
PRESIDENT'S MESSAGE

The Third Annual Meeting of the Prader-Willi Syndrome Association is past. Those of us that attended had a rare privilege. The scientist responsible for a major new medical discovery presented his findings. Dr. David Ledbetter presented his findings of abnormal genetic material in the cells of persons with Prader-Willi syndrome. The audience was a group of one hundred parents and professionals meeting at Florida Atlantic University of expand their knowledge for the benefit of PW persons. The quality of the presentation was probably best described by the parent who said, "I didn't know the medical terms but I know what he said." The field of medical genetics was aborning when I was a student in the early 1950's and the expansion of knowledge fills large books. Dr. Ledbetter's classic presentation has saved me many hours of searching through these large books. The full impact and importance of this discovery will develop over coming years, but even now it adds light in a tunnel that sometimes seems very dark and without an end.

Two other lectures were given during the meeting. Dr. Vanja Holm brought us through the development of all previous knowledge of the syndrome, even showing slides of possible cases dating back centuries as recorded in paintings. Mr. Jerold Siegan, a practicing attorney from Illinois, father of a PW child, and one of the first members of the association, defined the need for and the implications of creating a suitable will and trust that provides for the needs of disabled survivors and yet protects the estate from loss to government confiscation. More about this will appear on other pages of the GV.

The annual meeting of the Board of Directors was highlighted by several reports. The committee for Clinic Services, chaired by Dr. Betty Schultze established a level of quality work that will serve as a model for others. The Board was presented with the first copies of The Directory for Clinic Services. Availability of copies will be listed in the GV. Committees continue to be a good way to become involved in the work of this organization and everyone is encouraged to volunteer by contacting either the committee chairpersons or the PWSA office. Of major impact was the revelation that this organization cannot survive on dues alone. An important factor has been contributions (tax deductible), but in the past half year this source has fallen off significantly. We may have a volunteer chairman for fund raising and I am sure that there will be more on this topic in the future. In order to further strengthen this organization the board has initiated steps to assist in the formation of local or regional groups. The election returned Shirley Neason, Vanja Holm and Richard Wett to the board for three year terms.

Three half-day sessions were devoted to workshops covering a range of topics. This format was used to encourage interchange of ideas. I was not able to attend all of the workshops, but I learned something new at each one that I did attend.

PRESIDENT'S MESSAGE, Continued

At the evening banquet I had the pleasure of presenting engraved plaques in appreciation of the work done by Gene Deterling and Shirley Neason that caused this association to come into existence. Without their effort I would not have the pleasure of reporting through the Gathered View, which was created by Shirley, to you the persons organized by Gene.

Delfin J. Beltran, M.D.
President

SCOLIOSIS

A Wisconsin foster parent has asked us to alert parents of the possibility of scoliosis in young people with the Prader-Willi syndrome. She reported her foster son was found to have scoliosis in a routine screening check at school. Dr. Vanja Holm gave us some information about scoliosis when she talked at our first annual conference. There is also information included in the Prader-Willi book recently released by Dr. Holm.

Dr. Holm felt the incidence of scoliosis in the PWS was much higher than originally thought. She highly recommends that all parents have their children checked. Although the percentage of PW young people with scoliosis was high, the percentage that required treatment for their scoliosis was not high. Most patients had to be followed rather than requiring surgical treatment.

In the PWS book, Dr. Edwin Laurnen recommended a clinical examination be conducted every six months employing the examination technique described by the Scoliosis Research Society. He stated mild to moderate scoliosis is somewhat difficult to detect clinically with PWS patients because of obesity and relatively short stature. Early detection is essential for the best treatment results.

The Scoliosis Research Society has a pamphlet available entitled "Scoliosis: A handbook for patients." and is available from the society at 430 North Michigan Avenue, Chicago, IL 60611.

RESPONSE LETTER REGARDING PRESCHOOLERS

A Canadian Parent writes:

"This is an answer to TX Parent in the last newsletter. She was interested in the behavior of other pre-schooler PW's specifically 4 years. Our son is not 4 but he is 2-1/2 and he too appears very bright and is outgoing. Our one doctor has said that our son is one of the smartest PW youngsters she has ever seen. He shows no sign of craving for food, in fact he's a very fussy eater. We do not have a specific calorie controlled diet, but we have taken action to avoid sugar, salt, and some starchy foods as much as possible, in the hopes that if the food craving habits do show up, we will have had a head start in the battle.

We were one of the fortunate sets of parents that have had our child diagnosed early. He was diagnosed at 6 months of age. He began monthly trips to a therapist and when he was 1 year old he began trips to a speech therapist. I took him to a YWCA infant swim program. He was also involved in an infant stimulation program starting at 3 months old and ending at 2 years. He now attends a nursery school for handicapped children 4 mornings a week, where he receives the necessary therapy along with regular nursery school activities, i.e., storytime, singing, crafts and yes even snack time. His teachers are extremely cooperative in giving half portions and the "plus" so far is M doesn't complain when the others have more. He eats nice and slow.

RESPONSE LETTER (Continued)

I'm not saying everything has been "roses" for us. M has a terrible temper, is still quite hypotonic and he takes feverile seizures when his temperature goes too high. We do believe though that early diagnosis has been an extremely beneficial factor in the development of our son.

I hope our letter can help someone, although comparisons shouldn't be taken as fact, as our children are individuals, very special individuals."

SACRAMENTO AREA GROUP

The Sacramento area parent's group met in May. A presentation was made by Mr. Skip McDonald, director of a Developmental Living Center for autistic young adults, and psychologist with Behavior Associates. Behavior Associates is a group which specializes in helping out-of-home placement facilities to learn to deal constructively with difficult behaviors. This same service is now being offered to individual families on an in-home basis and has been quite helpful to some of our families of PW persons.

The discussion also concentrated on problems with self-esteem and self-image in PW individuals. We discussed potential ways of helping the child to develop a more positive self-esteem. Suggestions were offered by Tamar Palmer (Ph.D. candidate in psychology and former special education teacher) and by Skip McDonald. We discussed development of self-esteem by fostering successes in areas which are unrelated to and independent of the child's success or failure with food and dieting. Several parents wondered if there were ways that school programs could be made more aware of the child's needs in this area of development, and whether there were specific activities which could be included in the child's curriculum to help achieve this objective.

Summer camps and development of group homes were other topics discussed at this meeting.

Andrea N. Sechrist, M.S., R.D.

OVERVIEW OF THE SCIENTIFIC CONFERENCE IN CALIFORNIA

The Dubnoff Center (the organization that has opened the first PW home in California) co-sponsored a scientific developmental disabilities conference which featured the Prader-Willi Syndrome. I was fortunate to be able to attend and found the experience of great value which I hope to share in part with you.

Space allows only highlighting the two day conference. The first morning included presentation by Dr. Bryan Hall, Dr. David Ledbetter and Dr. Hans Zellweger. Dr. Hall gave an overview of the syndrome which included information that a lot has been learned in the past ten years regarding this syndrome and other forms of treatment will be available in the future (optimism is high). He stated the diagnosis is not an easy one to make early, most physicians will not diagnose the child at birth or in the first few months but will alert the parents of the possibility. He also stated in the past that children go through a critical stage of their lives without a diagnosis and the family without any direction and support. He also commented that believe it or not the syndrome is now over diagnosed opposed to the previous situation of being undiagnosed.

Dr. Zellweger talked chiefly about the hypotonia and comparisons of PWS with other disabilities that also include hypotonia.

CA CONFERENCE (Continued)

Dr. Ledbetter presented his work with cytogenetics and the incidences of the deletion of a portion of #15 chromosome. His work with the PWS has only been in the past two years. He reported apparent chromosomal abnormalities have been reported in the past but there was no consistent feature to these abnormalities. In the study of 45 patients that he has completed recently, 23 of these patients did have the #15 deletion. Other abnormalities were also noted. He stated, "we think now that the least we can say is that there is now a laboratory test available which can confirm the diagnosis of PWS, something that many people have been anxious to find. If the diagnosis of PW is suspected, high resolution chromosomal analysis can be performed and the finding of a deletion or other rearrangement of chromosome #15, we feel is very good evidence that the diagnosis of PW is applicable. If there's no chromosomal abnormalities found, you would not say that the diagnosis of PWS is ruled out, it is possible that deletions of chromosome #15 exist that are even smaller than we are presently able to detect and that the patients we now call normal will in fact show more subtle chromosome deletions as techniques improve."

In the afternoon Dr. George Bray gave an excellent report on his studies with PWS and obesity. Included in his remarks was the statement that all obesity problems are not the same. This statement certainly made sense but it was something I had not really thought about before. I assumed that when someone found a medication for obesity it certainly would help PWS patients. I found out this assumption was incorrect but was heartened by the fact that Dr. Bray has worked a great deal with this syndrome and is making inroads to solving the problem. His statement "effective alternative approaches are just around the corner" sent my hopes soaring. He also commented about a patient that they had in 1972 that was 6 feet tall and weighed 420 pounds which has been the largest patient that they have treated. Most of his patients fall in the usual category of approximately 5 foot height. Other comments of interest were his studies of gonadotrophins. In his studies of the sexual development most PW's stay in the pre-pubertal development stage. He has found with both male and female patients that this system can be turned on with a drug. In other words there is no impairment present, it is just that the system that controls this development does not turn on.

A panel of Drs. Tymchuk, Bray, Hall and Annette Dahlman (Associate Director of Dubnoff), included a short presentation by each and an opportunity for the people in attendance to ask questions. Dr. Hall stated there is a great deal of parental unhappiness with living accommodations and management by others of their PW children. He said enough people do not understand the problems of these patients, and the fact the PW patient is different from other retarded persons, which is true of some others also. The management is very complex.

Dr. Zellweger answered a question regarding the ability of the PW young person to make independent decisions. He stated that some certainly could, and have done so, but the ability is a fluctuating thing.

Dr. Karl Nystrom, psychiatrist, gave a presentation of one case that he has worked with followed by impressions of the same girl by her case worker. It was not surprising to hear the girl was doing well when it was learned she is being handled on a one-to-one basis. I'm sure all of us feel if we could devote our whole day (minus school time) to our PW child, things would operate a lot smoother.

CA CONFERENCE (Continued)

Ms. Dahlman explained their year of work preparing for the establishment of the group home for four PW young people aged 12-15. She also told us a manual will be available in August on how to open a group home and orders can be placed with them. Other statements included parents, on a whole, are dissatisfied with professional treatment of their children. "In general, being a parent is difficult; being a parent of a developmentally disabled child is more difficult; and parents of children who are identified either at birth or during their school years as developmentally disabled are faced with incredible obstructions in fulfilling their parental role." She also gave some statistics from the 250 forms that they have received, one statement "on a whole parents of PW's are very caring, very loving and very actively involved with their children". She noted a high incidence of marital conflict, strictness and irritability (all of which is very understandable to a PW parent).

The next day hard decisions had to be made as six workshops were presented for the first half morning and I could only attend one. The same happened for the second half of the morning. I chose to attend a workshop given by Dr. Alexander Tymchuk regarding successful behavioral programming in the home and in the group home arrangement. Dr. Tymchuk shared many of his papers with us and gave us an excellent view of the token economy method. An idea that impressed me was to use steel washers (various sizes with holes) as payment for accomplishments and they in turn can be used for buying "privileges". They can be kept on a shower ring clip that may be inserted onto a belt loop or pocket to prevent losing or being borrowed by other group home residents.

The second workshop I attended was a session presented by Gil Freitag, Ph.D. on problem solving. I am sure the people in attendance found this session very helpful in working in group home situations.

This concluded the presentations but did not include the opportunity I had for the two days to talk with the medical personnel in attendance as well as the parents that also came. Having the opportunity to hear about the new group home, see pictures of it, slides of the money raising gala, hearing the presentations and conversations all added to a very worthwhile meeting.

Marge Wett

LENDING LIBRARY

The PWSA has purchased five copies of the book edited by Drs. Holm, Sulzbacher and Pipes. We have also purchased one copy of "A Difference in the Family" by Helen Featherstone. (Life with a disabled child.) We now have these copies available for any of our members to check out. The only cost would be the 86¢ postage to return the book to us. Please request this book loan from the national office.

RESPITE CARE

Jolene Berry mentioned that four Massachusetts families are making their own respite care arrangements by keeping each others PW children. She said it worked very well and parents stated two PW children were easier to care for than one as they keep each other occupied. The home office has some alphabetical membership lists left from the conference available at \$1.00. Maybe some of you can find someone in your area interested in trying this arrangement to give you a needed occasional break.

TRANQUILIZERS

A Colorado parent sent us this quotation from a local college Special Ed. Department:
"people tranquilized will never learn to overcome or master their frustrations, their fears or their behavior problems if they are not allowed to deal with them with a clear and open mind and without the crutch to lean upon or depend upon."

THANKS

We appreciate all of you who take the time to write and tell us how much the GV means to you. We certainly try to keep you informed with all of the information that we receive. We thought we'd share a couple comments and an excerpt from a letter we received recently:

From a doctor at the National Institute of Health:

I have a very informed and capable staff to talk with parents of PW's but many prefer to read the GV and talk with other parents.

From an Ohio parent:

The GV has helped me to understand and be a bit more tolerant of these 'episodes' (outbursts), and now when they happen we keep a journal. If he (her PW son) begins to rant and rave at me, I very calmly hand him the notebook and tell him to pretend I'm out of town and he's writing me a letter. This has worked better than anything else during the years. When he has unloaded on paper, I read what he has written, and I respond on paper. We save the notebook for future reference, so that we don't have to keep covering the same ground. It has certainly de-fused many recent episodes.

From a CA parent:

As soon as the GV arrives, I retreat to the bathroom (that's my undisturbed area) and read the entire issue. I am happy to see lately that people are responding when the GV asks for input. Before there were good questions but few answers. (We appreciate the fact some of you are sharing with us also, and hope the number of responses will increase.)

PW THOUGHTS

A parent from Ohio shared this letter with us that her son had written:

"My name is _____. I am a 16 year old boy, white, born in (place, date and time). I live at _____. I live with my mother and father and adopted sister. We're not rich or not poor.

I had brain damage at birth. No one, neither my parents or any doctor knows how or why this happened. But it happened. However I have a good mind. I can learn as much as anyone. This problem does slow me down, and it's hard for me to do many things that most boys my age can do very easily.

Of course this makes for many difficulties which are hard to live with at times, but I know I must live with them and do what I can.

I am not happy about it but if this is the way it must be, I will find my happiness even so. Many things have made me very angry and have upset me during the years which I have tried to handle as well as I was able.

I feel overwhelmed by my problem and ask for help. Everyone I have asked has told me the same thing. I must somehow learn to get on top of whatever problem I have come up against and find a way to solve it. I can ask advice, but I can't ask anyone to solve it for me. HOW can I best do this?

Everyone in the world has a problem. Some are not as bad as mine. Some are even worse than mine."

RESEARCH

Two research forms have been sent to the PWSA membership in the past few months. One was a single page questionnaire mailed by the PWSA to approximately 650 members. Returns were over 200 forms. I do not know what percent of return this is because we do not have a definite figure as the number of our membrs with Prader-Willi children.

The second form was a very extensive form mailed by the Dubnoff Center in California. They are very happy to report a return of 250. As of this writing, they have entered 125 of these into their computer, which they will continue to do and have promised us a copy of the results when the project is completed.

In the near future we will mail the complete results of the PWSA form to the people that responded. A few forms were not identified so if you did submit a form to PWSA and have not received a copy, please request one if you would like one.

This is a synopsis of the PWSA form return: (197 forms)

The youngest aged child reported was 16-1/2 months; the oldest was 41. I have broken the statistics into five age groups: Infant through 5; 6 through 12; 13 through 18; 19 through 25; and 26 through 41. The average age of the patients was 13-1/2. Seventy-eight and one-half percent of the patients lived at home. The remainder was .09% in Group Homes, .005% with relatives, .02% in Foster Homes., .06% in a Residential School, .01% in a developmental type setting, .02% in State Hospitals, and .005% independent living.

I believe that all but a very few reports came from parents. This information was not requested on the form. Males reported were 107, females 89. The lowest weight was 15 pounds and the highest was marked 300+. The shortest was 29" and the tallest was 5'8".

One hundred and seventeen were listed receiving Special Education, 65 for combined type of education and 7 for regular education. A diet control of some type was listed for 184 which consisted mostly of watching calories. Five people state no food control was necessary.

The top concern of parents varied from one age group to the next but was consistent with previous beliefs that weight and behavior are the chief concerns.

The medical questions did not go into detail so the accuracy is questionable. Most chromosome studies were not recent. The question regarding nystagmus or albinism was frequently misunderstood. Only one question documented this actual condition. In the family history of cancer, a small percent was immediate family and only one reported a leukemia-type cancer in a person with the syndrome.

Although our form left much to be desired in specific information, it was purposefully a one-page uncomplicated questionnaire in order to obtain a large return. We sincerely thank the parents that did take the time to return their forms to us for this study. We are looking forward to seeing the complete report from the more extensive Dubnoff study.

ANESTHESIOLOGISTS

We have a couple of doctors that are interested in doing some studies with PW children from medically associated families. We would appreciate it very much if all medical doctors with PW children would write to the national office stating their medical specialty and former medical specialties particularly at the time their PW child was born. We would also appreciate hearing from operating room nurses, dental assistants and other related personnel (particularly anyone working with anesthesia agents). After receiving this information we will again contact you regarding the study.

THIRD ANNUAL NATIONAL PRADER-WILLI CONFERENCE

The Air Traffic Controllers cooperated and we held our third annual conference at Florida Atlantic University in Boca Raton, Florida in June. We were fortunate to have three major presentations (comments by Dr. Beltran in President's Message), followed by two more full days of workshop presentations. FAU did tape the entire conference and we hope to be able to make copies of these available to our membership. In the meantime I will review the conference highlights.

Opening presenter, Dr. Vanja Holm, University of Washington: We hope many of you will avail yourselves to the tapes when they do become available so you can hear her overview. She commented that the PWS is just one of many many syndromes but probably it has turned out to be one of the more common ones because of the incidence.

David Ledbetter, Ph.D., of the Kleberg Cytogenetics Laboratory, Baylor College of Medicine, Houston, Texas, did an excellent job of bringing a very complex subject down to an understandable level for parents. Information regarding this chromosome deletion is included in the President's Message and the CA meeting overview, this issue.

Jerold Siegan's presentation on wills was very well received by those attending. We hope to make this available to our membership on tape and in written form if we possibly can. I will comment on a few of his statements but the entire talk should be heard or read to have the whole picture of what his suggestions were and the reasoning for them.

Contact local ARC to obtain a list of lawyers with knowledge of wills and trusts for handicapped children.

It is a must to have an estate plan no matter what your assets are.

Estate plans enable you to transfer property that you have at your death in the manner you chose. They also provide financial security for your family. They minimize state and inheritance taxes while maximizing use of public available funds for the benefit of your child.

You are in trouble if you die without a will because state laws do not take special children into account.

A trust, with the proper wording, is necessary to provide your special child with what you want to provide.

State laws vary so it is important to check with local lawyers so your will is valid.

I will not try to review the workshops at this time. I personally was very impressed with the amount of information that was presented during the workshops. I believe the parents welcomed the opportunity to discuss sex education, behavior management techniques, educational aspects and various other subjects as well as learn about the establishment of group homes, parent support and advocacy groups, and parental attitudes.

The minutes of the board meeting will follow in the next issue of the GV. Items discussed:

Financial report: Small budget and the way we are presently operating. Present membership 682, projected membership of 900 by 1982, 2,000 by 1986.

Committee reports: Clinic Services Committee, chairperson Dr. Betty Schultze. First copies of the directory were presented to the board. The balance of the directories will be available in the near future. Motion made to place a fee of \$2.50 for this directory to members with \$3.00 fee for non-members.

Vocational Placement Committee, chairperson Lota Mitchell, MSW. Request for additional members as present committee is east coast only. Goals set to formulate information to furnish to workshops for proper placement of PWS person. Request from members to give committee information regarding the name and type of workshop that is now serving their PW child.

THIRD ANNUAL NATIONAL PRADER-WILLI CONFERENCE (Continued)

Residential Committee, chairperson Lois Olson. Report given by committee member Karen Virnig. Reported home opened in LA area for four PWS. New Jersey home to be opened later this summer, Minnesota home for 15 to be opened September 1st, San Diego home to be opened in near future and recently opened home in Massachusetts. She requested that people involved with these homes to share information with this committee so problems and successes can be studied.

Education Committee, D. J. Miller, chairperson. D. J. called on all members to reeducate everyone about the syndrome in every way possible. Publicity and presentations whenever possible make more awareness of the syndrome.

Research Committee, Toni Parker, chairperson. Report given by Isa Breneisen, committee member. She gave the results of the PWSA survey (summary this issue) and a medical survey regarding services and research. She named eight research projects now in progress.

Respite Care and Recreation Committee have not been active. We are seeking someone to volunteer to chair these committees so they could be formed.

President's report included information on the successful transition of the operation of the organization from the Deterlings' to the Executive Director and committees. He stated the prime responsibility of the Scientific Advisory Committee to provide appropriate supervision and approval of any research and provide qualified support persons for answering membership medical problems. He announced the committee members appointed by Dr. Bryan Hall:

Bryan Hall, M.D., chairman, University of Kentucky, Lexington

Vanja Holm, M.D., University of Washington, pediatrician

Jurgen Hermann, M.D., Medical College of Wisconsin, Milwaukee, pediatrician

George Bray, M.D., internist and endocrinologist, Harbor General Hospital, Torrance, CA

Andrea N. Seachrist, R.D., dietician, nutritionist, Alta Reg. Ctr., Sacramento

Steve Sulzbacher, Ph.D., psychologist, University of Washington

David Ledbetter, Ph.D., geneticist, Baylor College of Medicine, Houston

James Mascarello, Ph.D., geneticist, Children's Hospital, San Diego

Peggy Pipes, M.P.H., dietician, University of Washington

Dr. Beltran commented on other items covered by other reports, materials that we sell, reported 238 new members since last year's conference and the amount of correspondence that is handled by the home office. He reported that he appeared before the State of California Senate Committee on the Handicapped and was pleased to have David Loberg, Director of Developmentally Disabled for the State of California state that yes he was well aware of PWS and what was being done in the state. Loberg was also a guest speaker at the recent California scientific meeting. Dr. Beltran concluded his report with thanking Florida Atlantic University, Dr. Lou Caldwell and Marge Wett for the conference arrangements.

New Business included: A motion that the board direct the Executive Director to formulate informational guidelines for the formation of regional chapters. This motion was carried following a floor and board discussion on the matter that the board wants to encourage and help local chapters in every way possible.

A motion was made that the Executive Director be reimbursed for actual expenses incurred, up to the total amount of salary budgeted for that position, such expenses including travel, meals, and lodging for the Executive Director's attendance at the California conference, the organization's national conference this year, as well as similar expenses associated with travel in the future particularly associated with business with the local organizations.

A motion that the organization's dues for basic membership be increased to \$15.00 for domestic membership and \$20.00 for overseas membership to cover the additional costs for first class mailing and the annual distribution of the membership list, sorted by state, and an additional membership category be established to be called contributing membership which will have an annual dues of \$30.00 for domestic and \$35.00 for overseas membership, effective January, 1982. Following a discussion other categories of membership were also added.

THIRD ANNUAL NATIONAL PRADER-WILLI CONFERENCE (Continued)

Three bids were presented for consideration for next year's conference: Sacramento, Los Angeles or San Diego, California; Albuquerque, New Mexico; and Kansas City. The floor nomination of Dr. Lou Caldwell was added to the names of the three board members who ran for re-election. The terms of Shirley Neason, Vanja Holm and Richard Wett had expired. (Voting was conducted over the next day and ballots returned the three encumbant members to the board for another three year term.)

The other meetings, the banquet, and the chance to talk with other parents all added up to another very successful conference. As far as my children were concerned, the program for the PW's and their brothers and sisters was also a success. Our PW daughter looked forward to meeting her friends from last year and her pen pals and thoroughly enjoyed the three days of activities and meals that they shared.

Marge Wett

PUBLICITY

Every time we manage to get some publicity we reach more PW parents that are not aware of our organization or find their children fit the pattern of what they have just read or heard. D. J. Miller and her PW daughter from Pennsylvania recently were interviewed by a radio program, "All Things Considered". By chance this was carried on the local radio stations in the Florida area during the conference so many had the opportunity to hear the broadcast.

Channel 12, West Palm Beach, came over to the conference, took some pictures of the young people and interviewed our president. That was shown that evening on the 6 o'clock news.

A Fort Lauderdale paper also did a conference interview so hopefully we got some more coverage.

We often refer to our organization as a "sharing and caring" group. It is this policy that has made our group what it is. Keep sharing with the GV. Keep seeking publicity whenever possible so our growth and strength as an organization can continue to expand.

RECIPES

Peggy Pipes, nutritionist at the University of Washington, has offered to gather recipes designed for PW diets. If any member would like to share their special recipes we will forward them to Peggy. One Missouri parent shared this recipe with us:

BANANA BREAD

| | |
|------------------------------|--------------------------|
| 2 cups mashed ripe bananas | 2-1/2 tsp. baking powder |
| 1/3 cup shortening | 1/4 tsp. soda |
| 3 eggs, well beaten | 1/4 tsp. salt |
| 1-3/4 cups whole wheat flour | |

Mix all ingredients and place in a greased loaf pan. Bake at 350 degrees for 45 minutes. (Do not overbake.)

These are two of the graphs shown by our treasurer at the conference. He commented that we are operating on a very small budget with very low working capital. Hopefully a fund raising chairman will be able to change this picture so we will have some funds to work on additional projects.

| | 1980 | | 1981 | | 1982 |
|-------------------|-----------------|--------------------|-----------------|-----------------|-----------------|
| | <u>PLAN</u> | <u>ACTUAL</u> | <u>PLAN</u> | <u>ESTIMATE</u> | <u>PLAN</u> |
| MEMBERSHIPS (#) | 400 | 600 | 650 | 750 | 900 |
| <u>RECEIPTS</u> | | | | | |
| MEMBERSHIP DUES | \$4,440 | \$5,758.17 | \$7,000 | \$7,200 | \$9,000 |
| CONTRIBUTIONS | 3,500 | 8,174.96 | 6,000 | 4,000 | 5,000 |
| HANDBOOK | 200 | 825.00 | 500 | 1,000 | 600 |
| CONFERENCE PAPERS | | 1,232.50 | | 1,200 | 1,000 |
| OVERVIEW | | 94.00 | | 500 | 500 |
| PWS BOOK | | | | 4,500 | 500 |
| SAVINGS INTEREST | 100 | 253.41 | 200 | 300 | |
| CONFERENCE | <u>3,500</u> | <u>3,768.97</u> | <u>4,500</u> | <u>3,000</u> | <u>5,000</u> |
| | \$11,700 | \$20,107.01 | \$18,200 | \$21,700 | \$21,600 |
| <u>EXPENSES</u> | | | | | |
| SALARIES | \$5,000 | \$750.00 | \$750 | \$500 | \$8,500 |
| OPERATING | 3,185 | 5,768.60 | 6,475 | 5,650 | 7,925 |
| CONFERENCE | 3,000 | 4,470.12 | 4,000 | 3,000 | 4,000 |
| CAPITAL EQUIPMENT | | 1,715.50 | | 700 | 600 |
| PWS BOOK | | | | <u>4,300</u> | |
| | <u>\$11,185</u> | <u>\$12,704.22</u> | <u>\$17,975</u> | <u>\$14,150</u> | <u>\$21,025</u> |
| GAIN/LOSS | \$515 | \$7,402.79 | \$225 | \$7,750 | \$575 |

ESTIMATED EXPENSE BUDGETS FOR 1981 AND 1982

| | | |
|----------------------|------------|------------|
| SALARIES | \$500 | \$8,500 |
| PRINTING | 1,800 | 2,000 |
| POSTAGE | 2,000 | 2,500 |
| OFFICE EQUIPMENT | 700 | 600 |
| OFFICE SUPPLIES | 350 | 500 |
| COMPUTER SERVICES | 600 | 1,200 |
| WORD PROCESSING | 350 | 1,000 |
| CURRENCY DEVALUATION | 150 | 75 |
| TELEPHONE | 100 | 150 |
| NATIONAL COMMITTEES | 200 | 300 |
| CONFERENCE | 3,000 | 4,000 |
| PWS BOOK | 4,300 | |
| MISCELLANEOUS | <u>100</u> | <u>200</u> |
| | \$14,150 | \$21,025 |

PWS BOOK

The national office has sold the 200 copies that were ordered of the PWS book by Dr. Holm et al. We have not been able to obtain information from the publisher as to whether we can obtain a smaller shipment at the same price but we are working on it. The 130 books ordered in April and May by members were shipped in May and one book was returned without a label. Would the very patient member that did not receive their book please contact us?

SUGGESTED READING MATERIAL

"How to Provide for Their Future," published by:
The National Association for Retarded Citizens
P. O. Box 6109, 1709 Avenue E East
Arlington, TX 76011

Legal information

"Parents can be the Key," available from:
PACER Center

4701 Chicago Avenue South
Minneapolis, MN 55407

Information on education free to parents of Minnesota handicapped children. \$1.00 prepaid for single copy to others.

THE GATHERED VIEW is the official newsletter of the Prader-Willi Syndrome Association and is sent to all members. Membership dues are \$10.00 per year for U.S. members; \$15.00 per year for Canada, Mexico and overseas members. Send dues and change of address notices to PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436.
