



The Gathered View

for the younger set

Newsletter of the Prader-Willi Syndrome Association

PWSA Board Reports Progress in Operating

• Harvey Bush, Treasurer, reported our organization may top \$100,000 in income and expenses this year. Growth continues. Barbara Whitman, Education Committee Chair, made a presentation at the conference that was well received by those present. The Board approved a grant to not only cover the proposal but also enhanced it in order to develop further educational modules and purchase a professional display board for PWSA.

• Dr. Suzanne Cassidy reported the planning for the International Meeting, to be held in the Netherlands in May of 1991, was progressing nicely. Two days will be devoted to the scientists and two days to educational presentations. Several countries have representatives working on this conference.

• Sheldon Tarakan, Public Relations Director, made several suggestions to the board for furthering our exposure. He will be pursuing the possibility of a segment being developed for the *L.A. Law* television show, and will be developing a press kit that can be used by our membership when working on publicity. Other ideas will be pursued at a later time. When we make the TV approach we'll be asking your support in convincing the station a show should be done.

• PWSA will provide a grant to pay expenses for some professionals to meet in January and develop diagnostic criteria for this syndrome. Truly defining the syndrome is very important from a medical standpoint.

• Further work is being done to establish advocacy and trust assistance for members from the national organization. Unfortunately, these things need to be developed legally and take a great deal of work but hopefully will be available in the not-too-distant future.

• The current President and Vice President were re-appointed to serve in that capacity until January when the board will be concluding a search for new candidates. Dr. Beltran, who has been involved with the association since the early years, has served as President for many years and has resigned as of the end of the year.

• The Board, Officers and Executive Director will be searching for candidates for the Presidency and Vice-Presidency. Qualities being sought for these positions include a strong personality, good spokesperson, people person, inspirational, writing abilities, and a person who has the time to be involved with the organization. If you are interested in seeking one of these positions or recommending someone else, please contact any of the above people with your suggestion.

• The brochure committee was happy to report the reactions to the new brochures have been very favorable and work on one or two more will be accomplished in the future.

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Prader-Willi Syndrome Association

6490 Excelsior Boulevard, E-102
St. Louis Park, MN 55426
(612) 926-1947
Office Hours: 8:30 a.m. to 4:30 p.m. C.S.T.

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Annual Membership Meeting Held in Salt Lake City

The 13th Annual General Membership meeting was held during the conference. Following an introduction to the meeting by President "Sam" Beltran, "Bud" Bush, Treasurer, summarized the financial reports that were shared with those attending. He talked about support over the years to enhance services and programs and emphasized that our Association is a dues and contribution supported organization. We receive no outside funding. The organization is in good financial shape and have the proper controls and procedures set up. We maintain about two months' expenses readily available and invest the balance of the funds, averaging about 8-9% interest for the past six months. Bud assured the membership that the money is certainly going in the right places: services, support and programs.

Marge Wett, Executive Director, reported on growth of the organization with memberships totaling 1583, members from this country and 24 other countries. She thanked the members for those able to pay contributing and patron membership fees as this is helping us to grow. One excellent example is the new brochures. Later, a member questioned having subchapters or more chapters in one state and Marge informed her any group can apply for chapter status. During the President's report Sam talked about when the organization was founded and the growth since. He talked of the educational focus and the importance of letting people know what the syndrome is and what to do about the problems. He mentioned we now have 26 designated PW homes and 18 in the process of being formed. Later, the Board Chair spoke of Sam's contributions to the organization and of the time and expertise he has generously donated to PWSA.

Lota Mitchell, Board Chairperson, introduced the members of the Board and Advisory Board and told of their duties and responsibilities. Stewart Maurer, Chair of the C.I.T. Committee spoke of the use of these funds (see separate article this issue) and hoped more people in need would take advantage of this fund. Sam mentioned several people in attendance were interested in forming new chapters.

Explanations were also given in regard to our now having a nomination committee for new Board candidates and explaining the vote changing the number of votes required to pass a mail vote. (The membership did vote to change from unanimous to 2/3rd majority). The nominating committee supported Suzanne Cassidy as an incumbent and presented Curtis J. Shacklett and Frank Moss as the other two candidates to fill vacancies on the Board. One floor nomination was made but declined so the membership affirmed the committee's candidates. We are happy to welcome Curt, attorney, (Tulsa, OK) and Frank, businessman, (Camarillo, CA) to the board. Both are parents. We are certain their contributions to the Board will be many.

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President's Message

July 1975 — Volume I, Number 1 of *The Gathered View*: "This is the first issue of *The Gathered View*, a newsletter dedicated to providing a means of exchanging ideas and information among parents and others who must deal with the problems of people who have Prader-Willi syndrome." So opened the first issue of this newsletter as founded by Gene Deterling, the original president of this organization. Volume VI, Number 5, September-October 1980, the lead article of *The Gathered View* was a report written by me as I assumed the responsibilities as Gene's successor in the president's role, following the five years that I served as chairman of the Board of Directors.

During those first five years the membership under Gene's direction formed the foundation and established the roots for survival and growth. In the issue that carried my first letter some of the topics under discussion were the formation of the Scientific Advisory Board, the tasks of several new committees, the development of a home dedicated to the support of Prader-Willi persons, the concept of developing state PWS chapters, the introduction of the "orphan drug" legislative movement, substitution of the term "food-seeking" behavior for the term "food-stealing," the death of Daniel Neason, son of PWSA founder and original editor of *The Gathered View*, Shirley Neason, and an order form for all eight of the available publications on Prader-Willi syndrome.

Today's reader will easily recognize that the Prader-Willi Syndrome Association has not changed the goals that have created its strength. Spreading the word and knowledge that parents as experts learn through living and loving someone with Prader-Willi syndrome. If you had the privilege of attending the recent conference in Salt Lake City; if you read *The Gathered View*; if your area has chapter meetings; if you are all alone without others to share your hurts, but you call Marge Wett at St. Louis Park, you know that PWSA is you and you are willing to help a fellow member of the Association. It is what those real estate tax dodge schemes used to call a "win-win situation." By calling for help or sharing with another Prader-Willi supporter we give of ourselves in love and understanding and receive love and understanding in return and the gift becomes our own source of joy and happiness and comfort. With these solid roots of sharing expertise the membership has created a growing, nurturing, creative and mature association. I have been blessed to have been a part of this exciting development, watching your creative efforts, seeing the successes of home formation, chapter replication, research reporting, legislative successes, education of the public, development of PWS support concepts, entrance of vocational recognition, knowledge and expertise development and dissemination and above all seeing the dancers at the conference demonstrate socialization skills and weight loss.

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Our Supporters. Our Thanks!

From mid-June, through July and into mid-August, we acknowledge the following contributors:

- **Maranon memorials:** Davis, Bresani, Maranon, Gomis, Ortiz, Cortijo, McGill, Baker, Hasker, Semiglia, El-lanson, and Blum.

- **Other memorials and honorariums:** Uzendowski (Jurga), Buttz (Adams), Leonard (Sullivan), Luhman (Gerdes), Assoc. Rec. (Katzenberger) and Van Zomeren.

- **C.I.T. donations:** Schneider, Casey and Olson.

- **Research:** Ragan, Mays, Boyd (2), Casey, Walsh, Huse, Shoemaker, Frontier PW Reg'l. Assoc., Alterman, Needel, Cochran, Krempel, Mitchell, Gordon, Martens, Olson, Buchanan and Alterman.

- **Operating:** Tarakan, DeHaan, Alterman, Hutchins, and Krebsbach.

- All donations, large and small are greatly appreciated. Special thanks are due to three particularly generous donors this time: Alterman, Casey, and Tarakan. Due to the generosity of all contributors we were able to add \$4724 to our funds this period.

We also appreciate members who support our programs with additional dues:

- **Contributing Dues:** Nichols, Post, Trachtenburg, Giusti, Shults, Seal, Clement, Smith, Haller, Huffman, Garfinkel, Spears, Fuller, Machitelli, Johnson, Brock, Hawkinson, Cassidy, Canova, Minos, Stinogel, and Rattray.

- **Patron Dues:** Barkeley, Holm, Householder, Deterling, Nanzig, Kavanaugh, Trimble, Shadell, LaBossiere, Kirchhoff, Ayotte, Masterson, Tarakan, Quadrel and Levine.

Some Words About PWSA Funds

Even though we have publicized our funds many times, we have been told we still have members who are not aware that proposals for use of these funds may be submitted to PWSA.

The Research Fund is used primarily for research, but also includes other special projects in direct support of people with PWS. If you are interested in doing some research or seeking seed money for larger grant applications, please let us know of your interest. If you need assistance in paying for a special project that will enhance our purposes, please apply. An example of two grants awarded this year were to conduct a drug study and develop an exercise program. Results of the drug study will be shared with the membership when concluded. A manual and video tape will be available for parents and homes after the exercise project is completed.

The CIT Fund includes the following purposes: Funding to aid people in a crisis situation. This could include transportation to a hospital, treatment center, when the family cannot afford the cost. It can fund intervention grants for families facing crisis situations while waiting for a home placement. Short-term respite care, educational travel, camping, are other examples of some crisis needs. This fund is also used to cover travel expenses for experts to consult with primary providers when the organization cannot afford to pay this expense. Establishing good group homes and program are essential to serving our young people. Money could also be borrowed or used as collateral for start up costs for designated group homes. The fund has also been used for a training session to develop further resource people to aid in opening good homes. If you have a need, request a CIT Grant Application and your request will be considered. We are not interested in depleting this fund but we are interested in assisting families in need and are happy to have this funding available to do so.

The Conference Fund has been basically used to fund the cost of the conference. Each year we attempt to have income and expenses come out equal - we were close to obtaining that balance with this year's conference. With a little left over each year we have developed a back-up fund and in the past few years the Board has funded one or two families to attend the conference. This year 13 applications were made and 2 grants were funded. One family wrote: "We wanted to thank everyone at PWSA



Meet Laurie!

Laurie is looking for a pen pal friend. She is 10, in the 4th grade ICC classes with mainstreaming. Her hobbies are bowling, swimming, special olympics, and reading. Laurie's address is Windy Hill Estates, Rt. 2, Lot 27, Lexington, NC 27292. She'd love to hear from you.

PWSA - 1990 Income (as of July)

<u>FUND</u>	<u>INCOME</u>	<u>EXPENSE</u>
CIT	11,629	7,374
CONFERENCE	22,849	3,458
	(Aug bills 18,493)	
RESEARCH	7,946	5,700
OPERATING	54,647	44,330
FUND BALANCES:		
CIT	243,171	
CONFERENCE	17,964	(as of August)
RESEARCH	39,044	
OPERATING	84,286	

(If you would like a more detailed report at this time, please request. A year-end report will be shared in January.)

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It's Not \$21 Million Lotto, America, But It's Still Fun!

Attendees at the Annual Conference were very enthused after listening to the Educational Plan Committee Chair, Barbara Whitman, outline her suggestions for increasing the knowledge of this syndrome over the next few years. The Plan was later funded by a Board motion and the wheels are already turning BUT WHAT SHOULD WE CALL IT???

How about getting involved right from the start -- let's give this activity an official name. Send your suggestion to the national office before the end of October (after Halloween, it's too late), and win an award of \$100 for your efforts. PWSA's general theme is "Caring and Sharing", maybe that can be worked into this project's name or I'm certain you can come up with some great ideas. Dash them off to us today.

High Pain Treshold Concern

All too frequently we hear reports of our children with PWS having "minor" complaints of discomfort and then finding out they have a "major" problem. It is difficult to separate complaints and true illnesses.

A recent report was shared with us of the case of a young lady who had complained of a stomach ache a few times and twice commented she was too full to drink her beverage after a meal. Following examination it was discovered she had a hair ball in her stomach which had formed because she did pull, cut her hair and eat it. We are happy to report the surgery was successful and it was stated it was amazing she was able to eat at all. This is no surprise to us, as parents.

Banquet Honoree

Each year it is difficult to single out just one individual to honor at the conference banquet (so many people are deserving). The lady that was honored this year joined PWSA in April, 1977. That is over 13 years of involvement. Many times it takes some "digging" to really find out what a person's involvement has included. With this lady it didn't take any effort as she has been involved since the day she joined. One of her first letters stated:

"My little girl is 8. I have waged a constant battle since she was 2-1/2 to keep her weight down, and for the past three years I have been beating unsuccessfully on medical doors, trying to get a diagnosis of Prader-Willi. I find that physician ignorance and the fact that I have succeeded in

keeping her from becoming obese, stand in the way. Therefore, I have found little support in coping with her eating behaviors. I would like to have the names of those in my area who might be interested in forming some sort of local association."

From that point in 1978, Lota Mitchell has become a name recognized by anyone active with PWSA. She successfully formed the Tri-State Chapter in 1978, including members from Western Pennsylvania, Ohio, and West Virginia. In 1980 she not only started serving on the Board of Directors, she also published an overview (which is still used), and she worked with the Rehabilitation Institute of Pittsburgh establishing a camping program that later also led to the crisis center program. Not only have hundreds of people been served in this facility but many lives have also been saved.

Lota became the Board of Director's Chairperson in December of 1986. As usual, she jumped in with both feet and worked to operate the meetings more professionally. It's still difficult to get all of the members to follow Robert's Rules of Order but she's accomplished a great deal of handling a lot of business in our restricted time allotment.

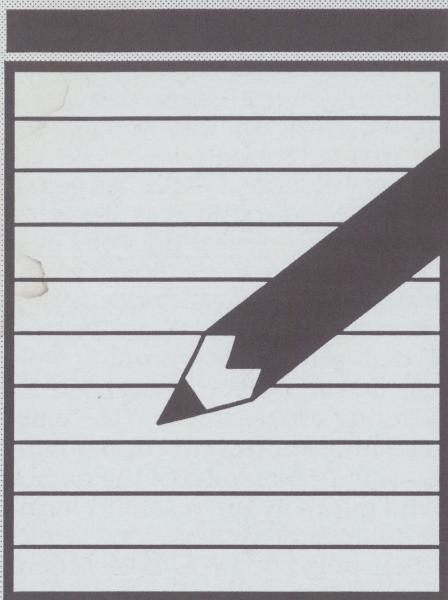
Fortunately, for us Lota is not a person that accomplished one task and then states I've done my part. Recently she committed herself to working with a committee developing new brochures. The fruits of that effort can be seen. Many people have already found the new brochures to be extremely helpful. And the good part is she's not finished yet - she is again working with a new group in her area to form another chapter.

We're not honoring Lota this year because she is retiring -- we expect her to continue full speed ahead in the future. We are just saying thanks to a very devoted, very great gal, Lota Mitchell.



Conference Evaluation

Every year a tremendous amount of effort goes into presenting another conference. Every year we attempt to make this one a little better than the one before. We feel the efforts of Judy and Frank Ipsen and their conference committee certainly accomplished this. And how would the YAAP manage without the return of Dana Bintz? His contribution year after year is tremendous. It was a terrific conference and well worth the many months of preparation. The final tally from this year's attendance was 254 adults, 89 people with PW, and 28 siblings. Feedback from those attending the sessions helps keep us on the right track. If you attended the conference, would you take a few minutes to jot down an evaluation of the sessions that you attended. Share with us ideas that you would like incorporated in the next one.



One of the most important components that came out of the conference was the percentage of professionals, representing many different areas, that attended. Many years ago we,

as parents, frequently found ourselves to be the only "experts" on the syndrome. How refreshing now to be able to fill in the gaps with the many professionals who are incorporated into the many allied health disciplines and are now providing services to our children and families. It is gratifying to see collaborative efforts between these professionals and the parents. Parents are beginning to recognize the role these people can play in the care of our children/adults. With this collaboration, we can better achieve the goals of our organization.

We would also like to take this opportunity to thank all of the presenters who donate their services, as well as pay their own expenses, to join us. (Many have done so for many years.) If our organization paid expenses and speaker fees for our presenters, we would have to charge a large registration fee which would eliminate the ability of many families to attend. We have a great many friends in the professional fields and we greatly appreciate what they do for us.

One member wrote: "Thanks to you and everyone else who made the conference in Salt Lake City such a meaningful experience for my husband and I. Jennifer enjoyed all of the Young Adult activities so much. They were obviously planned with great care. Dana and his crew were extraordinary."

At the conference a member shared information with us that we had not heard of previously. She stated the existence of a federally funded program, Katie Beckett, is available in many states for parents of handicapped children. This program is not based on income level, but pays expenses incurred for those under 19. (Even diapers if the child is over 2 yrs. of age.) If you are not able to obtain information in your area and are in need, let us know and we will pursue obtaining the information for you.

Opening Song Sets Tone for 1990 Conference

Many, many people have requested it, so here it is! *Look Beyond*, by Pat McKee (Calgary's Year of the Disabled) opened the 1990 Conference in Salt Lake City. Here are the words that inspired so many of us:

This is the year that has long been awaited (remembered); This year my song will be sung; I am determined that when it is over I will have only begun to show to the world my potential; To show to the world what I've done, I am a child of the Universe, too, Out of every seven, I'm one--So look beyond what I am I am a woman; I'm a child; I'm a man.

My family have cared and they've shared in the anguish Of progress so painfully slow; They have rejoiced at my smallest achievement And witnessed my confidence grow. I have learned to be humble and patient, But I am not timid or meek; I have taken command of my future And I'm reaching the goals that I seek So look beyond what I am not Then you will see just what I am; I am a woman; I'm a child; I'm a man!

If my legs are unable to carry my body, My voice can carry my song; It whistles and sings through doorways too narrow and echoes in stairways too low; It's a song that is heard through all nations Crying "Give me a chance to belong!" It's a song that poses the question: "Oh, when will the stigma be gone?!" So look beyond what I am not And you will see just what I am: I'm a woman; I'm a child; I'm a man.

I need so much more than just sheltered employment; I need less of pity and tears; I need your respect and I need your compassion—Lend me your eyes and your ears. Then see me and touch me and feel as I feel; Hear what I say—can't you see that I'm real! Look beyond what I am not And you will see what I am I'm a woman; I'm a child; I'm a man.!

I have composed the immortal concertos With ears that were silent and numb; I have touched the heart of a country—Across it on one leg I've run. I have led a nation of people From a chair under war-torn skies I have seen the world through my fingers I can hear the world through my eyes; So look beyond what I am not—Can you see just what I am: I'm a woman; I'm a child; I'm a man!

This is the year that will long be remembered This year my song will be sung; I am determined that when it is over I will have only begun.



For Those Who Snore!

For many, snoring is a constant nightly disturbance. In addition, it is frequently the cardinal symptom of a condition called "Obstructive Sleep Apnea", responsible for producing excessive tiredness and sleepiness, depression, headache, high blood pressure, and weight gain. *Stop Your Husband From Snoring* is written by Derek S. Lipman, M.D., an ear, nose, and throat specialist.

We have not reviewed this book, nor are we stating reading this will "solve" all of the symptoms mentioned above, but mentioned it as possibly being of interest to some of our members. The book can be obtained at book stores or ordered directly at \$8.95 from *Stop Your Husband from Snoring*, P.O. Box 4444, Portland, OR 97208.

Controlling Cavities

Post-meal chewing gum is being offered as one of the tastiest ways to fight cavities. University of Iowa researchers have found that chewing sugared or sugarless gum for 10-20 minutes after a meal neutralizes decay-causing acids that can lead to cavities. Gum chewing stimulates saliva production (frequently found lacking in PWS), lubricates the mouth, washes away food and helps restore acid levels.

Our Readers Respond: Scoliosis and Growth Hormones

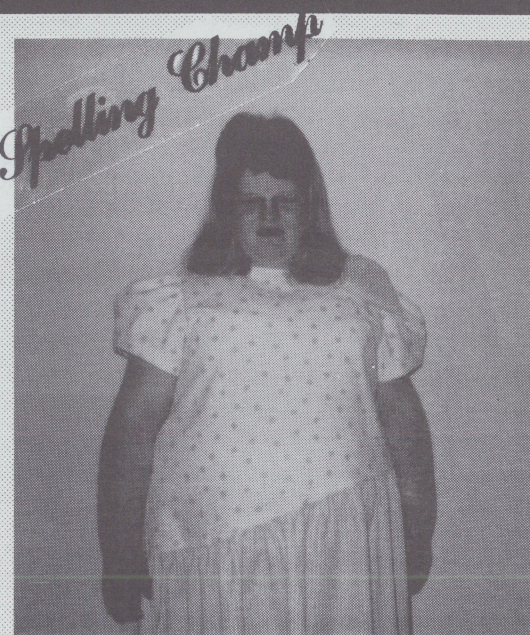
One mother responded her daughter has a double curvature of the spine and has been followed by an orthopedic surgeon for eight years, with a Charleston brace the last three years. Her scoliosis did not progress with the introduction of growth hormones.

It was asked if there was a change in temperament, and this mother responded that her daughter's outbursts have been minimal. Only when she read the article did she realize since the beginning of the growth hormone they had had only one tantrum. She could actually see her daughter having some control. The injections were given right before bedtime.

Congratulations to Cory

Corey had always spent a lot of time completing word-find puzzles, but she had always been leery of doing things in front of others, so she really surprised her parents when she won the 4th grade competition at her school. She didn't stop there, she went on to the District competition, worked her way to the top and won the 3rd place award.

Corey was a *winner*, not just because she won the 3rd place award, but because she overcame her fear of getting up in front of people and performing by herself. Her family is proud of her -- and the rest of us are too!



Notes for "The Younger Set"

A Parent Writes: I would like to share some tips with other parents of small children with PW. Our son David will turn 4 this summer. On the encouraging side, he is underweight for his age. Although he is at the point of always asking for "num nums", I explain to him he has to wait for snack time. Sometimes he accepts this and other times he gets upset. I keep a constant supply of homemade Oatmeal crackers and dish these out. I find he won't eat fresh vegetables yet and is even picky about fresh fruit. Since David will not drink water, I have always diluted his juice with filtered water. David was diagnosed at 3 months and entered phase II at 3 years. He is starting to put 3 to 4 words together (he is hard to understand at most times) and was fully toilet trained at 3. The biggest thing is to keep our little guy busy with what he enjoys. We do a lot of walking, picnics, and field trips. He is in preschool 2 days a week and loves school. Now he will be taking swimming lessons. Pets are extremely important in his life. In walking the neighbor dog, David held tight and kept up with that dog at a mighty fast clip to the effect that he was actually panting and sweating from the exercise (walks are usually slow and hard to keep him going). Music is also important - he loves to dance. Books are a must.

I give David sugarless gum to chew everyday. This takes the edge off asking for food, and it helps to keep his mouth clean of that sticky saliva. It also exercises his mouth. I always try to be positive and patient with our little guy. Smiles and encouragement go a long way. Glasses have made a big improvement as well as the therapies. I hope one day soon a cure will be found for our people. Nobody but us parents fully realize the extent of our challenges. It is an ongoing daily challenge to make the days positive and to live with the many problems PW presents. God bless to all the parents out there. Our children are indeed sent to us for a reason. They have taught us so many wonderful and valuable lessons that we could learn no other way. You are not alone.

Help Needed

I am writing regarding my son Sean who was diagnosed as having PWS at the age of 4 months. He is now 21 months old. He is involved in an infant program and also sees an occupational and a physical therapist twice a week. We are having a very difficult time trying to teach him to eat and drink. He does well on strained foods but relies totally for all fluids by way of a nasal tube. All the information that we have received seems to emphasize the second phase of PWS. We were wondering if any of you readers could share more information on the first phase or if anyone has had the same problems. Sean does not sit up, is now getting some head control. He does not roll over or vocalize. He is also starting to develop scoliosis. Any suggestions mailed to us will be shared with Sean's family and the GV in the future.

Thanks Sent in a Letter "Long Overdue"

I've thought for quite some time about writing to thank you for the PWSA, *The Gathered View*, and the efforts of everyone involved with the organization on behalf of the PW people and their families. A recent visit at the UCONN with Dr. Cassidy reminded me that I still had not written - please accept our thanks and appreciation for your efforts. Our son Jimmy is now 4 yrs. 4 months. The diagnosis was first mentioned at birth but not made until later by Dr. Cassidy. We see her yearly at UCONN. Jimmy is doing wonderfully — he has weekly OT and we've worked with the same therapist for the last 4 yrs. The Easter Seals has a wonderful early intervention program. Probably the biggest plus for anyone with a newly diagnosed PW person is knowing what PWS is!

Tax Information

- *Allowable deductions:* Educational programs: payments to special schools for handicapped children if the main reason for using the school is that it has resources for "relieving" the handicap.

- *Home care:* cost for test and evaluation, therapy and psychiatric care, special instruction or training, medicines, drugs, vitamins and special foods and beverages prescribed by a doctor.

- *Medical care:* payments for diagnosis, cure, alleviation, prevention and treatment of disease or dysfunction of the body.

- *Operations:* as long as they are legal and advised by a physician.

- *Special Services:* services incurred when treating your child's disability such as emergency room treatment, lab fees, rental of equipment and ambulance services.

- *Cost of Special Equipment:* must be necessary to alleviate the handicap and must be prescribed by a doctor.

- *Transportation:* travel incurred going to and from special schools and institutions, doctors' offices, etc. as well as cost of hiring a person to accompany a child who cannot travel alone.

- *Employment Related Child Care:* costs for the care of a handicapped dependent and for household services, providing parents are employed.

- *Legal Fees:* fees directly related to medical care and/or disability.

- *Barrier Removal:* expenditures which improve accessibility to the child's personal residence, such as entrance ramps, widening doorways, etc.

- *Helpful Hints:* Keep records - date, name, address, descriptions, amounts paid; keep copies of written doctor prescriptions.

- *Tax Return Filing Hint:* If you send a letter of explanation with your return, you are less likely to be asked to explain deductions in person.

Chapter/Support Group News & Notes

Chapter Presidents Meet, Offer Suggestions

Along with some other suggestions, some members mentioned that we should remind our members that the newsletter subscription can be given as a gift to those who would benefit from knowledge of the syndrome. Just drop them a note stating, "In appreciation for _____, we have ordered a subscription to *The Gathered View* for you." Recipients could be doctors, nurses, educators, relatives or whomever. We feel this would be a great idea and it helps "spread the word."

Starting New Chapters or Support Groups

Comments have been made, we'd like a group in our area but we have so few people. It only takes two people to start a support group. When you read an insert in the paper that such and such support group will be meeting next Tuesday evening, does it tell you how many will be attending? What it does share with you is the name of the group. Why not give it a try and see if you can find some interested members? At the conference interest in starting chapters was voiced by people from Wisconsin, Florida, Idaho, Wyoming, and other states. PWSA has a packet that they are very happy to share with anyone who would like to develop a chapter. Let us know if we can be of help.

New Western Pennsylvania Support Group

Elections were held in the newly formed support group in the Pittsburgh area: Sandy Immekus of Bethel Park was elected President, Barry Whoric of Scottsdale as Vice President, Donna Boughter of New Castle as Secretary-Treasurer. An early September family picnic will be held with a speaker scheduled for the November 3rd meeting. For information, contact Sandy (412) 831-9291.

Chapter Activity

The Illinois PW Chapter will be holding their annual quarterly meeting in Mahomet, October 6th, at the Public Library from 1-3 pm. The meeting is open to all families and professionals, with the main topic being the planning of the 1991 PWSA conference. Recent meetings have been very productive for a newly forming group is Western Pennsylvania. If you would like to obtain further information, contact Sandy Immekus, 5890 Monongahela Ave., Bethel Park 15102.

Welcome to some new Presidents of existing Chapters: Pauline Parent of The PWA of New England, Lee Forthman of the PWS Texas Assoc., Lonnie Dixon of the PWSA of Virginia, and Mike Hamblin of the PWSA of Kansas.

Annual Meeting

(Continued from Page 2)

Gene Deterling requested that the Board consider a motion at their meeting to reimburse the Board members and officers for a limited amount of expense money each year (such as \$500). He feels that we are limited to those individuals who can afford the expense of travel to attend Board meetings. A member asked that the Board consider this as a formal motion to the membership rather than the Board. (In order to do this a motion will have to be made and published three months prior to the next general meeting.) It was announced that next year's conference will be held in Chicago (Hyatt Lincolnwood) July 24-27, 1991. Request was made for bids for 1992. (To clarify, the Chicago meeting is the *regular* annual conference; the International meeting in the Netherlands is an *additional* meeting, *not* the 1991 annual conference.)

Bids Sought

PWSA is in need of insurance coverage for the Youth/Adult Activity Program at our annual conferences. This insurance could be a combination of that activity as well as office liability insurance. If any of our members would like to make a bid for this coverage, we would be happy to hear from you.

PWSA Funds

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for making it possible for our family to attend the conference. It is so hard to express how much we appreciated being able to go to Salt Lake. We met so many wonderful, friendly people, we learned so much more than we ever expected and I know this is knowledge we can use to live our everyday lives, and friendships that will last a lifetime. We are all truly thankful. The other mother wrote: "On behalf of my children and myself, we would like to thank you for making it possible for us to attend the conference. It was one of the most rewarding, educational, and helpful experiences of my life. We have brought home many precious memories, which will remain with us always... (this mother also thanked Michael Shaltry, who donated two frequent flyer tickets to this family to use in traveling to Salt Lake City.)

IEP Time is Rapidly Approaching

The rights of parents to participate in the planning of their child's education is clearly written into The Education of All Handicapped Children Act of 1975 (P.L. 94-142). The IEP (Individual Education Plan) meeting is designed for the purpose of identifying the educational needs, writing the educational goals, selecting the proper placement, meeting the staff and assuring your maximum involvement with the team.

Be Prepared

Learn what are your rights - your child's rights. You have the right to agree or disagree with their program and placement. Know what assessments were done that are determining their recommendations. List your ideas and suggestions - what are they based on? Learn the jargon - if you can't, don't hesitate to ask what any term means. The meeting need not be inconvenient (time-wise) for you, tell them you need it rescheduled if you can't make it. Be certain the meeting is scheduled with enough time to cover all aspects.

Be Active

Attend the meeting, and it doesn't have to be alone. If you need support ask a friend, relative or advocate to attend with you. Share your thoughts and feelings -- don't sit there and disagree in your head. Ask questions. If you feel insecure, tape the meeting and go over it again alone. Request copies of all material. Don't be afraid to disagree. Learn to negotiate. And remember, you do not have to sign the IEP at the end of the meeting. You may take a copy home and go over it completely if you aren't sure. The schools do not have the responsibility to teach you to be a full participant in your child's IEP - that rests on you. The PWSA office is always happy to be of assistance whenever we can. Have a question? Drop us a line or give us a call.

Be "On Top" of Things

School should provide challenge and fulfillment. With frustrations and struggle that can change to disappointment and dismay. Grade level or age level academic and social achievement required in schools can be a source of pain and stress. Your child needs to learn how best to cope.

Not all forms of stress are necessarily harmful. A certain amount is healthy - it is a motivator. You cannot protect your child from all stress, however, if the demands continue to exceed what they are capable of doing, then unhealthy stress can ensue.

People with PWS have learning problems. Frequently it has been proven that material needs to be presented in more than one form (for example, audio as well as visual). We hope in the future to be able to share more information on how language development in our children is important. Don't make the problems worse by having unrealistic expectations. Your special child is not like everyone else, they cannot compete at the same level. Adjustments are not easy for our children, remember when changes are necessary they have to be handled with special care. Some signs of unhealthy stress:

- Withdrawal reaction • Regression reaction • Displacement reaction
- Fears and phobias • Physical illness • Attention Seeking reaction

Some *do's*: Anticipate stressful experiences, inform your child others have stress too, treat your child's anxiety with respect, learn legitimate concerns, be consistent, consider your child's teacher an ally, accept your child's limitations, focus on your child's strengths.

Some *don'ts*: don't allow your child to blame everyone else, don't assume everyone else is always the wrongdoer, don't fight his/her every battle. Remember the teacher has stress too!

President's Message

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These wonderful and exciting times have resulted in a maturation of PWSA that calls for a new kind of leadership. The budget to achieve the annual goals of the association are soon to exceed \$100,000; the public relations necessary to support this budget with high grade fund raising; the educational efforts necessary to bring the exploding scientific knowledge of PWS to the public in a meaningful way; development of the PWSA advocate support system and its associated funding and monitoring activities are only a few

of the examples of tasks that will require a new president, working with your leaders on the Board of Directors. In recognizing the nature of these tasks I recalled Parkinson's Law that stated that executives tend to rise to levels of responsibility that exceeds their ability. I was once told that the most important responsibility of an executive is to identify the incompetent and fire them. Therefore, having tendered my resignation to the Board, I fire me! Remember — *blame Sam*. Then go do it right.

The Gathered View is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. The opinions expressed in *The Gathered View* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of the PWSA. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$20.00 per year Individual; \$25.00 per year Family; and \$30.00 per year for Agencies/Professionals (U.S. Funds). Send dues and change of address to: PWSA, 6490 Excelsior Boulevard, E-102, St. Louis Park, MN 55426. Any questions? Call us at (612) 926-1947.

PRADER-WILLI SYNDROME ASSOCIATION
6490 Excelsior Boulevard, E-102
St. Louis Park, MN 55426

First Class Mail