



# THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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## PRESIDENT'S MESSAGE

I looked down thirty-one thousand feet to see upstate New York passing below me. The Seventh Prader-Willi Syndrome Association Conference had ended. Thoughts, recollections, concerns, contrasts, successes, were running through my mind. Below the long slender Finger Lakes disappeared in a ridge of clouds.

Fifty years before, my father had come home from work on the beginning of the long July 4th weekend and announced that we were going to drive from our home in Milwaukee to see the Niagara Falls. As I write this my plane seems posed in the sky to let me see once again that rainbow formed in the horseshoe-shaped Niagara Falls. It seemed such a peculiar coincidence that a magic moment could occur almost a half century later. The prediction of such an occurrence is not possible. Once the nostalgia of recollection starts to ebb, a flood of wonderment sweeps in. Fifty years from now I will surely be dead (or 107 years old and very tired). Will there still be a need for the Prader-Willi Syndrome Association or will PWS pass into memory as other conditions have? Infantile paralysis fifty years ago afflicted the President of the United States and he started the March of Dimes. Now, polio is controlled by routine childhood immunization. Fifty years ago tuberculosis was a major killer and its victims were isolated in sanatoria. Now, most cases are managed with oral medicines without the loss of a day's work. Small Pox is reportedly absent from the earth. Diabetes can be treated by transplanting parts of human organs or administering insulin manufactured by genetic engineering. Small clusters of concerned people banded together, donating their concern, their talents, and their money so that caring and research, intervention and sustenance, education and advocacy, could be brought to bear against the killing effects of these medical problems and their devastating social effects.

Is it possible that our concern for available residential placements could become a thing of the past just as tuberculosis sanatoriums stand as stark markers of the past? The year that I graduated from medical school, Lansing, Michigan was devastated by the deaths of many of its children with bulbar poliomyelitis. When I arrived there for my internship, there were several victims of the disease still being supported in the iron lung. During the subsequent years of my training and early practice, I administered anesthesia for many procedures for treatment of the crippling effects of both of these diseases. Just this past year the medical headline, "Smallpox conquered" encircled the globe. Is it conceivable that in the next fifty years a news release will be headlined, "Last Prader-Willi person cured"? One can always hope, and hope like that is nurtured for me each year by attending the conference. Several people that I talked to expressed the feeling that this was the high point of their year as a Prader-Willi family member. Those who have PWS and attend express much the same enthusiasm. Our fellow members who submit themselves to that labor of love resulting in the annual conference once again deserve the sincere thanks of the Prader-Willi family as a whole.



Within the pages of this and future issues of THE GATHERED VIEW, you will have the opportunity to obtain solid information such as clauses that should be in your wills, as well as reports of progress on new dedicated residential facilities, and the effects of possible changes in laws that will affect your life as a member of the Prader-Willi family. The need for continued support of the National Developmental Center is critical. The need for direct involvement and awareness was forcefully demonstrated during the meeting. During my report to the Board of Directors, I indicated that the 7th PWSA Conference could be the last as no group had responded to repeated announcements that there is not a bid from anyone to host the 8th PWSA Conference in 1986. At that point people were touched personally by the possible loss of something that they have come to hold dear. It has become more and more obvious to your officers that there is no likelihood that any Federal agency or any major granting agency or fund or trust is going to respond positively to our applications for help to establish this National Developmental Center until someone with the power to expend the needed funds is personally touched by knowledge of PWS. This means, in brief, that each and every member of the PWSA family is a constant emissary to find those persons with the power to make our goal a possibility, make that person aware of how PWS touches their life and how great the need for involvement is. If you know of such a person that is a relative or a friend or an acquaintance or even your employer, it is up to you to make the contact, make that person informed and make him want to help this cause over all those others. My flight from Chicago to San Francisco was spent informing a business manager of PWS and the needs of those afflicted with the problem. Maybe a conversation like that will create the connection that could result in the establishment of the National Developmental Center for PWS. Remember -- George isn't going to do it for you, he's busy doing it for himself.

*Delfin J. Beltran, M.D.*

President

#### RESEARCH FUND - LATEST TOTAL \$12,074.23

May & June Contributors: (Through memorials) Flick, Maiten, LaPenta, Uzendowski, Sojka, Maurer, Nanzig, & Howe. (Direct) United Way DE, DeHaan, United Way DC, Berk & Maurer.

We thank all of you who continue to support this fund. We especially thank those who make United Way donations because we do not receive your name and cannot thank you directly. This month we give a special thanks to Andy Maurer who decided his weekly church donation should go into the Research Fund.

We also now have memorial cards & kits available for anyone to use. Please ask for one.

#### CTM CLUB FOR NDC - LATEST TOTAL \$47,782.56

May and June contributors: Sharp, Maurer, Veziroglu, Midlantic Chapter, Boyd, Wyka, DeHaan, Ipsen, Spencer Monday Club, Riesenman, Lincoln, Frey, Burton, Regester, Parent, Women's Club, Chausow, Kerosky, Y.C.Gr., Nanzig, Ziifle, Neason, Vogt, Dixon, Robbins, Abell, Shannon, Krueger, Ray, Jackson, Flick, Wyka, Wett, Otteman, Park, Uzendowski, Tsoules & Alterman.

May contributions totaled \$1086; June's total was \$4290. A special thank you to all.



NEW CHAPTERS AND PRESIDENTS

We are happy to welcome two new chapters, #13 & #14, to the official ranks:

**PRADER-WILLI FRONTIER REGIONAL ASSOCIATION**

Organized in Montana to also encompass N.Dakota, S.Dakota & Wyoming.

President: Phillip O'Donnell; Vice President: Roxy Brown;

Sec./Treasurer: Sandy O'Connor

**PRADER-WILLI UTAH ASSOCIATION**

Organized in the State of Utah

Presidents: Judy & Frank Ipsen; Vice President: Lynn Manning;

Sec./Treasurer: Bill Jacobs

Congratulations also to new Presidents: Mildred Lacy of KY and Mort Westman of MN.

BOARD OF DIRECTORS ELECTION RESULTS

Incumbant Board members returned to the Board by this election:

DOROTHY THOMPSON, MN   STEWART MAURER, GA   TED BRIGGS, TX

New Board member elected: LOUISE GREENSWAG of Iowa

Other floor nominations included Marjorie Smith of CT, Barbara Whitman of MO, Marilyn Bintz of CA, and Rita Welch of NY.

RAFFLE RESULTS:                      \$1000 WINNER PENNY PARK

The figure at the moment is that \$3579 was raised by our ticket and pen fund raiser which helps keep conference registration costs down. We can't thank all of you that did participate but without all of you, it would not have been a money raiser. We would like to thank a few super salespeople: Cellie Ledoux and the S.New England chapter. the MO chapter, Bill Stege of IL, Daniel Levine of NJ, Julie Mitchell and the Tri-State Chapter, DJ Miller and the Midlantic chapter, and the MN chapter.

We especially want to thank the big winner of the \$1000 prize who was PENNY PARK of Oklahoma City, a fairly new member, mother of a 19 month old son, who took her prize and in return donated it to the National Developmental Center.

We've heard it rumored we have a bunch of "Good Guys" in our membership. IT'S TRUE.

PUBLICITY

How many members returned home from the National Conference and called their local newspaper to publicize PWS? It's not too late!!! Give them a call, tell them about the conference and that you attended, then send us a copy of the clipping for our files.



ABBREVIATED STATE OF THE UNION MESSAGE - JUNE CONFERENCE

Marge Wett, Executive Director, gave a "State of the Union" message as part of the general meeting, which we have shortened for reprinting:

As most of you know, the major thrust of PWSA has been a parent support organization. Basically this has been achieved through the development of printed materials. (More detail was given about our first publications and subsequent additions to the present extensive source of information available.) We will continue to develop and assist in the development of more materials.

Over the past year we have gained 50 additional memberships. This number is a bit misleading because we actually enrolled over 200 new members but due to attrition, we only show a growth of 50. Financially we are also gaining ground but still not in the position of affording an office and paid staff. A 24-hour a week secretary was added at the beginning of the year. In talking with other organizations for the more uncommon disorders, it looks like we are doing better than most with the exception of a few that have achieved national publicity.

Our research fund has grown to almost \$12,000. (More information was shared about guidelines for using this fund.) In the research line, we have been working all year on an ongoing questionnaire which is being responded to by over 500 parents. Not all respondents return each questionnaire but we have accumulated a great deal of valuable information which will eventually be programmed into a computer. Information from these questionnaires was shared with two of the people from the University of Washington who used some of the figures at a recent meeting. The questionnaire that is currently being completed will be shared with personnel at the University of Iowa. An anesthesia article is also being completed.

A lot of my time this past year has been directed toward the establishment of the National Developmental Center, which is hoped to serve as an emergency placement for up to 50 young people and a badly needed training center for our syndrome. The CTM Club, which is for this center, has reached \$45,000.

Over the past few months contacts have been made with the March of Dimes (which unfortunately says our needs do not fit into their basic research policies), over one hundred other foundations seeking funds, with two professional fund raisers. I have met with numerous people in New York and Washington, DC which includes people from the government, National Institute of Health and elected officials. Other members have joined me in some of these meetings.

Other travel included chapter visits and work with other countries has transpired during the year. A presentation was given on PWS at the National Organization for Rare Disorders meeting recently in Washington DC and I learned more about how the legislature works. Drs. Holm, Sulzbacher and Thuline, University of Washington in Seattle, gave presentations to the AAMD meeting recently in Philadelphia and then Dr. Holm joined a panel later where both of us gave presentations. The purpose of a genetics symposium in DC, which I also attended recently, was to learn more about volunteer organizations as well as to discuss the possibility of forming a coalition of smaller organizations in order to demand more services for all of our groups.



The State of Missouri sent three representatives to our office and also met with Dorothy Thompson and toured Oakwood in preparation for their developing two homes in the state. Dorothy also visited this group as well as the groups in Michigan and Connecticut. I have also been working with the New York group as well as our two new chapters in Montana and Utah.

From these various meetings some conclusions have been drawn as well as information gained. As reported, I do not see any chance of the federal government stepping in and giving us any direct funding. I did learn recently our best contacts would be through the National Institute of Health Maternal & Child Care Division and through an organization called University Affiliated Facilities, that have funded programs existing in over 40 universities and centers. Two programs affecting us right now are the grant made to the Mental Research Institute in Valhalla, NY and an infant stimulation program in Louisiana. I hope to learn more about these contacts in the near future.

Our office was asked to refer some doctors for a drug testing program from a pharmaceutical company in Florida and that testing has just gotten underway. This drug was human tested and supposedly not only controlled compulsive eating but also improved behavior. (Recent newspaper accounts have reported encouraging reports on the use of Naltrexone with PWS, but at least one Canadian doctor has shared her disappointment with a Canadian parent's group.) I am sure we will be hearing more about these things, hopefully in the near future.

Our phone calls have increased, particularly from professionals who seem genuinely interested in learning more about PWS. One of the things Dr. Holm questioned at the AAMD meeting, and was also discussed at the Genetics Symposium, was would parents prefer to get an earlier diagnosis even if the outlook was not good news, and everyone agreed a correct diagnosis is better than not knowing.

In talking with others from other disorders, I still believe PW is one of the most devastating of syndromes and we certainly deserve more assistance than we are getting. It is difficult to put out a bi-monthly newsletter that will be helpful to our members with young children as well as face the problems of older parents, but we try.

I think we certainly can be proud of our organization and the number of participating members who continue to carry on our theme of "caring and sharing". It would make my job, as Executive Director, a bit easier if more joined the ranks of "participating members". It has often been said at these meetings, you are the experts on this syndrome and you have much to share.

All in all, from the national office, I have to say it's been a good year. Of course finding an "angel" to fund the NDC would have made it a great one.

*Marge A. Wett*

CORRECTION: From the last issue, the correct address for the member seeking to purchase old fountain pens is:

Jud Bell, Catamaran 2231

2400 S. Ocean Drive

Ft. Pierce, FL 33449

(zip code correction)

(Profits promised to PWSA)



### NATIONAL DEVELOPMENTAL CENTER

I wish I had the talent to write a very uplifting sales pitch and generate all the enthusiasm necessary for each and every member affected by PWS to run to the nearest door and shout to the world, "Help us, we need you." Unfortunately, I haven't that talent, and instead this is going to be another tell it like it is--dull report. You have already read one report from me in this issue and I hate to make you suffer through another one but I feel I have to make one more try. A year ago I introduced the subject of a National Developmental Center. For those who do not know, the purpose of this Center is to serve as an emergency shelter for up to 50 young people, to serve as a temporary (1-2 yr.) placement for family respite and weight reduction, and to serve until proper placements can be made available nearer to home. The Center would also be a training center for staff of other homes being opened around the country. Many other by-products would also come automatically.

In the past year, a small percentage of our members have climbed on the bandwagon and \$45,000 has been raised. This is a great start but a long way from the goal. At the conference I asked the board to give me another six months to attempt to convince the rest of the membership of the need for this project. During the conference several members came up and asked me not to give up on this concept. I'm not ready to give up yet, but I am convinced it will only succeed with the backing of a majority of our members.

Yesterday on the radio I heard a psychologist say Americans would rather talk about the hostage situation, they would rather talk about hunger in Africa, because these topics are removed enough to be easy to talk about. They do not want to talk about hunger in this country, they do not want to talk about street people who are mentally ill, nor the poor and ill because it is too close to home, and it makes them uncomfortable.

I'm writing this report in the first person, "I", because at times I feel very alone in my struggle to open this Center. On the conference evaluation sheet one member wrote under the heading of least enjoyable parts of the conference, "Marge Wett, (guilt trip)". I promise this is the last guilt trip I'll lay on you regarding this Center. It is a fact that a small percentage of our membership cannot accomplish this goal, it is a fact that no one is going to walk up and hand us this money, it is a fact that written proposals from this office have not gotten us the larger contributions that we need, it is a fact the project will only succeed if enough members forget their "discomfort" and make personal contacts. I'm dumping it in your lap now, I'll continue to do all I can to help by furnishing proposals to use etc., but now it's up to you.

### QUESTIONNAIRES - A NEW "FOUR LETTER WORD"?

Filling out these forms is not a waste of time -- valuable information will help us all. At the conference a group of professionals had the opportunity to get together and talk about the information that is being accumulated by the National office. This group will formulate the 7th and final questionnaire in our series and then proceed to feed this into a computer.

Two questionnaires were available at the conference. If you did not return these, they can be returned to the National office. Dr. Whitman would also appreciate the parents of PW's under 16 to ask for a copy, if they were not at the conference, and this information may help her obtain funding for further study.



### GONE BUT NEVER TO BE FORGOTTEN

7th ANNUAL NATIONAL PWS CONFERENCE - Over a year ago the Southern New England PWS Parent Support Group, Inc. jumped with great enthusiasm into the task of hosting this conference. "Hosting a PW Conference", a large collection of past experiences helped them to produce a better conference. This conference now joins the ranks of past experiences too.

ATTENDANCE: 256 Adults; 93 Children & Adults with PWS; 24 Brothers & Sisters.

\$12,358.66 worth of catered breakfasts, lunches, breaks, and banquets were served.

HOW ABOUT NEXT YEAR: As you have read the location has not been determined for lack of bids. Two or three groups are considering submitting bids. ANY GROUP may enter a bid for board consideration. QUALIFICATIONS: At least four individuals who are willing to donate several months of hard work. A nearby University or Health Center where some professionals are knowledgeable about the syndrome. A source for at least a dozen or more volunteers each day. Location is also a big consideration as we attempt to serve a different part of the country each year. You do not have to be professional conference planners in order to bid. The National office works by your side every inch of the way in planning and executing the meeting, as well as sharing past experiences. When we talked about the possibility of not having a conference next year, many voices were heard saying, "Don't even consider that. Our members need this yearly source of 'sharing and caring'. It's a tradition we cannot afford to stop."

WE'LL SUPPLY YOU WITH A COPY. That was said several times during the meeting. As soon as these are received we'll share them. If you want something that was promised during the meeting and you do not hear about it, write and ask. Over 15 hrs. of the conference was taped, transcription takes about 100+ hours -- don't give up, we'll have copies available at cost of reproduction as soon as we have them finished.

EVALUATION SHEETS: "I felt the conference was: Very Helpful 60, Helpful 33, Not Helpful 0. That's the vote count so far. Naturally we look at all of the comments and suggestions and try to improve each year, but remember we can't please everyone. What you suggest may be voted down by the next three evaluators. We do our best.

CAN'T END WITHOUT THANKS. Cellie Ledoux, who did not start out as general chairperson but certainly filled the role; Suzie Cassidy in her terrific job of planning and running the adult meetings; Tony LaPenta for his role in the Youth Activity Program; Marj Smith for staffing the registration and material sales; all of the members from the So.N.E. and Massachusetts Chapters, and last but not least the volunteers. Gail Miller, volunteer coordinator and Debbie Miller, staff coordinator for the conference center, although paid staff rather than volunteers, both gave above and beyond in their help.

### A FEW LINES FROM THE EVALUATION SHEETS TO SUM UP:

A job very well done--thanks to everyone.

Congrats on a job well done.

Very good, informative and enjoyable conference.

Great, I loved this--you all did very well. Thank you.

Had a great time. Great conference.



### WINNING A "SPECIAL" BATTLE

was the title of an article that appeared in the newsletter of the Yellowstone ARC. One of our members spoke at their monthly meeting and showed the slide presentation available from national. The article told of two very special people who had PWS and had joined Weight Watchers. One girl, Kay was 52 lbs. overweight in April of 1984 and reached her goal of 140 lbs. in February of 1985. The other girl, Stacy, is also well on her way with her goal of a 74 lb. loss. The article stated that both were able to work faster and longer in their job placement without the extra weight. It also stated they have been a great inspiration to the rest of those working on dieting. Stacy wrote:

#### This Is About Me

I am happy to be losing weight.  
I have lost about 53 lbs. in almost a year.  
I can't live without Weight Watchers ever.  
I wouldn't have lost that much weight on my own.  
Thanks, Rita Leader, for taking me to Weight Watchers.  
I like sports, too!

### A BATTLER FOR EXCELLENCE

Jan Erick of Reservoir (Australia), began to work for his Duke of Edinburgh Award on April 18, 1984. That was his 21st birthday, and in eight months he received the coveted prize. He also became the first Australian ever to complete the two levels of the award in less than 12 months. To earn his award, Jan Erick focused on the areas of service, expeditions, and physical recreation. His mother was thrilled with his award and we certainly send our congratulations too!

### A NEW MEMBER WRITES

"In reading thru the GV for the past ten years, I came across some very interesting and useful information. I appreciate the caring and giving attitude of this organization. When I read of the experiences of what others have gone thru with their PW child it helps me to be more thankful for what we as a family have. We have been very fortunate in that we have a good team of doctors and therapists from day one but our daughter was not diagnosed until 5 months ago. After 5 yrs. of knowing something was wrong because of the delayed development, but not knowing what, it was a relief to find out that there was a reason for all of her problems. "

The mother also went on to say that even a weight loss of 5 lbs. has made a difference in her daughter's desire to walk without complaining of being tired. We thank this member for sharing.

### MEDICAL ALERT

The following page is not numbered in order that you may remove from this newsletter and retain for use when hospitalization is necessary. The primary purpose of this alert is for including in the hospital chart in order for all personnel working with your child to be on the alert for these unique symptoms. It may also be shared with doctors, school nurses, and anyone else that you may feel can benefit from the information.

We sincerely thank Janalee Heinemann for preparing this form for your use.



## MEDICAL ALERT FOR PERSONS WITH PRADER-WILLI SYNDROME

Due to many unique symptoms of Prader-Willi syndrome and the general lack of knowledge regarding the syndrome, we are requesting that this information be posted in this child/adult's medical chart. Below are listed typical characteristics of the syndrome that could create complications during medical care:

- 1) Sleep apnea or generalized respiratory distress -- due to massive obesity-hypoventilation syndrome. Excessive sleepiness. Generally seen with the more obese child/adult with PW, but also seen in normal weight persons. Weight loss can alleviate the problem.
- 2) Adverse reaction to many drugs -- especially medication for weight reduction or behavior control. Prolonged sedation from usual doses of IM drugs.
- 3) High threshold of pain and a dysfunctioning thermostat -- both can be a factor regarding the risk of an undetected infection. Many persons with PWS will not complain of pain until the infection is severe, plus have poor body temperature control.
- 4) Lack of vomiting -- people with PW typically do not vomit, and some will ingest almost anything eatable (i.e.garbage). They are more likely to develop diarrhea.
- 5) Scratching and skin picking -- a common problem. The person with PWS may have scars and sores in various stages of healing. The sores are often kept irritated for months by picking. Treatment is difficult, prevention is most important. Related to pain threshold.
- 6) Hypotonia -- a) poor or little sucking reflex in infants; b) weak muscle tone; c) poor coordination of large motor skills, but good small motor coordination; d) poor speech and language development.
- 7) Hypogonadism -- a) underdeveloped genitals (usually present with undescended testicles frequent); b) minimal secondary sex characteristics (limited success with hormone treatment); c) all persons with PW are considered sterile; d) short in stature.
- 8) Hypomentia -- I.Q. averages 70, but can vary significantly above or below. Intellectual dysfunction more noticeable with advancing age. Persons with PWS do not function at their I.Q. level. Abstract thinking, math skills usually poor.

NOTE: The following two characteristics are the most difficult for family and staff to deal with:

- 9) Hyperphagia leading to obesity -- due to an insatiable appetite and a (suspected) metabolic disorder. Food is believed to be metabolized in an abnormal way, weight gain occurs even on low calorie diet. Although small during the first 1-2 years, at ages 2-4 the child becomes obsessed with food. It is thought that the message to the brain triggers "hunger", disregarding the amount of food in the stomach. Weight gain can be very rapid.

For hospital personnel this means: a) A typical diet menu may still be too many calories for the person with PW. b) Even if the person with PW is at a normal weight, he or she cannot be trusted around food. They become masters at sneaking food around age 4. Age only increases this skill. If the weight is



controlled, it is not because the patient has achieved control over their eating, but because the parent has achieved control over their situation (i.e. locks in kitchen, constant vigilance). c) People with PWS think, talk, and dream about food 24 hours a day. It is cruel to have food visible, or to have the child with a roommate who can readily eat all they want. d) To date, no medications have been proven helpful, and the stomach stapling/by-pass surgery has generally not been successful for long term weight control.

10) Behavior problems -- due to the CNS dysfunction, complicated by multiply factors, most children and adults with PW have difficulty with temper tantrums, stubbornness and depression -- which increases with age. These people are typically sweet in personality, and the flare-ups are unpredictable. When a person with PWS is distraught, "talking over" the problem generally accelerates their lack of control. Logical reasoning gets you no where. "Time outs" work the best. Verbal abuse is common during these periods. Check with the parents on what works best for their child, each person is different. Medications are not usually helpful.

Other typical health complications to be aware of are:

- 11) Scoliosis -- frequent. Often not recognized.
- 12) Diabetes -- weight related. Most commonly adult onset type.
- 13) Soft tooth enamel; thick, sticky saliva; poor oral hygiene.
- 14) Myopia, strabismus -- very common
- 15) Inguinal hernia and/or undescended testes.

Any problems or questions, please feel free to contact:

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St. Louis, MO  
(314) 454-6217

Library reference:

Current Problems in Pediatrics, Volume XIV, #1, January, 1984 Prader-Willi Syndrome  
by Suzanne B. Cassidy, M.D.

Additional information: Prader-Willi Syndrome Association  
5515 Malibu Drive  
Edina, MN 55436  
(612) 933-0113



### A MEMBER OBJECTS TO DESCRIPTION OF APPETITE

Portions of a member's letter: "The purpose of this letter is a concern I have regarding the descriptions of the 'P.W.' appetite which are: enormous, insatiable--they'll eat anything - never full, etc. I will refer to my daughter, as that is where my experience lays, but I'm sure others share my feelings. Angela's calorie intake is 850-900/day and if she were to increase that to 1000 calories /day, she would gain! It's a fact that her body gains weight much faster (than normal) while on a very restricted diet! My point is that 1000 calories a day is not an 'enormous appetite or over-eating by any means. I'm not disputing that the 'eating' would not be 'binge like' if conditions would allow. But, I feel that we wrongly describe the appetite if we fail to mention the rapid gain on a very low calorie intake!

When I emphasize to people the 'overly rapid' gain on 'much less' than normal intake, they get a better understand and appreciate of the hardships she faces instead of wrongly judging her to be overweight because she eats a 'large' amount of food, or is 'always eating'.

I would also like to know if any research has been done regarding why the weight gain is so rapid. "

Portion of answer: "Newspapers would much rather write something more sensational than informative. We hope we (as an organization) have not omitted that very important part in our GV articles. I did check a couple of publications, Lota Mitchell's Overview and Dr. Cassidy's Overview both mention the gain on lower calories. It is also mentioned in other places.

One of the explanations of the "why" was offered as the lack of muscle being involved. Men burn more calories than women because of their larger muscle mass, and that it seems with the lack of mass and tone, fewer calories would be burned with our kids."

If anyone else has any comments, we would appreciate hearing them.

### A MEMBER WRITES

A mother of a 6 yr. old daughter wrote she found the March-April issue of the GV "a bit depressing" and hoped the forthcoming issues will continue to be as encouraging as the May-June issue.

We answered (in part): "I certainly understand your letter but I would like you to understand us also. It is extremely difficult to have a newsletter serve the needs of people from birth through adulthood. I really debated before putting the parent letters in that issue but I felt the members had to know of the need for a developmental center to serve their immediate needs. I believe this center could create research opportunities that would be welcomed by all age groups; I believe the publicity would create an awareness of PWS that is so neglected; I believe future group homes could use this for proper staff training; and in addition to that, it could serve as an emergency placement for those facing life-threatening situations.

I don't believe your daughter is going to have the same needs parents face now. I really believe that research is going to change needs we face now. We like to have "encouraging" issues but we need also to assist parents by facing the needs that now exist."



OHIO SEEKS NAMES

The Tri-State Prader-Willi Chapter was fortunate enough to have at it's spring meeting a representative from a private provider of residential care. In order to consider a group home in the State of Ohio, this chapter must have the number of people interested in order to demonstrate needs. If you are a resident of Ohio and have a person with Prader-Willi 16 years or older, whom you are interested in placing in an appropriate group home, please send your name and address, along with the name and age of the person with Prader-Willi to:

Mr & Mrs. Ross Robbins, 796 Willowdale Ave., Kettering, OH 45429

WILLS WORKSHOP FROM CONFERENCE

Moderator Roy Smith shared some very interesting information regarding wills in this workshop. The terminology of the trust he suggested will be shared with the National office in the near future, and will be printed in the next issue of the GV. If you are interested in having it sooner, drop us a line and we will share the copy as soon as it is received. Roy also mentioned that some persons have all of their children listed as beneficiaries of their life insurance and this should be checked so funding of a person with PW will not be interrupted.

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THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members.

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