



THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

Several letters back the role of the PWSA as communicator was discussed. This was established as the primary role of the organization when it was incorporated twelve years ago. That is to say, the business of the organization known as the Prader-Willi Syndrome Association was designed at the outset to be a vehicle for exchanging knowledge about the syndrome to anyone who might be interested. It also means that the organization has undertaken the responsibility for creating an interest in PWS among those who are not aware of PWS and who should be to further the interests of PW persons.

We know who the people are that have an interest in PWS. They all read the Gathered View. They pay dues in support of the organization. They contribute their time by attending local and national meetings. They support PW person's daily needs in the home and school and on the health care team.

Since the first days it was incorporated as a non-profit corporation in the State of Minnesota, the responsibility for guidance has been vested in the Board of Directors. These twelve individuals are elected by the dues paying members for a term of three years. Each year the election is held at the annual conference. Every member has the responsibility to vote at the annual election. The ballot can be cast in person if that person attends the meeting. The ballot can also be cast by signing a "proxy" statement that is available in the Gathered View each year before the election. A proxy statement signed by an eligible voting member of PWS gives that right to vote to some other eligible voter who will, in fact, attend the meeting and perform that responsibility and privilege for you. A proxy statement can direct a proxy voter to vote for a specific named candidate. The statement can also specify that a proxy voter use the vote according to their best judgement and vote for the candidate they like best on the actual day of voting. Just as in any other organization that operates as a democracy, the right to vote is also the responsibility to vote. Failure to vote is a statement that the organization is to much of a bother to waste the effort on voting or assigning the vote to an appropriate proxy. Voting is as much an indication of support as sending in dues or making a voluntary contribution.

What then do these elected representatives do, what should their qualifications be, how can a voter select a representative that is unknown to them? There are many questions that arise in this matter when it is first considered and many more should the Board act or fail to act on a matter on concern to you. The only real requirement for election and retention of membership on the Board of Directors is enough interest and wherewithal to attend two meetings each year at their own expense. Failure to attend two meetings is cause for dismissal from the Board. One meeting is held in conjunction with the annual conference and consists of over eight

President's Message, cont.

hours of meetings spread over four days. The mid-term meeting is held in early December and is a full day on Saturday with a morning meeting the next day. In between meetings there are usually several communications that require evaluation and written response to be returned to the Executive Director.

In the past the persons nominated at the meeting have demonstrated continued interest in the organization by attendance and participation at enough of the conferences to be recognized by other voting attendants. Some have been selected because of an outstanding effort that has come to the attention of the voters. Others have continued to maintain contributing involvement since the founding days of PWSA.

If you have concerns regarding the nature of your PWSA these concerns must be expressed. No concern can be addressed by the PWSA unless it is known. Each member has as great a voice as any other member. It doesn't take a communications expert to yell, "Ouch" or even "Thank you." It does take responsibility and involvement of the membership to keep an organization alive. The PWSA can only serve its members to the degree that the membership is willing to provide support in the form of membership, contributions, interest and communication. To love is to say, "What part of me can I give to make you better?"

Delfin J. Beltran, MD

President

A PICTURE IS WORTH A THOUSAND WORDS

That old cliché is certainly apropos with PWS. When we are trying to educate people, having a picture so people can actually see--here is an actual person with a problem. We are seeking a national celebrity as a spokesperson. If we do decide to do some further direct mail fund raising, pictures would help. Several people have suggested our educational materials could be improved if we used more pictures. The CA Foundation has also asked our support in sharing of photos, particularly showing PWS occurs in all races.

Several pictures of one child would be great. It can be infant, pre-school, it can be slim to heavy, it can be heavy to slim--anything of that type shows how important diet can be, how necessary early therapy and exercise can be.

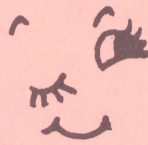
PWSA has a two person staff that spends full time each week working for you. It can be rather discouraging when we ask for membership response and get very little. We realize you all are busy people, we realize you have a life outside of raising a person or working with a person with PWS, but each issue only asks for a little of your time. This issue contains some very important requests. Won't you give an hour of your time right now and respond to these needs? (Please include a written permission with the photos.)

A FOLLOW-UP ON COMMUNICATIONS:

Why can't PWSA develop an educational plan for us to use?
Why not give us an IEP we can use?
Should my child be mainstreamed?

Children with PWS range from the 40's to the 90's in I.Q. This is from severely retarded to low-normal. They are served in rural to large city, classes that range from 3 to 23. Can you see why it is difficult to even conceive of samples to be used. The other problem is very few teachers have experience with several children.

As in many areas, we believe "sharing" is the answer to educational needs. You have fought for programs and seen them succeed; you have made mistakes; you have worked on IEP's; you have watched your child progress through the educational system. How about some help for those just starting? You needn't write fully developed articles ready for publication -- just jot down some of the successes you have had, maybe this is an area someone else hadn't even thought about. Send some copies of your IEP's. You have much to offer, it will be appreciated.



CHAIR OF BOARD

Lota Mitchell, Board Chair, made a statement at the conference that we feel is worth sharing with all of the members:

"We need your input. We need to hear from you as we look ahead, as we deal with present day issues, and as we try to plan for the future of this organization; we need to hear from you...whether it's something that you feel we're doing a good job on or if it's a suggestion you'd like us to consider, or whether you want to throw some rotten tomatoes at us and say you didn't like something very well. We need to hear that from you.

The other thing we need to hear from you about is your talents, your skills, what you can contribute to the organization. We're working hard and I know there are a lot of people out there that want to be involved. They've got talent to contribute. Have you got experience as a fund raiser, have you any background in long range planning, do you know how to to through the process. What kind of skills are out there. Come to us--we try to go to you but we surely would be happy to have you come to us and say this is what I can do. Can you use me?

Response can be made directly to Lota or to the PWSA office.

A Dietician student wrote:

"Thank you so much for the use of the slide presentation on PWS. It was extremely beneficial in my study. I won a statewide case study contest and was able to present my case using this slide presentation at a state meeting. Thanks again so much for your help."

Another Diet Book

"The latest nutrition book to find a place on the NY Times best-seller list is How to Be Your Own Nutritionist, is written on behalf of a doctor by a freelance writer, neither of which has the qualifications to write it in the first place" reports a Nutrition Letter. This reminds of us of a statement made by a doctor who said there is always a new diet book out because the last one didn't work. Their advice: "Ignore this best-seller".

CONGRATULATION TO TOYA STURGIS

Toya's parents shared a picture and a news clipping stating Toya has completed 10 years as a girl scout and was recently awarded the "Silver Award". To earn a Silver Award, a Girl Scout must complete the career exploration, skills and knowledge development, learning and demonstrating leadership ability projects and also complete a community service project.

This is the 2nd highest scouting award and few ever achieve it but Toya set this as a goal three years ago. Her new goal is to live in a group home for PW and attain a normal weight. We certainly wish her well in her new goal.

#15 CHROMOSOME DELETION

Most of our members are aware of the importance of chromosome testing at a young age so a PWS suspected diagnosis can be possibly confirmed.

PWSA does have some members where this deletion was present but atypical symptoms are later reported. One such member has requested we start a "Circle of Friends" pen pal group for these people. If you are interested, please send information to us and we will set up a circle.

We do have other circles presently operating and can always use new people who are interested in writing to someone in their own age group.

We also have not updated our pen pal listing for people with the syndrome in some time. We would be happy to add new names to this listing also.

We recently received a letter from a 15 year old girl in New Zealand who would like a "long list of names" so she can write to them all. Please let us know if you are interested.

Happy Holidays to all.

CRISIS PLANS MUST CHANGE

A few years ago an idea was formulated to meet the needs of many of our members who were not being served in their own area. It was a dream of an already existing facility being turned into a National Developmental Center for PWS. For \$350,000 we felt we could open this center to serve 50 young people in need of temporary or permanent residential placement, have needed vocational training, offer staff training for other facilities, offer respite care or camp to those in need, and offer the potential for research. We felt if the members really wanted this to happen, all of our members would do the necessary fund raising, begging, or deep-down giving to raise this sum in a short period of time. The few people in dire need responded immediately but the rest of the membership could not see the need or at least could not see that their contributions were essential.

When we discovered \$350,000 could not be raised, we looked for alternatives. Laura Baker School of Northfield, MN came up with an alternative plan that would at least address a greater percentage of the original goals, the most important being saving the lives of the young people in crisis condition. We offered the alternative, a Crisis Intervention and Transitional Center concept to our members and we continued to fund raise with our goal being lowered to \$200,000. In the meantime we felt our funds were sufficient to apply for the necessary requirements for licensure from the State of Minnesota. We set the wheels in motion. Even though the wheels moved slowly, things looked very promising in the beginning. We had felt obtaining state approval would not be a difficult task, but we soon found out that it was going to be a fight every step of the way. Well, what is new about PWS not fitting into authoritarian concepts?

A "needs determination" was denied because the "current thinking" in Minnesota and the rest of the nation is "smaller is better". Despite this, we tried to convince the state that a center for 12 would be most cost effective and staff efficient, but we were not successful. We felt if we could pressure this committee into reversing their decision, there would be so many restrictions on this Center it could not possibly meet the needs we want to serve.

A subcommittee of the board had been formed to work on the development of this Center. This committee is comprised of four board members and the executive director. After meeting recently, it was determined that even though "I give up" is very hard to include in our vocabulary, it is sometimes necessary to evaluate if following the set course is still a viable plan. In our opinion, it is no longer a viable plan in the State of Minnesota. We have had two offers from two other areas who are both interested in the crisis concept. We also have a rehabilitation institute that already has been working on intervention. It also has been suggested that some of the CIT funds be used to assist in facility development, i.e., loaning start up funding or to develop training programs at some existing facilities for new staff at other locations.

The money donated to the NDC and CIT concepts was donated with a designated use. In this situation, the organization must use these funds for the stated use. Whatever is developed, you will be fully informed of any plans before finalization and we will have legal council in determining the proper procedure to follow. We are now asking for your input. Although we have not been able to find a short term solution, in the long run we know something good can come from these funds. When this fund raising began, some of our members were skeptical of our ability to raise this amount of money. The inspiration of

CRISIS, cont.

what a Center could do for PWS led us through raising almost \$190,000. We do not feel the tremendous amount of effort in trying to open a Center has been in vain. Working on this concept has given hope to members with dire needs, it has also helped many in obtaining services in their own area. We have to feel if our original dreams are not realized, some future plan may be better. In 1979 there was one home designated for PW, there now are 21. What an outstanding increase. Dorothy Thompson, our group home expert, and the PWSA, has been very instrumental in assisting with the opening and staffing of many of these homes.

We have been discouraged by the membership participation in our attempts to open this Center. Even though 68 people sent in applications, we have had minimal support when requesting further information and action on the part of the applicant. The State of Minnesota may have looked at our application differently if many of the states submitting applications had pledged support for their residents. There has to be assurance from the state of origin as to the responsibility that they will assume in funding persons in the program. This did not come forth. When we asked the applicants to start proceedings to cause this to happen, we had a response from just two people. In August we asked these same 68 applicants to contact Laura Baker School directly, four people responded. Apparently the need for a center was not as great as we were led to believe. It was undoubtedly very discouraging that we couldn't accomplish our goals in a shorter time period. As an organization we could not apply enough pressure to surmount this last state denial, we needed support we did not have. We need to find solutions

that can be developed now, not a few years from now.

Do you want to work on the crisis concept in another location if it could be opened in the near future?

Do you want us to try to further develop placement possibilities in an existing facility?

Do you want us to financially assist individual efforts?

We need input to determine what a majority of the people who have contributed these funds desires. Even if you are not a CIT donor, if you have some ideas please feel free to share them. We need your input before the December 5th board meeting. Let us hear from you now.

VISITORS FROM SWEDEN


Our director was privileged to spend a few days with a psychologist, headmaster and three teachers from a residential school in Vingaker, Sweden. Olle Boethius, Jan Andersson, Lennart Falk, Lars-Goren Rudin and Yngve Pettersson spent several days in Minnesota visiting the 15-bed Oakwood Residence for PWS, a large sheltered workshop, and the 73-bed residential Laura Baker School in Northfield.

This school has had undiagnosed children with PW in the past and presently have two young men who have been diagnosed. The statement was made that doctors have not been aware of this syndrome for very many years there.

PWSA has also been working with a group that formed a Swedish organization over a year ago. They are hopeful that they will be able to send representatives to our next annual conference.

WE KEEP TRYING: Does anyone know anyone associated with the Scott Paper "Helping Hand" program? We'd certainly like to get an inside track on some of these corporate charities.

yes

SOME EXERCISES BETTER THAN OTHERS


All of us are aware that exercise must accompany dieting in order to be an effective weight loss or maintenance. The trick is to find the type of activity that is acceptable and better yet fun, if you can accomplish that. Exercises have to be for 20-30 minutes at one time to be effective, and done at least four times a week.

Burn 3 calories per minute with this list:

Baseball, bicycling, bowling, canoeing, modern dancing, social dancing, floor exercises, horseback riding, sailing, softball, table tennis, walking.

Burn 5 calories per minute with these:

Badminton, aerobic dancing, basketball, disco dancing, football, gymnastics, skiing, ice skating, roller skating, swimming, tennis, volleyball.

Most 8 calorie per minute exercises are not recommended or cannot be accomplished, such as handball, jogging, rope jumping, downhill skiing, etc.

CEREAL SNACK CRUNCH

1/3 c. honey	3 c. puffed wheat
1/4 c. butter	1/3 c. chop'd pecans
1/2 tsp. grd. cinnamon	

Combine honey, butter, cinnamon in 1 qt. saucepan. Bring to boil over med-hi heat, stir occasionally. Boil 5 mins., stirring frequently. Add to cereal with nuts, then mix well to coat evenly. Spread on wax paper, break into pieces. Store in tight covered container in refriger. Makes 5 cups, 10 servings. 118 calories each.

BROCCOLI-CHEESE QUICHE

Steam and drain 1 10 oz. pkg. Frozen Broccoli. Blend the following 2 mins: 4 lg. eggs, 2 c. s.milk, 1/4 c. flour, 1 slice bread (torn into pieces) salt & pepper to taste.

Spray 10" Quiche pan, lay broccoli on the bottom, pour over egg mixture and top with 4 oz. shredded cheese.

Bake 375° for 35-40 mins or until knife comes out clean. Serves 6. (Approximately 135 calories per serving)

Served with a tossed salad and fruit, it makes a light dinner.

SUMMER CAMP OPPORTUNITY

As all of you know, it is not too early to think of next year's camping in order to find a suitable place.

The Wonderland Camp in Missouri has been the site for spring and fall family retreats for PWS for three years. The Missouri chapter would like to find enough campers to have an exclusive PW week in July, 1988. Cost approximately \$200., transportation can be arranged from St. Louis airport if needed.

For further information, contact: Allen Moore, Wonderland Administrator, 301 W. 12th St., Eldon, MO 65026. (314) 392-5272. Brochures are also available for vacation possibilities in the area.

THESE DREAMS AREN'T REALISTIC YET

Members share articles they receive in the mail, "advertisements" from papers that look like news items, claims from other countries. In recent times many pills, pumpers, and procrastinations have become more prevalent in the "lose excess fat easily" market place. There are many books on how to lose weight without strain; pills to take which will remove fat with no effort or risk; machines to burn away fat.

Each one of these methods are to accomplish only one thing, to separate us from our money and make them rich. There are NO easy, fast, and safe methods to lose weight, you can be sure that it would be heard all over the world if there were. So, when you see or hear about a "new and revolutionary" way to lose fat, save your money and buy high fiber foods, fruits, and low fat foods. A well rounded diet with calorie control and moderate exercise is the only "good" method to lose unwanted fat and not get it back.

CHAPTERS

"Newsworth" Knowing About, 9-11-87, PWSA of Ohio, reached our desk a month or so ago. It is interesting to read of the hopes and achievements of chapters, but the calls for help is what is most prevalent from most chapters. Most chapters have a few individuals who donate a great deal of time and effort into state problems but become discouraged when a greater percentage of their members do not lend their support.

If you are a chapter member, please help whenever you can by responding when called upon. There are many needs in the state of Ohio right now and Peggy Ott is giving 100% to help all members. It is important that she have the backing from all Ohio members, just as it is in many other chapters. We hope all of our members realize what can be done with a little help.

From the PWS Newsletter of Central Canada and the PWSA of Ontario, a few gems:

"We also found camp to be an extremely positive experience for Sara because she is quite high functioning and was able to become a bit of a leader with a whole flock of friends, instead of a "special needs" kid, the brunt of daily teasing and barely a friend in the world. She has already learned to fully accept the most developmentally and/or physically handicapped people around her and has told us she prefers their company because the acceptance is mutual. It has helped us to accept her more as a wonderful child with a problem, rather than as a problem who happens to be our child."

"How much control? My problem must be reflected in the lives of many parents whose children, or adults, have PWS, but I have not yet seen an answer to the always nagging question: "How much control should one human being exert over another person," legally and morally?

Our people with PW can be considered "foodaholics" in their constant craving for food, and can be compared to the alcoholic and his craving for alcohol.

It is generally accepted that the alcoholic cannot be helped until he/she admits the need for help and is prepared to give up alcohol entirely.

However, the foodaholic, with the best intentions in the world, cannot give up food entirely. He/she must eat to live, and his/her hunger for food is beyond control, so let's not lay a guilt trip on the PW person who sees an opportunity to eat and takes advantage of it.

We tend immediately to blame the person who steals the supper pie or the candy bar left in the cupboard, when actually, the fault (if there is any fault) lies in the circumstances.

We also err when we look at the necessary control in a negative manner, as something we MUST do but resent doing it. There are many medical and physical conditions and illnesses that require a regular, often lifetime, commitment from care-givers, parents or others.

We should look at good control as being the medicine required to keep our loved one healthy and we should try to explain it in this way--even pointing out that many medicines are not very palatable to the receiver--or the dispenser.

This more positive approach to the question of control may also prove more acceptable when explaining to other involved people--teachers, supervisors, etc.--even family.

So! the answer to how much control, is --"Whatever is necessary."
Margaret and Geoff Willott"

"A PW person could easily be persuaded to give up a half of his after dinner fruit for a milk shake later on."

"Unflavored gelatin can also be used to make a special treat. Example, a milk shake can be made by using a little artificially sweetened Kool Aid and one packet of unflavored gelatin dissolved in water. When cool, whisk in 1 Tbsp. of ice cream."

"All foods have calories--the trick is to make a small weight of food look like a lot."

"Whole fruits take longer to eat where-as juice can be downed in two gulps."

"Stretch that scrambled egg by adding a few ounces of their milk allowance."

TIPS FROM A CONFERENCE HANDOUT

1. Self Monitoring

Keep a record of all foods consumed at mealtimes and snacks. Estimate the amount of food stolen or eaten without supervision. Look for any patterns, tantrums or difficult times. The Diet Diary should include:

1. The Date
2. Day of the week
3. Kind of food eaten
4. Amount of food eaten
5. The time it was eaten
6. Where, with whom and associated activities
7. Feelings associated

2. Structure Eating Schedules

All meals, including snacks, should be eaten at the same time and same place. All food should be consumed at the kitchen or dining room table. No food in front of the TV, with music or other activities going on.

Eat only 3 meals and 1 snack.

3. Replace Eating with other Avenues or Agents.

Each time your child is found searching for food or asking for food, redirect the child toward another behavior. For example, puzzles, games, painting, coloring, exercise.

4. Environmental Control of Food

1. Get rid of all the junk food, high fat food, and high sugar food.
2. Put high calorie foods out of sight and out of reach.
3. In some instances food may need to be locked up.

5. Weigh and Measure All Food

Check portion sizes!! Be sure of the amounts and no guess work. Slightly over size portions can add up to 2-300 calories each day.

6. Reward for Appropriate Dieting Behaviors

Reinforce or reward for behaviors associated with dieting. Don't make the mistake of only rewarding for weight loss. Many times weight loss is not a concept that children can understand. Rewards for weight loss alone are also not frequent enough to promote behavior changes.

Examples: Make a chart with stickers or star rewards for exercise or dieting behavior.

For every day of appropriate eating, money can be earned for tapes or records.

Give verbal praise in front of friends and family for a day without snacks or tantrums.

7. Negative Reinforcement for Inappropriate Eating Behavior

Food stealing or other behaviors can be dealt with by 1. public apologies, 2. Restriction of TV, 3. Early bedtimes, 4. Restriction of privileges.

8. Beware of Holidays and Vacations

Holidays and vacations are difficult times for dieters. Many times meal structure falls apart and food is everywhere. Plan ahead, keep meal times regular, and reward dieting efforts. Holidays can be made special without food: Give friends and relatives a list of small gift items they can offer your child during holidays instead of food.

9. Food Pushers

Many people have good intentions but they can sabotage our best efforts. Education and explanation are the best ways to combat unwanted food offerings to our children. Many people just do not know what else they can do for your child--give them a list.

10. Exercise

Consistent regular exercise is one of the keys to permanent weight loss. Exercise uses stored energy or calories. It also builds muscle and muscle uses more energy than fat. To reap the benefits of exercise it must be done continuously for 20-30 minutes and at least 3-4 times per week.

YOUNGER PARENTS SHARE:TIPS FROM A MOTHER FROM OK

"I love to sleep in on Saturdays, and resent being awakened at 6 am by my daughter. Now I leave a piece of fruit, 1 slice on thin wheat bread (wrapped in plastic wrap) and a mix package of hot chocolate (she adds the hot water). Tina enjoys "making her own breakfast" and seeing a smile on her mother's face."

"If your child loves to do school work, run copies of math and reading books (that you can purchase) and let them do them over and over. It not only keeps her busy but enforces her learning skills."

A WISCONSIN MOTHER WRITES:

I ordered some of the posters with photos and descriptions of children with PW and distributed them to the school and public businesses. The school believes they have others with many signs of PW and a few other children may be caught young. The posters are very important, as well as informative to the public and making them aware of PWS.

A MOTHER FROM WA WRITES:

"I have requested that my daughter be in a self-contained classroom for the MR. I'm afraid if she goes into a regular classroom she will just get lost in the system and feel failure because she can't keep up with the regular children. Now she feels success because she is in the top reading group and the top math group and is doing very well. I want her to like school, to succeed, and to feel good about herself.

She had a terrific camping experience this summer with horseback riding, swimming, boating, etc. They have one on one and put experienced counselors with PW. We met and talked with the director, the nurse and the cook."

FROM CO:

"I would like to advise the parents of younger children to not be intimidated by the so-called professionals. You, the parents, are the true professionals. The ones labeled pros have received their training thru books, and clinical observations. You have first hand knowledge. I am not saying to ignore all advise, but keep an open mind and know that your suggestions, your concerns, your thoughts and feelings do count.

It is important to take classes in the rights of your child's education. To know how important your role, again as the child's parent, is in their proper education. Do not just hand your child over to the school system, and feel comfortable that they will receive what is due them. Go to classes, find out what an IEP is, how it should be properly written and what right you have to correct any injustices being done to your child. Keep the line of communication open - make sure they know you are a member of the team working for the best interest of the child.

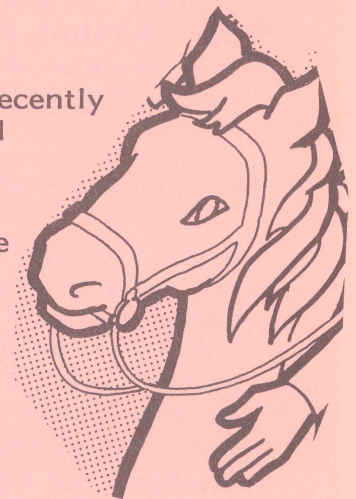
I have learned that people who do not have a handicapped child or family members can not comprehend what you are going through. Get yourself involved with a group that understands.

All children progress at their own speed, not just children with PW. Living in fear of when problems are going to develop is wrong. Take it one day at a time and love them for themselves.

EXERCISES:

Several parents have written recently of adding horseback riding and "Jazzercise" classes to their child's exercise programs.

One mother wrote that they are part of a special class where they have a special mounting platform. Another mother wrote that aerobics didn't work but jazzercise did.

MEDICAL REACTIONS:

One parent writes her daughter has tremendous behavior problems while taking the antibiotic "Bactrim". Her warning: watch for patterns, certain medications can cause adverse reactions.

* DONATIONS *

- * As always, we are very appreciative of those members who continue to support PWSA financially. The following donations were received in Sept. & Oct.:

- * RESEARCH: Budner (Ikline, Eisner, Weinstein, Fleischner), Howe, Henningsen, Ebel, Staples, Womer (Mitchum), Kraft, Van Zomeran, Kelleher, Mook (Smith, CT Chapter, Union fund, Scalia (Stanzione, Dippolito), PW KY Chapter, Combined Funds LA Totalling: 1318.52

- * CIT: Sharp (2), Chase (Morris), Boyd(2), Sojka, Olson (2), Dixon (2), Maurer (Bloomer), Kraft, Veziroglu, Gunnison (Hager), Parent, Sunde, Beltran Totalling: 985.00

- * We appreciate those who responded to our treasurer's report and added \$1378.40 to our operating budget: Sharp (2), Chase, Bell, Pearson (30 memorials), Rattray, Castle, IN Chapter, McBreen, Seggerman, Nanzig, Novak, DeHaan, Schauer, PW KY Chapter. Members make contributions to operating also by paying additional dues--we thank them too.

- * We recently read of an organization that received \$30,000 in two will bequests. While using Roy Smith's valuable information on wills, have you included PWSA in your will? Or how about the tax benefit of adding PWSA to your Christmas giving? Unlike many larger organizations, our operating budget is very low. Your contributions do make a difference in what PWSA can offer its members.

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RESEARCH SURVEYS

After a couple of years, believe it or not, we are now entering the information from our 7-part survey into a computer for research purposes. It is not that this information has not been used, as it has, but we are now making it more readily available to encourage more PWS research. Some parents returned all parts of this survey, others only returned some sections; we have new members since this study was done; we are asking all of our parents to take a few moments and fill in and return this form. We already have 677 participants, which is a tremendously large number for studies, but hope to increase this even more with your cooperation. When this portion is returned, we may contact some of you directly for additional information at a later date. Your efforts on behalf of PWS are truly appreciated.

The questionnaire is on the next two pages.

- * Louise Kelleher, lucky winner, who shared half her good fortune with us.
- * Those people who designate PWSA for memorial funds, especially Jan Pearson whose grandmother's memorials came from 30 people this past month.
- * The PW Kentucky Chapter who feel a certain portion of their fund raising is well used by PWSA.
- * The Kraft family for two generous donations.
- * Our "old faithfuls" that feel monthly contributions are a part of their budget.
- * The nice people who add notes on their correspondence and tell us we are appreciated.

Special People

- * SOMETHING TO LOOK FORWARD TO:
- * "Management of Prader-Willi Syndrome" edited by Louise Greenswag and Randell Alexander, has gone to the printers.
- * A great deal of effort has gone into the readying of the book and we look forward to being able to offer it to our members, hopefully by spring.

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QUESTIONNAIRE SECTION ONE

Questions pertaining to person with PWS.

NAME _____
Last Middle FirstSEX _____ BIRTHDATE _____ BIRTHPLACE _____
City State/Province

BIRTH WEIGHT _____ BIRTH LENGTH _____

PRESENT WEIGHT _____ PRESENT HEIGHT _____

Questions pertaining to mother/pregnancy of child with PW.

PROBLEMS ENCOUNTERED DURING PREGNANCY _____

WERE THESE PROBLEMS UNUSUAL FOR YOU Yes No (please circle right answer)

WERE ANY DRUGS TAKE DURING PREGNANCY Yes No IF SO, WHAT AND WHEN _____

DID YOU NOTE LESS MOVEMENT OF BABY DURING PREGNANCY Yes No

WAS LABOR Long Short and Difficult

IF PREGNANT BEFORE OR AFTER, WAS THIS LABOR DIFFERENT Yes No

WAS A CESAREAN SECTION NECESSARY Yes No IF YES, WHY _____

WAS THIS YOUR FIRST SECTION Yes No DELIVERY POSITION _____

Questions pertaining to infant

IF TRIED, WAS NURSING SUCCESSFUL Yes No

WAS RESUSCITATION NECESSARY AT BIRTH Yes No

WAS APPEARANCE OF BABY UNUSUAL Yes No IF YES, WHAT _____

WAS AN ISOLETTE USED Yes No HOW LONG _____ WITH OXYGEN Yes No

WAS THE BABY HYPOTONIC (Limp, floppy, decreased muscle tone) Yes No

IF SO, WHAT DEGREE Mild Moderate Severe Extreme

WAS A WEAK CRY NOTED AT BIRTH Yes No DID BABY CRY MUCH FIRST FEW

MONTHS Yes No DID DOCTOR COMMENT ON SIZE OF PLACENTA Yes No

Questions pertaining to family

AT TIME OF CONCEPTION, DO YOU RECALL ANY PARENTAL ILLNESS Yes No

OR MEDICATIONS THAT WERE TAKEN BY PARENTS Yes No

IF YES TO EITHER, PLEASE DESCRIBE _____

DID MOTHER CONSUME ANY ALCOHOL DURING PREGNANCY Yes No HOW MUCH
PER DAY _____

DID MOTHER SMOKE DURING PREGNANCY Yes No HOW MUCH PER DAY _____

DID ANYONE ELSE IN HOUSEHOLD SMOKE Yes No HOW MUCH PER DAY _____

STILLBIRTHS _____ MISCARRAGES _____ (please give number)

BIRTH DATE OF MOTHER _____ BIRTH DATE OF FATHER _____

QUESTIONNAIRE (cont.)OCCUPATIONS OF BIOLOGICAL PARENTS AT TIME OF CONCEPTION

PRESENT LIVING ARRANGEMENTS FOR PERSON WITH PW: HOME

MIXED GROUP HOME PWS ONLY GROU HOME RESIDENTIAL SCHOOL

INSTITUTION If living out of home, would you please give us name and address of residence:

NAME OF PERSON SUBMITTING INFORMATION

PHONE NUMBER () -

CAN WE ADD YOUR CHILD'S NAME TO OUR CONSENT LISTING Yes No

(This is a listing that we share with researchers if this information is necessary to their work, or we share it with other parents seeking contact, or with chapters who are working in your own locality. Certainly discretion will always be used.)

100% PARTICIPATION WOULD MAKE OUR SURVEY TREMENDOUSLY VALUABLE BUT
WE NEED YOU TO ASSIST TO MAKE THIS GOAL.

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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, 5515 Malibu Dr., Edina, MN 55436.

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