

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT

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5515 Malibu Drive
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PRESIDENT'S MESSAGE

For almost thirty years two phrases have been repeated often enough to have become identifiers of our way of life. They both have had many variations down through the years, but can be summed in the concepts: "my rights," and "not my job." As the son of an immigrant from the orient and a third generation Wisconsin farm girl, my mind fights these phrases with others more dear to me: "it's up to you, work hard and be better than me," and, "an empty wagon makes the most noise and the squeaky wheel gets the most grease." Midwestern middle-class morality never heard of rights, only responsibility, and it is always my job, for if I don't do it who will, and if you want it done right, do it yourself. I get the same feeling in the back of my neck when someone mails me a letter in Spanish because my name is Spanish-sounding. My wife once filled a minority quota for Spanish-speaking because of her name, it didn't make any difference that she is Danish-Bohemian.

It is with great reluctance that I leave that paragraph for the matters at hand. What does all this have to do with the Prader-Willi Syndrome Association? I am sure that the perspicacious in the audience will have found me out. You are right! The annual meeting is coming up in a matter of months. A small group of diligent workers nested in the southwest corner of the country is beavering to prepare time, place, and purpose for the 5th Annual National Conference and Business Meeting of the PWSA. Marge Wett, our Executive Director and guiding light for the overall project, will be mailing you more conference information in the very near future. My purpose is to focus on what does this meeting mean to you, parent or professional, concerned with PWS. I am concerned for your commitment, your feeling of responsibility, your willingness to take on the job.

Eight years ago, one person, Gene Deterling, took on the job and bore the responsibility. The task grew into an organization of 1000, with a central structure of officers and board members, a regular publication, and communication with a growing number of local chapters. This organization is available to people concerned with PWS for assistance and guidance, as a source of information and communication, and as a focus to share the problems of being involved.

The task that faces the members of the PWSA is to be actively involved. Making it to the National Meeting is the most profitable way to become involved. I use the word "profitable" because the investment of time and effort needed to attend pays off so well. There is a growing number of attendees from prior meetings that swear that they will travel the country to be at the next meeting. They know and have profited. Attendance provides profit from meeting and talking with others that have encountered PWS, as well as meeting professionals that have enabled many of the benefits that our children have received. You will profit from giving of yourself and your experience to expand our collective knowledge. These are the benefits of the conference.

President's Message (Cont.)

One morning of the meeting is devoted to the business of the PWSA in the form of the Annual Meeting of the Board of Directors and the election of new board members. This is an open meeting designed to carry on the business of the group. The board has the legal and moral responsibility to guide the actions of the group. As more and more local chapters are formed, they will have the opportunity to select and back for election to the board, someone in their area that reflects more widespread individual concerns, talents, and viewpoints.

It is also time to call upon some PWSA chapter or group or persons, to indicate that they have the commitment and responsibility to bid for the next annual meeting. It would even be desirable if we could have several bids for several successive years. It would be ideal if we could announce the 1984 meeting at this year's meeting; it would be stupendous to add the 1985 location. The process of selection involves a bid from interested persons in the form of a written bid that describes your interest and ability to perform the task.

The life of this association depends on the use of its resources: the members. Each year, new members join as their lives are touched by PWS. The initial benefit comes when they realize that someone else is similarly touched, that they have met the responsibility. Some have gone on to actively involve themselves by helping another with similar problems. If you have been helped, you have the responsibility to help another. Become more involved, support your local chapter, go to the meetings, be knowledgeable, communicate with others.

Delfin J. Beltran, M.D.

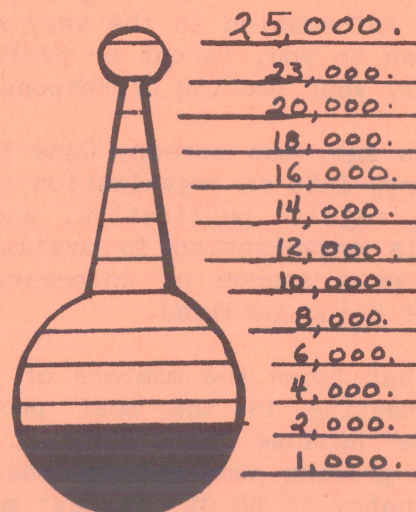
CONFERENCE INFORMATION AND REGISTRATION MATERIAL WILL BE RECEIVED BY THE MEMBERSHIP BEFORE THE END OF MARCH. REMEMBER: JUNE 16-18 IN SAN DIEGO!

RESEARCH FUND

PWSA expresses their sympathy to the LaMonica family for the loss of their son, John, and thanks members for their memorial donations for him. And thanks to others who have given February memorial donations in the amount of \$105.

We have also added \$735. additional dollars to the Research Fund because of individual gifts and funds from two companies. Our special thanks to members, and the Dams and Hamischs for their generous donations that allowed us matching company gift funds.

Research Fund Total: \$2,532.75



Prader-Willi Syndrome Association

Yearly Financial Report 12-31-82

RECEIPTS:

Membership dues.....	13019.21	
Donations.....	9455.28	
*Material Sales.....	5115.20	
National Conference.....	5763.80	
Interest.....	1604.25	
Miscellaneous.....	5.11	
		34962.85

EXPENSES:

PWS Book.....	2063.85	
National Conference.....	5588.96	
Printing.....	2457.11	
Postage.....	2813.04	
Travel & Expenses Reinbursement.....	5848.81	
Pass through donations.....	1009.00	
Office Equipment.....	5166.08	
Secretarial Service.....	220.00	
Computer Service.....	357.00	
Office Supplies.....	657.93	
Other Outside Services.....	82.50	
Telephone.....	132.59	
National Committees and Chapters.....	248.65	
Currency Devaluation.....	226.83	
Miscellaneous.....	22.73	
		26895.78

NET INCREASE.....		8067.07
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*Material Sales include Handbook, Conference papers, PWS book, Overview, Clinic Services Directory, Sibling's book, Membership lists, Brochures, and tape rental.

(This report is being published in the absence of the treasurer. Figures may have to be revised at a later date.)

ANOTHER OPENING

The Oconomowoc Developmental Training Center, Inc. has opened their group home for PW adults, call "The Gatehouse." It is located on the grounds with their other school-residence for younger people, and will be able to use the recently enlarged Sheltered Workshop.

ODTC is 27 miles west of Milwaukee. For information write:

OTDC, Inc.
36100 Genesee Lake Road
Oconomowoc, WI 53066 (414) 567-5515

SUMMER CAMPS

Yes, summer is coming! The GV has received its first notice of a PW camp to be held in PA this coming summer. Last year, the Rehabilitation Institute of Pittsburgh had a very successful summer program for 9 PW children and adolescents. Their program emphasizes social skills, physical fitness, and weight control through nutritional awareness. The children enjoyed swimming, hiking, and many developmental play activities intended to enhance social and motor development. The program is organized by a Child Development specialist, Speech-Language therapist, Occupational therapist, Nutritionist, Psychologist, or other commercial health insurance. If anyone is interested in more information about the program, please contact:

Bea Maier
Program Coordinator
The Rehabilitation Institute of Pittsburgh
6301 Northumberland Street
Pittsburgh, PA 15217

The GV has received several inquiries from patients interested in summer camps. We have not received any other official notices from camps as of yet, but here are the names of a few camps which have been available for PW campers in the past:

Meteor Ranch, Upper Lake CA (213) 287-5332.

Michael Reese Hospital, Dysfunctioning Child Center, 29th and Ellis, Chicago, IL 60616.
Camp Leemar, Lockawaxen, PA.

Gilbough Center, Rt. 6 A, P.O. Box G, Brewster, MA 02631.

Wisconsin Badger Camp, P.O. Box 240, Platteville, WI 53818.

Lions Camps, contact local Lions Clubs.

New Life Ranch, contact Mrs. Marion Shacklett, 6715 South Quincy, Tulsa, OK 74136.

Daybreak, 325 Chester Street, Uniondale, NY 11553.

"SOMETIMES I'M GLAD!"

This is an excerpt from a recent letter of a Canadian member.

"At the risk of sounding profusely thankful, please do tell Janalee that her book was as welcome as rain in May, roses in June, etc. I can now accept my daughter's adverse reactions to some of the things her PW sister does, the unkind remarks. I could not understand her selfishness--'she has everything in this world', I used to think--and when I read that all of this is 'normal', that my daughter has a 'right' to feel this way, an immense weight has been lifted from our shoulders. The book is well presented, I like the drawings, in a few words, I welcome the whole idea of it."

VIDEO TAPES

The national office has an one-hour video tape entitled, "The Challenge of Coping: Families and PW Syndrome." It is a discussion by parents of PW people about how they deal with their children, taped at the last conference. It is available for rent at \$20.00 for members, \$50.00 for non-members. Contact the PWSA office and please specify VHS or Betamax size when ordering.

A NEW FRIEND FOR PRADER-WILLI

A big step was made in our crusade for national recognition, thanks to Kenny Strongitharm, a 15 year-old PW boy from Duluth, MN. Kenny is pictured here with Richard Simmons, of television exercise fame, whom Kenny won over to the cause when he appeared on the Richard Simmons Show in February. The two exercisers became good friends after the Strongitharms wrote to Simmons and later traveled to CA to visit the show. Kenny was invited to appear with Richard on the program, where they cooked, exercised, and talked about PWS. Information about the syndrome, provided by Dr. Annette Dahlman, was read on the air, including the National address. Richard's exercise program has been Kenny's motivation to stick to his diet and lose 55 lbs! While the Strongitharms were in CA, Richard picked up the tab for their hotel, sent them on several tours, and even furnished a bouquet for their wedding anniversary. Beverly Strongitharm described Richard and a "beautiful person" who really cared about Kenny and even gave the family his home phone number so that they could call if they needed anything.



This is a big event both for the Strongitharms and the PWSA. We all hope that this new exposure will reach more families with undiagnosed children. And we hope that other PWs will follow Kenny's example in losing weight with as much success as he has had! The PWSA would like to thank Richard Simmons for his concern and conscientious supplying of information about PWS to his national audience.

PUBLICITY FOLLOWUP

The Jan-Feb GV included an article, "Publicity," which prompted a reply from a couple of members:

In the article, the sentence "Gorging and vomiting is definitely a symptom of anexoria" is incorrect. We were combining two disorders, anexoria and bulimia. Anexoria Nervosa is a condition where a person does not want to eat because they picture themselves as overweight, even though they are not. People with this condition do induce vomiting at times when they are forced to eat. Gorging and vomiting (also known as bingeing and purging) is a symptom of Bulimia, which is a disease marked by constant hunger. People with this condition do eat large quantities and then induce vomiting to avoid weight gain. We were pointing out these two conditions both included inducing vomiting and this is not similar to PWS.

Jack and Janet Slater, chairpeople of the Ontario PWSA, wrote us that they disagree with the statement "we object to the use of the word 'bizarre' and hope that it was not used by parents." They wrote that the word "bizarre" is used on the cover of their handbook,

PUBLICITY FOLLOWUP (Cont.)

and they stand by its selection as a totally appropriate adjective, when used in the correct context. We totally agree, when it is used as it is on their cover. The word refers to the syndrome, not the person with the syndrome. Objection to the use of the word "bizarre" is that we are afraid it will be picked up by journalists and used to describe the people with PWS, implying that our children are abnormal rather than handicapped.

SPRING SECRETS FOR LOSING WEIGHT

Matt Heinemann, correspondent for the PW Missouri Asso. Missouri View, and PW person, shares his secrets for losing weight. The following was written by Matt and is taken from the MO Chapter newsletter.

"I want to help other kids lose weight like me. I used to weigh 107 lbs. Now I weigh 76 lbs. I am happier, too.

When you are fat you get mad all the time. They used to call me names. I get mad at having to diet all the time, but I'm going to diet until I get skinny because I feel better now. When you are fat you can't walk, you can't run, you can't wear nice clothes. What helped me lose weight was:

- 1) LOCKS helped-- you need that so you don't sneak--it helped me a lot. I used to sneak at night time and when Dad was outside and in the morning before anyone was up.
- 2) SKIP JUNK FOOD--For a snack at school I have sugar-free mints. When there is a party at school I only have half the treat. At lunch I skip the dessert or the potatoes or the bread.
- 3) EAT DIET FOODS--I eat diet bread and butter, diet koolaid (we make regular koolaid with Sweet and Low), $\frac{1}{2}\%$ milk, diet jello and diet gum.
- 4) EXERCISE--any kind--running, hiking, swimming (real good), and sit ups."

The GV would like to thank the PW Missouri Chapter for sharing their delightful newsletter with us!

MAKING THE JOURNAL

Attention all doctors! A current issue of JAMA (Journal of the American Medical Association) features an article in the "A Piece of My Mind" column written by Richard J. Wett, M.D. about Lisa, his PW daughter. The article, titled "The Disabled Child," details the experiences of a family with a disabled child and makes some concrete suggestions to the medical profession about how to help such families. The article was also designed to inform physicians about the syndrome, and, hopefully, increase national awareness of PWS. Congratulations go to Dr. Wett for his insightful article.

OVERVIEW: OAKWOOD RESIDENCE DIETARY PROGRAM

Oakwood Residence, a PW group home in Minnetonka, MN, has been in operation about 1½ years. We thought our dietary program would be of interest to parents and other PWSA members.

Upon admission into the home in 1981, each PW person was weighed and, with all medical history available, a goal weight was established with the advice of a physician. There is no crash dieting, unusual food fads, or diet gimmicks to this program. All meals consist of regular foods modified to eliminate fats and sugars. Raw and cooked vegetables are also concentrated on. Vitamins are prescribed as a supplement, if the physician so orders.

The menus are such that they can be used forever, in any setting, to maintain a nutritional, sensible diet. By careful choosing, the diets are easily obtainable in most restaurants and are certainly not expensive. Everyone eats three meals each day and a light snack at night. Food is not used for reward or punishment. It is never taken away--not even desserts. It is treated as something everyone gets regardless of any circumstances, as the right of each individual.

Space does not permit more discussion. We will be glad to present more information if it is desired, either through the GV or at the conference.

Dorothy Thompson, Consultant

(Note: see the following page for more information on each resident's weight loss and diet.)

"DIET MANAGEMENT AND PROGRAMMING, A GOOD SYSTEM IS A GOOD SOLUTION!"

Our primary goals are healthy weight loss and long-term maintenance diets. We achieve these goals with a good system of diet management and programming, and with the cooperation of the program staff, who clearly understands these goals and works together in its efforts to achieve our objectives and winning attitude.

As the Diet Food Services Director and Cook, I organize and plan nutritionally adequate, attractive, and tasty meals with the advice and consultation of a licensed Dietician.

Upon entering the program, residents are placed on the 1000 cal. diet regime on the Nurse's recommendation and the Physician's approval. Each resident then has a goal weight set, and is placed on the Resident's Diet Outline, a diet plan which describes the calorie level as well as any modifications (i.e. sodium restriction). In addition, a personal file is composed outlining diet specifications, general diet history information, and any behavior modification information. The Health Services Coordinator records all weight loss or gain weekly, modifies the diet when needed, and works with the Consulting Dietician and Physician to review progress and make changes.

In our dieting program there are six calorie groups: 800 cals, 1000 cals, 1200 cals, 1500 cals, 1800 cals, and 2000 cals. Once a resident's goal weight is achieved, that person is placed on a progressive diet status so that that individual body can maintain a moderately consistent goal weight. At that time, the person is monitored on a maintenance diet. In addition to our dieting program, we have a regulated environment in which we supply support and set goals. Work programs, school programs, and parents are all aware of the resident's diet regulations, and are requested to support these needs. Program technicians are also aware of each resident's specific needs. They hold an important network position in coordinating an interesting and satisfying goal-orientated diet program. We use teamwork, acting as coaches; they have to push, and we have to give support and direction, but when they win, we win!

Curtis Rancour, Food Service Director

(Note: Watch for a sample Oakwood Residence meal plan in the next issue of the GV!)

OAKWOOD RESIDENCE, INC.
WEIGHT LOSS CHART

SEX	AGE	INITIAL WEIGHT	GOAL WEIGHT	9/81- 12/81	12/81- 3/82	3/82- 6/82	6/82- 9/82	9/82- 12/82	12/82- 2/83	TOTAL WEIGHT LOSS
1 M	20	270	130	224½	191	162	167	139	133	137
2 F	19	175	115	150½	134	125	133½	123	123	52
3 M	22	249½	125	209	188	165	150	143	136	113½
4 F	25	184	120	168½	158½	154	146½	144	141½	42½
5 M	18	82½	90-95	83½	85	92½	94	93	92½	-10
6 F	16	186	110	172	162	154	150	149½	148½	37½
7 M	31	216½	130	188	175	157	150	138	133½	83
8 M	32	165	130	154	130	125	132½	137	144½	20½
9 M	19	257	110	243½	220½	203	194	185	184½	72½
10 M	16	230	125	192½	170½	147	130½	120	124	106
11 M	16	104	90-92	91	86½	87½	91	94	97½	6½
12 F	20	147½	105	131	130½	127	118½	114½	105	42½
13 F	26	182	110	158	145	143	140½	146	148½	33½
14 F	16	135½	107-112	121½	113	110	109	109	112½	23
15 F	27	157	110	162½	169½	175½	172	165½	166	-9

Please note #5 on the chart. This male was quite seriously underweight from a long period of dieting. It has taken 18 mos. of steady 1800- 2000 cal. diet to bring him to a more healthful level. He had never lost his appetite. No. 15 female is totally unmotivated and her program at a large workshop is not helpful. Other plans must be made. Also note fluctuations around holidays and summer vacations. We are not too concerned with these conditions because the weight loss resumes when the person returns to schedule.

TOTAL LOSS 751 pounds

SOAPS, BATHS AND DRY SKIN

Itchy, dry skin is a problem many people have to deal with, and a problem that can really be a hazard for PW people, who tend to "worry" and pick at their skin when it itches. There isn't much that you can do to prevent dry skin, but many things can be done to improve your skin's condition, things such as careful bathing, using less irritating soaps, picking an effective lotion or moisturizer, and exercising.

Excessive bathing, especially with very hot water and soap, can do a lot of damage to a person's skin. As a matter of fact, it is recommended that a person with dry skin not bathe more than two to three times a week during winter. Between times, a sponge bath is adequate for day-to-day cleanliness. You should take a bath or shower with tepid, not hot, water. Hot water opens the pores and increases moisture loss from the skin. Avoid using a wash cloth, rinse well with tepid water, and dry by patting, not rubbing, the skin. Adding bath oil to your tub can help, but only after you've been soaking a while. If you add oil when you fill your tub, your skin will become coated with oil before it gets the chance to absorb moisture.

Some soaps, whether or not they are advertised as "gentle," can be very harmful for people with dry, sensitive skin. The results of a study conducted by dermatologists at the U. of PA and the U. of Munster in West Germany showed that some of the more inexpensive toilet soaps, especially Dove soap, which was found to be the least irritating to sensitive skin, performed much better than the more expensive "cosmetic" soaps such as Zest, Lava, Camay, Jergens, and Irish Spring (found to be among the most irritating). Many of the more expensive soaps also did not moisturize the skin nearly as well as some inexpensive toilet soaps and such pedestrian fats as petroleum jelly, vegetable shortening, and baby oil.

Experts recommend that dry skin should be treated daily with a substance, a lotion, cream or moisturizer, that reduces the evaporation of moisture. The best time to apply a moisture retardant is immediately after bathing (within a minute) while your skin is still damp. Baby oil can be used any time, but if used right after bathing it "soaks" into your skin without leaving a greasy feeling and retards evaporation without closing the pores. Baby oil and petroleum jelly are much more effective than moisturizing creams and lotions.

The difference between a "lotion" and a "cream" is basically that lotions are oil products in a water base, and creams are composed of water in an oil base. There are also creams known as "emollients" which are made using various oils. The oil and water in lotions and creams each play a role in soothing dry skin. The oil leaves a film on the skin that retards evaporation and smooths out rough, scaly surfaces; the water is what actually adds moisture to your skin. So a lotion or cream that is mostly oil helps retard further moisture loss, but does not actually moisturize the skin. Moisturizing lotions and creams are mostly water, and therefore they help make the skin feel smooth, but they are less effective in the long run because they do very little to retard the evaporation which dries out your skin.

Actually, the best treatment for skin is exercise. Vigorous exercise stimulates the circulation and causes sweating, which brings moisture to the skin's surface. Remember, though, not to undo all the good that exercise can do by bathing too energetically after each session and toweling off the moisture you've brought to your skin.

Based on excerpts from a Jane E. Brody article

A POSSIBLE GROUP HOME FOR PA

Lota Mitchell of Pittsburgh has asked the GV to repeat her request for people in the states around the PA area with children over 15 who are interested in a group home to contact her. She received only one response to her last inquiry, and feels more families living in these states may wish to see plans for a PW group home continued. Please send Lota the Child's name, age and address at:

844 Foxland Drive
Pittsburgh, PA 15243

Lota also asks that we mention that the Tri-State PW group's next meeting will be this Spring, and that the meeting's chairperson is Barbara Carter of PA.

PW COLORADO CHAPTER

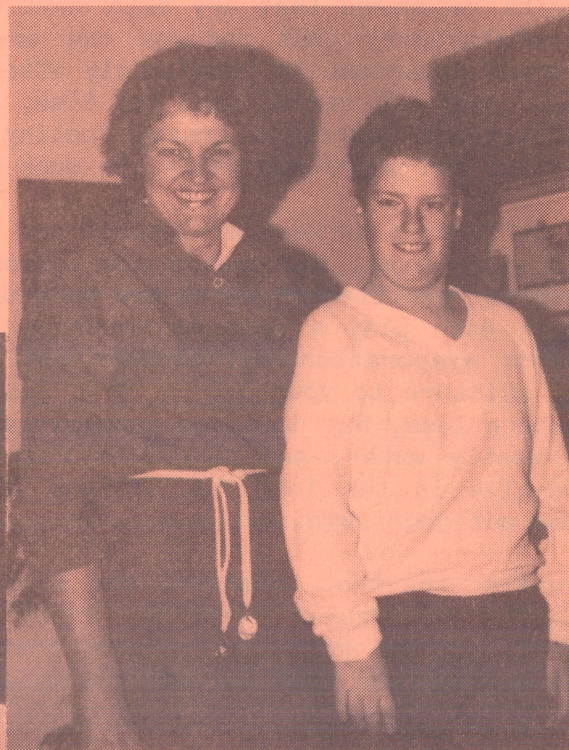
On February 10, the CO chapter held its last meeting to discuss its latest projects and goals. The group has decided to start its own library of literature about PWS. They recently added a complete set of GV issues and will support this reference with an index that the national office has just completed.

The chapter's next meeting will be March 10. Their chapter contact is: Joanne Levesque, 13105 East 5th Avenue, Aurora, CO 80011.

HERE'S TO YOU, JON!

These two pictures demonstrate the dramatic difference a good weight program can make! This is Jon, before he entered the Oconomowoc Training Center in WI, and on his 15th birthday, 11 months later and 80 lbs. lighter! Jon's mother sent these snapshots along with a note saying that she hopes sharing the pictures with the membership will give hope and inspiration to others.

Keep up the good work, Jon!



SPECIAL OLYMPIAN

Dear Gathered View:

"I am a Special Education teacher who has a PW 9 year-old boy. When he entered kindergarten he was quite overweight. His mother is very aware of the diet problem and works very diligently at it. He has very splayed feet, and his arms are a little short in comparison to his trunk. He tried to be active, but it was difficult for him because of his physical limitations. Through Special Olympics, Inc., we attended a "Let's Play to Grow" clinic. We learned simplified types of exercises and games for children with problems. During the summer, he attended swimming lessons, and the family was able to put in a backyard pool. . . As soon as he had his 8th birthday, he enrolled in the local Special Olympics. He trained very faithfully so that he could attend county and state games and compete. We could tell a definite difference in his coordination at the yearly school play day. He was still heavy, but not obese. . . Through the school year, he does the Special Olympics exercises through their training program, and once a week he trains with the local Special Olympic athletes. It provides an extra social outlet for him, as well as the physical training. We feel it has made a difference in his life! ! !"

If parents, guardians, or group home parents would like to know more about Special Olympics in their state they can write:

Special Olympics, Inc.

Joseph P. Kennedy, Jr. Foundation

1701 K Street, N.W.

Washington, D.C. 20006

or

For children under 8, write:

Let's Play to Grow

(at the same address)

The only requirement for enrollment is that the child be mentally handicapped.

NUMBER EIGHT!

The grand total of PWSA official chapters is now up to 8, with the addition of the Prader-Willi Association of New England, Inc. This newest chapter, headquartered in MA, consists of members from MA and NH. Their officers are: President, Jacqueline Huffman, Sudbury, MA; Treasurer, William Tsoules, Worcester, MA; Secretary, Pauline Parent, Manchester, NH.

Area parents and friends of PW children and adults who have not attended their meetings may make contact through the Children's Hospital Medical Center's Developmental Evaluation Clinic Staff, Margaret Van Gelder or William Mitchell of Boston, MA (617) 735-6501.

NEW WESTERN FACILITY

The GV has received word about a new dedicated PW facility in Arizona. For more information, contact:

CASA de SALUD

2911 Meadow Brook

Flagstaff, AZ 86003

(602) 526-2027

MEETING DATES

PW Midlantic Ass.: Spring Meeting, April 9, Camphill Village, USA, Kimberton, PA.
PW Greater NY Ass.: April 11 and June 6 at Bernard Fineson Developmental Center
Howard Beach, 7:30 pm. May 9, Nassau Hospital, 7:30 pm. (This meeting could be changed to the
afternoon if members from upstate NY would like to attend.)
PWA of MN: March 18, Honeywell Bldg., 7:30p.m. video tape from conference will be shown.

FOR PW SIBLINGS

Sometimes being a brother or sister of a mentally or physically disabled child can be just as much of a strain as being a parent. For those siblings who feel the pressure and need someone to share their feelings with, there is a newsletter designed to provide support for and information to siblings of handicapped people. The newsletter is put out by the Sibling Network, and anyone interested in more information about the Network or its newsletter may write to: Tom Powell, P.O. Box 791, George Peabody College, Vanderbilt University, Nashville, TN 37203

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

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