serious the injury, our daily routine may be minimally affected or for very serious problems catastrophic disruption may occur. In most cases, illness or injury results in some degree of medical intervention for a variable length of time that usually results in a return to a normal pattern of life, and the incident is frequently forgotten.

At the meeting in Kansas City this past June, one of the presentations was given by a genetics counselor, Lu Ann Weik from Milwaukee Children's Hospital. She noted that, in contrast to non-genetic disease as discussed above, genetic disorders do not have specific causes that come from outside the body, but rather there is a change in the genetic information system within the cells. This means that as those cells reproduce themselves to maintain the individual's continuing life, their abnormal genetics will repeat the error that makes them abnormal. The consequences of this underlying problem are multiple and include our inability to make the disorder go away and the occurrence of manifestations in seemingly unrelated parts of the body and personality. The complex and disabling effects of genetic disorders has an imposing effect on others that live and work with the person with the disorder.

I would like to redirect your attention to a single, important, all-pervading concept in relation to PWS. When it was brought to my attention by Marge Wett during a recent telephone conversation, it hit me like a bolt of lightning, unsuspecting and with massive impact. The concept is obesity!! The point is that somewhere along this tortuous path we have been wending for the past seven years, we have drawn such a complex pattern that we have failed to carry the message. It is as if the Sabbath-day message became so filled with concern for social ills and political entanglements that it stopped talking of a Supreme Being. My immediate response was similar to a response that is gaining force in other forms of education; "Back to Basics".

There are numerous manifestations of abnormality that are seen in the PWS, educational needs, stature, muscle weakness and skills, picking, tantrums, almond-shaped eyes, dentition, strabismus, and a host of other things. Every PW meeting, whether it be the annual international or two parents at the clinic, produces concerned discussion of one or more of these multiple problems. The lightning bolt that hit was not just obesity, it was a comment

PRESIDENT'S MESSAGE (Cont.)

about how obesity seems to be regarded. An observer stated that the impression gained from reading the GV, from seeing reports of meetings and from seeing pictures was that the adverse effects of obesity were not truly appreciated. If others respond in a similar manner, it is necessary to start back at Genesis.

We must start with the obvious. Maybe we could call it the bicycleseat test. Place the test subject on a bicycle seat and observe from the rear. If you can't see the seat, there is more work to be done. Some respond defensively to a focus on obesity; why make such a big thing about obesity when half the country suffers from Donlaps Disease (the belly donlap over de belt)? All PW persons overeat, it isn't going to change no matter what I do, how can the family tolerate the constant pressure of having to watch one person's diet? I like my wife plump and I ain't going to pick on the kid, if he didn't get so upset about everything else I could tolerate working on the food control!!!

Let us recall the studies of PWS reported by Dr. Vanja Holm's group at Seattle showing that early diagnosis and obesity control showed a positive correlation with the highest I.Q.s of those in the study. For a complete discussion of the effects of obesity there is a thirty-five page chapter in Dr. George Bray's book, The Obese Patient, that is entitled "The Risks and Disadvantages of Obesity." Dr. Bray opens the chapter with the statement, "Overweight may decrease longevity, it may aggravate the onset and clinical progression of other diseases, and it may modify the quality of life associated with one's social or economic status." The chapter then goes on to discuss in detail shortened longevity, incidence of high blood pressure, cardiovascular disease, lung function, gallbladder disease, diabetes and kidney function alterations associated with obesity. The chapter concludes with a discussion of the social, educational, and occupational disadvantages of obesity. An additional point to consider is the loss of self-esteem in the obese.

With all this in mind, it is essential that we all take a pause to recall the all-pervasiveness of food and the PW person and the devastating effects that result from obesity. If we have lost sight of the importance of weight control because of its constant presence, let us get back to basics.



Delfin J. Beltran, M.D.

HI SAM!

A member recently sent us this nice snapshot of our President to share with the GV readers.



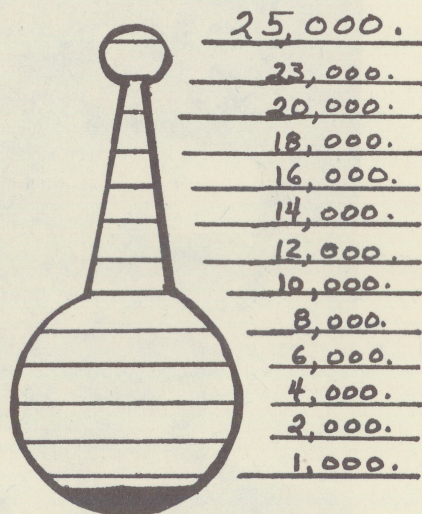
PWS RESEARCH FUND

"If only there was something I could do to help." That's a familiar expression that I've heard frequently since we formed our organization. I believe most people would sincerely like to help find some solutions to the problems associated with PWS. Many of you have been helpful in assisting with our organizational activities or local group home efforts. But there is still a better way to help get at the root of some of the problems.

Our PWS Research fund was designed to provide the type of aid that will directly benefit PWS people themselves. We described this fund to you in detail in our July-August issue of the GV. Basically, it provides for an increasing percentage of all contributions to the PWSA to go to the "Fund" which itself will provide for research and other special needs of PWS people. At the point where we have an adequate operating funds reserve, 100% of all the contributions amount will go to this fund. I don't think there is another organization anywhere that promises to apply such a high percentage of their contributions toward direct aid to those whom they represent.

In order to be effective, however, our "Fund" must grow to an amount that can at least be used for seed money to secure larger grants. We can't say what that amount must be for sure, but we believe it will need to exceed \$25,000. The actual distribution of any funds will be determined by our Scientific Advisory Committee.

With that amount in mind, we have set a goal to achieve that amount by the end of 1983. Since our kick-off in July our contributions into the "Fund" through September have only been \$710, so we have to see some major improvement in the months ahead. We have included a goal thermometer chart below to show you where we are and will include it in our future issues. We need all your help no matter how small or large if we are going to make this goal. This is the best chance we've got to help our PWS friends, and I would think you would all be hard-pressed to find a better place to put your money.



Gene Deterling

INFANT PROGRAMS

The benefits of Early Childhood stimulation and nursery school-type of programs have been proven to be very beneficial for young children with this syndrome. Parents are running into the problem of the high cost for programs of this type. Would any members have any suggestions or experiences they could share to help these families? Write the national office.

WELCOME TO OUR OFFICIAL CHAPTERS

The following list is the groups that have completed filing the necessary forms to be official chapters of PWSA:

- 1) So. New England PWS Parent Support Group
- 2) PW Greater NY Association
- 3) PW Kentucky Association
- 4) PWS Missouri Association
- 5) PW Midlantic Association
- 6) PW Minnesota Association

PWSA certainly welcomes these groups as chapters. We have great hopes about what can be accomplished by these chapters sharing their ideas and accomplishments with all of the other groups through the PWSA national office.

As part of the chapter proposal, the PWSA will refund \$2.00 per membership to those groups that are official chapters. If the secretaries of these groups will submit a list of their active members, a check will be forwarded to the chapters before the end of this year.

INTRODUCING...

Two more welcomes are in order for our newest board members, Betty Schultze and Stewart Maurer, both elected by the membership at the annual meeting in June. The membership may want to know a little more about them . . .

Stewart Maurer

Stew has been an active member of the PWSA for several years. He and his wife, Bronnie, have a 23 - year - old PW son who was diagnosed at age ten. Stew's business and civic service experiences will be a welcome asset to the Board. He has a BA from Cornell U., and he is also a certified Hotel Administrator who has managed several hotels throughout the country. Stew has also been actively involved with many civic and charitable organizations and has received several awards for his services. He has also previously served on various association boards. The membership may remember Stew and Bronnie as one of those five couples who shared their experiences on the video tape recorded during the conference this year. He will certainly be a fine addition to our board.



BETTY SCHULTZE

Betty comes to the board with a great deal of knowledge and experience in special education. She is an educator, teaching Spec.Ed. courses at Harris Stowe State College in MO. Betty holds a B. S. degree in Education from Central MO State U., and an M.S. in Speech Pathology from St. Louis U. She also has an M.A. and Ph.D. in Education from Saint Louis, specializing in Spec. Ed. and Early Childhood Development. Her Dissertation was about a PW child. She has also been an active member of PWSA on both the Education and Cline Services Committees. She recently completed the monumental task of organizing and acting as Co-Chairperson of the 1982 Conference. Betty sends the following message to our members: "I am looking forward to the opportunity of working with the Exec.Dir., the President, other board members, and the membership of the PWSA. The next few years present the Association with many challenges and opportunities to assist individuals with the syndrome, their families, and professional people to better understand PW. It is an exciting time to become part of the board and assist in meeting the challenges and opportunities inherent in such a position."

PW HOME

Oakwood Residence recently celebrated its 1st anniversary on Sept. 1, 1982. It is a 7 day a wk., 24 hr. a day facility; however, this does not mean that the residents are on campus at all times. The parents and family friends are encouraged to visit and to have the residents go home for visits. The family relationship is supported and protected. The home has demonstrated that these people live together fairly compatibly, and the weight loss is very satisfying.

The procedure of opening the home was not easy. It took about 2 years for the licensing and certification, but the effort was well spent.

Our residents range in age from 17 to 30. There are 5 in highschool and 10 in day programs, (wkshops, developmental achievement programs) out of residence.

A typical day starts early, 5 or 6 a.m. The residents are taken to their day programs, some are bused. After they return in the afternoon they have about 2 hrs. before dinner, less for those in work programs. This is the time for visiting with peers, homework, reading or grooming. Dinner is served family style at 5:30, with 5 residents, 1 staff at each table. Residents serve themselves with staff supervision. After dinner, residents help clean up and take turns performing daily tasks. The evening may be spent in various outside fun exercises, walks or in-home TV, living skills, room cleaning etc. Snack time (8:30) is usually crackers and cheese and a diet beverage or fruit. Bedtime for some comes after snacks, social for others. Lights out, 10:30. Residents meetings are held, banking is done. Residents sleep later on weekends and have one-to-one interaction with counselors.

Our total weight loss to date for our 15 residents is 748 lbs. Five of our residents are on weight maintenance, having reached their ideal weight.

Staff Report

NEW BOOK--NEW COLUMN? WE NEED YOU!

One of our members, Janalee Tomaseski-Heinemann has written a children's book "SOMETIMES I'M MAD, SOMETIMES I'M GLAD". This book is sharing what it is like to have a sister/brother with PWS. The book will be going to the publisher soon and be offered to our membership.

In this season of giving, how about putting the publication of this book on your gift list? With donations from our membership, we could do a very professional job on this book and still be able to offer it for sale to our membership at a reasonable cost. If your friends or family are asking for gift suggestions, why not this project?

Janalee also wrote us recently stating, "weight and behavior changes are the result of a slow, tedious process, with days of backsliding, we sometimes forget to stop and pat ourselves and our children on the back with a 'Good job done!'. We PW parents, children and siblings inadvertently end up with considerable strength and skills that go unacknowledged except in the newsletter (which I consider the greatest link for all PW families nationally)."

Janalee also volunteered to write a column for the GV, writing on issues personal to PW families--adding both the pain and humor of being a PW family, using true situations submitted from families combining both their difficult and humorous situations--that probably only a PW family could laugh at! She said, "we all shared some great stories at the last National conference."


Janalee's address: Janalee Tomaseski-Heinemann
12177 Oakwilde Court
Maryland Heights, MO 63043

With a good membership response, we could add this book to our published materials and this column to our newsletter. How about a check to PWSA and a letter to Janalee?

NEW PW TREATMENT PROGRAM

The J.F.Kennedy Institute, in collaboration with Johns Hopkins Univ. School of Medicine in Baltimore, is currently planning a program to provide comprehensive evaluation and treatment of PW people. The interdisciplinary program would be designed to study and treat medical, nutritional, and behavioral components of PWS. Specific objectives could include: 1) the systematic evaluation of individual problems, 2) intensive intervention during a brief inpatient admission, or, in some cases, on an outpatient basis, 3) specific procedures to effect transfer of treatment gains to clients' home environments and 4) follow-up to insure maintenance of improvement. Before proceeding any further, the organizers would like some more data on the need for such a program; any parents, teachers, and professionals knowing PW individuals who might benefit from the program are asked to contact Dr. Page at the following address. A survey questionnaire and detailed program description will be sent to each person who responds. Contact:

Dr. Terry Page, John F. Kennedy Institute
707 North Broadway, Baltimore, MD 21205
(301) 955-4023.



MARK YOUR CALENDAR NOW!! FIFTH ANNUAL PW CONFERENCE, JUNE 16-17-18, BAHIA
CONFERENCE CENTER, MISSION BAY, CALIFORNIA.

MATCHING GIFTS

Do you or your spouse work for a company with a Matching Gift Program? If so, the GV would like to remind you that the PWSA is a non-profit, 501(c)3 tax exempt corporation and is thus eligible for Matching Gift funds. We recently received a very generous donation from a member whose company will double the amount we will receive. The PWSA would like to thank this member and remind other members who may qualify for this program that this is an ideal way to make a meaningful donation to our Research Fund.

WHAT'S COOKING?

Here are a couple of lower-calorie meal plans to help with diet planning:

1300 Calorie Day

Breakfast (270 cals.)
a small banana, sliced.
1 oz. multivitamin and
iron-supplement cereal.
1 cup skim milk.

Lunch (385 cals.)
1/2 ham and cheese
sandw. ich on whole wheat toast.
1 stalk celery.
1 cup skim milk

Dinner (545 cals.)
Turkey Stroganoff.
1/2 cup cooked egg noodles.
1/2 cup peas.
1 small apple.

Snack (106 cals.)
Banana Shake:
Blend 1 cup skim milk,
1 small frozen ripe
banana, 1 drop vanilla
and a dash nutmeg until smooth.

1220 Calorie Day

Breakfast (320 cals.)
1/2 cup orange juice.
1/2 cup low-fat cottage cheese.
1 small corn muffin, toasted
and spread with 1 tsp. reduced-
calorie marg.
1/2 cup skim milk.

Lunch (320 cals.)
Tuna Salad made with reduced-
calorie mayo.
1 small tomato, sliced.
3 whole wheat crackers.
1/2 small pear.
1 cup skim milk.

Dinner (505 cals.)
Stuffed Zucchini.
1/2 cup cooked rice.
Lettuce wedge topped with
1 TBS. reduced-calorie dressing.

Snack (75 cals.)
2 vanilla wafers.
1/2 cup skim milk.

(Note: the recipes for Turkey Stroganoff and Stuffed Zucchini are included in this issue of the GV.)

PARLEZ-VOUS FRANCAIS?

The National office has just finished translating a synopsis of our Handbook into French. Knowing there are many differences between Canadian French and the Parisian French taught at our Universities, the translator would like to know if there are any French-speaking Canadian members who would be willing to donate a little time and criticism for the translation. If anyone would be willing to read over our translation, correct any grammatical errors there may be, and revise it for the French-Canadian audience, please contact Edie Marie at the Gathered View address.

UPDATE ON SAN DIEGO

At the last meeting of the San Diego parent's support group, August 31st, final arrangements were discussed for the opening of a new group home in Chula Vista. With support from the Friends of Handicapped Children organization, the group plans to have the home open and ready for its residents by November. The PWSA would like to applaud their perseverance in pursuing the best for their children, and we hope that other groups will soon be able to follow their lead by helping establish more residences specifically designed to meet the needs of PW people across the country.

GROUP HOME IMPACT STUDY

A 1982 study on the impact of group homes on surrounding neighborhoods just revealed that the presence of a group home in a residential area does not affect property values. The study, based on a random sample of 34 group homes and their surrounding neighborhoods, puts to rest the common fearful misconception of the neighborhood opponent that the presence of a home in their area will have a detrimental affect on the value of their houses. After researching the buying and selling of surrounding homes before and after group homes were established, the study concluded that "Neither the number nor the timing of property transactions in a neighborhood has anything to do with the establishment of a group home." Perhaps these findings will help ease the opposition of worried homeowners to much-needed group home facilities for PW children.

RECIPES

Some wintertime recipes for our membership:

Turkey Stroganoff

2 medium onions, sliced.
1 clove garlic, minced
2 Tbs. reduced-calorie marg.
1 lb. turkey cutlets, cut into bite-size pieces
3 cups fresh mushrooms, quartered
3/4 tsp. salt
1/4 tsp. pepper
1/8 tsp. allspice
1/8 tsp. paprika
1 1/2 tsp. cornstarch
1 cup low-fat plain yogurt
2 Tbs. chopped parsley

In a large skillet, saute onions and garlic in marg. Add turkey, cooking until lightly browned. Stir in next 5 ingredients. Cook 5-8 mins. until mushrooms are tender. Heat through. Remove 2 Tbs. liquid, stir into cornstarch. Return to skillet and cook until sauce is smooth. Stir in yogurt and heat through. Top with parsley. Serves four. Approx. 325 calories/serving.

Stuffed Zucchini

4 8oz. zucchini, halved lengthwise
3/4 lb. ground beef
12 scallions, cut into 2" lengths (2 cups)
2 cloves garlic, minced
2/3 cup beef broth
1/4 cup soy sauce
1 Tbs. cornstarch
1 tsp. sesame oil (optional)
1/4 tsp. ginger
Generous dash ground red pepper

Scoop out zucchini, leaving a 1/4" shell; chop pulp. Brown gr. beef in large skillet; drain. Stir chopped zucchini, scallions, and garlic into skillet; cook until just tender. Combine next 6 ingredients. Stir into skillet and cook until thickened. Place zucchini shells in oblong baking dish. Fill each with beef mixture. Bake, covered, in 375° oven for 30 mins. or until zucchini is tender. Serves four. Approx. 385 calories/serving.

CANADIAN POSTAGE

A brief reminder to our Canadian members: the Canadian postage rates to the U.S. have changed, letters with 30¢ Canadian are arriving 10¢ postage due! Please double-check the new rates before mailing!

SPREAD THE WORD

PWS has recently received some more media attention. During the week of Oct. 11 a Pediatrician and a parent from the PWSA appeared on a morning news program in Cleveland, OH. Evidently, they did a terrific job of making the PWSA address known, because that week we received a good number of letters from the Cleveland area, a few of which were families with undiagnosed children who appeared to have PWS. Robert and D.J. Miller from PA also had an opportunity to inform people about the Syndrome. They and their PW daughter appeared on a TV program out of Philadelphia. We are expecting another good response from that show. PWS was briefly mentioned in an article about orphan drugs that appeared in the Oct. 11 issue of Time magazine. Every little bit helps!

SOUTHERN NEW ENGLAND

The Southern New England Chapter of the PWSA will hold its next meeting on Nov. 17 at the Newington Children's Hospital at 7:30 pm. The proposed agenda includes reports on the PWS clinic at the U of CT and on group homes and grant applications, and a discussion on a bid for the 1984 annual conference.

ONTARIO PW GROUP

A special meeting of the Ontario group was called to hear a presentation by Dick and Marge Wett. Dick presented slides and information about the syndrome as a parent as well as from the medical view. Marge talked with the group about establishing communications between Canadian groups and States' groups. A good turnout of members enjoyed the meeting.

The Ontario group had just received their acceptance as an incorporated organization. They hope to continue to build their membership outside of the Toronto area and accomplish some of the goals that all of our groups have.

MIDWEST REGIONAL MEETING

The October 16th meeting at Riley Hospital had a great turnout of fifty parents/professionals and 15 children. Presentations were given by Drs. Wappner Butler, and Meaney, all of whom are involved in extensive research on PWS.

This group will not be meeting again until October of 1983 and are urging members to continue meeting in their respective states.

GOOD NEWS FROM THE ODTG

Dorothy Foulkes, R.N., Coordinator of Health Services at the Oconomowoc Developmental Training Center in WI writes that "plans for a Prader-Willi group home at ODTG proceed. It now appears that a facility for approximately eight Prader-Willi young adults should be ready within a year." Thank you, Dorothy, for sharing this good news with the membership.

PRADER-WILLI KENTUCKY ASSOCIATION

On September 25th, a group of nine PW families met in Lexington, KY to become acquainted with each other and form our new chapter. Dr. Bryan Hall attended and gave a presentation. Suggested goals for the new chapter include education of the public, attempting to reach other people in the area and increase membership, fund raising, and respite care. Anyone in the KY area who may wish for more information about this group, or may wish to give them a hand, can write to the group's secretary, Sarah Abell, at 1739 Lincoln Ave., Louisville, KY 40213. The next meeting will be December 4 th.

PWS MO CHAPTER

Allen Heinemann was elected as Acting President of the new PW MO Association during the October meeting. The group will be establishing goals for the coming year, and contacting the other Missouri families for their next meeting. One of their interest is establishing a clinic in St. Louis to provide multiple services for PW families. Please contact Al or PWSA if you are interested in this group and have not been contacted as yet.

UPDATE FROM MN

The PW MN Association met on Sept. 17 in Minneapolis. Guest speaker for the night was Dr. Richard Nelson of Gillette Children's Hospital in St. Paul who talked to the group about plans for opening a PW clinic at the hospital in Jan. This clinic would be a complete care facility for PW people and would eliminate the need for going to more than one location for specialized care. Anyone wishing more information on the clinic may write to Jean Janes, 871 Lakeview Ave., St. Paul, MN 55117 (612) 489-9690.

The group has also decided to save Campbell Soup labels with the hope of providing some equipment for Oakwood Residence, the PW group home in MN. They invite anyone who may wish to help collect labels to mail them to the group at the national address. A report was also given on the distribution of leaflets at the MN State Fair. The group had a booth at the Fair and they passed out a leaflet they had written concerning PWS and the Gillette clinic.

The next meeting of the MN group will be Nov. 19 at the Honeywell Bldg.

SUMMER CAMP REPORT

A TX member writes us that her son had a very positive experience this past summer at a PW camp. She reports that her son "lost weight, had a social life and good outdoor exercise. His diet was very well thought out, structured, and carried out and maintained. We have continued this diet since he has been home."

(Ed. note: It's nice to hear that there are summer facilities which are designed to meet our children's needs. As the readers may have noticed, however, any mention of the name or location of this camp has been edited from this letter. I feel a brief note of explanation is necessary to explain why this was done. In the last GV, a letter appeared severely criticizing a PW summer camp; since no mention of the name of that camp was made, the Editor feels it only fair that the same treatment be given to a positive review of a camp. Also, and more importantly, the GV feels unqualified to print any recommendation for a camp which we have not seen or experienced ourselves, and we urge all parents to not just rely on others' experiences with a camp in making the decision whether or not to enroll your child there. Your best course is to make a personal visit to the camp and see for yourself what is offered.)

NUTRITIONAL INFORMATION

Popular magazines often publish information on nutrition, but they are not always very accurate in what they report. The following is a published list of current magazines and their percentage of accuracy when dealing with nutrition.

Generally Reliable (50% to 100% accurate)

Parents
Redbook
Reader's Digest
Good Housekeeping

Unreliable (average 25% accurate)

Mademoiselle
Cosmopolitan
Harpers Bazaar
Organic Gardening
Prevention

Inconsistent (usually less than 50% accurate)

Woman's Day
Family Circle
McCalls
Ladies Home Journal

RECENT RESEARCH DIRECTIONS

Research Progress (Spring, 82) of the John F. Kennedy Center in Nashville, TN, recently published an article on the relationship between Vestibular stimulation and a child's motor skills development. Vestibular stimulation occurs in the inner ear when parents rock or bounce their babies, or simply carry them about. Since the inner ear helps to maintain balance and visual orientation, evidence is strong that early stimulation of this area by parents may improve the growth of their child's motor skills. Vestibular stimulation may have further ramifications as well, since there is evidence that motor competence may be a necessary prerequisite for more mature cognitive functioning as well.

Anyone wishing further information about this research can write the Office of Information Services, John F. Kennedy Center, Box 40, Peabody College, Nashville, TN 37203.

SHARE YOUR OVERVIEWS

"An Overview of the Prader-Willi Syndrome," written by Lota Mitchel, M.S.W., is a 19-page booklet that is available through the national office. Many parents have found this booklet very helpful to share with educators and medical people working with their children. This booklet includes clinical features of the syndrome, its etiology, treatment recommendation, and also a bibliography so further reading about PWS can be found.

We highly recommend the purchase of extra copies to be shared.

NEW ADULT LIVING SITUATION

Laurie Stokely is currently director of the Developmental Services Division of Straight Talk Clinic in CA. This clinic will soon be starting a new adult program called Apartment Alternatives for Adults in the Long Beach area of CA. This new facility will serve adults with developmental special needs, including adults with PWS. Any member wishing further information about this adult living alternative may contact Laurie Stokely at the Straight Talk Clinic, Developmental Services Division, 5712 Camp Street, Cypress, CA 90630.

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

PRADER-WILLI SYNDROME ASSOCIATION**5515 Malibu Drive****Edina, MN 55436**