

PRESIDENT'S MESSAGE

The goal of this Association for the past five years was established and carried forth by its founder, Gene Deterling. The Prader-Willi Syndrome Association is a legally constituted and incorporated organization that now has all the attributes necessary for the accomplishment of its stated purposes as defined in the Bylaws.

"The purpose of the organization shall be to protect and promote the best interests of all persons affected by Prader-Willi Syndrome; to act as a vehicle of communication on Prader-Willi Syndrome related matters and to publish and distribute such material to all members of the organization (but not necessarily restricted to members of the organization); to promote the establishment and improvement of facilities and the management of such facilities for the treatment, study, education, shelter, recreation, recuperation and other general benefit to Prader-Willi Syndrome affected persons; and to act as a focus for scientific, educational, and charitable activities related to the syndrome."

In order to accomplish these purposes the Board one year ago passed a motion creating the following committees: Residential, Clinic Services, Vocational Training and Placement, Fund Raising, Respite Care, Recreation, and Research Promotion. At this years meeting the Education committee was added. The Scientific Advisory Committee has also been mandated by Board action.

As responsibilities of the Association increase it is necessary to find volunteers for the jobs. At the present time ten percent of our membership has volunteered for committee positions, more are needed. This is an opportunity for each of us to become experienced and knowledgeable in one or more aspects of the Associations work. Your expertise will develop along with your fellow committee worker. The goal of committee work is to organize all information beneficial to persons affected with or interested in Prader-Willi Syndrome. This information will then be available through the Association office for all who need or desire it.

The scientific Advisory Committee will be chaired by Dr. Bryan Hall, who has been instrumental in defining our current understanding of Prader-Willi Syndrome. He has been given the task of forming a committee of persons knowledgeable in diagnosis and management of Prader-Willi Syndrome problems. I have assigned that committee the task of applying the principles of scientific investigation to information circulated by the Association.



GATHERED EXCHANGE, continuedHas anyone else had any experiences with this?

We have a 16 year old PW boy. We are presently trying Delatestryl injections to help his growth under supervision of an endocrinologist, and will probably have comments to make on the results by next year.

Georgia Parent

Smoking

An Illinois parent wrote us that she is very concerned about her Prader-Willi daughter smoking, and wondered if any other parent has been successful in helping them stop. If any of you would care to write your experiences, we will publish them in the next issue of the GV.

Clinical Research Unit

CRU has been involved in the treatment of clients with the PW syndrome for several years. Your newsletter is perused and enjoyed by most of our staff members. We have recently admitted our eighth (PW client), 3 of whom are still in residence. We continue to have excellent success in weight reduction, improvement of self-help skills and in reducing the frequency of self abuse. Our attempts to refine interpersonal skills have met with varied success and we have had very little effect on the frequency and severity of temper tantrums and aggressive behavior.

After-care remains a major problem. Only one resident has maintained an appropriate weight a year or more after termination of treatment. We do not know of an appropriate residential care facility in southern California for adult PW's.

Excerpt from letter of B. D. Marshall, Jr., M.D.  
Clinical Research Unit, Camarillo State Hospital

Colorado Member

Donna Gunnison is a 25 year old young lady living in Colorado that would like to become active with some other young Prader-Willi adults. Donna wrote us, "I'll consider myself very fortunate to have something about me in The Gathered View, in order to get a discussion group going in my area. The very thought of me being the initiator of such a group makes me feel happy inside."

Please write or call Donna if you live in her area. Her address is:

Miss Donna Gunnison  
2005 West 33rd Avenue  
Wheatridge, CO 80033

In Memoriam

It is with regret that we report the death of Paula Carman, M.O.T., O.T.R. Paula (formerly Paula Schmidt) was a member of the team of professionals at the Prader-Willi clinic at the Child Development and Mental Retardation Center of the University of Washington. Paula contributed the exercises for developing strength to our booklet, "Prader-Willi Syndrome—A Handbook for Parents". She was also a contributor to the book on Prader-Willi syndrome that is being edited by Dr. Vanja Holm and published by University Park Press. She will be greatly missed, as she gave more than her expertise to the children she served—she gave of herself as well.



WELCOME TO TWO OF OUR NEW BOARD MEMBERS

R. F. Scott  
Board of Directors

Bob Scott, age 44, lives in smoggy Pasadena, California, with his wife and family. Their oldest son, Robert, age 15, was diagnosed (as many PWS people) by the family, four years ago. This diagnosis was later confirmed by the medical profession.

When not actively involved as president of the Prader-Willi California Foundation, Bob is employed as a Senior Planning Consultant for Atlantic Richfield Company in Los Angeles. A native of Kentucky, he graduated from the University of Kentucky with a business major and from the University of Chicago with a masters degree in economics.

As those of you who attended the National Convention may remember, Bob intends to pursue an active role in the national organization with special interest in acquiring suitable educational and residential placement for those citizens with Prader-Willi Syndrome.

Andree Walczak, Board of Directors.

Here is my life in a "nutshell":

I was born in Bern, the capital of Switzerland. After graduating from the University of Geneva, I sailed to New York on the old Queen Mary. After my internship there, I finished my residency at the University of Chicago.

My husband is the president of a Savings and Loan Association. We have four children: Marc-Henry, 23, involved in music, Michelle, 22, studying to become a nurse, Colette, 20, who is studying ancient Greek and the classics, and Teddy, 15, the "professor" who dreams of a career in astronomy and physics.

After a swing at private practice, I was asked to fill in as the pediatrician of the Dysfunctional Child Center at Michael Reese Hospital (a multidiscipline team geared at evaluating and treating multiply handicapped children) and I became so involved in helping the children and their families that I have been working there for the past 16 years!



DEVELOPMENTAL CHARACTERISTICS OF THE MENTALLY RETARDEDDegrees of Mental RetardationPre-School Age 0-5    Maturation and Development

MILD	Can develop social and communication skills; minimal retardation in sensorimotor areas; often not distinguished from normal until later age.
MODERATE	Can talk or learn to communicate; poor social awareness; fair motor development; profits from training in self-help; can be managed with moderate supervision.
SEVERE	Poor motor development; speech is minimal; generally unable to profit from training in self-help; little or no communication skills.
PROFOUND	Gross retardation; minimal capacity for functioning in sensorimotor areas; needs nursing care.

School Age 6-20    Training and Education

MILD	Can learn academic skills up to approximately sixth grade level by late teens. Can be guided toward social conformity "Educable".
MODERATE	Can profit from training in social and occupational skills; unlikely to progress beyond second grade level in academic subjects; may learn to travel alone in familiar places.
SEVERE	Can talk or learn to communicate; can be trained in elemental health habits; profits from systematic habit training.
PROFOUND	Some motor development present; may respond to minimal or limited training in self-help.

Adult 21 and Over    Social and Vocational Adequacy

MILD	Can usually achieve social and vocational skills adequate to minimum self-support but may need guidance and assistance when under unusual social or economic stress.
MODERATE	May achieve self-maintenance in unskilled or semi-skilled work under sheltered conditions; needs supervision and guidance when under mild social or economic stress.
SEVERE	May contribute partially to self-maintenance under complete supervision; can develop self-protection skills to a minimal useful level in controlled environment.
PROFOUND	Some motor and speech development; may achieve very limited self-care; needs nursing care.



## RESIDENTIAL FACILITIES

Last issue of GV published a report from the Residential Facilities Chairman regarding the efforts to establish a home in Minnesota for Prader-Willi people. We couldn't begin to share everything the Minnesota group has done in time and effort, in their attempt to obtain this goal, but we felt you may be interested in an evening news commentator's report following the city council hearing:

Al Austin, Evening News Commentator, Channel 4, Minneapolis

Mr. Austin: For about a decade Minnesota has been moving away from the use of big State Hospitals and Institutions for people with handicaps or emotional, or mental disorders, in favor of community centers or group homes. A far better way, most agree, to prepare people for life in the real world, but there is a hitch. Where should the group homes go?

Wendy Virnig has a birth defect most people never heard of, Prader-Willi Syndrome. An addiction to food, unregulated, it could kill her. It has caused her some mental retardation, sterility, loss of coordination and other handicaps. Her friend, Kathy Olson, has the same disorder. When it was finally diagnosed about three years ago, she weighed 240 pounds. She's lost 80 pounds of that through an extremely limited and closely supervised diet along with therapy. A regime that can strain the family; cupboards and refrigerators must be locked, brothers and sisters with normal appetites must eat furtively. Wendy's mother, Karen Virnig, and other parents have been trying to start a group home for 15 young people with Prader-Willi Syndrome, where intense supervision and treatment will be possible.

Karen Virnig: (Karen made a comment about the type of home and neighborhood that the group was seeking for a home and stated we had found what we were looking for in the home in Minnetonka.)

Mr. Austin: There's one problem. (A lawyer representing the neighbors stated they wanted to maintain a single-family only neighborhood.)

Mr. Austin: Because of the neighborhood opposition, the group home can be approved only if 5 of the 7 Minnetonka Council members vote "Yes". Two, including Mayor Yager, say they'll vote "No" even though they say they are for it in concept. They won't vote against neighbors wishes. Mayor Yager offers to help find a location away from a neighborhood residential setting.

Karen Virnig: We recognize that handicapped individuals are people too. They have a right to live in regular neighborhoods, real neighborhoods. Not next to a box factory or something like that, but neighborhoods the same just as you and I do.

Mr. Austin: The City Council finally votes 5-2 to allow the group home. Other city councils have been less willing to buck neighborhood opposition. In Minneapolis, a group home for epileptics was rejected this month because Alderman Charlee White, indicating she favors such projects, engineered it's defeat because of neighbor resistance. Such resistance is not always as courteous as it was in the Minnetonka case.

Unidentified Spokesman: Everybody in the neighborhood is against this, to the best of my knowledge.

Mr. Austin: (Comments on a St. Paul attempt for group homes for adolescents.)

Unidentified Spokesman: You don't care how you spend it, you don't care about my feelings. I got my whole life savings in that house and I'm going to do every damn thing that I can think of to stop that thing from going in there because I don't think it's the place for it. If you want to do that sort of thing, go out in the country some place, buy a farm or something. I'm sure there is a lot of farm houses available for that.

continued



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## RESIDENTIAL FACILITIES, continued

Mr. Austin: (Commented recent group homes have been delayed with these arguments.) "A group home will hurt property values, cause traffic and parking problems and change the character of the neighborhood."

Group Home Spokesman: (He cited an example of a small group home for young retarded adults in another Minneapolis suburb that won over the neighborhood after it was established for 6-8 months.)

Mr. Austin: Beyond the fact that badly needed group homes are being delayed or rejected because of neighbors resistance, that resistance has an even more serious effect. It insults people with handicaps, signaling, however politely, that they are not welcome among normal people. One can't help wondering how those who want to keep their neighborhoods free of such homes can be sure that they, or their children, or their grandchildren, will never need this kind of help. And if they do, to which neighborhood will they turn?

### PWS ID CARD

A conference suggestion was made by Dr. Tom Johnson of Port Ewen, NY that an ID card be available in the event that a PW person does get arrested for shoplifting food. Unfortunately, "food sneaking" in the home becomes "stealing" in a store.

It was suggested by a couple of PW parents that this card be used discreetly so it would not become a license to steal.

We thank Dr. Johnson for writing this card for us and have attached a card to this issue of the GV. He also suggested lamination would preserve wallet carrying.

### "Brown Bagging Idea"

3 ounces drained canned kidney beans  
1/3 cup chopped celery  
1/2 medium dill pickle, chopped  
1-1/2 ounces diced cooked turkey  
1 ounce onion, grated  
1 tablespoon imitation mayonnaise  
1 tablespoon prepared mustard  
2-3 romaine lettuce leaves

Combine first 7 ingredients. Place lettuce in the bottom of a container or wide mouth insulated jar. Top with bean mixture; cover and chill. Makes 1 serving. (Md) Per serving: 245 cal, 23 g pro, 6 g fat, 28 g car, 752 mg sod.

### Three PW Campers in Florida





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PLEASE SEND ORDERS TO:

PRADER-WILLI SYNDROME ASSOCIATION  
5515 MALIBU DRIVE  
EDINA, MN 55436

We were hoping to be able to offer all of the conference papers at this time, unfortunately, the presenters are busy people and transforming an oral presentation to written form takes time. We will offer the following papers now and hope to add Dr. Hermann's paper (which he was unable to present at the conference) in November.

We were not able to secure papers from Dr. Sue Warren and Elizabeth McArthur.

The remaining presenters did not have material suitable for publication.



## WORKSHOPS

Free workshops for parents of handicapped children are scheduled in several Minnesota communities this year, sponsored by the Parent Advocacy Coalition for Educational Rights (PACER Center, Inc.)

The workshops will inform parents of their children's rights and responsibilities in special education and will help them learn how to communicate effectively with schools. Locations are: Brainerd, October 8th, Cragun's Lodge; Minneapolis-St. Paul, October 21st; Cold Spring, October 23rd; Bemidji, November 18th, Holiday Inn.

Additional workshops are planned for other Minnesota towns. Dates and locations will be announced in these communities.

BMT one day workshops are being presented around the country to instruct in the management of disruptive behavior. For information write:

Luke S. Watson, Jr.  
BMT, Inc.  
P. O. Box 3251  
Tuscaloosa, AL 35404  
(205) 345-1833

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THE GATHERED VIEW is the official newsletter of the Prader-Willi Syndrome Association and is sent to all members. Membership dues are \$10.00 per year for U.S. members; \$15.00 per year for Canada, Mexico and overseas members. Send dues and change of address notices to PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436.

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