



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

Following World War I, a sense of public responsibility to citizens with problems first became manifest in legislation with the Workman's Compensation laws passed in Wisconsin and then spreading throughout the country. Just prior to the second World War, congress increased the amount of social legislation in response to the depression, and, most notably, in the start of Social Security. Over the next forty years, social legislation burgeoned, and elections were won or lost over the amount of increased social welfare that was promised to the people. In 1976, PL 94-142 was added to the books in recognition that handicapped children need the opportunity to grow to their maximum potential with special educational facilities and situations with all associated techniques that would make it possible for learning to occur.

This scenario of increasing social awareness was initially developed under the concept of citizens doing what it is necessary to do in order to fulfill a responsibility that they felt toward those who could not do for themselves. Over the last fifteen to twenty years, the emphasis has rotated to the concept that the government must provide these benefits because those who cannot do have a right to receive that benefit from the state. The cry of rights has extended in all corners of our lives, now to the point where the protection and transgressions of rights fills the courtroom dockets of the country with millions of dollars in claims.

The vast variety of rights that the government has undertaken to fulfill now has expanded the public debt to the point that a recent newspaper article placed the personal debt of every man, woman, and child in this country at over \$30,000.00; that is \$120,000.00 for a family of four. In many cases, the realization of these numbers is as foreign to our thinking as Prader-Willi Syndrome was before it entered our families. But the increasing costs of social welfare programs is not foreign to the thinking of legislators. At a time when revenues are expanding at a slower rate than debt, the lawmakers are forced into rethinking how much can be trimmed from expenditures without causing too much havoc among voters. As a physician, there is little question in our minds that the government means to decrease expenditures on medical care by whatever means they can use. The dominant theme during the sixties, when Medicare and Medicaid were enacted, was similar to PL 94-142, bring the sick and poor and handicapped into the mainstream of the bountiful American way of life. That tune is changing markedly. As long ago as Lyndon Johnson's second state of the union message, when he recognized that Federal Research dollars were not producing enough bang for the buck that they had expected, it was recommended to cut back on expenditures. The newest wrinkle is paying on the basis of average cost for a disease. But what is even more frightening is the expanding concept that the dollar is more important than the individual, and the standard of excellence is determined by cost.

There are mechanisms being established that the government prefers to call cost-effectiveness guidelines and competition-inducing stimuli that will lead to the determination of who gets care and at what level, who can take care of you and at what location,

PRESIDENT'S MESSAGE (Cont.)

all based on the least cost, not on any individual responsibility of one human being caring for another. Just as medical care has been targeted for corrective action, so too have the needs of the handicapped, which tend to be initiated in the educational arena.

The reason for the diatribe and harangue is to stimulate people who are interested in helping our Prader-Willi persons to become and remain knowledgeable in what is happening in government that will affect your lives and the lives of your family and those persons to whom you bear a responsibility. Every person that knows what is affecting their life must respond to it, and hopefully will contact their government to help the changes being made to follow a path that they believe is appropriate to their lives.

DELFIN J. BELTRAN, M.D.

NOTES FROM THE NATIONAL CONFERENCE

Evaluation sheet comments: "SUPER," "THANK YOU TO THE CA GROUP," LOVED THE YOUTH ACTIVITY PROGRAM," "MASTERFULLY ARRANGED AND CONDUCTED."--I believe that says it all! Many, many people did a terrific job!

<u>Fund-raising drawing:</u>	Top Winner, \$1,000	BEVERLY BUSH of Vista, CA
	2nd prize, Clock-radio	DIANE BLACKWOOD of Vancouver, B.C.
	3rd prize, Stereo	MANFORD AMREN of Downey, CA

<u>Door Prizes:</u>	2 Diet cubes	CLAUDIA PAOLINI, CAROLE LABOSSIERE also of California
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The West Coast walked off with the prizes, even though we had good support for the raffle from all over the country. The raffle was a big success, due to many large purchasers and sellers of tickets and to the many others that felt it was worthwhile to lend their support. Over \$7,000 profit was made, enabling us to conduct a better meeting and to furnish copies of the conference to all. (Transcription will take time, but copies will be sent to attendees and supporters of the raffle as soon as they are available.)

Capsule Financial Report:

	<u>Income</u>	<u>Expenses</u>
Registration & Program	2,848.00	3,308.98
Youth Activity Program	795.00	1,504.45
Dinner	1,820.00	1,896.02
Donations	1,224.35	
Raffle	9,578.00	2,358.57
Estimated Additional Expenses*		3,550.00
Totals	16,265.35	12,618.02

*Anticipated expenses include reimbursement of expenses for some of the presentors, rebates to chapters for raffle sales, and the transcription, printing and postage of conference papers. If expenses do not run higher, we will have a credit balance for beginning next year's conference, for the first time!

NOTES FROM THE CONFERENCE (Cont.)Thank you Volunteers!

Volunteers enable us to run this type of conference on a small budget. Betty Shadell's volunteers who ran the Youth Activity Program, sold materials, set up equipment, handled registration; Laurie Stokely's volunteer presentors who paid their own expenses; the Taricas, who volunteered to do all of our CA printing without charge; and many, many more volunteers are responsible for our credit balance!

Board Election:

Proxy and attendee votes returned three incumbent board members for another three-year term on the Board: Lota Mitchell of PA, Gene Deterling of MN, and Fausta Deterling of MN. Two new members were elected: D.J. Miller of PA and Lee Forthman of IN. Bud Bush of CA will serve as an alternate. CUDOS TO ALL.

Roy Smith of CT volunteered to accept the office of Treasurer from Gene Deterling, who decided to retain his board seat and step down from his officer position.

Next Two Conferences:

The Board accepted the only two bids they received: 1984, bid by the MN Chapter and 1985, bid by the So. New England Chapter in CT.

Official Attendance:

Conference attendees: 166, Youth Activity Program: 51 young people with PWS, ranging in age from 2 to 31 years, and 9 PW siblings.

First Project for the Research Fund:

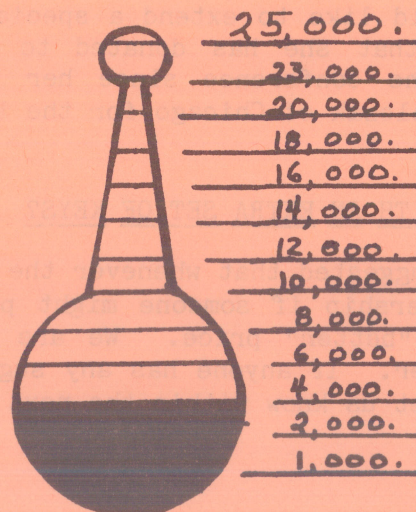
Subject to the approval of the Scientific Advisory Committee, the board approved awarding \$4,000 for seeding a psychological study on behavior of young people with PWS.

Many other good suggestions from members will be followed during the coming year. Thanks again to all, including those who attended, for another great conference!

MARGE A. WETT, EXECUTIVE DIRECTOR

RESEARCH FUND

May and June donations enabled our fund to grow by \$1,174, bringing the total to \$4,032. This growth is contributed to direct donations from the PWA-Minnesota and Midlantic chapters as well as generous donations by the following members: Rudin, Neason, Shadell and a relative of the Greens. The balance of contributions came from our loyal members that continue to support our efforts by their memorial contributions. Members Eager, Mitchell, Ingalls, Pearsall, Levine, Kavanaugh and Gretchen Korte's family were those who made donations. May we again thank all of them. As you will note in the conference notes, we are proposing our first project for this fund.



WE NEED A CHAMPION!

All of you can help with a campaign to get Richard Simmons to conduct his show at, or just to attend, our next conference. Following an appearance of a young man from Duluth, MN on his show a few months ago, we asked Richard to attend our San Diego meeting. The notice was short and made it very easy for him to decline. The suggestion was made in CA to make it harder for him to turn us down for next year. How can he possibly turn us down when we give him very ample time to plan and bombard him with letters of request from our membership? If he receives hundreds of letters with photos enclosed of our children, how can he help but consider our needs? So, take just a moment, sit down and write Richard Simmons a letter!

Dear Richard:

(First, tell him who you are--where you live--tell him that you and/or your child watch his show and how much you enjoy it and benefit from it.

Tell him more about your child:

...include before and after weight if your child has lost weight.


...give your child's weight and tell about his or her desperate need to lose, if such is the case.

...if your child is not overweight, tell him how hard it is to maintain control of his or her weight.

Tell him that your child has PWS and that you are a member of the PWSA. Tell him how terrific he is and how much your child needs his help.

Plead with him to attend our meeting in Minnesota next June.)

After allowing a month for you to write, the national office will again contact Simmons and ask him if he will agree to attend. This campaign will not work if you leave it to the "other person" to write the letter--you have to join us in our mass "attack"! Having Richard Simmons attend could mean terrific national exposure and publicity that we certainly need! DO IT TODAY!!!

The Richard Simmons Show
P.O. Box 5403
Beverly Hills, CA 90212

THANK YOU TO OUR RETIRING BOARD MEMBERS

PWSA would like to extend a special thank-you to Peggy Pipes of Seattle for the years of service that she has donated to the Board of Directors. We accepted her resignation before the conference since her three-year term was expiring. We also want to thank Andree Walczak of Chicago for the three-year term that she has just served.

ANYONE WITH AN EXTRA SET OF KEYS?

It was suggested that whenever the National Office needs some new equipment, we should ask the membership if someone might possibly be able to get a donation of that item, or at least a "better" price. We are currently in the market for a new electronic, memory typewriter. If anyone has any suggestions or offers of donating this piece of equipment, please let us know within the next couple of weeks.

AUGUST IS PWSA'S NATIONAL MEMBERSHIP MONTH!

Based on some terrific suggestions from our membership and the conference attendees, we have decided to make August PWSA membership month. The national PWSA is asking all of its members to make a special effort this month to recruit new members to our organization. We won't make the Guinness Book of World Records, but let's try to break all records for new members in one month! Just think, as Stewart Maurer, a board member, pointed out at the board meeting: "if each member took the responsibility of bringing in just one new member, a year from today we'd have 1800 members instead of 900, and the year following we'd reach 3600 members, which becomes a really meaningful number as far as getting research going and winning grants and services for our PW people!"

One of our Canadian members even suggested a clever way of getting that one new member: "if every family on the PWSA list were to ask their own relatives, brothers, sisters, aunts, uncles, parents, grandparents, to join the PWSA, it would rapidly increase the membership and at the same time, through....the GV, give a first-hand look at what we parents deal with every day to these people who care but don't have the necessary understanding of our problem. It might make them realize that our situations aren't unique, our children aren't just 'bad,' and that we need help and cooperation from our extended families in order to maintain the diet and behavior control our PW children need."

Other suggestions: Ask everyone you know in your area, or chapter, or parent support group who is interested in PWS, if they are members of the national organization. If they aren't, tell them what they're missing and urge them to join. Enlist your doctor, child's teacher, social worker, or other professional in our cause. If he or she has other clients with PWS whose parents are not members, describe how much needed support they would get if they joined. Ask your professional to mention the PWSA to other families or even suggest that your professional get a membership for him or herself to keep up to date on the latest research and techniques used with PW people.

Pulling together, we can make a meaningful increase in the ability of the PWSA to work for us and our PW persons. More members mean more services that we can develop and offer, more research that we can get going, more publicity that we can use to find other families with undiagnosed children who may desperately need our help. All we need is to get the ball rolling! Let's get the new memberships in by the end of August; we'll report in the September- October issue of the GV on how well you did!

CHARITY WEEK DONATION

They've done it again! Due mainly to a copy of the sibling book that we submitted to the student council of Edina High School, produced with funds they generously donated last year, the council elected to have us as one of the recipients of their charity week again this year. A very welcome check of \$1,500, raised by the student body, was received from them. Various projects will be funded with this donation, one being the completion of a video tape on group home living, including interviews with young people with the syndrome. Another project suggested at the last conference, and badly needed for some time, will be a formal slide presentation of our organization to be used for fund raising. THANK YOU to a great bunch of young people! (Have you, as members, approached this idea with the local high school in your area?)

RECIPES AND MEAL PLANS

Under 5-calorie per tablespoon salad dressings:

Yogurt-lime

Mix 2 tablespoons each lime juice and water with 1/8 teaspoon salt and a dash of white pepper. Add 1/4 cup plain low-fat yogurt and beat or shake in a tightly-covered jar until blended. Makes 1/2 cup.

Lemon/Mustard

Shake 2/3 cup water with 1/3 cup lemon juice, 1 T. prepared mustard, 1/4 teas. salt and 1/4 cup chopped green onion until well blended. Makes 1 cup.

Zesty Tomato

Shake 3/4 cup tomato juice with 1/4 cup wine vinegar, 2 teas. mixed Italian seasoning, 1 small clove garlic, minced, and 1/4 teas. salt until well blended. Makes 1 cup.

One tablespoon equals 3 to 4½ calories.

Menu Plans: 1,000-1,200 CALORIES**Day One:**Breakfast

Skinny shake

Lunch

Chicken Pita
(4-inch pocket bread;
3 thin slices chicken roll, 3 oz.;
1 cup shredded lettuce;
1 small tomato, chopped;
1/4 cup Yogurt-lime dressing)

1/2 Grapefruit

1 cup skim milk

Dinner

Broiled fish dinner
(4 oz turbot, flounder,
or sole fillets sprinkled with
paprika and lemon juice,
broiled)

2 small new potatoes, steamed

1/2 cup green peas

1 cup tossed greens with
low-cal dressing

a small apple

Day Two:Breakfast

Skinny Shake

Lunch

Hamburger on 1/2 bun

1 cup coleslaw

small orange

1 cup skim milk

Dinner

Poached chicken dinner
(4 oz skinned, boned chicken
breast poached with bay leaf
and peppercorns)

1/2 cup cooked rice

5 asparagus spears

1 cup pineapple chunks

GROUP COUNSELING WITH PW CLIENTS

The Woods School in PA has been providing group counseling for the past year for its PW clients, and Dr. Jeri J. Goldman, Chief Psychologist, sends us the following report of their progress.

"The group format arose from our awareness of the failure of many psychotherapeutic and behavioral interventions with PW clients. It represents an attempt at combining group process with increasing staff awareness of the difficulties in dealing with PW clients. Using the group format as a hub, extending it to inform and involve others, and placing the responsibility for cooperation directly on the PW clients appears to offer some promise as a form of treatment for PW people.

Our group has four PW participants, two males and two females, aged 18 to 19. All are mildly retarded (I.Q.'s of 50 to 70), and possess academic skills ranging from first to fourth grade levels. Their most severe academic deficiencies are in areas requiring comprehension of abstractions; these deficiencies have proven to be a clear issue in the clients' perceptions and behaviors. The four group participants have been in residence at The Woods School from two to four years, and all four present serious problems in social/behavioral adjustment. Participants are met at the door of the building by the therapist for each session and are escorted to the meeting room; they are not permitted to leave this room during the session. Group sessions are held weekly, with other meetings involving the PW clients, the dietician, and others who work with them. Written guidelines emerging from these meetings are handed out to all staff members who in some way come into contact with these residents.

The group meetings were clearly explained to the PW people at the start as working sessions that require their personal involvement and effort; the participants are required to exert themselves on their own behalf, helped by the staff, of course, but not simply relying on being 'managed.' Group sessions have focused mainly on sharing information about the syndrome, increasing appropriate social interaction and behavior, and beginning to formulate realistic future plans. Facing the reality of such PWS issues as retardation, academic deficiencies, sterility, lifelong dieting, and the need for continued supervision has been difficult for these clients, whose major psychological defense seems to be denial and its various expressions (i.e. lying, being argumentative and oppositional).

Sessions have been characterized from the beginning by shouting and screaming at each other over minor matters, constant interruptions in order to gain 'the floor,' extreme displays of wide-ranging emotions, and frequent ploys to leave the meeting room to roam the building unsupervised. The participants' limited reasoning abilities seem to be at the root of many of these explosions. (For example, one of the group members became irate that he had not received gravy on his meat, insisting that he had seen the word 'gravy' on his menu. What he had actually seen printed was 'no gravy.') If the entire group becomes so loud that it disrupts other people in the building, it is recorded on tape, and the playing of the recording to the group usually results in an immediate decrease in volume of the participants' voices. If a single participant becomes totally disruptive, he or she must leave the group and spend the remainder of the meeting under the supervision of a back-up psychologist who simply 'babysits,' providing no social interaction. This method seems to be effective, as one client remarked, 'I guess you noticed that my behavior is better after I got put out of the group the last time.'

GROUP COUNSELING (Cont.)

Such improvement is indeed noticed and praised by both the therapist and the other members of the group. The consistent structuring, clear limits, and repeated explanations to the participants within the supportive setting of the group seem to be having a beneficial effect. They have come to rely on the word of the dietician as to what is 'o.k.' for them to eat, and they now simply ask their therapist to refer to the dietician for answers to subsequent questions and complaints. They have accepted the facts about PWS given them by a parent active in the PWSA as authoritative, with a noticeable reduction in denial. As far as increased realism in their future planning is concerned, the group has come from an early angry insistence that they were going to become nurses and policemen to volunteering more appropriate potential occupations such as sheltered workshop worker, nurse's aide, and housekeeping or grounds maintenance workers. (However, all still cling to the hope of becoming food service workers!) The participants also seem to appreciate the fact that they are given personal copies of their diet each week, and the suggestion that they consult their 'official' printed menus before they decide that they have been cheated and turn on the 'offending' staff member seems to have aided in reducing their explosiveness at meal times.

Our PW residents continue to display predictable PW behaviors, but at an observably diminished rate, a result of the combined efforts of all of our staff. Without such a firm but benign structure as group counseling, the full repertoire of PW behaviors would probably be displayed regularly. With this structure, however, we have clearly seen improvements in our PW's behavior."

(Ed. note: Any members with questions or seeking additional information about the group counseling at The Woods School may contact Dr. Goldman at The Woods School, Langhorne, PA 19047.)

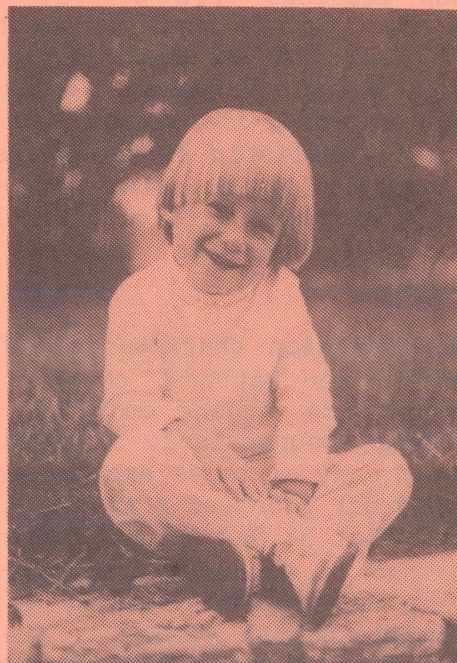
SMILE!

This cute little pixie is Kelly, whose mother writes us the following:

"I . . . would like to take a moment to thank the PWSA. I look forward to reading your newsletter. My Kelly is three, she was diagnosed at 2 by Dr. Bryan Hall, to whom I am greatly thankful. It was hard going two years without knowing, so my sympathy goes out to parents who were fighting in the dark.

I am so proud of Kelly. She gives me so much love which is what keeps me going.

Also, I would like to add that I am a member of the PW KY Asso. Before the first meeting I had never talked or met with a PW parent. It was a very rewarding experience."

ANOTHER VOLUNTEER AWARDED!

Charles J. Miller, a PWSA member, was also recently awarded the Volunteer of the year award for the state of Missouri. The reward was presented to Mr. Miller for his volunteer work with the handicapped as the founder and president of Wonderland Camp from 1970 through 1983. Congratulations!

NUTRITION AND OUR BASIC NEEDS--Part Three

Part two of this article on basic nutrition discussed water, protein, fats, carbohydrates, vitamins, minerals, and fiber. These are the main classes of basic nutrients essential to our health. By following the guidelines given in that article, you can assure an adequate amount of each of these important nutrients in your diet.

To conclude this basic nutritional study, here are some facts designed to dispel some common myths about foods and to discuss a couple of controversies surrounding your diet and the food you should eat. We will also include a few tips about PW persons' habits.

Many people are confused about calorie values, and there are many myths that prevail. Many widely-held beliefs about low-calorie foods or foods that are "better" for you are actually not true, for example:

Grapefruit does not burn up fat.

Large consumptions of fruits and fruit juices do add calories, and can add fat. Margarine does not have fewer calories than butter.

Substituting honey for sugar is not a good idea; despite what some may say, honey is not healthier than sugar, and an overusage of it is not good.

It is not true that certain vegetable oils, made from particular vegetables, have fewer calories than other vegetable oils.

You can not eat all the steak you want just because it is a "diet" food.

Potatoes and bread are not high in calories, only the butter or sour cream you add to them makes them fattening. Potatoes and bread are actually very good nutritious sources of many essential nutrients.

The term "dietetic" does not mean that a product is low in calories, only low in certain types of sugar.

"Natural foods" can contribute to obesity just like "refined foods" do, in some cases, they are even higher in calories than the "refined."

An area of controversy in discussing the diet is food additives such as preservatives, artificial colors or flavors, etc. The US government is trying to formulate a policy on food additives that protect the consumer while not interfering with individual choice. Dr. Feingold is probably the name that most people recognize for his work with food additives and hyperactive children. Controlled studies have shown improvement in behavior in some children, but not in all, and rarely did all observers agree that improvement had, in fact, taken place. There is very limited scientific support for Feingold's hypothesis, but many parents swear that avoiding food additives has helped their children's behavior. Dr. Sulzbacher, a member of PWSA, has done studies on the effect of sugar intake on a small number of children with PWS, but did not confirm that sugar affects their behavior.

As said in part one of this series, Alcohol should not be given to young people with PWS, among other things, it can stimulate the appetite. The same caution applies to smoking. Not only is it bad for one's health, but it can become a very ingrained habit for those with PWS. Some young people have been started on smoking with the old excuse, "it may help to control their appetite." Please don't let anyone convince you of this idea.

Because of their restricted diet, good nutrition is extremely important for a PW person. A lot of attention should be paid to it, and nothing beats the advice of a good nutritionist who is familiar with PWS. Your local state health department or state university can usually give you a good recommendation of who you could speak to if you wish to consult a nutritionist about your PW's diet.

CLINIC SERVICES DIRECTORY UPDATE

In 1981, our Clinic Services Committee compiled a directory of those professionals that we are aware of who work with PWS. Since many changes have taken place since that time, we would now like to reprint and update this directory. We would appreciate it very much, then, if our members would advise us if they are professionals who would like their name included, or if they know of any names and addresses of professionals working with their children. This directory is not useful, though, unless we have complete addresses. We would particularly like to expand the Australian and Canadian listings, and add England to our directory. When parents first have a diagnosis of PW, it is very helpful to have someone to turn to--please share this information with us. Please fill out the information form enclosed in this issue of the GV and mail it to us at the national address.

WELCOME NUMBER NINE!

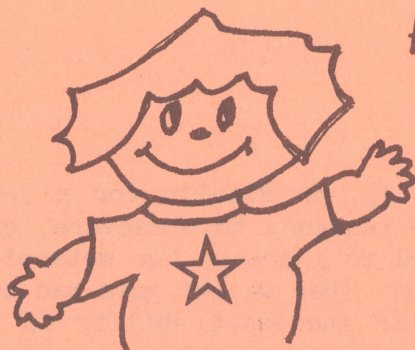
Our ninth and newest chapter, the PW Tri-state Assn, is now in full swing in OH, WV, and Western PA. Of particular interest to the members of this group are their goals of action, group homes, information and support. Their officers are: President, Pamela J. Vogt, OH; Vice President, Pat Testa, OH; Recording Secretary, Lynda Elam, OH; Corresponding Secretary, Kathy McGall, PA; and Treasurer, Tom Guisti, OH. Welcome to the Association!

LOW-CAL SWEETENER

One of our members had a company send us some samples containing the new sweetener, "Nutra-Sweet," which contains no saccharin or sucrose. The samples included the new sweetener, sugar substitute, "Equal," which has four calories per gram, along with Alba '77 "Fit 'n Frosty," a dairy drink with 70 calories per serving, Sugar-free "Kool-aid," and sugar-free gumballs. They also mentioned a new product with 70 calories per serving named "Shapely Shake." We are mentioning these products in case you may not have noticed them on your grocery shelves and may want to give them a try.

ACCURACY IS VERY IMPORTANT!

A chapter president suggested, "use the national office as a clearing house BEFORE doing any mailings on the PWS." A recent mailing, not put out by us, contained the statement that PWS was caused by a chromosome defect. A geneticist at the conference corrected that statement by saying, "If I convince all of you in this room that the defect in chromosome 15 does not cause the PWS, then I think I'll be happy." We heartily agree with him, so please check with us before doing any mailings. Erroneous statements such as this, can put all information in jeopardy. If we don't have the answers ourselves, we have many experts who can verify any controversial information.



Hi!

PRADER-WILLI AND YOU

by

Patricia J. Duno
Ann M. During
Janet M. Jeffers

Meet Jamie, a young PW person learning how to cope with the problems inherent in having Prader-Willi Syndrome. Through this colorful, positive book, directed at the person with PWS, Jamie helps the reader understand that having PWS means having to learn special things about feelings, activities, and diet.

This is an excellent learning and activity book for PW persons, who are encouraged to participate by coloring-in pictures, writing down ideas, and using food tickets to help control their diets. It's also a learning experience for PW parents or guardians, who, along with their children, learn how to restrict a diet to 800 or 1050 calories a day, how to lower the calories in food that they prepare, and how to encourage appropriate behavior in their PW persons.

The book includes complete instructions for a restricted, well-balanced diet, including food tickets that can be cut out and used by the PW person each day. In addition, there are low-calorie recipes and lists of the proper amounts of foods that should be eaten from each of the main food groups: milk, bread, fruit, vegetables, meat and fat. Also included are exercises and activities, a reward system for good behavior, and hints on helping PW persons boost their self-esteem by accepting themselves and their problems.

Prader-Willi and You is an invaluable resource for everyone involved with the syndrome, and a must reading for PW people of all ages. We're offering this book to the membership for \$5.50 per copy for US orders, \$6.50 for Canadian, and \$10.50 for shipment overseas. These prices include printing and mailing costs.

For your convenience, we have included an order form below:

Please send me _____ copies of "Prader-Willi and You" at \$5.50 (\$6.50, \$10.50 ea.)

NAME _____

ADDRESS _____

Zip _____

Check payable to: PWSA

Mail order to PWSA

5515 Malibu Drive

Edina, MN 55436

ON USING RITALIN

From a concerned parent member:

"I just wanted to tell you that we had our PW child, age 7½, on Ritalin for a 3-week period. It seemed to increase her picking behavior and her tendency to persevere, especially when she would be in a bad mood! At first it seemed to increase her metabolism, but during the last week while taking it, she gained 2 pounds! (Her weight gain had never been this great at one time--part of this may be due to her increased ability to find creative ways of sneaking food--food security is now much tighter.) After speaking to her class teacher and speech therapist, we determined that she was getting no real educational value from the drug, so it was stopped.

After stopping the drug, I can get her out of the bad moods and tantrums much faster, and she has lost ½ lb. after 3 weeks. I wanted to share this information with others who may be considering using Ritalin."

Ed. note: Ritalin is a medication usually used to calm down hyperactive children.

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.

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