



# THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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## PRESIDENT'S MESSAGE

"GET INVOLVED!" Now doesn't that sound familiar. How many times has your curiosity, or your "dander" or your "spleen" caused you to investigate the activity of a local group. When I get steamed up about something, at least steamed up enough to bother interrupting my daily routine and take the time to go to a meeting, my mind carries me in with all sorts of pre-conceived notions of justice and freedom for all. I just got back from our town hall, where the planning commission is meeting. Two weeks ago they sent out a notice that one of my neighbors was planning to have a satellite antenna installed on his property. Here, where a large number of the residents make their living from the high tech companies of Silicon Valley, there is a law against the installation of these harbingers of futuristic communication as they are offensive to the eye and spoil the natural beauty of the community. But, I got there too late, the use permit in question had already been discussed and recommendations made. I almost got involved.

We are all creatures of habit and woe unto him who disturbs our habit. Then every once in a while something happens that permits us to break out of our cocoon and search for a new truth, or charge out to correct our visualized wrongs. It never ceases to amaze me how strong a stimulus it sometimes takes to make us sufficiently aware of a problem to cause us to actually respond. From the time I was sixteen I smoked cigarettes, up to four packs a day. At that time our level of awareness regarding the hazards of smoking was very low. As an anesthesiologist, I was perhaps even more aware than most persons of potential problems related to the habit. I even quit for lent one year in college, but as my roommate clearly stated, the only thing I quit doing was buying the evil weed. As the years wore on I knew more and more that I should quit. But it wasn't until I was forty-eight and my brother called to say that those painful lumps on his scalp were metastatic lung cancer, that I put out my last cigarette.

"GET INVOLVED!" I had the pleasure of travelling to New York this month to participate in a meeting arranged by a truly involved parent. This meeting with high level officials opened our eyes to the amount of work and involvement it will take if the Prader-Willi Syndrome Association is going to be successful in its endeavor to create specialized residential centers for the appropriate care of Prader-Willi persons. We are far enough down the road to know that we must accomplish this if there is ever to be proper care and support for the Prader-Willi person after graduation out of the educational umbrella. The more I understand



about this problem, the more I realize how foresighted Marge Wett has been in conceiving the idea of a national Prader-Willi training center for emergency care of those with no place to go to survive and a place to train others in the special needs that must be recognized for appropriate care, as well as a center to administratively tie all of our efforts together into an efficient and meaningful force.

"GET INVOLVED!" No one can spoonfeed you to give the knowledge of what to do and how to do it. Read the GATHERED VIEW, communicate with other Prader-Willi supporters, ask questions, seek out answers, learn who locally, statewide or nationally needs to be informed about the needs of Prader-Willi persons. It will never happen unless YOU do it. Find out what I am talking about by being involved. The life you save may be in your own house.

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

## DONATIONS

The PWSA office has been very encouraged by the support of the membership over the past six weeks for the CTM Club for the National Developmental Center. In the month of January \$4441. was added to this club. The first two weeks of February has added another \$1061.00, which brings to total to over \$28,000. now.

The following members have been added to the club roster:

Base Camp Supporters: Dennis, Sharp, Watson, Neeley, Flick, Lincoln, Straight, Ipsen & Ray.

Up & Coming Achievers: Lamberson, Mears, Boyd, Henderson Memorial Fund, & Kass. The Crevasse Jumpers: Fick, Rush. Peak Achievers: Haller

The following members gave additional donations: Base Camp Supporters: DeHaan, Deterling, Sidlo, Straight, Sharp & Jackson. Up & Coming Achievers: Ingalls, Wyka, Westbrook, Whitlock, Castle, Herrmann, & Robinson. Crossing The Face: Burleigh.

Several donors moved to a higher category: Fox, Tobin, Krebsbach, Corcoran, Notbohm.

January's memorials and research donations totaled \$685. The following members and friends contributed: Clark, Sawyer, Johnson, Ball, Sojka, Swan, Uzendowski, Dincen, Evans, Savage, Wiernsz, Nance, Rassmussen, O'Farrell, Weintraub, Ferrari, Allen, Colony Square Hotel, Knott, & DeHaan. The first two weeks in February brought an additional \$70 from: Gallaway, Strauch, and Hellerman.

The members continued support for our fund raising projects is sincerely appreciated. The Fund Raising Committee is continuing to meet and has been very encouraged lately but the promised support of two professional fund raising groups. We hope to be able to share very good news in the future with our efforts to open the National Developmental Center.



## TAX TIME AGAIN

Several articles have appeared recently in regard to tax deductions for parents with disabled children. New rulings and decisions have been made this past year and should be investigated if you have questions. For example, under medical expenses, only prescription drugs and insulin are considered deductible. Naturally, if these are covered by any insurance, they are not deductible. New in 1984 is the allowance for lodging expenses incurred when obtaining medical care away from home, with the daily limit being \$50.00 per person.

Unusual expenses, such as modifying your home to met your child's needs, costs for special education or training, and certain transportation costs, can be deductible expenses, but many are based on a decision rather than an automatic acceptance. A swimming pool addition may be only in the amount in excess of the increased home value, or not accepted at all if a "Y" is conveniently close to your home. Special schooling or training transportation is usually figured at the nine cents per mile rate.

With recent changes, it may be helpful to consult with a tax accountant if you feel you may have some deductions.

## A MICHIGAN PARENT WRITES:

"A word about substituting sugarless candy for "trade off" treats. Many sugarless candies are sweetened with sorbital and besides the problem of diarrhea associated with it, they are often not so low in calories. Often a single Life Saver has fewer calories. So unless your child is a diabetic, this should also be considered."

## CONFERENCE TIME

It's hard to believe that the 7th Annual Conference is approaching so soon. (I am sure the conference committee is well aware of that fact.) Don't forget the dates:

JUNE 20, 21, 22 THE CONFERENCE CENTER AT HOWARD JOHNSON'S  
WINDSOR LOCKS, CONNECTICUT

Pre-registration and information will be in the mail to you very shortly. We hope for another record turnout.

## AAMD

Due to the letter writing on the part of one of our members, Tom Fox of Kansas, The American Association on Mental Deficiency will be including a presentation of PWS at their annual meeting in Philadelphia May 28th, 8:30-12:00. Dr. Theodore Tjossem, National Institute of Health will chair the presentation which will include a presentation on Genetics by Horace Thuline; a presentation on Controlling Obesity by Dr. Vanja Holm, and one on Behavioral Research by Steve Sulzbacher. These people are from the University of Washington's CMDRC in Seattle.

The AAMD is a large group and commands a large attendance at their annual meetings. Our thanks to Tom and our Seattle friends in helping to promote the knowledge of this syndrome.



MUSICAL ABILITY

Characteristically we have not found musical ability to be a strong point with our children with PWS but we have had it mentioned occasionally. One of our new members from Brazil has requested the sharing of information in this regard. Her 8 yr. old son memorizes passages that are repeated many times. She would appreciate any suggestions of what other parents have done. We will be happy to share these with members via the GV if anyone cares to respond.

ANNUAL MONEY RAISER WITH A "TWIST"WHAT OUR ANNUAL MONEY RAISER DOES:

Keeps conference registration fees lower.

Funds the completion of the conference papers.

Helps chapters earn money too.

Gives your friends a chance to help you support your organization.



The "twist" this year is we are giving you an option: Instead of selling raffle tickets, sell a ballpoint pen (with our name on it) and then give the purchaser a free raffle ticket on the \$1000 drawing. OR: Do the reverse, sell them the chance, let them fill in their name with our pen and then tell them to keep the pen. OR: Forget the drawing, just ask for a \$3.00 donation for the pen. Whichever way is more comfortable for you, that's the way to do it--just help us raise additional funds. This year the first \$5000. profit will be used to offset conference expenses, and additional profits will be used in support of the National Developmental Center. I have great confidence in your support--I ordered 7000 pens. Thanks to member John Gunnison, we got them at bargain prices.

Chapters receive 25¢ for each sale made by their members. If chapters order bulk quantities to share with their members it saves postage, but if you order separately, your chapter still receives credit.

To make the raffle equitable, tickets can be paid for in Canadian funds (and the prize would also be paid in discounted funds), or U.S. funds would be marked for full payment. Due to mailing costs, we would prefer that Overseas members sell chances only.

PLEASE join those who care about this organization by mailing your order today:

ANNUAL MONEY RAISER ORDER FORM:

Please send \_\_\_\_\_ tickets and pens, which will be bought or sold for \$3.00 per set, or 2 for \$5.00.

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

If these are for personal use let us know, we can fill in the chances for you and save mailing them to you. Also, please advise if you do not want the pens.



## SO NE CHAPTER

The Southern New England PWS Parent Support Group has been meeting every other month for 3 years. The parents who participate are accompanied by their adolescent or adult child, and the PW peer group meets separately. Members of the support group felt it would be beneficial for the PW peer group to have a therapist facilitate their efforts in an attempt to help them explore some of their feelings about the impact PW has had on their lives. Toni Frese, M.S.W., has met with the group twice so far, and on both occasions was impressed with their sensitivity, compassion and tolerance for each other. Below are her impressions of those two sessions.

"At my first meeting, I explained my role with the group and told them a little about myself. They each then took a turn describing themselves and their families and what they saw as my role in working with them. They presented as a cohesive group, and frequently looked to each other for cues as to whether they were saying the right thing or behaving in an appropriate manner. The second time we met, a new member joined us who had just been diagnosed. They all thought it would be a good idea to once again go around the room and explain about themselves to this new person, as they had done with me. The new member was asked to speak first. Her lack of information about PW soon became obvious to the group. At one point she expressed how scared she was that maybe she could die. Everyone in the group reacted immediately, each trying to assure her that having 'Prader-Willi Syndrome is not so bad.' All took turns sharing their own personal experiences and providing encouragement and support. The fear of death seemed to be prevalent in all group members, some being more anxious than others to express it.

The young men and women who participate in the group have been meeting together for approximately 2 years. They have shared their individual difficulties relating to dieting, vocational needs, peer relationships, etc., in a non-threatening, supportive setting. By providing some clear consistent structure, the opportunities for continued personal growth and productive peer relationship is most encouraging."

We thank Toni, of the Newington Children's Hospital, for sharing this information with us.

## THE ABC's OF PWS

In response to requests, Dorothy Thompson and Marge Wett are attempting to put together a handbook of the "how to's" for PWS. The chapter on the proper staffing of group homes will be tackled first because of the immediate need, but the finished product will start with Day one in the life of a child, and hopefully, will be of use to all parents in the various aspects of proper care.

## OUR SYMPATHY

PWSA and it's members extend their sympathy to Marge Henderson of Cleveland in the death of her son, Rick. Rick's death, of a cardiac arrest caused by obesity, is another needless death of one of our young people because of the lack of a proper placement. Marge is one of these parents that did everything humanly possible to obtain a place for her son and was unable to accomplish it.

She writes: "I loved my son and I grieve for him, but I hated his illness. I am very thankful for his life and the growth I might never have otherwise known, but I am hostile to a system which allows kids like ours to fall between the cracks."



NEED FOR SERVICES

In January, a meeting with Dr. B. Kilbourn, Assistant Secretary of Health & Human Services took place, thanks to some of our members in NY. NY people in attendance were Rita Welch, Gunther Lennhoff, Marv Raynes, Dr. Jack Sherman. D.J. & Bobbie Miller attended from PA, Dr. Sam Beltran from CA and Dr. Richard & Marge Wett from MN. Although we didn't walk away from the meeting with any money or promises of financial help, we did feel a great deal of educating took place. Dr. Kilbourn suggested that we make further contacts with some H & HS people in Washington, which we hope to arrange in the near future. One of Dr. Kilbourn's staff promised to forward some of our materials to the Head Start program to facilitate earlier identification of our young people. Marge Wett furnished them with a copy of some excerpts from membership letters. We felt it was very important for them to realize that some very desperate situations do exist that need immediate attention. We certainly hope that with the addition of services and medical advancement, that this bleak picture will change radically in the near future. Certainly that is one of the concepts of the National Developmental Center, but in the meantime it isn't something that is going to happen unless we make it happen.

We feel it is important that our membership is aware of the seriousness of the present lack of services for our young adults. We felt excerpts from some letters would be appropriate to share:

"Our daughter is still living with us at 35 yrs. of age..." (No placement available, elderly parents make a 42 mile round trip each day to her workshop.)

"Although I am past retirement age, I work in order to supplement (my son's income)...and make the monthly payment for his private placement." (Other placements had to be discontinued because of weight gain or heavy medications for behavior control.)

"...home life with (son)...deteriorated this past year....sullen, angry...at all of us, all of the time and extremely moody. (even affected mother physically) ...kitchen is locked at night...exercise bike available...temper tantrums in retaliation for not minding, not cleaning room."

(daughter) just spend 2 months in hospital (trying to keep her alive). She was 300 lbs. when she went in and lost 30 lbs. (Cost \$38,000) She has been on a 300 calorie diet since she came home. ...I'm afraid if they don't follow up on her she will slide back..."

"We struggled to maintain some degree of sanity but (daughter) was taking larger amounts of money from us...night hunting. Locks were broken, hinges undone...very ingenious... Tempers were very short, no one slept soundly...(At first placement, she lost 90 lbs., then returned home with no follow up, no outside support...schooling became a problem again....gradually weight came back on. (Next placement cost parents \$125./mo. and things went well for 2 yrs., 3rd year she became rebellious, disruptive, severe temper tantrums, foul language, stealing, weight gains, and was again released and sent home. New placement was more disastrous, 80 lbs. weight gain. Weight is now being lost again slowly in new placement.)

"My daughter is home with me, she is 17 yrs. old, and it is very difficult to control her, there are times I feel so hopeless..."



Services cont.

"There is no way I can think about what I may feel, when it comes to where (son) can be helped. He is dying before my eyes. He is out of control, and I am the same. (son) is up to 400 lbs. again. I am no good for him anymore. I can't help him anymore. I can't help myself. He shouldn't be with me anymore. I don't know the person I have become the past 2 yrs. I don't deal with him well at all. I feel so bad I wish I could die, God only knows I want to. I wish one of us could die, God only knows neither of us can go on like this anymore. I know there is no help for (him) anymore. I haven't met a soul who understands or can help him. I pray no other PW children are suffering like (my son)."

(daughter) is now 25, placed in a private residential placement. The cost for the parents is \$800./month.

"Juggling 24 hrs. of care and surveillance of (daughter) plus work, is hard. ...if something happened to me, no one else could do what I do. ...(daughter) threw a bad tantrum --she grabbed the wheel of my car and nearly killed us. I am very frightened as she is strong and unpredictable."

(daughter) is in an institution, but even a good one is not equipped to handle a person with PWS. There is too much food available and the opportunity to steal is easy.

(22 yr. old living at home--no work available, has been doing nothing since school. He is not getting any exercise, weight excessive. Battles with family.) "It's a losing battle."

(16 yr. old is over 300 lbs. Parents are being charged by the school with child abuse and neglect because of weight and behavior. No one at school is willing to listen to the facts.)

"The struggle to control her diet becomes harder as she becomes older. ...I can see no chance of her being able to do any work at all. She is quite lazy and cannot be forced or even persuaded to do any menial task. Tantrums can take place at the slightest upset, causing anguish and embarrassment. Life is certainly hard coping with a PWS person."

We have just recently learned of two young children, one is 9 yrs. old and weighs 248 lbs., the other is 12 and did weigh 384 before surgery. Maybe in the sharing of some of these situations the membership can understand why we feel the importance of immediate needs that are not being met. Certainly there are success stories to share also, and we certainly are happy to hear about them also, but a great deal of these are because of the parents effort, they did not just appear. Our united efforts do make a difference.

PWSA "TEAM"

A recent request has brought to mind the values of our membership working as a "team" in our efforts to benefits our members. One member's new doctor stated her son did not have PWS because he was not fat and retarded. The doctor read a published report that stated these as necessary symptoms. When any of our members plan on publishing, we would like to request they consider the "team" concept and consider working with the PWSA national office. Our membership list should not be shared with anyone without PWSA being informed. We hope our membership can see the value of all efforts coming out of one source in order that they be controlled to the greatest benefit of all members.



## PAIN AND SYMPTOMS

During the last few months, with three young men from the Oakwood Residence having hernia surgery, we have been made more aware of this medical problem with some persons with PWS. We should all know that a person with PWS does not have the same response to illness that the normal person has. How are they different? In very significant ways! Two of the more important areas are temperature control and pain.

The person with PWS does not have the usual body response to infection and injury. Fever is often not seen even with marked infection such as appendicitis or wound infection. The person with PWS also does not seem to have the resistance to infection that others have. Frequently our children do not have pain as a warning symptom of a problem.

For example, with the three inguinal hernias mentioned, symptoms were not very troublesome. For this reason we caution parents that a vague symptom, like a "stomach ache" should be investigated and followed. Pain and fever, in most people, are indications that a person is ill. These findings are often not present when a person has PWS.

My study on surgery and anesthesia in the person with PWS is now being completed. Here are some early statistics: I have been able to include 207 persons, who had a total of 373 operations. Some persons had over ten operations each, covering a few years in time. There were 105 females and 103 males. The three most frequent operations were: Inguinal hernia repair frequently with undescended testicles (54% of the males); eye muscle surgery to correct strabismus (11% over all); tonsilectomy and adenoidectomy (7.5% over all). Dental repair and teeth extractions were the next most frequent operations. Only a small number of persons needed to have surgery for scoliosis. Over all the complication rate was about 2.5%, this is, as you expect, higher than the usual rate of complications. The age range was from three weeks to 38 years, with many very young persons having had muscle biopsies for diagnosis.

*Richard J. Wett, MD*

## LEGISLATIVE INTEREST

For those with a keener interest in what is going on in the world of politics, a friend of PWSA has a newsletter published monthly. "Joint Venture" is a non-profit coalition of organizations and individuals in New York State that have formed together to achieve political recognition, vocational and educational opportunities along with social equality for the handicapped. Although this newsletter obviously alludes to the State of New York, it has valuable information regarding items of interest to all. If you are interested in subscribing, the dues are \$15.00 a year and application can be made to Joint Venture, Box 412, Plainview, NY 11803.



## MIDLANTIC FALL MEETING

Date: Sat., April 27th 9:30 am to 4:30 pm  
Place: Hasbrouck House Quality Inn, "Jonathans"  
283 Rt. 17 South, Hasbrouck Heights, NJ  
Speakers: Dr. Suzanne Cassidy, Rita Welch  
Reservations: Kathy Wyka, 289 Wallington Ave.,  
Wallington, NJ (201) 773-7935



## RECENT PUBLICATION ON OBESITY

The National Institute of Health recently released the findings of a federal panel on current knowledge about the dangers to health of various levels of obesity. The panel concluded that obesity is a killer and should receive the same medical attention as high blood pressure, smoking, and other factors that cause serious illness and premature death.

This is good news to parents of children that have been refused hospitalization for the reduction of weight only. It has also introduced that there are other means of determining obesity rather than it just being based on a number.

## "WE DON'T WANT OUR SON TO BE LABELED"

That heading in a recent publication of "Pacesetter", a newsletter of a MN educational organization caught my eye. The good neighbor advised the parent of a special child not to let the school label their son and have him placed in a special class away from the other kids. Some of Pacer's advice included: If your son does have a special problem, there are many special teaching methods in use today and many specially trained teachers who can provide the kind of help he needs. ...(having an evaluation or assessment) will describe your son as having one particular kind of handicapping condition. ...school personnel can plan together the kind of educational program that's necessary for a child with that handicap to make progress. (stigma of attaching a label)...not calling it by its name aren't going to make things better, no matter how much parents might hope otherwise.

They went on to say that a label is necessary in order to receive the federal and state monies that are available for the special help. (On I.E.P.'s, individualized educational programs)...It's very important that you, as a parent and a member of your youngster's educational planning team be ready to recognize and tell others about his individual differences and unique strengths and positive qualities. His IEP should be based on these factors.

Accepting your neighbor's suggestions for the best education is like accepting their doctor recommendations. The doctor with the best "bedside manner" is not necessarily the best informed physician. With our syndrome, it is very imperative that you make yourself very visible in planning your child's educational course. If you don't supply them with information about this syndrome, it is very possible they will not be informed. Getting a good start when your child first enters the system is very important, but if you didn't, it isn't too late now--better late than never.

## CO CHAPTER

The Colorado chapter has added "First Saturday" to their agenda. These special outings during the year are for the children and parents. Their first venture was a Valentine's Day Dance Party. The next will be in April with an Easter theme.

## FROM AN ENGLISH MEMBER:

Our 3 yr. old attends a M.H. nursery class 3 days a week. At home she is alert, happy, babbling, giggling, enjoys her exercise but at school she is just the opposite. Do other parents have this problem? Any guidance would be appreciate by me and her teachers. Write to the PWSA office and we will share.



CAMPING

The Rehabilitation Institute of Pittsburgh will have its 4th summer program for children and adolescents with PWS. Within the rehab. setting, these young people will participate in a multi-disciplinary program, in a camp-like atmosphere. The dates are: JRS. June 24-July 19; Seniors, July 29-August 23rd. For more information contact: The Rehabilitation Institute of Pittsburgh, Bea Maier, Ph.D., 6301 Northumberland St., Pittsburgh, PA 15217, or (412) 521-9000.

A parent has shared that her 32 yr. old son has been attending a camping program for the past four years and they have been very pleased with the program. Contact for this camp is: Winter Office: Daybreak, 325 Chester Rd., Uniondale, NY 11553, (516) 485-3978, or Summer Office: Daybreak, RD #3, Honesdale, PA 18431, (717) 253-3771.

Another camp recommended for PW: Rock Creek Farm, Thompson, PA. Another possibility to investigate is: Camp Buckskin, 3811 W. Broadway, Robbinsdale, MN, 55422, (612) 536-9749. The camp is located in Northern MN, in Ely.

TRI-STATE CHAPTER MEETING

The Rehabilitation Institute of Pittsburgh will be hosting the Spring Tri-State Chapter PW meeting on May 11th, 1985. For further information contact: Pam Vogt, 8360 Acadia NW, Massillon, OH 44646.

SOME FOOD HELPS FROM A PARENT

Add water when cooking ground beef - draws out the grease. Meat retains the seasoning even after draining.

Add Sweet & Low to cinnamon. Use on toast, apples, in baking etc.

You can use sugar substitutes in baking—if the recipe calls for 1 cup use  $\frac{1}{4}$  c. + sub. For less sweetness, do not use full equivalent of sugar substitute.

Nutradiet has jams/jellies, (S & W product) only 4 calories per teaspoon.

Use Shedd Spread -- okay as long as it's on low-moderate heat.

Other sources for help: The American Diabetic Association has many helpful nutrition/diet ideas and some exchange recipes. Dial 1-800-555-1212 for local toll free number.

Check you local U.S. Department of Agriculture/Agriculture Agent/ Home Economist. USDA Home & Garden Bulletin 72 is Nutritive Value of Foods. Very helpful in providing nutritional content, calories, and useful in trying to convert recipes into exchanges.

TYPEWRITERS

IBM made the offer of offering used typewriters at a low price to individuals who have a letter from their doctor indicating they are disabled and would receive therapeutic benefit from a typewriter. The PWSA is writing to the LA office, if you are interested, check with us and we'll let you know what we found out.



## YOUR COMPANY COULD MATCH YOUR CONTRIBUTION TO PWSA!

Is your employer listed below? If so, your gift to PWSA can be matched by your company. Your business or personnel office will give you the proper form to fill out.

### IS YOUR COMPANY LISTED BELOW?

AMF Inc.  
AT&T  
AT&T Long Lines  
Alco Standard Corporation  
Allied Chemical Corporation  
American Bell  
American Brands  
American Express Company  
The Andersons  
Armco, Inc.  
Atlantic Richfield Company  
Automatic Data Processing  
Avon Products Foundation  
BankAmerica Foundation  
Beatrice Foods Company  
Bernd Brecher and Assoc., Inc.  
Bird Companies Foundation  
The Boeing Company  
The Brunswick Corporation  
Bucyrus-Erie Company  
Buffalo Color Corporation  
Bunge Corporation  
Caterpillar Tractor  
Celanese Corporation  
The Chase Manhattan Bank, N.A.  
Chemical Bank  
Chubb & Son, Inc.  
Citicorp & Citibank, N.A.  
The Coca-Cola Company  
Connecticut General Insurance Corporation  
Consolidated Foods Corporation  
The Continental Bank Foundation  
The Continental Group

Frederick W. Cook & Company, Inc.  
Community Funds, Inc.  
Cooper Industries, Inc.  
Corning Glass Works  
CPC International, Inc.  
DEKALB AgResearch, Inc.  
DeLuxe Check Printers, Inc.  
Digital Equipment Corporation  
E-B Industries, Inc.  
Emhart Corporation  
Ensign-Bickford Foundation  
Equitable Life Assurance Society of the U.S.  
Esmark, Inc.  
Ethicon Inc.  
Exxon Corporation  
Federated Department Stores  
Fiduciary Trust Company  
Field Enterprises, Inc.  
Fireman's Fund Insurance Company  
Freeport McMoRan, Inc.  
GenRad, Inc.  
Gilman Paper Company  
B.F. Goodrich Company  
Grand Met USA, Inc.  
Great Northern Nekoosa Corporation  
Gulf Oil Company  
Gulf & Western Industries, Inc.  
Harsco Corporation  
H.J. Heinz Company  
Honeywell, Inc.  
IBM  
Interlake, Inc.  
International Minerals & Chemicals Corporation

Johnson & Higgins  
Johnson & Johnson Family of Companies  
Kennametal, Inc.  
Kimberly-Clark, Inc.  
Koppers Company, Inc.  
Lear Siegler, Inc.  
Lever Brothers Company  
Liggett Group, Inc.  
Little, Brown & Company  
McDonald's Corporation  
McGraw-Hill, Inc.  
The Meadville Corporation  
Merit Gasoline  
Minnesota Mining  
MITE Company  
Mobil Oil Corporation  
Monsanto Company  
Montgomery Ward Foundation  
Morton Norwich Products, Inc.  
Morgan Guaranty Trust Company of N.Y.  
MTS Systems Corporation  
Mutual Benefit Life Insurance Co.  
N.C.R. Corporation  
New Jersey Bell  
Newsweek, Inc.  
New York Community Trust  
N.Y. Telephone  
The Northern Trust Company  
Ortho Diagnostics, Inc.  
Pfizer, Inc.  
Pennzoil Company  
Pepsico  
PPG Industries, Inc.

PQ Corporation  
Phillip Morris, Inc.  
Playboy Enterprises  
Polaroid Corporation  
The Quaker Oats Company  
Arthur D. Raybin Associates, Inc.  
Rexnord, Inc.  
R.H. Macy Company  
R.J. Reynolds, Inc.  
Rockefeller Brothers Fund, Inc.  
RYCO, Inc.  
Sandoz, Inc.  
Jos. E. Seagram & Sons, Inc.  
Texas Eastern  
The Signal Companies, Inc.  
The Stanley Works  
Sun Company, Inc.  
TRW  
Tandy Co.  
Tennant Company  
Textron, Inc.  
Time Inc.  
The Times Mirror Company  
Transamerica Corporation  
The Travelers Insurance Company  
Union Pacific Corporation  
United Life & Accident Insurance Company  
United Parcel Service of America  
United Technologies Corporation  
The Washington Post Company  
Wellington Management Company  
Westinghouse Electric Corporation  
Yankelovich, Skelly & White  
Yarway Corporation

## Donors Get New Tax Break

If you are one of the 70 percent of Americans who don't itemize your income tax return, you are now eligible for a deduction for charitable contributions.

During 1984 you can deduct 25 percent of your contributions up to a total gift of \$300.00 (a \$75 maximum) for a joint return, \$150.00 (a \$37.50 maximum) for an individual return or married person filing a separate return. In 1985 you can deduct 50 percent of any charitable contributions and in 1986 you can deduct 100 percent of your charitable contributions.

There are two important things to keep in mind. One, this deduction expires at the end of 1986 unless it can be shown that it is widely used and valued. Take advantage of it now so Congress can be persuaded to extend it.

Two, be able to show receipts or descriptions of your gifts so that the Internal Revenue Service can verify them. The IRS is understandably concerned that this new major opportunity for givers will be impossible to monitor. It is in the best interest of everyone to be attentive to means of verification.

**Stolen from\*\*\***

**National Tuberous Sclerosis Association, Inc.**

### WORK EXPERIENCE



A MO parent wrote that their daughter, Sheila, who is 18, was able to have a job through a federally funded program for the second summer. The first year she worked as a custodial aide at the local school, and the second year she was hired by a non-profit day care center. She worked 30 hrs. a week for the 6-week program with children ages 2-12.

She did not miss one day of work, and her self-esteem just beamed as all of the children referred to her as "Miss Sheila." Of course eating is always a problem, but she at least maintained her weight and her good temperment far outweighed any bad effects there might have been.

Sheila also benefits greatly from the monthly meetings that the MO chapter holds, where the young people meet separately from the parents' meetings.



## VA MEMBER SHARES: LEARNING DISORDERS REVIEWED

An article written by Sandra Blakeslee of the NY Times News Service was very interesting regarding breakthroughs in biological mechanisms. The emerging view is that hundreds of different agents--genetic factors, drugs, hormones, infection, injury and so forth--can cause changes in brain structure or function that can lead to learning disorders. Brain tissue studies show patterns of abnormalities. Since the structures are formed during fetal development, it appears that some disorders stem from imperfections in prenatal "hardwiring." One geneticist found that the chromosome 15 may carry a gene, or genes, associated with one subgroup of reading disorder. One can't help but wonder if the reading strength of people with PWS may also be associated with this gene since a deletion has been noted.

Another researcher mentioned the association of the amount of testosterone produced by the fetus, and its association with brain development. Testosterone inhibits the development of major structures of the immune system, hence the association with allergies and learning disorders. Chromosome 15 plays an important role in testosterone production and immunities. All of this certainly makes us wonder about the various symptoms of PWS, the lack of sexual development, the existence of rare viral infections and so forth. Another genetics article recently stated they expect many genetic diseases to be eliminated in the 1990s. Many interesting things are happening.

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THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members.

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