

THE GATHERED VIEW

for the younger set

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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VOLUME II

MARCH - APRIL, 1987

NUMBER 2

PRESIDENT'S MESSAGE

ARE WE ON THE SAME WAVELENGTH? Not too many years back, somewhere around tailfins and the birth of rock, that was a popular expression. It was used by teenagers and was derived from the physics of radio transmission. If your radio isn't tuned to the same wavelength as a radio transmitter in your location, there will be no sound. Similarly, if you are tuned to the wrong wavelength, your radio won't receive the station that you want to hear. If two people wish to communicate, whether it be by conversation or by written word, they both need to be on the same wavelength.

Example. Last month my letter addressed the subject of our increasing cost of operating as an organization. I proposed one solution, increasing our membership and consequently our revenue from dues. Somehow we were not on the same wavelength. The response to that letter and the notice appended by Marge Wett along with the application form enclosed was striking. Thirty people, who were already members, reapplied for membership, and a small number (less than the number who reapplied) submitted new membership applications. As an example of successful communications, this is enough to make strong men weep.

Another recent experience makes me feel humble in the art of communication. I volunteered to be a class contact for a fund raising drive for my college fraternity. I devoted a full weekend to creating what I thought would be a stimulating mailing. I used multicolored paper, developed an updated mailing list, enclosed a return envelope, and even gave each recipient a set of mailing labels to take the opportunity to contact old buddies. Wow!! I thought of the great response to this effort and could hardly wait to hear from all those old friends that had not been seen for years. What was the bottom line? One apologetic excuse for not participating from a person known to me since kindergarten and a returned packet from a widow.

Your chuckles are ringing in my ears. "Sam, your communication skills need rejuvenation." Heck, they more likely need a whole new creation. Whatever they need, they also need two part harmony to create the transfer of information. Just like our radio, I need to transmit on the same wavelength that you are tuned into for any successful transmission to occur. Communication is a two-way street. I have just purchased a cellular telephone that permits the hospitals and my associates to establish a conversation indicating an emergency and gives me the ability to find out the nature of the problem, to recommend procedures or treatments until I can reach the bedside or even to find out if a true emergency exists or who else might be able to handle the problem. This has proved to be a vast improvement over the beeper-pager that I have carried for years. The difference is my ability to respond

President's Message, cont.

immediately to a question and for me to know immediately the nature of the problem. But if I fail to have the radio telephone with me, or if I don't turn it on, or if I failed to put the batteries in the charger, I won't find myself on the right wavelength.

None of this is new to Prader-Willi parents. How many times in your Prader-Willi life have you found yourself deeply involved in trying to solve a daily living problem for your person with Prader-Willi only to discover that he or she didn't even have their attention turned on to your wavelength. How about the last tantrum? Do you get the feeling that there is a wall between the transmitter and the transmittee, as if your words are just being mouthed and there is no sound coming out? The only sound being heard are the screams of agony as your child transmits their deep sense of injustice in the whole wide world. Remember then that each must be on the same wavelength for communication to occur.

Delfin J. Beltran, MD

P.S. Try re-reading last month's President's message. Your help is truly needed.

SIGNING WHIZ

"Scotty began kindergarten this year in a school with 400 'regular ed' kids and another building with 90 'special ed' kids. He is receiving a spectacular education! They mainstream him as often as his knowledge and patience will allow. He's considered the 'signing whiz' as we've taught him Signed English (over 300 signs at age 6) to supplement his speech delays."

NEW BOOKS

PARENTING YOUR DISABLED CHILD by Bernard Ikeler, available in paperback. Written by a man born with cerebral palsy, Mr. Ikeler addresses questions such as "How can the disabled child meet challenges such as stares, cruel remarks? How can the families of disabled children guide them to rich and productive lives?"

If you haven't read very many books on this subject, this may be a good start.

PARENTS ARE TEACHERS, A Child Management Program, by Dr. Wesley C. Becker. Papercover. Easy to understand manual, shows how to systematically use clear instructions and positive consequences in teaching appropriate behavior.

UNLOCKING DOORS, A booklet on communication skills and assertive behavior with content centered on parent/school/teacher situations. We can order from PACER for \$2.50.

OPENING THE DOOR TO GOOD NUTRITION, The authors explain the scientific relationships between diet and disease. Contains hundred of shopping and cooking tips. We can order from PEP, \$7.95.

CONVENIENCE FOOD FACTS. Nutrition breakdowns for more than 1500 popular name-brand processed foods. Food nutrition tables with calorie and other content included. We can order for \$7.50.

NO-NONSENSE NUTRITION FOR KIDS, Annette Natow, PhD, RD and Jo-Ann Heslin, MA RD. \$15.95. Thorough and practical handbook on child nutrition. Covers children 1 thru 13. Contains many excellent graphs and charts.

BREATHING PROPERLY WITH EXERCISES

While watching exercisers they talk about breathing but it is hard to catch when is the proper time to inhale and exhale. An easy rule of thumb is: exhale on the hard part, inhale on the release.

To increase strength and muscle control of the abdomen: Inhale deeply, hold for one second, exhale, contract your abdominal muscles 3 times. Repeat this 5 times.

COMMUNICATION - COOPERATION

At a recent meeting, a state official talked about the children and young adults that were placed in a group environment and then abandoned by their families. This made me think, here is another area where parents of people with PWS are unique. As a rule the people that I work with put a great deal of effort into finding the "right" school or living arrangement and are not just willing to settle for anything and then say, "that's done" we'll now go on with the rest of our lives. Why is this true? In my opinion one of the reasons is because we are forced from a very young age to be the principle care-giver; to be the authority; to teach others what needs to be done. Through this forced over-protectiveness, we begin to feel we are the only ones who do know what is correct. I certainly feel this way, and find I have to try very hard to let the professionals use their knowledge too. I am not stating that they do not need our help, they do, but I am stating if we really want the best for our children's care outside of the home, this must be a cooperative procedure.

It is an old school adage, if you won't believe everything the child tells you about me, I won't believe everything they tell me about you. This cooperation must be faced not only in the school situation but also when your child goes into a group home or residential school. Your active participation is needed in all aspects. We know how manipulative our children can be. If this child or young adult learns to play one authority off of the other and accomplishes something for themselves, you know very well that is exactly what is going to happen. I succumbed to this when my daughter first moved into a group home, I still fall for it once in awhile and she's been there for over six years.

Think of the school placement as a learning situation; think of it also as a treatment center. If your child had a chemical dependency, you wouldn't offer him that chemical as a reward for doing well. Treatment, whether it is weight control, behavior modification, or whatever should continue at home as well as in the school or group home. They aren't the bad guys and then the child comes home to the good guys! Communication -- Cooperation, is needed to establish a continuation of that treatment. You wouldn't promise your child he wouldn't have to go to school next year if he does well this year. You can't promise him if he loses weight and improves behavior that he can move back home later. Setting dates is particularly bad because of their time concept. Promises of future rewards can cause many problems in a residential school, regular school or group home. Can't you see them using this to tease other people, as an answer to staff requests, etc? Your support of their program is very essential. Communication must be very open with the staff or teacher. Think long and hard before you inform your child of any future plans. It's natural to think about offering incentives but we have to remember they do not think like we do. Open communication so your child is being served at his "away from home home" as well as his natural home, get on that same "wavelength" that Sam was mentioning, it's important to all involved.

Marge A. Hett

CAMPING

Representatives of the MO Chapter have been working on obtaining camping information. PWSA now has data on the following camps which are recommended for PWS use:

Rock Creek Farm, Thompson, PA	The Rehabilitation Institute of Pittsburgh, PA
Camp Blue Sky, St. Louis, MO	Trade Lake Camp, Grantsburg, WI
Camp Huntington, High Falls, NY	Shady Brook Camp, Modus, CT
Rosemont, Honesdale, PA	Camp Lee Mar, Lackawaxen, PA
Camp Wonderland, Rocky Mount, MO	Camp New Horizons, Shawnee-on-Delaware, PA
Keystone Camp, Mt. Pocono, PA	Camp Buckskin, Ely, MN
Daybreak, Honesdale, PA	

Sessions are booking now. Give us a call or drop us a note and we will be happy to furnish you with the necessary dates and addresses.

MEAL PLAN - 1237 Calories

Breakfast--Familia with skim milk; Lemon-Prune Spritzer

Lunch--Tuna Salad in Pita

Dinner--Chicken Fajitas with salsa; Mexican Cole Slaw; Honeyed Mango



Breakfast: $\frac{1}{2}$ c. familia with $\frac{2}{3}$ c. skim milk. $\frac{1}{2}$ c. prune juice, splash of seltzer or soda, squeeze of lemon. 308 calories 2 min. prep time

Lunch: Tuna Salad, 1 c. canned small white beans, drained, rinsed. 1 can ($6\frac{1}{2}$ oz.) chunk tuna in water, drained. $\frac{1}{4}$ c. minced parsley, tarragon, thyme or chives. 4 small sesame pita breads. 4 small lettuce leaves.

Vinaigrette dressing: $\frac{1}{4}$ c. defatted chicken broth. 1 Tb. extra-virgin olive oil. 2 Tb. vinegar or lemon. 2 tsp. Dijon Mustard. 1 clove garlic, minced. $\frac{1}{4}$ tsp. salt, pepper. Make dressing by whisking all ingreds or shaking in jar. Calories: 35/2 Tb. Make salad by mixing beans, tuna & dressing, refrigerate 20 mins. Just before serving, add herbs, tuck in lettuce leaf & tuna in pita pocket. Serves 2. 496 calories, 10 min. prep time + cooling.

Dinner: Chicken Fajitas with Salsa. $\frac{1}{4}$ c. defatted chicken broth. Juice of 1 lime. 1 scallion & 1 clove garlic, minced. 1 Tb. minced coriander. 1 tsp. olive oil. $\frac{1}{4}$ tsp. red pepper flakes. 1 whole chicken breast, skinned, cut into 1" strips. Salsa: 10 cherry tomatoes halved. 1 sm. scallion, minced. Juice of 1 lime. 1 Tb. coriander. $\frac{1}{2}$ jalapeno pepper, seeded, minced. $\frac{1}{8}$ tsp. salt, pepper. 2 flour 7" tortillas. Whisk all ingreds except chicken, salsa and tortillas. Stir in chicken & marinate 30 mins. Make salsa by combining all ingreds. Refrigerate. Remove chicken from marinade, broil 6" from heat until firm to touch, 4-5 mins. Wrap tortillas in foil, place under broiler with chicken. Top tortillas with chicken, salsa, roll up and serve hot. 20 + 30 min. prep time. Serves 2. 272 calories.

Mexican Cole Slaw: $\frac{1}{2}$ cup each finely shredded red & green cabbage. 1 med. carrot, grated. $\frac{1}{4}$ c. low-fat yogurt. $\frac{1}{4}$ tsp. grd. cumin. $\frac{1}{8}$ tsp. salt, pepper, chili powder. Combine all ingreds. Can serve right away or refrigerate. 49 calories, 10 min. prep.

Honeyed Mango: 1 ripe large mango, Juice of 1 lime and 1 Tb. honey. Pare mango, cut flesh away from pit lengthwise into lg. slices, place on serving plate. Mix juice and honey and drizzle over. Serve cold. Serves 2, calories 112.

Naturally, don't forget the beverages.

CONFERENCE SUPPORT NEEDED

Conference registration rates are kept down each year because we help defray costs by members buying and selling raffle tickets.

Let your friends help too. Don't forget to order some for yourself. Naturally, unsold tickets may be returned -- and you needn't be present to win.

Help us out -- place your order today!!!

Win \$500. 1st prize, \$125. 2nd prize, \$100. 3rd prize.

ANNUAL MONEY RAISER ORDER FORM:

Please send _____ tickets, which will be bought or sold for \$1.00 or 6 for \$5.00.

NAME _____ ADDRESS _____

The \$1.00 must be in US Funds. (or adjusted). It now costs us 75¢ for each Canadian or foreign check that we deposit in addition to the currency devaluation.

A MOTHER WRITES:

"I swear Missy has an I.Q. of 140 when it comes to getting food. She is 7 yrs. old now and has mastered getting food in one short week. This last week has been a real eye opener for us. We cannot allow her in the kitchen at all without us. Her behavioral problems have gotten worse and she has some real temper tantrums."



She also asked us to share some comments on the statement in the last CV, "I've put my son in God's hands, God knows what He's doing". This mother replied, "I believe in God very deeply and love him very much. I believe we all have a purpose in life, handicapped or not. God is first. I pray, read scripture & teach my children to trust in Him. I don't understand His ways but I trust Him. However, He gave me a mind that He expects me to use and He gave me a daughter that needs care. It's a whole lot easier and a real cop out to expect God to take care of my child and not have me take my responsibility for her. I have given her to Him but I take care of her and love her while she is here. There is nothing fair about PW or a constant diet but I do find comfort and acceptance because of my religion and faith in God."

REQUEST FROM CT CHAPTER

Due to the unexpected postage and packaging costs, we will need to charge a fee of \$1.50 for each order up to 20 posters, in addition to the \$1.00 fee each. Orders to Suellen Inwood, 335 Davis Rd., Fairfield, CT 06430. Checks to PWA of CT.

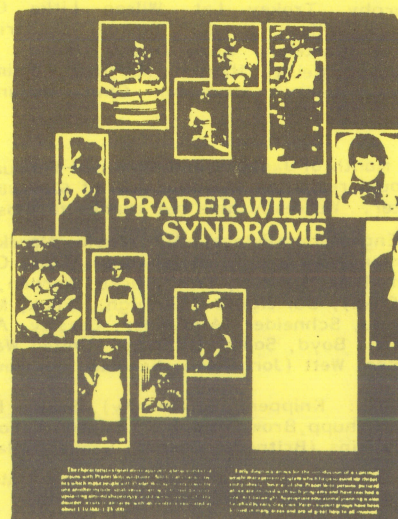
Although this copy does not do them justice, we included a copy. They are 14 x 17½, blue, white section lists major characteristics, bottom has additional information and you can add your chapter's name if you prefer. A great way for some PW publicity.

EXCERPTS FROM A MISTER ROGERS COLUMN

Our children are a part of us as no one else can be. Any damage to their emotional or physical well-being assaults our feelings and material resources. Many parents feel responsible, guilty, or resentful and angry. They might feel they are being punished for something they have done. Others see in their child's misfortune new meaning for themselves: a special calling to be caregivers to a child with extra needs. Most, perhaps, fall somewhere in between. Taking a deep breath, they leave the whys unanswered and do the best they can, with what they have, day by day.

However we feel, it's important to acknowledge those feelings and to let ourselves have them. There's no "should" or "should not" when it comes to having feelings. They are part of who we are, and their origins are beyond our control. When we can believe that, we may find it easier to make constructive choices about what to do with those feelings.

All life events are formative. All contribute to what we become, year by year, as we go on growing. It's my hope, ...all caregivers of children with disabilities, ... will find their own ways to help their children be the most of what they can become.



CLIMB THE MOUNTAIN (this was the name we used for a funding club for the National Development Center, now Crisis Intervention & Transitional Fund)

As our members contribute directly to this fund, or donations are made in their names, they move up from one category to the next. This listing is just the one specific fund, and does not include other donations for other purposes. (If we've made a mistake, let us know)

THE PEAK ACHIEVERS (donations of \$5,000 or more)

Smith Barkeley Haller

CROSSING THE FACE (donations of \$1,000 to \$5,000)

Mitchell Shadell Boyd Robbins Neason Huffman Burleigh Wett Eager Bintz Notbohm
Midlantic Chapter Bell Means Hadsall Beltran Alterman Park Krebsbach Schmidt Miller
Vermeulen Ingalls Nanzig Miller Carter Hamisch Castle Abell Manning Fuller Gulling
Foley Mleczewski Maurer

THE CREVASSE JUMPERS (donations of \$500 to \$1000)

Fox Regester Straight Wyka Foley VanZomeran Henderson Watson Boucher Labbe
Fick Rush Westbrook Flick Robinson Breneisen Clubb Herrmann Sojka Kentucky Chptr
Wagstrom Kappler Michigan Chapter Daly Whitlock Whitehead

UP & COMING ACHIEVERS (donations of \$100 to \$500)

Battersby LePenta Parent Anderson Cheng Hutchins Sidlo Gunnison Jackson Tobin
Huibregtse Deterling Sharp Evetts Howe Thompson Levine Stege Phillips Nelson
Marek Brock Texas Chapter Colorado Chapter Ussted Harrington Blair Kowna Chase
Brindisi Miller Zorn Hendrix Bentley King McKeen White Gordon Kubichek Lacy
Jensenman Veziroglu Levikoff Ziifle Johnson Carlyon Platner Corcoran Lamberson Mears
Kass Community Service Spear Toby Vogt Jaffray Metzger Chausow Allen Eleazer Goff
Antin Frontier Chapter Welch Otteman Tsoules Forthman Trentacosta Schauer Reynolds
Townsend Kraft Bush Hill Ranberg Grogger Valsecchi Miller Ackerson Seebach Webb
Lehman Eggers Persanis Bell Braun Lincoln Brewi Baletsa Lynch Olivo Novak Ponti
Maranon Shacklett Krocka Amren Smith Umbaugh Hall Sharter LaBella Geller Mays
Gardner Pflieger Krauss Hambrick Cillo Noordzy Trimble Holm Chiang LaMotte Dixon
Wolcott Aul Arnold Noll Finch Dam Sunde Klein Missouri Chapter Warden McAndrew
Atwood Heinemann Ledoux

BASE CAMP SUPPORTERS (donations up to \$100)

Van Houten Buchanan Mueller Sheeran Burke Baker Burton Marchitelli DeHaan Bishop
Klindworth Gootzit Cole Cty Damon Canova McIntyre Milana Gibson Keenan Weger
Alderson Costa Budner Dunn Grout Hinds Dunn Ioven Krueger Hartigan Menzer
Connecticut Chapter Garfinkel Thomas Parcell Sturgis Rosette Walsh Ayotte Stephens
Pike LaMonica Kimberly Dennis Watson Neeley Gilmore Ipsen Ray Rattray Zorn
Silverman Gottschalk Ryan Jacobs Harold Braunreiter Haskins Turner Yoncha Sucha
Porcella Shults Kellerman Doolittle Westman Cox Engleman Marcovici Rangitsch Vice
Berton Simmons Keepers Castelli Hunt Sauter Fritsche Greenswag Hruska Luhman
Weisel Sturm VanSwearingen Stevenson Shepard Ripley Archer Weeks Hellerman Bush
Horlick Houpis Zador Roberts Schramm Martsof Maas Redmond Weixeldorfer Thomas
Baar Youngblood Balinski Noffsinger List Schotthoefer Martin Hermans Walczak
Willott Watters Murphy Trokey Lat Wilson Litke Ott LaBossiere Lincoln Ouillette
Schneider Hiatt Bach Wilson Krauer Boston McEttrick Redeen Werner Kuhne Thomson
Carr Manchell-Ponsko Cortellini Shaw Hjort Ulland Scheuner Parker Payne Cooper
Raymond Korte Wicks Reiss Hansen Martinez Reiman Donlon Englund Kelash Cohen
Yannelli Kier Mines Beatty Alexander Ginn McManus Cassity Winstead

Additions during the month of January and thru mid-February (we are very happy to report) totaled \$9881.80. If this rate could continue, we could reach our building goal of \$200,000 and start working on emergency funding for the Crisis Intervention and Transitional Center. We really give our thanks to those people who feel lives of people with PWS are worth saving.

Contributors were: Englemann (Peters), Mleczewski, Marek (Lewandowski, Marek), Krauss, Foley, Dixon (2), Webb, Deterling, Bell, Castle & (Meyeraan), Miller & (Satterthwaite), Dam, Chase (Walker), Cheng, Smith & (Miller), Vermeulen & (Dade, Trader), Antin, Lincoln, Tobin, Fick, Lehman, Fox, Burke, Warden, PWS MO, Stephens, Mines, Atwood, Maurer (Colony Sq. Hotel, Greenwald), Lynch (Coke), Burleigh & (Burleigh), Flick, McAndrew, McManus, Daly, Krebsbach, Heinemann, Sunde, Carter, Menzer, Beatty, LaPenta, Schneider, Alexander, Cassidy, Alderson, Miller, Ginn, Winstead, Means, Parent, Gordon (Elkins), Ingalls (Stone), Beltran, Boyd, Sojka, Umbaugh (United Way), Wilson, Turner, Whitehead, Hunt, Ledoux, Eager, Whitlock, Garfinkel, Maas, Cooper, Wett (Jorgensen, Scanlan, Zastrow), Forthman (Smith), Lincoln (Locascio), Hiatt (Young), Mitchell.

RESEARCH FUND Donors: Knippenburg (Faherty), Smith, Howe, Hinds, McManus, United Way, LaPenta, Cassity, Alderson, Ginn, S.NV CFC, Jenkins & (Shupp, Brown, Lepper, Sweet, LaForce, Kanfeldt, Kaiser), Day, Hawkinson, McCarthy, Mook, Dunn, Garfinkel, Jackson, Jenkins (Britnec), Cooper, Scalia (Nolan, Bene, Francia, Scholz, Paley, Lowe, Hedden, Faulkner, Damico).

Donations directly to the Operating Fund were: Cooper, Mook, Garfinkel, DeHaan, Taylor, & Trawick. Members who pay contributing or patron dues also contribute to this fund.

We send a special thanks to all of our supporters.

One mother recently wrote: "My main reason for writing is to tell you of our experience with the Laura Baker School and maybe through our success more people will support your efforts for funding. Our son _____ has PWS. He is 14 yrs. old and the love of our family. We had tried everything possible to help him, with no success. He has seen countless doctors, been to one hospital after another, been thrown out of school, in mental hospitals, reform schools, and a lot of other things I don't care to talk about. I guess the biggest problem is me. I love him so much and I did everything I could to protect him really unaware that I was hurting him. I gave in to his always being hungry and at times I felt I couldn't go on another day with the temper, picking at sores and constant eating. Then about a year ago a very caring (professional), found the Laura Baker School. ...the funding came through. _____ was on his way to a school that he really wanted to go to.

Laura Baker has been everything and more than you could expect. (The school recently had a celebration with the loss of the first 50 lbs. for this young man.) He loves to go for walksthey take him to movies, he swims, has a nice room with all of his personal things. He is doing a lot better with his temper. I could probably go on and on about the school but I just wanted to get my point across that this really is a good school to support. If anyone would like to talk to us about anything at all, please feel free to share our name or address."

LOOKING FOR NEW SNACK IDEAS?

Fruits

1/2 cup fresh blueberries.....	41
1 med. tangerine.....	37
1 med. orange.....	62
1 Granny Smith apple.....	81

Vegies /Salads

1 cup shredded lettuce w/no calorie dressing.....	8
1 med. cucumber.....	18
1/2 cup cooked broccoli.....	23
1 carrot.....	31
1 med. tomato.....	24

Treats

1 tbsp. low-calorie jam.....	24
1 frozen fruit bar.....	70
1/3 c. sherbet.....	90

Drinks

No calorie sodas, coffee, tea	
8 oz. tomato juice.....	42
4 oz. skim milk.....	43
6 oz. orange juice.....	84

TIPS:

Use non-stick spray for frying.
Increase calcium with low-fat yogurt.
Oranges add more fiber than juice.
Air-popped popcorn is low in calories,
high in fiber, fun to eat.
Serve an extra no calorie beverage
with meals to add to fullness.

SOME TO AVOID:

1 cup raisins...420	1 cup peanuts...840
Hot dog & bun...300	Danish pastry...280
1 c. hard ice cr...270	1 c. applesauce...230
2/3 c. sunflower seeds...550	

THE BATTLE IN THE MOUTH

We have received mixed information regarding teeth over the past few years. Two dentists, examining teeth at a previous conference, reported there weren't that many with lots of cavities nor jaw alignment problems and yet we continue to hear the contrary from many parents.

Whether your child is prone to cavities or not, good mouth care is very important. Brushing and flossing, if not done well, is of little use. Frequent checking up by you and proper instruction is very important. A good dental hygienist will demonstrate that the floss must go down the side of the tooth all the way to the gum and on both sides (sliding between the teeth only is not sufficient). There are some warning signs if flossing is not done right or frequent enough:

Bleeding gums while brushing
Red, swollen or tender gums
Gums that have moved away from teeth
Teeth becoming loose, moving apart
Bad breath

Think of gum disease as a small war being fought in the mouth. When the plaque bacteria win a skirmish, they multiply, causing more plaque, which irritates the gums. Plaque not removed daily hardens into crustlike calculus or tartar. Gingivitis is an early stage of gum disease and can be totally reversed by proper daily brushing and flossing. If unchecked, this will lead to periodontal disease. Lost teeth mean the war is over--the victory belongs to the bad bacteria.

More volunteers sought: Several members have requested that PWSA form a legislative committee to start getting some "action" in Washington. If you would like to be a part of this committee, please drop PWSA a line.

A mother writes: "The University of Alabama, Sparks Developmental Center and committee did a very nice job of hosting our (PWS Southeastern) conference in July. My only regrets are they didn't get organized years earlier. ...it would have been so helpful had we had someone to turn to for support in our state when (our son) was a small child."

CALIFORNIA MEMBERS

We have received many requests from California members that would like to have small group meetings, but nothing has been organized. Bud Bush, a parent in the DD system on the State level, supports this concept. If you are interested in getting something started in your area, please contact Bud directly: Harvey Bush, 1244 Melrose Way, Vista, 92083. (619) 724-6985.

NEWS FROM OTHER GROUPS

We are happy to read in "The Open Door", publication of the PWSA of Australia, about their last year's accomplishments.

They include the establishment of clinics in several hospitals, the addition of more smaller groups, a successful camping experience and session for older PW's.

It was sad to read though of a 13-yr. old girl who had to be removed from a residence because of sexual abuse. The mother wrote they never dreamt that sort of thing would happen while she was receiving such good care and they felt she needed to be more informed on sexual matters.

Another mother wrote of the recent obesity-related death of a 22-yr. old. The Handicapped Person's Bureau stated that the parents had no right to stop him from eating himself to death. She also wrote, "Our PWS people don't fit into the system, and this world is made up of systems that do not cater for the needs of the PWS person." Unfortunately, so true.

The Netherland's group seems to be going great guns. We write "seems" because the material they share is in Dutch and we do not have a translator to help us out. They have published our handbook in Dutch and have a newsletter.

Christin Bauer and Nils Erik Andreassen write they are happy to report the national PWS organization has been formed in Norway, "Landsforeningen for Prader Willi's syndrom". They recently were invited to a governmental center for a two week session (first time for PWS). It was attended by 25 PW children, 8 sibs, and 35 parents. Terrific.

They also met recently with representatives from the Danish and Swedish groups.

Rosemary Erskine recently agreed to give Jan Williams a year of well deserved rest in offering to take over the PWSA-UK group.

The Central Canadian newsletter is always enjoyed and we are happy to keep up with their news.

We recently enjoyed being able to spend an afternoon with the Mauger family and meet their son, from New Zealand. We hope they enjoyed the rest of their trip.

WELCOME TO OUR NEWEST CHAPTERS

A grand welcome to Chapter #20, PWS Southeastern Association, which serves the states of Alabama, Georgia and Florida and welcomes any surrounding states.

This group was organized to hold a couple of conferences each year.

Officers are:

Dottie Cooper, President
Gregory Talley, Vice-President
Melody Walton, Secretary
Paul Alterman, Treasurer

We are also happy to officially welcome Chapter #21, PWSA of Ohio. This group decided it could serve needs better in their state by splitting off from the original Tri-State chapter.

New officers are:

Peggy Ott, President
Chuck Ott, Vice-President
Anne Hill, Secretary
Chuck Bush, Treasurer

WE EXTEND OUR SYMPATHY

to the family of Tommy Lesley, who passed away recently, and also to the family of Gia Scalia who lost their daughter in February.

Even though both of these families were newer members of our organization, they offered PWSA as a recipient of their memorial offerings.

Tommy's mother also shared this poem with us:

I'll Walk With Pride

Please don't stare, then turn away,
as I am retarded, can't you see?
And there are many children just like me.
Our minds may not think as fast as yours.
Also, there are many things we cannot do,
But we will still walk with pride.

So please don't stare at us, without feelings.
Or don't laugh at us without caring,
when you know we are hurting inside.
But we will still walk with pride.

So please accept us for the way we are
as we are God's children too.
And we have feelings just like yours.
But we will still walk with pride.

So please take our hands, don't turn away,
Let us share our love with you to show others
that you care -- that our lives are real.
But we will still walk with pride.

So please don't weep for us when we are gone
if you can't show us that you love us too.
You say you love us but then you don't.
But we will still walk with pride.

In God's hands we will find our peace.
There will be no more stares and no more
laughter.
There will be just love and happiness forever
after.

And we will walk with pride.

Patricia Jenkins
Tommy Lesley's Mother

ATTENTION WASHINGTON RESIDENTS

April 1st is the date for another get together at the University of Washington CDMRC. The purpose of the meeting is to talk about forming a new Northwest Chapter and start meeting on a regular basis. For further information call Judy LeConte (206)545-1283 or Bob Maloney, home (206)746-9988 or work 455-9530.

WHAT'S HAPPENING WITH THE CRISIS CTR.

As most of you know, we have been working on opening a national developmental center to serve crisis situations, as a transitional placement, for respite care and for research.

In response to a recently mailed application, we have 55 responses (approximately 20 of these are crisis). We also enclosed a donation envelope requesting support of any of our three funds. Unfortunately, the response to this has been poor. We have promised to pay for half of a building in order to open this center (\$200,000).

In addition to contact members, we are also contacting friends and relatives. We recently developed a brochure for this mailing. If you did not share the names and address of additional contacts in the past, we would appreciate having them now so we can increase our mailing.

A CRISIS CTR. IN '87 IS OUR GOAL!

EVERYTHING IS "BIGGER AND BETTER" IN TEXAS !!!

Will the PWSA membership change that?

Your attendance at the 9th ANNUAL PWSA CONFERENCE

JUNE 18 - 20, 1987

will confirm that statement.

The Host Committee, PWS Texas Association has done the "better" part already -- putting together a program including something for everyone. YOU have to make the "bigger" part by attending.

The conference starts with an extra day on Wednesday, June 17th. This will be our 2nd year providing professionals an opportunity to present papers on PWS. The call for papers has gone out -- we hope to fill this day with presentations aimed at professionals. The presentations will be technical (not aimed for parents), but if you would like to attend, you are welcome, however, no accommodations are made for youth (that starts on Thursday). (If you are a professional and did not receive the call for papers letter, it is not too late to submit an intention of participation -- see page ten for details.)

Last year we had a 3-hour Chapter Presidents meeting - this year we'll have all day Wednesday. Also group home administrators and staff will hold a symposium. This is an opportunity for caregivers to share their expertise with one another.

Thursday kicks off the regular meeting. A "Get Acquainted Session" is offered for first timers, a simultaneous meeting for others. From this, we go on to three full days of tremendous opportunities to learn, to ask questions, and to share with fellow members.

Thursday evening will be dinner on your own with a social from 7 to 9. Friday evening will be a Country Western BBQ to let you know you are in Texas.

AND the Youth Activity Program - only past committees can fully understand what goes into planning this program.

Full program for all ages
Activities all day and into the evening
Entertainment (not too tiring, we hope)

The trips and social activities for the youth sound great. A good tip -- if you don't want to attend another conference, don't bring your children, because if you do, they will be begging to come back again next year.

Friday afternoon board members will present a "State of the Union" session. This is your opportunity to ask questions, share your input, and nominate board members.

The Saturday afternoon wrap-up is fun for all, and more thrilling if you win one of the raffle checks.

WHERE IS ALL OF THIS HAPPENING?

The Hilton Conference Center in Houston (just a short ride from the Inter-Continental Airport on their shuttle bus). If you send in your reservations early, you will be assured of a convenient room close to the meetings. Can you believe it -- \$39.00 + tax, a day!

A larger capacity for food gives you more choice than previously available. The young people will have two box lunches and we'll all have lunch together on Saturday. All of the prices are lower (your support of the raffle helps keep them down).

Last year we had 255 adults, 89 children and adults with PWS, and 22 siblings attend. Let's make it "BIGGER AND BETTER" in Houston.

If you do not receive a pre-registration packet by the 6th of April, let us know and we'll get another one off to you.

Make your arrangements now, you won't be sorry. See you in June.

FIRST ANNOUNCEMENT
2nd Annual Prader-Willi Syndrome Scientific Conference
Houston, Texas June 17, 1987

February 13, 1987

Dear Colleague:

The 9th annual conference of the Prader-Willi Syndrome Association will be held June 18-20, 1987 in Houston, Texas. Last year, for the first time, a 1 day scientific program was held in conjunction with the PWSA conference. This was a success, and will be repeated this year in Houston.

On June 17, 1987, a 1 day Scientific meeting will be held consisting of contributed presentations (12 minutes plus 3 minutes for discussion) dealing with all areas of research on PWS. We wish to encourage papers on medical, nutritional, behavioral, and social aspects of this unique disorder. If too many abstracts are submitted for platform presentations, a poster session will be considered. **The deadline for receipt of abstracts will be May 1, 1987.**

Dr. John Opitz has graciously agreed to publish the proceedings of this conference in a special issue of the American Journal of Medical Genetics. Details are enclosed. You may have your abstract or a full paper published. **These must be ready for submission by the time of the conference for consideration.**

Suggestions regarding special presentation topics, formats, or other ideas for the conference are welcome (Call or write as soon as possible with suggestions). Susie Cassidy and Vanja Holm have already requested that people bring interesting cases of 15q deletions (or other rearrangements) with clinical features atypical of PWS.

A second announcement including abstract instructions, hotel information, and program for the parents conference (Thurs-Sat, June 18-20) will follow in March **only to those who return the form below.**

Please detach and return the form below no later than **March 20, 1987** if you wish to receive the Second Announcement and/or you wish to remain on the PWS Scientific Meeting mailing list for future years. Mail to:

David H. Ledbetter, Ph.D.
 Institute for Molecular Genetics
 Baylor College of Medicine
 Houston, TX 77030
 (713) 799-4984

☐ Yes, I plan to attend this year's scientific conference

☐ I plan to submit an abstract- General topic, area _____

I am interested in publishing my contribution as an abstract _____ full paper _____ in the Am J Med Genet special issue

☐ No, I cannot attend this year's meeting, but wish to remain on the mailing list

Name _____

Address _____

Phone _____

PLEASE RETURN BY MARCH 20, 1987

COMING IN IN THE MIDDLE OF A MOVIE

That was the statement made by a young mother during a meeting -- she found, as so many people find, when you join something that has been ongoing for many years it is so hard to catch up on what has happened previously. We'd like our new members to know we do keep this in mind but it is very difficult to remember when putting out the newsletter or when conducting parent's meetings.

PWSA was organized in 1975 by Fausta and Gene Deterling, parents of a young child, who found it impossible to learn much about the syndrome. While working with Vanja A. Holm, M.D. and Shirley Neason, another parent, they were able to develop a very good basis from which the present organization grew. An organization that started with a couple of dozen members has now grown into a registered membership of 1350 with members from the U.S., Canada, England, Australia, Norway, Germany, Spain, Israel, Switzerland, Denmark, New Zealand, South Africa, Mexico, Sweden, Channel Islands, Malta, Brazil, Scotland, Japan, Saudi Arabia, Netherlands, and Poland.

Goals included bridging the gap between parents and dedicated professionals, continue to search for ways to help, to support and inform -- to share and care. While the primary purpose of PWSA is still an organization to serve parents and families, we are very happy to be recognized as a link to the latest in information by professionals. The first few years of operation proved the need for this type of group and demonstrated the glaring lack of information available on the syndrome. We have grown from one handbook, our first publication, to having many additional books, booklets, articles and papers available. Materials in other languages such as Spanish, French, German and Dutch have also been added. Libraries, public and academic, have amassed considerable literature directed towards parents and children with birth defects. Such publications are an excellent source of information on general issues but frequently fall short of offering specific information which is needed. We hope PWSA has filled this need.

Naturally an organization cannot grow if no one is aware of its existence. The professionals, who are aware that parents need more than a diagnosis, share the knowledge of PWSA with their patients, clients and contacts. This helps spread the word. The parents also have to do their part. One way is to allow media interviews and share the knowledge of the syndrome along with circumstances of their own personal lives. This type of publicity, particularly when the parents make the effort to be sure to include PWSA name and address, increases requests, increases membership, and helps make PWS an known entity.

PWSA is operated on the structure headed by a 12-person Board of Directors. These directors are elected by the general membership yearly for a 3-year term. The election is held at the annual conferences. This board appoints/elects PWSA officers as well as the chair of this board. These appointments do not have a set term of office but are reviewed yearly by the board. The Executive Director is appointed by the President. A Scientific Advisory Committee, consisting of seven professionals, also exists.

As PWSA grew, a system of chapters was encouraged. Establishment of chapters has enabled the national PWSA offices to remain as the central hub for distribution of information while individual chapters are able to work on specific needs for their own area. Future expansion of this organization (YOUR ORGANIZATION) depends on you -- its members. Your active participation is necessary. Right now we need more sharing to make the younger GV more successful. It's up to you to do your part.

NEW DIRECTORY

At the last conference Mildred Lacy of Kentucky volunteered to assist in updating our Clinic Services Directory. She can't do it alone -- she needs your help.

We want to include names and addresses of anyone who can be of help to new members:

Advocacy
Clinics
Doctors
Educators
Lawyers
Nutritionists
Workshops

Who did you contact in your state when you needed help? The names and departments vary from state to state. Help the next person by having this information.

Mildred has asked some people to be their state representatives. We need to get this information in the near future to include. As Mildred has forwarded what she had to PWSA, please mail this information directly to the national office now.

Take a few minutes to help others.

A big thank you for those who did respond already.

THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. The opinions expressed in THE GATHERED VIEW represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of the PWSA. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$20./year Individual, \$25./year Family, and \$30./year for Agencies/Professionals. (U.S.Funds) Send dues and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.

PRADER-WILLI SYNDROME ASSOCIATION
5515 MALIBU DRIVE
EDINA, MINNESOTA 55436
U.S.A.

WE NEED YOUR HELP

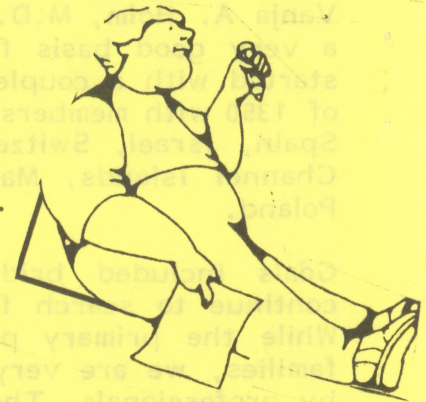
We occasionally get phone calls and a new member asks why is there so much ignorance about this syndrome? Why don't we get on 20/20 or the Donahue show and let people know about it? What can we do in our own area?

Believe me, the national files are very thick with our attempts to get more publicity and we will continue to do so in every way we know.

What can you do in your area? Number one, call your local newspaper, ask for a reporter by name that you have read and enjoyed (particularly if they write frequently about medical items) and ask him/her to do a story about your family. (Try very hard to get the national name and address in the article--this is how more people learn.) Number two, write to your state and federal representatives. Tell them your children and family are not getting the services needed -- ask for their help.

Federal Address

The Honorable
U.S. Senate or House
Washington, DC 20510



First Class Mail