

THE GATHERED VIEW

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PRESIDENT'S MESSAGE

As Prader-Willi parents we are subjected to all sorts of questions. Sometimes the answers are burned into our memories where we would prefer that they remained. Others are recalled with a burst of laughter or even tears. Many times the questions remain unanswered and floating in our minds at the expense of better thoughts. The really tough questions are those that need to be answered on the spot, no waiting, no hesitation, and to be put forth with a strength that commands the situation and leaves no alternative and brings forth no additional sallies of "why" or "but if" or "if that is true" or even "I agree with everything you have said, yet in this situation it is not enough".

You have guessed it right. No, I was not talking to my Prader-Willi daughter, nor was I giving one of my educational sermons. This was a new activity. An activity that more people are introduced to each day. In social studies it was discussed as part of the normal responsible action of a concerned citizen in a modern democracy. This new activity is simply talking to a legislator as one of many concerned Prader-Willi parents in California trying to support a new piece of legislation that would benefit our Prader-Willi family. This is not the type of encounter in life that a person looks forward to with relish. It is not even enjoyed in the experiencing of it. Perhaps I should not be too strict on this, there must be some people who enjoy the legislative way, there is certainly a large portion of the population involved.

The anticipation that precedes involvement can take many forms. In a sense it is no different than other adrenalin producing life encounters. It is not unlike facing a final exam. Before the actual en face encounter one needs to study and do homework. If you are smart and efficient the battle plan will be drawn and printed in a legible manner. Remember the song, "Mine eyes are dim, I cannot see". At the actual encounter it seems your memory is no better than your eyes.

If you are lucky the first office that you walk into will find the actual elected official out for the day. Then you will make the "spiel" to an assistant paid to be kind, gentle, understanding, attractive, conversant and willing. As you reenter the anonymity of the corridor a nervous smile creeps onto your face and in a dry, squeaking voice everyone at once questions, who is next on the list. Someone else asks if we remember to leave copies of the information sheets that cry our cause. That question is promptly answered by the disappearance of a large bundle of papers diving desperately back through the escape hatch.

Many hours, miles, dry coughs, sighs, yawns, sore calves later, the first day of legislative educating is done. A strange sense of accomplishment creeps into the consciousness. A realization that the dreaded task was actually accomplished. It is true, the team has met dozens of new people on their ground. Then you realize that most of them seemed eager to help, to please, to do their job well to represent their constituents. Once we got into the swing of it

President's Message (cont.)

PWSA

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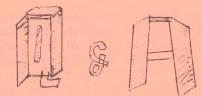
Executive Director & Editor: Marge A. Wett

the new unopened doors were less ominous, the new smiles were more true, the handshake and the interest in the problem more sincere. Our responses to questions became sharpened and the exchanges more meaningful. Somewhere along the way it finally becomes clear. We are the ones who know what we are doing, our goals are correct, and we know the solution to the problem. Our solution is the correct one because it is founded in the cumulative experience of the group. It is this experience that no others have. It is this experience that must be taught to others to achieve our goals.

These thoughts are ongoing as the California parents experience what others in over fifteen states have gone through to develop legislative interest in Prader-Willi syndrome for the establishment of appropriate residential facilities. It becomes obvious in these encounters that the true experts on PWS as a human affliction rests in the hands of PW parents. Although at times I have wondered, this type of encounter clearly defined the unique nature and needs of PWS and what it takes to permit these wonderful children of ours to survive.

Dolfin J. Beltran, MD

President



CAN WEIGHT BE KEPT TOO LOW? One parent reported they were proud of no weight gain for four years. This is not acceptable in a growing child unless they are in the process of losing excess weight. It is important that parents work with an informed physician and/ or someone qualified in nutrition. "Qualified" meaning experience with PW. Some experts feel no child under 12 show diet — we receive calls and have met children under 12 who are already massively obese. Weight control and good nutrition are essential.

MY CHILD DID NOT HAVE PHASE ONE, FAIL-URE TO THRIVE. WILL HE GET IT LATER? "Phase One, Failure to Thrive" is used to describe the presence of hypotonia at birth. The baby is weak, floppy, cannot suck and does not gain weight. If that condition is not present the first year to any degree, we would recommend questioning the diagnosis of PW. If the weakness is not severe, no, it is not something that will develop later. Contrary to some other syndromes, where hypotonia is present at birth and does not improve, with PW it does show marked improvement over time.

DOES MY CHILD HAVE A MILD CASE BECAUSE AT FIVE HE HAS NOT STARTED COMPLUSIVE EATING? One answer could be do you have a "mild" case of pregnancy. As in pregnancy, you either have PW or you don't. Does mild mean less symptoms or less severe involvement? or, do you want to think about each person as an individual? You do not have to have all of the symptoms to have PW and every person does not have to have the same degree of severity. "Averages" show the failure to thrive as the first year, the interest and ability to eat between 1 - 4, the complusion to eat at anytime (even as late as teens), or in a few cases, not at all.

Children with PW have ranged in reported I.Q.'s from 40 up to 105. Developmental delays range from 1-2 years and up to several years on more rare occasions. We are really dealing with a variety of abilities.

10th Annual National Conference June 23 - 25 Louisville, KY

Pre-conference day: June 22nd, which includes Scientific presentations, Group Home personnel session, and Chapter President's meeting.

The Conference is 4 FULL DAYS OF

LEARNING ENJOYMENT SOCIALIZING "CARING & SHARING" (PWSA THEME)

For the regular agenda, see your pre-registration form. (There's something for everyone!) The Youth Activity Program will include (for ages 13 and up) a trip to Fort Knox, the Patton Museum, and a tour of Churchill Downs. The ages 6-13 group will have a trip to the Bernheim Forest and the Museum of History and Science. Both groups will have SummerScene entertainment and crafts, lunches in the parks, pool parties, bowling and that Great Friday evening banquet and dance.

PARENTS and PROFESSIONALS that have attended in the past have stated it's an experience that can't be duplicated.

YOUTH that have attended can't wait until the next year's activities.

THE COMMITTEE NEEDS NUMBERS NOW.

Need a registration form? JUST ASK. Have one filled out but not mailed? TODAY'S A GREAT DAY TO DO THAT.

WE NEED YOUR SUPPORT - IT'S NOT TOO LATE (to help keep conference fees lower)

Our odds are better than most due to restricted sales. Give your friends a chance to help support your favorite charity. If the tickets are for your personal use, just let us know, we'll type in the stubs and enter them for you, saving us both mailing costs. If ordering for sale, stubs must be returned by the 10th of June.

FIRST DRAW	\$500.	SECOND	DRAW	\$125.	THIRD	DRAW	\$100.
			Steam Server				
ORDER FORM:							
Please send	tickets, v	which will	be bou	ght or s	old for \$1.0	0 each or	6 for \$5.00.
Name				ddress_			
The money mus							

a fund raiser for them too as 25¢ per ticket will be rebated to them.

The tickets are for us, just enter them in the drawing____

ACTUALLY WHAT IS PWSA

PWSA is an International support group for PWS. "International" because we have members from all over the world.

Why was PWSA formed? Like most support groups, there was a need. Knowledge was scarce, people needed information.

How does PWSA operate? A volunteer board and officers set policy and procedures. A full time director and part time secretary actually carry out the operation.

How is PWSA funded Strictly by dues and donations.

What is the purpose? Answering questions; supplying materials; carrying out the "Caring and Sharing" theme; bi-monthly newsletter; annual conferences; problem solving. What has PWSA done for you — that is the purpose.

Can I help? Right now, nominate some talented people to run for the board.

Respond to your first dues notice. (Save time & money for reminders)

Continue "caring and sharing".

Donations. (Your dues do not even meet our minimum operating expenses. Only through donations can be continue to grow, take on new projects, help more people.

Right now we are in the midst of our annual fund raising. The past two months the following people haveresponded. Donations are to general operating, C.I.T., Research and Conference funds. (Members are listed; non-members are in brackets.)

Van Zomeren (4), (Diehl 2)	E.Olson (2)	Boyd (2)	(Oravec)			
Krauss (Stieber) (Tobias)	Hill (2)	Mauger				
(Krauss)	Daly	Beltran	Wett (Jorgensen) (Scanlan) (Hill) (Herman) (Zastrow)			
Nanzig (A.Nanzig) (Valliere)	Morgan	Dixon (2)				
(O'Brien)	Maas (Maas)	(Lenihan)	(Zoia) (Brandstetter)			
Hiatt (Miller)	Wright	S.Miller	Forthman (F.Fritz) (Kelly)			
LaBella (S.Clark) (Marik)	Pickett	Guido	(Showaniec)			
(VanTuyle)	Tripp	Braun	Schneider (M. Schneider)			
Castle & (T. Graham) (Palmer)		J. Bell	(K.McDonald) (O.Simon)			
(Oliphant)	Gemar	(C.Mans)	(W.Schneider)			
Englund (Wasmund)	Lacy (C. First)		Sojka (2) (Harder) (Abramek)			
Mitchell (R. Dodds) (Larson)	Olivo (M. D'Elia)	R.Bell (Bryant)	Novak & (A.Schoepe)			
(Wachter) (Press) (Rodina)	Grout	Moloney	(Kokoska)			
(Van Cleef) (Cosgrove)	Toby	Levikoff	Hutchins (K.MacLeod) (Giles)			
(Gruneburg) (S.Small)		R.Basker	Vermeulen (J.O'Hara) (Rosen			
(Morrow) (G.Smith) (Leslie)	Heineman (Powers)	Wicks	(Hoffrichter) (Lorenz)			
(Mitchell) (Karras)	Jacobs (Sherard)	Herman	(Vermeulen)			
Youngblood (Peppas)	Maurer & (ColonySq.		Straight (Hornstein) (Norris)			
Gottschalk (C.Merrill)	Carton	Shadell	Knippenburg (Faherty)			
	Marcovici	Marchitelli	Brewi (Rocco) (Moore)			
Silverman (Blankenship)	Gilmore (Voorhess)	Neiger	Umbaugh (Reedy) (Haney)			
Wyka (Napovier) (Holland)	Hinds	Kuhne	(Klotz)			
(Marciniak) (Wyka) (Vuz)	Capital Area UW	Watson	Lehman (Perry) (R.Beck)			
I) Millor (E Possi) (Dissister)						
D.Miller (E.Rossi) (Blackfan)	Arbachauskas	Klein (Ghents)	Doolittle (Winnebago UF)			
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(Satterthwaite) Ingalls & (Jones) (Lapierre)	Underwood Flick (Lepre)	Small Allan	Noll & (A.Noll)(Gomeringer) (Porfido)			
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(Contributions received thru April 18th) Since this list was sizeable, we hope we didn't miss any. These donations added \$3185.59 to the General Operating Fund; \$3138.50 to the CIT Fund; \$2536.94 to Research; and \$410, to sending someone to the Conference. We hope to top last year's total if donations continue, we're about \$2000 short right now.

CONFERENCE TIME IS ELECTION TIME

PWSA is operated on the structure headed by a 12-person Board of Directors. These directors are elected by the general membership, at the annual conference, to serve a 3-year term. At the end of their 3-year term, board members are asked if they will be seeking another term. Those interested are requested to submit a photo, if available, and a few paragraphs of general information for our readers. Nominations for those same seats or for any vacant seats may be made at this time or when nominations are opened to the floor at the general meeting. To be a nominee, a person must be willing to attend two yearly board meetings at their own expense, and serve on committees during their term. Any nominations received prior to the printing of the ballots will appear on the ballot. Nominations made during the general meeting will be posted at the conference.

Members who are not able to attend the conference are given the opportunity to cast a proxy ballot. Proxy means you are asking someone else to represent you because you cannot be present to vote yourself. Your proxy ballot may be given to the person you have asked to represent you, or it may be mailed to the national PWSA office. If sent to PWSA, the proxy is turned over to the person at the conference. Members present at the conference are given their ballots at the registration desk following the general meeting. As a member you are allowed one ballot as an individual paid member or one ballot as a paid organization. Family memberships are entitled to receive two ballots. You are entitled to cast one vote for each board vacancy, for example this year there will be four seats up for election, but you may only cast one vote for each candidate of your choice. (Your four votes may not be cast for one person)

What is a proxy ballot? A proxy ballot gives you the opportunity to vote even though you cannot be present at the conference.

How do I pick my proxy? Anyone who is going to be at the conference can act as proxy for you. This can be a board member, an officer, or any member of PWSA. For your convenience, the board and officers are listed on page two.

Why should I submit a proxy? This is your opportunity to be an active member. If no proxies are submitted, just the members in attendance will make the decisions. Can I tell my proxy how to vote? Yes, you may direct him/her how you want your ballot cast, or you may let them choose.

What do I do with my proxy ballot? Give it directly to the person you choose, or mail to PWSA and they will give it to your proxy at the meeting.

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I would like the following person to act as my proxy in all voting transpiring during the 1988 general meeting:
Name of proxy:
Please vote on my behalf or follow these guidelines:
Date: Signature(s)(Must be returned to PWSA before June 1st.)

BOARD ELECTION

Two board members, whose terms have expired are asking for your support in their re-election to the board:

Dear Members: I wish to run for relection to the Board of Directors of the PWSA in 1988. As a parent of a 28 year old son with PWS, I have first hand knowledge of the syndrome over a long period of time and can share those experiences of infancy, childhood, adolescence and adulthood with the Board and membership.

Also, my business experience and contacts have been and will be helpful to the Association.

My desire is to serve and help prepare our Association for the future in order that we may support and assist all those whose lives are touched by PWS.

Sincerely,

Stewart Maurer

Dear Members: I wish to serve another term as a member of the Board of Directors of the PWSA. I feel that the composition of the board of directors should continue to include some professionals, such as myself, as well as parents. Such a blend ensures personal and professional collaboration and sensitivity to the children and their families. As a participant in the association since 1982 and as a director beginning in 1985, I have had many opportunities to work closely with board members, parents groups, and other professionals in an effort to expand and enhance services to individuals with PWS and their families. Since 1983 I have taken part in program presentations at annual national conferences, participated in meetings in several states and Canada, testified in behalf of children with PWS, co-edited a text book on management of PWS which will be available this summer, and continued as a researcher in PWS at the University of Iowa. I currently serve as consultant in PWS to the Iowa Child Health Specialty Clinics, which offers health care to children with special needs through a network of regional clinics. In this role I provide on-site community out-reach education and confer with primary providers and families about the needs of individuals. Much of what I am able to contribute to this community out-reach work is based on my personal and professional affiliation with PWSA.

As a board member I have learned a great deal from people committed to making life better for children with PWS. I seek re-election so I can continue to learn and grow with the organization.



Louise Greenswag, R N., PhD.

Sincerely,

Louise Greenswag

Please refer to further information regarding this election in this issue.

Four board positions are available. Two board members have chosen not to run for re-election.

Please give considerable thought to who can best make a contribution to PWSA as a board member and see that they are nominated. These people are making decisions for you as to how this organization should operate.



* viewpoint



The March-April issue of the GV contained the following article: "My daughter was asked to apologize to her group for stealing food. Do you feel this was appropriate?" "No, we really do not. Would you expect a blind person to apologize for his inability to see? Compulsive eating is a part of PWS. A person should not be shamed into better behavior."

The following two letters were received in response to this item. We thank the people for taking the time to share their opinion.

"concerning the appropriateness of apologies. The analogy between a person with PW and a person who is blind is curious. Of course, it would not be appropriate to ask a blind man to apologize for not being able to see. But it would be appropriate for a blind person to apologize to you if he/she accidently put his/her hand into your birthday cake.

The issue of responsibility for one's actions has several different facets. It is possible (probable) that the PW person may be unable to not steal food if food is available. If so, then there is no question of moral quilt in the theft of food (and hence, as you note, inappropriate). However, there is also a notion of responsibility, after the fact, for damages done to others. This is where your analogy fails. The blind man's inability to see does not harm another's property. The blind man accidentally putting his hand into your birthday cake does. It would certainly be appropriate for the blind man to apologize for accidently destroying your cake. In fact, he would be a bit of a cad if he didn't say he was sorry that the event occurred.

An apology means the most when it is voluntary and umprompted. But somewhere along the line the blind person would probably have had to be told

that apologizing was the appropriate behavior. And so with the PW person re theft of food. So, under the circumstances, it may be appropriate to ask a PW person to apologize for taking someone else's food.

If the PW person is mature enough, it may be appropriate to ask for more significant restitution than a mere apology for damages-for instance, if a PW person takes a sibling's piece of cake, maybe the PW person should do a chore usually done by that sibling (like taking out the garbage or such)!"

The second letter: "I just received my GV and, as usual, found it interesting and informative. However, I feel I must disagree with the opinion concerning the apology for stealing food. I feel no apology should be offered for the urge to steal food; but the act of stealing the food should be apologized for. The effects of PWS vary to such a degree that on one end of the continuum, a PW person may resist the desire to steal food most of the time. On the other end of the continuum, those with PW to a severe degree may never be able to resist.

The newsletter continually stresses that PWS is a unique syndrome with a very unique set of problems. May I add that each person within this unique group is a unique individual. You must know your PW person as an individual before you will know whether an apology should be made. Please do not lump all PW people together by saying an apology is always inappropriate, when, actually the individual circumstances are unknown.

My son is aware of my expectations for him. He is also aware of what he can expect when he follows the "urge". His teachers and other school personnel are aware of his difficulties and are very helpful and compliant with my wishes.

There can never be enough communication between parent and teacher. If it is not appropriate for your child to apologize before a group, then by all means, the teacher should be aware of this before the situation arises."

EE-EEEEE, SIZES 5-13

Extra width for men who need it, in excellent variety, styling and quality. Available only through our FREE CATALOG. Send for it!



STATE

HITCHCOCK SHOES, INC. Dept. 69C, Hingham. MA 02043

ATTENTION GROUP HOMES

In case you didn't notice, we are planning a repeat performance of the very successful group home day at the 1988 PWSA conference.

Dorothy Thompson, MS, QMRP, has agreed to return and repeat her excellent job of moderator in order for group home personnel to meet and exchange information on group homes for people with PWS.

Last year we had over 40 people attend, representing many different homes. The meeting will be held on Wednesday, June 22nd, (pre-conference day) and Dorothy will be presenting a summary to the conference attendees on Thursday.

Dorothy has a special request. She would like to poster pictures of homes dedicated to PWS. Would you send photos, along with information on size and location to Dorothy, at the PWSA address?

We hope all group home personnel will take advantage of this opportunity.

PARENT'S HANDBOOK

We are nearing the date for a new printing of the parent's handbook. The last revision was in 1984 and we would like to update again. "Appendix E: Reading List" is particularly outdated. Do you have some suggestions for books that have been particularly helpful to you?

Do you have some suggestions or comments on the regular text? We would be happy to have your input.

MITCHELL'S OVERVIEW

NEW!!!

The Overview of PWS has just undergone an update and we are pleased to announce the new copy has been greatly improved with the addition of photos of our children.

We particularly thank the parents who shared photos and made this possible. We are sorry we couldn't use all of them, but will keep the others for future use.

DISAPPOINTING NEWS

We had hoped to have copies of our latest publication, "Management of PWS" edited by Drs. Greenswag and Alexander available at the June conference but due to the late arrival of some of the material, the publisher will not be able to have the book ready until the second week of July.

The book will sell for \$27.50 (U.S.) and we will have more information regarding ordering in the next issue.

SPECIAL OFFER

We have ordered 50 copies of the above book as special editions. (These will be stamped, numbered and autographed by the editors). One very loyal member has offered to purchase copy #1 for \$1000. If you, too, would like to purchase one of these special editions, at the same price, we will accept offers now. Lower numbers will go to those orders received first.

JOIN THE EXCLUSIVE CLUB - and make that \$1000 donation today, so you can be the proud owner of one of these special editions.

SPECIAL REQUEST

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One of our members has requested that we designate a month to hold a fund raiser for PWSA.

HOW ABOUT THE MONTH OF JUNE ???

Fund raisers can be garage sales (get your neighbors to help), can be commissioned parties (such as Tuperware, jewelry etc.). The latest thing is hold a party in your office during the noon hour. These individual efforts do not raise thousands of dollars but if thousands of people hold parties, this can make a great difference.

JUNE IS FUND RAISER MONTH. Are you going to join us????

Another member asked if monthly donations could be made. We do have a number of regular donors and anyone is welcome to join them. We do what our budget allows, it's up to you how much we expand.

PATIENT TRANSPORATION

American Airlines is providing free transportation (space available) to patients with rare disorders who must travel to a specialized medical center. This cannot be used for "a second medical opinion". It will only be awarded to needy families, and those with doctor referral.

Highest priority will go to patients who will participate in clinical trials, but cannot afford transporation to and from the research facility.

For further information, contact: Maria Hardin, Patient Services Coordinator, National Organization for Rare Disorders, Inc., PO Box 8923, New Fairfield, CT 06812.

GRANT AWARDED

PWSA has awarded its first Conference grant this year. Up to \$500. will be given to a family to assist with conference attendance in June.

Five persons applied, and after it was established they were in need of financial assistance, their names were placed in a random drawing and one name was drawn. We are very pleased to be able to directly help someone in our organization.

It has been proposed that this will be a continuous grant each year and expanded when possible. In our latest fund drive, one category of giving was stated for this use.

The Board of Directors will also be discussing other ways of direct help to its membership at the next meeting.

LOW CAL RECIPES OFFERED

"Low Fat, Low Calorie Cooking" is a new spring 1988 leaflet from the American Dairy Assoc. It includes 10 recipes.

Choose from soups, salads, desserts. Nutritional information for each recipe is given. Order by name from American Diary Assoc. of MN, 2015 Rice St., St. Paul, MN 55112.

FRUIT YOGURT SHAKE

1 c. plain low-fat yogurt
 1 packet artificial sweetener
 3/4 c. frozen
 unsweetened strawberries, blue or raspberries

Place yogurt, vanilla & sweetener in blender. Gradually add frozen berries. Makes 2 cups. 1 cup is 95 calories.

CALIFORNIA ON THE MOVE

The CA association (Prader-Willi California Foundation) has been putting a tremendous amount of effort into securing services in their state. A great deal of effort went into amending a present Act to include PWS as a named developmental disability, but they were not able to get that passed. Another major effort has been in the desire to open a center similar to what was proposed by PWSA years ago. They have won Round One in this effort. They have a great deal of support (where needed) but unfortunately opposition also. Let's hope their sustained efforts will carry them through to approval.

CONGRATULATIONS TO MINNESOTA

It only took six months but parents were finally able to secure the necessary approval to move the present 15-bed "Oakwood Residence" into a different building. The Department of Human Services didn't approve but issued the necessary approval.

The Oakwood corporation has purchased a building which they feel will better serve their needs. The residents are all excited about their move.

ITEMS OF INTEREST FROM AUSTRALIA

Dawn Taylor reported in The Open Door, Australia's journal, some items of interest from their 2nd National Conference in W.A.

It was encouraging to read of one young man's success. Peter is 33 and reported through his own determination (at age 27) he joined Weight Watchers and lost 8 stone (112 lbs.) He stated he felt the best exercise was walking, and his weight loss has changed his life. He loved to be able to move freely and not be held a prisoner by his own body. Peter is self-employed as a printer in a family started business. He also reported he has improved his control of frustration tantrums. Sounds terrific.

Another speaker reported the need for individual educational programs. He also stressed the need for rest periods and reported how the child with P.W.'s concentration was much better after these rests. Rests may also reduce temper tantrums. He also spoke of the need for constant contact between parents and teachers, and the need to set realistic goals as achievement of these goals aids the self esteem of both teachers and pupils. Parent respite was also mentioned as a need.

A University of MN Ph.D. candidate recently reported (Walking: The Safe Road to Fitness), results of two studies. One study showed that the average sedentary person can walk the road to fitness, but anly if he/she walks briskly for an hour at least four times a week. In a comparison of walkers and joggers, she found (at the end of 20 weeks) that cardiovascular fitness has improved 21% for walkers and 31% for joggers. All of the women reached a good level of fitness. Her test also confirmed that exercise and diet are necessary for weight loss. There was one major difference between the two groups: injuries. 40% of the joggers had to drop from injuries, 7% of the walkers did.

Her second longer study showed the women plateaued if they did not increase intensity. She recommended increasing by swinging the arms across the body, elbows bent, swinging straight arms and taking longer strides (power walking),

and wearing weights around the waist. She did not recommend weighting the arms or legs because of greater stress on joints.

A MEMBER SHARES IDEAS FOR IEP

- 1 Know the PL 94-142 current law.
- 2 Know current facts about PWS.
- 3- Know what available in your school. Visit classrooms and programs.
- 4 Seek out helpful people in system.
 Ask others with children the same age.
- 5 List priorities (from essential to nice).
- 6 Know and understand IQ scores. Know your child's weaknesses and strengths. Develop a program that builds on strong areas (programs focused on the deficits lead to frustration. Have realistic expections.
- 7 Provide school & teacher with PWS materials.
- 8 Present yourself as a confident, informed person who will be a resource for them as well as an advocate for your child.
- 9 Insist on frequent communication.
- 10 Insist on making changes in the IEP during the year if things are not working.
- 11 Do not expect the school to offer you a "platter of goodies" to choose from.

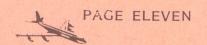
The most important work must be done by the parents before the meeting. Educate yourself. by Marilyn Bintz

RAISING A "PW"

I believe sometimes we get so wrapped up in working only with PW problems that we forget to teach our child to be a good person. Somethings need frequent work.

A Good Friend is someone who shares, takes turns, listens to others, cares about the feelings of others, does nice things for others, helps others when they need and want help, likes and accepts others despite their imperfections, and is loyal.

Work on teaching your child to be "A Good Friend".



ANOTHER ACCOMPLISHMENT

In the 9th Revision, The International Classification of Diseases issue, a publication of the U.S. Dept. of HHS, PWS was assigned an identification number lumped with 20 other syndromes. At the request of Rita Welch, Pres. NY Chapter, we applied for our own number, which she stated would enable a better description and facilitate insurance coverage for obesity on a medical basis.

Upon application, we were given the opportuntiy to appear before the determining committee (our thanks to Diane Cohen, Waldorf, MD for doing this for us), and it was decided to add another digit to our number so it would qualify as a seperate entity. This is only the first determination but should follow through the rest of the requirements without difficulty. Naturally, things are not speedy but our new number will become effective Oct., 1990.

BONE DETERIORATION

To our knowledge, it has not been determined if PWS causes an earlier than normal bone deterioration. In a recent study of elderly and astronauts, who spend months in space, bone deterioration was reduced by high-stress exercise. Exercise is the most important factor in maintaining bone mass, if you don't use them, you lose them.

This article only mentioned weight lifting and trampoline jumping as high stress exercises and that may or may not be recommended for your child. We feel the important message is that even if exercise is not needed for overweight, it is still necessary.

One parent was disturbed by our comment in the last issue warning parents not to let your child go "overboard", even with exercise. We certainly were not recommending cutting down good programs, we were warning when anything becomes an "overwhelming" compulsion, it can be a serious problem.

GROUP HOME FUNDING / TRAVELING ??

A note from the Robertsons' of NSW, Australia, mentioned their difficulties in obtaining a PW home due to "lack of funds". Unfortunately, many U.S. states are getting the same answer. One member was told, "get in line with the rest of the people who need service". How can you answer a mother who desperately needs a placement for her son and is told by the local people and the legislators, we sympathize but have nothing available?

The Robertsons' also requested that if anyone is traveling to their area, they would appreciate a visit and sharing. I'm sure this is true of our other members overseas too, give us a call if you are traveling.

FREE CATALOG

Thee Diet Shoppe is a catalog of diet foods, including sugar-free cheesecake and Swiss chocolates, fruit spreads and sauces. Available free, Thee Diet Shoppe, PO Box 1343, Northbrook, IL 60065-1343.

POACHING SAUCE

5 c. water

½ c.vinegar or
1 c.white wine +
1 Tbsp.vinegar

Parsley or dill sprigs

5 whole allspice
1 bay leaf
1 small onion
1 piece carrot

Mix and boil 10-15 mins. Add fish (can be salmon, trout, hake, whitefish) cutlets or chunks, bring to a boil, skim off scum, cover pan, simmer until flakes (8-10 mins. for pcs., 10-12 for trout, 15-20 for salmon).

PROTEIN

Facts: Most people eat twice as much protein as we really need for good nutrition.

You can get fat eating too much protein. Excess protein is of no use to the body except as an energy source - calories.

Most common sources of protein are high in fat and calories. Most contain a much greater percentage of calories from fat than from protein.

Excess protein also promotes bone loss.

MEET KATIE



Our daughter's name is Katie, she is 6 yrs.old, 32 lbs., 39" tall. Katie has had alot of special attention, hypotonic at birth, stomach tube fed. She was adopted at $1\frac{1}{2}$ yrs. old. For most part she is a "normal" 6 yr.old. She likes to get into her older sisters things, calls her brother a dork or geek – whatever that is. Katie's different side is loving everyone, being repetitious, saying inappropriate things, hating change, always wanting to know "When's breakfast", What's for dinner?"

Katie occasionally gets overwhelmed with excitement and cries. She has a "winding" action, arms around the back, eyes crossed, head down and stomping a foot. This action may be when she meets a new person.

Katie is in kindergarten in a MMH class. She has learned to print her first name, counts from 1-20, recognizes 1-8, says and knows A-Z, counts from 1-10 and sang Silent Night in Spanish. She is really very bright and loves to go to school. She is special to us and all of her friends. She is a happy and healthy little girl.

We feel Katie is "one of the family" because we have met her at conferences and are privilleged to watch her grow. We thank her parents for sharing her with us.

THE GATHERED VIEW is the offical 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 \$20./year Individual, \$25./year Family, and \$30./year for Agencies/Professionals. (U.S.Funds) Send dues and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.

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