



THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

Were you there? Did you see it? Did you hear it? What a meeting! The Eighth Annual Prader-Willi Syndrome Association Conference. Two hundred and seventy adults, eighty-nine young people with PWS, and twenty-two siblings. Now I should ask, "Did you feel it?" The next day after the closing the Sacramento Valley hit 106 degrees. Someone said it was all the hot air dispensed during the president's opening remarks. Marilyn Bintz, highly successful Sacramento meeting hostess, assigned me thirty minutes to open the meeting and introduce your officers and board with a historical rundown. Ninety minutes later Dr. Suzanne Cassidy promised me she would never follow me on the program again, as she passed me on the way to the podium to salvage what little time was left her to review the medical aspects of the Prader-Willi syndrome.

Actually the program started the preceeding day when twenty-two enthusiastic chapter presidents and representatives inaugurated a new committee designed to improve communication between local chapters and the national office. Faced with a previous weak showing, your representatives plan to solve the problem of how to accomplish national committee work if the committee members are scattered through several distant chapters. They have elected to enroll individual chapters as a committee. As it stands now, the Kentucky chapter will function as a committee to revise and update the "Directory of Clinic Services" that was compiled by one of the most successful previous committees. Janalee Heinemann, who was elected on Saturday to the open slot on the Board of Directors, along with her husband, Al, will guide the Missouri group as a committee examining camping and weekend retreat facilities. The California group, actively seeking to form three new chapters, volunteered to committee the knowledge and problems related to residences (you are correct, committee is not a verb). Tri-State will function as the committee on publicity. Utah has volunteered to become your expert source on education. Minnesota volunteered for respite care, but there are additional tasks to be assigned, so if your chapter is in the volunteering mood, contact me with your ideas. Your representatives were so enthusiastic that I was chastized for ending the meeting after three hours and they want a whole day next year. That, to me, is an indication of the level of dedication these people represent. Lively discussions arose at other times during the four days of meetings and this represents organizational good health.

The Eighth Annual Conference was a significant landmark from another very important standpoint. Dr. Vanja Holm, Chairperson of your Scientific Advisory Committee, organized a full day meeting for professionals involved in research into problems related to PWS. It was originally conceived as a small forum where active researchers could meet to discuss the problems of research and the directions that research into PW might be taking, while at the same time facilitating interchange between various active institutions to coordinate interdisciplinary projects. In

President's Message (cont.)

addition it became a focus of interest to many attendees to get a glimpse into what research is being done and what is new on the horizon. At next year's meeting in Houston, these scientific presentations will have a more important role in shaping the format of the meetings.

Once again I return home rejuvenated as a result of the wonderful experiences enjoyed at an annual conference. Hopefully we have attracted an additional number of devotees to that growing numbers of friends who will never miss the chance to come to the conference. Start planning now for a trip to Houston, Texas for the Ninth Annual Prader-Willi Syndrome Association Conference. I'll try not to make it so hot.

Delfin J. Beltran, MD

CONGRATULATIONS

In addition to adding a new board member, mentioned above, PWSA also welcomes Harvey "Bud" Bush to the post of our new Vice-President.

LOST AND FOUND AT THE CONFERENCE

We have a necklace that was turned in at our registration desk. A description and request will return this to you. We are missing a calculator that was borrowed from a member. If you find an unidentified one around the house, we would appreciate its return.

SPECIAL REQUEST

During the conference it is customary for the Executive Director to give a sort of State of the Union message which is too long to include in the GV, but this year it was requested by several members to print part of this report:

"It would be easy to stand here this morning and use several hours informing you what we have been doing and what has been accomplished this past year, instead I would like to repeat a technique that I heard at another meeting. I'd like all of you to close your eyes for a few minutes -- visualize the scene I am going to describe. We are all sitting in the forest, we are in a circle (isn't it great to have so many of us sitting in this large circle together?) We each have a log beside us, one by one we walk into the circle and place the log on a pile. What a tremendous pile that makes. The logs are lit, can you see how large the fire is?, can you feel the heat from the fire?, can you imagine how many miles away our fire can be spotted? Now, one by one each of us goes up and removes our log, we take it back and put it by our sides, our log continues to burn for a short time and then goes out. The large fire is gone, the heat is gone, the small fires can be seen for only a short distance and then they go out. We no longer can be seen from afar, we can no longer see the person sitting next to us. Each of us is an individual, each of us has something to contribute, but look what can be accomplished when we work as a group.

This is how I see PWSA, in the past and in the coming years. All of us should continue to have our own logs, and they can burn alone, but how much more can be accomplished when we work together. I feel we have been doing a terrific job of building that bonfire and I hope this coming year will have many individuals contributing to that fire and causing that fire to be heard, to be felt, to be seen."

VOCATIONAL PLACEMENT

One of our members asked if we would seek information from our membership regarding the successes and failures of vocational placement after high school. We would be happy to share our responses with this parent.

Information received by our office has been fairly consistent with most associations of doctors, schools, and workshops -- success depends on the person's ability to recognize the needs of this person.

Our young people can be very capable workers, certainly they are higher functioning than most people in a sheltered workshop situation. They have the ability to learn, they have the ability to do good work (particularly when small motor control is essential). Believe it or not they have the ability to do very meticulous and tedious jobs for many hours.

The problems stem from the fact the whole syndrome has to be considered in their placement. They have the ability to work outside of a sheltered environment but my favorite story is the factory manager who said he would be happy to hire a young man with this syndrome. The young man came in for an interview during the noon hour. The manager did not have time to go for lunch so the secretary brought him in a hamburger and a milk shake. The secretary then called him out of the office for a few minutes and the young man immediately consumed the sandwich and shake. When independent work is considered, you also have to consider the food environment. Factory workers would not be happy with a person that steals their food or their money in order to hit the vending machines. A hotel would not be happy if their laundry worker spends all of her time in the kitchen snitching food instead of delivering laundry to the linen closets. In addition to food, our young people also have some difficulties in other areas of independent employment. Their inability to adjust to change can frequently get in the way and be termed as "unable to accept supervision". The ability to use public transportation is also frequently a problem when independent work is considered.

Sheltered workshops can be very successful or they can fail -- this depends on the staff. Are they willing to learn about the syndrome and accept their behavior as a true disability, not just stubbornness or uncooperation on the part of the client? My example here is would they place a blind person in a different room every day and expect him to keep up maximum production? No, special allowances are made for this client because of his disability. The same is needed for our children. If the staff is willing to make these allowances for behavior, the placement can be very successful.

One parent recently wrote, "Kathy is doing quite well in her workshop and I am getting much more cooperation from people working with her. The more people know about PW the more they are willing to work with you. We work on Kathy's behaviors (which for us is a bigger problem than controlling weight) on a token system and I am on call for any outbreaks. My husband and I get there as soon as possible. So far she is still working and very good at production."

If any other parents would like to share, we would be happy to furnish further information to this parent seeking information.

NEW YORK STATE SURVEY

A survey conducted by one of our members, Natalie Milana, last fall show many concerns of parents. Although the report is too long to share in full, we felt you might be interested in the conclusion drawn from this report:

Nearly every parent (80 surveys) reported that the time of infancy and young childhood of the PW child was made much more difficult than it could have been by the attitudes of physicians. The lack of diagnosis is devastating; even more disastrous for the parents is the lack of awareness of potential of the infant with PW, the doctors' negative, hopeless attitude.

Parents need an understanding of the stages of growth of the child with PW, with crucial follow-up services: nutritional guidance, the need for structure regarding food before the second stage of insatiable eating develops, and behavioral management help when behavior difficulties begin to emerge. Professionals and parents must realize that parents can cope if proper assistance and guidance is available.

As with every child, schooling is of greatest importance. The survey shows that the lack of support and understanding of PW by educators destroys the family's ability to handle the syndrome at home. Flexibility in educational planning, controlling food and anticipating behavior difficulties is essential to providing the proper atmosphere for learning. Informed parents can give educators clues about how to handle the child, but educators must be willing to work with the parents.

Positive reinforcement for behavior management can be useful but not using food for reinforcement! Psychologist and psychiatrists can assist the family of the PW child, through understanding the importance of this eating compulsion, which cannot be controlled without outside help. Each day a child maintains his/her diet deserves praise, and this can be a reinforcer in itself.

Parents and siblings need support services -- respite, family therapy, in-home consultation on nutritional needs and behavior management. Our society today is diet conscious, whether to prevent ulcers, heart disease, cancer, or high blood pressure. Diet control for all children should be a part of every home. This attitude would allow the PW child to mature with less pressure, as their dietary needs could be part of an overall diet management at home.

As with school programs, workshops and day treatment centers should encourage food control in their cafeterias. Balanced, nutritional low-calorie meals are healthy for every client. The coordination between the residential and day programs is essential, and the PW individual needs additional supervision because of the behaviors associated with the syndrome.

With increased awareness by physicians, early diagnosis and follow-up support for families, a responsive educational system, and structured residential and vocational programs, the individual with PWS can live a long, healthy, dignified life.

ANOTHER WARNING ON WATER INTOXICATION

We had previously reported a case of water intoxication with a girl with PW when she was allowed only water one evening before some medical testing. Since she could not eat, she consumed large quantities of water. We now have received another report of a girl found unconscious and water intoxication found as the cause. This girl has been very consciously attempting to follow her diet and again was substituting water.

Disliking water has been reported many times with our children but in these cases it was obvious water was better than nothing therefore consumed to excess.

BUT THE OTHER SIDE OF THE COIN

Another parent shared a magazine clipping regarding the importance of water in our diets. She stated she had encouraged her daughter to drink a glass of water inbetween her meal and fruit dessert. She is now in the routine and asks if this is forgotten.

The article states some comments that are very well accepted: "Incredible as it may seem, water is quite possibly the single most important catalyst in losing weight and keeping it off. Although most of us take it for granted, water may be the only true 'magic potion' for permanent weight loss". "Water helps the body metabolize stored fat." "The kidneys can't function properly without enough water." (We do get water in all of our foods but probably not in sufficient quantity) "The overweight person needs more water than the thin one." "Water helps rid the body of waste." "Water can help relieve constipation." "The body will not function properly without enough water and can't metabolize stored fat efficiently. Retained water shows up as excess weight. To get rid of excess water you must drink more water. Drinking water is essential to weight loss."

How much is enough? The average suggested amount is 8 eight-ounce glasses every day. What is enough for young people with PW would be hard to say, but adding at least a glass per meal certainly would not hurt anyone and may help.

S.O.S.

Developmental Services, Inc. informed us of their S.O.S. (Stepping Out Service) which is a respite care program. If you live in Indiana you may be interested in receiving information regarding this program. They serve a seven county area. Contact: Tina Clark, Respite Care Coordinator, Developmental Services, Inc., 2920 10th St., Columbus, IN 47202 (812) 376-9404.

WE'RE SAYING THANKS NOT GOOD-BYE

How can you possibly say thanks to a person who has done so much. Shirley Neason, one of our co-founders and first editor of the GV, has recently resigned her position as Vice-President "to give someone else a chance". She hasn't left us, she's still there when she's needed and we all owe her a great deal of gratitude.

DIABETES IN PWS

New York shared a paper written by Fredda Ginsberg-Fellner, M.D. regarding the treatment of diabetes in PWS. She states, through their studies, it appears the diabetes associated with PWS is primarily of the type II variety and related, if not exclusively, primarily to the obesity that the patient develop. Therefore, they hypothesized that Insulin would not be the proper drug of choice in treating diabetes in PWS. Instead they are suggesting drugs in the category of oral antidiabetic agents such as Orinase, Diabinase and Tolinase. She also mentions a third drug DBI, phenformin, which is only available now for research, but felt this may be the best drug to use with this syndrome.

We would be very happy to share a copy of this paper with you if you would like further information.

REPORT FROM OUR NORTHERN NEIGHBORS

We were very surprised but happy to read in the Central Canada newsletter that they had a speaker reporting she was working full-time on chromosome 15 in her work in human genetics and that 50 to 60 laboratories in North America are currently working on similar projects to try to figure out PWS. Another speaker reported on the research on the drug naltrexone and its failures. He added that he felt that PWS will likely benefit from research done in other areas, such as alcohol and drug addiction.

Last year PWSA questioned the Department of Human Services to learn what we could of research. We were informed that one-half million dollars was spent on PWS research that year but when we read the listing we really could only identify one true project (in the amount of \$35,000. that was direct research). The other projects were on obesity, scoliosis and other related conditions. It's very difficult to find out what truly is happening in the research fields but we are always happy to hear when something is being done.

SAFETY OF ASPARTAME UPHELD AGAIN

The Food & Drug Administration's 1983 decision to approve aspartame for use in diet soft drinks has been upheld once more -- by no less than the U.S. Supreme Court. This marks yet another time that the courts have squelched aspartame critics' attempts to challenge the soundness of the method by which the FDA sanctioned the additive.

In our last issue we reported a member who reported improvement in her daughter's abilities after withholding Nutra-Sweet for eight months. She later wrote that she felt it was just another plateau -- something many of us have found with our children's development.

WELCOME TO CHAPTER #17

The end of April, PRADER-WILLI SYNDROME ASSOCIATION OF SOUTH CAROLINA joined the ranks of another official chapter. Under the leadership of Rhett Eleazer and a few very active members, this group is working already on a PW group home.

HOW TO TRIM FAT FROM MEALS

Knowing where fat is hidden can make it easier to reduce your consumption. Here are some tips to help you de-fat your daily meals:

Non-stick pots and pans - especially for pancakes, omelets, vegies, leftovers.

Nonfat liquid - such as chickenbroth, tomato juice, sauces for sauteing.

Steamer rack - for vegies, fish (another alternate, a microwave)

Trim off all visible fat from meat before cooking.

Broil meats, poultry, fish or poach in broth or juice. Can also season water with lemon juice, vinegar or dry wine with herbs and spices. For fish you can also use skim milk.

Buy only leanest cuts of red meat.

Avoid processed meats like bolonga, salami, sausage, hotdogs. Use the new cold cuts with lowfat labels, turkey, some hams.

Smaller chickens instead of roasters. Remove any fat inside of birds. Skin before cooking. (Actually skin is nearly all fat and accounts for half the fat in birds.) White fish (cod, flounder, haddock, scrod, halibut, shell fish) are lower than mackerel, salmon, swordfish. Tuna, bluefish, catfish are moderate.

Always buy waterpacked canned fish. (When tuna is packed in water you save 200 fat calories per serving)

Skim milk is 0 fat, and 160 calories less per cup.

Substitute plain yogurt for sour cream, save 349 calories per cup. This works especially well in salad dressings, dips, toppings. You can use yogurt for half of the mayo in potato salad or coleslaw. To keep yogurt from separating in cooked foods, add 1 tablespoon of cornstarch to yogurt.

Diet margarine. (half the fat of standard margarines) Whipped butter also contains less fat and fewer calories per serving than regular butter.

LOW FAT TURKEY LOAF

1 tbsp. vegetable oil

1 tsp. minced garlic

1 c. finely chopped celery

1 c. thinly sliced leeks or

½ c. chopped onion

1½ c. diced red pepper

2½ c. thinly sliced mushrooms

2¼ lbs. ground turkey

1 egg white or 2 whole eggs, slightly beaten

½ tsp. salt, if desired

½ tsp. pepper

dash nutmeg

½ c. fresh bread crumbs (1 slice)

½ c. minced fresh parsley

Heat oil briefly, saute first five ingreds, 3-5 mins. Meanwhile boil kettle of water and preheat oven to 375°. Add mushrooms, few add'l. mins. covered, then uncover and saute until liquid has evaporated. Set aside. Combine turkey and next five ingreds. Add to vegies. Place in greased loaf pan, set in large shallow baking dish. Add boiling water to outer pan after putting in oven, to a depth of 1", bake 1¼ hrs. Let the loaf rest 15 mins and then remove. Six servings.

ORANGE TAPIOCA

2 Tbsp. instant tapioca, 1½ c. unsweetened orange juice, 1 Tbsp. lime juice, 1 c. orange sections, seeded, freshly grated nutmeg.

In a saucepan, mix tapioca, juice. Let stand 5 mins. Bring to boil, stir occasionally. Remove from heat, add orange sections, chill. Sprinkle with nutmeg. 4 servings. Nutritive value: Calories 84, carbohydrates 20 gm. protein 1 gm. fat 0, sodium 2 mg. Food exchanges: 1/3 bread, 1½ fruit/ per serving.

LET THE DIETER BEWARE OF BOGUS DIET BOOKS

Dr. Dennis Styne, Endocrinologist, spoke at our Sacramento conference, and in addition to an extremely interesting report on growth hormones (which will appear with the conference papers when available), he also made a few comments regarding obesity. He stated that he was particularly interested in teen age obesity studies. He said, "There is no end as to advice you can get on obesity, in fact there's about twenty books a year published on dieting." He mentioned several but I don't know if he wants us to print the names. "There's commercial programs you can enroll in, some of them are pure quackery, some are downright dangerous, some aren't bad (I can single out Weight Watchers and Tops) a little expensive and they may not help your kids particularly, but be careful. Don't buy everything you see advertised." Again he stated names of some products that have toxins in them or powdered protein designed to change heart function, electrolytes. "Be very careful, if you are dealing with yourself be careful but if you are dealing with a growing child you are going to have to find someone who has some responsible outlook. We don't believe in slavishly cutting food, we believe in general in changing the amount of food and achieving a balance that a child can live with and grow with." "Don't go buying out the stores like the other people who spend two billion dollars a year on diet medications. The only reason we're publishing books, doctors making thousands of dollars, and going on the talk show circuits, is because people will buy them and we'll publish a new one because the last one sure didn't work. We do a new one and we'll start a new multi-million dollar company. Doctors aren't the only ones that do that, I'm just taking us to task but you know that many do. Grapefruits aren't going to help you, ...most of these books can be thrown away, they aren't going to help us. "

"The Redbook actually has a very valid diet which it publishes twice a year, I will put in a plug for them, but you've got to use common sense. You don't get something for nothing, you can't lose weight without working on it. Exercise is important, supervision is important, and good balance is important."

A nutritionist recently published a few telltale clues to help spot bogus diet books. Be leery of books that: Exclude one of the basic food groups: dairy, vegetables and fruit, meat and legumes, bread and cereal. Call for taking vitamin supplements. Promise weight loss greater than one or two pounds a week. Claim a single food or food group is a magic key. Require you to skip meals. Set a limit on calories. Disregard the importance of exercise. Promote products or advertise in nutritionally unreliable publications. She also stated you must pick a diet that you can follow the rest of your life, we all know this is the answer for our children.

FIRST SOUTHEAST REGIONAL MEETING

Thanks to a couple of staff members and one of our members, Dottie Cooper, the first Southeastern Regional PWS Conference is going to be held July 25th and 26th in Birmingham, Alabama. We hope members in that region will be able to join us in a couple of very informative days. For further information call the PWSA national office or Libba Gantt at Sparks Center for Development & Learning Disorders, University of Alabama in Birmingham.



POSTERS

The Connecticut chapter has developed a professional poster for PW publicity. This poster contains pictures and information regarding the syndrome with a space that can be used to add your chapter's name and address for contact. For further information, contact Suellen Inwood, 335 Davis Rd., Fairfield, CT 06430.

WELCOMED PUBLICITY

One of our members recently contacted G. Timothy Johnson, M.D. who has a TV and paper column. In response Dr. Johnson included a letter in his syndicated column which was a very good description of the syndrome and mentioned the national association. When this takes place we receive inquiries and are able to reach more people who are either seeking a diagnosis or have a diagnosis but are unaware of the group.

We also made it in the "biggie" in June. The June 20th issue of JAMA (Journal of the American Medical Association) had two articles. Donald E. Riesenbergr, M.D. contacted us several months ago and we were able to furnish him with information and the names of a few doctors that he could contact. His article entitled, "Progress in research, therapy of PWS, but numerous challenges remain to be overcome" gave a very good summary of the syndrome, included interviews with Dr. Suzanne Cassidy and Dr. Vanja Holm. The last paragraph included that our association hopes to build a national PW Center for families that lack local or state resources and gave our name, address and phone number. We are just starting to get some response from doctors in answer to this article. The other article in the same issue was a medical reprint regarding a patient with PWS that had a uveae with glaucoma.

As a last minute fill in for a program change at the conference, a half hour was spent discussing publicity. We thank member Ruth Levikoff for stepping in and assisting without any previous invitation. In addition to showing the 12-minute slide presentation on the syndrome Ruth and Marge Wett gave some helpful hints to members regarding contacts with the media. The main points that were emphasized were that it is very important to give some forethought when you have been approached to interview for a paper article or appear on a TV show. The following points were mentioned:

- ...practice ahead of time. Think about what you feel might be the most important points to get across. Think about how you might answer certain questions. Even use a tape and practice what you say and how you say it. When being interviewed for a paper or going on a taped TV show, if you give a long answer to a question only part of your answer may appear. You could spend ten minutes telling all of the terrific things about your child and make one statement like there are days when you would like to throw them out the window -- that is the statement that will get printed. If your child is going to be interviewed with you, give them a chance to practice too.

- ...realize most of these reporters and interviewers want to sell their product. The more sensational the better, don't allow them to dwell on the sensational parts of the syndrome, be sure you prepare statements to get in your needs or the needs of people with this syndrome. If they keep going back to food only, make a statement, yes, they do have an insatiable appetite but there is far more to this syndrome and then elaborate.

- ...stress to them the importance of having a name and address appear in the article or on the show. You cannot control this but give it a good try. When going to the TV station, print up national's name and address and give it to them ahead, they can make up a show card that will appear. Photos can also be taken along.

- ...if several people are appearing on a show, get together ahead of time and plan your "attack", plan how you will get certain point across. Even though the audience is not medical, talk about things that are important because these people talk to others and also you may be able to get a copy of the tape to use for another presentation. The cost of producing your own tape is expensive, you may be able to use this tape again.

- ...don't be afraid to change the subject, politicians do it all the time. They are using you, use them too.

- ...if you are contacted by national TV for a "big" show--PLEASE call National!!!

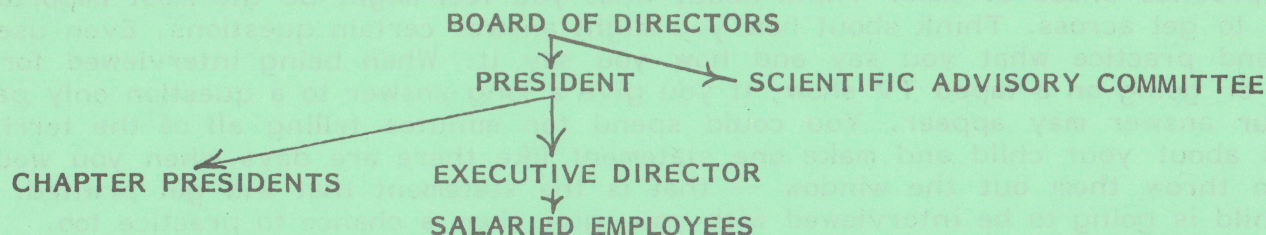
BOARD ELECTION RESULTS - OPERATIONAL AUTHORITY

Annually PWSA members have the opportunity to influence the operation of this association by electing members of the Board of Directors. This year five positions were open because of the increase in Board size previously. Four of the Directors ran for re-election and were returned to the Board by your vote -- they were Fausta and Gene Deterling, DJ Miller and Lota Mitchell. Floor nominations were made for Peggy Bertram, NY, Marilyn Bintz, CA, Janalee Heinemann, MO, Suellen Inwood, CT, Penny Park, OK, Marj Smith, CT, Rita Welch, NY, and Barbara Whitman, MO. Nominations were declined by Rita and Marj. Following the tallying of the votes, we are happy to welcome Janalee Heinemann as the newest board member.

We would also like to thank all of the board members for what is involved with being a member of this group (and that includes Lee Forthman who chose not to run for re-election). These people are elected to represent you in making decisions for the operation of PWSA. They do not receive any compensation for their time spent, they do travel to two board meetings each year at their own expense, and spend many hours deciding what is best for all of the membership. Even though they represent a certain part of the country by their residence, discussions and votes are always based on what is best for all of the membership. This group deserves your thanks and your support. The above statement also applies to the officers. You, as a voting member elect your board representatives and then they appoint officers who they feel are qualified to do a good job for you. At the present time the officers are: Delfin (Sam) Beltran, President, Harvey (Bud) Bush, Vice-President, Fausta Deterling, Secretary, and Roy Smith, Treasurer.

We were very disappointed that only 30 people "bothered" to send in a proxy vote when requested in the last GV. We were also disappointed in the fact not everyone at the conference "bothered" to vote. Some comments were made that some people do not understand this process, we will be very happy to go into detail on this before the next election.

The operational authority for PWSA is as follows:



PWSA is operated on the structure headed by a 12-person Board of Directors. (They are the bosses!) These directors are elected by the general membership yearly on a 3-year term. This board is the governing authority for the PWSA, the control and responsibility of the affairs and business of this corporation are vested in this Board. The Executive Director, who operates the national office, is under the direction of the President and the Board. All decisions made by the board are by vote following discussions of the issues. This board appoints PWSA officers. These officers do not have a set term of office but will be reviewed at the mid-term board meeting in December. If you want to have a say in the operation of PWSA, let the board hear from you. If you do not understand something, ASK. The Board appreciates hearing from you. Contrary to some comments made at the last conference, they do listen to what you have to say and are willing to make changes in procedures if they feel this is the desire of a majority of the members. PWSA is a growing group, the board is in the process of making some changes to accomodate to this growth, if you want further changes, address a letter to the Board Chairman and it will be presented at the December meeting.

NDC (CRISIS CENTER) CONCEPT STILL ALIVE

Donations of \$6709.83 and \$4813.75 were made to the NDC in May and June. We just received a \$5000 check from the Lear Siegler Foundation a couple of days ago. We are now looking at the total of over \$125,000. in this fund. One successful way to keep this fund alive is sharing names and addresses of friends and relatives that we can contact for a donation. This works!! If our members keep caring, this total will keep raising, and a crisis center can be a reality.

RAFFLE RESULTS

Our annual raffle fund raiser was instigated to assist with conference costs with hopes of keeping the conference affordable to all. Unfortunately, this year following our fund raising efforts for the NDC, we feel the raffle did not do as well. Actual sales from tickets came to \$3320., expenses came to \$920.18 (postage, rebate to chapters and the first prize of \$500), so we contributed \$2399.82 to the conference.

A Minnesota member graciously contributed a quilt to be raffled at the conference. Marilyn and her committee added a cookbook, a couple bottles of wine, and PWSA added a couple of posters so we had a second raffle. The following people were the lucky winners:

Sandra Levine, first prize \$500. Sandy is a member from New Jersey and has been a supporter of our yearly raffle.

Irene Slevin, 2nd prize \$150. Irene is the mother of our member Marilyn Johnson. Marilyn informed us her mother wanted to make a donation of the prize.

Keri Welch, 3rd prize \$100. Keri is the daughter of Rita Welch of New York and she also donated the prize back in her daughter's name.

Paul Alterman, Quilt Paul, from Marietta GA is also a member and one of our generous supporters. He also had the winning ticket for one of the posters.

Virgil Clark, Cookbook winner here.

Virgil, another member, from CO was the lucky

Jan Hutchins of MI and Marilyn Johnson of CA were the two winners of the wine and Wanda Eldredge of CA took the other poster home.

We do thank the supporters of our money raffle, a special thanks to Dorothy Aul of Hutchinson for donating her homemade quilt (which raised an additional \$350. for us), and the other people who participate and donated.

CONGRATULATIONS

One of our members and supporters, Peggy Brooks-Bertram, has been selected as a 1986 Achievement Award Winner for the Prader-Willi Syndrome Family Support Service at the Mental Retardation Institute. This award was given by the National Association of Counties.

We congratulate Peggy and want her to know we appreciate her interest in PWS. Peggy also joined us for the second year in a row as a speaker at the recent conference.

MAY AND JUNE DONATIONS

NDC: Trimble, Noordzy (Poole, Stickley, Hollenbeck, Ficken, Noordzy, Vollmer, Bevard, Noordzy, Jacobs, Spangler, Kobylski, Essex, McKenzie), Yannelli, Holm (Sweet, Gilchrist, Harris, Merisinnitt, DeHaven, Jackins, Crowe, Feucht, Washington, Robinson, Schinke), Noll, Wett (Schaefer, Nash, Schaefer), Krauss, Boston (2), Hadsall (Francavilla), Ingalls (Essa Hair, Ingalls, Fellowship, McMurdo, R. Snow, Morrison, Hegarty, Stonemem, Orn, Lamoreux, Lund, Cty. Cab, Ingalls, Roy, Harrison), Kowtna, Neason, Dixon (2), Umbaugh, Wyka (2), Haller, Carter, Mays (2), Sojka (Randall (2), Olinkiewica, Jones (2), Starsiak, Setterstrom, Abramek, Sojka (7), Hamisch (Atlantic), Gunnison, Wolcott, VanSwearingen, LaBelle (Romig, VanTuyle), Regester, Midlantic Chapter, Wagstrom (Kiwani), Gulling (Gulling (2), Powers), Sharp (3), Schramm, Gootzit, Dunne, Abell (Reinhart), R. Miller (1), (Monteleone), Beltran (2), Clubb, LaMotte (Sparks), Baletsa (Brodeur, Marsha), Eager (Fields, Shelton), Notbohm, Bintz (Sorooptimist), Townsend (Beta), Boyd (2), Rattray, Korte (Archambeau), Chiang, Zorn, Westbrook, Brock (Colony, Honor), Fick, Toby, Hambrick (Heniff), Dennis, Castle (House, Palmer), Lincoln, Yoncha (farley), Maurer, Chase, LaBossiere (Rydelotte), Alterman (3)+ (2), Labbe, R. Johnson, Weisel (Starner), Welch (McKenna, Gildea, Gregorovic, Byrnes, Keri). Some we do not know who to credit: Mans, Trescott, Turf Care, Buskstein, Hider, Heggstad, Beazley, Pontiac Jr. Hi, Carpenter.

Research: Van Zomeren (2), (Staples), Kappler (Nichols), Daly, Lynch (Rochester Coke), Goewey, A. Alterman. Also several United Ways and Combined Funds: D.C. Cap. Area, S. NV., Coastal Bend, CA., & MI.

OUR THANKS TO ALL OF OUR SUPPORTING MEMBERS.

SPECIAL PEOPLE

* * * * *

Next issue we're going to fill this little box. Having a list of people to thank just isn't sufficient, we have so very many special people who do such nice things for PWSA, we feel we have to have a better way to say thank you.

Recently we received generous donations from two people who were thanking one of our members for his assistance. Instead of accepting pay he asked them to make donations to the NDC. We had a young man give us the contents of his piggy-bank. We had two members do a temendous amount of fund raising. We could fill this whole page with the workers from the last conference, and I'm sure I'm forgetting some others, so from now on we are going to keep track and fill this box each issue with our special people.

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