

# THE GATHERED VIEW

## ewsletter of the PRADER-WILLI SYNDROME ASSOCIATION

JANUARY-FEBRUARY, 1989

VOL. XV, NO. 1

# 1988 is History

With the close of another year, we need to reflect

What has been accomplished this past year?

What are our future goals?

Are we meeting the needs of our membership?

Despite the lack of unlimited funds, we believe PWSA continues to move forward in giant steps. (PWSA, not only in the sense of the national office, but all of the membership.) The reason has to be the foresight of our founders, the interest of our professionals, the dedicated efforts of our volunteers, and the fact we have such great people to work with. Think back over the past year; what would have been accomplished if you had not put effort into your goals? Many members of PWSA have put forth a great deal of effort and it is not difficult to see what has been accomplished.

It is difficult to single out one major accomplishment because it would be unfair to all the other efforts expended in many different directions, but the efforts put into the publication of our new book, Management of Prader-Willi Syndrome, must be very high on the list. The foreseeing of the need for this book, and the many hours donated by the editors and contributors, have already affected many people.

Many projects, some already underway, will be completed as the year progresses. The membership continues to grow, more chapters are being formed, more group homes are being opened, more professionals are recognizing the needs of these young people and their families. Dr. Beltran mentions (President's Message) the time spent by the board in their efforts to select and act upon priorities for the coming year.

We will continue with our "caring and sharing" theme, attempting to do whatever possible for our membership. We hope you, too, will continue to make this organization the successful group that it can be.

PWSA 6490 Excelsior Blvd., E-102 St.Louis Park, MN 55426 (612) 926-1947 Office Hours 8:30-4:30 Executive Director: Marge A. Wett

Board of Directors:

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

Richard J. Wett, M.D. Edina, MN

Fausta Deterling Orono, MN

Gene Deterling Orono, MN

Stewart Maurer Rosemont, 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

W.Rhett Eleazer, A.A.L. Columbia, SC

Penelope Park Oklahoma City, OK

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

Officers:
President:
Delfin J.Beltran,M.D.
Portola Valley, CA

Vice-President: Stewart Maurer Rosemont, IL

Secretary: Fausta Deterling Orono, MN

Treasurer: Harvey H. Bush Vista, CA

Scientific Advisory Committee

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

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

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

David Ledbetter, Ph.D. Baylor Molecular Institute

Stephen Sulzbacher, Ph.D. University of Washington

Louise Greenswag, Ph.D. University of Iowa

Barbara Whitman, Ph.D. Cardinal Glennon Hospital

#### DEAR GATHERED VIEW:

We have always appreciated the newsletter through the years and find it especially important now as we face increased problems with our PWS child.

Our 15½ year old daughter has been giving us an extremely difficult time with her behavior. Some of it is destructive (shredding books, clothing and bedding) and then at times she has extended verbal outburst, during which she and everyone else in the house gets very little sleep. We've had a 3 day tantrum (stamping of feet, yelling, crying) and she has also begun to steal household money and jewelry. I understand that some PWS people exhibit this destructive behavior, and emotional episodes with the tantrums lasting not minutes as we had previously thought – but several consecutive days. How common is any of this? She seems to be getting worse.

The local hospital has recommended a psychiatric evaluation so that we can be prepared with a medication to use during the severe outbursts.

Our family is, of course, under much stress as these behavior problems are in addition to the usual constant food seeking. (We do lock refrigerator and food cabinets) Does anyone have any advice to offer?

I would like to hear from other parents who have faced the same challenging situation.

Editor comments: Personally, I feel extended tantrums are more typically hours rather than days. From what you write, it would be my opinion that your daughter is getting the upper hand in your family and it will continue to get worse if this is the case. To me, this is the time to introduce or really enforce what is called "tough love" in the drug world. I would sit her down and say, "we have had it", this is not the way we are going to live, we have this problem, and what do you suggest we do about it. From there draw up some rules and regulations, plans for what is going to happen when she explodes, and then carry through with them.

I really believe in positive reinforcement. In addition to the above, I would recommend drawing up some plans to reward good behavior.

Schedule extra calories when a week goes by without any money missing. Schedule a movie, skating, etc. when she goes a week without a tantrum. The important thing is for her to know good behavior is worthwhile, but also to know what is going to happen when she doesn't manage that.

Unfortunately, we have not found a medication that has worked for any period of time with our young people. Most of the experts have agreed there are times when behavior has gotten completely out of control or if the person portrays signs of depression, that hospitalization in a mental health clinic may be necessary. When hospitalized, drugs are used, but it is hoped that these will be able to be discontinued when the person returns to their normal residence.

We would appreciate any comments our parents (or professionals) may have on both issues and will be happy to share the responses in the next issue.

#### TREATMENT CENTER

We were able to place our daughter in a Residential Treatment Center for 3-1/2 years, CHAMPUS funded. We concentrated on our love relationship with her, not having to be the "controllers" so much on her visits home. We are all happier with each other and enjoy the times we have together. She moved easily to a new placement -- has learned better adaptive socialization skills.



#### A PARENT WRITES FROM NY

My daughter went to Europe with my Mom for 6 weeks and did very well. She biked, walked and visited.

She's a great kid -- drives us all crazy sometimes, but a great kid. She has a paper route daily of 38 papers. It gets her out of the house between the hours of 4:30-6 (which eliminates snack time), handles her own collections and payments.

#### GROWTH HORMONE THERAPY

Determining who will respond favorably to GH treatment is still limited, and possible longer-term effects of therapy are still unknown.

With a normal short statured child, the decision is generally based on the psychological status but with PW extra height can be helpful with weight control. It's frequently stated, "I'm not overweight, I'm underheight".

GH therapy is estimated at \$22,000/year, which is frequently, but not always, covered by insurance.

#### PRESIDENT'S MESSAGE

During the first weekend of December your Board of Directors convened its annual year end meeting. This is a major effort performed by the members, officers and the executive director. The annual budget is established, the activities of the Association are reviewed and the planning necessary for the continued life of the Prader-Willi Syndrome Association is carried out. This year the meeting was held in Minneapolis where we were able to visit the Wett residence (the old residence of the PWSA home office), the new office and the new location of Oakwood Residence, one of the original PWS dedicated residences.

Although the formal meetings consumed twelve hours of discussion, little else of the time was free of discussions important to the business of the meeting. Marge promised that the fearsome weather of Minnesota wouldn't attack while we were there and her promise held true. It wouldn't have made much difference as it seemed like the weekend was a flight in, bus to the hotel, meet for two days and bus back to the airport. Dr. Cassidy indicated that her move to Tucson has rendered her Connecticut tolerance to cold air extinct, consequently everyone voted to hold the 1989 year end board meeting in Tucson.

One of the most important actions of the meeting was a head knocking session conducted by chairman of the Board, Lota Mitchell. Each member in rotation identified organizational activity that they selected as the most important and stated supporting reasons. These thoughts were written on boards around the room. At the second session the items were voted on according to their level of importance. In this manner, the goals for planning and budgeting were developed. In descending order the four major concerns were: Educational projects, PWS crisis identification and management, fund raising, strengtening the national office. There are certainly many other functions and goals included in these selected topics. It is critical that the organization perform this type of exercise to determine where the priorities lie, where energies should be expended and just what flavor we are.

The Treasurer, Bud Bush, reviewed the financial condition, and budgeting for the coming year was planned as the result of the above thoughtful session and other discussions throughout the meeting. Great concerns were expressed regarding planning for that part of the annual conference that holds responsibilities for the care and entertainment of the persons with PWS who attend. Research grant applications were reviewed and the concept of an International Conference to be held in Europe was established. A new two hour video gathered from material

#### President's Message (cont.)

made available to the national office, over the past several years, was viewed during our "off hours". The latest edition of the Directory and updated bibliography are now also available.

One of the constant and major problems that plagues any group is that of finances and fund raising. Unlike our government, we can't make the mint run harder. A great deal of time was used to discuss future plans to expand the organization within the limited funds available. You will be apprised of our efforts along these lines in the near future.

Delfin J. Bellran, MD
President

#### **BUDGET FOR 1989**

#### CHARITY GIVING

Many charities are contacting their friends and donors with suggestions on how gifts can be INCOME given through insurance. Some examples: you owned a policy to insure the education of your 35,500 children and they are now all through 8,500 school--convert the beneficiary to a charity. 15,000 Take out a policy and pay the premiums, 3,500 naming a charity as the owner and beneficiary. 30,000 The premiums are deductible on your income tax return each year. Assign the annual Total 92,500 dividends of your present policies charity.

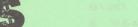
At the present time PWSA receives some memorial donations from its members. These are donations made in honor of someone who has died, often families designate PWSA as a recipient of gifts. If all of our members would keep this in mind, our donations would increase significantly.

It would be nice if PWSA were in a position to continue growth without having to consider increasing dues.





95,750



Membership dues Operating donations Material sales Interest Conference **EXPENSES** Salaries/Taxes 33,000 Travel 3,500 Rent 6,000 Printing 4,300 6,000 Postage Supplies 2,500 1,200 Phone 4,000 Publishing 1,500 Service Contracts 2,000 Capital Equipment 500 Committees/Chapters Conference 31,250

Total

## CRISIS INTERVENTION ASSISTANCE AND TRAINING FUND

Purpose

The Crisis Intervention Assistance & Training Fund (CIATF), was established by the Board of Directors in June, 1988, to "provide temporary assistance for individuals with Prader-Willi and their families in a crisis situation and training for residential care professionals dealing with individuals with PWS."

Funding

"The source of the funds for the CIATF shall be the accrued and future interest from the CIT fund until another specific purpose is designated for the CIT fund, at which time either the CIATF will cease to exist or another source of funds will be designated. Distribution of funds shall be limited to a maximum of \$3000 per case and shall be controlled by a CIATF grants committee composed of three individuals selected by the President and approved by the Board. Distributions shall be limited to the funds available and shall be with the unanimous agreement of the three members of the committee.

#### Guidelines

- 1. Only written requests shall be acted upon, and the crisis condition or need for training shall be verified by two people, one of whom is a professional care representative not related to the case person with PW.
- 2. Determination of true crisis condition or need shall be at the discretion of the CIATF grants committee; however, "crisis" shall normally be interpreted to mean life treatening, and "need" shall normally mean no other source of funds for training.
- The intent of the CIATF is to provide assistance and not necessarily complete solutions.
- 4. Assistance for a crisis condition may be provided regardless of financial need. The goal of the Fund is to help all individuals with PW and their families during a crisis condition and should not be limited to only those with financial difficulties. Preference, however, may be given to those with the greatest financial need.

- 5. Examples of crisis situations meeting the conditions of a CIATF grant are required hospitalization, special equipment (wheel chairs, oxygen supply, etc.), transportation to a treatment center, respite care for the sake of the family, and legal fees to acquire other aid.
- 6. Examples of need for training are cases where a person with PW is a resident or has the opportunity to be a resident in a facility where there is no experience in dealing with PWS, and the facility has no incentive or no funds available for training staff in the care of people with PWS.
- 7. Distribution of funds shall only be for verified expenses or known scheduled expenses. Distribution for known scheduled expenses will be made directly to the agency, company, or organization at which the expense will be incurred.
- 8. All requests for funds, and information related to the distribution of funds, shall be kept confidential by the CIATF funds committee, but shall be made available to outside auditors at their request. Requests for funds are to be made to the fund committee through the national office.

This granting fund was established in order to continue in our efforts to assist our membership. We are sharing the above information so you will be more aware of the fund, its purpose, and how to apply when there is a need.

## ONE OF OUR SPECIAL PEOPLE INJURED

Dorothy Thompson suffered compression fractures of two vertebra in a fall while out in Delaware to give a presentation. She was assisting the DE Chapter in their efforts to open a group home.

Recovery from this injury is rather lengthy, if you'd like to drop her a card her address is 5505 12th Ave. So., Minneapolis, MN 55417.

#### SEARCH FOR A BOARD SECRETARY

The Board of Directors may be in need of a person with capabilities of taking meeting minutes at two board meetings per year. (One meeting at the annual conference and the other at year end.) We would need someone willing to donate their services and pay their own expenses.

If you are capable and interested, please contact the national office.

#### CONFERENCE GRANT

The Board has again voted to award a grant to enable someone to attend the national conference.

A grant up to \$750 will be awarded for the Calgary conference.

If you are interested in being considered for this grant, please forward a request to the national office stating why you are interested in attending and why there is a financial need. Those qualified for the grant will have their names entered and a random drawing will be held in March to determine the grant recipient.

#### CIATF GRANT

PWSA is very happy to announce that the first grant has been awarded (using some of the interest from the CIT funds) to a family who needed assistance in transporting their son to a residential placement in another state.

Please refer to another article in this issue explaining this grant.

## FYI (FOR YOUR INFORMATION)

Professional members Louise Greenswag and Randy Alexander have volunteered to author a column titled "FYI" for this newsletter. They would probably cover one or two questions each issue. If the question falls in a category outside of their expertise, we will ask another professional to field the question.

Please send any questions you would like considered to the national office and the column will be started in the next issue.

#### EARNED INDEPENDENCE

Several parents have written lately that they have been able to give their children some independence in going places on their own by recording the time they leave home and having the group record their arrival and departure time.

Recording this information reinforces the feeling that wandering off or making extra stops is not allowed, and yet gives the person the right to go alone.

#### MANAGEMENT BOOK

"What a joy it is to know that we have a copy of 'Management of PWS' in our home library. It is an invaluable resource, and at times a comfort. We have shared it with professionals who are involved in our daughter's education and medical care. We're ordering an extra copy so we can lend one out. Thanks to Louise Greenswag, Randy Alexander, and PWSA!"

Editor: The publisher of this book, Springer Verlag released another book on PWS about the same time this management book was out and, unfortunately, it even looks similar. We would like to advise our members when recommending the management book to professionals to make sure they have the correct title, "Management of PWS", so they know this is the book we recommend.

#### PWSA RESEARCH FUND

A recent researcher was "disappointed" because he could not apply for a sizeable amount of money by writing a letter to us and having the check immediately sent to him.

We would like our members to know that we consider this donated money very precious and will not grant this to anyone without a very detailed proposal which is submitted to our Scientific Advisory Committee for their advice and then submitted to our Board for their approval.



TWO FAVORITES FROM OAKWOOD

## Hearty Oatmeal

4 c. skim milk

2 c. rolled oats (not instant)

1/4 t. salt

1/2 c. raisins

2 apples, pealed, chopped

1/4 c. sunflower seeds

1 tsp. cinnamon sugar

Combine milk, oats, salt, raisins, apples and bring to a broil, reduce heat, cover, simmer (stirring often) 5 minutes. Add seeds, cook another 5 minutes or until right consistency. Sprinkle over cinnamon mix.

Four servings; 1 c. is 1 bread, 1 milk exchange

## Burgundy-Spinach Burgers

1 10 oz. pkg. frozen, chopped spinach

1-1/2# ground beef

1/4 c. red wine

1/4 c. grated parmesan cheese

1/2 sm. onion, chopped

1 tsp. salt

1/8 t. pepper

Pre-heat broiler, squeeze spinach to remove excess liquid. Mix all ingreds until well blended. Form in 6 patties, broil 6" from heat, 5 minutes, each side for med.done.

### DEVELOPING SOCIAL SKILLS

It has been noted in several articles that older children with PWS do not have good social skills or self-esteem. Whether this can be changed dramatically or not is really not known but it certainly wouldn't hurt to work in that area with the younger children.

The ability to establish friendships and enjoy mutually satisfying relationships with other people do not occur accidently or automatically in human development. Early interactions between babies and loving parents and other caregivers lay a critical foundation for the infant's future ability to love other people. Early intervention programs can directly facilitate the parents' and child's ability to address problems in

social development. We do know from infancy, babies are learning about human relationships via parents and everyday life. Does PWS prohibit some of the learning to share, to follow the rules, to say hello and goodbye, is something we cannot say because we do not know exactly how these social skills are learned, but know children need opportunities to learn from experience.

Much of this can be learned in school settings but it can also be offered in the home. Include siblings in your plannings too.

A column recently by Joyce Maynard included information that she had researched an institute founded by Glenn Doman. Many of you have of this heard probably originally a physical man, therapist, that developed a method called "patterning". There has been amount of controversy a tremendous man's teaching. regarding this Joyce wrote, "On one level much of what this man was saying horrified and offended me: his belief, for instance, that what children really like best is to be like adults, and his total disregard for the role of fantasy or play in a growing child's world. Doman set forth the belief that geniuses are made, not born, and that he had come up with the recipe.

But I must add that after several days' exposure to the Better Baby way of thinking, I felt my own regarding early convictions education of my own child (and the one on the way) a little shaken. I began to picture my own beloved the company daughter in 3-year-olds trained at the institute and I found myself wondering if she would appear somehow deficient next I thought about Doman's to them. assertion that thousands of brain cells died with every passing year of a child's life. (Every passing day, even.) And I began to wonder: Should I have been working at teaching Audrey how to read?

As the months passed I came to marvel at having been briefly taken in by the whole superchild way of thinking. My son Charles was born the following winter—and though I often found myself tiptoeing into his room at night to watch him sleeping, I never felt the urge to flip the light switch on and off for sensory stimulation. I was just happy he was sleeping. Happy he was there.

I tell this story now, because in the years since I've observed a marked growth in the popularity of the Glenn Doman way of thinking about children and about the job of those who raise them. It's part of society's devaluation of childhood and parenthood, I'd say: this idea that it's worth somehow not an important or worthwhile enough occupation to be simply a child or to be simply raising children; children must achieve and we, their parents, must raise high-achieving children who can identify the Mona Lisa at 8 mos. and read before they're 2. What Doman and all the others who preach the superbaby sermon are telling us is that spending a day at home with a baby or young child should as nearly as possible be transformed into a competitive, goal-oriented, fast-track career.

Those who sign up for these pricey weeklong seminars in Philadelphia still consistute a distinct minority, of course. (Which is no doubt the way they like it. If everybody was busy teaching

### LOVE LEARNING (cont.)

their babies how to read, having such a baby would no longer appear so special.) But the fact is, almost wherever you go these days where parents of young middle-class children are gathered, there will be someone talking about kindergym and someone else signing her toddler up for piano lessons, someone whose 4-year-old is taking a class in French or art or acting for commercials. And there's bound to be some mother, studying her friend's child, and saying nervously, Gee, my 5-year-old doesn't know how to read yet. I wonder if anything's wrong.

The real question is not can you teach a baby to read, but why would you want to? How will it improve her life? Teach your baby a set of facts before too many brain cells die and she may retain those facts But raise her to feel for years. loved and accepted, safe in the world and curious about exploring it, and she will never stop growing. I believe the real job of parents isn't and teachers simply transmitting skills to our children. It's inspiring them with a love of learning that will go on forever."

This article is certainly not aimed at children with disabilities but we can't help but read between the lines and relate it to accepting the facts of PW and applying the same philosophy.

## BACK TO SCHOOL LABELS (from GA Chapter)

In Georgia, many PW students have benefited from being categorized as "Other Health Impaired" or O HI.

Unfortunately, special education in our state requires that our children be labeled. Fortunately though the label of OHI allows our children to earn more funding dollars. Until just recently (Aug. 88) this also assured OHI students lower class size/teacher pupil ratios.

Changes have been made that OHI students can be placed in classes with up to 16 students. They stated, "Why call it special education with class sizes this high?"

Many parents have successfully and appropriately fought the battle to avoid placement of their PW in a Behavior Disorder (BD) or Emotionally Disturbed (ED) class. PW behaviors are certainly unique and problematic, but typically not characteristic of or comparable to other BD students. Each PW child is individual. Please take the time to the research state and requirements before accepting placement or programming for your child. It is also very important that you follow up and monitor your child's classroom, teachers, related services and his/her IEP throughout the school

## PARENTS SHARE:

Our daughter did not walk until about 3 yrs. of age. A podiatrist recommended shoe inserts which made her walking easier. At  $4\frac{1}{2}$ , she can now even run a little.

Our 12 yr. old has come a long way since birth. She's given us a lot of joy along with the tears and I don't mind sharing that with anyone.

The importance of sharing is for parents to write what doesn't work along with what does.



It is frequently reported that children with PWS have fine motor skills but are lacking in gross motor skills. This includes sense of direction, sense of left and right, sense of two sides of the body, sense of balance, eye-hand coordination essential for handwriting and copying from a blackboard, control of large muscles needed to run, jump, climb, throw, etc. Psychologists also believe there is a link with abstract thinking.

Way to help your child: Simple games of catch (sponge ball, bean bags) Swimming Walking Aerobics exercise records (including motions of moving up, down, forward, backward, under, over Simon says - naming body parts Pretend animal games - crawling like a jumping like a kangaroo, galloping like a horse Sing songs such as "Head and Shoulders, Knees and Toes", "Put Your Fingers in the Air", etc.

Help can also be given for the trouble of understanding abstract concepts in math (including size, shape, quantity, the passage of time, intricacies of money, measurements). Some children cannot be taught in traditional ways, they must experience it or require concrete objects that can be seen, examined or held. Encourage younger children to play more number games, games with shapes, sizes. Use your trips to point out numbers on signs, shapes of signs. Count the people at the dinner table, the folding of napkins (halves, quarters), the silverware.

#### A FLORIDA PARENT ASKS

Our child is still young but should we be doing something now about finding a group home?

Editor: The answer to that question could fill a whole issue, but for now we'll make a few comments. In most instances, homes that meet the needs of persons with PWS must be opened. It is not the same as putting your child's name on the waiting list for your favorite nursery the day they are born. Group home placement (at the present time) is considered permanent placement and until such time that medicine or surgery will change this need, it is the lifestyle that PWSA recommends for our young adults.

Start early by placing your child in your state's system. There is no set way to do this, even the department names are different from state to state, and certainly different from the U.S. to other countries. Find out what department you should contact in your area and make that contact now. Obtain a caseworker/social worker to represent your child in the system. This will then be in place when you need funding for a pre-school program, placement in the regular system. or residential school placement. If you are unable to obtain this information, please ask national for assistance.

If you have a parent group--work with them, even if you personally do not have any specific need right now. What this group does now will affect you later.

## COURTS ON SSI

A federal appeals court (Zebly vs Bowen case) found social security procedures for deciding whether a child with disabilities is eligible for Supplemental Security Income (SSI) is unlawfully restrictive. (The court held that SSI must provide an opportunity for individualized assessment of severity of their functional limitations but also ruled that the child's condition be in the agency's listing of impairments.) SSI is important because it includes health care through Medicaid, even though the SSI benefits are stopped when the person reaches a certain income level. Hopefully this will make approval easier.

## BOOK REVIEW FROM TAP-IN TRIBUNE

How To Be A Better Parent by Hope Holiner and Arlene Shulman is one part of the The Thought-A-Week Guides. This book offers one child rearing concept per week. Each is one to two pages and suggest an activity for the upcoming week. The book is a guide for raising a child in an atmosphere of love and respect. Topics include: Parenthood is Not A Power Struggle, My Worth is Not Determined by My Child's Behavior, It is Never Too Late to Change, and more. 1986 publication, 115 pgs, cost \$2.95 + shipping. Available from Ballantine Books, 201 E. 50th St., NY, NY 10022.

#### RELATIONSHIPS

A recent article mentioned the importance of building relationships for any person with Developmental Disabilities (DD) moving into the community. relationships are complex and challenging for anyone and more so for a person with a disability. People with DD have their lives in segregated programs, for the most part, where friendships with others outside of their environment aren't encouraged supported since it takes time arranging. (And many times efforts aren't successful). The person is then introduced to the "community" with little preparation to "fit in". It has been stated, "Most of us don't make a lot of friends at the post office", suggesting that opportunities have to be created. Moving into an apartment or home continues this "insulation" and there may be little interaction with neighbors. Adequate support must be provided to foster new relationships.

Frequently a person introduced to more independent living is assigned companions, who come and go. Parents are encouraged to see where they can help with this process.

#### FAMILY ABROAD

One of our families spent 6½ years in Tokyo and felt their 24 yr. old daughter, Rachel, benefitted immensely. She increased confidence, developed her own mind, and in spite of her parent's initial fears about the effects of uprooting her, managed very well. She did not have a job but every day she did something useful, such as assisting at a nursery school, assisting the rector's wife with a new mothers and toddlers group, with individual neighbors who appreciated expert help and attended many classes. Her classes included a 5-yr. in flower course arranging, exercises, doll making, ink painting and others. She was very active in church related activities, friends, particularly with a young girl with cerebral palsy.

#### GENETIC EXPERIMENTS

Two California laboratories suggest that genetically engineered cells may offer promise for cancer and correcting brain disorders. The studies involve the use of cells that were genetically altered and then injected or grafted into lab animals. Researchers, for the first time, implanted genetically engineered skin cells into the brains of lab animals to correct a neurological defect.

The research is in its formative stages but has great potential for human use.

#### CALL FOR PAPERS

The call for papers to be presented at the July conference will be made soon. This year the committee is considering the possibility of dividing the pre-conference scientific day into medical and sociological papers. If you would like to receive this call for papers mailing, please let us know.

#### **OUR SPECIAL THANKS**

By looking at the projected budget, you can see that even though we have very low salaries and operating expenses, these figures cannot be covered by the amount of dues alone. It takes the dues, operating donations, and a small profit on our book sales to keep us operating. If we did not have members who care, we would not be able to continue to fund research projects, special grants, and continue to work on crisis needs. For November and December, we give a very special thanks— we had several very generous donations and several memorial donations. We thank:

Useted, Miller memorials (S.Miller, Tyrrell, Hoover, Gallagher), Dixon (2), Goff, Boucher, Olson memorials (Myers, Mann, Jacobson, Trager, Donovan, Moore, Lingafelter, Hunter, Clifford, Balla, Butler, Cline, McDermott), Wett, Shaefer, Sharp, L.Smith, Foley, Kuhne, Luhman, Barkeley, Offerdahl memorials (Schuster, Christianson, Rahm, Cummins, Diekelmann, Richardon), Parcell, Ziifle, Rattray (2), and North.

Late December additions: Dixon, Cortellini (Castiglia), Wett (Schaeffer), Warner, Moss (UW), Notbohm, Linonis, Shiovitz, UWash Moore memorial

RESEARCH DONORS: Richarz (2), U.W.Cap area (2), Quadrel, Robinson memorials (Low Cty), Boyd (2), Englund (Trade Lakes Camp), Hinson (Noon), HI Pac CFC, Beltran, TN C.C., Novak (Kokoska), Lynch(Coke), Basker, Levikoff, L.Smith, Castle (Herbst), Brennan (Tracy), PW KY Chapter, Krock, Townsend, Carrier (Goetz, Carrier, Waterman), Eisen, CT Chapter, Chase, Tarrakan (Library), LaBella, Fields, Olson memorials (Hagen, Staron), Offerdahl memorials (Gessner, Laper, Shriberg), & E.Fuller.

THE GATHERED VIEW is the offical 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./year Individual, \$25./year Family, and \$30./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.

PRADER-WILLI SYNDROME ASSOCIATION 6490 EXCELSIOR BLVD., E-102 ST. LOUIS PARK, MN 55426