



# THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT  
MARGE A. WETT, EXEC.DIRECTOR

5515 Malibu Drive  
Edina, MN 55436  
(612) 933-0113

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## PRESIDENT'S MESSAGE

The nicest things happen to you if you get to be the president of the Prader-Willi Syndrome Association. During this past week it was necessary for me to travel to Houston for a computer software school. This also gave me the opportunity to be the dinner guest of the Texas Chapter of PWSA. They, as you know, will be the hosts for the 1987 PWSA Annual Conference, June 18-19-20. How many of you remember the first conference eight years ago in Minneapolis. Does it seem possible for it to have been that long ago? From my chair I think of the great effort each local group has made to produce a conference. We have traveled to the extremities of our country and this year we are guided to the South Central part of the heartland. They do things big in Texas and the Texas chapter is out to break records. They are Texas proud and plans are being made for ya'll that will make each and every person that comes know that it was the biggest and the best conference ever.

Several days before I left for Texas, Mike Marchitelli, president of the Texas chapter had forwarded to me a copy of their tentative schedule. On the evening of the meeting they picked me up at my hotel and drove me to our dinner meeting. Food works to mellow PW parents too. There was enough to satisfy the Westbrooks, the Briggs, the Hicks, the Marchitellis, Dr. Dave Ledbetter, myself and three doggie bags left over. You can't always be on a diet and my trip to Houston blows mine til Christmas. Then we pounded our way through the plans for your conference next June. These people are organizers, they are drivers and I believe they are going to put on a show that you will be sorry you missed if you don't make it on down in June.

It wasn't bad enough that they poured on the hospitality that night, but the next afternoon Peggy Westbrook had to test this sentimental old fool's ability to resist crying. Caroline Parcell is the same age as my Sarah, 14, and was a patient at Methodist Hospital. She was one day out from having Harrington rods placed to correct her scoliosis problem. This super family let me into their lives for about an hour visit at her bedside. Peggy let me carry the helium balloon decorated floral gift for Caroline through the halls of that humongous medical complex and I felt so proud to see the smiles of people in the hallways, knowingly enjoying the goodwill the Texas chapter was sending to one of their patients.

After our hospital call, (is that a busman's holiday? I loved it.), Peggy drove me out towards my flight home, but we had the chance to look at the motel-convention center where the conference will be held. The facilities can house four hundred and if everybody planning this conference has their way, it will be filled to capacity with loving, caring friends of PWS. Specifics haven't yet been committed, but there

PRESIDENT'S MESSAGE cont.

will be a full day for chapter presidents to hash out organizational problems, a full day for professionals and invited specialists to discuss the latest scientific advances, parents of the younger set will have their time, those actively involved with the day to day operation of a residential facility will get together. Of course, a completely well supervised and interesting program is being arranged for our children to attend while we meet, learn, communicate and above all, enjoy the association benefits of another bigger and better conference on our first trip to Texas.

*Delfin J. Boltran, MD*

President

THE COURT CORNER

## Special Education Due Process Hearing:

A hearing was held in August, 7 witnesses presented testimony and 66 documents were entered in evidence. The purpose of the hearing was to consider the appropriateness of a current public school placement of a 16-yr. old girl with PW. It was the parent's contention that the girl required a 24-hr. educational placement because of PWS. It was the contention of the school that the girl's present and previous programs had been appropriate to meet her needs and that she had demonstrated progress.

The findings found for the public school district. One of the main factors brought out in the hearing was that even though the expert witnesses exhibited sufficient knowledge of the syndrome they had not observed the girl in her educational program and had no direct knowledge of her level of functioning within her present program.

If anyone would have need of the complete transcript of this hearing, we would be happy to share this.

A member suggested this would be a good permanent column to include -- does someone have a "case" for our next issue?

DIRECTORY UPDATE

As a result of the Chapter's President's Meeting in June, Mildred Lacy of Kentucky has volunteered to be the Chairperson of updating our directory of professionals with knowledge of PWS. As the first step of this update, Millie has requested the people now listed in our present directory to confirm their desire to be listed and their correct address. If you are a professional and did not receive this inquiry and do wish to be listed, please send your area of expertise, your name and address to Mildred at 5006 Red Fern Rd., Louisville, KY 40218. (We did save a bit of postage by not mailing this inquiry to some of our very active PWSA members if we knew their listing and address was correct.)

Millie is also appointing a contact person from every state to canvass their area in order to expand this directory and make it more useful for other members. Categories will include Advocacy, Dentists, Diagnosis & Evaluation, Doctors, Ophthalmologists, Education, Genetic Counselors, Guardianship, Nutritionists, Recreation, Respite Care, Workshops as well as continue with foreign lists and residential facilities. If every state supplies these contacts, this directory will be a tremendous resource for all members. We really look forward to the completion of this project and being able to offer it to our members.

OUR NEWEST BOARD MEMBER

During the last conference in June, Janalee Tomaseski-Heinemann was elected as the newest board member for PWSA. Janalee and her husband Al founded the first Missouri chapter of PWSA in 1982.

Jan received her master's degree in social work from Washington University in St. Louis and has many years of volunteer experience plus eleven years of professional experience in social work ranging from child abuse to hospice care. She is presently a pediatric medical social worker at Children's Hospital in St. Louis.

Janalee is the author of our sibling book, *Sometimes I'm Mad...* and various other articles which she has generously shared with our organization. Jan and Al are the parents of 5 children, including a 13-yr. old son, Matt, who has PWS, and 2 grandchildren. We are very fortunate to have such a talented lady willing to donate her expertise to our board.

REQUEST FROM MEMBER:

I am interested in contact with families whose children (not necessarily the PW child) who are on the Feingold diet.

(This mother has two children who are hyperkinetic with learning difficulties. She states one of her children had benefited from this diet and that her child with PW has gained weight but also benefited.)

She stated she would like to discuss the problems of weight management since there seems to be a somewhat higher proportion of fat vs the use of diabetic diet and substitutes.

Please contact her direct:

Marty Rucker  
113 Geranium Crescent  
Virginia Beach, VA 23456

SOME MEDICAL QUESTIONS THAT HAVE COME UP LATELY

We have been receiving questions from members and doctors regarding information on a few items recently. One is the latest weight-loss device for morbid obesity -- a balloon which is slipped into the stomach by way of the esophagus and then inflated. This is known as the Garren Gastric Bubble. It is meant to keep dieters feeling full, thereby a method of weight control.

The gastroenterologists who invented this are only recommending it in order to give their patients time to examine why they are overeating and learn how to make dietary changes. For this reason and others, we do not feel this is an option for people with PWS. One doctor likened the balloon to diet pills, saying appetite is depressed and eating habits aren't changed. It is also possible to sabotage any effects of the bubble by eating small amounts of food at a time. When overeating at meals, patients experience cramps. When eating small amounts of calorie-dense food, it is possible that no weight loss will occur.

A few complications have also occurred but nothing major. Another factor to consider though is that the price is between \$2,000 and \$5,000 and the balloon is usually left in for only 3-4 months.

Another question has been fat suctioning. This procedure is recommended for people who have lost all excess weight but still retain heavy chins, abdomens or thighs, or other localized areas of fat deposits. Like any other surgery, complications such as infections, bleeding under the skin etc. can occur. This is not recommended as a weight loss, and would not have any effect on skin flaps or folds that our children have following weight reductions.

Lastly, some articles have appeared with headlines, "Spray kills calories, desire" A low calorie mouth spray has been offered to dieters as a great way to get the taste of food without the calories. These have been recommended to use when the craving for food or a specific flavor gets too strong to resist, a person simply squirts the flavor on their tongue instead of giving in to eating the actual food. Again, we feel this offers nothing for our young people.

Believe me, when someone does come up with a true answer to obesity problems, we will share it with you but we are sure it will not be kept a secret.



HAVE WE FOUND OUR "PET ROCK" IDEA?

When talking about fund raising for the NDC, we have often remarked we need an angel for backing, some large donations from corporation or foundations, or a "pet rock" idea that will bring in a large sum of money. One of our California members has offered to donate 20,000 Emergency Car Kits at cost. At the moment he is in the process of trying to make contact with some national columnist, or some national organization that could give us the needed publicity to be able to profit from these kits. He is advocating that the publicity request a \$10.00 donation to PWSA and in return we will mail them a car kit. If the right source could be found and all 20,000 of these kits distributed, the profit could be over \$100,000 for our crisis center. While this member is making these efforts, we certainly would appreciate any comments or suggestions from any other member in case he is not successful in his attempts.

Unfortunately, it is always the "old game" of not what is the need but who do you know that makes these attempts successful. One suggestion was made that the Reader's Digest has had some of these types of articles lately and has a wide distribution. Do we have a member who has a personal contact with them? We certainly would appreciate hearing from any member that can help.



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PWS POSTERS ARE READY

In a previous issue, we mentioned the development of a PWS Poster by the CT chapter. These posters contain information regarding PWS, photographs (so undiagnosed children may be recognized), and includes a space where you can add your name or your chapter's name for further information.

The posters are now available to order directly from the CT chapter. To meet their costs, they need a minimum order of 10 posters. Prices are as follows:

Quantities of 10-100.....	\$1.00/ea.
101-250.....	.75¢/ea.
over 250.....	.50¢/ea.

Order from: Suellen Inwood  
335 Davis Rd  
Fairfield, CT 06430

Suggestions for use include placing them in doctor's offices, clinics, shopping centers, schools, meeting places etc. Here's your chance to further educate others on PWS.

CALORIE-REDUCED DESSERTS

Looking for some low calorie desserts to use on special occasions? A new 32-page booklet contains 20 recipes for such things as cheesecake, pies, etc. with reduced calories, sugar, fat, cholesterol and sodium.

The booklet also gives guidelines for modifying your own favorite recipes. For each booklet, sent 50¢ to:  
Cumberland Packing Corp., Dept. PK,  
60 Flushing Av., Brooklyn, NY 11205.

SIMMONS EXERCISE VIDEO

In a previous issue, we mentioned the latest Richard Simmon's book, "Reach for Fitness: A Special Book of Exercises for the Physically Challenged. One member wrote that they felt the exercises were very good for their child. (Profits from this book are being used for new exercise centers that might also benefit our young people.)

We have now been informed that these exercises are available in video tapes. They can be ordered from Karl-Lorimar Home Video, 17942 Cowan, Irvine, CA 92714, Attn: Anna Snepp. The cost is \$14.95 plus \$2.50 for shipping. Canadian: add \$5.00 more) CA residents must add sales tax. Catalogue #148. (They may also be available in stores.)

If you do order mention you read the information here, give PWSA a plug so our name becomes more known to Richard -- it can't hurt.

GREAT NEWS FROM TEXAS

"I wanted to share an experience with other parents of PWS children. Last summer my husband and I admitted our 15 yr.-old PWS daughter into the Gillette Children's Hospital in St. Paul, MN. Dauna stayed 5 days, during which time Dr. Nelson and staff worked with her. With proper diet and exercise, she was able to lose 8 lbs. Even more significant, was the understanding she received about her condition. Now Dauna wants to lose weight and is working diligently on her diet. She is steadily losing 2 lbs. a week, sometimes more, attending a spa every day and swims 2½ hrs. She has now lost 30½ lbs. We are so proud of her.

We wanted to extend our deepest gratitude to Dr. Nelson and the staff at Gillette.

NEW BUFFALO GROUP

Parents are meeting in the Buffalo area. If you are interested, write to Tina Caudill, 117 Military Rd., Buffalo, NY 14207, or call Tina at (716) 873-0593 or Sharon at (716) 823-3095.

## MANAGEMENT AREAS

I would now like to spend a few minutes discussing a couple of management areas. We talked a little about physical therapy, helping with feeding, we talked a little about the therapy of hormone deficiencies. Now I would like to give a brief overview of the fact that at different ages there are different areas that need to be approached for management. Management is still an area we have a lot to learn about but progress has been made over time and I think we should keep working on it. From the beginning we have to look at managing hypotonia and the failure to thrive, we need to think about possibly treating for a very small penis, especially for little boys who cannot stand up to urinate. We need to have early intervention in infancy. We need to try to identify PWS as early as possible because we can then help with nutritional intervention at an early age. We all believe and hope that the earlier we can identify the children with this disorder, the earlier we can establish weight control and the better the outcome will be. I think also the strabismus needs to be corrected to prevent loss of vision in one of the eyes. In early childhood again we need to keep an eye on the weight issue and we need to evaluate the child for educational placement. There are a lot of variables with PW people, some can be in regular classrooms with just a little help from a resource teacher, others need a lot of help, and you see everything inbetween. We need to make sure every child is treated as an individual but recognize from the beginning that every child will need a special education.

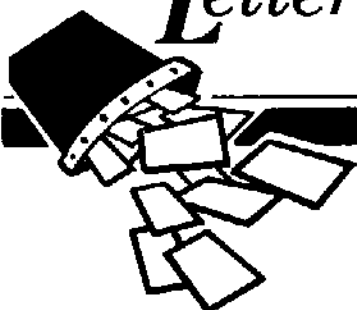
In adolescence we need to think about hormone replacement if that is something we are interested in. We need to think about vocations, we need to think about living situations, and we especially need to keep an eye out for scoliosis development and that treatment. I really stress the controlling of weight for prevention of heart problems related to the weight, which is really the major thing that shortens lifespans for PW people. We need to make sure we avoid diabetes if at all possible. We would also like to have the weight controlled so that the children can be more awake, more alert, so that they can learn more, can be more productive in society and be more active participants in life. We want to help them feel better about themselves and not to feel they are so out of control. We need to get them accepted socially because they are not so different in appearance from other children. There has been some early data to support the notion that their performance intellectually may be improved by weight control although this needs confirmation and careful examination. It is worthy of further study.

(Excerpts from an Overview of PWS by Suzanne Cassidy, M.D., Assistant Professor of Pediatrics at the University of Connecticut Health Center, presented at the 1986 ANNUAL NATIONAL PWSA CONFERENCE. Full presentation is included with conference papers, now available from PWSA.)

## ARC CALENDARS

The National Headquarters for ARC is holding their yearly sale of calendars. If any of our members would like to order, the calendars are 8-3/4 x 11-3/4 with plenty of space to note and of course your support of their work is reflected in your purchase. If we receive more than 25 orders the price will be approximately \$5.00 each, if under 25 around \$7.00. If interested, just send your name and we will fill orders and bill you.

## We get Letters



.....and some of them make our efforts worthwhile.

"For the past 3 yrs. I have thought often of writing but time and energy resources have been a limiting factor. My oldest son, Bryan, is PW. He will be 9 yrs. old. (Bryan was diagnosed 4 yrs. ago when his mother was pregnant and later had twins.) My husband (#2) could not accept the responsibilities of raising a disabled child and twins so I have been a single parent.. it is hard work but the rewards have been tremendous.

Bryan loves school and is progressing very well. He attends day-care after school in one of only four day-care facilities (in our area) with a Spec. Ed program. His brothers are in the same program. He also participates in Sunday School class with 'normal' children who are in grades 1-2 and this year will be in Cub Scouts, the only developmentally delayed boy in the pack. The boys, leaders, requested he be included. For me these are shining moments but there are dark ones too! Bryan has had a weight gain of approx. 8 lbs. in 3 wks and his behavior has reflected this change. I am trying now to determine where the problem is, i.e. diet change or exercise level. For me the most difficult facet of tracking his weight comes from his being out of my immediate control for so much of the day. Prior to this weight gain, Bryan had gained less than 5 lbs. in 3 yrs. And he has grown 2½ inches!

Bryan loves his brothers and vice-versa. All realize the uniqueness of our family. Bryan has always been quick to point out we have 2 'babies', on the other hand, (his brothers) are aware (though not yet

verbalizing) the uniqueness that is Bryans and the other disabled children in the center. Bryan has also begun participating in Special Olympics (bowling, track, hoping to add swimming). (This mother also wrote of a camping experience which was helped because another PW had been in the program previously and the ground work had been laid). Like every parent of a disabled child (especially a child with PW), I could easily write a book. But I hope to continue to share the triumphs of Bryan with others, and the back-sliding or stumbling stones too. We help each other when we reach out with information and share our success and occasional flops." (She closed with this wish of meeting everyone in Houston next June, and a salutation of "Because of Christ's Love".)

Another letter, "From the 'You Think You've Got it Bad' Department: I am a single mother trying to raise 3 kids on my own. My (daughter 11) has PWS, but is of normal weight and has only infrequent tantrums now (less than once a month). I lock the food, use positive reinforcement, and lots of TLC (including nightly back-rubs). My (son, 9) has Fetal Alcohol syndrome, is very skinny (no matter how much I feed him), is hyperactive, ...school problems. He also has his share of emotional and behavior problems due to this disorder (caused by his birth mother's alcoholism). My (son, 5) is 'normal' and gives our family a sense of balance. In spite of the hardships we have to endure, we are a happy little family. My advise to other parents: if you have a problem, don't just sit there and suffer, reach out to somebody for help -- friends, family or a caring professional. Don't let the bad days get you down, it's not always as bad as it seems. For my success in a difficult situation, I thank my loving family, caring teachers and doctors, and the helpful people I have met through PWSA!"



At age 11 Karie is 58 lbs. and looks great. Her favorite exercise is mountain hiking.

1986 CONFERENCE PAPERS ARE NOW READY

The tapes have been transcribed, the papers typed, and are now ready for distributing. Since some members are only interested in certain portions, we are making a one-time only offer for papers either on an individual basis or in a set, as follows:

<u>INDIVIDUALLY</u>	<u>TITLE</u>	<u>U.S.</u>	<u>CANADIAN/OVERSEAS</u>
Endocrinology factors,	Dennis Styne, M.D.	1.00	2.00
Diet and Nutrition,	Andrea Sechrist, M.S., R.D.	1.00	2.00
Wills & Trusts,	Roy Smith, Attorney	1.00	2.00
Language & Communication,	Donna Dagemais, M.A.	1.00	2.00
Successful Integration of PWS into Other Groups - Panel		1.00	2.00
Scoliosis,	Daniel Benson, M.D.	1.00	2.00
Educational Aspects, (including handouts)	Wilma Poage, EdD	3.00	5.00
Abstracts from medical presentations		1.00	2.00
Support Groups, Advocacy & Parent Survival,	Peggy Brooks-Bertrum, PhD., & William Mitchell, PhD.	1.00	2.00
Working with the Media,	Ruth Levikoff & Marge Wett	.50	1.00
Overview of PWS,	Suzanne B. Cassidy, M.D.	1.00	2.00
COMPLETE SET:	U.S. \$8.00; CANADIAN/OVERSEAS	\$11.00	

FALL MEETINGS

The Midlantic Chapter had a great agenda for their November 1st meeting. We hope all those good people appreciate the effort that goes into arranging such a completely rounded group of speakers. The Midlantic Chapter hosts two meetings per year, usually in the Eastern PA and surrounding areas. If you are not on their mailing list, drop Isa Breneisen a note and add your name. Her address is: 6336 Miriam Circle, E. Petersburg, PA 17520.

The Arizona Chapter has been holding meetings in two locations for convenience. The Tucson group met in September as a time of informal sharing, focusing mainly on the immediate and long-term needs of their children. The group donated a membership in PWSA for the gal who babysat all nine "kids" during the meeting. Since the babysitting included two rescues, one from the pool and the other of hamster food, they felt she deserved this donation. If anyone wants information about the Tucson group they may call Teresa Kellerman (602) 296-9172 and the Phoenix area is covered by Tyner Kirkpatrick (602) 966-6127.

The Prader-Willi New York Association has added their first group home and their first newsletter to their many accomplishments. Their 3rd Annual Conference was held on November 7th & 8th and included a panel of Dorothy Thompson, Sam Beltran and Marge Wett as representatives of national PWSA.

MEMBER ENCOURAGES SHARING WITH NATIONAL

One of our members has requested our membership to become more active in sharing all procedures of importance with their child with PWS with national. We have many files titled, Education Due Process Hearings, Group Homes, Guardianships & Wills, etc. When parents write of their experiences or send copies of processes these are filed for future reference when another parent is in need of guidance. This member recently went through an education request for private school placement so the "whole child's needs" could be met. Unfortunately, this request was denied in this case. If previous hearing accounts may have been available, it is possible this family could have anticipated some of the arguments and the outcome could have been positive. Many parents go through these processes and do not realize how effective their help could be to others. Please share these proceedings with others by having them on file in the national office.



CONTRIBUTIONS CONTINUE

We have been asked, "What does the list of names, the numbers, the parenthesis marks, in the GV mean?" PWSA has a system where any donations received automatically go into the Research Fund unless the donor specifies they want this donation used for another purpose. Two of the usual other specifications are the National Developmental Center (NDC) or general operating fund.

In the GV we thank these donors by listing their last names. If a number is included, (2) for example, that means more than one donation was received in the two month time period. If the member's name is followed by another name in parenthesis, that means another person made a donation in their name such as a memorial gift or a relative responding to our request for donations.

During the months of Sept. & Oct. the following donations were received for the Research Fund: Braun, Van Zomeren (2), Smith (2), Raglund, White, Capital Area UW, Capital Area CFC, and S.NV CFC for a total of \$160.22. After granting a \$4,000. grant to three physicians at the University of CT for research, this fund now has a balance of

**\$9,706.40**

In Sept. & Oct. the NDC received the following donations through two memorial requests, three very generous gifts, gifts from continuous supports and additional donations, which added \$6521. to this fund.

Memorial fund for Sara Abell's mother:  
 • Abell family, Rubel (2), Morris, Reinert, Spalding (5), Schneider, Clark, Smith (2), Osborne, Northcraft, Whitlock, Browning, Johnson, Kute & Hartlage. Memorials for Kathleen Eager's mother: Doupe, Moore, Eager, Murfin, Sid's Market and Starr.

We thank Norman Barkeley for his gift and enabling us to receive another donation from Lear Siegler Foundation, and Marilyn Bintz for the donation from Lexisoft. Other supporters were: Boyd (2), Dixon (2), Beltran (2), Wett (Schaefer (2) Mathes), Ingalls (Auburn Grange, Warden, Spencer Club, Lovelille), Wagstrom (Stenshoell), Mays (2), Lincoln, Sojka, Lacy, Carter, Umbaugh, Stephens, Alderson, Foley, Gunnison (Adv.Products), Castle, Welch (Moylan), Thompson, Parent, Kreuzer,

Lynch (Rochester Coke) and PW TX Assoc.

Thanks to our many faithful donors, these funds can continue to grow and benefits can be received. The office recently received a caller who said, "Since you people only represent one syndrome, why can't you do more?" The national office represents you, it's members. I think we are really making progress, but we can do more. It's up to all of you.

The NDC balance is now

**\$144,304.75**

VOCATIONAL PLACEMENT

We recently received a phone call regarding the placement of a young man just out of high school. This young man was unhappy with his work and in a fit of anger quit. When he returned the next day he was informed he was fired. His mother stated this was the only place in town that he could work, could they fire him?

We told her, unfortunately yes, they could but not being experts in vocational placement and regulations, we were wondering if some of our members had some comments of this type of situation.

We do have a listing of State Vocational Rehabilitation Agencies and these contacts maybe of some value to some of our members. If you want the address for your state, let us know and we will share this with you.

1987 COMING UP

With this last issue of the GV for 1986, we wish all of our members happy holidays and many blessings in the new year.

## MARK YOUR NEW CALENDARS

JUNE 18-20 in HOUSTON

AN AUSTRALIAN PARENT WRITES:

It is well documented how PWSP are 'very friendly and happy children'. This received raised eyebrows and condescending smiles from some as they believe that most mothers with handicapped children try and find something - anything nice to say about their children and fall back in desperation on the fact that they are friendly little things.

Well I would like to add my comments to those others who say how friendly their children are and proudly say that my little 2 yr. old PW is too.

On shopping excursions he sits regally in his stroller and waves majestically to anyone in sight. As he cannot say anything remotely near 'hello' he relies on his waving to make contact. If this doesn't succeed, he grabs them by the leg while passing or taps them on the shoulder (while I'm carrying him) and then proceeds to wave at them. This used to cause me embarrassment as he does it all the time, however I stopped looking at him and looked at the people he was waving to and realised he was making their day. Both old and young have had some human contact in a very busy and bustling supermarket and now I am very proud of my 'friendly' little boy. I realize this will change as he grows older to where he will grab food instead of legs, however I am enjoying the excursions we have now.

One issue that our family is concentrating on at the moment is giving our PW child as normal an upbringing as possible. We want to take the emphasis off Ryley's disabilities and make him nosh in with the others. We have found for example our visitors to the house will quickly greet our other two children and then concentrate their greetings on Ryley. He now expects most of the attention which is not natural for any child. I am urging friends and relatives to treat him the same as any other child, whilst remembering his special needs and problems.

I want him to have to compete for attention the same as our other two. Also we have found our other two will fight and compete over toys etc. and yet generously hand over anything to Ryley. This is commendable as it shows

unselfishness, however once again it is unnatural. We are trying to walk the fine line of treating him normally and yet make allowances for his special needs.

We are very grateful to the work and dedication being shown by you Americans as we have learned so much just from your newsletters and publications and have been enlightened by your positive approach towards overcoming each problem. We have only just established our own branch of PWSA of Western Australia, of which I am pleased to be secretary. Our association would be delighted to hear from anyone making the trip to Perth, W.A. or surrounding areas, we would welcome a visit, especially to share information.

We would also welcome names of those who would like pen pals from 'down under'. (If anyone would like to respond, contact national and we will forward a list to Dawn)

TURKEY STUFFED PASTA ITALIANO

1# Ground Turkey	1 c. red wine
1 c. minced onion	1 tsp. garlic salt
1 c. shred., peeled egg-plant	1 tsp. oregano leaves
2 cloves minced garlic	1 tsp. basil leaves
3 T. oil	½ tsp. tarragon leaves
¼ tsp. salt, 1/8 pepper	½ tsp. cayenne pepper
28 oz. can tomatoes	12 oz. pkg. jumbo pasta shells
8 oz. tomato sauce	½ c. grated Parmesan
	¾ c. shred. mozzarella

Brown meat, onion, eggplant and garlic in oil. Season salt/pepper. Set aside. Simmer tomatoes, sauce with wine and spices, 15 minutes.

Cook pasta in boiling water til al dente. Drain. Combine meat mixture with parmesan cheese and half of tomato sauce. Stuff shells, place in 13x9 pan, spoon over remaining sauce. Top with mozzarella cheese and bake at 350° 30 minutes. 8 servings. 373 calories per serving; 30 gm. protein, 42 gm. carbohydrates; 8 gm. fat; 797 mg. sodium; 599 mg. potassium.

IT'S NICE TO HAVE GOOD NEWS TO SHARE

We've been hearing great things about a program and would like to share information with our readers. A recent article in their newsletter stated: "For the past 5 years The Rehabilitation Institute has conducted intensive treatment programs for patients with PWS. Each patient admitted is observed, monitored, and treated according to their individual needs. A medically-supervised group setting is used to reduce deficits in gross motor coordination, balance and muscle tone as well as to encourage the development of nutrition awareness, social interaction skills, personal weight control, and self-motivation. Parents are an integral part of the rehabilitation program." Many patients have been from out of state. One Ohio family wrote, "We have felt so helpless and alone without any regular support or advice from the medical profession. However, since our first informative conversation with the Institute, we have felt that the staff realizes our difficult situation, are well aware of the many unusual manifestations of the syndrome, and can provide understanding, support, and practical suggestions for our daily life. This is a tremendous help for us and we feel for the first time in eight years that we have experts to whom we can turn as we encounter the many difficulties of raising a PW child...."

A typical daily schedule includes cardiovascular conditioning through the Physical Therapy Dept.; fine motor skills development by Occupational Therapy; social language skills development by Speech-Language Therapy; and pre-vocational skill instruction by the Vocational and Career Development staff. Group counseling is conducted by Social Service to enhance peer interaction and the understanding of the impact of the syndrome on daily living activities. In addition, dietitians work with patients on nutrition awareness and managing their calorie restricted diet through the Red, Yellow, Green system. (This system is an adaptation of a program created by the Western Psychiatric Institute and Clinic, which alerts those following it to "Stop" foods that they are to avoid, "Go" foods which they can enjoy fully, and "Yellow" foods with which they must be cautious. See other article regarding publication of this diet.) Central to the whole program is a group behavior modification program as well as individual treatment programs by the Psychology Dept. Treatment programs from all departments are reinforced and carried through by the Rehab. Nursing Services Staff.

Bea Maier, Ph.D., stated that losing weight is only part of the treatment program. It is equally important for each patient to achieve an awareness of their condition, to develop new social skills, modify negative behavior and to achieve self-control.

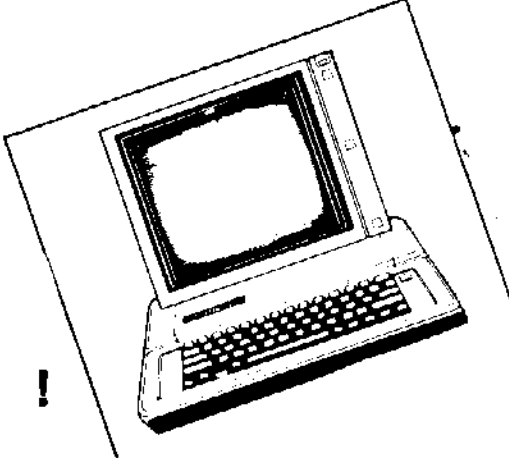
For more information on this program, please contact the Institute directly,  
The Rehabilitation Institute of Pittsburgh  
6301 Northumberland St  
Pittsburgh, PA 15217, (412) 521-9000 or in PA watts line 800-242-0606.

The diet mentioned above is scheduled to be published by Little, Brown & Company this coming spring. Washington Post health writer Sally Squires along with clinical psychologist Len Epstein, PhD are writing "The Stoplight Diet for Children". This eating plan, designed to develop nutritional awareness, has been tested by more than 250 families.

The Stoplight Diet teaches children to give various foods a red, green or yellow light, then the dangerous foods are restricted. It teaches that some "red" foods can be offset by proper eating at other times. They stated, "There's no way to keep your children from being exposed to non-nutritious foods, however, parents can foster wholesome eating habits that will make their children less impressed by and less obsessed with foods that do little or nothing to build strong bodies. (and in the case of PW, I am sure add weight would be added)

This anonymous poem was taken from Childhood Obesity by Platon J. Cillipp, M.D., Ed. By the way someone at the last conference recommended this book for reading.

Strict is my diet, I must not want.  
It maketh me to lie down at night hungry.  
It leadeth me past the confectioners.  
It trieth my willpower.  
It leadeth me in the paths of starvation for my figure's sake.  
Yes, though I walk through the aisles of the pastry department,  
I will buy no sweet rolls for they are fattening.  
The cakes and pies they tempt me.  
Before me is a table set with green beans and lettuce.  
I filleth my stomach with liquids.  
My day's quota runneth over.  
Surely calories and weight charts will follow me  
All the days of my life,  
And I shall dwell in fear of scales forever.



**we still need one !**

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

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