# The Gathered View

*Newsletter of the Prader-Willi Syndrome Association*

JULY-AUGUST 1989 VOLUME XV, NUMBER 4


## *Crisis Fund (CIT)*

Most of you recall in 1984 PWSA started fund raising for the purpose of establishing a national crisis intervention center. Over the years the organization has raised approximately $200,000 for this purpose. At that time, there was need in several areas. We wanted to serve people in crisis from all over the country. We also saw a need for training of personnel in existing group homes, and we felt a number of people located in one center would encourage research. At that time there were very few designated PW homes and very little interest from medical centers in meeting crisis needs. We found that the $200,000 raised was not nearly enough to fund such a center and we were unable to interest any states in providing the necessary licensing and foundations to support such an ambitious project. Fortunately, since 1984, we have seen at least 100% increase in the number of beds made available for people with PW in group homes and in specialized programs in larger residential settings. Also, the medical community has developed an interest in providing for people in crisis.

We are also well aware not everyone is being served but the picture is certainly much brighter now than it was in 1984. However, the availability of these added services does not insure the possibility of all people in crisis being served. Even getting to use the services can become a problem when people lack the necessary funding to travel to resources that are available. Because of our inability to use these funds as first established by the fund, the Crisis Intervention and Transitional Committee would now like to redirect usage of this fund. The needs are still there but we must find ways of providing relief. Therefore, our committee would like to place before you the following ideas for the use of this contingency fund:

1) Continue to provide CIT interest for funding the Crisis Intervention Assistance and Training Fund (established in June, 1988). Aiding people in crisis to receive necessary services: a) travel grants to the nearest approved hospital or rehabilitation center; b) intervention grants for families facing crisis situations (for example help while waiting for home placement, short term respite care, educational travel, camping).

2) Funding travel expenses for experts to consult with primary providers for: a) establishing programming and group homes; b) staff development and training; c) continued support; d) long range follow up.

3) Establish a mechanism for loan of CIT monies as collateral for startup funds in the development of quality group homes.

We are very fortunate to have a fund of this size available that we feel could be used to benefit our children and families in need. Because of our continued volunteer involvement, PWSA has a history of using our donations much more for individual needs than strictly to cover administrative costs. We hope changing the direction and focus of this CIT Fund may make it easier to continue to raise money for this service fund. You, as members and donors, have a responsibility and right to consider this change of focus. We need your input, your feelings and ideas, so the committee may present a proposal to the Board of Directors for their approval.

*-- Dorothy Thompson, Marge Wett, Committee Members*


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## *President's Message*

Over a week ago Marge Wett called to request that I attempt to get this letter to the office by last week so that the Gathered View could get off in time. I answered in the affirmative with the complete expectation that there would be time to make the response honest. After all, the world is filled with good intentions. Be that as it is, I am now over a week late and contrite, but unaccomplished in the task.

It has however been a full, interesting, challenging and emotion-filled week of delaying many tasks. Saturday morning a local Disabilities Board sponsored a presentation on the review of California's underlying, enabling legislation for the disabled. We were able to make a short presentation to the State Senator that carried the Senate Resolution that will cause this review. The fear of more loss of service if the current laws are altered is shaking the California disabled more than a 7.0 on the Richter Scale. The encouraging aspect was the legislative declaration in favor of strong grass roots input. Now we must respond with the grass roots effort. The remainder of the day was spent at two weddings. Linda and I haven't been to a wedding in five years only to have the children of close friends both pick the same day two hours apart for their flight from the nest. There is something deeply moving about seeing a new generation take flight.

Sunday found me exercising my tractor and sickle bar mowing the Canadian oats that surround our house. We live in the semi-rural San Francisco foothills and the dry fire season has arrived. Of all my fears, I am certain that the fear of being consumed by fire lies the deepest. The great feeling of communing with nature one gets cutting swaths across the face of a field of waving grain was displaced by the aggravation of broken equipment limping back to the shed.

Our operating room schedule was as crowded as ever and our three heart surgery rooms fill my day from sunup to sundown. This week was stimulating from the standpoint of keeping the cutting edge honed. One procedure that we do is only performed at a few other centers in the world and the past two weeks the team has done the procedure six times. Another procedure is the implantation of a heart defibrillator (shockers) inside of patients who have had one or more episodes of sudden death and survived. Our hospital's group has now implanted more of these devices than any other team and they kept us humming until the wee hours of the morning.

Tuesday found Linda and I being interviewed by a County Mental Health psychologist in relation to Sarah's IEP

*-- continued on page 11 --*

## *A Doctor Writes*

Henry Harris, M.D. pediatrician, wrote "I consider myself a reasonably smart doctor, and I try hard to be sensitive, perceptive, a good listener. But even sensitive doctors can slip sometimes. One morning, trying to comfort the mother of a child with Down's syndrome, I murmured, "I know just how you feel." She looked up slowly, Instead of appreciation in her eyes, I saw anger. "No, you don't," she snapped. "Only one person understands how a Down's parent feels -- another Down's parent!" She was right, of course. I realized that though I'd worked with other Down's families, I could never fully understand such parents' day-to-day sorrows and frustrations. But there was something I could do to help. Many years earlier, still new to private practice, I'd found myself with several insulin-dependent diabetic children on my hands, aged 10 and 11, all of whom had failed to get their diets and disease under control.

Their parents preached to them. I preached. Nothing had worked. But then I thought of a teen-age diabetic in my practice who was a model of self-discipline. Why not bring him together with the younger kids? It worked like one of Merlin's charms. They hadn't believe my sermons--I didn't have to jab myself daily with sharp needles, or say No to birthday cakes and chocolate fudge sundaes. But they believed 14-year-old Jeff, who spoke from personal experience. After two or three meetings, compliance was no longer a problem.

Something similar had occurred a few years later, when I found four children in my practice with colostomies. They felt "different" and depressed. I had them meet with an older youngster who had the same problem and was managing it well. I knew they'd be fine when the quietest of the boys remarked after the third session: 'I'm glad to know there are other kids like me. I thought I was the only one.' Shortly thereafter, I'd had great success using a support group to deal with one of the most terrible aspects of a pediatrician's practice -- crib death. How do you explain to a heartbroken mother and father a disease that has death as its first symptom?" The doctor went on to discuss other incidents and how he become active in organizing parent support groups. He concluded with " the biggest dividend is enjoyment. There's a lot of tedium in pediatrics. Support groups keep my practice vibrant. And they take care of so many parents' questions that they've modestly reduced my night calls." His closing line, "What do I do when Wayne is screaming and he's just dropped my pearls down the toilet?" I told her. "Save the jewels."

-- condensed from *Medical Economics,* July 18, 1988)

***Overseas Young Man Seeking Pen Pal***

Michael Gardener, 1 Acton Place, Avondale, Auckland, New Zealand. Michael is 33 years old. (postage: 1-2 pages 44 cents; up to 5 pages 88 cents, airmail)

## *11th Annual (1st International) PWSA Conference: July 20-22 in Calgary, Alberta*

Those dates are approaching fast! (Summer's really flying isn't it?) It's not too late to still attend this meeting, but we'd certainly appreciate receiving those registration forms as soon as possible to make our plans easier. The pre-conference day is July 19th. Scientific presentations, Group Home personnel session, and Chapter president's meeting will be held. The regular meeting starts bright and early Thursday morning. The Canadian host committee wants all of you to come to sunny Alberta and enjoy the fabulous scenery, as well as experience the support that comes when friend share their concerns and their solutions, as well as learn what is new in research - dealing with PWS. The Youth Activities Program includes:

- Prehistoric Day (Thurs.): starting with a visit to their unique Prehistoric Zoo, creative environment workshop in the afternoon and topped off with a bingo treat in the evening.
- Pioneer Day (Fri.): a visit to Heritage Park with a cruise on the sternwheeler, afternoon entertainment including a demonstration and practice for the big Square Dance that evening which will follow the annual banquet.
- Present Day (Sat.): includes such fun things as bowling (for the over 13 set) activities and swimming for the 6-12, and an entertaining afternoon.

If you are arriving early or staying on, there are many attractions around the city and more within easy driving range. Calgary, the "Foothills City," is 3450 feet above sea level, at the western edge of the prairies, 180 miles north of the US-Canadian border and an hour's drive from the Rockies. Banff and Lake Louise are 1-1/2 to 2 hours west, the Tyrrell museum of Paleontology is 1-1/2 hours east. If you have the time there are tours to Banff and the Columbia Icefields in the Banff-Jasper Parkway. Information will be available in the Hotel foyer and at the PWSA registration table. If arranging transportation is a problem, give us a call.

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## *Exercises: So Vital For Our People!*

Many exercises are recommended to promote coordination, strength and endurance, and enjoyment. Walking, bike (trike) riding, hiking, horseback riding, roller skating, dancing, soccer, swimming, bowling, golf - just to name a few, are good methods of keeping your son/daughter busy (and so much more fun when done with other people). Since these cannot always be done several times a week, supplement the activity with exercises that can be done in the home. Make exercise play time - not a must do, dreaded time. Walking or biking - use a map, keep track of your miles, travel from your city to another location. Swimming - chart actual time in the water, time or distance swam, time a lap, chart to see improvement. Dancing - learn new dances, check your library for instruction books. Bowling - bowl with one person not three or four so exercise is more consistent.

Name your exercises: Lie prone on stomach, raise arms, head, legs - make swimming motion. Call this one "Jaws" - hum the jaws music for background, starting slowly and increasing rhythm. Play catch, rolling ball back and forth while lying prone. Call this "Name That Bone," start by aiming for foot bone, then ankle bone, progress up body. Throw a ball in the air and catch it. "Helicopter" - start your motor, get ready, take off (throw), watch the blades go around, landing time (catch). Now be the helicopter yourself - sit in chair, elbows straight, stretch arms straight out. Bend at waist, lean to the left, then to the right. Do maneuvers, twisting and turning. Then the helicopter lands and you turn into a boat. Stretch arms out with hands in fists, bend elbows, row yourself.

"Here Comes the Rhino" - sit and roll hips, then sit-walk. Work on wrist movements, hand strength PRETEND "Tooth Brushing Time for the cat or dog." Stretch out arm, bend wrist, pick up (pretend) tooth paste, squeeze on brush, twist around getting all the teeth, did you get the ones in the back?, turn every which way, remembering to keep squeezing-don't let go of that brush! Then, I'm so good, I can do this left-handed.

In Minnesota (and we understand some places in the East) it's mosquito time. Stand, pretend it's flying all around you - extend arms straight out, slap all around you to get that guy.

To be of any benefit, exercises should be done 20-30 minutes at a time and at least four times a week. Most exercises that can be done by persons with PW are the variety that burn 3-5 calories per minute. All experts agree, diet is not sufficient, is must be accompanied by a good exercise program.

## *Is It What We Say and Do?*

Do you consciously develop a positive attitude about persons with disabilities in your children? Naturally we cannot know how our words and actions in other matters transfers to our children, but it certainly wouldn't hurt to think about it. A recent story brought up this thought:

A rainy day project of cleaning out the toy box found the mother tossing away Skeletor because his legs were gone and Stinkor because he didn't have arms or legs. A second thought brought the mother back to retrieve the figures saying, Skeletor is a paraplegic. He can't use his legs but the rest of him is just perfect. And Stinkor is a quadraplegic. He'll need some special help to ride Attack Track. Later the son asked the mother, what if somebody lost their head? The mother replied that would be sad. She later overheard her son explaining to a friend that he had a paraplegic, a quadraplegic and a sadaplegic. We don't have to throw them away, see they still can do things.

Lack of self-esteem is frequently mentioned in connection with older persons with PWS. Maybe this is something we have to work on a bit more, particularly with weight and athletic ability.

## *Newspaper Sharing*

We recently received a clipping from a family in South Carolina, written about their four year old son including a darling photograph. The family said they were glad to be able to inform the public somewhat about the syndrome. In response one woman called them and asked for information on how they were able to control their son's diet, another doctor called and asked if he could share their name with a family whose infant child might have PWS. The parents also wrote that so far their son hasn't been too much of a trial. He has only slight learning delays and they have been able to keep the weight in check. We would, however, appreciate any hints on toilet training from other parents as he doesn't seem to want anything to do with it. They concluded with "Thank you for all the support your organization provides."

## *Disability: Life-Style, NOT Life Sentence!*

Parents writing of their lives with a child with a disability frequently write "they would do it over again". How typical is this attitude? Is it real? A recent article from the Beach Center on Families and Disability, The University of Kansas talked of research along this line to answer these questions. Do rewards outweigh the frustrations? Are the benefits real or are these families simply trying to put the best light on their situation? Positive contributions the person with a disability had made to others include joy to the family, learning life's lessons, love, blessing or fulfillment, pride, strengthening the family. Families report developing more tolerance and appreciation of their own health, growing in patience, humility, compassion, closeness, acceptance, and understanding the true values of life.

Are these benefits real? What scientific evidence do we have for their existence? According to the Beach Center researchers, the reality of the benefits is not the issue, because research show that it is the way families react to events rather than the events themselves that determines how well families function. Thus, families who see benefits from their experiences are likely to have greater levels of well-being than those who see only problems, regardless of whether the benefits can be proved to exist. Having a family member who has a serious disability is not an experience that most people seek out but it can strengthen a family. Certainly it is not desirable to create a new disability label by implying that families who do not see the positives described are somehow deficient, rather, it can be useful to acknowledge and learn from the many families who accept the reality of a loved one's disability, yet who see that person as a contributing family member.

## *Nutrition Intervention*

Education of the parent or caregiver regarding the temporary failure to thrive with subsequent obesity should begin in infancy when the diagnosis is confirmed. Higher-calorie formulas and an oral motor stimulation program may be needed temporarily to provide adequate nutrients for growth. However, close follow-up is necessary to detect if the infant or child develops excessive eating behaviors which may lead to obesity. As a part of well-baby care, the parent or caregiver should meet regularly with the nutritionist for dietary counseling in order to plan a diet which will meet nutrient needs and prevent excess weight gain. Referral should be made to a specialty team (when available), which included a nutritionist and a behavioral specialist. The team can meet with the family to develop a plan to prevent obesity. The plan should include...a diet adequate in nutrients to allow for optimal growth and development; 1,000-1200 mg of calcium per day is recommended during childhood, and 1200 mg during adolescence...a diet that limits energy intake to appropriate levels...strategies to restrict food intake (such as locking refrigerator and cupboard doors and denying access to pet foods)...measures to insure that not only the family but also teachers, neighbors, and even bus drivers understand the need to restrict the child's food intake. ..steps to control the undesirable behaviors that the child develops when food is restricted. ..encouragement of the development of desirable behaviors, such as decreasing food requests and increasing physical activity.

### *Monitoring and desired outcomes*

The status of each child with PWS should be reviewed periodically, to be sure that he or she: ...participates in daily exercise program of specified type, frequency, and duration...consumes a variety of low-calorie foods...maintains or achieves constant and expected growth rate: between the 10th and 90th percentiles length for age during the first 3 years, and following channel on PWS charts from 3-23 years...maintains or achieves appropriate weight for height: for infants up to 12 months, between 10th and 50th percentiles weight for length; for children over 12 months, between the 10th and 75th percentiles weight for height...takes vitamin/mineral supplements (including calcium) regularly when reduction in food intake prevents the child from obtaining the Recommended Dietary Allowances (RDA) for individual nutrients. In addition, during the periodic review, the nutritionist should be sure that the family sets limits on food intake and makes appropriate menus substitutions.

*-- from "Nutrition Care Guidelines for Nutritionists," Sarah McCamman, M.S.,R.D., University of Kansas Medical Center*

## *Some "Before" and "After" Photos That Inspire Us All!*

One of our overseas members shared pictures of their daughter, taken in 1985 and 1988. We asked, how did you do it? The answer was "Much movement/activities and as little calories as possible. Sports activities, being strict, and having a lot of patience and good nerves."

## *Living Guidelines*

Here are 10 guidelines for Living with a child with PW:

1. Accept your child's limitations. Be tolerant and patient.
2. Provide opportunities for the development of muscle tone - long walks, for instance.
3. Keep home life organized. Keep mealtimes, chores, and bedtime consistent as possible. Household routines help him accept order.
4. Avoid fatigue. Exhaustion can break down the child's self control.
5. Avoid gatherings where the child's behavior would be inappropriate, embarrassing, and extremely difficult for a person on a restricted diet.
6. Maintain firm discipline through a few simple, clear, important rules - with others added only as needed. Avoid unnecessary rules and constant "Don't do that" with pre-planning.
7. Enforce discipline by sending the child to a quiet room.
8. Build up his ability to retain information in his memory. Read to him, color with him, play games of gradually increasing difficulty. Matching pictures is an excellent way to train his memory. Don't have so many toys around that they distract him.
9. Protect the child against overreaction by neighbors. He must always feel accepted by his family. For example, the weight gain is not acceptable, but it's the weight not that he is not acceptable.
10. Get away from time to time by having a babysitter or respite. If not possible take turns between parents, sharing responsibility for the child's care.

(Adapted from "10 Guidelines for living with a hyperactive child, Pediatrics.")

## *Shared Recipes*

Maria Ferraco, Residential Rehab, shared some of their "Green-Go" (meaning minimum calorie foods) recipes with us:

*Eggplant Salad*

2 Medium Eggplants (peeled and sliced thinly), 1 Medium Onion (peeled and chopped), Fresh Parsley (snipped), 2 Large Stalks of Celery (chopped), 1 T. oregano, Fresh garlic or 2 tsp. powdered garlic, - c. wine vinegar, c. soy sauce, 2 T. Lemon Pepper. Chop and peel all vegetables, then combine all ingredients.

*Frozen Fruit Cup with Berry Sauce*

2 c. Pineapple chunks, own juice, 2 c. Fresh or frozen plain strawberries, 2-3 small bananas, sliced. Sauce: 2-3 c. Frozen Blue or Blackberries, 2 T. cornstarch, 1 T. fresh lemon juice with grated peel, Diet sweetener to taste. Cook and stir berries and cornstarch until mixture thickens and bubbles. Add the sweetener and lemon juice.

## *Election Time!*

The annual election for members of the Board of Directors takes place during the conference. This year five positions are open. Three of the present board members have expressed their desire to serve another term on the board. Additional nominations may be made to the national office prior to the meeting or on the floor during the business meeting. The requirements include asking the person's permission to submit their name and their acknowledgement that they must attend two yearly board meetings at their own expense. If you cannot be present at the conference you may use the proxy ballot that appeared in the last newsletter. That same issue contained a couple of paragraphs from Lota Mitchell and Janalee Heinemann expressing their desire to remain on the board. D. J. Miller submitted the following request:

"I would like to continue serving as a member of the Board of Directors of the PWSA. Having worked with many other PW families in the Midlantic and PA PW associations, I feel there is so much to be done to aid the PW family.

A PW Development Committee has been meeting in PA to establish a model PW home. I am serving on that committee. The home will open this summer. Having attended all previous national meetings, I feel a strong commitment to do what I can to enhance and preserve this organization. I am serving on the Investment Committee and the Long-Range Planning/Fund Raising Committee of the Board. I would consider it a privilege to have the opportunity to continue these endeavors."

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## *Exercise Tape*

"It's Never Too Late" is the title of a video tape that presents an exercise program for older adults in Special Olympics. Whether or not the Olympics are the goal, this is a generally useful too. It is accompanied by a small booklet which helps a group leader develop a program based on each individual's own level of fitness. To order, contact Elizabeth DeBrine, The Shriver Ctr., 200 Trapelino Rd., Waltham, MA 02254 or (617) 894-3600. We do not know the price or how helpful this would be for PWS use.

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## *Don't Say Can't!*

Over the past several years, there has been many physical activities I longed for my daughter, Heather, to be able to do. However, as everyone is well aware, because of the low muscle tone, and the variety of other characteristics associated with PWS, I thought she would never be able to. This year, thanks to a very supportive school district, Heather now bowls. And thanks to a wonderful volunteer organization called Shared Adventures, Heather learned how to ski this winter. I can't begin to tell you what an accomplishment this has been for Heather, and what a wonderful feeling, as a parent, this has been for me. A word of wisdom...don't say your child can't do something until he or she tries it first.

## *Conference Fund Raiser*

The past few years, PWSA has held a fund raiser to supplement our conference monies. This has been held in order to keep our registration fees affordable, to continue to offer great programs, as well as offer conference grants. This year we are trying a new technique to raise some additional money. We are offering a 1990 Pocket Calendar which you can purchase for a donation of $10.00 U.S. ($12.00 Canadian). When you purchase this calendar, your name will be entered for several cash drawings. Early purchasers will be eligible for a $50 drawing in August, and then three additional drawings for $150 each will be held in January, February and March of 1990. These Pocket Calendars can be purchased as gifts (you can enter your own name for additional chances for the drawings or enter the name of the recipient of the gift), sold to other people, or just for your own use. If these are obtained through an official chapter, or the chapter name is supplied at the time of purchase, we will rebate $1.00 of the purchase price to your chapter, making it a fund raiser for you as well as for us! We hope you all will support our efforts by placing an order for several calendars today.

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## *Pocket Calendar Order Form*

Name:_____

Address:_____

_____

Please credit the following chapter:_____

Number of Calendars:_____ Enclosed is $_____

(Calendars are U.S. $10.00 or Canadian $12.00 each)

## *President's Message* (continued)

for the coming year. That is the kind of experience that seems to provide a strange mix of adrenalin and humble pie covered with a crust of fear and ignorance. I walked out the front door of the building with a headache that was thaaaat big! I didn't know whether to cry or punch a wall. This has all been the result of a special ed teacher threatening to flunk Sarah out of her class because her performance wasn't up to class standards -- try that on for size in the stupidity contest.

Friday was a day of joy! Our daughter Heather graduated from the eighth grade and the build-up in our school district was beyond my imagination. I didn't get that worked up and excited when I graduated from college. I don't even remember an eighth grade graduation. After Heather took care of her horses it was back to school for annual signing and general awards and she started with her share (I'm sorry you will just have to put up with a proud papa). The afternoon was in preparation for the later events which started by mid-afternoon. All of a sudden those little kids are physically reaching maturity, that is when eyeball to eyeball means looking straight ahead or upwards. Heather even wore a dress that her mother used as a senior in high school when she was elected to the national presidency of the Future Homemakers of America at a ceremony in Washington, D.C.

Saturday was another day in the OR capped by a surprise going- away party for Sarah. Next week her mother is taking her to a summer camp and seven week school session at the Institute of Logopedica in Wichita, Kansas. We had the pleasure of visiting the IOL with Sarah a month ago. We are looking forward to an outstanding experience for Sarah during her first stay away from home. It will also be the first respite that mom and dad have had in seventeen years. The party was given by a group of people who have come to know and love Sarah as Heather's greatest booster during the numerous Hunter-Jumper Horse Shows we have attended on the West Coast over the past five years.

I guess all I really wanted to share with you was how lucky we are to be alive, to be able to work and to live and to enjoy the world. And living with Sarah has made each of those enjoyments sweeter, more valuable and more lingering. Being the parent of a person with disabilities seems to wring a little more joy out of being alive.

*-- Delfin J. Beltran, M.D.*

## *The "Sharing" Part of Caring and Sharing*

PWSA is happy to share that we have enabled a parent to escort their son to an out-of-state placement through the CIATF fund, and are in the process of helping another parent with the same fund. We have also chosen the family to help to attend this year's conference through the Conference Fund. A recent calculation puts our time and spending as 83% Program, Services, Education; 14% Management (working with the Board, keeping accounts etc.); and 3% in Fund Raising. These figures are exceptional for any organization.

## *Management Book into Second Printing*

We are happy to report that a second order has been placed with the publishers for our latest book "Management of PWS", and many of the first printing were sold to non-members and professionals. The increased interest in this syndrome the past few years is very heartening. Over the past few years we have added a number of educational materials to our order form. If you are an older member and have not seen our listing recently, please let us know and we will share a copy with you. The Library also has materials that can be borrowed including: "A Difference in the Family," Featherstone; "Some Just Clap Their Hands", Mantle, (raising a handicapped child); "Reach for Fitness", Simmons; " Alternatives", Russell (legal guide); "Strategies", Shields (guide for dealing with professionals and systems); "Living with a Brother or Sister with Special Needs", Meyer et al; "Special Diets and Kids", Taylor and Latta; "Meeting the Challenge of Disability or Chronic Illness-A Family Guide", Goldfarb et al.

## *Record Keeping*

A recent change of officers in one of our chapters brought forth an offer PWSA made some time back. We are very happy to maintain a file for your chapter that includes a copy of all of your important papers, such as incorporation articles, bylaws, I.D. numbers, etc. so when years pass and officers change, important information is not lost. Just send us a packet and it will be filed.

## *Our Supporters*

The end of April, month of May and first half of June added $3030.89 to our Research Fund, CIT Fund, and Operating Fund.

- RESEARCH: Distr.65UAW, Kellerman, Richarz(2), Sojka (Uzendownski), Tobin, Boyd(2), R.Maurer(2), Weiner (Kandall), Congregational Church, Elliot (Senske), Sunlighers, Kappler Meml. (VandeWalker, Struve), VanZomeren, Reisenman, Rochester Coke, and Moss.
- CIT: Olson(2), Sharp, Braunreiter, Levikoff, Kass (Briar College), Wett (Schaefer), Curnell, Wagstrom (Viking Kiwanis), Clarissa Miller Memorial (McGuiness, Hahnefeld, Cunningham, Feliksa, Baum, Dean(2), Brinkmann, Throop, Thome).
- OPERATING: PW Utah, Tobin, Boyd, and Mitchell.

And a special thanks to PWSA/PA, Midlantic, and Carter for their donations toward the new brochure development.

*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 Blvd., E-102, St. Louis Park, MN 55426. Any questions? Call us at (612) 926-1947.

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