

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT

Edie Marie, Editor
5515 Malibu Drive
Edina, MN 55436

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PWSA 5th ANNUAL CONFERENCE

Most of us have at least once a year a time of hectic preparations, whether for Christmas, a wedding, graduation, a bar mizvah, or whatever. We all know what it's like to get a big event planned and executed. Your PWSA has the same experience each year at conference time, working with each new committee, in bringing about the annual conference.

We mailed a "proposed program" to you, along with registration information, in March. We hope you will notice two important statements on this pre-registration form: reservations are required by May 15th at the Bahia Hotel, and successful planning requires data. The hotel has set aside a block of rooms at a special price for your meeting; in order to assure a room at this price, you must send your reservation cards to the hotel now. PWSA would also appreciate hearing from you now. Early registration is very helpful to the chairpersons of this conference (particularly for Betty Shadell in organizing the necessary help for the Youth Activity Program). Many people have told us of their intentions to attend this year's conference, but few have actually sent in their registration forms.

The "proposed program" has now been firmed into a set agenda. We are very fortunate to have several doctors with years of experience in working with this syndrome. Dr. Richard Wett of Minnesota will be presenting a slide explanation of what we know about PWS. Medical Updates will be given by Dr. Vanja Holm of Washington, Dr. Bryan Hall of Kentucky, Dr. Marilyn Higgenbottom-Jones and Dr. George Bray of California. Dr. Daniel Overbeck of Arizona and Dr. Annette Dahlman of California will join some parents on panels in workshops designed for discussing sharing and intervention techniques. Laurie Stokely will chair two panels discussing living arrangements, family feelings and education.

Additional speakers will include some people that we have been privileged to hear before at previous conferences: Lota Mitchell, M.S.W., Margo Thornley, MEd. and Janalee and Al Heinemann, one of the sets of parents from the coping tape. Louise Greenswag, R.N., M.A., of Iowa will give parents an opportunity to add their input to an adult educational psychology study. Others with experience in helping PW persons, too many to name here, are involved with the panels to be presented.

Chairperson Harvey Bush and his committee, particularly Laurie Stokely, have been hard at work preparing an informative and interesting program for this conference.

Betty Shadell is very excited about what the Youth Activity Program will offer the young people with PWS and their brothers and sisters. Education mixed in with fun trips will compose the important parts of their program. We assure you that they will go home with the request of wanting to come back again next year.

Another important part of this conference is the annual business meeting. This is the only time each year that our Board of Directors gets together and plans the coming year for your organization. The meeting on Friday morning is not your typical "rubber stamp"

board meeting, but it is a meeting where you, as a member of the group, have the opportunity to include your input and ideas on what we should be attempting to achieve in the upcoming year. The past meetings have been well attended and enjoyed by the membership. The election of new board members will also be held at this time.

As we complete the 5th Annual Conference, we have to begin plans for the 6th meeting. We would like, at this time, to put out the call to any group that would like to submit their bid to hold the 6th Annual Conference in June of 1984. These bids should be submitted to the PWSA National Office prior to June 1st in order that they may be discussed at this year's meeting.

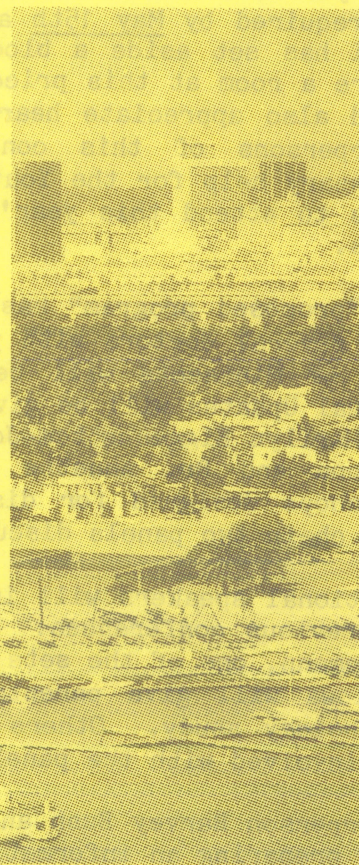
DON'T FORGET the deadline for returning ticket stubs for the fund raising drawing is June 1st. These must be returned to the national office.

THE TIME IS NOW: PRE-REGISTRATION TO THE PWSA OFFICE
HOTEL RESERVATIONS TO THE BAHIA HOTEL before MAY 15th
BIDS FOR 1984 MEETING TO THE PWSA OFFICE
TICKET STUBS TO THE PWSA OFFICE BEFORE JUNE 1st.

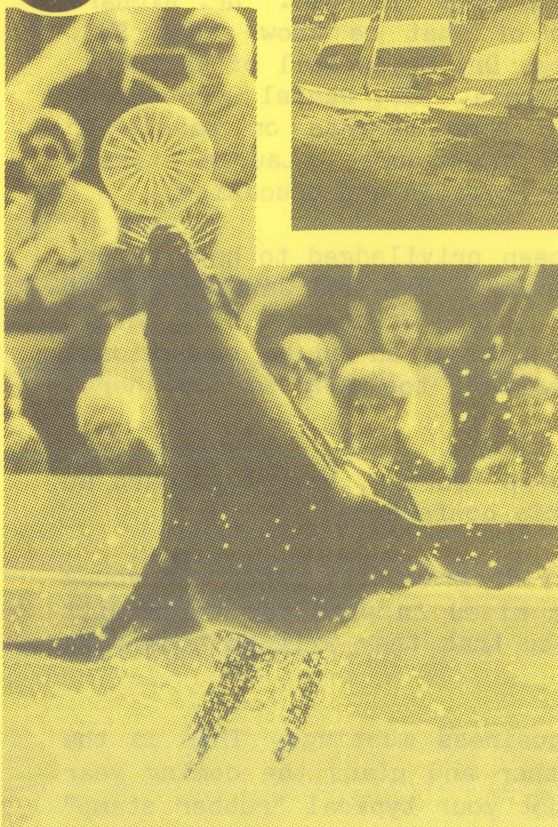
San Diego



Sailing on Mission Bay



San Diego Skyline



Sea World



La Jolla Cove

CONGRATULATIONS, GENE

One of our founders, Gene Deterling, was recently recognized by the National Developmental Disabilities program for his outstanding volunteer work. Gene's efforts on behalf of the PWSA earned him the Minnesota Outstanding Volunteer of the Year award, awarded to him by Jean Elder, commissioner of the Washington-based Developmental Disabilities Administration.

The PWSA would like to congratulate Gene, and thank him for his continuing support and efforts in helping his "Prader-Willi Syndrome Parents and Friends" grow into the strong, international organization that it now is!

ATTENTION PEN-WIELDING PW'S!

The GV has received a request from the PWSA (UK) to help Liam Quinn, a PW boy from Scotland, find an American pen-pal.

Liam is 14, and his hobbies include collecting and doing jigsaw puzzles, coloring books, reading, crossword and word-finder puzzle books, and outdoor sports. Liam would like a male pen-pal, and his address is: 148 Rochsoles Drive, Airdrie, Lanarkshire, Scotland.

The GV would also like to know if there are any PW people in this country who would like a pen-pal to write to either in the US or the United Kingdom. If so, please contact the GV at the national address.

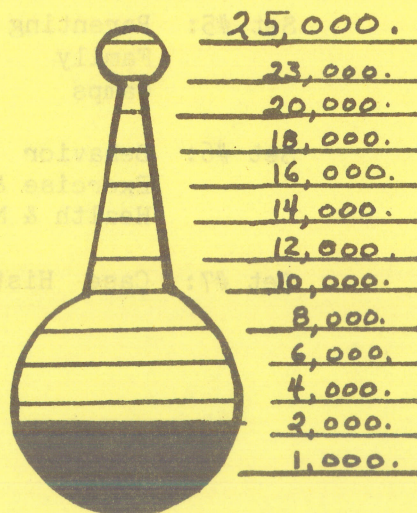
KENTUCKY MINUTES

The March 5 meeting of the PW KY Association heard presentations from members of Metro Industrial Services, a Handicap workshop, and the Director of DD Services in KY. The director discussed Public Law 94-192; he stressed parent advocacy in obtaining needed services for PW children. He also recommended two free booklets: Your Child's Education, and Partners in Advocacy. He strongly advised keeping a notebook to record any evaluations, medical records, or educational information relating to your children.

This chapter's next meeting will be Saturday, May 21; Dr. Bryan Hall will attend and speak at the meeting.

RESEARCH FUND

Our thanks to members who do care about progress in the Research area. March and April added \$292 directly to our fund. An additional \$75 memorial donations brings our present total to \$2,868.00



NEW MATERIALS AVAILABLE FROM PWSA

At the request of some members, the national office has now made available past issues of the GV from 1975-1982. We have also taken individual articles from these issues and grouped them together into general categories of interest to the membership. These categorized articles cover all information published in the GV on the topics listed below, and can serve as excellent resources for individuals, groups, or organizations. Also available is a comprehensive Index of the GV 1975-1982.

Listed below are the various sets and categories available; the accompanying prices cover printing and postage.

PREVIOUS issues of The Gathered View, includes all past issues from July, 1975 through December, 1982: \$15.00 US funds, \$18.00 Canadian, \$20.00 overseas.

INDEX of past issues plus all selected articles reprinted in categorized sets: \$15 US, \$18 Canadian, \$20 overseas.

COMPLETE set: (includes GV back issues, Index, and categorized articles): \$25 US, \$30 Canadian, \$35 overseas.

CATEGORIZED articles: \$2.00/set (as listed below), or \$1.00 each individual subject.

Set #1: Medical and Physical Development
Treatment and Medications
Clinics

Set #2: Diet
Nutrition
Recipes
Weight & Food Control

Set #3: Research
Vocational Placement
Prader-Willi Adults

Set #4: Publications
Residences
Education

Set #5: Parenting
Family
Camps

Set #6: Behavior
Exercise & Activities
Health & Medical

Set #7: Case Histories

OAKWOOD RESIDENCE MEAL PLAN

This is a sample Daily Meal Pattern for a 1000 Calorie Diet at Oakwood Residence. The Daily Total Exchange Pattern is divided into four meal groups. Each meal group has its allotted exchange food items and units. Selections are based on caloric intake, bulk, texture and consistency preferences. When the meal divisions are added up they correspond to the Daily Total exchange outline. Menus are planned and outlined according to a five-week cycle that rotates after the completion of each cycle. Each week is planned for good nutrition, food variety, fine quality, and portion control quantity. Seasonal foods are sometimes exchanged for planned foods.

I. Daily Total Exchange:			
Group	Exchange	Units	
Milk, Skim	2	2 cups	
Meat	5	5 ozs.	
Bread	3	3 slices	
Fat	2	2 tsp.	
Vegetables	2	8-12 ozs.	
Fruits	4	16 ozs.	
Free			
II. Breakfast Exchange:			
Group	Exchange	Units	Corresponding Menu
Milk, skim	$\frac{1}{2}$	4 ozs.	Fresh skim milk
Meat	1	1 oz.	Poached Eggs
Bread	1	1 slice	English Muffin
Fat	1	1 tsp.	Whipped Butter
Vegetables	No	No	
Fruit	1	2-4 ozs.	Strawberries
Free	No	No	
III. Lunch Exchange: (bag lunches)			
Group	Exchange	Units	Corresponding Menu
Milk, skim	1	8 ozs.	Chilled Milk
Meat	1.5	1.6 ozs.	Pork Roast Sandwich
Bread	1	1 slice	" " "
Fat	1	1 tsp.	Mayonnaise, chilled
Vegetables	1	2-4 ozs.	Carrot & Celery sticks
Fruit	1	2-4 ozs.	Pear
Free	No	No	
IV. Dinner Exchange:			
Group	Exchange	Units	Corresponding Menu
Milk, skim	$\frac{1}{2}$	4 ozs.	Chilled Milk
Meat	1.5	1.5 ozs.	Spiced Chicken
Bread	1	2-3 ozs.	Mashed Potatoes
Fat	No	No	
Vegetable	1	2-4 ozs.	Tossed Salad
Fruit	1	2-4 ozs.	Pineapple Fruit cup
Free	No	No	
V. Snack Exchange:			
Group	Exchange	Units	Corresponding Menu
Milk, skim	No	No	
Meat	1	1 oz.	Tuna Salad
Bread	1	1 slice	Cracker
Fat	No	No	
Vegetable	No	No	
Fruit	1	2-4 ozs.	Apple Sauce
Free	1	1 cup	Kool-aid made with diet sweetener
Coffee, tea and water available at all meals			

THE BRIDGE MODEL

The Parents' Campaign for Handicapped Children and Youth, and The Council for Exceptional Children have developed and recently released in published form, The Bridge Model, a manual providing a complete guide for building parent-educator teams for handicapped children. The manual contains step-by-step instructions designed to strengthen communication skills and positive working relationships among parents and educators. It has been successfully tested in urban and rural locations throughout the country.

In addition to supplying the manual, the project staff will provide technical assistance to groups wishing to use the Bridge Model, which consists of a sequence of planning activities culminating in a unique, highly-motivating one-day workshop. Single copies of The Bridge Model are available free with a minimal charge for postage and handling. 100 copies are available in Spanish. For a copy of the manual send \$2.00 to:

The Parents' Campaign for Handicapped Children and Youth
1201 16th Street N.W.
Washington, D.C. 20036

THANK YOU, GATHERED VIEW

"I can't thank you enough for your GV newsletter. Through your newsletter, we got acquainted with several living alternatives for our daughter. Nobody, including our Regional Agency, could give her a proper setting for her PW condition; therefore, having had terrible failures until we started investigating ourselves from the information given us by you. Now, our daughter is in Long Beach at the "Straight Talk Clinic Program" and she can't be happier. Needless to say, we feel for the very first time, a sense of satisfaction and happiness that words cannot describe!!!
We thank you so very much!!!"

PARENTS' CAMPING GUIDE

The American Camping Association has a listing of over 2,400 camps and includes a special listing for camps for mentally retarded and overweight children. We are sorry that we did not get this information sooner so we could order the listing and judge its value. If you are interested in the listing, order: #PG 03 Parent's Guide to Accredited Camps, 1983. payment in full in US funds must accompany order, and street address must be included for UPS delivery. Price is \$5.95, US, \$7.50 Hawaii and PR, \$8.00 Canada, and \$10.00 all others. (Editions shipped outside of US include international supplement to assist parents in selecting a US camp.)

Mail orders to Publications, American Camping Association, Bradford Woods, Martinsville, IN 46151.

NUTRITION AND OUR BASIC NEEDS--Part Two

In part one of this article, it was determined that the nutrients essential to the body can be divided into six basic classes: water, proteins, fats, carbohydrates, vitamins, and minerals. Fiber is also sometimes included as a seventh class.

The discussion in this part of the article will include some suggestions and guidelines for consuming the foods that will provide an adequate amount of each of these major nutrients.

As is commonly said, water is the basis of all life. Nutritionally, the human body needs to take in about $2\frac{1}{2}$ quarts of liquids per day to function properly. Nutritionists say that $1\frac{1}{2}$ quarts of these liquids should be consumed as liquid, i.e. drinking water, tea, coffee, and other beverages. The rest of your intake usually comes from the food you eat; almost all foods are sources of water.

Most Americans consume about 12-15% of their calories in the form of protein. Even though the need for protein depends upon such variables as the extent or speed of growth, age, and size, every body needs a continuous supply of protein to build and maintain cells. Proteins of animal origin, such as eggs, dairy products and meats, are the most well-balanced for human tissues. For the average adult, a sufficient amount of protein of excellent quality will be assured if the daily diet includes 3 or 4 average servings of milk, meat, fish, poultry, eggs, peas, beans, peanuts, or cheese. About 30 grams of protein from these food groups should be eaten.

Fats provide about 40-45% of the energy in the usual American diet. Most of those fats come from meat, dairy products, and pastries which have large amounts of added fat. Fat is also added to the diet in the form of cooking oil, salad dressings, butter and margarine. There is no official recommended level for the amount of fat nor the type of fat that should be eaten, but consuming some each day is essential. A recommended maximum level of 30-35% of the calories consumed should be from fat, according to current estimations. On the subject of calories, you should not confuse the term "low fat" with "low in calories." Many fat products can have a lowered fat content but still have the same amount of calories as a non low-fat product. The calories in low-fat yogurt, for example, are the same as in non low-fat yogurt because the amount of sugar and fruit syrup added is the same in both products.

Many people have been led to believe that eating carbohydrates is fattening and should be avoided. Much of this idea comes from the High Protein fad diets that are so popular and usually very ineffective. Contrary to these beliefs, however, carbohydrates provide most of the energy in the average diet and are no more fattening than any other source of energy. All food sources of energy, including protein, can be changed into and stored as fat if the calories taken in exceed the energy expenditures. When the carbohydrate supply is low, however, protein will be broken down and used for energy rather than for building tissues and performing its other essential functions. To prevent these potentially negative effects, the diet should include at least 70 to 1000 grams of carbohydrate. It has been suggested that more carbohydrate should be eaten in the form of starch rather than sugar. For example, a baked potato, when not loaded with butter or sour cream is very low in calories and an excellent source of carbohydrates.

NUTRITION AND OUR BASIC NEEDS -Part Two (Cont.)

Vitamins and minerals are essential to good health. Many things have been published about vitamins, particularly about mega-doses (large doses) of certain vitamins, but many of these claims have not been substantiated. For example, Linus Pauling published a book, Vitamin C and the Common Cold, in which he claimed that Vitamin C, taken at 1 to 3 grams a day, would prevent colds. He also claimed that it would shorten the duration of a cold and alleviate the worst of its symptoms. Subsequent controlled studies failed to substantiate most of these claims, however, although there is some reason to believe that at such high levels Vitamin C may act like an antihistamine and lessen the sniffing and stuffy nose of a cold. Fruits and vegetables are the best sources of Vitamin C; meat and milk have very little.

Vitamin A deficiency is probably the most widespread vitamin deficiency in the world, but the vitamin can also be toxic if taken in large doses, so it is very important to have a well-balanced intake of vitamin A. Half of your Vitamin A should come from milk, eggs, or butter, and the other half from liver or vegetables.

Vitamins are very sensitive to cooking and storage methods, and great care should be taken to preserve them. Thiamine, for example, (a B vitamin), deteriorates during storage and is destroyed by heating. Leafy vegetables stored for three days at room temperature lose all of their vitamins. It is not recommended, either, to add baking soda to vegetables to preserve their green color. If fruit is damaged or bruised, the enzyme destroys the vitamin C. Fruit should not be cut or peeled until you are ready to consume it. Actually, if fresh vegetables are not used right after picking, you get more vitamins from frozen vegetables because they are flash-frozen right after picking. Cooking in a copper pan destroys vitamins, as does cooking in iron cookware, although an iron pot can increase the amount of iron in your diet. The microwave oven is the best method of cooking to retain vitamins, and steaming is second. Vitamins are lost when vegetables are cooked in water, therefore canned vegetables have the least amount of vitamins. TV dinners and some other frozen convenience foods have also lost half of their nutritional value when packaged.

Estimating the requirements of various minerals is complicated by the many factors which influence the needs. Many physicians and researchers feel it would be beneficial for many to lower their intake of sodium (salt.) Zinc is an essential nutrient, but it is not the "miracle" nutrient many people think it is. If you are concerned about your mineral or vitamin intake and are taking vitamin and mineral supplements, they should be taken with a meal. When combined with food, a better use of them is made by the body. In no case, however, should vitamin or mineral supplements be taken instead of eating!

The term "fiber" refers to several different carbohydrates and related compounds, all resistant to digestion. A lack of fiber in the diet may be the cause of chronic constipation. Constipation, or hard stools, has been mentioned by some parents of PW young people. Unrefined and lightly processed carbohydrate foods are the best sources of fiber. The best way to increase dietary fiber intake in the diet is in the form of yeast-leavened, whole grain bread, whole-grain breakfast cereals, vegetables, and fruits. As is almost always the case, though, it is possible to overdo a good thing; large amounts of fiber in the diet can lead to complications.

FIBER FOODS

For those who would like a more specific list of the foods that are good sources of dietary fiber, the following are those foods which contain the highest amounts of fiber. Fiber plays an important role in helping regulate the bowels; it's especially useful in combating constipation.

- | | |
|--|---|
| 1. Dried Beans, peas and other legumes | 11. Green beans, pole beans, and Italian beans |
| 2. Bran Cereals | 12. Plums, pears and apples with skin |
| 3. Lima beans, fresh or frozen | 13. Raisins and prunes |
| 4. Green beans, fresh or frozen | 14. Greens: spinach, kale, collards, and swiss chard. |
| 5. Dried fruit, especially figs, apricots, and dates | 15. Nuts: almonds, brazil nuts, peanuts, and walnuts |
| 6. Raspberries, blackberries and strawberries | 16. Cherries |
| 7. Sweet corn | 17. Bananas |
| 8. Whole wheat and other whole grains | 18. Carrots |
| 9. Broccoli | 19. Coconut |
| 10. Baked potato with skin | 20. Brussels sprouts |

FROM A PARENT IN KS

"Our PW son will be 8 years old on May 15. He is 3' tall and weighs 44 lbs. He has blond hair and blue eyes and is quite charming when he wants to be. Most days I thank God that he picked us to be our son's parents, but there are days when I would like to send him back.

Our son's behavior is one of his main problems. His tantrums include loud screaming, head-banging, throwing toys, kicking walls, biting, etc. We are continually working to control these tantrums. At times he has been self-abusive. He has been put on medication for the behavior and it has helped some.

We are very fortunate to have a good Special-Ed program for our son. His teacher is a very loving person. We also are very fortunate in having two doctors to care for our son...These men have taken a personal interest in our family. I thank God for them."

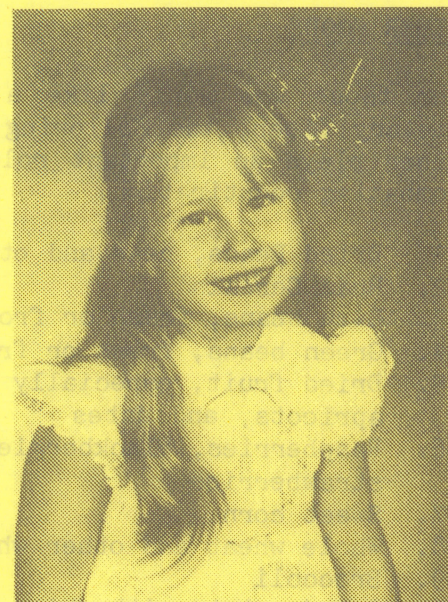
(Ed. note: The parent concludes that she would really appreciate hearing from other parents. If anyone with a child around this age would like to correspond with her, please contact the Editor at the national address.)

PRADER-WILLI AND YOU...

...is the title of the newest PWSA publication. Designed to be used by PW persons, this book was compiled by three graduate nutrition students with assistance from staff at Boston Children's Hospital. The book is presently at the printers, and we hope to be announcing its sale in the next GV. We are very excited about sharing this excellent new resource with our members!

DEAR PWSA.....

"Awhile back, my PW daughter, Alydia, who is five, was at a neighbor's house. The neighbor gave Alydia a freshly-baked cupcake. To my astonished delight, my neighbor told me that Alydia handed it back to her and said 'no thank you, I can't have this, I'm on a diet.' The neighbor replied, 'But Alydia, you're not fat.' Alydia said, 'I'm a PW child, that cupcake isn't good for me'.... Later, Alydia and her little brother went to visit relatives out of state. I sent along a list of 'do's and don'ts' and climbed on my soap box and preached the evils of fatty foods and the consequences of disobeying portion control. I made the relatives swear that they would continue Alydia's diet and portion control program, which they did. So off they went for a visit of five days, and Alydia came back 10 lbs. heavier. That was an average of 2 lbs. a day. I asked the relatives how did this happen? They just couldn't understand it. They swore they upheld her diet. It wasn't until several days after their return that Alydia proclaimed how much she liked Granny's biscuits and gravy and her peanut brittle.



It was then that I realized it was going to have to be Alydia who had to take responsibility for implementing her diet and portion control...From the very time Alydia could start comprehending, I told her that she was a PW child and she was very special. I continuously reinforced to her that there are three meals a day with no exception. Even at the age of 3, I started teaching her portion control. The more she was able to understand, the more I told her about PWS. I continuously reinforced that she would have to be on a diet the rest of her life through no fault of her own....It has been a year now, and Alydia has taken the 10 lbs. off. To date, she is 41" tall and weighs 37 lbs. The incident with the cupcake is proof that her programs are working and she is accepting responsibility for her diet...."

MIDLANTIC MEETING

The April 9, Spring meeting of the PW Midlantic Asso. included several speakers. Lota Mitchell and Bea Maier spoke about the summer camp at the Rehab. Institute of Pittsburgh. Lota also stressed support for the research fund and the future group home needs of younger PW people. Psychologist Dr. Mark Brenner discussed the psychological aspects of being a PW person; he asked parents to try and look at life from their PW child's point of view. Dr. Terry Page also gave a presentation of the PW program at JFK Institute. His program stresses behavioral intervention to try and control foraging for food.

This chapter also held a fund-raising event which collected \$854, half of which will be donated to the Research fund. Thank you and congratulations. The group now looks forward to their fall meeting, to be held sometime in October.

PROXY BALLOT

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

This proxy form must be received by PWSA no later than June 1, 1983.

Five board members' terms have expired: Fausta Deterling, Andree Walczak, Lota Mitchell, Gene Deterling, and Peggy Pipes. Peggy has notified the meeting she will not seek reelection. Nominations will be made during the meeting and a vote will be taken. (Direct vote from those attending and proxy votes returned to the National Office.)

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

Board members:

Chairman, Richard J. Wett, MD; MN _____

Fausta Deterling; MN _____

Vanja Holm, MD; WA _____

Claire Ledoux; CT _____

Shirley Neason; WA _____

Dorothy Thompson; MN _____

Gene Deterling; MN _____

Lota Mitchell, MSW; PA _____

Betty Schultze, EdD; MO _____

Stewart Maurer; GA _____

Andree Walczak, MD; IL _____

Officers:

Delfin J. Beltran, MD; CA _____

Marge A. Wett; MN _____

_____ Other (designate) _____

Your Signature(s)

date

(Ballot may be used by more than one family member)

Please mail to:
no later than June 1st

PWSA
5515 Malibu Drive
Edina, MN 55436

MINUTES FROM MN

The March meeting of the PW MN Chapter included an award presentation to Gene Deterling for his outstanding work and an update from Dr. Richard Nelson on the PW clinic at Gillette Hospital.

The Chapter's May 20 meeting will feature speaker John LeMay, an attorney who will give a presentation on custodial choices and estate planning. Special note to MN members: the annual family camping weekend and picnic at Lake Independence will be held August 19-21.

MORE MEETING DATES

The Southern New England PW Parent Support Group will hold its next meeting on May 25 at Newington Childrens' Hospital, Newington, CT; 7:30 pm.

SPECIAL THANK-YOU

The PWSA would like to thank all those members who continue to pay Contributing and Patron memberships. Since the basic membership fee of \$15.00 covers only the expenses of running the office and putting out our newsletter, any membership renewal over that amount can be used for many special projects, such as our children's books and categorized GV articles, that benefit the entire membership. Thanks again!

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, MN 55436

Debra J. Beltran, MD, CA

Marge A. Wells, MN

Other (designate)

Your Signature(s)
(Ballot may be used by more than one family member)

PWSA
5515 Malibu Drive
Edina, MN 55436

Please mail for
no later than June 1st