

# THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT

Gathered View Editor  
5515 Malibu Drive  
Edina, MN 55436

VOLUME VIII

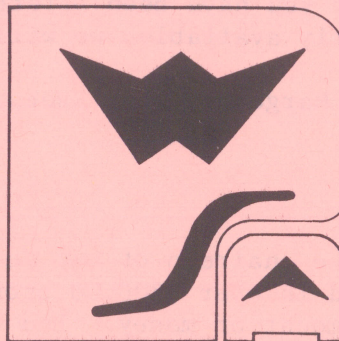
MAY-JUNE, 1982

NUMBER 3

## WELCOME ABOARD

The President's Message was preempted this issue in order to introduce two new additions to THE GATHERED VIEW.

We would like to introduce the new emblem for our organization:



Dr. Beltran took the time and effort to design this emblem for us to use for PWSA. I am sure you will agree this makes a nice looking addition for us to use on our materials.

The second new addition is a new editor for THE GATHERED VIEW. Starting with this issue, Edie Marie will be serving in this position.

Edie is a graduate of St. Catherine's College of St. Paul, MN (majored in English), received her master's degree from the State University of New York-Binghamton (in Comparative Literature), and recently completed her translation certification in French-English.

Edie will be working out of the national office, so items can be mailed to the GATHERED VIEW EDITOR, at the Edina address, as has been the practice the past few months.



NEWSLETTER CONTENT

At the present time we have a few members unhappy with the national PWSA office because they have submitted letters for the GV that were not printed. I would like to take this opportunity to clarify the position of the national office in regard to information that the GV does contain.

We are attempting to share with you all of the information that we can obtain that we feel would benefit the membership. If we do not print an article sent to us by a member or non-member it is because we did not have the room or because we did not have enough information regarding this subject to feel we should share this with you. I have stated in previous GV articles that we do not recommend nor endorse all of the information that is shared with you but we do not want to publish unsubstantiated methods of treatment, possible cures, and these types of articles that will just confuse parents of these children. Maybe some of you members feel this is unfair or a means of censoring what information is shared but we will continue to "pick and choose" and consult our Scientific Advisory Committee whenever we feel this is necessary.

Medical Quackery is a rising problem in this country. When people have children afflicted with a syndrome, such as our children, eventually you will hear about cases of "charlatans" that will be offering treatment or cures FOR A PRICE. Please feel free to contact our office, at any time, if you have been offered something that is questionable. If we do not have information readily available, we will do our best to obtain it for you.

Marge A. Wett, Executive Director

CONGRATULATIONS

Joanne and Lou Levesque (Lou is the chairman of our Fund Raising Committee) just wound up a candy sale campaign that resulted in over \$800.00 profit for PWSA. This is the second time that Lou has raised this amount of money. Lou wrote: "We realize that to promote candy sales is not necessarily a good way for some of us to raise money in view of the problem with our PWS kids. We did not do this alone! We got our parents, relatives and friends to help. Collectively, we were all able to raise this money. In selling our product, we also passed out information on the PWS to familiarize our customers of the worth-while organization that we were trying to support. We raised over \$800. in less than a month."

PWSA is very lucky to have such dedicated people who feel working for their organization is worth the time and effort.

FUND-RAISING IDEA

An OR member suggests a novel idea for generating funds for PWSA: ". . .my husband received (this donation) for selling old computer printouts he has been accumulating in his office. He received permission from his employer to turn this money over to PWSA. Perhaps this will give someone else some ideas."



AN UPDATE OF THE CONFERENCE

NAME: 4TH ANNUAL NATIONAL CONFERENCE AND BUSINESS MEETING  
PARENTS AND PROFESSIONALS FOR ACTION

TIME: JUNE 24, 25, 26, 1982

PLACE: REGENCY PARK MOTOR HOTEL, OVERLAND PARK, KANSAS  
(Hotel changed name from Glenwood Manor to Regency Park)

We regret the delay in the mailing of the finalized copy of the conference program, but unfortunately all of the details of arranging a program of this magnitude do take considerable time. You should all have the notices by now.

A change of ownership at the motor hotel caused a delay in receiving registration cards consequently 200 or so notices were mailed without these cards. You may also be confused on the name of the hotel. The name is now "Regency Park", formerly the Glenwood Manor. We are requesting hotel reservations be made directly by attendees of the conference. Please mail your reservation requests to: Regency Park, 9200 Metcalf, Overland Park, KS 66212

Include the following information: State you are attending the PWSA meeting. State name and address along with what accommodations you require and the dates needed. A deposit in the amount of the first night's lodging is required. If you received a card with the Glenwood name, you may still use this card.

The regular room rates are \$39. for a single and \$46. for a double. All the double rooms except the studios have two double beds. A cot will be an additional \$7. Studios are \$35.; suites with adjacent room are \$75.-\$100. You must state you are attending the PWSA meeting to get these special rates. If you have some question regarding the hotel, you may call Ted Cotton, Reservations Manager at 1-800-255-5030 (a no-charge number).

Please submit your conference registration to the national office. The Evening Reception and dinner is for parents and professionals. The young people will have their own dinner along with the Activity Program. EARLY REGISTRATION would be very helpful to the chairpersons of this conference (particularly in planning the needs for the Activity Program).

We look forward to a good turnout for this meeting. The program and the place sound SUPER.

RECENT TRAVEL

Our Executive Director and Board Chairman found their recent visits to three areas very worthwhile. A few days in Northern California were booked solid with visits to two regional centers, a evening with a parent group from the Sacramento area and a couple of days with the PWSA president and his family. We also met with a teacher from a special class and talked with the Rasmussens' who operate a home in Paradise, CA that includes some young people with this syndrome.

In April Marge and Dick Wett were able to attend the one day conference of the Middle Atlantic group, held this time in Lyndhurst, NJ. They made presentations regarding the national organization, health problems and group home placement. This meeting was attended by 82 adults and 31 PW young people and sibs spent a day at the zoo. Cheryl Nagel of St. Mary's Hospital in Bayside, NY gave a brief description of a chromosome study they are doing. Helene Zimmerman of NY, a psychiatric social worker, spoke about her involvement with the Long Island parent's group. The Levins' of NJ answered questions about their home. The Wetts were able to visit the Levin's home as well as visit the Wood's School in PA thanks to the chauffeuring of Bob and DJ Miller.



DO CEREALS GO AGAINST THE GRAIN?

The Minneapolis Tribune published this NY Times Service article by Jane E. Brody.

Often in a "What did you have for breakfast?" conversation, I've heard the apologetic reply, "I just had some cereal," as if there was something wrong with a cereal breakfast.

Cereal, it seems, has gotten a bad name, a consequence in part of the American veneration of animal protein and the torrent of nutritionally questionable sugar-laden products that have glutted the cereal market in recent decades.

Some cereals clearly deserve their ill repute, but many--particularly the old-time ready-to-eat products and hot cereals--can be the foundation of highly nutritious breakfasts that are better for you than bacon and eggs and vastly superior to doughnuts and coffee. On a cold winter morning a steaming bowl of oatmeal or whole-wheat hot cereal is especially inviting, providing instant warmth and energy.

Breakfast cereal served with low-fat or skim milk and perhaps topped with fruit is also an excellent snack for youngsters, far more nourishing and less fattening than cookies, candy, cake, ice cream and potato chips.

In their unrefined state (cereal grains) are important sources of dietary fiber, protein, vitamins and minerals, but are devoid of cholesterol and contain very little fat and relatively few calories. Contrary to popular impression, on an ounce-for-ounce basis grain foods such as cereal, bread, rice and pasta provide fewer calories than meat and cheese, which are high in fat. Surveys have shown that those who consume less fat, less cholesterol, less sodium and fewer calories than those who start the day with other fare, are cereal eaters.

But the blinding array of cereal products and the clamoring of youngsters for the sugary products they've seen advertised on TV can easily confuse a shopper trying to get good nutrition as well as good taste and keep food costs down. Cost does not go hand-in-hand with quality; in fact the cheaper cereals are usually nutritionally superior. Too often shoppers succumb to price-raising advertising gimmicks such as "all natural," "fortified with 100 percent of 10 essential vitamins," "no preservatives," "no added sugar" and "high fiber" and miss the fact that the product may also be high in fat, calories, natural sources of sugar and/or salt and other sources of sodium."

Ms. Brody goes on to say much can be learned from the label. Ingredients are listed in their order of predominance, with the leading ones first. Often there is more than one source of sugar, so even if it isn't listed first there may well be more sugar than any other ingredient. Avoid products in which sugar or honey, corn syrup, fructose or molasses is listed as the first ingredient. (Buying low sugar cereals and then added sugar when eating is defeating the purchase of the low sugar cereal, try sweetening with fruit).

If your children do eat presweetened cereals, make sure they are consumed with milk, and that teeth are brushed afterward. Cereals with dried fruit, such as raisins and dates, are concentrated sugar sources, and their chewy consistency encourages tooth decay. And honey is more damaging to teeth than ordinary table sugar.

Most cereals contain relatively large amounts of sodium as salt and sodium-containing additives. The quick and instant hot cereals often have more sodium than the slower cooking varieties. Most cereals are unnecessarily fortified with nutrients than are necessary. Fortification to 10 to 25% of daily requirements makes more sense and costs less. No matter how heavily fortified a cereal may be, if it is made from refined as opposed to whole grains, it's likely to be missing some essential nutrients that are lost in refining and not added back. Therefore it's always better to start with a whole-grain cereal.

All cereals are poor sources of calcium, an essential nutrient. Serving with milk, which is the best source of calcium, increases your daily intake.



SUGAR CONTENT OF COMMERCIALY AVAILABLE CEREALS

(Published by the California Assoc. for Neurologically Handicapped Children)

<u>Product</u>	<u>Sucrose Content %</u>	<u>Product</u>	<u>Sucrose Content %</u>
Shredded Wheat, Large	1.0	Team	15.9
Cheerios	2.2	Br.Sugar-Cin. Frosted Mini Wheats	16.0
Puffed Rice and Uncle Sam	2.4	All Bran	20.0
Wheat Chex	2.6	Granola (almonds & filberts)	21.4
Grape Nut Flakes	3.3	Alpha Bits	40.3
Puffed Wheat	3.5	Cocoa Puffs	43.0
Post Toasties, Product 19	4.1	Cap'n Crunch, Crunch Berries	43.3
Corn Total, Special K	4.4	Frankenberry, Frosted Flakes	44.0
Wheaties	4.7	Count Chocula	44.2
Corn Flakes (Kroger)	5.1	Quisp	44.9
Peanut Butter	5.2	Cocoa Crispies	45.9
Grape Nuts	6.6	Trix	46.6
Crispy Rice	7.3	Froot Loops	47.4
Corn Chex	7.5	Honeycomb	48.8
Total, Rice Chex, Crisp Rice	8.1	Pink Panther	49.2
Concentrate	9.0	Cinnamon Crunch, Lucky Charms	50.3
Rice Krispies, (Kellogg)	10.0	Cocoa Pebbles	53.5
Raisin Bran, (Kellogg)	10.6	Apple Jacks	55.0
Heartland, raisen	13.5	Fruity Pebbles	55.1
Life, Granola (date & raisen)	14.5	King Vitamin	58.5
Sugar Frosted Corn Flakes	15.6	Sugar Smacks	61.3
40% Bran Flakes (Post)	15.8	Super Orange Crisp	68.0

A TX MEMBER WRITES

". . .I really enjoyed my first issued of GV. . .I wanted to say that I believe the parent role model is most important. I could not expect my child to stay on a diet and exercise regularly when I was never able to. Since adopting my new attitude of strict dieting (exchange diet system) and regular exercise a month ago, my daughter has lost two pounds and I have lost ten! . . .

My solution to my 4-year-old daughter's skin-picking problem was to dip her fingers into non-toxic glue or paste, allow the paste to dry and let (her) pick the paste off her fingers. I also noticed that my daughter skin-picks in times of boredom or stress. I always make sure that she is busy. . .and do not allow her in bed unless I am sure she will be asleep in a few minutes."

PW GREATER NEW YORK ASSOCIATION

This group's March meeting featured Dr. Rosenbloom, a Philadelphia internist who works in nutritional medicine at the Brain Bio Center in Boston, MA. He has been working with PW people for approximately three months and is very interested in the syndrome; he discussed Mega-Vitamin Therapy with the group.

The group also held a meeting at the Crystal Run Village in Middletown, NY with Mr. Jim Fogelman, Crystal Run's Executive Director, to discuss the possibility of opening a Prader-Willi Unit on their grounds. Mr. Fogelman showed some interest and another meeting will be scheduled with Mr. William Coleman, owner of Crystal Run.



PW MINNESOTA GROUP

The March meeting of the Minnesota group was held at Oakwood Residence, (the dedicated PW home opened by this group). Members were given a tour of the residence as well as having an opportunity to hear Richard King, M.D. present information on a study that he is planning on conducting. Dr King has been working with other genetists in other parts of the country and is particularly interested in the origin of the problems that PW people have. He is planning on further research in the area of the chromosome 15 deletion and the lack of pigment in several areas of some young people with this syndrome.

May 21st will be the date of the annual meeting for this group. A speaker on stress and management will also be a part of the program.

SOUTHERN NEW ENGLAND PWS GROUP

This parent support group has two big projects now underway. One is a Prader-Willi Counseling clinic organized by Dr. Suzanne Cassidy at the U of CT Health Center. The first clinic was held April 16, and bi-monthly clinics are planned to follow. Dr Cassidy and Carrie Mukaida, R.D. are planning on meeting with clients to counsel and direct a program of nutrition and behavior control.

Lois Vandergrift, Cellie Ledoux, Dr. Cassidy and Carrie Mukaido were granted a hearing by the State of CT office of Mental Retardation, and the group has also been invited to submit an application for funds through the Vocational Rehabilitation Dept. of the DMR to be used towards organizing a group home for PW persons in the New England area.

FROM A PARENT IN CANADA

Regarding their PW daughter:"...She is...a very pretty young girl of 15 with beautiful coloring and green eyes...and she weighs 198 pounds. You might well imagine the difficulty in finding appropriate clothing for her age and taste, and our young lady wants stylish clothing!...she is an avid reader,...a very slow but good and neat writer...But all is done in her own good time; she is so slow that any turtle could catch up with her! She can set the table, answer and make her own telephone calls, comes home alone from school on the city bus (she even has to transfer), boils water for her diet hot chocolate; she can operate the oven and is very much aware of what goes on in the world...We, as parents, have never never thought 'why us?'; she is there, and she is ours, but for her: a life of torment, low esteem, frustrations, to name but a few of the things that PW people have to live with, as you know. I will not detail all that we have been able to do for her, save continued encouragement, praise when necessary, love, very close cooperation with all her teachers (special classes always), with her pediatrician, dentist, etc."

(Ed. note: I am sorry space does not permit us to include complete letters or all of the letters that we receive, but we try to share those that we feel are of most interest to our members. We appreciate your sharing with us your insights and experiences, please continue to write!)



STATISTICS

As of the 12th of April, PWSA had 815 members. Approximately 70% of these members are parents, 25% professionals, organizations etc., and 5% friends and relatives. Our membership includes people with syndrome (7); people both parent and professional (6); parents (575); group homes (19); professionals; which include doctors, teachers, nutritionists, social workers etc. (59); organizations; which include schools, ARC's hospitals, regional centers, training centers, MR offices, developmental centers, government agencies, etc. (115); other interested people (33).

We now have approximately 500 names on our Consent and Non-Consent List of people with this syndrome.

BACK CARE BOOKLET

A booklet, "Back Care," written by Arthur E. Grant, M.D. of the U of TX Medical School, contains helpful hints and exercises on how to stand, sit, lift, and sleep in order to keep the spine straight and the back muscles strong. This booklet could be of help in overcoming weak muscle tone and can be obtained, for \$1 (bulk rates available), from:

Medic Publishing Company  
Drawer O  
Issaquah, WA 98027

A NEW SCOLIOSIS TREATMENT

Trials are now going on, mostly in Canada, but also in the US, of an electrical spinal orthosis treatment for Scoliosis. A muscle stimulator, consisting of two electrodes wired to a power source, is still in the investigation stage, but appears to be a successful effort to stop Scoliosis from progressing without need for a brace or surgery. Dr. David Bradford, with the Twin Cities Scoliosis Center, has fitted 54 patients with the stimulator; they have experienced a 60 to 65% success rate. Dr. Bradford has cautioned that the stimulator is no "cure-all" and has not yet been authorized by the FDA for general use, but he is experimenting with it because many children with moderate curvatures were being put into a possibly unnecessary brace.

The usual procedure with Scoliosis patients is to take an initial X-ray to measure the curvature and, if it is found to be less than 20°, to send the patient home for six months before taking another X-ray to see if the curvature is stable or progressive. Dr. Bradford usually recommends surgery for curvatures greater than 40°.

Other centers have claimed success rates with this stimulator as high as 80%, and the Twin Cities center finds that their rate is improving as they become more experienced in selecting which patients can be helped by it. The stimulator has also had a good success rate with its developer, Dr. Walter P. Bobeckko, chief of orthopedic surgery at the Toronto Hospital for Sick Children.



FROM A PARENT IN FL

Regarding their 26-year old son: ". . . The turbulent years are in the past, however, now that we have reasonable control over the situation. To begin with, our son works at a sheltered workshop. He has a job there making air-conditioning vents. The most important aspect is that the nurse there has set up a W.O.W. (Watch Our Weight) program. He is on a daily diet of approximately 800 to 1000 calories a day. In the past six years he has lost about 75 lbs. He is now 190 lbs. . . He also likes walking and we do it every night. He belongs to the Jaycees, likes to do embroidery. He runs errands to the local grocery store for us. . . It is refreshing to be a part of PWSA and be able to share with other parents."

A young lady from CO that has PW wrote: "I would like to amend a more positive approach to how the letter (Synopsis Sheet) is written. . .the way the letter sounded that the problems couldn't be overcome." You are right, Donna, but the synopsis sheet is a description of the syndrome. We hope that in the GV we do share successes as well as problems and let parents know some of the problems are overcome. Thank you for writing.

MORE MAIL

QUESTION: "I am a rather new member so maybe I shouldn't ask but most of the articles in the GV seem to come from the East Coast. Is that because the membership is much higher there than in California?"

ANSWER: No, the membership is not higher on the East Coast. The States of California and Washington have a high membership also but the GV is only able to share information that it receives. (We just received the PW CA Foundation yearly report which is condensed in this issue.)

QUESTION: "Quite some time back there was a lovely article about a home that was opened in Minnesota but I have read nothing since. Is it still open?"

ANSWER: Yes, Oakwood Residence is still open and from what we understand is doing well. As stated above, the GV can only share information that is shared with them.

PW MIDWEST ASSOCIATION

The PWMA, a group just getting into full swing, held its second meeting in March in Peoria, IL. The meeting was attended by interested members from several midwestern states. The next meeting is planned for July 10th, to be held in Oconomowoc, WI.

VITAMINS

The use of salads as bulk in the PW diet is quite common. The vitamin content varies with some salad additives. We thought you might find this list helpful:

High Vitamin A & C

carrots  
cauliflower  
green pepper  
red pepper  
water cress

Low Vitamin A & C

celery  
radishes  
cucumbers  
mushrooms  
lettuce



COMMENTS ON EDUCATION ARTICLE

The March-April issue of the GV contained an article written by D. J. Miller, Chairperson of our Education Committee. Several members wrote regarding this article.

One parent wrote: "I was not too happy with the three items included in the Suggestions from the Education Committee. 1) mainstreaming is unsuitable for most PW children. This statement does include the word 'most' but I really feel we should stay away from broad statements like this about our children. My son is mainstreaming and doing very well. I have also known several other PW children that have mainstreamed successfully in the lower grades but have not been able to continue as they get older. 2) the PW child has unbelievable social habits. This statement really offends me. 3) the PW child may indeed eat himself to death. These last two statements I really do not know how to answer to but I guess I would rather read actual statistics about these two rather than read statements like that made by a committee member of our organization."

Another parent wrote: "Thanks for the suggestions from the Education Committee. I know very well that I should be doing something for PWSA but I just 'never get around to it'. This article has gotten me 'off my chair' and I am going to make an effort to share the synopsis sheet in my area."

Another parent wrote a rather long letter that we have tried to summarize: "I read with interest the comments of (above article), may I add a few suggestions of my own:

1) Do not wait until your child is of school age to worry about special education. Getting them into the 'system' earlier will make it much easier when they do reach school age. Check with your local school authorities.

2) Do not wait until your child is 18 for S.S.I. Many PW kids are eligible now. It may take awhile and you may have to answer alot of questions but with the free medicade and extra income, it does help. I took on the Social Security Administration and fought it all the way to a hearing--and won. (Ed. Note: Regulations do vary from state to state, most people we hear from do have to go beyond the first application but we have heard from a lot of people that have gotten these benefits eventually).

3) Ask questions of your Doctor about your child's condition. Know what tests your child has had. When your child does go to school, keep copies of tests he has taken, what he's being taught. If you move--like we have, it makes finding a new doctor or a new school much easier.

4) Keep lots of PW synopsis sheets on hand--make sure the doctors have one, one in his school file, health file, his teacher, his bus driver, his babysitter, and relatives and friends. Don't be afraid of discussing your child's problems. People are interested."

SUMMER CAMPS

The national office would like to update their listing of camps suitable for PWS campers. We would appreciate hearing the names and addresses of camps your children will be attending this summer. (We would also like a report if the camps were not satisfactory after attendance). We will share this listings with our members early next year.

Right now we have a Texas family that is seeking a summer camp for their 16 year old son and a Florida family seeking a 2 month placement for their 18 year old daughter. Please let the national office know if you can give them any help.



OCONOMOWOC TRAINING CENTER

We received a letter recently from the WI parent who, after experiencing much difficulty with a public middle school (her child gained 30 lbs. in the short period of time spent there), has placed her child with the Oconomowoc Training Center in WI. She has the following to report about the center: ". . .He has lost 33 lbs. in three months and looks really great. They have two other PW's there, and it's the first time in his entire life that I could take him someplace without months of education and input as to the nature of the PW person. They were so well informed because of one boy, age 16, who they have had for six years....This boy lost 75 lbs. the first year, and has stayed at 110 for five years. They have also managed to mainstream him in the Oconomowoc Public School system. My son is still in the residential part of the school program and will most likely stay there until the weight is down and stabilized. He had gotten to be such a runner and they have really handled that well....The controls that I had so effectively placed on him and his environment just totally unraveled once he hit Middle School. I feel a lot of this was due to the self-image and negative experiences with the other kids (700 of them). Eating seems to get prioritized when his self concept is low....Anyway, the Oconomowoc Developmental Training Center is a possible solution until age 18....I am hopeful we can encourage ODTTC to help develop a group home. They are interested in taking more youth in now...."

CONSUMER INFORMATION BOOKLETS

The latest edition of the Consumer Information Catalog contains several booklets which might be of interest to our membership. These booklets are put out by the Federal Government and can be obtained by writing: Consumer Information Center, Department EE, Pueblo, CO 81009; Att. R. Woods. Among the booklets on food and weight control which may be of help are the following:

Item No. 131K, Nutritive Value of Foods, \$3.25. 34pp. 1981. A table of 730 common foods listing the nutrients they contain: Water, calories, protein, fat, carbohydrate, and various vitamins and minerals; includes tables on the yield of cooked meat per pound of raw meat purchased; and the latest Recommended Daily Dietary Allowances.

530K, Sugar. Free. 3pp. 1981. How different types of sugar work in your body, caloric and carbohydrate values of various sweeteners, types of sweeteners available such as cane sugar, honey, corn syrup, etc.

149K, Aqua dynamics, \$2.25. 33pp. 1981. Illustrated guide to over 70 conditioning exercises that can be done in the water.

150K, Exercise and Weight Control, \$1.75. 8pp. 1980. How to balance food intake and physical activity and establish an exercise program; includes chart showing calories used per hour for various activities.

Include the Item No. with your order, these prices will be honored through June 30, 1982. Make check payable to-Supt. of Documents.

TANTRUM CONTROL

A group home administrator reports on her recent successes in dealing with temper tantrums: "...I have an 18-year-old PW young man in my newest group home...I have trained the staff on how to interact with him, especially on the tantrum behavior, and the live-in staff has been just great. We can deescalate the tantrum 99% of the time...It is also a skill that works with other disabilities as well...One particular young man who was having two to three per day has now gone three months without one incident. Training of the staff is the secret..."



PROXY BALLOT

In compliance with the bylaws of the Prader-Willi Syndrome Association, 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. 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 this business meeting.

This proxy form must be received by PWSA no later than June 7, 1982.

Three board member's terms have expired; Stephen Sulzbacher, Claire Ledoux and Jean Janes. Claire (Cellie) Ledoux will be the only one of the above three members that will be running for reelection. We will appreciate some nominations from our membership to fill these two board seats; particularly from the southern part of the U.S. and Canada, so our board represents all of our members.

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I designate the following person, whose name I have check on the appropriate line to represent me in any membership vote including the election of the Directors of the Corporation.

Richard J. Wett, M.D., Board Chairman

\_\_\_\_\_

Fausta Deterling, Board Member

\_\_\_\_\_

Vanja Holm, M.D., Board Member

\_\_\_\_\_

Claire Ledoux, Board Member

\_\_\_\_\_

Shirley Neason, Board Member

\_\_\_\_\_

Peggy Pipes, MPH, Board Member

\_\_\_\_\_

Gene Deterling, Board Member

\_\_\_\_\_

Lota Mitchell, MSW, Board Member

\_\_\_\_\_

Robert Scott, Board Member

\_\_\_\_\_

Andree Walczak, M.D., Board Member

\_\_\_\_\_

Delfin J. Beltran, M.D., President

\_\_\_\_\_

Marge A. Wett, Executive Director

\_\_\_\_\_

\_\_\_\_\_ Other (Designate)

\_\_\_\_\_

\_\_\_\_\_  
(Your signature)

\_\_\_\_\_  
(Date)

(Ballot may be used by more than one member)

Please mail to: PWSA, 5515 Malibu Drive, Edina, MN 55436  
no later than June 7th.



CALIFORNIA FOUNDATION

According to President Bob Scott, the PW CA Foundation has achieved much this past year. He reports that after a struggling start the Dubnoff Group Home in Granada Hills has its full complement of PW residents. Another Group home in San Diego, established by the Friends of the Handicapped in San Diego, has received the necessary funding to begin operation and is scheduled to open this summer. Also significant is the publication of an article in the New England Journal of Medicine by Dr. James Mascarello et al. regarding chromosome defects which isolates the abnormality in PWS to a particular chromosome in the genetic chain. The CA PW people and their parents played a significant part in these findings.

Bob Scott also announces in this report that he intends on resigning his position subsequent to the CA Foundation meeting in October.

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