

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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VOLUME X

JULY-AUGUST, 1984

NUMBER 4

6th ANNUAL NATIONAL CONFERENCE

Several Minnesota conference committee members breathed a sigh of relief as the conference drew to a close again. The many hours of effort had produced a star-studded event which affected the lives of many of our members. Some of our star features were:

Record turn out, with at least 270 adults and 132 children and young adults, from 33 states and Canada. 110 of these young people had PWS.

Dr. Andrea Prader attended from Zurich, Switzerland. Dr. Prader, who shared with us the pronuniciation of his name--it's now officially Prah-der, was very impressed with our organization, charmed everyone with his personality, gave an impressive dinner talk, and enjoyed the opportunity to meet the children and young adults.

Dr. Vanja Holm and Dr. Hans Zellweger, familiar friends, joined us again this year.

Tour of Oakwood Residence, home for 15 young adults, established by the Minnesota chapter.

Medical and non-medical "experts" from Minnesota and several other states who covered many aspects of the syndrome as presenters.

The opportunity for parents and professionals to talk to one another.

A higher percentage of professionals registered than in previous conferences.

Several people volunteered during the board meeting to become more active in publicity and fund raising. Thomas Fox got us some local newspaper coverage and wrote a press release that was shared for people to take with them for their local papers. Bob Moloney started his new job as Membership Chairman before the meeting even ended.

A new board member, Dr. Suzanne Cassidy of Connecticut, was elected to the board, and two encumbant members, Drs. Holm and Wett, were re-elected.

Raffle winners were Don Toby of Kentucky, \$1000.; Omar Othman of Minnesota, His and Her Watches; Reinard Nanzig of Michigan, Panasonic Radio/Recorder.

Opportunity for attendees to hear from several members about the prospects of opening a National Developmental Center for our young adults in immediate need of placement. One member pledged a \$1000. donation this week and stated if we could raise an additional \$5000. before the end of September, he would match that. Two members donated \$1000. each as the conference ended.

And Last but not least, the volunteers did a tremendous job.

CONFERENCE REPORT (continued)

As in the past, after the tapes are transcribed and approved by the presenters, we will make them available to our members.

We would appreciate the return of our Evaluation Sheets in order that we may continue to present what you would like at next year's conference.

A big thank you for all of the workers and attendees.

DONATIONS

May and June contributions for the Research Fund (direct and indirect memorial funds) were:

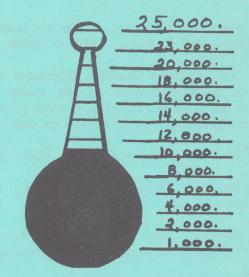
MAY: DeHaan, Ingalls, Spencer Monday Club, Sojka, Shepard, Zonta International Club, Verziroglu, Conry, and Atlantic Foundation, totaling \$702.00.

JUNE: DeHaan, Sojka, United Way of So.Delaware, Foley, Diel, Van Zomeren, Anderson and Smith, totaling \$1169.42. The 80% of these donations added \$1497.14 to our Research Fund. Subtracting \$440.70 expenditures, our new total is \$10,726.94.

(A couple of June donations have not been recorded due to lack of time with the conference.)

The National Development Fund has been started with donations from members, Whitlock, Huffman and Burleigh and non-member Rosenberg, for a total of \$2320.00.

We also thank those members who continue to support PWSA with contributing and patron dues.



TAPE SUGGESTION

When working with professionals, parents sometimes find it difficult to convince them of the severity of problems with temper. One member recorded a temper tantrum (without her son's knowledge) and played the tape for her doctor.

As the old adage goes, a picture is worth a thousand words. This tape equally did the job of accurate portraying the problem this parent was facing.

TWO NEW PARENT GROUPS

Kathleen Wyka has informed us that some NJ parents have started a self-help parent group, and met for the first time in May. Seven families attended and had a good discussion on PW that only PW parents can appreciate. This group will be meeting again in the fall. Most of these families also attend the Midlantic group meetings, which are held twice a year for several states in the same general area.

If anyone is interested, please contact Kathleen at 289 Wallington Ave., Wallington, NJ 07057.

With the help of the Developmental Disabilities Protection and Advocacy Board of the State of Illinois, a group called the Illinois Prader-Willi Group, has formed. A strong, active nucleus of parents have incorporated and is now in the process of becoming our next offical chapter. Their main objective is to open a group home in their state.

CALIFORNIA GROUP HOME

Lee Street House, which was written about in a previous issue, reportedly has two openings. This home specializes in serving adults with PWS, and could accomodate either male or female adult clients. The residents attend the Tehama Cty. Opportunity Center during the day.

When mentioning available placement, such as this home, we, of course, cannot recommend this as a placement but expect you, as parents, to do your own investigating. We have received two letters from parents that are presently using this facility, stating their children have done very well in this placement.

NUTRITION QUIZ

- 1. Ascorbic Acid used in cured meats, soft drinks, and cereals is dangerous to your health?
- 2. The breakfast cereal Quaker 100% Natural contains less sugar than Cheerios?
- 3. Watermelon may taste good, but it is not very nutritious?
- 4. American Cheese is more nutritious than skim milk?
- 5. When used as a sweetener or thickener, corn syrup is harmless?
- 6. Unlike sugar, the amount of salt used in processed foods is usually within acceptable limits?
- 7. Caffeine, which is present in coffee, tea, colas, and chocolate, may cause birth defects?
- 8. Glycerin, used in commerical candy, fudge and baked goods, is an unsafe additive?
- 9. Coconut and palm oils, like other vegetable oils, do not promote heart disease?
- 10. A ½ cup of fruit-flavored jello is better for you than a piece of whole wheat bread?

(Source of quiz, Center for Science in the Public Interest, answers on later page.)

COMMENT ON SODA POP

One member, who is also a member of the Central-Canada group, wrote them that 3 cans of diet soda pop per day made her daughter moody, uncooperative and lazy.

We have not been able to use any studies which do prove certain foods affect our children's behavior but it certainly is a good idea to "test" your own child by changing patterns and looking for results. Dr. Vanja Holm was asked one time whether growth hormones produced more aggressiveness in teens. Her comment was that when one was dealing with a teen-ager, it would be difficult to prove it was the medication and not the age that was changing behavior.

NATIONAL DEVELOPMENTAL CENTER

As many of you have heard, a fund raising drive was "kicked off" at the conference to open a facility to house, vocationally train and employ young adults with this syndrome. The fact that we had 110 young people in attendance at the conference, and 68 of them were over the age of 16, attests to the fact we are all learning weight can be controlled in the younger years and life can be extended. This extension of life brings us to our present problem. With the help of professionals, in some cases, many of us have brought our children through the teens and they now come to a time to enter other living arrangements and a vocation and there is nothing available.

Space does not allow me to present the many desperate situations that exist right now with many of our members. Following the appeal that appeared in the last issue of the GV, twenty-six parents responded that they were in need of an immediate placement and 10 others felt they probably would have to give up in their own area and also apply.

Members of the Minnesota chapter decided many months ago that an effort had to be made to open a national facility as a beginning to elivate this situation. A dozen members from other parts of the country have now joined this committee. The facility that we have envisioned would serve as a developmental center for our young adults—containing a live—in placement and also include vocational training and work placement. It could serve as a temporary residence until similar facilities become available closer to home, or it could be a permanent arrangement if that need exists. We agreed the only way we could develop this center would be to open a private non-profit facility. As some of you are well aware, crossing state lines and obtaining funding is practically impossible.

We certainly understand the parents who would like to develop something in their own state, certainly this is a goal for all, but realistically in many cases this can't be done now and in some states it will never be accomplished. We feel this center would just be the first step in trying to accomplish regional centers in other parts of the country.

We have located a building that is owned by the State of Minnesota, and is located on a beautiful site, about a half hour out of the city and with good transportation available. This building could be obtained on an indefinite lease with the only cost being the yearly utility charges. We estimate it would take 6 months to plow through the red tape to obtain this lease, and it would require an estimated \$250,000. to renovate, furnish and cover start-up funding for this program. That time frame would allow us to start the program within a year.

As I also stated in the Gathered View, this facility could also serve as a national office, which is also needed by PWSA to ensure a continuation of this organization.

Achieving this facility will require a tremendous amount of effort, but we have people willing to expend that effort. Start-up funding in addition to operating funding will be needed until we can achieve some income and foundation support. PWSA and the Minnesota chapter cannot do this alone—it has to be an effort on all of our members.

A few weeks ago I spoke to members of our Kentucky chapter. After the presentation, this group agreed to put aside their efforts to open their own facility and work with the national group first. This is what we are asking, just a temporary hold on your personal efforts, in order to help those who need this facility now. Certainly a resumption of efforts to meet the needs of your children in their own state or region would follow. This facility could also be used as an excellent source of training the personal to operate your own facility.

We would hope to accomodate somewhere between 40 and 50 young people. Future plans could well include a tremendous opportunity for research, internships, training facilities (as I mentioned) for other facilities, respite care, camping, and of course an opportunity for a better realization of this syndrome by others. Many offshoots, that we are not even planning at this time, could develop.

The needs of some of our young people in life-threatening situations have to be brought out into the open. We have to face the fact that some of the young people who have died this past year could have been saved. We have to face the fact that more will die this coming year. We have to face the fact that there are many young adults now facing desperate situations with no hope for help.

Donations of \$2000. and a promise of \$6000. later has started our drive. The first question foundations ask is what has your own membership done. We have many members capable of making donations. We are also aware there are numbers who cannot afford large donations but are capable of doing fund raising if they really care about helping their fellow members in need. The PWSA allocated \$8000. to finance a six month program of fund raising. For those of you who cannot afford larger donations, what about joining our \$1.00 a week club. Set aside a day each week, every Tuesday or pay day or some special day of some significance and put a dollar bill in an envelope and mail it to the national office. Efforts such as this can make this project a reality. Are we going to do it?

In order to finance a private facility, any person that is going to be placed has to have some financial backing. We do not want to limit entrance to only those who can afford to pay for some of their care, but we are going to have to limit entrance to those who support our fund raising either by their own donation, by their own fund raising efforts or by support of other members. This will have to be a criteria used for determining the beginning residents.

We have been asked to have \$5000. raised by the end of September to qualify for a matching gift. I am asking for \$250,000. within a six month period. We are either going to do it or we are going to ignore these desperate needs. It's up to you to decide.

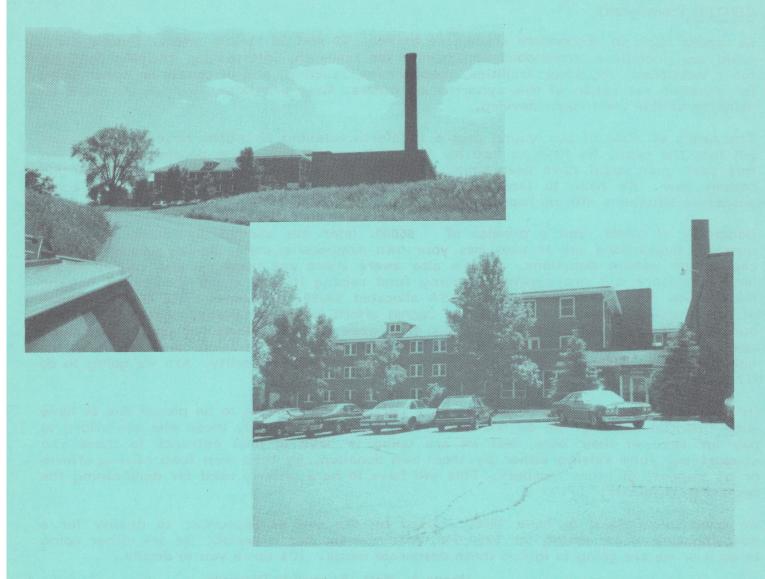
Marge A. Wett, Executive Director

l h	nave enclosed a donation of \$to open this facility.	
	cannot send a donation now, but please record a pledge of \$that bmit within the next six months.	I will
	will do fund raising for this cause, please send me a packet of information ailable) for this purpose	(when
l w	vant to join the \$1.00 a week club, enclosed is my first donation .	

COUNT ME IN FOR THE NATIONAL CENTER:

NAME

ADDRESS



CLOSE-UP AND DISTANT PHOTOS OF STATE FACILITY THAT COULD BE LEASED FOR NATIONAL DEVELOPMENTAL CENTER.

NEW PRODUCTS

Dole's Fruit 'n Juice Bars--available in strawberry, pineapple, orange, with mandarin orange and raspberry to be introduced later in the year. Available in four-packs, selling in the \$1.59 to \$1.79 range, with calorie count of 70 calories per bar. Real fruit frozen in 100% fruit juice.

Guido's Very Cherry Ice Juicee -- frozen fruit juice treat. Contains 70% apple juice, only 38 calories per serving (3 oz.size), contains no fat, no salt, and no preservatives.

(The parent that shared these items with us also commented that of course parents can freeze their own low-calorie fruit juices or punches in ice cube trays and add popsicle sticks (which can be purchased in packages.) Another idea is to make your own fruit sorbet by blending a package of unsweetened fruit chunks or slices (strawberries, peaches, berries, cherries) with a 2-3 teaspoons of lemon juice and 3-4 ice cubes, in a blender for a few seconds. Freeze in a mold or ice cube tray.



ONE OF OUR CONFERENCE VISITORS

MEET KATIE — she was one of our younger members that attended this year's conference. Katie is the adopted daughter of Don and Darlene Wilson of Indiana and is now $2\frac{1}{2}$ years old. Katie was diagnosed at birth and joined the Wilson family last April at 19 months of age. She could only lay and sit, and did not speak when she arrived. Since then she has started speech and physical therapies and can now repeat everything she hears. Bobbie Miller carried her around frequently during the conference increasing her vocabulary I'm sure. Katie is just starting to put words together, can stand up from laying, and walk without help.

If anyone else with a young child would like to correspond with the Wilsons, they would love to compare notes. Their address is R.R. #3, Box 54, Danville, IN 46122.

We hope Don, Angie & Andy, the other three Wilson children, enjoyed the conference too.

MEMBER SHARES SUGGESTIONS

One of our members from California suggests that outside psychological testing may be more valid than that given by the school system. In the case of her son, she found he had capabilities but did not respond/cooperate with the testing. She suggested checking with your own insurance company to see if they will cover psychological testing stating some may require a physician request before accepting this as a medical cost.

If you do find it is covered, check out some of the local child psychologists or family counseling services. Many are able to provide more accurate testing services. It is important that the testing be done in short segments in order that a feeling of trust/cooperation is established. It also allows the tester to recognize good and bad days when the potential response would be next to impossible. She also cited examples of environment playing an important role when children learn substitute words for those that appear in the tests. (I.E., sofa, couch, davenport, all being interchangeable for adults but not for children that have only been exposed to one term)

One other member wrote that her daughter's school testing started 15 minutes before the scheduled lunch time one day. The school psychologist wrote on the report the child was very uncooperative and repeatedly interupted to ask the time. Needless to say, the psychologist gave up and left very angry at the child. (And we doubt if he was very happy with the letter that the parent wrote to him informing him if he had any knowledge of this syndrome, which he should have had before the testing, it would never have been scheduled for that time period.)

SUGGESTIONS FOR BED-WETTERS

Cover the pillow in plastic underneath the regular pillow case. Also helpful for asthma sufferers.

A purchased cover or an old shower curtain can be used as a mattress cover.

Cut sheets in half (hospital or nursing home style) for faster night time linen changing.

PWS SURVEY (QUESTIONNAIRE #2, pages 3 & 4)

The second questionnaire in our series of several was bulk mailed to all parents that had returned questionnaire #1 to the national office. We also sent an inquiry to some parents that had not responded to our first page. We are happy to report that we have approximately 300 parents that have taken the time to return the first page of this survey. We do hope in our mailing of over 600 questionnaires that more parents realize the importance of the data we are collecting, and realize the importance of as many as possible in this study. The data we collect can be of great importance to our children.

If you are a parent, and have not received these mailings, please let us know at the national office and we will be happy to forward the pages to you. It is not too late, jump in now.

"TUMMY TUCK"

In response to our question in the last GV, we received a couple of doctor opinions on having the surgical "tummy tuck" done on people with this syndrome that had lost a great deal of weight and were bothered by the layers of skin flaps that remained. Both doctors stated, in their opinions, this was not a procedure recommended by them for our children. This type of surgery is a very bloodly procedure with blood replacement quite high, infections are very common, and they did not feel a person with PWS was a good candidate because the surgery should not be done on a person that may again regain this weight. Many of our children would find it difficult to leave this area alone during the healing process and many are slow healers. It is again a case of working with a doctor that is aware of the differences in people with this syndrome, their lack of muscle tone, and their inability to control their own weight.

One mother wrote her daughter had gone from 196 lbs. down to 92 lbs. and looked great, but not good. So she had a "tummy tuck". The doctor agreed to do the procedure because of the large flaps of skin but told them they would possibly be very disappointed in the finished product. He did not feel the surgery would be a threat to her health, however, he did caution that in the event she later put the weight back on, she would or rather could have problems because the skin would be much thinner and scar tissue does not stretch. It would also increase the likelihood of infection. This family was convinced that with this successful weight loss they did not have to worry about regained weight. Unfortunately, even though the girl looked terrific, this was not an incentive enough not to regain the weight. She has now gone back up to 172 lbs. and the weight is still rising. We do hope parents will consider these circumstances before they give in to the requests of their children to have this surgery done.

CANTALOUPE PEACH SMOOTHIE

 $1\frac{1}{2}$ c. diced cantaloupe $1\frac{1}{4}$ c. orange juice $\frac{1}{2}$ tsp. vanilla extract

1½ c. sliced peeled peaches ½ c. nonfat dry milk powder

Combine all ingredients in a blender until smooth.

This recipe serves 4, with 145 calories in each serving. It also contains 4 gm. of protein, 33 gm. of carbohydrate, 49 gm. of sodium, 536 mg. potassium, vitamins A & C, thiamin, riboflavin, niacin, clacium and iron.

Milk and liver are not the only sources of calcium and iron. Broccoli, cheese and yogurt all provide calcium; spinach, dried apricots and prunes are good sources of iron.

<u>UNDERSTANDING CHRONIC GRIEF</u> BY JANALEE (Stolen from The Missouri View, newsletter of the MO PWSA)

In my role as a social worker, I do a great deal of work with people who are trying to cope following the death of a loved one. I am constantly struck with the similarities of the "stages" and feelings of grief that a person must go through after the death of a loved one and the "stages" and feelings a parent of a mentally disabled child experiences. The main difference is that "when a human being is diagnosed 'handicapped' there is no obituary, so the public doesn't know you are in mourning (Steigen, 1976)". There have been many attempts to define the grief felt by parents who find out their child is mentally handicapped. It has best been defined as "chronic sorrow" or "chronic grief" because we parents of such children cannot complete the final phase of mourning. Our grief is unresolved, prolonged and recurrent. We grieve over the loss of the expected child who "will never be". In interviews with new fathers in Parents and Mentally Handicapped Children (Hannon, 1975), they tell of: guilt; a sense of failure; a feeling that they deserved better from God; resentment; wishing for the death of the child; feelings of inadequacy; and rage.

All of the stages/feelings related to grief, are experienced at one time or another by parents of brain-damaged children. The first "stage" is shock and denial, as was experienced by all parents of handicapped I've read about and personally know. The shock is a helpful buffer since the reality of the situation would be too overwhelming to accept all at once. The denial stage can last anywhere from days to years (or a lifetime) and leaves in bits and pieces. As the Collins' write in Keith and Kids (1976), "We all need a period of mourning. This comes only when we can see the prob lem in its real focus (p94)." It wasn't until Matt was eight years old and we met all of the PW adolescents at the national conference that Al faced the reality of the future for Matt, and cried in my arms that night. But, it wasn't until this happened, that Al was able to accept the reality that Matt wasn't going to "outgrow" the syndrome. He was only then able to begin working on fighting constructively against the predicted future. This is an all too typical roadblock for parents in our situation.

As with bereaved parents, there is a big risk factor to the marriage of parents of brain-damaged children. They go through the different stages of grief and/or healing at different times, and are unable to support one another. Typically, one parent is ready to go beyond denial before the other one, and must go on alone. Logically or not, each parent carries a piece of the guilt of their child's brain damage and may find some relief through wrapping their lives around this child. They also run the risk of one or the other parent becoming totally absorbed with the care of their special child, leaving no time or energy for their relationship.

Added to our grief is society's reaction to that grief (also a major problem of bereaved people). It is tragic that so much pain is added through people's vain attempts to "comfort". We have all experienced how destructive well-meaning people can be, i.e. remarks such as, "At least you have other normal children". This includes professionals who often subject parents to unwarrented trauma. We not only have to suffer from the underlying grief and the day to day difficulties of attempting to cope with our children, but also have to bear the guilt imposed on us by professionals who often decide how we "should or shouldn't" be feeling, what is "normal" or "abnormal" in our reactions, and impose unrealistic expectations on how we should interact with our children.

CHRONIC GRIEF (continued)

The alleged resolution of grief is to acquire the idealistic stage of "acceptance" and "getting over" your grief. I contend though that one does not get over grief. You adapt, feel less pain, and even find joy in your life again—but you never "get over" a significant loss, whether that loss is through an actual death or the loss of the child we had dreamed would be. Even though it makes other people uncomfortable, chronic sorrow is a natural and normal reaction. And, although we adjust our lives, why should we completely "accept" our child's fate in life? It is through our constant striving for a better life for our children and our perpetual faith, hope and determination that we will enable this generation of children with PWS to achieve more than was ever thought possible.

DOCTOR REPORTS SUBSTITUTE FOR LAXATIVES

Dr. Phillip Christiansen, chairman of the Gastroenterology (digestive diseases) Division at the University School of Medicine in Indiana reported he believed stool softeners and laxatives should be replaced by use of a high-fiber diet supplimented with unprocessed bran. Some of the reasons he stated were that habitual use of stimulant-type laxatives wears out the nerves, and no nerve action means no movement; frequent use of a salt-based laxative such as magnesium nitrate or even milk of magnesia can disrupt the body chemistry; oil-based laxatives can prevent the absorption of certain of the vitamins during the transit time through the gut; stool softeners are believed to be harmful in that they potentiate the activity of drugs and laxatives that a patient might be taking simultaneously, and thus increase the risk of liver damage.

Water is also suggested (at least a quart a day) for good bowel habits. Unfortunately, most of our children do not care for water, so other means have to be used to increase fluid intake.

PARENT PLIGHT

A mother of a young adult with PWS recently wrote: I think you, and those who plan for group residences for PWS adults, should be aware of our failure to have our daughter placed in a group residence that exists in our area. The Dept. of Mental Health and Retardation in that state decided the PW residence was too confining for a PWS victim. Obviously, it was a long path to this decision with considerable influence put on my daughter by the people in the group apartment that she was living in. She had been placed, because they said, for the lack of funds to do otherwise, in an apartment with two non-verbal people with Down syndrome. She was assigned to a day program in the local sheltered workshop but caused such trouble with theft that she had to leave. She also left the residence on numerous occasions without permission and one time was arrested for shop lifting and charged also with the felony of assaulting a uniformed police officer. When I and an attorney, who was also a friend of my daughters, finally decided enough was enough and she had to leave there and go to the PWS residence, and that the state was in fact now able to provide funds, we were informed that the PWS residence was not appropriate for her. My daughter was constantly "informed of her rights" by the people she was with and subsquently formally fired the attorney and said she did not want me on her Individual Service Plan team. Of course she wanted to stay where she was. All this took many months and was a great drain on me and my family. It was, and is, an unhappy situation.

INTERNAL MID-LIFE CRISIS WITHIN CRISIS

(Stolen from Marty Meyer, Editor of Parentele's The Crisscross)

Catchy title, huh? Anyone out there understand this? Well, a few months ago I looked into a mirror and saw a forty year old woman staring back, somehow not satisfied with what life had handed back to her. I felt like a dead piece of bamboo that needed the holes drilled to make the flute.

Crisis! Good heavens have I known crisis! Since John was born, it seems to be one after another and I manage through all them. If I don't have a medical emergency with John, it is another round with the school system. Yet, this time it was different...helping others is quite different from helping yourself. And I recognized a deep rumbling within, a restlessness that somehow wouldn't go away by throwing my "B" type personality into the "A" type work/achievement syndrome.

I thought of all the dreams I had twenty years ago—where did twenty years go? I certainly didn't feel any older. A former student came visiting, pulled up in a bright red MGB convertible, and I remembered that I vowed someday I would have one. My wardrobe was loaded with matronly attire—mostly gray and black. I remembered how much I liked red and yellow and blue. My brain was sleeping with no signs of a wake-up yawn. I remembered how much I liked history and science and philosophy.

How to deal with all this? Where to begin—where to find the courage to begin. Well, I have. In January I found and bought a sassy blue MGB roadster that eats highway; in January I went back to the comforting, loving arms of academia at Purdue, taking courses that I thought sounded interesting; in April I began a rainbow wardrobe in size 10. Lunacy? Unhinged? Nah! It's dealing with the next decade and being able to look in the mirror and say, "I am in control of my life. I like myself. I am meeting goals important to me."

So, this quarter my "words of wisdom" really don't have anything to do with having a disabled child, but the saving of "self." I've come to the conclusion I am no good to anyone unless I am good to "me". And "me" is feeling pretty good lately.

DNA BANK

The Department of Medical Genetics at the Indiana University is establishing a DNA bank to assist families with genetic diseases. There are 3,000 known inheritable diseases, and many times this number still unrecognized. This bank will serve as a repository to aid in the diagnosis of the more common hereditary diseases. DNA is being stored by families for tests which now exist as well as for tests that will be developed in the future.

Our "experts" in PWS do not believe PWS to be a hereditary condition, and the fact that we do not have any proven cases of more than one child being born in a family certainly leads us to this conclusion, but we are heartened by the tremendous advances, particularly in the field of genetics, that more will be learned in the future about this syndrome.

NUTRITION QUIZ ANSWERS

- 1. Ascorbic Acid (vitamin C) inhibits the formation of dangerous nitrosamines in cured meats and serves as a nutrient additive in soft drinks and cereals.
- The natural cereal contains 21% sugar, cheerios contain 3%.
 Watermelon is rich in vitamins A and C and also contain iron.
- 4. Both skim milk and cheese are rich in protein and calcium, but the cheese is loaded with saturated fat and sodium, which promotes heart disease and high blood pressure.
- 5. Corn syrup contains no nutritional value other than calories and promotes tooth decay.
- 6. In most instances where salt is used in processed foods, it exists in excessive quantities. 7. While caffeine does promote wakefulness, there is growing evidence that it may cause birth defects.
- 8. Glycerin forms the backbone of fat and oil molecules and is quite safe. The body uses it as a source of energy or a starting material in making more complex molecules.
- 9. Unlike other vegetable oils, coconut and palm oils are high in saturated fats and are not safe for the heart.
- 10. Jello is a junk food made of sugar, artificial coloring and flavoring, other additives. water and a little protein. Whole wheat bread is an excellent balanced food.

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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