

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

Yesterday was Christmas. For our family it will probably be a landmark. We returned to Albion, Nebraska to celebrate with Linda's family in the farmhouse where she grew up. It was everything that one could imagine and the media so weakly attempts to portray; church with sermon and choir, dinner with goose and mincemeat pie, a day of love and sharing. By the time we return again lives will have changed, but the purpose will be the same.

Three weeks before I shared a similar type of experience with your PWSA Board of Directors. For the 2nd year the mid-year meeting was hosted by board member Stewart Maurer at the Colony Square Hotel in Atlanta. A hotel that he manages. Since the first meeting of the Board of Directors, held in Seattle in 1977, changes have occurred that are noticeable and progressive, but the purpose of the association is retained. The PWSA exists for the benefit of PWS persons. This meeting of the board of directors is to me also a landmark event, and the products of the meeting are significant.

Up to this point the efforts of the board have been directed at creating a viable organization. I have come away from this meeting with the knowledge that the board has achieved this goal. The organizational structure has matured to become a functional system of defining responsibilities and carrying them out. The financial status has expanded to the point where your board has recommended that appropriate external accounting support and affirmation be sought.

When the first conferences were held professionals attended because it was an unusual opportunity to communicate with PW persons and their families, often with little to contribute. The opportunity to communicate continues to be a strong stimulus to participation but an added feature is the development of the conference into an important resource for scientific discussion and reporting at a more mature level of investigation that is necessary to enhance fruitful research for the benefit of PWS people.

Support continues for the concept of the National Developmental Center for PWS. It will be designed to provide emergent care on a temporary basis. There are currently 40-50 candidates for such care, unable to obtain support in their own communities. There is currently no center to provide training to the personnel necessary to function as effective care providers for PWS persons in their own communities. It will be a purpose of the NDC to provide this type of training as well as research into effective care management and vocational development. Extended research into the multiple professional disciplines involved and the housing and coordination of other organizational information are necessary for the associations successful continuity. Involvement in this project has spread

Pres.Message, cont.

from those who live with and know the importance of this project to now include the recently announced \$25,000 matching grant from McDonald's. Successful completion of this matching grant effort could bring the plan to the 15% level of completion.

Information about PWS has now spread to the point where legislative leaders have incorporated our concerns into laws. They, as well as professionals, are now familiar with the term PWS or can be directed to a contact person or the offices in Edina. Major databases have been developed by both the questionnaires from the association offices and by individual investigators. The initial products from this information will include the stimulus to develop and publish a new book directed to the care and management of PW persons. Another project will be the computerization of information on over 600 PW persons that will be available to guide and assist research. Individual anonymity protection, of course, is essential to all accumulated information bases.

Two meetings of special groups are planned for the annual conference to fulfill needs recognized by your board of directors. Dr. Vanja Holm plans to develop a program for physicians involved in meeting the medical needs of PW persons. As president of your organization, I will develop an agenda for a meeting of presidents of PWSA chapters. This meeting is planned to occur prior to the meeting of the board of directors at the annual conference and its purpose is to ensure that the needs and concerns of the chapters are given their appropriate voice and concern and to more personally develop a line of communication between the chapters themselves and the National organization.

Thank you for your attention and I believe that you will now agree that this has been a landmark period in the growth of the PWSA. Our purpose remains steadfast; all effort to the benefit of the PWS person. Please read through the articles prepared for your information that are contained in the remainder of this GV--it is information that you need to know.

Delfin J. Boltran, MD

President

YEAR END BRINGS THOUGHT TO THANKS

If we listed everyone who deserves thanks from PWSA this past year we would need this whole issue for the listing. Do some of you wonder how an organization such as ours can operate on a \$15.00 a year fee from each membership? Do some of you wonder who makes all of the necessary decisions to continue operation, add new services, publish this newsletter, fill your orders for materials, answer your letters, etc.? Some of you may know, but many members just know "it's there when they need it". PWSA has one 24-hr/week paid secretary; the board of directors, the officers, the director, and the many other people who donate their expertise to operate this organization are all volunteers. The yearly conferences, which are very important to our memberships, require months of work to organize by many more "volunteer" members. We are not a state or government agency, we do not have any outside source of funding. The people mentioned above and the rest of those who "CARE AND SHARE", make OUR organization what it is. If you know you are a "taker" not a "giver", how about 1986--your year to change sides. We'll grow by leaps and bounds and you'll be proud to know you're on our list for those who deserve thanks.

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SCHOOL PROBLEMS

"I am having a problem with the school system here in Maryland and my nine year old son. I would be interested in knowing if any of the other members have experienced a problem similar to mine. My son, Dusty, was suspended from school for 4 days for choking another child on the playground. Dusty has the usual temper tantrums although he is working very hard to keep himself under control. However, at times, he loses control completely and will strike out. This usually involved hitting someone with his fists, swinging wildly.

I am very curious if any of the other PW parents have experienced this violent behavior. I felt the school should have been aware that he can get aggressive and not suspend him for something that I believe is a part of his handicap. He is in a class of only 4 children with 3 special education teachers, surely they should be able to handle this, even if one does need extra supervision. Most of the time Dusty is quite lovable, but if someone teases or upsets him, look out!.

I would like to meet other PW parents in my area to exchange information and support. Please write to Susan C. Hall, 154 Barbara Rd., Severna Park, MD 21146."

Another mother writes: "I was called to school as my son had diarrhea. When I arrived he was lethargic, a doctor found his white count and blood sugar high. After hospitalization, it was determined the cause was poison from baking soda. Kyle had eaten some toothpaste, so the school decided he should brush with baking soda for 5 days. One day he poured some out and the aid lost her temper and gave him more. Kyle's mouth was burning and asked for water and she added more to the water."

While it is true that this could occur with any child, we have found it is more likely that persons with PW will have problems because of their abnormal hormone balances.

This same mother wrote about being very aware of school personnel and their reactions to your child. Investigate reports of "verbal abuse" from teachers, aids, bus drivers and others. If your child continually mentions comments being made, if he reacts with jumping back and apologizes over and over again for simple mistakes, it may be time to spend some time in his classroom and talking with these people.

REPRESENTATIVES

The Department of Health and Human Services, National Institute of Health, and such organizations such as the March of Dimes occasionally fund groups that deal with handicaps, mental retardation, etc., unfortunately, as an individual organization we have not been able to be the recipient of some of these funds. We did recently get a request for a representative for a Parent to Parent group in the Jacksonville, Florida area. If any of our members are interested that live near there, please let PWSA know. Other groups are starting in other parts of the state and other states also. Having a representative from our association working with these sponsored groups can be of some benefit.

PW PRACTICAL PARENTING?

An advice column on Practical Parenting by Vicki Lansky recently caught my eye. Frequently in conversation I have sometimes referred to having a child with PW is like living through the year or so of "terrible twos" that never ends, or living through those dreaded "teen years" many times multiplied. Several of Ms. Lansky's "thoughts for today" seem appropriate to share:

...Roll with the punches. It may be stormy--the word "tantrum" will take on new meaning for you--and it won't be easy, but it is not a personal affront no matter how much it seems like it. Bite your lip. First reactions are normal but not necessarily the best ones.

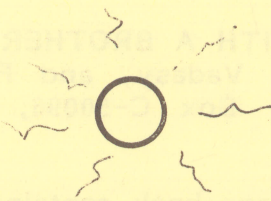
...Offer limited, not open-ended, choices to your child. (One other professional suggested only two choices for people with PW, don't confuse the issue by too many choices)

...Catch your terrible two at being terrific. Negative behavior is often used to get attention--any kind of attention. If you work at giving the right kind, your Two won't work as hard at getting the wrong kind.

...Develop diversionary tactics. While this might be slightly dishonest, it is a highly effective technique to head off many problems at the pass.

...Provide loving limits. Time-outs work for Twos as well as Teens. Let there be a place to vent anger and frustrations such as one's room.

...Avoid overkill: Punish once and forget it. Negative psychological warfare that continues all day will backfire.

DAY BRIGHTENER

"This time I have no requests and no complaints. I just want to thank you for the prompt and courteous way you have responded to my questions in the past.

When one considers that PWSA is only ten years old it seems incredible that it functions on such a sophisticated and professional level. Thanks to all of you."

MEDIA

NEWSPAPER CLIPPINGS

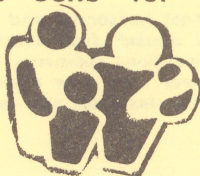
Members occasionally mail clippings regarding drugs, diet plans, articles about people with PW, and they are usually accompanied by notes asking if we want these. PLEASE continue to mail anything that you feel maybe of interest. Frequently articles only appear in a limited number of papers and we are always happy to get copies. We can follow up on some of these drug information articles, and sometimes inform researchers that PWS is another area they may consider in their research. Articles on our members are added to our scrapbook. We do appreciate receiving these copies.

"LIVING WITH A BROTHER OR SISTER WITH SPECIAL NEEDS" A Book for Sibs by Meyer, Vadasy, and Fewell, available from the University of Washington Press, PO Box C-50096, Seattle, WA 98145-5096, priced at \$8.95 + \$1.50 shipping.

This 110-page book contains 8 chapters with titles including: "What It's Like to Have a Sibling Who is Handicapped, Mental Retardation, Handicaps Children are Born With". The book also contains a 2-page description of PWS. The first chapter contains a paragraph: "In this chapter, we'll talk about the feelings and experiences you probably share with many other siblings. We will talk about all the kinds of feelings you have--both good and bad. We will also discuss some of the special qualities that siblings like you have--qualities that make you a very special person." The chapter goes on to discuss friends, unselfishness, anger, accepting differences, guilt, jealousy, overinvolvement, and many other feelings.

We recommend this book to parents who are dealing with these problems as well as the sibs themselves. We have one copy that may be borrowed from our library, and other libraries may also have copies, or information for ordering your own copy is above.

The PWSA booklet, "SOMETIMES I'M MAD, SOMETIMES I'M GLAD..on being a Prader-Willi family", written by one of our members, Janalee, is also still available. This 32-page booklet sells for \$2.75 U.S. funds and \$4.00 for Overseas and Canadian funds.



WHILE TALKING ABOUT SIBS....

A Mother wrote: "As I sat reading the 'Sibling Essay' in The Gathered View, I was once again struck by the common experiences and feelings of the families of people with PWS. Of course this is one reason the National Association is so successful and accounts for the hundreds of miles people travel to attend conventions on PWS. We all have a need to see that we are not alone, that our experiences and lifestyles can be understood by other people. My son's sisters, however, don't have many (if any) opportunities to share their feelings with their peers. If someone they know does have a developmentally disabled sibling, the disability is not as extensive as that of a PW person. Usually their entire lifestyle isn't altered by food control, temper control, etc. I think it would be a good idea to have a page devoted to siblings--not only essays but drawings, poetry, stories--any method a person choses to express his/her feelings."

We thank this mother for sharing, and as always are very happy to share whatever is shared with us.

Another mother wrote: "We enjoyed reading Sept-Oct. issue of the GV. It had so many things that seemed to hit home. We have a teen aged daughter who enjoyed reading "Sibling Essay". She has experienced some of the same feelings. It was good for her to read about someone else feeling the same way. Our lives have changed--about a year ago we admitted our son to a special school--a residential school. The name of the school is Lakemary Center, located in Paola, KS. This has been good for all of us. Our son has learned to do many things for himself. He has also lost 25 pounds. He is on a 800 calorie diet and he is in an extensive exercise program. For the first time in his 10 years of life, he has friends. The school is working on his behavior, which is a continuous challenge.

SIBS cont.

We decided to find a residential school because it was so difficult at home with him. The diet was out of control, the behavior was horrible. We simply could not find the energy to cope any longer. His weight was out of control and our pediatrician said that he was on his way to destruction. Admitting our son was very difficult. The school was located 7 hours from us so saying goodbye was hard. But the freedom from the tantrums and continuous stress is fantastic. The highly structured atmosphere is something he thrives in so the knowledge that he is being helped makes everything worthwhile.

His visits home are difficult. He tends to go back into old routines and then it is a battle. He has adjusted fast to being away from home. It is still difficult when he leaves to go back but once he's there, he's fine. Lakemary Center has been answered prayers for us. It is very expensive but whatever it takes we will try to keep him there. We feel now that living at home would eventually lead to death for our son. He was 80 lbs., 3'1", when he was admitted. He now weighs 59 lbs. His behavior is terrible but in a structured environment, it is better. We are very grateful to the Lord for giving us our son. Ten years ago when he was born I thought the world had come to an end. Now looking back over those years I see how we have grown. We understand things that we would have never understood if we had not had our son. Our faith has grown. I think we know about love--our family life is strong. This is because of our son. There have been tears, frustrations, feelings that you can't take anymore, and there are still those times. But after praying, you pick up the pieces and go on. Life is good. We will continue to pray for an answer to PWS. "

A Sibling wrote: "I have just finished reading the article entitled 'Sibling Essay', ... and as a sister of a person who has PWS I must say that I, myself, feel quite differently in most respects. Only on one point do I agree with the author of this essay, and that is in the respect that at times it is difficult to have a sister who is a PW child. Difficult in the sense that it is hard to realize that your sister will never be really thin, and that some people will always stare or make fun of her. Difficult to realize that your sister will never be able to experience the joys that most young girls do: (first kiss, falling in love, marrying and eventually having children). Difficult to realize that your beautiful sister may not be with you as long as you would like her to be. Don't get me wrong, I do understand what this young person is feeling. I remember times myself when I would feel self-conscious when people would stare or would meet my sister for the first time. But then I realized what a very special person and special part of my life she was and if they didn't want to accept her then I did not want or need these people in my life.

I am 25 years old. My sister is 21, and I, like this KY teenager realize that it has been hard on my parents at times in raising my sister, but I also know that had they the chance to go back and change things, they would not except maybe for my sister not to have some health problems that she recently experienced. My sister is a beautiful, exceptional person. She has more friends than the average 'normal' person. She is now working at a job in which she was placed five days a week and loves it. She just stood as godmother for my cousin's child, and when I get married, she will be my Maid of Honor. The only time I question God about my sister is when I really think of how much she will have missed in life, but then again maybe she is much better off than I realize.

SIBS cont.

My family has been brought much closer because of my sister. My sister has enriched my life more than anyone that I know. She also makes me very happy. Although everyone has to deal with their difficulties differently, I hope as this young person grows older he or she will realize that above and beyond the difficulties involved with being the sibling of a PW child, there is more to experience with them: Happiness, Joy, and most of all Love! I love my sister very much.

Thank you for letting me express my opinion on a subject which I am sure holds no boundries as far as feelings are concerned."

DID YOU KNOW?

Fresh tomatoes are an excellent source of Vit. C, A, and potassium.

Potatoes (3/4 c mashed) are only 93 calories. Also contain Vit.B2, B3, folic acid, some calcium and phosphorus. They are low in sodium, high in potassium, contain iron and magnesium.

Eggplant is high in Choline, a B-complex vitamin that helps the liver break down dietary fats. It's also considered a diuretic food.

Kiwi fruit is very high in potassium and Vit.C, substantial amounts of Niacin, Vit.E, and low in calories (only 46), and high in crude fiber. Great for diabetics. And low in sodium.

A lot of people think vitamins can replace food. They can't. In fact, vitamins can't be assimilated without ingesting food.

It's best to space your vitamin supplements as evenly as possible after meals. If you must take them at once, do so after your largest meal.

LOW-CAL DRESSING

Use Good Seasoning mix and add: 1 c. V-8 juice, 4 Tbsp. lemon juice and 4 Tbsp. of water. It tastes good and is totally fat free.

BOOKS

"SLIM CHANCE IN A FAT WORLD" Behavioral Control of Obesity, has been around for some time and recommended by some professionals. Research Press, Box 3177, Dept. D., Champaign, IL 61821, has the following available:

Condensed edition, papercover, 168 pages, Item 0623, \$8.95 + \$2.00 shipping
Program Cards for professionals direct weight control programs, item 0615, \$2.95/set + shipping.

Professional book, papercover, 254 pages, Item 0608, \$11.95 + \$2.00 shipping

Research Press states: "Written in a nontechnical style, the condensed edition is designed for the dieter. It provides a sensible and medically sound program for losing weight and keeping it off. This edition features the same practical principles presented in the professional book, but eliminates the research data which are of more interest to the therapist. Self-management procedures are emphasized and current developments in nutritional research are included. "

CONTRIBUTIONS

To review our policies, we are a non-profit 501C-3 organization and all donations are tax-deductible, but we have three specific designations for contributions as follows:

GENERAL OPERATING FUND - Income is from regular payment of dues, fees for publications ordered, 20% of monies donated for Research. Any amount added over regular dues and any donations specified for general fund are placed in this fund. Operating expenses are paid from this fund. At the present time we are coming out in the black because we have very little overhead (no office rent, very little salaries and reimbursed expenses).

RESEARCH FUND - (Set up July, 1982) - This fund is regulated by our total worth and at the present time 80% of monies donated to this fund are kept for research grants. Regulations state all donations not specified for other purposes (including memorial donations) go into this fund.

CTM CLUB FOR NATIONAL DEVELOPMENTAL CENTER - (Set up May, 1984) - Only funds specified for NDC are placed in this fund. When started we had hoped to be able to open a center within 12-18 months, but because the fund has not grown sufficiently we are still working on building it up to a useable level. The NDC would serve as offices for PWSA, a crisis center for immediate placement needs, training center for vocational needs, training center for group home staff, research center, and permanent residence as needed.

In 1985 the following monies were donated to these specified funds:

<u>National Development Center</u>			<u>Research</u>
Jan, Feb, Mar	\$4441. / 1441. / 4172.		685. / 130. / 476.26
Apr, May, June	6931. / 1086. / 4290.		245.83 / 160.29 / 308.91
Jul, Aug, Sep	566. / 865. / 2371.		576. / 140.79 / 1815.
Oct, Nov, Dec	1155. / 918. / 4600.		394.71 / 400.62 / 1830.

NDC Total: 32,836.00 minus resale items
733.40 = 32,102.60 gain for 1985.

RESEARCH TOTAL: 7163.41 - questionnaire
and one grant, 5133.60 = 2029.61 gain 1985.

OUR SPECIAL THANKS to all members who made any type of contributions in the months of November and December. We appreciate those who are able to add additional amounts to the regular dues and those who make regular contributions. Nov-Dec contributions for the Research Fund were received from Hayes, Pruet, Sageser, Van Zomeran, DeHaan, PW KY Chapter, Nashville Comm.Church, Capital Area United Way, Ulland, Sojka, Fick, Langenbucher, Flick and Maurer. NDC was from Parent, Mitchell, Boyd, Wyka, Castle, Flick, Sunde, Novak, Rangitsch, Lincoln, Breneisen, Chausow, Nanzig, Miller, Levikoff, Simmons, DeHaan, Castelli, Luhman, Abell, Gordon, Burleigh, Sauter, Sturgis, Sidlo, Wett, Westbrook, Daly, Sharp, Fritsche, Greenswag, Hruska, Doolittle, VanZomeran, and Goff. Very generous donations were received from members Fuller and Inwood for the Research Fund and from Barkeley and Beltran for the NDC fund. OUR HATS OFF TO ALL OF YOU FOR YOUR CONTINUED SUPPORT.

THE NDC TOTAL FUND NOW STANDS AT \$58,257.56 (Plus a promise of \$25,000 matching grant).

THE RESEARCH TOTAL FUND NOW STANDS AT \$11,946.64 (One grant of \$4040. was paid in 1985).

HAVING TEA PARTIES IS "NORMAL" LIVING

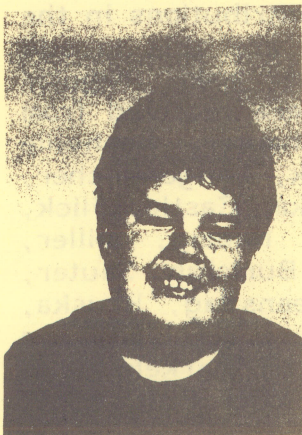
A recent exchange between a PW parent and a school system has brought to light an aspect of special education of which we all should be wary. Part of this child's education program included a "socialization" period when the children played with toy kitchens and had "tea parties" where they learned how to serve and share food with their classmates.

Although it is important that persons with PW, like other children, learn how to socialize and get along with others, teaching young children that food is involved in "normal" living and typical socialization is doing them a disservice. We're all too aware that our children's special problems with food will unavoidably lead them to a lifestyle without an emphasis on food, and chances are they may never find themselves in a situation where they will be responsible for preparing a meal. Encouraging our children's teachers to avoid using food in any form in the classroom can only make early acceptance of food control easier for our children with PW.

We'd like to also encourage parents to be as knowledgeable about their child's education program as possible. By asking about a child's program, not only can parents find out about possible areas of instruction which may involve special problems for people with PW, but they can also show their children's teachers that they are interested in what the educational programs are trying to accomplish and willing to be a part of the educational process.

Editor's note: I recall several years ago when sitting on a PTA board, a mother came with a list of what she considered "sexist infractions" in our elementary school. We all laughed at the top of her list, pink doors on the girl's bathrooms, blue doors on the boys. But when we think about the many hours of our children's lives that are spent in schools, it is important for that teacher to know the normal life of your child is going to be different, and now is the time to talk about and learn to accept that.

THIS IS DUSTY



Dusty -Age 9

Dusty's mother was not only nice enough to share the picture with the GV, but also writes about one of Dusty's talents: "...I would like to know if all PW kids are as quick at putting together puzzles as mine is and has been for years. While visiting his Grandmom's recently he had a race with his 11 year old brother and 11 year old cousin. The two of them were given a 100 piece puzzle to put together and Dusty was also given a 100 pc. puzzle to put together alone. You guessed it, Dusty won the race easily. My Mom used it to make a point to the two older boys not to tease Dusty just because they do most things so much better than he, because we all have things we are good at and puzzles is one of Dusty's!"

Thanks for sharing this with us; we love to hear about the special things that persons with PW are capable of accomplishing! Puzzle-making ability could easily be listed as one of the signs of PWS, we hear about this from many parents.

GUARDIANSHIPS

Questions that come up about guardianship:

Aren't we, as parents, natural guardians? You are only as long as the child is a minor, at age 18, this ends. At that time your daughter/son becomes a legal adult, with the right to make their own decisions.

What are their legal rights? Legal rights include the right to vote, marry, sign contracts, obtain credit cards, refuse medications and chose their own place to live.

What is a guardianship? If a person lacks the capacity to make competent decisions in any area, they may need a guardian to be their substitute decision-maker.

Is there only one type of guardianship? No, there are two types of guardianship, private and state. Private guardianship is usually preferable, because it enables you to recommend someone you know and trust to make important decisions. This guardian can be a parent, sibling, or any other interested relative or friend. A state appointed social worker may not have the necessary knowledge to make important decisions for your child.

Are guardians financially responsible? No, you are responsible for seeing that the basic necessities are provided, but this can be done through a variety of payment methods.

Will a guardian be automatically appointed when a person who is MR turns 18? No, guardianship require court hearings. If you do decide you want to proceed with this, it is recommended that an attorney be obtained, one who is acquainted with guardianship laws and the special needs of a person with PWS.

Are there other options? Conservatorship is a limited type of guardianship. Other options are less intrusive and do not require court hearings. You may only want to be appointed a financial representative, but we do recommend that you think seriously about what decisions you feel your child is capable of making without your help.

No form is right for everyone. Give serious thoughts to what the needs are.

PWSA now has the wording for establishing a trust for your child. These are recommendations that you may use when talking with your own attorney about providing for your child in your will. A payment of \$2.00 is appreciated to cover the cost of printing and mailing.

A PWSA board member also suggested at the last meeting that we make available a list of trustees that could be used when people are establishing trusts and wills. If you are interested in this being done, please let us know, as it will be talked about at the next board meeting.

HEPATITIS B PREVENTION

We have received several bulletins and articles recently regarding Hepatitis B vaccine. Residents for people with mental retardation appear to be at a higher risk for developing Hepatitis B infection. Therefore, it has been recommended that residents of ICFMR (Intermediate Care Facilities for the Mentally Retarded) are to provide Hepatitis B Virus (HBV) Vaccine.

Hepatitis B can be a minor flu-like illness, or a very serious disease. It can cause liver failure and is the single largest cause of primary liver cancer. There is no way to predict whether an infected individual will have a mild illness or a severe one, and since there is no effective treatment for the disease, prevention is imperative. If your son/daughter are living in this type of facility, we recommend you inquire about this vaccine.

THE IMPORTANCE OF RESEARCH

Following the last conference and Dr. Beltran's comments on the importance of autopsies, Dr. Suzanne Cassidy made some inquiries and found a pathologist who is very interested in dysmorphology and clinical genetics. This doctor, Will Blackburn, is in the Dept. of Pathology at the University of South Alabama. Dr. Blackburn wrote us: "My interest in this syndrome had been one of long standing, originating at Babies Hospital in NY and carrying over to my work at the Universities of Colorado and PENN ST Medical Centers. Even with some 3,000 necropsy experiences, I have examined only two of these children. Thus any sort of national coordination of such studies would greatly enhance our understanding of the disease complex, particularly at its end stage.

I believe that an effort should be made to identify the problem areas (e.g. CNS, respiratory, endocrine cardiovascular and reproductive systems) and ultimately develop a study protocol designed to answer many unsolved questions. In short, we should carefully plan necropsy studies in such a way that the greatest quantity of data can be harvested. "

PWSA has met with Dr. Blackburn, and is very happy for his interest. He is willing to fly anywhere and make arrangements for other pathologists to complete studies. With the same doctors doing autopsies, information can be obtained that would never surface otherwise. We are asking our membership to please consider giving PWSA a call immediately following the death of a person with PWS. We could then immediately contact Dr. Blackburn and have these arrangements completed. We are all aware that a greater interest in this syndrome is essential in order to find the answers that can be of value to our living children. We do hope you will think of others at the time of your loss.

GROUP HOMES

"In February of 1985 Edwin had an infected tooth, the flu and a sore throat, all in a 3-week period. He was taking medicine of different kinds for all three. One morning he was confused. I took him to his work activity center, they brought him home saying he was still confused and in danger at work. He became very hyper, was hospitalized and found to be a borderline diabetic and also found lots of small gall stones. We just could not handle him after his return home, and we ended up with a placement in a state hospital. His weight has gone from 240 lbs. to 165 lbs. He is happy there, he comes home frequently. He goes to school half days now and works in a bike shop. His diabetes is now gone with the weight loss and also his asthma. We hope that a group home will be available some day but for now this is a good placement."

We are happy to report progress is being made in several areas for group homes. Openings are near in the State of Michigan, State of Illinois, State of Missouri and Wisconsin to at least serve a few of our young people.

LIVING MEMORIALS

At the request of a member, we have developed a card which can be sent by PWSA or requested by any member, to be used as a "living memorial". These cards state that a gift has been made to PWSA in their honor. Of course, we still also have cards to be used for memorials to friends and relatives, in the event of a death. Please let us know if we can furnish these for your use.

DIET TIPS

We thank a NY member for sharing some tips and menu plans with us. She writes: Durkee is the spice company that makes butter flavored salt. Great for corn instead of butter, also for popcorn, noodles, rice and potatoes. Tastes delicious. She also shared this recipe: Mini Fruit Kabobs: Thread small wooden picks alternately with cubes of firm cheese and assorted fruit such as seedless grapes, pitted cherries, pineapple chunks, strawberries, blueberries and diced melon. Arrange on a serving tray with a dip made of honey-sweetened yogurt, thinned with orange juice.

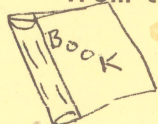
She also included a full week menu plan that she found in the October, 1985 Ladies Home Journal. Her daughter followed this diet and lost 2 lbs. a week, but she pointed out it was important to follow the diet exactly. Monday's calories were 165 Breakfast, 170 Lunch, 400 Dinner for a total of 735; Tuesday, 155 Breakfast, 170 Lunch, 430 Dinner for 755 calories; Wednesday 155, 150, and 405 for 710 daily total; Thursday, 160, 150, 410=720 total; Friday, 155, 165, 425=745 total; Saturday, 155, 150, 410=715 total; Sunday 145, 140, 400=685 total.

Breakfasts included cereal, fruits, eggs, toast, and cheese. Lunches included meat, bread, vegetables, fruit. Dinners included meat, vegetables, fruit, fish, fowl. We are sorry space does not allow us to reprint this whole diet, but if you are interested and cannot obtain a copy of the magazine through a friend or the library, please write and we will mail a copy to you.

SUCCESSFUL FUND RAISER

\$ "The Open House/Fundraiser was a success! It was a beautiful day and we had a good turnout--a real family affair. The tupperware dealer was great. She put together the invitations with a PWSA brochure, a catalog, and mailed them out, 120 plus. We did refreshments, open house greetings etc., distributing all of the ordered tupperware. It was a relatively easy way to do a fundraiser. We especially like this because we wanted to do an Open House to greet relatives and friends, and to get widespread exposure for PWSA via the brochures. We had excellent response re the brochure--it's so concise and clear. So much easier than trying to explain the syndrome. Thanks a million for sending the brochures, and everything. Enclosed is a \$250.00 check for the National Developmental Center." \$

Our thanks to Judy for her efforts on our behalf. We do have a copy of the invitation if anyone is interested in seeing how it was done. 15% of the proceeds from the tupperware sale were donated.



A group of midwestern professionals has recently published a book designed to help families cope with caring for a person with a disability or illness. Meeting the Challenge of Disability or Chronic Illness: A Family Guide, by Lori A. Goldfarb et al, is designed to be used by families to take stock of their situation, find help, and develop a process for making difficult decisions. It includes suggestions and exercises a family can use to improve communication and work out difficult problems. The book is available from Brookes Publishing Co., PO Box 10624, Baltimore, MD 21285-0624, order: Stock #559/Goldfar.Mtg. The Challenge \$14.95. PWSA will order this book for our library and review it later.

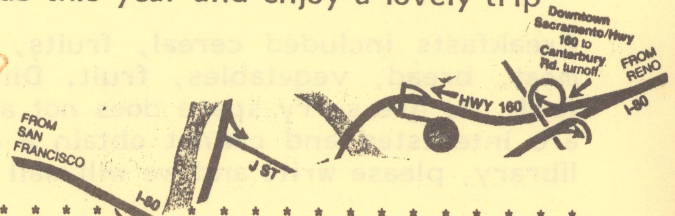
TIME TO MARK YOUR NEW CALENDAR!!!!

The contract has been signed with the WOODLAKE RESORT & CONVENTION HOTEL in SACRAMENTO, CA for the 19th, 20th, and 21st of JUNE, 1986, for the 8th ANNUAL PWSA CONFERENCE.

CHAIRPERSON MARILYN BINTZ has been able to obtain a block of rooms reserved at the unbelievable rate of \$40./single, \$46./double & up. A great effort to keep the cost of attendance as low as possible.

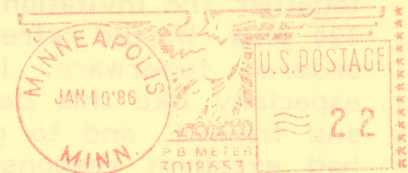
A tentative agenda and all the information you will need for registering will be bulk mailed to all members in March. Now is the time to inquire about good airline rates. Pre-registration will start on the evening of the 18th and continue the next morning for later arrivals. Activities will be planned for all day Thursday, Friday and end late on Saturday afternoon. (Bulk mail is not forwarded--be sure we have your up-to-date mailing address before this mailing.)

JUST ASK YOUR FELLOW MEMBERS -- attendance at these conferences can't be matched. Let's break all of our attendance records this year and enjoy a lovely trip to California.



 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 and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.

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