

## THE GATHERED VIEW

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## PRESIDENT'S MESSAGE

Look to the child. That expression resides somewhere in my memory, but its source is unknown to me now. It was jogged loose though, the other night, when my wife returned to the den after getting Sarah settled for the night, Linda prompted me with, "Sarah just apologized to me for being so grumpy today and said, 'Some days I just get so tired.'" It fell on me like a ton of bricks. My schedule had been rather hectic and my mood and ability to be a kind and loving father were somewhat less than optimal. Frankly, I had been feeling somewhat sorry for myself and was having difficulty understanding why there wasn't more support for my internally rumpled soul.

Look to the child. Another night, Linda was at our other daughter's school so Sarah and I were working on her math homework. She had done several multiplication problems involving numbers with two and three digits as the multiplier. In response to Linda's prompting, the teacher had drawn a series of squares under the line so that Sarah would be sure to keep her solutions in the proper rows and columns.

The purpose of these two anecdotes is to attempt to identify a source for solving some of the problems Prader-Willi families face. The source of course is, "Look to the child!" On several occasions I have had associates express fear because they were going to be called as a witness in a trial. My response has always been the same, "Don't let them intimidate you. You can only respond to that which you know and on that you are the world's expert." Who knows your child or your family better than you? Yes, your PW person has problems that make it difficult to learn, the achieve, to control or to communicate, but these are problems of degree. Not all other members of PW families carry their ideal weight for height. Nor are we as smart as we would like to be, nor as tall, nor as successful. Sometimes it is easier to accept the existance of a handicap and not do anything about it. Then our consciousness gets "jogged" and we become aware of a specific level of the handicap, we see a little of me in thee. There is a new awareness and a little more understanding. Love is not the Hollywood version of the gawker standing in rapt adoration of the beauty queen. Giving of oneself includes awareness of the needs of the beloved and meeting that need or fulfilling that void or complementing that weakness. Sarah's recognition that she was not feeling up to par some days and on those days she was not loving the world quite as much, was a major accomplishment, but it also made her equal to others in the household in respects that none of us probably ever gave much thought to. (A preposition is a word that you don't end a sentence with. Churchill)

## PRESIDENT'S MESSAGE (Cont.)

When Linda recognized the difficulty that Sarah was having with her multiplication and focused on the problem of rows and columns, the solution to the problem was readily apparent. That same night Sarah started using shortcuts and writing down answers after doing the step in her head. Again the errors started cropping up. It would have been easy to just correct each error as it occurred, but it was more effective to point out that when her older brother was being helped for similar problems, he made shortcut errors in the same way.

Sometimes the solution to a problem can evade recognition as we search far and wide for the answer. Maybe all that is needed is to pay closer attention to what our PW person is trying to tell us in their own special way, even when that special way may be causing us to extend the limits of our tolerance. Look to the child!

Delfin J. Beltran, MD.

President

## MISSOURI RETREAT - HOW ABOUT YOUR CAMPER NEXT SUMMER?

The PW MO Chapter held its first family weekend retreat at Wonderland Camp on the Lake of the Ozarks. Here's some of the young people that joined in the fun:



The weekend was made possible (free of charge) by the camp founder, Charlie Miller, who is also a PW parent. After an enjoyable weekend, the parents decided to pursue the possibility of setting up a week of camp exclusively for all PW people nationally, for next summer. Approximately 50 campers (at a camping fee of \$200/camper) would be needed. Transportation, of course, is not included in the fee. If interested, please contact MO Chapter President Jerri Evetts, 1435 Sunnytree Lane, Manchester, MO 63021, (314) 391-7118. (A family vacation could be planned in the same area, it's great vacationland.) LET JERRI KNOW NOW, IF INTERESTED.

As we complete our 10th year as an organization and our last issue of the GV for 1985, we wish all members Happy Holidays and many blessings for 1986.

## WARNING FROM PARENT

My daughter was ordered to fast for 24 hrs preceding some tests and could only have water (liquids). The following morning she could not be awakened, and had to be taken to the hospital by ambulance to the intensive care unit. The hospital stated she had water intoxication from the large quantity of water that had been drunk and it had offset her system. I felt other parents should be warned of this.

## NURSE MATES HEART OF GOLD AWARD

This annual program recognizes outstanding endeavors of nurses. PWSA has entry forms that you may request if you would like to nominate a nurse you feel has the necessary qualifications to win this award. (For example, one who has contributed so much to her/his patients, colleagues, and/or field, a story of an especially kind or heroic act, etc.)

(Deadline for entries are November 30th, so write now if you want an application.)

## GROUP HOME LIVING

A parent shares, "It was extremely difficult to put our daughter in a group home. Our family felt sure she'd not be able to cope with it, but felt we needed to give it a try. If anyone loved her home, her dog, her cat, her room, her personal belongings, and the routine we'd established, it was her. She fought going and it nearly destroyed my husband and myself to tell her she had to go.

We would bring her home on Saturdays and we were so thrilled the first time she asked to go back early so she wouldn't miss anything going on at the group home."

This particular girl and another resident of the same home have been very successful in a Weight Watcher's program, and through the excellent group home management, coordination, and professionalism at a sheltered workshop, there has been a real turn-around in her life. Her mother also wrote, "That's not to say there's no problems. She still has her bad days, tantrums, etc. but they are not as frequent or as severe as before, and since her weight loss, she's awake and isn't constantly falling off to sleep."

(Editor: This letter fits well with Sam's "Look to the child". It's difficult for all of us to realize we have to make decisions for our child because they sometimes need our assistance. We don't "put" our other children in certain schools, but we occasionally make decisions for what we know to be the best location for them. We don't "put" our child with PW in a group home because it makes life easier at home. Certainly this does occur, but the real reason for "allowing" them to leave home is for what is best for them. I once read, "Don't confuse guilt with your responsibility of what is best for the child." We have to work on our changing our terminology to really fit the true situation, we're not "putting"our children out of our homes, we're "allowing" them to get on with their lives in a proper setting. Our other children get on with their lives – sometimes making bad decisions along with the good ones. I frequently hear, "Let them learn by their mistakes!" Our other children can do this, our children with PW cannot. They need our assistance and guidance. Until future medical changes occur, group home placement is a way of allowing them to get on with their lives in a proper setting. It is a difficult decision, but the right one for them, in my opinion.)

## CRISIS SITUATION - PART TWO

Almost every parent of a PW person who is reading these words has known the pain of leaving your child in a hospital setting. Because you already know, I will not try to explain how I felt when I left Janey at the Gillette Clinic and returned home. This adult-child of ours, that we had totally cared for, would now depend on the care-givers of Gillette to meet her basic needs.

The pain of separation was felt, but also a tremendous sense of relief - knowing that Dr. Richard Nelson, the director of the Gillette Clinic, and his staff were fairly optimistic about Janey's prognosis. Indeed each day that passed, her condition became less critical.

For the first week of Janey's hospitalization, I was able to stay with her. (Janey's Dad had to return home after a few days because of business committments.) The first few days at Gillette involved mostly testing procedures. By the third day a specific plan of treatment had been established. Besides the medical program, the care plan involved the dietary, physical therapy, occupational therapy, respiratory and recreational departments of the Gillette Clinic. By day 4, Janey was starting to lose some of the fluid that had accumulated in her tissues and her breathing was slightly improved. Every day thereafter there was improvement.

We called Janey from home at pre-determined times each week. The first week or so she complained about her diet (or lack of it) but before long her voice became stronger and she was telling us about all the things she was doing. They kept her so busy, she had little time to be lonesome. Although we wanted to see Janey, we felt this was a time she would do better on her own. Dr. Nelson or a member of his staff called us regularly to keep us abreast of Janey's condition so we knew at all times how she was doing. Janey made some very close attachments to the people who were working with her. (PW parents know how much patience the caregivers must have.)

As the weeks passed, pounds melted away. Janey became more mobile, her breathing and circulation improved, and she looked forward to her therapy sessions. It was close to six weeks after Janey's admission that Dr. Nelson began to make plans for her discharge. Final arrangements were made with the group home in Mt. Pleasant, MI where Janey would be going to live. (Part of the committment for Janey's admission to Gillette was placement in a group home.) A physician was found in the Mt. Pleasant area to take over Janey's care and Dr. Nelson contacted him to pass along the care plan.

On October 4th, we met with Dr. Nelson and Janey at Gillette. He had prepared a contract for all to sign, wherein the obligations for Janey's treatment and continuing improvement would be met. Every aspect of her care plan was covered and Janey's signature certified her willingness to comply. (Dr. Nelson felt this would provide the caregiver with a reinforcing tool if Janey would tire of her regime and try to fall back into her old life-style.) On October 5th, Janey was discharged (proudly wearing her blue-jeans that she could not fit into for a very long time), she had lost 91+ pounds.

When we landed in Detroit, Janey de-planed and briskly walked through the terminal and even helped with the luggage. It was unbelieveable that just 7 weeks earlier—she could hardly walk to the electric cart that drove her to the boarding gate.

## CRISIS SITUATION - PART TWO (Cont.)

Janey is in the group home now, involved in a day program and doing very well. Plans are complete for PW group home in MI which should be ready for occupancy this spring.

We are most grateful to: <u>Dorothy Thompson</u>, of the National PWSA for all of her efforts in arranging for Janey's treatment at Gillette. <u>Marge Wett</u>, Executive Director of PWSA for allowing us to share this experience with the membership. <u>Dr. Richard Nelson</u>, and his exceptional staff at Gillette, for treating Janey with kindness and dignity and providing her with the tools to know a healthful and fulfilling life.

Maurice and Jean Vermeulen

## GV FOR THE YOUNGER SET

QUESTION: How can a newsletter be written to serve a syndrome that has a two distinct stage of development, helping parents with very different problems?

ANSWER: I don't believe it really can. Certainly some of the information is pertinent to parents of all ages , but it would be far more appropriate for several pages to be donated to a specific age group.

QUESTION: Can the PWSA continue with its present GV and print a special edition for the parents of children under 10?

ANSWER: We are willing to give it a try starting with our next issue. We have been contacted by parents who need information more fitting to the younger child and do not want to read about young people in a crisis situation and the lack of facilities. The past couple of years, as editor of the GV, I have been bothered because our membership of younger parents is growing, and I do not feel we are meeting their needs.

QUESTION: Where will you get the articles you need to have several pages to substitute?

ANSWER: From our membership. The only way this idea can succeed is by the younger parents sharing their experiences with us. We have not included a lot of articles in the past regarding the younger children because we do not hear often from these parents. Parents have a tremendous amount of experiences to share—how grateful new parents are to be able to read other people's experiences and successes.

We will automatically transfer all names (from our information) who belong in the younger group. With the receipt of the next issue you will know whether we made the change for you. If you want the new issue and do not get it, let us know. If you were changed or will be and prefer not to change, let us know that too. We want you in the group that you prefer.

The success of this separate issue depends on you. If we have enough to share, can work and will be written to better serve you.

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#### CHAPTERS TAKE NOTE

A recent event in the State of MN has brought to attention a matter that is of importance to all PWSA Chapters. Hopefully through several presidents and secretaries, important papers do get passed from one to another, but a "back-up" source would be a good idea.

PWSA office would be very happy to have each chapter mail a V.I.P. packet which contains copies of incorporation, federal determination letter, by-laws, etc., and would file this packet in your chapter file. Then, many years down the road if anyone would not be able to locate a past president or secretary's valuable book, copies could be obtained from this office. Getting these together will only take a little time and effort now but later would undoubtedly take a lot more.

In checking with the I.R.S. in regards to the MN tax exempt status, the office informed us that they only have five chapters listed in their records. If your chapter has formed a corporation, please check and make sure that you also followed through and received your determination letter from the federal people for tax exempt status as a 501C-3 organization. This should have been done at time of incorporation. Federal tax exempt status is separate from getting a state sales tax exemption.

#### PEN PALS

A New Zealand mother writes, "I joined your association 2 yrs. ago, and have found your newsletters and books of great interest and help. I have really appreciated being able to be a member of your association. The medical profession in N.Z. know very little of the syndrome, and I have been able to pass a lot of my information on to them.

I am writing to ask if you would share my son's name in the GV, as he would dearly love to have a Pen Pal. He loves writing letters, and receiving them. His hobbies are reading, drawing, jigsaws, swimming, and he loves animals." (Paul is 10 yrs. old, if you would like to write to him his address is:

Paul Thompson 30 James Foley Ave. Pirimai, Napier, New Zealand

(PWSA has a list of other pen pals that we are happy to share for anyone interested.)



Last month's GV requested the membership respond to the idea of producing a calendar which would include art work from our young people and information about the syndrome to help "spread the word" about PWS. Since we did not receive enough orders, we will not be able to use this idea. We do thank the young people that did submit art work and these will be kept in case we decide at a future date that this idea may be feasible.

#### LMBS NETWORK

The director of the Laurence-Moon-Biedl Syndrome has asked us to share the knowledge that a parent support group has been started in the U.S. LMBS is a rare genetic disorder and shares some of the same symptoms as PWS. The five cardinal symptoms are: retinitis pigmentosa, obesity, polydactyly (extra digits), hypogenitalism, and varying degrees of mental retardation. If any of our members have this diagnosis, they may obtain further information from: Barbara Mielcarek, 122 Rolling Road, Lexington Park, MD 20653, phone (301) 863-5658.

#### SOUTHEAST GROUP

One of our members from Alabama has contacted the Sparks University Center in Birmingham and has received great encouragement for organizing a clinic in their facility, assisting with a parent support group for the area, and organizing informational meetings for this part of the country. Two meetings are presently scheduled and a letter soliciting interest will be mailed out to members after Christmas. If you do not hear from this member or Sparks and are interested, let the PWSA office know and we will share your interest with them.

#### LOGO JEWELRY

What happened to all of the people who expressed an interest in obtaining key chains, pins etc. with our PWSA logo? We have a goodly supply left, available at \$2.50 each (\$3.50 Canadian funds or overseas mailing). Stock includes: Snake key chain, bronze or silver, 1" pin, both finishes, 2" tie bars, silver, Tie tacs, silver, lapel pins, silver, or 2" money clips, silver.

We'd be happy to fill your order.

## FAMILIAL OCCURENCE OF CHROMOSOMALLY NORMAL PWS: FIRST OBSERVATION

(The following report was shared with us by Mark Lubinsky, M.D., Clinical Genetics Center, Omaha, NE, Louise R. Greenswag, RN, Ph.D., and Hans Zellweger, M.D. of the University of Iowa)

We wish to report the unusual occurrence of four full siblings with PWS in one family. Three of the children (one girl and two boys, ages 27, 26, and 21) have been observed and examined by Mark Lubinsky, M.D. of Omaha, NE and Drs. Zellweger and Greenswag of the University of Iowa. The first born child, a girl, died at  $10\frac{1}{2}$  months of pneumonia. She was reported to have been very hypotonic, hard to feed, and developmentally delayed. There are no other normal children in the family. Recent chromosome studies by Dr. Ledbetter revealed normal findings in all of the siblings and their parents.

Reports of more than one child with PWS in the same family have been rare and with one exception (Hasegawa et al, 1984) those familial cases in the literature appear to have atypical findings such as descended testes (Brissenden and Levy, 1973), very early onset of obesity and seizures in infancy (Gabilan, 1962; Royer, 1963), and profound retardation (Jancar, 1971). Of the five affected family members described by De Fraites et al, (1975), only three were personally observed. Two brothers studied by Clarren and Smith (1977) had typical PWS features but one sibling was never able to walk or talk and was so severely retarded that the diagnosis of PWS may be questioned. Hall and Smith (1972) reported PWS symptoms in the cousin of an identified case. However, by maturity, the cousin had a normal I.Q. and stature. Hasegawa et al, (1984) investigated 2 first cousins both with PWS. The father of one and the mother of the other were siblings. A deletion on chromosome 15 was reported in both affected cousins, both related parents, and a grandmother.

The three siblings we have observed are typical of most cases of PWS. They were hypotonic at birth, sexually underdeveloped, difficult to feed, and developmentally delayed. They have remained short in stature, are moderately retarded, have many of the skeletal characteristics, are sexually underdeveloped, and although not overweight, they demonstrated many bizarre, food seeking behaviors and are emotionally unstable. This family group does not fit with the general assumptions that PWS is either a sporadic dominant mutation or a deletion on the 15th chromosome. Perhaps PWS should be considered as an autosomal recessive genocopy which supports Hanson's (1982) assumption that PWS is a heterogeneous condition. PWS with normal chromosomes is sporadic; PWS with certain chromosome abnormalities (translocations, and only if one of the parents has a translocation in balanced form) can, in rare instances run in families which makes our observation of these siblings unique. Further in depth evaluation of this family is planned.

(PWSA is also doing further investigation of two distant cousins reported with PWS, and a family of two children with some characteristics but also additional problems. We also have an infant with a chromosome 15 deletion that is not characteristically PW. We will continue to keep our membership informed.)

## PRADER-WILLI ASSOCIATION OF VIRGINIA

Claire Harrington welcomed everyone who attended the organizational meeting to develop a chapter in the State of Virginia. If anyone in this area is interested but has been missed, please contact Claire or come to the next meeting December 7th, at 196 Coventry Rd., Virginia Beach (23462).

## **NEW PARENT PROJECTS**

Eleven training projects, operated by and for parents of children with all handicaps, were newly funded this year by the U.S. Dept. of Education's Office of Spec. Ed. Programs. Parents may find these helpful:

Special Education Action Committee, Mobile, AL (205) 633-9588
Parents Encouraging Parents, Inc. Colorado Springs, CO (303) 635-9017
(CP Assoc. for "inner city") Detroit, MI (313) 871-0177
(Communication for native Americans) Bernalillo, NM (505) 867-3396
Parents Info Group/Exceptional Children, Syracuse, NY (315) 423-2735
Washington Pave, Tacoma, WA (206) 272-7804
Pilot Parents, Inc., Phoenix, AZ (602) 863-4048
Task Force/Educ. for the Handicapped, South Bend, IN (219) 234-7101
Involve New Jersey, Moorestown, NJ (609) 778-0599
NYC Parents Coalition for Educ.Advoc.for Children, Long Island, NY (718) 729-8866

#### CONFERENCE TIDBIT

With the holidays approaching, we felt it would be appropriate to share an excerpt from the last conference. Jim Bowman, therapist from Boston's Childrens, included in his presentation a comment, "We would essentially talk about the role of food in society, not whether they snitched or not, but they are cognizant of the fact during the holidays everyone else is walking around saying, 'I know it has a lot of calories, but try your diet next week'. And then we turn around to the PW individual and say, 'You can have a piece of celery and then get out of the kitchen. I told you not to be in there'. I think it is important for all of us to understand what the role of food is in this society, what we find accepted. What we are saying to the PW is that you'll have to find another way to be accepted because you can't have food."

We thought this was good "food for thought" in the next couple of months.



#### 1985 CONFERENCE PAPERS

Unfortunately, a few problems with tapes and microphones caused a delay in getting the 1985 transcriptions ready for sharing this year. We still have a few papers to include but should have the papers ready for the membership by the time this issue is released. Not all presentors will be included, and the reports only will be available from the workshops, but we are sure members will benefit from being able to read what was shared at the conference.

The papers can be ordered from PWSA, \$7.00 U.S., \$10.00 Canadian Funds & Overseas.

#### PWS NY CHAPTER

This chapter will be holding their 2nd Conference Nov. 15th 4 PM - 10 PM and Nov. 16th 8:30 AM - 4 PM in Albany. For further information contact the Resource Ctr. (212) 889-5760.

## EIGHT RESOLUTIONS TO CUT DIETARY FAT

Public Voice for Food and Health Policy, a Washington-based consumer research, education and advocacy organization, has developed these eight resolutions to follow to cut dietary fat.

1. Resolved: To eat a leaner sandwich.

Cut back on luncheon meats and hot dogs; they have more than 75% fat calories. Eat sliced breast of turkey or chicken and tuna, or try a "veggie" sandwich of sprouts, sliced tomatoes, cucumbers and lettuce. In contrast to bologna, turkey gets only about 20% of its calories from fat. A new dressing on your sandwich can make a difference too. Try plain yogurt or mustard instead of mayonnaise and save 80 or more fat calories.

- 2. Resolved: To change your breakfast bread. Eat more bagels, muffins or pita bread instead of doughnuts and pastries. A raisin bran muffin rather than a honey bun cuts 24 fat calories from your diet; a bagel saves you 41 calories. Making your own muffin or quick bread mix allows you to control the amount of fat even more. Tip: Soft butter or margerine spreads thinner.
- 3. Resolved: To use cheese more as a garnish than a main dish. Slice it thinner or grate less for recipes. Use cheese with less than 70% calories from fat. Using low-fat cottage cheese instead of higher-fat ricotta in lasagne, can cut 50 calories from a serving. Use skim mozzarella.
- 4. Resolved: To make your own salad dressing.
  Mayo and salad dressing are almost pure fat—85 to 98% fat calories. Low-calorie dressings cut about 50 fat calories. Home, such as yogurt or dill, lemon and tomato juice with herbs, can have less than 20 fat calories.
- 5. Resolved: To treat nuts as food accessories.

  Pecans have 95% fat, peanuts 73%, soybeans 40%. Eating dry roasted only lowers fat content a little. Substitute freshly popped corn, even pretzels have 50% fewer fat calories. Save 50 calories by removing from breads and cookies. Finely chop nuts if using at all and use less.
- 6. Resolved: To slice and share "must-have" fatty foods.

  Smaller wedges of cake or pie can save you 100 to 150 extra fat calories. Share a rich dessert with a friend (that statement is the humor touch: parents share with their child with PW or the person with PW is asked to share)
- 7. Resolved: To choose a lower-fat cookie.

  Gingersnaps, animal crackers, fig bars are examples of lower.
- 8. Resolved: To eat fruit, fruit, and more fruit, vegetables, vegetables and more vegetables.

Less than 4% of the calories from most fruits and vegetables are from fat.

(Consumer demand for leaner meat, coupled with a declining market for animal fats as vegetable oils have become more plentiful, has led to farmers to produce leaner hogs. A recent USDA study shows that in 1968 only 8% of the hog carcasses qualified as U.S. #1 (the leanest meatiest grade), by 1980 over 70% made that grade.)

(Popcorn air-popped=23 calories per cup, trace of sodium; oil popped add 20. On a 2 qt. batch, 3 T. butter, ½ tsp.salt raises calories to 74 and sodium to 203 mgs.per

cup.)

#### BIRTHDAY GIFT FOR PWSA

"I've been thinking frequently of what a little help from each PWSA member could do to assist in promoting the NDC project. Since this is our 10th year, I thought perhaps a small donation of one dollar for each year (\$10.) would not be burdensome and would constitute a 10th birthday present to the Association. It's not earth-shattering, of course, but if every member from everywhere made this birthday gift, it would be helpful as well as encouraging to those who have worked so hard on this project.

At any rate, I'm starting the ball rolling with the enclosed \$10. check. Would you please include this suggestion in the Nov.-Dec. GV. Thanks, thanks, and more thanks for the GV and your dedicated efforts to PWS."

In case some members are not aware, PWSA started a special fund (NDC) in order to obtain services for young adults in crisis situations that are lacking placement in their own area. With donations of \$2371. in Sept. and \$1155. in Oct., we now have a total of \$52,739.56. We hope to increase this to \$77,739.56 shortly with a promise of \$25,000 from the McDonald Corp. Our special thanks to the Haller family for their approach to the McDonald people; to the Straight family whose special fund raiser added \$760.; to the Hadsall and Bintz families for their very generous donations this month; and to members Boyd, Ingalls, Kellerman, Doolittle, Westman, Castle, Cox, Daly, DeHaan, Eleazer, Wyka, Vermeulen, Ziifle, Thompson, and Sharp. (Many of these members are making monthly contributions.) We hope the members will respond to the birthday idea above, and we also want everyone to know we'd be happy to supply a copy of the proposal that the Haller family used to request their donation. We need 100% backing from our members, and about ten more of these large contributions to achieve our goal.

## FAREWELL TO OAKWOOD RESIDENCE HOUSEPARENTS

Harold and Lois Olson have been the very faithful backbone of the Oakwood Residence in Minnetonka since their opening four years ago, and just retired in September. As part of the recognition for everything they did, a staff member took a picture of the Olsons and 12 of the 15 residents, and the board presented this picture to them on a rememberance plaque. (Lois has also been the driving force of efficiency and accuracy in assisting the residents in collating, folding and stapling our GV each issue)

We are happy to be able to share a copy of one of the photos:



## PARENTS SHARE CALORIE TIP

Angela learned to count calories when she was 12. We had just learned of PW. It was 3 months of fighting, arguing, crying, hugs and kisses, but we finally got it achieved. By her learning to count calories, she now had input to her meal planning (nutrition always came first) and she does a very good job of it. I have since then left cereals, breads (nothing too tempting like pastries, of course) in the cupboards. Her remark was "now that I can have the stuff, I don't have to steal it". What person would like to live without some input into their lives? I have to mention that up to the age of 12 years she was a professional "food thief"!! I know it can't be an answer for everyone but I feel that if one person benefits, it should be tried. Maybe a class to teach calorie counting (starting to learn) can be set up for the next conference.

## MIXED POPULATION HOMES VS PW HOMES

One parent writes, "Our Mike has been enrolled as a client in the Straight Talk Clinic for 3 yrs now and has reduced his weight from 280 lbs. to 148 lbs. as of last week. A concerted drive is being made to establish 'PW homes' in So.CA just for PW clients (3 or 4 are now in existence with no openings). We are convinced that this is the way to go as PW persons have many problems that are not readily addressed to in mixed housing clientele."

Editor note: Many people have written of the necessary adjustments that are not made in mixed homes, and many mixed homes call and ask for assistance in trying to adapt their homes to meet the needs of these clients. Luckily, some of the homes are successful and the needs are being met in both situations, but unfortunately many more homes are needed. The PWSA office receives several calls a week seeking placement for children and clients, and the callers cannot believe there is nothing available. This week we received a call from a minister is FL who has a parishioner, a young man in his early 20's that weighs 400 lbs.; a social worker in AZ whose young client with PW is now "living on the streets" because he has been kicked out of every home he has found; a parent with a 14 yr old boy whose weight and behavior is out of control; and a social worker from OH who finds it hard to believe we haven't a list to consult for a 14 yr old girl who needs a placement.

The situation is improving. Every week we hear news that another home is "nearly opened" and some of the needs are being met, but we still desperately need a crisis center or some alternative placement, until the needs of all these young people can be met.

## RESEARCH FUND

It is the policy of PWSA that memorial donations are placed in our Research Fund unless they are designated for some other purpose. Donations are also made directly to this fund. In September and October members and friends added \$1767.77 to this fund.

Special thanks are given to the Charles Pruet family for designating PWSA to receive memorial funds for their son Chas who died in August. Over \$900. was received. We also received a generous gift from the Napa Combined Fund Campaign. We cannot thank the donors in the cases where funds are received from this Fund or other United Funds because the donor is not specified, but we do appreciate these contributions. Other members who made donations these past two months are: Smith, DeHaan, Mukaida, Hadsell, Uzendowski, Staples, Van Zomeren, Burnham, and the Westline Methodist Church. This fund total now stands at \$14,202.14.

## PUBLICITY

We are happy to report that several very fine articles have appeared recently in various newspapers around the country. Every time an article appears we have more requests for information and knowledge of the syndrome increases. We have also had several TV morning shows lately that have helped further our educational goals.

Medical presentations are also being made by several of our professional members, a couple of behavioral psychologists made presentations, and several other presentations are scheduled for the near future by educators, parents, and other professionals. We feel this past year has been very productive.

Marge and Dick Wett just returned from a trip to England where they were able to spend one day with some of the PWSA (UK) members. The comment was made, "We're an ocean apart but our problems are so very similar." (Marge even managed to corner a doctor from Bombay, India in the waiting room of one of the airports and gave him a half hour education on PWS.)

It's a long, hard climb but we are on the move.

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