



THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT
MARGE A. WETT, EXEC.DIRECTOR

5515 Mallibu Drive
Edina, MN 55438
(612) 933-0113

VOLUME XI

MAY-JUNE, 1985

NUMBER 3

PRESIDENT'S MESSAGE

Can it possibly be true that another year has passed since we met in Minneapolis for the Sixth National Conference on Prader-Willi syndrome? Like others, who have attended conferences in the past, I look forward to the third weekend in June each year for the opportunity to meet with those who share the life of Prader-Willi syndrome. In a life problem, where many things are the same, it is good to have the opportunity to talk with old friends and new acquaintances about ways of change or improvements. It is a part of any life to seek security in the known and established, those things that we are familiar with and accustomed to. Security is essential to a sense of well being. The existence of the PWSA office in Edina, MN gives us a sense of security just as the recurrence of the annual conference lets us know that "our" organization is well and alive and there to help us solve some of our problems in living Prader-Willi syndrome.

There are other ways of achieving a sense of well being. One of the most potent is the recognition of a problem that creates in us a responsibility that we then fulfill. As one who live with Prader-Willi syndrome each of us can easily identify a wide range of problems peculiar to our way of life. Each of us also has met the challenge of these problems in a manner that will be unique to our individual lives and situations. The types of problems can be grouped into classes that help us sort them out for a solution. Some of these classes form the basis for the discussions that will be held at the conference in Connecticut. The only way your Prader-Willi problem's unique solution can help others is by sharing it in the discussions and Task Force meetings. Your solution to a problem makes you the expert--the kind of expert that may just be what a person with Prader-Willi may need. Read the program and put together your thoughts and questions and solutions, and bring your expert opinion to the annual conference.

The annual business meeting of your association is also held at the conference. It is the task of the Board of Directors to meet and carry on the business of the organization. This meeting is open to the membership as observers. It is an opportunity to become aware of the problems and solutions as well as providing opinion that can help the Board in its awareness and decisions. New members are elected to the Board each year. If your area wishes a stronger voice in how the PWSA carries out its function, you and your area members should come prepared to nominate and support a candidate. This is a sincere and strongly felt request. Only with the infusion of new ideas and persons willing to work for the benefit of the PWSA can we continue to function in support of persons with Prader-Willi. The only requirement of a candidate is membership in the association and ability to attend the meetings of the Board.

PRES.MESSAGE CONT.

Help yourself to be secure, support the PWSA Annual Conference. Make your plans to be there. Think about the Prader-Willi problems you have solved or for which you continue to seek solutions. Contact others in your area and organize for representation with a nominee to the Board. SEE YOU IN JUNE!

Delfin J. Beltran, M. D. President

Invite your doctor!

Dr. Cassidy obtained CME (20 hrs.) for physicians for our conference

DOLLARS AND SENSE

"My major reason for writing has to do with sharing thoughts from Holly's experience on how inappropriate treatment of PW persons can cost MORE in measurable dollars and cents than appropriate treatment would have cost. As legislators and insurance companies are often more concerned with cost-benefit ratios than human misery, I'll share my experience only from a cost viewpoint but must first say that the misery of many persons lives and most especially Holly's would have been avoided with appropriate care.

While living in VT and Holly attending Spec. Ed. Elem.Sch., she was diagnosed as PWS and also as having a scoliosis condition...(The mother continues to describe the difficulties of wearing a brace while obese, how doctors continued to watch the scoliosis but ignored the obesity) At age 18, the curve had increased to a point of requiring spinal fusion surgery. Holly was less than 5 ft. and 170 lbs. going into surgery. The Doctors knew they would have to do the highly unusual treatment of having her in a complete body cast for at least 3 mos. after surgery due to her obese condition. All other children were put in walking casts and could easily return home shortly after surgery because their bodies were not like bowls of jelly requiring a full body cast in order to keep the spine rigid. (The hospital) tried to have us take Holly home, (they didn't like the bed being tied up) but that was impossible as it took 4 people to turn Holly in the body cast and turning was essential for her health and skin etc. My excellent insurance would pay for no other type of care so at enormous rates she stayed. During this time period my job moved, so at great cost she was air-ambulated to our new location where she was cared for for over 2 mos.

While in this body cast she was weighed on a sling arrangement and thus the doctors believed the PW persons require fewer calories than normal just to maintain weight. After 4 mos. the bone had fused enough that she could be put in a walking cast and allowed to return home. Insurance ended up paying for 4 mos. of highly skilled hospital care rather than less than 2 wks. if her condition had not been obese." (The mother compares what a good PW group home costs would have been to what the actual costs amounted to. She also questions necessary psychiatric costs opposed to a good placement, and lastly talks about children even being able to stay in their own homes with services enabling the family to lead a more normal existence as opposed to outside placement.) Parents are very aware of these situations, how can we make the system aware and adaptable?

BOARD MEMBERS

Each year three board member's terms expire and they are given the opportunity to run again for their position. This year board members Cellie Ledoux, Dorothy Thompson and Stewart Maurer's terms will expire. Also Ted Briggs was appointed mid-year to fill a board vacancy. Dorothy, Stew and Ted have informed PWSA that they would be very happy to remain as board members if the membership so desires. The election is held yearly during the conference, where members have an opportunity to nominate other members for these posts and cast their votes for the four board positions. (A proxy will be included in this issue for those wishing to designate a representative if a member cannot be there in person to vote.)

Cellie Ledoux has decided not to seek a fourth term as a board member. When asked, Cellie responded that she "feels that there are others who should have an opportunity to serve on the board and would like to leave the position open to give someone else this chance." She also wrote: "Since being elected onto the Board of Directors in 1973 at the first PWSA National Conference, I feel that my accomplishments have been numerous and very beneficial to the people with PWS in Connecticut and to their families and parents and would like to list them at this time in order to inform others what can be done.

1 - Through public relations, word of mouth and articles in the newspapers, more persons with PWS and their families have been located throughout CT and the Northeast.

2 - Helped to organize and "Host" the 2nd Annual Conference held in Hyannis, MA. During which time I called a meeting of all of the East Coast people to encourage them to formulate regional groups (chapters) and establish parent support groups.

3 - Established the So.N.E. Parent Support Group (1982) which became the very 1st official Chapter to the National PWSA.

4 - PWS Clinic-Encouraged and supported the efforts to establish the PWS Clinic at the Univ. of CT Health Ctr. in Farmington, CT directed by Dr. Suzanne Cassidy who is also our physician advisor to the Parent Support Group.

5 - Group Home for PWS Persons-Very instrumental through personal contacts in establishing the 1st PWS Group Home in CT. Opened in April, 1984 for six PWS residents. Presently, work is being done towards establishing a 2nd group home."

Cellie concluded with: "It has been an honor to serve on the PWSA Board of Directors for the past six years and it goes without saying that I will certainly continue to working to the best of my ability for the behalf of the people with PWS and their families."

Anyone who has had the privilege of knowing and working with Cellie realizes her shoes on the board are going to be hard to fill. We sincerely thank her for all she has done and will continue to do as an "active" member of the PWSA family.



7th ANNUAL NATIONAL CONFERENCE, COMING SOON, JUNE 20, 21, 22

Conference registrations are coming in every day now and we look forward to seeing a lot of old friends and meeting new ones as we do each year. Our first overseas registration was received the other day, a new member family from Norway will be attending. We are pleased they are able to join us and hope others will too. We thank our Canadian friends for mailing in their registration checks in U.S. funds--glad they are smarter than we are because we neglected to put that on the registration form, and of course our prices aren't padded enough to cover that 25% currency devaluation.

Help us out--get your reservations in now. It makes our job a lot easier. See you in Windsor Locks, CT in June.



SUCCESSFUL PLACEMENT

"I wish to let you know that my daughter Donna, age 22, attends the Wiser Institute in Seattle, WA. and they have an excellent program for PW persons. My daughter weighs 105 lbs. and is in excellent health."

"Here is a picture of Donna and me (I am the one who has to lose weight)."

TRAVELING

For some members who do not fly frequently, there are a lot of "good deals" around right now in airfares. Be sure to shop around when making your conference reservations. (Some of the new ultra super saver rates require that tickets are purchased at least one month in advance--check now before its too late.)

When traveling by car, here are a few tips:

Leave before dawn. Take children directly from their beds to the car. Then they can sleep for a few hours at the beginning of the trip.

Secure any child up to 60# in a child safety seat. When traveling with more than one child, give them each their own space. Use a soft suitcase as the divider so they can claim their own side.

Keep toys in the trunk, and bring out new ones each time you stop. Rotate stock so there is always something new going on.

Make a list of games and songs before you go so you have more of a chance to think of them.

Let your child know that driving is serious and that "quiet" helps.

Bring along a supply of nutritious snacks that can be substituted for restaurant treats and desserts.

Let the children dress comfortably, far more important than the Easter finery look.

With a little preplanning, some patience and a sense of humor all of you will enjoy the trip .

CONGRATULATIONS

We welcome Flo Gunnison as the new President of the Prader-Willi Colorado Association and Jerry Evetts as the new President of the PWS Missouri Association.

Groups in the State of Utah and the State of Montana are also going great guns to get chapters organized in their areas.

PUBLICITY AND FUND RAISING

In recent months the PWSA National office has made the following attempts for more publicity and efforts in fund raising:

LETTER TO ANN LANDERS (in answer to reader who stated he was sick of organizations trying to make money by door-to-door selling.)

SUBMITTED AN ARTICLE TO Redbook, Good Housekeeping and Woman's Day magazines.

LETTER TO MPLS. STAR COLUMNIST (asking for assistance in funding).

SUBMITTED ABSTRACT TO NATIONAL ORGANIZATION FOR RARE DISORDERS. (This was accepted and we will be making a presentation at their May meeting.)

OFFERED TO JOIN PANEL AT AAMD MEETING. (We will actually have two time slots at this meeting, end of May in Philadelphia).

WROTE (AGAIN) to the Donahue Show, 20/20, Nightline and Today Show, asking for their investigation into our needs.

GAVE PERMISSION TO EXCEPTIONAL PARENT magazine to run an article about our sibling book.

FURNISHED INFORMATION to a staff writer for The Sacramento Bee (CA).

SUBMITTED AT LEAST A COUPLE OF DOZEN MORE FOUNDATION PROPOSALS.

We fully realize that most of our members cannot do all of the things listed above, but what did you do this past month??? One office making attempts is very small compared to what 800 parents could do if they really want to get involved. One way we did offer in the last GV was to sell tickets/pens to support our raffle. This not only raises money but it too promotes publicity. Thus far we have received orders from exactly 32 individuals and 4 chapters. These tickets would net us a profit of approximately \$1500. (Last year our profit was approximately \$6000.)

We are going to ask the membership to "Get Involved" with two suggestions. (We are sure that you can come up with other ways too.) ONE: Write to 20/20 stating you feel a segment on our syndrome would interest their viewers. Our one letter can be ignored easily, it is harder to ignore if they were to receive hundreds of letters. Their address is:

AV WESTIN, EXECUTIVE PRODUCER, 20/20
ABC, 7 W. 66th Street
New York, NY 10013

TWO: Support our fund raising raffle. Even if you only can sell a few or just buy a couple for yourselves, when 1000 people respond instead of 32, it does make a difference.

ANNUAL MONEY RAISER ORDER FORM:

Please send _____ tickets and pens, which will be bought or sold for \$3.00 per set, or 2 for \$5.00.

NAME _____ ADDRESS _____

If these are for personal use let us know, we can fill in _____ the chances for you and save mailing. Also, please advise if you do not want the pens.

ADDITIONAL RESPONSES TO THE LAST ISSUE

"In response to your query about musical ability we would like to mention that our daughter, Patricia, has taken piano lessons, first, at age about 15, for 4-5 yrs. and then again about 6 months ago. She seems to derive a great deal of satisfaction from them. She practices every day and plays them quite well much of the time although her performance is somewhat variable and she has trouble with timing the notes (she is reluctant to count out loud, which her teacher is quite anxious for her to do). She plays melody only at this time alternating her two hands as the lessons require. It seems to me that in her previous lessons she played melody and simple accompaniment both."

"In response to the item from an English member who finds her child displays totally different behavior at school, I would like to share the same experience. We were not aware of PWS until our son was 14 so bear in mind that we were 'in the dark' during those years. Until he began school we had virtually no problems. He was happy, pleasant, engaging, friendly, you-name-it.

Negative behavior appeared almost overnight and is still with us in varying degrees. He can be extremely abusive towards teachers or school staff, bus drivers, etc. Tantrums are reserved almost exclusively for school. Over the years, this has caused more than a few raised eyebrows on occasions when we have been called in to bring him home. Social workers involved would then suggest a meeting at our home on the pretext that it would be more convenient for us when the real reason was that they were highly curious about what type of home produced this 'little monster'.

We have not been able to reach a final answer for this behavior although we do have a few theories. He has always resented having to answer to more than one authority figure and usually became quite difficult with all but the chosen one. Of course any one of them could be his instant friend by giving him free reign. Perhaps the most logical explanation is that he is reacting to our 'strictness' at home and with that in mind we have tried on numerous occasions to 'let up' only to have him take extreme advantage of the situation and force us to revert to the original.

Despite being told many times of his bad behavior at school during these many years, there is still occasions when we are mildly shocked when we are told about a new incident. Not because we do not want to believe the teacher but perhaps because he left home in such a sunny mood and by the time he had been in school for five minutes - all hell had broke loose! We have spent time beyond reason trying to discover what triggers black from white but it escapes us. On a positive note, either he is improving or we are becoming immune but we are having longer truces. The only thing which we know for sure will help is to find the right teacher - no sweat!"

Another parent wrote that she "cut the cord" gradually by being a part of the preschool class and lessened her involvement time slowly. The child was greeted by the teacher with hugs and cuddling to make them feel more welcome. The parent started the exercise and then was joined by the staff member. Later she remained near, where her son could see or hear her, but was not his helper. She wrote, "Although it took some time to accomplish his total separation (from home to school), and obtain his cooperation, it was possible."

Another member (with PW) wrote: "In response to the article 'Need for Services' I can easily see myself in somewhat those pathetic circumstances. Although I lived independently, a lot of my upsets were caused by my own emotions. Right now I'm told I have to get to a certain weight before I ever get out again. My flights have always been to come home again. Eventually I might go and never come back. My

RESPONSES (CONT.)

sister used to live at home and now she doesn't. Unless I develop myself at home with my parents then home life will deteriorate for me. Sometimes I do things at irritate out of being sullen, angry and moody. Sometimes it feels like I retaliate for acting the way I do as far as cleaning my room goes. During gatherings is when I become disruptive. Thanks for letting me share.

Another mother said, "You can imagine how popular our twenty year old daughter was one evening when her father gave her an order and she responded, Mom is my boss, not you, I only have to do what she tells me."

"I have learned of an interesting way in which knowledge about M.R. (including PWS) can be effectively disseminated to professionals in a class at Stanford University, which has been taught the past seven years." The member described the program where the class was required to volunteer a specified number of hours per week at the pool helping disabled persons and also the parents shared information with the class. Many of these students are in pre-med and related fields. Why not check with your local colleges and ask if they have similiar classes and if they know about PWS?

GOOD NEWS

Sometimes we mention problems but our readers never hear the endings. We would like to share that a couple of our very heavy people are on their way to losing some weight, and a great deal of it is do to a walking fitness program. One school that was harassing a family has read some of our materials and is at least starting to accept the problem that faces this family. The charges have been dropped against another family (this is the situation where the girl filed abuse charges against family members and she was forcibly removed from her home), when the girl decided to admit the stories she had told were not true. Progress is also being made in several states that are working on opening suitable group homes.

One recent article stated you can walk your way to fitness and listed several facts about walking as an exercise. 1) if done briskly enough and long enough, it can be just as good as jogging. 2) can fit into normal living patterns without special equipment or clothing. 3) less stressful on muscles and joints. 4) provides cardiovascular endurance, weight control, reduction of emotional stress, increases lung action, stimulates circulation, activates many large muscle groups -- and burns calories. (Walking burns calories just as surely as running--it just takes a little longer, a fast-paced $\frac{1}{2}$ hr. walk can burn 200 calories.) They also recommend starting slow and easy, then gradually increase the distance. It works with our kids!!! We do have good reports.

OUT OF PRINT

Unfortunately when publishers do books on PWS the limited sales do not encourage them to stock the books forever. (The fortunate part is that they reach a much greater market than we can.) Our "Prader-Willi Syndrome by Suzanne Cassidy, M.D." published by Year Book was discontinued by them. They did (for a price of course) allow us to republish this overview, so we do have them in stock. We were just notified by University Park Press that "Prader-Willi Syndrome by Vanja Holm, M.D. et al." is now out-of-print. Being a regular hardcover book we do not know what arrangements can be made for duplications or whether they will allow it anyway, but we are investigating the possibility. In the meantime, we are sorry we no longer have any stock of this book for sale. We do have a few copies in our library that can be borrowed.

MISSOURI COUNCIL LOOKS AT NEEDS OF PERSONS WITH PW

With support of an ad hoc committee of the MO Planning Council for D.D., a group of parents with children with PWS have begun work to establish specialized services for such Missourians.

Chaired by Edward Newsome of Kansas City, the MO Planning Council Committee convened a meeting of parents in Jefferson City in March. The committee and parents met then with Dorothy Thompson, a MN consultant on the syndrome. Thompson discussed operation of Oakwood Residence, a facility now in its 3rd year, which houses 15 residents. (Three representatives of this committee also made a trip to MN, visiting Oakwood and the National office.)

Spurred by Helen and Cecil Sagaser, the MO council conducted a discussion on PWS in January. In February, Donald Killian, D.D.S., council chairman, asked Newsome to chair a special commission to investigate the establishment of specialized residential facilities within the state. Other members of the committee are Graham Williams, St. Dept. of Education, and Carl Calkins, Ph.D.

During the two day meeting tentative plans were made to work toward the establishment of one or two residential facilities, probably located in the Kansas City and St. Louis areas. Mr & Mrs Charles Spears, Kansas City, are leading efforts for a home in that area and Janalee and Al Heinemann are spearheading the St. Louis home.

The current effort to assess the need for such facilities is the first step toward eventual services. Newsome said he also encouraged regional D.D. councils to assist in that effort. Support for establishment of such service has also been expressed by Paul Ahr, Ph.D., M.P.A., Dept. of M.H. Division and John Solomon, acting director of the Div. of M.R.-D.D.

NEW SNACK IDEA

Raw rutabaga, a variety of turnip, is a low-calorie snack. A $\frac{1}{2}$ cup provides 30 calories, as well as some B and A vitamins. It would also contain about $\frac{1}{2}$ of the adult RDA for vitamin C, and is a good source of potassium. Cooking and mashing would increase the calories only 10 if you do not add margarine. Cooking decreases the vitamins but the density evens this out so you would end up with the same vitamin content.

GRAPEFRUIT PILLS ARE BACK

The grapefruit diet, like short skirts, goes in and out of fashion. Its back with a claim that you can eat as much as you want and still lose weight--simply follow their plan and take their pills. One TV ad gives you 45 pills (which is a 15-day supply) for only \$19.95. There is no evidence that shows grapefruit or grapefruit pills can help you lose weight, but the accompanying diet of 800 calories does make the difference.

FOUNTAIN PEN PROFITS -- those old fountain pens in your desk drawer you haven't used since ball points became popular can be turned into cash for PWSA. Member Jud Bell collects undamaged fountain pens with 14K points and will pay PWSA for each one sent to him. Parkers, Sheaffers, Watermans, Conklin, Swans, and other quality pens before 1950 bring \$1 to \$20 depending on condition and model. You feed his hobby and he feeds our kitty. Send them to: Judson H. Bell, Catamaran 2231, 2400 S. Ocean Dr., Ft. Pierce, FL 33439.

A letter to other P-W parents:

My daughter, Caryn, is an 8½ yr. old PW child. At birth, our pediatrician noticed that she was hypotonic, and referred her to a neonatologist, who sent us to Children's Hospital of Philadelphia. The Neurology dept. there put Caryn through a series of tests to attempt a diagnosis. I know that many other PW parents have had the same problem of diagnosis. After 5 yrs. of waiting for the chief of Neurology to make a firm diagnosis, I gave up. A physician friend of mine suggested NIH in Bethesda, MD. We were told that a Dr. at NIH was in the middle of a study of PW, and that he would evaluate Caryn for acceptance into his program. He studied her case history and confirmed the diagnosis of PW immediately. Once accepted in the PW study, Caryn went to NIH for 2 wks. for evaluation and a diet. She started off on a 300 cal/day diet to reduce from 45 lbs. to 34 lbs. She is now on a maintenance diet of 800 cal/day.

Before being diagnosed, we had no knowledge of PW or its related problems, but we could see an impending weight problem. We asked our pediatrician about diet control, and he said that she was not really obese but if we wanted we could mildly restrict her calorie intake. We also noticed her raiding the kitchen, and put up a gate to restrict access to the kitchen area. At no time did we allow Caryn's weight to exceed the top 10th %tile for her height (according to standard charts).

I can't say it's an easy job (especially on my wife's part) but at age 8½ she is 45" tall and weighs 40 lbs. We have developed cooperation with our local school and Caryn's eating is monitored by the teachers, she eats lunch with them instead of with the other kids. We also have recently installed an electronic alarm in the kitchen to prevent raids.

We have found that as long as Caryn stays on her diet, her temperament is better and she is less lethargic. We can even tell if she has been sneaking food because there is a sudden and dramatic change in her personality, she becomes temperamental and lethargic. I think that PWSA should have a much stronger emphasis on strict diet control. I have personally seen how important this is. While at NIH this month we met another PW child. Last year he was 14 yrs. old and weighed 225 lbs. and was on the verge of death. After his diet at NIH, he is down to 100 lbs. with a good prognosis, and a totally different personality, according to his mother.

After reading the April issue of the GV., I can't help but think that the worst enemies that a PW child can have are parents who think that if they ignore their child's problem it will go away, or worse, accept that a problem exists but are afraid that their child will be "labeled" and put off getting needed help at school. I would rather have my daughter "labeled" and getting the help she needs at school and in trim condition, than dead of gross obesity or fighting a losing battle to keep up at school.

In response to your "get involved" letter, I am writing this letter, and making plans to attend either the regional or national conference. Please send me 100 raffle tickets/pens combinations for us to sell to help with the conference. In closing, I feel definitely that the major goal for PWSA has to be educating physicians to enable early detection and diagnosis. A PWSA MEMBER

* PARENTS OF YOUNGER CHILDREN *

Do you have some information that you would like to see included in our proposed booklet regarding PWS? We would appreciate ideas from parents whose children are under school age, or have just gone through this stage. What you share will help others. Thank you.

LENTIL OATMEAL LOAF

2 c. cooked lentils	1 egg, beaten	Combine lentils, rice, carrot, onion, garlic and oats. Add egg, oil, paste, seasonings. Mix until well blended. Spoon into a greased loaf pan. Bake 350° for 45 mins. 8 servings. Each serving has 1 bread, vegetable and fat exchange, and 157 calories.
2 c. cooked brown rice	2 T. peanut oil	
1 carrot, grated	3 T. tomato paste	
1 onion & 1 garlic, diced	$\frac{1}{2}$ t. salt, $\frac{1}{4}$ t. pepper	
$\frac{1}{2}$ c. rolled oats	$\frac{1}{4}$ t. dried sage	

EXPERT CHALLENGES WEIGHT PROGRAM'S MERITS

Herbert Blonz, Ph.D., a nutrition specialist from the Univ. of MN, made several statements regarding the use of the Herbalife plan for weight loss. Further investigation has been going on regarding the sales practices. Perry Turner, chief legal counsel at the Herbalife headquarters answered some of the charges.

BLONZ: The regime uses caffeine pills, laxatives and a long list of unproven ingredients. It can cause diarrhea, interfere with medications and costs about \$30. a month. There are many reports of diarrhea, cramps and other forms of discomfort. The vitamin B6 content is 75 times greater than the generally recommended daily level.

TURNER: We use only very safe, high quality nutritional products. Complications are "fairly rare" and are the type some people suffer whenever they make a major change in what they eat. The caffeine is less than in a cup of coffee.

BLONZ: Because of the lack of scientific studies with the diet, there is concern about potential--although not yet known--health problems from long-term use. There is no direct control over what the distributors--who sometimes call themselves counselors--can say, and they seldom have the nutritional training needed to recognize potential problems.

TURNER: We've been in business for five years now which is ample time to show safety. The labeling on the products provide ample instructions.

BLONZ: The quick weight loss often reported with this diet can be deceptive because they are probably due to the temporary loss of body water as opposed to any loss of body fat. Most people regain weight because this diet doesn't emphasize a change in eating patterns.

TURNER: People continue taking the product, and this keeps their weight off.

We know of one girl with PW who gained a tremendous amount of weight by using this "diet". Her "counselor" told her to use the powder twice a day and "pig out" and eat whatever she wanted at her third meal. Needless to say, the meal contained over 4000 calories very frequently. Our association cannot recommend any of these "quick weight loss" plans for a lifetime problem.

A NOTE FROM A STUDENT

I again want to thank you for your help in sending information on PWS. I not only gained more information but also an understanding that these kids are very special and my love for my niece is even greater than before.

✓ REMINDER

A member asked us to remind members in the service that they can signify their Combined Funds to be donated to the PWSA. Pledges will be made in June.

PROXY BALLOT

In compliance with the by-laws 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 four directors

You may designate your proxy to vote as you direct.

This proxy form must be received by PWSA not later than June 1st.

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, M.D.; MN _____
- Fausta Deterling; MN _____
- Vanja Holm, M.D.; WA _____
- Claire Ledoux; CT _____
- Dorothy Thompson; MN _____
- Gene Deterling; MN _____
- Lota Mitchell, M.S.W.; PA _____
- Stewart Maurer; GA _____
- D. J. Miller; PA _____
- Lee Forthman; VA _____
- Suzanne Cassidy, M.D.; CT _____
- Ted Briggs; TX _____

- Officers: Delfin J. Beltran, M.D.; CA _____
- Shirley Neason; WA _____
- Roy L. Smith; CT _____

Director Marge A. Wett; MN _____

OR Your designated representative (Name) _____

Your signature(s)

Date

(Proxy can be used by more than one member, in the case of two parents, but may make only one designation for each organization.)

Mail to: PWSA 5515 Malibu Drive, Edina, MN 55436 before June 1.



SPECIAL THANKS -- PWSA has been encouraged by the continual support for the NDC but saddened by the fact we have not been able to reach more outside sources for larger donations. Norm Barkeley obtained a \$5000 check from a foundation, Jud Bell and Gloria Means made large donations, and we certainly thank them for their efforts. Other new donors include: Community Services, Krueger, Pflieger, Silverman, Gottschalk, Ryan, Jaffrey, Vogt, Anderson, Spear, Dixon, Toby, Jacobs, Harold (Diedrickx), Braunreiter, Haskins and Atwood. Members who contributed additional funds: Ipsen, Battersby, Flick, Kass, Miller, Boyd, DeHaan, Wyka, Sharp, Straight, Castle, Abell, Zorn, Henderson, Fick, Deterling, Westbrook, Lincoln, Gunnison, Foley, and Burleigh. As of the 3rd week in April, our NDC fund now stands at **\$41,262**.

The Research Fund balance now stands at almost **\$12,000**. We thank members for continuing to support this fund with direct donations and memorial gifts. The recent donors are: Daly, Lancaster, Uzendowski, Duclos, United Way (DE & OH), West, DeHaan, Zoller, VanZomeren, Waters, Porter, Maddux, Jordon, Sojka, Francavilla, Rasmussen, Corcoran, and Hill.

Last but certainly not least, we thank all of the members who continue to show their support by contributing extra dues and sharing information.

 THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. The opinions expressed in THE GATHERED VIEW represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of the PWSA. 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. \$20.00 per year for Canada and overseas. Send dues & change of address to : PWSA, 5515 Malibu Dr., Edina, MN 55436.

PRADER-WILLI SYNDROME ASSOCIATION
 5515 MALIBU DRIVE
 EDINA, MINNESOTA 55436