

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

A quiet Sunday morning and I sit staring at a small yellow light flashing on a computer screen. Just changed it to green. It seems more appropriate as I look out my office window at the green coastal California mountains. Press CTFL/SHIFT and hit the 6 and now the screen is blue like the sky above the mountains. I can recall sitting at my desk in school looking out at the green trees and blue sky or at Sylvia's yellow dress, as she was sitting in front of me in Miss Knutstad's 3rd grade at the Washington School. Then I was learning to convey thoughts by dipping a steel Esterbrook pen (no, I didn't have to sharpen my own quills) into the inkwell in the upper righthand corner of my desk. Now on my desk lay a letter addressed to an attorney in San Francisco, my summary of a case, reviewed for a pre-trial investigation of possible malpractice in the death of a child terminally ill with neoplasm. Next to it is an article and editorial from the Journal of the AMA. This article examines the role of anesthesia in relation to surgical death and identifies 27 anesthesia related cardiac arrests out of 449 cardiac arrests occurring in 163,240 anesthetics over 15 years. The editorial refers to the report of the first death under chloroform anesthesia in 1848 and the total bewilderment of the surgeon and the anesthetist.

Now that you have bored your way this far, through my nonsense, I'll throw a curve your way. The next document on my desk is a 449 page volume from the U.S. Dept. of Health & Human Services and it bears the title, "Prenatal & Perinatal Factors Associated with Brain Disorders". Obviously, the plaintiff attorneys handbook to riches. The scope of the problem is appalling. Let me quote from the 1st paragraph of the preface. "In the U.S., mental retardation affects 850,000 children, and cerebral palsy afflicts another 750,000 young people. Handicapped children constitute nearly 10 percent of all school-age children. The neurologic and communicative disorders that affect 42 million Americans cost society \$114 billion each year. Our review of the pre- and perinatal causes of mental retardation, cerebral palsy and epilepsy has revealed how little we know of the factors controlling, altering or modifying brain development--how minimal our knowledge of the causes of these disabling conditions." As you may have suspected, in my search for a topic for this letter, I reread what I had written while flying home from the annual conference. In that writing I had expressed a hope that research would bring us

Pres. Message cont.

a time when PWS would no longer exist. Hope always brings questions and now I wonder about the nature of the road that will bring us to that goal. Technology daily amazes us with new answers to old problems as well as new views of problems we never knew existed. Our ignorance is vast and even with existing technology we are not much different in discerning the causes of human tragedy than those who first noted a similar event many years in the past. As we live each day involved with persons carrying the burden of a disability it is not easy, convenient or worth the trouble to hope for a solution that may never touch our lifetime. On the other hand, it is sometimes too easy or convenient or worth our while to blame others and seek retribution or justice or even just an answer because saying, "I don't know" may be just too difficult. Sometimes in our own ignorance as humans, the only apparent path is one of arrogance or revenge. If I get smart enough at this point I look at Sarah or think of the thousands of cardiac patients that I have had the privilege of caring for and wonder how they have tolerated the pain, the knowledge that they can't as others about them can, the looking up to someone not short or not lying in bed, the wondering if tomorrow will be just as difficult as today.

Once again we look up with hope that technology in the hands of those who care will one day help to make it possible to put PWS in the medical history books. We are still young as an organization of concerned persons. 1985 is only our tenth anniversary.

Delfin J. Beltran, M. D. President

GROWTH HORMONES

Last year about 2,500 U.S. children were receiving human growth hormone, obtained exclusively from cadavers. Natural growth hormone is produced in the pituitary gland, a pea-sized gland at the base of the brain. It stimulates the liver to produce substances called somatomedins, which affect the growth of cartilage cells.

Early this year the U.S. Food and Drug Administration was expected to approve the use of genetically engineered human growth hormone and then the supply would become limitless. (We have not heard if this has been accomplished.)

Dr. Paul Saenger, who treats growth hormone-deficient children, stated: "There is no evidence that growth hormone treatment will indeed affect the final height of these children who are making a normal amount of growth hormone but are short. It will take many years for physicians to learn whether treatment can affect their height."

Genetically engineered growth hormone is made by stitching the growth hormone gene into the genes of E. coli bacteria. When the resulting bacteria are grown in a fermenting tank, they produce human growth hormone as an inevitable consequence of their own growth.

The new supply of synthetic hormone is not expected to lower the price because Genentech will be the sole supplier, and is expected to charge what the market will bear--close to the price for the natural product. Since treatment could last 10 years or more, a complete course of treatment could easily cost \$100,000, excluding doctor's fee and Medicaid or most private insurers would not be likely to pay the bill. (We know of at least one insurance company that did pay at least for a period of time.)

If parents have information to share on their child's treatment, we would be happy to share further information with the membership.

TUFTS DIET & NUTRITION LETTER HAS GOOD THINGS TO SAY ABOUT BOOK

"The do-it-yourself dieter is in for good news with the Weight Watcher's Quick Start Program Cookbook (New Amer. Library Bks., NY, 1984, \$17.95, cheaper in discount stores)." They go on to state this book offers a weight control program, nutrition primer, and tasty low-calorie recipes.

The quick start is a new approach designed to provide faster initial weight loss as well as greater flexibility and simplicity. The book uses the exchange system (recipes contain calorie count per serving but the quick start menu plans do not). Food substitutions are offered. The book opens with comprehensive day-by-day menu plans. (The men's and youth's calorie allowance may have to be lowered for those with PW). Each recipe is accompanied by nutrition information. Tips on basic nutrition, microwave instruction and others are included. Basically, the quick start menu plans, to be used for the first three weeks, are generally rounded intake but obvious that the weight loss comes from the low caloric intake. Most of the book consists of recipes. It may be worth your while to take a look at this book.

EFFORTS ON PUBLICITY

Maybe some of you have seen or read some of the recent efforts for publicity on PWS. Marilyn Bintz of CA appeared on a local show, Look Who's Talking, with a couple of professionals from her area. The CNN Cable News Channel carried a two-part report on an Illinois camp, interviewing some professionals and parents. One member recently had a very comprehensive article in the Honesdale, PA paper, and a short while back the KY chapter was mentioned in an article about a Perryville girl.

A couple of weeks ago the MA Chapter managed to get an article in the New York Times. This paper has great circulation and caused a bit of activity in the PWSA office. Unfortunately, the only activity has been from writers and reporters as the association's address or phone number was not included in the article. Calls were received from a medical editor in San Francisco, a local talk show hostess in Baltimore, MD, several other newspapers, a TV news reporter and paper reporter from Minneapolis. Local members were recommended to these people and some follow ups have already occurred. The San Francisco reporter has talked with our president and will interview some parents before this issue is released. The Baltimore talk show had Dr. Cassidy and several parents with their children on her show the middle of August. The Mpls. TV news reporter did some interviews at Oakwood Residence and hopefully has been aired by now. The Mpls. paper and the Globe out of Florida are also expecting to be published in the near future.

Some of our NY Chapter members were interviewed for National Public Radio, and Dr. Jack Sherman was interviewed for a Long Island Cable 25 station.

Although we are not always pleased with the full contents of these articles and interviews (certainly food is always the primary interest), it is still publicity and very welcomed.

Recently our Executive Director was invited to be one of 350 people to serve on a panel in Washington. While the number 350 seems large, when you look at the fact there are estimated to be 3000 genetic disorders, and 6000 syndromes, we are privileged to be included in a "select" group. It has only been through publicity and involvement that our name was chosen. KEEP UP THE GOOD WORK IN YOUR AREA.

PROPER PLACEMENT

A recent call from a school principal prompted a note on what does the PWSA recommend for "proper" placement for our young people. This principal was questioning why our organization was advocating a group home as the only satisfactory living arrangement. This assumption was made because of our efforts to open a National Developmental Center. In case this is the assumption of others, we would like to share the following information.

People with PW come in all ages, sizes, shapes, and abilities. There is no way that they can all be lumped into one little square hole and not treated as individuals. All of the following have to be considered when talking about out-of-home placement:

Age

Current and anticipated behavior
Current and anticipated compulsiveness for food
Availability of home supervision & management of problems
Stress on the whole family
I.Q. level and functioning level
School services offered & workshop opportunities
AND MOST IMPORTANTLY, What is best for the child

PWSA is here for you to question, we want to share what has worked and not worked for others. Some families with a young child cannot cope with the child's behavior and must seek outside placement, where another family copes very well and offers the best placement. Some families are able to control food intake and the child is not obese, another family cannot maintain a healthful weight and the child is destined to develop complications from obesity. The problems and the ability to deal with them has to play an important part in this decision.

In some locations, the school system makes a big difference. The principal that called was questioning this because the child that is placed in their school system is doing quite well. Other parents write that schools do not cooperate, one mother had to drive twenty miles two or three times a week to bring her child home everytime he had a temper outburst. While some school systems are excellent, others are sorely lacking in their ability to serve this child, and some vary from year to year depending on staff.

Problems arise because situations change and the young people themselves change. It has been suggested that early teens may be the best time to consider a placement out of the home. This age is chosen because of many factors including a possible change in temperament, the "hard" teen or puberty time of development, adjusting to group living as their way of life, the availability of food as more independence is achieved, etc. One very important factor to consider is that as the child grows older and is less adaptable, the parents are also growing older and less capable. The older the person with the syndrome is, the harder an adjustment to a different lifestyle may be, and sometimes this becomes a necessity due to health problems or family deaths. Due to these factors, we find ourselves suggesting an out-of-home placement between the ages of 14 and 21. The greatest success has been found in group homes designed for meeting PW needs at this age. This is still not to say that in all situations this is the only possible answer.


PROPER PLACEMENT (cont.)

The National Developmental Center concept was developed because we have over 30 young people who are in desperate need of assistance that is not available. The whole plan was developed around a way to be able to serve these emergency needs without the across-state lines funding problem. Private funding was seen as the only way we could accomplish our goal.

We hate to think of a crisis situation being left unserved, but we know this has been the situation in the past and will continue to occur. We cannot ignore the deaths that are happening, but at the present time we are incapable of meeting their needs. Only parents with a 150 lb. 11 year old, 300 lb. 13 year old, or 390 lb. 22 year old can understand how impossible food control can be. Parents of PW children that do not have the same problem find it hard to accept this as an impossible situation, how can we ever expect someone without a child to really understand?

PWSA recommends a "proper" placement and that "proper" is what is the best placement for each individual. A bigger problem than knowing what a proper placement is, is when that proper placement is not available.

Marge A. Welt



CONFERENCE TIME JUNE 19, 20, 21, 1986 SACRAMENTO, CALIFORNIA

When one conference ends, planning for the next one begins. This year there has been a 2-month interruption in that schedule as we did not have a bid for the 1986 conference. Since that time we have accepted an official bid from Marilyn Bintz in Sacramento, CA for the 1986 Conference and a bid from the Texas Chapter for the 1987 Conference in Houston.

Marilyn has already contacted six other key people that will be responsible for organizing another top-notch meeting. More information will follow in future issues.

We also thank three other groups who were willing to offer their services for a bid if no others were received. Our membership has come through, everyone agrees our yearly conferences are essential. MARK YOUR CALENDAR NOW and join us in Northern CA next June.

RUMINATION SURVEY UPDATE

Drs. Greenswag, Alexander and Nowak would like to thank the many members who took the time to respond to the questionnaire about ruminating, vomiting, and dental health information. The large number of responses has been encouraging. Preliminary review indicates of 315 responses, there were 77 individuals whose ability to vomit ranges from a few instances during their lifetime to very frequent (daily or weekly) episodes. Specific ruminating behavior has been described in 25 cases and 26 report both types of behavior. Systematic analysis of the data is in process and will be shared with PWSA members.

AGENCIES LISTING

Thanks to a staff member from Dr. Jean Elder's office (she's Commissioner of D.D. in Washington), we have a listing of Protection and Advocacy Offices that exist in most states. If anyone feels this office could be helpful, please write PWSA for the name and address.

FUND RAISING

One of our members has forwarded information on the availability of handicapped dolls as a fund raising idea. These dolls are available from a company in CO named, Bestfriends. Their standard model dolls sell for \$35.00 and custom, handmade dolls range in price from \$69.95.

If you have some activity coming up in the future where orders can be taken, we recommend this idea as a possibility. What a better way to make a child comfortable with handicaps than to have them own a doll with an obvious handicap. Doll samples include an amputee skier doll, a hearing impaired, blind, tennis player with a leg brace and others. (There's one little chubby fellow that we could name our PW doll) Please contact the PWSA office if you would like more information on availability.

One of our members recently called from OH and has been arranging a fund raising dance. She has been amazed at the help that she has gotten from other organizations. (in this case the JC's). She has also gotten a great response for merchant donations, she stated, "all you have to do is ask".

Another member recommended "couponing". She has a friend that banks around \$200 a month from this method. This member recommends some of our members start this process and send all or half of their savings to PWSA. We always have people asking how they can help, some of these things aren't too time consuming.

As you read about the fabulous sums raised by other organization, you can easily say it is easier for them because they are larger and well known. Ten years ago very few people were aware of PWS--our organization (and that means you as a member) has helped greatly to change that picture. Is it worth some of your time to help your organization progress more???

HELPFUL TIPS

Thanks to one of our ND members, we are sharing the following information.

A recent study suggest that obese teens are poor high school students. (A former study found the same to be true of elementary kids.) The study was conducted by SAT scores. It also stated, "childhood and teenager obesity have ramifications beyond the well-documented health and social problems".

COCONO - new product coming. Cocono is a cocoa alternative made from yeast and carob powder, it doesn't taste exactly like cocoa but it's close. It does not contain caffeine or theobromine, has less fat than chocolate and a slightly sweeter taste. This products is being used in icings, baked goods and ice cream as well as candies. It can replace cocoa on a 1 to 1 basis.

HELPFUL TIPS (cont)

Not all medications can be safely crushed or mixed in order to make them easier to swallow because crushing or dissolving any medication will alter its effects, according to the MO Coop Extension Service. If you desire to give medication with a fluid or crushed, check first with your doctor, nurse or pharmacist. Most coated tablets cannot be crushed or mixed because of the delaying release. Drug overdose is also a possibility in altering. Liquids such as milk or fruit juice can alter the solution and absorption of some drugs. The acidity of fruit juice can inhibit drug action by causing early decomposition of acid-sensitive drugs. Some coated medication may dissolve prematurely if taken with antacids and can cause irritation of the esophagus and stomach lining, partially destroying the drug or causing it to act at the wrong site.

We have previously reported the need for sufficient calcium, particularly in the teen years and that calcium supplements or calcium rich foods should not be consumed with foods high in oxalate or phytate which includes asparagus, spinach, rhubarb, beet /greens, bran and whole grains, because this does inhibit calcium absorption. Dr. Karen Rubin, at the last conference, also shared information regarding this and stated high protein diets may cause negative calcium balance by increasing urinary calcium excretion. Also high intake of caffeine in coffee, tea, and some soft drinks, and high intake of nicotine in cigarettes have also been shown to decrease calcium retention and thereby contribute to bone loss.

One other previously suggested tip was the fact that vitamin supplements require food to be absorbed therefore should be taken following your largest meal of the day to be most effective.

UPDATED BIBLIOGRAPHIES

Listing of medical publications re PWS
with content noted

Due to the efforts of one of our favorite people, Dr. Vanja Holm, we now have the annotated bibliography listings updated with current publications included. These are offered, along with our many other publications. The short version, which includes publications in addition to those listed in the back of the blue PWS book, will be approximately 28 pages, will sell for \$3.50 U.S. and \$5.00 Overseas, Canadian funds and to non-members.

The full listing, which is 49 pages in length, is available at \$7.50 per copy U.S., \$10.00 Overseas, Canadian funds and to non-members.

HYDROCEPHELUS

We have a new member with a 12 year old son with hydrocephelus, that would appreciate knowing and communicating with any other members whose child with PWS also has this complication. Please write to the PWSA National Office, and the letter will be forwarded to this family.

WORLD NEWS

Canada and England are preparing for fall conferences.

Australia just held their first conference in August.

Prader Willi Vereniging, newly formed Netherlands group has 60 members and is in the process of publishing a handbook in Dutch.

PWSA now has 18 countries represented in their membership.

CRISIS SITUATION

"Let me take this opportunity to introduce you to part of our family. We are Maurice and Jean Vermeulen and Janey is our 22 year old daughter who has Prader-Willi. We live in Plymouth, Michigan.

Because we have been unsuccessful in controlling Janey's weight, she had developed serious respiratory and vascular problems. (Janey is 5 ft. tall and weighs 390 lbs.) This critical situation was recognized by Dorothy Thompson when she met Janey last May while assisting the MI chapter to begin work on a group home.

Through Dorothy's efforts, we were given the opportunity to apply for admission, for Janey, to the Prader-Willi Clinic at Gillette Hospital in St. Paul, MN. This PW clinic is directed by Richard Nelson, M.D.

To be considered for treatment at Gillette, we were required to meet three conditions:

- 1) A letter from Janey's attending physician stating the serious nature of her life-threatening condition.
- 2) A statement from our insurance company (and ourselves) guaranteeing that the payment for hospitalization and medical treatments would be met promptly and on a continuing basis.
- 3) A care plan that would guarantee Janey's placement in a group home where dietary needs would be met so the weight loss would be permanent. (Gillette needed reassurance that the treatment program would not be a temporary loss which would escalate right back up.)

We are pleased to report these conditions were met and on August 19th, Janey was admitted to Gillette. Her condition at this time was rapidly deteriorating.

Her in-patient care will be a learning experience for the staff and hopefully a health-restoring experience for Janey.

We are so tremendously grateful that Janey is having this chance to turn her life around. Please allow us to continue our reports to you and advise you of Janey's progress." signed Maurice and Jean Vermeulen

The above letter is an example of the needs not being met discussed earlier in this issue. Because Janey is higher functioning, as so many of our young people are, the family had a great deal of difficulty controlling her weight and a dire need for a proper residential setting that did not exist in their state.

Other young people have been hospitalized for short stays and limited weight loss but regular hospitals are not equipped for longer stays. Insurance companies consider weight loss as cosmetic and not as life-saving, therefore have refused reimbursements. In the case of the Vermeulens' the decision had not yet been made when Janey was accepted.

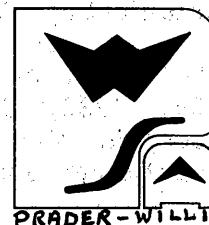
This family has agreed to share their feelings and experiences in the hope that others may benefit from their mistakes. Janey has a great challenge ahead of her but realizes this is her only hope for survival. These reports are not going to be easy for this family and we sincerely thank them for caring about others.

PWSA LOGO JEWELERY

Samples of these items were shown at the last conference. We now have them in stock for \$2.50 each (we'll need \$3.50 to offset Canadian devaluation and overseas postage). We'll fill orders until they are gone and probably not reorder until the next conference because we have to order in quantities of 500.

Those registering for these at the last conference must also place an order to receive, as we were only asking for interest in buying these for our members.

Snake key chain -- antique silver or bronze finish
 (key chain has 3/4" loop, 1" sq. metal, chain wound)
 Pin w/safety catch, 1" -- antique silver or bronze
 Tie bar, 2" -- antique silver
 Tie tacs, 1" -- antique silver
 Lapel pin w/spring back, 1" -- antique silver
 Money Clip, 2" -- antique silver

PRADER-WILLI CALENDARS

DO YOU WANT THIS IDEA FOR A FUND RAISER?

An artist friend has offered her services to design a calendar for us. If you want this idea for a fund raiser, we need **DRAWINGS** from your child/young adult, and **ORDERS** for the finished project. In addition to the art work, the calendar will also include information about the syndrome. Let your friends read what it's all about!!!

Ordering in large quantities will enable us to sell this competitively at \$7.00. Proceeds can be directed to the Research Fund, National Developmental Center or General Operating Budget for other projects.

Suggest a month to your child/adult and let them have a go at it. **DRAWINGS AND ORDERS** are needed now though as time is needed to complete. If there is enough interest, we will proceed with the development. Possibly this could be a yearly funder.

**** **

ORDER FORM

Yes, place my order for _____ calendars when they are ready. (Payment due on receipt)

You may also use this order form for the Logo jewelry above:

ITEM _____ FINISH _____ PAYMENT ENCLOSED _____

NAME _____

ADDRESS _____

IS PWS A TRULY RECOGNIZED SYNDROME?

As knowledge of this syndrome is growing, we are asked this question less frequently but it still comes up. If in dealing with a professional that does not care to accept this term, the following list of sources can be used to prove the validity of your claim:

Grossman, Herbert J. Manual of Terminology and Classification in Mental Retardation. American Association on Mental Deficiency, Special Publications Series N.2, 1973, p11.

U.S. Dept of Health & Human Services, Cumulated Index Medicus Vol. 24, 1983, Subject Index PI-Sk, pp12878. (note: many volumes will contain this heading, depending on what has been published for a particular 6 month time period.)

Goldenson, Robert (ed), Disabilities and Rehabilitation Handbook McGraw Hill, Inc., 1978, pp.618-9 and appendix for Ch.54 ppX.

Holm, VA, Sulzbacher, SJ, Pipes, PL. Prader-Willi Syndrome University Park Press, 1981.

National Center for Education in Maternal & Child Health, A National List of Voluntary Organizations in Maternal & Child Health, p.26.
Social and Psychological Aspects of Genetic Disorders: A Selected Bibliography p40.

Nora, James J., Fraser & Clarke. Medical Genetics: Principles and Practice, 2nd edition, 1981, p329 Lea & Febiger.

(Thanks to Dr. Louise Greenswag for sharing some of these sources with us.)

CLUB IDEA

"Let's Play to Grow" Clubs are popping up all over the country. The idea and program was created by the Joseph P. Kennedy, Jr. Foundation and has Eunice Kennedy Shriver as Executive Vice President. The goal is meeting the needs of families with handicapped children or young adults, states their literature although we have only seen articles previously regarding preschool nurseries.

If you are interested in starting a club in your area, want to locate the nearest already existing club, or avail yourself to their resource material, further information can be obtained by writing to: Eunice Kennedy Shriver, Let's Play to Grow, Joseph P. Kennedy, Jr., Foundation, 1350 New York Ave., N.W., Suite 500, Washington, DC 20005.

TASH

The Association for Persons with Severe Handicaps will be holding their 12th Annual Conference in Boston, December 5-7. The conference theme is Families and Friends. For further information contact: Conference Coordinator, 7010 Roosevelt Way NE, Seattle, WA 98115.

WELCOMING REMARKS

At a June Genetics meeting I was impressed by the welcoming address given by Robert C. Baumiller, S.J., Ph.D. and asked him to share it with our organization:

"As a Geneticist and as a priest, I too often have to give the information to parents that their newborn child has or is suspected of having a serious birth defect. To fill this role is both an obligation and a privilege. There is no easy way to bear such news and no set formulae that once recited excuses one's need to remain. The encounter lasts for hours generally and ends because everything the couple can think to ask or to question has been said, probably more than once. So much has changed for the couple from the moment I walked through the door. They are now faced with a different life than they had ever imagined. They are working with grief for the child they thought they would have, they are struggling to accept in the fullest sense the child they do have, and they hardly dare imagine the new life that lies before them. All this and a necessity of telling their family and friends something---something whose effect they do not yet comprehend.

I leave often amazed at the goodness and strength so many people possess; I leave often strengthened by the active faith and acceptance that sustains so many. I leave often bedazzled by the love that two people can show each other at so difficult a time. I leave with a certain feeling of accomplishment of having given bad news, but of having assisted at the beginning of healing. I leave depressed at having witnessed once again such sadness.

But I leave--all of us "professionals" leave, and you remain. You remain in all your strength and weakness, faith and doubt, love and distrust. You remain each day and every hour. You grow or wilt, have triumphs and losses, share joy and sorrow.

The best help for couples are others who also never leave. They speak from first-hand experience they truly know.

This conference is aimed at assisting those who would share their own experiences and reach out to help, making the uncertainty a little less and sharing in a real way what it means to struggle with and hopefully overcome the problems these families face. I am privileged to be here and be part of this."

We like to think of PWSA as the friend who never leaves, and our annual conferences and bi-monthly GVs as our opportunity for further sharing.

Yes, we are fatter this month! Due to enclosing the questionnaire with most issues, we added a page this month.

SIBLING'S ESSAY

The following essay was written by a Kentucky teenager, and was taken from the Kentucky chapter newsletter:

The most challenging event I have met in my life is dealing with a sister who has Prader-Willi Syndrome.

Prader-Willi Syndrome is a disorder resulting from a birth defect which has a variety of characteristics, including: insatiable appetite, mental retardation, and serious behavioral problems.

Many people realize how difficult it can be to live with someone who is mentally retarded, especially a brother or sister, but a person diagnosed with Prader-Willi can be even more difficult to live with.

My sister has had serious behavioral problems in the past. Even though she has gotten a lot of this under control, she still is very stubborn and has frequent temper tantrums. This has and still effects me tremendously. It effects my social life, my family life, and it effects me personally.

As a teenager my social life is very important to me. My sister has seemed to get in the way on numerous occasions. Most of the time she just embarrasses me, but sometimes I feel like everyone is going to turn away from me because of her. It is probably just my imagination, but it still makes me feel self conscious. I understand that she cannot help what she does and does not do it on purpose, but she seems to always be in the way.

Sometimes I feel cruel about feeling this way, but she appears to always be there.

My family life is a lot different from most families because of my sister. Since she has Prader-Willi it takes up most of my parents' time. I don't mind this much but it is hard on my mom and dad. She is on a special diet so my mom has to cook two meals at a time. One for us and one for my sister. Also since my sister can not take care of herself, my parents have had to take care of her for 23 years, however they are working on building a group home where my sister and others like her can live with a nurse or someone trained to take care of them.

My sister has effected me in many ways. She has brought a lot of trouble and pain to our family and I have questioned how God could have put her down here with us, knowing how much pain we would have to go through. The only conclusion I could come up with is to make our family stronger, even though in many ways I feel that it has weakened me.

This has been a life long event and it is not, and I don't think it will ever be over with, yet we have come a long way and I am sure we will be able to go to the end. There will still be pain and we will have to work hard at it, but I feel if we stick together we can make it.

CRUSTLESS TURKEY PIZZA

1 (8 oz.) can tomato sauce	Dash hot pepper sauce
1 tsp Italian seasoning	2 lb. ground turkey
1 egg, beaten	1/3 c. chopped green peppers
1/2 c. seasoned bread crumbs	1 (8 oz.) can sliced mushrooms, drained
3/4 c. finely chopped onions	1 c. grated mozzarella cheese
1 clove garlic, minced	

Combine tomato sauce and Italian seasoning. Measure 1/2 cup mixture into large bowl. Reserve remaining mixture. Add egg, bread crumbs, 1/2 cup onions, garlic, hot pepper sauce and turkey to tomato sauce in bowl. Mix well.

Pat turkey mixture evenly on lightly greased 14-inch pizza pan. Top with remaining onions, green peppers and mushrooms. Pour remaining sauce over top. Bake at 450° 10 mins. Sprinkle with cheese and bake 5 mins. longer or till browned around edges and cheese melts.

8 servings., 255 calories per serving. 32 gm/protein; 9 gm/carbohydrate; 9 gm/fat; 410 mg./sodium; 379 mg/potassium.

MARINATED VEGETABLES IN CARROT-LEMON DRESSING

2/3 c. canned carrot juice	1/8 tsp. ground black pepper
3 Tbsp. lemon juice	1 c. (1") carrot slices
2 Tbsp. safflower oil	2 c. broccoli florets
1/2 c. finely chopped onion	1 c. (1") green bean pieces
1 tsp. grated lemon peel	2 c. (1") zucchini slices
3/4 tsp. salt	

Combine carrot, lemon juices, oil, onion, peel, seasoning in small bowl. Set aside. Bring 1/2" water to boil in large saucepan. Add carrots, broccoli, beans and zucchini. Return to boil, then reduce heat and simmer, covered, until vegetables are barely tender, about 3 mins. Spoon hot vegies into serving bowl. Add dressing and toss to coat. Cover and refrigerate 2-3 hrs. before serving.

6 servings with 90 calories/serving. 3 gm/protein; 11 gm/carbohydrate; 5 gm/fat; 331 mg/sodium; 415 mg/potassium.

THOUSAND ISLAND DRESSING

1 c. low-fat yogurt	2 Tbsp. sweet pickle relish
1/2 c. catsup	1/2 c. nonfat milk

Mix yogurt, catsup, relish & milk; chill. Makes 1 1/2 cups dressing.
12 servings with 27 calories/serving. 1 gm/protein; 5 gm/carbohydrate; 0/fat; 149 mg/sodium; 81 mg/potassium.

PROBLEMS FOR ASTHMATICS

The metered-dose-inhalers (MDI) widely prescribed to control asthma can cause problems if they are not used properly. Studies show the vast majority of patients do not use MDI's correctly. Key Pharmaceuticals, Inc. has developed an easy, tone-emitting delivery system, InspirEase. May be something to look into if MDI's are used.

Another problem mentioned was sensitivity to sulfites, which are used to prevent wilting and discoloration of fresh fruits and vegetables, preserving baked goods and sausage meats. The FDA is considering the ban of sulfites.

CALCIUM SUPPLEMENTS

For those using calcium supplements to prevent osteoporosis (brittle bones), a recent article had some interesting facts. This article states calcium carbonate is the best calcium source. This supplement comes in many guises. You can buy it in the form of antacids (Tums, for example), as ground oyster shells or a synthetic. The calcium in the natural source is no different than in the synthetic ones. The antacids are practically the same as the dietary supplements but prices do vary. For example, 800 milligrams of calcium ranged from 7¢ for a generic brand of oyster shell to 10¢ for Tums to 21¢ for Oscal 500. Going overboard is another story. Taking 8-16 Tums-Regular at once can actually stimulate excessive acid secretion. It is recommended that the pills be spaced and taken with meals. It is also interesting that not all antacids can be used, some (for example, Roloids, DiGel, Maalox, Mylanta and Gelusil) contain aluminum instead of calcium so cannot be used as a supplement.

WE THANK OUR MEMBERS FOR THEIR CONTINUED GENEROSITY

Several professionals have inquired about our Research Funds lately, these proposed projects will benefit all of us. At the present time our Research Fund total is \$12,490.32. July and August contributors added \$606.29 to this fund. Our thanks to Van Zomeren, Forthman, Sojka, Shults, Anderson, DeHaan, Greentree, Handicap Awareness, the Combined Capital Area Fund, and the S.New England Chapter.

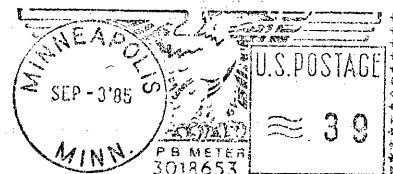
National Developmental Fund now has a total of \$49,103.56. July and August added \$1321. to this balance. Our thanks to those who feel this effort is worth pursuing: Parent, Boyd, Flick, Sucha, Wett, Henderson, Allen, Anderson, Levine, Dennis, Wyka, Sharp, Tobin, Gulling, Porcella, Lincoln, Shults, Huitbregtse, and Harrington.

A special thanks to the S.New England Chapter (which is changing their name to PWSA-CT CHAPTER) for their fund raising which added extra goodies to the conference, supported the Research Fund, and enabled more reimbursement to conference presentors. Thanks also to conference presentors who not only gave of their time but also made project donations with their reimbursement: Whiteside, Bates, and Porcella. And last but not least, our members who continue to donate contributing and patron dues which enables new projects.

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