

THE GATHERED VIEW

for the younger set

Newsletter of the PRADER-WILLI SYNDROME ASSOCIATION

September - October, 1988

Vol. III, No. 5

PRESIDENT'S MESSAGE

For the past year there has been an ongoing battle between California PWS people and the Department of Developmental Services of the State of CA. The focus of this dispute has been two pieces of legislation written for the benefit of CA citizens with PWS. One bill was directed at the problem of denying services to the multihandicapped person with PWS on the basis of an IQ test result higher than 70. The second bill was directed at the State sponsorship of a model facility designed to support the type of environment that would permit citizens with PWS to survive. The outcome of this dispute will be determined by the time that this letter is delivered. Whatever the outcome, it is certain that fewer legislators and bureaucrats in Sacramento will say "Prader-who?"

That a government bureau designed to serve the needs of citizens was at odds with those citizens should not have been a surprize. If nothing else, it has served to augment my belief that if you wish to accomplish a goal, personal effort will carry further than knocking on the doors of the bureaucracy. At any early meeting designed to overwhelm us with their importance in our lives, several titled persons identified why we shouldn't fight "city hall". The first rule was: "There are established rules to follow to gain their attention." This implied that our course of action didn't follow the rules and they opposed such a course. The course being that of using legislative action rather than courting administrative graces. The second hurdle they defined was the lack of funds for existing projects and our certain defeat should we attempt to define any new expenditures. We were then given a warning not to tamper with the existing legislation, namely the Lanterman Act, which had been won by legislative battles supported by and benefitting a larger group of the disabled than our minor group. It was the

old guilt trip all over, who were we to think that our cause was more important than all of the disabled in the State of CA. Their next comments completely negated any respect we might have had for these people. Their spokesperson informed us that the task and responsibilities of the Department of Developmental Services of the state included a very long list of specified and unspecified disabilities, that PWS was only a very small group of needy and that if we wished to obtain services and recognition, we should get in our proper position in the line. This was capped off with the comment that the system was such a mess that it probably wouldn't make any difference if we did get in line, it wasn't capable of handling the problems and responsibilities they already had.

Probably the most important rule of legislation learned by our group was that numbers count. At each step of the process, the appropriate legislators were bombarded with telephone calls in their offices, with letters in their mail, with people knocking on their office doors and informational material left on their desks and most importantly, attendance at all hearings. The first general hearing on the need for this legislation filled the council chambers of the LA City Hall, which incidentally is a magnificently impressive room of Spanish achitecture housed in the building made famous by the "Dragnet" TV series. The next hearing was that of the CA Assembly's Health Committee. That was an event that put PWS "on the map". So many people attended that hearing that a larger hearing room had to be found. It was the first time in the history of the CA Capitol that such a thing had occurred. The numbers of telephone calls and letters were leveraged members of the PWS group contacting all sorts of other affiliated groups including professional societies, unions and other disabilities groups. It was

Pres.(cont.)

repeatedly gratifying to go to a meeting with a legislative aid and hear them comment that they had heard of our efforts through numerous letters and calls.

Many of you will read this and recall the battles won to develop the dedicated residence that now supports your person with PW, and maybe even look forward to future or continuing efforts to expand this type of support in your community. On the other side, there are certainly those planning for and wondering about future efforts to develop this type of PWS support environment. For all of us this experience has clearly defined a fundamental truth in my way of thinking about the support of persons with PWS. The CA DDS accused us of wanting to create a restrictive institution, which was against the principle of least restrictive environment established by PL 94-142. It is now patently obvious that a properly functioning residence dedicated to the support of persons with PWS is, in fact, the least restrictive environment possible for their survival.

Delfin J. Beltran, M.D.

President

1989 CONFERENCE - CALGARY

It was my privilege to spend a few delightful days in Calgary with the Willotts', chairpeople for the 1989 conference. We were able to reserve The Marlborough Inn, a triple A, 4 Diamond hotel, for our July meeting, at a \$58./day rate (American, approximately \$44). A feature we haven't been able to offer before is that they have three top "key" floors with VIP service for only \$10/day more for those who want to splurge. The meeting room arrangements look excellent to meet our needs, which the Willotts' and their committees are already busily working on.

Geoff assures us that they will be offering excellent weather - avg. max temp is 76°, min temp 50° (anyone remember our TX meeting?), and sunset about 9:30 for a nice long day.

For those wanting to plan ahead, the famous Calgary Stampede will be the week before our meeting. If people are planning on going early, be sure to make arrangements well in advance. If you'd like to stay on, a day's trip to Banff and Lake Louise is highly recommended. (The Willotts treated me to that after all of our hard planning days.) We hope to include some "See Calgary" plans in with our agenda.

11th Annual PWSA (FIRST INTERNATIONAL) Conference, July 20-22 in Calgary, Alberta.

PWSA

6490 Excelsior Blvd., E-102
St. Louis Park, MN 55426
(612) 926-1947
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PWSAPOLICY?

Two sessions at the conference have brought to mind a point I guess needs bringing up now and then. One comment, "From what I read in the GV, that is PWSA policy", and the other, "From what I hear at the Conference, that is PWSA policy." I feel it is very important for our members to know it is our policy to share in the GV information that we are able to obtain that we feel will be helpful to our members. Some of these items may well be controversial - in fact we enjoy it very much when someone writes that they have a different outlook on what they have read.

Everything written in the GV does not reflect PWSA policy!

Speakers for the conference are chosen by recommendation (and it helps tremendously if they will speak without a fee), but we never require the contents of their presentation before they are given.

Everything presented at the conference does not reflect PWSA policy!

When someone calls the national office they generally get me (the Director). If I am able to answer questions or give suggestions, I do. If a referral has to be made or information sought, that is what I do. These suggestions are information that has been accumulated from 34 years of being the "unlicensed doctor" in the Wett household; from 23 years of having a daughter with PW (and incidently 6 other children too); and mostly from spending the past 10 years in the PWSA office, but....

Information shared by the director or from the PWSA files is not PWSA policy!

I find it tremendously difficult (and others do too) when we can't give people the answers they want. Parents of an infant know they have

a developmentally disabled child, not the child that was expected. They find it difficult to accept this fact - with time, it is accepted, my child is not going to be normal, but don't tell me he/she is going to have the symptoms or the problems other people have. It's hard when we look at these parents and recall similar statements from parents who are now turning to us for help with these problems. Certainly it does not have to be all "doom and gloom", we do not have a generation of children that were diagnosed in infancy to know the difference early intervention can make, but how can we older parents not face the reality of PWS? How can we foster the acceptance of PWS without it meaning "doom and gloom"? One of the tapes at the last conference stated you take people back when you ask them to list strengths of their families, it is far more common to hear about the weaknesses. 90% of the information shared with PWSA are "problems", the joys are there too, but they are just accepted, not written about.

From one of the conference tapes, the family decided mealtime was just a complaint time and the meals were not enjoyable anymore. The rule was made you couldn't speak at the meal unless you started out with something good. The young boy sat there and finally said, "The good thing that happened to me today was that this dinner sure looks better than what we had to eat last night." I think we can do better than that with the GV. Let's give it a try - how many "joy" things are in this issue? Not enough, then that is because they haven't been shared. In this issue we are going to have a return page, let's see how many joys are shared.

I'd also like your opinion on a routine I have followed the past few years. People write "success stories", but I do not share them unless I feel it will remain a success. Would it be a better learning experience to print all

success stories, but equally write when the success ends? An example, "Joey spent 2 months in a rehab program, lost 60 lbs., looks and feels terrific. He has now entered an alternative living situation, only needs an aid 2 hours a day. We are all so happy." Six months later, "Do you have any suggestions, Joey didn't make it in his apartment. He did well for 3 months and then everything fell apart. He now has all the weight back, he refuses to consider a change of placement. We know all of the health problems are going to return - what can we do?" There's is no way I can know if Joey is going to make it, I can only know from past experiences that the odds are stacked against this alternative working unless the parents or someone else gets tremendously involved with additional supervision. To me, writing a success story - and then taking it away, is a "downer" everyone talks about. To me, writing about the success and not the failure is giving people false hope - an unrealistic goal. What do you think?

At the conference a couple of people objected that PWSA only advocates group home living for young/older adults. If you ask Dorothy Thompson, Louise Greenswag, me, or other people who are "experts", you are going to get an opinion that is drawn from their experiences. Louise, who was conducting this particular session of the group home day, answered this parent, My feelings on that is we have to face reality. I think that we have to realize that there are those who are more severe and those that are less and there is always the exception. Overall, I think it has been proven that group home living, at this time, until we know more about it, where they have more controls, seems to be the answer. The thing that amazes me is the fact that with the structured environment, where they live, is so close to normal, that it is hard to believe that they need

structure at all. They do so well, but remove it and it is not very long before they go back. I think until we know more about it, until more is found out, we find more help for them in group homes and this is the best answer we have now. Somewhere in the future someone will come up with an answer. Louise continued later with, The other thing is realistic expectations. Many times the children who are in particular integrated group homes, because they are so verbal, fool you with their skills (they could sell ice boxes to eskimos), you tend to believe them when they say I can do this and that and they are placed in situations where they are competing with people who have better skills than they do in terms of being able to stick with something and really succeed, so they don't have the chance to succeed. It is very difficult to put them back down where they can succeed again. We don't want to set them up for failure. One of the things we talked about at lunch was the process of beginning to accept a child that is less than normal. It is almost like a grieving process, but the child is still with us. You feel a chronic sadness. Every time a developmental era or stage is past, and the child doesn't make it, there is an overwhelming feeling of sadness on the part of the parents. There is nothing wrong with planning that down the road they will have medications that will reduce the satiety problem.

I believe Louise has touched on a area that needs discussing. Is the choice of living arrangements really made for the adult with PW or for the parents? In the ghetto a young man says he is going to be president. The parents just smile, they know the chance of their son being president is pretty remote but they aren't going to take that dream away by saying, No way, you have to be kidding. They go along with the dream but what they really want for their son is happiness. A child with PW talks of growing up, getting

married, having a family just like other children do or they talk about going to college, living in an apartment, running a McDonald's, or buying a yacht and sailing around the world. You don't dash these dreams, but when you feel the person is mature enough to handle reality you explain their lifestyle is going to be different. The same as above, you go along with the dream but what you really want for your child is happiness. Can this be found in a group home or do you have to feel a home or an apartment has to be the goal? Buying a home or arranging for an apartment, equipped with live-in help as an alternative to a group home, to me is not making your child normal or their lifestyle normal, it does not guarantee happiness. Parents who have followed this route certainly disagree with me, but the independence the parents have bought for their child has a cost. Most of the time the cost is weight, if it is not lifethreatening weight that is acceptable. Sometimes the cost won't be seen until the parents are no longer around to supervise this type of living. It has not been proven to me that the young people are happier in this "less restrictive" type of living. What does it do to a person's self-esteem when they find they cannot handle this type of living and they have to be "put down" to a more restrictive placement? Is it better to start with the more restrictive and let them work their way to a less restrictive? From my experience, I agree with Louise, I believe the answer, for now, is group homes. The future can change this need completely. One of the researchers told me he feels genetic engineering is a real possibility for PWS, not in the next couple of years but certainly in the next 10 years or so.

I interviewed a young man who lives in a group home. He has been a resident in this home the past 7 years, entering when he was 20 years old. Allan had to be hospitalized

before being allowed to move into his home because he was wheelchair bound due to obesity and infections. He stated when he lived at home he did not have a diagnosis and therefore did not know that unrestricted foods would give him the problems that he had. So the main reason for the placement for Allan was to live in a restrictive setting that would allow him to return to a normal, healthy weight. Allan has accomplished this beautifully, and he feels he still needs this restriction to keep his weight down. He is working on contracts to learn how to deal with PWS, and how to learn control, and eat the proper foods. He enjoys living in this home, he has friends there, he enjoys his work. His job placement is at a sheltered workshop but it is a shop that offers levels to those more capable of handling more responsibility. Allan is very capable of doing very good work. He is also allowed to go out into the community for specific jobs, which he also enjoys. He said the best thing about them is that he is able to earn more money there, and he gets to meet new people. Does Allan dislike living in a group home, no, he doesn't but of course he is looking forward to the day when he can get his own apartment, make additional friends and work out in the community permanently. Is this a possibility? Of course it is, but it will happen when the group home knows that Allan is ready.

It is back to the situation we point out so often, each person is an individual, and certainly needs to be treated as an individual, but until such time that I can see more success in "independence", it is going to be my policy, not the policy of PWSA, to recommend group home living for our young adults.



PWSA SUPPORTERS (Last 4 months)

We are certain some of you are aware PWSA operates on a low-budget and yet we still do not have sufficient dues to survive. Here are the people who donated to the CIT and Research Funds: (#'s mean more than one donation; () means donation came from non-member in their name)

We especially thank our "frequent & generous givers": E.Olson (4), Boyd (4), Dixon (4), Sojka 4, (Uzendowski, 4, Trusz, Majka), Mitchell (Gordon, Austin, Schafer), Wett 2, (Schaefer), Beltran (2), Wagstrom (Kiwanis), P.Alterman (2), A.Alterman, Barkeley, Aul (Hutchinson UW), Brewi (Sheeron, Smocer), Miller (Ruddle), Ingalls (2 Cong.Church groups), Nanzig (C.Nanzig), Soroptimist Int'l., & Bintz.

Additional donors: Webb (Stoffel, Steinmetz), Goff, Englund (Lynch), Lacy (Gales), Gulling (P.Gulling, 2), Sheeran (Ciancis), Yannelli, Garfinkel (2), Jacobs (V.Cole, D.Pike), Rankin, Maurer (Smith, Braunreiter), Lehman (Hodgin), Umbaugh (D.Wagner), Burton (2), Evetts (Henderson), LaPenta, Knippenberg (Wilt), Westman, Schroeder, Hjort, Gerdes, UW of N.Utah, Scalia (Dippolito), L.Klein, American Inst., Hawaii CFC, Kerler, Carton, DeSa, Foley (2), UW Capital Area, Geller (D.Geller), Daly (Uttebrant), Maranon (Ablum, A.Maranon), Baletsa (Spychalk), E.St.John, Harrington, Louisville CFC, SC PW Chapter, Jornov (Goeway), Chase (Morris), Straight (Hudson), Townsend (Furr), S.Hall (Dietz, Singman), Brill (Kraft Fd.), Mays, Underwood, Sunde, Lynch (Coke), Moss (UW), Mook, Fritsch (Brynes), Ryan, Community Service Group, Harold, Singer, CA CFC, and Antin.

Here are some of the members who keep us afloat by supporting our request for extra dues and operating donations:

Mitchell (Clark, Meth.Ch), Willott, J.Bell, Marek, Castle, Bush (Severson, Chalgren), Herrmann, Eleazer, Rattray, Deterling, Raglund, Jackson, R.Olson, Ayotte, Trimble, Metzger, Gardner, Shadell, Kirchhoff, Trentacosta, McManus, Amren, A.Levine, Huitbregtse, Haller and Zorn.

A NEW LOOK?

You'll notice a few changes in this edition, with a few more to follow as we learn how to use our desktop publishing system. This has been in the plans for sometime and was suggested to the board in June. A recent newsletter, from another organization, stated with their new desktop publishing, new finish paper and new format was costing 89¢ per issue. The next newsletter has a letter from a member, who stated, go back to the cheaper edition and use that money for a better purpose. I liked the old one better anyway. We do want to continue to make progress, but we also do not want to lose sight of satisfying the needs of a majority of our members.

Other opinions on the GV, sought at the conference, shared wanting a column reflecting positive changes (addressed in another article in this issue). Another member wanted the GV more easily readable. We're not positive what that means but possibly shorter, more divided articles. We do try for that but sometimes they must be longer to include what we feel is necessary information. A format with set columns each month was another request. For example, page 3 is always on finances, page 5 letters etc. We do not always have articles that fall into set categories and feel this would increase an already difficult job of getting this paper out. We will keep trying to improve - and we do appreciate receiving suggestions. We will follow through with those we can.



"I've written many articles about living with chronic illness and am now writing a book on the benefits of support/self-help groups, which will be a compilation of experiences from support group members (including spouses, family members and friends) with different types of physical, mental, social, political, economical (etc.) problems and who have benefited from joining support of self-help groups which have helped them cope." If you would like a questionnaire, contact: Dorothy Jean, PO Box 10579, Costa Mesa, CA 92627.

SPECIAL CLOTHES

Wardrobe Wagon, a company that specializes in health-care apparel, has introduced a new line of clothing and shoes for people who are handicapped. It's called Easy-On, Easy-Off. Skirts and pants have full elastic waistbands, deep armholes, front closures. Prices are \$12 to \$18 for tops and pants. For a catalogue, write to Wardrobe Wagon, 555 Valley Rd., West Orange, NJ, or 1-800-992-2737.

NUTRITION

Salad bars has shed much of their nutritional advantage, unless you make your choices carefully. You can end up with a plate full of calories, fat and sodium. Stick strictly with crunchy vegetables, fruit. Be sure produce is fresh, packed in ice, avoid items stored in water as they lose Vitamin C, potassium, folate and calcium. For protien, select small amounts of cottage cheese, chopped eggs, garbanzo beans and cheese. Herbs and peppers are healthier seasonings than salt. Squeeze a lemon wedge over your salad instead of dressing, or if they do not have low-calorie dressing on the bar, ask for it.

A doctor and a dietitian who specialize in osteoporosis have collaborated on a book of high-calcium recipes, "Recipes for Better Bones" (Perigee Books, NY, 1988, 176 pages, \$9.95.) Victor Ettinger and Judy Fredal present more than 100 recipes plus these tips for better bones: Add 1/3 to 1/2 cup nonfat dry milk to dry ingredients for quick breads, cakes and puddings. Substitute yogurt for sour cream. Use spinach and other green leafies in place of iceberg lettuce. Use milk or buttermilk instead of water in preparing canned soups, hot cereals, and instant mashed potatoes. At dessert time, select frozen yogurt, ice milk and custard. Double calcium content of milk by stirring 1/3 cup nonfat milk into

each cup of liquid milk. Naturally, you have to be checking calories for these additions.

Not all starchy foods are equally nutritious. Potatoes, as they come from nature, are a nutritional bargain in terms of the calories, vitamins, minerals. A medium potato has 110, large 190, that is if you leave off all of the goodies. Try adding a little parsley, dill or chives as topping. If you boil them, preserve the nutrients by leaving on the skin. Naturally, if you start talking about frying or french fries, you not only add calories but destroy some of the nutrients. Sweet potatoes, without sweetener or fat, have about a third more calories and slightly less protein than white, but they are very rich in vitamin A, calcium, iron, and minerals.

You get the most nutrients if you buy whole-grain bread made from stone-ground flour. The next best thing is 100% whole wheat or other whole-grain. If you're buying white bread make sure its enriched. Brown breads contain little or no whole grain, just molasses for coloring. High-fiber breads are usually lower in calories but some brands, for example, Fresh Horizons, uses wood fiber instead of bran for roughage. There's no harm in that but you should realize you are not getting bran.

CONFERENCE FINANCIAL REPORT

An attempt is made with registration fees and donations to operate each year's conference on an even basis. This year we came pretty close. Income: Registration 15,949.75, Donations 1295.58, Raffle 2947.05; Expenses: Meeting Costs 12,843.35, Youth Program 5,149.69, Conference Grant 418.92, Raffle 1,182.21; Total Income 20,192.38, Expenses 19,594.17 for a profit of 598.21.

THE DEAR OLD IRS

The Commissioner of Internal Revenue has asked charities to accurately inform taxpayers regarding deductibility of purchasing fund raising tickets. If you purchase a ticket for a charity event, you may only deduct the amount above the actual cost of the event. For example, if you purchase a theater ticket for a special showing and pay \$10.00 for it and the usual admission is \$5.00, only \$5. is deductible, even if you do not use the ticket. Outright gifts are still completely deductible.

D.D. COUNCILS

Did you remember to call your local state Developmental Disabilities Council and ask that you be included in the survey for the National Association of D.D. Councils. If not, it isn't too late. Make sure there are a number of people with PWS included in their statistics of the unserved and underserved syndromes.



WE GET LETTERS!!!

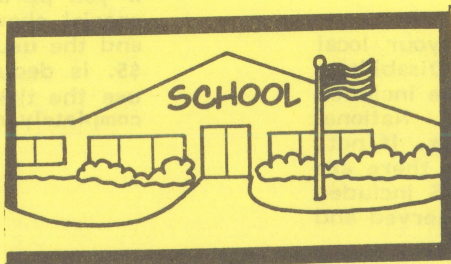
"We are growing slowly here in Quebec and I keep them informed as best I can. Our son Matthew has a job and things are going well. A computer was a great asset in keeping him busy and out of the kitchen - cannot recommend it enough to any parents. He spends long, happy hours on it. He is still monitored at work by his school (until 21) and they have a very successful vocational training and work placement program which is going to be presented at the Canadian Conference in Toronto September 24-25. Matthew is their only PW but all the children are handicapped. If anyone is interested in this programme - don't hesitate to contact me." (We'll supply the name & address to any who inquire.)

OKLAHOMA PARENTS???

"I would like to thank you for all of your hard work that you do for all of us. Receiving the GV is something I always look forward to. I hear your call for unity. The more we work together, the more we accomplish and the faster we reach our goals. I must say in Oklahoma we have not achieved unity. There have been attempts in our state but nothing ever developed. I went through a cycle of trying to reach out and becoming very upset that there was no real support nearby. I have come to learn to depend on myself and not look to others for much needed support - maybe there is some information on how we in Oklahoma can come together. (How about the Oklahoma members, we'll help!)

CREDIT CARD FUND RAISING

"Could we please have more information about the PWSA Mastercard in the next GV? We'd like to get one and other friends also." The California Foundation offered to make arrangements for this fund raiser and work in conjunction with us. As soon as the arrangements have been made, believe me, we'll get it right out to you. We believe this will be a great opportunity to supplement our funds.



ACID SMELL?

"Anyone out there ever notice that as an infant the top of their baby's head smelled of propionic acid (kind of a vinegar smell)? I'm sure it is important but don't know how or why." How about that members?

RESEARCH

We have been asked to share more information about ongoing research and also share more statistics on the syndrome that parents and chapters can use in their work. We will certainly work on this. The next letter mentions a research project that PWSA contributed \$1500. to assist with a small portion of the study.

"My daughter and I just came back from Seattle where we took part in a growth hormone research study. She was admitted to the University Hospital and stayed in overnight as they collected blood samples and recorded her brain activity during sleep. We hope the results will be helpful and useful. Dr. Holm and Dr. Costeff will be getting back to us in about a month.

Drs. Butler and Hill spent a great deal of time at the last conference working on a research study involving skin fold measurements and metabolism. They also presented during the regular conference on other studies. These papers are included in the conference paper summaries. Six year old Katie was in the testing room waiting for her next session with the researchers. The TV had a chocolate cereal commercial showing, and Katie looked at the screen and said, "That cereal has too many calories."

EDUCATION

My daughter will be changing schools in Sept. She has just completed her Grade 3 in a regular program with 2 hours of aide help each morning. We could see the frustration level rising during the last 4-5 months and experienced some skin picking which had not occurred before. Her new school offers a Resource Center where she will receive extra math and reading help. She will integrate into the regular classroom as much as she is able. The Resource class has 10 children with 1 teacher and 2 full time aides. She had Friday afternoon swim

EDUC. (cont.)

program, just earned her Red Cross Blue level badge. Also, as her new school is not our neighborhood school, she will be transported by taxi each day. I guess this system will have its draw backs too but we just could not see her coping with Intermediate level work without a great deal more help. We feel that we have reached a stage when the gap between her and her peers is widening

- socially and academically. We plan to keep close tabs on her program and hope the decision will be best for her.

The order form for the new book couldn't have come at a better time. As we change schools and meet new staff, we will want to provide some reading material. Dr. Holm was very enthusiastic about the book and recommended we get a copy."

SUGGESTIONS???

"Even though it is not an easy subject to approach, would you ask the other members if they have any suggestions on stopping our son from causing rectal bleeding? We have tried the open door policy on the bathroom use but really can't think of anything else to try."

SINGLE PARENTS

"You have told me that it was tried before with little results but would you try again. Aren't there other single parents out there that would like to form a pen pal group?" If you furnish the names, we will start a circle or match people with children in the same age group.

EXERCISES

"I try to find exercises that can 'last' as my daughter grows. We are working on hunting, fishing, swimming, horseback riding, roller skating, bicycle riding. We also spend a great deal of time learning to choose low calorie foods. We do role-playing to learn this. We use a cue word when her temper is getting away from her. (She also uses this on me when I yell). We believe it has helped."

NEW IDEAS

"We are working on piano lessons as a skill development and to improve self-esteem. We could certainly use some more suggestions on socialization and self-esteem. I could also use some new ideas on pumping up my own morale when I get depressed. How about some sharing?"

LABELS

"Our 13 year old daughter entered middle school this year and as in the past 6 years, she was mainstreamed in regular classroom and pulled for resource. Middle school, bringing a totally different environment, changing attitudes, peer pressures and socialization problems - the year turned into a disaster. She had been classified at "I.D.", then reclassified as "other health impaired", but this still was not what was needed. We all put our heads together and decided to reclassify her once more to "multi-handicapped" (which as easily done with all the medical facts on PWS). This reclassification qualified the school

for extra funding which in turn provided our daughter with an one on one aid and total resource (including adaptive PE, speech therapy, physical therapy, and counseling). Mainstreaming had always been our goal, trying to have our daughter live and become as close to "normal" as possible. As our daughter's age increased, so did the social problems and frustrations. Now, instead of being harassed in the halls, eating lunch by herself, and being alone on field trips--her aid is her partner and friend. She relates well to her aid, enjoys her company and our daughter's academics have improved drastically. The depression that was becoming common ground has lifted and our "sunny dispositioned little girl" has returned. "Multi-handicapped" seems drastic, but so is the change in our child."

CONGRATULATIONS WELL EARNED

"I would like to congratulate everyone involved in the conference makings. This was my first conference and I can't imagine missing another one. You all did a superb job and I would like to thank you. The youth program was terrific and the volunteers gave so much of their time and their caring to the program. A big pat on the back to those who gave so much to so many."

CAN'T BEAT THE SYNDROME

I believe one problem with PW is the stages - a baby with PW is so different than a child at 3. A child at 3 is so different than a child at 6. When these children grow, another drastic change. I know when my daughter was 3 and so content, I was interested in keeping food up and developing her pre-school skills. She was so happy, rarely any behavior problem - I wanted to be positive and not hear from someone with an older PW child that was having trouble. Secretly I believed I could beat the syndrome - it was quite a shock to find she did develop tantrums despite all of my hard work. I finally realized that there are some things I could not change and had to accept - PW for what it is.

I still work very hard to make my daughter the best she can be, but I just accept her limitations. I have been told that I am one of her best assets, but I still get frightened of her future."

This writer went on to question many of the same questions all of us have about the future, and then

came through as a typical PW parent and wrote, "On the lighter side, PW Parents Public Enemy #1: The Neighborhood Ice Cream Truck; Enemy #2: The Free Sample Table (at the supermarket). And, a closing tip, "I keep my purse locked in the food pantry so there is no temptation."

RESPONSE TO WATER

"This is my first letter to the organization. Our daughter is 18 months old. She was diagnosed at 7 months after going through numerous tests including CAT scans, blood tests, muscle and skin biopsies and nerve tests, but the diagnosis did not come until I went to the local library and read on my own about "floppy infants". Our daughter can now sit up alone, roll over, but does not crawl. Her gross motor progress seems very slow to us, despite physical therapy since the age of 3 months. On the positive side, she is an interactive, responsive, wonderful girl who has a sweet and sunny personality. She is beginning to say words and loves people. In the most recent GV we were interested in the information about temperature regulation. We have found our daughter is very sensitive to both heat and water. She sleeps excessively in the heat, sweats at almost nothing and has done so since birth. In contrast, she

responds unbelievably to cool water, swimming pools, baths, oceans. In fact, one of the rare times we can get her to stand with support is after her bath. Even as an infant when she barely moved at all, if we put her in a bath we could get a little response from her. As a result, we always undress her, try to put her in water as much as possible and it seems to keep her more alert and spry.

We appreciate receiving the GV although often, we read it with mixed feelings. As parents of a young child with PWS, it is still difficult to read about

problems we have yet to encounter. We try to take it "one day at a time" but it can be overwhelming and frightening. We still hope that early diagnosis, therapies and early intervention will help our daughter achieve her potential."

CREATIVE ACTIVITIES

We frequently hear that older people with PW are lacking in self-esteem. Promoting this in the younger child may frequently be accomplished with creative activities that can give a sense of accomplishment. How much better to keep them busy too than sitting in front of the TV. Initiate projects that can be learned and then done alone. Maybe some of these activities may be considered:

Knitting, crocheting, stitching pillows, bean bags, etc.

Latchhook rugs (the kids love them)

Christmas ornament kits

Gluing projects - collages of things you have around the house; paper-mache over a blown up balloon (make paste with flour and water, use newspaper cut into narrow strips)

Paper plate masks, bonnets

An indoor garden. Seeds from lemons, oranges, suspend an avocado pit, spice seeds - watch them grow.

Promote independence (and help them grow up) by encouraging them to do more of their own care. Make it easier by putting clothing racks at their level, shelves that they can reach. Use plastic color-coded baskets for books, games, even clothes. Naturally, much of their care is much easier and less time consuming for you to do yourself, especially when you need explicit directions and much repetition before it becomes a habit for them, but it is well worth the effort.

IT'S FALL - IT'S TIME TO CONTRIBUTE (GO AHEAD, FLOOD OUR MAILBOX)

The 1989 Conference has been changed to July due to school conflicts. We understand this may be true for many of our members. The Board is asking our members to let us know what their preference is:

Return the 1990 conference to the last week of June _____

Hold the conference in July _____ Which week ? _____

I have _____ have not _____ noticed the acid smell on my infant's head.

Add my name to the single parents listing for developing communication between us. _____

I'm interested in an Oklahoma support group _____

I do _____ do not _____ agree with your policy of sharing successes. My opinion is _____

I would like to share the following "joys" for the GV _____

I would like to order the following new materials that you have:

"Management of Prader-Willi Syndrome" edited by Greenswag, Alexander

_____ \$27.50 PWSA members (U.S.)

_____ \$32.00 non-member Additional \$10. needed for Canadian exchange and overseas air postage

1988 Conference Papers

_____ \$6.00 U.S. Additional \$1.50 for Canadian exchange & overseas postage.

New Video - 2 hours of "clips" from a dozen TV shows on PWS U.S. VHS

_____ \$20.00 U.S. Additional \$7.00 needed for Canadian exchange

NAME _____

ADDRESS _____

LOWER FAT ALTERNATIVES

<u>Higher-fat food</u>	<u>Fat grams</u>	<u>Calories</u>	<u>Alternatives</u>	<u>Fat grams</u>	<u>Calories</u>
Croissant (large)	11	210	Bagel (large)	1	180
PotatoChips, 2 oz.	4	300	Pretzels, 2 oz.	--	200
Jelly Doughnut	8.8	226	EnglishMuffin, 1 T.jelly	--	191
McDonald's Big Mac	35	570	Roast Beef, 3oz. b&b	16	320
B.King Whopper	41	640	BLT, B & 1 T.mayo	23	343
D.Q.Peanut Buster	34	740	1c.Ice Milk, 2Tfudge, pnuts	18.5	443
KY Chick.Nuggets(10)	29	460	4 Fishsticks, 1 oz.	10	200
French Fries (10)	13	227	B.Potatoe, pat butter	4	181
Cream Soup, 1 c.	7.5	125	Tomato-based soup, 1 c.	2	65
Bologna, beef, 2 oz.	5	160	Turkey Breast, 2 oz.	3	110
Tuna/oil 3 oz.undr.	13.7	245	Tuna/water, 3 oz. undr.	0.8	108
Peanuts, 2 oz.	32	421	Plain Popcorn, 4 c.	--	92
Buttery Crackers, 12	2	270	Rye Crackers, 12	--	100

 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 \$20./year Individual, \$25./year Family, and \$30./year for Agencies/Professionals. (U.S.Funds) Send dues and change of address to: PWSA, 6490 Excelsior Blvd., E-102, St. Louis Park, MN 55426.

PRADER-WILLI SYNDROME ASSOCIATION

6490 EXCELSIOR BLVD., E-102
 ST. LOUIS PARK, MN 55426

First Class Mail