



# *The Gathered View*

*for the Younger Set*

Newsletter of the Prader-Willi Syndrome Association

**JULY 25-27**

**IN CHICAGO**

It's hard to believe we are coming up so quickly upon another annual conference. The folks in Illinois have been working diligently for quite some time now preparing for what will be another great conference. The pre-conference registrations will be in the mail shortly. (If you have not received your pre-registration packet by the end of April, please check with National). We look forward to people registering early in order to assure we have enough volunteers lined for our Youth and Young Adult activity programs.

Registration cards will be included with the packet, make your reservation early with the Hotel. As in the past there will be a Pre-Conference Scientific day, on Wednesday, as well as a group home personnel workshop, and the Chapter President's meeting. The regular conference schedule, Thursday through Saturday, will allow you to hear a synopsis of these meetings. We hope to meet all needs -- offering presentations for parents of younger, school age, teens, and adult children with PWS and professionals. The agenda will offer things for everyone from first time attendees to those who have attended many times before.

Volume VI ~ Number 2  
March - April, 1991

In this issue:

You are not alone

2

Angel Fund tops \$23,000

5

Membership voting

6

Camping

10

Circles

11

## YOU ARE NOT ALONE

**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.

Marge A. Wett, Executive Director

*Board of Directors*

*Chairperson:*

Lota Mitchell, M.S.W., Pittsburgh, PA

Stewart Maurer, Buffalo Grove, IL

D.J. Miller, Doylestown, PA

Suzanne Cassidy, M.D., Tucson, AZ

Louise Greenswag, Ph.D., Davenport, IA

Janalee Heinemann, M.S.W.,  
 Maryland Heights, MO

Penelope Park, Oklahoma City, OK

Barbara Whitman, Ph.D., St. Louis, MO

Mildred Lacy, Louisville, KY

June W. Smith, Enfield, CT

Curt J. Shacklett, AAL, Tulsa, OK

Frank W. Moss, Camarillo, CA

*Officers*

Stewart Maurer, Vice President

Fausta Deterling, Secretary

James G. Kane, Treasurer

*Scientific Advisory Committee*

Vanja Holm, M.D., *Chairperson:*  
 University of Washington

Bryan Hall, M.D., University of Kentucky

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

David Ledbetter,  
 Baylor College of Medicine

Stephen Sulzbacher,  
 University of Washington

Louise Greenswag, Ph.D.,  
 University of Iowa

Barbara Y. Whitman, Ph.D.,  
 St. Louis University

The process and reactions parents face upon learning their child is disabled, or that "there is something wrong" can be paralleled to the process of grieving.

**Common reactions:** After the initial shock and disappointment in learning your child is not a perfectly healthy child, the reaction is that of denial. Denial which rapidly merges with anger. Anger directed at the medical personnel, a spouse, or anyone around. Given our society allows men to express their anger much more than women, men tend to lash out at their spouses or other children.

Another common reaction is fear. Fear of the unknown for the future, and unknown in some cases, the cause. Adding to the fear for other members of the family or fear of ever having another child. Many parents first thoughts are very bleak and filled with searching for explanations. An accompaniment to the fear is guilt. Guilt over possible reactions to handicapped persons in the past. Guilt over thinking the parents caused the condition, maybe they did something wrong while the child was yet unborn. Maybe God is punishing me.

Confusion often accompanies these other feelings, it is difficult to comprehend what others are saying, it is almost impossible to ask questions when you don't understand new terms and ideas being presented. You are torn between wanting to know everything and yet on the same hand not wanting to know anything because you already have too much mental stress or strain. The feelings of powerlessness and disappointment may be too overwhelming.

In order to alleviate the mental stress the next reaction is rejection, shut everything out. It is not uncommon to wish the child were dead, or wanting everyone to disappear.

Not all parents go through all these reactions or stages, but it is important for parents to identify with all the potential feelings, and know they are not alone in dealing with them. Once feelings are identified there will be a time to start constructive actions. Seek other parents who can identify with

## WHO ME?

Each of us has volunteered time and efforts into various projects in our lives. Have you ever sat back to take a look at what made that experience either uplifting or a total nightmare? Well, if you're thinking about it again, here are some tips and guidelines for you to consider.

When looking for volunteers:

- Comprise a list of those individuals whom you feel would be great to fulfill your need. Include everyone whether you think they would ever do it or not. Prioritize the list, not necessarily one by one, but maybe by groups of A,B,C.

- Write out a fair "job description" of what they will be asked to do, be sure to include how many they may be working under or how many will be working under them.

- Write down your reasons for thinking this person would be good for this job.

- Start contacting people (your top priority ones first), tell them who, what, where, and WHY you are asking them. A number of people are very willing to set aside time to volunteer they just need to be asked.

- If they turn you down ask them if there is anyone else they would recommend.

People are much more willing to take on a task if they know exactly what it will entail, the time commitment involved, and why they were asked to take the task on.

Next time you are asked to volunteer, if whomever is asking cannot give you most of the details, tell them exactly what you will commit to doing, it is your time.

Some of these same principles pertain to when you are asking for money as well.

It is much harder to turn down a plea which states this money will go to opening a group home for 12 young people, than it is to turn someone down who says our nonprofit organization needs money.

Explaining the reason for your request is a compliment to the people you've asked to carry it out. It shows them you have confidence in them and you believe they are rational thinking people.

### "Calorie-Reduced" Salisbury Steak

1-1/2 lbs. ground round  
 1 c. finely chopped onion  
 1/2 c. cooked long-grain rice  
 1 egg white  
 Vegetable cooking spray  
 1-3/4 c. presliced fresh mushrooms  
 2 T. Worcestershire sauce  
 2 (13-3/4 oz.) cans no-salt added beef broth  
 2 T. cornstarch  
 Combine meat, onion, rice cooked without salt or fat, 1/4 tsp. pepper and egg white, stir. Divide into 6 equal patties, 1" thick. Coat skillet with cooking spray, heat to 320 deg. Cook patties 5 mins. on each side. Drain on paper toweling, set aside, keep warm. Wipe drippings from skillet, recoat with spray, cook mushrooms at 420 deg. for 3 mins. Add sauce, salt, broth, cook at 420 deg. for 10 mins. Return patties to skillet, cover, reduce heat and simmer 15 mins. Place patties on platter, keep warm. Combine cornstarch and 3 T. water, stir, bring to a boil, cook 1 min. Serve over patties. 227 calories per serving.

## ADVOCATES-TRUSTS

One of the issues currently being discussed by the Board of Directors are the concepts of establishing estate trustees and advocates. National will be sending out a survey regarding your interest in these concepts, but thought it might be useful to do some explanation prior to sending the letter out. Even though it has been discussed and investigated for a couple of years, we are still uncertain if there is enough interest among our membership to make it worth the time and effort to further explore the concepts.

The first concept: establishing the process of having a list of available trustees. Those who would not name another family member as trustee could have someone with knowledge of PWS to supervise the trust or care of their child.

The second concept: an advocacy fund that could operate to look after those persons with PWS who no longer have living parents/relatives. This advocate would be responsible to supervise placement, fund needs not covered by outside funding (such as vacations, camping, larger purchases, etc.) Expenses for this supervision and actual funds expended would be contributed to an advocacy fund for this purpose. Unfortunately these are not simple procedures, but PWSA is willing to offer these services if enough people are interested.

## NEW TREASURER

PWSA is pleased to announce the new treasurer for the national association, Mr. James Kane. Jim and his wife, Kit, are the parents of two daughters, Kate and Molly. Kate is their 9 year old daughter with PW. Jim is very anxious to take on his new role as he has experience in taxes, accountg, and investmts. The Kanes' currently reside in Towson, Maryland. Jim is looking forward to serving the members of the association, and helping PWSA to fulfill its goals.

## KANSAS HOME

PWSA has been contacted by Kay Toothman of Wichita, Kansas who is presently following the procedures to open a private designated home there. She is interested in opening her home to two persons right now while working on the home. Kay's PW experience stems from the Institute of Logopedics. Kay can be contacted at 4801 Kimberly Lane, Wichita, KS 67204. (316) 838-4254

## INTERNATIONAL MEETING

May 2 and 3rd have been scheduled for a Research Workshop and May 4 and 5 for Parents and Professionals, at the De Leeuwenhorst Congress Center, Noordwijkerhout, The Netherlands.

If you are interested in attending, the time is now. Call and we'll drop an information booklet and registration form in the mail for you.

## OUR SUPPORTERS -- OUR THANKS

From mid December thru mid February, we acknowledge the following contributors:

**MEMORIALS:** In Memory of Mary Williams: Kitzing, Olsen, Stromquist, Frank, Schierioth, Krause, Monadnock Dressage Club, Simpson, McIntosh, McMullan, Hammond, Sobe, Pat Peak Ski, Bristol Vet, Emery, Greene, Monadnock Pony Club, Kaiser, and Hammond.

Other Memorials: Curry, Rose, Schmidt (Garafals), School 9 (Lynch), Luhman (Luhman), Evetts (Boyher), Smith (Schulty), Dwelly (Stone), Sojka & Uzendowski (Costellano), Maurer (Fanning).

CIT: Mears, Olson (2).

RESEARCH: Boyd (2), VanZomeren, Leonard, UW Monroe Cty. (Vermeulen), Casey, Miller, & Devine.

OPERATING: Casey, Allen, & Devine.

And a special thanks to our Angels:

CHERUBS: Evans, Cillo, Singer, Schramm, Rattray, Chase, Karlsson, Mackey, Wyka, Wilson, Kokoszka, Pfaff, Lindsey, Melchin, McKeon, Dorn, Gunnison, Buchanan, Martens, Merrill, Riffelmacher, Martin, Adleman, Yoncha, Shapowalenko, MacLeod, Bayless, Ciulla, Bendler, Totten, Geller, Snyder, Harvey, Gemmell, Becker, Armstrong, Marciniak, Redmond, McDonald, Wassell, Seebach, Spsychalski, Dorn, Stephens, Perry, Smith, Kerslake, Gales, Krebsbach, Banach, LaBella, Schneider, Okuda, Kestenbaum, Mackie, Sidlo, Moffett, Brindisi, Bartolucci, Gildea, Leonard, Klein & Fondell.

ANGELS: Tsai, Sidbury, Bush, Pappas, McDonald, Daly, Wolcott, Whitman, Hambrick, Ruen, Moss, Noll, LaPenta, Stratman, Kappler, Klein, Magalee, Eager, Horrigan, Matza, Rohan, Whyte, Proactive, Bolduc, Costa & Abramek.

ARCH ANGELS: Herman, Moran, Francavilla, Tippie, PWS DE, Pathways, Lehman, Houtman, Parcell, Levine, Saddock, Chausow, Lat, Deterling, Krautwurst, Burleigh, Berger, Smith, Plashal, Householder, Howkinson, Persanis, Rykowski, Pflieger, Gurr, McSorley, Miller & Gillen.

HEAVENLY ANGELS: Fuller, Alexander Hamilton Life (Hilgenberg), Bintz, Kane, Carter & Alterman.

We also thank members for Contributing dues: Percy, Benedikt, Kelly, Siegan, Castelli, Gallagher, Klausen, Keaveney, & Schramm.

Patron Dues: Smith, Beltran, Hicks, Zucchiatti, Carter, Greenswag, Goranson, Miller & Alterman.

TOTAL CONTRIBUTIONS for this year's annual fund raiser (BE AN ANGEL) has reached \$23,701 thus far. With the promised \$5,000 matching fund, it will grow to \$28,701. Last year our deficit budget came out in the black due to the annual fund raiser topping \$33,000. As you can see, we are a few thousand short of that total this year. We do hope those who have not sent in their contributions as yet will help us top last year's total.

## BOARD ACTIONS

The PWSA Board Of Directors met in Tuscon AZ the third weekend of January. They are the decision makers for the organization -- they always welcome your input. A brief summary of what was discussed and decided upon:

...The new position of Assistant Administrator was reviewed.

...The President's and Treasurer's resignations were accepted, a new treasurer was elected, the presidential spot will be filled shortly.

...Four board members are up for re-election in July. The Nominations Committee is seeking candidates.

...Grant money for the conference was approved from the conference fund totaling \$4,000. This money assists families in need of financial assistance to attend the Chicago conference.

... A \$25,000 Project Grant from Research was given to fund a genetic program including family occupational studies.

...A motion established a salary range of \$28,500-\$35,000 for the Executive Director's position. The present salary for the Executive Director of \$25,300 is below the established range at the request of the present Executive Director.

...The 1991 Operating Budget was approved:

Total Income Projected:

\$103,000

Sources:

Donations	\$40,000
Member Dues	\$40,000
Materials	\$17,000
Interest	\$ 5,000
Misc.	\$ 1,000

Total Projected Expenses:

\$119,800.

Expenditures:

Salaries/tax	\$68,700
Operating	\$32,100
Others	\$19,000

Total Projected Deficit:

\$16,800.

An election will take place during the July Conference for four members of your Board of Directors. Four positions will be decided by your vote - returning the present members interested in serving another term, replacing them if you so choose, or filling any vacancies created by someone choosing not to run for re-election. The present board is comprised of a combination of parents and professionals, with various areas of expertise. At the present time we have been notified that Louise Greenswag and Barbara Whitman are interested in continuing to serve PWSA in this capacity. Louise was first elected in 1985, re-elected in 1988. Barbara is just completing her first term. Barbara and Louise are both professionals that have contributed a great deal to PWS.

Information on the other two present board members and names submitted by the nominating committee will be included in the next issue along with a proxy vote for those unable to attend the July Conference.

A grant was approved by your Board of Directors to fund a meeting of professionals to establish a diagnostic criteria for PWS. This meeting took place in January, attended by Doctors Vanja Holm, Suzanne Cassidy, Merlin Butler, Frank Greenberg, Jeanne Hanchett, Barbara Whitman, and our Executive Director Marge Wett. A great deal was accomplished in the two sessions held, further refinement will take place and this criteria will be presented at the International Meeting in May.

Our organization is very fortunate to have these well-qualified experts willing to donate their time to the furtherance of published information on PWS.

## NOTES FROM THE VICE PRESIDENT

This issue of the Gathered View has something missing. The missing item is a letter from Dr. Sam Beltran, our President for the past ten years. Sam retired from the Presidency of PWSA effective as of the January Board of Directors meeting. His successor will be named prior to our annual meeting and conference in July.

The wisdom, dedication, inspiration, service, time, advice and friendship that Sam has given to those whose lives have been affected by PWS is immeasurable and appreciated by all. Sam, your leadership will be missed but we know that you will not give up your efforts to further the cause we represent. Thank you, Sam, from us all.

The year 1991 promises to be an exciting and challenging year for PWSA. Your Board of Directors held intensive meetings January 18-20 to approve the operating budget and set the course for the year ahead. Committee reports were reviewed and direction was given for continuing activity in the many areas in which we are involved. The Board accepted, with great regret, the resignation of our Treasurer, Bud Bush. We thank you, Bud, for all you have done for people with PW.

Your Board approved a \$25,000 grant to fund for one year a diagnostic testing program, at the University of Arizona, which will be available without charge to families. This project, we believe, will be extremely helpful to clinicians throughout the country in making a diagnosis of PWS.

As an organization grows, matures, and broadens its constituency, many diverse and divergent opinions are heard. Your Board and Officers have been elected by you to serve the needs of people with PW. The organization started in 1975 with no funds, and few members. Through the efforts of those few and an ever growing number of others, we have become a recognized source of information, support and assistance to people with PW and to those who surround them.

It is our intent to never lose sight of our purpose in that regard. How we go about that purpose is openly and healthily discussed within committees, board meetings and at our annual meeting and conference. Power struggles and selfish motives have no place in fulfilling our mission. Healthy disagreement is just that - healthy.

We intend to move forward, working together, to meet the needs of those we serve. We appreciate and welcome your input, comments and suggestions. Let us hear from you.

STEWART MAURER, VICE PRESIDENT

As has been written many times, PW experts do not recommend behavior medications except to get through "episodes" of threatening behaviors. We have been recently asked to obtain further information on the drug Prozac because it has been successfully used for some of our children.

Prozac (fluoxetine) has received wide exposure and is indicated for all types of depression. It is not an anxiolytic, although many cases relief of depression results in subsequent relief of anxiety. Reports suggest it may also be useful in treatment of other disorders including obsessive-compulsive disorder, panic disorder, bulimia, kleptomania, borderline personality disorder, obesity and addiction although it has not been approved for these conditions by the FDA. PWSA has not heard of the drug eliminating the compulsive eating desires but assisting with behavior control.

Prozac is non-sedating nor does it promote weight gain, compared with other antidepressants. With tricyclic antidepressants, physicians usually administer the lowest practical dose and increase as needed. Tricyclic antidepressants such as Elavil block the reuptake of all neurotransmitters, including serotonin and norepinephrine whereas Prozac is highly selective blocking only the reuptake of serotonin.

The initial dose is 20 mg. once a day, with results not being observed for two to four weeks or longer. Doses are then increased as needed. The most commonly reported side effects include nausea, nervousness, and insomnia. These effects tend to develop early, tend to be mild, and generally do not cause the discontinuation of the medication. Naturally the list of side effects is long, as is true of most medications. Some articles had been written stating more side effects had been seen, while other articles reported the opposite.

## LOWER IQ

## RESPONSE

Parents of PW's understand that IQ's vary. In the past issue information was requested regarding those who are lower functioning, or considered more severely retarded.

These proud parents wrote to tell their stories. One mother writes: Consistency for the behavior is the critical key. IEP meetings are attended not only by the parents but members from the group home as well. Also the reverse, someone from the school attends the six month planning meetings at the home. Behavior peaks when boredom sets in or when requested to do something they don't want to do. If an item is destroyed in a tantrum it is removed and not returned until calmed down. Music is used as a reinforcer. "I have found over the years it has always been left to me as a parent to educate and demand the services that my son and other developmentally disabled people are entitled to."

Another parent writes the biggest problem they face is their foster daughter is stubborn and has odd personality twists. She often demands too much attention or she just sits with a defiant look.

Both parents also stressed how important it is to keep notes and records to remember experiences and working methods.

## HELP IS NEEDED

We are looking for your input in the process of developing a new brochure on finding assistance and services. At the present time we have our directory of services that lists some of this type of information. It has been suggested this information would be helpful in a brochure form.

Unfortunately many states have different agencies and organizations, but we hope to put together a general guideline and possibly have an inserted card for each specific state. If you could write PWSA, 6490 Excelsior Blvd. Ste. E102, St. Louis Park, MN 55426, tell us your trials and tribulations, success and secrets in obtaining services it will greatly help.

## PW MEDICAL MYSTERY

We were pleased to see the three page article entitled: "Medical Mystery Tour: The Girl Who Couldn't Stop Eating" by Karen Ingwell in the University of Pittsburgh Health Sciences Review. This review is designed for a broad range of readers, including alumni of the Schools of the Health Sciences, Pitt faculty and staff, health sciences students, members of the media, federal agency personnel, foundation and corporation employees, and other friends of the University. And we thank Mrs. Sophie Miller for sharing information about her daughter Annmarie for the article.

## GOOD NEWS

Last February, 1990, the New Mexico legislature approved \$200,000 from H.E.D. funds to be spent on services and programs for New Mexicans with PWS. These funds will continue to provide support to PW families for years to come in the areas of respite services, education, nutrition, residential services, etc.

As if this isn't enough, the Medicaid DD Waiver is providing funding for services to three adults with PWS who share a four bedroom home in Albuquerque. Since they moved in, Sept 25, they have lost cumulative 100 pounds, and as most would suspect, are beginning to need completely new wardrobes. Their staff to client ratio during most of the hours they are home is two:three.

This home fits very inconspicuously into the neighborhood, with a household number much like that of the average family. The staff has experienced very few negative behaviors and attributes this to the high staff to client ratio, where there is more opportunity for positive reinforcement and nurturing of self-esteem.

The Association for Retarded Citizens of Albuquerque, who serves these three individuals, are hoping to open another three person home for people with PWS in March of this year. Let's hear it for New Mexico!

by Debbie Pierson

## ASSISTANCE GIVEN

## MOTION NOTICE

## MOTION TO MEMBERSHIP

The membership bylaws require any motion for the general membership be published three months prior to the general meeting held at the conference in July. Votes will be counted at that time including those votes received by mail as proxy.

Submitted by Gene Deterling  
As one of the founders of PWSA I feel it is appropriate to submit the motion below to the general membership. It relates to reimbursement of meeting expenses incurred by the Board of Directors and Officers. I am submitting it now because I am no longer a Board member or Officer and therefore have no conflict of interest. The motion is being submitted because I believe it is necessary to hold and attract members to the key positions in our organization without burdening them with significant expenses. Since our beginning we have had to have as one of the criteria for these positions that the person be able to afford meeting and travel expenses. Since that is limiting to the selection of candidates, I think we should do as any other organization does by reimbursing at least a portion of incurred expenses.

## MOTION TO THE GENERAL MEMBERSHIP

Whereas the members of the Board of Directors and Officers of PWSA must incur inordinate expenses because of travel to the two Board meeting locations each year and

Whereas the currently unreimbursable expenses make it prohibitive or undesirable for some members of PWSA to consider becoming candidates for the Board or Officers

It is therefore moved that the Board of Directors and Officers (President, Vice President, Treasurer and Secretary) be reimbursed for reasonable Board Meeting expenses up to a maximum of \$500 for each member per calendar year.

Dorothy Thompson recently traveled to new designated PW group homes in Delaware and Maryland. She will also be traveling back to Kentucky in March. We are pleased that these homes are interested in garnering all of the information they can to make them successful in serving the needs of the residents.

We are happy to report the St. Luke's Washington Place home opened in January in Southern Illinois. There was a delay in opening due to the suggestions of Louise Greenswag and Marge Wett after their visit, structural and programming changes.

## OHIO MEMBERS

Do you want to activate your Chapter again? With the purpose in mind to meet the residential needs of your children? PWSA will arrange and conduct a meeting if enough people respond that this is desired. Let us know.

## CAMPING

As the snow is blowing on this Valentine's day in Minnesota, it is difficult to think "CAMP", but registration time is here. Choosing the right camp for your son or daughter is important with this syndrome. Many parents have written that a week of camping meant ten pounds of unneeded weight - my daughter was very unhappy camping, none of the activities were at all interesting to her - no one was willing to even read about the syndrome to make this a positive experience for him. PWSA does have a camping list, just drop us a line and we will be happy to share it with you. We also would like to list a few camps that have had "glowing" reports:

Camp Wonderland, Rocky Mt., MO  
(314)392-8886

Camp Sky Ranch, Blowing Rock, NC  
(704)264-8600

The Rehabilitation Institute of  
Pittsburgh, PA (412)521-9000  
Trade Lake Camp, Grantsburg, WI  
(612)777-3522

CONTINUED FROM PAGE 2

your experience. These parents are often helpful in providing that first light of hope, that the world is not so bad. To be assured there will be programs and assistance all over the world is a comforting thought. The hope that no problem ever need be faced alone. Pain divided is not nearly so hard to bear as is pain in isolation. The idea begins to warm you into thinking about how special this child will be in your life, continue to see things which will happen day to day. Living with the reality of the day which is at hand is made more manageable if you throw out the "what if's and "what then's" of the distant future. Life is better when you are feeling positive. Remember though you will need to be prepared for the future.

Seek information, be informed of the future, and learn the terminology you will begin to be faced with. Some parents seek tons of information, but try to assure it is accurate information. Don't be afraid to ask questions, not everything is in written form. Write down questions, for appointments, for specialists you may encounter. It is the best idea to have a book or notebook to keep information together, and have accurate information for the future.

Your attitude is the most important thing to continue working on. There is always a positive side or outlook to even the bleakest situations. Such as keep in mind how healthy your child really is. Recognize there are some things in life which just cannot be changed and others which can be changed, set your sights on them. Don't be ashamed of having to take very good care of yourself, including taking time away from being with your child. Produce a sense of normalcy and consistency when life is hectic by handling problems as you have in the past.

The final thought to always bear in mind the fact you are not alone in this world. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love

and parenting. Love and enjoy your child, as well as discipline them. The child comes first; the handicap second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

(Paraphrased from the National Information Center for Children and Youth with Handicaps by Patty McGill Smith. You are Not Alone: For Parents When they Learn that their Child has a handicap.)

## PEN PALS

"Circles" began a number of years ago from member requests to write to other parents sharing their day to day lives, trials and tribulations, joys and experiences. The circles continue with three or more individuals connected by the national office. The circle operates as such, Person A writes to B, person B then writes to C including a copy of person A's letter, person C then writes to the national office including copies of A's and B's letters, National then continues the circle by writing to person A.

Recently it was requested to begin a circle for parents of infants to school age. If you have interest in being part of a circle please contact the national office and we will be happy to begin the circle (or circles if necessary!). Sharing provides a special personal support to those who live in states with few members, or states where chapters are not yet formed.

## CONFERENCE GRANTS

Each year PWSA attempts to operate the Conference on registration fees. Since all of our Conferences have been well attended, we have managed to accumulate some funding from year to year. Several years ago the practice was started of awarding grants to families who could not financially afford the cost of attending a Conference. Any member may submit a request to be considered for a grant. If you are interested, you need to submit a written request for assistance. The more information you can share, the quicker your application can be considered. Those eligible will be included in a random drawing which will be held in April. This year the board has approved the expenditure of up to \$4000, so we may help two or three families. Applications could also be submitted to the Crisis Fund if a Crisis situation could be helped by Conference attendance.

We would greatly appreciate any submission. Deadline April 1st.

*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*