THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION
DELFIN J. BELTRAN, M.D., PRESIDENT
MARGE A. WETT, EXEC.DIRECTOR

5515 Malibu Drive
Edina, MN 55436
(612) 933-0113

VOLUME X11 MAY - JUNE, 1986 NUMBER 3

PRESIDENT'S MESSAGE

Have you made your plans yet? Will you be in Sacramento for this year's conference? Just like all the junk mail that comes across my desk. Junk mail loaded with questions that are designed to entice me into going somewhere, doing something, donating to a cause, buying something, subscribing to a new magazine. Every day after I read my "mail" I have to take the garbage out.

But, if I don't catch your eye and direct your actions to continue reading, you might just pass me by. Did you ever while away the time during a lull in your life, (usually waiting for someone or something to happen) by giving inanimate objects life and a character of their own. I remember waiting for time to pass until it was time to board an airplane, looking at the bookcovers on the salesrack. I imagined them as people looking for someone to find them attractive enough to want to spend $3.95 to save them from some eventual doom, never read, never given the opportunity for someone to have the joy of experiencing what lay between their covers. What would cause a person to pick a particular book. Is it the size, short flight -- short book. Or it it the picture on the cover, or perhaps the author who gave you pleasure in a previous book, or maybe the title, "How to be a Millionaire, without lifting a finger" (you just know he's lying because you have to lift your pinky to turn the pages). Most of the time you have a mindset that needs fulfillment. If you are lucky, the picture on the cover catches your eye, the author's name is recalled and the title fits your mindset.

Mindset is important to how our lives are conducted. Decisions constantly face us. Even as I sit wondering how I am going to get a message across I am faced with decisions that permit me to go on with my ramblings or if I fail to make the decision I sit paralyzed into inactivity, wasting another of those limited minutes.

This is the season that we think about Prader-Willi Syndrome and the Annual Conference.

Now that I have your attention, how is this for a hair-raiser; donations to the National Developmental Center are now above the $100,000.00 level. Elsewhere in this edition Marge Wett will bring you up to the minute figures at press time. I just wanted to congratulate all of you who have made this level of effort possible. I also want to encourage all of you to continue the effort. My personal plan has been to make it an active part of my monthly budget. The number of causes that solicit our funds is endless, but I have responded to each of them by saying that my donated funds are going to the Prader-Willi Syndrome National Developmental

PRESIDENT'S MESSAGE (Cont.)

Center. This not only gets me off the hook to a batch of causes that I wanted to get away from but it also keeps my focus on the NDC goal. This is going to be my goal 'cause call it what you will, this is it until it becomes a reality. It won't happen overnight and I've given up the idea that there are angels waiting to dump large sums on my favorite cause. It will happen just as this organization has grown from a start of a few concerned persons, by continued active interest.

P.S. - don't throw this in the circular file yet, read on and then make your plans to join your friends in Sacramento in June.

Delfin J. Beltran, MD
President

FROM JANE BRODY'S GOOD FOOD BOOK

Satisfaction from high-carbohydrate meals is that the starchy foods come along with a low-calorie belly-filler--fiber. Fiber is plant material that cannot be digested. It is found in substantial amounts in all unrefined grains (whole wheat, rye, corn, oats, brown rice, etc.), dried beans, peas and all fruits and vegetables. Refined starches also contain fiber, but much less of it.

On average, fibrous foods take longer to eat than meats and dairy products, thus they slow down the consumption of calories. In other words, although you may spend more time eating, you actually consume fewer calories on a high-fiber diet. Furthermore, fiber takes up space in your stomach and small intestine, where it absorbs water and slows down digestion enough to prolong feelings of satiation. Then it is passed along to the colon, or large intestine, where it acts like a Roto-rooter, helping you to eliminate solid wastes without stress or strain. In the colon, resident bacteria partially digest some of the fiber, producing gases that may be absorbed by your digestive tract. But most of the fiber is excreted without making any caloric contribution to the consumer.

Thus, fiber gives you something for nothing, and eating high-fiber foods as part of your regular meals and snacks can help you to achieve and maintain a normal body weight. Fiber is best known for its laxative effect. People who live on high-fiber diets are almost never troubled by constipation. Nor are they likely to develop hemorrhoids, diverticulosis or a host of other intestinal problems, including cancer of the colon. Adding fiber to the diet actually increases the amount of fat that you excrete, which might help protect against heart disease as well as assist in weight loss. Fiber also helps to lower blood cholesterol and to maintain blood sugar on a more even keel. Since fluctuating blood-sugar levels in part influence feelings of hunger and irritability and energy level, high fiber meals also help to keep you on a more even keel. Diets rich in fiber and complex carbohydrates are now being routinely prescribed for diabetics.

Fiber is not one substance but at least six different kinds of substances, each with its own health effect. The main types of dietary fiber are: Cellulose and hemicellulose (bran, for example), Lignin (a wood substance also in cereal grains), Pectins (prominent in vegetables and fruits like apples and grapes), Gums (in oats and legumes like chickpeas), and Mucilages (in seeds).

Raw carrots, incidentally, might be a far more effective "bulking" agent than bran. Bran absorbs only five times its weight in water, whereas carrots can absorb 20-30 times their weight. To get the full benefits that fiber can offer, you should eat a variety of plant foods--grains, legumes, fruits and vegies--on a regular basis.

TEACHER'S RESPONSE

Regarding the article "Falling Into The Trap" in the last GV, one teacher wrote he was pleased to read this because even though an individual is labeled as being a member of a syndrome, their individual needs are still unique to them.

He also stated he feels strongly that the GV reinforces an adversary relationship between parents and school system. ...give the impression that school systems are monsters to be tamed.

In response we would like to point out if we had a group of 12 parents and 10 were satisfied with their school/family relationship, it would be the other two that we would hear from. Although we have never looked at the school system as "monsters", we certainly cannot state that our parents do not have problems. We would like to promote a strong, healthy relationship but we need to be of help to those with needs and we cannot do that without agreeing in many cases that the school is at fault. Our files are full of letters where problems vary tremendously from one year to another because of a teacher or school change. Thankfully we also have many letters where this good relationship does exist.

MEET REX

We thank Rex's mom for sharing a picture of him with us, celebrating his 13th birthday. His Mom writes that he is in the 6th grade EMH program and is doing quite well "most" of the time. We are happy to hear that his Mom is seeking a residential school program with the structure that Rex needs and luckily they live in a state where one exists. We certainly wish them a successful placement.



THANKS LOTTO WINNER

Linda Carraher "made our day" when we received her $20.00 donation check with the enclosed note: "Wow! I won the Lotto -- your 10% came to $4.33 so I rounded off the amount. Use where needed!"

Now we need Linda or one of our other members to win one of the "biggies".

8th ANNUAL PWS NATIONAL CONFERENCE

JUNE 19, 20, 21

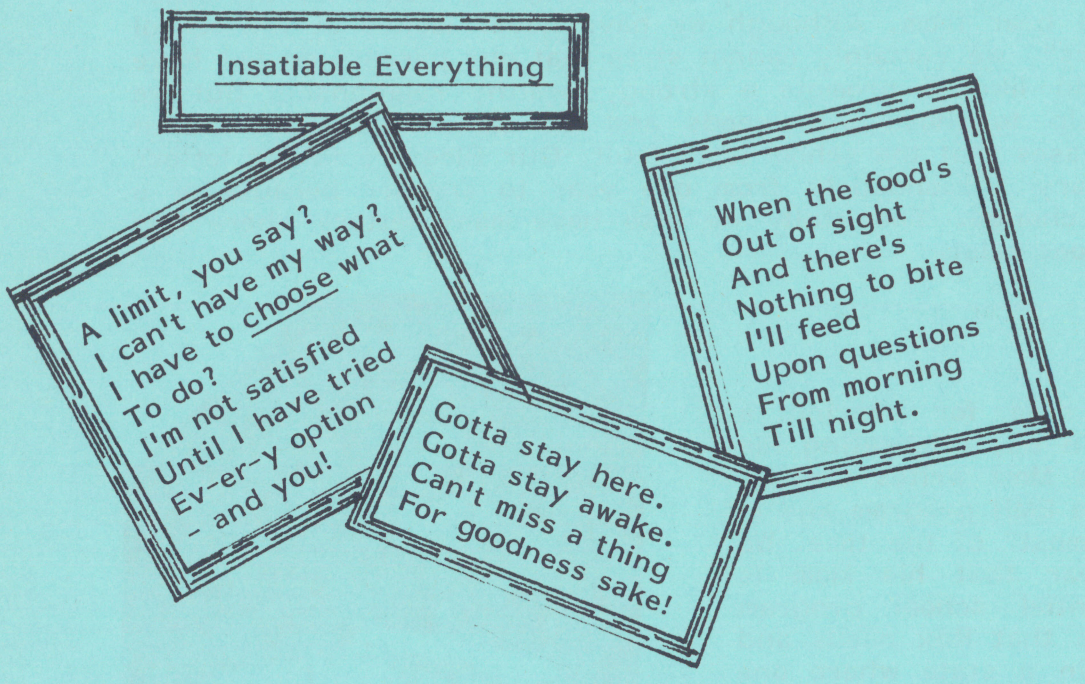
TIME'S AMOVIN' Help the planning committee, mail your reservation NOW.

(If you didn't receive the pre-registration packet by now, the PO has let us down. If you need one, just let us know.)

POSTERS AND POETRY

Luckily our members are always attempting new ways of advancing our contributions. Member Ray Sharp's company has 2000 posters. These are quality posters, a photograph of the Head of the Statue of Liberty, by a known photographer Jay Maisel. OKAY imaginative members, how can we make some money on these???????????

Member Betty McKeen has donated a small 18 page booklet entitled, "Prader-Willi Poems" which she has written. We would be happy to share these with members for a contribution of $2.00. It was hard to choose just one poem to share with you, but this is the one we picked:



RAFFLE TIME

Each year we ask our membership to support our conference by raising money through a raffle. We had an order form in the last GV but neglected to mention the prizes.

1st PRIZE $500 **2nd PRIZE $125** **3rd PRIZE $100**

With our restricted sales we offer better odds than most can offer. Right now the odds are too good - we've got to have some additional sales. If each member just ordered one book of tickets, the raffle would be a success. Surely everyone can find a couple of people willing to buy a $1.00 ticket.

Please use the order form today.

ANNUAL FUND RAISER FOR CONFERENCE COSTS

Please send _____tickets, which will be bought or sold for $1.00 (6 for $5.)

NAME_____ADDRESS_____

_____

We also have some pens left that can be sold for 50¢ each to support this project. Order # wanted here_____. If the tickets are for personal use, save time and money, just check here_____--we'll fill in the stubs for you. Checks can accompany order or payment can be made when sold. Unsold tickets can be returned.

We wish we had a better way to say thanks. This is a very insufficient way to thank the donors who responded to the McDonald Challenge. BUT IT IS TRUE -- we met that challenge by the middle of April due to the February donors, the members listed below and their friends and relatives.

Our members (118 of them) shared the names of 1170 people. From these contacts we have received $10,846 and they are still coming in.

The NDC Fund Total is now $104,288.39. ISN'T THAT TREMENDOUS. Our membership has given us a very definite signal that challenges can be met. Are we going to keep these donations coming in order to meet the goal of at least $300,000 to get our CRISIS CENTER started?
We thank the Hallers for the big boost -- we thank the members who responded with their efforts -- LET'S NOT QUIT NOW.

NATIONAL DEVELOPMENTAL CENTER FOR PRADER-WILLI SYNDROME -- it can be a reality, it's up to all of you.

DONATIONS: End of February thru April 25th

Ayotte
Boston (2)
(Young)
(Smith)
Burleigh (Bowles)
Cortellini
(Falisi)
Donlan
Flick (Lepre)
(Payne)
(Em-Ro)
(Giorgi 2)
Hutchins (2)
(MacLeod)
(Giles)
Ingalls (2)
(McMurdo 2)
(Bretlin)
(Stone 2)
(Guntor)
(Sullivan)
(St.Germaine)
(Budnik)
(Russell)
(GFW Club)
(Cardin 2)
(Young)
(Lamoureux)
(Lacroix)
(Starkey)
(LaPierre)
(St.Denis 2)
(Morton)
(Boucher)
(Wentworth)
(Lamplighters)
(Lucchesi)
(Snow)
(Herbeck)
(Olmstead)
(Jones)
(George)
Trokey
Veziroglu
Vermeulen (6)
(Perry)
(Rener)
(Fahrner)
(Gallager)
(Pizzimenti)
(McLain 2)
(Lorenz)

Atwood
Brewi (4)
Boyd (4)
(Cairns 2)
Braun, B.
Carlyon
Daly (2)
England
Fick
Forthman (Fritz)
(Pickett)
(Kelly)
(Brooks)
Haller (McDonalds)
Hall, S. (Conrad)
(Singman-Dietz)
Kuhne
Kubichek
Keepers
Lehman (2)
(Hodgin)
(Laws)
(Perry)
(Beck)
Maranon (3)
(Brewer)
(Brown)
Mitchell (4)
(Dodds)
(VanCleef)
Nanzig (2)
(Duncan)
(Valliere)
(Hackett)
(Napovier)
(Kelly 2)
Reiss (Weinberg)
Sheeran (Ciancio 2)
Sturgis
(Passantino)
Scheuner
Tobin (Trask)
VanZomeren (2)
(Diehl 2)
Walczak
Wett (Med.Anes.)
(Schaefer)
Youngblood
(Peppas)
(Beecheler)

Amren
Beltran (2)
Boorn
Bell,R.(Nichols)
Carr (IBM)
Chiang
Dixon
Eggers (Kelly)
Foley
Gilmore (Voorhess)
Geller (3)
(Meyer)
(Newman)
(Rotary Club)
Hamisch (Foster)
Jacobs, J.
(Cole)
(Pike)
Krauss (3)
(Busalacchi)
(Neugent)
(Stieber)
(Tobias)
Levikoff
Marcovici
Manchel-Ponsko
Miller, DJ (3)
(Ruddle)
(Blackfan)
(Chimples)
(Presto)
Noll (2)
(Shepard)
(Gomeringer)
Pflieger
Robinson
Redeen
Sauter
Schramm
Shartar
(Solmssen)
Trentacosta (2)
(Bodner)
Wilson
Willott
Webb (Martin)
(Steinmetz)
Yoncha

Abell
Baletsa
(L'Italien)
(Chaput)
(Spychalski)
Cooper,H.
Dunn
Evetts (Mercer)
(Ridling)
Gunnison
Hadsall
(D'Alessandro)
(Francavilla)
(Marchese)
Hambrick
(Henniff)
Krafts (Jenning)
(Molnar)
Krauer
Lincoln
LaBossiere
LaMotte
Levine,A.
Lynch (2)
(Watkins)
(Abbott)
(Covney)
(Pesce)
Maas
Noordzy
Notbohm
Noffsinger
(Tucker)
Ponti
Ryan
Raymond
(Hair Cor)
Sojka
Schmidt
Shaw
Thomas,D.
(Trump)
(Sinkbell)
Werner
Wicks
Wolcott
(Gosey)
(Whitty)

Bishop (Jones)
Breneisen (2)
(Crotti)
(Pearce)
Clubb (Torrini)
Carter, R.
Castle (2)
(Kuzmanick)
(Graham)
(Bondurant)
(Clinton)
(Tippie)
(Carr)
(Wickersham)
(Herbst)
(Townsend)
(Palmer)
(Potter)
(Beringer)
(Turner)
List (Harrell)
LaPenta
Litke
McNanney
McEttrick
Maurer,R.(2)
Murphy, J.
Miller, Cl.
Martin,R.(Clasen)
Novak (Schoepe 2)
(Kokoshka)
Ouillette (Foley)
Persanis (Lipetz)
(Larkin)
(Zaffarano)
(Zicchinelli)
(Lake)
Schneider
(St.Norberts 2)
(Simon)
Townsend (Furr)
Ulland (Nelson)
Vice (2)
Watson, J.
Wagstrom (Vikingld)
Wyka (3)
(Walczak)
(Bahr)
(Rosa)
(Humenik)
(Nieglos)
(VanBaaren)
(Marciniak)

Bryant
Bach, G.
Belville
Bowdre
Cole Cty.
Cillo
Dennis
Eager
Gordon
Gardner (2)
Hjort
Horlick
Howe (2)
(Ruttner)
Int.Machine
Korte (2)
(Transue)
Krocka
Lacy
(McCoy)
(Gales)
LaBella (2)
(Marik)
(Harvey)
(Mulcrone)
(Sorenson)
Mueller
Miller, Ch.
Mays
(Bristol)
(Walden)
Olivo (D'Elia)
Parent
Parker, P.
Reiman
Ray (Gooch)
Smith,S.
Stege, W.
Shacklett
Sharp
Thomson
Umbaugh
(Miller)
(Wagner)
(Reedy)
(Klotz)
(Walters)
(Haney)
(Thornton)

(Cooley) (Small) (Pence) (Martin 2) (Heidel) (Klinect) (Stanley)
(Lenihan) (Mahar) (Matesa) (Roosen) (Trader) (Howard) (Hoffrichter)
(Georges) (Oliver) (Hafeli) (Kappler) (Gregorich)

TV DINNERS

A member shared this helpful hint, Use TV dinner trays for your child with PWS. You can fill the tray (plate) and because it's a TV dinner it is already understood there are no second helpings. (The aluminum trays are best as they look bigger). Also, Swanson TV dinners have the calorie amount on the back - many are around 350 calories. The nice thing is there is a small dessert included so the child doesn't feel left out.

PARENTS QUESTION KARATE

Last issue we ran an article regarding the success of a karate program for one of our young children. A couple of parents questioned this instruction. "How is this mother going to control him when he is 15, having a temper and doesn't want to be controlled? I have a nephew that was given Karate lessons to help him learn self-control and discipline. He has temper problems, like PWS kids. He just put his little brother in the hospital, has kicked holes in every door of their house and caved in the side of the refrigerator. Giving a kid with temper problems Karate is no different than giving them a gun."

This "other side" is something to consider. Has any of our members with older children had the experience of karate?

TRI-STATE MEETING

The Tri-State Chapter will be holding their spring meeting May 17th in Mansfield, Ohio. Location; The Center, Rehab. Serv. of NC OH, Sterkei Blvd., no youth program this time, pot luck lunch. For more information: PAM VOGT Box 3182, Lexington, OH 44904.

WEIGHT LOSS

"I wanted to share how proud we are of Lee's weight loss. He has lost 60 lbs. since last March (1 year). He was 246 and is now 186. He feels so much better, disposition is better. This has been accomplished by cooking his food separately, preparing everything instead of buying ready-made. Needless to say, this is alot of work but, being the only child at home, it's possible. I should add, locks on refrigerator and pantry. "

CIRCLE OF FRIENDS

In the last GV we described an adult pen pal traveling letter. We have started three circles of friends and anxiously awaiting the privilege of reading the sharing and caring of our members. One group was not started because we did not have enough response in that age group. If you have an adult child with PWS and would like to correspond with other parents, please let us know so we can get this circle started. If you have a younger child you may still submit your name as we will start additional groups as needed.

OUR SMILE FOR TODAY

One mother wrote that their daughter did not speak until a friend (a drama teacher) worked with her for six months. She said, "Now we wonder why we paid for lessons, she never stops."

WHAT IS THE NDC OR CTM FUNDING CLUB?

Over the past couple of years we have printed several articles related to the reason we are having fund drives to open a National Developmental Center for PWS, and yet we still are questioned what we are trying to achieve. Please allow us to review for those who do not know or understand, what we are attempting to accomplish.

Due to the fact that facilities are not available in every state, parents find themselves in a situation where out-of-home placement is necessary and have no where to turn. The following letter may point out this need:

I am a single mother (due to a seperation & pending divorce because of alcoholism). I have 3 sons...(son with PW is 14). I never thought I would consider finding placement for my son in a group home until he graduated from....school....but the circumstances have changed considerably. I feel it is at a crisis point! I use to feel the uncontrollable desire to eat and weight was the biggest problem but I now feel it is his behavior that has become the major problem. It has become almost impossible for our family to cope....He has been rapidly regressing in all areas. His behavior is ...unmanageable...he is very argumentive, stubborn, unreasonable and uncontrollable. When he makes up his mind to do something there is no changing it...When discipline is used he lashes out in anger and fits of temper.... he needs constant supervision...he starts fires in his room...leaves ...goes into neighboring homes....stolen food or messed with belongings in other people's garages ... cannot be trusted to cross streets but goes...makes expensive phone calls by just dialing numbers...cuts electrical cords... destroys valuable belongings of ours and others...plugs the toilet with tissue and trash....picks skin. He gets into my and his brother's bedrooms...messes them...destroys belongings or steals money and tears it up into pieces...steals possessions. ... will dump a full bottle of shampoo into bath...uses full roll of toilet tissue at one time...gets into medications. He has no constructive passtime that he enjoys, therefore taking privileges away from him as a form of dicipline is almost impossible.

I can no longer find child care for him because sitters refuse to take care of him or those who are willing can not be trusted to give him constant supervision or just can't manage him. (The mother continued to describe attempts of varied employment etc.) My mental, physical and emotional health is exhausted. I am at my breaking point! Life for all of us has become very stressful. We all feel cheated of a normal life. His brothers have a lot of anger and resentment toward him. We feel we have no freedom to live our lives the way we wish. .....

This child and this family deserves to live a different life than they now find themselves trapped in. The National Developmental Center would serve as a crisis center, available for the mother above and others either on a temporary or permanent basis if necessary. We would hope that a one to two year placement would enable us to develop a plan for this child's needs and he could then be returned to his own state and served properly there. By developing a plan, we want to offer placement for all young people, not just those who can afford to privately pay for care or are able to obtain state funds. This plan would include a workshop designed to be operated for the young residents and senior citizens, and hopefully could eventually become self-supporting. Other very important desires are in the area of research and space for a permanent office for the national PWSA. Having a national center would also open the opportunities for PWS to become a known entity which is very important.

We are attempting to serve our membership in a way that is desperately needed but cannot do so without the funds.

WISCONSIN PICNIC

In an effort to develop interest in a support group for residents of Wisconsin, a picnic is being planned for June 22nd at the Alpine Valley camping area near Elkhorn.

Please call Marianne Garvens at (414) 642-9489 for details.

A CA MOTHER WRITES:

A word of hope and faith: I worked alone with (my daugher) for 22 years after being told she was so retarded she'd be a "vegetable" all her life. She is now 33, a very lively, active "vegie". Goes to workshop...writes articles for workshop newsletter, took part last summer in Special Olympics Track and Field winning 8 medals including 2 gold. Helps other clients at workshop to read and subscribes to a San Diego newspaper and the National Geographic Magazine. We are so proud of what she has achieved.

DEAR PWSA:

Enclosed are donations we have collected from family and friends. We received your newsletter stating that McDonalds will match the $25,000 goal you are trying to reach. We know you'll make it. We will try to collect more whenever we can, because we know how important it is for the National Developmental Center.

Our daughter, Kelly, ...4 yrs. old,...was diagnosed at 3...and we feel very lucky she was caught young. With the help of family and friends, her doctors, teachers and dietician, she is doing great. She's lost not only pounds, but inches! She's happy most of the time and has bad days, but other than being a few pounds overweight, you can't tell she's'special'. I use the word special because that's what she is. She brings us so much joy and happiness, we couldn't imagine life without her. She's beautiful, loving, and the simplest things make her happy. She's doing great in school..loves it...they love her.....

A few words of advice for other parents - DON'T GIVE UP! This is your child and do whatever it takes to get all the help you can for your child. Talk to the teachers at his/her school. Tell them about PW and what you feel your child's needs are. If they are really dedicated and caring they will understand and do their best. Dieticians have been very helpful to me also. I've explained Kelly's problems with her diet and they have given me good tips and places to write for dietary material. They will also send you anything helpful for your child's diet. The American Diabetes Assoc. has numerous books and recipes that are sugar-free and low-salt/no salt. Book stores and libraries also have many books and magazines...Kelly's pediatrician has helped us tremendously. ....(Food exchange has worked best).

As for Kelly's bad days--when she's had a tantrum or two or is just getting frustrated, we do something with her she really likes. We take a walk or ride in her favorite wagon or she loves to walk the malls at the shopping center. ... buying a coloring book makes her bad day all better and is more pleasant for all of us too!....more than anthing give lots of love--hugs, kisses and tons of praise...Don't worry about the future...enjoy your child now. (This mother also offered to share tips if you want to write to PWSA for her address)

PARENTS INTERESTED?

"My name is Mary Jo Thorpe. I am interested in starting a PW Parent Group in the DC, VA and MD area. I live in Fairfax, VA. Anyone interested please contact me at (703) 273-4208."

HANDY FROZEN SALAD

Frozen Fruit Slush Salad: 12 oz. 7-up or Sprite, 2 large bananas, sliced, 6 oz. can frozen orange juice, thawed, 15 oz. can crushed pineapple, 2 (10 oz.) pkgs. frozen raspberries or strawberries, thawed, 6 oz. can frozen pink lemonade,thawed. Mix together in a large bowl. Spoon into muffin tins with paper liners or other individual cups. Freeze. Thaw ½ hr. before serving. Makes 24 salads. (With no cal pop this should run approximately 20 calories per serving.

DON'T WANT RAW VEGIES?

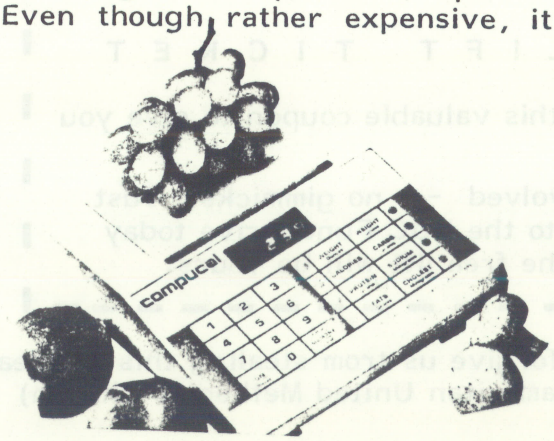
This low calorie dip may encourage the eating of raw vegetables. Zesty Shrimp Dip: Mix 8 oz. Light Philadelphia Brand Process Cream Cheese Product, ¼ c. Kraft Light reduced-calorie mayonnaise, 2 Tbsp. milk, smooth. Drain and rinse 1 can (4¼ oz) cocktail shrimp. Combine cheese mix, shrimp with ¼ c. chopped celery and a few drops of Tabasco; chill. Makes 1-3/4 cups. 2 Tbsp.=57 calories.

GUARDIANSHIP QUESTION

We were requested to repeat again the importance of obtaining some type of guardianship for our children with PW before the age of 18. Many circumstances have arisen particularly when a group home is involved, which has pointed out the necessity of such arrangements. Some parents have waited until the child was a legal adult and then have run into court situations where lawyers and psychiatrists, not understanding the syndrome, have ruled our young people capable of making their own decisions. It would be a shame to lose the possibility of a proper placement, when needed, because this was not taken care of at an earlier age. PLEASE request the information that we have on file or talk with your attorney.

COMPUCAL

One of our members shared an ad for a digital kitchen scale that calculates and displays the sodium, cholesterol, protein, carbohydrate, fat and calorie content of more than 600 foods. This scale can be ordered from 1-800-342-9988 for the price of $135.00. It's lightweight and portable, operates on an AC adaptor or on six C batteries. Even though rather expensive, it does sound pretty "snazzy".



GROUP HOME LIVING

After hearing about an inquiry that NJ members were receiving, we inquired about the new group home at the American Institute of Vineland (home actually Dorothy Group Home). We are happy to share some of the information that was written to us by Sharon Omrod, Dir. of Community Services: "....Briefly, the home serves 7 clients, 6 of whom have PW. The ages....early 20's - 30's. Staffing is 2/shift during waking hours and 1 from 12 midnight to 7 AM. We have learned a lot in the past year and feel we have made moderate success with the clients, particularly in the self confidence and esteem as well as behavior and appropriate social skills needed to live in the community. Regarding weight control, our dietician, has been most helpful in training staff and clients in nutritional, well balanced meals and monitoring on a bi-monthly basis." She continued telling us about food care and menus. Her letter concluded with, "It has been a most rewarding year for us, but I have been extremely fortunate to find exemplary staff. We still have our peaks and valleys, I'm sure we will continue to have them, however, we try to display a positive attitude and a client centered approach at all times.

It was interesting to read that last year Dorothy Group Home planted a vegetable garden that everyone took great pride in and enjoyed the bounty in their evening meals.

Dorothy Thompson, Fausta Deterling and Marge Wett were happy to have the opportunity to visit Laura Baker School in Northfield, MN. This school-residence was founded in 1897, is a private-non-profit organization which provides a wide range of residential and educational services for people who are mentally retarded. Among their 70 residents, they now have 6 with PW. Ages 15 to mid-thirties. We were very happy to hear of the success that has been achieved with this group. As one staff member stated, "I believe one of the reasons for our success is because we treat each person as an individual."

Seeing the genuine warmth, acceptance and encouragement of this staff toward their residents is encouraging.

Unfortunately, facilites are not available in every state, nor do they have openings when needed. It certainly is a goal that someday we will have proper placements for all who desire them. We mention again that PWSA cannot recommend specific places, we are happy to find out about them and share the names with our members but it is the responsibility of the parents to investigate the facilities themselves.

F R E E L I F T T I C K E T

Feeling down, use this valuable coupon to give you a lift.

No hidden costs involved -- no gimmicks. Just mail your donation to the NDC Fund Drive today and we guarantee the free lift will be yours.

(We know God will forgive us from stealing this ad idea from the Good Samaritan United Methodist Church)

Substitute use - PWSA Conference - Sacramento

MATERIALS AVAILABLE FROM THE NATIONAL OFFICE

We occasionally like to remind members of the National Office Library. We are happy to loan the following materials to members (the only charge is you must pay the postage):

Prader-Willi Syndrome edited by Drs. Holm, Sulzbacher and Pipes (now out-of-print and unavailable for purchase).

A Difference in the Family by Helen Featherstone (Life with a Disabled Child) A sensitive and genuinely helpful book addresses this issue for families.

Some Just Clap Their Hands by Margaret Mantle (Raising a Handicapped Child) New book (regularly priced at $16.95) which we honestly haven't finished reading yet but seems to handle the exploration of emotions and coping in an interesting manner. The book includes interviews and cases of children in addition to the author's own child.

Meeting the Challenge of Disability or Chronic Illness - A Family Guide by Goldfarb, Brotherson, Summers and Turnbull. The book is divided into two parts, Taking Stock and Problem Solving.

Alternatives (A Family Guide to Legal and Financial Planning for the Disabled) by L. Mark Russell. Chapters include Wills, Guardianship, Trusts, Government Benefits, Taxes, Insurance and Financial Planning.

Living with a Brother or Sister with Special Needs (A Book for Sibs) by Meyer, Vadasy and Fewell. A seven chapter book dealing with various types of special needs conditions.

Environments and Behavior (The Adaptation of Mentally Retarded Persons), edited by Kernan , Begab and Edgerton. Prominent researchers and authorities present their analyses of the importance of residential, community, work, educational, training and other setting variables in understanding the adaptive behavior of retarded adults and children.

A reminder also that we have some of our materials available in other languages. We have an overview available in Spanish and French, our brochure in German and a copy of the Dutch handbook.

We'd also like to mention the excellent overview of the syndrome, "Prader-Willi Syndrome" by Dr. Suzanne Cassidy which sells for $6.00 U.S. and our old standbys which we have had for years and are still very valuable informational sources: The Handbook, $3., Mitchell's Overview, $2.75, Sibling Booklet, $2.75, Children's Book (Diet & Feelings), $6.00. (All U.S. funds) , along with the conference papers and collected gathered view articles.

Please let us know if you would like to borrow a book or obtain an order form for other materials.

New book - just in: "Unraveling the Special Education Maze", An Action Guide for Parents. by Barbara Coyne Cutler

PROXY BALLOT

In compliance with the bylaws of PWSA, the membership is responsible for the election of the Directors of the Corporation. We realize that not all members can be present to cast their vote, therefore, the following proxy may be used by members who cannot be present at the general meeting in June. Please designate one of the names listed below (or your own selected delegate who will be attending) to represent you at this meeting. Your proxy will have the full power to act on your behalf in the election of five directors at the business meeting. You may designate your proxy to vote as you direct.

This proxy form must be received by PWSA no later than June 1st.

Board Members:

Chairman, Richard J. Wett, M.D. MN_____

Fausta Deterling, MN _____ Vanja A. Holm, M.D. WA_____

Dorothy Thompson, MN _____ Gene Deterling, MN _____

Lota Mitchell, MSW PA _____ Stewart Maurer, GA _____

D.J. Miller, PA _____ Lee Forthman, TX _____

Louise Greenswag,PhD, IA _____ Ted Briggs, TX _____

Suzanne Cassidy, M.D. CT _____

Officers:

Pres., Delfin J.Beltran, M.D. CA _____ V.P. Shirley Neason, WA_____

Treas., Roy Smith, CT _____

Director:

Marge A. Wett, MN _____

Your designated representative, (Name)_____

Signature(s):_____ _____

Date: _____ MAIL TO PWSA, 5515 Malibu Dr., Edina, MN 55436

BE AN ACTIVE MEMBER! SHOW YOU CARE! IT JUST TAKES A FEW MINUTES TO MAIL

A parent writes: After reading about Nutra-Sweet depressing the pituitary gland functions in rats, I became concerned with regression in speech patterns and learning capacity for my daughter. Nutra-Sweet intake was high from soft drinks and jello. Complete removal from her diet for 8 months has shown improvement. This is all subjective -- very hard to put a finger or number on but it is worth a trial for any other parent who might feel their child is not progressing. Since we know so little about how our children's metabolism/endocrine systems work, I feel we really have to be alert to all possibilities.

FREE COLOR ANALYSIS

No expiration date!

Free Personal Color Analysis

Support the NDC Fund Raising Drive and find out how colorful your life can be. Guaranteed to treat the blues. You'll color yourself happy. A rainbow of possibilities by knowing what your donation can accomplish.

Redeem this valuable coupon by sending your check for the NDC today.

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.

PRADER-WILLI SYNDROME ASSOCIATION
5515 MALIBU DRIVE
EDINA, MINNESOTA 55436
U.S.A.

First Class Mail