

THE GATHERED VIEW

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Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT

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PRESIDENT'S MESSAGE

As many of you know, I am not a doctor of anything that has to do with Prader-Willi syndrome. My vocation is cardio-vascular anesthesia. The great majority of our patients are on the opposite end of the age scale from our Prader-Willi children. Several weeks ago one of the surgeons on our team commented on the average age of a group of patients we had cared for that week, it was eighty-six with a range from seventy-eight to ninety-two. That brought to mind another statistic that had been presented in a newspaper article about the extensive exposure to toxic materials and cancer causing chemicals and all sorts of challenges to our bodies. The specific numbers are not important but the point was that in the face of these challenges, the average age of survival continues to increase and we living in the USA can expect to live some seventy-two years.

If your mind works as mine does such a statistic causes me to think; if all goes well I'll make it to seventy-two. Since I was somewhat curious at that point, I searched my library until I found a book with an actuarial table (a table statisticians use to discover how many people of a given age are expected to be still living). That was a revealing find because it taught me to look at the other side of the statistic. What they are really saying is that at any given time in the present, half of the people born seventy-two years before that time are still living. Isn't that something! Just by changing my perspective a whole new vista is before me, things that were hidden become apparent. It begs the obvious to say, "Turn over the coin to see the other side."

Now what has this to do with the Prader-Willi Syndrom Association. It has to do with involvement. Marge Wett sends me little epistles from Minnesota keeping me informed with the day to day activities of our organization. The latest letter included the tabulation to date of the votes for the various locations for next year's meeting. Seventy-two votes have been received, seventy-two members are involved. The flip side says, five hundred have not responded, five hundred are not involved. At the national meeting this past June one participant was surprised that this organization did not have a site committee that had meetings planned years in the future as most large organizations do. My response was, volunteer. We are not a large, structured, regionalized association with contacts in each area of the country who can be tapped for committee work, dollars, or time to serve. Our line of communication is this newsletter, our strength is your responses.

Let us turn the coin again. We are growing in size. As one of eight who met in Seattle in 1975 at a time when Shirley Neason reported twenty-six paid memberships, I find that our "paid for" membership almost at seven hundred is a most encouraging statistic. Our goal is to serve the needs of our Prader-Willi persons. In the long run the numbers become unimportant. Numbers follow, daily caring will keep us involved. When your time permits respond,

PRESIDENT'S MESSAGE, Continued

communicate. Every day we face new challenges and resolve them. Many of these solutions are new, or involve others who have special talents. Some solutions involve decisions by governmental agencies at various levels, local school boards, countrywide health agencies, state rehabilitation, Federal regulations. There are committees of this organization that need the information and input of knowledge that you have gained through your efforts to help a Prader-Willi person. Share your knowledge and others will benefit from your involvement.



Some Board Members and Presentors
from FL meeting.

One of the workshops from
the FL meeting.



CA June meeting at UCLA.

SPECIAL BROCHURE

VIA (Volunteer Information Agency) in Quincy, MA has a lovely illustrated brochure that we'd like to share the contents:

THERE IS SOMETHING SPECIAL ABOUT YOU.....You have a brother or sister with special needs in your family. Probably most of your friends don't have a child with special needs in their family.

What does a "child with special needs" mean?

One of the things it means is that the child needs more of your mother's and father's attention than the other children. Just because your mother and father have to give the special child more attention does not mean that they love him more. They love you just as much.

Having a child with special needs in the family means that your life (in a small way) is different from your friend's lives.

HOW IS IT DIFFERENT?.....Well, sometimes you can't do something you want to do because of the special child. That must seem unfair to you.

Sometimes you might feel angry when the special child breaks your toys or messes up a project of yours. It's all right to feel angry.

Sometimes there might be a special occasion when you don't want to be with this child. Did you know that lots of boys and girls feel like you do? Don't be afraid to talk to your mother and father about it and tell them how you feel.

There is something I'll bet you don't know...Do you know that your mother and father care about your feelings...they care about how you feel about having a special problem to deal with.

Tell your mother and father how upset you feel when the special child doesn't understand you. Don't forget...they get upset, too.

There are many nice things that happen to you with a special child. You get a greater feeling of pride over the special child's accomplishments.

There is a special thrill for you and your mother and father to share when the special child reaches a goal.

If you and your mother and father work together, you will have an extra feeling of closeness that only can come from sharing something with deep feelings.

You will develop a greater understanding of all people's limitations and that will make you special...specially nice to know!

THE GILBOUGH CENTER

Nancy M. Drwal, Program Coordinator of the Gilbough Center shared information regarding their new facility. They are currently servicing three girls, but have openings for three more clients in September. We do not know if these are filled at this time or not but they were considering boys or girls and out-of-state referrals.

The Gilbough Center, a program specifically designed to meet the special needs of PWS clients, opened on June 1, 1981. The Center's goal is to provide specialized residential and day services to meet the medical, behavioral, emotional, educational and vocational needs in attempting to lengthen the life span of these clients. The two components, skills center and group home, are able to service six clients 16 years of age and over.

The Skills Center is separate from the residence. The day's activities (9 to 3:30) include vocationally related academics such as time, money and language skills. Pre-vocational skills involve the world of work, job attitudes and preparation, and daily living. Work experience will either be a sheltered situation on the grounds or outside employment.

Their home is located in a neighborhood setting. The young people perform various household chores including laundry, vacuuming, grocery shopping and food preparation. The agency's goal is to create as normal and independent a life style as possible within the limits of the PW client. Teaching the responsibilities of adulthood, peer relationships and weight control is ongoing at the residence and performed by ADL teachers. A nutritionist develops a weekly menu with each day's calories between 900 and 1100. Weigh-ins are charted twice a day and all food sources are controlled. Food allotments are reduced as a result of weight gain from food stealing. A Recreational Therapist works in developing strength, coordination and balance through various activities and exercises. Health needs are also met.

Other activities that take place during the evening hours include diet and PW support group, personal hygiene counseling, and arts and crafts activities. Swimming, bowling and Special Olympics are additional events.

Appropriate behavioral, emotional and social responses are developed through behavior modification without food as a reinforcer. Privilege/reward system and group and individual counseling treatment plans are reviewed quarterly and include time related goals and objectives.

SINGLE PARENT REQUEST

From a MI parent, "I am curious as to how many one-parent homes there are with PW persons in them.....There are problems for single-parents with normal children, I know, and I wondered if there are any with a PW child."

We have started a Pen Pal list for children with PWS. Are you interested in a list for single parents? If you are, write to the home office and they will formulate a list to be shared with other single parents.

LETTER FROM FUND RAISING CHAIRMAN

At the annual convention in June, 1981 at Boca Raton, FL, an appeal was made for a fund raising chairman. After giving it some thought, along with a few encouraging words from Marge and Gene, I volunteered. My "bottom line" reason for raising my hand was NEED—the association's NEED and our PW children's NEED, including my son, Steve. Our association is still very young, and we've managed financially primarily through the membership dues. Members alone cannot support all that NEEDS to be done. We NEED research projects done; we NEED more group homes established; we NEED some paid positions in our organization to maintain continuity; we NEED to keep our association going in order to provide the necessary information for us (parents) to help cope with the NEEDS of our PW child. These NEEDS sound simple enough but the achievement of these NEEDS will be a bit difficult.

In the coming 10 to 12 months, I would like to lay the foundation for achieving these NEEDS. After the 12 month period, it then becomes the goal of all of us to continue and maintain what has been established. Because our membership is so spread out, it is obvious that I cannot tackle such a project alone. It will require an effort on everyone's part. We all NEED to "pitch in" and do a little in order to reap BIG.

Through the association, we will obtain a mailing list and send appeal letters along with information on PW to non-members. This will be on the order of pledges and hopefully, it will be an on-going project. This method has proven successful for other groups. Now, let me outline some ways in which YOU can help raise money.

- (1) Solicit donations from Foundations, Corporations, small companies and small organizations (VFW, K of C, Elks, etc.) You'll need an "in" to be heard by these people (yourself, friend, or relative). You'll also need some good sound information about PW and its' NEEDS in order to "sell" them on a donation. Use The Gathered View as a source of information for stories and our Financial Statement. Your own experiences along with pictures are also valuable.
- (2) Special Fund Raising Events could be started such as Bowling Tournaments, Golf Tournaments, raffles, auctions, etc. Get local merchants to donate prizes, goods to be raffled or auctioned.
- (3) Have your own garage sale or bake sale; have friends/relatives donate items for sale.
- (4) Conduct a Candy Sales Campaign. Kathryn Beich Candies works with non-profit organizations and allows as high as 50% profit margin. I have more details on this if you are interested.

If you need assistance with any of these projects, please contact me. This list is not all inclusive. I'm sure you can come up with ideas of your own. The important thing is that you will be willing to do something. The one key ingredient to remember though is that whatever you do, plan on making it an annual event, if possible. Remember, the entire time you're involved in the project, you'll be getting the word out on PW which is also an important function of our association.

This is my fund raising plan for the coming year. I challenge each member of our organization to undertake a profit making project in their local area. With a membership of approximately 700, if each of us raised ONLY \$100.00 that would mean a net gain of \$70,000.00 for our association. the PWSA needs financial support and also I think our kids are counting on us.

For any project you undertake, make all checks payable to the Prader-Willi Syndrome Association and send all money to the headquarters, 5515 Malibu Drive, Edina, MN 55436. Also, please let me know what you are doing and the bottom line profit after your project. Thank you.

Louis Levesque
Qtrs. 6457-A
USAF Academy, Colorado 80840

JUNE CONFERENCE, 1981



When we are in the position to conduct research, apply for grants, etc. we need statistics. We presently inform people we are aware of approximately 2000 young people with this syndrome. If we were to have to prove this figure, we have 217 names on our "Consent Form" list. We need to maintain a larger list to back up these figures.

Below is a form to add your child's name to our list. It can be either a "Consent" or a "Non-Consent" list. The Consent list would be available for research, the non-consent list would not be shared with anyone.

On the next page is a list of member's numbers that have already shared this information. On the upper left corner of the mailing list is a number, i.e., 010000235. This is 010000 followed by a three digit number. The last three digits (in this case 235) is your membership number. Please check this list, and if your number does not appear, would you complete and return this form to the national office?

PRADER-WILLI SYNDROME LIST

I/We provide below to the Prader-Willi Syndrome Association information including the name and birth date of our child with this syndrome.

NAME _____

ADDRESS _____

CHILD'S NAME _____

BIRTH DATE _____

I/We would like to add our child's name to the Consent List to be maintained by the PWSA to use for research and statistics. I/We understand this list will be shared but certainly with discretion.

SIGNATURE OF CONSENTING PARENT OR GUARDIAN _____

I/We would like to add our child's name to the Non-Consent List to be maintained by PWSA. I/We understand this list will not be shared, without parental consent, and will be maintained for statistics only.

SIGNATURE OF CONSENTING PARENT OR GUARDIAN _____

We thank you in advance for helping us to maintain a more accurate list.

Please return to:

PWSA
 5515 Malibu Drive
 Edina, MN 55436

Member's number already on our list.

3	50	104	155	239	332	408	523	620	708	768	837
4	51	105	158	243	342	424	532	622	709	770	843
8	52	107	166	246	343	436	543	632	714	774	851
9	56	110	168	251	347	441	546	633	720	775	855
13	58	111	177	253	348	446	547	643	722	779	862
14	60	112	185	256	356	449	550	644	724	780	866
20	62	117	191	258	357	465	557	655	729	787	870
23	66	120	198	263	359	480	562	657	731	788	871
24	68	123	200	269	365	482	565	659	736	791	872
25	69	129	201	283	368	498	568	662	738	794	892
26	73	130	205	292	369	502	572	668	740	795	
27	74	137	210	299	373	504	577	671	741	798	
33	76	143	215	300	375	511	581	674	743	800	
34	81	144	217	305	381	513	588	676	745	803	
36	82	146	222	312	382	514	592	683	749	811	
37	84	147	228	315	384	516	602	687	753	819	
42	89	149	232	321	387	519	605	688	754	820	
43	91	152	235	327	393	520	612	691	765	825	
45	98	154	237	329	402	521	615	693	767	834	

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.

PRADER-WILLI SYNDROME ASSOCIATION

**5515 Malibu Drive
Edina, Minnesota 55436**

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