

PRESIDENT'S MESSAGE

From my perspective, one of the more interesting aspects from our recent National Conference was the thirty-four Prader-Willi people who attended and took advantage of the opportunity to meet and know others like themselves who are learning to live with the syndrome. In spite of the truth that there is a remarkable similarity in characteristics between all Prader-Willi people, there was no shortage of individualism displayed by this group of people. They each brought their own distinct personalities, their own private concerns, and their own physical and mental capabilities. They came in differing sizes and shapes and varying degrees of personal development. In essence, they displayed the same variety of humanness that the rest of us have. It was only the range of capability that was limited. But where they had more obvious weakness, they demonstrated characteristics that all of us must admire. They carried their burden with a smile and friendly warmth that should make any parent as proud of them as of any child.

To my knowledge, this was the largest gathering ever of Prader-Willi people. They varied in age from three years old to twenty-eight and for many of them it was the first time they had ever seen another Prader-Willi person. They laughed and cried together and even fell in love with each other. Friendships were made that may very well be life-lasting. Not all of them, of course, shared the same exuberance, but I overheard enough to assure me that this event was one of the more memorable ones in these people's lifetimes. One nineteen year old young lady who freely admitted having fallen in love with a PW boy at the conference, remarked as she was leaving with tears in her eyes, "I'm coming to next year's conference even if I have to come without my parents." Most of the others parted with "I'll see you at next year's conference". The PW people's program was not the major portion of the National Conference, but it took on an element of major significance in the measurement of the success of our three-day gathering on Cape Cod.

You'll be reading more about the rest of the Conference on other pages of this "Gathered View", so I won't attempt to condense the results in this message. One of the key items from the Board of Director's Meetings, however, merits highlighting at this time. After five years, since the formation of our organization, we have a new President. We also modified our bylaws to provide for an Executive Director to manage the day-to-day operation of the organization.



PRESIDENT'S MESSAGE, continued

And then we established the new officer position of Recording Secretary and changed the title of treasurer to Secretary/Treasurer. I hope you will all warmly welcome our new President, Dr. Delfin Beltran, who will now provide the direction for our future as well as direct the activities of the Executive Director. Marge Wett has been appointed Executive Director and will continue to perform many of her previous duties as well as delegating as many of the routine activities as possible. Although Marge will now have more responsibility and more authority, she will also be able to hire assistants (within the constraints of our budget). The overall intent of these modifications is to establish the vehicle to manage the increasing workload associated with our growing organization.

Along with these three shifts in our organizational structure, Dr. Richard Wett has been elected Chairman of the Board to replace Dr. Delfin Beltran. This is the highest level position in our Association but depends upon the other board members for support and finalization of decisions. The Vice President position has been filled by Shirley Neason, one of the founders of our organization, and who after five years has stepped down as Editor of The Gathered View.

As I step down from President (I will still, however, remain for another year as Secretary/Treasurer and have just been elected to the Board of Directors), I do so with confidence that the goals we established for ourselves five years ago have now been met. Primarily, that means that "the organization has been established", and barring any tragic and unanticipated events, it will be perpetuated forever. I'm proud of that, and I'm proud of the support our membership is now providing. It truly has been an overwhelming amount of work for me because of my other fulltime job, but as I write these final words in my final President's message, I can honestly say it has all been worthwhile.

*Gene Deterling*

WELCOME

Along with the changes mentioned in Gene's message, you may have noticed a new name on the front page. Marilyn Jorgensen has agreed to take over the position of Editor for our newsletter. Even though Marilyn is a very talented individual, her success in this position will depend on you - the membership. A newsletter cannot be a success without participation of all of the contributors. PLEASE continue to share your knowledge and experiences with us.

Marilyn and her husband, Harlan, an Anesthesiologist, live in a western suburb of Minneapolis with three of their four sons. Brad is married, Greg and Craig are in college and Kurt is 13. The Jorgensen's have lived in Minnesota for 17 years and formerly were from Nebraska.

Marilyn and Harlan do not have a Prader-Willi child. Marilyn has very generously offered to do our newsletter on a volunteer basis. We hope support comes from all of you in the form of a full mail box.

THE MEDIA VIEW

Not long ago, Italian scientists found a protein they named bombesin, in the skin of a frog. Dr. V. Erspamer of the University of Rome suggests that bombesin may be useful in treating obesity. It causes the production of the chemical that signals your brain that you're full. Experts at the Salk Institute in San Diego say that bombesin reduces fever and influences the way carbohydrates are used by the body. All the scientists agree that the substance will play an important part in medicine in years to come.

from Current Health  
from a Wisconsin member



THE MEDIA VIEW, continued

Dr. Sarfer Niazi, an Illinois pharmacologist, has found a thinning compound, perfluorooctyl bromide, that coats your gastrointestinal tract, temporarily blocking the absorption of food. Foods pass through without depositing a single calorie.

Rat testing has shown no adverse effects to the drug, and the wastes they excreted were normal, if rich in nutrients. Tests with rabbits and guinea pigs were running smoothly. Next, Niazi will try the slenderizing drug on chimpanzees. If it works, he'll schedule tests for people who are dangerously overweight.

from the Detroit News  
from a Michigan member

After reading the above letter, we wrote Dr. Niazi a letter at the University of Illinois, Chicago. We received a form letter stating the drug was still in the testing stage. When talking with a couple doctors they stated the usual sequence was animal testing, publicity, grant application and then human studies, and that the usual time period was from five to seven years. This was rather discouraging news but at least we know some research is being conducted that may eventually help one of the problems in the syndrome.

MEMORIALS

The Association officers, board and members extend their sympathies to the families of Michele Marinari and Daniel Neason, two Prader-Willi young people that died recently.

We also extend our appreciation for the memorial funds that have been donated through their request.

2nd ANNUAL CONFERENCE

Over one-fifth of our membership was able to attend our conference at Cape Cod, Hyannis, Massachusetts in June, bringing along 34 Prader-Willi young people and other siblings. The parents and interested professionals were able to listen to several experts make presentations on various aspects of the PW syndrome. We feel the people were afforded ample opportunities to ask questions and discuss problems. We hope in the near future to make copies of some of the presentations available to anyone interested as we did last year.

Dr. Andree Walczak, Chicago, gave a very interesting presentation regarding their Dysfunctional Child Center and the multiple specialists involved in treating PW persons.

Dr. Stephen Sulzbacher presented the details of a study done with a group of PW persons if sugar consumption affects behavior. In his summary he concluded there was no proven effect.

Drs. Betty Schultze, Sulzbacher and Sue Warren presented a variety of facts involved with the education of PW persons and their legal rights as they relate to the exceptional child.

Continued



2ND ANNUAL CONFERENCE, continued

Elizabeth McArthur, Behavioral Specialist, talked about behavioral learning theories as well as joining in a panel including Jeanne Regan, Elizabeth Bahling and two previous presentors.

Following their presentation, Drs. Macko and Poole, scheduled appointments with a greater percentage of the PW people evaluating the dental and oro-facial problems which are particular to the PW person. They hope to add more statistics during the year at the University of Connecticut Health Center and return to next year's conference with their findings.

Dr. Stacy Roback, surgeon, presented a very interesting and frank look at testes surgery. He stressed each individual PW person needs to have his own type of treatment outlined by his own physician.

Dr. Ralph Nelson, Illinois, talked about some of the special medical findings about obesity in the PW person.

Dr. Bryan Hall presented information regarding features of the PW person and the increase of misdiagnosis. His presentation included a very interesting set of slides.

A special parent discussion program conducted by Dr. Beltran and Dr. Wett, closed the second annual meeting. Information provided by these two doctors as parents and the opportunity for parents to discuss problems was appreciated.

How fortunate we are to have the interest of so many of these people working with our children's problems.

A greater percentage of the members present attended the Annual Board Meeting and a summary of the business conducted is included in this newsletter.

Discussions on many subjects were held during the meetings and suggestions were made. We have listed some of these in this newsletter for your interest.

Robert Scott, President of the California foundation, made a presentation during the Friday evening dinner regarding their efforts in opening a group home. The Dubnof Center has hopes of opening their first PW home this year.

Due to the efforts of many people, we feel this year's conference was again a big success. Gene and Fausta Deterling, Cellie, Ralph Ledoux and their family, Don Salerno of the Greater Enfield Association for Retarded and Handicapped Citizens and his secretary Elaine Nason must be singled out for the time and effort expended in organizing and running this conference. We mentioned earlier how fortunate we are to have the interest of the professionals, we are equally fortunate to have such a dedicated membership.

submitted by Marge Wett



INFORMATION SOUGHT

Information which would be of value in defining the oral-facial characteristics of the PW syndrome is being sought by Dr. Douglas Macko and Dr. Andrew Poole, Department of Pediatric Dentistry, University of Connecticut Health Center, Farmington, Connecticut 06032.

- (1) Lateral and Anterior/Posterior Cephalometric X-Rays of the Head.
- (2) X-rays of the teeth (Panorex or Intra oral).
- (3) Wrist X-ray, preferably of left hand and wrist.
- (4) Upper and lower models of the teeth.
- (5) Data on Height and Weight with increasing age.
- (6) Photographs - full face from front.  
lateral head from right and left.  
(These should ideally be taken with the eyes looking straight ahead.)

We realize that all this information may be impossible to collect on every child but any information that can be obtained would be useful. Please send this to the above address and we will be glad to forward copies of the information when processed to anyone interested.

submitted by Dr. Douglas Macko and Dr. Andrew Poole  
Telephone (203) 674-2180

BOARD MEETING MINUTES, JUNE 20, 1980 - HYANNIS, MASSACHUSETTS

## Order of Business:

Formal report of the President - Mr. Deterling.

Significant events of the year; financial/projected/proposed budgets.

## Board Action:

Proposed budget approved.

## Proposed bylaw changes changing officer structure:

Paragraph 1, page 2, change of offices; Paragraph 3, second sentence regarding responsibility of President; add third paragraph regarding duties of Executive Director; add new paragraph regarding expenditure approval.

## Board Action:

Motion made for acceptance of bylaw changes by Dr. Sulzbacher, seconded by Dr. Wett.  
Motion carried.

## Open discussion regarding increase of dues.

## Board Action:

Motion made for increasing dues for Canada and overseas to \$15.00 per year, U.S. to remain at \$10.00 per year by Dr. Sulzbacher, seconded by Fausta Deterling. Motion carried.

Continued



BOARD MEETING MINUTES, continued

Open discussion on make-up of board members regarding separation of parents and professionals.

Board Action:

Motion made to increase board to 18 members. Second motion made to form a Scientific Advisory Committee separate from board consisting of all professionals, by Dr. Sulzbacher.

First motion increasing board size defeated.

Second motion forming S.A.C. carried.

Point of order question by Dr. Sulzbacher: Can the board change its size? Conclusion board could do so and membership can correct any action of board if they feel board is not behaving appropriately.

Motion proposed to increase board size to 12 by Dr. Beltran, seconded by Dr. Wett.

Motion carried.

Committee Reports:

(1) Dr. Betty Schultze, Chairman of Clinic Services

(2) Gene Deterling for Lois Olson, Chairman of Residential Placement

Bids were made by two individuals for location of next year's conference.

(1) Kansas City, MO Co-Chaired by Eleanor Watson and Dr. B. Schultze.

(2) Boca Raton, FL Chaired by Dr. M. Caldwell of Florida Atlantic University

Board Action:

Postponement of location decision.

Nominations for Board: Six places to be filled.

Robert Scott, CA (parent)

Lota Mitchell, PA (parent & professional)

Peggy Pipes, WA (professional)

Betty Schultze, MO (professional)

Dr. Hall, CA - declined

Andree Walczak, IL (professional)

Fausta Deterling, MN (parent)

Mary Lou Caldwell, FL (professional)

Dr. Zellweger, IA - declined

Gene Deterling, MN (parent)

Annette Dahlman, CA (professional)

Elain Unger, NY (parent)

Board Action:

Motion made to close nominations by Dr. Sulzbacher, seconded by Mrs. Deterling. Motion carried. Vote until noon the next day.

Officers slate presented for board appointment:

President: Delfin Beltran

Secretary/Treasurer: Gene Deterling

(Secretary, non-working, official keeper of seal.

Vice President: Shirley Neason

Recording Secretary: Richard Wett

Rec. Sec. Annual Meeting only)

Board Action:

Motion made to accept slate of officers by Dr. Beltran, seconded by Dr. Sulzbacher.

Motion carried.

Motion made to add "Education Committee" to forming committee's list by Shirley Neason, seconded by Dr. Hall. Motion carried.

Board meeting continuation:

Board Action:

Dr. Wett resigned as Recording Secretary to accept Chairman of Board position. Fausta Deterling accepted Recording Secretary position. Dr. Beltran appointed Marge Wett as Executive Director. Announced voting results: Fausta Deterling and Peggy Pipes re-elected. Gene Deterling, Andree Walczak, Robert Scott and Lota Mitchell elected as new board members.

Board Meeting was closed.



SUGGESTIONS MADE DURING CONFERENCE

Print more educational material in The Gathered View.

Ask for donations to fund committees.

Request people let us know what they are doing for the newsletter.

Invest savings for better interest.

Raise funds for conference by approaching corporations and foundations.

Raise dues to finance hiring part-time help to relieve workload of Secretary.

Increase dues and mail newsletter first class for faster delivery.

Add statement on application and renewal, minimum dues so those who can afford a larger amount can help support those who cannot afford dues increase.

Trial memberships

Earmark any united funding appeals to support our organization.

LET US HEAR WHAT YOU THINK ABOUT THESE SUGGESTIONS.

MOVING??????? HAVE YOU SENT US CHANGE OF ADDRESS???????

Bulk mail is not forwarded nor returned. If you want uninterrupted delivery of your newsletter, we must have your current address.

Please use 5515 Malibu Drive, Edina, MN 55436 for all business. Use Marilyn Jorgensen's address only for items for newsletter.

PUBLICITY

Due to our "Dear Abby" column, we were asked for information regarding our organization from the ABC TV Program 20/20. We have not heard anything from them since their request. Maybe a few letters from our membership would call attention to our organization again. They recently did a show on Anorexia Nervosa and did an excellent presentation. This type of exposure could help our organization in our seeking to be known to those who need information on the syndrome. Please use this address:

Alexandra Chalusiak  
Production Supervisor  
20/20, ABC  
77 West 66th Street  
New York, NY 10023



HEY! THAT'S GREAT!

Dan, Colorado Member



Steven, age 7

Dan is being congratulated as he was honorary engineer for the Mini-train, Burlington Northern, and was presented with a bronze belt buckle.

But Dan doesn't look the same now, three years later, because a proper home placement is not available in the Colorado area. His residence tries and they do care, but the food control is not adequate. Hopefully, we will be able to change this condition as the unique needs of these young people will be recognized and met.

Steven's parents are very proud of him and we are very proud of his parents. Steven's father recently wrote us this letter:

Several months ago, the PWS financial status was published in one of the monthly newsletters. It was indicated that a fund drive was conducted with some success, but the association was still in need of money. Personally, being an enlisted member in the Air Force, my budget did not allow for any significant contribution. However, I felt a need to try and do something. When you are the parent of a PW, your motivation seems to be there.

I decided that I would conduct a raffle to raise money for the Association. To assist me, I asked that the Air Academy Chapter Non-Commissioned Officer's Association at the Air Force Academy and the Knights of Columbus in Brunswick, Maine help sell the tickets. I am a member of both of these organizations. I wrote letters to both organizations and both responded favorably.

However, because gambling is not allowed on a military installation, the base legal office determined that the Air Academy Chapter NCOA could not conduct a raffle. On the other hand, the Knights of Columbus in Brunswick, Maine (my home town) were allowed and went ahead with a raffle. At this point all raffle tickets are sold and a drawing is scheduled for the 4th of July. The proceeds will be in the neighborhood of \$800.00. The check will be forwarded to you by the K of C sometime in July. The entire membership responded with this project. Many had never heard of PWS. I forwarded to them much literature on the subject to acquaint them with PWS. My brother is the Grand Knight of this council and did much to get things going. I believe that the check will be given in behalf of our son Steven, our PW.

Continued



HEY! THAT'S GREAT!, continued

I hope this will help with some of the expenses of the Association. I'm sorry that it wasn't more. I'm still working on the NCOA to make a one time donation. Hope it comes through. My heartfelt thanks really goes out to my fellow K of C members.

Member from Colorado

VOCATIONAL PLACEMENT

This letter was received from Robert C. Allia, Heritage Training Center II, in Peabody, Massachusetts:

I recently joined the PW Association and you sent me a letter mentioning that PW people have problems with vocational placements. The person in our shop with PW (there is only one) did have behavior problems in the larger sheltered workshop associated with us. This was rather disruptive to other workers there and resulted in several suspensions. Heritage II is a smaller workshop providing a lot more individual attention along with a lot of structure. Since this person has been with us, there was one minor incident over the past 4-1/2 months. Limits were set when needed and the rules of the workshop explained and there has been a lot of success. Food is not a problem since the workers bring their own lunch and we don't sell any food here.

We are a specialized workshop, dealing with ED/MR adults only and I agree that PW people need this type of service but with this format, I believe these people can be productive workers.

(Editorial note: Bob has added his name to the Vocational and Training Committee. We appreciate his letter and offer of assistance.)

SUPPORT GROUP

Excerpts from a report by David Volz, Residential Supervisor for a Minneapolis Residence:

Presently we have seven young adults with PWS that participate in a Support-Discussion Group for Young Adults. The basic format of the group was established by the participants and myself. All discussions are to remain confidential between group members. There is to be no information relayed to parents, counselors, or other staff involved with the participants.

All group participants decided that the reasons for meeting were:

1. To let out frustrations about constant dieting, and having parents or faculty staff monitor their food intake.
2. To discuss personal, medical, and behavioral problems as well as dating and relationship problems encountered by each other in their daily lives.

The group members also decided to form a "Prader-Willi Hot Line". This phone number exchange is to be used to help each other when one member feels the urge to go off his/her diet. The "Hot Line" has been used, and in several cases it was effective.

Continued



SUPPORT GROUP, continued

At present the members have used the group meetings very constructively. There has been much venting of frustrations, and some constructive solutions reached through counseling, and support by members and myself as moderator.

The group voted on an expansion of our functions to include outings in the community for recreation and socialization.

It is my personal feeling that the discussion-support group has been a successful venture for all persons involved. I do not feel that the group has helped curb the appetites of any member, but I do feel that it has provided a vehicle for our seven members to express their feelings, frustrations, and opinions about having PWS, and coping with their daily problems.

PW HOME

As some of you may be aware, the Minnesota group is attempting to open a PW residence. Work has been going on for many months now and unfortunately the process is very time consuming, the details and requirements unending. Two people have taken on the mammoth job of making this residence a reality. Through perseverance they have surmounted some of the obstacles in obtaining this goal. Two approvals have been granted, three remain yet to be obtained. Here is their report:

Within a few days of accepting the chairmanship of the Residential Facilities Committee, I was contacted by a health care consultant who knew of our need for a group home for PW young people. A home, located in a Minneapolis suburb, suited our needs. With the help of Karen Virnig, we decided the first step needed was educating the city residents regarding PWS. We also had the typical problem of dealing with very stiff neighborhood resistance because the home was in a neighborhood zoned single family residences only.

We began by first contacting the near neighbors, feeling that we wanted them to get the information directly from us rather than from unreliable rumors. We were not received cordially by the majority of them, although some did listen to our plans. The next day we met with pastors of several churches, explaining the syndrome and our need for the proposed home. They, in turn, gave us names of people active in the social concerns of their churches. Through these people, information was placed in publications, reaching a majority of citizens in the community. We were also interviewed by the St. Paul, Minneapolis and Minnetonka newspapers.

We arranged a meeting with the entire council so we could inform them of PWS and the need for this home. We searched out any individual or group that might help us. We got supportive letters from doctors, the churches, individuals and also people connected with the University of Minnesota. We asked any group we met with to circulate petitions to be signed in favor of the home. After applying for the permit, we made sure we contacted each member of the Planning Commission before that meeting and each of the Council members before that meeting. Further preparation for each of these meetings included lining up people to attend in support of us and, in some cases, to speak in our behalf.

Ultimately, we did receive our Conditional Use Permit from the City of Minnetonka to establish a home for 15 Prader-Willi young people.

In the next issue of The Gathered View we will give details about the meetings with these two groups and our progress in obtaining the state license for the home.

Residential Facilities Committee  
Lois Olson, Chairman



Dr. Walczak would like to obtain some background information regarding the descent and pregnancy of parents of PW people. She would appreciate you filling out and returning this form to:

Andree Walczak, M.D.  
Michael Reese Hospital & Medical Center  
3rd Floor, Kunstadter Building  
2915 South Ellis Avenue  
Chicago, IL 60616

PRENATAL AND PREGNANCY INFORMATION

Child's Name \_\_\_\_\_

Child's Birthdate \_\_\_\_\_

Rank in family, i.e. 1st, 3rd \_\_\_\_\_

MOTHER'S DESCENT

National Descent:

Maternal Grandmother:

Maternal Grandfather:

Great Grandmother (both sides):

Great Grandfather (both sides):

FATHER'S DESCENT

National Descent:

Paternal Grandmother:

Paternal Grandfather:

Great Grandmother (both sides):

Great Grandfather (both sides):

**Pregnancy:**

- 1) Mother's age at the time of birth:
- 2) Father's age at the time of birth:
- 3) Maternal illnesses:
- 4) Paternal illnesses:
- 5) Siblings' illnesses:
- 6) Maternal fever:
- 7) Maternal accident:
- 8) Maternal rash:
- 9) Maternal drugs:
- 10) Maternal excess weight gain:
- 11) Maternal high blood pressure:
- 12) Maternal anemia:
- 13) Maternal bleeding, spotting, cramps:
- 14) Type of delivery (head, breech, etc.):
- 15) Trip during pregnancy:
- 16) Other factors which might be relevant:



COMMITTEES

A very important part of the future growth of the PWSA is the formation of our eight committees. We have filled the Chairman position on six of these committees but still need two more people to take on the two remaining positions. More members are needed on both committees as well as on the Respite Care Committee. Help us fill in the blanks.

CLINIC SERVICES:	DR. BETTY SCHULTZE	RESIDENTIAL:	LOIS OLSON
VOCATIONAL TRG. & PMT.:	LOTA MITCHELL	RECREATION:	THOMAS JOHNSON
RESEARCH:	TONI PARKER	RESPITE CARE:	GORDON ATOL
EDUCATION:		FUND RAISING:	

\*\*\*\*\*

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.

Among the materials available from the Prader-Willi Syndrome Association is:

"Prader-Willi Syndrome—A Handbook for Parents." \$2.00 for the first copy to members; \$3.50 for non-members and subsequent copies to members.

\*\*\*\*\*